Hospital admissions for physical health conditions for people with intellectual disabilities: Systematic Review.

Abstract

Background: People with intellectual disabilities may have inequalities in hospital admissions compared with the general population. We aimed to investigate their admissions for physical health conditions.

Methods: We conducted a systematic review, searching six databases using terms on intellectual disabilities and hospital admission. Papers were selected based on pre-defined inclusion/exclusion criteria, data extracted, tabulated, and synthesised, and quality assessed. PROSPERO registration number: CRD42015020575.

Results: 7/29,613 papers were included. There were more admissions, and a different pattern of admissions (more medical/dental), for people with intellectual disabilities, but most studies did not take account of higher disease prevalence. Three papers considered admissions for ambulatory care-sensitive conditions, two of which accounted for disease prevalence and found higher admission rates for people with intellectual disabilities.

Conclusion: Admissions are common. Asthma and diabetes admission data suggests sub-optimal primary health care for people with intellectual disabilities compared with the general population, but evidence is limited.

Introduction

People with intellectual disabilities have more complex health needs and are thought to be admitted to hospital more frequently than the general population (Morgan & Kerr, 2000; Williams et al, 2005; van Schrojenstein Lantman-de Valk, 2009; Bebbington et al, 2013; Robertson et al, 2014). Their pattern of types of health needs also differs from the general population (Lin et al, 2003; Cooper et al, 2015). People with intellectual disabilities may also encounter barriers when admitted to hospital. This has been found across countries, for example in England (Mencap, 2007; Mencap 2012), Australia (Iacono et al, 2014), and the USA (Krahn et al, 2006). A recent review found problems with delivery of care in hospital including staff knowledge, skills, and attitudes (Iacono et al, 2014). An understanding of the frequency and types of admissions would provide knowledge that could be used to inform where and how to focus support for secondary care staff.

Psychiatric hospitalisations of people with intellectual disabilities, which are known to be more common, with multiple influences, have been extensively researched (Balogh et al, 2005; Charlot et al, 2011; Gustafsson, 1997). However, it is equally important to know about hospitalizations for physical conditions generally. It is unclear whether people with intellectual disabilities are admitted to hospital more frequently than the general population who

have the same physical health conditions (i.e. accounting for the prevalence of conditions). This is important to consider as the population with intellectual disabilities have more physical conditions than the general population, and one would expect that a higher prevalence of a condition would result in more hospital admissions (Balogh et al, 2010; Cooper et al, 2015).

Ambulatory care-sensitive conditions are defined as conditions which, if managed effectively at the primary care level, should not lead to a hospital admission (Billings et al 1993), as appropriate primary health care should delay the progression of the disease or prevent complications (Balogh et al, 2005; Jansen et al, 2004). Examples are diabetes and asthma. Studies with the general population have documented a relationship between high rates of hospitalisations for ambulatory care-sensitive conditions, and poor access to primary care (Caminal et al, 2004; Ansari et al, 2006). However, it is unclear if people with intellectual disabilities are admitted to hospital more frequently than the general population for ambulatory care-sensitive conditions. A number of lists of ambulatory care-sensitive conditions have been constructed by different researchers, some focussing on particular populations or regions. Purdy (2009) conducted a literature search of ambulatory care-sensitive conditions and found that various jurisdictions identified up to 36 different ambulatory care-sensitive conditions. The National Health Service (NHS) in

England commonly uses a subset of 19 of these conditions which are based on those used in the USA to measure access to primary health care (table 1). Additionally, Balogh et al (2011) has developed a list of eleven ambulatory care-sensitive conditions which are specific to people with intellectual disabilities e.g. constipation.

Table 1: Ambulatory care-sensitive conditions as identified by Purdy (2009)

1. Influenza and Pneumonia 2. Other Vaccine-Preventable Conditions 3. Asthma 4. Congestive Heart Failure 5. Diabetes Complications 6. Chronic Obstructive Pulmonary Disease (COPD) 7. Angina 8. Iron Deficiency Anaemia 9. Hypertension	10. Nutritional Deficiencies 11. Dehydration and Gastroenteritis 12. Pyelonephritis 13. Perforated/Bleeding Ulcer 14. Cellulitis 15. Pelvic Inflammatory Disease 16. Ear, Nose and Throat Infections 17. Dental Conditions 18. Convulsions and Epilepsy 19. Gangrene

Despite their high rates of physical health conditions, people with intellectual disabilities are reported to face a number of organizational, social, and physical barriers to accessing timely and appropriate primary health care services (Krahn et al, 2006; Emerson & Baines, 2010). A higher rate of admissions amongst people with intellectual disabilities compared with the general

population for either the same condition, or for ambulatory care-sensitive conditions might suggest poorer primary health care management.

This systematic review aims to investigate whether physical health care is equitable for people with intellectual disabilities, through focussing on hospital admissions. The research questions were:

1. Are people with intellectual disabilities admitted to hospital more frequently than the general population, and do any differences in admission rate persist when between-group disease prevalence differences are adjusted for?

2. Are people with intellectual disabilities admitted to hospital for the same reasons as the general population?

3. Are people with intellectual disabilities admitted to hospital more frequently for ambulatory care-sensitive conditions than the general population, and do any differences in admission rates persist when between-group disease prevalence differences are adjusted for?

Methods

The review was prospectively registered with the International Prospective Register of Systematic Reviews (PROSPERO, registration number: CRD42015020575). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was followed.

The literature search was conducted on 2nd February 2015, and updated on 8th February 2016. The specific search strategy included relevant terms for intellectual disabilities (including historical terms), and terms for hospital admission (Appendix).

The following databases were searched: Psych INFO, Science Direct, Medline, Cochrane database, NICE guidelines, and Web of Science Core Collection, dating back to 1st January 1960. Reference lists of included papers were scrutinised, as were citing papers. The initial search was conducted by a single researcher, with a second researcher searching a random selection of the retrieved papers; 5% of titles, and 5% of abstracts. This was done so that the reasons for any discrepancies in paper selection could be identified and resolved through discussion to enable a systematic approach to paper selection across all retrieved articles. Authors were contacted for further information where it was not clear if the study met the inclusion criteria.

Strict inclusion and exclusion criteria were used to select papers:

Inclusion Criteria

1. Intellectual disabilities

2. In-patient admissions

3. Reported frequency of, and/or reason for, hospital admissions, compared with the general population

4. English language

Exclusion Criteria

1. Psychiatric admissions only

2. Data for people with intellectual disabilities were not separately reported, or less than 50% of the sample had intellectual disabilities.

3. Case series of less than 20.

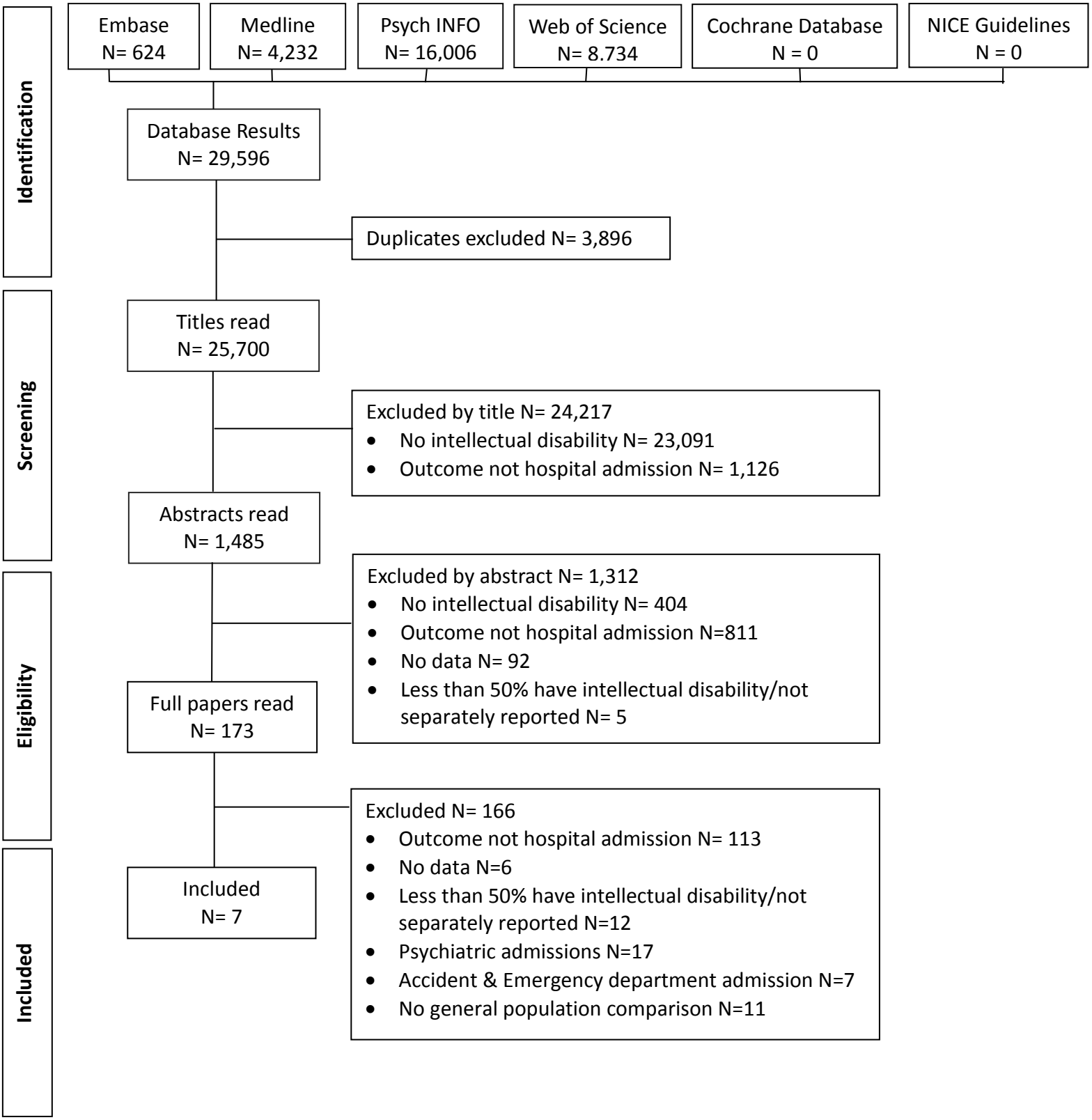
We used the NHS England list of 19 conditions to identify those conditions that were ambulatory care sensitive conditions. There was no age restriction. We deliberately excluded psychiatric papers at the outset, as we are aware of confusion in some of the psychiatric literature as to long stay and respite care stay versus acute psychiatric hospitalisations, and rates of psychiatric admissions are highly dependent upon third sector and private sector resourcing in the locality. We focussed on in-patient admissions, so excluded accident and emergency department attendance that did not lead to admission.

Data were extracted from selected papers using pre-prepared data extraction tables, and then summarised. Quantitative tools for assessing the quality of randomised controlled trials are well-described, but there is less consensus for observational studies. We assessed the quality of all the selected studies in a systematic way, ensuring we covered all the domains included in a systematic review of tools to assess quality of observational studies (Sanderson et al, 2007). This included the clarity of the stated aims, methodology (including age/gender standardisation, and whether group differences in disease prevalence rates were considered), design, participant selection, study size, measures used, data collected, analyses employed, results, biases, generalisability, conflicts of interests, and ethical procedures. Additionally, in order to generate a "score" we added up the number of items on the Oxford Critical Appraisal Skills Programme Checklist (CASP UK, 2013) that were addressed in each study. The reliability of the appraisal was checked by the appraisal being conducted and compared by two of the authors.

Results

A total of 29,613 papers were retrieved using the search strategy. The flow chart documents the number of papers included/excluded at each stage after

reading titles, abstracts, and full papers, and the reasons for exclusions (figure 1).



The first and second researchers fully agreed on all the titles and abstracts to be included at these stages, so further discussions were not required. One author was contacted and responded to a request for additional information. Seven papers met all inclusion criteria and were selected for inclusion.

Regarding the first research question, Table 2 presents the four studies which report the frequency of admissions overall (rather than only for ambulatory care sensitive conditions) for individuals with intellectual disabilities compared to a general population comparison group (Asberg, 1989; Morgan, Ahmed & Kerr, 2000; Williams et al, 2005; Derrington et al, 2013). Two studies focussed on adults, and two on children, one of which was specifically about children with Down syndrome. The studies were from Sweden, the UK, Australia, and the USA. Their results indicate that both adults and children with intellectual disabilities are admitted to hospital more frequently than members of the general population. However, none considered whether this difference in admission rate persisted when between-group disease prevalence differences are adjusted for. Evidence from these papers also suggests that, once admitted to hospital, adults and children with intellectual disabilities have a longer length of stay (Asberg et al, 1989; Morgan et al, 2000).

Regarding the second research question, table 3 summarises the three studies that consider an overview on whether people with intellectual disabilities are

admitted for the same reasons as the general population (Morgan et al, 2000; Williams et al, 2005; Ailey et al, 2014). Two studies focussed on adults, and one on children up to age 5. The studies were from the UK, Australia, and the USA. The more methodologically robust of the two adult papers reported that adults are more likely to be admitted for medical and dental reasons, and less likely for surgical reasons (Morgan et al, 2000). The other adult study did not report data in a comparable way, including only the five most common discharge diagnoses, all of which were medical reasons, and mostly more common in the group with intellectual disabilities (Ailey et al, 2014). Children with intellectual disabilities were more likely to be admitted than were the comparison group for numerous medical reasons, but not so for disorders of the oral cavity. None of these three papers standardised admission rates for the prevalence of disorders in the two groups.

Regarding the third research question, three papers reported admissions for ambulatory care-sensitive conditions (table 4). The studies were from Canada and the USA. Admissions for epilepsy or seizures were reported in two papers (Balogh et al, 2010; Ailey et al, 2014), and additionally for asthma and diabetes in one of these (Balogh et al, 2010), whilst the third focussed specifically on diabetes (Balogh et al, 2015). Only the studies by Balogh et al (2010, 2015) took account of the likely different prevalence rates of these conditions

between people with intellectual disabilities and the general population which would cause an anticipated difference in admission rates. Balogh (2010) found that admission rates for people with intellectual disabilities were higher for epilepsy, asthma and diabetes. Rate ratios for diabetes and asthma remained significant even after taking account of the population prevalence of these diseases. Balogh et al (2015) also found a significantly higher rate of admissions amongst people with intellectual disabilities and diabetes, which also remained significant after taking account of diabetes prevalence. A further paper which investigated factors associated with hospitalisations for ambulatory care-sensitive conditions, was initially selected, but excluded as it identified factors associated with hospitalisations and did not address the review questions (Balogh et al, 2013).

A systematic quality review revealed that there were limitations to most of the studies that were selected for inclusion in the review; we report these in the tables 4-6.

During our search, we identified several other papers which also reported on admission rates, but these studies did not meet our inclusion criteria as they did not include a general population comparison group. High levels of admission rates were recorded in all these studies, particularly during the first few years of life. A further study focussed only on admissions via emergency

departments (Venkat et al, 2011), and another reported admissions for people with developmental disabilities, but did not separately report people with intellectual disabilities (Walsh et al, 1997). A further nine studies detailed reasons for admission to hospital, typically medical conditions such as respiratory diseases, but did not contain a general population comparison group (Merrick et al, 2005; Merrick et al, 2006; Morad et al, 2007; Merrick et al, 2010a; Merrick et al, 2010b; Merrick et al, 2010c; Fitzgerald et al, 2013; Sullivan et al, 2008; Lin et al, 2007). Four papers reported respiratory diseases, cardiovascular diseases, and heart disease as reasons for admission for children with Down syndrome, but did not have comparison groups (Fitzgerald et al, 2013; So et al, 2007; Thomas et al, 2011).

Discussion

People with intellectual disabilities experience considerable health inequalities compared with the general population, yet the current contribution of health care and health care services to increasing or reducing these inequalities, remains unclear. We have demonstrated, albeit from a slender body of evidence, that people with intellectual disabilities have a higher rate, and different pattern of hospital admissions compared with the general population,

and found emerging evidence that poorer primary health care might contribute to this.

We found that the quantity and quality of existing research is surprisingly limited. Indeed, the study by Asberg (1989) may not be more widely generalisable, and that of Derrington (2013) was specifically of young Down syndrome children so cannot be synthesised with that on young children with intellectual disabilities by Williams (2004), given the different health profiles with congenital heart disease being common in Down syndrome. There was considerable differences in the ages studied, few studies overall, and none but two of the studies adjusted for the different prevalence rates of conditions experienced by people with intellectual disabilities and the associated anticipated difference in rate and pattern of hospital admissions in this population.

The limitations in the evidence are important findings, as firm conclusions cannot be drawn without robust evidence. In particular, further study of ambulatory care-sensitive conditions seems highly indicated; to better understand the relationships and contributions to the health care of people with intellectual disabilities across health care systems, and its impact on health inequalities. The studies included in the review were undertaken using data from countries with differing health care systems and support systems,

yet, whilst acknowledging the limitations in the evidence-base, they are suggestive of poorer health care for people with intellectual disabilities across these countries. This highlights that the problem of poor health care is not localised to one particular type of service organisation and delivery, and so does not have an easy solution, and needs to be further studied to be better understood.

Some concerns have been raised over the variation in lists of ambulatory care-sensitive conditions used in different studies, methods of categorizing admissions as “avoidable”, and the influence of socioeconomic factors on these types of admissions (Flores, 2005; Steiner, 2007), hence these caveats need acknowledging. However, rates of ambulatory care-sensitive admissions are increasingly used as a measure of the effectiveness of primary health care (Purdy et al, 2009). Indeed, Balogh et al (2011) developed a list of eleven ambulatory care-sensitive conditions which are specific to people with intellectual disabilities e.g. constipation. Future work could further explore ambulatory care-sensitive conditions which are unique to this population.

A further potential limitation is that length of hospital stay may be influenced by the patient requiring a new support package/home, or carers needing respite to deal with complex needs at home.

Our review throws light upon where within hospital settings, a focus on staff awareness of the needs of people with intellectual disabilities might have impact on a greater number of people, that is, in medical and dental settings, rather than surgical ones. It might seem surprising that surgical admissions were found to occur at a lower rate than for the general population. One might speculate that this is due to barriers accessing such procedures, but this cannot be confirmed by our review and would require further investigation, and primary data collection.

We systematically reviewed the quality of each of the included studies, and presented the limitations in tables 2-4. We also evaluated the quality of our own systematic review, using the Assessing the Methodological Quality of Systematic Reviews (AMSTAR) checklist, but recognise that there is an inherent bias in evaluating ones own work. The strengths of this review include the prospective registration of the review protocol, following best practice guidelines (PRISMA), clear inclusion and exclusion criteria, the comprehensive search strategy, including papers from 1960 to the present, and searching multiple databases, and double rating of paper selection and quality. However, the review is limited by excluding papers which were not available in English. As the review focussed on admissions for physical health conditions, we do not comment on psychiatric admissions for this population.

In conclusion, we can tentatively say that people with intellectual disabilities experience a higher rate and different pattern of hospital admissions compared with the general population, and there is emerging evidence that this might reflect poorer primary health care. The higher volume of admissions of people with intellectual disabilities in medical and dental areas highlights the importance of staff awareness on the need of people with learning disabilities in these areas, and guides as to focussing effort and resources, and prioritising, supporting and training staff working on these types of wards. Further work to better understand patterns of admissions on ambulatory care-sensitive conditions and relationships to health inequalities is indicated.

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References

Ailey, S. H., Johnson, T., Fogg, L., Friese, T. R. (2014). Hospitalizations of adults with intellectual disability in academic medical centers. *Mental Retardation.* ***52*****(3),** 187-192.

Ansari, Z., Laditka, J. N., Laditka, S. B. (2006). Access to health care and hospitalization for ambulatory care sensitive conditions. *Medical care research and review*, ***63*****(6),** 719-741.

Åsberg, K. H. (1989). The need for medical care among mentally retarded adults. A 5-year follow-up and comparison with a general population of the same age. *The British Journal of Mental Subnormality*. ***35*****(68),** 50-57.

Balogh, R., Brownell, M., Ouellette-Kuntz, H., Colantonio, A. (2010). Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability-a population perspective. *Journal of Intellectual Disability Researc.* ***54*****(9),** 820-832.

Balogh, R. S., Hunter, D., & Ouellette- Kuntz, H. (2005). Hospital utilization among persons with an intellectual disability, Ontario, Canada, 1995–2001. *Journal of Applied Research in Intellectual Disabilities*, *18*(2), 181-190.

Balogh, R. S., Ouellette-Kuntz, H., Brownell, M., & Colantonio, A. (2011). Ambulatory care sensitive conditions in persons with an intellectual disability–

development of a consensus. *Journal of Applied Research in Intellectual Disabilities*. **24(2)**, 150-158.

Balogh, R. S., Ouellette-Kuntz, H., Brownell, M., Colantonio, A. (2013). Factors associated with hospitalisations for ambulatory care-sensitive conditions among persons with an intellectual disability–a publicly insured population perspective. Journal of Intellectual Disability Research. 57(3), 226-239.

Balogh, R. S., Lake, J. K., Lin, E., Wilton, A., Lunsky, Y. (2015). Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. Diabetic Medicine. 32(2), 235-242.

Bebbington, A., Glasson, E., Bourke, J., de Klerk, N., & Leonard, H. (2013). Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983–1999: a population-based cohort study. *BMJ open*,*3*(2), e002356.

Billings, J., Zeitel, L., Lukomnik, J., Carey, T. S., Blank, A. E., Newman, L. (1993). Impact of socioeconomic status on hospital use in New York City. *Health affairs.* ***12*(1),** 162-173.

Blackman, J. A., & Gurka, M. J. (2007). Developmental and behavioral comorbidities of asthma in children. *Journal of Developmental & Behavioral Pediatrics*, ***28*(2),** 92-99.

Caminal, J., Starfield, B., Sánchez, E., Casanova, C., Morales, M. (2004). The role of primary care in preventing ambulatory care sensitive conditions.*The European Journal of Public Health*, ***14*(3),** 246-251.

Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., & Deutsch, C. (2011). Non- psychiatric health problems among psychiatric inpatients with intellectual disabilities. *Journal of Intellectual Disability Research*, *55*(2), 199-209.

Critical Appraisal Skills Programme (CASP) 2014. CASP Cohort Study Checklist (http://www.casp-uk.net/checklists) Oxford. CASP

Cooper, S-A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F. Morrison, J. (2015) Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. BMC Family Practice, DOI: 10.1186/s12875-015-0329-3.

Derrington, T. M., Kotelchuck, M., Plummer, K., Cabral, H., Lin, A. E., Belanoff, C., Grosse, S. D. (2013). Racial/ethnic differences in hospital use and cost among a statewide population of children with Down syndrome. *Research in developmental disabilities*. ***34*(10),** 3276-3287.

Emerson, E., & Baines, S. (2010) Health inequalities and people with learning disabilities in the UK:2010, Improving health and lives: learning disabilities observatory.

Fitzgerald, P., Leonard, H., Pikora, T. J., Bourke, J., Hammond, G. (2013). Hospital admissions in children with Down syndrome: experience of a population-based cohort followed from birth. *PLOS one.* ***8*****(8),** 70401.

Flore, G. (commentary in the Lancet, 2005). Preventing hospitalizations for children, **365**, 201-202

Gale, L., Naqvi, H., Russ, L. Asthma, smoking and BMI in adults with intellectual disabilities: a community-based survey. *Journal of Intellectual Disability Research* (2009). **53(9),** 787-96.

Gustafsson, C. (1997) The prevalence of people with intellectual disability admitted to general hospital psychiatric units: level of handicap, psychiatric diagnoses and care utilization. *Journal of Intellectual Disability Research*, 41, 519‑526.

Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014). A systematic review of hospital experiences of people with intellectual disability. *BMC health services research*, *14*(1), 1.

Jansen, D. E., Krol, B., Groothoff, J. W., & Post, D. (2004). People with intellectual disability and their health problems: a review of comparative studies. *Journal of Intellectual Disability Research*, *48*(2), 93-102.

Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental retardation and developmental disabilities research reviews*, *12*(1), 70-82.

Lin, J. D., Wu, J. L., & Lee, P. N. (2003). Healthcare needs of people with intellectual disability in institutions in Taiwan: outpatient care utilization and implications. *Journal of Intellectual Disability Research*, *47*(3), 169-180.

Lin, J. D., Loh, C. H., Yen, C. F., Li, C. W., Chwo, M. J., & Wu, J. L. (2007). Medical care services for people with intellectual disabilities living in the general community: A cross-sectional survey of inpatient care utilization in Taiwan, 2001. *Disability and rehabilitation*, ***29*(18)**, 1411-1416.

Mencap, Royal.(2007) "Death by indifference." *London, Mencap*.

Mencap, Royal. (2012) “Death by indifference: 74 deaths and counting. A progress report 5 years on.” London, Mencap.

Merrick, Y. (2005). National survey 1998 on medical services for persons with intellectual disability in residential care in Israel. *International Journal on Disability and Human Development*, ***4*(2)**, 139-146.

Merrick, J. (2006). National survey 1999 on medical services for persons with intellectual disability in residential care in Israel. *International Journal on Disability and Human Development*, ***5*(3)**, 303-308.

Merrick, J., Kandel, I., Lotan, M., Aspler, S., Fuchs, B. S., & Morad, M. (2010a). National survey 2008 on medical services for persons with intellectual disability in residential care in Israel. *International Journal on Disability and Human Development*, ***9*(1)**, 59-63.

Merrick, J., Kandel, I., Lotan, M., Aspler, S., Fuchs, B. S., & Morad, M. (2010b). National survey 2007 on medical services for persons with intellectual disability in residential care in Israel. *International journal of adolescent medicine and health*, ***22*(4)**, 575-582.

Merrick, J., Kandel, I., Raskas, M., Caplan, L., & Morad, M. (2010c). National survey 2004 on medical services for persons with intellectual disability in residential care in Israel. *International journal of adolescent medicine and health*, ***22*(2)**, 331-338.

Morad, M., Nelson, N. P., Merrick, J., Davidson, P. W., & Carmeli, E. (2007). Prevalence and risk factors of constipation in adults with intellectual disability in residential care centers in Israel. *Research in developmental disabilities*, ***28*(6)**, 580-586.

Morgan, C. L., Ahmed, Z., & Kerr, M. P. (2000). Health care provision for people with a learning disability Record-linkage study of epidemiology and factors contributing to hospital care uptake. *The British Journal of Psychiatry.**176*(1),** 37-41.

Purdy, S., Griffin, T., Salisbury, C., Sharp, D. (2009) Ambulatory care sensitive conditions: terminology and disease coding need to be more specific to aid policy makers and clinicians. *Public Health*. **123(2),**169-73.

Reichard, A., Stolzle, H. (2011) Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. *Intellectual and Developmental Disabilities.* **49(3)**, 141-54.

Robertson, J., Hatton, C., Emerson, E., Baines, S. (2015). Prevalence of epilepsy among people with intellectual disabilities: A systematic review. *Seizure*, ***29*****,** 46-62.

Sanderson, S., Tatt, I.D>, Higgins, J.P.T. (2007) Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *International Journal of Epidemiology*, ***36,*** 666–676.So, S. A., Urbano, R. C., Hodapp, R. M. (2007). Hospitalizations of infants and young children with Down syndrome: evidence from inpatient person-records from a statewide administrative database. *Journal of Intellectual Disability Research.* ***51*****(12),** 1030-1038.

Steiner, J. F. (2007). Hospitalizations for ambulatory care-sensitive conditions: where do we go from here?. *Academic Pediatrics*, *7*(3), 263.

Sullivan, S. G., Hussain, R. (2008). Hospitalisation for cancer and co-morbidities among people with learning disability in Australia. *British Journal of Learning Disabilities.* ***36*****(3),** 191-197.

Thomas, K., Bourke, J., Girdler, S., Bebbington, A., Jacoby, P., & Leonard, H. (2011). Variation over time in medical conditions and health service utilization of children with Down syndrome. *The Journal of pediatrics*, ***158*****(2)**, 194-200.

van Schrojenstein Lantman-de, H. M., & Walsh, P. N. (2008). Managing health problems in people with intellectual disabilities. *British Medical Journal*, *337*, a2507.

Venkat, A., Pastin, R. B., Hegde, G. G., Shea, J. M., Cook, J. T., Culig, C. (2011). An analysis of ED utilization by adults with intellectual disability. *The American journal of emergency medicine.* ***29*****(4),** 401-411.

Walsh, K. K., Kastner, T., & Criscione, T. (1997). Characteristics of hospitalizations for people with developmental disabilities: utilization, costs, and impact of care coordination. *American journal of mental retardation: AJMR*, ***101*****(5)**, 505-520.

Williams, K., Leonard, H., d'Espaignet, E. T., Colvin, L., Slack-Smith, L., & Stanley, F. (2005). Hospitalisations from birth to 5 years in a population cohort of Western Australian children with intellectual disability. *Archives of disease in childhood.* ***90*****(12),** 1243-1248.

Appendix. Database Search Terms

1. Mental

2. intellectual or learning or developmental or neurodevelopmental

3. handicap or disabilit* or difficult* or impairment or deficien* or incapacit* or delay or problem or subaverage

4. disorder or condition

5. subnormal

6. feeble minded or imbecile or idiot

7. moron

8. oligophreni*

9. aphreni*

10. defective

11. retard*

12. Down syndrome

13. 1 + 3

14. 2 + 3

15. 2 + 4

16. 12 + 13 + 14 + 15 + 5 + 6 + 7 + 8 + 9 + 10 + 11

17. Admission

18. Hospital

19. Inpatient

20. Secondary care

21. 17 + 18 + 19 + 20

22. 16 + 21

Table 2. Frequency of admissions to hospital

Paper	ID Patient Characteristics	ID Data Source	Comparison Group Characteristics and Data Source	Measures and Analyses	Findings	Critique/Quality
Asberg (1989)	N= 41 27 (65.9%)M 14 (34.1%) F 20-64[1] years 20-44 years= 68.3% 45-64 years= 31.7% ID level:Mild-16, Moderate-13, Severe-12, Profound-0 Uppsala, Sweden Cohort identified 01.07.1982	Medical records of one physician Retrospective review	N=Unspecified General population data from neighbouring district, not age nor gender matched 20-44 years= 58% 45-64 years= 42%	ID: Retrospective review of medical records for hospital admissions 01.07.1982-30.06.1987 General population: Mean number of admissions to the departments of medicine, surgery, psychiatry, and gynaecology, 1982-1985[2]	Mean number of admissions/person: • 20-44y: 0.3 for ID, compared to 0.06 • 45-64y: 0.3 for ID, compared to 0.09	• 9/14 CASP Score Lost points for recruitment (catchment area of one physician only), accuracy of exposure (N/A), confounding factors (few identified in the paper) and generalisability of results (due to recruitment method) Additionally: • Small sample • Data collected by the treating physician • Medical records may be incomplete • Comparison group from a different health district • Comparison group not age/gender matched • Comparison group data may have been for 4 rather than 5 years • Differences in disease prevalence rates not accounted for • Funding source not disclosed
Morgan et al (2000)	N= 1,595 5-75+ years ID prevalence per 1000 of 4.1 M, 3.2 F ID level not specified South Glamorgan Health Authority, UK Cohort identified 31.12.1996	ID register (known to Social Services/ID health service), or ID coded during hospital admission	N=434,000 Gender and age not specified South Glamorgan Health Authority, 1996	Secondary analysis of routinely collected hospital discharge statistics 991-1996; Record linkage to ID data sources	560,408 admissions for both ID and general population groups • 2,678 for ID • 557,730 for general population People with ID represents 0.48% of admissions, whereas 0.37% of study population has ID	• 10/14 CASP Score Lost points for accuracy of exposure (N/A), confounding factors (not taken into account in design) and follow-up (none) Additionally: • Administrative dataset of people with ID • No data on ID severity

[1] Identified as 20-62 in text, but 20-64 in tables.

[2] Discrepancy in text whether same 5 year period for both groups, or 5 years for ID and 4 years for the general population.

						• Comparison group not gender matched • Routinely collected data • Differences in disease prevalence rates not accounted for • Funding source not disclosed
Williams et al (2004)	N=3,522 Gender not specified 0-5 years ID level: Mild/moderate- 211, Severe- 223, Unspecified- 393, ID & Autism- 191, ID with a biomedical cause- 604 Western Australia Born 1983-1992	Australian Midwives Collection database; a Western Australia ID database (Disabilities Services Commission and Department for Education); Western Australia Hospital Morbidity Dataset	N= 238,317 Gender not specified 0-5 years Western Australia Born 1983-1992	Secondary analysis of routinely collected post-birth hospital admission data- first 5 years of life, 1988-1992; record linkage to ID data sources	2,788 (79%) admissions for ID cohort compared with 114,819 (48%) general population Relative risk=1.6 (95%CI 1.6-1.7), p<0.001 Median of 5.3 admissions per ID child compared to 2.2 per general population child. Mean number of child admissions: • Mild/moderate ID (4.3) • Severe ID (8.8) • Unspecified ID (4.8) • ID & Autism (3.0) • ID with a biomedical cause (7.6) • No ID (2.2)	• 13/14 CASP Score Lost points for accuracy of exposure (N/A) Additionally: • Routinely collected data • Not standardised for gender • Not all children with ID will have been identified by 5 years • Differences in disease prevalence rates not accounted for • Independent funding source stated
Derrington (2013)	N= 504 227 (50%) M 227 (50%) F 0- 3 years ID level not specified Down syndrome live births Massachusetts, USA Born Jan 1999-Dec 2004	Born to Massachusetts resident mothers, identified via birth certificates, and birth defects registry	N= 468,600 239,648 (51.1%) M 228,950 (48.9%) F 0-3 years All children without Down syndrome Massachusetts, same hospitals Born Jan 1999-Dec 2004	Secondary analysis of post birth hospitalizations (hospital discharge data) during first 3 years of life Jan 1999- Dec 2004; record linkage to Down syndrome data sources	236 (46.8%) admissions before age 3 years, compared with 48,518 (10.4%) general population Relative risk+4.5 (95% CI 4.1-5.0)	• 13/14 CASP Score Lost points for accuracy of exposure (N/A) Additionally: • Routinely collected data • Too young to specify level of ID • Not all children with ID will have been identified by age 3 years • Differences in disease prevalence rates not accounted for • Independent fundging source stated

F: female

ID: intellectual disabilities

M: male

N: number

CASP: Critical Appraisal Skills Programme Checklist (CASP UK, 2013)

Table 3. Reasons for hospital admission

Paper	ID Patient Characteristics	ID Data Source	Comparison Group Characteristics and Data Source	Measures and Analysis	Findings	Critique/Quality of Study
Morgan et al (2000)	N= 1,595 5-75+ years ID prevalence per 1000 of 4.1 M, 3.2 F ID level not specified South Glamorgan Health Authority, UK Cohort identified 31.12.1996	ID register (known to Social services/ID health services) or ID coded during hospital admission	N=434,000 Gender and age not specified South Glamorgan health Authority, 1996	Secondary analysis of routinely collected hospital discharge statistics 991-1996; Record linkage to ID data sources	(Standardized for age) Admission ratios for ID • Dental: 4.6 (95% CI 3.79-5.47) • Medical: 1.8 (95% CI 1.74-1.92) • Surgical: 0.6 (95% CI 0.59-0.69)	• 10/14 CASP Score Lost points for accuracy of exposure (N/A), confounding factors (not taken into account in design) and follow-up (none) Additionally • Administrative dataset of people with ID • No data on ID severity • Comparison group not gender matched • Routinely collected data • Differences in disease prevalence not considered • Funding source not disclosed
Williams, K. et al (2004)	N=3,522 Gender not specified 0-5 years ID level: Mild/moderate- 2111, Severe- 223, Unspecified- 393, ID & Autism- 191, ID with a biomedical cause- 604 Western Australia Born 1983-1992	Australian midwives Collection database: a Western Australia ID database (Disabilities Services Commission and Department for Education); Western Australia Hospital Morbidity Dataset	N= 238,317 0-5 years Western Australia Born 1983-1992	Secondary analysis of routinely collected post-birth hospital admission data first 5 years of life, 1988-1992; record linkage to ID data sources	Mean no of admissions in first five years (Severe ID, Mild/Moderate ID, Comparison): • Infections: 3.7***, 2.6***, 1.7 • Respiratory: 2.6*, 2.2**, 1.8 • Gastrointestinal tract: 2.2***, 1.8***, 1.3 • Central nervous system: 4.2***, 3.1***, 1.6 • Congenital abnormalities: 2.1**, 1.7*, 1.4 • Oral cavity: 1.2, 1.2, 1.1 • Perinatal period: 1.2**, 1.1, 1.1 • Injury and Poisoning:1.5***, 1.3***, 1.1 • Social admissions: 4.4***, 1.3*, 1.2 • Renal/genital:1.4*, 1.3***, 1.1 • Neoplasm: 10.3, 1.5, 3.5 • Other: 2.1***, 1.6**, 1.3 ***p=0.0000, **p<0.05, *p<0.05 compared with the comparison group.	• 13/14 CASP Score Lost points for accuracy of exposure (N/A) Additionally: • Routinely collected data • Not standardised for gender • Only 0-5 years • Not all children with ID will not have been identified by 0-5 years • Differences in disease prevalence rates not accounted for • Independent funding source stated
Ailey, S.H. et al (2014)	N= 39,397 Gender not specified 18+ years ID level not specified USA	Clinical database from alliance of 115 USA academic medical centres and 300	N=7,847,560 Gender and age not specified Adults without ID from same alliance of	Secondary analysis of discharge diagnosis data from a clinical	0.5% of people had ID ID was over-represented in discharges for their top 5 most prevalent condition groups: • Seizures: 4.1% • Respiratory infection: 2.3%	• 11/14 CASP Score Lost points for accuracy of exposure (N/A), confounding factors (not taken into account in design), and follow-up (length)

	Cohort identified July 2011-June 2013	affiliated hospitals	health care providers	database 07.2011-06.2013 Age standardised admission ratio	• Pneumonia: 0.9% • Psychosis: 2.6% • Septicaemia: 1.2%	Additionally: • Routinely collected data • Comparison group not gender matched • ID identified from secondary diagnosis on clinical database, so likely to be an undercount • Presentation of data precludes the extraction of other comparison data • Differences in disease prevalence rates not accounted for • Funding source not disclosed

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Table 4. Hospital admissions for ambulatory care-sensitive conditions

Paper	ID Patient Characteristics	ID Data Source	Comparison Group Characteristics and Data Source	Measures and Analysis	Findings	Critique/Quality
Balogh et al (2010)	N= 8,000 Gender not specified All ages All persons with ID living in Manitoba, Canada, 1999-2003	Administrative databases detailing contact residents of Manitoba have with health care, social services and education system	N=1,181,658, Gender not specified Manitoba residents without ID hospitalised between 01.01.1999-31.12.03	Secondary analysis of administrative data from Manitoba health care admissions for ambulatory care sensitive conditions Denominator representing person years, crude and adjusted rate ratios (adjusted for gender and 10 year age group) Asthma and diabetes took account of differences in disease prevalence	5 year adjusted rate ratio adjusted for age and sex was 6.1 (95% CI 5.58, 6.72) p<0.0001 Hospitalization rates adjusted for disease prevalence: • Asthma: 2.1 (95% CI 1.39, 3.16) P<0.0004 • Diabetes: 3.7 (95% CI 2.63, 5.29) p<0.0001)	• 13/14 CASP Score Lost points for accuracy of exposure (N/A) Additionally: • Administrative data • Identification of people with ID within routinely collected data • Asthma and diabetes adjusted for disease prevalence • Independent funding source stated
Ailey et al (2014)	N= 39,397 Gender not specified 18+ years ID level not specified USA Cohort identified July 2011-June 2013	Clinical database from alliance of 115 USA academic medical centres and 300 affiliated hospitals	N= 7,847,560 Gender and age not specified Adults without ID from same alliance of health care providers	Secondary analysis of discharge diagnosis data from a clinical database 07.2011-06.2013 Age standardised admission ratio	Most common discharge diagnoses for ID compared to non-ID: • Seizures: 3122 (7.9%) compared to 73,230 (0.9%) 73230 (0.9%) • Pneumonia: 1,098(2.8%) compared to 123,529 (1.6%)	• 11/14 CASP Score Lost points for accuracy of exposure (N/A), confounding factors (not taken into account in design), and follow-up (length) Additionally: • Routinely collected data • Comparison group not age/gender matched • ID identified from secondary diagnosis on clinical database, so likely to be an undercount • Presentation of data precludes the extraction of other comparison data • Differences in disease prevalence rates not accounted for • Funding source not disclosed
Balogh et al (2015)	N=28,567 15217 (53.3%) M 13350 (46.7%) F 30-69 years Ontario, Canada Cohort identified April 2005-March 2010	Institute for Clinical Evaluative Sciences in Ontario, Canada-health databases, registries, & census data Individuals with ID identified using Algorithm from Lin et	N= 2,261,919 1105168 (48.9%) M 1156751 (51.1%) F Random 20% sample of Ontarians without ID in the same health databases	Secondary analysis of diabetes data from Canadian health databases Adjusted odds ratio of ambulatory care sensitive conditions, taking account of diabetes prevalence	Odds of being hospitalized for an ambulatory care sensitive condition related to diabetes within a 5-year period: • Adjusted odds ratio: 2.6 (95% CI 2.21, 3.12)	• 13/14 CASP Score Lost points for accuracy of exposure (N/A) Additionally: • Administrative data • Identification of people with ID within routinely collected data • Unable to identify those with type-

		al (2013)				one and type-two diabetes • Takes account of disease prevalence • Independent funding source stated

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