



**Care Work in Europe**  
*Current understandings and future directions*

**Workpackage 8**  
**Work with Adults with Severe Disabilities**  
**A Case Study of Denmark, the Netherlands and Sweden**

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## Summary

### Chapter One: Introduction to the report

This report is part of the second stage of a research study *Care Work in Europe: Current Understandings and Future Directions*. It is one of three cross-national studies of particular forms of care work and focuses on work in services for adults with severe disabilities, both physical and developmental: the other two studies are concerned with centre-based services for young children (i.e. under 6 years) and residential and domiciliary services for elderly people. The main aim is to provide in-depth studies of understandings of care work in theory and practice – although it is also recognised that the term ‘care work’ is problematic and contentious.

This study compares three countries: Denmark, the Netherlands and Sweden. The study is based on interviews with: practitioners working in housing services, day care services and as personal assistants for individuals with disabilities; trainers of practitioners; and local and national policy makers. Interviews were supplemented by questionnaires (completed by practitioners), tours of centres and documentation.

### Chapter Two: The context for work with handicapped adults

This chapter consists of four sections, describing the context for work with adults with disabilities. The first section provides some demographic, labour market and economic details about Denmark, the Netherlands and Sweden. There are many similarities, including levels of national income and demographic developments. Important differences include the level of taxation (and, by implication, public expenditure) and maternal employment rates; the Netherlands is lower on both counts, but has much higher levels of part-time working among women. In all three countries, responsibility for handicap care policy is with ministries of social affairs or welfare; in Denmark and the Netherlands responsibility for services is divided between local and regional authorities, while in Sweden it is with local authorities only.

The second section contains specific information about the services offered – both their structuring and volume - and the workers in handicap care in general, and in this case study. In terms of the workforce, Denmark is distinctive: most workers in this field are pedagogues, a profession with a degree-level basic education and whose members work across a wide range of services for children, young people and adults (they are, for example, the mainstay of nurseries and other services for young children). The field therefore can better be defined as pedagogical, rather than care, work. Other staff in Denmark have a lower level education, similar to the majority of staff in the Netherlands and Sweden. In short, the Danish workers are generally better educated than their Swedish and Dutch counterparts and work in a generalist profession. In all three countries a new group of workers are emerging, handicap helpers or personal assistants, employed to work specifically with one handicapped person who in some cases is the direct employer.

One consequence of the different workforce structuring is that, compared to Denmark, Netherlands and Sweden have more groups in the handicap care workforce. The multiplicity of groups can place demands on team working and utilising the capabilities of the various groups, especially as these groups may differ in terms of status. Whereas the Danish pedagogue spans many fields and works both as a practitioner and manager, work in the Netherlands shows *horizontal* segregation into different areas of specialisation; while in Sweden there is *vertical* segregation as managers and practitioners have different educations, backgrounds and career paths.

The third section deals with themes in handicap policy in a historical perspective: normalisation, de-institutionalisation, integration and decentralisation. Although now global themes, they appeared early in Scandinavia: Denmark was ahead of Sweden in closing large isolated institutions, but Sweden has perhaps gone further than Denmark in the further de-institutionalisation of housing and employment for handicapped people. But in both countries today almost all handicapped people live in smaller housing units located in ordinary residential areas. By contrast, larger institutions outside residential areas are still present in the Netherlands, where the transformation process began later and is a source of some concern among care workers and relatives, who fear that closing institutions may expose handicapped people to more risks.

The fourth and final section analyses respondents' views on the issue of the rights of handicapped people, which is shaping policy and practice in all three countries. Three areas of rights are discussed: the right to social integration, including entitlement to specific services; the right to support from properly educated workers; and rights associated with the issue of compulsion or force (in Denmark and Sweden, compulsion is only permitted in very exceptional circumstances).

### **Chapter Three: The workers**

The Dutch respondents, notably the women, work fewer hours than their Scandinavian counterparts, reflecting the high level of part-time employment in the Netherlands and the extensive childcare services in Denmark and Sweden. Irregular working hours – common in some parts of handicap care where shift work is the norm – represent a positive feature, many of the respondents believe, and they are not thought to pose problems for family life. The spouse/partner and other relatives will take care of the children, which is a key precondition for workers' ability to achieve a balance between their work and family lives when they have younger children.

The paths leading the respondents into handicap care are quite diverse. Most of the Danish and Swedish, and a great deal of the Dutch, respondents have considerable life and work experience before they enter this field and several have worked in other care sectors. Several of the Swedish and Dutch respondents say that they ended up in the sector of handicap care by chance. The Danish pedagogues, however, are generally more deliberate in their choice. This may be a result of basic differences in the workforce and education. Most workers are recruited into handicap care in Denmark after they have completed a pedagogue education, which is itself well-known and popular. This education provides them with knowledge about handicap care. Personal knowledge about the area may constitute another route into the work, for example having a relative with a disability or a friend who works in the area.

Human considerations, feelings of solidarity with a group of citizens with a major need for support, and the joy of working with these people also play their part for some respondents. Highly educated care workers do not express any contradiction between having a graduate degree and a professional approach while viewing humanity and solidarity as major motivations – quite the opposite.

In Denmark, the male pedagogues explain their motivation for completing their education and working with people with disabilities in a different way to the female respondents, attaching more importance to the use of specific professional skills such as music or knowledge of nature. The men may have given their choice of career in a female dominated area more thought because they are breaking the pattern. Whereas, perhaps, the chances of ending up in an area that is traditionally dominated by your gender increases where there is a more random and unconscious choice of career.

## **Chapter Four: Gender**

Although care work is generally dominated by women, men workers are more common in the Scandinavian countries and in particular in Denmark where men make up about a quarter of the workforce in handicap care. Earlier project reports have also concluded that the debate about gender in care work is most prominent and profound in Scandinavia, taking place since the 1970s. The Danish and Swedish care workers pursue the ideal of having men in the area of handicap care, arguing in favour of more men on the basis of various perspectives, including that of the users. This is less pronounced among the Dutch respondents but we do not know whether this is generally the case in the Netherlands.

Gender seems to be reflected in the care work and the pedagogical work. The meeting between the two genders is sometimes a negative experience and sometimes a positive experience (e.g. flirtation) and it is accepted and applied as a resource. Gender is not just neutral. We might ask the question: are these citizens, handicapped people, whose daily life depends so much on professional care workers, entitled to meet both genders among the staff? It may be one of the ways in which they can be meeting more men.

With a more gender mixed workforce, the Danish pedagogues have a lot of experience collaborating with the other sex. They all agree that changes happen when men and women work together, and these changes are considered positive. There may also be some difference in what male and female pedagogues do in the workplace, with a tendency for women to do more 'care-related' work. The Danish pedagogues also seem to perceive a difference in the behaviour of male and female pedagogues. When they talk about relations between men and women staff, pedagogues often use clichés, for example: the metaphor of the chicken yard and the cock fight; talk of gossiping and creating intrigue; associating men with action, and so on. All these concepts help to maintain prejudice and prevent a multi-faceted understanding of gender. On the other hand, it is very striking that when the Danish respondents mention the two genders in relation to the users, their statements are more nuanced; they are making use of professionalism in their judgement of the quality that gender may contribute to their work. This may be an indication that in Denmark gender is not discussed thoroughly at the workplace regarding staff issues, whereas it is discussed and observed in a professional way in relation to the individual clients.

Our material does not show any of the three countries applying any specific strategies at national, regional or local levels to increase employment of men in handicap care.

## **Chapter Five: The work**

Care workers themselves have a positive view of their work because it provides challenges and because it is meaningful. But the Dutch and Swedish respondents in particular consider that their work has low status in society. Factors related to this low social status include: a general lack of public knowledge about, as well as negative prejudice towards, handicapped people; myths and false perceptions about the work itself, including the widespread view that it needs no education; and care workers' inexperience in explaining their work. There are specific national features. Care work in the Netherlands is ascribed low status being compared in a 'treatment paradigm' with treatment and nursing; but in Denmark, care work with handicapped people is seen as part of pedagogical work, which enjoys a relatively good status.

Three roles for workers in handicap care are discussed: the expert who knows what is good for and needed by the handicapped person; the catalyst who initiates processes and gets involved while



being conscious about his or her own values and attitudes; and the good-hearted personality who works on the basis of common sense, personal experience, feelings and a wish to help other people. Discussions arise about the role of professionalism and whether it creates workers who claim to know what is best for the handicapped person: some workers in the study do seem to assume this expert role. But, this is not inevitable and the inherent dilemmas of care work cannot be removed by doing away with professionalism. Other workers in the study appear to perform a catalyst role.

An important and growing issue concerns working alone. This is particularly relevant to handicap helpers or personal assistants who are employed to work with a particular disabled person who then acts as employer or day-to-day manager (although the local authorities may be the actual employer). These workers usually have no relevant, professional education, and their role is defined by *not* being an expert or a professional. Although handicap helpers/personal assistants are generally satisfied with their work, these schemes are not without their problems. Quite often, the worker will have to balance the expectations of being a friend, a family member, and a professional or local authority representative. Some respondents refer to the role of handicap helper/personal assistant as just being the extended arms and legs of another person. The power and asymmetry in such a relationship are quite complex and may result in stifling reciprocal relationships. Moreover, the handicapped person is not always qualified as a manager.

### **Chapter Six: Working with social networks**

Social networks and working with them are key issues in handicap care in all three countries. In the past, disabled people who lived in large 'total' institutions generally only had access to one network, made up of professional staff and fellow residents. This is being changed with normalisation, which involves the principle that disabled people need networks similar to those of other people. One aim of the changes that have taken place in services, in particular in Denmark and Sweden, has been enhanced physical and social integration. This has meant a changed role and new tasks for care workers.

In Denmark and Sweden, there is satisfaction with de-centralisation in spite of a few critics who argue that individualised housing may lead to social isolation. In both cases, disabled people have more contact with their families than in the past. But some relatives and staff in the Netherlands are opposed to this process, one reason being concerns about the vulnerability of disabled people if living in ordinary residential areas. This raises the issue of what conditions are needed if de-centralisation is to be successful, including adequate funding and enhanced staff qualifications, since the staff play a key role; they may act as a catalyst for establishing good relations.

The respondents in all three countries clearly underline that families usually provide handicapped people with their most important relations. But there can be tensions, for example if relatives treat handicapped adults as the family's child, rather than as a grown-up citizen, and on occasions when relatives mistreat the handicapped person. Several respondents mention the relations between people with disabilities and local communities and neighbours as a problem area. In Denmark, for example, even after several years of de-institutionalisation, people with handicaps are still not completely accepted and there is a lack of social integration with the residents of the local community.

The Danish and Swedish care staff have different views of their roles vis-à-vis the relatives and other network relations. The Danish pedagogues consider working with social networks as a key and natural part of their job; for them the work cannot be viewed apart from the social conditions of

the care recipient, for example the family situation. Care work is perceived not only as doing something for and together with people with disabilities, but also including the total social situation of the person in question. The Swedish care staff who are in direct contact with residents living in ordinary housing do not view themselves as networkers; they regard housing as a private place, and therefore the care staff cannot invite anyone else inside.

The social networking of the care staff bridges the gap between public sector institutional services and informal care. The staff are found at the interface between institutional care and family care. Public sector care does not mean replacing informal care but rather complementing it. The pedagogical work is about keeping informal networks in place, to strike a balance.

### **Chapter Seven: Pay, working conditions and working environment**

Dutch care workers, like the wider female workforce, mainly work part time: Danish and Swedish care workers mainly work full time. Important questions are raised about these different working patterns – both for the workers and those with whom they work.

The report adopts a model of the working environment which treats workers' experience as produced not by any one dimension but by the interplay of three dimensions: demands, control or decision latitude and reward. It also stresses that job satisfaction does not mean an absence of stress.

It is striking that care workers in all three countries are generally satisfied with their work, taken overall. The main specific cause of dissatisfaction is pay, which is perhaps not surprising as pay is relatively low (and probably lower in the Netherlands and Sweden than in Denmark where we see the effect of a largely professional workforce of pedagogues). Low pay is in itself a problem, but can also appear as a sign of the low social status of the work.

According to their questionnaires, more than a third of the care workers do not find their jobs stressful at all, although a fuller picture needs to take account of the interviews alongside the questionnaires; what workers say may often qualify how they complete a questionnaire. Among those who do select one or more stress items on the questionnaire, the four most common are lack of time, too few staff, low pay and lack of focus in their work. The workers, moreover, do find the work demanding, especially psychologically, although the Danish and Swedish workers are more likely to rate it 'highly' or 'very' demanding than their Dutch counterparts.

One issue that is raised as a substantial risk is working alone. This is the situation of many handicap helpers/personal assistants, an increasing group in the workforce.

One area where there are marked national differences among the workers interviewed concerns professional development. The Danish and Dutch workers are generally satisfied, while the Swedish workers are much less so. Furthermore Swedish workers are more likely than Danish workers to hold a negative view of managers, which may reflect different workforce structures: managers and care workers coming from different backgrounds in Sweden, but sharing a pedagogical education in Denmark.

Of particular importance, nearly all care workers interviewed in all three countries are satisfied with the decision latitude they enjoy – they feel they have considerable control over how they do their work. On the third dimension, rewards, again workers are mostly positive, reporting that overall their jobs are rewarding. They find their work meaningful, enjoy what they do and have fulfilling

relationships, with handicapped people with whom they work and with their work colleagues. They also feel recognised and valued by the relatives of those they care for. The same however cannot be said for the wider society; only a handful feel 'most' or 'very' satisfied with society's recognition of their work.

### **Chapter Eight: Training, education and professional development**

The need for well qualified staff does not appear to be generally accepted yet, being challenged by those who question expertise and professionalism (as leading to professionals who think they know best) or who fear that it can lead to a split in the workforce, for example between highly qualified managers and less qualified care workers. In the interviews, some respondents are cautious about the professionalisation of care work, but the reports generally underline that education is important for a number of reasons with the dominant view that education enhances quality in care work. Education needs to address the daily work, but also provide opportunities for further education and research.

Currently, workers in handicap care have varying qualifications for the work and, in some cases, none at all. Most Danish workers (pedagogues) are educated at a degree level (level 5); other Danish workers and most workers in Sweden and the Netherlands are educated at levels 3 or 4. In Sweden it seems to be common for the staff not to have completed any truly relevant professional education, while in Denmark it is almost only the handicap helpers who do not have any professional education, and this group is still at present small in number.

The Danish report stresses that there is wide support for the generalised pedagogue education, which is widely seen also to provide flexibility between areas and levels, which may help to solve labour shortages. The problems related to a lack of specialised knowledge are solved by further education and on-the-job training. The issue of generalised versus specialised education is also discussed in the Dutch report. In the Netherlands, a more differentiated training is combined with an increasing emphasis on competence-based education.

The national reports identify a range of competencies and competency needs required for the work: communicative competencies; analytic and reflective competencies; personal competencies; professional knowledge; musical and aesthetical competencies; competencies concerning the prevention of psychosocial and physical strain especially when working alone; intercultural competencies; and competencies in cross-professional work and general teamwork.

### **Chapter Nine: Understanding of Care**

This chapter provides a general outline of the understanding of care in the three countries based on the interviews with practitioners, trainers and policy makers. Views on care are generally characterised by the following three intentions: a good life; recognition of handicapped people as citizens; and prevention of problems and alleviation of already existing problems. These views are generally shaped by different paradigms: rights; solidarity; and charity.

Four broad concepts of care are identified, care as: family life; providing protection; citizenship and ensuring a near normal life in society; a service that can be purchased by a consumer. Four broad images or ideal constructs of the care worker can also be identified, as: the ethical human being (acting as one human being meeting another and recognising that person as an individual of equal worth); the mentor (applying views and competencies to guide another person with less experience

and knowledge); the professional person with judgement; and the service provider responding to the needs of a consumer (a concept on the borderline of the care/care worker concept).

The respondents themselves do not define care in any specific way. However, on the basis of how respondents describe the purposes and tasks of their work, care work can be said to include the following elements: fulfilling the recipient's fundamental physiological needs and needs for protection; supporting and building resources that relate to a person's development and self realisation; respecting and valuing the recipient as a unique individual; and supporting recipients to engage in social communities.

The Danish experience questions the concept of 'care work'. Pedagogues are by far the largest group in the workforce and their work is considered as *pedagogical* work. In this context, care – defined as specific basic, daily tasks - is just one part of pedagogy.

### **Chapter Ten: Recruitment, current discussions and future directions**

In all three countries, the policy makers and trainers mention the importance of measures to attract and retain labour for the handicap area because of increasing competition for smaller future generations of young people and a growing need for more care workers in elderly care. The Dutch policy makers and trainers focus on four main issues: working conditions, conceptualisation, further development of the profession and older care workers not currently employed in the field. The Danes highlight the importance of a flexible generalist education, not requiring students to select a specific pedagogical work area. This education, with its placement periods, provides a first taste of handicap care work for many students. There is a strong focus on the qualification of staff and the establishment of a professional environment to avoid the loss of qualified staff. People today demand development in their work lives. Among the Swedish respondents, the education issue is considered the most important way of recruiting and retaining staff in handicap care. Many workers lack education, and it is a low status area.

Looking ahead, respondents in all three countries express concern about current or possible future funding shortfalls in the handicap area. The Swedish respondents highlight, yet again, the educational question as the dominant theme. Several argue that educational reform is required in order for handicap work to meet the intentions of the law. One educational reform is to reduce the focus on the care content and sharpen the focus on pedagogical principles.

The Dutch themes indicate that the Netherlands is going through a period of fundamental change with a new paradigm of more market-oriented solutions, abandoning previous policies and practice in some areas. The sustained need for innovation results in policies and methods being quickly replaced. Dutch informants argue that making changes takes time, and some are sceptical about the way an innovation mentality dominates the field of handicap care at the moment. Innovation, they say, does not necessarily bring about development and better care quality.

The Danish policy makers are occupied by other themes. They are concerned about the financial resources in the area, and they focus strongly on workforce qualifications. However, unlike the Dutch respondents, the Danish policy makers do not talk about radical changes in the future; no new policies are in prospect in the handicap area. Rather future handicap policy will be based on the same set of ideas that have provided a calm and supportive environment for recent innovations.

# Chapter One: Introduction

## 1.1. Research project Care Work in Europe

This report is part of the second stage of a research project *Care Work in Europe: Current Understandings and Future Directions*. The work is funded by the European Commission as part of its Fifth Framework Programme, and involves research partners in six partner countries: Denmark, Hungary, Netherlands, Spain, Sweden and the UK. The overall objective is to contribute to the development of good quality employment in caring services that are responsive to the needs of rapidly changing societies and their citizens. More specific objectives include: describing and analysing the current care workforce; comparing different understandings of care work and different approaches to the structure and practice of care work; identifying conditions necessary for the development of employment that is both of good quality and sufficient to meet growing demand; and contributing to the development of innovative approaches, both in care work and cross-national research.

The project has three stages. The first stage, completed in 2002, involved mapping, surveying and reviewing: mapping care services and the care workforce; surveying demand, supply and use of care services; and reviewing recent literature on quality, job satisfaction and gender issues in the care workforce.

The second stage consists of three cross-national case studies to investigate in-depth particular forms of care work: centre-based work with children under 6 years (done in Denmark, Spain and Hungary); residential and domiciliary services for elderly people (done in England, Spain and Sweden); and services for adults with severe disabilities (done in Denmark, Holland and Sweden: the subject of this report). The second stage is completed by a fourth piece of work, which involves the development of methods for the cross-national study of practice.

The third stage, which began in Spring 2004, looks at innovative developments in care work, as well as undertaking dissemination of the project's findings.

For each part, national reports were prepared by all involved research partners followed by consolidated reports based on these national reports. These reports, including an overview report on Stage One and Stage Two, and summaries of consolidated reports are available on the project website at [www.carework.dk](http://www.carework.dk) or [www.ioe.ac.uk/tcru/carework.htm](http://www.ioe.ac.uk/tcru/carework.htm) (all in English, with summaries available in the languages of other partner countries, as well as Russian).

## 1.2 Care and pedagogical work with handicapped adults

### 1.2.1 Introduction

This report examines care work and pedagogical work with adults with seriously impaired physical or mental abilities in Denmark, the Netherlands and Sweden. In each country, the team of researchers performed a national study and prepared a report. This consolidated report collects, discusses and puts the results and considerations of the national reports of the three countries into perspective.

The teams of researchers in the three countries jointly agreed on the delimitation of the research field and the development of research design and specific methods. Wherever possible, the

researchers adopted the approach suggested by the other project case studies of care and pedagogical work in centre-based services for young children and services for elderly care.

The team of researchers consisted of Helle Krogh Hansen and Jytte Juul Jensen (Denmark); : Hans van Ewijk, Gery Lammersen and Herman Boers (the Netherlands); and Petra Norén (Sweden). The present report is prepared by the Danish team of researchers.

### ***1.2.2 Delimitation of the field***

It is not an easy task to delimit the field of care and pedagogical work relative to adults with seriously impaired physical and mental abilities. We chose to focus on care work and pedagogical practice relative to the group of people with a relatively large need of care and pedagogical support. Since the task of care workers and their roles depends very much on the target group, we examined care and pedagogical work with regard to both physically handicapped people and mentally handicapped people, but the project focus is set on care and pedagogical practice relative to people with serious *mental* handicaps and people with *both* mental and physical handicaps. So when we refer to ‘handicapped people’ without making any further indication of the handicap involved, we generally include people with serious mental handicaps or both mental and physical handicaps.

We exclude care work that specifically deals with elderly handicapped people, including dementia care.

We examined care and pedagogical work in a range of settings, including typical day care services, housing services, institutional services and the home of care recipients. For various reasons, including the varying social policy traditions of the three case study countries and other national differences, we adopted a pragmatic approach to the criteria for selecting settings. For example, it goes beyond the research field to examine matters relating to protected job places and teaching services - but there are several day care services in the study that include these two types of services.

Our focal point is on people performing direct and daily tasks within care work and pedagogical work, the frontline staff. This includes people without any education for the work, with short-term education and with a high level education to graduate level, and we interviewed people from all three groups. However, the distribution of the overall workforce across these groups engaged in direct care work varies substantially between the three countries. For example, in Denmark, the work is mainly done by graduate pedagogues while in the Netherlands and Sweden, much of the work is done by staff with lower level education and sometimes none at all.

### ***1.2.3 Research purpose and lead questions***

The purpose of the study is to provide in-depth understandings of concepts, processes and practices: how this type of care service and work is understood, how these understandings have been formed and may change, and how they shape the training, practice and composition of the work force (issues of quality, professionalisation and gender).

The study is subject to the following overall questions and issues:

- How the concept of care work is understood, including theoretical foundations of the work
- How this understanding has been constituted over time

- How it shapes training, practice and the composition of the workforce as well as relationships with other areas such as education and health
- Questions of quality, gender, professionalisation, and ethics

#### **1.2.4 Expressions and concepts**

Finding the right language, finding words (in English) that are accurate, appropriate, understandable and respectful, is very difficult. This applies both to the work itself, the workers doing the work and the group who are on the receiving end of the care and pedagogical practice that is examined. Some expressions will be correct in one country but inappropriate in another. For example, references to 'client', which is used in the Dutch report, would not be used in Denmark.

Not only are different concepts more appropriate in different countries – the concepts are dynamic and develop over time. For example, the concept of 'handicapped' has not always been acceptable in Denmark. But today it is again widely used in ordinary language and new research (cf. Bengtsson et al.: 2003).

The terms 'handicap' and 'handicapped' are applied by the UN, and in Denmark, the Netherlands and Sweden, for example by leading organisations in the area, e.g. the Swedish organisation *De Handikappades Riksförbund*, or the Dutch magazine *Nederlands Tijdschrift voor de Zorg aan verstandelijk gehandicapten*". In Denmark, the term is part of the name of *Det Centrale Handicapråd* and its English translation of 'Danish Disability Council'. In English, we refer to both 'handicapped people' and 'disabled people' but in Danish we only use what can be translated into English as *handicapped people* unless you use an extended description such as 'people with impaired physical and/or mental abilities'.

When quoting national reports, we have maintained the terminology of the individual reports translating these terms directly into English. As always, some terms have lost some of their nuances owing to translation, and we have not wanted to erase differences any further by harmonising the terminology in this report. Therefore, we applied a pragmatic approach to the issue at hand and thus use different expressions and concepts. For example, we may refer at different times to 'handicapped adults' or 'people with developmental disabilities' or 'people with reduced mental and/or physical functions'. This should remind the reader of the complexities of language, the simplifications that arise from translation and national differences in the very terms and concepts that underpin services and work in them.

Moreover, it is quite problematic to maintain a multi-faceted and adequate use of concepts relative to the range of day care facilities and 24/7 services. On a national perspective it may matter whether you refer to housing services or housing units, and in Denmark there is no such thing as institutions for adults with handicaps (i.e. meaning relatively large and self-contained settings), although many housing services are referred to as institutions. Again, we adopted a pragmatic approach to the use of these concepts.

We stress that our use of concepts when referring to the groups of workers represented among the informants also lacks precision. Generally speaking, we refer to care workers, but this may comprise a number of differing occupations and professions. Concerning Denmark, we refer mainly to pedagogues because of the overall dominance of this group in the case study field in Denmark and because the term 'care workers' is misleading when talking about this professional group. On a number of occasions, we just refer to practitioners.

Finally, we use the concept of informants who were the people interviewed during the case study. We greatly appreciate your tolerance with regard to our use of these concepts.

### **1.2.5 Methods**

#### *1.2.5.1. Research methods*

The field is examined using relatively extensive questionnaires and interviews of individuals, each interview lasting 1½ - 2 hours in each of the three countries. Interviews were conducted by each national team of researchers on the basis of a common interview guide. The questionnaire and interview guide are available in the three national languages - Danish, Dutch and Swedish – but were not translated into English. In addition, the researchers participated in guided tours at the institutions, day care facilities and 24/7 institutions covered by the study. The lead team of researchers (Denmark) participated on a field trip to the Netherlands and Sweden.

In addition, we incorporated various other sources such as social policy documents and databases, for example on national educational systems. We have also drawn on other research to some extent, for example to highlight the conditions and historical background of the handicap area within this field of work. The research literature has not only added specific information about the field but also served as a source of inspiration in the interpretation of our own case study.

#### *1.2.5.2 Informants*

The three national teams of researchers interviewed a total of 43 practitioners, of whom 21 were women and 12 were men (Table 1.1). Chapters Two and Three break down the practitioners in terms of employment sites, ages and education, as well as their background, motives and routes into the handicap work. In addition to being interviewed, all the informants completed an extensive questionnaire.

**Table 1.1. Informants by housing services, day care facilities and assistants for people with physical handicaps.**

Care service	Denmark	The Netherlands	Sweden
Housing services	6	7	5
Day care facilities	7	2	5
Assistants for people with severe physical handicaps	2	6	3
Total informants	15	15	13

In addition, we interviewed 15 policy makers and 12 trainers. The 15 policy makers are involved in high level political and administrative decision-making. The informants represent the government, regional or local levels, non-profit organisations that run handicap services, trade unions or associations of professional people, as well as organisations for users and relatives. The 12 trainers interviewed educate the care workers and pedagogues who make up the core of the study<sup>1</sup>.

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<sup>1</sup> One of the Swedish informants in this group is both a policy-maker and trainer, and is thus a member of both groups.



Although we did not aim to produce representative samples, we did try to obtain a spread of informants in terms of geographical location, age, gender and work experience.

### *1.2.5.3 Analysis*

All interviews have been transcribed and coded using the Nvivo software. The three national teams of researchers coded their material on the basis of a jointly prepared list of codes with the following themes: function/purpose, understandings, status and image, roles and tasks, daily work, working environment, working conditions, organisational and management issues, social networking, professional inspiration, gender, motivation, routes into the field, career opportunities, work life/private life balance, job satisfaction, personal competencies, educational issues, recruitment and innovation.

Each researcher/team of researchers coded the material on the basis of their own assessment of which codes applied to each part of each interview: a question about social networking might, for example, provide information about a range of subjects, justifying the application of multiples codes such as understandings, gender and roles and tasks.

Against the background of the coding of the material, each national team of researchers analysed and discussed the material, and prepared a national report. The Dutch national report has been translated into English, and we have read the Swedish national report in the original language.

The three national teams of researchers held four meetings at which we discussed methods and process, exchanged information and views, and clarified issues that are not easily understood across languages and traditions. In our experience, such meetings are crucial for effective cross-national research.

The national reports of the three countries represent the core of the current ‘consolidated report’, which was prepared by the Danish team of researchers. This report summarises the national reports’ main discussions and conclusions. We also discuss and put into perspective the information gained through comparison and incorporation of additional material from the three countries and by viewing the above from *our own perspective*.

We emphasise this last point because it is the Danish team of researchers which is responsible for themes, categories, concepts, problems, explanations, etc. that are generated on the basis of the three national reports and other documentation generated in the course of the research. We are very aware of that we, as Danes, interpret other people’s interpretations, discussions and conclusions. Although we have adopted a cautious approach, we do not let this curb any interesting questions or considerations. Therefore, various critical problems have been emphasised. This does not indicate any kind of truth regarding one or more of the countries involved but it does underline questions and problems that we, from our Danish perspective, have derived from the material of the three countries.

We applied a phenomenological and hermeneutic perspective in its widest sense; thus, we study material from self-interpreting people and view their statements as key statements about how care and pedagogical work is understood. In several chapters, we underline that the focus is the informants’ views on the subjects under consideration and therefore include a relatively large number of quotes from these interviews. Through hermeneutically inspired interpretations we move beyond what are strictly speaking phenomenological descriptions.

The informants' statements are valid but do not necessarily provide full coverage. Several issues were not mentioned or were only referred to explicitly. We gave this some thought and added our reflections to the extent we consider it relevant. Sometimes there may be regular differences between the informants in the three countries and sometimes it will be more correct to say that the answers reflect the type of interview, the situation of the interview, the subsequent interpretations of the national researchers as well as our interpretations. For example, why did the Dutch informants talk mostly about protection and the "dirty" aspects of the work when this subject was barely mentioned by the Danish pedagogues? We have included our reflections on these kinds of questions.

### **1.3 Additional report content**

Broadly speaking, the report follows a structure that is provided by the common codes. However, within each chapter we adopted an order that we considered appropriate for the content of that chapter. Each chapter covers all three countries. Sometimes questions and themes are discussed across countries. Sometimes we present questions and themes for each individual country separately. We did not apply a particular order for the three countries with regard to the presentation of the subjects but let the content and the discussions that ensued be the guide for the structuring of the chapters.

A few chapters are dominated by Danish descriptions. One reason is that the Danish material is quite voluminous; another reason is that we are more knowledgeable about Danish issues, and thus we were able to include these details for the purpose of putting the content of the three national reports into perspective. Our Danish understanding affects the report quantitatively and qualitatively. Thus, the report should be read as a Danish view on the three countries (whether it is possible ever to have a non-national view is an interesting and important issue).

In our view, the individual chapters can be read more or less independently of each other or in any other order than that set out by the report.

*Chapter Two* outlines the context of working with handicapped adults and is characterised by a broad coverage. We describe, in fairly general terms, the services and workers available in the three countries and in the specific services from which the case study informants were drawn. We describe handicap policy in a historical perspective and a current social policy perspective.

*Chapter Three* is about the workers. With the help of the informants we characterise the care providers in the three countries – who are they, how did they get into this kind of work and what are their views on the best and worse aspects of their work. The chapter is also about career opportunities and the balance between family and work life.

*Chapter Four* focuses on gender. Here we describe and discuss the issue of equal opportunities and the gender issue with regard to understanding care and pedagogical work. We examine the impact of gender on the various ways of performing the work in question, how it impacts staff groups and management, and we analyse the importance of the gender of staff to the recipients of care.

*Chapter Five* is about work status, image and the roles, functions and daily tasks of care workers. We take a closer look at the practical tasks involved with assistance, nursing and activities, and the

tasks of psychological, social and pedagogical support, and we examine the communication and co-ordination tasks facing the staff.

*Chapter Six* discusses networking. We examine the care workers' views on and actual networking tasks with regard to relatives and other people, including the issues arising when handicapped people move from an institution to their own house or small-scale housing services in an ordinary residential neighbourhood.

*Chapter Seven* focuses on salaries and working conditions, and the physical and psychosocial working environment of staff in care and pedagogical work with handicapped adults. We examine the key causes of stress for the informants, e.g. working alone, noise, violence or threats of violence. The chapter also discusses possible rewards of the work.

*Chapter Eight* is about education and professional development. We make a general account of the educational services in the three countries in terms of care and pedagogical work, and we outline a number of educational discussion topics that we detect and interpret on the basis of the national reports. For example, we discuss the question about the value of a generalist education and the issue of academisation of graduate studies, and we discuss education and competencies relative to working alone in a private home.

*Chapter Nine* deals with understandings of care. On the basis of the way in which the informants talk about care and pedagogical work, we identify a number of general images /categories of care and pedagogical practice and of care workers. We also embark on a definition of care and pedagogical practice relative to adults with reduced physical and mental abilities.

*Chapter Ten* provides specific suggestions about future developments with regard to recruitment of workers into the area of work with handicapped adults. A number of issues are emphasised which are considered important by the policy makers and trainers with a view to maintaining recruitment. In closing, the chapter outlines their reflections on current discussions and future developments.

## Chapter Two: Context for work with adults with disabilities

This chapter consists of four sections, describing the context which applies to working with adults with disabilities. The first section provides some demographic, labour market and economic details about Denmark, the Netherlands and Sweden. The second section contains specific information about the services offered and the workers in handicap care in general, and in this case study. The third section deals with themes in handicap policy in a historical perspective: normalisation, de-institutionalisation, integration and decentralisation. The fourth and final section analyses informants' views on the issue of the rights of handicapped people.

### 2.1 Background information

Table 2.1 below contains some demographic, labour market and economic details about the three countries in this case study.

The population of Denmark, Sweden and the Netherlands is, respectively, a little more than 5 million, almost 9 million and 16 million; thus, the population of the three countries is almost equivalent to a 1:2:3 ratio. The fertility rates of the three countries are nearly identical and at a high level compared with the rest of Europe. Considering women's labour force participation, there are differences between the Netherlands and the two Scandinavian countries, which have some of the highest participation rates in the world. Three-quarters of women in the two Scandinavian countries are active in the labour market compared with two-thirds of Dutch women. Dutch women stand out with regard to working hours relative to the two other countries and most other European countries. Almost 60 percent work part-time, whereas the number is around 20 percent in Denmark and Sweden. Dutch men also have a relatively high part-time working rate of 15 percent compared with 10 percent or less in the two other countries. Later, we will see how the differences in working hours are reflected by the care workers interviewed. In all three countries, the unemployment rate is relatively low. Notably the Netherlands enjoys a low unemployment rate of 2 percent for men and 3 percent for women whereas the unemployment rate is almost twice as high in Sweden. Since 2001 the unemployment rate in the Netherlands has increased dramatically to 6 percent for men and 7.5 percent for women.

One measure of the wealth of a particular country is its per capita GDP, and on this basis, all three countries enjoy high levels. Among the three countries, Sweden ranks third with US\$26,800 per inhabitant with the two other countries at slightly higher levels. Tax receipts as a proportion of GDP shows significant differences between the three countries; Sweden ranks highest at 54 percent, then comes Denmark with almost 50 percent, and the Netherlands ranks third at just over 40 percent. The figures reflect the large public sectors in the two Scandinavian countries funded by a tax income. This also applies to handicap care. In the Netherlands, there is a long tradition of applying other sources of funding as well. Regarding handicap care most are covered by the collective insurance system, and this may be one explanation for lower tax receipts in the Netherlands. Publicly-funded childcare services are also on a smaller scale than in Denmark and Sweden.

**Table 2.1: Demographic, employment and economic figures for the three case study countries. 2001**

Indicators	Denmark	Netherlands	Sweden
Population	5,360,000	15,990,000	8,900,000
Total fertility rate	1.7	1.7	1.6
Population under 15 as a percentage of the total population	19%	19%	18%
Population aged 65 and over as a percentage of the total population	15%	14%	18%
Female labour force participation	76%	66%	76%
Employed working part time <sup>2</sup> (2002)			
Women	23%	59%	21%
Men	10%	15%	8%
Unemployment rate			
Women	5%	5%	5%
Men	4%	2%	6%
Per capita GDP (using current PPPs <sup>3</sup> ) (2002)	US\$ 29,900	US\$ 29,400	US\$ 26,800
Tax receipts as percent of GDP (2000)	49%	41%	54%

(Source: OECD 2003)

## **2.2 Services and workers in disability care – general and case study specific**

### **2.2.1 Government responsibility and providers**

In Denmark, the handicap area is governed by the Ministry of Social Affairs (*Socialministeriet*). As a result of decentralisation, the responsibility for disability care was transferred in 1980 from the government to the municipal and county levels. Most housing units and day care services for severely handicapped people are run at county level<sup>4</sup>, and all interview sites for this study are run by the counties. The ‘handicap assistants’ (*handicapmedhjælper*) for people with physical handicaps who live in their own homes are provided by privately run organisations or individuals, but paid by the public sector.

In Sweden, the handicap area is also governed by the Ministry of Social Affairs (*Socialministeriet*). In line with Denmark, Sweden has gone through a comprehensive decentralisation process. At first, disability care was transferred to the regional level but in 1996 it moved to the local authority level, and today responsibility lies with the municipalities.

In the Netherlands, the disability field is the responsibility of the Ministry of Health, Welfare and Sports (*Ministerie van Volksgezondheid, Welzijn en Sports*). The residential homes and day centres

<sup>2</sup> Less than 30 usual hours worked per week in the main job.

<sup>3</sup> Purchasing Power Parities (PPPs) are the rate of currency conversion, which eliminates the differences in price levels between countries. They are used to compare the volume of GDP in different countries. PPPs are obtained by evaluating the costs of a basket of goods and services between countries for all components of GDP.

<sup>4</sup> There are a total of 14 counties at present.

for handicapped people are funded by the insurance system (*zorgkantoren*) and the 12 provinces have a co-ordinating role. The same applies for home care. In the Netherlands, there is a long tradition of organisations (non-profit) to provide services for people with disabilities. In this case study we interviewed several informants employed by these organisations.

### **2.2.2 Handicap services – general and case study specific**

Handicap care is a broadly based work area with many services and many perceptions of these services, and this is reflected in the type of care staff employed. As mentioned in Chapter One, the criterion applied to select the practitioners interviewed in each country was that they represent staff working in the field of care for adults with handicaps. The target group is adults with severe disabilities, who need comprehensive care services. Thus, we have selected a major social policy area, and a group of citizens in need of considerable support from society.

The main criteria are care work and each country's definition of care work in general. We have not, therefore, included hospital care and therapy, psychiatric services and protected employment where the work element is a dominant feature. Concerning adults with disabilities<sup>5</sup> we interviewed both staff in housing units and day care services, as well as staff working with people with severe physical disabilities who live in their own homes.

Although we have established the above criteria, we still face the question of what is care work, how is it perceived by each country and how do the researchers of the study perceive it. Considering the selected informants from the three countries, it is quite clear that this is a multi-faceted area. The core areas of housing units and day care services for people with disabilities are the main area of study but staff from bordering areas were interviewed too.

In Denmark, the work involving people with disabilities is pedagogical work, and most of the staff are pedagogues. The Danish selection criteria are based on pedagogical work with care being an integral part. One of the Danish informants, who is a pedagogue, works at a day care service for people with disabilities where creative and aesthetic activities - theatre, painting and music - come to the fore. In Denmark, this type of work lies with the pedagogues and therefore it naturally finds its place in this case study. These services are also provided in the Netherlands and are part of the care sector (*zorgsector*). Unfortunately, there are no Dutch interviews from here, as the professionals in those centres are not seen as care workers or pedagogues but as activation therapists, social cultural workers or community workers. The Swedish material contains an informant whose work may be seen by others as bordering on care work. The informant works at a factory with responsibility for a small group of people with disabilities who are integrated into the production at the factory. When the day care service was moved to the factory, the professional staff moved too and thus, in the Swedish context, the work is defined as belonging to the field of care according to the research project.

In Denmark, care for people with severe physical disabilities who live in their own homes, is mainly done by 'handicap assistants' directly employed by handicapped people. In Sweden, 'personal assistants' (*personliga assistant*) do the same job. In the Netherlands, this service is associated with home services. Some special services are offered, too, e.g. FOKUS which is a separate organisation providing home services.

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<sup>5</sup> Adults with disabilities are here used as the term for adults with developmental and intellectual disabilities.

Below we will provide some data on the extent of the various services dealt with in the case study. The discussion above regarding the definition of handicap care is also reflected in the statistics, rendering a direct comparison of the extent of the services more difficult; we have nonetheless decided to present these statistics because they give some indication of the extent of disability care services in our field.

#### 2.2.2.1 Housing services

In Denmark in 2003, there were 7,500<sup>6</sup> places at almost 400 housing units providing housing services for adults with physical or developmental disabilities (Danmarks Statistik. Sociale forhold, sundhed og retsvæsen, 2003).

In Sweden, in 2000, there were 16,900 people with disabilities in residential care with special services (Norén, 2002: Table 10).

In the Netherlands in 2002, there were 53,000 users in residential homes for people with developmental disabilities and 3,100 in residential homes for people with serious physical disabilities (including blind and deaf people) (Ewijk, 2002b: Table 3.1). There were 760 services (Ewijk et al., 2002a). The Netherlands has a relatively large number of residents living in residential homes compared to the two other countries (see chapter 9).

#### 2.2.2.2 Day care services

In Denmark in 2003, there were 360 day care services (activity and social services<sup>7</sup>) (*dagtilbud dvs. Aktivitets- og samværstilbud*) with 9,900 people enrolled.

In Sweden, there were 20,500 users in daily recreational centres (*daglig verksamhet*) (Norén, 2002: Table 10).

In the Netherlands in 2000, there were 16,400 users of day care centres (*dagcentrum*) for people with developmental disabilities and 1,800 users with serious physical disabilities (Ewijk, 2002b: Table 3.1). The figures from the Netherlands are much lower than for Denmark and Sweden because day centres at the residential homes are not included in the figures).

In all three countries, there are waiting lists reflecting shortage of places. In the Netherlands, there are waiting lists for both housing and day care services (Ewijk, 2002b). In the Danish and Swedish reports for this case study, the waiting lists for housing services are mentioned as well, and it is stressed that the appropriate day care services are not always available.

#### 2.2.2.3 Personal assistants for people with severe physical disabilities

In Denmark in 2000, 1,500 people were covered by the personal assistant scheme (Social tryghed i de nordiske lande, 2000: 142). In Sweden in 2002, the figure was 4,200 people (Norén, 2002: Table 10).

The following table shows the care service sectors in which the informants in the three countries work.

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<sup>6</sup> With 354 day users.

<sup>7</sup> According to the Danish Social Service Act, section 88.

**Table 2.2 Informants by housing sites, day care centres and assistants for people with physical handicaps**

Type of care service	Denmark	The Netherlands	Sweden
Housing services	6	7	5
Day care centres	7	2	5
Assistants for people with severe physical disabilities	2	6	3
Total informants	15	15	13

### **2.2.3 Care staff in general and the informants in the case study**

#### **2.2.3.1 Denmark**

The Danish report provides details from Statistics Denmark about care staff in the handicap area. In 2003, almost 12,300 staff (calculated as full-time equivalent employees) worked in the handicap sector including housing services (Sociale forhold, sundhed og retsvæsen, 2003). The breakdown by work area (according to DISCO<sup>8</sup>) was as follows: Management and administration, 5 percent; kitchen, cleaning and janitorial, 7 percent; and working directly with the residents, 88 percent.

Table 2.3 shows the last group who worked directly with the users broken down into work areas. The table shows the various types of work performed. By far the largest group, 10,835 staff, are employed in what is termed pedagogical work and care, of whom 6,076 (56 percent) are pedagogues (trained at a higher education level), and 3,755 (35 percent) are pedagogue assistants without any professional training, and 701 people (6 percent) are social and health assistants (trained at an upper secondary level)<sup>9</sup>.

**Table 2.3 Staff who work directly with residents in housing services for adults with severe physical or developmental disabilities by their work functions (DISCO), Denmark, 2002.**

Medical work	8	0.1 percent
Senior nurse	27	0.2 percent
Training, etc. (teacher)	15	0.1 percent
Psychology work	19	0.2 percent
Physiotherapy, etc.	131	1.2 percent
Nursing	75	0.7 percent
Social counselling	28	0.3 percent
Pedagogical work and care	6 076	56 percent
Pedagogical assistant	3 755	35 percent
Social and health assistants	701	6 percent
Total pedagogical work and care, etc.	10,835	99.8 percent

<sup>8</sup> DISCO is the Danish version of ILO's and the EU's official occupational classification, which makes it possible to keep together people who perform the same kind of work but who have not followed the same subjects or completed the same kind of education.

<sup>9</sup>For further information about pedagogues and the other types of worker in the three countries in this report, see the national and consolidated reports for Workpackage Three – Mapping Care services and the Care Workforce – at the Care Work in Europe website, [www.ioe.ac.uk/tcru/carework.htm](http://www.ioe.ac.uk/tcru/carework.htm)



There are no similarly detailed figures of staff employed in day care services, i.e. activity and social services. The staff numbers were 6,100 but they cover a broader work area than this study as this includes staff at rehabilitation and sheltered employment centres.

The handicap care sector makes up a small part of the total Danish pedagogical and care work field, totalling nearly 18,500 employees including rehabilitation centres and sheltered workshops. For example, there are more than 100,000 employees in services for children, and nearly 100,000 in elderly care. The 24-hour institutions for children and young people employ nearly 7,600 people (Social forhold, sundhed og retsvæsen, 2003)<sup>10</sup>.

As already mentioned, since the staff employed in disability care in Denmark are mostly pedagogues, we have chosen them as our informants. We interviewed a total of 12 pedagogues and one social and health assistant. We decided not to interview pedagogue assistants because this group of staff, at the interview sites, consisted of relief staff, students, etc. Six employees worked at housing units and seven at day care services. The interview sites were selected from two counties<sup>11</sup>, and all the informants are thus employed by the county (i.e. they are in the public sector).

With regard to people with severe physical disabilities who live in their own homes in Denmark, the work is often done by handicap assistants who are employed by the handicapped person. In this case study we interviewed two handicap assistants.

#### 2.2.3.2 Sweden

In Sweden it is not easy to find statistics that break down occupations according to the services in which people work. Nursing assistants (*vårdbiträde*), auxiliary nurses (*undersköterska*) and treatment assistants (*behandlingsassistent*) can all be employed to do different services or work in different care sectors. They are generalists and trained to work in both the health care sector and in the care for disabled and elderly people (Norén, 2002:21).

The Swedish researcher interviewed five care workers at housing units and one who worked as second in command at a unit. Three care workers and two therapists from daily recreational centres were interviewed in Stockholm and Umeå municipalities<sup>12</sup>. All employees are public sector staff.

Three personal assistants were also interviewed. Two of them were employed by the municipality, and one was employed by the municipality and a private company.

#### 2.2.3.3 The Netherlands

In the Dutch handicap care there are some 48,000 employees, most of whom work part-time so presumably about 30–35,000 employees calculated into full-time employees<sup>13</sup>. According to their training background, the workforce can be divided as follows: 14,500 nurses, 30,000 social pedagogues and 4,000 primary care providers. In Denmark we found that the number of pedagogues is over 90 percent of the total staff (incl. pedagogical assistants). In the Netherlands the number of

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<sup>10</sup> Staffing figures presented as full-time equivalents.

<sup>11</sup> [www.aarhusamt.dk](http://www.aarhusamt.dk), [www.viborgamt.dk](http://www.viborgamt.dk)

<sup>12</sup> [www.Umeaa.se](http://www.Umeaa.se), [www.sot.stockholm.se](http://www.sot.stockholm.se)

<sup>13</sup> According to the Dutch researchers.

social pedagogues is 60 percent, so the difference between the two countries is the number of nurses being much higher in the Netherlands.

Home care provides for several target groups. Care for physically disabled people is primarily delivered by home care, but it is impossible to unravel that in numbers. In home care we encountered primary care providers (levels 2 and 3, in particular) and nurses (level 4 or 5). In total 184,000 professionals work in home care<sup>14</sup>.

Seven of the Dutch informants were working in housing units, two in day care centres, and six as practical helpers / supervisors for people with severe physical disabilities. Compared with the Danish and Swedish informants, there are more Dutch workers involved with people with severe physical disabilities and fewer employed in day care centres. Several are co-ordinators and coaches. The position of the Dutch informants are: home care provider / supervisor (*praktische thuishulp/praktijkbegeleider*), client supervisors (*cliëntbegeleiders*) (three; two of them work with elderly users), care co-ordinators (*zorgcoördinatoren*) (four; two of them are also coaches), care specialists (*zorgkundigen*) (four; two of them are also coaches and one of them is an assistant), ADL assistant (*ADL-assistente*), C-care provider and non-residential worker (*verzorgende C en ambulante werker*).

The informants are employed by various private organisations that provide disability care in the Netherlands: Amerpoort, The Philadelphia Care Foundation, Esdége-Reigersdaal, Amsterdam Home Care and Fokus Foundation<sup>15</sup>.

### **2.3 Handicap policy in a historical perspective: normalisation, de-institutionalisation, integration and decentralisation**

The research project focuses on care and care work. The care and handicap policies, however, are associated and we will therefore include various themes and cover these from a general perspective. The purpose is to draw attention to key themes within the context of care and care work. We will examine the themes of normalisation, de-institutionalisation, integration and decentralisation, which have been key words globally and notably in Scandinavia in the past 30 years of disability policy (Tøssebro, 2000).

In many ways, the handicap policy developed in parallel in Sweden and Denmark, but Sweden was slower than Denmark to remove the large, isolated full-service institutions and to develop a disability policy, which aimed to provide “near-normal” conditions for people with disabilities. By contrast, Sweden seems to have gone further than Denmark in the de-institutionalisation of housing and the labour market for people with disabilities. In the Netherlands, it is quite common for people to live in an institution. Briefly put, Denmark has opted for solutions that in many ways lie between the solutions applied by Sweden and the Netherlands in terms of integration efforts, normalisation principles and other areas.

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<sup>14</sup> From Dutch national report.

<sup>15</sup> [www.amerpoort.nl](http://www.amerpoort.nl), [www.Philadelphia.nl](http://www.Philadelphia.nl), [www.esdege-reigersdaal.nl](http://www.esdege-reigersdaal.nl), [www.fokuswonen.nl](http://www.fokuswonen.nl), [www.amsterdamthuiszorg.nl](http://www.amsterdamthuiszorg.nl)

### 2.3.1 Denmark

As early as the 1950s, Denmark discussed de-institutionalisation and 'normalisation'. In 1952, a parent association was established, enjoying significant political clout and its influence, among other factors, led to the amended law on mentally handicapped people (the term then in use in Denmark: 'Åndsvagelov') in 1959. Following the law, it was confirmed that care of mentally handicapped people should be an individual and voluntary service, based on the key concepts of equality, equal rights and normalisation<sup>16</sup>. The altered political approach regarding this group opened the way for non-medical theories and professions (Kirkebæk, 2001).

A practitioner, who was interviewed in the Danish study, stresses the importance of the majority of staff in the adult disability area being pedagogues:

*We are talking about two fundamentally different ways of viewing human beings and that is one reason for the increasing number of pedagogues in psychiatric centres instead of care workers. It is a different concept of thinking. It is not that the care workers are not good people but they are trained to do something else. We focus on development and they focus on diseases. We do not focus on cure – that is the key difference, I believe.*

The expression of "near-normal", which was launched in the early 1950s by the well-known Bank-Mikkelsen, was almost a kind of magical thesis, Rønn (1996) says, indicating the beginning of possibly the most important U-turn in the history of the sector and with the decision to literally phase out the area in question. The concept of 'normalisation' had strong public appeal and was hard to oppose. Much effort has been put into explaining the true meaning of Bank-Mikkelsen's normalisation concept. His intentions were to focus on near-normal conditions to the widest extent possible (Kirkebæk, 2001; Rønn, 2002;) but the thesis has also been interpreted to mean that you should focus on helping people with disabilities to live a normal life in the sense of what is normal for the rest of society.

Øgendahl (2000) writes that care of people with developmental disabilities thrived in the 1960s and people's minds changed markedly in a short time. The focus was to render visible people who had been "forgotten" for a century in isolated institutions and a large-scale construction of community services was initiated (homes for elderly people, leisure-time centres, schools, houses, etc.). The aim of the 1959 law was to create a near-normal life for people with developmental disabilities to the largest extent possible but it was only partially successful during the period and was not properly realised until the transfer of care services to the counties and municipalities in 1980.

The decentralisation was followed by the establishment of new housing types, amended rules on social pension payments and other social benefits, etc., and all these measures were aimed at establishing rights and conditions on a par with those enjoyed by other citizens. But to a certain extent, Denmark maintained special ways of organising support. This was done in recognition of the special needs of these people. Denmark established housing services in ordinary residential areas, including ordinary apartments, but with small groups of residents living together in individual apartments and sharing common areas and a joint staff.

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<sup>16</sup> The 1959 law introduced compulsory teaching of mentally people with disabilities in line with other citizens, and voting rights for mentally people with disabilities who were not placed under guardianship.

Regarding daily activities, Denmark has not offered employment at ordinary workplaces to the same extent as the Netherlands and Sweden. Several services are offered by way of protected employment at ordinary workplaces and specialised production workshops but these developments have been affected by arguments that normalisation does not necessarily mean living a life in line with the majority of the population and having salaried work. In Denmark, activity and social centres are common where production plays a completely subordinate role. A Danish policy maker said that during the 1980s there was a strong production focus. Today, however, the services have a much wider remit. The marked development has created a dilemma

*because production was associated with an income, and our present income is not even one fifth of the level in the 1980s ... and we are talking millions when it comes to [our] county... It has involved a significant reorganisation of our efforts and staff numbers because when these huge amounts were provided, more people could be hired.*

Kristiansen (2001) writes about user involvement and citizenship, and that the concept of a near-normal life has developed into a citizenship approach, focusing on both rights and duties with a view to social integration and quality of life. In a perspective of citizenship the individual user is not defined as a 'pupil' or 'patient' placed with an institution but as a citizen and user of social services, and in this context the removal of the institution concept followed as a natural consequence. One of the interviewed policy makers sees the removing of the institution concept as an important measure that reflects the altered views of people with developmental disabilities and thus the service content.

*To begin with, the rules were changed so the social pension payment was not abolished when one moved into an accommodation facility. One kept the social pension but had to pay rent and pay for cleaning and fresh laundry on the basis of your pension payments – as other people do. With the Danish service legislation that came into effect in 1998 the legal foundation for the institution was removed [...] It is quite a milestone with regard to the perception of people with disabilities. This does not happen overnight. You begin by changing your attitude towards people with disabilities, seeing them as independent people who should not necessarily be treated as a group of people.*

There is another policy maker who is positive about the development and refers to a movement from a 'normalisation discussion' to a 'co-citizen approach'. He says that the improved conditions for people with mental disabilities represent one of the biggest successes in Danish social policy. At present, the staff are discussing how

*A co-citizen without a proper language may try to express his own views and definition of needs ... then I think we have come a long way. I believe there is a high degree of ... a relatively high educational level in the disability area in Denmark. I appreciate our view on other people ... the agenda determined by Bank-Mikkelsen in his normalisation thoughts has already been abandoned. We are far beyond that stage. Today, we are discussing the co-citizen approach to a much greater extent..."*

To put it briefly, disability policy in Denmark has been affected by decentralisation, de-institutionalisation and a physical and administrative integration as referred to by Tøssebro (2000). The major institutions have been removed and people with disabilities live in ordinary housing or small-sized communities that have maintained some of the benefits of the institutions but which are found in widespread locations and with private apartments for each resident. The legal framework

entails that apartments provided by the housing services are the private homes of the residents. However, the Danish disability policy has not focused on special legislation to deal with special rights for people with disabilities. This is covered in more details in the section on rights.

### 2.3.2 Sweden

Bakk and Grunewald (2000) write about the development in the Swedish care sector for people with developmental disabilities and they state that normalisation and integration have been key concepts. According to the two authors it was a very radical move in the 1960s and 1970s to claim that people with these disabilities ought to live together with ordinary people in society instead of in major institutions that were isolated from the population. Today, in Sweden, this is taken for granted, i.e. society and disability care must be organised to prevent segregation.

As mentioned, the normalisation debate emerged a little later in Sweden than in Denmark. A key driver of developments in Sweden was Professor Karl Grunewald, a medical doctor and later senior inspector at the health board with responsibility for the area, covering people with learning disabilities. Together with the Dane Bank-Mikkelsen he founded a Nordic association for the benefit of mentally handicapped people. Other key drivers – just as in Denmark – were a number of influential parent organisations. In Sweden, the concept of normalisation began to gather momentum in the late 1960s (Bakk and Grunewald 2000), and in his thesis from 1969 the Swede Bengt Nirje (1969) wrote about the inspiration provided by the Dane Bank-Mikkelsen:

*To discuss human endeavours to create wholesome programmes, facilities, and life conditions for other human beings in terms of one unifying principle might seem preposterous, especially when the mentally retarded are involved, a group which is characterized by wide variations in age, degree of handicap, complicating physical and emotional disorders, social backgrounds, and educational and personality profiles. Nevertheless, in the Scandinavian countries, a general principle which expresses the aims, attitudes, and norms implied in quality work for and with the mentally retarded has been found of value. As expressed by N.E. Bank-Mikkelsen of Denmark, this principle is given in the formula "to let the mentally retarded obtain an existence as close to normal as possible." Thus, as I see it, the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. This principle should be applied to all the mentally retarded, regardless whether mildly or profoundly retarded, or whether living in the homes of their parents or in group homes with other mentally retarded. The principle is useful in every society, with all age groups, and adaptable to social changes and individual developments. Consequently, it should serve as a guide for medical, educational, psychological, social, and political work in this field, and decisions and actions made according to the principle should turn out more often right than wrong."*

At present in Sweden, to put it briefly, people with developmental disabilities do not live in institutions but in their own apartments or other types of housing with a small group of people in their own small apartment with common areas. You could say that the housing conditions of people with disabilities and their daily activities are as near-normal as is possible. The Swedish national report notes, however, that integration efforts may result in the loss of quality of life for these citizens. A Swedish care worker in a housing unit provides an example of a model according to which the authorities have interpreted the normalisation concept too literally and ignored the requirements laid down by the law:

*normalisation was said to involve everyone going to live in their own apartments as ordinary people do. You would have a TV and a telephone. And normalisation is not always ..., and there you should not have any common facilities because not having this would be normal. It quickly turned out that this group of people are very lonely. Some of them do not know other people who are interested in them, or they are dead. They have very few friends. It developed into a catastrophe. These people are sitting all by themselves. Considering the LSS law, it is quite clear that there should be no more than five people in a housing unit and there should be common areas, you will understand this when you read the law.*

The Swedish report also points to the importance of integration efforts with regard to the visibility of people with disabilities in society, e.g. in conjunction with daily activities that are organised at ordinary workplaces. Visibility is perceived by several Swedish informants as a specific objective to be achieved by letting people with disabilities work at ordinary workplaces, and the general result is a more positive view, especially among young people.

Cost savings and threats of cutbacks in recent years have affected the staff's view on the level of priority given to their area of work. Owing to financial difficulties, the users are currently fighting to get the help that they are entitled to under the law. One Swedish informant says that the area is seen as a burden, which affects the users and the staff adversely. Similar thoughts are presented by the Dutch report. It makes you wonder how closely the ideals and views about people with disabilities in disability policy are associated with socio-economic conditions.

### **2.3.3 The Netherlands**

It is common for Dutch people with disabilities to live at an institution located outside ordinary residential areas. The Dutch researchers write that "institutional care for the disabled has been attained, and is still at a high level on the international scale. In the Netherlands there are currently as many disabled people in institutional facilities as there are in Great Britain and Scandinavia put together". However the institutions in the Netherlands today cannot be compared with the institutions that were removed long ago in Denmark and Sweden.

The Dutch national report associates the strong traditions of institutionalisation with, among other things, a lack of housing following the Second World War, and ties institutionalisation together with the affiliation of care to the Catholic and Protestant churches and the general block.

According to Gennep and Hove (2000), the institutionalisation and medical perception of care that dominated the 20th century until the 1970s was widely criticised in the Netherlands, and the two authors stress that at the end of the 20<sup>th</sup> century a new perspective named the "citizen paradigm and the inclusion in the community" was developed. But given the lack of a wholehearted adoption of this paradigm, as Gennep and Hove believe, an unfortunate neo-conservative counter reaction against de-institutionalisation followed.

In the Netherlands it is emphasised that integration cannot be assessed by the number of people who have moved away from the full-service institutions and into local communities. Dismantling the institutions does not automatically lead to genuine integration. Several researchers, including Gennep and Ruigrok (2002), stress that the integration efforts that were introduced with the

normalisation ideals in Scandinavia have been characterised by an understanding that integration takes place almost automatically after de-institutionalisation. This perception the authors stress is outdated and the inclusion paradigm is more relevant. They mention three movements in the de-institutionalisation process: (1) physical integration, (2) functional integration, and (3) social integration. The physical integration follows from the de-institutionalisation. The functional integration means supporting access for handicapped people to common facilities of society, e.g. theatres and sports facilities. Social integration is the only true integration, when you are accepted as an equal member of society.

Without entering a discussion of the quality of the integration efforts of the various countries, you could say that the Dutch transformation process (de-institutionalisation, decentralisation and integration) is in many ways still relatively new compared with Sweden and Denmark. According to the Dutch study, the transformation is supported in principle but it worries care workers, politicians as well as other citizens. They are concerned about striking a balance between integration and protection, the risk of losing the expertise available at the institutions, and that development gets out of control due to concurrent cost savings. The national report observes:

*Firstly, there is the concern about safety. In the residential setting, a very safe world has been created, both materially and immaterially. The latter primarily concerns the danger of discrimination and being harassed. In residential care, very specialised expertise is at hand. In small-scale facilities in the community, this knowledge is not (or only remotely) available. However, it is not just about expertise but also the physical specially-adapted facilities for sport, physiotherapy, learning and work. In the excellent premises in the woods, facilities have been built that are usually very well-adapted and comfortable, completely fulfilling the residents' needs. The government representative even talked of 'overcare'. In the [residential] homes, the facilities are so good that parents and professionals very quickly feel that a transfer to a community unit would be a direct step backwards. There is also a clear downside. In striving for community care, people can go too far, and so residential care comes under fire. We pass on the knowledge that has been built up, the positive sides of providing shelter in nature, in a created world where people can be happy and safe and are allowed to flourish. The development towards community care must not be seen as a counter-movement but as an alternative. And then the relationship may change, and more people may well end up in community care.*

The Dutch report continues:

*A second critical comment on de-centralisation is that the economic measures, which have been provided, do not match the intention to move over to small-scale facilities. In the Netherlands, the de-centralisation of care is not seen and felt to be an economic strategy (as was the case in Great Britain). The manager of the large care institution pointed to the problem that monitoring quality, supporting professionals and managing the budgets all becomes more difficult with a policy where the facilities are spread throughout neighbourhoods on a small scale. There is a real danger of losing quality.*

## **2.4 Informant views on the question about the social rights of handicapped people**

We turn now to consider the informant informants' views on the rights of people with severe and physical disabilities. The informants' views are the focal points but we will also refer to the

disability policy of the three countries to put their views into perspective. The main topic of this section is social rights. Civil and political rights are only dealt with very briefly. Chapter Nine also covers some of the themes of the section, e.g. the normalisation issue.

By allowing its citizens rights, the society shows recognition of its people and groups of people, and any lack of rights is thus reflected as a lack of recognition. When you deal with the rights of people with disabilities you are therefore dealing with society's view on disability as well as people with disabilities, and indirectly you are dealing with the demands, image and status of care work. The study shows that the informants experience this connection. They see it as offensive to the person with disabilities and to themselves when these rights are ignored.

The question about rights is both large and complex, as outlined by one of the Dutch informants:

*Legislation alone is not sufficient; of course it's also a question of mentality. Furthermore, 'rights' refers not only to formally established rights but also to complex problems such as compulsory treatment, whether or not one has the right to get married and have children, and probing ethical issues about medical intervention before and after birth.*

The theme is not dealt with systematically with regard to the three countries. Thus, legislation that is mentioned in relation to one of the countries may in fact be present in the other countries but is not mentioned in their national reports. The section therefore cannot conclude whether one country ensures people's rights any better than the other countries, but it does outline the differences and similarities of the discussions that are key to the rights issue.

An in-depth account of the rights issue in a historical perspective and an examination of international and national rights documentation go beyond the scope of this report. However, we will initially outline the UN's general provisions adopted in 1993 and which probably represent the most important material on international disability policy. The UN's general provisions outline the overall handicap policy objectives in a number of key areas of society. They are based on a definition of handicap as a description of a loss or limitation of the opportunities to participate in society on an equal footing with other people. The general provisions have had great impact, e.g. by focusing on surroundings that prevent people with disabilities from being equal citizens of society. We have adopted a similar focus in our study, i.e. on insufficiencies in the surroundings that prevent people with disabilities from being equal citizens of society and how our informants perceive these conditions.

#### **2.4.1 The Netherlands**

In 2003, the Netherlands passed the Act of Equal Treatment of the Disabled and Chronically Ill (*Wet gelijke behandeling gehandicapten en chronisch zieken goedgekeurd*). This law replaced the General Equal Treatment Act, which did not cover physical or mental impairment. According to the national Dutch report, the 2003 law provides: "disabled people with the right to any adaptations necessary so that they can function fully in society", and the report states, that "in this way discrimination is prevented. For the time being, the act is applicable in the fields of work, vocational education and public transport. In the future, the act can be extended to other fields".

With regard to the fairness of the principles of equal rights, the Dutch report states that the interviewed policy makers and teachers do not take a stand on these issues during the interviews:



*“In the interviews with policy makers and instructors there is no discussion on whether the principle of equal rights is fair in itself. The discussions concentrate directly on working issues”.*

The Dutch report reckons that *“for the care providers, the most demanding question is perhaps that of the duty to supply care”* and an informant is quoted stressing that care is a right but not one that can be ensured when financial limits apply. The law adds some value, however, because it applies additional pressure to increase the supply of services:

*The Exceptional Medical Expenses Act, a number of recent judicial verdicts and now the passing of the Equal Treatment Act have laid the foundation for a right of supply to be enforced. The providers point out that this right cannot be enforced in a funding system that is budgeted (i.e. it has an upper limit). However, the new act will increase and strengthen the extent of enforceability of care supply or adaptations at work, in the home, in public transport or in public places.”*

#### *2.4.1.1 Ethics, humanitarianism and professional care*

The Dutch practitioners largely do not mention the legislation but stress a number of themes that indirectly deal with rights. These themes, however, could be categorised as principles about humanitarianism and ethics in practice. They are about accommodating needs and giving them opportunities for influencing day-to-day life. The report provides quotes from an interview with a senior client supervisor that stresses the requirement to accommodate needs and read signals and also refers to the exercise of power in the relations:

*To know what the client wants, you really have to watch for the signals someone gives you. ‘You have to look really deeply. Even if they don’t say it, it’s still there’. So you’ve got to make an effort to be able to understand it. Every day you have to be aware that you’ve got full power over them, in principle, but at the same time you have to translate their misunderstood demands into ‘what do you mean exactly?’*

On inspection the interview quotes found in the Dutch report contain many statements that can be interpreted as representing the view that it is both a quality in care as well as a right for the care recipient that the professional knows the needs of the person in question. The report also contains a number of quotes criticising the care workers as knowing what is best for the person they are caring for. One informant says: *“Certain things you have to decide. But then the view behind it is very paternalistic: we know what’s best for you.”*

The Dutch report underlines that people with handicaps have been brought up with other people formulating their needs: *“In addition, residents/clients are not always used to making their wishes known, because, for example, the group leaders always determined what was good for them”*. It provides a quote from an interview that illustrates the problem:

*People have always thought for them and now they can think for themselves. Like if you say ‘what sort of work do you want to do?’ They’ve very much grown up thinking ‘the group leader decides what’s right’ ... It also appears that clients are influenced by other people. Then their own wishes are swept aside. For example, one client wanted to watch a particular video. His family didn’t agree with it. In a conversation with them, the client’s opinion was influenced. He changed his opinion.”*

The views of the Dutch practitioners on the rights of people with disabilities are summarised in the Dutch report. They have the right to:

- Continuity of care (less staff turnover).
- Privacy
- A good house and good support.
- Good information
- Not having any opportunities taken away from them
- An occupation

The report brings a warning – as expressed by one of the practitioners:

*It is their right that you don't put the bar too high. 'Putting the bar higher' is pure selfishness, because you yourself want to meet your challenges. That's a really bad thing. I do think it happens in care. Too much is asked of the client, when a bit of peace is all they need. They [care workers] work really hard during the day and I have a great deal of respect for that. They're never ill.*

#### 2.4.1.2 Use of compulsion

The rights issue is inevitably associated with the question about the balance and use of compulsion in day-to-day life. In care relations this is an ongoing issue (both as a conscious and unconscious factor). By definition, the care worker is the most powerful person in the relationship, although a complicated game may develop in which the handicapped person may also take the upper hand. In any circumstance, however, a formalised allocation of rights is inadequate to ensure dignity and quality of life. Care workers need to understand the importance of the balance of power in the care relations. The Dutch report refers to a teacher who stresses this issue: *"The instructors indicate that the realisation of rights calls for professionals who recognise their own position of power and who handle the demands and rights of their clients soundly."*

The Dutch report discusses the application of compulsion in several perspectives: (1) in forced treatment, and (2) staff eventually assessing what is best for a handicapped person, and (3) aimed at avoiding everyday accidents. These three ways of using compulsion or force share the common feature of involving a particular person with the right to define other people's needs and problems. The Dutch report refers to forced treatment and the lack of clear-cut rules in the area: *"for example in contraception and sterilisation or in treatment. One of the people interviewed states that here in the Netherlands there is too little investigation carried out and too little clarity. Here it is more down to a per-person and per-professional assessment"*.

As mentioned, the use of compulsion may also consist of an assessment of the day-to-day life that people with disabilities cannot genuinely control. General rules may be determined by the organisation or rules may be applied by way of requirements that emerge owing to professional assessments, e.g. a decision that a particular person must not eat as many French fries as he likes or that he cannot stay in bed all day. The informants tell that they apply coercion by persuading a person to change his wishes. Several informants are sceptical about the requirement that you should act in the best interests of the handicapped person, and they underline that the staff are generally ignorant about their power.

The report, however, does not mention any critical comments about the use of compulsion that may take place when a care worker is under pressure or not qualified to solve a conflict.

The rationale for using compulsion with a view to avoiding accidents may be closely associated with finances, as stated by an informant in the group of policy makers. It is important, the informant says, that the number of accidents are limited in view of the image of the institution. This statement reminds us that the obvious or hidden use of force may take place in order for the organisation to maintain its external image, and it also reminds us of the inherent dilemma of care with regard to the use of force versus individual freedom. This complex dilemma is not only about using force to protect another person at the expense of that person's freedom – it is also about using force when the care worker does not have the professional background required to understand how to avoid the use of force while protecting the person in question.

The report mentions the use of force that takes place when locking up a person, e.g. when a door is locked or strapping a person to a chair or bed, and it concludes *"You must always be able to justify the use of force and it must be reflected in the clients care plan"*.

#### **2.4.1.3 Duties**

The Dutch report states that rights are associated with duties and involve the right of having duties, but also refers to "the flipside of the rights". The right to your own housing results in the duty of paying rent and being a good tenant, and as a resident of an institution you must observe the rules, which may involve a dilemma relative to the target group in question. The statement suggests that the requirements expected of people with disabilities are generally debated; to what extent can you apply rights to impose specific duties and a specific behaviour?

#### **2.4.2. Sweden**

The Swedish report states at the beginning that care work staff and policy makers view the rights issue from different perspectives. The staff views things in the context of the user whereas policy makers view things from a structural and social perspective.

##### **2.4.2.1 Two key laws applying to people with handicaps**

The Swedish report explains the importance of the law. The two laws of LSS (Act concerning support and service) (*Lag om stöd och service till vissa funktionshindrade*) and LASS (the Assistance Benefit Act) (*Lag om assistansersättning*) were adopted in 1994 and have led to a clearer user-orientation in disability care.

The spectrum of people dealt with by LSS is divided into three groups. People with severe physical disabilities or severe mental disabilities *and* with a significant need for support form group 3. Inclusion in one of these groups is decided on a case-by-case basis.

LSS gives rights in ten areas of which the first nine only apply to all three groups. Once you know whether you are part of the target group, it is decided whether there is a need that is not met by other legislation and which is covered by one of the ten areas. If so, the service is not just an offer, it is a right. Group 3, however, is not entitled to daily activities, which is one of the ten areas.

The ten areas of LSS are: (1) counselling and other personal support, (2) personal assistant or financial aid to hire a personal assistant (in addition to the support provided under LASS), (3) companion service, (4) approval of contact person, (5) assistance at home, (6) short-term stay

outside your home, (7) short-term supervision of school children at the age of 12+, (8) family care or housing units for children and young people, (9) housing with services or appropriate housing for adults, (10) daily activities for adults (only groups 1 and 2). Under LASS, personal assistance is to be provided to people under the age of 65, who live in their own homes, 'service homes', with family or who have a long-term service need in excess of 20 hours per week (source:

*De Handikappades Riks-förbund*, the Swedish Federation for Handicapped People, [www.dhr.se](http://www.dhr.se))

The Swedish national report mentions an example of the importance of LSS – the individual handicapped person is no longer only to receive services that are made available but should be involved in a customised planning process. The report provides the following quote from a policy maker: *a person with a development disability would be able to do some planning after having completed school: What would I be interested in? What are my strengths? In what areas do I need support? What is my dream job? This is what LSS is about."*

LASS (law on assistant support), which entitles the users to a personal assistant, is emphasised as particularly important because it provides the users with influence on their own lives. Mainly physically handicapped people take advantage of the possibility of receiving the money they need to hire an assistant, but according to the Swedish report this opportunity is also available to people with developmental disabilities. As a matter of fact, only a few people with developmental disabilities are able to manage this themselves but the administrative work could be left to a representative. Denmark also offers a scheme under which people with reduced functional abilities may get cash to hire an assistant. However, the Danish scheme is different from that in Sweden since the recipient must be able to perform the employer role vis-à-vis the personal assistant. Thus, people with serious developmental disabilities are basically excluded from the scheme.

The LASS law is funded by the State rather than local government (LSS is provided and funded by the municipalities). This is comforting in the light of the financial difficulties facing the municipalities. The effects of the financial difficulties of the municipalities is mentioned several times in the Swedish report, and also in the context of the right of having your own home that cannot be met by the municipalities:

*Since the users are entitled to the service laid down by LSS, the municipalities must ensure the law is observed. If a person is granted a home under LSS, then the municipality must provide it or have to build it from scratch if needed. But owing to the financial difficulties that regularly face the municipalities and the high costs of disability care, the service granted is not always provided. This limits the user's ability to gain influence on their own life.*

#### 2.4.2.2 Practitioners and the legislation

As mentioned at the beginning of this section, the Swedish report stresses that the practitioners are more user-oriented while the policy makers are more focused on structures and society. In spite of the practitioners' user-oriented approach, however, they seem relatively well informed and conscious about disability policy principles and the relevance of the law in this area. In this respect, the Swedish care workers resemble the Danish pedagogues while they differ from the Dutch practitioners.

The Swedish report notes that several of the practitioners stress the LSS and LASS laws as key legislation:

*Several members of the staff group stress LSS and LASS as important for the structuring of housing and daily activities as well as for the user involvement and opportunities for influence and self-determination. As to the user rights and opportunities for self-determination they refer to the law and indicate that the municipalities may not always be doing what they are supposed to do.*

It quotes a woman working in a housing unit as follows:

*when you read a note in the news paper that the municipality has been taken to court because it has not been able to provide housing. According to LSS they are entitled to housing units and then the Stockholm city authorities or the municipality will argue that there is no housing unit available and that they cannot build anything because of lack of money. Then they are taken to court and are asked to pay millions. Which they will do, because it is apparently cheaper to pay these amounts rather than build new homes.*

#### *2.4.2.3 One person's life – another person's work*

The Swedish report includes the question about a correlation between management and the rights of handicapped people. One of the informants provides an example about people who were unable to participate in dances lasting until 11 pm because the staff's working day ended earlier.

This is an interesting example. It that allows us to generalise regarding the importance of a correlation between the organisation of care and the opportunities of self-determination and influence for handicapped people. This issue is probably relevant in all three countries studied. Care seems to be associated with a number of dilemmas with a common core: when a care worker and a care recipient work on the same task or activity (broadly defined), this represents the working time of one person and the personal life of the other person. The task is done at the workplace of the care worker and the home of the other person. The layout must be practical and prevent occupational injury for the care worker while the layout must be cosy and personal for the other person. The time is working time for the care worker and may be leisure time and pleasure for the other person. It is probably impossible to remove a number of these dilemmas but the care workers may become more aware of the existence of the handicapped person's specific wishes and needs and the work could be managed and organised to accommodate these.

#### *2.4.2.4 The right of self-determination versus the use of force with a view to providing better care*

The Swedish care providers tell us that they feel responsible for not taking over and they try to work according to the principle of the independence of handicapped people. The independence principle, however, involves a dilemma with regard to providing care that the care worker considers necessary while at the same time respecting a person's right of self-determination. The Swedish report talks about ethical dilemmas and how they are reflected in most of the interviews. One of the informants interviewed, a female worker in a housing unit, believes that the staff use force every day and gives the following example:

*One of people living here, when the question is about eating he is very positive but afterwards he is negative about everything. He does not want to do anything else. We say that we are using force – because he has to take a shower. He has to brush his teeth. He has to get dressed. It is a big battle each day. But there is no other way. He will not have a good life if we leave him to decide. [...] At the same time, I do not think this is a conflict, because*

*personally I do not feel that it is bad for him. I do not feel bad about it, I do not. It is more like a procedure that we have to perform each day. That we are fighting about certain things. Because later he is quite happy when it is all over, yes.*

Another Swedish informant stresses that under the law you must not force anyone to do anything. You must not force another person to take a shower or medicine, but you are still responsible. The complex demands about your duties of care for other people and not being able to provide care through the compulsion are further dealt with in the section on Denmark, because the theme is given much attention by the Danish informants. The Swedish report says that the care work sector try to solve the problems by collaborative agreements, detailing the care to be provided to each person.

### **2.4.3. Denmark**

In 1993, Denmark passed 'a parliamentary resolution concerning equalisation of opportunities for disabled people and non-disabled people'. But as early as the 1950s a debate was launched, criticising the existing conditions for people with disabilities and the ideal of 'a life as normal as possible'. The concept of 'normal' has grown into an issue over the years but it has become generally accepted in relation to the concept of 'normal rights', which underlines that this is not an indication of a normal way of living but rather of normal rights (cf. Chapter Nine).

The informants of the Danish study consider the service legislation as most important. The law deals with all types of social service and covers all target and age groups, and it stipulates that the work done for people with reduced mental or physical functional abilities should aim at strengthening the individual's development, activation and social integration. The law stresses that a coherent and general service is provided and that the aim of the overall service is to contribute to a more independent life for the individual while respecting personal wishes, needs and opportunities for self-realisation. The tools to manage the process include the requirement that the counties prepare written quality standards that are made available in public and are revised every second year. The minimum requirement is that the standards describe the following areas: (1) The number of homes at each housing service and the physical framework of the individual home, (2) common facilities associated with housing services, (3) the services included in the resident's payment under the service law, (4) optional services available to the residents, their price and price calculation, (5) the day care services and leisure-time services available to the residents, (6) allocation procedures, (7) staff policy, and the objective for competency levels and further education. There is a certain degree of control following the requirement that an action plan must be prepared for each user or resident and following the relatively tight rules on the use of force and duty of care.

According to the Danish practitioners, the service law is relevant in day-to-day business and they are generally positive about the rules, although the provisions about the use of forced duty of care pose difficult dilemmas for the pedagogues. The Danish report quotes a number of pedagogues, who say that the service law has had significant effects on practical work and that it has improved the ethics of the sector. One of the informants talks about the law and says:

*Yes, the residents who are able to, they are also involved in the decision-making, if they want to. We base much of our work on the service law. We keep it in mind when we talk about them, about their self-determination, that is for sure. It is really good to have that law, most certainly."*

The Danish report – in line with the Dutch report – mentions that a process has been initiated,

requiring that both staff and the recipients of care get ready for the new conditions stated in the service law some years ago. The report concludes that the Danish informants are aware that changes will not come overnight, as indicated by this pedagogue: *"Many users have never been prepared for such changes and they will not be prepared for a relatively long period of time."*

According to the Danish report, rights are about social rights, e.g. the right to a home, a job, education, income / pension payment, holiday stays, or rights that are secured by the law and which appear from quality standards or that can be agreed on in an action plan. Rights can also be secured by way of professional ethics. It is about transforming ideals of influence and self-determination in daily life, which are clearly important ideals in pedagogical work.

The Danish practitioners experience that they largely let the users and residents decide for themselves, but as we will discuss later, they also experience that their daily business involves dilemmas between the duty to give care and to respect another person's self-determination. The Danish report stresses communication as a key factor in conjunction with the rights issue. The pedagogues interviewed stress that it is important to be able to read what is on a seriously handicapped person's mind and the report lists a number of technical aids and pedagogical tools that can be used to facilitate communication.

#### *2.4.3.1 The right to make a choice*

Whatever the type of housing, any handicapped person's housing is a private home, and thus resident rooms or apartments are perceived as private homes and should be acknowledged as such. All residents receive social pension payments and they must therefore pay rent, for food and other things in line with all other citizens. Thanks to their financial situation they do have the opportunity to make choices.

The service law distinguishes between housing and services; thus, services are not associated with a specific type of housing. This ought to widen the number of opportunities for people with physical or mental disabilities because they are not tied to the social services offered in conjunction with their housing unit. Several of the Danish informants, however, stress that the separation of housing from other social services is not respected.

Some informants say that ignoring the principle that housing is allocated independently of the allocation of other social services may pose a threat to the quality of life for many handicapped people. For a number of years, for example, the allocation of specific housing did not mean that you would be referred to the specific activities offered at that particular place. Every day, the people with disabilities were taken to other social and activity services to bring them together with users from other areas of town and a whole range of housing types, including users living in ordinary homes. Thus, you are able to select the activity site that would suit the individual person irrespectively of his or her housing. This has allowed the individual to meet equal minded people and to face relevant challenges. Making this offer available is important because people with development disabilities, who live in the same place, are often characterised by completely different functional levels and interests, and they cannot achieve optimum self-realisation and development by only being together with fellow residents. One of the informants in the Danish study says that she is concerned that the day care services separated from the housing units will be shut down and that the users will instead be offered activities associated with their homes with a view to cutting e.g. transportation costs. The informant elaborates:

*this means expanding their housing units and activating them there, thus, there will be no change of environment for them and they will spend time together with the same people [...] There is no way, I believe, that such a change is warranted. They benefit greatly from each other [at the day care centre]”<sup>17</sup>.*

#### 2.4.3.2 Action plans and the right of involvement

We have already mentioned that the duty of preparing plans for care and pedagogical work is discussed by all three national reports. We cannot comment on whether these plans make up the primary management tool in the daily, practical work with regard to the individual recipient of care and pedagogical support. Moreover, we cannot account for the processes and the value added by these plans. But we stress the importance of their existence and that they are made available to users and, in certain circumstances, to the relatives with a view to their involvement and information.

Under the Danish service law, the municipalities and counties must draw up a written action plan for the work to be done for the benefit of people with severely reduced physical or mental disabilities. In practice, the drafting of the action plans is usually organised by on-site staff and it involves representatives from other appropriate public-sector bodies. To the largest extent possible, the recipient of support should be involved in the process. The law does not mention the involvement of relatives in the drawing up of an action plan but the Danish report states that the relatives are in fact involved in case-specific assessments.

The requirement to make action plans is an important factor for the Danish pedagogues, and the Danish report brings a couple of quotes on this subject. An informant stresses that the action-plan work

*is considered very serious work, that we must live up to, and it is widely used. We prepare action plans together with the parents and there are representatives from the county and various workplaces, and we are very focused on the aims of our work and evaluate on an on-going basis. It is also part of our daily life.*

Another informant emphasises that it is important that the action plans are prepared as written contracts and says that this enables the relatives to stick to the agreements:

*You can make action plans without using them, but the fact that a written agreement has been made which is known by the relatives (section III) then it helps to keep people committed. [...] when you prepare the contract you are together with the relatives at a meeting and you do the writing, but we will have had a preliminary meeting in advance with the units and the contact pedagogue, preparing our proposal for an action plan, and then we use the old draft to prepare new things and evaluate on the past goals that were decided on last year, discussing whether they have been met and what the general idea would be. Then we will make a new draft that is used at the meeting, but they [the relatives] do not receive it, however, we do send them the agenda.”*

The Danish report also provides a quote from an interview that shows that the relatives are not involved unless the handicapped person wants them to be (referred to as a pupil because the day

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<sup>17</sup> The informant refers to a political proposal that was discussed at the time of the interview. The proposal was not adopted.



care services are aimed at young people). The pedagogue, who is working at a day care services centre, says that a county consultant participates in the action plan meetings: *"and a site pedagogue, if one is present, and relatives, if relevant, and then the staff and the pupil."* However, the relatives will only participate if accepted by the pupil: *"If the pupil does not want them to participate, then they are not to join in. ... we can sense this."*

Generally speaking, the Danish pedagogues consider their collaboration with the relatives to be positive and constructive but some say that the relatives do not always acknowledge the handicapped person as an adult with rights and specific needs (cf. Chapter Six).

#### 2.4.3.3 *The use of compulsion and duty of care*

In Denmark, there are relatively strict rules on the use of compulsion, and the rules are associated with the rules on the duty to provide care. Everything is based on the Danish service law and its wording of the municipalities' duty to provide care for specific groups of people despite a lack of consent on behalf of the recipient, and rules on the use of compulsion that may be applied only in exceptional circumstances that are fully and exhaustively detailed. Thus, use of any type of compulsion that is not specifically listed by the law would be illegal. Following the main rule, the use of compulsion must only take place if a person is a danger to himself or the environment.

The service law stipulates the following with regard to the use of force and any intervention in the right to self-determination:

- Its use must be limited to a case of utmost necessity,
- Compulsion must never replace care, nursing and social pedagogical support,
- The use of compulsion must only take place if the person's behaviour may result in injury,
- Appropriate professional documentation must be provided with regard to reduced functional abilities,
- Everything must be done to ensure voluntary participation of the person in question,
- The measures applied must involve as little intervention as possible,
- The use of force must be applied as carefully and briefly as possible

The authorities must approve any use of compulsion. Approval may be obtained in advance and if intervention is urgent it may be obtained on subsequent reporting to the authorities that will decide whether the intervention can be approved within 2 weeks.

The set of rules on the use of compulsion also contains provisions about the staff's obligations to provide care. As mentioned in the Swedish report, dilemmas emerge between being obligated to provide care while being unable to do this in a situation where the recipient rejects care. According to the Danish informants, the rules are complicated although most of the informants agree that they are relatively simple to apply in practice.

The Danish report contains interview quotes with examples of violation of the law. One informant says that she does not accept that the handicapped people, of whom she is in charge, wear sandals if it is snowing: *"No matter the law, I do not agree to let people go out in a snow storm wearing sandals – this would be a case of lack of care. There are good arguments to support this view."*

Although this view may be an example of common sense and care, it also involves use of compulsion through forcing another person to wear specific clothing. An exception would be if that

person's choice of clothing poses a direct and serious threat to his health (walking naked outside in temperatures below zero). Under the law the informant quoted must motivate the residents to dress voluntarily; if she fails to motivate the person to change their footwear she must either accept the choice of clothing or let the person stay indoors unless he or she insists on going outside.

Another Danish informant says that if a person sits down on a busy street then they have to move the person away because he is a threat to himself. But if his life is not in danger, then it is acceptable. The informant elaborates with an example from daily life of a seriously, mentally handicapped young man who is still relatively well-functioning:

*during the past year he has developed a big passion for riding on a bus, so he walks down and gets on the bus [into town] and that is a little bit exciting too. His mother is very concerned that he will be sexually abused or abused in some other way, that he will get hurt, etc. Her anxiety is reasonable, but we cannot stand in the way of Peter, however, we tell him that we want him to inform us when he leaves, so that we agree on these things. We [the staff and the mother] do not agree about whether he can manage the situation, but this does not change the fact that Peter is able to manage and do stuff on his own.*

Despite the collaboration with parents and the pedagogues' wish of protecting this young man, the law says that they cannot forbid him to take the bus to town. He is entitled to do this, and the staff support his rights in spite of the mother's concerns.

The Danish report contains many examples of situations where the staff would consider intervention as appropriate care but where they are not entitled to and feel that they have to overstep ethical borders. These situations include the right to bad personal hygiene; the right to smoke despite your bad lungs; the right to eat fatty foods and sweets despite being overweight. One informant says that she feels guilty when a resident does not get her/his teeth brushed because this will adversely affect the person in the long term.

Another informant stresses that it is difficult to define a case as using or not using compulsion. Despite the specific wording of the law, you will experience borderline cases, and the informant appreciates that the staff may occasionally manipulate handicapped people to voluntarily accept care. The rules on the duty of care and use of compulsion are generally considered as satisfactory. The rules that were introduced in 1998 give rise to debates and new solutions: when the use of compulsion is out the question, the pedagogues and other staff face the challenge of deciding on a different solution and they realise that other methods exist which they did not figure out before. The law has provided a challenge with its wording that the use of compulsion must never replace care, nursing and social pedagogical assistance. The law thus prevents working conditions where problems are only solved by way of locked doors, strapping and similar measures, which according to the Danish report should never or only very infrequently take place at the housing and day care services under review<sup>18</sup>.

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<sup>18</sup> Under the law measures are not provided for this group of people; e.g., you must not lock the outer doors to prevent residents or users from exiting and collective surveillance is prohibited too.

## 2.5 Concluding remarks

All three national reports mention issues that we have grouped as follows:

- Overall, general and statutory human rights
- Humanitarianism and ethics in pedagogy and care practice
- The right of influence and integration in society
- Specific, practical and financial rights and the right to receive technical and professional support
- Rights associated with the issue of compulsion and forced care and treatment

The above issues are not ranked in any specific order with regard to importance or the frequency with which they appear in the three reports. They are mentioned with a view to providing the reader with an overview of the themes found in the reports of the three countries, and below we will add a few concluding remarks.

### ***2.5.1 Overall, general and statutory rights and specific legislation for handicapped people***

In all three countries, the care work is shaped according to overall rights and principles of handicap policy. The UN's general rules seem to have fed through to the area. The Netherlands and Sweden have implemented special legislation regarding rights for people with handicaps, while the rules in Denmark are contained in one piece of legislation that is common for all groups receiving social services (although with statutory orders and guidance notes regarding specific groups).

The difference between the countries does not provide us with any basis for conclusions on the quality of care or the general nature of the work of care providers.

The general and statutory rights are important from a political and administrative perspective and they also set out the course for daily work practice. We have examined how the practitioners view the legislation. Notably in Sweden and Denmark, the practitioners have certain knowledge of and think about the rules. This is not so apparent among the Dutch practitioners.

Considering whether there is any difference between the care workers' knowledge about, or their interest in, the legislation in the three countries, the relevance and importance of such knowledge in practical work might be questioned. We believe that the Swedish and Danish care workers apply the legislation as guidance in their reflections, discussions and planning of daily practice work. The practitioners know about the political intentions and adjust their work accordingly, but they are also aware of the weaknesses at the political and administrative level (e.g. that the Swedish municipalities are required to offer housing but that they are unable to do so and therefore pay compensation instead). This knowledge may help the individual care worker to view him or herself and the daily tasks in a greater perspective. Without this overview there is a theoretical risk of the care workers considering difficulties as a matter that is mainly associated with the care worker and the handicapped person.

### ***2.5.2 Humanitarianism and ethics in pedagogy and care practice***

The practitioners talk about rights and various ways of referring to ethics and humanitarianism in care and pedagogical efforts. The practitioners' statements are largely divided into three main categories. Some practitioners say that by virtue of being professionals they know what is best for other people and thus, they can secure the rights for these people. Other practitioners seem to view things from a common human empathy approach and based on a desire to help other people. A third group of practitioners put emphasis on the type of professionalism that consists of being a catalyst

for people with handicaps, helping these people to become as independent and integrated into society as possible based on what they consider as their needs.

### ***2.5.3 The right of influence and integration in society and specific, practical and financial rights***

Rights are also discussed with regard to being entitled to specific social services as e.g. the right to housing, personal assistance, pension payments and other financial support, technical aids etc. The informants generally agree that these services should be a common right. But the Dutch report questions the way these rights are formed, e.g. by discussing the balance between protection and freedom/independence, and the Swedish report discusses the issue of loneliness when people with serious handicaps are offered an ordinary home.

The ideal of protecting people with handicaps stands out in the Dutch report. In the Netherlands, a large number of people with serious handicaps live in large institutions located away from residential areas. In Sweden and Denmark, almost all people with handicaps live in ordinary homes or small-sized communities located among other homes without being referred to as a security threat.

The de-institutionalisation process (removal of large buildings and provision of customised services and rights as close to ordinary life as possible) has been underway for several decades in Sweden and Denmark - and with generally favourable experiences. The Danish and Dutch reports, however, both indicate that changing these conditions is a drawn-out process, one reason being that many handicapped people have become used to the staff assessing their needs.

### ***2.5.4 The right to receive technical and professional support***

We will briefly discuss the question about the right to technical and professional support – more details are provided in another chapter – and thus only mention that the debate is about the necessity of training and the amount of training, and the most appropriate type of education in handicap care. None of the three national reports question the value of training. The Swedish report says it may be difficult for a person without training to handle the tasks. The Danish report mentions, among other things, the importance of training with regard to advocating the handicapped person's interest vis-à-vis with society in general and sometimes towards the relatives who may not always possess the required skills to understand the handicapped person's wishes and needs and who do not have any knowledge about prevention of compulsion and forced treatment. A warning against a standard procedure that allows relatives a high degree of influence may be warranted (for example a procedure giving relatives high influence on use of compulsion in care). Instead of such standard procedures, relatives should have the opportunity to complain to another authority if experiencing unsatisfactory care or any unnecessary use of force against their handicapped family members.

A proper education should qualify care workers to offer care without use of compulsion and with respect for people's rights and wishes. This is clearly indicated by a number of statements from all three reports. Education, for example, provides insight into the society's requirements and communication competencies needed vis-à-vis handicapped people and their relatives (a precondition for accommodating other people's rights).

### ***2.5.5 Rights associated with the issue of force and forced care and treatment***

All three countries talk about the dilemmas regarding people's self-determination rights, ethical as well as legal rights. The rights are occasionally ignored when the staff provide nursing and care use compulsion. The Dutch report mentions forced treatment, locking of doors and strapping of people.

The rules in the Netherlands do not seem as tough as in Sweden and Denmark where the use of coercion is only allowed in completely exceptional circumstances but we have no data supporting more details.

In all three countries, there are informants who are sceptical about any use of compulsion and it is stressed that actions are occasionally carried through by manipulating the handicapped person. The use of compulsion may take place unknowingly and in undisclosed circumstances but the practitioners seem to be aware of the rules, notably in Sweden and Denmark. The rules trigger debate and professional development and the use of force is carefully considered.

Thoughts about the use of compulsion due to inadequate competencies to solve conflicts and a heavy workload are not directly and clearly reflected in the various country reports. The Swedish report, however, refers to an informant and a statement on the correlation between rights, compulsion and staff education. The statement is associated with the question of the worker's ability to set limits and deals very much with the issue of staff protection. We mention the statement in this context because the conditions facing care workers and their feelings of security and their abilities to set limits in a professional manner not only protect the staff against handicapped people. They also act as prevention against the use of force by staff on people with handicaps since these situations often occur as a result of workers feeling powerless.

## Chapter Three: The workers

This chapter begins with a section provided by the informants of the three countries outlining their routes into the sector of disability care. Secondly, we examine the best and worst parts, according to the informants, of their work and their job satisfaction. Their views on professional development and career opportunities are covered, including their considerations about the future. Finally, we will examine the informants' family status including the balance between their work and family life.

The informants' views on working time and pay are covered in Chapter Seven. Details about gender and educational backgrounds are provided in Chapters Four and Eight.

### 3.1 Routes into the sector of handicap care

This section covers the paths of the care workers that have led them into handicap care, including their past work experiences. Their paths into the sector are quite different. This section also touches on the recruiting issue, to which we return in Chapter Ten. But first we will look at the ages of the informants.

#### 3.1.1 Age breakdown

**Table 3.1. The age of the informants**

Age	Denmark	The Netherlands	Sweden
20-30	0	3	0
31-40	5	6	3
41-50	8	4	6
50+	2	2	4
Total	15	15	13

The ages of the Danish informants vary between 33 and 55, averaging at 44 years. The ages of the Swedish informants average at about the same as their Danish counterparts – 45 years – and vary between 31 and 60. The ages of the Dutch informants vary between 22 and 51. Their age of 34 years is about 10 years younger than both their Danish and Swedish counterparts.

#### 3.1.2 Coincidence – or a deliberate choice

The interviews show that the Swedish informants who began working in the sector of handicap care have done so because of coincidence – they just happened to end up there. Eight out of thirteen people confirm that this applies to them. None of them say that they made a deliberate decision to start working in this area. The Dutch interviews also reveal that most workers were introduced to handicap care more or less by chance and became, in turn, motivated.

In Denmark, the informants mainly entered the field of disability care through pedagogue education, except for handicap assistants. Therefore, the Danish report also covers the recruiting issue in relation to the informants' choice of pedagogue training, including their reasons for working specifically with handicapped people<sup>19</sup>. As opposed to the Swedish and Dutch informants,

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<sup>19</sup> Before 1992, there were three types of pedagogue training, one focused on work with handicapped people. Since 1992 the three types of training have been integrated into one, which qualifies pedagogues to work across a wide range of services and with many groups of children, young people and adults.

there are only a few Danish care workers who say that they got there by chance. These informants appear more deliberate in their choice of the area, in the way they refer to their choice and their reasons for working in the sector. For most of the informants who trained before 1992, their choice of study was associated with a motivation to work in the field of handicap care or other areas of social pedagogical work, or a general wish to work with other people. Some of the workers with the post-1992 pedagogue education did have their focus on work in services for young children and out of school care.

### 3.1.3 *Experience of work and life*

The Danish and Swedish informants in particular, and some of the Dutch, have gained significant experience in the labour market and in life before entering handicap care. Most of the Swedish informants are 30 years old, or older, with mixed educational backgrounds or no further education at all. The diversity is reflected by the Danish report as well. The Danish informants are all characterised by having work experience before embarking on their professional education; many have been to folk high schools<sup>20</sup> and a few have spent time abroad. Several of them have worked as pedagogue assistants which prompted their decision to become pedagogue students. Some are trained in other fields: three of the men are skilled workers, one is a baker and two are mechanics. One of the women is trained in the retail sector, another as a nursing aide. The Danish informants represent a very heterogeneous group in terms of experiences in life and work prior to their studies, and this is in line with the conclusions of the Evaluation Report concerning today's Danish pedagogue students (Pædagoguddannelsen, 2003).

The Swedish report also outlines the many routes that lead into the sector; for some, it was easy getting a job in the sector at the time they entered the labour market, others had to take on the jobs available at that time. Changing job owing to illness or reorganisation of work may have led to new occupational directions. Several informants mention family life and children as the reason for entering handicap care, and two Swedish and two Danish informants opted for a new working area when they became parents.

A Swedish informant explains how she entered the sector of handicap care. She was applying for a job with a housing unit.

*It was a temporary position for a couple of months, which suited me well at that time. I had been working with young people and old people, always been working with other people. This was just like adding another colour on the palette, it was like returning home in a way.*

This woman, and many of the other Swedish informants (7), have been working for most of their lives in other care work areas for adults, e.g. within hospitals, or with psychiatric or people with psychiatric illnesses or with senile dementia. However, they gradually found that this work was unsatisfactory and that it was running them down. An informant with 14 years of experience in psychiatric work says: “*But it was very tough, the psychiatry: my body and neck hurt.*” Another informant felt burnt-out, and a third person, who was working for five years with elderly people

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<sup>20</sup> Folk high schools (*højskoler*) are for adults. Students attend for 4-6 months studying cultural and aesthetic subjects, social subjects, sports etc. The folk high schools have a long tradition in Denmark and are popular among young people. The basic idea is to offer education on a voluntary basis. In a Danish context the aim is talked about as ‘enlightening’ people. [www.folkehojskoler.dk](http://www.folkehojskoler.dk)

with senile dementia, found that *“it was too disappointing not to see any development in your work.”*

The Danish pedagogue training qualifies you to work in many pedagogic work areas. Half the pedagogue informants (since graduation) have solely been working in the field of handicap care. Others have been working in other areas of social pedagogy with young people in residential care, criminals, drug addicts, handicapped children and children with special needs or outside the area of social pedagogy in ordinary day care institutions for young children and out of school centres. Placement in the sector of handicap care during their pedagogue training made several of the informants choose this area of work.

In Denmark, the move into the field of handicap care from other work in social pedagogy, e.g. residential care for children and young people, is explained in the same manner as some of the Swedish informants who have been working in hospital or services for people with psychiatric illness or senile dementia: the area is too tough and you get burnt-out. A male informant says that after working in a children's home, he has *“solely been looking for less demanding pedagogue jobs instead of the tough ones”*. After 20 years in residential care for children and young people, a male pedagogue embarked on the field of handicap care and says: *“It has been fascinating [...] I did not believe the pedagogical challenges were so big, but that was because of my lack of knowledge about the area.”*

The following extract of an interview with a male pedagogue from a day care unit with associated 24-hours housing units is an example of how Danish pedagogues work in a broadly defined profession, and that the individual pedagogue is considering a range of employment options. He explains why he did not opt for the social pedagogical area involving therapeutic work with adults nor to work in services for young children and gives his motivation for working with people with developmental disabilities.

*I like the days to be eventful. When you are here [...] there are lots of things going on. And with the combination of practical things that must be done during the day, and then making activities – I like that. [...] I am not the type of person who likes to be sitting and doing nothing for too long. Therefore, the therapy work area is probably not my cup of tea either, there is too much small talk there, right. You talk a lot in that work area and I am probably not that kind of person, and that is why I have chosen this field instead.*

*Interviewer: You did not think of services for young children, for example?*

*No, because when I get home – I have children of my own [...]. I do not feel like working with kids there during the day and then going home to do stuff with my own children as well. I guess we are all somewhat different in that respect.*

*I also believe this group of people with disabilities is very positive about your work and they are happy folk if you treat them decently. When things are happening in their life, you will experience that many things are perceived in a positive manner. You do not leave work in a state of...which may be the case if you are a therapy worker and you end your day being completely exhausted. You do not need to bring home stuff about the clients. It is tougher to forget about the social problems that are involved in your work. But you should be able to*



*go home and get some time off, I believe, [...]. but there may also be staff problems involved”.*

He also talks about the higher pay, owing to the allowances, which he considers to be a benefit of working in the 24-hours work area.

Some of the Dutch informants have been working in different areas of the care work sector. Several of them emphasise that working with people with a handicap in so many different ways is more attractive compared with the limited opportunities in other areas; the combination of providing care, the pedagogic (development, empowerment) and the creative features make the profession attractive.

### **3.1.4 Gender**

In terms of gender and recruitment, the two Swedish male informants have entered the sector in similar ways as their female counterparts. The male care worker in a housing unit says that he entered the area by chance with the help of a friend. He had skipped his technical education and needed a job; he became fond of the area and subsequently completed the basic courses of PPU or GPU<sup>21</sup>. The personal assistant also entered the area through a friend.

There are some interesting differences in gender among the Danish informants with regard to their paths into the field of handicap care. The male pedagogues (6) do not only differ in the way that they talk about their choice of education but also with regard to their motivation for working with people with disabilities. Three of the male informants explicitly state that they have chosen a pedagogue education because they wanted to work with music, creative issues (music, theatre, workshops) and nature. These three informants and another explain that they make much use of musical, creative and active subjects in their work with people with developmental disabilities, and that this is a key element of their motivation for staying in the job. This issue is not mentioned by any female informant, but this does not mean that the women are not putting emphasis on creative means of communication or are not competent in this respect.

### **3.1.5 Personal knowledge**

Jobs are frequently filled by way of informal contacts. Several informants say that they first got in touch with the sector of disability care through their friends who were working in the area themselves and who urged them to apply for work in the sector.

Personal knowledge about the area may prove to be another key road into the sector of handicap care, which is reflected by the Dutch report. The leader of one of the big institutions believes that in the Netherlands, around 40 percent of the employees in the field of handicap care have a relative with a disability. This applies to the leader as well:

*I have always had an affinity with care work and non-profit care. It has partly to do with the fact that my sister and one of my daughters are disabled. You often find that people in the VG-sector (sector for people with developmental disabilities) have disabled relatives. I estimate that percentage to be around 40 percent among the workers.*

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<sup>21</sup> See Chapter Eight.

The Swedish report stresses that only one informant associates her work with a personal contact with people with disabilities. She is trained as a teacher and is working part-time as a care worker in a day care unit. Her mother is a specialised school teacher/therapist, and she grew up in the home attached to her mother's work at the school, which took pupils with disabilities, and she *"was always surrounded by people with disabilities."* One of the personal assistants assists her brother and is thus closely associated with the area but does not relate it to her work.

Three of the Danish pedagogues were motivated to join the field of disability care at a very young age owing to personal knowledge. They always knew that they wanted to work in this area. Like one of the Swedish informants, the mother of one pedagogue had been working in that area for her entire life and she was therefore raised close to the field of handicap care: *"I always knew that this is what I wanted to do. I was never considering anything else"* and *"my mother is working here [...] and I have always done this. I have spent many Christmas Eves here. [...] I never felt alienated, not at all."*

The joy and positive sides of working with people with disabilities are mentioned by several others including these two Danish informants: *"It was a special feeling ... I felt it made me happy and I probably knew this all the time, but I was never involved with these people before."* The second informant uses the same terminology as a Swedish informant: *"It was like going back home in some sort of way."*

### **3.1.6 Humanity and solidarity**

As shown in the following section, most informants explain that the best thing about their job is working with disabled people. According to the Danish report, the Danish interviews reflect humanity and solidarity in relation to people less well off than them as a factor of motivation. This has always played a key role in Denmark within work that involves people with disabilities and probably also applies to the two other countries. A woman who graduated as a pedagogue in 1980, explains her entry into the pedagogue area as follows: *"I am from that time when many people were living in shared houses, and I was living in a shared house, and shared houses for treatment, etc. and that stimulated my interest in this [...] because... we believed that we had so many things to offer the children and young people who were having a tough time by living together with them".*

The human factor, she believes, contributed to her wish to help this group of people to a better life. In the 1970s, the area of social pedagogy was highly politicised with the trade unions and a large number of employees fighting for improved pay and working conditions, opposing the idea of their work as a vocation. But at the same time they showed much solidarity with the users (Øgendahl, 2000). The same pedagogue also says that she misses the spirit of that time: *"I think there is a big difference between students now and then when I was a student, the entire...well, spirit. Here, we are unable to get us a shop steward."*<sup>22</sup>

She says there is a certain lack of interest in trade union and political issues among the students and workers in the field of handicap care. The trade union vice-president points out that there must still be some social-political commitment alongside increasing professionalism: *"the day when the social pedagogues no longer have any responses, a human view on things and social-political*

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<sup>22</sup> A shop steward is elected at each workplace and represents the trade union and employee interests relative to management.

*commitment, then all your skills and competencies will not do any good – the users will shop somewhere else.”*

From a Danish perspective, it surprises us that two of the male pedagogues apply a very clear-cut Christian view on things. Christian views used to have a significant importance in this area in Denmark. It is interesting that it is mentioned by the Danish report in particular, since Danish handicap care is highly professionalised thanks to graduate degree studies.

It is quite clear though that it is professionalism and not a vocation to help that lies beneath the development of work in this field. One of the male pedagogues indicates that there are still some of the employees in the sector who are working in their leisure time for the residents.

*Yes, some still believe that it is too bad for these people and they feel a vocation to assist, right. I can hear the vocation call, but not so loud that I assist and work in my leisure time. I do have a life with my family as well. You really have to be very professional to be able to separate these things. Some will spend their leisure time shopping for the residents and buying them socks. It is quite all right, but then ...*

*Interviewer: This is not part of your work, you believe?*

*No. I will use the time set aside for this when I am at work. If we do not have the time to do this during the work hours then we either need to work extra hours, or do it next time, that is the way it has got to be.*

The Dutch report also mentions solidarity as a motivation for working in the field of handicap care, and one of the informants stresses this issue in contrast to the hospital and welfare sectors: *“Hospitals are detached and in my view the welfare sector is a bit vague.”*

### **3.2 Job satisfaction – the best and worse things about the work**

The previous section outlined the paths that lead to a job in the field of handicap care. This section examines how satisfied the care workers are in their jobs and what their reasons and motives are for working with people with disabilities. The job satisfaction issue is analysed for the Danish and Swedish informants on the basis of two key questions asked directly to almost all informants: What is the best thing about working with people with disabilities? What is the worst thing about working with people with disabilities?<sup>23</sup> What is interesting about the answers is that they provide the informants’ immediate answers to the question. The answers are made in general terms and cover their work in general and not specifically in relation to satisfaction/dissatisfaction with working conditions. As shown below, the answers also give details of their understanding of the central issues of care work in the field of handicap care.

The Dutch informants were asked about their job satisfaction by asking them how satisfied they were about their work and what makes them satisfied.

Chapter Seven analyses job satisfaction relative to working conditions in more detail on the basis of the questionnaire and other questions in the interview, and these two sections should be viewed in

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<sup>23</sup> We have good experiences with this particular question from the Danish national case study in Work package 7: Work with Young Children.

that perspective. Below we provide several quotes by the care workers from the three countries. There is a clear difference as to how the Danish and Swedish informants refer to the users and their views and opinions on their work compared with some of the Dutch care workers.

### 3.2.1 Denmark

#### 3.2.1.1 The best thing about the work

The following details are based on answers from 12 pedagogues<sup>24</sup>. It stands out that 10 pedagogues say that the best thing about their job is the time spent together and the relationships with people with severe disabilities. This answer is provided by most of the informants, immediately and without hesitation. Two pedagogues (both male) mention other factors, but this obviously does not mean that togetherness and relationships with the people with disabilities is not a key issue for them.

When the pedagogues describe the best part of their work, several statements refer to joy of life and heartfelt moments. Reference is made to the joy of both the service user and the worker. They talk about the value you gain from being together and that “it is developing me as a human being.”

The first interview extract about the best part of the work is taken from five pedagogues who are all working with residents or users with high support needs. Their views on people with disabilities and the challenges of their work are clearly reflected.

A male pedagogue at a day care service who is specialised in music says:

*The best thing? The best thing is the joy of life they show you when you are doing stuff that they like, say, when I am doing rhythmic music and movements. You can feel a change in sentiment, from being tired and then in high spirits afterwards. Music is a grateful thing. I play with them, music games and stuff like that, and we sing together. I feel they give me a lot of feedback. That feeling and seeing how their joy of life emerges makes my job more attractive,[...].”*

According to a male pedagogue at a housing unit:

*There are so many good things. When you begin work and they come to you and embrace you, dribbling on your shoulder. The joy of seeing the happiness they feel when meeting us. They are waiting by the window when we arrive and they wave us goodbye when we leave. Although they are not very talkative, they are still happy people, and we have something in common in one way or another.*

A female pedagogue at a housing unit talks about “all the wonderful people [residents]. A melting heart.” A little later, she elaborates:

*My heart melts when I think of Hanne, completely. I think it is just great. And when I go into see Sofie [resident] and she greets me with her special way of saying ‘good morning’. It is really quite extraordinary. It is worth it. My heart virtually melts.*

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<sup>24</sup>The question was not asked to one pedagogue. The answers from the two disability helpers are left out because the Danish report concentrates on working with people with disabilities and also on one single profession: pedagogues.

Here is a female pedagogue at a housing unit who stresses togetherness and relationships with residents and colleagues as the best thing:

*The togetherness, definitely. The best thing is when you leave after a day at work and you feel that you have really been in contact with them. [...] [T]he days with your colleagues where everything is one big success. I do not know whether you understand what I am saying, but any pedagogue in this place would.*

She gives an example about a user:

*a girl who is just sitting a lot in her room, I can easily feel if she is OK because then I will be able to have her sitting next to us in the evening. She is often sitting there, or there or there but if one night we succeed in...then she will be sitting there together with us and having a cosy time. Then I know she has been having a good time, right. Just such a small thing.*

There is a female pedagogue in a housing unit who finds this a tough question:

*It is all about the residents. The best thing about my work is when you meet happy people, because that is what they are. They are happy for the help they get. They are not grateful but happy. And they should not be grateful anyway.*

The following two extracts are taken from pedagogues who are working with young people needing less support. They explain how many benefits they gain from socialising. For the female pedagogue the work

*is highly enriching. Even if you are very sad when you get to work, your mood will always change. This is not just a rumour you know.[...] They are very enriching and incredibly sensitive. They know exactly how you are feeling. It is quite impressive. They know exactly whether you are feeling good or bad and it is quite OK not to feel well and to let other people know about it. They have a very precise feeling for the situation and they are very caring."*

The male pedagogue, who works in creative productions, says that

*they give you something in return, you give them a proposal and you get some feedback. They do not agree to everything. They are shy and they are human in the way that they do not go along with everything. Conversely, a disabled person is also less reserved, so you may experience that they are ready to embark on the things that you suggest."*

Other good things mentioned by a few informants include that the work is not monotonous; it involves freedom and good company with other colleagues. But these factors are not the main points raised when we ask about the best features of the job, although this is not to say that these factors are unimportant.

### **3.2.1.2 The worst thing about the work**

As emphasised by the Danish report, five informants respond to the question about the worst thing about the job by saying that they do not know or that they have never thought about it.

Subsequently, all but one provides an answer. As with the question about the best things, most replies refer to the relationship with the users, colleagues, and the environment.

With respect to relationship with the users, mention is made of various downsides to the work – violence and anxiety-provoking behaviour, losing contact with them if they die or leave the institution, that people with disabilities are exposed in creative production and areas of practical care work. With regard to colleagues, mention is made of staff group conflicts and the absence of colleagues in day-to-day work. One informant mentions the view of the surrounding community about people with disabilities, and another informant mentions the lack of career opportunities.

The fact that a relatively large number of informants say that they do not know what constitutes the worse thing may at first glance indicate a significant job satisfaction also considering the many positive responses to questioning the best things about the work. Chapter Seven on working environment shows that the Danish pedagogues, for example in the questionnaire, consider their pay and various aspects of working conditions to be negative but during the interview these factors do not stand out as a downside of the work. This may be because the informants are thinking more about the residents than their pay and working conditions while being interviewed. It should be kept in mind that the trade union is powerful in Denmark and the pedagogues probably believe that, to a large extent, it takes care of their interests in that area.

### 3.2.2 Sweden

Many of the Swedish informants are happy about one aspect of their work but unhappy about another aspect, with working conditions being the most commonly criticised feature of their work. The following two extracts from the interviews give examples of the dual response. First, a care worker in a housing unit who has been working for many years in the area gives her views on the best and worse thing about the work.

*The best thing is that it is very enriching. There is much freedom and you stay a lot outdoors. You do not have to spend all your time indoors. That is really great, I think. The worst thing is the work schedule, working during evenings and weekends. It is the working hours, I guess. It was great [...] when I had my child to take care of because then I could stay home during the week ...”*

This male care worker, also at a housing unit, is very fond of the work “despite” the negative aspects:

*The best thing is all about the people living here and whom you are meeting [...] it is very enriching. It really is. That makes it cool to stay on here. In spite of the bad working hours and low pay then [...] it is a job with much freedom. Of course you are subjected to many different things. [But ] you should be able to apply your own methods within the staff group.”*

Later in the interview he explains that he finds it difficult to see himself working elsewhere than in the sector of handicap care.

#### 3.2.2.1 The best thing about the work

The quote above is reflected by several other informants. The best thing about the job is the users and residents who you get to know: the joy of being together with them and the enriching and

encouraging experience of participating in their progress. One informant mentions that the reward lies in the development of something you have been working on for a long time. Another positive factor is to initiate activities and do activities with the uses and residents. According to a woman at a housing unit the best thing is to be allowed to participate in their lives:

*you are sharing everything. You are there in the early morning when they wake up. You are there in the late evenings when they go to sleep. You are there during sadness when someone dies. It is like you are....You are part of that person's life. It is a very enriching thing."*

A male care worker at a housing unit elaborates on a good day at work. His response clearly shows that much joy is associated with doing something difficult in his job concerning the residents. There are many professional challenges and much commitment involved in working with people who need much support. The quote also shows us his view on people with disabilities, the challenges of his work and his own professionalism.

The interviewer asks what makes a good working day for him:

*Well, I understand what you mean. [Pause] It is hard to think of something else other than the situation with Kerstin [female resident]. And Kerstin is not particularly interested in doing stuff, so much of your time is about making her feel at ease to make her agree to go outside for example. Well, in order to do something...but. When we have been outside doing something, whatever it is, when there has been no aggression.[...] she can be in a very self-destructive mood. When things have been good, when there have been no major discussions without doing what we agreed to. When we have been outside. When we have been shopping and she did manage the challenge. After all, she does not like to be among other people. She cannot stand small children because of their sudden movements and sounds, and she is sensitive about any high-pitched noise."*

The positive aspects about working conditions that are emphasised by the informants mainly deal with free and independent work that is also highly varied. Making decisions about your work, what to do and how to do it are factors highly appreciated by several of the employees in housing units and day care services. Freedom in your work and independence largely means that the middle manager does not participate in the detailed planning of work.

The following three women work at the same day care service. They consider their workplace as lively, creative and full of the joys of life. In their view, the work is creative and the staff group consists of competent people and there is a good sentiment within the group.

*There is room for creativity and the joys of life and much freedom of action when working in a day care centre, there is more room here for these things than in the field of home care, and that is really a benefit. (Work therapist and care worker)*

*I am happy in my work here and I consider it to be a lively and creative workplace, and with a very competent staff. There is a good sentiment too. We are supporting each other. We are met with much understanding. (Teacher and care worker)*

*In my view, the work is characterised by freedom and there is a focus on well-being and creativity. It is very stimulating, it is the job that dreams are made of. (Care worker)*

#### 3.2.2.2 *The worst thing about the work*

Some of the Swedish informants point to the users as another difficult aspect of their work. Some say that it is a negative aspect of their work when the staff do not meet the users in a proper manner. A woman who is working alone with a group of users in a day care centre says that

the worst part is probably that they are very demanding. If you are not fit yourself you will get very tired, and this is notably the case when you are working alone. [...] They will have to perform 110 percent. [...] The same questions over again, they do not stop. If you have to cope with all this by yourself, it is very demanding. I remember once, I was able to predict almost exactly what would happen and the questions that would be asked. It is tough that they are so demanding. But what is positive is when you experience that they are doing ok and everything is working out well.”

According to a male personal assistant, who works for people with severe physical disabilities, and who works alone, the worst thing about his job is

*not getting too involved and agreeing to something without learning how to say 'no'. Learning to protect yourself. I do this by not answering the phone when I do not feel like it. The caller will have to leave a message, but then later I will develop a guilty conscience, say, on the day when you have days off, you may be working for six days a week and then on the day you have off you will develop a guilty conscience because some poor soul is asking you to help because no one else can help them: 'I cannot get to the loo'. You will then be hunted by your guilty conscience on your day off.*

The Swedish researcher adds the following comment to the quote. The users can be viewed in a negative light or the situation can be viewed as a result of the way the work is organised. Perhaps the administrative routines do not work properly. But having a guilty conscience when you have time off seems unreasonable whatever the cause.

The worst aspects of the working conditions, which are emphasised by the informants, mostly are low pay and unusual working hours. A female care worker in a housing unit says that: “*The worst things are the pay and working hours.*” In her view, good working conditions are important in order for you to appreciate that your work matters to the wider society.

#### 3.2.3 *The Netherlands*

As mentioned in the introduction of this section, the Dutch report states that the issue of job satisfaction was examined by asking the informants about how satisfied they are with their work and how they achieve their satisfaction. Thus, the Dutch section mainly deals with the positive side of work but the following extracts from the interviews also reflect negative aspects. The views of the Dutch informants on the negative aspects of their work are also covered by the questionnaire, which is analysed in Chapter Seven.

The following were named in the Dutch national report as informants' sources of satisfaction:



- Pleasure and humour you find in working with people
- Satisfaction of having achieved something (even if it is only a minute response from a disabled person)
- Co-operation with colleagues
- Atmosphere in the team
- Opportunities for self-realisation.

A male informant from a housing unit says he is both satisfied and dissatisfied with working with the service users. The work is enriching, he believes, e.g. when the residents make small progress.

*I find it to be an enriching experience for myself, for my colleagues and for the residents.  
My presence. My work*

*Interviewer: How does it enrich you as a person?*

*When people finally pick up on the small signals.*

But he also says they represent a difficult group of people. He continues:

*The relationship with this target group is fairly difficult, because you get very little back. You have to be content with the small things. Essentially, this level is too low for me. Certainly as far as contact is concerned. But it was my choice... I once studied nursing and that level was too high. Having worked at a higher level for a while I wanted to see what it is like at a lower level. But when they come back from their holidays, for instance, then they all just lie there and essentially you don't get any reaction from them. If you work here longer then you get to see a difference in reaction. A smile or some other facial expression. But 'that's it'. I can't get satisfaction from that*

A female care co-ordinator at a day care centre for people with severe disabilities says that working with the users gives her much job satisfaction but also, again, that some aspects are hard to handle.

*Every day something crazy happens that makes me laugh my head off. Then you realise once again that the people aren't here because of their sweaty feet. I see the fun side of it. And then I think 'What is he doing now?' Disgusting things, like J, who eats someone else's snot. Those sorts of things. There is something funny going on every day. It's great fun and very varied work. I have been working here for the past ten years and I still enjoy it tremendously. You get a lot back from them. They are happy every time they see you. They come to you and shake hands with you and give you a big slap. That makes you feel appreciated by the participants. J is often overjoyed when he comes in after the weekend.*

### **3.3 Career opportunities and future considerations**

The section also deals with the question of whether care workers expect to stay in the area or whether they will be looking for other work. This is notably covered in the question during the interview about where they expect to be working 2-3-4 years from now.

**Table 3.2. Time spent working in care for people with disabilities**

Years in sector	Denmark	The Netherlands	Sweden
<2	1	1	-
2-5	4	7	2
6-10	3	1	4
11-20	6	4	5
+20	1	2	1

Table 3.2 shows how long the informants of the three countries have been working in the field of handicap care. As can be seen, most of the informants, particularly the Danish and Swedish care workers, are very experienced in the field of disability care. The Danish informants have worked between 1½ and 35 years in caring for disabled people, with an average of 10½ years. The Swedish informants have worked between 3 and 26 years in the sector, also with an average of 10½ years. The Dutch informants have worked between 1½ and 24 years in care for disabled people, with an average of a little more than nine years.

Some of the Danish informants have experience of several workplaces – others have more limited experience. Half of them have been working 5 to 10 years at their current workplace, and the rest of the informants have been working for less than 5 years. Several of them made a job move into the field of handicap care in search of new professional challenges and/or in response to the establishment of new services. The last factor reflects the large number of past and current restructurings in the field of handicap care with new services being established and others being closed down. Neither the female nor male informants are thinking about leaving the pedagogue profession.

One career opportunity for a pedagogue is to become the leader of a service or department in the area; some of the informants have tried this opportunity but are now working again as ordinary pedagogues. Other development and career opportunities involve working as trade union and safety representatives. Some of them are in these positions or have been in the past. The policy-maker informant from the trade union is educated as a pedagogue and has previously worked in the field of handicap care for several years.

Further and post-qualifying education is another career opportunity. It is not surprising that, with a group of informants who have several years of work experience in the pedagogical area, those with long experience have all completed further and post-qualification studies. Most of them have attended specialist courses, and some are doing guest lectures at pedagogue training college, amongst other places.

To get an understanding of the informants' future plans, we asked them where they would be working in 2 to 3 years time. The Danish informants provided many different answers and considerations; there was no commonly held opinion. By far most of the informants seem to be certain about continuing in the field of handicap care. The data also show that future considerations are, as might be expected, associated with your age.

One group of informants clearly states that they are going to stay in the same workplace. A female and male pedagogue say that they would like to work within their areas of competence in textiles and music, but such jobs are hard to find. Two of the men want to take on a leadership or consultant

positions to assist some of the services offered but the county has recently scrapped these functions. There is a female pedagogue who is thinking about teaching or setting up her own service together with some of her colleagues.

When the Dutch care workers were asked whether they see themselves working in the same setting in three or four years' time, most professional care workers in the interviews answered by saying that they expect to be working somewhere else in a couple of years time. What they have in mind is predominantly a position in the same organisation or elsewhere in disabled care, whether at a higher level or not. Thus, there seems to be a greater degree of mobility among the Dutch care workers than their Danish counterparts, at least among the informants of this study.

We have no data on the career opportunities and future considerations of the Swedish informants.

### **3.4 Work life and family life**

During the interviews we also touched on the question of how the informants achieve a balance between their work and their family lives. The balance between work and family life is a frequent theme of women's entry into the labour market including the issue of who is caring for the children. The same factor obviously applies to men but most often the main responsibility lies with the women who traditionally plan their work in accordance with their family life. The scope of their work comes into play but the working schedule is relevant too; not just how many hours, but when they are worked. Working with people with severe disabilities at a housing unit also involves evening, night and weekend shifts to ensure 24/7 availability.

The problems related to the balance of working life and social life outside working hours, including your family life, are obviously more broad-based than the task of caring for younger children. Other care tasks may also be relevant, e.g. care for older relatives or spouses. People living alone and / or who have older children will obviously consider and be affected by the scope and schedule of their work. Work may also affect family life and vice-versa. For example, a satisfactory and developing job will have a positive impact on your life outside working hours, and conversely hard and unsatisfactory work will have an adverse affect on your family life. Family life, how it is going and how family and friends perceive it, may also affect your work life. Respectively, how family friendly the workplace is and its focus on the work environment are important too.

A key factor for the individual with regards to achieving a balance between work and family life, especially where a care worker has children and / or older relatives requiring a lot of care, consists of society's support including services for young children, out of school care, home help and other care for elderly people. The informants touch on several of the above factors.

### 3.4.1 Family patterns

**Table 3.3 Informants' living situation**

<i>Living status</i>	Denmark	The Netherlands	Sweden
Single	2	3	3
With partner	1	2	4
With partner and child/children	10	8	3
Single with children	1	1	2
With parents		1	
With sister	1		
	15	15	12

**Table 3.4 Age of informants' children**

	Denmark	The Netherlands	Sweden
Age of children	N=13	N=8	N=10
<5	4	2	0
5-10	6	5	2
11-15	9	3	3
16-20	5	5	4
>20	6	1	9
Total number of children	34 <sup>1</sup>	16	18
Informants without children	2	No info	3

<sup>1</sup>. The ages of four children are not disclosed in the questionnaire

The age of the Danish pedagogue informants ranges from 33 to 55 years. Their family status reflects their different stages in life and the current diversity of family patterns in Denmark. They have a relatively large number of children. All of them, except two, have children who still live at home. Among the youngest informants, one is expecting a third child and the other informants still have young children and younger children at school who require more caring. Another group of informants have teenagers or children who are students and live at home. Most of them have a spouse / partner. Some live alone, and some are divorced and live with their children from a previous marriage. Some have met a new partner / spouse and live with their joint children. One lives with a sister, another lives alone.

Four of the male pedagogues have a spouse / partner working in the care work sector – two are pedagogues (and another informant's ex-wife is a pedagogue), another is a healthcare nurse and one works as a deacon. There is only one female informant who is married to a pedagogue – the spouses/partners of the other women have very different educational backgrounds.

The family and friends of the informants take a very positive view of the pedagogue profession and its status and image as we will see in Chapter Five. This makes particular sense for informants who have a spouse who also works as a pedagogue or in a related field. Mention is also made by several informants of the number of pedagogues among family and friends, and that they discuss the profession in these social networks.

The age of the Swedish informants ranges from 31 to 60 years. They are at different stages in their lives, reflecting the diversity of family patterns that exist in Sweden today. Three of the women live alone with their children. Three informants are single without children. Six informants' co-habit or are married, three of whom have children who live in their home and another three informants have children who have left home. One informant did not indicate her marital status but during the interview we learnt that her children no longer live at home.

The age of the Dutch informants ranges from 22 to 51 years, with an average that is 10 years less than the Danish and Swedish informants. Their family status is as follows: four are single, one has a child who lives at home, 10 informants live with a partner and eight informants have children. One informant says that he wanted to separate his work and private lives: *"I once had a partner who worked in care. With regard to that I had the idea that we should by all means keep work and private life apart and she agreed with me. Otherwise you discuss clients at the dinner table."*

For several of the informants, the introduction of children into their lives has changed their work areas. According to a Danish woman, she gave up her home assistance work because there was no caring facility for her child while she was working. Faced with working during shifts, being alone with her child and uncertain job prospects, another woman chose to abandon her work as nurse assistant. Today, they have both completed their pedagogue education and experience a good balance between their work and family lives.

### **3.4.2 Working hours**

Almost all of the Danish and Swedish informants, both female and male, work in full-time jobs. Their countries enjoy a very high employment rate compared with the rest of the world, and in line with the cultural norm even women with young children take on work, usually for many hours per week. The care workers who have been interviewed also reflect these patterns. They are satisfied with how many hours they work, even the women with young children. Several of the Swedish informants, however, are dissatisfied with the full-time jobs that have been withdrawn (currently, the reason is financial cutbacks). This Swedish, female care worker at a housing unit, aged 60, and clearly reflects the current full-time norm and the availability of services for children as opposed to the past. She is a good example of the historical changes that have taken place in the work lives of women in Sweden and Denmark:

*And then I was at home with my child for 6 years and then I was back on the labour market. [...] it has been a great job, I think, but with the changes now in schedules and working hours it will be difficult to make people work, there are no full-time positions. No one can do with just a part-time job today. That was do-able in the past. Then we would work part-time to be able to look after our children but today this has changed and everyone wants to be working full-time*

All the Danish male pedagogues work full time. One of the men has left a well-paid job with long working hours because he wanted to spend more time with his children:

*I found that it was just too hard so I said that I wanted to work 37 hours instead of working almost twice as much and discovering that I could not recognise my children any longer coming back from work. My manager did not agree with that so I chose to become unemployed, and stayed home with my children for a couple of years."*

All the Dutch informants work fewer hours than their Danish and Swedish counterparts. According to the professionals participating in the Dutch interviews, work can successfully be combined with the family and household. That is also because they (and especially the women) either do not work full-time or have a babysitter for the children. As opposed to the Swedish and Danish women, it is much more usual for the Dutch woman with children to take a break from the labour market, which is what this Dutch informant refers to: *“women have children, stay at home and at a given time go back to work, but not full-time, since they have another job to do at home.”*

### 3.4.3 Work schedules

Among the Danish informants, the women mostly work shifts. The female pedagogues with children say they are satisfied with a schedule of work, which involves evening, night and weekend shifts. This enables them to spend more time with their children on weekdays and the children will spend less time at the day care institution. *“When they return from school then they can be with me on all the days instead of sharing me during weekends with their siblings. They are given some better opportunities”*. The spouse / partner as well as the children also appreciate this.

To one of the families, these work hours seem to be part of their style of life. A Danish female pedagogue, who works for 30 hours at a housing unit with people with major support needs, has two small children and is pregnant with her third child. In her view, working during ‘off hours’ is a purely positive thing:

*it gives me a lot of days off during weekdays. I work every second weekend and have several days off during the weekdays. They do not have to go the kindergarten and family day care every day[...] There are many benefits of working like this. They will not be affected by stress, I will make sure that we don't have to hurry every day, not at all. That is really nice.*

After her third child, however, she would like to work in the daytime.

She tells us how the family has had many discussions about combining work and family life in the future with three small children. *“It is the big question right now, which we are discussing at home. What should we do? How do we make it work.”* She clearly states that she would prefer a period without work, when she can focus on her children. *“My children are first priority”*, she says, but she also explains how she would like to complete further education in the pedagogical field.

One of the Swedish women, who works as a personal assistant, also considered working in shifts as an advantage when her children were very young and she was living on her own. She finds that you have many days off when you are working in shifts. Her parents helped out by looking after her children. Other informants say that it may be difficult for single parents to combine their working hours with the opening hours of day care centres.

Some informants with children prefer to work normal hours. Several of the Swedish informants at a housing unit, who work the day shift, say it is really great working in the daytime when you have small children at home, and not having to work evenings and nights. But they also mention the issue of extra work to generate a higher income for the family. As with some of the Danish care workers, they work extra shifts to earn more money in a low-paid segment of the labour market.

In all three countries, several informants point to the fact that unusual working hours require that you have a spouse / partner if you have children in your family. Both the male and female informants in Denmark say that having a spouse / partner is very important with regard to combining your family life and employment if working 'off hours'. Their spouse / partner will look after and spend time with their children outside normal working hours, and this is assumed by both genders as being normal. Some informants mention that working 'off hours' may occasionally take place at the expense of your family life but it is a great benefit for the children. The Dutch report examines the question about distributing household chores within the homes of the informants, and there is a general contentment with regards to the division of household chores. Whether by previous agreement or not, the partner shares in the housework.

One of the Dutch informants, a female senior client supervisor, mentions that you need good organisational skills to make things work out well:

*I have been able to do practically everything because I am fairly well organised. We have organised things well at home. We haven't lost any friends or acquaintances. We have always had a good babysitter and so we could always go out in the evening. I haven't felt constrained in any way, ever. And our children have rarely been sick, we ourselves are as fit as a fiddle, so we are extremely lucky, too.*

It is quite clear to several of the male and female informants from Denmark that their family lives will remain a factor that has to be taken into account when considering the scope and schedule of their future work. For example, there is a female pedagogue who used to work for fewer hours when the children were younger but now she works full time. It is part of her considerations about the future to establish her own housing unit together with other people, "once the children have grown a little older", probably because such a move would require a greater work effort.

The Dutch material contains several examples of women who will take on more challenging work and work more hours when their children grow older. This is also reflected in the Danish data. This Dutch worker explains her thinking:

*My family has only enabled me to work as a senior coach over the past two or three years. I used to be a supervisor before that. That was a conscious choice. Before that I had always put my family before my work. As you get older you have more freedom and space to pep up your own life. Because I didn't think that work was more important than family*

Two of the male Danish pedagogues with young children largely adapt their working lives to the needs of their spouses and children. They make a continuous effort to solve the problem to the best possible benefit of the children: "It may be subject to a slight expense of family life [...] It gives us a tremendous amount of time with the children, and that is important". The other informant thinks hard about how to strike a balance between work life and family life. He explains that his family is the reason why he has chosen not to work in a childcare institution or in a treatment job. He works in the daytime at the moment and his wife works in elder care, but not full-time. She works night shifts and is able to be at home when their 9-year-old child returns from school. They have two younger school children. The evening shifts are good in relation to the children but "during weekends it may of course pose a problem". They make more money by working outside normal working hours, which is needed "because we are both working in a low-paid area."

One of the male Dutch informants says that his wife also works 32 hours a week during the daytime and that they have split the days between them so that one of them will always be at home with the children when they return from school (although the school would also have a solution to that problem). The children are aged 5 and 7. Several of the Dutch families organise their work so that both spouses participate in looking after and spending time with their children.

Care workers without children at home may also prefer working 'off-hours'. To a Swedish care worker without children living at home this choice has become a life style:

*say, if I had to apply for an ordinary job during the weekdays, I think I would be completely exhausted after a month. Because [...] , my God, if I had to work 8-4 from Monday to Friday. I mean how do you manage everything, with doctor's and dentist's appointments*

The opposite view is also reflected. A female pedagogue in Denmark, who is single and with a grown-up child who lives at home, is less satisfied about the schedule of her work. *"I would prefer to be working in the daytime. It is a big disadvantage for my social life to be working every second or third weekend."* The Swedish material refers to several informants who are very critical about the changes owing to cutbacks, which means that they have to work every second weekend as opposed to every third weekend in the past.

To one of the Swedish female informants,

*the worst thing is the schedule of work, with many evenings and nights shifts. It was great when I had my child to look after, because then it was a perfect match to be working evenings and to be at home during the week. Then I thought it was a great idea, but now I do not think the same."*

She is not the only one of the informants who has changed her view on the schedule of work, as her children have grown older.

Working 'off hours' may have repercussions on your leisure-time activities and social life. One of the Danish informants refers to this problem. The Dutch informants do not feel that the work constrains them in how they spend their free time. Sometimes it is difficult for them to take part in group activities (such as team sports or clubs) if they work irregular hours, but then they seek free time activities that suit their working hours. One of the informants participates in voluntary work and once a month he looks after a child and does voluntary work for the Red Cross.

One of the Danish male pedagogues also refers to the importance of leisure-time activities:

*Being able to strike a balance between my personal and work life? As a matter of fact, I have been thinking about this while considering a job move. My considerations were, would it enable me to do leisure-time activities in combination with a new job."*

#### **3.4.4 Work characteristics relative to own children and family life**

Generally, the informants do not appear to bring home their work. There are a few exceptions, however; the pregnant pedagogue from Denmark with two small children, for example. She works with some people who need very intensive support and says that she becomes very sensitive owing to all the hitting, and that it is tough when your children are small. A Dutch male informant talks



about how he becomes very exhausted: *“In that sense, work is very demanding. It takes a lot of your energy away from the tasks that you would want to do at home.”*

A female care worker from the Netherlands mentions that she finds it exhausting to work with people who are at the same development stage as her child:

*It may sound a little bit strange, but back then when my kids were still in nappies and I had care tasks to attend to here as well, I felt exhausted, both then and now. But the difference is that my children are developing steadily. It was a temporary phase in my children's lives and when it passed, they simply went on to the next one. That's less often so here. I once worked with a woman who was very difficult to get on with. My daughter was then in a phase where she behaved exactly like her, actually. That made me sick sometimes, but only for short periods of time. I thought 'I already have a child like this at home and then I come here to find myself in the exact same situation'. The difference is that the woman in question still behaves like that, while my daughter entered a new phase a long time ago.*

A Swedish, female informant, a teacher at a day care centre, without children of her own, talks about the same subject but she believes that you are able to achieve mutual benefit of experiences from your work and personal lives in relation to your children:

*it is quite obvious, that if your work is to give care and be pedagogical and then later have a child at home whom you must give care and be pedagogical. It is a bit the same. Obviously, you may learn from both situations and experiences.. But later you may of course be too exhausted.*

There is another Swedish care worker who compares the cleaning and laundry tasks at the housing unit where she works with the same tasks that she performs at home. She says she does not have the energy to do the same tasks in both places. The Swedish interviewer asked about the work and family life balance.

*Yes, it is big dilemma, but then I was fed up. After a time when I had been working I felt completed burned out, I had been making Christmas decorations at work and then again at home. It is not that I am a very fuzzy person but I want my stuff to be in the right place. And I had been home with my kids and then I felt it was just as if it had never stopped. But finally I had to stop, I could not go on. It was more demanding for my family but it also meant having things under control in your home. I did not have the energy to do the same stuff over and over again. It is exactly the same stuff you are doing at the housing unit.”*

It is interesting, we believe, that there is such a great similarity between household work and salaried work. The reason why she does not have the energy to do both may be the monotonous and routine features of her work, possibly resulting in burnout. Subsequently, she may quit her job, thus indicating the importance of the work not becoming too monotonous, in order to retain and recruit workers. Her statement about the content of work contrasts with the views of some of the Danish male pedagogues. They have chosen their line of work because it can be united with their leisure-time activities of music, theatre, drama, etc. In this context, salaried work and leisure-time activities are perceived as a kind of hobby, resulting in satisfaction and energy at home and at work and a state that is quite the opposite of being burnt out.

### 3.5 Concluding remarks

#### 3.5.1 *Routes into the sector of disability care*

There are some differences between the informants in the three countries; several of the Swedish and the Dutch informants say that they ended up in the sector of disability care by chance. The Danish pedagogues, however, are more deliberate in their choice.

In all three countries, the field of disability care is probably a less known working area among young people because of its relatively small size in comparison with other areas of care, e.g. young children and elderly people, and healthcare. Apparently, the area is not promoted among the public as a modern and attractive working area. Similarly, there may be a rather less social discourse about the area compared to other sectors of care work. The fact that the employees are recruited into the Danish sector of disability care mainly on the basis of a pedagogue education, which is itself well-known and popular, may be the reason why the Danish informants seem to be more deliberate in their choice, i.e. not necessarily because they know about the field of handicap care before their education but because their education provides them with knowledge about and the opportunity to work in that area.

In less known working areas, personal knowledge about the area may constitute a key path towards job entry. One of the Dutch informants believes that as many as 40 percent of the Dutch care workers in the sector of handicap care have a relative with a disability. This also applies to some of the Danish and Swedish informants who have a mother or friend working in the area.

In Denmark, the male pedagogues explain their motivation for completing their education and working with people with disabilities in another way than the female informants. They mention specific professional skills such as music or knowledge of nature. One reason why they explain their choice of work area in a different way than the women do may be that they have given their choice of career in a female dominated area more thought because they are breaking the pattern.

Many of the informants believe that they ended up in handicap care by chance. In their own view, they have ended up in this field of care and thus, by chance, in a traditionally female area of work: the care work sector. This leads us to ask whether the chances of ending up in an area that is traditionally dominated by your gender increases where there is a more random and unconscious choice of career.

Several informants have worked in other areas of care work. We recorded differences between the three countries in the informants' experiences, and opportunities for working, in other areas of care. In Denmark, handicap care is part of the area of (social) pedagogy, and the pedagogues enjoy many alternative working areas, e.g. services for young children, out of school care, residential care for children and young people, the field of disability care and socially-challenged adults. In the Netherlands, the alternative work areas for graduates lie in the health care sector or in the area of social pedagogical work, depending on whether the care worker is trained in the health care area or the social pedagogical area. In Sweden, there are alternative working areas in elderly care and health care.

Human considerations, feelings of solidarity with a group of citizens with a major need for support, and the joy of working with these people represent a key path into the sector for some informants. Highly educated care workers do not express any contradiction between having a graduate degree

and a professional approach while viewing humanity and solidarity as major motivations – quite the opposite.

The paths leading the informants into handicap care are thus quite diverse. Most of the Danish and Swedish, and many of the Dutch informants have considerable life and work experience before they enter the sector of care for people with disabilities. Several informants have worked in other care sectors. The users thus meet seasoned and mature care workers, assuming our informants represent a general pattern.

### ***3.5.2 Work life and family life***

There are significant differences between the weekly working hours of the Dutch informants compared with their Danish and Swedish counterparts. The Dutch informants work fewer hours, notably the women. In the Nordic countries, the women's employment rates are among the highest in the world, and this also applies to women with young children. They work for many hours and enjoy the service of public-sector day care institutions with guaranteed availability for all children, which is reflected in this case study.

Things are different in the Netherlands. Many mothers with small children are not working. Both women and men work fewer hours, a feature that is reflected in our case study. The mother and father usually take care of their young children who are rarely left in full-time day care services. The possibility of having a young child looked after is generally more limited compared with the Nordic countries. When it comes to taking care of children outside normal working hours, the informants from all three countries say that the spouse or other relatives do the job. Services are limited in this area in all three countries.

Irregular working hours represent a positive feature, many of the informants believe, and they are not thought to pose problems for family life. The spouse / partner and other relatives will take care of the children, which is a key precondition for workers' ability to achieve a balance between their work and family lives when they have young children. Some of the informants, however, prefer daytime working hours. There are several examples of informants who are changing their minds and prefer daytime working hours, as their children grow older.

Working off hours may have repercussions on your leisure-time activities and social life, and that problem is mentioned by one of the Danish informants. The Dutch informants do not feel their work constrains them in how they spend their free time.

## Chapter Four: Gender

The care and pedagogical sector is dominated by women – this was once again documented in the previous reports of the *Care Work in Europe* project. According to these reports most men were employed in the Scandinavian countries, and the debate about gender was most profound in these countries too. The debate about men working in this sector has been conducted mainly in relation to services for young children and out of school care.

In both Denmark and Sweden, discussions have been going on for many years about men and care work, both within public care and in relation to family life with many wishing to see more men in care work. These discussions have notably been made on the basis of various discourses: the equality of gender, children's need for men, staff group composition, prevention and safety and the labour market (Jensen 1996; Cameron, Moss and Owen, 1998; Nielsen, 2003). Despite the debate about men and care, the issue has been subject to surprisingly few research studies. In a recently published anthology in Denmark about men and care work, the editors note in their preface that *"During our work we have been surprised to see how little research has been done into this issue in Denmark and the rest of the world. Male care work – privately and professionally – has been subject to surprisingly little research."* (Hjort and Nielsen, 2003: 12).

One of the subjects of the *Care Work* project is gender. With a view to including the gender issue in the case studies, two or more male care workers were interviewed in each country. When it comes to gender and care of disabled people, the details below build on our empirical study and other research work, but the issue, we believe, is not adequately researched.

The case study of disabled people in Sweden involved a male care worker (*vårdare*) and a personal assistant (*personliga assistent*). In the Netherlands, three men were interviewed – one senior client supervisor (*senior cliëntbegeleider*), a peripatetic worker (*ambulant werker*) and a family care worker (*verzorgende C*). Nearly half the Danish informants were men percent: six pedagogues and one disability assistant. The Danish researchers requested a broad representation of gender, age, experience, etc., when contacting the providers of the care services for interviewees. Most frequently a man and woman were selected, which most likely reflects the reality that most Danish care institutions hire male pedagogues. The man interviewed in each case was not the only male employed.

The relatively high number of male informants among the Danish interviewees together with the fact that all of them except the handicap assistant are pedagogues with high education (level 5) as well as the greater proliferation of men in the sector may explain why the gender issue is covered in more detail in the Danish report than in the reports of the other two countries. Some of the findings from the Dutch interviewees can partly be caused by the fact that two of them are medium educated (level 3 and 4) and no social pedagogues (with level 5) were interviewed.

This consolidated report and its conclusions deal mainly with one of the sexes – the women's paid work in the field of disability care. Thus, the gender aspect is covered more or less explicitly in all chapters. This chapter focuses specifically on the issues dealt with by the three national reports under the gender heading and notably with a view to uncovering how male and female care workers discuss gender and care. The structuring of this section is based on the following: first we look at equality and the gender-divided labour market, and the relationship between gender and

understandings of care; then we look in turn at gender and the users, including safety and prevention, and gender and staff issues.

The labour market discourse, including issues of recruitment and future directions, is dealt with in Chapter Ten.

## **4.1 Equality**

### ***4.1.1 A gender-divided labour market***

The gender-divided labour market is usually described by examining the horizontal and vertical distribution of men's and women's positions in the labour market. As far as the horizontal distribution of care workers in the handicap sector the majority are women in Denmark, the Netherlands and Sweden.

In the Netherlands, it is mostly women who are employed in the care sector for disabled people. If men are employed they are in management positions (the vertical distribution of labour).

In Sweden, women mostly staff handicap care although the number of male employees is relatively high compared with the care of elderly people.

Of the three countries, Denmark has most men employed; 23 percent of the 8,500 employees working with people with disabilities. Percentage-wise, most men are employed in day-care services (30 percent of nearly 2,000 employees). When it comes to housing units and flat sharing, there are 21 percent men out of some 6,500 employees (Socialpædagogik og socialpædagogisk praksis i Norden, 2001:24). These figures include workers without professional training but most of the employees are trained pedagogues. According to another source, 15 percent of employees in housing units are male pedagogues (Krøjer, 2003), and thus untrained staff make up about 6 percent. Among the six male pedagogues interviewed for this study, five are employed in day care services with only one in a housing unit.

In Denmark, a 23 percent male participation in the handicap care sector is a high figure compared with services for young children and care for the elderly whereas a similar percentage of men is employed in the field of out of school care and residential care for children and young people.

On vertical distribution of labour in Denmark, we have only been able to obtain data for the entire social pedagogical work area, not specifically for the handicap care sector. In this larger field, in 1996, 55 percent of all management positions, including heads of department, were occupied by women (Kvinder – det farlige køn, 1998: 4), whereas women accounted for 74 percent of all staff. These figures relate to members of SL (the trade union of social pedagogues). Thus, in Denmark, there are slightly more women than men in management positions, but it is still a relatively low share compared to their total representation in social pedagogical work.

### ***4.1.2 Gender and understandings of care and pedagogical work***

Male workers in the care field means that the virtually automatic association of women with care work is or will be broken. The Swedish and Dutch reports refer to care work as a typical woman's job, and the Swedish and Dutch informants mention it too. The Swedish report introduces the section on gender "*with various aspects that have emerged following the tradition that this is a female occupation.*". According to the Danish report, the pedagogues do not refer to their work as women's work and thus no statements are made about why there is a majority of women working in

the field. A possible explanation may be that, in Denmark, pedagogical work and gender are rarely topics of discussion. We will get back to that issue later.

It is quite clear that the Danish and Swedish care workers have strong ideals about having men working in disability care. All pedagogues in Denmark were asked about the importance of gender relative to users and staff groups, and everyone responded (and most likely will have experienced it too) that this is an important issue, and that it makes a difference when there is a proper mix of gender in the staff group. Statements such as *“There should be room for both genders, absolutely”*, *“It is important for the people living here that we are both men and women”*, *“I think there are too few men [...] We need some more men. It [...] would be nice with half of each gender.”*, *“We need both genders. We enrich each other well, and we give each other a ‘kick’”*, are made by almost all male and female informants whether they work in a place with an equal distribution of men and women or work in a place with a majority of women. The Swedish care workers who touch on the issue of men in the staff group consider it very obvious that more men in care work would be a good thing.

The ideal of men in care work most likely reflects the discussion about equality in these two countries since the 1970s, including the debate about having more men in the care work field. The two countries are different today, however. Borchorst, Christiansen and Siim (2002) have commented that *“in the public life of Danish politics there is greater agreement (than in Norway and Sweden) about equality already being achieved, and since the 1990s, gender has taken on a more limited, political significance”* (260). This is a likely explanation of the fact that gender issues are not often a topic of discussion in Denmark.

Sweden is known for a major, public discourse about equality relative to Denmark (Dahlerup (2002). Many people are declared feminists (men too), which is uncommon in Denmark. There is a feminist tradition, and people talk about gender issues in the public and political spheres. One of the Swedish informants, a woman working in a day care service, expresses this view: *“I am a feminist and believe that we should try to develop equality in all areas”*. She believes that the development of equality does not only require more men but also more immigrants in the care sector.

*In my view, it is good with any kind of equality – I mean more men when the women dominate and more women when the men dominate. More immigrants when there are too few immigrants. [...] This is useful, necessary and enriching, I believe. It contributes to developments.*

She considers various way of attracting more men into the area: *“That is where you should start. Boys who are able to understand, while they grow up, that I can be working with this.”* She believes that the automatic association of the job with women should be changed, so that men *“will think these thoughts.”*

As discussed in the section about the paths leading to the education as pedagogue and the motivation for working with people with disabilities, the Danish male pedagogues mention that in their work they want to use their professional competencies in fields such as music, theatre, workshop and nature. They do not explain their motivation in terms of wanting to provide care or do pedagogical work. One of the male pedagogues, however, in explaining his motivation, does stress that men need to provide care just as much as women do:

*As men we need to be caring and provide care just as much as women do."*

*Interviewer: So, it is not that some users need men but rather that some men have a need to do this job because they feel like providing care?*

*Sure, otherwise they would not be pedagogues. I do know that too many male pedagogues become managers, but I do not think they choose this education to become managers. [...] It is a natural thing for men, too. Because of our upbringing we need to give care and we need to be in this profession.*

Some care workers in the Netherlands, unlike their Swedish and Danish counterparts, express a more traditional view on gender and care; it is a natural attribute of women to provide care, more so than a male attribute. One reason may be the informants' educational level and personal background. Another reason may be that men and care in the Netherlands have not been as much on the agenda as in the two Nordic countries. One of the Dutch care workers, a male senior client supervisor, expresses his view as follows:

*The difference [between men and women] lies in the manner of giving care. Particularly the women in my group, they just love bathing people or putting on nappies. For me these are skills you have to acquire entirely.*

*Interviewer: Are there any men who enjoy care work?*

*I don't know any [...] this target group, a fairly low level, attracts the women in particular. And especially mothers*

In contrast, the other male Dutch informant, a family carer, is afraid of generalising the gender issue:

*Then again, one tends to generalise so quickly. And then you end up with clichés. The women are somewhat more caring and the men stricter and more businesslike. The women are more intuitive and have more antennae to pick things up. Men are more businesslike and don't take things to heart so easily... but I have learned an awful lot from that, from one's feminine side. I try to make the best of both worlds and to be as versatile as possible. I try to be an all-rounder.*

Working together with men may also change your view on them. One of the Dutch care workers says that there is a woman at his workplace who is more business-like than one of the male colleagues, who is a more sensitive character, and against that background the informant associates differences with the individual person rather than with gender.

The Danish and Swedish interviews do not contain many statements about women and care as a natural combination. Some do touch on the subject, however. One of the Swedish care workers, from a housing unit, talks about the type of person rather than women and she thus makes no automatic association with gender (but her examples relate to women). She views things from a certain perspective and with some irony and distance: she expresses the view that she and her female friends contain "too much care". Many of her friends are also working in the care sector and they are discussing whether they should quit for other work:

*But while I was talking with one of my friends about jobs, then one of my friends, her name is X, she has been working in the care field for 35 years, I guess. She said, “wait and see, after 14 days [in another type of job], we will say: Is there no poor soul here whom we may sink our teeth into?” I believe it is a special kind of people who are working with people.*

In general, the Dutch interviewees (especially female) find that men are less flexible and more direct than women, whose reaction to ‘clients’ or situations is more frequently guided by emotions. This is expressed in the following extract from an interview with a female care worker:

*I think that the male care workers deal with particular things in a more businesslike fashion, because we put more ‘tenderness’, our feelings into certain things [...] Perhaps I should give an example. One of our clients falls in love with one of our female carers. And when he doesn’t get enough attention, he punctures her tyres, for instance. She is like “OK, fine, because, you know, I will talk to you about it.” He also has to cover the cost of the repair. The male colleague, on the other hand, says, “Hey, hold it.” You just have to tell him what’s what. “When I am on duty, and there is no one else around, I will not attend to you. For the time being I won’t come to you.” That’s what men are like, they simply draw the line more clearly, so that you think “Oh, OK.” And we sort of think, ‘he pays the costs and he gets a reprisal: ‘Hey, you can’t do that. That’s not how we treat one another.’ We do that in a different manner than men do. Men are quite resolute: Clear off, you won’t be attended to.*

Men and women handle these things differently, she believes. In the example that she provides, women act on the basis of an opinion that the ‘client’ is able to learn through conversation whereas men act and take specific sanctions. Thus, women and men act on a different professional basis.

One of the Swedish care workers expresses a fairly generalised perception of the men who are in care work with people with disabilities. She believes that the men in the care sector are special people; in her view, they are more sensitive and soft and it seems to be easier for them than other men to talk about and display their feelings relative to the users and other staff. The statement is often heard in the debate about men and care work. The material available to us does not show whether the male informants are in any way special, as in the manner described, but the very nature of their work obviously and certainly requires the competencies mentioned in order to achieve satisfactory performance.

According to the Danish report, the Danish male pedagogues express satisfaction in their work with other people. Some give high priority to family life and small children. They accept relatively low pay, they perform creative activities, and all this can be seen as so-called soft values.

## **4.2 Gender and users**

All three reports contain informants who stress a number of benefits for the users when both genders are represented among the staff. The users are given the opportunity to relate to both men and women. A Danish pedagogue explains the necessity of having both genders, and says that when both genders are represented among the residents, “*then they might also have a need to look upon some of us [male and female staff] since we are their role models.*” Men as role models is a strong argument used by our informants. Most of the care workers in the Danish report believe that both genders in the workforce provides a greater multiplicity and depth in relation to both staff and users.



The advantages are described in terms of nuanced differences rather than gender stereotypes. They seem to have been thinking about gender and to be using gender deliberately in their care work and pedagogical work.

A Danish and a Swedish care worker give examples of how gender is used deliberately as a resource in their work with adult people with disabilities. When the two sexes meet, things may happen: “*flirtation and stuff like that*”. A Danish male pedagogue says:

*It means something, the experience of relating to both men and women. The users share this experience too. Then, there are also other things which mean that...when you are not so well off intellectually, then you are usually closer to some basic things and your instincts, and this means that some female users react positively to male care workers and others react negatively to male care workers.*

*[...] Sometimes there is an elderly woman who is finding difficulty in eating and doing other things, so instead of fighting with her for 15 minutes, they ask me to come and join her. The flirtation and other stuff make her react positively to a man. In this situation we use it quite deliberately to smooth things out. There is also another elderly woman who is quite the opposite, when she is exhausted or very tired, then I better stay away.”*

The Swedish report contains several examples that strongly stress the necessity of male care workers for the benefit of the users, for example this female care worker from a housing unit:

*Well, we do have some very nice people living here. Several of them have their personal favourites. Some will say, ‘I really do not like her’ [...] There is a man who likes to go shopping with women. He likes it when we come to visit. He is not fond of the men. He finds that boring. You should not see this as anything personal. You should try make fun and to play along with a little flirtation.*

She seems to be viewing things very much from the users’ perspective and to be saying that they are entitled to their favourites. The same theme is found in the Danish report, which points to a focus on users’ reactions to the two genders and how efforts are made to take this into account. In line with the Danish report, ‘flirtation’ between the genders is mentioned. The arguments for more men are not only that they benefit the residents and the users but also that they benefit the women.

This is reflected by the following quote from a female Dutch care co-ordinator at a day-care centre. She explains how the female users are falling in love with the male care workers: “*But I see clearly that the participants react differently to M. being the only man in the house and thus romance, of course, develops, with the clients following him around all day long.*”

The introduction mentioned the safety of children as one of the discourses relating to men and care. The discourse is associated with the debate on paedophilia and men as potentially overstepping other people’s limits (Nielsen, 2003: 35) and on how to prevent abuse in day care institutions and other services for children and young people. In disability care there are past incidents of severe sexual abuse of disabled people by the staff.

The issue of the safety of users in relation to sexual abuse by staff is not given much attention in the three national reports. Mention of the issue is made only in the Danish report by a male pedagogue from a housing unit. He tells us about how he is helping a user when visiting a prostitute and he explains that two care workers always go together. One role of the Danish pedagogues is to provide sexual guidance, and in relation to this there exist rules about the protection of users against sexual abuse and the protection of staff against allegations.

*We go to a massage parlour. We go there with them twice a month, and there is always another colleague going with you, because as a male pedagogue this may very well be a source of misunderstanding when we are visiting a fancy woman with the users. I therefore always demand that we go two together on this kind of job.*

*Interviewer: So, occasionally you take him to a fancy woman?*

*Yes, to a prostitute.*

*Interviewer: There are two of you [pedagogues] going?*

*Yes, because we also need to lift him out of his chair and then we make sure that we have the proper documentation... there has been a lot of focus on this in the past year, well, I mean on male pedagogues, so we might as well be proactive. We often use the students for this kind of job to show them another side of our work. The law also states that we must help them with their sexual needs.*

It is hardly a coincidence that this subject is brought up by a man. Sexual abuse is usually and quite automatically associated with men although incidents of sexual abuse initiated by women are known too. The public debate about men and abuse (of children) and the questioning of men as (potential) offenders may curb the recruitment of men in the care work sector, not only in the area of work with children but also in the area of care for people with disabilities.

The people interviewed give examples of how sexual approaches from the users are tackled but they are rarely considered a burden (see Chapter Five).

According to a young, Danish female informant at a day-care centre for people with late brain injuries, the older users have a more traditional perception of gender roles. They only want men to do certain tasks (craftsman-like), which they do not believe women can perform. She tries to change this. This indicates a historical change in gender roles.

The chairman of LEV, a Danish organisation which represents the users, agrees that it is important that the users meet both female and male employees, because in her experience they act differently. She argues that the staff and parents often are a little too much of a “mother”, the “mother” as a metaphor for the protector, who in reality may be the parents and both the male and female staff. In her experience, however, the male pedagogues are keener to push the users to go and meet the outside world. She has a son with disabilities.

*You could say that both staff and parents tend here to be a “mother”, a little too much. [...]*

*I have an example and I am using it quite often, and it applies to both staff and parents. It is about money. My two children, I have a daughter aged 29 who is married and who has children, but when my children were younger, Asger [with a disability] was clearly the best*

*to take care of his money, but he is now the one being put under administration. We have talked a lot about this with the staff where he is living, and they say “no, some things he just does not understand” It is true, he does not quite understand everything about money, but he does realise things that are expensive, and he does not want to buy anything that is expensive. It is not a problem for him to manage that and he can withdraw the money himself, but they still say that “no, do not withdraw more than 600 kroner” and “ do not withdraw more than ...” [...] This is specifically about money, but it may concern other things as well. ‘Remember to ...’ It is pretty possessive, instead of acknowledging that he is a young man aged 26 who can do this on his own and who never forgets his keys or anything else, but then they still have to remind him about it. This is really unnecessary.*

*Interviewer: What about the men? There must have been some male...?*

*I think they are better at letting them go on their own and to let them try out their limits. I really think so. That is the difference.”*

According to a number of Dutch interviewees it would be more pleasant, notably for some of the male users, if there were more men working in the care sector. One of the male informants, a family care worker, answers the question about whether the users react differently to him because he is male:

*Yes, I think so. One female user runs away from a male worker, or vice versa. It differs from user to user, of course. But it clearly influences the care you provide. The impact can be positive or negative. It can be acceptance, something like, “Hey, it’s great to have a man in here at last”. It can also be less positive, though: “No, I don’t need a guy near my body. Or else I’ll turn Muslim and then only women will be allowed to attend to me”.*

*Interviewer: What do you think of such comments?*

*I become furious. Totally.*

The latter issue is also seen in the field of intimate care in services for young children and elderly people.

#### **4.3 Gender and staff**

The fact that ideals may be reflected when it comes to hiring staff is mentioned by one Swedish care worker and by a Danish pedagogue. The first informant states that “*being a man is not a disadvantage*”, and the Danish pedagogue says “*it is easier to get the job if you are male [...] gender is a factor in this context*”. They both indicate that men will more easily get a job because of their gender.

The reports contain examples of critical comments from three men about how entering a field dominated by women may involve some difficulty. They have felt that they are treated differently because of their gender. These critical comments are interesting because they provide understanding, experiences and expectations from care workers of both genders.

This Swedish care worker has previously been working in a place as the only man. He felt that he was given preferential treatment because of his gender. If he was replacing a light bulb, the women believed that he had done enough work for the entire week.

*This is quite obvious. It is great with a good gender mix. It certainly is. Going back to Småland, when I was working there, I was the only guy among many other people, and I felt I was given special treatment. If I was replacing a light bulb it was as if this effort equalled the work I would have done for the entire week. Sometimes I felt like that.*

We interpret this statement to mean that he felt it discriminating that he was not to do so much work, and in this way his general working efforts were not respected – appreciation only applied to the work that was typical of a man's job and which only accounted for a small portion of his work. He felt patronised by the women.

There is a male family care worker from the Netherlands who tells us about his experiences back in the 1960s, and by way of his example, one can see how male actions can be performed today as opposed to in the past:

*Some elements of my training had a very sixties feel about them. It was undoubtedly the soft sector, as it was called back then. It was difficult for a guy to bring some male aspects into it. To give you a good example, I am crazy about soccer. I absolutely love to throw myself into the game on the soccer field, but I didn't dare to stand up for it. Soccer was 'not done' and you just conformed to the majority.*

*A male informant from Denmark tells about his experiences being a male care worker in a female dominated area. At the time of the interview he was the only man in his workplace, a day care institution.*

Then I am the only guy here, so I feel that I am being focused on in another manner and must be able to do things that they cannot do. This is how I feel about it. I am happy that I have music." [...]

*If you ask a women who is working in a man's world, then I think it is just the same [...] say, a female engineer. It is more or less the same. Maybe they also feel that they need to be at a higher level to survive in a man's world. Then they will be recognised."*

He speaks carefully about how women and men are doing things differently. But, in his view, it is difficult to work as the only man in an environment dominated by women. He believes that women may have very high expectations towards him because he is a man, and he fulfils their expectations by being good at something (music). This is how he shows his worth. This statement may indicate that men may find at some workplaces in the care sector they must be able to do certain things and contribute something other than the women are able to, and to do work at a higher level (to perform better).

Although a greater number of men in the care work sectors of Denmark and Sweden are an ideal, men are hard to get as the Danish report stresses, notably when it comes to housing units that involve residents with significant care requirements. One of the departmental heads puts it this way: *"It is highly relevant and a great wish to have more male staff but they are difficult to attract to the*

*jobs that involve significant nursing tasks.”* In this way, the work in housing units becomes associated with the traditional female role, as this female pedagogue observes:

*They do not want to do all the bathing, splashing and drying. That is my opinion. It is not a very male thing, I guess.[...]*

*We have had male students here but they preferred the youth centre with kids and more action going on. I think it is more a female thing, you know...and it is not because they do not like the residents, not at all, but they are not fond of all that nursing and bathing. They do not consider it pedagogical, they just do not.*

In the Swedish report, a female care worker also mentions the issue of men and women doing different things. At her workplace many men are substitutes (i.e. covering when permanent staff are not available), and she believes they are great with the residents. But they are not too competent when it comes to household work. One reason is, she believes, that it is part of the substitute's role not to take on responsibility for these tasks, say, cleaning, doing laundry, cooking. The Swedish researcher wonders whether there are similar expectations of female substitutes.

These two female care workers have raised an interesting issue. The Danish pedagogue says that the more intimate work and practical tasks such as doing the laundry are perceived by some of the male pedagogues as not being pedagogical work. This issue is touched on by a Danish research study about the reasons for the skewed gender composition with regard to management positions in the area of social pedagogy, including the sector with disabled people (*Women – a dangerous gender*, 1998). In the study, the pedagogues are asked

*whether there is a specific division of work according to gender at their workplace, and if so what functions are gendered. The answers show that in institutions with both male and female social pedagogues, 30 percent believe that there is a certain division of labour in their workplace. [...] The female functions include; shopping, cooking/kitchen duties, cleaning/clearing work, care work, nursing, repairing clothing/sewing and textile workshops. The male functions include activities that involve repairing bikes, go-carts, cars and buses, activities that involve computers and machinery, craftsmanship/workshop activities, physical/violent conflicts and the use of force, boys' games, wild and forceful or outdoor activities. (9; original emphasis).*

Although in Denmark, it is the same staff (pedagogues with the same education) who perform all tasks, it appears that a number of gender-specific tasks are emerging in some of the workplaces and among some of the pedagogues too. This would indicate that equality in the workplace is taken for granted or that it is not being discussed, and in particular that nursing and care work as an integral part of the pedagogical work is not sufficiently discussed, and that those tasks are not seen as challenging pedagogical work. A number of the tasks performed by men are defined as social pedagogical work. But this does not apply to some of the tasks that are usually performed by women, and the women themselves do not define these as social pedagogical work. According to the above study, women do not feel professionally qualified to apply for a management position. One of the conclusions is as follows:

*Hence, the social pedagogical appreciation of professionalism may be seen as a male definition, since it solely acknowledges women's (and not men's) relations as undermining*

*the professional level, while separating some of the traditionally female (but not male) work functions and properties from the definition of what is professionally valid work. (ibid.: .21).*

You may consider whether these views are characterised by the perception that what the women are doing *is* care work. Very often the tasks performed by women are equated with those tasks often defined or considered care work. Men also perform care tasks but it may be done in a different manner. It seems as if those tasks performed by men are often defined as not being care work, for instance the Dutch male and his statement about playing soccer. These perceptions influence your career paths, among other things, in this sector. According to the Danish research study, the employees are advancing their careers on the basis of 'pedagogy' but not on the basis of 'care'.

Both the Swedish and Danish informants mention the many advantages of a staff group with a proper mix of gender, and the same issues are highlighted: it provides for a comfortable environment with good sentiment, and a more outgoing atmosphere at work.

The Danish report stresses that the pedagogues believe it makes a difference with a staff group in which gender is mixed. They all agree that changes happen when both men and women are working at the same workplace. The changes mentioned are considered to be positive by everyone. The Danish pedagogues, who all have experience of working in groups with a mix of gender, stress several of the same differences between women and men. It is mentioned by several pedagogues that the two genders do things differently and provide each other with opposite views, which results in the development of the workplace. Here a male day care worker comments that

*We need both, we are enriching for each other and we give each other a kick. Some things are done differently by men and girls or women, and they shall just be there. [...] in the spirit of collaboration [...] it is a kick. If there are too many men, then there are too many cocks who want to do too many things. With too many women, you've got yourself a regular chicken yard of women. A good mix is powerful, in my view.*

The 'chicken yard' metaphor is also mentioned by another informant.

A male pedagogue gives us an example of how the two sexes do things differently. Men are only thinking about one thing at a time, whereas women maintain the overview:

*We are lucky enough (as many men are) that we only need to think about one thing at the time as opposed to women. Women are incredible with catching up on things all the time, dealing with problems, whereas men try to solve the problems as they go along or they prefer to wait*

A female informant says: "There is probably less gossiping when it comes to men, usually the men do not care about this, that is the difference."

It is an interesting feature that both genders are critical about their own gender but speak highly about the opposite gender. This might indicate that the ideal of a staff group with a good gender mix is a key issue for them. When women talk about other women they say that they are gossiping, creating intrigue and discussing too much, which prevents decision-making. Men see other males as cocks fighting for power. They lack overview, postpone things or do not take much interest in these

issues. A male, Swedish care worker makes the following critical remarks about his own gender, believing “*that the work and sentiment are adversely affected by a majority of men and that women are better at getting things going.*”

There is only one female pedagogue among the Danish informants who criticises her male colleagues. In her current workplace, there is a “good” distribution of the sexes with 3 men and 5 women. But she has had bad experiences with a majority of men in the staff group, where she has experienced clear differences between men and women in the organisation of work and with regard to user relations:

*When we started out, there were four men and two girls, and I was very excited to see how that combination would work out. I like to work with men. They are straightforward. But that combination was not perfect – there were too few girls, after all.*

*Interviewer: Well, what is the difference?*

*We work in different ways. We see different things. The girls see more details. They are good communicators, good at computer work and stuff. The men are...it differs a lot, also with regard to users. There are many different things that the users use us for, it all depends..., it might as well be the boys who are making use of us girls. There are many different things.*

*Interviewer: So there are no common characteristics?*

*No, that I would not say. Well, yes, when it comes to details [women do that]. Say, to follow up on agreements. All these notes. There are thousands of notes about courses and stuff that the residents should attend. To get this prioritised, all these things that make it work in day-to-day life.*

#### **4.3.1 Management**

In the Dutch report, gender and management is a key theme. The Dutch interviews show that men working in this sector often have an executive or managerial function, or are more active in assisting and supporting users than in providing physical or domestic care.

One male informant relates the question of men to a hierarchy based on status. On the one hand, primary care (nursing and care) is connected with the healthcare sector and considered low status work, so few men are working in that field. On the other hand, there are high status jobs in other areas of the healthcare sector where many men are working. A female informant mentions that the image of the disability area prevents it from attracting men:

*Care work is often perceived as home care. In effect, bathing and caring for people [...] that is the image of care work in the Netherlands. Then men, even if they take up work in the care sector, end up in youth care or in managerial positions.*

It appears as if men and high status jobs are closely associated in the Dutch care sector.

A recently promoted female informant, a senior client supervisor, uses some pretty strong language: “*It is crazy that the hierarchical structure is comprised exclusively of men. It’s absurd, isn’t it?*” She recently accepted a more managerial position. She explains the lack of women in management

by the fact that this is more than a full-time position, and that it is hard to combine with a family life and with (small) children.

*There are a number of female cluster managers, but it is still the men who have the upper hand. That has to do with many aspects. The family, the home, what sorts of arrangements have been made with the children at home and whether you can work long hours. Because the management work more than 36 hours a week. For years I have put my family in first place. Often I have been offered a position, but I have always said 'no', because my kids were too young. I believe that quite a lot of women struggle with this problem.*

A Dutch, male care worker explains why women are not becoming managers so readily:

*It may sound old-fashioned, but women have children, stay at home and at a given time go back to work, but not full-time since they have another job to do at home. Then they think to themselves: "I do my job, and I do it well, but I leave the rest to others".*

By contrast, no mention is made in the Danish and Swedish reports about management in relation to the gender issue. Men and management are not discussed by the Danish pedagogues. As already mentioned, a little more than half (55 percent) of the managers and heads of department are female, and this may be one reason why the informants do not bring up this issue. But in general, management is not frequently mentioned by the Danish informants. Managers are often pedagogues and thus they have the same educational background as the other employees, services are small workplaces and characterised by very flat structures. At the same time, the managers are usually physically closer to the actual services, which may provide for better communication between the care worker and management.

The Swedish informants mention the issue of management quite a lot, but make no mention of management and gender. To some informants, management is problematic because it is too far away from the "work floor". In Sweden, management is usually middle managers (*enhetschefer*), often female.

#### **4.4 Concluding remarks**

It is quite clear that the Danish and Swedish care workers pursue the ideal of having men in the area of disability care. The "*cultural revolution, consisting of the possibility of associating the two concepts of care and men*" (Hjort and Nielsen, 2003: 12) has taken place in these two countries. This is less pronounced among the Dutch informants but we do not know whether this is generally the case in the Netherlands.

The Danish and Swedish care workers argue in favour of more men in the care sector on the basis of various perspectives, including that of the users. According to the care workers, it is both an important and good thing that men and women with disabilities can be together with staff of both sexes. The purpose is not so much the furthering of the traditional perception of the two sexes but rather that this group of citizens need to meet both genders through the staff to have contact with both role models that the staff represent.

Gender seems to be reflected in the care work and the pedagogical work. The meeting between the two genders is sometimes a negative experience and sometimes a positive experience (flirtation) and it is accepted and applied as a resource. Gender is not just a "neutral" thing. To this group of



citizens whose daily life depends so much on professional care workers, this may be one of the ways in which they can be meeting other men. In a small-scale Danish study of the social networks of people with disabilities<sup>25</sup>, there was a distinct overrepresentation of women, which is in line with several other studies conducted in other countries (Hansen, 2002). Although, unlike the past, women and men use the same services together, both day care and housing, we might ask the question: Are these citizens entitled to meet both genders among the staff?

The Danish pedagogues have a lot of experience in their collaboration with the other sex. Our study indicates that the Danish pedagogues perceive a difference in the behaviour of male and female pedagogues. When they talk about men and women in relation to staff collaboration, they are using clichés to describe the gender relations. They are using the metaphor of the chicken yard and the cock fight. They speak of gossiping and creating intrigue. They associate men with action, and so on. All these concepts help to maintain prejudice and prevent a multi-faceted understanding of the genders. On the other hand, it is very striking that when the Danish informants mention the two genders in relation to the users, their statements are more nuanced.

They are making use of professionalism in their judgement of the quality that the gender may contribute relative to the users. This may be an indication that in Denmark gender is not discussed thoroughly at the workplace regarding staff issues, whereas gender is discussed and observed in a professional way in relation to the individual users.

Our material does not show any of the three countries applying any specific strategies at national, regional or local levels with a view to hiring and retaining men in the care sector for people with disabilities. The Danish trade unions have been actively involved in this area, for example by initiating a study about women being managers in the social pedagogical area (Kvinder – det farlige køn, 1998) But the two heads of department at the county level in Denmark who were interviewed in our study were not preoccupied with the distribution of gender among their staff.

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<sup>25</sup> Social networks by way of family members, friends and visiting friends.

## Chapter Five: The Work

### 5.1 Status and image

#### 5.1.1 Introduction

In this section we present a range of issues relating to the status and image of care work. The three national studies lead us to view this issue from many different angles but they are far from covering all relevant matters. Moreover, we do not distinguish between the different types of care work for adults with disabilities, although we will assume that there is a difference in the status and image of care and pedagogical work with people suffering from physical as opposed to developmental disabilities. There is possibly also a difference in whether you are working in day care services, a small housing unit, as a personal assistant in the home of a disabled person or in a major institution. Similarly, we would expect differences related to whether you have no professional education, only a lower level education or a higher education.

Although we will not cover all relevant matters, are inconsistent with regards to concepts and have not distinguished between different places of employment and education, a number of obvious patterns stand out which will enables us to ask questions and suggest a range of general conclusions. We will point to themes, highlighting status and image against the background of the different job groups relative to the status of corresponding groups with identical educational levels and employment in other areas. Moreover, we will stress themes with a view to highlighting the care workers' subjective perceptions of how other citizens and society in general view their work.

The informants' experiences are at the centre of this section, and only a few other sources are included in the analysis. The chapter provides a separate examination of the question about status and image for each of the three countries – Netherlands, Denmark and finally Sweden. For comparison purposes, however, we include questions and explanations across the countries on an ongoing basis. Finally, we present some concluding remarks on all countries.

#### 5.1.2 The Netherlands

According to the Dutch report, the Dutch care workers generally have a favourable view on the work itself, but they experience that it is viewed as low status work by society. The low status is mostly related to the question of recognition rather than to pay. It is explained how the strong differentiation in the Dutch 'zorg (care) sector' is affecting the status and image of working with adults who suffer from disabilities. Care work is part of a hierarchy in which hospital treatment/cure enjoys the highest status, and care for disabled people has the lowest status:

*In the Netherlands, we see a strong segmentation in the care sector. This segmentation is not only in terms of co-ordination but also an order in prestige or status. The first, and highest in status, is the segment including hospitals and specialised medical healthcare. The next is that of mental healthcare and psychiatry. The third is that of the family doctors and the primary medical and psychological care. Then we have care for the elderly (nursing homes, old people's homes), care for the physically disabled and care for the mentally handicapped. Apart from that, and as far as status goes, somewhere in the middle, we have youth care. Welfare work, including social work, is also a special segment and will not be very far away in status from the mentally handicapped sector. Welfare work is under discussion a lot more. Naturally, the status order falls somewhat short and has not really been examined. But the line does run from cure to care to welfare (or social work).*

In terms of status, therefore, disability care is valued against the background of a comparison with treatment in the health care sector. The explanation may be that many of the employees in Dutch disability care have completed a health-related education, e.g. as nurse. Alternative job opportunities are in nursing and treatment, and therefore the health sector is applied as a model for the hierarchy and the job opportunities. This 'model' for the employees affects how other groups of professionals view care work. The national report provides quotes from interviews that deal with the problem about working with health, which enjoys a higher status than disability care. The following quote is from an informant with a management position in vocational training:

*Students more frequently opt for the hospital than caring for the disabled or elderly. That is due to the successes of healthcare. There is more propaganda for hospitals.*

One of the informants in the group of policy makers also talks about differences in status between the sectors:

*I think the most difficult part of the image is the picture that disabled care doesn't have a high status. This is linked to the fact that in the current training systems, the somatic side has received a great deal of emphasis. People in the hospitals also think they're genuinely better nurses than in disabled care. That's measured on somatics and not on perceiving qualities. There is still a lot of room for improvement there.*

In Denmark, where the pedagogues represent by far the largest group of employees for people with a handicap, their reference point in assessing the status of their work is primarily work with children and young people, i.e. other pedagogical work. If you agree that the Danish status paradigm is of a pedagogical nature, when viewed against this background, i.e. the set of values and ideals that determines the status of work in the field of disability care is associated with pedagogical work, then it is only fair to suggest that the Dutch status paradigm of disability care is characterised by treatment and nursing work. In Sweden, the picture is somewhat more blurred. The Swedish informants do not point to any specific profession as a reference point against which to compare the status of their work in disability care. We will return to the factors that come into play later in this chapter.

According to the Dutch report, the low status of disability care in professional terms is not only in relation to 'the dominance of cure' but also 'the dominance of pedagogics, of the desire to develop'. The report provides quotes from the interview that underline this problem:

*You also notice that there are hardly any psychiatrists working in this sector, which is odd. This too says something about the status. The sector is at the bottom of the hierarchy. Hospitals and mental healthcare institutions are higher up. In the domain of pedagogics, youth care and welfare work is much more inviting for most pedagogic workers. The most pedagogic-minded personnel have high ambitions and want to develop and support. If you're working with someone who is really small, can only sit and lie down and can look around with their eyes, then you're much more occupied with care. There is a certain gradation from a strong accent on caring, dealing with difficult behaviour and developing and supporting. A scale of treating, developing and caring.*

You will note that care has been separated as a third field of work, independent from and of a lower status to both treatment and pedagogy. This, however, does not only consist of pressure from two professional areas. It is also about working with development that enjoys a higher status than care, and with the principal task of ensuring that people have a decent daily life without special needs for development by way of pedagogical efforts.

We view this separation as being partially in contrast to the Danish situation where all tasks in relation to people with serious mental disabilities are generally considered to be pedagogical work. Whatever the extent and seriousness of a disability, care and development are integrated in pedagogy. Although development work is an area that involves a certain status in Denmark, the delimitation is not quite as clear-cut as in the Netherlands.

The Dutch report also indicates that care for the elderly is putting increasing pressure on disability care and thus affecting the status and image of work:

*The government representative made another comment. If the various care segments, referring particularly to caring for the elderly and disabled, are allowed to merge together more, it would have the disadvantage that the things specific to working with the disabled would be cast aside. He is already seeing how the discussions about care are primarily to do with caring for the elderly, the problem of population ageing, funding, the shortage of hands at the bedside, and attention to the disabled loses out as a result. His position is that if there is no clear picture of working with the mentally handicapped, if there is no longer an image, as it were, then we have a severe problem.*

According to the report, disability care may almost be made invisible because of the pressure from elderly care, and a quote from an interview elaborates on the problem:

*We are now going AWBZ-wide<sup>26</sup> and then the question is where our specific target group will stay. Soon your 'own people' are no longer recognisable. That's becoming more and more difficult. We're still looking for ways to continue providing tailor-made care. In fact, care for the elderly is dominating too much in the modernisation of the AWBZ. That leads to oversimplification, and our ideas just get drowned out. And we're concerned about keeping up an adequate profile. But we do have that law of equal treatment ready as leverage if it all becomes too terrible.*

This gives rise to an interesting and principle-based discussion about the meaning of one area becoming part of a general scheme (professionally, legally, etc.). The Dutch report highlights the question about whether the handicap area is becoming less visible; and, indirectly it asks the question about whether there will be a tougher competition about financial resources and whether this will result in a lower status of work. Although the informants may be affected by a certain degree of uncertainty during a period of transition, we are starting to see an indication of a negative development in relation to the status and image of the Dutch care workers in the field of handicap care. The Dutch researchers report that the general status of working in the handicap area is also 'threatened' because elder care and disability care are developing towards a more integrated system. Nurses and care workers mostly carry out elder care. The number of pedagogues and social workers

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<sup>26</sup> ABWZ Exceptional Medical Expenses Act (Algemeen Wet Bijzondere Ziektekosten)

is very low in this field. When elderly care and disability care are becoming more integrated systems there is a risk that groups with less training will replace the latter groups of professionals.

In Denmark, uncertainty affected a group of workers when their education was terminated in the early 1990s for the benefit of a generalised education (that is, the integration in 1992 of education for pedagogues trained to work with adults with disabilities into a general pedagogue education). Many of the employees felt that their professionalism was under-rated, but viewed in a broader perspective. The handicap care in Denmark has benefited from being part of the general services offered to the citizens, and the status and image have not been adversely affected by the tasks being performed by pedagogues who are educated as generalists. The Danish experiences, however, are not immediately comparable with the conditions in the Netherlands. Apart from differences in the welfare systems of the two countries, another significant difference lies in the fact that the major changes in the field of handicap care in Denmark took place during a period with fair financial prospects in Denmark and while the relatively homogenous group of staff in this area enjoyed a significant improvement of their education.

The developments in Sweden largely compare with those in Denmark in terms of decentralisation, de-institutionalisation, etc., but the changes in Sweden occurred later and in some areas they were more radical than in Denmark. With Sweden having cut back its resources for a number of years, the Swedish care workers have not had as much time as their Danish counterparts to consolidate their status and image.

The above details about status and image in the Netherlands mainly build on the Dutch researchers' discussion and presentation of their results based on interviews with policy makers and trainers, and a focus on structural factors. The following sections build more on the report's discussion and presentation of the results from the care worker interviews.

As mentioned at the beginning, the Dutch care workers have a positive view of their work. The Dutch report summarises the informants' views as follows:

*People think care work is important because the residents need them and because it's important for the staff themselves. They feel like they're doing something useful. You get satisfaction from it. It's nice, you learn from it and you can take something positive from it.*

The report provides quotes about the importance of the handicapped people's independence in shaping workers' perceptions of doing important work. This view is expressed as follows: "*If we're not here then people here have no chance of survival*" and by the following statement: "*Those people really need us.*" You can group these statements into one category designated as 'the importance of being someone for another human being'. Other statements highlight the personal development that you may achieve by working with handicap care, for example in the following statement: "*I get a great deal of satisfaction from it. I also learn a great deal from it.*"

On the subject of the care workers' opinions about how their work is viewed by other people and its general image and status in society, the Dutch report states that these views differ somewhat. The report summarises the interviews as follows:

*When we asked what society thinks about caring for the disabled, care workers say that the reactions vary. They think it's really clever, although sometimes the work is given too much praise. It seems like people are suddenly going to say hello if you're out walking with a disabled person. They don't think about it, unless they see it nearby. Or it's all great, just as long as it doesn't come too close to them in their neighbourhood. They've got no real picture and only see the nice laughing kid with Down's syndrome. They are seen as a separate group. They still look at them like they're odd. The target group isn't very appealing, for example, they don't score highly on intelligence. Caring for the disabled has a very low image because it doesn't pay that well, for instance... The negative points include: the work is simple, the target group puts people off, people think it's dirty or nasty, they develop so slowly, or dribble, and the work is physically hard.*

On the subject of reactions from family and friends with regard to the status and image of work, the Dutch report concludes as follows:

*They think it's really nice, they think it's meaningful, important work, they see it as a vocation or as rewarding work. They think it's completely normal, nothing special. The standard remarks about the work being hard and that they wouldn't be able to do it themselves.*

On the basis of conclusions and comments from the Dutch researchers and quotes from interviews with the Dutch care workers we are listing the following aspects that we assume to be key factors in relation to the image and status of work:

- The phenomenon of 'care' has a low status relative to 'cure' (treatment)
- The target group (people with severe disabilities) has a low status in society
- People generally have very little knowledge about the area
- In some ways, this is 'dirty work'
- The work is low-paid

The first item shows that the Dutch care workers agree with the interviewed policy makers that care has a low status relative to work that involves treatment/cure and associated nursing. As already noted, the comparison made with the status of nursing and treatment/cure is found in the Dutch report only.

The second item indicates that the target group for this work has a low status in society and the third item highlights the general ignorance of people with regard to this area. The two items are related and probably apply to all three countries of the study. The Netherlands is characterised by a large part of carework for people with severe developmental disabilities taking place in large institutions in isolated locations, whereas people with all sorts of disabilities in Denmark and Sweden are usually living in their own apartments and – especially in Sweden - working in ordinary companies.

For several years, the organisation of care in Denmark and Sweden has underpinned integration. The Danish informants indicate, however, that there is a lack of integration although housing services are located in ordinary residential areas. Here we are distinguishing between the citizens' knowledge of and commitment to the conditions applying to disabled people and the citizens' access to meeting care workers in action. The housing and job services, which are located in

ordinary residential areas and in conjunction with other places of work, will at least result in making the tasks and efforts of the care workers more visible in the eyes of other people.

The fourth item refers to the different comments about the work being dirty; the Dutch informants indicate that there are many tasks involving personal hygiene. They say that their work brings them into contact with vomit, faeces, etc. The connection between dirt, bodily fluids and status is a general phenomenon in all types of work and possibly also in all countries. But it is interesting that it is mentioned relatively more by the Dutch care workers whereas the Danish and Swedish informants do not treat the subject with any great significance. Presumably, there is no simple explanation to such differences, and the differences may be based on coincidence. It is possible, however, that the Danish informants, who mainly consist of pedagogues, are not particularly occupied with the questions about personal hygiene because they do not view these tasks as being part of pedagogical work (cf. Chapter Four on gender). Moreover, Denmark and Sweden may be characterised by a more relaxed view on the physical body than in the Netherlands.

Finally pay is mentioned as a key factor. The informants mention pay as a reason for, rather than a result of, the low status of their work. The fact that women dominate the work area is not mentioned by the Dutch report, although female work, low pay, part-time work and status are commonly associated factors. The question about the correlation between gender and status is analysed in the chapters about gender (Chapter Four) and working conditions (Chapter Seven).

### **5.1.3 Denmark**

We have already introduced the concept of the 'status paradigm' to express how the status and image of care work are assessed within the value system of the professional area, and we stressed that in Denmark, disability care is assessed within the paradigm of pedagogical work. We are basing our view on the fact that most workers in handicap care, including management, have completed a pedagogical education. The Danish pedagogues are educated to perform a very broad spectrum of work, and the informants in the study have decided to work with handicap care instead of for example, working in day care institutions for young children or in 24-hour services for children.

Asked about the general image and status of his work, a Danish male pedagogue answers that it depends on what you compare it with. Being a pedagogue, he "*often experiences that the area of handicap care has a slightly higher status than working with children.*" This is his experience from his studies at the training college, and in his view it is still the case that "*in the world of pedagogues you will achieve a slightly higher status by being able to say that you are working with disabled people and as a social pedagogue as opposed to changing the nappy of a child, right*". The Danish informant stresses that this difference in status is unfair because the work involving young children is actually "*very important work, or preventive work you could say.*"

The Danish national report provides another example that working with handicapped adults enjoys a higher status than working with children, but it also contains an example of the opposite view. One of the informants explains that pedagogical work with children has undergone developments that have raised its status to an extent that has affected the pedagogical work in the field of handicap care:

*the focus we have seen on notably the children area and the look on pedagogues as doing other things than changing nappies and looking after children, and where your work is*

*targeted on professionalism and professional identity, I think this is also impacting our area. [...] I think it is lifting the entire group – the discussion in society[...] It brings into focus to how important this work is, society-wise.*

The Danish report stresses that several factors may explain the different views of whether working with handicapped people enjoys a higher or lower status than working with children and youth. One explanation is that these are personal experiences and assessments. Another explanation is that the work of these informants is performed within different types of services for adults with a handicap. Despite the disagreement, both statements contribute to underlining that the status and image of disability care in Denmark are assessed on the basis of a different paradigm than in the Netherlands.

The Danish report stresses that the status of working with handicapped people has increased with the introduction of a generalised education for pedagogues. Until around 1970, students were trained specifically to work in the area of handicap care including people with developmental disabilities. Later, students, who graduated as ‘social pedagogues’ were qualified to work within a more broadly defined area including day care services for very young children (i.e. under 3 years). Since 1992, this more specialist ‘social pedagogy’ education was replaced by a generalised education, with a common education covering all facets of pedagogical work. Consequently, when you are introducing yourself as a pedagogue today, you are introducing yourself as a person with a considerable work area potential and with a BA degree.

The professional identity is pretty strong. First of all, you are a pedagogue. Secondly, you are a pedagogue who has chosen to work with adults with disabilities.

Mention of the relatively strong professional identity, however, should not be made without mentioning the myths and prejudices that adversely affect the profession. Although pedagogues are mostly met with respect for their work, they are also confronted with prejudices that are rooted in the political activities in which many pedagogues participated during the 1970s: the pedagogues represent a big professional group with almost 100 percent trade union membership. The pedagogues and their unions have had a high profile in social debates since the 1960s. They have achieved an image of being a highly left-wing group with a commitment to the women’s movement and other grassroots movements. The pedagogue caricature is one of a woman with political interest, dressed in batik-coloured clothes, and the ‘purple nappy’<sup>27</sup> has become a symbol of the profession.

This image does not apply to today’s pedagogues, but remains associated as part of the pedagogical image, which is mentioned in some of the Danish interviews. One of the male informants, who has entered the pedagogical working area because of health related problems, which forced him to end his career as a manual worker, explains that he was very unaware of the challenges ahead before he got going:

*I did not believe the pedagogical challenge would be so big, but that was because of my lack of knowledge about this area. I have had to change this, because there is really [...] Once, being a pedagogue - this was mostly something I experienced in day care institutions – was something about the purple nappy, and kind of being looked down upon in a certain way.*

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<sup>27</sup> It was a trend among Danish pedagogues to use a dyed nappy as a headscarf, and the most popular colour was purple.



The purple nappy is also mentioned by one of the female informants: “To some, pedagogues are people who are just drinking coffee, and then the purple nappy, but I really do not believe this gives justice to the profession”. The perception of a special kind of style being associated with pedagogues makes one of the informants say the following:

*it is really problematic using the word “pedagogue”[...] I think some people have a general view of what a pedagogue is – that pedagogues are drinking lots of coffee and are smokers. I am a non-smoker and do not drink coffee either. Sure, I dress in freak clothes. ‘But, you are not wearing pedagogue clothes’, they will say. It is really a peculiar perception. Pedagogues are just so different, right – I do think I could do without some of these myths.”*

The question about the target group’s status in society and the general lack of knowledge about this area are two other themes of the Danish report. As already mentioned, it is quite common for disabled people to be living in ordinary homes or small-sized housing services in normal residential areas, making use of the day care services made available in residential or industrial areas. In Denmark, the target group is fairly visible but this, in itself, has not solved the integration difficulties. Also In Denmark, there is a general lack of knowledge about handicaps and what it means to be a disabled person.

There is another perspective in relation to the question about the knowledge of the general public that stands out more clearly in the Danish report. The report says that the pedagogues are not good at making their work visible, as one of the Danish female informants explains:

*I do not think we are very good at showing what we are doing as pedagogues. Compared with nurses who are facing patients with a broken arm, and that is a lot easier to describe, but we have not been good enough at describing our work and making it visible to others, right. I think this is the case, because there has been much focus on this issue, so we want to be better in this respect, to be better documenting what we are doing, and that is important. We are really poor at describing this, and very little is communicated in writing. This factor has been reintroduced again. I think there has been a lack of this before. Many people do not know what has been going on. But I believe that we have been more successful in profiling ourselves in the rest of the city, organising holiday trips and other stuff. To obtain a little more focus. We are really keen on media coverage, and have succeeded in having some things covered by a magazine, in a social debate, etc., and that is important in order to get the message to people. To tell them what we are doing, because this is unknown to many. We have not been good at this before, but I hope we will succeed in the future.*

The pedagogue above compares her work with that of a nurse, but we would emphasise that the comparison does not consist of placing the work itself in a hierarchy in which treatment, cure and care are the most important issues. The pedagogue refers to the nurse’s work because she is viewing nurses as representing a relevant professional group for comparison, although the nurses’ work is more easily described. Making your work visible by way of descriptions and documentation is a key theme in the Danish debate on pedagogical work. As a result, written skills and communication have generally been given higher priorities by the educational institutions. This aspect of visibility is associated with the professionalisation and the growing educational academisation that have

resulted in a debate on academisation versus a retention of practical skills. This issue is covered in Chapter Eight on education and competencies.

The Danish report also discusses how the informants are facing the opinion that it is good that someone is doing this kind of work. The report points to the fact that in the view of the informants, this kind of reaction is clearly associated with a general ignorance about the actual job content and its nature. One informant says: *“The most common reaction from people who learn about my work is that ‘it is good that there are people who want to do this job. I would not be able to’”*. He goes on to explain that any person not doing the work but with some idea of the characteristics of the work would know that it brings you in close contact with other people *“and that is true – many people in our society do not like this. This way they are expressing a kind of gratitude to the people who are doing care work, but that is about as far as they go”*. Another informant explains that the reaction of other people may be explained by their ignorance: *“I hear people say that they find it interesting, can you do this and how do you cope with it in the long run? Your relationship with these people is likely to be very different from what you can imagine as an external observer.”*

The Danish report quotes an informant stressing that she is met by the phrase that her work involves “looking after”, which she comments on as follows:

*but I am not looking after them, I am living together with them. I mean, I am not looking after, this is not the way I would describe it myself. I am trying to live a life together with them. When I am here, we are living the same life, right.*

We have already mentioned that the Danish informants are not pre-occupied with the ‘dirty’ aspects of their work and we have suggested that this may be explained by a different focus of their work and a different view on bodily contact owing to cultural differences. The Danish pedagogues seem to focus on the pedagogical ideas of their work and their reflections on this theme are fairly abstract. This discussion raises the possibility that the Danish pedagogues are making a taboo of the ‘dirty’ aspects of their work because they view them as not being a true component of the pedagogical tasks, although there is a general tendency towards saying that all types of tasks should have some pedagogical relevance. Finally, we should note the possibility of bias in the interviews of both the Danish and Dutch informants.

We are not proposing any answers to these questions. But on the basis of our own knowledge about the field of pedagogical work, we suggest that the first explanation is particularly important, i.e. that the ‘dirty’ aspects of the work do not figure strongly in the consciousness of the pedagogues because they are focusing on other aspects of their work. If this is the case, we should connect this with the fact that the sanitary conditions are generally fairly good in the housing and day care services for handicapped people. With proper bathrooms and ancillary tools it is not a major problem to perform intimate tasks.

In Denmark, there are relatively a lot of men employed in the area of handicap care, and with a tendency towards the men being primarily employed in day care services, but the area has generally a large number of male employees and this possibly affects the status and image of the work. Being a pedagogue means being in a profession that does not “only” involve female work. Moreover, the work is being paid in line with any other kind of pedagogical work, which is largely on a par with the salaries of nurses and teachers. The Danish report provides quotes from two male informants on status in relation to the pay level. One of the informants says that pedagogues *“would never be able*

*to enjoy the same status as a male IT employee who is making a fortune – when talking about the kind of status of a really well paid job. The rest should depend on the individual person's human views, what does status mean to you, what kind of view of life are we communicating here?"* The other male informant is working in a project with people with developmental disabilities, in particular with graphic art and music:

*I would probably not be doing this work solely because of the pay; I would go into teaching or something similar, doing research or presentations, but since I love creating things I am working here to create stuff. This is also the place for the students to create the stuff that they would not be able to elsewhere. We have a great reputation and represent a big asset for society, so we cannot ask for more.*

#### **5.1.4 Sweden**

The Swedish report also concludes that the care workers have a very positive view of their work but some of the informants feel that their work does not enjoy a high status in society. The national Swedish report bases its analysis of the status and image of care work on how the management and financial situation are affecting the care workers' perceptions of the status of their work. The report concludes that:

*The financial planning is often separated from those doing the care work. Distrust and a feeling of not being taken serious when the management does not understand the danger of a poorly prepared budget may result in a negative view on the work among the staff groups. The woman who talks about a situation in which they suddenly were presented with a "Donald Duck budget" is sceptical about the management's tackling of the situation, and it was a tough time for the staff group. The feeling that the work you do is not considered important and a high priority by management may emerge when you are not supported in tasks that you consider need to be done.*

Several of the Swedish informants express indignation in relation to the poor conditions that are offered by society to handicapped people, and they associate the status and image of the care work with the question of social justice. When people with disabilities are offered poor conditions, the care workers feel their work is not taken seriously.

Following our analysis in the sections on the Netherlands and Denmark, in the Swedish context, the 'status paradigm', we believe, consists of 'thoughts about rights' or a 'rights paradigm'. It seems to us that the Swedish care workers assess the status of care work on the basis of the question about society's treatment of handicapped people who are recipients of care, and on the basis of the question about society's treatment of the care workers. The Swedish care workers are talking about a lack of rights and a lack of 'rights being fulfilled' when asked about the status and image of their work. We stress that the 'rights paradigm' does not refer to whether there is a deficit of rights in Sweden; the point is that the informants are referring to the issue of rights as a parameter influencing the status and image of care work.

As outlined by the German social philosopher A. Honneth (2003), social rights express a general recognition of the citizens ("a right-oriented recognition as a morally sane member of society"). Coupled with the experience of emotional contact in love and friendship and recognition in communities and workplaces, social rights are paramount for people's perception of recognition. People who do not meet sufficient recognition get a feeling of social contempt, Honneth believes.

Swedish informants express these experiences about how handicapped people and care workers often see their own reasonable expectations and requirements being ignored by society and managers in the workplace. The Swedish care workers are talking about low pay, poor management, a lack of educational offerings, perceptions about the care worker being a 'good Samaritan' (see below) and the like, all this being an expression of low status.

As already mentioned, the Swedish informants believe that the low pay is a key reason for and the main consequence of care work being regarded as low by society. The report refers to a male informant's statement about the correlation between the status of work (low pay) and the historical past. The informant refers to the roots of the work as being associated with the view that you ought to be merciful and do the work because of religious beliefs and thus for free, what he terms the Samaritan approach:

*this is about the Samaritan approach, where the staff had to be religious, and it was often nuns and the like who were working with a deaconess, and then you had to be religious in the sense that you were working for free, and that is being misused by everyone today. And today there is a misuse in that you have to think about the weak in society, and that is what you then will do, and that is why I have applied for this job, but according to the wage negotiations and old-fashioned beliefs this is supposed to be a kind of ideal work.*

One of the female informants who works in a housing service, gives her thoughts on the possible labour shortage in this area. This ought to lead to higher pay, although this may be difficult to force through because the employees are easily replaced:

*But the fewer we are, the more we are needed by the community, and then we ought to get a higher pay, if the demand increases. Because it is, it is. We are easily replaced as a group. That will also keep a lid on the pay.*

According to the Swedish report, the general society's view on care work is negative, and the status has declined in recent years. Reference is made to the fact that it is "The most unfavourable sector" and it concludes that society's tolerance towards handicapped people and the care sector has decreased. According to the Swedish report, the decreasing status is attributable to financial cutbacks.

However, the report also shows that the reactions are positive when people without handicaps meet people with handicaps in daily life, which confirms that integration efforts may remove prejudice and create understanding:

*An informant working in an integrated day care institution believes that one of the reasons behind the strong focus on integration is to be able to change people's attitudes towards other people with functional disabilities and mental disabilities. Maybe it is the work itself that is experienced in a negative manner by society while the attitudes towards the care receivers are generally positive? The staff in a day care institution talks about how the ordinary employees at the work place have a pretty good attitude relative to the users.*

You might assume that greater integration would affect the status and image of the work of the care

workers but the Swedish report questions this assumption. The report reflects on the possibility that the status of handicapped people might increase while the status of the care workers is decreasing, though not due to a direct cause / effect relationship. This hypothesis is in line with researchers' description of how groups of handicapped people are gaining more power, e.g. through their own powerful organisations (cf. Williams, 2001; Bonfils, 2003). Thus, you may ask whether this is a development in which handicapped people, or certain groups of handicapped people, are gaining power and recognition while the care workers are increasingly losing power and recognition (made powerless through their work which is characterised by working alone; or as a member of a multiplicity of professional groups with a weakened professional identity; or because their group is being split organisationally and being de-professionalised). This is an important question, but we do not know the answer to it.

## **5.2 Care worker roles and tasks in daily work**

The roles and tasks of care workers are defined in the context of whether they involve roles and tasks of a day care service, an institution, a quasi-institutional housing service or ordinary private homes. Moreover, the different types of handicaps involved define the roles and tasks as well as the entirely individual wants and needs of the handicapped person. Differences are also associated with the various competencies of the professional groups.

This chapter does not deal with any specific professional role relative to other roles because, in our view, professionalism is part of every role of care work. Being a fellow human being is another role that should be performed with professional care as shown in several of the statements from the practitioners in all three countries. We do not distinguish between roles, tasks or functions.

Although roles and tasks are defined by the relevant context, the three national reports point to a number of common factors that enable us to break down the care workers' roles and tasks into the following categories:

1. Individual, practical assistance, nursing and activities
  - a. Practical and nursing-related tasks at home/the institution
  - b. Workplaces for handicapped persons and day care centre activities
  - c. Leisure time and activities
2. Psychological, social and pedagogical support for disabled people
  - a. Being a significant other/building relationships
  - b. Protection, recognition and empathy
  - c. Challenges and motivation
3. Intermediary and co-ordinating functions
  - a. Between people with disabilities and their environment, including ties with the social welfare system
  - b. Organisational factors
  - c. Society-related

The section elaborates on each of these areas as they appear in the three national reports. We combine examples about care in private homes, housing services and institutions, and wherever relevant, for the general message, the source of the example is disclosed. Finally, we will present

two discussions based on the findings of the study. Analyses and conclusions are solely based on the empirical work of the study.

### ***5.2.1 Individual, practical assistance, nursing and activities***

Much care work is about individual and practical assistance. As already mentioned, the tasks depend entirely on individual circumstances and whether they are performed in a day care service centre or a housing service/an institution (accommodation / institution). We have divided the roles and tasks into the categories of (a) practical and nursing-related tasks at home / an institution, (b) support in performing work and activities of other day care services, and (c) participation in leisure-time activities. The practical tasks at home / an institution include both household tasks and tasks involving personal hygiene. There is no clear-cut separation of the practical tasks and the nursing-related tasks. Practitioners refer to very elementary nursing tasks only, and for those with the lowest level of education the nursing tasks solely involve assisting, for example, nurses. The study, however, does not provide any basis for a specific assessment of the extent to which certain staff groups are performing genuine nursing tasks.

#### ***a) Practical and nursing-related tasks at home/the institution***

When it comes to caring for people with seriously reduced mental and physical functions, the informants in all three countries examined mention that their work consists of performing work related to or assisting a handicapped person getting him/herself out of bed, eating, bathing, brushing his/her teeth, getting dressed, getting into the wheelchair, changing a nappy and administering medicine. A couple of the Dutch informants say that they administer medicine but stress that the dose is set by a nurse. Mention is also made of shopping and household work such as cooking, cleaning and washing clothes. Some care workers are also required to handle the financial matters of the disabled person and others mention the task of escorting people with disabilities to the day care service.

Danish informants, who are working in housing services and who are educated as pedagogues, give examples of day-to-day practical tasks, e.g. how they assist the residents to get out of bed. Usually, there are 5 to 10 disabled people living in a house<sup>28</sup>. Whenever possible, the residents will go to a day care service, but usually they will take turns and stay at home (e.g. once a week) together with some pedagogues who train with them, see a doctor, dentist, go shopping etc<sup>29</sup>. In some cases, the pedagogues participate in the cooking of food and the washing of clothes because they involve the residents in these tasks and thus see it as an integral part of their pedagogical work.

Nursing-related tasks and tasks involving treatment and re-training are not given much mention in the national reports of the three countries. The main reason is the focus of the study on the tasks of daily care work and the fact that we have categorised personal hygiene as a practical task. Additional work may involve administering medicine, treating wounds and walking exercises. Concerning the specific nursing-related tasks, care workers with a lower level education monitor the demand for assistance requiring nursing skills. They contribute by assisting nurses (e.g. replacing

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<sup>28</sup> Danish pedagogues often use the term 'a house'. Each house is a separate – more or less independent unit in a its own building.

<sup>29</sup> Residents see their own general doctor and dentists, in the same ways as other people in the society. Usually accommodation facilities do not employ their own doctors.

catheters) but also perform more simple nursing-related tasks. The Danish pedagogues, however, perform relatively wide-reaching tasks, say, in relation to the administering of medicine.

One of the Swedish informants stresses that despite the job title of *vårdare* (in this case a kind of nursing assistant) they do not perform nursing tasks: *"We are in their homes and we support people in their homes. And should the situation arise that nursing is needed we bring in primary care people."*

When it comes to care work in private homes and notably involving people with physical disabilities, the Swedish national report states that

*'the extended arm' or to be their arms and legs, eyes and ears is an expression that recurs in the interviews when they talk about what their work involves. To do what the users cannot do themselves and at the same time to not do too much are important aspects of being a support for the user. For the personnel, the work at housing units is reflected a lot in making sure that the home environment is secure and that they do not take over too many of the user's everyday chores.*

The tasks consist of assisting people in getting out of bed, personal hygiene and getting dressed, and ordinary chores of cooking and washing dishes.

*Replying to the questions about the contents of his function, a male personal assistant from Sweden explains:*

But that's easy, it says in my job description that I am the user's extended arms and legs, and ears and nose as well, all the things he wants to do is my job to make sure he is able to, then you have to set your own limits. (...) I work with a person who, or I have worked with a person that doesn't care about agreements, he cares about himself, his rights, he's very particular about that and that everybody adapts to what it's like for him, you're supposed to think about what it's like to be blind and all that, but he never thinks about what it's like to do what I do, that is. He'll say "Do that, do that." and I'll answer "yes but wait a moment, I'm doing other things right now, I just can't, I have to do one thing at a time". And then I have to interrupt that and go there, but he doesn't have an understanding when it comes to the fact that you're a person, he doesn't think that I am, he doesn't understand that I have to visit the toilet and that. No, I'm just a slave.

Two Danish informants also talk about being the extended arms and legs of another person. These Danish informants are employed as handicap helpers, i.e. they work for the disabled person in his or her private home. This position largely corresponds to a personal assistant in Sweden, but in Denmark a handicapped people suffering from significant developmental disabilities does not employ helpers. The reason is that the handicapped person is required to be able to manage the employer role. In line with the Swedish informant quoted above, the Danish handicap helpers stress the lack of recognition involved in being the extended arms and legs of another person. The Danish informant talks about the problem by stressing that his current employer (the disabled person) does not solely consider him as his extended arms and legs:

*Working for L. is very nice because he does not look on you as only his extended arms and legs. We talk just as we are doing now, as two human beings. He is able to allow*

*you some mental freedom and he does not reduce you to his extended arms and legs as other people may do. That is very important.*

The question about being another person's extended arms and legs is also covered in the section on working conditions.

*b) Workplaces for handicapped persons and day care centre activities*

We are here talking about workplaces for handicapped persons and about different kind of day care services. Day care services are usually referred to in many ways – activity centres, day care centres or social and activity offerings, etc. We will apply the term of day care centre to cover all types of day care services that are not described as a workplace - although the disabled people may frequently perceive the day care centre as a workplace.

The roles and tasks of care workers are diverse. Their primary tasks are to initiate various activities that will stimulate, train and create quality of life and establish a social environment, but there are also other tasks related, for example, to personal hygiene (changing nappies) and feeding. Other work includes communicating with the authorities and home/housing services of the user.

The Danish report refers to the diversity of day care centre activities, and we see that this diversity applies to the day care centres in all three countries. Aesthetic and artistic activities in the Netherlands have been a major source of inspiration for the staff involved in Danish services to people with significant mental disabilities. The day care centres offer workshop activities, music, theatre, art, computers, sports, outings, etc. Some day care centres specialise in specific activities, e.g. day care centres that focus on visual art. Some day care centres have groups working with hobby activities and groups that work with producing things that are subsequently offered for sale, and other day care centres have dedicated outdoor groups where most of the hours at the day care centre are spent on outdoor activities, e.g. looking after a group of animals.

The Danish report provides an example of everyday life at a day care centre by quoting a pedagogue with responsibility for a group of nine men and women with significant developmental disabilities. The pedagogue explains that they

*are at very different levels and they need to be handled individually, and that is obviously great fun but tough at the same time. It requires much flexibility. Today, I have been changing towels [...] together with two of them. One takes the dirty towel and the other puts on a clean one. And I have been buying grocery goods and someone had to go to the toilet to change a nappy and all that stuff. Then you arrived [the interviewer] and later I am going to a staff meeting. Staff meetings are once a week [...] tomorrow, I am going swimming and there is a users' meeting and I am going [...] to the xx school, so this is going to be a long day... There are some recurring activities, e.g. horseback riding and swimming and our walking and outdoor teams, all this takes place every day. All the things we do are very much in our own hands."*

A brief mention should be made of the informants from the day care centres in the Danish study. They say that occasionally they participate in the planning of major projects that span several days and involve everybody at the day care centre in joint activities, e.g. circus activities. Moreover, the day care centres may be involved in bigger projects together with other day care centres.



The roles and tasks of care providers who are assisting handicapped people to perform a job may involve being located in an ordinary business with a group of people with disabilities working under special conditions. It may involve working in a business specifically designed to offer work for disabled people. We refer to these jobs as 'special workplaces' whether the work is done at an ordinary workplace or at a company where the work is designed for disabled people.

At the special workplace the care worker has to organise the work and ensure that the tasks are consistent with the resources of the disabled person. One of the Swedish informants (the only one employed in this kind of job in the study) says that the competitive environment of the company should not put pressure on the employees with reduced abilities. The care provider's role is to create a comfort zone, to teach the disabled staff to do the tasks and be part of the team in question. Other tasks are to develop modes of communication, one purpose being to enable the disabled staff to orientate themselves at the workplace and follow certain instructions with respect to the tasks of their job.

Special workplace schemes are quite popular in the Netherlands and Sweden. In both countries, disabled people are entitled to a job. In 1996, in the Netherlands, 85,000 people with physical, mental or psychiatric handicaps were employed in special workplaces. Besides those workplaces, an unknown number of disabled people have regular jobs with or without some support (technical, financial and in training). According to the Danish researcher Bengtsson (1996), this system is highly developed and runs smoothly, and competition from ordinary companies has so far been avoided. In Sweden, Samhall (a government-owned, limited company with the aim of offering jobs for people with reduced physical or mental abilities) employed some 26,000 people in 2003.

In Denmark, this kind of scheme is not widespread and we have not been able to obtain information about the number of employees in this segment, although we do know that a number of people are employed in various types of protected environments at ordinary workplaces. For the people with significantly reduced physical or mental abilities the Danish day care services mainly consist of social and activity offerings. The Danish policy in this area has been characterised by the discussion that 'normalisation' does not necessarily mean living in the same way as the majority of the population, including the idea that salaried work is not necessarily an appropriate concept of a better life. A recent survey, however, indicates that in the coming years, the Danish day care services will step up their efforts to increase the number of users who enter the labour market via the care services (Socialt Udviklingscenter, 2002).

### *c) Leisure time and leisure-time activities*

Care workers are involved in different roles and tasks in relation to leisure-time activities of disabled people. These tasks may consist of assisting a disabled person in private hobbies at home or escorting that person to spontaneous or scheduled activities that are not associated with the business of the day care centre. Or, the purpose may simply be to have a good time, playing games or watching television.

Several of the Dutch care workers refer to specific moments when they spend time chatting. They see it as part of their job to have a good time with the users and residents. The purpose is not just training, but the exercising of social and practical competencies follows as a natural development of socialising. One informant explains that she cooks with the residents as her audience.

*In principle, I cook myself, but they will always come into the kitchen to see what I'm doing. Those kinds of moments are great for socialising; they have a cup of tea and I drink my coffee while I'm preparing dinner. I enjoy those moments. We always chat about what everyone did that day or during the week. Usually we only see each other once a week. That's the down side of working irregular shifts. I always enjoy catching up with them, though. They tell me all sorts of stories about their families and what they've been up to all week. Then we clear the table, like you would do in a normal family. That's how I see it. It's not a real family, but that's what it feels like.*

To the Swedish personal assistants care tasks also involve assisting the handicapped person with personal interests and having a good time. One of the Swedish informants mentions that he works with a woman:

*She wants to do the things that she's interested in and she wants me to join in a little bit. So, I mean, I listen to music and watch videos and I do jigsaw puzzles and I help her sew different things. I don't do the sewing but she needs help with putting the thread in the needle.*

Several of the Danish informants, who are working in housing services, stress that living at the housing unit should be similar to living an ordinary life, and the residents must have their own leisure time. Since the majority of the residents in the housing services participate in planned activities on all weekdays, the evenings and weekends should allow sufficient time for watching television, chatting or playing games, and spontaneous activities such as baking a cake or going to the cinema. To several of the Danish pedagogues, outdoor activities are given high priority, and the study shows that the pedagogues and the persons living in the housing units often spend time in the garden or going on an outing to the beach or forest in any kind of weather.

The category of leisure-time activities includes holiday travel, which is mentioned by several of the Danish informants. Since the people with disabilities receive their pension payments irrespective of their housing situation, several of them can afford to go abroad. The pedagogues usually participate in these travels. One of the housing units included in the study applies the rule that all its residents must be offered support to travel abroad at least once a year.

Also in the Netherlands and in Sweden disabled people are travelling. The Dutch researchers note that travelling abroad is popular and generally many volunteers are involved in those activities.

### ***5.2.2 Psychological, social and pedagogical support for disabled people***

Evidently, psychological, social and pedagogical support is closely associated with all kinds of tasks and functions of care work. To provide an overview, we have chosen to describe these tasks separately, as three different roles. In practice however, a separation is not feasible.

The material outlines three key types of roles that are associated with individual support with a psychological, social and pedagogical nature. The first role (a) is called 'the significant other', describing the role of another human being with whom the handicapped person can reflect his/her personality, receive mentoring, build relations and trust, feel comfortable, and share memories. It is the role of the person who is familiar with a handicapped person's life, notably when there is an insufficient or non-existing social network. The second role (b) is closely associated with the first role. It is about providing protection, recognition and empathy. The third role of (c) is that of the

challenger and motivator who helps the handicapped person in using his/her resources and achieving development.

*a) Being a significant other/building relations*

The Dutch report quotes an informant saying:

*I think you have a different relationship with each resident. You don't have the same relationship with every resident. Also, I know some residents better than other residents. There are residents who I've known a really long time, where you've already got thirty years of memories with them.*

This aspect of the work underlines the role of 'the significant other'. The quoted care worker talks about her personal relations with handicapped people, that she knows them in person and that they share memories. But the report also points out that care workers put emphasis on being able to follow another person's development, and several informants are quoted saying how important it is for them to be there for other people. Thus, the report touches on the importance of the relationship for both the giver and receiver of care.

The Swedish study also shows that care workers represent a significant other. One of the Swedish informants describes the role very accurately: "*We have a need for this, the basic significance of being seen and maybe on some occasions to be given a hug and sort of exist as a person, to be in contact with other people.*"

In line with their Dutch and Danish counterparts, the Swedish care workers are conscious about handling their roles in a professional manner. A Swedish informant who works as a personal assistant provides following description:

*But the hard thing is to protect yourself against ... is to avoid getting too private, you shouldn't be like a friend, you should try to be professional in your work, but many users don't have any friends and are so dependent on us, so they want us to be friends they say. But that's not that good really because there's something about friendship that erases boundaries and then, you have to retain some sort of distance.*

Another Swedish informant tells us that care workers usually say that you have to be personal, not private.

The Danish study shows that the pedagogues generally get involved with their feelings while underlining that the relations are of a professional nature. Pedagogues see it as one of their professional tasks to be 'the significant other' to a handicapped person with whom they are working. One informant explains:

*I may very well leave in two years from now and that will involve some emotional problems in relation to that person, but I am damn sure that during the five years I have been working with that person, that there have been things which were much more sustainable than any loss of care that I may have contributed to. I will hope that there will be another person who will continue my work. That is just one of the tough things of living in an institution.*

*b) Protection, recognition, empathy*

We have just stressed the role of the significant other. This role may overlap with that of the protector and the role that shows recognition and empathy: but not necessarily. 'The significant other' emerges in conjunction with personal relations, but you could very well be involved in the protection of people with disabilities without getting involved in any personal relationships.

The Dutch report refers to the protection paradigm as an important factor in disability care. Protection, in this context, is closely associated with social-political efforts towards more integration, and it is stated that the integration efforts should not ignore that this is a group of people in need of protection. Protection is thus part of the social-political discussion and a concept of care. Protection is closely related to other quality aspects of care, and the question about protection may thus be expressed in several ways. But the interviews with the Dutch practitioners nonetheless indicate that in their daily care work they do not focus more on protection than, for example, on self-determination.

Several of the Dutch practitioners stress the importance of being able to interpret other people's needs and possessing empathy. This notably applies in relation to severely handicapped people, because they are not always able to communicate their wants and needs. For instance, care workers will pay attention to wounds or other health-related issues, and they will intervene against behaviours that isolate a disabled person from other people. One care worker says:

*I think it's an essential part of my job as a care provider to point out issues that a client doesn't see himself. I explain what the consequences of his behaviour are in a way that's not offending to him. Just to the point.*

The Dutch practitioners experience situations in which they intervene and feel that they are going against the principle of equality and self-determination, but find such action necessary. One of the informants feels that occasionally he acts as a police officer, and "then you don't really get the impression of having an equal relationship". This issue has been thoroughly covered by other care research studies, including the mention of unavoidable asymmetric relations (as described by the Norwegian researcher Kari Wærness). You could say that care work is characterised by facing dilemmas between the principle of protection and the principle of every human being's right to self-determination. Illustrating this point, the Dutch report provides details of the difficulties involved in motivating a lady who was living alone under very poor conditions together with two dogs that were not properly treated. There are no legal rules clearly defining the borderlines between the duty to provide care for people with mental or physical disabilities and the duty to respect different habits and ways of living of other people. This issue is dealt with in more detail in Chapter Two (cf. section 2.4 on rights).

The Dutch report suggests:

*there is a certain tension between the empathising, understanding and experience-based care, and that of performances, products and demand orientation. The government representative, who sits between both approaches as it were, points to developments in Australia and New Zealand, for example, where the change towards service provision in place of care also leads to the idea that we must be rid of professionals 'who tell you what's good for you.' There is a certain resistance voiced*

*against pedagogic, controlling professionals who think for the client. The attitude is that disabled people primarily want to have normal services provided.*

The informant, who is quoted above, stresses the problem of professionalism by referring to the professionals as people “*who tell you what’s good for you*”. The interviews with the Dutch practitioners, however, indicate, as a rule of thumb, that they do not wish to determine what is good for disabled people – although they do not doubt that we should all decide as far as possible about our own way of living, which is in line with the view of the informant quoted. By contrast, several informants refer to not telling other people what is good for them as a professional competency.

The Swedish report also indicates the importance of being able to interpret the needs of a handicapped person:

*People who are at housing units where the users have severe functional impairments and serious mental retardation, talk a lot about the fact that their function in relation to the users is to interpret their needs and to make their everyday life meaningful and rich.*

A Swedish woman, who is a carer at a daily activity<sup>30</sup> unit, tells us that it is an important function to ensure a good atmosphere even though it is a place of work:

*This is a place of work. Both for us the personnel and the ‘workers’, the comfort and well-being has to be the most important thing. That there is a good atmosphere, a good feeling about the place. And you achieve that by being flexible and accommodating. And where everybody has to be allowed to take up space. Of course, in real life it may look as though a person that isn’t doing well takes up more space than all the others. But we have to see everybody else. And catch the ones that you never notice or hear anything from, too. That is our role. It’s important.*

The aspects of protection, recognition and empathy mentioned above (from the Dutch and Swedish reports) are also reflected in the Danish report. From the Danish report we would like to offer an example of protection that consists of protecting a handicapped person against exploitation of that person’s family. A Danish informant explains that he has several times experienced a disabled person being financially exploited by relatives. Once, he experienced “*a girl aged 18 sitting in a wheelchair*” who suddenly “*goes out and buys herself a car - and we have never seen that car.*” In this situation, the pedagogue took on the role as “*her lawyer*”. He has performed this role to take care of the interests of disabled people not only towards their families but “*also towards society.*” He deals with these problems “*because they are like our children. You also take care of your own children, preventing them from getting into deep shit, to say it bluntly, and that is also part of our job.*”

The Danish informants also talk about a number of generally accepted pedagogical theories and concepts that are key to their day-to-day roles and tasks. A widely applied pedagogical theory is characterised by the idea that ‘it does make a difference’ (the name of the theory) which is covered in Chapter Nine. Below we will mention a less used pedagogical approach that is inspired by Gentle Teaching (GT) because it relates to the mother and father roles. GT was developed by John McGee,

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<sup>30</sup> A daily activity (*daglig verksamhet*) unit is a term for different kinds of day centres or placement in ordinary workplaces

an American, and represents a concept or, more specifically, an ideology of care for disabled people with severe behavioural difficulties. GT is influenced by unconditional recognition and deep respect for other human beings, and is mainly about being present as an equal human being, achieving direct contact with the other person without professional and theoretical filters, without prejudice and a feeling of superiority. The keywords are 'unconditional love', 'unconditional valuing', 'companionship' and 'feeling safe and loved' (Lindsø Larsen 2003). One of the informants in the Danish study tells us that in GT care workers may take on the father or mother role. 'Mother' is used as a metaphor of the unconditional recognition and 'father' is used as a metaphor of the person who sets the limits e.g. by telling you to stop, in a clear and adequate manner.

Except for the pedagogues who work with gentle teaching, the roles or metaphors of 'father and mother' are only applied in conjunction with a more subtle comparison of specific tasks, and when the informants underline that they do *not* adopt these particular roles.

### *c) Challenges, guidance and motivation*

Several of the statements quoted in the Dutch report indicate how important it is for care workers to challenge and motivate disabled people to manage as many things as possible by themselves in day-to-day life. Several informants talk about the role of the coach or being in a coaching position. Sometimes, the disabled people are only capable of very small tasks, but according to the informant no task is too small: *"What I do now is they hold the shower head themselves, I put the shampoo on, but then I let them rub it into their hair. So you see what they can do, however small it is. It takes a great deal of patience."* Sometimes there is very little you can do to activate a disabled person. One informant who, however, indicates that activity and development remain the ideal objectives gives this example: *"He's still alive and that was the aim. Sometimes it's not that easy to see the really small successes."*

The challenge, guidance and motivation role also aims at teaching people with developmental disabilities to live together with other people. One informant explains this task: *"I work in a group of seven disabled people who are in different stages of development. I'm really focused on the group and how we can improve their social skills, so we can avoid conflicts and they can do some housework."*

The Swedish report provides a separate section on supporting functions, although with the following reservations: *"The roles or functions of the carers often overlap each other and it is hard to tell the difference between a routine-based everyday chore or a supporting act. Often these things take place at the same time."* In the section on supporting functions, the report explains the importance of not relieving the handicapped person of the tasks that he or she cannot cope with. However, it is not always easy *"keeping your hands behind your back"*, as one of the informants puts it. Notably with more seriously disabled people you will too quickly take over too many functions instead of allowing them the time needed to get dressed. The supporting function consists of staying back whenever possible but also to *"encourage and try to raise their spirits"* (quoting one of the Swedish personal assistants) when the tasks become too difficult for the disabled person.

The Danish study underlines similar tasks, functions and problems as the Dutch and Swedish reports concerning challenges, guidance and motivation. The Danish report, however, incorporates to a greater extent than the other reports the question about the pedagogue's role of providing guidance to the relatives of a disabled person. This does not constitute a specific work area but is associated with their daily work in the housing service. The contact with relatives occasionally

involves pedagogical aspects, e.g. supporting the family in letting go of their grown-up child or supporting the family in getting involved in the daily tasks of their son or daughter who lives at a housing unit.

The Danish study points to a very specific role of raising people with developmental disabilities: the informants repeatedly underline the respect for self-determination but also emphasise how they intervene when the alternative would be perceived as a lack of care. One informant, for example, explains that he demands the users of the day care service wash their hands after having been to the toilet, and another informant explains that she requires the residents of the housing service to dress in clean and nice clothes to make other people feel like spending time with them. However, there is generally an ongoing debate among the pedagogues about the ethical and legal limitations.

### ***5.2.3 Intermediary and co-ordinating functions***

The intermediary and co-ordinating role contains three categories that can only be separated analytically; one role is about being an intermediary and co-ordinating the relationship between the individual handicapped person and the surrounding environment. The intermediary and co-ordinating role also applies to the organisational level, e.g. organising work and communicating information between different groups of staff and staff on different schedules. According to the informants, the planning part of their job is time-consuming. Finally, there is a role in relation to society. It is primarily Danish informants who mention this role; it involves communicating knowledge about, and understanding of, disabled people, their situations and rights. But it is also about solving a societal problem. The intermediary and co-ordinating functions appear to increasingly dominate care work. Putting the explanation very briefly, people with disabilities are currently considered as consumers who choose among different services.

#### ***a) Intermediary and co-ordinating tasks in relation to disabled people***

A significant part of the tasks performed in relation to the individual handicapped person is about communicating and co-ordinating social services made available by society and private organisations. In the Netherlands, social services are provided by numerous organisations. Bengtsson (1996) writes that in Denmark, as opposed to the Netherlands, all social work has been incorporated into one single, local-authority giant, a reference to how, to a great extent, all social services are covered by one set of legislation, and the local-authority level carries out all assessment and allocation of resources. The Dutch model with its string of providers enjoys many benefits, Bengtsson believes, but his description also shows that the Netherlands is saddled with a giant monitoring body and inherent bureaucracy, and creates a need for advice about the range of services provided by the various organisations.

The large number of providers coupled with the possibilities in recent years of shopping around, as well as decentralisation and de-institutionalisation, are factors that affect the role of care workers. Thus, the Dutch national report says that in recent years the care worker role has changed markedly. A typical example of the views of policy makers and trainers is provided by the Dutch report: *“Supporters of the disabled have become more intermediaries between the disabled and society”*. And the report concludes that the role of intermediary requires the attitude of a consultant and, similarly, that of a contractor. The role thus consists of being an intermediary between the individual disabled person and society. The role is associated with the view that the disabled person and his/her family will make decisions themselves and select the services needed. Care workers provide guidance and acts as an intermediary of the services. One of the Dutch informants, a trainer), says:

*What will, and indeed must change is that workers must have a more businesslike bias. They're partly also a guide in the jungle that is the care facilities. They are an information source for the people.*

Care workers' intermediary and co-ordinating roles and tasks also include creating networking opportunities between people from the same day care service or who are living together, and to establish contacts with a view to building and maintaining a social network outside the institutional framework described in Chapter Six. The Dutch practitioners' experience of having a co-ordinating and intermediary role focuses on these aspects and their tasks of performing care on the basis of dialogue with the disabled person and the closest relatives that leave most of the decision-making to the disabled person or his/her family. Thus, the care worker becomes very much of a service provider. The Dutch report concludes as follows:

*Care providers who work in a group often feel it is part of their job to improve the atmosphere and social contacts within the group. Informants who work with individual clients who are living independently, spend more time on expanding their clients' social networks and supporting in organisational matters, such as finances, completing forms, shopping and so on.*

And the report continues, saying,

*It is striking that care workers describe their role as supporter and guide rather than taking the role of care provider, in the sense of providing care. The description implies that guiding and supporting means letting the client do as he or she chooses. Looking at where his or her interest lies, but also setting boundaries and guiding clients.*

One of the Dutch care workers says:

*We work with people who represent the clients' interests. These are often the parents, but also general practitioners and dentists. And we always discuss matters with the clients. For instance, when you need to make an appointment for a financial audit, you discuss with the client if it's all right to call his parents and when it would suit him. We don't do anything behind their back, and keep them informed at all times. You can't do it any other way.*

The Swedish report highlights some of the same tasks indicated by the Dutch and Danish reports, but also provides an interesting example of a lack of mediation, underlining the dilemma in the wake of the de-institutionalisation and individualisation of care. A care worker, who is employed by a housing unit, says that the residents are individual tenants and that the staffs do not consider them as a group. Therefore, the staffs do not set up meetings with relatives, etc., because, it is argued, you do not set up meetings with relatives for any group of ordinary neighbours in a residential area. This statement makes you think about the balance between normalisation and lack of care. The Swedish report, however, concludes that care workers are conscious that they are providing care to individuals but at the same time they are aware that living on your own may result in loneliness and isolation.



Several of the Danish informants perform the role of a contact person. In this case, the employee has the specific responsibility of contact with a particular handicapped persons relatives. The employee holds specific knowledge about that person's life and needs. The Danish informants have been asked whether they perceive their role as a kind of lawyer on behalf of the residents and users. They all answer affirmatively. They see themselves as working as a kind of lawyer or spokesperson for the disabled person, for example in relation to the parents who do not want to recognise the wishes of their grown-up son or daughter. The Danish interviews contain several examples supporting this view. In the section above on protection, recognition and empathy we referred to an informant who explains how the families from time to time take advantage financially of a disabled person.

The need for spokespersons is also reflected by the Dutch report, quoting one of the informants:

*For example, one client wanted to watch a particular video. His family didn't agree with it. In a conversation with them, the client's opinion was influenced. He changed his opinion. Then the client is denying himself. I think it's a shame.*

This informant highlights a problem but does not take on the role as the person's lawyer in opposition to the family and regrets the family's decision.

The co-ordinating and intermediary role may also involve care workers assisting disabled persons in establishing contact of a sexual nature. Several informants in the Danish report refer to this task as being ordinary. According to the Danish report, the disability sectors are increasingly training their employees to provide sexual guidance.

#### *b) Organisational factors*

In all three countries, care workers perform organisational tasks, but the extent and content differ according to the terms of employment. The roles and tasks concerning organisational issues do not figure prominently in the three national reports. The main reason, we believe, is that these issues were not specified in the interview guidelines. However, the informants were asked to elaborate on their daily work, and several of them briefly mention that they are occupied with various organisational tasks. Some mention that this leads to time pressure and requires communicative and organisational competencies. In all three countries, the tasks of care workers include writing a report for the next person on duty, preparing care plans, planning, participating in and writing minutes of meetings, arranging joint and individual activities. While the Danish report explicitly stresses the growing requirements related to professional documentation competencies and written communication in general. Moreover, there are the roles and tasks of being a mentor for students in trainee positions, which is also mentioned explicitly by Danish pedagogues.

One of the Danish policy-makers says that adjusting to the current demands of documentation and written competencies has been tough:

*I think the climate or the pedagogical environment has changed dramatically with the ongoing drive for quality and documentation ... and at the same time, our resources have been reduced. I am quite convinced, and I do believe I can provide proof or documentation. There is a growing demand for written work being done. Having a*

*heart in the right place has gone out of fashion. It is tough for the generation of co-workers who have become pensioners or have early retirement.*

### *c) Society-related*

The question about the societal role is for example reflected in the care worker's consciousness of and commitment to furthering knowledge of handicaps and the lives of people with serious disabilities, and all this is reflected in care workers' targeted efforts on improving the lives for these people. Our study suggests that the practitioners involve themselves in the living conditions of people with physical or mental disabilities, and several practitioners occasionally work with projects aimed at expanding the knowledge of the lives of disabled people and altering attitudes in relation to disabled people.

The Danish study emphasises that the pedagogues represent people with disabilities and their case vis-à-vis society, for example by reacting to cost-cutting in the area through their trade union. One pedagogue explains that he met with the local authorities, representing the pedagogues' trade union, *"to tell them about a person who was unable to participate in a baptism in his own family because of the lack of staff to accompany the client. This is unacceptable, yes, absolutely."*

The interviewed Danish pedagogues, however, does not talk very much of being an intermediary at the society level. One Danish informant does mention that it is part of his work to highlight that issue, and although everything appears to be in order at first glance, it sometimes changes on closer inspection, but he also says that he is not as active in this area as he believes he ought to be and that he has been earlier. The Danish researchers believe that many of the pedagogues, who have been working in the sector for several years, were politically active during their youth, and they spoke on behalf of the disabled people, and one of the informants is saddened by the lack of political commitment among new graduates.

Generally speaking, the informants do not refer to themselves as having any significant societal tasks and roles, i.e. roles and tasks that are not only relevant to disabled people but also decisive for the society as a whole. The viewing of one's work as solving problems or performing tasks related to society is only briefly reflected in all three countries.

In all three countries of the study, the debate in relation to society about the living conditions for disabled people is conducted by powerful organisations, but we will not cover this issue in greater detail since it is not directly related to care workers' roles and tasks.

## **5.3 Concluding remarks**

### **5.3.1 Status and image**

Care workers have a positive view of their work because it provides challenges and because it is meaningful. However, the Dutch and Swedish informants in particular consider that their work is associated with low status in society. The studies conducted in the three countries indicate a number of factors that affect and are affected in various ways and to different extents by the status and image of care workers.

#### *5.3.1.1 Citizens' knowledge and views on people with handicaps*

A general lack of public knowledge as well as negative prejudice in relation to the target groups of handicap care applies to all three countries. In the Netherlands, handicapped persons often live in institutions that are isolated from other ordinary residential buildings and people in general do not

know much about them. But also in Sweden and Denmark (where handicap services are more integrated in the society) there seems to be a general lack of knowledge about being handicapped. Therefore there is a demand for better knowledge of and contact between people with and without a handicap.

#### *5.3.1.2 The status of care work in relation to different professions and paradigms*

We have outlined three types of paradigms, characterising the status of care work. In the Netherlands, there is an indication of care for handicapped people being evaluated in relation to treatment and nursing. Care work is rated low in this 'treatment paradigm'. In Denmark, there is a 'pedagogical paradigm'. Since care for people with extensive handicaps is considered to be part of pedagogy and is performed by pedagogues, then care work enjoys a relatively good status in Denmark. The Swedish informants do not point to any specific correlation with professions and professional groups. But some of them relate the status of care work to the lack of rights of the users and care workers; it is in this context 'rights paradigm' that care work has a low status.

#### *5.3.1.3 The citizens' knowledge about the actual work content*

Among external observers, myths and erroneous perceptions about the work are widespread. Apparently, it is quite common for care workers in the three countries to face the view that their work is either distasteful, unchallenging or developing. The informants in all three countries also face the view that it is a good thing that someone is actually doing this work. These views reflect a lack of knowledge about the actual job content.

#### *5.3.1.4 The professional group's image*

This factor is mentioned notably in relation to the Danish pedagogues and has both negative and positive dimensions. The negative dimension relates to the historically determined myths about pedagogues as rebellious, provocative and left-wingers. The second dimension is the current situation where the pedagogues appear as a well-educated, professionally strong and homogeneous group of both men and women who have deliberately chosen to work with adults that suffer a handicap.

#### *5.3.1.5 The competition for financial resources between the disability sector and other sectors*

Cutbacks owing to, for example, increasing costs of care for elderly people, are mentioned in both the Dutch and Swedish reports as factors that have brought handicap care into a competitive situation with other sectors. Handicap care is considered expensive, and a lack of willingness is emerging which spins off onto the status and image of the work.

#### *5.3.1.6 Care workers' experience in highlighting their work. e.g. by way of public, written communication*

In general, care workers do not have much experience in highlighting their work for example by way of public or written communication. This issue is mentioned only by the Danish report, but it is probably an issue that applies to all three countries and therefore is of general interest. According to the report, care workers are generally not trained in communicating their work experience to the public.

#### *5.3.1.7 Management issues*

Management issues characterised by a lack of knowledge about daily tasks is mainly a problem raised in the Swedish report which says that care workers do not feel any recognition when their work is not properly managed and the management lacks knowledge about daily tasks.

#### *5.3.1.8 Low pay*

The Swedish informants in particular talk about how low pay is reflecting a low status but the correlation between low pay and low status is mentioned by all three reports.

#### *5.3.1.9 Views on education*

Handicap care is often assumed to be work that does not require any education. Obviously, it is only in certain care work segments that education is not a precondition, but here the status is low. A Swedish informant explains these feelings and underlines that a care worker without professional education is easily replaced and you cannot obtain higher pay through further education if education is not a requirement in the first place.

#### *5.3.1.10 Care work is women's work*

This issue is mentioned mainly indirectly and mainly through the researchers' thoughts about the informants' explanations. But it is a fact that the Danish informants express the highest satisfaction with the status and image of their work and include the highest proportion of male employees.

#### *5.3.1.11 Education and professional identity*

The relatively high status reflected by the Danish pedagogues and their work, which involves care for people with serious handicaps, is associated, among other things, with the fact that it is a homogenous group of well-educated and professional people with a relatively strong professional identity.

### **5.3.2 Two discussions on roles and tasks.**

#### *5.3.2.1 The expert, the catalyst and the good-hearted personality*

Against the backdrop of the quotes recorded in the three countries of the reports, and the researchers' commentaries, we have defined the roles of 'expert' and 'catalyst'. Reading the interview extracts of all three reports, we have chosen to include a third role, which may be referred to as the 'good-hearted personality'. The role is reflected in statements where people perceive their roles as that of a loving human being and do not attach any importance to educational background.

Obviously, these are completely abstract models that are used to illustrate different categories of opinions about the professional roles of care workers and the consequent competency requirements. In actual fact, no care worker fits into one of these categories only but the model may still be illustrative for the discussion about the dominant and preferred features of the various professions and care services:

1. The expert – knows what is good for and needed by the handicapped person
2. The catalyst – initiates processes and gets involved while being conscious about own values and attitudes
3. The good-hearted personality - working on the basis of common sense, personal experience, feelings and a wish to help other people; educational background is not considered particularly important

In the section on psychological, social and pedagogical support we included a quote from one of the Dutch informants (a policy maker) who elaborates the problematic issue of professionalism in care work, for example by saying that "*there is a certain resistance voiced against pedagogic, controlling professionals who think for the client*". In the same section, we stress that this statement

is contrary to our view of the Dutch practitioners who participated as informants in the study. Generally, they express a wish of not thinking thoughts on behalf of other people and not telling people what is good for them. Thus, the informants of our study do not confirm the criticism that was referred to by the Dutch policy maker.

However, both the Dutch, Swedish and Danish reports contain quotes from practitioners who express their views on their tasks in a way that may be interpreted as if they actually do believe 'they know what is best for you'. We are categorising the statements of these informants as expressing that they consider themselves not as professionals but rather as experts. We have therefore assigned an 'expert role' to them. The expert knows what is best for other people. The professional works professionally but this does not necessarily include knowing what is best for other people; in fact, it may be quite the opposite, i.e. that you are supporting the self-determination and self-management of another person.

The educated care workers are professional people. They command professional knowledge about preventing and remedying physical, mental, social and health-related problems, and they say that their professional knowledge may clash with the respect for the rights of disabled people to decide for themselves. Taken separately, however, this is not an argument in favour of de-professionalising their work. You cannot remove the dilemmas of care work by doing away with professionalism.

Several statements from the informants in the study confirm our view that these dilemmas reflect that underlying problems will emerge when care workers analyse their work professionally. But it may make sense to adjust the profession perception and/or argue that professionalism prevents you from applying power and compulsion that may stem from 'knowing what is best'. The professional is able to counter the use of this by being familiar with the possible mechanisms and by being trained to act as a catalyst without the professionalism dogmatically controlling the process but rather being included in the basis on which disabled people are guided. The data included in our study shows that several care workers actually express their views in a manner that shows they are performing a catalyst role.

#### 5.3.2.2 *Working alone as 'extended arms and legs'*

The issue of working alone is covered in particular by the Danish and the Swedish national reports as a particular problem with care workers – handicap or personal assistants - being employed to work with a particular disabled person who then acts as employer or day-to-day manager (the local authorities being the actual employer). In Sweden, the employer or manager may be a person with a physical or mental handicap. In practice, in Denmark, the employer can only be a physically disabled person because that person is required to be able to perform the employer role him/herself.

The handicap helper (Denmark) and the personal assistant (Sweden) would usually be a person without any relevant, professional education. The role of handicap helper/ personal assistant is defined by *not* being an expert or a professional (cf. the above discussion). Our research has shown that the role of handicap helper/personal assistant may be difficult to fulfil. Quite often, care workers will have to balance the expectations of being a friend, a family member, and a professional or local authority representative. As mentioned above, and in the chapter on education, care workers may face a dilemma between the various roles, and he/she may have views that are valid as a professional and as employed by the local authority but which cannot be communicated because the handicapped person acts as manager/employer and does not agree with such views.

Some informants refer to the role of handicap helper/personal assistant as just being the extended arms and legs of another person, and one of the Swedish informants talks about being another person's slave. The power and asymmetry in such a relationship are quite complex and may result in possibly suppressing reciprocal relationships. The Swedish informant who considers herself as a slave also says that the relations between a disabled person and a personal assistant may develop into 'an old marriage', and the Danish informants express a need for having a third party involved for the purpose of professional guidance, supervision and assistance in conflict solving.

The opportunities for disabled people to hire a personal assistant and act as employer or manager are associated with human and social qualities and financial benefits that should not be underestimated. The study also shows that handicap helpers / personal assistants are generally satisfied with their work. But these schemes are not completely trouble free. The study shows that care workers may experience a lack of recognition, and it points to that obvious as well as hidden suppression that may take place with respect to both parties. This may include relatives of the handicapped person possessing a non-deliberate influence that neither the handicapped person nor the personal assistant / disability helper will be able to handle. Moreover, the study shows that the handicapped person is not always qualified as a manager. One of the Danish informants provides several examples of how the employer responsibility has not been fulfilled, for example that handicap helpers were acting as travel companions but without proper insurance cover.

The problem of working alone and having a handicapped person as your employer thus results in a number of questions, e.g. questions about care workers' working conditions and professionalism, about preventing and suppressing mechanisms and about issues related to the handicapped person as an employer.

## Chapter Six: Working with social networks

In this case study about care for adults with severe disabilities the team of researchers decided to deal with the question of working with social networks as a focal point. Social networks and working with social networks are key issues in handicap care in all three countries. As shown below, there are a number of common as well as different themes present in all three countries, which reflect how the social networks of handicapped people and the care workers' role and work are perceived and discussed in the three countries.

The large number of theories on working with social networks and their importance will not be referred to. This chapter, however, is empirically embedded in the informants of the three countries, and it is their statements that are given space. We have kept several of the quotes because we believe they are substantive and that they describe our user group and how the informants view it.

In this case study we are not particularly interested in disabled people's networks as such but more in staff roles and work tasks relating to the networks, and how this is reflected in the understanding of their work. To varying degrees this chapter highlights that in the three countries care cannot be interpreted separately from the social situation of the care recipient, for example family factors. A key conclusion of the study is thus that the care staff's social networking consists of bridging the gap between the institutional services in the public sphere and informal care in the private sphere, which provides the creation of important links between formal and informal sectors.

This chapter is mainly about care staff's social networking with people who have developmental disabilities and not people with severe physical handicaps. The Danish section takes up a relatively large amount of space, as the theme is addressed a lot by the Danish informants. The issues raised by them are probably of more general interest and some are reflected in the reports of the two other countries.

'Social networks' is the label given to important social relations that people enter into. Entering into close relations with other people is the key to the welfare of people, their development and health. Every person's social networks can be grouped into informal, formal and third networks. The informal network relations are personal relations with family, other relatives, friends and neighbours, and they represent the primary network of most people. Formal networks are your relations to organisations in the public sphere, for example professional care staff. This network often consists of a secondary network although some people may take on the role of a primary network contact (see definition. The third network deals with your relations to people doing voluntary work (see below the use here of formal, informal and secondary networks). The mapping of your social relations is often done by drawing up a network map for the person in question. The map is divided into circles and the closer your relations are with the person mapped, the closer to the centre circle that person is mapped.

For any disabled person the network map could typically be broken into the following:

*Informal network:* Family, relatives, girl / boyfriend, neighbours / friends (not disabled people), fellow-workers (not disabled people). Relations with other disabled people at a housing unit and day care service make up a special part of the informal network because disabled people do not usually decide for these relations themselves. However, close relations may emerge in this context.

*Formal network:* Professionals in housing services, day care services and leisure-time activities/other places

*Third networks:* Visiting friends, contact persons, etc.

In the following, we will focus on care staff's networking efforts relative to disabled people's informal and third networks. The family and other relatives make up the network most frequently mentioned by the informants, and take on a dominant position in the following.

In all three countries, most of the residents of the large 'total institutions', back in history, did not use to be in touch with their relatives. The relatives were urged by the professionals to forget about their handicapped child. This move was supported by the geographical location of total institutions in deserted areas distant from other people and where handicapped people were solely socialising with professionals and other handicapped people. The handicap policy mainly pursued the aim of isolating handicapped people from the rest of society – and *visa versa*. Other disabled people used to live with their parents for life but family care was occasionally just as incapacitating and isolating as life in a large, total institution with few contacts outside the family.

With the emergence of other views on disabled people, these ideas about relationships and networks changed. The current political aim is one of handicapped people in close contact with their families as well as other significant people. Thus, the handicap policy is changing the roles of the professional staff.

## **6.1 Denmark**

### **6.1.1 Relatives**

#### *6.1.1.1 Policy makers*

The question about relatives is dealt with firstly on the basis of the statements made by the Danish policy makers. They help to design, manage and organise handicap policy, thus setting the conditions for the staff. The section on policy makers is fairly dominant because the informants during the interviews had a lot to talk about, and listening to what they have to say is quite fascinating.

The Danish policy makers (and pedagogues) clearly say that they consider the task of care, support and development of disabled people to be a public sector responsibility, to be met through housing units, day care services and leisure-time activities. Renewed political interest in involving the informal, primary network including families in the solution of socio-political tasks has not led policy makers to believe that families should be asked to take on more tasks in relation to their relatives with a handicap.

However, the relatives are much more involved with their handicapped family members than earlier. The five policy makers interviewed<sup>31</sup> all talk about a big change in family roles; as one of the informants says "*it is one of the most dramatic changes*". Both heads of departments at the county level say that this has taken place in the last 10 to 15 years. Relatives are in close contact with disabled relatives. They are no longer humble but are advocates of the cases of their relatives,

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<sup>31</sup> Four have been working in various areas for several years and express during the interviews strong personal interest in the field.



making demands on the services and entering into genuine dialogue with the professionals and the system. A senior trade union official comments that *“We have seen many humble relatives [...] They have come here looking for one big excuse for themselves, but fortunately that is history.”*

The change is closely associated with the change of handicap policy in Denmark, which is also changing the role of the professionals. In the past, adult people with disabilities used to live with their parents, who had the main responsibility, or in large, centralised institutions, where they had lived since their childhood. Many of them had no contact with their parents and other family members. At that time, it was believed that parents were best off forgetting about their handicapped child, and they were urged to do so by the professionals. One of the policy makers says that

*in the old institutions, it was for a long time said that you should “surrender your child and forget about them”. It was the old school thought. It meant and was probably said with all the best intentions that they would have better lives with them[in the institutions] and now they [the parents] would have to get on with their lives, and that their children should not be victims of their situation. I do not believe it was said with any bad intentions. One consequence was that the primary network of the residents was basically non-existent.*

Most children with handicaps today live with their parents, and there are many public sector support opportunities made available. When they grow up and become older / adults, they move away from home, but there are still some disabled adults who live with their parents. The informant from the organisation of relatives makes a division into two categories: older handicapped people with old parents who rejected sending their children to the former large institutions; and young disabled people with young parents who are waiting to get into a housing service. Waiting lists for housing services represent a general national problem.

The same informant has a fairly clear opinion about how natural it is for young people with disabilities to move away from home like other young people: *“We have brought up the young people whether they are graduates or ...[suffer from a disability] to live an independent life and that they must take a stand on things themselves.”* She touches on the theme that young disabled people have been brought up under different conditions, and among this group of citizens there is a more modern youth demanding different and new services. One example is a hall of residence for young people where your stay is limited to 2 to 3 years, at which one of the Danish informants works.

The question about the most appropriate age at which a disabled person should leave home is discussed by several informants. One of the informants stresses the individual differences that disabled people have. He quotes a woman who is suffering from muscular atrophy: *“that people with a handicap are just as different as all the other young people or all other people. [...] We are different, some of us will hide away at home with our mummy until we are 38 years old and others cannot wait to get away when they are 12 years old”*. There is no definite answer to the optimum timing for moving away from home.

Some parents find difficulty in letting go of their child who may be highly dependent on the care of other people, including support and care, and on the other hand, some adults with disabilities find it tough to let go of their parents. According to the informant from the organisation of relatives, this also applies to other families. One reason is that *“you do not have faith that the people to whom you*

*leave your child will be capable of taking proper care of them*”. Here she touches on the key role of the pedagogue.

There is a socio-political aim that handicapped people should be in close contact with their nearest family because the professionals cannot provide the close and general relations based on feelings. Today, most of disabled people stay in touch with their relatives. One reason is the location of the housing service in the local community, a fact that is highlighted by one of the departmental heads at the county level. The explanation is not just about geographically closer locations. The physical changes to the residential conditions with small-sized housing units and independent apartments and a common living room for all residents make the residence more home-like and family-friendly, and this has most likely resulted in more frequent visits from relatives. This is in clear contrast to the previously total institutions and the former socio-political aim of avoiding contact with the relatives (for example, reflected in the geographical location and physical layout)

Other explanations include a change of mind among the pedagogues or the professionals regarding the importance of networks and their role in building and maintaining networks for disabled people.

Several policy makers stress the key importance of the family members because they will be there all the time as opposed to the professionals who are of a more transitory nature. The relatives are key people because, in the words of this county level policy maker,

*we will never constitute the same emotional primary network in that way. We must be professionals when we are together with them. We may caress their hair and comfort them but we will never acquire the same feelings that a family member has. Therefore, it is important for us to ensure that there is family or an adult person around who can support that part.*

The policy makers quoted also tell us that some of the county institutions have been trying to record the life stories of their residents. Pedagogues:

*will take them to their father's and mother's grave to make them understand where they come from. They are often confused people and do not understand such things. Then you will dig into their family tree and they will realise that they have a sister. Today, basically all of them are in touch with their families in one way or the other.*

Today, the relatives enjoy a certain level of influence and participate in preparing the action plan, for instance if the disabled person cannot make decisions independently. One informant highlights that the relatives often advocate the interests of disabled people.

The importance of relatives for disabled people leads to close collaboration between the professionals and relatives. Several Danish policy makers mention that the professionals and relatives do not always share the same views about the best thing for the person with severe disabilities in question. The problem is that the relatives sometimes maintain the person with severe disabilities as the family's handicapped child instead of viewing the person as an adult citizen with independent needs, interests and rights. From a socio-political perspective, disabled people are seen as citizens of society, and based on this view the professionals must perform their care work, support and development. One of the policy makers sees it as an ethical dilemma.

*This is a true dilemma. By and large, we are doing well with the relatives, their involvement and influence but once in a while we risk keeping a disabled person in an unnecessarily dependent situation vis-à-vis the relatives [...]*

*[If] there is a person seriously disabled, who is virtually unable to do anything on his own, then you may, if there is no formalised guardian, then we may say that the relatives will take care of the interests of that person. But how far will you go? There may very well be, and I think this is an ethical dilemma, and I do not know the solution, but there may very well be a situation in which the relatives consider the disabled person to be less competent than the professional staff believes. The staff may think he or she is able to do a little more and should be allowed to do more, taking more risks. This may include the risk of disappointment and failure, which constitute a lesson learned for the disabled person.*

The deputy president of the trade union mentions the possibility of opposing interests among the relatives and the disabled person, and how the intermediary role of the professional staff develops into a key task. Replying to the question about the role of the relatives, he says “*relative to adults with a handicap I think that the citizenship issue should be taken seriously. The citizen who needs help is a citizen of society.*” The informant goes on to say that the pedagogue, “*thanks to his professionalism*”, must make the relatives understand that their grown-up handicapped family member has been talking about things they do not understand.

*It may be a difficult issue. It may be about sexuality or basic stuff about eating habits or how to spend your money, or it may be about the wish of getting another place to live, having a girlfriend or boyfriend or whatever.*

He stresses that a key competence of a care worker is to be able to collaborate and enter into dialogue with relatives:

*it is part of what you should include in contemporary competencies. Making a decent and professional conversation with the relatives, [...] where you explain that you are there to represent their relative and you believe they are moving in the wrong direction. Saying this and being able to live with it afterwards.*

As opposed to the past when people with disabilities were solely left with their family or in total institutions, deprived of control over one’s affairs, a strong ideal stands out among the today’s Danish policy makers. People with disabilities are citizens of society with the rights and duties as any other person. Necessary care, support and development are considered to be a public responsibility performed by professional pedagogues.

The interest expressed in the important role of the relatives in relation to people with disabilities shows up in one of the counties that have just agreed on a policy with regard to relatives. The Head of Department explains:

*The policy is also about sending a clearer message that they are adults with their own pension benefits and independent ways of living, they are all above 18 years of age, they enjoy voting rights, pay tax, etc. [...] just like you and me. Citizens of society on an equal par with their parents. But parents who have taken care of a handicapped child for 18 years and who have had to handle everything themselves, fighting for the rights and opportunities of their child, will find it very difficult overnight to say to*

*themselves that, "from now on, I will no longer interfere in your life". Of course they should still do this and we tell them this, 'of course, you will do this and we would like to enter into a good dialogue on this topic with you. But please remember that they are independent unless you [...] have become guardians, otherwise they are independent citizens with the right to choose'".*

The Danish policy makers do not express any wish that the relatives should take over any of the public sector care tasks. By contrast, one of the department heads at the county level says that the public sector may expand its role as care provider and network builder, easing the burden for the relatives of being together with their handicapped family member. He says that the public sector

*may improve its work of collaborating with parents and relatives, and supporting this activity. We are actually putting a lot of effort into this [...] we may very well ask a number of pedagogues to go along on family outings, etc., because many people cannot cope with it as they grow older [...] Emotionally, they would like to spend time with them but they are prevented by practicalities [...]. Who would say that we cannot provide a service in order to keep the primary network together, and provide a service that means we can participate with staff also in family-related get-togethers [...] We have just introduced for this kind of service a fixed hourly rate, i.e. you can buy our staff to provide this service.*

#### 6.1.1.2 Pedagogues

A key aim in the Danish pedagogues' perception of care work is to involve disabled people in the community. This chapter about working with social networks mainly deals with the pedagogues' network roles relative to involving disabled people in family communities, but their roles with regard to creating a community at the housing unit, the day care service, between girl/boyfriends, at leisure-time activities and with neighbours are additional themes that are covered in brief in line with the Danish report.

The Danish pedagogues and social- and healthcare assistants at the housing units who were interviewed provide many examples of how their roles include maintaining, developing and building network relations with relatives of residents and other people. The informants cover care work with people with high support needs, as well as with well-functioning people who have just moved away from home; the age range is from young to old. The subject is mentioned by both female and male pedagogues, which may indicate that the building of networks is widely recognised as a working method in the field of pedagogical work in Denmark.

Notably three of five informants from housing units make much mention about networks and how they work with them. They are clearly viewed by the Danish report as networkers and thus they put the objectives of the handicap policy into practice.

The following male pedagogue, working in a housing unit with older residents with high support needs, is one of those that expresses a very conscious focus on the importance of social networks and his role as a networker and provides a string of examples. He also mentions the many different types of network – the family and other relatives, day-care service colleagues ('fellow-workers') and friends.

*If we have enough staff, then we can let them eat at their own apartment and they can invite a few others to join them as well. Or we will arrange a family get-together during weekends, or if siblings or other people visit, then they may want to join us for dinner assisted by a pedagogue, or on birthdays. For next Tuesday, we have invited people from the activity house of the resident I am taking care of for coffee, because of his recent birthday. That is an important event. Several of them cannot create social networks on their own as 'ordinary' people do with their friends. One of the other residents has just returned from a football match in Italy together with a pedagogue and other people.*

A female networker works with young and well-functioning disabled people at a hall of residence for young people. She coaches the young people, helping them to enter the labour market where they will meet fellow workers. She also does a lot of work in creating friendships between disabled people. She previously worked in various housing units:

*I am talking a lot about networks and all that stuff because people will quickly become lonely, and they become lonely more quickly than we do. We have seen the same trends in flat sharing where they will be watching television all the time if you do not take an initiative on their behalf. I think it is very important they learn these things while they are young. That they learn all this stuff, that they learn how to socialise with other people and stick to friendships, that they learn to take the initiative or otherwise they will just be sitting there.*

A pedagogue with 30 years of experience in the handicap area has been assisting elderly handicapped people who had been living with their parents for their entire lives but whose parents have now died. These experiences explain her very clear view that sooner or later they must move away from home and live independent lives in line with the objectives of the handicap policy:

*I believe that when they reach a certain age, the parents ought to urge them to move on as you do with children of average intelligence. That is what makes the most sense. It was quite terrible...I once had to assist residents after the last of their parents had died and they had been living at home for their entire lives. Taking over a person at the age of 40, 50 or 60 years, who is away from home for the first time – that is not funny at all, I'm telling you. They are very frustrated and they do not know where they belong and they will run around, calling out for their father and mother. It is really a terrible situation. It would probably be a lot better if they just move on and learn that is how life is. They can still learn new things. They have no problem with that.*

The family is very crucial to this group of citizens as it is for most people. Knowing that you are a member of a particular family and knowing your roots are important. Most residents face “significant family needs, coming back to visit their families and being together with their families.” One of the Danish pedagogues stresses that many parents will try to make their other children (siblings of the handicapped child) take over tasks when they pass away or become too old because “family relations must be maintained.”

Several informants say that the parents are the primary, permanent people in the life of a person with a handicap, and the professional staff will always be characterised as “people passing by

during their lives” or as “cheap replacements”. The pedagogues recognise the limitations of the role of the professionals in relation to the emotional aspects and they thus acknowledge the central role of the relatives as a primary, informal network.

*In my view, parents are those who truly master, right, somewhere in what is called comfort, love and care. The rest of us – we are just cheap replacements that is the way it is. I think you should have deep respect for this and look on it as an opportunity for collaboration instead of looking at it as if we know better than you because we are pedagogues, therefore we know best [...] I think this is really great – that the [residents and relatives] establish good relations with each other. It also matters for the handicapped people to have a primary point of contact. [...] we are just people who are passing through. They have been in the same situation many, many times before. They [relatives] will always be there and, i.e. until they pass away.*

The housing unit staff have formal and informal contact with relatives of the residents. The housing staff say that most residents are in regular contact with their relatives, but the staff at two different housing units each talk about residents virtually without any contact with their relatives. According to a small-scale Danish study (Hansen, 2002: 66), 8 percent of disabled people are solely in touch with professionals and other disabled people at the housing unit and the day care services.

The informant who works at a small-size housing unit located at a former ‘total institution’ says that the residents are in good contact with their relatives. One of the mothers, for example, stays at a hotel for several days at a time when she visits her grown-up child. Other residents, however, have only little or no such contact. She explains that

*many parents are old and back then they were just told to give birth to another, I mean ... [...] many of the residents have suffered from this development [...] they have virtually no contact with their parents. I believe that if you were not supported in maintaining contact.*

She points to an important task facing the pedagogues – supporting contact.

A housing unit in our study located in a small-sized community will receive residents from the local area. The interviews indicate that the residents at this institution are in closer contact with their parents. The explanation of the informants is that all the parents live in the neighbourhood. Commenting on the visit to parents or siblings, one pedagogue says that “most of them will be home every second weekend [...]. Their network is pretty good, it really is, a real good network – they are very fortunate”. Many parents will pay regular visits to their grown-up disabled child, some will even make daily visits and some visit so much that it adversely affects both the lives of the handicapped person and the parents themselves.

The socialising with relatives follows the same pattern at the other housing units in our study. It takes place at the housing unit or the parents’ home, but also they do things together such as go on holiday. The relatives suddenly emerge, pop by and others are used to more regular visits, or the staff will drive them for home visits or participate in home visits. One of the housing units has

annual traditions with Christmas parties, barbecues and going to the Sølundfestivalen<sup>32</sup> in which most relatives will participate.

One example of how the informants listen to the residents' wishes to be in touch with their parents is the use of pictograms as a communication tool. They are readily available and during the tour the interviewer asks whether the residents will make use of them to express their wish. The informant replies: *"She may very well do that. Notably if it was about whether she was going to visit her mother. Stuff she is very fond of"*. And, another example (male resident):

*We have a certain book that he will usually bring us when he is going on a bus ride or to a party. Often, he also shows us his mother and father. He wants to say "I want to go home"' or "Am I going home soon?"*

Informants from various housing units find parental visits with joy on the part of the disabled people, but also on the part of other residents and the staff. They also explain how they work on supporting this contact. A male pedagogue says *"sometimes they just pop by, they will bring a cake or they just come by to say a little something for a cup of tea in the afternoon and stuff like that. This is great"*. And a female pedagogue adds that

*They may just visit us to say hello and others have regular visits every week. The staff like this as well and other residents believe it is cosy with visiting mothers or fathers. This is a fact – but it is important to establish these things at the beginning.*

The Danish informants provide examples of how the relatives perform practical tasks together with the disabled people, such as buying new furniture, clothes and joining them for a haircut. But they are not expected to do these practical tasks. None of the informants have a general wish for the relatives to perform more tasks or to be involved in other areas. One of the informants at a housing unit, however, would like to see greater involvement of relatives in the care and practical nursing part of the work and mentions that there was greater parent involvement when she was working with children with disabilities at a 24-hour institution.

One of the pedagogues supports contact between residents and their parents in various ways. He does not believe, however, that the parents ought to take on more tasks – by contrast, he feels he is 'relieving' older parents by making private home visits.

*They have never had the same feeling as the rest of us when your children move away from home and are going to handle things themselves and become fully-fledged. They have never had that experience, and it is therefore important that they step back to live a good life, I am referring to the parents.*

*Interviewer: You do not think they should do any practical ...?*

*No, and the parents should not feel obliged to bring them home every second weekend. We discuss this issue with them, but the parents believe that they have to do this because of their network back home, that we have to take care of our son at 50, right.*

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<sup>32</sup> An annual festival for disabled people all over Denmark. It takes place at Sølund, a former 'total institution' which now is divided into smaller units.

*There is also the issue about how all this is viewed by the neighbour in a small village and why does he only come to visit his parents every fortnight, and stuff like that. It is very much about society's assessment of the parents. [...] we indeed talk with the parents if they are unable to have them at home for 3 days on an extended weekend. We [the resident and the pedagogue] will then go back for a cup of coffee in the afternoon and then we will take off during the morning and head back in the evening.*

The fact that the pedagogues consider the parents and other relatives as the key element in the emotional relationships of disabled people means that much attention is paid to dialogue and collaboration with them. One of the informants says that the staff group has put much work into the collaboration with relatives, and a few years ago “*there was indeed not the same kind of collaboration with relatives. At that time, you had quite a different views of relatives, I believe, as opposed to the current development*”.

Another informant points out that

*You must look on [the parents ...] as a resource. My views may be affected by my background in psychiatry where you had no relatives to support you. It was quite rare, and it was like a pleasant surprise when there was actually someone you could draw on.*

It is tough on the parents – as for all parents – when their handicapped child decides to move away from home. One of the Danish pedagogues, working in a housing unit, gives us an example of her support and appreciation of the parents. The example is about a particular resident “*who left home at the age of 40 and at that time it was tough for the mother so I took her along and talked a lot with her about what was going on, because she did not know what a 24-hour institution actually meant to her*”.

In line with the policy makers there are several informants who mention that today parents have changed and they welcome the change. Parents are more critical and have changed from being thankful to making demands. Similarly, they have raised their children to enable them to do more for themselves. One pedagogue at a hall of residence for young people says:

*they have some extremely good parents today. They are critical and that is really good. It is quite different from back then. I think this is really great. But they have also been living at home for many years. [...] they have so many things with them from home. They have learned a lot of things that they can benefit from. When they come here, they really know a lot of cool stuff. [...]. Table manners, what you do, how to get along not at home, and that is pretty important in order to be accepted by others.”*

One of the activity institutions in the study used to have elderly residents but now they get young people among their users as well. This is changing the group of parents from being aged 70-80 to 40+, and the change is characterised by the pedagogue as follows: “*It is a change from gratitude to demands, to put it in tabloid terms; the old used to be grateful for what we were doing but the new generation makes demands on what we do, to our approach and what we are doing with their children*”.



Several of the Danish pedagogues state that in certain situations you may face a dilemma between taking care of the residents and the interests of the relatives. Because the pedagogues find that the relatives take on a central role, it does not mean that there are no dilemmas. In the following quote we will see how they do not always agree with the relatives even though the relatives may believe that they 'know what is best'. But instead of forcing through their views, the pedagogues have to wait until this is realised by the parents by using dialogue and by using more time. The alternative is to simply accept approach chosen by the parents. They have to strike a balance with the parents.

*This pedagogue works with young people who has just left home and tells about the dilemmas involved in her work with the relatives:*

*There are dilemmas – but I do not think it is very tough. I do not believe there are many who think it is tough. Well, yes, maybe the new graduates do [...] But I think we try to advocate a good dialogue with the parents and talk with them about these things. We are very understanding as to the tough situation facing the parents; it is hard to let go at that age. There are so many things that they have to say goodbye to all of sudden and without knowing us very well [...] We] try to be open and enter into dialogue, we do this a lot. [...] Again and again, we see how they become more comfortable and will withdraw with respect to a number of things and become calmer. I think we are very conscious about the position of the parents and that is really important. Otherwise, the residents may be lost in a terrible situation [between parents and staff].*

Another informant gives us an example of how she enters into dialogue with parents about matters that the two parties do not completely agree on. She provides one example during the tour when we talked about one of the rooms of the residents:

*She uses a wheel-chair. You can see that she is playing and stuff like that. You will understand that she should not have any sofas and sofa tables and similar stuff. It has no value to her.*

*Interviewer: So is it the opinion of the relatives?*

*Yes, it is what the relatives believe. I do understand them very well. [...]. She is such a caveperson [...]. A cave will be built for her including pillows ...[...] she just loves sitting and playing on the floor. [...] It may take some time before they understand that their daughter of 32 years would rather sit on the floor and play instead of having a decent sofa with pillows. That she does not like to have any visits. When she has a visitor she would like it to take place in the common [room].*

During the interview we revert to the issue about disagreement with the parents regarding the layout of the housing, and the informant elaborates:

*Yes, but we will have to wait for as long as it takes [...] But this is not a very good idea if it becomes a barrier. If the relations of that person are weakened vis-à-vis us or by the parents affecting her in such a manner that her relations towards us are weakened. Or, we influence her in such a way that her relations with her parents are*

*weakened. This would not be fair – because who is the person that we put into a tight corner? The people we are working for and with.*

The Danish report discusses the informants' views that a large number of parents would like to continue viewing their children as children, and that they are uncertain about whether the staff will be able to provide the same level of care and practical nursing. According to one pedagogue

*the parents would like to – with the very best intentions – but often their approach is characterised by an assumption of helplessness with a view of doing the very best, clinging too to them and doing things on their behalf instead of teaching them to be independent. [...] In my view, we just want to do what is best for our children and I believe we all will have to take over some of the tasks for them. Notably with regards to handicapped people, it is going to be this way.*

Another informant talks about a mother who finds it difficult to leave the intimate care of her daughter in the hands of the pedagogues, and about how they have to teach her that it is her and not the daughter who faces a problem:

*Teaching them [the parents] to let go, and trying to show by way of action that we will make sure she goes to the toilet, and you do not have to meet her at 4 pm to help her to go to the toilet. We can do it. You will have to step back in order for us to be able to show you this. If you choose not to come and let her know that you will not be here until 5 pm, then she will have to ask us for help when she needs to go for a pee. It is not a problem for her, I add, it is only a problem for you. She knows very well that we can help her.*

Other examples show that parents may be very concerned and too protective of their grown-up child. The pedagogues view it as part of their job to ensure that grown-up people with disabilities are met with challenges and opportunities for development, and do not become overly protective. A male pedagogue provides the following example. It is about a young user who

*in recent years has discovered that he loves to go on a bus ride to [a bigger town nearby] and it was a little exciting too. His mother is pretty afraid that he will be sexually harassed or abused, be injured or face another problematic situation. This is a genuine feeling of anxiety for her but we cannot stop Peter [...] We also disagree about whether he can handle it but this does not change the fact that Peter is capable of doing this as well as many other things.*

Owing to the rules on the use of force, the pedagogue is not allowed to detail the user against his or her will but the pedagogue concludes that he is also capable of going on a bus ride downtown.

Another pedagogue provides a similar example of how she challenges and gives the disabled people different experiences than those provided by their parents. In line with most of the institutions, the housing unit has its own bus, and the informant will go together with them in rainy and snowy weather although the parents do not always agree:

*incidentally we learned that she has never really got used to being outside in rainy weather. She said “This is great. It is raining!” Experiencing that you can go outside*

*in any kind of weather. We also take them outside for a snow fight. This is new to them as well. The parents did not have snow fights and take them out in rainy weather. We have sat in the harbour when the ferry comes in [...] while it was raining and eating soup. It was very cosy. [...] and they learn the difference between weather and wind. When they are freezing we will say "Maybe you should wear the clothes I asked you to?" Usually they go and sit in the bus and are taken to work and back again. This does not involve any fresh air.*

She continues with a big laugh, explaining: *"The parents thought of it as some kind of harassment" and 'the worst part is that some parents will say 'Oh, poor souls, they have to go out in such weather' "*

Informing and keeping the parents updated are key tasks for the staff. However, some events in the life of a disabled person should not be communicated to others either when the person does not want this or the pedagogue determines that the information is personal and sensitive and best kept with the handicapped person. This is yet another example of how the pedagogue must analyse and assess his or her actions relative to the disabled people and their parents. One pedagogue says: *"We are of course not supposed to chat or go behind the backs of the residents, if one of the residents has something sexual or something else. But openness is required with regard to most issues".* Another informant says:

*They are not going to get all the details, and some will say "Do not tell this or that to my mother or father". We tell them that we are not going to do this. The parents are not going to get all the details, again this depends on how you feel about the particular issue, what are the issues, and that assessment may be difficult.*

The financial affairs of the residents are an area in which the pedagogues must collaborate with the relatives. The residents receive their pension payment and should, at least in principle, manage their own money. The staff will assist them based on discussion with the parents or guardian, if relevant, for example if the disabled person is going to spend a large amount of money on e.g. foreign travel where they also have to pay for the participant fare.

Financial matters may pose problems in collaborating with parents, but only one of the Danish informants mentions this issue. The informant knows housing units where the staff need to ask for any money to spend on behalf of the disabled person. The relatives with whom she is in contact, however, are understanding:

*Our residents all get the same pension payment and enjoy reasonable financial conditions. We once went to a football match at Parken [national league] and that was fairly expensive. Then, he was very well off. The mother did think this was somewhat unnecessary – why did he not just watch the game on television? We then discussed the matter and argued that it was something that he really wanted to do, and everything was OK [...] In order to ensure good collaboration we always tell the parents about these things. We have travelled abroad as well but such trips have generally become very costly. Fortunately with our parents, however, whenever it comes to a positive experience, then money does not matter (they do have the money, anyway).*

Collaboration about financial issues that involve the relatives, however, does sometimes lead to clashes. Some of the pedagogues tell us about the relatives' misuse of the funds of handicapped people, requiring the intervention of the pedagogue (see, for example, Chapter Five, section 5.2 on roles). This clearly weakens the collaboration with the parents.

In the above, we have dealt with the social networking among pedagogues working in housing units. Pedagogues in day care services all said that the main responsibility of social networking lies with the housing units who have the most frequent contact with relatives. In day-to-day business, they do not meet the parents very often because these places are considered as the workplaces of the residents or where daily activities take place. Activities take place during the daytime and contact with relatives mainly takes place outside ordinary working hours. Like other care workers, they do not believe that the relatives are going to perform more tasks or play any greater role.

At one of the slightly bigger activity centres, a male pedagogue says that the relatives are invited to

*an annual meeting where they are given a tour of our place, and we visit the groups and explain what they are doing. The main purpose of the meeting is to allow them to go deeper into particular issues or feel the atmosphere at our place. There are a number of events during the year where we invite the parents to join us and prepare for Christmas, a meeting during summer time with a barbecue in the garden [...] On some occasions, siblings will participate because the parents have grown too old. The other residents and staff from their housing units are invited too.*

At some of the activity sites, some of the residents live at home with their parents and here the informants will have an extended discussion with the parents. One informant explains that they talk with the parents once in a while when they bring and pick up their children. They talk on the phone, and write messages in their contact books.

### **6.1.2 Networks relations outside the family**

So far, we have dealt with the Danish pedagogues and their perception of their roles with regard to building networks between the handicapped person and the family. Other types of networks and communities are important but they are given less coverage in the Danish report section on social networks. Communities existing between residents and users of day care services lie at the core of daily work and are dealt with elsewhere in the Danish and current reports. Only brief coverage is provided here. We will also examine the pedagogues' roles relative to girl/boyfriends, leisure-time activities involving other disabled people and neighbours viewed from a network perspective.

One of the ideas of flat sharing and housing units is that the residents live together and benefit from being close to each other. According to the pedagogues, some of the residents are in touch with other users and others are not. There is one problem, however, as the residents are not selected on the basis of personal preferences: in the area of housing, therefore, residents make no personal choices about whom they live with. One of the departmental heads at the county level would like the individual to select a particular housing unit in the future and to be able to move to another site, just as other citizens can move from place to place during their lifetime.

One of the Danish informants says that:

*there are many who have not so much to offer. They spend time living their lives and sleeping, some are even members of the humour club that go on trips together, e.g. to Germany, but they do not have a close social relationship to each other that we others do enjoy. Several of them cannot sit quietly with a cup of coffee together with three fellow residents. They need a pedagogue or someone to be the chairman, or how should I put it.*

His job here is that of a mediator between the residents and to support their time together. Another informant explains that the residents often watch television together

*and this is one of our focal points. You may very well pop by another fellow resident and have a good time. It does not always have to take place outside in the common [...] There are some quite clear relations between the residents that they have created on their own.*

One of the objectives of handicap policy in Denmark is to separate housing units and day care services. Thus, disabled people will meet people other than those from their housing units. The day care services examined during the Danish interviews are socialising and activity services, where residents are together with other people with disabilities and professional staff. The hall of residence for young people, however, represents an exception with the pedagogue working as a coach to create day care services for young people at ordinary workplaces, giving them the opportunity to get in touch with non-disabled people at the workplace.

The residents and users may establish relations as boyfriends and girlfriends. One of pedagogues says that her role involves talking with the girls about ensuring that they take the pill, or use other means of contraception. Otherwise, they cannot sleep together:

*Some will have a girlfriend or boyfriend at another institution, or know friends there. They consider themselves as sweethearts but in our view it is more of a regular friendship. They want to sleep together, which we allow assuming the necessary measures are taken.*

In recent years in Denmark, it has become a common thing to create opportunities for disabled people to meet other disabled people with a view to strengthening their own culture. This is done by way of leisure-time activities, cultural festivals, etc. The pedagogue at the hall of residence for young people explains the attention given to this area by its importance.

*So that they don't have to believe that they will have to find a girl or boyfriend at a downtown discotheque, or that they need to go there to meet new friends. Some of them do believe this is the case. It is probably one of the toughest tasks that we face – to give them that self understanding of their own disabilities and learning to accept it.*

They therefore work a lot on creating network relations with other young disabled people:

*We carry out a large number of projects. Right now, it is the song contest, just as we did last year, and we turn it into a festival in which we all participate, and we do it*

*together with users from other sites, i.e. with some of their friends whom they may get further involved with. At the beginning, they did not know too many other people. Many of them came from out of town and did not know anyone else in [this city..]. The network [...] we need to learn how to build it before they move on. I think we have made much progress in this area. Many of us do have ties with the network [in this city]. We know what is available – how many young people are there and what are the opportunities.*

She suggests an interesting thought – that young and disabled people may also need to create a sub-culture just as other young people do, and that the pedagogues may be required to support such a move:

*They may need a gentle push, telling them that they can create a sub-culture of their own which is a little wild and slightly beyond the limits. They are young people, they are really...we may have to participate on a small scale. I think they have already started this process out here, in my view. They are using mobile phone and text messaging on a large scale. They are doing this a lot, just like other young people.*

Her view and that of her workplace, the hall of residence for young people, represents the stronger focus in recent years on the special needs of young people with disabilities.

Compared with other activities that involve an opportunity to meet other people it appears that this group of citizens often go on holiday trips because they have the same right to time off as anyone else. Similarly, it appears that their leisure-time experiences involve not only the pedagogues from the housing and day care services but also their family.

When it comes to neighbours of the housing units, most of the Danish pedagogues agree that there is little contact. This may indicate that social integration by way of neighbour friendships is not too widespread. One of the pedagogues, however, represents the opposite view. She says (see quote below) that the move to the local area has increased their visibility and that they are generally favourably looked on by the local population. But there is no close network with the neighbours; the handicapped people will have to go elsewhere. She says that

*there has been a tremendous shift in the past 14-15 years. In the past, I believe, they were all packed away at major institutions. This is not a negative thing – but the view of things. I think the development has been too fast for the disabled people when you think about the psychiatric patients [...]. [Our residents, on the contrary [...]] are well received by the city. Many know them as neighbours from the housing complexes. You will not develop any closer relations with these people as neighbours but they will say hello and bring flowers on birthdays, and make friendly conversation with you, and stuff like that. But they will not become part of their lives. That is not the way that I view it. They have to find their own networks. People do not mind saying hello and they accept them.*

Another pedagogue clearly states that it is not the job of the housing unit to invite neighbours and local community to any kind of event because “*this is the home of the residents – therefore, we cannot do it. It is not an institution in the traditional sense*”. She compares it with her own home to which she does not invite the local community. Here, we might have included a discussion about

whether the de-institutionalisation has gone too far and prevented various pedagogical opportunities. By viewing the resident's home as a private place, the pedagogues are prevented from setting up social events that may offset solitude and isolation on the part of the disabled people.

They are in touch with the local community by way of village fairs, through their use of the shops in the area, the hairdresser, cinema, etc. The residents are well received here but she believes that *"people do not want to accept that there is an institution with handicapped people in the town."* She talks in general terms about society's reaction to disabled people and provides an example of a colleague who went to a festival

*together with some of the residents and they were very poorly received there, and they said that they would never go there again. People were hostile in a very direct manner, asking them why they had brought such insane people with them. By contrast, I once went to the festival in Samsø and had a quite opposite experience with people among the audience holding the hands of the residents, dancing with them and other stuff. That was quite the opposite.*

This seems to indicate that in Denmark, even after several years of de-institutionalisation, there are still places where disabled people are not accepted. She also highlights that the small housing units have residents without close relations to the local community.

### **6.1.3 Voluntary work**

The task of the Danish welfare state is to provide a fundamental service for disabled people. But in the past 10 to 20 years, the socio-political debate has also focused on how to involve not only the relatives but also voluntary work, which could be incorporated into the solutions of socio-political tasks. The policy makers interviewed only touch on this theme.

Hansen (2000) describes the alternating views in Denmark, how the pendulum has swung back and forth regarding voluntary and social work in relation to people with disabilities, and the views of the professionals on this type of work swing back and forth. During the period of total institutions, the disabled people were only allowed contact with other handicapped residents and professional staff. At the beginning of the 1950s, the type of voluntary work that Hansen calls "the visiting and parcel aunts" gradually gathered pace, and in the decades after there emerged "a certain degree of openness and tolerance from the professionals" with regard to voluntary work. The pendulum swings back again around 1970 where the professionals according to Hansen looked upon those 'ladies' negatively; the critical view of the professionals with regard to this voluntary, unsalaried work was supported by the political opinion about social work, which was considered to be a task only for the public sector. In the 1990s did the attitude change again, with voluntary social work being accepted and the concept of the 'visiting aunts' having today changed name to 'visiting friends'.

All the Danish policy makers say that there is only a very limited tradition for basing services provided to disabled people on voluntary work, which, it is believed, should be left to the public sector. The deputy president of the trade union clearly states that if *"people need support, development or care, then I am a strong advocate that it is provided by the welfare state"*. He is afraid of leaving the most needy to the services of voluntary work. It may very well result in that *"people in the toughest situations [...] are saddled with more problems."*

He mentions a few examples of voluntary work which he does not believe undermine the responsibility of the public sector in this area. Visiting friends and travel clubs have often emerged from parent organisations with *“a wish for a holiday free of pedagogues, etc., and with, say, 30 people going to Malta without any professional staff”*. He does not believe voluntary work will emerge although he appreciates its values: *“but we have no tradition for it and I think it is going to be an uphill struggle. I must say. I cannot contribute any intelligent ideas besides [in sports and leisure time...] regarding what they might do.”*

The president of LEV<sup>33</sup> advocates a scheme based on voluntary work in which friendships and contacts with people without disabilities could be promoted. Many disabled people do not have any social relations with non-disabled people. She refers to the Best Buddy organisation in the US and the contact person scheme in Sweden, and would like to see similar initiatives in Denmark.

The policy maker from the Danish ministry of social affairs touches on a related issue, associating it with the socio-political development concerning more individualised housing, which has taken place with the removal of the institutional concept. There are lonely people who just sit in their apartments, people with physical handicaps and developmental disabilities, and where the services of civil society could be utilised to a greater extent. He does not believe, however, that there is a long line of voluntary organisations waiting to provide their services.

In Denmark, there is an attendant scheme with 15 hours of every month, one purpose being to provide support and create a network for handicapped people. However, the attendant is not 'a friend' but, under the law, a person who is accompanying people with disabilities.

## **6.2 Sweden**

The Swedish report contains a section on social networks that concentrates on care staff statements and some statements from trainers. Compared with both the Danish and the Dutch report, the resident's social networks outside the family are given more coverage. In the following, we will begin with a section on care staff and relatives. The staff talk about how they meet the relatives and their roles in relation to their contact. They also outline the residents' relationships with the relatives, and the staff explain their views on the roles of the relatives with regard to the various housing services and day-to-day activities. The second section is about staff statements concerning various social network relations outside the family, for example, the work group, handicap organisations and contact persons, and the roles and work tasks of the staff in this context.

### **6.2.1 Relatives**

The staff of the housing units and the day-to-day activities have said that they do not meet the relatives very often, at least not in any organised manner. They describe how some of them will pop by to say hello to their children or siblings, but this is not organised by the site. The Swedish report's section on staff's interaction with the relatives concludes that *“it is not a matter for the staff or the care organisation to keep in touch with the relatives”*. This clearly differs from the Danish pedagogues who view the networker role as a key part of their job.

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<sup>33</sup> LEV is The Danish National Association for Persons with an Intellectual Disability. [www.lev.dk](http://www.lev.dk)



The staff explains the lack of social networking by saying that this activity is not fixed by separate agreements because the site is “normal”. In line with the Danish section on the perception of your home as a private place, this means that the care staff do not believe they should initiate social events that may reduce the isolation of their residents. At some of the day care services, meetings are not arranged with the relatives because they are seen as a workplace.

As shown in the Danish material, most residents at the housing units are in touch with the relatives. However, the contact established between the user and his/her relatives varies significantly from one person to the other. Many of the residents are regularly in touch with their family. They visit their parents during holidays, etc., and their families will visit them too. Others conduct a more sporadic contact and rarely visit any of their family (if they have any family at all). One of the female care workers at a housing unit provides an example: *“the people living here are elderly people and have either none or very old parents. They have basically no one to pay them a visit and the staff’s contact is limited too”*.

When it comes to elderly, handicapped people, the lack of contact with their relatives is associated with the development in handicap politics. One of the informants says that contact with relatives has improved. This is confirmed by Tideman (2000:63)<sup>34</sup> who documents that adult, disabled people following the dismantling of the large institutions have enjoyed some more contact with their relatives because they now live nearby. The Swedish informant quoted below, a care worker at a housing unit, compares the development with the past when the users were generally left with the institution as very young children and the parents were expected to forget about them. The informant does not believe it was easy being a parent at that time.

*Well, I do believe it has improved a lot today because of the improved conditions at the onset. In the past, it was very difficult because of the lack of acceptance. But today, things have improved [...] Because they are going to make most of the decisions. As long as they are, because when they grow up then it is quite clear that they are gradually leaving the parents but they are probably maintaining some level of contact. It may be a mistake not to let them grow up. It is really tough striking a balance because it is very important and it's a good thing if they are able to go back home on visits and get visits.*

*[...] It is probably not easy to be a parent and then look at how other people do and take care of them and so on. Then you may think that “I am not able to see this. I am not going there because of this. It is just as good that I leave it”.*

She understands that it is difficult for the parents to let go of their children and to see them as grown up people. She believes it is difficult for the parents to strike the proper balance.

In line with the Danish informants – and as will appear from the statements of the Dutch informants below – there is an issue about whether the parents maintain their adult child as the family’s handicapped child instead of viewing him or her as an adult. Another informant says:

*I mean we have relatives who come in and interfere in every little thing. The person’s entire life. And then I feel that this is going to, in the long term it is going to have a*

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<sup>34</sup> In his article Tideman analyses a Swedish study of the social contacts of disabled people compared with the rest of the population.

*very negative impact on that person's development. If during your entire life you say: "Yes, but he is just a little boy", although in fact he is a grown-up man. (emphasis added)*

The parents involve themselves too much and continue to consider their grown-up child as a small child, and the consequences *"are adversely affecting the development of that person"*. She is presumably saying that she views disabled people as people who are able to develop themselves and that she contributes to the development by being a member of the staff. If they are viewed and treated as children, however, the same development is not achieved.

One of trainers from Sweden talks a lot about the staff frequently having a negative view of parent involvement. She describes how she teaches others about this subject and how she has a parent with a grown-up, disabled child who tells about her experiences. She thus stresses that training may enable the staff to better take the perspective of parents. She most likely sees training as a key factor in your ability to collaborate with the relatives of the user. Among the Swedish practitioners interviewed in our study we did not find anyone who was negative about the parents, and this goes for the Danish pedagogues too.

*To make the staff understand that it is probably not a question of ill intentions that the parents are very protective and behave in a different manner. It is common to find conflicts between staff and parents. It is not unusual at all. The staff tends to moralise a bit about the parents' inability to let go of their grown-up children, their uncertainty and reactions. That they do not understand that children must be independent. And, the staff often believes that they are hopeless, which they may very well be. But in my view, there is an explanation to this. You just have to look at yourself as a parent when your children move away from home to understand the difficulty of the situation. If your child is completely dependent on other people, it only makes it a lot more difficult. Just to get your thoughts started on this subject. Understanding what lies beneath."*

This informant quoted here has worked with two different municipalities and explains the big cultural differences with regard to parent involvement. In one case, the municipality and the heads of staff are not concerned with or do not try to involve the parents in the care work; at the other, parent involvement is considered a necessity.

Others believe that the role of the relatives is that of a family, doing things like a 'normal' family. They should be like a good friend of yours, like your mother who you call once in a while, they should keep you company and behave like a family. In other words, the staff apply their own experiences when they discuss family and relatives. *"The perfect situation would be that they think in the same manner as your mother or sister. Being good friends. That you, you exist. Someone you can call during weekends."* They do not say that the family must take over some of the public sector care, nursing and support tasks but that the relatives must enter into very emotional relations and establish the same contact as parents do with their grown up children who are not handicapped.

Several informants believe that the role of relatives in the care services is to link residents and staff. They may assist in providing information and help and give support in day-to-day life. They may assist in preparing care plans, and they may occasionally participate too.

A more formal aspect of the role of the relatives could be as the guardian. The guardian comes into play when the user, for example, is unable to handle his own finances. You will then select a guardian with responsibility and control for the finances and property of the user. The guardian may also be responsible for ensuring that the user gets the care, nursing and support that he or she is entitled to and also that of liaising with the authorities<sup>35</sup>.

Several of the informants refer to the issue of the guardian and how the user benefits from the relatives taking on this role. Others believe, however, that the involvement of the relatives as guardians in the life of their children/siblings does not always benefit the user. Some informants are very critical of this choice because of bad experiences in this area, and say that parents and other relatives should not interfere with the finances of the residents. This informant, a female care worker in a housing unit, believes that similar situations occur in elderly care, and that the children will think about their inheritance and will spend the parent's money accordingly.

*Quite often the relatives and guardians are the same person, which I think is really foolish...you need some separation. In elderly care I saw many children with old parents who were very careful with the money they spent because they knew that when their mother died then they were going to inherit the rest. In my view, the children and parents should keep this in mind, they should bring a cake on birthdays and go back home to celebrate Christmas, and so on. They should not be involved in the financial matters.*

The Swedish report underlines the importance of a strong family network. The report refers to the parents as a key pressure group ensuring that grown-up children get what they are entitled to. They may act as a driving force by assisting the residents with the care that he or she is entitled to, which is indicated by one informant, a male worker in a housing unit:

*in most instances, they are fighting for their children. They really do... They are active in FUB<sup>36</sup> and they are mostly. ... they are fighting for them and I think this is really important because otherwise many may not get the things that they deserve. We may also perform this task as staff but the parents will still have to do most of the job and ensure most of the commitment when it comes to ensuring their rights and similarly issues. The LSS-Act.*

He goes on to provide an example of one of his residents who did not thrive in the group, and how the staff informed the municipality. The resident had to explain himself that he wanted to move, then the parents put pressure on and finally a ruling was made against the municipality, and the resident now lives in his own home. This example clearly shows the importance of a family network.

The Swedish report also underlines the importance of social networks with regard to the rights of the handicapped people. Those with a strong network achieve better results. In other words, the law does not regulate the system properly, as the Swedish report writes, because the parents who put

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<sup>35</sup> From the website of Umeå municipality, [www.umea.se](http://www.umea.se)

<sup>36</sup> FUB - the Swedish National Association for People with an Intellectual Disability. [www.fub.se](http://www.fub.se)

more pressure on will be able to affect the situation for their children. Parents fight for the rights of their children, and their commitment is hard for the staff to copy for each user.

The examples show that handicap policy cannot solely rely on networks. Some will have a strong network, others will have a weak one or no network at all, and others still will have a network that, for example, may try to misuse their money.

### **6.2.2 Network relations outside the family**

*The Swedish report contains a section on social networks outside the family. The relations to the 'colleagues' in the day-facilities and their co-residents are covered by the report, including leisure-time activities and other activities that bring together handicapped people with other people, girlfriends, boyfriends, and the important role of the contact person as a networker. These factors communicate an appreciation of the importance for this group of citizens of having a broad network and the important role played by the staff in achieving these objectives.*

#### **6.2.2.1 Relations between users and residents**

Two of the informants who work in day facilities emphasise their pleasure at how well the work group/users collaborate. They deliberately pursue a strategy to ensure good collaboration with the work group. The Swedish informant mentions a positive feature of the work that the individual user is well-functioning and that the group function well together.

*What is positive, however, is when you experience how well they collaborate and get along. And things work out well between them. Because it is important, as they are very close. [...] And they get along really well and support each other, although they are very different levels ranging from 3, 6 and 10 years.*

The people in the work group help and support each other, the woman explains. She believes that they have become friends. Mutual happiness and benefit among the users are important, another informant, working in a day facility in a factory, says:

*I am really happy about this group that we have been working with because of the progress made, and before we, the staff, had to be involved in everything, but now the group has separated itself and socially the people get along really well, they have much fun and benefit from each other, and there is a really great feeling associated with these people[...] and we are not all equally important and I sense that we have succeeded.*

This clearly shows the care worker in the catalyst role with regard to the relations between users and where the ideal is becoming superfluous.

The staff have worked hard at making the group more independent, enabling the members to get along socially without interference of the staff group. The aim is to expand the social network of the group and achieve greater mutual benefit. Even the staff of the housing unit point to the pleasure if two or more disabled people who live in the same housing unit benefit from each other and get along well.

#### 6.2.2.2 Leisure-time activities

The handicap organisations and municipalities arrange trips and events in which the users participate, the staff explain. One of the care workers ensures that a couple that do not live together can go on holiday. The staff thus underline the importance of their role in relation to supporting the resident network, as this care worker in a housing unit explains:

*Most of them live in their own apartments, and I think there has been some moving around. X has been living at one of the other units. And she has met a boyfriend (Y) who suffers from a severe handicap. And since they do not meet each other regularly, we try to get them on the same holiday trip every summer when they go to Gotland on a one-week trip for disabled people.*

#### 6.2.2.3 Contact person schemes

As opposed to Denmark and the Netherlands, Sweden operates a scheme with specific contact persons<sup>37</sup>. Those who are subject to LSS are entitled to a contact person. A contact person does not work together with the user but may be a friend who provides support in daily life. It may be seen as a social function, a social network funded by the municipalities. The contact person is paid SEK 1,000 per month, and there is no cost to the user. One of the informants, who works in a housing unit, is a contact person herself but

*it has nothing to do with my work at this place but it is out there where I live. There are several residents here who have contact persons. ...[one of the residents] has a woman and she is picking her up and takes her to a café and out for pleasure and this is their role. They shall never do the work directly with the residents.*

### 6.3 The Netherlands

#### 6.3.1 Social networks and the move to local community sites

The Dutch section about policy makers and trainers and their statements about social networks mainly deal with the roles and attitudes of parents and professional staff with regard to the move away from large institutions to local community sites. The Dutch report provides the background for understanding their social network statements. Partly as a result of the pursuit of de-centralisation, much more attention has been placed, in policy and in practice, on the importance of networks. It is well known that people with a *verstandelijk handicap* (mental handicap) mainly obtain this from the formal institutional network (professionals) and also from family members. The main problem is building their own circle of friends and taking part in general societies and activities.

The Dutch report thus associates social networks with the pursuit of moving away from large total institutions to small-scale, local area housing units and thus integrating and normalising the disabled people into the local community. One of the objectives of the physical de-centralisation is social integration, giving the handicapped people a more 'normal' network consisting of other people than their family and professional staff.

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<sup>37</sup> The Danish material also mentions the contact person but by way of an 'internal' arrangement at the housing units where a staff member is assigned the responsibility of being the point of contact for a particular resident.

The policy makers and trainers interviewed underline the difficulty facing many parents of handling the move of their (grown-up) children to the local area, smaller scale unit, and frequently there is agreement between the professionals and the parents. Several examples are provided of how the de-centralisation has created opposition among parents and staff who are concerned that the safety of the handicapped people is jeopardised, that their quality of life is impaired and that the service level will be reduced because adequate staff and expertise are not automatically ensured. The move may also give the parents more responsibilities, which they are not used to, so major changes in attitudes must take place. The following two quotes elaborate on the concerns mentioned:

*A great deal of change in attitude still has to take place. Often, parents aren't used to having everything in their own hands, that process is very slow to get going. You have to use good examples to show them what's possible. Community care is a very difficult concept, some parents' associations are cautious about it. It's very important to guarantee a child's safety and quality of life. Reformed Protestant parents' associations look at the subject of sexuality from a biblical perspective. Then it's difficult to get a common view on the matter. The use of contraception doesn't come into it, neither does the issue of sex before marriage.*

*A residential care organisation has completely dismantled its institution and moved everything over to small-scale facilities and arranged accommodation through local authority housing. There, the client is central and the aim is that, to a significant extent, the client shapes what he wants in the way of care and counselling. And then you see two protesting parties, the parents who think that what's happening to their children is going too far, safety is endangered and secondly, quality, for instance, the issue of whether there is sufficient staff and expertise available. And on that point, they agree with the staff.*

The opposition from parents and staff does not only relate to the de-centralisation away from large institutions to small units but also to changes at the large institutions. One of policy makers says:

*You also see how workers resist changes to a client's surroundings. [...] Also, parents can sometimes be extraordinarily conservative. Then I show them how the house itself is secured, the fence around the house, the fence around the grounds, those awful fences, and then I tell them we still can't guarantee safety. It's much more important how you handle your people. Sometimes you act against the parents for the sake of your residents. You keep consulting.*

In spite of the wish of listening to parents and collaborating with them, the Dutch informants believe that the politicians often oppose the parents who want to maintain the status quo. The central government informant says that

*in Australia and New Zealand there came a time when a ban was placed on admitting children under 18 into an institution. We checked with the State Secretary here whether they could reinforce this idea, but this was not achieved because of opposition from the parent organisations.*

Thus, there is a political wish from the government of getting away from the large institutions, but the parent organisations disagree.

Considering the free-choice paradigm, the informant believes that the parents and people with a handicap should be given the opportunity to choose the residential setting, and they stress the loss of the positive features of the large institutions. The strategies of both groups are to deal with the opposition by allowing the positive features of the improvements to be experienced, and to ensure sustained communication between parents and professionals.

The growing attention paid in the Netherlands to residents' networks appears for example from one of the trainers who explains how she trains the students in network theories. She tells us about her experiences from the US, which provides a good example of how networks relations are created outside the family and professional staff. Moreover, she allows the students to map their own networks:

*One part of the training session consists of mapping out your own network. Removing the 'inner circles' – the people closest to you - reflects what the social network of many people with a handicap looks like. This is often shocking for the training session participants.*

This statement indicates that according to the informant in the Netherlands many disabled people do not have any emotional relations with another human being.

### **6.3.2 Relatives**

The Dutch report deals with the views of practitioners on the social networks of residents vis-à-vis the relatives only, and other networkers are not mentioned. The practitioners talk about their roles with regard to the relatives, and the role of the relatives.

Several of the Dutch practitioners talk about the importance of networks with regard to the disabled people. Emphasis is put, for example by this worker in a housing unit, on the importance of staff who do not become the key people in providing care:

*I still think we should make more use of that network, so we don't become the most important person for the client in terms of care. That there are more people in society, family ties and friendship bonds, that's really important, you need that. Because clients, too, have hobbies and want to go on holiday. We want everything to be as normal as possible, so normally speaking, I'd go on holiday with my girlfriend too. So why not the client.*

The efforts of the staff workers with regard to residents' networks are reflected by one of the major Dutch institutions where the mapping of networks and the work related to widening networks are key aspects of the compulsory *zorgplanen* (care plan):

*It appears that people with a mental disability have a very small social network. It's important to have a healthy network. So in every care plan there's a heading 'social network'. So, what does that look like? What are the possibilities for expanding it? That's also very important. That also goes hand-in-hand with emancipation.*

Some parents want a significant influence on care provided to their grown-up child and others prefer less influence.

*The family has a great deal to say about the care of their child. Provided they're just the guardians. Some families even say that they absolutely want that and that you can't organise anything without consulting them. With other family members it's like "yeah, everything you're doing is good".*

At the institution, where care plans are prepared every second year, parents are invited to participate. Some will participate and others will not:

*Usually we give them a ring beforehand. With participants who have been sitting here for years, the parents sometimes say "I've had to put up with hearing that K. picks his nose for ten years, do I have to hear it again?" And I understand it too. Those participants are over fifty. But it doesn't happen often. And it's once every two years that the care plan is discussed. You do have to be able to produce that for your child.*

One practitioner states that family members take on activities themselves now and again, for example, minding the residents once during a staff evening but nothing else besides that. Also, the user's parents are, in some cases, already quite elderly. Another practitioner says that: *"There are a number of clients whose parents actually play a really important role, take a good chunk of work off our hands."*

The Dutch report summarises the answers of the practitioners to the question about their expectations of the user's families as follows:

- Parents could do more, but they do not know exactly what
- They would like some parents to care a little bit more about their children, for example, to come more often and do nice things together with their grown-up child.
- They would like parents to be more involved emphasising that parents have a role in letting the user do things independently as much as possible. *"What I often see now is that parents are still too dominant, too much like parents"*.
- That parents offer their thoughts, input their ideas and say what is important to them.

Thus, some of the practitioners would like the parents to be more involved and to do more things with their children because of the importance attached to that by them.

The practitioners see themselves as occupying a key role with regard to supporting parental contact and involvement with their grown-up children, and the staff provide information about the disabled people to their parents. Below we have provided two examples of how they try to encourage contact with parents:

*I always tell them what the clients like. Then one day when they come here, I tell them what he's done or what he likes. I've even got it to such a stage that a father bathed his son once, even though he'd never done that before.*

*Anyway, I always ask whether parents want to give their child coffee, or want to do something else, so that the contact between child and parents does remain. And so we don't do everything. Because that's very important, for the parents as well.*



In reply to the question about the expectations of the informant from the parents, one of the informants turns the question around, saying that she is “*more concerned with what they expect from us*”. Several informants indicate that they want the parents to voice their opinions, to say what they want from the staff and to take a critical view of the staff. One informant provides a pretty specific example:

*We are open to everything they want and say. We're happy for them to phone if there's something wrong. We always want to make it enjoyable when they come here, give them a cup of tea. The parents here are considerably critical. A while back we were sitting drinking tea with a father. When the father said “I think it's terribly nice, mind you, but why isn't my daughter making the tea? I'm visiting her”. Indeed. He was completely right about that. I thought it was awfully nice that he said that.*

The informant expresses respect and openness towards the parents and how she will be able to learn from them. But another informant mentions that not all her colleagues are as understanding towards parents:

*I think it's nice that the family says what they want. Because very often the family does have a good idea. I myself have said something like “sometimes the family knows that person really well too”. I'm just happy about that. But it's not like that with everyone, mind you. Some colleagues say things like “there she is, nagging again”. Then I think “it is their child, after all” and in principle, parents naturally have the responsibility for their child because they're the guardians, of course. They should naturally have that participation, that control. That's more useful than when families say “just do it, everything's fine”. That's no use to me. Because everything's not always fine.*

Supporting parents' involvement is seen as a key task for the staff. But it is also indicated that some parents continue to perceive their grown-up children as children and because of that are too dominant and protecting. The children do not achieve independence and face more challenges. Making this comprehensible to the parents is a key task:

*What I often see now is that parents are still too dominant, too much like parents. These people are much older than six, you know. So talk to them as if they are. That they let go of them a lot more. I think that's a really big task.*

It thus appears that the practitioners indicate that the parents are key people in the life of the handicapped person, and that the staff's support of this contact is very important. Understanding, supporting and involving parents represents a key and challenging task for the staff. But for some it is difficult to fulfil.

The Dutch practitioners would like even greater parent participation, but frequently the parents do not know how to do this. This is not reflected in the statements of the Danish and Swedish informants. One reason may be that the parents are generally less involved in the Netherlands, for example because handicap care is partially provided by large institutions although some are divided into smaller units. These institutions, in line with Denmark and Sweden, have not had a tradition of involving the parents. The difference, however, may also arise from different expectations of relatives in the Netherlands; or be explained by coincidence among the informants interviewed in this study.

## **6.4 Concluding remarks**

In the past, the disabled people who lived in large 'total' institutions generally only had access to one network, made up of professional staff and fellow residents. The idea behind these institutions was largely to guard the group of citizens from society and thus prevent contact with 'normal' society, and vice versa. Other disabled people used to live their entire lives with their parents, but family care occasionally led to the same loss of autonomy and isolation as life in the 'total' institutions.

This is being changed with normalisation, which also involves the principle that disabled people need networks similar to those established by other people, and they need social relations with family and other relatives, boyfriends, girlfriends, friends among other people and non-disabled people, to spend time with other residents and users of housing and day-care services, leisure-time friends and contact by way of ordinary services and shops. These are the ideal objectives for the social networks of this group of citizens.

The purpose of the altered organisational framework for disabled people and their everyday life, which predominantly has taken place in Denmark and Sweden, has mainly been enhanced physical and social integration. The move away from centralised institutions and to smaller housing units located in the local community, the day care services separated from housing units, the day care services at ordinary workplaces, the leisure-time and holiday activities involving other disabled people and non-disabled people, and the presence of people with disabilities on the street have all been aimed at establishing broad-based social relations for disabled people. These measures have also changed the role of care workers and their work tasks.

In Denmark and Sweden, almost all of the people with disabilities live in smaller housing units located in ordinary residential areas. There are only a few of the larger institutions left, and these are divided into smaller units. The Netherlands, however, still runs several large institutions.

### **6.4.1 Physical integration**

The physical integration of the housing units, the Danish informants say, has contributed to creating closer contact between people with a handicap and their families. The geographical location close to the family, its layout and the networking efforts of the pedagogues are cited as reasons for the fact that most disabled people are in close contact with their families today. Both the Swedish and Danish material show that disabled people have stepped up their family contact compared to the past.

### **6.4.2 De-centralisation – satisfaction and dissatisfaction about the move**

In Denmark and Sweden, there is satisfaction with the de-centralisation in spite of a few critics who argue that the individualised housing may lead to social isolation. But the study indicates that some of the Dutch relatives and professional staff are opposed to this process. The Dutch opposition is explained by concern about a lack of sufficient staff and expertise in smaller-scale housing units. This leads to greater responsibility on behalf of the parents of the disabled people, and this development is criticised. Moreover, some of the informants mention that they know of incidents where local citizens have treated the disabled people poorly.

The concerns expressed by the Dutch informants may be justified. The physical integration in the local residential areas has occasionally led to harassment and lack of protection of disabled people. The major institutions are in this context viewed as a safe and secure place to live. It is also

indicated that the de-centralisation itself does not guarantee freedom and integration, but that it may provide a new kind of dependence among the disabled people, one reason being resourceful parents. The Dutch discussion thus seems to couple user involvement (e.g. parents), de-professionalisation and less expensive solutions.

Bakk and Grunewald (1998) refer to handicap care in other countries. Their examples show that a proper alternative must be made available when the 'total' institutions are removed. In their coverage of the US they write that "*several states have closed their institutions and thus left the disabled people on the street with all their belongings*" (231). They also cite experiences from Norway where the de-centralisation was implemented quickly during a 5 year period, resulting in a lack of properly educated staff.

Thus, we face a discussion about whether certain conditions should be met before the de-centralisation becomes a general success. Favourable experiences were gained in Denmark during a period with sound financial resources and enhanced staff qualifications, and there was strong support among the staff for the de-centralisation concept. Denmark has presently maintained the small housing units in the local community, striking a balance between the 'total' institution and the individualised solution. Good experiences have been gained with respect to this kind of housing that provides a certain level of protection of the residents and also enables freedom and independence. The professional staff, therefore, play a key role in de-centralisation. They may act as a catalyst for establishing good relations between relatives and people with disabilities, thus ensuring a proper de-centralisation and quality of life for the disabled person.

#### **6.4.3 The family – the most important relationship**

The informants of all three countries clearly underline that the families usually represent the most important relationships. Thus, the person in question becomes more than an institutionalised individual, but an individual with a father, mother, brother, etc. Belonging to a family is an important part of your identity. The professional care workers will remain transitory and pass through the disabled person's life and they can never replace the family's permanent relations although the care worker is often a significant person for people with disabilities.

#### **6.4.4 Different views of care staff roles relative to networks**

The study clearly shows that the Danish and Swedish care staff have different views of their roles vis-à-vis the relatives (and other network relations). The Danish pedagogues consider working with social networks as a key part of their job. Care and pedagogical work also consist of involving residents and users in good network relations. The Swedish care staff who are in direct contact with the residents do not view themselves as networkers. One explanation provided is that they regard housing as a private place, and therefore the care staff cannot invite anyone else inside. We may also discuss whether the de-institutionalisation has gone too far, preventing certain pedagogical opportunities from being applied. By perceiving resident homes as private places, the care staff are prevented from setting up social events that may offset solitude and isolation on the part of people with disabilities.

#### **6.4.5 Striking a balance between people with disabilities, relatives and professional staff**

As shown above, the care workers of all three countries apply talk their statements about the balance between people with disabilities, relatives and professional staff. Several parents continue to see their grown-up children as children in need of protection. This may prevent disabled people

from escaping a state of self-trained helplessness that will prevent that person from dealing with new challenges and opportunities for development. Care workers believe their role is to challenge and develop while at the same time to create a safe framework for people with disabilities. Most of them say that by way of dialogue, collaboration and openness they are in pursuit of a common understanding shared with the parents and for the benefit of the people with disabilities. The Danish pedagogues, for example, say that they enjoy parental contact but that it may also present a difficult, professional task.

#### ***6.4.6 From gratitude to requirements***

Many informants point to the fact that the parents and other relatives have changed. In the past, they expressed humbleness and gratitude but today they make demands and want to enter into dialogue and collaboration with the care staff.

#### ***6.4.7 A grown-up citizen of society or the family's handicapped child***

There is a strong ideal emerging among the Danish policy makers that people with disabilities should be viewed as citizens of society – but also as a group of citizens in need of significant care, support and development. The care is believed to be a fundamental task for society and a public sector service, and it must be performed by competent and qualified staff.

A view can also be found that relatives provide protection and consider their grown-up child as a child whereas the professional staff ensure both protection and development of the grown-up human being with a handicap. We thus face two different views on humans with disabilities: the grown-up citizen of society and the family's handicapped child.

#### ***6.4.8 Strong and weak family networks***

The study shows the big differences between networks. Examples are given of how people with disabilities have been subject to financial mistreatment by relatives, and of a weak or non-attentive network due, for example, to elderly parents. Others enjoy strong networks that fight for the rights of the handicapped person. This is an indication that the handicap policy cannot solely be left to an informal network and privatisation because of the resulting, major inequalities among people with disabilities. Social networks cannot replace public-sector offerings but they do represent a possible resource for people with disabilities.

#### ***6.4.9 Training in social networking***

According to Swedish and Dutch trainers, training in social networks is quite important. Thus, the care workers will be better at understanding the feelings of relatives and not just condemning or questioning the feelings of the relatives with regard to their grown-up handicapped child. Training gives you the competencies to communicate better with the relatives and the ability to focus on the key importance of networks.

#### ***6.4.10 Lack of social integration in local communities***

Several informants mention the relations between people with disabilities and local communities and neighbours as a problem area. In the section on the Netherlands, there are examples of harassment of handicapped people. In the Danish report, there is just one informant who mentions the poor acceptance of people with disabilities and lack of contact with local residents. This is an indication that in Denmark, even after several years of de-institutionalisation, people with handicaps

are still not completely accepted and there is a lack of social integration with the residents of the local community.

Hansen (2000:35-36) refers to a Norwegian study (Hansen, 1992), showing that the closer you live to people with disabilities, the more positive you are about them. At the same time, the neighbours express uncertainty about the nature of their relations with the people with disabilities. They had some fairly clear expectations from the staff about "*advice on how to behave in their relationships with disabled people*" (Hansen 1992: 31, quote taken from Hansen, 2000:36). The author of the study and Hansen both point to the key role and work task of the professional care staff. They must 'teach' the population how to get along with people with disabilities. Taken separately, physical integration does not create social integration in the local community, and disabled people need a catalyst to become integrated socially in local communities and establish friendships with non-disabled people.

#### ***6.4.11 Advantages of the major institutions***

In our study, the Dutch informants mention the advantages of large institutions. One of the advantages we would like to stress here is that the 'own culture' and 'otherness' of people with disabilities are accepted there. Several of the institutions are currently open to the local community who may use their recreational areas. In this way the 'others' from the outside are invited to join the disabled people. The same trend is reflected in the Danish material with one of the interview sites being a former 'total' institution that has been divided into smaller units. Now they called it 'The Village'. The Danish informants also talk about the fact that the residents are able to go safely to the nearby town where the people are used to serving and getting along with people with disabilities.

#### ***6.4.12 Contact person scheme arranged and funded by the public sector***

As opposed to the two other countries Sweden runs a contact person scheme arranged and funded by the public sector. The contact person is a visiting friend who decides the content and scope of this involvement. The scheme reflects an understanding of the limitations of the role of the professional staff and the importance of having a friend for disabled people. The Danish attendant scheme is quite different. The attendant only accompanies the disabled person and the scheme does not have the intention that the attendant and the person with a disability are friends. The attendant is a 'technical' person. The importance of the scheme lies in the handicapped people having experiences for example without their 'professional' pedagogue.

#### ***6.4.13 Voluntary visiting friends***

The policy makers mention voluntary visiting friends in the Danish material only, and networking with this group is not mentioned by pedagogues which seems to indicate that working with this type of network does not lie at the core of their work. Hansen (2000) says that although the Danish housing units have accepted social networks by way of visiting friends, they are not sufficiently recognised by pedagogues and are not sufficiently part of their work. This seems to be confirmed by this study as far as the Danish pedagogues are concerned.

#### ***6.4.14 No expectations about informal and voluntary work to solve more tasks***

According to the study, the Danish and Swedish informants do not reflect any expectations that the informal and voluntary networks are going to take over more of the public sector's current care tasks.

#### ***6.4.15 Working with disabled people's 'own culture'***

The study shows that some of the Danish pedagogues consider it to be a key part of their work to foster disabled people's 'own culture' by promoting meetings among people with disabilities to bring them together with peers at festivals, leisure-time activities, etc. This may lead to friendships and love affairs.

#### ***6.4.16 The ordinary labour market***

The study mentions a care worker who is employed at a factory supporting a small group of people with disabilities. The care staff have followed the residents into the ordinary labour market. This type of day care service is found in the two other countries as well, and work or day care services at ordinary workplaces create other forms of and frameworks for care work.

#### ***6.4.17 Care and pedagogical work include working with social networks***

The Danish section in particular clearly highlights that care and pedagogical work cannot be viewed separately from the social conditions of the care recipient, for example the family situation. Care work is perceived not only as doing something for and with people with disabilities, but also includes the whole social situation of the person in question.

We see the social networking of the care staff as bridging the gap between public sector institutional services and informal care. The staff are found at the interface between institutional care and family care. Public sector care does not mean replacing informal care but rather complementing it. The pedagogical work is about keeping informal networks in place, to strike a balance. The work is seen as neither just being built on compassion, which may be quite humiliating, nor being built on pure management, with care becoming a merchandised service (see Chapter Nine on Understandings).

In Denmark, working with social networks is a natural part of care and pedagogical work, and it is perceived as social pedagogical work<sup>38</sup>. The Danish material also indicates the importance of having social networking incorporated as an integral part of your work that cannot be performed by other staff groups. It should be performed by the staff that work directly with the residents and those who "stand by to serve coffee" when the relatives pop by.

If you are serious in saying that disabled people must be ordinary citizens of society, then our study indicates that it is necessary to have qualified workers who can integrate and empower people with disabilities.

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<sup>38</sup> In many countries, working with social networks is associated with the social work profession but in is Denmark also linked to the pedagogue profession.

## Chapter Seven: Pay, working conditions and working environment

This case study of care work for people with a handicap examines the opinions of a number of the interviewed care workers about their wages, working conditions and working environment by way of questionnaires and interviews. As already mentioned in the section on methods (Chapter One), the selection of the informants is somewhat random with regard to workplace and care staff. They have been selected by the workplace, and they are therefore likely to be committed employees, which is reflected in their replies. In relation to their opinions about wages, working conditions and working environment we assume that this factor may affect their opinions in two ways; (1) by being generally satisfied with their work, and (2) by being generally more critical about the conditions in the handicap sector. The *Care Work in Europe* project has previously reviewed care workers' pay and working conditions, and notably the reviews of literature focused on the job satisfaction of care workers. In this chapter, we will make reference to the national reviews from Denmark, the Netherlands and Sweden, and the consolidated report (Ewijk, Hens and Lammersen, 2002; Jensen and Hansen, 2002; Johansson and Cameron, 2002; Johansson and Norén, 2002).

### 7.1 Wages and working conditions

In Denmark, the Netherlands and Sweden, wages and other working conditions are determined by the trade unions of the relevant staff groups. Everyone enjoys the rights of standard working hours per week, paid vacation, paid illness, maternity and paternity leave and paid care days during a child's illness, etc.

In Denmark and Sweden, trade union membership is very usual, and all the Danish and Swedish care workers, including handicap assistants and personal assistants, are members of a trade union. Some of the Danish pedagogues are participating actively in trade union work. With regard to trade union membership, the Dutch informants differ from their Danish and Swedish counterparts, with a minority being trade union members (4 out of 15), and with one being a member of a professional association.

#### 7.1.2 Pay

According to the replies to the questionnaire, discussed below (see Table 7.2), pay is the work-related aspect that is subject to the highest dissatisfaction in all three countries, this is also confirmed by the interviews.

The pay of the Danish pedagogues depends on seniority, management position, and special allowances for evening, night and weekend work. The pedagogues interviewed, who are working full-time, earn DKK 20,000 – 25,000 per month (€2665-€3335), the latter being a departmental manager. The informant with a 30 hour working week earns little more than DKK 16,000 per month. The social and health assistant earns just over DKK 18,000 per month (€2400), and the two handicap helpers earn DKK 18,000 and DKK 20,000 (€2400 and €2665), respectively, per month. The wages of these two groups are generally lower than graduate pedagogues.

The interviewed Swedish care workers, excluding personal assistants, who are working full-time, earn just over SEK 16,000 (€1740) and SEK 21,000 (€2285) per month, the latter being inclusive of allowance for evening, night and weekend work. The assistant unit manager earns SEK 23,000 (€2500) per month. The two personal assistants (full time) earn around SEK 15,000 (€1630). This job is generally lower paid.

Several informants mention that the pay is generally too low in the handicap care sector. The people who are working shifts believe that it is the allowance that makes ends meet. Several of the people who are working in the day care sector without evening and night shifts stress that they have regular extra jobs or work extra time now and then. One woman is working on the side at a housing unit during weekends and another has a background in hairdressing and works as a freelance stylist for a recording business. The pay can be so unsatisfactory that some Swedish informants do extra work to earn more money. This is also seen among the Danish informants. This is an indication of a low-paid area.

There is no data covering the wages of the Dutch informants. Several informants explain that the dissatisfaction with their pay is related to the high level of responsibility they have that ought to result in higher pay. Several informants compare themselves to other professions and sectors. A male informant says that:

*Everyone wants more money, but I don't have that much. So I think the basic salary could be higher. Especially when you look at people with the same level of education. I have friends who work in technology, the stock market or in banks. I don't think money is that important, but they make three times more than I do.*

### 7.1.3 Working hours and permanent contract employment

**Table 7.1. Weekly working hours of informants**

<i>Hours</i>	Denmark	The Netherlands	Sweden
<20		5	
21-30	1	5	2
>30	14	5	11

The average working week in Denmark runs to 37 hours, and all the interviewed people are working full time (37 hours) except two employees. One woman works 30 hours, and another works 20 hours while studying on the side. The pedagogue working 30 hours has deliberately opted for a reduced working week because of her two small children, and she would like to reduce her workload to 25 hours when she gives birth to her third child soon. They are all satisfied with the number of working hours. They all have permanent contract employment, except one who is employed in a two year temporary position.

The Swedish informants are working full-time except for three, with one working 85 percent full-time (working reduced time because of a child) and one working 24 hours. They are all in permanent contract employment, except one who is working in a six month temporary position. Two of the three personal assistants interviewed are working full-time and they are all in permanent contract employment. This is unusual; the personal assistants are usually not in permanent contract employment, or they are usually working part-time.



The Swedish informants are satisfied with their working hours. In line with the Danish informants they take the necessity of working for granted. None of them have any small children. However, they are sceptics of part-time positions. In some workplaces, full-time work can be difficult to find because of cut-backs.

There are considerable differences among the Dutch informants relative to their counterparts in the Nordic countries: They are working fewer hours. Five of the female informants work less than 20 hours each week and five work for 20 to 30 hours. The three Dutch men work for 32 hours (the public sector average is 32 hours). All have permanent work contracts.

#### **7.1.4 Meeting hours**

The staff work at different times of the day, and working hours depend on where they are working. With regard to work with people with severe disabilities, employment in a housing unit also involves evening, night and weekends shifts because the staff must be available 24/7. Among the Danish informants, women work the most 'off-hours'.

Working in shifts is known to pose working environment problems. Many of the informants, however, said they were satisfied with working 'off hours', notably when their children were very young. But some care workers without children also like to work these hours, though some of them preferred day-time work (see Chapter Three, section 3.4 on working environment and family life).

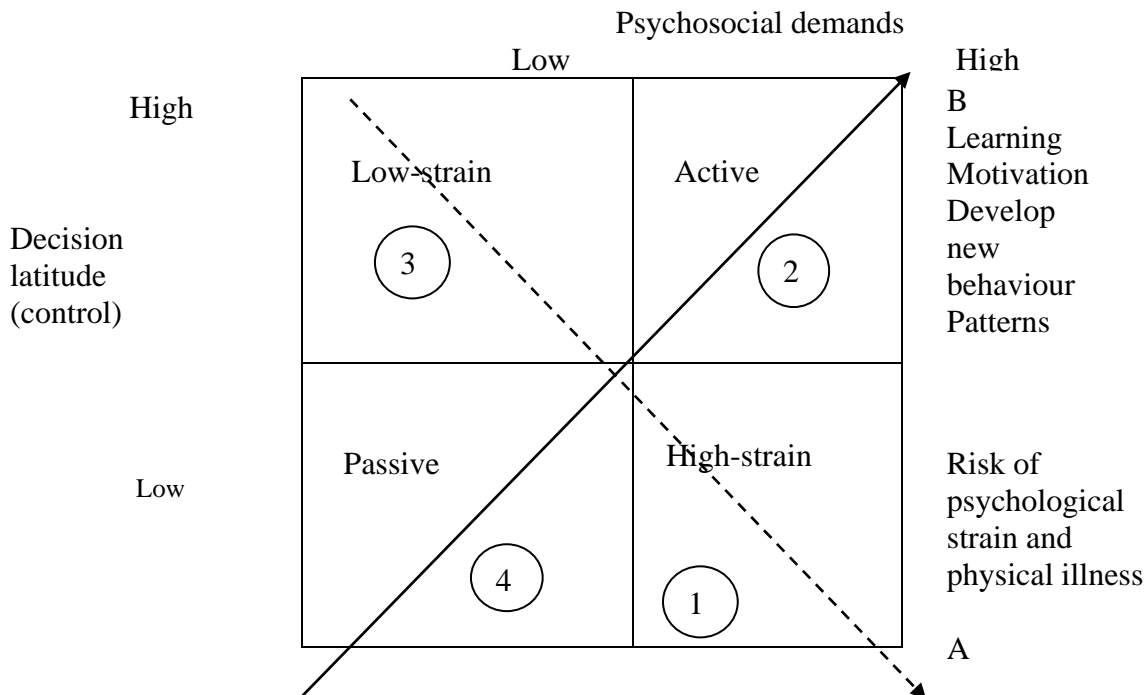
In the case of personal assistants, the Swedish report mentions a particular problem with regard to privately run services. For staff employed by local authorities, there are agreements regulating working hours, but these do not cover private operations. This issue is mentioned by one of the female personal assistants. She says that she has experiences from previous workplaces where the user would decide when he/she no longer needed any help that day. This is not the case, however, at her current workplace. They have agreements that determine these things, and they work quite well.

#### **7.2 The psychosocial working environment**

In both Denmark, the Netherlands and Sweden, the working environment is governed by law to ensure the safety, health and well-being of labour. In 1975, Denmark passed its law on the working environment (The Health and Safety of Work Act), and in 1977, Sweden introduced its Work Environment Act. The legislation in the Netherlands dates back from 1998 and is called The Working Condition Act.

The care workers' opinions about their working environment have been examined by way of a number of questions contained in the questionnaire and asked during the interview. The questionnaire has been inspired by the working environment researchers Karasek and Thorell, and the model they have applied (see more details in Johansson and Cameron (2002), and the following model is taken from their work

**Figure 7.1. Psychosocial demand / decision latitude model**



The Karasek-Thorell model is two-dimensional. Four different kinds of psychosocial work experience are generated by the interactions of high and low levels of psychosocial demands and decision latitude: high-strain jobs, active jobs, low-strain jobs and passive jobs. The interesting feature of the model is that the major psychosocial demands in the work together with the employee's possibility of making decisions about the performance of the job will result in active jobs; the active jobs are characterised by a low risk of problems associated with the psychosocial and psychosocial working environment.

Another researcher in working environments, Siegrist (Christiansen, 1994), includes a third dimension – reward. He has demonstrated that the risk of psychosomatic, working environment problems depends on the balance between effort and reward. What is interesting is that he clearly visualises the reward factor, because this is particularly interesting within care work. The previous work of the *Care Work in Europe* project has shown that reward by way of working with people is a significant factor in care work.

In the following section we will analyse the interviewed care workers' statements on the basis of these three dimensions (demands, decision latitude, and reward). Below we have listed the issues covered by each dimension.

**Figure 7.2 The three dimensions of the psychosocial working environment**

<b>Demands</b>	<b>Decision latitude (decision and control options)</b>	<b>Reward</b>
Physical demands Psychosocial demands Lack of time and staff Social issues Working alone Sound and noise Violence and threats of violence Sexual harassment Working life vs. family life/private life	Influence on decision-making Professional development Social support.	Meaningful work Recognition, status and image Pay

The three dimensions should be interpreted as follows; if there is a balance for the individual care provider between the demand dimension and the two other dimensions of decision latitude and reward, then s/he enjoys a good psychosocial working environment. If the demands are too big for her/him, psychological and psychosocial working environment difficulties will occur. A very demanding job with significant decision latitude and a major reward is an attractive and developing job that is located in the upper right corner of the Karasek model.

On the basis of the questionnaire, the chapter initially reviews the interviewed care workers' general satisfaction with their working conditions, and the question about the factors that they believe trigger work-related stress. Subsequently, the working environment is analysed following the headlines of the above model (demands, decision latitude and reward). There follows some concluding comments.

### ***7.2.1 Job satisfaction and causes of stress***

In one of the previous sections (Chapter 3.2) we examined job satisfaction on the basis of the best and worse parts of the work. In this section we will review job satisfaction in the more narrow context of working conditions. We like to emphasise that job satisfaction does not mean total lack of stress, and that a very broad definition of stress is applied, which may be perceived differently by the informants ('positive stress', for example, is mentioned by one of the informants).

**Table 7.2. Practitioners' satisfaction with work overall and pay**

	<b>Highly Satisfied</b>	<b>Very satisfied</b>	<b>Satisfied</b>	<b>Less satisfied</b>	<b>Not at all satisfied</b>
Work – overall					
<b>Denmark (N= 13)</b>	<b>2</b>	<b>7</b>	<b>3</b>	<b>1</b>	<b>0</b>
<b>The Netherlands (N=15)</b>	<b>2</b>	<b>9</b>	<b>4</b>	<b>0</b>	<b>0</b>
<b>Sweden (N=12)</b>	<b>1</b>	<b>7</b>	<b>2</b>	<b>1</b>	<b>1</b>
Pay					
<b>Denmark (N=13)</b>	<b>1</b>	<b>0</b>	<b>6</b>	<b>6</b>	<b>0</b>
<b>The Netherlands (N=15)</b>	<b>0</b>	<b>1</b>	<b>7</b>	<b>7</b>	<b>0</b>
<b>Sweden (N=12)</b>	<b>0</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>5</b>

As it appears from Table 7.2, the informants of the three countries are generally satisfied with their work; in fact, most of them are very satisfied with their working conditions. The response pattern is almost identical in all three countries. Looking at satisfaction with the different aspects of work, pay is the parameter with the lowest rating in all three countries<sup>39</sup>. In Denmark and the Netherlands, half of the informants are satisfied with their pay while the other half is less satisfied. While in Sweden, there is a group of informants who are 'not at all satisfied' with their pay, a feature not found in the two other countries.

The Danish informants ticked an average of three factors that cause stress in their daily work, the Dutch informants selected four factors and the Swedish selected an average of four and a half factors (Table 3.3). The number of factors causing stress does not tell us anything about the degree of impact. Just one factor but causing a high level of stress may indicate a more serious problem than three that cause only minimal stress. 'Lack of time' and 'lack of staff' were frequently chosen, but rather similar numbers of informants said they did not find their work stressful. Many of the above factors are detailed in the rest of the chapter.

According to the Dutch informants, the causes of work-related stress are mainly lack of time (8 informants) and staff (7), and working shifts alone (6). Also, emotional stress, bad working conditions and too many different tasks are considered stress factors. Monotonous tasks, irregular

<sup>39</sup> In the Swedish questionnaire, the satisfaction with work clothes is rated even lower, but this issue is not reviewed in the other countries.

shifts, relationships with co-workers, the approach of society towards disabled people and pay are the most infrequently mentioned factors. Five informants mentioned they did not find their work to be stressful.

**Table 7.3. Informants' reasons for stress in day-to-day work**

	Denmark N=12	The Netherlands N=15	Sweden N=11	All Informants No information N=38
Much responsibility	3	2	3	8
Psychosocial demands	3	4	2	9
Physical strains	2	2	2	6
Violence and threats of violence in the workplace	3	2	1	6
Too much width and inadequate focus on job assignments	4	4	2	10
Too monotonous work, lack of challenges	0	1	4	5
Alternating working hours	2	1	No information	3
Too little influence	0	2	2	4
Poor atmosphere in the workplace	1	5	1	7
Working alone	1	6	2	9
Relations with residents and users	1	3	1	5
Relations with relatives	0	2	0	2
Relations with management	0	3	3	6
Relations with colleagues	2	0	2	4
Society's view of people with handicaps	0	1	No information	1
Pay	2	1	7	10
Lack of time	6	8	4	18
Lack of staff	1	7	5	13
Lack of professional knowledge/relevant education	1	No information	3	4
Work life and family life/private life	2	3	No information	5
Other	1	2	1	4
Total issues mentioned	35=2.9 / resp.	59=3.9 / resp.	50=4.5 / resp.	
My work is not stressful	5	5	4	14

The informants were able to tick off as many replies as they wanted to.

The Danish pedagogues give lack of time a top rating (6), and too wide and too little focus in their tasks, high responsibility, violence or threats of violence, and 3 or 4 pedagogues chose psychosocial demands. Five informants do not feel any stress, with one who experiences the occasional positive

stress. Only one of the Danish pedagogues feels any stress because of lack of staff and when working alone, which applies to almost half of the Dutch informants.

The Swedish care workers feel that the most stressful factors are low pay (7), lack of staff (5), monotonous work (4), lack of time (4), high responsibility (3), management relations (3), and lack of relevant education (3). As in the two other countries, one third of the informants do not feel any stress at all.

One third of all informants (14) in the three countries do not find their work stressful. Some informants, however, have ticked off that stress factors may apply now and then. As we will uncover later (Table 7.4), many informants consider their work to be physically and psychosocially demanding, but to many other informants it does not cause any stress. The decision latitude and reward of the work may contribute towards demanding work not causing stress.

The general view that the work is not considered stressful is confirmed throughout the interviews in all three countries. The work in the field of handicap care and especially with people with developmental disabilities is not considered particularly stressful by the interviewed staff according to the Swedish report. The Dutch report comments that when asked how stressful it is to be working with disabled people, most informants replied that the work itself is not considered to be stressful. There might be situations which cause stress or users or residents who do, as well, but this is often short term or incidental.

*One of the Swedish informants, a male care worker in a housing unit, replies as follows to the question about whether his work is stressful:*

Well, overall it is not stressful. But in some situations it is, I believe. When you are working in a housing unit, the mornings may be stressful when everyone has to get ready and get started to go to their workplaces at the same time. This is concentrated to an hour or two hours in the morning and later everything is pretty quiet. Otherwise, it is not particularly stressful. It is probably one of the advantages of this job.

*He elaborates, saying that it is not the relations with the residents that may cause stress but the external demands and demands from management, which affect many of the tasks you are to handle:*

People from outside and from management will ask you to do stuff. You have to fix this and that, and check this and that, and write this and that, and so on. There may be too many things to handle at the same time. But the job itself and the relations with the residents are rarely stressful. It is not. ”

The above statements show, in line with many others, that it is difficult to make any general conclusions about the interviewed care workers’ perception of stress. The questionnaires and interviews seem to uncover a range of views on stress and the concept of stress. One of the Danish pedagogues expresses this comment during the interview:

*I also explained in the questionnaire that I am not stressed at work, but you often believe you could have done things better if you had had the time. [...]. Stress is a symptom of a disease. If we were talking about being out of breath, then we would all*

*have been out of breath, and there would have been someone who had been very much out of breath now and then.”*

Much mention is thus made about the work not being stressful, but at the same time there are many statements referring to impacts and reactions that you could interpret as expressing stress.

### 7.2.2 Work-related demands

This section covers the demand dimension. The interviewed care workers have mentioned various demands in their work. A demanding work may not be a burden for the person performing it, but it may become a burden and result in psychosocial and psychosomatic problems.

#### 7.2.2.1 Physical demands

Work with people with severe physical handicaps involves a large number of lifting jobs that can cause pain in your back and shoulders. In particular work done in the housing units with such people would involve a lot of this type of work, though the impact of this work may largely be alleviated by the use of modern technical appliances. Several of the informants are working with this group of residents or users.

As shown in Table 7.4, the informants do not provide a uniform picture of whether they consider their work physically and psychosocially demanding. The data of course reflects the specific workplaces and user groups.

**Table 7.4. Informants’ view on physical and psychosocial demands of the work**

	Highly demanding	Very demanding	Now and then	Not at all
<b>Physically demanding</b>				
Denmark (N=13)	0	3	9	1
The Netherlands (N=15)	2	3	9	1
Sweden (N=12)	0	5	3	4
<b>Psychosocially, mentally demanding (emotionally)</b>				
Denmark (N=12)	1	8	3	0
The Netherlands (N=15)	0	2	11	2
Sweden (N=12)	1	8	3	0

During the Dutch interviews hardly any comments were made about physical stress, because there is ample use of technical aids, such as lifts. However, a few informants mentioned that the houses are not always suitable or they are insufficiently reconstructed for using these aids. Most of the interviewed Danish pedagogues believe that their work is not physically demanding. The Danish services also provide equipment for lifting jobs, etc., and it is mentioned that a member of staff at one of the housing units is educated as a lifting instructor who is “*keeping an eye on*” and instructing the other staff in lifting techniques. Nonetheless, the two informants at this workplace believe that the work is very physically demanding, but the residents represent a psychically demanding people. The two personal assistants find their work very physically demanding. Five of

the Swedish informants refer to the work as very physically demanding; two are personal assistants (working alone), two are from housing units and one from a day care service.

Work in a private home as done by handicap assistants may create a dilemma between, on the one hand, the wish to keep the home de-institutionalised for the benefit of the person with a disability with a view to making it more like a normal home; and on the other hand, the use of often large and dominating equipment that takes the staff's working environment into account.

#### 7.2.2.2 A psychosocially demanding work

Care work means working with people. Care work with people with severe handicaps is a type of work where those people are highly dependent on professional care workers. As outlined in a previous section (section 3.2 in Chapter Three), the best part of the work for the care workers is working with people. It constitutes the key and the meaningful content, and it is a source of joy in their work. The disadvantage of the work, which requires such strong communication abilities and empathy, is that it is often psychosocially demanding and may become a strain on the staff.

These factors are reflected among the informants (see Table 7.5). The majority of the Danish and Swedish care workers believe that their work is 'highly' or 'very psychosocially demanding' whereas the majority of the Dutch informants believe it is psychosocially demanding 'now and then'.

The national reports mention several care workers who talk about how you are indeed "*utilising yourself*" as a person in the job. One of the Danish pedagogues says that "*what makes it tough is that you are utilising yourself all the time to make it work*", but this also makes her happy in her work, and it makes the work exciting and fun. Another informant explains how the residents "*are able to read your state of mind immediately when they meet you in the morning*". A third informant, a male pedagogue in a day care service, says that the workplace will re-allocate the staff resources among the individual user to prevent causes of stress:

*Some users suck out all your energy, they suck out all the energy of the staff, maybe because of their brain damage. They want attention all the time, they want to be supported and this may really be a burden on the staff that has to do the lion's share of the work every day. It is therefore very important that the staff are rotating to ensure fresh resources of staff. This will create new impulses and it will avoid the work from becoming a strain on the staff. It also reduces our stress level.*

It is really demanding to utilise yourself this much while remaining in psychosocially balanced. A Dutch care worker explains how significant staff problems in their group meant that a particular member of staff was unable to work with residents with 'outward-oriented reactions' (i.e. behaviour that might be considered violent)

Examples are given of how the care workers feel they could do better, and that they are too ambitious. This causes the staff to burn out and results in stress. The following quote from a Dutch female care co-ordinator at a small housing unit communicates the feeling of always wanting to do better:

*Yes, that's hard. It's quite common in health care to always feel you're not doing enough. You want to do more than is possible and it's very hard to find a balance. I*



*frequently analyse to see if I can still justify my actions. Is my performance still acceptable? I often have doubts about that. It's a delicate issue. Usually, it's not caused by just one situation. I can think of one clear example where I seriously considered quitting. That happened in the previous group. All of the clients were incontinent and had to be changed constantly. There was a woman who didn't want to come when I asked her if she needed a clean diaper. I figured that if I took her to the bathroom, she'd understand what I wanted to do. Much later I realised I could have just as easily taken a diaper downstairs to show her what I wanted to do. I really hated it that I hadn't thought of it before. It was just so thoughtless. If I had been her mother, I would have thought; "That group leader doesn't even know how to communicate with my child!" I seriously considered quitting at that point. I felt so bad about it and felt I had failed my client. I hadn't looked at the situation from the client's point of view.*

The example above clearly shows that relations with the residents are key to her job (as is the case for most of the care workers). If she, in her own view, believes she is doing something wrong, she may go as far as to leave her job. This emphasises the importance of having discussions with fellow workers, supervision, and a certain level of education that will enable each care worker to discuss and reflect on any such events.

Several of the informants characterise their work as being challenging and demanding, owing to the many things that they must handle at the same time (relations with the users and the entire range of other demands, including meetings, written communication, etc.). This Danish pedagogue, working in a day care service, talks about how he is

*relating to a large number of things, which is a genuine requirement, and at the same time you have 12 users on your mind, and you need to go and check the canteen in 15 minutes, remember to finish the assessment of a user's practical training. And, management wants a draft for the upcoming staff meeting. To keep cool about all these tasks, it gets more and more difficult, the older you get. There are many, during the day time, there are many different demands. You do not know what is going to happen in ten minutes, who will need you to do what.*

A female pedagogue from Denmark working in a housing unit, provides another example:

*Being a pedagogue, you need to take a stand on so many different things, and you are continuously facing a large number of problems every day that you need to decide on, and there is lots of stuff that you must solve and get to understand. Problems and conflicts. I think... but this also makes it exciting. I know quite a lot of the pedagogues here who have been working as mailmen for a year or so because ... they just needed to work on auto-pilot.*

Many of the informants clearly show that care work is not monotonous and based on routines. Two days are never alike. The unpredictability of the users and residents makes the daily flow of events very much dependent on their state of mind, which may change the events of each day completely relative to the plans made by the staff. This presents a challenge but it may also be a burden and place specific demands on the competencies of the care worker. In a book on pedagogical work in

Denmark with people who suffer from severe developmental disabilities and who are living in their own homes, Rothuizen (2001) stresses that pedagogical work, among other things, is characterised by not knowing what will happen in advance:

*In non-defined relationships that are not dominated by triviality, indecision and a lack of colour, the relations are continuously tested. The professionalism therefore does not only consist of performing a pre-defined plan but commanding a sufficient overview to determine what is wise and appropriate in that particular moment. (103)*

#### 7.2.2.3 Lack of time and staff

Lack of time is the factor mentioned by most of the interviewed care workers in the three countries as causing stress (Table 7.3).

Time and staff allocations are closely related. The lack of staff is mentioned as the second most frequent cause of stress. Almost half of the Dutch informants and five of the Swedes refer to this. But only one Danish informant has done so, whereas many have selected lack of time. Thus, the subjective experience of lack of time appears, to some of the informants, as if it cannot be solved by more staff. It will appear from the example below that a couple of the Danish informants mentioned lack of staff during their interviews.

Almost all Dutch informants think that the lack of time and staff is a major issue. This is often acknowledged when they cannot provide proper and essential care. One of the Dutch policy makers, who is managing a large institution and other services for handicapped people, says that

*there is an extremely high workload. Part of the workload is caused by a too ambitious approach. [...] There are now almost twice as many people working per client than a few years ago, but the workload that is experienced only seems to increase*

He says that because care workers set themselves higher standards for their work, their workload may have increased although staffing levels have doubled in the last few years. But as we see it not only the care workers are applying higher ideals to care work. Their higher ideal may stem from the way the residents and users, the relatives and the political system put more demands and expectations on the staff, and new norms may also emerge. Fulfilment of these factors may require more staff and better educated staff.

A female informant in a day care unit in Sweden believes that stressful work is closely associated with insufficient staff. When there are not enough staff, she experiences increased stress.

*Not here [in the current work place] but in my previous work, the work was usually slightly stressful. This is just when you do not have sufficient staff; then things become very stressful [...]. When you have to keep five people in check and still have to be ready to do other tasks. These kinds of absurd situations. You have to listen to many terrifying stories about this. [...] The rules that are in place as to the number of people you are taking care of and stuff like that. But now they are trying to change this. It is really stupid.[...] so that temporary staff will not be hired, and so on. You should maintain the good things and not start changing them. But now we have to be idealistic and start working for two of us.*

She raises several interesting issues, one being the importance of staff allocation, which she thinks to be currently at risk because of cuts. She clearly states that these cuts are making their work harder. She also states that the workers now have to be idealists and start doing the work for two. This may be a typical female statement and mode of action. One of the Danish male pedagogues touches on the same theme. He has identified gender differences in the reactions to the staff cuts, which in particular leaves the women in his workplace “out of breath”:

*I can feel it from my colleagues over there, they become stressed because there are so many things that you have to do. The quality level has not been lowered. It has not yet become visible that the level has been lowered. It has not really fed through. Therefore, we all have to work more quickly. I also believe it is because of the small number of men that we represent there. We have been lucky enough, as many other men have experienced, that we only can think of one thing to handle at a time compared with the women. The women are quite extraordinary in following up on things all the time, on problems; whereas we men many times solve the problems as we go along or we say, then it must wait. [...] I sense this from some of the girls, they are out of breath.*

#### 7.2.2.4 Social strains

It is important that the staff maintain good relationships with management, fellow workers and relatives, and that there is a positive atmosphere in the workplace. Table 7.3 shows that only a few care workers in the study consider these factors to be causes of stress. There is a certain degree of difference between the three countries: several of the Dutch informants have ticked off these factors as opposed to very few of the Danish informants.

Among the Dutch and Swedish informants, three have replied that the management is the cause of stress (Table 7.4). The Swedish report says that most of the informants do not say anything at all about the importance of their leaders or management to their work. Some, however, view unappreciative management as a negative aspect of their work. This may involve not being granted adequate responsibility from leaders or a lack of understanding of care and the care aspects of work. One informant says that management lacks competencies in understanding the staff’s need for reflection and discussion. Another informant believes that the leaders are so overloaded with work that they are not attentive to the staff’s needs.

One of the Swedish informants talks about her past work place with poor management, notably in relation to the use of temporary staff, and this adversely affected the workplace atmosphere, although

*we had some really skilled people working there. [...] I believe many shared this feeling: we have no worth, and our job has no worth. If you have to listen to stuff about cutting costs. There was a lot of talk about this, and that what we were doing did not mean a thing. No one pays any attention to us. You easily end up in this kind of vicious circle. This makes it very hard. You are completely focused on ... whether you need to hurry, and when you have to lift a person. That is what characterises your daily work. This is probably difficult to understand. That you are doing lifting jobs and putting on a jacket. There are people with severe disabilities. You may think this is not hard, but it is. It is really difficult. You have to be calm. You need to have the*

*proper body language. You need the proper mental attitude, otherwise you will burn out. It is really easy to get into that state.*

Compared with her previous workplace she considers the current management to be positive and encouraging. The workplace is very open and the staff and the users may contribute with new ideas to the service. She also considers the “*the service’s common approach*” as a positive thing.

None of the Danish pedagogues believe that the management is a cause of stress. By contrast, the informants during their interviews mention the competent leader and the activating leader as a source of inspiration and support. Management does not appear as a major problem in Denmark. This obviously reflects that most of the leaders by far are pedagogues with the same kind of education as the care workers. This makes communication easier because you are speaking the same language and applying the same ethics. Many of the Danish services for people with disabilities consist of small units where you are close to the management in the day-to-day practice, and in the pedagogical field there is a tradition of a very flat and non-hierarchical management.

Most of the informants from the three countries are satisfied with their relations to fellow workers, and many examples are given of the support and advice they give each other. The informants, however, also provide many examples of how other workplaces are subject to staff conflicts. One of the Danish pedagogues says that “*personal conflicts in the workplace*” are one of the things that she dislikes the most. Another pedagogue finds that for him the cause of stress is not from users but poor management and colleagues. A couple of pedagogues mention in particular that some of the senior pedagogues have not developed themselves since the central institutions were closed down.

A large-scale and representative study of the entire Danish pedagogical labour force shows that pedagogues change jobs because of a bad atmosphere in the workplace. The survey also covers pedagogues working in the handicap area (Holm, Jensen and Andersen, 2000). One of the Danish policy makers, the trade union vice-president stresses that

*the biggest problem related to the working environment in pedagogical work is that people are unable to speak openly and honestly with each other about the existing challenges. I believe this has been the cause of illness for many people as opposed to back pain.*

A high staff turnover and an absence of shared opinions are other factors mentioned as strains. Similarly, guidance of students is a demanding job (Danish example). Relatives are covered in the section on social networks. Most of the informants do not find it stressful but this element of the work may represent a challenge. One example causing stress is if the relatives are suspicious about the staff in relation to the residents’ money. This issue is covered by the Danish report, but it is not reported as a problem at the current workplaces of the informants.

#### 7.2.2.5 Working alone

Several studies of the working environment show that working alone may be both demanding and a cause of stress. Nine of the 38 informants have selected the working alone factor as a cause of stress, and this also goes for as many as six out of the Dutch informants (Table 7.4). A Dutch female care co-ordinator at a day centre says that the stress related to working alone is about the balance between necessary care and the users’ wishes.

*Of course, especially when you're working a shift alone you can't do everything perfectly. You can't discuss issues or divide tasks with a colleague. For example, when you've worked alone for a week, you need to have a conversation with someone who's at the same level as you are, but you have to do what needs to be done. It would be nice to be able to talk about anything else other than work. But that's because you work alone. Physically it's not such a burden. There are ample technical aids, like a lift. Well, especially when you're working alone and an incident occurs. For instance when they bite each other. That's really gross, but you can't do anything about it. In general the balance is reasonable.*

In Sweden, it appears as if much of the work in the field of handicap care involves working alone, notably in the new types of housing. A Swedish informant, who is working in a housing unit but with a management job at the institution, believes that care work currently involves working alone. We are therefore surprised that only two of the Swedish informants choose working alone as a cause of stress on the questionnaire. This is also confirmed by the interviews. Working alone is the everyday way of life for many care workers; but, as the Swedish reports notes, since your fellow workers are always nearby, the working alone factor is not seen as a significant problem.

One of the Swedish informants, who is working with a group of people with disabilities at an integrated factory, works alone, which she occasionally considers to be difficult. A colleague performs supervision once a week, however, and this supports her a lot. The integration of people with disabilities into the ordinary labour market with support workers will involve more working alone for care workers. Therefore, the modern type of housing and the integration into the ordinary labour market has resulted in more care staff working alone. This development is compensated for, the Swedish informants say, by participation in work groups, staff meetings and supervision.

There is only one of the Danish pedagogues who has selected working alone as a cause of stress. Until recently, he was working alone in a day care service (forestry group with five users) but he has just received part-time support from a colleague. He is fond of his new colleague but is very conscious that their communication and the time they spend together must not take away their time with the users. Again, the users are the focal point:

*it is great with a partner but ... [we] have to pay attention to not talking too much and not exchanging too much information because of the silence and opportunities that should be available to each user, because they do not talk that much, the residents I have [...] That is the difficult part about being team mates. We must not dominate too much, so as to make room for that during the hours they are here, so they on shift experience to become the centre of events, or that they can get through to us*

Personal assistants or handicap helpers work alone. The Swedish report stresses this issue for this group as well as other special factors in their working environment. A Swedish leader at a unit offering personal assistance says that the staff are usually not educated in the nursing and care areas, and they do not have any experience from other care institutions when they are taken on. The leader says that since assistants are often working alone, it is difficult to find a time for colleagues to meet and to talk with the group leader.

#### 7.2.2.6 Noise

“Users with sound effects”, is how a Danish male pedagogue from a day care service describes his users, and says that this can be a big strain.

*There may be other users who are happy and enter a room with high-pitched sounds, which are actually just sounds of joy. They come close to you and scream very loudly, followed by these high-pitched sounds. It is really tough on your ears[...], and the older you get, the tougher it is. The other ones who scratch you slightly, that is a minor problem...[but it is] very difficult to do anything about.*

#### 7.2.2.7 Violence and threats of violence

Violence and threats of violence are known to be a serious problem when working with certain groups of people with disabilities. It does not only comprise violence or threats of violence towards the staff but also violence between the users or residents themselves, and may thus represent a strain on your work. The terminology usually applied is violence or threats of violence relative to the users' actions with respect to the staff. In Denmark, it is being discussed whether you should avoid characterising the behaviour of people with disabilities as violence, but as ‘outward-oriented reactions’. Characterising any behaviour as violent implies deliberate action, which rarely applies to this group of citizens. The same attitude is apparent in the Dutch report: *“Inappropriate reactions from clients are usually explained by most employees as part of the clients' personality, or caused by their disability.”*

Most of the Dutch informants have had no or few explicit experiences with sexual harassment or verbal and physical abuse. Most organisations have protocols for violence, aggressive behaviour and sexual harassment. A Dutch female senior client supervisor from a major housing unit talks about residents with outward-oriented reactions, but the organisation strongly supports the staff in preventing aggressive actions and the use of compulsion, and provides a trauma group to handle any damage done.

*We have been beaten by a resident, though. We discuss such incidents in the team meeting and then you realise that he does things like that out of frustration. He just doesn't understand our message. When we tell him we'll be there in a minute, he doesn't understand what 'a minute' is. I know there are a lot of incidents in another department and they work very hard on prevention.*

The workplace has some measures to minimise the risks for example there are a lot of workshops and a trauma team for back up. In another context, she says:

*We try to control aggressive behaviour with two people; one holds the client by the arms and as soon as he or she is dressed or undressed, he or she has calmed down. That's not how you should look at aggression anyway. We wear special sleeves when we handle a particular resident, so he can keep hitting us without causing any injuries. He doesn't wear a helmet and he's not chained to the bed. We use force only to protect them from themselves or to prevent disfigurement. You always must have a good reason to use force.*

Violence and threats of violence are given much coverage in the Danish report. The reason is probably the focus in recent years on the two themes: the use of compulsion and violence as a

method of expressing yourself. As already mentioned, the law has been tightened on the use of compulsion, making the application generally illegal. Under the law, any use of force must be reported (Chapter Two). In the past ten years, a nationwide project on the working environment has been conducted including violence as a means of expression, with a view to preventing violence and threats of violence, and to introduce procedures at the workplace for handling any violence that may occur. Outward-oriented behaviour may also be triggered by the physical context. One of the policy makers at the county-level believes that the most likely reason behind its record low frequency of violence is the maximum number of six residents in each of its small housing units.

A number of the Danish pedagogues in the study occasionally experience violence or threats of violence in their workplace, but to most of them the extent is limited. At two workplaces, a housing unit and a day care institution, there are residents and users with outward-oriented reaction, and they are in close contact with violence and threats of violence. Most of the workplaces have established crisis management procedures if the staff are facing violence or threats of a severe nature that may require psychological first aid.

One of the pedagogues, who has been working with a group of residents requiring a high level of support that also suffer from psychiatric disorders and who have outward-oriented reactions, considers the violence and threat of violence to be clearly the worst part of her job: *“The worst part. It is the violence, the physical and psychosocial violence and the psychosocial pressures”*. She explains:

*I broke down mentally here once when I was facing two residents, with one hitting me and the other pulling me. It is very often that...I have experienced so much, much, much hitting and spitting, and threats and kicks. I have also noted [in the questionnaire] about the major psychosocial pressures here because of the psychiatric nature of our work. The psychosocial pressures are pretty big.*

She is clearly affected by the tough working environment while, at the same time, she is very fond of her work. She is pregnant with her third child and wants to move on to another job as pedagogue after the maternity.

*The residents with special needs, I cannot handle them anymore. It is too tough for me with the kicking and then my three young children.[...] I find it a tough place. It is a violent place to be in, and it is tough, and I have decided that I will not continue this way. I will never do it again in my life. I have done this for 8 years but now it is over. I feel I have become more sensitive. I feel it is changing me, being hit, put into psychosocial extreme, I believe it is affecting me. Being yelled at, being required to do stuff all the time. Being pulled...*

At her workplace they have determined procedures for handling violence and she is very satisfied with efforts done at the workplace. But she still considers the violence to be too much of a burden.

Another female pedagogue in a day care service confirms the strain of violence and how it affects her:

*Offences or violence – it is very unpleasant. It hurts you psychosocially. Physically, it makes me ... Once I tried, when someone was coming ... it was not here then ... and tried to strangle me. I felt the pain for a long time afterwards.*

*Interviewer: Did you feel anxiety?*

*No, it was pain, I felt the fingers and of course there was some anxiety, but I feel completely all right about it today, because then it was me who was not....I was inexperienced, did not set the limits, I went along, in a situation that was both fun and serious, but still there is anxiety ... no, you are affected by it. I can therefore easily imagine people working here for 25 years, and then suddenly it all falls apart.*

She is addressing an important issue. It is easy to believe that you have caused the violence yourself. Another informant mentions this. Sometimes, the resident will react in an outward-oriented manner against a particular member of staff, and then it is important to address the issue to prevent asking yourself *"Is he hitting me because I am not good enough?"* This stresses the importance of a supportive staff who are helping and showing complete trust in each other, communicating openly about these issues so that the individual pedagogue does not *"feel a personal responsibility"*.

Violence and threats of violence are not mentioned in the Swedish report, but the questionnaire shows that violence is the cause of stress to one of the informants.

#### 7.2.2.8 Sexual harassment

As already mentioned, most Dutch informants have had no or few explicit experiences with sexual harassment. The Danish informants reflect this as well. The informants provide examples of how they are tackling sexual harassment but it is rarely considered a strain on their work.

A Danish female pedagogue in a day care centre expresses this view:

*with sex. If I feel someone..., because I have to be conscious about my own limits and I must be able to review others, and if I feel that they are coming too close, then I will tell them. I try to turn the situation into something positive. "No, you do not have to think about it, I am married, so that would never work out."*

The Danish female handicap helper, who works alone with a user with severe physical handicaps, gives this example of a fellow worker who felt that a male user (who actually is her employer) tried to come onto her and said things she did not like. She says: *"I am careful to avoid rubbing myself against him, and with the way I dress, etc., to prevent any situation.[...]Being conscious about keeping a distance with regard to touches"*.

#### 7.2.2.9 Work life and family life

All three reports mention only a few examples of how the strain of the work is brought home to the family, thus affecting your family or personal lives. A few spill-over examples from personal to work life were also provided (see section 3.4 in Chapter Three on work life and family life)



### 7.2.3 Decision latitude

This section deals with the decision latitude dimension of work. Karasek's model of job strain says that if the employees enjoy a high job decision latitude, they can handle big demands in their work, and can prevent psychosocial job strains. As shown above, the informants/care workers in all three countries said that many areas of their work were demanding and would involve strain. This section examines whether they believe they have many or few opportunities to make decisions and control their work. We have used three headings: decision-making influence, professional development and social support.

#### 7.2.3.1 Decision-making influence

**Table 7.5 Informants' satisfaction with their own and the users influence on decisions made about care work**

	Highly satisfied	Very satisfied	Satisfied	Less satisfied	Not at all satisfied
<b>Informants' influence on decisions made about care work</b>					
Denmark (N= 3)	2	8	3	0	0
The Netherlands (N=15)	1	2	12	0	0
Sweden (N=12)	1	6	4	1	0
<i>Users' influence on decisions made about care work</i>					
Denmark (N=11)	0	4	5	2	0
The Netherlands (N=13)	1	3	7	2	0
Sweden (N=12)	0	7	3	2	0

All the care workers except one are satisfied, very satisfied or highly satisfied with their own influence on the performance of care work (Table 7.5). In particular, the Danish and Swedish informants express strong satisfaction with their level of influence. They communicate this view in the interviews as well, and they are very happy about the amount of influence and independence they have in their work. It is compared positively with other kinds of jobs that are perceived as less challenging and independent (mailman, office work, assembly line work at a factory). As shown above, the work is characterised by unpredictability. The lack of control of the work is attributable to the users. However, eight out of 38 informants (Table 7.4) report that high responsibility causes stress. To them, their responsibility and decision latitude have become a strain.

The informants were also asked in the questionnaire about their attitude to the users' influence on care work (Table 7.5). Since the objective of care work in the three countries is a high degree of user involvement, the perception that the users exercise a lot of influence may create more job satisfaction. Most of the informants are satisfied with the level of user involvement. Notably the Swedish informants are very satisfied, but "*there is always room for improvement here*", adds one of the informants in the questionnaire.

#### 7.2.3.2 Professional development

Most of the Danish interviewed pedagogues are satisfied with their opportunities for post-qualification education and further training. They confirm having books, magazines and other material available in the workplace, and they are satisfied with these opportunities. Few of them are

required to participate in post-qualification and further education but one third are required to attend courses. One of the workplaces applies the rule that the staff must complete one week of further education each year, including course participation.

Most Dutch informants are satisfied or extremely satisfied with the opportunities for further professional development. Some informants are required to go to courses, on subjects such as basic care, physical stress, networking, First Aid, supervision, addiction, autism, video interaction, injections.

Several of the Dutch informants mention that their job satisfaction includes educational and development opportunities by way of courses, concentration on tasks, etc. The teamwork is also mentioned as being important, and the possibilities of career moves are mentioned as providing satisfaction in work. Several of the informants are supervisors: *“I find it great to train people, to supervise them and help them work towards the profession,”* says a female, senior client supervisor.

Relative to the Danish and Dutch informants, a majority of Swedish informants are not at all satisfied or less satisfied with their opportunities in post-qualification education and training. More than half of the informants do not have books and magazines at their disposal in the workplace. To most of the informants, participation in further education is not compulsory whereas more than half of them are participating in compulsory courses, e.g. on lifting techniques.

#### 7.2.3.3 Social support

Chapter Three, section 3.2 showed how the relations with the users represent the best thing about the work for the majority of the informants/care workers. It provides much joy in their work and reward, although the relations are demanding. Good relations with management, fellow workers and a good workplace atmosphere are key factors in the psychosocial working environment. Several say that it provides development of their work.

The Swedish report contains a separate section on the work group, i.e. the staff that work together. All the informants agree that a smoothly running work group is important, but differences lie in the extent to which they are in contact with other staff members. The informants who work in day-care services and housing units where they work together in work teams stress that a staff group is positive and important for doing a better job. However, most informants agree that more time is required for discussions in the staff group as well as more time for planning. Discussions about the objectives and methods of the service are important, and less time should be used on discussions about budget issues and structural problems.

Guidance is provided in several of the workplaces in the three countries. The Swedish report stresses that guidance is first and foremost provided in the case of users with outward-oriented reactions, and where the staff need to discuss their work with external parties. This is also seen in the Danish and Dutch reports. The Danish report contains examples of guidance and instruction in lifting techniques, and this is probably also the case in the two other countries.

A Danish informant explains how the interaction with the residents is key to development, but that also the fellow workers

*add to the dynamics as well. Being in such a big organisation. Being part of the county and the society. It all adds to the overall dynamics. [...] New rules are implemented, and new*

*things are added. There are governmental rules that you must follow, and this is part of the dynamics. Then you have to understand how you fit in to the great scheme of things.*

In her view, the county and governmental policies contribute to the dynamics and the development of her work.

One of the Danish male pedagogues stresses that the mix of gender in the staff group provides for

*a comfortable environment where your social needs are met too. This is paramount when it comes to interacting with each other, which contributes to the developing environment, and then it is a nice environment to be in, all your social needs are fulfilled here too. It is a very social workplace and we know just how to be good to each other and we have club activities in the night time.*

High staff turnover is mentioned as a factor that causes strain. Conversely, it is viewed as a positive thing that some of the staff members stay with the institution for a long period of time. The housing units in Sweden where interviews were conducted are not subject to a high staff turnover. However, temporary staff are often employed for different periods of time. Some of the informants mention that a stable workforce provides comfort for the residents and their relatives. The advantages for the residents and relatives are stressed here as opposed to the staff. Again, this underlines the top priority given to these relations. A Swedish female care worker from a housing unit, who has been working with the same users for ten years, elaborates on the advantages:

*You learn how they are. How to interpret their state of mind and read their face and so on. To see whether they are sorry or sad.[...] The staff has been very stable, and several have been her for a long time. That is the way it is. It is comforting for them and it is comforting, most comforting for the relatives, I believe.*

Regular staff meetings and the affiliation with a staff group may, the Swedish informants believe, compensate for the disadvantages of working alone. The Swedish report writes that many people work alone, but the loneliness does not become a big problem because your fellow workers are nearby. They all meet up with each other in a big staff group, they perform daily shifts involving each other and they seem to think they belong to a staff group although to a large extent they work alone with the users.

#### *7.2.4 Reward*

This section covers the final dimension, which is about reward. Balancing the high demands of work and any subsequent reward may offset the risk of psychosocial and psychosomatic disorders. Reward received from the recipients of care is a dominant factor for most of the workers. The conditions of reward examined in this context involve the informants' opinions about meaningful work, recognition and their pay.

##### *7.2.4.1 Meaningful work*

There is no doubt that the care workers in this case study believe their work is very meaningful; it clearly appears in the previous section on job satisfaction where the best thing about the work was the joy and the satisfaction of working with people with development disabilities. The joy of working with a group of citizens needing high levels of care is a key driver in the work and a great reward.

We have found the same factor in other case studies of the *Care Work in Europe* research study. This is often the case with people who are working in the care field. Being something for other people and taking part in relations with other people is an essential part of care work. We think it should be stressed that this is not solely a psychosocial phenomenon; it may also be viewed in an existential perspective and as a basic human need of being something for someone else.

#### 7.2.4.2 Recognition, status and image

**Table 7.6. Informants' satisfaction with the recognition of work**

<i>Appreciation by</i>	Most satisfied	Very satisfied	Satisfied	Less Satisfied	Not at all satisfied
<b><i>The Netherlands</i></b>					
Users/residents	0	4	6	0	0
Management	1	2	8	3	0
Co-workers	1	5	7	0	0
Relatives	3	4	7	0	0
Society	1	2	6	4	1
<b><i>Denmark</i></b>					
Users/residents	7	4	1	0	0
Management	3	6	3	0	0
Co-workers	2	7	2	1	0
Relatives	2	1	7	0	0
Society	0	2	5	3	2
<b><i>Sweden</i></b>					
Users/residents	6	3	1	0	0
Management	1	4	3	1	2
Co-workers	4	4	3	0	0
Relatives	4	5	1	1	0
Society	1	0	2	6	2

As shown in Table 7.7 the Danish and Swedish informants in particular are highly satisfied with the user recognition, but the Dutch informants are satisfied too. Here, a big reward lies in their work. Similarly, they are satisfied with the recognition of fellow workers and relatives, both of which are rewarding. Most of them are satisfied with the management's recognition but among both the Dutch and the Swedish informants there are three who are less or not at all satisfied with the management, whereas all the Danish informants are satisfied or more than satisfied.

The informants of all three countries are least satisfied with society's recognition of their work. This also appeared quite clearly from the section on status and image, which is detailed in a previous section (5.1 in Chapter Five). Reward is not found in this area.

#### 7.2.4.3 Pay

As already outlined, the pay factor generates the most dissatisfaction among the informants. They clearly believe that they do not receive sufficient financial compensation for their work. Not only

the real value of their pay but also its symbolic value is mentioned: low pay is felt to reflect the social devaluation of the work. Low pay, therefore, is associated with the feeling of a lack of recognition from society with regard to the importance of their work.

### **7.3 Concluding remarks**

Dutch care workers, like the wider female workforce, mainly work part time: Danish and Swedish care workers mainly work full time. Important questions are raised about these different working patterns – both for the workers and those with whom they work.

We have adopted a model of the working environment which treats workers' experience as produced not by any one dimension but by the interplay of three dimensions: demands, control or decision latitude and reward. We have also stressed that job satisfaction does not mean an absence of stress.

It is striking that care workers in all three countries are generally satisfied with their work, taken overall. The main specific cause of dissatisfaction is pay, which is perhaps not surprising as pay is relatively low (and probably lower in the Netherlands and Sweden than in Denmark where we see the effect of a largely professional workforce of pedagogues). Low pay is in itself a problem, but can also appear as a sign of the low social status of the work.

According to their questionnaires, more than a third of the care workers do not find their jobs stressful at all, although a fuller picture needs to take account of the interviews alongside the questionnaires; what workers say may often qualify how they complete a questionnaire. Among those who do select one or more stress items on the questionnaire, the four most common are lack of time, too few staff, low pay and lack of focus in their work. The workers, moreover, do find the work demanding, especially psychosocially, although the Danish and Swedish workers are more likely to rate it 'highly' or 'very' demanding than their Dutch counterparts.

One issue that is raised as a substantial risk is working alone. This is the situation of many handicap helpers/personal assistants, an increasing group in the workforce.

One area where there are marked national differences among the workers interviewed concerns professional development. The Danish and Dutch workers are generally satisfied, while the Swedish workers are much less so. Furthermore Swedish workers are more likely than Danish workers to hold a negative view of managers, which may reflect different workforce structures: managers and care workers coming from different backgrounds in Sweden, but sharing a pedagogical education in Denmark.

Of particular importance, nearly all care workers interviewed in all three countries are satisfied with the decision latitude they enjoy – they feel they have considerable control over how they do their work. On the third dimension, again workers are mostly positive, reporting that overall their jobs are rewarding. They find their work meaningful, enjoy what they do and have rewarding relationships, with handicapped people with whom they work and with their work colleagues. They also feel recognised and valued by relatives of those they care for. The same however cannot be said for the wider society; only a handful feel 'most' or 'very' satisfied with society's recognition of their work. We return again to the issue of low pay.

## Chapter Eight: Training, education and professional development

The Netherlands, Sweden and Denmark apply different educational systems and educations to care work for disabled people. In each of these countries there are various types of education that aim at the same kind of work area and even the same kind of practical care and pedagogy tasks. Moreover, all three countries in the case study have implemented educational reforms, and consequently, the field of care for disabled people employs staff with both new and past educations.

Thus, there is a multiplicity of education concerning care and pedagogical work with disabled adults in these three countries. This chapter's description of different types of education and their levels is not entirely complete as it does not include specifically designed training courses, e.g. where an experienced employee may complete an education in a shorter-than-average time or specialised courses targeted at immigrants.

Below we will highlight a number of issues and present some of the discussions contained in the three countries' national reports. We stress that the educational discussions in question must be viewed as examples of the topics currently on the agenda in these three countries, and that, although the discourses mentioned in this report most frequently are associated with one of the countries, they may be just as relevant and important for the other countries.

After the description of education and coverage of a number of educational questions in the three countries, we carry on with a section presenting the national reports' discussions about the issue of job-related competencies and the question about having an education or not having an education.

In this context, 'education' means studies at an educational institution and 'training' means a practical education. But when quoting other studies and the Eurydice Database, we are applying the original terminology. Please also refer to the comments about the use of the concepts of 'education' and 'training' in Chapter 4 of Johansson and Moss (2003).

### 8.1 Education in the Netherlands

On the subject of the multiplicity of education and of educational reform, the Dutch researchers write that about 10 years ago, an educational reform was made within the area. The report states that:

*In higher vocational education, in particular, a puzzling multitude of all sorts of training courses emerged. Analysis argues that because of this transformation the work domain did not have sufficient insight into what could be expected of a new graduate leaving higher vocational education. It was decided to set up five occupational domains: nursing, care, social pedagogy, social work (maatschappelijk werk) and community work/leisure time pedagogy (sociaal cultureel werk). At the same time, efforts were made to create a more transparent system of training levels. Right now, the following levels are distinguished: 2,3,4 (upper secondary vocational education) and 5 (higher vocational education). Above these is the academic level (researcher, scientist, specialist), and underneath we find the level of unskilled people. In the sector of caring for disabled people we primarily come across levels 3, 4 and 5.*

Informants in the Dutch study are characterised by different professional educations and they are at different levels. One person does not have any education at all. One informant has a low-level

education based around home care combined with a 12-month supplementary training. Others are trained in nursing (one is specialised in the care of disabled people, and another is specialised in psychiatric care). Others are educated in social pedagogical work. Both educations in nursing and social pedagogy are represented at several levels. The Informants in the group of policy makers and trainers are characterised by a high educational level.

The Dutch national report states the following about labour in care for the disabled:

*According to the training background, the workforce can be divided as follows; 14,500 nurses, 30,000 social pedagogues and 4,000 primary care providers. Of all professionals in institutions for mentally people with disabilities 8,000 are at level 5 (higher vocational education), 26,000 at level 4 (upper secondary vocational education) and 14,000 at level 3. Professionals working in care for disabled people in home care are not included. Home care provides for several target groups. Care for physically disabled people is primarily delivered by home care, but it is impossible to unravel that in numbers. In home care we encounter primary care providers (levels 2 and 3, in particular) and nurses (level 4 or 5). In total 184,000 professionals work in home care.*

Thus, it appears that the social pedagogical education dominates in the care of disabled people if you ignore home care. Moreover, it appears that level 4 is dominant but this does not lead us to draw any conclusion about the educational level that is dominant in each group of professionals. Most likely, you will find levels 3, 4 and 5 represented in the areas of nursing and social pedagogy. With a view to better understanding the educational levels you must get to know the length and degree of specialisation of a particular level, as well as details about the admission criteria of each educational level. We have obtained this information from the Eurydice Database (Eurybase):

- Level 1 is described as assistant training (*assistentopleiding*): courses at assistant level that equip students to perform simple executive tasks. These courses are intended for those who are not able to obtain a basic qualification (level 2) but can thus obtain a certificate nonetheless. The training varies in length from 6 to 12 months. There is no admission requirement.
- Level 2 is described as basis vocational training (*basisberoepsopleiding*): training that prepares students to perform executive tasks at a slightly higher level. The diploma awarded at this level is equivalent to a basic qualification, which is the minimum qualification that every one should have. The training varies in length from 2 to 3 years. There is no admission requirement.
- Level 3 is described as professional training (*vakopleiding*): holders of a professional training diploma are able to carry out tasks completely independently. The training varies in length from 2 to 4 years. Admission requirement is at least a certificate of pre-vocational secondary education (VMBO) or a certificate of junior secondary education (MAVO). According to the Dutch national report, the care sector for disabled adults employs around 14,000 people with level 3 training.
- Level 4 is described as middle-management training (*middenkaderopleiding*) or specialist training (*specialistenopleiding*): this prepares students to carry out tasks completely independently, combined with the ability to perform a broad range of tasks or specialisation in a particular field. The training varies in length from 3 to 4 years. A specialist training varies from

1 to 2 years. According to the admission requirement described in the Eurybase it is possible to start studying at the middle-management training level with a VMBO or a MAVO certificate or proof that the first three years of upper general secondary education (HAVO) or pre-university education (VWO) have been successfully completed. The Dutch national report states that the care sector for disabled adults employs around 26,000 people with level 4 educations. Level 4 is dominant among social pedagogues and nurses.

In order to understand the admission levels, it is important to know that, when Dutch children reach the age of 12, they are divided. Some children will follow a vocational education (VMBO) while others will follow an academic line of study (HAVO). The minimum admission requirement for education at levels 3 and 4 is the completion of basic school, either the vocational or academic education, i.e. 9 to 10 years of schooling. In general, therefore, it seems that the admission requirement of the Dutch level 3 is comparable to that of the Danish social and health helper education (*social- og sundhedshjælper*), and level 4 to that of the Danish social and health assistant education (*social- og sundhedsassistent*). The admission level also largely compares with the requirements in Sweden for upper secondary school education where you can select care (*omvårdnadsprogrammet*) as a line of study. We stress, however, that this comparison is solely based on the admission level and the length of studies. The study does not enable us to compare the educational content.

According to the Dutch national report, the sector of care for disabled people employs 8,000 people with a level 5 education excluding people employed in home care. According to information from the Dutch researcher H. van Ewijk about two-thirds are social pedagogues and the rest are nurses.

Level 5 is a higher education (*hogere onderwijs*) or higher professional education (*hogere beroepsonderwijs - hbo*). It is for student aged 17 and above. Higher education in the Netherlands is now considered as a bachelor degree. Admission requirements are an upper general secondary education (HAVO) certificate, or a middle-management training or specialist training certificate or a pre-university education (VWO) certificate.

### **8.1.1 Educational questions in the Netherlands**

#### **8.1.1.1 Level and professional groups (specialised vs. generalised knowledge)**

The Dutch national report states that

*There is ongoing debate in the Netherlands as to whether the division into five occupational domains should be adjusted. A broad social work domain has been envisaged within which more room would be generated for specialisation courses. The issue of levels is also hotly debated.*

As already mentioned, the five occupational domains are; nursing, care, social pedagogy, social work and community work. The debate about the appropriateness of dividing education and work into five separate areas results in another discussion about education, which is raised by the Dutch report, namely the relative merits of broad generalised knowledge versus specialised knowledge:

*The risk of not going deep enough is also mentioned. On the other hand, we also find that a lot of interviewees stress the necessity to look at work from various perspectives and disciplines, which also calls for a broad approach. Presumably, the current*



*occupational domain division causes more problems in the sector providing care for mentally people with disabilities than in many other sectors, because here the caring, the nursing and the pedagogic aspects mix to a great extent.*

#### 8.1.1.2 Didactics<sup>40</sup>

There is another discussion that is also mentioned in the Dutch report, which is about the didactic concept. The Dutch researchers write as follows:

*The traditional form of transferring knowledge via lessons, where the teacher decided on the content of his classes and exams, has changed into the concept of learning to learn, of problem-oriented education, of creating integral programmes in which the specific subjects are integrated in the case treatment. In the past years, there has been a shift from learning on the basis of qualifications and professional profiles towards learning on the basis of competencies.*

The didactics discussion should be viewed in the perspective of the question about specialised versus generalised knowledge and the question about the possibility of adopting care work to changes in society, including new requirements of users and relatives. The didactics of recent times such as 'learning to learn' is favouring the competencies that are later discussed, e.g. the ability for critical self-reflection.

#### 8.1.1.3 Educational content and theory-practice issues

The Dutch report mentions the question about who is responsible for drafting profiles of professions - who is responsible for deciding which professions there are and are wanted? In the last decades the mainline of thinking has been that representatives of the branch (or sector), e.g. trade unions and employer organisations are responsible for the professional profiles and the universities and colleges for the education profiles. But the Dutch researcher H. van Ewijk suggests that the Netherlands in the very latest years seems to have moved slightly away from this approach, giving universities some more room for determining the professional profiles. The Dutch report raises an important question: to which extent should educational programmes be determined by practice or by educational institutions? Our study gives no answer. We can only mention that in principle people in practice know what they need in their sector, and universities and colleges know how to develop curricula and they are responsible for developing training programmes for a broad field and for the future. Thus the question is how to establish reciprocal development.

We can see here some educational issues that are present in all three countries in this case study. For example, there is a tendency towards a theory-practice dichotomy. Courses at educational institutions, where you learn the theory and the ability of reflection, are often opposed to competencies, which are required in practice. In other words, reflection and action are contrasted. *Learning about something* is considered separately from *learning to do something*, as if they are opposite instead of complementary factors. Or, to put in another way: It is widely believed that learning *about* the disabilities and disabled persons and the tasks at hand is opposed to learning how *to* perform these tasks. One of the informants of the Dutch report explains that you must be able to do both:

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<sup>40</sup> The concept of 'didactics' is used in the continental tradition

*A number of times we have turned people down who were gardeners, bakers and bus drivers. They are out of place here. The target group is so intensive and difficult, and you have to pay attention to so many things that you can never be up to it without proper training. Everybody can learn how to bathe and dress clients within two weeks, but after that questions arise; How do you do that? How do you make decisions? Why does the one behave like this and the other like that? You need to have a theoretical background for that.*

## **8.2 Education in Sweden**

The Swedish informants of the study have very different educational backgrounds. Some of the practitioners have completed a short-term, basic education, e.g. related to people with physical disabilities (*grundutbildning för psykiskt utvecklingsstörda – GPU*). One informant has a supplementary education aimed at mentally disabled people (*påbygggnadsutbildning för psykiskt utvecklingsstörda – PPU*). Some informants are educated to provide care targeted at elderly people or children, but during the 1990s this kind of education was replaced by upper secondary school education specifically targeted at care work. Half of the practitioners in the Swedish study are graduates or have completed studies at graduate level. Two of these informants with graduate degrees are occupational therapists.

Generally speaking, the Swedish informants are worried about the educational level in care work for adult people with disabilities. An option in upper secondary school aimed at care work (but not specifically care for disabled people) has replaced the old education at the basic level, which was targeted directly at this area. Moreover, there is a choice of education at the graduate level, which we will return to after discussing the upper secondary school education.

The Swedish upper secondary school (*gymnasieskolan*) is offered to everyone who has completed compulsory schooling (*grundskolan*). Upper secondary school is three years of studies, from 16 or 17 years of age, where the students select between 17 nationally determined programmes, all of which enable the students to continue at college or university level. There are eight core subjects (*kärnämner*), e.g. English and mathematics, which are studied in all programmes. Thirteen of the programmes contain compulsory elements targeted at business life. Among the 13 programmes, there are two which are specifically targeted on social work, care and pedagogy; the children and leisure-time programme (*Barn- och fritidsprogrammet*) and the health and nursing programme (*Omvårdnadsprogrammet*) that aims at care work with people of all ages – in health and medical care.

In addition, adults above the age of 20 are offered the opportunity to study for these upper secondary programmes and qualifications (*komvux*). According to the Swedish National Agency for Education (*Skolverket*) this option is utilised by a growing number of people. ([www.skolverket.se](http://www.skolverket.se)).

The health and nursing programme is targeted at care work in general. The local institutions decide the format and content of the education provided, and several of the Swedish informants believe that, in particular, care for people with mental and physical disabilities is a low priority area in this programme. One informant indicates that there is no education that will make you a personal care assistant, and another informant explains that the children and leisure-time programmes actually have a relatively high content of disability issues. One informant characterises the health and nursing programme as follows: *"It is just like any other course. It is not a real education."* Considering the experiences of the Swedish informants, we conclude that Sweden has not yet

fulfilled the educational needs of the area. This problem was identified many years ago by Karl Grunewald, who subsequently stated that: "During all my time as chief inspector, the education of our staff was vividly discussed, and quite honestly, I must admit that the education of the care workers (*vårdpersonalens*) is the only area in which we failed" (Graninger and Levén, 1994).

People with an education from the care area at upper secondary level (*omvårdnadsprogram*) (also *komvux*) are employed in a number of occupations: care worker for disabled people (*vårdare av utvecklingsstörda*), care assistant (*omsorgsassistent*), rehabilitation assistant (*habiliteringsassistent*) or auxiliary nurse (*undersköterska*). With regard to the education intended for adults (*komvux*), there is also a 12-month supplementary course in care, home nursing and rehabilitation subjects (*omvårdnad och omsorg, hemsjukvård och rehabilitering*). Admission usually assumes that you have completed the health and nursing programme or command similar work experience. At the tertiary level, care studies of 1 to 2 years are offered, but this education is not widespread among Swedish practitioners.

In addition to the upper secondary level education and the BA level, which we will discuss later, the care staff obtain further training by way of a range of courses offered by the educational institutions and the municipalities. According to the Swedish national report, it is very much up to each workplace to decide the type and number of courses offered to its staff. Since the mid-1990s, when the responsibility was transferred from the counties (*landstinget*) to the municipalities, and owing to financial cutbacks, the educational level has been sharply reduced according to the Swedish informants. The majority of the courses mentioned by the Swedish informants are half-day or full-day courses.

Higher education studies are offered at university or university college levels (*högskole*), equivalent to the Dutch level 5. With regard to care for people with mental and physical disabilities, this mainly relates to a bachelor of science in occupational therapy (*arbetssterapeut*), bachelor of science in nursing (*sjukskötare*) and bachelor of social science (*socionom*). The latter education may include a specialisation in care of elderly and disabled people. You either complete a programme involving a relatively fixed plan of education or else it is possible to compose an individual bachelor education with different courses, and usually the education is conducted by way of distance learning (Högskoleverket, [www.hsv.se](http://www.hsv.se)).

One of the quotes from the Swedish national report highlights the line of thought of educating yourself through a number of courses chosen to fit your personal plans. The informant, a woman care worker employed in a day care service, is asked about her further education preferences, and she explains:

*What I would like to do is to select a little of everything. But in this area.... I was thinking about whether there would be an education in, for example, behavioural disorders (*beteendestörningar*) or autism at university level for 12 months or the like, and then with an option of further research. Part-time or half-time. But, I would certainly stay here. It is an excellent workplace.*

The Swedish study does not provide any data about the distribution of qualifications in this area of care work with handicapped people. Thus, we cannot provide any details about the horizontal distribution, for example whether the occupational therapists (*arbetssterapeut*) represent a dominant group of professionals in daily activity. However, we are able to say that the vertical distribution

shows a tendency towards higher-educated staff performing administrative and advisory tasks instead of practical, daily care tasks. This trend differs from the conditions in the field of Danish care for disabled people where pedagogues with a bachelor degree<sup>41</sup> largely perform all kinds of care tasks, including management and administrative functions.

### **8.2.1 Educational questions – Sweden**

#### **8.2.1.1 Lack of educational offerings by way of courses**

The Swedish report puts much emphasis on the problems related to a lack of courses (schooling and higher education). The reforms of the 1990s led to a large-scale decentralisation of care tasks, moving them away from the counties (the regional level) to the municipalities, and because of their poor financial position the municipalities have become unable to offer the care staff a sufficient number of courses. Moreover, the Swedish informants explain the courses offered mostly deal with administrative matters or about tackling threats and violence in daily work. They lack courses that relate to the development and needs of disabled people. The demand for courses should be seen in the light of the disability policy: people with disabilities are largely living in their own apartments and hiring personal assistants. It should also be seen in the light of the fact that the upper secondary education programme in care work (*omvårdnadsprogram*) does not meet the educational needs and that it is inadequately focused on working with adults who have mental and physical disabilities.

According to the Swedish informants, it is quite common to employ staff without any professionally relevant education. Some of these employees are subsequently trained by way of courses, including distance courses. But generally the area appears to be characterised by a decline in professional education among practitioners (i.e. a de-professionalisation of the group of ‘front line’ workers).

#### **8.2.1.2 Educational academisation**

In a book written by Stina Johansson (2002), a Swedish professor, academisation is discussed as an important educational issue in Sweden. Johansson explains the two opposing views of the debate: one is a sceptical view on academisation because extended theoretical education might distance the graduates from the clinical/practical work and lead them into administrative work and research. The opposite view in the debate advocates academisation, one reason being that theoretical development is required for the survival of subjects as a profession, for the possibility of a life-long career and for strengthening the quality of practical work.

Johansson is sceptical about both views, that argue for and against academisation. The question is whether there is a need for a clear-cut link towards practice or towards theory. In fact, both links may be needed, Johansson believes, and she writes that theoretical knowledge may be able to lead the social care work back to the target groups and to competencies related to the target groups. She stresses a number of problems in relation to care knowledge, but we will only mention one, namely that the personnel manager and subordinate staffs do not share the same fundamentals (*kunskapsbas*):

Social care in the municipalities has changed with a bigger knowledge gap between the personnel manager and subordinate staff. This does not mean that the personnel managers command more of the subordinate staff’s knowledge, but they have a different basis of knowledge in terms of the format and content of knowledge (*Johansson, 2002:131*).

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<sup>41</sup> In Denmark, we refer to ‘profession bachelors’ when we want to distinguish between an education that involves practical training and is targeted on a specific profession as opposed to general bachelor degrees. The report makes frequent use of the term of ‘bachelor’.

The problem emphasised by Johansson in her book is mentioned by one of the Swedish informants: *“a personnel manager should command the fundamental competencies. Then he/she should carry on with training in management.”*

In the section about educational questions in Denmark we will return to the issue of academisation of care work and pedagogical work.

### 8.3 Education in Denmark

By far the majority of the practitioners interviewed in the study are educated as pedagogues. Some have completed their education before the 1992 reform, which resulted in an amalgamation of three different types of pedagogical education. These Danish informants are, therefore, educated as a social pedagogue or a leisure-time pedagogue or a kindergarten pedagogue. But already prior to the reform, these types of education had many similarities and paved the way for a wide range of jobs. Moreover, by working as tutors for student trainees, these informants have gained experience in the generalised education that was introduced by the educational reform in 1992. They perceive and refer to themselves as ‘pedagogues’, using the general description.

One of the Danish informants is educated as a social and health care assistant. While the study reveals a dominance of the pedagogue education, the education courses in social and health care are outlined in relative detail below with a view to providing a comparison to other countries. Two of the informants, who are working as helpers for disabled people and who are hired by the disabled person, have no relevant, professional education.

The education as pedagogue involves 3½ years of studies equalling the Dutch level 5 and the Swedish college and university studies. The admission criteria are upper secondary level education or a number of upper secondary level subjects combined with work experience, travel abroad or folk high school<sup>42</sup>.

The pedagogue education has a long history and an association with the type of education back in the 1960s that specifically targeted care of people with reduced mental abilities. It therefore appears that Grunewald and Bakk (2000) are correct when they conclude *“Denmark has been a pioneer in educating employees”*.

Since 1992, the education as pedagogue has involved generalised studies and in 2002 it acquired status as a professional bachelor degree. Pedagogues are trained to work with all target groups in the pedagogical field. Thus, their education must provide broad coverage and should in many ways ensure that the pedagogues command some general and overall competencies and that they are prepared for continuous in-service education. The studies include a number of psychological and pedagogical subjects, social and health subjects and aesthetic subjects. Moreover, there are three periods of practical work with at least one period involving pedagogical work with people with significantly, reduced mental and physical abilities or social problems, or children and young people who are left in an institution.

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<sup>42</sup> Folk high schools are adult services. Usually, students attend for 4-6 months while studying cultural and aesthetic subjects, social subjects or sports. The folk high schools enjoy a long tradition in Denmark. The fundamental idea is to offer a liberal education on a voluntary basis (in a Danish context the aim is talked about as ‘enlightening people’). More info at [www.folkehojskoler.dk](http://www.folkehojskoler.dk)

Although there is a tendency in some areas in Denmark towards hiring staff with a shorter education, the pedagogues make up by far the largest group of staff in relation to disabled adults. The remainder have mostly completed the fundamental social and health education, while a few have completed another kind of higher education (e.g. nurse, ergo therapist or teacher). The Danish pedagogue education is thoroughly described in a previous national report (Jensen and Hansen, 2002) and at [www.socialeducator.dk](http://www.socialeducator.dk)

At a lower educational level, Denmark has a fundamental social and health education<sup>43</sup>. It is a coherent system of three different generalised studies, targeting care, nursing, practical and pedagogical assistance for people of any age. Young people who are continuing on directly after nine years of primary and lower secondary school, and sometimes a tenth optional year, must first complete a course of basic studies of 20 to 40 weeks before gaining admission to the actual education. The basic course itself does not qualify you for work.

The education as social and health care helper<sup>44</sup> is the shortest course of study in this field. It runs for 14 months, alternating between studies and practical work. The admission requirements are completed basic training (as outlined above) or at least 12 months of other studies or work experience after compulsory school (9 years). The social and health care helper education mainly targets home care employment.

The education as social and health care assistant lasts 20 months, alternating between schooling and practical work. In order to gain admission to this, you must be educated as a social and health care helper or have similar qualifications by way of study or employment experience, or a combination of both. Social and health care assistants are employed in home care institutions, nursing homes, other institutions, service flats/housing services and hospitals.

The third type of education in the Danish system of fundamental social and health education is the pedagogical basic education (PGU) (not to be confused with the professional education for pedagogues discussed above). It lasts for 19½ months. The admission criteria are the same as for the social and health care helper education. The pedagogical basic education targets the area of pedagogical work in general.

With the social and health care assistant education or the pedagogical basic education you can apply for a number of social and health studies at BA-level (to qualify as a nurse, occupational therapist, pedagogue and others). It is a precondition, however, that the applicant has completed specific subjects such as Danish and mathematics at upper secondary level in addition to the social and health education.

The Danish study includes two informants without any professionally relevant education: they are disability helpers hired by a disabled person. The public sector pays the salary but the disabled person hires the helper himself and thus acts as employer. Usually, the disability helpers do not

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<sup>43</sup> We have used the term 'fundamental' for the Danish term 'grundlæggende' to differentiate the educations in question from social- and health education at higher levels. We do not use the term 'basic' as this term is the official name for an introductory period (20 to 40 weeks of training) for very young students.

<sup>44</sup> It should be stressed that in Denmark, the education as 'helper' is at a lower level than that of 'assistant'.

have any professional education. According to one of the informants in our study, some disabled people prefer hiring unskilled assistance.

These disability helpers state that their qualifications mainly consist of being interesting to spend time with, and being able to maintain a professional stance while working as a fellow human being in the home of the employer.

### **8.3.1 Educational questions - Denmark**

#### **8.3.1.1 The generalised education**

In line with the Dutch report, the dilemma between a need for knowledge at the specialist level and the need for a broad-based generalised education is stressed. The Danish informants generally agree that the generalised education has many advantages and that the need for specialised knowledge can be catered for by post-qualifying and further education, and by on-the-job training. One of the major and obvious advantages of a generalised education is related to hiring and the flexibility of labour. Pedagogues who embark on this education because they want to work with children and young people will during their studies realise that working with adults who suffer from disabilities is quite an interesting job. Another advantage, as described by a lecturer, is that the students learn to reflect at a higher level of abstraction:

*After all, this may be the biggest gain from comprehensive studies, this kind of generalised education. The content of our education, in my view, clearly shows that there is a greater focus on a common language, to learn about concepts and to be able to discuss these things. To learn about analysis, to understand how you look at things in practice and to make sense of separating these things and describing them in words.*

Knowledge, skills and attitudes, according to the informant, become transferable: “hence, when you are talking about ethics and power and the power of definition, then you are talking about fundamental concepts and fundamental comprehension that apply to anyone.”

#### **8.3.1.2 Academisation of education**

The Danish national report states that at educational institutions and in pedagogical practice there is a lot of discussion about the pedagogue education being academised. The discussion should be seen in the light of the fact that in Denmark, in line with the two other countries covered by the study, there is a tradition of higher education outside the universities, i.e. in training colleges. For several years now, the pedagogue education have been at tertiary level. The Danish discussion about the academisation of the pedagogue education is that study formats and requirements, which traditionally belonged to university studies, are now being applied and adapted to colleges. For example, the students are now required to be familiar with research conducted in relation to each subject.

Some people view academisation as an obvious benefit while others are sceptical, and a third group pursues a more ambivalent view. The Danish study does not provide an unambiguous picture of the views about academisation. But it does stress that academisation is a good development, assuming the fundamental qualities are not lost and that you can achieve an academisation of the musical and aesthetical professional areas without losing the practical skills. One of the Danish informants, a college lecturer, stresses the benefit of academisation, assuming that it goes hand in hand with thinking about learning processes, that is, that the academisation must be supported by substantial

supervision of each student. The pedagogue education cannot be achieved only through lectures. It is the supervision at the college as well as in practice periods that may promote the learning processes for the students and provide them with the necessary support.

*The practical training sessions are a pretty tough experience, plus the level of the studies. If we start ignoring the learning processes, then we lose everything. This does not only apply to our area but also to teachers and nurses, and other comparable groups, say, social workers, because there should be time for these processes.*

The academisation of the pedagogical education may ease the transition for the students when proceeding onto further university studies, and it may promote research in care for disabled people. The need for a promotion of research is mentioned in an anthology written by researchers at SFI (the institute for social research), CLH (the centre for equal treatment of disabled) and AKF (the research institution of the counties and municipalities). The authors of the anthology point out that the Danish research into disability care is too widespread and diffused, and also characterised by weak connections with the universities. One explanation, according to the authors, is that the professional groups who work in the area of care for disabled people have not developed any post-graduate studies until recently, and this development is likely to promote research efforts in the area. (Bengtsson, Bonfils and Olsen 2003)

#### *8.3.1.3 Education versus practical work*

The Danish informants largely agree that the pedagogue education makes a good match with the care and pedagogy requirements of disabled adults. Some of the informants, who have graduated before the educational reform in 1992, did obtain very specialised knowledge in this area, and they stress that newly graduated generalists are lacking such knowledge about the area of disability care. However, none of the informants indicate that the current generalised education should be replaced by a more specialised education. Instead they propose that these problems are resolved by way of diverse practical placement opportunities, enhanced opportunities for studying during the practical work sessions (instead of students being treated as just another member of staff), and courses for new employees. A couple of informants stress that the education does not provide sufficient knowledge about psychiatry, and another couple of informants say that one should preserve the musical and other aesthetical elements of the course of study.

#### *8.3.1.4 In-service training and further higher education*

The Danish report underlines the lack of a uniform picture of the conditions related in service training and further education (post-qualifying education). Some informants consider the opportunities to be good while others believe the resources are insufficient. Generally speaking, many short-term courses are being offered and some informants are being offered long-term, post-qualification education. There is a great demand for continuous development. The popular subjects for in-service training include neuro-pedagogy, prevention and handling of violence, and threats of violence at the workplace, dementia, supervision by fellow workers, 'pedagogy that matters', and the Marte Meo method. A few informants are offered a proper post-qualification higher education without pay reduction during their studies.

#### *8.3.1.5 Learning in the workplace*

The Danish report debates the question about learning in the workplace as a kind of further training. Several of the places that are covered by the Danish study are organising study events and the like



for the staff. The informants mention the benefits of mutual learning in their day-to-day work and the value of job rotation, i.e. that you swap work for a period of time with a colleague from another workplace. One informant mentions a study group that is established at her workplace. For example, it may involve work with life stories of pedagogical work or offering care to mentally people with disabilities who are going to develop dementia. Another kind of learning in the workplace consists of professional supervision where each fellow worker receives guidance in conjunction with difficult tasks and personal development. Moreover, study days are organised, for example about Marte Meo in pedagogical work, non-violent communication, special illnesses, etc. One of the places is involved in specialised projects that embark on a massive support of the individual user (disabled person) and systematic follow-up with a view to developing pedagogical work in general, and finally several of the pedagogues talk about the good support from their team leader.

The concept of “the learning organisation” has penetrated several of workplaces and the study points to a tendency for smaller workplaces to pool their efforts to secure enough resources to conduct courses.

#### *8.3.1.6 Working alone in a private home with the care recipient as your employer*

The work performed by handicap helpers without professional education takes place in private households where the care recipient (a person with reduced physical capabilities) is the employer. The scheme assumes that the care recipient is able to manage the tasks involved with being an employer. The work as handicap helper in a private home is characterised by complexity and dilemmas; these helpers are working alone while taking on considerable responsibilities.

The handicap helpers interviewed in the Danish study state that they lack education in the following areas: communication, techniques in moving and lifting other people, first aid, hygiene, psycho-social working environment, the rights of employees, and conflict management. The need for education, courses and supervision is associated with, for example, the difficulties that emerge when you are working without colleagues, and because establishing limits vis-à-vis the employer (the disabled person) may be difficult, including how to handle the balance between being hired and a being a friend. Another issue concerns how to handle problems that arise when the disabled person's family are making demands that are contrary to the wishes of the disabled person. One of the informants suggests making it compulsory for the employer to participate in courses about his role and responsibility.

The problems that may arise when the care recipient is your employer also involves the potential situation of the helper facing both the municipality and the patient as employers. Johansson (2002) refers to this as a triangle of labour in which the work is characterised by a triangle of power and influence. Referring to Gough, she emphasises that conflicts do not end just because the user is able to select his staff individually and introduce his problems, but that the asymmetric relationship will take on a different shape, where the question about superior and inferior becomes more complex. Moreover, Johansson refers to a study underlining that poor education coupled with a lack of influence at work may result in violence against the user. We will therefore stress the possible downside to the tendency of involving unskilled people in tasks that are performed without daily contact with fellow workers, without professional management and supervision and which take place in the user's home. In the section about roles and tasks (5.2 in Chapter Five) we have discussed this issue and highlighted the following statement of a Swedish personal assistant: *“I am just a slave”*.

#### 8. 4 Summary of educational backgrounds and questions

There are both differences and similarities between the three countries concerning the education that leads to working with disabled adults. In all three countries, the labour is applied at several educational levels: both people with short-term studies and with a higher-level education that have developed into degrees on a BA level in recent years. In all three countries, labour is applied without any real education in the area in question, although the extent to which this applies differs from country to country.

In the Netherlands, many employees are educated at level 3 or level 4, i.e. they have completed studies of 2 to 4 years following school with either a theoretical or a vocational line of study. When the Dutch students embark on level 3 or level 4 studies they are comparable to the Danish and Swedish pupils leaving compulsory school in terms of the minimum admission requirements. In terms of admission requirements and length, the Dutch level 3 compares with the Danish education as social and health care helper (including the first basic year of study). The Dutch level 4 educations are largely comparable with the Danish social and health care assistant studies in terms of admission criteria and length. The latter one lasts for about three years when the 14 months of studies related to the social and health care helper education are included. This is basically a precondition for taking the education to the next level.

Sweden offers a three-year, programme of study in health and nursing at the upper secondary school level (*omvårdnadsprogram*), one of 17 options, and adults are allowed to complete the study by way of a special scheme. The admission requirements are similar to those that apply to young people in the Netherlands who are applying for levels 3 and 4 education, and in Denmark they compare to the admission criteria of all three fundamental social and health studies. An upper secondary level education in Sweden grants admission to higher education at the university level. This also applies to the Danish social and health care assistant and pedagogical fundamental educations, but only when certain conditions apply and only in relation to social and health care educations (not to university studies in general as history, science, language etc).

In all three countries, people are also being educated at a higher level (in the Netherlands this is level 5) with a view to performing care and pedagogical tasks for disabled adults. In recent years, these types of education have developed into bachelor degrees and have been formalised as such. The study does not enable us to specifically describe the frequency at which staffs with this higher level of qualification participate directly in specific and practical care tasks.

In Denmark, however, it is common for staff in housing and day care services for disabled people to have been trained at this higher level, as pedagogues. This reflects a view that pedagogical work cannot be divided into some tasks that are suitable for less qualified staff, while other tasks are for staff with the highest education. By contrast, it seems to be more common in Sweden and the Netherlands that staff with a degree or other higher qualification perform managerial and administrative tasks, while staff with lower qualifications do the care work involving direct contact with people with disabilities.

In the Netherlands and Sweden, there are a large number of different professional groups in the field of care for adults with disabilities, and in Sweden it seems to be common for the staff not to have completed any truly relevant professional education. This has grown after the range of degree studies that specifically targeted this area was abolished in the 1990s. In Denmark, it is almost only the handicap helpers (people employed by a person with a physical handicap) who do not have any

professional education, and this group of people represents only a small number. The pioneer work achieved by Denmark with regard to educational levels in the field of care provided to people with significantly reduced physical capabilities is highlighted by Karl Grunewald, who has been spearheading the fight for general improvements in the field of care for disabled people.

Working on your own in the home of the person who is receiving care is difficult work that is largely left to people without any education and who are facing an employer without proper education in relation to his role. The handicap helper/personal assistant may be squeezed between the care recipient's requirements, the requirements of the relatives of the care recipient, personal views and the municipalities.

The Dutch report underlines that the multiplicity of professional groups places demands on teamworking and utilising the capabilities of the various groups, and it stresses how the various professional groups differ in terms of status (see the section on work-related status and image in Chapter Five).

The issue of generalised and specialised education is discussed by both the Dutch and Danish reports. There is a need for in-depth and specialised knowledge as well as broad-based and cross-educational knowledge. The Danish report in particular stresses that, among other benefits, a generalised education, such as pedagogue education, provides flexibility between areas and levels, which may help to solve labour shortage difficulties. Further education and on-the-job training solve the problems related to a lack of specialised knowledge.

According to both the Danish and Dutch reports, the generalised education assumes that students master learning and that they will be working with the art of problem solving. The Danish report points out that the generalised education is challenging the students to aim for a higher level of abstraction since the courses do not allow the students enough time to acquire knowledge about the entire spectrum covered by their education. The Dutch report emphasises the demand for a practitioner-oriented education, but it also warns against loss of theoretical depth.

The question about whether an education is appropriate for practice and the question about who is to decide the relevant educational content is a subject of an ongoing debate in the three countries. If the education is to be designed on the basis of requests arising from the practice field, it requires that practice has the necessary conditions for properly defining educational content. There are tensions between the needs of the individual, specific institution that represents practice and the necessity of a broadly based education for the purpose of labour flexibility. The question about whether the education matches practice is thus closely associated with the issue of specialised versus generalised knowledge.

The need for well-qualified labour does not appear to be self-evident yet. The educational level is facing ongoing challenges by way of different views on expertise and professionalism. Lindquist (2000) refers to criticism of expert dominated institutions as being a dominant factor in the de-institutionalisation that took place in Sweden in the 1980s. The discussions contained in the Swedish national report indicate that the discussion to which Lindquist refers is also relevant with regard to the current discourses with regard to care provided in private homes. Johansson (2002) touches on this discussion by raising the issue of the tendency towards academisation of care education. She also stresses that this discussion tends to be polarised although you may argue that a

high educational level does not necessarily mean an education that places the care recipient at a distance.

In Sweden, Johansson believes, it has been widely debated whether it is fair that the higher level social care education programmes in Sweden are largely qualifying students to proceed directly to managerial posts instead of management being a post-qualification education (Johansson, 2002). As a consequence, there is not much common knowledge shared between managers and staff. The Dutch study associates the question of a lack of common knowledge more closely with a specialisation into five professional areas, thus representing a problem of horizontal relationships as opposed to the Swedish problem of vertical relationships. In Denmark, where the generalist education as pedagogue represents the key education in relation to the work conducted in direct contact with a disabled person and also management tasks, there are no significant problems in terms of a lack of a common knowledge foundation.

## **8.5 About competencies and the importance of education**

### **8.5.1 The Netherlands**

The Dutch report defines the concept of ‘competencies’ as *“the sum of knowledge, skills and attitudinal aspects that are necessary in order to be able to perform a certain professional duty”*. The Dutch report states that

*training courses are turning more and more towards competence-based education. A certain profession is comprised of a defined set of necessary competencies. In that, difference is made between competencies that are directly oriented towards the core tasks to be performed, and more general competencies, which are linked to certain levels (HBO, MBO) and to certain types of training (pedagogic, nursing, caring).*

The Dutch informants (notably policy makers and teachers) are emphasising the importance of the following competencies: *“to be able to communicate, to understand, to have interaction”*. Moreover, the importance of the will to go deep is stressed, i.e. “persisting in going deep”, and referring to the German concept of *verstehen* this will or ability is defined as *“the ability to identify with another person so much that you can feel and think with them”*. The pedagogical attitude *“is given much emphasis in the interviews, although in different words”*, according to the Dutch researchers. Moreover, the Dutch report underlines the importance of the ability to perform critical self-reflection. It states that

*someone at HBO-level may be expected to always take a critical distance on their own actions and to keep approaching the care receiver from different perspectives and on different theoretical bases. This competency requires not only a certain attitude but also a theoretical framework that one can fall back on.*

The Dutch practitioners largely share the same views as the group of policy makers and trainers. The practitioners stress the importance of being able to communicate and to observe, look, analyse, and put things into context. In addition, they underline the importance of being able to view and create opportunities, the ability to be spontaneous, optimistic and realistic. The informants’ experiences concerning care for people from a minority ethnic background enable us to determine the needs for competencies in inter-cultural awareness.

Yet another key competence is outlined by the Dutch report. It is about the ability to work against the background of “*various perspectives and disciplines. A worker in the care sector for the disabled has to be able to look and act from the caring, the nursing and the pedagogic perspectives and disciplines* “. The report stresses the following problem:

*the Dutch education system distinction has been made between the caring or social pedagogic and the nursing or social pedagogic aspects [...] That can lead to blindness. That is the reason why social pedagogues often underestimate the significance of physical and mental limitations.*

The report suggests a solution by underlining the importance of cross-professional teamwork.

The Dutch report thus discusses the very important and difficult question of care for disabled people, i.e. the complexity involved. Care is a complex phenomenon with social, health, learning and developmental aspects. Ideally, care does not consist of offering health-related *and* social and development-oriented support; rather it consists of integrating these different aspects as complementary factors that promote each other. Otherwise, there is risk of inadequate care.

The Dutch report also shows how the area is fighting against dualism, health versus social pedagogical development, and health education versus pedagogical and social education. This problem is not a particular Dutch issue. It is a general problem in our cultures that these two aspects of life are being separated.

The report refers to a certain kind of blindness that may emerge when professionalism is narrowed or specialised: “*social pedagogues often underestimate the significance of physical and mental limitations*”. Such care can be criticised. This is obvious we think, and we will not bring that further into the discussion. Instead we want to give attention to the sentence because it represents a good example of a health and care-related paradigm. In another paradigm, for example from the point of view of social pedagogy, you may as well criticise the problems that emerge when the social and development-related resources are neglected, and you may also point to blindness and lack of competencies among other professionals relative to these aspects of quality in life for people with disabilities.

A policy maker gives some important and critical thought about the educational level of the care provided for disabled people in the Netherlands. He refers to developments in Australia and New Zealand, where care work is not so professionalised, but the tasks are solved satisfactorily according to the Dutch informant:

*‘Not so professionalised’ means with lower training and, where possible, with less training. It’s linked to the emancipation idea. You shouldn’t bring in more professionals than you need. None of those professionals who tell you what’s good for you. There they do it for half the cost, and reasonably well. This also emerges from studies into satisfaction levels. Perhaps here we’re over-professionalised.*

The statement illustrates a tension involved in discussions about competency, and where professionalism is some times described as an expensive and repressive solution that is opposed to the inexpensive solution that gives freedom to the citizens. This way of thinking may be contrasted

with a view that education may prevent repression and give care workers some necessary qualifications to operate as a catalyst instead of taking over tasks.

In this respect, it seems to be an important question whether or not there is a positive correlation between the satisfaction level and a low educational level. A positive answer to that question can be seen as is in contrast to a view that recipient's experience of satisfaction is not in itself always an adequate and unambiguous parameter of good care. For example, the care worker interviewed states that the preventive and health-related considerations occasionally put pressure on the user in a manner that is opposed to his wishes.

All three countries discuss the question about the importance of education of care workers. We have previously mentioned the concerns about an educational academisation, but later in the section on Sweden we will return to the question about views about the importance of education to the quality of care.

### **8.5.2. *Denmark***

As described in the section about work status and image, the health studies in the Netherlands enjoy higher status than the social and social pedagogical studies, and the development-oriented pedagogical work enjoys a higher status than care with the sole purpose of creating quality in everyday life, i.e. without any particular development purpose. In Denmark, this issue does not stand out in the disability area in which the pedagogical profession dominates both daily work with disabled people and the management level. The pedagogical profession in Denmark is relatively homogenous and all pedagogues who have graduated after 1992 have completed the same kind of generalised education.

According to the conclusions of the Danish report, there is generally much satisfaction about the pedagogue education being a generalised education although this involves a need for further training in specialised areas. Generally, the tasks in the area of care for disabled people are considered to be of a pedagogical nature, including the practical tasks concerning daily living conditions, since the association of practice with the issues of ethics, dignity, development, maximum life quality, involvement and self-determination in actions is considered to be pedagogical. In large places nursing and treatment tasks related to physical illness and disorders are solved by having a few employees with a health-related background and in other places by having assistance or guidance from the health system.

The conclusions of the Danish report on competencies in pedagogical work are that the practitioners' views of their personal and professional competencies are closely in line with the views of lecturers and policy makers. The question about personal and professional qualifications is closely related: the personal factor is the professional tool of the pedagogue, the pedagogues are aware of the correlation and of the importance of their life-long development, and they know how to distinguish between private and personal factors. With regard to personal competencies, they point out that you must have human qualities such as being able to accommodate other people's feelings, and to be patient and tolerant. Other important factors are knowledge - consciousness – about 'philosophy of man', professional knowledge about the user groups, knowledge and skills in specialised pedagogical methods and value systems such as neuro-pedagogy or 'it matters-principles' (see section 9.5.3 in Chapter Nine), the Dutch communication theory of Marte Meo and, in particular, oral and written communication skills and knowledge about ethics.

Reflection competencies are mentioned as a general skill with particular importance in relation to personal and especially professional issues. This competency is important with a view to adjusting your daily work and being able to develop yourself. The Danish pedagogues are trained to adjust their work continuously and reflectively within the community of their fellow workers rather than pursuing objectives and means determined externally.

The Danish report provides additional coverage of the aesthetical and musical competencies. The study says that there is agreement about the importance of these activities in pedagogical work. The male pedagogues in particular are performers of music.

Both the Dutch and Danish reports discuss the importance of a cross-professional approach. At some workplaces, the main group consists of pedagogues and a few people with a different educational background. There may be ten pedagogues and one nurse or a social and health-care assistant. Only one of the institutions included in the Danish study employs a cross-professional staff group. The Danish report mentions that some informants appreciate being in a cross-professional team whereas other informants prefer working only with pedagogues. One of the informants (with decision-making responsibilities) stresses that a homogeneously composed group is important for ensuring that your thinking is based on a holistic approach instead of dividing user needs into sub-disciplines.

The Danish report stresses that a well-educated labour force does not need detailed plans to be prepared by anyone else other than the professional staff group. The pedagogue is capable of performing, planning and assessing his work and to provide theoretical arguments to support it. Referring to the Norwegian researcher Erling Lars Dale, Danish pedagogues can be said to be professionals (Dale, 1989). Thanks to their professionalism they ensure that quality of care and pedagogy is not solely associated with the individual practitioner's personal and human skills.

This is reflected by one of the interviews in which the policy maker interviewed compared the educational conditions in the UK and Denmark based on his experience during a field trip to Manchester. In Manchester they mainly used

*unskilled labour and we mainly make use of educated staff [...] They were quite good people who were also doing a good job... They have to systemise the way in which they create pedagogical content in the things they are doing. They make much use of schedules and systems to gain an overview of what is required to support their fellow workers doing their job. We take a quite different approach. We have skilled fellow workers whom we do not support in this manner, because, in our view, this is what they have to manage, and instead we examine the results of their work. This is one of the major differences between these two systems... the disadvantage of the British system was [...] that it was highly people-driven. That would create a significant dependence on ... when you do not have any theories to lean back on, and you only have the ancillary tool that can assist you in uncovering needs of the person in question, and how to handle the situation. This may very well be sufficient as an ancillary tool but it will only work if it is people-driven. You only have your own knowledge and experience and your own ethics to support you. That is a disadvantage, I believe. It means that the individual person is very much left to ... it would mean a big difference between whether one person or another is involved.*

Other informants in the Danish report are quoted stressing that the qualification of a long-term and thorough education should be reflected in the direct work with the users, and one of the Danish policy makers is quoted emphasising that only a well-trained labour force can stand and see the challenges of the toughest care tasks. Well-trained staff will reflect upon their work, will process their experiences in both written and oral ways, prepare action plans and evaluate and adjust their efforts. The Danish report quotes one of the informants saying that a high level of reflection will prevent a vicious spiral and regular battles for power between the disabled people and the staff (due to difficult working conditions, ongoing pressure and needs that cannot be fulfilled).

Since the pedagogues usually provide guidance for pedagogue students in their practice periods, the Danish report deals with the question about competencies with a view to working as a tutor. The report mentions requirements related to knowledge and skills in guidance/supervision, assessment and conflict handling situations. The task as a tutor also involves solid knowledge about educational matters and the development of the subject, and represents a rather demanding task.

### 8.5.3 Sweden

The Swedish report covers the views of the informants on competencies, including their statements about educational needs. They talk about ergonomics, first aid, sign language, data, ethics and knowledge about diseases and disabilities, e.g. the knowledge about Down's syndrome and epilepsy. The different views are attributable to the actual differences in the informants' working conditions and to their different backgrounds.

The multiplicity of the care worker's educational background confuses the picture of general and necessary competencies, and for the untrained staff it may be difficult to formulate a list of competences of which they are not aware. A large survey conducted in Stockholm is uncovering competency needs, and indicates that more knowledge about this matter is required. The survey will target an action plan across the otherwise decentralised schemes with a view to improving the educational level. Apart from a general enhancement of the educational services, one of the objectives is to establish a common introductory course. Moreover, there are objectives associated with competency development by establishing job rotation, networking, and study groups.

Several Swedish informants underline, just as the Dutch and Danish informants, the importance of being able to interpret the needs and wants of people with serious disabilities:

*People that work in housing units where the users have severe functional impairments and serious mental retardation, talk a lot about the fact that their function in relation to the users is to interpret their needs and to make their everyday life meaningful and rich.*

Other statements from the Swedish report point to the fact that it is important for the informants to have competencies that help them keep an appropriate distance from the care recipient. One of the informants puts it this way: *"It is usually said that you can be personal but not private"*.

A completely different aspect of the question of maintaining a certain distance is mentioned by another informant: care workers should keep in mind the fact that some people with serious disabilities are living their entire lives with the most intimate parts of their body being touched by different people. Attention to this fact should enable the care worker to show adequate respect with respect to the body contact that is required.



In addition to the details about educational preferences, the Swedish report also contains a general discussion about being educated or not being educated. The Swedish informants discuss the meaning of education, among other things in relation to the size of their salaries. One informant states that it is difficult to claim the right for higher pay because of your education when education is not a work requirement.

The Swedish informants differ in their opinions about the importance of education. Several believe that education provides for a more professional stance and enhanced contact with the users, but others believe that the tasks of a personal assistant would not be performed in any better way if the assistants had completed some sort of education. We feel it rather obvious to suggest the hypothesis that people lacking an education do not envisage any educational needs when it comes to performing the tasks of a personal assistant; whereas people who have completed an education consider education as a necessity in relation to any kind of task. The Swedish report mentions the importance of education with a view to establishing contact based on equality, preventing violence and building interaction (personal relations that are not of a private nature). Moreover, it is stressed that being a person with a “warm heart” does not suffice. Some people do well without an education whereas other people (in spite of a “warm heart”) may risk treating the users in an undignified way, for example using an expression such as “how nice they are”.

## **8.6 Concluding remarks**

The competencies and competency needs mentioned by the three national reports can be categorised into the following groups:

1. Communicative competencies: these are competencies in relation to communication with people who are disabled and communication with collaboration partners and authorities, drafting of reports, etc., and data processing. The Danish report puts emphasis on the need for written and oral communication skills.
2. Analytic and reflective competencies: these include the ability for critical self-reflection, attention to own opinions and the ability to plan, evaluate and adjust your work independently.
3. Personal competencies: such as patience, the will to go deeper and the ability to exert empathy.
4. Professional knowledge: such as knowledge about specific disabilities, care-oriented knowledge and knowledge about social science, e.g. developing social networks between people.
5. Musical and aesthetical competencies.
6. Competencies concerning the prevention of psychosocial and physical strain especially when working alone: these competences consist, for example, of knowledge about ergonomics and how to perform first aid<sup>45</sup>.
7. Intercultural competencies.
8. Competencies in cross-professional work and general teamwork.

The importance of education is discussed. Some informants believe that you should go easy on the professionalisation of care work, but the reports generally underline that education is important with a view to assessing the needs for different kinds of support, preventing violence, being able to work with your own personal development (important for performing your work successfully), and entering into dialogue with the disabled persons, the users, based on equality, etc. Education is

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<sup>45</sup> We have rated first aid as a competency that is associated with the psychosocial work environment. The explanation that it is a psychosocial burden if you are unable to act adequately when facing a life-threatening situation for the care recipient (we have become aware of this problem while interviewing one of the Danish disability helpers).

targeted on the daily work as well as on further education and research. The dominant view is that education provides positive quality to the care work, but the reports also indicate that this quality is subject to an ongoing debate. The educational level is being discussed in relation to the question about the care recipient's autonomy and right to make an independent selection of a care provider, including the question about the necessity of expert knowledge or professionalism. Moreover, the question about educational levels is viewed in relation to general socio-economic conditions. Good education – or education at all - is a quality that you *cannot* take for granted when it comes to caring for people with mental and physical disabilities.

## Chapter Nine: Understanding of care

### 9.1 Introduction

The question about the understanding of care and pedagogy relative to disabled adults is a broad and complicated issue. In principle, all questions, answers and analysis of the study contribute to answering how care is perceived in the countries involved. The various types of disability policy, educational services, practical organisation, daily activities, etc., all contribute to the understanding of the terms 'care and pedagogy'. The views presented in this chapter about the understanding of care and pedagogy relative to adults with reduced physical or mental functional abilities should therefore be carefully cross-referenced with the other chapters of the report.

The perspective applied is phenomenological with a pragmatic use of the concept. Thus, we focus on the principles and values expressed by our informants and their statements on communication, togetherness, relations and various pedagogical services, etc. Their descriptions may help us to pinpoint the question about how care and pedagogy are understood inside the area. In other words, we have examined what practitioners, trainers and policy makers *say* about care and pedagogical work in relation to adults with handicaps and what we think these statements tell us about the understanding of care and care work. We will briefly reflect on the care views communicated by legislation and the structure of services offered.

In this chapter we mainly deal with the common characteristics of the informants in the three countries but we will also point to individual topics or discussions that are particularly characteristic of the individual countries.

Against the background of our analysis of the three country reports we have formulated a number of common characteristics that apply to the understanding of care and care workers. The characteristics are outlined below by way of a number of categories and abstract ideal typical figures. The categories and abstract figures should be seen as expressing the very essence of our empirical interpretation. They are therefore *our* view on how the specific empirical background can be applied to associate concepts with this understanding. We end the chapter by stressing four types of actions that, when taken together, define care in the way that we have seen it in the context of this study.

### 9.2 The concept of care: some preliminary suggestions

#### 9.2.1 *The good life, recognition and prevention*

The informants in our study either work with developing, managing and organising handicap care or teach or perform care and pedagogical work for adults with seriously reduced mental or physical abilities (cf. information on the target group in section 2.1 of Chapter Two). On closer study, the material shows that informants tend to talk about care and pedagogical work on the basis of three broad categories of care and pedagogical work intentions: 'the good life', where the intentions are to provide opportunities that ensure each citizen optimum conditions for a good life; 'recognition as citizens', where the intentions are to recognise each individual as a citizen with rights, influence and opportunities to participate, irrespective of that person's functional abilities; and 'prevention', where the intentions are about preventing social and health problems among exposed groups of people and taking measures to reduce the consequences of serious social and health problems that

currently exist. These categories overlap but they nonetheless illustrate the mindsets of the study informants.

*What* do you consider as good conditions, *when* do you recognise a person as a fully legitimate citizen and *how* do you alleviate or prevent problems – these are not unambiguous or fully clarified questions but themes in an ongoing debate. The debate involves a ‘normalisation discussion’ that has been going on for several years in the light of the question about what would be normal and whether one would be able to define anything as ‘normal’ – is normal what the majority believes? is it fair to make other people fit into the life patterns of the majority? etc. Another major issue is whether we have overestimated the importance of de-institutionalisation and the ideal of integration, which Tøssebro (2000) refers to as a ‘contemporary orthodox’, and which frequently translates into a purely administrative or physical routine instead of social integration. At present, there is also much discussion about participation; influence and choice in care work (see also Chapter Two, section 2.3 that deals with developments in disability policy in greater detail).

### **9.2.2. Social rights, solidarity or charity**

In very general terms, the question about understanding of care may be viewed in the perspective of thoughts on rights versus thoughts on solidarity or charity, and the informants’ statements indirectly reflect these perspectives. In the following, we briefly discuss these three different approaches to the understanding of care and pedagogical work.

In relation to handicap policies, rights are about entitling people to support and treatment, and the concept of rights stresses that special groups should be ensured access to social services on an equal footing with other people. Most people probably perceive these rights as an ideal or possibly non-negotiable requirement in modern societies. The rights are translated into thoughts on rights and/or solidarity. The latter involves a discussion about institutional solidarity or personal solidarity.

In the context of disability policy, ‘*thoughts on rights*’ is about ensuring fair treatment, help and support to people with disabilities on the basis of *special laws* and provisions. Laws give specific rights to particular groups and laws emphasize that ordinary, universal rights are for all groups.

By referring to ‘thoughts on rights’, we talk about an ideal of predetermined rights ensuring people their social rights on objective criteria instead of demanding concrete, individual assessments (among other things because individual assessments in principle depend on different professionals doing the assessments influenced by local policies etc). We thus see ‘thoughts on rights’ as a paradigm connected to an ideal of independency.

One problem, however, arises from the ‘thoughts on rights’ because specific professional and political priorities and assessments are rendered difficult. In the paradigm of rights, equal opportunities for help and support must be ensured for everyone, which leads us to ask whether equal opportunities for different people are justified. It is believed that the services rendered must be identical when the needs are identical but it is difficult to assess whether two citizens have identical needs. These things will have to be simplified. Another problem is that the thoughts on rights (or - to be more precise – the “principle of legal rights” relative to the social services) imply that these services must be made visible in a manner that can be specifically assessed and compared with other services and other people’s services. Thus, measurable standards are made necessary for every service. The rules become so extensive and thus non-transparent and are affected by opportunities for control (see for example the discussion by Andersen, 2001).

This may lead to a higher degree of instrumentalisation of care work, which, according to this line of thought, must observe the standards rather than a specific assessment in each situation.

Researchers have found that this adversely affects the opportunities for influence of both the provider and recipient of care. The two parties do not enter into an open agreement about specific services because their actions are laid down in a contract. From research done in elderly care in particular (also relevant to research in handicap care) we will refer the reader to a Danish researcher who discusses the standardisation that is associated with the introduction of a common working language in the care field. The common language is about specific standard concepts of needs and services. The researcher writes:

*By making care an object, we risk losing the flexibility and so the complexity of care communication that takes place at the lower home service level. It is simplified away; the kind of communication that cannot be based on standards is not embedded into the language or conceptually codified on a par with the communication that belongs to standardised nursing forms. Transparency is obtained at the risk of losing the flexibility associated with the practical knowledge and case-by-case assessments (Højlund, 2001: Our translation).*

Care standards are also discussed by Swedish research: “*Help has become more flexible for the help system and less flexible for the users*” (Thorsen and Dyb, 1994, quoted from Szebehely 2003).

Moreover, there is a risk of rendering invisible and thus neglecting or underestimating the care work that cannot be measured or detailed in standards.

Our study indicates that the thoughts on rights have a significant impact on Swedish disability policy where general social rights are supplemented with specific rules for handicapped people. The Swedish practitioners, who are informants in our study, however, do not mention any experiences as direct negative consequences of the thoughts on rights. They only stress that it is difficult for the authorities to meet the rights outlined.

The Swedish practitioners say that it is quite clear that LSS is a functional law and that it is used for guidance (*riktmärke*) with the view of changing the rights of functionally disabled people. The staff quoted in the Swedish report stress that: “*the law is good because it is compulsory and it deals with rights. The rights of the users have become more visible today*”. Citing the law, Swedish people may sue the municipalities if they do not provide the services to which a handicapped person is entitled.

A Danish policy maker and informant refers to the thoughts on rights in Sweden, and stresses one of the differences between Denmark and Sweden:

*In Sweden, it is quite clear that there is a large programme to provide help [...] and they have specific legislation about help schemes, rights, and as far as I know, it goes beyond the normal service level. That part of it is destroying the financial foundation of everything because they have just implemented rights legislation that goes beyond what the municipalities can incorporate into their service systems [...] You could say that the rights legislation – as it is perceived here – is very much like the US system; if you cannot enter a shop, then you are either entitled to go into the shop in spite of the step or you can sue the owner of the shop from whom you may claim damages. We are*

*not too fond about this model and neither are the disability organisations. On the other hand, however, they find it slightly fascinating. I should add that I have been to New York with the president of The Danish Council of Organisations of Disabled People (DSI<sup>46</sup>) where we went on a bus ride. I would not be able to do that in Copenhagen, but that is possible in New York, going on a bus ride with him. You cannot do this in Copenhagen. ... You could argue this applies to Sweden and Norway to a certain extent, although their approach is more systematic than the one we generally use. We are using a fairly broad-based approach. Deep down, we are not too fond of planning and stuff like that.*

We have decided to include this extensive quote because it is an expression of the apparent ambivalence in Danish disability policy. On the one hand, there is no wish for specific thoughts on rights, and on the other hand, there is a wish for the inherent opportunities. The quote, for example, explains how the Danish policy maker respectfully talks about his experiences with a handicapped person with whom he was moving around in a city that is more handicap-friendly than Copenhagen.

In addition to the thoughts on rights, the study also reflects *thoughts on solidarity*. The thoughts on rights and solidarity are not necessarily opposed; you may say that thoughts on rights are socially and publicly organised thoughts on solidarity. You may refer to institutionalised solidarity, but it has been emphasised that thoughts on rights and solidarity *may* appear as contradictions. Thoughts on rights may put solidarity under pressure. By upholding special rights for certain groups of people you may undermine the general solidarity of society and between different stakeholders of society. According to this view, the population is generally freed of personal responsibility and personal solidarity when knowing that special groups with particular needs are provided for by the legislation in force. Moreover, competition and envy may arise between groups of people who are fighting for their individual rights through their personal interest groups.

These concerns are reflected in the Danish national report with reference to information from the Danish Disability Council (2002):

*at the beginning of the 1990s, the debate on disability policy measures was revived when the USA passed the ADA Act (The Americans with Disabilities Act). The Act prohibits discrimination of disabled persons. Similar anti-discrimination legislation was also discussed but did not gain support in Denmark either with the authorities or among most of the disabled people's organisations. Such laws were, in a Danish context, considered to be an expression of undesirable individualisation and legalisation and thus also a risk of undermining the principle of solidarity which otherwise characterises Danish disability policy. It was also feared that such legislation would, if anything, contribute to the separation of disabled citizens as a group from the rest of the society and thus rather prevent than promote equal opportunities and equal participation.*

Currently, Danish disability policy is situated somewhere between thoughts on rights and on solidarity. Some of the arguments against strict thoughts on rights and specific rules for handicapped people have been that you ought to implement rules that apply to all citizens, that you do not want to stigmatise specific groups and that you want to avoid a maze of different rules. In the

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<sup>46</sup> DSI has 29 national member organisations representing more than 300.000 people with disabilities in Denmark. DSI is the only Danish umbrella organisation in the disability field

past ten years or so, however, Denmark has also seen a growing tendency to thinking on rights rather than on welfare as the basis of general considerations and solidarity, and a look at elder care in Denmark indicates that the thoughts on rights are generally gathering momentum.

A third perspective of the understanding of care is about charity. Charity is not defined as a particular right because actions taken on the basis of rights do not involve charity. Moreover, charity is not solidarity either ('solidarity' defined as recognition of all persons importance for the community) (Honneth, 2003) because charity is rather about taking care of the people who are considered to be outside the community.

The table below shows charity in correlation with other types of care thinking and the different social frameworks, ideal perceptions and requirements placed on the provider that arise from different kinds of understanding of care. Charity is diaconal and motivated by religion. The first four columns of the model have been prepared by Hjort-Hansen and Høeg (1999). The fifth has been added by Hansen (2002).

	<b>1 Informal care</b>	<b>2 Religious<sup>47</sup></b>	<b>3 Professional</b>	<b>4 Service management</b>	<b>5 Life-long learning/ participation</b>
<b>Social context</b>	Family sphere	Church	Treatment relationship	Market	Pedagogical relations
<b>Ideal</b>	Confirming the relations	Showing charity	Performing scientifically treatment	Selling a service product	Authority and autonomy of the citizen
<b>Requirement</b>	Putting yourself aside	Serving a person in need	Factualness	Providing service	Learning processes
<b>Focus</b>	The well-being of the other person	Saviour of the soul	Prevention and treatment	Contractual obligations	Establishing knowledge, skills and development processes
<b>Recipient</b>	Relatives	People in social and bodily need	Assessed people only	Client segment	The learning co-citizen

In our view, the thoughts on rights are closely associated with the category 'Professional' (treatment relations) and the 'Service management' (columns 3 and 4). Solidarity thoughts are more closely associated with informal care and lifelong learning and participation (columns 1 and 5). This is reflected in social networking, focusing on bridging the gap between informal care and public service that supports people with disabilities as co-citizens (see Chapter Six). Charity is placed as informal care and religious (columns 1 and 2). The model provides an overview of care paradigms but one of its weaknesses is that it does not include voluntary social work since informal care is associated with the family sphere.

Much disability care is based on the church, and in the Netherlands much care is run by church organisations. We do not, however, assign Dutch handicap care to being charitable for that reason instead of expressing thoughts on rights and solidarity. Denmark is a quite secular society but a

<sup>47</sup> The Danish researchers use the term 'deacony' in the Danish book.

number of Danish informants adopt a Christian approach to life; they do not however, cite their background as a particular reason for their care work.

### 9.3 The concept of care in research

Many researchers have been working on pinpointing the concept of care, and some conclude that care is characterised as being very difficult to pinpoint, and as crossing various sectors and spheres of society. Theories and concept clarifications often build on philosophical discussions and/or theoretical perspective about power, i.e. the discussions deal with care as an ethical issue or an expression of power. Other approaches to clarify care and care work are more based on social science and feminist views with definitions frequently being focussed on structural matters, defining care as work that extends family life, and thus work that is predominantly performed by women and resembling a number of unpaid job functions. Other approaches discuss care in the light of socialisation theories with female upbringing as the key theme for the furthering of care and the specific qualities of care.

We cannot go into depth about the different suggestions of care research as to the characteristics of care and care work but we can provide a few examples to illustrate the spectrum:

Marta Szebehely (1995) states that up until the 1990s, Anglo-Saxon care research notably built on theories on the basis of observations from private life (informal care) whereas Scandinavian care research has focussed on both formal and informal care. Until the end of the 1980s, the Anglo-Saxon and Scandinavian research developed without any contact.

From the Anglo-Saxon research, Szebehely refers to Abel and Nelson who define approaches to care – one being care as practical work and the other as emotional work. Abel and Nelson state that both approaches are too one-sided:

*Those who stress the practical content of care work consider care as female suppressing work that is filled with alienation. Care is seen as an involuntarily chosen activity forced upon you by material and ideological forces. Those who stress the emotional component stress the positive aspects of care work and view the provider as meaningful and purpose-building.*

The one-sidedness, according to Abel and Nelson, consists of the first approach neglecting the emotional aspects of care work while the second approach risks making care work too idyllic and neglecting the workload involved<sup>48</sup>.

Szebehely also refers to the anthology *Labour of Love* (Finch and Groves, 1983) that combines the understanding of care as salaried work and emotional work. The authors of the anthology underline that care is physical work, emotionally demanding, invisible and unsalaried, it is performed by women for other family members with whom they have loving ties – and occasionally it is also done after the love is gone because the women's responsibility of giving care is based on

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<sup>48</sup> The pros and cons of care work seen from the point of view of how work is perceived by the care provider are discussed by Jensen and Hansen (2002). They state that job satisfaction is a problematic indicator in the discussion of quality because satisfaction is very much about expectations. The care providers may be very satisfied with their work, which involves significant burdens, and thus job satisfaction is only one of many factors that relate to the care work qualities.



‘compulsory altruism’, according to Szebehely who refers to Land and Rose (1991). According to Szebehely, Land and Rose argue in favour of a public alternative to informal care:

*but even this research is one-sided too. One one-sidedness has a centre of gravity at the care givers, i.e. the women who take care of the family’s children, sick and old people. The researchers are not interested in the perspective of the care recipients and do not take into consideration both sides of care relations* (our translation).

According to Fiona Williams, the last 30 years of academic care research has developed a number of overlapping paradigms. From the 1970s, research on informal care took two different paths: one dealt with emphasising informal care and the other dealt with feminist research with a view to uncovering gender differences in labour tasks and the public-sector’s role in maintaining the status quo: “*Central to this was the concept of care as (oppressed) labour and the political demand for the recognition and reward of carers*” (Williams, 2001: 475).

In the 1980s, the paradigm changed from the fight of the female movement against oppression of women to “*the celebration of women’s difference and a woman-centred culture. The focus of care shifted similarly to an investigation of the meanings of care for women, for their identity, and for their view of the world*” (ibid: 475).

In the 1990s, the focus shifted again to differences. Williams refers to a ‘paradigm of difference’. One path of the paradigm was largely influenced by marginalized people (people with handicaps, lone parents, etc.) The relations of power in care work were the focal point. Another direction during the 1990s was an attempt to solve the conflict between care ethics and ‘an ethic of justice’ rather than discussing care in a gender perspective. A discourse emerged which viewed care as part of a democratisation process and understanding of citizenship. Williams quotes Tronto: “*Care helps us rethink humans as interdependent beings. It can serve as a political concept to prescribe an ideal for a more democratic, more pluralistic politics.*” (Quoted in Williams 2001: 477).

Williams also mention the discourse about interdependency. She refers to user discussions (primary representatives of ‘the paradigm of diversities’) and refers to Wood:

*Disabled people have never demanded or asked for care! We have sought independent living, which means being able to achieve maximum independence and control over our own lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our life* (Quoted in Williams 2001: 478).

Sevenhuijsen suggests that “*an ethics of care would replace the idea that dependency forms an obstacle to autonomy with the concept of interdependency and recognition of the ways in which good care can contribute to behaviours and choices which enhance people’s feelings of self-respect*” (Quoted in Williams 2001: 479).

Much of Scandinavian care theory refers to Kari Wærness who distinguishes between care work and personal service and applies the distinction to associate her care concept with the question about power and the asymmetry of relations. Wærness views care work as work done by the care provider on behalf of the care recipient, because the recipient is not able to do the work in line with generally accepted standards; while personal service is work that the care recipient could do himself

and where the care worker is secondary. According to Karen Jensen (1998), Wærness thus ties care work to the norms about being able to help yourself and the relational factor is decisive with regard to the type of care work: *“Thus, the superior or subordinate characteristics of the care work (not the job content) determine whether the care worker performs care work or personal service”*.

Szebehely (1998) challenges the reasoning of Wærness:

*Although the recipient often is subordinate to the care provider, then this relationship is not always the case; the balance of power between people is not always determined by physical power. Class is another important factor. A salaried care worker may be in a class-based subordinate position relative to the recipient of care in spite of the elderly person being unable to perform the tasks done by the care worker”*.

The quote is about elderly care but in our view it is similarly relevant in disability care.

Szebehely's understanding of the relations of power between the recipient and provider of care as something that is more complex is, we believe, not just a theoretical possibility but real in a complex late modern welfare society. With the current and especially future generations of elderly and handicapped people, care workers will meet wealthy, well-informed, critical and demanding care recipients. With current developments concerning care recipient's enhanced possibilities of choosing and possibly employing a personal helper (through direct payment schemes), and complaint possibilities, influence on action plans, etc., relations may be exploited by stronger recipients of care who will obtain a fairly powerful position vis-à-vis the care provider.

The modernisation of the social and health area in the past 10 years thus questions the asymmetry view of care relations although it has been criticised for putting weak citizens in a difficult situation despite ongoing steps to involve the users, make services optional, and introduce self management. Williams (2001) underlines the paradox:

*For whilst it empowers disabled people by giving them choice and control, it does so by repositioning them as active consumers of welfare, reinforcing the commodification of welfare services. In fact, in practice, as Tom Shakespeare (2000) points out, relationships between disabled people and personal assistants are generally marked by mutual respect and shared negotiation”*.

Jensen (1998) draws attention to Wærness' distinction between care work and care. Care is associated with ideas about

*doing what is best for another person whether guidelines for what is “best” exist and who is to judge whether that objective is met. The separation of care from care work targets this normative problem because we are able to determine when there is a risk of not providing what is best for the recipient, i.e. when care work is done without care.*

In her thesis Jensen refers to Svante Beckman whose views are based on generally accepted norms of being able to help yourself. According to Jensen, Beckman sees care as what it takes to bring a person back within the accepted norms after having crossed them. This perception of care, Jensen says, may also apply to the definition of social policy. While Wærness's definition points to the

balance of power between the care provider and recipient of care, Beckman's definition stresses a different kind of power balance (society's ability to maintain standards for acceptable living). Thus, both Wærness and Beckman believe care is embedded in asymmetry and power and they are not particularly optimistic about care as a potential medium for equal and democratic developments.

Szebehely's perspective is a challenge to Wærness' care perception: The relation between care provider and recipient of care is obviously not an unambiguous power relation. If you go one step further and follow Beckmann, you may point to the importance of social reality but – we believe – not solely as a social power factor that defines the care function and brings people back who have gone astray. We want to underline social reality as a condition for care provider *and* recipient and their relations and interactions. Social reality may suppress and curb both parties living their lives but also provides development opportunities for the parties – individually and in their relations, and we stress that the parties contribute to the creation of social reality. The discussion about the embedding of care in the social reality is frequently given too little focus or completely ignored by care theories and thus reduces care to a matter between the provider and recipient of care.

#### **9.4 From care to pedagogy – thoughts about developments in Denmark**

This research project *Care Work in Europe* examines 'care work'. As explained in other reports the 'care' concept poses problems in various ways<sup>49</sup>. In Denmark, the concept is used as either a social policy concept of elderly care and handicap care or associated with something else such as nursing, expressing the special way of performing this work (cf. Wærness' expression "care rationality" that has significant importance in Scandinavian care discourses). This perception of care as something associated with various disciplines was also found in the project's study of elderly care (Johannsson and Moss, 2003).

Within the disability area, the term 'care' is particularly problematic. In the handicap area in Denmark, the pedagogues are by far the biggest group of professionals and their work is considered to be *pedagogical* work (care which designates specific basic, daily tasks is just one of the qualities of pedagogy). We will examine the Danish approach a little closer as an example of care work as pedagogical work that is done by pedagogues with the help of assistants. The following also provides a picture of past institutional conditions, which had a big impact on the present understandings of care<sup>50</sup>. We name the section 'From care to pedagogy', which should be taken with a pinch of salt because it expresses a more linear approach than we actually apply to these developments.

To understand the importance of pedagogues making up the majority of the staff in this area in Denmark and to understand the current principles and values of the area, a summary of past developments is helpful. Until the 1880s, care for people with reduced mental abilities was an 'educational project' or what we also can describe as a pedagogical and psychological matter although it involved different values and methods than today. From 1884 to 1970, medical doctors dominated care management in institutions for mentally handicapped people<sup>51</sup>. Mentally

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<sup>49</sup> See for example the research project's first consolidated report "Mapping of Care Services and the Care Workforce" which pinpoints care as a domain with elements from social, health and educational areas (Moss, 2002).

<sup>50</sup> Concerning integration ideals, etc., the development largely resembles developments in Sweden. According to Tøssebro (2000), the de-institutionalisation, normalisation and decentralisation have enjoyed a broad-based international trend, notably in North Europe and North America.

<sup>51</sup> The timing of developments from ideals about raising/educating mentally people with disabilities to medical treatment coincides somewhat with that seen in the Netherlands (Gennep and Hove, 2000)

handicapped people were generally placed in large so-called 'central institutions'<sup>52</sup>. They were grouped in these full-service institutions and separated from the rest of society and underwent medical treatment. In 1952, an association for parents was established which gained significant political influence. Its influence, for example, led to the introduction of a new law on care for mentally handicapped people in 1959. The law confirmed that care of mentally handicapped people should be individual and voluntary and based on the key words of equality, equal rights and normalisation<sup>53</sup>. The altered political views about mentally handicapped people paved the way for fresh theories and other groups of professionals than those with a background in natural science (Kirkebæk, 2001).

In her thesis Kirkebæk writes that mentally handicapped people, from 1855 to around 1890, were going to be rescued by way of pedagogical measures and skills and brought back into society (but based on different values and methods than in current pedagogical practice). From 1890 to around 1950, society was going to be rescued, Kirkebæk writes, from the mentally handicapped by way of medical and biological measures and skills, and from 1959 to 1970 the quality of life of mentally people with disabilities was to be rescued by legal, pedagogical and psychological measures and skills that placed mentally handicapped people on a par with the rest of society (Kirkebæk, 2001).

Øgendahl writes that the sector enjoyed its most prosperous time during the 1960s. In a very short time, the mindset changed markedly. Mentally handicapped people were now to be visible after having been kept in the dark in isolated and remote full-service institutions for a hundred years, and the construction of community institutions (homes for elderly people, leisure-time homes, schools, etc.) was initiated to integrate the mentally handicapped into society again. The objective of the 1959 law to create a near normal existence for this group, however, was only partially met during that period and was not realised until the transfer of care services to the counties and municipalities in 1980 (Øgendahl, 2000).

The new thoughts on care led to the establishment of genuine education for staff in the sector of care for mentally handicapped people. That was in 1961. Combining theory and practice for three years, education could make you a care assistant. Thanks to the education, the staff became far more pedagogically-oriented than in the past and the changes were cemented thanks to the merger of the education for these care assistants with that for pedagogues working with young children at the beginning of the 1970s (Øgendahl 2000)<sup>54</sup>.

Some of the large institutions still exist but since 1980 the counties instead of the state have run them. The number of residents at each institution has been sharply reduced; the institutions have been modernised, with small-scale, independently run units replacing old dormitories. One of the

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<sup>52</sup> In 1969, 22,000 people were under treatment from the sector with 9,000 in centralised institutions. The estimated total of mentally handicapped people in Denmark at that time was 50,000 (Øgendahl, 2000).

<sup>53</sup> The 1959 law introduced compulsory education of mentally people with disabilities in line with other people and the mentally handicapped were also given voting rights if they were not incapacitated.

<sup>54</sup> As mentioned elsewhere in the report, the pedagogue education went through yet another reform in 1992 into a generalist education covering all ages. Pedagogues work in day nurseries, kindergartens, schools and leisure-time institutions, residential (24-hour) services for children and young people, with social work among young people and adults and all groups of handicapped people. This educational background of the single biggest staff group working with care and pedagogy for handicapped adults has undoubtedly had significant impact on the understanding of care and pedagogy in the area.

pedagogues working at a large institution<sup>55</sup> was asked about the importance of the organisational and attitude changes that have led to the sites mainly employing pedagogically trained staff to perform care and pedagogical tasks and being pedagogically instead of medically run. He confirmed that the staff and management changes had had significant impact:

*They are two fundamentally different ways of dealing with people and this is one reason why more and more pedagogues than care assistants [plejere]<sup>56</sup> are entering [the work]. They represent a different mindset. It is not that the care assistants are not excellent people but they have been trained for something else. We are thinking about development and they are thinking about illness. We do not think about how people get well. That is the entire difference, I think.*

A male pedagogue, working at a day care centre for severely mentally handicapped people says that:

*the view on mentally handicapped people has improved a lot. You can read how they were perceived back in 1960. [...] Then it was believed that you could not make any progress with them, with our users. They would remain in the same place. I have read the views of the principal at Sølund at that time, and they reflected that opinion. I have read about it in some old material, when I went back to examine stuff. [...] The ethics have certainly improved a lot [...] and the aim is to achieve progress. Fortunately, this is the current view – that they are able to make a little progress. It is about opening your eyes to what kind of development they can achieve [...] and then to be patient, as much as necessary.”*

The above quotes from two informants of the Danish study provide a positive view of the development and tally with our general impression based on empirical findings from the study. The quotes, however, contrast with the concerns raised by Kirkebæk (2002):

*The question we should ask ourselves today is whether we are agreeing so much on ideology [normalisation] that we cannot muster a broad-based fight for utopia? The period of consensus that we are experiencing may be more dangerous for people with disabilities than a period of battle as the one, which developed in the 1950s and 1960s. When consensus rules, there is an imminent danger of uncritical indifference.*

## **9.5 Care and pedagogy in a phenomenological perspective**

Section 9.3 explained how care research has largely been trying to pinpoint and define the field of care and it is quite clear that this is a very difficult research field. Literature also shows that research is characterised by very different epistemological interests. The question about women's conditions are, for example, discussed in the light of the repressive mechanisms of unsalaried work and the importance of the informal qualifications that are introduced into the work by women owing to their gender/upbringing. Our study underlines the relevance of these discussions but it also highlights the importance of a view that unifies work and private life in new ways.

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<sup>55</sup> The institution concept has been removed from the legislation in force. We apply the concept in its sociological meaning.

<sup>56</sup> This education (that applied to quite a number of male students) was abolished in 1992 and substituted by the education programme to qualify as a 'social and health care assistant'

Much research and debate are affected by the industrial society's perception of salaried work as qualitatively different from family life and leisure time and from action driven by a vocation. Salaried work is largely viewed as selling labour to finance family life and leisure-time. This remains a relevant perspective but it should be, we think, supplemented by a contemporary perception of work as a source of personal satisfaction and without any sharp distinction between what is done for money and what is emotionally conditioned. The informants of our study largely seem to experience such a dual purpose of their work: it both represents a necessary source of income *and* gives meaning to their life.

We will not examine these discussions about care any further or provide more theoretical constructions of care. Since we have carried out this research project for several years working with empirical studies, we will only supplement the existing theories by presenting a number of thoughts about care and pedagogical work that we have drawn from practitioners, trainers and policy makers and their views about pedagogical practice, care and care work<sup>57</sup>. The key issues, we believe, are therefore *their* views of the 'what and why' of care relations.

#### ***9.5.1. Care as a diffuse issue - defined by what it is not***

The three national reports reflect a tendency for the practitioners perceiving care as being delimited by nursing, social service and pedagogy. Some of the Swedish informants thus explicitly underline, that they do *not* perform nursing but care, support and service. This definition thus delimits care from nursing (which they do *not* perform) and support and service (which they provide *together with* care). The research project's case study on elderly care also made it clear that the informants largely define care by what it does not comprise, its borderlines and associations (Johansson and Moss, 2003).

The informants in our study of handicap care describe care in somewhat diffuse terms and some perceive care as *doing something for someone*. Their views are, for example, reflected by the Swedish informants' discussion about not becoming *too* care-oriented because you have to ensure that the user manages as many tasks as possible. The Swedish report quotes a care worker saying that she hardly thinks about working with care. Her work is about helping a group of mentally handicapped people to function socially in the framework of ordinary work life; she hardly sees it as care because of the high skill level of the group of people with whom she works.

Some of the Danish informants were directly asked whether they distinguish between care and pedagogy, and the answers provided also reflected a diffuse perception of care. Being associated with pedagogy, care is almost about serving people's basic physiological needs, i.e. food, clothes, hygiene, etc. while specific ways of performing the job are considered pedagogical practice.

In brief, the study informants understand care as doing something for other people. The care workers in the Netherlands and Sweden refer to care as something *not* being nursing, support and service, and the pedagogues in Denmark refer to it as *not* being pedagogical practice but rather a kind of practical assistance, but the informants do not provide us with any specific definitions of care. To approach the concept further we will take a closer look at the information given by the informants about their day-to-day tasks, assuming they perform care work - thus, their statements about their work tell us something about their understanding or definition of care work.

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<sup>57</sup> For several years we have been involved in empirical care studies. The process includes our studies of the child and elderly care areas. The chapter draws on all this knowledge but we only include examples from the case study in the context of handicap care.

Following this presentation of the informants' statements (mainly practitioners) concerning their specific work we will then present the information given by the practitioners about theories and methods of care and finally we will present a number of 'abstract figures' (abstractions) on the basis of the material. As already mentioned, we will closely follow the empirical findings of our study and take the opportunity to supplement, confirm and possibly even challenge existing theories.

### **9.5.2. Care work defined by its purpose and content**

As already mentioned, it is difficult and maybe even impossible to give an ontological account of care or simply pinpoint the essence of care although most people know what care is about: "*Anyone beyond the first years of infancy has lived long enough to know what receiving care is about*" (Noddings, 1995).

We do not doubt that the informants of our study know what care is about but apparently their knowledge is so self-evident and taken-for-granted that they do not provide any explicit definitions. They refer to specific tasks and relations instead of abstract ideas. In order to determine the phenomenological essence of care and care work, we have examined the large number of different statements produced by our study with respect to the purpose, characteristics and intentions of the work. We include some quotes, which *illustrate* our interpretation. Taken separately, they are not intended as representative of the individual countries and as the basis for our conclusions.

Briefly put, the practitioners describe the purpose of their work as being to ensure a way of living for handicapped people, which is virtually independent, i.e. ensuring a life that is as normal as possible, and creating a comforting environment that provides opportunities for quality of life (security, equality, influence and development).

The work content is described in various ways with details about meeting handicapped peoples fundamental physiological needs. They talk about providing food, clothing, health-related matters and medication. According to the practitioners in the three countries care is also about creating comfort, happiness, laughter and cosiness (quality of life). Many informants underline that that is one reason why it matters to keep an eye on and interpret the handicapped person's state of mind and signals.

*We are incredibly happy about the big corner sofa. We used to have two small sofas but it is really important to be able to sit close together with the residents, because in this context they are bodily and emotionally like children. [And one of the residents] he just loves having his hair caressed and someone else, the big guy over there, he likes to spend 10 minutes every night with his hand in my lap while I caress his chin. Others do not tolerate more physical contact than just a brief pat on the shoulder.*  
(Danish female pedagogue, housing unit)

The practitioners also say that their work is about meeting people's development and recognition needs. They talk about exploiting the handicapped person's resources, showing respect and attention, creating motivation (and being attentive to small things and minor progress), building good relations, respecting the need of having a private life, supporting development and understanding the handicapped person's perspective and feelings.

Moreover, as this Dutch practitioner explains, their work is about creating structures in time, space and tasks, and to provide people with influence within this framework.

*Every day you have to be aware that you are in control of your clients, but at the same time you have to explain things to them and give them some kind of structure, like tell them when they need to get up, otherwise they stay in bed all day. So we control their daily structure, but consider each client separately as well.*

Moreover, the practitioners stress that their work is about compensating specific handicaps and alleviating problematic behaviour with a view to preventing injury and lack of prosperity for the individual and the entire group. The work done by the practitioners ranges from functioning as another person's arms and legs to embarking on specific upbringing/education.

Care work is about problem solving and testing limits. Care work thus presents ongoing challenge and development of competences. Practitioners talk about being creative and finding alternatives in problem solving to alleviate and prevent injury owing to handicaps, though problems quite often are defined by care workers and not by disabled people themselves.

*Basically the limit is, at least for me, the moment a client goes over the limit set by society, and those aren't very wide limits, then my limits have been reached too.*  
(Dutch practitioner)

Care work is also about establishing learning processes (learning something under specific conditions, and learning to decide for yourself).

*They've very much grown up thinking "the group leader decides what's right". So it's tremendously difficult to let them choose for themselves now, because basically they've never learnt that. So there they have different issues from the people here. Here parents are much more critical and are very quick to say things like "what about this" and "why are you doing that?" And that doesn't happen next door. Of course, those parents have also grown up in that culture of "we decide".* (Dutch practitioner)

Care work is also about establishing communities, networks and relations, preventing solitude and involving the parents. Thus, care is underlined as an aid to create development and communities.

*In the past, everything went through us, through the staff and now our group has almost disengaged itself and socially we are functioning very well, we have great benefit and joy from each other and all this is a great experience for everyone involved* (Swedish care worker).

Finally, care work is to advocate for the handicapped person by taking care of the person's rights and involving him or her in decision-making.

The brief account above of the practitioners' statements about care indicates that the study informants understand care in practice as to:

- Fulfil the recipient's fundamental physiological needs and needs for protection
- Support and build resources that relate to people's development and self realisation



- Respect and value the recipients as unique individuals and qualify them as self-directing persons
- Support recipients to engage in social communities.

### 9.5.3. Theories and methods of care work

The Danish informants put much greater emphasis than their Swedish and Dutch counterparts on their knowledge about various theories and methods of care and pedagogical practice. The following details are about Danish issues.

A male pedagogue, who works in a housing services unit, provides the following statement, which is fairly characteristic of the Danish informants:

*We are working within a number of special interest fields that we use in different ways and for inspiration but which are not pedagogical systems like those in the old days [...] in the old days, pedagogy was just one thing but today there is a large range of goods available on the shelves that allow us to do this in that situation and something else in another situation, e.g. “behavioural modification” (that we usually do not like) and “it matters-principle”. In this situation we may apply communication theories and in a third situation we will do something else. In this way, we have gone from one specific kind of pedagogy to a shelf full of options that are available when you need them.*

A female pedagogue employed at a day care service unit explains as follows:

*We are probably using several different theories. We do not use one specific [theory] ... I make use of basic views, opinions about life, and you know the tools of your trade.*

A male pedagogue at a day care unit says: “I certainly do not go for a specific theory but I have clearly been inspired by others”. Inspiration for this pedagogue comes for example from Erling Lars Dale’s theory about how people develop theories about themselves and Gardner who

*has significant impact on our universe. The uniqueness of each person is the focal point and that fits nicely with what we are doing, but we would never become a Gardner-based institution, or based on Reggio Emilia, that is not the case.*

The above shows that the pedagogues mention the very popular approach referred to as ‘it matters’. Behavioural modification is mentioned along with the theories of the Norwegian Erling Lars Dale, Howard Gardner as well as Reggio Emilia pedagogy. The Danish national report shows that the pedagogues talk a lot about neuro-pedagogy, the US-inspired pedagogy of ‘Gentle Teaching’ and the Dutch origin Marte Meo approach.

Various forms of theoretically based practice are mentioned but usually with a pragmatic approach to theories and methods. They combine the most useful things in each instance, which harmonise with the fundamental view on people that has developed in the specific staff group.

The pedagogical practice with the greatest impact in the last 20 years has mostly been based on the principle ‘it matters’, which we will cover in more detail: this is not a genuine pedagogy or a tool but rather a description of working principles concerning people with developmental handicaps. The key thing is to believe that it matters – that opportunities are present however serious the

mental or physical handicap is. The approach is based on humility, absence of power, and unconditional acceptance of other people's behaviour. You have to meet another person at the point of that person's development, feelings and temperament. Thus, the human being is viewed as a coherent person and specific skills, resources or problematic behaviour are not therefore focal points. You must be able to accept and handle all kinds of feelings. According to the 'it matters' approach, employees must acknowledge behaviour that is generally considered as problematic and unacceptable when it does not present any serious danger to that person or anyone else. The employee must provide motivation for different behaviour while maintaining respect and fundamental acceptance at all times (Larsen, 2001).

The 'it matters' pedagogy applies different tools for planning and pedagogical analysis. Either an ordinary action plan or an extended version is used. The ordinary action plan contains a problem description, behaviour details, hypothesis, objectives, action plan, success criteria, emergency solution, and evaluation and attitude discussion themes. The extended action plan further incorporates functional details, development details, social summaries and pedagogical analysis on the basis of medical, psychological behavioural and pedagogical aspects. The extended action plan model also features the preparation of problem description, search model, analysis, objective and an actual action plan.

Communication is a key aspect of all care and pedagogy but it is notably stressed in conjunction with the 'it matters' pedagogy. Work is done to develop communication tools such as pictograms, photo tables, specific objects and the use of colour systems as orientation aids for people with mental handicaps, and the efforts include speech-supporting sign language (not the sign language used by deaf people).

#### ***9.5.4. Abstractions derived from informants' care understandings***

From the way in which the informants refer to care, we have developed a number of abstract 'ideal models and figures', which do not exclude one another. The informants' statements about care and care staff are frequently characterised by elements of several figures that are separated here solely for analysis purposes. Below we will initially review figures that relate to overall thoughts on care and figures that describe the perception of the care worker as an abstraction / an 'abstract figure'.

##### ***9.5.4.1 Good family life***

All three countries provide a comparison of care work and family life, a comparison that is mainly made by practitioners. All informants who compare care work with family life stress that the care workers cannot replace the family of a handicapped person. In this context, 'family' is simply a model of good care work. Comparison is made with the committed relations of family life and the comfort of a family with a mutual interest in each other, mutual caring and sharing of practical tasks according to the individual person's skills.

*I see this as a big family. Obviously with everyone as individuals, just like you have in a family. Seeing who works or lives nicely together and what sort of a set structure you have to aim for; you have to look for a set structure to encourage tolerance. So that people don't bash each other's heads in. I normally have to deal with that quite often. That's why I compare it with a family. Not that I want to make it seem like a family, because it's definitely not. And I'm certainly not aiming for that. But you notice that that's rather the way of things here. And I think that's really fascinating. And you give support in that. (Dutch care worker)*

*It's not a real family, but that's what it feels like. Everything runs smoothly. Some of them need encouragement with certain tasks, but that's what you're supposed to do. This is not a hotel, but their home.* (Dutch care worker)

*Like trying to move away from the nursing approach as much as possible - this is an ordinary home and we behave just like in any other private home. That is the key to it all, I think.* (Swedish housing service worker)

Our research does not indicate that the care of seriously handicapped people is perceived as a replacement for family life, e.g. with the purpose of bringing more women into the labour market, which is somewhat the case in elderly care (Johansson and Moss, 2003). The difference between handicap care and elderly care or childcare may stem from handicap care having been heavily institutionalised for many years. In the past, the families would hand over a handicapped child to an institution and were asked to forget about their child. The family was not expected to take care of things, and in some periods, society wanted people with serious handicaps to be segregated for the protection of society. Thus, for historic reasons, care of seriously handicapped adults is mainly seen as a task for society and the family involvement in recent years is largely an attempt to create quality of life for handicapped people while recognising that we all need an informal social network. In simple terms, public care of handicapped adults is not seen as primarily a family responsibility. It is rather the opposite, with family involvement seen as improving public care.

With family life as the reference point, you could say that care and care work are about establishing an environment and social relations with as much resemblance as possible to 'the good family life'. The key words, which can be applied, are individuality, community, protection, understanding and respect, commitment and continuity (staff turnover may impede continuity although it remains important for the practitioners).

The characteristics of the 'good family life' model are occasionally referred to as female and male qualities in various research contexts. But the practitioners in our study speak very little about gender and sex roles. As a rule there are no explicit mother or father roles in the care understanding based on the family model.

#### 9.5.4.2 Protection

A number of statements point to a perception of care being largely about protecting handicapped people, including protection against discrimination and various risks that exist outside the specifically organised framework of the institution. The Dutch informants, however, only explicitly and significantly reflect care provided for the purpose of protection. These informants stress this perspective as extremely important. The Dutch report refers to a 'protection paradigm' and says for example: "*We pass on the knowledge that has been built up, the positive sides of providing shelter in nature, in a created world where people can be happy and safe and are allowed to flourish*".

*Now we're working hard to put them back into society again. At the same time, violence in society is increasing and many parents wonder if it's wise to expose those vulnerable groups to that sort of society and how you can then ensure their safety.* (Dutch policy maker).

*Withdrawing into nature can have a healthy effect, perhaps even permanent. In the community vulnerable people can be confronted with the terror of the neighbourhood.*  
(Dutch trainer)

Discourse on protection also shows reflections that care has a social policy aim protecting and guarding other citizens of society against the people with disabilities 's behaviour. These statements, however, do not refer to the care workers' personal views about job content but their experiences of other people and their concerns about having people with disabilities as neighbours and about sharing residential areas, shops, workplaces, playing areas, etc., with people with disabilities.

The Dutch informants' greater focus on protection than the informants of the two other countries may be related to the Netherlands being in the midst of a 'de-institutionalisation process' that took place in Sweden and Denmark some 20 years ago. In these two countries, however, the informants talk about the de-institutionalisation having created a threat of solitude for people with disabilities and that care workers should pay considerable attention to this issue. Thus, the statements are not about protecting people with disabilities against people without disabilities but against isolation of other people.

#### 9.5.4.3 Citizenship

Another abstract feature of the material is what we refer to as citizenship. In Sweden and Denmark, the approach stems as far back as to the normalisation debate that began in Denmark as early as the 1950s. Sweden and Denmark have come relatively far in decentralisation, deinstitutionalisation and social rights services with the aim of ensuring a near-normal life for the individual<sup>58</sup>. The same line of thought is currently found in the Netherlands (Gennep and Hove, 2000).

The Danish national report states that the individual according to the citizen perspective is not defined as a pupil, client or patient placed within an institution but as a citizen using a social service. A natural consequence of this perspective is the abolition of the institution concept.

*At the beginning, there were rules about managing your pension payments when you used 24 hour services (i.e. you would receive your pension but had to pay rent, laundry and cleaning in line with other people). Thus, the service law that came into force in 1998 abolished the institution [...] It is quite an achievement in the way that you perceive people with handicaps. This does not happen overnight. First, you begin by changing your attitude towards people with handicaps, to saying that they are independent individuals who should not necessarily be treated as a group. (Danish policy maker)*

Policy makers and trainers in particular view care from the perspective of managing co-citizenship. But the same perception is communicated more indirectly by the practitioners in all three countries, and involvement and co-determination are performed in practice but most frequently at very specific levels because most of the practitioners work with seriously handicapped people .

*We always look at it from the resident's perspective. We try to pick activities the residents will enjoy and we take into account what is feasible for each client. We also*

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<sup>58</sup> More details about 'normalisation discussion' are found in Chapter Two, section 2.3.

*have a council in which residents can have a say about certain matters. We have a system for that. We discuss all sorts of issues that are relevant to our residency. For example rules of conduct for staff and clients. They came up with a whole list of issues about that. They also have a say in the summer programme; whether or not they'd rather work or recreate. With special occasions, such as parties, they have more input. For example, with the celebration of carnival. Ultimately, we try to have the residents organise as much as possible themselves, such as refreshments. (Dutch care worker)*

The citizenship approach to care expresses a perception of care as something that differs from family care. It is not a supplement or replacement because the family cannot handle the task. It is different because it offers something else than that provided by family life.

Citizenship partially contains the same elements as 'the good family life' but is targeted more on the individual's social rights and position in society. The concept of inclusion is associated with this understanding, i.e. that people do not only need nursing and the fulfilment of basic needs, food, hygiene, security, emotional contact, etc., but that they also need to participate in social life. In this perspective, care is focused on the handicapped person's voice, which is acknowledged in social debates, and deals for example with cultural productions for and with handicapped people.

*What matters most is participation and availability, that is, the respect for the individual and the person with a physical handicap and enabling participation in every aspect of social life. Being a fully-fledged citizen and being as available as possible. (Swedish policy maker)*

*In my view, it is [great] with the current pension legislation, we do not have to depend on other people's favours and pocket money, but we do receive the same pension payments as everyone else in this country and we can buy the services that we need during life. As a handicapped person you are given opportunities to shop on your own. (Danish policy maker)*

The citizenship approach to care challenges by and large all sectors of society (work, housing, education, traffic, health, culture, etc.) and the views of citizens. It assumes a strengthening of people's social networks and that practitioners are competent social networkers. The Dutch researchers write as follows:

*It should also mean the mobilisation of 'the other party', the environment, the institutions, the informal network. In the case of most professionals this competency is, as yet, underdeveloped.*

#### 9.5.4.4 Services

Some informants refer to the systems as service providers and to care workers as service performers. These concepts of care are notably applied by policy makers and trainers who discuss care in various ways as a system that consists of a broad spectrum of individually adjusted services for the handicapped person to choose between. Thus, care is viewed as a *service* that can be purchased by the independent consumer. With care as a product, which is supplied by a service performer and received by a consumer, care in its ideal form is closely associated with privatisation

and commercial thinking i.e. care is a service supplied on market conditions and subject to free competition.

*We are for the change towards needs-based service provision or demand-orientated work or whatever you want to call it. Clients are more and more in a position to obtain care themselves from providers. As an institution you have to respond to this in a more and more commercial way. (Dutch policy maker)*

Care as a service takes up an important position in the current handicap policy in all three countries. It is a result of the contemporary welfare policy but it poses a problem when it comes to care for people with seriously reduced abilities.

The Swedish researcher Szebehely (1995) criticises this line of thinking. She refers to the Swedish LSS law, which came into force in 1994, and says that the law has strengthened the position of handicapped people. They have become users of a service instead of recipients of care. She mentions “the independent living movement” that employs its own assistants and look on themselves as employers. The user perspective of the handicap movement is compared with that of the provider perspective of care, which forces us to examine ourselves as providers and our perceptions of ourselves and those in need of assistance. The provider perspective implies that the giver is the strong person who assesses the weak person. According to the user perspective, the person in need of help is ordering the services that he or she believes there is a need for. The provider perspective is based on the recipients of care and help; the user perspective involves users, service providers, consumers and clients.

None of the perspectives are problem-free. The provider perspective involves a risk of the recipient of help becoming an object for other people’s decisions. The user perspective assumes that everyone can be a user, capable of taking responsibility for his or her own situation (Szebehely, 1995).

Furthermore, care considered as a service is closely associated with the perception that all people are able to perform the user/consumer role. We can also see a tendency for ‘care as a service’ to be associated with a perception that contrasts the individual with the collective in a good-bad dichotomy, with individualisation being the current dogma.

*We really want to work on a much more individual basis. You just can’t avoid all group arrangements. That also means that people are more or less forced to live together with others. You can’t pick and choose. (Dutch policy maker)*

Some informant link care considered as a service with the question of education. A number of informants say that education is important but a informant says that education may counter the ideal of equal and dignified treatment of all people in society. As discussed elsewhere in the report, it is believed, according to this line of thought, that education results in all-knowing care workers and that this will undermine the equality of the provider and recipient of care. In this context, we refer to the opposite viewpoint, i.e. that education prevents repressive behaviour and the use of force by care workers because the training partly increases their knowledge about other possible actions in difficult situations and partly prepares them to be less private/mothering in their work.

The concepts of 'good family life', 'protection', 'citizenship' and 'service' relate to the understanding of care and notably its social purpose. In the following, we will examine the concepts related to the care workers in the way the informants of the study understand these concepts.

#### 9.5.4.5 *The care worker as ethical human being*

With regard to the understandings of what care work is and what a care worker is, the material shows that the care workers in many ways see their function as that of 'a significant other', i.e. building relations that are valuable in themselves (besides being practical and providing social assistance). Other chapters reflect and provide details of care workers frequently mentioning protection, recognition, empathy and the like.

Through a number of different expressions we see an ideal model or rather 'an abstract figure' appearing in practitioners' narratives that we refer to as '*the ethical human being*'. The concept of 'the ethical human being' is broad and a more normative category than the concept of the 'significant other'. For example, ideas about dignity and dignified social relations represents another key aspect for the ethical human being. This matter is not a necessary condition for being a significant other (in theory, you can be a significant other in a fairly unethical manner)<sup>59</sup>.

Understanding care as being 'an ethical human being' implies that the specific care work is about acting like a person who meets another human being while recognising that person as a individual with similar worth as any other person. Moreover, this understanding implies that you will treat that person in the same way as you want to be treated yourself in the same situation. The Swedish report explicitly states that the question "How would I have preferred to be treated?" is asked by the staff in all care areas covered by the study. In this respect, it does not seem to matter that their work is paid. In this context, however, their relations are characterised by one party's work being part of the other party's personal life, which may affect the quality of care according to the informants. Generally, and in the specific care relations, the informants do not mention these tasks as work but as relations between human beings.

*In order to be a good carer or to be good to work with and with people on the whole, I think that you, you always have to go to yourself. And in that context I think, I said that before too, that, that it's important to work with yourself in some way. I don't mean that you have to go to a psychologist or anything, but that you in some way have a sense of empathy in yourself too. How would I like to be treated? If I were in need of such a large amount of, of support from someone else, how would I like to be treated? Since there is no difference between the needs of ..., a new-born baby and an old lady and a mentally handicapped person or a down-and-out person, they all have the same basic needs really. And I reckon that this is what is forgotten all the time. We have a need for this, the basic significance of being seen and maybe on some occasions to be given a hug and sort of to exist as a person, to be in contact with other people. (Swedish carer in a housing unit)*

Several informants express indignation with regard to the conditions facing handicapped people and the opinions communicated to people with handicaps. One of the Danish informants says that other

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<sup>59</sup> The question about dignity is stressed as a particularly important feature for the informants in the case study on elderly care (Johansson and Moss, 2003).

people frequently say that it is great that there is someone to take care of them (handicapped people), and goes on to say:

*But I am not taking care of them - I am living together with them. I am not caring, this is not the concept that applies, I believe. I try to live a life together with them. When I am here, I am living their lives, right.*

#### 9.5.4.6 The care worker as mentor

This is another ‘abstract figure’ in the informant statements – the ‘mentor’. Our informants do not make specific reference to a mentor, but the mentor concept, we believe, perfectly characterises statements in particular from the practitioners of all countries. An alternative label could be that of a consultant because this concept has gained momentum in recent years’ handicap policy developments and downgraded the past ideal figures of ‘the nurse’ and ‘the teacher’ (in a didactic sense).

*You’re not just a staff member in a team. But you also have to work more as a consultant and contractor towards the client. You consult with the individual client. You no longer have a fixed range of duties. (Dutch policy maker/trainer)*

The reason why we have not selected the ‘consultant’ concept is that this label does not cover what is communicated by the practitioners. Their statements show that they are not just working as consultants; the consultant provides information and guidance, means and methods for people who are expected to be able to make a qualified decision on the basis of this input. The consultant commands a professional responsibility that is not driven by personal commitment to any significant extent.

The information provided by the practitioners contains some elements of consultant work but goes beyond that as well. Thus, we have chosen the mentor concept as the ideal figure that appears from the practitioners' statements. The mentor is our concept of a person who applies his views and competencies to advise and guide another person with less knowledge and experience. The mentor also performs a protective function and the ‘mentor’ concept reflects the ideal of the practitioners: the care worker is a professionally competent person with mature views and attitudes who applies his/her respect for the handicapped person’s individuality and unique situation to assist that person by asking questions and by studying the person with regard to his/her needs and wants, thus involving that person in actions instead of acting on the basis of routines, and who is capable of maintaining a comforting and protecting routine and framework.

The mentor draws on his/her values and applies his/her professional knowledge. This figure is less ‘neutral’ than the consultant but is not possessive with regard to the person being mentored. Being a mentor and having a mentor constitutes a relation. In other words, the relational aspect is more important for the mentor role than the consultant role<sup>60</sup>.

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<sup>60</sup> The name of Odysseus’ friend was Mentor, and he provided parental advice and guidance for his son when Odysseus was away. The friendship is what separates the mentor from the contemporary consultant. In this context, it is irrelevant that the informants of the study are paid workers and that they stress that they cannot establish private relationships with handicapped people. What matters is that the quality of their work ideally should compare with the behaviour of a mentor.



*The social pedagogue education has been based on the idea that “we have been trained to ensure care for these people around the clock”. This is still the case but now we put greater emphasis on independence, involvement of the citizen’s wishes and we try to communicate that “You should not do it for them but together with them”. This is being discussed in the entire area, it is a development that is underway. This is not something that we can do ... you cannot decide that from 1 July 1998 we will do it like this<sup>61</sup>. (Danish policy maker)*

#### *9.5.4.7 The care worker as professional person with judgement*

The third abstract figure that we have constructed on the basis of the material is the ‘*professional person with judgement*’. The ideal is to offer care on the basis of the professional’s assessment when such assessment is made on the basis of that person’s ability to balance assessments and actions relative to universal and professional knowledge (theories) on the one side and the situation in question and the personal commitment on the other side.

*It’s always at 4 o’clock on a Tuesday, no other time. You can’t turn up at twenty past four and give them a shower, because they won’t have one. If they are an autistic person it can be like this. Everything that you do in a day is carefully detailed, well otherwise there will be anxiety and you start to sort of slide here and there. (Swedish care worker in a housing unit)*

*But the hard thing to protect yourself against is to avoid getting too private, you shouldn’t be like a friend, you should try to be professional in your work, but many users don’t have any friends and are so dependent on us, so they want us to be friends they say. But that’s not that good really because there’s something about friendship that erases boundaries and then, you have to retain some sort of distance. (Swedish personal assistant)*

In all three countries, the care workers talk about being professional and personal without being private. The study indicates that the care workers generally view their role as communicating a universal and technical professionalism on the basis of personality and personal assessments. Professionalism must not be dogmatic but should be present to prevent the care worker from effecting private assessments and actions.

*[T]hat’s how you think because you can get tired of using yourself up all the time. You have to think of what you say and what you do and that you don’t lose your temper and... You can’t get too private even if it’s like a home.*

*Interviewer: How do you deal with that?*

*Well, that’s something that, we’ve had some training concerning that, as simple as that I think. To distinguish between different things. What is usually said is that you can be personal but not private. (Swedish care worker in a housing unit)*

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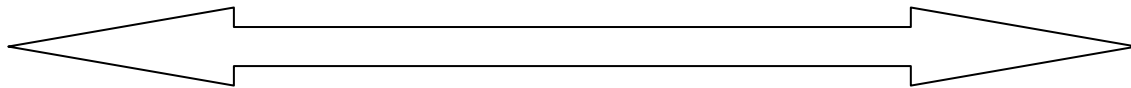
<sup>61</sup> The informant refers to the date on which the service law came into force.

It is difficult to say there is a purely professional side of the matter because professionalism in care work is associated with the personality of the care worker. But if we refer to 'pure professionalism' for illustrative purposes, we could say that it is weighted differently and associated with different values by the various care workers of the study.

With a view to illustrating the correlation between the personal and professional we will refer to a book that is based on a pedagogical development project in Denmark (Refsauge and Bak, 2001). This book applies a model with a continuum between professional dogma, representing one pole, and the private at the opposite pole. The authors put professionalism and professional identity (personality) in the middle, representing complementary factors: the professional factor ensures that the personal factor is not driven towards the private part while the private factor ensures that the professional competency is not driven toward professional dogmatism. The model can be simplified as follows:

Professional, dogma  
The private

Professional competency/identity



As mentioned in Chapter Five there are statements describing the care worker as an expert, a catalyst or a good-hearted person but in spite of the different perceptions of professionalism there is generally a clear tendency towards perceiving care as a combination of professional and personal factors in a manner where the two dimensions are complementary and provide balanced judgement.

#### 9.5.4.8 *The care worker as service provider*

We have outlined the perception of care as a service. One of the consequences of this perception is that handicapped people are perceived as consumers of a service; and the care worker is seen as the service provider who renders a particular service requested by another person and who ideally does not possess the appropriate answers or knowledge. Some of the informants who work as a personal assistant (they are employed by a handicapped person) see themselves functioning as a person's arms and legs. By this metaphor they downgrade their own assessment and decisions involved in their work. The service provider in charge of another person's arms and legs will do what he is told by the recipient. There is a risk that the care is not provided properly because care is also about giving what the recipient does not ask for. Following Wærness (see section 9.3), who defines service as the performance of tasks that you are able to do yourself, we conclude that the service provider as an abstract figure is on the borderline of the concept of care work/care worker as defined by our study.

## 9.6 Concluding remarks

Against the background of the practitioners, trainers and policy makers and their references to care we have provided a general outline of the understanding of care in the three countries. We have largely focussed on general features and subsequently proposed a number of overall intentions and categories according to which care is seen as measures intending to create good life conditions, recognition and prevention and that these can be seen in relation to rights, solidarity and charity.

We have discussed care seen as measures intending relationships with the quality of a good family life, and with access to getting help to build relations with one or more people. We have stressed that the references to family life should not be understood to mean that care is to replace family life but rather it should ideally supplement family life with alternative opportunities and support the building of social networks. We have underlined that the metaphor of family life does not involve a gender discourse.

Moreover, we suggest that care as described by the informants is characterised by an ideal of offering qualities related to citizenship (going beyond family life).

Furthermore care is also viewed as a service that can be chosen by the individual person/consumer.

The descriptions have provided an outline of the care worker as seen by the informants; the care worker is ideally an ethical human being, a mentor, a professional with personal judgement, and a service provider (who we place on the borderline of the care/care worker concept in consideration of care versus service).

Our analysis can be summarised as follows. Thoughts on care are generally characterised by the following three intentions:

- A good life
- Recognition
- Prevention of problems and alleviation of already existing problems

In a fairly general perspective we have found that thoughts on care are affected by different paradigms:

- Rights
- Solidarity
- Charity

Our empirical analysis points to four abstract figures of care:

- Family life
- Protection
- Citizenship
- Service

The empirical analysis also points to a number of perceptions of care workers. In terms of abstract figures, they are referred to as:

- The ethical human being
- The mentor
- The professional person with judgement
- The service provider (a concept on the borderline of the care/care worker concept)

The informants do not define care in any specific manner. Care is associated with and seen relative to other tasks. However, the descriptions of purpose and actual tasks show that the practitioners also mention the performance of fundamental physiological needs, protection, challenges, actions targeted on developing individuality and competencies to participate in the community.

These general features have led us to point to understandings that define care and pedagogical practice as actions performed on the basis of the care worker's professional and personal competencies and with elements of the following four items:

- Fulfilling the recipient's fundamental physiological needs and needs for protection
- Supporting and building resources that relate to a person's development and self realisation
- Respect and value the recipients as unique individuals and qualify them as self-directing persons
- Supporting recipients to engage in social communities.

## **Chapter Ten: Recruitment, current discussions and future directions according to policy makers and trainers**

This chapter deals with and focuses on the statements of policy makers and trainers regarding recruitment, current discussions and future directions in the handicap area. Up to now, we have only covered the themes that emerged in the interviews. However, other themes are of course on the agenda in the three countries. We stress that handicap policy as such has not been a focal point although we asked the informants about the policy during the study. In this chapter we focus on some of the recruitment questions, current discussions and future directions in the views of policy makers and trainers.

The policy makers, in particular, are key players in the performance of handicap policy, and their statements are therefore important. Thus, the statements from care staff regarding these issues are not covered; but in Chapter Three we examined how the informants with practical work experience are recruited to work with handicapped people. The teachers' thoughts on current educational issues and future directions are dealt with in Chapter Eight. Several of the previous chapters have discussed the question about recruitment, current discussions and future developments.

Some of the previous *Care Work in Europe* reports contain a general analysis of recruitment issues, current discussions and future directions in the three countries, covering the entire field of care included in the research project. The analyses can be found in the two national reports from each of the three countries - *Mapping of Care Services and the Care Workforce* and *Surveying Demand, Supply and Use of Care* - and in two consolidated reports ([www.carework.dk](http://www.carework.dk)).

### **10.1 Recruitment according to policy makers and teachers**

#### **10.1.1 The Netherlands**

Earlier national reports (see above) have as mentioned in the current Dutch report described how the population of the Netherlands is ageing, which may eventually result in a shortage of health care professionals. How quantity and quality measures are implemented, currently and in the future; workload and working conditions; and new target groups for recruitment (people who return to the labour market, people from minority ethnic groups and older people) are key issues.

The following is from the Dutch report's summary of the interviews with policy makers and trainers. The increasing number of people who need care and the decrease in the working population cause the quantitative issue in health care. In the next decades, many professionals will retire, and this loss will no longer be compensated by the entry of younger professionals. One of the informants suggested that the current largest group of care providers consists of women between thirty and fifty years old who have mainly returned to the labour market after a break for child rearing. This group will soon decrease. Nowadays, women continue working after having children and are all qualified. The group of unskilled women looking for a job in health care is therefore decreasing fast.

In order to ensure a steady intake of care providers, the participating policy makers and instructors focus on four main issues: working conditions, conceptualisation, further development of the profession and the role of senior care providers.

In terms of working conditions, salary and workload are the focal points. In the past few years, attempts to decrease workload and absence through illness have proven to be successful. However, there is a risk that these statistics might worsen again if the issue is no longer a first priority.

In terms of conceptualisation, the informants do not have any concrete recommendations, but they do think it is an important issue.

Part of the answer to this issue lies within the third issue; further development of the profession. Informants in general pointed out that care for people with developmental disabilities is not classified as a profession. It is divided into care providers, nurses and social pedagogues. There should be a general profile and more specialized education.

The fourth issue concerns targeting senior care professionals who are currently not employed in the field. This can partly involve paid workers, because a lot of people, who are older than fifty, are inactive but still available for the labour market. Also, volunteer work in informal care can be stimulated. There is a certain need for solidarity; not everything can be transferred to the younger generation. One of the informants also suggested recruiting more care providers from abroad.

### **10.1.2 Denmark**

In the following section, we will focus on recruitment of pedagogues for the handicap area but not how students are recruited in general to train as pedagogues<sup>62</sup>. In other words, our analysis will deal with the ‘fight for generalists’ once they have qualified.

According to the departmental heads, their counties do not face any recruitment problems – even in rural areas – but this will change and competition for the limited generations of young people in the future is set to intensify. They both mention the existence of pedagogue colleges in their areas as a key source of recruitment. Moreover, the generalist studies, one of the departmental heads believes, generate a more broad-based spectrum of applicants for the pedagogue education since the students do not need to decide on a future pedagogical work area at the onset of their studies. Through practice work during their studies some of the students get an understanding of the nature of work in the handicap area.

Thus, both the departmental heads at county level do not assume there will be a sufficient supply of labour in the future and they apply suggest different strategies to retain and recruit people. According to them, both counties are targeting their efforts on making handicap a high status work area, enjoying a favourable image. One of them says that the county authority is known as a well-organised organisation that supports its staff. It runs a team of specialised consultants supporting the professional development of staff and invests many resources in post-qualification training.

The other head of department comments on his county’s efforts to retain labour in the area of handicap care:

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<sup>62</sup> The three Danish informants from different pedagogue colleges all touch on the issue of whether the bachelor status of the pedagogue studies may result in attracting more young people while preventing those who are more practice-oriented from joining the studies (see Chapter 8: Training).

*It has been a deliberate part of our discussion regarding most of the efforts we have done that this factor is going to strengthen our position in the competition for the limited generations of young people [...] how are we going to be able to sell and market the area of adults with disabilities as an area in which trained pedagogues will be able to work, develop and refine their professional skills. If we can make the students think “Hey, something is going on over there”, and if it becomes part of our image, well, then we are several steps ahead in the fight for the limited generations of young people.*

An example provided from a former ‘total’ institution is that it was suffering from recruitment problems owing to its poor image. A large-scale educational initiative was launched for both trained and untrained staff, as a result of which the institution overcame its recruitment problems.

The two departmental heads at county level are both optimistic about future recruitment in the handicap area, but only by way if there is a targeted initiative at county level. The trade union vice-president, however, foresees “a recruitment problem in the Danish handicap area”. He is more sceptical and foresees several negative trends that may currently threaten the recruitment and retaining of labour.

The trade union has been discussing whether the status and image of pedagogical work with citizens with intensive support needs has decreased. In some counties, some of the housing services are not staffed by pedagogues but mainly by social and health assistants, and during weekends by high school students who want to earn extra pocket money. The reason is not a lack of pedagogues but poor management at county and institutional level.

Work with such residents in particular involves a key theme: the need to create a professional environment that provides the individual staff member and resident with personal development. Without this, you would not be able to hire anyone for this group. This is about work involving

*those with the biggest needs. Those who will bang their head into the wall, who bite you, who do not communicate, who do not want a shower and otherwise distance themselves from their environment. The [staff], I believe, will leave right away and say: “Then I would rather spend time with a sweet mongol”.*

The vice-president of the trade union believes that it is not difficult to attract staff in general and pedagogues in particular if there are opportunities for professional development for staff and residents. People today want their work lives to bring development for themselves and the residents. However, because of cut-backs and poor management some of these initiatives are being dismantled.

He stresses that managers must act as drivers of the staff group. Recruitment at the individual workplace depends a lot on:

*people telling each other about how exciting the work is at that particular place. There you can do just what you find exciting. They involve you in the decision-making and there is enough time for supervision and training. Thus, the pedagogues will apply for work there. But if no one bothers to sort this out, if one of the residents hits you on the head, then....*

Making this work attractive is a top priority. He praises the one-man projects<sup>63</sup>, which are well funded and target individual disabled people with outward-reacting behaviour. Here

*they understand to upgrade [the pedagogical work] to make it exciting. You can make use of this in your CV. The young people will have this in mind. "Oh, so you have been working there. Then you know how to do analysis work and what it takes to be supervised. And, you may be able to work with video-recording tools".*

He is sceptical about a way of living for people with high support needs, including outward-reacting behaviour; this is too individual and isolating. This may trigger recruitment problems that hamper the work of creating a professional staff environment. Examples of this development have been seen abroad. In his view, small-scale residential communities will pave the way for a professional environment.

Two of the Danish informants, who are trainers, also mention that placement during studies makes some students decide to work in the handicap area. One of the informants is an educational consultant at a site with 350 pedagogues and a large number of pedagogue students on placement: *"we note that many are crying when they get here and just as many are crying when they leave"*. The college literally forces them to take their placement in the handicap area, and *"they begin by being opposed and clearly voicing their opposition by saying 'It is here that I am going to work'"*. The other trainer co-ordinates practice work at a major pedagogue college. She generally believes that when the students embark on their studies *"several of them refer to working with disabled people, saying that 'I am not going to have anything to do with them'"*. During their placement, however, they change their minds.

One of the Danish informants (another trainer) stresses that post-qualification training helps to retain the staff. She is an educational consultant at a site with several housing units for people with handicaps, and further education of staff often takes place. She explains that it is about *"making it attractive for the staff to be here, and that is our overall objective to offer both group training and individualized post-qualifying training."*

### **10.1.3 Sweden**

According to the Swedish report there is no national strategy on recruiting handicap care staff. The responsibility lies with the local authority to ensure that the care and nursing needs of disabled people are appropriately met, and that adequate staff resources are available. However, just as in other European countries, the elderly population is growing, and a large number of people born in 1940es will soon be retiring, increasing the need of staff in the care sector. The problem is recognised by the trade unions and the national authorities who are discussing the recruitment issue. In 2001, Svenska Kommunförbundet and Landstingsförbundet undertook a study, forecasting the need for care and nursing staff. The study indicated a significant recruitment need that cannot be met by high school graduates and post-qualification training:  
(<http://www.lf.svekom.se/artikel.asp?A=1719&C=1107>).

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<sup>63</sup> One-man projects provide targeted support for individual people working with disabled people during a particular period during which all lessons learned are carefully recorded.



The sections below deal with recruitment issues that the Swedish policy maker informants have touched on in the Swedish report. They believe that recruitment in the handicap sector is cyclical. During a boom in the economy, few people seek jobs in the area and during a recession more people do. The reason is that there is no required educational qualification for the field. During a boom, it is easier for people without education to get a job with higher pay and which is less demanding.

*It is in fact cyclical. When many jobs are available, it is bad for the nursing and care sector because it is easier to get a job with a better pay and which is less demanding than care work. But during a recession in the labour market, then it is easier.*

One of the informants says that relying on young employees would be insufficient because “*people are both entering and leaving this group*”. It is important to consider the factors that are going to retain the staff so that they will experience personal development of their competencies over the years. It is necessary to create an environment of development.

*You should be able to see that the person holding that position for ten years is not doing the same things as one is expected to do as a new employee. [...] And that it is possible to develop your key competencies and become an expert in a particular area, etc.*

In Stockholm, the mapping of staff showed that many of the staff members were young people and few were aged more than 55 and working in handicap care. The policy maker believes that you should analyse what happens to the senior staff members and develop opportunities for them to stay in the job.

One trainer works full time, co-ordinating training of staff in the city of Stockholm. All 18 city areas participate in the project. She initiated the project when she realised that staff and management were very dissatisfied because of poor access to competency development for the staff. It was also difficult for the handicap services to recruit staff. She saw a need for the entire city's participation in the project and that the staff should get involved in the analysis stage where they themselves find out about the competency development that they need.

The educational factor is a key issue in the recruitment debate. The training provided at high school level and for adults leads to an education (undersköterske examen) that is targeted on the care area. The policy maker from the handicap movement stresses that the training in handicap care suffers from a poor reputation because it focuses too much on care and nursing; it ought also to contain an ideological element, e.g. regarding human rights. The training and work area would become more attractive to young people if it contained more such ideological features, she believes. She stresses that many young people with handicaps and disabilities do not need home care. They want someone “*with knowledge about the conditions needed so that a person with disabilities can participate in all aspects of life.*” She advocates an education that provides both knowledge about care and focuses on the staff abilities to include handicapped people in society in general.

The personal assistants are generally unqualified and no job-specific training is provided. One of the policy makers does not understand why properly trained staff is not required considering the strong wording about quality in the important LSS legislation. She says:

*why and how can you live with this situation. How do you get so strong a reform and wording about quality as seen in handicap care provisions applying to, for example, assistants. Can you communicate this message [...] while accepting the lack of training? In my view, this is very difficult.*

She stresses the recruitment problems facing the area, owing to the low work status and that the only way of improving the status is by “demanding training with a pay to match.”

## **10.2 Current discussions and future directions according to policy makers and trainers**

In the following section, we discuss the themes put forward by the three countries’ policy makers and trainers during their interviews. They may have other key themes on their agendas, which are not mentioned, and we need again to emphasise that the informant statements do not necessarily represent the current discussions in the countries regarding the handicap area and future directions in the area.

### **10.2.1 The Netherlands**

The following is the Dutch report’s summary of the interviews with policy makers and trainers. The explicit question about innovations resulted in confirmation of earlier subjects. Most comments were about the consequences of demand control and commercialisation. Demand control by means of individual budgets managed by people needing care services could change the whole financing and management system and the role of the care professional (from care provider to service provider). Moreover, some informants suspect that the influence of users on management and supervision of institutions will increase. The influence of the Government will correspondingly decrease, also because it is government policy to make insurers more responsible for providing and financing care.

A sensitive issue can be interpreted as working against innovation. It concerns the cuts in costs for care and welfare in the Netherlands under the neo-liberal government. Related to this cutting expenses policy is the policy to change the current care system. So far, care for the disabled is mainly guaranteed and financed by the Law on exceptional expenses for care (AWBZ). In current debates the national policy is to exclude a number of services from this law, such as household services and activation. The local communities are expected to take over the responsibilities for social care. Only the cure related care will be covered by the AWBZ. The point under discussion is the transfer of budgets to the municipalities and the drafting of a new law on local care and welfare services. Some people expect a positive effect in giving communities the full responsibility for the care and welfare of their citizens, whereas opponents fear for a loss of quality and social rights. In their eyes we are moving from a care system based on an assurance system and entitlements, to a system based on local responsibilities and targeting policies, with a so far unclear budget system.

Another development, which will unfold, is the earlier mentioned standardisation that will focus on legal involvement (the tendency in society to solve issues in court, even though other means are available). People in need of professional care more often can turn to legal means to enforce their rights. It is difficult to predict what the long-term effect will be for care provision, compulsory treatment, genetic manipulation and other ethical issues.

Some informants refer to more and further applications of ICT at the workplace, such as e-learning, communication and protection systems and intelligent household appliances.

Perhaps a proper conclusion would be a somewhat critical evaluation of innovative thinking in the past few years. As one of the instructors indicates, quite often policy makers and managers interpret 'innovative' as meaning 'new'. There is a tendency to support new ideas and approaches. This will lead to two fundamental problems.

The first one is a denial of history. 'new' is not quite as 'new' as is declared. Emphasizing 'new' prevents innovators from learning from past experiences. The second is the possibility that innovative thinking eliminates development. Innovations should be considered to be more organic or improvements of existing methods. This prevents a disrespectful dismissal of history, which is a trend with policy makers and managers, according to one of the informants. The constant need to innovate results in a rapid replacement of policies and methods with newer ones. Time is not taken any more to mature innovations, so they can never become embedded.

### **10.2.2 Denmark**

The Danish policy makers all talk about the issues of curbs on spending and the qualification of the workforce. They also discuss innovation and provide some thoughts about the future of the handicap area. Generally, the statements of the trainers do not deal with the handicap area in particular but with their views on the current discussions and future considerations regarding pedagogue education. These topics have already been examined in Chapter Eight.

#### **10.2.2.1. Curbs on spending<sup>64</sup>**

The handicap area is the biggest success in Danish social policy, in the opinion of the two policy makers. Normalisation and decentralisation gathered momentum with the transfer of handicap care in 1980, and, according to several informants, the move was backed by favourable financial conditions and lots of experiments. All five policy makers express concern about the current resources available to the area. According to the government informant, the big challenge facing Denmark today is to provide an adequate level of service due to spending limits, and all the Nordic countries face this problem. One of the informants at county level says that the area, for the first time ever, is going to compete for resources with the hospital sector and residential care for children and young people. At the time of the interview, the other county was planning cost savings in the area, and according to the head of department, a lack of resources may result in service cutbacks.

Waiting lists for housing units are commonly referred to and described as a problem by some of the policy makers. There are no waiting lists in one county whereas the other county has 70 people on a waiting list. The Danish organisation *De Samvirkende Invalideorganisationer* (DSI) believes, according to the trade union vice-president, that there is a shortage of 7,000 homes in this area, and in some of the counties people are still sharing rooms. The organisation representing the relatives says that there is a lack of housing especially for young people. The trade union vice-president is strongly critical of the fact that this group of citizens do not have a free choice of where to live as is enjoyed by other citizens.

Several informants say that major housing units have been built or are in the offing, or that small housing units will be grouped into larger homes. One county, however, maintains the small-sized housing units. The president of the organisation representing the relatives believes that the implementation of larger housing units is a setback, because, she believes, it is less expensive and indicates a change of opinion based on the argument that at larger housing units the people with

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<sup>64</sup> The expense limits are attributable to the taxation limits implemented by the current government.

disabilities will feel more safe, they can walk around without being in danger and socialise with similarly handicapped people. The cost savings, according to the trade union informant, have resulted in larger housing units and thus fewer managerial jobs for pedagogues.

#### *10.2.2.2 Labour qualification*

Several informants mention the importance of the staff's professional development and the establishment of professional communities. Both departmental heads at county level mention staff training as a key issue; one wants to give the educational efforts a higher priority than staff cuts if it is required to prioritise. It is important to focus on staff training, and both counties invest many resources in post-qualification training of their staff. The president of LEV says that professional communities are important; they can be created by way of joint management, and they can provide enhanced resource utilisation and allow the pedagogues and managers to move freely around according to their needs.

The vice-president of the trade union mentions various professional challenges that lie ahead. Living in a society that is based on information and documentation, competency and skills, so relating to users and staff is what matters. There is "*a burden on the relations today*". The older generation masters the relations whereas the younger generation has more up-to-date competencies. Here he refers to the past when social pedagogical work was based on attitudes and views on human nature whereas the focal points have shifted to competencies and skills. This may result in the staff losing their social policy commitment. He is generally missing a policy debate within society about handicap policy, with wider participation.

The trade union informant is concerned about the work performed relative to the weakest people. With fewer financial resources you can end the view that it always pays to make an extra effort with a view to making other people feel better. As a result, private and unskilled people may be asked to do the job.

#### *10.2.2.3 Innovations and visions*

The policy makers touch on various innovations and visions in the handicap area. One county has just agreed on a new employment concept - What kind of job can I get? As a result of which each disabled person will select his/her individual day care service. The departmental head has a vision that in the future this will also apply to the housing area. People with disabilities should be given a choice between different types of homes. They should not necessarily be living in the same place for the rest of their lives but should be able to move when new needs occur, just like ordinary people do. He provides an example of how the county works with the dreams of the disabled people. Their dreams should be taken serious but should also be realistic with a view to being put into practice. This may be tough for the disabled person to realise.

The importance of qualified staff is already mentioned above as part of one of the current discussions. One of the departmental heads at county level explains his vision for the professional qualification of staff in the handicap area, and the county's approach. He also mentions the necessity of documentation in this area.

The informant from the organisation representing relatives has a vision of specific housing, more education and schools for younger people with disabilities. She also calls for more psychologists specialised in people with disabilities.

The informant at the government level believes technology developments may both benefit and isolate people with a handicap. Denmark is a wealthy society but with too many physical barriers for people with physical handicaps. He also calls for more jobs in the normal labour market.

One of the trainers refers to some of the newest day care offerings, for example by way of art schools, which have emerged during the last 5 to 10 years in Denmark. He says that:

*You are acknowledging that they [people with disabilities and mental diseases] have special talents [...] and they should be allowed to develop this field as their work area. [...] there is a borderline between using that in a pedagogical context. You are acknowledging that their means of expression are unique and then someone defines it as art.*

He mentions the establishment of a museum for art in Denmark (Brulé Art, which is the French label for this sort of art made by ‘deviants’) and similar museums are also found in France and the Netherlands, he says. The services offered do not only include graphic art but also theatre and music. The new offerings have resulted in altered training needs for the pedagogues. The trainer quoted above has initiated a 20-week post-qualification graphic art training course for pedagogues, where he also teaches.

The trade union informant wants more day care services at companies recognising their ethical responsibility. The source of inspiration is Life-Work, a privately run organisation, with significant growth in the states of Minneapolis and Minnesota in the US. These services will break with the protected workshops but still involve social pedagogical work since the pedagogues also move to the companies. He would also like to see more of the new types of day care services and believes that the output produced by people with development disabilities might as well be a theatre production instead of emptying paper bins. His statements reflect the change of society from being based on industrial production to services. Thus, some of the day care services, assuming they follow the trends of society, will change from being found in the industry sector to the service sector, involving for example theatre, music, cafe, shops and graphic art. The day care services of the countries examined reflect this trend.

### **10.2.3 Sweden**

The educational issue is the big discussion topic in Sweden. The Swedish report refers to a report made by the National Board of Health and Welfare: *Competence development in care and nursing of elderly people and people with development disabilities* (<http://www.sos.se/Hs/aldreenh/kompfor/index.html>). It contains a separate section on handicap care staff, stressing that the number of employees is growing but that the number of untrained staff is growing too. The services are having a difficult time hiring qualified staff, and 50 percent of the handicap care work force lack general training.

The Swedish policy makers and trainers interviewed also consider education to be a key theme now and in the future, and this theme is discussed the most during the interviews. One policy maker goes as far as to say that “*it should be a national priority when it comes to training staff*”. She believes educational reform is required: “*It must be done if we are going to have [...] dignified services with LSS*”, and the objective is to make the handicap area more attractive and that dignified work is being done. She criticises parts of the handicap movement which believes that staff training makes workers less qualified for their jobs. According to her, they say that:

*the more they are trained, the worse it gets. It is about getting staff [...] who believe they know what is best for disabled people. [...] Instead [it is a question] of staff with professional training that knows how one be good at listening. It is something quite different. [...] It is about a stronger focus on pedagogical and social views rather than care.*

She strongly advocates a future, professional training of handicap staff who will be able to deal with the recipient of care in an equal and dignified manner. This should be done by the training focusing more strongly on pedagogical and social approaches to the work to be done rather than solely considering work as provision of care.

One of the informants (a trainer at a care training college) believes that there is significant demand for training. The care staff in the area of handicap care and elderly care, she says, are crying out for more training and in particular they want to learn new methods. The handicap work used to be very much a 'common sense job area', but today work requires training, particularly involving people with severe disabilities, because "*you do not understand what the person wants or needs, since they are not giving you many signals*". For example, the staff need to learn about methods of communication – how are pictograms used and how do they apply sense and tactile stimulation.

The handicap area faces scarce financial resources and, according to the previously mentioned report from the National Board, things do not look any brighter in the future owing to the growing numbers of elderly people. The Swedish national report refers to the National Board's report which discusses the cost savings in handicap care and thus also about future priorities in this area. One of the informants, a Swedish policy maker, already faces this problem. She states that there is an accumulated need for various initiatives. Certain types of housing units have been subjected to cutbacks, and therefore many people are now waiting to move into their own homes. However, with a lack of funding, these homes cannot be built, and eventually the funding may be transferred from other areas of handicap care.

Another policy maker believes that the integrated workplaces will be a key issue in the future. For example, there could be a place of work at a factory producing for the manufacturer and with care staff working together with people with disabilities at that factory. The policy maker adds that support provided at ordinary homes should be further developed for people with disabilities. For example, they could continue living in their own apartments while new ways of supporting networks and support from relatives are developed.

One of the policy makers believes that diversity in the staff group is important. The examples that she provides underline the importance of gender diversity in the staff groups. Regarding care of people with severe physical handicaps, she provides an "*example of a young girl who needs assistance, and she may prefer a female assistant. If you are male, you may prefer a male assistant. It is about being able to choose*". She states that handicap care has attracted many men compared with other areas of care.

### **10.3 Concluding remarks**

#### **10.3.1 Recruitment**

In all three countries, the policy makers and trainers mention the importance of some sort of measure to attract and retain labour for the handicap area because of competition for the smaller

future generations of young people and a growing need for more care workers in elderly care. Again, we refer to Chapter Three and its analysis of the paths into handicap work of the practitioners interviewed.

In order to ensure a steady intake of care providers, the participating Dutch policy makers and trainers, as we have seen, focus on four main issues: working conditions, conceptualisation, further development of the profession and the role of senior care providers.

The Danish section highlights the importance of a flexible generalist education. Being general, the studies do not require the students to select a specific pedagogical work area. The education and its periods of placement provide a first taste for some of the students with regard to the handicap area, which is a less well-known area of work. The geographical location of schools and colleges is another key factor in recruitment. A pedagogue college located in the vicinity will contribute to the supply of adequate and qualified labour, and it stresses the importance of diversified college locations in these countries.

A common feature for the Danish informants is a strong focus on the qualification of staff and the establishment of a professional environment to avoid the loss of qualified staff. The two Danish policy makers at county level both express optimism about retaining and recruiting labour in the handicap area, but it requires a concerted effort on their behalf. Work is being done to upgrade the status of this area and to create an associated favourable image, and many resources are invested in post-qualification training and professional support of the staff.

The trade union vice-president in Denmark, however, is more sceptical and emphasises several negative trends – financial cutbacks and poor management in some counties and institutions results in a lack of development for the staff and the residents. Recruitment and retention problems follow because people today demand development in their work lives, i.e. development for themselves and the residents. He also stresses that work with support-intensive users should be made attractive; otherwise, no one wants to work with this group of people. He believes that too individualised types of homes for people with significant support requirements and outward-reacting behaviour will generate recruitment problems because it is difficult to establish a professional environment with this type of housing.

Among the Swedish informants, the education issue is considered the most important way of recruiting and retaining staff in handicap care. Many of the employees lack education, and it is a low status area. They believe it is necessary that more staff become trained with a view to meeting the recruitment requirements and to make the work more dignifying for the users.

Several informants argue that post-qualification and further education of the current staff is a priority area with a view to retaining staff – they should be able to see how their competencies grow over the years. One informant argues that a specific education should be established for personal assistants as part of the recruitment strategy and to meet the legal quality requirements.

### ***10.3.2 Current discussions and future directions***

Among all three countries, the informants express concern about current or possibly future scarce resources in the handicap area. In the Netherlands and Sweden, concern is voiced about resources being under pressure, owing to a growing elderly population, and with the handicap and elderly

areas competing for funding and staff. In Denmark, this discussion is not expressed by the informants who, however, are concerned about the currently limited financial resources.

The Swedish informants highlight the educational question as the dominant theme. Several argue that educational reform is required in order for handicap work to meet the intentions of the law. One educational reform is to reduce the focus on the care content and sharpen the focus on pedagogical and ideological principles (including the question about human rights) and social inclusion. Reading the Swedish informants' thoughts on the educational reform they would like to see, we believe that the proposed content is similar to the current Danish pedagogue education with its pedagogical views, human rights and social inclusion.

The Dutch informants talk a lot about demand control and commercialisation. The Dutch themes indicate that the Netherlands is going through a period of fundamental change with a new paradigm and a discussion of more market-oriented solutions, replacing old traditions.

The Dutch researchers and their sceptical considerations about the innovative thinking in the past few years also indicate that the Netherlands is currently discussing more radical changes and is abandoning previous policies and practice in some areas. They talk about denying history that prevents the innovators from learning the lessons of the past. The sustained need for innovation results in policies and methods being quickly replaced. They argue that making changes takes time. Thus, the Dutch researchers are sceptical about the way an innovation mentality dominates the field of handicap care at the moment. Innovation itself does not necessarily bring about development and better care quality. If the innovation mentality is automatically denying all the old approaches, then better conditions for people with handicaps are not necessarily ensured.

One of the risks of innovations is that they are being created starting from a new national strategy or paradigm overruling the existing systems too rudely. A popular new Dutch strategy is on market orientation. So, innovations are developed in a full belief that market orientation will improve the care system. Cash for care, privatisation of care providers, and privatisation of the insurance companies are going hand in hand, without a careful reconsidering the existing practices and looking for a balanced approach.

The Danish policy makers are occupied by other themes. They are concerned about the financial resources in the area, and they focus strongly on workforce qualifications. Concerning the financial resources, the tax limits imposed by the current government have led to intensified competition for the resources available. The concerns of the Danish policy makers indicate that adequate resources in the handicap area are not taken for granted. However, as opposed to the Dutch informants, the Danish policy makers do not talk about any radical changes in the future; the Danish report stresses that there are no new policies to be introduced in the handicap area. The innovations and visions suggested by the informants should be seen as an extension of the policy pursued since 1980. Danish handicap policy is fundamentally based on the same set of ideas that have provided a calm and supportive environment for new experiments and innovations<sup>65</sup> that are based on and consist of the development of established policies and practice. The Danish development is characterised by steady developments but we do see some concern as to whether it will be adversely affected by a lack of resources.

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<sup>65</sup> The same level of stability characterised the day-care services policy for young people as opposed to Hungary and Spain. See Korintus and Moss (2004) Chapter 2.1.



There are some suggestions for innovation and visions in the handicap area put forward by the Danish informants, for example, people with disabilities should increasingly be able to choose their day care services and housing. Mention is also made of several targeted services by way of specialised housing and training provided to young people with disabilities. Several informants voice a wish for more day care services or jobs at ordinary companies. With more day care services at ordinary companies and specialised services for young people, the pedagogues will also be facing different qualification requirements.

The handicap area also reflects the developments from industrial society to a service-based society. Thus, some of the day care services – assuming they follow the developments of society – will change from typical industry employment to service-sector jobs, for example related to theatre, music, cafe, shops, and graphic art. These new types of day care services are mentioned not only by the Danish informants but already exist in the day care services of the three countries examined. The new services will contribute to a change in the working fields of care workers and will require more specialised competencies.

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