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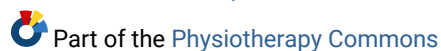
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Understanding Falls in People with Intellectual Disability in Western Australia

Portia Ho

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Understanding Falls in People with Intellectual Disability in Western Australia

Portia Ho

Bachelor of Physiotherapy

Submitted in fulfilment of the requirements for the Doctor of Philosophy



School of Physiotherapy
Fremantle

July 2020

Declaration by Author

This thesis is composed of my original work. It contains no material that has been previously published or written by any other person except where due reference has been made in the text. I have clearly stated the contributions by others and co-authored productions that I have included in my thesis.

I have clearly stated the contributions of others to my thesis, including the study design, statistical and data analysis, technical research procedures, professional editorial advice, disability specific advice and any other research work used or reported in my thesis. The content of my thesis is the result of the work I have carried out since the commencement of my higher research degree candidature in 2015 and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution.

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PhD Candidate

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Anne-Marie Hill

Principal Supervisor

Abstract

Adults with intellectual disability (ID) experience earlier age-related changes, compared with other age-matched populations, but concurrently their life expectancy is increasing. Falls often result in serious injuries and reduced health-related quality of life, however there is limited research regarding falls in older adults with ID. The purpose of this research was to investigate falls among community dwelling older adults with ID, including the epidemiology, risk factors and experiences when engaging with health services after a fall.

A meta-analysis of the incidence and prevalence of falls in adults with ID was initially conducted to inform the research aims. Prospective research was then conducted using a mixed methods convergent design, comprising quantitative and qualitative phases. Underpinned by ethical guidelines, a consent procedure was developed with the aim of engaging holistically with older adults with ID throughout the research.

The meta-analysis demonstrated that the pooled proportion of older adults with ID who fell was 39% [95% CI (0.35%-0.43%), very low GRADE evidence]. The developed consent procedure was found to be a respectful method of determining the support older adults with ID required to provide informed consent. The prospective cohort study enrolled 78 participants [median (IQR) age 49 (43-60) years, female n=32 (41%)]. There were 296 falls reported by 36 (46%) participants with 12 participants sustaining one fall and 24 participants sustaining more than one fall. The incidence of falls was 5.7 falls (injurious falls =0.8) per person year. A history of falls [adjusted OR: 6.37, 95% CI (1.90-21.34)] and being ambulant [adjusted OR: 4.50, 95% CI (1.15-17.67)] were associated with an increased risk of falling. Emergent themes from the qualitative phase of the study (n=17 interviews) demonstrated that participants had limited knowledge about falls. Reporting of falls to health professionals did not prompt access to falls prevention services.

Falls are a substantial health problem for older adults with ID and further research is required to evaluate tailored falls prevention interventions. Guidelines for addressing fall prevention for older adults with ID are urgently required. Older adults with ID should be screened for falls and associated risk factors as part of regular health care.

Keywords

accidental falls, intellectual disability, injurious falls, falls rates, falls risk factors, ethics, prevention and control, delivery of health care

Trial registration

This study was registered with the Australian New Zealand Clinical Trial Registry (ACTRN12615000926538).

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List of Abbreviations

ABC	Aberrant Behaviour Checklist
CFCS	Communication and Functional Classification System
DSW	Disability support workers
HRQol	Health related quality of life
ID	Intellectual Disability
JBI	Joanna Briggs Institute
IRR	Incident rate ratio
OR	Odds ratio
RCT	Randomised controlled trials
RR	Risk ratio
SD	Standard Deviation
STROBE	Strengthening the reporting of observational studies in epidemiology
STS	Sit to stand
TUG	Timed up and go
WA	Western Australia
95% CI	95% Confidence interval

Statement of Contributors

Contributions to Jointly Authored Works Contained in the Thesis

Signed statements of consent for inclusion of jointly authored works in this thesis were obtained from all co-authors (see Appendix A).

- **Ho, P.**, Bulsara, C., Patman, S., Bulsara, M., Downs, J., Hill, A.-M. (2018). Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for prospective observational cohort study. *BMC Geriatrics*, 18(1), 171. doi: 10.1186/s12877-018-0862-8.

PH, AMH, CB and SP were responsible for the study conception and design. MB was responsible for contributing to the calculation of the sample size and provided statistical advice. CB contributed to the qualitative design and recommending the method for qualitative data analysis. PH was primarily responsible for drafting the manuscript with support from AMH, SP, CB and JD. AMH, SP, CB and JD were responsible for ongoing study procedure, data management and analyses. All authors critically reviewed the manuscript for content and style and approved the final version of the manuscript for submission.

- **Ho, P.**, Patman, S., Bulsara, B., Downs, J., Bulsara, M., Hill, A.-M. (2017). Incidence and prevalence of falls in adults with intellectual disability living in the community: A systematic review protocol. *JBIR Database of Systematic Reviews and Implementation Reports*, 15(7), 1819-1823. doi: 10.11124/JBISRIR-2016-003155

PH was primarily responsible for drafting the systematic review protocol with support from AMH, SP, CB, MB and JD. All authors critically reviewed the systematic review protocol for its content and approved the final version of the systematic review protocol for submission.

- **Ho, P.,** Downs, J., Bulsara, C., Patman, S., Hill, A.-M. (2018). Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability. *British Journal of Learning Disability*, 46(2), 92-100. doi:10.1111/bld.12217

PH, AMH, CB and SP were responsible for the study conception and design. PH was primarily responsible for data collection, collating the data and drafting the manuscript with the support of CB, DP, JD and AMH. All authors critically reviewed the manuscript for content and style and approved the final version of the manuscript for submission. In June 2019, it was reported that this article was one of the journal's most top downloaded papers published between January 2017 and December 2018 following online publication.

- **Ho, P.,** Bulsara, M., Downs, J., Patman, S., Bulsara, C., Hill, A.-M. (2019). Incidence and prevalence of falls in adults with intellectual disability living in the community: A systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, 17(3), 390-413. doi:10.11124/JBISRIR-2017-003798

PH was primarily responsible for drafting the systematic review with support from AMH, SP, CB, MB and JD. SP and JD were responsible for assessing the methodological quality of the retrieved studies. PH and AMH were responsible for the extraction of the data from the studies that were included in the systematic review and MB provided statistical advice. All authors critically reviewed the systematic review for its content and approved the final version of the systematic review for submission.

- **Ho, P.,** Bulsara, M., Patman, S., Downs, J., Bulsara, C., Hill, A.-M. (2019). Incidence and associated risk factors for falls in adults with intellectual disability. *Journal of Intellectual Disability Research*, 63(12), 1441-1452. doi:10.1111/jir.12686

PH, AMH, CB and SP were responsible for the study conception and design. MB was responsible for contributing to the calculation of the sample size and provided statistical advice. PH was primarily responsible for drafting the manuscript with support from AMH, SP, CB and JD. AMH, SP, CB and JD were responsible for ongoing study procedure, data management and analyses. All authors critically reviewed the manuscript for content and style and approved the final version of the manuscript for submission.

- **Ho, P.**, Bulsara, C., Patman, S., Bulsara, M., Downs, J., Hill, A.-M. (2020) Exploring enablers and barriers to accessing health services after a fall among people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 33(3), 604– 617. doi:10.1111/jar.12704.

PH, AMH, CB and SP were responsible for the study conception and design. CB contributed to the qualitative design and recommending the method for qualitative data analysis. PH was primarily responsible for drafting the manuscript with support from AMH, SP, CB and JD. AMH, SP, CB and JD were responsible for ongoing study procedure, data management and analyses. All authors critically reviewed the manuscript for content and style and approved the final version of the manuscript for submission.

Contributions to the Thesis as a Whole

Professor Anne-Marie Hill was the principal supervisor who conceptualised the research and the design of each study with Portia Ho. Portia Ho was the primary researcher and was responsible for data collection, analysis and writing the thesis. Associate Professor Shane Patman, and Associate Professor Jenny Downs were co-supervisors who contributed at all stages of the research and gave editorial advice in the drafting of each manuscript and the thesis. Professor Caroline Bulsara contributed to the conceptual design of the qualitative phases of the research, qualitative data analysis and editorial advice for drafting of the manuscripts that contributed to this thesis. Professor Max Bulsara contributed to the statistical calculations of sample size, quantitative data analysis and provided expert statistical advice throughout the research.

Oral Presentations by the Author

International conferences

- 11th International Association of Gerontology and Geriatrics (IAGG) Asia/Oceania Regional Congress; Taipei, Taiwan, 2019

Ho P, Bulsara M, Patman S, Downs J, Bulsara C, Hill A-M. Incidence and associated risk factors for falls in adults with intellectual disability.

- 4th World Disability & Rehabilitation Conference (WDRC); Bangkok Thailand, November 2019

Ho P, Bulsara M, Patman S, Downs J, Bulsara C, Hill A-M. Incidence, prevalence and risk factors for falls in older adults with intellectual disability in Western Australia. (Awarded best presenter for the session "Growing Old and Disability Management")

- 4th World Disability & Rehabilitation Conference (WDRC); Bangkok Thailand, November 2019

Ho P, Bulsara C, Downs J, Patman S, Hill A-M. Enablers and barriers to accessing health services after having a fall among older adults with intellectual disability.

National conferences

- National Disability Services. WA Clinical and Allied Health Forum; Wembley Western Australia, May 2016

Ho P, Bulsara C, Patman S, Bulsara M, Downs J, Hill A-M. Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for prospective observational cohort study.

- Australasian Society for Intellectual Disability (ASID). WA Divisional Conference; Floreat, Western Australia, August 2017

Ho P, Bulsara C, Patman S, Bulsara M, Downs J, Hill A-M. Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for prospective observational cohort study.

- Australasian Society for Intellectual Disability (ASID). WA Divisional Conference; Floreat, Western Australia, August 2017

Ho P, Downs J, Bulsara C, Patman S, Hill A-M. Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability.

- Western Australian Grass Roots Falls Festival; Fremantle, Western Australia, February 2017

Ho P, Bulsara C, Patman S, Bulsara M, Downs J, Hill A-M. Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for prospective observational cohort study.

- Western Australian Grass Roots Falls Festival; Fremantle, Western Australia, September 2019

Ho P, Bulsara M, Patman S, Downs J, Bulsara C, Hill A-M. Incidence and associated risk factors for falls in adults with intellectual disability.

- Western Australian Grass Roots Falls Festival; Fremantle, Western Australia, September 2019

Ho P, Bulsara C, Patman S, Downs J, Hill A-M. Exploring enablers and barriers to accessing health services after a fall among people with intellectual disability.

- Australian Association of Developmental Disability Medicine (AADDM) Telethon Kids Institute, Perth Children's Hospital, Western Australia, October 2019

Ho P, Bulsara C, Patman S, Downs J, Hill A-M. Exploring enablers and barriers to accessing health services after a fall among people with intellectual disability.

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Thesis Introduction and Outline

1.1 Introduction

In Australia, people with intellectual disability (ID) comprise approximately 3% of the population (Australian Institute of Health and Welfare, 2008). They also comprise one of the largest proportions of the population that require support from disability services (Australian Institute of Health and Welfare, 2017), as ID is the most common type of primary disability (25%). A diagnosis of ID is made when an individual is assessed as having under-developed intellectual functioning and adaptive behaviour (American Psychiatric Association, 2013). The classification states that these impairments of skills are manifested during the developmental period (International Statistical Classification of Diseases and Related Health Problems, 2016).

Higher proportions of people with ID experience multimorbidity (70%) compared to the general population (McCarron et al., 2013). At the same time, people with ID face inequalities in primary health care delivery (Weise, Pollack, Britt, & Trollor, 2017) and are twice as likely to suffer preventable deaths compared to the general population (Trollor, Srasuebku, Xu, & Howlett, 2017). Older adults with ID are even more vulnerable because of premature aging (Hermans & Evenhuis, 2014; Carmeli, Iman, Bachar, & Merrick, 2012; Connolly, 2006) evident before the age of 65 years.

Falls are a substantial socio-economic problem among older adults with approximately 111,000 fall related injuries requiring hospitalisation between 2014-2015 (Pointer, 2018) at an estimated cost of \$600 million in acute hospital settings (Public Health Association of Australia, 2012). A limited number of studies in this field have also identified that older adults with ID have multiple falls compared to the general community dwelling older adult population (aged 65 years and over). Falls are the most frequent cause of injuries in adults with ID (Finlayson, Morrison, Jackson, Mantry, & Cooper, 2010) and these falls may result in reduced mobility, premature admission to institutional care and reduced quality of life (Willgoss, Yohannes, & Mitchell, 2010).

Hospitalisation in older adults with ID following a fall incur longer lengths of stay and readmissions are more likely compared to the general population (Axmon, Ahlström, & Sandberg, 2019). Falls have been investigated previously (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010; Hsieh, Rimmer, & Heller, 2012; Pal, Hale, Mirfin-Veitch, & Claydon, 2014), however, these studies have been conducted in

people with ID across a wide age group (> 18 years) or a sample recruited from a single residential setting (Grant, Pickett, Lam, O'Connor, & Ouellette-Kuntz, 2001; Salb et al., 2015; Wagemans & Cluitmans, 2006). A higher quality of life is associated with living in the community in adults with ID compared to living in an institutional setting (McCarron et al., 2019) and therefore understanding falls is important in supporting older adults with ID to live in the community safely. Studies of falls experienced by community dwelling older adults with ID are limited with only two known prospective studies ($n \leq 86$) (Enkelaar, Smulders, van Schroyen Lantman-de Valk, Weerdesteyn, & Geurts, 2013; Smulders, Enkelaar, Weerdesteyn, Geurts, & Schroyen Lantman-de Valk, 2013), hence there is uncertainty regarding the rate of falls in this population.

It has also been suggested that risk factors for falls in older adults with ID (Enkelaar et al., 2013) differ from those among older community dwelling older people (Ambrose, Paul, & Hausdorff, 2013) and therefore the multiple national guidelines and recommendations for falls prevention in older people are not tailored for people with ID. Additionally, no randomised controlled trials have evaluated the efficacy of strategies to reduce falls in adults with ID and there is scant evidence on how to reduce falls in adults with ID.

Further research is urgently required. People with ID are not well represented in research (Feldman, Bossett, Collet, & Burnham-Riosa, 2014) and many research studies have excluded people with ID even if the outcomes are directly relevant to them (Cleaver, Ouellette-Kuntz, & Sakar, 2010; Russell et al., 2019).

While the research investigating falls in adults with ID is gaining momentum, the number of studies is still limited compared to studies investigating falls among community dwelling older adults. There are also significant methodological variations between these studies (Hsieh et al., 2012; Pal et al., 2014; Smulders et al., 2013) and many of the study designs do not adhere to guideline recommendations for conducting falls research (Lamb, Jørstad-Stein, Hauer, & Becker, 2005). Therefore, there is uncertainty regarding the extent of falls as a problem for adults with ID, the risk factors that contribute to their falls and the falls prevention care they are receiving.

To address these gaps, the purpose of this research was to investigate the nature of falls, risk factors for falls and experiences when engaging with health services after a fall among older adults with ID living in the community in Western Australia (WA).

1.2 Organisation of Chapters

Chapter 2

Chapter 2 reports the findings from a systematic review and meta-analyses of studies that investigated the incidence and prevalence of falls among adults with ID.

The chapter is based on two published articles, the first being a protocol for the systematic review and the second being the systematic review:

Ho, P., Patman, S., Bulsara, B., Downs, J., Bulsara, M., & Hill, A.-M. (2017). Incidence and prevalence of falls in adults with intellectual disability living in the community: A systematic review protocol. *JBIS Database of Systematic Reviews and Implementation Reports*, 15(7), 1819-1823. doi: 10.11124/JBISRIR-2016-003155

Ho, P., Bulsara, M., Downs, J., Patman, S., Bulsara, C., & Hill, A.-M. (2019). Incidence and prevalence of falls in adults with intellectual disability living in the community: A systematic review. *JBIS Database of Systematic Reviews and Implementation Reports*, 17(3), 390-413. doi:10.11124/JBISRIR-2017-003798

Chapter 3

Chapter 3 reports on the methods for the observational cohort investigation and follow up qualitative investigation conducted as part of the research.

This chapter is based on a published article:

Ho, P., Bulsara, C., Patman, S., Bulsara, M., Downs, J., & Hill, A.-M. (2018). Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for prospective observational cohort study. *BMC Geriatrics*, 18(1), 171. doi: 10.1186/s12877-018-0862-8.

Chapter 4

Chapter 4 describes the consent process that was developed and used as part of the research when engaging people with intellectual disability.

This chapter is based on a published article:

Ho, P., Downs, J., Bulsara, C., Patman, S., & Hill, A.-M. (2018). Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability. *British Journal of Learning Disability*, 46(2), 92-100. doi:10.1111/bld.12217

Chapter 5

Chapter 5 reports on a prospective study which investigated the incidence, prevalence and associated risk factors for falls in a cohort of older adults with ID living in the community.

This chapter is based on a published article:

Ho, P., Bulsara, M., Patman, S., Downs, J., Bulsara, C., & Hill, A.-M. (2019). Incidence and associated risk factors for falls in adults with intellectual disability. *Journal of Intellectual Disability Research*. doi: 10.1111/jir.12686

Chapter 6

Chapter 6 reports on a qualitative study that explored the experiences of the participants when seeking healthcare services after a fall and the barriers they faced when taking up evidence-based falls prevention recommendations that were provided to them.

This chapter is based on a manuscript under review in a peer-reviewed medical journal:

Ho, P., Bulsara, C., Patman, S., Bulsara, M., Downs, J., & Hill, A.-M. Exploring enablers and barriers to accessing health services after a fall among people with intellectual disability. (*Submitted to a peer review journal and undergoing second round of peer review*)

Chapter 7

Chapter 7 synthesises the findings from this research and discusses the findings in relation to the research aims. It also provides suggestions for clinical practice and future research in the area of falls prevention in older adults with ID. It also provides suggestions for health policies to improve health services to provide falls prevention services catered to older adults with ID.

1.3 References

- Ambrose, A. F., Paul, G., & Hausdorff, J. M. (2013). Risk factors for falls among older adults: A review of the literature. *Maturitas*, 75(1), 51-61. doi: 10.1016/j.maturitas.2013.02.009
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)*. 5th ed. Arlington, US: American Psychiatric Publishing.
- Australian Institute of Health and Welfare. (2008). *Disability in Australia: Intellectual Disability*. (Bulletin no.67. Cat. no: AUS 110. Canberra: AIHW). Retrieved from: <https://www.aihw.gov.au/getmedia/5a1b2a34-78bb-4696-a975-3121658a9505/bulletin67.pdf.aspx?inline=true>
- Australian Institute of Health and Welfare. (2017). *Australia's welfare series no. 13. AUS 214. Chapter 8.1. People with Disability*. Canberra: AIHW. Retrieved from: <https://www.aihw.gov.au/getmedia/088848dc-906d-4a8b-aa09-79df0f943984/aihw-aus-214-aw17.pdf.aspx?inline=true>
- Axmon, A., Ahlström, G., & Sandberg, M. (2019). Falls resulting in health care among older people with intellectual disability in comparison with the general population. *Journal of Intellectual Disability Research*, 63(3), 193-204. doi:10.1111/jir.12564
- Carmeli, E., Imam, B., Bachar, A., & Merrick, J. (2012). Inflammation and oxidative stress as biomarkers of premature aging in persons with intellectual disability. *Research in Developmental Disabilities*, 33(2), 369-375. doi:10.1016/j.ridd.2011.10.002
- Cleaver, S., Ouellette-Kuntz, H., & Sakar, A. (2010). Participation in intellectual disability research: a review of 20 years of studies. *Journal of Intellectual Disability Research*, 54(3), 187-193. doi:10.1111/j.1365-2788.2010.01256.x
- Connolly, B. (2006). Issues in aging in individuals with life long disabilities. *Brazilian Journal of Physical Therapy*, 10, 249-262
- Cox, C. R., Clemson, L., Stancliffe, R. J., Durvasula, S., & Sherrington, C. (2010). Incidence of and risk factors for falls among adults with an intellectual disability. *Journal of Intellectual Disability Research*, 54(12), 1045-1057. doi:10.1111/j.1365-2788.2010.01333.x
- Enkelaar, L., Smulders, E., van Schroyen Lantman-de Valk, H., Weerdesteijn, V., & Geurts, A. C. H. (2013). Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities. *Research in Developmental Disabilities*, 34(11), 3754-3765. doi:10.1016/j.ridd.2013.07.041

- Feldman, M. A., Bossett, J., Collet, C., & Burnham-Riosa, P. (2014). Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of Intellectual Disability Research*, 58(9), 800-809. doi:10.1111/jir.12091
- Finlayson, J., Morrison, J., Jackson, A., Mantry, D., & Cooper, S. A. (2010). Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *Journal of Intellectual Disability Research*, 54(11), 966-980. doi:10.1111/j.1365-2788.2010.01319.x
- Grant, H. J., Pickett, W., Lam, M., O'Connor, M., & Ouellette-Kuntz, H. (2001). Falls among persons who have developmental disabilities in institutional and group home settings. *Journal on Developmental Disabilities*, 8, 57-73.
- Hermans, H., & Evenhuis, H. M. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 35(4), 776-783. doi:10.1016/j.ridd.2014.01.022
- Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 442-454. doi:10.1352/1944-7558-117.6.442
- International Classification of Health and Disease. (2016) *Mental retardation. (F70-F79). Mental and behavioural disorders. Chapter V*. Retrieved from: <https://icd.who.int/browse10/2016/en#/F70-F79>
- Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., & Becker, C. (2005). Development of a common outcome data set for fall injury prevention trials: The prevention of falls network Europe consensus. *Journal of the American Geriatrics Society*, 53(9), 1618-1622. doi:10.1111/j.1532-5415.2005.53455.x
- McCarron, M., Lombard-Vance, R., Murphy, E., May, P., Webb, N., Sheaf, G., . . . O'Donovan, M.-A. (2019). Effect of deinstitutionalisation on quality of life for adults with intellectual disabilities: a systematic review. *BMJ Open*, 9(4), e025735. doi:10.1136/bmjopen-2018-025735
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion, P. (2013). Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Research in Developmental Disabilities*, 34(1), 521-527. doi:10.1016/j.ridd.2012.07.029
- Pal, J., Hale, L., Mirfin-Veitch, B., & Claydon, L. (2014). Injuries and falls among adults with intellectual disability: A prospective New Zealand cohort study. *Journal of Intellectual and Developmental Disability*, 39(1), 35-44. doi:10.3109/13668250.2013.867929

- Pointer, S. (2018). *Trends in hospitalised injury due to falls in older people, 2002–03 to 2014–15*. (Injury research and statistics series no. 111. Cat. no. INJCAT 191. Canberra: AIHW). Retrieved from:
<https://www.aihw.gov.au/reports/injury/hospitalised-falls-older-people-2002-03-to-2014-15/contents/table-of-contents>
- Public Health Association Australia. (2012). *Policy-at-a-glance – Fall injury prevention in older people policy*. Public health association Australia’s injury prevention special interest group. Retrieved from:
<https://www.phaa.net.au/documents/item/236>
- Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T., & Ford, T. (2019). Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Molecular Autism, 10* (Art: 9). doi:10.1186/s13229-019-0260-x
- Salb, J., Woodward, C., Offenhäuser, J., Becker, C., Sieber, C., & Freiberger, E. (2015). Prevalence and characteristics of falls in adults with intellectual disability living in a residential facility: A longitudinal study [PreFallID]. *Intellectual and Developmental Disabilities, 53*(3), 228-239. doi:10.1352/1934-9556-53.3.228
- Smulders, E., Enkelaar, L., Weerdesteyn, V., Geurts, A. C. H., & Schrojenstein Lantman-de Valk, H. (2013). Falls in older persons with intellectual disabilities: fall rate, circumstances and consequences. *Journal of Intellectual Disability Research, 57*(12), 1173-1182. doi:10.1111/j.1365-2788.2012.01643.x
- Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open, 7*(2), e013489. doi:10.1136/bmjopen-2016-013489
- Wagemans, A. M. A., & Cluitmans, J. J. M. (2006). Falls and fractures: A major health risk for adults with intellectual disabilities in residential settings. *Journal of Policy and Practice in Intellectual Disabilities, 3*(2), 136-138. doi:10.1111/j.1741-1130.2006.00066.x
- Weise, J., Pollack, A., Britt, H., & Trollor, J. N. (2017). Primary health care for people with an intellectual disability: an exploration of consultations, problems identified, and their management in Australia. *Journal of Intellectual Disability Research, 61*(5), 399-410. doi:10.1111/jir.12352
- Willgoss, T. G., Yohannes, A. M., & Mitchell, D. (2010). Review of risk factors and preventative strategies for fall-related injuries in people with intellectual disabilities. *Journal of Clinical Nursing, 19*(15/16), 2100-2109. doi:10.1111/j.1365-2702.2009.03174.x

Incidence and Prevalence of Falls in Adults with Intellectual Disability living in the Community: A systematic review

Preface

The incidence and prevalence of falls in adults with ID living in the community has not previously been synthesised in the literature.

This chapter describes a systematic review of the incidence and prevalence of falls in adults with ID living in the community. The chapter is based on two published articles, the first being a protocol for the systematic review and the second being the systematic review:

- Ho, P.,** Patman, S., Bulsara, C., Downs, J. Bulsara, M. & Hill, A.-M. (2017). Incidence and prevalence of falls in adults with intellectual disability living in the community: a systematic review protocol. *JBI Database of Systematic Reviews and Implementation Reports*, 15(7), 1819-1823. doi: 10.11124/JBISRIR-2016-003155. [see Appendix B]
- Ho, P.,** Bulsara, M., Downs, J., Patman, S., Bulsara, C., Hill, A.-M. (2017) Incidence and prevalence of falls in adults with intellectual disability living in the community: a systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, 17(3), 390-413 doi: 10.11124/JBISRIR-2017-003798

The authors' versions of these publications are presented with modifications to suit the style and format of this thesis.

2.1 Abstract

Objective

To synthesise the best available evidence to determine the incidence and prevalence of falls among adults, aged 18 years and older, with ID living in the community.

Methods

A systematic search was conducted across 11 electronic databases. Published and unpublished studies in English from 1990 to 2017 were considered for inclusion. Study designs that were considered for inclusion were cohort studies, case-control and cross-sectional studies. Studies that used an experimental design, both randomised controlled and quasi experimental design were also considered. Studies which reported percentage/numbers of individuals who fell, and the total number of falls and injurious falls sustained from a fall were included for consideration. Two independent reviewers conducted critical appraisal using the Joanna Briggs Institute (JBI) standardised critical appraisal instrument for prevalence studies. The GRADE (Grading of Recommendations Assessment, Development and Evaluation) tool was also used to grade the quality of the evidence.

Results

The pooled proportion of people with ID who fell was 39% [95% CI (0.35%-0.43%), very low GRADE evidence]. The rate of falls ranged from 0.54 to 6.29 per person year (very low GRADE evidence). The rate of injurious falls (2 studies, 352 participants) ranged from 0.33 to 0.68 per person year (very low GRADE evidence).

Conclusion

Synthesised findings demonstrate that adults with ID, who live in community or residential settings, may fall more frequently, and at a younger age, compared to general community populations. Studies should take a consistent approach to measuring and reporting falls outcomes. Further research is recommended to identify the impact of falls on health-related outcomes for adults with ID and subsequently evaluate falls interventions for their efficacy.

2.2 Introduction

In 2014, between 100,000 to 120,000 Australians over the age of 65 were admitted to hospital after sustaining a fall related injury, with each admission being on average eight days (Rubenstein, 2006). The estimated direct health care cost for falls was over AUD\$498 million in 2001 and this is projected to increase to AUD\$1.4 billion in 50 years' time (Australian Commission on Safety and Quality in Healthcare, 2009).

People with ID are particularly vulnerable to falling (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010; Smulders et al., 2013a; Wagemans & Cluitmans, 2006). A diagnosis of ID is made when an individual has either an IQ score lower than 75 or limited intellectual and adaptive functioning (Cox et al., 2010; Finlayson, Morrison, Jackson, Mantry, & Cooper, 2010; Hsieh, Rimmer, & Heller, 2012; Pal, Hale, Mirfin-Veitch, & Claydon, 2014; Wagemans & Cluitmans, 2006), as per the criteria defined in the American Psychiatry Society (APA, 2013) 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). People with ID share similar risk factors for falls to those of people aged 65 years and older, such as reduced muscle strength and balance (Rubenstein, 2006), but they also have additional risk factors such as epilepsy (Willgoss, Yohannes, & Mitchell, 2010) and reduced safety awareness (Cahill, Stancliffe, Clemson, & Durvasula, 2014). Falls may be a problem for people with ID at a younger age compared to older community dwelling adults, as many experience age-related changes from their third decade of life (Carmeli, Imam, Bachar, & Merrick, 2012; Strydom et al., 2010).

It is challenging to establish the rate of falls in adults with ID due to high heterogeneity in both study methods and reported data (Cox et al., 2010; Finlayson et al., 2010; Grant, Pickett, Lam, O'Connor, & Ouellette-Kuntz, 2001; Hsieh et al., 2012; Pal et al., 2014; Salb et al., 2015; Smulders, Enkelaar, Weerdesteyn, Geurts, & Schroyen Lantman-de Valk, 2013; Wagemans & Cluitmans, 2006). Studies conducted in adults with ID suggest that the rate of falls varies widely and may be up to 6.29 falls per person year (Pal et al., 2014). Falls research guidelines recommend that falls data should be collected prospectively with daily recording of falls and a minimum of monthly follow-ups by the research team (Lamb, Jørstad-Stein, Hauer, & Becker, 2005). These recommended guidelines for falls research can be difficult to implement among people with ID due to challenges implementing informed consent

processes (McDonald & Kidney, 2012) and difficulties in engaging people with ID in research (Lennox et al., 2005). Falls and falls injuries are recommended to be reported as rates, and reporting the proportion of participants who fall within the observational period is also recommended (Lamb et al., 2005), however previous studies have not always reported these outcomes (Cox et al., 2010; Finlayson et al., 2010; Hsieh et al., 2012; Wagemans & Cluitmans, 2006).

A variety of methods for collecting and measuring falls data have been used. Some studies have collected falls data prospectively, whilst others used retrospective data collection. For the studies that collected data prospectively, only one study collected falls data using daily recordings (Smulders et al., 2013b). Other studies relied on organisational incident reports or recording the number of falls based on participants' reports at the end of the study period (Cox et al., 2010; Finlayson et al., 2010; Hsieh et al., 2012; Pal et al., 2014; Wagemans & Cluitmans, 2006). This method of data collection is not recommended as falls data collected through recall has been found affect accuracy in the area of falls research (Hauer, Lamb, Jorstad, Todd, & Becker, 2006; Lamb et al., 2005). The studies also encompassed varied settings and participant groups (Cox et al., 2010; Finlayson et al., 2010; Hsieh et al., 2012; Pal et al., 2014; Smulders et al., 2013b; Wagemans & Cluitmans, 2006). Participants' ages ranged from 16 to 89 years old (Finlayson et al., 2010; Salb et al., 2015). Participants who had a variety of living arrangements were also recruited, including, residential facilities, campus facilities, living independently or living in shared housing with formal care arrangements (Cox et al., 2010; Finlayson et al., 2010; Hsieh et al., 2012; Pal et al., 2014; Salb et al., 2015; Smulders et al., 2013b; Wagemans & Cluitmans, 2006). Therefore, it is challenging to determine the incidence of falls in specific populations of people with ID. It is important to make this distinction and also to establish the incidence and prevalence of falls among adults with ID to be able to quantify the extent of the problem, and to subsequently allow robust testing of falls reduction interventions and development of services that are specifically suitable for these populations.

Large systematic reviews have examined the prevalence and incidence of falls among older people living in the community (Gale, Cooper, & Aihie Sayer, 2016; Kwan, Close, Wong, & Lord, 2011; Rubenstein, 2006). However, previous reviews of falls among people with ID have primarily focused on risk factors and preventative strategies (Willgoss et al., 2010), gait and balance capacities (Enkelaar, Smulders, van

Schrojenstein Lantman-de Valk, Geurts, & Weerdesteyn, 2012) and prevention of unintentional injury (Sherrard, Ozanne-Smith, & Staines, 2004). No review has specifically synthesised the evidence for the prevalence and incidence of falls among adults with ID to identify the underlying scope of the problem.

2.3 Methods

This systematic review was conducted according to a previously published systematic review protocol (Ho et al., 2017), using the JBI method for the systematic review of prevalence and incident data (Munn, Moola, Lisy & Riitano, 2014). A senior librarian who provides expert advice on behalf of the Joanna Briggs Institute (JBI) to researchers conducting systematic reviews in WA was consulted and provided detailed guidance on the search mapping and completion. The protocol including methods and search approaches are detailed in systematic review protocol in the appendix (see Appendix B).

2.3.1 Participants

This review considered studies, conducted worldwide, that included people with mild to severe levels of ID according to the limitations in intellectual and adaptive functioning classification in the DSM-5 (American Psychiatric Association, 2013). Studies that used the term ‘learning disability’ which uses the same criteria as ID in DSM-5 were also included. Studies that used a broader inclusion criteria of ‘developmental disability’ (Richmond, 1983) were also included as these studies would likely have included participants with ID, since ID is one type of developmental disability. The review considered studies involving participants aged 18 years and older. Studies that included participants younger than 18 years were included if the mean age was 18 years or older, or if data from participants who were 18 years or older could be separately extracted.

Studies that included only participants who were under 18 years of age, adults who had a cognitive impairment resulting from an acquired brain injury or age-related diseases of cognition, such as dementia, were excluded.

2.3.2 Condition

The World Health Organisation 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’ (World Health Organisation, 2018) and a fall was classified as injurious if it resulted in bruising, laceration, dislocation, fracture or complaining of the onset of persistent pain as a result of the fall (Hill et al., 2011). Studies were included in this review if they reported on falls prevalence and/or incidence as a primary or secondary outcome measure. Outcome measures could include the rate of falls (expressed as the number of falls experienced by participants during the total observation period of the study, i.e. falls per person year, number of falls per 1000 person days), the proportion of participants who became fallers (expressed as percentage of participants who fell), the rates of injurious falls (expressed as the number of falls with injury experienced by participants during the observation period i.e. injurious falls per person year, number of falls with injury per 1000 person days), and the proportion of participants who had an injurious fall (expressed as the number of participants who sustained an injury as a result of a fall). Studies which did not provide the above data but provided data which could be used to calculate the falls or injurious falls rate per person time or the proportion/number of participants who fell one or more times were also included.

2.3.3 Context

This review considered all studies that included participants with ID who lived in either community based settings or residential facilities. This context differs from the stated protocol (Appendix B) for this systematic review, which stipulated that only participants with ID living in community-based settings would be considered. Some studies reviewed during the present search included participants who lived in a variety of community settings, but did not describe the exact nature of the setting, making it challenging to distinguish if these participants were living in a residential facility, community or an accommodation setting that had both types of living arrangements. Studies which were conducted in hospitals or studies that included participants who were in a hospital setting remained excluded.

2.3.4 Types of studies

This review considered studies 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 used an experimental design, both randomised controlled and quasi-experimental designs were included. Single-case studies were excluded.

2.3.5 Data Sources and Search Strategy

A three-step search strategy was used to identify both published and unpublished studies written in English. First a limited search of MEDLINE and CINAHL was undertaken using an initial set of key words (fall, falls prevention, intellectual disability), followed by the analysis of the text words contained in the title, abstract and the index terms used to describe the article. Second, an extended search using all identified keywords and index terms was undertaken across 11 databases. Search strategies for all databases are displayed in Appendix C. Third, the reference lists of all identified reports and articles retrieved for their full-text were searched for additional studies.

MEDLINE, CINAHL, Embase and PsycINFO were databases searched via the EbscoHost platform and the AMED database was searched via the Ovid platform. The Cochrane Central Register of Controlled Trials (CENTRAL) was also searched. A clinical trial registry database, Current Controlled Trials (<http://www.isrctn.com>) and the National Institute of Health Clinical Database (<http://www.clinicaltrials.gov>) were also searched. To avoid publication bias, the search for unpublished studies was conducted using TROVE, Google Scholar and ProQuest Theses and Dissertations. For specific research into people with ID the websites of Rehabilitation Research and Training Center on Developmental Disabilities and Health (<http://ahs.uic.edu/disability-human-development#centers>), Centre for Developmental Disability Health Victoria (www.cddh.monash.org) and the Centre for Applied Disability Research (www.cadr.org.au) were also searched

2.3.6 Study Selection

Studies published from 1990 to December 2017 were considered for inclusion. The start date of 1990 was 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 (Gillespie et al., 2012; Goodwin et al., 2014) have included studies dating from 1990 (Campbell et al., 1990; Carpenter & Demopoulos, 1990). All studies identified were retrieved and examined by two independent reviewers (PH, JD) who read the title and abstract, to ensure relevance and that they met the inclusion criteria with arbitration about final inclusion from a third independent reviewer (AMH) if required.

2.3.7 Assessment of Methodological Quality

Articles selected for retrieval were assessed by two independent expert reviewers (SP, JD) for methodological validity before they were included in the review using the Joanna Briggs Institute standardised critical appraisal instrument for prevalence studies (Munn, Moola, Lisy, Riitano, & Tufanaru, 2015). The checklist for prevalence studies were also used for experimental studies with the checklist being used to appraise how the baseline falls data were collected and analysed, as that was the outcome of interest for this review. Any disagreements that arose between the reviewers were resolved through discussions, or by further discussion with a third reviewer (AMH). Guidelines for conducting falls research (Hauer et al., 2006; Lamb et al., 2005) recommend that prospective falls data collection is undertaken to reduce recall bias, therefore question seven of the critical appraisal (Was the condition measured in a reliable way?) was rated 'No' if falls data were collected based on recall. Studies that scored five or more 'Yes' ratings out of nine were included in the review.

2.3.8 Data Extraction

Quantitative data were extracted from the selected studies by the two independent reviewers (PH, AMH) using the standardised extraction tool from the Joanna Briggs Institute's System of the Unified Management, Assessment and Review Information (JBI SUMARI), version 5, 2016. Data that included specific details about the populations, study methodology and outcomes of significance or those that allowed the outcomes of significance to be calculated (number of falls, falls rates,

number/proportion of people who fell, number of injurious falls and injurious falls rates) were extracted. For the one study (Van Hanegem, Enkelaar, Smulders, & Weerdesteyn, 2014) that used an experimental design, data extracted included the falls data that were collected at baseline only. Any disagreements that arose between the reviewers were resolved through discussions, and where necessary a third reviewer (SP) was asked to make a final decision.

2.3.9 Data Synthesis

All data were subjected to double data entry. Statistical meta-analysis was conducted for the outcome of number of fallers (proportion of people who fell). The number of fallers and non-fallers in each group were entered and data were pooled using STATA version 14 (StataCorp, College Station, TX, USA), using the metaprop command. Metaprop implements procedures which are specific to binomial data (Nyaga, Arbyn, & Aerts, 2014). It computes 95% confidence intervals using the score statistic and the exact binomial method and incorporates the Freeman-Tukey double arcsine transformation of proportions (Miller, 1978). This also allows the within-study variability to be modelled using the binomial distribution. A random effects model was used to calculate estimates. Heterogeneity was assessed using the I^2 squared statistic and was rated as low, moderate or high (Higgins, Thompson, Deeks, & Altman, 2003). Heterogeneity was subsequently explored by undertaking a sensitivity analysis, based on the methods that the studies used to collect falls data, including whether falls data were collected using prospective or retrospective data collection methods.

The number of falls in each study and the days of observation were used to calculate the incidence as a rate per person year. It was not possible to pool the incidence rates for the included studies because patient level data were not presented and neither were data which would allow an estimate of the degree of uncertainty of the incidence rate reported, such as the standard error of the falls rate data. Therefore results for falls rates were presented as falls per person year for each study and summarised in table form. The studies that reported the number of injurious falls or the number of people who sustained an injurious fall also did not report patient level data or data that would allow an estimate of the degree of uncertainty, therefore these data were not pooled for meta-analysis and were presented as a narrative synthesis with a table of results.

2.4 Results

2.4.1 Included Studies

After all databases were searched and duplicates were removed from retrieved records, 2,951 titles and/or abstracts were screened (Appendix C). Articles that did not fit the inclusion criteria were excluded resulting in 22 citations identified as appropriate for detailed assessment. Thirteen studies were excluded after reading the full text. These studies were excluded because the outcomes of interest (prevalence/incidence of falls) were either not measured in these studies or could not be calculated from the data collected in the study. Where the same cohort of participants was used in multiple studies the data were only included once. Studies that were conducted in a population that did not meet inclusion criteria, such as participants being under 18 years old, were excluded. The excluded studies and their reasons for exclusion are presented in Appendix E. The remaining nine articles were selected for critical appraisal and all were included in the analysis. The study selection and inclusion process is detailed in the PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2010) flowchart (Figure 2.1).

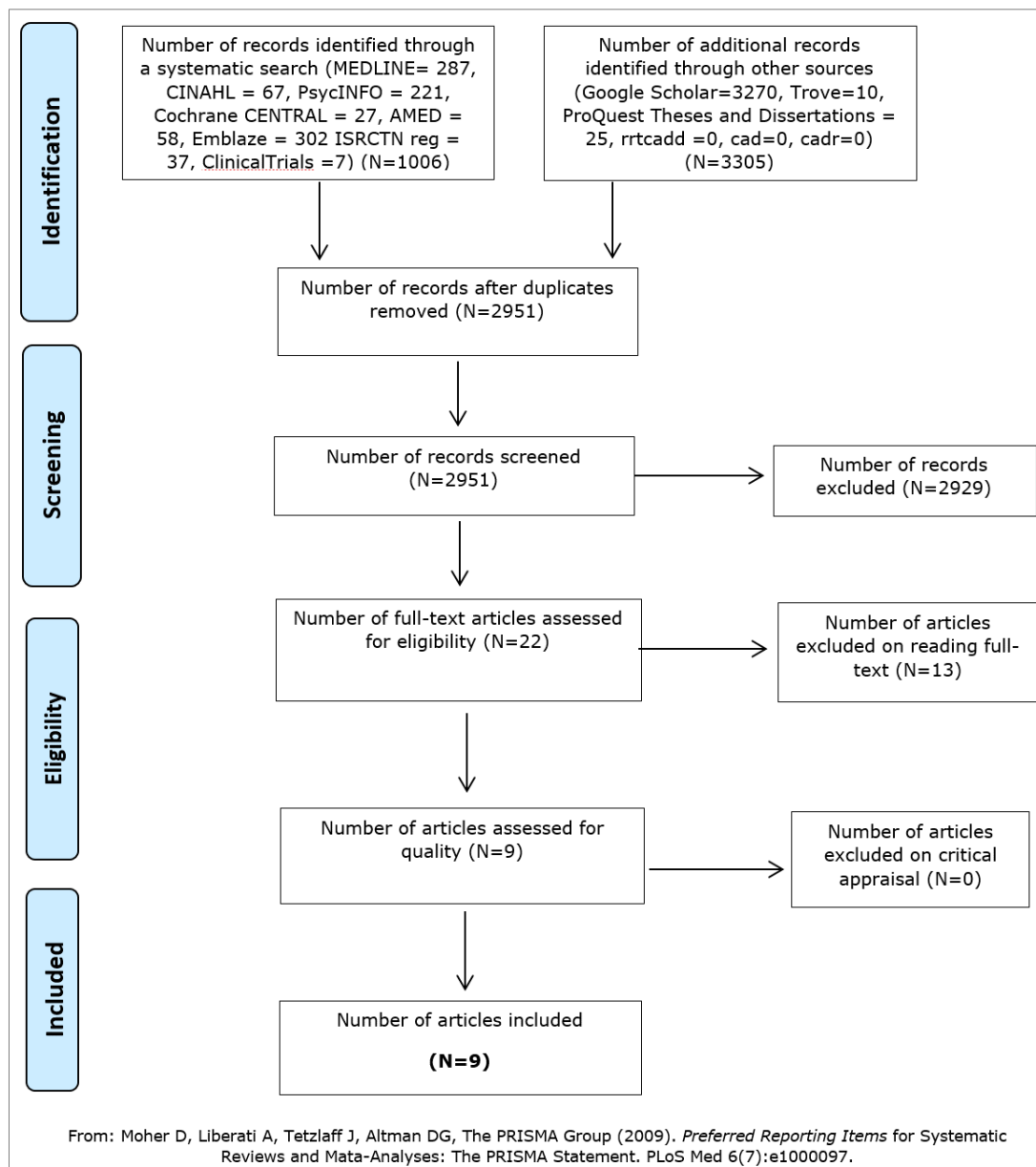


Figure 2.1 PRISMA Flow Diagram of Search and Study Selection Process

2.4.2 Methodological Quality of Studies

The nine included studies were critically appraised by the two independent reviewers (SP, JD) using the Joanna Briggs Institute’s standardised critical appraisal instrument for prevalence studies (Munn et al., 2015). Results of the methodological quality evaluation are shown in Table 2.1. The checklist for prevalence studies was also used for the single quasi-experimental study, where the appraisal was focused on how the baseline falls data were collected and analysed. The eight studies that investigated the incidence or prevalence of falls in people with ID scored between six to eight (out of nine), and were considered of an acceptable quality for inclusion in

meta-analysis. One study (Van Hanegem et al., 2014) scored five out of nine: this was a quasi-experimental study and falls data collected at baseline were examined. This study scored well on the selection of the sample but not on the measurement and analysis of the falls data. Five of the nine studies reported that they used a recommended method of collecting falls data, namely, prospective data collection with regular follow ups (Table 2.1, Q7). Four of the nine studies scored 'No' on selecting an appropriate sample as one study (Smulders et al., 2013b) excluded people with ID who had a diagnosis of Epilepsy, two studies (Salb et al., 2015; Wagemans & Cluitmans, 2006) had a significantly higher proportion of women and one had a small sample size (Van Hanegem et al., 2014). One study (Pal et al., 2014) did not describe participants' level of ID and this study was rated as 'Unsure'.

Table 2.1 Methodological Assessment Score of the Included Studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Total score
Cox et al., 2010	Y	Y	Y	Y	Y	U	N	Y	Y	7
Finlayson et al., 2010	Y	Y	Y	Y	Y	N	N	Y	Y	7
Grant et al., 2001	Y	N	Y	Y	Y	Y	Y	N	Y	8
Hsieh et al., 2012	Y	N	Y	Y	Y	N	N	Y	Y	6
Pal et al., 2014	U	Y	N	Y	Y	Y	Y	Y	Y	7
Salb et al., 2015	N	N	Y	Y	Y	Y	Y	Y	Y	7
Smulders et al., 2013	N	Y	Y	Y	Y	Y	Y	N	Y	7
Van Hanegem et al., 2014	N	Y	Y	Y	Y	U	U	U	Y	5
Wagemans and Cluitmans, 2006	N	N	Y	N	Y	Y	Y	Y	Y	6
Y%	44.5	55.6	88.9	88.9	100	55.6	55.6	66.7	100	

Legend:

Y=Yes, N=No, U=Unclear, N/A = Not Applicable

Q1 Was the sample frame appropriate to address the target population?

Q2 Were study participants sampled in an appropriate way?

Q3 Was the sample size adequate?

Q4 Were the study subjects and the setting described in detail?

Q5 Was the data analysis conducted with sufficient coverage of the identified sample?

Q6 Were valid methods used for the identification of the condition?

Q7 Was the condition measured in a standard, reliable way for all participants?

Q8 Was there appropriate statistical analysis?

Q9 Was the response rate adequate, and if not, was the low response rate managed appropriately?

2.4.3 Characteristics of Included Studies

Characteristics of the nine included studies are shown in Table 2.2. One of the nine included studies was a quasi-experimental study (Van Hanegem et al., 2014) while the other eight used an observational design. Sample sizes ranged from 39 (Van Hanegem et al., 2014) to 1,515 (Hsieh et al., 2012) participants and two studies had a higher proportion of female compared to male participants (72.5% and 75.5% being female) (Salb et al., 2015; Wagemans & Cluitmans, 2006). The mean age of participants was able to be calculated from eight studies and was 47.6 years. The age of participants in all nine studies ranged from 16 to 89 years. There were four studies that enrolled participants from one residential facility (Grant et al., 2001; Salb et al., 2015; Van

Hanegem et al., 2014; Wagemans & Cluitmans, 2006) and five of the other studies had participants from a mixture of living arrangements (Cox et al., 2010; Finlayson et al., 2010; Hsieh et al., 2012; Pal et al., 2014; Smulders et al., 2013b). Seven studies used an observational period of 12 months, one study had an observational period of 33 months (Wagemans & Cluitmans, 2006) and one study had an average follow up period of four years and five months (Grant et al., 2001). Two studies only enrolled participants who had mild or moderate levels of ID, based on the rationale that participants would be required to understand the instructions to participate in baseline tests (Smulders et al., 2013b; Van Hanegem et al., 2014). One study excluded participants who had a diagnosis of epilepsy (Smulders et al., 2013b). Four studies collected falls data retrospectively and five studies collected falls data prospectively, either from daily records kept by completing monthly calendars (Smulders et al., 2013b) or from falls incidence reports from accommodation support providers (Grant et al., 2001; Pal et al., 2014; Salb et al., 2015; Wagemans & Cluitmans, 2006). Six studies (Cox et al., 2010; Finlayson et al., 2010; Hsieh et al., 2012; Salb et al., 2015; Smulders et al., 2013b; Wagemans & Cluitmans, 2006) provided data on the number of adults who fell, six studies provided data on number of falls during the observation period (Grant et al., 2001; Pal et al., 2014; Salb et al., 2015; Smulders et al., 2013b; Van Hanegem et al., 2014; Wagemans & Cluitmans, 2006). Only two studies specifically followed falls research recommendations (Lamb et al., 2005) by reporting falls rates (Salb et al., 2015; Smulders et al., 2013). The remaining four studies provided data which allowed the rate of falls to be calculated (Grant et al., 2001; Pal et al., 2014; Van Hanegem et al., 2014; Wagemans & Cluitmans, 2006). Two studies reported on the number of injurious falls which allowed the injurious falls rate to be calculated (Salb et al., 2015; Wagemans & Cluitmans, 2006).

Table 2.2 Characteristics of Included Studies

Author	Setting	Methods/Study design	Participants	Outcome measures/results	Missing data
Cox et al., 2010 ⁴ NSW, Australia	Australian Medical Clinic	Retrospective, recall of falls in past 12 months from a question as part of a survey from a proxy	Sample Size: n = 114 Age: ≥ 18 (18 – 68) years Mean age=38 Gender: male = 55.3%; female = 44.7% Level of ID: mild = 36.9%, moderate = 41.4%, severe/profound = 16.2%, unknown = 5.4 % Place of residence: formal care = 52.6%, non-formal care = 47.4%	Prevalence - Number of fallers ^a ; n = 39 (34%) Proportion of participants who sustained one of more injuries as a result of a fall; n = 31/37 (83.8%)	Number of falls ^b Incidence - Falls rate ^c Number of injurious falls ^d Number of injuries ^e Incidence - Injurious falls rate ^f
Finlayson et al., 2010 ⁶ Glasgow, UK	All adults with ID who were registered with a GP/family physician in the geographical area of Greater Glasgow, Scotland	Retrospective recall of injuries and accidents over previous 12 months during an interview using a semi-structure questionnaire with a proxy	Sample size: n = 511 Age: ≥ 16 (16-79) years, mean = 43.7 ± 14.2 Gender: male = 53.4%; female = 46.6% Level of ID: mild = 39.3%, moderate = 22.9%, severe = 19.0%, profound = 18.8% Place of residence: Family care = 42.7%, Lives independent of any care = 8.6%, Paid care support = 45.0%, Congregate care = 3.7%	Prevalence - Number of fallers; n = 205 (40.1%) Proportion of participants who sustained one of more injuries as a result of a fall; n = 62 (30.2%)	Number of falls Incidence - Falls rate Number of injurious falls Number of injuries Injurious falls rate

Author	Setting	Methods/Study design	Participants	Outcome measures/results	Missing data
Grant et al., 2001 ¹⁵	Adults with ID living in a residential or group home setting from an agency in Canada.	Incident reports were completed and filed when a fall occurred with their clients. Falls data were pulled from the agency's database where falls incident reports were kept. There were 507 person years of follow up data.	Sample size: n = 114 Age: 18-77 years, mean = 43.7 Gender: male = 55.3%; female = 44.7% Level of mental retardation: mild/moderate = 59.6%; Severe/profound = 40.4%	Prevalence - Number of falls = 275 Injurious falls = 79% Fallers = 7 out of every 10 people	Number of fallers Falls rate Number of injurious falls Number of injuries Injurious falls rate
Hsieh et al., 2012 ⁷ United States of America (USA)	Across 50 states in the USA	Retrospective recall of falls in past 12 months as part of a Longitudinal Health and ID Survey	Sample size: n = 1515 Age: ≥ 18 (18-86) years, mean = 37.43 ± 14.48 Gender: male = 55.1%; female = 44.9% Place of residence: Least supported = 29.7%, Moderately supported = 68.8%, Most supported = 3.3% Ambulatory status: Use of walking aid = 8.6%	Prevalence- Number of fallers; n = 372 (24.6%)	Number of falls Falls rate Number of injuries Number of injurious falls Injurious falls rate
Pal et al., 2014 ⁸ New Zealand (NZ)	3 service providers; 2 from South island, 1 from north island of NZ	Prospective collection of falls incidents forms with monthly follow up with residential manager. 3 different cohorts with a 3 month and two, 6 month observational period	Sample size: n = 135 Age: ≥ 18 (22-71) years Gender: male = 52%; female = 65% Place of residence: Residential homes = 83%, Supported independent living = 7%, With parents = 8%, Unknown = 2% Ambulatory status: Used assistive devices = 15% Independently ambulate = 85%	Prevalence - Number of fallers; n = 37 (27.4%) Number of falls = 125	Falls rate Number of injuries Number of injurious falls Injurious falls rate

Author	Setting	Methods/Study design	Participants	Outcome measures/results	Missing data
Salb et al., 2015 ¹⁶	A residential facility in Bavaria, Germany. >200 residence with up to 20 residence living on the same floor/building	12 month longitudinal prospective data collection of falls using an electronic report form completed by staff members Included definition of fall ^a	Sample size: n = 147 Age: 21- 89 years, mean 55.2 ± 16.1 Gender: male = 24.5%; female = 75.5% Level of ID: Mild/moderate = 37.4% Severe/Profound = 62.6% Ambulatory status: Use of walking aid = 17 %	Prevalence- Number of fallers; n= 51 (34.7%) Number of falls = 140 Number of injurious falls= 48 (34.3%) Incidence - Falls rate = 0.96 falls per person year	Number of injuries Injurious falls rate
Smulders et al., 2013 ¹⁴ Netherlands	3 service providers for person with ID in the Netherlands	Prospective study for 12 months using monthly fall registration calendars. Calendars were collected end of the month Included definition of fall ^a	Sample size: n = 82 Age: > 50 (51.6-84.6) years, mean = 62.9 ± 7.6 Gender: male = 58.5%; female = 41.5% Place of residence: Group home = 89% Campus facility = 4.9% Independent with ambulatory support = 6.1% Inclusion criteria included able to walk independently for 10m, understand simple instructions, have mild to moderate ID (IQ 37-70) Exclusion criteria included having epilepsy	Prevalence - Number of fallers; n= 37 (45%) Number of falls = 77 Incidence - Falls rate = 1.0 falls per person year	Number of injuries Number of injurious falls Injurious falls rate

Author	Setting	Methods/Study design	Participants	Outcome measures/results	Missing data
Van Hanegem et al., 2014 ³⁵ Netherlands	A residential facility for people with ID	Retrospective data collection of falls data at baseline for a quasi-experimental study implementing a falls prevention exercise program Included definition of fall ^g	Sample size: n = 39 Age: mean = 55.1 ± 10.7 years Gender: male = 53.8%, female = 46.2% Level of ID: Mild = 23.1% Moderate = 17.9% Severe = 53.8% Profound = 5.1% Inclusion criteria included high falls risk, recent history of falls and ambulant Exclusion criteria included not having the ability, cognitively and functionally, to participate in the program and testing	At baseline – Number of falls in last 12 months = 131	Number of fallers Number of injurious falls Injurious falls rate Falls rate Injurious rate
Wagemans and Cluitmans, 2006 ⁵ Netherlands	338-person campus-based residential setting in the Netherlands	33 month prospective falls data collection by staff members. Data sampled weekly.	Sample size: n = 338 Age: all age groups (<20 - > 80) Gender: male = 27.5%, female = 72.5% Functional state: Bedridden = 11% Walking outside = 75% Walking inside = 4 % Wheelchair = 10 %	Prevalence - Number of fallers; n= 205 (60.6%) Number of falls = 1200 Number of injurious falls = 383	Number of injuries Falls rate Injurious falls rate

Notes:

^a Number of fallers = number of participants who sustained more than one fall during the study period

^b Number of falls = the total number falls observed during the study period from the total sample population

^c Falls rate = Number of falls per person year. Calculated with number of falls/sample size and converted to a 12 month period.

^d Number of injurious falls = Number of falls that resulted in one or more injuries.

^e Number of injuries = Number of injuries there are sustained from the falls occurred in the study period

^f Injurious falls rate= Number of injuries falls per person year. Calculated with number of injurious falls/ sample size and converted to a 12 month period.

^g Where not indicated, studies did not indicate that a fall was defined in the study.

2.4.4 Findings of the Review

All the outcomes as outlined under the inclusion criteria were analysed with the data extracted from the included studies. The findings are presented for the three outcomes of i) incidence of falls (falls rates), ii) proportion of participants who experienced one or more falls, and iii) falls that resulted in injuries (injurious falls rates).

Falls Rates

Six studies presented data which allowed the rate of falls to be calculated. The sample size, number of falls and the period of observation (months) and the falls rate for each of these studies are presented in Table 2.3. The falls rates ranged from 0.54 falls per person year (Grant et al., 2001) (114 participants observed) to 6.29 falls per person year (Pal et al., 2014) (28 participants observed).

Table 2.3 Results of falls rates of included studies

Study	Observation period	Sample (n)	Falls (n)	Falls rates ^a (per person year)
Salb et al., 2015	12 months	147	140	0.95
Smulders et al., 2013	12 months	82	77	1.06
Van Hanegem et al., 2014	12 months	99	131	1.32
Wagemans and Cluitmans, 2006	33 months	205	1200	2.13
^b Pal et al., 2014 (A)	3 months	28	44	6.29
^b Pal et al., 2014 (B)	6 months	33	39	2.37
^b Pal et al., 2014 (C)	6 months	74	42	1.14
Grant et al., 2001	507 person yrs ^c	114	275	0.54

^aFalls rates were calculated by taking number of falls/sample size and converting it to a 12 month period.

^bPal et al., 2014, reported on three different studies, each with a different cohort, the authors conducted in one publication. To calculate the falls rates we kept the studies separately and presented them as study A, B and C.

^cStudy did not report observational period for each participant but reported on the total number of person years available for follow up.

Proportion of participants who experienced one or more falls

Pooled Analysis

Six studies that provided comparable statistics regarding the proportion/number of adults with ID who experienced one or more falls during the study period were pooled for meta-analysis. Pooled results demonstrated that the proportion of adults with ID who fell one or more times was 40% (CI 0.27-0.53). (See Figure 2.2). However, there was a high degree of heterogeneity ($I^2 = 92.89\%$).

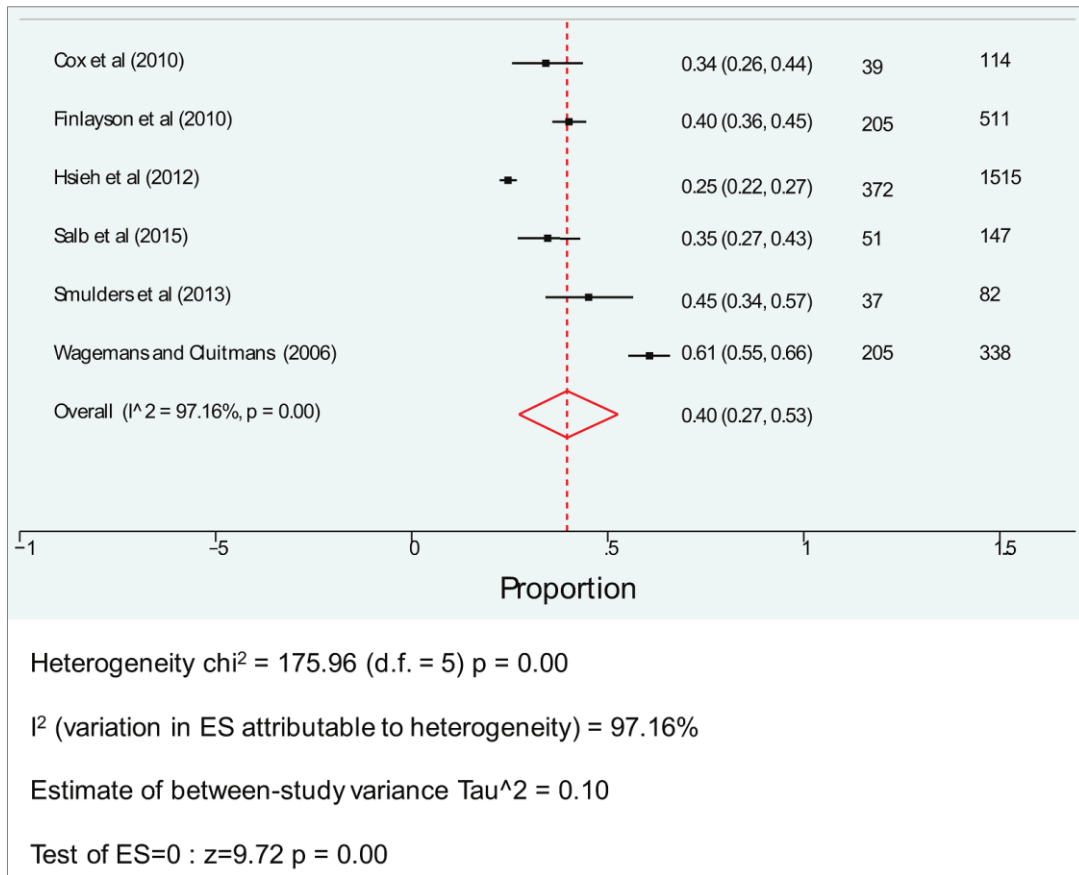


Figure 2.2 Meta-analysis of the Proportion of People with ID who Experienced One or More Falls (six studies)

Sensitivity Analysis

Two (Hsieh et al., 2012; Wagemans & Cluitmans, 2006) of the six studies that reported data on the number of participants who fell one or more times used methods that differed from the other four studies. One study had an observation period of 33 months (Wagemans & Cluitmans, 2006), compared to the other five studies which observed participants for 12 months (Cox et al., 2010; Finlayson et al., 2010; Hsieh et

al., 2012; Salb et al., 2015; Smulders et al., 2013b). One study collected falls data using a nationwide survey (Hsieh et al., 2012) while the other five studies used interviews or organisation based incidence reporting. When these two studies were removed from the meta-analysis, heterogeneity became low ($I^2 = 20.13\%$). Pooled results of the remaining four studies showed that the proportion of adults with ID who fell one or more times was 39% (95% CI 0.35-0.43) (Figure 2.3).

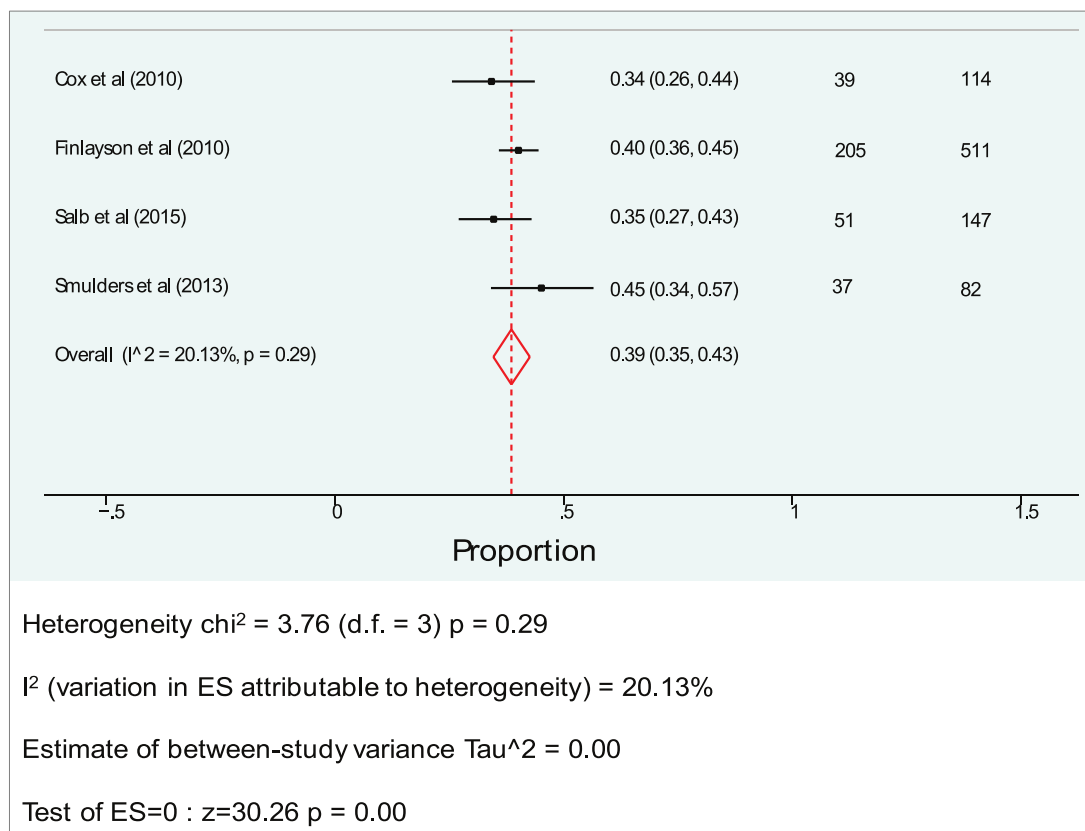


Figure 2.3 Meta-analysis of the Proportion of People with ID who Experienced One or More Falls: Sensitivity Analysis Based on Falls Data Collection (four studies)

Injurious falls

Two studies (Salb et al., 2015; Wagemans & Cluitmans, 2006) reported on the number of falls that resulted in one or more injuries (data presented in Table 2.3). The number of falls that resulted in one or more injuries was 48 (34.3%) in the study conducted by Salb et al., 2015 and 383 (31.9%) in the study conducted by Wagemans and Cluitmans, 2006. These two studies also reported data which allowed the rate of injurious falls to be calculated. The incidence rate of injurious falls ranged from 0.33 to 0.68 per person year (presented in Table 2.2). However, these studies differed, with Wagemans and Cluitmans, 2006 study period being 33 months while Salb et al., 2015

used a 12 month observational period. Therefore, the data reporting the number of adults who fell in these two studies were not appropriate to pool in a meta-analysis. The other studies (Cox et al., 2010; Finlayson et al., 2010; Grant et al., 2001; Hsieh et al., 2012; Pal et al., 2014; Salb et al., 2015; Smulders et al., 2013; Van Hanegem et al., 2014) did not provide data that allowed an injurious falls rate to be calculated. Grant et al., 2001 reported that 78.5% of falls resulted in injuries but did not report the actual number of injurious falls and therefore was not included in Table 2.4.

Table 2.4 Results of injurious falls rates of included studies

Study	Observation period (months)	Sample (n)	Number of injurious falls (n)	Injurious falls rates^a (per person yr)
Salb et al., 2015 ¹⁶	12	147	48	0.33
Wagemans and Cluitmans, 2006 ⁵	33	205	383	0.68

^aInjurious falls rates were calculated by taking number of falls events that resulted in one or more injuries and the observation period for each participant to calculate the incident rate of injurious falls per person period. Each study result was converting to a rate of injurious falls per person year for comparison.

2.4.5 GRADE Certainty Assessment and Results

The certainty of the evidence presented in each of the studies used in the systematic analysis of all three outcomes were assessed using the GRADE approach (Schünemann, Broz'ek, Guyatt, & Oxman, 2013). The certainty of evidence was graded as very low in all three of the outcomes (Table 2.5). The risk of bias was rated serious for all groups of studies used in all three outcomes.

Table 2.5 GRADE Summary of Findings

Outcomes	Impact	No. of participants (studies)	Certainty of the evidence (GRADE)
Proportion of people who experienced one or more falls (fallers vs non falls) assessed with: retrospective recall, prospective incident reporting, daily recording Follow-up: 12 months	There were 39 per 100 participants fell (95% CI 35 to 43)	854 (4 observational studies)	⊕○○○ VERY LOW a,b,c
Incidence of falls (falls rates per person year) assessed with: daily recording of falls, prospective incident reporting Follow-up: range 3 months to 33 months	Falls rate range from 0.54 to 6.29 falls per person year	722 (8 observational studies)	⊕○○○ VERY LOW c,d,e
Incidence of falls that resulted in one or more injuries (Injurious falls rates) assessed with: prospective incident reporting Follow-up: range 12 months to 33 months	Injurious falls rates range from 0.33 to 0.68 per person year	352 (2 observational studies)	⊕○○○ VERY LOW c,f,g

CI: Confidence interval

GRADE Working Group grades of evidence

High certainty: We are very confident that the true effect lies close to that of the estimate of the effect

Moderate certainty: We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different

Low certainty: Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect

Very low certainty: We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect

Explanations

^a Falls events not measured according to recommended guidelines in three of four studies (Cox et al., 2010; Finlayson et al., 2010; Grant et al., 2001).

^b Imprecision: The confidence intervals across the 4 studies ranges from 26% to 57%, indicating a degree of uncertainty of the weighted effect size (39%)

^c Publication bias is suspected to be serious as authors found published conference abstracts regarding the prevalence of falls in people with ID, but these studies were not found in the systematic search to be included in this review

^d Only one study (Smulders et al., 2013b) collected falls data according to recommended guidelines and the severity of participants' intellectual disability or participants' co-morbidities are not always specified

^e The estimated falls rates vary widely (and show inconsistent variance when compared to the fall rates of community dwelling older people (known to be approximately 1.2 falls per person year) (Campbell et al., 1990).

^f Only two studies were able to be included in the analysis (Salb et al., 2015; Wagemans & Cluitmans, 2006).

^g The injurious falls rates vary in the two studies (Salb et al., 2015; Wagemans & Cluitmans, 2006).

Inconsistency was rated depending on the heterogeneity of the study design, data collection, the participants' age group and living arrangements. For the outcome of Proportion of Participants Who Experienced One or More Falls, inconsistency was rated as low. Inconsistency was rated as low for the outcome of Rate of Injurious Falls because the study design and data collection were similar, which enabled injurious falls rates to be calculated from the number of injuries provided in included studies. Inconsistency was rated as very serious for the outcome of Falls Rates.

Imprecision for the studies was rated serious to very serious for all of the outcomes and publication bias was strongly suspected.

2.5 Discussion

The aim of this review was to investigate the prevalence and incidence of falls in adults with ID living in community-based settings. After an extensive search and quality assessments of the studies, nine studies were included in the systematic review, of which six were used to contribute data to meta-analyses.

Meta-Analysis

The pooled analysis of the studies found that the proportion of adults with ID who fell during the study observation period was 39% (ranging from 35% to 43%). This compares with previous large studies (Milat et al., 2011; Rubenstein, 2006) conducted in community populations which found that approximately 30% to 40% of people 65 years and over, fall in a 12-month period, with approximately 50% of people over the age of 80 years old falling in a 12 month period. Falls in adults with ID needs more investigation as this pooled analysis consisted of adults with ID in both residential and community settings. Other studies that were not suitable to include in the meta-analysis reported 27% of adults with ID living in the community had a fall during 3-6 month observation period (Pal et al., 2014) and 57-79% of their participants fell within a 33 month to 5 year observations period (Grant et al., 2001; Wagemans & Cluitmans, 2006). This also emphasises the need for falls related studies to be conducted in a consistent manner and report similar outcomes so that useful comparisons can be made.

The mean age of the participants in this review was 47.6 years, indicating that adults with ID experience a high prevalence of falls at a younger age compared to the

general community where falls are not considered a problem until people are aged 65 years and over. Therefore, it is important for health professionals to note that falls prevention is highly relevant when providing healthcare to adults with ID throughout their adult life, rather than delaying such interventions until they are over the age of 65 years. Adults with ID are highly likely to benefit from falls prevention services that are designed in a similar way to falls services for older people (Feder, Cryer, Donovan, & Carter, 2000), with additional tailoring for individual needs (Smulders et al., 2013a).

Nine of 22 studies investigating falls among adults with ID identified were screened as appropriate to be included in the review. It was not possible to pool data from all nine studies to determine the overall prevalence and incidence of falls for adults with ID living in the community because the study populations (age groups, living arrangements) differed, as did the study designs. The number of studies and the data they reported were limited, hence we were unable to report falls rates for any particular subgroup such as age groups. Therefore this review was only able to provide data for adults with ID as a homogenous sample.

There was also a wide variation of falls rates ranging from 0.54 to 6.29 falls per person year. This may not be an accurate representation of the true incidence rates of falls in this population, as individual study results were not consistently higher or lower than reported falls rates within the older population, which are estimated at 0.74 per person year (Campbell et al., 1990). It was not possible to determine if the variation was entirely due to heterogeneity in population differences or study reporting. For example, low and high falls rates were found in studies that had participants living in residential as well as mixed living arrangements. Studies that collected falls data using recommended methods (Lamb et al, 2005) (prospective data collection) also reported a wide range of falls rates.

Quality of Studies

This review also aimed to investigate injurious falls rates. However only two studies provided data on injurious falls (falls that resulted in an injury or injuries) and two separate studies (Salb et al., 2015; Wagemans & Cluitmans, 2006) reported the number of participants who sustained an injury as a result of a fall. These data were not able to be pooled in meta-analysis to report the number of participants sustaining an injurious fall or a pooled incidence rate of injurious falls.

Quality of Evidence

The risk of bias using the GRADE Approach (Schünemann et al., 2013) was rated as serious for all groups of studies as less than 50% of the studies did not have a sample frame that clearly addressed the target population and four out of nine studies either recruited participants from only one residential setting (Grant et al., 2001; Salb et al., 2015; Wagemans & Cluitmans, 2006) or recruited participants who responded to an online or posted survey (Hsieh et al., 2012).

Inconsistency was rated depending on the heterogeneity of the study design, data collection and the participant's age group and living arrangements. In the outcome Proportion of Participants Who Experienced One or More Falls, the inconsistency was rated low, as a sensitivity analysis was carried out based on studies with similar study design. Falls data were collected prospectively from residential facilities or from care staff of service providers who had direct contact with the participants and observation period was 12 months in the included studies.

Inconsistency was also low in the outcome Rate of Injurious Falls as the study design and data collection was similar, which enabled the calculation of injurious falls rates possible from the number of injuries provided in included studies. Inconsistency was rated as very serious for Falls Rates as estimated falls rates varied widely and showed inconsistent variance when compared to the fall rates of community or nursing home dwelling older people (known to be approximately 0.74 falls (Campbell et al., 1990) in the community and 3.6 falls (Rubenstein, Josephson, & Robbins, 1994) per person year in nursing home settings. Imprecision for the studies were rated serious to very serious for the outcomes.

The confidence interval across the four studies used in the outcome Proportion of Participants Who Experienced One or More Falls ranged from 26% to 57%, indicating a high degree of uncertainty of the weighted effect size at 39%. The range of reported falls and the injurious falls rates from all included studies in the review was wide, therefore the results were considered imprecise for the population.

Publication bias is strongly suspected in this systematic review as authors found a poster abstract reporting the prevalence of falls in older adults with ID residing in Ireland (Foran, McCallion, & McCarron, 2016), however none of the studies included in this review were from Ireland. The studies included were also from one facility in

Germany (Grant et al., 2001) or from a single regional area in United Kingdom (Finlayson et al., 2010). There is also a large proportion of people living with ID worldwide who have not been included in the studies.

2.5.1 Limitations

Only six studies were included in the meta-analysis, out of which four were included in the sensitivity analysis, therefore the results need to be interpreted cautiously. Furthermore, due to the limited number of studies, it was necessary to combine studies which investigated the prevalence and/or incidence of falls in adults with ID living in community based as well as residential settings. Therefore the results obtained from the pooled analysis for fallers were not limited to people with ID living in community based settings as we stated our published protocol (Ho et al., 2017). Patient characteristics such as muscle weakness, mobility status and cognitive impairment have been shown to affect the risk of falls. There were insufficient data to conduct these types of subgroup analyses (Rubenstein, 2006). It was also not possible to pool the incidence rates of falls because patient level data were not presented and neither were data which would allow an estimate of the degree of uncertainty of the incidence rate reported. Individual patient data for each study would be ideal to conduct this meta-analysis in the future. It is recommended that future falls related research in older adults with ID follow the recommendations for falls research closely so that outcomes are collected and reported consistently. Conducting research in older adults with ID can be challenging and it is recommended that consensus be developed for conducting falls related research in older adults with ID. Methods used should be sensitive to older adults with ID and special considerations be given to close follow up during data collection to acknowledge that the data collection can add demands to the older adult with ID and their caregivers.

Researchers should also note that analysis of the studies using the JBI GRADE (Schünemann et al., 2013) criteria showed that the evidence pooled from the included studies was of very low quality and therefore we recommend caution in the interpretation of the results.

2.5.2 Implications for Practice

The finding of this review suggest that falls become a health problem for people with ID at an earlier age in life compared to the general community-dwelling population and that the prevalence of falls remains high throughout their adult life. Health practitioners should consider regular assessments, management of falls risk and provision of falls interventions for all adults with ID and their care providers. In particular they should be aware that falls management may need to commence at an earlier age by including adults with ID who are approaching the age of 40 years, rather than commencing falls management when they are over 60 years of age. This approach varies from population falls guidelines for general community populations that direct their recommendations towards people who are 65 years of age and older (World Health Organisation, 2018; Centers for Disease Control and Prevention, 2019).

2.6 Conclusion

There was a high level of heterogeneity between the included studies, making it challenging to compare the outcomes of interest. This systematic review found that 39% adults with ID fall once or more in a 12 month period (very low certainty of GRADE evidence). This prevalence is reported at a younger age when compared to the prevalence of falls in the broad community dwelling population. Falls rates ranged widely from 0.54 to 6.29 falls per person year, with unexplained heterogeneity. Based on the limited data, the review was not able to estimate the prevalence of injurious falls. We recommend that more high quality research regarding falls incidence in people with ID is conducted in accordance with recommended guidelines.

2.7 Recommendations for Future Research

The uncertainty of the true prevalence and incidence of falls and injurious falls among people with ID is a serious limitation for both researchers and health care services. Robust trials that evaluate the effectiveness of falls prevention interventions for people with ID are urgently required. To conduct these efficacy studies, accurate measurement of falls outcomes is critical and additionally researchers need to accurately estimate sample sizes required. There are currently high levels of variability in the studies conducted to measure falls rates in this population, making estimates uncertain. This is a critical gap as injuries resulting from falls are a significant problem

in older populations (Australian Institute of Health & Welfare, 2018), therefore more studies are needed to evaluate the extent of this problem among people with ID.

There are challenges in conducting falls research with adults with ID and further work is required to develop methodology for adhering to guidelines for conducting falls research among adults with ID. Health care services also need to understand the true extent of the problem of falls and injurious falls among adults with ID, to appropriately deliver targeted resources and services.

2.7.1 Research Aims

The purpose of the research conducted for this thesis was to investigate the nature of falls, risk factors for falls and experiences when engaging with health services after a fall among older adults with ID living in the community in WA. The specific research aims were:

- Study 1 (Chapter 2): To synthesise the current evidence on the prevalence and incidence of falls in older adults with ID.
- Study 2 (Chapter 4): To develop and describe an informed consent process for use when recruiting older adults with ID.
- Study 3 (Chapter 5): To investigate the falls rate, injurious falls rate and associated risk factors for falls in older adults with ID living in the community.
- Study 4 (Chapter 6): To explore the experiences of older adults with ID and their support persons when seeking healthcare services after a fall and the barriers they face when taking up evidence-based falls prevention recommendations that were provided to them.

2.7.2 Overview of The Research Structure

An overview of the structure of the research, including how each phase of the research contributes to the chapters of the thesis is presented in Figure 2.4.

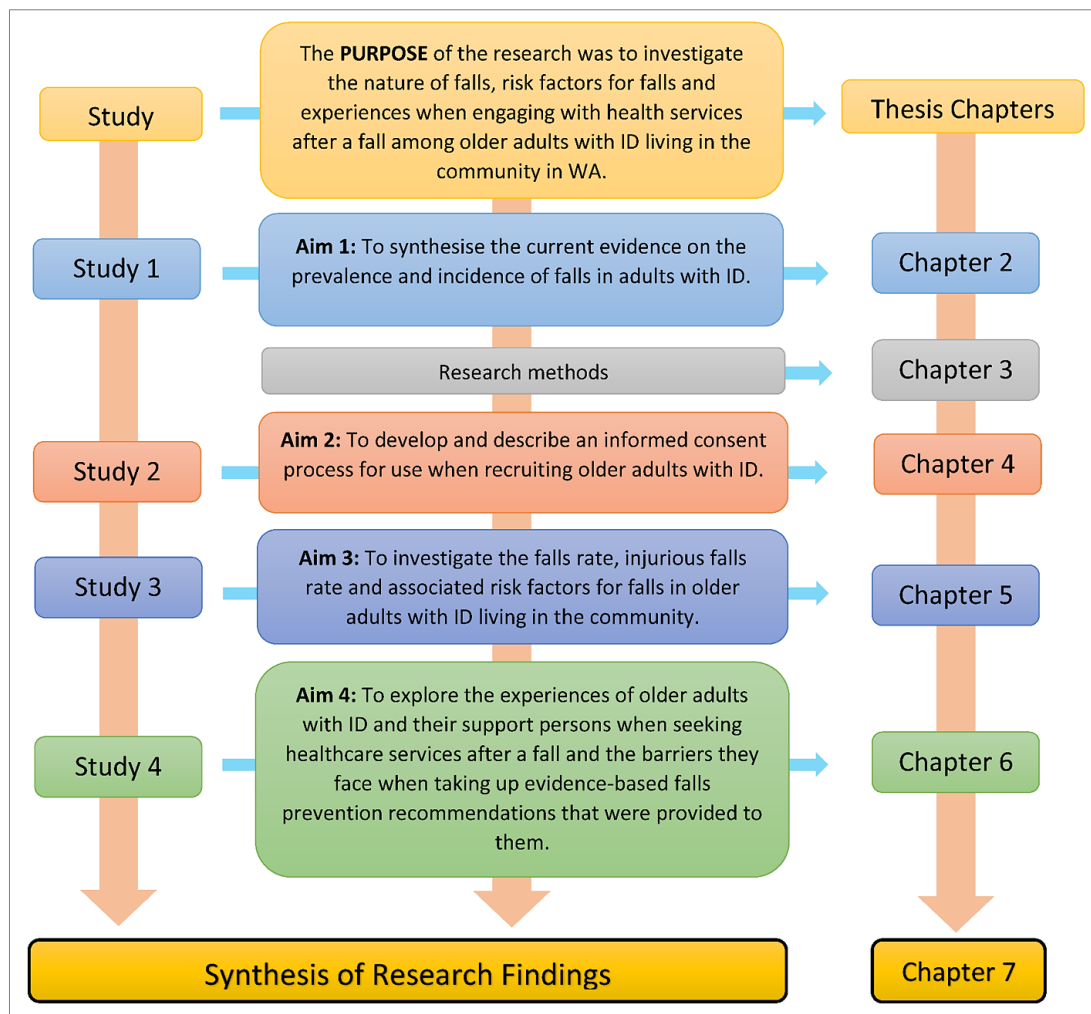


Figure 2.4 Overview of the Research Structure

2.8 References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)*. 5th ed. Arlington, US: American Psychiatric Publishing
- Australian Commission on Safety and Quality in Healthcare. (2009). *Preventing falls and harm from falls in older people: Best practice guidelines for Australian community care*. Retrieved from: <https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Guidelines-COMM.pdf>
- Australian Institute of Health and Welfare. (2018). Trends in hospitalised injury due to falls in older people 2002-03 to 2014-15. Cat.no: INJCAT 191. Retrieved from: <https://www.aihw.gov.au/reports/injury/hospitalised-falls-older-people-2002-03-to-2014-15/contents/table-of-contents>
- Centers for Disease Control and Prevention. (2019) Keep on your feet—Preventing older adult falls.
Retrieved from: https://www.cdc.gov/injury/features/older-adult-falls/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Ffeatures%2Folder-adult-falls%2Findex.html
- Cahill, S., Stancliffe, R. J., Clemson, L., & Durvasula, S. (2014). Reconstructing the fall: individual, behavioural and contextual factors associated with falls in individuals with intellectual disability. *Journal of Intellectual Disability Research*, 58(4), 321-332. doi:10.1111/jir.12015
- Campbell, A. J., Borrie, M. J., Spears, G. F., Jackson, S. L., Brown, J. S., & Fitzgerald, J. L. (1990). Circumstances and consequences of falls experienced by a community population 70 years and over during a prospective study. *Age and Ageing*, 19(2), 136-141.
- Carmeli, E., Imam, B., Bachar, A., & Merrick, J. (2012). Inflammation and oxidative stress as biomarkers of premature aging in persons with intellectual disability. *Research in Developmental Disabilities*, 33(2), 369-375.
doi:10.1016/j.ridd.2011.10.002
- Carpenter, G. I., & Demopoulos, G. R. (1990). Screening the elderly in the community: controlled trial of dependency surveillance using a questionnaire administered by volunteers. *BMJ (Clinical Research Ed.)*, 300(6734), 1253-1256.
- Cox, C. R., Clemson, L., Stancliffe, R. J., Durvasula, S., & Sherrington, C. (2010). Incidence of and risk factors for falls among adults with an intellectual disability. *Journal of Intellectual Disability Research*, 54(12), 1045-1057.
doi:10.1111/j.1365-2788.2010.01333.x

- Enkelaar, L., Smulders, E., van Schrojenstein Lantman-de Valk, H., Geurts, A. C. H., & Weerdesteyn, V. (2012). A review of balance and gait capacities in relation to falls in persons with intellectual disability. *Research in Developmental Disabilities, 33*(1), 291-306. doi:10.1016/j.ridd.2011.08.028
- Feder, G., Cryer, C., Donovan, S., & Carter, Y. (2000). Guidelines for the prevention of falls in people over 65. *BMJ, 321*(7267), 1007.
- Finlayson, J., Morrison, J., Jackson, A., Mantry, D., & Cooper, S. A. (2010). Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *Journal of Intellectual Disability Research, 54*(11), 966-980. doi:10.1111/j.1365-2788.2010.01319.x
- Foran, S., McCallion, P., & McCarron, M. (2016) The Prevalence of falls among older adults with intellectual disability in Ireland. *Age and Ageing, 45*(suppl_2), ii13–56.
- Gale, C. R., Cooper, C., & Aihie Sayer, A. (2016). Prevalence and risk factors for falls in older men and women: The English Longitudinal Study of Ageing. *Age Ageing, 45*(6), 789-794. doi:10.1093/ageing/afw129
- Gillespie, L. D., Robertson, M. C., Gillespie, W. J., Sherrington, C., Gates, S., Clemson, L. M., & Lamb, S. E. (2012). Interventions for preventing falls in older people living in the community. *The Cochrane Database of Systematic Reviews, 12*(9), CD007146.pub3. doi:10.1002/14651858.CD007146.pub2
- Goodwin, V. A., Abbott, R. A., Whear, R., Bethel, A., Ukoumunne, O. C., Thompson-Coon, J., & Stein, K. (2014). Multiple component interventions for preventing falls and fall-related injuries among older people: systematic review and meta-analysis. *BMC Geriatrics, 14*, 15. doi:10.1186/1471-2318-14-15
- Grant, H. J., Pickett, W., Lam, M., O'Connor, M., Ouellette-Kuntz, H. (2001). Falls among persons who have developmental disabilities in institutional and group home settings. *Journal on Developmental Disabilities, 8*(1), 57-73.
- Hauer, K., Lamb, S. E., Jorstad, E. C., Todd, C., & Becker, C. (2006). Systematic review of definitions and methods of measuring falls in randomized controlled fall prevention trials. *Age and Ageing, 35*(1), 5-10. doi:10.1093/ageing/afi218
- Higgins, J. P. T., Thompson, S. G., Deeks, J. J., & Altman, D. G. (2003). Measuring inconsistency in meta-analyses. *BMJ, 327*(7414), 557.
- Hill, A.-M., Hoffmann, T., McPhail, S., Beer, C., Hill, K. D., Oliver, D., . . . Haines, T. P. (2011). Evaluation of the sustained effect of inpatient falls prevention education and predictors of falls after hospital discharge--follow-up to a randomized controlled trial. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 66*(9), 1001-1012. doi:10.1093/gerona/qlr085

- Ho, P., Patman, S., Bulsara, C., Downs, J., Bulsara, M., & Hill, A.-M. (2017). Incidence and prevalence of falls in adults with intellectual disability living in the community: a systematic review protocol. *JBIC Database of Systematic Reviews and Implementation Reports*, 15(7), 1819-1823. doi:10.11124/jbisrir-2016-003155
- Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 442-454. doi:10.1352/1944-7558-117.6.442
- Kwan, M. M., Close, J. C., Wong, A. K., & Lord, S. R. (2011). Falls incidence, risk factors, and consequences in Chinese older people: A systematic review. *Journal of the American Geriatrics Society*, 59(3), 536-543. doi:10.1111/j.1532-5415.2010.03286.x
- Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., & Becker, C. (2005). Development of a common outcome data set for fall injury prevention trials: The Prevention of falls network Europe consensus. *Journal of the American Geriatrics Society*, 53(9), 1618-1622. doi:10.1111/j.1532-5415.2005.53455.x
- Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D. M., & Boyle, F. (2005). Beating the barriers: recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research*, 49(4), 296-305. doi:10.1111/j.1365-2788.2005.00618.x
- McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 27-39. doi:10.1111/j.1741-1130.2011.00319.x
- Milat, A. J., Watson, W. L., Monger, C., Barr, M., Giffin, M., & Reid, M. (2011). Prevalence, circumstances and consequences of falls among community-dwelling older people: results of the 2009 NSW Falls prevention baseline survey. *NSW Public Health Bulletin*, 22(4), 43-48.
- Miller, J. J. (1978). The Inverse of the Freeman – Tukey double arcsine transformation. *The American Statistician*, 32(4), 138. doi:10.1080/00031305.1978.10479283
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2010). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *International Journal Surgery*, 8(5), 336-341. doi:10.1016/j.ijsu.2010.02.007
- Munn, Z., Moola, S., Riitano, D., & Lisy, K. (2014). The development of a critical appraisal tool for use in systematic reviews addressing questions of prevalence. *International Journal of Health Policy and Management*, 3(3), 123-128. doi:10.15171/ijhpm.2014.71

- Munn, Z., Moola, S., Lisy, K., Riitano, D., & Tufanaru, C. (2015). Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and cumulative incidence data. *International Journal Evidence Based Healthcare*, 13(3), 147-153.
doi:10.1097/xeb.0000000000000054
- Nyaga, V. N., Arbyn, M., & Aerts, M. (2014). Metaprop: a Stata command to perform meta-analysis of binomial data. *Archives of Public Health*, 72(1), 39.
doi:10.1186/2049-3258-72-39
- Pal, J., Hale, L., Mirfin-Veitch, B., & Claydon, L. (2014). Injuries and falls among adults with intellectual disability: A prospective New Zealand cohort study. *Journal of Intellectual & Developmental Disability*, 39(1), 35-44.
doi:10.3109/13668250.2013.867929
- Richmond, D. T. (1989). *Inquiry into Health Services for the psychiatrically ill and developmentally disabled*. Department of Health, NSW: State Health Publication No. (DP 83-020), Part 2:p9. Retrieved from:
<https://nswmentalhealthcommission.com.au/sites/default/files/Inquiry%20into%20Health%20Services%20for%20the%20Psychiatrically%20Ill%20and%20Developmentally%20Disabled%20-%20Richmond%20Report%20-%201983.pdf>
- Rubenstein, L. Z. (2006). Falls in older people: epidemiology, risk factors and strategies for prevention. *Age and Ageing*, 35(suppl_2), ii37-ii41.
doi:10.1093/ageing/af1084
- Rubenstein, L. Z., Josephson, K. R., & Robbins, A. S. (1994). Falls in the nursing home. *Annals of Internal Medicine*, 121(6), 442-451. doi:10.7326/0003-4819-121-6-199409150-00009
- Salb, J., Woodward, C., Offenhäuser, J., Becker, C., Sieber, C., & Freiberger, E. (2015). Prevalence and characteristics of falls in adults with intellectual disability living in a residential facility: A longitudinal study [PreFallID]. *Intellectual and Developmental Disabilities*, 53(3), 228-239. doi:10.1352/1934-9556-53.3.228
- Schünemann, H., Broz'ek, J., Guyatt, G., & Oxman, A. (2013). GRADE handbook for grading quality of evidence and strength of recommendations. The GRADE Working Group, 2013. Retrieved from:
<https://gdt.gradepro.org/app/handbook/handbook.html>
- Sherrard, J., Ozanne-Smith, J., & Staines, C. (2004). Prevention of unintentional injury to people with intellectual disability: a review of the evidence. *Journal of Intellectual Disability Research*, 48(7), 639-645. doi:10.1111/j.1365-2788.2003.00570.x

- Smulders, E., Enkelaar, L., Schoon, Y., Geurts, A. C., van Schroyen Lantman-de Valk, H., & Weerdesteyn, V. (2013a). Falls prevention in persons with intellectual disabilities: Development, implementation, and process evaluation of a tailored multifactorial fall risk assessment and intervention strategy. *Research in Developmental Disabilities, 34*(9), 2788-2798. doi:10.1016/j.ridd.2013.05.041
- Smulders, E., Enkelaar, L., Weerdesteyn, V., Geurts, A. C. H., & Schroyen Lantman-de Valk, H. (2013b). Falls in older persons with intellectual disabilities: fall rate, circumstances and consequences. *Journal of Intellectual Disability Research, 57*(12), 1173-1182. doi:10.1111/j.1365-2788.2012.01643.x
- Strydom, A., Shoostari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., . . . Maaskant, M. (2010). Dementia in older adults with intellectual disabilities-epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities, 7*(2), 96-110. doi:10.1111/j.1741-1130.2010.00253.x
- Van Hanegem, E., Enkelaar, L., Smulders, E., & Weerdesteyn, V. (2014). Obstacle course training can improve mobility and prevent falls in people with intellectual disabilities. *Journal of Intellectual Disability Research, 58*(5), 485-492. doi:10.1111/jir.12045
- Wagemans, A. M. A., & Cluitmans, J. J. M. (2006). Falls and fractures: A major health risk for adults with intellectual disabilities in residential settings. *Journal of Policy and Practice in Intellectual Disabilities, 3*(2), 136-138. doi:10.1111/j.1741-1130.2006.00066.x
- Willgoss, T. G., Yohannes, A. M., & Mitchell, D. (2010). Review of risk factors and preventative strategies for fall-related injuries in people with intellectual disabilities. *Journal of Clinical Nursing, 19*(15-16), 2100-2109. doi:10.1111/j.1365-2702.2009.03174.x
- World Health Organization. (2018) *Falls fact sheet*. Geneva, Switzerland: World Health Organization. Retrieved from: <https://www.who.int/news-room/fact-sheets/detail/falls>

Investigating Falls in Adults with Intellectual Disability in Community Based Settings and their Experiences of Post-fall Care Services: Research Methods

Preface

This chapter describes the methods for the observational cohort investigation (Study 3) and follow up qualitative investigation (Study 4) conducted as part of the research for this thesis.

The chapter is based on a published article:

Ho, P., Bulsara, C., Patman, S., Bulsara, M., Downs, J., Hill, A.-M. (2018). Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for prospective observational cohort study. *BMC Geriatrics*, 18(1), 171. doi: 10.1186/s12877-018-0862-8.

The author's version of the article is presented with modifications to suit the style and format of this thesis.

3.1 Abstract

Background

Falls among older adults with ID are recognised as a serious health problem potentially resulting in reduced health-related quality of life and premature placement in residential care. However there are limited studies that have investigated this problem and thus falls rates among older adults with ID remain uncertain. Furthermore, older adults with ID rely heavily on familial and professional care support to address health problems, such as after having a fall. No studies have explored the post-fall care that older adults with ID receive.

Method

The research for Studies 3 and 4 was carried out using a convergent mixed methods design consisting of a quantitative phase (Study 3) and a qualitative phase (Study 4). The aim of Study 3 was to estimate the falls rate by prospectively observing a cohort of older adults (≥ 35 years) with ID ($n=90$) for six months. Study 3 was conducted according to STROBE guidelines. In Study 4, participants from Study 3 who experienced a fall(s) were asked to participate in a semi-structured interview to explore their post-fall experiences.

Methods for the Systematic Review, (Study 1), are described in full in Chapter 2 and the published protocol for the systematic review is presented as Appendix B. The methods for Study 2, which aimed to develop and evaluate an informed consent process used in the research for this thesis are detailed in Chapter 4.

Ethical considerations

The observational study in this thesis (Studies 3 and 4) received ethics approval from The University of Notre Dame Australia, Human Research Ethics Committee (015067F) (Appendix F) and the affiliated local organisation for people with ID (Appendix G). All participants (or their legal representative or next-of-kin) provided written informed consent to participate in the study.

3.2 Introduction

Falls among older adults with ID living in the community are a cause for concern. Adults with ID have been observed to experience signs of ageing from their third decade in life (Hermans & Evenhuis, 2014; Connolly, 2006; Strydom et al., 2010), and as such are considered 'older adults.' At least 50% or more of these falls result in injury (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010; Smulders, Enkelaar, Weerdesteyn, Geurts, & Schroyenstein Lantman-de Valk, 2013a) and between 6-11% result in severe injuries, such as fractures and concussion (Smulders et al., 2013a; Wagemans & Cluitmans, 2006). Qualitative research undertaken among adults with ID found that falls may lead to reduced activity and independence and increase the burden of care on their caregivers (Cahill, Stancliffe, Clemson, & Durvasula, 2014). Through observation, it has been suggested that falls by adults with ID are associated with an increased risk of institutionalisation (Bruckner & Herge, 2003). Few studies have investigated falls rates amongst older adults with ID living in community based settings. Estimates range from 0.93 to 6.29 falls per person year (Pal, Hale, Mirfin-Veitch, & Claydon, 2014; Salb et al., 2015a; Smulders et al., 2013a; Wagemans & Cluitmans, 2006). Other studies have reported between 25% and 40.1% of adults with ID experienced a fall(s) during the observation period, but did not report the number of falls (Cox et al., 2010; Finlayson, Morrison, Jackson, Mantry, & Cooper, 2010; Hsieh, Rimmer, & Heller, 2012; Lamb, Jørstad-Stein, Hauer, & Becker, 2005). Only four studies provided sufficient data to estimate injurious falls rates and these were 0.38 – 0.73 injurious falls per person year (Salb et al., 2015a; Smulders et al., 2013a; Enkelaar, Smulders, van Schroyenstein Lantman-de Valk, Weerdesteyn, & Geurts, 2013a; Wagemans & Cluitmans, 2006). Research guidelines recommend reporting falls and injurious falls rates, as well as the proportion of people who fall when conducting falls related studies (Lamb et al., 2005). Additionally only one study implemented prospective daily recording of falls (Smulders et al., 2013a), which is recommended for falls prevention trials (Lamb et al., 2005) to ensure accurate and comprehensive collection of falls data. Limitations to these study designs, poses uncertainty about the extent of the problem of falls among older adults with ID. Additionally a limited amount of studies have investigated risk factors and preventive strategies for falls among older adults with ID (Cox et al., 2010; Hsieh et al., 2012; Pal et al., 2014). A review which examined risk factors and preventative strategies for falls

prevention in people with ID was only able to include seven studies, and found there was a lack of evidence about falls management for people with ID, prompting authors to recommend that more research in this area be undertaken (Willgoss, Yohannes, & Mitchell, 2010).

It can be challenging to conduct robust research with older adults with ID (Rodgers, 1999) and conducting falls research with this group is no exception. There are ethical and legal considerations in gaining informed consent (Iacono, 2006) and extensive adaptations are recommended to maximise the participation of people with ID (Kidney & McDonald, 2014). Falls recommendations for older community-dwelling people have been developed from established evidence from large meta-analyses in the older community dwelling population (Gillespie et al., 2012), however these recommendations are not specifically applicable to older adults with ID (Willgoss et al., 2010). The perspectives that older adults with ID have about falls and falls prevention services are also unknown, as there have been no studies which have sought to understand what experiences older adults with ID have when they fall and subsequently seek access to existing falls prevention services.

The primary aim of Study 3 was to investigate the rate of falls in older adults with ID living in community based settings. The secondary aims were to:

- i. investigate the rate of injurious falls
- ii. determine the risk factors for falls in this population

The aim of study 4 was to:

- i. explore the participant's experience when seeking health services after having a fall
- ii. investigate barriers that participants may encounter when seeking to undertake evidence based falls prevention strategies that are recommended by the health service

3.3 Methods

3.3.1 Design

A convergent mixed methods approach was used in this study (Creswell, 2014). The theoretical framework in mixed method incorporates elements of both quantitative and qualitative approaches. Therefore, quantitative aspects were

underpinned by testing objective theory and qualitative aspects were underpinned by phenomenological inquiry (Creswell, 2014). In Study 3, a prospective observational cohort study was conducted in accordance with STROBE guidelines (von Elm et al., 2014). In Study 4, participants' experiences of falls and access to falls prevention services was explored using a descriptive phenomenological approach. Phenomenology is a research method used to describe a person's lived experience of an event or 'phenomenon' (Liamputtong, 2013). In this case, it was the experience participants had when they sought healthcare services after a fall and the barriers they could have encountered while accessing or engaging in falls prevention recommendations. The results from Study 4 will be presented in accordance with the Standards for Reporting Qualitative Research (O'Brien, Harris, Beckman, Reed, & Cook, 2014). Data from the two studies were analysed independently and the findings were subsequently synthesised (Figure 3.1).

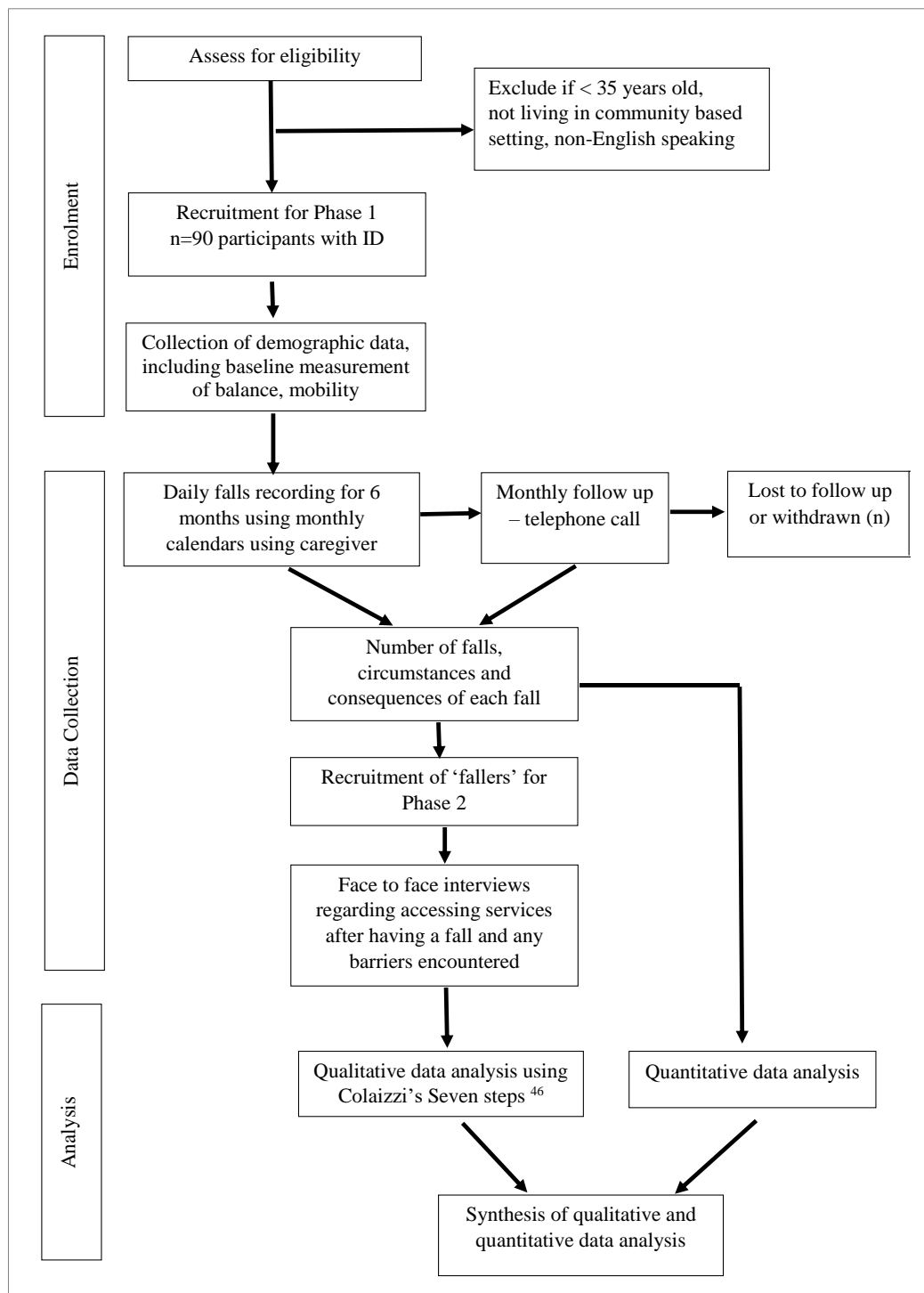


Figure 3.1 Participant flow through the study

The protocol for the study was registered with the Australian New Zealand Clinical Trial Registry (ACTRN12615000926538) on 7 September 2015 (Australian New Zealand Clinical Trial Registry, 2015).

3.3.2 Ethics and informed consent

All studies conducted for the research in this thesis received ethics approval from The University of Notre Dame Australia, Human Research Ethics Committee (015067F) (Appendix F) and the affiliated local organisation for people with ID (Appendix G). All participants (or their legal representative or next-of-kin) provided written informed consent to participate in the study.

Three consent forms were prepared:

- i. a consent form adapted to facilitate the participant's understanding of the study and for what they are providing informed consent to (Appendix H)
- ii. a version for a family member or legal guardian to record their agreement for the person with ID to participate in the study and that in their opinion, the participant is not likely to object to participating in the study (Appendix I)
- iii. a form for the caregiver(s) to provide informed consent that they were willing to support the participant with daily falls recordings and to facilitate communication with the researcher (Appendix J)

Ethical guidelines for research conducted in Western Australia (WA) contained information specific to adults who may lack the capacity to give consent (National Health and Medical Research Council, the Australian Research Council and Universities Australia., 2018). These guidelines were also followed when conducting this study. The guidelines specified that in accordance with the Guardianship and Administration Act (Australian Legal Information Institute, 1990), there was no provision for responsible persons to provide informed consent for a person who was assessed as being incapable of doing so, to take part in medical research (Australian Legal Information Institute, 1990). Therefore in this research, where there was any uncertainty regarding the ability of the participant to provide consent, their guardian or next-of-kin were asked to sign a separate consent form which recorded that they agreed to the participant under their legal care participating in the study and that they believed the participant was not likely to object to participating in the study. Informed consent was gained directly from the potential participant with ID where possible. The family member or caregiver was asked to be present during this process to facilitate

the participant's understanding of what participation in the study entailed and witness the participant completing the consent form.

A step by step informed consent procedure was developed and explored (Study 2) with each older adult with ID and their caregiver prior to determine if the older adult with ID was able to provide their own consent or if a proxy consent was required. Further details of this consent procedure are described in Chapter 4.

After initial recruitment, the researcher maintained contact with the participant with monthly follow ups, either by telephone or face to face, during the six month observational period. Telephone interviews were also conducted when the participant experienced a fall. These contact points provided an opportunity for the participant and the caregiver to raise any issues concerning data collection. It also provided the opportunity for the researcher to assess the participant's capacity to continue with the study and to seek verbal consent for continued participation. For participants who provided consent independently, the researcher also gained their consent to inform a suitable person who was involved in the participant's care, to inform the researcher if there was a decline in cognitive function or health status. The researcher would follow with an assessment to determine their ability to provide consent and seek the legal representative for the participant where required, for continued participation.

In the later stages of the observation period, a caregiver who was involved in the care of a participant who experienced one or more falls was asked to participate in an interview regarding their post-fall experience. Consent was sought from the caregiver as well as the participant, for the caregiver to share their experiences with the researcher.

3.3.3 Participants

People were eligible for inclusion in the study if they had a primary diagnosis of ID or a confirmed diagnosis of ID where it co-existed with a primary condition, such as Down Syndrome, Retts Syndrome or Cerebral Palsy. Older adults with ID in this study were defined by the American Psychiatric Association (APA), DSM – V criteria as people who present with limited intellectual and adaptive functioning (American Psychiatric Association, 2013). This was confirmed by their family or a caregiver. For the purpose of this project, older adults with ID were eligible if they were aged 35

years or older as adults with ID experience age related changes as early as their third decade in life (Connolly, 2006; Hermans & Evenhuis, 2014) such as people with Down Syndrome showing signs of dementia in their 30s (Holland, Huppert & Stevens, 2000). Studies have also shown older adults with ID are experiencing falls in their 30s (Hsieh et al., 2012; Pal, Hale, Mirfin-Veitch, & Claydon, 2014).

Only older adults with ID living in the community were eligible for inclusion. Community settings in Western Australia most often comprise the older adults with ID living at home with their families, in independent units or in small group homes comprising three to six housemates. Paid support caregivers are usually present for varying amounts of time within each living arrangement, to provide assistance with activities of daily living and community participation activities. Medical, allied health and social services are accessed through community options.

Potential participants with ID were excluded if they were younger than 35 years old or if they or their caregivers were unable to understand English. They were also excluded if they were in hospital or living in a residential aged care facility such as a nursing home as the model of care and level of community participation is different to those living in the community. Contemporary views support the inclusion of people in ID to be included in the community and it was deemed important to translate the research findings to community dwelling older adults in the community. Falls prevention treatment differs significantly between settings and previous studies were found to have mixed accommodation settings making comparisons challenging.

3.3.4 Setting and Recruitment

Participants were recruited from 2014 through to 2018, through organisations that provided services to people with ID. These organisations operated in WA and provided an array of support services to people with disability across the metropolitan and rural areas (Rocky Bay, Nulsen Disability Services, IdentityWA, MyPlace, Enable WA, MyPlace, Autism Association of Western Australia).

Participants were recruited from advertisements and flyers posted on social media (Facebook and website) and within the common areas of the supporting organisations. Staff members of the organisation were also encouraged to provide study information to their eligible clients. Participants were consecutively recruited until the target

sample size of 90 participants was achieved. Participants who experience a fall in Study 3 were subsequently purposefully selected and invited to participate in Study 4. The aim was to purposefully select participants who had experienced a fall(s) in Study 3 with different characteristics (Palinkas et al., 2015) and/or consequences of the fall, in order to ensure a diverse sample to capture data that would closely represent the experiences of older adults with ID they sought health services after a fall.

This sample was guided by the participants who fell in Study 3. Where possible, purposeful selection included participants of different gender, age, diagnosis, level of independence and differing levels of communication (including verbal and non-verbal participants). Participants with different living arrangements (living with family or independently with or without support) and those who reported varying circumstances surrounding their falls were also be considered when selecting the sample. Interviews continued until it was considered that saturation of themes had occurred (Liamputtong, 2013) however it was understood that amongst this ‘hard-to-reach’ population this might not be entirely achievable

3.3.5 Sample Size



The incidence of falls in this population is uncertain, but based on previous studies it was estimated to be about 0.27% (Pal et al., 2014; E. Smulders et al., 2013a). If the expected result was 0.27%, we wanted 95% confidence, within a 1% absolute margin of error that the true incidence rate frequency laid between 0 % and 1.27% (Dean, Sullivan, & Soe, 2015). Therefore a minimum sample size of 78 was estimated to be required for Study 3. As the study population had both physical and social disability and the observation period extended for six months, a drop out of approximately 15%, would be allowed for, which was higher than the 5% drop-out in a previous observational falls cohort study of older community dwelling (Hill et al., 2011). Therefore the aim was to recruit 90 participants for Study 3.

3.3.6 Outcome measures

The primary outcome of Study 3 was the number of falls experienced by participants during the six month trial period. A fall was defined as ‘an event which

results in a person coming to rest inadvertently on the ground or floor or other lower level' (World Health Organisation, 2018). Fall events were collected prospectively with daily recordings of any fall occurrences for six months (Smulders et al., 2013a).

Participants were provided with a monthly calendar (Figure 3.2) for six months on which they, or their caregiver, marked a cross on the day(s) if a fall occurred and drew a smiley face on day(s) where a fall was not experienced. The diary contained a prominent phone number and participants were encouraged to contact the researcher at any time. Prospective daily falls recordings are recommended for falls related research to ensure accurate falls data collection (Lamb et al., 2005) and support from the researcher was provided to adhere to this method. It was envisaged that family and caregivers (paid and unpaid) were providing substantial support and sometimes would be entirely relied upon to collect the falls data. If families or caregivers found that this method of data collection was not accurate, such as if daily recordings were not sustainable, other strategies were discussed and actioned as appropriate. These strategies could include but were not limited to, the researcher making contact more frequently, making contact with more than one caregiver or leaving a falls record form with questions from the post-fall telephone interview. Other strategies used were initiating contact with participants and informing others who supported the participant to be aware of their participation, to ensure that all falls were recorded.

Name: _____

Please draw an **X** on the day you have a fall and a 😊 face on the day you do not have a fall.

January 2018							
Week	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1	1	2	3	4	5	6	7
2	8	9	10	11	12	13	14
3	15	16	17	18	19	20	21
4	22	23	24	25	26	27	28
5	29	30	31				
				Please send back in envelope provided			

Note: If you need help to fill in the diary or have any questions please contact Portia Ho on mobile: xxx xxx xxx or email: xxx@my.nd.edu.au

Figure 3.2 Example of Monthly Falls calendar

At the end of the month, the participants were asked to send the calendars back to the researcher. The researcher followed up with a phone call at the end of every month to enquire if a fall had occurred or if participants experienced difficulty completing their diary. When a fall occurred, participants were encouraged to contact the researcher. Caregivers were also encouraged to call when a fall was witnessed or when an unwitnessed fall was suspected. The details of the circumstances of the fall and any falls related injuries were collected through a telephone call or face to face interview. This procedure followed recommended guidelines for conducting falls research (Lamb et al., 2005).

Data about the fall such as where and when the fall occurred, what happened at the time of the fall and if the fall was a result from a seizure was collected. The number, type and location of any resulting injuries and any medical or first aid attention received was also recorded. A fall was classified as injurious if it resulted in bruising, laceration, dislocation, fracture or complaint of an onset of persistent pain as a result of the fall, which was concordant with previous research conducted in this area (Hill et al., 2011).

A list of variables were identified as important information to collect when they have been found to be associated with risk factors for falls in previous fall related studies in older people and older adults with ID (Ambrose, Paul, & Hausdorff, 2013;

Cox et al., 2010; Deandrea et al., 2010; Enkelaar et al. 2013a; Fernando, Fraser, Hendriksen, Kim, & Muir-Hunter, 2017; Hsieh et al., 2012). Baseline demographic data including age and other medical history such as diagnosis including number of comorbidities, any history of fracture, stroke or other condition affecting falls risk, number and type of medications, history of visual impairment and falls history, which have been previously identified as being risk factors for falls (Ambrose et al., 2013) were collected. Medical history was verified by medical notes where available and medications were taken down from current prescriptions, Webster packs or from packaging presented to the researcher that the participant was taking from.

Other measures known to be associated with falls in adults with ID (Cox et al., 2010; Enkelaar, Smulders, van Schrojenstein Lantman-de Valk, Weerdesteyn, & Geurts, 2013; Hsieh et al., 2012) that were collected at baseline were body mass index, indoor and outdoor mobility, use and type of walking aid and classification of IQ score when known. Other supporting information about the participants that were collected include education and employment history and level of care support.

Functional mobility was measured using the Timed-up and Go test (Podsiadlo & Richardson, 1991) while the Four step-square test (Dite & Temple, 2002) and the Four-test balance Scale (Gardner, Buchner, Robertson, & Campbell, 2001) were used as functional measures balance. Five times Sit to Stand (Buatois et al., 2010) were used to measure lower limb strength. These physical outcomes were measured using standardised procedures (Buatois et al., 2010; Gardner et al., 2001; Podsiadlo & Richardson, 1991). It has been shown that balance and mobility test are feasible to be carried out with people with ID (Enkelaar et al., 2013b). The Timed-up and Go and similar balance test have been reported to be reliable and valid for measuring mobility and balance in people with ID (Blomqvist, Wester, Sundelin, & Rehn, 2012; Enkelaar et al., 2013b; Salb et al., 2015b). These test will also be carried out by a physiotherapist who has experience working with older adults with ID. Where required, the procedure was modified appropriately and documented according to the participant's communication styles and understanding.

Strategies used to modify the instructions included the methods described in Salb et al., 2015 (Salb et al., 2015b) which have demonstrated that the reliability of these tests used among people with ID is maintained. Participants' ability to perform activities of

daily living was measured using The Katz Index of Independence in Activities of Daily Living (Katz, 1983). The Personal Well-being Index for people with ID (Cummins & Lau, 2005) was used to collect the participant's perspective on their perceived HRQoL. Where participants were unable to rate their HRQoL, the EQ-5D-5L (Diaz-Redondo, Rodriguez-Blazquez, Ayala, Martinez-Martin, & Forjaz, 2014) was used to ask caregivers to act as a proxy to rate the participant's HRQoL as they perceived it.

Qualitative data gathered during Study 4 of the study explored the participants' experiences when accessing falls prevention services after experiencing a fall. These data were collected using structured face-to-face interviews, which were conducted and recorded by the researcher (PH). The researcher was a therapist who was experienced in working with people with ID. Questions were modified as appropriate using various strategies such as having a familiar family member and /or caregiver present to interpret the questions in the context in which the participant could understand. Participants who had limited verbal communication were included in Study 4. Where appropriate, alternative forms of communication (key word signs, augmentative and alternative communication devices, natural gestures) were used to facilitate the interview. The researcher provided additional support to the participant such as allowing time for them to express themselves, exploring the environment where the fall took place and where suitable, drawing their attention to the part of their body where an injury was sustained. With permission, the interviews were also video recorded to capture any non-verbal communication such as facial expressions, body language, gestures and use of sign language to complement data from the interviews.

Caregivers who were supporting the participant at the time of the fall or who provided support relating to treatment or intervention following the fall were invited to participate in a separate interview, which was also conducted by the researcher (PH). The participant (older adult with ID or a caregiver) was asked to describe the events that took place after the fall with specific attention to any medical or healthcare services that they received. When required, the interviewer prompted using a code, which was designed around the recommended evidence-based service pathway for falls prevention outlined in the WA falls model of care (Department of Health, WA, 2014). The interviewer specifically asked the participant if they were seen by a medical provider after their fall, such as a medical hospital outpatient clinic or their family doctor for falls risk assessment, and if they were provided with any follow up referrals to an

intervention such as physiotherapy for strength and balance exercises or an optometrist for a vision assessment. Open questions were used to explore participants' experiences in further scope and depth. Participants were asked if they sought and received the intervention or a plan was in place for them to undertake the intervention at a later date. Depending on what the participants shared, they were asked if they encountered any barriers when they sought to undertake the intervention that was recommended.

3.3.7 Statistical Analysis

Quantitative Data Analysis

Data were analysed using the SPSS 23.0 software package (SPSS Inc., Chicago, IL, USA) and STATA 14.0 (StataCorp. 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP). Descriptive statistics were used to summarise the clinical and demographic characteristics of the participants. Falls analyses followed recommended statistical guidelines for analysing falls data (Haines & Hill, 2011; Hill et al., 2011).

The primary outcome measure (rate of falls) was expressed as an incidence rate per person year. The number of participants who experienced a fall was expressed as a percentage of people falling in the cohort. The rate of injurious falls was expressed as the incident rate per person year. Generalised linear mixed modelling was conducted to examine the participant demographic and clinical characteristics that were predictive of falls, injurious falls and the risk of falling in the six months observation period.

The modelling strategies started with unadjusted univariate analysis, followed by multivariate analysis, adjusting for age, severity of ID, presence or absence of epilepsy, level of assistance required with activities of daily living, level of mobility and a history of falls in the six months prior to enrolment in the study. These variables had been previously shown to be predictive of falls in either older people or adults with ID.

Qualitative Data Analysis

The management of the qualitative data was assisted by the data management software package NVivo 12 for windows 10 (QSR International Pty Ltd. Version 12, 2018). Data collected from Study 4 interviews were analysed using Colaizzi's seven stages of thematic analysis for phenomenological studies (Liamputtong, 2013; Sanders, 2003). To bring forth accurate key themes to describe a phenomena, Colaizzi

devised seven steps of the analysis which aimed to ensure vigour and trustworthiness of the research material. In this study, the last step was not undertaken where material is returned to participants, as following one of the criticisms of the Colaizzi method, the researchers and participants will inevitably have differing perspectives (Giorgi, 2006). The qualitative data were subsequently compared and contrasted against falls prevention recommendations and guidelines that describe preventive and post falls health care services.

To acquire a sense of each transcript, the researcher (PH) initially listened to the audio recording and watched the video recordings of each interview. This researcher (PH) wrote down any thoughts and feelings that arose while listening or examining the videos of the interviews in a reflective diary to assist with the bracketing process. It was important that bracketing was part of the analysis process to avoid any of the researcher's preconceptions or assumptions (Tufford & Newman, 2012). The researcher then transcribed all audio recorded interviews and subsequently identified and extracted significant phases and statements that described the participant's experience. The transcripts were then sent to other research team members (CB, AMH) who provided independent identification of significant themes and reviewed if the interpretive process of the data was clear in regard to the relationships, clusters and emergent themes. Theme clusters and emergent themes were integrated and presented as an exhaustive description of experiences that the participants had when accessing evidence based falls prevention recommendations. The resulting presentation of the phenomena was then reduced by all three researchers to an essential structure (Sanders, 2003) to explain the falls experience among older adults with ID. The stages of analysis were illustrated in Figure 3.3. This final structure was subsequently integrated with the quantitative statistical findings in order to add value and explain the relationship between the nature of the falls and the experiences of participants.

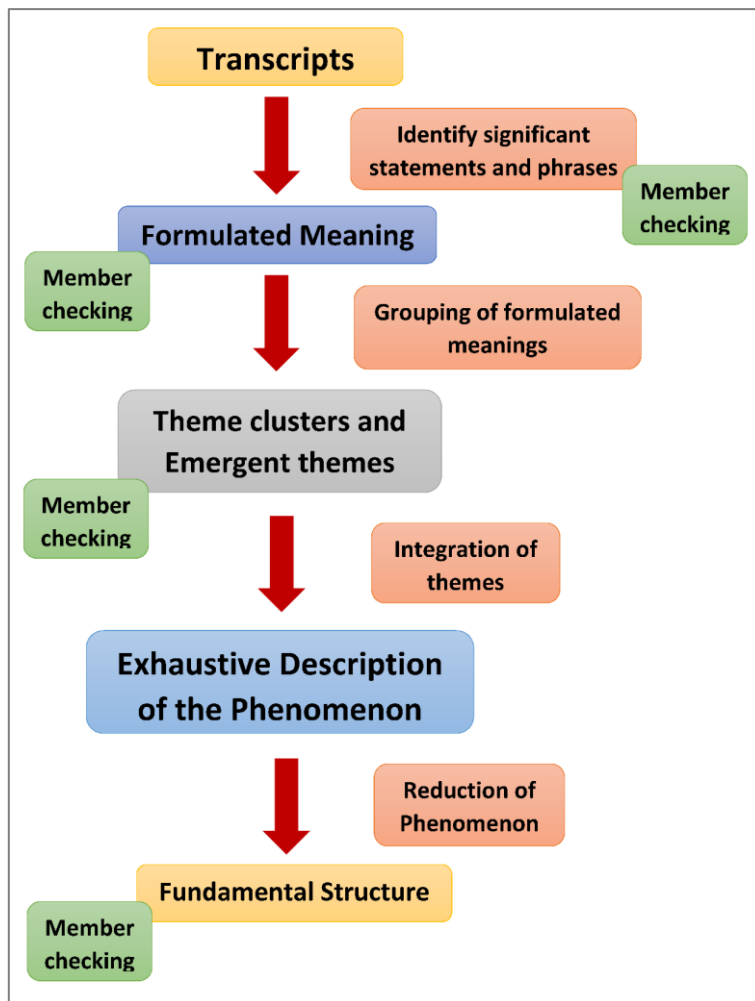


Figure 3.3 Flow of Qualitative analysis adapted from Colaizzi's Method of Interpretation

3.4 Discussion

There has been an increased attention and interest about facilitating “Ageing in Place” for older adults with disability, which operates on the principles of providing older adults with ID the choice of staying in their preferred residence and engaging within communities that are familiar to them (Bigby, 2008). Falls are known to frequently cause serious injuries such as fractures among older adults with ID (Smulders et al., 2013a; Wagemans & Cluitmans, 2006) , which could lead to a negative impact on HRQoL (Hartholt et al., 2011). It is important to understand the extent of the problem of falls in this population so as to provide targeted and effective services. Presently there are limited services that have been specifically designed or tested for addressing falls prevention among adults with ID (Smulders et al., 2013b).

This study was designed in accordance with recommendations for conducting falls research (Lamb et al., 2005). The study targeted participants 35 years and older as it has been observed that adults with ID start to develop age related changes from the mid to late third decade of their lives (Connolly, 2006; Hermans & Evenhuis, 2014). This study also explored participants' experiences when accessing falls prevention services after they experience a fall. This would assist to understand what barriers could be present when older adults with ID attempt to access falls prevention services and undertake relevant interventions.

Falls research guidelines recommends that falls data should be prospectively collected for 12 months (Lamb et al., 2005) however, the study only collected falls data for six months. Most of the participants were not likely to be able to complete the recordings independently and thus the tasks of recording falls would mainly be undertaken by paid and unpaid caregivers. The length of the observational period was chosen as being less burdensome to participants and their caregivers, while still providing robust data about falls rates among older people living with ID. Strategies to increase the likelihood of falls data being collected reliably, such as building a rapport with the caregivers and increasing their awareness about the importance of falls prevention/management have been attempted, but this could form a limitation if there are incomplete data. Falls that were unwitnessed and not subsequently reported to the caregiver by the person with ID could not be collected. Incomplete data where participants are found on the floor and are unable to tell their caregiver or family what occurred were also likely. Data on fear of falls were not collected although recommended (Foran, McCarron, & McCallion, 2013), as piloting demonstrated that it was difficult to seek this type of response directly and consistently from potential participants. Some pilot work showed that this could possibly be obtained for some older adults with ID by proxy reporting, but given the reality that multiple caregivers are involved in different care environments (e.g. supported living, family home, community), proxy reporting may not be reliable (Foran, et al., 2013).

The study was advertised through social media and organisations in WA that provided services to older adults with ID. The information of the study may not have reached to older adults with ID who did not have relationships/partnerships with the organisations and therefore the sample may not have been representative of the wider population of older adults with ID. However, this study collected detailed information which could be used by other organisations with similar populations.

3.5 References

- Australian Legal Information Institute, Western Australian Current Acts. *Guardianship and Administration Act 1990*. Retrieved from:
[https://www.slp.wa.gov.au/statutes/swans.nsf/\(DownloadFiles\)/Guardianship+and+Administration+Act+1990.pdf/\\$file/Guardianship+and+Administration+Act+1990.pdf](https://www.slp.wa.gov.au/statutes/swans.nsf/(DownloadFiles)/Guardianship+and+Administration+Act+1990.pdf/$file/Guardianship+and+Administration+Act+1990.pdf)
- Australian New Zealand Clinical Trial Registry. (2015). Understanding the falls experience in people with intellectual disability in Western Australia. ACTRN12615000926538. Available from:
<https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=368990&isReview=true>
- Ambrose, A. F., Paul, G., & Hausdorff, J. M. (2013). Risk factors for falls among older adults: A review of the literature. *Maturitas*, 75(1), 51-61.
doi:10.1016/j.maturitas.2013.02.009
- American Psychiatric Association. (2013) *Diagnostic and statistical manual of mental disorders (DSM-5)*. 5th ed. Arlington, US: American Psychiatric Publishing.
- Bigby, C. (2008). Beset by obstacles: a review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 33(1), 76-86.
doi:10.1080/13668250701852433
- Bruckner, J., & Herge, E. A. (2003). Assessing the risk of falls in elders with mental retardation and developmental disabilities. *Topics in Geriatric Rehabilitation*, 19(3), 206-211. doi:10.1097/00013614-200307000-00007
- Buatois, S., Perret-Guillaume, C., Gueguen, R., Miget, P., Vançon, G., Perrin, P., & Benetos, A. (2010). A simple clinical scale to stratify risk of recurrent falls in community-dwelling adults aged 65 years and older. *Physical Therapy*, 90(4), 550-560. doi:10.2522/ptj.20090158
- Cahill, S., Stancliffe, R. J., Clemson, L., & Durvasula, S. (2014). Reconstructing the fall: individual, behavioural and contextual factors associated with falls in individuals with intellectual disability. *Journal of Intellectual Disability Research*, 58(4), 321-332. doi:10.1111/jir.12015
- Connolly, B. (2006). Issues in aging in individuals with life long disabilities. *Brazilian Journal of Physical Therapy*, 10, 249-262.
- Cox, C. R., Clemson, L., Stancliffe, R. J., Durvasula, S., & Sherrington, C. (2010). Incidence of and risk factors for falls among adults with an intellectual disability. *Journal of Intellectual Disability Research*, 54(12), 1045-1057.
doi:10.1111/j.1365-2788.2010.01333.x

- Creswell, J. W. (2014). *Research design: qualitative, quantitative, and mixed method approaches*. (4th ed.). Thousand Oaks, California: Sage Publications Inc.
- Cummins, R. A. & Lau, A. L. D. (2005). *Personal wellbeing index - intellectual disability* (3rd ed.). Melbourne, Victoria. School of Psychology: Deakin University Australian Centre on Quality of Life. Retrieved from: <http://www.acqol.com.au/uploads/pwi-id/pwi-id-english.pdf>
- Dean, A. G., Sullivan, K. M., Soe, M. M. (2015). Open source epidemiologic statistic for public health, Version 3.0.1. Available from: https://www.openepi.com/Menu/OE_Menu.htm
- Deandrea, S., Lucenteforte, E., Bravi, F., Foschi, R., La Vecchia, C., & Negri, E. (2010). Risk factors for falls in community-dwelling older people: a systematic review and meta-analysis. *Epidemiology (Cambridge, Mass.)*, 21(5), 658-668. doi:10.1097/EDE.0b013e3181e89905
- Department of Health, Western Australia. (2014). *Falls prevention model of care. Perth: Health Strategy and Networks*. Department of Health, Western Australia. Retrieved from: https://ww2.health.wa.gov.au/Articles/F_I/Falls-Prevention-Health-Network
- Diaz-Redondo, A., Rodriguez-Blazquez, C., Ayala, A., Martinez-Martin, P., & Forjaz, M. J. (2014). EQ-5D rated by proxy in institutionalized older adults with dementia: Psychometric pros and cons. *Geriatrics and Gerontology International*, 14(2), 346-353. doi:10.1111/ggi.12108
- Dite, W., & Temple, V. A. (2002). A clinical test of stepping and change of direction to identify multiple falling older adults. *Archives of Physical Medicine and Rehabilitation*, 83(11), 1566-1571.
- Enkelaar, L., Smulders, E., van Schrojenstein Lantman-de Valk, H., Weerdesteyn, V., & Geurts, A. C. H. (2013a). Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities. *Research in Developmental Disabilities*, 34(11), 3754-3765. doi:10.1016/j.ridd.2013.07.041
- Enkelaar, L., Smulders, E., van Schrojenstein Lantman-de Valk, H., Weerdesteyn, V., & Geurts, A. C. H. (2013b). Clinical measures are feasible and sensitive to assess balance and gait capacities in older persons with mild to moderate intellectual disabilities. *Research In Developmental Disabilities*, 34(1), 276-285. doi:10.1016/j.ridd.2012.08.014
- Fernando, E., Fraser, M., Hendriksen, J., Kim, C. H., & Muir-Hunter, S. W. (2017). Risk factors associated with falls in older adults with dementia: A systematic review. *Physiotherapie Canada*, 69(2), 161-170. doi:10.3138/ptc.2016-14

- Finlayson, J., Morrison, J., Jackson, A., Mantry, D., & Cooper, S. A. (2010). Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *Journal of Intellectual Disability Research*, *54*(11), 966-980. doi:10.1111/j.1365-2788.2010.01319.x
- Foran, S., McCarron, M., & McCallion, P. (2013). Expanding assessment of fear of falling among older adults with an intellectual disability: A pilot study to assess the value of proxy responses. *International Scholarly Research Notices Geriatrics*, *2013*(Art. 493042). doi:10.1155/2013/493042
- Gardner, M. M., Buchner, D. M., Robertson, M. C., & Campbell, A. J. (2001). Practical implementation of an exercise-based falls prevention programme. *Age and Ageing*, *30*(1), 77-83. doi:10.1093/ageing/30.1.77
- Gillespie, L. D., Robertson, M. C., Gillespie, W. J., Sherrington, C., Gates, S., Clemson, L. M., & Lamb, S. E. (2012). Interventions for preventing falls in older people living in the community. *The Cochrane Database of Systematic Reviews*, *9*(Art. No.: CD007146) doi:10.1002/14651858.CD007146.pub3
- Giorgi, A. (2006). Concerning variations in the application of the phenomenological method. *The Humanistic Psychologist*, *34*(4), 305-319. doi:10.1207/s15473333thp3404_2
- Haines, T. P., & Hill, A.-M. (2011). Inconsistent results in meta-analyses for the prevention of falls are found between study-level data and patient-level data. *Journal of Clinical Epidemiology*, *64*(2), 154-162. doi:10.1016/j.jclinepi.2010.04.024
- Hartholt, K. A., van Beeck, E. F., Polinder, S., van der Velde, N., van Lieshout, E. M., Panneman, M. J., . . . Patka, P. (2011). Societal consequences of falls in the older population: injuries, healthcare costs, and long-term reduced quality of life. *Journal of Trauma*, *71*(3), 748-753. doi: 10.1097/TA.0b013e3181f6f5e5.
- Hermans, H., & Evenhuis, H. M. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities*, *35*(4), 776-783. doi:10.1016/j.ridd.2014.01.022
- Hill, A.-M., Hoffmann, T., McPhail, S., Beer, C., Hill, K. D., Oliver, D., . . . Haines, T. P. (2011). Evaluation of the sustained effect of inpatient falls prevention education and predictors of falls after hospital discharge--follow-up to a randomized controlled trial. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, *66*(9), 1001-1012. doi:10.1093/gerona/66.9.1001

- Holland, A.J., Hon, J., Huppert, F.A. and Stevens, F. (2000). Incidence and course of dementia in people with Down's syndrome: Findings from a population-based study. *Journal of Intellectual Disability Research*, 44: 138-146. doi:10.1046/j.1365-2788.2000.00263.x
- Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 442-454. doi:10.1352/1944-7558-117.6.442
- Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability*, 31(3), 173-179 177.
- Katz, S. (1983). Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living. *Journal of the American Geriatrics Society*, 31(12), 721-727.
- Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability and Society*, 29(7), 1013-1030. doi:10.1080/09687599.2014.902357
- Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., & Becker, C. (2005). Development of a common outcome data set for fall injury prevention trials: The prevention of falls network Europe consensus. *Journal of the American Geriatrics Society*, 53(9), 1618-1622. doi:10.1111/j.1532-5415.2005.53455.x
- Liamputtong, P. (2013). *Research methods in health: foundations for evidence-based practice* (Vol. 2). South Melbourne, Victoria: Oxford University Press.
- Milat, A. J., Watson, W. L., Monger, C., Barr, M., Giffin, M., & Reid, M. (2011). Prevalence, circumstances and consequences of falls among community-dwelling older people: results of the 2009 NSW Falls prevention baseline survey. *NSW Public Health Bulletin*, 22(4), 43-48. doi.org/10.1071/NB10065
- National Health and Medical Research Council, the Australian Research Council and Universities Australia. (2018). *The National Statement on Ethical Conduct in Human Research 2007 (updated 2018)*. Commonwealth of Australia, Canberra: National Health and Medical Research Council, Chapter 4.5. Retrieved from: <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245-1251. doi: 10.1097/ACM.0000000000000388

- Pal, J., Hale, L., Mirfin-Veitch, B., & Claydon, L. (2014). Injuries and falls among adults with intellectual disability: A prospective New Zealand cohort study. *Journal of Intellectual and Developmental Disability, 39*(1), 35-44. doi:10.3109/13668250.2013.867929
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health, 42*(5), 533-544. doi:10.1007/s10488-013-0528-y
- Patton, M. Q. (2002). *Qualitative research and evaluation methods Qualitative research and evaluation methods*. (Vol. 3) United States of America: SAGE.
- Podsiadlo, D., & Richardson, S. (1991). The timed "Up and Go": a test of basic functional mobility for frail elderly persons. *Journal of the American Geriatrics Society, 39*(2), 142-148.
- Rocky Bay Inc. (2019): Information on services. Retrieved from: <https://www.rockybay.org.au/services/>
- Rocky Bay Inc. (2019). About our customers. Retrieved from: <https://www.rockybay.org.au/about-us/our-customers/>
- Rodgers, J. (1999). Trying to get it right: Undertaking research involving people with learning difficulties. *Disability and Society, 14*(4), 421-433. doi:10.1080/09687599926046
- Rubenstein, L. Z. (2006). Falls in older people: epidemiology, risk factors and strategies for prevention. *Age And Ageing, 35*(suppl_2), ii37-ii41. doi:10.1093/ageing/afl084
- Salb, J., Woodward, C., Offenhäuser, J., Becker, C., Sieber, C., & Freiberger, E. (2015a). Prevalence and characteristics of falls in adults with intellectual disability living in a residential facility: A longitudinal study [PreFallID]. *Intellectual and Developmental Disabilities, 53*(3), 228-239. doi:10.1352/1934-9556-53.3.228
- Salb, J., Finlayson, J., Almutaseb, S., Scharfenberg, B., Becker, C., Sieber, C., & Freiberger, E. (2015b). Test–retest reliability and agreement of physical fall risk assessment tools in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 59*(12), 1121-1129. doi:10.1111/jir.12216
- Sanders, C. (2003). Application of Colaizzi's method: interpretation of an auditable decision trail by a novice researcher. *Contemporary Nurse, 14*(3), 292-302.

- Smulders, E., Enkelaar, L., Weerdesteyn, V., Geurts, A. C. H., & Schrojenstein Lantman-de Valk, H. (2013a). Falls in older persons with intellectual disabilities: fall rate, circumstances and consequences. *Journal of Intellectual Disability Research, 57*(12), 1173-1182. doi:10.1111/j.1365-2788.2012.01643.x
- Smulders, E., Enkelaar, L., Schoon, Y., Geurts, A. C., van Schrojenstein Lantman-de Valk, H., & Weerdesteyn, V. (2013b). Falls prevention in persons with intellectual disabilities: Development, implementation, and process evaluation of a tailored multifactorial fall risk assessment and intervention strategy. *Research in Developmental Disabilities, 34*(9), 2788-2798. doi:10.1016/j.ridd.2013.05.041
- Strydom, A., Shoostari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., . . . Maaskant, M. (2010). Dementia in older adults with intellectual disabilities-epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities, 7*(2), 96-110. doi:10.1111/j.1741-1130.2010.00253.x
- Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work, 11*(1), 80-96. doi:10.1177/1473325010368316
- von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gøtzsche, P. C., & Vandenbroucke, J. P. (2014). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for reporting observational studies. *International Journal of Surgery, 12*(12), 1495-1499. doi:10.1016/j.ijso.2014.07.013
- Wagemans, A. M. A., & Cluitmans, J. J. M. (2006). Falls and fractures: A major health risk for adults with intellectual disabilities in residential settings. *Journal of Policy and Practice in Intellectual Disabilities, 3*(2), 136-138. doi:10.1111/j.1741-1130.2006.00066.x
- Willgoss, T. G., Yohannes, A. M., & Mitchell, D. (2010). Review of risk factors and preventative strategies for fall-related injuries in people with intellectual disabilities. *Journal of Clinical Nursing, 19*(15-16), 2100-2109. doi:10.1111/j.1365-2702.2009.03174.x
- World Health Organization. (2018) *Falls fact sheet*. Geneva, Switzerland: World Health Organization. Retrieved from: <https://www.who.int/news-room/fact-sheets/detail/falls>

Addressing Challenges to Engage People with ID in Research

Preface

This chapter describes the consent process that was developed and used as part of the research study when engaging older adults with ID.

This chapter is based on the published article:

Ho, P., Downs, J., Bulsara, C., Patman, S., Hill, A-M. (2018). Addressing challenges in gaining informed consent for a research study investigating falls in people with ID. *British Journal of Learning Disability*, 46(2), 92-100. doi:10.1111/bld.12217.

The author's version of the article is presented with modifications to suit the style and format of this thesis.

4.1 Abstract

Background

People with ID encounter substantial healthcare problems, yet are under-represented in research. While people with ID can make valuable contributions to research and consequently improve their quality of life, researchers encounter multiple challenges including them in research. One challenge is to support them in making an informed decision to participate in research. Therefore, the aim of this study was to describe and reflect on a consent procedure used while gaining informed consent, when recruiting potential participants into an ongoing study.

Methods

A systematic and holistic consent procedure, underpinned by ethical guidelines, was developed and used alongside recommended strategies to engage people with ID in a research study.

Results

Only three participants (7.5%) were deemed capable of consenting independently, while 37 participants (92.5%) required the support of a proxy. Of these 37 participants, 22 participated in the consent process, while 15 depended mainly on their caregiver to make decisions for them. Adapted communication strategies were found to facilitate a person who has an ID's participation in the consent procedure. The adapted written information sheets were of secondary importance.

Conclusion

The consent procedure was a respectful means of determining a person's capacity to consent and indicating where there was a need for proxy consent. Appropriate communication strategies and the inclusion of familiar caregiver(s) were critical components for facilitating the person with an ID to participate in the consent procedure.

4.2 Introduction

People with ID are under-represented in medical research (Feldman, Bosett, Collet, & Burnham-Riosa, 2014), and there are barriers to their participation (Iacono,

2006; Iacono & Murray, 2003). The reason poorer health outcomes in people with ID persist is partly due to multiple barriers to receiving health services and therefore require evidence-based interventions that are tailored specifically for them (Bartlo & Klein, 2011). Therefore, including people with ID in research is one pathway to the provision of evidence-based and targeted services. It is important to recognise that people with ID not only have the equal right, but also can make the valuable contributions to the betterment of their lives through meaningful participation in research (McDonald, Kidney, & Patka, 2013).

There is still no clear consensus about how to meaningfully include people with ID in the informed decision-making processes for participation in research (McDonald & Kidney, 2012; McDonald & Patka, 2012), but researchers in this area have identified several challenges in this regard. It is highlighted that the comparatively lengthy consent processes (Taua, Neville, & Hepworth, 2014), recruitment legalities (Lennox et al., 2005) and limitations in the participant's ability to provide consent independently (Dye, Hare, & Hendy, 2007) are barriers to including people with ID in research studies. Researchers in the field have systematically shared strategies to address these challenges (Archibald & Munce, 2015; Becker, Roberts, & Morrison, 2004; Kidney & McDonald, 2014), and this study adopted several of them to develop the informed consent process.

Upholding the ethical principle of respect (The National Health and Medical Research Council, the Australian Research Council and the Australian vice-chancellors' Committee, 2007) when involving people with ID in research can be challenging, and further investigation of optimal mechanisms to include people with ID in research is much needed. Therefore, the aim of this study was to describe an informed consent process used when recruiting persons with ID for a study which is currently investigating falls among people with ID, and to reflect on the methods of informed consent used.

4.3 Methods

4.3.1 Research Aims and Study Design

The aims of the study were to investigate the rate of falls in older adults with ID living in the community, with daily recordings of falls, and to explore the

participants' experiences when seeking healthcare services after having a fall using semi-structured interviews.

This research is currently in the recruitment phase. This study describes the consent process undertaken with the first 40 participants of the study and describes the researcher's experiences in using this consent process.

4.3.2 Participants

The study focuses on older adults with ID, aged 35 years and over, living within the community; therefore, participants are either living at home with their family, in independent units with or without paid support, or in small group homes with three to six co-inhabitants with paid support.

Participants were recruited from a supporting organisation who provide services to people with ID. Potential candidates who fulfilled the inclusion criteria were identified by the employees of the organisation who work closely with them. The employees who were familiar with the older adult with ID were responsible for making contact and gaining permission for the researcher to approach them and/or their legal guardian to discuss the research project.

4.3.3 Procedure and Materials

Ethics

The study aligns with human research ethics guidelines from the National Health and Medical Research Council (NHMRC) and the specific ethical guidelines for researchers in Western Australia (WA) in relation to adults who may lack the capacity to give consent (WA Health Ethics Application Form, 2013). Where there was any uncertainty regarding the ability of the potential participant to provide informed consent, their guardian or next-of-kin is asked to sign a separate consent form which records that they agree to the person under their legal care participating in the study and that they believe the person is not likely to object. The research received ethics approval from The University of Notre Dame Australia, Human Research Ethics Committee (015067F) (Appendix F) and the affiliated local organisation for people with ID (Rocky Bay Inc. 2017) (Appendix G).

Informed consent procedure

Informed consent to participate in the study investigating falls in people with ID was gained directly from the potential participant where possible. The informed consent process for this study was designed to provide a collective perspective of the capacity of the person with ID to consent. It involves the researcher undertaking repeated observations of the participant and gives the caregiver the opportunity to provide their opinion as to whether the individual with an ID can understand what the study involves and has capacity to provide consent. It also includes a Three-item Decisional Questionnaire (3-IDQ) adapted from Palmer et al., 2005 (Figure 4.1). The researcher adapts the wording of questions, when required, to ensure that the person who has an ID understands the questions in their own context as far as possible. A score of more than three of a total score of six suggests that the potential participant adequately understands the research and the extent of their participation, thereby signifying their ability to provide informed consent independently. Figure 4.2 presents the processes of the informed consent procedure.

1)	What is the purpose of the study?	0	1	2
2)	What are the risk?	0	1	2
3)	What are the benefits?	0	1	2
	Total:			
Score of 0 = incapable, 1= questionable, 2 = capable of each question				
A higher total score reflects a better understanding of the study				
(Adapted from Palmer et al, 2005)				

Figure 4.1 Three-item Decisional Questionnaire

The researcher adapted the wording of questions, when required, to ensure that the older adult with ID understood the questions in their own context as far as possible. A score of more than three out of a total score of six suggests that the potential participant adequately understands the research and the extent of their participation, thereby signifying their ability to provide informed consent independently. Figure 4.2 presents the processes of the informed consent procedure.

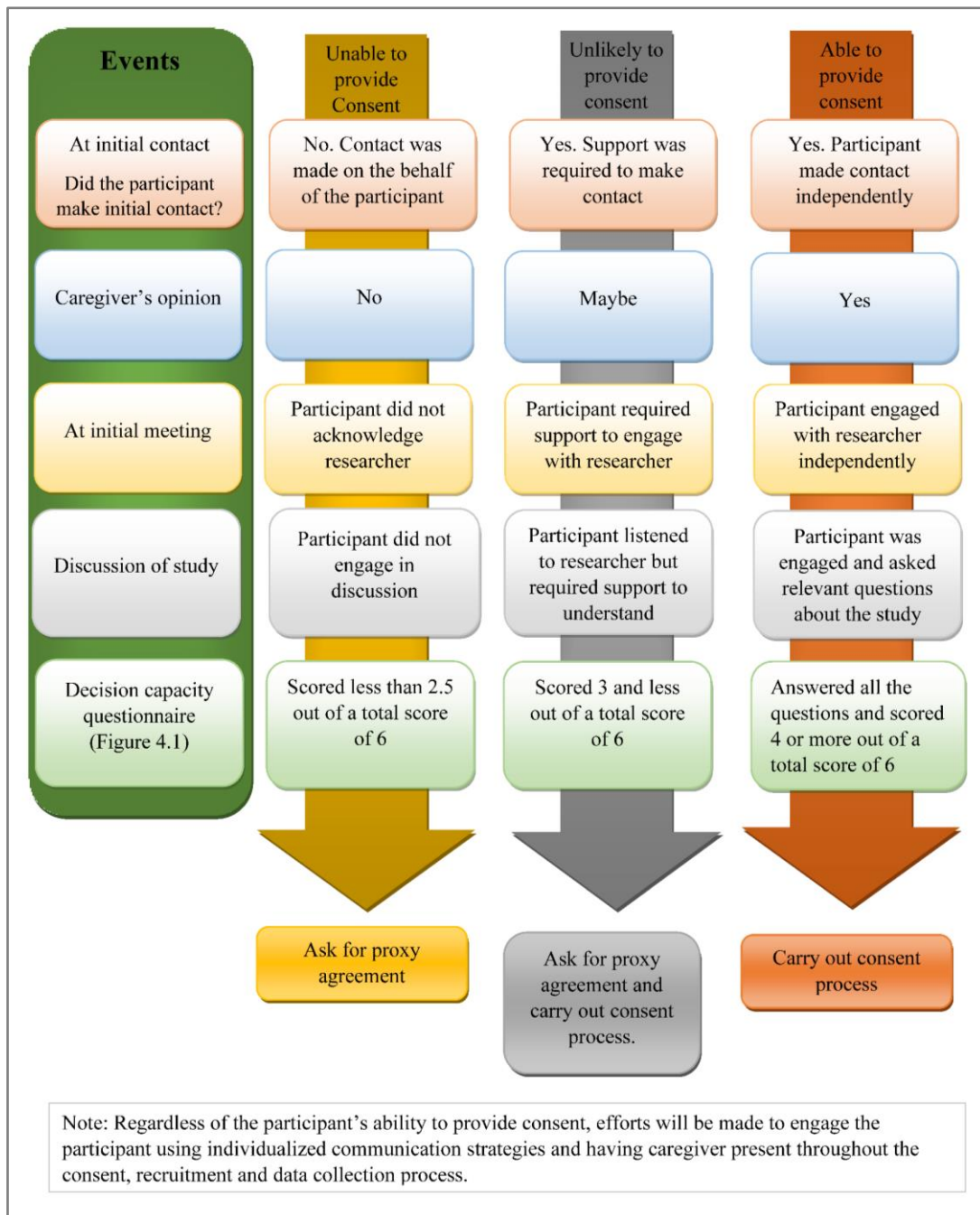


Figure 4.2 Flow of Events during Consent Process

Adapted plain language statements (Appendix H) were prepared and used with the person with ID when the study is first discussed. The study was explained using information sheets (Appendix H) prepared according to recommendations for engaging people with ID in research (Kidney & McDonald, 2014). The next of kin, family member or caregiver was asked to be present during this process to provide a supportive, comfortable environment and to provide oversight to the discussion.

Each meeting was an opportunity for the researcher to engage with the older adult with ID and their caregiver as relationship-building with the older adult with ID and their caregiver was crucial for the researcher to gain an understanding of the capacity of the older adult with ID and their interest to participate in the study.

Consent forms

Three consent forms were prepared:

- i. a consent form adapted to facilitate the participant's understanding of the study and the procedures (Appendix H);
- ii. a version for a family member or legal guardian to record their agreement for the person with ID to participate in the study (Appendix I);
- iii. a form for the caregiver(s) to provide informed consent that they are willing to support the participant with daily falls recordings and facilitate communications with the researcher (Appendix J).

4.4 Results

From October 2015 to January 2017, 68 individuals were approached after they or their caregiver agreed to an initial discussion. Of these, 28 (42%) did not proceed, either because they were not interested, or their legal guardian declined on their behalf. As part of the consent process, the researcher explained the level of commitment required and asked whether the person with ID and their caregiver had capacity to participate. In doing so, the legal guardians made the informed decision with the person with ID to proceed or not with participating in the research. Guardians declined either because they felt that the person with ID did not have the capacity to participate in the study or because they could not undertake the caregiver role of helping with data collection, or both reasons. The informed consent process was subsequently conducted with 40 individuals who all subsequently enrolled in the study.

Participants' median age was 42.5 years (range 35–86 years), and further demographic information is presented in Table 4.1. Responses from the participants and their caregivers during the consent process are recorded in Figure 4.3. Two participants were able to organise an initial meeting with the researcher independently,

and four required support from caregivers. For the other 34 participants, the initial meeting was organised between the researcher and the caregiver.

Table 4.1 Participant demographics

Variable	Categories	n (%)
Age (year)	35– 40	4 (10)
	41– 50	17 (42.5)
	51 – 60	8 (20)
	61 - 70	4 (10)
	71 – 80	4 (10)
	> 80	3 (7.5)
Gender	Male	25 (62.5)
	Female	15 (37.5)
Living arrangements	Independent living with paid support	4 (10)
	Living at home with family with paid support	17 (42.5)
	Group home ^a with paid support	19 (47.5)
Mobility status when indoors	Independent without aid ^c	21 (52.5)
	Independent with aid	9 (22.5)
	Dependent ^b without aid	2 (5.0)
	Dependent with aid	8 (20.0)
Mobility status when outdoors	Independent without aid	19 (47.5)
	Independent with aid	7 (17.5)
	Dependent with aid	14 (35.0)

^a A group home is where 3-6 people with a disability are provided with paid support staff to live in the community

^b To be dependent for mobility is to have another person support

^c An aid is either a walking aid, a shopping scooter, a manual wheelchair or a powered wheelchair

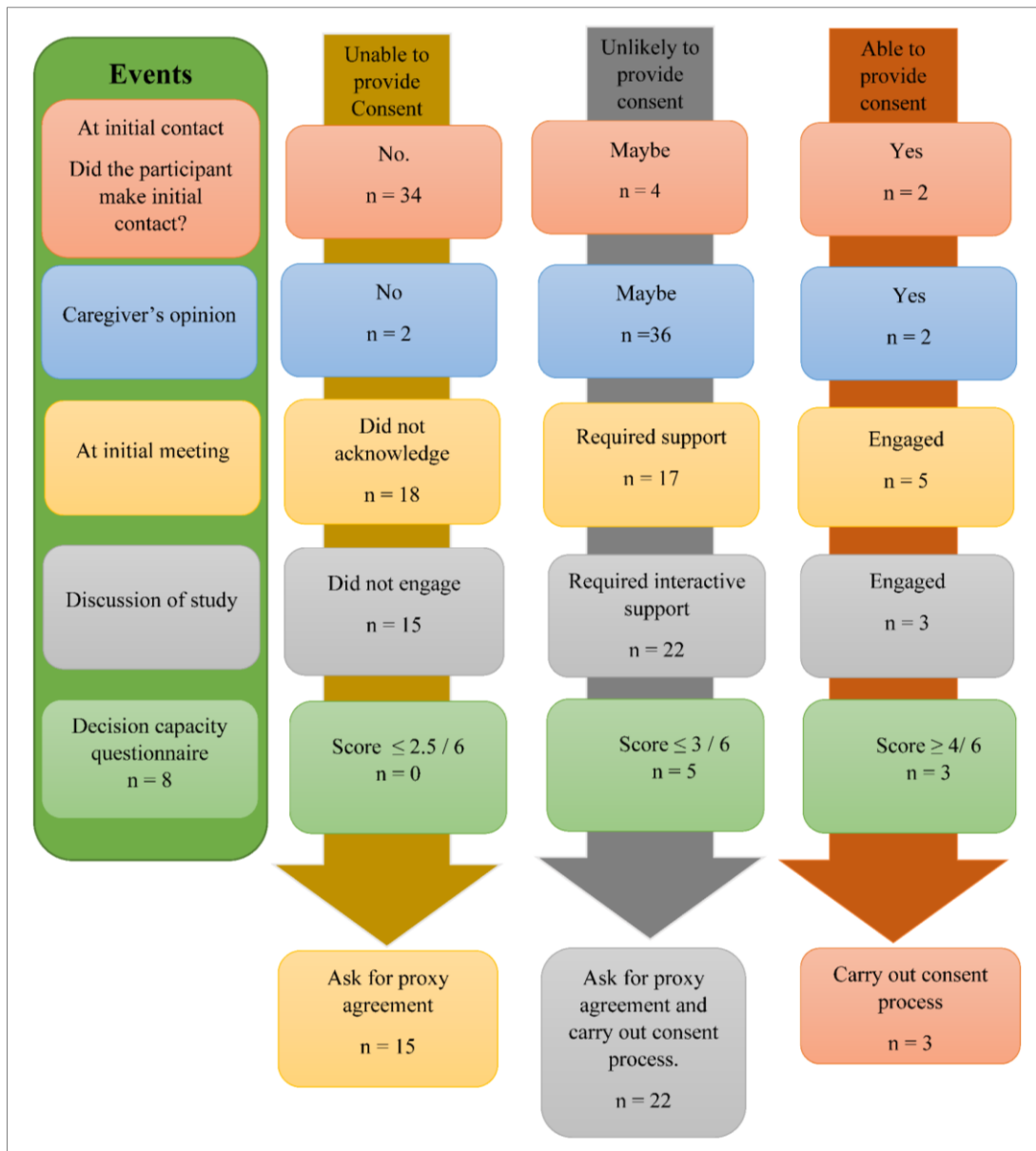


Figure 4.3 Flow of Participants through the Consent Process

Fifteen participants did not participate in the discussion about the study. Their legal guardians were asked to sign the consent form which recorded that, in their opinion, the person with ID for whom they were responsible would not object to participating.

A total of 25 participants showed interest and engaged in the discussion with researcher. Three of these participants took part in the discussion of the study without any support and subsequently were deemed capable of providing consent independently by successfully scoring four to six on the 3-IDQ (Figure 4.1), and showing their ability to understand risks, benefits and purpose of the study.

The remaining 22 participants required support to understand the research, and the researcher used the adapted information sheets (Appendix H). It was found that all these participants still preferred additional interpretation from their caregiver such as the use of words, examples and objects of reference that were familiar to them. Only five of these 22 participants took part in the 3-IDQ as they indicated adequate understanding and maintained their level of engagement with the researcher up to this point of the consent process. They scored less than three which indicated limited understanding of the study. Therefore, these 22 participants signed the consent form in the presence of their caregiver (Appendix H) and their caregivers also signed the legal guardian consent form (Appendix I).

All paid and unpaid caregivers who were required to support the person with ID to complete the daily falls recordings and facilitate communication with the researcher were asked to complete the caregiver consent form. Two examples of the consent process undertaken are presented as case studies below in case studies 1 and 2.

Case study 1: Illustrates the consent process undertaken with a participant who was unable to independently provide informed consent.

Case Study 1

The researcher was alerted to *Participant X* being potentially eligible for inclusion in the study by staff members from the supporting organisation. It was advised that the most suitable person to contact to discuss the study was his mother, “A”. A phone call was made to the family home, where A received the call. The researcher explained and discussed the research with A over the phone. In her opinion, X was not likely to object being part of the research. The researcher requested that A discusses the research with *Participant X* prior to a visit and if she felt if there was any indication that X was not interested, she should contact the researcher to cancel the visit. Prior to the appointment, the researcher spoke to and confirmed with A that X was not opposed to the researcher visiting.

X was seen standing in the middle of the driveway in front of the house and swinging his arms in a playful manner. After noticing that the researcher parked the car on the road in front of the house, X walked back into the house.

The researcher was greeted at the front door by *A* and was shown into the house. The researcher observed that *X* responded to the researcher's presence with a nod and a smile. *X* only took a seat next to *A* when *A* beckoned him to sit on the couch next to her.

It was noticed that *X*'s response was very compliant in nature. He responded with a definite nod to questions he understood such as “it's a wonderful day, isn't it?” and a smile to open-ended questions he did not quite understand, for example, “do you know why I am here?”

As the study was being explained to *X* and *A*, *A* used references and examples to *X*'s life. For example, when a “fall” was mentioned, *A* provided the reference to the fall *X* had about a year ago at a community show.

To convey in simple terms, the risk and benefits of participation, the researcher explained to *X* that he would not get hurt by participating in the study and that he was not going to get any sweets if he participated.

When asked whether he would still like to participate, *X* smiled and nodded. His mother *A* supported his decision and stated that he would not object to participating. *A* stated that in her opinion, *X*'s behaviour indicated that he was willing to participate. *A* stated that if he was not interested, he would not have sat with the researcher for that length of time and he would have walked outside to where he was previously, or chosen to be in his room.

Prompts were provided to *X* while he was carrying out the 3-IDQ:

What is the purpose of the study?

Prompt: What is (the researcher) here for? You remember we talked about you falling at the Royal show. She is here to study your falls. Yes?

Response: Smiled and nodded (Score 0)

What are the risks?

Prompt: Will you get hurt if you are in the study? Yes or no?

Response: No—shook head (Score 1)

What are the benefits?

Prompt: Can (the researcher) give you any candy? Yes or no?

Response: No (Score 1)

A advised that she was confident that **Participant X** was agreeable to participate because his behaviour during the visit and his body language was positive, but she was also certain that he did not understand the broader purpose of the research. His understanding was limited to task-specific instructions such as “have your dinner” or “go change.” *X* signed the consent form in the presence of *A*. *A* also gave consent to **Participant X** participating.

Although *X* participated in the 3-IDQ, he did not demonstrate adequate understanding of the study, and therefore, his next of kin, *A*, was asked to provide consent.

Case study 2: Illustrates the consent process undertaken with a participant who was able to independently provide informed consent.

Case Study 2

Participant Y was a 58-year-old gentleman who lived alone in an independent unit. He had support for personal care, cleaning and meal preparation. The researcher was alerted that *Y* could be potentially eligible for inclusion in the study from a fellow colleague, “*B*,” who provided him with in-home therapy services. *B* advised *Y* of the research and discussed his potential involvement in the study. *B* reported that *Y* showed interest in being involved and consented for the researcher to contact him. According to *B*, *Y* lived on his own and made his own decisions. *B* reported he was able to organise his own appointments, services and transport on a daily basis.

Y was contacted by the researcher by phone, and he mentioned that his therapist had told him that she was going to make contact. Over the phone, the researcher explained the research, particularly the level of involvement that would be required of *Y* if he chose to participate. *Y* responded that he could manage that and would like to help where he could. The appointment was organised over the phone, and with *Y*'s permission, his therapist was also informed, as she would be able to remind him about the appointment. *B* had reported that her experience with *Y* was that he could get

confused with dates and events that were not routine. He retained events in his memory by associating them with the day of the week.

Y was alone when the researcher arrived. The researcher was pleasantly invited in, and *Y* mentioned that he was expecting the visit. *Y* parked his wheelchair in front of the television and continued to watch the programme that was on television. Respecting that he did not want to turn off his television, the researcher explained the research to him again, interrupting him only at commercial breaks. The researcher used short sentences and frequently asked *Y* what he understood from the researcher. *Y* expressed that he felt he understood the research and was initially reluctant to interrupt his television time. However, he was happy to discuss the research in detail, once the researcher explained that it was necessary to ensure that he understood all that was involved and he then responded in the affirmative. After the explanation of the study, the researcher administered the 3-IDQ to *Y*:

What is the purpose of the study?

Response: About falls (Score 2)

What are the risks?

Modification: Will any harm come to you if you take part in my study?

Response: No (Score 2)

What are the benefits?

Modification: Can I give you any money or rewards if you participate in the research

Response: No (Score 2)

Y required some modifications to the questions to correspond to the language and words the researcher used during the explanation of the study. He did not elaborate when asked about what the study was, other than it was about falls, despite the researcher's previous efforts to describe and discuss the research. From his interaction with the researcher, reports from "**B**" his therapist and his responses which he provided with or without support demonstrated reasonable understanding of the research and his involvement, therefore, *Y* provided consent independently.

Monthly follow-ups (either by phone or face-to-face contact) provided the opportunity for participants to ask any questions they may have had regarding the research, including any issues related to their participation. To date, 27 of these 40 participants have completed the 6-month observational period, and there have been no withdrawals.

4.5 Discussion

4.5.1 Informed consent and use of proxy

When considering all eligible potential participants, slightly more than 40% of caregivers declined on behalf of the person with ID. Reasons given by family were illness (family member or the individual), they had “too much going on,” or they believed that the person with ID had nothing valuable to contribute to this study.

Of 40 participants enrolled, only three could successfully and independently answer the questions about the study and were considered to have understood the potential risk involved. There were 22 participants who engaged with the researcher and were able to have a discussion about their involvement in the study, with help from their caregiver. Fifteen of the 40 participants did not engage with the researcher, and the consent process was completed without their involvement. These fifteen participants were severely affected and did not have the cognitive ability to engage decision-making in all parts of their lives. Daily decisions about their care are made on their behalf. The ability for people with ID to be involved in research is often influenced by the people with whom they are directly dependent.

4.5.2 Overall learnings

A patient (often time-consuming), sincere and flexible approach was taken in order to overcome barriers and to build trust and respect between the researcher, the person with ID and their support network. Many of the successful approaches taken in this study echo the efforts taken in other studies reporting success in reaching out to people with ID (Horner-Johnson & Bailey, 2013; Kidney & McDonald, 2014; Lennox et al., 2005). Successful strategies included a multilevel strategy for the provision of information and gaining of consent, and making the effort to be mindful of their abilities, lifestyle, family, formal and informal care supports. Our procedure, of necessity, was time-consuming and required multiple interactions with potential

participants and their caregivers, and like others, it was recognised that this had budgetary implications in conducting this research (Pal, Hale, & Mirfin-Veitch, 2013).

Current experience in using the jurisdictional ethics guidelines (The National Health and Medical Research Council, the Australian Research Council and the Australian vice-chancellors' Committee, 2007) and recommendations published in the literature (Kidney & McDonald, 2014; Palmer et al., 2005) formed a useful checklist during the study preparation, especially for the development of the recruitment procedure. The toolkit for accessible and respectful engagement (Kidney & McDonald, 2014) of people with ID in research was helpful to explain the current study in some instances, particularly when individuals with ID were interested and could understand the pictures used to represent their involvement. However, caregivers were still required to provide further explanations using familiar references from their daily lives (Case Study 1). For other participants who did not engage in conversation with the researcher (n = 15), the toolkit was not useful. These participants were more severely affected and more dependent on care support. The research team in this study had extensive experience in working with people with ID, with the lead researcher employed full time in an organisation that provides services to people with disability including a large proportion of people with ID. Appropriate training and experience are required to successfully interact and achieve good research outcomes in this group (Archibald & Munce, 2015).

Other than the three participants who provided consent independently, the remaining participants who completed the 3-IDQ required support to interpret the questions asked. This is consistent with Palmer et al. (2005) where the questions were re-explained or clarified when the response was vague or indicated a misunderstanding. The questions were useful as guiding questions to determine whether they understood the researcher adequately and their involvement in the study. The three participants who scored four or more of a total of six, indicating adequate understanding of the study, reflected high levels of engagement and independence during the informed consent process. Thus, the use of the 3-IDQ gave an accurate representation of their decision-making capacity. Palmer et al. (2005), also concluded that the 3-IDQ was sensitive to individuals with cognitive limitations.

4.5.3 Limitations

This study describes the informed consent process used with the first 40 participants of the study, and a further 38 participants are expected to be recruited to the study. Therefore, there is potential for new experiences to come to light. Communication with the person with ID proved challenging, particularly when the potential participant did not live with their family and the caregivers supported the individual for only a portion of their life. Five of the participants had consent provided on their behalf by their legal guardians from the office of the public advocate, who did not have day-to-day care responsibilities. Family members, who are more familiar with the person, often provided useful communication strategies, but it was not always possible to meet with families. Furthermore, the researcher had limited time to interact with the person with ID and was necessarily, and in part, dependent on the opinions of the caregiver as to whether the person with ID was able to provide consent. These study procedures have been facilitated by the extensive experience of the researchers in our local healthcare settings regarding ID, meaning our procedures may not directly translate to other settings. However, these procedures may provide a useful guide for researchers who would like to conduct research with people with ID in their own local setting.

4.6 Conclusion

This study found that the systematic and holistic approach described in our study procedure allowed the person with ID to participate in the consent process to the best of their ability. The procedure provided the opportunity for the caregiver to provide their opinion, the researcher to provide a clinical judgement and the participant themselves, within the limits of their cognitive abilities, to provide informed consent to participate in the study. It was found that adapted communication strategies were the most important means of building rapport and subsequent engagement with participants.

Researchers should continue to investigate and report on the methods for conducting research, including gaining informed consent, in this hard to reach population, in order to provide more opportunities for people with ID to benefit from research.

4.7 References

- Archibald, M. M., & Munce, S. E. P. (2015). Challenges and strategies in the recruitment of participants for qualitative research. *University of Alberta Health Sciences Journal*, *11*(1), 34–37.
- Bartlo, P., & Klein, P. J. (2011). Physical activity benefits and needs in adults with intellectual disabilities: Systematic review of the literature. *American Journal on Intellectual and Developmental Disabilities*, *116*(3), 220–232.
doi:10.1352/1944-7558-116.3.220
- Becker, H., Roberts, G., & Morrison, J. (2004). Recruiting people with disabilities as research participants: Challenges and strategies to address them. *Mental Retardation*, *42*(6), 471–475. doi:10.1352/0047-6765
- Dye, L., Hare, D. J., & Hendy, S. (2007). Capacity of people with intellectual disabilities to consent to take part in a research study. *Journal of Applied Research in Intellectual Disabilities*, *20*(2), 168-174. doi:10.1111/j.1468-3148.2006.00310.x
- Feldman, M. A., Bosett, J., Collet, C., & Burnham-Riosa, P. (2014). Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of ID Research*, *58*(9), 800-809. doi:10.1111/jir.12091
- Government of Western Australia (WA), Department of Health. (2013) WA Health Ethics Application Form. Section 2.2. Retrived from:
fh.health.wa.gov.au/~media/Files/.../wa_health_ethics_application_form.ashx
- Horner-Johnson, W., & Bailey, D. (2013). Assessing understanding and obtaining consent from adults with intellectual disabilities for a health promotion study. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(3), 260-265.
doi:10.1111/jppi.12048
- Iacono, T. (2006). Ethical challenges and complexities of including people with ID as participants in research. *Journal of Intellectual and Developmental Disability*, *31*(3), 173-179.
- Iacono, T., & Murray, B. (2003). Issues of informed consent in conducting medical research involving people with ID. *Journal of Applied Research in Intellectual Disabilities*, *16*(1), 41.
- Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability and Society*, *29*(7), 1013-1030.
doi:10.1080/09687599.2014.902357

- Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D. M., & Boyle, F. (2005). Beating the barriers: recruitment of people with ID to participate in research. *Journal of Intellectual Disability Research*, 49(4), 296-305. doi:10.1111/j.1365-2788.2005.00618.x
- McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 27-39. doi:10.1111/j.1741-1130.2011.00319.x
- McDonald, K. E., Kidney, C. A., & Patka, M. (2013). 'You need to let your voice be heard': research participants' views on research. *Journal of Intellectual Disability Research*, 57(3), 216-225. doi:10.1111/j.1365-2788.2011.01527.x
- McDonald, K. E., & Patka, M. (2012). "There is no black or white": Scientific community views on ethics in intellectual and developmental disability Research. *Journal of Policy and Practice in Intellectual Disabilities*, 9(3), 206-214. doi:10.1111/j.1741-1130.2012.00348.x
- National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee. (2007) *National Statement on Ethical Conduct in Human Research*, Updated 2018. Commonwealth of Australia Canberra. Retrieved from: <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>.
- Pal, J., Hale, L., & Mirfin-Veitch, B. (2013). Experiences of therapist trying to reduce falls risk for people with intellectual disability. *Journal of Policy and Practice in Intellectual Disability*, 10(4), 314–320. doi:10.1111/jppi.12058
- Palmer, B. W., Dunn, L. B., Appelbaum, P. S., Mudaliar, S., Thal, L., Henry, R., . . . Jeste, D. V. (2005). Assessment of capacity to consent to research among older persons with schizophrenia, Alzheimer disease, or diabetes mellitus: comparison of a 3-item questionnaire with a comprehensive standardized capacity instrument. *Archives Of General Psychiatry*, 62(7), 726-733.
- Taua, C., Neville, C., & Hepworth, J. (2014). Research participation by people with ID and mental health issues: An examination of the processes of consent. *International Journal of Mental Health Nursing*, 23(6), 513-524. doi:10.1111/inm.12079

Incidence and Associated Risk Factors for Falls in Adults with Intellectual Disability Living in the Community

Preface

This chapter describes Study 3 of the research that investigated the incidence and prevalence of falls along with the associated risk factors for falls in a cohort of older adults with ID.

This chapter is based on a published article:

Ho, P., Bulsara, M., Patman, S., Downs, J., Bulsara, C., Hill, A.-M. (2019). Incidence and associated risk factors for falls in adults with intellectual disability. *Journal of Intellectual Disability Research*, 63(12), 1441-1452. doi:10.1111/jir.12686

The author's version of the manuscript is presented with modifications to suit the style and format of this thesis.

5.1 Abstract

Background

People with ID experience age-related changes earlier in life and as such falls among people with ID are of serious concern. Falls can cause injury and consequently reduced quality of life. Limited studies have investigated the incidence of falls among older adults with ID and the associated risk factors. The purpose of this study was to investigate the incidence of falls and risk factors for falling in older adults with ID living in the community.

Methods

A prospective observational cohort (n=78) of community dwelling older adults with ID. Characteristics measured at baseline included falls history, medication use, balance and mobility. Falls were reported for 6 months using monthly calendars and phone calls. Data were analysed using univariate and multivariate logistic regression to identify risk factors associated with falling.

Results

Participants [median (IQR) age 49 (43-60) years, female n=32 (41%)] experienced 296 falls, with 36 (46.2%) participants having one or more falls. The incidence of falls was 5.7 falls (injurious falls =0.8) per person year (one outlier removed from analysis). A history of falls [adjusted OR: 5.88, 95% CI (1.98-18.33)] and being ambulant [adjusted OR: 3.88, 95% CI (1.03-14.53)] were associated with a significantly increased risk of falling. Falls were significantly less frequent among participants taking more than four medications [(adjusted OR 0.3, 95% CI (0.1-1.0)] and participants who were continent [(adjusted OR 0.2, 95% CI (0.1-0.7)].

Conclusion

Older adults with ID fall at a younger age compared to the broader community. The associated falls risk factors also differ to older community dwelling adults. Health professionals should prioritise assessment and management of falls risk in this population.

5.2 Introduction

People with ID experience signs of aging from 35 years old (Connolly, 2006; Hermans & Evenhuis, 2014) and as such can be considered ‘older adults.’ Some studies have reported that the prevalence of falls in adults with ID is over 40% (Smulders, Enkelaar, Weerdesteyn, Geurts, & Schroyen Lantman-de Valk, 2013) and incidence of falls is over two falls per person year (Pal, Hale, Mirfin-Veitch, & Claydon, 2014; Van Hanegem, Enkelaar, Smulders, & Weerdesteyn, 2014), which suggests that the prevalence and incidence of falls in older adults with ID are higher than aged matched populations and more aligned with falls rates among older adults. In a recent study in Helsinki, comparisons between people with ID and age matched peers also showed that people with ID have almost double the rate falls (Axmon, Ahlström, & Sandberg, 2019).

However, it is challenging to establish the extent of this problem in older adults with ID as study designs, methods and data reported are heterogeneous. One study suggested a falls rate as high as 6.29 falls per person year (Wagemans & Cluitmans, 2006). Falls research guidelines recommend prospective collection of falls data with daily recordings and monthly follow up (Lamb, Jørstad-Stein, Hauer, & Becker, 2005) such as conducted in one study conducted among people with ID (Smulders et al., 2013). However, it requires substantial resources to implement this methodology among adults with ID.

There is also limited research that has sought to understand risk factors for falls in adults with ID (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010; Enkelaar, Smulders, van Schroyen Lantman-de Valk, Weerdesteyn, & Geurts, 2013a; Hsieh, Rimmer, & Heller, 2012). Contributing risk factors for falls in adults over 65 include impairments to gait, poor balance and vision, history of falls and polypharmacy (Ambrose, Paul, & Hausdorff, 2013). Additional factors suggested to be associated with falls in older adults with ID include a diagnosis of epilepsy, the ability to ambulate and unsafe behaviours such as unnecessary rushing and distractibility (Cahill, Stancliffe, Clemson, & Durvasula, 2014; Willgoss, Yohannes, & Mitchell, 2010). However, these studies have been carried out in cohorts which include participants 18 years and older (Cox et al., 2010; Hsieh et al., 2012), not only among older adults with ID (Willgoss et al., 2010).

Hence while falls prevention recommendations for adults 65 years and older are informed by high quality evidence (Australian Commission on Safety and Quality in Healthcare, 2009; Department of Health, Western Australia, 2014) these are not specific to people with ID. This is a gap because consequences of falls in adults with ID also include serious injuries such as fractures and head injuries (Pal et al., 2014; Wagemans & Cluitmans, 2006) and importantly may result in decreased independence and subsequent need for increased care (Cox et al., 2010). Further research is recommended to identify population characteristics and estimate of the extent of this problem to guide the development of targeted falls prevention services for people with ID (Willgoss et al., 2010).

The primary aim of the study was to investigate the prevalence and incidence of falls in older adults with ID living in the community. The secondary aims were to: i) investigate the rate of injurious falls, and ii) the associated risk factors for falls in this population.

5.3 Methods

5.3.1 Study Design

A prospective cohort study with a six month observation period. STROBE guidelines (von Elm et al., 2014) and recommendations from international consensus for conducting falls related research (Lamb et al., 2005) informed the study design. The protocol for the study (Ho et al., 2018) has been reported more in detail in Chapter 3.

5.3.2 Participants and Setting

Briefly, participants were recruited through service providers for people with ID in Western Australia from 2014 to 2018. Older adults with ID were eligible to be included if they had a confirmed diagnosis of ID defined by the American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders –V criteria as an individual who presents with limited intellectual and adaptive functioning (American Psychiatric Association, 2013). Exclusion criteria were being younger than 35 years old, or living in a residential facility such as a nursing home.

5.3.3 Ethical considerations

Ethics approvals were granted from the service provider and the university committees. A systematic and holistic consent procedure was specifically created to enable all potential participants to participate in the consent process to the best of their ability. The use and effectiveness of this consent procedure was described in Chapter 4. All participants and/or their carers provided written informed consent prior to being enrolled in the study.

5.3.4 Data collection

Procedure has been described in full in Chapter 3. Briefly, face to face interviews were conducted with the participants and their caregivers present to collect baseline demographic data including age, gender, body mass index, diagnosis and medical history. Data describing factors previously identified as risk factors for falls (Ambrose et al., 2013; Willgoss et al., 2010) were collected including history of falls, mobility status, visual impairment, number of medications, use of neuroleptic medications, diagnosis of epilepsy, and continence. Other supporting data collected, included communication ability measured using the Communication and Functional Classification System (CFCS) (Hidecker et al., 2011), and presence of challenging behaviour measured using the Aberrant Behaviour Checklist (ABC) for the community (Aman, Burrow, & Wolford, 1995). Functional mobility was measured using Timed-Up and Go Test (Podsiadlo & Richardson, 1991), balance using Four Step-Square Test (Dite & Temple, 2002) and Four-test Balance Scale (Gardner, Buchner, Robertson, & Campbell, 2001) and lower limb strength using the timed Five Times Sit to Stand Test (Buatois et al., 2010). The EQ-5D-5L (Diaz-Redondo, Rodriguez-Blazquez, Ayala, Martinez-Martin, & Forjaz, 2014) was administered to caregivers to proxy rate participants' health related quality of life and the Well-Being Index for people with ID (Cummins & Lau, 2005) was administered to all participants.

Falls were recorded daily for six months using monthly falls calendars. A fall was defined as when a participant “inadvertently comes to rest on the ground, floor or lower level” (World Health Organisation, 2018) and the fall was classified as injurious if there was resultant bruising, laceration, dislocation, fracture or complaints of an onset of persistent pain (Hill et al., 2011). When a participant experienced a fall, they were

asked (with or without support) to contact the researcher to ensure that a fall was recorded according to the definition. Participants sent calendars to the researcher at the end of every month. The researcher also contacted each participant at the end of every month as a reminder to ensure that calendars were returned and to confirm data from the calendars.

At the time of recruitment, the research also interviewed the participant and their caregiver present to understand the lifestyle of the participant to ensure that the researcher could cater the most suitable approach to engage the participant. Information such as the preferred methods of communication, activities, times of contact and caregivers were noted. With permission, the researcher also made contact with all the service providers that the participant received services from to inform them of their participation and contacted them regularly for follow up. Where this was not possible, the researcher requested that the main caregiver inform all the caregivers that the participant had contact with of the participant's involvement in the research to ensure that all falls were recorded. Each time the researcher followed up with the participant, these information was discussed to ensure that the current approach was suitable and where necessary the researcher would adjust accordingly. Education was also provided at recruitment and each follow up where required, especially where there was a new caregiver, to ensure that the purpose of the research and data collection was clearly understood. Follow ups were also an opportunity for participants and their caregiver to any clarify and queries. These procedures were aimed to ensure the fidelity of the data collection and resultant quality of data.

5.4 Statistical Analysis

5.4.1 Sample Size

The sample size was calculated based on the incidence of falls at 0.27 reported in previous studies (Pal et al., 2014; Smulders et al., 2013). For 95% confidence within a 1% absolute margin of error that the true incidence rate frequency was between 0-1.27, a minimum of 78 participants was required.

Data were analysed using Stata SE version 15 software (StataCorp, College Station, Texas). The clinical and demographic characteristics of the participants were summarised using descriptive statistics.

The incidence of falls and injuries related to falls were expressed as a rate of falls (number of falls per person per year) and rate of injurious falls (number of injurious falls per person per year). Number of fallers (proportion of participants who experienced one or more falls during the observation period) and injurious falls (a fall that resulted in one or more injuries) were also reported.

All variables other than age, body mass index and living arrangement were treated as binary when undertaking regression analyses. The presence of challenging behaviour and the ability to complete physical tests such as Timed Up and Go test were categorised as yes/no. Mobility was categorised as ambulant/nonambulant, continence as continent/non-continent and communication ability as CFCS score of $<3/\geq 3$.

Univariate logistic regression analysis was used to evaluate the association between all demographic and fall risk factor covariates with the outcome (binary) of the risk of sustaining one or more falls. Negative binomial regression analysis with adjustment for exposure (participant length of stay in the study) was used to evaluate the association between all demographic and fall risk factor covariates with the outcome of number of falls. Covariate effects were summarised using odds ratios, incidence rate ratios and 95% CI. All hypothesis tests were two-sided, and P values <0.05 were considered statistically significant.

Based on a recommended modelling strategy (Harrell, 2015), all covariates were subsequently entered into a full multivariable model. Logistic regression modelling was undertaken for the risk of sustaining one or more falls and negative binomial regression modelling for examining the outcome of number of falls. Covariates where $P < 0.05$ were subsequently removed one at a time until only covariates with a value of $P < 0.05$ remained in the model. The exception to this was the covariates that were known risk factors for falls (epilepsy, taking four or more medications, mobility, communication ability as a measure of the severity of ID and challenging behaviour) (Cox et al., 2010; Hsieh et al., 2012; Enkelaar et al., 2013a) remained forced into the final model regardless of their statistical significance. Bivariate interactions between all covariates of interest were explored in turn, and any interactions where $P < 0.2$ were added into the model to check for significance.

5.5 Results

The participant flow through the study is shown in Figure 5.1. Two individuals who were younger than 35 years (30, 34 years) were recruited as they showed interest in the research and were experiencing falls. One participant, who did not have any recorded falls, died three months after recruitment. The available data for this participant were included in the analysis. The study originally planned to recruit 90 participants to allow for potential drop-out or loss to follow up. When participant number 78 was recruited there were no recorded drop outs. Hence since the statistical analysis required 78 participants, recruitment ceased at that point. Participants were evenly recruited from all the services providers (Rocky Bay, Nulsen Disability Services, IdentityWA, MyPlace, Enable WA, MyPlace, Autism Association of Western Australia) that operated within WA and about half of the participants had services from more than one of these services. About 10% of the participants were made aware of the research from social media, conference presentations and word of mouth. There were two participants who lived in regional areas in WA.

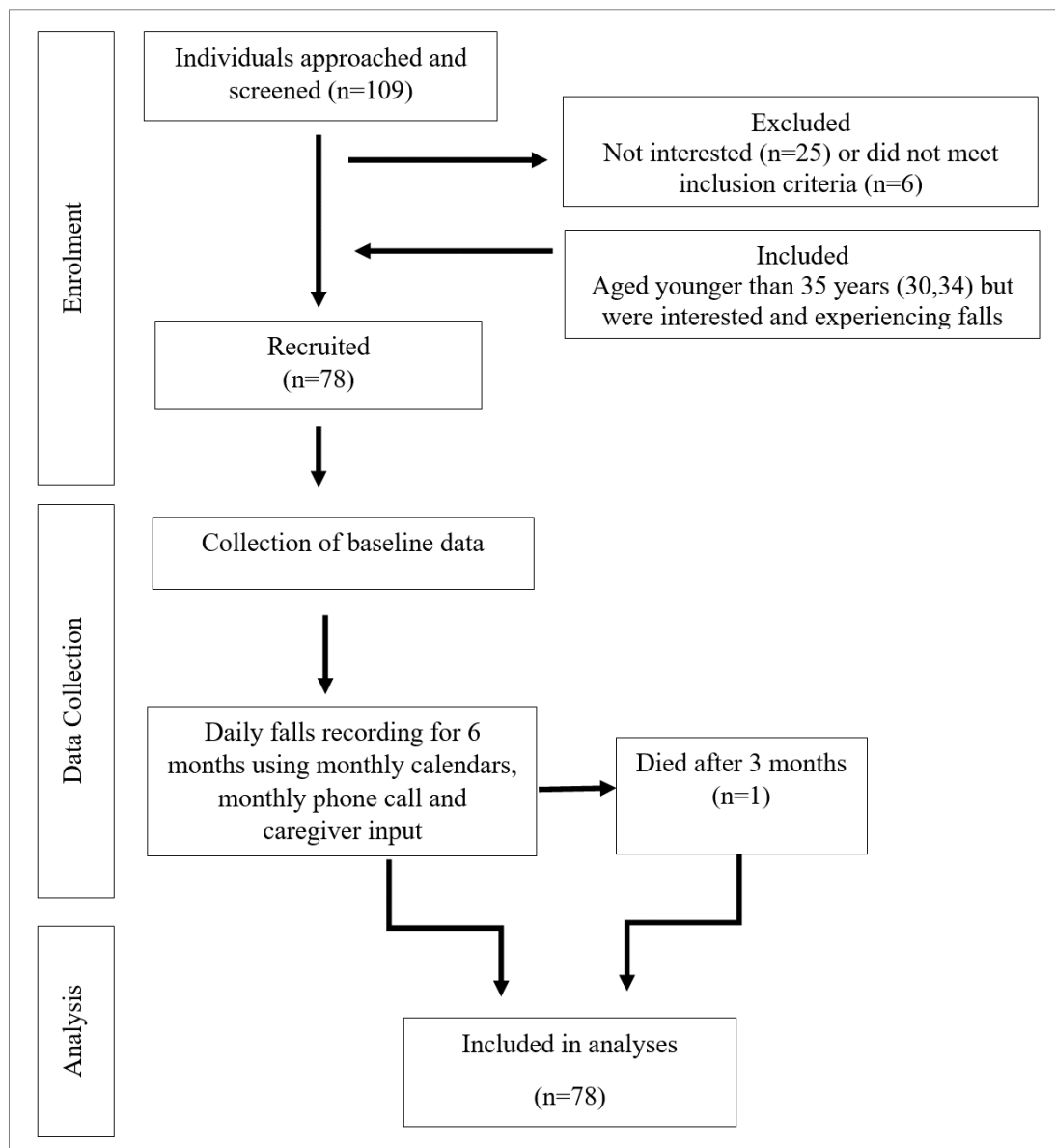


Figure 5.1 Participant Flow through the Study

Participant characteristics are presented in Table 5.1. Living arrangements were categorised as: (i) living with family; (ii) in group homes; (iii) living independently. Participants who were living with family were either living with their parents or with siblings. Participants living in group homes typically resided with three to six other adults with ID, with access to 24 hour care support onsite. Participants who lived independently had intermittent formal care support when required.

Table 5.1 Demographic characteristics of Participants

Characteristic*	Total Sample (n=78)	Faller (n=36)	Non-Faller (n=42)
Age yrs, mean (SD)	52.5 ± 12.5	54.2 ± 13.1	51.0 ± 11.8
< 45	24 (30.7)	10 (27.8)	14 (33.3)
45 – 64	40 (51.3)	17 (47.2)	23 (54.8)
> 65	14 (18.0)	9 (25.0)	5 (11.9)
Gender, female	32 (41.0)	17 (47.2)	15 (35.7)
Body Mass Index			
< 20	11 (14.1)	2 (5.55)	9 (21.4)
20 – 25	20 (25.6)	10 (27.8)	10 (23.8)
> 25	47 (60.3)	24 (66.7)	23 (54.8)
Primary Diagnosis,			
Intellectual disability	41 (52.6)	19 (52.8)	22 (52.4)
Down syndrome	10 (12.8)	3 (8.3)	7 (16.6)
Cerebral Palsy	10 (12.8)	4 (11.1)	6 (14.3)
Autism spectrum disorder	2 (2.6)	1 (2.8)	1 (2.4)
Other ^a	15 (19.2)	9 (25.0)	6 (14.3)
Living arrangement			
With family	17 (21.8)	6 (16.7)	11 (26.2)
Group home	55 (70.5)	28 (77.8)	27 (64.3)
Alone with support	6 (7.7)	2 (5.6)	4 (11.1)
Attended school			
Yes	71 (91)	33 (91.7)	38 (90.5)
No	7 (9)	3 (8.3)	4 (9.5)
Method of communication			
Verbal and behaviour	27 (34.6)	11 (30.6)	16 (38.1)
Learned signs and pictorial aids	9 (11.5)	5 (13.9)	4 (9.5)
Behaviour, gestures and natural signs	35 (44.9)	18 (50.0)	17 (40.5)
Behaviour and expressions	7 (9.0)	2 (5.6)	5 (11.9)
Communication ability ^b			
Mild	13 (16.7)	5 (13.9)	8 (19.0)
Moderate	20 (25.6)	12 (33.3)	8 (19.0)
Severe/Profound	45 (57.7)	19 (52.8)	26 (61.9)
Challenging behaviour	24 (30.8)	15 (41.7)	9 (21.4)
Proxy HR-QoL ^c completed	57 (73.1)	30 (83.3)	27 (64.3)
Dolan score, mean (SD),	0.5 (±0.3)	0.5 (±0.3)	0.5 (±0.4)
VAS/100, mean (SD) ^d	74.3 (±16.3)	73 (±13.6)	75.4(±18.7)
Well-Being Index completed	16 (20.5)	5 (13.9)	11 (26.2)
11 point scale	14 (17.9)	5 (13.9)	9 (21.4)
2 point scale	2 (2.56)	0 (0.0)	2 (4.8)

Characteristic*	Total Sample (n=78)	Faller (n=36)	Non-Faller (n=42)
Mobility			
Ambulant ^e	56 (71.8)	30 (83.3)	26 (61.9)
Non-ambulant	22 (28.2)	6 (16.7)	16 (38.1)
History of falls in previous 12 months	47 (60.3)	29 (80.6)	18 (42.9)
Visual impairment	28 (35.9)	11 (30.6)	17 (40.5)
Visual Aids	21 (26.9)	9 (0.3)	12 (28.6)
Takes 4 or more medications	57 (73.1)	23 (63.9)	34 (81.0)
Uses neuroleptic medications ^f	53 (68.0)	24 (66.7)	29 (69.0)
Epilepsy	30 (38.5)	16 (44.5)	14 (33.3)
Continence			
Continent during day	30 (38.5)	12 (33.3)	18 (42.9)
Continent during night	25 (32.1)	8 (22.2)	17 (40.5)
Functional Independence of ADL ^g (Mean ± SD)	2.8 (±2.0)	2.7 (±1.8)	2.8 (±2.2)
Timed up and go Test completed	42 (53.8)	20 (55.6)	22 (52.4)
Sec (Mean ± SD)	21.4 (±13.8)	22.7 (±15.3)	20.3(±12.6)
Five times sit to stand completed	37 (47.5)	14 (38.9)	23(54.7)
Sec (Mean ± SD)	23.8 (±15.8)	26.8 (±22.8)	21.9 (±9.6)
Single leg stance for 10 completed	7 (9.0)	2 (5.6)	5 (11.9)
Four step balance test	12 (15.4)	4 (11.1)	8 (19.0)
Sec (Mean ± SD)	18.4 (±8.2)	20.1 (±12.6)	17.5(±5.9)

Abbreviations: SD, Standard Deviation; ID, Intellectual Disability, ADL, Activities of Daily Living; HR-QoL, Health Related – Quality of Life

*All data are presented as n (%) unless otherwise stated.

Footnotes

^a Includes rare disorders associated with a genetic mutation.

^b Rated using the Communication Function Classification System (CFCS). CFCS I = mild, CFCS II or III = moderate, CFCS IV or V = severe.

^c HR-QoL measured using the EQ-5D-5L (Dolan method), range -0.59 to 1.0 higher indicates better self perceived health-related quality of life.

^d Visual analogue scale, range 0–100 higher indicates better self-perceived health-related quality of life.

^e Able to weight bear on their feet to ambulate and/or transfer indoors. Includes independent or assisted walking, with or without a walking aid.

^f Medications that are known to alter the brain chemistry, includes sodium valproate, Risperidone and Olanzapine.

^g Functional independence of ADL measured using Katz index of independence ADL scale, six item scale with total score ranging ranges from 0 to 6, higher score indicates more independence.

It was reported that seven of the participants never received an education as schools did not accept children with severe ID during their schooling years. All other participants went to schools providing education for children with special needs or mainstream schools with additional specialised educational support.

Nearly half (42.3%) of the participants were able to communicate effectively with familiar communication partners (CFCS ≤ 3) (Hidecker et al., 2011). The remaining participants, scoring higher on the CFCS, were not able to communicate effectively on a consistent basis with others, indicating more severe impairment.

Falls outcomes are presented in Table 5.2. There were 296 falls reported by 36 (46.2%) participants during the six-month observation period. Five participants reported a high number of falls (>24 falls). When falls data from one outlier (n=94 falls) were removed, the falls rate was 5.7 falls per person year. This participant in particular was very active and involved in sport and many community activities. He had poor muscle control and deformity in his lower limbs. He frequently fell due to reported rushing and impulsive behaviour. There were 20 (25.6%) participants who sustained one or more injurious falls. Falls resulting in one or more injuries (n=61, 20.6%) included one fracture (lower limb) and one concussion requiring hospitalisation.

Table 5.2 Falls Outcomes

Outcome	<i>n=78</i>
Falls ^a /injurious falls/fractures, <i>n</i>	296/61/1
Fallers, <i>n</i> (%)	36 (46.2)
Falls rate per person year ^b	8.2 (5.7)*
Injurious fall rate per person year	1.7 (0.8)*
Fracture rate per person year	0.03
Falls per participant, <i>n</i> (%)	
0	42 (53.8)
1	12 (15.4)
2	11 (14.1)
3	3 (3.9)
4	1 (1.3)
5	1 (1.3)
6	1 (1.3)
8	2 (2.6)
>8	5 (6.4) ^a

*Value in brackets was the falls and injurious falls rate when one outlier with multiple falls (94) and resulting injurious falls (30) recorded was removed from the analysis

^a 5 participants had 25, 28, 33, 42 and 94 falls

^b Days of observation - 13127

Univariate analysis for the outcomes of the risk of falling and number of falls are presented in Tables 5.3 and 5.4. Final multivariate models presenting adjusted risk factors for outcomes of risk of falling and number of falls are presented in Figure 5.2.

Table 5.3 Univariate Analysis and Final Multivariate Models^a on the association between Participant Characteristics and the Risk of Sustaining one or more Falls

Independent Variable	Univariate			Adjusted multivariate		
	OR	95% CI	<i>p</i>	AOR	95%CI	<i>p</i>
Age	1.02	0.98-1.06	0.26			
Gender	1.61	0.65-4.00	0.30			
Body Mass Index	1.36	0.54-3.44	0.52			
Communication Ability	1.46	0.43-4.90	0.54	0.43	0.08-2.30	0.32
Epilepsy	1.60	0.64-4.01	0.32	2.91	0.77-10.96	0.21
History of Falls	5.52	1.98-15.43	0.00	6.37	1.90-21.34	0.00
Ambulant	3.08	1.05-9.02	0.04	4.50	1.15-17.67	0.03
Takes 4 or more Medications	1.20	0.44-3.29	0.72	0.50	0.12-2.17	0.36
Use of Neuroleptic Medication	0.90	0.35-2.33	0.82	0.54	0.131-2.19	0.39
Visual Impairment	0.65	0.25-1.66	0.36			
Continent	0.67	0.26-1.68	0.39	0.64	0.17-2.46	0.51
Functional Independence	1.03	0.82-1.28	0.83			
Challenging Behaviour	2.62	0.97-7.07	0.06	3.10	0.83-11.61	0.09
5 Sit to Stand (STS) Test	0.53	0.21-1.30	0.16	0.23	0.06-0.94	0.04

^aAll analyses adjusted for days of observation in the study. Abbreviations: IRR, Incidence Rate Ratios, OR, Odds ratios, CI – Confidence Interval.

Table 5.4 Univariate analysis and final multivariate models^a on the association between participant characteristics and the outcome of falls

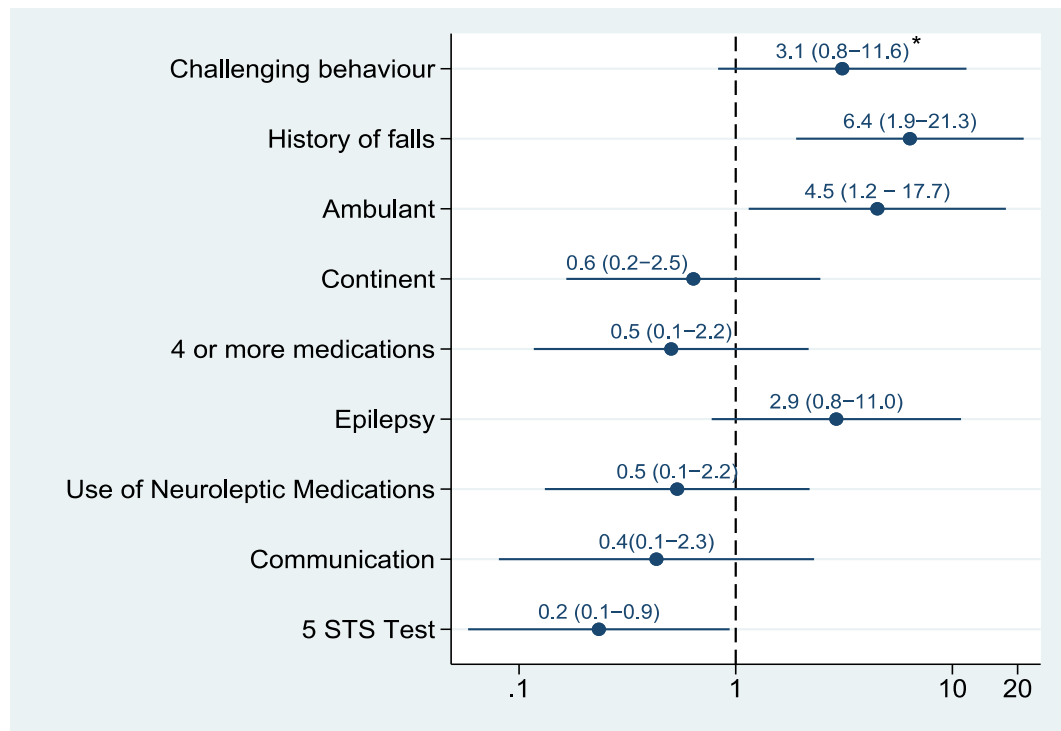
Independent Variable	Univariate			Adjusted multivariate		
	IRR	95% CI	<i>p</i>	AIRR	95% CI	<i>p</i>
Age	0.99	0.94-1.04	0.59			
Gender	0.49	0.17-1.44	0.20			
Body Mass Index	6.44	2.23-18.67	0.01			
Communication Ability	0.61	0.15-2.50	0.49	0.30	0.06-1.44	0.13
Epilepsy	0.82	0.27-2.44	0.72	1.36	0.49-3.80	0.56
History of Falls	17.35	6.02-50.04	0.00	11.65	3.78-35.88	0.00
Ambulant	0.26	0.84-0.77	0.02	0.93	0.25-3.46	0.92
Takes 4 or more Medications	0.32	0.10-1.01	0.05	0.22	0.06-0.83	0.03
Use of Neuroleptic Medication	0.46	0.15-1.40	0.17	0.58	0.15-2.19	0.42
Visual Impairment	0.83	0.28-2.53	0.75			
Continent	0.45	0.15-1.32	0.14	0.25	0.07-0.91	0.04
Functional Independence	1.34	0.92-1.95	0.12			
Challenging Behaviour	0.70	0.22-2.24	0.55	2.45	0.65-9.26	0.19

^aAll analyses adjusted for days of observation in the study. Abbreviations: IRR, Incidence Rate Ratios, OR, Odds ratios, CI – Confidence Interval.

Participants with a history of falls and who were able to ambulate indoors had a significantly increased risk of falling (see Figure 5.2a). The rate of falls was significantly less among participants, who were continent, had higher communication scores on the CFCS and were taking four or more medications not classified as neuroleptic (see Figure 5.2b).

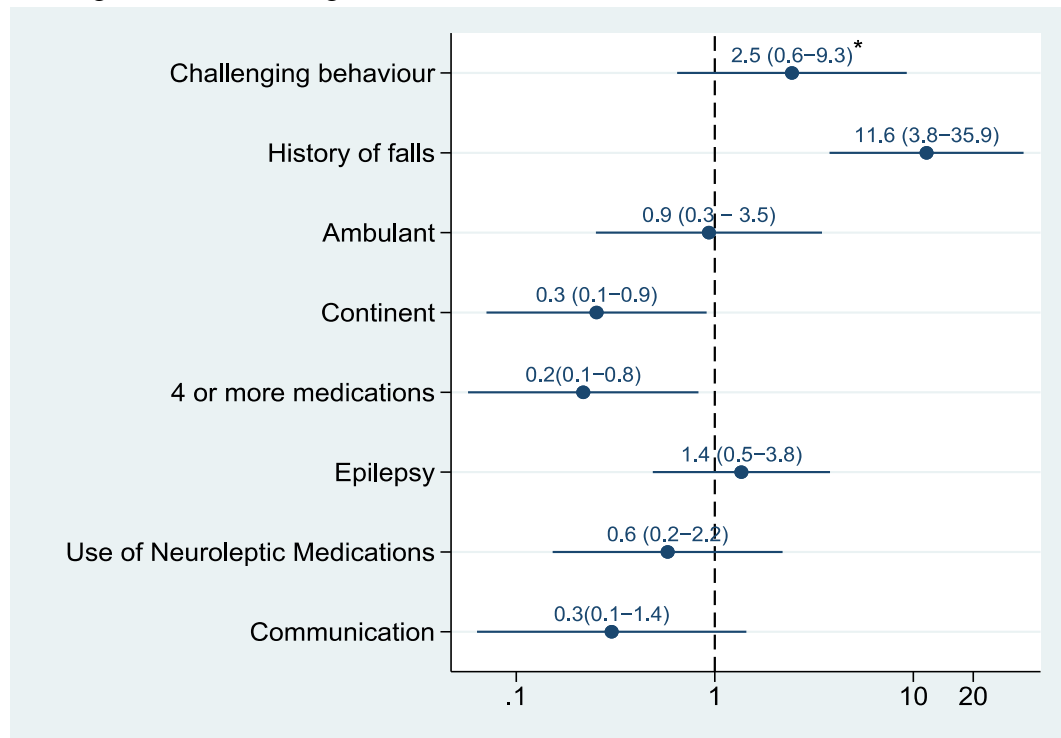
The number of recorded injuries was not adequate to conduct a univariate analysis.

(a) Logistic regression for outcome of sustaining one or more falls



*=All values are adjusted incidence ratios (95% confidence interval)

(b) Negative binomial regression for outcome of falls



*=All values are adjusted incidence ratios (95% confidence interval)

Figure 5.2 Final Multivariate Models presenting Associated Risk Factors for Outcomes of Falls and Risk of Falling

5.6 Discussion

This observational cohort study found that over 46% of the cohort fell during the six month observation period, a higher prevalence than reported in other studies in this population (Cox et al., 2010; Hsieh et al., 2012; Pal et al., 2014; Smulders et al., 2013) and higher than community dwelling older populations (Gillespie et al., 2012). This was a higher falls rate compared to other studies conducted in people with ID. Study designs vary but our study most closely resembled two studies conducted in the Netherlands (Enkelaar et al., 2013a; Smulders et al., 2013). These studies (Enkelaar et al., 2013a; Smulders et al., 2013) collected falls prospectively from a similar population (older adults with ID \geq 50 years old) for 12 months and both had a falls rate of 1.0 fall per person year while our observed falls rate was 8.2 falls per person year, eight times greater in 6 months. This was inclusive of all participants including several who had a very high number of falls. When the outliers (five participants who had more than eight falls) were removed the falls rate of 2.2 falls per person year was more closely aligned with the results from these studies (Enkelaar et al., 2013a; Smulders et al., 2013). The mean age of our sample (52.5 years) was younger than that of the previous studies, where the mean age of their participants were 62.8 years (Enkelaar et al., 2013a) and 62.9 years (Smulders et al., 2013). However participants in that study were required to be able to walk 10 metres independently (Smulders et al., 2013), whereas this study included participants who required assistance to ambulate with assistance and out of the 70% who could ambulate about 30% were unable to complete a TUG test, meaning our participants may have been at a higher risk of falls. These findings indicate that falls are a serious health problem for adults with ID living in the community.

A history of falls was predictive of falling in this cohort, similar to older community dwelling cohorts (Ambrose et al., 2013). However, there were other falls risk factors which were found to be important in particular for older adults with ID. Participants were more likely to sustain a fall if they had epilepsy, displayed challenging behaviour and were ambulant. Unlike previous studies (Cox et al., 2010; Hsieh et al., 2012), in this population advancing age was not shown to be a significant factor for falls, however these studies enrolled participants aged 18 years and over, whereas our population was older (>35 years). Both these studies also found taking a high number of medications was associated with falls but in our cohort participants who took four or more medications had less falls. Participants in this study who took

more medications could indicate that they are of poorer health and therefore less likely to be physically active. This finding importantly highlights that older adults with ID should not be viewed as identical to older community dwelling older people.

These differing falls risk factors suggest that falls risk screening and assessment tools designed for older people may not be suitable for older adults with ID.

Several falls related studies reported on the level of ID of their participants (Hsieh et al., 2012; Enkelaar et al., 2013a; Smulders et al., 2013). The level of ID was not used in this study as not all participants were aware of their level of ID. The CFCS that was developed to provide an indication of the effectiveness of communication with others was scored as a practical means to represent the participants' level of cognition and social interaction. The CFCS has been shown to be significantly related to intellectual functioning (Choi, Park, Choi, Goh & Park, 2018). Falls were found to be less likely to occur in participants who were less able to communicate effectively. Studies have not consistently found that the severity of ID poses as a risk factor for falls in adults with ID. A previous study (Hsieh et al., 2012), reported that participants with severe levels of ID were more likely to fall while in another it was reported that participants with mild levels of ID were at higher risk of falls likely because they tend to be more active (Enkelaar et al., 2013a). Another study (Cox et al., 2010) reported that severity of ID was not a significant factor for falls. In this study, it may be that participants who took more medications and who communicated less effectively had more health problems and more severe levels of ID. This could suggest that they were unable to participate in more physically demanding activities and hence experienced less falls. A study on older people with ID (>50 years) suggested the people with mild levels of ID were at an increased risk of falls because they were able to participate in more activities (Enkelaar et al, 2013a). More investigation is still required to determine if there is a correlation between the ability and level of participation in the area of falls so that reasons for low levels of participation can be explored and addressed.

Epilepsy was not significantly associated with falls in this cohort, which differed to previous studies (Cox et al., 2010; Hsieh et al., 2012). Our study sample size may not have allowed us to detect this effect. Additionally our cohort diagnosis of epilepsy may have included participants whose epilepsy was well controlled. Urinary incontinence is known to contribute to falls in older community dwelling older adults

(Soliman, Meyer, & Baum, 2016) but was also not found to be a contributing risk factor for falls in this cohort. The likely reason for this is that in this cohort, participants who were not continent, had limited executive function to independently complete toileting.

The results from the strength, mobility and balance tests were not shown to have significant correlation with the risk of sustaining a fall or the number of falls. This may be due to limited data from these tests as only approximately 50% of participants completed the strength and mobility tests. Participants who were classified as non-ambulant in this study and who were not able to follow instructions did not participate in the physical tests. These tests were chosen as they are simple to follow and have found to be feasible and reliable in people with ID (Enkelaar, Smulders, van Schroyenstein Lantman-de Valk, Weerdesteyn, & Geurts, 2013b; Hilgenkamp, van Wijck, & Evenhuis, 2013; Salb et al., 2015). Similar to previous studies, these tests had low completion rates among participants with limited ability and severe to profound ID (Hilgenkamp et al., 2013). In other studies, only people with mild to moderate disability were recruited (Blomqvist, Wester, Sundelin, & Rehn, 2012; Enkelaar et al., 2013a) while in this study the level of ID was not part of the recruitment criteria.

Over 80% of participants were less than 65 years old, whereas in the broad community falls predominantly become an increasing problem from aged 65 years onwards, confirming other studies in populations with ID (Cox et al., 2010; Hsieh et al., 2012; Pal et al., 2014; Wagemans & Cluitmans, 2006). A lesser proportion of participants (25.6%) reported one or more injurious falls compared to other studies in this population (Cox et al., 2010; Smulders et al., 2013) but there was a high injurious falls rate (1.7 per person year) indicating that falls-related injuries are also a serious problem. Overall these findings strongly suggest that people with ID need to be screened for falls risk from a younger age and falls prevention services that are unique to people with ID and their caregivers are required to manage identified risk factors appropriately in this population.

5.6.1 Strength and Limitations

A strength of the study was that falls data were collected prospectively with daily recording of falls and monthly follow up which accords with guideline recommendations (Lamb et al., 2005). Additionally, a multi-step informed consent process described in Chapter 4 which was specially developed for the study ensured

that all the participants were engaged to the best of their abilities, with the aim of strengthening the accuracy and reliability of the data collected.

Falls guidelines recommend that data are collected for 12 months but it was felt that this could form an added burden to the carers of the older adults with ID. Level of ID was not known for all the participants and therefore could not be analysed and compared against other studies. However, the CFCS was used which is a more functional measure of interaction with others.

A limitation of the study was that not all participants were able to complete the mobility and balance assessments which may have limited risk factor findings. However the cohort reflects the diversity of adults with ID living in the community. The diversity amongst the participants also meant that limited number of participants had a particular risk factor. Power calculations for each risk factor was not considered beneficial when the regression analysis was conducted. The sample size in comparison to the larger community of older adults with ID is small and while there was an attempt to recruit older adults with ID from a wide geographical area, it may not be representative of the population. More research into the risk factors for falls in older adults with ID is highly recommended.

5.7 Conclusion

The incidence and prevalence of falls are high in community dwelling older adults with ID aged 35 years and older, with over 45% of participants falling in a six month period. Risk factors differ compared to older (65 years and over) community dwelling populations. Health care for older adults with ID should prioritise screening and management of falls risk to prevent falls and resulting injury, with the aim of maintaining and enhancing a high quality of life. Future falls research in older adults with ID should be conducted in accordance with guideline recommendations for falls research to allow comparison between studies.

5.8 References

- Aman, M. G., Burrow, W. H., & Wolford, P. L. (1995). The Aberrant Behavior Checklist-Community: factor validity and effect of subject variables for adults in group homes. *American Journal of Mental Retardation*, *100*(3), 283-292.
- Ambrose, A. F., Paul, G., & Hausdorff, J. M. (2013). Risk factors for falls among older adults: A review of the literature. *Maturitas*, *75*(1), 51-61.
doi:10.1016/j.maturitas.2013.02.009
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)*. 5th ed. Arlington, US: American Psychiatric Publishing
- Australian Commission on Safety and Quality in Health Care. (2009). *Preventing falls and harm from falls in older people – Best practices guidelines for Australian Community Care*. Retrieved from:
<https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Guidelines-COMM.pdf>
- Axmon, A., Ahlström, G., & Sandberg, M. (2019). Falls resulting in health care among older people with intellectual disability in comparison with the general population. *Journal of Intellectual Disability Research*, *63*(3), 193-204.
doi:10.1111/jir.12564
- Bloch, F., Thibaud, M., Dugué, B., Brèque, C., Rigaud, A. S., & Kemoun, G. (2010). Episodes of falling among elderly people: a systematic review and meta-analysis of social and demographic pre-disposing characteristics. *Clinics (Sao Paulo, Brazil)*, *65*(9), 895-903. doi:10.1590/S1807-59322010000900013
- Blomqvist, S., Wester, A., Sundelin, G., & Rehn, B. (2012). Test-retest reliability, smallest real difference and concurrent validity of six different balance tests on young people with mild to moderate intellectual disability. *Physiotherapy*, *98*(4), 318-324. doi:10.1016/j.physio.2011.05.006
- Buatois, S., Perret-Guillaume, C., Gueguen, R., Miget, P., Vançon, G., Perrin, P., & Benetos, A. (2010). A simple clinical scale to stratify risk of recurrent falls in community-dwelling adults aged 65 years and older. *Physical Therapy*, *90*(4), 550-560. doi:10.2522/ptj.20090158
- Cahill, S., Stancliffe, R. J., Clemson, L., & Durvasula, S. (2014). Reconstructing the fall: individual, behavioural and contextual factors associated with falls in individuals with intellectual disability. *Journal of Intellectual Disability Research*, *58*(4), 321-332. doi:10.1111/jir.12015

- Choi, J. Y., Park, J., Choi, Y. S., Goh, Y. R., & Park, E. S. (2018). Functional communication profiles in children with cerebral palsy in relation to gross motor function and manual and intellectual ability. *Yonsei Medical Journal*, 59(5), 677-685. doi:10.3349/ymj.2018.59.5.677
- Connolly, B. (2006). Issues in aging in individuals with life long disabilities. *Brazilian Journal of Physical Therapy*, 10, 249-262.
- Cox, C. R., Clemson, L., Stancliffe, R. J., Durvasula, S., & Sherrington, C. (2010). Incidence of and risk factors for falls among adults with an intellectual disability. *Journal of Intellectual Disability Research*, 54(12), 1045-1057. doi:10.1111/j.1365-2788.2010.01333.x
- Cummins, R. A., & Lau, A. L. D. (2005). *Personal Wellbeing Index - Intellectual Disability* (3rd ed.). Deakin University Australian Centre on Quality of Life, School of Psychology.
- Department of Health, Western Australia. (2014). *Falls prevention model of care. Perth: Health Strategy and Networks*. Department of Health, Western Australia. Retrieved from: https://ww2.health.wa.gov.au/Articles/F_I/Falls-Prevention-Health-Network
- Diaz-Redondo, A., Rodriguez-Blazquez, C., Ayala, A., Martinez-Martin, P., & Forjaz, M. J. (2014). EQ-5D rated by proxy in institutionalized older adults with dementia: Psychometric pros and cons. *Geriatrics & Gerontology International*, 14(2), 346-353. doi:10.1111/ggi.12108
- Dite, W., & Temple, V. A. (2002). A clinical test of stepping and change of direction to identify multiple falling older adults. *Archives of Physical Medicine and Rehabilitation*, 83(11), 1566-1571. doi:10.1053/apmr.2002.35469
- Enkelaar, L., Smulders, E., van Schrojenstein Lantman-de Valk, H., Weerdesteyn, V., & Geurts, A. C. H. (2013a). Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities. *Research in Developmental Disabilities*, 34(11), 3754-3765. doi:10.1016/j.ridd.2013.07.041
- Enkelaar, L., Smulders, E., van Schrojenstein Lantman-de Valk, H., Weerdesteyn, V., & Geurts, A. C. H. (2013b). Clinical measures are feasible and sensitive to assess balance and gait capacities in older persons with mild to moderate Intellectual Disabilities. *Research in Developmental Disabilities*, 34(1), 276-285. doi:10.1016/j.ridd.2012.08.014
- Gardner, M. M., Buchner, D. M., Robertson, M. C., & Campbell, A. J. (2001). Practical implementation of an exercise-based falls prevention programme. *Age and Ageing*, 30(1), 77-83. doi:10.1093/ageing/30.1.77

- Gillespie, L. D., Robertson, M. C., Gillespie, W. J., Sherrington, C., Gates, S., Clemson, L. M., & Lamb, S. E. (2012). Interventions for preventing falls in older people living in the community. *The Cochrane Database of Systematic Reviews* (9). doi:10.1002/14651858.CD007146.pub2
- Hermans, H., & Evenhuis, H. M. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 35(4), 776-783. doi:10.1016/j.ridd.2014.01.022
- Hidecker, M. J. C., Paneth, N., Rosenbaum, P. L., Kent, R. D., Lillie, J., Eulenberg, J. B., . . . Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine and Child Neurology*, 53(8), 704-710. doi:10.1111/j.1469-8749.2011.03996.x
- Hilgenkamp, T. I. M., van Wijck, R., & Evenhuis, H. M. (2013). Feasibility of eight physical fitness tests in 1,050 older adults with intellectual disability: results of the healthy ageing with intellectual disabilities study. *Intellectual and Developmental Disabilities*, 51(1), 33-47. doi:10.1352/1934-9556-51.01.033
- Hill, A.-M., Hoffmann, T., McPhail, S., Beer, C., Hill, K. D., Oliver, D., . . . Haines, T. P. (2011). Evaluation of the sustained effect of inpatient falls prevention education and predictors of falls after hospital discharge--follow-up to a randomized controlled trial. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 66(9), 1001-1012. doi:10.1093/gerona/glr085
- Ho, P., Bulsara, C., Patman, S., Bulsara, M., Downs, J., Hill, A.-M. (2018). Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for prospective observational cohort study. *BMC Geriatrics*, 18(1), 171. doi: 10.1186/s12877-018-0862-8.
- Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 442-454. doi:10.1352/1944-7558-117.6.442
- Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., & Becker, C. (2005). Development of a common outcome data set for fall injury prevention trials: The prevention of falls network Europe consensus. *Journal of the American Geriatrics Society*, 53(9), 1618-1622. doi:10.1111/j.1532-5415.2005.53455.x
- Milat, A. J., Watson, W. L., Monger, C., Barr, M., Giffin, M., & Reid, M. (2011). Prevalence, circumstances and consequences of falls among community-dwelling older people: results of the 2009 NSW Falls prevention baseline survey. *NSW Public Health Bulletin*, 22(4), 43-48. doi: 10.1071/NB10065

- Pal, J., Hale, L., Mirfin-Veitch, B., & Claydon, L. (2014). Injuries and falls among adults with intellectual disability: A prospective New Zealand cohort study. *Journal of Intellectual and Developmental Disability, 39*(1), 35-44. doi:10.3109/13668250.2013.867929
- Podsiadlo, D., & Richardson, S. (1991). The timed "Up and Go": a test of basic functional mobility for frail elderly persons. *Journal of the American Geriatrics Society, 39*(2), 142-148.
- Salb, J., Finlayson, J., Almutaseb, S., Scharfenberg, B., Becker, C., Sieber, C., & Freiberger, E. (2015). Test–retest reliability and agreement of physical fall risk assessment tools in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 59*(12), 1121-1129. doi:10.1111/jir.12216
- Smulders, E., Enkelaar, L., Weerdesteyn, V., Geurts, A. C. H., & Schrojenstein Lantman-de Valk, H. (2013). Falls in older persons with intellectual disabilities: fall rate, circumstances and consequences. *Journal of Intellectual Disability Research, 57*(12), 1173-1182. doi:10.1111/j.1365-2788.2012.01643.x
- Soliman, Y., Meyer, R., & Baum, N. (2016). Falls in the elderly secondary to urinary symptoms. *Reviews in Urology, 18*(1), 28-32.
- Van Hanegem, E., Enkelaar, L., Smulders, E., & Weerdesteyn, V. (2014). Obstacle course training can improve mobility and prevent falls in people with intellectual disabilities. *Journal of Intellectual Disability Research, 58*(5), 485-492. doi:10.1111/jir.12045
- von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gøtzsche, P. C., & Vandembroucke, J. P. (2014). The Strengthening the reporting of observational studies in epidemiology (STROBE) statement: Guidelines for reporting observational studies. *International Journal of Surgery, 12*(12), 1495-1499. doi:10.1016/j.ijssu.2014.07.013
- Wagemans, A. M. A., & Cluitmans, J. J. M. (2006). Falls and fractures: A major health risk for adults with intellectual disabilities in residential settings. *Journal of Policy and Practice in Intellectual Disabilities, 3*(2), 136-138. doi:10.1111/j.1741-1130.2006.00066.x
- Willgoss, T. G., Yohannes, A. M., & Mitchell, D. (2010). Review of risk factors and preventative strategies for fall-related injuries in people with intellectual disabilities. *Journal of Clinical Nursing, 19*(15-16), 2100-2109. doi:10.1111/j.1365-2702.2009.03174.x
- World Health Organization. (2018) *Falls fact sheet*. Geneva, Switzerland: World Health Organization. Retrieved from: <https://www.who.int/news-room/factsheets/detail/falls>

Exploring Enablers and Barriers to Accessing Health Services after a Fall among Older Adults with Intellectual Disability

Preface

This chapter describes Study 4 that explored the experiences of older adults with ID when seeking health services after having a fall.

This chapter is based on a submitted manuscript:

Ho, P., Bulsara, C., Patman, S., Bulsara, M., Downs, J., Hill, A.-M. Exploring enablers and barriers to accessing health services after a fall among people with intellectual disability. *(Submitted to a peer reviewed journal undergoing second round of peer review)*

The author's version of the manuscript is presented with modifications to suit the style and format of this thesis.

6.1 Abstract

Background

Adults with ID experience high rates of falls at a younger age than the general community. In general, falls services are tailored for the needs of older adults including those with dementia and not specifically for adults with ID. The purpose of the study was to seek the perspectives of older adults with ID and their caregivers to i) explore the experiences of older adults with ID when seeking healthcare services after a fall, and ii) identify enablers and barriers they encounter taking up evidence-based falls recommendations that were provided to them.

Method

A qualitative exploratory study was undertaken as part of a prospective observational cohort study (n=78). Semi-structured interviews were conducted with a purposeful sample of participants after falls events were reported. Data were analysed thematically using Colaizzi's seven step method.

Results

Seventeen interviews were conducted with 21 participants (five adults with ID, one parent, one nurse and 14 disability support workers). Emergent themes demonstrated that participants had limited knowledge about evidence-based falls prevention interventions. Barriers included not being offered access to established fall prevention service pathways designed for older adults. For some participants with ID hospital admission after a fall acted as an enabler, with provision of short-term individualised falls prevention treatment. Advocacy by caregivers influenced the level of services received.

Conclusion

Multiple barriers impacted on the quality of care provided to older adults with ID after a fall, including limited access to evidence-based service pathways. Caregivers provided high quality advocacy for the older adults with ID, however they had low levels of knowledge about falls prevention and received limited support from healthcare providers.

6.2 Introduction

The systematic review and meta-analysis of nine studies in Chapter 2 reported that the prevalence of falls in adults with ID (mean age = 47.6 years) is approximately 40% (95% CI 0.25 – 0.53) (Ho et al., 2019a). This prevalence is higher than in the general community where falls increase at an older age and where 25 -35% of adults aged 65 years and older fall each year (Bloch et al., 2010; Milat et al., 2011). Identified risk factors for falls amongst people with ID include having a history of falls, seizures, challenging behaviours and higher levels of mobility (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010; Enkelaar, Smulders, van Schrojenstein Lantman-de Valk, Weerdesteyn, & Geurts, 2013; Hsieh, Rimmer, & Heller, 2012, Ho et al., 2019b).

RCTs and multiple systematic reviews (Hopewell et al., 2018; Hu et al., 2016; Sherrington et al., 2019) provide established evidence for effective strategies that reduce the risks and rate of falls in community dwelling adults aged 65 years and older. These include exercise programs that include a balance component, Tai Chi and functional based activities (Hu et al., 2016; Sherrington et al., 2019), and falls risk screening followed by single or multicomponent management of risk factors identified (Hopewell et al., 2018). The evidence is strongest for exercise interventions, as well as vision assessment and treatment, environmental assessment and modification, and vitamin D and calcium supplementation (Tricco et al., 2017). As a result, national and international guidelines and falls models of care have been developed to increase awareness of these strategies in the wider community and their supporting health professionals (Australian Commission on Safety and Quality in Healthcare, 2009; Department of Health, Western Australia, 2014; Moncada & Mire, 2017).

While there has been limited research investigating the best available evidence for reducing falls among adults with ID, evidence suggests that exercise-based interventions, environmental safety and caregiver education are important to reduce falls and fall-related injuries (Van Hanegem, Enkelaar, Smulders, & Weerdesteyn, 2014; Cahill, Stancliffe, Clemson, & Durvasula, 2013; Axmon, Ahlström, & Sandberg, 2019). Further large scale research conducted in populations of adults with ID to evaluate the effects of falls prevention strategies and to inform development of falls services for adults with ID is required (Finlayson, 2018). Current falls guidelines and models of care are not specifically applicable to older adults with ID, in part

because their risk factor profile differs from the general population (Enkelaar et al., 2013; Willgoss, Yohannes, & Mitchell, 2010). However, researchers have observed broadly that individualised approaches are beneficial when tailoring a range of healthcare services to adults with ID (Bergstrom, Elinder, & Wihlman, 2014; Reppermund & Trollor, 2016; Smulders et al., 2013).

While more improvements are required to develop suitable evidence-based falls prevention recommendations and tailored services for older adults with ID, accessing existing services is also a cause for concern. Older adults with ID face multiple barriers when seeking to access health care for preventable health conditions due to the lack of awareness and support of services (Ali et al., 2013). Further barriers, such as limited caregiver support and individualised care programs, impede the uptake of health recommendations (Bergstrom et al., 2014; Taliaferro, Block, & Moran, 2013).

Currently, no studies have specifically investigated the experiences of older adults with ID who seek health services immediately after having a fall nor identified the barriers to taking up falls prevention services. The aim of the study was: i) to explore the experiences of older adults with ID when seeking healthcare services after a fall; and ii) identify enablers and barriers to taking up falls prevention recommendations that were provided for them.

6.3 Methods

6.3.1 Design

A convergent mixed methods study in two phases was conducted. The protocol for the mixed methods study, including definitions of a fall and injurious fall are described in Chapter 3. Study 4 formed the qualitative phase of the research. A descriptive phenomenological approach was taken for this qualitative phase of the research as it allowed the researcher to report on the lived experience of the participants in relation to falls events (Liamputtong, 2013). We knew that many participants would have difficulty with communication. Hence, this study used a unique and modified approach to phenomenological methodology given the ethical necessity to ensure that participants with ID were given a voice. This is described in the sample selection.

6.3.2 Ethical considerations

This study received ethics approval from The University of Notre Dame Australia Human Research Ethics Committee (015067F). All participants provided informed consent. Where participants with ID did not have the capacity to consent, written consent was provided by the next-of-kin or legal guardian. The procedure for gaining informed consent from the participants is presented in Chapter 4. Caregivers were also made aware that the participants were engaging in the interviews. Written informed consent was also provided by the caregivers who participated in the interviews.

6.3.3 Sample selection

Participants in Study 3 (presented in Chapter 4) were purposefully sampled and recruited for the follow up interviews conducted as part of Study 4. A purposive sampling technique was employed to gain multiple perspectives on the issues around the topic (Patton, 2002).

Participants were selected using maximum variation sampling strategy with the aim of ensuring the sample included participants with variability in age, gender, mobility status and care support needs. Caregivers who supported the participants after the fall were also invited to participate in the interviews, since it was known (from Study 3) that over 90% of participants required caregivers' support to provide informed consent and support to communicate with the researcher. Data obtained from the interviews were continuously examined by the research team to explore the emerging themes and to examine whether the data adequately described the participants' experiences. Data saturation was assessed based on the themes relating to the framework listed in the interview schedule (Appendix K). Interview transcripts were analysed by two researchers as each interview was completed and interviews ceased when researchers agreed that data saturation had been reached, with no new data being generated and data gathered fitting into previously described themes (Liamputtong, 2013).

6.3.4 Data collection and procedure

Data collection is detailed in Chapter 3 when describing the outcome measures. Briefly, individual face to face, semi-structured interviews were conducted with

participants at their preferred location and were approximately 30 to 45 minutes in length. The interviews were organised as soon as possible after the fall was reported to ensure that recall of events were as accurate as possible (Lamb, Jørstad-Stein, Hauer, & Becker, 2005). Semi-structured interviews permitted open ended questions for informants to share their experience without restrictions. Interviews were audio-recorded and where participants consented, a video was recorded to capture any information that could have been conveyed through non-verbal means, such as facial expressions or gestures to complement the interview transcripts.

The interview schedule (Appendix K) was designed in accordance with national evidence-based falls prevention recommendations (Australian Commission on Safety and Quality in Healthcare, 2009; National Institute of Health and Care Excellence, 2013; Moncada & Mire, 2017). The researcher (PH) tailored the interview according to the experiences shared and if the participant was an older adult with ID, appropriate lay language was used. Alternative forms of communication were used where preferred. The researcher also prepared adapted communication resources to facilitate the interview. These adapted communication resources were developed based on recommendations for respective engagement of adults with ID during research (Kidney & McDonald, 2014).

6.3.5 Analytical approach

The analytical approach is detailed in Chapter 3 when describing the study's statistical analysis. Following Colaizzi's descriptive method of interpretation (Sanders, 2003), the researcher (PH) transcribed all the interviews and familiarised herself with each interview during the transcribing process. Interview videos were also reviewed and notes made regarding body language and gestures that participants with ID used to contribute to the interview. Subsequently, the verbatim transcripts of the interviews and notes from video observations were analysed using the data management program NVivo 12 (QSR International Pty Ltd. Version 12, 2018) whereby the researcher searched for statements significant to the research aims. Meanings were formulated from the statements while observing the concept of bracketing, focusing on the recording experiences to ensure that the researcher did not analyse the data with preconceived ideas on falls recommendations. 'Bracketing' is noted as capturing the participant's experience whilst remaining outside the

experience, in other words “looking beyond preconceptions” (Tufford & Newman, 2012). Themes and theme clusters were generated from the formulated meanings. The experiences of seeking and receiving health care after a fall and the perceived barriers were described using these themes.

The final step undertaken following Colaizzi’s method is the returning of results to the participants. This step was not completed as the research team concurs with one of the criticisms of this final step in that the researchers and participants will inevitably have differing perspectives (Giorgi, 2006).

The elimination of bias and contributions to the rigour of the results were fulfilled by two other team members (CB, AMH) who both had experience in qualitative methodology and methods. They were also independent of the data collection process and had no contact with participants. These two team members (CB, AMH) checked the themes, liaised with the researcher (PH) regarding themes and the hierarchical coding structure and agreed with the final statement.

6.4 Results

6.4.1 Participant characteristics

There were 36 participants who sustained one or more falls in the earlier quantitative phase of the research (Chapter 5). Of these, 13 participants and /or their caregivers were followed up for an interview. Twenty-one participants (five older adults with ID, one parent, one nurse, 14 DSWs) engaged in 17 interviews. The characteristics of the sample are presented in Table 6.1. Four separate interviews were conducted with older adults with ID, who were capable of holding a conversation with the researcher and one interview was conducted with a DSW and an older adult with ID. One interview was conducted with a nurse and one with a parent separately. One group of three DSWs and one group of two DSWs were interviewed together as they were all involved in the post-fall care of an older adult participant with ID. Eight interviews were conducted with individual DSWs. Seven of the 13 older adults with ID who fell sustained an injury (including two fractures), and of those seven, there were three who required a hospital admission.

Table 6.1 Characteristics of Participants and Post-fall Experience

Participant	Characteristics	Supported environment	Fall event	Post-fall experience
1	65 year old female with ID	Group home	Non injurious fall when transferring from wheelchair.	Health professionals informed with limited implementation of strategies.
2*	DSW, female 3 years of experience (Worked for 8 months with participant 1)	DSW team leader in group home.		
3*	DSW, female 9 years of experience (Worked for 1.5 years with participant 1)	Group home.		
4	DSW, female 1 year of experience (Worked for 2 months with participant with ID who fell)	Independent unit	Non injurious falls by 71 year old male, while walking up drive way.	Health professionals informed with limited implementation of strategies.
5	DSW, female 1 year of experience (Worked for 3 months with participant with ID who fell)	Independent unit		
6	DSW, female 2 years of experience (Worked for 8 months with participant with ID who fell)	Independent unit	Non-injurious fall from falling out of wheelchair, by 49 year old male, while trying to retrieve item that was out of reach.	Health professional was informed with implementation of strategies to reduce risk.

Participant	Characteristics	Supported environment	Fall event	Post-fall experience
7	DSW, female 12 years of experience (Worked for 14 months with participant with ID who fell)	DSW team leader in group home	Multiple falls in a single day around the home by a 59 year old, female participant. No detectable injuries.	Was hospitalised and short term rehabilitation services provided for safe discharge. Medication review completed.
8	DSW, female 12 years of experience (Worked for 6 months with participant with ID who fell)	DSW team leader in group home.	Non injurious fall by 61 year old male participant. Fell while dressing in morning.	Health professionals informed with limited implementation of strategies.
9	DSW, female 6 months of experience (Worked for 6 months with participant with ID who fell)	Group home	Non injurious fall by 71 year old male participant after tripping over feet while walking.	Health professionals informed with limited implementation of strategies.
10	67 year old male with ID	Independent unit with daily support	Minor injuries from a fall walking through a park.	First aid was provided and visited the doctor without further referral or recommendations.
11	Community Nurse, female 25 years of experience. (Worked for 5 years with participant 10)	Independent unit		
12	DSW, female 10 years of experience (Worked for 8 months with participant with ID who fell)	Independent unit	Injurious fall (cut and bruise) by 49 year old male participant with ID while walking.	Sought medical attention with doctor. No referral or comprehensive pathway recommended.
13	DSW, male 5 years of experience (Worked for 6 months with participant with ID who fell)	Activity centre		

Participant	Characteristics	Supported environment	Fall event	Post-fall experience
14*	31 year old male with ID	Group home	Minor injuries (bruises) from a fall in the community. Lost balance while trying to push someone else in a wheelchair.	Did not seek medical attention.
15*	DSW, female 1 year of experience (Worked for 1 year with participant 14)	Community access		
16*	DSW, female 7 years of experience (Worked for 2 years with participant with ID who fell)	Group home	Injurious fall (fracture to lower limb) by 60 year old male participant, while transferring from bed.	Hospitalised followed by short term rehabilitation services for safe discharge. No referral to falls clinic.
17*	DSW, female 4 years of experience (Worked for 4 years with participant with ID who fell)	Group home		
18*	DSW, male 5 years of experience (Worked for 3.5 years with participant with ID who fell)	DSW team leader in group home.		
19	35 year old male with ID	Independent unit with intermittent support	Injurious fall (fracture to lower limb) after slipping in the shower.	Hospitalised followed by short term rehabilitation services for safe discharge. No referral to falls clinic.
20	41 year old male with ID	Home with parent	Minor injuries (bruises) from multiple falls when transferring from wheelchair.	Did not seek medical attention.
21	Parent	Home	Bruised and abrasion suffered after a fall by 42 year old female participant while walking in the community.	Visited the doctor for injuries and wound care.

*Participant 2 and 3, 14 and 15, 16, 17 and 18 were interviewed together.

6.4.2 Emergent Themes

Examples of how formulated meanings were derived from significant statements are presented in Table 6.2.

Table 6.2 Example of Analysis – how Formulated Meanings were derived from Participants’ Significant Statements

Significant statements of barriers	Formulated meanings
<i>“they checked her, checked her blood pressure, check her nose, checked her breathing, thought that there might have been a bit of a blockage but they checked and everything seemed to be fine” (P14)</i>	The doctor was focused on assessing for injuries after a fall but no falls risk assessment or recommendations to engage in falls prevention strategies were provided.
<i>“the one for his shoulder, we just kept an eye on it, we checked movement here and you were fine weren’t you. So we just did an incident report and kept an eye on it, after the next day it was forgotten.” (P9)</i>	DSW did not report fall to a health professional, not aware of the importance of reporting falls.
<i>“I don’t really talk about my falls with people” (P1)</i>	Participant with ID was not aware that communicating about falls is important, making it challenging for others to support with falls prevention management.
<i>“Vision, we had her vision tested as well because we were worried about depth perception, because she brought everything close to her. The doctors actually couldn’t say whether she had vision problems or not” (P9)</i>	The inability to carry out a comprehensive assessment with the participant with an ID is a barrier to understanding the cause of falls
Significant statement of enablers:	
<i>“It was when (participant) went into hospital is when I really hammered asking for help because we were then going into the new area of changing over of funding.....can you help us? Well they sent physios out to us.” (P10)</i>	Hospitalisation provided an avenue for DSW to advocate for the participant with ID who fell.

From these meanings, seven theme clusters were identified; the account of the fall, consequences of the fall, immediate care after a fall, rehabilitation after a fall related hospitalisation, knowledge of falls and how falls impact on the health of people with ID, intrinsic and extrinsic barriers to engaging in falls prevention and enablers to receiving health services after a fall. Examples of how the emergent themes were derived from the theme clusters are presented in Table 6.3. Five emergent themes informed the phenomena and they are presented as follows.

Table 6.3 Identified Theme Clusters and Resultant Emergent Themes

Formulated Meanings	Theme Clusters	Emergent Theme
Participant with ID seems to be unaware of his limitations and the insight to the precautions required to prevent a fall	Intrinsic and extrinsic barriers to engaging in falls prevention	Limited awareness about falls as a problem to be addressed and about falls prevention strategies
Participant with ID was seen by their local doctor but falls risk was not assessed and DSW did not advocate for further review		
Participant with ID fell because there was uneven ground and it was dark. No changes were made to environment and a health professional was not informed.	Account of the fall	
DSW did not report fall to a health professional which indicates that the DSW was not aware of the importance of reporting falls.	Immediate care after a fall	No comprehensive falls prevention pathway commenced after a fall even if injurious
The doctor treated the fall as an isolated event.		
Participant with ID was not aware that communicating about falls is important, making it challenging for others to support him to engage in falls prevention strategies.		
Inability of health professionals to carry out a comprehensive assessment with the participant with an ID is a barrier to understanding the cause of falls	Intrinsic and extrinsic barriers to engaging in falls prevention	
Participant with ID visits specialist for review of medical condition (Epilepsy)	Knowledge about how falls impact on the health of people with ID	Risk factors for falls that were addressed incidentally when other medical health checks were completed
Participant with ID has annual health checks at the local doctor		
Visible needs (spectacles and foot deformity) prompts health reviews (vision and podiatry)		

Formulated Meanings	Theme Clusters	Emergent Theme
Hospitalisation provided an avenue for DSW to advocate for the participant with ID who fell.	Facilitators to receiving health services after a fall	Advocacy played an important role in receiving services after a fall
DSW requested further investigation when participant when to the local doctor after a fall.		
DSW provided feedback to the organisation that more training around falls prevention is required.		
DSW expressed need for more support and training to undertake falls prevention management for clients.	Consequences of the fall	
Falls prevention strategy was implemented to prevent similar a fall that resulted after hospital admission.		
After hospital discharge, rehabilitation services were provided increase mobility post fracture		
Caregiver found a method to motivate the Participant with ID to participate in physical activity	Knowledge of falls and demands of disability	
Caregiver finds a creative and attractive method to incorporate incidental exercise for the participant with ID		

Limited awareness about falls as a problem to be addressed and about falls prevention strategies

Limited awareness that falls were a problem and should be reported and investigated was repeatedly demonstrated in the participants' reflections about their post fall experiences. Participants' reflections also exposed their limited knowledge about suitable falls prevention strategies. This included participants with ID, DSWs, family members and health professionals. Not being aware that reporting falls is recommended in current guideline care (Moncada & Mire, 2017) formed a barrier to engaging in evidence-based strategies. A participant with ID reported, "*I don't discuss my falls with them (family doctor, physiotherapist)*" (P20) and "*I don't really talk about my falls with people*" (P20). An experienced DSW reported that DSWs do not receive the training regarding falls prevention in people with ID.

The challenge is with staff training, um, behaviours attributed to self-harm to what a fall can happen because we are not actually assisting that person the correct way and their reaction to cause a fall, they do, they need training. It's

very difficult for people, they go in and do their induction, their (manual handling) those sorts of things. They don't focus on the triggers that cause falls or what things that can cause falls. (P 7)

This was confirmed during interviews completed with four other DSWs, with experience ranging from two months to 12 years of experience, who reported that they had not received any falls specific training for adults with ID. Only one parent reported seeking information about falls because she was taking care of her parents:

Bits and pieces from experience, probably also in the early days it was also information that was sent to (my) parents, um, reading up on, problems for elderly online and looking at the, the risk factors for elderly people like steps and stuff like that. (P21)

No comprehensive falls prevention pathway commenced after a fall even if injurious

National guidelines for managing falls risk for older adults state that local doctors should ask older patients about their falls history annually (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017). A multifactorial assessment is recommended after the older adult has a fall(s) to identify risk factors and develop a tailored intervention plan to reduce the risk of having another fall (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017). While there are no falls prevention guidelines designed specifically for older adults with ID, when falls were reported to a health professional, participants shared that there was no initiation of services through an existing falls prevention pathway of care (see Figure 6.1). One of the service providers was noted to have a falls policy whereby it was mandatory for a person with ID to visit a doctor after a fall. When the interviews were conducted with this providers' DSWs they concurred that the doctors were either in a rush, "*Dr (name) was really really rushed, he sort of just came straight through and had a quick look, so I dealt mostly with the nurse*" (P12) or treated each visit as an isolated incident without follow up care, "*the GP (general practitioner) just asked him if he had any pain? And then try to check his pulse, um blood pressure and then have a look over and it was all good,*" followed by "*just write, like, all good and he is under observation in case of any changes you should take him back.*" (P9)

Where a fall resulted in hospitalisation, the event acted as an enabler to addressing some falls risk factors for the participant with ID. However, allied health services such

as occupational therapy and physiotherapy services were predominantly provided to facilitate safe discharge from the hospital. One DSW shared that “*(the occupational therapist) came in and they fitted the bed rail on that same morning (of discharge)*” (P17) and “*in the first week physio was like (here) ... every day, they are here for a few hours*” (P18). However no DSW observed the health professional incorporating falls risk assessment and implementing falls prevention care for the participant with ID who had sustained the injurious fall. One DSW reported that exercises programs were prescribed to two persons with ID but additionally stated that the team of DSWs, were not confident with the program.

Staff like to have pictorial (prompts) and to be shown, actually being shown that it’s the safe way to protect themselves and the individuals that they are working with, um, and I don’t think any training has been carried out ...” (P8)

Risk factors for falls and fall injuries that were addressed incidentally when other medical health checks were completed

Although people with ID were not provided with specific falls prevention services after a fall, some fall risk factors found to be associated with falls in older adults were addressed incidentally when broader aspects of health care were being managed. All participants with ID were under the care of a local doctor and for some participants, it was during these annual health visits that some risk factors for falls were addressed. These were reported as including medication reviews, commencing vitamin D supplementation for bone health, eye health test and blood marker screening (Sousa et al., 2017). However, these healthcare behaviours, while in some cases incidentally addressing falls risk factors, did not include specific falls prevention screening. One nurse stated, “*two or three times a year, nevertheless, we would have (P10) to the doctor for blood tests and for immunisation and for follow up*” (P11). The four participants with ID interviewed independently also reported being vigilant in taking care of their own health care needs with one participant sharing that, “*every so often I get tested for my epilepsy and I get my brain scanned and all that*” (P20).

Falls prevention guidelines recommend that older people engage in specific strength and balance exercises, with this being established as an effective means of reducing falls (Australian Commission on Safety and Quality in Healthcare, 2009; Guirguis-Blake, Michael, Perdue, Coppola, & Beil, 2018) and injurious falls (Tricco et al., 2017). Nearly all the caregivers were making efforts to assist the participant with

ID to engage in some form of physical activity such as attending a pool, gym, park or social dancing, however these were carried out as recreational activities that did not include specific exercises recommended for reducing falls risk, namely sustained levels of balance challenge (Sherrington et al., 2019). One participant shared that, “*in the pool, the swimming instructor has got me doing ‘ballet leg’ exercises*” (P1) and demonstrated this point by raising her hands and flexing her knees (video observation). More than half of the persons with ID discussed were not participating in any formal exercises or activities that incorporated elements known to be effective for falls prevention (Guirguis-Blake et al., 2018; Sherrington et al., 2019).

Foot care was reported as being comprehensively addressed for all of the participants with ID which is known to reduce falls risk (Corbacho et al., 2018; Spink et al., 2011). Participants visited the podiatrist regularly for reported conditions such as diabetes or foot deformity. One parent shared that “*(participant with ID) always has to have closed in footwear because of her slightly deformed foot, um, so she always has fairly steady, well made joggers*”. (P21)

Advocacy played an important role in receiving services after a fall

People with ID are known to be more likely to receive health screening if another individual advocates on their behalf (Lennox et al., 2016). Interviews consistently demonstrated that all participants with ID required a care provider to advocate for care needs, “*(his father) knows about it (falls) and he might talk about it (to the GP/therapist)*” (P1) and “*(After having a fall) I called somebody (DSW) and um they (DSW) rang for somebody (ambulance) to come around*” (P19). Advocacy ranged from reporting the fall to a health professional to implementing falls prevention strategies such as exercise programs. The strength of advocacy sometimes required was conveyed by one participant who reflected: “*It was when (participant) went into hospital is when I really hammered asking for help because we were then going into the new area of changing over of funding.....can you help us? Well they sent physios out to us*” (P7). A DSW described advocating for more services for a participant from her employer stating that “*the funding was the hiccup for us and it did cause us some concern, but we got them (the employer) on board, I got to mention that falls are really important*” (P7).

Individualised strategies were effective in overcoming barriers to undertaking falls prevention strategies

Supporters recognised that it was challenging to implement specific strength and balance activities for adults with ID and therefore any mode or intensity of physical activity was viewed as achieving a positive outcome. A common theme of using individualised strategies emerged as a means of encouraging the person with ID to engage in physical activity. One of these strategies was the use of incidental exercise, *“they always put the ramp down and I don’t always want them to because he is quite capable of getting on and off buses.”* (P15). The participant with ID (P14) who was with P15 during the interview concurred with this statement by nodding in agreement. He smiled and vocalised positively upon hearing about the bus ride. He also sat up tall and pointed up reinforcing the message that he likes climbing the steps (video observation).

One parent advised that, *“you have to keep making it fun for her”* (P21) suggesting that it was important to create a safe but enjoyable space for the participant with ID:

So when she is on one of the bikes, she can actually watch the boys on the skate board ramp and she loves that. And she can actually sit there and ride her bike (in the gym) and watch the boys doing their thing and she can have a laugh and have a giggle at them. (P21)

Another DSW identified individual interests of the adult with ID as motivators that could increase levels of physical activity:

I’ve introduced pet therapy into the house which we are getting permission forAnd she is very very good around the dog....that would increase her mobility, her stamina, her strength and she is motivated which makes sense where she is motivated to do things something that really interest her. (P7)

Another means of encouraging physical activity was to enable the person with ID to engage in the decision making so that they enjoyed what they did, *“I think in a behavioural way definitely because my job with (participant) is to do the stuff that he wants to do that he enjoys”* (P15).

Overall this prospective exploratory study found that the lived experience of older adults with ID after a fall was that a service pathway to provide guideline standards of falls prevention management was not commenced after a fall was reported. This is

presented as a framework (Figure 6.1) illustrating how health care offered to the person with ID differed from the recommended guidelines for providing post-fall risk assessment and treatment. Health professionals did not refer participants falls management services and annual falls risk screening was also not initiated. Hospitalisation prompted provision of health services that could be considered relevant for falls prevention but this did not prompt the primary healthcare provider such as the local doctor to continue with follow up screening of fall risk and subsequent targeted interventions.

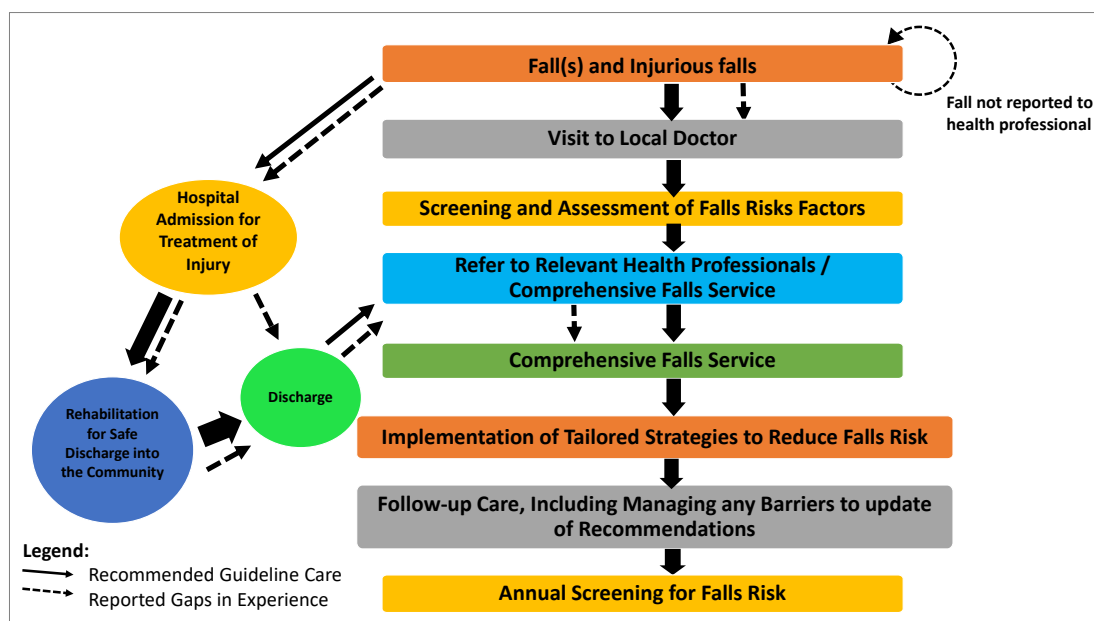


Figure 6.1 Participants’ experience of follow up health care after a fall compared to guideline recommendations for follow up care after a fall

6.5 Discussion

This study explored the experiences of the older adult with ID and their caregivers when seeking health care after a fall. Participants’ experiences did not accord with guidelines of recommended care for falls prevention. Even reporting an injurious fall to a health professional did not trigger screening of fall-risk, falls management and referral to relevant falls prevention services. Other studies that investigated strategies to reduce falls in people with ID also found barriers to providing evidence-based care, including lack of consistent support for the person with ID, issues with caregiver attitudes and limited financial resources, both for access to and implementation of services (Pal et al., 2013; Smulders et al., 2013). This is the first prospective study to directly interview older adults with ID and their caregivers immediately after the falls

and systematically compare subsequent actions against national falls management guidelines. Substantial gaps were found between guideline recommendations (Moncada & Mire, 2017) and participants' experiences regarding the healthcare services they received, including risk screening, immediate follow up care after a fall and ongoing preventive management. Gaps in service delivery and barriers to providing screening, preventative care and adequate interventions for people with ID have also been found in other health areas including oral health (Petrovic et al., 2016), vision (Uzdrowska & Woodhouse, 2016) and mental health care (Whittle, Fisher, Reppermund, Lenroot, & Trollor, 2018). Lack of specialised services, inadequate caregiver support and limited awareness of the health condition were some of the barriers identified (Ali et al., 2013; Whittle et al., 2018).

Low levels of awareness about falls prevention were observed at multiple levels, from the older adult with ID and their caregivers through to healthcare providers they encountered as part of their post-fall experiences. A significant number of falls were not reported to a health professional indicating low levels of awareness about the importance of reporting falls. National falls guidelines state that older people should be asked once yearly if they have fallen because it has been established that one of the most significant predictors of falls is having a history of previous falls (Australian Commission on Safety and Quality in Healthcare, 2009). Conversely findings also demonstrated that care providers were well-placed to identify the health needs of the older adults with ID and subsequently were able to advocate for services on their behalf. Therefore, care providers' lack of awareness about falls prevention formed a barrier to advocating for fall-risk screening and intervention for older adults with ID. Participant's inability to comprehend the need for, or the importance, of engaging in falls prevention strategies has also been described as a barrier to reducing falls risk for adults with ID (Pal, Hale, & Mirfin-Veitch, 2013). Previous research has identified increasing the level of awareness about falls encourages the engagement in falls prevention interventions (Hale, Vollenhoven, Caiman, Dryselius, & Buttery, 2019).

Although falls were sporadically reported to a doctor, especially if injury occurred, further screening to identify modifiable of falls risk factors and subsequently refer to existing falls prevention services did not follow. This concurs with research findings in the broader area of fall prevention for community dwelling older adults, where it has been identified that there is limited engagement from local doctors

regarding falls prevention. Research findings strongly suggest that a majority of doctors are unfamiliar with falls guidelines of care and only a small percentage of doctors screen older adults for fall risk (Mackenzie & McIntyre, 2019). No participants were referred to available comprehensive falls services or clinics, therefore it was not possible to comment on the suitability of these services for older adults with ID.

Adults with ID experience high rates of falls at an early age (Cox et al., 2010; Hsieh et al., 2012, Ho et al., 2019b) and the most common cause for injuries among adults with ID is falls (Finlayson, Morrison, Jackson, Mantry, & Cooper, 2010). Health professionals should therefore commence screening for older adults with ID for falls risk at a younger age compared to the general population. It was found that participants with ID were not routinely screened for falls and reporting a fall to a health professional only occurred if the fall resulted in an injury which needed medical attention or according to one service provider, the organisational falls policy. National guidelines strongly recommend yearly screening for all older adults to ask if they have sustained any falls, since the strongest predictors of falls is a history of a prior fall (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017). Falls-risk screening followed by tailored recommendations to manage fall identified risk factors were not demonstrated in the present study. Therefore identifying barriers to engaging in recommended falls prevention strategies was challenging.

The interviews identified that some of the participants received an annual health check at the local doctor and that some risk factors were screened and managed, such as medication, eye health and the need for calcium and vitamin D supplements from blood test. However bone density scans and vision assessment by an optometrist were not undertaken and these are also important to reduce fracture and falls risk. Research findings demonstrate that people with ID have poor levels of bone health (Burke et al., 2019) and have an increased prevalence of osteoporosis and osteopenia (Srikanth, Cassidy, Joiner, & Teeluckdharry, 2011) than aged-matched populations. People with ID also have a higher prevalence of visual defects (Uzdrowska & Woodhouse, 2016), which can be addressed with suitable optical means (Eisenbarth, 2018). These gaps in health screening are a significant barrier to reducing fall and resulting injury among older adults with ID.

Low levels of reporting, screening and management of risk factors for falls is not dissimilar to previous findings from other studies in adults with ID. Injury risk assessments and the management of risk have been shown to be limited and variable in people with ID (Finlayson, Jackson, Mantry, Morrison, & Cooper, 2015). Conversely, health checks have been identified to have positive effects on the enhancement of health care in individuals with ID (Robertson, Hatton, Emerson, & Baines, 2014).

When a fall resulted in hospitalisation, rehabilitation services were provided to enable safe discharge home, however there was neither multifactorial assessment nor periodic follow up as recommended in falls prevention guidelines (Moncada et al., 2017). This is problematic as it has been found that when a fall results in a hospital admission, adults with ID are more likely to be readmitted within 30 days compared to the general population (Axmon et al., 2019) making post-discharge planning and follow up management critical in this population.

Exercise has been shown to be effective in reducing falls in adults with ID (Crockett, Finlayson, Skelton, & Miller, 2015; Hale, Mirfin-Veitch, & Treharne, 2016; Van Hanegem, Enkelaar, Smulders, & Weerdesteyn, 2014). Since adults with ID fall at rates which are higher than aged matched populations (Enkelaar et al., 2013; Ho et al., 2019b) it is important that adults with ID engage in specific exercises for falls prevention. However participants reported very limited engagement in exercises of suitable intensity and mode. Participants were not provided with suitable recommendations and some caregivers reported needing more support to assist the older adult with ID to exercise effectively. Despite this, care providers shared individualised strategies that they used to motivate and encourage participants to engage in physical activity. These individualised strategies could also be used to facilitate falls prevention exercise programs, concurring with other research findings regarding exercise based interventions for falls prevention in adults with ID (Crockett et al., 2015; Pal et al., 2013).

Care providers' knowledge about disability was a strong enabler for them advocating for participants to receive health services. Conversely, lack of awareness that falls were a problem resulted in many falls not being reported to a health professional. When care providers were aware of participants' disability, experiences and falls risk factors they were able to advocate on their behalf for fall prevention services.

6.5.1 Strengths and Limitations

Multiple steps were taken to ensure trustworthiness of the data (Lincoln & Guba, 1985). Data were collected and analysed based on a methodology which included strategies to ensure rigour and trustworthiness (Sanders, 2003). All the participants underwent a thorough consent process to ensure they were making an informed decision to participate in the study (Ho et al., 2018). They were further sampled with maximum variation purposive sampling to ensure that the sample included participants with different characteristics and care situations in order to capture a wide array of experiences. Where possible interviews were conducted with the participants and their care providers separately which ensured that their experiences shared were authentic and not influenced by other parties. Interviewing caregivers augmented the narratives from the older adult with ID, providing a more holistic story of the fall trajectory, as caregivers were intrinsically part of the post-fall experience. All data were analysed and reported based on participants' first-hand accounts of their post-fall experiences.

Multiple perspectives were purposefully sought for one fall event to assist in understanding the post fall experience. A large proportion of adults with ID depend on multiple care providers and it was challenging to interview every individual involved. Therefore, accounts of the post-fall experience was in some cases based on the knowledge of one informant. A limitation of the study was that not all participants with ID were able to provide a perspective about their fall. Over half of the participants enrolled in the earlier quantitative phase of this study had severe difficulties in communicating and hence were not able to share "first hand" experiences. However out of the 13 falls sampled, five post-fall experiences were directly described by the participant with ID.

Perspectives from other individuals who participated in the participants' post-fall experience, such as the local doctor and allied health practitioners would also be valuable to amplify the post-fall experiences of older adults with ID. Health practitioners' perspectives regarding treating this population are an important avenue for further investigation. These perspectives would aid in development of tailored and responsive fall prevention services for older adults with ID.

6.6 Conclusion

Older adults with ID receive health care for injuries sustained after a fall, but are rarely screened for fall risk factors and provided with subsequent interventions and preventive services that would assist to prevent future falls and injuries. Establishing comprehensive falls prevention services specifically tailored for older adults with ID is urgently required. These services may enable people with ID and their caregivers to seek targeted information and engage in falls prevention strategies. Education and resources are also recommended to empower care providers with the necessary awareness, knowledge and skills to reduce falls risk and maintain healthy ageing. Further research to address the barriers people with ID face to engagement in suitable exercise programs is also urgently required.

6.7 References

- Ali, A., Scior, K., Ratti, V., Andre, S., King, M., & Hassiotis, A. (2013). Discrimination and other barriers to accessing health care: Perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS ONE*, 8(8), e70855. doi:10.1371/journal.pone.0070855
- Ambrose, A. F., Paul, G. & Hausdorff, J. M. (2013). Risk factors for falls among older adults: A review of the literature. *Maturitas*, 75(1), 51-61. doi: 10.1016/j.maturitas.2013.02.009
- Australian Commission on Safety and Quality in Healthcare. (2009). *Implementation guide for preventing falls and harm from falls in older people: Best Practice Guidelines for Australian Community Care*. Retrieved from <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/preventing-falls-and-harm-falls-older-people-best-practice-guidelines-australian-community-care>
- Axmon, A., Ahlström, G., & Sandberg, M. (2019). Falls resulting in health care among older people with intellectual disability in comparison with the general population. *Journal of Intellectual Disability Research*, 63(3), 193-204. doi:10.1111/jir.12564
- Bergstrom, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities--a qualitative study. *Health Education Research*, 29(2), 259-271. doi:10.1093/her/cyt111
- Bloch, F., Thibaud, M., Dugué, B., Brèque, C., Rigaud, A. S., & Kemoun, G. (2010). Episodes of falling among elderly people: a systematic review and meta-analysis of social and demographic pre-disposing characteristics. *Clinics (Sao Paulo, Brazil)*, 65(9), 895-903. doi:10.1590/S1807-59322010000900013
- Burke, E., Carroll, R., O'Dwyer, M., Walsh, J. B., McCallion, P. & McCarron, M. (2019). Quantitative examination of the bone health status of older adults with intellectual and developmental disability in Ireland: a cross-sectional nationwide study. *BMJ Open*, 9, e026939. doi:10.1136/bmjopen-2018-026939
- Cahill, S., Stancliffe, R. J., Clemson, L., & Durvasula, S. (2014). Reconstructing the fall: individual, behavioural and contextual factors associated with falls in individuals with intellectual disability. *Journal of Intellectual Disability Research*, 58(4), 321-332. doi:10.1111/jir.12015

- Corbacho, B., Cockayne, S., Fairhurst, C., Hewitt, C. E., Hicks, K., Kenan, A. M., . . . Torgerson, D. J. (2018). Cost-effectiveness of a multifaceted podiatry intervention for the prevention of falls in older people: The reducing falls with orthoses and a multifaceted podiatry intervention trial findings. *Gerontology*, *64*(5), 503-512. doi:10.1159/000489171
- Cox, C. R., Clemson, L., Stancliffe, R. J., Durvasula, S., & Sherrington, C. (2010). Incidence of and risk factors for falls among adults with an intellectual disability. *Journal of Intellectual Disability Research*, *54*(12), 1045-1057. doi:10.1111/j.1365-2788.2010.01333.x
- Crockett, J., Finlayson, J., Skelton, D. A., & Miller, G. (2015). Promoting exercise as part of a physiotherapy-led falls pathway service for adults with intellectual disabilities: a service evaluation. *Journal of Applied Research in Intellectual Disabilities*, *28*(3), 257-264. doi:10.1111/jar.12119
- Department of Health, Western Australia. (2014). *Falls prevention model of care*. Perth: Health Strategy and Networks. Department of Health, Western Australia. Retrieved from: https://ww2.health.wa.gov.au/Articles/F_I/Falls-Prevention-Health-Network
- Eisenbarth, W. (2018). Vision assessment in persons with intellectual disabilities. *Clinical and Experimental Optometry*, *101*(2), 267-271. doi:10.1111/cxo.12600
- Enkelaar, L., Smulders, E., van Schroyen Lantman-de Valk, H., Weerdesteijn, V., & Geurts, A. C. (2013). Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities. *Research in Developmental Disabilities*, *34*(11), 3754-3765. doi: 10.1016/j.ridd.2013.07.041
- Finlayson, J. (2018). Fall prevention for people with learning disabilities: key points and recommendations for practitioners and researchers. *Tizard Learning Disability Review*, *23*(2), 91-99. doi:10.1108/TLDR-06-2017-0026
- Finlayson, J., Jackson, A., Mantry, D., Morrison, J., & Cooper, S. A. (2015). The provision of aids and adaptations, risk assessments, and incident reporting and recording procedures in relation to injury prevention for adults with intellectual disabilities: cohort study. *Journal of Intellectual Disability Research*, *59*(6), 519-529. doi:10.1111/jir.12154
- Finlayson, J., Morrison, J., Jackson, A., Mantry, D., & Cooper, S. A. (2010). Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *Journal of Intellectual Disability Research*, *54*(11), 966-980. doi:10.1111/j.1365-2788.2010.01319.x

- Giorgi, A. (2006). Concerning variations in the application of the phenomenological method. *The Humanistic Psychologist*, 34(4), 305-319.
doi:10.1207/s15473333thp3404_2
- Guirguis-Blake, J. M., Michael, Y. L., Perdue, L. A., Coppola, E. L., & Beil, T. L. (2018). Interventions to prevent falls in older adults: Updated evidence report and systematic review for the US preventive services task force. *JAMA*, 319(16), 1705-1716. doi:10.1001/jama.2017.21962
- Hale, L. A., Mirfin-Veitch, B. F., & Treharne, G. J. (2016). Prevention of falls for adults with intellectual disability (PROFAID): a feasibility study. *Disability and Rehabilitation*, 38(1), 36-44. doi:10.3109/09638288.2015.1017613
- Hale, L., Vollenhoben, E., Caiman, L., Dryselius, A., & Buttery, Y. (2019). Feasibility and acceptability of Otago exercise programme and prevention of falls for adults with intellectual disability: a multiple case study design. *International Journal of Therapy and Rehabilitation*, 26(6), 1-15. doi: 10.12968/ijtr.2018.0054
- Ho, P., Bulsara, M., Downs, J., Patman, S., Bulsara, C., & Hill, A.-M. (2019a). Incidence and prevalence of falls in adults with intellectual disability living in the community: a systematic review. *JBIR Database Systematic Reviews Implementation Reports*, 17(3), 390-413. doi:10.11124/jbisrir-2017-003798
- Ho, P., Bulsara, M., Patman, S., Downs, J., Bulsara, C., Hill, A.-M. (2019b). Incidence and associated risk factors for falls in adults with intellectual disability. *Journal of Intellectual Disability Research*, 63(12), 1441-1452. doi:10.1111/jir.12686
- Ho, P., Downs, J., Bulsara, C., Patman, S., & Hill, A.-M. (2018). Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability. *British Journal of Learning Disabilities*, 46(2), 92-100. doi:10.1111/bld.12217
- Hopewell, S., Adedire, O., Copsey, B. J., Boniface, G. J., Sherrington, C., Clemson, L., ...Lamb, S. E. (2018). Multifactorial and multiple component interventions for preventing falls in older people living in the community. *The Cochrane Database of Systematic Reviews*, 7(Cd012221).
doi:10.1002/14651858.CD012221.pub2
- Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 117, 442-54. doi:10.1352/1944-7558-117.6.442

- Hu, Y.-N., Chung, Y.-J., Yu, H.-K., Chen, Y.-C., Tsai, C.-T., & Hu, G.-C. (2016). Effect of Tai Chi exercise on fall prevention in older adults: Systematic review and meta-analysis of randomized controlled trials. *International Journal of Gerontology*, 10(3), 131-136. doi:10.1016/j.ijge.2016.06.002
- Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability and Society*, 29(7), 1013-1030. doi:10.1080/09687599.2014.902357
- Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., & Becker, C. (2005). Development of a common outcome data set for fall injury prevention trials: The prevention of falls network Europe consensus. *Journal of the American Geriatrics Society*, 53(9), 1618-1622. doi:10.1111/j.1532-5415.2005.53455.x
- Lennox, N., McPherson, L., Bain, C., O'Callaghan, M., Carrington, S., & Ware, R. S. (2016). A health advocacy intervention for adolescents with intellectual disability: a cluster randomized controlled trial. *Developmental Medicine and Child Neurology*. 58(12), 1265-1272. doi:10.1111/dmcn.13174
- Liamputtong, P. (2013). *Research methods in health: foundations for evidence-based practice*. Melbourne, Victoria: Oxford University Press.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications, Inc.
- Mackenzie, L., & McIntyre, A. (2019). How do general practitioners engage in falls prevention with older people? A pilot survey of GPs in NHS England suggests a gap in routine practice to address falls prevention. *Frontiers in Public Health*, 7(32). doi:10.3389/fpubh.2019.00032
- Milat, A. J., Watson, W. L., Monger, C., Barr, M., Giffin, M., & Reid, M. (2011). Prevalence, circumstances and consequences of falls among community-dwelling older people: results of the 2009 NSW Falls prevention baseline survey. *NSW Public Health Bulletin*, 22(4), 43-48. doi:10.1071/NB10065
- Moncada, L. V. V., & Mire, L. G. (2017). Preventing falls in older persons. *American Family Physician*, 96(4), 240-247.
- National Institute for Health and Care Excellence. (2013). Falls in older people: assessing risk and prevention, *CG161*. Retrieved from <https://pathways.nice.org.uk/pathways/preventing-falls-in-older-people>
- Pal, J., Hale, L., & Mirfin-Veitch, B. (2013). Experiences of therapists trying to reduce falls risk for people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 10(4), 314-320. doi:10.1111/jppi.12058

- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. United States of America: SAGE publishing.
- Petrovic, B. B., Peric, T. O., Markovic, D. L. J., Bajkin, B. B., Petrovic, D., Blagojevic, D. B., & Vujkov, S. (2016). Unmet oral health needs among persons with intellectual disability. *Research in Developmental Disabilities, 59*, 370-377. doi:10.1016/j.ridd.2016.09.020
- Reppermund, S., & Trollor, J. N. (2016). Successful ageing for people with an intellectual disability. *Current Opinion in Psychiatry, 29*(2), 149-154. doi:10.1097/ycp.0000000000000228
- Robertson, J., Hatton, C., Emerson, E., & Baines, S. (2014). The impact of health checks for people with intellectual disabilities: An updated systematic review of evidence. *Research in Developmental Disabilities, 35*(10), 2450-24. doi: 10.1016/j.ridd.2014.06.007
- Salb, J., Woodward, C., Offenhäuser, J., Becker, C., Sieber, C., & Freiberger, E. (2015). Prevalence and characteristics of falls in adults with intellectual disability living in a residential facility: A Longitudinal Study [PreFallID]. *Intellectual and Developmental Disabilities, 53*(3), 228-239. doi:10.1352/1934-9556-53.3.228
- Sanders, C. (2003) Application of Colaizzi's method: interpretation of an auditable decision trail by a novice researcher. *Contemporary Nurse, 14*(3), 292-302.
- Sherrington, C., Fairhall, N. J., Wallbank, G. K., Tiedemann, A., Michaleff, Z. A., Howard, K., . . . Lamb, S. E. (2019). Exercise for preventing falls in older people living in the community. *The Cochrane Database of Systematic Reviews*, (1). doi:10.1002/14651858.CD012424.pub2
- Smulders, E., Enkelaar, L., Schoon, Y., Geurts, A. C., van Schrojenstein Lantman-de Valk, H., & Weerdesteyn, V. (2013). Falls prevention in persons with intellectual disabilities: Development, implementation, and process evaluation of a tailored multifactorial fall risk assessment and intervention strategy. *Research in Developmental Disabilities, 34*(9), 2788-2798. doi:10.1016/j.ridd.2013.05.041
- Sousa, L. M., Marques-Vieira, C. M., Caldevilla, M. N., Henriques, C. M., Severino, S. S. & Caldeira, S. M. (2017). Risk for falls among community-dwelling older people: systematic literature review. *Revista gaúcha de enfermagem, 37*(4), e55030. doi:10.1590/1983-1447.2016.04.55030
- Spink, M. J., Menz, H. B., Fotoohabadi, M. R., Wee, E., Landorf, K. B., Hill, K. D. & Lord, S. R. (2011). Effectiveness of a multifaceted podiatry intervention to prevent falls in community dwelling older people with disabling foot pain: randomised controlled trial. *BMJ, 342*, d3411. doi:10.1136/bmj.d3411

- Srikanth, R., Cassidy, G., Joiner, C. & Teeluckdharry, S. (2011). Osteoporosis in people with intellectual disabilities: a review and a brief study of risk factors for osteoporosis in a community sample of people with intellectual disabilities. *Journal of Intellectual Disability Research*, 55, 53-62. doi:10.1111/j.1365-2788.2010.01346.x
- Taliaferro, A., Block, M., & Moran, T. (2013). Physical activity and youth with disabilities: barriers and supports. *The Prevention Researcher*, 20, 18-21.
- Tricco, A. C., Thomas, S. M., Veroniki, A. A., Hamid, J. S., Cogo, E., Striffler, L.,...Straus, S. E. (2017). Comparisons of interventions for preventing falls in older adults: A systematic review and meta-analysis. *JAMA*, 318(17), 1687-1699. doi:10.1001/jama.2017.15006
- Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work*, 11(1), 80-96 17p. doi:10.1177/1473325010368316
- Uzdrowska, M. & Woodhouse, J. M. (2016). Visual defects in special Olympics participants from Europe. *Clinical Journal of Sports Medicine*, 26(2), 133-138. doi:10.1097/jsm.0000000000000204
- Van Hanegem, E., Enkelaar, L., Smulders, E. & Weerdesteyn, V. (2014). Obstacle course training can improve mobility and prevent falls in people with intellectual disabilities. *Journal of Intellectual Disability Research*, 58(5), 485-492. doi:10.1111/jir.12045
- Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2018). Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, 11(1), 69-102. doi:10.1080/19315864.2017.1408724
- Willgoss, T. G., Yohannes, A. M. & Mitchell D. (2010). Review of risk factors and preventative strategies for fall-related injuries in people with intellectual disabilities. *Journal of Clinical Nursing*, 19(15-16), 2100-2109. doi:10.1111/j.1365-2702.2009.03174.x

Synthesis of Research Findings, Conclusions and Recommendations

Preface

This chapter summarises and synthesises the findings in this thesis, followed by a presentation of the overall strengths and challenges of the research. Implications for clinical practice and suggestions for future research are presented. Recommendations for health policy to address falls prevention in community dwelling older adults with ID are also discussed.

7.1 Background to the research

Adults with ID often experience age related changes as early as their third decade in life (Connolly, 2006; Hermans & Evenhuis, 2014; Strydom et al., 2010). Compared to the general population, they often live with multiple comorbidities (McCarron et al., 2013) and have a shorter life expectancy (Coppus, 2013). Children who have been diagnosed with ID often have reduced gross motor proficiency (Alesi, Battaglia, Pepi, Bianco, & Palma, 2018) and issues with mobility persist into adulthood. For example, adolescents, with mild to moderate levels of intellectual impairment demonstrate reduced postural balance and muscle performance compared to their typically developing peers (Blomqvist, Wester, Sundelin, & Rehn, 2012). This may explain the deviations in gait patterns and reduced recovery response from a slip reported in adults with ID (Haynes & Lockhart, 2012).

It has been suggested that adults with ID experience a higher number of falls (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010; Hsieh, Rimmer, & Heller, 2012, Smulders, Enkelaar, Weerdesteyn, Geurts, & Schrojenstein Lantman-de Valk, 2013a) and fall at a younger age than the general population (Milat, 2011, Rubenstein, 2006). These falls may be a result of early onset of age-related changes observed in this population (Carmeli, Imam, Bachar, & Merrick, 2012, Coppus, 2013). The falls risk factors identified in various groups of adults with ID have been found to differ from community dwelling people aged 65 years and over (Sousa et al., 2017) and include higher levels of mobility, Epilepsy and challenging behaviour (Cox et al., 2010; Enkelaar, Smulders, van Schrojenstein Lantman-de Valk, Weerdesteyn, & Geurts, 2013; Ho et al., 2019). However the extent of the problem of falls in older adults with ID is still uncertain, as there are limited studies investigating falls and risk factors for falling in people with ID and each study has differing inclusion criteria, designs and included different subgroups of the population with ID (Cox et al., 2010; Enkelaar et al., 2013; Hsieh et al., 2012).

Falls are recognised as a health problem in the general population when people are aged 65 years and over (World Health Organisation, 2018). Guidelines for falls prevention for community dwelling older adults have been developed from evidence-based research, based on large RCTs and systematic reviews (Hopewell et al., 2018; Sherrington et al., 2019; Tricco et al., 2017). Existing falls prevention guidelines have

not been tailored for community dwelling older adults with ID and barriers have been described when implementing falls prevention services for people with ID (Hale, Mirfin-Veitch, & Treharne, 2016; Pal, Hale, & Mirfin-Veitch, 2013; Smulders et al., 2013b). Perspectives of older adults with ID and their caregivers about seeking health services after a fall were not known, particularly what barriers or enablers they found when seeking health services after a fall.

People with ID are underrepresented in research (Feldman et al., 2014) due to various challenges, including complex and extensive ethical requirements required for research participation (Iacono & Carling-Jenkins, 2012). When examined in the context of recommended guidelines for conducting falls research (Lamb, Jørstad-Stein, Hauer, & Becker, 2005), these guidelines can be challenging to implement when conducting falls in older adults with ID. The responsibilities of supporting an older adult with ID to record falls on a daily basis and facilitating communication with the researcher during follow-ups will rest with multiple caregivers, including family members and disability support workers from various organisations. Each organisation may have differing ethical requirements and processes for their employees and clients to participate in research. Information provision and informed consent will also be required from each caregiver.

7.2 Aims and methods of the research

The purpose of the research was to investigate the nature of falls, risk factors for falls and experiences when engaging with health services after a fall among older adults with ID living in the community in WA. The specific research aims were:

1. To synthesise the current evidence on the prevalence and incidence of falls in adults with ID.
2. To develop and describe an informed consent process for use when recruiting older adults with ID.
3. To investigate the falls rate, injurious falls rate and associated risk factors for falls in older adults with ID living in the community.
4. To explore the experiences of older adults with ID and their support persons when seeking healthcare services after a fall and the barriers they face when taking up evidence-based falls prevention recommendations that were provided to them.

A convergent mixed methods design was used to collect data from a variety of sources to give strength to the research findings (Creswell, 2014). This was achieved with four studies. Study 1 was a systematic review and meta-analysis which synthesised current evidence on the prevalence and incidence of falls in adults with ID, to inform the extent of the problem. To understand falls incidence and experiences post-fall, direct engagement and falls recording is recommended (Lamb et al., 2005). Therefore, Study 2 developed and evaluated an informed consent process used during the recruitment of older adults with ID to address in part the barriers in including them in research. Study 3 was a prospective observational cohort study that evaluated the incidence, prevalence and risk factors for falls in older adults with ID. In Study 4 participants who had fallen in Study 3 were purposefully sampled and invited, with their caregivers, to participate in semi-structured interviews to understand their post-fall experiences.

The results from the studies were analysed separately to answer the research aims. A rich understanding about falls in older adults with ID living in the community was gained through synthesising findings from data from Study 1 and Study 3 whilst incorporating the perspectives of older adults with ID and their caregivers through the findings from Study 4 (Creswell, 2014).

7.3 Summary of studies

7.3.1 Study 1, Systematic review of the research problem

Aim 1: To synthesise the current evidence on the prevalence and incidence of falls in older adults with ID.

A systematic review, including a meta-analysis, was conducted (Chapter 2) according to a published protocol (Ho et al., 2018a). The pooled proportion of people with ID who fell was 39% (95% CI 0.35-0.43). There were limited studies that investigated the incidence of falls in adults with ID and there were high levels of heterogeneity between study designs. When using the JBI GRADE approach to determine levels of evidence and grades of recommendations (Schünemann, Broz'ek, Guyatt, & Oxman, 2013), the certainty of evidence was graded as very low for the falls outcomes; proportion of people who fell, rate of falls and rate of injurious falls.

These results demonstrated that more robust research using prospective samples and following guidelines for conducting falls research was warranted. Reporting of

falls data such as the number of people who experienced a fall, number of falls recorded, period of observation (days of observation) and number of injurious falls reported were inconsistent between the studies analysed in the systematic review. Prospective daily recordings of falls for 12 months with monthly follow-ups (Lamb et al., 2005), as recommended for falls research, was not implemented in all the study designs and this may have been due to researchers' evaluations that the majority of the participants would not be able to fulfil the responsibilities of the research (Feldman, Battin, Shaw, & Luckasson, 2013) and that data collection requires substantial support from caregivers, which may increase the existing burden of care. However using retrospective data collection or incident reporting has been found to lead to inaccuracies when recording falls events (Hill et al., 2010; Lamb et al., 2005).

7.3.2 Study 2, Developing and implementing an informed consent process

Aim 2: To develop and describe an informed consent process for use when recruiting older adults with ID.

Multiple challenges have been described by researchers attempting to include people with ID in research due to concerns raised by organisational gate keepers (McDonald & Kidney, 2012), the limitations in the participants' ability to understand their involvement (Horner-Johnson & Bailey, 2013) and the need for proxy consent (Iacono & Carling-Jenkins, 2012). This research aimed to improve outcomes for older adults with ID, therefore it was important that older adults with ID were included in the research and were provided with an opportunity to be recognised for their valuable contributions.

A systematic approach to gain informed consent was developed and evaluated to address potential barriers to participation in research (Chapter 4). Adapted information sheets, using recommendations to engage people with ID in a respectful manner (Kidney & McDonald, 2014) were prepared.

After recruiting the first 40 participants this procedure was reviewed. Results demonstrated that the procedure facilitated a holistic perspective that assisted to determine if the older adults with ID could independently provide consent, required support via a proxy consent or a combination of the both (Ho, Downs, Bulsara, Patman,

& Hill, 2018). For older adults with ID who were more severely or profoundly affected and required full support to engage with the researcher, these recommendations were not useful. The consent process was effective to gain an understanding of the older adult with ID's ability to provide informed consent and for the caregiver to provide their opinion also.

7.3.3 Study 3, Incidence of falls, injurious falls and associated fall risk factors

Aim 3: To investigate the falls rate, injurious falls rate and associated risk factors for falls in older adults with ID living in the community.

The primary aim of Study 3 (Chapter 5) was to investigate the incidence of falls in older adults with ID living in community settings. The secondary aims were to investigate the proportion of people who fell, incidence of injurious falls and associated risk factors for falls in this population.

Study 3 was a prospective observational cohort (n=78) study that was carried out for six months. There were 296 falls reported by 36 (46.2%) participants during the six months) observation period. The falls rate was 8.2 falls per person year. Five participants experienced a high number of falls (≥ 25) including one who had 94 falls. The participant with 94 falls was considered an outlier and when removed from the analysis, the falls rate was 5.7 falls per person year. This falls rate was much higher than falls rates reported in other studies that investigated falls in community dwelling cohorts with ID (Cox et al., 2010; Enkelaar et al., 2013; Hsieh et al., 2012; Pal, Hale, Mirfin-Veitch, & Claydon, 2014; Smulders et al., 2013a). The high falls rates recorded could be explained by the close follow up and prospective daily recordings of falls. Efforts were also made to ensure that all close stakeholders were aware that as part of the participant's enrolment in the study all falls were being recorded. Previous studies collected data retrospectively and via incident reporting which could have resulted in falls not being reported (Cox et al., 2010; Hsieh et al., 2012; Wagemans & Cluitmans, 2006). This study also had a very broad inclusion criteria, unlike other studies (Enkelaar et al., 2013; Smulders et al., 2013a) and included adults with all levels of ID, mobility or comorbidity status.

There were 61 (20.6%) injurious falls reported by 20 (25.6%) participants, including one fracture which required hospitalisation. The injurious falls rate was 1.6 per person year. The proportion of injurious falls at 20.6% is lower than some studies where the proportion of injurious fall were found to be more than 30% (Salb et al., 2015; Wagemans & Cluitmans, 2006). The rate of injurious falls in this study was higher than the majority of other studies which were estimated to be less than 0.7 per person year (Salb et al., 2015; Wagemans & Cluitmans, 2006). One study that was also conducted for six months in community dwelling older adults with ID estimated that the injurious falls rate was 1.4 per person year (Enkelaar et al., 2013). Injuries reported in this study resulted in one fracture, which is lower than other studies that reported three fractures between 6-12 months (Enkelaar et al., 2013; Smulders et al., 2013a). However these studies, only included people with mild to moderate levels of ID and who could walk at least 10 metres without assistance, which may indicate those populations being more physically capable and active. The fracture rate in our sample was 0.03 per person year. Other studies that had a larger sample ($n > 78$) and had longer observation periods (12 to 53 months) reported three (Grant et al., 2001) to 26 fractures (Wagemans & Cluitmans, 2006). Minor injuries are a challenge to report, as bruises and abrasions may not be immediately apparent and unobserved falls may have resulted in unexplained injuries being found on participants.

Participants with a history of falls were six times more likely to sustain a fall during the study [adjusted OR 6.4, 95% CI (1.9-21.3)]. Participants were more likely to sustain a fall if they were more mobile [adjusted OR 4.5, 95% CI (1.2-17.7)] but were less likely to fall if they had more strength in their lower limbs as indicted by motor skills testing [adjusted OR 0.3, 95% CI (0.1-0.9)]. Participants had less falls if they were taking four or more medications [adjusted OR 0.2, 95% CI (0.1-0.8)] and were continent [adjusted OR 0.3, 95% CI (0.1-0.9)]. Participants who had Epilepsy or challenging behaviour were more likely a fall or have a higher rate of falls but these factors were not significant ($p > 0.05$). The sample size determined for this study was only 78 participants which may not be an adequate sample for risk factor calculation.

Overall the proportion of older adults with ID who sustained one or more falls in this research was 46% which is higher than the general older population and similar to older adults with a high risk of falls (Milat et al., 2011; Rubenstein, 2006). The falls rates of 5.7 per person year is also considerably higher than reported falls rates in the

broad community of 1.6 per person year (Rubenstein, 2006), suggesting that the magnitude of the problem of falls in community dwelling older adults with ID is a considerably large health care issue.

7.3.4 Study 4: Post-fall experience in seeking health services and barriers to undertaking evidenced-based falls prevention strategies provided

Aim 4: To explore the experiences of older adults with ID and their support persons when seeking healthcare services after a fall and the barriers they faced when taking up evidence-based falls prevention recommendations.

People with ID have been shown to have multiple health issues and at the same time services that provide health care to people with ID may not be adequate to meet their needs. There are no known reports of older adults with ID or their caregivers receiving services for falls prevention. Therefore Study 4 (Chapter 6) explored the participant's experience when seeking health services after having a fall using a phenomenological approach. Participants who experienced a fall in Study 3 were purposefully selected and invited to participate in Study 4. Semi-structured interviews were conducted using an interview schedule that was based on national guidelines for fall prevention and care (National Institute of Health and Care Excellence, 2013, Moncada & Mire, 2017).

Low levels of awareness of falls as a problem that could be addressed was a critical barrier to falls prevention management. A large number of falls were not reported to a health professional by the participant with ID or their caregiver which created an immediate challenge to implementing falls prevention strategies. When falls were reported to a health professional, this did not initiate participants being directed towards a falls prevention health service pathway. No participants were triaged into a fall prevention service, such as a fall clinic for older adults. Hospitalisation after a fall, provided an avenue for services that addressed some identified falls risk factors, however these services were mainly provided for the participant to be safely discharged into the community rather than to address their fall risk.

Some known falls and fall injury risk factors such as eye health were incidentally addressed for some participants when they attended for general health checks at the local

doctor. However specific and systematic screening for falls risk such as asking for falls history or testing of balance were not performed. Caregiver support has been highly valued when supporting people with ID especially around advocacy for health education and services (Bergstrom, Elinder, & Wihlman, 2014; M. A. Feldman et al., 2012). Caregiver advocacy plays a critical role in accessing health services, however caregivers reported that they were uncertain as to what services they should be advocating for.

Some individualised strategies were perceived as successfully reducing falls risk, especially regarding physical activity, which echoes other research that implemented falls prevention services for adults with ID (Hale et al., 2016; Pal et al., 2013). However, engagement in specific activities such as Tai Chi, functional based activities or strength and balance exercises that are known to be effective in reducing falls (Sherrington et al., 2019) were not reported by the participants in this study.

7.3.5 Understanding the falls experience, synthesis of studies 1, 3 and 4

To our knowledge, this research was the first in Australia to identify the incidence of falls by prospectively collecting falls data from community dwelling older adults with ID on a daily basis. It is also the first study to interview older adults with ID and their caregivers to explore their post fall experiences and systematically compare them to guideline falls prevention pathways for older community dwelling people.

Synthesising findings, it was found that the problem of falls in older adults with ID was more serious than previously described. Compared to the meta-analysis in Study 1, the proportion of people who fell was higher at 46%. The falls rate found in Study 3 was also higher at 5.7 per person year compared to other studies at 1.0 falls per person year (Enkelaar et al., 2013; Smulders et al., 2013a) where falls data were also collected with prospective daily recordings. Despite this, older adults with ID in our sample were not receiving falls prevention services. Many falls were not reported to health professionals, partly because of a lack of awareness among older adults with ID and their caregivers that falls are a serious problem and that falls can be prevented. Even when falls were reported to a health professional, older adults with ID were not receiving guideline-recommended falls prevention services. Some services were provided when a fall resulted in hospitalisation and when caregivers advocated for falls prevention services on their behalf. However, these were limited to strategies directed

towards safe discharge into the community and not individualised for participants such that their falls risk factors were addressed.

Research into falls in older adults with ID has also not received adequate attention. Studies reviewed in this thesis showed large heterogeneity in study designs which made analysing their results challenging. Internationally, the extent of falls in older adults is still unclear. Variables and characteristics that identify the risk of falls for an adult with ID requires additional research. Some mobility and balance tests were studied for their feasibility in adults with ID, however comprehensive screening tools to alert a clinician to the falls risk for an ID and guide suitable approaches, such as a clinical pathway, has yet to be developed. Exercises and physical activity has been valued by some researchers as a strategy to reduce falls in older adults with ID and have some research into exercises for falls reduction have begun to emerge (Crockett et al., 2014; Pal et al., 2013; Hale et al., 2016). Strategies to facilitate physical activity such as adopting individualised strategies were also identified in this study showing existing efforts in falls reduction. However, there are other falls reduction strategies such as review of medication, vision check and home safety assessments have been shown to be useful in falls reduction (Hopewell et al., 2018) in older people which have not been investigated in older adults with ID.

The triangulation of the results demonstrated that the gaps in health services for falls prevention resulted in a negative cycle of repeated falls. Post-fall care in this study did not include older people living in the community and therefore did not identify health service inequalities. However, in the course of the research, there were many instances where inequalities in health care were identified in older adults with ID. The majority of our participants interviewed were not offered falls screening after a falls and many did not receive specific interventions for falls prevention which is contrary to recommendations provided to older people in the community. More investigation into the inequalities of falls prevention within the healthcare services to older adults with ID is required.

People with ID experience falls at a younger age and at a higher rate compared to the general population. This research has demonstrated that falls cause serious injuries that sometimes result in hospitalisation. The economic cost of falls in older adults with ID is unknown as reports on the economic burden of falls have not

provided a subgroup analysis regarding older adults with ID. However since 3% of people in Australia are diagnosed with ID and they experience falls at a younger age and at a higher rate, their health care costs is likely to be a substantial proportion of the annual cost of approximately \$600 million for falls related episodes of care in Australian hospitals (Public Health Association of Australia, 2012). While not investigated in the research it has also been suggested that a high proportion of older adults with ID develop a fear of falling after a fall (Foran, McCarron, & McCallion, 2013) which is associated with reduced participation and quality of life (Mendes da Costa et al., 2012; Yardley & Smith, 2002).

In summary, findings demonstrate there is an urgent need to create falls prevention services for older adults with ID, including building capability regarding falls prevention for older adults with ID, their caregivers and service providers, as discussed in Section 7.7.

7.4 Strengths of the Research

Three key elements contributed to the strength and robustness of this research. These included: i) exploring ethical mechanisms to support older adults with ID to contribute to the research, ii) using a mixed methods approach, and iii) incorporating recommendations for falls research into the study design. The population was chosen to provide a representative sample of older adults with ID living in the community, with inclusion criteria being from age 35 years and onwards to avoid only sampling from a frail older population.

Study 2 evaluated the procedures for providing information regarding the research and obtaining informed consent to ensure that these were effective in determining if the older adult with ID was able to consent independently or if a proxy consent was required. The researchers also worked with caregivers at every stage of the procedure to ensure that they were aware of the older adult with ID's participation. Caregivers provided support and reassurance for the participant and facilitated communication with the researcher. These procedures contributed to the robustness of the data collected. Recommendations for respectful engagement of older adults with ID (Kidney and McDonald, 2014) that were found to be effective were subsequently used throughout the research to facilitate participants' understanding of their involvement in the research and to gain consent at each stage. These methods supported participants'

rights to consent or withdraw at any stage of the research and concurrently supported their ability to make valuable contributions to falls prevention research for this population. The step by step process developed is easy to follow making it transferable and repeatable when recruiting older adults with ID in other falls-related research. The publication that resulted from Study 2 (Ho, Downs, Bulsara, Patman, & Hill., 2018b) generated immediate impact and visibility to the field. It was one of the most downloaded articles in the year following publication (personal communication via email from Wiley online library, 6 June 2019). It was in the top 25% of all research outputs scored by Altmetric and among the highest-scoring outputs from this source. It also had a good attention score compared to outputs of the same age and source (71st percentile).

A mixed methods approach (Creswell, 2014) collected both qualitative and quantitative data, with the aim of presenting multiple perspectives to understand the falls experience in older adults with ID. The triangulation of quantitative results from Study 3 and qualitative results from Study 4 (presented in this final chapter) strengthened the reliability and internal validity of the research (Creswell, 2014).

A mixed methods approach has also been used in another study investigating falls prevention in adults with ID (Hale et al., 2016) since falls among adults with ID are multifactorial in nature and the provision of care for adults with ID can be complex and involve multiple stakeholders. Repeated use of this methodology demonstrates the credibility of this research in investigating falls in older adults with ID (Polit & Beck, 2013).

Trustworthiness of the research was further strengthened by the dependability and authenticity of data collection (Polit & Beck, 2013). The interview schedule was developed from existing guidelines for falls prevention care (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017) and the researcher systematically enquired about each step of the recommended clinical pathway for falls prevention. Caregivers, who had a shared experience with the older adult with ID in seeking services after a fall, were also invited to participate in the interviews which augmented the narratives from the participants. Including caregivers also contributed to providing a holistic and comprehensible story of the falls experience.

The researcher has experience working with adults with ID, enabling strong and practical interactions with participants in their personal environment. Her experiences also allowed her to be mindful that people with ID have numerous paid and unpaid caregivers from different living and working environments and all needed to be aware that the older adult with ID was participating in the research. This contributed to the robust daily falls data collection including regular follows ups as is recommended in guidelines for conducting falls research (Lamb et al., 2005).

Regular follow ups and ongoing communication ensured that participants' engagement and their role in the research and the research aims were understood by all stakeholders involved. The researcher was also mindful that caregivers were required to support data collection throughout the research, which added to their existing caregiver responsibilities. Hence, the researcher was alert to provide support at all stages of data collection; problem solving and offering convenient and time saving strategies. This support facilitated accurate and complete data collection. Prospective daily falls records were thus successfully obtained in this research reducing the risk of missing data from not recalling falls.

Meeting at regular stages in the research was an opportunity to build rapport with participants and their support network. Building a relationship and gaining trust was deemed extremely important by the research team to provide a safe space for all involved to feel comfortable to share their knowledge and experience with the researcher during the interviews (Hollomotz, 2017; Tassé, Schalock, Thompson, & Wehmeyer, 2005).

Involving caregivers and ensuring they understand the research is an approach that has been used previously when investigating falls in people with ID to increase the success of collecting robust data (Pal et al., 2014). There were no dropouts during this research and no participants requested to withdraw because they were unable to fulfil the demands of the research.

7.5 Limitations and Challenges of the Research

The research was advertised through disability service providers and people with ID living in Western Australia who were not receiving services from a provider may not have known about the research. However, approximately 8000 people with ID in

WA receive support from a disability service provider, as people with ID comprise the highest proportion of service users in WA (Disability Services Commission, 2013). Community dwelling older adults with ID in WA tend to live independently with paid support, with family or in group homes which this sample also reflects.

Unwitnessed falls are problematic in this population as communication and recall to report such falls is limited. Reports of minor, unexplained injuries such as bruises or skin abrasion were not uncommon at follow ups. Using technology such as falls detectors or security cameras to monitor falls was considered to be unethical and impractical for the purposes of this research. However, all participants either had daily paid support or were living with a family member, hence falls were mostly recalled by caregivers. Observation of falls events is recommended to be 12 months but this study only collected falls data for six months. Since caregivers undertook almost sole responsibility for data collection, it was deemed to add to the burden of care, thus falls data were only collected for six months.

More perspectives could have strengthened the research findings. While five participants were directly interviewed to gain first-hand accounts of their falls experience, other interviews obtained were from caregivers. Healthcare professionals and disability services providers could have provided additional perspectives regarding falls and subsequent post fall services and this would be an important topic for future research.

The research team did not have the resources to confirm the level of severity of ID (mild, moderate, severe, profound) for each participant. Therefore, communication ability was used as a surrogate measure of intelligence, which may not have been an accurate representation when used to examine associations with falls, injurious falls and risk factors for falling.

7.6 Recommendations of the Research

7.6.1 Implications for research

Research participation

People with ID are underrepresented in research and there is increasing evidence that strict inclusion criteria are excluding more severely affected individuals (Russell

et al., 2019). Since the human rights act of 1948, Australia has made substantial improvements to ensure that people with disability have equal rights and opportunity. However, it has been reported that further development to enact these rights is still required to benefit people with ID (Ozdowski, 2017). The disability reform scheme, the National Disability Insurance Scheme (NDIS), launched recently in 2013 aims to improve the quality of life for people with ID by increasing their opportunities for employment, social inclusion and community participation. Research is fundamental to providing the evidence to determine what interventions are necessary to improve outcomes for people with ID. These individuals should be given equal opportunity to contribute to this body of knowledge as they may directly benefit. In Study 3, it was found that older adults who were more likely to experience a fall were more active. More research regarding how to include people with ID in research that evaluates how to increase their physical activity in the community is required.

Older adults with ID were a valuable source of data for this research. Although at times, it was time consuming and challenging to involve older adults with ID, researchers are encouraged to use effective procedures (Boxall & Ralph, 2009; Ho et al., 2018b; Kidney & McDonald, 2014; Lennox et al., 2005) to engage people with ID in research it directly contributes to their well-being. The methods used in this study to engage older adults with ID (Study 2 and 3) such as building rapport, gaining familiarity with preferred means of communication and careful attention to follow ups provided the participants with ID the opportunity to be engaged in the research and allowed the researcher to provide the support the participants required. There were no dropouts during the research due to close follow ups and multiple opportunities to clarify research aims and procedures with participants and their caregivers.

The researcher also observed that some older adults with ID were not given the opportunity to participate in the research because caregivers and legal guardians decided that they would not participate, without consultation with the older adult with ID. Every individual with ID has the right to participate in research and practical strategies have been identified to support the individual with ID in their decision-making process (Bigby, Whiteside, & Douglas, 2017). It would be beneficial for researchers to engage with the community of providers and advocacy groups to increase awareness and discussion of how adults with ID, of all abilities, can contribute to research within safe and ethical research boundaries.

Falls research

Study 1 found that research about falls in community dwelling older adults with ID is limited and heterogeneity between the studies were high. More research to determine the prevalence and incidence of falls is still required. Researchers are encouraged to incorporate the recommendations for conducting falls research (Lamb et al., 2005) into their research designs. Having a distinct age group and clearly defined setting of care will also help to identify features in models of care that suggest benefits to falls prevention. Reporting of common set of fall indicator outcomes will also allow data to be pooled into systematic reviews and meta-analysis to inform the extent of falls as an issue in older adults with ID on a global scale. More research to identify a common set of functional outcome measures that are reliable for measurements in older adults with ID that are valid for predicting falls risk is also recommended. Having common set of recommended outcomes can also help with pooling data together in systematic reviews. An expert consensus on conducting falls research in adults with ID can then be developed to guide falls related research in older adults with ID (Finlayson, 2018).

Estimates of the economic cost of falls in the general older population have been undertaken (Australian Institute of Health and Welfare, 2012; Public Health Association of Australia, 2012). However these costs have not been specifically estimated for older adults with ID, even though it has been reported that older adults with ID are likely to stay in hospital three times longer than the general population and are more likely to be readmitted after an episode of care (Axmon, Ahlström, & Sandberg, 2019). Future research could identify and report data specific to people with ID when analysing and reporting statistics relating to falls.

Education

Caregiver reporting of falls (Study 4) was found to be inadequate, and even when falls were reported health professionals did not support the participants to commence guideline recommendations for falls risk reduction (Moncada & Mire, 2017). Caregivers were not given educational opportunities to learn about falls prevention for older adults with ID, however they are in the best position to advocate for services for the people they care for. Health outcomes for people with ID improve with health education, promotion and using a person-centred approach (Roll, 2018). These

strategies can be adapted and trialled with older adults with ID and their caregivers to evaluate their effectiveness for improving engagement in relevant fall prevention activities and reducing falls.

Risk factors and strategies

This research did not examine strategies to reduce falls or falls risk factors in older adults with ID. To date no studies have evaluated interventions for adults with ID, such as exercise-based interventions, in large randomised controlled trials. These gaps in research make development of evidence-based guidelines for falls prevention in older adults with ID challenging. More studies will add to the body of evidence to develop best practice guidelines for falls prevention in older adults with ID.

7.6.2 Implications for Practice

According to the United Nations Convention on the rights of persons with Disability, people with ID have the right to quality health services that support them to prevent further disability (United Nations Convention on the Rights of Persons with Disabilities, Article 25), the right to education with educational material adapted to their needs (United Nations Convention on the Rights of Persons with Disabilities, Article 24) and have the right to have health services that are accessible to their needs (United Nations Convention on the Rights of Persons with Disabilities, Article 9).

This research demonstrated that older adults with ID and their caregivers were not provided with opportunities to develop awareness and knowledge that falls are a preventable problem, which resulted in multiple falls not being reported. Disability health providers are well positioned to organise regular workshops and information sessions for older adults with ID and their caregivers regarding falls prevention. Health professionals could also provide adapted educational information sheets on falls prevention for older adults with ID.

Health professionals who work with older adults with ID should be encouraged to screen each individual for falls risk and, in partnership with their caregivers, investigate the most appropriate falls prevention care. Screening tools available for people aged 65 years and over such as the Falls Risk for Older People in the Community (FROP-COM) assessment tool (Russell et al., 2009) and the Home Falls and Accident (HOME-FAST) Screening Tools (Mackenzie, Byles, & Higginbotham,

2000) could be used for caregivers and health professionals to screen for falls risk and develop tailored action plans. These screening tools, while not specifically tailored for adults with ID can be used as a guide to identify risk factors. Areas of the screening forms can be trialled for adaptation with a detailed subjective examination, bearing in mind the different risk factors that have been found to be associated in older person with ID (Cox et al., 2010; Enkelaar et al., 2013; Ho et al., 2019; Hsieh et al., 2012).

While some exercises were provided to participants by health care professionals the caregivers shared that instruction was not provided and felt they were not adequately supported to implement the exercise program with the older adult with ID. Health professionals should provide adequate support to upskill caregivers to carry out tailored exercise programs for the older adult with ID they care for. In a more cost-effective manner, group exercise programs, incorporating educational sessions, could be encouraged and tailored for older adults with ID and their caregivers where they are both given the opportunity to participate and learn about falls prevention collaboratively. Creating exercise videos in collaboration with the older adult with ID may also be beneficial to allow for their communication needs and aid with engagement in the exercise program. These strategies have not been specifically investigated for falls prevention exercises but have resulted in positive outcomes when applied to improving physical activity in older adults with ID (Hall & Thomas, 2008).

7.6.3 Implication for policy

The key objectives of the “The New South Wales service framework to improve the health care of people with ID, 2012” (New South Wales Ministry of Health, 2012) are to ensure that the people with ID and their caregivers are provided with quality health care and that services have the capacity to be sensitive to the needs of people with ID. It recommends a tiered approach from policy development to primary, specialist and multidisciplinary person-centred care, to a state-wide specialist centre for health care for people with ID where specialist training and research is carried out. Falls prevention in adults with ID was not specifically mentioned but this tiered approach may be used to develop and deliver falls prevention services to adults with ID.

Health policies and actions proposed to improve the health in people with ID in Australia have focus heavily on primary health care equality and mental health of people with ID (Intellectual Disability Network 2017; Council for Intellectual

disability, 2019). There are no policies that specifically focus on falls and safety for people with ID. Exercises have been shown to be valuable in reducing falls in older people (Guirguis-Blake, Michael, Perdue, Coppola, & Beil, 2018; Tricco et al., 2017) and its an established effective intervention for reducing falls risk community dwelling older people (Hopewell et al., 2018; Hu et al., 2016; Sherrington et al., 2019). Though its challenging to engage older adults with ID in specific falls prevention exercises (Pal et al, 2015), physical activity is also acknowledged as useful to reduce risk of falls (Crockett, Finlayson, Skelton, & Miller 2015; Hale, Mifrin-Vietch & Trehane; 2015). Physical activity is associated with multiple benefits including better bone health, functional independence, fitness and body mass (WHO, 2020; Bartle and Klein 2011). This study has shown that community engagement has been supportive for physical activity in adults with ID. In the short term, before health policies are developed with a focus on falls prevention, emphasis on engaging people with ID in physical activity in daily settings through existing policies such as within accommodation or community participation policies are recommended.

Falls policies developed for Australian health care (Clemson, Finch, Hill, & Lewin, 2010) have also not tailored or adapted their recommendations to adults with ID. In keeping with the general population, adults with ID have equal rights to receive health services, however simultaneously they are unique in that they are largely dependent on the advocacy of others to receive services. At a national health care level, it is strongly recommended that falls prevention in adults with ID be highlighted as a primary health area of care. Organisations should also be encouraged to provide education, disability and healthcare services regarding falls prevention to adults with ID and have a falls prevention policy which incorporates relevant training, education, screening and risk management action plans.

7.7 Conclusion

This thesis has contributed to the body of knowledge regarding the incidence and prevalence of falls and injurious falls in older adults with ID living in the community. It has also revealed that older adults with ID living in the community in WA are receiving limited post-fall services. Adults with ID are not only experiencing a higher rate of falls, they are also experiencing falls at a younger age compared to the general community dwelling aged matched population. Yet concurrently, they are not

receiving much needed falls prevention services. Reporting falls to a health professional did not initiate commencement of a comprehensive falls prevention service pathway. Screening for falls risk occurred incidentally through general medical screening and services provided were, at best, short term and fragmentary.

Developing and implementing falls prevention services with people with ID requires a tailored approach and strong involvement of their caregivers is also crucial. Initially existing falls policies and guidelines are recommended to be adapted to include people with ID to inform evidence-based care. Concurrently, more high-quality research is recommended in areas including falls education, service delivery, identifying fall risk factors and developing effective falls prevention strategies.

7.8 References

- Alesi, M., Battaglia, G., Pepi, A., Bianco, A., & Palma, A. (2018). Gross motor proficiency and intellectual functioning: A comparison among children with Down syndrome, children with borderline intellectual functioning, and typically developing children. *Medicine*, *97*(41), e12737. doi:10.1097/md.00000000000012737
- Australian Commission on Safety and Quality in Healthcare. (2009). *Implementation guide for preventing falls and harm from falls in older people: Best Practice Guidelines for Australian Community Care*. Retrieved from <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/preventing-falls-and-harm-falls-older-people-best-practice-guidelines-australian-community-care>
- Australian Institute of Health and Welfare. (2012) Hospitalisations due to falls in older people, Australia 2007-08. Cat. no: INJCAT 137. Available from <https://www.aihw.gov.au/reports/injcat/137/hospitalisations-falls-in-older-people-2007-08/report-editions>
- Axmon, A., Ahlström, G., & Sandberg, M. (2019). Falls resulting in health care among older people with intellectual disability in comparison with the general population. *Journal of Intellectual Disability Research*, *63*(3), 193-204. doi:10.1111/jir.12564
- Bergstrom, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities--a qualitative study. *Health Education Research*, *29*(2), 259-271. doi:10.1093/her/cyt111
- Bigby, C., Whiteside, M., & Douglas, J. (2017). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disability*, 1-14. doi:10.3109/13668250.2017.1378873
- Blomqvist, S., Wester, A., Sundelin, G., & Rehn, B. (2012). Test; retest reliability, smallest real difference and concurrent validity of six different balance tests on young people with mild to moderate intellectual disability. *Physiotherapy*, *98*(4), 318-324. doi:10.1016/j.physio.2011.05.006
- Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disability*, *34*(1), 45-54. doi:10.1080/13668250802688306

- Carmeli, E., Imam, B., Bachar, A., & Merrick, J. (2012). Inflammation and oxidative stress as biomarkers of premature aging in persons with intellectual disability. *Research in Developmental Disabilities, 33*(2), 369-375. doi: 10.1016/j.ridd.2011.10.002
- Clemson, L., Finch, C. F., Hill, K. D., & Lewin, G. (2010). Fall prevention in Australia: policies and activities. *Clinics in Geriatric Medicine, 26*(4), 733-749. doi:10.1016/j.cger.2010.07.002
- Commonwealth of Australia. (2011) *2010-2020 National Disability Strategy – An initiative of the Council of Australian Governments*. Attorney-General's, Robert Garran Offices, National Circuit, Canberra ACT
- Connolly, B. (2006). Issues in aging in individuals with life long disabilities. *Brazilian Journal of Physical Therapy, 10*, 249-262.
- Coppus, A. M. W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews, 18*(1), 6-16. doi:10.1002/ddrr.1123
- Cox, C. R., Clemson, L., Stancliffe, R. J., Durvasula, S., & Sherrington, C. (2010). Incidence of and risk factors for falls among adults with an intellectual disability. *Journal of Intellectual Disability Research, 54*(12), 1045-1057. doi:10.1111/j.1365-2788.2010.01333.x
- Creswell, J.W. (2014). *Research design: qualitative, quantitative, and mixed method approaches*. (4th ed.) Thousand Oaks, California: Sage Publications Inc..
- Disability Services Commission. (2013) *Disability in Western Australia*. Legislative Assembly, tabled paper number 1247. Parliament of Western Australia. Retrieved from: [https://www.parliament.wa.gov.au/publications/tabledpapers.nsf/displaypaper/3911247ae81bfa2834303a8948257c370029ee9f/\\$file/1247.pdf](https://www.parliament.wa.gov.au/publications/tabledpapers.nsf/displaypaper/3911247ae81bfa2834303a8948257c370029ee9f/$file/1247.pdf)
- Enkelaar, L., Smulders, E., van Schrojenstein Lantman-de Valk, H., Weerdesteyn, V., & Geurts, A. C. H. (2013). Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities. *Research in Developmental Disabilities, 34*(11), 3754-3765. doi: 10.1016/j.ridd.2013.07.041
- Feldman, M. A., Battin, S. M., Shaw, O. A., & Luckasson, R. (2013). Inclusion of children with disabilities in mainstream child development research. *Disability and Society, 28*(7), 997-1011. doi:10.1080/09687599.2012.748647
- Feldman, M. A., Bossett, J., Collet, C., & Burnham-Riosa, P. (2014). Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of Intellectual Disability Research, 58*(9), 800-809. doi:10.1111/jir.12091

- Feldman, M. A., Owen, F., Andrews, A., Hamelin, J., Barber, R., & Griffiths, D. (2012). Health self-advocacy training for persons with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(11), 1110-1121. doi:10.1111/j.1365-2788.2012.01626.x
- Finlayson, J. (2018). Fall prevention for people with learning disabilities: key points and recommendations for practitioners and researchers. *Tizard Learning Disability Review, 23*(2), 91-99. doi:10.1108/TLDR-06-2017-0026
- Foran, S., McCarron, M., & McCallion, P. (2013). Expanding assessment of fear of falling among older adults with an intellectual disability: A pilot study to assess the value of proxy responses. *ISRN Geriatrics*, Article ID 493042. doi:10.1155/2013/493042
- Grant, H. J., Pickett, W., Lam, M., O'Connor, M., & Ouellette-Kuntz, H. (2001). Falls among persons who have developmental disabilities in institutional and group home settings. *Journal on Developmental Disabilities, 8*, 57-73.
- Hale, L. A., Mirfin-Veitch, B. F., & Treharne, G. J. (2016). Prevention of falls for adults with intellectual disability (PROFAID): a feasibility study. *Disability and Rehabilitation, 38*(1), 36-44. doi:10.3109/09638288.2015.1017613
- Hall, J. M., & Thomas, M. J. (2008). Promoting physical activity and exercise in older adults with developmental disabilities. *Topics in geriatric Rehabilitation, 24*(1), 64-73. doi:10.1097/01.tgr.0000311407.09178.55
- Haynes, C. A., & Lockhart, T. E. (2012). Evaluation of gait and slip parameters for adults with intellectual disability. *Journal of Biomechanics, 45*(14), 2337-2341. doi:10.1016/j.jbiomech.2012.07.003
- Hermans, H., & Evenhuis, H. M. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities, 35*(4), 776-783. doi:10.1016/j.ridd.2014.01.022
- Hill, A.-M., Hoffmann, T., Hill, K., Oliver, D., Beer, C., McPhail, S., . . . Haines, T. P. (2010). Measuring falls events in acute hospitals-a comparison of three reporting methods to identify missing data in the hospital reporting system. *Journal of the American Geriatrics Society, 58*(7), 1347-1352. doi:10.1111/j.1532-5415.2010.02856.x
- Ho, P., Bulsara, C., Patman, S., Bulsara, M., Downs, J., & Hill, A.-M. (2018a). Investigating falls in adults with intellectual disability living in community settings and their experiences of post-fall care services: protocol for a prospective observational cohort study. *BMC Geriatrics, 18*(1), 171-171. doi:10.1186/s12877-018-0862-8

- Ho, P., Downs, J., Bulsara, C., Patman, S., & Hill, A.-M. (2018b). Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability. *British Journal of Learning Disabilities*, *46*(2), 92-100. doi:10.1111/bld.12217
- Ho, P., Bulsara, M., Patman, S., Downs, J., Bulsara, C., & Hill, A.-M. (2019). Incidence and associated risk factors for falls in adults with intellectual disability. *Journal of Intellectual Disability Research*. doi:10.1111/jir.12686
- Hollomotz, A. (2017). Successful interviews with people with intellectual disability. *Qualitative Research*, *18*(2), 153-170. doi:10.1177/1468794117713810
- Hopewell, S., Adedire, O., Copsey, B. J., Boniface, G. J., Sherrington, C., Clemson, L., . . . Lamb, S. E. (2018). Multifactorial and multiple component interventions for preventing falls in older people living in the community. *The Cochrane Database of Systematic Reviews*, *7*, Cd012221. doi:10.1002/14651858.CD012221.pub2
- Horner-Johnson, W., & Bailey, D. (2013). Assessing understanding and obtaining consent from adults with intellectual disabilities for a health promotion study. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(3), 260-265. doi:10.1111/jppi.12048
- Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, *117*(6), 442-454. doi:10.1352/1944-7558-117.6.442
- Iacono, T., & Carling-Jenkins, R. (2012). The human rights context for ethical requirements for involving people with intellectual disability in medical research. *Journal of Intellectual Disability Research*, *56*(11), 1122-1132. doi:10.1111/j.1365-2788.2012.01617.x
- Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, *29*(7), 1013-1030. doi:10.1080/09687599.2014.902357
- Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., & Becker, C. (2005). Development of a common outcome data set for fall injury prevention trials: The prevention of falls network Europe consensus. *Journal of the American Geriatrics Society*, *53*(9), 1618-1622. doi:10.1111/j.1532-5415.2005.53455.x
- Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D. M., & Boyle, F. (2005). Beating the barriers: recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research*, *49*(4), 296-305. doi:10.1111/j.1365-2788.2005.00618.x

- Mackenzie, L., Byles, J., & Higginbotham, N. (2000). Designing the home falls and accidents screening tool (HOME FAST): Selecting the items. *British Journal of Occupational Therapy*, 63(6), 260-269. doi:10.1177/030802260006300604
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion, P. (2013). Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Research in Developmental Disabilities*, 34(1), 521-527. doi:10.1016/j.ridd.2012.07.029
- McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 27-39. doi:10.1111/j.1741-1130.2011.00319.x
- Mendes da Costa, E., Pepersack, T., Godin, I., Bantuelle, M., Petit, B., & Leveque, A. (2012). Fear of falling and associated activity restriction in older people. Results of a cross-sectional study conducted in a Belgian town. *Archives of Public Health*, 70(1), 1. doi:10.1186/0778-7367-70-1
- Milat, A. J., Watson, W. L., Monger, C., Barr, M., Giffin, M., & Reid, M. (2011). Prevalence, circumstances and consequences of falls among community-dwelling older people: results of the 2009 NSW Falls prevention baseline survey. *NSW Public Health Bulletin*, 22(4), 43-48.
- Moncada, L. V. V., & Mire, L. G. (2017). Preventing falls in older persons. *American Family Physician*, 96(4), 240-247.
- National Institute for Health and Care Excellence. (2013). *Falls in older people: assessing risk and prevention, CG161*. Retrieved from <https://pathways.nice.org.uk/pathways/preventing-falls-in-older-people>
- New South Wales Ministry of Health. (2012) *Service framework to improve the health care of people with intellectual disability*. Inter Government and Funding Strategies and Integrated Care. Retrieved from: <https://www.health.nsw.gov.au/disability/Publications/health-care-of-people-with-ID.pdf>
- Ozdowski, S. (2017) *Human rights for people with intellectual disabilities in Australia: where to from here?* Australian federal human rights commissioner and disability discrimination commissioner. Inclusion international 13th congress, Melbourne. Retrieved from: <https://www.humanrights.gov.au/about/news/speeches/human-rights-people-intellectual-disabilities-australia-where-here>

- Pal, J., Hale, L., & Mirfin-Veitch, B. (2013). Experiences of therapists trying to reduce falls risk for people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities, 10*(4), 314-320. doi:10.1111/jppi.12058
- Pal, J., Hale, L., Mirfin-Veitch, B., & Claydon, L. (2014). Injuries and falls among adults with intellectual disability: A prospective New Zealand cohort study. *Journal of Intellectual and Developmental Disability, 39*(1), 35-44. doi:10.3109/13668250.2013.867929
- Polit, D. F., & Beck, C. T. (2013). *Essentials of nursing research: Appraising evidence for nursing practice*. Philadelphia: Lippincott Williams and Wilkins.
- Public Health Association Australia. (2012). *Policy-at-a-glance – Fall injury prevention in older people policy*. Public health association Australia's injury prevention special interest group. Retrieved from: <https://www.phaa.net.au/documents/item/236>
- Roll, A. E. (2018). Health promotion for people with intellectual disabilities - A concept analysis. *Scandinavian Journal of Caring Sciences, 32*(1), 422-429. doi:10.1111/scs.12448
- Rubenstein, L. Z. (2006). Falls in older people: epidemiology, risk factors and strategies for prevention. *Age and Ageing, 35*(suppl_2), ii37-ii41. doi:10.1093/ageing/af1084
- Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T., & Ford, T. (2019). Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Molecular Autism, 10*(Art: 9). doi:10.1186/s13229-019-0260-x
- Russell, M. A., Hill, K. D., Day, L. M., Blackberry, I., Gurrin, L. C., & Dharmage, S. C. (2009). Development of the falls risk for older people in the community (FROP-Com) screening tool. *Age and Ageing, 38*(1), 40-46. doi:10.1093/ageing/afn196
- Salb, J., Woodward, C., Offenhäuser, J., Becker, C., Sieber, C., & Freiberger, E. (2015). Prevalence and characteristics of falls in adults with intellectual disability living in a residential Facility: A longitudinal study [PreFallID]. *Intellectual and Developmental Disabilities, 53*(3), 228-239. doi:10.1352/1934-9556-53.3.228
- Schünemann, H., Broz'ek, J., Guyatt, G., & Oxman, A. (2013). *GRADE handbook for grading quality of evidence and strength of recommendations*. The GRADE Working Group, 2013. Retrieved from <https://gdt.gradepro.org/app/handbook/handbook.html>.

- Sherrington, C., Fairhall, N. J., Wallbank, G. K., Tiedemann, A., Michaleff, Z. A., Howard, K., . . . Lamb, S. E. (2019). Exercise for preventing falls in older people living in the community. *The Cochrane Database of Systematic Reviews*, 1 (Art: CD012424). doi:10.1002/14651858.CD012424.pub2
- Smulders, E., Enkelaar, L., Weerdesteyn, V., Geurts, A. C. H., & Schrojenstein Lantman-de Valk, H. (2013a). Falls in older persons with intellectual disabilities: fall rate, circumstances and consequences. *Journal of Intellectual Disability Research*, 57(12), 1173-1182. doi:10.1111/j.1365-2788.2012.01643.x
- Smulders, E., Enkelaar, L., Schoon, Y., Geurts, A. C., van Schrojenstein Lantman-de Valk, H., & Weerdesteyn, V. (2013b). Falls prevention in persons with intellectual disabilities: Development, implementation, and process evaluation of a tailored multifactorial fall risk assessment and intervention strategy. *Research in Developmental Disabilities*, 34(9), 2788-2798. doi:10.1016/j.ridd.2013.05.041
- Sousa, L. M., Marques-Vieira, C. M., Caldevilla, M. N., Henriques, C. M., Severino, S. S., & Caldeira, S. M. (2017). Risk for falls among community-dwelling older people: systematic literature review. *Revista Gaúcha de Enfermagem*, 37(4), e55030. doi:10.1590/1983-1447.2016.04.55030
- Strydom, A., Shoostari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., . . . Maaskant, M. (2010). Dementia in older adults with intellectual disabilities-Epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities*, 7(2), 96-110. doi:10.1111/j.1741-1130.2010.00253.x
- Tassé, M.J., Schalock, R., Thompson, J.R., & Wehmeyer, M. (2005). *Guidelines for interviewing people with disabilities: Supports intensity scale*. American Association on Intellectual and Developmental Disabilities: Washington, DC.
- Tricco, A. C., Thomas, S. M., Veroniki, A. A., Hamid, J. S., Cogo, E., Striffler, L., . . . Straus, S. E. (2017). Comparisons of interventions for preventing falls in older adults: A systematic review and meta-analysis. *JAMA*, 318(17), 1687-1699. doi:10.1001/jama.2017.15006
- United Nations, Department of Economic and Social Affairs Disability. *Convention on the Rights of persons with disabilities – Articles*. Article 25- Health. Retrieved from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>
- United Nations, Department of Economic and Social Affairs Disability. *Convention on the rights of persons with disabilities – Articles*. Article 24 – Education. Retrieved from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-24-education.html>

United Nations, Department of Economic and Social Affairs Disability. Convention on the rights of persons with disabilities – Articles. Article 9 - Accessibility. Retrieved from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-9-accessibility.html>

Wagemans, A. M. A., & Cluitmans, J. J. M. (2006). Falls and fractures: A major health risk for adults with intellectual disabilities in residential settings. *Journal of Policy and Practice in Intellectual Disabilities*, 3(2), 136-138. doi:10.1111/j.1741-1130.2006.00066.x

Yardley, L., & Smith, H. (2002). A prospective study of the relationship between feared consequences of falling and avoidance of activity in community-living older people. *The Gerontologist*, 42(1), 17-23. doi:10.1093/geront/42.1.17

APPENDICES

Appendix A Co-Author Signed Consent Forms

Max Bulsara

Re: Published articles and manuscript under review in the thesis

I consent to the inclusion of the articles I co-authored to be submitted by Portia Ho and accept the declarations made by the author.

Name of co-author: Max Bulsara

Signature of co-author:  Signature Redacted

Date: 09/09/2019

Caroline Bulsara

Re: Published articles and manuscript under review in the thesis

I consent to the inclusion of the articles I co-authored to be submitted by Portia Ho and accept the declarations made by the author.

Name of co-author: Caroline Bulsara

Signature of co-author:  Signature Redacted

Date: 09/09/2019

Shane Patman

Re: Published articles and manuscript under review in the thesis

I consent to the inclusion of the articles I co-authored to be submitted by Portia Ho and accept the declarations made by the author.

Name of co-author: Shane Patman

Signature of co-author:  Signature Redacted

Date: 09/09/2019

Jenny Downs

Re: Published articles and manuscript under review in the thesis

I consent to the inclusion of the articles I co-authored to be submitted by Portia Ho and accept the declarations made by the author.

Name of co-author: Jenny Downs

Signature of co-author:

Signature Redacted

Date: 09/09/2019

Anne-Marie Hill

Re: Published articles and manuscript under review in the thesis

I consent to the inclusion of the articles I co-authored to be submitted by Portia Ho and accept the declarations made by the author.

Name of co-author: Anne-Marie Hill

Signature of co-author:

Signature Redacted

Date: 09/09/2019

Appendix B Published Article: *JBI Database of Systematic Reviews and Implementation Reports* (contributing to Chapter 2)

SYSTEMATIC REVIEW PROTOCOL

Incidence and prevalence of falls in adults with intellectual disability living in the community: a systematic review protocol

Portia Ho^{1,5} • Shane Patman¹ • Caroline Bulsara² • Jenny Downs³ • Max Bulsara² • Anne-Marie Hill⁴

¹School of Physiotherapy, University of Notre Dame, Fremantle, Australia, ²Institute for Health Research, University of Notre Dame, Fremantle, Australia, ³Telethon Kids Institute, West Perth, Australia, ⁴School of Physiotherapy and Exercise Science, Curtin University, Perth, Australia, and ⁵The Western Australian Group for Evidence Informed Healthcare Practice: a Joanna Briggs Institute Centre of Excellence, Perth, Australia

Review question/objective: The objective of this review is to synthesize the best available evidence to determine the incidence and prevalence of falls in adults with intellectual disability living in the community.

Keywords Community; developmental disability; falls; injurious falls; intellectual disability

JBI Database System Rev Implement Rep 2017; 15(7):1819–1823.

Background

Falls are a leading cause of injury among older Australians.¹ In 2011–2012, 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 intellectual disability (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 functioning^{7–11} as defined by the Australian Psychological Society 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 it ranges 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 with 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 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 recording of falls daily and data collection at least monthly.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, while others used retrospective data collection.

Correspondence: Portia Ho, portia.ho1@my.nd.edu.au

There is no conflict of interest in this project.

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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 to 71 years.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 at the individual age groups.

There are limited studies that 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 which affect their short- and long-term compliance to falls prevention strategies,²⁰ therefore 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 in order 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, JBI Database of Systematic Reviews and Implementation Reports, PubMed, CINAHL and PROSPERO found no recent systematic reviews either published or underway on this topic. Therefore, it is necessary to synthesize the findings of the studies that have been conducted in this area, systematically including their strengths and limitations, to identify evidence on the incidence of falls among adults with ID. The negative impact 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

The current 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” that follows the same criteria as ID in DSM-5 will also be included. Studies that use a broader inclusion criterion 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

The current 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 complaints 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

The current review will consider only studies conducted with participants living in 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 in the community and provided data that can be analyzed separately.

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 rate 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

The current 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, ID, developmental disability and 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. Third, the reference lists 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^{25,26} have included studies dating from 1990.^{27,28} 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 Dissertations and Theses. 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 ID, 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 JBI critical appraisal checklist for studies reporting prevalence data,²⁹ randomized controlled trials,³⁰ quasi-experimental studies,³¹ cohort³² and cross-sectional³³ studies as applicable. Any disagreements that 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 flowchart.³⁴

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 System for the Unified Management, Assessment and Review of Information.³⁵ 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 RevMan³⁶ 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% confidence intervals (CIs) and will list the individual proportions with their 95% CI 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.

Acknowledgements

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References

1. Tovell AH, Harrison JE, Pointer S. Hospitalised injury in older Australians, 2011–12. Injury research statistics series no. 90. Cat. no INJCAT 166. Canberra: AIHW; 2014.
2. Rubenstein LZ. Falls in older people: epidemiology, risk factors and strategies for prevention. *Age Ageing* 2006;35(Suppl 2):ii37–41.
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):43–8.
4. Preventing Falls and Harm From Falls in Older People. Commonwealth of Australia. Sydney: Australian Commission on Safety and Quality in Healthcare (ACSQHC); 2009.
5. World Health Organization. Global report on falls prevention in older age. Geneva, Switzerland: World Health Organization; 2007; Available from: http://www.who.int/ageing/projects/falls_prevention_older_age/en/index.html [Cited December 17, 2016].
6. Smulders E, Enkelaar L, Weerdesteijn V, Geurts ACH, Schroyen 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. *Am J Intellect Dev Disabil* 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;13: 1–18.
16. Strydom A, Shoostari 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 Schrojenstein 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):1001–12.
25. 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:CD007146.
26. 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.
27. 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.
28. 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.
29. Munn Z, Moola S, Lisy K, Riitano D, Tufanaru C. (2015) Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and incidence data. *Int J Evid Based Healthc* 2015;13:147–53.
30. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for randomized controlled trials. 2016. Available from: <http://joannabriggs.org/research/critical-appraisal-tools.html>. [Cited February 18, 2017].
31. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for quasi-experimental studies. 2016. Available from: <http://joannabriggs.org/research/critical-appraisal-tools.html>. [Cited February 18, 2017].
32. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for cohort studies. 2016. Available from: <http://joannabriggs.org/research/critical-appraisal-tools.html>. [Cited February 18, 2017].
33. The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews. Checklist for analytical cross sectional studies. 2016. Available from: <http://joannabriggs.org/research/critical-appraisal-tools.html>. [Cited February 18, 2017].
34. 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.
35. 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. [Accessed September 15, 2016].
36. Review Manager (RevMan) [Computer program]. Version 5.3. Copenhagen: The Nordic Cochrane Centre, The Cochrane Collaboration, 2014.

Appendix C Search Strategy of Databases Used to Conduct the Systematic Review

In all searches, date range was from 1990 to December 31st 2017 (Search date – 7th March 2018)

MEDLINE (OVID)

Search Strategy

1. exp Accidental Falls/ (20295)
2. fall\$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (220031)
3. fall prevention.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2034)
4. exp Intellectual Disability/ (89749)
5. exp developmental disabilities/ (17951)
6. exp learning disorders/ (20894)
7. intellectual disabilit\$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (58446)
8. developmental disabilit*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (20715)
9. learning disabilit\$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (7439)
10. mental retard*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (28252)
11. 4 or 5 or 6 or 7 or 8 or 9 or 10 (144180)
12. 1 or 2 or 3 (220031)
13. 11 and 12 (1142)
14. limit 13 to ("young adult (19 to 24 years)" or "adult (19 to 44 years)" or "young adult and adult (19-24 and 19-44)" or "middle age (45 to 64 years)" or "middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)") (368)
15. limit 14 to yr="1990 - 2017" (287)

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R) <1946 to March 07 2018>

CINAHL

Search Terms	Search Options	Actions	Results
S4	(TX accidental fall*) AND (S1 AND S2)	Limiters - Published Date: 19900101-20171231; Age Groups: Adult: 19-44 years, Middle Aged: 45-64 years, Aged: 65+ years Search modes - Boolean/Phrase	View Results (67)
S3	(TX accidental fall*) AND (S1 AND S2)	Search modes - Boolean/Phrase	View Results (125)
S2	TX accidental fall*	Search modes - Boolean/Phrase	View Results (17,430)
S1	TX intellectual disability or mental retardation or learning disability or developmental disability or learning disabilities	Search modes - Boolean/Phrase	View Results (67,974)

PsycINFO

Search Strategy

1. fall\$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (40510)
2. fall prevention.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (615)
3. exp developmental disabilities/ (13406)
4. exp learning disorders/ (32423)
5. intellectual disabilit\$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (13778)
6. developmental disabilit*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (14661)
7. learning disabilit\$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (25460)
8. mental retard*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (26882)
9. exp FALLS/ (2390)
10. exp Intellectual Development Disorder/ (41120)
11. mentally disabled persons.mp. (84)
12. 1 or 2 or 9 (40510)
13. 3 or 4 or 5 or 6 or 7 or 8 or 10 or 11 (95449)
14. 12 and 13 (693)
15. limit 15 to ("300 adulthood <age 18 yrs and older>" or 320 young adulthood <age 18 to 29 yrs> or 340 thirties <age 30 to 39 yrs> or 360 middle age <age 40 to 64 yrs> or "380 aged <age 65 yrs and older>" or "390 very old <age 85 yrs and older>") (231)
16. limit 16 to yr="1990 - 2017" (221)

Database: PsycINFO <1967 to March Week 1 2018>

AMED

Search Strategy

1. exp Accidental falls/ (2055)
2. exp Developmental disabilities/ (978)
3. exp Learning disorders/ (1076)
4. intellectual disabilit\$.mp. (2526)
5. developmental disabilit*.mp. (1034)
6. learning disabilit\$.mp. (3585)
7. mental retard*.mp. (2517)
8. 2 or 3 or 4 or 5 or 6 or 7 (8278)
9. fall*.mp. (4112)
10. intellectual development disorder*.mp. (0)
11. exp Mental handicap/ or exp Mental retardation/ (3890)
12. 1 or 9 (4112)
13. 8 or 10 or 11 (9629)
14. 12 and 13 (59)
15. limit 15 to yr="1990 - 2017" (58)

Database: AMED (Allied and Complementary Medicine) <1985 to March 2018>

Cochrane Library

ID	Search	Hits
#1	MeSH descriptor: [Accidental Falls] explode all trees	1433
#2	MeSH descriptor: [Accidental Falls] this term only	1433
#3	"Falls" or "Faller":ti,ab,kw (Word variations have been searched)	18558
#4	#1 or #2	1433
#5	MeSH descriptor: [Intellectual Disability] this term only	675
#6	"learning disability" or "developmental disability" or "mental retardation":ti,ab,kw (Word variations have been searched)	1588
#7	#5 or #6	2073
#8	#4 and #7	2
#9	MeSH descriptor: [Developmental Disabilities] this term only	566
#10	#5 or #6 or #9	2073
#11	#1 or #3	18558
#12	#10 and #11	27

EMBASE

Search Strategy

1. exp Accidental Falls/ (34290)
2. fall\$.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] (272563)
3. fall prevention.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] (2599)
4. xp Intellectual Disability/ (449879)
5. exp developmental disabilities/ (35687)
6. exp learning disorders/ (32090)
7. intellectual disabilit\$.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] (17836)
8. developmental disabilit*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] (6365)
9. learning disabilit\$.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] (9880)
10. mental retard*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] (37928)
11. 4 or 5 or 6 or 7 or 8 or 9 or 10 (516347)
12. 1 or 2 or 3 (272563)
13. 11 and 12 (7383)
14. limit 13 to ("young adult (19 to 24 years)" or "adult (19 to 44 years)" or "young adult and adult (19-24 and 19-44)" or "middle age (45 to 64 years)" or "middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)") [Limit not valid in Embase; records were retained] (7383)
15. limit 14 to yr="1990 - 2017" (6888)
16. from 15 keep 1-287 (287)
17. exp Down syndrome/ (31293)
18. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 17 (516347)
19. 12 and 18 (7383)
20. limit 19 to exclude medline journals (849)
21. limit 20 to (adult <18 to 64 years> or aged <65+ years>) (306)
22. limit 21 to yr="1990 - 2017" (302)

Database: Embase <1974 to 2018 March 07>

Current Controlled Trials

<http://www.isrctn.com>

- Text Search: Falls
- Condition: Mental and behavioural disorder
- Limiters: Adults, Completed trials
- Results = 37

National Institute of Health Clinical Database

<http://www.clinicaltrials.gov>, searched

- Advance Search: Limiters Age 18 and over, Year of publication: 1990-2017
- Condition: Fall, Other terms: Intellectual disability OR Learning Disability OR Developmental Disability OR Mental Retardation = 7

TROVE

Search	Query	Results
#1	Keyword: Falls Title: Falls* AND Intellectual Disability*	7
#2	Keyword: Falls Title: Falls* AND Developmental Disability*	1
#3	Keyword: Falls Title: Falls* AND Learning Disability*	0
#4	Keyword: Falls Title: Falls* AND Learning Disability*	2

Limiters – published date: 1990 – 2017, Age: adults

Total = 10

Google Scholar

- "falls in people with intellectual disabilities" = 32
- "falls in people with learning disabilities" = 8
- "falls in people with mental retardation" = 0
- "falls in people with developmental disabilities" = 0
- "prevalence of falls" AND intellectual disability = 85
- "incidence of falls" AND intellectual disability = 3270

ProQuest Theses and Dissertations 7th March 2018

Search	Query	Results
#1	noft(falls*)	9798
#2	noft (accidental falls)	138
#3	noft (falls AND falls prevention)	929
#4	noft (accidental falls) OR noft (falls AND falls prevention) OR noft (falls*)	10397
#5	(noft (intellectual disability)	2048
#6	noft (developmental disability)	4776
#7	noft (learning disorder)	5390
#8	noft (mental retardation)	3140
#9	noft (intellectually disabled)	162
#10	noft (intellectually impaired)	42
#11	(noft (intellectual disability) OR noft (developmental disability) OR noft (learning disorder) OR noft (mental retardation)) OR noft (intellectually disabled) OR noft (intellectually impaired))	12600
#12	((noft (intellectual disability) OR noft (developmental disability) OR noft (learning disorder) OR noft (mental retardation)) OR noft (intellectually disabled) OR noft (intellectually impaired)) AND ((noft(accidental falls) OR noft (falls AND falls prevention)) OR noft (falls*))	25

Limiters – Language: English, Published date: 1990 – 2017, Age: adults

Rehabilitation Research and Training Center on Developmental Disabilities and Health

rttcadd.org

Searched through all current and published research projects. = 0

Centre for Developmental Disability Health Victoria

www.cddh.monash.org

Searched through all current and published research projects. = 0

Centre for Applied Disability Research

www.cadr.org.au

Searched through all current and published research projects. = 0

Appendix D JBI Critical Appraisal Checklist for Prevalence Studies



JBI Critical Appraisal Checklist for Studies Reporting Prevalence Data

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Was the sample frame appropriate to address the target population?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were study participants sampled in an appropriate way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was the sample size adequate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were the study subjects and the setting described in detail?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Was the data analysis conducted with sufficient coverage of the identified sample?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were valid methods used for the identification of the condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Was the condition measured in a standard, reliable way for all participants?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Was there appropriate statistical analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

Appendix E Studies Excluded on Full-text

Crockett J, Finlayson J, Skelton DA, Miller G. Promoting exercise as part of a physiotherapy – led falls pathway service for adults with intellectual disabilities: a service evaluation. *J Appl Res Intellect Disabil.* 2015;28:257-64

Reason for exclusion: The outcome of interest was not clearly documented. The focus of the study was not to investigate incidence/prevalence of falls.

Enkelaar L, Smulders E, van Schrojenstein Lantman-de Valk H, Weerdesteyn V, Geurts AC. Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities. *Res Dev Disabil.* 2013;34 3745-65

Reason for exclusion: The focus of the study was the risk factors for falls and falls rates were not the focus of the study. Therefore the outcomes of interest was not reported clearly.

Finlayson J, Morrison J, Skelton DA, Ballinger C, Mantry D, Jackson A, Cooper SA. The circumstances and impact of injuries on adults with learning disabilities. *Br J Occup Ther.* 2014;77(8):400-9

Reason for exclusion: This paper describes the same population used in an included study and falls rates were not the outcomes of interest in this study.

Hale LA, Mirfin-Veitch BF and Treharne GJ. Prevention of falls for adults with intellectual disability (PROFAID): a feasibility study. *J Intellect Disabil Res.* 2007; 51: 260-8

Reason for exclusion: The focus of this study was to measure the outcome of a falls prevention program. None of the outcomes reported were specific to falls rates.

Hsieh K, Heller T and Miller AB. Risk factors for injuries and falls among adults with developmental disabilities. *J Intellect Disabil Res.* 2001;45(1):76-82

Reason for exclusion: The focus of the study was the risk factors for falls and falls rates were not the focus of the study. Therefore the outcomes of interest was not reported clearly.

Schoufour JD, Echteld MA, Bastiaanse LP, Evenhuis HM. The use of frailty index to predict adverse health outcomes (falls, fractures, hospitalization, medication use, comorbid conditions) in people with intellectual disabilities. *Res Dev Disabil.* 2015; 38: 39-47

Reason for exclusion: The outcome of interest was not clearly documented

Sherrard J, Tonge BJ, Ozanne-Smith J. Injury in young people with intellectual disability: descriptive epidemiology. *Inj Prev.* 2001; 7: 56-61

Reason for exclusion: This study collected epidemiological data on the number of injuries in people with ID. Falls data were reported in relation to the injuries sustained and not as the main focus of the study. Outcomes of interest were not documented clearly.

Strauss D, Shavelle R, Anderson TW, Baumeister A. External causes of death among persons with developmental disability: The effect of residential placement. *Am J Epidemiol.* 1998;147(9):855-62.

Reason for exclusion: The focus of this study was to look at causes of death. Falls were only recorded if it caused death. Therefore outcome of interest was not reported.

Oppewal A, Hilgenkamp TIM, van Wijck R, Schoufour JD, Evenhuis HM. The predictive value of physical fitness for falls in older adults with intellectual disability. *Res Dev Disabil.* 2014;35:1317-25

Reason for exclusion: The outcome of interest was not documented clearly.

Morgan PE, McGinley JL. Falls, fear of falling and falls risk in adults with cerebral palsy: A pilot observational study. *Eur J Physiother.* 2013;15(2):93-100

Reason for exclusion: Study included participants with Cerebral Palsy and not ID. The Abbreviated Mental Test score was used to score level of cognitive impairment. It was not clear if the subjects had intellectual disability fulfilling the DSM-5 criteria.

Bruckner J, Herge, EA. Assessing the risk of falls in elders with mental retardation and developmental disabilities. *Top Geriatr Rehabil.* 2003;19(3):206-11

Reason for exclusion: The length of the observational period was not mentioned for the documented falls against each participant. Therefore, there was insufficient data to calculate the outcome of interest.

Smulders E, Enkelaar L, Schoon Y, Geurts AC, van Schrojenstein 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.

Reason for exclusion: This study reports on an intervention strategy. The focus was not on the incidence of falls. Outcome of interest was not documented.

Cahill S, Stancliffe RJ, Clemson L, Durvasula S. Reconstructing the fall: individual, behavioural and contextual factors associated with falls in individuals with intellectual disability. *J Intellect Dev Disabil.* 2014;58(4):321-32.

Reason for exclusion: A qualitative design study reporting on themes that contributed to falls in nine participants. The outcome of interest was not the focus of this study.

Appendix F Ethics Approval Letter: University of Notre Dame



THE UNIVERSITY OF
NOTRE DAME
A U S T R A L I A

19 Mount Street (PO Box 1225)
Fremantle, Western Australia 6959
Telephone: +61 8 9433 0555
Facsimile: +61 8 9433 0544
Email: enquiries@nd.edu.au
Internet: www.nd.edu.au

ABN: 69 338 645 230
CRICOS PROVISIONAL CODE: 010 123

20 July 2015

Associate Professor Anne-Marie Hill & Ms Portia Ho
School of Physiotherapy
The University of Notre Dame, Australia
Fremantle Campus

Dear Anne-Marie and Portia,

Reference Number: 015067F

Project Title: "Understanding falls in people with intellectual disability in Western Australia."

Your response to the conditions imposed by the university's Human Research Ethics Committee, has been reviewed and assessed as meeting all the requirements as outlined in the *National Statement on Ethical Conduct in Human Research* (2014). I am pleased to advise that ethical clearance has been granted for this proposed study.

All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.


On behalf of the Human Research Ethics Committee, I wish you well with your study.

Signature Redacted

Dr Natalie Giles
Research Ethics Officer
Research Office

cc Prof Peter Hamer, Dean, School of Physiotherapy,
A/Prof Shane Paiman, SRC Chair, School of Physiotherapy

Appendix G Rocky Bay Research Letter



ROCKY BAY
60 McCabe Street
Mosman Park WA 6012
PO Box 53,
Mosman Park WA 6912
T: (08) 9383 5111
F: (08) 9383 1230
www.rockybay.org.au
ABN 66 028 387 386

Ms Portia Ho
Master of Philosophy
The University of Notre Dame Australia
School of Physiotherapy
19 Mouat Street (PO Box 1225)
Fremantle, Western Australia 6959
Telephone: 0432 984 008
Email: portia.ho1@my.nd.edu.au

10th July 2015

Dear Portia,

RESEARCH ETHICS APPLICATION

Thank you for your application to conduct research in conjunction with Rocky Bay. We have assessed your project "Understanding the falls experience in people with intellectual disability in WA" and the impact it will have upon Rocky Bay, staff and clients.

We are pleased to support your project which is supervised by Associate Professor Caroline Bulsara and Dr Anne-Marie Hill from Notre Dame, on the understanding that Rocky Bay's primary obligation is the welfare of its clients and their families, and with the following conditions:

- Participation from individuals, their families and care givers is voluntary
- A Rocky Bay supervisor (Manager Therapy – Youth & Adult) will be assigned to ensure the project continues to meet Rocky Bay's requirements from implementation to completion
- Any deviation from, or amendment to, the original project proposal that has the potential to impact on participating clients of Rocky Bay and/or their families, must be submitted in writing to the Chair of Rocky Bay Ethics Committee for approval, with, where relevant, a copy of the University human research ethics committee approval to the amendment/s

abilityfirst
AUSTRALIA

70
CELEBRATING 70 YEARS

- The researcher will liaise with the Rocky Bay supervisor no less than quarterly to provide updates on the status of the project
- The Rocky Bay supervisor must approve, in advance, all processes, practices, and instruments to be used in contacting Rocky Bay clients
- Rocky Bay will be supplied with a copy of all proposed publications and industry presentations at least five working days prior to the release or distribution of the documents and will have the right to require amendments, where deemed necessary, to protect Rocky Bay's interests. No publications or industry presentations shall be released or distributed prior to receiving the written approval of Rocky Bay. We undertake, however, that no such approval shall be unreasonably withheld
- The researcher will comply with all reasonable instructions from Rocky Bay staff when involving Rocky Bay clients in any stage of this project
- If Rocky Bay perceives that any aspect of the research project has the potential to jeopardize Rocky Bay's reputation we reserve the right to withdraw our support of the project. This support may include recruitment of participants, use of Rocky Bay equipment and facilities, or staff time. In such an event, Rocky Bay will require the researcher to contact all participants who are clients of Rocky Bay and/or their families as soon as feasible, informing them of Rocky Bay's decision, or provide relevant contact details so that Rocky Bay may contact them. Rocky Bay clients and/or their families who have consented to participate in your study, may continue their participation should they wish to do so
- If the actions of the researcher/s are deemed by Rocky Bay to not comply with the requirements of the National Statement on Ethical Conduct in Human Research, and with particular regard to vulnerable participants, including people with a cognitive impairment or intellectual disability; and children or young people, Rocky Bay reserves the right to inform any relevant University Human Research Ethics Committee of our concerns
- Rocky Bay will receive written recognition in all publications and presentations identifying our contribution to the project

Please do not hesitate to contact me if you require additional information. We look forward to working with you on this exciting project.

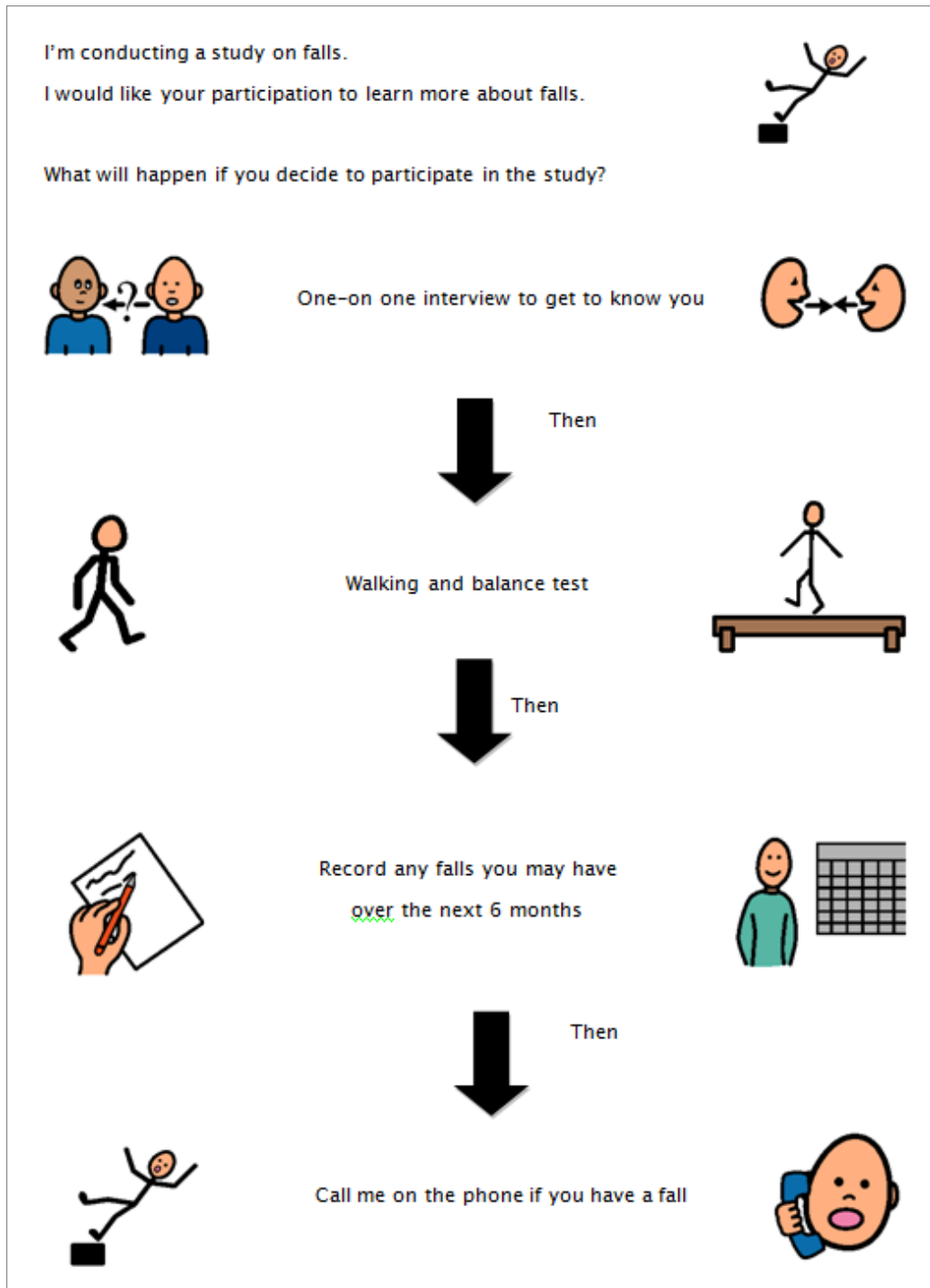
Signature Redacted

TREVIS LAWTON
 Director Strategy & Infrastructure
 Chair Rocky Bay Ethics Panel

Appendix H Information Sheet and Consent Form for People with ID

H.1 Information Sheet

Information on the Study

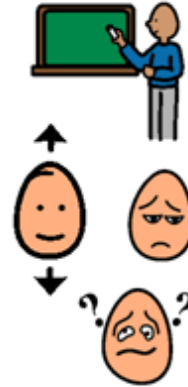


Meeting Schedule

Study on Falls: Meeting Schedule

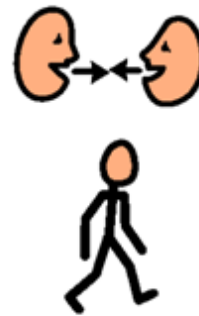
Meeting #1: Informed Consent

- Learn about the falls study
- Talk about what is involved
- Learn about the risk and benefits of participating
- Ask questions you have about the project



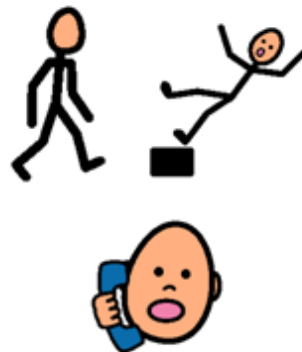
Meeting #2: Individual Interview and Assessment

- Getting to know you
- Participate in walking and balance test



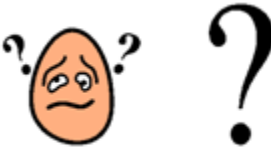


Meeting #3: Telephone interview about your fall

- Hear about what happened when you fell






Options

 <p>YES</p>	 <p>NO</p>
 <p>I don't know</p>	

While you are participating in the study:
Your Options:

At any time you may:

Stop for today	
Take a break	
Keep going	

H.2 Consent Form



THE UNIVERSITY OF
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A U S T R A L I A



Research Title: Understanding falls in people with intellectual disability in Western Australia

Dear _____,

We would like you to join us in a study about falling over.

We would like you to complete a walking and a balance test.

We would also like know what help you receive from others.

We also want to know how happy you feel on a scale of 0 – 100.

We want to know the number of falls you may have in the next 6 months.

To help us, you would need to place a cross "X" on the day you fall and a smiley face "☺" on the day you do not have a fall.

For example:

January 2015							
Week	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1				1	2	3	4
2	5	6	7	8	9	10	11
	☺	X					
3	12	13	14	15	16	17	18
4	19	20	21	22	23	24	25
5	26	27	28	29	30	31	
						Please send calendar	

When you do have a fall, please call me and let me know.
My mobile number is 0432 984 008.

PLAIN LANGUAGE STATEMENT

FINAL VERSION

04/06/2015



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 AUSTRALIA



If you do have a fall, I may ask you share with me what happen after you fell.



Everything that you share will be confidential.

Your name will not be on the page about our talk.

You can choose not to participate at any point in the study, and that is ok – you won't cause any trouble and it won't affect what you do with Rocky Bay.


If you choose to participate in the study, you can learn more about falls.

If you would like to participate, please sign here:

_____	_____	_____
Participant Name	Signature	Date
_____	_____	_____
Portia Ho Researcher's Name	Signature	Date

Appendix I Information Sheet and Consent Form for Next of Kin

I.1 Information Sheet



THE UNIVERSITY OF
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AUSTRALIA

INFORMATION SHEET FOR GUARDIAN OR NEXT-OF-KIN

PROJECT TITLE: Understanding Falls in people with Intellectual Disability in WA
CHIEF INVESTIGATOR: Dr Anne-Marie Hill
STUDENT RESEARCHER: Portia Ho
STUDENT'S DEGREE: Doctor of Philosophy

Dear Family member/Guardian,

You are invited to participate in the research project described below.

What is the project about?
People with intellectual disability have been found to have difficulty with balance and mobility and as a result, may experience falls. Sometimes these falls can lead to injuries or fear of falling. We have good evidence that falls in older people can be significantly reduced with a range of falls prevention and treatment options. However, there is very limited evidence to guide our treatment when people with intellectual disability have a fall.

The aim of this study is to investigate the incidence of falls in community dwelling people with intellectual disability. We also want to investigate the circumstances of the fall and understand what treatment is undertaken after the fall.

At the end of the study we plan to develop a preliminary set of falls prevention guidelines to assist in providing the best services possible to people with intellectual disability.

Who is undertaking the project?
This project is being conducted by Portia Ho. This will form the basis for the degree of Doctor of Philosophy at The University of Notre Dame Australia, under the supervision of Dr Anne-Marie Hill.

What will I be asked to do?

- If you agree to you relative/person you represent taking part in this study, we will have an initial meeting with the person you care for and his/her caregiver(s). We would like to gather information about his/her diagnosis, educational achievements and employment, medical and falls history. We may need to look at his/her medical records and confirm his/her diagnosis

PLAIN LANGUAGE STATEMENT FINAL VERSION 16/04/2016 pg1

INFORMATION SHEET FOR GUARDIAN OR NEXT-OF-KIN

with the Disability Services Commission. With support and close guidance, we will also like him/her to carry out a walking test and balance test if suitable, a functional test that indicates level of independence and complete a well-being questionnaire. This initial meeting will last about an hour.

- He/she will then be provided with a monthly calendar for 6 months. He/she will have to indicate a cross 'X' when a fall(s) occur and a smiley face on days where no falls occur which should take no more than a minute each day. We ask that the main researcher be informed when a fall(s) occurs. The main researcher will ask a few questions about the fall. The phone interview will last approximately 10 mins. We ask that the calendar be sent back at the end of every month. A pre-paid envelop will be provided. The main researcher will also make a follow up contact at the end of every month. This will be a quick 5 min phone call, to see if your relative/person you represent has had more falls.
- We ask that, if required, the participant to be supported with filling up the diary, making contact with Portia Ho and participating in the interview(s).
- If your relative/person you represent experiences a fall(s), he/she may be asked to participate in an interview regarding the events that may have come about after the fall(s) at a time of his/her choosing either at Rocky Bay Inc. or at a place of his/her convenience. The length of the interview is subjected to change but it is not expected to last for more than an hour.

Are there any risks associated with participating in this project?

We do not foresee additional risk in participating in this project above that of everyday living. It is possible to suspend or even end the participation of this project if distress occurs.

What are the benefits of the research project?

We are unable to guarantee or promise that the person whom you represent will receive any benefits from this project. However, by taking part in this project, you will learn more about falls prevention. There will be a wider benefit in establishing falls prevention guidelines that will help people with intellectual disability in the future.

Can I withdraw from the study?

Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without adverse consequences. Withdrawing from the study will not affect any current or future services he/she is or will be receiving from Rocky Bay Inc. and/or the relationship he/she has with those who provide their services at Rocky Bay Inc.

INFORMATION SHEET FOR GUARDIAN OR NEXT-OF-KIN

Will anyone else know the results of the project?

Information gathered about you will be held in strict confidence. This confidence will only be broken in instances of legal requirements such as court subpoenas, freedom of information requests, or mandated reporting by some professionals.

Any information obtained in connection with this project and that can be used to identify the participant will remain confidential. The participant's name will not appear on any documentation or publication. During the course of the study, names of participants will be replaced with an ID number in a password protected electronic database only accessible to the main research student, Portia Ho.

Once the study is completed, the data collected from you will be de-identified and stored securely in the School of Physiotherapy at The University of Notre Dame Australia for at least a period of five years. The data may be used in future research but you will not be able to be identified. A copy of the resulting thesis will be available at the university library.

Will I be able to find out the results of the project?

The final thesis will be made available through the university library and the outcome of the research will be presented in a journal article.

A final report will be presented to the participants and the supporting organization, Rocky Bay Inc. There will also be a presentation of the results at Rocky Bay Inc. for staff members and participants.

Who do I contact if I have questions about the project?

You may ask any questions pertaining to the study by contacting Portia Ho at Rocky Bay Inc, 60 McCabe Street, WA 6107 on mobile: 0432 984 008 or email: portia.ho1@my.nd.edu.au

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (ref number 015067F). If you wish to make a complaint regarding the manner in which this research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943, research@nd.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want to participate! How do I sign up?

If you agree for the person you care for to participate in this study, please sign the attached consent form and kindly contact the main researcher who will organize a time to meet with you.

Yours sincerely,

Portia Ho

I.2 Consent Form



THE UNIVERSITY OF
NOTRE DAME
AUSTRALIA



CONSENT FORM

Understanding falls in people with intellectual disability in Western Australia

INFORMED CONSENT FORM FOR GUARDIAN OR NEXT-OF-KIN

I, (*Next-of-Kin/Guardian's name*) _____ hereby agreed to my relative/ the person I represent, (*participant's name*) _____ being a volunteer participant in the above project.

- I have read and understood the Information Sheet and any questions have been answered to my and my relative's / the person's satisfaction whom I represent.
- I understand that my relative / the person I represent may participate in this study, realising that I, or my relative / the person I represent, may withdraw at any time without prejudice.
- I believe that my relative / the person I represent has not previously expressed an objection or would not be likely to object to inclusion in this study.
- I understand that all information gathered by the researcher will be treated as strictly confidential, except in instances of legal requirements such as court subpoenas, freedom of information requests, or mandated reporting by some professionals.
- I understand that the protocol adopted by the University Of Notre Dame Australia Human Research Ethics Committee for the protection of privacy will be adhered to and relevant sections of the *Privacy Act* are available at <http://www.nhmrc.gov.au/>
- I agree that any research data gathered for the study may be published provided my name or my relative's / the person's name whom I represent and other identifying information is not disclosed.
- I understand that research data gathered may be used for future research but my name and/or my relative/ the person's name I represent and other identifying information will be removed.
- I understand that my relative/ the person I represent will be audio-taped if they have consented to participate in the interview in the second part of the study.

PARENT/GUARDIAN'S SIGNATURE:		DATE:	
------------------------------	--	-------	--

RESEARCHER'S FULL NAME:	PORTIA HO		
RESEARCHER'S SIGNATURE:		DATE:	

If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943, research@nd.edu.au .

CONSENT FORM

FINAL VERSION

04/06/2015

Appendix J Information Sheet and Consent Form for Care Givers

J.1 Information Sheet



STUDY INFORMATION SHEET FOR CAREGIVER

PROJECT TITLE: Understanding Falls in people with Intellectual Disability in Western Australia

CHIEF INVESTIGATOR: Dr Anne-Marie Hill

STUDENT RESEARCHER: Portia Ho

STUDENT'S DEGREE: Doctor of Philosophy

Dear support carer,

You are invited to participate in the research project described below.

What is the project about?

People with intellectual disability have been found to have difficulty with balance and mobility and as a result, may experience falls. Sometimes these falls can lead to injuries or fear of falling. We have good evidence that falls in older people can be significantly reduced with a range of falls prevention and treatment options. However, there is very limited evidence to guide our treatment when people with intellectual disability have a fall.

The aim of this study is to investigate the incidence of falls in community dwelling people with intellectual disability. We also want to investigate the circumstances of the fall and understand what treatment is undertaken after the fall.

At the end of the study we plan to develop a preliminary set of falls prevention guidelines to assist in providing the best services possible to people with intellectual disability.

Who is undertaking the project?

This project is being conducted by Portia Ho. This will form the basis for the degree of Doctor of Philosophy at The University of Notre Dame Australia, under the supervision of Dr Anne-Marie Hill

What will I be asked to do?

- If you consent to support the person you care for in participating in the study, we will need your assistance to gather background information on the person you care for. We would like information about his/her diagnosis, educational achievements and employment, medical and falls history. With support and close guidance, we will also like him/her to carry out a walking

STUDY INFORMATION SHEET FOR CAREGIVER

test and balance test if suitable, a functional test that indicates level of independence and complete a well-being questionnaire. This initial meeting will last about an hour.

- The person you care for will then be provided a monthly falls calendar to fill up for 6 months to record the number of falls experienced. You will be requested to assist in filling up this falls diary. Indicate a cross 'X' when a fall(s) occur and a smiley face on days where no falls occur which should take no more than a minute each day. When a fall(s) occur, please assist the person you care for to contact the main researcher. The main researcher will ask a few questions about the fall. This phone interview will last approximately 10 mins. At the end of every month, please send the calendar back to the research in the pre-paid envelope provided. The researcher will also make a follow up phone call to you and the person you care for at the end of every month. This will be a quick 5 min phone call, to see if the person you care for has had any more falls.
- If a fall(s) occur, the person you care for may be invited to participate in another interview about their post-falls experience. In this case, we would ask that you participate in the interview as well. The length of the interview is subjected to change but it is not expected to last for more than an hour.

Are there any risks associated with participating in this project?

We do not foresee additional risk in participating in this project above that of everyday living.

What are the benefits of the research project?

We are unable to guarantee or promise that the person whom you represent will receive any benefits from this project. However, by taking part in this project, you will learn more about falls prevention. There will be a wider benefit in establishing falls prevention guidelines that will help people with intellectual disability in the future.

Can I withdraw from the study?

Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without adverse consequences. Withdrawing from the study will not affect any current or future services, the person you care for is/or will be receiving from Rocky Bay Inc and/or the relationship with whom they work with at Rocky Bay Inc.

Will anyone else know the results of the project?

Information gathered about you will be held in strict confidence. This confidence will only be broken in instances of legal requirements such as court subpoenas, freedom of information requests, or mandated reporting by some professionals.

Any information obtained in connection with this project and that can be used to identify the participant will remain confidential. The participant's name will not appear on any documentation or

STUDY INFORMATION SHEET FOR CAREGIVER

publication. During the course of the study, names of participants will be replaced with an ID number in a password protected electronic database only accessible to the main research student, Portia Ho.

Once the study is completed, the data collected from you will be de-identified and stored securely in the School of Physiotherapy at The University of Notre Dame Australia for at least a period of five years. The data may be used in future research but you will not be able to be identified. A copy of the resulting thesis will be available at the university library.

Will I be able to find out the results of the project?

The final thesis will be made available through the university library and the outcome of the research will be presented in a journal article.

A final report will be presented to the participants and the supporting organization, Rocky Bay Inc. There will also be a presentation of the results at Rocky Bay Inc. for staff members and participants.

Who do I contact if I have questions about the project?

You may ask any questions pertaining to the study by contacting Portia Ho at Rocky Bay Inc, 60 McCabe Street, WA 6012, on mobile:0432 984 008 or email portia.ho1@my.nd.edu.au.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (ref. number 015067F). If you wish to make a complaint regarding the manner in which this research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943, research@nd.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want to participate! How do I sign up?

If you agree to participate in this study, please sign the attached consent form and kindly contact the main researcher who will organize a time to meet with you.

Yours sincerely,

Portia Ho

J.2 Consent Form



THE UNIVERSITY OF
NOTRE DAME
AUSTRALIA



CONSENT FORM

Understanding falls in people with intellectual disability in Western Australia

INFORMED CONSENT FORM

I, (*participant's name*) _____ hereby agree to being a participant in the above research project.

- I have read and understood the Information Sheet about this project and any questions have been answered to my satisfaction.
- I understand that I may withdraw from participating in the project at any time without prejudice.
- I understand that all information gathered by the researcher will be treated as strictly confidential, except in instances of legal requirements such as court subpoenas, freedom of information requests, or mandated reporting by some professionals.
- I understand that the protocol adopted by the University Of Notre Dame Australia Human Research Ethics Committee for the protection of privacy will be adhered to and relevant sections of the *Privacy Act* are available at <http://www.nhmrc.gov.au/>
- I agree that any research data gathered for the study may be published provided my name or other identifying information is not disclosed.
- I understand that research data gathered may be used for future research but my name and other identifying information will be removed.
- I understand that I will be audio during the interview phase of the study.

PARTICIPANT'S SIGNATURE:		DATE:	
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RESEARCHER'S FULL NAME:	PORTIA HO		
RESEARCHER'S SIGNATURE:		DATE:	

If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943, research@nd.edu.au

CONSENT FORM FOR CAREGIVER

FINAL VERSION

04/06/2015

Appendix K Interview Schedule Used when Conducting Semi-Structured Interviews

