

3. Health Indicators for People with Intellectual Disability

Health is a major concern in most people's thoughts about their quality of life (Felce, 1997); for people with intellectual disability this is as applicable as it is for the general population. The preceding chapter presented an evidence-base of health disparity between people with intellectual disability and their fellow citizens. This chapter will describe the use of health indicators as a method to measure health, the need to include health indicators for people with intellectual disability in the overall health-monitoring programme for Europe, and considerations in the development of health indicators specifically for those with intellectual disability.

3.1. Health Indicators as a Method to Measure Health

The World Health Organisation defines health indicators as follows (www.who.int):

“Health indicators summarize data that have been collected in order to answer questions relevant to the planning and management of health programmes. Health indicators can be used to assess the health status of a group, a population, or the differences between groups, at a certain moment. Health indicators can also be used to monitor changes over time, the effect of a programme, i.e. implementation and outcome, etc. Care providers may use health indicators to provide the necessary care and to control the quality of the care provided. Public health officers may use health indicators to survey the health status of groups or to survey the outcome of care provision for specific groups. Researchers may want to evaluate programs, search for a knowledge base, or highlight issues that need more attention from policy makers and/or care providers”.

From: www.who.int/reproductivehealth Oct 6, 2004.

Health indicators must be measurable and can be expressed in various ways. The following are examples:

- Rate per unit of population per unit of time, e.g. % of Down's Syndrome births within a country per year.
- Proportion at a point in time e.g. % of children in a country that receive full vaccination before 2 years of age.
- Average point in a time e.g. life expectancy at birth for Down's Syndrome females in 2004.
- Categorical measure at a point in time, e.g. existence of a law protecting autonomy for people with intellectual disability
- Absolute number in a defined population e.g. the number of hospital beds for people with intellectual in a country or a region, such as Italy, or the province of Limburg in the Netherlands.

The development and implementation of a set of health indicators specifically designed to monitor the health of people with intellectual disability will provide valuable baseline data regarding health disparities and inequalities experienced by this population. In addition, a health monitoring system promoting the ongoing collection of such data will evaluate the effects of any interventions implemented to reduce health disparities and inequalities among this population.

3.2. European Commission's Health Monitoring Programme

The European Commission Health Monitoring Programme (1997-2002) was adopted by the European Parliament and the Council on 30 June 1997. The aim of the programme was the establishment of a health monitoring system throughout the European Union. This aim was specified in a number of objectives and activities set out in three pillars:

- Measure health status, determinants, and trends throughout the Community
- Facilitate the planning, monitoring and evaluation of Community Programmes and actions
- Provide Member States with appropriate health information to make comparisons and support national policies

Overall, the European Union (EU) Health Monitoring System aims to produce comparable information on health and health related behaviour of the population, on diseases and health systems. This information will be based on an agreed set of European-wide indicators with regard to their definition, their collection and use.¹

Three Pillars direct these activities:

Pillar A: The establishment of community health indicators

Pillar B: The development of a community-wide network for sharing data

Pillar C: Analysis and reporting

A number of projects have received funding from the European Commission to explore and develop how a Health Monitoring System could be implemented across the European Union. Projects are classified according to the three pillars outlined above. The present project, *POMONA: Health Indicators for People with Intellectual Disability in the Member States*, is funded under Pillar A: The establishment of community health indicators. Another project, "*European Community Health Indicators Project; ECHP*", also funded under the European Health Monitoring Programme aims to identify a set of health indicators for the general population across the European Union. This project commenced in 1997 and has been employed by many subsequent projects, including POMONA, as a framework for the development of health indicators. This project is briefly outlined below.

¹ *Interim Report from the Commission to the Council, the European Parliament, the Economic and Social Committee and the Committee of the Regions on the implementation of the programme of Community action on health monitoring within the framework for action in the field of Public Health (1997-2001) (Decision No 1400/97/CE of the European Parliament and of the Council)*

3.2.1. The European Community Health Indicators Project (ECHI)

The European Community Health Indicators Project (ECHI) aimed to address Pillar A: The establishment of community health indicators. Its stated objective was:

To propose a coherent set of European Community Health Indicators, meant to serve the three purposes formulated for the HMP, selected on the basis of explicit criteria, and supported by all Member States (ECHI, 2001 p.8)

In selecting an appropriate set of health indicators for the general population in the European Union, ECHI stated that an indicator set should:

- Be comprehensive (cover all domains in the public health field)
- Take account of existing indicators (such as WHO, OECD, etc)
- Cover areas of public health that are of specific interest to Member States.

The specific selection of indicators was guided by a series of prerequisites:

- ❖ The selection should be guided by scientific principles
- ❖ Indicators should meet methodological and quality criteria
- ❖ Indicators should be flexible enough to meet changing policy interests
- ❖ The selection should be based on existing and comparable datasets

Using these criteria four key categories for the indicator set were developed. The four categories and grouping of indicators within each category are presented below.

1. Demographic & socio-economic factors	1.1 Population 1.2 Socio-economic factors
2. Health Status	2.1 Mortality 2.2 Morbidity, disease specific 2.3 Generic health status 2.4 Composite health status measures
3. Determinants of health	3.1 Personal and biological factors 3.2 Health behaviours 3.3 Living & working conditions
4. Health Systems	4.1 Prevention, health protection and health promotion 4.2 Health care resources 4.3 Health care utilisation 4.4 Health expenditures and financing 4.5 Health care quality/performance

Specific indicators were then developed within each grouping. In the third category ‘Determinants of Health’, for example, the grouping ‘3.1: Personal and Biological Factors’ contains the health indicators body mass index, low birth weight, blood pressure, serum cholesterol and nutritional status indicators. Similarly, in the fourth category ‘Health Systems’, the grouping ‘4.2. Health care resources’ contains the health indicators hospital beds total, hospital beds acute care, and psychiatric care beds. An original set of European Community Health Indicators (ECHI) was produced by the ECHI- 1 project and can be viewed at

(http://europa.eu.int/comm/health/ph_projects/1998/monitoring/monitoring_project_1998_full_en.htm#8). Following these findings ECHI 2 was commissioned to further develop these indicators: (http://europa.eu.int/comm/health/ph_projects/2001/monitoring/monitoring_project_2001_full_en.htm#8).

ECHI-1 and ECHI-2 have developed a comprehensive list of indicators, in close cooperation with many of the other projects run under the programme. By March 2003 approximately 400 indicators were proposed. A shortlist of indicators is now being selected to prioritize the work for harmonisation of data collection among Member States.

3.3. Health Indicators for People with Intellectual Disability

While health indicators for people with intellectual disability do not exist in a standard format across the European Union, examples are available in the United States. Please note, the US data come from a service delivery model that represents persons with significant disabilities that occur before the age of 18, called developmental disabilities. While persons with intellectual disabilities represent a substantial percentage of persons with developmental disabilities in the US, persons with other disabilities are also included in this category.

3.3.1. Health Indicators for People with Developmental Disability in the United States

In December 1996 the United States’ National Association of State Directors of Developmental Disability Services (NASDDDS) agreed to sponsor the Core Indicator Project. The aim of the project was to develop nationally recognised performance and outcome indicators that would enable a state’s developmental disability service to benchmark the performance of its services against those at national level. The Core Indicator Project is now conducted in collaboration with the Human Services Research Institute (www.hsri.org). The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes. A selection of indicators is presented below. The full list of indicators is available at: http://www.hsri.org/docs/NCI_RevisedPhaseV_Indicators.doc

Subdomain	Concern	Indicator	Data Source
Work	People have support to find and maintain community integrated employment	The average monthly earning of people who have jobs in the community	Consumer Survey
Health	People secure needed health services	The proportion of people who have had a physical examination in the past year	Consumer Survey
Access & Support Delivery	Family members with disabilities get the	The proportion of eligible families who	All Family Surveys

Delivery	services and support they need	report having access to an adequate array of services and supports	
Skill	Are staff knowledgeable, adequately trained and confident in their abilities	Proportion of case managers who feel confident in their abilities	Case Manager Survey

From http://www.bsri.org/docs/NCI_RevisedPhaseV_Indicators.doc 13 October 2004

Potential participants are identified using state developmental disability registers. These registers are considered representative of the population of adults with developmental disabilities. Twenty-four states now participate in the Core Indicator Project and two waves of data collection have recently been completed.

Participating states are requested to:

- Identify a stratified random selection of approximately 400 adults who receive services from state registers of developmental disabilities to participate in a face-to-face consumer survey.
- Identify 1,000 randomly selected families to participate in a mail survey who (1) have an adult family member with developmental disability living in the household and (2) either the individual or the family receive at least one support service.
- Identify 1,000 randomly selected families to participate in a mail survey who (1) have a child family member with developmental disability living in the household and (2) either the individual or family receive at least one support service.
- Service providers in each participating state are invited to submit data at two levels; on behalf of individual service users and on behalf of staff.

Findings from the Core Indicator Project conducted during 2001-2002 from one participating state, North Carolina (Havercamp, 2002,) are available and are based on case manager reports for 514 individuals and consumer interviews with 472 individuals. Where possible, responses are compared with a general population survey "Behavioural Risk Factor Surveillance System" (BRFSS) which comprises an annual random telephone survey of state residents over 18 years (living in households with a telephone). The intention is to produce regular reports enabling the monitoring of health status and use of health services among individuals with developmental disability.

3.3.2. European Community Health Indicators for People with Intellectual Disability

To date, no systematic health monitoring of individuals with intellectual disability occurs across the European Union. Funding from the Health Monitoring Programme within the European Commission has provided a unique opportunity for the present project, POMONA, to examine the first step in this process, the development of a draft set of indicators for people with intellectual disability.

Cognisant of evidence base indicating considerable health disparities and health inequalities between people with intellectual disability and the general population, a systematic health monitoring system of this population across the European Union should provide a benchmark of these disparities and inequalities and provide data to evaluate interventions aimed at reducing this inequity. A key factor in the use of the disparity-inequality model to address need in public health is the choice of appropriate comparator populations. For people with an intellectual disability, the comparator is typically population norms.

However due to an obvious increase in biological predisposition to inequality in health status, within and between comparisons among populations of people with intellectual disability are equally valuable.

3.4 Conclusions

The European Union Health Monitoring System will provide valid and systematic data on the health of Member State citizens. ECHI, the European Community Health Indicators are currently under revision and, when prepared, will pioneer health monitoring throughout the European Union. Only one mention of people with intellectual disability appears in ECHI, those with Down's Syndrome. Those with other forms of intellectual disability are therefore excluded from this endeavour. In addition to this exclusion, people with intellectual disability will be doubly disadvantaged as health matters specific to this population are not present in the ECHI indicators. A specific set of indicators for those with intellectual disability is therefore required to ensure the health of this population is monitored to a standard comparable to the general population. The Core Indicators Project in the United States provides a useful template of how such health monitoring can be achieved however the heterogeneous nature of the European Union and its many health systems require the establishment of a unique set of indicators for this population.

3.5 References

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