

# 4. POMONA - Method

---

Please note: Chapter 4 reports the methods utilized in meeting the aims of the POMONA project. The findings are reported in Chapter 5.

## 4.1. Background

POMONA: Health Indicators for People with Intellectual Disabilities in the Member States, funded under the Health Monitoring Programme of the European Commission, received approval in June 2002 and was officially launched in November 2002.

The project aims were threefold:

- To determine what health indicators, if any, are in place across the Member State related to the health of people with intellectual disability
- To consult on practices, referring to scientific evidence, about optimal indicators for this population
- To propose a set of health indicators for people with intellectual disability across the Member States

The project aims to initiate the development of a set of health indicators for people with intellectual disability that may ultimately be used throughout the Member States. The project draws on two main sources of previous work to integrate evidence about the health of EU residents with intellectual disability and the general population. This strategy supports and contributes to a unified strategy for health promotion and health monitoring. Firstly, as previously reviewed (Section 2), there is a considerable evidence base identifying disparities in health between those with intellectual disability and the general population. Secondly, as previously reviewed, (Section 3), health indicator data will assist in the future planning and evaluation of health services throughout the European Union.

## 4.2. Project Partners

A list of project partners is presented below. The first three partners Professor Patricia Noonan Walsh (Ireland), Dr. Henny van Schrojenstein Lantman –de Valk (Netherlands) and Professor Mike Kerr (United Kingdom) comprise the project Steering Committee.

<b><i>Ireland:</i></b>	Professor Patricia Noonan Walsh, Centre for Disability Studies, University College Dublin Christine Linehan, Centre for Disability Studies, University College Dublin
------------------------	---

<b><i>The Netherlands:</i></b>	Dr. Henny van Schrojenstein Lantman -de Valk, Dept of General Practice, University of Maastricht
<b><i>United Kingdom:</i></b>	Professor Mike Kerr, Welsh Centre for Learning Disabilities, University of Wales, College of Medicine
<b><i>Austria:</i></b>	Dr. Germain Weber, Institute of Psychology, University of Vienna Dr. Cecilia Heiss, Institute of Psychology, University of Vienna
<b><i>Belgium:</i></b>	Prof. Geert van Hove, University of Ghent (previously Dr. Jan Meireleire, Managing Director, Stichting Gouverneur Kinsbergen Gehandicaptenzorg)
<b><i>Denmark:</i></b>	Frank Ulmer Jørgensen, Landsforeningen LEV
<b><i>Finland:</i></b>	Dr. Tuomo Määttä, Service Centre of Kuysanmaki
<b><i>France:</i></b>	Professor Charles Aussilloux, Servide de Médecine Psychologique Enfants Adolescents PEYRE PLANTADE, CHU Montpellier Dr. Bernard Azema CREA Languedoc Roussillon
<b><i>Germany:</i></b>	Professor Meindert Haveman, University of Dortmund
<b><i>Italy:</i></b>	Dott. Serafino Buono, IRCCS OASI MARIA SS
<b><i>Luxembourg:</i></b>	Dr. Raymond Ceccotto, & Marion Kamper Fondation Association des Parents D'enfants Mentalement Handicapés
<b><i>Spain:</i></b>	Dr. Luis Salvador, Professor of Psychiatry & Marco Garrido Cumbreira, Research Fellow, University of Cadiz
<b><i>Sweden:</i></b>	Dr. Monica Björkman, Landstingets Hjärnskadecenter

### 4.3. Methodology utilized for each aim

#### 4.3.1. Aim 1: Determining what health indicators, if any, are in place across the Member States.

A number of sources were examined to determine what health indicators, if any, are in place across the Member States that examine the health of people with intellectual disability:

- Literature pertaining to health indicators specific to people with intellectual disability.
- Health indicators employed for the general population.
- National population statistics regarding intellectual disability.

- Health interview and health examination surveys at Member State level that may contain information regarding the health of people with intellectual disability.
- Data at Member State level regarding POMONA health indicators for people with intellectual disability.

Aim 1 Results are presented in Section 5.1.

### **4.3.2. Aim 2: To consult on practices, referring to scientific evidence, about optimal indicators for this population**

### **& Aim 3: To propose a set of health indicators for people with intellectual disability across the Member States**

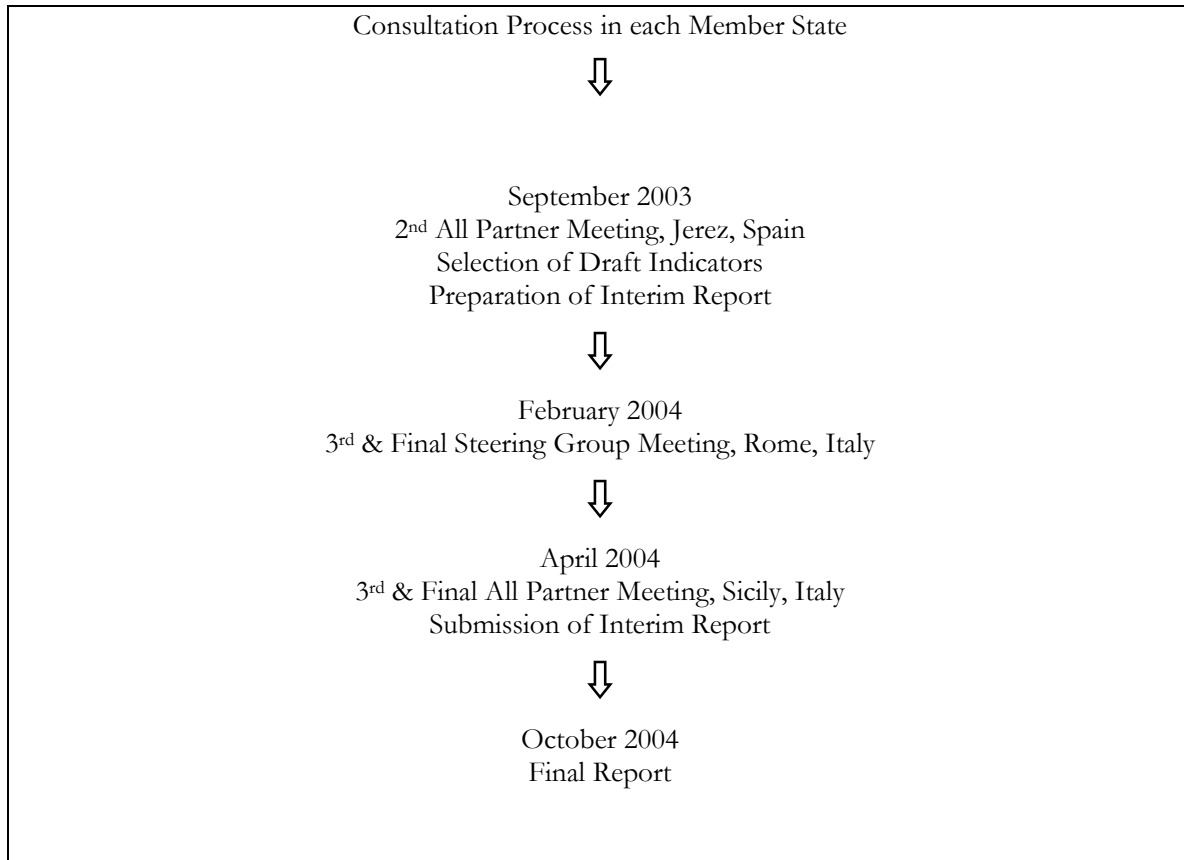
Probably the most unique and interesting methodology utilized in the POMONA project was associated with the latter two aims. A comprehensive, collegial, multi-step process was utilized that actively involved a vast array of stakeholders. As it serves as a model for future collaborative efforts in this area, it is described here in considerable detail. The remainder of this chapter describes this methodology.

Aim 2 Results are presented in Section 5.2.

Aim 3 Results are presented in Section 5.3.

#### **4.3.2.1. Outline of Collaborative Methodology Timeline**





## 4.3.2.2. Collaborative Meetings

### 4.3.2.2.1. 1<sup>ST</sup> STEERING GROUP MEETING, MAASTRICHT, NOVEMBER 2002

The 1<sup>st</sup> Meeting of the Steering Group took place 14<sup>th</sup> –17<sup>th</sup> November, 2002 in Maastricht, Netherlands. Overall aims of the project were clarified with ‘disparity’ being cited as a driving element in the identification of health indicators. The European Community Health Indicators were reviewed as a potential blueprint for the current project. Partners were forwarded a copy of the original ECHI 1 Report in order to familiarise themselves with the concept of health indicators and how such measures are constructed. A schedule of events over the duration of the project and budgeting issues were also discussed. A summary of the minutes of this meeting appears in Appendix A.

The following decisions were agreed by Steering Group Members at the conclusion of the meeting:

- Disparity in health status between people with intellectual disability and the general population is a key factor in the identification of health indicators for people with intellectual disability. Specifically, indicators will be prioritised where there is:
  - Evidence of a difference in health through:
    - Increased mortality
    - Increased morbidity

- Increase in negative determinants of health, such as poverty
- Evidence of a difference in health care through:
  - Access to services
  - Quality of services.
- ❑ The ECHI classification of health indicators will be used as a working framework to identify health indicators for people with intellectual disability. Specifically the classification system of demographics, health status, health determinants and health systems will be retained and used to guide the selection of indicators.
- ❑ An article regarding the aims and objectives to the project was prepared for submission to the *European Journal of Public Health* to raise awareness of health issues among people with intellectual disability among the public health fraternity. This article is now published:

Walsh, P.N., Kerr, M., van Schrojenstein Lantman-de Valk, H., (2003). Health Issues for People with Intellectual Disability: A European Perspective. *European Journal of Public Health*, 13, (3 Supplemental) 47-50.

#### 4.3.2.2.2. 1<sup>ST</sup> ALL PARTNER MEETING, MONTPELLIER, FEBRUARY 2003

The 1<sup>st</sup> all partner meeting took place in Montpellier, France 6<sup>th</sup>-9<sup>th</sup> February, 2003. The meeting commenced with an overview of the aims and objectives of the project. The role of partners throughout the duration of the project was outlined followed by a series of presentations by members of the Steering Group (Professor Mike Kerr and Dr. Henny van Schrojenstein Lantman-de Valk) on the identification of health indicators for people with intellectual disability. Following discussion among partners, the use of the ECHI (European Community Health Indicators) document as a working framework for the POMONA project was discussed. Partners reviewed the classification system of indicators employed by ECHI: (1) demographic and socio-economic indicators (2) health status indicators (3) determinants of health indicators and (4) health system indicators. A summary of the minutes of this meeting is presented in Appendix B.

The following decisions were agreed by all partners at the conclusion of the meeting:

- ❑ Disparity in health status between people with intellectual disability and the general population will be a key factor in the identification of health indicators for people with intellectual disability.
- ❑ Unless otherwise specified, health indicators will relate specifically to the person with intellectual disability – Parental issues, for example, will refer to parents with intellectual disability and not parents whose children have an intellectual disability.
- ❑ The ECHI classification of health indicators will be used as a working framework to identify health indicators for people with intellectual disability.

- ❑ Partners will undertake a consultation process in their Member State to determine the suitability of the ECHI indicators for people with intellectual disability. A wide variety of potential consultants were recommended including people with intellectual disability, carers and family members, direct care staff workers, health professionals working with people with intellectual disability, policy makers and service providers. Consultations may take a variety of formats including face-to-face interviews, focus groups, questionnaires, written submissions and workshops.

#### 4.3.2.2.3. 2<sup>ND</sup> STEERING GROUP MEETING, VILLEPINTE, APRIL 2003

The 2<sup>nd</sup> Steering Group meeting took place 24-27 April 2003 in Villepinte, France. Literature reviews were underway in each of the three Steering Group Member States examining issues of health disparity (Ireland, Netherlands, United Kingdom). A workplan was devised outlining tasks to be undertaken between this meeting and the 2<sup>nd</sup> All Partner Meeting in Jerez. A dissemination strategy was also discussed. A summary of the minutes of this meeting appears in Appendix C.

The following decisions were agreed by all partners at the conclusion of the meeting:

- ❑ Literature reviews on key aspects of health and intellectual disability were commenced with the understanding that they would continue throughout the duration of the project
- ❑ Consultation processes were scheduled to take place during the summer months in Member States.
- ❑ Guideline documents suggesting a methodology for the consultation process were to be sent to all partners for use throughout the summer. These documents appear in Appendix D.
- ❑ Partners were expected to present the findings of their consultations at the 2<sup>nd</sup> All Partner Meeting in Jerez, Spain in September 2003.

#### 4.3.2.3. The Consultation Process, Summer 2003 (Interviews and focus groups with stakeholders conducted in each Member State)

Throughout the summer months of 2003 (and some beyond) partners conducted a wide variety of consultations in their Member States. A list of these consultations is presented below.

##### **AUSTRIA**

Head of Service Agency (N=1): Interview 05.08.03  
 Researcher (N=1): Interview 04.08.03  
 Parent & Parent Representative (N=2): Interview 08.08.03/04.08.03  
 Self advocates (N=3): Interview 11.09.03  
 Self advocates (N=2): Interview 12.09.03  
 Medical doctor (N=1): Interview 17.09.03

##### **BELGIUM**

Vlaamse Liga tegen Epilepsie <http://www.epilepsieliga.be/> (Claudine Van Daele)  
 Dr. E. Schmedding, Dienst Neurologie, AZ-VUB

Prof. JP Fryns, Departement Menselijke Erfelijkheid, UZ-KUL  
Prof. P. De Cock, Centrum Preventieve Gezondheidszorg, UZ-KUL  
Vlaams Instituut voor Gezondheidspromotie [www.vig.be](http://www.vig.be) (Peter Verduykt)  
Vlaams Fonds voor Sociale Integratie van Personen met een Handicap [www.vlafo.be](http://www.vlafo.be) (Ann Van den Abeele)  
Prof. B. Maes, Centrum voor Orthopedagogiek, KUL  
Nationaal Instituut voor Statistiek, [http://www.statbel.fgov.be/home\\_nl.asp](http://www.statbel.fgov.be/home_nl.asp)  
Centrum voor Ontwikkelingsstoornissen, UZ-Ugent (Luc Goossens)  
Kind en Gezin, [www.kindengezin.be](http://www.kindengezin.be)  
Wetenschappelijk Instituut voor Volksgezondheid, <http://www.iph.fgov.be/> (Stefaan Demarest)  
Vlaams Welzijnsverbond, <http://www.vlaamswelzijnsverbond.be/vwv/Website2.nsf> (Diane Serneels)  
Prof. K. Demyttenaere, Afdeling Psychiatrie, UZ-KUL  
E.De Belie, Vakgroep Orthopedagogiek, Ugent  
Oogpunt, 't Kruispunt vzw (Ann Vanhevel)  
Opleidingsaanbod Universiteit Gent,  
<http://aiwww.ugent.be/Studentenadministratie/Studiegids/2004/EN/STUDY/P/P140/INDEX.HTM>  
Prof. L. Martens, Departement tandheelkunde, Ugent  
Ons Erf, Dienstverleningscentrum voor personen met een mentale handicap (Evelyn De Baere, Dr. Vansteenkiste)  
Belgische Overheid, Sociale Zekerheid <http://socialsecurity.fgov.be/>

#### **DENMARK**

People with intellectual disabilities (N=3): Focus Group 29.07.03  
Parents of people with intellectual disabilities (N=3): Focus Group 29.07.03  
Child therapists/Physiotherapists (N=13): Telephone Calls 04.08.03  
Social Pedagogue: Survey 05.08.03  
Representatives from Down Syndrome Association: Survey (N=2)  
Representative from Fragile X Syndrome Association: Survey  
Hospital representatives of people who work with Intellectual disability: Survey  
Psychiatric hospital employees (N=2): Survey  
Representative from Ministry of Health: Survey  
Representative from Ministry of Social Affairs: Survey  
Representative from Local Support Centre: Survey  
Representatives from small, medium & large municipalities (N=3): Survey  
Representative from regional centre for disability: Survey  
Representatives from group homes & children's homes (N=4): Survey  
Representatives from regional hospital (N=2): Survey

#### **FINLAND**

Local expert team (N=6): Meeting 12.06.03  
Leading experts (N=29): Email 01.07.03  
Representatives from national association of Mental Retardation (N=9): Email 03.07.03  
Representatives from 2<sup>nd</sup> national association of Mental Retardation (N=9): Email 03.07.03  
Leaders for Social Services for people with intellectual disability (N=17): Email 01.07.03  
Physicians working with people with intellectual disability (N=16): Email 02.07.03  
Representatives from the Board of Intellectual Disability (N=7): Email 03.07.03  
Representatives from the Board of Intellectual Disability (N=6): Meeting 15.08.03  
Representatives from Municipal Authorities (N=11) Email & Meetings 03.07.03/05.09.03

**FRANCE**

Psychologists working with people with intellectual disability (N=2): Interview September 2003  
Psychologist working with people with intellectual disability (N=1): Interview September 2003  
Carers and social workers in disability (N=22): Focus Group September 2003  
Carers and social workers in disability (N=9): Questionnaire September 2003  
General practitioner in disability (N=1): Interview September 2003  
Nurse working in disability (N=1): Interview September 2003  
Policy Maker (N=1): Call for contribution September 2003  
Anatomopathologist and epidemiologist (N=2): Call for contributions July 2003  
Family member (N=1): Interview  
Odontostomatologist (N=1): Call for contribution June 2003  
Psychiatrist (N=1): Interview and questionnaire September 2003  
Policy Maker and care giver (N=1): Call for contribution June 2003  
General practitioner in disability service (N=1): Interview and questionnaire September 2003  
Occupational therapist in disability service (N=1): Interview and questionnaire September 2003  
Physiotherapists (N=2): Interview and questionnaire September 2003  
Psychomotricity therapist (N=1): Interview and questionnaire September 2003

**GERMANY**

Person with intellectual disability (N=1): Interview 25.06.03  
Person with intellectual disability (N=1): Interview 25.06.03  
Staff member working with people with intellectual disability (N=1): Interview 25.06.03  
Director of residential service for people with intellectual disability (N=1): Interview 25.06.03  
Person with intellectual disability (N=1): Interview 01.07.03  
Person with intellectual disability (N=1): Interview 01.07.03  
Staff member working with people with intellectual disability (N=1): Interview 01.07.03  
Physician working with people with intellectual disability (N=7): Interview 07.07.03

**IRELAND**

Parent & Member of Health Promotion Group for People with Disabilities: Written sub 30.06.03  
Consultant from University Department of Public Health & Epidemiology: Interview 16.10.03  
Advisors to the Department of Health & Children: Interview 02.07.03  
Chief Executive Officer, Service Provider for People with Disabilities: Interview 04.07.03  
Parent & Advisor to University Centre for Disability: Interview 10.07.03  
Consultant Psychiatrist in Intellectual Disability: Interview 11.07.03  
Nurse Specialist in Ageing & Disability: Interview 18.07.03  
Lecturer in Intellectual Disability Nursing Specialty: Interview 22.07.03  
Advocate and Advisor to University Centre for Disability: Interview 01.08.03  
Federation of Voluntary Bodies providing services to people with disabilities: Survey 07.07.03  
Statistical Representatives of Department of Health and Children: Interview 08.08.03  
Representative of National Nursing Organisation: Survey 14.08.03  
Medical advisor to Department of Health and Children: Phone call 14.08.03  
Paediatric Researcher: Phone call 01.09.03  
Representative from National Disease Surveillance Centre: Phone call 01.09.03  
Central Statistics Office: Survey 02.09.03  
Department of Community, Rural & Gaeltacht Affairs: Survey 02.09.03  
Department of Education & Science: Survey 02.09.03  
Department of Enterprise, Trade & Employment: Survey 02.09.03  
Department of Health & Children Survey: 02.09.03  
Department of Justice, Equality & Law Reform: Survey 02.09.03

Department of Social & Family Affairs: Survey 02.09.03  
Revenue Commissioners: Survey 02.09.03  
Individuals with Intellectual Disability (N=8): Interviews 02.09.03 – pending  
Parents of individuals with intellectual disability (N=10): Survey 02.09.03 – pending  
National Association of Intellectual Disability: Written Submission 15.09.03  
Consultant to World Health Organisation: Email 16.09.03  
Dental Health Consultant: Written Submission 17.09.03

### **ITALY**

Doctors (N=5): Interview 10.06.03  
Psychologists (N=3): Interview 10.06.03  
Psychologists (N=2): Interview 11.06.03  
Family members (N=10): Focus Group 20.06.03  
Policy Maker (N=1): Interview 24.06.03  
Teachers (N=18): Focus Group 27.06.03  
Therapists (N=5): Focus Group 08.07.03  
Nurses (N=6): Focus Group 08.07.03  
Lawyers (N=2): Interview 11.07.03  
Administrators (N=4): Interview 12.07.03  
Family Members (N=15): Focus Group 15.07.03  
Educator (N=5): Focus Group 17.07.03  
Administrator (N=2): Interview 17.07.03  
Doctors (N=10): Focus Group 19.07.03  
Social Worker (N=5): Focus Group 21.07.03  
Therapist (N=10): Focus Group 23.07.03  
Nurses (N=10): Focus Group 23.07.03  
Pedagogist (N=3): Interview 23.07.03  
Therapist (N=3): Interview 25.07.03  
Policy Maker (N=1): Telephone interview 28.07.03  
Lawyer (N=2): Interview 28.07.03  
Family Members (N=3): Interview 29.07.03  
Psychologist (N=5): Focus Group 30.07.03  
Family Members (N=9): Interview 31.07.03  
Policy Maker (N=1): Interview 01.08.03  
Insurer (N=1): Telephone interview 02.08.03  
Psychologist (N=5): Interview 01.09.03  
Pedagogist (N=5): Focus Group 05.09.03  
Therapist (N=5): Interview 05.09.03  
Social Worker (N=3): Interview 06.07.03  
Doctors (N=3): Interview 08.09.03  
Policy Makers (N=1): Interview 08.09.03  
Family Members (N=3): Interview 09.09.03  
Educators (N=2): Interview 09.09.03  
Administrator (N=1): Interview 10.09.03  
Lawyer (N=1): Interview 10.09.03  
Psychologist (N=3): Interview 12.09.03  
Psychologist (N=2): Interview 13.09.03  
Researchers (N=5): Focus Group 16.09.03

### **LUXEMBOURG**

Psychologist: Interview & Questionnaire 01.07.03

Pedagogics (N=2): Interview & Questionnaire 01.07.03  
Parents of people with intellectual disability (N=17): Interview & Questionnaire 14.07.03  
Parents of people with intellectual disability (N=5): Interview & Questionnaire 16.07.03  
Educators (N=2): Questionnaire 16.07.03  
Nurses (N=6): Interview & Questionnaire 24.07.03  
Ministry of Family: Questionnaire 24.07.03  
Ministry of Health: Questionnaire 24.07.03  
Medical practitioners (N=19): Questionnaire 24.07.03  
Association members of national organisation (N=44): Questionnaire 11.07.03

#### **NETHERLANDS**

People with Intellectual disability (N=9): Focus Group 13.08.03  
People with intellectual disability (N=4): Interviews  
Academic Economist (N=1): Interview  
Professor of Health Care (N=1): Interview  
Psychologist (N=1): Interview  
Service Provider (N=1): Interview  
Public Health Specialist (N=1): Interview  
Researcher (N=3): Interview  
Professor of Intellectual Disability (N=1): Interview  
Ministry of Health Welfare and Sports (N=4) Interview

#### **SPAIN**

Professor of the University Autonomous of Madrid (N=1): Interview 08.05.03  
Psychologist of the Foundation Valcarcel (N=1): Interview 08.05.03  
Officer of the Catalonia Department of Welfare – ICASS: (N=1): Interview 22.05.03  
Professor of Disabilities Studies at the University of Salamanca (N=1): Phone call & email 23.05.03  
Chief of the Division of People with Disabilities of the Department of Welfare of the Autonomous Community of Andalucía (N=1): Interview 08.06.03  
Officer of the Catalonia Department of Welfare – ICASS: (N=1): Interview 22.05.03  
Officer of the Division of People with Disabilities of the Department of Welfare of the Autonomous Community of Andalucía (N=1): Interview 08.06.03  
Scientific Chief of the National Federation of Associations of People with Intellectual Disabilities in Spain – FEAPS (N=1): Interview 15.06.03  
Officer of the Spanish Disability Observatory of the IMSERSO/Ministry of Labour and Social Welfare of Spain (N=1): Interview: 15.06.03  
General Director Division of People with Disabilities of the Department of Welfare of the Autonomous Community of Andalucía (N=1): Phone call 15.07.03  
President of the Foundation of People with Intellectual Disabilities - PROMI President of CEEMH: (N=1): Phone call and email 07.07.03  
Officer for the Spanish Association for the Scientific Study of the Healthy Ageing AECES (N=1): Interview 07.07.03  
Expert Adviser within the Catalonia Department of Health Service – CatSalut: (N=1) Phone call & email 03.08.03  
Chief of the Department of Welfare of the Jerez City Hall; (N=1): Interview 09.08.03  
Psychologist of the Association of People with Intellectual Disabilities – AFANAS: (N=1) Interview 08.08.03  
Officer of the Catalonia Department of Welfare – ICASS: (N=1): Interview 11.08.03

## **SWEDEN**

Community and Council Administrators (N=141): Questionnaire  
Community and Council Administrators (N=30): In depth questionnaire  
People with intellectual disability (N=15): Questionnaire  
Families with a family member with intellectual disability: (N=30): Questionnaire

## **UNITED KINGDOM**

People with intellectual disability and family members (N=80): Workshop May 2003  
Psychiatrists working with people with intellectual disability (N=10): Workshop 30.09.03  
Senior Officials from the Welsh Assembly Government (N=4): Consultation 06.10.03  
Researchers in the disability field (N=9): Consultation November 2003

### **4.3.2.2. – Collaborative Meetings (continued)**

#### **4.3.2.2.4. 2<sup>ND</sup> ALL PARTNER MEETING, JEREZ, SEPTEMBER 2003**

The 2<sup>nd</sup> all partner meeting took place 24<sup>th</sup>-27<sup>th</sup> September 2003 Jerez, Spain. The meeting commenced with a series of presentation on the consultation process conducted in each Member State during the summer of 2003. Small working groups were then formed to discuss the selection of indicators in each of the four key ECHI domains, (1) Demographic and Socio-economic Indicators (2) Health Status Indicators (3) Determinants of Health and (4) Health Systems. Partners were asked to evaluate each of the ECHI health indicators and those additional indicators identified throughout the consultation process for inclusion in the draft selection of indicators. Indicators were evaluated using the following criteria devised by the Steering Group:

- (1) Is the health indicator important for people with intellectual disability?
- (2) Is there a disparity between the prevalence rates of the health indicator for those with intellectual disability when compared with those of the general population?
- (3) Is the health indicator a useful tool to improve the health status of people with intellectual disability?
- (4) Is there information on the health indicator in (each) participating Member State?

A summary of the minutes of this meeting is presented in Appendix E.

The following decisions were agreed at the conclusion of the meeting:

- A draft set of indicators was identified by partners (See Section 4.3.6)
- The final selection of indicators would be selected by the Steering Group and would be forwarded to partners for consensus.
- The collation of evidence-based literature in support of each candidate indicator was ongoing.
- Partners were requested to submit evidenced based research in support of candidate indicators.

#### 4.3.2.4. Draft List of Indicators, September 2003

Based on the deliberations at the 2<sup>nd</sup> All Partner Meeting in Jerez, the Steering Group recommended the following indicators for inclusion in a set of health indicators for people with intellectual disability. These 30 draft indicators were circulated to and agreed by all partners after the meeting.

---

***DRAFT SET OF INDICATORS – SEPTEMBER 2003***

---

<b><i>Demographics</i></b>	<ul style="list-style-type: none"><li>1.1 Prevalence</li><li>1.2 Household Composition</li><li>1.3 Employment</li><li>1.4 Income/socio-economic status</li><li>1.5 Life Expectancy</li><li>1.6 Location of people</li></ul>
<b><i>Health Status</i></b>	<ul style="list-style-type: none"><li>2.1 Epilepsy</li><li>2.2 Dental Health</li><li>2.3 Weight</li><li>2.4 Mental Health</li><li>2.5 Mortality</li><li>2.6 Challenging Behaviour</li><li>2.7 Sensory</li><li>2.8 Mobility</li><li>2.9 Activities of Daily Living</li></ul>
<b><i>Determinants</i></b>	<ul style="list-style-type: none"><li>3.1 Social Support Networks</li><li>3.2 Exercise</li><li>3.3 Body Mass Index</li><li>3.4 Carer's ability to cope</li><li>3.5 Respite</li><li>3.6 Self Injury</li><li>3.7 Communication of Self Needs</li></ul>
<b><i>Health Systems</i></b>	<ul style="list-style-type: none"><li>4.1 Information for staff &amp; family</li><li>4.2 Medication</li><li>4.3 Hospitalisation</li><li>4.4 Regular check ups/screening/gp visits</li><li>4.5 Postgraduate training for staff working with people with intellectual disability</li><li>4.6 Manpower</li><li>4.7 Health Promotion</li><li>4.8 Vaccination</li></ul>

---

#### **4.3.2.5. Draft Review of Literature on Indicators**

A review of literature on each of the indicators was commenced to determine whether an evidence base existed to support the inclusion of each indicator. The electronic review was conducted using PubMed, a service of the National Library of Medicine. The service provides access to over 14 million citations for evidence-based biomedical articles dating from the 1950s. These citations are from MEDLINE and additional life science journals. PubMed includes links to many sites providing full text articles and other related resources. PubMed can be accessed via <http://www.ncbi.nlm.nih.gov/PubMed/>

Global electronic searches on each of the draft indicators were undertaken using key terms. Abstracts from these searches were then evaluated for relevance. The following criteria were used to determine the relevance of articles in support of health indicators:

- Articles must have a full abstract citation. Where possible, full articles were accessed.
- Articles must be specific to populations with intellectual disability.
- Articles presenting prevalence estimates were of particular interest.
- Articles highlighting the importance of an indicator for people with intellectual disability were of particular interest.
- Articles identifying a possible operationalisation or measurement tool for indicators were of particular interest.
- Articles examining the efficacy of specific drug trials/interventions were excluded.
- Articles relating to specific case studies were excluded.
- Articles relating to children (except prevalence studies) were excluded.

In addition to this electronic searching, partners were requested to submit material on behalf of their own Member State. This material could include evidence-based research, policy papers, unpublished data, etc. Given the volume of literature being identified in searches, literature reviews commenced, but were later discontinued, on indicators that were later omitted from the draft list. This material is, however, retained by the Steering Group.

#### **4.3.2.6. Draft List of Indicators, February 2004**

As agreed at the 2<sup>nd</sup> All Partner Meeting in Jerez, the Steering Group retained the final decision on the inclusion or exclusion of potential indicators. During the period between the meeting in Jerez (September 2003) and the final Steering Group meeting in Rome (February 2004) a total of three indicators were removed from the draft list:

(1) Household Composition (1.2) and Location of People (1.6) were considered by the Steering Group to overlap and were therefore collapsed into one indicator entitled 'Living Arrangements'

(2) Mortality (2.5) was considered to overlap with Life Expectancy (1.5) and was therefore omitted.

(3) Body Mass Index (3.3) was considered to overlap with Weight (2.3) and was consequentially omitted.

A total of 27 indicators remained:

---

***DRAFT SET OF INDICATORS – FEBRUARY 2004***

---

<b><i>Demographics</i></b>	1.1 Prevalence 1.2 Living Arrangements 1.3 Employment 1.4 Income/socio-economic status 1.5 Life Expectancy
<b><i>Health Status</i></b>	2.1 Epilepsy 2.2 Dental Health 2.3 Body Mass Index 2.4 Mental Health 2.5 Challenging Behaviour 2.6 Sensory 2.7 Mobility 2.8 Activities of Daily Living
<b><i>Determinants</i></b>	3.1 Social Support 3.2 Physical Activity 3.3 Carer's ability to cope 3.4 Respite 3.5 Self Injury 3.6 Communication of Self Needs
<b><i>Health Systems</i></b>	4.1 Information for staff & family 4.2 Medication 4.3 Hospitalisation 4.4 Medical Check Up 4.5 Postgraduate training for staff working with people with intellectual disability 4.6 Manpower 4.7 Health Promotion 4.8 Vaccination

---

#### **4.3.2.2. – Collaborative Meetings (continued)**

##### **4.3.2.2.5. 3RD STEERING GROUP MEETING, ROME, 5-8 FEBRUARY 2004**

The 3<sup>rd</sup> Steering Group Meeting took place 5<sup>th</sup> – 8<sup>th</sup> February 2004 in Rome, Italy. Key topics discussed at this meeting included:

- The submission of a Draft Interim Report in February 2004

- The replacement of the Belgium Partner, Dr. Jan Meireleire, Managing Director, Stichting Gouverneur Kinsbergen Gehandicaptenzorg who resigned from his post in August 2003. Following consultation with the Directorate C Public Health Administration, Professor Geert Van Hove, Department of Orthopedagogy, University of Ghent was invited, and agreed, to represent Belgium.

A summary of the minutes of this meeting is presented in Appendix F.

The following decisions were agreed at the conclusion of the meeting:

- ❑ Operationalising the indicators should now commence and the review of literature should continue, while cognisant of the reduction in indicators.
- ❑ The evidence base in support of each indicator should reflect the criteria previously outlined by the Steering Group (Section 4.3.5)
  - (1) Is the health indicator important for people with intellectual disability?
  - (2) Is there a disparity between the prevalence rates of the health indicator for those with intellectual disability when compared with those of the general population?
  - (3) Is the health indicator a useful tool to improve the health status of people with intellectual disability?
  - (4) Is there information on the health indicator in each participating Member State?
- ❑ The choice of indicators should reflect the rationale of the project; the ECHI indicators may not have the same relevance for those with intellectual disability they have for the general population. In some cases, indicators cross both populations, such as 'Body Mass Index'. Other indicators, such as 'Challenging Behaviour' are specific to people with intellectual disability and are identified as indicators because of the scientific or clinical evidence of disparity.
- ❑ A proposed conference scheduled for December 2003 was cancelled in favour of two presentations by Steering Group members at conferences. In November 2003, Dr. Henny van Schroyen Lantman de Valk spoke at the MAMH Conference: Manifesto on Health for People with Intellectual Disability while Professor Mike Kerr spoke at the 11<sup>th</sup> Annual EUPHA Conference 2003. In addition, submissions were made to the International Association for the Scientific Study of Intellectual Disability (IASSID) for a number of presentations regarding the development of health indicators at the 12<sup>th</sup> World Congress of IASSID (International Association for the Scientific Study of Intellectual Disability) in Montpellier in June 2004. The Steering Group supported the promotion of the project at these venues in preference to the proposed conference scheduled for December 2003.
- ❑ A commitment was made to publish four academic papers in key peer-reviewed journals outlining the work of the project. Suggested publications include:
  - Process & Methodology of developing health indicators for people with intellectual disability; Suggested publication: Journal of Intellectual Disability Research.
  - Health indicators for people with intellectual disability; Suggested publication: Journal of Intellectual Disability Research.

- Integration of health issues for people with intellectual disability among the mainstream public health arena: Suggested publication: The Journal of Policy and Practice in Intellectual Disabilities.
- Review of health disparities aimed at the European Public Health audience: Suggested publication: European Journal of Public Health.

#### **4.3.2.2.6. 3<sup>RD</sup> ALL PARTNER MEETING, TROINA, SICILY, 15<sup>TH</sup>–18<sup>TH</sup> FEBRUARY 2004**

The 3<sup>rd</sup> All Partner Meeting took place 15<sup>th</sup> – 28<sup>th</sup> February 2004 in Troina, Sicily. Partners were sent three documents prepared by Christine Linehan (Senior Researcher with University College Dublin; Irish POMONA grant team) prior to this meeting for review. These documents comprised:

- Report of partners' submission regarding the available evidence-base for each indicator in their Member States
- Report presenting possible operationalising of each of the proposed indicators
- Report outlining peer-reviewed literature gathered on each of the proposed indicators.

The main activities of the meeting included:

- ❑ Dr. Henny van Schrojenstein Lantman de Valk reviewed the purpose of health indicators and their selection.
- ❑ Christine Linehan outlined the methods used to operationalise health indicators to ensure comparability and validity using examples from Health Interview Surveys and Health Examination Surveys conducted throughout the European Union.
- ❑ Partners were then assigned to one of three small groups to discuss a selection of indicators. Partners were asked to determine whether the indicator should be retained (mindful of the (1) important (2) disparity (3) useful (4) data criteria used previously) and if so, to determine the feasibility of the proposed operationalisation.
- ❑ Professor Patricia Noonan Walsh concluded by addressing each of the outstanding issues of debate raised during the proceedings.
- ❑ Partners agreed that a reduction of indicators from the current proposed set of 27 to a more manageable 10-20 would be appropriate given the pioneering nature of this work. Partners agreed that, armed with their deliberations throughout this meeting, the Steering Group would decide the final set of indicators using the evidence base to guide their judgement. Partners were free to suggest additional indicators but were asked to providing documenting to support their choice.

A summary of the minutes of this meeting is presented in Appendix G.

### 4.3.2.7. Final List of Indicators, September 2004

As agreed at the 3<sup>rd</sup> All Partner Meeting in Troina, the Steering Group retained the final decision on the inclusion or exclusion of potential indicators. Cognisant of the call for a reduction in the quantity of indicators, the Steering Group revisited the indicators and reduced the draft set from the 27 indicators proposed in February 2004 to a final set of 18 indicators agreed by September 2004. The changes, which are listed below, were guided by a) the quality and quantity of supportive literature, b) the capacity to operationalize the indicator, and c) the clarity of each indicator for the intended purpose in the context of persons with intellectual disabilities.

(1) Employment (1.3) was renamed 'Daily Occupation' to reflect the inclusion of those people with intellectual disability who were not engaged in typical forms of employment throughout their day. The change of name may be considered 'aspirational' in nature as firstly, the evidence base outlining daily activity beyond employment is extremely limited at present. Secondly, the operationalisation of a measure of 'daily activity' across Member States will require a common framework of daily activities to ensure comparability of data. This common framework does not currently exist and would require further exploration.

(2) Dental Health (2.2) was renamed 'Oral Health' to permit the broadening of this category beyond dental issues (concerned with teeth) to oral health issues (concerning the teeth and mouth).

(3) Challenging Behaviour (2.5) and Self Injury (3.5) were collapsed into one indicator 'Challenging Behaviour' on the basis that Self Injury is a form of Challenging Behaviour. This indicator was then moved from 'Health Status' to a 'Determinant of Health' as this was considered a more appropriate reflection of the impact of this indicator on the health of people with intellectual disability.

(4) Activities of Daily Living (2.8) was removed as an indicator. Its possible inclusion under the indicator 'Prevalence' 1.1 is addressed in detail in the Section of this report outlining the operationalisation of these indicators.

(5) A number of indicators were removed from the category 'Determinants of Health'. These include (3.1) Social Support, (3.3) Carer's ability to cope, (3.4) Respite and (3.6) Communication of Self Need. All of these indicators were excluded on similar grounds, that while each indicator highlighted an important issue for people with intellectual disabilities, difficulties of operationalisation could not be overcome during the timespan of the project. The inclusion of these indicators in due course, pending a valid operationalisation, is possible.

(6) Medication (4.2) was renamed 'Psychotropic Medication Use' to reflect the boundaries of this indicator and was moved from 'Health Systems' to 'Determinants of Health'

(7) Two indicators were excluded from Health Systems: (4.1) Information for staff & family, (4.6) Manpower on the basis of difficulties in operationalisation. The inclusion of these indicators in due course, pending a valid operationalisation, is possible.

(8) A further indicator in Health Systems (4.8) Vaccination was subsumed under the category (4.7) Health Promotion due to a dearth of literature on this topic.

(9) Three indicators (4.3) Hospitalisation; (4.4) Medical Check Up and (4.5) Post graduate training for staff Working with People with Intellectual Disability were renamed to better reflect their content. The new titles were (4.1) Hospitalisation and Contact with Health Care Professionals, (4.2) Health Check and (4.4) Specific training for Physicians.

The final set of 18 indicators are presented below:

---

**FINAL SET OF INDICATORS – SEPTEMBER 2004**

---

<b><i>Demographics</i></b>	1.1 Prevalence 1.2 Living Arrangements 1.3 Daily Occupation 1.4 Income/socio-economic status 1.5 Life Expectancy
<b><i>Health Status</i></b>	2.1 Epilepsy 2.2 Oral Health 2.3 Body Mass Index 2.4 Mental Health 2.5 Sensory 2.6 Mobility
<b><i>Determinants</i></b>	3.1 Physical Activity 3.2 Challenging Behaviour 3.3 Psychotropic Medication Use
<b><i>Health Systems</i></b>	4.1 Hospitalisation & Contact with Health Care Professionals 4.2 Health Check 4.3 Health Promotion 4.4 Specific training for Physicians

---

#### **4.4. Dissemination Strategy**

Given the scope of the current project across thirteen European Member States and the over-arching aim of the project (i.e to identify an agreed set of health indicators), considerable effort was undertaken to disseminate the progress of the project throughout its lifespan. From its inception, a fourfold dissemination strategy was envisaged:

(1) Project partners were invited to participate in this project specifically on the basis of their expertise and networks in the field of intellectual disability. Project partners have provided information on the project to a variety of informants including the IDRESNET (The European Intellectual Disability Research Network), ARFIE (L'Association de Recherche et de Formation sur L'insetion en Europe) and the National Council for the Professional Development of Nursing and Midwifery (Ireland).

(2) Partners have conducted an extensive consultation process in each Member State as outlined in Section 4.3.4. These consultations were conducted with a wide variety of informants including people with intellectual disability, advocates, family members, carers, health care workers, service providers and policy makers. The consultation process has generated wide interest in the project among consultants in all Member States.

(3) A series of international presentations has brought this topic to a wide audience of academics, practitioners and people with intellectual disability. A list of these presentations is presented below.

<b>Organisation</b>	<b>Venue</b>	<b>Date</b>
NAMHI (National Association for Mental Handicap, Ireland)	Ireland	May 2003
ERHA Conference on Nursing & Midwifery,	Ireland	May 2003
13 <sup>th</sup> Annual Roundtable of IASSID Ageing Special Interest Group	Greece	May 2003
Special Olympics World Games Scientific Symposium	Belfast	June 2003
National Conference on Good Practice in the Care of People with Intellectual Disabilities	Ede, NL	June 2003
Keynote address on 28 June to a National Conference on the Physical, Mental & Social Health of People with Developmental Disabilities – hosted by the University of Sydney (Centre for Developmental Disability Studies)	Australia	June 2003
and  Workshop on Health Indicators presented to a group of Health professionals at the University of Sydney – Centre for Developmental Disability Studies – on 1 <sup>st</sup> July		
Annual Meeting of IASSID Health Issues Special Interest Research Group	New York, USA	August 2003
7 <sup>th</sup> International Seminar: Health indicators for People with Intellectual Disability: Asociation Espanola para el Estudio Cientifico del Retraso Mental	Spain	September 2003
MAMH Conference: Manifiesto on Health for People with Intellectual Disability	Rotterdam	November 2003
11 <sup>th</sup> Annual EUPHA Conference 2003,	Rome	November 2003
12 <sup>th</sup> World Congress IASSID	Montpellier	June 2004
Symposium 1: Health Indicators: A European Perspective: Moderator Professor Patricia Noonan Walsh		
(1) Professor Mike Kerr: Health Disparities; (2) Dr. Henny van Schrojenstein Lantman-de Valk: Selection of Health Indicators relevant for persons with intellectual disability (3) Professor Patricia Noonan Walsh & Christine Linehan; What is a healthy life? Views of Advocates and Professionals.		

---

Symposium 2: Health Systems and People with Intellectual Disabilities:  
A European Perspective. Moderator: Christine Linehan

(1) Christine Linehan, Patricia Noonan Walsh, Germain Weber, Cecilia Heiss, Henny van Schrojenstein Lantman-de Valk & Mike Kerr; Perspectives from Austria, the Netherlands, Ireland & the United Kingdom. (2) Tuomo Määttä, Frank Ulmer Jørgensen, Monica Björkman, & Meindert Haveman: Perspectives from Denmark, Finland, Sweden & Germany. (3) Bernard Azema, Serafino Buono, Raymond Ceccotto, Marco Garrido Cumbreira, Marion Kamper & Luis Salvador-Carulla: Perspectives from France, Italy, Luxembourg and Spain.

---

The publication of an article specifically relating to the project, and published in the European Journal of Public Health (as presented in Section 4.3.1), has served to create awareness of the needs of people with intellectual disability within the wider field of public health.

An additional presentation of the project will be made at a one-day seminar “Healthy, Wealthy & Wise” hosted by the Centre for Disability Studies, University College Dublin on Wednesday December 1<sup>st</sup> 2004.

(4) The Final Report of the projects findings, containing an agreed set of health indicators, is presented to those individuals and organisations that participated in the consultation process. To reiterate, these consultants included people with intellectual disability, advocates, family and carers, health professionals, service providers and policy makers.

## 4.5. Conclusion

National consultations were undertaken in the 13 participating Member States to identify and agree to a set of health indicators for people with intellectual disability. Two key principles concerning the identification of these indicators were agreed by project partners and guided the work of the project. The first underlying principle was that disparity is a key criterion for the identification of health indicators for this population. The second was that the ECHI framework could be used as a starting point from which indicators specific to people with intellectual disability could be identified. Using these guidelines a comprehensive draft list of 30 indicators was identified and investigated. The list was gradually reduced over the time period of the project to a final set of eighteen indicators. These indicators are presented in detail in Chapter 5.