Health indicators for people with intellectual disabilities

European Commission
Health & Consumer Protection DG
Dir C - Public Health and Risk Assessment
C2-Health Information

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Pomona-1  2002-2004
Pomona-2  2005-2008

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Public Health in the EU

- Article 152 of the *Amsterdam Treaty* obliges the EU to ensure health protection in implementing all Community policies and activities.

- Community Action (2001-2006)- priorities:
  - Improving health information and knowledge
  - Responding rapidly to health threats
  - Addressing health determinants
Health Indicators

- **Demographic**
  - Population
  - Socio-economic factors

- **Health status**
  - Mortality
  - Morbidity
  - Generic health status
  - Composite health status measures

- **Determinants**
  - Personal and biological factors
  - Health behaviours
  - Living and working conditions

- **Health systems**
  - 1 - Prevention, health protection, promotion
  - 2 - Resources
  - 3 - Utilisation
  - 4 - Expenditures
  - 5 - Quality/performance
Why develop health indicators for persons with intellectual disabilities?

- In the enlarged EU, there are an estimated 5 million persons with intellectual disabilities.  
  - Individuals with significant limitations in intellectual functioning and adaptive behaviour originating before age 18 years.
- There is considerable evidence about health disparities between people with intellectual disabilities and the general population
  - For example - prevalence of mental health difficulties
- Monitoring systems in the Member States do not typically document the health of citizens with intellectual disabilities.
Determinants of health differentials

- Natural, biological variation
- Health-damaging behaviour - chosen
- Transient health advantage
- Health-damaging behaviour - restricted choice
- Exposure to unhealthy conditions
- Inadequate access to health, other services
- Health-related social mobility: original ill health unavoidable, but low income preventable

Whitehead 1990
Risk factors - people with intellectual disability

- **Nutrition**
  - Overweight, obesity, undernutrition, dysphagia, pica

- **Lack of exercise**
  - Individual difficulties, environmental barriers

- **Medication**
  - Polypharmacy, inadequate reviews, side effects

*From: Beange, 2002*
Obesity: a global issue

- One billion adults are overweight, and 300,000,000 clinically obese (WHO, 2002)
- Obesity is common among individuals with ID
  - More common among women with ID - up to 60% of women (Rimmer et al., 1994).
- Special risk for people with Down syndrome
- In a UK study, 13% men and 24% women among n=500 residents were obese
  - (Robertson et al., 2000).
Some of today’s older adults experienced institutional living

Residents in large institutions often had a poor diet, little physical activity, stressful working and living conditions, no family contact, limited access to health care - such as dentistry - and few opportunities to make choices.
Pomona project 2002-2004

- Partners from 13 EU countries worked together to develop an evidence-based set of 18 health indicators.
- Review of literature on evidence relating to healthy persons with intellectual disabilities
- Summary evidence from each Member State about systems in place to monitor the health of the general population and also those with intellectual disabilities
- Consultation with advocates – family members-experts in each Member State
- Collaborative meetings to appraise the initial list of indicators and to agree on the final list
Pomona-1: Final set of 18 indicators

- **Demographic**
  - Prevalence
  - Living arrangements
  - Daily Occupation
  - Income/status
  - Life Expectancy

- **Health Status**
  - Epilepsy
  - Oral health
  - BMI
  - Mental Health
  - Sensory
  - Mobility

- **Determinants**
  - Physical activity
  - Challenging behaviour
  - Psychotropic medication use

- **Health Systems**
  - Hospitalisation, contact with health care professionals
  - Health check
  - Health promotion
  - Specific training for physicians
Pomona-2:
*Using an indicator set*

- The over-arching **aim** of Pomona-2 is to promote the quality of life and health of people in Europe through building health information and knowledge.

**Objectives -**
- to **build** on experience gathered in Pomona-1
- To operationalise indicators and gather **data**
- To build ways to **sustain** the flow of information about the health of people with ID within the European Community and internationally

- Austria
  - Germain Weber, University of Vienna
- Belgium
  - Geert van Hove, University of Gent
- Finland
  - Tuomo Maatta, Kuusanmäki
- France
  - Bernard Azema, CREA, Montpellier
- Germany
  - Meindert Haveman, U of Dortmund
- Ireland
  - PN Walsh, University College Dublin
- Italy
  - Serafino Buono, Troina, Sicily

- Lithuania
  - Arunas Germanavicius, U of Vilnius
- Netherlands
  - HMJ van Schrojenstein Lantman-de Valk, University of Maastricht
- Norway
  - Jan Tossebro, U of Trondheim
- Romania
  - Alexandra Câra, Sc Medfam Apolo
- Slovenia
  - Dasa Moravec, Institute of Public Health
- Spain
  - Luis Salvador, AEECMR, Cádiz
- United Kingdom
  - Mike Kerr, Cardiff University
Workplan

- Our core objective is to operationalise the indicator set and gather data in 14 Member States
- 9 work packages
- 3 meetings of all partners: -
  - Rome - 26-29 May 2005 - San Raffaele Foundation
  - Maastricht - August 2006
- 3 small, regional meetings to build networks with competent authorities, experts and ngos
  - November 2005 - Graz - EUPHA conference
Other presentations:

- October 2005 – MHMR (Mental Health and Mental Retardation) Conference in Barcelona
- June 2006 – Toronto – Conference of the Physical and Mental Health Research Groups of IASSID – *International Association for the Scientific Study of Intellectual Disabilities*
- August 2006 – Maastricht - The 2nd Pomona project partners’ meeting will take place just before the 2nd European Conference of IASSID – *International Association for the Scientific Study of Intellectual Disabilities* – (400+ participants).
Contact

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