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# Carers in the Welfare State

– On Informal Care and Support  
for Carers in Sweden

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Carers in the Welfare State – On Informal Care and Support for  
Carers in Sweden

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### *List of publications*

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

- I. Jegermalm, M. Informal care in Sweden: a typology of care and care-givers. Accepted for publication in *International Journal of Social Welfare*.
- II. Jegermalm, M. (2004). Informal care and support for carers in Sweden: Patterns of service receipt among informal caregivers and care recipients. *European Journal of Social Work*, 7, (1), 7-24.
- III. Jegermalm, M. (2002). Direct and Indirect Support for Carers: Patterns of Support for Informal Caregivers to Elderly People in Sweden. *Journal of Gerontological Social Work*, 38, (4), 67-84.
- IV. Jegermalm, M. (2003). Support for Carers of Older People: The Roles of the Public and Voluntary Sectors in Sweden. *Social Policy and Administration*, 37, (7), 756-771.

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## ABSTRACT

The general aim of this dissertation is to describe and analyse patterns of informal care and support for carers in Sweden. One specific aim is to study patterns of informal care from a broad population perspective in terms of types of care and types of carer. A typology of four different care categories based on what carers do revealed that women were much more likely than men to be involved at the 'heavy end' of caring, i.e. providing personal care in combination with a variety of other caring tasks. Men were more likely than women to provide some kind of practical help (Study I).

Another aim is to investigate which support services are received by which types of *informal caregiver*. Relatively few informal caregivers in any care category were found to be receiving any kind of support from municipalities or voluntary organizations, for example training or financial assistance (Study II).

The same study also examines which kinds of help *care recipients* receive in addition to that provided by informal carers. It appears that people in receipt of personal care from an informal caregiver quite often also receive help from the public care system, in this case mostly municipal services. However, the majority of those receiving personal, informal care did not receive any help from the public care system or from voluntary organizations or for-profit agencies (Study II).

The empirical material in studies I and II comprises survey data from telephone interviews with a random sample of residents in the County of Stockholm aged between 18 and 84.

In a number of countries there is a growing interest among social scientists and social policymakers in examining the types of support services that might be needed by people who provide informal care for older people and others. A further aim of the present dissertation is therefore to describe and analyse the carer support that is provided by municipalities and voluntary organizations in Sweden. The dissertation examines whether this support is aimed directly or indirectly at caregivers and discusses whether the Swedish government's special financial investment in help for carers actually led to any changes in the support provided by municipalities and voluntary organisations. The main types of carer support offered by the municipalities were payment for care-giving, relief services and day care. The chief forms

of carer support provided by the voluntary organizations were support groups, training groups, and a number of services aimed primarily at the elderly care recipients (Study III).

Patterns of change in municipal carer support could be discerned fairly soon. The Swedish government's special allocation to municipalities and voluntary organisations appears to have led to an increase in the number of municipalities providing direct support for carers, such as training, information material and professional caregiver consultants. On the other hand, only minor changes could be discerned in the pattern of carer support services provided by the voluntary organizations. This demonstrates stability and the relatively low impact that policy initiatives seem to have on voluntary organizations as providers (Study IV).

In studies III and IV the empirical material consists of survey data from mail questionnaires sent to municipalities and voluntary organizations in the County of Stockholm.

In the fields of social planning and social work there appears to be a need to clarify the aims of support services for informal carers. Should the support be direct or indirect? Should it be used to supplement or substitute caregivers? In this process of reappraisal it will be important to take the needs of both caregivers and care recipients into account when developing existing and new forms of support. How informal caregivers and care recipients interact with the care system as a whole is undeniably a fertile field for further research.

## INTRODUCTION

In social policies and research there is an emerging interest, internationally as well as in Scandinavia, in informal care and in analysing the types of support services that might be needed by carers. In recent years Sweden and other countries have implemented statutory, financial investments with the aim of acknowledging carers and developing support services for them (Almberg & Holmberg, 2002; Scharlach *et al.*, 2001; Silverstein & Parrott, 2001; Tjadens & Pijl, 2000; With Respect to Old Age, 1999).

Interest in informal care increases when welfare states are under pressure and are obliged to discuss potential prioritising and the rationing of welfare services. The range of services and care and the relationship between the state, the market, voluntary organizations and the informal care sector (that is, family, friends and neighbours) vary between different kinds of welfare state (Anttonen, Baldock & Sipilä, 2003; Daatland, 1992; Evers, 1995). The Swedish welfare state is characterized by a widespread coverage of social services, such as old-age care and child-care, and these services are largely financed and delivered by the public sector (Baldock & Evers, 1992; Szebehely, 1999; Thorslund, 1991; Trydegård, 2000). Worsening public finances in the 1990s caused local authorities in Sweden to make cutbacks in a number of areas within the social and medical services (Bergmark, Lindberg & Thorslund, 2000; Palme *et al.*, 2003; Thorslund, 2004; Thorslund, Bergmark & Parker, 2000). Deteriorating public finances and an ideological critique of the Swedish welfare state as too expensive and bureaucratic has also given rise to greater interest on the part of the state in informal carers as providers of care and in voluntary organizations as providers of social services (Jeppsson Grassman & Svedberg, 1999; Lundström & Svedberg, 2003; Sundström & Johansson, 2004; Sundström, Johansson & Hassing, 2002).

Sweden and a number of other countries are confronted with a number of social changes that may have an impact on demand and supply factors of informal care. Changes in marriage and divorce patterns, family size and an aging population are examples of such social changes. These changes also put values and norms concerning family responsibilities under pressure, something which might have an

influence on the willingness and ability to provide informal care (Borgermans, Nolan & Philp, 2001; OECD, 1999; Salvage, 1995; Twigg & Atkin, 1994).

The growing interest in social policy and in research into informal care and carer support gives rise to a number of questions. How can the nature of informal care be characterized? Which informal caregivers are likely to need which kinds of support? Which informal caregivers and which care recipients actually receive support services from the public care system and voluntary organizations? What characterizes the informal caregivers and the care recipients with regard to issues such as the sex and age of caregivers, the relationship between caregivers and care recipients, number of hours of help given and so on? What kinds of support services for carers are provided by the public care system and what kind of support are provided by voluntary organizations? Is this support aimed directly or indirectly at the carers and is the pattern of support changing over time?

Even though these issues are truly international, the empirical studies presented in this thesis will chiefly describe, analyse and problematize patterns of informal care and support for carers in Sweden.

## Aims of the dissertation

The general aim of this dissertation is to describe and analyse patterns of informal care and support for carers in Sweden from a variety of perspectives. The issue of informal care and support for carers will be approached from a broad population perspective, studying the different types of care and carers, the receipt of support services among different types of caregiver, and what kinds of help care recipients receive in addition to that provided by informal caregivers. The issue of support for carers will also be investigated with focus on what support services are offered for the informal carers of older people by municipalities and voluntary organizations.

More specific aims of the studies are:

- to describe and analyse patterns of informal care in terms of types of care and types of carer,
- to describe and analyse patterns of support for carers by examining which support services are received by which types of carer, and

which kinds of help care recipients receive in addition to that provided by informal carers,

- to describe and analyse the kinds of support for informal caregivers of older people provided by municipalities and voluntary organizations, and whether this support is aimed directly or indirectly at the caregivers,
- to describe and compare short-term trends in support services for informal carers of older people provided by municipalities and voluntary organizations respectively.

The issues raised in the four articles (studies I-IV) will form the basis for a general discussion of some of the main conclusions in the studies. The focus of this discussion will be the nature of informal care, the gender aspect of informal care, and what implications the findings from these studies can have for social policies and for future research.

## INFORMAL CARE IN CONTEXT

### The elastic nature of informal care

The terminology used to describe carers and the people for whom they care is a delicate and contested area. In this thesis I use the term ‘informal care’ rather than ‘family care’. Family care refers mainly to caregiving provided by family members, while informal care is a wider term that also includes neighbours and friends.

The nature of informal care has been studied and analysed from a variety of perspectives. According to Parker and Lawton (1994) earlier research has chiefly attempted to broaden our understanding of informal care using a variety of dimensions such as *who does it? for whom? what is done?* and *why?*

### *Who are the carers?*

Describing the relationship between the caregiver and the care recipient has been considered important in earlier studies in order to get a

better understanding of *who* the informal carers are and for *whom* they are caring.

Some studies have concentrated on spouses caring for a wife or husband, daughters caring for elderly parents, parents caring for children with disabilities, men as carers and so on (Anahensel *et al.*, 1995; Arber & Ginn, 1990; Kramer & Thompson, 2002; Lewis & Meredith, 1988; Parker, 1993; Winqvist, 1999).

In such studies, *gender*, *age* and *race/ethnicity* have been seen as important discriminating variables.

Gender especially has been regarded as a fundamental aspect of the experience of caring. The importance of gender has been acknowledged by researchers, who have recognized the importance of the family in social policy in general, and the role of women's unpaid labour in particular (Finch, 1993; 1995; Nolan, Grant & Keady, 1996; Twigg & Atkin, 1994; Ungerson, 1987; Waerness, 1996). According to Twigg and Atkin (*ibid.*), feminists have demonstrated that women's position as informal carers has been assumed and taken for granted in social policy. However, some studies have shown that it is relatively common for men to be carers, something which has consequently challenged the earlier assumption that caring was almost exclusively a women's issue (Arber & Ginn, 1990; Jeppsson Grassman & Svedberg, 1999; Kramer & Thompson, 2002; Nolan, Grant & Keady, *ibid.*; Parker & Lawton, 1990; 1994).

In earlier research age has been considered a significant factor in the provision and receipt of informal care. A number of studies have shown that informal caregiving is most common among middle-aged women (45-60); typically these women provide care for a mother or a father (Biegel & Blum, 1990; Brody, 1990; Dooghe, 1992; Lingsom, 1997).

Earlier assumptions that older people are largely a burden on society have been somewhat modified, because several studies have demonstrated that they represent a substantial informal care resource. Older caregivers are likely to provide personal care and heavy nursing tasks, typically for a spouse in their own homes (Arber & Ginn, 1990; Kane & Penrod, 1995; Qureshi & Walker, 1989; Wenger, 1994).

When looking at the age of the care recipients, a great many of earlier studies have focused on older people as recipients of informal care (Anahensel *et al.*, 1995; Binstock & George, 2001; Maddox & Powell, 1993). However, some studies have shown that younger recipients of informal care (up to the age of 65) are most likely to receive personal care, while older care recipients are more likely to receive some kind

of practical help. The finding that older people are likely to receive practical help rather than personal care from the informal carer indicates, according to some researchers, that a lot of older people prefer to receive help with personal care from the formal care system (Arber & Ginn, 1990; Brody, 1995; Nolan, Grant & Keady, 1996; Parker, 1998; Szebehely, 2003a).

Several researchers have recognized that our understanding of the organization and dynamics of informal care in different ethnic communities and minorities is limited. There is a need for further empirical studies about what it means to be an informal carer within an ethnic minority (Atkin & Rollings, 1992; 1993; Forssell, 2004; Katbamna *et al.*, 1997; Nolan, Grant & Keady, 1996; Scharlach *et al.*, 2003; Wenger, Grant & Nolan, 1996). According to Nolan, Grant and Keady (*ibid.*) erroneous myths and stereotypes about ethnic groups still exist. For example, that ethnic minority groups are likely to live in an extended family system which is homogenous in terms of family organization and culture. It is also maintained that the issue of migration and the related patterns of settlement and adaptation are often overlooked.

### *What do carers do?*

One important task of research into informal care has been to describe and analyse what carers *do*. Caring is frequently defined as performing tasks for someone who cannot manage to do them for him or herself. Typical examples are personal care tasks such as lifting, toileting and washing (Twigg, 2000; 2003; Twigg & Atkin, 1994; Walker, Pratt & Eddy, 1995). According to Twigg and Atkin (*ibid.*) it is, however, often difficult to differentiate between caring and the patterns of personal tending in families. One gender aspect of the distinction between caring and personal tending is that women are likely to perform tasks for spouses and other close relatives that would be categorized as caring if performed by men.

Waerness (1983; 1996), makes a conceptual distinction between personal 'service' and 'caring' work. She argues that personal service means that the recipients of the service are capable of performing the task in question by themselves, while caring means that the recipients are not able to do so.

Several researchers (Horowitz, 1985; Johansson, 1991; Parker & Lawton, 1994; Szebehely, 1999; Sørensen, Pinquart & Duberstein, 2002;

Walker, Pratt & Eddy, 1995), have acknowledged that informal care, besides practical 'hands on' assistance, also consists of emotional help, such as keeping someone company and keeping an eye on someone. Studies have shown that the care recipients find emotional help equally useful, which demonstrates the importance of including both practical and emotional help when studying informal care.

One distinction that has been used is between informal care and what can be termed '*informal helping*'. Informal care is often provided by carers who are 'heavily involved', providing personal and physical care for long hours and over relatively long periods of time. Informal help mainly refers to people who provide practical help such as housework, paperwork or taking someone out for relatively few hours. These 'helpers' are commonly part of a 'network' where others, in some cases, take the major responsibility (Nolan, Grant & Keady, 1996; Parker & Lawton, 1994; Wenger, 1994).

### *Why caring?*

Another trajectory in studies about informal care has described and analysed carers in terms of *why* they care, based on their obligations to care and on their position in the life-cycle (Finch, 1995; Finch & Mason, 1990; 1993; Parker & Lawton, 1994; Ungerson, 1987).

Finch and Mason (ibid.) have studied the ways in which caring roles and responsibilities are negotiated between close relatives, for example between siblings or between spouses. One of their findings is that most people understand that relationships between close relatives are built on a sense of obligation. However, there is no clear consensus about what kind of help it is reasonable to expect – this is rather something that has to be negotiated as the situation arises.

Several researchers have acknowledged that social changes such as an aging population, changes in family formation with regard to marriage and divorce patterns, put values and norms concerning family responsibilities under pressure. These changes can have an impact on the informal care system, leading to a reduction in the willingness and ability to provide informal care (Salvage, 1995; Tjadens & Pihl, 2000; Twigg, 1996).

However, according to some studies there seems to be very little evidence of a significant unwillingness to care on the part of families. Population studies in Great Britain, Norway, Sweden and the United



States, which have studied trends in the prevalence of informal care from a caregiver perspective, show a stable pattern in the prevalence of care over time (Jeppsson Grassman & Svedberg, 1999; Lingsom, 1997; National Alliance for Caregiving and the American Association of Retired Persons, 1997; Parker, 1998; Scharlach *et al.*, 2003; Svedberg, 2001). One conclusion that can be drawn from these studies is that there does not seem to be any straightforward link between social changes, cutbacks in the welfare state and substantial changes in the prevalence of caregiving.

## Support services for carers

Defining the kinds of support that carers might need is not an uncomplicated matter. Earlier research has mainly attempted to describe and analyse types of *service-based* support for carers, such as information about available services, individual counseling, carer support groups, day care and respite services (within mainstream services) (Bedini & Phoenix, 1999; Drewett, Olsen & Parker, 1994; Greene & Coleman, 1995; Johansson, 2001; Nolan, Davies & Grant, 2001; Sörensen, Pinquart & Duberstein, 2002; Twigg & Atkin, 1994; Whittier, Coon & Aaker, 2001). Another issue that has been investigated is the importance of ‘payment for care’ with the aim of supporting carers (Evers, Pijl & Ungerson, 1994; Mossberg Sand, 2000; Ungerson, 1990; 1998).

One of the objects of this thesis is to study patterns of service receipt among informal caregivers and care recipients from a population perspective (studies I and II). Another object is to study kinds of service-based support that informal caregivers of older people may receive from the formal care system (mainly municipalities) and from voluntary organizations (studies III and IV). Support that informal carers might receive in their role as caregivers from other parts of a ‘network’, such as a relative, neighbour or friend, will not be under scrutiny in this thesis.

## *Direct and indirect support*

In order to analyse kinds of service-based support for carers a number of researchers have attempted to scrutinize whether the support is aimed directly or indirectly at carers (Bedini & Phoenix, 1999; Greene & Coleman, 1995; Twigg & Atkin, 1994). According to Twigg and

Atkin (ibid.), support services can be seen from a carer perspective as a continuum in which support aimed directly at carers often has the word carer in the name, for example carer support groups or carer training groups. Services destined for the care recipient, for example home help or day care, can be seen as indirect support for carers, a by-product of the mainstream services.

Twigg and Atkin (ibid.) argue that analysing support services as direct or indirect helps to illustrate the fact that caring takes place in a relationship between informal caregivers and care recipients, and that the support needs of caregivers as well as recipients should not be seen in isolation from the social service system as a whole. However, Twigg and Atkin (ibid.) also argue that this kind of analysis often reveals that support services are relatively seldom aimed directly at carers. One reason for this is that the relationship between carers and the public care sector is often unclear and ill-defined. Carers are not clients or patients, and yet they are part of an equation which may involve informal care, the public sector as well as voluntary organizations.

### *Support for carers in social policies*

The importance of support for carers in social policies has been investigated in earlier research. From this we can distinguish two distinct perspectives. The first is an economic-political perspective, according to which the response of virtually all developed countries to their ageing population has been to institute a policy of community care in an effort to achieve a more cost-effective use of scarce resources (Borgermans, Nolan & Philp, 2001; Brody, 1995; Dahlberg, 2004; Dooghe, 1992; Kramer, 1988; Lingsom, 1997). The informal care system has been perceived as an alternative to institutional care for older people, and informal caregivers are generally seen as a resource which can *substitute* the public care system. From this perspective the main aim of support for carers is to promote the informal care system as the mainstay of care provision for older people and people in other age groups in need of care.

The second point of view is based on the idea of a *partnership*, with caregiving for older people and other age groups seen as a joint function shared by the informal and the public care systems (Chappell & Blandford, 1991; Lingsom, 1997; Litwak, 1985; Trydegård, 2000; Walker, Pratt & Eddie, 1995). An older person receiving care from the

family as well as supportive home help from the municipality is regarded as an example of shared responsibility and a partnership between the public and informal care systems.

Even though statutory and financial investments have been made in a number of countries to develop support services for carers – in line with the concept of partnership – the more commonly espoused perspective is the economic-political one, according to which carers are seen as a usable resource (Askham, 1998; Baldock, 2003; Banks, 1999; Evers, 1995; Manthorpe & Twigg, 1995).

Some researchers argue that there is a gap between policies designed to support carers and how support is actually implemented in community care practice. Studies have shown that carers often fail to receive the necessary information about support services, and practitioners seldom offer carers an assessment which directs them to support to which they might be entitled (Arksey, Hepworth & Qureshi, 2000; Jeppsson Grassman, 2001; Lundh & Nolan, 2001; Nolan, Grant & Keady, 1996; Pijl, 2002; Qureshi *et al.*, 1998; Whittier, Coon & Aaker, 2001). One conclusion that can be drawn from these studies is that it is time for a policy re-think to clarify whether the policies actually encourage people to become fulltime carers rather than share responsibility in a partnership with statutory and voluntary organizations.

Baldock (2003), argues that the rhetoric of ‘support’ for carers in social policies can be interpreted in various ways. For example, a real, if not always intended, outcome of carer-friendly policies can be to reinforce rather than ease the burden of informal care work, especially for women.

### *Which carers are likely to need support?*

Earlier research has also looked at which carers are most likely to need some kind of support service. Several researchers have argued that information about different types of care and different types of carer is an important platform in social policy for determining which types of service might be required to support informal care in the community (Hirst, 2002; Parker, 1992; Parker & Lawton, 1990; 1994; Philp, 2001).

According to Parker and Lawton (*ibid.*), information about what the carers do rather than who they are makes it possible to distinguish, for example, which carers are at the ‘heavy end’ of the caring spectrum, giving personal care for many hours, and which are at the ‘lighter end’.

In terms of social policy, they argue that it can be helpful to think about providing support for carers on the basis of what they actually do rather than on the basis of the relationship between the carer and the care recipient. Parker and Lawton (ibid.) do not deny that the relationship between the carer and the care recipient may influence both perceived need of support and the way in which that support might best be delivered.

However, they argue that knowing what carers do has a clear, 'service shaped' and practical relevance, while knowing only who they are can leave a whole range of levels of involvement and, consequently, support needs, undiscovered.

Some researchers have criticized analysis based on what the carers do with the argument that the primary purpose of carrying out this kind of analysis is to distance caring from its social or relational context (Corbin & Strauss, 1988; Gubrium, 1995; Nolan, Grant & Keady, 1996; Rolland, 1994). Nolan, Grant and Keady (ibid.) argue that what emerges from this kind of analysis is mainly an instrumental model of caring, since such models seem unable to move beyond the physical dimensions of caring and often fail to capture the dynamic nature of informal care. Yet they also find such analyses constructive because they can help to put the issue of informal care into perspective, for example when it comes to identifying which carers are involved in heavy caring, which are involved at the 'lighter end' of the caring spectrum, and which might more accurately be called *informal helpers*. Nolan *et al.* (ibid.) also suggest that this kind of information helps us to identify which carers might need particular kinds of support services.

In this thesis the distinction between informal carers and informal helpers, which has been developed in earlier research, will be used as an analytical tool when attempting to distinguish between types of care and carers.

## Informal care: demand and supply

Changes in family formation and in the profile of the older population are examples of social changes that are assumed to have an impact on demand and supply factors of informal care.

## *Family formation*

Changes in *marriage* and *divorce patterns* and *family size* are examples of transformations that may have an impact on the demand and supply side of informal care. In most Western industrial nations marriage rates are declining, with marriage occurring later in life or not at all. Throughout the European Union the crude marriage rates<sup>1</sup> fell from an annual rate in the early 1970s of 7.6 per 1000 of the population, to 5.1 per 1000 in the late 1990s. Of these countries, Sweden currently has the lowest marriage rate, at 3.8 per 1000 inhabitants in 1998. France, Ireland, Finland and the Netherlands experienced the most marked decline in the marriage rate between the 1970s and 1990s, that being around 66 percent. The United States currently has the highest marriage rate of any similarly industrialized country: 8.8 per 1000 inhabitants in 1996 (Eurostat, 1998; 2002a; b; Harper, 2003).

Falling marriage rates and increasing age at marriage are somewhat compensated for by a growth in pre-marriage cohabitation by both never-married and formerly married couples. In the late 1990s just under 10 percent of all people living in couples in the European Union were cohabiting, and around 90 percent were married. Among those aged 30 or under living in couples, nearly 30 percent were cohabiting. However, the percentages of cohabitation vary across Europe, from 25 percent in Denmark, 15 percent in Sweden to less than 3 percent in Southern Europe and Ireland (Eurostat, 1998; Harper, *ibid.*).

In a number of Western countries, there was a sharp increase in divorce rates throughout the 1970s, which plateaued out during the early 1980's (Harper, 2003). In the European Union, there was an increase in the crude divorce rate between 1980 and 2000 from 1.4 per 1000 of the population to 1.9 (Eurostat, 2002a).

According to several researchers, an increase in divorce rates among married couples combined with separations among cohabiting couples may complicate issues of family loyalties and responsibilities, resulting in a blurring or confusing of the lines of 'responsibility' for the care of parents and other relatives (Dooghe, 1992; Drewett, Olsen & Parker, 1994; Salvage, 1995; Walker, 1995). Drewett, Olsen and Parker (*ibid.*) argue that there is so far little concrete evidence of the

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<sup>1</sup> The crude marriage/divorce rates are the ratios of the number of marriages/divorces to the mean population in a given year (Eurostat, 2002a).

effect that these changes actually have on people's responsibility for their (ex-) relatives. Work by Finch and Mason (1993) has shown that women especially feel a sense of responsibility for ex-partners who become chronically ill or disabled after divorce.

In many European countries there is a tendency towards smaller families. Ireland had the highest average household size in the early 1990s (3.3 persons), while Denmark, Germany and Sweden just had over 2 persons (Eurostat, 2002b; Tjadens & Pijl, 2000). In 2000, Sweden had an average household size of 2.0 persons (Statistics Sweden, 2003). Smaller households mean a relatively larger share of single-person households both among younger and older people. In the late 1990s, around 11 percent of all people in private households in Europe lived in single-person households, compared with 8 percent in 1981. The figure is forecasted to rise to 13 percent in 2010. In the late 1990s the percentages varied across Europe; in Sweden 24 percent lived in single-person households, Finland and Denmark around 15 percent, and in Portugal and Ireland around 5 percent (Eurostat, 1999).

When a care need arises in a situation where there are smaller families and an increase in single-person households, the call for care outside of the household will occur more quickly than elsewhere. In order to maintain the availability of informal care the number of children and married-in children may be important. The continuing increase of smaller households and single-person households will, according to several researchers, probably lead to an increased need for vertical (intergenerational) family care relationships (Bengtson & Silverstein, 1993; Donfut & Arber, 2000; Salvage, 1995).

### *Population change among older people*

People in need of care are not necessarily the older members of a society, yet the greatest need for care does unambiguously exist among the older segments of the population (Bass & Morris, 1993; Nolan, Grant & Keady, 1996; Thorslund, 2004; Thorslund & Larsson, 2002; Twigg & Atkin, 1994). Demographic developments influencing the demand for formal and informal care are primarily linked to the increasing number of older people in society, and the rising probability with greater age that the person will be less able to take care of him or herself, which is likely to result in a growing demand for care.

In the OECD-countries the proportion of the population aged 65 or over is expected to have more than doubled between 1950-2050, from an average of less than 10 to about 20 percent of the population. This demographic change is, however, expected to be greater for the number of people aged 80 or over. During the period 1960-2040, the central and northern European countries are likely to have an increase of at least 200 percent in the numbers of those aged 80 or over (OECD, 1996; Trydegård, 2000).

According to Trydegård (2000), Sweden, with some 9 million inhabitants, is no exception from this demographic trend. In the late 1990s Sweden had the oldest population in the world with 17 percent of the population aged 65 or over. The same pattern holds for people over 80 years of age; in 2000 Sweden was the first country in the world to have reached the 5 percent level. This can be compared with the United States 3.5 percent, Japan 3.6 percent, Great Britain and Denmark 4.1 percent (Trydegård, *ibid*).

In Sweden, population change among older people is expected to increase the demand for medical care and social services even if the projections are based upon assumptions of general health improvements in the elderly population (Lagergren & Batljan, 2000; Rosén & Stenbeck, 2000). Recently, however, results indicate a trend of worsening health in the elderly population in Sweden (Parker, Ahacic & Thorslund, 2005; Rosén & Haglund, 2005; Thorslund *et al.*, 2004).

## THE SWEDISH CARE SYSTEM

### Welfare state regimes

By looking at international variations in social rights and welfare state stratification it is, according to Esping-Andersen (1990; 1999; 2003), possible to identify different arrangements concerning how the state, market and family are interrelated. These different arrangements produce three welfare state regimes, which have been a common departure for research into the characteristics of welfare systems in a number of western industrialised countries (Baldock *et al.*, 1999; Gilbert, 2002; Kautto *et al.*, 1999; Sainsbury, 1994; 1999).

The 'liberal welfare state regime' is associated with strict entitlement rules, limited universal transfers, and market solutions predominate. Typical countries of this model are the United States, Australia and Canada.

The second regime-type, the 'conservative', is characterised by status differentials, meaning that rights are attached to class and status. In accordance with the principle of 'subsidiarity', the family's ability to service its members has to be exhausted before the state will intervene. Germany, France and Italy are typical countries of this regime-type.

The Scandinavian 'social-democratic regime' is, according to Esping-Andersen (ibid.), contrasts greatly with the other two regimes. The social-democratic welfare state is characterized by universal welfare programmes which include the working class and the middle class under one universal insurance system. Another characteristic of this regime-type is that the state is involved in subsidizing the care of children, the aged, and the helpless. The state has also a major commitment to full employment, which implies that the right to work has equal status with the right to income protection (Bussemaker & van Kersbergen, 1999; Esping-Andersen, ibid.; Sainsbury, 1999).

Esping-Andersen's theory about welfare state regimes has been questioned and criticized by some researchers because gender is absent from the analysis of the regimes (Daly & Lewis, 2000; Gornick, 1999; Lewis, 1992; 1997; O'Connor, 1996; Orloff, 1993; Sainsbury, 1994; 1999). Bringing the gender perspective into the analysis of the regimes shows, according to these researchers, that gender cuts across welfare state regimes. Taxation systems which deter women from taking gainful employment, and childcare systems designed to encourage female employment are two examples of welfare schemes that may cut across welfare state regimes.

A further critique of Esping-Andersen's regimes is that they are preoccupied with paid work and income-maintenance programmes, and therefore fail to bring informal care and the provision of social services by the public sector and voluntary organizations into comparative welfare state research (Lundström & Svedberg, 2003; Sainsbury, 1999; Szebehely, 1999).

One consequence of the critique of Esping Andersen is that it has become more common among some researchers to use Anttonen's (1990) distinction between the *social insurance state* and the *social service state* (Anttonen, Baldock & Sipilä, 2003; Sipilä, 1997; Szebehely, 1999).



One of the characteristics of especially the Scandinavian welfare state model is that beside income transfers, social care services, such as old-age care and child-care play a major role. The public sector finances, controls and often provides these services (Baldock & Evers, 1992; Kautto *et al.*, 1999; Trydegård, 2000). The Scandinavian countries can thus be described both as social insurance states and as social service states.

However, several researchers argue that the expansion of the social service state and the high participation of women in the labour market have largely not changed the division of labour between men and women (Anttonen, 1990; Jacobs, 1993; Sipilä, 1997; Szebehely, 1999). According to Leira (1993), the dual-earner family is not the same as a dual-carer family. The distribution of caring in Scandinavia is probably as gender biased as in other countries, but one difference is that in Scandinavia more caring work is carried out by women who are in paid employment.

The Swedish care system and the characteristics of the *formal care system* (with focus on the public old-age care), the *market*, *informal care* and the *voluntary sector* will be outlined in the section below.

## Formal care

The responsibility for formal care in Sweden with regard to public care and social services is divided between the national, regional and local level. At the national level, the Parliament and the government set out policy aims and directives by means of legislation and national policy-declarations. At the regional level the responsibility for health and medical care rests with the county councils. According to law, the municipalities are obliged to meet the care and service needs of older people and other age groups at local level.

Within the framework of the national legislation, the Swedish municipalities have substantial autonomy concerning standards for services and care provided. This tradition of local independence applies to all the Scandinavian countries (Bergmark, Lindberg & Thorslund, 2000).

## *Old-age care*

It is the municipalities in Sweden which are, for the most part, responsible for care of the elderly, and the services are essentially financed by

municipal taxation (Bergmark, Lindberg & Thorslund, 2000). This responsibility includes home help services (*bemjänst*) and the institutional care of the elderly (*särskilda boenden*). The municipalities have also, since 1992, been responsible for most of the long-term health care provided for elderly people (NBHW, 2000a; Trydegård, 2000).

Compared with other OECD countries, Sweden and the rest of the Scandinavian countries have had a high proportion of elderly people (65+) receiving home help. In the early 1990s, at least 10 percent of elderly people in Sweden and the other Scandinavian countries received home help, compared to between 6 and 10 percent in the United Kingdom and France, and not more than 5 percent in Germany, Italy, Japan and United States. Sweden is not among countries with the highest proportion of elderly receiving long-term care in institutions. In the early 1990s about 5 percent of elderly (65+) in Sweden, United Kingdom, Germany and the United States received long-term care in institutions, compared with more than 6.5 percent in countries Canada, Finland and Norway. However, in countries Italy, Portugal and Spain only around 1 percent of elderly received long-term care in institutions (OECD, 1996; With Respect to Old Age, 1999).

Home help has been considered a cornerstone of the Swedish old age care system, since it is universal and reaches large groups of elderly. In the 1950s an important initiative was taken by the Swedish Red Cross, which, with inspiration from Great Britain, organized the first home help for elderly people in Sweden. Soon it became clear that many elderly persons preferred to be cared for in their homes. In the late 1950s the municipalities took over responsibility for home help services from the Swedish Red Cross (Lundström & Wijkström, 1995; Larsson & Thorslund, 2002; Trydegård, 2000).

The development of the home help system in Sweden during the 1960s and up to the mid-1970s was characterized by a substantial increase in the number of home help recipients (Daatland *et al.*, 1997; Edebalk, 1990; 2002; Trydegård, 2000). The 1980s and 1990s saw a fall in the proportion of elderly receiving home help. Table 1 shows that the development of home help receipt in Sweden is somewhat different than in the other Nordic countries, and especially when compared to Denmark and Norway. In the early 1980s the pattern of home help receipt was about the same in the Nordic countries. In 2000 there were substantial differences between these countries. Denmark had by far the most home help recipients among the elderly; in Finland just over 10 percent received home help, and in Sweden less than 10 percent.

**Table 1. Home-help recipients, percentage in the population of people 65/67+**

|         | 1980-1982 | 1990-1992 | 2000 |
|---------|-----------|-----------|------|
| Denmark | 16        | 18        | 25   |
| Finland | (15)*     | 21        | 11   |
| Norway  | 18        | 10        | 16   |
| Sweden  | 16        | 10        | 8    |

Source: Szebehely, 2003a. \*Data for 1975.

One consequence of the relative decline in the home help system in Sweden has been that elderly people with the greatest needs have received more home help, while a large group who earlier received help does not now get any help at all, especially with tasks such as cleaning and shopping (Blomberg, Edebalk & Petersson, 1999; Daatland *et al.*, 1997; Szebehely, 2000; Thorslund & Parker, 1995). The consequences for the informal caregivers of cut-backs and targeting the elderly with the greatest needs are still relatively unknown (Sundström, 1997; Sundström & Hassing, 2000; Szebehely, 2003b; Trydegård, 2000).

According to Bergmark, Lindberg and Thorslund (2000), from a gender perspective the Swedish home help system seems to treat single men and single women equally. They argue that if 'need' is held constant, elderly women living alone and elderly men living alone have about the same odds of receiving home help (Bergmark, Lindberg & Thorslund, *ibid*; see also Larsson & Thorslund, 2002; Szebehely, 2000). Women are much more likely to live alone in the final stage of their lives, partly because they live longer than men but also because a great number of women are married to older men. At the time of decrease, about 70 percent of men in Sweden are living with a spouse compared to about one third of women (Bergmark, Lindberg & Thorslund, *ibid*; Gurner & Thorslund, 2003, Sundström, 1997; Szebehely, *ibid*).

At the end of life, when care and service needs are expected to be at a height, the majority of men are likely to have a wife by their side while most women have to cope on their own. Given that women dominate the home help recipient group, one important gender dimension is that women will be affected by cutbacks more than men (Bergmark, Lindberg & Thorslund, 2000; Szebehely, 2000).

## The market

In addition to financial problems and criticism in the 1990s of the Swedish welfare state as too bureaucratic, there has been a shift towards increasing privatisation and market practices in local services (Bergmark, Lindberg & Thorslund, 2000; Blomqvist & Rothstein, 2000; Montin, 1995; Palme *et al.*, 2003; Trydegård, 2001). According to Bergmark, Lindberg and Thorslund (*ibid.*), private financing coming from higher fees has become somewhat more common, but wholly privately financed solutions are still relatively uncommon, especially in an international perspective.

In Sweden, welfare services have traditionally been both financed and provided by the public sector, but in the 1990s there was an increase in the proportion of non-public agencies providing publicly financed welfare services such as health care, child-care and old-age care. In the early 1990s, 6 percent of employees were employed in non-public agencies, compared with nearly 13 percent in 2000, an increase of more than 100 percent. This increase was most substantial in old-age care. In the early 1990s just over 2 percent of staff were employed in non-public agencies; this rose to nearly 13 percent in 2000, an increase of more than 400 percent (Trydegård, 2001). However, between 2000 and 2003 there were only insignificant changes in the proportion and numbers of employees working in non-public agencies providing old-age care (NBHW, 2005).

## Informal care

Even though research and policy debates concerning the care of older people and disabled people in Sweden have mainly focused on the public care system, several studies have indicated that informal care plays a significant role in the total provision of care. Studies which have asked older people about their help providers have shown that elderly people living outside institutions get at least two to three times more care from spouses and other family members than from public care services (Johansson, 1991; Sundström & Johansson, 2004; Sundström, Johansson & Hassing, 2002).

Studies which have investigated the extent of informal caregiving to the elderly and other age groups from a caregiver perspective have, on the one hand, shown that the prevalence of informal caregiving

seems to be stable over time, but on the other hand these studies have not said very much about whether there have been any changes over time in the *content* of the caregiving (Busch Zetterberg, 1996; Jeppsson Grassman & Svedberg, 1999; Jeppsson Grassman, 2001).

### *Support for carers*

In Sweden, support services for carers have not been acknowledged by the state to any significant extent until recently. Support services for carers have been strengthened through changes in legislation and a special financial investment. A new paragraph (section 5) in the Social Service Act 1998 requires municipalities to support caregivers. In the latest Elderly Bill (1997/98:113) the Swedish Government decided to invest SEK million 300 in a *special project* (Anhörig 300) between 1999-2001 to develop services for caregivers. This money was distributed to the municipalities according to the number of residents aged 65 years and older. The general aim of the investment was, according to the Swedish Government, to develop a variety of kinds of support for carers, with the aim of improving their quality of life, and preventing the occurrence of physical and psychological ill health. Before the investment was implemented it was stressed by the Government that voluntary organizations like the Red Cross, carer organizations, pensioners' organizations and religious organizations would play an important role in complementing public support services for carers.

In order to receive this money, municipalities were required by the Swedish Government to collaborate with voluntary organizations over support for carers. Given that this was the first time that the Swedish state was making this kind of financial investment, it represented a substantial increase in support for carers. However, from another perspective this SEK 300 million was only slightly more than one thousandth of the municipalities' total financial costs for old-age care over a three-year period (NBHW, 2000b).

### *The voluntary sector*

In the 1990s, deteriorating public finances and an ideological critique of the Swedish welfare state as too expensive and bureaucratic led to greater interest on the part of the state in voluntary organizations as providers of social services (Jeppsson Grassman & Svedberg, 1999;

Svedberg, 2001). According to studies conducted in the 1990s, the Swedish voluntary sector is as extensive as that of any other comparable industrial country, whether measured in terms of economic importance, membership figures or popular participation in voluntary activities (Jeppsson Grassman & Svedberg, 1996; 2001; Lundström & Wijkström, 1997; Lundström & Svedberg, 2003).

Studies of voluntary organizations and their activities in Sweden have shown that they are quite extensive, especially in areas such as cultural and recreational pursuits (mainly sports), but also trade union activities. But as a provider of the kinds of services that are seen in Sweden as core areas of welfare (e.g. health, social services and education), voluntary organizations are more a minor supplement to statutory services (Jeppsson Grassman, 1993; Jeppsson Grassman & Svedberg, 1999; 2001; Lundström & Svedberg, 2003).

## MATERIAL AND METHODS

### Material and methods used in the dissertation

All studies (I-IV) in this dissertation are part of a three-year research project (1999-2002) about informal care and support for carers conducted by the Research Department at the Sköndal Institute, Ersta Sköndal University College, Sweden.

The aim of the project was to describe and analyse informal care in a broad sense and from a variety of perspectives. A number of studies were conducted and several reports were published: *The prevalence and characteristics of informal care and informal helping* (Jeppsson Grassman, 2001; 2003). *Informal caregiving among members of ethnic minorities* (Forssell, 2003; 2004). *Informal caregiving for older people living at a nursing home* (Whittaker, 2002; 2004). *Support for carers provided by municipalities and voluntary organizations* (Jegermalm, 2002). *Patterns of informal caregiving among 'heavily' involved carers to older people* (Orsholm, 2002).

The project was part of the special financial investment made by the Swedish Government during this period that was mentioned earlier. The project was financed by the Stockholm County Association of Local Authorities.

## *Studies I and II – survey interviews*

Studies I and II are based on a population survey study conducted in 2000 in the county of Stockholm. The county of Stockholm is the largest in Sweden, with 1.7 million residents living in 25 municipalities and the city of Stockholm. The overall aim of the survey was to obtain a better understanding of informal care and informal helping from a broad perspective, and the survey as a whole has been described and analysed by Jeppsson Grassman (2001; 2003). The aim of studies I and II in this thesis was to describe and analyse patterns of informal care and support for carers based on what carers do. What types of care and carers could be distinguished? What kinds of support services are received by which types of carer? What kinds of help do care recipients receive in addition to that provided by other categories of carer?

A random sample of residents aged between 18 and 84 was drawn from the total Swedish population register that contains information about the respondent's age and sex, marital status and personal income. Data was collected by means of telephone interviews. The interviews were conducted during the spring of 2000. In an attempt to increase the response rate, a second wave of interviews was conducted in the early fall of 2000. After excluding people not able to speak Swedish or not living in the county, the sample consisted of 2, 697 individuals. The final response rate was 61 % (n=1639). Trained interviewers working at a Swedish institute for market research (TEMO) conducted the interviews.

The 39 % non-respondents could be divided into four subgroups: 1) almost two thirds of the non-respondents could not be contacted by telephone because they did not have a telephone number or because the phone number was wrong, no longer existed or was ex-directory, 2) the second group of non-respondents (about one quarter) comprised those who refused to participate in the study, 3) the third group (about 10 %) of non-respondents was those who had a telephone but could not be reached even after at least 10 attempts, 4) the fourth, small, group (about 3 %) consisted of those who could not participate because they were sick, absent or doing military service.

Table 2 shows that there were no major structural differences between the interviewed and non-respondents for such variables as sex and age. Some differences can be noted, however, namely that the youngest age group (18-24), the lowest income group (SEK 0-199,000)

and those who were not married were overrepresented among the non-respondents. The latter can thus be summarized as being somewhat younger, more poorly paid and more likely not to be married than the interviewed.

**Table 2. Structure of interviewees compared to the net sample and non-respondents**

|                |                        | Interviewees<br>n=1639<br>(%) | Non-re-<br>spondents<br>n=1058<br>(%) |     |
|----------------|------------------------|-------------------------------|---------------------------------------|-----|
| Sex            | Men                    | 48                            | 51                                    |     |
|                | Women                  | 52                            | 49                                    |     |
| Age            | 18-24                  | 9                             | 15                                    | **  |
|                | 25-44                  | 40                            | 40                                    |     |
|                | 45-64                  | 34                            | 29                                    | **  |
|                | 65-84                  | 17                            | 16                                    |     |
| Income/year    | 0-199 (SEK thousand)   | 56                            | 71                                    | *** |
|                | 200-399 (SEK thousand) | 36                            | 23                                    | *** |
|                | 400- (SEK thousand)    | 8                             | 6                                     | *   |
| Marital status | Married                | 47                            | 35                                    | *** |
|                | Not married            | 53                            | 65                                    | *** |

\*\*\*=  $p < .001$ . \*\*= $p < .01$  \*=  $p < .05$ .

The questionnaire used a structured multiple-choice approach, and the questions covered three basic areas. The first part consisted of three screening questions aiming to identify the prevalence of informal carers. The *first* screening question asked whether they helped, on a regular basis, a next of kin they did not live with or neighbours, friends or colleagues with activities such as housework, transport, gardening, or looking after or keeping an eye on them. The *second* screening question asked whether the informal help identified in the first screening question was being given to someone who was sick, handicapped or elderly and in need of special care. The *third* screening question asked all respondents whether or not they on a regular basis helped someone living in the same household who was sick, handicapped or elderly with special care needs.

“On a regular basis” implied that the help was given at least once a week. The question about whether the recipient was in need of special



care revealed whether the caregiver was regularly helping someone who was sick, disabled or elderly and unable to look after themselves in certain ways.

Jeppsson Grassman (2001; 2003) has described and analysed three carer profiles based on the screening questions. The first profile consists of those who provided help for a non-household member who was *not* sick, disabled or elderly and needing special care. The second profile consists of caregivers helping a non-household member who *was* sick, disabled or elderly with special care needs. The third profile provided care for a household member who was sick, handicapped or elderly with special care needs.

The second part of the questionnaire contained questions focusing on the relationship with the person being cared for, the amount of time spent caring, and the nature of the tasks performed. Respondents were asked to estimate the average number of hours spent helping a recipient per week over the last year. The respondents were also asked about seven different caring tasks, namely: 1) Keeping company (e.g. visiting, sitting with), 2) Keeping an eye on (e.g. checking that everything is alright, regular phone contact), 3) Personal care (e.g. dressing, bathing, feeding, using the toilet, giving medicines), 4) Housework (e.g. preparing meals, cleaning, shopping, laundry), 5) Paperwork (e.g. filling in forms, dealing with bills, banking), 6) Taking out (e.g. taking out for a drive or walk), and 7) Gardening, household repairs, etc.

The third section addressed the consequences of caregiving, support for carers and attitudes towards caregiving. All participants in the study answered a set of background questions. The interviews took about 25-30 minutes if the respondent could be identified as a carer by the screening questions.

Several statistical methods were used when processing data from the study. A two-way comparison (contingency co-efficient) of caring tasks was conducted in order to measure the degree of association between pairs of caring tasks. Chi-square test was used to investigate whether discrete variables such as sex, marital status and relationships between the carer and care recipient varied significantly between different types of care. Continuous variables such as age and number of hours of help given were tested with anova one-tailed variance analysis to see whether they varied significantly between the care typologies. A multinomial logistic regression analysis was conducted in order to further analyse the differential characteristics of the care typologies.

### *Studies III and IV – mail questionnaires*

Study III is based on a survey study conducted in 1999 in the county of Stockholm. Study IV is based on the 1999 survey together with a follow-up survey conducted in 2001. The main reason for conducting the surveys in these particular years was that the special financial investment in support for carers made by the Swedish Government, mentioned earlier, took place during this period. The aim was to describe and analyze support services provided by municipalities and voluntary organizations for people providing informal care for the elderly in terms of what kinds of support were offered, whether the support was aimed directly or indirectly at the carers, and whether the pattern of support was changing over time.

The data for the 1999 and 2001 studies were collected by means of two separate mail questionnaires on each occasion, four questionnaires in all. The first was addressed to the municipalities. Questionnaires were sent to each municipality and to the 18 local districts within the city of Stockholm. The questionnaires were answered by the social workers who were responsible for developing support services for carers at local level. All municipalities replied to the questionnaires in 1999 as well as in 2001.

The second questionnaire was directed at voluntary organizations in the Stockholm region. A two-step approach was used to select the voluntary organizations in the 1999 study. Firstly, five types of voluntary organization were identified that could be expected to provide some kind of support service for carers: 1) pensioners' organizations, 2) the Red Cross, 3) volunteer centres, 4) carer organizations, and 5) religious organizations. Secondly, to obtain information about these five types of organization at local level, a combination of municipal registers and the organizations' own registers were scrutinized. Six hundred and forty voluntary organizations in the Stockholm region were identified. A random sample of 284 organizations was selected for the 1999 study. The questionnaires were sent to the chairperson (or similar) of the organization. Altogether, answers were received from 208 of the 284 organizations (73 %). The 27 % of voluntary organizations which did not respond were relatively equally distributed between the different types of organization. Carer organizations had the highest response rate (89 %) and religious organizations the lowest (69 %).

The questionnaire in the 2001 study was sent to the 284 voluntary organizations that participated in the 1999 study. After the first dispatch

of the questionnaire it was learnt that 13 of the organizations that participated in the 1999 study no longer existed. Thus 271 voluntary organizations participated in the 2001 study. Altogether, answers were received from 215 of the 271 organizations (79 %) in the 2001 study. The 21 % of voluntary organizations which did not respond in the 2001 study were, as in the 1999 study, relatively equally distributed between the different types of organization. Carer organizations had the highest response rate (93 %) and pensioners organizations the lowest (73 %).

The questionnaire sent to the municipalities and the one sent to the voluntary organizations used a structured multiple-choice approach supplemented with open-ended questions. The questions focused on support for informal caregivers looking after people who were 65 years of age or older. Support services were broadly defined as activities primarily aimed at making it physically, psychologically and socially easier to be a carer. The questions were about the extent and content of types of carer support, such as financial support, day care, relief services, support groups, training and other activities that can be classified as support for caregivers. To enable us to study trends in support services, the same questionnaire was used in 2001 as in 1999.

## PRESENTATION AND RESULTS OF STUDIES

### Study I

Jegermalm, M. Informal care in Sweden: a typology of care and caregivers. Accepted for publication in *International Journal of Social Welfare*.

#### *Aims*

The aim of this article was to describe and analyse the characteristics of informal care in Sweden in order to see how a better understanding of care and carers could influence support services for informal caregivers. The main questions addressed in the study were: What types of care are provided? How prevalent are the different types of care?

What types of carer can be distinguished? In what way are gender role patterns found by the study related to findings in previous studies?

## *Results*

Thirty-nine percent of all the respondents (n=1639) replied that they helped, on a regular basis, a next of kin they did not live with or neighbours, friends or colleagues with activities such as housework, transport, gardening, or looked after or kept an eye on them.

The 39 percent who responded that they cared for someone in another household could be divided into one group helping someone who was *not* sick, handicapped or elderly or needed special care (22 %), and another group (17 %) helping someone who *was* sick, handicapped or elderly and in need of special care. Just under 5 percent of the respondents replied that they regularly gave care to a household member who was sick, handicapped or elderly and in need of special care. There were no large differences overall in the prevalence of men and women carers.

About 5 percent of all caregivers identified by the screening questions (n=676) were helping someone in the same household as well as someone not living in the same household. The main focus in this study was on the caregivers and there was only one question asked about caregiving tasks even if the caregiver was helping more than one recipient. The analysis group was thus based on the number of caregivers and not on the number of caregiving relationships.

When the data were divided into a typology of *four* different care categories based on various caring tasks and the actual number of carers, the carers could be distinguished relatively clearly according to a number of variables.

Both carers and recipients were oldest in the category providing *personal care*. They were more likely than the other categories to be female, to be giving help to a mother, spouse or a child usually for more than fifteen hours per week. This was the category where it was most common by far for the carer and the recipient to be living in the same household.

The majority of carers *keeping someone company* and/or *keeping an eye on someone* were women. Carers in this category were more likely than those in other care categories to help someone without special care

needs who did not live with them, and they were likely to provide less than five hours of help per week.

The majority of carers who provided *practical help in combination with keeping someone company/keeping an eye on someone* were women, but the difference in the numbers of male and female carers was not as large as in the first two categories. Nearly half of carers in this category were helping someone in a separate household who was sick, handicapped or elderly with a need of special care, and they were most likely to be looking after a mother or a neighbour/friend, and they provided at least five hours of help per week.

In contrast to the other care categories, slightly more than two thirds of carers providing *practical help only* were men. Slightly more than one third in this category provided help for someone with special care needs in another household, and they were most likely to be helping a neighbour/friend or a mother, providing fewer than five hours of help per week.

## *Conclusions*

One major conclusion that could be drawn from this study is that the *four* types of caring that were identified demonstrated significant differences with regard to a number of variables such as gender, age of carer and care recipient and number of hours of help given.

At the 'heavy end' of the caring spectrum we identified one category of carer providing *personal care* in combination with a variety of tasks such as practical help and giving many hours of company. These carers were typically women, usually an elderly wife providing many hours of personal care for a husband with whom she lives, or a daughter providing personal care for a mother with whom she does not live.

At the 'lighter end' of the caring spectrum we identified three categories of carer concerned in activities *not* involving personal care, and who could more accurately be called *informal helpers*. However, between the three categories not providing personal care there were significant differences with regard to the sex of helper, age of the help recipient, and whether or not the recipient was in need of special care.

The results obtained from this study seem to describe a similar pattern of gender roles as described in earlier studies, namely that women overall, and especially older women, provide most of the personal care for a large number of hours, and that it is relatively common for both

women and men to be involved as informal helpers, providing different kinds of practical help. The findings indicate that it is important for social policy to develop programs that take into account the support needs of both caregivers and care recipients, and not to see the needs of caregivers and recipients in isolation from the social care system as a whole.

## Study II

Jegermalm, M. (2003). Informal care and support for carers in Sweden: Patterns of service receipt among informal caregivers and care recipients. *European Journal of Social Work*, 7, (1), 7-24.

### *Aims*

The aim of this article was to describe and analyse patterns of support services received by different categories of informal carers in Sweden, and the kinds of help that care recipients receive in addition to that provided by these different categories of carers.

### *Results*

This study's approach was to use the typology of four different care categories that was defined in Study I, and in the next step to further investigate in Study II what support services were received by which type of carer and whether the care recipients received any additional help from anyone else. Carers in all categories were asked whether they received any of four kinds of service; namely support groups, training, relief service and financial support. Nearly 90 percent of all carers responded that they did not receive any of the support they were asked about. Receiving some kind of support was most common among carers providing personal care; slightly more than one fifth in this category received some support compared to less than one tenth in the three other care categories.

All carers were asked whether the care recipient was also receiving additional help from someone else, for example another relative, the formal care system or a voluntary organization. The most common additional help in all care categories was from some other relative or

relatives. Care recipients who received personal care from an informal caregiver were most likely to get help provided by the municipalities and home medical care provided by a county hospital. Very few carers in all care categories replied that the care recipient got any help from voluntary organizations or for-profit agencies (the market).

### *Conclusions*

Two main conclusions could be drawn from this study. *Firstly*, overall there were relatively few carers in any care category receiving any kind of support. Less than one tenth of the carers in the categories not providing personal care responded that they received support. Even though support was most common in the category providing personal care, nearly 80 percent responded that they did not receive any support.

*Secondly*, the results indicated that the majority of all types of caregivers were not the care recipients' only source of care. In all care categories it was most common for the care recipients to be receiving additional help from another relative. Additional help from neighbours or the public care system was relatively common, but very seldom from voluntary organizations or for-profit agencies. Help from the public care system, in this case mostly municipal, was quite often provided for care recipients also receiving personal care from an informal caregiver. Yet the majority of recipients receiving personal care from an informal carer did not receive any help from the public care system or from voluntary organizations or for-profit agencies. The fact that the majority of recipients in all care categories in this study obtain most of their help from informal carers indicates that the informal care system in Sweden plays an important role in helping people with needs.

### *Study III*

Jegermalm, M. (2002). Direct and Indirect Support for Carers: Patterns of Support for Informal Caregivers to Elderly People in Sweden. *Journal of Gerontological Social Work*, 38, (4), 67-84.

## *Aims*

The aim of this article was to describe and analyze support services provided by municipalities and voluntary organizations for people providing informal care for the elderly. What kinds of support are offered to informal caregivers? Is the support aimed directly or indirectly at the carers? Do the municipalities and the voluntary organizations offer the same kind of support services? These issues were the empirical basis for a discussion of whether or not support for carers has any impact on the balance between formal and informal care.

## *Results*

The results showed that both municipalities and voluntary organizations offered a number of kinds of support service for carers. Financial support for carers was only provided by the municipalities, and the municipalities were also practically the only provider of relief service and day care as a support for the carer. Support groups are a direct and specific form of carer support that was relatively common among the municipalities. The support offered by the voluntary organizations focused on training and support groups, a form of support that is usually small-scale and aimed directly at the carer. The voluntary organizations also provided services, such as a visitor service, targeted at the elderly care recipient that can be seen as a form of indirect relief for the caregiver.

## *Conclusions*

One conclusion that could be drawn from this study was that there are different patterns of support dependent upon whether the support comes from the formal care system or the voluntary organizations. The main types of support for carers offered by the municipalities are payment for care, relief services and day care. The carer support provided by the voluntary organizations focused on support groups, training groups, individual counselling and a number of services aimed primarily at the elderly care recipient. The results thus indicated a pattern where the services offered by the formal system and the voluntary organizations seem to complement rather than compete with each other. From the carer's point of view, most of the support services



were indirect. However, the findings demonstrated that the voluntary organizations were more likely than the municipalities to offer direct forms of support.

## Study IV

Jegermalm, M. (2003). Support for Carers of Older People: The Roles of the Public and Voluntary Sectors in Sweden. *Social Policy and Administration*, 37, (7), 756-771.

### *Aims*

This study was based on the survey conducted in 1999, which was the basis for Study III, together with a follow-up study conducted in 2001. The overall aim of this study was to describe and analyse short-term trends in support services for the carers of older people provided by municipalities and voluntary organizations. This formed the basis for a discussion about whether the special financial investment in help for carers made by the Swedish state 1999-2001 led to any substantial changes in the support provided by municipalities and voluntary organizations.

### *Results*

The findings demonstrated a considerable increase between 1999 and 2001 in the numbers of municipalities providing information material written specifically for carers. There was also a significant increase between the 1999 and 2001 surveys in the number of municipalities reporting that they ran training for carers. There was a clear rise in the number of municipalities reporting using professional caregiver consultants- only a few municipalities in the first survey yet almost one-fifth in the follow-up. In services such as relief and day care it was possible to distinguish a more distinct carer perspective, since a number of the municipalities had set up flexible forms of relief services and day care. Where financial support for carers was concerned, the results demonstrated minor changes over time.

In both 1999 and 2001 about one fifth of the voluntary organizations reported that they ran support groups and training as support

for carers. Information material aimed at carers and relief services are two forms of support which showed a decreasing trend. The voluntary organizations reported in both studies that they ran visitor services targeted at the older care user, something that also can be regarded as indirect relief for the caregiver. None of the municipalities reported a service of this kind.

## *Conclusions*

One conclusion that can be drawn from these studies is that the implementation, by the state, of special financial investments in support for carers led to an increase in the number of municipalities providing support aimed directly at carers, such as training, information material and professional caregiver consultants. The Swedish welfare state thus seems to be following an international trend by taking informal caregivers into consideration and investing in support services for them.

A second conclusion that can be drawn is that the results indicated only minor changes over time in the pattern of support services for carers provided by the voluntary organizations. On the one hand this demonstrates stability, but on the other it indicates that the voluntary organizations have not set up many new forms of support service. Municipal expectations that the voluntary organizations would offer more relief services do not seem to have been realized in the form of actual investments by the voluntary organizations. Nor have the expectations of the state that financial investment would result in an increase in the amount of support for carers provided by voluntary organizations. The question is what the state could expect, given that the funding rules were unclear regarding exactly how the voluntary organizations were supposed to increase their role as providers of such services. The findings here appear to indicate that such policy initiatives have relatively little impact on voluntary organizations as providers.

## *Methodological considerations*

This thesis uses survey approaches that are appropriate for the aims and issues of each individual study. The pros and cons of using mail and telephone techniques as an alternative to face-to-face interviews or proxy interviews when collecting data in survey studies has been acknowledged earlier (Campbell & Alwin, 1996; Herzog & Kulka, 1989;

Nachmias & Nachmias, 1996; Trydegård, 2000). One disadvantage of mail-questionnaires can be that elderly respondents may have poor vision or be cognitively impaired and may find it hard to answer mail-questionnaires, something that increases the risk of a high non-response rate. According to Thorslund and Wärneryd (1990), face-to-face interviews are one way to tackle these problems, but these can be more expensive, especially if one wants to reach a large number of respondents. Herzog and Kulka (ibid.) argue that the cost advantages of telephone and mail surveys, coupled with the lack of evidence of severe problems with data quality and response rates, indicate that a more serious look at the advantages of alternatives to the traditional face-to-face interview is in order.

Studies I and II used telephone interviews as a survey technique and studies III and IV used mail questionnaires. Some methodological concerns regarding the methods used in this thesis will be outlined and discussed in the section below.

### *Selections and samples*

One methodological shortcoming that has been discussed by some researchers is that studies aiming to characterize informal carers have often used fairly small, non-representative samples (Bookwala, Newman & Schultz, 2002; Horowitz, 1985; Jani-Le Bris, 1993; Kramer, 2002; Salvage, 1995). These researchers identify a need for studies based on representative samples of carers and reflecting their socio-demographic and socio-cultural characteristics, their needs and the assistance they provide for older people and other disabled relatives. In order to study gender differences, for example, Bookwala, Newman and Schulz (ibid.) argue that it is important to have large samples of male and female caregivers so that more advanced data analyses may be carried out. These larger samples should ideally be selected using random, probability sampling techniques which will make the male and female samples more representative of caregivers as a whole.

Studies I and II in this thesis are based on a random representative sample that was drawn from the total population register that contains information about the respondent's age and sex, marital status and personal income. Using this kind of sample made it possible to study, for example, gender and age differences between different categories of carers.

## *Generalizability*

One aspect related to the generalizability of the results of the study is the question how representative the county of Stockholm is of Sweden as a whole. Earlier Swedish studies have produced somewhat contradictory results regarding differences in the prevalence of informal care between urban areas and small, rural areas. Some have indicated that informal care is slightly more common in rural areas, while others have indicated that the differences between urban and rural areas are insignificant (Busch Zetterberg, 1996; Jeppsson Grassman, 2001; Jeppsson Grassman & Svedberg, 1999). Given that earlier research has failed to produce any clear picture of differences between urban and rural areas with regard to the prevalence of informal care and that the county of Stockholm includes the city of Stockholm as well as rural areas, it is reasonable to assume that the findings from this study are relatively representative of Sweden as a whole.

When it comes to international comparisons of informal care and support systems for carers, several researchers advice caution (Johansson, 2001; Low, Payne & Roderick, 1999; Parker, 1998; Tjadens & Pijl, 2000). One reason for this is that the relation between state and family varies between different kinds of welfare state. How support systems for carers are designed depends upon country-specific factors such as demography, culture, politics and economic structures. The circumstances and conditions behind informal care and support for carers in countries with limited public care differ considerably from those in countries with a greater provision of public care.

## *Response rates*

The response rate in the telephone survey used in studies I and II was 61 %. Before conducting the interviews a letter containing information about the aim of the study was sent to all participants. The aim of this letter was to explain the study and encourage people to participate. Interviews were conducted during the spring of 2000. In an attempt to increase the response rate a second wave of interviews was conducted in the early fall of 2000.

Almost two thirds of the non-respondents could not be contacted by telephone because they did not have a telephone number or because the phone number was wrong, no longer existed or was ex-directory. The second largest group of non-respondents comprised those

who refused to participate in the study. Given that the largest group of non-respondents consisted of people who could not be contacted by telephone, the response rate would probably have been higher if this group had been contacted about a face-to-face interview. The main reason for not contacting the largest group of non-respondents offering them a face-to-face interview was that the financial consequences would have exceeded the limits of the study's budget.

The important question is whether the non-response rate had an impact on the results of the study. The non-respondents were somewhat younger, had a lower income and were more likely to be unmarried than the respondents. Since a typical informal carer in studies I and II was older, had a higher income and was more likely to be married than the non-respondents, a higher response-rate among the younger respondents might have produced a lower prevalence of informal care.

Studies III and IV were based on survey studies conducted in 1999 and 2001, on each occasion by means of two separate mail questionnaires, four questionnaires in all. The first was addressed to all the municipalities in the Stockholm region. All municipalities replied in 1999 as well as in 2001. The second questionnaire was directed at a random sample of voluntary organizations in the region. Chairpersons (or similar) of the organizations answered the questionnaires. About three quarters of the organizations participated in 1999 as well as in 2001. Measures were taken in the 1999 and the 2001 study to increase the response rate of voluntary organizations. Three weeks after the questionnaire was sent out, a follow-up letter was mailed to those who had not replied. After a further three weeks, the remaining non-respondents received a reminder and a further copy of the questionnaire. A telephone follow-up was also arranged, aimed at getting the non-respondents to return the questionnaire. Given the measures that were taken, it is unlikely that a higher response rate would have been achieved by using face-to-face interviews. All the voluntary organisations who were contacted were requested to answer the questionnaire irrespective of whether or not they provided any support for carers. One reason for not responding could be that some of the organisations that did not provide support for carers to older people found the questionnaire irrelevant to them.

### *A temporal perspective*

Because there is a lack of longitudinal research studying patterns of informal care over time, most research about informal care has been cross-sectional (Bookwala, Newman & Schultz, 2002; Campbell & Alwin, 1996; Kramer, 2002; Nolan, Grant & Keady, 1996). We thus know little about how caregivers adapt over time, and how needs vary across the caregivers trajectory. Parker (1998), who has analysed trends in informal care 1985-1995 based on the General Household Surveys (GHS) in Great Britain, concludes that trying to explain differences over time is difficult. According to Parker (*ibid.*), the conclusions reached were necessarily tentative, because further analysis that allows the impact of larger demographic and economic changes to be studied is clearly needed. The cross-sectional design used in studies I and II allowed us to study differences between different types of care and carers for a number of variables, but it did not allow us to analyse patterns of caregiving over time.

The design used in Study IV allowed us to study whether there were any increases or decreases in the number of municipalities and voluntary organisations providing support services over a short period of time. However, the design did not allow us to examine whether there were any changes over time in the quality of services provided and in the number of carers that may have received some support.

### *A caregiver perspective*

In earlier research into informal caregiving, a relatively common approach has been to ask elderly people whether they receive various kinds of support and care, and if so, who provides it (Chappell & Blandford, 1991; Johansson, 1991; Sundström, Johansson & Hassing, 2002; Szebehely, 1998; Walker, Pratt & Eddy, 1995). This care recipient approach has produced “second-hand” information about the informal caregivers.

The surveys in studies I and II looked at informal care from a *care-giver* perspective, which in turn means that all data regarding the care recipients must be viewed as “second-hand” information (Busch Zetterberg, 1996; Jeppsson Grassman, 1993; Jeppsson Grassman & Svedberg, 1999; National Alliance for Caregiving and the American Association of Retired Persons, 1997; Parker & Lawton, 1994; Scharlach *et al.*, 2003). According to Walker, Pratt and Eddy, (1995), the danger

of both the caregiver approach and the care recipient approach is that they may result in underestimations, especially of the numbers of elderly women providing informal care. These authors argue that there are a number of elderly women who, in studies with a caregiver perspective, are likely not to regard looking after an elderly frail husband as caregiving, because, for example, they are only doing tasks that they have been performing for a long time anyway. On the other hand, in studies with a care recipient perspective, an elderly man may report that he is not dependent on informal care even if he is clearly unable to perform, for example, household tasks, because his spouse has always done these tasks. The caregiver perspective with self reporting used in studies I and II may have particularly affected the reliability of the findings about whether elderly women regarded themselves as caregivers, leading to an underestimation of the prevalence of female carers.

### *Identification of informal carers*

One methodological issue regarding aspects of validity and reliability in the thesis concerns how the informal carers in studies I and II were identified. We identified carers in the population by means of what in earlier studies has been described as a ‘maximalist definition’, which includes carers providing personal care for many hours as well as those providing various kinds of practical help such as housework, taking out or gardening (Arber & Ginn, 1990; National Alliance for Caregiving and the American Association of Retired Persons, 1997; Parker & Lawton, 1990; 1994). The major reason for using this broad definition was to facilitate an analysis in which different kinds of care and different kinds of carers could be identified and compared.

The results of studies I and II reveal no large differences in the prevalence of men and women carers. However, when the data were divided into a typology of different care categories based on what the carers do, there were substantial differences. Women were much more likely than men to be involved at the ‘heavy end’ of caring, i.e., providing personal care in combination with a variety of other caring tasks. Men were more likely than women to provide some kind of practical help. In all probability, this broad definition of informal care helped especially to identify male carers who would not have been found with a more narrow definition of informal carers. A narrower definition would have given a different picture of informal care. If we

had used a definition which only included carers providing personal care (such as help with dressing, bathing, feeding etc.), we would have excluded a substantial number of both male and female informal helpers who provide kinds of practical help not involving personal care.

## GENERAL DISCUSSION

The objective of this thesis is to describe and analyse informal care and support for carers from a variety of perspectives. The following section will discuss some of the main results and their possible implications for social policy and further research.

One general feature of earlier research into caring has been the attempt to distinguish between informal care and patterns of reciprocal help common within family relations. Caring has often been refereed to as performing tasks for someone who is not capable of carrying out these tasks themselves. In this thesis we attempted to distinguish informal care from what can be seen as genuinely reciprocal forms of support within a relationship by asking the respondents whether the help was provided on a regular basis and whether or not they were providing the help for someone who was sick, disabled or elderly and in need of special care. On a regular basis implied that the help was given to a recipient at least once a week. The question about whether the recipient was in need of special care revealed whether the caregiver was regularly helping someone who was unable to look after themselves in certain ways.

Another aspect of informal care that has been addressed in earlier research is the distinction between informal care and 'informal helping'. Informal care typically means carers providing personal care in combination with practical help for many hours, while informal helping is mainly used to refer to activities not involving personal care tasks (National Alliance for Caregiving and the American Association of Retired Persons, 1997; Nolan, Grant & Keady, 1996; Parker & Lawton, 1994; Rowlands, 1998).

Although issues such as how to define "on a regular basis", who should be considered "sick, disabled or elderly and in need of special care", and who should be defined as an informal carer or informal helper are complicated issues, the analysis in studies I and II based on what carers *do* provided a relatively clear picture of various categories



of informal carers providing personal care and of informal helpers providing help *not* involving personal care in terms of their gender, age, the kind of help provided, time spent helping and so on.

One conclusion from this thesis and earlier research is that there is no single way to define the elastic nature of informal care. It is a rather complex phenomenon which has to be placed in context using a variety of factors such as age, gender, the relationship between caregiver and care recipient, what carers do and how the caregiving process can be understood in a temporal perspective.

## A gender issue

In earlier research and social policy discussions on informal care, gender has been considered highly important and informal care has largely been seen as a female domain.

The overall picture of informal care revealed in Study I showed that there were no large differences in the prevalence of men and women carers, which might be seen as a somewhat surprising result. However, in agreement with previous studies, the results demonstrated that analysing the prevalence of informal care on the basis on what the carers do and distinct categories of care and carers clearly revealed gender differences between male and female carers (Arber & Ginn, 1990; Jeppsson Grassman, 2001; National Alliance for Caregiving and the American Association of Retired Persons, 1997; Parker, 1998; Parker & Lawton, 1994).

When the data were divided into a typology of four care categories there were large differences in the number of male and female carers. We identified one category of carers providing *personal care* in combination with a variety of tasks such as practical help and keeping company. Although some men provided personal care, typically these carers were women, usually an elderly wife providing many hours of personal care for a husband with whom she lives, or a daughter providing personal care for a mother with whom she does not live. The picture of women typically being involved at the heavy end of caring is confirmed in a number of studies, internationally as well as in Scandinavia (Bengtson, Rosenthal & Burton, 1996; Brody, 1990; Jeppsson Grassman, 2001; National Alliance for Caregiving and the American Association of Retired Persons, 1997; Parker, 1998; Szebehely, 1998; Winqvist, 1999).

We identified three categories of carers concerned in activities *not* involving personal care, and who could more accurately be called *informal helpers*. However, between the three categories not providing personal care there were significant differences with regard to the sex of the helper, the age of the help recipient, and whether or not the recipient was in need of special care. Men were most likely to provide *practical help only*, while women often *kept someone company/ kept an eye on someone*. Some researchers have pointed out that it is fairly seldom acknowledged that women also seem to be involved at the lighter end of caregiving as informal helpers (Jeppsson Grassman, 2001; Minkler & Chehimi, 2003; Parker & Lawton, 1990; 1994). It is fairly common for men to be involved in caregiving, although most likely as informal helpers providing some kind of practical help (Arber & Ginn, 1990; Jeppsson Grassman, *ibid.*; Jeppsson Grassman & Svedberg, 1999; Kramer & Lambert, 1999; Parker, 1998).

One central question here is how we can understand the findings of this thesis in a Swedish context. One may assume that the relatively high availability of social care services provided by the public welfare system in Sweden would minimize gender role differences with regard to informal care. However, the results obtained here seem to describe a pattern of gender roles that is similar to those described in earlier studies in at least two regards. Firstly, that women overall, and especially older women, provide most of the personal care for a large number of hours, and secondly, that it is relatively common for both women and men to be involved as informal helpers, providing various kinds of practical help often in combination with keeping someone company or keeping an eye on someone for relatively few hours. The main point we can learn from this is that even though the Swedish welfare state has been described as universal and characterized by an extensive system of benefits and services intended to cover the entire population, the results here indicate that informal care in Sweden plays an important role and that the gender role patterns have much in common with informal care patterns in other types of welfare state.

## The issue of support for carers

### *Social policy initiatives*

A number of countries have recently acknowledged carers and the need to develop services for them. This acknowledgement has included financial investments and changes in legislation to improve carers' opportunity to receive various kinds of support. However, there has often been confusion about which support services should be developed, and which carers are most likely to benefit from which kinds of support. Some researchers have tried to clarify this ambiguity about what carers themselves regard as support by describing and analysing support services in the form of a continuum, in which support aimed directly at carers often has the word carer in the name, for example carer support groups or carer training groups. Services destined for the care recipient, for example home help or day care, can be seen as indirect support for carers, a by-product of the mainstream services (Bedini & Phoenix, 1999; Greene & Coleman, 1995; Twigg & Atkin, 1994).

One of the aims of this thesis was to describe and analyse short-term trends in support for carers in Sweden during a period of public financial investment. The results demonstrated that this investment seemed to bring about some change in the short term. An increase could be discerned in the number of municipalities providing support aimed directly at carers, such as training, information material and professional caregiver consultants. A more distinct carer perspective could be distinguished in services such as relief and day care, since a number of the municipalities had set up flexible forms of relief services and day care. The results thus indicate that the Swedish welfare state seems to be following an international trend by taking informal caregivers into consideration and investing in support services for them.

Given that this financial investment over a three-year period was the first time that the Swedish state has made this kind of investment, it represented a substantial increase in support for carers. However, this investment was only a small fraction of the municipalities' total financial costs for old-age care (Almberg & Holmberg, 2002; NBHW, 2000a).

Whereas patterns of change can be discerned in the support provided by municipalities, very few changes over time can be observed in

the pattern of support services for carers provided by the voluntary organizations. In both 1999 and 2001 about one fifth of the voluntary organizations reported that they ran support groups and training as support for carers. Information material and relief services aimed at carers are two forms of support services which showed a decreasing trend. This demonstrates that the Governmental investment did not encourage voluntary organizations to set up many new forms of support services.

One might ask what changes the Swedish Government was expecting, given that the funding rules were unclear regarding how the voluntary organizations were supposed to extend their role as providers of such services. If in the future voluntary organizations are expected to increase their support for carers, one strategy might be to give funding directly to the voluntary organizations instead of, as in the Swedish case, distributing financial resources to the municipalities only.

The findings here appear to demonstrate that policy initiatives of this kind have relatively little impact on voluntary organizations as providers. The Swedish welfare state is apparently not in line with other European countries, where it is more common for voluntary organizations to be providers of support for carers.

### *Patterns of service receipt*

Although one of the main results of Study IV was that a number of municipalities did increase over time the support services aimed directly at carers, the study did not, however, tell us anything about which carers are likely to need support and which carers actually receive some kind of support. Some researchers argue that a knowledge of the different types of care and different types of carers is important for social policy because it can be used to analyse the types of services that might be needed to support informal carers, and the numbers of carers who might need such support (Allen & Perkins, 1995; Parker, 1992; Parker & Lawton, 1994; Whittier, Coon & Aaker, 2001).

The care typology used in this thesis gave a clear picture of which carers might need support. Studies I and II identified three categories of male and female carers concerned in activities not involving personal care, and who can be called informal helpers. Study II demonstrated that typically these helpers did not receive any support aimed directly at carers and that the care recipients most likely received help

from the informal helper only or additional help from some other relative, but relatively seldom from the public care system. These informal helpers clearly play an important role in helping people with needs, but it is unlikely that they have the same need of support from the public care sector as those who are most heavily involved.

Even though support was most common in the category providing *personal care*, the majority responded that they did not receive any support aimed directly at carers, such as support groups, training, relief service or financial support. Relief services were the most widespread form of support for carers providing personal care. Given that the majority of carers in the category providing personal care were women, the results indicate that there are a number of women, especially elderly ones, giving care for a large number of hours, who do not receive any support.

One aspect to consider when discussing support for carers in terms of direct or indirect support is whether care recipients receive any help in addition to that provided by informal caregivers. The finding in Study II that most help from the formal care system, in this case mostly municipal, was received by care recipients also receiving personal care from an informal carer indicates that services provided by the formal care system are primarily targeted at recipients also receiving personal care from an informal carer. To what extent public sector services supplement the type of care which informal carers are already providing, or whether there is a real substitution effect (where the public service input means that the carer does not become involved in certain types of care), has to be further investigated. Earlier studies have given a somewhat complex picture. On the one hand, some of the informal carers with the heaviest care burden have been most likely to receive services which apparently supplement the type of care they are already involved in. On the other hand, for a number of informal carers there is some evidence of substitution, with personal care coming from formal rather than informal sources (Litwak, 1985; Parker, 1998; Parker & Lawton, 1994; Szebehely, 2000; Walker, Pratt & Eddy, 1995).

The studies in this thesis found that help from the formal care system was relatively often going to care *recipients* also receiving *personal care* from an informal caregiver, yet one fifth of the recipients of personal care did not get any help other than from the informal caregiver. However, in the latter category there were substantial differences between care recipients living in a separate household from the carer and recipients living in the same household. Recipients living in a separate

household from the carer were much more likely to receive support from the formal care system or from a further relative than those recipients who were living in the same household as the carer. This result is in line with the findings of earlier studies (Larsson, 2004; National Alliance for Caregiving and the American Association of Retired Persons, 1997; Parker, 1998; Parker & Lawton, 1994).

Even if Study II had no information about how many caregivers and recipients may have refused an offer of support, these results indicate that the public care sector does not so far seem to have sufficiently acknowledged that a number of especially heavily involved female caregivers and their recipients might need some kind of support. However, deciding which kinds of support they might most benefit from is not an uncomplicated issue. Training, support groups and relief services are examples of already existing forms of direct support for carers that might enable them to continue as caregivers. Home help services aimed primarily at the care recipient might in some cases supplement the type of care in which carers are already involved, or might sometimes substitute some of the tasks that informal carers already provide.

The results of this thesis indicated, in line with earlier studies, that even where statutory, financial investments have been made it is so far relatively uncommon for informal carers to receive any kind of support (Arksey, Hepworth & Qureshi, 2000; Pijl, 2002; Qureshi *et al.*, 1998; Tjadens & Pijl, 2000). Social planning and social work need to clarify the aims of existing and new forms of support services for carers; for example, should support services supplement caregivers or should they be a substitute? An important feature of this process of reappraisal will be to take the needs of both caregivers and recipients into account when developing existing and new forms of support.

## Prospects for informal care and support for carers in social policy and research

What impact changes in the welfare state might have on the relationship between the informal and formal care systems has been investigated in earlier research. Some researchers have attempted to describe the relationship between the informal and the formal care system in terms of a *partnership* or as a *substitution* effect (Chappell & Blandford,

1991; Dahlberg, 2004; Kramer, 1988; Lingsom, 1997; Litwak, 1985; Walker, Pratt & Eddy, 1995). The substitution effect implies that the informal care system is a resource which can substitute the formal care system, and that an expansion of the formal care system will probably reduce the availability of informal carers willing to provide care. However, several researchers argue that there is very little evidence of a substitution effect, i.e. that more formal care encourages informal carers to reduce or withdraw the amount of care they provide (Brody, 1995; Lingsom, *ibid*; Parker, 1998). A number of earlier studies conducted from a caregiver perspective in Sweden, Norway, the United Kingdom and the USA, reveal a pattern of stability in the prevalence of informal care (Busch Zetterberg, 1996; Jeppsson Grassman & Svedberg, 1999; Lingsom, *ibid.*, National Alliance for Caregiving and the American Association of Retired Persons, 1997; Rowlands, 1998; Scharlach *et al.*, 2003). One conclusion is that the substitution effect does not seem to explain changes within and between the formal and informal caring systems.

The idea of a *partnership* mainly sees informal caregiving as a joint function shared by the informal and the public care systems (Chappell & Blandford, 1991; Lingsom, 1997; Litwak, 1985; Trydegård, 2000; Walker, Pratt & Eddie, 1995). One example of shared responsibility and a partnership between the public and informal care systems is when an older person receives care from the family as well as supportive home help from the municipality.

The results of Study IV demonstrate that social policy initiatives aiming to increase support for carers in the short term seemed to bring about some change, for example the tendency among municipalities to provide a greater amount of direct support for carers in the form of training, information material, and professional caregiver consultants. A further expansion of direct support for carers could be a signal of a growing partnership between informal caregivers and the public care system.

The issue of partnership is, however, related to the development of indirect support for carers, i.e., mainstream services such as home help and institutions for older people financed by the public old-age care system. Public provision for the elderly in Sweden has changed over time. In the 1960s and 1970s the number of home help recipients increased substantially. The 1980s and 1990s witnessed a trend of changing priorities and services targeted at older people with the greatest needs. One consequence of this was a substantial fall in the

number of home help recipients (Blomberg, Edebalk & Petersson, 2000; Szebehely, 2003b; Thorslund, 2004; Trydegård, 2000).

The finding in Study II that most help from the municipal services was received by elderly people also receiving personal care from an informal carer, indicates that informal care is sometimes carried out in a partnership with the public care sector. Yet the majority of informal carers and recipients in all care categories did not receive any formal help whatsoever. One may thus conclude that social policy initiatives in Sweden aiming to increase the partnership between different care sectors seem so far to have been political rhetoric; they have not brought about tangible changes for informal caregivers and recipients. How informal caregivers and care recipients interact with the care system as a whole is indeed a rich field for further research.



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