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**Personal Assistance and Social Reform**  
**According to the Swedish Relative Model of Disability:**  
**a Qualitative Analysis of the 1994 Reforms.**

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## **Abstract**

The 1994 legal reforms provided a well-defined group of disabled people with rights to ten different services. One of these, personal assistance could be viewed as constituting a paradigm shift from former communitarian type services to autonomous rights. Swedish courts base their decisions on interpretations of arguments and aims present in the political documents behind legislative reforms: Government Proposals and Reports from the Parliament Standing Committee.

The legal ideas present in these texts are analysed and compared with ideals of social justice found to be associated with the British social model of disability and the Independent Living Movements philosophy of personal assistance. The analysis uses the concepts of 'redistribution' and 'recognition' as these are defined by Fraser in her status model. Furthermore, a limitation to the social roles connected with work and family life/parenthood is done. These are chosen due to their inherent assumptions of self-determination and dependency. Thus, thought to yield interesting conclusions as compared with assumptions of self-determination connected with ideals of personal assistance and assumptions of dependency connected with disability.

Findings revealed how the Swedish relative model of disability creates a disabled identity, where disabled persons are valued on account of difference but denied recognition of participation parity. The relative model categorises disabled people as persons unable to perform in normal social roles. Disabled people in general are perceived as incapable of employment and provided with rights to the service of 'occupational activity' under the reforms. This is viewed as not belonging to the labour market and, therefore, neither recognised as participating on equal terms nor

rewarded with a salary. Disabled people are, also, not perceived as capable of the social role of parenthood and personal assistance is not provided to enable this.

Autonomous rights to personal assistance in connection with work and family life are found to be provided mainly to enable non-disabled parents to remain gainfully employed and to relieve them from the burden of caring for a disabled child. Disabled persons participating in the labour market, or having an indeterminate identity in connection with capacity for employment, are also provided with the self-determination personal assistance can provide. Breaking the assumption of dependency by performing in the social roles associated with employment seems to merit recognition and, thereby, self-determination. Thus, they are provided with autonomous rights to personal assistance during time spent working.

The conclusion is that the ideology of normality, and its connected assumption of dependency, occupies a hegemonic position in the Swedish welfare state. The proposals and negotiated outcomes of the 1994 reforms contain legal ideas fitting the dominant perceptions of disabled people. As a result, the relative model, with its focus of remedies on the psychosocial and psychological level, will never have the strength to break this dominance. Existing disabling assumptions persist in focusing on individual inabilities

# Chapter 1

## Introduction

### Background

The Swedish Government Commission on Disability established in 1989 published a series of reports in the beginning of the 1990s (SOU 1992:52). Based on surveys, research and discussions with a wider circle of stakeholders, they focused on the service organisation for disabled people in Sweden and pointed out areas for improvement. One of these reports (SOU1991:46) resulted in legislative reforms, enacted in 1994, providing a well-defined group of disabled people rights to ten different services:

- advisory support,
- personal assistance,
- accompanying services,
- personal contact,
- in home relief service,
- short stay away from home,
- leisure care outside school hours,
- family-home or housing with special services for children and adolescents outside their own home,
- housing with special services or specially adapted housing for adults and
- occupational activities.

While, most of these services are shaped in old-fashioned, municipal, in-kind format, the right to personal assistance involves a paradigm shift. Instead of services attached to activities or premises, personal assistance follows the individual person. Thus, the intention is to allow disabled people freedom and flexibility, enabling a choice of lifestyle otherwise granted only to non-disabled. Personal assistance, and the right to direct payments for such, also gives control over who to choose as the assistant and where, when, and how this assistance is provided (Ratzka 1997). The rights are provided under the Support and Service Act (SFS 1993:387) and direct payments through the social insurance system are provided under the Assistance Benefits Act (SFS 1993:389).

Personal assistance is one of the core concepts of the Independent Living Movement, ILM. This was born in Berkeley on the American west coast in the 1960s (Martinez 2003). The independent living philosophy is based on four assumptions: the value of all human life, the capacity of anyone regardless of impairment to exert choice, disabled peoples right to fully participate in society, and to assert control over their lives (Morris 1993; Martinez 2003). Independence, as the ILM views it, is mainly connected to the issues of choice and control.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation.

Independent Living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbors and friends take for granted (Ratzka 1997a).

The philosophy and practice of the ILM was first brought to Sweden at a seminar in 1983. At this event speakers from the US as well as UK were present. Four years later Sweden's first Independent Living cooperative was started (Berg 2004). STIL, the Stockholm Cooperative for Independent Living has administered direct payments for personal assistance since 1987 and is the example referred to in the new reforms (Prop. 1992/1993:159).

Choice and control through direct payments for personal assistance offer the potential to break with disabled people's traditional dependency. However, assumptions of dependency can remain at the heart of social policy and societal organisation according to how and in what contexts personal assistance is provided. This dissertation aims to investigate whether or not the 1994 reforms in Sweden tried to break these assumptions. In so doing, it analyses the complete parcel of rights enacted 1994. Some of the other nine rights are complementary to the right to personal assistance - and in some cases accessing one of these complementary rights means forfeiting the right to personal assistance. The analysis also takes into account the Swedish relative model of disability and how this constitute disabled people in the reforms. The relative model is the basis for all social policy on disability, thus, having a profound effect on legal reforms.

Assumptions of dependency surrounding care, and social policy aimed at breaking these, are at the centre of the welfare state's organisation (Oliver 1990). Knowledge of why and when self-determination is provided can indicate areas of strenght as well as problem areas, which can provide useful information for disabled people struggling for social change.



In investigating the reforms the concepts of recognition and redistribution (Fraser 1997) are used. It is argued that disabled people are subjected to oppression both of political-economic and cultural-devaluation kind, and these concepts are used as measures of any shift towards self-determination. The investigation also focuses on the areas of labour market and family life (parenthood), as these are viewed as historical sites of self-determination and dependency (Fletcher 2002).

The data analysed are the political texts behind the reforms. These are used as interpretative tools in the administrative and legal process, which materialises ideology contained in the texts. The administrative and legal process articulates the dominant ideology (Boswell et.al. 1995) and creates reality out of legal rights. Assumptions contained within the texts, thus, have a vital influence on the outcome of the legal reforms. Therefore, this study comprises a secondary content analysis of the political documents providing rights in the Swedish reforms of 1994. The dissertation deals solely with the level of ideology in law, analysing the texts that have a formal status as legal interpretative tools.

### **Legislative process**

The parliament is the legislative body in Swedish society. Legislative reforms are often initiated through the use of government commissions which are appointed to examine and make suggestions for social change within an assigned area. Their assignment is political but, as they are only advisory to the political process, their reports are not part of this analysis. On the basis of the government commission

reports, or on other indications, the government recommends reform proposals to the parliament chamber – what are termed ‘Government Proposals’. The members of parliament are then given the option to respond by introducing a Private Member’s Bill arguing for or against part or all of the proposals.

One of the distinguishing characteristics of Swedish democracy is a culture of negotiation. Political decisions on reform proposals are, thus, negotiated within the responsible parliament standing committee. The government proposals, the private member bills connected with this and other member bills raising relevant issues, and in some cases reports from other committees on specific issues, are sent to the committee responsible where they are debated. The outcome of the negotiations, together with references of opinions voiced on the issues, are then recorded in the Parliament Standing Committee’s Report. This addresses the proposals made by the government in relation to issues raised in the member bills, the reasons and arguments for the outcome, and whether or not the issues of the member bills are seconded or rejected. As, the political formation of the committees is based on the political representation in the parliament, the negotiated outcomes are in most cases voted through without change in the chamber. The reforms were originally voted through during a period of conservative-liberal government, 1991-1994. The later amendments took place under social-democratic rule.

The political documents used as research data in this dissertation are these Government Proposals and the Reports of the Parliament Standing Committee of Social Affairs and Welfare. In those cases where content from the Private Member Bills is used, this is based on discussions of this in the committee reports. The direct

quotations are, however, taken from the member bills since this is the original source of the quotation.

In writing this dissertation, use is made of non-English, international sources that mostly use a different terminology to that advocated in Britain by organisations of disabled people (Oliver 1990). Furthermore, the discussion frequently uses extracts from Swedish sources. These have been translated by the author, who has chosen to leave the Swedish terms *funktionshinder* and *handikapp* in direct quotations and elsewhere in the text. This is done because direct translation of Swedish terms can be rather confusing from a (British) social model perspective. *Funktionshinder* roughly corresponds with 'disability' as defined in the World Health Organization's (WHO 1980) International Classification of Impairments, Disabilities and Handicaps (ICIDH); while *handikapp* is equivalent to ICIDH's use of 'handicap'. Disability, according to ICIDH, is an incapacity, due to injury or disease, to perform activities in the manner or within the limits considered 'normal'. Handicap is the disadvantage an individual experience when this incapacity prevents fulfilling of expected social roles.

This analysis starts by investigating how the Swedish relative model of disability views disabled people in the reforms. The model's definition of *funktionshinder* creates a disabled identity, which recognise disabled individual's on account of their difference, at the same time as it constitutes this disabled people as incapable of performing in normal social roles.

The following chapter analyses how this disabled identity interacts with assumptions of self-determination connected to the concept of work. How gainful employment is

enabled for non-disabled parents to disabled children through rights to several types of services enacted in the reforms. How disabled people are constituted as incapable of performing in the social roles connected with labour and the consequences this has for the definition of employment as opposed to the right to *occupational activity* provided in the reforms. Employment is found to merit both redistribution in form of a salary and self-determination in form of personal assistance provided during time spent working. *Occupational activity* is not rewarded either with remuneration or right to autonomous services during time spent in this.

The investigation, then, moves on to analyse the area of family life, particularly the social role of parenthood. While, Swedish social policy break the divide between public and private spheres, assumptions connected with social roles remain. The concept of care and the assumptions of dependency connected with this remain. Disabled parents are viewed as incapable of performing in the social role of parenthood and the autonomous right of personal assistance is denied in connection to this. While, assumptions of self-determination connected with employment can qualify disabled people as capable if they manage to access this area, assumptions of dependency connected to family life deny disabled parents' capabilities.

The concluding chapter addresses the issue, of how the disabled identity created by the Swedish relative model, fails to break disabling assumptions. And how recognition at the individual level, present in the reforms, does not provide recognition of participation parity according to Fraser's (2001) status model, nor rights designed according to the British social model and independent living principles.

## Chapter 2

### Social justice Swedish style

#### Redistribution, recognition or both?

Justice, or as it is sometimes referred to social justice, is at the same time the goal and the foundation of welfare society. However, any

discussion about welfare politics will always be incomplete if the normative problems, round the issue of what is intended by *social justice*, is not considered (Rothstein 2002:7)

The guiding principle behind the political goal of justice was up to the 1980s redistribution. Social justice, as it was perceived by both European political ideals connected with Marxism and American liberal egalitarianism, was a question of economic equality (Honneth 2001). Social justice through redistribution deals with the morally proper way of distributing resources. Its basic principle, that “economic activity should be socially and collectively regulated” (Young 1990:67), aiming for maximum collective welfare, reinforces the principle that “citizens have a right to have some basic needs met” (1990:69). Economic equality and, thus, redistribution “can be seen in political terms as a manifestation of the era of social democracy” (Honneth 2001:43)

However, recently a politics of difference, aiming for respect and dignity for groups with distinctive cultural characteristics, challenges the “old” notion of redistribution as

key to justice. Proponents of this principle seek “a world where assimilation to majority or dominant cultural norms is no longer the price of equal respect” (Fraser 2001:21). This change emerged with

a series of political debates and social movements, which in their own right, demanded a more pronounced consideration of the idea of **recognition** [emphasis added] ... From here, it was a small step to the generalized realization, that the moral quality of social relations cannot be measured solely in terms of fair or just distribution of material goods.

(Honneth 2001:45)

While, social justice as redistribution, as well as recognition, has its followers advocating supremacy for “their” principle, present day debates also include proponents advocating a combination of the two principles. Young (1990) severely criticises the extension of the distributive paradigm of justice to embrace such things as social rights, opportunity or self-respect. She claims that defining social justice as redistribution

fails to appreciate that individual identities and capacities are in many respects themselves the products of social processes and relations  
(Young 1990:27).

Conflicts and struggle for social change, restricted to distributive issues, are limited to the social budget and, thus, depoliticised (Young 1990). While, Young remains

critical of the distributive paradigm and extensively dwells on cultural aspects of oppression, her definition of oppression is bipartite (Fraser 1997)).

Oppression consists in systematic institutional processes which prevent some people from learning and using satisfying and expansive skills in socially recognized settings, or institutional processes which inhibit people's ability to play and communicate with others or to express their feelings and perspectives on social life in contexts where others can listen (Young 1990:38).

This definition of oppression is interpreted by Fraser as turning "one of its faces towards problems of culture and the other towards problems of political economy" (1997:193). Political/economic oppression, described in the first half of Young's definition, demands a remedy of redistribution, according to Fraser. And cultural/devaluating oppression, described in the second half of the definition, demands a remedy of recognition (Fraser 1997). What Fraser calls, bivalent collectives are differentiated "by virtue of *both* the political-economic structure *and* the cultural-valuation structure of society" (Fraser 1997:19). They demand both redistribution and recognition as remedies. Disabled people, subjected to both ostracising from the labour market and devaluation as being perceived dependent and incapable, is such a bivalent collective.

The aim and location of the remedy of recognition is also a debated issue. Identity politics, for example as advocated by Honneth (2001), views recognition foremost as an issue of gaining self-respect, self-confidence and self-esteem. This demands

recognition by another subject and, thus, locates the wrong within individual or interpersonal psychology. Fraser holds a differing view and treats recognition as an issue of social status, “what requires recognition is not group-specific identity but rather the status of group members as full partners in social interaction” (Fraser 2001:24).

Misrecognition, accordingly, does not mean the depreciation and deformation of group identity. Rather, it means *social subordination* in the sense of being prevented from *participating as a peer* in social life. (Fraser 2001:24)

Using what she calls the “status model”, Fraser escapes essentializing cultural group identity, and promoting self-awareness or consciousness as a substitute for social change. She also focuses on institutionalised norms avoiding the “psychologisation” that is just a short step away from “blaming the victim” (Fraser 2001:27)

### **Communitarian or autonomous rights**

In Sweden, social justice is very much defined as distribution of goods. Both economic reality and theory can be found behind this system. In the aftermath of the stock exchange crises in 1929, decreasing export incomes, increase in already high unemployment figures and rapid movement of workers from farm labour to industries, demanded economic remedies. Keynesian economic theories enabled the government, in the beginning of the 1930s, to finance social reforms and create jobs through budget deficits (Holgerrsson 1992; Esping-Andersen 1990). At the same time



the social reforms, themselves, became a remedy against the concurrent population crises. Free maternal health care, preventive child health care and mothers' help were reforms aimed at increasing birth rates (Holgersson 1992). The Swedish welfare state evolved focusing on labour market and family policies.

Another wave of social reforms came in the 1960s, when growing wage pressures, declining profitability, inflation and payment difficulties, demanded measures against economic inflation. The deflationary tool, chosen by the Swedish government, was the mobilisation of a new manpower reserve – the female labour force (Esping-Andersen 1990). This created a “unique feminization of the welfare state” (1990:202) with a hugely professionalized welfare sector. However, it is argued that the male role (as primary provider) and the associated organisation of the labour market were never questioned or changed. As a result, when women entered the labour market they were mainly located within the newly organised public sector, which had taken over the caring role of the family (SOU 1990:44). The stark divide between the private and public spheres was broken down but women continued to undertake the task of care-giving, although now in a paid capacity.

The concept of care is increasingly used, mainly in Britain and Scandinavia, in feminist analyses of the welfare state (Daly and Lewis 2000). The concept originated as an endeavour to conceptualise women's life conditions.

The nature of the labour involved in caring was a key consideration from the outset, the goal being to define in its own right the activity that makes up caring for others, to identify its specific if not unique features and to

analyse how this activity and the responsibility for it reinforced the disadvantaged position of women (Daly and Lewis 2000:283)

The development of the concept broadened, incorporating both changing practical arrangements of care and scholarship analyses. This development is reflected in the differentiating terms used, as for example “caring about, taking care of, care-giving and care-receiving” (Daly and Lewis 2000:284). Dalley (1996) points to the difference in “caring about” and “caring for”. The former is constitutional of the typical male role as the provider; the person responsible for the resources. The latter constituting the typical female role of caring by providing unpaid, voluntary help. Women’s subordination to the demands of the nuclear family is described by Dalley as part of the ideology of familism.

Whatever the differentiation of the concept of care, at its core lays the fundamental assumption of disabled people’s dependency. Care is

the activities and relations involved in meeting the physical and emotional requirements of **dependent** [emphasis added] adults and children, and the normative, economic and social frameworks within which these are assigned and carried out. (Daly and Lewis 2000:285)

The concept of care can therefore be said to influence perceptions of both female dependency and disabled people’s dependency. It is a battleground of assumptions where unfortunately two subordinated groups engage each other (Morris 1993). As, the dominant assumptions of dependency connected to both women and disabled

people are inherent in the area, it is not surprising that services belonging to the care area often are organised according to communitarian ideals.

Autonomy can be seen as a trivial and natural principle. It is hard to find antagonists to such things as equal voting rights, general gender equality or religious freedom in principle. But examining Swedish public policy, it is clear that autonomy is far from the ruling principle. Instead, Swedish policy is to a large extent communitarian.

[H]uge ... parts of the public service sector [has been] built on the idea of standard solutions, i.e. the same type of day care, schools, care of the elderly, to all citizens completely independent of their own wishes  
(Rothstein 2002:59)

In Sweden disabled people, needing personal services, entered the community during the 1960s and onwards (Berg 2003) at the same time as social reforms was enacted to mobilise the female labour force. Cluster housing became the alternative to institutions. "The common pattern ... 10-15 special apartments dispersed through one large compartment complex ... connected via intercom to a staff" (Ratzka 1986:17). The communitarian character of these semi-institutions and the professionalism of staff made self-determination and individual life projects impossible.

## **The Swedish relative model of disability**

The communitarian way of organising services is based on a view of disabled people as dependent. A view which, social model theorists claim, is produced, upheld and reinforced by society itself. Disability is something “imposed on top of our impairments by the way this society is organised to exclude us” (UPIAS 1976:5).

Being excluded from society, “taken care of”, whether inside institutions or custodial community based services, is equivalent to being deemed incapable of functioning independently. This preconceived and widespread assumption lies at the core of what has been called the ‘social death’ model of disability (Finkelstein 1991).

Institutions and services, directed towards disabled people, are merely a more or less human way of handling the time between social death, i.e . impairment and actual death. In reality society has ceased to count the service receivers as social beings.

The distributive paradigm of the Swedish welfare system also underpins the Swedish relative model of disability, as this basically regards equality in terms of outcomes. Division of welfare, as a preferred solution, is certainly highlighted in Ekensteen’s book - *On the backyard in the people’s home* (1968), possible the starting point for the relative model. Concurrent with Hunt’s *Stigma* (1966), which also contains major criticism of disabled people’s socio-economic situation, Ekensteen discusses the issues from a more general left-wing political perspective. Disabled people, according to Ekensteen, is one of a number of vulnerable and disadvantaged groups, all referred to as *handikappade*.

If the general public got its eyes open to the principle similarity between the situation of physically *handikappade* and socially and economically *handikappade*, something would be won (Ekensteen 1968:30).

While, the social model clearly cuts the causality between impairment and disability (UPIAS 1976; Oliver 1990), the relative model does not. The Official Governmental Report *Culture for Everybody* from 1976 describes *handikapp* as follows:

We use the word ... to characterise a person, who because of physical or psychological reasons, experiences more difficulties in daily life. within this description lies the meaning that a *handikapp* is affected by the individual's living conditions, by the design of society ... it is not the injury itself we think of when we use the word ... but the **consequences** [emphasis added] an injury can result in (SOU 1976:20: 45-50)

The relative model is connected to the World Health organisation's *International Classification of Impairment, Disability and Handicap*, ICIDH (WHO 1980), through Söder's (1982) translation and adaptation of its terminology. His aim was to identify needs or groups with special needs, to enable channelling of resources to these groups, and to clarify the process creating these needs (Calais van Stokkom and Kebbon 1996). The connection with ICIDH is reinforced and strengthened with its revision and reformulation as the *International Classification of Functioning, Disability and Health* – ICF (WHO 1999).

Persons with "*funktionshinder*", is the politically correct way to refer to disabled people in Sweden. Söder (1982) meant that, attaching *funktionshinder* to the person, rather than letting it stand in front as a defining characteristic, allowed the description to remain neutral and value-free. It simply relates to certain capabilities and activities "not to the human being in relation to an ideal image" (Söder 1982:6). From a Swedish viewpoint disability remains fundamentally a consequence of injury or disease. Even if the consequences can be limited and sometimes obliterated, the causality between impairment and disability remains at its core.

Thus, according to the relative model, disability exists on a shifting scale somewhere between the individual and the institutional level. Therefore, it is not surprising that social justice concerned with disability is viewed as relative and shifting from a Swedish perspective. As influences from theories concerned with culture and recognition enter the Swedish debate, they are interpreted to suit the existing matrix of the relative model. While, denying the existence of a cultural group identity for disabled people and noting the relevance of recognition from a norm of participation parity as in Fraser's status model, follower's of the relative model feel the need to focus on the individual level as well.

[B]y including also a psychosocial and a psychological level we bring in levels that Fraser wants to avoid and it certainly is difficult to relate such levels to relevant specific political remedies. Nevertheless, we think that knowledge of mechanisms operating on these levels have to be important inputs into any political remedies and action on cultural and socio-economic levels. (Danermark and Gellerstedt 2004:351)

## Independent Living Movement philosophy

Disabled people, through the social model of disability, challenge the assumption of dependency claiming that inability to perform daily living tasks does not create dependency. In contemporary society dependency is the norm and disabled people's dependency is not "different in kind from the rest of the population but different in degree" (Oliver 1990:84). Dependency, disabled kind, is created by society's organisation. To uphold control mainstream society regards disabled people, not as individuals with capacities, but as a group united by incapacities. Defining disabled people, as unable to control tasks involved in daily life activities, separates the group from non-disabled peers. Society then will take on the duty to care *for*, rather than care *about* disabled people's self-determination.

Caring *about* someone does not bestow the right to make choices for them, to curtail their autonomy, just because they have a physical impairment, any more than marriage confers the right on men to control women. Neither does the state, in the form of care managers, care workers, have the right to take charge of a disabled person's life, any more than the state has the right to take charge of a woman's fertility. (Morris 1993:152)

The ILM provides the concrete solution to "care" issues fitting social model theory. Personal assistance, and direct payments for such, means that the users of services exercise control over these according to individual life choices. It "requires that the

individual user decides who is to work, with which tasks, at which times, where and how" (Ratzka 1997). Personal assistance is a key issue for the ILM (Morris 1993) and direct payment for such assistance is the tool to achieve choice and control over this.

The philosophy of ILM is indubitably centred on a concept of autonomy. At its core, irrespective of other national differences, are principles such as self-determination, self-respect, peer support, empowerment and risk-taking (ILRU 1999). In this lies a demand for recognition, for valuation of group identity and capacity. Research results from several British studies, referenced by Glasby and Littlechild (2002), also show that direct payment not only increases choice and control in the assistance situation, but improve wellbeing of assistance users.

Social justice according to the ILM, thus, involves personal assistance through direct payment. This is a solution highlighting individual capability. It rejects services of communitarian kind in favour of autonomous. Its aim is to remedy both political-economic as well as cultural-devaluation oppression. It can, thus, be said to aim for both redistribution and recognition.

## **Chapter 3**

### **Investigating law as ideology**

#### **Location of hegemony**

This analysis of legal reforms as a tool for societal change is founded on the social model's split between impairment and disability (UPIAS 1976; Over 1990). The social



model view disablement as existing within society and because of societal organisation. Disability is oppression and reality for disabled people. Therefore, legal reforms, even in the area of individual benefit rights, are part of the material relations, “physical, structural or institutional” (Priestley 1998:80) wherein disablement resides. It is not cultural representations, which disables persons in need of personal assistance. It is the lack of, resources needed to obtain personal assistance, and institutional structures, ensuring these resources.

In a historical framework, state policy and practise carry within them ideological responses to former structures. “[H]uman beings give meanings to objects in the social world” (Oliver 1990:2). These meanings are part both of materialism as first nature, which are the inherited structures, as well as materialism as second nature, which are the remake and successions of structures (Gleeson 1997). Assumptions of dependency, present in legal reforms, can therefore be seen as ideology, a material force created and recreated within society.

In modern day society law and legal systems are strongholds for existing ideology. “Law does not stand above politics and cannot be treated as a non-ideological tool for settlement of social conflicts” (Priban 2002:120). The critical legal view combines ideology and politics excluding perceptions of law as a neutral instrument. Generally law tends to be seen as above “interest”, but when examined historically “law has not merely defined social relations, but *defined the nature of the beings involved in them*” (Cotterrell 1992:124). Law is not only produced by the dominant groups in society, in itself it also erects the “identity” and status of these groups themselves. Law can, thus, be seen as a tool to uphold domination and prevent attacks on dominant

positions that would cause social instability. In this way, assumptions of dependency within legal reforms continue to define the social relations creating disablement, and thereby reinforce and justify disabled people's dependency. Although, there is a considerable debate around the relative autonomy of ideology from dominant economic and political interests, recent trends within Marxist theory break with views of ideology as having a mandatory function of reproducing existing relations of production (Boswell et. al. 1995).

The democratic welfare state is not a static project, but a permanently transforming entity. Within this, ideological interests and principles existing within dominant groups as well as subordinate groups struggle for recognition within the existing hegemony. Non-class struggles as race, sex and disability cannot be reduced to class or economic hegemony. This does not mean that ideology is a separate force from economic and historical structures but "that not all social relations can be reduced to relations of production" (Boswell et. al. 1995:377).

Law is consequently not a system of rules unified by fundamental principles. It rather consists both of principles and counter-principles and, therefore, must be perceived as a political battlefield in which different values, standards and principles are permanently contested and confronted (Priban 2002:125).

It can, of course, be argued that resistance to dominant perceptions is futile. However, from a disabled perspective such arguments seem disempowering. They might even be perceived as part of the dominant ideology and, thus, by their

existence prevent political change. The social model is not only a heuristic device for understanding reality. It is also a tool for political struggle.

In short, the social model is a tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and practises to facilitate their eradication (Barnes 2003:8).

Analysing law from a sociological standpoint involves interpreting legal ideas and relating them to social relationships in general. Focusing on the matrix which creates these relationships, it can be argued that such an analysis is specifically concerned with notions of justice:

Legal ideas are a means of structuring the social world. To appreciate them in this sense and to recognise their power and their limits, is to understand them sociologically. (Cotterrell 1998:192)

The texts sampled for this analysis are those used as guidelines when courts and administrators interpret the Acts. Court decisions interpreting the paragraphs of legal Acts are based on arguments and aims presented within these texts. Thus the legal ideas present in the Government Proposals and Parliament Standing Committee's Reports will shape the legal outcome. Participants in the legal process interpret these texts from a legal perspective. However, this does not exclude the possibility of analysing the legal ideas from a sociological perspective, to extend the analysis outside the scope of legal decision-making. To achieve this, the analysis has to reflect law's own methodology.

It does not necessarily *replace* [the legal participant's] perspectives or *contradict* them by the use of a specific methodology foreign to the diverse methods already used ... the methodology of sociological understanding of legal ideas is the deliberate *extension* in carefully specified directions of the specific ways in which legal participants themselves think about the social world in legal terms (Cotterrell 1998:189-190).

Thus, the present analysis aims to extend the interpretation of the legal ideas behind the Swedish reforms comparing them with ideas connected with social justice and the social model's understanding of reality.

### **Themes and areas used in the analysis**

The focus of this analysis is the relation, between the ideological content of the texts representing the official policy behind the 1994 reforms, and the ideological ideal of personal assistance according to social model theory. This means "*reading through or beyond the data*" (Mason 2002:149), interpreting how aspects in the texts fit or fight disabling assumptions. It means extending the legal interpretation to include the sociological assumptions that underpin those ideas (Cotterrell 1998).

A secondary content analysis of the Governmental Proposals and Parliamentary Standing Committee's Reports will produce knowledge showing how policy in Sweden view disabled people. This is, then, compared to the ideals of social model thinking. The interpretation is done on data, sampled from the texts, coded according

to its ideological belonging (Bryman 2001), an exercise which uses the themes of redistribution and recognition, and the areas of work and family life.

The Swedish relative model of disability differs from the British social model. How this difference presents itself in the reforms yields vital information as to why ideological contents might deviate from social model ideals. After this, the analysis focuses on the rights to services. Power over vital personal services is a fundamental tool against disablement from a social model perspective. The ILM's concept of personal assistance is, therefore, used as an ideal solution for services. Personal assistance independent living style is based on the core concepts of choice and control (Morris 1993).

A "self-determined life", as the ILM phrase it, comprehends the right to choose which context to participate in and social roles to perform. It also demands control over resources to enable development and exercising of individual capacities in these contexts. In this manner, the concepts of choice and control, generally limited to the assistance situation itself, have to be applied to the whole life project in this analysis. As the reforms comprise a parcel of ten rights to different services, the analysis will try to answer the questions of: Why is personal assistance provided in certain contexts? What kinds of service are provided instead of assistance in other contexts? And what are the ideological arguments for doing it this way?

Choice and control in a wider meaning, as the right to individual life-choices, what to participate in and what social roles to perform, demand a remedy of recognition. And choice and control connected to the more limited issues of personal assistance, as

having the control over resources, whom to employ and when to schedule assistance, demands the remedy of redistribution. Personal assistance, as an ideal, can, thus, be seen as a Janus-faced tool for both recognition and redistribution. The two kinds of oppression and the possible remedies to them (Young 1990; Fraser 1997) are, therefore, used as themes. The ideological preferences present in the texts behind the reforms are interpreted and measured, as to how and why they enable cultural and political-economic oppression, and if and how they provide remedies of recognition and redistribution.

While, different contexts and social roles can be valued as more or less important from an individual perspective, this dissertation is limited to an analysis of two areas comprising differing social roles. From an epistemological standpoint, the two areas of work and family life (parenthood) are chosen because they comprise social roles connected with status in society. The Swedish welfare state developed focusing on policies connected with work and family (Holgersson 1992). Reforms connected with family policy are also used as a means to provide women with economic independence (Esping-Andersen 1990). The Swedish state obviously finds these areas important. Also, feminist legal theorists focusing on the public/private divide (Fletcher 2002) connects assumptions of self-determination and dependency to these areas.

[F]inancial independence, emotional self-sufficiency, physical distance, cultural formality and sexual restraint have come to be dominantly associated with the “public”, while norms of dependence, care, closeness,

informality and indulgence have become emblematic of the “private” (Fletcher 2002:14).

Self-determination is the key concept for the ILM (ILRU 1999). Dependency is the assumption behind disablement (Finkelstein 1991; Morris 1993; Oliver 1990).

As, this analysis has the social model of disability as its ontological base, Fraser’s status model of recognition is used (Fraser 2001). This is not aimed at valorising group identity but to “*de-institutionalize patterns of cultural value that impede parity of participation and replace them with patterns that foster it*” (Fraser 2001:25 italics in original quote). Work and family are areas strongly targeted for participation parity in the Swedish welfare state. They also have a stark connection to assumptions relevant in this analysis. It can, therefore, be argued that these areas will yield essential knowledge of assumptions connected to disability.

### **Choosing and sampling documents for analysis.**

Legal reform proposals are put forth to the Swedish Parliament by the Government. They are the results of political decisions sometimes based on reports, from specially appointed commissions, and statements on the matter, given by authorities, organisations and other official bodies to which these has been referred. Government Proposals, thus, comprise the ideology of the executing political majority after reflection on the statements from societal bodies.

Government proposals are, then, subjected to negotiation between the political parties represented in the Parliament Chamber. The present proposals, comprising among other issues the right to personal assistance, were negotiated within the Parliament Standing Committee on Social Affairs and Welfare. Private Member Bills, both specifically addressing the proposal, and social affairs on a more general scale but containing relevant issues, also form part of this negotiation. The Social Affairs and Welfare Committee Reports present arguments for and against aspects in the proposals, where differing political opinions exist. In this way, both the ideology of the ruling political parties as well as the ideology of the parliamentary opposition, is present in the committee's report.

This analysis is performed on the level of ideology in law. It is, therefore, limited to the documents comprising the negotiated aims and arguments behind the reforms. These documents are viewed as official statements of political intention and, thus, used to interpret the actual acts in court rulings concerning individual cases. In the end, the acts and how the intentions behind them are interpreted by the courts will decide the actual outcome of the reforms.

The data generated are from the documents which contain the ideological thinking of the government, of the political opposition, and the negotiated outcomes found in the Parliament Standing Committee Reports. As the legal reforms of 1994 have been amended several times, a sample has been taken that excludes documents connected with amendments thought irrelevant to this study. Amendments dealing with fiscal matters, and distributing costs between the state and municipal budgets.



Clarifications concerning the applicability of certain labour regulations have also been made.

The final data set comprised:

(a) The original proposal and committee report behind the reforms.

- Government Proposal *Support and Service to Persons with Certain Functional Impairments* (Prop. 1992/1993:159)
- Parliament Standing Committee Report *Support and Service* (Bet. 1992/1993 SoU19)

(b) Amendment focusing on 'rocketing' costs that contains proposals to restrict the right to personal assistance, the negotiations and results.

- Government Proposal *Certain Issues on Personal Assistance* (Prop. 1995/1996:146)
- Parliament Standing Committee Report *Certain Issues* (Bet. 1995/1996 SoU15)

(c) Amendment to ensure persons older than 65 the right to retain personal assistance.

- Government Proposal *Personal Assistance to persons older than 65 years* (Prop. 2000/2001:5)
- Parliament Standing Committee Report *Personal Assistance over 65* (Bet. 2000/2001 SoU03)

**Valid, general and reliable?**

Using official documents makes it somewhat easier to assess the validity of research, as it will be possible to view the data at a later time. The fact that the documents used are created within the official realm, approved and archived by the source of them itself, also add to their validity. By, then, clearly stating which concepts are used as themes and why these are chosen, readers of this analysis can critically review the conclusions made.

The reliability of the analysis rests on the choice of documents and the data generated. Measuring ideological “preferences”, connected to the two themes, in both the social areas of work and family, makes it possible to cross-check the conclusions. If the Swedish reforms truly break disabling assumptions they have to do so in a manner that covers social roles connected to different spheres in society; spheres where concepts as self-determination and dependency generate differing and often gendered roles. This is necessary in order to reach any general conclusion on how the relative model views disability on a wider scale and to what extent it promotes empowerment instead of dependency. It is also necessary to draw more general conclusions on what the effects of personal assistance rights have on participation and inclusion in society; not only on the quality of service it provides compared with former in kind services.

## Chapter 4

### The ideology of normality and the assumptions of dependency behind the assessment criteria

#### Is everyone allowed the right to choice and control?

The 1994 legal reforms are based on the Swedish relative model of disability. This is fundamentally different from the British social model in that it does not break the causality between impairment and disability. The question, of what effect the keeping of causality has on society's views of disabled people and the reforms enacted according to these, has to be answered to gain insight into how the legal ideas in the reforms fit with ideas of social justice.

Personal assistance in the Swedish reforms is certainly based on the independent living example. The Stockholm Independent Living Cooperative (STIL) was highlighted in the government proposal as an "interesting attempt to create alternatives to home help services and increase freedom of choice for disabled people" (Prop. 1992/1993:159: 45). At the same time, the reforms are based on the Swedish relative model of disability which, claims that "*handikapp* is not an individual characteristic, but a relation between the injury or disease and the individual's environment" (Prop. 1992/1993:159: 42). Therefore the central question is: what effect does the Swedish model have on the social model and ILM philosophy.

One of the fundamental assumptions of ILM is that anyone is capable of exercising choice and asserting control over their life (Morris 1993). In a social model setting,

the state has an obligation to provide resources, enabling choice and control, to anyone and everyone who need them. The Swedish reforms, however, circumscribe the group granted the right to personal assistance in a two-step process.

- First, applicants must fit into one of three identified categories forming the *entitled group*. This group has a right to be assessed for any of the ten services under the Act.
- Second, an assessment takes place, based on individual needs as well as situations in which assistance is needed. This determines whether or not personal assistance is required. This procedure is the same for the other rights.

The group entitled to rights under the act, henceforth referred to as the *entitled group*, is described using a medical model approach. Diagnosis is the basis for criteria describing the first category – “persons with intellectual impairments [*utvecklingsstörning*], autism and autistic traits” (SFS 1993:387 sec.1.1.).

*Utvecklingsstörning* in literal translation is “developmental disorders”. The second category is described as “persons with significant and permanent intellectual *funktionshinder*, due to traumatic brain injury acquired in adulthood and caused by external violence or physical disease” (SFS 1993:387 sec.1.2.). Here the medical model is present in the connection between *funktionshinder* and a specific injury or disease.

The description of the third over-arching category uses medical model criteria in a manner that firmly establishes the assumption of dependency behind this. The category is described as:

persons with other permanent, physical or psychiatric *funktionshinder*, which obviously are not due to normal processes of ageing, if they are extensive and cause significant difficulties in daily life activities and, thereby, extensive need for support and service. (SFS 1993:387 sec.1.3.).

*Funktionshinder* is, thus, a qualifier to the rights. It is described as a limitation or obstacle which is, “a result of injury or disease”, and prevents persons from performing activities “in the manner or within the boundaries of what is considered normal” (Prop.1992/1993:159:167). This is almost identical with the ICIDH’s (WHO 1980) definition of “disability”. Disabled people are deemed as unable to perform activities in the “normal” manner. In fact this non-normal characteristic is the basis for accessing the rights.

### **The use of limiting criteria to control the entitled group.**

The reforms of 1994 do not provide rights to all disabled people. The responsible minister clearly states that, the majority of disabled people should be able to get support and services by provisions in the general legislation. The new reforms are aimed at “those who have the greatest need of societal support”, and, thus, the reforms are “concentrating on the persons most *funktionshindrade*” (Prop.1992/1993:159: 55). The reason behind reforms directed towards this group is

probably their miserable conditions highlighted in a government inquiry report (SOU 1990:19). This shows lack of choice and control in the service situation which lead to disempowerment. Only eight per cent of the disabled people in the survey could choose who would provide care in very private situations. This eight per cent figure is quoted both in the government proposal (Prop.1992/1993:159) and the committee report (Bet. 1992/1993SoU19).

The *entitled group* comprise of persons having a comprehensive and permanent *funktionshinder*.

It shall be of a character or extent that strongly influence several life areas at the same time ... for example if a person as a result of *funktionshinder* is very dependent on technical aids on a daily basis, or has recurrent need of another person's help (Prop 1992/1993:159:55)

The *funktionshinder* shall, thus, cause significant difficulties in daily life. That is, inability to manage daily routines independently of others, for example "toilet chores, dressing, meal management, transportation indoors and outdoors, occupation or performing necessary training or treatment" (Prop.1992/1993:159: 56). Difficulties in communicating with others as well as understanding communicated information, is also mentioned, as is the risk of isolation. The difficulties shall, then, cause extensive need for support and service in quantitative and/or qualitative aspects.

The extensive use of qualifying criteria to describe the group, embraced by the reforms, generates an added assessment. Before the actual needs assessment,

persons have to be assessed as fitting the *entitled group*. Assessment procedures run the risk of becoming an actual obstacle for autonomy and independence (Morris 1993). This emphasises the professional approach to services. It creates positions, where professionals act as experts on disability and gatekeepers of scarce resources. The two-step assessment procedure of the Swedish reforms is built around the expertise of professionals.

I [the responsible minister] am aware of the difficulties of assessing group belonging in every individual case. It is, according to my opinion, important that, assessments of these issues are done by staff with knowledge of *funktionshinder* and its consequences. ... In specially complicated situations, or if staff with sufficient knowledge within the area is not employed ... statements should be collected from staff within for example ... the rehabilitation system” (Prop.1992/1993:159: 57)

Inquiries could also be collected from professionals in health care, child care, school health care and social services among others. In this manner, the Swedish reforms take the medical model, used in the descriptions of the group, and connect this to the ‘administrative’ model of disability. According to Finkelstein (1993), this is an ‘adapted’ model shifting the power over disabled people from the medical professions to the administrative professionals of the welfare state without addressing the basic assumptions connected with disability.

Most of the limiting criteria are connected to comprehensiveness of impairment but the reforms, also, clearly exclude age-related impairments. The reason given is that, the reforms aim to

provide persons with life-long or very long-lasting *funktionshinder* the special support which, they need to build and retain life conditions equivalent to other persons (Prop. 1992/1993:159: 56).

Thus, persons with impairments obviously not due to normal ageing are still entitled to some of the rights in the reforms, while elderly people with similar or same needs are not. This seems to imply that, it is natural for old people to be dependent and deprived of choice and control, as if dependency is a characteristic of age. From a social model perspective increasing dependency is seen “not as the inevitable consequence of the ageing process but as the product of dependency creating structures, services and assumptions” (Oliver 2001:4-5).

The right to personal assistance in the Swedish reforms was explicitly denied to persons older than 65 years, the general retirement age. The reason for this was economical (Prop.1992/1993:159; Bet. 1992/1993 SoU19). However, limiting personal assistance, on account of age, raised opposition from both political left and right. Several private member bills pointed out the insecurity and lack of continuation this creates.

We [the Christian Democrats] have to question the proposal that, in legislation, exclude benefits to those who have turned 65. Primarily, this



applies to those who have personal assistants and at a fixed age-limit will lose the continuation these offer (Mot. 1992/1993 So24).

The majority of the private member bills opposing the age-limit do not propose equal rights to people over 65. They propose a right to keep assistance already granted before retirement age. In spite of opposition to the age-limit and the parliament committee viewing it as morally doubtful to cut rights for economic reasons, the age-limit was incorporated in the legislation (Bet. 1992/1993 SoU19).

The age-limit continued to be the subject of political conflict. Finally, a government proposal extending the right is made (Prop. 2000/2001:5). Once again miserable conditions, as well as huge differences depending on where the users live, are the cause. The ideological conflict existing in the parliament eventually forced a compromise to be made in the reforms. However, this is limited to those already granted a right to personal assistance before turning 65.

The reason is, foremost, that the government want to promote continuity of the service or the benefit. A person who has become used to and established his [sic] life on the basis of the support and security which can be provided through assistance, shall not need to feel worried facing their 65<sup>th</sup> birthday (Prop. 2000/2001:05)

Furthermore, the proposed extension grants only the right to keep the level granted before 65. A right to higher level of support is deemed as impossible to assess. Deciding what, part of the increased need is connected to "process of normal

ageing/age related disease or causes due to disease or injury behind the original *funktionshinder* deteriorating” (Prop. 2000/2001:05), is too difficult.

### **Needs accepted as ground for personal assistance**

According to the social model, personal assistance services “shall serve people with all types of impairments and all ages on the basis of functional need” (Barnes 1993:77). When the reforms were enacted in 1994, personal assistance was not limited to persons with specific types of impairments. It was provided to persons, regardless of type of impairment, who needed assistance in “demanding or in different respect complicated situations, as a rule of very personal character” (Prop. 1992/1993:159: 64). However the proposal stated that:

It should be decisive that the individual need help to care for tasks connected with personal hygiene, dressing and undressing, eating or communicating with others (Prop. 1992/1993:159:64).

This was one of the areas singled out in the government proposal (1995/1996:146) trying to cut rocketing social insurance costs connected with personal assistance. The needs described in the original proposal (1992/1993:159) were not explicitly incorporated in the Support and Service Act (SFS 1993:387 sec.9.2.). Now the proposal was to incorporate these examples of “fundamental needs” (1995/1996:146: 13) in the act as specified assessment criteria.

[I]t clarifies the care needs which, after individual assessment, are required to receive personal assistance ... The clarification means that it is, foremost, persons with physical *funktionshinder* and the most extensive needs who will be entitled to ... personal assistance (1995/1996:146:13).

However, as several of the private member bills pointed out, the definition of fundamental needs incorporated in the act would limit the group entitled to personal assistance to persons with physical impairments. More particularly, persons who in theory are physically able to dress, eat etc., but in practise unable to do so without motivation and activation, are at risk of loosing their personal assistance rights.

Evident discrimination, of persons with psychiatric *funktionshinder*, exists today concerning access to rights regulated in [the Act]. The Left Party [joint member bill expressing party opinion] fear that this discrimination will increase, with the strengthening of the impression that, the act will mainly apply to persons with *funktionshinder* of physical character (Mot. 1995/1996:So13)

Opposition to the proposal came from within all parties. This paved way for a compromise where the proposed restriction of the group was slightly softened. The outcome was a new section of the act, sec.9.a (Bet.1995/1996 SoU15), which incorporates a definition of personal assistance and the needs required for accessing this.

With personal assistance according to sec. 9.2., is intended a personally designed support which, is provided by a limited number of persons, to those who, due to extensive and permanent *funktionshinder*, need help with their personal hygiene, meals, to dress and undress themselves, to communicate with others or help of other kind which, presupposes thorough knowledge about the impaired person (fundamental needs).

(SFS 1993:387 sec.9a)

“Fundamental needs” are the key. Disabled people assessed as having such needs access the right to personal assistance in these and other situations as well.

### **Separation and specialisation in the reforms**

The “age-old problem of separating out those who would not from those who could not conform to the new order” (Oliver 1990:33) is still present in modern capitalist welfare societies. Further separation and specialisation is perceived as necessary to manage and control sections within this group. The 1994 reforms are an almost perfect example of this separation and sub-division of groups.

While *funktionshinder* from a relative model perspective is thought to be a neutral and value-free description (Söder 1982), it is clear that the three categories of the *entitled group* feed into the medical and administrative models of disability. In particular, the description of category number three – overarching the others – incorporates the ideology of normality as well as the assumption of dependency. An individual described as having or not having certain capabilities can, of course, receive

recognition on the individual level (Honneth 2001; Danermark and Gellerstedt 2004). However, it is questionable if recognition in the form of participation parity (Fraser 2001) will be possible. Important social roles are, after all, played out on arenas perceived to demand ability to perform “in the manner or within the boundaries of what is considered normal” (Prop.1992/1993:159:167). Surely, the perceived inability to do this will cause “*social subordination* in the sense of being prevented from *participating as a peer* in social life” (Fraser 2001:24).

The right to personal assistance is the only service provided according to autonomous ideals in the reforms. Personal assistance follows the individual service user. Direct payments connected to it enable self-determination (Morris 1993; Ratzka 1997). In the reforms, personal assistance is, almost exclusively, granted to persons with physical impairments. It is doubtful if disabled people with the need of motivational and activating services will receive personal assistance.

It can be argued that the reforms and especially personal assistance are enacted in order to alleviate the miserable conditions identified in the parliament inquiry report. This inquiry can be seen as the result of political pressure from a group with a “relatively” strong position in society. In particular, the example of STIL, which probably is incorrectly perceived as mainly comprising persons with physical impairments, shows the relative strength of this group. At the time of the inquiry, persons with psychiatric impairments were still institutionalised to a large extent. Their unfulfilled needs and unacknowledged right to inclusion are not brought out in the surveys.

The Swedish relative model's view of disability as something caused by injury or disease creates a disabled identity where individuals are viewed as incapable of performing normal social roles. The effect of this in the reforms are that disabled people are constituted as inherently flawed. The problem of dependency is assumed as due to this individual characteristic, not to the organisation of the welfare system. Disabled people in Sweden are viewed as a category that needs to be controlled and managed by experts, not as persons in their own rights entitled to self-determination. The question is, therefore, why are some persons within the group provided with autonomous rights to personal assistance? Why are they perceived as being capable of managing themselves?

## **Chapter 5**

### **Disabling assumptions connected to labour market**

#### **The perceived ability to work as basis for autonomous rights.**

As, the area of work is connected to assumptions of competence and self-sufficiency in society (Fletcher 2002), it is interesting to investigate how these assumptions connected to the social area interact with assumptions connected with disability. Does the disabled identity created by the Swedish relative model of disability have consequences for disabled people in connection with work? How do assumptions of self-determination connected with work interact with assumptions of dependency connected with disability?

The organisation of the labour market has been identified as the chief disabling mechanism (Oliver 1990; Gleeson 1997) and the importance of labour is not just emphasised within capitalism but also by the political left (Abberley:1997). Disabled people ousted from the labour market are perceived as burdens and this perception is the central basis for the assumption of dependency.

As the concept of work is frequently connoted with gainful employment, it should be clarified that work in this dissertation does not mean occupational activities rewarded with salaries. The disabling organisation of labour frequently defines work as something done by non-disabled people while disabled people's work are often defined as in terms of occupational therapy, vocational training etc. The Swedish reforms, thus, provide disabled people with a right to what is called *occupational activity*. While it is clearly stated that this is not to be viewed as employment, the activities can be of the same kind that:

“exist within day centres and other forms of occupation as well as at Samhall [state company providing sheltered employment] and employers on the regular labour market” (Prop. 1992/1993:159: 181).

Swedish style democracy and welfare is centred on work. The common principles of social policy being its purpose of:

- de-commodification, i.e. protecting the workers from the whip of the market
- defining the boundaries of collective identity; social identities, status communities, solidarities (Esping-Andersen:1990).

Principles behind social policy connected to labour, thus, belong to both the area of redistribution and recognition (Fraser 1997). De-commodification challenges the “systematic institutional processes which prevent some people from learning and using satisfying and expansive skills in socially recognized settings” (Young 1990:38). Work also promotes a valued identity, status and solidarity. It provides a position where people are able “to play and communicate with others or to express their feelings and perspectives on social life in contexts where others can listen” (Young 1990:38). The Swedish reforms recognise both these aspects of work.

To have a job is of vital importance, for life quality and participation in society, for all individuals. It is mainly through work that adults can be ensured good material provisions. Work, however, is not only material welfare. It is also a response to fundamental human needs for fellowship, development and a meaningful life (Prop.1992/1993:159: 88).

It is also evident that access to work, or ability to work, is considered part of normality.

Public measures must be designed so that, persons with *funktionshinder* or families with a child with *funktionshinder* , shall be able to live as normal a life as possible. Both parents shall, if they so desire, be able to remain in gainful employment ...The ambition shall be that, persons with *funktionshinder* – just as other citizens – shall be provided with possibilities



to acquire a good education, be gainfully employed ... (Prop: 1992/1993:159:43-44).

### **Disabled people's right to employment**

Personal assistance is not the only right in the reforms enabling work. The Support and Service Act also provides an explicit right to *occupational activity* (SFS 1993:387 sec.9.10.) This right exists already under the Special Care Act (SFS 1985:568) and the group entitled under the old legislation maintain it. The issue in the new reforms is whether it should be granted to the whole *entitled group* – also including category three.

[M]any persons with extensive *funktionshinder* ... lack other occupational activity outside the home. In view of this, it would now be desirable to propose that, the whole group entitled under the new law, is given a legislative right to occupational activity. However, due to the situation of state finances I deem this impossible at the present time (Prop.1992/1993:159:90).

It is evident that assumptions regarding disabled people's capacity on the labour market are found behind the right to *occupational activity*. These assumptions are not based on functional needs but on the disabled identity created by the relative model. As high unemployment figures are cited as reason for this right (1992/1993:159), it is safe to assume that disabled people's low presence in the labour force is contributed to *funktionshinder* and inability to perform activities "in the manner or within the

boundaries of what is considered normal” (Prop.1992/1993:159:167), rather than disabling structures within organisation of labour.

It can be argued that the right to *occupational activity* is valuable and important for disabled people in need of this. But it is a huge difference between providing services based on needs assessment and presuming needs because persons fit categorisation and classification criteria based on impairment. It is also a huge difference between perceiving disabled people as incapable of work and questioning the concept of work and the disabling structure of labour market.

Moreover, providing *occupational activity* does not necessarily generate redistribution:

Within the special care organisation certain compensation ... is paid out to a person participating in occupational activity ... The aim is to actively stimulate the individual to participate in the activity. I recommend that the responsible authority pays some sort of compensation to the individual for participating ... It should be emphasised that occupational activity is not to be seen as a form of employment. It is not ... gainful employment and its purpose is not to produce goods or services (Prop. 1992/1993:159:90).

Disabled people are, thus, supposed to feel “fellowship, development and a meaningful life” without receiving “good material resources” (Prop.1992/1993:159:88) from participating in occupational services. Fraser (1997) argues that recognition without redistribution does not work for bivalent collectives, like disabled people.

Thus, it does not matter if disabled people are provided with work in order to give individual recognition unless this is concretely backed up with redistribution. In fact, valued identities follow from gainful employment rather than occupational activities.

Other people work, disabled people do *occupational activities*

As work is connected to characteristics like self-determination and independence it is not surprising that, personal assistance is not provided during time spent in *occupational activity*. This was highlighted in the 1995/1996 amendment trying to cut costs. In a slightly indirect manner personal assistance during time spent in *occupational activity* was excluded.

Children and adults with *funktionshinder's* need for special support in for example child care, school and occupational activities should in principle be provided within the framework of the municipal organisation. Personal assistance shall therefore ... not replace staff needed to run the service. It is the task of the responsible authority to make sure that, resources [for example extra staff] necessary in consideration of the needs of the person with *funktionshinder*, is supplied (Bet. 1995/1996 So15)

The result was a new section in the Support and Service Act stating that care is included within *occupational activity* (SFS 1993:387 sec.9 c). This excludes the right to personal assistance since this is only provided if needs are not satisfied in another manner. Thus, during *occupational activities* care is provided after communitarian principles. Participants are viewed as a collective group justifying standardised

solutions (Rothstein 2002). Resources upholding the services are part of the larger municipal budget making gatekeepers of administrators (Oliver 1990).

It seems that employability, or at least the absence of evidence to the contrary, is an important factor to access rights to autonomous services. There is a huge group of disabled people unemployed, not having the right to *occupational activity*. While this group have personal assistance during activities occupying their days, it can be argued that they do so due to an at this time indeterminate work identity. Whether or not this breaks assumptions connected with dependent social roles is questionable. It is more probable that this is connected to the Swedish relative model of disability where “*handikapp* is affected by the individual’s living conditions”, being “the consequences an injury **can** [emphasis added] result in” (SOU 1976:20: 45-50).

### **Care of disabled people as obstacle to work**

The reforms of 1994 are not solely directed at disabled people. Their aim is also to provide services alleviating the burden of having a disabled child. Personal assistance to disabled children is clearly aimed at “parental need for relieving of care” or making it possible for “parents to remain in gainful employment” (Prop.1992/1993:159.43). Swedish social policy breaks the divide between public and private spheres. This is especially prominent since the 1960s when women entered the labour market (SOU 1990:44; Holgersson 1992). Female economic dependency is the reason for focusing on this divide (Fletcher 2002) and it can be argued that the intentions of the 1994 reforms in this area are, foremost, to enable women to escape this.

Trying to cut reform costs in 1995/1996 resulted in several proposals from the expert advisor investigating the issue. One of these was to deny children personal assistance while participating in child care and school. Another was to totally deny disabled children under the age of 16 the right to personal assistance. However, the government declared itself unwilling to make such changes for all disabled children. Children with extensive impairments were still going to be provided with a right to personal assistance when they participated in municipal programmes.

There is ... certain children with severe *funktionshinder* for whom parental responsibility in combination with for example care benefit, relief services, child care and school is not sufficient. The possibility to receive personal assistance shall even in the future exist for these children (Bet. 1995/1996So015).

Also connected to this issue was a proposal to include a section in the Assistance Benefit Act (SFS 1993:389) clarifying parental responsibility. The assessment should, according to this, take into account "that which normally can fall within the framework of parental responsibility, which ... is the duty of all custodians" (Bet.1995/1996So015). This proposal met with opposition from several political parties. It was regarded as offensive to stress general parental responsibility to those already taking on more responsibility than others in society. Once again the possibility to work was emphasised.

The assistance reform opened up totally new possibilities for these parents. For example the possibility to gainful employment, something other parents consider a societal right (Mot.1995/1996So14).

Disabled children obviously are not the target group for personal assistance. It is considered enough for them to receive care, even of very intimate character, after communitarian principles during time spent in child care, school and relief services. Autonomous services as personal assistance are not deemed necessary except in very special cases. The conclusion has to be that this is aimed at parental autonomy.

Hence, it can be argued that assumptions of dependency connected to children in general enhance assumptions of dependency connected with disability. As pupils are enrolled in school up to the age of eighteen, this would indicate that disabled people are viewed as children throughout adolescence. The assumptions of dependency, and their resulting view of disabled people as incapable of self-determination, are very much present during these formative years. The right to personal assistance for disabled children and teens is in reality a parental right to autonomy for parents of disabled children.

### **Capacity to work valued, not disabled people**

The compensatory dimension of the Swedish welfare system allows its citizens to escape being financially dependent on the family but does little to break assumptions connected with social roles. This certainly is the case with personal assistance to disabled children. It is clear that disabled people are perceived as incapable of self-

determination during childhood and adolescence. Thus, communitarian services are provided in child care and school. The group escaping this is children with impairments that so extensive that they are thought to “disturb” their parents right to self-determination. Personal assistance is provided in those cases when the communitarian system fails to un-burden the parents in any other way. In this manner non-disabled parents, especially women, are recognised as having a right to participation parity (Fraser 2001). The group of children provided with a right to personal assistance in school and day care is small. However, the parents do have a strong position in the battlefield of legal ideology (Priiban 2002)

Disabled people can break the assumptions of dependency and receive autonomous services in the form of personal assistance especially if they are of working age and at the disposal of the labour market. When disabled people are granted *occupational activity* this is viewed as evidence of incapacity. Thus, neither adequate compensation nor right to personal assistance is deemed necessary. Fraser’s (1997) theory of a bivalent collective demanding both recognition and redistribution, as well as her status model of recognition as participation parity (Fraser 2001) explain this. It is clear that the reforms aim to provide recognition on an individual level to disabled people participating in *occupational activities*. However, this does not provide redistribution regularly connected with work. Participants in *occupational activities* are not viewed as peers to the working population and this clearly devalues them both on an institutional and individual level.

It can be argued that, the Swedish relative model and its created disabled identity not only have consequences for how disabled people are perceived, but for what

activities will be considered as gainful employment and worth the recognition associated with the concept of work in general. After all, the tasks can be the same but if provided through the labour market agencies they are considered employment and if through the social service organisation *occupational activity*. The first provides redistribution in form of salary, the second does not. Employment merits autonomous rights. *Occupational activity* does not. It is, thus, safe to conclude that, having gainful employment and capacity to fit into the labour market is recognised as a sign of capacity for self-determination, while having a disabled identity is recognised as being dependent and incapable of work.

## **Chapter 6**

### **Family and the concept of care in the Swedish welfare state**

#### **Breaking the public private divide**

While, participating in the labour market comprise an assumed competence for self-determination, performing in social roles such as parenthood connected with family life is clouded with assumptions of dependency (Fletcher 2002). Gainful employment as an activity or even individual goal, thus, is recognised and rewarded with autonomous rights in the reforms. As, social roles connected with family life and particularly parenthood in general do not carry assumptions of self-determination in themselves, the question is how this will interact with assumptions connected with disability? Does Swedish social policy in general break assumptions connected with family life? And if so, will this have an impact on assumptions of dependency connected with disability are affecting the reforms?



Family policy is another important area in the development of the Swedish welfare state. Social reforms focused on labour market are initiated by the economic crisis in the 1930s, and policies directed at family life are initiated by the concurrent population crisis. Free maternal health care, preventive health care for children, mothers' help and prohibiting expulsion of pregnant women from jobs (Holgerson 1992) were followed by a huge wave of social reforms during the 1960s providing also for the elderly and disabled people (Holgerson 1992). These initiate the break of the divide between public and private and the undermining of the assumptions of female dependency.

The concept of care is deeply connected to the concept of family. Caring **for** family members is the typical female role of providing un-paid, voluntary care. Caring for is providing direct hands on care. Caring **about** someone belongs to the typical male role – provider of resources (Dalley 1996).

The 1995/1996 proposal and the negotiations surrounding this, to clarify the issue of parental responsibility for disabled children, highlighted these two aspects of care.

The governmental proposal pointed to the Parental Act and the parental responsibility laid down in this. However, the responsibility in this is a responsibility to care about children.

The Parental Act is directed at the judicial care of children – not the actual care. For example parents are not obliged to teach children to read, but they have a duty to make sure that children go to school. According to the

text of the government proposal, however, considerations shall now take into account that parents also have the actual care duty for their children, not just the judicial, as hitherto under the legislation, when assessments of rights to personal assistance are done for children under the age of 16 (Mot 1995/1996 So17).

The Swedish welfare state provides services for children through its organisation of child care, education, etc. It offers to take over the parental responsibility to care for children from the private sphere. What remains is the parental responsibility to make sure children receive the necessary care. The welfare state does not intend for parents to disabled children to take on responsibilities exceeding this. Thus:

a custodian can be a personal assistant, if the effort can be deemed to exceed what is included in parental responsibility and if it is in situations where the prerequisites for ... personal assistance are applicable (Bet. 1995/1996 So15).

Care for disabled children is organised and provided very much as care for non-disabled children. Swedish municipalities provide child care and schooling for all children. If a disabled child is in need of additional support, within these services and other municipal programmes, this falls within the municipal duty. Only when the child's impairment is viewed as so 'severe' that it is not possible to provide support within communitarian services will personal assistance be provided.

Care for disabled children outside municipal social service organisation and personal assistance is also a responsibility for the welfare state. The right to personal assistance as well as several of the other rights provided under the Support and Service Act aim at providing care for disabled children. In rights to services as home relief service, short stay away from home, leisure care outside of school hours, and family-home or housing with special services for children and adolescents outside their own home (SFS 1993:387 sec. 9.3.5-8.), caring for disabled children is made a public responsibility in the reforms.

Thus, the rights directed towards disabled children in the 1994 reforms are very much part of the welfare system's organisation in Sweden. One of its chief aims is to break the divide between public and private and enable women to escape economic dependency. In this respect, rights for disabled children in the reforms are in practise directed at the family unit. The aim of personal assistance is for example:

often to satisfy the parents' need of relieving care or to provide the family with possibility to carry out those activities which the child does not participate in. (Prop.1992/1993:159.60)

### **Support to enhance parental competence in parents to disabled children**

In its 1990 inquiry report, the Government Commission on Disability found disabled people to be in a state of disempowerment. This was attributed to the organisation of services and the culture of professionalism. Professionals have, by the force of their knowledge and professional status, authority to interpret disabled people's needs. If

they also control the necessary resources to satisfy those needs, there is very little room for self-determination (SOU 1990:19).

The presumed incapacity connected with impairment generates a need for professional experts. The reforms of 1994 underline this. It is present, foremost, in the right to advisory support (SFS 1993:387 sec.9.1.).

[P]ersons with severe *funktionshinder* and their relatives have such a vulnerable situation that their access to supplementary, special expert support shall be legislated (Prop.11992/1993:159.59).

This perceived need for expertise to manage impairment is present in services provided through the welfare system. It is also present in the rights connected to the area of family life within the reforms. Families with disabled children are highlighted in the proposal regarding the right to advisory support. To become parent of a disabled child is for most people “a severe psychological crisis”.

Parents are often put in a state of disorientation, bringing insecurity of what the family future has in store ... Early and qualified psychological and practical support can be decisive for the possibility of the parents to sort the situation out and for their possibility to provide the child with good care and security. (Prop. 1992/1993:159.60)

While the Swedish reforms obviously see impairment as something that needs to be managed with expertise, it is also evident that non-disabled parents, with the help of

professionals, can acquire this expertise. Parental competence is viewed as natural but still amenable to support and advice. Thus, the commonly assumed ability to care about children is strengthened through the right to advisory support to accommodate expertise viewed necessary to care about a disabled child.

The parental responsibility of judicial care to disabled children was also behind an extended right to so called “contact days”. These are part of the temporary parental cash benefit which also covers the need for parents to stay at home from work to care for a sick child. Two contact days per year and per child are provided to enable parents to visit their child in for example child care or school. This is extended in the reforms, providing parents to disabled children with a right to ten days per year and disabled child. The right is also extended from 12 to 16 years of age. .

Thus, the parts of the welfare system that enhance parental competence are extended to provide also for competence necessary to care about a disabled child. A right to extended contact days are provided under the General Insurance Act (SFS 1962:381 chap.4 sec. 10.3.) and a right to advice and support under the Support and Service Act (SFS 1993:387 sec.9.1.). In this manner parents to disabled children’s competence to care is not perceived as different from parents to non-disabled children. The difference is in the degree of advice and support required. Their parental competence is therefore recognised and valued by society.

While, the right to advice and support in the reforms is also a right for disabled people, the possibility of parenthood was not present in the arguments for this. The

issue of for example advice and support to parents with learning difficulties is not addressed. The right is concerned with:

efforts of advisory and generally supportive character, where the medical, psychological, social and pedagogical aspects of *funktionshinder* is considered (Prop. 1992/21993:159.59-60)

This might of course be interpreted as including advice necessary to fulfil parental responsibility for this group. But, as *funktionshinder* is defined as an inability to perform in normal social roles it is probable that the existing assumptions of dependency and incapacity will create difficulties for disabled people to access this right in connection to parenthood. Assumptions of dependency and their resulting assumption of disabled people's incompetence in the parental role are present elsewhere in the reforms which relate to the right to personal assistance. These assumptions are part of the ideology incorporated in the reforms and are used as a matrix for interpreting when and how disabled people will be provided with the right to advisory support.

### **Assumed parental incompetence in disabled parents**

The assumption of dependency constitutes disabled people as asexual, child-like and, therefore, unfit for parenthood (Shakespeare et.al. 1996). Thus, it is not surprising that the question of personal assistance to disabled parents only entered the Swedish reform process after the Council of Legislation's review of the proposed reforms. And even then it did not address the assistance needed to fulfil the parental

role. Instead, the argument if and when to grant personal assistance to disabled parents was based on the emotional and developmental needs of the child during its first years.

A child's need for care is principally not a task for the parent's personal assistant. During the earliest period in a child's life it is, however, emotionally and practically totally dependent on an adult, in most cases a parent. If the parent, then have support from a personal assistant it is, therefore, natural that the assistant, if it is a person suited for this, also help the disabled parent to manage the practical care for the child, for example with breast-feeding and change of napkins. The needs of the child can obviously motivate other or additional support measures. The responsibility for this rests with the municipal social service organisation. According to the Social Service Act the municipality has a duty to, in close cooperation with the home, provide the protection and support children, who run the risk of unfavourable development, need. (Prop. 1992/1993:159: 176).

It is explicitly stated that personal assistants in these cases help the disabled parent "with the care [of the child] he or she cannot provide him/herself" (prop. 1992/1993.159.66). As the concept of normality lies behind the view of *funktionshinder* in the Swedish relative model and the reforms, this must mean that disabled parents are not deemed competent to perform child care in the 'normal' manner. It is a reference to impairment and to the inability to perform the actual care of the child.

As discussed above, the Swedish welfare system equates general parental responsibility with caring about children. The responsibility of actual care, the caring for children is incorporated in the welfare system. While, non-disabled parents can choose to care for their children themselves or use the services provided within the welfare system, disabled parents do not have this choice. In fact, disabled parents in need of personal assistance to perform the actual care of children are prevented from doing this, even in situations when they are expected to do so by the welfare system, during holidays and leisure time, and after child care and school hours.

It can be argued that this denial of parental responsibility for actual care prevents disabled parents to take on the judicial responsibility of caring about. How will a disabled parent make sure the child goes to school and learns to read, when the tasks of tying the child's shoes and following it to the school is not part of the right to personal assistance.

### **Parenthood enabled and parenthood prevented**

Non-disabled parents to disabled children have rights to a series of services enabling them to take on and carry out the parental responsibility. They are provided with advisory support aimed at giving them expert knowledge which will enhance their ability to provide the best care and support to their children. They also have rights to services relieving them of the burden of the disabled child, allowing them to take part in activities where the child is not included, spending time with the siblings alone.



Disabled parents are not provided with explicit rights to advisory support to perform well in the parental role. If they have the right to personal assistance for their own personal needs, this is not intended to provide assistance with the caring for a child. And if disabled parents do not belong to the group entitled to personal assistance this is not provided when the need for this arises due to parenthood.

Swedish social policy breaks the public-private divide in that it takes over the responsibility of actual parental care. However, this break does not seem to have affected the assumptions behind the social role. Women still perform the majority of care, though now in paid capacity. While, this breaks the economic dependency of women and bring recognition on an individual level, it must be concluded that the recognition of participation parity (Fraser 2001) is not provided. Thus, the concept of care still defines women and their roles within society (Dalley 1996). Disabled people are viewed as incapable of fulfilling the social role of parenthood. Again, this must be viewed as a consequence of the Swedish relative model and its definition of *funktionshinder*. As, this is viewed as an inability to perform activities “in the manner or within the boundaries of what is considered normal” (Prop.1992/1993:159:167), it excludes disabled people from the normal social role of parenthood. The conclusion must be that assumptions of dependency connected to family life and the concept of care as well as disability remain firm in the reforms. Becoming a disabled parent does not mean that autonomous rights are provided to perform in that role. While, assumptions of self-determination connected with the concept of work qualify disabled people for personal assistance, assumptions of dependency connected with the concept of care do not.

## Chapter 7

### Conclusions

#### **Struggle for social change**

In Swedish social service organisations, the recently enacted right to personal assistance and direct payments signify a possible paradigm shift. Communitarian ideals of standardised services imposing collectivist moral ideas of the suitable life are found throughout the development of the welfare state in connection to disabled people. The legal reforms of 1994 seem to break away from this notion and acknowledge the self-determination and autonomous rights of some, if not all, disabled people.

However, autonomy in the form of personal assistance is not provided to all and certainly not in every social role. If, law and legal reform are seen as a battlefield where ideological principles within dominant and subordinate groups struggle for hegemony, the 1994 reforms are the result of the relative strength of some subordinate groups in Sweden. It can be argued that, the subordinate group with most power to further their interest against the dominant ideology is non-disabled parents of disabled children. It is certainly the case that several of the rights under the Support and Service Act are aimed at alleviating the burden of caring for a disabled child. Attacks on this group during the amendment due to rising costs also generated support in the form of private member bills from a very broad political spectrum within the parliament. This possibly is an indication of political support for their perspective.

Making it harder for disabled children to access personal assistance under time spent in child care, school or other municipal activities, does have an obvious and stark adverse effect on parental obligations. It means parents have to provide the logistic glue between these compartmentalised activities and function as backup when the child cannot participate in a planned activity. This problem can be seen as the reason for allowing children with extensive impairments the right to personal assistance in municipal activities. Communitarian services and their standardised solutions will fail more frequently for children with extensive impairments. To enable their parents the same relief as parents to other disabled children personal assistance is provided. This has nothing to do with the disabled child or adolescent's right to self-determination or integrity.

The other subordinate group that can be seen as having a relative position of strength in the struggle for autonomy is persons with physical impairments. The focus on "fundamental needs" as criteria for the right to personal assistance certainly singles out this group for self-determination. It can be argued that other groups comprising persons with functional needs of personal assistance, just as qualifying and necessary to fulfil for self-determination, will have an almost impossible fight to access this. It is hard to avoid the existence of the STIL example as anything but decisive in this outcome. Although STIL has members with a range of impairments, the prevailing impression is of a cooperative of persons with mainly physical impairments.

The two groups succeeding in pushing through changes in the legal reforms can, thus, be said to comprise:

- First, those already able to negotiate self-determination through agreement with municipalities before the legal reforms, for example STIL.
- Second, those parents able to negotiate this right either in their own interest or their children's.

### **Redistribution in the form of access to work or direct payments**

The goal of “full employment” and the de-commodifying character of social policy in the Swedish welfare state both feed into the distributive paradigm of social justice. Direct payments for personal assistance can, thus, be seen as fitting the organisation of this. Self-determination is also a concept closely connected with perceptions connected with labour market participation. Arguments in the reforms behind rights to services aiming for relieving the care burden of a disabled child are often connected to enabling participation in the labour market for their non-disabled parents. This is part of a process whereby social policy breaks the divide between public and private spheres, as highlighted in reforms seeking gender equality. However, the Swedish social policy connected with this break does not challenge typically gendered social roles. Thus, direct payments for personal assistance to children with extensive impairments can be used as a means to pay women to continue the task of caring, while escaping economic dependency on men.

Rights in the reforms designed to enable non-disabled parents access to the labour market are based on assumptions of their 'abilities'. Disabled people, on the other hand, are widely assumed to be incapable of participating in the labour market. This is highlighted in the right to *occupational activity* which is provided on the basis of disabled people's low presence in the workforce. *Occupational activity* is, then, explicitly defined as not being employment even when comprising tasks of a similar character to those performed in situations defined as employment. Consequently, redistribution in the form of a salary is denied to persons participating in these activities. And redistribution in the form of direct payments is also ruled out as rights to personal assistance are denied for the time spent in *occupational activity*.

It can be argued that, disabled people accessing autonomous rights in connection to work do so because they have broken the assumptions of dependency and incapacity in practise. Thus, if a disabled person overcomes the disabling structure of labour market organisation he is viewed as capable. In this manner, self-determination is granted on the basis of actual evidence of individual capability. Assumptions of self-determination connected with employment can, thus, be said to override assumptions of dependency connected with disability in individual cases.

### **Recognition on account of group identity or participation parity**

The right to *occupational activity* is provided on arguments highlighting the importance of work for self-confidence, well-being and social identity. It is obvious that the reforms aim to provide recognition to the *entitled group*. However, this recognition is of a character connected with group identity, where disabled people

should be recognised and valued in their capacity as disabled people. The recognition, foremost, exist on the individual psychological level. Recognition in the form of participation parity and the right to be seen as equal is not addressed in these reforms.

Disabled people are encouraged to be involved in work-like situations through the right to *occupational activity*. It is widely argued that disabled people have a group identity that incorporates the need for recognition, on the psychological level, connected with every-day work-like situations. However, the perceived group identity does not recognise disabled people in the social roles connected to family and parenthood. They are explicitly described in the reforms as incapable of caring for children, to the point of defining the situation for their children as risking unfavourable development. Rights to advisory support or personal assistance enabling the parental role are not provided in the reforms. In fact, right to personal assistance in connection with caring for or about a child is explicitly denied. Hence, the assumed dependency connected with the concept of care strengthens the assumptions of dependency connected with disability.

The Swedish relative model of disability permeates social policy and the reforms of 1994. The social model's separation of impairment and disability has no equivalent in Swedish policy. Instead *funktionshinder* is seen as a possible, and in most cases a probable consequence of an injury or disease. *Funktionshinder* is, furthermore, defined as a personal characteristic preventing fulfilment of social roles in the normal manner or within boundaries considered normal. In this way, society constructs a disabled identity where the group is viewed as individuals worthy of recognition on

account of their difference. This recognition, however, does not comprise the right to be recognised as equals by the rest of society. Participation parity is not granted to the group. This should not be surprising as, the group identity is constituted mainly on assumptions connected to the ideology of normality. Therefore, the assumptions of dependency remain intact.

The ideology of normality, and its connected assumption of dependency, occupies a hegemonic position in the Swedish welfare state. The proposals and negotiated outcomes of the 1994 reforms contain legal ideas fitting the dominant perceptions of disabled people. As a result, the relative model, with its focus of remedies on the psychosocial and psychological level, will never have the strength to break this dominance. Existing disabling assumptions persist in focusing on individual inabilities. A model that includes this as a possible cause will always allow dominant groups to enact legal reforms feeding existing hegemony. In the battlefield of legal reforms subordinate groups are going to remain subordinate as long as the analytical tools used do not challenge the prevailing disabling assumptions.

In conclusion, the Swedish relative model creates a disabled identity constituting disabled people as inherently flawed, not able to perform in normal social roles. Though, disabled people are recognised as valued individuals, they are done so on account of their difference. This recognition on a psychological and psychosocial level is, however, not recognition of them as equals. Recognition of participation parity is not provided in the relative model. Thus, the autonomous right of personal assistance in the 1994 reforms is the exception which confirms the rule. It has to be questioned if reforms based on the Swedish relative model of disability will ever be

able to break disabling assumptions. It is more probable that recognition on the individual psychosocial level when faced with evidence of miserable conditions will result in rights to communitarian services. This reduces the gap without closing it between non-disabled people and disabled people's living conditions.

The reforms analysed in this dissertation have been in force since 1994. During this decade, there has never been a time when the autonomous right to personal assistance has not been under threat – it has been amended, investigated and questioned. And it has to be concluded that as long as the Swedish social policy grant social justice to disabled people based on the disabled identity created by the Swedish relative model self-determination through autonomous rights will never be an hegemonic legal idea.



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