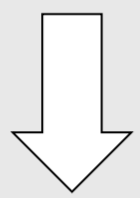




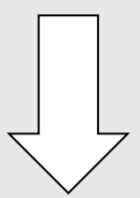
Lisa O'Leary, Laura Hughes-McCormack, Sally-Ann Cooper

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 population¹
- There is speculation that the deaths of people with intellectual disabilities are less likely to be investigated, than those in the general population²



- There is a need for a robust appraisal of the evidence for low life expectancy and specific cause of death profile in the intellectual disability population³



- We undertook a systematic review, in order to synthesise this evidence

Inclusion criteria



- 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)

Results

- All undertaken in high income countries



What is the life expectancy of people with intellectual disabilities?



- The studies found that 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

What are the main causes of death of people with intellectual disabilities?



- The studies found that respiratory and circulatory disease were the main causes of death. They also found that:



- Respiratory, congenital malfunctions, gastrointestinal and neurological causes of death were more common in the intellectual disability population
- Cancer was less common in the intellectual disability population

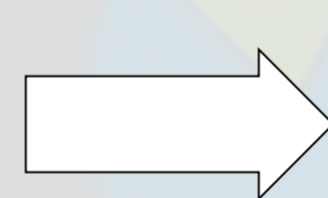
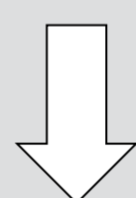
Research Questions



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

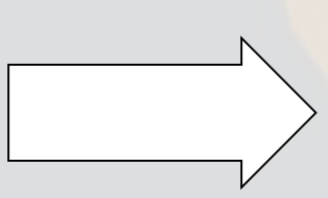
Flow diagram illustrating studies identified

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



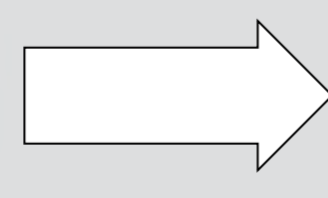
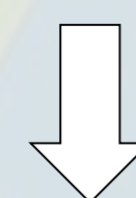
Duplicates removed (N=5471)

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



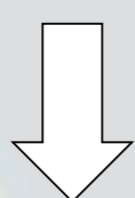
Titles excluded (N=15,828)

Abstracts screened (N=2000)



Abstracts excluded (N=1687)

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



Studies included in synthesis of findings (N=25)

Methods

- The following online databases were searched for key words: CINAHL, MEDLINE, PsychINFO, Web of Science, Embase)



- Key search terms related to 'Death' and 'Intellectual Disability'

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

Limitations

- Limited baseline-data for populations
- Limited age-gender matched general population comparisons
- Reliance on administration samples
- Reliance on death certificates

Future Directions

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

Key references

- Heslop, P., Blair, P., Fleming, P., Houghton, M., Marriott, A., and Russ, L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final Report. University of Bristol: Norah Fry Research Centre
- MENCAP (2007), Death by indifference: Mencap. London
- Robertson, J., Hatton, C., Baines, S. and Emerson, E. (2015), Systematic Reviews of the Health or Health care of People with Intellectual Disabilities: A Systematic Review to Identify Gaps in the Evidence Base. Journal of Applied Research in Intellectual Disabilities, Edinburgh 28: 455-523