

Health indicators for people with intellectual disabilities

A European perspective

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People with intellectual disabilities make up about 1% of the population of Europe. As trends toward community life advance, they have become more visible and more likely to access generic health systems. Yet evidence suggests that there are striking disparities between the health of this group and that of the general population. Increased longevity means that adults in this group expect to live longer lives and thus to encounter age-related risks for various health conditions. The 'Pomona' project, funded by the EU Health Monitoring Unit, aims to develop a set of health indicators for people with intellectual disabilities. It will build on the work accomplished by the team developing ECHI – European Community Health Indicators. This article outlines the rationale for the project, key elements in its implementation and expected outcomes.

Keywords: health indicators, people with intellectual disabilities

Today, people with intellectual disabilities may expect to live longer and to live and work in their own communities. While they increasingly share many adult life experiences with other citizens, disparities in health status and health outcomes are striking.^{1,2} In the European Union, closing such gaps is a priority if people in this group are to achieve equity and social inclusion.

An estimated 3.5 million persons with intellectual disabilities live in the Member States of the European Union, if it is assumed that most developed countries report an overall prevalence rate of 1%.³ Individuals in this group have significant decrements in both intellectual and adaptive functioning with an onset during the developmental period – before age 18 years.⁴ *Intellectual disability* has emerged as the preferred term, but others persist: *mental retardation* in the USA, *learning disability* in the UK and *mental handicap* elsewhere.

In the recent past, separate care for people with disabilities dominated the policy landscape. A high percentage of individuals with physical, sensorial or intellectual disabilities and those with mental health difficulties were encouraged to live in institutions. This pattern prevailed in Ireland,⁵ in the UK,⁶ and in other countries with developed market economies and formal social or health service systems.⁷ Darker forces promoted the systematic euthanasia of people with disabilities in Germany in the 1930s and 1940s, when thousands of children and adults with disabilities were killed outright⁸ in the interests of public health.

Today people with intellectual disabilities in most countries are likely to live with their families or in community residences. Reflecting a trend toward greater life expectancy, they will live longer lives: many will live well into middle age with their elderly parents. Others will reach *the third age* in their turn, some with specific vulnerabilities to age-related diseases. For example, those with Down syndrome are at particular risk of developing Alzheimer's Disease. In Europe, diverse forms of support for people with intellectual disabilities in family homes, in group homes or large residences and in workplaces in their communities have emerged, reflecting national policies and traditions. Their full participation in society is endorsed by the EU, which has adopted a rights-based model of disability.⁹ It supplants an earlier model in which the person with disability was the locus of the problem rather than the social and physical environment. The rights-based model of disability is the engine of the European Union's social policies, driving towards equal opportunities for people with intellectual disabilities to experience social inclusion. Nonetheless, Europeans with intellectual disabilities are more likely to be poor, to have lower educational attainments, to be unemployed and to experience diminished social and vocational inclusion.

Despite a unified set of policies, it is nonetheless difficult to compare the prevalence of impairments, disabilities or handicaps across the Member States, as the figures depend on the age structure of the groups surveyed and the indicators used in a particular country or region.¹⁰ Even less is known about the health status and outcomes of individuals with intellectual disabilities. Healthy ageing for people with intellectual disabilities expresses both WHO and EU policy.^{11,12} Yet health risk factors have to date been less systematically identified for people in this group.

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Public health strategies have rarely targeted people with intellectual disabilities in national initiatives. The consequences in terms of heightened morbidity, poorer health outcomes and diminished quality of life for this population may only be estimated. There is as yet no coherent, evidence-based strategy for monitoring the health of people with intellectual disabilities in the Member States so as to permit comparisons between this population and their peers without disabilities, or between the Member States. Without such a strategy, attempts to implement European policies and thus promote the healthy ageing of Europeans with intellectual disabilities will falter.

This article presents a rationale for developing a set of health indicators for people with intellectual disabilities within a new public health initiative led by partners in 13 of the Member States. It presents a brief summary of the knowledge base related to the physical and mental health of people with intellectual disabilities and outlines the work plan for a new project, *Pomona*.

KNOWLEDGE BASE

Knowledge of the determinants of health of people with intellectual disabilities hovered at a modest level for much of the last century. This dearth of knowledge was associated with the removal of many people in this group to remote institutions where they led invisible and relatively short lives. Recently, findings of great importance to health-related research have punctuated this equilibrium. A set of reports on the healthy ageing of adults with intellectual disabilities was prepared for the WHO.^{12,13} Key risk factors for ill health among people with intellectual disabilities have been documented – such as nutrition, medication and lack of exercise.³ Health system factors also have a bearing on the health of people with intellectual disabilities. Often, primary care health professionals do not have training to ensure that they will communicate effectively, nor do family members have relevant information about how to promote their relative's health. Clinicians may find that continuity of care across sectors – for example, primary care and mental health care – is fragmented. Crucially, men and women with intellectual disabilities themselves lack the skills needed to pursue healthy lives.

For people with intellectual disabilities, compromises to their health arise at different levels. They may have untreated, yet treatable, conditions; untreated specific health issues related to the individual disability; and in addition they may fail to access generic health promotion, such as blood pressure screening.¹⁴ Mental health problems may be masked by the presence of developmental or other disabilities and hence elude treatment.¹⁵ Antecedent conditions may include life stressors, limited social networks and fewer opportunities for social learning. In addition, adverse reactions may be exacerbated among adults with intellectual disabilities due to cognitive impairments, poor self-esteem and relatively poor social support.

Gender helps to determine health for people with intellectual disabilities, as for other individuals. Men and women with intellectual disabilities thus experience health risks associated with their gender, but also with conditions related to the presence of intellectual disability. Women with intellectual disabilities, for example, have particular life experiences and risks to their reproductive and sexual health.¹⁶ Individuals in this group have poor literacy skills, and consequently they do not often avail of education on menstrual hygiene, sexually transmitted diseases, contraception and related topics. Nor do these women have equal access to screening programmes for breast or cervical cancer. Men with intellectual disabilities, too, have specific health risks. These include increased rates of morbidity and mortality – due to biological factors; harmful health behaviours and poor access to health care.¹⁴ Males with intellectual disabilities appeared to have sexually transmitted diseases eight times more often than their peers without disabilities.¹⁷ In addition, both men and women in this group may experience *comorbidity* of conditions such as hypothyroidism, obesity and epilepsy; *psychiatric illnesses* that may persist without being diagnosed or treated;¹⁸ or *lifestyles* with sparse opportunities to promote healthy patterns of nutrition and physical exercise.¹⁹

Addressing these risks vigorously throughout the Member States is not only humane, it is a fiscally prudent and socially valuable investment in the health of citizens:

In the end, when fiscal resources are considered, investments to build a healthy population in childhood and through the lifespan will pay off in later age when health care costs for ageing-related problems are decreased owing to a healthy older population and the overall society experiences a more productive and healthier ageing.^{12,p.173}

First, essential information about how Member States currently monitor the health of citizens with intellectual disabilities must be sought.

HEALTH INDICATORS AND PEOPLE WITH INTELLECTUAL DISABILITIES

The ECHI project group prepared a set of health indicators that apply to the general population, thus meeting objectives of public health monitoring in the European Community.²⁰ They were developed in order to measure health status, determinants and trends; to facilitate planning, monitoring and evaluation; and to provide information and thus make comparisons across Member States and support national health policies.

Do these indicators usefully apply to individuals with intellectual disabilities? Available evidence about the health of people in this population suggests that the four categories of indicators in the ECHI Report – *Demographic, Status, Determinants* and *Systems* – are potentially valuable. For example, Robertson *et al.*²¹ found that the prevalence of poor diet, obesity in women and physical inactivity was high in a population of 500 adults with intellectual disabilities living in residential settings in the UK. Further, physical inactivity was associated with residents' lower ability and more restrictive residential

settings. These findings suggest that the ECHI Report's inclusion of 'living and working conditions' under its category *Determinants* may well have particular relevance for people with intellectual disabilities.

Further, the authors of the ECHI Report devised *User Windows* – subsets of the indicators serving as critical pathways for individuals with particular interests or requirements. This flexibility is appropriate in considering the health of particular groups of people with intellectual disabilities. Those with a history of institutional living may have missed opportunities as young adults to develop a healthy lifestyle in terms of diet and exercise. Older people may not have ready access to regular screening for sight and hearing deficits. Women may not receive information on sexual and reproductive health matters in a form that they understand. And many adults may have unidentified – and thus untreated – mental health conditions.

THE POMONA PROJECT

The overall aim of this new project is to identify a set of health indicators that reflect areas of most importance in achieving greater quality of life and health equity for people with intellectual disabilities. Drawing on the ECHI Report, these indicators should be flexible and based on evidence. The project aims

- to collect information on any indicators currently available or used in the Member States, and
- to modify the existing indicators and apply specifically to this target population.

A consultation process with individuals who have intellectual disabilities, family members, advocates, health professionals and policy-makers is planned to take place during the life of the project in each country.

There are three cross-cutting themes in the *Pomona* project. First, given that policies and services vary from country to country, it is important to make clear that the project adopts a Quality of Life paradigm. Health is paramount among indicators of Quality of Life – a construct with relevance for individuals with and without disabilities.^{22,23} People with disabilities are perceived as citizens with inherent rights to equal opportunities for social inclusion.²⁴ All citizens, including those with disabilities, have a right to equal opportunities for accessing health care and services.

Second, people with intellectual disabilities also have a right to be as healthy as anyone else. In this project, we shall try to identify evidence related to health indicators important for people with intellectual disabilities. If there are disparities between the health of people in this group and in the general population, what are the factors related to such gaps? At what level do they arise – population level, or health system level, for example? Some health indicators apply to all, while others apply more specifically to people with intellectual disabilities.

Finally, personal choice is an integral element in self-determination, increasingly viewed as a desired outcome for individuals with intellectual disabilities. But choice is often used as an argument to condone poor health status

and practices: 'He is happy watching television and eating snacks all day'. If people were appropriately informed, would they make more healthful choices? How can health practitioners chart a safe course between risk and autonomy?

Funded in November 2002, the *Pomona* project is led by three steering group members – the present authors – who met in Maastricht in November 2002. The project name was selected as it is easy to recall, it reflects European traditions and it suggests fruitfulness or well-being. A first meeting of 13 partners (see note) took place in Montpellier, France in February 2003, adopting a workshop format. Partners contributed actively to this meeting by working in small groups to give information on what are most urgent issues related to health of people with intellectual disabilities in their countries. It was apparent, first, that there is great diversity across the Member States in how systems of health care are provided and funded. A second emergent theme was that individuals with intellectual disability have different labels across Member States – *cognitive*, *learning* and *mental* were some of the words used to modify *disability*. In some countries – Ireland, for instance – there is a national database of person with intellectual disabilities,²⁵ while in others, no information is available nationally.

Pathways to health care at many levels – covered in the fourth category of the ECHI list – may be haphazard for men and women in this population. Indeed, some partners commented that people in this group may be invisible to the public health agenda in their own countries. With a few notable exceptions, there are simply no national sources of information about how and when people with intellectual disabilities engage with the health system, and how these practices may or may not reflect those recorded for the general population. Thus, the value of addressing such vital issues in a European context within this project appears to be even greater than had been envisaged. Data about health care utilization, resource use and coverage will be obtained from key stakeholders in each Member State during the life of the project. Each partner is well placed to consult with leading experts in health and disability policy, given the particular attributes of the health and social care service system in the partner's own country.

At Montpellier, partners also i) made proposals for a provisional list of health indicators; and ii) agreed to plan national consultation at all stages of the project. To extend the project fully throughout the 15 Member States, the third author will attend an international roundtable in Volos, Greece, in May 2003. The event is organized by IASSID – International Association for the Scientific Study of Intellectual Disability <www.iassid.org>, and a presentation about the *Pomona* project is included in the scientific programme. Efforts have been made to identify suitable contacts for collaboration in Portugal, using the existing partners' sizeable networks. The project name has been registered and one partner has been developing a web-site to make information available in this way. A detailed account of

the Montpellier workshops was prepared and sent to each partner.

A review of literature is underway. The key domains include public health, health disparities, health of people with intellectual and other disabilities, health policy and health promotion. Recent policy documents are valuable for their own analysis of content but also for wide-ranging lists of international references. For example, Horwitz *et al.*²⁶ at Yale University, USA, have prepared a critical review, *The Health Status and Needs of Individuals with Mental Retardation* (intellectual disability). The *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation* (intellectual disability) is a second valuable resource in this field.¹

At a 2nd meeting in September 2003 in Spain, *Pomona* partners will consolidate information about national priorities, the proposed measures, the evidence base yielded by a literature review and the outcomes of consultative processes in each country to produce an interim report for the EU. Finally, partners will have an opportunity to revise the draft report during their 3rd meeting in April 2004. The *Pomona* team will draw on successful methods carried out by previous projects to complete its work. Notably, the consultative processes reported by the *Peristat* and *Child* projects have been examined carefully and elements of these will serve as useful templates for ensuring that national experts play their part appropriately in the new project.

SUMMARY

The *Pomona* project addresses global concerns – how to promote healthy ageing of individuals with intellectual disabilities. It will do so in harmony with local experts – people with disabilities, their family members and other advocates and health professionals. Consultation will help to ensure that the project reflects national priorities and that its findings will help to shape policy and inform evidence-based practice in pursuit of an enhanced quality of life for people with intellectual disabilities.

NOTE

The *Pomona* partners are:

Charles Aussilloux (FR); Monica Bjorkman, (SWE); Serafino Buono(IT); Raymond Ceccotto (LUX); Meindert Haveman (GER); Frank Ulmer Jorgensen (DK); Mike Kerr (UK); Tuomo Maatta (FIN); Jan Meireleire (BE); Luis Salvador (SP); HMJ van Schrojenstein Lantman de Valk (NL); P.N. Walsh (IRL); and Germain Weber (AUS).

The authors acknowledge the support of the *Pomona* project partners and also colleagues in their respective universities in preparing this article: however, they are responsible for any errors that may inadvertently appear.

The opinions expressed in this article do not necessarily reflect those of the universities with which the authors are affiliated.

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