

# 7. Appendices

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The following appendices are presented in this Chapter:

- 7.1 Appendix A – Summary Minutes Steering Group Meeting 1, Maastricht
- 7.2 Appendix B – Summary Minutes All Partner Meeting 1, Montpellier
- 7.3 Appendix C – Summary Minutes Steering Group Meeting 2, Villepinte
- 7.4 Appendix D – Guidelines for Partners’ National Consultation
- 7.5 Appendix E– Summary Minutes All Partner Meeting 2, Jerez
- 7.6 Appendix F – Summary Minutes Steering Group Meeting 3, Rome
- 7.7 Appendix G – Summary Minutes All Partner Meeting 3, Troina
- 7.8 Appendix H – Survey of HES & HIS surveys in participating European Member States
- 7.9 Appendix I – Survey of recent Member State data
- 7.10 Appendix J – Sample of Health Checks for People with Intellectual Disability.

## 7.1 Appendix A – Summary Minutes Steering Group Meeting 1, Maastricht

The first meeting of the Steering Group comprising Professor Patricia Noonan Walsh, Professor Mike Kerr and Dr. Henny van Schrojenstein Lantman de Valk occurred on 14-17 November 2002 in the University of Maastricht. All members of the Steering Group were present.

The following activities were undertaken:

- Review of aims of the project: Discussion of key themes – paradigm, disparity & choice
- Review of ECHI report as suitable template to generate indicators – discussion regarding the possible inclusion of intellectual disability specific indicators to this set and the omission of generic indicators that would not reveal a disparity between the general population and those with intellectual disability.
- Guidelines to encourage maximum participation of Member States – proposed consultation at national level in each Member State; dissemination of material via website [www.pomonaproject.org](http://www.pomonaproject.org)
- Suggestion to prepare and submit publication to the European Journal of Public Health to disseminate information of the health needs of people with intellectual disability among the wider public health fraternity
- Time plan over the duration of the project: outline of project meetings and deliverables
- Agreement to disseminate ECHI report to project partners at the commencement of the project to facilitate discussion of the report at partner meetings
- Clarification of our population – those with intellectual disability as a primary condition.
- Budget issues.

## 7.2 Appendix B – Summary Minutes All Partner Meeting 1, Montpellier

The first All Partner meeting took place in Montpellier, France between 6-9<sup>th</sup> February 2003.

Attendants:

Ireland: Professor Patricia Noonan Walsh & Christine Linehan  
Netherlands: Dr. Henny van Schrojenstein Lantman de Valk  
United Kingdom: Professor Mike Kerr  
Austria: Dr. Cecilia Heiss  
Belgium: Dr. Jan Meireleire  
Denmark: Frank Ulmer Jorgensen  
Finland: Dr. Tuomo Määttä  
France: Professor Charles Aussilloux & Dr. Bernard Azema  
Germany: Professor Meindert Haveman  
Italy: Dott. Serafino Buono & Eleonora Di Fatta (translator)  
Luxembourg: Dr. Raymond Ceccotto, & Marion Kamper  
Spain: Marco Garrido Cumbreira  
Sweden: Dr. Monica Björkman

The following activities were undertaken:

- Introduction and review of project
- Presentations by Dr. van Schrojenstein Lantman de Valk on the European Community Health Indicators project and by Professor Kerr on the challenges of gathering data on this population.
- A short presentation by each partner outlining the health services available to people with intellectual disability resident in their Member State.
- The primary topic of discussion was the appropriateness of the ECHI indicator set as a working framework for the present project. Using a template from the ECHI model, a primary examination was undertaken of each indicator using the following criteria.
  - (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?
- Partners were requested to commence the consultation process in their own Member State using a blueprint based on the deliberations at this meeting. The blueprint would be forwarded to partners along with the minutes of the meeting.

## 7.3 Appendix C – Summary Minutes Steering Group Meeting 2, Villepinte

The second meeting of the Steering Group comprising Professor Patricia Noonan Walsh, Professor Mike Kerr and Dr. Henny van Schrojenstein Lantman de Valk occurred on 24-27 April 2003 in Villepinte, France. All members of the Steering Group were present.

The following activities were undertaken:

- Review of minutes of 1<sup>st</sup> Steering Group meeting at Maastricht
- Update on progress at Steering Group level: activities include the commencement of consultations in Maastricht and attendance by project partner at a colloquium, presentations and consultations with service providers and parents in Ireland and the commencement of literature reviews in the United Kingdom.
- Contact with project partners indicated that the consultation process had commenced in some Member States
- Budget issues
- Organisation of 2<sup>nd</sup> All Partner meeting.
- Discussion regarding the possibility of involving EUPHA in the project and presenting at their conference in November 2003
- Workplan May – September 2003
- Dissemination activities at international conferences
- Discussion regarding use of the World Health Organisation's ICF in future projects related to this area.

## 7.4 Appendix D – Guidelines for Partners’ National Consultation

### POMONA

**Questions for Consultation Process (devised by Professor Mike Kerr)**  
*(Consultants will require information on indicators prior to answering these questions)*

#### 1. Questions for colleagues and policy makers:

- 1.1. Can you identify any other areas that would be appropriate as indicators?
- 1.2. How could we change the indicators already identified?
- 1.3. Can we measure these indicators?
- 1.4. How accessible is health care for people with ID?

#### 2. Questions for clients with ID and family members:

- 2.1. Are these indicators acceptable to people with ID and their family members?
- 2.2. What is your greatest worry in health?
- 2.3. How can *good* health limit your well being and affect your care needs?
- 2.4. How can *bad* health limit your well being and effect your care needs?
- 2.5. What advice would you give other people with ID to help them with their health?
- 2.6. Do you feel that you get the care that you need/wish?

### POMONA

#### Information on Indicators

#### What is POMONA?

POMONA is a European Commission funded project that aims to identify health indicators for people with intellectual disability. It is hoped that these health indicators will direct the future systematic collection of health data across all Member States in the European Community. This type of health data will facilitate the planning, monitoring and evaluation of health programmes throughout the Community. The project is being co-ordinated by Professor Patricia Noonan Walsh, University College Dublin, Professor Mike Kerr, University of Wales College of Medicine and Dr. Henny van Schroyen Lantman-de Valk, University of Maastricht, and has representatives from thirteen Member States as project partners.

Why do we need to identify Health Indicators for People with Intellectual Disability?

A set of health indicators has been identified for the general population through the work of the ECHI team (European Community Health Indicators). The ECHI Report, published in 2001 under the auspices of the European Community, classified health indicators under four key categories:

- (i) Demography and Socio-economic factors (*e.g. including health indicators such as the proportion of the population aged over 65 years*),
- (ii) Health Status (*e.g. including health indicators such as life expectancy*),
- (iii) Determinants of Health (*e.g. including health indicators such as tobacco smoking prevalence*), and

(iv) Health Systems (e.g. including health indicators such as the number of acute hospital beds).

While this broad framework can be used by the POMONA project to classify health indicators for people with intellectual disability, the ECHI indicators themselves may not be appropriate for people with intellectual disability. There is now a considerable body of evidence indicating disparities in health status and use of health services between people with intellectual disability and their non-disabled peers. In comparison with the general population for example, individuals with intellectual disability are less likely to receive vaccinations (Schor et al., 1981<sup>1</sup>), have an increased probability of being obese (Bell and Bhate, 1992<sup>2</sup>), and are significantly more likely to have a congenital heart defect (Martin, 1997<sup>3</sup>). In addition, despite the fact that individuals with intellectual disability have an increased prevalence of certain health conditions (e.g. thyroid disease or diabetes) these conditions are poorly addressed by primary care providers (Jones and Kerr 1997<sup>4</sup>). The evidence would therefore suggest that the health indicators identified by ECHI on behalf of the general population may not always be appropriate health indicators for people with intellectual disability.

- The Consultation Process -

Throughout the project, a consultation process will be conducted in each Member State with a variety of interested parties such as individuals who have intellectual disabilities, family members, advocates, health professionals and policy makers.

The primary aim of this consultation process is to generate possible health indicators for people with intellectual disability and to provide, where possible, suggestions to the valid measurement of these indicators in each Member State.

Those invited to participate in the consultation process are being asked to review a preliminary set of health indicators devised by the POMONA project partners. A list of the main classification of indicators, with examples, is presented below.

As a participant in the consultative process we would like you to assist us in generating a set of indicators for people with intellectual disability by reviewing the attached list and sharing your opinion on the following issues:

*Can you identify any other areas that would be appropriate as indicators?*

*How could we change the indicators already identified?*

*Can we measure these indicators?*

*How accessible is health care for people with intellectual disability?*

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<sup>1</sup>Schor E. L., Smalky, K. A., and Neff, J. M., (1981). Primary care of previously institutionalised retarded children. *Paediatrics*, 67; 536-540.

<sup>2</sup> Bell, A. J., & Bhate, M. S., (1992). Prevalence of overweight and obesity in Down's Syndrome and other mentally handicapped adults living in the community.

*Journal of Intellectual Disability Research*, 36, 359-364

<sup>3</sup> Martin, B. A., Primary Care of Adults with Mental Retardation living in the Community. *Am Fam Phys*. 56: 485-494

<sup>4</sup> Jones, R. G., & Kerr, M. P., (1997). A randomized control trial of an opportunistic health screening tool in primary care for people with intellectual disability.

*Journal of Intellectual Disability Research*. 41; 409-415

## Health Indicators Identified by ECHI:

### Class 1. Demographic and socio-economic factors

– these indicators provide a general picture of the situation in a country or region and provide a denominator (population data) for many other indicators.

#### 1.1 Population

(e.g. the total population in a country, the total number of deaths in a country; the population over 65 years in a country)

#### 1.2 Socio-economic factors

(e.g. percentage of population by occupational class in a country; percentage of population not in the labour force in a country)

### Class 2. Health Status

- these indicators provide information on the actual health situation of the population in each country

#### 2.1 Mortality

(e.g. Infant mortality – number of deaths of those aged <1 year; number of deaths due to causes such as diabetes, disease of the circulatory system, suicide, accidents, etc.)

#### 2.2 Morbidity, disease specific

(e.g. Incidence/prevalence of diseases such as dementia/alzheimer's, congenital abnormalities, road traffic injuries, etc.)

#### 2.3 Generic health status

(e.g. perceived health as defined by % responding 'good, fair, etc.,' on WHO recommended instrument; % able to complete basic activities of daily living such as feeding, bathing, etc.)

#### 2.4 Composite health status measures

(e.g. Disability free life expectancy)

### Class 3. Determinants of health

- these indicators comprise all factors determining health outside the health care system

#### 3.1 Personal and biological factors

(e.g. % of population in each Body Mass Index classification; average blood pressure of population)

#### 3.2 Health behaviours

(e.g. % of regular smokers in the population; % of population who drink alcohol, average daily consumption of bread and cereals).

#### 3.3 Living and working conditions

(e.g. air pollutant levels; average number of rooms in households; exposure to chemicals in work environment; incidents of work related accidents)

### Class 4. Health Systems

- these indicators comprise activities in disease prevention, health promotion as well as health care utilization and resources

#### 4.1 Prevention, health protection and health promotion

(e.g. % of children immunised against diphtheria; % of mothers receiving neonatal screening)

#### 4.2 Health care resources

(e.g. number of acute care hospital beds per 100,000 population; number of physicians employed per 100,000 population).

#### 4.3 Health care utilisation

(e.g. number of hip replacements per 100,000 population; number of Caesarean sections per 100,000 population; use of analgesics, benzodiazepines, etc.)

#### 4.4 Health expenditures and financing

(e.g. total expenditure on health; % of total expenditure on in-patient care)

#### 4.5 Health care quality/performance

(e.g. average waiting time for specific services)



## 7.5 Appendix E – Summary Minutes All Partner Meeting 2, Jerez

The second All Partner meeting took place in Jerez, Spain between 25<sup>th</sup>-28<sup>th</sup> September 2003.

Attendants:

Ireland: Professor Patricia Noonan Walsh & Christine Linehan

Netherlands: Dr. Henny van Schrojenstein Lantman de Valk

United Kingdom: Professor Mike Kerr

Austria: Dr. Cecilia Heiss

Denmark: Frank Ulmer Jorgensen

Finland: Dr. Tuomo Määttä

France: Dr. Bernard Azema

Germany: Professor Meindert Haveman

Italy: Dott. Serafino Buono & Eleonora Di Fatta (translator)

Luxembourg: Marion Kamper

Spain: Professor Luis Salvador & Marco Garrido Cumbreira

Sweden: Dr. Monica Björkman

Note: The project representative from Belgium, Dr. Jan Meireleire, had resigned from his position of employment at this time and efforts were underway to secure a replacement. Subsequently Professor Geert van Hove was appointed as the Belgium representative.

The following activities were undertaken:

- Presentation by each partner of the findings from their national consultation process using the ECHI framework: Demography, Health Status, Determinants of Health & Health Systems.
- Small working groups were established to discuss the feedback from Member States across each of the classifications used in ECHI. A large group discussion then followed where unresolved issues were outlined.
- A workplan was devised for partners between this meeting and the final All Partner meeting in April 2004-10-28

## **7.6 Appendix F – Summary Minutes Steering Group Meeting 3, Rome**

The third meeting of the Steering Group comprising Professor Patricia Noonan Walsh, Professor Mike Kerr and Dr. Henny van Schrojenstein Lantman de Valk occurred on 5-9 February 2004 in Rome, Italy. All members of the Steering Group were present.

The following activities were undertaken:

- Discussion regarding the recent submission of the project's Interim Report
- Discussion regarding preparation of a draft Final Report
- Budget
- Commitment to publish findings of project in peer reviewed articles for dissemination among both the intellectual disability field and the public health field.
- Discussion regarding the presentation of the project's progress at the 12<sup>th</sup> World Congress of IASSID, the International Association for the Scientific Study of Intellectual Disability.
- Preparation for the 3<sup>rd</sup> and final All Partner meeting in Troina, Sicily, April 2004
- Workplan
- Possible attendance of project partner at ECHI meeting in Luxembourg 19-20 February

## 7.7 Appendix G – Summary Minutes All Partner Meeting 3, Troina

The third and final All Partner meeting took place in Troina, Italy between 15<sup>th</sup>-18<sup>th</sup> April 2004.

Attendants:

Ireland: Professor Patricia Noonan Walsh & Christine Linehan  
Netherlands: Dr. Henny van Schrojenstein Lantman de Valk  
Austria: Dr. Cecilia Heiss  
Belgium: Professor Geert van Hove  
Denmark: Frank Ulmer Jorgensen  
Finland: Dr. Marja-Leena Hassinen (representing Dr. Tuomo Määttä)  
France: Dr. Bernard Azema  
Germany: Professor Meindert Haveman  
Italy: Dott. Serafino Buono & Eleonora Di Fatta (translator)  
Spain: Professor Marco Garrido Cumbreira  
Sweden: Dr. Monica Björkman

Apologies:

Luxembourg: Marion Kamper  
United Kingdom: Professor Mike Kerr

The following activities were undertaken:

- Presentation by Dr. Henny van Schrojenstein Lantman de Valk on a review of health indicators and their selection
- Presentation by Christine Linehan regarding the Operationalisation of Health Indicators as per Health Examination/Health Interview surveys in Europe.
- Dissemination of draft documents prepared by Christine Linehan:
  - Suggested operationalisation of draft set of indicators
  - Summary Data on Pomona Indicators as submitted by partners
  - Supporting literature review to accompany draft set of indicators
- Small working groups were established to discuss the operationalisation of indicators

## 7.8 Appendix H – Survey of HES & HIS surveys in participating European Member States

In order to determine the current availability of health indicator data related to the health of people with intellectual disability across participating Member States of the European Union, an extensive review of all national Health Interview Surveys (HIS) and Health Examination Surveys (HES) in participating Member States was conducted.

The most comprehensive inventory of health surveys in Europe is the European Health Interview & Health Examination Surveys Database and is available via the Internet at <https://www.iph.fgov.be/hishes/>. The database is the outcome of a European Union Health Monitoring Programme project conducted in 2000. The project, 'Health surveys in the European Union: European Health Interview & Health Examination Surveys (HIS and HIS/HES) evaluations and models (Phase 1 and Phase 2)' can be accessed at <http://europa.eu.int/comm/health/>.

The European Health Interview & Health Examination Surveys Database defines health surveys using the following criteria:

- Surveys aiming to give a complete picture of health, medical consumption, lifestyle and preventive behaviour
- Surveys with a significant health or health related component, like surveys on impairment, disability and handicaps
- Multipurpose surveys
- Living conditions surveys
- Health related questions of the European Community Household Panel (ECHP) and the Eurobarometer

All Health Interview Surveys and Health Examination Surveys from Member States participating in the current project were extracted from the database and individually searched.

A total of fifty-four surveys from the thirteen participating Member States were examined. Where previous versions of a contemporary survey were cited, the most recent version of the survey was examined.

Each survey was examined to determine:

### **(1) Does the survey contain questions addressing the agreed set of health indicators generated by this project?**

To address this query, the full questionnaire as presented on the HES HIS database website was manually searched for questions which address the health indicators generated by this project. Surveys that do not contain items pertinent to these health indicators will not be of use to this project. Surveys that do contain pertinent items (e.g. BMI, sensory impairment, etc.) were further examined as stated in (2) below.

### **(2) Can data be extracted from the survey solely on people with intellectual disability?**

Information is provided on each HIS and HES regarding sample selection for each survey. Two selection criteria are of relevance to the current project:

1. The HIS HES database provides information on whether or not respondents were included from 'institutions for the mentally handicapped'
2. The HIS HES database also provides information on whether or not proxy respondents were employed where adults were 'not at home' or 'unable to reply' – Dr. Jean Tafforeau, Scientific

Institute of Public Health, Brussels, who coordinates the HIS HES database confirms that intellectual disability is one reason why proxy respondents are employed.

In addition to manually checking whether either of these criteria were adhered to, the contact person for each HIS HES survey was contacted and asked to provide further information as to whether health data could be specifically extracted on people with intellectual disability. Consultations with specific contact persons are acknowledged below.

## 1. HIS/HES DATA AVAILABLE IN AUSTRIA

Three Health Interview Surveys have been conducted in Austria: (1.1) the Disabled Person's Survey, (1.2) the Sports, Leisure Time & Home Accidents Survey and (1.3) the Microcensus. No Health Examination Surveys are identified as having been conducted in Austria.

### 1.1 Disabled Persons' Survey (1976, 1986, 1995).

Health Interview Survey

(N=60,000 individuals in sample; 31,000 households)

*Does the survey address health indicators proposed by this project?*

Yes, this survey comprises 17 questions in total and includes items on visual ability, hearing ability, mobility, and use of health services.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey did include a sample of respondents from 'institutions for mentally handicapped' people. In addition, the database states that proxy respondents were used for children, 'adults not in the home' and 'adults who are not able to reply'. Further inquiries to the survey co-ordinator however revealed that information solely related to people with intellectual disability could not be extracted from this database.

**Contact Person:** [Barbara.Leitner@statistik.gv.at](mailto:Barbara.Leitner@statistik.gv.at)

### 1.2 Sports, Leisure Time and Home Accidents

Health Interview Survey

*Does the survey address health indicators proposed by this project?*

None of the 21 questions address health indicators generated in the current project.

*Can data from this survey be extracted specifically on people with intellectual disability?*

No.

### 1.3 Microcensus

Health Interview Survey

(N=60,000 individuals in sample; 31,000 households)

*Does the survey address health indicators proposed by this project?*

Yes, this survey comprises 20 questions in total and includes items on use of medication, medical check up, vaccination, BMI, health screening and physical exercise.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from 'institutions for mentally handicapped' people. However the database states that proxy respondents were used for children, 'adults not in the home' and 'adults who are not able to reply'. The sample may therefore include people with intellectual disability who are not resident in institutional settings but may be resident in the family home, in independent settings, etc. Further inquiries to the survey co-ordinator however revealed that information solely related to people with intellectual disability could not be extracted from this database.

**Contact Person:** [Barbara.Leitner@statistik.gv.at](mailto:Barbara.Leitner@statistik.gv.at)

**Conclusion:** Data regarding the health of people with intellectual disability resident in Austria cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

## 2. HIS/HES DATA AVAILABLE IN BELGIUM

Two Health Interview Surveys have been conducted in Belgium: (2.1) the Health Interview Survey, and (2.2) the General Socio-Economic Survey. No Health Examination Surveys are identified as having been conducted in Belgium.

### 2.1 Health Interview Survey (1997, 2001, 2004)

Health Interview Survey

(N=10,221 individuals in sample; 4,664 households)

*Does the survey address health indicators proposed by this project?*

Do you suffer a long-standing illness, handicap? Health service utilisation, medication use, ADL, mobility, self care, GP, consultants, dentist, hospitalisation, immunisation, BMI, diet, physical activity, education, employment, income, mental health, social support, health checks, demographics.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from 'institutions for mentally handicapped' people. However the database states that proxy respondents were used for children, 'adults not in the home' and 'adults who are not able to reply'. Further inquiries to the survey co-ordinator revealed that where data may have been collected on a respondent with intellectual disability, the disability was defined by the subjective impression of the proxy respondent. The co-ordinator recommended that the Health Survey should not be considered a valid data source for health information regarding people with intellectual disability.

**Contact Person:** [Jean.Tafforeau@iph.fgov.be](mailto:Jean.Tafforeau@iph.fgov.be)

### 2.2 General Socio-Economic Survey (2001)

Health Interview Survey

(N= 4,289,445 households; 10,296,350 individuals)

*Does the survey address health indicators proposed by this project?*

No: Four health questions are cited: self reported health, long-standing, chronic illness or handicap (not intellectual disability specific), carer status and number of children.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does include a sample of respondents from 'institutions for mentally handicapped' people and that proxies were employed on behalf of adults who were unable to reply. The questions above however are unrelated to the health indicators identified in this project.

**Conclusion:** Data regarding the health of people with intellectual disability resident in Belgium cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

### 3. HIS/HES DATA AVAILABLE IN DENMARK

Two Health Interview Surveys have been conducted in Denmark: (3.1) the Danish Health & Morbidity Survey, and (3.2) the Health & Morbidity in Denmark Survey. No Health Examination Surveys are identified as having been conducted in Denmark.

#### **3.1 Danish Health & Morbidity Survey (HIS) (1987, 1991, 1994)**

Health Interview Survey

(N=4,668)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, mental health, medication use, health care utilisation, medical check up, sensory and mobility, dentistry, social support, stress, physical activity, BMI, income, self reported health, social support, demographics.

*Can data from this survey be extracted specifically on people with intellectual disability?*

No – inquiries to the co-ordinator of the survey indicated that less than seven individuals with intellectual disability have completed this survey and as such it could not be considered as a suitable data source for examining the health of people with intellectual disability.

**Contact Person:** Ola Ekholm [ock@si-folkesundhed.dk](mailto:ock@si-folkesundhed.dk)

#### **3.2 Health & Morbidity in Denmark (1987, 1994, 2000)**

Health Interview Survey

(N=16,690)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, long-standing illness or disability, medication use, medication use, medical check up, health service utilisation, sensory deficits, oral health, social support, physical activity, BMI, vaccination (only MMR), income.

*Can data from this survey be extracted specifically on people with intellectual disability?*

No - As above.

**Contact Person:** Ola Ekholm [ock@si-folkesundhed.dk](mailto:ock@si-folkesundhed.dk)

**Conclusion:** Data regarding the health of people with intellectual disability resident in Denmark cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

## 4. HIS/HES DATA AVAILABLE IN FINLAND

Nine Health Interview Surveys have been conducted in Finland: (4.1) the Living Conditions Survey, (4.2) the Finnish Health Care Survey (4.3) Finrisk 97 (4.4) Health 2000 (4.5) Survey on Health Behaviour (4.6) European Community Household Panel (4.7) Health Behaviour Survey among the Elderly (4.8) Health Behaviour Survey among the Adult Population and (4.9) the National Finrisk Survey. Three Health Examination Surveys have been conducted in Finland, each connected to one of the above Health Interview Surveys; (4.3.1) Finrisk 97 (4.4.1) Health 2000 and (4.9.1) National Finrisk.

### **4.1 Living Conditions Survey (1986, 1994, 2004)**

Health Interview Survey

(N=8,650)

*Does the survey address health indicators proposed by this project?*

Yes, self reported health, chronic illness or disability (asked to define), medication use, mobility, sensory impairment, mental health.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from 'institutions for mentally handicapped' people. The database also states that proxy respondents were not used for people unable to reply. The exclusion of individuals in institutionalised settings and the exclusion of people who would be unable to reply indicate that a considerable proportion of people with intellectual disability would be excluded from participating in this survey. Any data that may be available on people with intellectual disability from this survey would therefore be unrepresentative of the population. Correspondence with the co-ordinator of this survey indicates that this survey is not an accurate source of health data for people with intellectual disability.

**Contact Person:** [Riitta.Harala@stat.fi](mailto:Riitta.Harala@stat.fi)

### **4.2 Finnish Health Care Survey (1964, 1968, 1976, 1987, 1995/96)**

Health Interview Survey

(N=6,000 households)

*Does the survey address health indicators proposed by this project?*

Yes, has any person been institutionalised because of illness? Medical expenses & income, hospitalisation, GP health care utilisation, medication usage, sensory deficit, education, employment, pension, GP visits, hospitalisation, oral health.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from 'institutions for mentally handicapped' people. However the database states that proxy respondents were used for children, 'adults not in the home' and 'adults who are not able to reply'. Further inquiries to the co-ordinator of this survey revealed that data cannot be extracted specifically on people with intellectual disability.

**Contact Person:** [Mika.Gissler@stakes.fi](mailto:Mika.Gissler@stakes.fi)

### **4.3 FinRisk 97 (1997, 2002)**

Health Interview Survey

(N=11,500 individuals aged 25-74)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, income, annual check up, medication usage, mental health, oral health & check ups, physical activity, BMI, social support.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from 'institutions for mentally handicapped' people. However the database states that proxy respondents were used for children, 'adults not in the home' and 'adults who are not able to reply'. Consultation with the co-

ordinator of the survey revealed that while people with intellectual disability may have been included in the survey, it is not possible to elicit information specifically on this group.

**Contact Person:** [Tiina.Laatikainen@ktl.fi](mailto:Tiina.Laatikainen@ktl.fi)

#### **4.3.1 FinRisk Health Examination Survey**

(72; 82; 92; 97; 02)

(N=11,500 aged 25-74 years)

*Does the survey address health indicators proposed by this project?*

No, the survey contains data regarding mobility, blood pressure, blood sample, cholesterol, cardiovascular tests, sensory function, MMSE, etc.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This health examination survey does include a sample of people from 'institutions for mentally handicapped' people. The database provides information relevant to only one health indicator generated in this project, 'mobility' and therefore is unlikely to provide a useful source of health data for the health indicators being examined in the present study. Consultation with the co-ordinator of the survey revealed that while people with intellectual disability may have been included in the survey, it is not possible to elicit information specifically on this group.

**Contact Person:** [Tiina.Laatikainen@ktl.fi](mailto:Tiina.Laatikainen@ktl.fi)

#### **4.4 Health 2000 (78-80, 2000-2001)**

Health Interview Survey

(N=10,000 over 18 years)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, income, mental illness, sensory impairment, hospitalisation, health service utilisation, mental health services, medical check up, medication use, oral health, mobility, work experience.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does include a sample of respondents from 'institutions for mentally handicapped' people and that proxies were employed on behalf of adults who were 'unable to reply'. Consultation with the survey co-ordinator indicates that approximately 10-20 individuals with intellectual disability may have participated in the survey. Given the small numbers it is unlikely that this database is of use as a source of health data for those with intellectual disability.

**Contact Person:** [Seppo.Koskinen@ktl.fi](mailto:Seppo.Koskinen@ktl.fi)

#### **4.4.1 Health 2000 Health Examination Survey**

(N=8,028 aged 30+)

*Does the survey address health indicators proposed by this project?*

Yes, cardiovascular, BMI, ECG, blood samples, dental health, sensory function, MMSE & neuropsychological functioning, RT, mental health measures.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This health examination survey does include a sample of people from 'institutions for mentally handicapped' people. In addition, the database provides information relevant to a number of health indicators generated in this project. As stated above however the number of participants with intellectual disability is estimated to be between 10 and 20 and as such is not a representative sample of people with intellectual disability.

**Contact Person:** [Seppo.Koskinen@ktl.fi](mailto:Seppo.Koskinen@ktl.fi)

#### **4.5 Survey on Health Behaviour 94;95;96;97;98;99;2000, 2001**

*Aikuisväestön terveyskäyttämistutkimus*

Health Interview Survey (N=5,000 aged 15-64)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, mobility, do you have an illness or disability that affects your work and functional ability (long-standing illness), mental health, medication, health checks, oral health, BMI, physical activity, health promotion.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does include information from people with intellectual disability who are resident in 'institutions for mentally handicapped people'. Further information obtained from the co-ordinator of this survey revealed however that data cannot be extracted from this database specifically on people with intellectual disability.

**Contact Person:** [antti.uutela@ktl.fi](mailto:antti.uutela@ktl.fi)

#### **4.6 European Community Household Panel (1996;1997;1998;1999;2000;2001)**

Eurooppalainen Elinolotutkimus

Health Interview Survey

(N=6,000 people, 3,000 households aged 16+)

*Does the survey address health indicators proposed by this project?*

Self reported health, long-standing chronic illness or disability, ADL, hospitalisation, annual health check, smoking, BMI

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not provide information on people who are resident in 'institutions for mentally handicapped people' however proxies are used for 'adults in the home' and adults who are 'not able to reply'. Information supplied by the coordinator of the survey revealed that while respondents with disabilities are identified as participants, those with the specific disability of 'intellectual disability' are not identified. It would not therefore be possible to extract information specifically on those with intellectual disability.

**Contact Person:** [Irmeli.Penttila@stat.fi](mailto:Irmeli.Penttila@stat.fi)

#### **4.7 Health Behaviour Survey among the Elderly (1985, 2001, 2003)**

Aikuisväestön terveystyöntutkimus

Health Interview Survey

(N=2,400 people, aged 65-84)

*Does the survey address health indicators proposed by this project?*

N/A – ageing population only.

*Can data from this survey be extracted specifically on people with intellectual disability?*

Information obtained from the co-ordinator of this survey revealed that data cannot be extracted from this database specifically on people with intellectual disability.

**Contact Person:** [antti.uutela@ktl.fi](mailto:antti.uutela@ktl.fi)

#### **4.8 Health Behaviour Survey among the Adult Population (1978, 2001, 2002)**

Kansanterveyslaitos

Health Interview Survey

(N=5,000 people, aged 15-64)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, GP visits, pension, ("recognition of disability"), mobility, mental health & stress, use of medicines, medical check up, dental care, BMI, physical activity, health promotion ("are you aware of X campaign").

*Can data from this survey be extracted specifically on people with intellectual disability?*

Information obtained from the co-ordinator of this survey revealed that data cannot be extracted from this database specifically on people with intellectual disability.

**Contact Person:** [antti.uutela@ktl.fi](mailto:antti.uutela@ktl.fi)

#### **4.9 The National FinRisk Survey 1972;1977; 1982; 1987; 1992; 1997;2002**

*FINRISKI TUTKIMUS*

Health Interview Survey

(N=9,000 households, stratified in 10 year age bands)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, income, GP visits, hospitalisation, medical check up, use of medication, specific morbidity, mobility, medication use, mental health & stress, oral health, physical activity, BMI, finance, social support.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from 'institutions for mentally handicapped' people and that proxies were not employed on behalf of children, 'adults not in the home' and adults who were 'unable to reply'. Information obtained on behalf of respondents with intellectual disability from this survey would exclude those in institutionalised care and those unable to reply. The sample would not therefore be representative of this population and as such this database would not be an accurate source of health data for the present study. Information from the database co-ordinator revealed that people with intellectual disability may have participated in the survey, however their data could not be extracted from the main dataset.

**Contact Person:** [Tiina.Laatikainen@ktl.fi](mailto:Tiina.Laatikainen@ktl.fi)

#### **4.9.1 FinRisk Health Examination Survey**

**(82, 87, 92, 97, 02)**

(N=13,500)

*Does the survey address health indicators proposed by this project?*

Only one: BMI, cardiovascular, cholesterol, blood samples, fitness.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This health examination survey does include a sample of people from 'institutions for mentally handicapped' people. The database however only provides information relevant to one health indicator generated in this project and therefore may not provide a useful source of health data for the health indicators being examined in the present study. In addition, correspondence with the survey co-ordinator revealed that specific data on people with intellectual disability could not be extracted from this dataset.

**Contact Person:** [Tiina.Laatikainen@ktl.fi](mailto:Tiina.Laatikainen@ktl.fi)

**Conclusion:** Data regarding the health of people with intellectual disability resident in Finland cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

## 5. HIS/HES DATA AVAILABLE IN FRANCE

Eight Health Interview Surveys have been conducted in France: (5.1) the Health and Care Interview Survey, (5.2) the Health and Social Protection Survey and (5.3) the Handicaps, Disabilities and Dependency Survey (5.4) Health Barometer (5.5) French Survey on Living Conditions and Aspirations (5.6) Continuous Survey on Household Living Conditions (5.7) Survey on Household Living Conditions and (5.8) the National Survey on Health and Health Insurance. No Health Examination Surveys have been conducted in France.

### **5.1 Health and Care Interview Survey (60;70;80;91/92; 96, 2002-2003)**

*Enquête sur la santé et les soins médicaux*

Health Interview Survey

(N=8,000 households: 21,500 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, hospitalisation, chronic long-standing illness (includes “Infirmity, handicap from birth, blindness, trisomy21, congenital dislocation of the hip...”), GP visit, medication, BMI, hospitalisation, health check ups, medication, “are any members of the household disabled?” Q125 – specifies intellectual disability; mobility, Q129 “does the person attend a specialised institution?” eligibility for disability allowance, income, sensory functioning, oral health, medication, mental health, working conditions, mobility, ADL.

*Can data from this survey be extracted specifically on people with intellectual disability?*

Information from the HIS HES database reveals that this survey does not include a sample of respondents from ‘institutions for mentally handicapped people’ and that proxies were not employed on behalf of children, ‘adults not in the home’ and adults who were ‘unable to reply’. Information obtained on behalf of respondents with intellectual disability from this survey would therefore exclude those in institutionalised care and those unable to reply. The sample would not therefore be representative of the population of people with intellectual disability and as such this database would not be an accurate source of health data for the present study.

No response from survey co-ordinator at the time of printing.

### **5.2 Health and Social Protection Survey (88, 98, 2001)**

*Enquête sur la santé et la protection sociale mise à jour*

Health Interview Survey

(N=23, 000)

*Does the survey address health indicators proposed by this project?*

Yes, BMI, mobility, Q.6 long standing illness “Disability, birth defect, blindness, deafness, congenital dislocation of the hip, trisomy, debility etc.” oral status, sensory functioning, medication.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The HIS HES database indicates that this survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people. Proxies were however used on behalf of adults who were ‘unable to reply’. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings.

No response from survey co-ordinator at the time of printing.

### **5.3 Handicaps, disabilities and dependency survey (1999, 2001)**

*Enquête Handicaps, Incapacités, Dependance*

Health Interview Survey

(N=16,900)

*Does the survey address health indicators proposed by this project?*

Yes, employment, Q12. In everyday life, are you faced with either physical, sensorial, intellectual or mental difficulties? Q13. What kind of impairment, disability do you suffer from? ADL, mobility, mental health, cognitive functioning, sensory functioning, medical check up, GP visit, demographics,

social support, use of health aids, housing, transport, access, Q151 do you live in an institution for handicapped children or adults, education, Q158 Do you attend a school for the mentally disabled? Q174 for disabled people Is it a sheltered or reserved job?, disability allowance, income.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does include a sample of respondents from ‘institutions for mentally handicapped’ people. Proxies were also used on behalf of children, and adults who were ‘unable to reply’. Unfortunately data can only be extracted on behalf of those with intellectual disability combined with those with ‘mental disability’. This latter group includes those with psychiatric disorder, pervasive developmental disorder, etc., and would therefore include people who do not have intellectual disability. The survey co-ordinator recommends the following website for further examination: <http://rfr-handicap.inserm.fr>

**Contact Person:** [Pierre.mormiche@insee.fr](mailto:Pierre.mormiche@insee.fr)

#### **5.4 Health Barometer (95:97:99, 04)**

*Baromètre santé grand public*

Health Interview Survey

(N= 13,685 aged 12-75)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, employment, education, social support, physical activity, vaccinations, BMI, mental health, health service utilisation, prescription medication, Q195/407 “do you have a long-standing physical illness, which one?” physical health checks, GP visit, hospitalisation, income.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people and that proxies were not employed on behalf of children, ‘adults not in the home’ and adults who were ‘unable to reply’. Information obtained on behalf of respondents with intellectual disability from this survey would exclude those in institutionalised care and those unable to reply. The sample would not therefore be representative of this population and as such this database would not be an accurate source of health data for the present study.

#### **5.5 French Survey on Living Conditions and Aspirations (Yearly from 1978+)**

*Enquête conditions de vie et aspirations des Français*

Health Interview Survey

*Does the survey address health indicators proposed by this project?*

No. Medication & health expenditure – attitude towards cost of medicine.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database does not provide information relevant to the health indicators generated in this project and therefore does not provide a useful source of health data for the health indicators being examined in the present study. The survey co-ordinator confirms that data from those with intellectual disability is not available from this database.

**Contact person:** Regis Bigot [bigot@credoc.fr](mailto:bigot@credoc.fr)

#### **5.6 Continuous survey on household living conditions (1999, 2000)**

*Enquête permanente sur les conditions de vie de menages*

Health Interview Survey

(N= 5,780 households, 11,000 individuals; aged 15+)

*Does the survey address health indicators proposed by this project?*

Yes, self reported health, employment, social support, mobility, physical activity, GP visits, medical check up, medication use, hospitalisation, oral health, sensory functioning.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The database indicates that this survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people. Proxies were however used on behalf of adults who were ‘not at

home'. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings.

**Contact person:** incorrect email – could not be contacted.

### **5.7 Survey on Household Living Conditions (1996-2003)**

*Enquête permanente sur les conditions de vie de ménages (EPCV)*

Health Interview Survey

(N=8,000 households, 5,500 individuals? Aged 15+)

*Does the survey address health indicators proposed by this project?*

No details are provided regarding individual questions on this survey. The following statement is contained on the HIS HES database website:

“The questions asked in 2001 (and which are planned for 2002 and 2003) are equal to the 19 questions asked in 2000.

Kindly consult F 07 for the specific question wording.”

*Can data from this survey be extracted specifically on people with intellectual disability?*

It is not possible at this time to state with any certainty whether this survey would be useful for the present study. No details are provided regarding the individual items on the survey and it is not possible to contact the survey co-ordinator using the email address supplied by the HIS HES database.

### **5.8 National Survey on Health and Health Insurance (1988-1998; 2000;2002; 2004)**

*Enquête sur la santé et la protection sociale mise à jour (ESPS)*

Health Interview Survey

(N= 7,000 households, 20,000 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, medical check up, sensory functioning, hospitalisation, GP visits, vaccinations, demographics, Q76 Does the person attend a specialised establishment for disabled people? Employment, income.

*Can data from this survey be extracted specifically on people with intellectual disability?*

Information from the HIS HES database reveals that this survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people. Proxies were however used on behalf of children, ‘adults not in the home’ and adults who were ‘unable to reply’. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings.

**Conclusion:** Information available at the present time indicates that data regarding the health of people with intellectual disability resident in France cannot be extracted from the majority of the current omnibus Health Interview Surveys or Health Examination Surveys. Difficulties were however experienced in accessing information from some sources. In particular, the Handicaps, Disabilities and Dependency Survey 1999 & 2001, (5.3) requires further investigation as a possible source of data.

## 6. HIS/HES DATA AVAILABLE IN GERMANY

Four Health Interview Surveys have been conducted in Germany: (6.1) Survey on Living Conditions, Health & Environment, (6.2) German National Health Interview Survey and (6.3) Questions on Health and (6.4) Questions on Health Microcensus. Only one Health Examination Survey has been conducted in Germany: (6.2.1) the German National Health Examination Survey.

### **6.1 Survey on Living Conditions, Health & Environment (1998)**

*Lebenssituation, Umwelt und Gesundheit*

Health Interview Survey

(N=4,843 – minimum age 45)

*Does the survey address health indicators proposed by this project?*

Yes, physical activity, GP visits, hospitalisation, Q31 Do you have a recognised disability, ADL, education, employment, income,

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people. In addition, proxies have not been used on behalf of adults who are either ‘not at home’ or who are ‘not able to respond’. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings and the exclusion of those who do not live in the family home or who are unable to reply.

No response from survey co-ordinator at the time of printing.

### **6.2 German National Health Interview Survey (97;98)**

*Bundes Gesundheitsurvey*

Health Interview Survey

(N=7,124 aged 18-79 years)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, specific morbidities, mental illness, Q25 Do you have a specific disability recognised by the pension board etc., sensory functioning, medical check up, hospitalisation, knowledge of health promotion campaigns.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people. In addition, proxies have not been used on behalf of adults who are either ‘not at home’ or who are ‘not able to respond’. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings and the exclusion of those who do not live in the family home or who are unable to reply.

No response from survey co-ordinator at the time of printing.

### **6.2.1 German National Health Examination Survey (84, 87, 90, 98)**

(N=13,222 aged 18-79)

*Does the survey address health indicators proposed by this project?*

Yes, BMI, blood samples, urine samples, blood pressure, measure of mental health.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This health examination survey does not include a sample of people from ‘institutions for mentally handicapped’ people. In addition, the database only provides information relevant to two health indicators generated in this project and therefore does not provide a useful source of health data for the health indicators being examined in the present study.

No response from survey co-ordinator at the time of printing.

### **6.3 Questions on Health (86;89;92;95;99;03)**

*Fragen zur Gesundheit*

Health Interview Survey

(N=400,000)

*Does the survey address health indicators proposed by this project?*

Yes, does your disability have official notification, hospitalisation, BMI.

*Can data from this survey be extracted specifically on people with intellectual disability?*

Information from the HIS HES database reveals that this survey does include a sample of respondents from 'institutions for mentally handicapped people' and that proxies were employed on behalf of children, 'adults not in the home' and adults who were 'unable to reply'. Information from the survey co-ordinator however revealed that it is not possible to extract data specifically on people with intellectual disability.

**Contact Person:** [Heiko.Pfaff@destatis.de](mailto:Heiko.Pfaff@destatis.de)

### **6.4 Questions on Health Microcensus (1978; 1982; 1986; 1989; 1992; 1995; 1999; 2003)**

Health Interview Survey

*Does the survey address health indicators proposed by this project?*

"The question in the Microsensus 2003 are exactly the same as the questions in 1999, in accordance with the 1996 Microsensus Law in Germany. See D 01 for the individual health related questions"

*Can data from this survey be extracted specifically on people with intellectual disability?*

Comments relating to Survey 6.3 above apply.

**Contact Person:** [Heiko.Pfaff@destatis.de](mailto:Heiko.Pfaff@destatis.de)

**Conclusion:** While not all surveys could be investigated in depth, preliminary investigation would suggest that data regarding the health of people with intellectual disability resident in Germany cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

## 7. HIS/HES DATA AVAILABLE IN IRELAND

Two Health Interview Surveys have been conducted in Ireland: (7.1) the Survey of Lifestyle, Attitude & Nutrition (SLAN), and (7.2) the Living in Ireland Survey. Only one Health Examination Survey has been carried out in Ireland (7.1.1) the SLAN Health Examination.

### **7.1 Survey of Lifestyle, Attitude and Nutrition (SLAN) (1998; 2002)**

Health Interview Survey

(N=6,539 18+ years)

*Does the survey address health indicators proposed by this project?*

Yes, Q.5 Is your daily activity limited by a long term disability, ADL, QoL, general health check, sensory functioning, oral health, BMI, physical health check, physical activity, demographics, education, employment.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample from ‘institutions for the mentally handicapped’ however proxies are used for adults. The survey would not be of use in the present context as the question that identifies a respondent as having a disability, does not request the respondent to specify the disability itself. Specific data relating to those with intellectual disability could not therefore be extracted from this database.

**Contact Person:** Professor Cecily Kelleher – personal communication: Data specific to intellectual disability cannot be extracted.

#### **7.1.1 SLAN Health Examination Survey**

*Does the survey address health indicators proposed by this project?*

BMI, blood samples, blood pressure.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This health examination survey does not include a sample of people from ‘institutions for mentally handicapped’ people. In addition, the database only provides information relevant to one health indicator generated in this project and therefore does not provide a useful source of health data for the health indicators being examined in the present study.

**Contact Person:** Professor Cecily Kelleher – personal communication: as above.

### **7.2 Living in Ireland Survey (94;95;96;97;98;99; 2000;2001)**

*Living in Ireland Survey; Irish element of ECHP*

Health Interview Survey

(N=3,387 households; 10,013 individuals)

*Does the survey address health indicators proposed by this project?*

Q2. Do you have any chronic disability – what is the nature of it? Mobility, hospitalisation, medical check ups, BMI, mental health, demographics, employment, income.

*Can data from this survey be extracted specifically on people with intellectual disability?*

‘Not applicable’ but proxies used for adults not at home and adults not able to reply. The survey coordinator stated that data could not be elicited specifically on those with intellectual disability as respondents were not asked to indicate their type of disability.

**Contact person:** [brian.nolan@esri.ie](mailto:brian.nolan@esri.ie)

**Conclusion:** Data regarding the health of people with intellectual disability resident in Ireland cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

## 8. HIS/HES DATA AVAILABLE IN ITALY

Two Health Interview Surveys have been conducted in Italy: (8.1) Aspects of Daily Life and (8.2) Health Conditions and Use of Health Services. No Health Examination Surveys have been conducted in Italy.

### **8.1 Aspects of Daily Life (94;95;96;97;98;99; 00)**

*Aspetti della vita quotidiana*

Health Interview Survey

(N=20,000 households; 60,000 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, (5.2) Are you suffering from a chronic disease or a permanent disablement which reduces your personal freedom to the extent of requiring the assistance of other people for everyday needs at home or away from home? Medication use, medical check up, education, demographics, Q.143 Is there a reduction in your self sufficiency caused by a long term handicap (ID not listed in choice of handicap), hospitalisation, physical activity, property, income, demographics, education, health service utilisation, GP visit, physical exercise.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of respondents from 'institutions for mentally handicapped' people. However, proxies have been used on behalf of children, adults who are 'not at home' and adults who are 'not able to respond'. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings and given the fact that the questionnaire does not request information on the respondent's type of disability.

No response from survey co-ordinator at the time of printing.

### **8.2 Health Conditions and the Use of Health Services (80;83;86;90/91;94;99/00, 04)**

*Condizioni di salute e ricorso ai servizi sanitari*

Health Interview Survey

(N=60,000 households; 180,000 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, demographics & short-term illness; Q11. Are you affected by a long-term illness that affects your freedom Q12: invalidity due to mental handicap? BMI, diet, medical check up, hospitalisation, social support, physical activity, vaccinations, health screening, mobility, ADL, sensory functioning, housing, income, self-reported health, mental health, medication use.

*Can data from this survey be extracted specifically on people with intellectual disability?*

The survey does not include a sample of respondents from 'institutions for mentally handicapped' people. Proxies have however been used on behalf of children, adults who are 'not at home' and adults who are 'not able to respond'. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings.

No response from survey co-ordinator at the time of printing.

**Conclusion:** It is unlikely that data regarding the health of people with intellectual disability resident in Italy can be extracted from current omnibus Health Interview Surveys or Health Examination Surveys. Difficulties in contacting survey co-ordinators at the time of printing however suggest that further examination of these surveys is required.

## 9. HIS/HES DATA AVAILABLE IN LUXEMBOURG

Five Health Interview Surveys have been conducted in Luxembourg: (9.1) the Eurobarometer, (9.2) the Panel Living in Luxembourg (9.3) the European Community Household Panel (9.4) Socio Economic Panel Living in Luxembourg and (9.5) the 2002 LFS ad hoc module employment of people with disabilities. No Health Examination Surveys have been conducted in Luxembourg.

### **9.1 Eurobarometer (73/74-1999; 1996; 2000 / 2002)**

*Health Interview Survey*

(N=1,000 over 15 years)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, employment, awareness of health promotion campaigns, BMI, self-reported health, oral health, medication use, hospitalisation, medical check up. Q28 Do you have a long standing disability? ADL, sensory functioning, mental health, physical activity.

*Can data from this survey be extracted specifically on people with intellectual disability?*

There is no information on the sampling scope of this survey. Contact with the Eurobarometer researchers however revealed that these surveys are not a suitable data source for information regarding people with intellectual disability.

Contact person: [marleen.desmedt@cec.eu.int](mailto:marleen.desmedt@cec.eu.int)

### **9.2 Panel Living in Luxembourg (94;95;96;97;98;99;00)**

*Panel socio-économique Liéven zu Letzebuerg*

Health Interview Survey

(N=2,554 households; 6,605 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, Health service utilisation, hospitalisation, BMI.

*Can data from this survey be extracted specifically on people with intellectual disability?*

While individuals resident in 'institutions for mentally handicapped', proxy respondents were used in this survey for children, adults 'not in the home' and adults that are 'not able to reply'.

Correspondence with the survey coordinator revealed that it is not possible to extract data from this survey specifically on people with intellectual disability.

Contact person: [Frederic.gerger@ceps.lu](mailto:Frederic.gerger@ceps.lu)

### **9.3 European Community Household Panel (94; 95; 96; 2000, 2001)**

Health Interview Survey

*Does the survey address health indicators proposed by this project?*

Yes, self-reported health, do you have a long-standing illness or disability, ADL, hospitalisation, GP visits, smoking, BMI,

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of respondents from 'institutions for mentally handicapped' people. In addition, proxies have not been used on behalf of adults who are either 'not at home' or who are 'not able to respond'. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings and the exclusion of those who do not live in the family home or who are unable to reply.

Consultation with the survey co-ordinator revealed that information specifically on those with intellectual disability cannot be extracted from this database.

Contact person: Dr. van den Berg [jbrg@cbs.nl](mailto:jbrg@cbs.nl)

### **9.4 Socio-Economic Panel living in Luxembourg**

(1994;1995;1996;1997;1998;1999;2000;2001)

*Panel Socio-Economique Liéven zu Letzebuerg*

Health Interview Survey

(N=2,431 households, 6,242 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, GP & health visits, hospitalisation, medication use, BMI.

*Can data from this survey be extracted specifically on people with intellectual disability?*

While people resident in 'institutions for mentally handicapped' were not included in this survey, proxies for children 'adults not in the home' and 'adults who are not able to reply' were employed. Consultation with the survey coordinator however revealed that this survey could not be used as a data source for the health of people with intellectual disability.

**Contact person:** [Frederic.gerger@ceps.lu](mailto:Frederic.gerger@ceps.lu)

#### **9.5 2002 LFS ad hoc module employment of people with disabilities (1983-2003)**

*European Labour Force Survey*

Health Interview Survey

(N=300,000 aged 16-64 years)

*Does the survey address health indicators proposed by this project?*

No. Do you work in sheltered employment, assistance to participate in the workforce?

*Can data from this survey be extracted specifically on people with intellectual disability?*

The questions in this survey do not address the health status of respondents and as such it is not a suitable data source for the present project.

**Contact person:** [simone.casali@statec.etat.lu](mailto:simone.casali@statec.etat.lu)

**Conclusion:** Data regarding the health of people with intellectual disability resident in Luxembourg cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

## 10. HIS/HES DATA AVAILABLE IN THE NETHERLANDS

Two Health Interview Surveys have been conducted in the Netherlands: (10.1) the Continuous Quality of Life Survey and (10.2) the Patient Survey – Second Dutch National Survey of General Practitioners. Only one Health Examination Survey has been conducted in the Netherlands (10.3) the Netherlands Health Examination Survey.

### 10.1 Continuous Quality of Life Survey (81;...;98; 1999,2000,2001,2002)

POLS GEZO (Permanent Onderzoek Leefsituatie Gezondheid)

Health Interview Survey

(N=9,323)

*Does the survey address health indicators proposed by this project?*

Yes, GP, mobility, health specialists, ADL, health service utilisation, medication use, hospitalisation, attitude towards health checks, oral health, sensory functioning, working conditions, social support, education, employment. Q.184 Item on 'Mental Handicap': 'Has your child been treated or checked for this by a doctor?'

*Can data from this survey be extracted specifically on people with intellectual disability?*

While one item (Q184) does cite 'mental handicap', the responses may not be useful for present purposes. The question does not identify the respondent as having an intellectual disability, thereby allowing the extraction of data specifically on people with intellectual disability. Rather, the question is directed at parents and asks whether they have liased with a physician regarding the possibility of their child having an intellectual disability. This survey may also be unsuitable for the present study on the grounds that the survey does not include a sample of respondents from 'institutions for mentally handicapped' people. In addition, proxies have not been used on behalf of adults who are either 'not at home' or who are 'not able to respond'. The contact person is currently on maternity leave.

### 10.2 Patient Survey – Second Dutch National Survey of General Practitioners (1988; 2001)

*Patient enquête - Tweede Nationale Studie Huisartsen*

Health Interview Survey

(N=13,000)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, income, employment, education, ADL, mental health, BMI, sensory functioning, specific morbidities, Q.85 have you any long term illness not previously mentioned? Social support, mobility, GP visits, contact with specialists, oral health, medication use, health screening, physical activity.

*Can data from this survey be extracted specifically on people with intellectual disability?*

Contact with the survey coordinator revealed that the number of respondents with intellectual disability would be extremely low and difficult to select from this database. In addition, individuals resident in 'institutions for the mentally handicapped' were not included. This survey could not therefore be considered a reliable source of data regarding the health of individuals with intellectual disability in the Netherlands.

**Contact person:** [gert.westert@rivm.nl](mailto:gert.westert@rivm.nl)

### **10.3 Netherlands Health Examination Survey (98, 99, 00, 01)**

*Regenboog*

HES

(N=6,979)

*Does the survey address health indicators proposed by this project?*

BMI, blood samples, blood pressure, joint function.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This health examination survey does not include a sample of people from 'institutions for mentally handicapped' people. In addition, the database only provides information relevant to one health indicator generated in this project and therefore does not provide a useful source of health data for the health indicators being examined in the present study. The survey co-ordinator states that this database is not a suitable source of data regarding the health of people with intellectual disability.

**Contact person:** [lucie.viet@rivm.nl](mailto:lucie.viet@rivm.nl)

**Conclusion:** Data regarding the health of people with intellectual disability resident in the Netherlands cannot be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.

## 11. HIS/HES DATA AVAILABLE IN SPAIN

Two Health Interview Surveys have been conducted in Spain: (11.1) the National Health Survey and (11.2) the Impairments, Disabilities and Health Status Survey. No Health Examination Surveys have been conducted in Spain.

### **11.1 National Health Survey (87;95;97;01)**

*Encuesta nacional de salud*

Health Interview Survey

(N=8,600)

*Does the survey address health indicators proposed by this project?*

Yes, medication use, visits to medical specialists, oral health & services, hospitalisation, physical activity, BMI, sensory functioning, ADL, education, employment, demographics.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people. In addition, proxies have not been used on behalf of adults who are either ‘not at home’ or who are ‘not able to respond’. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings and the exclusion of those who do not live in the family home or who are unable to reply. The survey co-ordinator states that this database is not a suitable source of data regarding the health of people with intellectual disability.

**Contact person:** [lbiglino@msc.es](mailto:lbiglino@msc.es)

### **11.2 Impairments, Disabilities and Health Status Survey (86;99)**

*Encuesta Discapidades, Deficiencias y Estado de Salud*

Health Interview Survey

(N= 79,000 households and 230,000 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, education, employment, Q20 Has anyone connected with the house been resident in an institution for people with disabilities, sensory functioning, difficulties with self care, mobility, Q24 comprehending complex and simple tasks, Q40 compared to children of a similar age, does the child give the impression of being slow or weak. Q44 has the child been diagnosed by a physician to suffer a serious problem lasting over a year for which the child requires specialist services, income, Q55 Have you been diagnosed to have Down’s Syndrome, Q73 specify the underlying impairment of the disability which led to your membership of one or more NGO, special education & training, BMI, medication use, physical activity.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of people resident in ‘institutions for the mentally handicapped’. It does however provide proxies for ‘adults who are not able to reply’. Given the comprehensiveness of the survey items stated above it is possible that this database would provide a source of health data for people with intellectual disability who are not resident in institutionalised settings, that is, those who live within the family home, in independent settings, etc. Use of the ‘impairment’ variable, as opposed to the ‘disability’ variable is recommended by the survey coordinator to extract information on the health of individuals with intellectual disability.

**Contact person:** [monlopez@ine.es](mailto:monlopez@ine.es)

**Conclusion:** Data regarding the health of people with intellectual disability resident in Spain may be extracted from current omnibus Health Interview Surveys or Health Examination Surveys – further investigation is required.

## 12. HIS/HES DATA AVAILABLE IN SWEDEN

Only one Health Interview Surveys has been conducted in Sweden: (12.1) the Living Conditions Survey. No Health Examination Surveys have been conducted in Sweden.

### 12.1 Living Conditions Survey (75-00)

Undersökningen av levnadsförhållanden

Health Interview Survey

*Does the survey address health indicators proposed by this project?*

Yes, Q2 do you suffer from any long term disability Q3 what is the nature of this condition, medication use, employment, sensory functioning, mobility, ADL, GP visit, BMI, oral health,

*Can data from this survey be extracted specifically on people with intellectual disability?*

This health interview survey does include a sample of people from 'institutions for mentally handicapped' people and proxies are used for adults. In addition, the database provides information relevant to a number of health indicators generated in this project. The possible use of this database as a source of health data for the health indicators examined in the present study could not be established as neither contact person responded to requests for information. Alternatives attempts to contact the coordinators will be made.

**Conclusion:** Data regarding the health of people with intellectual disability resident in Sweden may be extracted from current omnibus Health Interview Surveys or Health Examination Surveys. Further investigation is required.

### 13. HIS/HES DATA AVAILABLE IN UNITED KINGDOM

Eight Health Interview Surveys have been conducted in the United Kingdom: (13.1) the Health and Lifestyle Survey, (13.2) the Survey of Psychiatric Morbidity and (13.3) the Scottish Health Survey (13.4) the Disability Survey, (13.5) the Health Education Monitoring Survey, (13.6) the Health Survey for England, (13.7) the General Household Survey and (13.8) the Census. Two Health Examination Surveys have been conducted in the United Kingdom, (13.3.1) the Scottish Health Survey Health Examination and (13.6.1) the Health Survey for England Health Examination.

#### 13.1 Health & Lifestyle Survey (84/85;91/92)

Health Interview Survey

(N=5,352 aged 25+)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, social support, medication use, Q28 Do you have a long standing disability – what is wrong with you? ADL, GP visit, hospitalisation, BMI, physical activity, employment, education, income, mental health.

*Can data from this survey be extracted specifically on people with intellectual disability?*

No – people defined as ‘incapacitated or senile’ were automatically excluded from the sampling frame.

#### 13.2 Survey of Psychiatric Morbidity (93/94, 2000)

Health Interview Survey

(N= 10,108 aged 16-64 years)

*Does the survey address health indicators proposed by this project?*

Yes, self reported health, Q2 Do you have any long-standing illness, disability or infirmity? – what is the matter with you? Medication use, GP, BMI, mental health, Q124 does s/he have any long-standing illness. Hospitalisation, check ups, ADL, life events, employment.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of people resident in ‘institutions for the mentally handicapped’. It does however provide proxies for ‘adults who are not able to reply’. The exclusion of a sample of people with intellectual disability in institutional care would render this sample biased in favour of those with greater levels of ability who are less likely to reside in institutionalised settings. The database is unlikely to be identified as a useful source of health data for people with intellectual disability. Consultation with the survey co-ordinator however revealed that a screening tool was used to identify those with intellectual disability. Therefore limited data would be available on those with intellectual disability who do not reside in institutionalised settings.

**Contact:** Howard Meltzer

#### 13.3 The Scottish Health Survey (1995 & 1998)

Health Interview Survey

95 (N=7,932 aged 16-64 years)

98 (N=9,093 households, 12,939 individuals aged 2-74 years)

*Does the survey address health indicators proposed by this project?*

Yes (1995) Demographics, Q16. Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time? ADL, mobility, specific morbidities, health checks, physical activity, dental check up, employment, benefits (financial).

(1998) Mental health, demographics, Q91 Do you have any long-standing illness, disability or infirmity? What is the matter with you? Mobility, hospitalisation, medical check ups, accident, physical activity, oral health, employment, education, occupation.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey excludes people in institutional care and does not provide proxies for people who are not able to respond. Consultation with the survey co-ordinator revealed that people with moderate,

severe and profound levels of ability were excluded from this survey. A small proportion of individuals with mild levels of intellectual disability would have responded, however this group would be unrepresentative of the population of people with intellectual disability.

**Contact person:** Paola Primatesta

### **13.3.1 The Scottish Health Examination Survey (1995 & 1998)**

*Does the survey address health indicators proposed by this project?*

Yes, BMI, BP, respiration, blood samples, saliva samples

*Can data from this survey be extracted specifically on people with intellectual disability?*

Consultation with the survey co-ordinator revealed that people with intellectual disability were excluded from these health examination surveys.

**Contact person:** Paola Primatesta

### **13.4 Disability Survey (96/97)**

Health Interview Survey

(N=8,816 over 16 years)

*Does the survey address health indicators proposed by this project?*

**Yes, Q1.** Do you have any long term health problems or complaints which affect your everyday activities? What is your health problem or complaint? Mobility, ADL, sensory functioning, mental health, hospitalisation, medical check up, medication use, education,

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey excludes people in institutional care and does not provide proxies for people who are not able to respond. It is possible therefore that people with mild levels of intellectual disability are among the respondents. The sample would however be biased in favour of those with higher levels of ability and could not therefore be considered representative of the population of people with intellectual disability. Further details from the survey coordinator revealed that a former version of this survey conducted in 1986 did include samples from institutionalised settings and therefore may provide limited information on people with intellectual disability.

**Contact:** Howard Meltzer

### **13.5 Health Education Monitoring Survey (95;96;98 – no longer carried out by ONS)**

Health Interview Survey

(N=5,800 aged 16+ years)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, employment, Q16. Do you have any long-standing illness, disability or infirmity? What is the matter with you? ADL, mental health, social support, cognitive ability, employment, physical activity, education, employment, income.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of respondents from 'institutions for mentally handicapped' people. In addition, proxies have not been used on behalf of adults who are either 'not at home' or who are 'not able to respond'. The use of this database as an accurate source of health data is questionable given the exclusion of people with intellectual disability from institutionalised settings and the exclusion of those who do not live in the family home or who are unable to reply. Further details from the survey coordinator revealed that this database would not provide information on those with intellectual disability.

**Contact:** Howard Meltzer

### **13.6 Health Survey for England (1998) 91;92;93;94;95;96;97;98;99;2000:**

Health Interview Survey

(N=9,208 households; 19,654 individuals)

*Does the survey address health indicators proposed by this project?*

Yes, demographics, Q5. Do you have any long-standing illness, disability or infirmity? – If yes, what is the matter with you? GP visits, hospitalisation, disease specific morbidity, medical check up, education, physical activity.

*Can data from this survey be extracted specifically on people with intellectual disability?*

This survey does not include a sample of respondents from ‘institutions for mentally handicapped’ people. In addition, proxies have not been used on behalf of adults who are either ‘not at home’ or who are ‘not able to respond’. The use of this database as an accurate source of health data for people with intellectual disability is questionable. Consultation with the survey co-ordinator revealed that respondents who were deemed unable to comprehend individual survey items were excluded and that this database could not therefore be considered to contain a representative sample of people with intellectual disability.

**Contact person:** Paola Primatesta

### **13.6.1 Health Survey for England Health Examination (98;99;2000; 2001;2002**

HES 1998 - 2002

*Does the survey address health indicators proposed by this project?*

Yes. BMI, blood pressure, blood samples, saliva samples, cognition.

*Can data from this survey be extracted specifically on people with intellectual disability?*

Consultation with the survey co-ordinator revealed that people with intellectual disability are not included in this survey.

**Contact person:** Paola Primatesta

### **13.7 General Household Survey (71;96;98;20002000)**

Health Interview Survey

(N=8,600 households, 20,000 individuals aged 16+)

*Does the survey address health indicators proposed by this project?*

Demographics, Q.11 Do you have any long-standing illness, disability or infirmity? What is the matter with you? GP visits, hospitalisation. Q53 Does (NAME) have any long-standing illness, disability or infirmity? Social support.

*Can data from this survey be extracted specifically on people with intellectual disability?*

Consultation with the survey co-ordinator revealed that people with intellectual disability may have been included in this survey, but only those with mild levels of intellectual disability. Archival data from this survey is stored at the University of Essex and could be used to establish a suitable sample size. The exclusion of people with lower levels of ability however may render this database unsuitable for monitoring the health of people with intellectual disability.

**Contact person:** Leicha Rickards

### **13.8 Census (2001)**

Health Interview Survey

*Does the survey address health indicators proposed by this project?*

No - Q13. Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?

*Can data from this survey be extracted specifically on people with intellectual disability?*

This database cannot be used as a data source to monitoring the health of people with intellectual disability as while respondents may include a sample with intellectual disability, questions relating to health are not included. Consultation with an expert in health surveys indicated that a disability screen has not been included in any census in the UK

**Contact:** Howard Meltzer

**Conclusion:** Limited data regarding the health of people with intellectual disability resident in United Kingdom can be extracted from current omnibus Health Interview Surveys or Health Examination Surveys.