

Inclusion Europe

The European Association of Societies of Persons with Intellectual Disabilities and their Families
L'Association Européenne Associations des Personnes Handicapées Mentales et leurs Familles

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“Discrimination by Association”

The Situation of Family Carers of Persons with Intellectual Disabilities

1. Introduction

Family members who provide care for a relative with a disability are providing an important service that allows disabled people to live in the community. They are thus saving a lot of public money, but – as we will see below – they are often not supported adequately by the public authorities.

Research from many European countries shows a similar picture: Two thirds of family members who take care for their relatives are women and carers are mainly in their 40s and 50s, and thus in a phase of their lives that usually is the most economically productive. While it is estimated that one half of all carers look after someone aged over 75, the majority of the other half looks after disabled family members. When asked to describe the reasons that they were providing care, the majority of those carers – 60 per cent – said they were looking after someone with a physical disability, a further 15 per cent were looking after someone with both a mental and a physical disability, and 7 per cent looked after someone who was unable to care for him or herself because of a mental health problem.

Parents who care for persons with disabilities may begin a relationship with their son or daughter knowing, from well before the birth takes place, that their child's needs and disability will mean there will be a need for care, far exceeding that needed by most children, until the child becomes an adult and sometimes for even longer. Of the estimated total 5.7 million people who are carers in Great Britain, 1.7 million devote at least 20 hours a week to caring. Of those, 855,000 care for 50 hours a week or more. The amounts of time spent by men and women on caring were very similar. People who share a household with the person they are caring for tend to spend more of their time caring – 38 per cent of them spent at least 50 hours a week. Nearly a quarter of carers had been looking after the person they had cared for at least ten years, and a further quarter had looked after him or her for between 5 and 9 years.

The parents of disabled people soon give up exterior work to the unpaid home “work”, i.e. the daily care for their children. Thus, they take over a role that the state should normally assume.

2. Disabled people and their family carers

Disabled people have very different needs and access to services during their lifetimes. For a young child, often much time is spent with visits to doctors or with therapy sessions. Disabled children of kindergarten or school age most often have services and schools provided by the states. However, even in West European countries, it is common practice that children with

severe and profound disabilities are excluded from schooling. If they are not cared for by special services, parents often take care for them for 24 hours per day.

Normally, children should leave their family homes as young adults to start an independent life in the community. For young adults with a disability, this is often not the case. Due to lack of working places or the inadequate payment in sheltered workshops, they often cannot live independently. The limited number of places in residential services often causes waiting lists, which prevent young adults with disabilities to leave their family homes. The result is that parents often continue to provide care for a disabled adult for many years or even decades. This can lead over the years to an “unhealthy” dependency between the person with a disability and the parents.

We will now attempt to better define who are the carers in our societies. As mentioned before, it is often the mothers of children with high dependency needs that take over this role. If we take a closer look at the European salaries, either from the private or the public sector, we notice that men earn more than women ... and in the European private sector, women get on average 82% of a man's salary¹. Many of the family carers chose to work part time, and as a result they have less interesting positions, with little responsibility and basically no chance of promotion or career plan².

“Carers” or “caregiver” is an Anglo-Saxon concept, and designates a person that ensures attention, care and education to a dependent person. The dependent person may be a senior citizen or a disabled person, as well as a very ill person, who is part of the family or not. The carer is often the father or the mother of this person. The carers give a significant part of their own life to another person and often they also work at the same time. Taking care of somebody is something very personal and individual, but which also pertains to the social sector.

Carers are a very diverse group of persons (with their own professional and family situation) and with different needs. But they all need help and support in order to be able to continue taking care of a dependent person. The carers have very different tasks. They organize care, its evaluation and follow-up on the one hand, and, on the other, they assist the dependent person in the kitchen, in cleaning etc. on a daily basis. There are also the personal care tasks, such as self-cleaning, feeding, medical care, medicine administration, etc. Finally, they give the dependent person social and emotional support by means of company and conversation, particularly for those that suffer the most from marginalisation, exclusion and discrimination. The carers are at the same time decision-makers, organisers, assistants and mediators.

Relieving the carers is often a good way to help those that they are taking care of. The carers should be correctly recognised and supported. Taking care of a dependent person may lead to sleepless nights, and physical efforts that impact on health. The life of carers is so much linked to that of the dependent person that they themselves are in danger of losing their independence. All human beings need time for themselves, possibilities and energy to pursue their own interests.

The main claim of the carers is the well being of the person they are taking care of, having, at the same time, the liberty to chose their own way of life and staying in good health. Quality of life becomes therefore a key issue. The carers should trust the services available, as otherwise, their needs are but partially satisfied.

¹ <http://europa.eu.int/comm/eurostat/>

² PEEMANS-POULLET, H.: Partage des responsabilités professionnelles, familiale et sociales; Luxemburg: Office for official Publications of the European Communities, 1984

There is a lack of services and support to help carers take care of a dependent person³. If disabled and senior citizens are facing a society that marginalizes the different, it is a fact that families that live with a dependent person must also face exclusion, inadequate services and stigmatising attitudes. The carers should be able to talk about their care activity without fearing stigmatisation or discrimination, especially when it comes to employment.

Women are more often carers than men and 2/3 of them are employed⁴. Nevertheless, men's share is increasing. Mothers are particularly affected by the lack of support since they have to face a triple task: their job, the assistance to the dependent person, and their family with its daily requirements. Some of them spend more than 60 hours a week only for taking care of their disabled child or of a dependent person. Under these circumstances, it is obvious that it is difficult to stay on the job market. The loss of employment naturally leads to a reduction of future professional opportunities, to a pension reduction, to increased stress and isolation due to loss of social contacts and to the difficulty to get back to the job market in the future. This high level of stress, the lack of training, the lack of professional and social support may also be dangerous for the dependent persons.

3. Job opportunities and employment of family carers

Carers want to work for financial and psychological reasons⁵. The salary level is important for the well being of the family. The financial costs involved for a disabled child are very high. Social security often does not cover all disability-related costs and those linked to job loss. Working is also a source of satisfaction and self-esteem and helps the parents being active citizens. But most of them do not find an employment flexible enough to allow them to reconcile their family and professional life.

European societies often are not organised in function of full-time employment of the two parents. They do not take into account either their work or family situation (for example single-parent families). One notes that when professionals (schools, hospitals) or administrations negotiate convenient meeting times, the parents come to better reconcile their professional life and care. The parents are often reluctant to ask their employer for the flexibility they need, as this is viewed as a favour rather than a right, especially when their employment is not ensured. The parents that have understanding and reconciling employers are more involved in the enterprise and more loyal to their employer.

Flexibility is a central value in the working environment of the carers. There are advantages for the employers that grant facilities to carers and exercise a carer-friendly employment policy. One advantage may be the reduction of the turn-over for reasons of absence and sickness. It is always useful for the employer to have a diversified team. It is also a fact that motivation plays a major role as there is an improvement of the employee's morale, an increase of loyalty and a reduction of stress as well as an increased performance of the employees, which is a key element for the enterprise.

Most carers work and want to work in order to preserve their financial independence. On the one hand, this allows for the covering of care costs, but also for the possibility to focus on an exterior interest, which brings them a source of satisfaction. Among others, the possibility to work gives them the means to maintain a social network. The carers who reduce or cut off

³ Roeher Institute: Caregivers of persons with disabilities in Canada and Policy Implications. 2003

⁴ Working and Caring. Development at the workplace for family carers of disabled and older people. European Foundation for the improvement of living and working conditions. Dublin; 1999

⁵ KAGAN C, LEWIS S & HEATON P.: Caring to work: Accounts of working parents of disabled children", Family Policy Center, London, 1998

working have to face important financial and relational implications such as a salary drop, the loss of colleagues, social exclusion, etc.

The needs and the problems of working carers are often linked to the degree of dependence of the person they are in charge with and to the time they spend caring. A feeling of guilt (leaving the dependent person at home) and anxiety (employment security and relations, quality of life, etc.) as well as seclusion, frustration and a certain irritation from the part of the colleagues are daily problems encountered by carers at work.

This may affect the carer's capacity to concentrate and entails consequences, which are harmful like bad productivity and performance at work, a high absenteeism rate, a diverted use of working time (for example, to use working time to telephone the doctors). The carers often take their annual holidays to take care of the dependent person and therefore do not have respite. The care responsibilities can have as result the exclusion of the labour market and affect the professional opportunities all through the life and not only during the time of the care responsibility.

A recent study from Belgium points out the major reasons why people work part-time. It is striking that 29,1% of all women and 3,5% of all men give as reason the care for children and that 25,7% of the women and 14,5% of the men give other family reasons, among them care for disabled people, as reason why they could not work full-time.

Principal reason to work part-time	Men	Women
Retired can only work part-time	3,90%	0,50%
Does not find full-time job	31,30%	20,20%
At another job (part-time) in complement	6,10%	1,60%
Alternated training (part-time work and training)	10,20%	1,20%
Cannot work full-time for health reasons	6,10%	2,20%
Has to care of the children	3,50%	29,10%
Other reasons for personal or family reasons	14,50%	25,70%
Does not wish to work Full-time	6,60%	9,30%
Other reasons	17,80%	10,20%
Total	100,00%	100,00%

If the reasons for the part-time vary according to the gender, the same is true for the Belgians work time. Men devote more time to remunerated work and women to the domestic tasks and to the children. But the fact of having less remunerated work does not encourage men to take more part in the housework or childcare. Women remain more active in the care responsibility of a dependent person if they work or not⁶. The public authorities continue to consider women's work as an auxiliary work and particularly in the case of the part-time.

"Part-time work causes an addition of the disabilities and has a negative effect on the employment perspectives. Moreover, the fact that it is often a low qualified work reduces the long-term work perspectives for women. It locks women in the trap of an employment less well remunerated and without much promotion chance."⁷ When the part-time work is not chosen by the carer, it risks to confine women and men in inequality and in traditional roles.

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⁶ Glorieux, I. and Vandeweyer, J.: 24 heures à la Belge. Employment survey of the time, 1999

⁷ Tam, M: "Part time employment, a bridge or a trap? Alderschot, Averbury, 1997

Discrimination by association

As it was said several times in this Position Paper, parents having a disabled child with a major dependency on care encounter problems which make their participation in the labour market more difficult than for an ordinary family. They are victims of what can be called **discrimination by association**.

The negative attitudes of society are often expressed against the whole family of the disabled child. As a result, the family is very frequently in danger of social exclusion. The care of a person with severe and profound disability and their costs reduce the economic activities of the persons who take care. Consequently, the European and national non-discrimination legislation and the concept of reasonable accommodation must be enlarged to the families having a disabled family member by ensuring that the disability does not reduce their economic and social situation.

Parents meet obstacles to equal opportunities at several levels:

- a) In **education**, the authorities are often not aware of the disabled children's potential. Too often, the physical, sensorial or communication disability excludes disabled children from ordinary school. Consequently, they are placed in special schools or services, which while being adapted to their needs, isolate nevertheless these persons and move them away from ordinary social relationships. Moreover, when there are no places in schools or services which correspond to the special needs of these children, the family is obliged to keep them at home what isolates more of their social life.
- b) At **work**, parents of children having complex needs are victims of a higher unemployment rate than the remaining population, without even considering unemployment for lack of availability to the labour market. This has obviously an effect on the quality of the family's life and the family income.
- c) In **transport**, "transport for all" still remains an utopia in our highly mobile societies. Despite of all efforts, public transport remains inaccessible for many groups of persons, including mothers with small children, older people, or persons with reduced mobility. The architectural barriers further increase this inaccessibility.
- d) In **housing**, the lack of financial resources involves sacrifices for certain families, including the inability to acquire a house which would make it possible to feel less limited with a severely disabled child. Too small houses cause problems when the child has to move or even when it makes noise.

Sometimes the choice of housing according to the disability puts the family in a permanent unsafe state. For example, some families choose a ground floor well adapted to the dependent child but the cost exceed their means. These difficulties connected with housing and the financial state of the parents increase stress and anxiousness of the carers.

- e) At **social security** level, the additional costs connected with a family member with severe disability discriminates the families financially. The constant need of many severely disabled persons is a very expensive health care.

Often, a double family income permits to remain in financial balance despite high expenses incurred by the disability. However, numerous families are confronted with a paradox: one of the parents stops working to ensure the care of the disabled child to give it decent life. But the fact of stopping the professional activities leads to the decrease of the decent life too.

Discrimination by association vis-à-vis other discriminations is important and so far completely neglected by non-discrimination and equal opportunities. It reflects the realities in all EU member states and must be taken into account by creating rights for families. The concept of **reasonable accommodation** applied in this context means that the society has to adapt to the possibilities of a disabled person and the family, and not the reverse, unless this adaptation

requires disproportionate efforts. "To refuse reasonable accommodation testifies a lack of goodwill which can be understood as a discriminatory behaviour"⁸.

In conclusion, it is important to underline to what extent the character of discrimination reveals the complexity of the discriminatory process and the difficulty of implementing measures to combat it. The fight against discrimination involves a transformation of mentality and a participation of all economic, political, and social actors. The public authorities must be led to incorporate the families of persons with disabilities into their remits.

This requires the formulation of policies aiming to encourage the participation of parents of persons with severe disabilities at the economic and social processes, while respecting freedom of choice. However, we could ask ourselves whether discrimination by association should be subject of specific legislation, which would follow the law against discrimination and for a reasonable accommodation. Finally, we must not forget the fact that the measures taken for families having a highly dependent member will be advantageous to other disadvantaged groups.

5. Recommendations

Public authorities should support careers of family carers by encouraging the creation and the improvement of rest environments, care services for ill children, collective and community-based services for all the parents and in particular for the families having a disabled member or having a member with major dependency among them. It is also necessary that the public authorities develop part-time work by raising the guaranteed minimum salaries and by a development of the working conditions with a view to a possible conciliation of the working time and family time and an improvement of the social welfare. However, the development of part-time work can only be envisaged by a parallel development of family support services and the services for people with major dependencies.

Three elements should support the conciliation between the professional and the family life in the case of the major dependency of a family member. First of all, legal provisions such as credit-time, parental holidays, the extension of paternity and maternity holidays need continuous development. Secondly, political decision-makers have to encourage companies to take into account the problems of parents taking over a care responsibility. Finally, we must take care to increase the number and the quality of respite care and family support services. Under these conditions, parents caring for a person with major dependency will be able to merge family and professional life continuously.

The following recommendations address different levels of action and policy:

General

- To include in the concept and legislation regarding reasonable accommodation family carers who are victims of discrimination by association.
- To remunerate parents discriminated by association for the care given to the dependent person at home and consider that as reasonable accommodation
- To avoid the increase of discrimination by creating more community-based services for disabled people.

⁸ From: Press Release of Greet Van Gool on 16 May 2002

At the level of support for families

- To claim the **right to benefit from all public services.**
- To encourage a **multidisciplinary support** according to the requirements of each person (psychological, information, or social Security need) from birth to adulthood.
- To develop **various adapted services** according to the needs of the disabled children (for example leisure, nursery, respite care, etc.) with trained staff in relation to each stage of life.
- To increase and improve **early support** and **respite care services.**
- To arrange **short stay services** for disabled people in case of emergencies.
- To set up **information services for carers,** so that they become real partners in the provision of care to the person they are looking after, with the means to provide that care as well as possible, and with better sources of information about the help and services which are available to them.
- To **care for carers,** so that they can make real choices about the way they run their lives, so that they can maintain their health, exercise independence, and so that their role can be recognised by policymakers and the statutory services.

At the level of assistance at home

- To create services of **trained ambulant nurses** for people with severe and profound disabilities.
- To require **flexible and trained support at home** for a disabled person and to **revalue** this profession by a better remuneration.

At the level of external support

- To create **social services** to serve as coordination, accompaniment and information centres (for example, to organise a reference person to accompany a sick child in the absence of the parents).
- To subsidise **nurseries and kindergartens** which accept a quota of disabled children with severe and profound disabilities.

At research level

- To stimulate **scientific research** in the disability field.
- To increase and/or create **reference centres** adapted to the specific character of each disability.
- To encourage **study centres** for the needs of disabled people with major dependency and their families.