European Manifesto

BASIC STANDARDS OF HEALTHCARE

FOR PEOPLE WITH

INTELLECTUAL DISABILITIES

Rotterdam
November 28th, 2003

Subject: **Health care for people with intellectual disabilities**

Dear Madam / Sir,

On the 27th November 2003, at the end of the 'European Year for People with Disabilities', an invitational conference -held in Rotterdam, the Netherlands- about health care for individuals with intellectual disabilities took place. The meeting was organised by **NVAVG-** the Netherlands Society of Physicians for persons with Intellectual Disabilities, and **MAMH**- 'European Association of Intellectual Disability Medicine', in collaboration with **Erasmus MC**- the department of specialist training of physicians for people with intellectual disabilities.

The aim of the meeting was to finalise and accept a **European Manifesto** about "Health care for people with intellectual disabilities."

The text of the Manifesto and an explanatory memorandum are hereby enclosed.

This Manifesto attempts to clearly summarise the elements of adequate health care for individuals with intellectual disabilities.

We hope this Manifesto will, through stimulating governments, organisations and individuals, improve health care for people with intellectual disabilities, considering their rights as citizens, their rights to access mainstream healthcare and when needed, their right to access specialist care.

We ask people involved in the care of people with intellectual disabilities in all European countries (eg. Individuals with intellectual disabilities and their representatives, health care workers, policy makers, care providers, associations of professionals or researchers) to form task forces to develop adequate health care for this group of patients. Action plans should be drawn up with regard to the specific situations of each country.

We ask every government to support these task forces to improve medical care for people with intellectual disabilities along the lines we have pointed out in this Manifesto.

Finally, we ask for the support of the European Commission and WHO in these developments. In order to achieve this we hope that this Manifesto can be part of the final report of the 'European Year of Disabilities 2003'.

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

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Preface

People with intellectual disabilities are citizens of their country. They have an equal right to be included in society, whatever their level of disability.
People with intellectual disabilities have many gifts and abilities. They also have special needs. They 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. They must participate in all decisions that concern their lives (Inclusion Europe).

In this manifesto we regard 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 as the political and moral foundation. The Standard Rules have been 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 client. Therefore, information for the client and his 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 healthcare at every level of healthcare organisation.
In this document the word ‘health’ is used as defined by the World Health Organisation:
“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

Manifesto

BASIC STANDARDS OF HEALTHCARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Rotterdam 2003

The following criteria should be universally recognised 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 programmes, 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 co-operation and co-ordination 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. These 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 aetiology, some frequent syndromes, aetiology-related health problems, communication, legal and ethical aspects.
    d. Training in attitude and communicational skills is as important as clinical skills and therefore is part of the training programs.
    e. Guidelines on specific health issues are available through 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 specialised in the specific health needs of individuals with intellectual disabilities are available as a back-up 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 Programmes 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 specialised 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) centres of expertise.
    c. Research on health issues of people with intellectual disabilities is stimulated in co-operation with academic centres. Academic Chairs in Intellectual Disability Medicine should be created to initiate, stimulate and co-ordinate research projects.

4. **Health care for individuals with intellectual disabilities often needs a multidisciplinary approach.**

    a. Specific health assessments and/or treatments need co-ordination between different health professionals (eg. visual and hearing impairment, mental health care, care for people with multiple and complex disabilities, care for the elderly, 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 age related problems.

5. **Health care for people with intellectual disabilities needs a pro-active approach.**

    a. Participation in national screening programmes 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 programmes are developed and implemented. In the development of Health Indicator Systems special attention is paid to people with intellectual disabilities.
    d. Responsibility for the development of anticipating investigation programmes and for their implementation must be clarified (primary care physicians, Public Health Doctors or specialised physicians).
    e. People with intellectual disabilities and their families have a right to aetiological investigations.

Explanatory memorandum

NVAVG - Netherlands Society of Physicians for persons with Intellectual Disabilities, and **MAMH -** European Association of Intellectual Disability Medicine together with **Erasmus MC -** Department of 'Specialist Training for Physicians for People with Intellectual Disabilities' recognised the need for this Manifesto and have taken the initiative for its development.

The Dutch Ministry of Health, the Dutch Organisation of Service Providers, the Federation of Parent Associations and the Dutch National Committee EYPD 2003 (European Year for People with Disabilities) were part of the organising committee.

The organising committee formulated five basic criteria for 'Adequate Health Care of People with Intellectual Disabilities'. By means of a questionnaire, completed by medical professionals and non-governmental organisations from Europe and other Continents, it was able to gain an overview of the health care for individuals with intellectual disabilities in different countries: the positive aspects as well as the shortcomings. Consulting the literature and governmental documents helped the committee to form a broader view.

We concluded that presently there are several shortcomings in the organisation and quality of the health care for people with intellectual disabilities in different European countries. Some of these shortcomings are to a certain extent already recognised or being improved upon in several countries, but none of the responders defined the quality of health care for people with intellectual disabilities in their own country as adequate.

Based on the information from the literature and the questionnaire, the organising committee formulated a draft version of a *manifesto for basic standards for adequate health care for people with intellectual disabilities*. After consulting interested professionals and stakeholders, the Manifesto was finalised at the 'Invitational Conference' on the 27th November 2003.

At the meeting on the 27th November, these 'Criteria for Adequate Health Care' were discussed with (representatives of) persons with intellectual disabilities, professional organisations, service providers and politicians. Attention was also paid to the implications of the Manifesto.

At the congress, on the 28th November, representatives of EASPD (European Organisation of Service Providers), Inclusion Europe and the Euro Parliament gave their comments on this Manifesto. Their remarks are reproduced in this final version.

Overview

Research shows that many individuals with intellectual disabilities have specific health needs. They may have more general and specific to their condition - related physical and psychiatric health problems compared to individuals without a disability. Communication problems are also often present. Inclusion of individuals with intellectual disabilities into society is the accepted strategy of most European countries; it requires a holistic approach, including education, housing, employment, leisure services and use of mainstream services. Mainstream health services should be accessible for people with intellectual disabilities and should be capable to deal with the disability – related health needs.

This premise has consequences for primary health care, specialist care and the general health care system. Physicians, professions allied to medicine and psychological therapists have to improve their knowledge of individuals with intellectual disabilities and their health problems. However, health practitioners, who are involved with only a few individuals with intellectual disabilities can not be expected to have specialised knowledge about the specific health problems of people with intellectual disabilities. Specialists are therefore needed to support them.

Based on the information gained by questionnaires, governmental reports and literature we made the following observations (please note that the following remarks don't have the status of a scientific report nor are a display of the opinion of the authors):

<u>Organisational aspects:</u>

It is reported that general health services do not always succeed in delivering adequate health services to persons with intellectual disabilities.

There are major differences in the quality and the organisation of health care for persons with intellectual disabilities in different European countries. In southern and eastern European countries the quality of medical care for individuals with intellectual disabilities appears to be rather insufficient. In most western and northern European countries the quality of medical care is reported as better, but even in these countries general practitioners (GP's) often seem to display a lack of knowledge, communication skills and time.

Paediatricians generally have special knowledge about children with intellectual disabilities. However, according to our responders they often concentrate on the 'health' problems only, without co-ordinating the total medical care and without supporting the families in other aspects.

Since the life-expectancy of people with intellectual disabilities has increased significantly over the past few decades, problems arise when transition to adult care becomes necessary. Because of the multidisciplinary aspects of health care for individuals with intellectual disabilities, specialised therapists and behavioural scientists are sometimes needed but not always available and their collaboration with regular and specialised services needs better organisation.

<u>Medical aspects:</u>

Although psychiatric problems are present more often in individuals with intellectual disabilities, there are only few psychiatrists with special interest or expertise in this speciality, especially for children with intellectual disabilities.

Sensory impairments are often present. These very important conditions are seriously under-diagnosed. Special screening programmes are usually not developed and/or implemented. Since some syndromes are often associated with specific health problems, health monitoring of these syndrome-associated problems should be available.
Responders emphasise that it is necessary to pay special attention to people with complex and profound disabilities, who often also have other medical problems, such as visual and hearing impairments, cerebral palsy, epilepsy and eating problems. Their health problems sometimes require specially trained nurses, allied health professionals, psychological therapists and physicians, who are not always available.
When people with intellectual disabilities live in community settings, their complex health needs sometimes interfere with the maintenance of values of normal living, respectful treatment and privacy. For people with serious motor or sensory impairments adequate technical adaptations in their living and work place are often missing.

Dental care:

Dental care for people with intellectual disabilities is generally reported as poor. Even for the general population there seems to be a lack of dentists in many countries. There is a reported need for dentists who are willing to take some more time to treat people with intellectual disabilities, and try to overcome the difficulties of communication and anxiety. This is even more important when one realises that the diagnosis of dental abnormalities can contribute to the aetiological diagnoses of intellectual disabilities.

Lifestyle:

People with mild intellectual disabilities, who live in society with a minimum of support, can often adopt unhealthy habits. It is important to support them to avoid health or social risks.

The participation of people with intellectual disabilities in screening programmes for the general population is reported as poor and has to be improved. People with intellectual disabilities themselves and also their carers do not always seem to be aware of the need for screening.

Research:

Medical care for people with intellectual disabilities needs to be evidence based. Research is necessary, as it is the basis of good practice. Although it is acknowledged that there is a significant increase in the number and quality of publications in intellectually disability medicine, a lot of work has still to be done in this area. There are only a few academic chairs in Europe.

Social-economical aspects:

Many individuals with intellectual disabilities suffer from poverty or have a low income. Health care for people with intellectual disabilities is sometimes expensive. More time means more costs and funding will need to reflect this.

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