Looking across health and healthcare outcomes for people with intellectual and developmental disabilities and psychiatric disorders: population-based longitudinal study

Elizabeth Lin, Robert Balogh, Hannah Chung, Kristin Dobranowski, Anna Durbin, Tiziana Volpe and Yona Lunsky

Background

Intellectual and developmental disabilities (IDDs) and psychiatric disorders frequently co-occur. Although each has been associated with negative outcomes, their combined effect has rarely been studied.

Aims

To examine the likelihood of five negative health and healthcare outcomes for adults with IDD and mental health/addiction disorders (MHAs), both separately and together. For each outcome, demographic, clinical and system-level factors were also examined.

Method

Linked administrative data-sets were used to identify adults in Ontario, Canada, with IDD and MHA (n = 29 476), IDD-only (n = 35 223) and MHA-only (n = 727 591). Five outcomes (30-day readmission, 30-day repeat ED visit, delayed discharge, long-term care admission and premature mortality) were examined by logistic regression models with generalised estimating equation or survival analyses. For each outcome, crude (disorder groups only) and complete (adding biosocial covariates) models were run using a general population reference group.

Results

The IDD and MHA group had the highest proportions across outcomes for both crude and complete models. They had the highest adjusted ratios for readmissions (aOR 1.93, 95%CI 1.88–1.99), repeat ED visit (aOR 2.00, 95%CI 1.98–2.02) and long-term care admission (aHR 12.19, 95%CI 10.84–13.71). For delayed discharge, the IDD and MHA and IDD-only groups had similar results (aOR 2.00 (95%CI 1.90–2.11) and 2.21 (95%CI 2.07–2.36). For premature mortality, the adjusted ratios were similar for all groups.

Conclusions

Poorer outcomes for adults with IDD, particularly those with MHA, suggest a need for a comprehensive, system-wide approach spanning health, disability and social support.

Keywords

Developmental disorders; intellectual disability; mortality; psychotic disorders; patients.

Copyright and usage

Background

Adults with intellectual and developmental disabilities (IDDs) have been shown to have more physical health problems, including elevated rates of obesity, diabetes and cardiovascular disease, compared with individuals without IDD,[1,2] as well as high rates of mental illness and addiction.[3] Consistent with these higher rates, they are also more likely to access formal health services such as primary and hospital-based care.[4–6] Despite this greater access, people with IDD experience higher rates of outcomes that suggest poor quality or poor coordination of care. Compared to the general population, they are more likely to reuse in-patient and emergency department services, often within 30 days of a previous discharge or visit, suggesting insufficient support for managing their health issues in the community after discharge.[7,8] Once in hospital, they are more likely to remain despite being deemed ready for discharge.[9] They are also more likely to be admitted into long-term care (LTC) facilities at a younger age,[10] and to die earlier.[11] It has been suggested that when individuals also have a mental health and/or addiction (MHA) disorder in addition to their disability, they encounter further complications with healthcare use. For instance, those with IDD and MHA are more likely than other adults with MHA to be rehospitalised[12] and to die prematurely.[13]

These findings suggest a need for a more comprehensive strategy to inform delivery of healthcare interventions for the IDD population, especially when there is a psychiatric disorder at play. However, there are at least two knowledge gaps that need to be addressed to support such an approach. First, existing studies primarily focus on single outcomes and single healthcare sectors. One exception is a study by Reichard et al,[8] which reported higher proportions of frequent emergency department use, repeat hospital admissions and mortality in adults with IDD relative to other Medicare recipients in the USA. Second, published studies often use the entire general population as is, or control for age and gender, but not morbidity, when conducting comparisons. This raises questions as to whether poor outcomes are unique to people with IDD or are common across other high-morbidity populations such as those with a psychiatric disorder.

Objective

To address these knowledge gaps, we used a population-based cohort of adults in Ontario, Canada, with IDD and a random sample of the remaining adults (without IDD) to explore the following questions:

(i) Are adults with IDD, both those with and without a psychiatric disorder (MHA), overrepresented across a range of negative outcomes (30-day readmission, 30-day repeat emergency department visit, delayed discharge, early admission to LTC, premature mortality) compared with adults with MHA only or adults with neither IDD nor MHA?

(ii) Do differences in these negative outcomes among those with IDD, MHA or both remain after the influence of other possible

explanatory factors, such as sociodemographic, clinical or system-level variables, are accounted for?

Method

Setting

All residents of Ontario, Canada, are eligible for the provincial health insurance plan, which provides universal coverage for basic and emergency health services, including physician, in-patient and emergency department care. Like many other groups with elevated risk for health issues/challenges, individuals with IDD have experienced a gradual shift away from institutionalised to community-based care. Changes have involved the closing of all Ontario institutions providing care for those with IDD, along with government and other initiatives to enhance or improve community-based services. These include efforts to develop and disseminate IDD-specific primary care guidelines and tools, and a regional approach to mental health service coordination for adults with IDD.

Data sources

The primary data analysed for this study were provided by seven provincial administrative data-sets. The Ontario Registered Persons Database provided demographic and mortality information for all residents of Ontario who were eligible for the province's universal health insurance coverage. Five databases contained health administrative data on all in-patient discharges from acute and psychiatric hospitals (Discharge Abstract Database, Ontario Mental Health Reporting System), all visits to emergency departments (National Ambulatory Care Reporting System), all fee-for-service physician claims (Ontario Health Insurance Plan) and all residents in LTC (Continuing Care Reporting System). The seventh data-set captured information on all adults who applied and were deemed eligible for provincial disability income support (Ontario Disability Support Program).

In addition, hospital-level information from the Institution Information System, which contains information about Ontario healthcare institutions funded by the Ministry of Health and Long-Term Care, was used to calculate specific measures of the availability of healthcare resources (e.g. numbers of beds available in a region, distance to nearest hospital).

These data-sets were linked by unique, encoded identifiers, and analysed at ICES, which is a prescribed entity under section 45 of Ontario's Personal Health Information Protection Act. Section 45 authorises ICES to collect personal health information without consent, for the purpose of analysis or compiling statistical information with respect to the management, evaluation or monitoring of the allocation of resources to, or planning for, all or part of the health system. Projects conducted under Section 45 by definition do not require review by a Research Ethics Board. This project was conducted under Section 45 and approved by the ICES Privacy and Legal Office (#2016 0900 116 001). The exemption from ethics review for all studies under Section 45 has been affirmed by the Sunnybrook Hospital REB (the hospital where ICES is located).

Definitions

IDDs

The method for identifying a cohort of Ontarians with IDD has been previously described.[14] In brief, health administrative and disability income support data were linked to identify Ontarians aged 18–64 years, in fiscal year 2009 (that is, 1 April 2008 to 31 March 2009), who were assigned a diagnosis consistent with diagnostic codes identified in the literature[15] and the provincial legislative definition. Because the government definition was broad, encompassing IDDs, and because service delivery is targeted toward this

broader group, the codes we used were equally broad and included conditions such as intellectual disability, autism spectrum disorder, Down syndrome and foetal alcohol spectrum disorder, as well as other conditions such as chromosomal abnormalities thought to correlate highly with IDD[16] (see Supplemental Appendix 1 available at http://doi.org/10.1192/bjp.2020.202 for the full list of IDD codes). The original cohort comprised 66 484 adults,[14] but decreased by the time of this study to 64 699 owing to deaths and out-migration. For our analyses, this cohort was divided into two analytic groups: those who had a psychiatric diagnosis (IDD and MHA, n = 29 476) and those who did not (IDD only, n = 35 223). MHA was defined as any ICD-10 F-codes, ICD-9 chapter 5 codes or DSM-IV codes (minus the codes used to define IDD) in the individual administrative data in the 2 years before the baseline year of fiscal year 2009[17,18] (see Supplemental Appendix 2 for the full list of MHA codes).

Other groups

A random sample comprising 20% of the Ontario population aged 18–64 years in fiscal year 2009, and who were not in the IDD group, was drawn. This sample was then divided into those with an MHA diagnostic code in the 2 years before baseline (MHA only, n = 727 591) and those without such a diagnosis (reference, n = 1 955 941).

Outcomes

Five outcomes, interpreted as potential signals of poor quality or continuity of care, were chosen because they were measurable, identified as concerns for both policy and clinical practice, and were also monitored for the general population in Canada. The first three outcomes were measured annually over a 6-year period post-baseline, from fiscal year 2010 to fiscal year 2015 (fiscal year 2015 was the date, at the time of analysis, for which the most current administrative data were available). For the last two outcomes, an individual was followed from baseline to the end of follow-up or the occurrence of either outcome. These outcomes and their definitions were 30-day readmission, defined as admission, for any reason, to any hospital within 30 days of a previous hospital discharge; 30-day repeat emergency department visit, defined as a return to any emergency department, for any reason, within 30 days of a previous emergency department visit; delayed discharge, defined as remaining in hospital despite being medically cleared for discharge; LTC, defined as admission to an LTC facility such as a nursing home; and premature mortality, based on the World Health Organization's definition of death before 75 years of age[19] (all deaths were considered premature because no one in this study was older than 74 years of age).

Covariates

The Andersen Behavioral Model of Health Services Use[20] was used as a framework to identify potentially important covariates. This model has been used for decades to conceptualise the relationship between conceptually important predictors and outcomes for multiple populations and clinical groups, including those with IDD.[20] The specific covariates measuring the model's broad categories of predisposing, enabling, needs-based or health service resource factors are shown in Table 1. (Covariates measured using predefined classifications include rurality, using Statistics Canada's definition,[21] and morbidity, using the Johns Hopkins ACG® System Version 10/Resource Utilization Bands (RUBs).[22]) With the exception of gender, all covariates were treated as time-varying based on the assumption that recent or acute exposures were the most relevant. For most covariates, this meant measurement either at the start of each fiscal year or over the previous fiscal year. For MHA, however, because of the episodic nature of some mental disorders,

Table 1 Covariates used in the analysis categorised according to the Andersen Behavioral Model of Health Services Use

Variable	Categories (bold indicates reference)	Measurement period
Predisposing		
Age, years	<25	Start of each fiscal year
	25–49	
	>49	
Gender	Female	Baseline (fiscal year 2009)
	Male	
Rural[36]	**Urban**	Start of each fiscal year
	Rural	
	Missing	
Enabling		
Disability income support	Yes	Baseline (fiscal year 2009)
	No	
Neighbourhood income quintile	1 (poorest)	Start of each fiscal year
	2, 3, 4	
	5 (wealthiest)	
Visit to GP/FP	Yes	1-year lookback from start of each fiscal year
	No	
Visit to any specialist	Yes	1-year lookback from start of each fiscal year
	No	
Continuity of care (% of primary care visits made to usual primary care provider)	< 3 visits	2-year lookback from start of each fiscal year
	Medium (<0.75)	
	High (≥0.75)	
Need		
Presence of MHA	Yes	2-year lookback from start of each fiscal year
	No	
Morbidity (ACG System Resource Utilization Bands[25]	Non-user	
	Healthy user	
	Low/moderate user	
	High/very high user	
Health services resources per geographic subregion of residence		
Hospital beds per 10 000 subregion population	Continuous	Start of each fiscal year
GP/FP FTE per 10 000 subregion population	Continuous	
Specialist physician FTE per 100 subregion population	Continuous	
Distance to nearest hospital from individual's residence	0–1 km	
	1–5 km	
	6–10 km	
	10+ km	

GP/FP, general practitioner/family practitioner; MHA, mental health/addiction disorder; ACG, Adjusted Clinical Groups®; FTE, full-time equivalent.

we were concerned that a 1-year window would not be adequate, and consequently chose a 2-year window instead.

Analyses

All statistical analyses were performed with SAS version 9.4 for UNIX.[23]

To answer the first research question, descriptive analyses were used to calculate the percentages of the three analytic groups (IDD plus MHA, IDD only, MHA only) and the reference group that had experienced each outcome. In addition, the 6-year cumulative percentages for healthcare service use and the five outcomes were calculated for these same groups.

For the second question, two multivariable analyses were conducted for each outcome: a 'crude' model that included only the three analytic groups as compared with the reference group, and a complete (i.e. 'adjusted') model that added all the covariates in Table 1. The per cent change between the crude and complete models was also calculated. Three outcomes were treated as dichotomous, repeatable events (30-day readmission, 30-day repeat emergency department visit, delayed discharge) and analysed with generalised estimating equation, logistic regression models with a robust variance estimator to account for repeated measures. The units of analyses for these models were either hospital discharge or emergency department visit. The other two (LTC, premature mortality) were considered

terminal outcomes and were analysed with Cox proportional hazards survival analyses, with individuals being censored in the event that they lost eligibility for the provincial healthcare insurance. For the LTC outcome, this was a competing risks model, with death as a censoring event. The unit of analysis for these models was the individual. All logistic regression and survival analyses accounted for clustering at the Ontario regional planning level. All covariates (with the exception of gender and disability income status) were modelled as time-varying covariates, which were measured at the start of every fiscal year from baseline to fiscal year 2015.

Given our large sample sizes, we used effect sizes to define which differences were meaningful. The thresholds used to categorise small, medium and large effect sizes were 1.68, 3.47 and 6.71 and their reciprocal values for the odds ratios,[24] and 1.22, 1.86 and 3.00 and their reciprocal values for the hazard ratios.[25] These thresholds were used conservatively in that they were applied to both the point estimates and the 95% confidence intervals. Thus, for example, an odds ratio of ≥6.71 was interpreted as a large difference only if the confidence interval did not include values <6.71.

Results

Table 2 shows the sociodemographic, clinical and other characteristics for all groups at baseline. Compared with the two cohorts

Table 2 Baseline sociodemographic, clinical and other characteristics

| | IDD groups | | Non-IDD groups | |
| | IDD and MHA | IDD only | MHA only | Reference[a] |
Characteristic	n = 29 476	n = 35 223	n = 727 591	n = 1 955 941
Sociodemographic characteristics (fiscal year 2010), %				
Age, years				
19–24	20.79	21.74	9.90	13.02
25–49	52.85	53.50	55.20	55.62
50–64	26.36	24.76	34.91	31.35
Female	44.32	41.38	58.17	48.29
Rural	13.67	17.62	10.21	11.55
Neighbourhood income quintile				
1 (poorest)	32.09	29.01	20.41	18.08
2	21.47	21.30	19.88	19.52
3	17.21	17.82	19.92	20.16
4	15.49	16.49	20.32	21.30
5 (wealthiest)	12.92	14.74	19.09	20.56
Missing	0.82	0.65	0.37	0.37
Clinical characteristics (fiscal year 2010), %				
Morbidity[25]				
Non-users/healthy users	0.05	19.35	<0.01	20.53
Low morbidity	4.82	19.55	5.50	23.05
Moderate	55.35	47.48	63.97	45.12
High	25.64	10.21	23.49	9.65
Very high	14.13	3.42	7.04	1.66
Other (fiscal year 2010), %				
Disability income support	79.41	79.30	6.07	1.53

IDD, intellectual and developmental disability; MHA, mental health/addiction disorder.
a. 20% general population (no IDD, no MHA).

without IDD, adults with IDD were younger (21–22% v. 10–13%, aged 15–24 years), more likely to live in the poorest neighbourhoods (29–32% v. 18–20%) and more likely to receive disability income support (79% v. 2–6%). The MHA-only group had the largest proportion of females (58% v. 41–48%) and, together with the IDD and MHA group, had the largest proportions of high morbidity[25] (23–26% v. 10%). The IDD and MHA group also had the largest proportions of very high morbidity. In addition, in terms of broad psychiatric disorder categories (not shown), the IDD and MHA group and MHA-only group had similar proportions of addiction (14.5 v. 13.9%, respectively) and non-psychotic disorders (91.1 v. 92.5%, respectively). However, the IDD and MHA group had a considerably higher proportion of psychotic disorders compared to the MHA-only group (25.9 v. 3.4%).

Table 3 shows the cumulative use of hospital and emergency department services and the experiences of the negative outcomes for all groups across the 6 years between fiscal years 2010 and 2015. The group with the highest proportion of all-cause hospital admissions and emergency department visits was the IDD and MHA group (42 and 80%), followed by the MHA-only (28 and

70%) and IDD-only (26 and 67%) groups. The IDD and MHA group also had the highest percentages experiencing all five outcomes (and the reference group had the lowest). The IDD-only and MHA-only groups had similar percentages revisiting the emergency department within 30 days (27–28%), but the IDD-only group results were slightly higher for 30-day readmission, two to three times higher for premature mortality and delayed discharge, and over seven times higher for LTC (nearly 3% v. <0.5%).

Comparisons between the crude and adjusted odds and hazard ratios are shown in Table 4. The most apparent result was that all of the meaningful associations (as measured by effect size) found in the crude models remained even with full adjustment. All groups continued to show large effect sizes for the adjusted LTC model. Small effect sizes persisted for the IDD and MHA group for the remaining four outcomes, for the IDD-only group for delayed discharge and premature mortality, and for the MHA-only group for premature mortality.

Also evident in Table 4, however, is that there are important contributions made by the factors added in the fully adjusted models. These are particularly apparent for LTC and premature

Table 3 Six-year service use and 6-year outcomes

| | IDD groups | | Non-IDD groups | |
| | IDD and MHA | IDD only | MHA only | Reference[a] |
Characteristic	n = 29 476	n = 35 223	n = 727 591	n = 1 955 941
6-year service use (fiscal year 2010–2015), %				
All-cause hospital admission	41.90	26.34	27.86	18.63
All-cause emergency department visit	80.19	66.85	69.99	56.04
6-year outcomes (fiscal year 2010–2015), %				
30-day readmission (all-cause)	10.96	4.49	3.76	1.71
30-day repeat emergency department visit (all-cause)	42.76	27.62	27.12	16.83
Delayed discharge	6.08	3.31	1.21	0.49
LTC	4.23	2.79	0.38	0.09
Premature mortality	7.01	5.37	2.47	1.26

IDD, intellectual and developmental disability; MHA, mental health/addiction disorder; LTC, long-term care.
a. 20% general population (no IDD, no MHA).

Table 4   Associations of IDD and MHA with 6-year outcomes (fiscal year 2010–2015): crude versus adjusted odds and hazard ratios

Outcome		Group (versus reference[a])		
		IDD and MHA	IDD only	MHA only
Odds ratios (95%CIs)				
30-day readmission	Crude	3.25 (3.17–3.33)[b]	1.73 (1.66–1.81)	1.65 (1.62–1.67)
	Adjusted	1.93 (1.88–1.99)[b]	1.14 (1.09–1.20)	1.38 (1.36–1.40)
	% Change	41%	34%	16%
30-day repeat emergency department visit	Crude	3.56 (3.53–3.59)[c]	1.52 (1.50–1.54)	1.53 (1.52–1.54)
	Adjusted	2.00 (1.98–2.02)[b]	1.03 (1.02–1.04)	1.27 (1.27–1.28)
	% Change	44%	32%	17%
Delayed discharge	Crude	3.26 (3.11–3.41)[b]	3.94 (3.71–4.19)[c]	1.59 (1.55–1.64)
	Adjusted	2.00 (1.90–2.11)[b]	2.21 (2.07–2.36)[b]	1.41 (1.37–1.45)
	% Change	30%	44%	10%
Hazard ratios (95%CIs)				
LTC	Crude	64.66 (59.80–69.92)[d]	31.09 (28.42–34.01)[d]	5.99 (5.62–6.40)[d]
	Adjusted	12.19 (10.84–13.71)[d]	8.90 (7.92–10.00)[d]	3.53 (3.21–3.88)[d]
	% Change	81%	71%	37%
Premature mortality	Crude	6.63 (6.34–6.93)[d]	4.23 (4.03–4.44)[d]	2.46 (2.42–2.51)[c]
	Adjusted	1.75 (1.60–1.91)[b]	1.84 (1.72–1.96)[b]	1.52 (1.46–1.58)[b]
	% Change	74%	57%	38%

IDD, intellectual and developmental disability; MHA, mental health/addiction disorder; LTC, long-term care.
a. 20% general population (no IDD, no MHA).
b. Small effect size.
c. Medium effect size.
d. Large effect size.

mortality where the percentage change between the crude and adjusted hazard ratios ranged between 36 and 81% for LTC and 38 and 74% for mortality. An examination of the covariate hazard ratios for these two outcomes (not shown) revealed that older age and very high morbidity were the largest contributors (age >49 years: aHR 8.14 (95%CI 7.38–8.98) and aHR 4.54 (95%CI 4.35–4.73); very high morbidity: 5.52 (95%CI 4.73–6.45) and 4.76 (95% CI 4.49–5.05); for LTC and premature mortality, respectively). Overall, adults with IDD and MHA had the greatest percentage changes across all outcomes except for delayed discharge, where the greatest change was observed for the IDD-only group. The contribution of the added factors to premature mortality resulted in adjusted hazard ratios that were quite similar (1.52–1.84) across the three groups.

Discussion

We found that adults with IDD in Ontario, Canada, experience poor outcomes in considerably higher proportions compared to our general population reference group and in higher proportions compared with another group with elevated risk for health issues/challenges, specifically individuals with MHA diagnoses. Having a comorbid MHA diagnosis was associated with the highest likelihood of poor outcomes. Although other factors, such as age and morbidity, account statistically for some portion of these elevated percentages, importantly IDD and non-IDD differences persisted after the contribution of these factors were accounted for. In the adjusted models, the presence of IDD, particularly in combination with MHA, continued to be associated with small-to-large effect sizes for all of the health and health system outcomes measured. Only for premature mortality were the adjusted hazard ratios similar across the IDD and MHA groups.

The finding that psychiatric disorder (quite common in those with IDD) predicts poor outcomes over time, speaks to the importance of mental health services for this group, which are difficult to access.[26] Our finding that the IDD group had such a high proportion of recorded psychotic disorders compared with the non-IDD group suggests that services targeted for these particular mental illnesses and how these services are integrated with other healthcare and supports are particular areas that need attention. It will also be critical to evaluate whether or not such attention could decrease the gap between the IDD and MHA group and other groups in terms of the outcomes we measured. In Canada, there is limited training in IDD psychiatry and an absence of local community-based clinical teams to support this group,[27] and staff in both primary and emergency care settings report feeling ill equipped to support individuals with IDD.[28,29] Importantly, the adjusted analyses in this study highlight that there are many contributors to these poor outcomes in addition to the psychiatric disorder itself, suggesting other opportunities to intervene. An intersectional approach is important when approaching people with IDD as they have multiple health issues and often experience inequities in terms of the social determinants of health.

Thus, in answer to our two research questions, our findings indicate that adults with IDD do worse than the general population and MHA comparators across a range of health and health system outcomes. Further, these differences persist even when sociodemographic and clinical factors are accounted for. The implication is that there is some aspect of experiencing health issues as a person with IDD, *per se*, which contributes to negative outcomes that is not captured in our analyses.

The poor outcomes for people with IDD and MHA reported in the current study occurred despite disability support policies and programmes for those with IDD in a jurisdiction with a fully funded healthcare system and a provincial mental health and addictions strategy. Importantly, beyond published primary care guidelines specific to the IDD adult population, there are few specialised health-based services for this group, and little to no mention of people with IDD in mental health policy.[30] This suggests that a more comprehensive and system-wide approach, spanning health, disability, social and other kinds of support, is needed, as has been suggested in a provincial ombudsman's review.[26] However, as pointed out by Bigby,[31] the higher-level policies that would mandate such an approach are necessary, but not sufficient ingredients. In reviewing the literature and the IDD accommodation support policies for elderly people in five countries, they concluded that an important disconnect occurs between the broader

vision captured by high-level policy and the operational or implementation plans that should be addressed by mid-level policies. Ontario has similar high-level policies, but no mechanisms to integrate people with IDD into existing health practices at the regional level.

Our finding that these patterns persist in different parts of the healthcare system reignites another question often raised, which is whether to ensure that larger campaigns focused on specific health sectors or issues (e.g. mental health, ageing, transition planning out of hospital) include individuals with IDD or alternatively whether IDD-specific programmes and interventions need to be implemented.[31] Pros and cons include the greater likelihood of obtaining resources and clinical uptake for larger population-wide initiatives versus the better outcomes sometimes found for specifically tailored services.[31] Recent moves have been made in other jurisdictions to prioritise this population in terms of both health service provision and training. The National Health Service has prioritised adults with IDD in its most recent 10-year plan, and committed to sector-wide IDD training. Similarly, in Australia, there has been a recent commitment to prioritise the mental health of this group. It may be equally important to recognise the existing strategies being applied to other larger groups (e.g. adults with dementia) and demonstrate how they can be extended to the IDD population. Regardless of which alternative is chosen, and there may be an argument that both may be valuable to take advantage of context-specific opportunities, our findings suggest that it is critical to ensure that efforts across initiatives are not siloed and that individuals with IDD do not continue to 'fall through the cracks'. Mandatory monitoring of indicators for this population, as is mandated in the UK with regard to hospitalisations and premature mortality, is one step toward doing this.[32]

We recommend that future efforts, particularly for those with IDD and MHA, not be sector- or outcome-specific. Resources are required to improve healthcare delivery in the community and in hospital, to improve transitions across different parts of the healthcare system, and to ensure that necessary social service-based supports, including housing, employment, carer and financial support, are in place. Although education of healthcare providers is essential both in and outside of hospitals, patients and carers also would benefit from being further educated about the types of health issues that can occur, how to best navigate healthcare, and ways to be better prepared and to prevent health complications.

The strengths of our study are that we were able to use different population-based groups drawn from the same geopolitical area and assess them with identical variables across multiple outcomes. This allowed us to provide a more comprehensive picture of how adults with IDD fare in terms of problematic health and health system outcomes, and what some of the relevant predictors are that should be considered. However, interpretation of our findings should be tempered in light of several limitations. Although the strength of our administrative data is their comprehensive coverage, their primary limitation is their lack of details about other important factors, such as the quality of care received, the nature of provider–patient interactions and patient preference. Another limitation that our study shares with other administrative health data research is that our definition of IDD has not been externally validated. One barrier to such validation is that IDD comprises several heterogeneous conditions. Published results have been variable and dependent on the specific kind of administrative data (poor results for hospital administrative data[33] and the specific condition (moderate sensitivity and high specificity for Down syndrome[34]; reasonable to good results for autism spectrum disorders).[35] Also, despite using both health and disability income support data to identify our IDD group, it is likely that some individuals with

IDD were missed. The addition of other data sources has been shown to increase the coverage of the IDD population,[14] as well as the reliability and validity of the case ascertainment,[36] so the use of such augmented data to replicate our results would be informative.

Elizabeth Lin (ID), Office of Education, Centre for Addiction and Mental Health; ICES; and Department of Psychiatry, University of Toronto, Canada; **Robert Balogh**, ICES; and Faculty of Health Sciences, University of Ontario Institute of Technology, Canada; **Hannah Chung**, ICES, Canada; **Kristin Dobranowski**, Faculty of Health Sciences, University of Ontario Institute of Technology, Canada; **Anna Durbin** (ID), ICES; Department of Psychiatry, University of Toronto; and Li Ka Shing Knowledge Institute, St. Michael's Hospital, Canada; **Tiziana Volpe**, Azrieli Adult Neurodevelopmental Centre, Centre for Addiction and Mental Health, Canada; **Yona Lunsky** (ID), ICES; Department of Psychiatry, University of Toronto; and Azrieli Adult Neurodevelopmental Centre, Centre for Addiction and Mental Health, Canada

Correspondence: Elizabeth Lin. Email: Elizabethbetty.lin@camh.ca

First received 8 Jun 2020, final revision 22 Sep 2020, accepted 24 Sep 2020

Supplementary material

Funding

Acknowledgements

Data availability

The data-set used in this study is held securely in coded form at ICES. Because of the terms of the data sharing agreements governing the specific data analysed in this study, they are available only under highly restricted conditions. These include access only by individuals, such as the authors, who are officially affiliated with the ICES, in a highly limited fashion consistent with privacy legislation, and for preapproved projects. Under these conditions, the data supporting the findings in this study are not available to external individuals. What is available are the specific diagnostic codes and definitions of the study groups (as provided in the article and Supplementary tables available at https://doi.org/10.1192/bjp.2020.202). In addition, although the analytic code is not necessary to replicate the study results, third-party researchers may still request the analytic code if they wish, from the corresponding author, E.L.

Author contributions

This is an original work and is not being considered for publication elsewhere. All seven authors have been actively involved in creating this work as per the ICMJE criteria. E.L. had co-primary responsibility (along with R.B.) for formulating the research questions and the underlying conceptual approach, designing the study and overseeing the analyses. She wrote the complete first draft and also integrated all co-author input into the final manuscript. In addition to responsibilities shared with E.L., R.B. provided major input into results interpretation and framing of the article and the discussion. H.C. conducted the analyses and contributed to writing and revising the description and discussion of the results. K.D. contributed conceptually to the framing and discussion of the manuscript as well as to manuscript revisions. A.D. contributed to the study design and made substantial contributions to the revised versions of the manuscript. T.V. contributed to the framing, discussion and writing of the manuscript and revisions. Y.L. contributed to formulating the research questions and underlying approach and to framing the manuscript. She also made substantial contributions to the revisions, particularly the discussion. All authors have reviewed the final version and agree to be accountable for all aspects of this work.

Declaration of interest

None.

References

1 Jansen DEMC, Krol B, Groothoff JW, Post D. People with intellectual disability and their health problems: a review of comparative studies. *J Intellect Disabil Res* 2004; **48**(2): 93–102.

2 Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? *J Appl Res Intellect Disabil* 2014; **27**(5): 431–46.

3 Lunsky Y, Balogh R, Durbin A, Selick A, Volpe T, Lin E. The mental health of adults with developmental disabilities in Ontario: Lessons from administrative health data. *Healthc Q* 2018; **21**(1): 6–9.

4 Hall A, Wood D, Hou T, Zhang J. Patterns in primary health care utilization among individuals with intellectual and developmental disabilities in Florida. *Intellect Dev Disabil* 2007; **45**(5): 310–22.

5 Lunsky Y, Lin E, Balogh R, Klein-Geltink J, Wilton AS, Kurdyak P. Emergency department visits and use of outpatient physician services by adults with developmental disability and psychiatric disorder. *Can J Psychiatry* 2012; **57**(10): 601–7.

6 Lauer E, Nicola ND, Warsett K, Monterrey R. Contributions of mental and behavioral health conditions to health service utilization among people with intellectual and developmental disabilities in Massachusetts. *Inclusion* 2019; **7**(3): 188–201.

7 Axmon A, Björkman M, Ahlström G. Hospital readmissions among older people with intellectual disability in comparison with the general population. *J Intellect Disabil Res* 2019; **63**(6): 593–602.

8 Reichard A, Haile E, Morris A. Characteristics of Medicare beneficiaries with intellectual or developmental disabilities. *Intellect Dev Disabil* 2019; **57**(5): 405–20.

9 Devapriam J, Gangadharan S, Pither J, Critchfield M. Delayed discharge from intellectual disability in-patient units. *Psychiatr Bull* 2014; **38**(5): 211–5.

10 Ouellette-Kuntz H, Martin L, McKenzie K. The risk of re-institutionalization: examining rates of admission to long-term care among adults with intellectual and developmental disabilities over time. *J Policy Pract Intellect Disabil* 2017; **14**(4): 293–7.

11 O'Leary L, Cooper SA, Hughes-McCormack L. Early death and causes of death of people with intellectual disabilities: a systematic review. *J Appl Res Intellect Disabil* 2018; **31**(3): 325–42.

12 Li X, Srasuebkul P, Reppermund S, Trollor J. Emergency department presentation and readmission after index psychiatric admission: a data linkage study. *BMJ Open* 2018; **8**(2): e018613.

13 Morgan VA, Leonard H, Bourke J, Jablensky A. Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. *Br J Psychiatry* 2008; **193**(5): 364–72.

14 Lin E, Balogh R, Isaacs B, Ouellette-Kuntz H, Selick A, Wilton ASAS, et al. Strengths and limitations of health and disability support administrative databases for population-based health research in intellectual and developmental disabilities. *J Policy Pract Intellect Disabil* 2014; **11**(4): 235–44.

15 Westerinen H, Kaski M, Virta L, Almqvist F, Iivanainen M. Prevalence of intellectual disability: a comprehensive study based on national registers. *J Intellect Disabil Res* 2007; **51**(Pt 9): 715–25.

16 Lunsky Y, Klein-Geltink JE, Yates EA. *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*. Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health, 2013 (https://www.ices.on.ca/Publications/Atlases-and-Reports/2013/Atlas-on-Developmental-Disabilities).

17 World Health Organization (WHO). *International Statistical Classification of Diseases and Related Health Problems*, 10th Revision. WHO, 2004.

18 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders* (4th Edition). American Psychiatric Association, 1994.

19 Canadian Institute for Health Information (CIHI). *Health Indicators 2011*. CIHI, 2011 (https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC1635).

20 Babitsch B, Gohl D, von Lengerke T. Re-revisiting Andersen's Behavioral Model of Health Services Use: a systematic review of studies from 1998–2011. *Psychosoc Med* 2012; **9**: Doc11.

21 Statistics Canada. *Standard Geographical Classification (SGC). Volume I. The Classification, 2006.* Minister of Industry, 2007 (http://www.statcan.gc.ca/pub/12-571-x/12-571-x2006001-eng.pdf).

22 The Johns Hopkins University. *ACG System Version 10.0 Technical Reference Guide*. The Johns Hopkins University, 2011 (https://www.hopkinsacg.org/document/acg-system-version-10-0-technical-reference-guide/).

23 SAS Institute. Base SAS 9.4 Procedures Guide: Statistical Procedures. SAS Institute, 2013.

24 Chen H, Cohen P, Chen S. How big is a big odds ratio? Interpreting the magnitudes of odds ratios in epidemiological studies. *Commun Stat Simul Comput* 2010; **39**(4): 860–4.

25 Olivier J, May WL, Bell ML. Relative effect sizes for measures of risk. *Commun Stat - Theory Methods* 2017; **46**(14): 6774–81.

26 Dubé P. *Nowhere to Turn: Investigation into the Ministry of Community and Social Services' response to situations of crisis involving adults with developmental disabilities*. Ombudsman Ontario, 2016 (https://www.ombudsman.on.ca/resources/reports-and-case-summaries/reports-on-investigations/2016/nowhere-to-turn).

27 Lunsky Y, Garcin N, Morin D, Cobigo V, Bradley E. Mental health services for individuals with intellectual disabilities in Canada: findings from a national survey. *J Appl Res Intellect Disabil* 2007; **20**(5): 439–47.

28 Zworth M, Selick A, Durbin J, Casson I, Lunsky Y. Improving care for adults with intellectual and developmental disabilities. *Can Fam Physician* 2019; **65**(suppl 1): S8–10.

29 Spassiani NA, Abou Chacra MS, Selick A, Durbin J, Lunsky Y. Emergency department nurses' knowledge, skills, and comfort related to caring for patients with intellectual disabilities. *Int Emerg Nurs* 2020; **50**: 100851.

30 Hamdani Y, Ary A, Lunsky Y. Critical analysis of a population mental health strategy: effects on stigma for people with intellectual and developmental disabilities. *J Ment Health Res Intellect Disabil* 2017; **10**(2): 144–61.

31 Bigby C. A five-country comparative review of accommodation support policies for older people with intellectual disability. *J Policy Pract Intellect Disabil* 2010; **7**(1): 3–15.

32 Lin E, Balogh R, Durbin A, Holder L, Gupta N, Volpe T, et al. Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario. Institute for Clinical Evaluative Sciences, 2019 (https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities.aspx).

33 Bourke J, Wong K, Leonard H. Validation of intellectual disability coding through hospital morbidity records using an intellectual disability population-based database in Western Australia. *BMJ Open* 2018; **8**: e019113.

34 Jensen KM, Cooke CR, Davis MM. Fidelity of administrative data when researching Down syndrome. *Med Care* 2014; 52(8): e52–7.

35 Burke JP, Jain A, Yang W, Kelly JP, Kaiser M, Becker L, et al. Does a claims diagnosis of autism mean a true case? *Autism* 2014; **18**(3): 321–30.

36 Van Naarden Braun K, Pettygrove S, Daniels J, Miller L, Nicholas J, Baio J, et al. Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders – autism and developmental disabilities monitoring network, 14 sites, United States, 2002. *MMWR Surveill Summ* 2007; **56**: 29–40.

EXTRA CONTENT ONLINE