

Merrick J, Morad M, Kandel I, Ventegodt S. health policy and intellectual disability. BMJ Rapid responses 2004 Aug 20. <http://bmj.bmjournals.com/cgi/eletters/329/7463/414#71560>

<http://bmj.bmjournals.com/cgi/eletters/329/7463/414#71560>

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## People with intellectual disability, health needs and policy 20 August 2004

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EDITOR--- This communication in response to the recent editorial by Sally-Ann Cooper, Craig Melville and Jillian Morrison on people with intellectual disability and health inequality (1).

Last year was the European Year of People with Disabilities with many activities in Europe in order to focus on this part of the population. The first author participated in the historic event in late 2003 at the graduation of ten physicians, who became the first specialists in intellectual disability medicine in the world after three years of studies under the guidance of professor Heleen Evenhuis, MD, who in the year 2000 became the first professor of intellectual disability at the Erasmus University Medical Center in Rotterdam at the Department of Family Medicine.

In connection with the graduation an invitational conference of professionals from 12 different countries was held in Rotterdam about health care for individuals with intellectual disabilities. The meeting was organised by NVAVG (the Dutch Society of Physicians for persons with Intellectual Disabilities, the MAMH (European Association of Intellectual Disabilities Medicine) and the Erasmus Medical Center Department of specialist training for physicians for people with intellectual disabilities with the aim to finalise and accept a European Manifesto about "Health care for people with intellectual disabilities", maybe the most vulnerable group of persons with disability (2).

We have also recently finished a major study on the health profile and utilization of 2,282 adults with intellectual disability aged 40 years and older living in residential care in Israel (3). Results showed that age was a significant factor in health status with cardiovascular disease, cancer and sensory impairment increased significantly with age for both genders, cardiovascular disease in this population was less prevalent when compared to the general population.

### PEOPLE WITH INTELLECTUAL DISABILITY

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 and 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 the manifesto below (2) the participants of the November 2003 Rotterdam Meeting regarded 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 for this special population. 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 consideration the following documents:

1. The International Bill of Human Rights, comprising the Universal Declaration of Human Rights
2. the International Covenant on Economic, Social and Cultural Rights
3. the International Covenant on Civil and Political Rights
4. the Convention on the Rights of the Child
5. the Convention on the Elimination of All Forms of Discrimination against Women
6. the World Programme of Action concerning Disabled Persons
7. World Health Organization, International Classification of Impairments, Disabilities, and Handicaps (Geneva, 1980) and the International Classification of Functioning, Disability and Health (ICF) (Geneva, 2001).

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 or manifesto below the word 'health' is 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 ABOUT THE BASIC STANDARDS OF HEALTH CARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES

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 of 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 etiology, some frequent syndromes, etiology-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 disability, 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.

We hope that the above goals for the population of children, adolescents and adults with intellectual disability or for that matter any disability will be fulfilled in the coming years with many countries following the good example of Holland.

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Competing interests: None declared

## Health policy and intellectual disability

22 August 2004

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EDITOR---This communication in response to the recent editorial by Sally-Ann Cooper, Craig Melville and Jillian Morrison on people with intellectual disability and health inequality (1).

More than 25 years have passed since the shift in care for people with intellectual disability from institutional to community care (often called de-institutionalization or normalization), but many gaps prevail in many domains of the medical system and in the ideology of providing care (2).

### TRANSITION TAKING PLACE

We have not yet succeeded to overcome that kind of shift from institution to community care and we are facing the new transition characterised by aging, increased life expectancy and accumulation of degenerative diseases and chronic illness characterising the general population (3).

This increase in life expectancy contribute to the increasing number of people with intellectual disability and the aging of this population (4,5). If the population does not receive health surveillance these people with intellectual disability will have a significant functional decline, increase the burden of disease and demands more expensive resources with higher cost due to high technology services (6). If this trend is expected and measures taken to accomodate health promotion, screening and focus shifted to a healthy life style, we would expect to have less disability and dependence among people with intellectual disability (7) .

### BURDEN OF DISEASE

Most of the burden of diseases in later life, much earlier in people with disabilities than the general population could be caused in large extent by chronic diseases and their consequences that causes functional decline and decrease quality of life. Thus we need more screening, bigger efforts to diagnose early, better compatible models for case management of chronic

diseases and prevention of complications and secondary diseases caused by disability (8,9). It is known now that most of the disease burden among people with intellectual disability is caused not by the level of disability, but rather by the level of functional decline accompanying it (10).

## SERVICE MODELS

In order to have models of services addressing universal and unique needs of this population, there is an imminent need for their inclusion, not only in the community but also include them in trials and projects addressing health promotion, screening, health education, use of therapeutic and diagnostic measures. This should be done in order to avoid adopting evidence from the population without intellectual disability to this population, because there could be a danger as proved to be with other parts of the society (11,12).

Policy makers are always worried about an increase in costs of services, if there would be a shift to address needs and expectations of this population with disability. This in spite of evidence that many of the causes of morbidity and mortality leading to higher utilization of services in this group are either curable or preventable and therefore an investment in earlier age would show cost-benefit (13,14).

Socio-economic factors were found to be much more implicated in health status and morbidity of people with intellectual disability than the rest of the population, demanding interventions of other authorities beside the medical community (15).

## SUPPORT SYSTEMS

Supports of professional staff may be expensive (16), but does not seem or was not proved to be better than informal support or support offered by voluntary or other specific remedial communities, except for the medical care in its narrow spectrum.

Finally, regarding the role of legislation to remove disparities in health is not straightforward, but has to be coupled with a change of attitudes in the public, professionals and policymakers and there has to be a political clear agenda with the core of inclusion of people with intellectual disability woven firmly into it.

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Competing interests: None declared

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