Beyond the individual: a contextual perspective on mental health in children with mild to borderline intellectual disabilities

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Maxine Storm

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Maxine Margaréta Carmen Storm

COLOPHON

Beyond the individual. A contextual perspective on mental health in children with mild to borderline intellectual disabilities

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Beyond the individual

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Chapter 1

General introduction

The following case is entirely fictional and does not represent any real individual.

Imagine a 12-year-old boy, whom we will refer to as Ben, recently diagnosed with a mild intellectual disability. At school, Ben struggles with concentration, often becomes frustrated and angry, and frequently disrupts the classroom. Teachers tend to interpret his behavior as defiance rather than distress, and his peers avoid him. At home, Ben withdraws socially and exhibits oppositional behavior when his parents attempt to engage with him. Concerned about his escalating emotional and behavioral difficulties, a professional from child welfare services referred him to The Banjaard, a specialized outpatient mental health care center for children with intellectual disabilities. Although Ben and his parents attended the initial assessment, maintaining consistent engagement in the treatment plan has been challenging: his parents are difficult to reach, and appointments are frequently missed or cancelled.

When we take a closer look at Ben's broader environment, a complex picture emerges. At home, Ben shares a cramped bedroom with his younger twin brothers. He lives with them, his two older sisters, and both parents. His father works irregular hours as a window cleaner, making it difficult to attend Ben's appointments without risking his job. His father also has a history of traumatic experiences and shows signs of mood instability, often reacting to stress with anger or aggression. Ben's mother, currently unemployed, carries the main burden of managing the household. However, chronic health problems, including frequent headaches, symptoms of depression and anxiety, and sleep problems, affect her ability to function daily. Financial stress places a constant strain on the family, further limiting their ability to provide consistent emotional and practical support, including reliable transportation to Ben's mental health appointments. Neither parent completed their education, leaving them with little understanding of how best to support Ben's learning and development. They often feel incapable when trying to help him and find it difficult to communicate effectively with his school about his needs and challenges.

Ben's living environment adds yet another layer of adversity. The family rents a small apartment in a densely populated urban area. The building has numerous problems: thin walls, constant drafts from poorly sealed windows, and leaky ceilings that the landlord has repeatedly failed to repair. Noise from neighbouring apartments is ever-present, and the community is marked by high rates of unemployment, low educational attainment, and frequent violence.

The case of Ben illustrates that developmental vulnerabilities, challenging family dynamics, socio-economic hardship, and environmental stressors, intertwine to shape a child's daily life. Children like Ben often enter specialized mental health care due to symptoms such as anger, anxiety, and social withdrawal. However, these symptoms are not isolated; they are expressions of deeper, interconnected struggles rooted in the broader context of a child's life. Although research increasingly acknowledges the importance of context in child mental health, children with both intellectual disabilities and mental health problems have remained largely underexamined from this perspective. Understanding these layers of adversity is crucial in determining how care can best respond to the needs of children like Ben.

Therefore, this dissertation aims to understand not just that children like Ben experience mental health problems, but whether and to what extent these problems relate to the broader conditions in which they live. Therefore, the emphasis is placed on identifying contextual factors such as socio-economic hardship, parental health problems, and neighborhood disadvantage. The dissertation draws on a series of interrelated studies to examine multiple levels of a child's environment in which they grow up. Together, these studies contribute to a more comprehensive view of how contextual factors across multiple life domains relate to mental health in this population.

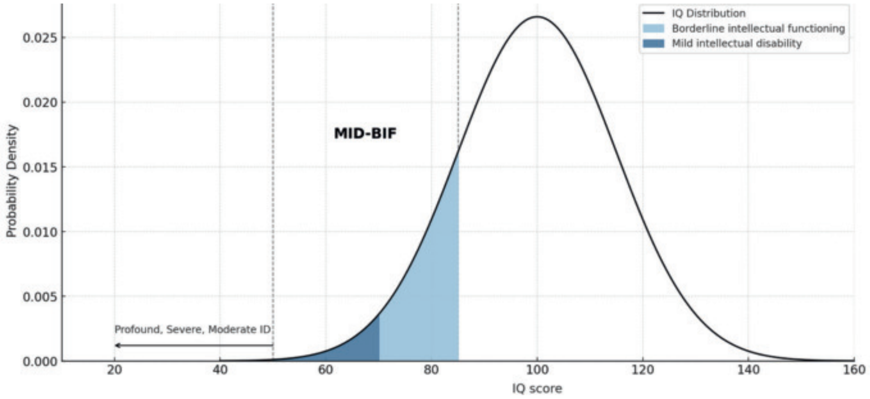
This chapter outlines the conceptual, empirical, and methodological foundation for this dissertation. It begins by defining key concepts and outlining the theoretical framework. It then identifies relevant knowledge gaps, describes the methodological approach, and presents the structure of the dissertation.

Definitions of key concepts & theoretical framework

Intellectual Disability

According to the DSM-5, Intellectual Disability (ID) is a neurodevelopmental disorder characterized by significant deficits in intellectual functioning (e.g., reasoning, problem-solving, planning, abstract thinking) and adaptive behavior (e.g., social and practical skills), with onset before the age of 18 years (American Psychiatric Association, 2022; Schalock et al., 2021). The severity of ID is classified as mild, moderate, severe, or profound, based on the level of support required for daily functioning.

Figure 1. Normal Distribution of IQ Scores and ID severity categories



Despite this severity classification, variation exists across clinical, educational, and research contexts in how children with cognitive and adaptive difficulties are categorized, particularly with regard to those functioning in the borderline range (Peltopuro et al., 2014). According to most international diagnostic frameworks, individuals with borderline intellectual functioning (BIF) are not formally classified as having an ID. Nevertheless, there is growing recognition that many individuals with BIF experience developmental and adaptive challenges comparable to individuals with mild intellectual disabilities (MID; Hronis, 2021; Peltopuro et al., 2023).

Reflecting this comparability, Dutch policy and clinical practice have adopted a broader and more inclusive conceptualization of intellectual functioning. This approach considers both cognitive capacity and adaptive behavior across the full MID to BIF spectrum (Douma, 2018; Wieland et al., 2014; Woittiez et al., 2018). In line with this inclusive approach, children with BIF in the Netherlands are typically eligible for the same specialized support services as children with MID, particularly when they experience significant psychosocial or adaptive difficulties (Hronis, 2021; Schalock et al., 2021).

This dissertation focuses on children whose intellectual functioning falls within the MID (IQ 50–70) to BIF (IQ 70–85) range and who also exhibit significant deficits in adaptive behavior. Figure 1 illustrates their position on the normal distribution of IQ scores, with the MID range highlighted in dark blue and the adjacent BIF range in light blue. Reflecting the Dutch policy and practice context, as well as previous research (e.g., Seelen-de Lang et al., 2019; Te Brinke et al., 2021), these children are collectively referred to as the MID-BIF group in this dissertation.

Mental health problems in children with MID-BIF

Research investigating children across all severity levels of ID consistently shows that they have substantially higher rates of mental health problems compared to their typically developing peers (Totsika et al., 2022). A meta-analysis reported that between 38% and 49% of youth with ID experience clinically significant emotional or behavioral difficulties (Buckley et al., 2020). This prevalence is nearly twice the rate observed in the general population (Verhulst, 1997). Rates of ADHD, anxiety, and conduct disorders are particularly elevated among youth with ID. These problems often emerge early in life, tend to persist over time, and result in substantial impairments in daily functioning, including difficulties in social relationships, challenges in school adjustment, and reduced prospects for future independence (Einfeld et al., 2011; Kolaitis, 2008; Wallander et al., 2006).

Moving from ID in general to the MID-BIF group specifically, evidence suggests that these children experience psychiatric disorders at similarly elevated rates (Dekker & Koot, 2003; Emerson et al., 2010; Kok et al., 2016). These children show elevated rates of both internalizing and externalizing problems, and symptoms frequently continue into adolescence. This raises a key question: Which factors are associated with the heightened risk of mental health problems among children with MID and BIF?

Several perspectives offer possible explanations. From a biological standpoint, researchers point to genetic vulnerabilities and neurodevelopmental differences that may underlie both cognitive and emotional difficulties (e.g., Dykens et al., 2000). Psychological perspectives emphasize challenges in emotional regulation, self-awareness, and coping skills, which further compromise mental health in this population (e.g., Nader-Grosbois, 2014). In addition to these individual-level perspectives, a growing body of research highlights the role of contextual factors on child mental health (Macintyre et al., 2018). Building on this line of research, this dissertation adopts a contextual perspective on the mental health of children with MID-BIF.

Contextual factors

In this dissertation, *contextual factors* – or *social determinants* - refer to aspects of a child's broader living environment that may be associated with their mental health. These include characteristics of the family (e.g., family structure, financial hardship, parental mental and somatic health), housing conditions (e.g., housing tenure), and neighborhood context (e.g., urbanization class). Available research suggests that adverse contextual factors are particularly prevalent and persistent in the lives of children with ID. These children are more likely than their typically developing peers to grow up in families affected by poverty, financial strain, and limited access to social and educational resources (Emerson et al., 2006; Emerson & Hatton, 2007a, 2007c). In addition, these disadvantages often intersect with broader contextual factors such as substandard housing and neighborhood deprivation (Emerson, 2021a).

While some existing studies provide important insight into the structural disadvantages faced by many children with ID, they typically do not distinguish between ID severity levels. As a result, relatively little is known about contextual factors in relation to mental health problems in children with MID-BIF. This lack of differentiation is problematic, as the role of these contextual factors may differ depending on the severity of ID. Children with more severe forms of ID are typically identified early based on clearly observable cognitive and adaptive impairments (Harris, 2006). They are often referred to care on the basis of these impairments alone (Institute of Medicine et al., 2015; Patel et al., 2020). By comparison, children with MID-BIF may present with less obvious developmental delays. As a result, they are often referred to care at a later stage, typically when mental health problems become more apparent (Doyle et al., 2022; Peltopuro et al., 2023). In their case, entry into care may depend more heavily on the presence of contextual adversity. In stable and supportive environments, families and schools may buffer their mental health difficulties, reducing the perceived urgency for professional intervention (Vervoort-Schel et al., 2021). However, in the face of (cumulative) adverse contextual factors, such as poverty, unstable home situations, or parental health problems, their mental health problems may become more visible and escalate.

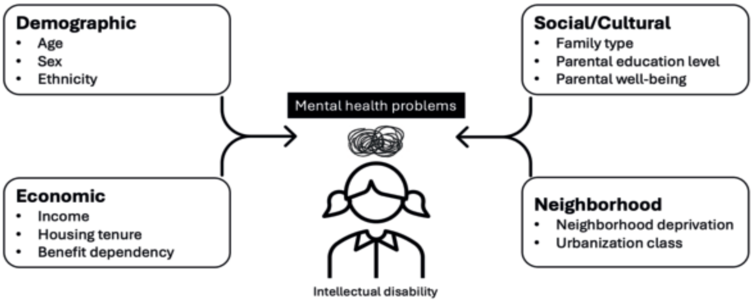
To conceptualize the wide range of contextual factors, several theoretical models have been developed. These models differ in emphasis and scope, but they share the recognition that individuals develop and function within broader social and environmental systems. One of the most influential frameworks in the social sciences is Bronfenbrenner's ecological systems theory, which describes human development as shaped by interactions across multiple levels of the environment (Bronfenbrenner, 1979). These include the microsystem (e.g., family, school), the exosystem (e.g., neighborhood conditions), and the macrosystem (e.g., cultural values, socioeconomic systems), all of which influence development over time through what Bronfenbrenner termed the chronosystem. The model highlights that children do not develop in isolation, but within a web of interrelated and evolving environmental contexts.

In medical and psychological sciences, Engel's biopsychosocial model (1977) has played a similarly foundational role. It argues that biological (e.g., genetics), psychological (e.g., coping mechanisms), and social (e.g., relationships, socioeconomic status) factors are all interdependent determinants of health and illness (Engel, 1977).

Building on Bronfenbrenner's ecological model, a relatively recent framework by Lund et al. (2018) provides a more operational approach to categorizing contextual factors, referred to as the social determinants of mental health. Originally developed to guide global mental health research and policy, the framework classifies these determinants into five interrelated domains: demographic, economic, neighborhood, environmental events, and social/cultural. It offers a practical structure for capturing the complexity of contextual influences on mental health across diverse settings.

In this dissertation, we draw on the framework proposed by Lund et al. (2018), organizing these factors into four interrelated life domains: (1) Demographic, (2) Economic, (3) Social/Cultural, and (4) Neighborhood. The domain of environmental events (e.g., conflict, natural disasters) was excluded, as these factors are less relevant in the present context. An overview of the selected domains and illustrative contextual factors is provided in Figure 2. These domains serve as a conceptual guide for the studies presented in this dissertation.

Figure 2. Overview of domains and example contextual factors



Identifying Gaps

Despite the growing recognition of the importance of broader contextual factors on mental health, relatively little is known about whether these factors relate to mental health in children with ID, particularly when distinguishing between different levels of ID severity. The two major existing reviews in this area have primarily examined individual-level characteristics, including age, gender, and severity of ID (Einfeld et al., 2011; Witwer & Lecavalier, 2007). This limited scope highlights the need for an up-to-date and more systematic synthesis of the available empirical evidence on contextual factors in this population. Therefore, the first step in this dissertation is a systematic literature review (Chapter 2), aimed at mapping and structuring current knowledge in this field. While the upcoming review will provide a more comprehensive and systematic overview, several preliminary knowledge gaps can already be outlined:

First, while some studies have shown that children with ID are more likely to live in poverty (Emerson, 2021), we still know little about how specific contextual factors, both within and beyond poverty, relate to their mental health. Factors such as household composition, financial strain, parental education, and neighborhood deprivation may each play a role, but research in this area remains scarce. This knowledge gap may be particularly relevant for children with MID-BIF, whose difficulties are often less visible and whose access to support may depend more strongly on contextual conditions.

Second, limited insight exists into whether such contextual factors operate independently or co-occur in broader patterns of disadvantage, an important consideration for understanding cumulative burden and risk clustering (Emerson & Hatton, 2007b). Children growing up in environments characterized by multiple disadvantages may face co-occurring stressors that overlap and potentially reinforce each other. Together, these stressors may add to psychological vulnerability, especially in children with ID who already experience difficulties with adaptive functioning.

Third, it is unknown whether the associations between contextual disadvantage and mental health differ across groups of children with varying diagnoses or levels of treatment intensity. Identifying such subgroup differences is important, as it may reveal that certain clinical profiles are more vulnerable to contextual risks than others, which has implications for tailoring support and intervention strategies.

Fourth, little is known about whether parental health is associated with mental health problems in children with MID-BIF. Addressing this gap is important for advancing our understanding of intergenerational health vulnerability, particularly in families exposed to socioeconomic adversity (Reiss, 2013).

Against this background, the overarching aim of this dissertation is to examine the associations between contextual factors and mental health problems in these children with MID-BIF. It is structured around three interrelated overarching sub-aims:

1. To review and structure the current empirical evidence on associations between contextual factors and mental health in youth with ID;
2. To investigate whether (patterns of co-occurring) disadvantage across multiple life domains relate to mental health problems in youth with MID-BIF, including variation across clinical subgroups;
3. To explore the association between parental health and child mental health in children with MID-BIF.

Together, these sub-aims contribute to an integrated understanding of the multiple levels of the child's environment, moving beyond individual traits to highlight contextual patterns of risk.

Methodological Approach

This dissertation adopts a novel, register-based research design that integrates routinely collected data from multiple administrative and clinical sources. These linked datasets form the methodological foundation of the empirical studies presented in Chapters 3, 4, and 5. Table 1 provides an overview of all chapters and their key characteristics.

Table 1. Overview of the studies included in this dissertation

Chapter	Sub-aim	Study design	N	Relevant domains	Data sources
2	1	Systematic literature review	51 studies	Demographic, economic, social/cultural, neighborhood	Published peer-reviewed studies
3	2	Cross-sectional population-based case–control study	19,632 children	Demographic, economic, social/cultural, neighborhood	SN microdata, mental health care records, municipality data
4	2	Cross-sectional population-based study with subgroup analyses	10,452 children	Demographic, economic, social/cultural	SN microdata, mental health care records
5	3	Cross-sectional comparative study	22,533 parents: 12,375 mothers 10,158 fathers	Social/cultural	SN microdata, mental health care records, general practitioner records

Note. SN = Statistics Netherlands

Extramural LUMC Academic Network

The empirical studies in this dissertation were based on custom linkages across different data sources, made possible through the regional Extramural LUMC Academic Network (ELAN). ELAN is a population-based data infrastructure that supports research on population health, integrated care, and the social determinants of health (Ardesch et al., 2023; Kist et al., 2024). The infrastructure facilitates secure linkage of routinely collected data from regional general practitioners, hospitals, mental health care providers, and municipal records in the province of South Holland, the Netherlands. This is complemented by nationwide administrative registers, including microdata of Statistics Netherlands (CBS in Dutch). This combination results in a large and diverse population-based resource that is updated annually. Its unique capacity to integrate pre-existing population-level data across several life domains makes it particularly well-suited for examining interrelated patterns of health, care, and social disadvantage. These linkages enabled us to reconstruct individual- and family-level trajectories of care, adversity and context.

Rationale for Register-Based Design

The choice for a register-based observational design was driven by both practical and conceptual considerations.

Practically, this approach allowed for the inclusion of families who are often underrepresented in empirical research due to high caregiving demands and complex life circumstances (Lennox et al., 2005). By relying on pre-existing data, this design avoided participant burden and reduced the risk of selection bias commonly associated with survey or interview-based studies. In addition, the large-scale coverage of routinely collected registers ensured sufficient statistical power to study subgroups.

Conceptually, linking routinely collected data across multiple life domains provided the basis for adopting a contextual and ecological perspective on child mental health. Intergenerational linkages enabled the examination of adversity within families, including associations between parental and child health. In addition, the design facilitated the identification of cumulative patterns of vulnerability.

Children with MID-BIF and mental health problems could be identified through their receipt of specialized outpatient mental health care, as documented in routinely collected mental health care data. The use of this data ensured that all included cases had been professionally assessed for significant mental health problems.

Altogether, this register-based approach offers a strong foundation for examining the mental health of children with MID-BIF and mental health problems in their broader context, and for identifying structural patterns in contextual adversity. A critical reflection on the methodological approach used in this dissertation is provided in Chapter 6.

Study population

The empirical studies included large samples of children aged 0–17 living in urban or suburban areas of The Hague or surrounding regions (The Netherlands). Two out of three studies (Chapter 3 and 5) employed a comparative design with the following groups:

1. Children with MID-BIF receiving outpatient mental health care (group A);
2. Children receiving outpatient mental health care but without MID-BIF (group B);
3. Children from the general population, matched on age and sex, living in the same residential area (group C).

As described above, receipt of specialized outpatient care was used as an indicator of clinically relevant mental health problems. Children from the general population were drawn from national registry data. This selection strategy enabled direct comparisons between children with MID-BIF and mental health problems (group A) and two reference groups (B and C). This allowed for the identification of vulnerabilities specific to the children with MID-BIF and mental health problems.

Outline of the current thesis

This dissertation is structured around a series of studies, each addressing one of the three sub-aims.

Chapter 2 presents a systematic literature review synthesizing existing empirical evidence on associations between social determinants of mental health and mental health problems in youth with ID. The review highlights both risk and protective contextual factors, providing a conceptual foundation for the subsequent empirical work.

Chapter 3 presents a population-based case–control study examining associations between social determinants of mental health across several life domains and mental health problems in youth with MID-BIF. Children with MID-BIF and mental health problems (group A) are compared to peers with mental health problems without MID-BIF (group B) and to matched controls from the general population (group C). Through multivariate analyses, this chapter identifies unique contextual vulnerabilities among children with MID-BIF and mental health problems relative to reference groups.

Chapter 4 builds on Chapter 3 by extending the examination of socio-economic disadvantages among children with MID-BIF and mental health problems (group A). First, their socio-economic conditions are compared to those of matched controls from the general population (group C). Second, the chapter assesses the accumulation of co-occurring socio-economic disadvantages. Finally, subgroup analyses examine whether these disadvantages vary within group A by diagnostic profile and by the intensity of mental health care received.

Chapter 5 examines the somatic and mental health of parents of children with MID-BIF and mental health problems (group A), using linked general practitioner health records. The presence and diversity of parental health problems are compared with those of parents of children with mental health problems without MID-BIF (group B) and with parents from the general population (group C), providing insight into intergenerational health disadvantage.

Chapter 6 summarizes the main findings across all studies and reflects on their contribution to understanding contextual factors in the mental health of children with MID-BIF. This chapter also discusses methodological considerations and outlines implications for clinical practice, policy, research, and professional training.

References

American Psychiatric Association. (2022). *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR). American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890425787

Ardesch, F. H., Meulendijk, M. C., Kist, J. M., Vos, R. C., Vos, H. M. M., Kiefte-de Jong, J. C., Spruit, M., Bruijnzeels, M. A., Bussemaker, M. J., Numans, M. E., & Struijs, J. N. (2023). The introduction of a data-driven population health management approach in the Netherlands since 2019: The Extramural LUMC Academic Network data infrastructure. *Health Policy*, *132*, 104769. https://doi.org/10.1016/j.healthpol.2023.104769

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press. https://doi.org/10.4159/9780674028845

Buckley, N., Glasson, E. J., Chen, W., Epstein, A., Leonard, H., Skoss, R., Jacoby, P., Blackmore, A. M., Srinivasjois, R., Bourke, J., Sanders, R. J., & Downs, J. (2020). Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and meta-analysis. *Australian & New Zealand Journal of Psychiatry*, *54*(10), 970–984. https://doi.org/10.1177/0004867420924101

Dekker, M. C., & Koot, H. M. (2003). DSM-IV Disorders in Children With Borderline to Moderate Intellectual Disability. I: Prevalence and Impact. *Journal of the American Academy of Child & Adolescent Psychiatry*, *42*(8), 915–922. https://doi.org/10.1097/01.CHI.0000046892.27264.1A

Douma, J. (2018). *Jeugdigen en (jong)volwassenen met een licht verstandelijke beperking: Kenmerken en de gevolgen voor diagnostisch onderzoek en (gedrags)interventies*. Landelijk Kenniscentrum LVB.

Doyle, A., O'Sullivan, M., Craig, S., & McConkey, R. (2022). Predictors of access to healthcare professionals for people with intellectual disability in Ireland. *Journal of Intellectual Disabilities*, *26*(1), 3–17. https://doi.org/10.1177/1744629520937835

Dykens, E. M., Hodapp, R. M., & Finucane, B. M. (2000). *Genetics and mental retardation syndromes: A new look at behavior and interventions*. Paul H. Brookes Pub. Co.

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability, 36*(2), 137–143. https://doi.org/10.1080/13668250.2011.572548

Emerson, E. (2021). Social and Environmental Determinants of Health Among People With Disabilities. In E. Emerson, *Oxford Research Encyclopedia of Global Public Health*. Oxford University Press. https://doi.org/10.1093/acrefore/9780190632366.013.325

Emerson, E., Einfeld, S., & Stancliffe, R. J. (2010). The mental health of young children with intellectual disabilities or borderline intellectual functioning. *Social Psychiatry and Psychiatric Epidemiology*, *45*(5), 579–587. https://doi.org/10.1007/s00127-009-0100-y

Emerson, E., & Hatton, C. (2007a). Contribution of Socioeconomic Position to Health Inequalities of British Children and Adolescents With Intellectual Disabilities. *American Journal on Mental Retardation*, *112*(2), 140. https://doi.org/10.1352/0895-8017(2007)112[140:COSPTH]2.0.CO;2

Emerson, E., & Hatton, C. (2007b). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, *191*(6), 493–499. https://doi.org/10.1192/bjp.bp.107.038729

Emerson, E., & Hatton, C. (2007c). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: A replication. *Journal of Intellectual Disability Research: JIDR*, *51*(Pt 11), 866–874. https://doi.org/10.1111/j.1365-2788.2007.00951.x

Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, *50*(12), 862–873. https://doi.org/10.1111/j.1365-2788.2006.00900.x

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*(4286), 129–136. https://doi.org/10.1126/science.847460

Harris, J. C. (2006). *Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment*. Oxford University Press.

Hronis, A. (2021). Cognitive Behaviour Therapy for People with Intellectual Disabilities— How Far Have We Come? *International Journal of Cognitive Therapy*, *14*(1), 114–132. https://doi.org/10.1007/s41811-020-00091-6

Institute of Medicine, Boat, T. F., Wu, J. T., & National Academies of Sciences, Engineering, and Medicine (Eds.). (2015). *Mental disorders and disabilities among low-income children*. National Academies Press.

Kist, J. M., Vos, H. M. M., Vos, R. C., Mairuhu, A. T. A., Struijs, J. N., Vermeiren, R. R. J. M., Van Peet, P. G., Van Os, H. J. A., Ardesch, F. H., Beishuizen, E. D., Sijpkens, Y. W. J., De Waal, M. W. M., Haas, M. R., Groenwold, R. H. H., Numans, M. E., & Mook-Kanamori, D. (2024). Data Resource Profile: Extramural Leiden University Medical Center Academic Network (ELAN). *International Journal of Epidemiology*, *53*(4), dyae099. https://doi.org/10.1093/ije/dyae099

Kok, L., Van Der Waa, A., Klip, H., & Staal, W. (2016). The effectiveness of psychosocial interventions for children with a psychiatric disorder and mild intellectual disability to borderline intellectual functioning: A systematic literature review and meta-analysis. *Clinical Child Psychology and Psychiatry*, *21*(1), 156–171. https://doi.org/10.1177/1359104514567579

Kolaitis, G. (2008). Young people with intellectual disabilities and mental health needs. *Current Opinion in Psychiatry*, *21*(5), 469–473. https://doi.org/10.1097/YCO.0b013e3283060a7b

Lennox, N., Taylor, M., Rey-Coonde, T., Bain, C., Purdie, D. M., & Boyle, F. (2005). Beating the barriers: Recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research*, *49*(4), 296–305. https://doi.org/10.1111/j.1365-2788.2005.00618.x

Lund, C., Brooke-Sumner, C., Baingana, F., Baron, E. C., Breuer, E., Chandra, P., Haushofer, J., Herrman, H., Jordans, M., Kieling, C., Medina-Mora, M. E., Morgan, E., Omigbodun, O., Tol, W., Patel, V., & Saxena, S. (2018). Social determinants of mental disorders and the Sustainable Development Goals: A systematic review of reviews. *The Lancet Psychiatry*, *5*(4), 357–369. https://doi.org/10.1016/S2215-0366(18)30060-9

Macintyre, A., Ferris, D., Gonçalves, B., & Quinn, N. (2018). What has economics got to do with it? The impact of socioeconomic factors on mental health and the case for collective action. *Palgrave Communications*, *4*(1), 10. https://doi.org/10.1057/s41599-018-0063-2

Nader-Grosbois, N. (2014). Self-perception, self-regulation and metacognition in adolescents with intellectual disability. *Research in Developmental Disabilities*, *35*(6), 1334–1348. https://doi.org/10.1016/j.ridd.2014.03.033

Patel, D. R., Cabral, M. D., Ho, A., & Merrick, J. (2020). A clinical primer on intellectual disability. *Translational Pediatrics*, *9*(S1), S23–S35. https://doi.org/10.21037/tp.2020.02.02

Peltopuro, M., Ahonen, T., Kaartinen, J., Seppälä, H., & Närhi, V. (2014). Borderline Intellectual Functioning: A Systematic Literature Review. *Intellectual and Developmental Disabilities*, *52*(6), 419–443. https://doi.org/10.1352/1934-9556-52.6.419

Peltopuro, M., Vesala, H. T., Ahonen, T., & Närhi, V. M. (2023). Borderline Intellectual Functioning and Vulnerability in Education, Employment and Family. *Scandinavian Journal of Disability Research*, *25*(1), 334–349. https://doi.org/10.16993/sjdr.965

Reiss, F. (2013). Socioeconomic inequalities and mental health problems in children and adolescents: A systematic review. *Social Science & Medicine*, *90*, 24–31. https://doi.org/10.1016/j.socscimed.2013.04.026

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An Overview of *Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports* (12th ed.). *American Journal on Intellectual and Developmental Disabilities*, *126*(6), 439–442. https://doi.org/10.1352/1944-7558-126.6.439

Seelen-de Lang, B. L., Smits, H. J. H., Penterman, B. J. M., Noorthoorn, E. O., Nieuwenhuis, J. G., & Nijman, H. L. I. (2019). Screening for intellectual disabilities and borderline intelligence in Dutch outpatients with severe mental illness. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1096–1102. https://doi.org/10.1111/jar.12599

Te Brinke, L. W., Schuiringa, H. D., & Matthys, W. (2021). Emotion regulation and angry mood among adolescents with externalizing problems and intellectual disabilities. *Research in Developmental Disabilities*, *109*, 103833. https://doi.org/10.1016/j.ridd.2020.103833

Totsika, V., Liew, A., Absoud, M., Adnams, C., & Emerson, E. (2022). Mental health problems in children with intellectual disability. *The Lancet Child & Adolescent Health*, *6*(6), 432–444. https://doi.org/10.1016/S2352-4642(22)00067-0

Verhulst, F. C. (1997). The Prevalence of DSM-III-R Diagnoses in a National Sample of Dutch Adolescents. *Archives of General Psychiatry*, *54*(4), 329. https://doi.org/10.1001/archpsyc.1997.01830160049008

Vervoort-Schel, J., Mercera, G., Wissink, I., Van Der Helm, P., Lindauer, R., & Moonen, X. (2021). Prevalence of and relationship between adverse childhood experiences and family context risk factors among children with intellectual disabilities and borderline intellectual functioning. *Research in Developmental Disabilities*, *113*, 103935. https://doi.org/10.1016/j.ridd.2021.103935

Wallander, J. L., Dekker, M. C., & Koot, H. M. (2006). Risk factors for psychopathology in children with intellectual disability: A prospective longitudinal population-based study. *Journal of Intellectual Disability Research*, *50*(4), 259–268. https://doi.org/10.1111/j.1365-2788.2005.00792.x

Wieland, J., Haan, S. K.-D., & Zitman, F. G. (2014). Psychiatric Disorders in Outpatients with Borderline Intellectual Functioning: Comparison with Both Outpatients from Regular Mental Health Care and Outpatients with Mild Intellectual Disabilities. *The Canadian Journal of Psychiatry, 59*(4), 213–219. https://doi.org/10.1177/070674371405900406

Witwer, A. N., & Lecavalier, L. (2007). Autism screening tools: An evaluation of the Social Communication Questionnaire and the Developmental Behaviour Checklist–Autism Screening Algorithm. *Journal of Intellectual & Developmental Disability, 32*(3), 179–187. https://doi.org/10.1080/13668250701604776

Woittiez, I., Eggink, E., Putman, L., & Ras, M. (2018). *An international comparison of care for people with intellectual disabilities* (SCP-publication 2018-18). Netherlands Institute for Social Research (SCP). https://www.scp.nl/publicaties/publicaties/2018/07/06/an-international-comparison-of-care-for-people-with-intellectual-disabilities

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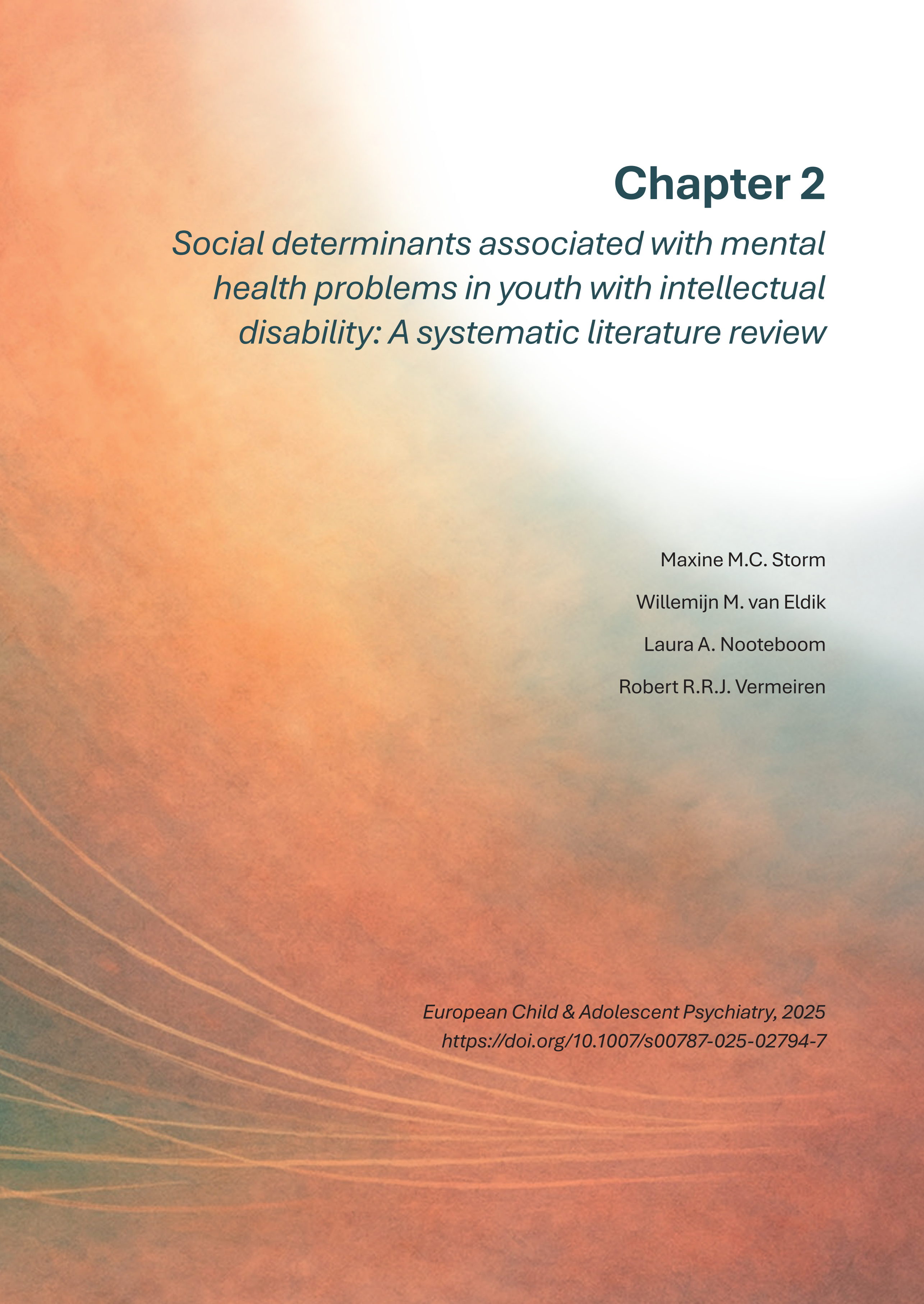

Chapter 2

Social determinants associated with mental health problems in youth with intellectual disability: A systematic literature review

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Abstract

Individuals with intellectual disability (ID) face a higher risk for developing mental health problems. Recent research emphasizes the relevance of social determinants of mental health (SDOMH) in relation to this risk. This review aims to synthesize evidence on the associations between SDOMH and mental health in youth with ID, focusing on risk and protective factors across demographic, economic, social, and neighborhood domains. A systematic search of multiple databases identified 51 relevant studies, including 36 cross-sectional and 15 longitudinal studies. Using a framework-led approach, the strongest evidence emerged from the social/cultural domain (n=46), followed by economic (n=17), demographic (n=8), and neighborhood (n=1). A key finding is the substantial variability and mixed results across studies, highlighting complex, context-dependent associations. Nonetheless, some patterns emerged within the social/cultural domain. Based on both cross-sectional and longitudinal evidence, the most consistent links were found between social and cultural stressors and mental health vulnerabilities. Specifically, in families where children with ID displayed more behavioral problems, 1) parents experienced high distress or internalizing problems; 2) parenting behaviors were more negative; and 3) children faced stressful life events. The review also reveals notable research gaps, including limited attention to broader environmental and neighborhood factors, few longitudinal and multivariate studies, and minimal focus on protective factors. Future research should adopt a systematic approach, prioritize underexplored environmental and protective factors, apply longitudinal and multivariate designs to examine causal pathways, incorporate qualitative methods, and standardize measures to enable consistent analysis across studies.

Introduction

Individuals with intellectual disability (ID) are at elevated risk of experiencing mental health problems (Buckles et al., 2013). As traditional research has centered on exploring biological or individual demographic factors contributing to these problems (Dykens et al., 2000), recent studies emphasize the significant role of a comprehensive set of socio-demographic factors across different life domains (Emerson, 2021; World Health Organization, 2014). This shift acknowledges the associations between mental well-being and aspects of the social, economic, and cultural environments, collectively referred to as social determinants of mental health (SDOMH; Baird et al., 2022; Lund et al., 2018). SDOMH represent the structural conditions individuals encounter throughout life, including where they live (e.g., housing), work (e.g., employment), and age (e.g., neighborhood conditions; World Health Organization, 2014; Allen et al., 2014; Kirkbride et al., 2024). Compelling evidence is increasingly connecting these SDOMH to the likelihood of experiencing mental health problems (World Health Organization, 2022).

Previous studies demonstrate that encountering adverse SDOMH early in life can have significant implications for later mental well-being (Allen et al., 2014; Blas et al., 2010; Kessler et al., 2010). This might especially be relevant for youth with ID, since they are at a greater risk of facing unfavorable SDOMH during their lifetime (Emerson & Spencer, 2015). In fact, these children bear a dual burden. First, youth with ID are particularly vulnerable to environmental disadvantages, placing them at a heightened risk of occupying a lower social stratum (Emerson et al., 2006). For instance, studies revealed that youth with ID are more often raised in disadvantaged households compared to their typically developing peers (Emerson et al., 2006; Emerson, 2021). Such social positioning is associated with elevated levels of cumulative stress, which may contribute to greater mental health vulnerabilities (Allen et al., 2014). Second, there are inherent limitations associated with ID itself, complicating their ability to adapt and cope with difficulties. For instance, children with ID may have difficulty communicating distress and regulating their reactions to their environments, which has been linked to internalizing or externalizing mental health symptoms. In physically adverse environments, such as overcrowded noisy areas, these challenges can become even more pronounced, making them more vulnerable to stress (Baird et al., 2022). Thus, the ID itself adds another layer of complexity to the ability to manage stress and adversity, which may be linked to a higher likelihood of mental health problems for these children.

Given the potentially significant role of adverse SDOMH for the mental well-being of youth without ID (Allen et al., 2014; Eijgermans et al., 2021), it is surprising that empirical evidence regarding children with ID is sparse. To date, two reviews have synthesized findings on factors related to mental health problems in children with ID (Einfeld et al., 2011; Witwer & Lecavalier, 2008). One mainly focused on individual demographic variables, such as age, gender, and level of functioning (Einfeld et al., 2011). The other examined a limited range of contextual SDOMH, including parental psychopathology, stress, family functioning, single-parent households, and socio-economic status (SES; Witwer & Lecavalier, 2008), which were more consistently linked to child psychopathology. Together, the reviews provided a first foundation for understanding the role of some SDOMH. However, these reviews were restricted in their scope, as they did not investigate associations between psychopathology and structural conditions children encounter throughout life such as neighborhood conditions and social support. A more recent review on risk factors for developing ID, rather than mental health problems, did focus on additional SDOMH such as various environmental factors, including geographical remoteness, air pollutants, and soil concentration (Leonard et al., 2022). This shift reflects a growing recognition of the broader environmental SDOMH. Therefore, in this review, we have chosen to expand the scope to include a focus on broader social and environmental factors related to mental health in children with ID. Addressing these factors is important for developing a more comprehensive understanding of the interconnectedness between contextual characteristics and mental health in children with ID.

Accordingly, this literature review aims to synthesize existing empirical knowledge about associations between SDOMH and mental health problems in youth with ID, focusing on both risk and protective contextual factors. To provide a comprehensive overview and enhance the understanding of the role of different SDOMH, we will summarize, analyze, and categorize them based on the theoretical framework of Lund et al. (2018), which outlines several overarching domains of SDOMH, including the demographic, economic, social/cultural, and neighborhood domain. Drawing on the concept of a dual burden, we generally expect that adverse SDOMH across all domains will be linked to greater mental health problems in youth with ID. Specifically, since prior literature reviews suggest that poorer parental mental health, higher family stress, and a dysfunctional home environment are associated with increased mental health problems in children with ID (Witwer & Lecavalier, 2008), we anticipate particularly strong associations in the social/cultural domain. For other SDOMH domains (demographic, economic, and neighborhood), where reviews have provided inconsistent or limited evidence, we take a more exploratory approach to identifying potential associations. By synthesizing this knowledge, our goal is to support a more nuanced understanding of the associations between SDOMH and mental health in youth with ID–informing the development of comprehensive, evidence-based strategies for identifying patterns of vulnerability and addressing the needs of affected families.

Method

A record of the current research protocol was prospectively registered in the International Database of Prospectively Registered Systematic Reviews in Health and Social Care (PROSPERO, registration number CRD42022334214) following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Liberati et al., 2009). The study selection process was a stepwise procedure based on the PRISMA flow diagram (Figure 1).

Search strategy

The present review received assistance from a medical research librarian from Leiden University Medical Center in formulating the search strategy. Subsequently, a literature specialist from Parnassia Groep Academia with extensive knowledge about the subject performed a final check on the search strategy. A systematic search was conducted by consulting the following electronic databases: PubMed, PsycINFO, MEDLINE, Cochrane Library, and Web of Science.

The search was focused on the following four predefined categories: (A) ID (including mental retardation, learning disability, and intellectual deficit), (B) youth (including infant, child, adolescent, and young adult), (C) psychopathology (including both internalizing and externalizing problems, as well as developmental disorders such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD)), and (D) SDOMH, defined as circumstances that affect an individual’s health condition, as outlined by the World Health Organization (World Health Organization, 2014). The conceptual theoretical framework presented by Lund et al. (2018) guided our selection of relevant terms for SDOMH, supplemented by input from a librarian or literature specialist, and prior literature (Emerson, 2021). We tailored this framework, originally consisting of five domains: demographic, economic, social/cultural, neighborhood and environmental events (Lund et al., 2018), to align with our study's objectives. This modification ensured that the framework addressed the unique circumstances of youth with ID, with a specific emphasis on the developmental perspective prevalent among children in Western countries. Consequently, we incorporated parental and family factors across various subdomains to better integrate this proximal environment associated with childhood mental health. For instance, parental ethnicity (i.e., demographic domain) and parental education (i.e., social/cultural domain) were included as they reflect the structural and contextual characteristics that shape a child's environment. When needed, we held extensive discussions among co-authors to ensure a clear and systematic classification of all factors. Moreover, we omitted the domain of environmental events, including war and natural disasters, as they are extreme circumstances with limited occurrence in industrialized societies. Appendix A illustrates the theoretical framework, providing examples of factors within each domain for clarity.

The complete search strategy with specific search queries for each database can be found in Appendix B. All identified studies were imported to the bibliographic reference manager Endnote® (X9). Additionally, the reference lists of the included studies were searched manually to identify potentially relevant articles that were missed during the computerised search. The final search was executed on September 5th, 2024.

Eligibility Criteria

To be included in this study, records had to meet the eligibility criteria presented in Table 1.

Table 1. Summary of inclusion and exclusion criteria

Study characteristic	*Inclusion criteria*	*Exclusion criteria*
Participants	Focus on study samples including youth aged 0 to 23 years old to capture childhood through late adolescence, with a mean age under 23 years Diagnosed with ID, encompassing all severity levels (mild, moderate, severe, profound) in accordance with DSM-5 criteria (American Psychiatric Association, 2022)	Samples with <80% diagnosed with ID
Outcome	Must report on mental health problems. Mental health problems were assessed via validated instruments or meeting diagnostic criteria (Frick & Silverthorn, 2002)	-
Risk and protective factors	Report on SDOMH, fitting the framework of this study	Individual characteristics, such as child's age, gender and ethnicity
Association	Investigating the relationship between SDOMH and mental health problems in youth with ID	-
Study design	All study designs were accepted, including qualitative, quantitative, and mixed-method approaches	-
Publication type	Peer-reviewed manuscripts in English or Dutch, available as full-text articles	Publications such as conference abstracts or position papers
Publication year	No restrictions on the year of publication	-

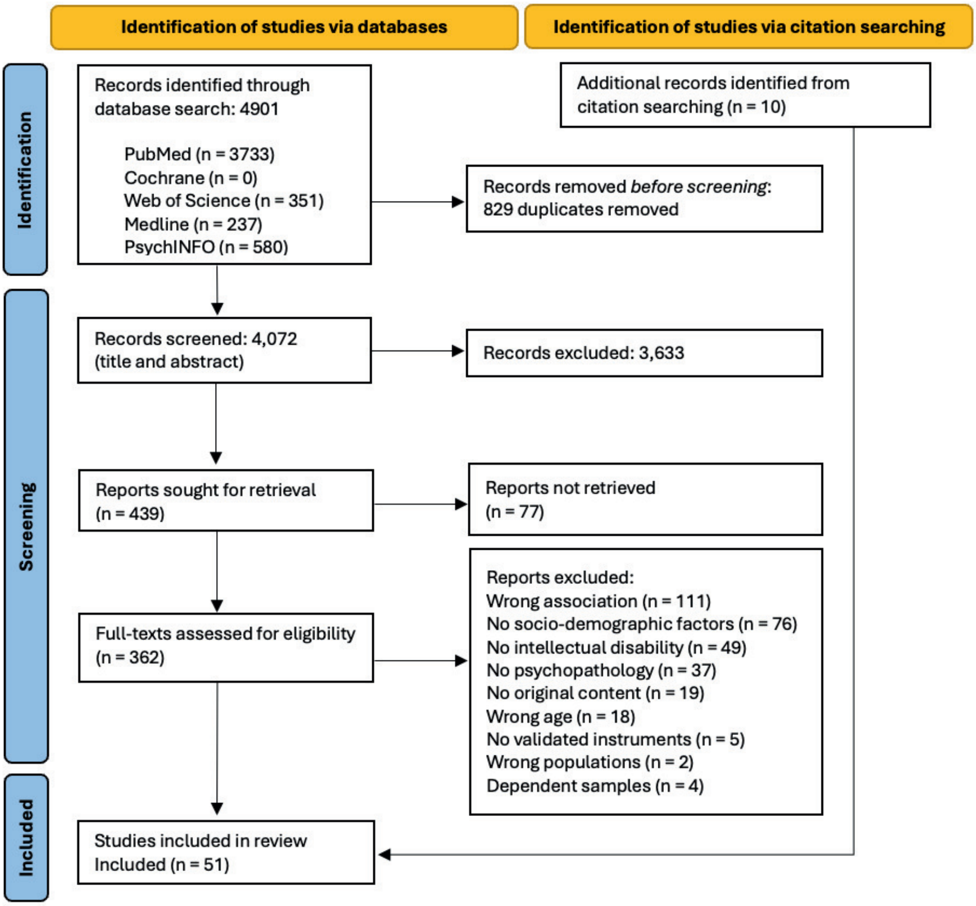
Study selection

The study selection process followed a stepwise procedure. Initially, our database search yielded 4,901 studies, with 3,583 non-duplicate publications. Subsequently, the remaining studies were transferred to Rayyan software for labeling and selection (Ouzzani et al., 2016). Two independent reviewers (MS and WE) evaluated the studies based on their titles and abstracts, guided by predefined inclusion and exclusion criteria. Any disagreements between the reviewers were resolved through discussion to achieve consensus. The inter-rater agreement for this screening round, measured by Cohen's Kappa, was 0.85, indicating almost perfect agreement between the two reviewers (Landis & Koch, 1977). Then, the first reviewer (MS) assessed the full text of the remaining articles, with any uncertainties resolved in a meeting with the second independent reviewer (WE). Figure 1 illustrates an overview of the study selection procedure.

Data Extraction and Synthesis

As a foundation for data extraction, we extended the Cochrane Data Extraction Template with additional relevant factors and pilot tested the form on ten randomly selected publications. Then, MS reviewed the eligible research articles and extracted key information into a data extraction table, including the title, authors, publication year and type, study description, methodology, and sample demographics. Any doubts regarding the eligibility of research articles were addressed and resolved during a meeting with WE to reach a consensus. To prevent publication bias, all studies were screened for using identical datasets.

Figure 1. PRISMA flow diagram



Among these, four studies shared identical datasets. In such cases, the longitudinal study was preferred over the cross-sectional. If both studies had the same design, the study including most SDOMH was chosen. After completing the data extraction, we categorized the SDOMH into four main domains: demographic, economic, social/cultural, and neighborhood. A synthesis of the findings was then conducted to evaluate the evidence within each domain. A detailed overview of the study characteristics can be found in Appendix C.

Quality appraisal

Individual study quality was assessed using the Appraisal Tool for Cross-Sectional Studies (AXIS; Downes et al., 2016), specifically designed for non-experimental research. AXIS includes 20 items assessing key elements such as sample size justification, use of validated measures, and statistical methods. Prior to assessment, each of the 20 questions was assigned a weighting score (1, 1.5, or 2) based on the researchers mutually agreed-upon perception of its importance. Scores were assigned for questions answered affirmatively (‘yes’), except for two items that were reverse-coded based on their wording. Subsequently, after the assessments, these scores were aggregated to generate a total score per article, ranging from 0 to a maximum of 26. As AXIS lacks fixed cut-off scores, we established thresholds for the total scores based on the distribution of quality appraisal scores across the included studies (range: 6–26), to create a relative approach to assessing study quality. A complete list of the AXIS items and their assigned weights is provided in Appendix D. The scores were divided into tertiles and based on this distribution, studies were categorized as high quality (≥19 points), medium quality (14–18 points), and low quality (≤13 points). Two authors independently evaluated each study, resolving discrepancies through consensus or involving a third author, if necessary, to ensure a robust evaluation process. A detailed overview of the critical appraisal scores per domain can be found in Appendix E.

Strength of evidence

To clarify which domains were characterized by substantial evidence and which by insufficient evidence (Granholm et al., 2019; Harbour & Miller, 2001), we evaluated the strength of evidence per domain. This method facilitates a comprehensive comparison of multiple studies across demographic, economic, social/cultural, and neighborhood domains, allowing for a relative assessment of overall quality using five predefined criteria.

- *Size of Evidence: The strength of evidence was determined by the number of studies within each domain. Domains with 38 or more studies (>75% of the total reviewed) were classified as substantial (+); those with 13 to 37 studies (25–75%) as moderate (±); and those with fewer than 12 studies (<25%) as limited (−).*
- *Quality of studies: Based on the quality assessment for individual studies, the overall quality of the domain was assessed. A high rating (+) was assigned to domains where over 75% of studies were high quality; medium (±) for 25 to 75%; and low (−) where less than 25% were rated as high quality.*
- *Consistency of findings: Consistency of findings was assessed across domains, with results classified as consistent (+), mixed (±), inconsistent (−), or contradictory (−−). Findings were considered consistent when all studies within the same domain supported similar conclusions. Results were classified as mixed when at least one study, compared to the others, focused on different subpopulations and produced varying results. Findings were labelled inconsistent when two studies on the same subpopulation produced different results, with one finding an association and the other not. Finally, findings were deemed contradictory when at least two studies on the same subpopulation produced opposing results, such as one study finding a positive association and another finding a negative association.*
- *Context: Each domain's context was classified as either mixed or specific. Mixed contexts (+) reviewed studies where results were observed across a diverse population, such as general community samples spanning a variety of psychological disorders. Specific contexts (−) were designated for domains focusing on a particular sample, such*

as specific groups of children with a syndrome or the focus on a specific type of mental health problem.

- *Perspective (source of evidence): SDOMH or child's mental health problems based on evidence from two or more perspectives (informants), including youth, parents, and teachers, were deemed multiple (+), while SDOMH or child's mental health problems relying on evidence from a single perspective were labeled single (−).*

The overall strength of evidence was based on cumulative scores across five criteria: size of evidence, study quality, consistency of findings, context, and perspective. For each criterion, the evidence was rated using the following scale: + (positive), ± (mixed), − (negative), or −− (contradictory; only applicable to consistency of findings). For the cumulative scoring, these ratings were translated as follows: + = 1 point, ± = 0.5 points, − = 0 points, and −− = 0 points. The strength of evidence then was classified into the following categories: very strong (5 points), strong (3.5–4.5), medium (2–3), limited (0.5–1.5), or no evidence (0).

Results

Study characteristics

This review included 51 studies−36 cross-sectional and 15 longitudinal−mostly conducted in the USA and UK. The studies covered samples across a wide age range, mainly focusing on early to middle childhood, with some also including adolescence and multiple age stages. Sample sizes varied significantly, from 17 to 10,438 participants (*M* = 892, *SD* = 2.06). Most studies showed a male gender imbalance, with male participation ranging from 44% to 88.2%. The majority of studies addressed a wide range of ID severities, covering at least three levels (e.g., mild, moderate, and severe). However, 14 studies did not specify the severity level of ID. Four studies (8.2%) focused on specific syndromes, such as Down and Fragile X syndrome (FXS). Regarding mental health problems, the most common were behavior problems (n=16), followed by ASD symptoms (n=14), unspecified psychopathology (n=9), internalizing and/or externalizing problems (n=7). Less common were anxiety (n=3), depression (n=3), conduct disorder (n=3), hyperactivity (n=2), ADHD symptoms (n=2), emotional problems (n=3), and maladaptive behavior (n=2). Notably, 37 out of 51 studies (72.5%) used only univariate analyses, and no qualitative studies were identified in the search. Critical appraisal classified 19 studies as high quality, 14 as medium, and 18 as low. High-quality studies were primarily studies with clearly defined research objectives, justified sample sizes, validated measures for mental health problems, and transparent reporting of statistical methods. A detailed overview of study characteristics is provided in Appendix C.

Outcomes

The aim of this review was to synthesize evidence on the associations between SDOMH and mental health problems in youth with ID using a framework-led approach (Dixon-Woods, 2011). A great variety of SDOMH was found within the studies, which led us to categorize them into subdomains within our four main domains. Moreover, we explored whether associations within each SDOMH domain varied across subgroups based on ID severity, child age, and type of mental health problems. Table 2 summarizes the strength of evidence for each SDOMH domain, excluding the neighborhood domain, which had only one study and could not be assessed.

Table 2. Summary of strength of evidence per domain

Domain	Size of evidence (no. of studies)	Quality (individual studies)	Consistency of findings	Context	Perspective	Overall strength of evidence
Demographic	-	±	-	+	+	Medium
Economic	±	±	--	+	+	Medium
Social/cultural	+	±	--	+	+	Strong
Neighborhood	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.

Note. + = substantial evidence/high quality/consistent findings/mixed contexts /multiple perspectives; ± = moderate evidence/medium quality/mixed consistency; - = limited evidence/low quality/inconsistent findings/specific contexts /single perspective; -- = contradictory findings; N.A. = not applicable.

Associations across subgroups of ID severity, age and type of mental health problem

To examine potential patterns within subgroups, studies were categorized based on ID severity, including individual levels (severe, moderate, mild, and borderline) as well as combined severity categories. Table 3 in Appendix F provides an overview of studies across these ID severity levels within each domain. This table presents the number of studies for each level or combination of ID severity across domains, indicating how many reported at least one significant result. Studies were fairly distributed across severity levels, with the social/cultural domain most consistently examined and yielding the highest proportion of significant findings. However, no consistent pattern of significant associations between SDOMH and mental health problems emerged across domains, indicating that specific domains were neither more frequently studied nor more strongly associated with mental health issues in any ID severity group.

Studies were then grouped based on age categories, including individual stages (early childhood [0–6 years], middle childhood [6–12 years], early adolescence [12–16 years], and late adolescence [16+ years]) as well as combined age groups. As shown in Table 4 of Appendix F, similar to findings by ID severity, there was no clear indication that specific domains are either more frequently studied or more closely linked to mental health issues across different age groups.

Finally, due to substantial variability in types of mental health problems reported and the absence of specified mental health conditions in some studies, conducting subgroup analyses for all mental health conditions was not feasible. We therefore focused on the two most frequently reported outcome groups–ASD and externalizing problems–based on a subset of 41 articles. Externalizing problems included studies reporting on outward-directed behaviors such as aggression, hyperactivity, conduct issues, and general behavioral problems. These conceptually similar constructs were grouped together to allow for meaningful comparison. As shown in Table 5 of Appendix F, the social/cultural domain was again the most frequently studied and showed the highest proportion of significant associations for both ASD and externalizing problems.

However, the proportion of significant findings was greater for externalizing problems than for ASD within this domain. A similar trend was observed in the economic domain, despite the smaller number of studies overall. In contrast, ASD showed more significant associations in the demographic domain, relative to externalizing problems.

Domain 1. Demographic

The demographic domain included SDOMH reflecting general population characteristics, which were divided into two distinct subdomains: parental ethnicity and parental age. A total of eight studies examined these factors.

Parental ethnicity

Five studies examined associations between parental ethnicity and mental health problems in children with ID, including four cross-sectional and one longitudinal. The findings were mixed. Among the four cross-sectional studies, one reported significant differences in maternal race/ethnicity between children with ID only (higher proportion of non-Hispanic black mothers) and those with both ID and ASD (Schieve et al., 2015). However, three other studies reported no association between ethnicity and problem behaviour in children with ID (Dekker & Koot, 2003; Eisenhower & Blacher, 2006; Hatton & Emerson, 2009). Additionally, one longitudinal study focused on maternal migration rather than ethnicity directly, finding that children born earlier than four years before maternal migration were less likely to have ID with autism compared to those born in the year following maternal migration (Morinaga et al., 2021).

Parental age

Four cross-sectional studies examined the relationship between parental age and mental health problems in children with ID, though findings were inconsistent. One study found that mothers of children with both ID and ASD were significantly younger than those of children with ID only (Schieve et al., 2015). Another reported no age differences (Akdemir et al., 2009), while a third found that maternal age was not associated with emotional or conduct problems, but that older maternal age was linked to more hyperactivity (Avci, 2024). A fourth study found no association between parental age under 18 and behavior problems in young children with developmental delays (Emerson & Brigham, 2015).

Domain 2. Economic

Within the economic domain, seventeen studies examined the role of economic factors in relation to mental health problems in children with ID. To synthesize the results, the economic factors were categorized into three subdomains: family income, income-related factors, and composite SES measures.

Family income

Four cross-sectional and two longitudinal studies examined a direct relationship between family income and mental health problems in children with ID, yielding inconsistent results. Whereas three cross-sectional studies reported no link between family income and mental health issues (Baker & Blacher, 2021; Baker et al., 2012; Emerson & Hatton, 2007), one cross-sectional study found that children with ID from lower-income households were more likely to have psychiatric disorders (Emerson, 2003). Longitudinally, one study found no link (Baker et al., 2010), whereas the other study reported slower income growth over eight years in families of children with both ID and ASD compared to families with children who have only ID (Pinborough-Zimmerman et al., 2011).

Income related factors

Six studies–five cross-sectional and one longitudinal–examined income-related factors and mental health in children with ID, with mixed results. Cross-sectional evidence indicated that household poverty was significantly associated with increased behavioral problems in children with ID (Williams et al., 2022). Consistently, another study found that mothers of children with severe ID and behavior problems felt a greater need for financial help (Quine, 1986). However, three studies found no significant associations between income-related factors, such as rented accommodation or reliance on benefits (Chadwick et al., 2008), Family Affluence Scale scores (Dworschak et al., 2016), and health insurance coverage (Saunders et al., 2015), and mental health problems in children with ID. The longitudinal study found that over eight years, families with children with ID and ASD paid significantly lower federal taxes than those with only ID (Pinborough-Zimmerman et al., 2011).

Composite SES measures

Six cross-sectional studies investigated composite SES measures, including financial hardship and socio-economic position. Remarkably, half of these studies did not specify how SES was measured. The results were either inconsistent or contradictory. In one UK study low socio-economic position, measured by household income, occupational prestige, and maternal education, was associated with more behavior problems in children with developmental delays (Emerson & Brigham, 2015). Similarly, in another sample, lower SES (i.e., unspecified measures) was associated with increased behavior problems in children with ID (Schuiringa et al., 2015). In contrast, another study found that families of children with only ID had significantly lower SES compared to those with both ID and ASD, based on education level, occupation, employment status, and total household income (Baker et al., 1993). Contrastingly, three studies found no significant link between SES and mental health problems in children with ID (Kimura & Yamazaki, 2016; Scambler et al., 2007; Weiss et al., 2016).

Domain 3. Social/Cultural

The social/cultural domain covers the broadest range of factors related to the mental health of children with ID. These factors are grouped into five subdomains: parental well-being, employment and education level, parent-child relationship, family dynamics, and life events. A total of 46 studies explored these associations.

Parental well-being

Parental well-being was reported in 23 studies, encompassing six different subcategories of well-being: general mental health, (di)stress, internalizing problems, substance use, maternal somatization and maternal life satisfaction. Each subcategory yielded results that were either mixed or inconsistent.

Ten studies, including eight cross-sectional and two longitudinal, examined the association between parental mental health and the mental health of children with ID. Cross-sectionally, six studies reported a link between lower parental mental health and increased psychological problems in children (Hatton & Emerson, 2009; Emerson & Brigham, 2015; Weiss et al., 2016; Kobe & Hammer, 1994; Stewart et al., 2023; Emerson, 2003). Caregiver mental health problems were associated with higher rates of psychiatric diagnoses in children (Stewart et al., 2023; Emerson, 2003), particularly in boys (Dekker & Koot, 2003), and to increased depression and severe behavioral issues (Weiss et al., 2016; Kobe & Hammer, 1994). Contrastingly, two studies found no significant difference in parental mental health between parents of children with and without behavioral problems (Embregts et al., 2010; McCarthy, 2008). Longitudinally, both studies found that parental mental health problems were linked to increased psychopathology in children with ID one year later. One study associated parental mental health treatment history with variations in internalizing and externalizing problems (Wallander et al., 2006), whereas the other found that parental mental health issues predicted psychiatric disorders in children (Dekker & Koot, 2003).

Ten studies–five cross-sectional and five longitudinal–consistently linked greater parental (di)stress to increased behavior problems in children with ID, with seven focusing on maternal distress (Williams et al., 2022; Baker et al., 2003; Hall et al., 2007; Long et al., 2015; Neece & Baker, 2008; Robinson & Neece, 2015; Staunton et al., 2020). Cross-sectionally, all five studies found at least one significant association between greater parental distress and increased child behavior problems (Williams et al., 2022; Hall et al., 2007; Long et al., 2015; Robinson & Neece, 2015; Staunton et al., 2020), though links with having ASD were not significant (Staunton et al., 2020). Longitudinally, all five studies found a bidirectional relationship between parental distress and child behavior problems over time (Baker et al., 2003; Neece & Baker, 2008), particularly for children's externalizing problems (Bailey et al., 2019; Hastings et al., 2006; Wallander et al., 2006). However, some associations, such as overall psychopathology (Wallander et al., 2006), were not significant.

Eight studies investigated parental internalizing problems, encompassing depression (n=7), anxiety (n=3), and general internalizing problems (n=1). Among the seven studies on parental depression, five were cross-sectional and two were longitudinal. Cross-sectionally, three studies found that higher maternal depression was associated with increased mental health problems in children with ID, specifically ASD (Baker & Blacher, 2021), child depression (Kobe & Hammer, 1994), and maladaptive behavior (Long et al., 2015), whereas two studies reported no significant link with behavioral problems (Hatton & Emerson, 2009; Embregts et al., 2010). Longitudinally, one study found that higher maternal depression levels predicted increased internalizing and externalizing problems in children over time (Smith et al., 2016), whereas another study reported no association with internalizing problems (Hastings et al., 2006). Of the three studies on parental anxiety, two were cross-sectional, both showing that higher anxiety in parents was linked to more behavioral or psychiatric issues in children with ID (Hatton & Emerson, 2009; Baker & Blacher, 2021), whereas the longitudinal study found no significant link with internalizing or externalizing problems (Hastings et al., 2006). Regarding general parental internalizing problems, one cross-sectional study found no association with FX syndrome and autism but linked higher maternal internalizing symptoms to behavioral problems in adolescents and adults with FX syndrome (Baker et al., 2012).

Parental substance use was examined in two cross-sectional studies. One study found that parental addiction was linked to increased externalizing symptoms in children with ID (Lapshina & Stewart, 2021), whereas another found no link between parental alcohol or drug abuse and behavior problems in children with developmental delay (Emerson & Brigham, 2015).

Two studies linked higher maternal somatization to increased behavioral problems in children with ID. A cross-sectional study found this among Latina caregivers of children with maladaptive behavior (Long et al., 2015), whereas a longitudinal study identified maternal somatization as a significant predictor of increased behavioral problems over two years, particularly in mothers of children with both ID and ASD (Baker et al., 2003).

Maternal life satisfaction was examined in two studies. One cross-sectional study found no link with behavioral problems in children with ID (Williams et al., 2022). A longitudinal study similarly reported no association over an eight-year period (Bailey et al., 2019).

Employment and education level

Employment and education levels were reported in 19 studies, divided into four subcategories: child employment, parental employment, parental education, and a combination of parental employment and education. The findings within each subcategory were mixed, inconsistent or contradictory.

One longitudinal study explored employment among young adults with ID and found that those in open employment for two years had a decline in behavior problems, whereas those in training, sheltered employment or day recreation programs, showed no change (Foley et al., 2014).

Nine studies examined parental employment and child mental health, comprising seven cross-sectional and two longitudinal. Among the cross-sectional studies, two found that unemployment or lower job status correlated with more child behavior issues (Kimura & Yamazaki, 2016; Emerson, 2003) and ASD (Kimura & Yamazaki, 2016). Consistently, children with ID from lower social classes were more likely to have conduct disorders, ADHD, and autism (Emerson, 2003). Inconsistently, three studies found no link between maternal employment and child behavior problems (Eisenhower & Blacher, 2006; Akdemir et al., 2009; Baker & Blacher, 2021), nor did the two others find a link between occupational prestige or social class and behavior disorders (Emerson & Hatton, 2007; McCarthy, 2008). Longitudinally, one study found that low SES did not predict psychopathology but was linked to increased internalizing problems (Wallander et al., 2006), whereas another reported no association between parental social class, employment status, and child psychopathology over time (Tonge & Einfeld, 2003).

Nine studies examined the link between parental education and child behavior problems, covering seven cross-sectional and two longitudinal. Cross-sectionally, two studies found that lower parental education was associated with increased behavior problems (Avci, 2024; Emerson & Hatton, 2007). Specifically, children of mothers without qualifications showed more conduct and emotional disorders (Emerson & Hatton, 2007). Contradictory, one study found a reverse relationship, where higher maternal education was more common among mothers of children with both ID and ASD (Schieve et al., 2015). Four cross-sectional studies reported no association between parental education levels and behavior problems in children with ID (Akdemir et al., 2009; Baker & Blacher, 2021; Baker et al., 2012; Chadwick et al., 2008). Longitudinally, one study found that lower parental education predicted increased disruptive disorders over one year but not DSM-IV diagnoses in general, anxiety, or mood disorders (Dekker & Koot, 2003), whereas another found no evidence that parental education predicted child psychopathology over time (Baker et al., 2010).

Three studies, comprising two cross-sectional and one longitudinal, examined a composite measure of parental education and occupational level. Cross-sectionally, two studies found that lower parental education, unemployment, and unskilled work were associated with higher rates of psychopathology (Koskentausta et al., 2007) and greater internalizing and externalizing problems in children with ID (Van Rest et al., 2020). Longitudinally, one study found that lower SES was linked to increased internalizing problems over one year but did not predict total psychopathology (Wallander et al., 2006).

Parent-child relationship
The parent-child relationship was examined in 14 studies, split into positive and negative subcategories, yielding inconsistent results.

Seven studies–four cross-sectional and three longitudinal–examined positive elements of the parent-child relationship, including parental behaviors, feelings, and dyadic interactions. Findings varied depending on the type of mental health problem studied. Cross-sectionally, three studies found inverse links between these positive relationship elements and mental health problems (Schuiringa et al., 2015; Embregts et al., 2010; Kobe & Hammer, 1994). A higher parental sense of competence was associated with fewer behavioral problems (Schuiringa et al., 2015; Embregts et al., 2010) and lower depression levels (Kobe & Hammer, 1994), whereas higher attachment levels were linked to lower depression but not behavioral problems (Kobe & Hammer, 1994). Remarkably, positive discipline (i.e., structured, corrective consequences rather than punitive or harsh measures) was associated with higher externalizing behaviors (Schuiringa et al., 2015). Longitudinally, some positive parent–child interactions were linked to fewer behavior problems over time, though effects varied by age and behavior type. Early positive parenting was associated with reduced behavioral issues in childhood, but some effects did not persist (Totsika et al., 2020). Maternal warmth and scaffolding were generally linked to better behavioral outcomes, though their impact differed across behaviors and conditions (Baker et al., 2010; Smith et al., 2016).

A total of 14 studies, encompassing 10 cross-sectional and four longitudinal, examined negative parenting behaviors, such as hostility, overprotection, and negative parental feelings. Cross-sectionally, seven studies linked these behaviors to mental health difficulties (Emerson & Brigham, 2015; Baker & Blacher, 2021; Chadwick et al., 2008; Schuiringa et al., 2015; Lapshina & Stewart, 2021; Emerson, 2003; Hemm et al., 2018), with harsh discipline consistently associated with behavioral problems (Chadwick et al., 2008; Schuiringa et al., 2015; Emerson, 2003) and with ASD diagnoses (Baker & Blacher, 2021). Emotional abuse, parenting difficulties, and parental criticism were associated with increased behavioral issues (Emerson & Brigham, 2015; Chadwick et al., 2008; Hastings et al., 2006; Lapshina & Stewart, 2021), but one study found that overall maltreatment rates–including emotional abuse–did not differ between children with ID and those with both ID and ASD (McDonnell et al., 2019). Maternal overprotection was linked to child anxiety, but paternal overprotection was not (Hemm et al., 2018). Varying results were found for negative parental feelings, with role restriction unrelated to behavioral problems (Embregts et al., 2010) or depression (Kobe & Hammer, 1994), whereas discontinuity in care was linked to behavior issues (Chadwick et al., 2008). Longitudinally, maternal criticism and adverse parent–child relationships were linked to lasting behavioral problems, though effects varied. Criticism predicted more severe externalizing symptoms and behavior problems (Smith et al., 2016), whereas another study found no link (Hastings et al., 2006). Further, no long-term effects on internalizing or autism symptoms were observed. Mothers whose children were later diagnosed with ADHD exhibited more negative parenting and dyadic conflict (Baker et al., 2010). Early adversarial parenting contributed to later conduct problems but did not persistently impact emotional difficulties, hyperactivity, or overall behavior (Totsika et al., 2020).

Family Dynamics

Various family dynamic factors were reported in 29 studies, which can be divided into the following four subcategories: family structure, the interparental relationship, family functioning, and social networks. Each subcategory yielded results that were either mixed, inconsistent or contradictory, illustrating the scattered nature of findings.

Family structure, examined in 16 studies, included marital status (n=13), family size (n=3), and birth order (n=4). Regarding marital status, ten studies were cross-sectional and three were longitudinal. Cross-sectionally, six studies found an effect, though the findings were contradictory. Three studies linked single parenthood to higher risks of psychiatric and behavioral problems (Emerson & Hatton, 2007; Quine, 1986; Emerson, 2003), whereas the other three showed that mothers of children with ID and dual diagnoses were more likely to be married (Schieve et al., 2015; Baker et al., 1993; Kimura & Yamazaki, 2016). The other studies found no significant associations between marital status and behavioral outcomes (Eisenhower & Blacher, 2006; Baker & Blacher, 2021; Avci, 2024; Chadwick et al., 2008). Longitudinally, single parenthood predicted externalizing and internalizing problems but was not linked to overall psychopathology (Wallander et al., 2006). Mental health trajectories over time did not significantly differ between adolescents from single- and two-parent households (Hatton et al., 2018), nor was nonfamily care associated with increased psychopathology risk (Hatton et al., 2018; Tonge & Einfeld, 2003). Regarding family size, no associations with behavioral problems were found among the three cross-sectional studies (Emerson & Brigham, 2015; Quine, 1986; Koskentausta et al., 2007). Results on the role of birth order on mental health in children with ID varied, with three cross-sectional studies and one longitudinal. Cross-sectionally, being the youngest sibling was linked to increased hyperactivity (Avci, 2024) but not to emotional, conduct problems, or overall psychopathology (Koskentausta et al., 2007). Longitudinally, being the youngest sibling was associated with increased behavioral problems over time (Williams et al., 2024).

Of six cross-sectional studies on the interparental relationship, three found that higher marital satisfaction was linked to lower levels of behavior problems or depressive symptoms in children with ID (Robinson & Neece, 2015; Embregts et al., 2010; Kobe & Hammer, 1994). In contrast, three studies found no such associations: one reported no link between parental marital satisfaction and children with FX syndrome and autism (Baker et al., 2012), another found no association between marital quality and severe behavior disorders in adulthood (McCarthy, 2008), and no differences in parental conflict were linked to children’s behavioral problems (Margalit et al., 1989).

Family functioning was examined in 11 studies across five aspects: family dysfunction (n = 3), family cohesion (n = 2), domestic violence (n = 2), family quality of life (n = 2), and sibling factors (n = 3). Regarding family dysfunction, one cross-sectional study found that children with ID from families with more unhealthy functioning were more likely to have a diagnosed, emotional, or anxiety disorder (Emerson, 2003). The two longitudinal studies showed that family dysfunction predicted disruptive disorders but not anxiety or mood disorders (Dekker & Koot, 2003) and uniquely contributed to total psychopathology, externalizing, and internalizing problems (Wallander et al., 2006). Two cross-sectional studies showed that family cohesion was not associated with behavioral problems in children with ID (Baker et al., 2012; Margalit et al., 1989). Regarding domestic violence, defined as exposure to physical or verbal violence within the family setting, one cross-sectional study associated witnessing domestic violence with more externalizing symptoms in children with ID (Lapshina & Stewart, 2021), whereas another cross-sectional study found no such link for children with ID (Emerson & Brigham, 2015). Family quality of life was not linked to challenging behaviors or psychiatric diagnoses, but it was lower for youth with ASD or maladaptive behavior based on cross-sectional evidence (Weiss et al., 2016; Staunton et al., 2020). Regarding sibling factors, cross-sectionally, sibling mental health difficulties were linked to co-occurring psychiatric diagnoses (Stewart et al., 2023). Longitudinally, sibling referral to mental health care did not predict disorders after one year (Dekker & Koot, 2003), and neither sibling warmth nor conflict predicted behavior problems or disorders (Williams et al., 2024).

Five cross-sectional studies examined social networks, focusing on social support (n = 3) and parental isolation (n = 2). Regarding social support, one study found that children with both ID and ASD had significantly worse family and friend relationships compared to those with ID alone (Boehm & Carter, 2019). Another found no link between social support and either ASD or challenging behaviors (Staunton et al., 2020). A third study showed that higher perceived social support from family, friends, teachers, and the community was associated with fewer emotional and conduct problems, but not hyperactivity (Akdemir et al., 2009). As for parental isolation, one study found that parents of children with ID and behavioral problems were more socially isolated than those without such problems (Embregts et al., 2010), though this isolation was not linked to the presence or severity of the child's depression (Kobe & Hammer, 1994).

Life Events

Eight studies–six cross-sectional and two longitudinal–examined the association between life events and mental health, mostly focusing on negative or stressful experiences, with mixed results. Cross-sectionally, children with ID experiencing more stressful events were generally more likely to be diagnosed with psychiatric disorders (Weiss et al., 2016; Embregts et al., 2010; Lapshina & Stewart, 2021; Emerson, 2003; Ghaziuddin et al., 1995), though one study found no significant association (Emerson & Brigham, 2015). Longitudinally, one study found that negative life events predicted DSM-IV disorders, including mood disorders, after one year (Dekker & Koot, 2003), whereas another showed that life event exposure uniquely contributed to internalizing problems but not to total psychopathology or externalizing problems (Wallander et al., 2006).

Domain 4. Neighborhood

Theoretically, the neighborhood domain includes environmental factors related to the area in which a family lives, such as neighborhood deprivation and violence, access to recreational facilities, and availability of services. One cross-sectional study addressed this domain and found that living in a violent neighborhood was linked to increased externalizing problems in children with ID (Lapshina & Stewart, 2021).

Discussion

This is the first review to comprehensively synthesize findings on the association between a wide range of social determinants of mental health and mental health problems in children with ID, expanding on previous reviews with a narrower focus (Einfeld et al., 2011; Witwer & Lecavalier, 2008). In doing so, this review highlights the diverse environmental contexts that are associated with variations in mental health problems among youth with ID. Using an existing framework to categorize SDOMH (Lund et al., 2018), we identified significant variability in both the types of SDOMH studied in relation to mental health problems and the findings across these studies. Consequently, the substantial heterogeneity and mixed results across studies indicated that drawing firm conclusions may be premature. Associations appear complex, context-dependent, and varying by individual child characteristics and across different life domains. Nonetheless, findings within the social/cultural domain generally aligned with our expectations. As anticipated, more adverse SDOMH in this domain were generally related to greater mental health problems in children with ID, supporting the idea that social and cultural stressors are associated with increased mental health vulnerabilities. Our exploratory approach to other life domains revealed less consistent patterns and important gaps, highlighting the need for further investigation into the interplay between multiple environmental stressors and mental health in this population.

This review encompasses studies on youth with a broad spectrum of ID severities, including specific groups such as children with Down syndrome and FXS, while also capturing the diverse expressions of mental health problems. Even more, the studies spanned different age groups, from early childhood to young adulthood. By not focusing on a single mental health problem, this review provided a broader understanding of how different mental health problems in youth with ID are connected to SDOMH, aiming to uncover common underlying associations across different conditions. Thus, a key observation from this review is the inherent variability within this population across multiple levels, including ID severity, age, and the varied expressions of mental health problems. However, this variability also introduces complexity. For instance, whereas ASD has a strong genetic component influenced by environmental factors, it differs significantly from behavioral problems, which are more directly associated with environmental factors (Wei et al., 2021; Tordjman et al., 2014). This contrast in underlying mechanisms may help explain our subgroup findings: externalizing behaviors were more often associated with SDOMH than ASD in the social/cultural and economic domains. In contrast, ASD showed relatively more associations in the demographic domain, possibly reflecting a different pattern of relationships. These findings suggest that social and economic environments are more consistently or directly associated with externalizing behavior problems, while the pathways linking SDOMH to ASD symptoms may be more complex or indirect. Other types of mental health problems could not be examined in this way due to the limited number of studies, highlighting an important direction for future research. Subgroup analyses by ID severity and age did not reveal any clear domain-specific patterns.

Despite the challenges posed by variability, some key patterns emerged. Overall, the review found that social, cultural, and economic factors were studied more frequently than demographic and neighborhood factors in research on mental health issues in youth with ID. Most evidence, both longitudinal and cross-sectional, was found in the social/cultural domain, particularly regarding associations between parental well-being, parenting behaviors, life events, and children’s mental health. Specifically, studies found that in families where children exhibited more behavioral problems: (1) parents experienced higher distress or internalizing problems themselves, such as anxiety and depression; (2) parenting behaviors were less positive or more negative (i.e., harsh discipline was consistently associated with behavioral problems); and (3) children were exposed to stressful life events. These results align with a previous review (Witwer & Lecavalier, 2008), which already identified family dysfunction, parental stress and psychopathology as significant factors. This study reinforces and extends these insights by providing further empirical support within the context of children with ID. Viewed through the lens of the dual burden concept, these findings provide some support for one aspect of the concept: children with

ID who experience more adverse SDOMH, particularly in the social/cultural domain, also exhibit higher levels of mental health problems. However, empirical comparative studies are needed to determine whether these adversities are more prevalent among children with ID and more strongly associated with mental health problems than in their typically developing peers.

Findings for SES and income within the economic domain of SDOMH have been inconsistent, aligning with previous reviews (Einfeld et al., 2011; Witwer & Lecavalier, 2008). This inconsistency is particularly evident in cross-sectional studies. Longitudinal studies have shown somewhat more consistent associations over time, but the limited number of longitudinal studies restricts conclusions about long-term effects. The variability in findings may stem from differences in SES measurement–such as income alone versus composite indicators–and that SES rarely operates in isolation. Low SES is often linked to poorer child mental health, particularly when combined with risks such as family adversity or parental psychological distress (Reiss, 2013). For example, education and income are closely related, and without multivariate analyses, their independent or combined relationship with mental health remains unclear. As a result, observed associations may be oversimplified, requiring cautious interpretation as they may not fully capture the multidimensional nature of SDOMH. Contextual factors, such as regional social support systems and income equality, may further influence SES-related findings across settings.

Although research in this area has expanded compared to previous reviews (Einfeld et al., 2011; Witwer & Lecavalier, 2008), our findings reveal four significant gaps. First, while much research has focused on proximal family characteristics, broader social and environmental contexts–such as housing, neighborhood conditions, and community diversity–have received considerably less attention. This is underscored by the presence of only one study in the neighborhood domain, despite growing evidence linking neighborhood deprivation to poor mental health outcomes (Visser et al., 2021). In addition, factors such as geographical remoteness, air pollution, and soil contamination remain underexamined, even though children with ID often live in disadvantaged areas where such risks are prevalent. Investigating these environmental factors is essential for a more comprehensive understanding of their mental health. A second key limitation in the current literature is the predominance of cross-sectional (86.1%) and univariate (75.5%) studies, which restricts causal inference and hinders the identification of the direction and relative importance of SDOMH over time. By focusing on isolated SDOMH, these studies often fail to account for confounding factors or explore potential mediating and moderating effects, thereby overlooking the complex interactions that are likely associated with mental health and limiting the reliability of findings within each domain. The narrow scope of most reviewed studies may partly account for inconsistent findings. To address these gaps, future research should prioritize longitudinal, multivariate designs that can more effectively capture the dynamics and interconnected nature of SDOMH. Third, while research has largely centered on identifying risk factors, protective factors have received considerably less attention. This highlights the need for a more balanced and comprehensive approach to research in this area. Fourth and final, this review found no qualitative studies, leaving significant gaps in understanding the subjective experiences and contextual nuances of SDOMH. Future research should incorporate qualitative methods to capture these experiences more comprehensively.

Strengths and limitations

This review has several strengths. First, we minimized reporting bias by registering our protocol prospectively in PROSPERO. Second, we enhanced generalizability by including a wide range of mental health problems and ID severities. Third, we reduced selection bias through independent article screening by two researchers. Fourth, to enhance the reliability of the findings, two independent researchers critically appraised the individual studies and assessed the strength of evidence within each domain. Finally, the review offers a comprehensive overview of SDOMH across various domains, emphasizing environmental contexts and using an adapted version of Lund et al.’s (2018) framework. This approach offers a holistic view of SDOMH’s role in youth with ID, deepening our understanding of the complex nature of these mental health problems and highlighting the need to consider broader social contexts, such as neighborhood, alongside individual factors.

Nonetheless, some limitations must be acknowledged as well. First, due to the exploratory nature of this review, as well as the diverse topics and varied findings of the included studies, a meta-analysis was not feasible. Second, focusing on Western populations combined with the inclusion of studies published only in English and Dutch, may have introduced selection bias, limiting the generalizability of findings to non-Western or developing countries. Lastly, it was beyond the scope of this review to examine the role of environmental events-such as conflict, displacement, and natural disasters–which may be key SDOMH in non-industrialized contexts (Lund et al., 2018).

Meaning of this review

Despite the diversity and variability within this field of research, some patterns have emerged, particularly within the social/cultural domain. Within this domain, parental well-being, parenting behaviors, and exposure to stressful life events are key factors consistently linked to mental health problems in children with ID. These findings highlight the need for support systems addressing parental mental health and family stressors together with children's mental health, moving beyond symptom-focused interventions. Therefore, we recommend a multidisciplinary, integrated family approach that strengthens collaboration between adult and child mental health services, providing comprehensive, intergenerational support tailored to the needs of families (Stolper et al., 2024). Equally important, however, are critical gaps in research–both with regard to the focus of and quality of studies. To advance this field, future research should adopt a more systematic approach, focusing on structured analyses of different SDOMH and their associations with varied mental health problems, using consistent measures. Moreover, longitudinal studies with mediating and moderating variables are essential to better understand the complex interplay between children's mental health and their environment, to strengthen theoretical and empirical insights, and to improve the identification of specific at-risk groups.

References

Akdemir, D., Pehlivantürk, B., Unal, F., & Ozusta, S. (2009). Comparison of attachment-related social behaviors in autistic disorder and developmental disability. *Turk Psikiyatri Dergisi = Turkish Journal of Psychiatry, 20*(2), 105–117.

Allen, J., Balfour, R., Bell, R., & Marmot, M. (2014). Social determinants of mental health. *International Review of Psychiatry, 26*(4), 392–407. https://doi.org/10.3109/09540261.2014.928270

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders (DSM-5-TR).* American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890425787

Avci, D. (2024). Mental health problems among adolescents with mild intellectual disability and relation to sleep quality and perceived social support: A comparative study. *Journal of Psychosocial Nursing and Mental Health Services, 62*(3), 39–50. https://doi.org/10.3928/02793695-20230821-04

Baird, A., Papachristou, E., Hassiotis, A., & Flouri, E. (2022). The role of physical environmental characteristics and intellectual disability in conduct problem trajectories across childhood: A population-based cohort study. *Environmental Research, 209*, 112837. https://doi.org/10.1016/j.envres.2022.112837

Bailey, T., Totsika, V., Hastings, R. P., Hatton, C., & Emerson, E. (2019). Developmental trajectories of behaviour problems and prosocial behaviours of children with intellectual disabilities in a population-based cohort. *Journal of Child Psychology and Psychiatry, 60*(11), 1210–1218. https://doi.org/10.1111/jcpp.13080

Baker, B. L., & Blacher, J. (2021). Behavior disorders and social skills in adolescents with intellectual disability: Does co-morbid autism matter? *Journal of Mental Health Research in Intellectual Disabilities, 14*(2), 174–188. https://doi.org/10.1080/19315864.2020.1871451

Baker, B. L., Blacher, J., & Pfeiffer, S. (1993). Family involvement in residential treatment of children with psychiatric disorder and mental retardation. *Hospital & Community Psychiatry, 44*(6), 561–566. https://doi.org/10.1176/ps.44.6.561

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4–5), 217–230. https://doi.org/10.1046/j.1365-2788.2003.00484.x

Baker, J. K., Seltzer, M. M., & Greenberg, J. S. (2012). Behaviour problems, maternal internalising symptoms and family relations in families of adolescents and adults with fragile X syndrome. *Journal of Intellectual Disability Research, 56*(10), 984–995. https://doi.org/10.1111/j.1365-2788.2012.01580.x

Blas, E., & Kurup, A. S. (Eds.). (2010). *Equity, social determinants and public health programmes*. World Health Organization.

Boehm, T. L., & Carter, E. W. (2019). Family quality of life and its correlates among parents of children and adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 124*(2), 99–115. https://doi.org/10.1352/1944-7558-124.2.99

Buckles, J., Luckasson, R., & Keefe, E. (2013). A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003–2010. *Journal of Mental Health Research in Intellectual Disabilities, 6*(3), 181–207. https://doi.org/10.1080/19315864.2011.651682

Chadwick, O., Kusel, Y., & Cuddy, M. (2008). Factors associated with the risk of behaviour problems in adolescents with severe intellectual disabilities. *Journal of Intellectual Disability Research, 52*(10), 864–876. https://doi.org/10.1111/j.1365-2788.2008.01102.x

Dekker, M. C., & Koot, H. M. (2003). DSM-IV disorders in children with borderline to moderate intellectual disability. II: Child and family predictors. *Journal of the American Academy of Child and Adolescent Psychiatry, 42*(8), 923–931. https://doi.org/10.1097/01.CHI.0000046891.27264.C1

Dixon-Woods, M. (2011). Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Medicine, 9*, 39. https://doi.org/10.1186/1741-7015-9-39

Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open, 6*(12), e011458. https://doi.org/10.1136/bmjopen-2016-011458

Dykens, E. M., Hodapp, R. M., & Finucane, B. M. (2000). *Genetics and mental retardation syndromes: A new look at behavior and interventions*. Paul H. Brookes.

Dworschak, W., Ratz, C., & Wagner, M. (2016). Prevalence and putative risk markers of challenging behavior in students with intellectual disabilities. *Research in Developmental Disabilities, 58*, 94–103. https://doi.org/10.1016/j.ridd.2016.08.006

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability, 36*(2), 137–143. https://doi.org/10.1080/13668250.2011.572548

Eisenhower, A., & Blacher, J. (2006). Mothers of young adults with intellectual disability: Multiple roles, ethnicity and well-being. *Journal of Intellectual Disability Research, 50*(12), 905–916. https://doi.org/10.1111/j.1365-2788.2006.00913.x

Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research, 47*(1), 51–58. https://doi.org/10.1046/j.1365-2788.2003.00464.x

Emerson, E. (2021). Social and environmental determinants of health among people with disabilities. In E. Emerson (Ed.), *Oxford research encyclopedia of global public health*. Oxford University Press. https://doi.org/10.1093/acrefore/9780190632366.013.325

Emerson, E., & Brigham, P. (2015). Exposure of children with developmental delay to social determinants of poor health: Cross-sectional case record review study: Children with developmental delay. *Child: Care, Health and Development, 41*(2), 249–257. https://doi.org/10.1111/cch.12144

Emerson, E., & Hatton, C. (2007). Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. *American Journal on Mental Retardation, 112*(2), 140–150. https://doi.org/10.1352/0895-8017(2007)112[140:COSPTH]2.0.CO;2

Emerson, E., & Spencer, N. (2015). Health inequity and children with intellectual disabilities. In *International review of research in developmental disabilities* (Vol. 48, pp. 11–42). Elsevier. https://doi.org/10.1016/bs.irrdd.2015.03.001

Emerson, E. (2021). Poverty and children with intellectual disabilities in the world's richer countries. *J Intellect Dev Disabil, 29*, 319–38. https://doi.org/10.1080/13668250400014491

Embregts, P. J. C. M., du Bois, M. G., & Graef, N. (2010). Behavior problems in children with mild intellectual disabilities: An initial step towards prevention. *Research in Developmental Disabilities, 31*(6), 1398–1403. https://doi.org/10.1016/j.ridd.2010.06.020

Foley, K.-R., Jacoby, P., Einfeld, S., Girdler, S., Bourke, J., Riches, V., & Leonard, H. (2014). Day occupation is associated with psychopathology for adolescents and young adults with Down syndrome. *BMC Psychiatry, 14*, 266. https://doi.org/10.1186/s12888-014-0266-z

Frick, P. J., & Silverthorn, P. (2002). Psychopathology in children. In P. B. Sutker & H. E. Adams (Eds.), *Comprehensive handbook of psychopathology* (pp. 881–920). Kluwer Academic Publishers. https://doi.org/10.1007/0-306-47377-1_31

Ghaziuddin, M., Alessi, N., & Greden, J. F. (1995). Life events and depression in children with pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 25*(5), 495–502. https://doi.org/10.1007/BF02178296

Hall, S. S., Burns, D. D., & Reiss, A. L. (2007). Modeling family dynamics in children with fragile X syndrome. *Journal of Abnormal Child Psychology, 35*(1), 29–42. https://doi.org/10.1007/s10802-006-9081-4

Harbour, R., & Miller, J. (2001). A new system for grading recommendations in evidence based guidelines. *BMJ, 323*(7308), 334–336. https://doi.org/10.1136/bmj.323.7308.334

Hatton, C., & Emerson, E. (2009). Does socioeconomic position moderate the impact of child behaviour problems on maternal health in South Asian families with a child with intellectual disabilities? *Journal of Intellectual & Developmental Disability, 34*(1), 10–16. https://doi.org/10.1080/13668250802676012

Hatton, C., Emerson, E., Robertson, J., & Baines, S. (2018). The mental health of adolescents with and without mild/moderate intellectual disabilities in England: Secondary analysis of a longitudinal cohort study. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 768–777. https://doi.org/10.1111/jar.12428

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111*(1), 48–61. https://doi.org/10.1352/0895-8017(2006)111[48:MDAEEC]2.0.CO;2

Hemm, C., Dagnan, D., & Meyer, T. D. (2018). Social anxiety and parental overprotection in young adults with and without intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*(3), 360–368. https://doi.org/10.1111/jar.12413

Kessler, R. C., McLaughlin, K. A., Green, J. G., Gruber, M. J., Sampson, N. A., Zaslavsky, A. M., … Williams, D. R. (2010). Childhood adversities and adult psychopathology in the WHO World Mental Health Surveys. *The British Journal of Psychiatry, 197*(5), 378–385. https://doi.org/10.1192/bjp.bp.110.080499

Kimura, M., & Yamazaki, Y. (2016). Mental health and positive change among Japanese mothers of children with intellectual disabilities: Roles of sense of coherence and social capital. *Research in Developmental Disabilities, 59*, 43–54. https://doi.org/10.1016/j.ridd.2016.07.009

Kirkbride, J. B., Anglin, D. M., Colman, I., Dykxhoorn, J., Jones, P. B., Patalay, P., … Griffiths, S. L. (2024). The social determinants of mental health and disorder: Evidence, prevention and recommendations. *World Psychiatry, 23*(1), 58–90. https://doi.org/10.1002/wps.21160

Kobe, F. H., & Hammer, D. (1994). Parenting stress and depression in children with mental retardation and developmental disabilities. *Research in Developmental Disabilities, 15*(3), 209–221. https://doi.org/10.1016/0891-4222(94)90012-4

Koskentausta, T., Iivanainen, M., & Almqvist, F. (2007). Risk factors for psychiatric disturbance in children with intellectual disability. *Journal of Intellectual Disability Research, 51*(1), 43–53. https://doi.org/10.1111/j.1365-2788.2006.00871.x

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33*(1), 159–174. https://doi.org/10.2307/2529310

Lapshina, N., & Stewart, S. L. (2021). Traumatic life events, polyvictimization, and externalizing symptoms in children with IDD and mental health problems. *Research in Developmental Disabilities, 116*, 104028. https://doi.org/10.1016/j.ridd.2021.104028

Leonard, H., Montgomery, A., Wolff, B., Strumpher, E., Masi, A., Woolfenden, S., … Glasson, E. (2022). A systematic review of the biological, social, and environmental determinants of intellectual disability in children and adolescents. *Frontiers in Psychiatry, 13*, 926681. https://doi.org/10.3389/fpsyt.2022.926681

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gotzsche, P. C., Ioannidis, J. P. A., … Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: Explanation and elaboration. *BMJ, 339,* b2700. https://doi.org/10.1136/bmj.b2700

Long, K. A., Kao, B., Plante, W., Seifer, R., & Lobato, D. (2015). Cultural and child-related predictors of distress among Latina caregivers of children with intellectual disabilities. *American Journal on Intellectual and Developmental Disabilities, 120*(2), 145–165. https://doi.org/10.1352/1944-7558-120.2.145

Lund, C., Brooke-Sumner, C., Baingana, F., Baron, E. C., Breuer, E., Chandra, P., … Saxena, S. (2018). Social determinants of mental disorders and the Sustainable Development Goals: A systematic review of reviews. *The Lancet Psychiatry, 5*(4), 357–369. https://doi.org/10.1016/S2215-0366(18)30060-9

Margalit, M., Shulman, S., & Stuchiner, N. (1989). Behavior disorders and mental retardation: The family system perspective. *Research in Developmental Disabilities, 10*(3), 315–326. https://doi.org/10.1016/0891-4222(89)90019-X

McCarthy, J. (2008). Behaviour problems and adults with Down syndrome: Childhood risk factors. *Journal of Intellectual Disability Research, 52*(10), 877–882. https://doi.org/10.1111/j.1365-2788.2008.01104.x

McDonnell, C. G., Boan, A. D., Bradley, C. C., Seay, K. D., Charles, J. M., & Carpenter, L. A. (2019). Child maltreatment in autism spectrum disorder and intellectual disability: Results from a population-based sample. *Journal of Child Psychology and Psychiatry, 60*(5), 576–584. https://doi.org/10.1111/jcpp.12993

Morinaga, M., Hollander, A., Heuvelman, H., Lundberg, M., Dalman, C., Rai, D., & Magnusson, C. (2021). Migration and risk of intellectual disability with and without autism: A population-based cohort study. *Acta Psychiatrica Scandinavica, 144*(5), 487–500. https://doi.org/10.1111/acps.13350

Neece, C., & Baker, B. (2008). Predicting maternal parenting stress in middle childhood: The roles of child intellectual status, behaviour problems and social skills. *Journal of Intellectual Disability Research, 52*(12), 1114–1128. https://doi.org/10.1111/j.1365-2788.2008.01071.x

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan–A web and mobile app for systematic reviews. *Systematic Reviews, 5*(1), 210. https://doi.org/10.1186/s13643-016-0384-4

Pinborough-Zimmerman, J., Bilder, D., Bakian, A., Satterfield, R., Carbone, P. S., Nangle, B. E., … McMahon, W. M. (2011). Sociodemographic risk factors associated with autism spectrum disorders and intellectual disability. *Autism Research, 4*(6), 438–448. https://doi.org/10.1002/aur.224

Quine, L. (1986). Behaviour problems in severely mentally handicapped children. *Psychological Medicine, 16*(4), 895–907. https://doi.org/10.1017/S0033291700011909

Reiss, F. (2013). Socioeconomic inequalities and mental health problems in children and adolescents: A systematic review. *Social Science & Medicine, 90*, 24–31. https://doi.org/10.1016/j.socscimed.2013.04.026

Robinson, M., & Neece, C. L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of young children with developmental delays. *Journal of Mental Health Research in Intellectual Disabilities, 8*(1), 23–46. https://doi.org/10.1080/19315864.2014.994247

Saunders, B. S., Tilford, J. M., Fussell, J. J., Schulz, E. G., Casey, P. H., & Kuo, D. Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health, 33*(1), 36–45. https://doi.org/10.1037/fsh0000102

Schieve, L. A., Clayton, H. B., Durkin, M. S., Wingate, M. S., & Drews-Botsch, C. (2015). Comparison of perinatal risk factors associated with autism spectrum disorder (ASD), intellectual disability (ID), and co-occurring ASD and ID. *Journal of Autism and Developmental Disorders, 45*(8), 2361–2372. https://doi.org/10.1007/s10803-015-2402-0

Schuiringa, H., van Nieuwenhuijzen, M., Orobio de Castro, B., & Matthys, W. (2015). Parenting and the parent–child relationship in families of children with mild to borderline intellectual disabilities and externalizing behavior. *Research in Developmental Disabilities, 36*, 1–12. https://doi.org/10.1016/j.ridd.2014.08.018

Smith, L. E., Hong, J., Greenberg, J. S., & Mailick, M. R. (2016). Change in the behavioral phenotype of adolescents and adults with FXS: Role of the family environment. *Journal of Autism and Developmental Disorders, 46*(5), 1824–1833. https://doi.org/10.1007/s10803-016-2714-8

Staunton, E., Kehoe, C., & Sharkey, L. (2020). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish Journal of Psychological Medicine*, 1–8. https://doi.org/10.1017/ipm.2020.4

Stewart, S. L., Dave, H. P., & Lapshina, N. (2023). Family dynamics, trauma, and child-related characteristics: Examining factors associated with co-occurring mental health problems in clinically-referred children with and without an intellectual (and developmental) disability. *Journal of Intellectual Disabilities, 27*(3), 701–714. https://doi.org/10.1177/17446295221093967

Stolper, H., Van Doesum, K., & Steketee, M. (2024). An integrated family approach in the practice of adult and child mental health care. *Frontiers in Psychiatry, 15*, 1298268. https://doi.org/10.3389/fpsyt.2024.1298268

Tonge, B. J., & Einfeld, S. L. (2003). Psychopathology and intellectual disability: The Australian Child to Adult Longitudinal Study. In *International review of research in mental retardation* (Vol. 26, pp. 61–91). Elsevier. https://doi.org/10.1016/S0074-7750(03)01002-4

Tordjman, S., Somogyi, E., Coulon, N., Kermarrec, S., Cohen, D., Bronsard, G., … Xavier, J. (2014). Gene × environment interactions in autism spectrum disorders: Role of epigenetic mechanisms. *Frontiers in Psychiatry, 5*, 53. https://doi.org/10.3389/fpsyt.2014.00053

Totsika, V., Hastings, R. P., Emerson, E., & Hatton, C. (2020). Early years parenting mediates early adversity effects on problem behaviors in intellectual disability. *Child Development, 91*(3), e602–e617. https://doi.org/10.1111/cdev.13273

Van Rest, M. M., Van Nieuwenhuijzen, M., Kupersmidt, J. B., Vriens, A., Schuengel, C., & Matthys, W. (2020). Accidental and ambiguous situations reveal specific social information processing biases and deficits in adolescents with low intellectual level and clinical levels of externalizing behavior. *Journal of Abnormal Child Psychology, 48*(11), 1411–1424. https://doi.org/10.1007/s10802-020-00676-x

Visser, K., Bolt, G., Finkenauer, C., Jonker, M., Weinberg, D., & Stevens, G. W. J. M. (2021). Neighbourhood deprivation effects on young people’s mental health and well-being: A systematic review of the literature. *Social Science & Medicine, 270*, 113542. https://doi.org/10.1016/j.socscimed.2020.113542

Wallander, J. L., Dekker, M. C., & Koot, H. M. (2006). Risk factors for psychopathology in children with intellectual disability: A prospective longitudinal population-based study. *Journal of Intellectual Disability Research, 50*(4), 259–268. https://doi.org/10.1111/j.1365-2788.2005.00792.x

Wei, H., Zhu, Y., Wang, T., Zhang, X., Zhang, K., & Zhang, Z. (2021). Genetic risk factors for autism-spectrum disorders: A systematic review based on systematic reviews and meta-analysis. *Journal of Neural Transmission, 128*(6), 717–734. https://doi.org/10.1007/s00702-021-02360-w

Weiss, J. A., Ting, V., & Perry, A. (2016). Psychosocial correlates of psychiatric diagnoses and maladaptive behaviour in youth with severe developmental disability. *Journal of Intellectual Disability Research, 60*(6), 583–593. https://doi.org/10.1111/jir.12278

Williams, C. A., Bailey, T., & Hastings, R. P. (2022). Modelling triadic relationships in families of children with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 35*(3), 843–855. https://doi.org/10.1111/jar.12988

Williams, C. A., Thompson, P. A., Hayden, N. K., & Hastings, R. P. (2024). Sibling relationship and behavioral adjustment in families of disabled children: Cross-lagged associations. *American Journal on Intellectual and Developmental Disabilities, 129*(1), 73–85. https://doi.org/10.1352/1944-7558-129.1.73

World Health Organization. (2014). *Social determinants of mental health*. World Health Organization. https://iris.who.int/handle/10665/112828

World Health Organization. (2022). *World mental health report: Transforming mental health for all*. World Health Organization. https://iris.who.int/bitstream/handle/10665/356119/9789240049338-eng.pdf?sequence=1

Appendix A. Categorization of SDOMH

Domain	**Factor within SDOMH**
Demographic	Parental age Parental ethnicity Population density
Economic	Household poverty Health insurance coverage Economic recessions Survival Economic inequality Macroeconomic policy
Social/Cultural	Education Literacy Social support or isolation Participation / activities Life events Parental education and literacy Parental employment Quality of family relationships Well-being and health of family members Social support, isolation or participation experienced by caregivers Acceptance of the child Social stability
Neighborhood	Exposure to crime Access to playgrounds Involvement in community events Accessibility to public transportation Infrastructure Neighborhood deprivation Violence Built environment

Note. In accordance with the framework of Lund et al. (2018), (parental) education and employment are classified under the social/cultural domain rather than the economic domain.

Appendix B. Search strategy

PubMed

Pubmed search strategy on September 5th, 2024: 3,733
(“Intellectual Disability”[Majr] OR “Intellectual disabilit*”[ti] OR “Mental Retardation”[ti] OR “Mentally Retarded”[ti] OR “Learning Disabilit*”[ti] OR “Intellectual Development Disorder*”[ti] OR “Mental Deficienc*”[ti] OR “Mentally Deficien*”[ti] OR “Developmental disabilit* “[ti] OR “Intellectual deficit*”[ti] OR “Persons with Mental Disabilities”[Majr] OR “mild mental”[tiab] OR “mild intellectual”[tiab] OR “borderline intellectual”[tiab])

AND (“Adolescent”[MeSH] OR “Child”[MeSH] OR “Young Adult”[MeSH] OR “Infant”[MeSH] OR “child*”[tw] OR “schoolchild*”[tw] OR “baby”[tw] OR “babies”[tw] OR “newborn*”[tw] OR “new-born*”[tw] OR “neonat*”[tw] OR “infant*”[tw] OR “infancy”[tw] OR “adolescen*”[tw] OR “boy”[tw] OR “boys”[tw] OR “boyhood”[tw] OR “girl”[tw] OR “girls”[tw] OR “girlhood”[tw] OR “youth”[tw] OR “youths”[tw] OR “toddler*”[tw] OR “teen”[tw] OR “teens”[tw] OR “teenage*”[tw] OR “Puberty”[Mesh] OR “puberty”[tw] OR “preschool”[tw] OR “pre school”[tiab] OR “pre-school”[tw] OR “juvenile”[tw] OR “juvenescence” [tw] OR “young”[tw] OR “youngster*”[tw] OR “kid”[tw] OR “kids”[tw] OR “underage*”[tw] OR “under age*”[tw] OR “puberal”[tw] OR “pubescent”[tw] OR “prepubescent”[tw] OR “prepuberty”[tw] OR “school age*”[tw] OR “schoolage*”[tw] OR “Pediatrics”[Mesh] OR “Pediatric*”[tw] OR “Paediatric*”[tw] OR “Pediatr*”[Journal] OR “Paediatr*”[Journal] OR ”undergraduate”[tw] OR “undergrad”[tw] OR “highschool”[tw] OR “high school”[tw] OR “secondary school”[tw] OR “college”[ti] OR “first-grader*” [tw] OR “second-grader*”[tw] OR “third-grader*”[tw] OR “fourth-grader*”[tw] OR “fifth-grader*”[tw] OR “sixth-grader*”[tw] OR “seventh-grader*”[tw] OR “freshman”[tw] OR “freshmen”[tw] OR “sophomore*”[tw])

AND (“Mental health problem*”[tiab] OR “Psychopatholog*”[tiab] OR “Mental health symptom*”[tiab] OR “Mental disorder*”[tiab] OR “Mental health disorder*”[tiab] OR “Psychiatric disorder*”[tiab] OR “Psychiatric diagnos*”[tiab] OR “Psychiatric morbid*”[tiab] OR “Behavior problem*”[tiab] OR “Behaviour problem*”[tiab] OR “Behavioral problem*”[tiab] OR “Behavioural problem*”[tiab] OR “Emotional problem*”[tiab] OR “Psychopathology”[majr] OR “Mental Disorders”[majr] OR “mental illness*”[tiab] OR “mentally ill”[tiab] OR “mental disease*”[tiab] OR “psychiatric disease*”[tiab] OR “psychiatric illness*”[tiab] OR “psychiatric symptom*”[tiab] OR “psychiatric sign*”[tiab] OR “behavior disorder*”[tiab] OR “problem behavio*”[tiab] OR “Child psychiatry”[mesh] OR “Adolescent psychiatry”[mesh] OR ”Behavioral Symptoms”[tiab] OR ”Impulsive Behavior”[mesh] OR ”Self-Injurious Behavior”[tiab] OR ”Obsessive Behavior”[tiab] OR ”Paranoid Behavior”[tiab] OR ”Problem Behavior”[tiab] OR “neuropsychiatric disease*”[tiab] OR “neuropsychiatric disorder*”[tiab] OR “neurodevelopmental disorder*”[tiab] OR “psychological disorder*”[tiab] OR “psychological disease*”[tiab] OR “psychological illness*”[tiab] OR “psychological disturbance”[tiab] OR “addiction*”[tiab] OR “adjustment disorder*”[tiab] OR “alexithymi*”[tiab] OR “anxiety disorder*”[tiab] OR “autism*”[tiab] OR “dissociative disorder”[tiab] OR “emotional disorder”[tiab] OR “Emotional Development*”[tiab] OR “Eating Disorders”[tiab] OR “mental instability”[tiab] OR “Mood Disorders”[tiab] OR “Obsessive-Compulsive Disorder”[tiab] OR “pathological lying”[tiab] OR “Personality Disorder*”[tiab] OR “psychosexual disorder”[tiab] OR “psychosis”[tiab] OR “psychotrauma”[tiab] OR “thought disorder”[tiab])

AND (“Social Factors”[majr] OR “Social Determinants of Health”[majr] OR “Home Environment”[Mesh] OR “Built Environment”[Mesh] OR “Vulnerable Populations”[Mesh] OR “Social”[ti] OR “divorce*”[ti] OR “Literacy”[ti] OR ”illiteracy”[ti] OR “illiterateness”[ti] OR “Poverty”[ti] OR “poverty”[Title] OR “poverty”[ot] OR “Unemploy* “[ti] OR “Deprivation “[ti] OR ”deprived”[ot] OR ”destitute”[ot] OR “maltreatment”[ti] OR “peer pressure”[ti] OR “Insurance”[ti] OR “Bully*”[ti] OR “Participation in activities”[ti] OR “engaging in activities”[ti] OR “inequalit*”[ti] OR “Health disparit*”[ti] OR “Health inequit* “[ti] OR “Risk* “[ti] OR “Cultural “[ti] OR “Protective “[ti] OR “Prevention”[ti] OR “Demographic”[ti] OR “Community diversity”[ti] OR “Population density”[ti] OR “Longevity”[ti] OR “Economic*”[ti] OR “Macroeconomic*”[ti] OR “Neighborhood “[ti] OR “Neighbourhood “[ti] OR “Infrastructure”[ti] OR “Built environment”[ti] OR “Environmental event*”[ti] OR “Family”[ti] OR “Families”[ti] OR “Socio-economic”[ti] OR “Socioeconomic”[ti] OR “minorit*”[ti] OR “Life event*”[ti] OR “Marital Status”[ti] OR “Population Group*”[ti] OR “Ethnic group*”[ti] OR “Married”[ti] OR “Separated”[ti] OR “Single Parent”[Mesh] OR “Single-Parent Family”[Mesh] OR “Single-Parent”[ti] OR “One-parent”[ti] OR “Employment”[Mesh:NoExp] OR “Employment”[ti] OR “Income*”[ti] OR “income*”[ot] OR “debt*”[ot] OR “indebted”[ot] OR “Affluence”[ti] OR

“Disadvantaged”[ti] OR “Living standard*”[ti] OR “Marginal*”[ti] OR “Standard of living”[ti] OR “Financial difficult*”[ti] OR “Financial problem*”[ti] OR “Financial security”[ot] OR “Financial insecurity”[ot] OR “Occupation*”[ti] OR “Jobless”[ti] OR “Inequit*”[ti] OR “Job insecurity”[ti] OR “Workless”[ti] OR “Residence”[ti] OR “Safety”[ti] OR “Recreational facilit*”[ti] OR “Access to health service*”[ti] OR “Crime rate*”[ti] OR “Housing”[ti] OR “Psychosocial”[ti] OR “Psycho-social”[ti] OR “Education*”[ti] OR “Vulnerable Population*”[ti] OR “oppressed”[ti] OR “racial”[ti] OR “inequalit*”[ti] OR “injustice”[ti] OR “unrepresented”[ti] OR “underprivileged”[ot] OR “impoverish*”[Title] OR “impoverish*”[ot])

NOT (“mutation”[ot] OR “gene”[ot] OR “genes”[ot] OR “genetic”[ot] OR “mutation”[ti] OR “gene”[ti] OR “genes”[ti] OR “genetic”[ti])

PsycINFO

PsycINFO search strategy on September 5th, 2024: 580
(MM (“Intellectual Development Disorder” OR “Down’s Syndrome”) OR TI (“Intellectual disabilit*” OR “mental disabilit*” OR “Mental Retardation” OR “Mentally Retarded” OR “Learning Disabilit*” OR “Intellectual Development Disorder*” OR “Mental Deficien*” OR “Mentally Deficien*” OR “Developmental disabilit*” OR “Intellectual deficit*” OR “Persons with Mental Disabilities” OR “mild mental” OR “mild intellectual” OR “borderline intellectual”)) AND (DE (“Puberty” OR “Pediatrics”) OR TX (“child*” OR “schoolchild*” OR “baby” OR “babies” OR “newborn*” OR “new-born*” OR “neonat*” OR “infant*” OR “infancy” OR “adolescen*” OR “boy” OR “boys” OR “boyhood” OR “girl” OR “girls” OR “girlhood” OR “youth” OR “youths” OR “toddler*” OR “teen” OR “teens” OR “teenage*” OR “puberty” OR “preschool” OR “pre school” OR “pre-school” OR “juvenile” OR “young” OR “youngster*” OR “kid” OR “kids” OR “underage*” OR “under age*” OR “puberal” OR “pubescent” OR “prepubescent” OR “prepuberty” OR “school age*” OR “schoolage*” OR “Pediatric*” OR “Paediatric*” OR “juvenescence” OR “Pediatr*” OR “Paediatr*” OR ”undergraduate” OR “undergrad” OR “highschool” OR “high school” OR “secondary school” OR “college” OR “first-grader*” OR “second-grader*” OR “third-grader*” OR “fourth-grader*” OR “fifth-grader*” OR “sixth-grader*” OR “seventh-grader*” OR “freshman” OR “freshmen” OR “sophomore*”)) AND (TI (“Mental health problem*” OR “Psychopatholog*” OR “Mental

health symptom*” OR “Mental disorder*” OR “Mental health disorder*” OR “Psychiatric disorder*” OR “Psychiatric diagnos*” OR “Psychiatric morbid*” OR “Behavior problem*” OR “Behaviour problem*” OR “Behavioral problem*” OR “Behavioural problem*” OR “Emotional problem*” OR “Psychopatholog*” OR MM (“Psychopathology” OR “Adolescent Psychopathology” OR “Child Psychopathology” OR “Mental Disorders” OR “Affective Disorders” OR “Anxiety Disorders” OR “Autism Spectrum Disorders” OR “Bipolar Disorder” OR “Borderline States” OR “Chronic Mental Illness” OR “Dissociative Disorders” OR “Eating Disorders” OR “Gender Dysphoria” OR “Mental Disorders due to General Medical Conditions” OR “Neurocognitive Disorders” OR “Neurosis” OR “Paraphilias” OR “Personality Disorders” OR “Psychosis” OR “Serious Mental Illness” OR “Sleep Wake Disorders” OR “Somatoform Disorders” OR “Substance Related and Addictive Disorders” OR “Thought Disturbances” OR “mental illness*” OR “mentally ill” OR “mental disease*” OR “psychiatric disease*” OR “psychiatric illness*” OR “psychiatric symptom*” OR “psychiatric sign*” OR “behavior disorder*” OR “problem behavio*” OR “Child psychiatry” OR “Adolescent psychiatry” OR ”Behavioral Symptoms” OR ”Impulsive Behavior” OR ”Self-Injurious Behavior” OR ”Obsessive Behavior” OR ”Paranoid Behavior” OR ”Problem Behavior” OR “neuropsychiatric disease*” OR “neuropsychiatric disorder*” OR “neurodevelopmental disorder*” OR “psychological disorder*” OR “psychological disease*” OR “psychological illness*” OR “psychological disturbance” OR “addiction*” OR “adjustment disorder*” OR “alexithymi*” OR “anxiety disorder*” OR “autism*” OR “dissociative disorder” OR “emotional disorder” OR “Emotional Development*” OR “Eating Disorders” OR “mental instability” OR “Mood Disorders” OR “Obsessive-Compulsive Disorder” OR “pathological lying” OR “Personality Disorder*” OR “psychosexual disorder” OR “psychosis” OR “psychotrauma” OR “thought disorder”)) AND (MM (“Socioeconomic Factors” OR “Economic Disadvantage” OR “Home Environment” OR “Built Environment” OR “Vulnerable Populations” “Economic Resources” OR “Employment Status” OR “Income Level” OR “Social Class” OR “Social Disadvantage” OR “Socioeconomic Status” OR “Single Parents” OR “Single Fathers” OR “Single Mothers”) OR TI (“Social” OR “divorce*” OR “Literacy” ”illiteracy” OR “illiterateness” OR “Poverty” OR “Unemploy* “ OR “Deprivation “ OR ”deprived” OR ”destitute” OR “maltreatment” OR “peer pressure” OR “Insurance” OR “Bully*” OR “Participation in activities” OR “engaging in activities” OR “inequalit*” OR “Health disparit*” OR “Health inequit*

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Web of Science

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Cochrane

Cochrane search strategy on September 5th, 2024: 0
("Intellectual disabilit*" OR "mental disabilit*" OR "Mental Retardation" OR "Mentally Retarded" OR "Learning Disabilit*" OR "Intellectual Development Disorder*" OR "Mental Deficien*" OR "Mentally Deficien*" OR "Developmental disabilit*" OR "Intellectual deficit*" OR "Down's Syndrome" OR "Down Syndrome" OR "Downs Syndrome"):ti AND ("child*" OR "schoolchild*" OR "baby" OR "babies" OR "newborn*" OR "new-born*" OR "neonat*" OR "infant*" OR "infancy" OR "adolescen*" OR "boy" OR "boys" OR "boyhood" OR "girl" OR "girls" OR "girlhood" OR "youth" OR "youths" OR "toddler*" OR "teen" OR "teens" OR "teenage*" OR "puberty" OR "preschool" OR "pre school" OR "pre-school" OR "juvenile" OR "young" OR "youngster*" OR "kid" OR "kids" OR "underage*" OR "under age*" OR "puberal" OR "pubescent" OR "prepubescent" OR "prepuberty" OR "school age*" OR "schoolage*" OR "Pediatric*" OR "Paediatric*"):ti,ab,kw AND ("Mental health problem*" OR "Psychopatholog*" OR "Mental health symptom*" OR "Mental disorder*" OR "Mental health disorder*" OR "Psychiatric disorder*" OR "Psychiatric diagnos*"

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MEDLINE

MEDLINE search strategy on September 5th, 2024: 237

(MM (“Intellectual Development Disorder” OR “Down’s Syndrome”) OR TI (“Intellectual disabilit*” OR “mental disabilit*” OR “Mental Retardation” OR “Mentally Retarded” OR “Learning Disabilit*” OR “Intellectual Development Disorder*” OR “Mental Deficien*” OR “Mentally Deficien*” OR “Developmental disabilit*” OR “Intellectual deficit*” OR “Persons with Mental Disabilities” OR “mild mental” OR “mild intellectual” OR “borderline intellectual”)) AND (DE (“Puberty” OR “Pediatrics”) OR TX (“child*” OR “schoolchild*” OR “baby” OR “babies” OR “newborn*” OR “new-born*” OR “neonat*” OR “infant*” OR “infancy” OR “adolescen*” OR “boy” OR “boys” OR “boyhood” OR “girl” OR “girls” OR “girlhood” OR “youth” OR “youths” OR “toddler*” OR “teen” OR “teens” OR “teenage*” OR “puberty” OR “preschool” OR “pre school” OR “pre-school” OR “juvenile” OR “young” OR “youngster*” OR “kid” OR “kids” OR “underage*” OR “under age*” OR “puberal” OR “pubescent” OR “prepubescent” OR “prepuberty” OR “school age*” OR “schoolage*” OR “Pediatric*” OR “Paediatric*” OR “juvenescence” OR “Pediatr*” OR “Paediatr*” OR ”undergraduate” OR “undergrad” OR “highschool” OR “high school” OR “secondary school” OR “college” OR “first-grader*” OR “second-grader*” OR “third-grader*” OR “fourth-grader*” OR “fifth-grader*” OR “sixth-grader*” OR “seventh-grader*” OR “freshman” OR “freshmen” OR “sophomore*”)) AND (TI (“Mental health problem*” OR “Psychopatholog*” OR “Mental health symptom*” OR “Mental disorder*” OR “Mental health disorder*” OR “Psychiatric disorder*” OR “Psychiatric diagnos*” OR “Psychiatric morbid*” OR “Behavior problem*” OR “Behaviour problem*” OR “Behavioral problem*” OR “Behavioural problem*” OR “Emotional problem*” OR “Psychopatholog*” OR MM (“Psychopathology” OR “Adolescent Psychopathology” OR “Child Psychopathology” OR “Mental Disorders” OR “Affective Disorders” OR “Anxiety Disorders” OR “Autism Spectrum Disorders” OR “Bipolar Disorder” OR “Borderline States” OR “Chronic Mental Illness” OR “Dissociative Disorders” OR “Eating Disorders” OR “Gender Dysphoria” OR “Mental Disorders due to General Medical Conditions” OR “Neurocognitive Disorders” OR “Neurosis” OR “Paraphilias” OR “Personality Disorders” OR “Psychosis” OR “Serious Mental Illness” OR “Sleep Wake Disorders” OR “Somatoform Disorders” OR “Substance Related and Addictive Disorders” OR “Thought Disturbances” OR “mental illness*” OR “mentally ill” OR “mental disease*” OR “psychiatric disease*” OR “psychiatric illness*” OR “psychiatric symptom*” OR “psychiatric sign*” OR “behavior disorder*” OR “problem behavio*” OR “Child psychiatry” OR “Adolescent psychiatry” OR ”Behavioral Symptoms” OR ”Impulsive Behavior” OR ”Self-Injurious Behavior” OR ”Obsessive Behavior” OR ”Paranoid Behavior” OR ”Problem Behavior” OR “neuropsychiatric disease*” OR “neuropsychiatric disorder*” OR “neurodevelopmental disorder*” OR “psychological disorder*”

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Appendix C. Study characteristics

Authors (year)	**Country**	**Design**	**Sample size number with ID**	**Age-based stages**	**Severity of ID**	**Type of mental health problems**	**SDOMH**	**Quality of the study**
Schieve, Clayton, Durkin, Wingate, and Drews-Botsch (2015)	USA	Cross-sectional	4821	Middle childhood	Severe + moderate + mild	ASD	Maternal race/ethnicity, Maternal education, Maternal age, Mother unmarried at birth	High
Dekker & Koot (2003)	The Netherlands	Longitudinal	474	Middle childhood + early adolescence + late adolescence	Severe + moderate + mild + borderline	Anxiety, Disruptive Disorder, Mood Disorder, Psychopathology	Psychopathology of primary caregiver, Parental referral to mental health care, Sibling referral to mental health care, Family dysfunction, Low parental educational level, Non-Dutch parents, Single parent, Low SES, Negative life events	High
Eisenhower & Blacher (2006)	USA	Cross-sectional	226	Late adolescence	Severe + moderate	Behavior Problems	Employment status, Marital status, Ethnic group	Low
Hatton & Emerson (2009)	UK	Cross-sectional	123	Early childhood + middle childhood + early adolescence + late adolescence	Severe	Behavior Problems	Ethnicity of the mother, Parental anxiety, Parental distress, Parental health, Parental depression	Low
Morinaga, Hollander, Heuvelman, Lundberg, Dalman, Rai, and Magnusson (2021)	Sweden	Longitudinal	8857	Early childhood + middle childhood + early adolescence	Unknown	ASD	Timing of Child's Birth in Relation to Maternal Migration	High

Akdemir, Pehlivantürk, Ünal, and Özusta (2009)	Turkey	Cross-sectional	37	Early childhood	Mild + borderline	ASD	Parents level of education, Parental employment statement, Maternal age, Paternal age	Low
Avci (2024)	Turkey	Cross-sectional	91	Early adolescence + late adolescence	Mild	Emotional Problems, Conduct Problems, Hyperactivity	Birth order, Maternal age, Mothers education level, Fathers education level, Perceived social support,	High
Emerson & Brigham (2015)	UK	Cross-sectional	2236	Unknown	Unknown	Behavior Problems	Socio-economic position, Parent in care or abused, One parent family, Parent under 18, 3+ children under five, Separation/ divorce, Family bereavement, Violence within family, Parent abuses alcohol, Parent abuses drugs, Parenting difficulties, Parental mental health	Medium
Pinborough-Zimmerman, Bilder, Bakian, Satterfield, Carbone, Nangle, Randall, and McMahon (2011)	USA	Longitudinal	245	Middle childhood	Unknown	ASD	Income, Federal taxes paid, Tax exemptions	Medium
Baker, Neece, Fenning, Crnic, and Blacher (2010)	USA	Longitudinal	236	Early childhood	Moderate + mild + borderline	ADHD	Maternal Education, Family Income (% > 50 K), Scaffolding, Positive Parenting, Negative Parenting, Dyadic pleasure, Dyadic conflict	High

Baker & Blacher (2021)	USA	Cross-sectional (part of longitudinal study)	161	Early adolescence	Moderate + mild + borderline	ASD	Maternal education, Maternal employment, Maternal marital status, Family income, Maternal anxiety, Maternal depression, Maternal hostility, Maternal Interpersonal Sensitivity, Maternal Somatization	Low
Baker, Seltzer, and Greenberg (2012)	USA	Cross-sectional	115	Early adolescence + late adolescence	Unknown	ASD, Behavior Problems	Maternal internalising symptoms, Marital satisfaction, Family cohesion, Income, Maternal education	Medium
Chadwick, Kusel, and Cuddy (2008)	UK	Longitudinal	82	Early adolescence	Severe	Externalising Problems, Overactivity, Destructive Behavior, Self-Injury	Family's housing tenure, Single parent, No maternal educational qualifications, Main source of household income, Lack of continuity in maternal care, Lack of continuity in paternal care, Expressed parental criticism, Expressed parental warmth, Disciplinary aggression	High
Emerson & Hatton (2007)	UK	Cross-sectional	10438	Middle childhood + early adolescence	Unknown	Conduct Disorder, Emotional Disorder	Household income, Occupational prestige, Maternal education, Single parenthood, Household income, Occupational prestige, Maternal education, Single parenthood	High

Williams, Bailey, and Hastings (2022)	UK	Cross-sectional	574	Middle childhood + early adolescence	Unknown	Behavior Problems	Household poverty, Maternal life satisfaction, Maternal distress	High
Quine (1986)	UK	Cross-sectional	200	Early childhood + middle childhood	Severe	Behavior Problems	Single parent, Family size, Financial help	Low
Dworschak, Ratz, and Wagner (2016)	Germany	Cross-sectional	1629	Middle childhood + early adolescence + late adolescence	Severe + moderate + mild + borderline	Challenging Behavior	SES	Medium
Saunders, Tilford, Fussell, Schulz, Casey, and Kuo (2015)	USA	Cross-sectional	1983	Early childhood + middle childhood + early adolescence	Unknown	ASD	Health insurance coverage	Low
Schuiringa, van Nieuwenhuijzen, Orobio de Castro, and Matthys (2015)	The Netherlands	Cross-sectional	113	Middle childhood + early adolescence	Mild + borderline	Behavior Problems	SES, Involvement, Positive parenting scale, Monitoring, Positive discipline, Physical punishment, Rules, Acceptance, Sense of competence, Closeness	High
Baker, Blacher, and Pfeiffer (1993)	USA	Cross-sectional	234	Middle childhood + early adolescence + late adolescence	Severe + moderate + mild	Psychopathology	Parents marital status, Family socioeconomic status	Low
Kimura & Yamazaki (2016)	Japan	Cross-sectional	613	Early childhood + middle childhood + early adolescence + late adolescence	Unknown	ASD	Employment status, Marital status, Standard of living	Low

Scambler, Hepburn, Hagerman, and Rogers (2007)	USA	Cross-sectional	17	Early childhood	Unknown	ASD	SES	Medium
Weiss, Ting, and Perry (2016)	Canada	Cross-sectional	141	Middle childhood + early adolescence	Severe	Psychopathology, Maladaptive Behavior	Parental mental health problems, Family quality of life, Total negative life events, Financial Hardship	Low
Baker, McIntyre, Blacher, Crnic, Edelbrock, and Low (2003)	USA	Longitudinal	82	Early childhood	Moderate + mild	Behavior Problems	Parental stress level	Medium
Hall, Burns, and Reiss (2007)	USA	Cross-sectional	150 families	Middle childhood	Moderate + mild	Behavior Problems	Maternal distress	Medium
Long, Kao, Plante, Seifer, and Lobato (2015)	USA	Cross-sectional	192	Middle childhood	Severe + moderate + mild + borderline	Maladaptive Behavior	Overall maternal distress, Maternal despressive symptoms, Maternal somatic symptoms	Medium
Neece & Baker (2008)	USA	Longitudinal, 2 years	189	Middle childhood	Moderate + mild + borderline	Behavior Problems	Maternal parenting stress	Medium
Robinson & Neece (2015)	USA	Cross-sectional	44	Early childhood	Moderate + mild	Behavior Problems	Marital satisfaction, Parental distress	Medium
Staunton, Kehoe, and Sharkey (2020)	Ireland	Cross-sectional	33	Middle childhood + early adolescence	Moderate	Challenging Behaviors, ASD	Parental psychological stress, Family quality of life, Level of support	Low
Bailey, Totsika, Hastings, Hatton, and Emerson (2019)	UK	Longitudinal cohort study	555	Early childhood + middle childhood	Unknown	Internalising and Externalising Problems	Maternal life satisfaction, Maternal distress	High

Hastings, Daley, Burns, and Beck (2006)	UK	Longitudinal	T0: 75; T1: 56	Early childhood + middle childhood + early adolescence + late adolescence	Unknown	Internalising and Externalising Problems	Maternal depression, Maternal criticism, Maternal anxiety, Maternal distress, Maternal criticism	Low
Wallander, Dekker, and Koot (2006)	The Netherlands	Longitudinal	474	Middle childhood + early adolescence	Severe + moderate + mild + borderline	Psychopathology, Internalising and Externalising Problems	Parental distress, Parents mental health treatment history, Family dysfunction, Life events exposure, Low SES, Single parent	High
Embregts, du Bois, and Graef (2010)	The Netherlands	Cross-sectional	45	Early adolescence	Mild + borderline	Behavior Problems	Parents sense of competence, Restriction of role, Attachment, Parental depression, Parents health, Parental social isolation, Relationship with spouse, Negative life events, Positive life experiences	Low
Kobe & Hammer (1994)	USA	Cross-sectional	29	Early childhood + middle childhood	Severe + moderate + mild	Depression	Maternal depression, Attachment, Restriction of role, Sense of competence, Parental social isolation, Relationship with spouse, Parental health	Low
Stewart, Dave, and Lapshina (2023)	Canada	Cross-sectional	517	Middle childhood + early adolescence	Severe + moderate + mild + borderline	Psychiatric Diagnosis	Parental mental health difficulties, Sibling mental health difficulties, Traumatic life events	High
McCarthy (2008)	UK	Cross-sectional	193	Middle childhood + early adolescence	Unknown	Severe Behavior Disorder	Quality of marriage, Parental mental health, Social class	Low

Smith, Hong, Greenberg, and Mailick (2016)	USA	Longitudinal	147	Late adolescence	Unknown	Behavior Problems, Internalising, Externalising Problems, ASD	Maternal depression, Criticism, Warmth	Low
Lapshina & Stewart (2021)	Canada	Cross-sectional	502	Middle childhood + early adolescence	Severe + moderate + mild + borderline	Externalising Problems	Sexual assault/abuse, Physical assault/abuse, Emotional abuse, Witnessed domestic violence, Parental addiction, Death of a parent, Death in family, Parental abandonment, Violent neighborhood, Witnessed severe accident (disaster, terrorism, violence, or abuse)	High
Emerson (2003)	UK	Cross-sectional	264	Middle childhood + early adolescence	Unknown	Conduct Disorder, ADHD, Emotional Disorder, Anxiety Disorder, Depression, ASD, Psychopathology	Head of household classified in partly skilled and unskilled occupations, Household income, Single parents, Psychiatric morbidity among carers, Patterns of family functioning, Use of punitive strategies, Potentially stressful life events	Medium
Hatton, Emerson, Robertson, and Baines (2018)	UK	Longitudinal cohort study	572	Early adolescence + late adolescence	Moderate + mild	Psychopathology	Workless household, Single-parent household	High
Tonge & Einfeld (2003)	Australia	Longitudinal	976	Middle childhood + early adolescence	Severe + moderate + mild	Psychopathology	Family employment status, Social class, Living in nonfamily care	Low
Koskentausta, Iivanainen, and Almqvist (2007)	Finland	Cross-sectional	75	Middle childhood	Severe + moderate + mild	Psychopathology	SES, Number of children in the family, Birth order	Medium

Williams, Thompson, Hayden, and Hastings (2024)	UK	Longitudinal	296	Middle childhood + early adolescence	Moderate + mild	Behavior Problems	Birth order, Sibling warmth, Sibling conflict	High
Margalit, Shulman, and Stuchiner (1989)	Israel	Cross-sectional	39	Middle childhood + early adolescence	Moderate	Disruptive Behavioral Problems	Family Environmental Scale (Cohesion), Family Environmental Scale (Conflict)	Low
Boehm & Carter (2019)	USA	Cross-sectional	529	Early childhood + middle childhood + early adolescence + late adolescence	Severe + moderate + mild	ASD	Family relationships, Friend relationships	High
Totsika, Hastings, Emerson, and Hatton (2020)	UK	Longitudinal	555	Early childhood + middle childhood + early adolescence	Moderate + mild	Emotional Problems, Hyperactivity, Conduct Problems, Behavior Problems	Positive relationship, Adversarial parenting	High
McDonnell, Boan, Bradley, Seay, Charles, and Carpenter (2019)	USA	Cross-sectional	4988	Early childhood	Severe + moderate + mild	ASD	Overall maltreatment	High
Hemm, Dagnan, and Meyer (2018)	UK	Cross-sectional	21	Late adolescence	Mild + borderline	Anxiety	Parental overprotection	Medium
Van Rest, Van Nieuwenhuijzen, Kupersmidt, Vriens, Schuengel, and Matthys (2020)	The Netherlands	Cross-sectional	220	Early adolescence	Mild + borderline	Externalising Problems	SES	High
Ghaziuddin, Alessi, and Greden (1995)	USA	Cross-sectional	22	Middle childhood + early adolescence + late adolescence	Mild + borderline	Depression	Mean Life Events Score	Low

Foley, Jacoby, Einfeld, Girdler, Bourke, Riches, and Leonard (2014)	Australia	Longitudinal	T0: 118; T1: 103	Late adolescence	Unknown	Behavior Problems	Day occupations: open employment, Day occupations: training, Day occupations: sheltered employment, Day occupations: day recreation programs	Medium

Appendix D. AXIS quality appraisal criteria and assigned weights

No.	**Question**	**Max. weight**
1	Were the aims/objectives of the study clear?	1.5
2	Was the study design appropriate for the stated aim(s)?	2
3	Was the sample size justified?	1
4	Was the target/reference population clearly defined? (Is it clear who the research was about?)	1
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?	1
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?	1
7	Were measures undertaken to address and categorise non-responders?	1
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?	2
9	Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?	2
10	Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)	1
11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?	2
12	Were the basic data adequately described?	1
13 (R)	Does the response rate raise concerns about non-response bias?	1
14	If appropriate, was information about non-responders described?	1
15	Were the results internally consistent?	1
16	Were the results presented for all the analyses described in the methods?	2
17	Were the authors' discussions and conclusions justified by the results?	1.5
18	Were the limitations of the study discussed?	1
19 (R)	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	1
20	Was ethical approval or consent of participants attained?	1

Note. (R) = reversed. Items 13 and 19 are reverse-coded; a 'no' response on these items was considered a positive indicator of quality.

Appendix E. Extended findings

Domain	**Size of evidence (no. of studies and % of total studies)**	**Quality (individual studies)**	**Consistency of findings**	**Context**	**Perspective**	**Overall strength of evidence**
Demographic	n = 8 (15.7%) (Akdemir et al., 2009; Avci, 2024; Dekker & Koot, 2003; Eisenhower & Blacher, 2006; Emerson & Brigham, 2015; Hatton & Emerson, 2009; Morinaga et al., 2021; Schieve et al., 2015)	High: 4 Medium: 1 Low: 3	Inconsistent	Specific (n = 3) Mixed (n = 5)	Single (n = 7) Multiple (n = 1)	Medium
Economic	n = 17 (33.3%) (Baker & Blacher, 2021; Baker et al., 1993; Baker et al., 2010; Baker et al., 2012; Chadwick et al., 2008; Dworschak et al., 2016; Emerson & Brigham, 2015; Emerson & Hatton, 2007; Hatton et al., 2018; Kimura & Yamazaki, 2016; Pinborough-Zimmerman et al., 2011; Quine, 1986; Saunders et al., 2015; Scambler et al., 2007; Schuiringa et al., 2015; Weiss et al., 2016; Williams et al., 2022)	High: 5 Medium: 6 Low: 6	Contradictory	Specific (n = 9) Mixed (n = 8)	Single (n = 13) Multiple (n = 4)	Medium
Social / cultural	n = 46 (90.2%) (Akdemir et al., 2009; Avci, 2024; Baker & Blacher, 2021; Baker et al., 1993; Baker et al., 2003; Baker et al., 2010; Baker et al., 2012; Chadwick et al., 2008; Dekker & Koot, 2003; Dworschak et al., 2016; Eisenhower & Blacher, 2006; Emerson, 2003; Emerson & Brigham, 2015; Emerson & Hatton, 2007; Embregts et al., 2010; Foley et al., 2014; Ghaziuddin et al., 1995; Hall et al., 2007; Hastings et al., 2006; Hatton & Emerson, 2009;	High: 19 Medium: 11 Low: 17	Contradictory	Specific (n = 18) Mixed (n = 29)	Single (n = 34) Multiple (n = 13)	Strong

	Hatton et al., 2018; Hemm et al., 2018; Kimura & Yamazaki, 2016; Kobe & Hammer, 1994; Koskentausta et al., 2007; Lapshina & Stewart, 2021; McCarthy, 2008; McDonnell et al., 2019; Morinaga et al., 2021; Neece & Baker, 2008; Pinborough-Zimmerman et al., 2011; Quine, 1986; Robinson & Neece, 2015; Saunders et al., 2015; Scambler et al., 2007; Schieve et al., 2015; Schuiringa et al., 2015; Smith et al., 2016; Staunton et al., 2020; Stewart et al., 2023; Totsika et al., 2020; Van Rest et al., 2020; Weiss et al., 2016; Williams et al., 2022; Williams et al., 2024; Wei et al., 2021)					
Neighborhood	n = 1 (1.2%) (Lapshina & Stewart, 2021)	High: 1 Medium: 0 Low: 0	N.A.	Specific (n = 0) Mixed (n=1)	Single (n = 1) Multiple (n = 0)	N.A.

Note. N.A. = not applicable. Size of evidence = number of studies and percentage of total included studies; Quality = distribution of study quality ratings (high/medium/low); Consistency = extent to which findings align across studies (e.g., consistent, inconsistent, contradictory); Context = whether findings were observed in narrowly defined samples (e.g., specific diagnoses or subgroups) versus broader or more diverse populations (specific vs. mixed); Perspective = number of informants contributing to the evidence (single vs. multiple); Overall strength of evidence reflects a cumulative rating of the five criteria (see Methods for full definitions).

Appendix F. Summary of results categorized by domain and subgroup

Table 3. Severity of ID

Domain	**Severe**	**Severe + Moderate**	**Moderate**	**Moderate + Mild + Borderline**	**Mild**	**Mild + Borderline**	**Entire spectrum**	**Unknown**
n	*4*	*1*	*2*	*9*	*1*	*7*	*13*	*15*
Demographic	0/1	0/1	-	-	1/1	0/1	1/2	1/2
Economic	1/3	-	-	0/2		0/1	1/2	4/9
Social/Cultural	4/4	0/1	1/2	7/9	1/1	5/6	10/12	10/11
Neighborhood	-	-	-	-		-	1/1	-

Note. The first number in each cell represents the number of studies that found a significant result, while the number after the slash indicates the total number of studies.

Table 4. Age groups

Domain	**EC**	**EC + MC**	**MC**	**MC + EA**	**EA**	**EA + LA**	**LA**	**Combination**	**Unknown**
n	*6*	*3*	*6*	*13*	*4*	*3*	*4*	*11*	*1*
Demographic	0/1	-	1/1	-	-	1/1	0/1	1/3	0/1
Economic	0/2	1/1	1/1	2/5	0/1	0/1	-	1/4	1/1
Social/Cultural	3/5	3/3	5/5	9/12	4/4	2/3	3/4	7/7	1/1
Neighborhood	-	-	-	1/1	-	-	-	-	-

Note. EC = Early childhood; MC = Middle childhood; EA = Early adolescence; LA = Late adolescence. The first number in each cell represents the number of studies that found a significant result, while the number after the slash indicates the total number of studies.

Table 5. Mental health conditions (sub-analysis)

Domain	**ASD**	**Externalizing problems**[a]
n	*14*	*31*
Studies:	*(Akdemir et al., 2009; Baker & Blacher, 2021; Baker et al., 2012*; Boehm & Carter, 2019; Emerson, 2003*; Kimura & Yamazaki, 2016; McDonnell et al., 2019; Morinaga et al., 2021; Pinborough-Zimmerman et al., 2011; Saunders et al., 2015; Schieve et al., 2015; Scambler et al., 2007; Smith et al., 2016; Staunton et al., 2020*)*	*(Avci, 2024; Baker et al., 2003; Baker et al., 2010; Baker et al., 2012*; Bailey et al., 2019; Dekker & Koot, 2003; Dworschak et al., 2016; Eisenhower & Blacher, 2006; Emerson, 2003; Emerson & Brigham, 2015; Embregts et al., 2010; Foley et al., 2014; Hall et al., 2007; Hastings et al., 2006; Hatton & Emerson, 2009; Kimura & Yamazaki, 2016; Lapshina & Stewart, 2021; Long et al., 2015; Margalit et al., 1989; McCarthy, 2008; Neece & Baker, 2008; Quine, 1986; Robinson & Neece, 2015; Schuiringa et al., 2015; Smith et al., 2016; Staunton et al., 2020*; Totsika et al., 2020; Van Rest et al., 2020; Weiss et al., 2016; Williams et al., 2022; Williams et al., 2024)*
Demographic	*2/3*	*1/4*
Economic	*2/7*	*4/8*
Social/Cultural	*7/11*	*27/30*
Neighborhood	*-*	1/1

*Note. The first number in each cell represents the number of studies that found a significant result, while the number after the slash indicates the total number of studies. *Study included in both mental health conditions. [a]outward-directed behaviors such as behavioral problems, aggression, hyperactivity, or conduct issues.*

3

Chapter 3

Social determinants of youth with mild intellectual disability in outpatient care for mental health disorders: a case-control study

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Abstract

This study examined the unique role of multiple social determinants of mental health (SDOMH) associated with mental health disorders (MHD) for children with mild intellectual disability (MID), advancing understanding in a fragmented research area. Using a population-based case-control study design, four groups aged 0-17 years (M_{age} = 10.6, 35.6% female) were studied: children receiving outpatient mental health care for MHD with MID (*n*=505) and without MID (*n*=2,767), each with a matched control group from the general population (*n*=2,525 and *n*=13,835, respectively). Through multivariate logistic regression analyses, both MHD groups were compared to their control group and each other to examine the likelihood of a SDOMH associated with receiving mental health care for MHD in children with and without MID. Children with MID receiving mental health care showed significant differences in multiple domains compared to their control group and to children receiving mental health care without MID. They were less likely to have European-born mothers, more likely to have parents with moderate or low education levels, and tended to live in smaller, single-parent, lower-income households. Similar, though less deviant, patterns were observed for children receiving mental health care without MID compared to the general population, except for parental education. Our study highlights that SDOMH are associated with the likelihood of receiving care for MHD in children. Moreover, children with MID face disproportionate disadvantages, particularly regarding low parental education and household income. Thus, interventions should not only target the child but also their family and environmental context.

Introduction

Children with mild intellectual disability (MID) face specific challenges threatening their development, particularly their mental health. Research consistently highlights the increased risk of psychopathology among children with MID compared to peers without MID (Emerson, 2003; Einfeld et al., 2011; Bailey et al., 2019). In the socio-cultural, systemic paradigm, this heightened susceptibility is theorized to be shaped by a complex interplay of socio-demographic factors experienced by these children (Emerson & Hatton, 2007). These factors, collectively known as social determinants of mental health (SDOMH), include ethnicity, socioeconomic status, household conditions, family dynamics, and neighborhood deprivation (Bruun Jensen, 2013; Allen et al., 2014; World Health Organization, 2014). Although research has examined some SDOMH individually in relation to psychopathology in children with MID (Emerson, 2021; Baird et al., 2022; Wallander et al., 2006; Witwer & Lecavalier, 2008), the field remains fragmented. A critical gap persists in understanding the relative importance and collective role of multiple SDOMH in shaping mental health disorders (MHD) in this population. By identifying key SDOMH that are collectively associated with MHD in children with MID and comparing these findings with relevant groups, we aim to assess which SDOMH play a unique role for this population.

The few studies investigating the impact of SDOMH on children with MID reveal a concerning double burden. First, these children are vulnerable to experience environmental disadvantages, increasing their susceptibility to a lower social stratum (Emerson et al., 2006; Emerson & Brigham, 2015). This, in turn, exposes them to higher levels of cumulative stress, stigmatization, and discrimination, which increases the risk of developing mental disorders (Emerson & Hatton, 2013). Secondly, children with MID frequently face restricted access to vital resources such as wealth, social support, and problem-solving skills—key contributors to resilience in the face of adversity (World Health Organization, 2014; Avci, 2024). Consequently, it can be hypothesized that adverse SDOMH will be more prevalent in children with both MID and MHD compared to their peers without MID (Emerson & Hatton, 2013; Emerson et al., 2009). Testing this hypothesis and improving our understanding of the roles of different SDOMH will help address the unique challenges faced by children with MID and MHD.

To achieve this, we will organize SDOMH across domains using the conceptual framework of Lund et al. (2018). Each domain in this framework—demographic, social and cultural, economic, neighborhood, and environmental events—is hypothesized to be associated with mental health through various pathways. However, the last domain, encompassing factors such as war and natural disasters, is less common in the Netherlands and thus will not be addressed. This framework, initially developed for adults, will be extended to include SDOMH at parental and household levels for children.

Reviewing prior empirical studies in light of this framework, it becomes evident that demographic factors, particularly ethnicity, have been extensively studied as a variable associated with MHD among children with MID (Baker & Blacher, 2021). Although some studies found no link between ethnicity and MHD (Wallander et al., 2006; Van Rest et al., 2020), a systematic review of healthcare for minority ethnic groups with MID in the UK and findings from a scoping review indicate that current conclusions might be due to the potential underrepresentation of minority groups in both health services and research samples in general (Robertson et al., 2019; Weiss et al., 2024).

Second, the social and cultural domain encompasses frequently studied family and parental characteristics. For instance, studies on the impact of a single-parent household on behavior problems yielded divergent findings; some studies reported no significant association (Chadwick et al., 2008; Hatton et al., 2018), others showed associations between single parenthood and higher levels of behavior problems (Emerson, 2003; Emerson & Hatton, 2007; Totsika et al., 2020). Regarding economic factors, two systematic reviews came to the similar conclusion that associations between socioeconomic status (SES) and MHD were far from definite (Einfeld et al., 2011; Witwer & Lecavalier, 2008). Some studies found an association between lower SES and more MHD for children with MID (Emerson & Hatton, 2007; Koskentausta et al., 2007), whereas others reported no significant association (Wallander et al., 2006; Dekker & Koot, 2003). Importantly, some studies did not specify a method or criteria used for measuring SES, leaving the relative roles of different aspects of SES as contributors to MHD poorly understood (Dekker & Koot, 2003). Finally, few studies have explored neighborhood factors in relation to children with MID (Baird et al., 2022; Lapshina & Stewart, 2021), despite the generally well-documented impact of neighborhood deprivation on young people’s mental health and well-being (Visser et al., 2021).

This study aims to deepen our understanding of the associations between SDOMH and MHD in children with MID by comparing four groups: children with MID receiving mental health care, children without MID receiving mental health care, and their respective matched control groups from the general population. Additionally, we compare children without MID receiving mental health care to their matched control group from the general population. While some SDOMH have been individually examined in relation to MHD in both children with and without MID, a comprehensive analysis of their unique or combined effects is lacking. Comparing these associations across groups will identify key SDOMH related to MHD in children with MID. We hypothesize that adverse SDOMH, such as lower parental education, lower household income, and single-parent households, will be more prevalent in the group of children with both MID and MHD compared to children without MID receiving mental health care and the matched control group. Enhancing our understanding of the roles of SDOMH will help address the unique challenges faced by both children with and without MID who experience MHD, and inform preventive policy and intervention strategies to better support their mental health.

Method

Sources of data

The study used data from the Extramural LUMC Academic Network data warehouse, a comprehensive regional population-based data infrastructure (Ardesch et al., 2023). Three primary data sources were analyzed: microdata from Statistics Netherlands (SN; the central register agency), The Hague municipality data, and patient data from specialized youth mental health care institutions, including one for children with MID and MHD.

SN data provides insights into Dutch society, economy, and environment, comprising longitudinal microdata on demographics and socio-economic indicators (Bakker et al., 2014). The Hague municipality data provided neighborhood-specific information on urbanization, income, and education levels. Patient data included variables such as age, sex, and (un)registration in mental health care institutions.

Participants

Participants were categorized into four groups: two clinical case groups and two matched population-based control groups. The clinical case groups were receiving outpatient treatment for MHD at a specialized facility and resided in The Hague or its surrounding areas. One group consisted of children diagnosed with MID (IQ 55-85) and MHD (Group A: MID+MHD) and the second included those with MHD, but without MID (Group B: MHD only). Participants were identified from patient data recorded in 2017. We used receipt of outpatient mental health care as a proxy for identifying children with MHD. Children were included if they were 0 to 17 years old and received outpatient care in 2017 at a participating mental health facility. Group A was identified from a mental health care facility specialized in the psychiatric assessment and treatment, including cognitive behavioral therapy and pharmacotherapy, of children with MID ($n_A = 505$). Group B was identified from registrations at other participating centers that provide mental health care for children without MID ($n_B = 2{,}767$). All participants resided in urban or suburban areas, as this was a selection criterion based on the predominantly urban setting of The Hague and its surroundings. The year 2017 was chosen for its availability of essential demographic and patient data. Only outpatient children were included to explore family-related characteristics, as they resided at home.

Thereafter, two control groups were formed for Group A and B, comprising children from the general population matched by sex and age using the SN database: Group C1 ($n_{C1} = 2{,}525$) for Group A and Group C2 ($n_{C2} = 13{,}835$) for Group B. Five controls were selected per case, residing in the same areas, with randomized postal codes for residential comparison. Baseline characteristics for all groups are presented in Table 1.

Ethical Approval and data linkage

This study was exempted from the Medical Research Involving Human Subjects Act by the Medical Ethics Committee (CEP number: N22.048). Routinely collected health data was securely stored, pseudonymized, and kept anonymous from researchers. Each participant received a unique record identification number (RIN) to ensure accurate linkage from three sources, preserving anonymity. Parents were linked to children via their RIN for family characteristics. SN staff verified output results to mitigate disclosure risks. Details on the linking procedure are available elsewhere (Bakker et al., 2014).

Variables

The dependent variable varied across analyses. For the first and third comparisons, it was the receipt of outpatient mental health care in a specialized center for children with MID, used as a proxy to identify children with both MID and MHD. For the second comparison, it was the receipt of outpatient mental health care, serving as a proxy to identify children with MHD. The independent variables encompassed various aspects across multiple domains.

Demographic domain

The demographic domain included child's sex, age, birth country, and parental age and birth country. For both case groups, the child's sex was determined from mental health care data. For the control groups, sex and age information was derived from SN, along with the birth country data of children and their parents for all groups. The use of country of birth as a substitute for ethnicity is widely accepted in Dutch literature (Stronks et al., 2009).

Social and cultural domain

The social and cultural domain comprised four variables sourced from SN, each offering insight into various facets of the familial context. Firstly, the number of children in a household indicates the count of individuals, regardless of age or marital status, who share a child-parent relationship with one or both parents residing within a household. This encompasses biological, adopted, and stepchildren but excludes foster children. Secondly, family type, initially comprising eight categories, was later condensed into three: dual-parent households, single-parent households, and others, which encompass for example children from institutional households. Finally, maternal and paternal educational levels were examined, categorized as low, middle, or high based on the classification provided by SN. This categorization was determined by the highest level of education attained: primary education for low, vocational training for middle, and Higher Professional Education or university for high.

Economic domain

Standardized disposable household income was included, capturing the net annual amount available for spending, expressed in percentiles. This measure accounts for household size and composition. Disposable income was determined by subtracting a household's total liabilities from its total assets. Relative disposable household income was based on population percentiles. Specifically, private households were categorized into 100 equal sized percentile groups, each defined by their standardized income. This approach ensured a fair and unbiased assessment of socioeconomic positions across the population, accounting for inflation.

Neighborhood domain
The neighborhood domain included three key factors, sourced from municipality data of The Hague. First, urbanization class was included based on average environmental address density (EAD) and categorized as densely (EAD ≥ 1500) and sparsely populated (EAD < 1500). EAD was computed as the number of addresses within a one-kilometer radius divided by the area. Second, "% low neighborhood education level" was included, representing the proportion of individuals aged 15 to 74 with lower educational attainment in neighborhoods within The Hague, determined by district codes (e.g., primary education, lower vocational education). Third, relative economic standing of a neighborhood was measured by low median disposable income percentiles per postal code, adjusted for household size. Derived from standardized disposable income, this variable evaluates low median disposable income percentile within neighborhoods, ranging from the first to the twentieth percentile based on a national level. This score was adjusted for household size and composition within each postal code area.

Approach to analysis

The analyses comprised several phases. First, descriptive statistics (*M* or %) for the SDOMH were calculated for all groups. Subsequently, univariate analyses were conducted to assess the individual association of each SDOMH with the presence of MID and MHD (Group A vs. Group C1). These analyses were not the focus of the study but served as a preliminary step to inform the multivariate models by identifying potential differences. Full multivariate logistic regression models then assessed associations between each SDOMH and the co-occurrence of MID and MHD (Group A vs. Group C1), adjusting for all other factors in the model. Further univariate and multivariate analyses examined the association between SDOMH and MHD without MID (Groups B vs. Group C2), and compared SDOMH for children with MHD with and without MID (Group A vs. Group B).

The "mice" (version 3.16.0), "modelsummary" (version 1.4.1), "forestplot" (version 3.1.1), and "stats" (version 4.3.1) packages for the R statistical software were used (v4.2.3; R Core Team, 2020).Unadjusted and adjusted odds ratios

(*ORs*), 95% confidence intervals (CIs), and p-values (*p*) were calculated. We applied a significance level (*α*) of .05 to all statistical tests. Each OR represents the likelihood of a SDOMH being associated with receiving mental health treatment for MHD in children with or without MID, compared to the control or between clinical groups. Multicollinearity among covariates was assessed using Pearson's correlation coefficients and the Variance Inflation Factor. The logistic regression model was then fitted using the glm function, with coefficients exponentiated to yield ORs. The 'modelsummary' package derived standardized ORs from our models, allowing comparison of the relative strength and direction of the relationships. Multiple imputations handled missing values, which ranged from 0% (child's sex, age, birth country) to 50.4% (low median neighborhood income; see Table 1). Assuming data were missing at random, the Multivariate Imputation by Chained Equations method was used, which iteratively estimates each missing value through regression models conditional upon other variables. Twenty datasets were analyzed and pooled.

Results

Descriptive statistics

The study comprised 19,632 children (*M* = 10.6 years, *SD* = 3.2, range: 0 to 17), 35.6% of whom were female. Descriptive statistics of all the SDOMH are presented in Table 1 for each group. There were some differences in characteristics between the two case groups (Groups A and B). Children with MID receiving mental health care were significantly younger (see Figure 3). Both case groups had a predominance of males, but children with MID receiving mental health care had the highest percentage, with 64.4% male.

Table 1. Baseline characteristics by group

	Total sample N (%) N = 19,632	**Group A: MID+MHD N = 505**	**Group C1: Controls N = 2,525**	**Group B: MHD-only N = 2,767**	**Group C2: Controls N = 13,835**
Demographic domain					
Child sex:	19,632 (100%)	-	-	-	-
- Female	-	180 (35.6)	900 (35.6)	1,231 (44.5)	6,155 (44.5)
- Male	-	325 (64.4)	1,625 (64.4)	1,536 (55.5)	7,680 (55.5)
Age child (years)	19,632 (100%)	10.6 (4.1)	10.6 (4.1)	12.0 (3.9)	12.0 (3.9)
Child's country of birth:	19,632 (100%)	-	-	-	-

- The Netherlands	-	462 (91.5)	2,301 (91.1)	2,443 (88.3)	12,677 (91.6)
- EU (excluding NL)	-	20 (4.0)	102 (4.1)	137 (5.0)	511 (3.7)
- Outside EU	-	23 (4.5)	122 (4.8)	187 (6.7)	647 (4.7)
Age mother (years)	19,438 (99.0%)	40.1 (7.1)	41.6 (6.4)	42.0 (6.9)	43.0 (6.4)
Mother's country of birth:	19,632 (100%)	-	-	-	-
- The Netherlands	-	296 (58.6)	1,574 (62.3)	1,761 (63.6)	8,815 (63.7)
- EU (excluding NL)	-	43 (8.5)	203 (8.1)	216 (7.8)	1,064 (7.7)
- Outside EU	-	166 (32.9)	748 (29.6)	790 (28.6)	3,956 (28.6)
Age father (years)	18,321 (93.3%)	44.2 (7.9)	45.0 (7.2)	45.9 (7.6)	46.4 (7.0)
Father's country of birth:	19,632 (100%)	-	-	-	-
- The Netherlands	-	281 (55.6)	1,589 (62.9)	1,730 (62.5)	8,890 (64.3)
- EU (excluding NL)	-	32 (6.4)	164 (6.5)	188 (6.8)	836 (6.0)
- Outside EU	-	192 (38.0)	772 (30.6)	849 (30.7)	4,109 (29.7)
Social and cultural domain					
Number of children (in household)	19,618 (99.9%)	2.0 (1.1)	2.3 (1.0)	2.0 (1.0)	2.3 (1.0)
Family type:	19,618 (99.9%)	-	-	-	-
- Dual parent household	-	274 (54.3)	1,997 (79.1)	1,550 (56.0)	10,857 (78.5)
- Single parent household	-	187 (37.0)	500 (19.8)	1,055 (38.1)	2,825 (20.4)
- Institutional household/ other	-	44 (8.7)	28 (1.1)	162 (5.9)	153 (1.1)
Education level mother:	13,566 (69.1%)	-	-	-	-
- High	-	46 (12.0)	804 (45.3)	643 (32.4)	4,199 (44.6)
- Moderate	-	165 (43.1)	523 (29.5)	681 (34.3)	2,735 (29.0)
- Low	-	172 (44.9)	446 (25.2)	781 (33.3)	2,490 (26.4)
Education level father:	11,199 (57.0%)	-	-	-	-
- High	-	38 (14.8)	759 (50.5)	539 (37.3)	4,020 (50.3)
- Moderate	-	104 (40.5)	380 (25.3)	442 (30.6)	2,069 (25.9)
- Low	-	115 (44.7)	364 (24.2)	464 (32.1)	1,905 (23.8)

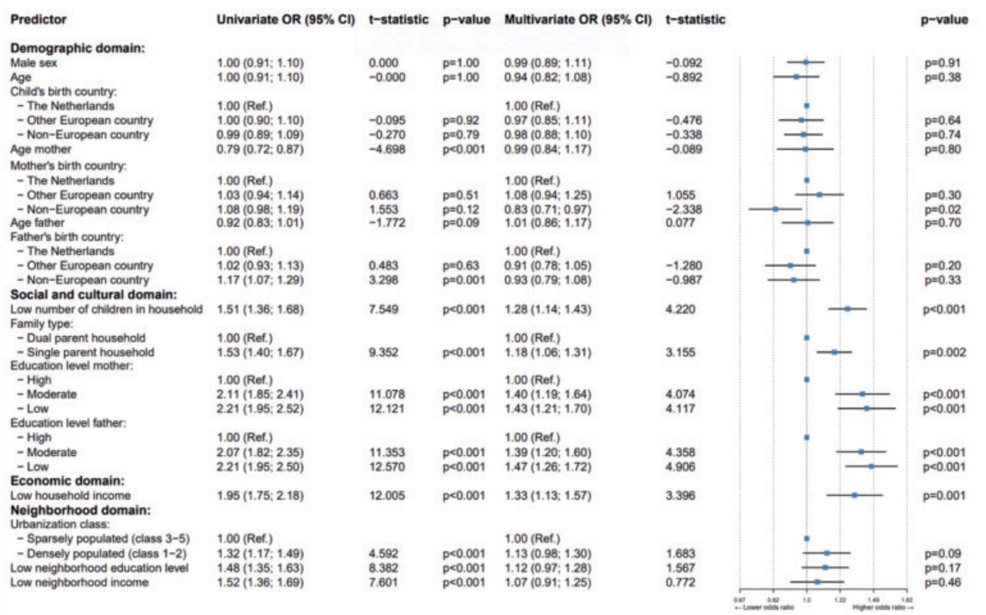
Economic domain					
Household income (in percentiles)	19,296 (98.3%)	33.5 (24.2)	52.0 (30.5)	42.6 (28.8)	53.7 (30.1)
Neighborhood domain					
Urbanization class:	19,632 (100%)	-	-	-	-
- Densely populated (class 1-3)	-	463 (91.7)	2,108 (83.5)	2,473 (89.4)	11,374 (82.2)
- Sparsely populated (class 4,5)	-	42 (8.3)	417 (16.5)	294 (10.6)	2,461 (17.8)
% low neighborhood education level	14,456 (73.6%)	36.3 (12.8)	31.3 (14.1)	33.0 (12.9)	31.4 (14.2)
low median neighborhood income (in percentiles)	9,733 (49.6%)	15.0 (7.6)	12.9 (7.7)	13.2 (7.5)	13.1 (7.8)

Note. MID = mild intellectual disability; MHD = mental health disorders; NL = The Netherlands; EU = Europe. N = total number of observations for each variable without missing. For continuous variables, the mean and SD are provided (SD in brackets). For categorical variables, the N and percentages are given. Percentages in parentheses are calculated based on the non-missing (valid) N.

Key findings

In our first comparison, we compared children with MID receiving mental health care for MHD (referred to as MID+MHD, Group A) against their respective controls (Group C1). Figure 1 shows a forest plot presenting both univariate and multivariate ORs. Interpreting the multivariate results, our analysis revealed statistically significant associations between SDOMH and MID+MHD. Within the demographic domain, having a mother born outside Europe, was associated with lower odds of MID+MHD (*OR*: 0.83, *p* = .02). In contrast, the univariate analysis, which considers the variable in isolation, yielded slightly higher odds (*OR:* 1.08, *p* = .12) for children whose mothers were born outside Europe. Regarding the social and cultural domain, a lower number of children in a household was associated with higher odds for MID+MHD (*OR*: 1.28, *p* < .001). Living in a single-parent household was also associated with higher odds for MID+MHD (*OR*: 1.18, *p* = .002). Additionally, having a mother with a moderate (*OR*: 1.38, *p* < .001) or low education level (*OR*: 1.42, *p* = .001) was associated with higher odds of MID+MHD. A similar result was shown for the education level of fathers (moderate, *OR*: 1.40, *p* < .001; low, *OR*: 1.49, *p* < .001). In the economic domain, low household income was associated with MID+MHD (*OR*: 1.33, *p* = .001). Finally, in the neighborhood domain, no significant associations were observed between SDOMH and MID+MHD when compared to control children.

Figure 1. Forest plot of SDOMH among domains, comparing children having both ID and MHD (Group A) to their respective controls (Group C1)

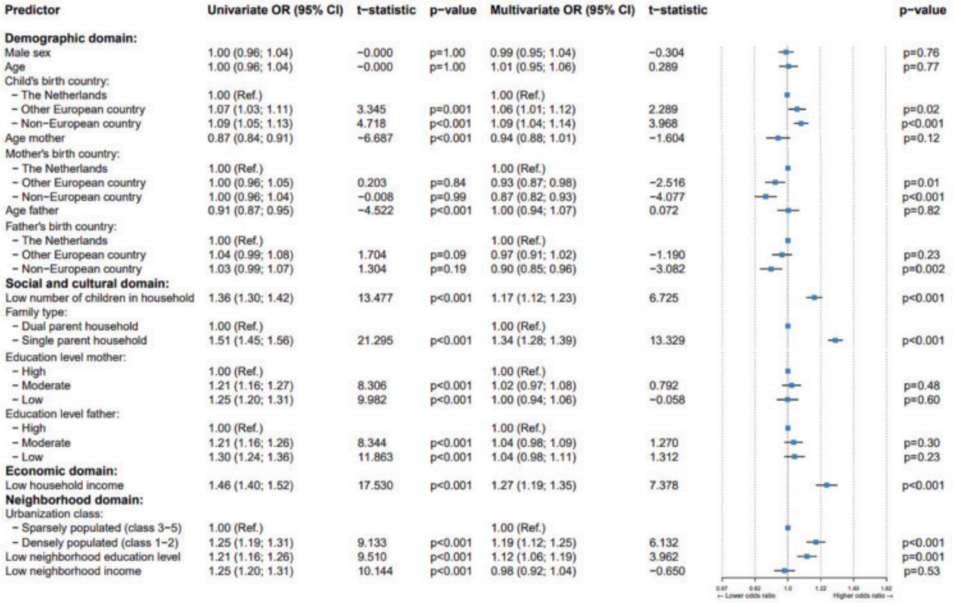


Predictor	Univariate OR (95% CI)	t-statistic	p-value	Multivariate OR (95% CI)	t-statistic	p-value
Demographic domain:						
Male sex	1.00 (0.91; 1.10)	0.000	p=1.00	0.99 (0.89; 1.11)	−0.092	p=0.91
Age	1.00 (0.91; 1.10)	−0.000	p=1.00	0.94 (0.82; 1.08)	−0.892	p=0.38
Child's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.00 (0.90; 1.10)	−0.095	p=0.92	0.97 (0.85; 1.11)	−0.476	p=0.64
− Non−European country	0.99 (0.89; 1.09)	−0.270	p=0.79	0.98 (0.88; 1.10)	−0.338	p=0.74
Age mother	0.79 (0.72; 0.87)	−4.698	p<0.001	0.99 (0.84; 1.17)	−0.089	p=0.80
Mother's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.03 (0.94; 1.14)	0.663	p=0.51	1.08 (0.94; 1.25)	1.055	p=0.30
− Non−European country	1.08 (0.98; 1.19)	1.553	p=0.12	0.83 (0.71; 0.97)	−2.338	p=0.02
Age father	0.92 (0.83; 1.01)	−1.772	p=0.09	1.01 (0.86; 1.17)	0.077	p=0.70
Father's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.02 (0.93; 1.13)	0.483	p=0.63	0.91 (0.78; 1.05)	−1.280	p=0.20
− Non−European country	1.17 (1.07; 1.29)	3.298	p=0.001	0.93 (0.79; 1.08)	−0.987	p=0.33
Social and cultural domain:						
Low number of children in household	1.51 (1.36; 1.68)	7.549	p<0.001	1.28 (1.14; 1.43)	4.220	p<0.001
Family type:						
− Dual parent household	1.00 (Ref.)			1.00 (Ref.)		
− Single parent household	1.53 (1.40; 1.67)	9.352	p<0.001	1.18 (1.06; 1.31)	3.155	p=0.002
Education level mother:						
− High	1.00 (Ref.)			1.00 (Ref.)		
− Moderate	2.11 (1.85; 2.41)	11.078	p<0.001	1.40 (1.19; 1.64)	4.074	p<0.001
− Low	2.21 (1.95; 2.52)	12.121	p<0.001	1.43 (1.21; 1.70)	4.117	p<0.001
Education level father:						
− High	1.00 (Ref.)			1.00 (Ref.)		
− Moderate	2.07 (1.82; 2.35)	11.353	p<0.001	1.39 (1.20; 1.60)	4.358	p<0.001
− Low	2.21 (1.95; 2.50)	12.570	p<0.001	1.47 (1.26; 1.72)	4.906	p<0.001
Economic domain:						
Low household income	1.95 (1.75; 2.18)	12.005	p<0.001	1.33 (1.13; 1.57)	3.396	p=0.001
Neighborhood domain:						
Urbanization class:						
− Sparsely populated (class 3−5)	1.00 (Ref.)			1.00 (Ref.)		
− Densely populated (class 1−2)	1.32 (1.17; 1.49)	4.592	p<0.001	1.13 (0.98; 1.30)	1.683	p=0.09
Low neighborhood education level	1.48 (1.35; 1.63)	8.382	p<0.001	1.12 (0.97; 1.28)	1.567	p=0.17
Low neighborhood income	1.52 (1.36; 1.69)	7.601	p<0.001	1.07 (0.91; 1.25)	0.772	p=0.46

Note. OR = Odds ratio; CI = confidence intervals. The error bars represent the 95% CI of the mean.

In our second comparison, we compared children receiving mental health care for MHD, without MID (referred to MHD-only, Group B) to their respective controls (Group C2), as illustrated in Figure 2. The following results will be based on multivariate ORs. In the demographic domain, the MHD-only group was more likely to be born outside the Netherlands within Europe (*OR*: 1.06, *p* = .02) or outside Europe (*OR*: 1.09, *p* < .001). Conversely, maternal birth outside the Netherlands, whether in Europe (*OR*: 0.93, *p* = .01) or outside Europe (*OR*: 0.87, *p* < .001), was associated with lower odds of MHD-only. Similarly, paternal birth outside Europe (*OR*: 0.90, *p* < .001) was linked to lower odds of MHD-only. In the social and cultural domain, a lower number of children in the household (*OR*: 1.17, *p* < .001) and single-parent households (*OR*: 1.34, *p* < .001) were associated with higher odds of MHD-only. In the economic domain, low household income (*OR*: 1.26, *p* < .001) was associated with MHD-only, aligning with the findings from the comparison between MID+MHD and controls. Regarding the neighborhood domain, residing in a densely populated urban area (*OR*: 1.19, *p* < .001) and areas with low neighborhood education levels (*OR*: 1.12, *p* = .001) were both linked to an increased OR for MHD-only.

Figure 2. Forest plot of SDOMH among domains, comparing children having MHD (Group B) to their respective controls (Group C2)

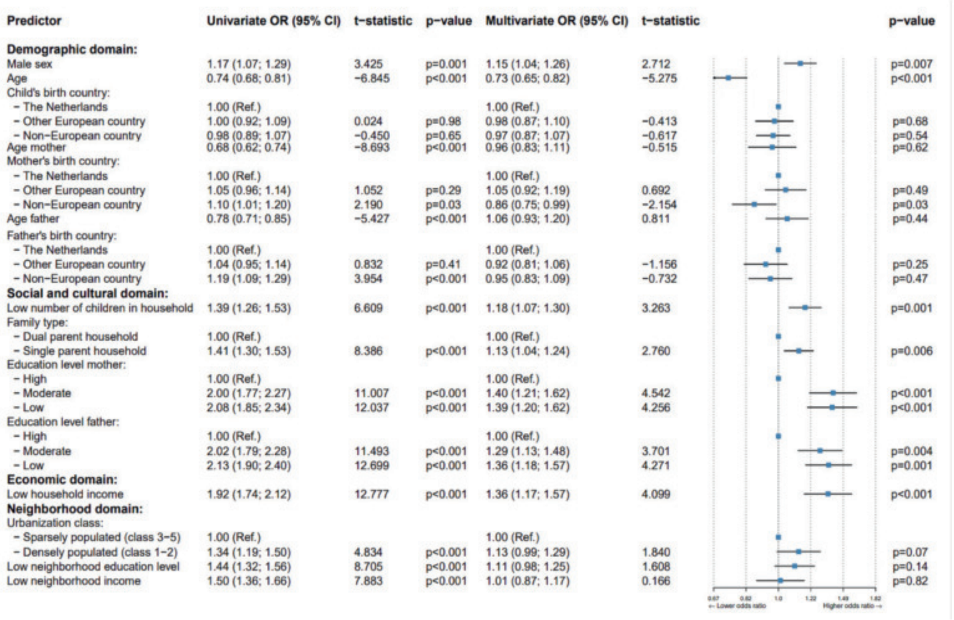


Predictor	Univariate OR (95% CI)	t-statistic	p-value	Multivariate OR (95% CI)	t-statistic	p-value
Demographic domain:						
Male sex	1.00 (0.96; 1.04)	−0.000	p=1.00	0.99 (0.95; 1.04)	−0.304	p=0.76
Age	1.00 (0.96; 1.04)	−0.000	p=1.00	1.01 (0.95; 1.06)	0.289	p=0.77
Child's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.07 (1.03; 1.11)	3.345	p=0.001	1.06 (1.01; 1.12)	2.289	p=0.02
− Non−European country	1.09 (1.05; 1.13)	4.718	p<0.001	1.09 (1.04; 1.14)	3.968	p<0.001
Age mother	0.87 (0.84; 0.91)	−6.687	p<0.001	0.94 (0.88; 1.01)	−1.604	p=0.12
Mother's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.00 (0.96; 1.05)	0.203	p=0.84	0.93 (0.87; 0.98)	−2.516	p=0.01
− Non−European country	1.00 (0.96; 1.04)	−0.008	p=0.99	0.87 (0.82; 0.93)	−4.077	p<0.001
Age father	0.91 (0.87; 0.95)	−4.522	p<0.001	1.00 (0.94; 1.07)	0.072	p=0.82
Father's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.04 (0.99; 1.08)	1.704	p=0.09	0.97 (0.91; 1.02)	−1.190	p=0.23
− Non−European country	1.03 (0.99; 1.07)	1.304	p=0.19	0.90 (0.85; 0.96)	−3.082	p=0.002
Social and cultural domain:						
Low number of children in household	1.36 (1.30; 1.42)	13.477	p<0.001	1.17 (1.12; 1.23)	6.725	p<0.001
Family type:						
− Dual parent household	1.00 (Ref.)			1.00 (Ref.)		
− Single parent household	1.51 (1.45; 1.56)	21.295	p<0.001	1.34 (1.28; 1.39)	13.329	p<0.001
Education level mother:						
− High	1.00 (Ref.)			1.00 (Ref.)		
− Moderate	1.21 (1.16; 1.27)	8.306	p<0.001	1.02 (0.97; 1.08)	0.792	p=0.48
− Low	1.25 (1.20; 1.31)	9.982	p<0.001	1.00 (0.94; 1.06)	−0.058	p=0.60
Education level father:						
− High	1.00 (Ref.)			1.00 (Ref.)		
− Moderate	1.21 (1.16; 1.26)	8.344	p<0.001	1.04 (0.98; 1.09)	1.270	p=0.30
− Low	1.30 (1.24; 1.36)	11.863	p<0.001	1.04 (0.98; 1.11)	1.312	p=0.23
Economic domain:						
Low household income	1.46 (1.40; 1.52)	17.530	p<0.001	1.27 (1.19; 1.35)	7.378	p<0.001
Neighborhood domain:						
Urbanization class:						
− Sparsely populated (class 3−5)	1.00 (Ref.)			1.00 (Ref.)		
− Densely populated (class 1−2)	1.25 (1.19; 1.31)	9.133	p<0.001	1.19 (1.12; 1.25)	6.132	p<0.001
Low neighborhood education level	1.21 (1.16; 1.26)	9.510	p<0.001	1.12 (1.06; 1.19)	3.962	p=0.001
Low neighborhood income	1.25 (1.20; 1.31)	10.144	p<0.001	0.98 (0.92; 1.04)	−0.650	p=0.53

Note. OR = Odds ratio; CI = confidence intervals. The error bars represent the 95% CI of the mean.

In our final comparison, we specifically focused on children receiving mental health care for their MHD, comparing children with and without MID (Groups A and B, respectively), as depicted in Figure 3. Although the multivariate results were quite similar to those in Figures 1 and 2, some differences were observed. Within the demographic domain, as these two groups had not been matched for age and sex, significant differences emerged. Being male *OR*: 1.15, *p* = .008), along with a younger age (*OR*: 0.74; *p* < .001) were linked to higher odds of MID+MHD. Children with MID+MHD were less likely to have mothers born outside Europe compared to children with MID-only (*OR*: 0.86, *p* = .03). Within the social and cultural domain, MID+MHD tended to come from households with fewer children (*OR*: 1.18, *p* < .001) and were more likely to live in single-parent households (*OR*: 1.13, *p* = .006) compared MHD-only. Moreover, MID+MHD were significantly more likely to have parents with moderate (mother: *OR:* 1.38, *p* < .001; father: *OR:* 1.38, *p* = .001) or low education levels (mother: *OR:* 1.39, *p* < .001; father: *OR:* 1.39, *p* < .001). In the economic domain, households of children with MID displayed a significantly lower income (*OR*: 1.36, *p* < .001) compared to households of children without MID, mirroring the trends observed in previous comparisons. Within the neighborhood domain, no SDOMH was significantly linked to the likelihood of MID+MHD compared to MHD-only.

Figure 3. Forest plot of SDOMH among domains, comparing children having both ID and MHD (Group A) to those with MHD only (Group B)



Predictor	Univariate OR (95% CI)	t-statistic	p-value	Multivariate OR (95% CI)	t-statistic	p-value
Demographic domain:						
Male sex	1.17 (1.07; 1.29)	3.425	p=0.001	1.15 (1.04; 1.26)	2.712	p=0.007
Age	0.74 (0.68; 0.81)	−6.845	p<0.001	0.73 (0.65; 0.82)	−5.275	p<0.001
Child's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.00 (0.92; 1.09)	0.024	p=0.98	0.98 (0.87; 1.10)	−0.413	p=0.68
− Non−European country	0.98 (0.89; 1.07)	−0.450	p=0.65	0.97 (0.87; 1.07)	−0.617	p=0.54
Age mother	0.68 (0.62; 0.74)	−8.693	p<0.001	0.96 (0.83; 1.11)	−0.515	p=0.62
Mother's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.05 (0.96; 1.14)	1.052	p=0.29	1.05 (0.92; 1.19)	0.692	p=0.49
− Non−European country	1.10 (1.01; 1.20)	2.190	p=0.03	0.86 (0.75; 0.99)	−2.154	p=0.03
Age father	0.78 (0.71; 0.85)	−5.427	p<0.001	1.06 (0.93; 1.20)	0.811	p=0.44
Father's birth country:						
− The Netherlands	1.00 (Ref.)			1.00 (Ref.)		
− Other European country	1.04 (0.95; 1.14)	0.832	p=0.41	0.92 (0.81; 1.06)	−1.156	p=0.25
− Non−European country	1.19 (1.09; 1.29)	3.954	p<0.001	0.95 (0.83; 1.09)	−0.732	p=0.47
Social and cultural domain:						
Low number of children in household	1.39 (1.26; 1.53)	6.609	p<0.001	1.18 (1.07; 1.30)	3.263	p=0.001
Family type:						
− Dual parent household	1.00 (Ref.)			1.00 (Ref.)		
− Single parent household	1.41 (1.30; 1.53)	8.386	p<0.001	1.13 (1.04; 1.24)	2.760	p=0.006
Education level mother:						
− High	1.00 (Ref.)			1.00 (Ref.)		
− Moderate	2.00 (1.77; 2.27)	11.007	p<0.001	1.40 (1.21; 1.62)	4.542	p<0.001
− Low	2.08 (1.85; 2.34)	12.037	p<0.001	1.39 (1.20; 1.62)	4.256	p<0.001
Education level father:						
− High	1.00 (Ref.)			1.00 (Ref.)		
− Moderate	2.02 (1.79; 2.28)	11.493	p<0.001	1.29 (1.13; 1.48)	3.701	p=0.004
− Low	2.13 (1.90; 2.40)	12.699	p<0.001	1.36 (1.18; 1.57)	4.271	p=0.001
Economic domain:						
Low household income	1.92 (1.74; 2.12)	12.777	p<0.001	1.36 (1.17; 1.57)	4.099	p<0.001
Neighborhood domain:						
Urbanization class:						
− Sparsely populated (class 3−5)	1.00 (Ref.)			1.00 (Ref.)		
− Densely populated (class 1−2)	1.34 (1.19; 1.50)	4.834	p<0.001	1.13 (0.99; 1.29)	1.840	p=0.07
Low neighborhood education level	1.44 (1.32; 1.56)	8.705	p<0.001	1.11 (0.98; 1.25)	1.608	p=0.14
Low neighborhood income	1.50 (1.36; 1.66)	7.883	p<0.001	1.01 (0.87; 1.17)	0.166	p=0.82

Note. OR = Odds ratio; CI = confidence intervals. The error bars represent the 95% CI of the mean.

Discussion

In this case-control study, we examined the associations between various SDOMH and MHD in children with MID receiving mental health care. We compared children receiving mental health care with MID to their matched control group and to children without MID receiving mental health care. Additionally, we compared the latter group to their matched controls. By analyzing a comprehensive set of SDOMH across multiple domains, we aimed to identify those uniquely connected to children with MID receiving mental health care. Our findings indicate that SDOMH across various domains are associated with receiving mental health care in children, irrespective of MID status. Children with MID face greater challenges, encountering more adverse SDOMH across multiple domains, which aligns with our hypothesis. Their disproportionate vulnerabilities emphasize the need for a comprehensive approach to mental health care that addresses the diverse challenges these children face. The study highlights three primary findings: the unique contributions of various domains of SDOMH, the significant effects of low parental education and household income, and the distinct neighborhood effects on children with and without MID.

As a first key finding, this study emphasizes the unique contribution of SDOMH in multiple domains, encompassing social, cultural, economic, and neighborhood contexts (Lund et al., 2018). To the best of our knowledge, this study is the first to offer insight into how different SDOMH collectively play a role in receiving care for MHD among children with and without MID in the Netherlands. Our analyses revealed that the independent roles of several SDOMH across these domains remained significant, even when considered together in a multivariate model. Similarly, another study identified multiple determinants, such as lower SES and parental psychopathology, that were strongly associated with child behavioral problems in a multivariate model (Zhang et al., 2020). However, their study focused on children aged 9–11 without MID. These findings underscore the importance of recognizing the cumulative challenges faced by children with MHD and their families. Additionally, both these and our results highlight the need for a syndemic approach to address these complex healthcare needs. Such an approach recognizes the interconnected nature of MHD and prioritizes integrated family care over symptom-focused interventions (Parry & Thornicroft, 2020).

Our second key finding showed significant, independent links between low parental education levels and low household income with the likelihood of receiving mental health care, particularly among children with MID. Although parental education and income often correlate and are part of composite SES measures, these factors were particularly distinctive for children with MID. Regarding moderate and low parental education levels, these were only significantly more prevalent for children with MID. This association may be explained by several mechanisms. First of all, it aligns with prior research suggesting a connection between lower parental education and the likelihood of a child having an ID (Jandrić & Kurtović, 2021). As lower parental education levels may be indicative of lower parental cognitive abilities, this association may be driven by the genetic hereditary of (M)ID (Lichtenstein et al., 2022). Alternatively, in the framework of Lund et al. (2018), parental education level is viewed as an integral component of an individual’s social capital or network, which could be associated with the quantity and quality of social skills and support in the family. Additionally, lower social support has been linked to increased parenting stress, lower child resilience, and poorer child mental health (Hassall et al., 2005; Langford et al., 1997; Peer & Hillman, 2014). These factors support the double burden outlined in the introduction: children with MID face additional challenges due to a lack of resources; as a result, their mental health may be more vulnerable to the adverse effects of SDOMH. Furthermore, contemporary society’s shift in Western countries towards individualism may present additional challenges, particularly for individuals with lower educational levels and resources. This shift emphasizes self-reliance over collective aid, exacerbating the difficulties faced by these children (Humphrey & Bliuc, 2021; Santos et al., 2017).

Regarding lower household incomes, families with children receiving care for their MHD have lower household incomes compared to matched controls, regardless of whether the children have MID. However, households with children who have MID have the lowest incomes, as indicated by an OR just below the level associated with parental education. This aligns with previous research indicating that youth with MID often come from economically disadvantaged households compared to their peers without MID (Emerson, 2021; Emerson et al., 2006; Emerson & Spencer, 2015), supporting the first part of the double burden discussed in the introduction. The World Health Organization stated that MHD are closely linked to poverty, creating a cycle of systemic disadvantage (World Health Organization, 2022). This link may partially be explained by family processes of insecurity and cumulative stress (Allen et al., 2014; Gard et al., 2020), while poverty is also associated with worse physical health status or stigma, which could play an additional role for MHD (Lund et al., 2018). On a broader policy level, the high demand for mental health care among marginalized groups raises questions regarding the inclusivity of Dutch society and the efficacy of preventive policies, particularly given the widening gap between the affluent and the underprivileged (Sociaal en Cultureel Planbureau, 2024).

The third main finding is the difference in findings within the neighborhood domain for the two clinical case groups. Residing in areas with low neighborhood education levels and more densely populated areas was linked to an increased OR for children receiving care for MHD without MID, compared to the general population, but not for children with MID. This finding aligns with a systematic review showing that lower neighborhood SES was associated with increased problem behaviour in children without (M)ID (Visser et al., 2021). To our knowledge, no studies have investigated neighborhood characteristics associated with the MHD in children with (M)ID. In our study, we did not observe significant multivariate effects for neighborhood characteristics in the MID+MHD group. However, we found that these children often lived in more densely populated, lower-income areas with lower levels of educational attainment. Future research should replicate these findings to better understand the role of neighborhood characteristics in MHD development in children with MID. Two potential explanations for the lack of significant neighborhood SDOMH include the comparatively smaller size of the MID+MHD group, which might result in limited statistical power, and a relatively greater importance of individual adversities for this group.

The study has several strengths. Firstly, it represents the first large-scale investigation conducted in the Netherlands examining children with MID receiving mental health care. Our study leveraged extensive clinical and population-based samples, enabling a detailed analysis of SDOMH. This approach facilitated comparisons between children with and without MID receiving mental health care, enhancing the representativeness of our findings. Additionally, our study benefited from utilizing all available clinical data from a specialized mental health care center, ensuring diverse representation of children across various SES and ethnic backgrounds. Finally, our interpretation of multivariate results accounted for the independent effects of a comprehensive set of factors, providing a thorough understanding of the interconnected nature of SDOMH’s impact on mental health outcomes. This nuanced approach allowed us to identify the unique contributions of SDOMH on outcomes while controlling for potential confounders.

However, the results of this study might be interpreted in light of the following limitations. First, our study predominantly relied on data from a single institution specialized in care for children with MID and MHD. Although this institution is the largest in the area, the external validity of our findings remains uncertain. Consequently, it is necessary to validate our results using samples from other institutions, in more rural areas, and in different countries, as the roles of SDOMH can vary between societies. Additionally, we rely on data from children already engaged in outpatient mental health care, using service receipt as a proxy for identifying MHD. While this ensures a clinically validated approach, it excludes children with untreated mental health conditions and may underrepresent groups less likely to access these services, such as certain ethnic minorities (Weiss et al., 2024; Van Der Draai et al., 2021). Furthermore, our reliance on real-world data led to a substantial number of missing data for some variables. Therefore, these results should be interpreted cautiously, particularly regarding low median neighborhood income, for which 50.4% of the data were missing. Another limitation is the reliance on cross-sectional data, restricting the ability to establish temporal and potential causal relationships. Finally, our selection of SDOMH was guided by literature from the general adult population without MID (Lund et al., 2018) and the availability of measurable variables. However, it remains uncertain whether other important SDOMH were omitted from this study, potentially limiting the comprehensiveness of our findings.

Taken together, our study underscores the profound role of SDOMH on children with MHD and MID, revealing the unique and severe challenges they face. The findings advocate for a holistic, context-oriented approach to mental health care that addresses the diverse adversities experienced by these children. Moving forward, it is crucial for policymakers and practitioners to integrate comprehensive support for children and their family, alongside inclusive community strategies to reduce these systemic disadvantages, thereby creating a more equitable and supportive environment for all children.

References

Allen, J., Balfour, R., Bell, R., & Marmot, M. (2014). Social determinants of mental health. *International Review of Psychiatry, 26*(4), 392–407. https://doi.org/10.3109/09540261.2014.928270

Ardesch, F. H., Meulendijk, M. C., Kist, J. M., Vos, R. C., Vos, H. M. M., Kiefte-de Jong, J. C., et al. (2023). The introduction of a data-driven population health management approach in the Netherlands since 2019: The Extramural LUMC Academic Network data infrastructure. *Health Policy, 132*, 104769. https://doi.org/10.1016/j.healthpol.2023.104769

Avci, D. (2024). Mental health problems among adolescents with mild intellectual disability and relation to sleep quality and perceived social support: A comparative study. *Journal of Psychosocial Nursing and Mental Health Services, 62*(1), 39–50. https://doi.org/10.3928/02793695-20230821-04

Baird, A., Papachristou, E., Hassiotis, A., & Flouri, E. (2022). The role of physical environmental characteristics and intellectual disability in conduct problem trajectories across childhood: A population-based cohort study. *Environmental Research, 209*, 112837. https://doi.org/10.1016/j.envres.2022.112837

Baker, B. L., & Blacher, J. (2021). Behavior disorders and social skills in adolescents with intellectual disability: Does co-morbid autism matter? *Journal of Mental Health Research in Intellectual Disabilities, 14*(2), 174–188. https://doi.org/10.1080/19315864.2020.1871451

Bakker, B. F. M., van Rooijen, J., & van Toor, L. (2014). The system of social statistical datasets of Statistics Netherlands: An integral approach to the production of register-based social statistics. *Statistical Journal of the IAOS, 30*(4), 411–424. https://doi.org/10.3233/SJI-140803

Bailey, T., Totsika, V., Hastings, R. P., Hatton, C., & Emerson, E. (2019). Developmental trajectories of behaviour problems and prosocial behaviours of children with intellectual disabilities in a population-based cohort. *Journal of Child Psychology and Psychiatry, 60*(11), 1210–1218. https://doi.org/10.1111/jcpp.13080

Bruun Jensen, B. (2013). *Early years, family and education task group: Report: European review of social determinants of health and the health divide in the WHO European Region*. WHO Regional Office for Europe. https://www.who.int/europe/publications/i/item/9789289000567

Chadwick, O., Kusel, Y., & Cuddy, M. (2008). Factors associated with the risk of behaviour problems in adolescents with severe intellectual disabilities. *Journal of Intellectual Disability Research, 52*(10), 864–876. https://doi.org/10.1111/j.1365-2788.2008.01102.x

Dekker, M. C., & Koot, H. M. (2003). DSM-IV disorders in children with borderline to moderate intellectual disability. II: Child and family predictors. *Journal of the American Academy of Child & Adolescent Psychiatry, 42*(8), 923–931. https://doi.org/10.1097/01.CHI.0000046891.27264.C1

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability, 36*(2), 137–143. https://doi.org/10.1080/13668250.2011.572548

Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research, 47*(1), 51–58. https://doi.org/10.1046/j.1365-2788.2003.00464.x

Emerson, E. (2021). Social and environmental determinants of health among people with disabilities. In *Oxford Research Encyclopedia of Global Public Health*. Oxford University Press. https://doi.org/10.1093/acrefore/9780190632366.013.325

Emerson, E., & Brigham, P. (2015). Exposure of children with developmental delay to social determinants of poor health: Cross-sectional case record review study. *Child: Care, Health and Development, 41*(2), 249–257. https://doi.org/10.1111/cch.12144

Emerson, E., & Hatton, C. (2007). Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. *American Journal on Mental Retardation, 112*(2), 140–150. https://doi.org/10.1352/0895-8017(2007)112[140:COSPTH]2.0.CO;2

Emerson, E., & Hatton, C. (2013). *Health inequalities and people with intellectual disabilities*. Cambridge University Press. https://doi.org/10.1017/CBO9781139192484

Emerson, E., Graham, H., McCulloch, A., Blacher, J., Hatton, C., & Llewellyn, G. (2009). The social context of parenting 3-year-old children with developmental delay in the UK. *Child: Care, Health and Development, 35*(1), 63–70. https://doi.org/10.1111/j.1365-2214.2008.00909.x

Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research, 50*(12), 862–873. https://doi.org/10.1111/j.1365-2788.2006.00900.x

Emerson, E., & Spencer, N. (2015). Health inequity and children with intellectual disabilities. In *International Review of Research in Developmental Disabilities* (Vol. 48, pp. 11–42). Elsevier. https://doi.org/10.1016/bs.irrdd.2015.03.001

Gard, A. M., McLoyd, V. C., Mitchell, C., & Hyde, L. W. (2020). Evaluation of a longitudinal family stress model in a population-based cohort. *Social Development, 29*(4), 1155–1175. https://doi.org/10.1111/sode.12446

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405–418. https://doi.org/10.1111/j.1365-2788.2005.00673.x

Hatton, C., Emerson, E., Robertson, J., & Baines, S. (2018). The mental health of adolescents with and without mild/moderate intellectual disabilities in England: Secondary analysis of a longitudinal cohort study. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 768–777. https://doi.org/10.1111/jar.12428

Humphrey, A., & Bliuc, A.-M. (2021). Western individualism and the psychological wellbeing of young people: A systematic review of their associations. *Youth, 2*(1), 1–11. https://doi.org/10.3390/youth2010001

Jandrić, S., & Kurtović, A. (2021). Parenting sense of competence in parents of children with and without intellectual disability. *Europe's Journal of Psychology, 17*(1), 75–91. https://doi.org/10.5964/ejop.3771

Koskentausta, T., Iivanainen, M., & Almqvist, F. (2007). Risk factors for psychiatric disturbance in children with intellectual disability. *Journal of Intellectual Disability Research, 51*(1), 43–53. https://doi.org/10.1111/j.1365-2788.2006.00871.x

Langford, C. P. H., Bowsher, J., Maloney, J. P., & Lillis, P. P. (1997). Social support: A conceptual analysis. *Journal of Advanced Nursing, 25*(1), 95–100. https://doi.org/10.1046/j.1365-2648.1997.1997025095.x

Lapshina, N., & Stewart, S. L. (2021). Traumatic life events, polyvictimization, and externalizing symptoms in children with IDD and mental health disorders. *Research in Developmental Disabilities, 116*, 104028. https://doi.org/10.1016/j.ridd.2021.104028

Lichtenstein, P., Tideman, M., Sullivan, P. F., Serlachius, E., Larsson, H., Kuja-Halkola, R., et al. (2022). Familial risk and heritability of intellectual disability: A population-based cohort study in Sweden. *Journal of Child Psychology and Psychiatry, 63*(9), 1092–1102. https://doi.org/10.1111/jcpp.13560

Lund, C., Brooke-Sumner, C., Baingana, F., Baron, E. C., Breuer, E., Chandra, P., et al. (2018). Social determinants of mental disorders and the Sustainable Development Goals: A systematic review of reviews. *The Lancet Psychiatry, 5*(4), 357–369. https://doi.org/10.1016/S2215-0366(18)30060-9

Parry, S. J., & Thornicroft, G. (2020). The syndemic approach in relation to clinical practice and research in psychiatry. *Consortium Psychiatricum, 1*(2), 3–6. https://doi.org/10.17650/2712-7672-2020-1-2-3-6

Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92–98. https://doi.org/10.1111/jppi.12072

R Core Team. (2020). *R: A language and environment for statistical computing*. R Foundation for Statistical Computing.

Robertson, J., Raghavan, R., Emerson, E., Baines, S., & Hatton, C. (2019). What do we know about the health and health care of people with intellectual disabilities from minority ethnic groups in the United Kingdom? A systematic review. *Journal of Applied Research in Intellectual Disabilities, 32*(6), 1310–1334. https://doi.org/10.1111/jar.12630

Santos, H. C., Varnum, M. E. W., & Grossmann, I. (2017). Global increases in individualism. *Psychological Science, 28*(9), 1228–1239. https://doi.org/10.1177/0956797617700622

Sociaal en Cultureel Planbureau. (2024). *De leefwerelden van arm en rijk*. SCP. https://www.scp.nl/publicaties/publicaties/2024/04/05/de-leefwerelden-van-arm-en-rijk

Stronks, K., Kulu-Glasgow, I., & Agyemang, C. (2009). The utility of “country of birth” for the classification of ethnic groups in health research: The Dutch experience. *Ethnicity & Health, 14*(3), 255–269. https://doi.org/10.1080/13557850802509206

Totsika, V., Hastings, R. P., Emerson, E., & Hatton, C. (2020). Early years parenting mediates early adversity effects on problem behaviors in intellectual disability. *Child Development, 91*(1), e1–e17. https://doi.org/10.1111/cdev.13273

Van der Draai, D. A., Van Duijn, E., De Beurs, D. P., Bexkens, A., & Beekman, A. T. F. (2021). Factors of specialized mental health care use in the Netherlands: A scoping review applying Andersen-Newman’s care utilization model. *Health Services Insights, 14*, 11786329211048134. https://doi.org/10.1177/11786329211048134

Van Rest, M. M., Van Nieuwenhuijzen, M., Kupersmidt, J. B., Vriens, A., Schuengel, C., & Matthys, W. (2020). Accidental and ambiguous situations reveal specific social information processing biases and deficits in adolescents with low intellectual level and clinical levels of externalizing behavior. *Journal of Abnormal Child Psychology, 48*(11), 1411–1424. https://doi.org/10.1007/s10802-020-00676-x

Visser, K., Bolt, G., Finkenauer, C., Jonker, M., Weinberg, D., & Stevens, G. W. J. M. (2021). Neighbourhood deprivation effects on young people’s mental health and well-being: A systematic review of the literature. *Social Science & Medicine, 270*, 113542. https://doi.org/10.1016/j.socscimed.2020.113542

Wallander, J. L., Dekker, M. C., & Koot, H. M. (2006). Risk factors for psychopathology in children with intellectual disability: A prospective longitudinal population-based study. *Journal of Intellectual Disability Research, 50*(4), 259–268. https://doi.org/10.1111/j.1365-2788.2005.00792.x

Weiss, M. D., Daniolos, P. T., Coughlin, K., Mulvaney-Day, N., Cook, B., & Rosenblum, D. (2024). A scoping review of the intersectionality of autism and intellectual and developmental disability with social inequity on diagnosis and treatment of youth. *Journal of Child and Adolescent Psychopharmacology, 34*(5), 292–301. https://doi.org/10.1089/cap.2023.0058

Witwer, A. N., & Lecavalier, L. (2008). Psychopathology in children with intellectual disability: Risk markers and correlates. *Journal of Mental Health Research in Intellectual Disabilities, 1*(2), 75–96. https://doi.org/10.1080/19315860801988327

World Health Organization. (2014). *Social determinants of mental health*. World Health Organization. https://www.who.int/publications/i/item/9789241506809

World Health Organization. (2022). *World mental health report: Transforming mental health for all*. World Health Organization. https://www.who.int/publications/i/item/9789240049338

Zhang, H., Lee, Z. X., White, T., & Qiu, A. (2020). Parental and social factors in relation to child psychopathology, behavior, and cognitive function. *Translational Psychiatry, 10*(1), 80. https://doi.org/10.1038/s41398-020-0761-6

4

Chapter 4

Broad perspective on socio-economic disadvantages in youth with mild to borderline intellectual disabilities in mental health care

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Abstract

The objective of this study was to understand how socio-economic disadvantages relate to mental health problems (MHP) among children with mild intellectual disability or borderline intellectual functioning (MID-BIF) in outpatient care by extending beyond traditional economic measures, incorporating cumulative risks, and analyzing variations across clinical subgroups. Using a population-based case-control design, data from Statistics Netherlands and mental health records were analyzed for 1,742 children with MID-BIF receiving mental health care (M_{age} = 9.6, 33.1% girls) and 8,710 age- and sex-matched controls aged 0–17. Logistic regression revealed that children with MID-BIF and MHP were significantly more likely than controls to come from families facing socio-economic disadvantages, such as single parenthood, lower parental education, reliance on social benefits, low income, and subsidized housing. Socio-economic risks were more likely to cluster in the case group, with 15.3% of children exposed to five risk categories and 6.7% to all six, compared to 6.7% and 3.6% in controls, respectively. Children in the internalizing and externalizing symptom-based groups faced more pronounced socio-economic disadvantages than those in the developmental group. Additionally, more extensive care was unexpectedly linked to more favorable socio-economic conditions, suggesting a complex interplay between care needs and socio-economic conditions. Taken together, this study showed that children with MID-BIF receiving outpatient care for their MHP often face greater and more clustered socio-economic disadvantages. Simultaneously, children from socio-economically disadvantaged backgrounds received less specialized mental health care. This underscores the importance of addressing barriers in mental health care and promoting family- and community-based care.

Introduction

Children with mild intellectual disabilities or borderline intellectual functioning (MID-BIF) are among the most vulnerable groups to develop mental health problems (MHP; Einfeld & Tonge, 2007; Emerson, 2003). Research suggests that socio-economic factors, such as poverty, may contribute to this increased risk (Emerson & Hatton, 2007; Emerson et al., 2009). Some studies suggest that children with MID-BIF are disproportionately affected by socio-economic disadvantages, including poverty (Emerson & Hatton, 2007; Hatton et al., 2018; Storm et al., 2025). However, the link between socio-economic disadvantages and MHP in children with MID-BIF remains fragmented. Developing a deeper understanding of this relationship is crucial for identifying the specific needs of these children and their families, ensuring they receive appropriate support and care. This study addresses this gap by moving beyond conventional economic measures, adopting a cumulative perspective–i.e., considering the extent to which families experience multiple, co-occurring socio-economic disadvantages–and examining variations among clinical subgroups.

While some studies identify a connection between lower socio-economic status (SES) and increased behavioral or psychiatric problems, the findings are inconsistent–some report an association, others do not–often depending on how SES is measured (e.g., income alone vs. composite measures; Baker & Blacher, 2021; Emerson & Brigham, 2015) and the type of analysis used (e.g., univariate vs. multivariate; Stewart et al., 2023). Findings from a recent analysis, derived from a subset of the current sample, showed that families of children with MID-BIF were more likely to have lower household incomes, higher rates of single-parent households, and lower parental education levels compared to matched controls and families of children with MHP without MID-BIF (Storm et al., 2025). We aimed to extend these findings in a larger group of children with MID-BIF and MHP and explore additional dimensions of economic vulnerability, such as income sources, reliance on government benefits, and housing conditions, which may independently relate to mental health. In the Netherlands, reliance on government benefits often reflects financial instability and insecurity, as these benefits are typically accessible only to low-income families. Housing tenure, whether owning or renting, reflects economic challenges as well: families in social housing face long waitlists, while private renters struggle with rising costs. Poor housing–characterized by leaky roofs, dampness, and inadequate heating–

has already been linked to higher rates of MHP among low-income populations (Pevalin et al., 2017). For tenants, resolving such deficiencies frequently depends on landlords or housing associations. Broadening the scope beyond traditional SES measures allows for a more comprehensive understanding of how socio-economic disadvantages relate to mental health outcomes in children with MID-BIF and MHP.

Moving beyond individual socio-demographic factors, the clustering of socio-economic disadvantages deserves greater focus, as they contribute substantially to reinforcing cycles of adversity and vulnerability (Emerson, 2021). Evidence from samples of children without MID-BIF demonstrated that interconnected risk factors–such as poverty, low parental education, and family instability–tend to cluster and interact (Afroz et al., 2022), with cumulative socio-economic disadvantages disproportionately affecting individuals with low SES and MHP, often leading to worsened outcomes from childhood into adulthood (Evans-Lacko et al., 2024). Given that children with MID-BIF and MHP are particularly vulnerable to socio-economic disadvantage (Emerson & Hatton, 2007; Storm et al., 2025), we hypothesize that this population will also experience greater clustering of socio-economic disadvantages.

Another approach to understanding the link between socio-economic disadvantage and MHP in children with MID-BIF is to investigate clinical subgroups. Most studies treat this population as homogenous, potentially overlooking important subgroup variations, or focus narrowly on specific syndromes, such as Down syndrome (Dekker & Koot, 2003; Foley et al., 2014) or Fragile X Syndrome (FXS; Hall et al., 2007; Scambler et al., 2007; Smith et al., 2016), limiting generalizability. Examining variations by symptom profiles and care extensiveness could yield valuable insights. Regarding diagnostic subgroups, limited evidence suggests that externalizing problems, such as disruptive behavior, conduct issues, and hyperactivity, are more strongly influenced by direct socio-economic stressors, whereas internalizing problems tend to be less sensitive to these factors in children with MID-BIF (Bailey et al., 2019; Koskentausta et al., 2007; Totsika et al., 2020). However, these studies often considered a narrow range of socio-economic stressors, and their findings are not consistently supported by other research (Avci, 2024; Chadwick et al., 2008; Wallander et al., 2006; Weiss et al., 2016). Similarly, the role of mental health care extensiveness–reflecting the total amount of care received–has been underexplored in relation to socio-economic factors within the MID-BIF population. Evidence from the general population indicated that lower socio-economic status is linked to higher healthcare utilization and expenditures (Loef et al., 2021). Accordingly, it is hypothesized that families of children with MID-BIF and MHP facing greater socio-economic disadvantages will require more frequent or extensive health care, as such stressors likely worsen mental health outcomes.

Overall, this study examines the socio-economic conditions of children with MID-BIF receiving outpatient care for MHP, aiming to improve our understanding of how socio-economic disadvantages relate to MHP. The objectives are threefold: (1) to compare the socio-economic conditions of children with MID-BIF and MHP to those of age- and sex-matched peers from the general population, hypothesizing greater socio-economic disadvantages in the clinical group; (2) to assess the accumulation of co-occurring socio-economic disadvantages within the clinical group compared to controls; (3) to explore whether socio-economic conditions differ across clinical subgroups within the population of children with MID-BIF receiving mental health care, acknowledging the heterogeneity of this group. Subgroups are defined by symptom profile and the total amount of mental health care received.

Method

Sources of data

The study relied on data derived from the Extramural LUMC (Leiden University Medical Center) Academic Network data warehouse, which served as a comprehensive regional integrative population-based data infrastructure (Ardesch et al., 2023; Kist et al., 2024). Two primary data sources were analyzed: non-public microdata from Statistics Netherlands (SN; the central register agency; Bakker et al., 2014) and patient data from a specialized mental health care institution for children with MID-BIF and MHP. The SN microdata provided demographic and socio-economic indicators at both the individual and family levels. Patient records contributed variables such as age, gender, diagnostic information, duration of care, and registration dates from mental health care services.

Participants

Participants were divided into two groups: a clinical case group and a matched population-based control group. The clinical case group included children with MID or BIF (IQ 55–85 or similar functional levels) receiving outpatient mental health care at a specialized facility. All children in this group resided in The Hague or its surrounding urban and suburban areas. Cases were identified from patient records (2011–2020) and included children aged 17 years or younger who received at least 240 minutes (four hours) of direct or indirect mental health care. A control group of children from the general population was matched by sex and age using the SN database, with five controls selected per case. Controls resided in the same areas, with postal codes randomized for residential comparison.

Ethical Approval and data linkage

This study received an exemption from the Medical Research Involving Human Subjects Act (CEP number: N22.048) by the Medical Ethics Committee. Mental health data routinely collected from patients was securely stored, pseudonymized, and kept anonymous from the researchers, with an opt-out option available to allow patients or guardians to decline participation in data collection. To ensure accurate linkage across three data sources, each participant was assigned a unique record identification number (RIN), allowing for comprehensive data connection while maintaining confidentiality. Parents and children were linked using their RINs to retrieve family-related information. Additionally, SN staff reviewed output results to minimize any risk of disclosing identifiable information. Further details on the data linkage process can be found in Ardesch et al. (2023).

Variables

Child demographics

Child demographics included sex, age, and country of birth. In the case group, sex and age were obtained from mental health care records, while for the control group, sex and age were sourced from SN. For all groups, country of birth data for children were classified based on the SN categorization into Western and Non-Western countries, using the publicly available table accessible (Centraal Bureau voor de Statistiek, 2024).

Social characteristics

Social characteristics were obtained from SN. The selection year of these variables corresponded to the year cases initiated treatment at the mental health care center, capturing social characteristics reflective of the familial context at treatment onset. First, the number of children in a household represented all individuals who share a child-parent relationship with one or both parents living in the same household. This included biological, adopted, and stepchildren, but foster children were excluded. Second, family structure was categorized into three groups: dual-parent households, single-parent households, and other types, which include children in institutional settings. Finally, both maternal and paternal education levels were analyzed and classified as low, middle, or high, based on SN's guidelines (Statistics Netherlands, 2024). The classification was based on the highest level of education achieved, with low representing primary education, middle for specialized vocational training, and high for higher professional education or university degree.

Economic circumstances

Five economic measures were obtained from SN. Again, the selection year of these economic variables aligned with the year cases started treatment. First, standardized disposable household income (percentiles) represented net income adjusted for household size, composition, liabilities, and inflation, using the OECD-modified equivalence scale as applied by SN. For the interpretation of the odds ratio (OR; see Figure 1), the data were pooled, with higher percentiles reflecting relatively lower incomes. Second, household income source identified the main income source, distinguishing between labor and transfer income, and specifying the primary category within the highest income type. Third, benefit dependency measured reliance on social security benefits over four years, expressed as the percentage of household income from benefits. Only households eligible for benefits throughout these four years were included. Fourth, the main benefit type was the largest contributor to household income, categorized into no benefit, unemployment, disability, welfare, or other social provisions. Lastly, household homeownership classified households as owners or non-owners, with non-owners further divided into renters with or without subsidies. The selected variables reflected both data availability and prior research, expanding on earlier work (Storm et al., 2025) by combining multiple SES dimensions to provide a more comprehensive view of disadvantage.

Clinical features
Two clinical features for the case group were extracted from mental health records. First, diagnoses were based on the primary DSM-IV codes assigned by treating clinicians at the end of treatment (American Psychiatric Association, 1998), as this classification system was predominantly used during the study period (2011–2020). If intellectual disability was the primary code, the main secondary diagnosis was selected to reflect the main presenting symptomatology. Comorbidity was not considered; individuals were classified based on the primary diagnosis–or the secondary diagnosis when MID-BIF was primary–to capture the most prominent clinical presentation and ensure consistency in analyses. End-of-treatment diagnoses were prioritized for accuracy; start-of-treatment diagnoses were reviewed when end-of-treatment data were missing but added no additional information. Although based on formal DSM diagnoses, we grouped them into three empirically supported symptom clusters–internalizing, externalizing, and developmental–rather than strictly following DSM chapter divisions. The internalizing group encompassed conditions characterized by inwardly directed symptoms such as anxiety, depression and stress-related disorders. The externalizing group included those marked by outward behaviors, such as ADHD, behavioral disorders and substance use disorders. The developmental group covered autism spectrum disorder (ASD), communication, tic, enuresis, and neurocognitive disorders. We acknowledge that ADHD is classified as a neurodevelopmental disorder in the DSM-5. However, for the purpose of this study, we grouped ADHD within the externalizing domain due to its predominant behavioral expression–impulsivity and hyperactivity–and its empirical clustering with other externalizing conditions such as oppositional defiant disorder and conduct disorder (Cosgrove et al., 2011; Beauchaine et al., 2017). This decision aligns with dimensional and transdiagnostic classification models, such as the Achenbach System of Empirically Based Assessment and early versions of the Hierarchical Taxonomy of Psychopathology, which emphasize symptom profiles over strict diagnostic categories (Kotov et al., 2017). To avoid confusion, we consistently refer to these subgroups as symptom-based rather than diagnostic categories throughout the manuscript.

Secondly, total allocated time for both direct and indirect care activities served as a proxy for the extensiveness of mental health care. Direct care included all face-to-face interactions, such as therapy and diagnostics, while indirect care covered activities such as interprofessional consultations, administrative tasks, and care coordination (Nanninga et al., 2018; Pouls et al., 2023). The total care time was categorized into five levels, from very low (0–20%) to very high (80–100%). Time allocations for these categories were as follows: very low (240–1,478 minutes, ~4–24.6 hours, *N* = 349), low (1,478–2,780 minutes, ~24.6–46.3 hours, *N* = 349), medium (2,780–4,264 minutes, ~46.3–71.1 hours, *N* = 347), high (4,264–6,899 minutes, ~71.1–115 hours, *N* = 347), and very high (6,899–27,542 minutes, ~115–459 hours, *N* = 349).

Statistical analysis

The analysis followed a multi-step approach. First, descriptive statistics (*M*, *SD*, frequencies, and percentages) were calculated for child demographics, social characteristics, and economic circumstances. These were reported separately for the clinical case group (and subgroups) and the control group.

For our first objective, univariate logistic regression analyses were conducted to compare the socio-economic conditions of children with MID-BIF and MHP to those of age- and sex-matched peers. Standardized odds ratios (ORs), 95% confidence intervals (CIs), and p-values were reported to allow comparison of effect sizes across variables. ORs indicated the likelihood of a variable's association with case vs control group membership. Multivariate models were not conducted due to conceptual overlap between variables (e.g., household income and benefit dependency). Logistic regression models were implemented using the *glm* function (McCullagh & Nelder, 1989), chosen for their suitability with binary outcomes and flexibility with different predictor types. Missing data (0 to 51.2%) were handled through multiple imputation by chained equations (MICE; Azur et al., 2011), generating ten imputed datasets using iterative regression-based predictions conditioned on all other variables.

For our second objective, the accumulation of co-occurring socio-economic disadvantages was assessed through distribution visualizations for the case and control group, with their difference tested using a linear-by-linear Chi-square test (Greenwood & Nikulin, 1996).

For our third objective, univariate analyses were conducted to examine socio-economic similarities and differences across the two clinical subgroups. Continuous variables were analyzed with ANOVA (Fisher, 1925) or the Kruskal–Wallis test (Kruskal & Wallis, 1952) for skewed distributions, while categorical variables were assessed using Chi-square tests (Greenwood & Nikulin, 1996). A significance threshold of $\alpha = .05$ was applied. All computations were performed using R (version 4.4.0; R Core Team, 2021), with the packages ‘mice’ (v3.16.0), “forestplot” (version 3.1.1), ‘modelsummary’ (v2.2.0), and ‘ggplot2’ (v3.5.1).

Results

First objective: Socio-economic differences between cases and controls

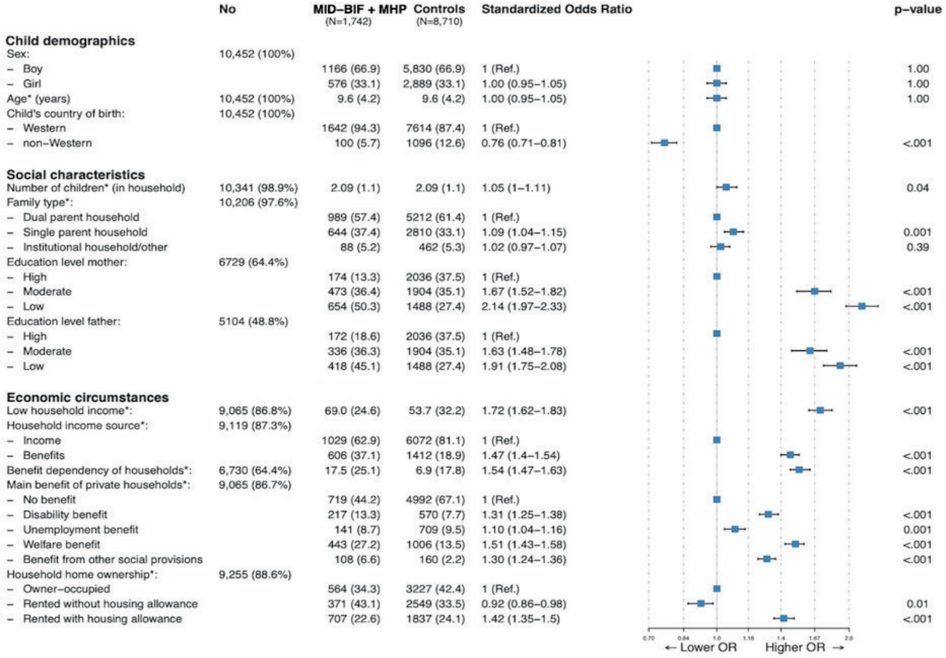
Descriptive statistics

We compared children with MID-BIF and MHP (n = 1,742) to their peers from the general population (n = 8,710), resulting in a total sample of 10,452 children. Since children with MID-BIF and MHP were matched by age and sex, both groups had identical age distributions (*M* = 9.6 years, *SD* = 4.2) and gender proportions (33.1% girls). Differences in country of birth emerged, with children with MID-BIF and MHP having a higher predominance of being born in a Western country, *OR* = 0.76 $p < .001$.

Main findings

Regarding social characteristics, family composition differed notably. Children with MID-BIF and MHP were more likely to live in single-parent households, *OR* = 1.09, $p = .001$. Parental education levels were significantly lower in the MID-BIF and MHP group. Among mothers, 50.3% had low education compared to 27.4% in controls, *OR* = 2.14, $p < .001$. Fathers showed a similar trend, with 45.1% having low education compared to 25.9% in controls, *OR* = 1.91, $p < .001$. Next, differences in economic circumstances were also evident. Families of children with MID-BIF and MHP were more likely to live in low-income households, *OR* = 1.72, $p < .001$, and to rely on benefits as their primary income source (37.1% vs. 18.9%), *OR* = 1.47, $p < .001$. Housing patterns also differed, with families in the MID-BIF and MHP group being more likely to rent with housing allowances (43.1% vs. 24.1%), *OR* = 1.42, $p < .001$, and less likely to own a house (34.3% vs. 42.4%).

Figure 1. Forest plot of demographic and socio-economic characteristics of children with MID-BIF and MHP compared to controls



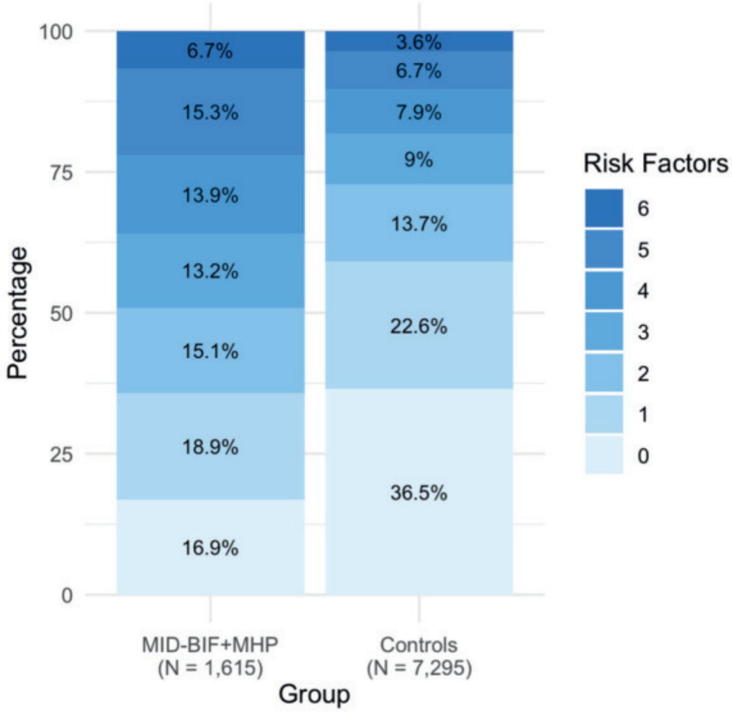
	No	MID–BIF + MHP (N=1,742)	Controls (N=8,710)	Standardized Odds Ratio	p–value
Child demographics					
Sex:	10,452 (100%)				
– Boy		1166 (66.9)	5,830 (66.9)	1 (Ref.)	1.00
– Girl		576 (33.1)	2,889 (33.1)	1.00 (0.95–1.05)	1.00
Age* (years)	10,452 (100%)	9.6 (4.2)	9.6 (4.2)	1.00 (0.95–1.05)	1.00
Child's country of birth:	10,452 (100%)				
– Western		1642 (94.3)	7614 (87.4)	1 (Ref.)	
– non–Western		100 (5.7)	1096 (12.6)	0.76 (0.71–0.81)	<.001
Social characteristics					
Number of children* (in household)	10,341 (98.9%)	2.09 (1.1)	2.09 (1.1)	1.05 (1–1.11)	0.04
Family type*:	10,206 (97.6%)				
– Dual parent household		989 (57.4)	5212 (61.4)	1 (Ref.)	
– Single parent household		644 (37.4)	2810 (33.1)	1.09 (1.04–1.15)	0.001
– Institutional household/other		88 (5.2)	462 (5.3)	1.02 (0.97–1.07)	0.39
Education level mother:	6729 (64.4%)				
– High		174 (13.3)	2036 (37.5)	1 (Ref.)	
– Moderate		473 (36.4)	1904 (35.1)	1.67 (1.52–1.82)	<.001
– Low		654 (50.3)	1488 (27.4)	2.14 (1.97–2.33)	<.001
Education level father:	5104 (48.8%)				
– High		172 (18.6)	2036 (37.5)	1 (Ref.)	
– Moderate		336 (36.3)	1904 (35.1)	1.63 (1.48–1.78)	<.001
– Low		418 (45.1)	1488 (27.4)	1.91 (1.75–2.08)	<.001
Economic circumstances					
Low household income*:	9,065 (86.8%)	69.0 (24.6)	53.7 (32.2)	1.72 (1.62–1.83)	<.001
Household income source*:	9,119 (87.3%)				
– Income		1029 (62.9)	6072 (81.1)	1 (Ref.)	
– Benefits		606 (37.1)	1412 (18.9)	1.47 (1.4–1.54)	<.001
Benefit dependency of households*:	6,730 (64.4%)	17.5 (25.1)	6.9 (17.8)	1.54 (1.47–1.63)	<.001
Main benefit of private households*:	9,065 (86.7%)				
– No benefit		719 (44.2)	4992 (67.1)	1 (Ref.)	
– Disability benefit		217 (13.3)	570 (7.7)	1.31 (1.25–1.38)	<.001
– Unemployment benefit		141 (8.7)	709 (9.5)	1.10 (1.04–1.16)	0.001
– Welfare benefit		443 (27.2)	1006 (13.5)	1.51 (1.43–1.58)	<.001
– Benefit from other social provisions		108 (6.6)	160 (2.2)	1.30 (1.24–1.36)	<.001
Household home ownership*:	9,255 (88.6%)				
– Owner–occupied		564 (34.3)	3227 (42.4)	1 (Ref.)	
– Rented without housing allowance		371 (43.1)	2549 (33.5)	0.92 (0.86–0.98)	0.01
– Rented with housing allowance		707 (22.6)	1837 (24.1)	1.42 (1.35–1.5)	<.001

*Note. *at the year of treatment onset for the case group. MID-BIF = mild intellectual disability or borderline intellectual functioning; MHP = mental health problems; No = total number of observations for each variable without missing. For continuous variables, the mean and SD are provided (SD in brackets). For categorical variables, the N and percentages are given. Percentages in parentheses are calculated based on the non-missing (valid) N. The error bars represent the 95% CI of the mean.*

Second objective: Accumulation of disadvantages

The accumulation of co-occurring disadvantages, illustrated by Figure 2, was assessed based on six key risk factors: residing in a single-parent household, low maternal and paternal education levels, a household income below the 25th percentile (first quartile in the control group), reliance on benefits as the primary income source, and living in a rented house supported by a housing allowance. The control group was more likely to have no risk factors (36.5% vs. 16.9%), whereas the case group more frequently faced multiple risks (e.g., 6.7% had all six risk factors compared to 3.6% in the control group). A linear-by-linear association Chi-square test confirmed a highly significant association between group status and risk accumulation, $\chi^2(1) = 370.48$, $p < .001$, indicating that the case group experienced a greater accumulation of socio-economic risks than the control group.

Figure 2. Accumulation of co-occurring socio-economic disadvantages by group



Third objective: Subgroup Analysis Within the Case Group

Descriptive statistics

The case group included 1,742 children, stratified by symptom profile (see Table 1) and care duration (see Table 2). Symptom-based subgroups were derived from diagnostic information and included an externalizing group (n = 362), an internalizing group (n = 287), and a developmental group (n = 478). An additional 27.7% of cases (n = 478) could not be classified into these groups due to diagnoses not aligning with the three profiles. We also stratified the case group by age (<12 and ≥12 years) and sex to verify whether unexpected differences existed (see Appendices A and B); yet none were observed.

Main findings: stratification by symptom-based subgroups

The internalizing subgroup had a balanced gender distribution (51.9% boys) and included the oldest children. Among all subgroups, the internalizing group had the lowest maternal education levels (58.1% classified as low), the highest reliance on disability benefits (19.0%) and rented housing with allowances (46.0%) and received the most extensive mental health care (29.6% very high), particularly compared to the developmental group.

The developmental subgroup, the youngest group, had the highest proportion of boys (74.7%) and was most likely to live in dual-parent households (67.9%). Fathers in this group had the highest levels of education (25.5% with higher education). Economically, these families experienced the least reliance on benefits (29.5%) and had the highest rate of homeownership (42.5%), distinguishing them positively from the other subgroups.

The externalizing subgroup, predominantly boys (71.5%), displayed characteristics that were generally intermediate between the internalizing and developmental subgroups. They were more likely to live in single-parent households (39.3%) than children in the developmental group but less so than those in the internalizing group. A similar pattern was observed for maternal education (52.9%), benefit reliance (35.3%), and homeownership (35.9%), positioning this subgroup between the other two symptom-based groups on these indicators.

Table 1. Demographic and socio-economic characteristics stratified by symptom-based subgroups in children with MID-BIF and MHP

	MID-BIF+MHP N (%) N = 1,127	**Internalizing N = 287**	**Developmental N = 478**	**Externalizing N = 362**	**Test statistic**	**p-value**	**Effect size**
			Child demographics				
Sex:	1,127 (100)	-	-	-	χ^2=45.93	*p*<.001	V=.20
- Boy	-	149 (51.9)	357 (74.7)	259 (71.5)	-	-	-
- Girl	-	138 (48.1)	121 (25.3)	103 (28.5)	-	-	-
Age* (years)	1,127 (100)	11.9 (3.64)	8.33 (4.30)	10.4 (3.59)	H=136.36	*p*<.001	η^2=.12
Child's country of birth:	1,127 (100)	-	-	-	χ^2=2.47	*p*=.291	V=.05
- Western	-	267 (93.0)	457 (95.6)	344 (95.0)	-	-	-
- Non-Western	-	20 (7.0)	21 (4.4)	18 (5.0)	-	-	-

Social characteristics							
Number of children* (in household)	1,121 (99.5)	2.13^{b} (1.14)	2.04^{c} (1.09)	2.15^{a} (1.10)	F=1.20	*p*=.305	η^2=.002
Family type*:	1,118 (99.2)	-	-	-	χ^2=15.22	*p*=.004	V=.08
- Dual parent household	-	162 (56.8)	322 (67.9)	204 (56.8)	-	-	
- Single parent household	-	111 (38.9)	133 (28.1)	141 (39.3)	-	-	
- Institutional household/other	-	12 (4.2)	19 (4.0)	14 (3.9)	-	-	
Education level mother:	824 (73.1)	-	-	-	χ^2=25.84	*p*<.001	V=.13
- High	-	19 (9.4)	62 (18.0)	28 (10.1)	-	-	-
- Moderate	-	66 (32.5)	149 (43.2)	102 (37.0)	-	-	-
- Low	-	118 (58.1)	134 (38.8)	146 (52.9)	-	-	-
Education level father:	592 (52.5)	-	-	-	χ^2=13.77	*p*=.008	V=.11
- High	-	16 (11.8)	68 (25.5)	31 (16.4)	-	-	-
- Moderate	-	53 (39.0)	81 (30.3)	74 (39.2)	-	-	-
- Low	-	67 (49.2)	118 (44.2)	84 (44.4)	-	-	-
Economic circumstances							
Household income* (in percentiles)	1,068 (94.8)	31.0 (23.6)	34.1 (25.7)	31.7 (23.7)	H=2.41	*p=.300*	η^2<*.01*
Household Income Source*	1,070 (94.8)	-	-	-	χ^2=6.79	*p*=.034	V=.08
- Income	-	169 (61.5)	315 (70.5)	225 (64.7)	-	-	-
- Benefits	-	106 (38.5)	132 (29.5)	123 (35.3)	-	-	-
Benefit dependency of households*	858 (76.1)	17.6 (25.2)	14.4 (23.8)	17.7 (25.3)	H=4.78	*p=.091*	η^2<*.01*
Main benefit of private households*	1,068 (94.8)	-	-	-	χ^2=20.24	*p=.009*	V=.10
- No benefit	-	109 (39.8)	234 (52.5)	160 (46.0)	-	-	-
- Unemployment benefit	-	25 (9.1)	34 (7.6)	26 (7.5)	-	-	-
- Disability benefit	-	52 (19.0)	57 (12.8)	45 (12.9)	-	-	-
- Welfare benefit	-	66 (24.1)	104 (23.3)	100 (28.7)	-	-	-
- Benefit from other social provisions	-	22 (8.0)	17 (3.8)	17 (4.9)	-	-	-

Household Home Ownership*	1,074 (95.3)	-	-	1,642 (94.3)	χ^2=11.11	*p*=.025	V=.07
- Owner-occupied	-	87 (31.8)	192 (42.5)	125 (35.9)	-	-	-
- Rented without housing allowance	-	61 (22.3)	101 (22.3)	76 (21.8)	-	-	-
- Rented with housing allowance	-	126 (46.0)	159 (35.2)	147 (42.2)	-	-	-
Clinical features							
Amount of mental health care received	1,127 (100)	-	-	-	χ^2=21.30	*p*=.009	V=.10
- Very low	-	42 (14.7)	69 (14.4)	67 (18.5)	-	-	-
- Low	-	48 (16.7)	109 (22.8)	81 (22.4)	-	-	-
- Medium	-	48 (16.7)	106 (22.2)	77 (21.3)	-	-	-
- High	-	64 (22.3)	102 (21.4)	72 (19.8)	-	-	-
- Very high	-	85 (29.6)	92 (19.2)	65 (18.0)	-	-	-

*Note. *at the year of treatment onset. MID-BIF = mild intellectual disability or borderline intellectual functioning; MHP = mental health problems. For continuous variables, the mean and SD are provided (SD in brackets). For categorical variables, the N and percentages are given. Percentages in parentheses are calculated based on the non-missing (valid) N. H = Kruskal-Wallis test statistic. Superscripts indicate statistically significant differences between groups (p < .05). Means with different superscripts differ significantly from one another.*

Main findings: stratification by care duration

Children who received the highest total amount of mental health care were characterized by a higher representation of girls (40.1%), smaller household sizes (1.88 children on average), and higher maternal education levels compared to those who received less care. Economic conditions tended to improve with the amount of care received: families in the group receiving the most care had higher household income percentiles (33.0%) and were more likely to rely on income as their primary source (64.7%) than families in the group receiving the least care (28.7% income percentile, 57.0% income reliance). Homeownership was most common in the high care group (39.1%) but declined slightly in the group receiving the most care (35.7%). Reliance on welfare benefits steadily decreased as the amount of care increased, from 32.1% in the group receiving the least care to 22.6% in the group receiving the most care, though disability benefits remained prevalent in the medium and high care groups (15.7% and 13.3%, respectively).

Table 2. Demographic and socio-economic characteristics stratified by total amount of mental health care received in children with MID-BIF and MHP

	MID-BIF+MHP N (%) N = 1,742	**Very low N = 349**	**Low N = 349**	**Medium N = 347**	**High N = 347**	**Very high N = 349**	**Test statistic**	**p-value**	**Effect size**
Child demographics									
Sex:	1,742 (100)	-	-	-	-	-	χ^2=15.01	*p*=.005	V=.09
- Boy	-	248 (71.1)	235 (67.3)	249 (71.8)	225 (64.7)	209 (59.9)	-	-	-
- Girl	-	101 (28.9)	114 (32.7)	98 (28.2)	123 (35.3)	140 (40.1)	-	-	-
Age* (years)	1,742 (100)	9.95 (4.30)	9.18 (4.20)	9.46 (4.34)	9.46 (4.14)	9.76 (3.78)	F=1.796	*p*=.127	η^2=.004
Child's country of birth:	1,742 (100)	-	-	-	-	-	χ^2=2.75	*p*=.601	V=.04
- Western	-	324 (92.8)	334 (95.7)	328 (94.5)	327 (94.0)	329 (94.3)	-	-	-
- Non-Western	-	25 (7.16)	15 (4.30)	19 (5.48)	21 (6.03)	20 (5.73)	-	-	-
Social characteristics									
Number of children* (in household)	1,734 (99.5)	2.15^{a} (1.23)	2.23^{b} (1.18)	2.20^{c} (1.16)	2.00 (1.02)	1.88^{abc} (1.05)	F=5.903	*p*<.001	η^2=.01
Family type*:	1,722 (98.9)	-	-	-	-	-	χ^2=13.05	*p*=.11	V=.06
- Dual parent household	-	177 (51.2)	207 (60)	204 (59.6)	208 (60.6)	193 (55.8)	-	-	
- Single parent household	-	146 (42.2)	122 (35.4)	124 (36.3)	123 (35.9)	129 (37.3)	-	-	
- Institutional household/other	-	23 (6.6)	16 (4.6)	14 (4.1)	12 (3.5)	24 (6.9)	-	-	
Education level mother:	1,301 (74.7)	-	-	-	-	-	χ^2=35.22	*p*<.001	V=.12
- High	-	24 (9.3)	30 (11.3)	39 (14.8)	49 (19.1)	32 (12.5)	-	-	-
- Moderate	-	73 (28.2)	91 (34.2)	98 (37.3)	97 (37.9)	114 (44.4)	-	-	-
- Low	-	162 (62.5)	145 (54.5)	126 (47.9)	110 (43.0)	111 (43.2)	-	-	-
Education level father:	926 (53.2)	-	-	-	-	-	χ^2=9.07	*p*=.34	V=.07
- High	-	30 (18.0)	31 (16.1)	37 (18.6)	45 (22.8)	29 (17.1)	-	-	-
- Moderate	-	64 (38.3)	62 (32.1)	68 (34.2)	71 (36.0)	71 (41.8)	-	-	-
- Low	-	73 (43.7)	100 (51.8)	94 (47.2)	81 (41.1)	70 (41.2)	-	-	-

Economic circumstances									
Household income* (in percentiles)	1,628 (93.5)	28.7^{a} (24.4)	30.0^{ab} (25.2)	29.1^{ab} (24.0)	34.1^{c} (24.6)	33.0^{bc} (24.2)	H=19.88	*p*<.001	η^2=.01
Household Income Source*	1,635 (93.9)	-	-	-	-	-	χ^2=10.13	*p*=.038	V=.08
- Income	-	184 (57.0)	201 (60.7)	208 (64.0)	227 (68.2)	209 (64.7)	-	-	-
- Benefits	-	139 (43.0)	130 (39.3)	117 (36.0)	106 (31.8)	114 (35.3)	-	-	-
Benefit dependency of households*	1,314 (75.4)	19.3 (25.9)	17.8 (25.1)	18.6 (26.3)	16.2 (24.0)	15.7 (24.5)	H = 2.26	*p*=.688	η^2<.001
Main benefit of private households*	1,628 (93.5)	-	-	-	-	-	χ^2=28.23	*p=.030*	V=.07
- No benefit	-	135 (42.1)	134 (40.7)	140 (43.2)	161 (48.6)	149 (46.1)	-	-	-
- Unemployment benefit	-	25 (7.8)	34 (10.3)	30 (9.3)	28 (8.5)	24 (7.4)	-	-	-
- Disability benefit	-	29 (9.0)	43 (13.1)	51 (15.7)	44 (13.3)	50 (15.5)	-	-	-
- Welfare benefit	-	103 (32.1)	99 (30.1)	90 (27.8)	78 (23.6)	73 (22.6)	-	-	-
- Benefit from other social provisions	-	29 (9.0)	19 (5.8)	13 (4.0)	20 (6.0)	27 (8.4)	-	-	-
Household Home Ownership*	1,642 (94.3)	-	-	-	-	-	χ^2=17.90	*p*=.022	V=.07
- Owner-occupied	-	93 (28.9)	106 (31.7)	112 (34.3)	131 (39.1)	122 (35.7)	-	-	-
- Rented without housing allowance	-	159 (49.4)	156 (46.7)	146 (44.6)	120 (35.8)	126 (38.9)	-	-	-
- Rented with housing allowance	-	70 (21.7)	72 (21.6)	69 (21.1)	84 (25.1)	76 (23.5)	-	-	-

*Note. *at the year of treatment onset. MID-BIF = mild intellectual disability or borderline intellectual functioning; MHP = mental health problems. For continuous variables, the mean and SD are provided (SD in brackets). For categorical variables, the N and percentages are given. Percentages in parentheses are calculated based on the non-missing (valid) N. H = Kruskal-Wallis test statistic. Superscripts indicate statistically significant differences between groups (p < .05). Means with different superscripts differ significantly from one another.*

Discussion

In this study, we aimed to enhance our understanding of the link between socio-economic disadvantages and mental health problems (MHP) in children with MID-BIF receiving outpatient mental health care in three ways: by moving beyond traditional economic indicators, including a cumulative perspective, and examining variations across clinical subgroups. Our findings revealed three key insights. First, families of these children face significant socio-economic disadvantages, with economic vulnerability extending beyond income. Second, these disadvantages were more likely to cluster in these families compared to age- and sex-matched peers from the general population. Third, children in the internalizing and externalizing group exhibited more pronounced socio-economic disadvantages compared to families of children in the developmental group. Notably, families of children who received more hours of care showed somewhat less socio-economic disadvantage, suggesting a complex interplay between care needs and socio-economic conditions.

Regarding our first key insight, our results confirmed that, compared to the general population, families of children with MID-BIF and MHP face multiple socio-economic disadvantages. Using a large, population-based design, this study highlighted higher rates of single-parent households, lower parental education levels, and lower household incomes, providing a detailed perspective on these disparities. These findings align with prior research emphasizing the key role of socio-economic and family risk factors in children's mental health (Emerson & Hatton, 2007). Additionally, previous multivariate analyses conducted on a subset of this population showed that these socio-economic characteristics were independently associated with the likelihood of receiving mental health care (Storm et al., 2025). The current study expanded on commonly recognized socio-economic factors, demonstrating that families of children with MID-BIF also relied more heavily on government benefits and were more likely to live in subsidized rental housing, reflecting broader financial instability and insecure living conditions.

With respect to our second key insight, our results revealed that the clustering of these socio-economic risk factors was evidently more common in children with MID-BIF and MHP compared to their controls, consistent with our hypothesis. Such clustering is especially concerning in light of the adversity accumulation model, which suggests that the combined effects of multiple socio-economic disadvantages are greater than the sum of individual factors (Kessler et al., 2010; Schilling et al., 2008). Prior research has already shown that exposure to these layered adversities intensifies stress pathways, increasing risks of depression, anxiety, and impaired psychological well-being for children and adolescents in the general population, which can persist into adulthood (Afroz et al., 2022; Nurius et al., 2015; Reiss et al., 2019). Given that raising a child with an intellectual disability already presents significant stressors (Peer & Hillman, 2014), these cumulative socio-economic risks may pose an even greater challenge for affected families.

Concerning our third key insight, the study contributes to the existing literature by demonstrating that socio-economic disadvantages differed across clinical subgroups. Specifically, it highlights that children in the internalizing and externalizing group face more pronounced socio-economic challenges compared to those in the developmental group. Although the cross-sectional design limits causal interpretations, the observed differences between symptom-based groups may indicate distinct mechanisms linking socio-economic disadvantages to specific mental health conditions. While internalizing and externalizing symptom profiles are influenced by both genetic and environmental factors, previous research points to a relatively larger role for environmental stressors, such as economic stress and parenting challenges (Hendriks et al., 2020). Conversely, developmental conditions such as ASD tend to be more strongly associated with genetic predispositions, suggesting that their prevalence might be less immediately sensitive to environmental challenges (Tordjman et al., 2014; Wei et al., 2021). An additional explanation for the observed differences may be that socio-economic contexts influence the way professionals assess and interpret symptoms that children manifest. The presence of clustered socio-economic challenges in families may complicate the distinction between child-specific factors and external influences, with symptoms often attributed to systemic stressors or parenting dynamics (Mathew et al., 2019).

Concerning variation between symptom-based groups, we found that families experiencing greater socio-economic disadvantages tended to receive shorter durations of care. This contrasted with our hypothesis and diverged from findings in the general population, where lower SES is typically associated with higher healthcare utilization (Loef et al., 2021). One possible explanation is that important clinical variables, such as symptom severity, were not captured in our data. Families from disadvantaged socio-economic backgrounds often face practical and financial barriers that limit sustained care engagement (Bornheimer et al., 2018). These barriers may lead families to deprioritize mental health care when basic needs are unmet (Van Der Draai et al., 2021), for example in households with lower maternal education or single-parent structures, as seen in our sample, where limited time, support, and competing demands might disrupt continuity of care. In contrast, higher-SES families often benefit from greater resources and social capital, enabling them to navigate the system more effectively (Reiss, 2013). Even in systems designed to offer equitable access, such as the Dutch healthcare system, income and referral processes can create substantial disparities (Tordjman et al., 2014). Additionally, mistrust in institutions may further deter engagement, as fears of stigmatization or punitive consequences can outweigh perceived benefits (Giordano & Lindström, 2016; Paquin et al., 2024). Future research should explore the reasons for treatment discontinuation in more detail, including the extent to which early termination may result from non-attendance or other access-related barriers.

This study has several strengths and limitations. Combining microdata from SN with patient records enabled a thorough analysis of the socio-economic characteristics of children with MID-BIF receiving care for MHP, effectively avoiding selection bias by including all children in care. However, this strength is counterbalanced by access-to-care bias, as children unable to access the care they needed could not be included. The large sample size enhanced statistical power and enabled meaningful subgroup analyses, though missing data, such as for paternal education, may affect reliability. Additionally, the study’s focus on cumulative socio-economic disadvantage provided a unique perspective on layered risks, marking a novel exploration of accumulated socio-economic factors in families of children with MID-BIF in mental health care. Despite these contributions, the cross-sectional design limits causal interpretations, and the reliance on data from a single specialized institution, as well as the study’s focus on the Dutch socio-economic and healthcare context, may reduce the generalizability of findings to other settings or countries. While total treatment time provides a practical and measurable way to assess care extensiveness, facilitating consistent group comparisons, the study does not address qualitative differences in care, which may oversimplify the relationship between socio-economic factors and care provision. Furthermore, it remains unclear whether these children receive follow-up care after treatment at other facilities. Finally, although our analyses are based on country of birth, this variable is sometimes interpreted as a proxy for ethnicity in Dutch research (Stronks et al., 2009). However, it does not fully capture cultural background or self-identification. Therefore, future research should consider more nuanced measures of ethnicity.

Taken together, the findings of this study have implications for policy and practice as they call for increased attention to socio-economic context in the design and delivery of mental health services. Promoting family- and community-based approaches that prioritize socio-economic well-being is essential, particularly for those facing structural barriers related to income, housing, or access. Integrated, family-centered models–such as co-located care combining mental health support with social services (Hodgkinson et al., 2017) –offer a promising way forward by addressing both clinical and social needs in a holistic manner. From a policy perspective, strengthening cross-sector collaboration could reduce drop-out rates and improve engagement among vulnerable families. For practice, a better understanding of how socio-economic stressors shape the well-being of children with MID-BIF and their care trajectories can support more tailored interventions. To further improve practice and policy, future research should explore (1) why vulnerable families disengage from care, (2) how care characteristics–such as accessibility and service fit–affect outcomes, (3) the mechanisms linking socio-economic disadvantage to a reduced amount of care received, and (4) the long-term impact of cumulative adversity on mental health and service use in this population.

To conclude, this study reveals a concerning pattern: children with MID-BIF receiving mental health care for their MHP often face 1) greater socio-economic disadvantages, especially among children in the internalizing and externalizing groups, and 2) a greater clustering of disadvantages. At the same time, children from socio-economically disadvantaged backgrounds receive less specialized mental health care, suggesting a complex interplay between care needs and socio-economic conditions. These findings underscore the need to better understand how socio-economic disadvantage affects care access, engagement, and outcomes for children with MID-BIF.

References

Afroz, N., Kabir, E., & Alam, K. (2022). Clustering of socio-demographic factors and their association with the mental health of Australian children and adolescents: A latent class analysis. *Research Square*. https://doi.org/10.21203/rs.3.rs-1821998/v1

American Psychiatric Association. (1998). *Diagnostic and statistical manual of mental disorders: DSM-IV; includes ICD-9-CM codes effective 1. Oct. 96* (4th ed., 7th printing).

Ardesch, F. H., Meulendijk, M. C., Kist, J. M., et al. (2023). The introduction of a data-driven population health management approach in the Netherlands since 2019: The Extramural LUMC Academic Network data infrastructure. *Health Policy, 132,* 104769. https://doi.org/10.1016/j.healthpol.2023.104769

Avci, D. (2024). Mental health problems among adolescents with mild intellectual disability and relation to sleep quality and perceived social support: A comparative study. *Journal of Psychosocial Nursing and Mental Health Services, 62*(3), 39–50. https://doi.org/10.3928/02793695-20230821-04

Azur, M. J., Stuart, E. A., Frangakis, C., & Leaf, P. J. (2011). Multiple imputation by chained equations: What is it and how does it work? *International Journal of Methods in Psychiatric Research, 20*(1), 40–49. https://doi.org/10.1002/mpr.329

Baker, B. L., & Blacher, J. (2021). Behavior disorders and social skills in adolescents with intellectual disability: Does co-morbid autism matter? *Journal of Mental Health Research in Intellectual Disabilities, 14*(2), 174–188. https://doi.org/10.1080/19315864.2020.1871451

Bakker, B. F. M., Van Rooijen, J., & Van Toor, L. (2014). The system of social statistical datasets of Statistics Netherlands: An integral approach to the production of register-based social statistics. *Statistical Journal of the International Association for Official Statistics, 30*(4), 411–424. https://doi.org/10.3233/SJI-140803

Bailey, T., Totsika, V., Hastings, R. P., Hatton, C., & Emerson, E. (2019). Developmental trajectories of behavior problems and prosocial behaviors of children with intellectual disabilities in a population-based cohort. *Journal of Child Psychology and Psychiatry, 60*(11), 1210–1218. https://doi.org/10.1111/jcpp.13080

Beauchaine, T. P., Zisner, A. R., & Sauder, C. L. (2017). Trait impulsivity and the externalizing spectrum. *Annual Review of Clinical Psychology, 13,* 343–368. https://doi.org/10.1146/annurev-clinpsy-021815-093253

Bornheimer, L. A., Acri, M., Gopalan, G., & McKay, M. M. (2018). Barriers to service utilization and child mental health treatment attendance among poverty-affected families. *Psychiatric Services, 69*(10), 1101–1104. https://doi.org/10.1176/appi.ps.201700317

Centraal Bureau voor de Statistiek. (2024). *Landenindeling van de variabele herkomstland, 2022*. CBS Maatwerk. https://www.cbs.nl/nl-nl/maatwerk/2024/08/landenindeling-van-de-variabele-herkomstland-2022

Chadwick, O., Kusel, Y., & Cuddy, M. (2008). Factors associated with the risk of behavior problems in adolescents with severe intellectual disabilities. *Journal of Intellectual Disability Research, 52*(10), 864–876. https://doi.org/10.1111/j.1365-2788.2008.01102.x

Cosgrove, V. E., Rhee, S. H., Gelhorn, H. L., Boeldt, D., Corley, R. C., Ehringer, M. A., Young, S. E., & Hewitt, J. K. (2011). Structure and etiology of co-occurring internalizing and externalizing disorders in adolescents. *Journal of Abnormal Child Psychology, 39*(1), 109–123. https://doi.org/10.1007/s10802-010-9444-8

Dekker, M. C., & Koot, H. M. (2003). DSM-IV disorders in children with borderline to moderate intellectual disability. II: Child and family predictors. *Journal of the American Academy of Child & Adolescent Psychiatry, 42*(8), 923–931. https://doi.org/10.1097/01.CHI.0000046891.27264.C1

Einfeld, S. L., & Tonge, B. J. (2007). Population prevalence of psychopathology in children and adolescents with intellectual disability: I rationale and methods. *Journal of Intellectual Disability Research, 40*(2), 91–98. https://doi.org/10.1046/j.1365-2788.1996.767767.x

Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research, 47*(1), 51–58. https://doi.org/10.1046/j.1365-2788.2003.00464.x

Emerson, E. (2021). Social and environmental determinants of health among people with disabilities. In *Oxford research encyclopedia of global public health.* Oxford University Press. https://doi.org/10.1093/acrefore/9780190632366.013.325

Emerson, E., & Brigham, P. (2015). Exposure of children with developmental delay to social determinants of poor health: Cross-sectional case record review study. *Child: Care, Health and Development, 41*(2), 249–257. https://doi.org/10.1111/cch.12144

Emerson, E., Graham, H., McCulloch, A., Blacher, J., Hatton, C., & Llewellyn, G. (2009). The social context of parenting 3-year-old children with developmental delay in the UK. *Child: Care, Health and Development, 35*(1), 63–70. https://doi.org/10.1111/j.1365-2214.2008.00909.x

Emerson, E., & Hatton, C. (2007). Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. *American Journal on Mental Retardation, 112*(2), 140–150. https://doi.org/10.1352/0895-8017(2007)112[140:COSPTH]2.0.CO;2

Evans-Lacko, S., Font Gilabert, P., & Knapp, M. (2024). The double disadvantage faced by adolescents from low socioeconomic backgrounds with mental health problems affects earnings up to mid-life. *Social Science & Medicine, 362,*117385. https://doi.org/10.1016/j.socscimed.2024.117385

Fisher, R. A. (1925). *Statistical methods for research workers.* Oliver and Boyd.

Foley, K. R., Jacoby, P., Einfeld, S., et al. (2014). Day occupation is associated with psychopathology for adolescents and young adults with Down syndrome. *BMC Psychiatry, 14,* 266. https://doi.org/10.1186/s12888-014-0266-z

Giordano, G. N., & Lindström, M. (2016). Trust and health: Testing the reverse causality hypothesis. *Journal of Epidemiology & Community Health, 70*(1), 10–16. https://doi.org/10.1136/jech-2015-205822

Greenwood, P. E., & Nikulin, M. S. (1996). *A guide to chi-squared testing*. Wiley.

Hall, S. S., Burns, D. D., & Reiss, A. L. (2007). Modeling family dynamics in children with Fragile X syndrome. *Journal of Abnormal Child Psychology, 35*(1), 29–42. https://doi.org/10.1007/s10802-006-9081-4

Hatton, C., Emerson, E., Robertson, J., & Baines, S. (2018). The mental health of adolescents with and without mild/moderate intellectual disabilities in England: Secondary analysis of a longitudinal cohort study. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 768–777. https://doi.org/10.1111/jar.12428

Hendriks, A. M., Finkenauer, C., Nivard, M. G., et al. (2020). Comparing the genetic architecture of childhood behavioral problems across socioeconomic strata in the Netherlands and the United Kingdom. *European Child & Adolescent Psychiatry, 29*(3), 353–362. https://doi.org/10.1007/s00787-019-01357-x

Hodgkinson, S., Godoy, L., Beers, L. S., & Lewin, A. (2017). Improving mental health access for low-income children and families in the primary care setting. *Pediatrics, 139*(1), e20151175. https://doi.org/10.1542/peds.2015-1175

Kessler, R. C., McLaughlin, K. A., Green, J. G., et al. (2010). Childhood adversities and adult psychopathology in the WHO World Mental Health Surveys. *British Journal of Psychiatry, 197*(5), 378–385. https://doi.org/10.1192/bjp.bp.110.080499

Kist, J. M., Vos, H. M. M., Vos, R. C., et al. (2024). Data resource profile: Extramural Leiden University Medical Center Academic Network (ELAN). *International Journal of Epidemiology, 53*(4), dyae099. https://doi.org/10.1093/ije/dyae099

Koskentausta, T., Iivanainen, M., & Almqvist, F. (2007). Risk factors for psychiatric disturbance in children with intellectual disability. *Journal of Intellectual Disability Research, 51*(1), 43–53. https://doi.org/10.1111/j.1365-2788.2006.00871.x

Kotov, R., Krueger, R. F., Watson, D., Achenbach, T. M., Althoff, R. R., Bagby, R. M., Brown, T. A., Carpenter, W. T., Caspi, A., Clark, L. A., Eaton, N. R., Forbes, M. K., Forbush, K. T., Goldberg, D., Hasin, D., Hyman, S. E., Ivanova, M. Y., Lynam, D. R., Markon, K., … Zimmerman, M. (2017). The hierarchical taxonomy of psychopathology (HiTOP): A dimensional alternative to traditional nosologies. *Journal of Abnormal Psychology, 126*(4), 454–477 https://doi.org/10.1037/abn0000258

Kruskal, W. H., & Wallis, W. A. (1952). Use of ranks in one-criterion variance analysis. *Journal of the American Statistical Association, 47*(260), 583–621. https://doi.org/10.1080/01621459.1952.10483441

Loef, B., Meulman, I., Herber, G. C. M., et al. (2021). Socioeconomic differences in healthcare expenditure and utilization in the Netherlands. *BMC Health Services Research, 21*(1), 643. https://doi.org/10.1186/s12913-021-06694-9

Mathew, N. E., Burton, K. L. O., Schierbeek, A., Črnčec, R., Walter, A., & Eapen, V. (2019). Parenting preschoolers with autism: Socioeconomic influences on wellbeing and sense of competence. *World Journal of Psychiatry, 9*(2), 30–46. https://doi.org/10.5498/wjp.v9.i2.30

McCullagh, P., & Nelder, J. A. (1989). *Generalized linear models* (2nd ed.). Chapman and Hall. https://doi.org/10.1007/978-1-4899-3242-6

Nanninga, M., Jansen, D. E. M. C., Knorth, E. J., & Reijneveld, S. A. (2018). Enrollment of children in psychosocial care: Problems upon entry, care received, and outcomes achieved. *European Child & Adolescent Psychiatry, 27*(5), 625–635. https://doi.org/10.1007/s00787-017-1048-1

Nurius, P. S., Green, S., Logan-Greene, P., & Borja, S. (2015). Life course pathways of adverse childhood experiences toward adult psychological well-being: A stress process analysis. *Child Abuse & Neglect, 45,* 143–153. https://doi.org/10.1016/j.chiabu.2015.03.008

Paquin, V., Miconi, D., Aversa, S., et al. (2024). Social and mental health pathways to institutional trust: A cohort study. *bioRxiv.* https://doi.org/10.1101/2024.12.05.24318551

Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92–98. https://doi.org/10.1111/jppi.12072

Pevalin, D. J., Reeves, A., Baker, E., & Bentley, R. (2017). The impact of persistent poor housing conditions on mental health: A longitudinal population-based study. *Preventive Medicine, 105,* 304–310. https://doi.org/10.1016/j.ypmed.2017.09.020

Pouls, K. P. M., Cuypers, M., Mastebroek, M., et al. (2023). Mental healthcare for adults with mild intellectual disabilities: Population-based database study in Dutch mental health services. *BJPsych Open, 9*(2), e48. https://doi.org/10.1192/bjo.2023.31

R Core Team. (2021). *R: A language and environment for statistical computing.* R Foundation for Statistical Computing. https://www.R-project.org

Reiss, F. (2013). Socioeconomic inequalities and mental health problems in children and adolescents: A systematic review. *Social Science & Medicine, 90,* 24–31. https://doi.org/10.1016/j.socscimed.2013.04.026

Reiss, F., Meyrose, A. K., Otto, C., Lampert, T., Klasen, F., & Ravens-Sieberer, U. (2019). Socioeconomic status, stressful life situations and mental health problems in children and adolescents: Results of the German BELLA cohort-study. *PLOS ONE, 14*(3), e0213700. https://doi.org/10.1371/journal.pone.0213700

Scambler, D. J., Hepburn, S. L., Hagerman, R. J., & Rogers, S. J. (2007). A preliminary study of screening for risk of autism in children with Fragile X syndrome: Testing two risk cut-offs for the Checklist for Autism in Toddlers. *Journal of Intellectual Disability Research, 51*(4), 269–276. https://doi.org/10.1111/j.1365-2788.2006.00874.x

Schilling, E. A., Aseltine, R. H., & Gore, S. (2008). The impact of cumulative childhood adversity on young adult mental health: Measures, models, and interpretations. *Social Science & Medicine, 66*(5), 1140–1151. https://doi.org/10.1016/j.socscimed.2007.11.023

Smith, L. E., Hong, J., Greenberg, J. S., & Mailick, M. R. (2016). Change in the behavioral phenotype of adolescents and adults with FXS: Role of the family environment. *Journal of Autism and Developmental Disorders, 46*(5), 1824–1833. https://doi.org/10.1007/s10803-016-2714-8

Statistics Netherlands (CBS). (2024). *User's guide educational information.* https://www.cbs.nl/en-gb/our-services/customised-services-microdata/microdata-conducting-your-own-research/microdata-catalogue/education

Stewart, S. L., Dave, H. P., & Lapshina, N. (2023). Family dynamics, trauma, and child-related characteristics: Examining factors associated with co-occurring mental health problems in clinically-referred children with and without an intellectual (and developmental) disability. *Journal of Intellectual Disabilities, 27*(3), 701–714. https://doi.org/10.1177/17446295221093967

Storm, M. M. C., Giltay, E. J., Eldik, W. M., et al. (2025). Social determinants of youth with mild intellectual disability in outpatient care for mental health disorders: A case-control study. *European Child & Adolescent Psychiatry.* https://doi.org/10.1007/s00787-025-02718-5

Stronks, K., Kulu-Glasgow, I., & Agyemang, C. (2009). The utility of "country of birth" for the classification of ethnic groups in health research: The Dutch experience. *Ethnicity & Health, 14*(3), 255–269. https://doi.org/10.1080/13557850802509206

Tordjman, S., Somogyi, E, Coulon, N., et al. (2014). Gene x environment interactions in autism spectrum disorders: Role of epigenetic mechanisms. *Frontiers in Psychiatry, 5,* 53. https://doi.org/10.3389/fpsyt.2014.00053

Totsika, V., Hastings, R. P., Emerson, E., & Hatton, C. (2020). Early years parenting mediates early adversity effects on problem behaviors in intellectual disability. *Child Development, 91*(3), e608–e624. https://doi.org/10.1111/cdev.13273

Van Der Draai, D. A., Van Duijn, E., De Beurs, D. P., Bexkens, A., & Beekman, A. T. F. (2021). Factors of specialized mental health care use in the Netherlands: A scoping review applying Andersen-Newman's care utilization model. *Health Services Insights, 14,* 11786329211048134 https://doi.org/10.1177/11786329211048134

Wallander, J. L., Dekker, M. C., & Koot, H. M. (2006). Risk factors for psychopathology in children with intellectual disability: A prospective longitudinal population-based study. *Journal of Intellectual Disability Research, 50*(4), 259–268. https://doi.org/10.1111/j.1365-2788.2005.00792.x

Wei, H., Zhu, Y., Wang, T., Zhang, X., Zhang, K., & Zhang, Z. (2021). Genetic risk factors for autism-spectrum disorders: A systematic review based on systematic reviews and meta-analysis. *Journal of Neural Transmission, 128*(6), 717–734. https://doi.org/10.1007/s00702-021-02360-w

Weiss, J. A., Ting, V., & Perry, A. (2016). Psychosocial correlates of psychiatric diagnoses and maladaptive behavior in youth with severe developmental disability. *Journal of Intellectual Disability Research, 60*(6), 583–593. https://doi.org/10.1111/jir.12278

Appendix A. Socio-economic characteristics of the case group stratified by sex

	MID-BIF+MHP *N (%)* *N = 1,742*	**Boy** **N = 1,166**	**Girl** **N = 576**	**Univariate OR (95% C.I.)**	**p-value**
Child demographics					
Age* (years)	1,742 (100)	9.0 (4.0)	10.8 (4.1)	1.59 (1.43; 1.76)	*p*<.001
Child's country of birth:	1,742 (100)	-	-	-	-
- Western	-	1,098 (94.2)	544 (94.4)	1 (Ref.)	-
- Non-Western	-	68 (5.8)	32 (5.6)	0.99 (0.89; 1.09)	*p*=.82
Social characteristics					
Number of children* (in household)	1,734 (99.5)	2.1 (1.17)	1.99 (1.06)	0.87 (0.79, 0.97)	*p*=.009
Family type*:	1,722 (98.9)	-	-	-	-
- Dual parent household	-	648 (56.2)	341 (59.9)	1 (Ref.)	-
- Single parent household	-	449 (38.9)	195 (34.3)	0.91 (0.82; 1.01)	*p*=.08
- Institutional household/other	-	56 (4.9)	33 (5.8)	1.02 (0.93, 1.13)	*p*=.62
Education level mother:	1,301 (74.7)	-	-	-	-
- High	-	111 (12.7)	63 (14.8)	1 (Ref.)	-
- Moderate	-	322 (36.8)	151 (35.4)	0.91 (0.77; 1.09)	*p*=.30
- Low	-	442 (50.5)	212 (49.8)	0.92 (0.77; 1.10)	*p*=.35
Education level father:	926 (53.2)	-	-	-	-
- High	-	112 (17.8)	60 (20.3)	1 (Ref.)	-
- Moderate	-	238 (37.8)	98 (33.1)	0.88 (0.73; 1.06)	*p*=.19
- Low	-	280 (44.4)	138 (46.6)	0.96 (0.80; 1.16)	*p*=.66
Economic circumstances					
Household income* (in percentiles)	1,628 (93.5)	30.0 (24.1)	33.0 (25.3)	0.89 (0.80; 0.98)	*p=.02*
Household Income Source*	1,635 (93.9)	-	-	-	-
- Income	-	675 (61.6)	354 (65.7)	1 (Ref.)	-
- Benefits	-	421 (38.4)	185 (34.3)	0.92 (0.83; 1.02)	*p*=.11
Benefit dependency of households*	1,314 (75.4)	17.8 (25.0)	16.8 (25.4)	0.96 (0.86; 1.08)	*p*=.51
Main benefit of private households*	1,628 (93.5)	-	-	-	-
- No benefit	-	466 (42.7)	253 (47.1)	1 (Ref.)	-
- Unemployment benefit	-	96 (8.8)	45 (8.4)	0.96 (0.68; 1.07)	*p*=.46
- Disability benefit	-	136 (12.5)	81 (15.1)	1.03 (0.93; 1.15)	*p*=.56
- Welfare benefit	-	319 (29.2)	124 (23.1)	0.86 (0.77; 0.97)	*p*=.01
- Benefit from other social provisions	-	74 (6.8)	34 (6.3)	0.96 (0.68; 1.07)	*p*=.45
Household Home Ownership*	1,642 (94.3)	-	-	-	-
- Owner-occupied	-	352 (32.0)	212 (39.2)	1 (Ref.)	-
- Rented without housing allowance	-	250 (22.7)	121 (22.4)	0.91 (0.81; 1.02)	*p*=.12
- Rented with housing allowance	-	499 (45.3)	208 (38.4)	0.83 (0.74; 0.94)	*p*=.002

*Note. *at the year of treatment onset for the case group. MID-BIF = mild intellectual disability; MHP = mental health problems, GP = general population; N = total number of observations for each variable without missing. For continuous variables, the mean and SD are provided (SD in brackets). For categorical variables, the N and percentages are given. Percentages in parentheses are calculated based on the non-missing (valid) N.*

Appendix B. Socio-economic characteristics of the case group stratified by age

	MID-BIF+MHP N (%) N = 1,742	**< 12 years old N = 1,133**	**12 years and older N = 609**	**Univariate OR (95% C.I.)**	**p-value**
Child demographics					
Sex:	1,742 (100)	-	-	-	-
- Boy	-	840 (74.1)	326 (53.5)	1 (Ref.)	-
- Girl	-	293 (25.9)	283 (46.5)	1.54 (1.39; 1.69)	p<.001
Age* (years)	1,742 (100)	7.04 (2.60)	14.3 (1.72)	-	-
Child's country of birth:	1,742 (100)	-	-	-	-
- Western	-	1,075 (94.9)	567 (93.1)	1 (Ref.)	-
- Non-Western	-	58 (5.1)	42 (6.9)	1.08 (0.98; 1.18)	*p*=.13
Family characteristics					
Number of children* (in household)	1,734 (99.5)	2.1 (1.12)	2.1 (1.17)	0.94 (0.85; 1.04)	*p*=.26
Family type*:	1,722 (98.9)	-	-	-	-
- Dual parent household	-	676 (60.0)	313 (52.5)	1 (Ref.)	-
- Single parent household	-	407 (36.1)	237 (39.8)	1.12 (1.01; 1.24)	*p*=.03
- Institutional household/other	-	43 (3.8)	46 (7.7)	1.20 (1.09, 1.33)	*p*<.001
Education level mother:	1,301 (74.7)	-	-	-	-
- High	-	125 (14.4)	49 (11.4)	1 (Ref.)	-
- Moderate	-	323 (37.1)	150 (34.8)	1.18 (0.99; 1.42)	*p*=.07
- Low	-	422 (48.5)	232 (53.8)	1.08 (0.90; 1.30)	*p*=.39
Education level father:	926 (53.2)	-	-	-	-
- High	-	122 (18.9)	50 (17.8)	1 (Ref.)	-
- Moderate	-	242 (37.5)	94 (33.5)	1.09 (0.90; 1.32)	*p*=.38
- Low	-	281 (43.6)	137 (48.8)	0.96 (0.80; 1.18)	*p*=.80
Economic circumstances					
Household income* (in percentiles)	1,628 (93.5)	29.8 (24.0)	33.4 (25.4)	0.87 (0.78; 0.96)	*p=.005*
Household Income Source*	1,635 (93.9)	-	-	-	-
- Income	-	682 (63.6)	347 (61.6)	1 (Ref.)	-
- Benefits	-	390 (36.4)	216 (38.4)	1.04 (0.94; 1.15)	*p*=.43
Benefit dependency of households*	1,314 (75.4)	17.7 (25.3)	17.0 (25.0)	0.97 (0.87; 1.09)	*p*=.61
Main benefit of private households*	1,628 (93.5)	-	-	-	-
- No benefit	-	467 (43.7)	252 (45.0)	1 (Ref.)	-
- Unemployment benefit	-	90 (8.4)	51 (9.1)	1.01 (0.91; 1.13)	*p*=.80
- Disability benefit	-	129 (12.1)	88 (15.7)	1.08 (0.97; 1.20)	*p*=.14
- Welfare benefit	-	302 (28.3)	141 (25.2)	0.94 (0.84; 1.05)	*p*=.26
- Benefit from other social provisions	-	80 (7.5)	28 (5.0)	0.90 (0.80; 1.01)	*p*=.06
Household Home Ownership*	1,642 (94.3)	-	-	-	-
- Owner-occupied	-	375 (34.9)	189 (33.4)	1 (Ref.)	-
- Rented without housing allowance	-	232 (21.6)	139 (24.6)	1.08 (0.96; 1.21)	*p*=.22
- Rented with housing allowance	-	469 (43.4)	238 (42.0)	1.00 (0.89; 1.13)	*p*=.95

*Note. *at the year of treatment onset for the case group. MID-BIF = mild intellectual disability; MHP = mental health problems, GP = general population; NL = The Netherlands; EU = Europe. N = total number of observations for each variable without missing. For continuous variables, the mean and SD are provided (SD in brackets). For categorical variables, the N and percentages are given. Percentages in parentheses are calculated based on the non-missing (valid) N.*

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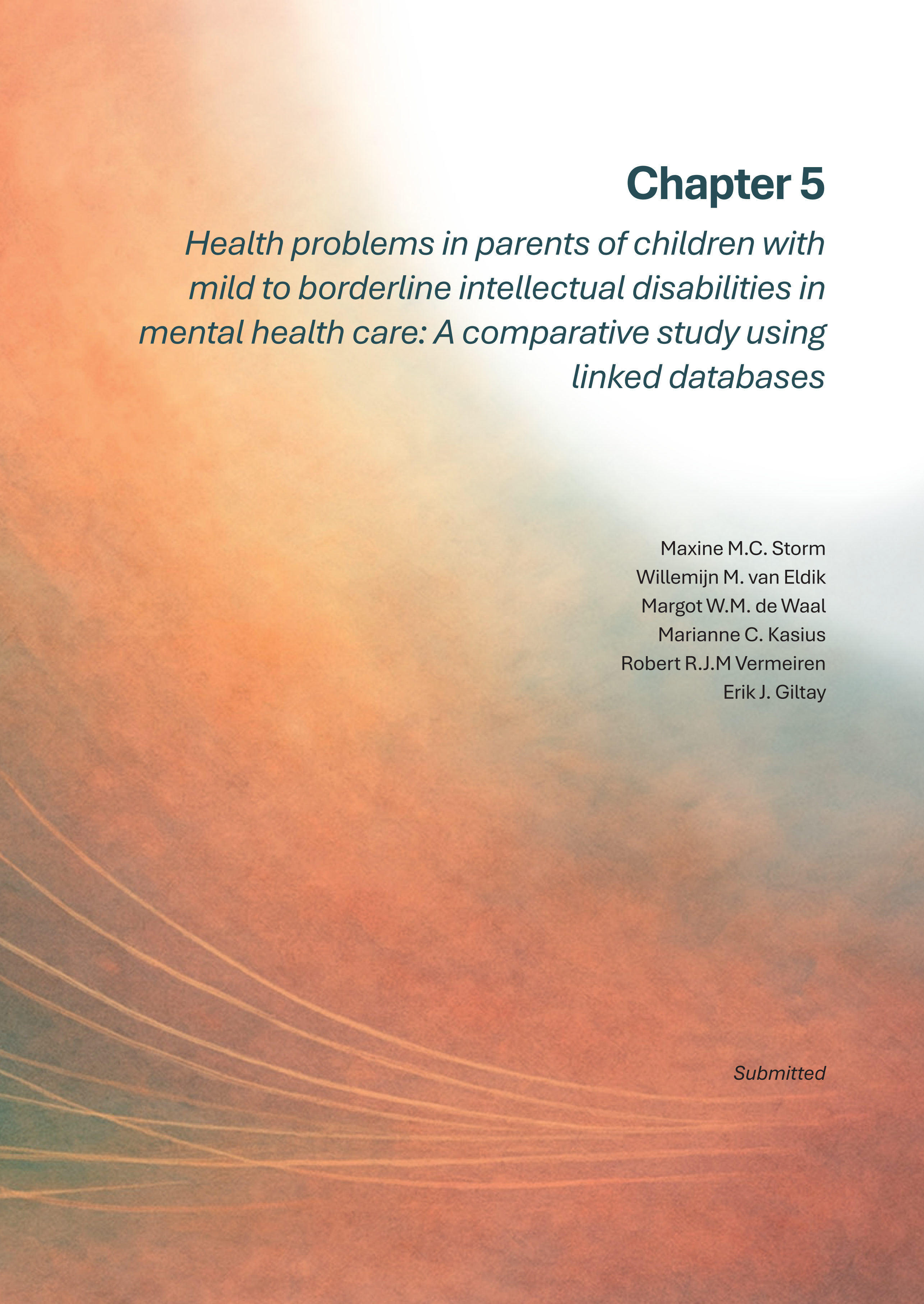

Chapter 5

Health problems in parents of children with mild to borderline intellectual disabilities in mental health care: A comparative study using linked databases

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Submitted

Abstract

Background: Little is known about health problems of parents whose children have mild intellectual disability or borderline intellectual functioning (MID-BIF) and mental health problems.

Objective: To quantify the presence and diversity of health problems among parents of children with MID-BIF and mental health problems.

Methods: This cross-sectional study uses linked data from Statistics Netherlands, mental health care providers, and general practices (GP). Parents were classified as group A ($n_{mothers}$=565, $n_{fathers}$=436; child with MID-BIF and mental health problems), group B ($n_{mothers}$=3,830, $n_{fathers}$=3,137; child with mental health problems only), or group C ($n_{mothers}$ =7,938, $n_{fathers}$=6,552; general population). GP-reported ICPC-1 codes quantified health problems across body sytems, into 1) presence of health problems, i.e., having at least one problem in a system, and 2) diversity, i.e., counting the number of systems with at least one problem. Analyses were adjusted for parental age and GP registration duration.

Results: Both groups A and B had a significantly higher presence of health problems than group C in several body systems. The largest group A differences were found in the endocrine/metabolic/nutritional, psychological, and digestive tracts, with ORs of 1.50–1.85 for mothers and 1.27–1.52 for fathers. Few group differences between A and B were significant. Both groups A and B had health problems in significantly more body systems than group C, indicating greater diversity.

Conclusions: Parents of children with mental health problems–regardless of MID-BIF–experience a higher presence and diversity of health problems than those whose children have no mental health problems, underscoring the need for integrated family care.

Introduction

Children with mild intellectual disability to borderline intellectual functioning (MID-BIF) have an increased risk of developing mental health problems (Bailey et al., 2019; Einfeld et al., 2011; Emerson, 2003). A growing body of research highlighted a bidirectional relationship between child mental health and parental well-being (Baker & Blacher, 2021; Gallagher & Whiteley, 2013), shaped by factors such as the demands of caregiving, shared environmental (socioeconomic) stressors, and shared genetic predispositions. Emerging evidence suggests that parents of children with intellectual disabilities (ID), across all severity levels, tend to have poorer physical and mental health (Chandravanshi et al., 2017; Staunton et al., 2020; Zhou et al., 2022). However, no studies have examined the health of parents of children with MID-BIF and mental health problems specifically. Importantly, unaddressed parental health problems are likely to exacerbate the child's mental health, reinforcing a cycle of intergenerational vulnerability (Campbell et al., 2021; Condon et al., 2020). Understanding the full scope of somatic and mental health problems among these parents could highlight unique health disparities within these families. This understanding may inform more integrated, family-oriented mental healthcare and facilitate early recognition.

More generally, parents of children with ID or mental health problems are known to experience high levels of psychological and physical health problems. Mental illness was significantly more common among parents of children with average intelligence in mental health services than in the general population (Campbell et al., 2021). A scoping review reported prevalence rates ranging from 16% to 79%, with higher estimates for mothers than for fathers. Additionally, elevated symptoms of depression and anxiety were consistently reported among parents of children with ID in the few available studies, particularly mothers and those whose child has additional mental health problems (Chandravanshi et al., 2017; Sharma et al., 2021; Tak et al., 2018). These findings suggested that the caregiving context may contribute to parental distress, especially when complicated by child cognitive challenges and mental health problems. Beyond psychological problems, parents also showed higher rates of somatic symptoms, fatigue, and sleep disturbances. Yet, these have received less empirical attention, despite their known bidirectional relationship with psychological distress as emphasized in the biopsychosocial model (Engel, 1977; Jansen et al., 2022). One recent qualitative study highlighted broad mental and physical health burdens among parents of children with ID, including cumulative stress and exhaustion affecting daily life (Barratt et al., 2025). However, no studies have quantified the relative extent to which these problems occur and span multiple body systems (Arnold & McPherson, 2024).

Parents of children with MID-BIF may face distinct challenges, as suggested by a few studies (Dekker & Koot, 2003b; Embregts et al., 2010; Fenning et al., 2007; Kleefman et al., 2015; Riemersma et al., 2022). Unlike the more visible needs of children with severe ID, those of children with MID-BIF are often less apparent, involving more subtle cognitive difficulties (Kok et al., 2016; Nouwens et al., 2017; Snell et al., 2009). Nevertheless, children in this group also frequently experience emotional and behavioral problems (Dekker & Koot, 2003b), with studies estimating clinical levels up to 50% of cases (Dekker & Koot, 2003a; Kok et al., 2016). These child-related characteristics may be linked to increased parental stress (Kok et al., 2016), although empirical evidence on this connection remains limited. One study found that parents of children with MID and behavioral problems reported higher stress levels, lower perceived parenting competence, greater social isolation, and more dissatisfaction in relationships compared to parents of children with MID without such problems (Embregts et al., 2010). These difficulties were associated with increased vulnerability to psychological, as well as some somatic problems, although evidence for somatic conditions remains limited. Focusing on the children themselves, studies have shown that those with MID who also have a parent with mental health problems reported higher levels of social-emotional problems than children facing only one of these risk factors (Riemersma et al., 2022). Taken together, these findings point to a pattern of heightened, mutually reinforcing both somatic and psychological vulnerabilities in both these parents and children.

Guided by previous research, the overall aim of this study is to quantify and compare health problems of parents across three distinct groups: (1) parents of children with MID-BIF and mental health problems, (2) parents of children with mental health problems without MID-BIF, and (3) matched parents from the general population. We compared these groups in terms of the presence (i.e., any recorded health problem in a body system) and diversity (i.e., number of body systems with a problem) of somatic and mental health problems, using body systems from the International Classification of Primary Care (ICPC-1; Lamberts

& Hofmans-Okkes, 1996). We hypothesize that parents of children with MID-BIF and mental health problems experience both a higher presence and greater diversity of health problems, particularly mental health problems, compared to other parent groups. Our descriptive approach provides an empirical foundation for future research, as this is the first study to examine parental health differences in this population using general practice data.

Method

Sources of data

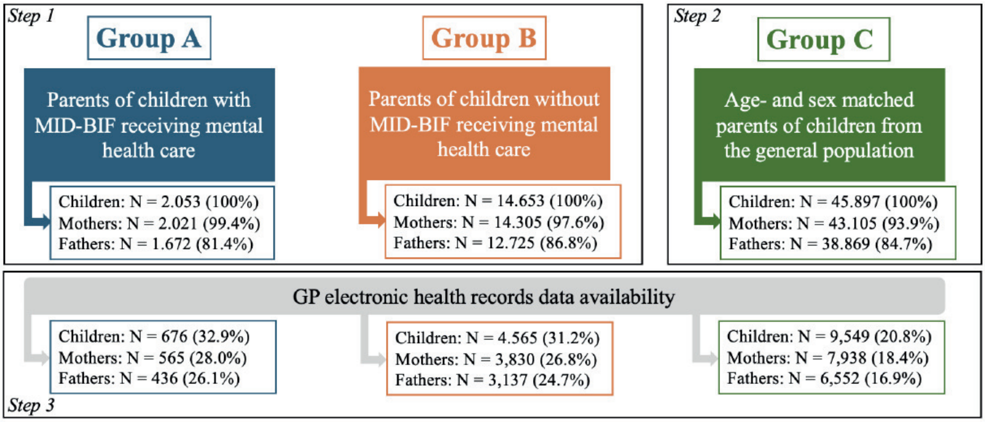
This study utilized data from the Extramural LUMC Academic Network, a regional population-based data infrastructure (Ardesch et al., 2023; Kist et al., 2024). Three data sources were analyzed: (1) non-public microdata from Statistics Netherlands (SN; results based on calculations by LUMC-Curium in project number 9269; Bakker et al., 2014); (2) patient records from multiple outpatient mental health centers for children with mental health problems; and (3) routinely collected GP electronic health records from ELAN-affiliated practices, covering a regional subset of practices.

The SN microdata provided unique identifiers (record identification numbers, RINs), demographic variables, and parent–child linkages. Mental health patient records included age, sex, and mental health service registration dates, as well as diagnostic information. GP electronic health records contained information on health problems and care episodes.

Populations

The study population consisted of parents of children aged 17 or younger, divided into three groups. Group A included parents of children with MID-BIF (IQ 55–85 or similar functioning) who received outpatient mental health care between 2011 and 2020 at a specialized facility in the Hague. The children in this group had a mean age of 9.6 years (*SD* = 4.2, 63.8% male). Group B included parents of children with mental health problems without MID-BIF (M_{age} = 11.0, *SD* = 4.5, 54.8% male), identified through general child mental health centers. Group C served as a population-based reference group, matched on sex and approximately on age (±1 year) to children in groups A and B combined (M_{age} = 10.3, *SD* = 4.9, 55.6% male). Although the aim was to select three reference individuals per child in groups A and B, the final number was slightly lower due to a limited matching pool. After identifying children in groups A and B, matched children for group C were selected (see Figure 1 for flow chart). All parents in all three groups resided in The Hague or its surroundings.

Figure 1. Sampling flowchart



Ethical approval and data linkage

This study was exempted from review by the Medical Ethics Committee of Leiden-The Hague-Delft (CEP number: N22.048). For both mental health and GP data, information was securely stored and pseudonymized for researchers, with individuals given an opt-out option for data use. Confidential data linkage was performed using pseudonymized RINs. SN staff reviewed outputs to prevent identification risks. Further details on data linkage are available elsewhere (Ardesch et al., 2023).

Variables

Outpatient mental health care registration was used as a proxy to identify children with mental health problems. Parental demographic variables included age, birth country, family type (based on household composition at the parent's registered residential address), and household income in percentiles (see Table 1). Demographic characteristics were measured at the start of the child's treatment; for group C, values correspond to the matched child's reference year. Covariates were parental age and GP registration duration. Parental health problems were derived from their GP records coded using ICPC-1, which allows to group conditions into body system-based tracts to distinguish types of psychological and somatic problems (Lamberts & Hofmans-Okkes, 1996).

Of these, 16 tracts are relevant to females and 15 to males. Each tract, denoted by a letter (A to X or Y), covers a specific body system and includes codes for symptoms, complaints, and diagnoses commonly seen in primary care. Each ICPC chapter distinguishes between symptoms or complaints (codes 01–29) and formally diagnosed conditions (codes 70–99; Magnée et al., 2017; Pouls et al., 2023). For example, code P01 refers to “feeling anxious/nervous/tense”, whereas P76 denotes “depression”. In this study, we focused exclusively on codes 70 and above, as these reflect diagnosed somatic or mental health conditions. These codes were extracted from each parent’s episode list, reflecting all recorded diagnoses available during their period of registration. Tract Z (social problems) was excluded, leaving 15 tracts for females and 14 for males. Within these tracts, seven ICPC codes rated as non-problematic (score = 0) on the Cumulative Illness Rating Scale (CIRS; Linn et al., 1968) were excluded (e.g., A97 no disease, W78 confirmed pregnancy). To assess presence, we recorded whether each parent had at least one reported health problem within each tract. To assess health problem diversity, we added the number of tracts with at least one documented health problem per parent. A detailed overview of the ICPC tracts is provided in Appendix A.

Statistical analysis

Descriptive statistics were computed for parental age and the number of ICPC tracts per parent. Central to both analyses was the comparison among the three parent groups (see Figure 1).

In the first analysis, we examined the presence of health problems within each ICPC tract. Separate logistic regression models were conducted for mothers and fathers to estimate the odds of having at least one health problem in each tract across the three parent groups, adjusting for parental age and GP registration duration. Odds ratios (ORs) with 95% confidence intervals (CIs) were calculated for each ICPC tract, with OR > 1 indicating greater odds relative to the reference group.

In the second analysis, we assessed the number of ICPC tracts with at least one problem per parent separately for mothers and fathers and tested group differences using negative binomial regression, adjusting for parental age and GP registration duration. This model estimated incidence rate ratios (IRRs) and accounted for overdispersion in the count data.

Missing data (7.5% for GP registration duration) were handled using multiple imputation by chained equations under a missing-at-random assumption.
For ICPC codes, the absence of a recorded diagnosis was interpreted as the absence of that condition. Analyses were conducted in RStudio (R v4.2.3; R Core Team, 2021) using *mice* for imputation and *stats* for generalized linear models. Logistic regressions were fitted with *glm*, and odds ratios (ORs), 95% confidence intervals, and p-values were reported ($\alpha = .05$).

Results

Study population

The study included 22,458 parents, 12,333 mothers and 10,125 fathers of 14,790 children ($M_{age} = 10.4$, $SD = 4.8$) registered with participating GPs (see Figure 1). Fathers were generally older than mothers at the year of mental health treatment onset of their child in groups A and B. Parents in group B were slightly older than those in group A. On average, parents were registered with their GP for approximately 9.6 years (SD ≈ 6.0), with somewhat shorter durations observed in group C. Descriptive statistics are presented in Table 1.

Table 1. Parental characteristics at the time of child's mental health care onset

	Mothers			**Fathers**		
	Group A	*Group B*	*Group C*	*Group A*	*Group B*	*Group C*
N	565	3,830	7,938	436	3,137	6,552
Mean (and *SD*) age* in years	39.4 (7.1)	40.9 (7.4)	39.1 (7.3)	43.9 (8.4)	44.5 (8.2)	42.7 (7.9)
Mean (and *SD*) years registered with GP	9.65 (5.96)	9.92 (5.95)	8.28 (5.74)	10.23 (6.01)	10.08 (6.15)	8.69 (5.96)
Birth country (N, %)						
- The Netherlands	327 (57.9%)	2,344 (61.2%)	4,438 (55.9%)	246 (56.4%)	1,998 (63.7%)	3,869 (59.1%)
- Other European country	34 (6.0%)	263 (6.9%)	945 (11.9%)	13 (3.0%)	153 (4.9%)	641 (9.8%)
- Non-European country	204 (36.1%)	1223 (31.9%)	2,555 (32.2%)	177 (40.6%)	986 (31.4%)	2,042 (31.2%)
Family type* (N, %)						
- Dual parent household	329 (58.2%)	2,267 (59.2%)	4,585 (57.8%)	318 (72.9%)	2,155 (68.7%)	4,174 (63.7%)
- Single parents household	204 (36.1%)	1,377 (36.0%)	2,708 (34.1%)	27 (6.2%)	216 (6.9%)	661 (10.1%)
- Other	32 (5.7%)	186 (4.9%)	645 (8.1%)	91 (20.9%)	766 (24.4%)	1,717 (26.2%)
Mean (and *SD*) household income* (in percentiles)	31.61 (23.95)	41.57 (28.30)	44.64 (30.83)	39.41 (26.74)	50.36 (28.67)	54.75 (30.76)

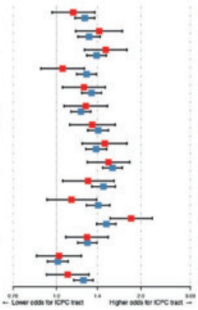
Note. *For groups A and B, values reflect the parental situation in the year the child started treatment; for group C, the matched child's year was used.*

Presence of health problems per tract

Mothers

Figure 2 shows the proportion of mothers with at least one health problem per ICPC tract and corresponding ORs (groups A and B vs. reference), adjusted for age and GP registration duration. Both mothers of children with MID-BIF and mental health problems (group A) and those of children with mental health problems only (group B) had significantly higher odds of having at least one recorded health problem in several ICPC tracts. Higher odds were observed in 10 of 15 tracts for group A, and in 14 of 15 tracts for group B. The largest differences relative to the reference group were observed in the endocrine/metabolic/nutritional tract (T), with adjusted ORs of 1.85 for group A and 1.51 for group B; the psychological tract (P), with ORs of 1.53 (group A) and 1.58 (group B); and the digestive tract (D), with ORs of 1.50 (group A) and 1.39 (group B). Groups A and B differed significantly in the eye (F) and skin (S) tracts, with higher odds in group B, and in the endocrine/metabolic/nutritional tract (T), where group A showed higher odds.

Figure 2. Comparison of health problems among mother groups



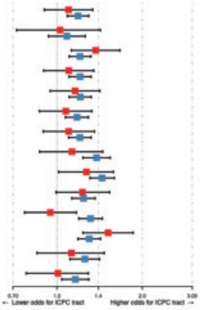
ICPC tract	Group A	Reference group	ORs (95% CI)	p–value	Group B	ORs (95% CI)	p–value
A: General and unspecified	333/ 565 (58.9%)	4322/ 7938 (54.4%)	1.15 (0.96–1.37)	p=0.12	2359/ 3830 (61.6%)	1.26 (1.17–1.37)	p<0.001
B: Blood/blood organs	160/ 565 (28.3%)	1678/ 7938 (21.1%)	1.42 (1.17–1.72)	p<0.001	1028/ 3830 (26.8%)	1.31 (1.19–1.43)	p<0.001
D: Digestive	300/ 565 (53.1%)	3282/ 7938 (41.3%)	1.50 (1.26–1.78)	p<0.001	1967/ 3830 (51.4%)	1.39 (1.28–1.50)	p<0.001
F: Eye	217/ 565 (38.4%)*	2826/ 7938 (35.6%)	1.05 (0.88–1.26)	p=0.58	1677/ 3830 (43.8%)*	1.28 (1.18–1.39)	p<0.001
H: Ear	253/ 565 (44.8%)	2961/ 7938 (37.3%)	1.25 (1.05–1.49)	p=0.01	1802/ 3830 (47.0%)	1.33 (1.23–1.45)	p<0.001
K: Cardiovascular	242/ 565 (42.8%)	2822/ 7938 (35.6%)	1.27 (1.06–1.52)	p=0.008	1675/ 3830 (43.7%)	1.22 (1.13–1.33)	p<0.001
L: Musculoskeletal	375/ 565 (66.4%)	4555/ 7938 (57.4%)	1.34 (1.11–1.62)	p=0.002	2641/ 3830 (69.0%)	1.41 (1.29–1.53)	p<0.001
N: Neurological	191/ 565 (33.8%)	1953/ 7938 (24.6%)	1.49 (1.24–1.78)	p<0.001	1264/ 3830 (33.0%)	1.39 (1.27–1.51)	p<0.001
P: Psychological	260/ 565 (46.0%)	2721/ 7938 (34.3%)	1.53 (1.29–1.82)	p<0.001	1790/ 3830 (46.7%)	1.58 (1.46–1.72)	p<0.001
R: Respiratory	441/ 565 (78.1%)	5630/ 7938 (70.9%)	1.30 (1.05–1.61)	p=0.02	3073/ 3830 (80.2%)	1.47 (1.34–1.62)	p<0.001
S: Skin	427/ 565 (75.6%)*	5623/ 7938 (70.8%)	1.13 (0.92–1.39)	p=0.24	3045/ 3830 (79.5%)*	1.41 (1.28–1.55)	p<0.001
T: Endocrine, metabolic, nutritional	313/ 565 (55.4%)*	3131/ 7938 (39.4%)	1.85 (1.55–2.20)	p<0.001	1963/ 3830 (51.3%)*	1.51 (1.39–1.63)	p<0.001
U: Urological	287/ 565 (50.8%)	3386/ 7938 (42.7%)	1.28 (1.08–1.53)	p=0.005	1935/ 3830 (50.5%)	1.29 (1.19–1.40)	p<0.001
W: Pregnancy, family planning	261/ 565 (46.2%)	3487/ 7938 (43.9%)	1.02 (0.85–1.23)	p=0.83	1631/ 3830 (42.6%)	1.01 (0.93–1.10)	p=0.81
X: Female genital	287/ 565 (50.8%)	3688/ 7938 (46.5%)	1.10 (0.92–1.30)	p=0.30	2052/ 3830 (53.6%)	1.25 (1.15–1.35)	p<0.001

*Note. Group A = Mothers of children with MID-BIF and mental health problems; Group B = Mothers of children with mental health problems without MID-BIF; Reference group = Mothers of children from the general population. ORs reflect the odds of having ≥1 health problem per ICPC tract (vs. reference), adjusted for maternal age and GP registration duration. Red boxes = group A vs. reference; Blue boxes = group B vs. reference; * = significant group A vs. B difference.*

Fathers

Figure 3 shows the proportions of fathers with at least one health problem per ICPC tract and ORs (groups A and B vs. reference), adjusted for age and GP registration duration. A similar but less pronounced pattern than among mothers was observed. Compared to fathers in the reference group, significantly higher odds were found in 3 of 14 tracts for group A and in 13 of 14 tracts for group B. The largest differences were again observed in the endocrine/metabolic/nutritional tract (T), with adjusted ORs of 1.52 for group A and 1.30 for group B; the digestive tract (D), with ORs of 1.37 and 1.21, respectively; and the psychological tract (P), with ORs of 1.27 and 1.44. A significant difference between groups A and B was found only in the skin tract (S), with higher odds in group B.

Figure 3. Comparison of health problems among father groups



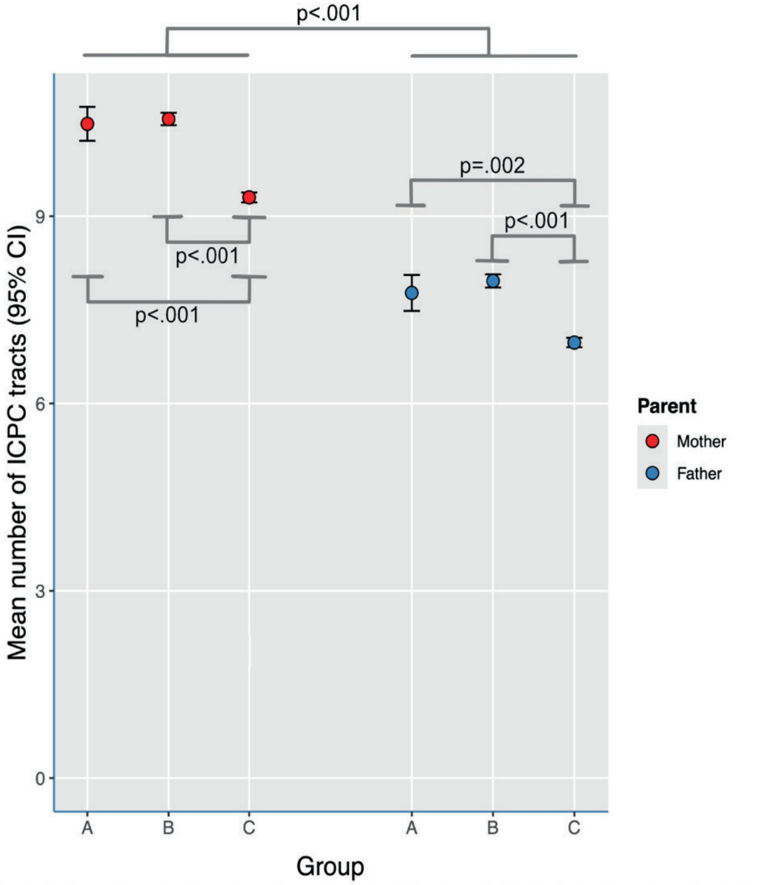
ICPC tract	Group A	Reference group	ORs (95% CI)	p–value	Group B	ORs (95% CI)	p–value
A: General and unspecified	199/ 436 (45.6%)	2743/ 6552 (41.9%)	1.10 (0.90–1.34)	p=0.34	1493/ 3137 (47.6%)	1.19 (1.09–1.29)	p<0.001
B: Blood/blood organs	40/ 436 (9.2%)	543/ 6552 (8.3%)	1.03 (0.72–1.42)	p=0.88	305/ 3137 (9.7%)	1.08 (0.93–1.26)	p=0.29
D: Digestive	201/ 436 (46.1%)	2397/ 6552 (36.6%)	1.37 (1.12–1.67)	p=0.002	1340/ 3137 (42.7%)	1.21 (1.10–1.32)	p<0.001
F: Eye	168/ 436 (38.5%)	2225/ 6552 (34.0%)	1.10 (0.90–1.35)	p=0.35	1268/ 3137 (40.4%)	1.21 (1.10–1.32)	p<0.001
H: Ear	175/ 436 (40.1%)	2260/ 6552 (34.5%)	1.16 (0.95–1.42)	p=0.15	1288/ 3137 (41.1%)	1.21 (1.11–1.32)	p<0.001
K: Cardiovascular	152/ 436 (34.9%)	2008/ 6552 (30.6%)	1.07 (0.87–1.33)	p=0.51	1179/ 3137 (37.6%)	1.18 (1.07–1.29)	p=0.001
L: Musculoskeletal	280/ 436 (64.2%)	3852/ 6552 (58.8%)	1.10 (0.89–1.36)	p=0.37	2070/ 3137 (66.0%)	1.20 (1.10–1.32)	p<0.001
N: Neurological	78/ 436 (17.9%)	987/ 6552 (15.1%)	1.13 (0.87–1.45)	p=0.35	661/ 3137 (21.1%)	1.38 (1.23–1.54)	p<0.001
P: Psychological	116/ 436 (26.6%)	1378/ 6552 (21.0%)	1.27 (1.01–1.58)	p=0.03	914/ 3137 (29.1%)	1.44 (1.31–1.59)	p<0.001
R: Respiratory	309/ 436 (70.9%)	4194/ 6552 (64.0%)	1.23 (0.99–1.53)	p=0.06	2213/ 3137 (70.5%)	1.24 (1.13–1.36)	p<0.001
S: Skin	288/ 436 (66.1%)*	4208/ 6552 (64.2%)	0.95 (0.77–1.17)	p=0.62	2269/ 3137 (72.3%)*	1.31 (1.19–1.45)	p<0.001
T: Endocrine, metabolic, nutritional	178/ 436 (40.8%)	1951/ 6552 (29.8%)	1.52 (1.23–1.86)	p<0.001	1189/ 3137 (37.9%)	1.30 (1.19–1.43)	p<0.001
U: Urological	69/ 436 (15.8%)	842/ 6552 (12.9%)	1.12 (0.85–1.47)	p=0.40	543/ 3137 (17.3%)	1.25 (1.11–1.41)	p<0.001
Y: Male genital	80/ 436 (18.3%)	1139/ 6552 (17.4%)	1.01 (0.78–1.29)	p=0.95	634/ 3137 (20.2%)	1.16 (1.04–1.30)	p=0.007

*Note. Group A = Fathers of children with MID-BIF and mental health problems; Group B = Fathers of children with mental health problems without MID-BIF; Reference group = Fathers of children from the general population. ORs reflect the odds of having ≥1 health problem per ICPC tract (vs. reference), adjusted for paternal age and GP registration duration. Red boxes = group A vs. reference; Blue boxes = group B vs. reference; * = significant group A vs. B difference.*

Diversity of health problems

As shown in Figure 4, mothers in groups A and B did not differ significantly ($p = .98$), but each had significantly more tracts than the reference group (IRR = 1.13, $p < .001$ for both). A similar pattern was observed among fathers, with no significant difference between groups A and B ($p = .27$), and both having significantly more tracts than the reference group C (group A: IRR = 1.07, $p = .002$; group B: IRR = 1.10, $p < .001$). Comparisons were adjusted for parental age and GP registration duration.

Figure 4. Mean number of ICPC tracts with ≥ 1 health problem



Note. Group A = parents of a child with MID-BIF and mental health problems; Group B = parents of a child with mental health problems; Group C = matched parents from the general population

Discussion

To our knowledge, this is the first study using GP-recorded data to quantify somatic and mental health problems in parents of children with MID-BIF and mental health problems, and compare them to health problems of parents of children with mental health problems only, and parents from the general population. Parents of children with MID-BIF and mental health problems showed a greater presence and diversity of health problems, including—but not limited to—psychological problems, compared to parents in the reference group.

However, largely similar patterns of health problems were found in parents of children with mental health problems only, suggesting that child mental health problems, rather than MID-BIF, may be the main factor driving the higher presence and greater diversity of health problems among parents.

Together, the combination of elevated presence and greater diversity of health problems across body systems could points to a wide-ranging health burden in line with the biopsychosocial model (Engel, 1977). This is particularly relevant given that several domains with higher presence—i.e., the psychological, endocrine/metabolic/nutritional, and digestive systems—are known to be especially sensitive to prolonged stress (Cohen et al., 2007; Leigh et al., 2023). Similar multi-systemic patterns have been reported in parents of children with autism, where chronic parenting stress was associated with both psychological symptoms and physiological dysregulation (Dijkstra-de Neijs et al., 2024; Van Der Lubbe et al., 2025).

Our findings address a critical gap in the literature, as evidence on the quantification of somatic and mental health problems in this parent population has been lacking. Previous studies have reported particularly elevated psychological and physical symptoms experienced by parents of children with ID (Chandravanshi et al., 2017; Sharma et al., 2021; Staunton et al., 2020; Tak et al., 2018; Zhou et al., 2022) and by parents of children receiving mental health care without ID (Campbell et al., 2021). Our study extends this work by focusing on parents of children with co-occurring MID-BIF and mental health problems—a group previously understudied—and by providing a comprehensive overview of their mental and somatic health problems across body systems. Altogether, this underscores the need to understand somatic and mental health as interconnected, especially within family systems.

Strengths and limitations

To contextualise our findings, it is important to consider both strengths and limitations. Relying on clinically recorded health data reduced the risk of recall and selection bias, which is especially valuable in research involving parents of children with complex needs. Additionally, the large sample size increased statistical power, and families in the sample reflect the region's ethnic and socioeconomic diversity. However, our database covers a subset of GPs (Ardesch et al., 2023). Second, the use of the nationally standardised ICPC coding system supports consistent documentation across practices. Still, validity may vary with clinical judgment and recording practices, and routine care data may be subject to underreporting or misclassification. Third, by including both somatic and mental health problems in both parents, we provide a more comprehensive picture of parental health in line with the biopsychosocial model. The current cross-sectional design limits conclusions about the temporal order and bidirectionality of health problems, suggesting directions for future longitudinal research.

Conclusion and implications

Parents of children with mental health problems, with or without MID-BIF, show a higher presence and diversity of health problems, reflecting the complexity and vulnerability of their family systems. Given earlier evidence of associations between parental and child health (Baker & Blacher, 2021; Gallagher & Whiteley, 2013), our findings point to the importance of integrated, family-oriented care across mental health services, GPs, and youth care. Recent evidence increasingly supports the effectiveness of family-systems interventions in reducing parental stress and strengthening coping within families facing complex needs (Stolper et al., 2024; Sutherland et al., 2023). Beyond the family level, integrated care for both parents and children may also have favorable implications for broader societal costs, including healthcare use and labor participation (Trautmann et al., 2016; Venema et al., 2021). GPs are uniquely positioned to detect emerging problems in both generations, given their long-term involvement with families and their gatekeeping role in the healthcare system. Recognising family-level patterns of health problems can support timely referrals and coordination of multidisciplinary care.

References

Ardesch, F. H., Meulendijk, M. C., Kist, J. M., Vos, R. C., Vos, H. M. M., Kiefte-de Jong, J. C., Spruit, M., Bruijnzeels, M. A., Bussemaker, M. J., Numans, M. E., & Struijs, J. N. (2023). The introduction of a data-driven population health management approach in the Netherlands since 2019: The Extramural LUMC Academic Network data infrastructure. *Health Policy*, *132*, 104769. https://doi.org/10.1016/j.healthpol.2023.104769

Arnold, D. L., & McPherson, S. (2024). A systematic review on the mental health of parents of individuals with learning disabilities. *Human Systems: Therapy, Culture and Attachments*, *4*(2), 59–75. https://doi.org/10.1177/26344041231217104

Bailey, T., Totsika, V., Hastings, R. P., Hatton, C., & Emerson, E. (2019). Developmental trajectories of behaviour problems and prosocial behaviours of children with intellectual disabilities in a population-based cohort. *Journal of Child Psychology and Psychiatry*, *60*(11), 1210–1218. https://doi.org/10.1111/jcpp.13080

Baker, B. L., & Blacher, J. (2021). Behavior Disorders and Social Skills in Adolescents with Intellectual Disability: Does Co-Morbid Autism Matter? *Journal of Mental Health Research in Intellectual Disabilities*, *14*(2), 174–188. https://doi.org/10.1080/19315864.2020.1871451

Bakker, B. F. M., Rooijen, J. van, & Toor, L. van. (2014). The System of social statistical datasets of Statistics Netherlands: An integral approach to the production of register-based social statistics. *Statistical Journal of the International Association for Official Statistics*, *30(4)*, 411–424. https://doi.org/10.3233/SJI-140803

Barratt, M., Lewis, P., Duckworth, N., Jojo, N., Malecka, V., Tomsone, S., Rituma, D., & Wilson, N. J. (2025). Parental Experiences of Quality of Life When Caring for Their Children With Intellectual Disability: A Meta-Aggregation Systematic Review. *Journal of Applied Research in Intellectual Disabilities*, *38*(1), e70005. https://doi.org/10.1111/jar.70005

Campbell, T. C. H., Reupert, A., Sutton, K., Basu, S., Davidson, G., Middeldorp, C. M., Naughton, M., & Maybery, D. (2021). Prevalence of mental illness among parents of children receiving treatment within child and adolescent mental health services (CAMHS): A scoping review. *European Child & Adolescent Psychiatry*, *30*(7), 997–1012. https://doi.org/10.1007/s00787-020-01502-x

Chandravanshi, G., Sharma, K., Jilowa, C., Meena, P., Jain, M., & Prakash, O. (2017). Prevalence of depression in mothers of intellectually disabled children: A cross-sectional study. *Medical Journal of Dr. D.Y. Patil University*, *10*(2), 156. https://doi.org/10.4103/0975-2870.202103

Cohen, S., Janicki-Deverts, D., & Miller, G. E. (2007). Psychological Stress and Disease. *JAMA*, *298*(14), 1685. https://doi.org/10.1001/jama.298.14.1685

Condon, L., Driscoll, T., Merrell, J., Storey, M., Thomas, A., Mansel, B., & Snelgrove, S. (2020). Promoting children's health when a parent has a mental health problem: A mixed methods study of the experiences and views of health visitors and their co-workers. *BMC Health Services Research*, *20*(1), 195. https://doi.org/10.1186/s12913-020-5015-z

Dekker, M. C., & Koot, H. M. (2003a). DSM-IV Disorders in Children With Borderline to Moderate Intellectual Disability. I: Prevalence and Impact. *Journal of the American Academy of Child & Adolescent Psychiatry*, *42*(8), 915–922. https://doi.org/10.1097/01.CHI.0000046892.27264.1A

Dekker, M. C., & Koot, H. M. (2003b). DSM-IV Disorders in Children With Borderline to Moderate Intellectual Disability. II: Child and Family Predictors. *Journal of the American Academy of Child & Adolescent Psychiatry*, *42*(8), 923–931. https://doi.org/10.1097/01.CHI.0000046891.27264.C1

Dijkstra-de Neijs, L., Boeke, D. B., Van Berckelaer-Onnes, I. A., Swaab, H., & Ester, W. A. (2024). Parental Stress and Quality of Life in Parents of Young Children with Autism. *Child Psychiatry & Human Development*. https://doi.org/10.1007/s10578-024-01693-3

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability*, *36*(2), 137–143. https://doi.org/10.1080/13668250.2011.572548

Embregts, P. J. C. M., du Bois, M. G., & Graef, N. (2010). Behavior problems in children with mild intellectual disabilities: An initial step towards prevention. *Research in Developmental Disabilities*, *31*(6), 1398–1403. https://doi.org/10.1016/j.ridd.2010.06.020

Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, *47*(1), 51–58. https://doi.org/10.1046/j.1365-2788.2003.00464.x

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*(4286), 129–136. https://doi.org/10.1126/science.847460

Fenning, R. M., Baker, J. K., Baker, B. L., & Crnic, K. A. (2007). Parenting children with borderline intellectual functioning: A unique risk population. *American Journal of Mental Retardation: AJMR*, *112*(2), 107–121. https://doi.org/10.1352/0895-8017(2007)112[107:PCWBIF]2.0.CO;2

Gallagher, S., & Whiteley, J. (2013). The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children’s challenging behaviours. *Journal of Health Psychology*, *18*(9), 1220–1231. https://doi.org/10.1177/1359105312464672

Jansen, M., Chapman, C., Richardson, T., Elliott, P., & Roberts, R. (2022). The relationship between mental and physical health: A longitudinal analysis with British student. *Journal of Public Mental Health*, *21*(3), 218–225. https://doi.org/10.1108/JPMH-11-2021-0147

Kist, J. M., Vos, H. M. M., Vos, R. C., Mairuhu, A. T. A., Struijs, J. N., Vermeiren, R. R. J. M., Van Peet, P. G., Van Os, H. J. A., Ardesch, F. H., Beishuizen, E. D., Sijpkens, Y. W. J., De Waal, M. W. M., Haas, M. R., Groenwold, R. H. H., Numans, M. E., & Mook-Kanamori, D. (2024). Data Resource Profile: Extramural Leiden University Medical Center Academic Network (ELAN).

International Journal of Epidemiology, *53*(4), dyae099. https://doi.org/10.1093/ije/dyae099

Kleefman, M., Reijneveld, S. A., & Jansen, D. E. M. C. (2015). Prevalence and determinants of need for formal parenting support among parents raising a child with a borderline to mild intellectual disability. *Journal of Intellectual and Developmental Disability*, *40*(1), 49–56. https://doi.org/10.3109/13668250.2014.956659

Kok, L., Van Der Waa, A., Klip, H., & Staal, W. (2016). The effectiveness of psychosocial interventions for children with a psychiatric disorder and mild intellectual disability to borderline intellectual functioning: A systematic literature review and meta-analysis. *Clinical Child Psychology and Psychiatry*, *21*(1), 156–171. https://doi.org/10.1177/1359104514567579

Lamberts, H., & Hofmans-Okkes, I. (1996). The core of computer based patient records in family practice: Episodes of care classified with ICPC. *International Journal of Bio-Medical Computing*, *42*(1–2), 35–41. https://doi.org/10.1016/0020-7101(96)01179-8

Leigh, S., Uhlig, F., Wilmes, L., Sanchez-Diaz, P., Gheorghe, C. E., Goodson, M. S., Kelley-Loughnane, N., Hyland, N. P., Cryan, J. F., & Clarke, G. (2023). The impact of acute and chronic stress on gastrointestinal physiology and function: A microbiota–gut–brain axis perspective. *The Journal of Physiology*, *601*(20), 4491–4538. https://doi.org/10.1113/JP281951

Linn, B. S., Linn, M. W., & Gurel, L. (1968). CUMULATIVE ILLNESS RATING SCALE. *Journal of the American Geriatrics Society*, *16*(5), 622–626. https://doi.org/10.1111/j.1532-5415.1968.tb02103.x

Magnée, T., De Beurs, D. P., Boxem, R., De Bakker, D. H., & Verhaak, P. F. (2017). Potential for substitution of mental health care towards family practices: An observational study. *BMC Family Practice*, *18*(1), 10. https://doi.org/10.1186/s12875-017-0586-4

Nouwens, P. J. G., Lucas, R., Smulders, N. B. M., Embregts, P. J. C. M., & van Nieuwenhuizen, C. (2017). Identifying classes of persons with mild intellectual disability or borderline intellectual functioning: A latent class analysis. *BMC Psychiatry, 17*(1), 257. https://doi.org/10.1186/s12888-017-1426-8

Pouls, K. P. M., Cuypers, M., Mastebroek, M., Wieland, J., Koks-Leensen, M. C. J., Leusink, G. L., & Assendelft, W. J. J. (2023). Mental healthcare for adults with mild intellectual disabilities: Population-based database study in Dutch mental health services. *BJPsych Open*, *9*(2), e48. https://doi.org/10.1192/bjo.2023.31

R Core Team. (2021). *R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria*. [Computer software]. https://www.R-project.org/

Riemersma, I., Van Santvoort, F., Van Doesum, K., Hosman, C., Janssens, J., Weeland, M., & Otten, R. (2022). Social-emotional problems of children with mild intellectual disabilities having parents with mental health concerns: A quantitative comparison study. *Journal of Intellectual Disabilities*, *26*(4), 811–823. https://doi.org/10.1177/17446295211030092

Sharma, R., Singh, H., Murti, M., Chatterjee, K., & Rakkar, J. S. (2021). Depression and anxiety in parents of children and adolescents with intellectual disability. *Industrial Psychiatry Journal*, *30*(2), 291–298. https://doi.org/10.4103/ipj.ipj_216_20

Snell, M. E., Luckasson, R., Borthwick-Duffy, W. S., Bradley, V., Buntinx, W. H. E., Coulter, D. L., Craig, E., Gomez, S. C., Lachapelle, Y., Reeve, A., Schalock, R. L., Shogren, K. A., Spreat, S., Tassé, M. J., Thompson, J. R., Verdugo, M. A., Wehmeyer, M. L., & Yeager, M. H. (2009). Characteristics and Needs of People With Intellectual Disability Who Have Higher IQs. *Intellectual and Developmental Disabilities*, *47*(3), 220–233. https://doi.org/10.1352/1934-9556-47.3.220

Staunton, E., Kehoe, C., & Sharkey, L. (2020). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish Journal of Psychological Medicine*, 1–8. https://doi.org/10.1017/ipm.2020.4

Stolper, H., Van Doesum, K., & Steketee, M. (2024). An integrated family approach in the practice of adult and child mental health care. *Frontiers in Psychiatry, 15*, 1298268. https://doi.org/10.3389/fpsyt.2024.1298268

Sutherland, D., Flynn, S., Kurzeja, O., Griffin, J., & Hastings, R. (2023). Family-systems interventions for families of people with an intellectual disability or who are autistic: A systematic review. *Journal of Intellectual Disability Research*, *67*(10), 1003–1028. https://doi.org/10.1111/jir.13068

Tak, N. K., Mahawer, B. K., Sushil, C. S., & Sanadhya, R. (2018). Prevalence of psychiatric morbidity among parents of children with intellectual disability. *Industrial Psychiatry Journal*, *27*(2), 197–200. https://doi.org/10.4103/ipj.ipj_39_18

Trautmann, S., Rehm, J., & Wittchen, H. (2016). The economic costs of mental disorders: Do our societies react appropriately to the burden of mental disorders? *EMBO Reports*, *17*(9), 1245–1249. https://doi.org/10.15252/embr.201642951

Van Der Lubbe, A., Swaab, H., Vermeiren, R., Van Rossum, E. F. C., Van Balkom, I. D. C., & Ester, W. A. (2025). Chronic Parenting Stress in Parents of Children with Autism: Associations with Chronic Stress in Their Child and Parental Mental and Physical Health. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-025-06736-9

Venema, A., Van Zon, S. K. R., & Bültmann, U. (2021). *Verzuim door psychische en somatische aandoeningen bij werkenden*. Trimbos-instituut / TNO. https://www.trimbos.nl/docs/af1092-verzuim-door-psychische-en-somatische-aandoeningen-bij-werkenden.pdf

Zhou, J., Gao, S., Sun, T., Gao, W., Fu, W., Ying, Z., & Mao, W. (2022). Sleep Quality, Anxiety, Somatic Symptoms, and Features of Brain Structure in Parents of Children with Disabilities. *Social Behavior and Personality: An International Journal*, *50*(6), 96–109. https://doi.org/10.2224/sbp.11557

Appendix A. Overview of ICPC tracts

Letter	**Tract**	**Examples**
A	General and unspecified	Infectious mononucleosis, tuberculosis
B	Blood, blood-forming organs, immune mechanisms	Acute lymphadenitis, iron deficiency anaemia
D	Digestive	Ulcus ventriculi, disease of oesophagus, cholecystitis
F	Eye	Blepharitis, hypermetropia, myopia
H	Ear	Otitis externa, perforation tympanic membrane, deafness
K	Cardiovascular	Heart failure, atherosclerosis
L	Musculoskeletal	Infections of musculoskeletal system, osteoporosis
N	Neurological	Concussion, facial paralysis
P	Psychological	Anxiety disorder, depressive disorder
R	Respiratory	Asthma, chronic bronchitis, pneumonia
S	Skin	Eczema, psoriasis, urticaria
T	Endocrine, metabolic, nutritional	Diabetes, obesity, gout
U	Urological	Cystitis, urinary calculi
W	Pregnancy, childbearing, family planning	Abortion, toxaemia
X	Female genital	Vaginitis, premenstrual tension syndrome
Y	Male genital	Balanitis, orchitis

6

Chapter 6

General discussion

Children with mild intellectual disability (MID) and borderline intellectual functioning (BIF) are at increased risk of developing mental health problems (Dekker & Koot, 2003; Kok et al., 2016). Yet despite this vulnerability, these children remain underrepresented in research (Emerson & Hatton, 2007b), including studies on whether contextual factors relate to their mental health (Nouwens et al., 2017). Some evidence points to higher rates of poverty and parental stress among children with intellectual disabilities (ID) of all severity levels (Barratt et al., 2025; Emerson, 2021). However, the extent to which several contextual factors relate to mental health remains poorly understood, particularly for children with MID-BIF. Their support needs are often less readily recognized than those of children with more severe forms of ID, whose cognitive and adaptive impairments are typically more visible early in life (Harris, 2006). As a result, mental health problems in children with MID-BIF may emerge more gradually, and possibly in closer interaction with environmental stressors. This makes it especially relevant to examine contextual factors in this group, whose specific position is often overlooked when findings are aggregated across the broader ID severity spectrum.

In response to this gap, the present dissertation adopts a contextual perspective, shifting the focus to the broader environments in which children with MID-BIF grow up. The overarching aim of this dissertation is to examine whether contextual factors relate to mental health problems in children with MID-BIF, guided by three interrelated sub-aims:

1. To review and structure the current empirical evidence on associations between contextual factors and mental health in youth with ID.
2. To investigate whether (patterns of co-occurring) disadvantage across multiple life domains relate to mental health problems in youth with MID-BIF, including variation across clinical subgroups.
3. To explore the association between parental health and child mental health in children with MID-BIF.

These aims are addressed in four interrelated studies. Chapter 2 presents a systematic literature review on the social determinants of mental health in youth across the full ID severity spectrum (sub-aim 1). Chapters 3 and 4 use population-based register data to examine whether various contextual factors are associated with mental health problems in children with MID-BIF (sub-aim

2). Chapter 5 uses the same register data to examine parental health, offering a comprehensive overview of both somatic and mental health problems in this population (sub-aim 3). Figure 1 provides an overview of the study samples and comparison groups used in each chapter.

Figure 1. Overview of study samples and comparison groups

	Intellectual disability + Mental health problems	Mental health problems	General population
Chapter 3	N = 505 children	N = 2,767 children	N = 16,360 children
Chapter 4	N = 1,742 children	-	N = 8,710 children
Chapter 5	1,001 parents of N = 676 children	6,967 parents of N = 4,565 children	14,490 parents of N = 9,549 children

This general discussion summarizes the four studies individually and subsequently offers a collective reflection on their overall findings. Methodological considerations are then discussed, followed by implications for clinical practice, policy, professional education, and future research. The chapter concludes by returning to the case of Ben, illustrating how the findings of this dissertation can inform support for children like him.

Summary

Chapter 2 presented a systematic literature review synthesizing empirical research on social determinants of mental health in youth aged 0 to 23 years across the full ID severity spectrum. The review aimed to identify contextual risk and protective factors across four domains (i.e., demographic, economic, social/cultural, and neighborhood) that are associated with mental health problems in youth with ID. In total, 51 studies were included, mostly cross-sectional. The most consistent evidence was found in the social/cultural domain, particularly regarding poor parental mental health, high family stress, and negative parenting practices. Evidence in the demographic and economic domains was limited or inconsistent, and only one study examined neighborhood factors. More broadly, heterogeneity was evident in both the operationalization of contextual factors and the methodological approaches. Given the predominance of cross-sectional and univariate approaches, the evidence base remains inconsistent and sometimes contradictory, making firm conclusions premature. Associations appeared complex, often context-dependent, and varying across individual and family characteristics. Subgroup analyses by ID severity, age, and type of mental health problems revealed no consistent differences by severity or age. Some variation did emerge by problem type: externalizing problems were more often linked to social and economic factors, and autism to demographic factors, though evidence was limited. Overall, the review revealed major gaps, particularly the lack of longitudinal evidence, the underrepresentation of protective factors, and the minimal focus on neighborhood factors.

Chapter 3 assessed the contextual characteristics of children with MID-BIF and mental health problems, in comparison to two reference groups: age- and sex-matched peers from the general population, and children with mental health problems without MID-BIF. Using a multivariate framework, we examined the unique associations of individual factors across four life domains (i.e., demographic, social/cultural, economic, and neighborhood) simultaneously. The analyses revealed that children with MID-BIF and mental health problems differed systematically from both control groups across multiple domains. Most notably, they were significantly more likely to have parents with lower education levels, live in lower-income households, and grow up in single-parent families. Together, these factors reflect socio-economic disadvantage. In addition, they tended to come from households with fewer children and were less likely to have mothers born outside Europe. By contrast, no significant associations were found for neighborhood-level factors, such as urbanization class, neighborhood education levels, or neighborhood income, after adjusting for other factors.

Chapter 4 expanded on these findings by examining the economic context of a larger group of children with MID-BIF and mental health problems, using a more specific operationalization of economic disadvantage. The chapter aimed to deepen insight in three ways: (1) by comparing the socio-economic conditions of this extended sample to those of age and sex matched peers from the general population; (2) by examining the accumulation of multiple co-occurring disadvantages within families; and (3) by exploring variation in socio-economic conditions across subgroups within the clinical population, based on symptom profiles and care intensity. Compared to their peers from the general population, children with MID-BIF and mental health problems were significantly more likely to live in families characterized by socio-economic disadvantages, including low parental education, low income, benefit dependency, single-parenthood, and residence in rented or subsidized housing. These disadvantages tended to cluster within families: 15.3% of children with MID-BIF and mental health problems were exposed to five risk factors, and 6.7% to all six, compared to 6.7% and 3.6% in the general population, respectively. Subgroup analyses showed that socio-economic disadvantage was particularly pronounced among children with internalizing or externalizing problems. By contrast, children who received more intensive mental health care tended to come from relatively more advantaged backgrounds, indicating potential inequalities in access to or continuity of care.

Chapter 5 examined parental health as an integral part of the child's broader context. Using general practice records, the study compared the presence and diversity of health problems among three groups: parents of children with MID-BIF and mental health problems, parents of children with mental health problems without MID-BIF, and parents from the general population. Health problems were coded across body systems, including both mental and somatic health problems. The results showed that parents of children mental health problems –regardless of MID-BIF– had a significantly higher presence and broader diversity of health problems than parents in the general population. These differences were most pronounced in the endocrine/metabolic/nutritional, psychological, and digestive systems, which are often associated with chronic stress (Cohen et al., 2007; Leigh et al., 2023). Importantly, patterns were largely similar between parents of children with and without MID-BIF, suggesting that child mental health problems, rather than MID-BIF specifically, may be the key driver of parental health vulnerability. These findings underscore the interdependence of child and parental health and highlight the importance of a family-oriented perspective in mental health research.

Discussion of main findings

Together, the findings provide an integrated picture of contextual factors associated with mental health problems in children with MID-BIF. They shed light on which life domains remain underexamined, which types of disadvantage appear most relevant, and where specific patterns of contextual vulnerability may be particularly prominent in this population. In line with sub-aim 1, Table 1 presents an overview of contextual factors across four life domains: (1)

Demographic, (2) Economic, (3) Social/Cultural, and (4) Neighborhood. This selection draws on factors identified in the literature review and our empirical studies, complemented by the conceptual framework on social determinants of mental health developed by Lund et al. (2018). The table is not meant to be exhaustive but offers a structured overview of frequently examined and conceptually relevant factors. It indicates which factors have been studied in previous research or in this dissertation (colour coding) and summarizes the level of evidence for associations with mental health in children with ID: '+' for consistent, '~' for mixed or inconsistent, and '○' for no evidence. This overview also highlights where this dissertation contributes most clearly and where important gaps remain.

Table 1. Overview of contextual factors

Domain	Contextual factor	Systematic review (Ch. 2)	Empirical studies (Ch. 3-5)
Demographic	Ethnicity mother	~	+
	Maternal age	~	○
	Paternal age	🟩	○
	Ethnicity father	🟥	○
Economic	Household income	~	+
	Benefit dependency	○	+
	Housing tenure	○	+
	Household income source	🟥	+
	Main benefit type	🟥	+
	Parental financial stress	+	🟥
	Debt	🟥	🟥
	Income instability	🟥	🟥
Social/Cultural	Maternal somatic health	+	+
	Maternal & paternal mental health	~	+
	Maternal & paternal education level	~	+
	Family size	○	+
	Paternal somatic health	🟥	+
	Family type	🟥	+
	Parental stress/distress	+	🟥
	Birth order	+	🟥
	Family dysfunction	+	🟥
	Parental isolation	+	🟥
	Parental life satisfaction	~	🟥
	Parental substance use	~	🟥

	Parental employment status	🟩 ~	🟥
	Positive parent-child relationship	🟩 ~	🟥
	Negative parent-child relationship	🟩 ~	🟥
	Marital satisfaction	🟩 ~	🟥
	Marital status	🟩 ~	🟥
	Life events	🟩 ~	🟥
	Domestic violence	🟩 ~	🟥
	Family quality of life	🟩 ~	🟥
	Sibling factors	🟩 ~	🟥
	Social support	🟩 ~	🟥
	Family cohesion	🟩 ○	🟥
	Parental literacy	🟥	🟥
	Culture	🟥	🟥
Neighborhood	Neighborhood income	🟥	🟩 ○
	Neighborhood education	🟥	🟩 ○
	Urbanization class	🟥	🟩 ○
	Neighborhood violence	🟩 +	🟥
	Neighborhood deprivation	🟥	🟥
	Infrastructure	🟥	🟥
	Neighborhood safety	🟥	🟥
	Leisure opportunities	🟥	🟥
	Neighborhood social cohesion	🟥	🟥

Note. Green boxes indicate examined factors; red boxes indicate factors not examined. Symbols: + consistent evidence for association, ~ mixed or inconsistent evidence, ○ no evidence for association.

Together, this dissertation offers the first systematic exploration of associations between contextual factors and mental health problems in children with MID-BIF spanning multiple life domains and comparison groups. These findings help disentangle which contextual factors are most common, which may be specific to MID-BIF, and the extent to which these factors cluster within families. On this basis, three overarching insights emerge from the empirical chapters:

1. Contextual vulnerability is multidimensional

In answer to sub-aim 2, results across the chapters of this dissertation showed that children with MID-BIF and mental health problems consistently grew up in disadvantaged contexts. These disadvantages spanned multiple, interrelated life domains, and the patterns proved robust across different studies and comparison groups. Importantly, several contextual disadvantages such as low parental education, single-parent households and limited financial resources were each independently associated with mental health problems, even when considered together in the same model. In addition, disadvantages across multiple domains often co-occurred. Families facing hardship in one area were frequently exposed to difficulties in others, with a considerable proportion of children with MID-BIF and mental health problems experiencing multiple forms of socio-economic disadvantage. This reinforces the conclusion that contextual vulnerability in this group is not limited to one area but reflects a multidimensional and layered pattern of disadvantage.

2. Shared contextual vulnerability

Some contextual disadvantages were observed in families of children with mental health problems, regardless of MID-BIF status. Both children with and without MID-BIF more often lived in single-parent households. In both groups, parents showed a higher presence and broader diversity of mental and somatic health problems compared to the general population (as explored in sub-aim 3). These findings suggest that not all contextual disadvantages are unique to children with MID-BIF; instead, they may reflect broader patterns of disadvantage among children receiving mental health care. Nonetheless, the combination of MID-BIF and mental health problems was associated with more pronounced socio-economic disadvantage, particularly lower parental education and reduced household income. These limited resources, in turn, may reduce families' capacity to buffer stressors or access timely support (Lund et al., 2010; Reiss, 2013).

3. Contextual vulnerability differs within the MID-BIF group

Subgroup analyses showed that contextual vulnerability was not evenly distributed across children with MID-BIF and mental health problems. Children with internalising or externalising problems were more likely to grow up in socio-economically disadvantaged families than those diagnosed with developmental conditions such as autism. These patterns suggest that contextual disadvantage differs by symptom profile and underscore that children with MID-BIF are heterogeneous both clinically and contextually. Such subgroup differences point to underlying mechanisms. Internalising and externalising symptoms tend to be more strongly associated with environmental stressors such as economic hardship and parenting strain (Reiss, 2013). By contrast, developmental conditions such as autism are often more genetically influenced and potentially less sensitive to contextual variation (Tordjman et al., 2014; Wei et al., 2021).

While these findings offer important initial insights, further research is needed to replicate these subgroup differences.

Methodological considerations

The empirical studies in this dissertation adopted a register-based observational design, drawing on routinely collected data from children receiving outpatient mental health care and their families. Access to these data was made possible through the Extramural LUMC Academic Network (ELAN). This population-based data-infrastructure facilitates the secure linkage of datasets from multiple institutional sources. These include regional data from general practitioners, hospitals, mental health care providers, and municipal records in South Holland (the Netherlands). ELAN is further complemented by nationwide administrative registers such as microdata from Statistics Netherlands (Ardesch et al., 2023; Kist et al., 2024). By relying on routinely collected data, this design avoided participant burden, supported inclusion of structurally underrepresented groups, and enabled a contextualized and ecological perspective of child mental health in its broader social context. The table below summarizes the main methodological strengths and limitations of the ELAN data-infrastructure in relation to the aims and scope of this dissertation.

Table 2. Methodological strengths and limitations of the data-infrastructure

Aspect	**Strength**	**Limitation**
Data coverage	Large population-based samples suitable for (sub)group comparisons; linked data enabled analysis at several levels	Availability of some variables varied over time due to changes in care systems and registration practices; sources not designed for research.
Contextual scope	Integration of data across multiple life domains; supports system-level analysis of structural patterns	No insight in everyday experiences or interpersonal processes
Group classification	Use of mental health care data to define a clinically specific MID-BIF group with mental health problems	Children with MID-BIF outside specialized mental health care could not be identified
Representativeness	Reduced selection bias; includes families often missed in research; no participant burden	Limited generalizability to rural Dutch regions or to international contexts with different cultural or service systems
Data quality	Routinely collected care and administrative data; no recall or response bias; high ecological validity	Substantial missing data for some variables; use of proxy measures where direct measures were unavailable

Data coverage

The use of data from multiple data providers enabled access to large, representative samples. As a result, these data allowed comparisons across demographic and clinical subgroups and enabled linkage at multiple levels, including individuals, households, and families. This multilevel linkage enabled the study of patterns across generations. However, the data were not originally gathered for research purposes. Moreover, variable availability varied over time and between sources due to changes in care systems, administrative structures, and registration practices.

Contextual scope

The integration of data across four key life domains (i.e., demographic, economic, social/cultural, and neighborhood) enabled a system-level view of structural disadvantage in children’s lives. This multidomain integration provided an ecological perspective on mental health. As relational and subjective factors are not captured, the design is less suitable to studying specific behavioral expressions or interpersonal dynamics. Consequently, it may therefore complement research that focuses on lived experience and family processes.

Group classification

Children with MID-BIF and mental health problems were identified through specialized mental health services for this group, resulting in a clinically well-defined case sample. However, since identification relied on care use and nationwide registers lack reliable measures to identify MID-BIF, children with MID-BIF who did not receive mental health services could not be detected. As a result, a control group of children with MID-BIF without mental health problems could not be constructed, which limits inferences about differences attributable to MID-BIF in the absence of mental health problems.

Representativeness

As the data covered a large urban population, the studies included families often missing in conventional research, such as those facing structural disadvantage and with a migration background (Lennox et al., 2005). This reduced selection bias in both the target group (i.e., children with MID-BIF and mental health problems) and the comparison groups, thereby strengthening the internal validity of between-group comparisons. However, the findings may not generalize to children living in rural areas or to international contexts with different cultural or service systems.

Data quality

The use of routinely collected care combined with administrative data avoided recall and response bias and provided structured, uniform information on service use and socio-economic conditions and ensured high ecological validity. However, substantial missing data in some variables (e.g., paternal education level) limited the robustness of analyses. In addition, in some analyses, proxies had to be used where direct indicators were unavailable (e.g., total minutes of care as a proxy for care intensity and problem severity).

Together, the analyses using data from the ELAN data-infrastructure offer a unique combination of clinically defined groups and population-level insight into the ecological context of child mental health. Rather than capturing individual symptom trajectories, it enables the examination of broader structural conditions under which care is received and adversity accumulates (Storm et al., 2023). This makes the design particularly well-suited to identifying patterns of inequality, clustering of contextual risk factors, and systemic variation across subgroups at the individual, family, and neighborhood level. In doing so, it complements more intensive, participatory forms of research by highlighting who receives care, under what conditions, and the nature and scope of the support provided.

Implications

The findings presented in this dissertation have several important implications for future research, as well as for clinical practice, policy development, and professional education.

Research implications

Five overarching areas for further research are highlighted and discussed in more detail: (1) understanding longitudinal pathways, (2) advancing research on contextual factors, (3) reaching underserved children with MID-BIF and mental health problems, (4) studying cross-cultural and international variation, and (5) exploring the potential role of syndemics.

First, as all empirical studies in this dissertation used cross-sectional designs, it limits inferences about directionality. Longitudinal designs are needed to clarify temporal relationships, track contextual adversity over time, and examine potential bidirectional dynamics, such as between parental and child mental health. Existing data-infrastructures such as ELAN offer a strong basis for such research, particularly if supplemented with additional assessments. One promising approach would be to build on such existing data-infrastructures, enabling longitudinal linkage of routine data across several domains at the individual level. Although ELAN is not a prospective cohort with structured, standardized follow-up measurements, it offers a strong foundation for integrative research. Supplementing such infrastructures with embedded cohort-based components could greatly enhance our understanding of how contextual adversity and child development interact over time.

Second, future research should explore the gaps identified in Table 1. Neighborhood factors in particular offer important opportunities for further investigation. These specifically include community diversity, population density, neighborhood deprivation, safety, infrastructure, leisure opportunities, and social cohesion. Other relevant contextual factors, such as debt, parental literacy, and culture, also deserve attention because they can shape children’s opportunities, stress exposure, and access to support. To address these gaps, future studies should aim to complement quantitative research with qualitative or mixed method designs, incorporate multi-informant assessments, and apply participatory approaches to better capture underrepresented aspects of children’s context. Such approaches can offer deeper insight into how structural disadvantages are experienced in daily life, how children and families navigate stressors, and which contextual factors they perceive as most relevant.

Third, future research should focus on children with MID-BIF and mental health problems who do not access specialized mental health care. This dissertation was limited to children who had already entered care, leaving an important knowledge gap regarding those who remain unseen. Barriers to care may include underrecognition of needs, limited help-seeking behavior, or structural access problems. Further research is needed to understand the characteristics of these underserved groups and the barriers they face. However, identifying these underserved groups poses methodological challenges. One promising strategy may involve the use of routine screening data from preventive child health services, such as the Dutch consultation bureaus, which all families are routinely invited to attend during the first years of a child's life (Vanneste et al., 2022). These services collect data on developmental milestones, growth, family circumstances, and psychosocial risk factors. Analyzing such information could help researchers to better characterize children at risk and to understand early indicators of vulnerability for mental health problems in these children.

Fourth, future research should examine contextual risk and protective factors in settings beyond the urban, high-income, Western European context. This dissertation focused primarily on children living in urban and suburban areas in the western part of the Netherlands. However, experiences of disadvantage, access to care, and cultural interpretations of mental health may differ across geographic regions, socio-political systems, and cultural backgrounds (Bizzego et al., 2020; Draper et al., 2024; Gutmann et al., 2019). Comparative studies focussing explicitly on non-Western or migrant populations, or research conducted in low- and middle-income countries, are needed to assess the generalizability of findings. Such studies can also help to explore context-dependent variations in child mental health among children with MID-BIF.

Finally, future research should explore the applicability of a syndemic framework to this population. This dissertation documented the co-occurrence of contextual factors and mental health problems but did not assess whether these adversities interact to exacerbate children's difficulties. Syndemic theory suggests that multiple co-occurring risks may reinforce each other, leading to disproportionate increases in the severity or persistence of mental health problems (Mendenhall et al., 2022). Such a perspective may be particularly relevant for children with MID-BIF, given their cognitive and adaptive vulnerabilities, which could heighten sensitivity to the combined effects of contextual risks. Future studies should therefore go beyond identifying co-occurring risks and examine their potential interactive and mutually reinforcing effects, as well as the role of social context in shaping these dynamics.

Clinical implications

A central clinical message emerging from this dissertation is the need for a more holistic and context-sensitive approach to assessment and treatment for children with MID-BIF and mental health problems. This requires attention to four key areas in clinical practice.

First, the findings across all studies underline the importance of adopting a holistic and context-sensitive perspective during both the assessment of the child's mental health problems and treatment planning. This implication is particularly relevant for professionals involved in clinical assessment and case formulation, such as youth mental health practitioners, child psychologists, orthopedagogues, and multidisciplinary diagnostic teams. For children with MID-BIF and mental health problems, clinical needs cannot be understood in isolation from the environments in which they grow up. Clinicians are therefore encouraged to move beyond symptom-based diagnostic categories and to systematically integrate contextual information into their decision-making. This requires a shift from traditional, linear cause-and-effect thinking toward a more circular and systemic view of how child, family, and environmental factors interact over time (Storm et al., 2023).

Second, the results highlight the need for greater awareness of the cumulative and clustered nature of contextual adversities in this population. Rather than facing isolated risk factors, children with MID-BIF and mental health problems often encounter multiple, co-occurring challenges across various life domains. Their cognitive and adaptive vulnerabilities reduce their capacity to cope, leaving them with fewer psychological and social resources than typically developing peers (Emerson et al., 2010). Clinically, this calls for systematic mapping of both the number and the life domains of contextual adversities present in a child's life. Structured risk assessment tools or contextual interviews could support this process. This can help prioritize treatment goals and inform decisions about whether additional social, educational, or family support services should be engaged. Systematic assessment of contextual adversity is also relevant at the organizational and service level. Interdisciplinary collaboration and integrated care pathways are needed to ensure that children with complex contextual risks receive timely support that goes beyond the mental health domain alone.

Third, the dissertation underscores the importance of engaging parents and the broader family system throughout the care process of the child with MID-BIF. The studies demonstrated that parents of children with MID-BIF and mental health problems themselves often experience of mental and somatic health problems. This underscores the need for clinicians to routinely assess parental wellbeing, provide psycho-education about the bidirectional relationship between child and parental mental health, and, where necessary, involve adult mental health or social care services. Integrated parent-child interventions may also be particularly relevant for this population, as they offer opportunities to strengthen parent-child relationships while addressing the individual needs of both parent and child. Furthermore, enhancing communication and coordination between different professionals involved with the child and family, including school staff, social workers, and adult mental health providers, may help create more coherent and responsive care pathways. Beyond clinical practice, this calls for structural collaboration between youth and adult services to ensure that families receive coordinated and system-oriented support. Recent work on integrated family approaches in mental health care illustrates how closer collaboration between child and adult mental health services, with shared attention to family dynamics and social context, can help clinicians translate this broader perspective into practice (Stolper et al., 2024). Although this integrated family approach was developed within adult mental health settings, its underlying principles are highly relevant for clinicians working with children with MID-BIF and complex contextual risks. These principles emphasize a whole-family perspective and the integration of knowledge from multiple disciplines.

Fourth, the dissertation also raises important questions about how mental health services can be organized in ways that better align with the everyday realities of children and families. This includes the need to explore and support innovative service models that bring care closer to the home environment. One promising initiative in community-based service delivery is already being implemented: the GIJS bus (in Dutch: *'GGZ In Jouw Straat'*; "Mental Health Care in Your Street"). This mobile treatment room was specifically designed for children with MID-BIF and mental health problems and aims to provide low-threshold care directly within the child's living environment. By reducing both the stress and the financial and practical burdens of traveling to mental health care appointments, this approach offers a more accessible and context-sensitive alternative by bringing care directly to the family. Such initiatives highlight the value of outreach-oriented care and suggest a reconsideration of conventional outpatient approaches. Therefore, structural investment in the further development and rigorous evaluation of such models is needed.

Policy implications

The implications extend beyond the boundaries of child mental health care itself. At policy level, this requires practical agreements and funding that enable professionals from different sectors, including health care, social services, education, and community support, to collaborate effectively in supporting these families. Without such structural support, coordination between sectors remains difficult, increasing the risk of fragmented care and unmet needs among families already facing multiple challenges. Effective policy is therefore not merely supportive but essential to enabling integrated care in practice.

Although recent national policy developments increasingly emphasize the importance of integrated, cross-sectoral approaches in youth care (Nooteboom et al., 2021), translating these ambitions into effective structures and daily practice remains challenging (Nooteboom et al., 2020). The findings of this dissertation provide additional empirical support for these policy directions by documenting the extent and clustering of contextual risks among children with MID-BIF and mental health problems and their families. This underscores the relevance of investing in structural conditions that facilitate interprofessional communication, shared care planning, and effective collaboration across sectors. Such investments are essential to ensure that the complex needs of this group are addressed in a timely, coordinated, and family-centered manner.

Implication for education and training of professionals

The findings of this dissertation also highlight the need for changes in the education and training of professionals working with children with MID-BIF and mental health problems. Currently, many training programs for mental health professionals, social workers, and educators are strongly discipline-focused, with limited integration across sectors (Bookey-Bassett et al., 2023). In addition, they are often age-specific, with separate tracks for child and adult services. This separation may hinder a coherent, family-oriented approach when problems span generations. As a result, professionals may benefit from additional training that enhances their ability to navigate other service systems and to collaborate effectively across sectors when addressing the complex needs of children and families. To support this, education and training programs should place greater emphasis on developing competencies in interprofessional communication, contextual risk assessment, and system-oriented case formulation. Exposure to other professional fields may help future professionals adopt a more integrated and family-centered perspective. This can be promoted through joint training modules, intersectoral case discussions or collaborative field placements.

Back to Ben: how can we help him?

This dissertation opened with the case of Ben, a 12-year-old boy navigating the combined challenges of a mild intellectual disability and escalating mental health problems in the context of family stress, financial strain, and neighborhood adversity. The findings of this dissertation reinforce that his individual problems cannot be understood when decontextualized from the broader environment in which they unfold. When a child like Ben acts out in class, it may not simply reflect individual defiance or disorder, but also signal instability at home, financial stress, or parental mental health problems. A context-sensitive perspective encourages professionals to ask not only “what is wrong with the child?” but also “what is happening around the child?”, and equally, “what unmet needs might this behaviour reflect?”

For Ben, this means that both his school and care providers need to consider how different layers of adversity may interact and shape his daily functioning. Teachers who are aware of contextual stressors may respond with greater understanding and flexibility. Likewise, mental health services should not only treat Ben’s symptoms, but also assess the support needs of his parents, explore barriers to engagement, and offer outreach-based, family-centered care. Rather than fragmenting support across domains, an integrated approach can make a crucial difference in the lives of children like Ben.

In short, the knowledge from this dissertation suggests that helping Ben requires a shift in how we define and deliver care. Not as a series of isolated interventions targeting the child (or parent) alone, but as an integrated, contextualized approach that moves beyond the individual to address the broader environment, family system, and structural conditions.

References

American Psychiatric Association. (2022). *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR). American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890425787

Ardesch, F. H., Meulendijk, M. C., Kist, J. M., Vos, R. C., Vos, H. M. M., Kiefte-de Jong, J. C., Spruit, M., Bruijnzeels, M. A., Bussemaker, M. J., Numans, M. E., & Struijs, J. N. (2023). The introduction of a data-driven population health management approach in the Netherlands since 2019: The Extramural LUMC Academic Network data infrastructure. *Health Policy*, *132*, 104769. https://doi.org/10.1016/j.healthpol.2023.104769

Barratt, M., Lewis, P., Duckworth, N., Jojo, N., Malecka, V., Tomsone, S., Rituma, D., & Wilson, N. J. (2025). Parental Experiences of Quality of Life When Caring for Their Children With Intellectual Disability: A Meta-Aggregation Systematic Review. *Journal of Applied Research in Intellectual Disabilities*, *38*(1), e70005. https://doi.org/10.1111/jar.70005

Bizzego, A., Lim, M., Schiavon, G., Setoh, P., Gabrieli, G., Dimitriou, D., & Esposito, G. (2020). Child disability and caregiving in low and middle income countries: Big data approach on open data. *Research in Developmental Disabilities*, *107,* 103795. https://doi.org/10.1016/j.ridd.2020.103795

Bookey-Bassett, S., Espin, S., Northwood, M., Jeffs, L., & Veerasuntharam, A. (2023). “There’s No Room for Silos.” Interprofessional Education in Hospital to Home Integrated Care Programs. *Health, Interprofessional Practice and Education, 5*, 5. https://doi.org/10.61406/hipe.294

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press. https://doi.org/10.4159/9780674028845

Buckley, N., Glasson, E. J., Chen, W., Epstein, A., Leonard, H., Skoss, R., Jacoby, P., Blackmore, A. M., Srinivasjois, R., Bourke, J., Sanders, R. J., & Downs, J. (2020). Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and meta-analysis. *Australian & New Zealand Journal of Psychiatry*, *54*(10), 970–984. https://doi.org/10.1177/0004867420924101

Cohen, S., Janicki-Deverts, D., & Miller, G. E. (2007). Psychological Stress and Disease. *JAMA*, *298*(14), 1685. https://doi.org/10.1001/jama.298.14.1685

Dekker, M. C., & Koot, H. M. (2003). DSM-IV Disorders in Children With Borderline to Moderate Intellectual Disability. I: Prevalence and Impact. *Journal of the American Academy of Child & Adolescent Psychiatry*, *42*(8), 915–922. https://doi.org/10.1097/01.CHI.0000046892.27264.1A

Douma, J. (2018). *Jeugdigen en (jong)volwassenen met een licht verstandelijke beperking: Kenmerken en de gevolgen voor diagnostisch onderzoek en (gedrags)interventies*. Landelijk Kenniscentrum LVB.

Doyle, A., O’Sullivan, M., Craig, S., & McConkey, R. (2022). Predictors of access to healthcare professionals for people with intellectual disability in Ireland. *Journal of Intellectual Disabilities*, *26*(1), 3–17. https://doi.org/10.1177/1744629520937835

Draper, C. E., Cook, C. J., Ankrah, E. A., Beltran, J. A., Cibrian, F. L., Johnson, J., Lakes, K. D., Mofid, H., Williams, L., & Hayes, G. R. (2024). Young Children’s Mental Well-Being in Low-Income South African Settings: A Qualitative Study. *Journal of Child and Family Studies*, *33*(11), 3455–3471. https://doi.org/10.1007/s10826-024-02929-5

Dykens, E. M., Hodapp, R. M., & Finucane, B. M. (2000). *Genetics and mental retardation syndromes: A new look at behavior and interventions*. Paul H. Brookes Pub. Co.

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability*, *36*(2), 137–143. https://doi.org/10.1080/13668250.2011.572548

Emerson, E. (2021). Social and Environmental Determinants of Health Among People With Disabilities. In E. Emerson, *Oxford Research Encyclopedia of Global Public Health*. Oxford University Press. https://doi.org/10.1093/acrefore/9780190632366.013.325

Emerson, E., Einfeld, S., & Stancliffe, R. J. (2010). The mental health of young children with intellectual disabilities or borderline intellectual functioning. *Social Psychiatry and Psychiatric Epidemiology*, *45*(5), 579–587. https://doi.org/10.1007/s00127-009-0100-y

Emerson, E., & Hatton, C. (2007a). Contribution of Socioeconomic Position to Health Inequalities of British Children and Adolescents With Intellectual Disabilities. *American Journal on Mental Retardation*, *112*(2), 140. https://doi.org/10.1352/0895-8017(2007)112[140:COSPTH]2.0.CO;2

Emerson, E., & Hatton, C. (2007b). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry, 191*(6), 493–499. https://doi.org/10.1192/bjp.bp.107.038729

Emerson, E., & Hatton, C. (2007c). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: A replication. *Journal of Intellectual Disability Research: JIDR*, *51*(Pt 11), 866–874. https://doi.org/10.1111/j.1365-2788.2007.00951.x

Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, *50*(12), 862–873. https://doi.org/10.1111/j.1365-2788.2006.00900.x

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*(4286), 129–136. https://doi.org/10.1126/science.847460

Gutmann, M. T., Aysel, M., Özlü-Erkilic, Z., Popow, C., & Akkaya-Kalayci, T. (2019). Mental health problems of children and adolescents, with and without migration background, living in Vienna, Austria. *Child and Adolescent Psychiatry and Mental Health*, *13*(1), 35. https://doi.org/10.1186/s13034-019-0295-y

Harris, J. C. (2006). *Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment*. Oxford University Press.

Hronis, A. (2021). Cognitive Behaviour Therapy for People with Intellectual Disabilities—How Far Have We Come? *International Journal of Cognitive Therapy*, *14*(1), 114–132. https://doi.org/10.1007/s41811-020-00091-6

Institute of Medicine, Boat, T. F., Wu, J. T., & National Academies of Sciences, Engineering, and Medicine (Eds.). (2015). *Mental disorders and disabilities among low-income children*. National Academies Press.

Kist, J. M., Vos, H. M. M., Vos, R. C., Mairuhu, A. T. A., Struijs, J. N., Vermeiren, R. R. J. M., Van Peet, P. G., Van Os, H. J. A., Ardesch, F. H., Beishuizen, E. D., Sijpkens, Y. W. J., De Waal, M. W. M., Haas, M. R., Groenwold, R. H. H., Numans, M. E., & Mook-Kanamori, D. (2024). Data Resource Profile: Extramural Leiden University Medical Center Academic Network (ELAN). *International Journal of Epidemiology*, *53*(4), dyae099. https://doi.org/10.1093/ije/dyae099

Kok, L., Van Der Waa, A., Klip, H., & Staal, W. (2016). The effectiveness of psychosocial interventions for children with a psychiatric disorder and mild intellectual disability to borderline intellectual functioning: A systematic literature review and meta-analysis. *Clinical Child Psychology and Psychiatry*, *21*(1), 156–171. https://doi.org/10.1177/1359104514567579

Kolaitis, G. (2008). Young people with intellectual disabilities and mental health needs. *Current Opinion in Psychiatry*, *21*(5), 469–473. https://doi.org/10.1097/YCO.0b013e3283060a7b

Leigh, S., Uhlig, F., Wilmes, L., Sanchez-Diaz, P., Gheorghe, C. E., Goodson, M. S., Kelley-Loughnane, N., Hyland, N. P., Cryan, J. F., & Clarke, G. (2023). The impact of acute and chronic stress on gastrointestinal physiology and function: A microbiota–gut–brain axis perspective. *The Journal of Physiology*, *601*(20), 4491–4538. https://doi.org/10.1113/JP281951

Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D. M., & Boyle, F. (2005). Beating the barriers: Recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research*, *49*(4), 296–305. https://doi.org/10.1111/j.1365-2788.2005.00618.x

Lund, C., Breen, A., Flisher, A. J., Kakuma, R., Corrigall, J., Joska, J. A., Swartz, L., & Patel, V. (2010). Poverty and common mental disorders in low and middle income countries: A systematic review. *Social Science & Medicine*, *71*(3), 517–528. https://doi.org/10.1016/j.socscimed.2010.04.027

Lund, C., Brooke-Sumner, C., Baingana, F., Baron, E. C., Breuer, E., Chandra, P., Haushofer, J., Herrman, H., Jordans, M., Kieling, C., Medina-Mora, M. E., Morgan, E., Omigbodun, O., Tol, W., Patel, V., & Saxena, S. (2018). Social determinants of mental disorders and the Sustainable Development Goals: A systematic review of reviews. *The Lancet Psychiatry*, *5*(4), 357–369. https://doi.org/10.1016/S2215-0366(18)30060-9

Macintyre, A., Ferris, D., Gonçalves, B., & Quinn, N. (2018). What has economics got to do with it? The impact of socioeconomic factors on mental health and the case for collective action. *Palgrave Communications*, *4*(1), 10. https://doi.org/10.1057/s41599-018-0063-2

Mendenhall, E., Kohrt, B. A., Logie, C. H., & Tsai, A. C. (2022). Syndemics and clinical science. *Nature Medicine*, *28*(7), 1359–1362. https://doi.org/10.1038/s41591-022-01888-y

Nader-Grosbois, N. (2014). Self-perception, self-regulation and metacognition in adolescents with intellectual disability. *Research in Developmental Disabilities*, *35*(6), 1334–1348. https://doi.org/10.1016/j.ridd.2014.03.033

Nooteboom, L. A., Mulder, E. A., Kuiper, C. H. Z., Colins, O. F., & Vermeiren, R. R. J. M. (2021). Towards Integrated Youth Care: A Systematic Review of Facilitators and Barriers for Professionals. *Administration and Policy in Mental Health and Mental Health Services Research*, *48*(1), 88–105. https://doi.org/10.1007/s10488-020-01049-8

Nooteboom, L. A., Van Den Driesschen, S. I., Kuiper, C. H. Z., Vermeiren, R. R. J. M., & Mulder, E. A. (2020). An integrated approach to meet the needs of high-vulnerable families: A qualitative study on integrated care from a professional perspective. *Child and Adolescent Psychiatry and Mental Health*, *14*(1), 18. https://doi.org/10.1186/s13034-020-00321-x

Nouwens, P. J. G., Lucas, R., Smulders, N. B. M., Embregts, P. J. C. M., & van Nieuwenhuizen, C. (2017). Identifying classes of persons with mild intellectual disability or borderline intellectual functioning: A latent class analysis. *BMC Psychiatry, 17*(1), 257. https://doi.org/10.1186/s12888-017-1426-8

Patel, D. R., Cabral, M. D., Ho, A., & Merrick, J. (2020). A clinical primer on intellectual disability. *Translational Pediatrics*, *9*(S1), S23–S35. https://doi.org/10.21037/tp.2020.02.02

Peltopuro, M., Ahonen, T., Kaartinen, J., Seppälä, H., & Närhi, V. (2014). Borderline Intellectual Functioning: A Systematic Literature Review. *Intellectual and Developmental Disabilities*, *52*(6), 419–443. https://doi.org/10.1352/1934-9556-52.6.419

Peltopuro, M., Vesala, H. T., Ahonen, T., & Närhi, V. M. (2023). Borderline Intellectual Functioning and Vulnerability in Education, Employment and Family. *Scandinavian Journal of Disability Research*, *25*(1), 334–349. https://doi.org/10.16993/sjdr.965

Reiss, F. (2013). Socioeconomic inequalities and mental health problems in children and adolescents: A systematic review. *Social Science & Medicine*, *90*, 24–31. https://doi.org/10.1016/j.socscimed.2013.04.026

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An Overview of *Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports* (12th ed.). *American Journal on Intellectual and Developmental Disabilities*, *126*(6), 439–442. https://doi.org/10.1352/1944-7558-126.6.439

Seelen-de Lang, B. L., Smits, H. J. H., Penterman, B. J. M., Noorthoorn, E. O., Nieuwenhuis, J. G., & Nijman, H. L. I. (2019). Screening for intellectual disabilities and borderline intelligence in Dutch outpatients with severe mental illness. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1096–1102. https://doi.org/10.1111/jar.12599

Stolper, H., Van Doesum, K., & Steketee, M. (2024). An integrated family approach in the practice of adult and child mental health care. *Frontiers in Psychiatry*, *15*, 1298268. https://doi.org/10.3389/fpsyt.2024.1298268

Storm, M. M. C., Van Eldik, W. M., Palstra, E. C., Özgen, M. H., van Vliet, C. L. M., & Vermeiren, R. R. J. M. (2023). Koppelen van ggz- en CBS-microdata om zorgeffectiviteit te meten. *Tijdschrift voor Psychiatrie*, *65*(6), 383–387.

Te Brinke, L. W., Schuiringa, H. D., & Matthys, W. (2021). Emotion regulation and angry mood among adolescents with externalizing problems and intellectual disabilities. *Research in Developmental Disabilities*, *109*, 103833. https://doi.org/10.1016/j.ridd.2020.103833

Tordjman, S., Somogyi, E., Coulon, N., Kermarrec, S., Cohen, D., Bronsard, G., Bonnot, O., Weismann-Arcache, C., Botbol, M., Lauth, B., Ginchat, V., Roubertoux, P., Barburoth, M., Kovess, V., Geoffray, M.-M., & Xavier, J. (2014). Gene x Environment Interactions in Autism Spectrum Disorders: Role of Epigenetic Mechanisms. *Frontiers in Psychiatry, 5*. https://doi.org/10.3389/fpsyt.2014.00053

Totsika, V., Liew, A., Absoud, M., Adnams, C., & Emerson, E. (2022). Mental health problems in children with intellectual disability. *The Lancet Child & Adolescent Health*, *6*(6), 432–444. https://doi.org/10.1016/S2352-4642(22)00067-0

Vanneste, Y. T. M., Lanting, C. I., & Detmar, S. B. (2022). The Preventive Child and Youth Healthcare Service in the Netherlands: The State of the Art and Challenges Ahead. *International Journal of Environmental Research and Public Health*, *19*(14), 8736. https://doi.org/10.3390/ijerph19148736

Verhulst, F. C. (1997). The Prevalence of DSM-III-R Diagnoses in a National Sample of Dutch Adolescents. *Archives of General Psychiatry*, *54*(4), 329. https://doi.org/10.1001/archpsyc.1997.01830160049008

Vervoort-Schel, J., Mercera, G., Wissink, I., Van Der Helm, P., Lindauer, R., & Moonen, X. (2021). Prevalence of and relationship between adverse childhood experiences and family context risk factors among children with intellectual disabilities and borderline intellectual functioning. *Research in Developmental Disabilities*, *113*, 103935. https://doi.org/10.1016/j.ridd.2021.103935

Wallander, J. L., Dekker, M. C., & Koot, H. M. (2006). Risk factors for psychopathology in children with intellectual disability: A prospective longitudinal population-based study. *Journal of Intellectual Disability Research*, *50*(4), 259–268. https://doi.org/10.1111/j.1365-2788.2005.00792.x

Wei, H., Zhu, Y., Wang, T., Zhang, X., Zhang, K., & Zhang, Z. (2021). Genetic risk factors for autism-spectrum disorders: A systematic review based on systematic reviews and meta-analysis. *Journal of Neural Transmission*, *128*(6), 717–734. https://doi.org/10.1007/s00702-021-02360-w

Wieland, J., Haan, S. K.-D., & Zitman, F. G. (2014). Psychiatric Disorders in Outpatients with Borderline Intellectual Functioning: Comparison with Both Outpatients from Regular Mental Health Care and Outpatients with Mild Intellectual Disabilities. *The Canadian Journal of Psychiatry*, *59*(4), 213–219. https://doi.org/10.1177/070674371405900406

Witwer, A. N., & Lecavalier, L. (2007). Autism screening tools: An evaluation of the Social Communication Questionnaire and the Developmental Behaviour Checklist–Autism Screening Algorithm. *Journal of Intellectual & Developmental Disability*, *32*(3), 179–187. https://doi.org/10.1080/13668250701604776

Woittiez, I., Eggink, E., Putman, L., & Ras, M. (2018). *An international comparison of care for people with intellectual disabilities* (SCP-publication 2018-18). Netherlands Institute for Social Research (SCP). https://www.scp.nl/publicaties/publicaties/2018/07/06/an-international-comparison-of-care-for-people-with-intellectual-disabilities

Nederlandse Samenvatting

Kinderen met een licht verstandelijke beperking of zwakbegaafdheid (LVB-ZB) hebben een verhoogd risico op mentale gezondheidsproblemen. Toch zijn ze vaak ondervertegenwoordigd in onderzoek, met name in studies waarin contextuele factoren worden onderzocht, zoals gezinsstructuur, ouderlijke gezondheid, sociaaleconomische omstandigheden en buurtkenmerken. Aangezien de ondersteuningsbehoeften van kinderen met LVB-ZB vaak minder zichtbaar zijn dan bij zwaardere vormen van een verstandelijke beperking, wordt op basis van eerder onderzoek verondersteld dat mentale problemen bij deze groep mogelijk sterker samenhangen met contextuele stressoren. Dit proefschrift vertrekt daarom vanuit een contextueel perspectief: in hoeverre hangen contextuele factoren samen met de mentale gezondheid van kinderen met LVB-ZB?

Drie deelvragen vormen de rode draad door dit proefschrift: (1) wat weten we uit bestaand empirisch onderzoek over de samenhang tussen contextuele factoren en de mentale gezondheid bij kinderen met een verstandelijke beperking? (2) in welke mate komen deze verbanden ook terug in een grote Nederlandse steekproef: hoe hangen contextuele factoren over verschillende levensdomeinen samen met mentale problemen bij kinderen met LVB-ZB, en verschilt dat tussen klinische subgroepen? en (3) hoe verhouden gezondheidsproblemen van ouders zich tot de mentale gezondheid van het kind?. Deze vragen zijn beantwoord in vier samenhangende studies. Deelvraag 1 wordt beantwoord met een systematische literatuurstudie en deelvragen 2 en 3 aan de hand van drie registerstudies met gekoppelde populatiegegevens uit zorg-, huisartsen- en administratieve registraties. Daarin wordt de groep kinderen met LVB-ZB en mentale problemen vergeleken met kinderen met mentale problemen zonder LVB-ZB en/of kinderen zonder mentale problemen en zonder LVB-ZB.

Hoofdstuk 2 beschrijft een systematische literatuurstudie naar de samenhang tussen contextuele factoren en mentale gezondheid bij kinderen met een verstandelijke beperking, ongeacht de ernst daarvan. In totaal werden 51 internationale studies geïncludeerd, grotendeels cross-sectioneel van opzet en sterk uiteenlopend in methodologie en in definities van de contextuele domeinen (demografisch, economisch, sociaal-cultureel en buurt) die als kader in deze review worden gehanteerd. Van de vier domeinen bood het sociaal-culturele domein de meeste en meest consistente evidentie: vooral ouderlijke mentale problemen, gezinsstress en negatieve opvoedingsstrategieën bleken samen te hangen met mentale problemen bij kinderen met een verstandelijke beperking. Bevindingen over demografische en economische factoren waren beperkter en minder consistent, en de buurtcontext bleek nauwelijks onderzocht. De heterogeniteit van de studies en het gebrek aan longitudinaal onderzoek laten zien dat de kennisbasis over de wijze waarop contextuele factoren samenhangen met mentale gezondheid nog beperkt en gefragmenteerd is.

De eerste registerstudie (hoofdstuk 3; N = 19.632) zet vervolgens de context van kinderen met LVB-ZB en mentale problemen af tegen twee referentiegroepen: kinderen met mentale problemen zonder LVB-ZB en leeftijds- en seksegematchte leeftijdsgenoten uit de algemene populatie. In een multivariaat model tekende zich een duidelijk patroon af: kinderen met LVB-ZB en mentale problemen groeien vaker op in gezinnen met ouders met een lager opleidingsniveau, een lager huishoudinkomen en in eenoudergezinnen. Deze kenmerken wijzen op sociaaleconomische kwetsbaarheid. Wanneer rekening werd gehouden met de andere contextuele factoren, kwamen kinderen met LVB-ZB en mentale problemen vaker uit kleinere huishoudens en hadden hun moeders minder vaak een migratieachtergrond buiten Europa. Buurtkenmerken, zoals stedelijkheid of gemiddeld buurtinkomen, hingen wel samen met mentale problemen, maar bleken geen afzonderlijke rol te spelen wanneer andere factoren werden meegewogen.

In de tweede registerstudie (hoofdstuk 4; N = 10.452) staat de sociaaleconomische context centraal. We onderzoeken in welke mate sociaaleconomische risicofactoren zich in gezinnen opstapelen en of ze verschillen tussen klinische subgroepen binnen de LVB-ZB groep. Ten opzichte van de algemene populatie leven kinderen met LVB-ZB en mentale problemen vaker in gezinnen met een laag inkomen, lagere opleiding van ouders, uitkeringsafhankelijkheid, huur- of gesubsidieerde woning en eenouderhuishoudens. Deze omstandigheden komen vaak samen: 15,3% van de kinderen met LVB-ZB had vijf risico’s tegelijk, tegenover 6,7% in de algemene populatie. Binnen de klinische groep van kinderen met LVB-ZB valt op dat internaliserende en externaliserende gedragsprofielen vaker samengaan met de sterkste sociaaleconomische kwetsbaarheid, terwijl bij kinderen met ontwikkelingsproblematiek, zoals autisme, deze contextuele kwetsbaarheden gemiddeld genomen minder uitgesproken zijn. Opvallend was dat juist kinderen uit sociaaleconomisch gunstiger gezinnen vaker meer uitgebreide zorg ontvingen, wat wijst op een complex samenspel tussen zorggebruik en sociaaleconomische omstandigheden.

De derde registerstudie (hoofdstuk 5; N = 22.458) verlegt de focus naar de gezondheid van ouders van kinderen met LVB-ZB en mentale problemen. In huisartsendossiers is gekeken naar zowel mentale als somatische gezondheidsproblemen. De conclusie luidt: Ouders van kinderen met mentale problemen (met en zonder LVB-ZB) hebben vaker én een bredere variatie aan lichamelijke en psychische gezondheidsproblemen dan ouders uit de algemene populatie. De meest uitgesproken verschillen vonden we in lichamelijke processen die gevoelig zijn voor chronische stress, zoals hormonale, metabole en spijsverteringsfuncties, en in het voorkomen van psychische klachten. Belangrijk is dat de patronen grotendeels gelijk zijn bij ouders van kinderen met en zonder LVB-ZB. Dat suggereert dat vooral de mentale problematiek van het kind (en minder het cognitieve ontwikkelingsniveau op zich) samenhangt met gezondheidsproblemen van ouders. Deze bevindingen onderstrepen het belang van een gezinsgerichte benadering in onderzoek en praktijk wanneer mentale problemen van kinderen worden behandeld.

De studies tezamen brengen drie belangrijke inzichten naar voren. Ten eerste is de contextuele kwetsbaarheid meerdimensioneel: verschillende risicofactoren spelen tegelijk, vervullen een unieke rol in onderlinge samenhang, en clusteren binnen dezelfde gezinnen. Ten tweede blijkt een deel van de contextuele kwetsbaarheid gedeeld: factoren als laag inkomen, eenoudergezinnen en ouderlijke gezondheidsproblemen zijn niet uniek voor kinderen met LVB-ZB, maar kenmerken veel gezinnen waarin kinderen mentale problemen hebben. Tegelijk zien we dat de sociaaleconomische achterstand gemiddeld groter is bij kinderen met LVB-ZB en mentale problemen, waardoor de draagkracht van deze gezinnen mogelijk verder onder druk komt te staan. Ten derde blijkt de groep kinderen met LVB-ZB niet homogeen. Kinderen met internaliserende of externaliserende problematiek leven vaker in sociaaleconomisch kwetsbare gezinnen dan kinderen met ontwikkelingsstoornissen. Dit wijst op verschillende onderliggende mechanismen en benadrukt de noodzaak van flexibel en context-sensitief ingerichte zorg, afgestemd op subgroepverschillen.

Methodologisch leunt dit proefschrift op de ELAN-infrastructuur (Extramuraal LUMC Academisch Netwerk), waarin gegevens uit verschillende domeinen met elkaar zijn gekoppeld, waaronder geestelijke gezondheidszorg, huisartsenpraktijken, ziekenhuizen, gemeentelijke registraties en landelijke administratieve bestanden van het CBS. Dit levert grote, populatiegebaseerde steekproeven op met multilevelkoppelingen op het niveau van individu, huishouden en familie, en maakt het mogelijk klinisch gedefinieerde groepen te onderscheiden. Deze opzet bevordert de ecologische validiteit en verkleint de selectiebias, wat bijzonder relevant is voor gezinnen die doorgaans ondervertegenwoordigd zijn in onderzoek. Tegelijk brengen routinegegevens beperkingen met zich mee, zoals onvolledigheid, variatie in registraties over de tijd en het gebruik van proxy-maten. Daarnaast konden kinderen met LVB-ZB alleen worden geïdentificeerd op basis van hun gebruik van gespecialiseerde zorg, waardoor kinderen met LVB-ZB buiten deze zorg onzichtbaar bleven en een referentiegroep zonder mentale problemen ontbreekt. Binnen deze grenzen is het ontwerp goed geschikt om structurele patronen van kwetsbaarheid, clustering van risico's en variatie tussen subgroepen zichtbaar te maken, en vormt het een vertrekpunt voor longitudinaal vervolgonderzoek.

Implicaties

De bevindingen in dit proefschrift hebben belangrijke implicaties voor toekomstige studies, de klinische praktijk, beleidsontwikkeling en de opleiding van professionals.

Implicaties voor onderzoek

Toekomstig onderzoek zou zich allereerst moeten richten op longitudinale studies. De registerstudies in dit proefschrift waren cross-sectioneel van aard, waardoor geen uitspraken konden worden gedaan over de richting van de verbanden. Longitudinaal onderzoek is nodig om beter te begrijpen hoe contextuele factoren zich over tijd ontwikkelen en samenhangen met de mentale kwetsbaarheid bij kinderen met LVB-ZB. Langdurige koppelingen van routinematig verzamelde data, bijvoorbeeld binnen infrastructuren als ELAN, maken het mogelijk om veranderingen in contextuele kwetsbaarheid over de tijd te volgen. Daarnaast biedt uitbreiding van dergelijke datanetwerken kansen om de interactie tussen kind, gezin en context, inclusief de wederkerige relaties tussen ouder en kind, te onderzoeken.

Als tweede dient opgemerkt dat veel verbanden tussen bepaalde contextuele factoren en mentale problemen nog onvoldoende onderzocht zijn. Vooral buurtkenmerken, zoals diversiteit, sociale cohesie, veiligheid en infrastructuur, zijn nauwelijks onderzocht. Ook factoren als schulden, ouderlijke laaggeletterdheid en culturele achtergrond verdienen aandacht. Om dergelijke aspecten beter te begrijpen, is het waardevol om kwantitatieve analyses aan te vullen met kwalitatieve of participatieve methoden, waarin de perspectieven van kinderen en gezinnen centraal staan.

Een derde onderzoeksrichting betreft kinderen met LVB-ZB die géén gespecialiseerde zorg ontvangen, maar die dat mogelijk wel nodig hebben. Dit proefschrift richtte zich uitsluitend op kinderen die in zorg zijn geregistreerd; over kinderen die niet in deze registraties voorkomen, omdat de beschikbare data hen niet kunnen identificeren, is weinig bekend. Zij kunnen hinder ondervinden van beperkte herkenning, terughoudend hulpzoekgedrag of ontoegankelijke voorzieningen. Routinematige gegevens van bijvoorbeeld de GGD kunnen helpen om deze groep in beeld te brengen en vroege signalen van kwetsbaarheid te identificeren.

Verder is onderzoek nodig naar contextuele risico's en beschermende factoren buiten de Nederlandse of West-Europese context. Zowel de literatuur uit de systematische review als de registerstudies in dit proefschrift zijn vrijwel volledig gebaseerd op stedelijke populaties in een hoog-inkomensland. Culturele, geografische en sociaaleconomische verschillen kunnen sterk bepalen hoe mentale problemen ontstaan en worden herkend. Vergelijkende studies, zowel internationaal als binnen migrantenpopulaties, zijn daarom cruciaal om de generaliseerbaarheid van de resultaten te toetsen.

Tot slot kan het syndemisch perspectief waarin gelijktijdige risico's elkaar versterken nieuwe inzichten bieden. Dit proefschrift liet zien dat contextuele kwetsbaarheden vaak samen voorkomen, maar niet of en hoe ze elkaar versterken. Onderzoek naar dergelijke interacties kan helpen verklaren waarom sommige kinderen bijzonder kwetsbaar zijn en hoe cumulatieve stress de ontwikkeling van mentale problemen beïnvloedt.

Implicaties voor de klinische praktijk

Een kernboodschap van dit proefschrift is de noodzaak van een holistische, contextgevoelige benadering in de diagnostiek en behandeling van kinderen met LVB-ZB en mentale problemen. Mentale problemen kunnen niet los worden gezien van de gezins- en leefomgeving. Hulpverleners worden daarom aangemoedigd om verder te kijken dan symptoomdiagnoses en systematisch contextuele informatie te integreren in casusbesprekingen en behandelstrategie binnen de gespecialiseerde ggz.

Ten tweede vragen de bevindingen om meer aandacht voor de cumulatie van risico’s. Veel kinderen ervaren meerdere, samenhangende problemen binnen hun gezin of leefomgeving. Het structureel in kaart brengen van deze contextuele kwetsbaarheid, bijvoorbeeld via gestandaardiseerde vragenlijsten of interviews, kan hulpverleners in de gespecialiseerde ggz helpen om prioriteiten te stellen en tijdig aanvullende ondersteuning te initiëren. Op organisatieniveau onderstreept dit het belang van interdisciplinaire samenwerking en geïntegreerde zorgtrajecten.

Een derde punt is het actief betrekken van ouders en het bredere gezinssysteem. Ouders van kinderen met LVB-ZB en mentale problemen hebben vaker zelf lichamelijke of psychische gezondheidsproblemen, wat de draagkracht van het gezin beïnvloedt. Het is daarom essentieel om ouderlijke gezondheid te bespreken, psycho-educatie te bieden en, waar nodig, samenwerking met volwassenenzorg te zoeken. Gezinsgerichte interventies, waarin ouder en kind gezamenlijk worden ondersteund, kunnen bijdragen aan herstel en veerkracht.

Tot slot vraagt de praktijk om zorgvormen die beter aansluiten bij de dagelijkse realiteit van gezinnen. Initiatieven zoals de GIJS-bus (‘GGZ In Jouw Straat’) vanuit de Banjaard (Youz, Parnassia Groep) laten zien dat outreachende, laagdrempelige zorg mogelijk is. Investeren in en evalueren van dergelijke modellen is nodig om te onderzoeken hoe de GGZ dichter bij huis kan worden georganiseerd.

Implicaties voor beleid

De bevindingen benadrukken dat effectieve zorg voor kinderen met LVB-ZB en mentale problemen niet kan worden gerealiseerd zonder structurele samenwerking tussen zorg, onderwijs, jeugdhulp en sociale diensten. Beleidsmatig vraagt dit om duurzame afspraken en financieringsstructuren die sectoroverschrijdende samenwerking mogelijk maken. Hoewel recente beleidsontwikkelingen integrale zorg beogen, is de vertaling naar de praktijk nog beperkt. De resultaten van dit proefschrift bieden empirische onderbouwing voor de noodzaak van zulke intersectorale samenwerkingsstructuren.

Implicaties voor opleiding en professionalisering

Ten slotte heeft dit proefschrift implicaties voor de opleiding van professionals. Veel opleidingsprogramma's zijn sterk disciplinespecifiek en leeftijdsgericht, waardoor kennisdeling tussen kinder-, jeugd- en volwassenenzorg beperkt blijft. Daarnaast ontbreekt scholing over de grenzen van disciplines en sectoren heen, terwijl juist deze groepen elkaar regelmatig ontmoeten in de praktijk. Opleidingen zouden meer aandacht moeten besteden aan interprofessionele communicatie, contextuele risicotaxatie en systeemgericht werken. Intersectorale stages, gezamenlijke casusbesprekingen of multidisciplinaire trainingsmodules kunnen toekomstige professionals beter voorbereiden op de complexe realiteit van gezinnen waarin problemen zich over domeinen en generaties heen opstapelen.

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Rick, de liefste partner die mijn (PhD-)leven zoveel mooier en ook makkelijker maakt(e). In bijna al mijn artikelen sta jij genoemd, en terecht. Je dacht inhoudelijk met me mee en was er altijd wanneer ik je nodig had — om te luisteren, je gedachten te delen en me af te remmen wanneer ik te veel van mezelf vroeg. Jouw onvoorwaardelijke steun en vertrouwen betekenen alles voor me. Ik kijk uit naar alles wat ons te wachten staat.

Curriculum Vitae

Maxine Margaréta Carmen Storm was born on November 29th, 1996, in Rotterdam, the Netherlands. She completed her secondary education (VWO) at De Ring van Putten in Spijkenisse in 2015. In the same year, she started studying Pedagogical Sciences at Erasmus University Rotterdam. During her studies, she completed the minor Learning from Big Data and conducted a research internship at the Department of Psychology, Education and Child Studies. Her bachelor’s thesis, on the psychometric properties of the Hierarchical Personality Inventory for Children in young adults, was awarded Best Bachelor’s Thesis of the year. In 2018, she started the Master’s programme in Statistics & Data Science at Leiden University, specializing in Life and Behavioural Sciences. During her master's thesis, she conducted a simulation study on Pairwise Maximum Likelihood within a Confirmatory Factor Analysis framework. Alongside her Master’s, she worked as a research assistant and statistics tutor at Erasmus University Rotterdam, and assisted SPSS practicals at Leiden University. In September 2021, Maxine started her PhD project at the Department of Child and Adolescent Psychiatry of Leiden University Medical Center and Youz (Parnassia Groep). In addition to her PhD research, she taught statistics courses to psychology students at Leiden University and worked as a BodyCombat and Yin Yoga instructor at several gyms. She also volunteered at several organizations, including the Surf Project, which offers surf lessons to children with Down syndrome, autism, and ADHD to boost their development and self-confidence. She recently began volunteering with Vitalis Maatjes, where she supports children growing up in vulnerable family systems, a role she chose based on insights from her dissertation. In December 2025, Maxine started working as a Data Research Coordinator in a hybrid position between the departments Bedrijfsinformatie & Data Science (BIDS) and Parnassia Groep Academie (PGA), where she contributes to strengthening data-driven research in mental healthcare and enhancing collaboration across the organization.

Publications

In this dissertation

- **Storm, M. M. C.**, van Eldik, W. M., Nooteboom, L. A., & Vermeiren, R. R. J. M. (2025). Social determinants associated with mental health problems in youth with intellectual disability: A systematic literature review. *European Child & Adolescent Psychiatry*. Advance online publication. https://doi.org/10.1007/s00787-025-02794-7
- **Storm, M. M. C.**, Giltay, E. J., van Eldik, W. M., Palstra, E. C., van Duin, E. D. A., van den Berg, D., & Vermeiren, R. R. J. M. (2025). Social determinants of youth with mild intellectual disability in outpatient care for mental health disorders: A case–control study. *European Child & Adolescent Psychiatry*. Advance online publication. https://doi.org/10.1007/s00787-025-02718-5
- **Storm, M. M. C.**, van Eldik, W. M., Kasius, M. C., Vermeiren, R. R. J. M., & Giltay, E. J. (2025). Broad perspective on socio-economic disadvantages in youth with mild to borderline intellectual disabilities in mental health care. *European Child & Adolescent Psychiatry*. https://doi.org/10.1007/s00787-025-02934-z
- **Storm, M. M. C.**, van Eldik, W. M., de Waal, M. W. M., Kasius, M. C., Vermeiren, R. R. J. M., & Giltay, E. J. (n.d.). Health problems in parents of children with mild to borderline intellectual disabilities in mental health care: A comparative study using linked databases. Manuscript submitted for publication.

Other publications

- **Storm, M. M. C.**, van Eldik, W. M., Palstra, E. C., Özgen, M. H., van Vliet, C. L. M., & Vermeiren, R. R. J. M. (2023). Koppelen van ggz- en CBS-microdata om zorgeffectiviteit te meten. *Tijdschrift voor Psychiatrie, 2023*(6), 383-387.
- Terry, J., Ross, R. M., Nagy, T., Salgado, M., Garrido-Vásquez, P., Sarfo, J. O., Cooper, S., Büttner, A. C., Lima, T. J. S., Öztürk, İ., Akay, N., Santos, F. H., Artemenko, C., Copping, L. T., Elsherif, M. M., Milovanović, I., Cribbie, R. A., Drushlyak, M. G., Swainston, K., Shou, Y., Leongómez, J.

D., Palena, N., Abidin, F. A., Reyes-Rodríguez, M. F., He, Y., Abraham, J., Vatakis, A., Jankowsky, K., Schmidt, S. N. L., Grimm, E., González, D., Schmid, P., Ferreira, R. A., Rozgonjuk, D., Özhan, N., O'Connor, P. A., Zsido, A. N., Stiglic, G., Rhodes, D., Rodríguez, C., Ropovik, I., Enea, V., Nurwanti, R., Estudillo, A. J., Beribisky, N., Himawan, K. K., Geven, L. M., van Hoogmoed, A. H., Bret, A., Chapman, J. E., Alter, U., Flack, Z. M., Hanna, D., Soltanlou, M., Banik, G., Adamkovič, M., van der Ven, S. H. G., Mosbacher, J. A., Şen, H. H., Anderson, J. R., Batashvili, M., de Groot, K., Parker, M. O., Helmy, M., Ostroha, M. M., Gilligan-Lee, K. A., Egara, F. O., Barwood, M. J., Thomas, K., McMahon, G., Griffin, S. M., Nuerk, H.-C., Counsell, A., Lindemann, O., van Rooy, D., Wege, T. E., Lewis, J. E., Aczel, B., Monaghan, C., Al-Hoorie, A. H., Huber, J. F., Yapan, S., Garrido-Vásquez, M. E., Callea, A., Ergiyen, T., Clay, J. M., Mertens, G., Topçu, F., Tutlu, M. G., Täht, K., Mikkor, K., Caso, L., Karner, A., **Storm, M. M. C.**, Daroczy, G., Zein, R. A., Greco, A., Buchanan, E. M., Schmid, K., Hunt, T. E., de Keersmaecker, J., Branney, P. E., Randell, J., Clark, O. J., Steltenpohl, C. N., Malu, B., Tekeş, B., Ramis, T., Agrigoroaei, S., Badcock, N. A., McAloney-Kocaman, K., Semenikhina, O. V., Graf, E. W., Lea, C., Ogba, K. T. U., Guppy, F. M., Warhurst, A. C., Lindsay, S., Al Khateeb, A., Scharnowski, F., de Kwaadsteniet, L., Francis, K. B., Lecompte, M., Webster, L. A. D., Morsanyi, K., Forwood, S. E., Walters, E. R., Tip, L. K., Wagge, J. R., Lai, H. Y., Crossland, D. S., Darda, K. M., Flack, T. R., Leviston, Z., Brolly, M., Hills, S. P., Collins, E., Roberts, A. J., Cheung, W.-Y., Leonard, S., Verschuere, B., Stanley, S. K., Xenidou-Dervou, I., Ghasemi, O., Liew, T., Ansari, D., Guilaran, J., Penny, S. G., Bahnmueller, J., Hand, C. J., Rahajeng, U. W., Peterburg, D., Takacs, Z. K., Platow, M. J., & Field, A. P. (2023). Data from an international multi-centre study of statistics and mathematics anxieties and related variables in university students (the SMARVUS dataset). *Journal of Open Psychology Data, 11*(8), 1–25. https://doi.org/10.5334/jopd.80