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

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Ensure good quality mental and physical health care

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. 5: "Ensure that good quality mental and physical health care is coordinated and sustained".

"Children and young people with intellectual disabilities need the same access to health care as other children but may also need access to specialist treatment and care."

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Statement of priority

Children with intellectual disabilities (ID) need full and equal access to both mainstream and specialist health care. Health care provision should meet their common and specific health needs and should be available and accessible to them all. Access to medical and rehabilitation services also depends on society's attitude to disability. Today people with learning disabilities often experience health inequalities and barriers to health care services as a result of poor communication and discriminatory attitudes. The discrepancy between existing policies and discriminatory practices needs to be addressed.

Background and action needed

Children and young people with ID are more prone to a wide range of additional physical and mental health problems than the general population. Despite this, the health problems of children with intellectual disability are often unrecognized and therefore untreated. Children with ID are not provided with health services according to their needs (Beecham et al., 2002). Organizational barriers to access to health care include those related to physical access and communication, as well as the attitudes of health care staff (Alborz, McNally and Glendinning, 2005). A common problem is the attribution of physical and mental problems to the intellectual disability owing to diagnostic "overshadowing" (Reiss and Syszko, 1993). Barriers to access to health care also include carers' lack of identification of the health care needs of children with ID.

Children with ID need inclusive and accessible mainstream health care systems. Providing adequate support, particularly with regard to their more specific associated health problems, requires particular skills, in which all health care professionals should be trained. A proactive approach is required to the health care of children with ID, including careful monitoring of both physical and psychosocial development. Regular health checks in primary care are effective for uncovering unmet health care needs (Roy, Martin and Wells, 1997; Hunt, Wakefield and Hunt, 2001). Health professionals specialized in the specific health needs of children with ID must, however, also be available to back up mainstream health services, providing advice, treating specific medical problems or managing a part of the medical care.

These children's health care needs are often complex and require a multidisciplinary and child/family-centred approach. Coordination and integration of the various professional contributions is a priority challenge, extending across sectors. Provider-centred financing of health care supports existing institutions and systems, and often does not create economic incentives for developing community-based and more adaptive alternative services.

Building solutions

Every government has a responsibility to organize high-quality health care for all residents, including children with ID. This will include:

1. Effective health systems

- The establishment of legislative rights to universal and inclusive mainstream health care.
- The development of financial systems that guarantee children with ID and their families the support they need, with the use where appropriate of empowering mechanisms like personal budgets.
- The creation of inspection services for the provision of care to children with ID, with public reporting of the findings.
- The education of sufficient numbers of specialized health professionals.
- Cooperation at the European level to improve care for these children in every area of life affecting their health or wellbeing.
- The development of health care financing systems to support person- and family-centred care by e.g. switching from provider-centred budgeting to models which promote person-centred care.

2. Child- and family-centred health services

- Children and young people with ID and their families must be involved in the planning and delivery of care.
- Health services need to develop collaboration with other sectors to enable full inclusion of children with ID in education and social programmes.
- Families, children and young people need information in order to make informed choices. This includes:
 - easy-to-understand health information for children and young people with ID to help them understand and take care of their health (including diet, behaviour and sexual health), as well as to encourage them to participate in screening programmes and cope with illness and dying;
 - information on legal rights; and
 - information on the services available (including aids and adaptations).
- A seamless transition to adult care is needed, because the need for specialized care within mainstream services, proactive in nature and delivered in a multidisciplinary context, does not end with childhood. In most countries, however, children's services do end at a predetermined age, giving rise to discontinuity at this point. Health systems must guarantee a planned transfer to appropriate adult services, with access to continuing specialist health interventions and coordination.

3. Access to good mainstream health care
 - All professionals in the health system must receive basic training in intellectual disability.
 - All training programmes for health professionals should address the needs of people with ID, including common etiologies and syndromes, etiology-related health problems, communication and legal and ethical aspects. Awareness of health inequalities and disability equality, and heightened attitude and communication skills, are essential and vitally important complements to clinical skills.
4. Availability of specialist services
 - Multidisciplinary teams of specialists in ID are required to support mainstream services, provide specialist assessments and care, develop new programmes and guidelines, and transfer knowledge to non-specialist health workers and students.
 - Care providers with specialized knowledge of ID should be available. This includes providers with the knowledge and skills to care for children with ID with, for instance, sensory impairments, attention deficit and hyperactivity disorder, autistic spectrum disorders, epilepsy, mental health problems, behavioural/forensic problems, physical and complex disabilities, swallowing and feeding problems and postural care (body shape protection) needs.
5. The need for a pro-active approach
 - Screening programmes should be implemented in an inclusive fashion, and the participation of children and young people with ID should be encouraged
 - Primary care-based health checks should be routine, including screening for visual and hearing impairments.
 - General and specific health monitoring programmes should be developed and implemented.
 - People with ID and their families should have a right to etiological investigations, which may inform treatment decisions or have implications for future family planning decisions.

Examples of successful practice

Germany

The basic course in intellectual disability medicine has been a post-doctorate training programme for physicians of all disciplines and specialties since 2009. The course comprises a theoretical part of fifty hours and a clinical part of five days in an institution for people with ID.

Montenegro

The decentralization process in health care has given family doctors a key role vis-à-vis the medical problems of people with disabilities. A specific training programme (in the field of disability) for family doctors and paediatricians was held in 2008. The Ministry

of Health, Labour and Social Welfare is in the process of establishing eight “developmental counselling centres”, focusing on both early detection and intervention, as well as family counselling and medical rehabilitation services.

In 2008, a reform of evaluation and referral commissions for children with disabilities was begun. Eighteen new multidisciplinary commissions have been established, covering the 21 municipalities of the country. Their members (medical doctors, special education teachers, social workers, specialists in pedagogy) have completed an 18-month programme and designed modern tools for multidisciplinary evaluation of the children’s abilities and needs. A manual of procedures for these commissions has also been finalized, including specific chapters on ethics, cooperation with families and communities, participatory approaches in evaluation, etc. A pool of local experts has been established to continue training relevant stakeholders at the municipal level during 2010–2011.

Netherlands

In 2000 the Minister of Health recognized the medical care of people with ID as a new medical specialization. This training takes place at the Erasmus Medical Centre in Rotterdam and is accommodated in the Institute for General Practitioner Training. It is a three-year postgraduate university course for physicians, combining academic and clinical training. The course includes rotations in closely related fields such as neurology, genetics and psychiatry. Completion confers the official title of “Arts voor Verstandelijk Gehandicapt: AVG” (Physician for People with Intellectual Disability).

These specialists work within institutional settings but are also available for people with ID living at home or in group homes. The AVG is part of a multidisciplinary team that includes psychologists and paramedical therapists. General practitioners can refer to the AVG.

United Kingdom

Specialist training is offered in the psychiatry of learning disability, leading to a Certificate of Completion of Specialist Training after three years of theoretical and clinical supervised training in intellectual disability services. Trainees must have completed general specialty training in psychiatry and passed the membership examination of the Royal College of Psychiatrists.

There is, consequently, a workforce of psychiatrists who are specialized in this area, capable of addressing not only mental illness and behaviour disorders but also how they relate to physical health and underlying etiological conditions.

Psychiatrists work either in inpatient settings or as part of community learning disability teams, which usually comprise learning disability nurses, clinical psychologists, speech and language therapists, occupational therapists and physiotherapists, working in partnership with social services. These teams carry out holistic assessments of health and, in addition to providing health interventions and support, are involved in facilitating access to other specialist and mainstream services.

In England and Wales there have been initiatives, directed by the Department of Health, encouraging general practitioners in primary care to provide annual health checks for people with learning disabilities over the age of 18. Research has shown that people with ID have high rates of undetected, common health problems that can be identified through routine health checks; conditions posing a significant risk of morbidity and mortality can also be picked up.

England, Wales and Scotland each have a national strategy for people with ID in which the health needs of this group are identified and strategies described for enabling access to both general and specialist health services.

References, resources and contacts¹

References

Alborz A, McNally R, Glendinning C. Access to health care for people with learning disabilities: mapping the issues and reviewing the evidence. *Journal of Health Services Research and Policy*, 2005, 10:173–182.

Beecham J et al. Children with severe learning disabilities: needs, services and costs. *Children and Society*, 2002, 16:168–181.

Hunt C, Wakefield S, Hunt G. Community nurse learning disabilities: A case study of the use of an evidence-based screening tool to identify and meet the health needs of people with learning disabilities. *Journal of Learning Disabilities*, 2001, 5:9–18.

Reiss S, Syszko J. Diagnostic overshadowing and professional experience with mentally retarded persons. *American Journal of Mental Deficiency*, 1993, 95:204–214.

Roy A, Martin DM, Wells MB. Health gain through screening – Mental health: developing primary care services for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 1997, 22:227–239.

European recommendations

European Association of Intellectual Disability Medicine. *European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities*.

<http://www.mamh.net/Manifesto/Manifesto.htm>

Platform of European Social NGOs. *Quality of social and health services. Social NGOs' recommendations to EU decision-makers*.

http://cms.horus.be/files/99907/MediaArchive/Policies/Services_of_General_Interest/08-06-26%20Final%20common%20position%20on%20quality%20social%20and%20health%20services.pdf

¹ All web sites accessed 7 October 2010

National strategies/policies

England

The Department of Health has an extensive list of government-backed publications that can be found at

http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Learningdisabilities/DH_4001805

Scotland

The same as you? A review of services for people with learning disabilities

<http://www.scotland.gov.uk/ldsr/docs/tsay-03.asp>

Wales

National Service Framework for Children, Young People and Maternity Services.

Chapter 5: Disabled Children and Young People (including transition standard)

http://www.wales.nhs.uk/sites3/Documents/441/EnglishNSF_amended_final.pdf

South-eastern Europe

A number of publications are available from Disability Monitor International (DMI) for South East Europe at <http://www.disabilitymonitor-see.org>, including:

Chiriacescu D. *Shifting the paradigm in social service provision: Making quality services accessible for people with disabilities in south-east Europe*. Sarajevo, Handicap International, 2008

Adams L. *The right to live in the community: Making it happen for people with intellectual disabilities in Bosnia and Herzegovina, Montenegro, Serbia and Kosovo*. Sarajevo, Handicap International, 2008

Adams L, Axelsson C, Granier P. *Beyond de-institutionalization: The unsteady transition towards an enabling society in south-east Europe*. Belgrade, Handicap International, 2004.

National nongovernmental initiatives

Germany

A declaration on health care for people with intellectual and/or physical disabilities from the Potsdam Conference 2009

Potsdamer Forderungen der Fachtagung "Gesundheit für's Leben"

www.gesundheitfuersleben.de/wGesundheitstagung/abstracts/potsdamer_Forderungen.php

England

The Getting it Right Campaign (MENCAP)

This initiative, led by health professionals and coordinated by a national charity, has produced a checklist for doctors so that they can better understand and meet the needs of people with ID and a charter spelling out the nine key activities that all health care professionals should do to ensure that there is equal access to health.

www.mencap.org.uk/page.asp?id=4363

National information and learning networks

United Kingdom

The United Kingdom Learning Disability and Health Network is supported by the Foundation for People with Learning Disabilities.

www.learningdisabilities.org.uk/ldhn

St George's University of London maintains a web site providing information on a range of health topics relevant to people with learning disabilities. The site is designed for medical and nursing students, but it is also useful for other health professionals.

www.intellectualdisability.info