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Development of Children of Parents with Intellectual Disability: A Systematic Review

Abstract: The number of families in which at least one parent has an intellectual disability remains unknown. Little is also known about the experiences of children growing up in such families. Single studies (e.g. retrospective studies of adult children) provide knowledge about such risk factors for child and family development as parentification or social stigma. The article presents the results of a systematic review of the literature (using the PsycArticles and PsycInfo databases) on the development of children in families with at least one parent with intellectual disability. The aim of the review was to explore the empirical research conducted so far in this area. The article ends with a list of recommendations for further empirical research.

Keywords: intellectual disability, children of parents with intellectual disability

Słowa kluczowe: niepełnosprawność intelektualna, dzieci rodziców z niepełnosprawnością intelektualną

INTRODUCTION

Intellectual disability (ID) is a significant reduction in the general level of intellectual functioning co-occurring with difficulties in adaptive behaviour. In the ICD-11 it falls under the heading of neurodevelopmental disorders. It affects approximately 1% of the population, with a prevalence rate of 10.37/1000 births (Maulik et al., 2011). The diagnostic criteria for intellectual disability include a reduced intellectual level (expressed as an IQ below 70 points) and adaptive difficulties. Intellectual disability thus translates into difficulties and challenges in functioning in social groups, forming romantic relationships or starting a family – the greater the disability, the more profound. However, people with intellectual disabilities also undertake developmental tasks in early adulthood, such as finding a partner or starting a family.

In the face of historical and cultural changes, we are now discovering clear gaps in knowledge about the sexuality of people with intellectual disability (Kościelska, 2004; Lew-Starowicz, 2005; Jurczyk, 2018; Kijak, 2019; Fornalik, 2020; Pieńkowska, 2021). The methodological and substantive challenges faced by researchers seeking to learn about the sexuality of this specific group of people mean that to date, there are few such studies (and those that do exist are largely based on case studies or limited numbers of participants), and this applies to the study of psychosexual development, sexual dysfunction, and parenting in people with intellectual disabilities.

The only available population-based data on parenthood of people with intellectual disabilities come from Norway (Tøssebro et al., 2017). They showed that .19% of Norwegian children have a parent with intellectual disability. This figure has been decreasing since the mid-1980s, which is explained by the increased availability of contraception and sex education also for this group of people. At the same time, the study found twice as many mothers as fathers with intellectual disability, which may be due to the fact that mothers with intellectual disability often associate with men within intellectual norm or report the father of their child as unknown.

Little is known about the experiences and development of children growing up in such families. Indeed, most research in this area has focused on assessing parental competence and testing the effectiveness of interventions designed to support this competence. Individual studies (e.g. retrospective studies of adult children of parents with intellectual disabilities) provide insight into risk factors for child and family development, such as parentification, social stigma or social exclusion (e.g. Booth, Booth, 2004; Wołowicz-Ruszkowska, McConnell, 2017; Weiber et al., 2019).

Diversity in the functioning of families with parents with intellectual disabilities

The first empirical studies of parents with intellectual disabilities were published in the 1980s and 1990s (e.g. Tymchuk et al., 1988; Mørch et al., 1997). They pointed to a number of difficulties faced by parents with intellectual disabilities or, in fact, mainly mothers with mild to moderate levels of intellectual disability (to date, there has been little research on fathers with intellectual disabilities – McConnell et al., 2017), such as difficulties in parenting, providing a poorer developmental environment for children (both physically and socially), not always responding adequately to the child's needs, or difficulties in making decisions related to daily childcare (e.g. Feldman, 1994). In response to these issues, ideas for interventions to support parenting competence and applied research to test the effectiveness of such training and interventions for parents with intellectual disabilities have begun to emerge (e.g. Tymchuk et al., 1988; Feldman, Case, 1999; Hodes et al., 2017; Knowles et al., 2017; Augsberger et al., 2021). A review of parenting skills training available to date indicates its effectiveness and usefulness for parents with intellectual disability and their children (Wade et al., 2008).

Factors other than intellectual disability (or co-existing with ID) that contribute to the development of parenting competence in people with intellectual disability have also begun to be explored. The role of social support, parents' somatic and mental health, family socio-economic status, child characteristics and a range of social factors have been examined (e.g. Llewellyn, 1995; Durling et al., 2018; MacIntyre et al., 2019; Atkin, Kroese, 2022). These data clearly show that families with parents with intellectual disabilities are diverse and that the problems they face are not solely due to the disability itself.

The vast majority of researchers have used as participants parents with intellectual disability, possibly their extended family or professionals who know the family well (e.g. social workers, psychologists, doctors). Attention is now turning to an unheard voice – that of the children of parents with intellectual disability (Feldman, Aunos, 2020). Retrospective research with adult children of parents with intellectual disability focuses on perceptions of the parent's disability, the history of discovery of the parent's disability, and the role of support from significant others (other than parents) in the child's development and well-being (Booth, Booth, 1998; Traustadóttir, Sigurjónsdóttir, 2005).

Children of parents with intellectual disabilities are a very heterogeneous group – families with parents with intellectual disabilities may include children with intellectual disabilities or other developmental problems or disabilities, as well as typically developing children within the intellectual norm (Collings, Llewellyn, 2012). At the same time, it is pointed out that, in the absence of population-based research, it is difficult to demonstrate the extent to which possible developmental delays in children are an "effect" of their parents' intellectual disability, or more precisely their parenting practices, and the extent to which they depend on the effects of adverse living conditions, including poverty, social isolation, mental health problems or limited social relationships, which are much more common in this group of families

(Slayter, Jensen, 2019). These are important public health questions, particularly in light of data indicating that the practice of removing children from their biological parents with intellectual disability and placing them in foster care is common (e.g. Collings, Llewellyn, 2012). Data from several countries (Denmark, Germany, Belgium, Norway, New Zealand, Australia, USA, and the UK) show that in the 1990s, between 30% and 50% of children of parents with intellectual disability ended up in permanent foster care. Studies from the early 2000s indicate similarly high percentages (e.g. Booth, Booth, 2004).

A significant problem faced by parents with intellectual disability is the dependence on others to raise their own child, or at least the need for increased support from others in this process. On the one hand, there is a widespread perception that people with intellectual disability are incapable of caring for their children themselves, which is explained by their limited independence, which can result in difficulties in caring for, nurturing, or educating their children. On the other hand, reliance on other individuals or institutions is also socially perceived as unacceptable (Kijak, 2019). This is surprising given that, with regard to families with parents within the intellectual norm, it is generally assumed that it takes a whole "village" to raise a child. Social stigma is, therefore, a distinct issue that can prevent parents with intellectual disability from seeking help and potentially pose a developmental risk to their children.

Research on the relationship between parental intellectual disability and child development appears to have produced inconsistent results. Some studies have shown that children of parents with intellectual disability are at risk of developmental delays (e.g. Mørch et al., 1997; Keltner et al., 1999; Feldman, Walton-Allen, 2002), while others have found no association between parental intellectual disability and child development (e.g. McConnell et al., 2003; McGaw et al., 2007; Aunos et al., 2008). This raises the question of what we know about the development of children of parents with intellectual disability, what we do not yet know, and what would be useful to support their development effectively in the future.

METHOD

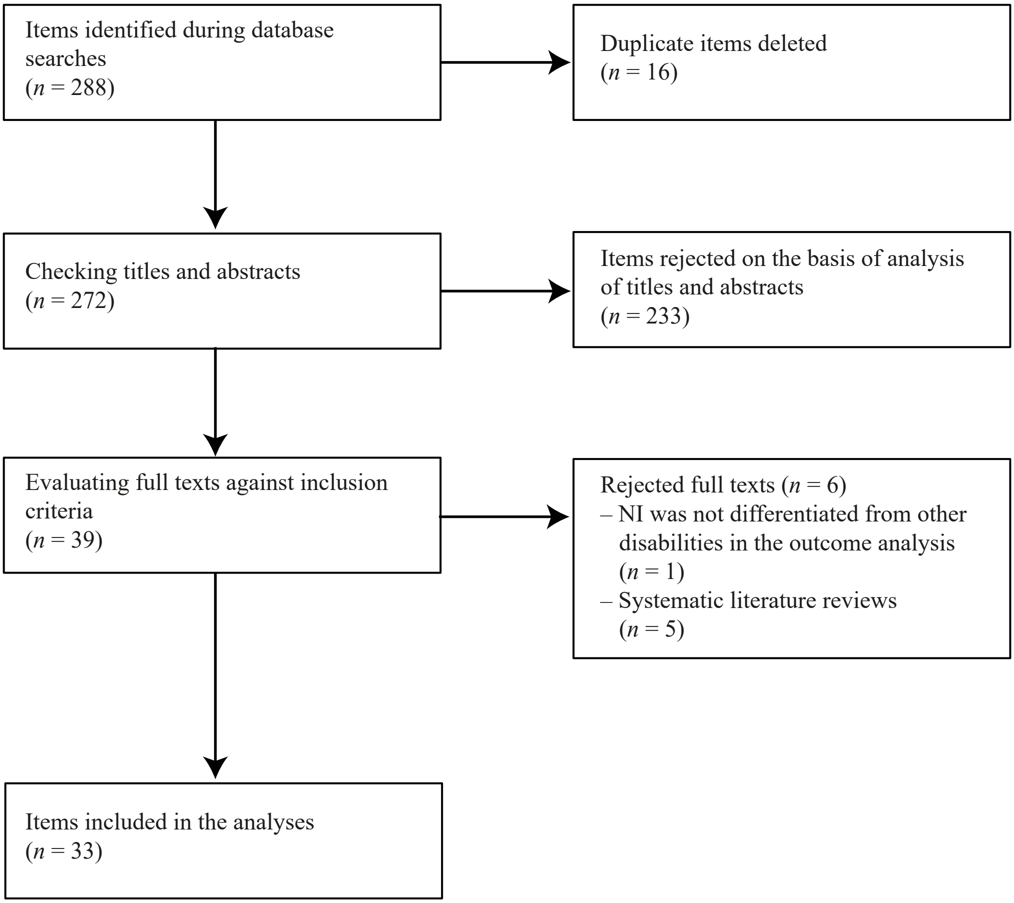
The systematic literature review conducted was exploratory in nature. Its aim was to collect and analyse research on the broadly understood development (both mental, social and physical) of children with at least one parent with intellectual disability. There were no time limits in order to cover as much of the empirical knowledge in this area as possible. The review was conducted in such a way as to provide insight into the directions of interest of researchers in the field of development of children of parents with intellectual disability and to synthesise the knowledge we have.

The systematic review of the literature was conducted using the APA PsycArticles and APA PsycInfo databases (EBSCOHost). It was conducted in accordance with the Cochrane guidelines for systematic reviews of literature (Higgins, Green, 2011). Inclusion criteria were peer-reviewed empirical articles in English on the development of children of at least one parent with intellectual disability. Two exclusion criteria were applied: no distinction between intellectual disability and other disabilities in the analysis of the study results and systematic reviews of the literature.

The bases were searched on 12 May 2023. No time limits were applied. A variety of terms were used to search the databases due to the number of terms used to describe intellectual disabilities over time. Ultimately, the following terms were used: (children) AND (parent OR mother OR father) AND ("intellectual* disab*" OR "intellectual* limit*" OR "learning difficulties" OR "learning disability" OR "cognitive* impair*" OR "cognitive* limit*" OR "mental* retard*").

Figure 1 shows the successive stages of article inclusion in the analyses. The search identified a total of 288 articles. After removing duplicate articles (*n* = 16), titles and abstracts were checked. As many as 233 texts were discarded as they did not deal with the development of children of parents with intellectual disability but focused on other aspects of family functioning, e.g. measuring the level of parental competence, the effectiveness of interventions by services (e.g. general practitioners, psychologists, or social workers), etc. The 39 full texts extracted in this way were analysed against the inclusion criteria. Five systematic literature reviews and one study that analysed the development of children of parents with intellectual disabilities, together with the development of children of parents with other disabilities, were rejected because they did not allow conclusions to be drawn about this specific group of children. As a result, 33 articles were included in the analyses.

Figure 1. Flow diagram of article selection



Source: own elaboration.

Table 1. Overview of the articles analysed

Authors	Country	Type of test	Participants	Research area
Atkin C., Kroese B.S. (2022)	United Kingdom	Qualitative	$N = 8$ mothers with intellectual disability	Survey of mothers with intellectual disabilities' experiences regarding proceedings for child protection and care and their ability to care for their children's development.
Augsberger A. et al. (2021)	USA	Mixed	$N = 133$ (total parents with intellectual disability and social care staff)	Investigating the effectiveness of interventions aimed at supporting parenting skills and reducing the risk of children of parents with intellectual disability being placed in foster care
Aunos M. et al. (2003)	Canada	Quantitative	$N = 47$ mothers with intellectual disability	Comparing behavioural problems in children of mothers with intellectual disability who have custody and those who do not
Booth T., Booth W. (2004)	United Kingdom	Quantitative	$N = 437$ court cases involving a total of 828 children of which: $n = 66$ cases involving 127 children of parents with intellectual disability	Analysis of court hearings on the custody of children by parents with intellectual disabilities
Collings S., Grace R., Llewelyn G. (2017)	Australia	Qualitative	$N = 7$ children of mothers with intellectual disability	Investigating the role of extensive institutional support in the development of children (school age) of mothers with intellectual disability
Collings S., Llewelyn G., Grace R. (2017)	Australia	Qualitative	$N = 7$ children of mothers with intellectual disability	Investigating environmental influences on the development of children (school age) of mothers with intellectual disability
Durling E. et al. (2018)	United Kingdom	Qualitative	$N = 14$ of which: family and local com-munity members ($n = 10$), parents with intellectual disability ($n = 4$)	Investigating the role of social support in the development of parenting skills of parents with intellectual disability and the development of their children

Emerson E., Brigham P. (2014)	Australia	Quantitative	N = 46 025 households of which: n = 588 homes with at least one parent with intellectual disability	Study of the development of children of parents with intellectual disability
Fairthorne J. et al. (2020)	Australia	Quantitative	N = 7800 mothers with intellectual disability (two comparison groups: Aboriginal and non-Aboriginal)	Comparison of pregnancy and neonatal development of children born to Aboriginal and non-Aboriginal mothers with intellectual disability
Feldman M.A., Walton-Allen N. (2002)	Canada	Quantitative	N = 52 children of which: n = 27 children of moth-ers with intellectual disability	Comparing levels of intellect, school achievement, and behaviour of children (school age) of mothers with and without intellectual disability
Forslund T. et al. (2022)	Sweden	Quantitative	N = 52 mother-child dyads of which: n = 26 diad mother with intellectual disability–child	Investigating the relationship of child behaviour problems to the mother's intelligence, her sensitivity towards her child, and her traumatic experiences
Granqvist P. et al. (2014)	Sweden	Mixed	N = 23 mothers with intellectual disability	Investigating the relationship between the traumatic experiences of mothers with intellectual disability and their children's attachment (aged 60–103 months)
Hindmarsh G. et al. (2015)	United Kingdom	Quantitative	N = 18 189 mothers of infants of which: 74 mothers with intellectual disability	Comparing developmental levels of children (at 9 months of age) of mothers with and without intellectual disability
Hindmarsh G. et al. (2017)	United Kingdom	Quantitative	N = 74 mother-to-child dyads with intellectual disability	Investigating the socio-emotional well-being of 3-, 5- to 7-year-old children of mothers with intellectual disability

Hodes M.W. et al. (2017)	Netherlands	Qualitative	$N = 85$ parents with intellectual disability	Investigating the effectiveness of an intervention aimed at supporting parental competence, reducing parental stress and developmental outcomes for children (aged 2 and 3 years) of parents with intellectual disability
Höglund B. et al. (2012)	Sweden	Quantitative	$N = 340\ 950$ mothers of which: $n = 326$ mothers with intellectual disability	Comparing the course of birth, risk of premature neonatal death and neonatal development of children born to mothers with and without intellectual disability
Keltner B.R. et al. (1999)	USA	Quantitative	$N = 70$ mothers of two-year-old children of which: $n = 38$ mothers with intellectual disability	Comparing developmental levels of 2-year-old children of mothers with and without intellectual disability
Knowles C. et al. (2017)	USA	Qualitative	$N = 4$ (2 parents with intellectual disability – child dyads)	Investigating the effectiveness of an intervention aimed at supporting parental competence and reducing symptoms of behaviour disorder in children of parents with intellectual disability
Lindberg L. et al. (2017)	Sweden	Mixed	$N = 48$ diad mother with intellectual disability–child	Investigating the relationship between child attachment development and sensitivity to child cues in mothers with intellectual disability
MacIntyre G. et al. (2019)	Scotland	Qualitative	$N = 47$ health system staff and local authority representatives	Investigating the role of social support in the development of parenting competencies of parents with intellectual disability and the development of their children
McConnell D. et al. (2003)	Australia	Quantitative	$N = 37$ children of mothers with intellectual disability	Investigating the development of children (aged 5 to 78 months) of mothers with intellectual disability
McGaw S. et al. (2007)	United Kingdom	Quantitative	$N = 107$ of which: $n = 49$ parents with intellectual disability: $n = 58$ children of parents with intellectual disability	Investigating the relationship of cognitive and socio-emotional development and mental health of children (aged 5–17 years) to the mental health of their parents with intellectual disability

Meppelder M. et al. (2015)	Nether-lands	Quantitative	*N* = 268 (134 parents with intellectual disability and their children)	Investigating the role of parental stress and social support in the emergence of behavioural difficulties in children (aged 1-7 years) of parents with intellectual disability
Mueller B.A. et al. (2019)	USA	Quantitative	*N* = 103 mothers with intellectual disability	Investigating the course of pregnancy, neonatal development, risk of child rehospitalisation and perinatal mortality rates among mothers with intellectual disability
Perkins T.S. et al. (2002)	USA	Mixed	*N* = 36 children of mothers with intellectual disability	Investigating the relationship between a child's (aged 9 –17) attachment to his mother with intellectual disability and self-esteem
Powell R.M., Parish S.L. (2017)	USA	Quantitative	*N* = 1561 mothers of which: *n* = 263 mothers with intellectual disability	Comparing the behaviour and cognitive development of 3-year-old children of mothers with and without intellectual disability
Rubenstein E. et al. (2021)	USA	Quantitative	*N* = 267 395 infants of which: *n* = 1696 children of mothers with intellectual disability	Comparing developmental achievements of infants who are children of mothers with and without intellectual disability
Slayter E.M., Jensen J. (2019)	USA	Quantitative	*N* = 211 993 of which: *n* = 2450 parents with intellectual disability	Analysis of court hearings on abuse and neglect of parents with intellectual disability towards their children
Tøssebro J. et al. (2017)	Norway	Quantitative	*N* = 30 834 of which: *n* = 59 children of par-ents with intellectual disability	Investigating changes in the prevalence of children of parents with intellectual disability and the frequency of children being placed in foster care
Wade C. et al. (2015)	Australia	Quantitative	*N* = 120 parents with intellectual disability	Investigating the impact of the mental health of parents with intellectual disability on the psychological well-being of their children

Weiber I. et al. (2019)	Sweden	Qualitative	$N = 4$ adult daughters of parents with intellectual disability	A retrospective study of perceived developmental opportunities from the perspective of daughters of parents with intellectual disability
Wickström M. et al. (2017)	Sweden	Quantitative	$N = 478\ 577$ children of which: $n = 2\ 749$ children of mothers with intellectual disability	Comparing the risk of harm, violence, and psychiatric disorders in children (birth to 7 years) of mothers with and without intellectual disability
Wołowicz-Ruszkowska A., McConnell D. (2017)	Poland	Qualitative	$N = 23$ adult children of mothers with intellectual disability	A retrospective study of perceived developmental opportunities from the perspective of children of mothers with intellectual disability

Source: own elaboration

FINDINGS

Research overview

Table 1 summarises the main methodological aspects of the 33 articles analysed. The studies were published between 1999 and 2022. They were conducted in nine countries: Australia, Canada, the Netherlands, Norway, Poland, Scotland, Sweden, the USA, and the United Kingdom. 20 studies (61%) were quantitative, 9 (27%) were qualitative, and 4 (12%) were mixed. The methods used were individual interviews (in 14 studies), self-report questionnaires (in 10 studies), analysis of data collected by government health systems and analysis of national records (in 9 studies), analysis of court documents (in 2 studies), observations (in the child's home in 1 study, in the laboratory in 1 study), and analysis of video recordings (in 2 studies).

The total number of participants in the studies ranged from 4 to 478 577. In 18 studies, the number of participants was less than 100; in 6 studies, it was between 100 and 500; and in 8 studies, it was more than 500. Although all the studies referred to the development of children of parents with intellectual disability, the participants in the studies were not only the children (in 17 studies) but also parents with intellectual disability (in 9 studies), mothers with intellectual disability (in 12 studies) or other people – social workers, psychologists, extended family, local authorities, and health professionals (in 3 studies). 22 of the 33 studies reported the age of the parents at the time of participation in the study (ranging from 18 to 58 years), while 6 studies reported only the age of the mother at the birth of her first child (ranging from 13 to 40 years). Regarding the age of the children, the studies looked at their development from the prenatal period to the end of the first year of life (6 studies) or from the age of 2 to 17 years (14 studies). In two retrospective studies where the participants were adult children of parents with intellectual disability (2 studies), their memories covered the whole period of childhood and adolescence. 11 studies included children from infancy to adulthood.

Prenatal to infant development

The most disturbing findings about the development of children of parents with intellectual disability come from studies tracking their development from the prenatal period through the perinatal period to infancy. Even at this early stage, maternal intellectual disability is associated with developmental problems in the children. Pregnant women with intellectual disability are more likely than women without intellectual disability to have pregnancy complications, a higher risk of caesarean section, and preterm birth, and their children are more likely to have a stillbirth, low birth weight, low Apgar scores, infant death within the first 12 months of life, and a higher need for rehospitalisation of mother and child after birth (Höglund et al., 2012; Mueller et al., 2019; Fairthorne et al., 2020; Rubenstein et al., 2021). The reasons for these phenomena are unclear. One hypothesis put forward by the authors of the studies is that is not uncommon for mothers with intellectual disability to have a generally poorer somatic condition. Intellectual disability is often associated with physical disability or may be part of a wider genetic syndrome – so it may be that a weaker physical condition, rather than the intellectual disability itself, impedes the effort of pregnancy and childbirth. The second hypothesis sees the reasons for the difficulties in mothers with intellectual disability seeking specialist help too late. Reduced intellectual functioning could potentially translate into a misunderstanding or difficulty in recognising distressing body signals. In many countries, people with intellectual disabilities also experience significant limitations in access to sex education, which translates into poor knowledge of female physiology in general, the course of a healthy pregnancy, etc. Misunderstanding or ignorance can potentially delay seeking medical or obstetric help. Thirdly, attention is also drawn to the inadequate preparation of gynaecologists, midwives, paediatricians, and other specialists to provide medical care to female patients with intellectual disability and their children – ignorance of the specifics of the cognitive functioning of people with intellectual disability may result in the same forms of communication (and content) being applied to them as to female patients within the intellectual norm – meanwhile, they may be largely misunderstood by the specialist.

Development from post-infancy to adolescence

Reports on the development of older children remain inconsistent. On the one hand, children of parents with intellectual disability have been found to be at increased risk of developmental delays, speech and language disorders, behavioral problems (more common in sons than in daughters), accidents, injuries, psychiatric disorders, psychosomatic disorders or lower school achievement than children of parents without intellectual disability (Keltner et al., 1999; Feldman, Walton-Allen, 2002; Emerson, Brigham, 2014; Powell, Parish, 2017; Wickström et al., 2017; Forslund et al., 2022). A large representative Australian study (Emerson, Brigham, 2014) found that children of parents with intellectual disability were significantly more likely than children of parents without intellectual disability to have developmental delays (30% of children of parents with intellectual disability vs. 5% of children of parents without intellectual disability), speech and language difficulties (26% vs. 5%), and behavioural problems (32% vs. 7%). On the other hand, other studies have found no deviation from developmental norms in social, physical, cognitive, and self-care domains for children of mothers with intellectual disability (McConnell et al., 2003) and no developmental differences compared to children of mothers without intellectual disability (Hindmarsh et al., 2015). One longitudinal study found an increased risk of poorer well-being for children of mothers with intellectual disability at ages three and five but not at age seven (Hindmarsh et al., 2017).

Few studies have attempted to examine the level of intellect of children of parents with intellectual disability. One study in the UK (McGaw et al., 2007), which included parents with moderate, mild, or borderline intellectual disabilities, found that 22% of their children had learning difficulties and attended special schools. A Swedish study (Wickström et al., 2017), which tracked the development of children born between 1999 and 2005 from birth to the age of seven, observed that children of mothers with intellectual disability were more likely to be diagnosed with intellectual disability (1.6%) than children of mothers without intellectual disability (.2%) (without specifying the degree of intellectual disability). A Canadian study with a small number of participants (Feldman, Walton-Allen, 2002) showed that children of parents with mild intellectual disability had lower levels of intelligence as measured by the WISC-R ($M = 80.54$ IQ) than children of parents without intellectual disability ($M = 102.88$ IQ).

Environmental factors in child development

Selected studies have attempted to identify environmental factors in the development of children of parents with intellectual disability. For example, a longitudinal study conducted in the USA found that a proportion of children of mothers with intellectual disability exhibit aggressive behaviour, but only in families where the income earned is close to the poverty line (Powell, Parish, 2017). The impact of the mental health of parents with intellectual disability on the well-being of children has also been observed. Mental health problems in parents with intellectual disability have been linked to cognitive and developmental difficulties in children (including attention deficit disorder, anxiety disorders, and autism) (McGaw et al., 2007). Higher levels of parental stress were associated with more frequent child behavioural problems (and social support reduced this association) (Meppelder et al., 2015; Wade et al., 2015). One study also found that low sensitivity and responsiveness in mothers with intellectual disabilities (which may be a direct result of cognitive limitations) led to the development of disorganised attachment in children (Lindberg et al., 2017). However, another study showed that a secure attachment style characterised the majority of children of mothers with intellectual disability studied, and only children of mothers with traumatic experiences were characterised by an insecure attachment style (Granqvist et al., 2014).

Research has shown that families with parents with intellectual disability are more likely to experience psychological abuse, and children may experience increased distress; additionally, emotional parentification is observed, and children may feel overburdened with responsibilities compared to their peers (Slayter, Jensen, 2019; Weiber et al., 2019). Increasing problems in families related to parenting inefficiencies lead to more children of parents with intellectual disabilities ending up in foster care (Booth, Booth, 2004; Tøssebro et al., 2017).

An important protective factor for the development of children of parents with intellectual disability has also been identified – this is the (variously conceptualised) social support provided to parents with intellectual disability. Support from social workers, volunteers, family, friends, and the local community is associated with positive outcomes for child development (Meppelder et al., 2015; Collings et al., 2017; Wołowicz-Ruszkowska, McConnell, 2017; Durling et al., 2018; MacIntyre et al., 2019; Weiber et al., 2019; Atkin, Kroese, 2022). Importantly, what emerges from the research is the need for support expressed by parents with intellectual disabilities and, on the part of their children, the need for the adult world to respond when parents fail to meet their responsibilities and the need to end family secrecy regarding parental intellectual disability. On the other hand, the social environment of families with parents with intellectual disability revealed difficulties in providing support and a lack of knowledge about appropriate ways of providing support without interfering too much with the parents' role. Several studies have shown that effective interventions can improve the parenting skills of parents with intellectual disability and protect the child from abuse, as well as increase the child's well-being or reduce symptoms of behaviour disorder in children (Augsberger et al., 2021; Hodes et al., 2017; Knowles et al., 2017).

DISCUSSION

The systematic review of the literature aimed to identify research directions concerning the development of children of parents with intellectual disabilities and to integrate the existing knowledge on this topic. The review showed that there is little research interest in this topic. Still, on the other hand, the research addresses very diverse threads – the development of children in the psychological, social, and physical spheres from the prenatal period to the threshold of adulthood.

The results showed that maternal intellectual disability is associated with an increased risk of developmental problems in the prenatal and infant period. During these particularly sensitive periods of development, when the child is completely dependent on adult care, the mother's intellectual disability may hypothetically make it difficult for her to recognise signals from her own body (during pregnancy) or from the child, and thus make it impossible to adapt an appropriate response to ensure the child's proper development. It is particularly important information for professionals working with families with parents with intellectual disabilities.

In the older years, when the child interacts more with other people or institutions (e.g. kindergarten, school), a number of factors other than the intellectual disability of the parent have been observed to influence the child's development, such as the socio-economic status of the family and the mental health status of the parent. Social support, the need for which was reported by both parents with intellectual disability and their children in the interviews conducted, appears to be particularly important. The results of the study indicate both reported and observed indirect (improved parental competence) and direct effects of social support on the normal development of children. It remains an open question to what extent the parental roles or tasks of parents with intellectual disabilities can be taken over by other adults in their environment, to what extent they provide support and when they potentially begin to disrupt the family structure. A major challenge is to determine the extent to which help is needed from outside the family or the nature of the support provided.

However, what now seems to require more in-depth research is the nature of the children's developmental difficulties. Research to date suggests that children of parents with intellectual disabilities are at increased risk, and some protective factors in the form of social support have been identified. However, surprisingly little is known, for example, about the intellectual level of the children of parents with intellectual disability – several studies have shown that, on average, the children of parents with intellectual disability have a lower level of intelligence than the children of parents without intellectual disability. However, there is a lack of detailed data on how many children of parents with lowered intellectual functioning are also diagnosed with intellectual disability, to what extent, and also – what the intellectual level of those children who fall within the broad intellectual norm is.

The weaknesses of the review – the restriction to two bases and English-language articles – probably limited the results of the study. Nevertheless, the development of children of parents with intellectual disabilities remains an area of only basic understanding. A number of further research needs emerged from the literature review conducted.

Adapting research instruments to the abilities of the parent and the child with intellectual disability – research instruments need to be adapted to the cognitive abilities of the person with intellectual disability (if a parent is involved in the study), but in the case of people with mild intellectual disability, the need for modification is not always necessary, or the modifications need to be less about content and more about changing the form, from written to spoken. It may, according to some authors (e.g. Feldman, 2002; Feldman, Aunos, 2020), encourage researchers to intensify empirical research on this specific group.

1. Including children's and parents' perspectives – many studies focus only on mothers; more studies of mothers, fathers, and children from the same families are needed to provide different perspectives in assessing families' parenting capacity.
2. The need for intergenerational research – this would allow a broader perspective to be taken, e.g. including the impact of a parent's previous experience of intellectual disability (including their family of origin) on their parenting style, the child's development and the functioning of the whole family system.
3. The need for research from the field of positive psychology – to find out how the personal qualities and personal history of the parent with intellectual disability (and not just the intellectual disability itself) affect parenting, family functioning and child development.
4. Research on the needs of professionals and supporters of parents with intellectual disabilities and their children – basic and applied, in order to be able to equip the social and institutional environment with the most effective techniques and forms of support.

REFERENCES

Papers selected for the systematic review are marked with asterisk (*).

*Atkin C., Kroese B.S. (2022), Exploring the experiences of independent advocates and parents with intellectual disabilities, following their involvement in child protection proceedings. *Disability & Society*, 37(9), 1456–1478. doi: 10.1080/09687599.2021.1881884.

*Augsberger A., Zeitlin W., Rao T., Weisberg D., Toraif N. (2021), Examining a child welfare parenting intervention for parents with intellectual disabilities. *Research on Social Work Practice*, 31(1), 65–74. doi: 10.1177/1049731520958489.

Aunos M., Feldman M., Goupil G. (2008), Mothering with intellectual disabilities: Relationship between social support, health and well-being, parenting and child behaviour outcomes. *Journal of Applied Research in Intellectual Disabilities*, 21, 320–330. doi: 10.1111/j.1468-3148.2008.00447.x.

*Aunos M., Goupil G., Feldman M. (2003), Mothers with intellectual disabilities who do or do not have custody of their children. *Journal on Developmental Disabilities*, 10, 65–79.

Booth T.A., Booth W. (1998), *Growing Up with Parents Who Have Learning Difficulties*. London: Psychology Press.

*Booth T., Booth W. (2004), Findings from a court study of care proceedings involving parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1(3–4), 179–181. doi: 10.1111/j.1741-1130.2004.04032.x.

*Collings S., Grace R., Llewellyn G. (2017), The role of formal support in the lives of children of mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 492–500. doi: 10.1111/jar.12361.

Collings S., Llewellyn G. (2012), Children of parents with intellectual disability: Facing poor outcomes or faring okay? *Journal of Intellectual and Developmental Disability*, 37(1), 65–82. doi: 10.3109/13668250.2011.648610.

*Collings S., Llewellyn G., Grace R. (2017), Home and the social worlds beyond: Exploring influences in the lives of children of mothers with intellectual disability. *Child: Care, Health and Development*, 43(5), 697–708. doi: 10.1111/cch.12456.

*Durling E., Chinn D., Scior K. (2018), Family and community in the lives of UK Bangladeshi parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1133–1143. doi: 10.1111/jar.12473.

*Emerson E., Brigham P. (2014), The developmental health of children of parents with intellectual disabilities: Cross sectional study. *Research in Developmental Disabilities*, 35(4), 917–921. doi: 10.1016/j.ridd.2014.01.006.

*Fairthorne J., Bourke J., O'Donnell M., Wong K., de Klerk N., Llewellyn G., Leonard H. (2020), Pregnancy and birth outcomes of mothers with intellectual disability and their infants: advocacy needed to improve well-being. *Disability and Health Journal*, 13(2), 100871. doi: 10.1016/j.dhjo.2019.100871.

Feldman M.A. (1994), Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities*, 15, 299–332. doi: 10.1016/0891-4222(94)90009-4.

Feldman M.A. (2002), Parents with intellectual disabilities and their children: Impediments and supports. In: D. Griffiths, P. Federoff (eds.), *Ethical Dilemmas: Sexuality and Developmental Disability*, 255–292. Kingston, NY: NADD Press.

Feldman M.A., Aunos M. (2020), Recent trends and future directions in research regarding parents with intellectual and developmental disabilities. *Current Developmental Disorders Reports*, 7, 173–181. doi: 10.1007/s40474-020-00204-y.

Feldman M.A., Case L. (1999), Teaching child-care and safety skills to parents with intellectual disabilities through self-learning. *Journal of Intellectual & Development Disability*, 24, 27–44. doi: 10.1080/13668259900033861.

*Feldman M.A., Walton-Allen N. (2002), Effects of maternal mental retardation and poverty on intellectual, academic, and behavioral status of school-age children. *The best of AAMR: Families and mental retardation: A collection of notable AAMR journal articles across the 20th century*, 235–246.

Fornalik I. (2020), Edukacja seksualna osób ze spektrum autyzmu i osób z niepełnosprawnością intelektualną [Sexual education of people on the ASD spectrum and people with intellectual disability]. *Dziecko Krzywdzone. Teoria, Badania, Praktyka*, 19(2), 80–107.

*Forslund T., Lindberg L., Granqvist P. (2022), Behavior problems among children of mothers with mild intellectual disability: The role of maternal sensitivity, trauma history, and intelligence. *Disabilities*, 2(3), 488–500. doi: 10.3390/disabilities2030035.

*Granqvist P., Forslund T., Fransson M., Springer L., Lindberg L. (2014), Mothers with intellectual disability, their experiences of maltreatment, and their children's attachment representations: A small-group matched comparison study. *Attachment & Human Development*, 16(5), 417–436. doi: 10.1080/14616734.2014.926946.

Higgins J.P.T., Green S. (2011), *Cochrane Handbook for Systematic Reviews of Interventions*. London: The Cochrane Collaboration.

*Hindmarsh G., Llewellyn G., Emerson E. (2015), Mothers with intellectual impairment and their 9-month-old infants. *Journal of Intellectual Disability Research*, 59(6), 541–550. doi: 10.1111/jir.12159.

*Hindmarsh G., Llewellyn G., Emerson E. (2017), The social-emotional well-being of children of mothers with intellectual impairment: A population-based analysis. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 469–481. doi: 10.1111/jar.12306.

*Hodes M.W., Meppelder M., de Moor M., Kef S., Schuengel C. (2017), Alleviating parenting stress in parents with intellectual disabilities: A randomized controlled trial of a video-feedback intervention to promote positive parenting. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 423–432. doi: 10.1111/jar.12302.

*Höglund B., Lindgren P., Larsson M. (2012), Newborns of mothers with intellectual disability have a higher risk of perinatal death and being small for gestational age. *Acta Obstetricia et Gynecologica Scandinavica*, 91(12), 1409–1414. doi: 10.1111/j.1600-0412.2012.01537.x.

Jurczyk M. (2018), *Seksualność osób z niepełnosprawnością intelektualną. Nauczycielskie (de)konstrukcje* [The sexuality of people with intellectual disability. The teachers' (de)constructions]. Warszawa: Difin.

*Keltner B.R., Wise L.A., Taylor G. (1999), Mothers with intellectual limitations and their 2-year-old children's developmental outcomes. *Journal of Intellectual and Developmental Disability*, 24(1), 45–57. doi: 10.1080/13668259900033871.

Kijak R. (2019), *Rodzice z niepełnosprawnością intelektualną* [Parents with intellectual disability]. Warszawa: PWN.

*Knowles C., Blakely A., Hansen S., Machalicek W. (2017), Parents with intellectual disabilities experiencing challenging child routines: A pilot study using embedded self-determination practices. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 433–444. doi: 10.1111/jar.12303.

Kościelska M. (2004), *Niechciana seksualność. O ludzkich potrzebach osób niepełnosprawnych intelektualnie* [The unwanted sexuality. About the human needs of people with intellectual disability]. Warszawa: Wydawnictwo Czarna Owca.

Lew-Starowicz Z. (2005), Seksualność niepełnosprawnej młodzieży [The sexuality of disabled youths]. In: J. Głodkowska, A. Gieryński (eds.), *Seksualność osób z niepełnosprawnością intelektualną* [The sexuality of people with intellectual disability], 28–34. Warszawa: Wydawnictwo Akademii Pedagogiki Specjalnej.

*Lindberg L., Fransson M., Forslund T., Springer L., Granqvist P. (2017), Maternal sensitivity in mothers with mild intellectual disabilities is related to experiences of maltreatment and predictive of child attachment: A matched-comparison study. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 445–455. doi: 10.1111/jar.12300.

Llewellyn G. (1995), Relationship and social support: Views of parents with mental retardation/intellectual disability. *Mental Retardation*, 33, 349–363.

*MacIntyre G., Stewart A., McGregor S. (2019), The double-edged sword of vulnerability: Explaining the persistent challenges for practitioners in supporting parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(6), 1523–1534. doi: 10.1111/jar.12647.

Maulik P.K., Mascarenhas M.N., Mathers C.D., Dua T., Saxena S. (2011), Prevalence of intellectual disability: A meta-analysis of population based studies. *Research in Developmental Disabilities*, 32, 419–436. doi: 10.1016/j.ridd.2010.12.018.

McConnell D., Feldman M., Aunos M. (2017), Parents and parenting with intellectual disabilities: An expanding field of research. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 419–422. doi: 10.1111/jar.12362.

*McConnell D., Llewellyn G., Mayes R., Russo D., Honey A. (2003), Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual & Developmental Disability*, 28(2), 122–134. doi: 10.1111/jar.12362.

*McGaw S., Shaw T., Beckley K. (2007), Prevalence of psychopathology across a service population of parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities*, 4(1), 11–22. doi: 10.1111/j.1741-1130.2006.00093.x.

*Meppelder M., Hodes M., Kef S., Schuengel C. (2015), Parenting stress and child behaviour problems among parents with intellectual disabilities: The buffering role of resources. *Journal of Intellectual Disability Research*, 59(7), 664–677. doi: 10.1111/jir.12170.

Mørch W.-T., Sår J., Andersgård A. (1997), Mentally retarded persons as parents: Prevalence and the situation of their children. *Scandinavian Journal of Psychology*, 38, 343–348. doi: 10.1111/1467-9450.00044.

*Mueller B.A., Crane D., Doody D.R., Stuart S.N., Schiff M.A. (2019), Pregnancy course, infant outcomes, rehospitalization, and mortality among women with intellectual disability. *Disability and Health Journal*, 12(3), 452–459. doi: 10.1016/j.dhjo.2019.01.004.

*Perkins T.S., Holburn S., Deaux K., Flory M.J., Vietze P.M. (2002), Children of mothers with intellectual disability: stigma, mother–child relationship and self-esteem. *Journal of Applied Research in Intellectual Disabilities*, 15(4), 297–313. doi: 10.1046/j.1468-3148.2002.00140.x.

Pieńkowska E. (2021), *Rodzina wobec seksualności dziecka z niepełnosprawnością intelektualną* [The family towards sexuality of the child with itnellectual disability]. Warszawa: Difin.

*Powell R.M., Parish S.L. (2017), Behavioural and cognitive outcomes in young children of mothers with intellectual impairments. *Journal of Intellectual Disability Research*, 61(1), 50–61. doi: 10.1111/jir.12308.

*Rubenstein E., Ehrenthal D.B., Mallinson D.C., Bishop L., Kuo H.H., Durkin M.S. (2021), Birth outcomes affecting infants of mothers with intellectual and developmental disabilities. *Paediatric and Perinatal Epidemiology*, 35(6), 706–716. doi: 10.1111/ppe.12765.

*Slayter E.M., Jensen J. (2019), Parents with intellectual disabilities in the child protection system. *Children and Youth Services Review*, 98, 297–304. doi: 10.1016/j.childyouth.2019.01.013.

*Tøssebro J., Midjo T., Paulsen V., Berg B. (2017), Prevalence, trends and custody among children of parents with intellectual disabilities in Norway. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 533–542. doi: 10.1111/jar.12304.

Traustadóttir R., Sigurjónsdóttir H.B. (2005), Adult-children of mothers with intellectual disabilities: Three life histories. In: A. Gustavsson, J. Sandrin, R. Traustadóttir, J. Tøssebro (eds.), *Resistance, Reflections and Change: Nordic Disability Research*, 147–161. Lund: Studentlitteratur.

Tymchuk A.J., Andron L., Rahbar B. (1988), Effective decision-making/problem-solving training with mothers who have mental retardation. *American Journal on Mental Retardation*, 92, 510–516.

Wade C., Llewellyn G., Matthews J. (2008), Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 351–366. doi: 10.1111/j.1468-3148.2008.00449.x.

*Wade C., Llewellyn G., Matthews J. (2015), Parent mental health as a mediator of contextual effects on parents with intellectual disabilities and their children. *Clinical Psychologist*, 19(1), 28–38. doi: 10.1111/cp.12055.

*Weiber I., Tengland P.A., Berglund J.S., Eklund M. (2019), Everyday life when growing up with a mother with an intellectual or developmental disability: Four retrospective life-stories. *Scandinavian Journal of Occupational Therapy*, 27, 418–430. doi: 10.1080/11038128.2018.1554087.

*Wickström M., Höglund B., Larsson M., Lundgren M. (2017), Increased risk for mental illness, injuries, and violence in children born to mothers with intellectual disability: A register study in Sweden during 1999–2012. *Child Abuse & Neglect*, 65, 124–131. doi: 10.1016/j.chiabu.2017.01.003.

*Wołowicz-Ruszkowska A., McConnell D. (2017), The experience of adult children of mothers with intellectual disability: A qualitative retrospective study from Poland. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 482–491. doi: 10.1111/jar.12322.