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Better health, better lives: children and young people with intellectual disabilities and their families

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Enable children and young people with intellectual disabilities to grow up in a family environment

The European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families: Better Health, Better Lives outlines ten priorities for action aimed at ensuring healthy and full lives for these children and their families.

The purpose of this paper is to provide background information and offer pragmatic steps in relation to priority no. 2: "Enable children and young people with intellectual disabilities to grow up in a family environment".

"Promoting secure attachments and improving family functioning limits the impact of intellectual disability. Ongoing support to families is essential."

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Statement of priority

Secure family attachments throughout childhood contribute to healthy personal development and stable relationships in adult life; this is equally important for children with intellectual disabilities. A strong focus on promoting healthy early child development reduces the impact and extent of intellectual, psychosocial and developmental impairments in adulthood.

Ongoing support enables all families to care for their children at home. If this is not possible, for example because of parental illness or death, it is vitally important that children are not moved into institutions. Children who cannot live with their families of origin need adoptive or foster families or carers who can provide the essential family qualities of acceptance, warmth, personal support and encouragement, with sensitivity to the culture and needs of the individual child. These alternative families also need practical help and guidance to ensure that the child's needs are fully met. Arrangements to provide alternative family care should ensure that sibling relationships are supported, and that children with intellectual disabilities are cared for alongside their siblings.

Background and action needed

Over 400 000 children from countries that are members of the Organisation for Economic Co-operation and Development (OECD) remain in institutions (Yuster, 2009). A survey of 31 European countries in 2003 found that 11.2 per 10 000 children under three years old were living in institutions (Browne, 2005). Research has shown that disabled children living in residential placements tend to lack close family relationships and normal childhood support, and are known to be particularly vulnerable to abuse (Department of Health, 2001). Transfer of children and young people who are currently living in institutions into adoptive or foster families in the community supports healthy development. To enable successful care by families in the community, whether families of origin or adoptive or foster families, effective specialist support is also essential.

Having a child with intellectual disability can be a major and usually unexpected blow to any family. However, most families show great resourcefulness and adapt to give their child as well as themselves a happy and rewarding life (Grant et al., 1998; Grant, Ramcharan and Flynn, 2007). Informal and formal supports such as other family members, neighbours and nongovernmental organizations (NGOs), and the development of local community services, are essential for these families and enable them to keep their child at home. The only substantial reason for removing a child from the family home against the parents' wishes is evidence of neglect, or physical or sexual abuse.

The services required by the parents, which will vary according to the severity and complexity of the disability and family resources, include practical help such as equipment; regular and emergency respite care arranged in partnership with the family; advice about behaviour; help with communication problems, and the ability to find emergency or specialist help at short notice. The latter includes access to mental health care as well as physical care; substantive research has shown that there is a much higher

prevalence of psychiatric disorders in children and adolescents with learning disabilities than in those without (Wright, Williams and Richardson, 2008).

In addition, since not all families have access to an informal family or social network, it is vitally important that they have a social support worker or health visitor designated to visit the home, and to provide advice and support on an informal basis from day to day. These basic priorities must be met if families are to be enabled to continue to care for their children at home throughout their childhood and to ensure that the children have the best chance of enjoying their childhood and making a successful transition to adulthood. These needs are no different to those of any other family experiencing parenting problems, and research has confirmed the efficacy of home visiting programmes on long-term outcomes, including reducing the prevalence of abuse and neglect (Olds et al., 1997).

There is evidence that the prevalence of intellectual disability is higher among low-income families. There are multidimensional linkages between poverty (social, economic and political) and disability (Emerson, 2004). Families of people with disabilities (including children with intellectual disabilities) face a higher risk of poverty owing to difficulties in reconciling caring responsibilities with employment (Inclusion International, 2009; Mansell et al., 2007). Poverty can also contribute to higher parental stress and lower stimulation in the home. Poor children are still over-represented in the care system across Europe.

Social protection systems of families with disabled children need to support the balance between family life and professional life, and to ensure pension and social security rights.

Many “avoidable” care placements are still taking place because of a lack of appropriate family- and community-based services for families. In Hungary, for example, one third of placements are primarily due to poverty (Herczog, 2009). The increased differences in standards of living present a major challenge in many European countries. There are more poor families, living in poor communities, with inadequate service provision. Local services are under-developed, social workers’ caseloads are too high, “gatekeeping” systems fail to recognize urgent need, and there are no quality control processes in place. In poorer countries a higher proportion of young children are in institutions as a result of abandonment, disability and medical problems (Browne, 2005). This research emphasizes that support to families must be available at all times, so that parents can make a realistic choice about whether they can care for their child themselves. If families decide that they are unable to support a child at home, for example because of parental illness or death, then the alternatives must be of a standard high enough to be acceptable to them.

Building solutions

Universally accessible services are a precondition for ensuring that everybody enjoys equal rights. To achieve this may require disability discrimination legislation, to ensure that services recognize their responsibilities to facilitate access for disabled children and their families (see e.g. United Kingdom Parliament, 2005). Access also needs to be

coupled with high-quality services, and this requires the introduction of effective quality assurance programmes.

Support services for families need to be systematically planned and their provision monitored. Parents value short breaks from caring provided by a trusted childminder or a respite stay for the child in another family. They also value the support and advice of a named key worker, who guides them in obtaining welfare benefits and specialist advice, and who introduces them to parent groups and advocacy services. Access to high-quality daytime care for children with intellectual disabilities on equal grounds with other children contributes to work-life balance in families.

In addition to the provision of services and support, the dwelling of a child with disabilities must be adapted to the needs of the child. This might include the provision of equipment and adaptations when a child also has physical impairments, such as hoists (to reduce the risk of back problems for parent carers), wider doors, a ramp to the front door, or fencing of a yard to keep a child safe. Technological aids should be provided promptly where necessary, whether this is to support feeding, mobility or communication.

The services provided must be efficient, respond to the individual needs of users and be offered by qualified staff. Service delivery must be focused on respect, empowerment and participation of children and their families. These requirements are discussed further in the papers addressing other priorities.

It is suggested that services should not be developed in a piecemeal fashion, but that responsible ministries should consult with parents and young people with intellectual disabilities to prepare a national action plan with an implementation timetable. Funding currently allocated to institutions should be reallocated to provide support and empowerment for biological, adoptive and foster families. Governments will also need to work with local authorities and NGOs to develop, implement and maximize the impact of their national plans.

Examples of successful practice

The examples of current practice described here have been submitted from a limited range of European countries. A useful source of information regarding a wider range of countries is a report detailing the implications for people with disabilities arising from national policy developments during 2006–2008, in accordance with the European Union (EU) strategies for social protection and inclusion (Shima and Rodrigues, 2009).

Estonia

Estonia's national report on strategies for social protection and social inclusion 2008–2010 (Ministry of Social Affairs, 2008) reports inter alia on government support for a specific child-minder service for parents of disabled children.

Ireland

The Citizens Information Act 2007 (Oireachtas, 2007), which replaced the Comhairle (Amendment) Bill 2004, included the introduction of a personal advocacy service for people with disabilities. This state-funded service is beginning to be of assistance to families and individuals in Ireland.

Sweden

In 1994 personal assistance became a legal right in Sweden for people with certain impairments, both children and adults. Today more than 15 000 people in Sweden have state-funded personal assistance. About 40% of them have intellectual disabilities, and 21% are children and young people under 21 years of age. To be included under this law, people must have a need for support and service with regard to their basic needs, such as personal hygiene, dressing, eating and communicating with others. The local authority is responsible for the service, but there is state funding through the social insurance system when assistance is needed for more than 20 hours per week. Funding is given in the form of a fixed sum per hour, for unlimited hours, to cover all costs. The system allows the person with disabilities to decide how the service is to be organized and designed, with the help of his or her parents or legal representative. He or she can choose the local community, a non-profit-making cooperative or a private company as a service provider and is also free to choose the assistants.

With respect to children, it is very common for parents to be paid to work as assistants. This is important for two reasons: it ensures that the family still has some private life, and that the child avoids having staff around all the time.

The personal assistance reform has made it clear that the practical support necessary for people with intellectual disabilities and severe and complex needs cannot be provided just through housing. Some people with intellectual disabilities may need considerable support, but this does not mean that they need a less individually organized service than others, or should be given less self-determination in life. People with intellectual disabilities are individuals, who also need to have the opportunity to live a life in freedom.

There is a need for good examples and role models. In Sweden, there are many families who have received personal assistance and thus achieved a successful family life. With effective organization and support, the personal assistance programme can become a powerful tool for children to achieve an equal position in the family (see also Clevnert and Johansson, 2007).

United Kingdom

The Children Act 2004 (United Kingdom Parliament, 2004) legislates for the right of disabled children to grow up within their family of origin, and it recognizes that families need individualized support to achieve this goal. It called for the appointment of a Children's Commissioner with a remit to be a champion for all children and to promote awareness of their views and interests (and of certain groups of vulnerable young adults).

The white paper *Valuing people* (Department of Health, 2001) was designed to improve support for people with learning disabilities and their families. It was followed by *Valuing people now* (Department of Health, 2009), which outlined a cross-government strategy for people with intellectual disabilities in the United Kingdom for the next three years.

The recent United Kingdom initiative *Aiming high for disabled children* (HM Treasury and the Department for Education and Skills, 2007) aims to promote inclusion and combat the negative images of disabled children. It provides a package of services, including short breaks for parents and carers, accessible child care, a “transition to adulthood” programme and parental involvement in service development. The underpinning value base in the United Kingdom is that disabled children should be supported to remain in their biological families or kinship network, wherever possible, but if not possible, they should live in family-based alternative care (fostering or adoption).

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Resources

Contact a Family. United Kingdom-wide charity supporting families with a disabled child (<http://www.cafamily.org.uk>)

Department for Children, Schools and Families (2007). *Every disabled child matters* (www.dcsf.gov.uk/everychildmatters)

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