ORIGINAL ARTICLE

Hospitalisations from birth to 5 years in a population cohort of Western Australian children with intellectual disability

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Aims: To describe the hospitalisation history in the first five years of life for all children born in Western Australia (WA) between 1983 and 1992 and diagnosed with intellectual disability (ID).

Methods: Unit record linkage of the WA Midwives Collection, WA Intellectual Disability Database, and the WA Hospital Morbidity Dataset provided the population database of WA born children with and without ID. Affected children were divided into those co-affected with autism spectrum disorders (ASD), and those whose ID had or had no known biomedical cause. Those without a biomedical cause were further subdivided into mild-moderate and severe categories.

Results: On average, ID affected children were more likely than non-affected children to be admitted to hospital (RR: 1.64; 95% CI 1.6 to 1.7), on more occasions (5.3 versus 2.2 admissions), for longer (29.6 versus 8.3 days), and for a larger range of clinical diagnoses. The only exception was the group of children co-diagnosed with ASD whose hospitalisation profile resembled more that of non-affected children.

Conclusions: This total population study is unique because of the availability of the system of linkable population registers and administrative health databases in WA. The results indicated that this vulnerable population of children with ID has substantial medical needs. This paper points to the need for authorities to develop supportive programmes for this population especially in the current climate of de-medicalisation of ID. More research is not only needed on the welfare of the affected children but also on the impact of the substantial medical and other needs of affected children on the rest of their immediate and extended families.

Although intellectual disability (ID) comprises about 7% of all disabling conditions in Australia,¹ relatively little is known about its causes and sequelae. A similar situation applies in other economically developed countries. In a recent blueprint for action aimed at improving the health of persons with ID (commonly referred to as mental retardation in the USA), the US Surgeon General recently argued that "the lack of population-based data on prevalence of mental retardation and the health status and service needs of this population impedes planning and allocating resources for their care".² The blueprint specifically called for the need to collect data on the health status of persons with mental retardation in relation to the use, organisation, and financing of their health services.

This population based study aimed to describe hospital admissions for children with ID compared with non-affected children. It examined and compared the principal causes, frequency and duration of admissions for the first five years of life.

METHODS

Health researchers in Western Australia (WA) have access to a comprehensive system of population based datasets linkable at unit record level.³ Records on children with ID were linked to the WA Hospital Morbidity Database and the WA Midwives Collection to produce a population database of WA born children with and without ID.

The ID records were sourced from the WA Disability Services Commission (DSC), the major provider of disability services in the State, and from the WA Department of Education. Children identified through DSC were considered to have an ID if: (1) they had an intelligent quotient less than 70 on formal testing; (2) they had a condition known to be associated with ID (for example, Down's syndrome); or (3)

they are clearly documented in their DSC records as having ID. The education sector defines children as ID affected "if they demonstrate significant deficits in adaptive behaviour and academic achievement and demonstrate intellectual functioning two or more SDs below the mean on an approved measure of cognitive functioning".⁴

The Heber version of the American Association on Mental Retardation (AAMR) classification system⁵ allows for the division of ID cases into those with and without ASD. ID cases were divided into those with ASD, those with a biomedical cause and the remainder into mild-moderate, severe, and unspecified categories.

Although ID is typically diagnosed before 5 years of age, some mild cases may not be identified until well into school age. Allowing for this lag, we feel that the information we have on the ID status of the cohort of infants born in WA from 1983 to 1992 inclusive, is now fairly complete. Our denominator for this study was children born in WA. We excluded infants who died in the first four weeks with the deaths being mostly from birth defects, and complications of low birth weight and prematurity. We have no information on children who left the State within the first five years of their life. We, however, estimated out-migration for the total WA population to be about 6% from 2001 Australian census unpublished data that we requested from the Australian Bureau of Statistics. At this stage, we have no reason to believe that the families of children with or who subsequently develop ID were more or less likely to move from WA. Our study base therefore included 241 839 neonatal survivors, 3522 of whom were affected with ID (table 1).

Abbreviations: AAMR, American Association on Mental Retardation; ASD, autism spectrum disorders; DSC, Disability Services Commission; ID, intellectual disability; WA, Western Australia

Table 1 Hospital admissions for first five years of life for neonatal survivors among cohort of children born in WA 1983–92 by ID status

	Children with ID					All children with ID	All children without ID
	With ASD	Medically diagnosed	Severe	Mild or moderate	Unspecified		
Total number of children	191	604	223	2111	393	3522	238317
No. of children admitted to hospital	124	569	192	1586	317	2788	114819
Proportion of children admitted (%)	64.9	94.2	86.1	75.1	80.7	79.2	48.2
No. of hospital admissions	370	4348	1692	6836	1522	14768	253431
Mean no. of admissions per child (SD)	1.9 (3.3)**	7.2 (8.3)	7.6 (11.1)	3.3 (4.9)	3.9 (5.4)	4.2 (6.3)	1.1 (2.1)
Median no. of admissions per child (interquartile range)	1 (0–3)	5 (2–8)	4 (1–10)	2 (1–4)	2 (1–5)	2 (1–5)	0 (0–1)
Mean no. of admissions per child admitted (SD)	3.0 (3.7)*	7.6 (8.3)**	8.8 (11.5)**	4.3 (5.0)**	4.8 (5.7)**	5.3 (6.7)**	2.2 (2.5)
Median no. of admissions per child admitted (interquartile range)	2 (1–4)	5 (3–9)	5 (2–11)	3 (1–5)	3 (1–5)	2 (3–6)	1 (1–2)
Mean of total no. of days in hospital per child admitted (SD)	9.5 (16.0) NS	45.3 (63.4)**	50.0 (82.0)**	23.4 (49.3)**	30.5 (54.2)**	29.9 (55.9)**	8.3 (18.6)
Median no. of days in hospital per child admitted (interquartile range)	4 (1–10)	21 (8–54)	20 (6–59)	8 (3–22)	9 (3–27)	10 (3–30)	3 (1–8)

The interquartile range refers to data pertaining to the 25th and 75th centiles.

All statistical tests done row-wise against value for non-ID affected children. NS, not significant; * $p < .05$; ** $p < 0.001$.

We have reported on all hospital admissions occurring in the first five years of life including those originating in the neonatal period but excluding those associated with normal birthing episodes. Morbidity data were viewed at both episode and at individual child level. The principal diagnosis, for each admission episode, was constructed from information available at time of hospital discharge and coded using the Australian amended version of the Ninth Revision of the International Classification of Diseases (ICD-9).⁶ Researchers had used these principal diagnoses to develop a list of 15 clinically relevant categories (see Appendix for list of codes) for a previous study into hospitalisation in WA children.^{7, 8} To allow for comparisons with their broad findings, we used the same list of clinically relevant categories. Duration of stay was calculated based on admission and discharge dates. Duration was allocated 0.5 days where admission and discharge occurred on the same day.

We derived means (with their standard deviations) as well as medians (and their associated interquartile range—25th and 75th centiles) to describe measures of central tendency in the data. Relative risks and their 95% confidence intervals were used to test the relation between categorical variables; and Student's *t* tests to assess differences in means. All analyses were conducted using Stata version 8.⁹

This project was approved by the Institute's institutional ethics committee (Princess Margaret Hospital Ethics Committee), and by the WA Health Department Confidentiality of Health Information Committee.

RESULTS

Causes for admission to hospital

Seventy nine per cent of children with ID had been admitted to hospital in their first five years compared with 48% of children without ID (table 1). These proportions yielded a relative risk of 1.64 (95% CI 1.6 to 1.7, $p < 0.001$). The proportions admitted to hospital ranged from 65% for children co-affected by ASD to 94% for those with a definite medical diagnosis. Compared with non-affected children these proportions yielded relative risks that ranged from 1.3 (95% CI 1.2 to 1.5) for the children with ASD to 2.0 (95% CI 1.9 to 2.0) for children with medically diagnosed ID (table 2).

As would be expected for children with ID, there were high relative risks of admission for morbidities associated with the central nervous system and mental conditions, and to a lesser extent with congenital anomalies. Although smaller in magnitude, the risks of hospitalisation for the other clinically

relevant categories were also significantly higher for children with ID. The 124 children with ASD were the exception with a morbidity admission pattern more similar to those without ID.

Frequency and duration of admission to hospital

Children with ID had on average been admitted 4.2 times (SD 6.3) in the first five years of their life compared with 1.1 admissions (SD 2.1) for children not affected by ID ($p < 0.001$) (table 1). With each admission lasting 3.8 days on average, each of the 114 819 children without ID who was admitted would have spent on average 8.3 days (SD 8.6) in hospital by their fifth birthday (tables 1 and 4). In contrast, children with ID had significantly higher corresponding means for all ID categories combined. The mean number of admissions per child admitted ranged from 3.0 for ID children with ASD to 8.8 for children with severe ID (table 3). With the exception of children with ID and ASD, all children with ID had significantly longer hospital stays (per child admitted and per admission episode) compared with children without ID. The mean duration of hospitalisation for children admitted in the first five years of their life ranged from 9.5 days (SD 16.0) for ID children with ASD (not statistically different from non-ID children) to an average of 50.0 days (SD 82.0) for children with severe ID.

While 48% of unaffected children had a hospital admission, this applied to 94% of children with medically diagnosed ID (RR: 1.96, 95% CI 1.9 to 2.0) and 65% of those children with ASD (RR: 1.4, 95% CI 1.2 to 1.5). Only 12% of children without ID had been admitted three or more times compared with 47% for all children with ID (RR: 4.1, 95% CI 3.9 to 4.2) (table 4). Even those with ASD recorded a level twice that for children without ID. Over the history of their admissions, only 6% of children without ID had been admitted for three or more clinically relevant categories (table 5). This compared with 34% of all children affected with ID (RR: 5.4, 95% CI 5.2 to 5.7).

DISCUSSION

To our knowledge, this is the first report to describe the hospitalisation pattern in a total population of children with ID. This study has provided useful information on hospital admissions up to 5 years of age for children with ID compared with the general population. It also allowed comparison by type and severity of ID. This study focused on hospitalisations in the first five years of life, and thus for

Table 2 Risk of admission to hospital up to 5 years of age for neonatal survivors among cohort of children born in WA 1983–92 by principal diagnosis and ID status

Clinically relevant category	Intellectual disability associated with ASD (n = 191)		Medically diagnosed intellectual disability (n = 604)		Severe intellectual disability (n = 223)		Mild or moderate intellectual disability (n = 2111)		Intellectual disability unspecified (n = 393)		No intellectual disability (n = 238317)	
	No. of children admitted	Relative risk (95% CI)	No. of children admitted	Relative risk (95% CI)	No. of children admitted	Relative risk (95% CI)	No. of children admitted	Relative risk (95% CI)	No. of children admitted	Relative risk (95% CI)	No. of children admitted	Reference group
All categories	124	1.3 (1.2–1.5)	569	2.0 (1.9–2.0)	192	1.8 (1.7–1.9)	1586	1.6 (1.5–1.6)	317	1.7 (1.6–1.8)	114819	1.0
Infections	61	1.4 (1.2–1.7)	417	3.1 (2.91–3.2)	127	2.5 (2.3–2.8)	998	2.1 (2.0–2.2)	185	2.1 (1.9–2.3)	53802	1.0
Respiratory	12	1.0 (0.6–1.7)	132	3.4 (2.9–4.0)	57	4.0 (3.2–5.0)	310	2.3 (2.1–2.6)	61	2.4 (1.9–3.1)	15226	1.0
Gastrointestinal tract	28	2.0 (1.4–2.8)	188	4.3 (3.8–4.8)	94	5.8 (4.9–6.7)	442	2.9 (2.6–3.1)	88	3.1 (2.5–3.7)	17453	1.0
Central nervous system	8	16.0 (8.1–31.6)	98	61.9 (50.8–75.4)	62	106.0 (84.6–132.8)	102	18.4 (15.0–22.6)	36	34.9 (25.3–48.2)	625	1.0
Mental	15	28.2 (17.2–46.1)	18	10.7 (6.7–17.0)	10	16.1 (8.7–29.6)	39	6.6 (4.8–9.1)	13	11.9 (6.9–20.4)	664	1.0
Congenital abnormalities	25	3.7 (2.6–5.4)	313	14.7 (13.6–15.9)	54	6.9 (5.4–8.7)	250	3.4 (3.0–3.8)	60	4.3 (3.4–5.5)	8401	1.0
Oral cavity	7	1.4 (0.7–3.0)	53	3.4 (2.7–4.5)	17	3.0 (1.9–4.7)	111	2.1 (1.7–2.5)	27	2.7 (1.9–3.9)	6079	1.0
Perinatal period	29	1.4 (1.0–2.0)	134	2.1 (1.8–2.4)	74	3.1 (2.6–3.7)	437	1.9 (1.8–2.1)	107	2.5 (2.1–3.0)	25719	1.0
Injury and poisoning	20	1.3 (0.9–2.0)	120	2.5 (2.1–2.9)	46	2.6 (2.0–3.4)	355	2.1 (1.9–2.3)	59	1.9 (1.5–2.4)	18883	1.0
Social admissions	na	0.5 (0.2–1.4)	66	2.7 (2.2–3.4)	24	2.7 (1.8–3.9)	153	1.8 (1.6–2.1)	30	1.9 (1.3–2.7)	9528	1.0
Renal/genital	8	1.2 (0.6–2.4)	27	1.3 (0.9–1.9)	12	1.6 (0.9–2.7)	111	1.5 (1.3–1.8)	19	1.4 (0.9–2.2)	8184	1.0
Neoplasm	na	1.3 (0.2–8.8)	18	7.1 (4.5–11.2)	na	na	8	0.9 (0.5–1.8)	na	1.2 (0.3–4.8)	1002	1.0
Other	24	2.1 (1.4–3.0)	248	6.8 (6.2–7.5)	74	5.5 (4.6–6.7)	375	3.0 (2.7–3.3)	80	3.4 (2.8–4.1)	14312	1.0

Each child can be in more than one category.
na, less than five children.

Table 3 Mean number of admissions and days spent in hospital up to 5 years of age for neonatal survivors among cohort of children born in WA 1983–92 by principal diagnosis and ID status

Clinically relevant category	Intellectual disability associated with ASD (n = 191)			Medically diagnosed intellectual disability (n = 604)			Severe intellectual disability (n = 223)			Mild or moderate intellectual disability (n = 2111)			Intellectual disability unspecified (n = 393)			No intellectual disability (n = 238317)		
	Mean no. of admissions per child	Mean no. of days per admission	Mean no. of admissions per child	Mean no. of days per admission	Mean no. of admissions per child	Mean no. of days per admission	Mean no. of admissions per child	Mean no. of days per admission	Mean no. of admissions per child	Mean no. of days per admission	Mean no. of admissions per child	Mean no. of days per admission	Mean no. of admissions per child	Mean no. of days per admission	Mean no. of admissions per child	Mean no. of days per admission		
All categories	3.0**	3.2	7.6***	5.9***	8.8***	5.7***	4.3***	5.4***	4.8***	4.3***	2.2	8.3						
Infections	2.0	2.6	3.4***	4.7***	3.7***	4.7***	2.6**	3.8***	2.6**	4.3***	1.7	2.9						
Respiratory	2.1	2.7	2.9***	6.0***	2.6*	4.9***	2.2**	3.9***	2.6**	5.6***	1.8	2.7						
Gastrointestinal tract	1.3	3.1	2.1***	5.9***	2.2***	5.8***	1.8***	5.1***	2.0***	6.5***	1.3	3.4						
Central nervous system	2.0	5.8	3.0***	5.8***	4.2***	5.1*	3.1***	4.1	2.9**	7.5***	1.6	3.9						
Mental	1.1	1.7	1.3	7.1***	1.2	4.0	1.1	4.3**	1.4*	1.7	1.1	3.1						
Congenital abnormalities	1.1	3.1	2.2***	8.6***	2.1**	7.1	1.7*	7.6***	2.0*	8.0*	1.4	5.3						
Oral cavity	1.0	0.5	1.1	1.6*	1.2	1.2	1.2	1.3	1.2	1.3	1.1	0.9						
Perinatal period	1.1	8.0	1.1	14.0*	1.2**	18.3***	1.1	21.1***	1.1	19.2***	1.1	10.8						
Injury and poisoning	1.1	2.7	1.5***	9.5***	1.5***	8.3***	1.3***	5.1***	1.3*	4.5*	1.1	2.6						
Social admissions	1.3	3.1	2.2***	4.8*	4.4***	2.7	1.3*	3.4	1.6**	4.0	1.2	3.3						
Renal/genital	1.0	0.7	1.1	2.5	1.4*	2.7	1.3***	3.3***	1.2	3.8*	1.1	1.5						
Neoplasm	1.0	7.0	7.6*	2.8	10.3	5.9	1.5	2.0	6.0	11.8**	3.5	3.4						
Other	2.2*	2.3	1.8***	3.8***	2.1***	4.0**	1.6*	3.8***	1.7	3.7*	1.3	2.6						

****p = 0.0000; ***p < 0.001; **p < 0.01; *p < 0.05 compared with children with no intellectual disability.

Table 4 Frequency of hospital admissions up to 5 years of age for neonatal survivors among cohort of children born in WA 1983–92 by ID status

No. of times admitted	Intellectual disability associated with ASD		Medically diagnosed intellectual disability		Severe intellectual disability		Mild or moderate intellectual disability		Intellectual disability unspecified		No intellectual disability	
	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort
Never admitted	67	35.1	35	5.8	31	13.9	525	24.9	76	19.3	123498	51.8
Admitted at least once	124	64.9**	569	94.2**	192	86.1**	1586	75.1**	317	80.7	114819	48.2
1	48	25.1	58	9.6	29	13.0	461	21.8	82	20.9	61691	25.9
2	27	14.1	61	10.1	22	9.9	279	13.2	63	16.0	25513	10.7
3+	49	25.7	450	74.5	141	63.2	846	40.1	172	43.8	27615	11.6
Total	191	100.0	604	100.0	223	100.0	2111	100.0	393	100.0	238317	100.0

* $p < 0.05$; ** $p < 0.001$, comparing ID affected children admitted at least once with children free of intellectual disability and never admitted to hospital.

children with ID was independent of the age at which ID was diagnosed. The results clearly show that children with ID were more likely to be admitted to hospital on more occasions and with a larger range of clinical diagnoses than non-affected children. The only exception was in the group of cases co-diagnosed with ASD.

This study has only been possible because of the existence of a population based ID register in WA. The ID register is the only such one in Australia and other than those few US centres in Atlanta, Florida,^{10–11} and California,¹² it is one of the few places in the world with the capacity to carry out rigorous epidemiological ID research. A unique feature of our register is that it is capable of being linked at unit record level to a variety of other databases including the WA Midwives and Hospital Morbidity databases,³ as well as the WA Cerebral Palsy¹³ and WA Birth Defects Registers,¹⁴ also maintained by our Institute. This infrastructure has the capacity to provide a window on all of childhood disability that also extends to include the investigation of the antecedents and co-morbidities.

What we have done in this study is to make an important start in measuring the health status of the ID population to allow for appropriate planning for health service needs. This is however very much a first step as this report only focuses on the hospital morbidity patterns for the first five years of life and does not consider later childhood or the adult population. There were a number of reasons for this. We used the previously identified cohort of WA children born between 1983 and 1992¹⁵ to ensure that ascertainment of ID was as complete as possible and that those children only being ascertained through educational sources would have had the opportunity to be identified. Thus, as we were limited in the

number of years of hospitalisation history that would be available for the later births, we elected to restrict our analysis to the first five years of life.

Given what we have achieved in relation to the existing literature this is a landmark study. Because of the clear need to develop policy for the medical management of people with ID a review of international studies comparing the prevalence of health problems in people with and without ID was recently conducted.¹⁶ Only seven studies were identified meeting the criteria for research quality and of these only one could be considered population based. This was a Dutch study which, using a computerised general practice database to identify 318 people with ID and compare them with 48 459 people without ID, found that those with ID had 2.5 times more health problems.¹⁷ None of the other studies, with samples of between 29 and 336 ID affected people, were population based. Although it is difficult to make an exact comparison between the health problems identified in general practice and our findings using hospitalisation data, there were some similarities. As might be expected some of their highest odds ratios were for categories such as congenital anomalies (OR 13.8, 95% CI 8.2 to 23.4), epilepsy (OR 15.4, 95% CI 10.7 to 22.2), premature/immature live born infant (OR 4.4, 95% CI 2.5 to 7.8), other disorders CNS (OR 4.4, 95% CI 2.6 to 7.7), and all perinatal morbidity (OR 3.4, 95% CI 2.0 to 5.7). However, we reported in our childhood population that although admission for central nervous system and mental conditions provided the higher relative risks for admission to hospital, the greatest burden in terms of the number of individual children hospitalised were for infections, conditions operating in the perinatal period, gastrointestinal and respiratory conditions, as well as injury

Table 5 Number of diagnostic categories experienced by children up to 5 years of age for neonatal survivors among cohort of children born in WA 1983–92 by ID status

No. of diagnosis categories at admission	Intellectual disability associated with ASD		Medically diagnosed intellectual disability		Severe intellectual disability		Mild or moderate intellectual disability		Intellectual disability unspecified		No intellectual disability	
	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort	No. of children	% of cohort
Never admitted	67	35.1	35	5.8	31	13.9	525	24.9	76	19.3	123498	51.8
Admitted at least once	124	64.9**	569	94.2**	192	86.1**	1586	75.1**	317	80.7**	114819	48.2
1	60	31.4	87	14.4	36	16.1	591	28.0	114	29.0	71842	30.1
2	31	16.2	128	21.2	33	14.8	422	20.0	88	22.4	28083	11.8
3	19	9.9	134	22.2	44	19.7	258	12.2	50	12.7	9933	4.2
4+	14	7.3	220	36.4	79	35.4	315	14.9	65	16.5	4961	2.1
Total	191	100.0	604	100.0	223	100.0	2111	100.0	393	100.0	238317	100.0

* $p < 0.05$; ** $p < 0.001$ comparing ID affected children admitted at least once with children free of intellectual disability and never admitted to hospital.

What is already known on this topic

- Very little is known on a population basis about the health status and hospitalisation patterns of children with intellectual disability
- The lack of such data is impeding progress in planning health services and allocation of resources to this population

What this study adds

- It provides for the first time information on hospitalisation patterns for a total population of children with intellectual disability in the first five years of their lives
- We have been able to show how the patterns vary by category of intellectual disability and by the clinical category of the hospitalisation.

and poisoning. A weakness of the Dutch study is that it does not provide an age breakdown of the populations although it is stated that 20% of those with ID and 30% of the remainder were over 50 years. Thus one would surmise that it is a predominantly adult population.

In their review, Jansen and colleagues¹⁶ commented on the methodological weaknesses of many of the seven studies such as the absence both of a case definition for people with ID and information about ID level. They also mentioned that method of recruitment influences representativeness of the sample and the issue of bias if consent is required where those who do consent may be different from those who do not. The major benefits of our study design include having a clear case definition, information on type and severity of ID, population based ascertainment (and thus no consent related bias), and no data acquisition burden on medical practitioners as our information is obtained by record linkage.

In general we found that the risks of hospitalisation were increased for all children with ID except for those with ASD. The behavioural characteristics of children with ASD may make it more difficult for their parents to engage them within the health system or, as often has been our clinical perception, they may be physically healthier than other children with ID. The risks of hospitalisations were higher for those with severe and medically related ID and a little lower for those with mild-moderate and unspecified ID. Children with Down's syndrome comprise a substantial proportion (40%) of those with a medical diagnosis. In a questionnaire study we previously described the co-morbidities of these children and their use of health services from a parental perspective.¹⁵ During the previous year just over a third were reported to have had a hospital admission—commonly for dental procedures, ear surgery, eye problems, and respiratory problems. The methods we have developed and followed here would now allow us to separate out and examine the hospital experience of children with Down's syndrome or in other specific ID categories. Our results are also consistent with some other recent Australian research. A study of young Australians (aged 5–29 years) with ID reported a rate of injury hospitalisations twice that for the general population.¹⁸ Another study reported the median length of stay for a child with trisomy 21 (without congenital heart disease) with common respiratory conditions was 2–3 times greater than in patients without trisomy 21.¹⁹

In conclusion, we believe these results have substantial relevance and implications for policy at an international level. There has been, in the current climate of de-medicalisation of ID, a universal trend away from the provision of specific clinical services for these children. The results presented in this paper clearly show that children with ID have substantial medical needs that culminate in higher risk of hospitalisation for a variety of clinical diagnoses in the first five years of their life. The impact of these admissions most likely not only impact on the welfare of the affected children but also on the rest of their immediate and extended families. Moreover there is concern that as more and more people with ID are de-institutionalised there is not the necessary primary care

infrastructure to provide for their medical care.¹⁶ This is an often hidden population²⁰ in which we have shown at least in early childhood to have high medical needs.

This preliminary report is thus an important first step to understanding the health status and medical needs of this vulnerable population. These medical needs may not necessarily decline as these children progress into adulthood. Our next priority will be to extend the analysis over a larger birth cohort to provide more statistical power and to use more sophisticated techniques to allow for examination of patterns of hospital morbidity throughout childhood. We also see a need to supplement this quantitative research with qualitative work to document the associated personal, social, and economic costs to ensure evidence based policy and programme decisions for affected children and their families.

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APPENDIX

See table A1 for a list of ICD-9 codes used for the various clinically relevant categories.

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Table A1 List of ICD-9 codes used for the various clinically relevant categories

Clinically relevant categories	ICD-9-CM codes
Infections	001–139; 320–326; 372.0; 373.4–373.5; 376.0–376.1; 380.1; 381.0–381.5; 382; 383.0–383.3; 383.9; 390–398; 420–422; 460–466; 473–475; 480–490; 494; 510; 511.0–511.1; 523.3; 540; 580; 590; 595; 599.0; 604; 614; 616.0–616.4; 646.6; 658.4; 675; 680–699; 711; 730; 780.3; 780.6; V04.8; V12.0; V18.8; V75 (exclude 090)
Respiratory	470–472; 476–478; 491–493; 495–508; 511.8–519.9; 786; V17.5–V17.6; V42.6; V71.2 (exclude 516.9; 786.6)
Gastrointestinal tract	530–578; 783; 787; 789; 793.4; V12.7; V18.5; V55.0–V55.4 (exclude 540)
Central nervous system	331–359.9 (exclude 335.0; 359.0–359.3)
Mental	290–319; V11; V17.0; V18.4; V40; V62.8–V62.9; V66.3; V67.3; V71.0; V79
Congenital anomalies	090; 228.0–228.1; 243; 255.2; 270.0–271.3; 272.6–272.7; 275.1–275.4; 276.3; 277.0–277.2; 277.5; 282; 286; 288.2; 330; 335.0; 359.0–359.3; 362.7; 371.5; 389.1; 457.8; 524.0; 579.0; 579.8–579.9; 593.0; 593.7; 648.5; 654.0; 654.6–654.8; 740–759.9; 762.8; 771.0–771.2; 776.5; 778.0; 778.6; V13.6; V19.5; V82.4
Oral cavity	520–529; V41.6; V53.4; V58.5; V72.2 (exclude 523.3; 524.0)
Perinatal period	760–779; V13.7 (exclude 762.8; 771.0–771.2; 776.5; 778.0; 778.6)
Injury and poisoning	800–999; V15.5–V15.6; V66.4; V67.4; V71.3–V71.6; V82.5
Social admissions	V20; V60–V65, (exclude V62.8–V62.9)
Renal/genital	250.4; 581–589; 591–629; 646.2; 788; 791; 793.5; 794.4; V18.6–V18.7; V43.5; V50.2; V53.6; V55.6; V56.0–V56.8; V59.4 (exclude 593.0; 593.4; 593.7; 595; 599.0; 604; 614; 616.0–616.4)
Neoplasms	140–239; V10; V16; V58.0–V58.1; V66.1–V66.2; V67.1–V67.2; V71.1; V76 (exclude 228.0–228.1)
Pregnancy/newborn and birth admission (all excluded)	630–676; V22–V29; V30–V39; (exclude 646.2; 646.6; 648.5; 654.0; 654.6–654.8; 675)
All other	All other codes not included above

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