



**World Health
Organization**

REGIONAL OFFICE FOR **Europe**

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

Bucharest, Romania, 26–27 November 2010

EUR/51298/17/PP/1
18 October 2010
ORIGINAL: ENGLISH

Protection from harm and abuse

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. 1: "Protect children and young people with intellectual disabilities from harm and abuse".

"All children and young people with intellectual disabilities, wherever they live, must be guaranteed lives free from bullying, harm or abuse and should not live in fear or neglect."

Conference Secretariat

WORLD HEALTH ORGANIZATION REGIONAL OFFICE FOR EUROPE

Scherfigsvej 8, DK-2100 Copenhagen Ø, Denmark Telephone: +45 39 17 17 17 Fax: +45 39 17 18 18

E-mail: BucharestConference@euro.who.int World Wide Web address: http://www.euro.who.int/intellectual_disabilities

Acknowledgements

We would like to acknowledge the help received with the preparation of this briefing paper from Dr Roger Banks (United Kingdom), with contributions from (in alphabetical order) Professor Eric Emerson (United Kingdom), Dr Michael Göpfert (United Kingdom), Professor Veronika Ispanovic-Radojkovic (Serbia), Professor Robert Jones (United Kingdom) and Dr Julia Nelki (United Kingdom). Administrative and research assistance was provided by Mr Gabriel Banks.

© World Health Organization 2010

All rights reserved. The Regional Office for Europe of the World Health Organization welcomes requests for permission to reproduce or translate its publications, in part or in full.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either express or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use. The views expressed by authors, editors, or expert groups do not necessarily represent the decisions or the stated policy of the World Health Organization.

Background and action needed

The United Nations Convention on the Rights of the Child explicitly upholds the right of all children to be protected from all forms of harm and abuse, and for states to ensure that there are systems for prevention, identification, reporting, referral, investigation treatment and follow-up (1).

The environment in which children grow up is a significant determinant of their immediate and long-term health (2,3). Socioeconomic adversity has been shown to have marked effects on physical and mental health (4–7). Toxic environmental factors, such as pollution or poor sanitation, are more readily recognized, but equally important social equivalents include poverty, violence, disruption of family relationships, despair and alienation; these affect families and communities and can lead to parental neglect and abuse. This social toxicity (8) reflects not only individual characteristics of carers but also the possibility for the social environment to be supportive, rather than damaging. Children with intellectual disabilities are more vulnerable and less likely to be resilient than other children, so exposure to toxic levels of adversity may be even more damaging for them.

Experience and studies have shown that children with disabilities are at greater risk of abuse than others; this applies to children with all types and severity of impairments. A review of two large, population-based studies in the United States of America and the United Kingdom drew attention to the consistency of the findings that children with disabilities showed significantly higher frequencies of physical, emotional, sexual abuse and of neglect: 4–5 times the likelihood of experiencing one of these categories of abuse (9). Nevertheless, there is little systematic data collection or research on the abuse and protection of children (10,11).

Research evidence on the reasons underlying the vulnerability to abuse is limited. Factors that may be related to abuse include:

- lack of awareness of vulnerability of disabled children;
- lack of awareness of the signs and symptoms of abuse;
- denial and underreporting;
- general devaluing of disability and disempowerment of disabled people by society;
- stigma and exclusion leading to less participation in society and less access to preventive or protective services;
- disabled children's lack of choice in and control over their lives;
- poor or no support for children and their families in the community;
- lack of effective child protection systems;
- poor systems for assessing children's development, leading to a failure to recognize indicators of neglect and abuse;
- diagnostic overshadowing, in which all emotional and behavioural responses are attributed to the disability, resulting in failure to recognize them as a response to abuse.

Children with disabilities are more likely to be cared for away from the family home, in residential or foster care. Disabled children in residential care are vulnerable to all forms of abuse (12) but institutions also generate other risk factors, such as poor diet and feeding, poor and inadequate personal care, lack of stimulation, attention and emotional support, aversive and punitive interventions for controlling behaviour problems, including the excessive use of medication. Such evidence adds further weight to the need to prevent children being admitted to institutional care and for them to be brought up in safe and nurturing family environments. A study of cases of abuse or neglect of people with intellectual disabilities in state institutions in the United States of America was able to identify characteristics of the occurrences and the perpetrators of abuse (13). Attitudes, expectations and awareness of paid carers and other professionals and the perpetuation of institutional practice are areas of concern where children are in long-term residential care. Lack of training, guidelines and policies for staff, or even a complete absence of criteria and standards for employment, along with a lack of mechanisms or willingness to carry out criminal records checks or other vetting procedures, places children at high risk.

It has been demonstrated that case workers may be more likely to see children with disabilities as having characteristics that contributed to their abuse and also to feel “at least some empathy” with abusive parents, this being greatest when the child had emotional/behavioural problems (14). There may also exist a “hierarchy of abuse” in the attitudes of staff working with people with intellectual disabilities, with individuals making their own judgements about what constitutes serious abuse before deciding whether to report any concerns (15).

It should also be acknowledged that a relatively high proportion of both children and adults with intellectual disabilities are at risk of being bullied and that such bullying may persist over long periods (16,17). Intervention studies designed to reduce the rate of bullying of people with intellectual disabilities are beginning to be published (18,19).

Building solutions

Protecting children with disabilities from abuse and neglect should be a public health priority and included in all national policies and regulations related to children (19). This could lead to the establishment of a national programme to determine the size and scope of abuse, to create an action plan and to establish systems for evaluation, supervision and inspections. Governments and health professionals should ensure clear systems of accountability that ensure that they focus on the best interest of the child and treat children with dignity and respect.

Health systems need better identification of abuse in health services, better links with child protection systems and incentives for healthy behaviour by children (20). This needs to be balanced with health-system efforts to build resilience in children with intellectual disabilities and their families and actively to address inequity by ensuring that services are available, accessible and effective for all.

Necessary actions to stop abuse of children with intellectual disabilities can be considered under four main headings: safeguarding, investigation, therapeutic and policy (10).

Safeguarding

- Professional bodies should be required to have clear and explicit standards of behaviour and professional care, along with robust mechanisms for monitoring, reporting and disciplining professionals for any breaches of these standards.
- Children should be educated, through adapted and accessible means, about relationships, sexuality, personal boundaries and personal safety.
- Genuine engagement with children – seeking their views, understanding their feelings and enabling participation and choice – should lead to greater empowerment of individuals and greater sensitivity and awareness of carers, professionals and institutions.
- Selection, training and supervision of staff (carers, clinicians and other professionals) are essential to raise awareness, increase knowledge and develop more open and safe ways of working in environments in which abuse can not only be prevented but also more readily and openly discussed and concerns or actual incidents reported and rigorously investigated.
- Greater integration of services in communities needs to develop, along with a community responsibility for the provision of safe and accessible activities and facilities.
- Encouraging greater community involvement in the opening up and decommissioning of institutions should lead to less stigmatization and isolation and more awareness of the need for protection of this vulnerable group.

Investigation

- Ensure that all health care staff have been trained in awareness and recognition of abuse of children with intellectual disabilities.
- Ensure that children with disabilities are not disadvantaged or do not encounter barriers in access to child protection systems –adaptation of procedures and settings (e.g. in interviews), enabling communication.
- Professional practice in health and social care should be regularly audited against standards of safety, quality, record-keeping, and interprofessional and interagency communication.
- Clear supervision, reporting and investigation protocols (internal protocols specific to the institution or foster care) should be developed for child abuse and neglect.

Therapeutic

- There is a need to develop therapeutic skills and services to work with children with disabilities, particularly those who have been abused.

- Professional education and continuing professional development must address the lack of recognition of the need for therapeutic interventions or denial of their potential applicability and benefit.
- Established routine therapeutic models and interventions for working with children and families need to be extended, adapted and made accessible and effective for those with intellectual disabilities (21–24).

Policy

- The vulnerability of children placed outside their families and in segregated, communal care should be explicitly addressed by health care services and the need for interagency working, information-sharing and adherence to common care standards, inspection and monitoring frameworks must be recognized by all concerned.
- Such standards have to state clearly and openly the kind of practices that are unacceptable, such as using restrictive interventions that limit the freedom of movement and participation of children with intellectual disabilities who still live in residential facilities. They should also address the issues of staff competence and training and the need for mandatory training in child protection and other procedures for the protection of those who are vulnerable
- There should be more effective communication and collaboration between social care, education and health agencies, and justice systems, to identify children at risk and potential perpetrators of abuse.
- Anti-stigma programmes and activities can be developed at national and local levels to change public knowledge of and attitudes towards disability, to promote a more inclusive society and to reduce negative stereotyping and low expectations of all people with disabilities.
- Governments should enable and support external monitoring by independent human rights organizations of children's protection from harm and abuse.
- Children with intellectual disabilities should have ready access to legal aid, advocacy and support for self-representation.
- While greater commitment and resources should be focused on eliminating admissions to institutional care, children with intellectual disabilities who are living in institutions should not be neglected. There should be a clear plan to implement proactive strategies to prevent abuse, injury or neglect of such children.
- Make the general public aware that child abuse and neglect can occur in institutions. It is helpful to discuss these issues through the mass media long before an actual incident occurs.
- Educate everyone about children's rights.
- Open up institutions and minimize isolation. Encourage community involvement in institutions through volunteer and student training programmes. Be sure that family members can easily visit children in care.
- Educate children in care about sex, personal boundaries and personal safety in ways that are age and ability appropriate.

- Ensure that institutions have adequate and well-resourced and -supported workforces.
- Recruit appropriately qualified staff. Consult with previous employers, check for criminal records and ask for and check references of applicants.
- Ensure appropriate training and professional development and regular supervision of all staff.
- Develop clear written guidelines on standards of care for institutional practice. Develop and regularly conduct safety and quality audits of clinical practice.
- Develop protocols reporting for child abuse and neglect (internal protocols specific to the institution or foster care).
- Develop an independent process for assessing child abuse and neglect within institutions.
- Designate people both within and outside institutions quickly to establish and conduct investigations of alleged harm/abuse.

Examples of successful practice

Serbia

The Ministry of Social Policy of Serbia adopted in 2005 a “special protocol on protecting children in social care institutions from abuse and neglect”; most children in institutions in Serbia have disabilities. The staff of the institutions have been trained to implement the protocol, and more cases of abuse and neglect appear to be reported as a result.

United Kingdom

The Keeping Children Safe Coalition (a number of aid and development agencies in Switzerland and the United Kingdom, along with the National Society for the Prevention of Cruelty to Children – NSPCC) developed a toolkit (25) containing standards that should ensure that staff and other representatives are able to keep children safe from harm through awareness, good practice and robust systems and procedures. Based on these standards, Save the Children Norway developed codes of conduct that are an obligatory part of contracts with their partners to implement projects in south-eastern Europe.

The Books Beyond Words series (26) provides a resource to support children and young people with intellectual disabilities who cannot read or who have difficulty reading. These books, in which people with intellectual disabilities are involved in the design and trialling, address the emotional aspects of difficult events and in particular cover issues of sexual abuse and its disclosure, being a victim of mugging and the use of counselling (23,24).

References, resources and contacts

References

1. *United Nations Convention on the Rights of the Child*. New York, United Nations, 1989 (<http://www2.ohchr.org/english/law/crc.htm>, accessed 13 October 2010).
2. Hertzman C, Boyce T. How experience gets under the skin to create gradients in developmental health. *Annual Review of Public Health*, 2010, 31:329–347.
3. Shonkoff JP, Boyce WT, McEwen BS. Neuroscience, molecular biology, and the childhood roots of health disparities: Building a new framework for health promotion and disease prevention. *JAMA*, 2009, 301:2252–2259.
4. Clark C et al. Does the influence of childhood adversity on psychopathology persist across the lifecourse? A 45-year prospective epidemiologic study. *Annals of Epidemiology*, 2010, 20:385–394.
5. Poulton R et al. Association between children’s experience of socioeconomic disadvantage and adult health: a life-course study. *Lancet*, 2002, 360:1640–1645.
6. Kuh D et al. Social pathways between childhood and adult health. In: Kuh D, Ben-Shlomo Y, eds. *A life course approach to chronic disease epidemiology*. Oxford, Oxford University Press, 1997.
7. Lundberg O. Childhood conditions, sense of coherence, social class and adult ill health: exploring their theoretical and empirical relations. *Social Science and Medicine*, 1997, 44:821–831.
8. Garbarino J. *Supporting parents in a socially toxic environment*. Madison, University of Wisconsin-Madison, 1998 (<http://parenthood.library.wisc.edu/Garbarino/Garbarino.html>, accessed 13 October 2010).
9. Sobsey R. Intellectual disabilities and child abuse. In: International Coalition on Abuse and Disability [web site]. Alberta, J. P. Das Developmental Disabilities Centre, University of Alberta, 2008 (<http://icad.wordpress.com/2009/02/10/intellectual-disabilities-child-abuse>, accessed 13 October 2010).
10. Miller D. *Disabled children and abuse*. London, National Society for the Prevention of Cruelty to Children, 2002 (NSPCC Research Briefing; http://www.nspcc.org.uk/Inform/research/briefings/disabledchildrenandabuse_wd_a48224.html, accessed 13 October 2010).
11. Department of Health. *People like us: the report of the review of the safeguards for children living away from home [Utting report]*. London, The Stationery Office, 1997.
12. McCartney JR, Campbell VA. Confirmed abuse cases in public residential facilities for persons with mental retardation: a multi-state study. *Mental Retardation*, 1998, 36:465–473.
13. Manders JE, Stoneman Z. Children with disabilities in the child protective services system: an analog study of investigation and case management. *Child Abuse & Neglect*, 2009, 33:229–237.

14. Jenkins R, Davies R, Northway R. Zero tolerance of abuse of people with intellectual disabilities: implications for nursing. *Journal of Clinical Nursing*, 2008, 17:3041–3049.
15. Crosse SB, Kaye E, Ratnofsky AC. *A report on the maltreatment of children with disabilities*. Washington, DC, National Centre on Child Abuse and Neglect, 1993 (<http://www.eric.ed.gov/PDFS/ED365089.pdf> , accessed 13 October 2010).
16. Sheard C et al. Bullying and people with severe intellectual disability. *Journal of Intellectual Disability Research*, 2001, 45:407–415.
17. Dickson K, Emerson E, Hatton C. Self-reported anti-social behaviour: prevalence and risk factors amongst adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 2005, 49:820–826.
18. McGrath L, Jones RSP, Hastings RP. Outcomes of anti-bullying intervention for adults with intellectual disabilities. *Research in Developmental Disabilities*, 2010, 31:376–380.
19. Marge DK, ed. *A call to action: ending crimes of violence against children and adults with disabilities*. Syracuse, State University of New York Upstate Medical University, 2003.
20. Glennerster H et al. *Reducing the risks to health: the role of social protection. Report of the Social Protection Task Group for the Strategic Review of Health Inequalities in England Post 2010*. London, Centre for Analysis of Social Exclusion, London School of Economics and Political Science, 2009 (CASE Papers, CASE/139).
21. Allington-Smith P, Ball R, Haytor R. Management of sexually abused children with learning disabilities. *Advances in Psychiatric Treatment*, 2002, 8:66–72.
22. Banks R. Psychological treatments. In: *Psychiatry*. New York, The Medicine Publishing Company, 2003.
23. Hollins S, Sinason V. *Jenny speaks out*. London, St George’s Mental Health Library, 1992.
24. Hollins S, Sinason V. *Bob tells all*. London, St George’s University of London, 1993 (<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbwonlineversions.aspx>, accessed 13 October 2010).
25. Keeping Children Safe: A Toolkit for Child Protection [web site]. London, Keeping Children Safe, 2010 (http://www.keepingchildrensafe.org.uk/index.php?option=com_content&view=article&id=5&Itemid=4; accessed 13 October 2010).
26. *Books Beyond Words: What are they?* London, The Royal College of Psychiatrists, 2007 (<http://www.rcpsych.ac.uk/publications/booksbeyondwords/aboutbbw.aspx>; accessed 13 October 2010).

Resources

Ann Craft Trust (www.anncrafttrust.org): United Kingdom national organization providing information, advice, support and training related to the abuse of children and adults with learning disabilities

Respond (www.respond.org.uk): United Kingdom charity providing assessment and therapeutic services for intellectually disabled victims and perpetrators of sexual abuse, and training and support for people caring for or working with them