Out of sight, out of mind? The inclusion and identification of people with intellectual disability in public health research

Authors

Katie Brooker
Queensland Centre for Intellectual and Developmental Disability, School of Medicine, The University of Queensland, Mater Hospital, South Brisbane, QLD 4101, Australia
Email: katie.brooker@uqconnect.edu.au

Kate van Dooren
Queensland Centre for Intellectual and Developmental Disability, School of Medicine, The University of Queensland, Mater Hospital, South Brisbane, QLD, Australia

Chih-Han Tseng
Queensland Centre for Intellectual and Developmental Disability, School of Medicine, The University of Queensland, Mater Hospital, South Brisbane, QLD, Australia

Lyn McPherson
Queensland Centre for Intellectual and Developmental Disability, School of Medicine, The University of Queensland, Mater Hospital, South Brisbane, QLD, Australia

Nick Lennox
Queensland Centre for Intellectual and Developmental Disability, School of Medicine, The University of Queensland, Mater Hospital, South Brisbane, QLD, Australia

Robert Ware
Queensland Centre for Intellectual and Developmental Disability, School of Medicine, The University of Queensland, Mater Hospital, South Brisbane, QLD, Australia; School of Population Health, The University of Queensland, South Brisbane, QLD, Australia

Corresponding author:
Katie Brooker, as above

Keywords
intellectual disability; inclusion; epidemiology; research design; systematic review

Abstract

Aims: Adults with intellectual disability experience substantial health inequities. Public health research aiming to improve the lives of this population group is needed. We sought to investigate the extent to which a sample of international public health research includes and identifies people with intellectual disability.

Methods: In this systematic review, we examined a select number of public health journals to determine (1) how often people with intellectual disability are explicitly included in randomised controlled trials (RCTs) and cohort studies and (2) how the presence of intellectual disability is identified and reported.

Results: Among eligible articles in these selected public health journals, it was found that cohort studies passively exclude people with intellectual disability, while RCTs actively exclude this population. Most general population articles that explicitly identified people with intellectual disability did so through self-report or proxy report and databases.

Conclusions: A more extensive and adequate evidence base relating to the health of this overlooked population group is needed. A useful first step would be for researchers specialising in intellectual disability to identify how we can best assist mainstream researchers to include and identify people with intellectual disability in their population-level studies.

Approximately 1-3% of the world's population experience intellectual disability.[1] Historically, health professionals and researchers defined intellectual disability according to the medical model, which describes intellectual disability as a limitation on intellectual functioning (usually based on IQ score) and adaptive behaviour (e.g. communication, social skills, self-care) originating before 18 years of age.[2] This definition emphasises the cognitive impairments of individuals and places them at the centre of their disability. Increasingly, self-advocates and advocates have acknowledged the need for definitions based on the social model of disability whereby cognitive impairment is distinct from disability (changing the term to 'dis/ability'), which is caused by societal, community and service responses to individuals' impairment.[3]

Despite great medical and social gains made over the past several decades, the health of people with intellectual disability generally remains poor.[4] Adults with intellectual disability have shorter life expectancies[5] and experience many more co-morbidities than do the general population.[4] Although not all health disparities are unfair, evidence suggests much of the poor health experienced by people with intellectual disability is amenable to change through clinical intervention, improved environment and/or health promotion.[6–8] However, public health approaches to address these well-documented health inequities are sporadic. People with intellectual disability receive less health promotion and screening than do members of the general population, despite their arguably greater need across multiple domains.[9–11]

People with intellectual disability have the right to the highest attainable standard of health.[12] Researchers have a critical role to contribute to reductions in health inequities experienced by this group by generating an appropriate evidence base

Copyright © Royal Society for Public Health 2014
SAGE Publications
ISSN 1757-9139 DOI: 10.1177/1757913914552583

to inform the formulation and implementation of targeted policies and to identify and address the barriers this population group systematically face in relation to their health and wellbeing.[13] However, health surveillance for people with intellectual disability is currently inadequate,[14] making it difficult to understand the complex causal pathways for poor or better health, trends in health over time or to determine where best to allocate public health resources. Currently, in a field that relies on 'gold standard' studies providing the 'highest hierarchy of evidence', we must often rely on evidence that is descriptive or arising from small community samples.

Research aiming to include people with intellectual disability as research participants can be logistically challenging and resource intensive. A number of barriers to recruitment and participation of people with intellectual disability exist.[15,16] First, study recruitment often depends on engagement with communication channels that may not be accessible to this group and may result in people with intellectual disability being 'screened out' of research.[17] For example, limited access to telephones and media (e.g. community newsletters) may limit recruitment efforts.[18] Second, the process of gaining informed consent is complex. Although many people with intellectual disability are able to provide informed consent, others require a substitute decision maker, which can complicate recruitment processes and add extra time to studies.[15,16] Furthermore, evidence suggests that service organisations who are often approached given their work with people often 'gate-keep' access to their clients and members.[15,19] Third, research ethics committees sometimes place protective conditions on research that result in exclusions of people with cognitive impairment.[20] Finally, the design and demands of some studies may be inaccessible for many people with intellectual disability, for example, through the use of long, complex surveys[17] or the requirement for lengthy or complicated travel to research sites.[18]

The identification of people with intellectual disability is often difficult, especially in research involving individuals living in the community. Traditionally, for ascertainment of participants with intellectual disability to be considered valid, IQ and adaptive behaviour tests administered by psychologists have been required.[21] These tests can be costly and time-consuming and are not practical for large public health studies. Screening tools to identify the possible presence of intellectual disability are available; however, they often over-identify disability due to low diagnostic specificity.[22] Another option is self-report of disability status; however, this requires people to classify themselves as having a disability, which someone with intellectual disability either may not wish to do or may not be capable of doing. Consequently, the identification of individuals with mild and 'borderline' disability is challenging.[23]

An implicit corollary to these challenges is that mainstream public health research is ill-equipped to identify and include people with intellectual disability, limiting research to specialised intellectual disability researchers and dissemination of findings to specific journals. Some attention has been given to the inclusion of people in medical trials,[24] and quite substantial focus has been placed on emancipatory and inclusive research methodologies in qualitative research with people with disability (although less so for those with intellectual disability).[25] However, little work has been undertaken around inclusion in public health research more broadly. Given the different aims of clinical, qualitative and population-based studies, it is important to determine the extent of this group in public health interventions.

Two research questions exist in relation to people with intellectual disability and public health research: (1) how often people with intellectual disability are included in public health research and (2) how the presence of intellectual disability is identified and reported by public health researchers. Although it was beyond our ability to contribute systemically to these large questions in relation to all public health studies, as a contribution to address this research gap, we conducted a small audit of a select number of prestigious medical and public health journals. In particular, our aims were to systematically review a select number of public health journals to determine (1) how often people with intellectual disability are explicitly included in randomised controlled trials (RCTs) and cohort studies and (2) how the presence of intellectual disability is identified.

METHOD

Inclusion of people with intellectual disability

To determine how often people with intellectual disability are explicitly included in a select group of public health RCTs and cohort studies, we systematically searched issues of four journals (*British Medical Journal, International Journal of Epidemiology, New England Journal of Medicine* and *Australian and New Zealand Journal of Public Health*) published from January 2010 to December 2011 to identify articles that included people with intellectual disability. It was beyond the scope of this review to audit all public health journals as this process would have required a detailed, resource-intensive review. These four journals were chosen based on their high impact factors (a proxy for widely read journals) and reflect prestigious general medical and public health journals that publish the study design in which we were interested.

The *British Medical Journal* was reviewed by searching the title and abstract using the following search terms: cohort OR cohort study OR randomised trial. 'Cohort profiles' within the *International Journal of Epidemiology* were reviewed. The *New England Journal of Medicine* was reviewed by searching abstracts using the following search terms: cohort OR randomised trial and then limiting to speciality 'public health research, policy and training'. The *Australian and New Zealand Journal of Public Health* was reviewed by searching abstracts using the following search

terms: cohort OR cohort study OR randomised trial. After identifying potentially relevant articles, we read each in detail, and recruitment, selection criteria and data collection methods were extracted.

We defined studies as being inclusive of people with intellectual disability when an article described a research design or research process that *may* have included people with intellectual disability. Note that this definition does not relate to 'inclusive research' that typically relates to the inclusion of people with intellectual disability in research processes such as study design and data collection. We defined research processes that may include people with intellectual disability as follows: (1) recruitment methods accessible to people with intellectual disability, (2) flexible process(es) of informed consent which may include the option of a substitute decision maker, (3) appropriate and accessible data collection methods for people with intellectual disability without being over-burdensome and (4) participant selection criteria inclusive of people with intellectual disability.

Articles that *actively* excluded people with intellectual disability were identified. Active exclusion was defined as when an article described inclusion or exclusion criteria for participants that referred or related specifically to intellectual disability or cognitive impairment. For example, an article's exclusion criteria may have required that participants had no complicating conditions or had no cognitive impairments. Furthermore, articles requiring participants to read and/or speak English fluently to interact with data collection tools or communicate in complex ways without support were considered to actively exclude people with intellectual disability. We believed these studies did not make the accommodations required when involving a person with intellectual disability in data collection. These accommodations may have included allowing appropriate time for participants to respond, elaborating or explaining questions and terms in language a person with intellectual disability can understand and taking precautions to reduce acquiescence.

Articles that *passively* excluded people with intellectual disability were also identified. Passive exclusion was defined as instances where high demands were made on participants (e.g. frequent and detailed long surveys or burdensome tests), recruitment methods were unlikely to reach people with intellectual disability (e.g. driver licence lists) or the informed consent process was inflexible to the needs of people with intellectual disability. This definition was based on evidence that suggests that some recruitment and data collection methods cannot be relied on due to challenges with low literacy.[17]

Identification of people with intellectual disability

Again, it was beyond the scope of this review to audit all public health journals to determine how the presence of intellectual disability is identified and reported in mainstream public health research. To fit within the constraints of the review, we chose the top 10 ranking public health journals based on impact factors and the highest ranking Australian public health journal (*American Journal of Epidemiology, American Journal of Preventive Medicine, American Journal of Public Health, Bulletin of the World Health Organization, Epidemiology, European Journal of Epidemiology, International Journal of Epidemiology, Journal of Clinical Epidemiology, Journal of Epidemiology and Community Health, Preventive Medicine* and *Australian and New Zealand Journal of Public Health*).

Across these 11 journals, we reviewed articles published from January 2010 to December 2011; each journal was searched using the terms 'intellectual disability', 'learning disability', 'learning difficulties', 'mental retardation' and 'developmental disability'. As the aim of this part of the study was to determine how people with intellectual disability are identified in mainstream public health research, studies specific to this population were excluded. Each potentially relevant article was reviewed to identify the method that researchers used to identify people with intellectual disability.

We defined the identification of people with intellectual disability as when an article described the study population and it included people with intellectual disability. The article had to also describe how it was determined that participants had an intellectual disability (e.g. researchers asked whether participants identified as having an intellectual disability).

All articles were assessed by two reviewers (K.B., C.-H.T.). Potential articles were discussed with other authors (R.W., L.M., K.v.D) to determine eligibility.

RESULTS

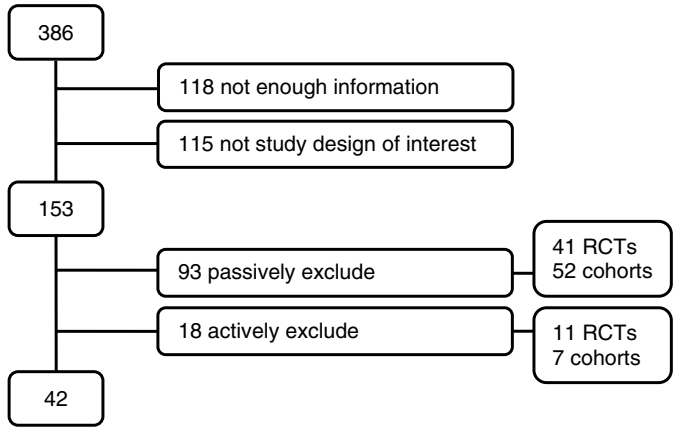
The results are presented in two sections. In the section 'Inclusion of people with intellectual disability', we present the results of the review of the inclusion of people with intellectual disability in RCTs and cohort studies in selected public health journals. In the section 'Identification of people with intellectual disability', we present the results of the review of the identification of people with intellectual disability in selected public health journals.

Inclusion of people with intellectual disability

Our first systematic review identified 386 potential articles from the four target journals (see Figure 1); none of the articles arose from the same individual study. Of these, 118 did not provide sufficient information to conclude whether they were inclusive of people with intellectual disability and 115 did not meet the study design criteria of a RCT or cohort study involving human participants. Of the 153 remaining articles, 93 were classified as passively excluding and 18 as actively excluding people with intellectual disability. To demonstrate our decision-making process, we have provided an example of active and passive exclusion: Green *et al*.[26] excluded participants if they attended a special learning disability

Figure 1

Flow of articles selected: inclusion of people with intellectual disability



RCTs: randomised controlled trials.

school and thus was classified as actively excluding people with intellectual disability; Cockayne *et al*.[27] excluded participants who were unable to provide their own informed consent and asked participants to complete a postal or online questionnaire four times during the study period and thus was classified as passively excluding people with intellectual disability.

The 111 articles that passively and actively excluded people with intellectual disability were composed of 52 RCTs and 59 cohort studies. Among the articles that were classified as actively excluding people with intellectual disability, 11 articles (64%) were RCTs. Of the cohort articles that excluded people with intellectual disability, 52 articles (88%) could be classified as passively excluding people with intellectual disability.

The remaining 42 articles did not specifically identify they had included people with intellectual disability in their article; however, their exclusion and inclusion criteria, recruitment strategy, consent process and data collection could possibly have included this population group.

The 42 articles classified as possibly having included people with intellectual disability included 4 RCTs and 38 cohort studies (see Table 1). The articles reporting RCTs potentially included people with intellectual disability due to their inclusion and exclusion criteria relating to hospital admission ($n=1$), flexible consent ($n=1$), use of an inclusive database ($n=1$) and by including infant participants ($n=1$).

The 38 cohort articles consisted of 14 (37%) prospective cohort studies and 24 (63%) retrospective cohort studies. Of the 38 cohort articles, the majority (79%) of the articles pertain to either routine databases ($n=16$) or clinical and research databases ($n=15$). The method of possible inclusion of people with intellectual disability among the remaining cohort articles involved hospital admissions ($n=4$), home visits ($n=1$), flexible consent ($n=1$) and infant participants ($n=2$); articles that implemented these methods were all prospective cohort articles. All retrospective cohort articles classified as possibly including people with intellectual disability involved data accessed primarily through routine databases or clinical and research databases. Among the prospective cohort articles, six articles relied on routine databases and clinical and research databases, thus possibly including people with intellectual disability.

The 42 articles were broadly classified into three topics: diseases and treatment ($n=25$), maternal and/or child health ($n=15$) and social determinants of health ($n=2$). The majority of cohort studies (89%) and RCTs (75%) had no patient involvement in the data collection process. Other methods of data collection for cohort articles included home visits ($n=2$) and a questionnaire completed by parents ($n=3$). The one RCT article that involved some form of participant contact included the use of questionnaires completed by proxy for data collection.

Identification of people with intellectual disability

In the systematic search of 11 public health journals, 113 articles were identified (Figure 2); none of these arose from the same individual study. Of these, 39 were not empirical and 24 provided insufficient information to conclude whether they were inclusive of people with intellectual disability. Of the remaining articles, 30 did not specify that they had identified people with intellectual disability. A total of 14 articles specifically investigated intellectual disability.

Six articles were found that identified people with intellectual disability. The identification method used by each article varied; however, none used an IQ test or adaptive functioning tests administered by a psychologist. Methods of identification included self-report or proxy report, routine databases and an intellectual disability–specific database.

Two articles used self-report or proxy report of intellectual disability and then verified the diagnosis of intellectual disability by examination of a doctor. Thakur *et al*.[28] conducted a cross-sectional survey to investigate adverse outcomes related to reproductive and child health and highly toxic waste ($n=3,666$). They identified people with intellectual disability by asking mothers of the participants whether their child had been diagnosed with intellectual disability or whether the child had missed language or developmental milestones. Intellectual disability was then verified by a medical doctor. Zheng *et al*.[29] compared the prevalence of disability in

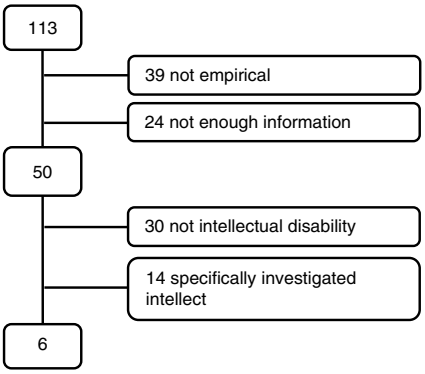
Table 1 Possible method of inclusion of people with intellectual disability

	RCTs	Retrospective cohort studies	Prospective cohort studies
Hospital admission	1	0	4
Flexible consent	1	0	1
Routine database	0	14	2
Clinical and research database	1	10	4
Home visits	0	0	1
Infant participants	1	0	2

RCTs: randomised controlled trials.

Figure 2

Flow of articles selected: identification of people with intellectual disability



China using data from two national surveys conducted in 1987 and 2006. They identified people with intellectual disability by using a self-report or proxy report of studying difficulties, and intellectual disability was confirmed by medical examinations by study doctors.

Four of the six articles included used databases to identify participants. Two articles used data from routine databases to identify people with intellectual disability. Knudsen *et al*.[30] investigated the health of non-participants in a population-based health survey ($n = 18,565$). They identified people with intellectual disability through disability pensions in which the main disabling condition was mental retardation. Moeller *et al*.[31] used data from a cross-sectional survey of people who receive Medicare in the United States. They identified people with intellectual disability by a self-report or proxy report of a diagnosis of mental retardation by a doctor. Two articles identified people with intellectual disability through the Western Australian database Intellectual Disability Exploring Answers (IDEA) that records all diagnoses of intellectual disability using medical and educational systems records from 1983 to 2010. Morgan *et al*.[32] and O'Donnell *et al*.[33] used this database to identify risks of schizophrenia and child and paternal factors related to increased risk of child maltreatment in Indigenous Australian children, respectively.

DISCUSSION

Our 'snapshot' audit of selected medical and public health journals suggests among a substantial number of public health research articles, few specify the identification or inclusion of people with intellectual disability. Although it is intuitive to suggest that, given our findings, there exists a paucity of research that includes adults with intellectual disability, we must approach such interpretations cautiously. Over half of the articles that identified people with intellectual disability used databases that had no patient involvement. One in four articles reviewed did not provide enough information to determine whether they included or identified people with intellectual disability in their study.

In relation to our aim to identify the extent of inclusion (using the definitions provided), among the articles we identified, those presenting RCTs tended to actively exclude people with intellectual disability, usually through their strict recruitment inclusion criteria. In contrast, cohort studies were more likely to passively exclude people with intellectual disability, usually through restrictive data collection or participant recruitment methods.

In relation to our aim to identify methods of identifying people with intellectual disability, articles reported identification through self-report, proxy or database. The use of screening tools or validated instruments was non-existent. Although in the future identification of people with intellectual disability may be aided by advances in data linkage (see Balogh *et al*.[34]), it is also important to note that screening tools or validated instruments may not identify the 'hidden majority' of people with mild or borderline intellectual disability. These individuals are very difficult to recruit, not least because they may not identify as having a disability; however, it is critical that researchers continue to develop innovative ways to identify and include these individuals in public health studies to ensure that their health-related needs are captured and ultimately addressed.[12]

Limitations

Our findings must be considered in the context of several study limitations. First, due to the resource and time constraints in undertaking a review of the larger public literature, we limited our scope to auditing 13 prestigious medical and public health journals in English language. We attempted to ameliorate this limitation by choosing journals that are the most widely read (using impact factor as a proxy measure). Arguably, these journals are most relevant to our study aims as they are likely to represent the level of intellectual disability research relevant to most public health

researchers (who are not specifically interested in intellectual disability research). Research investigating other journals, including those in other languages, is needed.

Second, we concentrated on studies considered to offer the highest hierarchy of evidence in quantitative public health research: RCTs and cohort studies. Certainly, descriptive quantitative studies and well-conducted qualitative research are essential to the development of our knowledge about the health-related experiences of people with intellectual disability. Our small scope is the key limitation of our study results; however, it allowed us to focus in detail on a substantial and well-read portion of the literature. Third, many articles provided insufficient detail when describing recruitment, data collection and identification methods, and, again, it was outside the scope of our resources to follow-up with authors. Over one-fifth of the articles failed to report sufficient information about the population in their study to determine whether and how they identified people with intellectual disability. Generally, insufficient information was provided about the sample population. Many articles did not report recruitment and sample characteristics, instead reporting secondary data analysis. This lack of information is problematic – data disaggregated by disability status would allow for a better understanding of the health disparities experienced by people with intellectual disability or at the very least would provide comparative data. Finally, our results may be representative of publication bias: given the challenges associated with conducting research with this population group,[35] including complex issues of informed consent,[36] descriptive or qualitative study designs may not be considered adequate by many journal editors. Inclusive research involving people with intellectual disability may be published in lower impact journals that were not searched.

Despite these limitations, we are confident that we have produced a small, but accurate audit of the extent to which public health research identifies and includes people with intellectual disability. In doing so, we provide further evidence of the need for data relating to the health of people with intellectual disability. A stronger evidence base would inform those responsible for legislating health policies by establishing measurable and achievable benchmarks and targets. We would also be better equipped to advocate the need for improvements to be made to the amenable factors affecting health and wellbeing for this vulnerable and often marginalised group.

Implications

To ensure we build an adequate evidence base relating to the health of this overlooked population group, researchers specialising in intellectual disability should identify how they can best assist public health researchers to include and identify people with intellectual disability in their population-level studies. We argue that it is insufficient to merely claim that mainstream public health research is currently lacking and exclusive. It would be more productive to work with mainstream researchers to make 'reasonable accommodations' – necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden to the research process – to their study designs. Effort is needed to clarify definitional issues relating to intellectual disability and to recommend ways to overcome recruitment issues. Intellectual disability researchers must seek out research opportunities where the health of people with intellectual disability should be prioritised, be clear about the benefits and opportunities of working with this group and be open to drawing on others' expertise in public health. Although we do not have the immediate answers to these complex and overlapping challenges, we hope that raising them in this forum will stimulate debate and movement forward. In particular, to ensure that people with intellectual disability are included in public health efforts, researchers need to be aware of the issues revolving around gaining written informed consent, data collection and other barriers to participation. We have provided a summary of research approaches that mainstream researchers can apply and which may be more inclusive of people with intellectual disability. Our proposed research approaches are similar to those recently proposed to promote inclusion of people with intellectual disability in medical research:[24]

- A common form of passive exclusion is the process of informed consent. The issue of informed consent provides a clear case study of a complex issue that has stimulated substantial debate in the intellectual disability research literature[36] that should be highlighted to mainstream public health researchers. The process of gaining informed consent should be flexible and have the option of having a substitute decision maker able to provide consent with the research participant proving their assent.
- The strict selection criteria imposed by research studies may be considered a challenge to active inclusion. Feldman *et al*.[24] recommended educational activities targeted at researchers and ethics review board members promoting people with intellectual disability's right to be involved in research. They also draw attention to the risk of *not* including people with intellectual disability rather than the potential harm people with intellectual disability may experience from participating in research.[24]
- To overcome passive exclusion through recruitment methods, we recommend boarding recruitment materials beyond mainstream media and presenting the information in an easy-to-read format. When recruiting through third parties, such as health practitioners, discussing the selection criteria and stressing the research is inclusive of all population groups is important. A Canadian review of research involving people with intellectual disability found that

higher participation was found in articles that directly contacted participants (as opposed to service organisations).[19] It has also been found that personally informing and motivating the carer of the person with an intellectual disability may result in a higher participation rate.[37] Multiple attempts to contact and enrol this group in research may also increase participation.[20]

- Another form of passive exclusion which we propose could be overcome is exclusion through data collection methods. For example, participants can be provided support to complete surveys or are given multiple options to complete the survey (e.g. completing the survey over the phone, researcher visits and assists participant to complete). Also, invasive data collection methods requiring participants to travel to research sites can easily be addressed.

It is well established that the health of people with intellectual disability is poorer than that of the general population.[4] As public health researchers, we believe an important first step is to address health inequities through inclusive research practices. We need researchers to prioritise inquiry and provide accurate and timely evidence relating to the health of people with intellectual disability, through peer-reviewed studies and national health surveys, and research investigating the social determinants of health.

ACKNOWLEDGEMENTS

The authors have no funding or conflicts of interests to declare. There was no ethical approval required for this review.

References

References marked with a star indicate they were included in the review.

1. World Health Organization (WHO). *The World Health Report 2001 – Mental Health: New Understanding, New Hope*. Geneva: WHO, 2001.
2. American Psychiatric Association (APA). *Intellectual Disability*. APA, 2013. Available online at: http://www.dsm5.org/Documents/Intellectual%20Disability%20Fact%20Sheet.pdf (Last accessed 14th March 2014).
3. World Health Organization (WHO). *World Report on Disability*. Geneva: WHO, 2011.
4. Krahn GL, Hammond L, Turner A. A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 2006; 12: 70–82.
5. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *The Lancet* 2014; 383: 889–95.
6. Felce D, Baxter H, Lowe K, Dunstan F, Houston H, Jones G *et al*. The impact of repeated health checks for adults with intellectual disability. *Journal of Applied Research Intellectual Disabilities* 2008; 21: 585–96.
7. Ouellette-Kuntz H. Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research Intellectual Disabilities* 2005; 18: 113–21.
8. Emerson E, Glover G. The 'transition cliff' in the administrative prevalence of learning disabilities in England. *Tizard Learning Disability Review* 2012; 17: 139–43.
9. Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: A cluster randomized trial. *International Journal of Epidemiology* 2007; 36: 139–46.
10. Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM *et al*. Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings. *Journal of Applied Research Intellectual Disabilities* 2010; 23: 303–11.
11. Morin D, Merineau-Cote J, Ouellette-Kuntz H, Tasse MJ, Kerr M. A comparison of the prevalence of chronic disease among people with and without intellectual disability. *American Journal on Intellectual and Developmental Disabilities* 2012; 117: 455–63.
12. United Nations. *Convention on the Rights of Persons with Disabilities*. Geneva: United Nations, 2006. Available online at: http://www.un.org/disabilities/convention/conventionfull.shtml (Last accessed 11th March 2014).
13. Brolan C, Ware R, Taylor Gomez M, Lennox N. The right to health of Australians with intellectual disability. *Australian Journal of Human Rights* 2011; 17: 1–32.
14. Bielska IA, Ouellette-Kuntz H, Hunter D. Using national surveys for mental health surveillance of individuals with intellectual disabilities in Canada. *Chronic Diseases and Injuries in Canada* 2011; 32: 194–9.
15. Lennox N, Taylor M, Rey-Conde T, Bain C, Purdie DM, Boyle F. Beating the barriers: Recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research* 2005; 49: 296–305.
16. Molinari AL, Gill CE, Taylor HM, Charles PD. Barriers to conducting research with community-dwelling adults who have intellectual disabilities. *Intellectual and Developmental Disabilities* 2011; 49: 392–6.
17. Young L, Moni K, Jobling A, Kraayenoord C. Literacy skills of adults with intellectual disabilities in two community based day programs. *International Journal of Disability Development and Education* 2004; 51: 83–97.
18. Emerson E. Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 2007; 13: 107–13.
19. Cleaver S, Ouellette-Kuntz H, Sakar A. Participation in intellectual disability research: A review of 20 years of studies. *Journal of Intellectual Disability Research* 2010; 54: 187–93.
20. Swanson GM, Ward AJ. Recruiting minorities into clinical trials toward a participant-friendly system. *Journal of the National Cancer Institute* 1995; 87: 1747–59.
21. Patel DR, Merrick J. Intellectual disability. In DR Patel, DE Greydanus, HA Omar, J Merrick (eds) *Neurodevelopmental Disabilities: Clinical Care for Children and Young Adults*. Dordrecht; New York: Springer, 2011, pp. 161–71.
22. Hayes S. *Identifying Intellectual Disability in Offender Populations – And What Then?* Liverpool: Prison Research Project, 2004.
23. Emerson E. Health status and health risks of the 'hidden majority' of adults with intellectual disability. *Intellectual and Developmental Disabilities* 2011; 49: 155–65.
24. Feldman MA, Bosett J, Collet C, Burnham-Riosa P. Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of Intellectual Disability Research*.2014; 58: 800–9.
25. Walmsley J, Johnson K. *Inclusive Research with People with Intellectual Disabilities: Past, Present and Futures*. London: Jessica Kingsley Publications Ltd, 2003.
26. Green JM, Wood AJ, Kerfoot MJ, Trainor G, Roberts C, Rothwell J *et al*. Group therapy for adolescents with repeated self harm: Randomised controlled trial with economic evaluation. *British Medical Journal* 2011; 342: d682.
27. Cockayne S, Hewitt C, Hicks K, Jayakody S, Kang'ombe AR, Stamuli E *et al*. Cryotherapy versus salicylic acid for the treatment of plantar warts (verrucae): A randomised controlled trial. *British Medical Journal* 2011; 342: d3271.
28*. Thakur JS, Prinja S, Singh D, Rajwanshi A, Prasad R, Parwana HK *et al*. Adverse reproductive and child health outcomes among people living near highly toxic waste water drains in Punjab, India. *Journal of Epidemiology and Community Health* 2010; 64: 148–54.
29*. Zheng X, Chen G, Song X, Liu J, Yan L, Du W *et al*. Twenty-year trends in the prevalence of disability in China. *Bulletin of the World Health Organization* 2011; 89: 788–97.
30*. Knudsen AK, Hotopf M, Skogen JC, Øverland S, Mykletun A. The health status of nonparticipants in a population-based health study: The Hordaland health study. *American Journal of Epidemiology* 2010; 172: 1306–14.
31*. Moeller JF, Chen H, Manski RJ. Investing in preventive dental care for the Medicare population: A preliminary analysis. *American Journal of Public Health* 2010; 100: 2262–9.

32*. Morgan VA, Valuri GM, Croft ML, Griffith JA, Shah S, Young DJ *et al*. Cohort Profile: Pathways of risk from conception to disease: The Western Australian schizophrenia high-risk e-Cohort. *International Journal of Epidemiology* 2010; 40: 1477–85.
33*. O'Donnell M, Nassar N, Leonard H, Jacoby P, Mathews R, Patterson Y *et al*. Characteristics of non-Aboriginal and Aboriginal children and families with substantiated child maltreatment: A population-based study. *International Journal of Epidemiology* 2010; 39: 921–8.
34. Balogh R, Brownell M, Ouellette-Kuntz H, Colantonio A. Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability – A population perspective. *Journal of Intellectual Disability Research* 2010; 54: 820–32.
35. Robotham D, King M, Canagasabey A, Inchley-Mort S, Hassiotis A. Social validity of randomised controlled trials in health services research and intellectual disabilities: A qualitative exploration of stakeholder views. *Trials* 2011; 12: 144.
36. Iacono T. Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability* 2006; 31: 173–9.
37. Heilgenkamp T, Bastiaanse L, Hermans H, Penning C, van Wijck R, Evenhuis H. Study health ageing and intellectual disabilities: Recruitment and design. *Research in Developmental Disabilities* 2011; 32: 1097–106.