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Identifying the needs of each child and young person

The European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families: Better Heath, 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. 4: "Identify the needs of each child and young person".

> *"Early identification and early intervention improve long-term outcomes. Children and young people require repeated assessment of their needs and planned support to make seamless transitions at each life stage."*

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Statement of priority

Challenges to identifying the needs of children and young people with intellectual disabilities are evident at all levels – individual, regional, health system and globally. Universal screening for developmental delay should lead to a policy of early referrals and the provision of educational, medical and allied health professional assistance at home. Transition to adulthood is often a difficult period for young people with intellectual disabilities and their families, and poor coordination between relevant agencies leads to poorer outcomes for the young people.

Background and action needed

A review of available evidence suggests that, to date, mainstream health services have failed to meet the needs of people with intellectual disabilities (Balogh et al., 2008; Michael, 2008). Shortcomings relate to identification of children with intellectual disabilities, implementing early intervention, addressing health inequalities and ensuring access to health care. Globally, there is a serious deficiency of services and resources allocated to the care of persons with intellectual disabilities, especially in most low- and middle-income countries (WHO, 2007a; Bilson & Harwin, 2003).

Identification

There are currently two promising approaches for identification and assessment of children with intellectual disability in low- and middle-income countries, albeit limited by a widespread lack of awareness of "normal" development and negative attitudes to developmental delay (Robertson, Hatton & Emerson, 2009). First, there are some valid screening measures in use that rely on parental report of "culturally appropriate age-specific developmental milestones". The second approach is the use of the Ten Questions Screen, which is based on concerns about a child's relative development and has been found to be effective in identifying children with any form of developmental disability, not specifically intellectual disability.

Early intervention

Early intervention aims to influence the development and learning of children from birth to five years of age. In general, evidence supports the conclusion that high-quality, comprehensive intervention programmes are effective (Baker & Feinfield, 2007; WHO, 2010), and there is some evidence that parent-led interventions are also effective (McConkey et al., 2000; Sanders, Mazzucchelli & Studman, 2003).

The early diagnosis of and interventions in children with intellectual and developmental disabilities represent a key aspect of work to promote the future quality of life. They require trained professionals and a multidisciplinary approach (medical, (re)habilitation, early education, psychosocial, etc.). Their output takes the form of coherent planning of the habilitation and rehabilitation measures that children will need in order to be able to live as normal a life as possible. Other services in the community (preschool and school education, health care, vocational training, etc.) will also rely on these individual plans of intervention, as they reflect the particular needs of each child or young person.

In many European countries, procedures for early diagnosis and early intervention are currently being introduced, strongly influenced by the person-centred approach and emerging quality systems in the field of disability services.

Health inequalities

There is a growing body of evidence indicating that people with intellectual disabilities are especially disadvantaged. Poverty is associated with the presence of intellectual disabilities and accounts in part for the health and social inequalities experienced by children and young people and their families (Emerson, 2007; Emerson & Hatton, 2008). A key public health function is to address health disparities and the social determinants of health, specifically as they relate to disability (Drum, Krahn & Bersani, 2009). Poor, less educated parents experience more communication problems with health providers (United States Department of Health and Human Services, 2008) and are less likely to report that their children with special needs require special services (Porterfield & McBride, 2007).

Access to health care

Children and young people with intellectual disabilities are at risk of co-morbid secondary health conditions throughout their lives but experience barriers in access to healthcare. The availability of health services to children and adolescents with intellectual disabilities tends to increase with country income level, ranging from 75% of these groups in low-income countries to 97% in high-income countries (WHO, 2007a).

But even in better-off countries, the presence of poverty impacts on children’s access to optimal health care. Available health care may falter owing to poor communication, and people with intellectual disabilities may experience unreliable access to health services or inexpert responses from health professionals (Krahn, Hammond & Turner, 2006; Michael, 2008; Walsh & McConkey, 2009). Some parents report that their health care providers sometimes or never listen carefully, explain things clearly, show respect for what they have to say, or spend enough time with them (WHO, 2007a).

The structure of health services may impede timely access: Development of services based on a biomedical approach has tended to result in facilities that are clustered in urban areas, near to health expertise. These services, when available, were reported to be expensive and integrated with other health services that did not necessarily align with the needs and preoccupations of persons with intellectual disabilities and their families (WHO, 2007a).

Building solutions

There is little published evidence to support the efficacy of individual assessment of children and young people with intellectual disabilities in Europe, nor is the impact on health of individual assessment and interventions grounded in assessment. However, in the light of current models of global policy and evolving practice, based on promotion of the rights of people with intellectual disabilities, it is still possible to suggest building solutions to support identification of individual needs.

Implement early identification of intellectual disability

Early identification of the needs of children and young people with intellectual disabilities allows these needs to be addressed promptly, with resulting benefits for the child and family (Bailey et al., 2005). Various strategies can and have been used to increase the identification of unmet needs (e.g. dedicated clinics, annual health checks). No one strategy stands out as being best, and variations in local organizational structures in the health, education and social work sectors necessitate different approaches. What is important, however, is that there is a strategy, and that efforts are made to identify these needs: it is known where they exist, it is known how to look for them; all that is required of local policy-makers is that resources are allocated to this important task, to improve the short- and long-term outcomes for children and young people with intellectual disabilities (Guralnick, 1998).

Implement gatekeeping

In order for policies to become effective and for people with disabilities fully to access high-quality health care and rehabilitation measures, one of the main preconditions is to have efficient gatekeeping procedures for these services. A primary objective of gatekeeping is to divert children from initial entry into public care through the development of community-based support programmes for children and their parents and by a shift in the dominant decision-making paradigms on how to help children. It is also a function of the gatekeeper to ensure that children entering institutional or other forms of state care are not left to drift, but that their situation is regularly reviewed and action is taken to promote their return to family and community (Bison & Harvin, 2003).

Effective gatekeeping systems provide information and referral procedures that help people to access the most appropriate service for their needs. The gatekeeping system is a combination of assessments and decision-making procedures, realized at both individual (“micro”) level of the person in need for services, as well as at the level of a community or region (“macro”-level assessment and planning).

It has been suggested that effective implementation of gatekeeping consists of the following elements (Bison & Harvin, 2003):

- establishment of a purchaser with clear incentives to serve clients, not the provider;
- changes in financing procedures to allow output-oriented financing to providers;
- development of tools for reaching agreement between the purchaser and the provider (contracts, rules on pricing, tendering); and
- reform of existing providers.

Implement needs assessment

Modernized systems of disability assessment, in terms of procedures and tools, are recommended. Ideally, comprehensive individual intervention plans should be the main output of the assessment process. In the light of the interactive and dynamic model of disability expressed in the International Classification of Functioning, Disability and

Health (ICF) (WHO, 2007b), it is important to document not only the child’s characteristics but also the environment in which each child or young person lives, in order to assess its mediating role in disablement (Simeonsson et al., 2003).

Training of professionals

All health professionals need to be trained in modern approaches to supporting and communicating with people with intellectual disabilities (the social model, human rights), inclusive communities, and multidisciplinary cooperation among professionals and service providers. General practitioners (physicians), primary health care workers, midwives and skilled birth attendants should receive training and guidance in the prevention and identification of intellectual disabilities, and in early intervention for such disabilities (WHO, 2007a).

Examples of successful practice

South-eastern Europe: Moving from a medical model to person-centred care

In south-eastern Europe, referring people with disabilities to community services remains predominantly the responsibility of the medical profession. Access to certain types of services in some countries is still restricted to those granted a “disability certificate”, documenting the type and “degree” of their disability and provided by the “categorization commission”.

The evaluation tools and criteria used for assessing peoples’ needs and situations are still predominantly medical, and the type of impairment rather than the abilities and choices of the person determine the access to services. Several countries in the area (Albania, Bosnia and Herzegovina, Croatia, Montenegro, Romania, Serbia) have made commitments, in nationally approved strategic policy documents and/or action plans, to begin a programme of reform. Published plans include commitments to change the composition of commissions to become multidisciplinary teams, introduce case management and person-centred approaches in these commissions and establish “one stop shop”-type agencies or bodies for information and guidance of children and young people with disabilities.

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