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

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Safeguard the health and well-being of family carers

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. 6: "Safeguard the health and well-being of family carers".

"In order for a child with intellectual disabilities to grow up and develop within a family, the health and well-being of the family as a whole should be supported. Enabling families to care for their child from the time of identification of intellectual disability through to adulthood can prevent harmful family strain or rejection of the disabled child."

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Statement of priority

As the primary unit of society, the family plays a fundamental role in the child's development and inclusion in society (1). All disabled children should live with their own family, which is the natural environment for the growth and well-being of a child, unless there are exceptional circumstances that prevent this (2). The primary role of the family and its right to appropriate social, legal and economic protection, aimed at ensuring the full development of the child towards inclusion and independent life in society, have been recognized in the United Nations Convention on the Rights of the Child (3), the European Social Charter (4) and the revised European Social Charter (5).

Children with intellectual disabilities have the same human value as any other children and are entitled to basic human rights and fundamental freedoms, including the right to grow up in a family environment (6,7). As their enhanced education and care needs can challenge the family's capacity to fulfil their parental functions, leading to exhaustion and isolation (8), parents and relatives living with a child with intellectual disabilities should therefore be entitled to a higher level of protection in the best interests of the child. Adequate support proportional to the child's needs should be secured for families by public authorities, in order to strengthen their internal resources and their capacity to ensure their child enjoys equal opportunities to develop his or her potential and avoid placement in an institutional setting and exclusion (9).

Background and action needed

The family is the primary social environment. Joining the family environment is the child's first step towards inclusion and participation in society (10). Children's abilities to learn and develop are inextricably intertwined with the strengths and needs of their parents and other family members (11,12). Where appropriate support is available, parenting a child with intellectual disability need not be a distressing experience. Many parents report their enjoyment of and satisfaction with the role (13,14).

Adequate support should be provided to families to enable them to cope with their child's needs (particularly in cases of challenging behaviour), to meet their responsibilities, and to contribute to the harmonious development of the disabled child's personality, self-determination and independence, with due regard for his or her fundamental rights and dignity (15–17). Although there is no one type of family and each family is unique in terms of both structure and patterns of relationship, when interviewed on their experiences, parents of children with intellectual disabilities generally report a need for more information, psychological support and respite care services (18). Support to families should therefore meet these needs and prevent parents from feeling overwhelmed or inadequate to deal with their children's special needs.

To implement adequate support to families of children with intellectual disabilities, health care professionals' training curricula need to include family support skills, and programmes of support for family members and carers need to be developed.

Building solutions

Communication of the diagnosis and information

The diagnosis should be communicated within a rights-based perspective of disability, because how the diagnosis is communicated can influence the family's ability to contribute to their child's development. Accessible language should be used to describe the child's condition. The child's human value and potential should be highlighted, avoiding any misconstruction of disability as a short-term condition, as this can lead to families focusing their every effort on fighting the disability in the hope that it will disappear. A failure to recognize and value the child's potential may lead to hyper-protectiveness, which can cause further disability in the long term (19). Both these attitudes may become an obstacle to the child's development and inclusion in society. Timely reliable information should be provided on the child's individual needs, strength and rights and on how to contribute to the child's development (20). Adequate communication with families can be supported by development of clinical guidelines and training activities for health care staff.

Emotional support

Health care providers need to include emotional support in the services offered in connection with identification of intellectual disability. The birth of a child with intellectual disability can represent an event that requires adjustments in the family, as parents need to review their expectations and projects about the future, often in situations of uncertainty about the child's development. While fully respecting the autonomy of the private sphere and of families, all those rearing children with intellectual disabilities should have access to emotional support on request. Such support can be delivered by professionals or peers, and it should never undervalue the dignity of the child. It should help parents achieve a good level of understanding of disability and develop an attitude of respect and appreciation towards the child with disability, thus also contributing to build gratifying and affectionate relationships between siblings, as their attitude towards disability is often an expression of that of the parents (21).

Family counselling and training

Development of training programmes for parents, family members and carers will empower and support the well-being of the whole family. As a priority, parent training should make clear how the child with intellectual disability is to be respected as a person, what the family's rights and responsibilities are and how the child's participation should be promoted (22). Training should allow parents to acquire the necessary competence to fulfil their responsibilities, to prevent child neglect and abuse, including inappropriate treatment and punishment, and to boost their confidence in their ability to cope with the child's needs (23). Parents advocacy organizations should be involved in empowering families to defend the rights of their children.

Involvement of families in health care

Health services that respect the agency and expertise of children and their families and their capacities to take initiatives regarding their own health, family life and use of

services contribute to families' empowerment and well-being. Because of its knowledge of the child's needs and strengths and its motivation to help him/her, the family is the best resource for health care in learning about the individual strengths and needs of each child and building a common project in the child's best interest. Getting the family actively involved in a care programme increases the child's chances of development (24,25). At the same time, by restoring their parenting roles and their confidence in their abilities, it is also the most effective means of relieving parents of their feelings of guilt and inadequacy (26,27). Education and training programmes for health care staff emphasizing person- and family-centered care will contribute to better health services for people with intellectual disabilities.

Respite care

Welfare legislation that provides possibilities and financial support for respite care supports families. Families are generally more able to care for their children's needs when they experience a range of positive relationships, both with the family and with others. Parents also benefit from being able to take up paid employment. Day-time care offered to children with intellectual disabilities on equal grounds with other children will support a healthy work–life balance in families. Periods of respite care should be available to give the family of a child with intellectual disabilities a chance to find new energy to cope with their enhanced responsibilities (28).

Examples of successful practice

Estonia

The Vaimupuudega Laste Vanemate Ühing, a parents' association in Estonia, promotes motivational programmes for parents of children with intellectual disabilities. The organization cooperates with physicians and maternity hospitals and provides support for the mothers of newborn babies with mental disabilities and Down syndrome (19).

The European project “Side by Side”, led by APPDA, the Portuguese association for development disorders and autism, with the support of the European Commission's Directorate-General for Education, under the 2003–2005 Socrates Grundtvig programme involving partners from the Czech Republic, Hungary and Spain, offers a training course to families and non-technical staff using an interactive web page. Autism-Europe disseminates the results of the project among its members across European Union member countries (29).

Ireland

In Ireland, respite care is provided to a varying degree at a number of locations around the country for people with different disabilities. The person being cared for may be admitted to a Health Service Executive (HSE) (public) nursing home for a period of two weeks. Respite care is organized through public health nurses or family doctors (general practitioners). Alternative care with a family and summer camp arrangements are available for children with disabilities. These are funded by local HSE areas at no cost to individuals. The Respite Care Grant is an annual cash payment made by the Department of Social and Family Affairs to certain carers, to use as they wish. It is

automatically paid to those receiving the Carer's Allowance, Carer's Benefit, Domiciliary Care Allowance, Constant Attendance Allowance or Prescribed Relative's Allowance (31).

United Kingdom

In England, the EarlyBird Programme, set up by the National Autistic Society (NAS), provides an autism-specific model of early intervention using a parent programme offering group training sessions to help parents work with their child. The EarlyBird Programme aims to support parents in the period between diagnosis and school placement, empowering them to foster social communication and appropriate behaviour within the child's natural environment and to prevent the development of inappropriate behaviours (30).

In Scotland, the Respite Care Scheme is organized by the Highland Council and offers a caring service to children with a disability and their families by providing regular periods of care for the child to give their family a break. Families of a child with a disability who wish to use this type of family-based service are matched with an approved carer or family who will take over the care of the child for periods of time agreed in consultation with the child's Care Manager and the carer's Social Worker. Respite care is offered on a regular basis and may be for a few hours or a few days at a time (32).

In the United Kingdom, there are around 300 young carer services, most of which offer clubs, activities and mentoring to the siblings of children with disabilities, alongside other children who may be in a caring role for a family member. Typically, they also provide advice and advocacy to parents (33).

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