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Physical and mental health of young people with and without intellectual disabilities: Cross-sectional analysis of a whole country population

Keywords: Transition to adulthood; physical health; mental health; intellectual disabilities; young people

Abstract

Background: Transition to adulthood may be a period of vulnerability for health for individuals with intellectual disabilities. No large-scale studies have compared the health of individuals with and without intellectual disabilities undergoing transition. The aims of this study were (1) to compare health during transition for individuals with and without intellectual disabilities across a whole country population, and (2) to establish whether transition is associated with health in the population with intellectual disabilities.

Method: Data were drawn from Scotland's Census, 2011. Frequency data were calculated for young people with and without intellectual disabilities. Logistic regressions were used to determine the extent to which intellectual disabilities account for seven health outcomes (general health; mental health; physical disabilities; hearing impairment; visual impairment; long-term illness; day-to-day activity limitations), adjusted for age and gender. Within the intellectual disabilities population, logistic regressions were then used to determine whether age group (13-18 years or 19-24 years) is associated with the seven health outcomes, adjusted by gender.

Results: 5,556/815,889 young people aged 13-24 years had intellectual disabilities. Those with intellectual disabilities were 9.6-125.0 times more likely to have poor health on the seven outcomes. Within the population with intellectual disabilities, the 19-24 year olds with intellectual disabilities were more likely to have mental health problems than the 13-18 year olds, but did not have poorer health on the other outcomes. The difference between age groups for mental health problems was greater for young people who did not have intellectual disabilities, but their overall level of mental health problems was substantially lower than for the young people with intellectual disabilities.

Conclusion: This largest-to-date study quantifies the extent of the substantial health disparities experienced by young people with intellectual disabilities compared to people without intellectual disabilities. The young population with intellectual disabilities have substantial health problems, therefore transition between child and adult services must be carefully planned in order to ensure that existing health conditions are managed and emerging problems minimised.

Background

There is evidence that health in both children (e.g. Allerton et al., 2011; Oesburg et al., 2011) and adults (e.g. Cooper et al., 2015) with intellectual disabilities is poor compared to those without intellectual disabilities. This health inequality may be attributed to social determinants of health, such as poverty; increased health risk caused by common comorbidities associated with intellectual disability, such as congenital heart defects in Down syndrome; reduced health literacy; and deficiencies in access to and quality of health care among the population with intellectual disabilities (Emerson & Baines, 2010).

Individuals with intellectual disabilities may be more likely to experience health inequalities during transition to adulthood. Transition is defined here as the move from childhood to adulthood. Traditional models of transition consider leaving school and entry into the labour market as defining markers of adulthood (Pollock, 2002). More holistic conceptualisations of transition focus on the attainment of personal characteristics, including independence and responsibility (e.g. Worth, 2009). For individuals with intellectual disabilities, transition may also include moving from child to adult health and social services.

Transition may be a period of intense change and upheaval for young people with intellectual disabilities as they leave the relatively sheltered school environment and adjust to new routines and environments. The literature describes poorer transition outcomes for young people with intellectual disabilities compared to those without intellectual disabilities, with studies demonstrating that individuals with intellectual disabilities are less likely: to be employed (Verdonschot et al., 2009); to live independently (Gray et al., 2014); or to experience community participation (Verdonschot et al., 2009) than their non-disabled counterparts. These outcomes may all have an impact on health status: a lack of community involvement or structured daytime activity may result in isolation, leading to mental health issues such as depression or anxiety. Furthermore, evidence suggests that the transition between child and adult health and social services is experienced by families as discontinuous and chaotic (Hudson, 2006), and some authors have suggested that adult services may be less suited to caring for individuals with intellectual disabilities than child services, for example by facilitating less family involvement in the individual's care (Barron & Hassiotis, 2008). This situation may result in disruption to the management of existing health conditions, or a lack of detection of new health conditions. However, few studies have investigated the health of young people with intellectual disabilities during transition. Indeed, a recent systematic review identified only 16 studies and 1 published dataset on this topic, most of which were small scale or qualitative studies (Young-Southward et al., 2016).

The National Longitudinal Transition Study-2 in the USA reported parent- and self-rated general health for 862 young people with intellectual disabilities aged 13-25 years at five time points across almost ten years, between 2001 and 2009. Parent-ratings of 'fair' or 'poor' general health increased with age; from 13.5% at the second wave of data collection (age 15-17 years), to 22.2% at the final wave of data collection (age 23-25 years), suggesting a negative effect of transition on health. However, this study did not include a comparison group without disabilities.

All young people with intellectual disabilities undergo some form of transition. It is hence vital to gain an accurate picture of their health status during this important period in order to inform future care, supports and policy. The aims of this study were (1) to compare health during transition for individuals with and without intellectual disabilities across a whole country population, and (2) to establish whether transition is associated with health in the population with intellectual disabilities.

Methods

Approval

Approval to access the data was granted by the custodian of the data, the National Records of Scotland (NRS). Ethical approval was also granted from the University of Glasgow, College of Medical, Veterinary and Life Science ethics committee.

Data Source

Scotland holds a Census once every ten years to provide an accurate picture of the health and household circumstances of the population of Scotland on the Census date. The Census was administered to the whole population of Scotland on 27th March 2011. Questionnaires were completed on paper, or electronically, in English or Gaelic, for everyone in each household, and for everyone in communal establishments. The Census requires the form to be completed by the head of household or joint head of household for all occupants of private households, and the manager for all occupants of communal dwellings. It is clearly stated on the form that it is a legal requirement to complete the Census, and that if a head of household does not complete it, or supplies false information, she/he can be fined £1,000. The Census team follow up non-responders, and also provide help to respond when that is needed. This accounts for the high response rate of 94% (National Records of Scotland, 2013). The Census was not in an easy-read version. Full details of the Census methodology are available at: <http://www.scotlandscensus.gov.uk/supporting-information>. Scotland's Census (2011) included the following question:

Do you have any of the following conditions that have lasted, or are expected to last at least 12 months? Tick all that apply.

- Deafness or partial hearing loss
- Blindness or partial sight loss
- **Learning disability (for example Down’s syndrome)**
- Learning difficulty (for example, dyslexia)
- Developmental disorder (for example, autistic spectrum disorder or Asperger’s syndrome)
- Physical disability
- Mental health condition
- Long-term, illness, disease or other condition
- Other condition
- No condition

The term “learning disability” as used in Scotland is synonymous with “intellectual disability”. As intellectual disabilities were distinguished from developmental disorders or learning difficulties, Scotland’s Census (2011) provides a unique opportunity to compare the health of people with and without intellectual disabilities at a population level.

Procedures

Following Scottish Government approval, data from Scotland’s Census 2011 were analysed under the auspices of a collaborative research project with National Records of Scotland. All resulting statistical tables of census data were checked to ensure they did not breach statistical disclosure control thresholds and were published on Scotland’s Census website, available under the Health topic at: <http://www.scotlandscensus.gov.uk/ods-web/data-warehouse.html#additionaltab>

Analysis

Analysis was conducted on data from young people aged 13-24 years who returned the Census questionnaires (n = 815,889, of whom 5,556 reported having intellectual disabilities). This age group is in line with Arnett’s (2000) conceptualisation of transition as a period spanning adolescence and the early twenties. In Scotland, individuals leave school between the ages of 16 and 19 years. For some analyses, the cohort was therefore split into two age groups; those aged 13-18 years who were still in school (‘pre-transition’) and those aged 19-24 years who had left school (‘post-transition’).

Leaving school was hence conceptualised as a central transition point which might coincide with numerous other changes, such as transitioning between child and adult health and social services.

Frequency tables were generated and quality checked by NRS. All analyses were conducted using the Statistical Package for Social Science (SPSS), version 22.

Health in the whole population

For the whole population, we used seven enter method binary logistic regression analyses to calculate odds ratios (95% confidence intervals) for ability (intellectual disabilities versus no intellectual disabilities), age group (19-24 years versus 13-18 years), and gender (female versus male) in independently statistically predicting each of seven dependent variables. The seven dependent variable were the seven health outcomes:

- 'Poor' general health rating (health rating of 'fair', 'bad' or 'very bad' on the Census questionnaire)
- Presence of a mental health condition
- Presence of a physical disability
- Presence of a long-term illness, disease or condition
- Deafness or hearing impairment
- Blindness or visual impairment
- Day-to-day activities limited due to a health condition or disability.

Health in the population with intellectual disabilities

Within the population with intellectual disabilities, we then used seven enter method binary logistic regression analyses with each health outcome as the dependant variable, to calculate odds ratios (95% confidence intervals) of age group (19-24 years versus 13-18 years) and gender (female versus male) independently statistically predicting the health outcome.

Results

The population

Of the 815,889 individuals aged 13-24 years, 5,556 reported having intellectual disabilities (0.7%). The population with intellectual disabilities comprised 3,396 males (61.1%) and 2,160 females (38.9%). The population without intellectual disabilities comprised 407,962 males (50.3%) and

402,371 females (49.7%). 77.9% of young adults with intellectual disabilities and 95.1% of the children with intellectual disabilities were living in the family home, compared with 75.1% and 98.1% without intellectual disabilities. The proportion of post-transition adults with intellectual disabilities in paid employment was only 10%, with a further 28% in further education.

Health in the whole population

Table 1 shows the number and percentage of young people with and without intellectual disabilities reporting each health outcome.

Insert Table 1, Reported health status in the populations with and without intellectual disabilities, about here

In the whole population, the seven regressions revealed that having intellectual disabilities statistically predicted having 'poor' general health; a mental health condition; a physical disability; a long-term illness, disease or condition; deafness or a hearing impairment; blindness or a visual impairment; and day-to-day activity limitations, having adjusted for age group and gender. For these seven outcomes, the odds ratios for intellectual disabilities ranged from 9.6 to 125.0 (Table 2).

Older age was a statistical predictor of five health outcomes in the whole population. Individuals aged 19-24 years were more likely to report 'poor' general health; to have a mental health condition; to have a physical disability; deafness or a hearing impairment; and blindness or a visual impairment than were individuals aged 13-18 years. Younger age was a statistical predictor of two health outcomes in the whole population. Individuals aged 13-18 years were more likely to have a long-term illness, disease or condition and to report that their day-to-day activities were limited due to health conditions or disabilities than were individuals aged 19-24 years (Table 2). However, they were far less likely to experience these health difficulties when compared with the population of people with intellectual disabilities, as odds ratios were much lower in all of the seven regressions than were those for intellectual disabilities (Table 2).

Intellectual disabilities had considerably greater influence on statistically predicting the health outcomes than did gender, although gender was also a statistical predictor of the seven health outcomes in the whole population. Females were more likely to report 'poor' general health; to have a mental health condition; and a long-term illness, disease or condition than were males. Males were more likely to report four of the outcomes: having a physical disability; having deafness or a hearing impairment; having blindness or a visual impairment; and day-to-day activities being limited due to health conditions or disabilities than were females (Table 2).

Insert Table 2, Independent statistical predictors of seven health outcomes in the whole population,
about here

Health in the population with intellectual disabilities

Older age was a statistical predictor of one health outcome in the population with intellectual disabilities. Individuals aged 19-24 years were more likely to have a mental health condition than were individuals aged 13-18 years. Younger age was a statistical predictor of two health outcomes in the population with intellectual disabilities. Individuals aged 13-18 years were more likely to have a long-term illness, disease or condition, and to report that their day-to-day activities were limited due to health conditions or disabilities than were individuals aged 19-24 years, as for the whole population (Table 3).

Gender was a statistical predictor of five health outcomes in the population with intellectual disabilities. Females were more likely to report 'poor' general health (as in the whole population); to have a physical disability; to have deafness or a hearing impairment; and to have blindness or a visual impairment than were males (these last three being contrary to findings in the whole population). Unlike the whole population, males were more likely to have a mental health condition than were females (Table 3).

Insert Table 3, Independent statistical predictors of seven health outcomes in the population with
intellectual disabilities, about here

Discussion

Principal findings

No previous studies have provided a whole country investigation of health during the transition period for the population with intellectual disabilities compared to the population without intellectual disabilities. Health was much poorer for the young people with intellectual disabilities compared to those without intellectual disabilities, revealing significant health disparities during this transitional period: the young people with intellectual disabilities were between 9.6 and 125.0 times more likely to have each of the seven health outcomes investigated than were those without intellectual disabilities.

The data presented here suggest that transition, conceptualised here as the move from school, does not seem to be associated with poorer health in the population with intellectual disabilities on six of the outcomes we investigated, the exception being mental health: the 19-24 year olds were more likely to have a mental health condition than the 13-18 year olds. Given this mental health finding,

and the substantial burden of health problems in the youth with intellectual disabilities, it is clear that transition planning at this time of change from child to adult services must be carefully planned in order to ensure that existing health conditions are managed and emerging problems minimised.

The difference in the prevalence of some of the health outcomes between the younger and older age groups in the population with intellectual disabilities was smaller than for the population without intellectual disabilities. This reflects the fact that there were very few health problems in the pre-transition general population, who then start to acquire health problems as they enter adulthood, but at a much lower level overall than for the population with intellectual disabilities. By contrast, there are substantial health problems reported by the younger age group with intellectual disabilities.

Individuals with intellectual disabilities aged 13-18 years were more likely to have a long-term illness, disease or condition and to report that their activities were limited 'a little' or 'a lot' due to health conditions or disabilities than were individuals aged 19-24 years. As the study is cross-sectional, we cannot explain this with certainty. It is possible that the most disabled young people with intellectual disabilities fail to reach adult years, as long-term conditions are, by definition, long-term, so one would not otherwise expect to see a reduction with age.

Within the population with intellectual disabilities, being female was associated with four of the seven health variables investigated. The National Longitudinal Transition Study-2 found a similar disparity in the health of young men and women with intellectual disabilities undergoing transition: 12.2% of parents rated their daughters' health as fair or poor at the second wave of data collection, when young people were aged 14-18 years, compared to 7.5% of parents of sons. At the fifth and final wave of data collection, when young people were aged 21-25 years, 17.4% of parents rated their daughters' health as fair or poor, compared to 13.9% of parents of sons.

The data presented demonstrate a significant disparity in health between the young populations with and without intellectual disabilities. There are numerous socio-economic factors, including inequalities in access to health and social services that may affect health in the population with intellectual disabilities, especially during the transition period. For example, the Census data demonstrates that only 10% of post-transition young people with intellectual disabilities were in paid employment, and 28% in further education (Scottish Learning Disabilities Observatory, 2016). A lack of meaningful daytime activity may result in a more sedentary lifestyle and isolation from the general community, which itself may have negative implications for health. Future research investigating socio-economic factors and their association with health during transition to adulthood in this population is necessary.

Strengths and Limitations

Strengths include that Scotland's Census (2011) systematically enquired about the presence or absence of intellectual disabilities for each person, and distinguished it from both specific learning disabilities and autism, and that the Census covered communal establishments as well as private households. Lack of these factors has been criticised as a limitation in previous research on intellectual disabilities when using large data sets, where operationalised criteria have had to be developed to estimate who has intellectual disabilities, and with much general population survey data being restricted to private households (Emerson et al, 2013). An additional strength is the high completion rate at 94% (National Records of Scotland, 2013), and that the analysis was conducted on an entire country's population within the age range studied. The overall adult prevalence of intellectual disabilities identified by Scotland's Census (0.5%) is as expected for a high income country, according to a recent systematic review of population-based studies which reported a rate of 4.94/1,000 (Maulik et al., 2011). For children, the Census underestimates prevalence of intellectual disabilities in the early years, with identification of intellectual disabilities increasing year-on-year up to age 9 years, making comparisons with other studies difficult as they are dependent on the exact ages studied. For the age range in this study, the prevalence in Scotland's Census is 0.7% (higher than the overall adult rate, as expected, given the younger age).

Given the style and questions on Scotland's Census, we consider it very unlikely that people with intellectual disabilities would have been able to complete the form without help. As the great majority in both age groups were living with family, the head of households were highly likely to be a parent. It can therefore be assumed that the majority were proxy-ratings completed by parents. The extent to which parent-ratings agree with self-ratings could be questioned; however, self-rating is not possible for people with more severe intellectual disabilities, and much of health care with this group also relies upon proxy-ratings.

In addition, this analysis presents cross-sectional comparisons of individuals with intellectual disabilities within different age groups, and so causation cannot be established. A longitudinal study following individuals with intellectual disabilities in comparison to those without intellectual disabilities throughout the course of transition would help to better establish whether life changes associated with transition affect health and wellbeing measures.

Conclusions

Health during transition is poor in the population with intellectual disabilities compared to those without intellectual disabilities. Given that health in the young population with intellectual

disabilities is so poor, it is crucial that transition between child and adult health services is carefully planned in order to ensure that existing health conditions continue to be managed and emerging mental health problems are minimised.

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Table 1: Reported health status in the populations with and without intellectual disabilities

Variable	Intellectual disabilities				No intellectual disabilities			
	Males 13-18 years n = 1,740	Males 19-24 years n = 1,656	Females 13-18 years n = 1,037	Females 19-24 years n = 1,123	Males 13-18 years n = 191,647	Males 19-24 years n = 216,315	Females 13-18 years n = 183,373	Females 19-24 years n = 218,998
General health								
Very good	393 (22.6%)	360 (21.7%)	218 (21.0%)	229 (20.3%)	156,912 (81.9%)	159,103 (73.6%)	147,281 (80.3%)	150,024 (68.5%)
Good	629 (36.1%)	581 (35.1%)	345 (33.3%)	385 (34.3%)	29,414 (15.3%)	47,727 (22.1%)	30,521 (16.6%)	57,362 (26.2%)
Fair	509 (29.3%)	499 (30.1%)	332 (32.0%)	333 (29.7%)	4,369 (2.3%)	7,557 (3.5%)	4,599 (2.5%)	9,513 (4.3%)
Bad	137 (7.9%)	150 (9.1%)	81 (7.8%)	118 (10.5%)	752 (0.4%)	1,542 (0.7%)	812 (0.4%)	1,752 (0.8%)
Very bad	72 (4.1%)	66 (4.0%)	61 (5.9%)	58 (5.2%)	200 (0.1%)	386 (0.1%)	160 (0.09%)	347 (0.2%)
Mental health								
Has a mental health condition	314 (18.0%)	322 (19.4%)	152 (14.7%)	200 (17.8%)	1,805 (0.9%)	4,555 (2.1%)	1,983 (1.0%)	7,635 (3.5%)
Physical disability								
Has a physical disability	522 (30.0%)	472 (28.5%)	389 (37.5%)	400 (35.6%)	1,631 (0.9%)	2,086 (0.9%)	1,344 (0.7%)	1,904 (0.9%)
Long-term illness, disease or condition								
Has a long-term illness, disease or condition	711 (40.9%)	577 (34.8%)	422 (40.7%)	444 (39.5%)	12,562 (6.6%)	11,739 (5.4%)	11,583 (6.3%)	15,122 (6.9%)
Deafness or hearing impairment								
Has deafness	117 (6.7%)	120 (7.2%)	108 (10.4%)	120 (10.7%)	1,351 (0.7%)	1,883 (0.9%)	1,178 (0.6%)	1,723 (0.8%)
Blindness or visual impairment								
Has blindness	178 (10.2%)	161 (9.7%)	138 (13.3%)	146 (13.0%)	891 (0.5%)	1,335 (0.6%)	757 (0.4%)	968 (0.4%)
Day-to-day activities limited								
Activities not limited	193 (11.1%)	201 (12.1%)	83 (8.0%)	161 (14.3%)	178,593 (93.2%)	204,265 (94.4%)	173,893 (94.8%)	206,353 (94.2%)
Activities limited a little	419 (24.1%)	409 (24.7%)	244 (23.5%)	224 (19.9%)	8,988 (4.7%)	8,026 (3.7%)	6,988 (3.8%)	9,146 (4.2%)
Activities limited a lot	1,128 (64.8%)	1,046 (63.2%)	710 (68.5%)	738 (65.7%)	4,066 (2.1%)	4,024 (1.9%)	2,492 (1.4%)	3,499 (1.6%)

Table 2: Independent predictors of seven health outcomes in the whole population (results from 7 regression analyses)

Health outcomes and independent predictor variables		Odds ratio	95% confidence interval of odds
Poor health			
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	19.952	18.887 – 21.006
Age group	13-18 years (reference)	-	-
	19-24 years	1.661	1.623 – 1.699
Gender	Male (reference)	-	-
	Female	1.175	1.149 – 1.201
Constant	-	0.028	-
Mental health condition			
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	12.084	11.243 – 12.986
Age group	13-18 years (reference)	-	-
	19-24 years	2.655	2.564 – 2.750
Gender	Male (reference)	-	-
	Female	1.484	1.439 – 1.531
Constant	-	0.009	-
Physical disability			
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	54.463	51.226 – 57.905
Age group	13-18 years (reference)	-	-
	19-24 years	1.122	1.015 – 1.108
Gender	Male (reference)	-	-
	Female	0.943	0.902 – 0.985
Constant	-	0.008	-
Long-term illness, disease or condition			
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	9.620	9.106 – 10.162
Age group	13-18 years (reference)	-	-
	19-24 years	0.951	0.935 – 0.968
Gender	Male (reference)	-	-
	Female	1.122	1.102 – 1.142
Constant	-	0.065	-
Deafness or hearing impairment			
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	11.989	10.866 – 13.229
Age group	13-18 years (reference)	-	-
	19-24 years	1.220	1.162 – 1.282
Gender	Male (reference)	-	-
	Female	0.938	0.894 – 0.985
Constant	-	0.007	-
Blindness or visual impairment			
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	25.777	23.574 – 28.185

Age group	13-18 years (reference)	-	-
	19-24 years	1.179	1.111 – 1.251
Gender	Male (reference)	-	-
	Female	0.835	0.787 – 0.886
Constant	-	0.004	-
Day-to-day activities limited			
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	124.979	115.030 – 135.789
Age group	13-18 years (reference)	-	-
	19-24 years	0.940	0.923 – 0.957
Gender	Male (reference)	-	-
	Female	0.890	0.873 – 0.906
Constant	-	0.068	-

Table 3: Independent predictors of seven health outcomes in the population with intellectual disabilities (results from 7 regression analyses)

Health outcomes and independent predictor variables		Odds ratio	95% confidence interval of odds
Poor health			
Age group	13-18 years (reference)	-	-
	19-24 years	1.042	0.937 – 1.59
Gender	Male (reference)	-	-
	Female	1.44	1.026 – 1.275
Constant	-	0.730	-
Mental health condition			
Age group	13-18 years (reference)	-	-
	19-24 years	1.153	1.005 – 1.324
Gender	Male (reference)	-	-
	Female	0.841	0.729 – 0.970
Constant	-	0.215	-
Physical disability			
Age group	13-18 years (reference)	-	-
	19-24 years	0.927	0.828 – 1.038
Gender	Male (reference)	-	-
	Female	1.394	1.243 – 1.564
Constant	-	0.429	-
Long-term illness, disease or condition			
Age group	13-18 years (reference)	-	-
	19-24 years	0.840	0.754 – 0.936
Gender	Male (reference)	-	-
	Female	1.102	0.986 – 1.231
Constant	-	0.665	-
Deafness or hearing impairment			
Age group	13-18 years (reference)	-	-
	19-24 years	1.057	0.874 – 1.279
Gender	Male (reference)	-	-
	Female	1.573	1.300 – 1.903
Constant	-	0.073	-
Blindness or visual impairment			
Age group	13-18 years (reference)	-	-
	19-24 years	0.958	0.810 – 1.132
Gender	Male (reference)	-	-
	Female	1.367	1.156 – 1.617
Constant	-	0.113	-
Day-to-day activities limited			
Age group	13-18 years (reference)	-	-
	19-24 years	0.736	0.623 – 0.869
Gender	Male (reference)	-	-
	Female	1.041	0.878 – 1.234
Constant	-	8.928	-