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CHAPTER 3

Personal Assistance Reforms in Sweden: breaking the assumption of dependency?

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Introduction

In Sweden, personal assistance, and direct payments for such assistance, became a legislative right for a limited group of disabled people, through the enactment of the Support and Service Act, and the Support and Finance Act, in 1994. These legislative reforms were passed in 1993 to provide individual rights to ten different kinds of social services (SFS 1993: 387 section 9). This chapter focuses on one of these services, namely, personal assistance.

The paradigm shift, from dependency creating services in kind to 'independent living' cash payments, was not accepted by all political interests at the time and the future of the reforms is, therefore, hardly secure against tomorrow's political decisions. In the context of the Swedish welfare system, the goal of social justice is largely viewed in terms of the re-distribution of resources. More specifically, and in line with this general approach, the Swedish 'relative model of disability' has been developed to guide policy with respect to disabled people. This chapter will explore some of the main issues raised about the potential of the 1993 reforms to challenge the assumptions of dependency that surround disabled people.

In writing this chapter, use is made of various 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 contains frequent excerpts 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 experiences when this incapacity prevents fulfilling of expected social roles.

Entitled consumers or empowered individuals?

The employment of personal assistants, and specifically using direct payments for this purpose, is a key issue for those promoting 'independent living' (Morris 1993) because, without it, disabled people who need help with everyday life activities, risk segregation and institutionalisation (Oliver 1990; Barnes 1991). Institutions are the 'ultimate human scrap-heaps' (UPIAS 1976:2) and disabled people fought against incarceration for decades (Hunt 1966) before the use of personal assistants for everyday tasks became a reality. In Sweden, the struggle for personal assistance was carried out, against a background of cluster housing and limiting home help services, in the 1980s. The hierarchic organisation of these developments prevented choice and control and made them into what the embryonic Swedish Independent Living Movement (ILM) defined as 'ambulatory' institutions (Ratzka 1986).

The assumption of dependency is the reason for, and the justification of, institutionalised services:

When ... impairment means that there are things that someone cannot do for themselves, daily living tasks with which they need help, the assumption is that this person is 'dependent' (Morris 1993: 22).

Assumptions of dependency justify paternalism and communitarian-type services. Being classified as dependent implies that you are unable to make life choices and determine what is best for you. However, 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). To uphold control over disabled people, therefore, 'mainstream' society regards us, not as individuals with capacities, but as a group united by our incapacity thus separating us from non-disabled peers. The social model of disability challenges this assumption and contends that it is the organisation of services and wider

societal structures that disables people with impairments. This approach underlines the contention that the individualistic medical model of disability correlates with the administrative paradigm for those in control of disability services and so justifies their continued power over disabled people (Finkelstein 1993).

While, in contrast, the ILM demands control and choice in everyday life as a human and civil right for disabled people (Ratzka 2003), and so embraces the full range of action to achieve those rights (Morris 1993). It is not therefore based on a single model of disability. Its philosophy therefore takes on different cloaks depending on the source of its advocacy. In the United States, where the ILM started, a key division exists between those concerned with service provision and those with civil rights.

It is an interesting side note that many claim that California was the origin of both the demand for services and the fight for civil rights. They lump both together under the name of the Independent Living Movement. Others claim Massachusetts was the origin of both ... under the name of the Disability Rights Movement (Pfeiffer 1992: unpagged).

Once this split is recognised within the political struggle for political change, it is not surprising to find that arguments by supporters of the ILM range over both social justice and market discourses in promoting the importance of direct payments (Pearson 2000). Personal assistance is a 'bread and butter' issue and these tend to encourage a pragmatic stance. Ratzka (1986) applied a 'consumer perspective' from the start, and has been criticised for using this discourse without examining the possible consequences. This includes:

a very real concern that responsibility for ensuring that needs are met will be abdicated to the vagaries of 'market forces' and the rationale of economic efficiency (Zarb 1989: 213).

At the same time, the source of this early criticism, Zarb, was one of the researchers on the British Council of Disabled People's study of cost and effectiveness of direct payments (Zarb and Nadash 1994), which incorporated arguments belonging to a market discourse.

Outside the group of disabled people who need personal assistance, empowerment through cash benefits remains a contentious issue between advocates for a more or less communitarian or autonomous principle behind organisation of social services. While, the communitarian view is based on a collectivistic ideal where the state impose certain moral principles on its citizens and so prevents undesirable life choices, the

autonomous view is that the state should remain neutral to the life choices of its citizens (Rothstein 2002).

The conflict, between communitarian and autonomous ideals, is evident within debates on Swedish welfare (Rothstein 2002), where there has been a ‘feminisation’ of the social workforce and strong distributive trends (Esping-Andersen 1990). It also certainly exists between disabled people and non-disabled feminists (Morris 1991; Dalley 1996).

Disabled people view personal assistance and direct payments as the way of achieving empowerment for users of services. Feminists argue that direct payments will result in a flea market of ‘care’ that disempowers the predominantly female ‘carers’ and in the end destroys the quality of services provided (Ungerson 1997). However, many disabled activists are aware of the devastating effects that a totally free market can have on access to assistance. While maintaining that direct payments are ‘about promoting collective responsibility for protecting individual rights’ (Morris 1997: 60) some critics have expressed concerns over the trend towards turning personal assistance users into consumers.

A relative model for strategy and pragmatism

The legislative reforms implemented in 1994 are clearly located within the Swedish relative model of disability (Prop.1992/1993:159). Basically, the relative model can be described as a variant of ICIDH, subsequently revised as the *International Classification of Functioning, Disability and Health* (abbreviated as ICF) (WHO 1999). The Swedish terminology follows that of the original WHO scheme quite closely, although considerable confusion remains over the use of key terms such as ‘disability’ and ‘handicap’: for example, ‘*Funktionshinder* and *handikapp* are often used as synonyms’ (Prop. 1992/1993:159: 52).

The relative model is usually said to date back to the 1960s, when Vilhelm Ekensteen’s book – *On the back yard in the people’s home* (1968) – was published. This appeared just two years after Paul Hunt’s *Stigma* (1966), and also contains major criticisms of disabled people’s socio-economic situation. However, the contributors to Hunt’s anthology voice a perspective focused in disabled people’s own experience, while Ekensteen, even though a disabled person active within disability politics discusses the issue from a general left-wing political perspective. Ekensteen’s critique is above all concerned with the manifest inequalities within the division of welfare. His preferred remedy is a fairer distribution of income and wealth (Ekensteen 1968).

It can be argued that the differences between the social model and the relative model were present from the start. While the Union for the Physically Impaired Against Segregation (UPIAS 1976) continued with its development of the social interpretation of disability, the relative model quickly became integrated into the official disability policy of the Swedish state and annexed by the establishment. In 1976 the Official Parliamentary Report *Culture for Everybody* describes *handikapp* as follows:

The word *handikapp* has different meanings. 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 an injury can result in (SOU 1976:20: 45-50).

The social model clearly states that it is society that disables people with impairments; while in the Swedish viewpoint disability is relative, but remains fundamentally a consequence of injury or disease. Even if, the consequences can be limited and sometimes obliterated, the relative model does not cut the causality between impairment and disability as has been the case with the social model (Oliver 1990).

Instead, the relative model has been increasingly connected with ICIDH. Thus, Calais van Stokkom and Kebbon have claimed that 'a well-known application of the environmental relative' (1996: 35) model is also a feature of ICIDH since 'the individual is described in relation to the environment and its demands' (p. 37). The connection with ICIDH is reinforced and strengthened with its revision and reformulation as ICF. The Swedish Council for Working Life and Social Research (FAS), the main funding body for research in the area of disability, in its current programme for research on *funktionshinder* and *handikapp*, states that:

the classification [has] now left an earlier hierarchical and disease orientated medical model of *funktionshinder*, which means that one identifies the problem within the individual ... Within another contrasting social model *funktionshinder* is mainly viewed as a socially created problem and principally a question of complete integration of individuals into society ... The present ICF is built on a combination of these two contradictory models, and tries to generate a more complex picture with an interactive model (FAS 2001: 17).

This move towards a more complex picture can, from a Swedish perspective, be traced back to Martin Söder's (1982) translation of ICIDH terminology. It has been argued that Söder was worried about the risk of socio-political passivity in a relative concept (Holme 1995). He believed that, if obstacles existed solely within the environment, very large, perhaps unreasonable levels of resources would be needed to achieve societal change at the expense of services aimed at individual needs. His aim with the recommended terminology was to identify needs or groups with special needs, to enable the channelling of resources to these groups, and to clarify the process creating these needs (Calais van Stokkom and Kebbon 1996).

Social justice as it is widely understood in Sweden is mainly concerned with promoting a more even distribution of income and wealth. From the start of modern welfare society in the 1930s, Keynesian economic theories encouraged the use of budget deficits to finance social reforms and create jobs in an expanding public sector (Esping-Andersen 1990; Holgersson 1992). This trend has been present throughout the development of the modern welfare state in Sweden. The primary remedy for social injustice and inequality has been policies to improve the distribution of resources through action in respect of the social insurance system, welfare benefits and social services.

This distributive paradigm underpins the relative model of disability, as this basically regards equality in terms of outcomes. This 'division of welfare' solution is certainly highlighted by Ekensteen (1968), who viewed disabled people as one of a number of vulnerable and disadvantaged groups, who are all referred to as *handikappade*.

If the general public got its eyes opened to the principal similarity between the situation of physically *handikappade* and socially and economically *handikappade*, something would be won. People then would be freed from the fatal fixation with the seemingly inescapable role and identity, as *handikappade* and object for care, of the physically *handikappade*, i.e. in the conventional meaning *handikappade* (Ekensteen 1968: 30).

This also seems to be Söder's (1982) aim with his translation of terminology as a way of achieving a matrix of social reforms based on economic re-distribution.

The relative model offers a specific strategy rooted in pragmatism and flexibility, which places disability on an ever shifting line somewhere between the individual and the environment. It is a political tool to achieve

rather than design social reforms. From a relative model perspective personal assistance through direct payments is a form of compensation for individual incapacities. It is also a compensation for obstacles of other kinds, not necessarily belonging to the personal sphere. The assumption of dependency is, therefore, not really questioned from a relative model perspective. And while reforms emphasising choice and control, as stressed by the ILM, can be argued from a relative model perspective, self-determination through choice and control is not necessarily an integral part of this approach.

Personal assistance in the Swedish reforms

Independent living as a legislative role-model

Independent living is unquestionably the philosophy behind the right to personal assistance in the 1994 reforms (Berg 2003). The Stockholm Co-operative of Independent Living (STIL) provided direct payments after reaching agreements with an increasing number of municipalities in the Stockholm area. Other Independent Living Co-operatives were up and running in different areas of the country. A direct payment for personal assistance was becoming a more widely accepted solution. Indeed, STIL was identified in the government bill as an 'interesting attempt to create alternatives to home help services and increase freedom of choice for disabled people' (Prop. 1992/1993:159: 45). Freedom of choice and integrity were emphasised as the most important concepts within disability policy.

It is obvious that the welfare state sometimes has shown altogether too little consideration for the wishes of the individual. Also, disabled people and their families must gain greater control over their own lives (Prop. 1992/1993: 159: 43).

The philosophy behind independent living is indubitably centred on a concept of autonomy. At the core of the ILM, irrespective of other national differences, are principles such as self-determination, self-respect, peer support, empowerment and risk-taking (ILRU 1999). This individualistic view of rights and duties is thoroughly incompatible with the previous organisation of social services in Sweden. Historically, social services belonged to the 'care' category and were organised on communitarian ideas. However, during recent decades, there has been a shift towards a greater balance between communitarian and autonomous ideals (SOU 1990:44; Rothstein 2002).

This view of the relationship between democracy and societal organisation is echoed in the Parliamentary Report on which the government bill is based. It states that:

every political system must find a point of balance between, on the one hand a collectivist democratic ideal protecting the rights of the majority to enforce their will, and on the other hand, a democratic ideal centred on the individual, which protects the right to self-determination (SOU 1991:46: 99).

The right to personal assistance might be taken from the ILM's concept of choice and control, but a closer investigation shows that both ideals of communitarian and autonomous services co-exist within the scope of reform. The law addresses the needs of a limited section within the disabled population, namely individuals assessed as having extensive and permanent impairments. The Minister responsible for this legislation stated that:

the majority of persons with *funktionshinder* already should be able to have their needs for support and services satisfied within the framework of regulations contained within the more general legislation (Prop. 1992/1993:159: 54).

Personal assistance is, then, only granted to a smaller sub-group, those with essential needs of at least one of the following kind: 'help' with intimate hygiene, eating, dressing or undressing, communicating, or other essential needs which require thorough knowledge about the impairment. This means that the vast majority of disabled people still does not have any explicit right to choice and control, and receives services of the old custodial kind.

A continuing question is whether the right to choice and control in the Swedish reforms is intended to break the disabling assumption of dependency. Arguments for personal assistance given in the bill are found:

- in the area of integrity, as assistance in very private situations;
- in connection with compensatory measures on account of disease or impairment, as in rehabilitative training; and
- in connection with compensation for disabling barriers, as in avoiding isolation or enabling work or education (Prop 1992/1993:159).

The general argument from the individual to the societal levels is more compatible with the relative model of disability than it is with the social model's attack on assumptions of dependency and incapacity. These arguments also demonstrate the relative model's fondness for compensating needs, connected to all levels in the ICIDH, that is, impairment, disability

and handicap, by measures contained within the welfare solution to the division of wealth.

When advocating for change, there is nothing as powerful as using an example of very bad practice, and this was provided by the Parliamentary Disability Commission's Status Report in 1990.

In the interview enquiry, conducted by the Centre for Disability Research at Uppsala University on behalf of the Disability Commission, different obstacles for influence are listed. These comprise professionalism turning into paternalism, inflexible regulatory systems, the organisation of services, and social conceptions of *handikapp* (Prop. 1992/1993:159: 44).

Only eight percent of the respondents could decide who would provide services within the Swedish home help system. It is probably safe to say that evidence of poor standards within existing services is the main reason behind the demand for assistance, not an analysis of the disabling nature of the assumption of dependency, nor a will to provide autonomous services as a result of such analysis.

The fondness for communitarianism and the obsession with employment

Swedish politics exist within a culture of negotiation. Government bills are debated in parliamentary committees before reaching the final vote in the Chamber. The Parliamentary Committee for Social Affairs and Welfare dealt with several private member bills related to the government bill. The Private Member's Bill SoU18 by social democrats Bo Holmgren et al. (Bet. 1992/1993 SoU19) expresses support for reform but advocates above all the need to protect the general welfare system.

[I]n countries which have chosen more selective politics, where special solutions for *handikappade* are prioritised at the expense of more universal measures, persons with *funktionshinder* are in a much worse situation than in Sweden (Bet. 1992/1993 SoU19).

Another Private Member's Bill So245 by social democrats Jan Andersson et al. (Bet. 1992/1993 SoU19) argued that 'freedom of choice' should not be simply a question of freedom for producers of services to choose. Instead the importance of co-operatives and experiences from disabled people's own projects like STIL and GIL should be disseminated (Bet. 1992/1993 SoU19).

Empowerment as promoted by the ILM is not really compatible with mainstream social democratic ideology. Admittedly, there was a group within social democracy in the beginning of the 1990s that called for 'self-

empowerment', but this was very different from the concept of freedom of choice for the individual. 'Self-empowerment' was fundamentally concerned with the decentralisation of decision making that allowed small groups of workers control over their working conditions. It was about taking power together, as in a co-operative organisation (Trägårdh 1999), and the co-operative organisation of the Swedish ILM should not be underestimated. It possibly tipped the scale in favour of personal assistance more than once. The Parliamentary Committee, reflecting the Conservative-Liberal majority of the chamber, rejected the suggestions of these Private Members' Bills (1992/1993 SoU19).

The emphasis on employment and the labour market as central to the welfare state is a key factor underpinning the concept of 'self-empowerment'. Swedish style democracy is about power over working conditions, and this power is executed collectively. The organisation of work has been identified as the chief disabling mechanism in society (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.

One has sometimes described the dominant conception of persons with *funktionshinder* as an idea about 'eternal childhood'.

They are perceived as children; dependent on the help and support of others and therefore incapable of self-determination and an independent life (SOU 1990:19, 372).

From the late 1960s onwards in Sweden, the responsibility for this 'burden' was shifted from the family to the social welfare system. A further contemporary political influence was created by the wave of female labour entering the labour market due to both economic and integrative forces (SOU 1990:44; Holgersson 1992). However, it is argued that, the male role (as primary provider) and the associated organisation of the labour market was never questioned or changed. The result was that 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 'caring' tasks although now in a paid capacity.

It can be argued that the compensatory dimension to the Swedish welfare system allows its citizens to escape being economically dependent on the family but does little to break assumptions connected with

dependent social roles. If this is true of policy measures for gender equality, it is also present in the 1994 reforms. Entry into the labour market is the main priority and the welfare system is the central means by which this is turned into reality.

The right to parenthood, and the right to associated supportive measures, displays in an interesting way the remaining assumptions connected with gender equality and disability, as well as the emphasis on employment. The reforms clearly state that personal assistance should not assume the ordinary duties connected to parenthood or the responsibilities of child-care and schools for disabled children. However, when a child has extensive 'care needs' then personal assistance should be granted.

Both parents shall, if they want to, be able to remain in gainful employment, shall have the same possibilities as other parents to maintain friendships and cultivate interests outside the family (Prop. 1992/1993:159, 44).

It is clear that this 'parental assistance', to non-disabled parents, is aimed at alleviating the 'burden' of having a disabled child. The family unit is the priority and emphasis is placed on the importance of adapting this form of support to the individual family and in so doing provides parents with a decisive influence over the assistance given.

The aim with assistance [in these cases] is often to satisfy parents' need for relief of care or to provide the family with possibilities to carry out activities in which the child does not participate (Prop. 1992/1993:159, 66).

Though the wording of the Swedish reforms is gender neutral, it is safe to say that this is a measure to prevent female economic dependency on male providers. It is another tool for eroding the barrier between the private and public spheres, while doing relatively little to alter traditional social roles (SOU 1990:44). Thus, it belongs to what feminists identify as the 'ideology of familism' in 'care' policies (Dalley 1996), which stresses the 'caring', nurturing role of women, or more correctly, non-disabled women. The reforms clearly aim to allow parents (mothers) the right to paid employment. A secondary aim is to give support to the family, so it will stay together and continue taking basic responsibility for a disabled child.

Disabling assumptions behind the reforms

The assumption of dependency around disabled people constitutes us as asexual, child-like, and therefore unfit for parenthood (Shakespeare et al. 1996). Thus, the question of 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 for granting personal assistance to disabled parents is based on the emotional and developmental needs of the child during its formative years.

First, a child is gradually able to develop an understanding about her/himself and relate to other persons. It is, therefore, important for the child's development that it, during this time, can have its essential needs met by only a limited number of adults. If any of the parents have personal assistance, it is in my opinion natural that the assistant, if he or she is suited for this ... should also help the parent with the care he or she cannot provide him/herself. This does of course not exclude the possibility that the child may have need for other or additional support (Prop. 1992/1993:159, 66).

It is clear that parenthood is not expected of disabled people. Personal assistance is not granted for activities performed as a consequence of fulfilling the social role of being a 'caring' and 'competent' disabled parent. When a child is mature enough to be able to 'handle close relations outside a limited circle', or if disabled people do not have assistance needs (as defined by the legislation) except in their parental role, support is provided through the general welfare system (Prop. 1992/1993, 159). The reforms do not address the assumption of dependency in the context of a disabled person's right to parenthood. 'A child's need for care is principally not a task for the personal assistant of the parent' (Prop. 1992/1993:159, 178).

Another life situation where personal assistance was not considered necessary was 'old age':

An important aim with personal assistance should be to achieve conditions for persons with extensive lifelong or prolonged *funktionshinder*, which are equivalent to those of people of a similar age. Therefore, I mean that the right to personal assistance should be limited to persons who have not reached the general retirement age, 65 years (Prop 1992/1993:159, 64).

The reasons for this are mainly economic - certainly at the time when the legislation was introduced. However, a survey, conducted for the National Board of Health and Welfare after the first five years of the reforms, showed that losing the right to personal assistance at the age of 65 'meant support of a lesser extent and lower quality for many of those concerned' (Prop. 2000/2001: 5, 9). One consequence was that further

legislation was passed to grant those already receiving personal assistance the right to keep this after reaching 65 years, although it was limited to the existing level of support.

As has been shown, personal assistance in the 1994 reforms is not really intended for older (disabled) people, for disabled parents, or for disabled children, unless their 'care' need is extensive enough to disturb their parents' ability to work. It appears that the priority given to paid employment and labour market concerns extends to the area of disabled people of working age, while the assumption of dependency remains secure.

Conclusion

The social model, as outlined by UPIAS (1976), cut the causal link between impairment and disability and instead focused on analysing the 'disabling society'. This provided a mechanism for understanding where the responsibility lies for the social exclusion of people with impairments. It also emphasises that reforms must address disablement across all areas of social life. The Swedish relative model offers a different analytical approach. Responsibility for disablement is regarded as flexible and this highlights the potential value of limited reforms without contradicting assumptions within conventional explanations of disability.

Personal assistance, in the recent Swedish experience, is based on the relative model's flexible view, and aims at compensating assistance needs linked with all levels of the ICIDH: whether injury or disease, resulting functional incapacity, or disabling conditions due to environmental factors. While it is certainly true that personal assistance enables some disabled to board the 'accessible' subway in Stockholm, this does not address the basic assumptions of dependency directed at disabled people generally.

This assumption underpins a view of disabled people as child-like and incapable. It reinforces the principle of a need for 'care', as in 'taking care of' instead of 'caring for', and confirms orthodox ideals of service provision by a variety of (professional) experts. The ILM principle of self-determination has resulted in demands for services controlled and run by users is based on the opposite ideal of 'independence' and autonomy. As argued above, the Swedish right to personal assistance was enacted, not primarily as a right to self-determination for disabled people, but more as a necessary political remedy to the miserable conditions experienced by disabled people within the municipal home help services of the time. A general welfare system, built on a high taxation level, has to create

sufficiently equal living conditions, otherwise the whole system risks losing its legitimacy. The reforms of 1994 bridged the welfare gap within social service provision for a specific section of the disabled population but did not break the underlying assumptions of dependence. Disabled people outside this 'privileged' minority are still receiving services based on traditional communitarian ideals.

Swedish welfare policy is built around an emphasis on employment and breaking down the wall between the private and public domains. Thus, it should not be surprising that legislation applied the same criteria when considering changes in the area of personal assistance. Consequently, personal assistance for disabled children is clearly aimed at making gainful employment possible for non-disabled parents (a gender issue), almost to the point of their self-determination being the priority. At the same time, personal assistance for disabled people is not regarded as a general, human right. In childhood, it does not replace measures within day care and schools; in parenthood, it is not granted as part of the parental role; and in older age, it is only provided at the level awarded when a person was sixty-five.

It can, therefore, be argued that the weakness of reforms based on the relative model and the continuing assumption of dependency may generate future problems. Compensating disabling barriers through personal assistance may lead to rocketing costs within the social security system. Continuing disabling mechanisms in the employment sector may prevent disabled people entering the labour market in spite of policy support and assistance. This creates a political climate where the value of reforms may be questioned. In the current economic context, where other groups such as older disabled people live under horrendous conditions, advocates of traditional communitarian services may gain general support. Whether disabled people in Sweden are moving forwards on the road to self-determination or going backwards towards the municipal scrap heap remains to be seen.

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