



BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

Hospitalisation rates for epilepsy, asthma, and insulin-dependent diabetes in 796,190 school aged children and young people with, and without, intellectual disabilities: a record-linkage cohort study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2024-088809
Article Type:	Original research
Date Submitted by the Author:	15-May-2024
Complete List of Authors:	Smith, Gillian; University of Glasgow Institute of Health and Wellbeing, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB Fleming, Michael ; University of Glasgow, Public Health Cooper, Sally-Ann; Glasgow University , Institute of Health and Wellbeing Henderson, Angela; University of Glasgow, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB Pell, Jill; Univ Glasgow, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB Melville, Craig; University of Glasgow Cairns, Deborah; University of Glasgow, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB
Keywords:	Epilepsy < NEUROLOGY, Asthma < THORACIC MEDICINE, Community child health < PAEDIATRICS, DIABETES & ENDOCRINOLOGY, Adolescents < Adolescent

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Hospitalisation rates for epilepsy, asthma, and insulin-dependent diabetes in 796,190 school aged children and young people with, and without, intellectual disabilities: a record-linkage cohort study

Gillian S. Smith,[†] Michael Fleming,[†] Sally-Ann Cooper, Angela Henderson, Jill P. Pell, Craig A. Melville, *Deborah Cairns

[†]Joint first author

School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB

*Correspondence

Word count: 3,420

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objectives

To investigate hospitalisation rates for the ambulatory care sensitive conditions of epilepsy, asthma, and insulin-dependent diabetes in school-age children and young people with intellectual disabilities, in comparison with their peers.

Design

Record-linkage cohort study. Scotland’s Pupil Census, 2008-2013, was used to identify pupils with, and without, intellectual disabilities, and was linked with the Prescribing Information Service to identify pupils with epilepsy, asthma, and insulin-dependent diabetes, and the Scottish Morbidity Records (SMR-01) to identify hospital admissions.

Setting

The general child population of Scotland.

Participants

School pupils aged 4-19 years; 18,278 with intellectual disabilities, and 777,912 without intellectual disabilities.

Outcomes

Overall, emergency, and non-emergency hospitalisations for epilepsy, asthma, and/or diabetes; and length of stay.

Results

Epilepsy and asthma were much more prevalent ($p<0.001$) in the pupils with intellectual disabilities, whereas insulin-dependent diabetes ($p=0.841$) was not. After adjusting for prevalence, pupils with intellectual disabilities and epilepsy had more admissions due to epilepsy than their peers (aHR 2.24, 95% CI 1.97, 2.55). For emergency admissions only, these were of longer duration than for controls (aIRR 2.77, 95% 2.13, 3.59). Pupils with intellectual disabilities and asthma had similar admission rates due to asthma as control pupils with asthma (aHR 0.81, 95% CI 0.62, 1.06), but their emergency admissions were of longer duration (aIRR 2.72, 95% CI 1.49, 4.96). Pupils with intellectual disabilities and insulin-dependent diabetes had similar admission rates to controls (aHR 0.94, 95% CI 0.63, 1.41), but admissions were of shorter duration; (aIRR 0.71, 95% CI 0.51, 0.99).

Conclusions

Our findings suggest pupils with intellectual disabilities may receive poorer community healthcare than their peers for the common conditions of epilepsy and asthma. Hospital admissions are disruptive and stressful for both the child and their family. Additionally, epilepsy and asthma are associated with avoidable deaths, hence a better understanding of these hospitalisations is important.

Strengths and limitations

- Large national study.
- Identification of over 18,000 children and young people with intellectual disabilities.
- Diagnoses of epilepsy, asthma, and insulin-dependent diabetes was based on encashment of prescriptions.
- Cannot distinguish between mild and severe intellectual disabilities.
- Unable to investigate whether there are any ethnic variations.

Funding

MRC Mental Health Pathfinder Award (MC_PC_17217), and the Scottish Government via the Scottish Learning Disabilities Observatory.

Competing interests

None declared.

1
2
3 **Introduction**
4
5
6

7 Ambulatory care sensitive conditions are health conditions for which timely and effective
8 community health care helps to reduce the risks of hospitalisation by preventing the onset
9 of illness, controlling an acute episode of illness, or managing an enduring condition.¹
10 Examples include epilepsy, asthma, and diabetes. General population studies have
11 revealed an association between high rates of hospitalisations for ambulatory care
12 sensitive conditions, and poor access to primary care.^{2,3} Intellectual disabilities are a group
13 of conditions resulting in an intelligence quotient of less than 70, the need for daily support
14 in adaptive functioning, and onset in childhood. People with intellectual disabilities face
15 barriers in accessing community health services.⁴⁻⁶ However there has been little previous
16 study of hospital admissions for ambulatory care sensitive conditions for people with
17 intellectual disabilities in comparison with the general population,⁷ particularly with
18 regards to school-aged children and young people.
19
20
21
22
23
24
25

26
27 Previous studies have reported the frequency of all admissions (rather than specifically for
28 ambulatory care sensitive conditions) for pre-school children with intellectual disabilities
29 compared with the general population. One study, from the USA, reported on children with
30 Down syndrome up to age 3 years, rather than all children and young people with
31 intellectual disabilities,⁸ whilst another, from Western Australia, reported from birth to age
32 5 years.⁹ Both showed higher rates of hospitalisation than for the control population, but
33 they did not take into account different prevalences of conditions between the populations.
34 Likewise, a large study using hospital billing data from four USA states investigated
35 admissions of children aged under 18 years with a combined, heterogenous range of
36 intellectual and developmental disorders (e.g. intellectual disabilities, autism, cerebral
37 palsy).¹⁰ It found the relative risk of hospitalisation was 19.43 (18.56-20.34) for epilepsy
38 and 3.60 (3.33-3.90) for asthma, but did not take account of the different prevalences of
39 these conditions. A further study was focussed specifically on ambulatory care sensitive
40 conditions.¹¹ It included 8,000 people of all ages (children and adults) with intellectual
41 disabilities living in Manitoba, Canada between 1999 and 2003. It reported hospitalisation
42 rate ratios for 14 conditions combined of 6.38 (95% CI 5.30, 7.67) at ages 0-9 years, and
43 8.47 (95% CI 6.89, 10.42) at ages 10-19 years. For specifically asthma and diabetes, it
44 adjusted for the prevalence of the condition, reporting rate ratios of 2.10 (95% CI 1.39,
45 3.16) for asthma and 3.73 (95% CI 2.63, 5.29) for diabetes; however, it did not report
46 rates separately for children or young people for these conditions. A smaller study
47 investigated 107 children and young people with "cognitive and developmental delays"
48 and 943 children and young people without, up to age 18 years, in Quebec, Canada.¹² It
49 did not find any difference in hospitalisation ratios for ambulatory care sensitive conditions
50
51
52
53
54
55
56
57
58
59
60

between the two groups, however the cognitive and developmental delays group was very heterogenous due to coding issues, and included, for example, specific learning disabilities, and speech and language disorders. A further study of 1,148 children with intellectual disabilities and 2,255 control children aged 2-24 years in South Carolina, used hospital billing data to explore eight ambulatory care sensitive conditions but they did not include epilepsy.¹³ They reported more events in the children with intellectual disabilities: an incidence rate ratio (IRR) of 1.23 (1.05-1.44) for emergency room visits, and IRR of 2.62 (1.95-3.32) for in-patient admissions. Finally, a large observational study in England reported rates of emergency admissions for ambulatory care sensitive conditions for people of all ages with intellectual disabilities; with some limited results for children and young people separately.¹⁴ Those aged 0-24 years in the study had 71.0 emergency admissions per 1,000 person-years (95% CI 66.0, 76.4), compared to 15.2 per 1,000 (95% CI 15.1, 15.4) in children/young people without intellectual disabilities. However, the study did not adjust for the prevalence of these conditions or provide further data such as incidence rate ratios for this age group.¹⁴ Hence, the results of existing studies are not directly comparable, accounting for their contradictory findings: we have much to learn on this topic.

The aim of this study was to investigate hospitalisation rates for the ambulatory care sensitive conditions of epilepsy, asthma, and insulin-dependent diabetes in school age children and young people with intellectual disabilities, in comparison with similarly aged control children taking account of the different prevalence of these conditions in the two groups. Epilepsy and asthma were selected as they occur commonly in children with intellectual disabilities. They are also long-term conditions hence the children establish a relationship with their primary health care professionals. The selected linked-dataset that includes these conditions also holds data on insulin-dependent diabetes, hence its inclusion in our aim.

Methods

Approval

This study was approved by the NHS National Services Scotland Privacy Advisory Committee and Public Benefit and Privacy panel (Reference 1617-0259).

Data sources and record linkage

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

This study used administrative data from Scotland’s annual Pupil Census to identify all children and young people with intellectual disabilities in Scotland. The census is held by the Scottish Government, and includes pupils from all local authority schools including special schools, and funded placements; an estimated 95% of schoolchildren across Scotland. The Pupil Census also contained records of any child receiving additional support needs at school due to intellectual disabilities. We used a strict definition of at least two records of support for intellectual disabilities (i.e. 2 years) to identify children with intellectual disabilities. Entry date was defined as the date the second record of support for intellectual disabilities was accrued. The comparison group was formed of pupils with at least two census records, who did not have any records of intellectual disabilities or autism, with the date of their second census record assigned as the study entry date. Only pupils aged between 4 and 19 years at entry were included in the study. Information on sex and neighbourhood deprivation were also derived from the census; deprivation was ascertained using the Scottish Index of Multiple Deprivation (SIMD) 2012, which is based on individual postcode data. SIMD score from the first census record was used for each pupil. Records were linked using probabilistic matching, based on sex, date of birth, and postcode of residence, to administrative health datasets in Scotland, held by Public Health Scotland (PHS). The highest scoring match was used, and unlikely or duplicate matches were excluded.

Information was extracted from the Prescribing Information System (PIS) which recorded all prescriptions encashed in Scotland between 1st January 2009 and 31st December 2013. Data were extracted on medications with British National Formulary (BNF) codes relevant to ambulatory care-sensitive conditions: epilepsy, asthma, and insulin-dependent diabetes. Information was extracted from the Scottish Morbidity Records (SMR) dataset on acute inpatient and day case episodes (SMR-01), and maternity inpatient and day case episodes (SMR-02). These are episode-based datasets on all acute hospital admissions (SMR-01), and all maternity admissions (SMR-02) across Scotland, which record the admission and discharge dates; the main condition or diagnosis for the admission using ICD 10 codes; and whether the admission was an emergency or routine admission. Maternity records (SMR-02) were used to identify any child from a multiparous birth born in Scotland, who were then excluded to remove any potential mismatching between same sex siblings with the same birthdate, as the linkage methodology could not distinguish between them.

Exposure definitions

Encashed prescriptions for disease-specific medications were used as proxy measure for each condition, using methodology validated in previous studies.¹⁵⁻¹⁸ Pupils prescribed at

least one antiepileptic drug (BNF section 4.8) were defined as having epilepsy. Pupils with more than one prescription during the same calendar year for an inhaled steroid and either a long-acting or short acting β -agonist (BNF sections 3.1, 3.2, and 3.3) were defined as having asthma; pupils who only met one of these criteria were excluded. Pupils with at least one insulin prescription (BNF section 6.1.1) were defined as having insulin-dependent diabetes; pupils on oral anti-diabetic medication only were excluded. All conditions were analysed exclusively. Pupils without recorded prescriptions for any of the ambulatory care-sensitive conditions were assigned to the control group for the analysis. For the epilepsy, asthma, and diabetes analyses, the pupils' entry dates were re-assigned as the latest date out of either their diagnosis or their index pupil census record.

Statistical analyses

We calculated the prevalence of three ambulatory care-sensitive conditions - epilepsy, asthma, and diabetes - for pupils with, and without, intellectual disabilities. For each condition, group differences in sex and deprivation quintiles for those with, and without, intellectual disabilities were compared. For each ambulatory care-sensitive condition, all prospective hospital admissions up to the censor date of 13th February 2015, or, if earlier, the date of death, or date the pupil reached age 25 years, were extracted. Data were extracted for admissions due to epilepsy, status epilepticus, or seizures (ICD-10 codes G40, G41, and R568); for asthma or status asthmaticus (ICD-10 codes J45 and J46); and for insulin-dependent diabetes (ICD-10 codes E10-E14). The number of pupils admitted to hospital prospectively during the study, and mean number of admissions per person were compared for pupils with, and without, intellectual disabilities using χ^2 -tests and t-tests, respectively. For each of the ambulatory care sensitive conditions, we reported the incidence rates (pupils with an incident hospitalisation, per 1,000 pupils per year) for those with, and without, intellectual disabilities (including stratified for emergency and routine admissions). Univariate Cox proportional hazards models were used to assess the risk difference between pupils with, referent to without, intellectual disabilities. Cox models adjusted for age at study entry, sex, and neighbourhood deprivation level were also employed. The length of stay in hospital in days was calculated using the admission and discharge dates. Median length of stay and proportion of day cases were compared for pupils with and without intellectual disabilities using Mann-Whitney U tests and χ^2 -tests, respectively, with one day classified as a day-case admission to hospital. Zero-truncated negative binomial regression models were used to report differences in total length of stay for pupils with, referent to without, intellectual disabilities for admitted pupils only (minimum stay of 1 day) for each condition. Robust standard errors for incidence rate ratios (IRR) were used to adjust for multiple admissions per person. Statistical analyses were undertaken using Stata, version 15.0 (StataCorp).

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Patient and public involvement

This research was undertaken within the Scottish Learning Disabilities Observatory. Initially, a systematic review was completed on the topic.⁷ Its findings were presented to the steering committee of the Observatory, which included people with intellectual disabilities, and representatives of two third-sector organisations for people with intellectual disabilities, and family carers. The discussion that followed identified this area as one that should be taken forward for further research and the study design was approved by the steering committee.

Results

Cohort demographics

18,278 (1.9%) pupils were recorded as having intellectual disabilities over the study period, 2009-2013, of whom 11,891 (65.1%) were male. The control group consisted of 777,912 pupils, of whom 389,160 (50.0%) were male. There were more pupils with intellectual disabilities living in areas of greater neighbourhood deprivation; 5,822 (31.9%) in the most deprived quintile compared with 169,038 (21.7%) without intellectual disabilities. More detailed demographic information has previously been reported for this cohort.¹⁹

There were 3,660 pupils who were in receipt of prescriptions for asthma who did not meet our full definition and so were excluded from the asthma analysis. 503 pupils were prescribed an oral anti-diabetic drug but not insulin and so were excluded from the diabetes analysis.

Prevalence of conditions

Table 1 shows the prevalence of each condition in the pupils with, and without, intellectual disabilities, using proxy definitions based on their prescribing information. Epilepsy ($P<0.001$), and asthma ($P<0.001$) had a much higher prevalence among pupils with intellectual disabilities, whereas insulin-dependent diabetes ($P=0.841$) occurred at similar rates in the two groups. 1,608/18,278 (8.8%) pupils with intellectual disabilities had epilepsy, and 6,441/777,912 (0.8%) control pupils. 1,621/18,196 (8.9%) pupils with intellectual disabilities had asthma, and 53,363/774,334 (6.9%) control pupils. 94/18,238 (0.5%) pupils with intellectual disabilities had insulin-dependent diabetes, and 3,924/777,449 control pupils (0.5%).

- Insert Table 1 about here -

Hospital admissions

Epilepsy

Pupils with both intellectual disabilities and epilepsy had more frequent all-cause hospital admission rates compared with control pupils with epilepsy (62% versus 37%, $p < 0.001$). Data on all-cause admissions can be seen in the supplementary data (Table S1). Table 2 shows that pupils with intellectual disabilities and epilepsy had more admissions and day case admissions due to epilepsy than did control pupils with epilepsy (aHR 2.24, 95% CI 1.97, 2.55). Overall, their admissions were for a longer period, but not significantly so.

For the pupils with intellectual disabilities and epilepsy, 864/1,134 (76.2%) epilepsy admissions were emergency admissions, and 270/1,134 (23.8%) were routine admissions. Among control pupils with epilepsy, 828/1,256 (65.9%) epilepsy admissions were emergency admissions, and 428/1,256 (34.1%) were routine admissions. There was an increased risk of an epilepsy emergency admissions for pupils with intellectual disabilities compared to control pupils (aHR 2.50, 95% CI 2.15, 2.91) and for routine epilepsy admissions (aHR 1.57, 95% CI 1.28, 1.91). There was no significant interaction with sex (emergency admission; $p_{\text{interaction}} = 0.112$).

- Insert Table 2 about here -

For emergency admissions, the pupils with intellectual disabilities and epilepsy had longer lengths of stay than the control pupils (IRR 2.77, 95% CI 2.13, 3.59). For routine admissions, the lengths of stay were not significantly different (IRR 0.74, 95% CI 0.53, 1.03).

Asthma

Pupils with both intellectual disabilities and asthma had more frequent all-cause hospital admissions than control pupils with asthma (33% versus 26%, $p < 0.001$). Data on all-cause admissions can be seen in the supplementary data (Table S2). Table 3 shows that pupils with intellectual disabilities and asthma had fewer admissions and day case admissions due to asthma than did control pupils with asthma, but survival analysis showed no significant difference in risk of admission (aHR 0.81, 95% CI 0.62, 1.06). Overall, their admissions were for a similar length of stay.

For the pupils with intellectual disabilities and asthma, 95/146 (65.1%) asthma admissions were emergency admissions, and 51/146 (34.9%) were routine admissions. Among control pupils with asthma, 4,889/5,340 (91.6%) asthma admissions were emergency

admissions, and 451/5,340 (8.4%) were routine admissions. Amongst pupils with asthma, pupils with intellectual disabilities were at similar risk of emergency admissions (aHR 0.83, 95% CI 0.63, 1.08). Data for routine asthma admissions are not shown due to statistical disclosure, as the total 51 routine admissions were for a group of less than 5 pupils with intellectual disabilities; i.e. almost all of the pupils with intellectual disabilities and asthma who were admitted had emergency admissions.

- Insert Table 3 about here -

For emergency admissions, the pupils with intellectual disabilities and asthma had longer length of stay than the control pupils (aIRR 2.72, 95% CI 1.49, 4.96). Calculations were not undertaken for routine admissions.

Diabetes

Pupils with both intellectual disabilities and insulin-dependent diabetes had similar all-cause hospital admission rates compared with control pupils with insulin-dependent diabetes (56% admitted versus 52%, $p<0.353$). Data on all-cause admissions can be seen in the supplementary data (Table S3).

Table 4 shows that pupils with intellectual disabilities and insulin-dependent diabetes had fewer admissions and day case admissions due to diabetes than did control pupils with insulin dependent diabetes, but survival analysis shows no statistical difference (aHR 0.94, 95% CI 0.63, 1.41). Overall, their admissions were of a shorter length of stay (aIRR 0.71, 95% CI 0.51, 0.99).

For the pupils with intellectual disabilities and insulin-dependent diabetes, 47/54 (87.0%) diabetes admissions were emergency admissions, and 7/54 (13.0%) were routine admissions. Among control pupils with insulin-dependent diabetes, 2,849/3,089 (92.2%) diabetes admissions were emergency admissions, and 240/3,089 (7.8%) were routine admissions. Amongst pupils with insulin-dependent diabetes, pupils with intellectual disabilities were at similar risk of emergency admissions (aHR 0.83, 95% CI 0.54, 1.30), and of routine admissions (aHR 1.85, 95% CI 0.87, 3.94).

- Insert Table 4 about here -

For emergency admissions, the pupils with intellectual disabilities had shorter lengths of stay than the control pupils (aIRR 0.67, 95% CI 0.47, 0.95). Calculations were not undertaken for routine admissions.

Discussion

Principle findings and interpretation

For two of the three ambulatory care sensitive conditions we investigated (epilepsy and asthma), our findings suggest that pupils with intellectual disabilities receive poorer community health care than do control pupils. Among pupils with epilepsy, those who also have intellectual disabilities are at higher risk of both emergency and routine hospital admissions for epilepsy than control pupils and spent longer in hospital following the former. Among pupils with asthma, the pupils who also had intellectual disabilities spent longer in hospital following emergency admissions. In contrast, they spent less time in hospital following emergency admission for diabetes. We consider our findings novel, as there is little previous research with which we can compare our findings.

There are several potential interpretations of these findings. The higher risk of epilepsy admissions in the pupils with intellectual disabilities could reflect them having more severe epilepsy than the control pupils, or poorer management of their epilepsy in the community, or both. The longer duration of emergency asthma admissions for pupils with intellectual disabilities suggests that their asthma may be more difficult to resolve once they are admitted, which could plausibly be due to delayed admission due to poorer community management being tolerated for longer than for the control pupils.

Whilst the shorter duration of admissions for diabetes for pupils with intellectual disabilities might be explained by better management in the community it is more likely to be explained by the fact that pupils with intellectual disabilities are less likely to self-administer their insulin than control pupils. Given that adherence is lower among young people,²⁰ administration of medication by parents or carers may improve day-to-day management in the community and/or mean that changes to management in-hospital are quicker to implement.

Comparison with the existing literature

Epilepsy and asthma have previously been reported to be more common among children and young people with intellectual disabilities. We found similar rates of insulin-dependent diabetes in the two groups.

It is difficult to draw comparisons on hospitalisation ratios with previous literature due to study design differences. One study compared child/young person hospitalisation data on 14 ambulatory care sensitive conditions combined, showing them to be more common in

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

those with intellectual disabilities.¹¹ Whilst they were able to account for differences in population prevalence rates for asthma and diabetes in their further calculations, they did not report the ratios separately for children and young people. Some studies we referenced had populations which are not directly comparable to the children and adolescents with intellectual disabilities in our study.^{10,12} Some studies did not adjust for the different prevalence rates,⁸⁻¹⁰ and some studied younger, pre-school children only, so are not comparable to our study.^{8,9}

Strengths and Limitations

A strength of the study is its large size covering all of Scotland, with over 18,000 children and young people with intellectual disabilities. The diagnoses of epilepsy, asthma, and insulin-dependent diabetes were based on encashment of prescriptions; these conditions require drug treatment as they are otherwise life threatening, so this method of identification should be reasonably robust. We used school records to identify the children and young people with intellectual disabilities, and therefore cannot distinguish between mild and severe intellectual disabilities. We were unable to investigate whether there are any ethnic variations.

Implications

Our findings suggest that pupils with intellectual disabilities may receive poorer community health care than their peers for epilepsy and asthma. These are common conditions in children and young people with intellectual disabilities. It has previously been reported, almost exclusively through qualitative research, that adults with intellectual disabilities receive poorer community healthcare, and that many issues contribute to this, including sharing of information within and between care teams. For most children and young people, their healthcare is supported by their parents rather than care teams, so the disparity in quality of epilepsy and asthma care is important to note and understand. Poor inhaler technique may be an issue for some children with intellectual disabilities, but is not insurmountable, as aerochambers, and the larger nebulizers and volumatic spacer devices are available to aid coordination, once the issue has been identified. Additionally, electric or gas-driven nebulizers can be used for bigger doses and to deliver the medication deeper into the chest.

People with ambulatory care sensitive conditions ideally are not admitted to hospital. If admitted they may experience further barriers to care, including those due to staff knowledge, skills, and attitudes,²¹ highlighting the need for support for secondary care staff.

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Enseignement Supérieur (ABES).

Hospital admissions are disruptive to child development and education, and stressful for both the child and their family. In addition, epilepsy and asthma are associated with avoidable deaths, hence a better understanding of hospitalisation for these ambulatory care sensitive conditions is particularly important. Parents and teachers of children and young people with these conditions may benefit from greater support and information.

References

1. Billings J, Zeitel L, Lukomnik J, *et al.* Impact of socioeconomic status on hospital use in New York City. *Health Affairs* 1993;**12(1)**:162-173.
2. Caminal J, Starfield B, Sánchez E, *et al.* The role of primary care in preventing ambulatory care sensitive conditions. *Eur J Public Health* 2004;**14(3)**:246-251.
3. Ansari Z, Laditka JN, Laditka SB. Access to health care and hospitalization for ambulatory care sensitive conditions. *Med Care Res Rev* 2006;**63(6)**:719-741.
4. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation Development Disabilities Res Rev* 2006;**12(1)**:70-82.
5. Cooper S-A, Hughes-McCormack L, Greenlaw N, *et al.* Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: a population-based cohort study. *J Applied Res Intellectual Disabilities* 2017;**31(S1)**:68-81. Doi: 10.1111/jar.12386
6. Hughes-McCormack L, Greenlaw N, McSkimming P, *et al.* Changes over time in the management of long-term conditions in primary health care for adults with intellectual disabilities, and the health care inequality gap. *J Applied Res Intellectual Disabilities* 2021;**34(2)**:634-647. Doi: 10.1111/jar.12833
7. Dunn K, Hughes-McCormack L, Cooper S-A. Hospital admissions for physical health conditions for people with intellectual disabilities: Systematic Review. *J Applied Res Intellectual Disabilities* 2017;**31(S1)**:1-10. DOI: 10.1111/jar.12360
8. Derrington TM, Kotelchuck M, Plummer K, *et al.* Racial/ethnic differences in hospital use and cost among a statewide population of children with Down syndrome. *Res Developmental Disabilities* 2013;**34(10)**:3276-3287.
9. Williams K, Leonard H, d'Espaignet ET, *et al.* Hospitalisations from birth to 5 years in a population cohort of Western Australian children with intellectual disability. *Archives of Disease in Childhood* 2005;**90(12)**:1243-1248.
10. Lindgren S, Lauer E, Momany E, *et al.* Disability, hospital care, and cost: utilization of emergency and inpatient care by a cohort of children with intellectual and developmental disabilities. *J Pediatrics* 2021;**229**:259-266.

11. Balogh R, Brownell M, Ouellette-Kuntz H, *et al.* Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability-a population perspective. *J Intellectual Disability Res* 2010;**54(9)**:820-832.

12. Nachshen J, Martin-Storey A, Campisi L, *et al.* Health and psychiatric disparities in children with cognitive and developmental delays: implications for health policy in Quebec. *J Applied Res Intellectual Disabilities* 2009;**22**:248-255.

13. Hand BN, Boan AD, Bradey CC, *et al.* Ambulatory care sensitive conditions in individuals with autism spectrum disorder, intellectual disability, and population controls. *Autism Research* 2019;**12(2)**:doi.org.1002/aur.2050

14. Glover G, Williams R and Oyinlola J. An observational cohort study of numbers and causes of preventable general hospital admissions in people with and without intellectual disabilities in England. *Journal of Intellectual Disability Research*; 64: 331-344. Observational Study Research Support, Non-U.S. Gov't. DOI: <https://dx.doi.org/10.1111/jir.12722>.

15. Fleming, M. , Fitton, C. A., Steiner, M. F.C., McLay, J. S., Clark, D., King, A., Mackay, D. F. and Pell, J. P. (2019) Educational and health outcomes of children and adolescents receiving antiepileptic medication: Scotland-wide record linkage study of 766 244 schoolchildren. *BMC Public Health*, 19, 595. (doi: 10.1186/s12889-019-6888-9) (PMID:31101093) (PMCID:PMC6525436)

16. Fleming, M. , Fitton, C. A., Steiner, M. F.C., McLay, J. S., Clark, D., King, A., Mackay, D. F. and Pell, J. P. (2019) Educational and health outcomes of children treated for asthma: Scotland-wide record linkage study of 683,716 children. *European Respiratory Journal*, 54(3), 1802309. (doi: 10.1183/13993003.02309-2018) (PMID:31196949) (PMCID:PMC6727030)

17. Fleming, M. , Fitton, C. A., Steiner, M. F.C., McLay, J. S., Clark, D., King, A., Mackay, D. F. and Pell, J. P. (2017) Educational and health outcomes of children treated for attention deficit hyperactivity disorder: Scotland-wide record linkage study of 766,244 children. *JAMA Pediatrics*, 171(7), e170691. (doi: 10.1001/jamapediatrics.2017.0691) (PMID:28459927)

18. Fleming, M. , Salim, E. E., Mackay, D. F. , Henderson, A. , Kinnear, D., Clark, D., King, A., McLay, J. S., Cooper, S.-A. and Pell, J. P. (2020) Neurodevelopmental multimorbidity and educational outcomes of Scottish schoolchildren: A population-based record linkage cohort study. *PLoS Medicine*, 17(10), e1003290. (doi: 10.1371/journal.pmed.1003290)

19. Smith GS, Fleming M, Kinnear D, *et al.* Mortality in 787,666 school pupils in Scotland with and without autism: a cohort study. *Autism* 2021;**25(1)**:300-304. doi: 10.1177/1362361320944037

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Enseignement Supérieur (ABES).

20. Borus JS, Laffel L. Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Curr Opin Pediatr* 2010;22:405-411.
21. Iacono T, Bigby C, Unsworth C, *et al.* A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Res* 2014;**14(1)**:1.

Contributions

GS, MF, and S-AC conceived the study, and GS and S-AC drafted the manuscript. GS and MF undertook the statistical analyses. All authors contributed to the study design, interpretation of findings, and approved the final version.

Data sharing statement

Data may be obtained from a third party, following appropriate approvals, and are not otherwise publicly available. This study linked patient information held across several administrative health data sets within Public Health Scotland, with education data held by the Scottish Government and National Records of Scotland. Linkage and de-identification of data was performed by Public Health Scotland. A data processing agreement between NHS NSS and University of Glasgow and a data sharing agreement between the Scottish Government and University of Glasgow was signed. The University of Glasgow were authorised to receive record-linked data controlled and held by PHS, via access through the national safe haven. The PHS Statistical Disclosure Control Protocol was followed. It is therefore not possible to share data with other parties.

Acknowledgements

We thank the Scottish Government (formerly Scottish Exchange of Educational Data - ScotXed) Pupil Census, the National Records of Scotland and Public Health Scotland, for providing data and the eData Research and Innovation Service team at PHS for assisting with the data linkage.

Disclaimer

The funders had no role in the study design, collection, analyses or interpretation of data, writing the report nor the decision to submit the article for publication.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Enseignement Supérieur (ABES).
Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Table 1. Prevalence of epilepsy, asthma, and diabetes for pupils with, and without, intellectual disabilities.

Condition	Intellectual disabilities		Controls		p-value	Total	
Epilepsy							
Prevalence	1,608/ 18,278	8.8%	6,441/ 777,912	0.8%	p<0.001	8,049/ 796,190	1.0%
Excluded pupils	0		0			0	
Asthma							
Prevalence	1,621/ 18,196	8.9%	53,363/ 774,334	6.9%	p<0.001	54,984 / 792,530	6.9%
Excluded pupils	82		3,578			3,660	
Insulin-dependent diabetes							
Prevalence	94/ 18,238	0.5%	3,924/ 777,449	0.5%	p=0.001	4,018/ 795,687	0.5%
Excluded pupils	40		463			503	

Table 2. Hospital admissions due to epilepsy, status epilepticus, or seizures** amongst pupils with epilepsy, with, and without, intellectual disabilities, including incidence rate ratios, Cox proportional hazards models for risk of admission, and zero-truncated negative binomial regression for total length of stay

All acute admissions due to epilepsy**	Intellectual Disabilities and epilepsy*		Controls and epilepsy*		p-value ^b
Total pupils, n	1,608		6,111		
Total admissions, n	1,134		1,111		
Pupils admitted, n %	395	24.6%	9.0%		p<0.001
Males admitted, n %	230	24.2%	10.9%		p<0.001
Females admitted, n %	165	25.1%	7.7		p<0.001
Mean admissions per person, (sd)	2.87	(4.7)	6 (2.5)		p=0.003
N day cases, % admissions	401	35.4	31.0		p=0.023
Length of stay, days, median (IQR)	2	(1, 3)	(1, 3)		p<0.444
(excluding days cases)	3	(2, 4)	(2, 4)		p<0.028
Incidence of admission / 1,000 person years (95% CI)	Rate per 1,000 (95% CI)		Rate per 1,000 (95% CI)		
All pupils	79.67	(72.19, 87.93)	32.00	(29.87, 35.14)	
Males	79.57	(69.92, 90.54)	36.11	(32.86, 41.45)	
Females	79.82	(68.53, 92.98)	28.99	(25.87, 32.49)	
Cox PH models:	HR (95% CI)				
Intellectual disabilities	2.55	(2.25, 2.90)			
	aHR^a (95% CI)				
Intellectual disabilities	2.24	(1.97, 2.55)			
Length of stay models:	IRR (95% CI)				
All pupils admitted, (n=2,390)					
Intellectual disabilities	1.28	(0.84, 1.94)			
	Adjusted IRR^a (95% CI)				
All pupils admitted, (n=2,390)					
Intellectual disabilities	1.32	(0.92, 1.89)			

*pupils with anti-epileptic drug (AED) prescription; **ICD 10 codes G40, G41, R568; a - adjusted for age at entry, sex, and deprivation quintile (SIMD)
b - χ^2 test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person, Mann-Whitney U test was used for length of stay

For peer review only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

Table 3. Hospital admissions due to asthma or status asthmaticus** amongst pupils with asthma with, and without, intellectual disabilities, including incidence rates, Cox proportional hazards model for risk of admission, and zero truncated negative binomial regression for total length of stay

All admissions due to asthma**	Intellectual Disabilities and asthma*		Control and asthma*		p-value ^b
Total pupils, n	1,621		53,363		
Total admissions, n	146		5,340		
Pupils admitted, n %	56	3.5%	2,661	4.9%	p=0.005
Males admitted n %	42	3.7%	1,453	4.9%	p=0.085
Females admitted, n %	14	2.8%	1,208	5.1%	p=0.019
N day cases, % admissions	66	45%	1,594	30%	p<0.001
Length of stay, days, median (IQR)	2	1,3	2	1,3	p=0.050
(excluding days cases)	3	2,5	3	2,4	p=0.009
Incidence of admission / 1,000 person years (95% CI)	Rate per 1,000 (95% CI)		Rate per 1,000 (95% CI)		
All pupils	10.76	(8.28, 13.98)	13.1	(12.64, 13.64)	
Male pupils	11.53	(8.52, 15.61)	12.6	(11.99, 13.29)	
Female pupils	8.95	(5.31, 15.11)	13.7	(13.04, 14.59)	
Cox PH models:	HR (95% CI)				
Intellectual disabilities	0.77	(0.59, 1.00)			
	aHR^a (95% CI)				
Intellectual disabilities	0.81	(0.62, 1.06)			
Length of stay models:	IRR (95% CI)				
All pupils admitted, (n=2,717)					
Intellectual disabilities	1.88	(0.71, 4.92)			
	Adjusted IRR^a (95% CI)				
All pupils admitted (n=2,717)					
Intellectual disabilities	1.95	(0.78, 4.89)			

*Prescription for asthma (inhaled steroid and β-agonist); **ICD 10 codes J45, J46; a - adjusted for age at entry, sex, and deprivation quintile (SIMD)

b – X² test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person, Mann-Whitney U test was used for length of stay

Table 4. Hospital admissions due to diabetes** amongst pupils with insulin-dependent diabetes with and without, intellectual disabilities, including incidence rates, Cox proportional hazards models for risk of admission, and zero-truncated negative binomial regression for total length of stay

All admissions due to diabetes**	Intellectual Disabilities and diabetes*		Control group and diabetes*		p-value ^b
Total pupils, n	94		3,924		
Total admissions, n	54		3,089		
Pupils admitted, n %	24	25.5%	1,227	31.3%	p=0.235
Males admitted, n %	15	27.3	532	26.6	0.908
Females admitted, n %	9	23.1	695	36.2	0.092
Mean admissions per person, (sd)	2.25	(2.3)	2.7	(3.4)	p=0.704
N day cases, % admissions	16	29.6%	545	17.6%	p=0.023
Length of stay, days, median (IQR)	2	1, 3	3	2, 4	p=0.031
(exc. days cases)	3	2, 4	3	2, 4	p=0.371
Incidence of admission / 1,000 person years (95% CI)	Rate per 1,000 (95% CI)		Rate per 1,000 (95% CI)		
All pupils	96.72	(64.83, 144.30)	95.7	(90.55, 10.27)	
Male pupils	102.88	(62.02, 170.65)	79.0	(72.57, 86.01)	
Female pupils	87.94	(45.76, 169.01)	114.3	(106.14, 123.16)	
Cox PH models:	HR (95% CI)				
Intellectual disabilities	0.98	(0.65, 1.47)			
	aHR^a (95%CI)				
	0.94	(0.63, 1.41)			
Length of stay models:	IRR (95% CI)				
All pupils admitted, (n=1,251)					
Intellectual disabilities	0.70	(0.51, 0.97)			
	Adjusted IRR^a (95%)				
All pupils admitted, (n=1,251)					
Intellectual disabilities	0.71	(0.51, 0.99)			

*Prescription for insulin; **ICD 10 codes E10-E14; a - adjusted for age at entry, sex, and deprivation quintile (SIMD) b – X² test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person, Mann-Whitney U test was used for length of stay

For peer review only

Supplementary tables:

Table S1. All-cause admissions among pupils with epilepsy with, and without, intellectual disabilities including incidence rates, Cox proportional hazards models for risk of admission for pupils with epilepsy with, versus without, intellectual disabilities

All-cause admissions	Pupils with intellectual disabilities and epilepsy		Controls with epilepsy	p-value ^b
Total pupils, n	1,608		6,413	
Total admissions, n	6,235		7,600	
Pupils admitted, n %	985	61.3%	2,330	36.7% p<0.001
Mean admissions per person, (sd)	6.33	(15.9)	2.3	(5.6) p<0.001
Incident admissions / 1,000 (95% CI) – All pupils	316.06	(296.93, 336.43)	166.4	(165.18, 179.04)
- Males	301.28	(277.50, 327.11)	166.4	(145.69, 165.58)
- Females	338.70	(307.70, 372.82)	164.2	(175.65, 194.85)
All emergency admissions				
Total admissions, n	2,723		3,013	
Total pupils admitted, n %	686	42.6%	1,100	23.9% p<0.001
Mean admissions per person, (sd)	3.97	(5.6)	2.2	(3.7) p<0.001
Incident admissions / 1,000 (95% CI) – All pupils	164.71	(152.83, 177.51)	166.4	(91.72, 101.36)
- Males	160.56	(145.56, 177.12)	166.4	(79.87, 93.65)
- Females	170.84	(152.18, 191.80)	164.2	(97.72, 111.11)
All routine admissions				
Total admissions, n	3,512		3,833	
Total pupils admitted, n %	733	45.6%	1,400	23.1% p<0.001
Mean admissions per person, (sd)	4.79	(17.0)	2.5	(4.5)
Incident admissions / 1,000 (95% CI) – All pupils	188.02	(174.89, 202.13)	166.4	(88.89, 98.39)
- Males	178.24	(161.91, 196.22)	166.4	(78.80, 92.57)
- Females	202.60	(181.48, 226.18)	164.2	(93.45, 106.50)
PH Cox models All-cause admissions:		HR (95% CI)		
All admissions – Intellectual disabilities	1.82	(1.69, 1.96)		
Emergency admissions – Intellectual disabilities	1.74	(1.59, 1.91)		
Routine admissions – Intellectual disabilities	2.04	(1.86, 2.22)		
		aHR^a (95%CI)		
All admissions – Intellectual disabilities	1.82	(1.69, 1.96)		
Emergency admissions – Intellectual disabilities	1.75	(1.60, 1.92)		
Routine admissions – Intellectual disabilities	2.01	(1.83, 2.20)		

a – adjusted for age, sex, age at entry, and SIMD b – X² test was used for comparing n pupils admitted; t-test was used for mean admissions per person

Table S2. All-cause admissions among pupils with asthma with, and without, intellectual disabilities, including incidence rates, Cox proportional hazards models for risk of admission for pupils with asthma with versus without intellectual disabilities

All-cause admissions:	Pupils with intellectual disabilities and asthma		Controls with asthma	p-value ^b
Total pupils, n	1,621		53,363	
Total admissions, n	2067		27,910	
Total pupils admitted, n %	533	32.9%	13,737	25.7% p<0.001
Mean admissions per person, (sd)	3.88	(11.0)	2.1	(3.5) p<0.001
Incident admissions / 1,000 (95% CI)				
- All pupils	132.03	(121.28, 143.73)	78.1	(77.56, 80.20)
- Males	121.38	(109.30, 134.78)	75.1	(73.69, 77.11)
- Females	158.66	(137.26, 183.39)	83.1	(81.46, 85.60)
All emergency admissions				
Total admissions, n	977		16,794	
Total pupils admitted, n %	348		9,290	p<0.001
Mean admissions per person, (sd)	2.81	(4.3)	1.1	(2.7) p<0.001
Incident admissions / 1,000 (95% CI)				
- All pupils	77.03	(69.35, 85.56)	49.6	(48.86, 50.89)
- Males	71.90	(63.20, 81.79)	48.4	(46.73, 49.37)
- Females	89.66	(74.80, 107.47)	52.7	(50.71, 53.87)
All routine admissions				
Total admissions, n	1,090		11,116	
Total pupils admitted, n %	331	20.4	6,742	12.6% p<0.001
Mean admissions per person, (sd)	3.29	(12.4)	1.5	(2.3) p<0.001
Incident admissions / 1,000 (95% CI)				
- All pupils	73.15	(65.68, 81.48)	34.8	(34.06, 35.73)
- Males	65.82	(57.51, 75.32)	32.1	(31.10, 33.22)
- Females	91.00	(76.09, 108.82)	38.5	(37.19, 39.86)
PH Cox Models All-cause admissions:	HR (95% CI)			
All admissions - Intellectual disabilities	1.59	(1.45, 1.73)		
Emergency admissions - Intellectual disabilities	1.48	(1.33, 1.64)		

Routine admissions – Intellectual disabilities	2.01	(1.80, 2.24)	
	aHR^a (95% CI)		
All admissions – Intellectual disabilities	1.56	(1.43, 1.71)	
Emergency admissions – Intellectual disabilities	1.45	(1.30, 1.61)	
Routine admissions – Intellectual disabilities	2.00	(1.79, 2.23)	

a – adjusted for age, sex, age at entry, and SIMD b – X² test was used for comparing n pupils admitted, n cases; t-test was used for mean admissions per person, Mann-Whitney U test was used for length of stay

Table S3 . All-cause admissions among pupils with insulin-dependent diabetes with, and without, intellectual disabilities, including incidence rates, Cox proportional hazards models for risk of admission for pupils with diabetes, with versus without intellectual disabilities

All-cause admissions:	Intellectual Disabilities & diabetes		Controls with diabetes		p-value ^b
Total pupils, n	94		3,924		
Total admissions, n	245		6,729		
Total pupils admitted, n %	53	56.4%	2,022	51.5%	p=0.353
Mean admissions per person, (sd)	4.62	(9.5)	3.33	(5.8)	p=0.115
Incident admissions / 1,000 (95% CI)					
- All pupils	314.01	(239.89, 411.02)	197.16	(89.75, 205.94)	
- Males	342.04	(244.40, 478.69)	174.45	(68.68, 185.92)	
- Females	273.84	(174.67, 429.32)	222.70	(101.78, 236.42)	
All emergency admissions					
Total admissions, n	100		5,222		
Total pupils admitted, n %	34	36.2%	1,761	44.9%	p=0.093
Mean admissions per person, (sd)	2.94	(2.6)	2.97	(3.7)	p=0.364
Incident admissions / 1,000 (95% CI) – All pupils	151.71	(108.40, 212.32)	158.20	(115.98, 165.76)	
All routine admissions					
Total admissions, n	145		1,507		
Total pupils admitted, n %	34	36.2%	750	19.1%	p<0.001
Mean admissions per person, (sd)	4.26	(10.8)	2.01	(6.1)	p=0.045
Incident admissions / 1,000 (95% CI) – All pupils	22.85	(10.90, 47.94)	13.36	(1.67, 15.30)	
PH Cox Models All-cause admissions:					
HR (95% CI)					
All admissions – Intellectual disabilities	1.46	(1.11, 1.92)			
Emergency admissions – Intellectual disabilities	0.91	(0.65, 1.28)			
Routine admissions – Intellectual disabilities	2.61	(1.85, 3.69)			
aHR^a (95% CI)					
All admissions – Intellectual disabilities	1.44	(1.10, 1.90)			
Emergency admissions – Intellectual disabilities	0.90	(0.64, 1.26)			
Routine admissions – Intellectual disabilities	2.61	(1.85, 3.69)			

a – adjusted for age, sex, age at entry, and SIMD b – χ^2 test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person

For peer review only

BMJ Open

Hospitalisation rates for epilepsy, asthma, and insulin-dependent diabetes in 796,190 school aged children and young people with, and without, intellectual disabilities: a record-linkage cohort study

Journal:	BMJ Open
Manuscript ID	bmjopen-2024-088809.R1
Article Type:	Original research
Date Submitted by the Author:	14-Nov-2024
Complete List of Authors:	Smith, Gillian; University of Glasgow Institute of Health and Wellbeing, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB Fleming, Michael ; University of Glasgow, Public Health Cooper, Sally-Ann; Glasgow University , Institute of Health and Wellbeing Henderson, Angela; University of Glasgow, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB Pell, Jill; Univ Glasgow, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB Melville, Craig; University of Glasgow Cairns, Deborah; University of Glasgow, School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow, G12 8TB
Primary Subject Heading:	Epidemiology
Secondary Subject Heading:	Public health, Health services research
Keywords:	Epilepsy < NEUROLOGY, Asthma < THORACIC MEDICINE, Community child health < PAEDIATRICS, DIABETES & ENDOCRINOLOGY, Adolescents < Adolescent

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Hospitalisation rates for epilepsy, asthma, and insulin-dependent diabetes in 796,190 school aged children and young people with, and without, intellectual disabilities: a record-linkage cohort study

Gillian S. Smith,[†] Michael Fleming,[†] Sally-Ann Cooper, Angela Henderson, Jill P. Pell, Craig A. Melville, *Deborah Cairns

[†]Joint first authors

School of Health and Wellbeing, University of Glasgow, School of Health and Wellbeing, University of Glasgow, Clarice Pears Building, Byres Road, Glasgow G12 8TB, UK

*Correspondence to:
Deborah Cairns

Word count: 3,435

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objectives

To investigate hospitalisation rates for the ambulatory care sensitive conditions of epilepsy, asthma, and insulin-dependent diabetes in school-age children and young people with intellectual disabilities, in comparison with their peers.

Design

Record-linkage cohort study. Scotland’s Pupil Census, 2008-2013, was used to identify pupils with, and without, intellectual disabilities, and was linked with the Prescribing Information Service to identify pupils with epilepsy, asthma, and insulin-dependent diabetes, and the Scottish Morbidity Records (SMR-01) to identify hospital admissions.

Setting

The general child population of Scotland.

Participants

School pupils aged 4-19 years; 18,278 with intellectual disabilities, and 777,912 without intellectual disabilities.

Outcomes

Overall, emergency, and non-emergency hospitalisations for epilepsy, asthma, and/or diabetes; and length of stay.

Results

Epilepsy and asthma were more prevalent pupils with intellectual disabilities, (8.8% and 8.9% respectively, compared to 0.8% and 6.9% among pupils without intellectual disabilities, $p<0.001$), whereas insulin-dependent diabetes was not (0.5% prevalence). After adjusting for prevalence, pupils with intellectual disabilities and epilepsy had more epilepsy-related admissions than their peers (aHR 2.24, 95% CI 1.97, 2.55). For emergency admissions, these stays were longer compared to controls (aIRR 2.77, 95% CI 2.13, 3.59). Pupils with intellectual disabilities and asthma had similar admission rates due to asthma as control pupils with asthma (aHR 0.81, 95% CI 0.62, 1.06), but emergency admissions were longer (aIRR 2.72, 95% CI 1.49, 4.96). Pupils with intellectual disabilities and insulin-dependent diabetes had similar admission rates to controls (aHR 0.94, 95% CI 0.63, 1.41), but with shorter admissions; (aIRR 0.71, 95% CI 0.51, 0.99).

Conclusions

Our findings suggest pupils with intellectual disabilities may receive poorer community healthcare than their peers for the common conditions of epilepsy and asthma. Hospital admissions are disruptive for both the child and their family. Epilepsy and asthma are associated with avoidable deaths, hence a better understanding of these hospitalisations is important.

Strengths and limitations of this study

- Large, national study.
- Identification of over 18,000 children and young people with intellectual disabilities.
- Diagnoses of epilepsy, asthma, and insulin-dependent diabetes was based on dispensing of prescriptions.
- Cannot distinguish between mild and severe intellectual disabilities.
- Unable to investigate whether there are any ethnic variations.

For peer review only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

INTRODUCTION

Ambulatory care sensitive conditions are health conditions for which timely and effective community health care helps to reduce the risks of hospitalisation by preventing the onset of illness, controlling an acute episode of illness, or managing an enduring condition.¹ Examples include epilepsy, asthma, and diabetes. General population studies have revealed an association between high rates of hospitalisations for ambulatory care sensitive conditions, and poor access to primary care.^{2,3} Intellectual disabilities are a group of conditions resulting in an intelligence quotient of less than 70, the need for daily support in adaptive functioning, and onset in childhood. People with intellectual disabilities face barriers in accessing community health services.⁴⁻⁶ However there has been little previous study of hospital admissions for ambulatory care sensitive conditions for people with intellectual disabilities in comparison with the general population,⁷ particularly with regards to school-aged children and young people.

Previous studies have reported the frequency of all admissions (rather than specifically for ambulatory care sensitive conditions) for pre-school children with intellectual disabilities compared with the general population. One study, from the USA, reported on children with Down syndrome up to age 3 years, rather than all children and young people with intellectual disabilities,⁸ whilst another, from Western Australia, reported from birth to age 5 years.⁹ Both showed higher rates of hospitalisation than for the control population, but they did not take into account different prevalences of conditions between the populations. Likewise, a large study using hospital billing data from four USA states investigated admissions of children aged under 18 years with a combined, heterogenous range of intellectual and developmental disorders (e.g. intellectual disabilities, autism, cerebral palsy).¹⁰ It found the relative risk of hospitalisation was 19.43 (18.56-20.34) for epilepsy and 3.60 (3.33-3.90) for asthma, but it did not take account of the different prevalences of these conditions. A further study was focussed specifically on ambulatory care sensitive conditions.¹¹ It included 8,000 people of all ages (children and adults) with intellectual disabilities living in Manitoba, Canada between 1999 and 2003. It reported hospitalisation rate ratios for 14 conditions combined of 6.38 (95% CI 5.30, 7.67) at ages 0-9 years, and 8.47 (95% CI 6.89, 10.42) at ages 10-19 years. For specifically asthma and diabetes, it adjusted for the prevalence of the condition, reporting rate ratios of 2.10 (95% CI 1.39, 3.16) for asthma and 3.73 (95% CI 2.63, 5.29) for diabetes; however, it did not report rates separately for children or young people for these conditions. A smaller study investigated 107 children and young people with "cognitive and developmental delays" and 943 children and young people without, up to age 18 years, in Quebec, Canada.¹² It did not find any difference in hospitalisation ratios for ambulatory care sensitive conditions between the two groups, however the cognitive and developmental delays group was very

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Enseignement Supérieur (ABES)

heterogenous due to coding issues, and included, for example, specific learning disabilities, and speech and language disorders. A further study of 1,148 children with intellectual disabilities and 2,255 control children aged 2-24 years in South Carolina, used hospital billing data to explore eight ambulatory care sensitive conditions but they did not include epilepsy.¹³ They reported more events in the children with intellectual disabilities: an incidence rate ratio (IRR) of 1.23 (1.05-1.44) for emergency room visits, and IRR of 2.62 (1.95-3.32) for in-patient admissions. Finally, a large observational study in England reported rates of emergency admissions for ambulatory care sensitive conditions for people of all ages with intellectual disabilities; with some limited results for children and young people separately.¹⁴ Those aged 0-24 years in the study had 71.0 emergency admissions per 1,000 person-years (95% CI 66.0, 76.4), compared to 15.2 per 1,000 (95% CI 15.1, 15.4) in children/young people without intellectual disabilities. However, the study did not adjust for the prevalence of these conditions or provide further data such as incidence rate ratios for this age group.¹⁴ Hence, the results of existing studies are not directly comparable, accounting for their contradictory findings: we have much to learn on this topic.

The aim of this study was to investigate hospitalisation rates for the ambulatory care sensitive conditions of epilepsy, asthma, and insulin-dependent diabetes in school age children and young people with intellectual disabilities, in comparison with similarly aged control children taking account of the different prevalence of these conditions in the two groups. Epilepsy and asthma were selected as they occur commonly in children with intellectual disabilities. They are also long-term conditions hence the children establish a relationship with their primary health care professionals. The selected linked-dataset that includes these conditions also holds data on insulin-dependent diabetes, hence its inclusion in our aim.

METHODS

Data sources and record linkage

This study used administrative data from Scotland's annual Pupil Census to identify all children and young people with intellectual disabilities in Scotland. The census is held by the Scottish Government and includes pupils from all local authority schools including special schools, and funded placements; an estimated 95% of schoolchildren across Scotland. The Pupil Census also contained records of any child receiving additional support needs at school due to intellectual disabilities. We used a strict definition of at least two records of support for intellectual disabilities (i.e. 2 years) to identify children with

intellectual disabilities. Entry date was defined as the date the second record of support for intellectual disabilities was accrued. The comparison group was formed of pupils with at least two census records, who did not have any records of intellectual disabilities or autism, with the date of their second census record assigned as the study entry date. Only pupils aged between 4 and 19 years at entry were included in the study. Information on sex and neighbourhood deprivation were also derived from the census; deprivation was ascertained using the Scottish Index of Multiple Deprivation (SIMD) 2012, which is based on individual postcode data. SIMD score from the first census record was used for each pupil. Records were linked using probabilistic matching, based on sex, date of birth, and postcode of residence, to administrative health datasets in Scotland, held by Public Health Scotland (PHS). The highest scoring match was used, and unlikely or duplicate matches were excluded.

Information was extracted from the Prescribing Information System (PIS) which recorded all prescriptions dispensed in Scotland between 1st January 2009 and 31st December 2013. Data were extracted on medications with British National Formulary (BNF) codes relevant to ambulatory care-sensitive conditions: epilepsy, asthma, and insulin-dependent diabetes. Information was extracted from the Scottish Morbidity Records (SMR) dataset on acute inpatient and day case episodes (SMR-01), and maternity inpatient and day case episodes (SMR-02). These are episode-based datasets on all acute hospital admissions (SMR-01), and all maternity admissions (SMR-02) across Scotland, which record the admission and discharge dates; the main condition or diagnosis for the admission using ICD 10 codes; and whether the admission was an emergency or routine admission. Maternity records (SMR-02) were used to identify any child from a multiparous birth born in Scotland, who were then excluded to remove any potential mismatching between same sex siblings with the same birthdate, as the linkage methodology could not distinguish between them.

Exposure definitions

Dispensed prescriptions for disease-specific medications were used as proxy measure for each condition, using methodology validated in previous studies.¹⁵⁻¹⁸ Pupils prescribed at least one antiepileptic drug (BNF section 4.8) were defined as having epilepsy. Pupils with more than one prescription during the same calendar year for an inhaled steroid and either a long-acting or short acting β -agonist (BNF sections 3.1, 3.2, and 3.3) were defined as having asthma; pupils who only met one of these criteria were excluded. Pupils with at least one insulin prescription (BNF section 6.1.1) were defined as having insulin-dependent diabetes; pupils on oral anti-diabetic medication only were excluded. All conditions were analysed exclusively. Pupils without recorded prescriptions for any of the other ambulatory

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Enseignement Supérieur (ABES).

care-sensitive conditions were assigned to the control group for the analysis. For the epilepsy, asthma, and diabetes analyses, all pupils' entry dates were re-assigned as the latest date out of either their index prescription or their index pupil census record.

Outcome definitions

All prospective hospital admissions up to the censor date of 13th February 2015, or, if earlier, the date of death, or date the pupil reached age 25 years, were extracted. Data were extracted for admissions due to epilepsy, status epilepticus, or seizures (ICD-10 codes G40, G41, and R568); for asthma or status asthmaticus (ICD-10 codes J45 and J46); and for insulin-dependent diabetes (ICD-10 codes E10-E14). The length of stay in hospital in days was calculated using the admission and discharge dates, with one day classified as a day case admission to hospital.

Statistical analyses

We calculated the prevalence of three ambulatory care-sensitive conditions - epilepsy, asthma, and diabetes - for pupils with, and without, intellectual disabilities. For each condition, group differences in sex and deprivation quintiles for those with, and without, intellectual disabilities were compared. The number of pupils admitted to hospital prospectively during the study, and mean number of admissions per person were compared for pupils with, and without, intellectual disabilities using X²-tests and t-tests, respectively. For each of the ambulatory care sensitive conditions, we reported the incidence rates (pupils with an incident hospitalisation, per 1,000 pupils per year) for those with, and without, intellectual disabilities (including stratified for emergency and routine admissions). Univariate Cox proportional hazards models were used to assess the risk difference between pupils with, referent to without, intellectual disabilities. Cox models adjusted for age at study entry, sex, and neighbourhood deprivation level were also employed. Median length of stay and proportion of day cases were compared for pupils with and without intellectual disabilities using Mann-Whitney U tests and X²-tests, respectively. Zero-truncated negative binomial regression models were used to report differences in total length of stay for pupils with, referent to without, intellectual disabilities for admitted pupils only (minimum stay of 1 day) for each condition. Robust standard errors for incidence rate ratios (IRR) were used to adjust for multiple admissions per person. Statistical analyses were undertaken using Stata, version 15.0 (StataCorp).

Patient and public involvement

This research was undertaken within the Scottish Learning Disabilities Observatory. Initially, a systematic review was completed on the topic.⁷ Its findings were presented to the steering committee of the Observatory, which included people with intellectual

1
2
3 disabilities, and representatives of two third-sector organisations for people with
4 intellectual disabilities, and family carers. The discussion that followed identified this area
5 as one that should be taken forward for further research and the study design was
6 approved by the steering committee.
7
8
9

10
11 **Ethics approval**

12 This study was approved by the NHS National Services Scotland Privacy Advisory
13 Committee and Public Benefit and Privacy panel (Reference 1617-0259).
14
15

16
17 **RESULTS**

18
19
20 **Cohort demographics**

21 18,278 (1.9%) pupils were recorded as having intellectual disabilities over the study
22 period, 2009-2013, of whom 11,891 (65.1%) were male. The control group consisted of
23 777,912 pupils, of whom 389,160 (50.0%) were male. There were more pupils with
24 intellectual disabilities living in areas of greater neighbourhood deprivation; 5,822 (31.9%)
25 in the most deprived quintile compared with 169,038 (21.7%) without intellectual
26 disabilities. More detailed demographic information has previously been reported for this
27 cohort.¹⁹
28
29
30
31

32
33
34 There were 3,660 pupils who were in receipt of prescriptions for asthma who did not meet
35 our full definition and so were excluded from the asthma analysis. 503 pupils were
36 prescribed an oral anti-diabetic drug but not insulin and so were excluded from the
37 diabetes analysis.
38
39

40
41 **Prevalence of conditions**

42 Table 1 shows the prevalence of each condition in the pupils with, and without, intellectual
43 disabilities, using proxy definitions based on their prescribing information. Epilepsy
44 (P<0.001), and asthma (P<0.001) had a much higher prevalence among pupils with
45 intellectual disabilities, whereas insulin-dependent diabetes (P=0.841) occurred at similar
46 rates in the two groups. 1,608/18,278 (8.8%) pupils with intellectual disabilities had
47 epilepsy, and 6,441/777,912 (0.8%) control pupils. 1,621/18,196 (8.9%) pupils with
48 intellectual disabilities had asthma, and 53,363/774,334 (6.9%) control pupils. 94/18,238
49 (0.5%) pupils with intellectual disabilities had insulin-dependent diabetes, and
50 3,924/777,449 control pupils (0.5%).
51
52
53
54
55
56

57
58 **Hospital admissions**

59 **Epilepsy**
60

Pupils with both intellectual disabilities and epilepsy had more frequent all-cause hospital admission rates compared with control pupils with epilepsy (62% versus 37%, $p < 0.001$). Data on all-cause admissions can be seen in the supplementary data (Table S1). Table 2 shows that pupils with intellectual disabilities and epilepsy had more admissions due to epilepsy than did control pupils with epilepsy (aHR 2.24, 95% CI 1.97, 2.55). Overall, their admissions were for a longer period, but not significantly so.

For the pupils with intellectual disabilities and epilepsy, 864/1,134 (76.2%) epilepsy admissions were emergency admissions, and 270/1,134 (23.8%) were routine admissions. Among control pupils with epilepsy, 828/1,256 (65.9%) epilepsy admissions were emergency admissions, and 428/1,256 (34.1%) were routine admissions. There was an increased risk of an epilepsy emergency admissions for pupils with intellectual disabilities compared to control pupils (aHR 2.50, 95% CI 2.15, 2.91) and for routine epilepsy admissions (aHR 1.57, 95% CI 1.28, 1.91). There was no significant interaction with sex (emergency admission; $p_{\text{interaction}} = 0.112$).

For emergency admissions, the pupils with intellectual disabilities and epilepsy had longer lengths of stay than the control pupils (IRR 2.77, 95% CI 2.13, 3.59). For routine admissions, the lengths of stay were not significantly different (IRR 0.74, 95% CI 0.53, 1.03).

Asthma

Pupils with both intellectual disabilities and asthma had more frequent all-cause hospital admissions than control pupils with asthma (33% versus 26%, $p < 0.001$). Data on all-cause admissions can be seen in the supplementary data (Table S2). Table 3 shows that pupils with intellectual disabilities and asthma had fewer admissions due to asthma than did control pupils with asthma, but survival analysis showed no significant difference in risk of admission (aHR 0.81, 95% CI 0.62, 1.06). Overall, their admissions were for a similar length of stay.

For the pupils with intellectual disabilities and asthma, 95/146 (65.1%) asthma admissions were emergency admissions, and 51/146 (34.9%) were routine admissions. Among control pupils with asthma, 4,889/5,340 (91.6%) asthma admissions were emergency admissions, and 451/5,340 (8.4%) were routine admissions. Amongst pupils with asthma, pupils with intellectual disabilities were at similar risk of emergency admissions (aHR 0.83, 95% CI 0.63, 1.08). Data for routine asthma admissions are not shown due to statistical disclosure, as the total 51 routine admissions were for a group of less than 5 pupils with

intellectual disabilities; i.e. almost all of the pupils with intellectual disabilities and asthma who were admitted had emergency admissions.

For emergency admissions, the pupils with intellectual disabilities and asthma had longer length of stay than the control pupils (aIRR 2.72, 95% CI 1.49, 4.96). Calculations were not undertaken for routine admissions.

Diabetes

Pupils with both intellectual disabilities and insulin-dependent diabetes had similar all-cause hospital admission rates compared with control pupils with insulin-dependent diabetes (56% admitted versus 52%, $p<0.353$). Data on all-cause admissions can be seen in the supplementary data (Table S3).

Table 4 shows that pupils with intellectual disabilities and insulin-dependent diabetes had fewer admissions due to diabetes than did control pupils with insulin dependent diabetes, but survival analysis shows no statistical difference (aHR 0.94, 95% CI 0.63, 1.41). Overall, their admissions were of a shorter length of stay (aIRR 0.71, 95% CI 0.51, 0.99).

For the pupils with intellectual disabilities and insulin-dependent diabetes, 47/54 (87.0%) diabetes admissions were emergency admissions, and 7/54 (13.0%) were routine admissions. Among control pupils with insulin-dependent diabetes, 2,849/3,089 (92.2%) diabetes admissions were emergency admissions, and 240/3,089 (7.8%) were routine admissions. Amongst pupils with insulin-dependent diabetes, pupils with intellectual disabilities were at similar risk of emergency admissions (aHR 0.83, 95% CI 0.54, 1.30), and of routine admissions (aHR 1.85, 95% CI 0.87, 3.94).

For emergency admissions, the pupils with intellectual disabilities had shorter lengths of stay than the control pupils (aIRR 0.67, 95% CI 0.47, 0.95). Calculations were not undertaken for routine admissions.

DISCUSSION

Principal findings and interpretation

For two of the three ambulatory care sensitive conditions we investigated (epilepsy and asthma), our findings suggest that pupils with intellectual disabilities receive poorer community health care than do control pupils. Among pupils with epilepsy, those who also have intellectual disabilities are at higher risk of both emergency and routine hospital admissions for epilepsy than control pupils and spent longer in hospital following the former. Among pupils with asthma, the pupils who also had intellectual disabilities spent

longer in hospital following emergency admissions. In contrast, they spent less time in hospital following emergency admission for diabetes. We consider our findings novel, as there is little previous research with which we can compare our findings.

There are several potential interpretations of these findings. The higher risk of epilepsy admissions in the pupils with intellectual disabilities could reflect them having more severe epilepsy than the control pupils, or poorer management of their epilepsy in the community, or both. The longer duration of emergency asthma admissions for pupils with intellectual disabilities suggests that their asthma may be more difficult to resolve once they are admitted, which could plausibly be due to delayed admission due to poorer community management being tolerated for longer than for the control pupils.

Whilst the shorter duration of admissions for diabetes for pupils with intellectual disabilities might be explained by better management in the community it is more likely to be explained by the fact that pupils with intellectual disabilities are less likely to self-administer their insulin than control pupils. Given that adherence is lower among young people,²⁰ administration of medication by parents or carers may improve day-to-day management in the community and/or mean that changes to management in-hospital are quicker to implement.

Comparison with the existing literature

Epilepsy and asthma have previously been reported to be more common among children and young people with intellectual disabilities. We found similar rates of insulin-dependent diabetes in the two groups.

It is difficult to draw comparisons on hospitalisation ratios with previous literature due to study design differences. One study compared child/young person hospitalisation data on 14 ambulatory care sensitive conditions combined, showing them to be more common in those with intellectual disabilities.¹¹ Whilst they were able to account for differences in population prevalence rates for asthma and diabetes in their further calculations, they did not report the ratios separately for children and young people. Some studies we referenced had populations which are not directly comparable to the children and adolescents with intellectual disabilities in our study.^{10,12} Some studies did not adjust for the different prevalence rates,⁸⁻¹⁰ and some studied younger, pre-school children only, so are not comparable to our study.^{8,9}

Strengths and limitations

A strength of the study is its large size covering all of Scotland, with over 18,000 children and young people with intellectual disabilities. The diagnoses of epilepsy, asthma, and insulin-dependent diabetes were based on dispensing of prescriptions; these conditions require drug treatment as they are otherwise life threatening, so this method of identification should be reasonably robust. We used school records to identify the children and young people with intellectual disabilities, and therefore cannot distinguish between mild and severe intellectual disabilities. We were unable to investigate whether there are any ethnic variations.

Implications

Our findings suggest that pupils with intellectual disabilities may receive poorer community health care than their peers for epilepsy and asthma. These are common conditions in children and young people with intellectual disabilities. It has previously been reported, almost exclusively through qualitative research, that adults with intellectual disabilities receive poorer community healthcare, and that many issues contribute to this, including sharing of information within and between care teams. For most children and young people, their healthcare is supported by their parents rather than care teams, so the disparity in quality of epilepsy and asthma care is important to note and understand. Poor inhaler technique may be an issue for some children with intellectual disabilities, but is not insurmountable, as aerochambers, and the larger nebulizers and volumatic spacer devices are available to aid coordination, once the issue has been identified. Additionally, electric or gas-driven nebulizers can be used for bigger doses and to deliver the medication deeper into the chest.

People with ambulatory care sensitive conditions ideally are not admitted to hospital. If admitted they may experience further barriers to care, including those due to staff knowledge, skills, and attitudes,²¹ highlighting the need for support for secondary care staff.

Hospital admissions are disruptive to child development and education, and stressful for both the child and their family. In addition, epilepsy and asthma are associated with avoidable deaths, hence a better understanding of hospitalisation for these ambulatory care sensitive conditions is particularly important. Parents and teachers of children and young people with these conditions may benefit from greater support and information.

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Enseignement Supérieur (ABES).

Contributors

GS, MF, and S-AC conceived the study, and GS and S-AC drafted the manuscript. GS and MF undertook the statistical analyses. All authors contributed to the study design, interpretation of findings, and approved the final version.

Data availability statement

Data may be obtained from a third party, following appropriate approvals, and are not otherwise publicly available. This study linked patient information held across several administrative health data sets within Public Health Scotland, with education data held by the Scottish Government and National Records of Scotland. Linkage and de-identification of data was performed by Public Health Scotland. A data processing agreement between NHS NSS and University of Glasgow and a data sharing agreement between the Scottish Government and University of Glasgow was signed. The University of Glasgow were authorised to receive record-linked data controlled and held by PHS, via access through the national safe haven. The PHS Statistical Disclosure Control Protocol was followed. It is therefore not possible to share data with other parties.

Acknowledgements

We thank the Scottish Government (formerly Scottish Exchange of Educational Data - ScotXed) Pupil Census, the National Records of Scotland and Public Health Scotland, for providing data and the eData Research and Innovation Service team at PHS for assisting with the data linkage.

Funding

MRC Mental Health Pathfinder Award (MC_PC_17217), and the Scottish Government via the Scottish Learning Disabilities Observatory. The funders had no role in the study design, collection, analyses or interpretation of data, writing the report nor the decision to submit the article for publication.

Competing interests

None declared.

References

1. Billings J, Zeitel L, Lukomnik J, et al. Impact of socioeconomic status on hospital use in New York City. *Health Affairs* 1993;**12(1)**:162-173.

2. Caminal J, Starfield B, Sánchez E, et al. The role of primary care in preventing ambulatory care sensitive conditions. *Eur J Public Health* 2004;**14(3)**:246-251.

3. Ansari Z, Laditka JN, Laditka SB. Access to health care and hospitalization for ambulatory care sensitive conditions. *Med Care Res Rev* 2006;**63(6)**:719-741.

4. Krahm GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation Development Disabilities Res Rev* 2006;**12(1)**:70-82.

5. Cooper S-A, Hughes-McCormack L, Greenlaw N, et al. Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: a population-based cohort study. *J Applied Res Intellectual Disabilities* 2017;**31(S1)**:68-81. Doi: 10.1111/jar.12386

6. Hughes-McCormack L, Greenlaw N, McSkimming P, et al. Changes over time in the management of long-term conditions in primary health care for adults with intellectual disabilities, and the health care inequality gap. *J Applied Res Intellectual Disabilities* 2021;**34(2)**:634-647. Doi: 10.1111/jar.12833

7. Dunn K, Hughes-McCormack L, Cooper S-A. Hospital admissions for physical health conditions for people with intellectual disabilities: Systematic Review. *J Applied Res Intellectual Disabilities* 2017;**31(S1)**:1-10. DOI: 10.1111/jar.12360

8. Derrington TM, Kotelchuck M, Plummer K, et al. Racial/ethnic differences in hospital use and cost among a statewide population of children with Down syndrome. *Res Developmental Disabilities* 2013;**34(10)**:3276-3287.

9. Williams K, Leonard H, d’Espaignet ET, et al. Hospitalisations from birth to 5 years in a population cohort of Western Australian children with intellectual disability. *Archives of Disease in Childhood* 2005;**90(12)**:1243-1248.

10. Lindgren S, Lauer E, Momany E, et al. Disability, hospital care, and cost: utilization of emergency and inpatient care by a cohort of children with intellectual and developmental disabilities. *J Pediatrics* 2021;**229**:259-266.

11. Balogh R, Brownell M, Ouellette-Kuntz H, et al. Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability-a population perspective. *J Intellectual Disability Res* 2010;**54(9)**:820-832.

12. Nachshen J, Martin-Storey A, Campisi L, et al. Health and psychiatric disparities in children with cognitive and developmental delays: implications for health policy in Quebec. *J Applied Res Intellectual Disabilities* 2009;**22**:248-255.

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Enseignement Supérieur (ABES).

13. Hand BN, Boan AD, Bradey CC, *et al.* Ambulatory care sensitive conditions in individuals with autism spectrum disorder, intellectual disability, and population controls. *Autism Research* 2019;**12(2)**:doi.org.1002/aur.2050
14. Glover G, Williams R and Oyinola J. An observational cohort study of numbers and causes of preventable general hospital admissions in people with and without intellectual disabilities in England. *Journal of Intellectual Disability Research*; 64: 331-344. Observational Study Research Support, Non-U.S. Gov't. DOI: <https://dx.doi.org/10.1111/jir.12722>.
15. Fleming, M., Fitton, C. A., Steiner, M. F.C., McLay, J. S., Clark, D., King, A., Mackay, D.F., Pell, J.P. (2019) Educational and health outcomes of children and adolescents receiving antiepileptic medication: Scotland-wide record linkage study of 766 244 schoolchildren. *BMC Public Health*, 19, 595. (doi: 10.1186/s12889-019-6888-9) (PMID:31101093) (PMCID:PMC6525436)
16. Fleming, M., Fitton, C.A., Steiner, M. F.C., McLay, J.S., Clark, D., King, A., Mackay, D.F., Pell, J.P. (2019) Educational and health outcomes of children treated for asthma: Scotland-wide record linkage study of 683,716 children. *European Respiratory Journal*, 54(3), 1802309. (doi: 10.1183/13993003.02309-2018) (PMID:31196949) (PMCID:PMC6727030)
17. Fleming, M., Fitton, C. A., Steiner, M. F.C., McLay, J. S., Clark, D., King, A., Mackay, D. F., Pell, J. P. (2017) Educational and health outcomes of children treated for attention deficit hyperactivity disorder: Scotland-wide record linkage study of 766,244 children. *JAMA Pediatrics*, 171(7), e170691. (doi: 10.1001/jamapediatrics.2017.0691) (PMID:28459927)
18. Fleming, M., Salim, E. E., Mackay, D.F., Henderson, A. , Kinnear, D., Clark, D., King, A., McLay, J. S., Cooper, S.-A., Pell, J.P. (2020) Neurodevelopmental multimorbidity and educational outcomes of Scottish schoolchildren: A population-based record linkage cohort study. *PLoS Medicine*, 17(10), e1003290. (doi: 10.1371/journal.pmed.1003290)
19. Smith GS, Fleming M, Kinnear D, *et al.* Mortality in 787,666 school pupils in Scotland with and without autism: a cohort study. *Autism* 2021;**25(1)**:300-304. doi: 10.1177/1362361320944037
20. Borus JS, Laffel L. Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Curr Opin Pediatr* 2010;22:405-411.
21. Iacono T, Bigby C, Unsworth C, *et al.* A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Res* 2014;**14(1)**:1.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Enseignement Supérieur (ABES).
Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Table 1. Prevalence of epilepsy, asthma, and diabetes for pupils with, and without, intellectual disabilities

Condition	Intellectual disabilities		Controls		p value	Total	
Epilepsy							
Prevalence	1,608/ 18,278	8.8%	6,441/ 777,912	0.8%	p<0.001	8,049/ 796,190	1.0%
Excluded pupils	0		0			0	
Asthma							
Prevalence	1,621/ 18,196	8.9%	53,363/ 774,334	6.9%	p<0.001	54,984 / 792,530	6.9%
Excluded pupils	82		3,578			3,660	
Insulin-dependent diabetes							
Prevalence	94/ 18,238	0.5%	3,924/ 777,449	0.5%	p=0.001	4,018/ 795,687	0.5%
Excluded pupils	40		463			503	

Table 2. Hospital admissions due to epilepsy, status epilepticus, or seizures** amongst pupils with epilepsy, with, and without, intellectual disabilities, including incidence rate ratios, Cox proportional hazards models for risk of admission, and zero-truncated negative binomial regression for total length of stay

All acute admissions due to epilepsy**	Intellectual Disabilities and epilepsy*		Cox PH models and epilepsy*		p-value ^b
Total pupils, n	1,608		6,134		
Total admissions, n	1,134		1,134		
Pupils admitted, n %	395	24.6%	395	9.0%	p<0.001
Males admitted, n %	230	24.2%	230	10.9%	p<0.001
Females admitted, n %	165	25.1%	165	7.7	p<0.001
Mean admissions per person, (sd)	2.87	(4.7)	2.87	(2.5)	p=0.003
N day cases, % admissions	401	35.4	401	31.0	p=0.023
Length of stay, days, median (IQR)	2	(1, 3)	2	(1, 3)	p<0.444
(excluding days cases)	3	(2, 4)	3	(2, 4)	p<0.028
Incidence of admission / 1,000 person years (95% CI)	Rate per 1,000 (95% CI)		Rate per 1,000 (95% CI)		
All pupils	79.67	(72.19, 87.93)	32.10	(29.87, 35.14)	
Males	79.57	(69.92, 90.54)	36.11	(32.86, 41.45)	
Females	79.82	(68.53, 92.98)	28.99	(25.87, 32.49)	
Cox PH models:	HR (95% CI)				
Intellectual disabilities	2.55	(2.25, 2.90)			
	aHR^a (95% CI)				
Intellectual disabilities	2.24	(1.97, 2.55)			
Length of stay models:	IRR (95% CI)				
All pupils admitted, (n=2,390)					
Intellectual disabilities	1.28	(0.84, 1.94)			
	Adjusted IRR^a (95% CI)				
All pupils admitted, (n=2,390)					
Intellectual disabilities	1.32	(0.92, 1.89)			

*pupils with anti-epileptic drug (AED) prescription; **ICD 10 codes G40, G41, R568; a - adjusted for age at entry, sex, and deprivation quintile (SIMD)
b – χ^2 test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person, Mann-Whitney U test was used for length of stay

For peer review only

Table 3. Hospital admissions due to asthma or status asthmaticus** amongst pupils with asthma with, and without, intellectual disabilities, including incidence rates, Cox proportional hazards model for risk of admission, and zero truncated negative binomial regression for total length of stay

	All admissions due to asthma**		Intellectual Disabilities and asthma*		Control and asthma*		p-value ^b
	Total pupils, n	1,621			53,363		
	Total admissions, n	146			5,340		
	Pupils admitted, n %	56 3.5%			2,661	4.9%	p=0.005
	Males admitted n %	42 3.7%			1,453	4.9%	p=0.085
	Females admitted, n %	14 2.8%			1,208	5.1%	p=0.019
	N day cases, % admissions	66 45%			1,594	30%	p<0.001
	Length of stay, days, median (IQR)	2 1,3			2	1,3	p=0.050
	(excluding days cases)	3 2,5			3	2,4	p=0.009
	Incidence of admission / 1,000 person years (95% CI)		Rate per 1,000 (95% CI)		Rate per 1,000 (95% CI)		
	All pupils	10.76 (8.28, 13.98)			13.14	(12.64, 13.64)	
	Male pupils	11.53 (8.52, 15.61)			12.64	(11.99, 13.29)	
	Female pupils	8.95 (5.31, 15.11)			13.79	(13.04, 14.59)	
	Cox PH models:		HR (95% CI)				
	Intellectual disabilities	0.77 (0.59, 1.00)					
			aHR ^a (95% CI)				
	Intellectual disabilities	0.81 (0.62, 1.06)					
	Length of stay models:		IRR (95% CI)				
	All pupils admitted, (n=2,717)						
	Intellectual disabilities	1.88 (0.71, 4.92)					
			Adjusted IRR ^a (95% CI)				
	All pupils admitted (n=2,717)						
	Intellectual disabilities	1.95 (0.78, 4.89)					

*Prescription for asthma (inhaled steroid and β -agonist); **ICD 10 codes J45, J46; a – adjusted for age at entry, sex, and deprivation quintile (SIMD); b – X² test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person; Mann-Whitney U test was used for length of stay

Table 4. Hospital admissions due to diabetes** amongst pupils with insulin-dependent diabetes with, and without, intellectual disabilities, including incidence rates, Cox proportional hazards models for risk of admission, and zero-inflated negative binomial regression for total length of stay

All admissions due to diabetes**	Intellectual Disabilities and diabetes*	Control and diabetes*	p-value ^b
Total pupils, n	94	3,924	
Total admissions, n	54	3,089	
Pupils admitted, n %	24 25.5%	1,227 31.3%	p=0.235
Males admitted, n %	15 27.3	532 26.6	0.908
Females admitted, n %	9 23.1	695 36.2	0.092
Mean admissions per person, (sd)	2.25 (2.3)	2.7 (3.4)	p=0.704
N day cases, % admissions	16 29.6%	545 17.6%	p=0.023
Length of stay, days, median (IQR)	2 1, 3	3 2,4	p=0.031
(exc. days cases)	3 2,4	3 2,4	p=0.371
Incidence of admission / 1,000 person years (95% CI)	Rate per 1,000 (95% CI)	Rate per 1,000 (95% CI)	
All pupils	96.72 (64.83, 144.30)	95.7 (90.55, 10.27)	
Male pupils	102.88 (62.02, 170.65)	79.0 (72.57, 86.01)	
Female pupils	87.94 (45.76, 169.01)	114.3 (106.14, 123.16)	
Cox PH models:	HR (95% CI)		
Intellectual disabilities	0.98 (0.65, 1.47)		
	aHR^a (95%CI)		
	0.94 (0.63, 1.41)		
Length of stay models:	IRR (95% CI)		
All pupils admitted, (n=1,251)			
Intellectual disabilities	0.70 (0.51, 0.97)		
	Adjusted IRR^a (95%)		
All pupils admitted, (n=1,251)			
Intellectual disabilities	0.71 (0.51, 0.99)		

*Prescription for insulin; **ICD 10 codes E10-E14; a – adjusted for age at entry, sex, and deprivation quintile (SIMD); b – X² test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person, Mann-Whitney U test was used for length of stay

For peer review only

Supplementary tables:

Table S1. All-cause admissions among pupils with epilepsy with, and without, intellectual disabilities including incidence rates, Cox proportional hazards models for risk of admission for pupils with epilepsy with, versus without, intellectual disabilities

All-cause admissions	Pupils with intellectual disabilities and epilepsy		Controls with epilepsy	p-value ^b
Total pupils, n	1,608		6,413	
Total admissions, n	6,235		7,600	
Pupils admitted, n %	985	61.3%	2,330	36.7% p<0.001
Mean admissions per person, (sd)	6.33	(15.9)	2.3	(5.6) p<0.001
Incident admissions / 1,000 (95% CI) – All pupils	316.06	(296.93, 336.43)	166.4	(165.18, 179.04)
- Males	301.28	(277.50, 327.11)	166.4	(145.69, 165.58)
- Females	338.70	(307.70, 372.82)	164.2	(175.65, 194.85)
All emergency admissions				
Total admissions, n	2,723		3,013	
Total pupils admitted, n %	686	42.6%	1,100	23.9% p<0.001
Mean admissions per person, (sd)	3.97	(5.6)	2.2	(3.7) p<0.001
Incident admissions / 1,000 (95% CI) – All pupils	164.71	(152.83, 177.51)	166.4	(91.72, 101.36)
- Males	160.56	(145.56, 177.12)	166.4	(79.87, 93.65)
- Females	170.84	(152.18, 191.80)	144.2	(97.72, 111.11)
All routine admissions				
Total admissions, n	3,512		3,833	
Total pupils admitted, n %	733	45.6%	1,400	23.1% p<0.001
Mean admissions per person, (sd)	4.79	(17.0)	2.5	(4.5)
Incident admissions / 1,000 (95% CI) – All pupils	188.02	(174.89, 202.13)	133.5	(88.89, 98.39)
- Males	178.24	(161.91, 196.22)	135.4	(78.80, 92.57)
- Females	202.60	(181.48, 226.18)	199.7	(93.45, 106.50)
PH Cox models All-cause admissions:		HR (95% CI)		
All admissions – Intellectual disabilities	1.82	(1.69, 1.96)		
Emergency admissions – Intellectual disabilities	1.74	(1.59, 1.91)		
Routine admissions – Intellectual disabilities	2.04	(1.86, 2.22)		
		aHR^a (95%CI)		
All admissions – Intellectual disabilities	1.82	(1.69, 1.96)		
Emergency admissions – Intellectual disabilities	1.75	(1.60, 1.92)		
Routine admissions – Intellectual disabilities	2.01	(1.83, 2.20)		

a – adjusted for age, sex, age at entry, and SIMD b – X² test was used for comparing n pupils admitted; t-test was used for mean admissions per person

Table S2. All-cause admissions among pupils with asthma with, and without, intellectual disabilities, including incidence rates, Cox proportional hazards models for risk of admission for pupils with asthma with versus without intellectual disabilities

All-cause admissions:	Pupils with intellectual disabilities and asthma		Controls with asthma	p-value ^b
Total pupils, n	1,621		53,363	
Total admissions, n	2067		27,910	
Total pupils admitted, n %	533	32.9%	13,737	25.7% p<0.001
Mean admissions per person, (sd)	3.88	(11.0)	2.1	(3.5) p<0.001
Incident admissions / 1,000 (95% CI)				
- All pupils	132.03	(121.28, 143.73)	78.1	(77.56, 80.20)
- Males	121.38	(109.30, 134.78)	75.4	(73.69, 77.11)
- Females	158.66	(137.26, 183.39)	83.5	(81.46, 85.60)
All emergency admissions				
Total admissions, n	977		16,794	
Total pupils admitted, n %	348		9,290	p<0.001
Mean admissions per person, (sd)	2.81	(4.3)	1.1	(2.7) p<0.001
Incident admissions / 1,000 (95% CI)				
- All pupils	77.03	(69.35, 85.56)	49.6	(48.86, 50.89)
- Males	71.90	(63.20, 81.79)	48.4	(46.73, 49.37)
- Females	89.66	(74.80, 107.47)	52.7	(50.71, 53.87)
All routine admissions				
Total admissions, n	1,090		11,116	
Total pupils admitted, n %	331	20.4	6,742	12.6% p<0.001
Mean admissions per person, (sd)	3.29	(12.4)	1.5	(2.3) p<0.001
Incident admissions / 1,000 (95% CI)				
- All pupils	73.15	(65.68, 81.48)	34.8	(34.06, 35.73)
- Males	65.82	(57.51, 75.32)	32.14	(31.10, 33.22)
- Females	91.00	(76.09, 108.82)	38.50	(37.19, 39.86)
PH Cox Models All-cause admissions:				
HR (95% CI)				
All admissions – Intellectual disabilities	1.59	(1.45, 1.73)		
Emergency admissions – Intellectual disabilities	1.48	(1.33, 1.64)		

Routine admissions – Intellectual disabilities	2.01	(1.80, 2.24)	
	aHR^a (95% CI)		
All admissions – Intellectual disabilities	1.56	(1.43, 1.71)	
Emergency admissions – Intellectual disabilities	1.45	(1.30, 1.61)	
Routine admissions – Intellectual disabilities	2.00	(1.79, 2.23)	

a – adjusted for age, sex, age at entry, and SIMD b – X² test was used for comparing n pupils admitted, n cases; t-test was used for mean admissions per person, Mann-Whitney U test was used for length of stay

Table S3 . All-cause admissions among pupils with insulin-dependent diabetes with, and without, intellectual disabilities, including incidence rates, Cox proportional hazards models for risk of admission for pupils with diabetes, with versus without intellectual disabilities

All-cause admissions:	Intellectual Disabilities & diabetes		Controls with diabetes		p-value ^b
Total pupils, n	94		3,924		
Total admissions, n	245		6,729		
Total pupils admitted, n %	53	56.4%	2,022	51.5%	p=0.353
Mean admissions per person, (sd)	4.62	(9.5)	3.33	(5.8)	p=0.115
Incident admissions / 1,000 (95% CI)					
- All pupils	314.01	(239.89, 411.02)	197.16	(89.75, 205.94)	
- Males	342.04	(244.40, 478.69)	174.45	(68.68, 185.92)	
- Females	273.84	(174.67, 429.32)	222.70	(101.78, 236.42)	
All emergency admissions					
Total admissions, n	100		5,222		
Total pupils admitted, n %	34	36.2%	1,761	44.9%	p=0.093
Mean admissions per person, (sd)	2.94	(2.6)	2.97	(3.7)	p=0.364
Incident admissions / 1,000 (95% CI) – All pupils	151.71	(108.40, 212.32)	158.20	(115.98, 165.76)	
All routine admissions					
Total admissions, n	145		1,507		
Total pupils admitted, n %	34	36.2%	750	19.1%	p<0.001
Mean admissions per person, (sd)	4.26	(10.8)	2.01	(6.1)	p=0.045
Incident admissions / 1,000 (95% CI) – All pupils	22.85	(10.90, 47.94)	13.36	(1.67, 15.30)	
PH Cox Models All-cause admissions:					
HR (95% CI)					
All admissions – Intellectual disabilities	1.46	(1.11, 1.92)			
Emergency admissions – Intellectual disabilities	0.91	(0.65, 1.28)			
Routine admissions – Intellectual disabilities	2.61	(1.85, 3.69)			
aHR^a (95% CI)					
All admissions – Intellectual disabilities	1.44	(1.10, 1.90)			
Emergency admissions – Intellectual disabilities	0.90	(0.64, 1.26)			
Routine admissions – Intellectual disabilities	2.61	(1.85, 3.69)			

a – adjusted for age, sex, age at entry, and SIMD b – χ^2 test was used for comparing n pupils admitted, n day cases; t-test was used for mean admissions per person

For peer review only