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

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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.

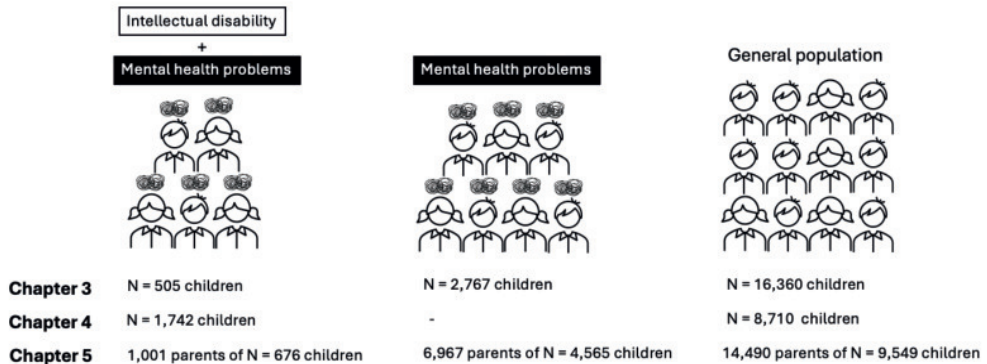
In response to this gap, the present dissertation adopts a contextual perspective, shifting the focus to the broader environments in which children with MID-BIF grow up. The overarching aim of this dissertation is to examine whether contextual factors relate to mental health problems in children with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



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)
<b>Demographic</b>	Ethnicity mother	~	+
	Maternal age	~	○
	Paternal age		○
	Ethnicity father		○
<b>Economic</b>	Household income	~	+
	Benefit dependency	○	+
	Housing tenure	○	+
	Household income source		+
	Main benefit type		+
	Parental financial stress	+	
	Debt		
	Income instability		
<b>Social/Cultural</b>	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		
<b>Neighborhood</b>	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
<b>Data coverage</b>	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.
<b>Contextual scope</b>	Integration of data across multiple life domains; supports system-level analysis of structural patterns	No insight in everyday experiences or interpersonal processes
<b>Group classification</b>	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
<b>Representativeness</b>	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
<b>Data quality</b>	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 (Nootboom et al., 2021), translating these ambitions into effective structures and daily practice remains challenging (Nootboom 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., Kieft-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](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](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/fpsy.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/fpsy.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](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>