JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Journal of Intellectual Disability Research doi: 10.1111/jir.12927

VOLUME 66 PART 5 pp 442–453 MAY 2022

Healthcare utilisation and unmet health needs in children with intellectual disability: a propensity score matching approach using longitudinal cohort data

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Abstract

Background Health disparities for children with intellectual disabilities can be challenging to measure due to many other factors that can impact health and healthcare use. The aim of the current study was to use longitudinal cohort data to compare children with intellectual disability (ID) in Ireland between 2006 and 2014 on healthcare utilisation and unmet need, at ages 9 and 13, using a propensity score matching (PSM) approach.

Methods Using data from the Growing up in Ireland study, PSM was used to identify an appropriate control sample to compare with a sample of children with ID (n = 124). Participants were matched on variables that are known to influence healthcare utilisation to reduce the impact of confounding variables between groups so that differences between the groups can be estimated. Logistic regression was used to estimate effects at ages 9 and 13.

Results Children with ID were no more likely to have visited a general practitioner or emergency department in the past 12 months than children without ID. They did have a greater likelihood of visiting a doctor in a hospital in the past 12 months and of having an overnight stay in hospital by age 9. Primary caregivers of children with ID were more likely to report unmet health needs at ages 9 and 13.

Conclusions This approach is a novel means of comparing healthcare use in this population by balancing the impact of other factors that may result in inequities, to which children with ID may be more vulnerable.

Keywords children, healthcare utilisation, intellectual disability, propensity score matching

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[Correction added on 13 May 2022, after first online publication: IReL funding statement has been added.]

Introduction

The utilisation of health services is dictated by multiple complex factors that extend beyond health

status, and patterns of usage are often indicative of wider disparities within a health system. Social inequities often play a key role in use of health services with people from lower socio-economic backgrounds being typically higher users of health services such as primary care and the emergency department (ED) (Klein *et al.* 2011; Salami *et al.* 2012). The reasons for this are manifold as people from lower socio-economic status backgrounds typically have lower levels of education, poorer health literacy (Morrison *et al.* 2013) and are more likely to suffer from a chronic illness (Mair and Jani 2020). For paediatric populations, factors that influence the use of health services are particularly complex as both child and parental factors become key indicators of usage, as well as the broader social context and accessibility of the health system (Nicholson *et al.* 2020). Parents with low levels of social support are often higher users of the ED for lower acuity conditions (Cabey *et al.* 2018). Single parent families (Zandieh *et al.* 2009), migrant populations (Ellbrant *et al.* 2018) and maternal depression (Bartlett *et al.* 2001) can also influence the decision to attend an ED. Moreover, interactions with healthcare providers can also be challenging for certain populations who often feel they have less partnership and shared decision making with healthcare professionals (Willems *et al.* 2005). Such inequities give rise to health disparities where access to, use of and experience of health services varies for different populations.

Health disparities for people with intellectual disability (ID) have been well documented and can encompass a greater utilisation of health services, poorer health maintenance and promotion, poorer experiences of healthcare, and higher mortality rates. Poorer health status and greater limitations from long-term health conditions is more pronounced in child populations with ID (Hughes-McCormack *et al.* 2018), while young people with ID are more likely to report poorer health outcomes such as general health, mental health, physical disabilities and long-term illness (Young-Southward *et al.* 2017). In children under the age of 17 in Ireland, mortality rates have been reported as 7 times higher for those with ID compared with the general population (McCarron *et al.* 2015) while in Scotland, the risk of death for children with IDs is 12 times that of their peers (Smith *et al.* 2020). Controlling for factors such as age, sex, insurance status, income and chronic illness, children with ID tend to have greater use of health services compared with the general population, and they are more likely to attend an ED for ambulatory care sensitive conditions (Hand *et al.* 2019), non-traumatic dental conditions resulting in an admission (Chi *et al.* 2014) and epilepsy (Nachshen *et al.* 2009). Health disparities for people with ID are often unavoidable; therefore, when examining health disparities in this population, it is important to utilise methodologies that allow disparities that are unjust and avoidable to be isolated (Ouellette-Kuntz 2005).

While there is much evidence that people with ID use health services at a higher rate than those without, there is a risk that confounding variables may obfuscate the disparities between people with and without ID with regards to health service use. As described above, there are a multitude of other factors that can influence use of health services, and such factors may disproportionately affect people with ID. For instance, people with ID are more likely to be socio-economically disadvantaged than people without ID (Emerson 2015). They typically report poorer health status (Hughes-McCormack *et al.* 2018); however, greater prevalence of chronic illness in this population is less clear given potential under-reporting of some symptoms (Morin *et al.* 2012). Parents of children with ID have reported specific difficulties they encounter during interactions with their primary care provider, who often avoid discussing challenging behaviours and other comorbidities that may be present (Fredheim *et al.* 2011). Indeed, general practitioners (GPs) often cite a lack of training and expertise around working with this population (Freed *et al.* 2009). Preventative primary care can reduce avoidable hospital admissions in children (Cecil *et al.* 2018), and indeed, regular health checks with a GP for people with ID has been associated with reduced emergency admissions (Cuccu *et al.* 2020). Few studies have sought to compare children with and without ID by balancing the numerous factors that influence healthcare use, and thus, the true impact of ID on use of health services is less clear.

In addition to the complexity of assessing healthcare utilisation, measuring use of health service for people with ID can produce specific challenges that are often amplified for children. Data regarding the healthcare utilisation of people with ID is critical to ensuring that health inequities are monitored and addressed

(Emerson and Hatton 2013), and while there are multiple sources of potential data available, not all are of equal quality. Administrative health records can provide valuable data (Heutmekers *et al.* 2017); however, there are inherent limitations and biases to using such data for research purposes (Emerson and Hatton 2013), particularly for paediatric research. Children with ID are often underrepresented in research using administrative databases due to poor coding of ID in routine data and low rates of disclosure from caregivers when seeking health care (Emerson *et al.* 2013; Emerson and Hatton 2013; Kenten *et al.* 2019). Using diagnosis classifications as a means to identify children with ID may overlook children who have not yet received a diagnosis (Nachshen *et al.* 2009), and mild or moderate ID are also less likely to be identified in hospital data (Bourke *et al.* 2018). The use of longitudinal national surveys on children can provide a valuable source of information (Emerson and Hatton 2013) as the data are typically high quality and the sampling frameworks employed result in a representative sample of children from the general population for investigation. The aim of the current study was to use to identify children with ID from longitudinal cohort data, collected in Ireland between 2006 and 2014, in order to compare this group with children without ID on healthcare utilisation and unmet need, at ages 9 and 13, using a propensity score matching approach.

The primary research questions were as follows: (1) Are children with ID more likely to have utilised health services in a 12-month period compared with children without ID? (2) Are children with ID more likely to have stayed overnight in a hospital compared with those without? (3) Are primary caregivers of children with ID more likely to report an unmet healthcare need for their child compared with primary caregivers of children without ID?

Methods

Context of health system

Ireland operates a mixed public and private health system. Approximately, 43% of the population have free access to a GP through the General Medical Services scheme (GMS) (this is referred to as a 'medical card') or a GP visit card (Department of Health 2019). Eligibility for the GMS scheme is means-tested or provided to those for whom paying for health services would be burdensome (approximately 3.6% of GMS holders) (Fitzpatrick *et al.* 2015). The remainder hold private health insurance (43%) (Department of Health 2019), or are covered by neither insurance or the GMS, and pay an average of €51 per visit to their GP (Competition Authority 2010). ED care in Ireland costs €100 per visit and is free only to those on the GMS scheme, referred by a GP, or arriving by ambulance.

Data sources

Growing up in Ireland is a national Government-funded longitudinal cohort study of children in Ireland, which investigates their well-being and records detailed information on children including their experience of and use of health services (Greene *et al.* 2010). The present study utilised a Child Cohort that comprises of 8500 children and their parents/caregivers recruited at age 9 in Wave 1, which took place in 2006 with further follow ups at 4-year intervals. The sampling frame for the growing up in Ireland study consisted of a two-stage process with a clustered sample design. Children were randomly selected from a stratified random sample of 910 mainstream and special schools in Ireland (82% response rate). A total of 8500 children participated at 9 years of age, which represented 1 in 7 of 9 years olds in Ireland at the time of recruitment. To avoid biasing the sample, no oversampling or booster sampling was employed for any specific groups (such as ID) (Murray *et al.* 2010). At Wave 2 (when the children were 13 years) the response rate was 91.2%, resulting in a final sample of 7525 child participants. At Wave 3, the response rate was 81% resulting in a sample of 6039 participants. The survey was completed by a primary caregiver on behalf of the study child. At the initiation of data collection for the survey, Ireland had a population of approximately 4.4 million people.

Data

Cohort selection

At Wave 3 of the study (age 17), primary caregivers were asked in the survey 'Does this young person have an ID?' Based on responses to this question, a categorical variable for children with and without ID was created. Data from Wave 3 were then used to

identify this specific cohort of children with ID at the earlier timepoints.

Use of health services

Four categorical variables were created from the responses to serve as the outcome variables in the study relating to the number of times they attended specific health services in the past 12 months including (1) GP, (2) ED, and (3) contact with a medical doctor in a hospital. The fourth categorical variable was based on the request to respondents to state the number of times the child spent overnight in a hospital during their lifetime up to the time of data collection (excluding when they were born).

Unmet need for healthcare

At Wave 1, primary caregivers were also asked to report, 'Was there any time in the last 12 months when, in your opinion, the Study Child needed medical care or treatment for a health problem but he/she did not receive it?' and at Wave 2, 'Was there any time during the past 12 months when <child> really needed to consult a GP or specialist but did not?' Two categorical variables were created to measure whether there was an unmet need at ages 9 and 13.

Further detail on this unmet need was also provided as the primary caregivers were asked to select the reasons for the unmet need from a set of categorical variables including (1) could not afford to pay, (2) necessary medical care was not available or accessible, (3) could not take time off work, (4) wanted to wait and see if child got better, (5) child refused/fear of doctor, (6) child still on waiting list, (7) travel and (8) other.

Statistical analysis

Propensity score matching was used to identify an appropriate control group to match with a treatment group (i.e. children with ID) identified in the data to reduce the impact of confounding variables when using observational data (Rosenbaum and Rubin 1983). Propensity score matching is a balancing method that eliminates or reduces covariate imbalance between the treatment and control group so that the difference between the groups on specific outcomes can be estimated. The propensity score is the probability of being assigned to the treatment group based on scores on the specified covariates (Rosenbaum and Rubin 1983; Austin 2011). Participants with the same value propensity score are matched with other participants with the same score, and therefore, assignment of a control group is assumed to be random. This approach can offer a more robust and less biased means of examining causal effects using observational data than standard regression analyses (Biondi-Zoccai *et al.* 2011; Amoah *et al.* 2020) that have been used in previous research into this topic.

A number of covariates relating to both the child and the primary caregiver were selected to match the group of children with ID with a control group. These were selected based on their likelihood to impact a child's use of unscheduled health services (Nicholson *et al.* 2020). The available covariates were as follows: gender of the child, the number of siblings, health status in the past year (v*ery healthy, healthy* and *sometimes quite ill/almost always unwell*), whether or not they have been diagnosed with a respiratory illness (Yes/No), medical card status, health insurance, age of primary caregiver, equivalised household income, primary caregiver depression score and whether or not the primary caregiver had a partner in household. Children with any missing data on any of the variables were excluded from the final analyses.

In order to be matched to a member of the group with IDs, control participants must have had a propensity score within a specified distance (i.e. calliper width) from the treated subjects (Austin 2011). Using one-to-many matching can increase precision in cohort studies (Rassen *et al.* 2012); however, there is potential for a slight increase in bias (Austin 2010; Rassen *et al.* 2012). 1:3 nearest neighbour matching was applied in the present study.

In the matching analysis, a calliper distance of 0.1 of the propensity score was applied. Specifying a calliper distance ensures that any members of the untreated population who fell within this range could be matched with a member of the treated sample. Participants were matched with replacement so that one untreated member could be matched with more than one member of the treated, which allows for more similar matches (Kelleher *et al.* 2020). A sensitivity analysis was applied to test the sensitivity of the results to a wider calliper width and one match per person in the treatment group. We assessed the

sensitivity of the results at (1) 1:3 with 0.5 calliper distance, (2) 1:1 with 0.5 calliper distance and (3) 1:1 with 0.1 calliper distance.

To assess differences between the groups on use of health services and unmet need following matching, logistic regression was used to estimate the treatment effect on the treated (ATT) in order to determine whether the treatment group were more likely to have attended the GP, ED, had contact with a medical doctor in a hospital, had an overnight stay in a hospital during their lifetime, and reported an unmet healthcare need. Stata 16 software was used to conduct the analyses.

Ethics

Ethical approval was granted for this research by the University College Dublin Research Ethics Committee (ref: LS-19-64 Nicholson).

Results

Descriptive statistics

Wave 1 contains data for the sample at age 9 with a total of $N = 8568$ children and their primary caregivers and Wave 2 contains data from $N = 7702$ 13-year-olds and their primary caregivers. One hundred and twenty-four children with ID were identified from the database. This represents a prevalence of 1.45% at Wave 1 and 1.61% at Wave 2.

Descriptive statistics outlining the demographic characteristics of the study children and primary caregivers at Waves 1 and 2 before matching are displayed in Table 1. Factors that may impact use of health services were also included. In line with prevalence rates for ID, there were more male participants reported in the ID group (59%) compared with the rest of the sample (48%).

Table 1 Demographic characteristics of child sample and primary caregivers

	Wave 1	**Wave 1**	**Wave 2**	**Wave 2**
	Intellectual disability group (*n* = 124)	**Controls (*n* = 8444)**	**Intellectual disability group (*n* = 124)**	**Controls (*n* = 7578)**
Age	8.9 (0.20)	9 (0.12)	13 (0.16)	13 (0.12)
Gender	73 (59%) male	4090 (48%) male	72 (58%) male	3610 (48%) male
Number of siblings	1.6 (0.07)	1.6 (0.84)	1.9 (1.2)	1.7 (1.1)
Ongoing chronic condition present	60 (48%)	810 (9.6%)	53 (43%)	712 (10%)
Behavioural/Mental & congenital malformation	48 (38%)	113 (1.6%)	37 (29.4%)	140 (1.8%)
Primary caregiver (PC) age	39.92 (5.43)	39.97 (5.82)	44.04 (5.9)	44.11 (5.3)
PC gender	123 (99.2%) female	8342 (98.8%) female	118 (97%) female	7222 (97%) female
Medical card				
No medical card	83 (67%)	6841 (81%)	72 (58%)	5774 (76%)
Full cover	41 (33%)	1603 (19%)	52 (42%)	1804 (24%)
Health insurance				
No insurance	65 (52.5%)	3747 (44%)	61 (49%)	2919 (41%)
Full cover	59 (47.5%)	4697 (56%)	63 (51%)	4481 (59%)
PC total depression score	3.5 (4.5)	2.1 (3.2)	3.8 (4.5)	2.4 (3.3)
PC health status				
Excellent	36 (29%)	2843 (35%)	39 (32%)	2506 (34%)
Very Good	45 (36%)	3429 (40%)	49 (40%)	2883 (39%)
Good/Fair	43 (35%)	2168 (25%)	34 (28%)	2041 (27%)
Equivalised household income	€19 577.631 (€18 534.95)	€21 284.172 (€13 638.71)	€15 069.5 (€7416.98)	€17 667.8 (€10 765.96)
Region	65 (52%)	3825 (45%)	Not reported	Not reported

Continuous variables *M* (SD); categorical variables *N* (%).

At Wave 1, 48% of the group with ID reported having an ongoing chronic illness or disability, compared with 9.6% of the wider sample, and further examination found that 38% of these diagnoses were categorised as behavioural/mental or congenital malformations, which suggests that this category may have overlapped with the cause of disability. At Wave 2, 43% of the group reported having an ongoing chronic illness or disability, compared with 10% of the wider sample, with 29.4% of these categorised as behavioural/mental or congenital malformations.

At Wave 1, 33% of the sample with ID had a medical card compared with 19% of the wider sample, with 42% having a medical card at Wave 2 compared with 24% of the wider sample. Similarly, 47.5% of the sample with ID reported having full health insurance at Wave 1 compared with 56% of the wider sample with 51% and 59% at Wave 2, respectively.

The average age of the primary caregivers was 39.9 years, and the majority were female (99.2%). Regarding total depression score, primary caregivers of children with ID reported higher scores compared with the wider sample in Waves 1 and 2.

Propensity score matching

Use of health services at ages 9 and 13

Table 2 outlines the results of the logistic regression using propensity score matching to compare the groups on use of health services and unmet need at ages 9 (i.e. Wave 1) and 13 (i.e. Wave 2). The group with ID were more likely to have had an overnight stay during their lifetime (ATT = 0.12; 95% CI: 0.018–0.22) and report contact with a medical doctor in a hospital at age 9 (ATT = 0.1, 95% CI: 0.032–0.17). No significant differences were observed around use of the ED (ATT = −0.021; 95% CI: −0.09 to 0.05) or GP (ATT = 0.02; 95% CI: −0.132 to 0.09) at age 9. The effects regarding overnights stays in hospital (ATT = 0.042; 95% CI: −0.05 to 0.135) and contact with a medical doctor (ATT = 0.01; 95% CI: −0.05 to 0.08) are not maintained at age 13. Regarding use of the ED at age 13, the direction of the effect suggests that the children without ID were more likely to have utilised these services in the past year; however, the effect is only significant at the trend level (ATT = −0.06; 95%

Table 2 Propensity score matching results

		Coef (estimated difference)	AI robust standard error	z	*P*	95% Confidence intervals
Age 9 (Wave 1)						
Overnight in hospital	ATT intellectual disability (1 vs. 0)	0.12	0.53	2.31	0.02*	0.018 to 0.22
Contact with medical doctor	ATT intellectual disability (1 vs. 0)	0.100	0.034	2.88	0.004**	0.032 to 0.17
ED attendance	ATT intellectual disability (1 vs. 0)	−0.021	0.038	−0.55	0.58	−0.09 to 0.05
GP attendance	ATT intellectual disability (1 vs. 0)	−0.02	0.057	−0.035	0.72	−0.132 to 0.09
Age 13 (Wave 2)						
Overnight in hospital	ATT intellectual disability (1 vs. 0)	0.042	0.047	0.89	0.37	−0.05 to 0.135
Contact with medical doctor	ATT intellectual disability (1 vs. 0)	0.011	0.036	0.31	0.76	−0.05 to 0.08
ED attendance	ATT intellectual disability (1 vs. 0)	−0.06	0.038	−1.65	0.09	−0.13 to 0.012
GP attendance	ATT intellectual disability (1 vs. 0)	−0.05	0.046	−1.24	0.22	−0.15 to 0.03

Wave 1: number of ob: 7323; matches requested = 3 (max = 5; min = 3); ID group = 107. Wave 2: number of ob: 6899; matches requested = 3 (max = 5; min = 3); ID group = 114.
*$P < 0.05$,
**$P < 0.01$.

CI: −0.13 to 0.012) and insignificant for the GP (ATT = −0.05; 95% CI: −0.15 to 0.03).

Unmet need at ages 9 and 13

Further analyses were carried out to determine whether the primary caregivers of children with ID were more likely to report an unmet health need at both time points. At age 9, the group with ID were more likely to report an unmet need (when asked about needing healthcare) (ATT = 0.068; 95% CI: 0.016–0.12), and this effect was also evident at age 13 (ATT = 0.044; 95% CI: 0.005–0.08) (refer to Table 3).

The most common reasons for unmet need reported by parents of children with ID at age 9 were that necessary care was not available or accessible (60%) and/or that the child was on a waiting list (50%). For the group without ID at age 9, the most common reasons were also that the necessary care was not available or accessible (39%) and/or that the child was still on a waiting list (48%).

At age 13 for the group with ID, the most common reasons were that the child still on a waiting list (71%) or that the necessary care was not available or accessible (28%). For the group without ID, the most common reasons included that the parents wanted to wait and see if the child improved (57%) or that they could not afford to pay (32%).

Sensitivity analysis

The sensitivity of the results was tested by altering the calliper distance and number of matched pairs included in the PSM analysis. Extending the calliper distance did not significantly affect the results; however, when 1:1 matching was applied, the findings at age 9 (Wave 1) became non-significant. The full results can be found in Appendix 1.

Discussion

The current study utilised propensity score matching to identify differences in healthcare use and unmet need in a cohort of children with and without ID, at ages 9 and 13. Preliminary descriptive analyses revealed that children with ID reported higher incidence of ongoing chronic illness compared with children without ID. The use of propensity score matching allows for a balance between the samples on observed confounding variables that are known to impact use of health services, therefore, providing a more precise estimate of the impact of ID on use of health services and unmet health needs. The results of these analyses suggest that children with ID were no more likely to visit a GP or ED in the past 12 months than children without ID when certain covariates were controlled for. However, they had a greater likelihood of having seen a doctor in a hospital in the past 12 months and of having an overnight stay in hospital during their lifetime. These effects were only observed at age 9 and not at age 13. Regarding unmet need, the primary caregivers of children with ID were more likely to report an unmet health need at both ages.

The present findings build on existing evidence regarding poorer health status of young people with ID (Hughes-McCormack *et al.* 2018) as well as evidence around disparities in rates of hospitalisation and ED admissions for children with ID (Nachshen *et al.* 2009; Chi *et al.* 2014; Hand *et al.* 2019).

Table 3 Unmet health need at Waves 1 and 2

		Coef (estimated difference)	AI robust standard error	z	P	95% Confidence intervals
Didn't receive needed care (Wave 1)	ATT intellectual disability (1 vs. 0)	0.068	0.026	2.58	0.01*	0.016–0.12
Didn't receive needed care (Wave 2)	ATT intellectual disability (1 vs. 0)	0.044	0.019	2.23	0.026*	0.005–0.08

Wave 1: number of ob: 7323; matches requested = 3 (max = 5; min = 3); ID group = 107. Wave 2: number of ob: 6899; matches requested = 3 (max = 5; min = 3); ID group = 114.
*$P < 0.05$,
**$P < 0.01$.

However, higher use of the ED and GP is greatly influenced by multiple confounding factors (Nicholson *et al.* 2020) beyond ID and indeed, with a balancing methodology applied in the current study, no difference was found between the children with and without ID in whether they had visited a GP or ED in the past 12 months. Previous work in this area was conducted in the United Kingdom, the United States, and Canada, and differences in the configuration of health systems across jurisdictions can make direct comparisons on attendance patterns challenging; however, the inequities faced by this population are a universal issue (Ouellette-Kuntz 2005; Emerson 2015) that support the generalisability of the results. The findings are in line with previous evidence that has demonstrated higher likelihood of hospitalisations for children with ID and when the comparable health status of the two groups over the past year is taken into consideration, the results emphasise a clear disparity for children with ID, which reflects existing literature. It is worth noting that the reasons for attendance at the GP or ED or for hospitalisations were not available in the current data and future research could examine potential disparities in reasons for attending to determine whether these attendances, and more so hospitalisations, could be deemed avoidable.

Key disparities that emerged in the sample at age 9 were focused on hospital-based care (i.e. contact with a medical doctor) and overnight stays in hospital with no difference between the groups in likelihood to have used a GP or ED. This finding suggests that use of health services among this population may be more likely to take place in a hospital-based setting than at the primary care level in their community compared with children without ID. Primary care is a key element in the maintenance and promotion of health in the paediatric population and a priority for paediatric healthcare in Western Europe (Wolfe *et al.* 2013). Regular health checks at primary care for people with ID with their GP have been shown to reduce avoidable hospitalisation admissions (Cuccu *et al.* 2020) and are important for alleviating unmet health needs (Baxter *et al.* 2006), yet there is little evidence of their effectiveness for children. A strong system of primary care is critical for families of children with ID and families rely on their GP as a key conduit for further services and supports in their communities (Fredheim *et al.* 2011). Adults with ID may be less likely to report having a medical examination with their GP (Maltais *et al.* 2020); however, the findings that there was no difference between children with and without ID on likelihood of having a GP visit suggests that this may be different for children where health appointments would be sought and managed by a parent or primary caregiver. Policy and planning initiatives that seek to strengthen and improve access to primary care systems should consider equality impact assessments to safeguard the specific needs of children with ID and their families.

Children with ID were more likely to have an unmet health need at ages 9 and 13 compared with children without ID, which reflects existing evidence regarding unmet needs for adults with intellectual and developmental disabilities (Shooshtari *et al.* 2012; Maltais *et al.* 2020). At age 9, the unmet health need was related to a lack of medical care or treatment for a health problem while at age 13, it focused on need to consult a GP or specialist but did not. This finding may reflect an unwillingness of parents of older children to engage with services due to a perceived lack of efficacy at previous encounters (Weiss and Lunsky 2010). Upon further examination, much of the unmet need for the group with ID was related to a lack of necessary or accessible care or that the child was on a waiting list. It is worth noting that these reasons were similar for the group without ID and therefore, may reflect broader challenges within the health system. While the findings provide some evidence of unmet health need in a child population with ID, given the paucity of more in-depth detail, future research could explore these unmet needs further to identify opportunities for intervention.

Strengths and limitations

The prevalence rate of ID in the present study was 1.45–1.61% across the two waves of data. Based on data provided by the Census of Ireland 2016, the prevalence rate of ID in Ireland is 1.4% (CSO 2016), and therefore, the prevalence rate was comparable with that of the wider population. There were a number of limitations identified in the present study. The analysis relied on the self-reported use of health services and thus, may have been prone to recall bias by relying on parents' memory from over the past year and their child's lifetime (for the number of hospitalisations). However, the challenges inherent in

examining healthcare utilisation for children with ID necessitate the use of such data when hospital administrative data is unsuitable due to poor coding and a lack of diagnosis for children with ID (Emerson and Hatton 2013). Moreover, the clinical reasons and degree of the severity of illness for use of health services was not reported, which limited our ability to identify disparities in reasons for use and critically, if children with ID have a greater risk of avoidable hospitalisation for instance, ambulatory care sensitive conditions (Glover *et al*. 2020) and/or differences in attendance for physical or mental health illness. Finally, due to the small sample sizes available, we were unable to examine disparities across categories of ID to determine whether those with severe and profound disability are at greater risk than those with mild or moderate disability.

Conclusion

The present study adopted a novel methodology for estimating differences in health service use between children with and without IDs to account for a number of potential confounding variables to which children with ID may be more vulnerable. The results suggest that children with ID are more likely to receive health care in a hospital setting than in primary care settings in their community compared with children without ID. Additionally, primary caregivers of children with ID are more likely to report unmet healthcare needs compared with those without ID; however, further details on these unmet needs remain unclear. The findings have implications for health policy and service planning as the increased likelihood of hospital care for children with ID, as well as unmet needs, are suggestive of systemic challenges for this population.

Acknowledgements

Growing Up in Ireland (GUI) is funded by the Department of Children, Equality, Disability, Integration and Youth (DCEDIY). It is managed by DCEDIY in association with the Central Statistics Office (CSO). Results in this report are based on analyses of data from Research Microdata Files provided by the Central Statistics Office (CSO). Neither the CSO nor DCEDIY take any responsibility for the views expressed or the outputs generated from these analyses. Open access funding provided by IReL.

Source of funding

This work was supported by the Health Research Board (HRB) under an Applying Research into Policy and Practice Fellowship awarded to the first author (grant ARPP-A-2018-003). The funder had no role in the research.

Conflict of interest

The authors report no conflicts of interest.

Ethics approval statement

Ethical approval was granted for this research by the University College Dublin Research Ethics Committee (ref: LS-19-64 Nicholson).

Data availability statement

The data that support the findings of this study are available on request subject to criteria from the Central Statistics Office (CSO) at https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/rmfregister/.

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Accepted 18 February 2022

Appendix 1

Table A1. Sensitivity analyses at Waves 1 and 2

		Coef [estimated difference] (AI robust standard error)		Coef [estimated difference] (AI robust standard error)		Coef [estimated difference] (AI robust standard error)
Age 9 (Wave 1)						
	0.1 with 1 match		0.5 with 3 matches		0.5 with 1 match	
Overnight in hospital	ATT intellectual disability (1 vs. 0)	0.037 (0.67)	ATT intellectual disability (1 vs. 0)	0.122 (0.05)*	ATT intellectual disability (1 vs. 0)	0.04 (0.07)
Didn't receive needed care	ATT intellectual disability (1 vs. 0)	0.028 (0.035)	ATT intellectual disability (1 vs. 0)	0.68 (0.3)**	ATT intellectual disability (1 vs. 0)	0.03 (0.06)
Contact with medical doctor	ATT intellectual disability (1 vs. 0)	0.037 (0.05)	ATT intellectual disability (1 vs. 0)	0.10 (0.03)**	ATT intellectual disability (1 vs. 0)	0.04 (0.05)
ED attendance	ATT intellectual disability (1 vs. 0)	−0.08 (0.05)	ATT intellectual disability (1 vs. 0)	−0.021 (0.04)	ATT intellectual disability (1 vs. 0)	−0.08 (0.05)
GP attendance	ATT intellectual disability (1 vs. 0)	−0.03 (0.07)	ATT intellectual disability (1 vs. 0)	−0.02 (0.06)	ATT intellectual disability (1 vs. 0)	−0.02 (0.07)
Age 13 (Wave 2)						
	0.1 with 1 match		0.5 with 3 matches		0.5 with 1 match	
Overnight in hospital	ATT intellectual disability (1 vs. 0)	0.00 (0.05)	ATT intellectual disability (1 vs. 0)	0.04 (0.05)	ATT intellectual disability (1 vs. 0)	0.00 (0.05)
Didn't receive needed care	ATT intellectual disability (1 vs. 0)	0.04 (0.02)*	ATT intellectual disability (1 vs. 0)	0.04 (0.02)*	ATT intellectual disability (1 vs. 0)	0.04 (0.02)*
Contact with medical doctor	ATT intellectual disability (1 vs. 0)	0.00 (0.05)	ATT intellectual disability (1 vs. 0)	0.01 (0.04)	ATT intellectual disability (1 vs. 0)	0.00 (0.05)
ED attendance	ATT intellectual disability (1 vs. 0)	−0.06 (0.05)	ATT intellectual disability (1 vs. 0)	−0.06 (0.04)	ATT intellectual disability (1 vs. 0)	−0.06 (0.05)
GP attendance	ATT intellectual disability (1 vs. 0)	−0.11 (0.05)	ATT intellectual disability (1 vs. 0)	−0.06 (0.05)	ATT intellectual disability (1 vs. 0)	−0.10 (0.06)

Wave 1: number of ob: 7323; ID group = 107. Wave 2: number of ob: 6899; ID group = 114. *$P < 0.05$, **$P < 0.01$.