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## Onset of maternal psychiatric disorders after the birth of a child with intellectual disability: A retrospective cohort study



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#### ABSTRACT

Mothers of a child with intellectual disability (ID) have more psychiatric disorders after the birth of their child than other mothers. However, it is unclear if this is because they have more psychiatric disorders before the birth or if the increase is related to the burden of caring for the child. We aimed to calculate the rate of new psychiatric disorders in mothers after the birth of their eldest child with ID born between 1983 and 2005 and to compare these with rates in women with a child with no ID or autism spectrum disorder (ASD) born during the same period. By linking data from Western Australian population-based registries, we selected women with no psychiatric history who survived the birth of their live-born child (N = 277,559) and compared rates of psychiatric disorders for women with a child with ID and women without a child with or ASD. Negative binomial regression with STATA 12 was used for all analyses. Mothers of children with mild-moderate ID of unknown cause had around two to three and a half times the rate of psychiatric disorders of mothers of children with Down syndrome and no pre-existing psychiatric disorder showed resilience and had no impairments in their mental health. Interventions and services are needed for mothers of other children with ID to improve their mental health. Further research is implicated to explore the mental health of mothers of children with ID and a pre-existing psychiatric disorder.

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#### 1. Introduction

Intellectual disability is diagnosed in people with an IQ of less than 70 and deficits in adaptive functioning which are present before 18 years (American Psychiatric Association, 2000). Children with intellectual disability have more challenging behaviours (Baker et al., 2002), more sleep disorders (Richdale et al., 2000) and more psychopathologies than typically developing children (Emerson, 2003). Their mothers also have increased expenses (Parish and Cloud, 2006) perceive more stigma against themselves or their child (Green, 2007) have lower employment levels (Shearn and Todd, 2000) and less informal and family support (Shearn and Todd, 2000) than other mothers. Therefore, it is not surprising that research has identified poorer mental health in mothers of children with intellectual disability compared to the parents of children with no disabilities (Bourke et al., 2008; Emerson et al., 2010; Olsson and Hwang, 2001).

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In a previous study (Fairthorne et al., submitted for publication), we found that mothers with an outpatient psychiatric history were about twice as likely to have a child with intellectual disability compared to mothers of children with no intellectual disability. We hypothesised that this might be due to shared genetics of the mother and the child with intellectual disability or prenatal use of medication or life-style factors in women with a psychiatric disorder. In the current paper, we wanted to ascertain whether mothers of a child with intellectual disability and no previous psychiatric history were at increased risk of having a psychiatric disorder after the birth of their child. We reasoned that these comparisons would enable us to discern whether the burden of caring for a child with intellectual disability contributed to the increased rate of psychiatric disorders in their mothers. This being so, better informed services and interventions might be instituted with the aim of reducing the burden of these mothers and improving their mental health.

No previous research has attempted to differentiate whether the excess of psychiatric disorders in mothers of children with intellectual disability after the birth of their child is due to the increased burden of caring, a prior disposition to psychiatric disorders or to



increased exposure to ante-natal risk factors for intellectual disability in women with a previous psychiatric disorder. Moreover, grouping mothers, according to the level of intellectual disability of their child and according to whether the cause is known would enable the most vulnerable groups of mothers to be identified.

Therefore, according to type and level of intellectual disability, we aimed to:

- Compare the incidence of any psychiatric diagnosis in mothers after the birth of a child with intellectual disability compared to mothers with no child with intellectual disability or autism spectrum disorder (ASD) where mothers had no record of a psychiatric disorder before the birth of their child.
- 2. Compare the incidence of the most frequent psychiatric diagnostic categories, in mothers after the birth of a child with intellectual disability compared to mothers with no child with intellectual disability or ASD and where mothers had no record of a psychiatric disorder before the birth of their child.

#### 2. Methods

#### 2.1. Study population

The study population consisted of all women who gave birth to a live child in Western Australia (WA) between 1st January 1983 and 31st December 2005 inclusive. We linked de-identified data-sets from four statutory state-based registries and a state-wide disability database (Holman et al., 1999). The Hospital Morbidity Data System (HMDS) (Department of Health WA, 2011) provided us with admission dates and ICD-9 and ICD-10 codes for all hospital separations in WA from 1970 to 2010. The Mental Health Information System (MHIS) (Department of Health WA, 2011) provided us with appointment dates and the associated ICD-9 and ICD-10 codes for all public outpatient mental health contacts in WA from 1970 to 2010. The Midwives Notification System (MNS) provided us with the birth dates of all children born in WA during the collection period and socio-demographic information which we used to create explanatory variables. The WA Death Registry provided death dates of mothers and children to enable us to adjust the period when women were at risk of a psychiatric disorder due to the burden of care of their child. Using the Intellectual Disability Exploring Answers (IDEA) Database (Petterson et al., 2005), we gathered diagnostic information of children born between 1983 and 2005. Personnel from WA's Data Linkage Unit (Department of Health WA, 2011) created a unique code for each mother enabling us to link these data-sets. After removing 20, 583 (6.9%) mothers with a psychiatric disorder prior to the birth of their index child and all mothers and babies who had died on the date of the index birth, our cohort comprised 277,559 mothers.

#### 2.2. Maternal groups

We excluded mothers of children with ASD from the comparator group because researchers have also found that the mental health of mothers of children with ASD is poorer than that of mothers of typically developing children (Daniels et al., 2008; Montes and Halterman, 2007). Hence our comparator group was all women with a live child born between 1st January 1983 and 31st December 2005 and who had no child diagnosed with intellectual disability or ASD before December 31st, 2010. For comparator mothers, the index child was the first child born during the collection period. We allocated mothers of one or more children with intellectual disability (but not ASD) into one of four case groups. These were labelled *mild–moderate intellectual disability of*  unknown cause, severe intellectual disability of unknown cause, Down syndrome and intellectual disability of known cause excluding Down syndrome. For these women, the index child was the eldest child with an intellectual disability. When choosing our case groups, we considered the particular challenges likely to result in differential burdens of care. For example, we separated mothers of children with severe intellectual disability of unknown cause from mothers of children with mild-moderate intellectual disability of unknown cause because children with severe intellectual disability are likely to have a much greater medical burden. Hence, the challenges faced by mothers could be expected to vary. We also separated mothers of children with Down syndrome from other mothers of children with intellectual disability of known cause. This was because the numbers for the former were sufficiently large and because research has identified that these mothers of children are less likely to have poorer mental health outcomes than mothers of children with other intellectual disability of known cause. The interrelationships of these case groups are illustrated in Fig. 1.

#### 2.3. Psychiatric disorders before the index birth

Mothers with a psychiatric disorder before the birth of their index child were excluded from our data-set. These were all women with one or more diagnoses from the eleven blocks of Chapter 5 of the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (World Health Organisation, 2004) or an ICD-9 equivalent code (Supplementary Table 1).

#### 2.4. Explanatory variables

We have previously demonstrated that socio-economic disadvantage, young maternal age and high parity are associated with the risk of mild-moderate intellectual disability of unknown cause (Leonard et al., 2011). Therefore, we included measures of these traits as variables in our model. We calculated a four-level variable for socio-economic status (SES) from the Index of Relative Socioeconomic Disadvantage (Australian Bureau of Statistics, 2009) for 2001. Where this was missing, we used the same statistic but for 1996 or 2006 or a similar statistic for 2001 termed 'Statistical local areas' rather than 'Collection Districts'. Maternal age at index birth was categorised as <20, 20-35 and >35 years. Parity at the time of index birth was categorised as No previous child; One previous child; 2-3 previous children; and >3 previous children. The birth year of the index child was grouped into bands of 1983-88; 1989-94; 1995-2000 and 2001-5. We did not include births after 2005 as we reasoned that a five year lee-way period was needed for children with mild intellectual disability to have a reasonable opportunity to be diagnosed.

#### 2.5. Psychiatric status

We used seven of the eleven blocks defined in ICD-10 (World Health Organisation, 2004) to categorise psychiatric status after the index birth (Supplementary Table 1). Block 1 (Organic disorders), Block 8 (Mental retardation), Block 9 (Disorders of psychological development) and Block 10 (Behavioural and emotional disorders with onset usually occurring in childhood and adolescence) were omitted because we saw these as unlikely to develop in response to care-giving or because they were life-long disorders. In order to determine the most frequent diagnostic categories, we created variables which counted the number of women with one or more diagnoses in each of the seven blocks of interest. For blocks with higher numbers of affected mothers, we created measures for women with one or more episodes from the block. These women were allocated a score which was equal to the sum of hospital admissions and outpatient contacts which were associated with an

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