Symposium Title: Mental Health and Intellectual Disabilities

Chair: Angela Henderson1

Overview: Mental health is an important component of quality of life, and is known to be poorer in people with intellectual disabilities and in people with autism. In this symposium we consider the relative contribution of both intellectual disabilities and autism to the higher rate of mental ill-health found when compared with the rest of the population. We then focus specifically on affective disorders in people with intellectual disabilities, and highlight mania which has been little studied previously in this population. Finally, we consider the wider environmental context of people with intellectual disabilities, by considering the mental health of fathers of people with intellectual disabilities, and reciprocal impact of mental health within families.

Paper 1 of 3

Paper Title: The Relative Influence Of Intellectual Disabilities and Autism on Mental and General Health: A Cross-Sectional Study of a Whole Country of 5.3 Million Children and Adults

Authors: Deborah Kinnear1, Ewelina Rydzewska3, Kirsty Dunn1, Laura Hughes-McCormack1, Craig Melville1, Angela Henderson1 Sally-Ann Cooper1

Introduction: Both intellectual disabilities and autism occur not uncommonly in children and adults, and can co-occur. Children and adults with intellectual disabilities have notably poorer mental and general health than other people (Cooper et al. 2007; Emerson & Hatton, 2007; Hughes-McCormack et al. 2017) and this has also been reported for autistic children and adults (Simonoff et al. 2008; Croen et al. 2015), although the quantity of research is limited, particularly with regards to adults. As intellectual disabilities and autism have tended to be studied separately, the relative extent to which being autistic, or having intellectual disabilities accounts for their poor population health is not clear. This is important to understand, given the frequent co-occurrence of these conditions, and the more recent change in co-occurrence due to higher frequency of diagnosis of autism. The aim of this paper is to study the extent to which autism and intellectual disabilities are independently associated with poor mental and general health, in children and adults.

Methods: Approval was gained from the Scottish Government for secondary analysis of the Scotland Census, 2011 data, and access to a subset of data was provided. Scotland’s Census 2011 may be unique world-wide, as all people with intellectual disabilities and all people with autism across the whole of Scotland can be identified as a result of including a question on ‘intellectual disability’ and ‘autism’. The Census also systematically asked about mental health and general health. Logistic regressions investigated odds of intellectual disabilities and autism predicting mental health conditions, and poor general health, adjusted for age and gender.

Results: Of the children and young people there were 9,396/1,548,819 children/young people with intellectual disabilities, and 25,063/1,548,819 with autism. Of the adults aged 25 years and over there were 16,953/3,746,584 with intellectual disabilities and 6,649/3,746,584 with autism. Both intellectual disabilities (OR=7.0) and autism (OR=25.1) independently increased the odds of having a mental health condition, more so for autism. In adults, a similar pattern was seen with both intellectual disabilities (OR=3.5) and autism (OR=5.3) independently predicting a mental health condition. Both intellectual disabilities (OR=18.3) and autism (OR=8.4) independently increased the odds of having poor general health, more so for intellectual disabilities. In adults, a similar pattern was seen with both intellectual disabilities (OR=7.5) and autism (OR=4.5) independently predicting poor general health.

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Discussion: Due to poor health, sufficient services/supports are needed. This is not just due to co-existence of these conditions, or just to intellectual disabilities, as autism also is associated with substantial health inequalities across the life-course.

References/Citations:

Paper 2 of 3

Paper Title: Incidence of Depression and Mania in Adults with Intellectual Disabilities

Authors: Sally-Ann Cooper1, Elita Smiley2, Linda Allan3, Jill Morrison1

Introduction: Affective disorder is common, and two longitudinal studies suggest depression is more common in adults with mild intellectual disabilities than in other people (Maughan et al, 1999; Collishaw et al, 2004; Richards, et al, 2001) However, these studies included few people with intellectual disabilities, had substantial cohort attrition, biased cohort retention, and did not include people with moderate to profound intellectual disabilities. They did not report findings for mania. In contrast, a large record linkage study reported much lower rates of unipolar depression and similar rates of bipolar affective disorder in people with intellectual disabilities compared with published general population rates, though the data excluded contacts with primary care and private psychiatrists (Morgan et al, 2008). This study aims to describe the incidence of affective disorders in adults with mild to profound intellectual disabilities, compared with that previously reported for the general population, and to determine the factors that predict incident unipolar depressive episode in this population.

Methods: The population with intellectual disabilities aged 16 years and over and living within Greater Glasgow, Scotland, was identified. The adults were recruited into a longitudinal cohort study at the first time point (T1), and underwent detailed mental and physical health assessments conducted by nurses, family physicians and psychiatrists. Demographic and social data were also measured. At the second time-point (T2), two years later, their mental health was reassessed. The incidence of unipolar and bipolar depression and mania was calculated, and standardized incidence ratios (SIR) calculated. Logistic regression analysis was undertaken to determine the odds ratios (OR) of factors predicting incident unipolar depression.

Results: At T2, the potential cohort size was 936, of whom 651 (69.6%) participated; 355 (54.5%) were men and 296 (45.5%) were women. There was no difference between participants and persons for whom consent was not gained at T2, in terms of T1 age, gender, level of intellectual disabilities, type of accommodation/support, or prevalence of mental ill-health. Despite high mood stabilizer use (22.4%), the two-year incidence of mania was much higher than that seen in the general population, at 1.1%. The incidence of first episode of mania was also high at 0.3% (SIR=41.5, or SIR=52.7 excluding Down syndrome). For any bipolar episode, SIR=2.0, or 2.5 excluding Down syndrome. The two year incidence of depression was 7.2%, which is similar to the
general population (SIR=1.2), suggesting depression is more enduring/untreated given its higher prevalence. Problem behaviours (OR=2.3) and life-events (OR=1.3) predicted incident episodes of unipolar depression.

**Discussion:** The much higher incidence of mania in adults with intellectual disabilities has not previously been emphasized. This is important so that this treatable condition is not overlooked in practice, nor confused with problem behaviours nor hyperkinetic disorders which have different treatment indications.

**References/Citations:**

**Paper 3 of 3**

**Paper Title:** The Experience of Caring for a Son or Daughter with Intellectual Disabilities: Older Father Carers’ Perspectives

**Authors:** Kirsty Dunn¹, Andrew Jahoda², Deborah Kinnear ³

**Introduction:** Increased longevity for people with intellectual disabilities has meant that parents are now caring for their children longer than previous generations, and perhaps longer than may have been anticipated at their child’s birth (Minnes & Woodford, 2004). As parent carers move into old age themselves, their own health may impact their ability to care for their child and brings with it fresh challenges and different perspectives on their caregiving role (Chadwick et al 2013). Most research on older parent carers has been conducted with mothers, as they have traditionally been viewed as the main caregiver in the family unit. However, a number of factors make it prudent to include father carers in the discussion. As fathers enter retirement they are more available to assist their partner in caregiving activities, and their partner’s deteriorating health or death may make this alteration necessary. Changing societal attitudes also mean that fathers are now expected to participate more fully in the caring process (Dotti & Treas, 2016). Therefore, it is important to explore the mental health and well-being of older father carers of people with intellectual disabilities. The overarching aim of this study was to better understand how the caregiving experience of older fathers of a son or daughter with intellectual disabilities changes over time, and how caregiving impacts their mental health.

**Methods:** Older father carers were recruited through charities and organisations providing services or supports to people with intellectual disabilities and/or their families in Scotland upon receiving ethical approval. Once contact had been established, interviews were arranged at a time, date and place convenient to the participant. A constructivist methodology was used with the intention of creating a joint understanding, shared by the interviewer and the participant, of each participant’s experiences. Grounded theory (Charmaz, 2000) was used as a method of analysis. Interviews were audio-recorded, with participants’ consent, transcribed, and analysed using constructivist grounded theory analysis. A bottom-up approach to analysis was used to determine which categories and themes arose naturally from the data, rather than having prescribed categories and trying to fit data into these.

**Results:** Semi-structured interviews with 7 older (aged 60+) father carers of a son or daughter with intellectual disabilities were carried out as part of a larger (three-phased) study. Fathers were aged between 61 and 67. All of the fathers were married. Five offspring were diagnosed as having moderate to severe intellectual disabilities in the first few years of their life, while the
remaining two offspring were diagnosed with mild intellectual disabilities. Interviews lasted approximately 60 minutes. Fathers experiences of caring for their child were conceptualized as an ongoing process of ‘making adjustments’ and 8 key themes emerged from the data including: ‘New beginnings’- which captured fathers experiences of becoming not only a parent but a parent of a child with intellectual disabilities; ‘Taking it on’ - where fathers accepted and fought for the needs of their child; ‘Wearing Different hats’- which encompasses the various identities that fathers perceived themselves to have – from father, husband to breadwinner; ‘Caregiving burden’ – which describes caring contributing to putting a financial strain on fathers, which subsequently impacted their mental health, and restricted their social opportunities; ‘Fighting the system’- where services were often poor or unattainable and impacted on their mental health; ‘Being supported’- by family, the community and charitable organisations which positively impacted on fathers mental health; ‘Moving forward’ capturing the impact of ageing on the caregiving role and ‘Father-child relationship’ signifying the unique bond and rewarding relationship between father and child.

**Discussion:** Under current austerity policies within the UK, services for people with intellectual disabilities and their carers continue to be at risk. Given that fathers have identified the resulting service cuts from such policies as the greatest impact on their mental health, it is essential that services and policy makers ensure that adequate provision is available for fathers to protect their mental health and allow them to continue to care for their child with intellectual disabilities.

**References/Citations:**