

# Families and Intellectual Disability in Europe



**Inclusion Europe**



Report

---

Inclusion Europe and its 40 members in these 29 countries are fighting for the rights of people with intellectual disability and their families:

- Austria
- Belgium
- Bulgaria
- Czech Republic
- Denmark
- England
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Israel
- Italy
- Lithuania
- Luxembourg
- Macedonia
- Moldova
- Netherlands
- Poland
- Portugal
- Romania
- Russia
- Scotland
- Slovenia
- Spain

Our members in English-speaking countries are:

MENCAP      123 Golden Lane  
London EC1Y 0RT  
United Kingdom  
Tel.: (44) 207-454.04.54

ENABLE      Top Floor  
7 Buchanan Street  
Glasgow G1 3HL  
Scotland  
Tel.: (44) 141-226.45.41

NAMHI      5 Fitzwilliam Place  
Dublin 2  
Ireland  
Tel.: (353) 1-676.60.35

ISBN 2-930078-74-X

© Inclusion Europe, Brussels 2002

Art on cover page: "Carnival fools" by Gert Lueder from Austria

This publication presents the views of Inclusion Europe and does not necessarily reflect the position or opinion of the European Commission. The European Commission and Inclusion Europe are not liable for any use that may be made of the information contained in this publication.

---

---

## **Introduction**

The family is the basic social group in all societies worldwide. However, patterns of family life are changing significantly in all European countries: birth-rates fall, the age of marriage is rising, the average size of families is decreasing, and one-parent families or other forms of family life are more and more prevalent. Parents and children adapt to these changes.

Families are of course also of primary importance for people with intellectual disability. In all European countries parents are the primary providers of care for children as well as adults with intellectual disability; in most countries it is estimated that more than 60% of adults with intellectual disability are still living with their parents. Thus, unpaid family carers take care of most of the needs of people with intellectual disability, thus saving society significant costs. It is therefore a matter of social justice not to leave these families alone, but to provide them with all necessary help and support.

**Unpaid family members are the primary carers for children and adults with intellectual disability. They need the support of society.**

In the past years, people with intellectual disability themselves have more and more claimed the right to marry and to have children. Many painful examples from all European countries show how this basic human right is often denied to them without proper assessment and reason. While concerns for the welfare of children of people with intellectual disability are as justified as those for any other children, there are many examples that show that people labelled as intellectually disabled can be loving and caring parents. It is a challenge for society not to deny them a priori a basic human right, but to consider carefully if counselling and support services cannot help them to lead a normal family life.

**Many people with intellectual disability want to be parents. Society should not a priori deny this basic human right.**

This brochure wants to draw the attention of European politicians, decision-makers, professionals and organisations to the situation of families with members — be it as children or as parents — with intellectual disability. Special contributions came from I. Körner (Germany), G. Christensen (Denmark) and L. Cooper (United Kingdom) in form of their presentations to the European Conference “Valuing Diversity — The changing role of families in Europe” that took place on 24 and 25 May 2002 in Madrid.

Inclusion Europe and its members are committed to enhance the recognition of the role of families with members with intellectual disability and to improve support for them in all European countries.

---

## **Families with members with intellectual disability**

The situation of families with disabled members has changed significantly in the past decades. There are more services, more support and better cooperation with professionals. The constant fight of parent's associations in all European countries has improved the situation of families with disabled children. They are proud of their sons and daughters with intellectual disability and they support a life for them as normal as possible. Families with disabled members are also not per se unhappy or distressed — often the contrary: most parents love and enjoy their disabled children as much as their other sons and daughters.

However, many parents of a child with intellectual disability do not feel better than before. In parallel to the improvement of the services for the families, the family networks in general have been lost. Families are more split up and the pressure on parents has increased. Shortly after the birth of a disabled child, parents might be confronted with statements like “This child could have been prevented”, indicating that developments in genetic testing and counseling

Families with a disabled child represent the whole spectrum of society. But they often have a different agenda.

make parents responsible for the ‘quality’ of their children. Later, expectations are to become a ‘professional’ parent, the expert for their child. While support services have improved, parents are often expected to coordinate a quite large number of professional services who direct their attention to the family.

The common experience to have a disabled child does not make these families a homogeneous group: families with members with intellectual disability represent the spectrum of the whole society with all its differences. However, it is important to recognise the different agendas of parents with disabled and non-disabled children:

- While parents of non-disabled children enjoy the first steps of their child, parents of disabled children may visit the specialist paediatrician.
- While non-disabled children start going to school, disabled children may be involved in development programmes.
- While parents of non-disabled children talk about the exam results of their child, parents of disabled children may receive a special education statement.
- While non-disabled children go to college or university, parents of disabled children may need respite care and home support.
- While others start working, parents of disabled children may apply for benefits for their child.

- 
- While other children get married, parents of disabled children may try to arrange residential care.
  - And while other parents enjoy their grandchildren, parents of disabled children continue to fight for the basic rights of their child.

Therefore parents of disabled children often feel isolated and cut off from the rest of the community. This isolation of the families does not help parents to support their child to be part of an inclusive society. However, families are the most important and most effective place to achieve inclusion of people with intellectual disability into the normal life of society, and therefore they should be supported.

Furthermore, many families have to spend a substantial part of their income on (co-)financing support and/or technical aids that are not financed by state support or insurance systems. Especially when the disabled child is young or severely or profoundly disabled, one family member — often the mother — tends to stay at home to take care of the child and therefore cannot contribute to the family income. In all European countries it is a recognised fact that families with members with intellectual disability tend to be poorer and more vulnerable to poverty than other families.

Direct and indirect discrimination, financial disadvantages and social isolation are the main reasons that families with intellectually disabled members are more vulnerable than other families to social exclusion. This is prevalent in all European countries. It is very important to recognise that the fight against social exclusion cannot focus only on the disabled person, but must include the family and other primary social relations as well. This fact must be taken into account in all activities at European, national and local level against poverty and social exclusion.

Families with a member with intellectual disability are more vulnerable to discrimination, poverty and social exclusion.

Families are not at all passive recipients of help and support. They respond to the needs of all their members and are also socially very active. The history of the movement of parents of people with intellectual disability in all European countries has clearly demonstrated that mutual support between parents of disabled children is a unique source of strength and energy. The achievements of the parent's movement in the past decades are a clear indicator of the power and commitment that families can provide.

Organisations of parents and families at the local level are the core for social and emotional support among the members and enable a very effective exchange of information. Authorities at different levels should recognise this and provide the necessary resources to improve the families' basis for self-help. Self-help needs the active support of society to enable the family carers

---

to support the inclusion of people with intellectual disability.

Already in 1971, the United Nations stated in their Declaration on the Rights of Mentally Retarded Persons that the family with which a person with intellectual disability lives should receive assistance. Necessary support can be classified into financial assistance, services, and time, identified by CO-FACE Handicap as the three parts of a family policy triangle.

Services can be grouped into those directed to the disabled person, like early intervention, kindergarten, school, work opportunities, etc. and those directed to the family as a whole. It is obvious that services for people with intellectual disability that enable them to spend time away from home, are already a big relief and support for the families. This is the reason why parents organisations have worked and campaigned in the past decades for the implementation and improvement of these services.

Services directed to the family include many mainstream services that should also be accessible and useful for families with disabled members, including for example family counselling or housing arrangements. However, families with disabled members also have specific support needs. These could include for example parent groups and organisations, respite care arrangements, care in the family, leisure time activities, short term housing, or emergency care for the disabled person. All these services should be developed in a network that works community-based and close to the family.

A specific problem of older parents of people with intellectual disability is the care for their son or daughter when they get too old to care for their child or even die. It is a challenge for support services to develop adequate transition strategies. ANAHM in Belgium has developed here a remarkable model of good practice.

Services, financial resources and time help families with disabled members to support their inclusion in society.

The financial burden that a disabled member places on a family should not be underestimated. As mentioned before, families with disabled members are more vulnerable to poverty and social exclusion than others. Therefore they must be compensated in full for the extra costs of disability. If family members provide basic care for a disabled person beyond the extend normal within a family, they should receive a remuneration that stabilises the family income. After all, family care is much less expensive for the public budget than services.

Finally, time is the third essential element of a family policy that benefits families with disabled members. Flexible work arrangements, additional leave in emergency situations paid by social security, early retirement possibilities, etc. would decrease the level of stress often felt by parents of disabled children.

---

## **Parenthood of people with intellectual disability**

The public opinion concerning parenthood of people with intellectual disability does not differ very much in Europe: people who are not able to care for themselves in every day life can not be able to educate and take care of a child of their own. Particularly people with intellectual disability are often seen as children themselves, even when they are 60 years old.

That is why in the past the parents of adult daughters with intellectual disability (more than those of sons) took any effort to avoid parenthood – mostly through sterilization and prohibition of partnership.

In the beginning of the 1990's a change took place in several European countries. New guardianship legislation did not allow any longer sterilization of people under age and made it very difficult in cases of people not able to consent. Therefore people with intellectual disability legally have the same right to have children as people without disability. But the reality is different.

Many sad and heartbreaking stories of people with intellectual disability tell about their discrimination and denial of their basic human rights in this area. Many couples wishing to live together and start a family of their own are faced with strong resistance from their own parents, service providers, authorities and the general public. Very often they are denied the necessary support and do not receive adequate information that would clarify their role and duties as parents.

However, the concerns of parents and professionals must be taken seriously. Many people with intellectual disability, especially those with severe and profound disabilities, will not be able to take care of a child. It can, however, not be accepted that intellectual disability automatically leads to exclusion from parenthood, regardless of the abilities of the individual.

The preconditions for a child are parents who are able to give security, love and care. Many people think that people with intellectual disability cannot provide those, but they have a lot of time and love — certainly as much as other parents. Parents with intellectual disability need, however, adequate support services and accessible information. We need to take away uncertainty, we need changing attitudes, we need examples of good practice and

Men and women of full age  
(...) have the right to marry  
and to found a family.

Universal Declaration of  
Human Rights (Art. 16)

Many people with  
intellectual disability  
could give their children  
as much love, security  
and care as other people.  
They need adequate  
support and information.

---

we need more inclusive living to change public opinion.

Any discussion about parenthood is lead by emotions, but the issue can no longer be ignored. The people concerned — self-advocates — have to be asked about their opinion. Parents or staff members of services get nervous or anxious with the wish for parenthood. There are few ideas, no imagination how the daughter or son with intellectual disability would behave as a parent.

Research carried out in Germany by the University of Bremen provides interesting indicators for the situation. 700 participating services knew about 970 cases of parenthood with together 1370 children. It can be assumed that the real number of intellectually disabled parents with children is considerably higher. The results concerning the situation of these parents were as follows:

- One third of these parents lived in a partnership where the other partner was not the real father or mother.
- Their living situation was that
  - about 33 % were living in an own apartment (with or without support),
  - about 25 % were living in an institution,
  - about 13 % were living in the family of their parents,
  - the rest is unknown.
- There was an increasing number of cases of parenthood since the beginning of the 1970's.
- In 25 % of the cases the children were living together with both parents. In 14 % they lived or are living together with one parent. Adopted children or children living in a nursing family were 20 %. Only 8 % are living in the origin family of one of the parents and 9% in an institution.
- One quarter of the pregnancies were planned

The parents with intellectual disability often spoke about psychosocial stress and only seldom reported about helpful reactions on the pregnancies from the personal environment. In some cases the relatives or the professionals responsible for the support pushed for abortion. Therefore some mothers stayed secretly pregnant as long as possible.

It was significant that those parents living together as a couple – married or unmarried – had better chances to live together with their child and for a longer time. Nearly half of the parents that had been separated from their children (directly after birth or years later) could imagine a life together with their child if they would have had adequate support. Nearly all parents expressed their happiness and proudness having children, even those living separated from them. Difficulties were mentioned by some parents of older children especially in combination with visiting schools.

Professionals made clear that pregnancy and parenthood is not only a challenge for people with intellectual disability but also for the staff members

---

---

of services. Nowadays, issues like sexuality, marriage and contraception are rather often discussed in many institutions and services but issues like the wish to have a baby and parenthood are often avoided. However, avoiding the subject often means that all people concerned are under great pressure when decisions must be taken if a pregnancy is known.

Faced by a lack of knowledge or support by the service providers and by a missing confidence in the capabilities of the future parents most of the staff members found that abortion was the only way out of this dilemma. In addition they wanted to avoid a kind of 'signal': If it would become known that we have found a possibility for one couple with a child to live in this institution or to be cared for by this service, there could be more.

This research from Germany describes a situation that can be found with minor variations in almost all countries of the European Union. It shows that there are already many cases of parenthood of people with intellectual disability, but that the response of parents, professionals, service providers and policy has so far been less than adequate.

Most important is accessible information on issues around sexuality and parenthood. Most of the available material assumes that people are able to read and to transfer the knowledge to their own situation. This is often not the case for people with intellectual disability. Careful counselling, easy-to-understand information material and practical experiences regarding the duties of a parent could make it easier for them to take an informed choice.

In all European countries there is a growing need for services that look after the needs of parents with intellectual disability and their children. There are only a few model projects in existence; this is the beginning of a new branch of support services that we need much more.

The support of parents and children must be as individual as the persons themselves are. The overall aim is to avoid that the child is separated from the parents. Adequate housing, either in independent apartments or as part of a living facility is of course the basic prerequisite. The support should cover everyday life and be mainly in the field of empowerment: self-help skills for the parents, health and education for the child. Support and counselling concerning psychosocial problems and the organization of connections and relationships within the family are also important.

**The support for parents with intellectual disability and their children must be as individual as the persons themselves are.**

With these supports and services, many people with intellectual disability will be able to make informed choices and to live with their children in a situation where both their needs and those of their children are ensured.

---

## **Conclusions and recommendations**

The UN Standard Rules state that persons with disabilities should be enabled to live with their families. Families with disabled members therefore need more attention and support at European as well as at national or local level, both as primary contact persons for people with intellectual disability as well as providers of care and support.

Families with disabled members need more inclusion in mainstream resources available to all families right from the start. They need also a whole range of specific services, including respite-care and attendant-care, that are coordinated and linked to each other. This would be facilitated by an inclusive social policy that takes measures against social exclusion of families with disabled members.

Social policy must include measures against the social exclusion of families with members with an intellectual disability.

Inclusion Europe and its members will collect more data on the extend of family care and support in Europe to highlight the contribution of these families to society. We will also collect examples of good practice for public support to families and highlight families in the National Action Plans against social exclusion.

Through a better understanding by the public and a better support to parents and their organisations, parents of disabled children get the opportunity to be a parent first, to enjoy their children with time to be a family. It would maintain this indispensable resource for care and support of people with intellectual disability in society.

The UN Standard Rules also state that persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. The wish for parenthood also of people with intellectual disability must be recognised, although it raises difficult ethical questions for which there are no general answers or solutions. The availability of appropriate information, counselling and individualised support are certainly key factors.

Parenthood of people with intellectual disability must be recognised. But it raises difficult ethical questions.

Inclusion Europe will collect more information on the right of persons with intellectual disability to have children and about the situation of parents with intellectual disability in different countries. We will also publish models of good practice on information on parenthood and on individualised support services for families with disabled parents in Europe.

---

## Literature

- BARGFREDE, S.; BLANKEN, I.; PIXA-KETTNER, U.: Dann waren sie sauer auf mich, dass ich das Kind haben wollte ...". Baden-Baden, 1996.
- BARGFREDE, S.; BLANKEN, I.; PIXA-KETTNER, U.: Geistig behinderte Menschen mit Kindern - Lebenssituation und Lebensperspektiven von Eltern und Kindern. Bremen, 1995
- BARONNET, P.: Filiation et handicap. L'impossible séparation. Lyon, 1999.
- BUNDESVEREINIGUNG LEBENSHILFE (Ed.): Familien mit behinderten Angehörigen: Lebenswelten - Bedarfe - Anforderungen. Marburg, 2002.
- BUNDESVEREINIGUNG LEBENSHILFE (Ed.): Familienentlastende Dienste - Selbstverständnis und Konzeption, Finanzierung und Organisationsentwicklung. Marburg, 1996.
- COFACE et al.: .. de paroles et de silences.. Familles de personnes handicapées: la communication, source d'équilibre, d'égalité des chances, de participation à la vie sociale. Brussels, 1999.
- COFACE Handicap: Financial Resources, Services, Time: The three parts of a family policy triangle. Publication in English and French. Brussels, 2001.
- DEPARTMENT OF HEALTH: Family Matters - Counting Families In. London, 2001.
- FEDERATIE VAN OUDERVERENIGINGEN: Kinderen verzorgen : Wat heeft een kind allemaal nodig? Utrecht.
- FERLAND, F.: Au-delà de la déficience physique ou intellectuelle. Un enfant à découvrir. Montréal, 2001.
- KEMPENEERS-FOULON, T.: Support AHM - An "After Parents" Service. Presentation at Inclusion International World Congress. Melbourne, 2002
- LAMBERT, J.-L.; LAMBERT-BOITE, F.: Education familiale et handicap mental. Fribourg, 1993.
- MITTLER, P.; MITTLER, H.: Partnership with Parents. Developing Horizons in Special Education Series. National Council for Special Education publication. Stratford, 1982
- RINGLER, M.: L'enfant différent. Accepter un enfant handicapé. Paris, 1998.
- SERVAIS, P.: Handicap et famille. A la recherche du sens. Louvain, 2001.
- SERVAIS, P.; STEICHEN, R.: Handicap. Accueil, solidarité et accompagnement en famille. Louvain-la-Neuve, 2002.
- UNAPEI (Ed.): La famille en tant qu'acteur de l'accompagnement de la personne handicapée mentale vers son autonomie. Paris, 1994.
- UNITED NATIONS: Families and Disability. Occasional Papers Series, N°10. New York, 1994.
- VERDUGO, M. Á. (Ed.): Familias y Discapacidad Intelectual. Madrid, 2000.
- ZUCMAN, E.: Famille et handicap dans le monde. UNAF, Paris, 1989.
- ZUCMAN, E.: Famille et handicap: reconnaître et citer le surhandicap des familles. CTNERHI, Paris, 1982.

# Inclusion Europe

The European Association of Societies  
of Persons with Intellectual Disability  
and their Families

Inclusion Europe is a non-profit organisation. We campaign for the rights and interests of people with intellectual disability and their families. Our members are national organisations from 29 countries in Europe.

People with intellectual disability are citizens of their country. They have an equal right to be included in society, whatever the level of their disability. They want rights, not favours.

People with intellectual disability have many gifts and abilities. They also have special needs. They need a choice of services to support their needs.

Inclusion Europe focuses on three main policy areas:

- Human Rights for people with intellectual disability
- Inclusion in society
- Non-discrimination

Inclusion Europe co-ordinates activities in many European countries, including conferences, working groups and exchange meetings. It responds to European political proposals and provides information about the needs of people with intellectual disability. Inclusion Europe advises the European Commission and members of the European Parliament on disability issues.



**Inclusion Europe**

Galleries de la Toison d'Or  
29 Chaussée d'Ixelles #393/32  
B-1050 Brussels  
Tel. : +32-2-502 28 15  
Fax : +32-2-502 80 10  
secretariat@inclusion-europe.org  
www.inclusion-europe.org



Supported by the European Commission

EN