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

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Collect essential information about needs and services and assure service quality

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. 9: "Collect essential information about needs and services and assure service quality".

"Quality standards and adequate information systems are needed to monitor quality of care, with transparent responsibilities for all stakeholders."

Acknowledgements

Statement of priority

The lack of reliable health monitoring data, fragmentation of health care services and the need for partnerships across many agencies at every level of the public and private sectors pose major challenges for quality assurance. To ensure that the priorities in the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families are met, adequate information systems are needed that enable knowledge to be transferred and the quality of care to be monitored, while ensuring transparent responsibilities and roles for all stakeholders coupled with systems of accountability.

Background and action needed

Effective measurement is an essential component of effective and efficient health and welfare systems. Reliable information is also required to support action towards meeting many of the priorities in this Declaration. Good information is essential for estimating need; describing and monitoring change in the health status of populations and groups; evaluating the impact of social policies; and establishing approaches to quality enhancement/improvement (1–17). Without such information it is all too easy for the health needs of children with intellectual disability to be ignored. The development of effective systems for monitoring progress towards meeting needs is a key component of all approaches that seek to ensure the most effective use of resources. It is critical to the development and implementation of effective social and health care policies and to the provision of effective support to individual children and their families. It is for these reasons that one of the three "overarching recommendations" of the WHO Commission on the Social Determinants of Health was to "measure and understand the problem and assess the impact of action" (18).

Quality is a relative term and one that is viewed and defined differently by different stakeholders. As such, it is important that indicators of quality need to be credible to all of the key stakeholders involved, including government agencies, nongovernmental organizations (NGOs) and disabled people's organizations (DPOs). Indicators may either be chosen by consensus across stakeholder groups or, alternatively, reflect the distinct concerns of different groups (11).

There are significant methodological challenges associated with identifying representative populations of people with intellectual disability, understanding their specific concerns regarding health and collecting information on their health and well-being (4, 6). Some of these concerns are particularly relevant to collecting information from and about children with intellectual disability (19). Very few self-report measures of health status have been validated specifically for respondents with intellectual disability, suggesting that existing self-report general health status measures should be used with caution (20).

In summary, effective information systems need to:

- collect information that is central to the concerns of key stakeholders;

- be methodologically sound in that the information needs to be reliable and "fit for purpose" (or valid);

- collect, analyse and disseminate information in a timely manner;

- disseminate information in a manner that makes it accessible to key stakeholders

- be cost-effective and robust over time.

Building solutions

Identifying the level and nature of need and monitoring progress towards meeting need

In almost all instances, it will be more cost-effective to build on existing information systems rather than develop new systems. The first step, therefore, should be to review the current adequacy and future potential of existing information systems (e.g. national and local surveys, administrative record systems) with regard to providing credible and accessible information on:

- the number of children with intellectual disability in need of support (nationally and within local administrative areas);

- the health status and needs of children with intellectual disability (nationally and within local administrative areas);

- inequalities in the extent and nature of need by family circumstances (e.g. ethnic group, single-parent status, socioeconomic position); and

- change over time in the population's level of need.

In order for the results of the review to be credible to all the key stakeholders involved, the review process should include the active participation of NGOs and DPOs. It is feasible for such a review to be completed within six months and contain a list of options (if needed) for improving the adequacy of existing information systems.

In most if not all countries, such a review is likely to highlight inadequacies in existing systems. The second step, therefore, is to agree some specific realistic targets with set timescales (of no more than 12 months) for enhancing the capacity of existing systems in relation to one or more of the above four functions. It is recommended that no more than three targets are set. The nature of these targets will, of course, reflect national circumstances. Some potential examples are given below.

- Improve the accuracy and comprehensiveness of the identification of children with intellectual disability in primary and secondary care health records.

- Set up systems to extract information on children with intellectual disability from electronic health records systems.

- Agree and introduce a harmonized question (or set of questions) to identify children with intellectual disability in existing health and social surveys (e.g. UNICEF multiple indicator cluster surveys, national health surveys) (*21*).

- Review progress towards achievement of these targets and, as necessary, set new targets.

Making information accessible

The information generated by most information systems is often of a complex statistical nature. Rarely is it disseminated in a manner that makes it accessible to people with intellectual disabilities, their carers, DPOs and NGOs. As such, opportunities for promoting change are missed. One possible solution to this problem is to give responsibility to a particular organization (government or nongovernmental) for the collation and widespread dissemination of more accessible information on the health needs of people with intellectual disabilities (or disabled people more generally) and the progress being made to address these needs.

Making information work

Information on need, inequality and progress is important. However, it will only have a major impact in improving the lives of children with intellectual disability if it is actively used to manage the performance of governmental and nongovernmental organizations responsible for the commissioning and delivery of health, educational and social supports for children with intellectual disability and their families.

A process of review, target setting and re-review as outlined above should be undertaken to determine:

- the extent to which information that is already available on the health needs of children with intellectual disability (and progress to meeting these needs) is used in the performance management of governmental and nongovernmental organizations responsible for the commissioning and delivery of health, educational and social supports for children with intellectual disability and their families; and

- what specific improvements can be made to ensure that the performance management of such organizations is more responsive to accurate information on their success in making progress towards meeting the health needs and improving the lives of children with intellectual disability.

References, resources and contacts[1]

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Resources

Improving Health and Lives Learning Disabilities Observatory (www.ihal.org.uk)
An organization established in England to disseminate existing information and improve the scope and quality of future information on the health and well-being of people with intellectual disabilities.

Centres for Disease Control and Prevention
(http://www.cdc.gov/ncbddd/disabilityandhealth/index.html)
A United States government organization monitoring health, including the health of disabled people. Currently scoping work on improving information on the health of Americans with intellectual disability.

National Core Indicators (http://www2.hsri.org/nci/)
A long-standing project used to monitor the quality of life of and support for people with intellectual disabilities in most states in the United States.

The Council on Quality and Leadership
http://www.thecouncil.org/Personal_Outcome_Measures.aspx)
A United States organization that developed personal outcome measures for use in services for people with intellectual disabilities.

Delivering Outcomes to People (http://www.outcomestopeople.ie/default.asp)
An Irish organization seeking to improve the use of personal outcome measures for use in services for people with intellectual disabilities.

NHS Quality Improvement Scotland
(http://www.nhshealthquality.org/nhsqis/2957.html)
A Scottish government organization responsible for monitoring the quality of health care services, including those for people with intellectual disabilities.