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Parents with intellectual disability

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Questions around parents with intellectual disability have changed according to sociocultural shifts in the position and rights of people with intellectual disability. The early research focus on capacity for parenting has given way to a contextual model of parenting and child outcomes, increasingly tested in population-based samples. Epidemiological research shows that contextual variables such as low income, exposure to violence, and poor mental health partly account for negative outcomes. As theoretical models developed for other at risk populations prove increasingly helpful for understanding the challenges of parenting with intellectual disability, it becomes viable to adapt existing evidence-based parenting interventions and test these for this population. Ultimately, parenting research should become fully inclusive.

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Introduction

Scientific attention towards parents with disability dates back at least from the 1940s [1,2] when eugenic sterilization laws were in place (Buck vs. Bell, 274 U.S. 200, 207, 1927) and parenting capacities of the 'feeble-minded' were held in doubt. Attitudes towards people with disabilities have changed and deinstitutionalization has facilitated the pursuit of conventional life courses, although disparities and prejudice still linger. The United Nations Convention on the Rights of Persons with Disabilities of 2006 pledges respect for the rights of people with disability to decide freely and responsibly on the number and spacing of their children (article 23) and calls for support in exercising their rights regarding family life. Compared to developmental, sensory, and physical disabilities, intellectual disability has garnered the most attention in parenting research. Partly thanks to international coordination efforts [3], parenting with a disability has evolved from a specialty topic for small-scale, descriptive research with clinical samples towards a more mainstream topic. This review of findings since 2011 examines what the intensified focus on descriptive epidemiology, theory development, and research on adapting interventions has yielded.

Prevalence

The American Association on Intellectual and Developmental Disabilities [4] defines intellectual disability as significant limitations originating before the age of 18 in intellectual functioning and in social and practical skills to adaptively function. Specific criteria differ across countries and historical periods. When an IQ-test score lower than 70–75 is accepted as a significant limitation in intellectual functioning, depending on people's adaptive skills, up to 5% of the general population may fall under the label. Synthesis of research on people with intellectual disabilities is hampered by the large variation in how these and other definitions are operationalized and whether people with borderline intellectual functioning are also included (*e.g.*, Ref. [5]).

A large representative Australian national disability household survey ($N = 61\,900$, aged 15–64) found that 0.41% of the population were parents with intellectual disability [6], based on screening for 'difficulty learning and understanding things' (p. 3) in combination with a lifelong causal condition such as speech impairment. Being a parent was defined as sharing a private dwelling with a child younger than 15 years. Of the people with intellectual disability, 8% were parents, which was lower than populations with other disabilities (21%) or no disabilities (30%). Among adults between 16–49 years old in an UK nationally representative household survey ($N = 14\,373$), 66% of adults with intellectual disability (defined by both lack of educational qualifications and scoring lower than two standard deviations below the mean on standardized cognitive tests) had biological children, similar to adults without intellectual disability (57%) [7•]. Not only age, criteria for intellectual disability, and national context were different from the Australian study, but adults were categorized as parents if they had ever given birth to or fathered a child, irrespective of whether that child was at present still living with them or not. While these studies overcome the biases inherent in previous informant-based prevalence studies (*e.g.*, Ref. [8]), the field is still far from providing clear estimates.

Epidemiology of outcomes and risks

Concern about the overrepresentation of children of parents with intellectual disability in child protection services has been a main driver of research on parenting. Child maltreatment investigations in Canada revealed that social workers noted "cognitive impairment of one or both parents" in 10% of the cases [9], but without knowing how often that label applies to non-investigated parents, it is unclear how alarming that number is. Neglect (56%) was the typical form of maltreatment noted in the files, while physical (23%) and sexual abuse (4%) occurred relatively less frequently.

Given the concerns of child protection workers, intervention efforts have sought to address these risks by focusing on relevant parenting skills (*e.g.*, Ref. [10]). Population-based studies do not always indicate elevated health and safety risk specifically for children born to parents with intellectual disability. Hindmarsh *et al.* [11] analyzed data from the UK Millennium Cohort Study ($N = 18\,189$ children). This study included 74 mothers who self-identified as having an intellectual impairment or displayed low education and literacy. Families regarded as 'sensitive' for research due to high risk were excluded. Birth outcomes were similar for children born to mothers with or without intellectual disability, and when infants were 9 months old, rates of accidents and immunization were also similar. Infants of mothers with intellectual disability did show more fine motor delay on a standardized test, but gross motor delay was not more frequent. While direct comparison with data from parents without intellectual impairment was a strength, the authors caution against over interpretation given the relatively small and selective subsample. In the Fragile Families and Child Wellbeing Study [12•], which prospectively follows a birth cohort representative for families of unmarried mothers living in US cities, the health of children (maternal rating) up to age 3 was similar for children ($n = 263$) of mothers with intellectual disability (verbal IQ test score <80) compared to children of mothers without intellectual disability ($n = 1298$). Also rates of asthma, being overweight, and obesity were similar. Among 487 577 children born between 1999 and 2005 in Sweden, 2749 children were identified as born to women diagnosed with intellectual disability (IQ <70 and deficient adaptive functioning) [13•]. These children on average had lower birth weight, lower gestational age, and more frequently had epilepsy. Also, children of mothers with intellectual disability had a 48% higher risk of injuries due to traffic, burns, suffocation, poisoning, or drowning, although the incidence in this population was still low (4.4%). Overall, estimates of health risk very much depend on study design. Given the comprehensive nature of the Swedish registry study [13•], physical health and safety risk should not be easily dismissed.

In domains outside physical health, results of multiple studies are cause for concern. Health visits to 46 025 households with young children in three UK primary care regions identified 588 households with a parent with visitor-rated learning disability [14•]. Visitor survey data revealed elevated risks for child developmental delay, speech and language problems, child behavior problems, and frequent accidents and injuries among children in families with a parent with intellectual disability compared to other families, with odds ratios ranging from 4.96 (CI 2.71–9.07) to 8.92 (CI 7.43–10.70). However, families with a parent with intellectual disability were also considerably more often exposed to other risk factors, including low income, unemployment, poor housing, single parenthood, social isolation, family violence, parental mental health problems, parent history of being victim of abuse (odds ratios from 3.62 to 16.39). While aggregation of risk around having an intellectual disability partly explained negative outcomes, parental intellectual disability still showed an unique statistical effect (ranging from 1.93 to 3.57) except for frequent accidents and injuries. Data suggest that inept parenting may play a role. Parenting problems were noted in 56% of families with a parent with intellectual disability compared to 6% in other families. Parenting problems significantly and uniquely accounted for negative child outcomes after taking other risk factors into account. In the Swedish cohort study of children born to mothers with intellectual disability [13•], elevated risks were reported for child intellectual disability diagnosis, mental health problems, injuries due to falls, and falling victim to violence and child abuse, with odds ratios ranging from 1.25 (CI 1.14–1.38) to 6.68 (CI 4.95–9.02). Risks remained elevated when odds rations were adjust for maternal characteristics (age, education, tobacco use, substance abuse, mental health).

Theory development

The epidemiological findings on contextual risk and protective factors are put into meaningful perspective by co-opting theories from the wider literature. The Family Stress Model [15], for example, connects economic pressures to parents' mood, which would not only directly affect nurturing involvement with their children, but also indirectly through heightened interparental conflict. Building on that model, Wade *et al.* [16] found partial support for an adapted version of the Family Stress Model using parent self-report data ($N = 120$). While parental mental health partially mediated statistical effects of neighborhood disadvantage and social support on parenting warmth, access to support was also directly positively associated with parenting involvement and parental child care efficacy, with the latter variable emerging as most directly linked to child well-being.

If parenting is vulnerable to intellectual disability, it could imply that other parenting related outcomes are

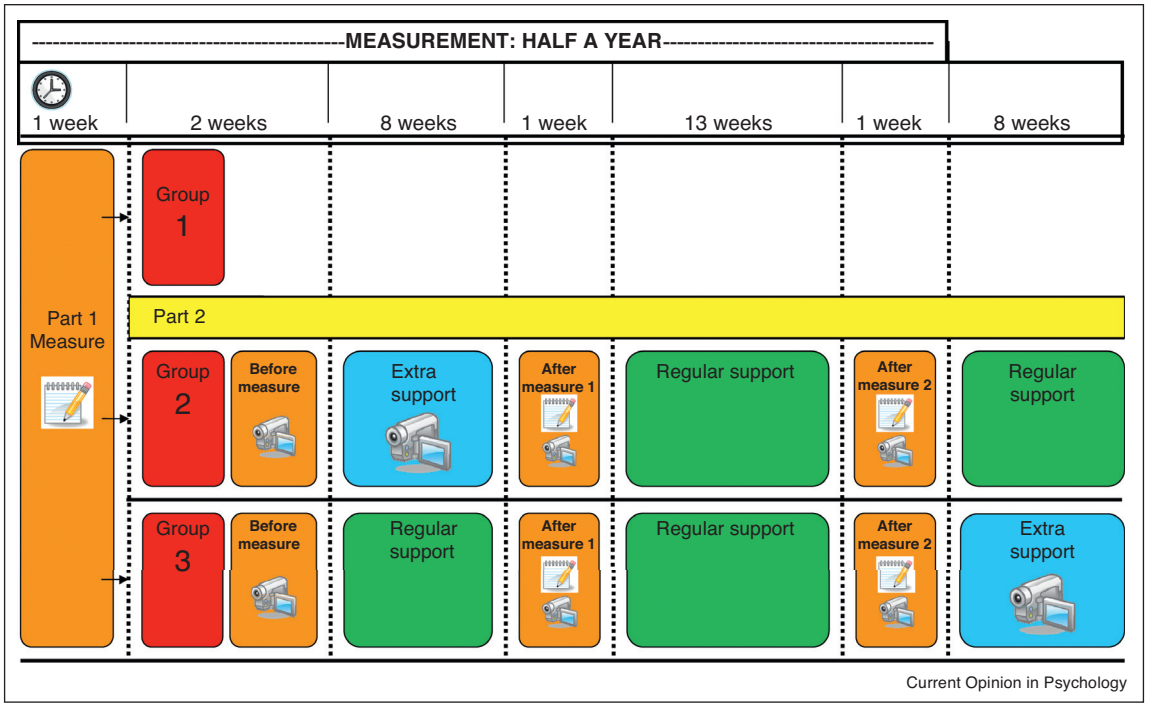
affected as well. In order to test whether children of mothers with intellectual disability more often would have insecure or disorganized mental representations of their attachment relationships, a Swedish study matched mother–child dyads with maternal intellectual disability (n = 23) to dyads without maternal intellectual disability (n = 25), thereby controlling for confounding variables such as socioeconomic and neighborhood adversity. Mothers with intellectual disability were observed to be less sensitive, and sensitivity was associated with less disorganized attachment representations [17]. However, differences in attachment security and disorganization were not significant, suggesting that protective mechanisms may play a role as well [18•].

Intervention research

Research on intervention effectiveness speak to the benefit that parents may draw from parenting support and education [19]. A Dutch study found that 40% of professionals working with parents with intellectual disability subscribed to a mindset that their clients are who they are, and that supporting them will not essentially change their functioning [20]. Recent reviews of single case experiments and small-group trials of behavioral skills training of parents with intellectual disability concluded that the evidence leaves many questions unanswered, not only regarding the generalizability and long-term maintenance of the skills being trained, but also about the generalizability across the heterogeneous population of parents with intellectual disability [5,21].

While applied behavior analysis is a helpful intervention component to address basic parenting knowledge and skills despite intellectual disability, outcomes may still be poor unless the constellation of risk factors is addressed [19,22]. Parenting interventions that have not been developed specifically with parents with intellectual disability in mind but that have been shown effective may be made more inclusive by tailoring professional worker skills, materials, and procedures to wider variations in intellectual and adaptive functioning than current protocols allow. The latter approach leverages the accumulation of experience and evidence from work in populations that share many risk factors. Furthermore, scale benefits might make implementation more feasible. One example is the attachment-based Video-feedback Intervention for Positive Parenting, focused on Sensitive Discipline [VIPP-SD; 23]. Building on the original model, home visits were broken down in seven visits for video recording parent-child interaction, seven visits to support parenting using those recordings as feedback material, and one rounding off session [24]. A randomized clinical trial of this intervention (N = 85) showed stronger reduction in parenting stress with this intervention than with only the usual practical and social support [25]. The study also demonstrated how parents with intellectual disability helped

Figure 1



Supporting pictographic material for informed consent of participants in trial of Videofeedback Intervention for Positive Parenting—Learning Disabilities (Hodes *et al.*, [25]).

with developing study materials and explanations to support full informed consent for participating in a complicated trial design (see Figure 1 for an example), showing that inclusivity can also promote the success of research [24].

Conclusion

Rather than special status, special education, special institutions, and special services, sociocultural changes towards inclusion and normalization put more emphasis on gradual than categorical differences. Research on parents with intellectual disability only partly reflects that perspective, and also large scale population-based studies and trials, with their frequent reliance on verbal and written modes of data collection, continue to present barriers for demonstrating its fruitfulness. Despite this limitation, the current wave of new research is in a better position to inform the societal and policy debate by addressing long-held assumptions over parents with intellectual disability and may reduce unhelpful stigmatization.

Conflict of interest

We wish to draw the attention of the Editor to the following facts which may be considered as potential conflicts of interest.

Carlo Schuengel, Sabina Kef, Marja Hodes, and Marieke Meppelder have received funding from ZonMw, grant 57000006 (The Netherlands Organisation for Health Research and Development) for research on intervention for parents with intellectual disability. Marja Hodes is employed by ASVZ, a care organization for people with intellectual disability that offers support to parents with intellectual disabilities such as described in the article.

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- • of special interest

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7. • Emerson E, Llewellyn G, Hatton C, Hindmarsh G, Robertson J, Man WYN, Baines S: **The health of parents with and without intellectual impairment in the UK**. *J Intellect Disabil Res* 2015, **59**:1142-1154 http://dx.doi.org/10.1111/jir.12218.
Undertook a secondary analysis of data from the UK Understanding Society household panel survey (https://www. understandingsociety.ac.uk/). Unique for this large scale survey was the battery of cognitive testing in one of the waves, allowing the identification of 299 people with intellectual impairments among the 14371 participants. Results show that health disadvantages of parents with intellectual disability can be explained by household socio-economic disadvantages. Neighbourhood social capital was also low for this population, but did not explain additional variance.

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This study analysed data from the Fragile Families longitudinal birth cohort study of families living in four large US cities. A subsample of the cohort ($N = 1561$) completed the Peabody cognitive test, of which 263 scored 80 or below and were classified with an intellectual disability (although this cut-off also included parents with borderline intellectual functioning). Child health was assessed through parent report and showed no differences between children of parents with or without intellectual disability, before and after taking into account that parents with intellectual disability were significantly more often at socioeconomic disadvantage.

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This Swedish study combined data from the Medical Birth Register, National Patient Register, and the multi-generation register. This allowed the identification of 2749 mothers with intellectual disability who had their first born child between 1999 and 2005, out of 478,577 mothers with first born children. Maternal and child risk factors were overrepresented for mothers with intellectual disability, and more negative outcomes were reported. Even taking into account these risk factors, maternal intellectual disability was uniquely associated with heightened risks such as intellectual disability in the child (1.6% versus 0.2%), mental health problems (7.8% versus 3.1%), and exposure to violence or child abuse (0.8% versus 0.1).

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Undertook a secondary analysis of needs analysis data collected by surveys with 46 025 families of young children served by primary care organizations in the UK. Trained health visitors conducted these surveys, using interview and observation. These health visitors also classified whether parents had learning difficulties still needing support ($n = 588$), but did not conduct cognitive testing. Validity and reliability of the ratings were unknown. Findings are notable in that increased risk of child delays and problems when parents had learning difficulty were only partly explained by socioeconomic disadvantages. Findings suggest that parenting problems also explain part of the association.

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Rather than attempting to control for confounders for the effect of maternal intellectual disability by analysing survey and self-report data from large population surveys, this study used a matched comparison design to control for wellknown confounders, allowing more informative albeit more labour-intensive interview and observational measurements. This allowed the team to test the hypothesis that maternal intellectual disability may somehow affect the security of their children's internal working model of attachment. No significant effect was found, but the sample size ($n = 23$ mothers with intellectual disability and $n = 25$ comparison) only provided enough statistical power for detecting a large effect. Within the group with intellectual disability, disorganized child attachment representation was associated with a maternal history of trauma.

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