

Review Title

The incidence and prevalence of falls among adults with intellectual disability living within the community: a systematic review protocol

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Review title

The incidence and prevalence of falls among adults with intellectual disability living within the community: a systematic review protocol

Review question/objective

The objective of this review is to synthesize the best available evidence to determine the incidence and prevalence of falls among adults with intellectual disability (ID) living within the community.

Key Words

Falls, injurious falls, intellectual disability, developmental disability, community

Background

Falls are a leading cause of injury amongst older Australians.¹ In 2011-12 there were nearly 96,000 hospitalizations from fall-related injuries in Australia, with each hospital stay lasting on average eight days.² It is estimated that one third of people aged 65 years and over, who are living in the community, experience at least one fall per year.^{2,3} Falls are a significant socio-economic problem. The health care cost associated with falls was estimated to be over \$498 million in 2009 and it is expected to increase to approximately \$1.4 billion by 2051.⁴ The World Health Organization has recognized that falls are a worldwide health concern as fall-related injuries can account for up to 50% of hospitalizations in older people.⁵

Healthcare professionals have observed that people with ID are also experiencing falls and studies suggest that the incidence of falls is higher than that of the broader community-dwelling population of older adults. People with ID defined in these studies either have an IQ score lower than 75⁶ or present with limited intellectual and adaptive functioning⁷⁻¹¹ as defined by the Australian Psychological Society (APA), fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria.¹² Studies that have investigated the rate of falls among adults with ID suggest that falls range from 0.93 falls per person year to 1.29 falls per person year.⁶⁻¹¹ This higher rate of falls could be because people with ID share similar risk factors to those of older people, such as the use of a walking aid^{9,13} and impaired mobility,^{2,14} but they may have additional unique risk factors such as epilepsy and behavioral difficulties.¹⁴ Furthermore, people with ID may experience falls at a younger age than that of the general older population because age-related changes can begin from their third decade of life.^{15,16}

It is challenging to establish what the rate of falls is in adults with ID, as the majority of the studies in this area have not followed rigorous methodologies for data collection and reporting. A set of guidelines for conducting falls research was published in 2005¹⁷ and recommended that falls data should be collected prospectively with daily recording of falls and at least monthly data collection.¹⁷ Falls and falls

injuries should be reported as rates, as well as the proportion of people who fall within the observational period.¹⁷ Previous studies have reported only the proportion of people who experienced a fall(s) during the observational period, but not the rate of falls (number of falls per person year).^{7-9,11} Participants who had fallen in these studies also sustained injuries but details of the injuries were not reported.

Studies have also used variable methods of data collection. Some collected data prospectively, whilst others used retrospective data collection. For the studies that collected data prospectively, only two studies collected falls data prospectively with daily recordings of falls^{6, 10} while the others relied on incident reports or recording the number of falls based on what the participants recalled at the end of the study period.^{7-9,11} It has been reported that the latter methods of measurement is unreliable.¹⁷

These studies also encompassed varied settings and participant groups.⁶⁻¹¹ The age group of the participants ranged from 18-71 years old.⁶⁻¹¹ Participants were recruited from health clinics, nursing homes and community based service providers.⁶⁻¹¹ It is therefore challenging to make comparisons between the studies to determine the incidence of falls among each of these groups of people with ID. It is important to make this distinction to be able to appropriately target health services to the individual age groups.

There are limited studies which have investigated how falls prevention strategies should be provided for adults with ID. Studies implementing falls prevention strategies for adults with ID have reported challenges such as the high reliance on caregivers to provide relevant history¹⁸ or to be present to implement exercise programs.¹⁹ This challenge is further impacted by caregivers often not being present at times of healthcare service delivery and paid support is often inadequate to implement falls prevention programs.²⁰ People with ID also have limited cognitive ability to understand the importance of falls prevention, affecting their short and long term compliance to falls prevention strategies²⁰ and population-specific prevention strategies need to be developed and investigated. Being able to establish the incidence and prevalence of falls among adults with ID is important to quantify the extent of the problem, and to subsequently inform the design of further research and development of services that are suitable for this population.

Multiple systematic reviews have examined the incidence of falls among older people living in community based settings^{2, 20} but there has not been a review that has specifically investigated the incidence of falls among adults with ID. It is not clear if previous reviews included adults with ID and if so, none reported the data concerning sub-groups of participants with ID separately.^{2, 20} To date, studies investigating the incidence of falls in people with ID have not been systematically assessed. Any previous reviews that have made references to falls among people with ID have been related to risk factors,¹⁴ preventative strategies,¹⁴ gait and balance capacities²¹ and prevention of unintentional injury but not incidence of falls.²²

A preliminary search of the literature through The Cochrane Database of Systematic Reviews, The JBI Database of Systematic Reviews and Implementation Reports (JBISRIR), PubMed, CINAHL and PROSPERO found no recent systematic reviews either published or underway in this topic. It is necessary to synthesize the findings of the studies that have been conducted on this area systematically including their strengths and limitations, to identify the evidence about the incidence of falls among

adults with ID. The negative impacts and high economic burden of falls among older people²¹ are well established and a close estimate of the incidence in adults with ID will allow a direct comparison with the incidence of falls among older people in the broader community dwelling population. It is important to determine the scope and extent of the problem of falls in adults with ID.

Inclusion criteria

Types of participants

This review will consider studies, conducted worldwide, that include people with mild to severe levels of ID according to the severity classification in DSM – 5.¹² Studies that have used the term ‘learning disability’ which follows the same criteria as ID in DSM-5 will also be included. Studies that use a broader inclusion criteria of ‘developmental disability’²³ that includes people with ID will be included. The review will consider studies involving participants aged 18 years and older. Studies that include participants younger than 18 years will be included if the mean age is 18 years or older, or if data from participants who are 18 years or older can be separately extracted.

Studies that include participants who have participants under 18 years of age, adults who have been cognitively affected by trauma or old age related decline such as dementia will not be included.

Condition

This review will consider studies reporting on falls and injuries sustained from a fall among adults with ID. The World Health Organization has defined a fall as ‘an event which results in a person coming to rest inadvertently on the ground or floor or other lower level’^{5 (p.1)} and a fall will be classified as injurious if it results in bruising, laceration, dislocation, fracture or complain of an onset of persistent pain as a result of the fall.²⁴ Studies that report falls or injurious fall rates among adults with ID or the proportion of people who fall will also be included.

Context

This review will consider only studies conducted with participants living within the community. This will include participants living at home with family or living in independent units with or without support. Studies that have included participants who live with other people with disability in group homes with or without paid support will also be included. Studies that have participants who live in residential care settings such as nursing homes will be excluded unless the studies have included participants living within the community, and provided data that can be analysed separately.

Types of outcomes

Studies will only be included in this review if they include falls prevalence and/or incidence as an outcome measure. Outcome measures related to falls prevalence and/or incidence may include the rate of falls (expressed as the number of falls per 1000 person days); the proportion of participants who became fallers (expressed as the percentage of participants who fell); the rates of injurious falls (expressed as the number of falls with injury per 1000 person days); and the proportion of participants who had an injurious fall (expressed as the percentage of participants who sustained an injury as a result of a fall). Studies that measure falls rates as secondary outcome measures will be included if they

provide data where the falls rate can be calculated.

Types of studies

This review will consider any study with an observational design including prospective and retrospective cohort studies, case-control and cross-sectional studies. Due to the paucity of literature in this area, studies that use an experimental design, both randomized controlled and quasi experimental design will be included. Single case studies will be excluded.

Search strategy

The search strategy aims to find both published and unpublished studies written in English. A three-step search strategy will be utilized in this review. First a limited search of PubMed and CINAHL will be undertaken using an initial set of key words (fall, accidental fall, falls prevention, intellectual disability, developmental disability, learning disability), followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second extended search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published from 1990 to present will be considered. The start date of 1990 is considered appropriate as research into falls prevention is a relatively recent field of research and other large systematic reviews investigating the evidence for falls interventions^{26, 27} have included studies dating from 1990.^{28, 29} All studies identified during the database search will be retrieved and examined to ensure relevance and that they meet the inclusion criteria using the title and abstract by two independent reviewers, with arbitration from a third independent reviewer if necessary.

The databases to be searched will include The Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, CINAHL, AMED and PsychINFO. The search for unpublished studies will include TROVE, Google Scholar and ProQuest Theses and Dissertations. A clinical trial registry database, Current Controlled Trials (<http://www.isrctn.com>) and the National Institute of Health Clinical Database (<http://www.clinicaltrials.gov>) will also be searched. For specific research into people with intellectual disability the websites of Rehabilitation Research and Training Center on Developmental Disabilities and Health (rrtcadd.org), Centre for Developmental Disability Health Victoria (www.cddh.monash.org) and the Centre for Applied Disability Research (www.cadr.org.au) will also be searched.

Assessment of methodological quality

Articles selected for retrieval will be assessed by two independent reviewers for methodological validity before inclusion in the review using standardized critical appraisal instruments for the Joanna Briggs Institute – Critical Appraisal Checklist for Studies Reporting Prevalence Data,³⁰ Randomized Controlled Trials,³¹ Quasi-Experimental Studies,³² Cohort³³ and Cross-sectional³⁴ studies as applicable. Any disagreements that will arise between reviewers will be resolved through discussions, or by further discussion with a third reviewer, which will be any one of the associated reviewers, if necessary. The

inclusion process will be reported using a PRISMA flow chart.³⁵

Data extraction

Quantitative data will be extracted from papers included in the review by two independent reviewers, using the adapted data extraction tools from JBI-SUMARI.³⁶ The data extracted will include specific details about the populations, study methods, interventions, and outcomes of significance to the review question. For studies that use an experimental design, data extracted will include details such as outcomes used and falls data. If these trials have repeated measures of falls only falls data from the control phase or group will be extracted. Any disagreements that will arise between reviewers will be resolved through discussions, or with a third reviewer. Where data are missing the authors of primary studies will be contacted if necessary, to seek clarification.

Data synthesis

Quantitative data, where possible, will be pooled in statistical meta-analysis using Rev Man³⁷ software. All results will be subjected to double data entry. Statistical analysis will be carried out for primary outcomes wherever possible using the inverse variance method. Heterogeneity will be assessed statistically using the standard Chi-square test. Where data can be pooled, the resultant meta-analysis will give the relevant summary falls statistic and 95% CIs and will list the individual proportions with their 95% confidence interval values from individual studies. If meta-analysis is possible and if applicable, a sub-group analysis will be used to assess the contribution of each study to the overall heterogeneity. Where statistical pooling is not possible data will be presented in a narrative form including table and figures to aid in data presentation wherever appropriate.

Conflicts of interest

The reviewers have no conflict of interest to declare.

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References

1. Tovell AH, J.E and Pointer, S. Hospitalised injury in older Australians, 2011-12. Canberra: AIHW: Injury reserach statistics series no. 90; 2014.
2. Rubenstein LZ. Falls in older people: epidemiology, risk factors and strategies for prevention. Age Ageing. 2006;35 Suppl 2:ii37-ii41.

3. Milat AJ, Watson WL, Monger C, Barr M, Giffin M, Reid M. Prevalence, circumstances and consequences of falls among community-dwelling older people: results of the 2009 NSW Falls Prevention Baseline Survey. *N S W Public Health Bull.* 2011;22(3-4):43-48
4. Preventing Falls and Harm From Falls in Older People. Commonwealth of Australia: Australian Commission on Safety and Quality in Healthcare (ACSQHC); 2009.
5. World Health Organization. Global report on falls prevention in older age. 2007; www.who.int/ageing/projects/falls_prevention_older_age/en/index.html Accessed: 17.12.16
6. Smulders E, Enkelaar L, Weerdesteyn V, Geurts ACH, Schroyensteen Lantman-de Valk H. Falls in older persons with intellectual disabilities: fall rate, circumstances and consequences. *J Intellect Disabil Res* 2013;57(12):1173-82.
7. Cox CR, Clemson L, Stancliffe RJ, Durvasula S, Sherrington C. Incidence of and risk factors for falls among adults with an intellectual disability. *J Intellect Disabil Res.* 2010;54(12):1045-57.
8. Finlayson J, Morrison J, Jackson A, Mantry D, Cooper SA. Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *J Intellect Disabil Res.* 2010;54(11):966-80.
9. Hsieh K, Rimmer J, Heller T. Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities.* 2012;117(6):442-54.
10. Pal J, Hale L, Mirfin-Veitch B, Claydon L. Injuries and falls among adults with intellectual disability: A prospective New Zealand cohort study. *J Intellect Dev Disabil* 2014;39(1):35-44.
11. Wagemans AMA, Cluitmans JJM. Falls and Fractures: A Major Health Risk for Adults with Intellectual Disabilities in Residential Settings. *J Policy Pract Intellect Disabil.* 2006;3(2):136-8
12. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5).* 5th ed. Arlington, US: American Psychiatric Publishing; 2013
13. Deandrea S, Lucenteforte E, Bravi F, Foschi R, La Vecchia C, Negri E. Risk factors for falls in community-dwelling older people: a systematic review and meta-analysis. *Epidemiology.* 2010;21(5):658-68.
14. Willgoss TG, Yohannes AM, Mitchell D. Review of risk factors and preventative strategies for fall-related injuries in people with intellectual disabilities. *J Clin Nurs.* 2010;19(15/16):2100-9.
15. Connolly BH. General effects of aging on persons with developmental disabilities. *Top Geriatr Rehabi.* 1998:1-18.
16. Strydom A, Shooshtari S, Lee L, Raykar V, Torr J, Tsiouris J, et al. Dementia in Older Adults With Intellectual Disabilities-Epidemiology, Presentation, and Diagnosis. *J Policy Pract Intellect Disabil.* 2010;7(2):96-110.
17. Lamb SE, Jørstad-Stein EC, Hauer K, Becker C. Development of a Common Outcome Data Set for Fall Injury Prevention Trials: The Prevention of Falls Network Europe Consensus. *J Am Geriatr Soc.* 2005;53(9):1618-22.
18. Pal J, Hale L, Mirfin-Veitch B. Experiences of Therapists Trying to Reduce Falls Risk for People With Intellectual Disability. *J Policy Pract Intellect Disabil.* 2013;10(4):314-20.
19. Smulders E, Enkelaar L, Schoon Y, Geurts AC, van Schroyensteen Lantman-de Valk H, Weerdesteyn V. Falls prevention in persons with intellectual disabilities: Development,

- implementation, and process evaluation of a tailored multifactorial fall risk assessment and intervention strategy. *Res Dev Disabil.* 2013;34(9):2788-98.
20. Kwan MM-S, Close JCT, Wong AKW, Lord SR. Falls Incidence, Risk Factors, and Consequences in Chinese Older People: A Systematic Review. *J Am Geriatr Soc.* 2011;59(3):536-43.
 21. Enkelaar L, Smulders E, van Schrojenstein Lantman-de Valk H, Geurts ACH, Weerdesteyn V. A review of balance and gait capacities in relation to falls in persons with intellectual disability. *Res Dev Disabil.* 2012;33(1):291-306.
 22. Sherrard J, Ozanne-Smith J, Staines C. Prevention of unintentional injury to people with intellectual disability: a review of the evidence. *J Intellect Disabil Res.* 2004;48(7):639-45.
 23. Richmond DT. NSW Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled. Department of Health New South Wales;1983. Part 2: 9p
 24. Hill AM, Hoffmann T, McPhail S, Beer C, Hill KD, Oliver D, et al. Evaluation of the sustained effect of inpatient falls prevention education and predictors of falls after hospital discharge--follow-up to a randomized controlled trial. *J Gerontol A Biol Sci Med Sci* 2011; 66(9):1001-1012
 25. Heinrich S, Rapp K, Rissmann U, Becker C, König HH. Cost of falls in old age: a systematic review. *Osteoporos Int.* 2010;21(6):891-902.
 26. Gillespie LD, Robertson MC, Gillespie WJ, Sherrington C, Gates S, Clemson LM, et al. Interventions for preventing falls in older people living in the community. *Cochrane Database Syst Rev.* 2012(9): CD007146.
 27. Goodwin VA, Abbott RA, Whear R, Bethel A, Ukoumunne OC, Thompson-Coon J, et al. Multiple component interventions for preventing falls and fall-related injuries among older people: systematic review and meta-analysis. *BMC Geriatrics.* 2014;14:15.
 28. Campbell AJ, Borrie MJ, Spears GF, Jackson SL, Brown JS, Fitzgerald JL. Circumstances and consequences of falls experienced by a community population 70 years and over during a prospective study. *Age Ageing.* 1990;19(2):136-41.
 29. Carpenter GI, Demopoulos GR. Screening the elderly in the community: controlled trial of dependency surveillance using a questionnaire administered by volunteers. *BMJ (Clinical Research Ed).* 1990;300(6734):1253-6.
 30. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for Prevalence Studies. 2016; <http://joannabriggs.org/research/critical-appraisal-tools.html>. Accessed: 18.02.17
 31. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for Randomized Controlled Trials. 2016; <http://joannabriggs.org/research/critical-appraisal-tools.html>. Accessed: 18.02.17
 32. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for Quasi-Experimental Studies. 2016; <http://joannabriggs.org/research/critical-appraisal-tools.html>. Accessed: 18.02.17
 33. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for Cohort Studies. 2016; <http://joannabriggs.org/research/critical-appraisal-tools.html>. Accessed: 18.02.17

34. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for Analytical Cross Sectional Studies. 2016; <http://joannabriggs.org/research/critical-appraisal-tools.html>. Accessed: 18.02.17
35. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic review and meta-analysis: The PRISMA statement. *Int J Surg*. 2010;8(5):336-41
36. Joanna Briggs Institute - System for the Unified Management, Assessment and Review of Information (JBI - SUMARI). [Online software program]. Adelaide; JBI; Copyright 2016. Available from: jbisumari.org
36. Review Manager (RevMan) [Computer program]. Version 5.3. Copenhagen: The Nordic Cochrane Centre, The Cochrane Collaboration, 2014.