Ageing with intellectual disability –
a study based on six national registers

GERD AHLSTRÖM, PROFESSOR & MAGNUS SANDBERG, PHD
The need of the project came from the practice of disability service

• Questions about what happens in the ageing with intellectual disability (ID) was expressed by staff working in disability services already for 15 years ago.

• More recently for example have the managers wondering how they best can support the staff to manage the everyday care and service with the steadily growing number of older people with ID living in group homes.

• The leaders expressed that they wanted the research to help them understand how they could help their staff in the everyday care and service.
Scientific rationale for this project

• Increased life expectancy, both in the general population and in people with intellectual disabilities (ID)

• Little is known about ageing in this group

• Few comprehensive studies, usually small sample sizes, cross-sectional, including all/low ages, and/or without control group

• Few studies looking at the ‘big picture’, i.e. just investigating one outcome, for example use of one type of healthcare
1) Literature review

The literature review revealed that epidemiological knowledge from Sweden about ageing among people with intellectual disability since childhood is missing.

2) Decision of design of the project

Design: 6 national register including ID and reference group from population register.

3) Reference group with managers and representative of FUB (user participation) from year 2012

4) The studies investigate different research questions.

5) Knowledge dissemination to the practice

There is a large need of education and preventative intervention to reduce ill-health and unplanned health utilization.

4) Identifying problematic areas

3) Reference group with managers and representative of service users

5) Knowledge dissemination to the practice

Definitions

- *Intellectual disability* (ID) is a disability characterized by significant limitations in both *intellectual functioning* and in *adaptive behavior*, which covers many everyday social and practical skills. This disability originates **before the age of 18**

- The LSS: the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments [Lagen om stöd och service till vissa funktionshindrade]. LSS describes which persons are covered by the law. They are divided into three groups based on different assessment bases, so-called personal circles.
  - Personal circles 1 (Personkrets 1): With developmental disorder, autism or autism-like condition.
Support and services according to LSS

- Counselling and other personal support
- Personal assistance
- Companion service
- Contact person
- Relief service in the home
- Short stay away from home
- Daily activities

- Residence with special services for adults or other specially adapted housing
- Short period of supervision for schoolchildren over the age of 12
- Living arrangements in a family home or in a residence with special services for children and adolescents
Three different acts for people with ID

- the **LSS-Act** for support and service for certain disability (for all ages, municipalities' responsibility)

- the **Social Services Act** (for persons 65 years old or above, municipalities' responsibility)

- the **Health and Medical Services Act** (for all ages, county councils’ responsibility)
Ethical considerations before project start

- Ethical approval from The Regional Ethical Review Board in Lund
- Ads in a newspapers about the study and how to withdraw
- Additional ethical reviews by Statistics Sweden and Swedish National Board of Health and Welfare
- Anonymized dataset
- Encrypted data files stored on external hard drives
- Analyzed on computers without internet access
Research group

Gerd Ahlström
Project leader

Magnus Sandberg

Anna Axmon

Nawi Ng

Peter Höglund

Eva Flygare-Wallén

Jonas Eberhard

Hans Westergren

Magnus Tideman

Jimmie Kristensson

Patrik Midlöv

Barry Karlsson

Lena Nylander

Petra Björne

Naida El Mrayyan

Lund University
To use registers as proxy

- To be 'creative' in using the registers
- Diagnoses – also a measure of the prevalence of a disease?
- Prescribed medications – a measure of consumed medications?
- Clinically relevant question vs. available data
Validity of the registers

- Poor validity for some of the registries for some of the years (i.e. Social Services)
- Lacking information for certain registers (i.e. primary care)
- Registers connected to reimbursement system -> higher validity
- Administrative registers (of which municipalities are responsible for) are less fitted for research purposes.
LSS-register

Alive Dec 31, 2012
LSS support in 2012
55+ years in 2012

ID cohort
n=7936

LSS 2004-2012
ID prevalence
(published)

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3. Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden
Prevalence of ID among men and women

Prevalence of ID for people by age group and sex

Ng N, Sandberg M, Ahlström G. J Intellect Disabil Res. 2015 Dec;59(12):1155-67

Moran’s scatterplot map.
Main Results - *Prevalence of older people with intellectual disability in Sweden*

- The prevalence of ID among older individuals aged 55+ in Sweden increased from 2004 to 2012.
- The prevalence was consistently higher among men, and the gender gap increased slightly in recent years.
- Age-specific prevalence estimates showed ID to be higher in younger age groups, and the gender gap decreased in older age groups.
- The prevalence was higher in northern counties in Sweden (over 500 individuals per 100,000 population aged 55+).
- Higher prevalence areas were clustered in northern municipalities, whereas municipalities with high prevalence of older individuals with ID in the middle and southern regions of Sweden demonstrated a more widespread distribution.
The Total Population Register (RTB)

- Statistics Sweden
- Excerpt from the Tax Register
- Vital data on all people in Sweden
  - Personal identification number
  - Age
  - Sex
  - Residence (county, municipality, congregation, house)
  - Civil status
  - Etc
LSS-register

Alive Dec 31, 2012

LSS support in 2012

55+ years in 2012

ID cohort
n=7936

Matched by sex and year of birth

RTB

gPop cohort
n=7936

LSS 2004-2012
ID prevalence
(1 publ)
The National Patient Register (NPR)

- In-patient care since 1987
  - Recorded at discharge
- Outpatient visits since 2001
  - Including day surgery and psychiatric care
- Patient data
- Geographical data
- Administrative data
- Medical data (ICD-10)
LSS 2004-2012 ID prevalence (1 publ)
LSS-register

ID cohort n=7936
Alive Dec 31, 2012
LSS support in 2012
55+ years in 2012

RTB

Matched by sex and year of birth

NPR

Somatic diagnoses
(1 publ)

Somatic health care
(1 publ, 1 man)

Psychiatric diagnoses
(1 publ, 2 subm)

Psychiatric health care
(1 publ)

Falls
(submitted)

Geographical variations
(man)

gPop cohort n=7936

LSS 2004-2012 ID prevalence
(1 publ)

Magnus Sandberg (1), Gerd Ahlström (1), Anna Axmon (1,2) Jimmie Kristensson (1,3)

1. Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden
2. Department of Occupational and Environmental Medicine, Lund University, Lund, Sweden
3. Department of Health, Blekinge Institute of Technology, Karlskrona, Sweden
Main results *Somatic healthcare utilisation patterns*

- In the younger age groups, the ID group had higher healthcare utilisation compared with the general population sample, with higher risks for planned and unplanned somatic in- and outpatient care, particularly for unplanned inpatient care.

- Decreasing healthcare utilisation were seen with age; with lower risks in the ID group for the oldest age groups.

- In those with at least one health care visit, the ID group had a longer unplanned length of stay in the younger age groups, but fewer planned visits to physicians in somatic outpatient care compared with the control group.
The Prescribed Drug Register (PDR)

- All dispensed drugs since July 2005
- About 84% of all drug sales
- Patient data
- Geographical data
- Administrative data
- Medical data (ATC)

Anna Axmon (1,2), Gerd Ahlström (2) and Peter Höglund( 3)

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2. Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden
Main results *Prevalence and treatment of diabetes mellitus (DM) and hypertension (HT)*

- People with ID were 20% more likely than the general population to have a diagnosis of DM, and 26% more likely to have prescription of drugs for DM.
- People in the general population were 81% more likely to have a diagnosis of HT, and 9% more likely to have a prescription of drugs for HT.
- Among those with diabetes, ID was associated with higher occurrence of prescription of insulin combination drugs and sulfonylureas, but lower occurrence of prescription of dipeptidyl peptidase (DPP) 4-inhibitors and exenatide/liraglutide.
- Among those with HT, ID was associated with higher occurrence of prescription of diuretics, but lower occurrence of prescription of calcium channel blockers and angiotensin II antagonists.
LSS 2004-2012 ID prevalence (1 publ)
LSS-register
ID cohort n=7936
Alive Dec 31, 2012 LSS support in 2012 55+ years in 2012
RTB
gPop cohort n=7936
Matched by sex and year of birth

Somatic diagnoses (1 publ)
Somatic health care (1 publ, 2 man)
Psychiatric diagnoses (3 publ)
Psychiatric health care (1 publ)
Falls (submitted)
Geographical variations (man)

NPR
Depression (1 man)
Down syndrome (1 man)
Autism (1 submitted)
Dementia

PDR
Respiratory (1 publ)
DM & HT (1 publ)
FRIDs and falls (submitted)
PIMs (1 publ)
Pain (man)
Antipsychotics (man)
Drug prescription (1 publ)

PDR
Health care (1 publ)

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People with dementia with certain prescriptions

- Percentage of people with dementia with prescriptions of antipsychotics (grey dotted line), benzodiazepine derivatives (grey solid line), anti-cholinesterases (black dotted line), and memantine (black solid line) in a group of people with intellectual disability (ID; bottom) and a general populationsample (gPop; top).
Main results *Use of antipsychotics, benzodiazepine derivatives, and dementia medication*

- People with ID/ASD and dementia were more likely than people with ID/ASD but without dementia to be prescribed antipsychotics (50% vs 39% over the study period; odds ratio (OR) 1.85, 95% confidence interval 1.13–30.3) and benzodiazepine derivatives (55% vs 36%; OR 2.42, 1.48–3.98).

- They were also more likely than people with dementia from the general population to be prescribed antipsychotics (50% vs 25%; OR 3.18, 1.59–6.34), but less likely to be prescribed Acetylcholinesterase inhibitor (AChEIs) (28% vs 45%; OR 0.32, 0.16–0.64).
The Cause of Death Register

- All deaths among Swedish citizens (in Sweden or abroad) (since 2012 all deaths in Sweden, regardless of citizenship)
- Started in 1961
- Cause of death (ICD-10)
- Geographical data
- Administrative data
LSS-register

ID diagnosis (ICD-10)
F70-73, F78-79, F84-89, Q90
Hospitalization 2002-2015

NPR

Services 2007-2015
55+ years when included

LSS-register

ID cohort n=15,289

1:5 Matched by sex and year of birth

RTB

gPop cohort n=76,445

Cause of Death register

Mortality patterns (1 publ)

Mortality patterns (1 publ)

LUND UNIVERSITY

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4. Department of Health Sciences, Faculty of Medicine, Lund University, P.O. Box 157, SE-221 00 Lund, Sweden.
Main results *Mortality patterns and risk among older men and women with intellectual disability*

- The overall mortality rate among individuals with ID was 2483 per 100,000 people compared with 810 in the control population.
- Among those who died, more individuals with ID were younger than 75 years and unmarried.
- Leading causes of death among individuals with ID were circulatory diseases (34%), respiratory diseases (17%) and neoplasms (15%).
- Leading causes of death in a sub-sample with Down syndrome (DS) were respiratory diseases (37%), circulatory diseases (26%) and mental/behavioural disorders (11%).
- Epilepsy and pneumonitis were more common among individuals with ID than controls.
- Alzheimer’s disease was common in the control population and individuals with DS, but not among those with ID when DS was excluded.
- Individuals with ID had a higher overall mortality risk (hazard ratio [HR] 4.1, 95% confidence interval [CI] 4.0–4.3) and respiratory disease death risk (HR 12.5, 95% CI 10.9–14.2) than controls.
Care for this group, particularly during the terminal stage of illness, needs to be tailored based on understanding of their main health problem.
Gerd Ahlström; 18-01-24
Summary

- 6 registries
- 15 researchers/authors
- 5 (3?) year project
- 13 accepted publications
- 3 submitted papers
- 7 papers in manuscript
Publication list


Thank you for your attention!
<table>
<thead>
<tr>
<th></th>
<th>Individuals with intellectual disability (n=15,289)</th>
<th>Matched control population (n=76,445)</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td></td>
<td>Sub-sample of individuals with DS (n=942)</td>
<td>Sub-sample of individuals with ID (DS excluded) (n=14,347)</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>486 (51.6)</td>
<td>7,844 (54.7)</td>
</tr>
<tr>
<td>Women</td>
<td>456 (48.4)</td>
<td>6,503 (45.3)</td>
</tr>
<tr>
<td><strong>Age group in 2002</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42 – 44 year</td>
<td>88 (9.3)</td>
<td>1,720 (12)</td>
</tr>
<tr>
<td>45 – 54 year</td>
<td>440 (46.7)</td>
<td>6,044 (42.1)</td>
</tr>
<tr>
<td>55 – 64 year</td>
<td>360 (38.2)</td>
<td>4,182 (29.2)</td>
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<tr>
<td>65 – 74 year</td>
<td>50 (5.3)</td>
<td>1,755 (12.2)</td>
</tr>
<tr>
<td>75 – 79 year</td>
<td>1 (0.1)</td>
<td>401 (2.8)</td>
</tr>
<tr>
<td>80+ year</td>
<td>3 (0.3)</td>
<td>245 (1.7)</td>
</tr>
<tr>
<td><strong>Mean age at death (standard deviation)</strong>*</td>
<td>63.5 (5.4)</td>
<td>72.1 (9.4)</td>
</tr>
<tr>
<td><strong>Number of deaths during 2002-2015 (%)</strong></td>
<td>761 (80.8)</td>
<td>3,977 (27.7)</td>
</tr>
<tr>
<td><strong>Mortality rate during 2002-2015 (per 100,000 people)</strong>*</td>
<td>8,600</td>
<td>2,186</td>
</tr>
</tbody>
</table>

*Note: * significantly differences (p<0.001).