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Family as failure? The role of informal help-givers to disabled people in Sweden

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Based on a survey mapping all unpaid help and care work in the county of Stockholm, this article focuses on the informal help and care carried out for long-term ill and/or disabled people aged 64 or younger. The findings indicate that these forms of support are common and that the informal help-givers work many hours every month. Yet the impact of this work is quite invisible in texts on disability policy and there is a void of research addressing this issue. This article argues that, in spite of welfare state arrangements and reforms, families play a crucial role in providing resources, notably help and care for disabled family members. Their invisibility is interpreted as an expression of the fact that the care concept has become politically incorrect. In the light of modern disability policies, with its ideals of autonomy and empowerment, help and care provided by families to adults aged 64 or younger stand out as a dilemma and a contradiction. Making help and care provided by families invisible can be interpreted as one way of solving this contradiction.

Keywords: family; family care; informal care; informal help-givers; long-term illness; disability

Background and aim of the article

The focus in this article is on the informal help and care provided for long-term ill and/or disabled people aged 64 or younger in Sweden, and on the characteristics of the help-givers. In the survey and its findings, on which the discussion in the article is based, the *perspective of help-givers* is the point of departure. The following questions are addressed:

- How common is informal help and care given to long-term ill and disabled people aged 64 or younger?
- Who are the providers?
- How do they differ from those providing help and care for older people in terms of background, types of help given, and in conditions of their informal work?
- What are the contexts of help and caregiving, for instance in terms of collaboration with formal care provision?
- What are the consequences of the informal involvement for the help-givers?

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- How are we to understand the fact that there is a void of research concerning this group, and what are the reasons and consequences of its invisibility in contemporary disability discourse?

In this article the term 'informal help-giver' is used to denote individuals who regularly provide informal, unpaid help and care to others.

The public interest in informal help and care and its potential has increased considerably in Sweden in the past 10 years. Policies aiming at 'supporting informal caregivers' have been developed, often formulated with instrumental overtones. The same trend can be seen in other European welfare states (Jegermalm 2005). An explanation may be found in current demographic and economic situations, but may also have to do with an ideological veer: it is the increasing needs of care for *older people* that are in focus and informal caregiving, implicitly, most often means provisioning help in various forms to the elderly and frail, carried out by family members, in a context of the 'welfare mixes' that are now often a part of the welfare agenda (Anttonen and Sipilä 1996). Parallel to this, dynamic research on social care has emerged, not least in the Nordic countries, where patterns of formal and informal care in the welfare state are explored, and where the role of family, mainly in relation to the elderly, is scrutinized (Anttonen, Baldock, and Sipilä 2003; Kröger 2005). The contrast is striking when this situation is compared to that of adults with chronic illness and/or disabilities under the age of 65. While informal caregiving to the elderly has been highlighted, informal help and care to younger disabled adults is largely invisible and the giver of such service and support often seems non-existent. In the Swedish context, this is noticeable in official texts concerned with care issues in general (for instance SOU 2000:38), as well as in official texts addressing disabled people, such as reports from the Governmental Committee on Disability (SOU 1990:19, 1991:46, 1992:52) and the Action Plan for Disability Policies (Proposition 1999/2000, 79). Above all, there is hardly any Swedish or Nordic research tradition in this field – either concerning the help-giver or the recipient (SOU 2001:56). In the new Swedish 'support for informal carers' rhetoric, informal help and care given to the disabled and people suffering from long-term illness is only marginally addressed, and then mainly in relationship to mental illness (NBHW 2002). Since the discourse on 'care' has come to imply a subordination of the care recipient to the caregiver (Morris 1993, 1997; Ekensteen 2000; Jacobson 2000; Swain et al. 2004), the concept of care has become politically incorrect and problematic in the research context. This is a parallel to patterns shown in political, official texts. The same goes for the concept of family, in relationship to disabled adults. Yet, surveys carried out in Sweden over the past 15 years, one of which forms the empirical basis of this article, provide ample evidence of the fact that it is not only common to provide informal help and care to people older than 65, but that this form of support also plays a major role in meeting the needs of younger adult individuals faced with disability or long-term illness. Furthermore, it seems to be of increasing importance (Olsson, Svedberg, and Jeppsson Grassman 2005).

Informal help and care

The literature on informal help and care, in its broad sense, has since the 1980s continually grown and is today internationally extensive (Gubrium 1995; Hansson, Jegermalm, and Whitaker 2000; Nolan, Grant, and Keady 1996; Sand 2005). Research on Swedish and Nordic informal care did not receive any serious attention until the 1990s (Kröger 2005), although some scholars had brought this issue up much earlier (Daatland 1983; Sundström 1983; Waerness 1978, 1984). In Sweden, interest in this issue has particularly expanded since the second part of the 1990s, not least because family care was politically recognized for the first time and the Swedish government decided to allocate earmarked grants to the municipalities to stimulate support for informal caregivers (Hansson, Jegermalm, and Whitaker 2000; Jegermalm 2005; Jeppsson Grassman 2003). This growing bulk of research, however, concerns first and foremost informal *elder* care. For example, Nordic literature reviews published in the past few years have generally limited their scope to informal help and care to older people in need of care (Hansson, Jegermalm, and Whitaker 2000; Helset 1997; Ingebretsen and Eriksen 2004; Sand 2005). The welfare state perspective in research on care has often been coupled with a feminist perspective, in Nordic as well as British care research (Baldwin and Twigg 1991; Waerness 2005). The overall picture of this now rather well developed research area is that informal care to older people, which is mainly carried out by family members, is extensive and of growing importance.

When it comes to informal help to younger adults with particular care needs, long-term ill or disabled people – the state of the art conveys another, rather contrasting, picture. The overall impression reflects a scarcity of any research tradition, in the Nordic as well as in other European countries. This was confirmed by a literature search, targeting family caregiving and informal help, spanning some of the major journals of disability research (*Disability & Society*, *Scandinavian Journal of Disability Research*, *Journal of Disability Policy Studies* and *Disability Quarterly*). There were few hits and most of them focused on informal caregiving to young disabled children and adolescents.[1] A broader database search of this topic confirms this overall picture: This field is dominated on one hand by research about help and caregiving to young disabled children (e.g. Read 2000; Brett 2002; Tøssebro and Lundeby 2002; Todd and Jones 2005), and on the other hand informal help and care to intellectually disabled people, with a budding interest in the ageing process of these people and its consequences for parents and siblings (e.g. Dew, Llewellyn, and Balandin 2004; Jokinen and Brown 2005; McConkey 2005; Sjørengen et al. 2005; Thorsen 2006). Some writers have addressed issues of life course and disability specifically from the point of view of the family (De Marle and Le Roux 2001; Nolan, Grant, and Keady 1996; Seddon 1999). Very little is known about informal help and caregiving to physically disabled *younger adults*, about the role of the family, and the identity of the caregivers; in fact, very little, on the whole, is known about the phenomenon of informal help and care in this context. Is it to be understood in the same way as informal care provided to older people? There may be a risk of adopting that same framework, as pointed out by Parker and Baldwin (1992, 202) who criticize 'the way in which emphasis in the caring literature on the needs of older people and their carers has been moved uncritically across to younger, physically disabled people'. There is a need for a critical discussion around caring and disability, as argued for instance by Morris (1993).

In contrast to the described pattern in research on informal help and caregiving, there is a growing bulk of Swedish research concerning paid work in the form of *personal assistance* within the framework of the new legislation on personal assistance in the major disability reform of 1994 (LSS/LASS). A main ingredient in this new legislation is the right for people with extensive disabilities to receive formal personal assistance and to be in charge of their own assistance. This research focuses on assistance from different perspectives, including that of the provider, the personal assistant. A number of the people employed as personal assistants are, in fact, family members to the disabled person (NBHW 2007); there are, however, no statistics indicating how common this phenomenon is. Research focusing on this new professional group is the closest Swedish research seems to get to research concerning help-givers and caregivers to disabled people. This research has a strong connection with the research tradition of 'disability studies' (NBHW 2005). Considering this trend, a question arises whether this mirrors a situation where informal caregiving to young and middle-aged long-term ill or disabled adults has become less important. However, some earlier findings contradict this assumption: what is previously known about informal caregivers to younger, long-term ill or disabled people can mainly be extrapolated from results from a couple of earlier surveys, in which respondents were asked about *their needs for care.*

One example is a survey (1998/99) presented in a volume published by the Swedish Welfare Commission (SOU 2001:56). Among disabled people living at home, two thirds needed some form of help in their daily living, and 25% with personal body care. In the survey, 70% of those disabled, between the ages of 16 and 64, stated that they received help from a family member with whom they cohabited, and 30% stated that they received informal care from either a family member with whom they did not cohabit or a friend or neighbour. Half as many of the younger respondents (14%) reported getting help from the formal care system as compared with those in the older age group (aged 65–84). While the patterns of care among older people had changed markedly over the past two decades, towards increased informalization according to the survey results, the care pattern, with low levels of formal care, seemed to have remained stable among younger, disabled adults in the 1990s. A similar picture emerged in a report based on a survey mapping living conditions of disabled people[2], carried out by the Swedish Research Institute for Disability Policy several years later (HANDU 2005). The overall picture here was that family members provide the major part of all help and care supplied, and more so among those aged 16–64, than among the older group surveyed. As such, it is surprising to note that these very facts are not even mentioned in the summary of the report – a striking illustration to the ambiguity that informal care is associated with in this context.

The mentioned surveys take the *recipients' perspective* as a point of departure – they have reported on their care needs and from whom they receive care. To date, the *help-giver's perspective* has not been addressed in Swedish surveys on help and care conditions of disabled people. Thus, the results presented in this article, where this perspective is the point of departure, provide insight, filling a gap in our current knowledge.

Material and methods

The discussion in this article is based on results from a survey, conducted in 2000, which focused on informal help and care and its various dimensions, and was based on a statistically representative sample of people aged 18–84 from the county of Stockholm (1639 respondants, representing a response rate of 61%). The county of Stockholm has a population of 1.8 million, which accounts for 21% of the Swedish population. It covers an extensive territory and includes areas of various degrees of urbanization: from metropolitan areas to smaller communities and rural areas. The sample has been weighted, yet the metropolitan areas still dominate the sample. By including both informal help *and* caregiving in the initial general selecting question, the ambition was to capture the phenomenon in its broad sense and from the help-giver's perspective. A three-step set of introductory questions were asked in order to capture the incidence of informal help and care:

> In this survey we are interested in finding out to what extent people carry out help in areas such as household work, driving, gardening, looking out for, tending or other forms of unpaid help. Do you, on a regular basis, carry out such help for relatives, with whom you do not cohabit, or for neighbours, friends or colleagues at work?

In a second step, those who had answered yes to this question were asked:

> Does the person (or persons) whom you help have particular needs of care? We are thinking of long-term ill, disabled people and frail old people.

In a third step, all respondents were, in a corresponding manner, asked whether they in their own household cohabited with one or more people who had particular needs of care and whom they regularly helped.[3] With this approach a broad set of results concerning involvement in informal help and caregiving was acquired, in fact indicating several types of help-givers and caregivers (Jeppsson Grassman 2001, 2003).

The focus of earlier analyses based on material from this survey has been on informal caregiving to older people (Forssell 2004; Jegermalm 2005; Jeppsson Grassman 2001, 2003; Whitaker 2004). For the present analysis a new set of categories were created. Those respondents who had answered in the affirmative to the first question were grouped into four categories, depending on how they answered the second question, according to *the age of the help and care recipient,* and on whether he/she had *particular needs of care*: help-givers to (1) someone 64 or younger, without particular care needs; (2) someone 64 or younger who has particular care needs; (3) someone 65 or older without particular care needs; or (4) someone 65 or older with particular care needs. Into the two categories of help-givers providing for person(s) with particular needs of care were also included those who had answered positively to the third question: those who cohabited with a care-needing recipient and whom they helped. Help and caregiving to more than one person turned out to be a common phenomenon, mostly implying help and care to two people within the same category in terms of age and care needs. Yet, the categories also overlap to some extent (i.e. about 10% of the respondents were counted in two categories in terms of age and care needs). Testing for statistically significant differences between the categories thus becomes too approximate. Therefore, the percentages presented in Tables 1–4 may rather be viewed as descriptive statistics and sensitizing patterns.

Patterns of informal help and caregiving: younger and older care recipients

How common is informal help and caregiving in Sweden? From three national surveys on civic involvement of various kinds, conducted in 1992, 1999 and 2005, a conclusion can be drawn that it is quite common and there has been a gradual increase, on a general level and nationally, in informal help and caregiving in the past 15 years in Sweden – from 30% in 1992 to 50% in 2005 (Jeppsson Grassman 1993; Jeppsson Grassman and Svedberg 1999; Olsson, Svedberg, and Jeppsson Grassman 2005). Since the earlier surveys have indicated that informal help and care is less common in

Table 1. Informal help-giving, by age and particular care needs of recipients (%), and by mean number of monthly care hours, in the county of Stockholm, in 2000.

	Help-giver to person(s) <64 years (no particular care needs)	Help-giver to person(s) <64 years (particular care needs)	Help-giver to person(s) 65+ (no particular care needs)	Help-giver to person(s) 65+ (particular care needs)
%	15	7	6	15
N	270	119	98	242
Mean hours	17	50	19	37

metropolitan areas than elsewhere, it is interesting to note that in the county of Stockholm, the focus of this article, as much as 41% of the population (in 2000) reported being involved in some form of informal help or caregiving, to person(s) with or without particular care needs, or both. In Table 1, the distribution of help-givers is presented by the categories of help and care to younger and older recipients. It is important to underline that, in all, only 6% of the help-givers reported that the person(s) they helped was/were under the age of 18. So 'younger recipients' in this material principally implies an adult person.

As can be seen in columns 1 and 4 of Table 1, the largest categories of informal help-givers provide help to recipients under the age of 64 who, according to the respondent, have no particular care needs, and to people 65 and older who have particular care

Table 2. Demographic, education and health characteristics of informal help-givers and non-help-givers (%) in the county of Stockholm, in 2000.

	Not help-giver	Help-giver to person(s) <64 (no particular care needs)	Help-giver to person(s) <64 (particular care needs)	Help-giver to person(s) 65+ (no particular care needs)	Help-giver to person(s) 65+ (particular care needs)
Mean age	46.	43.	46.	47	50
Women	50	50	58	48	62
Married or cohabiting	61	71	64	65	68
Higher education	37	36	36	38	37
Blue collar worker	29	34	44	37	32
First gen. immigrant	11	12	27	11	15
Paid employment	65	72	65	69	69
Poor over all health	6	3	10	2	6
Insomnia or occasional problems with sleep	21	19	27	21	25
No reported psychological or stress symptoms	54	55	35	59	50
N	967	270	119	98	242

needs. The first category should mainly embrace help provided for recipients who basically could perform the task themselves if they had to (whether it is babysitting, gardening, transport or administrative work, etc.), while the category in column 4 illustrates informal care carried out for older people, too frail or disabled to manage the tasks by themselves, or only with great difficulty. The category that we are particularly interested in here is the group presented in column 2, *help-givers to people aged 64 or younger* and who, according to the respondent, have *particular needs of care*, i.e. mainly younger adults with long-term illness and the disabled. This category represents a small share of all the help-givers, 7% (in numbers, this represents approximately 102,000 people, aged 18–85, in the population of the county of Stockholm). Although fewer in number than help-givers to older people, they are the ones who by far seem to provide the *most hours of help-giving*; a conclusion drawn from the estimates of time devoted to informal help and care reported by the respondents. Recalculated into actual numbers, this represents the input of approximately 32,000 full time jobs per month, which is not a negligible amount of work. An equivalent pattern for this group, in terms of scope and time, was found in an analysis of the results from the national survey of 2005 in which the issue of informal help and care was addressed through identical basic questions (Olsson, Svedberg, and Jeppsson Grassman 2005).

What characterises these help-givers? As seen in Table 2, the informal help-givers to long-term ill or disabled people under the age of 65 do not differ from other groups, in terms of age or higher education. Just like help-givers to older people with particular care needs, the help-giver in question is more likely to be female. This pattern is in line with findings in numerous earlier studies which have pointed out the gendered character of the informal care provided to people with particular care needs. Just like other help-givers and caregivers, they are more likely to be married or cohabiting than non-help-givers. No other informal help-givers are more likely to belong to the blue collar category, but at the same time, this group of help-givers has other (paid) employment slightly less often than other help-givers. A striking pattern has to do with ethnic background: help-givers to care-needing people under the age of 65 appear almost twice as likely to be first generation immigrants as those caring for older people.

Help-givers to care-needing recipients under the age of 65, on the whole, seem to have poorer health than any of the other categories: they are more likely than non-help-givers and other categories of help-givers to assess their over all health as poor and, more often than other categories, report insomnia or occasional problems with sleep. Furthermore, their overall mental health seems poorer than for other groups: only 35% maintained that they did not suffer from any stress or psychological symptoms, compared to around 55% for the other groups. Thus, help-givers to disabled or chronically ill people under the age of 65 stand out as particularly vulnerable in certain respects, according to the results. However, since the results are exploratory, conclusions must be drawn with precaution.

The focus of informal help-giving

What is the focus of the informal help given to people with particular needs of care? Whom do informal help-givers help, i.e. what is their relationship to the care recipient? What sort of tasks do they carry out? Are there great differences in these respects between help-givers to older people with particular needs of care, and help-givers to young disabled or chronically ill people? In Table 3, these two categories of

Table 3. The focus of informal help-giving (%) in the county of Stockholm, in 2000.

	Help-giver to person(s) <64 (particular care needs)	Help-giver to person (s) 65+ (particular care needs)
Relationship to help recipient:		
Spouse	11	7
Child	29	9
Mother	28	37
Father	11	19
Sibling	14	6
Type of informal tasks performed:		
Contact, togetherness	69	72
Tending, looking after	63	57
Household work	56	53
Gardening, repair work	41	38
Transport	43	51
Administration	31	39
Personal (body) care	25	25
N	119	242

help-givers are compared. First, the five most common groups of care recipients are presented. As expected, help-giving to spouses and adult children is common among those helping younger recipients, while help-giving to older people most commonly implies help to parents, particularly mothers. It is, however, interesting to note that help given to a mother in need of care is also quite common among help-givers to people under the age of 65. Fathers with care needs presumably receive help from their spouses.

Which are the tasks carried out? Looking at Table 3, a conclusion to be drawn from the comparison is that, from the help-giver's perspective, there do not seem to be any important differences between informal help to older and to younger people, although the context, style and purpose may be different. Our data do not address these aspects: i.e. whether the help aims at providing care or is given with enabling, or empowering purposes, etc. There are no great differences between the two groups of help-givers as to what sort of tasks they purport to perform. The emotional care (contact, togetherness) and the invisible type of caring (tending, looking after) are actually the most common types of informal caregiving in both categories. This is in line with earlier research concerning informal support and care to older people, in which the common tendency to overlook this type of informal care has also been pointed out (Sörensen, Pinquart, and Duberstein 2002; Walker, Pratt, and Eddy 1995). The second most common type of informal task has to do with practical work in the house, followed by transportation. Administrative tasks are reported by approximately a third of the help-givers, irrespective of whether they help younger or older people. Besides tending to everyday paper work, etc., this category of tasks probably involves efforts such as getting in touch with and securing formal care services for the person they help, administrating personal assistance, etc. Care work connected with bodily needs is reported by 25% in each category of caregivers, which would mean that one out of four informal help-givers regularly perform this type of caregiving.

The context and consequences of giving help and care

The *context* of giving help and care may imply various things, having to do with place or time, but also practices and collaborative patterns, etc. Here we have chosen to look at the extent help-givers share care tasks with other people. As seen in Table 4, most help-givers are not alone with their responsibility they share help and caregiving tasks with other family members. In 'support from the municipality' the various forms of services and care provided by the formal systems are implied: it could be home-help services as well as assistance within the framework of the LSS/LASS legislation. There is a difference here between the two categories of help-givers in this respect: those providing help to younger disabled or long-term ill people, less often report that the recipient also receives support from the formal system than those who provide informal care for older people. This pattern may seem astonishing in view of the reinforcement of formal support that the LSS/LASS legislation represents to disabled people. And on this point, our data (from 2000) may be somewhat obsolete: formal resources for disabled people have in fact increased since 2000, while the opposite is true for formal elder care. At the same time it is important to note that the increase in resources to the disabled above all have been targeted to the restrained group of severely disabled who fulfil the qualifying criteria for LSS/LASS-legislation. Resources have particularly increased for young, severely disabled adults while the large group of people with less significant disabilities have received no equivalent increase in formal resources (Szebehely and Trydegård 2007; cf. SOU 2001:56). Overall, however, most informal help and care work seems to be carried out *without* support from the formal welfare and care systems, which is in line with the results reported from the earlier mentioned surveys by the Swedish Welfare Commission (SOU 2001:56) and by HANDU (2005).

The *consequences* of being an informal help-giver were captured through a few questions in the survey. The findings in this area give a complex picture which perhaps illustrates the ambiguity of family ties and obligations: informal help-giving seems connected with feelings of satisfaction for about half of the help-givers, but also with stress, worry and feelings of confinement for others. In fact, many caregivers express both types of feelings, and this pattern, which pertains to both categories of help-givers, is in line with previous studies concerning informal care (e.g. Furåker and Mossberg 1997). Most informal help-givers do not report any important economic consequences of their help and caregiving. Yet, the negative

Table 4. The context and consequences of informal help-giving (%), in the county of Stockholm, in 2000.

	Help-giver to person(s) <64 (particular care needs)	Help-giver to person(s) 65+ (particular care needs)
Alone as help-giver	24	20
Recipient receives support from municipality	24	31
Feeling of confinement	25	28
Feeling of satisfaction	55	50
Feeling of stress and worry	25	30
Impact on economy	16	10
N	119	242

impact of caregiving seems to be somewhat more important among help-givers to younger adults with particular care needs than to those providing care for older people.

Discussion

The findings presented in this article emphatically illustrate the role of family and help given by family in the lives of long-term ill and disabled people in Sweden. While the results emanate from a survey covering only the county of Stockholm, results from a more recent national survey show similar trends (Olsson et al. 2005). In spite of welfare state arrangements and reforms – such as the LSS/LASS legislation – aiming at enhancing the autonomy of disabled people, it seems clear that informal help-givers, most often family members, still play a key role in the everyday lives of these groups. Just as for older people, there seem to be reasons to speak of 'welfare mixes' of formal and informal resources, to a greater or lesser degree. Yet, in many cases, informal help to long-term ill and disabled people seems to be the only source of care, according to the results. 'The persistent myth of family decline' (Borsay 1990, 107) seems once more to have been refuted. The findings indicate that informal help and care to those with long-term illness or disability is quite common and that the informal help-givers provide many hours of unpaid work every month. In certain ways these help-givers are characterised by being 'just like everybody else'. In other respects they are likely to be more vulnerable than the population in general – not least because of poorer health, both physically and mentally. It is also important to note that, contrary to prevailing arguments about differences, in many ways their 'help and care profile' looks quite similar to that of those informal help-givers who help and care for older people. The help and care tasks are of the same character, for instance. The same goes for the contexts of caregiving, in terms of collaborative patterns. The majority of help-givers are not alone in their informal help and care. Yet, only about 24% of the help-givers seem to carry out their work in some form of collaboration with the formal care system. The emotional consequences for the informal caregiver seem more or less the same for help-givers to younger, disabled people and for help-givers to older people. Yet, while informal help-giving to older people has been highlighted in debate and policies, as well as in research, particularly in the past decade, the informal help and care to younger disabled adults is largely invisible and the informal help-giver often seems non-existent. How are we to understand this situation? And what are the consequences?

The explanations for the invisibility of family and informal help and caregiving to disabled adults seem to emanate from at least three different discursive areas, connected with specific policies. The first one has to do with the *area of care in general*, in the Swedish welfare state, and the dominating position of elder care: the general discourse concerning care resources in the welfare state most often implies the resources extended for older people (or child care). Therefore, rather than being the result of a premeditated policy, one reason why informal care to disabled younger adults becomes invisible in the care discourse, generally speaking, may have to with the simple fact that the greater part of all care recipients are older people. By their number alone, they have come to dominate the 'care issue', including the issue of informal help and care. An illustrative pattern of this may be found in how Swedish home help services are commonly referred to and researched as 'elder care' in a way that hides the fact that, although older people constitute the largest part of users, this service is also used by younger persons with care needs (Jönson and Taghizadeh Larsson 2006). Along the same line, the rhetoric about 'support for informal carers' unreflectively omits support for carers to younger recipients. There is definitely a void of research in this area critically scrutinizing this situation.

The second area is *the disability activism and policy* field. Here, the invisibility of informal help-givers seems to have to do with the dilemma of reconciling the care concept with the image of the disabled adult as an empowered, autonomous and participating citizen. The contesting of the care concept that this entails, appears, in a more explicit way, to be a politically informed process. The relative void of reference to these help-givers in official texts on disability issues can undoubtedly be understood in the light of contemporary Swedish disability policy. This policy has adopted the explicit goal of changing attitudes towards people with disabilities 'from objects for care to participating citizens', which may leave little room for a 'carer' (Handikappombudsmannen 2003; Proposition 1999/2000, 79). It also seems to be the result of the substantial criticism towards the care concept, not least from the disability movement in alliance with researchers. This debate has been particularly vivid in the British research context and concerns formal as well as informal care (Glucksmann 2006; Keith 1992; Morris 1997; Parker and Baldwin 1992). In the struggle for better living conditions and social status for disabled people, an explicit goal has been to bring about a shift of power between the disabled person and the caregiver. An important part of this endeavour has been to redefine independence as a way to achieve goals and control one's life. Here, the right to, and control over, personal assistance is regarded as crucial. While 'assistance', in this reasoning, is connected with control over resources of service and individual rights (Ekensteen 2002; Jacobson 2000; cf Waerness 2005; Shakespeare 2006), the care concept is linked to dependence and subordination. To quote Morris (1997, 54), referring to formal as well as to informal care, 'One cannot, therefore, have care *and* empowerment, for it is the ideology and the practice of caring which has led to the perception of disabled people as powerless'. It is interesting to note that very little research has been undertaken regarding the consequences of this transformation for the actual 'help situation' of the disabled person (and his or her family).

A third area in which to look for explanations to the invisibility of informal help and care and help-givers might be to look into *discourses on age and the 'normal life course'*. It is a fact that the care concept can relatively freely be used when speaking about young disabled children and old persons with particular needs, as well as about the crucial role of family as caregivers in this respect, probably because it is considered 'normal for age' to receive care from family members in these age groups on the whole. It is more problematic for the age groups 18–64 – ages for which it is considered 'normal' to be active, capable and independent (Priestley 2003) – also from your family. This is a right and an obligation. It is also in these age groups that it is probably considered most deviant from 'the normal' life course to be in need of care. Hence the greater need to, righteously, claim assistance and control, but also the greater need to disregard other aspects of a complex situation of different help and care needs that a disabled person may have (Whitaker 2008).

These are fascinating and important processes in society. Yet, as has been stated, there is hardly any research inquiring into these processes. The role of family and informal help and care to disabled adults seems absent from the Nordic research tradition on social care, on one hand, and from the tradition of disability research, on the other hand, and for different reasons. The Nordic research on social care that has been developed, particularly in the past decade, has its main focus on older people and their formal and informal care situation. In this research tradition, the situation of younger disabled adults is most often not included. Amidst these larger groups of care recipients it seems to have been ‘forgotten’ by scholars. In the disability research tradition, on the other hand, the exploration of help and caregiving by families seems to have been omitted from research for ideological reasons: since the care concept has become politically incorrect and the role of the family as help and caregivers stands out as ambiguous in this respect, it is not mentioned in the research discourse. In its effort to support the claims of independence within the disability movement, disability research may have become normatively selective as to what can be said and explored. In a sense, it is an expression of solidarity to the expense of an open and critical research approach.

It is possible that family as carer and help-giver is seen as an expression of ‘failure’ within the disability field, in policy as well as in research. In the context of a successful struggle for realizing major reforms, aiming at empowering adult disabled persons by enabling them to have a larger influence over the personal situation and over the help and care given, the family as help and caregiver represents a ‘negative aspect’, connected with dependency, obligation, gratitude, etc. The right to independence, influence, participation and equality also includes the right to be independent of family. The consequences of this is that the support and help provided by family has come to have quite an ambiguous position – of being counted upon, yet made invisible, of crucial importance in the daily lives of many disabled people, yet a failure in the light of modern disability policy/research and the disability field in general. This problematic position may have negative consequences for the informal help-givers *as well as* for the disabled persons that they provide for. Family as failure in a certain sense seems to imply that there is an antagonistic relationship between the needs for empowerment of the disabled person and the presence of family member(s) providing help and care. Whether this is the case, or necessarily has to be so, is beyond the scope and aim of this article to untangle. It might be a topic for further research. However, the consequence of making the informal help and care and the help-giver invisible is that this, in turn, camouflages the real extent of resources needed by the disabled adult – whether it is called care, assistance or service, as well as the needs that, in fact, the informal help-giver may have, not least their needs of support in order to have the strength to go on with their unpaid work. By making family and informal help and care invisible, society is spared from a more serious debate on what it takes to achieve the goal of ‘full participation for all’ – and what it actually implies.

Notes

1. An exception was found to be the *Journal of Intellectual Disabilities* in which 224 out of 412 articles on family caregiving concerned care for grown up intellectually disabled people and their caregiving parents and siblings.
2. Members of four of the largest disability organizations in Sweden were included in the survey: De handikappades riksförbund [DHR], Hörselskadades riksförbund [HRF], Sveriges dövas riksförbund [SDR] and Synskadades riksförbund [SRF]. An additional sample was drawn of non-members with the same disabilities.
3. Results from the survey indicated that the share of the population who were caregivers to someone in their own household was only 5%, which means that the majority of caregivers help person(s) they do not cohabit with.

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