
European Manifesto on Basic Standards of Health Care For People with Intellectual Disabilities

M. M. Meijer*, S. Carpenter†, and F. A. Scholte‡

*Erasmus Medical Center, Rotterdam, the Netherlands; †Bristol North CLDT, Bristol, UK; and ‡s Heeren Loo Midden-Nederland, Apeldoorn, the Netherlands

Abstract An invitational conference organized by the Netherlands Society of Physicians for Persons with Intellectual Disabilities (NVAVG) and the European Association of Intellectual Disability Medicine (MAMH), in collaboration with the Erasmus Medical Center's Department of Specialist Training for Physicians for People with Intellectual Disabilities, had as its aim the development and issuance of an European manifesto on adequate health care for people with intellectual disabilities (ID). This paper provides an overview of the basis for the conference and the manifesto and lays out recommendations for the implementation of the manifesto's main points. The group's product, the European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities, summarizes the core elements of adequate health care for individuals with ID, and offers guidance on how Europe's nations may address deficiencies in health provision for people with ID. The manifesto's main points include a call for greater available and accessible health care, increasing the competencies in ID of health professionals, educators, and researchers, a greater reliance on a multidisciplinary approach to health care, more specialist services, and a proactive emphasis on personal health management.

Keywords: intellectual disability, health care, health planning

BACKGROUND

Research shows that many individuals with intellectual disabilities (ID) have specific health needs (Evenhuis, 2002; van Schrojenstein Lantman-de Valk, 1998). These may at times reflect a need for generic health care, but also for specialist care and interventions depending on individual's needs. Some individuals with ID evidence more physical and psychiatric health problems when compared to individuals in the general population without a disability. Such problems are not the only ones evident, for communication problems, frequently associated with sensory impairments, may be also often present.

As a matter of policy, the inclusion of individuals with ID into mainstream society is the accepted strategy of most European countries. Such inclusion requires a holistic approach, including a combination of education, housing, employment, leisure services, and use of mainstream services. Thus, mainstream health services should be accessible for people with ID and should be capable of dealing with a range of disability-related health needs.

This premise has consequences for primary health care, specialist care, as well as the generic health care system. Physicians, other professions allied to medicine, and psychological and other

therapists need to improve their knowledge of individuals with ID and their health problems. However, health practitioners, who are involved with only a few individuals with ID, cannot be expected to have specialized knowledge about the specific health problems of people with ID. Specialists with such thorough knowledge are therefore needed to support them.

To delineate specific health-related standards and practices, a consortium made up of several Dutch organizations, medical programs, and select international experts, undertook a process of coordinating and producing a manifesto on health care. The group's organizing committee formulated five basic criteria for adequate health care of people with intellectual disabilities and began an extensive investigative and exploratory process to expand upon these. Based on the information gleaned from questionnaires, governmental reports (National Health Service, 2002; *Samen Leven in de Samenleving*, 2002; US Department of Health and Human Services, 2002; UK Department of Health, 2001; US Department of Health and Human Services, 2003) and public policy literature (Böhmer, 1996; van Splunder, 2003) as well as the research literature (Böhmer, 1996; Evenhuis, 2002; van Schrojenstein Lantman-de Valk, 1998; van Splunder, 2003), the organizing committee made the following observations.

Received December 4, 2003; accepted January 20, 2004

Correspondence: Frans Scholte, Secretary of MAMH, 's Heeren Loo Midden-Nederland, De Voorwaarts 61, 7325 AA Apeldoorn, the Netherlands. E-mail: frans.scholte@sheerenloo.nl

ORGANIZATIONAL ASPECTS

General health services do not always succeed in delivering adequate health services to people with ID and there are major

differences in the quality and the organization of health care for people with ID in the various European countries. In southern and eastern European countries the quality of medical care for individuals with ID appears to be rather inconsistent. In most western and northern European countries the quality of medical care is more formalized, but even in these countries general practitioners often seem to display a lack of knowledge of ID and have limited communication skills and time for interactions with their clientele.

Barriers exist along the lifespan for people with ID. Pediatricians generally have special knowledge about children with ID; however, they often concentrate on health-related problems only, without coordinating the child's total medical care and without supporting the family in related aspects. In addition, because the life expectancy of people with ID has increased significantly during the past few decades, problems arise following the transition from pediatric/youth to adult health care. Although internists and general practitioners often provide care to adults, another challenge is the problem of finding geriatric specialists who understand the nature of aging and its impact on disability as the adults age. Further, because of the multidisciplinary aspects of health care for individuals with ID, specialized therapists and behavioral scientists are often needed, but not always available, and their collaboration with regular and specialized services are not always well organized.

Medical Aspects

Although psychiatric problems are more often coincident in individuals with ID (Tyrrell & Dodd, 2002), most countries in Europe have few psychiatrists with a special interest or expertise in this specialty, especially for children with ID. In addition, sensory impairments are often present and these may interact or be the underlying cause of behavioral difficulties. Such comorbidities are also seriously under-diagnosed (van Splunder, 2003). Further, compounding difficulties in assessment, special screening programs are usually not developed and/or implemented. As certain syndromes are often associated with specific health problems, health monitoring of these syndrome-associated problems should be readily available. Further, there is a need to pay special attention to people with complex and profound disabilities; as such conditions are often coincident with other medical problems, such as visual and hearing impairments, cerebral palsy, seizures, and eating problems. In many situations, such health problems require the availability of specially trained nurses, allied health professionals, psychological therapists and physicians, who are not always available. When people with ID live in community settings, their complex health needs sometimes interfere with goals for normal living, respectful treatment, and privacy. For people with serious motor or sensory impairments adequate and appropriate technical adaptations in their living and work place are often found wanting.

Oral Health Care

Oral and dental care for people with ID is generally reported as lacking or deficient for a number of reasons. One is the insufficient number of dentists trained to care for people with special dental care needs, with severe disabilities, or with other conditions involving particular challenges for oral health practitioners. Another reason is the lack of a sufficient number of dentists to provide dental care to the general population in many European countries. Another difficulty is the insufficient level of funding for dental care and the time involved often to provide specialist dental care for people with special needs. There is a need to adequately compensate dentists who are willing to take the time to overcome the difficulties of communication and anxiety in order to treat people with disabilities, and there is an overall need for more dentists who are willing to take on patients with ID. The import of this is seen when one realizes that the presence of dental abnormalities often contributes to the etiological diagnosis of ID.

Lifestyle

People with mild ID, who live in the general community with a minimum of support, can often adopt unhealthy lifestyles and poor health habits. It is important to provide education and support to help persons in these situations to avoid risky behavior that contributes to later-life health or social problems. The participation of individuals with ID in screening programs for the general population is reported as poor and should be improved. Further compounding these problems is that individuals with ID themselves as well as their carers do not always seem to be aware of the need for such screenings.

Research

Medical care for people with ID needs to be evidence based. To this end, research is necessary, as it is the basis for good practice. Although there has been a significant increase in the number and quality of publications addressing ID medicine in recent years, more work is necessary to further enhance research reports in this area. Further, most European academic institutions have not embraced underwriting and supporting research in this area, or supporting specialty academic chairs in this medical specialty, thus resulting in a lack of robust studies examining the nuances of health and ID.

Social-Economical Aspects

Many individuals with ID live in poverty or on very low incomes. Generic health care is costly, as is specialized health care for people with ID. If people with such disabilities do not have the means to purchase quality health care or medical services,

then it means they go unserved and their needs are unmet. Unfortunately, many national health schemes look to efficiencies and base payments on physician contact hours and number of patients seen. When high-need patients are seen, more time means more costs, but funding is often not provided to compensate the physician for his or her time. Certainly, health payment schemes should be modified to accommodate this situation.

GAINING A CONSENSUS

To arrive at a consensus among many disparate contributors, the organizing committee used a multi-stage approach in developing the European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities. The process first involved a 12-month period of preparatory data gathering and then the convening of a consensus meeting. The data gathering included the broad distribution of a medical needs survey questionnaire which was then completed and returned by practitioners, policy makers, and other constituents. The survey contained questions on health care needs associated with people with ID, how they were able or unable to access services, commentary on health outcomes, and suggestions for health provision policy and practice. In addition, the organizing committee reviewed a series of government reports and documents related to health provision and disability from Europe, North America, and other areas, as well as relevant articles published in the medical literature.

To begin, a consortium made up of the NVAVG and MAMH, together with Erasmus Medical Center, identified the need for a manifesto on health care and coordinated the initiative to develop it. The process was supported in part by the Dutch Ministry of Health, the Dutch Organization of Service Providers, the Federation of Parent Associations, and the Dutch National Committee EYPD 2003 (European Year for People with Disabilities), all of whom were members of the organizing committee. To begin the process, the organizing committee formulated five basic criteria for adequate health care of people with ID. By means of a questionnaire (completed by medical professionals and non-governmental organizations from numerous European countries as well as countries on other continents) the organizing committee gained an understanding of the key cross-cutting health care issues for individuals with ID across different countries, including both positive aspects as well as shortcomings. Additionally, consulting the literature and gleaning information from government documents helped the committee to form a broader view of the issues.

Following the data-gathering phase, the organizing committee concluded that there were a number of shortcomings in the organization and quality of the health care for people with ID across the various European countries. Some of these shortcomings were, to a certain extent, already recognized or being improved upon by select countries. However, it is important to note that none of the European countries could unequivocally state that the quality of health care for people with ID in their country was entirely adequate or exemplary.

Using the information gleaned from the questionnaire and the publications reviewed, the organizing committee formulated a draft version of the manifesto for basic standards for adequate health care for people with ID and circulated it to a number of interested professionals and representatives of persons with disabilities and carers. Next, the organizing committee scheduled and then held an invitational consensus meeting in November 2003 in Rotterdam, the Netherlands (on the occasion of the graduation of the first class of specialist medical trainees at the Erasmus Medical Center's Department of Specialist Training for Physicians for People with Intellectual Disabilities). The aim of this meeting was to make final and accept the European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities (see Appendix A for the text of the manifesto). Appendix B lists the persons and organizations represented at the consensus meeting. As drafted, the manifesto framed and summarized the elements and recommended provisions for a system of adequate health care for individuals with ID.

At the invitational consensus meeting, the draft of the European Manifesto for Basic Standards for Adequate Health Care was presented and discussed with representatives of persons with ID, university educators, professional organizations, service providers, and politicians. The group was also charged to address the implications of the manifesto and recommend how it could be implemented. To gain greater consensus on the elements of the manifesto and its potential implementation representatives of the European Organization of Service Providers (EASPD), Inclusion Europe, and the European Parliament, among others, who were attending a congress at Erasmus Medical Center the day following the consensus meeting, were asked to provide comments and make suggestions on the document. Following this meeting, their collective comments and suggestions were then incorporated into the final version of the manifesto.

CONCLUDING STRATEGIES

The intent of the organizing committee was that the manifesto serve as a stimulant for governments, organizations, and individuals to work collectively to improve health care provision for people with ID throughout Europe – and thus positively affect their overall health status. Underlying the framework of the manifesto is the belief that people with ID are valued and that there is a strong adherence and consideration of their full rights as citizens, that they have every right to access mainstream health care, and when needed, that they have a right to access specialist care. To ensure that the manifesto has an impact and is infused into public health policy at the national level, it was recommended that people involved in advocacy on behalf of individuals with ID (e.g., individuals with ID and their representatives, health care workers, policy makers, care providers, associations of professionals or researchers) – in all European countries – work toward forming regional or national task forces which are then charged with framing public policy and implementing the mechanisms

necessary to structure the provision of appropriate health care to this group of Europe's citizens. It was recommended, also, that these task forces develop action plans attuned to the specific situations of each country.

The organizing committee also recommended that each European government support these task forces and help to improve health care for people with ID along the lines pointed out in this manifesto. It was also recommended that the European Commission and World Health Organization lend their support to these developments and ensure that the manifesto become part of the final report of the EYPD 2003.

ACKNOWLEDGMENTS

The organizing committee wishes to thank The Dutch Ministry of Health (VWS), the Dutch association of care providers (Vereniging Gehandicaptenzorg Nederland, VGN), the Nationale Collectie Verstandelijk gehandicapten (NCVG), and the Trust Foundation Erasmus University of Rotterdam, for their financial contribution to the invitational conference and congress.

REFERENCES

- Böhmer, C. J. M. (1996). *Gastro-esophageal reflux disease in intellectually disabled individuals*. Amsterdam: Vrije Universiteit Amsterdam.
- Evenhuis, H. M. (2002). "Want ik wil nog lang leven," background study "Samen Leven in de Samenleving". Den Hague, the Netherlands: Raad voor de Volksgezondheid & Zorg.
- National Health Service. (2002). *Promoting health, supporting inclusion*. The national review of the contribution of all nurses and midwives to the care and support of people with disabilities. Edinburgh: Author.
- Samen Leven in de Samenleving*. (2002). Den Hague, the Netherlands: Raad voor de Volksgezondheid & Zorg.
- van Schrojenstein Lantman-de Valk, H. M. J. (1998). *Health problems in people with intellectual disabilities*. Maastricht: Universiteit Maastricht.
- van Splunder, J. (2003). *Visual impairment, prevalence and causes of visual impairment in adults with intellectual disabilities*. Rotterdam: Erasmus MC Rotterdam, University Utrecht.
- Tyrrell, J., & Dodd, P. (2002). Psychopathology in older age. In P. W. Davidson, V. P. Prasher, & M. P. Janicki (Eds.), *Mental health, intellectual disabilities and the aging process* (pp. 22–37). Oxford: Blackwell Publishing.
- UK Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st Century*. London: Author.
- US Department of Health and Human Services. (2002). *Closing the Gap: A National Blueprint to Improve the Health Disparities and Mental Retardation*. Report of the Surgeon General Conference on Health Disparities and Mental Retardation. Rockville, MD: Author.
- US Department of Health and Human Services. (2003). Disability and secondary conditions (Chapter 6). In Centers for Disease Control and Prevention and National Institute on Disability and Rehabilitation Research, US Department of Education (Lead agencies), *Healthy people 2010: Understanding and Improving Health*, Washington: Author.

APPENDIX A

European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities

Rotterdam, 2003

Preface

- People with intellectual disabilities are citizens of their country and they have an equal right to be included in society, whatever their level of disability.
- People with intellectual disabilities have many gifts and abilities, but they may also have special needs and may need a choice of services to support their needs.
- People with intellectual disabilities have the same human rights as other citizens.
- People with intellectual disabilities have the right to equal participation in society and to participate in all decisions that concern their lives.

The political and moral foundation for this manifesto is the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, as adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993.

The Standard Rules were developed on the basis of the experience gained during the United Nations Decade of Disabled Persons (1983–1992), taking in regard the following documents:

- The International Bill of Human Rights, comprising the Universal Declaration of Human Rights
- The International Covenant on Economic, Social and Cultural Rights

- The International Covenant on Civil and Political Rights
- The Convention on the Rights of the Child
- The Convention on the Elimination of All Forms of Discrimination against Women
- The World Programme of Action concerning Disabled Persons
- World Health Organization, International Classification of Impairments, Disabilities, and Handicaps (Geneva, 1980).
 - Informed consent is essential in the relationship between the health professional and his or her client. Therefore, information for the client and his or her family about diagnostic procedures and therapies should be in an easily understandable format.
 - People with intellectual disabilities and their representatives should influence all decisions about health care at every level of health care organization.
 - In this document, the World Health Organization definition of health is used: *Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*

The Manifesto

The following criteria should be universally recognized and accepted as basic standards of adequate health care for individuals with intellectual disabilities.

1. **Optimal availability and accessibility to mainstream health services with primary care physicians playing a central role. This means that people with intellectual disabilities will:**
 - a. Use mainstream health services.
 - b. Receive more time for consultations in the clinic or in home visits, when needed.
 - c. Receive adequate support in communication, when needed.
 - d. Receive a proactive approach to their health needs.
 - e. Have no extra financial, physical or legislative barriers to use mainstream services.
 - f. Be able to participate in screening programs, in the same way as anybody else.
 - g. Be supported in achieving and maintaining a healthy lifestyle that will prevent illness and encourage positive health outcomes.
 - h. Receive understandable information about health and health promotion (also available to family and carers).
 - i. Receive healthcare with good cooperation and coordination between different professionals.
2. **Health professionals (especially physicians, psychiatrists, dentists, nurses and allied professionals) in mainstream health services will have competencies in intellectual disabilities and therefore in some of the more specific health problems in people with intellectual disabilities. This will require that:**
 - a. Health professionals have a responsibility to achieve competencies in the basic standards of health care for people with intellectual disabilities.
 - b. Such competencies include the awareness that not all the health problems of people with intellectual disability are caused by their disability.
 - c. All training programs for health professionals pay attention to intellectual disabilities, including the most common etiology, some frequent syndromes, etiology-related health problems, and communication, legal and ethical aspects.
 - d. Training in attitude and communicational skills is as important as clinical skills and therefore is part of training programs.
 - e. Guidelines on specific health issues are available through the Internet, CD-ROM, or otherwise.
 - f. Health care professionals in mainstream services have easy access to, and are able to get, advice from specialist colleagues without extra financial, practical or legislative barriers.
3. **Health professionals (physicians, psychiatrists, dentists, nurses and allied professionals) who are specialized in the specific health needs of individuals with intellectual disabilities are available as a backup to mainstream health services. These professionals can advise, treat specific medical problems or take over (a part of) the medical care for people with intellectual disabilities. This will require that:**
 - a. Training programs are available for health professionals who want to gain competencies in health issues of people with intellectual disabilities.
 - b. These specialists create and maintain networks with specialized colleagues in and outside of their own profession, in order to improve their knowledge and skills. This can be achieved by personal contacts or by creating (virtual) centers of expertise.
 - c. Research on health issues of people with intellectual disabilities is stimulated in cooperation with academic centers and academic Chairs in Intellectual Disability Medicine should be created to initiate, stimulate and coordinate research projects.
4. **Health care for individuals with intellectual disabilities often needs a multidisciplinary approach.**
 - a. Specific health assessments and/or treatments need coordination between different health professionals (e.g., visual and hearing impairment, mental health care, care for people with multiple and complex disability, care for elderly persons, rehabilitation care).
 - b. Specialist training for nurses and other carers is stimulated; this includes learning how to support and care for people with intellectual disabilities who have for instance sensory impairments, autistic spectrum disorders, epilepsy, mental health problems, behavioural/forensic problems, physical and complex disabilities, swallowing and feeding problems, and aging-related problems.
5. **Health care for people with intellectual disabilities needs a proactive approach.**
 - a. Participation in national screening programs should be encouraged.
 - b. Anticipating health investigations on visual and hearing impairments and other frequent health problems should be evidence-based and routinely available.

- c. General and specific health monitoring programs are developed and implemented, and the development of Health Indicator Systems special attention is paid to people with intellectual disabilities.
- d. Responsibility for the development of anticipating investigation programs and for their implementation must be clarified (i.e., primary care physicians, public health doctors or specialized physicians).
- e. People with intellectual disabilities and their families have a right to etiological investigations.

APPENDIX B

Participants: Invitational Conference of November 27, 2003

M. A. Arvio	Paavarvi Inter-Municipal Association, Lammi, Finland
M. Bijwaard	Dutch Association of Service Providers (VGN), Utrecht, the Netherlands
M. V. Björkman	Bellstasund Utredningscenter, Upplands-Vsby, Sweden
M. Brown	NHS Trust, Glasgow, UK
S. Carpenter	NHS Trust, Bristol, UK; President of MAMH
S. Duffels	Vizier, Gennep, the Netherlands
H. M. Evenhuis	Erasmus Medical Center, Rotterdam, the Netherlands
F. Fea	Centro di Riabilitazione "Scuola Viva", Rome, Italy
K. de Haan	Werveling, Utrecht, the Netherlands
M. Hardeman	EASPD, Brussels, Belgium
T. Holland	Cambridge University, UK
K. Hutsebaut	Inclusion Europe, Brussels, Belgium
M. K. Kaski	Rinneke Foundation, Espoo, Finland
P. A. M. Leemans	Dutch Health Care Inspectorate, Den Haag, the Netherlands
M. van Leeuwen	Dutch Federation of Parent Organisations, Utrecht, the Netherlands
A. Mantovani	Azienda Ospedaliera San Paolo, Milano, Italy
M. M. Meijer	Erasmus Medical Center, Rotterdam, the Netherlands
J. Merrick	Israeli Ministry of Social Affairs, Jerusalem, Israel
E. Powrie	University of Aberdeen, UK
F. A. Scholte	's Heerenloo Midden Nederland, Apeldoorn, the Netherlands; President of NVAVG and Secretary of MAMH
H. M. J. van Schrojenstein Lantman-de Valk	University of Maastricht and Pepijn en Paulus, Echt, the Netherlands
J. Th. Sluiter	Dutch Ministry of Health, den Haag, the Netherlands
G. Skeie	Habiliterings Unit Hedmark, Ottestad, Norway
K. Sörensen	Aarhus Psychiatric Hospital, Risskov, Denmark
T. Zomi	Hand in Hand Foundation, Budapest, Hungary

Organizing Committee

H. M. Evenhuis, Erasmus Medical Center
 E. Gorter, Dutch Ministry of Health
 M. von der Möhlen-Tonino, Erasmus Medical Center, Ipse Foundation
 M. M. Meijer, Erasmus Medical Center
 W. J. den Ouden, Dutch Ministry of Health
 F. A. Scholte, NVAVG, MAMH
 J. Smits, National Committee EYPD 2003
 C. Steman, VGN