Life expectancy and causes of death of people with Intellectual disabilities: a systematic review

Lisa O’Leary, Laura Hughes-Mccormack, Sally-Ann Cooper

Introduction
- The life expectancy of people with intellectual disabilities has increased in recent years but it is still thought to remain lower than the general population.
- There is speculation that the deaths of people with intellectual disabilities are less likely to be investigated, than those in the general population.
- We undertook a systematic review, in order to synthesise this evidence.

Methods
- The following online databases were searched for key words: CINAHL, MEDLINE, PsychINFO, Web of Science, Ebase.
- Key search terms related to 'Death' and 'Intellectual Disability'.

Research Questions
- What is the life expectancy of people with intellectual disabilities?
- What are the main causes of death of people with intellectual disabilities?

Inclusion criteria
- All undertaken in high income countries
- Report deaths or mortality rates
- At least 50% of population have an intellectual disability
- Peer reviewed
- Primary research
- All ages, years and study designs

Exclusion criteria
- Full paper not available in English
- Proportion of participants with intellectual disabilities unclear or not reported separately
- >50% lived in institutions
- Case studies <20 people
- Resettlement/relocation studies
- Post operative or post-treatment deaths
- Studies exclusively comprising specific populations (Down Syndrome)

Flow diagram illustrating studies identified

Results from searching of databases and other sources (n=23,299)

Duplicates removed (N=5471)

Titles screened after duplicates removed (N=17,828)

Titles excluded (N=15,825)

Abstracts screened (N=2000)

Abstracts excluded (N=1687)

Full-text articles assessed for eligibility (N=313)

Studies included in synthesis of findings (N=25)

Results
- The studies found that the average life expectancy is 10-20 years lower than the general population. They also found that:
  - Women with intellectual disabilities have higher standardised mortality rates than men
  - This demonstrates a greater inequality in death rates for women with intellectual disabilities compared to men
  - The studies also found that the following subgroups have lower life expectancy and higher mortality rates than the general population:
    - Individuals with severe intellectual disabilities
    - Individuals with co-morbidities such as epilepsy and mobility/visual/hearing impairment
    - Individuals with genetic syndromes

Limitations
- The studies found that respiratory and circulatory disease were the main causes of death. They also found that:
  - Respiratory, congenital malfunctions, gastro-intestinal and neurological causes of death were more common in the intellectual disability population
  - Cancer was less common in the intellectual disability population

Conclusions
- Individuals with intellectual disabilities have a shorter life expectancy than the general population
- The cause of death profile differs to the general population, with respiratory disease being most common, and likely to be preventable in some cases
- Primary care and health promotion interventions are required to target these premature and specific causes of death

Future Directions
- The Scottish Learning Disabilities Observatory is investigating life expectancy and causes of death in the intellectual disability population further

Key references