Title: General health status in young people with intellectual disabilities with and without Down syndrome in, and transitioning from, special education. Findings from the National Longitudinal Transitions Study-2 (NLTS2)

Authors: Ewelina Rydzewska, Michael Fleming, Daniel Mackay, Genevieve Young-Southward, Jan Blacher, Yasamin Bolourian, Keith Widaman, & Sally-Ann Cooper

Ewelina Rydzewska
Institute of Health and Wellbeing, University of Glasgow
ewelina.rydzewska@glasgow.ac.uk
+44 141 211 3889

Michael Fleming
Institute of Health and Wellbeing, University of Glasgow
Michael.Fleming@glasgow.ac.uk
+ 44 141 330 3415

Daniel Mackay
Institute of Health and Wellbeing, University of Glasgow
Daniel.Mackay@glasgow.ac.uk
+ 44 141 330 2567

Genevieve Young-Southward
Institute of Health and Wellbeing, University of Glasgow
g.young-southward.1@research.gla.ac.uk
+44 (0)141 211 0690/3927

Jan Blacher
Graduate School of Education, University of California, Riverside
jan.blacher@ucr.edu
+1 951-827-3875/3849

Yasamin Bolourian
Graduate School of Education, University of California, Riverside
ybolo002@ucr.edu
+1 951-827-3849

Keith Widaman
Graduate School of Education, University of California, Riverside
keith.widaman@ucr.edu
+1 951-827-4633

Corresponding author:
Professor Sally-Ann Cooper
Institute of Health and Wellbeing
University of Glasgow
Mental Health and Wellbeing Group
1st Floor, Administrative Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH
Scotland, UK
Email: Sally-Ann.Cooper@glasgow.ac.uk
Phone: +44 141 211 0690/3701

Acknowledgments: This work was funded through Lord Kelvin Adam Smith fellowship at the University of Glasgow.

Conflict of interest: none

Funding: This work was funded through a Lord Kelvin Adam Smith fellowship at the University of Glasgow.

Abstract

Background: There has been little prior investigation of the general health of young people with intellectual disabilities across transition, nor separately for youth with intellectual disabilities with or without Down syndrome, despite general health being a strong predictor of subsequent health service use, hospital admissions, and mortality in the general population. We aimed to investigate general health status in youth with intellectual disabilities with and without Down syndrome over the transitional period, and quantify the extent to which personal characteristics, parental relationship, and household income are associated with general health status.

Methods: The National Longitudinal Transitions Study-2 includes a nationally representative sample of youth receiving special education services aged 13-17 years at wave 1, followed up over 10 years in five waves of data collection. Data on general health status of youth with intellectual disabilities with and without Down syndrome were obtained from parent reports. We summarised overall demographics and general health status, and plotted general health status for those who had health data available for all 5 waves. We then used random-effects ordered logistic regression to investigate whether wave, age, sex, Down syndrome, ethnicity, parental relationship status, and household income are associated with general health status.

Results: At wave 1, data on intellectual disabilities were available on 9,008/9,576 (94.1%), and 871/9,008 (9.7%) had intellectual disabilities, of whom 125/871 (14.4%) had Down syndrome. Youth with intellectual disabilities, with or without Down syndrome have low rates of excellent or very good health. Across waves 1-5, there was a shallow gradient in the proportion with intellectual disabilities reporting excellent/very good health, from 57.1% at 13-17 years to 52.6% at 21-25 years, being more marked for those without Down syndrome (57.8% at 13-17 years to 51.8% at 21-25 years). However, contrary to our expectations, an ordinal measure of general health status did not decline over this transitional period, and did not differ between the youth with, versus without, Down syndrome. There was a gradient with higher income associated with better health, significantly so over $50,001 (OR=0.559, 95% CI 0.366-0.854), and poorer health experienced by youth with Hispanic, Latino or Spanish ethnicity (OR=1.790, 95% CI 1.051-3.048). Female sex and parental relationship status was not associated with health status.

Conclusion: Young people with intellectual disabilities have bad health, so require support across all ages, including transition. Schools, teachers, and staff in transitional services should consider health, health care and health support during transitional planning due to change of service provision, and be aware of ethnicity and the stressful effects of low household income. This is important as interventions based on provision of greater support can prevent adverse consequences.

Keywords: intellectual disabilities, Down syndrome, health, young people, transition, longitudinal cohort

Background

Poor physical health (Oesburg et al. 2011; Hughes-McCormack et al. 2018) and mental health (Einfield et al. 2011; Emerson & Hatton 2007a; Hughes-McCormack et al. 2017) is more prevalent among young people with intellectual disabilities compared with the general population. Individuals with intellectual disabilities may experience a decline in health during transition to adulthood, particularly during the move from child to adult health and social services (Hudson 2006; Young-Southward 2017a), but few studies have investigated this.

Transition to adulthood refers to the move from childhood to adulthood in terms of service provision, a restructuring of daytime activity, and more holistically in the sense of attaining increased independence and performance across a range of adult roles (Young-Southward et al. 2017b). Transition can be regarded as a prolonged period spanning much of adolescence and early adulthood, including the years approaching leaving school and the period of extended exploration after school exit. Arnett (2014) refers to the ages of 18 to 25 as 'emerging adulthood'. A recent systematic review identified only 16 studies and one published dataset on the health of youth with intellectual disabilities during transition (Young-Southward et al. 2017b). It concluded that there was tentative evidence for decline in health of youth with intellectual disabilities over the transition period, however, all of the studies were cross-sectional in design, they were mostly small qualitative studies, and did not study youth with intellectual disabilities separately for those with and without Down syndrome. This later point is important given the differing health profiles for people with intellectual disabilities with and without Down syndrome (Kinnear et al. 2018).

There are biological and related social reasons why transition may be a vulnerable time for youth with intellectual disabilities. Allostatic load (physiological "wear and tear") is the physiological cost of making adaptive shifts across a range of physiological systems to match internal functioning to environmental demands. It may be an important underpinning mechanism linking intellectual disabilities and poor health. Stressful environments negatively interact, and probably more so during critical periods of development such as puberty (McEwen & Gianaros 2010). This leads to secondary metabolic and immunological consequence, implicated in a range of pathology. Adults with intellectual disabilities have higher levels of inflammatory cytokines, and increased level of oxidative stress (Carmelli et al. 2012), suggesting they may be particularly vulnerable to allostatic load. Allostatic load leads to morbidity and poorer psychosocial functioning (Seeman et al. 2001), and is related to cumulative socioeconomic disadvantage (Gustafsson et al. 2011; Juster et al. 2009). In children without disabilities, at age 9 years, increased allostatic load indices are associated with low socioeconomic status features (Evans 2003). By 13, early adversities exacerbate allostatic load levels further (Evans et al. 2007). By 17 years, people who have experienced chronic poverty have working memory impairments, mediated through increased childhood chronic stress (Evans & Schamberg 2009). The interplay between risk and resilience factors, within the context of maturing biological systems probably determines the expression of disorders and at which age.

Studies have suggested that children and young people with intellectual disabilities experience inequalities in socioeconomic position and social capital, such as household income and living arrangements (e.g. Emerson & Hatton 2007b; Emerson & Hatton 2007c), so they may be particularly vulnerable to accumulated allostatic load. Additionally, they may be more vulnerable during the critical developmental period of puberty, and transition; given biological changes and the stressors of leaving school, balancing emerging adulthood with some remaining dependence on families, and changes to health services and support services, and possibly living arrangements. Perturbations to development can be exacerbated (or compensated for) during sensitive periods such as puberty, in contrast to after development is complete (Rice & Barone 2000), and at this time are also amenable to intervention (Knudsen 2004; Anderson et al. 2008). Hence, it is particularly important to study changes in health over the transitional period given the limited studies on this topic, to understand the extent of risk for youth with intellectual disabilities, which may need intervention.

Subjective general health status is commonly measured in general population studies, as there is a strongly predictive linear gradient across health status (from best to poorest) associated with subsequent number of medical appointments, hospital admissions, and mortality (Miilunpalo et al. 1997; Burstrom & Fredlund 2001; Heistaro et al. 2001; Schnittker & Bacak 2014). However, we have identified only four papers that investigated general health status among children and young people with intellectual disabilities (Emerson & Hatton 2007a; Emerson & Hatton, 2007b; Young-Southward et al. 2017a; Hughes-McCormack et al. 2018). These clearly show that youth with intellectual disabilities experience poorer general health than do other young people. However, all four studies were cross-sectional in design, with no longitudinal follow-up of trends in general health status and hence do not address changes in health of youth with intellectual disabilities over the transitional period. Young-Southward et al (2017a) reported that 43.5% of 5,556 youth with intellectual disabilities aged 13-24 years had fair, bad, or very bad health, compared with only 3.9% who did not have intellectual disabilities, and that of the youth with intellectual disabilities, females were more likely to have poor health than males, as were youth aged 19-24 years compared with those aged 13-18 years. This suggests that health status may change over time, but the study's design was cross-sectional. Hughes-McCormack et al (2018) found that 48.0% of 5,234 children and young people with intellectual disabilities aged <16 years had fair, bad, or very bad health, compared with 2.1% of the other children. Emerson & Hatton (2007b) reported an odds ratio of 4.22 for intellectual disabilities being associated with fair, bad, or very bad health with 264 children with intellectual disabilities at age 5-15, but the actual proportions with poor health were not reported (Emerson & Hatton 2007b). Using a different dataset with 593 children with intellectual disabilities aged ≤16 years or at school aged 17/18 they also reported an odds ratio of 2.49 in predicting having fairly/not good health, but the actual proportions with poor health were not reported (Emerson & Hatton 2007c).

The aim of this study was to investigate the general health status of youth with intellectual disabilities with and without Down syndrome longitudinally for 10 years over the transitional period, and to quantify the extent to which personal characteristics, parental relationship status and household income are

associated with poorer health over this period. We hypothesise that general health status will decline over time, more so for the youth without Down syndrome than those with Down syndrome, and that female sex, ethnicity, parental relationship status, and lower income is associated with poorer health in emerging adulthood.

Methods

Approval

Approval to access and analyse data was granted by the Institute of Education Sciences of the United States Department of Education (License number: 16090007).

Study context

Transition is defined in this study as the process of moving from childhood to adulthood, occurring between the ages of 13 and 25 years. This age range incorporates the period before secondary school exit, and the period of 'emerging adulthood' described by Arnett (2014).

Secondary education in the USA covers the last seven years of statutory formal education grade 6 (age 11–12) through grade 12 (age 17–18). It occurs in two phases. The first phase covers junior high school or middle school for students grade 6 (age 11–12) through grade 8 (age 13–14). The second phase covers high school for students grade 9 (age 14–15) through grade 12 (age 17–18). Education is compulsory for all students until ages 16 to 18 depending on the individual state. Most high school students graduate at the age of 17 or 18 years old.

The Individuals with Disabilities Education Act (IDEA) is a federal law that authorises special education for children with disabilities in the USA. IDEA requires states to provide special education and related services consistent with federal standards as a condition of receiving federal funds. IDEA entitles every student to a free and appropriate public education in the least restrictive environment. Under IDEA, students with disabilities are entitled to receive special educational services through their local school district from age 3 to age 18 or 21. To receive special education services, a student must demonstrate a disability in one of 13 specific categories, one of which is 'mental retardation'. Depending on the students' individual needs, they may be included, mainstreamed, or placed in a special school, and/or may receive specialised services in a resource room or self-contained classroom. In addition to academic goals, the goals documented in the Individual Education Plan (IEP) may address self-care, social skills, physical, speech, and vocational training (Lipkin et al. 2015).

Dataset

The National Longitudinal Transition Study-2 (NLTS2) dataset is a follow up of an original National Longitudinal Transition Study, funded by the US Department of Education and conducted by SRI International. It provides a national picture of the circumstances of young people with special education needs in the USA as they transition to adulthood. The NLTS2, funded by the National Center for Special

Education Research at the Institute of Education Sciences, includes a nationally representative sample of youth receiving special education services under the IDEA.

The NLTS2 is a longitudinal dataset and includes five waves of data collection. Data collection began in school year 2000/2001 (wave 1) when participants were aged 13-17 years and in grade 7 or above and was repeated in school years 2002/2003 (wave 2), 2004/2005 (wave 3), 2006/2007 (wave 4) and 2008/2009 (wave 5), when participants were aged 21-25 years. Data were collected through a variety of sources, including a parent/young person phone interview or mail survey, a school survey, and a young person assessment on a range of experiences and outcomes. These included youth characteristics, household characteristics, school characteristics, school programs, access to services, family involvement, results in school, adult services and supports, and results after secondary school.

Variables

We identified individuals with intellectual disabilities using responses to the following question from parent phone interview and/or mail survey: '[YOUTH] is included in this study because [his/her] school or school district indicated at the beginning of the 2000 school year that [he/she] may have received special education services and had an Individual Education Program (IEP). With what physical, sensory, learning or other disabilities or problems has [YOUTH] been diagnosed? Code all that apply.' Respondents answered to each of the following 22 response options: 1) has no problem/disability/not getting special services, 2) asthma, 3) attention deficit disorder/ attention deficit hyperactivity disorder (ADD/ADHD), 4) autism or Asperger's, 5) (blindness) complete blindness, 6) cerebral palsy, 7) deafness, 8) deafness and blindness, 9) Down syndrome, 10) dyslexia, 11) emotional disturbance/behaviour disorder, 12) hard of hearing/hearing impairment, 13) health impairment (specify disease), 14) learning disability, 15) mental retardation, 16) physical or orthopaedic impairment, 17) speech impairment/communication impairment, 18) spina bifida, 19) traumatic brain injury, 20) visual impairment/partial sight, 21) developmental delay, 22) other (specify).

For the purpose of this study we interpreted responses to options 9) Down Syndrome and 15) mental retardation, as relating to people with intellectual disabilities and derived the categories of 'intellectual disabilities without Down syndrome', 'Down syndrome' and 'intellectual disabilities' the latter of which included people both with and without Down syndrome. Responses relating to response option 21) developmental delay were excluded from 'intellectual disabilities' since this term is normally used in the USA in reference to young children under the age of 5 and is not directly synonymous with intellectual disabilities.

Data on parent-rated health of youth with and without intellectual disabilities were obtained from responses to the following question: 'Would you say [his/her] general health is: 1) excellent, 2) very good, 3) good, 4) fair, 5) poor'.

Data on ethnicity were obtained from responses to the following question: 'Please choose one or more categories that best describe [youth's] race: 1) White, 2) African American or Black, 3) American Indian or Alaska Native, 4) Asian, 5) Native Hawaiian, or Other Pacific Islander, 6) other (specify). During the original data coding process, categories 4 and 5 were collapsed into 'Asian/Other Pacific Islander', an additional category of 'Hispanic, Latino or Spanish' was derived and a multi-racial background was coded under the category of 'Multi/Other'. We used the same orderding of categories in our analysis.

Data on family circumstances of the youth with intellectual disabilities were obtained from responses to questions on marital status of parent/legal guardian of youth, and household income. The question on marital status included the following response options: 'Are you/is she/is he/are they/are [YOUTH's parents]? 1) married, 2) in a marriage-like relationship, 3) divorced, 4) separated, 5) widowed, 6) single, never married, or 7) other'. We collapsed these categories to married/in a marriage like relationship, divorced/separated/widowed, single/never married, and other.

The question on household income was phrased as follows: 'Please tell me which group best describes the total income of all persons in your household in the last tax year, including salaries or other earnings, money from public assistance, retirement, and so on, for all household members, before taxes: 1) $5,000 or less, 2) $5,001 to $10,000, 3) $10,001 to $15,000, 4) $15,001 to $20,000, 5) $20,001 to $25,000, 6) $25,001 to $30,000, 7) $30,001 to $35,000, 8) $35,001 to $40,000, 9) $40,001 to $45,000, 10) $45,001 to $50,000, 11) $50,001 to $55,000, 12) $55,001 to $60,000, 13) $60,001 to $65,000, 14) $65,001 to $70,000, 15) $70,001 to $75,000, or 16) over $ 75,000?'. We collapsed these categories to $10,000 or less, $10,001-$30,000, $30,001-$50,000, $50,001-$70,000 and $70,001 or more.

Data analysis

We summarised the numbers and percentages of youth with intellectual disabilities with and without Down syndrome, and their sex, ethnicity, comorbidities, family income, and parental/guardian relationships at wave 1. We then summarised the number and percentage of youth with intellectual disabilities with and without Down syndrome reporting excellent, very good, good, fair, and poor health across all waves of data collection in order to investigate trends in general health status over the transitional period. We identified youth at wave 1 who had general health status recorded at all five waves of data collection, and plotted changes in general health status across the developmental period for all youth with intellectual disabilities, and separately for those with and without Down syndrome.

We investigated whether wave of data collection, age, sex, ethnicity, Down syndrome, parental/guardian relationship status, and household income were associated with general health status (excellent, very good, good, fair, and poor) using random-effects ordered logistic regression models to adjust for correlations between observations repeated on the same people across different waves (Twisk 2013). In order to further investigate whether the association between co-existing Down syndrome and health status changed over the transition period, we included an interaction term

between Down syndrome and wave and intended to perform subgroup analyses if significant. All analyses were conducted in STATA software version MP 16.1.

Where data were missing on a record of intellectual disabilities or Down syndrome at subsequent waves, we imputed the record from wave 1 where data were available for all 871 observations. Information on age was missing for 1 observation at wave 1 where we imputed the middle value of 15 years old. For the remaining waves, we imputed the missing data on age using the formula of 'age at wave 1 + 2' for age at wave 2, 'age at wave 1 + 4' for age at wave 3, 'age at wave 1 + 6' for age at wave 4 and 'age at wave 1 + 8' for age at wave 5, as each wave of data collection was conducted with a two year interval. Data on sex and ethnicity were available for all 871 observations at wave 1, so for waves 2-5 we imputed the records from wave 1. Information on parental marital status had 34 missing records at wave 1, so we randomly assigned one of the four categories of parental marital status. For waves 2 and 3, we set marital status as recorded at the previous wave. For waves 4 and wave 5, data on marital status were missing entirely, so we imputed the data recorded at wave 3. Information on household income and health was imputed using multiple imputation by chained equations (MICE) using the mi package in STATA. We used MICE for health status and household income only because these two variables were the only ones where the values could potentially change over time, i.e. intellectual disability, Down syndrome, sex and ethnicity do not change across waves and age was incremented by 2 given the regular intervals in the data collection process. Marital status could not be imputed using MICE because data were completely missing for waves 4 and 5 for this variable (Appendix 1).

Results

At wave 1, data on whether or not the young person had intellectual disabilities were available on 9,008/9,576 (94.1%) young people; at wave 2, for 6,722/9,576 (70.2%); at wave 3, for 5,532/9,576 (57.8%); at wave 4, for 3,830/9,576 (40.0%); and at wave 5, for 5,300/9,576 (55.3%) young people. At wave 1, 871/9,008 (9.7%) young people were recorded to have intellectual disabilities of whom 125/871 (14.4%) had Down syndrome; at wave 2, 679/6,722 (10.1%) of whom 105/679 (15.5%) had Down syndrome; at wave 3, 576/5,532 (10.4%) of whom 92/576 (16.0%) had Down syndrome; at wave 4, 580/3,830 (15.1%) of whom 95/580 (16.4%) had Down syndrome; and at wave 5, 555/5,300 (10.5%) of whom 91/555 (16.4%) had Down syndrome. All the youth recorded to have Down syndrome were recorded to have 'mental retardation'.

Participant characteristics

Table 1 shows sex, ethnicity, comorbidities, parental/guardian relationship, and family income, and parental/guardian relationship at wave 1, for all the youth with intellectual disabilities, and separately for those with and without Down syndrome. As expected, there was a similar proportion of females and males in youth with Down syndrome, but more males than females in youth with intellectual disabilities without Down syndrome. A higher proportion of youth with Down syndrome was white and a lower proportion African American, than in the youth with intellectual disabilities without Down syndrome. The youth with Down syndrome had lower rates of all comorbidities except deafness, hard of

hearing/hearing impairment, deafness and blindness, and speech/communication problem, than youth with intellectual disabilities without Down syndrome. Youth with Down syndrome were more likely to have parents who were married/in a marriage like relationship, and to have a higher total household income, than youth with intellectual disabilities without Down syndrome.

-Insert Table 1-

Parent-rated general health status

The youth with intellectual disabilities had bad health. When separated into the youth with Down syndrome, and the youth with intellectual disabilities but without Down syndrome, both groups had bad health. For all the youth with intellectual disabilities, across waves 1-5, there was a shallow gradient in the proportion reporting excellent/very good health, with fewer doing so with increasing age over the transition period, from 57.7% at ages 13-17 years to 52.6% at ages 21-25 years. This finding was predominantly due to the health of youth with intellectual disabilities without Down syndrome. Regarding specifically excellent health, for all the youth with intellectual disabilities, 29.8% reported excellent health at ages 13-17 years, declining to 20.0% at ages 21-25 years. 30.4% of youth with intellectual disabilities without Down syndrome reported excellent health at ages 13-17 years, declining to 20.4% at ages 21-25 years. (Table 2).

-Insert Table 2-

Three hundred and thirty-two young people with intellectual disabilities had a record of parent-rated general health status at all five waves of data collection; 61 with Down syndrome and 271 without Down syndrome. Figures 1-3 show their general health status across the transition period. For those without Down syndrome, the proportion with excellent health appeared to decline across time.

-Insert Figures 1-3-

Results from a random-effects ordered logistic regression model on all 871 young people with intellectual disabilities are shown in Table 3. Wave was not significantly associated with general health status, and nor were age, sex, Down syndrome, and parental/guardian relationship status. There was a gradient with higher income associated with better health, significantly so over $50,001 (OR=0.559, 95% CI 0.366-0.854), and poorer health was experienced by youth with Hispanic, Latino or Spanish ethnicity (OR=1.790, 95% CI 1.051-3.048) over this transition period. When we further investigated whether the association between having/not having Down syndrome and health status changed over the transition period, we found that the interaction term between Down syndrome and wave was not statistically significant.

-Insert Table 3-

Discussion

Summary of principal findings

Youth with intellectual disabilities, with or without Down syndrome have bad general health, with low rates of excellent or very good health. However, contrary to our expectations, longitudinally, an ordinal measure of general health status did not decline over this transitional period, and did not differ between the youth with, versus without, Down syndrome. Our hypothesis was correct that lower income is associated with poorer health in emerging adulthood, as is Hispanic, Latino or Spanish ethnicity. Female sex, and parental relationship status was not associated with health status. Longitudinally, there appeared to be a gradient in the proportion reporting excellent health, with fewer doing so with increasing age over the transition period, but the regressions within which health was entered as an ordinal variable were not statistically significant.

We do not know why transition was not statistically associated with decline in general health status, but speculate that the disadvantage in having intellectual disabilities in terms of allostatic load indices (Carmelli et al. 2012) is overwhelming in comparison to the biological changes in puberty.

Comparison with existing literature

We are not aware of any other longitudinal studies of general health status in young people with intellectual disabilities over the transition period with which to draw comparisons, or cross-sectional studies comparing health of young people with intellectual disabilities with and without Down syndrome. The rates of fair/poor health we found in this USA cohort are lower than those reported in Scotland (Young-Southward et al. 2017b; Hughes-McCormack et al. 2018). Young-Southward et al. (2017b) also reported that females with intellectual disabilities were more likely to have poor health than males with intellectual disabilities, unlike in our study. However, these two cross-sectional studies are not directly comparable with our data, due to the different age ranges, categories used to describe general health status, and country of origin.

Implications

Young people with intellectual disabilities have bad general health, and so require support across all ages, including transition, and consideration of their ethnicity and personal circumstances. Consideration of health, health care, and health support during transitional planning is needed for health problems, due to changes in the services being accessed in transition. This is important for schools, teachers, and staff in transitional services to recognise. Importantly, studies on support interventions for stressful circumstances can reduce accumulated allostatic load which is a mechanism underpinning bad health (McEwen & Gianoros 2010), and low household income is a stressor. This warrants investigation with youth with intellectual disabilities in comparison with other youth as it could provide evidence to support policy change to the advantage of people with intellectual disabilities. This is important as interventions based on provision of greater support can prevent adverse consequences.

Strengths and limitations of the study

The NLTS2 provides a large scale, unique source of 10-year longitudinal information on experiences of pupils with disabilities from a nationally representative sample of secondary school students receiving special education services in grade 7 or above, as they transition through to their early adult years. We consider that findings can be generalised to other youth with intellectual disabilities. Data on health were reported by parents of the young people via either a telephone interview or a self-administered mail survey, which represent subjective reports rather than objective measurements. Data from proxy general health reports requires consideration. It is important to note that without them, we would have no information on youth unable to self-report due to severe/profound intellectual disabilities, and proxy-reporting is the basis for much of the healthcare provided for people with intellectual disabilities who cannot self-report. Causes of general inaccuracies have been described in both self and proxy reports on general health, with the conclusion that overall, proxy reports are a useful addition to determine aspects of wellbeing in people with intellectual disabilities when the need arises (Perkins 2007). Recently published studies with other datasets have also used self/proxy-reported general health status among children and young people with intellectual disabilities (Emerson & Hatton 2007a; Emerson & Hatton 2007b; Young-Southward et al. 2017a; Hughes-McCormack et al. 2018). There was no comparison group without special educational needs in the NLTS2 dataset.

References:

Andersen S.L., Tomada A., Vincow E.S., Valente E., Polcari A. & Teicher M.H. (2008). Preliminary evidence for sensitive periods in the effect of childhood sexual abuse on regional brain development. Journal of Neuropsychiatry and Clinical Neuroscience **20,** 292–301.

Arnett J. J. (2014). Emerging Adulthood: The Winding Road from the Late Teens Through the Twenties. 2nd ed. Oxford: Oxford University Press.

Bourke J., Nembhard W.N., Wong K. & Leonard H. (2017). Twenty-five-year survival of children with intellectual disability in Western Australia. Journal of Pediatrics **188**, 232-239.

Burnstrom B. & Fredlund P. (2001). Self-rated health: is it as good a predictor of subsequent mortality among adults in lower as well as in higher social classes? Journal of Epidemiology and Community Health **55**, 836-840.

Carmelli E., lmam B., Bachar A. & Merrick J. (2012). Inflammation and oxidative stress as biomarkers of premature aging in persons with intellectual disability. Research in Developmental Disabilities **33,** 369-375.

Cui J. (2007). QIC program and model selection in GEE analyses. Stata Journal **7**, 209-220.

Emerson E. & Hatton C. (2007a). The mental health of children and adolescents with intellectual disabilities in Britain. British Journal of Psychiatry **191**, 493–499.

Emerson E. & Hatton C. (2007b). Contribution of socio-economic position to the health status of children and adolescents with intellectual disabilities in Britain. American Journal of Mental Retardation **112**, 140-150.

Emerson E. & Hatton C. (2007c). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication. Journal of Intellectual Disability Research **51**,866-874.

Einfeid S.L., Ellis L.A. & Emerson E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. Journal of Intellectual and Developmental Disability **36**, 137–143.

Evans G.W. (2003). A multimethodological analysis of cumulative risk and allostatic load among rural children. Developmental Psychology **39**, 924-933.

Evans G.W., Kim P., Ting A.H., Tesher H.B. & Shannis D. (2007). Cumulative risk, maternal responsiveness, and allostatic load among young adolescents. Developmental Psychology **43,** 341–351.

Evans G.W. & Schamberg M.A. (2009). Childhood poverty, chronic stress, and adult working memory. Proceedings of the National Academy of Sciences **106**, 6545–6549.

Gustafsson P.E., Janlert U., Theorell T., Westerlund H. & Hammarström A. (2011). Socioeconomic status over the life course and allostatic load in adulthood: results from the Northern Swedish Cohort. Journal of Epidemiology and Community Health **65**, 986-992.

Heistaro S., Jousilahti P., Lahelma E., Vartiainen E. & Puska P. (2001). Self-rated health and mortality: a long-term prospective study in Eastern Finland. Epidemiology and Community Health, **55**, 227-232.

Hudson B. (2006). Making and missing connections: leaving disability services and the transition from adolescence to adulthood. Disability and Society **21**, 47-60.

Hughes-McCormack L.A., Rydzewska E., Henderson A., MacIntyre C., Rintoul J. & Cooper S.-A. (2017). Prevalence and general health status of people with intellectual disabilities in Scotland – a total population study. Journal of Epidemiology and Community Health **72**, 78-85.

Hughes-McCormack L.A., Rydzewska E., Henderson A., MacIntyre C., Rintoul J. & Cooper S. (2017). Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population, British Journal of Psychiatry Open **3**, 243-248.

Juster R.P., McEwen B.S. & Lupien S.J. (2009). Allostatic load biomarkers of chronic stress and impact on health and cognition. Neuroscience & Biobehavioral Reviews **35**, 2-16.

Knudsen E.I. (2004). Sensitive periods in the development of the brain and behavior. Journal of Cognitive Neuroscience **16**, 412-25.

Kinnear D., Morrison J., Allan L., Henderson A., Smiley E. & Cooper S-A. (2018) The prevalence of multi-morbidity in a cohort of adults with intellectual disabilities, with and without Down syndrome. *BMJ Open*, **0**:e018292.

Lipkin, P. H. & Okamoto, J., Council on Children with Disabilities & Council on School Health. (2015). The individuals with disabilities education act (IDEA) for children with special educational needs. Pediatrics **136**, e1650-e1662.

McEwen B.S. & Gianaros P.J. (2010). Central role of the brain in stress and adaptation: links to socioeconomic status, health, and disease. Annals of the New York Academy of Sciences **1186**, 190-222.

Miilunpalo S., Vuori I., Oja P., Pasanen M. & Urponen H. (1997). Self-rated health status as a health measure: the predictive value of self-reported health status on the use of physician services and on mortality in the working-age population. Journal of Clinical Epidemiology **50**, 517-28.

Oesburg B., Dijkstra G.J., Groothoff J.W., Reijneveld S.A. & Jansen D.E. (2011). Prevalence of chronic health conditions in children with intellectual disability: a systematic literature review. Intellectual and Developmental Disabilities **49**, 59-85.

Perkins E. A. (2007). Self- and proxy reports across three populations: older adults, persons with Alzheimer's disease, and persons with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities **4**, 1-10.

Rice D. & Barone S. Jr. (2000). Critical periods of vulnerability for the developing nervous system: evidence from humans and animal models. Environmental Health Perspectives **108 Suppl 3,** 511-33.

Schnittker J. & Bacak V. (2014). The increasing predictive validity of self-rated health. PLoS ONE **9**, e84933.

Seeman T.E., McEwen B.S., Rowe J.W. & Singer B.H. (2001). Allostatic load as a marker of cumulative biological risk: MacArthur studies of successful aging. Proceedings of the National Academy of Sciences of the United States of America NAS **98**, 4770-4775.

Twisk J.W. (2013). Applied longitudinal data analysis for epidemiology: a practical guide. Cambridge University Press.

Young-Southward G., Rydzewska E., Philo C. & Cooper, S.-A. (2017a). Physical and mental health of young people with and without intellectual disabilities: cross-sectional analysis of a whole country population. Journal of Intellectual Disability Research **61**, 984-993.

Young-Southward G., Philo C. & Cooper S.-A. (2017b). What effect does transition have on health and well-being in young people with intellectual disabilities? A systematic review. Journal of Applied Research in Intellectual Disabilities **30**, 805-823.

Table 1. Demographic characteristics of young people with intellectual disabilities with and without Down syndrome at wave 1

	All youth with intellectual disabilities N=871 (100%)	Youth with intellectual disabilities and Down syndrome N=125 (100%)	Youth with intellectual disabilities without Down syndrome N=746 (100%)
Gender			
Male	513 (58.9%)	61 (48.8%)	452 (60.6%)
Female	358 (41.1%)	64 (51.2%)	294 (39.4%)
Ethnicity			
White	527 (60.5%)	84 (67.2%)	443 (59.4%)
African American	156 (17.9%)	16 (12.8%)	140 (18.8%)
Hispanic, Latino or Spanish	150 (17.2%)	22 (17.6%)	128 (17.2%)
Asian/Pacific Islander	25 (2.9%)	1 (0.8%)	24 (3.2%)
American Indian/Alaska Native	10 (1.1%)	2 (1.6%)	8 (1.1%)
Multi/Other	3 (0.3%)	<3	3 (0.4%)
Comorbidities			
Autism	133 (15.3%)	<3	133 (17.8%)
Blindness	78 (9.0%)	3 (2.4%)	75 (10.1%)
Visual impairment/partial sight loss	137 (15.7%)	9 (7.2%)	128 (17.2%)
Deafness	25 (2.9%)	<3	23 (3.1%)
Hard of hearing/hearing impairment	71 (8.2%)	10 (8.0%)	61 (8.2%)
Deafness and blindness	6 (0.7%)	<3	5 (0.7%)
Asthma	18 (2.1%)	<3	17 (2.3%)
Cerebral palsy	127 (14.6%)	<3	125 (16.8%)
Spina bifida	4 (0.5%)	<3	4 (0.5%)
Traumatic brain injury	19 (2.2%)	<3	19 (2.5%)
Health impairment	301 (34.6%)	20 (16.0%)	281 (37.7%)
Physical or orthopaedic impairment	215 (24.7%)	8 (6.4%)	207 (27.7%)
Emotional disturbance or behaviour disorder	49 (5.6%)	3 (2.4%)	46 (6.2%)
Developmental delay	54 (6.2%)	<3	52 (7.0%)
Speech/communication impairment	138 (15.8%)	20 (16.0%)	118 (15.8%)
Dyslexia	3 (0.3%)	<3	3 (0.4%)
Learning difficulties	116 (13.3%)	5 (4.0%)	111 (14.9%)
ADD/ADHD	210 (24.1%)	8 (6.4%)	202 (27.1%)
Multiple disabilities	22 (2.5%)	<3	20 (2.7%)
Other	215 (24.7%)	14 (11.2%)	201 (26.9%)

Marital status of parent/legal guardian[1]			
Married/in a marriage like relationship	573 (68.5%)	90 (75.6%)	483 (67.3%)
Divorced/separated/widowed	185 (22.1%)	17 (14.3%)	168 (23.4%)
Single/never married	77 (9.2%)	11 (9.2%)	66 (9.2%)
Other	<3	<3	<3
Total household income[2]			
$10,000 or less	65 (9.0%)	5 (5.1%)	60 (9.7%)
$10,001-$30,000	237 (33.0%)	21 (21.2%)	216 (34.8%)
$30,001-$50,000	165 (22.9%)	24 (24.2%)	141 (22.7%)
$50,001-$70,000	121 (16.8%)	19 (19.2%)	102 (16.5%)
$70,001 or more	131 (18.2%)	30 (30.3%)	101 (16.3%)

Cell size <3 suppressed due to statistical disclosure

[1] 837 responses for all youth with intellectual disabilities (34 responses missing), 119 for youth with Down syndrome (6 responses missing) and 718 for youth with intellectual disabilities without Down syndrome (28 responses missing)

[2] 719 responses for all youth with intellectual disabilities (152 responses missing), 99 for youth with Down syndrome (26 responses missing) and 620 for youth with intellectual disabilities without Down syndrome (126 responses missing)

Table 2. General health status of young people with intellectual disabilities with and without Down syndrome

General health status	Wave 1 Aged 13 -17 years	Wave 2 Aged 15-19 years	Wave 3 Aged 17-21 years	Wave 4 Aged 19-23 years	Wave 5 Aged 21-25 years
All youth with intellectual disabilities					
Excellent	248 (29.8%)	177 (26.1%)	137 (24.6%)	124 (24.5%)	98 (20.0%)
Very good	232 (27.9%)	201 (29.7%)	183 (32.9%)	164 (32.3%)	159 (32.5%)
Good	227 (27.3%)	192 (28.4%)	143 (25.7%)	146 (28.8%)	146 (29.9%)
Fair	100 (12.0%)	82 (12.1%)	70 (12.6%)	59 (11.6%)	67 (13.7%)
Poor	25 (3.0%)	25 (3.7%)	23 (4.1%)	14 (2.8%)	19 (3.9%)
Excellent/very good combined	480 (57.7%)	378 (55.8%)	320 (57.6%)	288 (56.8%)	257 (52.6%)
Total	832 (100.0%)	677 (100.0%)	556 (100.0%)	507 (100.0%)	489 (100.0%)
Youth with Down syndrome					
Excellent	31 (26.1%)	24 (23.5%)	20 (22.7%)	24 (28.9%)	16 (19.3%)
Very good	37 (31.1%)	37 (36.3%)	34 (38.6%)	32 (38.6%)	31 (37.3%)
Good	36 (30.3%)	29 (28.4%)	19 (21.6%)	17 (20.5%)	24 (28.9%)
Fair	10 (8.4%)	9 (8.8%)	10 (11.4%)	10 (12.0%)*	8 (9.6%)
Poor	5 (4.2%)	3 (2.9%)	5 (5.7%)		4 (4.8%)
Excellent/very good combined	68 (57.1%)	61 (59.8%)	54 (61.4%)	56 (67.5%)	47 (56.6%)
Total	119 (100.0%)	102 (100.0%)	88 (100.0%)	83 (100.0%)	83 (100%)
Youth with intellectual disabilities without Down syndrome					
Excellent	217 (30.4%)	150 (27.0%)	114 (25.1%)	98 (24.0%)	80 (20.4%)
Very good	195 (27.3%)	160 (28.8%)	144 (31.7%)	126 (30.8%)	123 (31.4%)
Good	191 (26.8%)	153 (27.5%)	119 (26.2%)	124 (30.3%)	117 (29.8%)
Fair	90 (12.6%)	71 (12.8%)	59 (13.0%)	49 (12.0%)	57 (14.5%)
Poor	20 (2.8%)	22 (4.0%)	18 (4.0%)	12 (2.9%)	15 (3.8%)
Excellent/very good combined	412 (57.8%)	310 (55.8%)	258 (56.8%)	224 (54.8%)	203 (51.8%)
Total	713 (100.0%)	556 (100.0%)	454 (100.0%)	409 (100.0%)	392 (100.0%)

*Cells combined to avoid statistical disclosure

Table 3. The longitudinal effect of individual waves, age, sex, Down syndrome, ethnicity, parental/guardian relationship status, and household income in predicting health in the whole population with intellectual disabilities

Variable	Odds Ratio	Std.Err.	t	P>|t|	95% CI
Wave					
1	ref	ref	ref	ref	ref
2	1.280	0.171	1.45	0.149	0.915-1.790
3	1.437	0.299	1.21	0.225	0.800-2.582
4	1.378	0.455	0.70	0.482	0.563-3.372
5	1.902	0.602	1.07	0.286	0.582-6.209
Age	1.001	0.074	0.02	0.986	0.865-1.159
Sex					
Male	ref	ref	ref	ref	ref
Female	0.764	0.178	-1.51	0.130	0.540-1.083
Down syndrome					
No	ref	ref	ref	ref	ref
Yes	0.862	0.265	-0.56	0.574	0.512-1.450
Ethnicity					
White	ref	ref	ref	ref	ref
African American	0.979	0.251	-0.08	0.933	0.598-1.602
Hispanic, Latino or Spanish	1.790	0.271	2.15	0.032	1.051-3.048
Asian/Pacific Islander	1.318	0.521	0.53	0.597	0.474-3.661
American Indian/Alaska Native	4.038	0.858	1.63	0.105	0.747-21.825
Multi/Other ethnicity	0.171	1.455	-1.21	0.225	0.010-2.969
Marital status of parent/legal guardian					
Married/in a marriage like relationship	ref	ref	ref	ref	ref
Divorced/separated/widowed	0.976	0.222	-0.11	0.913	0.631-1.510
Single/never married	1.052	0.316	0.16	0.874	0.565-1.956
Other parental relationship status	1.856	0.873	0.71	0.480	0.332-10.357
Total household income					
$10,000 or less	ref	ref	ref	ref	ref
$10,001-$30,000	0.799	0.177	-1.27	0.209	0.562-1.136
$30,001-$50,000	0.660	0.183	-2.27	0.024	0.460-0.946
$50,001-$70,000	0.559	0.215	-2.71	0.007	0.366-0.854
$70,001 or more	0.556	0.264	-2.22	0.028	0.330-0.937

Figure 1. Health of all youth with intellectual disabilities identified at Wave 1 and followed across Waves 1-5

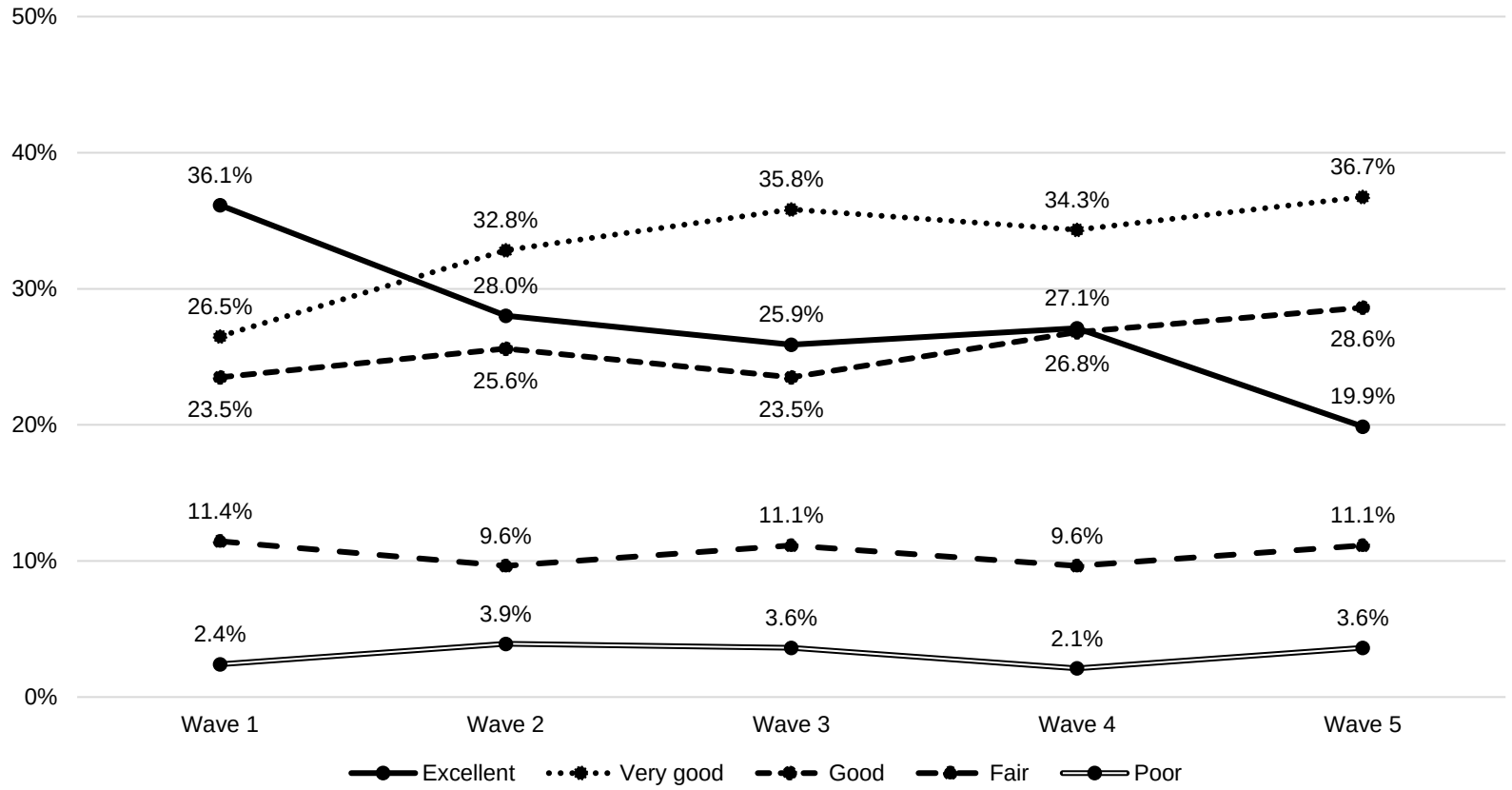


Figure 2. Health of youth with Down syndrome identified at Wave 1 and followed across Waves 1-5

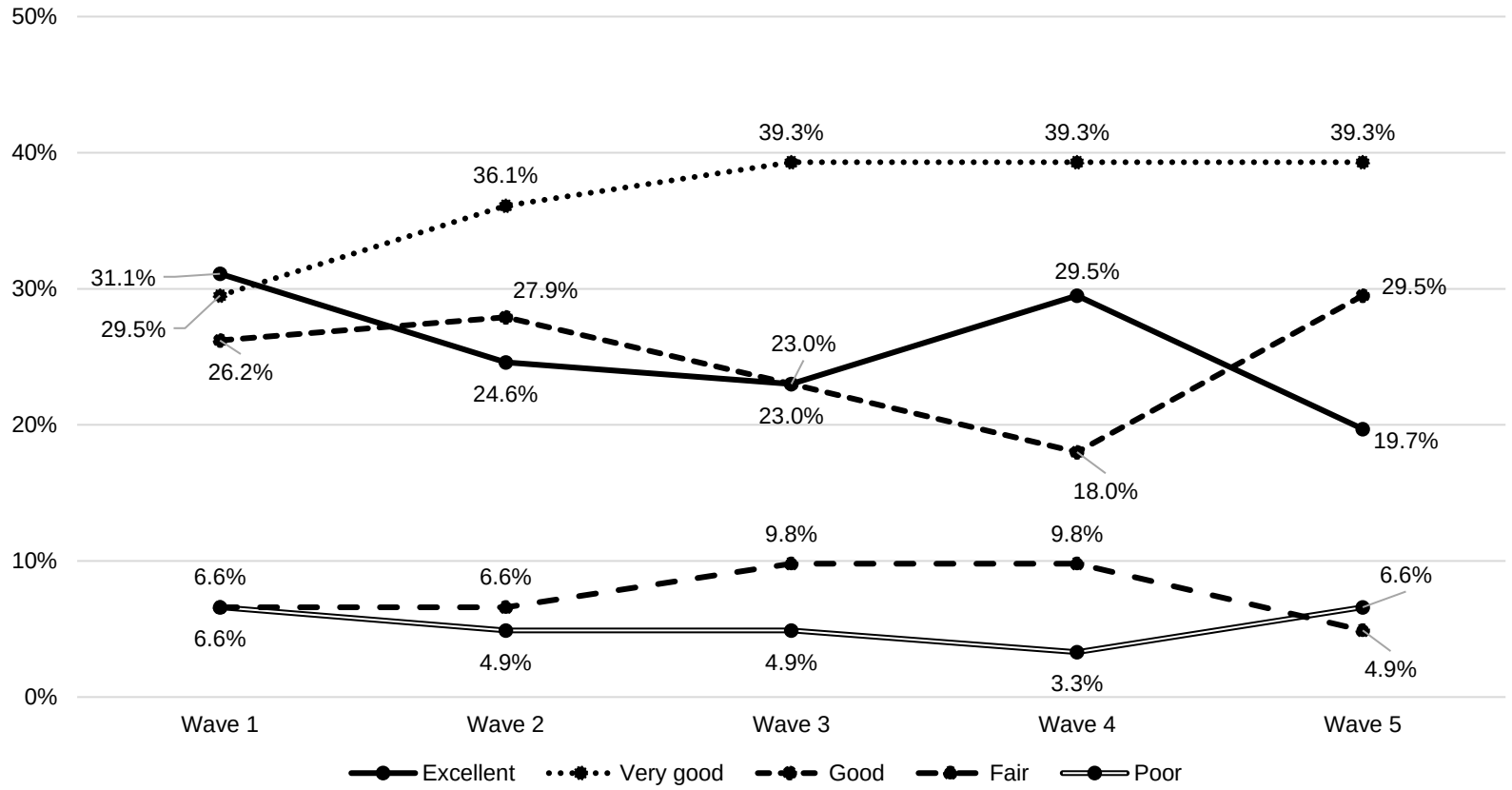
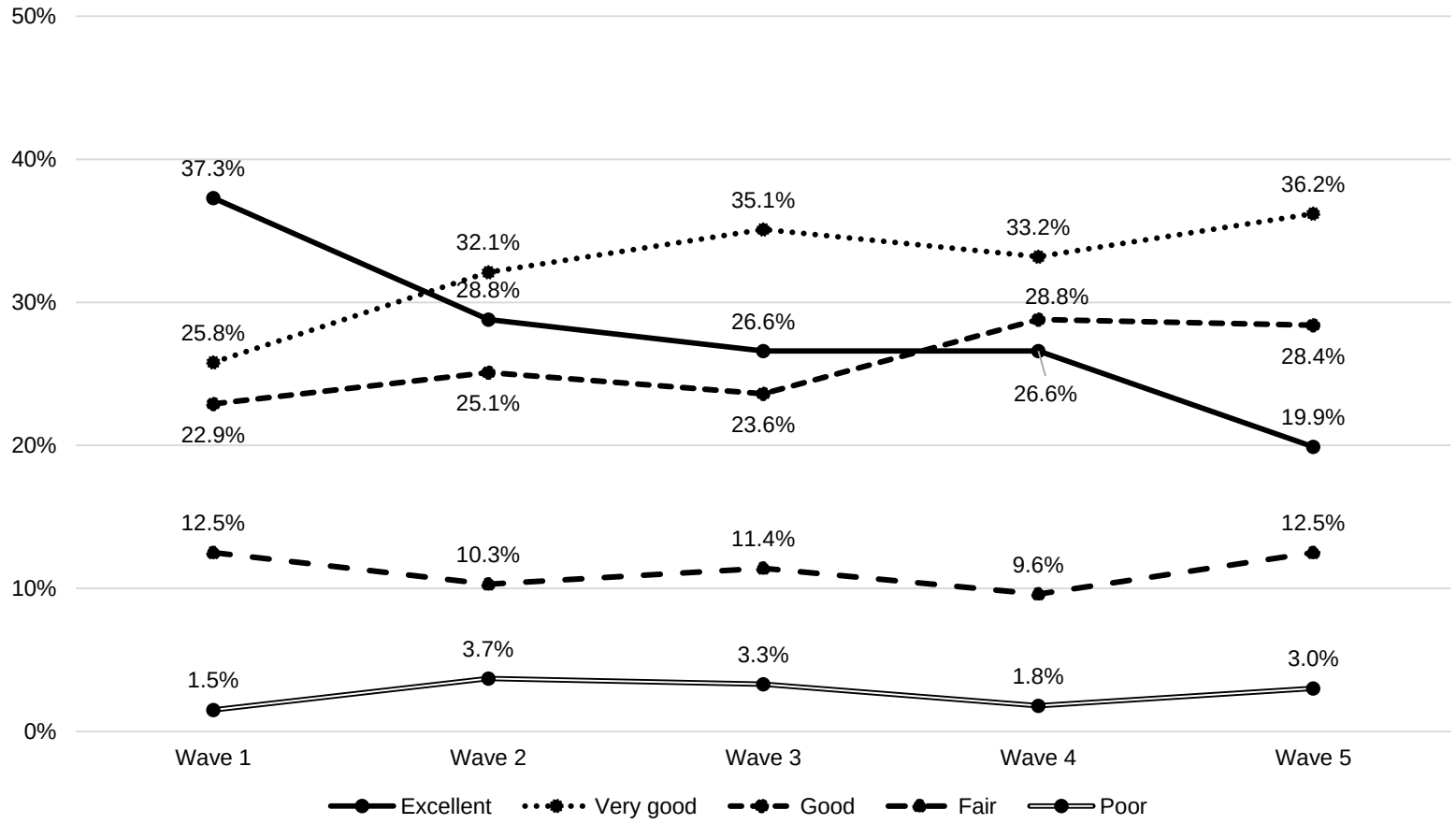


Figure 3. Health of youth with intellectual disabilities without Down syndrome identified at Wave 1 and followed across Waves 1-5



Appendix 1. Number of observations missing across waves 1-5

Variable	Wave 1 (n)	Wave 2 (n)	Wave 3 (n)	Wave 4 (n)	Wave 5 (n)
Intellectual disabilities	0	211	310	308	332
Down syndrome	0	211	310	308	332
Age	1	211	310	308	332
Sex	0	211	340	308	871
Ethnicity	0	211	871	871	871
Parental marital status	34	227	353	871	871
Household income	152	321	364	431	447
Health	39	213	310	308	332