Symposium Title: Health and Care Outcomes for Children and Young People with Intellectual Disabilities

Chair: Deborah Kinnear

Overview: People with intellectual disabilities experience considerable inequalities, dying up to 20 years earlier than people in the general population and experiencing high rates of physical and mental illness. However, there are few large-scale studies investigating the health and care of children and younger people with intellectual disabilities. This symposium presents results from a programme of research investigating the health of children and young people with intellectual disabilities, using routinely collected data from Scotland and America. We will present analysis of data from the National Longitudinal Transition Study-2 in the US which investigates the risk of poor health and medication use. We will then present analysis of linked data from Scotland which investigates birth rates and outcomes for children with Down syndrome. The final paper reports analysis of linked data from all Scottish school pupils to investigate rates of psychotropic prescribing in children and young people with intellectual disabilities and with autism.

Paper 1 of 3

Paper Title: General Health Status and Medication Use in Young People with Intellectual Disabilities in, and Transitioning from, Special Education. Findings from the National Longitudinal Transitions Study-2 (NLTS2)

Authors: Ewelina Rydzewska¹, Genevieve Young-Southward¹, Jan Blacher², Yasamine Bolourian², Keith Widaman², & Sally-Ann Cooper¹

Introduction: Despite concerns about rising treatment of young people with prescription medications (e.g. Olfson et al., 2015; Sultan et al., 2018), little is known about trends and patterns of their use in the population with intellectual disabilities. Additionally, there has been little prior investigation of the general health of young people with intellectual disabilities during transition (Young-Southward et al., 2017a; Young-Southward et al., 2017b).

Methods: The National Longitudinal Transition Study-2 (NLTS2), funded by the National Center for Special Education Research at the Institute of Education Sciences, U.S. Department of Education, includes a nationally representative sample of 9,576 youth aged 13 through 16 and receiving special education services in grade 7 or above under the Individuals With Disabilities Education Act (IDEA). The NLTS2 data were collected on sample members from multiple sources in five waves, in 2001, 2003, 2005, 2007, and 2009. We used the information from parent phone interview and/or mail survey at Wave 2 to identify the individuals with intellectual disabilities. We investigated descriptive statistics, and odds ratios (OR) with 95% confidence intervals (CI), of intellectual disabilities regarding 1) proxy-rated general health status, 2) medication use for attention, behaviour, activity level or mood.

Results: At Wave 2, data on whether or not the young person had intellectual disabilities were available on 6,722/9,576 (70.2%) of the young people. 679/6,722 (10.1%) young people were recorded to have intellectual disabilities; 574 (8.5%) had intellectual disabilities, and 105 (1.6%) had intellectual disabilities and Down syndrome.

For the young people identified to have intellectual disabilities at Wave 2, across Waves 1-5, 15.0%, 15.8%, 16.8%, 13.8% and 16.8% of their carers rated their child’s health as fair or poor compared with 9.3%, 10.6%, 11.3%, 11.9% and 13.8% of parents of children receiving special education services but without intellectual disabilities. Across Waves 1-5, intellectual disabilities had an OR=1.703 (1.345-2.156), OR=1.564 (1.251-1.955), OR=1.546 (1.205-1.982), OR=1.173 (0.886-1.554) and OR=1.239 (0.946-1.623) for predicting fair/poor health.
Across Waves 1-4, 28.2%, 28.7%, 27.2% and 28.0% of young people with intellectual disabilities were recorded to take medication for attention, behaviour, activity level or mood compared with 24.7%, 21.6%, 20.8% and 18.8% of young people receiving special education services but without intellectual disabilities. Across Waves 1-4, intellectual disabilities had an OR=1.244 (1.034-1.498), OR=1.496 (1.250-1.791), OR=1.445 (1.175-1.778), and OR=1.695 (1.363-2.109) for predicting medication use (data not available for Wave 5).

**Discussion:** Young people with intellectual disabilities were more likely to experience poor health and be in receipt of prescription medication for attention, behaviour, activity level or mood than their peers without intellectual disabilities, but using special educational services.

**References/Citations:**

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1 University of Glasgow
2 University of California, Riverside

**Paper Title:** Birth Prevalence and Hospitalisation Rates of Children and Young People with Down Syndrome in Scotland 1990-2015: A Birth Cohort Study

**Authors:** Laura Hughes-McCormack, 1 Ruth McGowan, 1 Jill Pell, 1 Daniel McKay, 1 Angela Henderson, 1 Lisa O’Leary, 2 Sally-Ann Cooper 1

**Introduction:** Improvements in healthcare and attitudes to disability over time have contributed to increase the live birth prevalence and survival of people with Down syndrome (Jacobs et al, 2016). Given this, alongside a limited evidence base, a better understanding of the population size and health care needs of people with Down syndrome is crucial.

**Methods:** All live-births with Down syndrome, 1990-2015, identified via Scottish regional cytogenetic laboratories, were each age-gender-neighbourhood deprivation matched with 5 non-Down syndrome controls, using Scotland’s unique NHS identifiers (CHI). Record-linkage was undertaken to routinely collected hospital statistics data (Scottish Morbidity Records 01), and National Records of Scotland death data. Time to event analysis (cox regressions) was undertaken to compare time to first hospitalisation and rate of readmission to hospital, and linear regression was undertaken to compare length of hospital stay between the children/ young people with and without Down syndrome by estimating Hazard Ratios (HR)/Beta (B) (with 95% confidence intervals), accounting for age at first admission, gender, neighbourhood deprivation and discharge type.

**Results:** 1,458 children and young people with Down syndrome were identified, 689 females (47.3%) and 769 males (52.7%). Prevalence of Down syndrome births were variable over time but lowest during the early 1990’s (0.06%-0.10%), peaking around
2004-2005 (0.12%-0.15%) and becoming more stable from 2005-2015 (0.10%-0.12%). In total, 96 (6.6%) people with Down syndrome had died compared to 23 (0.4%) without Down syndrome.

Total admissions were higher (n=10,563) for people with Down syndrome with an incidence rate of 759.4 admissions per 1000-person years compared to controls (n=8,802) with an incidence rate of 194.5 admissions per 1000-person years. People with Down syndrome had been admitted to hospital at least once (n=1,162, 78.5%), more often when compared to controls (n=3,362, 52.1%) (HR=1.7, 1.6-1.8). The mean duration of first admission was significantly longer for people with Down syndrome (4.80 days, SD=11.69) compared to controls (1.30 days, SD=3.64) (B=3.50, 3.06-3.95). Readmission rates were higher (n=988, 66.8%) for people with Down syndrome compared to 1,700 (26.3%) of controls (HR=1.8, 1.7-2.0).

Top admission causes among people with Down syndrome were congenital (n=2,441, 23.1%), respiratory (n=2,352, 22.3%), abnormal symptoms/signs (n=995, 9.4%) and digestive (n=926, 8.8%) compared with controls whose top reasons were congenital (n=1,599, 18.2%), digestive (n=1,385, 15.7%), abnormal symptoms/signs (n=1,159, 13.2%) and injury/poisoning (n=925, 10.5%). Emergency admissions were more common among people with Down syndrome (n=899, 77.6%) compared to controls (n=2,410, 72.0%) (χ²=14.548; df=2; P=0.001). Age at first admission was significantly different with a younger age of first admission (in years) for people with Down syndrome (M=1.07, SD=2.4) compared to controls (M=3.33, SD=4.5) (t(4529)=16.1, p<.001). Gender at first admission was significantly different for both people with Down syndrome and controls. More females experienced at least one admission, compared to males (χ²=345.962; df=1; P<0.001).

Discussion: Children and young people with Down syndrome have high admission rates, highlighting need for family support. Survival of people with Down syndrome is improving: information on health care needs is important for families, and for service planners.

References/Citations:

1 University of Glasgow
2 Edinburgh Napier University

Paper 3 of 3

Paper Title: Antipsychotic, Antidepressant and Attention Deficit Hyperactivity Disorder (ADHD) Drug Prescribing in Children and Young People with Intellectual Disabilities and With Autism in Scottish Schools Compared with Other Children and Young People

Authors: Angela Henderson¹, Deborah Kinnear¹, Bethany Stanley¹, Nicola Greenlaw¹, Michael Fleming¹, Jill Pell¹, Colin McCowan¹, Sally-Ann Cooper²

Introduction: Children and young people with intellectual disabilities and with autism experience mental ill health at rates higher than those for children and young people in the general population (Emerson and Hatton 2007). However, there are few population level studies investigating psychotropic drug use in children and young people with autism and with intellectual disabilities. The aim of this study was to investigate patterns of prescribing of antipsychotics, antidepressants and drugs for ADHD in children and young people with intellectual disabilities and with autism, compared to those in the general population.
Methods: This cohort study comprised all pupils (aged 4-19) attending Scottish primary, secondary and special schools between 2010 and 2013 (>704,000) linked to the Scottish Prescribing Information System. Logistic regression models were used to investigate whether intellectual disabilities, and separately autism, were associated with antidepressant prescribing and ADHD medication use. We also explored whether there were any associations between children being prescribed antipsychotic drugs and our outcomes (anti-depressants/ADHD medications), before extending these models to explore whether any population effects observed differed by antipsychotic drug use.

Results: Children were included in the intellectual disabilities (n=16,142 (2.3%)) cohort if they had two or more records of intellectual disabilities; and in the autism (n=9,061 (1.3%)) cohort if they had two or more records of autism. Children in each cohort were significantly more likely than other children to be prescribed antidepressants, antipsychotics or ADHD medications. 1.2% of children with intellectual disabilities, and 2.6% with autism were prescribed antidepressants compared with 0.7% and 0.6% of other children respectively (Odds Ratio and corresponding 95% Confidence Interval for intellectual disabilities is 1.79 (1.55-2.07) and for autism 4.05 (3.54-4.62)). However, following adjustment for antipsychotic use, intellectual disabilities were not statistically significant in explaining antidepressant use, and the effect of autism was reduced (OR 1.93, 95% CI 1.64-2.25). Children with intellectual disabilities and children with autism taking antipsychotics were significantly less likely to be taking antidepressants than other children who were taking antipsychotics (OR 0.37, 95% CI 0.26-0.52) and (OR 0.46, 95% CI 0.33-0.63) respectively. 5.5% of children with intellectual disabilities, and 9.2% with autism were prescribed drugs for ADHD compared with 0.9% of other children (OR 6.58, 95% CI 6.12-7.07 and OR 11.49, 95% CI 10.65-12.39 respectively). When adjusted for antipsychotic use the effect of both intellectual disabilities and autism were reduced but remained significant (OR 5.62, 95% CI 5.20-6.06 and OR 9.16, 95% CI 8.44-9.93 respectively).

Discussion: Children with intellectual disabilities and children with autism are prescribed antipsychotics, antidepressants and drugs for ADHD at higher rates than other children. However children with intellectual disabilities and children with autism, who are prescribed antipsychotic drugs are less likely than other children, who are prescribed antipsychotics, to also be prescribed antidepressants. This suggests that whilst concern has been expressed that antipsychotics may be over prescribed, conversely antidepressants may be under prescribed for children and young people with intellectual disabilities or with autism.

References/Citations:


1 Univeristy of Glasgow