

### 5.3.2. Operationalisation of Health Indicators for People with Intellectual Disability

The following section presents possible methods to ‘operationalise’, that is measure, each indicator.

Each indicator is presented using the following headings;

***Indicator*** – the name of the indicator

***Potential source type*** – where possible, data sources are identified. Unlike health monitoring systems for the general population no data sources have been identified that specifically collect and record health data on behalf of people with intellectual disability resident in the Member States. In the absence of data sources, suggestions are made as to how this data may be collected. These suggestions mostly comprise ‘sample surveys’ and ‘registers of services users that may be linked to health data’. These limited options are a consequence of the lack of data regarding the prevalence of intellectual disability in Member States (typically used as the denominator for health indicators) and the lack of systematic data collection regarding the health of people with intellectual disabilities. These challenges are addressed in the tables below.

***Currently present in*** – where possible, items have been selected from generic health surveys. The use of such items would allow for the direct comparability of health information between those with intellectual disability and the general population and would conform with the current harmonisation of data advocated by the European Commission.

***Stratify by*** – specific breakdowns of data by sub-samples on the basis of variables such as age, gender or level of ability are recommended for each indicator.

***Operationalisation*** – Possible measurements for each indicator are presented. Where multiple options are provided, the indicator presented in a shaded box has been prioritised as the most important data collection procedure.

### 5.3.2.1:(1.1) INDICATOR OF PREVALENCE FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<p><b>1.1 POPULATION STATUS</b>            Following ECHI 2: In principle, prevalence data provides the denominator for the calculation of other indicators, including stratification by gender, age or region and the calculation of standardised rates (i.e. corrected for differences in population structures between countries). Difficulties in estimating the prevalence of intellectual disability however suggest that alternative population parameters may be required.</p>				
<ul style="list-style-type: none"> <li>Total population</li> </ul>	At the moment this type of information can only be obtained through extrapolation from national population statistics, sample surveys or register based data.	<p>Population information regarding people with intellectual disability is largely unavailable in the European Union. Data that is available is collected in an unsystematic fashion and is not comparable across Member States.</p> <p>Possible methodologies to collect this data in a valid and systematic fashion, either by census or sample survey, are discussed in Section 1 Definition and Prevalence of Intellectual Disability.</p>	See sections outlined below	<p><b>INDICATOR:</b></p> <p>In principal this indicator should identify all people with intellectual disability – approximately 1-3% of the population of the European Union.</p> <p>Until such time as a full epidemiological prevalence study is conducted in each Member State, the true prevalence of intellectual disability will remain unknown, or will be based on other sources such as register-based samples of those known to service providers.</p> <p>A considerable body of work has been conducted by the United Nations outlining possible methods to determine the prevalence of disability. The inclusion of ‘intellectual disability’ in these deliberations would greatly enhance current efforts to determine prevalence.</p> <p>Given the challenges outlined above, it is unlikely that the prevalence of intellectual disability will be determined in Member States prior to the application of health indicators for this population. For practical purposes it may therefore be necessary to limit the definition of those with intellectual disability to those individuals who are known to service providers. A degree of flexibility in defining intellectual disability is recommended in order to embrace new developments in estimating the prevalence of this population.</p>

<ul style="list-style-type: none"> <li>Population by region</li> </ul>	<p>Register if linked to diagnosis of intellectual disability</p> <p>Survey</p>	<p>There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.</p>		<p><b>INDICATOR:</b> Population estimates of prevalence should be presented by region as defined using EU regional breakdown advocated by the ISARE project:</p> <p>Proportion of individuals with intellectual disability resident in the following regional breakdowns:</p> <p>Austria: 9 regions: Bundesländer Belgium: 11 regions: Province Denmark: 14 regions: Amtskommuner England: 99 regions: Health Authorities France: 26 regions: Region Germany: 16 regions: Land Ireland: 10 regions: Health Board Italy: 21 regions: Regioni Luxembourg: 1 region: National Level Netherlands: 50 regions: GGD Portugal: 5 regions: Health care region Spain: 17 regions: Autonomous Communitie Sweden: 21 regions: County Greece: 17 regions: Health region (proposed) (note: England is only nation identified in UK; Scotland &amp; Wales are omitted).</p> <p>Consultation with the ISARE project is recommended.</p>
<ul style="list-style-type: none"> <li>Population by Gender</li> </ul>	<p>Register if linked to diagnosis of intellectual disability</p> <p>Survey</p>	<p>There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.</p> <p>This data is collated on the general population in ECHI 2.</p>		<p>Proportion of the population who are male. Proportion of the population who are female.</p>

<ul style="list-style-type: none"> <li>Population by Age</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.  This data is collated on the general population in ECHI 2.		Health indicators suggested in this report are currently limited those over 18 years. The inclusion of children with intellectual disability would require additional and unique indicators.  The recommended breakdown of prevalence data by age are those advocated by ECHI 2 18-25 years 26-50 years 54-65 years 66-80 years
<ul style="list-style-type: none"> <li>Population by level of ability, adaptive behaviour, or activities of daily living.</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.		While 'level of ability', 'adaptive functioning' or 'activities of daily living index' data would provide valuable information regarding the relationship between these variables and health, the need for valid and standardised measures to collect this data currently poses a challenge. An array of measures is available however none are validated and normed across all European Union Member States. The inclusion of this indicator is therefore aspiration until the development of valid and normed measure that can be employed throughout the European Union.
<ul style="list-style-type: none"> <li>Population by behavioural phenotype Down's Syndrome</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	ECHI 2		Proportion of population who have Down's Syndrome. Proportion of population who do not have Down's Syndrome.

### 5.3.2.2: (1.2) INDICATOR OF LIVING ARRANGEMENTS FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>1.2 LIVING ARRANGEMENTS</b>				
<ul style="list-style-type: none"> <li>Population by living arrangement</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender	The proportion of people with intellectual disability who spend the majority of their week resident in: <ol style="list-style-type: none"> <li>In family home: As defined by living with both parents, one parent, sibling(s), relative, non-relative (e.g. neighbour, family friend), adoptive family, foster family). Adopted from National Disability Database Ireland, Mulvany &amp; Barron, 2003).</li> <li>In independent or semi-independent residence (maximum 2 hours supervision daily) living alone or with other(s).</li> <li>In residential setting provided by service provider with over 16 residents (as defined by Larkin <i>et al.</i>, (2003). Selected Changes in Residential Service Systems Over a Quarter Century 1977-2002. Mental Retardation, 41, 4, 303).</li> <li>In residential setting provided by service provider with less than 16 residents (as defined by Larkin <i>et al.</i>, (2003).</li> <li>In nursing home, psychiatric hospital, other intensive placement with special requirements due to challenging behaviour or profound and/or multiple handicap.</li> <li>Vagrant or homeless</li> </ol>

### 5.3.2.3: (1.3) INDICATOR OF DAILY OCCUPATION FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>1.3 DAILY OCCUPATION</b>				
<ul style="list-style-type: none"> <li>Population by daily occupation</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.  Employment data is available in many HIS/HES surveys for the general population and the format of this question could be retained for comparability of data	Age Gender	<p><b>INDICATOR 1</b></p> <p>Are you in employment? (Yes/No)</p> <p>What is the income from this employment?</p> <p><i>Source: Status and Future of Health Surveys in the European Union.</i></p> <p>A specific indicator on ‘employment’ as a daily occupation is recommended given the evidence based literature supporting the inclusion of people with intellectual disability in the work force (Bray, A. (2003). Work for adults with an intellectual disability: Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability. Donald Beasley Institute).</p> <p><b>INDICATOR 2</b></p> <p>The development of an indicator to identify ‘daily occupation’ for those not in paid employment is recommended. Currently no ‘universal’ typology of daily occupations for people with intellectual disability exists. A review of these options among Member States is recommended to assist in the development of this indicator.</p>
<ul style="list-style-type: none"> <li>Population by number of hours worked</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	European Community Household Panel		Total number of hours ‘working’ (in daily occupation) per week.

### 5.3.2.4: (1.4) INDICATOR OF INCOME FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Source Type	Present in:	Stratify by	Operationalisation
<b>1.4 INCOME &amp; SES</b>				
<ul style="list-style-type: none"> <li>Population by gross annual income</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	For the general population: European Community Household Panel (conducted annually)	Age Gender	This indicator is dependent on the development of an indicator to identify 'sources of income' – see below.
<ul style="list-style-type: none"> <li>Source of annual income</li> </ul>		For the general population in European Community Household Panel (conducted annually)	Age Gender	This indicator is dependent on the development of an indicator to identify 'sources of income' – see below. (which can subsequently be classified according to socio-economic status) is recommended. Currently no 'universal' typology of income for people with intellectual disability exists. A review of these options among Member States is recommended to assist in the development of this indicator.  Gross annual income may obtained from the following sources:  Total sickness/invalidity benefit Any other personal benefits Assigned social assistance Current wage and salary earnings Private transfers received

### 5.3.2.5:(1.5) INDICATOR OF LIFE EXPECTANCY FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Source Type	Present in:	Stratify by	Operationalisation
<b>1.5 MORTALITY AND LIFE EXPECTANCY</b>				
1.5.1 Life expectancy				
<ul style="list-style-type: none"> <li>Life expectancy</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	WHO and EUROSTAT – but not intellectual disability defined	Level of intellectual disability / adaptive behaviour / activities of daily living	Birth, ages 1, 15, 45, 65, 75 Gender
<ul style="list-style-type: none"> <li>Life expectancy in Down's syndrome</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	WHO and EUROSTAT	Level of intellectual disability / adaptive behaviour / activities of daily living	Birth, ages 1, 15, 45, 65, 75 Gender
1.5.2 General Mortality				
<ul style="list-style-type: none"> <li>Crude death rate</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	WHO and EUROSTAT – but not intellectual disability defined	Level of intellectual disability / adaptive behaviour / activities of daily living	0-64, 65+
<ul style="list-style-type: none"> <li>Cause specific mortality</li> </ul>	Register if linked to diagnosis of intellectual disability	WHO and EUROSTAT – but not intellectual disability defined	Level of intellectual disability / adaptive behaviour / activities of daily living  Gender	Crude death rate as compared with non ID population As in ECHI list appendix 5

### 5.3.2.6: (2.1) INDICATOR OF EPILEPSY FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>2.1 EPILEPSY</b>				
2.1.1 Mortality and related indicators				
<ul style="list-style-type: none"> <li>Standardised Death Rate</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Region Gender Level of intellectual disability / adaptive behaviour / activities of daily living	Compare with: Europe standard population 0-64, 65+ ID population non epilepsy 0-64, 65+ Routine mortality data under-codes epilepsy if not direct cause of death
<ul style="list-style-type: none"> <li>Death rate from Sudden Unexplained Death in Epilepsy</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Region Gender Level of intellectual disability / adaptive behaviour / activities of daily living	National surveys suggest SUDEP under recorded and under diagnosed
2.1.2 Morbidity and related indicators				
<ul style="list-style-type: none"> <li>Seizure rate</li> </ul>	Survey	There is no systematic data collection across the European Union for this	Region Gender Level of intellectual disability /	Suggest below compared with general population data and for ID population <ul style="list-style-type: none"> <li>Percent seizure free</li> <li>Percent less than one seizure per month</li> <li>Percent greater than one seizure per month</li> </ul>

		information on behalf of people with intellectual disability.	adaptive behaviour / activities of daily living	
<ul style="list-style-type: none"> <li>Epilepsy related hospitalisation</li> </ul>	<p>Register if linked to diagnosis of intellectual disability</p> <p>Survey</p>	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	<p>Region</p> <p>Gender</p> <p>Level of intellectual disability / adaptive behaviour / activities of daily living</p>	<p>Suggest below compared with general population data and for ID population</p> <ul style="list-style-type: none"> <li>Admission rate to casualty</li> <li>Admission rate with seizure</li> </ul>
<ul style="list-style-type: none"> <li>Epilepsy related quality of life</li> </ul>	Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	<p>Region</p> <p>Gender</p> <p>Level of intellectual disability / adaptive behaviour / activities of daily living</p>	<p>Tools exist:</p> <p>ELDQOL</p> <p>GEOS</p> <p>(development needed for translation and European population norms)</p>
2.1.3 Prevalence of epilepsy in people with intellectual disability				
<ul style="list-style-type: none"> <li>Prevalence of epilepsy in population of people with an intellectual disability</li> </ul>	<p>Register if linked to diagnosis of intellectual disability</p> <p>Survey</p>	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	<p>Region</p> <p>Gender</p> <p>Level of intellectual disability / adaptive behaviour / activities of daily living</p>	

### 5.3.2.7: (2.2) INDICATOR OF ORAL HEALTH FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>2.2. ORAL/DENTAL HEALTH</b>				
<ul style="list-style-type: none"> <li>Prevalence of DMFT scores in population of people with an intellectual disability</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	WHO – Oral Health Surveys criteria or national/local dental epidemiological indices for the general population only	Age Gender Level of intellectual disability / adaptive behaviour / activities of daily living	DMFT (the number of decayed, missing or filled permanent teeth).  DMFT information is available at varying ages for most countries on WHO website. The following age stratification is recommended: 12, 15, 35-44 and 65-74 years.

### 5.3.2.8: (2.3). INDICATOR OF BODY MASS INDEX FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>2.3. BODY MASS INDEX</b>				
<b>2.3.1 Prevalence of morbidity</b>				
<ul style="list-style-type: none"> <li>Proportion of population classified by each BMI category</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	This data is collected on the general population by: (1) WHO (global data on BMI to be released soon) (2) OECD (3) EU (Eurobarometer)	Age  Level of intellectual disability / adaptive behaviour / activities of daily living	(1) WHO (1996) BMI: BMI < 18 18 ≤ BMI < 20 20 ≤ BMI < 25 25 ≤ BMI < 27 27 ≤ BMI < 30 BMI ≥ 30

### 5.3.2.9: (2.4) INDICATOR OF MENTAL HEALTH FOR PEOPLE WITH INTELLECTUAL DISABILITY

(Note: this indicator is currently restricted to examining the prevalence of psychiatric disorder – there is no attempt to at this stage to measure positive aspects of mental health)

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>2.4 MENTAL HEALTH</b>				
2.4.1 Prevalence				
<ul style="list-style-type: none"> <li>Prevalence of psychiatric disorder.</li> </ul>	Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Level of intellectual disability / adaptive behaviour / activities of daily living	Proportion of population reaching criterion for psychiatric disorder using a standardised assessment tool specific for people with intellectual disability.  Assessment & diagnostic tools exist for adults only and tend to focus on the broad spectrum of psychiatric disorder in adults with ID: (Gustafsson, 2003) (1) Reiss Screen for Maladaptive Behaviour (Reiss, 1988) (2) Psychopathology Inventory for Mentally Retarded Adults (Matson, 1988) (3) PAS-ADD (Moss <i>et al.</i> , 1993) (4) Present Psychiatric Scale – Learning Disabilities Scale (PPS-LD: Cooper 1997)
Note: Use of medication for mental health disorders will be address under ‘Medication’				

### 5.3.2.10: (2.5) INDICATOR OF SENSORY IMPAIRMENT FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>2.5 SENSORY IMPAIRMENT</b>				
2.5.1				
<ul style="list-style-type: none"> <li>Prevalence of visual impairment</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Region	<p>From: IASSID Consensus statement “Early identification of hearing and visual impairment in children and adults with an intellectual disability”. Heleen M. Evenhuis &amp; Laura M.D. Nagtzaam (Eds) Special Interest Research Group on Health Issues.</p> <p>Visual and hearing functions in cooperative adults can be screened by health physicians with methods that are normally used in adults without an intellectual disability.</p> <p>Hearing function in insufficiently or non-cooperative individuals can be assessed with objective methods (OtoAcoustic Emissions, Auditory Brainstem Responses) or adapted subjective methods (whispered speech, adapted methods of subjective tone and speech audiometry; visual function by adapted methods of visual acuity measurement and assessment of other visual functions), requiring special expertise and equipment such as Teller Acuity Cards and Cardiff cards.</p>
<ul style="list-style-type: none"> <li>Prevalence of hearing impairment</li> </ul>				

### 5.3.2.11: (2.6) INDICATOR OF MOBILITY FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>2.6 MOBILITY</b>				
<ul style="list-style-type: none"> <li>Prevalence of mobility impairment</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	Currently being examined in ECHI2 for the general population and outlined in draft 16.02.04	Age Gender Region.	Operational definition: <ol style="list-style-type: none"> <li>1. able/unable to go outside the home independently (1)</li> <li>2. able/unable to walk 500 meters; able/unable to walk stairs (2)</li> <li>3. five-points scale: (3)               <ol style="list-style-type: none"> <li>3.1 walks independently</li> <li>3.2 walks independently but unable to climb stairs</li> <li>3.3 walks only short distances, e.g. in the home, not outside</li> <li>3.4 temporary unable to walk (e.g. due to fracture)</li> <li>3.5 unable to walk, wheelchair-bound or bedridden</li> </ol> </li> </ol> A variation of this scale can be: <ol style="list-style-type: none"> <li>4.1 walks independently</li> <li>4.2 walks independently, or can move around in wheelchair, unable to climb stairs</li> <li>4.3 walks –or moves around in wheelchair- in the house</li> <li>4.4 temporarily unable to move around by self</li> <li>4.5 wheelchair-bound, and needs help in moving around in wheelchair or in bed.</li> </ol>

### 5.3.2.12: (3.1) INDICATOR OF PHYSICAL ACTIVITY FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Source Type	Present in:	Stratify by	Operationalisation
<b>3.1 PHYSICAL ACTIVITY</b>				
Physical Activity	Survey	<p>Indicator 1 - Current EUROSTAT recommendation for the general population: Based on WHO (1996), EUROHIS (2001 &amp; 2002) &amp; EUROREVES (2000)</p> <p><b>Indicator 2</b> – Used in Eurobarometer 52.1 conducted in 1999 for the general population.</p> <p>INDICATOR 3 – Institute of European Food Studies (IEFS)</p>	<p>Region Age Gender</p> <p>Note: exercise is undefined</p>	<p>INDICATOR 1 Physical Activity Practices:</p> <ol style="list-style-type: none"> <li>1. Proportion of population who practice hard training and competitive sports more than once a week in their leisure time activity</li> <li>2. Proportion of population who practice jogging and other recreational sports or heavy gardening at least 4 hours a week in their leisure time activities</li> <li>3. Proportion of population who practice walking, bicycling or other light activities at least 4 hours a week in their leisure time activities</li> <li>4. Proportion of population who practice reading, watching TV or other sedentary activities in their leisure time activities.</li> </ol> <p>(If more than one code is applicable, choose the most active)</p> <p>Source: Health in Europe Results from 1997-2000. European Communities 2003</p> <p>INDICATOR 2 Proportion of population who exercise at least twice a week Source: Health Statistics, Key data on health 2002, Data 1970-2002 (European Communities, 2003)</p> <p>INDICATOR 3 Proportion of population who participate in the four most popular physical activities in a typical week:</p> <ol style="list-style-type: none"> <li>1. Walking</li> <li>2. Gardening</li> <li>3. Cycling</li> <li>4. Swimming</li> </ol>

		Dublin, Supported by the European Commission – general population.		(From 17 suggested activities by the EU, for 30 minutes continuously) <i>Source: Health Statistics, Key data on health 2002, Data 1970-2002 (European Communities, 2003)</i>
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### 5.3.2.13: (3.2) INDICATOR OF CHALLENGING BEHAVIOUR FOR PEOPLE WITH INTELLECTUAL DISABILITY

Note: The term ‘challenging behaviour’, in the absence of psychiatric disorder, encompasses a wide range of behaviours that may be harmful to people or property, may be difficult to manage and may limit access to community facilities (Brylewski & Duggan, 2001)<sup>†</sup>. The currently favoured definition of challenging behaviour is ‘culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities’ (Emerson, 1995)<sup>‡</sup>

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>3.2 CHALLENGING BEHAVIOUR</b>				
Prevalence				
<ul style="list-style-type: none"> <li>Prevalence of challenging behaviour.</li> </ul>	Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Level of intellectual disability / adaptive behaviour / activities of daily living	Proportion of population reaching criterion for challenging behaviour using a standardised assessment tool specific for people with intellectual disability.  Aberrant Behaviour Checklist (Aman & Singh, 1986) Behaviour Problem Inventory (Rojahn et al., 2001)  Aman, M.G. & Singh, N.N. (1986) <i>Aberrant Behavior Checklist Manual</i> . New York, Slosson Educational Publications. Aman, M.G., Singh, N.N., Stewart, A.W. & Field, C.J. (1985a) <i>The Aberrant Behavior Checklist: a behavior rating scale for</i>

<sup>†</sup> Brylewski, J., Duggan, L., (2001). Antipsychotic Medication for Challenging Behaviour in People with Learning Disability (Cochrane Review). In: The Cochrane Library, Issue 1, 2004. Chichester, UK: John Wiley & Sons, Ltd.

<sup>‡</sup> Emerson, E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Difficulties*. Cambridge: Cambridge University Press

				<p>the assessment of treatment effects. <i>American Journal of Mental Deficiency</i>, 89, 485-491.</p> <p>Rojahn, J., Matson, J. L., Lott, D., Esbensen, A. J., &amp; Smalls, Y. (2001). The Behavior Problems Inventory: An instrument for the assessment of self-injury, stereotyped behavior and aggression/destruction in individuals with developmental disabilities. <i>Journal of Autism and Developmental Disorders</i>, 31, 577–588.</p>
<ul style="list-style-type: none"> <li>Prevalence of self-injurious behaviour</li> </ul>	Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Level of intellectual disability / adaptive behaviour / activities of daily living	Assessed from relevant section of scales above.

### 5.3.2.14: (3.3) INDICATOR OF PSYCHOTROPIC MEDICATION USE FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>3.3 PSYCHOTROPIC MEDICATION USE</b>				
3.3.1 Use of psychotropic medication	Register if linked to diagnosis of intellectual disability  Survey	For the general population: HIS/HES National Surveys for Belgium, Denmark, France, Ireland, Italy, Netherlands, Austria and Iceland <sup>1</sup>  There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Residence Region	Percent of population who have used psychotropic medication (e.g. anti-psychotics, tranquillizers, anti-depressants, mood stabilizers) prescribed by a physician during the past (surveys specify either A: two weeks or B: one month period). Note: EUROHIS (Nosikov & Gudex 2003) recommend two weeks as a reference period as cited in Aromaa, Koponen & Tafforeau (2003)  <i>Source:</i> Health in Europe: Results from 1997-2000 Survey. European Communities 2003.  British National Formulary 4.2.4.1.1 4.2.3

<sup>1</sup> Surveys recording this information include:

Belgium: Health Interview Survey (conducted every three years)

Denmark: Danish Health & Morbidity Survey (conducted every 6-7 years)

France: Health & Social Protection Survey (conducted every 2 years)

Ireland: Survey of Lifestyle, Attitudes and Nutrition SLAN (conducted every 4 years)

Italy: Health Conditions and the use of Health Services (conducted every 4 years) and Aspects of Daily Life (conducted every year)

Netherlands: Continuous Quality of Life Survey (continuous)

Austria: Microcensus (irregular)

Iceland: Health & Living Conditions in Iceland (irregular)

Polypharmacy	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Residence Region	Proportion of respondents taking more than one psychotropic medication  S. Reiss & M. G. Aman (1998) (Eds) Psychotropic Medications and Developmental Disabilities: the International Consensus Handbook. Nisonger Center for Mental Retardation and Developmental Disabilities, the Ohio State University, OH.
3.3.2 Psychotropic Medication Review	Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Residence Region	Proportion of respondents receiving a review of their psychotropic medication on a three month cycle (as recommended by IASSID Lennox et al., 2002)

### 5.3.2.15: (4.1) INDICATOR OF HOSPITALISATION & CONTACT WITH HEALTH CARE PROFESSIONALS FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>4.1 HOSPITALISATION &amp; CONTACT WITH HEALTH CARE PROFESSIONALS</b>				
4.1.1 In-patient hospitalisation	Register if linked to diagnosis of intellectual disability  Note: Registers such as HIPE (Hospital Inpatient Enquiry System) are likely to grossly underestimate the % of patients with ID being discharged from hospitals  Survey	Present for the general population in European Community Household Panel (1998) (conducted annually)	Age Gender Region Residential Type	<b>SPECIFIC HOSPITALISATION FOR:</b> Fracture A&E General Medicine Neurology Surgery  <b>INDICATOR 1</b>  Number of respondents with in-patient hospitalisation in the last 12 months: ‘During the last twelve months have you been admitted to a hospital as an inpatient?’  <b>INDICATOR 2</b>  Number of nights spent in hospital during the last 12 months ‘How many nights have you spent in hospital over the last 12 months?’

4.1.2 Day-patient hospitalisation	Survey	Limited comparability: Data available for the general population in national surveys in conducted in Germany, Portugal & the UK <sup>2</sup>		Number of respondents with day-patient hospitalisation in the last 12 months.  <i>Source: Health in Europe Results from 1997-2000 Surveys. European Commission (p.119)</i>
• Contact with physician	Survey	Indicator 1 HIS HES National surveys <sup>3</sup> Germany, Spain, Netherlands, Austria, Iceland, Norway- general population  Indicator 2 HIS HES National Surveys <sup>4</sup> for France, Italy, Austria, Iceland, Norway – general population	Age Gender Region Residential Type	<b>INDICATOR 1</b>  Proportion of the population who consulted a medical doctor (GP, specialist) during the past 12 months  <b>INDICATOR 2</b>  Number of visits to a medical doctor (GP, specialist during the last 12 months)

<sup>2</sup> Surveys recording this information include:

Germany: German National Health Examination and Interview Survey (conducted every 6-7 years)

Portugal: National Health Survey (conducted every three years if possible)

United Kingdom: General Household Survey (continuous) and the Health Survey for England

<sup>3</sup> Surveys recording this information include:

Germany: German National Health Evaluation and Interview Survey (conducted every 6-7 years)

Spain: National Health Survey (irregular)

Netherlands: Continuous Quality of Life Survey (continuous)

Austria: Microcensus (irregular)

Iceland: Health & Living Conditions in Iceland (irregular)

Norway: Survey on Living Conditions (every 3-4 years)

<ul style="list-style-type: none"> <li>• Contact with mental health professional</li> </ul>	Survey	For the general population: Eurobarometer 58.2	Level of intellectual disability / adaptive behaviour / activities of daily living	<p>Suggest comparison with Eurobarometer</p> <p>In the last twelve months did you seek help from somebody in respect of a mental health problem?</p> <p>No</p> <p>Yes, a general practitioner</p> <p>Yes, a chemist</p> <p>Yes, a psychiatrist</p> <p>Yes, a psychologist</p> <p>Yes, a nurse</p> <p>Yes, a social worker</p> <p>Yes, other professional help</p> <p>Yes, other (spontaneous)</p> <p>Don't know</p>
<ul style="list-style-type: none"> <li>• Contact with dentist</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	HIS/HES in various Member States collect this data allowing comparison with the general population. (Source: Health in Europe Results from 1997 to 2000, European Commission)	Level of intellectual disability / adaptive behaviour / activities of daily living	Has the individual been to a dentist in the last 12 months?

<sup>4</sup> Surveys recording this information include:

France: Health & Social Protection Survey (conducted every 2 years)

Italy: Health Conditions and the use of Health Services (conducted every 4 years) and Aspects of Daily

Austria: Microcensus (irregular)

Iceland: Health & Living Conditions in Iceland (irregular)

Norway: Survey on Living Conditions (every 3-4 years)

### 5.3.2.16: (4.2) INDICATOR OF HEALTH CHECK UPS FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>4.2 HEALTH CHECK UP</b>				
General Prevention Examination	Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Age Gender Region Residential Type	<p>Proportion of population who have received a medical check up (yes/no) in the previous twelve months.</p> <p>Health check up should cover items such as those assessed by:  <i>Three checklists are presented for consideration:</i>            (1) <i>Cardiff Health Check (Kerr)</i>            (2) <i>St. Georges Health Check Questionnaire</i>            (3) <i>Structured Health Check, (Martin, 2003)</i></p> <p>A sample of checklists appear in Appendix J</p>

### 5.3.2.17: (4.3) INDICATOR OF HEALTH PROMOTION FOR PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>4.3 HEALTH PROMOTION</b>				
4.3.1 Health promotion				
<ul style="list-style-type: none"> <li>Breast cancer screening coverage</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Level of intellectual disability / adaptive behaviour / activities of daily living	Women with intellectual disabilities age 50+ who have received a mammogram in preceding 2 years
<ul style="list-style-type: none"> <li>Cervix cancer screening coverage</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Level of intellectual disability / adaptive behaviour / activities of daily living	Women with intellectual disabilities aged 35-50 years who have ever received a pap test  Women with intellectual disabilities aged 35–50 years who have received a pap test in the last 3 years
<ul style="list-style-type: none"> <li>Hypertension/cholesterol screening coverage</li> </ul>	Register if linked to diagnosis of intellectual disability  Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Level of intellectual disability / adaptive behaviour / activities of daily living	Adults with intellectual disabilities who have had blood pressure measured in last 2 years  Adults with intellectual disabilities who have had blood cholesterol screening in the last 5 years.

<ul style="list-style-type: none"> <li>Vaccination</li> </ul>	<p>Register if linked to diagnosis of intellectual disability</p> <p>Survey</p>	ECHI	Level of intellectual disability / adaptive behaviour / activities of daily living	<p>The proportion of adults who have received vaccinations for the following during the previous 10 years:</p> <p>Tetanus</p> <p>Influenza</p> <p>Hepatitis B</p>
4.3.2 Information need				
<ul style="list-style-type: none"> <li>Accessible information</li> </ul>	Survey	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Regional	Presence of accessible information on screening procedures specifically targeted at people with intellectual disability, their family and advocates.

### 5.3.2.18: (4.4) INDICATOR OF INTELLECTUAL DISABILITY SPECIFIC TRAINING FOR PHYSICIANS WORKING WITH PEOPLE WITH INTELLECTUAL DISABILITY

Indicator (group)	Potential Source Type	Currently present in:	Stratify by	Operationalisation
<b>4.4 INTELLECTUAL DISABILITY SPECIFIC TRAINING FOR PHYSICIANS</b>				
<ul style="list-style-type: none"> <li>Intellectual disability specific training for physicians</li> </ul>	University and statutory health services training prospectus.	There is no systematic data collection across the European Union for this information on behalf of people with intellectual disability.	Region	Number of hours of intellectual disability specific training on undergraduate medical curriculum.  Number of hours of intellectual disability specific training to primary care physicians in training.