

Health of people with intellectual disabilities in Scotland -a total population study

Laura Anne Hughes-McCormack, Ewelina Rydzewska, Angela Henderson, Sally Ann Cooper



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Health of people with intellectual disabilities

- little is known about how people with intellectual disabilities/and or carers report health status across the lifespan
- few studies identified focus on reported health of people with intellectual disabilities using robust methods
- investigating how people with intellectual disabilities (or carers) rate their health, we may be able to better understand health inequalities and health needs of people with intellectual disabilities

Reported health status

Only two studies were identified investigating self-reported general health of adults with intellectual disabilities with a general population comparison.

Population-based studies reporting the prevalence of poor general health of people with intellectual disabilities

Publication	Number (n)	Country	Sample	Method of assessment	Prevalence of poor health		Limitations
					General population	Intellectual disabilities	
Emerson et al (2014)	(1)n=316† (2)n=415*	England	Adults 16-49, two population based household surveys	(1)Life Opportunities Survey (LOS) (Office of National Statistics) 2009-11, (n=37,513), 16+/ (2)Understanding Society (McFall and Garrington, 2011) 2009-11, 50,976, 16+	(1) 10.4% (2) 12.9%	(1) 50.6% (2) 66.0%	- Identified sample from low educational attainment and self-reported difficulties in learning. -Age range restricted to 16-49 due to historical changes in qualifications in the UK. -Used surveys which likely excluded people with severe intellectual disabilities or people living in residential settings
Haider et al (2013)	n=897*	Australia	Adults 18 years and over/ mean age 38.4 years from an administrative database of adults known to department of human services, population based cohort study	Computer assisted telephone interviews/surveys of health, well-being and lifestyle questions	18.3%	24.5%	-low participation rate -use of administrative database to identify participants with intellectual disabilities

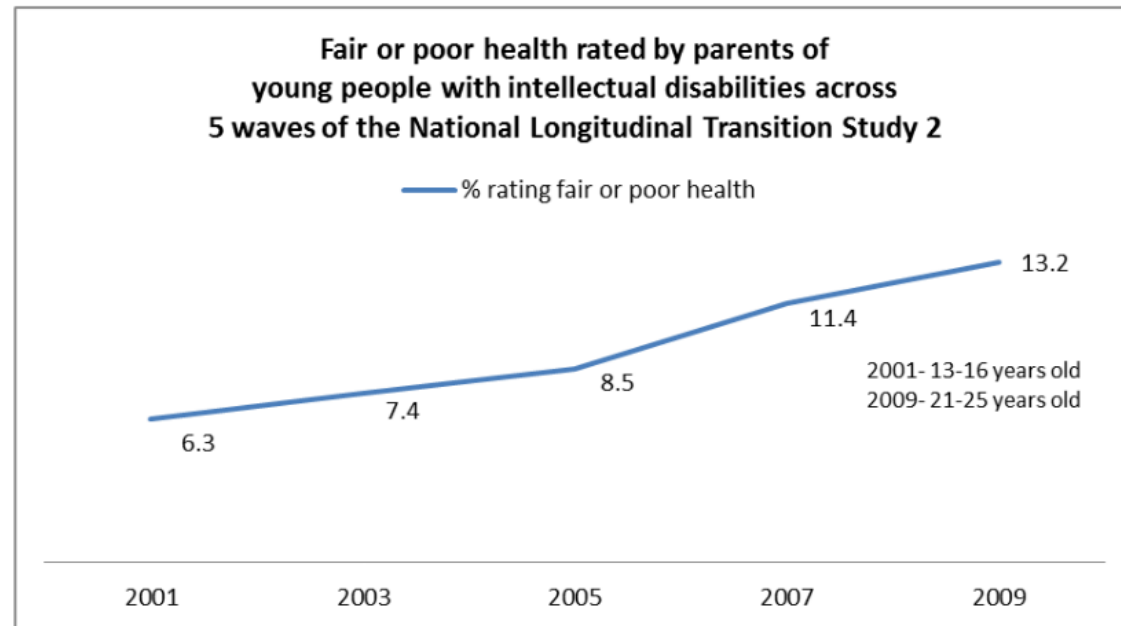
Binary variables created by authors from five point scale of general health to represent 'poorer health'

† scale of very good, good, fair, bad, very-bad (poor health = fair-very bad responses)

* scale of excellent, very good, good, fair, poor (poor health = fair-poor responses)

National Longitudinal Transition Study 2

- study of young people with additional support needs, 13-25 years in the USA
- data collected at five time points (waves) across 2001-2009



- ratings of fair or poor health made by parents (n=862 in 2001) for children/young people with intellectual disabilities increased at each data collection point

Key limitations of previous research

- From current evidence, we can not conclude if people with intellectual disabilities report poorer health across the lifespan compared to the general population or not.
- This is due to a lack of robust studies, which include;
 - large sample sizes
 - complete populations
 - general population comparisons
 - gender or age comparisons

Aims/Research Questions

For people with and without intellectual disabilities in the whole of Scotland, we compared reported:

- 1) general health status
- 2) mental health and other disabilities
- 3) numbers of co-morbidities
- 4) health limitations



Analysis of Scotland's Census 2011 data

- Data were downloaded from the National Records of Scotland census data archive

Measures/variables

General health status

- single question with a five point response scale: 'How is your health in general;
- *very good, good, fair, bad, very bad*

Long term conditions

- deafness or partial hearing loss
- blindness or partial sight loss
- learning disability (for example, Down 's syndrome)**
- learning difficulty (for example, dyslexia)
- developmental disorder (for example, ASD or Asperger's Syndrome)
- physical disability
- mental health condition
- long-term illness, disease or condition
- OR other condition (specify)
- OR no condition

Number of conditions

- either 1, 2, or 3+ other conditions from the above options
- for people with intellectual disabilities- any additional conditions counted

Daily limitations due to health problem

- single question with a three point response scale: 'Are your day to day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (includes problems related to old age)
- *yes limited a lot, yes limited a little, no*

Analysis

- generated descriptive statistics comparing people with and without intellectual disabilities
- examined general health, mental health and other disabilities
 - age differences
 - gender differences



3 Results

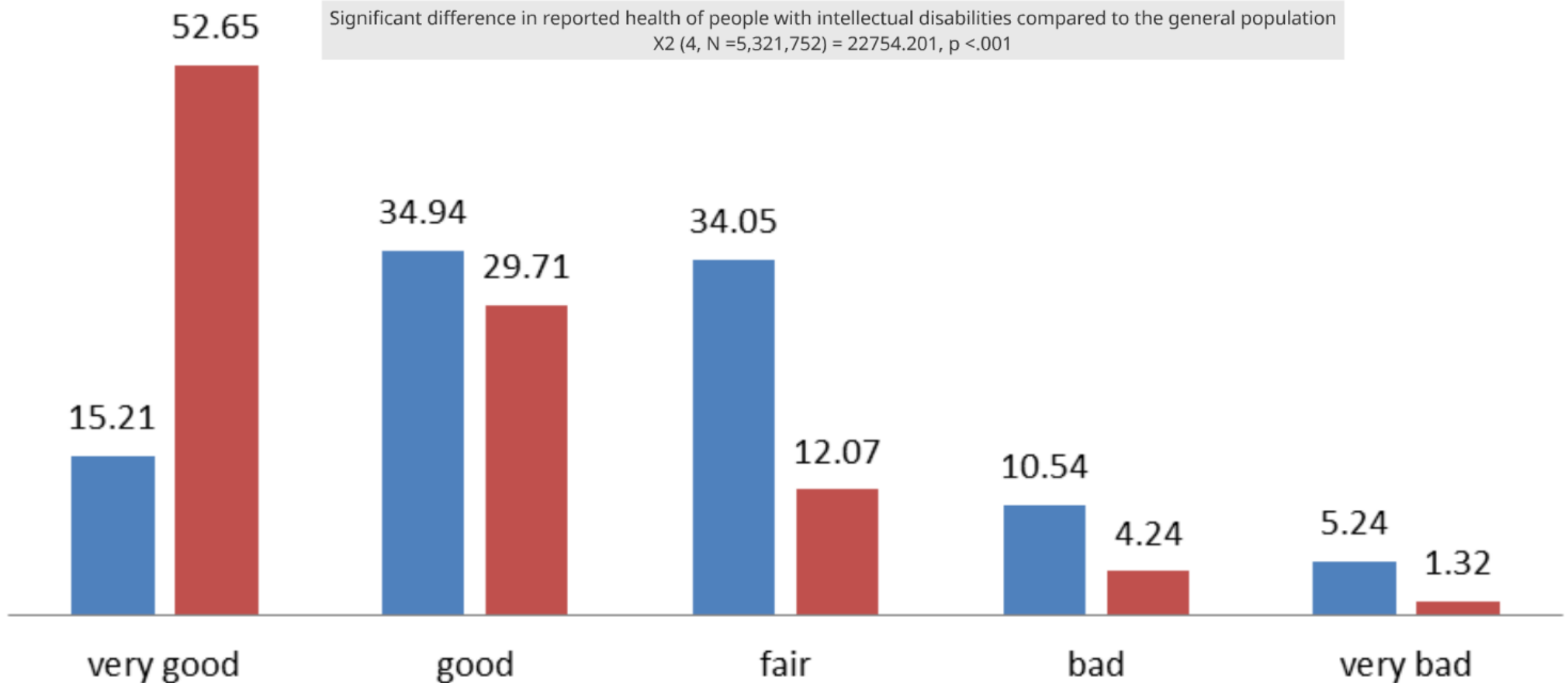
Prevalence of intellectual disabilities

- identified 26,349 people with intellectual disabilities;
0.5% of the total Scottish population (n=5,295,403)
 - 11,200 (42.5%) females
 - 15,149 (57.5%) males
 - 5,234 children (0-15 years)
 - 21,115 adults (16-85+ years)

Reported health status of Scottish people aged 0-85+

■ % of people with intellectual disabilities ■ % of general population

Significant difference in reported health of people with intellectual disabilities compared to the general population
 $\chi^2(4, N = 5,321,752) = 22754.201, p < .001$

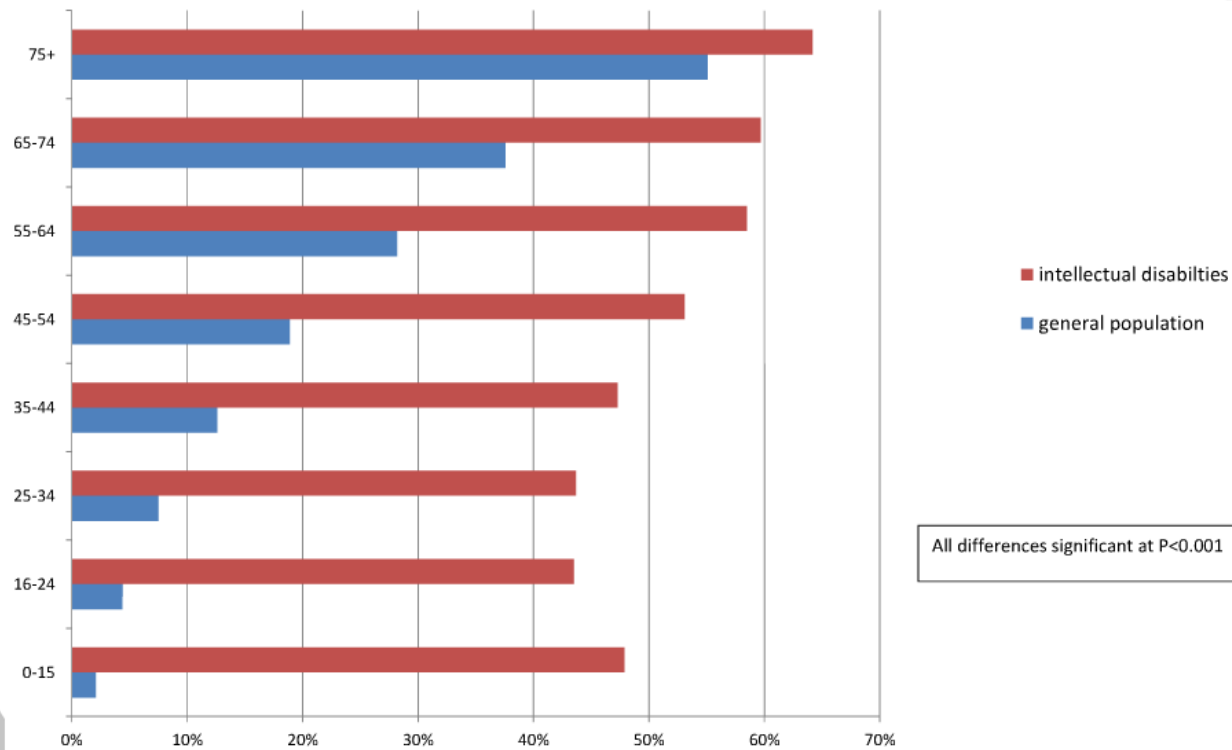


General health status

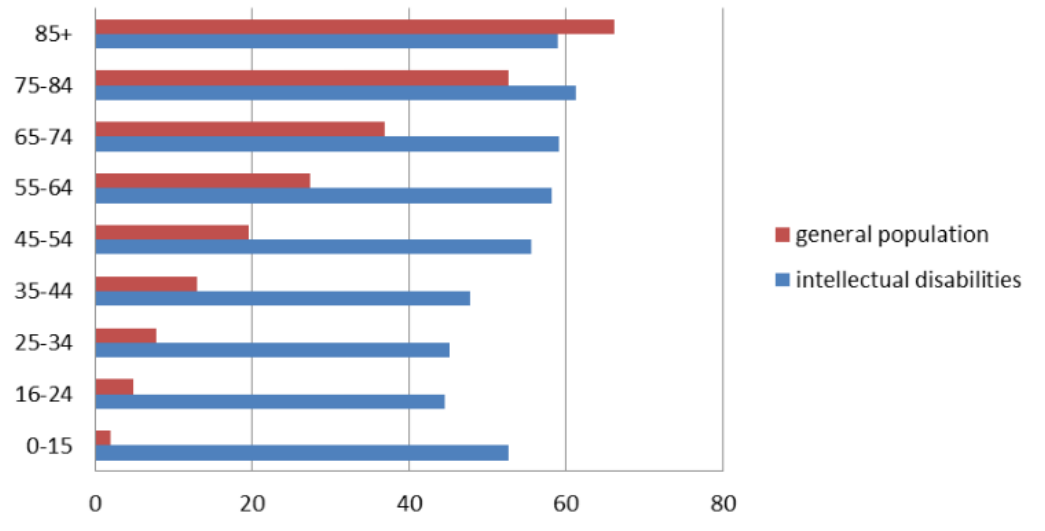


- people with intellectual disabilities reported poor health (*fair/bad/very bad*) more frequently than the general population (49.84% vs. 17.36%)
- OR= 4.593 (4.483-4.705), $p < .0001$
 - how does this compare to previous studies?
 - only one part of Emerson *et al's* (2014) study* & no others directly comparable
 - 50.6% for adults in Emerson *et al* (2014)
 - 50.3% for 'adults' only in the current study

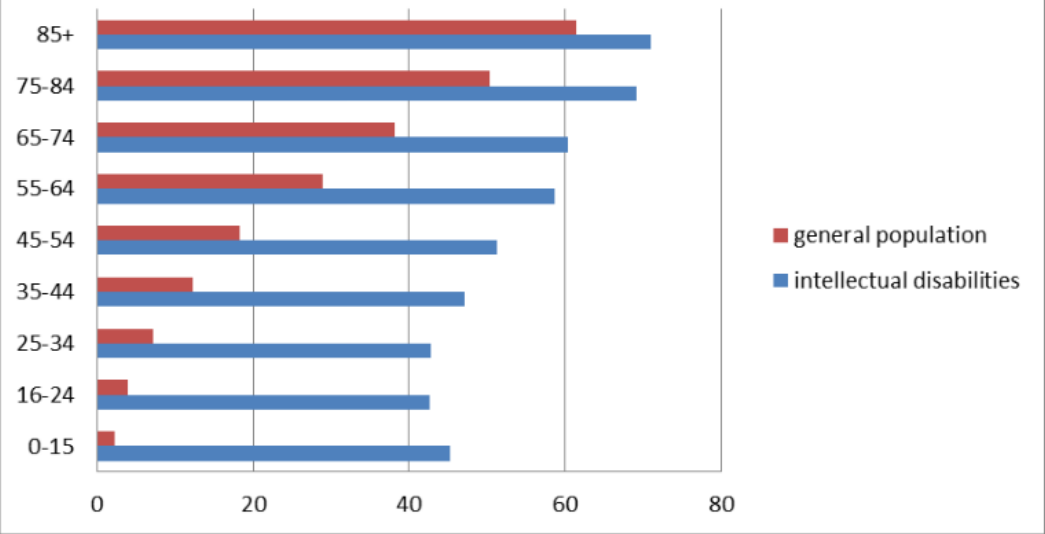
Poor general health by age



Poor health by age for females in Scotland

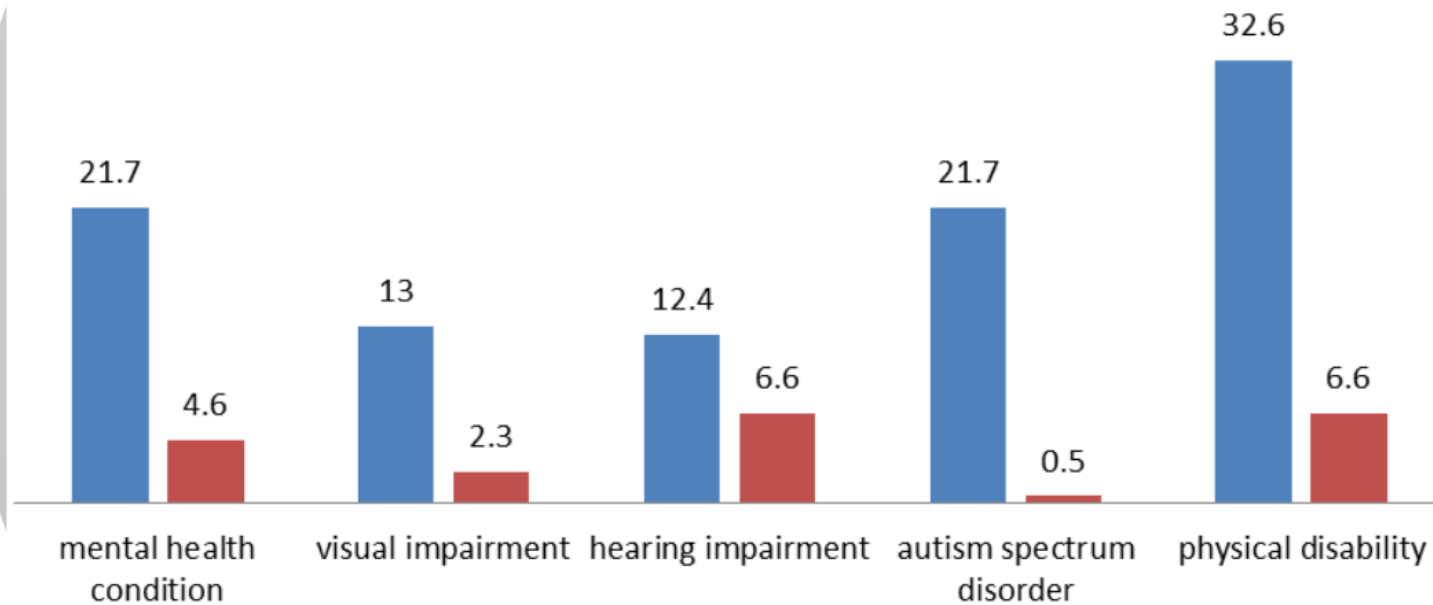


Poor health by age for males in Scotland

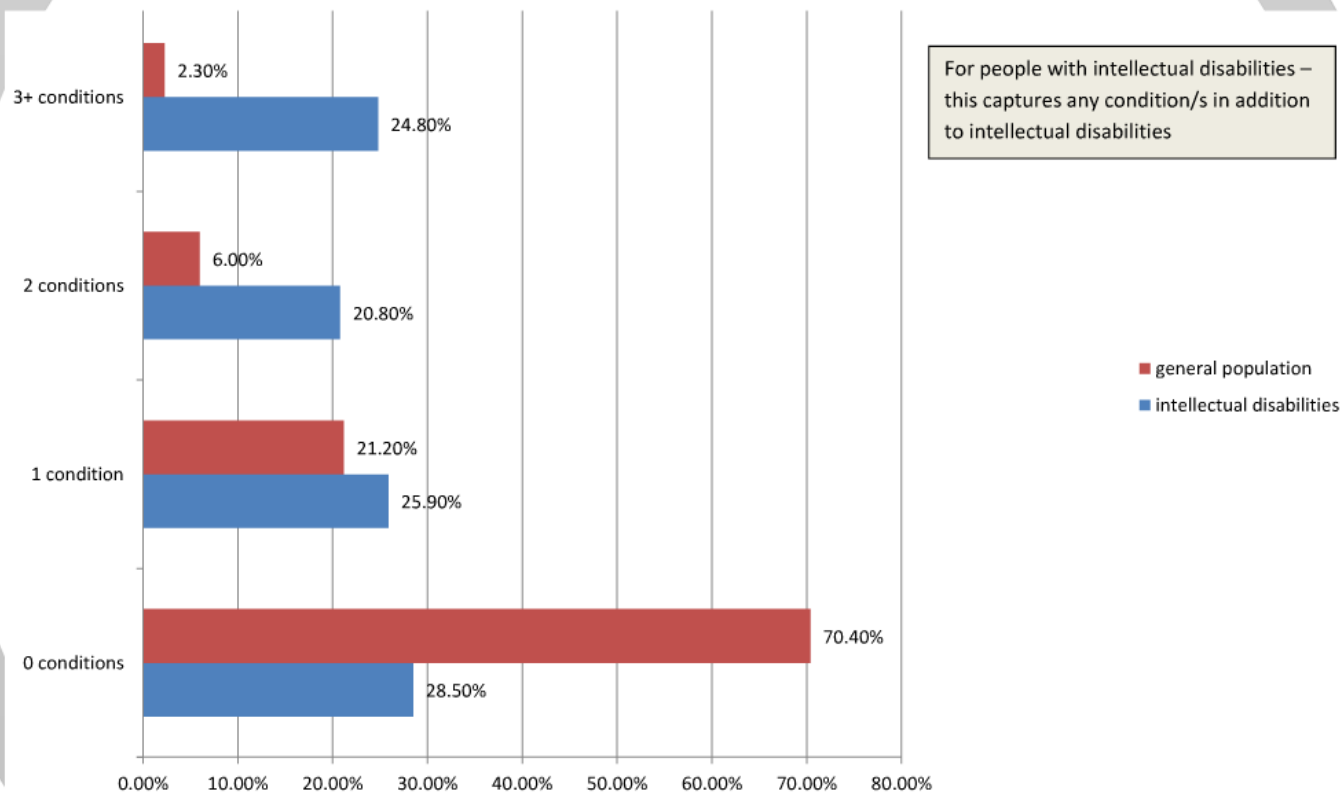


Prevalence of mental health conditions & other disabilities

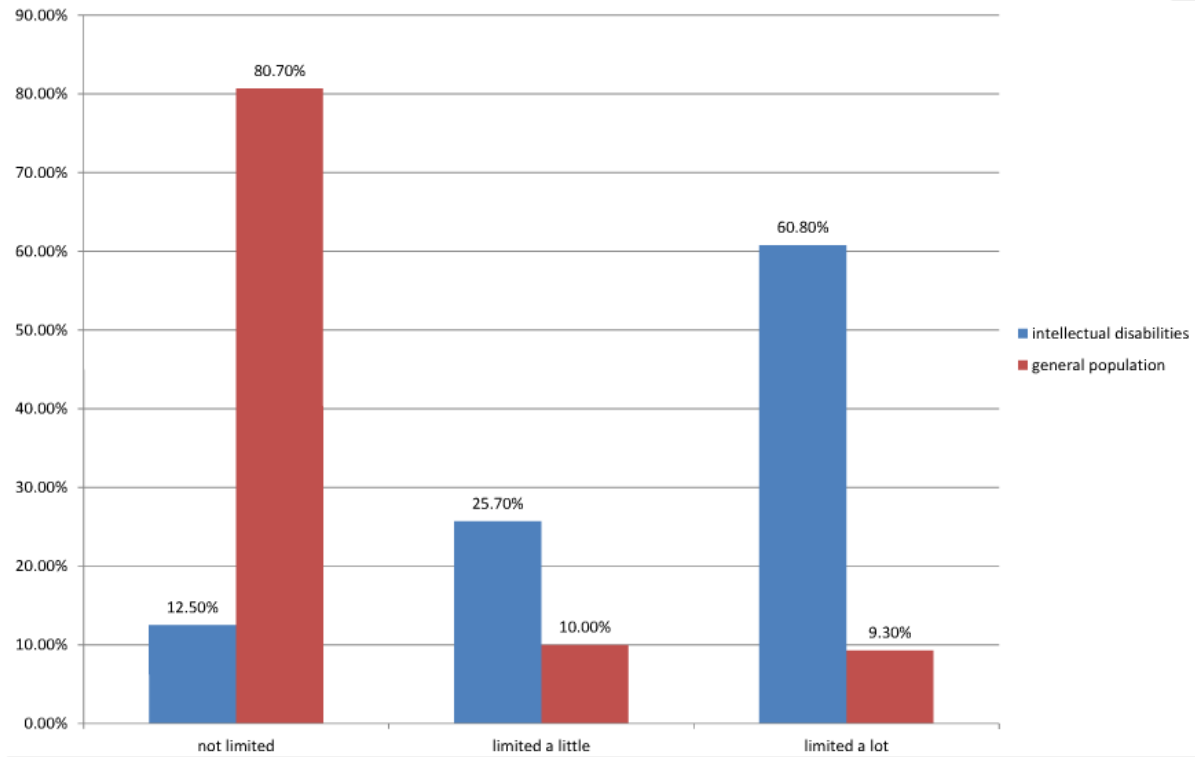
■ % of people with intellectual disabilities ■ % of general population



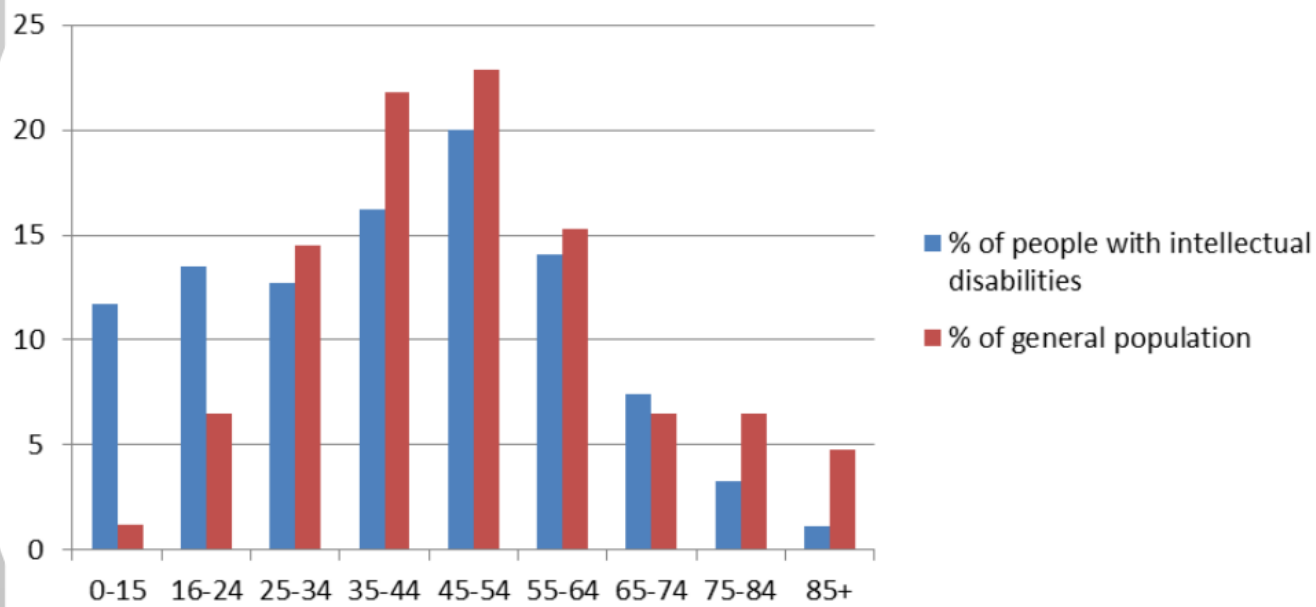
Number of other conditions



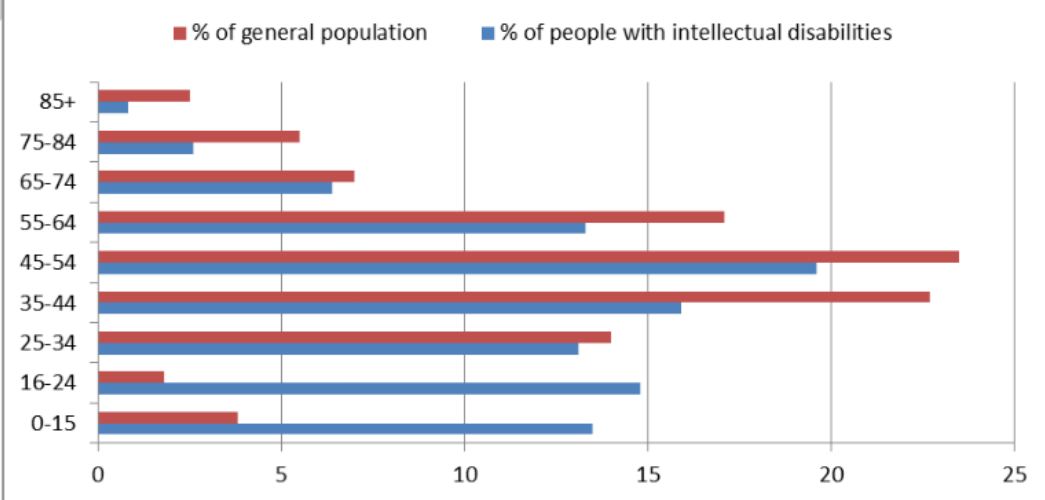
Health limitations



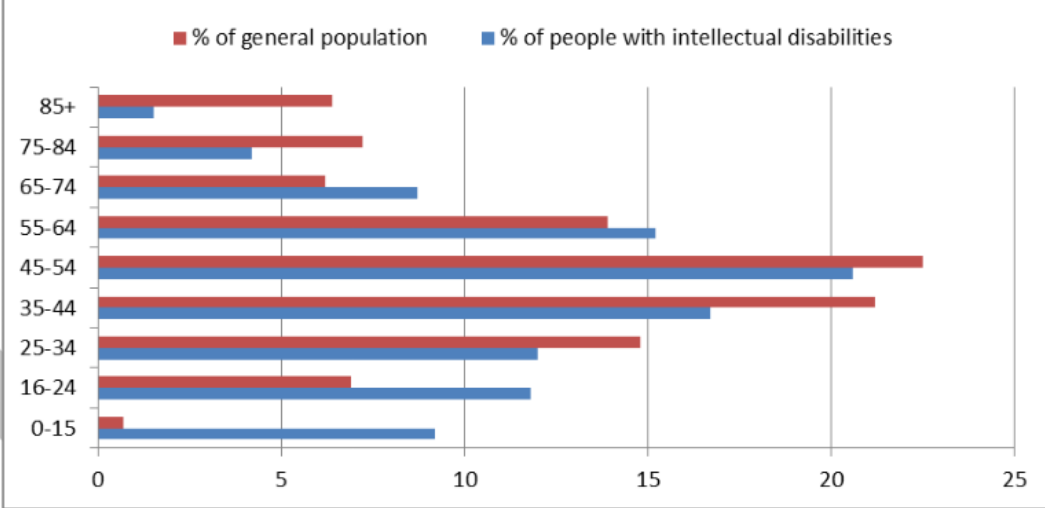
Mental ill-health by age



Prevalence of mental-ill health among Scottish males by age group



Prevalence of mental ill health among Scottish females by age group



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**limitations
& strengths**

Limitations

- unable to establish proxy from self reports of people with intellectual disabilities
- cannot identify severity of intellectual disabilities
- based on subjective reporting of intellectual disabilities and health

Strengths

- The first whole population study in Scotland investigating health status of people with intellectual disabilities
 - Largest study identified investigating reported health across the lifespan

conclusions

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Conclusions

- 1) People with intellectual disabilities rate their health less favourably than the general population at all ages
 - poorest for younger people with intellectual disabilities
 - in particular, females with intellectual disabilities at younger age groups
- 2) People with learning disabilities report more mental illness than the general population
 - most prominent among young people with intellectual disabilities
 - in particular, males with intellectual disabilities
- 3) People with learning disabilities report more other disabilities than the general population
 - more multi-morbidity
- 4) Health limitations were more burdensome for people with intellectual disabilities, with a larger impact reported on daily activities, than for the general population.

This is being further investigated by the Scottish Learning Disabilities Observatory