Poverty and the mental health of families with a child with intellectual disabilities

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Abstract

Research with representative samples of children with intellectual disabilities and their parents has consistently demonstrated much higher levels of psychopathology and poorer well-being amongst both children with intellectual disabilities and their parents compared with those without intellectual disabilities. Although these differences in psychopathology are often assumed to be an inevitable consequence of the child's intellectual disability and therefore to result in an inherently stressful parenting role, here, we briefly review the research evidence for an alternative proposition, namely that poverty and socio-economic position may play an important part in the development and maintenance of psychopathology in both children with intellectual disabilities and their parents. We review evidence that families with a child with intellectual disabilities are more likely to be living in poverty, and that differences in socio-economic position between families with a child with or without intellectual disabilities can substantially account for differences in child and parent psychopathology. Potential mechanisms linking poor socio-economic position to family psychopathology are outlined, together with some brief implications for policy and practice.

Keywords children; families; intellectual disabilities; mental health; parents; poverty; psychopathology; socio-economic position

Psychopathology amongst children with intellectual disabilities and their parents

Evidence is rapidly accumulating that the prevalence of psychopathology amongst children with intellectual disabilities is substantially higher than for non-disabled children. Despite variations in reported prevalence rates of psychopathology according to the size and representativeness of study samples and psychopathology assessment methods,[1] a series of studies using larger, population-based samples in several countries[2–6] and secondary analysis of nationally representative surveys of children and adolescents[7,8] have consistently reported high rates of psychopathology amongst children and adolescents with intellectual disabilities.

For example, an Australian study[3] reported that 40% of 454 children with intellectual disabilities aged 4–18 met criteria for psychiatric caseness, compared with 14% of Australian children without intellectual disabilities identified in a random community sample.[9] In the UK, a secondary analysis of surveys of representative samples of 18,415 children aged 5–15[8] reported that 36% of 641 children operationally defined as intellectually disabled met criteria for an ICD-10 psychiatric disorder compared with 8% of 17,774 children without intellectual disabilities (OR = 6.5, $p < 0.001$). In terms of specific psychiatric disorders, this study reported significantly higher rates of emotional disorder (12.0% ID vs 3.7% non-ID, OR = 3.6, $p < 0.001$), anxiety disorder (11.4% ID vs 3.2% non-ID, OR = 3.9, $p < 0.001$), hyperkinesis (ADHD; 8.3% ID vs 0.9% non-ID, OR = 8.4, $p < 0.001$), conduct disorder (20.5% ID vs 4.3% non-ID, OR = 5.7, $p < 0.001$), autistic-spectrum disorder (8.0% ID vs 0.3% non-ID, OR = 33.4, $p < 0.001$) and tic disorder (0.8% ID vs 0.2% non-ID, OR = 5.2, $p < 0.01$), although there were no significant differences in the prevalence of depressive disorder (1.4% ID vs 0.9% non-ID, OR = 1.7, ns) or eating disorder (0.2% ID vs 0.1% non-ID, OR = 1.3, NS).

Although constructs and methodologies are more diverse, similar findings have been consistently reported concerning the well-being and mental health of parents of children with intellectual disabilities, with numerous studies reporting higher rates of distress and lower rates of well-being among mothers and, occasionally, fathers of children with intellectual or developmental disabilities.[10–12] As with the child literature, secondary analyses of well-constructed nationally representative samples consistently report higher levels of psychological distress and mental health problems amongst parents of disabled children.[13–16]

For example, a secondary analysis of mothers of a nationally representative sample of UK children and adolescents[13] reported that 35% of mothers of child with intellectual disabilities were at risk of a psychiatric disorder compared to 25% of mothers of a child without intellectual disabilities ($p < 0.001$). A secondary analysis of mothers of 3-year-old children in the UK Millennium Cohort Study reported that 24% of mothers of children with early cognitive delay had probable mental illness compared with 10% of mothers of typically developing children.[14]

Within the intellectual disability research literature, accounts of these findings have principally located the cause of these differences within the child with intellectual disabilities,[17–19] with the intellectual disability and co-occurring problem behaviours resulting in increased stress, burden and poorer well-being for parents.[20] The result of such accounts has been a concentration on behavioural and pharmacological interventions targeting children's behaviour, and behavioural/psychological interventions aiming to reduce parental stress and increase their capacity for coping with their child's behaviour.[17]

Poverty and families with a child with intellectual disabilities

In recent years, research has begun to investigate the largely ignored proposition that poverty and socio-economic position

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may be an important determinant of the psychopathology of both children with intellectual disabilities and their parents.[19]

All societies are hierarchically structured, with key social institutions (e.g., the labour market, education and legal systems) operating to position individuals within a social hierarchy. A person's position in this hierarchy shapes their (and their children's) access to and control over key resources (e.g. wealth, social connections, health, skills, access to educational, health and welfare services) that have an important role in determining their health and well-being and maintaining or improving their position in the social hierarchy and the position of their children.[21] We use the term *socio-economic position* to refer to the position occupied in a social hierarchy by an individual or family. Socio-economic position is not an inherent property of individuals or families, but the result of the interaction between the impact of powerful social institutions in stratifying the social order and people's active involvement in recreating and maintaining the social hierarchy through cultural and social practices.[21]

People occupying lower socio-economic positions may have difficulty accessing resources that are necessary to enable them to live lives that are considered appropriate or decent within their society. That is, they may experience *poverty*.[22,23] Following the classic Townsend approach to defining relative poverty,[24] we will use the term poverty to refer to the situation of individuals or families who are unable '*due to lack of resources*, to participate in society and to enjoy a standard of living consistent with human dignity and social decency'.[25] At its most extreme, poverty may involve such a level of deprivation of resources that health or life itself is significantly threatened (a situation often referred to as 'absolute' poverty).

The general lack of attention paid to family poverty as an important construct in its own right (rather than as a confounding variable to be controlled for) is particularly surprising given that families supporting a child with intellectual or developmental disabilities are in general significantly more likely than other families to be located in lower socio-economic positions and to experience poverty.[14,27–29]

Recent research has begun to investigate the proposition that differences in socio-economic position between families with a child with intellectual disabilities and families with a child without intellectual disabilities may partly account for the higher rates of psychopathology reported in children with intellectual disabilities and their parents.

With regard to children with intellectual disabilities, research suggests that increased exposure to low socio-economic position/poverty may account for: (1) 20–50% of the increased risk for poorer health and mental health among two nationally representative cohorts of British children and adolescents with intellectual disabilities[8,30,31]; (2) 29–43% of the increased risk for conduct difficulties, 28–48% of the increased risk for emotional difficulties and 36–43% of the increased risk for peer problems among a nationally representative cohort of 6–7-year-old Australian children with intellectual disabilities or borderline intellectual functioning[32]; (3) a significant proportion of increased rates of self reported antisocial behaviour and smoking among adolescents with intellectual disability.[33,34] Given the link between child behaviour and maternal well-being,[11,35,36] the impact of socio-economic position on child well-being is also likely to have an adverse impact on the well-being of their parents.

With regard to parents of children with intellectual disabilities, research has suggested that increased risk of exposure to low socio-economic position/poverty may account for: (1) over 50% of the risk for lower self-efficacy and self-esteem and 100% of the increased risk of unhappiness among a nationally representative sample of approximately 7000 British mothers of children with and without intellectual disability[37]; (2) 50% of the increased risk for probable psychiatric disorder among a nationally representative sample of approximately 4000 Australian mothers of 4–5-year-old children with disabilities[15]; (3) 74–83% of the increased risk for probable psychiatric disorder among a nationally representative sample of approximately 13,000 UK mothers of 3-year-old children with developmental delay.[38] More recently, Olsson and Hwang have also reported that social and material hardship and poorer general health accounted for the increased risk of poorer maternal well-being in a sample of Swedish families.[16] These results represent a direct challenge to the 'stress reaction' models that underlie much current family research by suggesting that the poorer well-being of parents of children with intellectual disabilities may result more from their exposure to socio-economic adversity than specific stresses associated with their child's disability.

Mechanisms for understanding the link between poverty and family well-being

What mechanisms might underpin the link between poverty and well-being in families with a child with intellectual disabilities? Evidence focusing on families with a child with intellectual disabilities is lacking,[19] but there does exist a wealth of evidence documenting the negative impact of exposure to low socio-economic position and/or poverty on attainment, productivity, health, well-being and social exclusion in the general population.[39–48] This literature suggests three ways in which poverty may be associated with negative outcomes for families.

First, research suggests that negative outcomes associated with the experience of low socio-economic position are greater in families with a greater duration or depth of exposure to poverty.[49–52]

Second, it is clear that the negative outcomes associated with exposure to low socio-economic position and/or poverty are mediated through a multiplicity of pathways, including increased risk of exposure to a range of material and psychosocial hazards such as adverse birth outcomes, exposure to a range of toxins and teratogens, poorer nutrition, poor housing conditions, exposure to less than optimal parenting, poorer educational and occupational opportunities, injury and accidents, adverse life events, poorer health and welfare services, and poorer quality neighbourhoods.[41–43,47,48,53–60] Family functioning and parenting practices may be particularly important influences on child exposure to several of the hazards mentioned above.[41,55,59,61] Conger and colleagues, in their Family Stress Model, suggest that economic pressures associated with exposure to low socio-economic position/poverty have a negative impact on parental well-being and family functioning that influence child development through their impact on parenting

