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

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Citation

Storm, M. M. C. (2026, March 6). *Beyond the individual: a contextual perspective on mental health in children with mild to borderline intellectual disabilities*. Retrieved from https://hdl.handle.net/1887/4296757

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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.

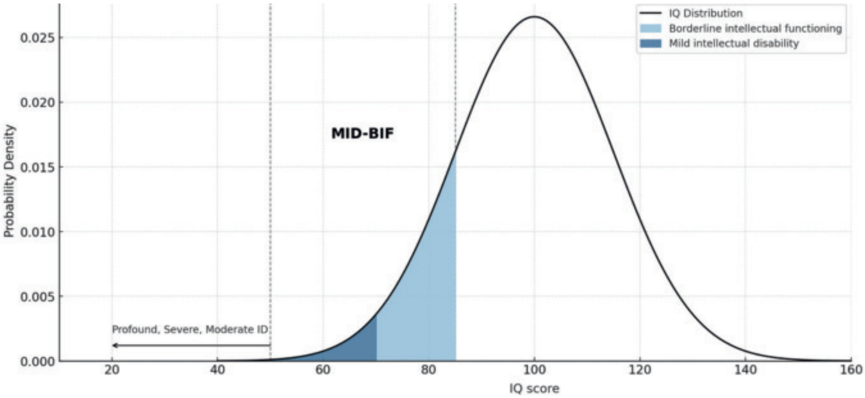
This chapter outlines the conceptual, empirical, and methodological foundation for this dissertation. It begins by defining key concepts and outlining the theoretical framework. It then identifies relevant knowledge gaps, describes the methodological approach, and presents the structure of the dissertation.

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.

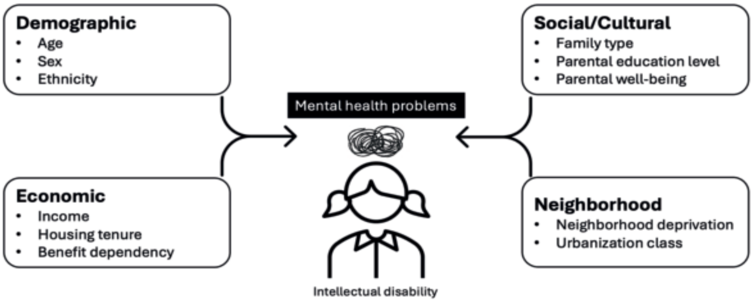
To conceptualize the wide range of contextual factors, several theoretical models have been developed. These models differ in emphasis and scope, but they share the recognition that individuals develop and function within broader social and environmental systems. One of the most influential frameworks 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.

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