Shared roads, shared risks: understanding the needs of youth with severe and enduring mental health problems

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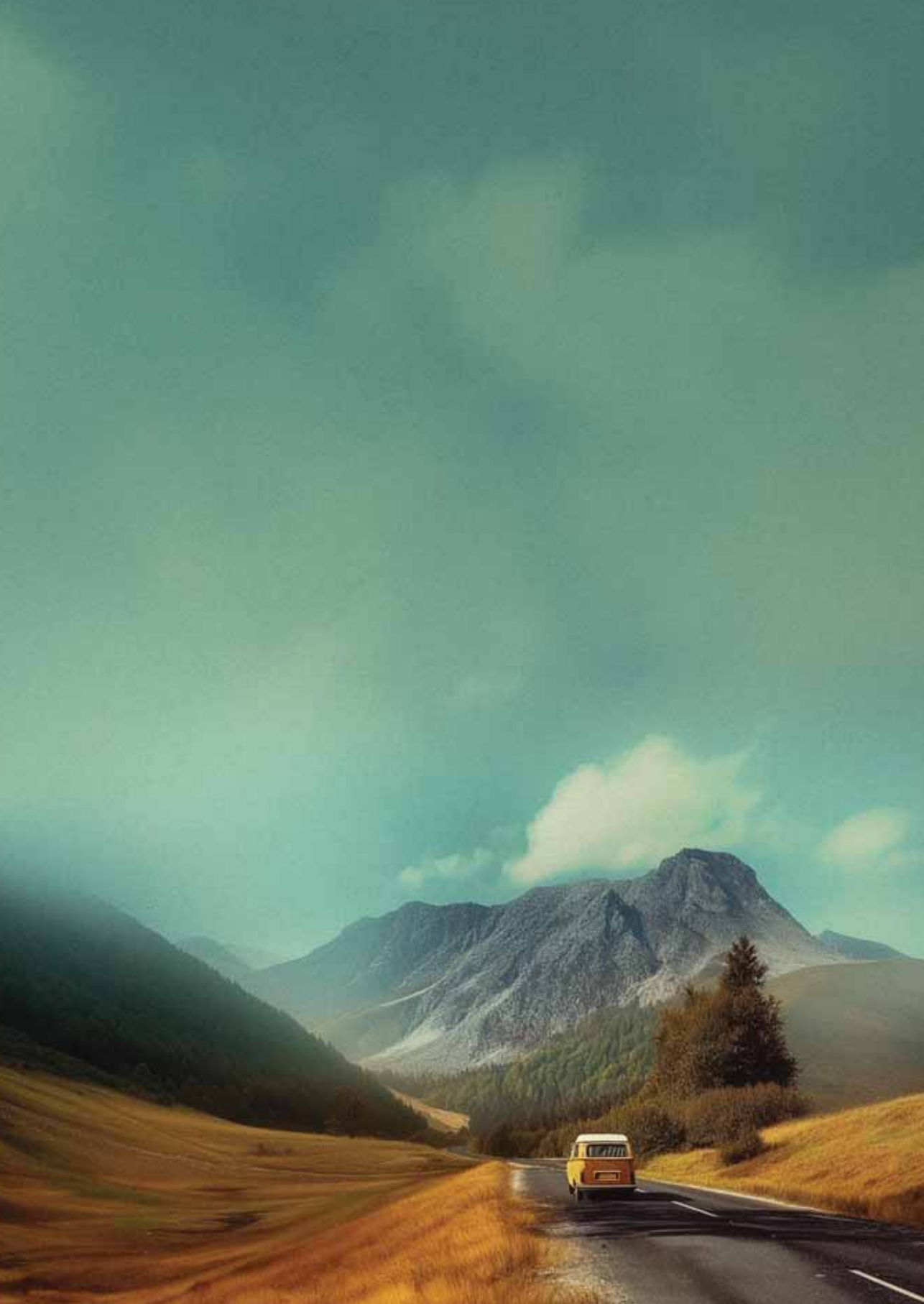

Chapter 1

General introduction

Background

In recent years, concerns have grown over the rising rates of mental health problems among youth (Caspi et al., 2020; McGorry, Gunasiri, Mei, Rice, & Gao, 2025). Within this broader trend, a specific group of youth stands out: those with severe and enduring mental health problems (SEMHP). Often described as 'complex' in clinical settings and public discourse, these youth struggle with mental health problems despite receiving prolonged and intensive care. They typically face persistent, shifting, and co-occurring symptoms, engage in high-risk behaviors, and experience significant impairments across multiple domains of daily life (Bansema et al., 2023; Bansema et al., 2024; Herpers, Neumann, & Staal, 2020; Woody et al., 2019; Wright et al., 2017). Many of them drop out of care or move from one treatment to another without meaningful improvement, as their symptoms persist or exacerbate (Dean, 2017; Sellers et al., 2019; Warren, Nelson, Mondragon, Baldwin, & Burlingame, 2010). These unresolved trajectories not only perpetuate individual suffering but also carry devastating consequences for families, practitioners, and society at large.

A large proportion of mental disorders emerge early in life, with 23.6% developing before the age of 14 and 62.5% before the age of 25 (Solmi et al., 2022). When left insufficiently treated, severe mental health problems in adolescence persist during adulthood, resulting in long-term dysfunction, reduced quality of life, emotional distress for families, and substantial societal costs (Friele, Hageraats, Fermin, Bouwman, & van der Zwaan, 2019; Kessler et al., 2007; Sellers et al., 2019; Warren, Nelson, Burlingame, & Mondragon, 2012). In parallel, recent statistics reveal another alarming trend: suicide is now the leading cause of death among youth in the Netherlands, with rates continuing to rise - particularly among those already receiving mental health care (Balt, Vrinzen, Salmi, Eiekelenboom, & Merelle, 2025; Centraal Bureau voor de Statistiek, 2025; Merelle et al., 2020). Also, in clinical practice, it becomes increasingly clear that some youth are getting stuck in the system, moving from one provider, diagnosis, or treatment to the next, yet continuing to feel hopeless and engage in serious self-destructive behavior. Their struggles often leave practitioners uncertain about how to proceed, and mirror reports in the media of youth with extensive care histories yet receiving inadequate support (Inspectie Gezondheidzorg en Jeugd, 2021). Despite the urgency of the situation, there is still limited understanding of why current mental health services fail to adequately meet the needs of youth with SEMHP.

The DevelopRoad research project was initiated in response to these challenges. DevelopRoad aimed to bridge this gap between care provision and the needs of youth, with two primary goals: (1) to gain a deeper

understanding of the characteristics of youth with SEMHP in child and adolescent psychiatry (CAP), and (2) to explore what these youth need in CAP treatment to foster better outcomes. The first aim is addressed in the dissertation by Bansema (2025). This dissertation focuses on the second aim, drawing on the perspectives of youth, caregivers, and practitioners to identify treatment barriers and facilitators in CAP, and opportunities for change. In doing so, this dissertation aims to contribute to a more responsive and effective mental healthcare system for youth with SEMHP.

Theoretical background

The theoretical background for this dissertation is structured in four parts. It begins with an outline of the characteristics of youth with SEMHP, followed by an exploration of the child and adolescent psychiatry (CAP) system in which they receive care. The third part focuses on the role of practitioners and caregivers, and finally, attention is given to the broader care services that determine how care is shaped. This layered approach provides the theoretical foundation for the research questions addressed in this dissertation.

Youth with severe and enduring mental health problems

As part of the DevelopRoad project, recent research in CAP has begun to systematically describe the characteristics of youth with SEMHP (Bansema et al., 2023; Bansema et al., 2024). This group is marked by the presence of multiple psychiatric classifications and mental health problems at once, enduring suffering, impairments across various life domains, and long-term care history. A distinctive feature of this group, mostly girls in their adolescence (Leyenaar, Freyleue, Arakelyan, Schaefer, & O'Malley, 2025), is the prevalence of high-risk behaviors, such as self-harm, suicidal behavior, and disordered eating.

In addition to individual vulnerabilities, such as trauma, a negative self-image, and interpersonal distrust, these youth often experience a lack of social support, stigma, and a sense of exclusion from both mental healthcare and society. To understand SEMHP adequately, it is essential to consider these characteristics within a broader, ecological framework, recognizing the dynamic interaction between the individual, their social environment, the healthcare system, and societal factors (Bansema et al., 2024).

Another important finding is that the difficulties of youth with SEMHP are not merely individual in nature, but are shaped in part by their experiences within the care system itself. This highlights the need to better understand the interaction between the healthcare system and its impact on youth and caregivers (Bansema et al., 2024). These outcomes align with the focus of

this dissertation, which explores experiences, barriers, and facilitating factors in treatment, further emphasizing the importance of addressing systemic influences on the well-being and outcomes for youth and their families.

Youth with SEMHP in child and adolescent psychiatry

In the Netherlands, children and adolescents with mental health problems typically first receive support through general or community-based services, referred to as 'primary care'. These services include local support teams, general practitioners, and centers for youth and family. Primary care professionals (generalists) provide low-threshold support for common psychosocial issues and may offer basic interventions or guidance (Netherlands Youth Institute, 2019). In 2024, 10.8% of all children and adolescents under the age of 23 in the Netherlands received some form of youth care, reflecting a substantial demand for mental health and social support services in this age group (Centraal Bureau voor de Statistiek, 2025). When these low-intensity services prove insufficient due to the severity or complexity of the problems, youth may be referred to more intensive forms of care, including secondary and tertiary services. Tertiary care refers to specialized mental health services that are typically provided within clinical settings. In the Netherlands, In the Netherlands, CAP is part of this tertiary care system and falls under the domain of specialized mental healthcare. Access to these services is not open-ended; it requires a formal referral based on a clinical indication or a municipal decision, in accordance with the Youth Act (Jeugdwet).

CAP in the Netherlands offers a continuum of care, ranging from outpatient services, such as individual therapy, family interventions, and pharmacotherapy, to more intensive forms of treatment, including day treatment programs, residential care, and acute crisis interventions via High & Intensive Care (HIC) units (Pelzer & Winters-van Eekelen, 2024). Within this system, treatment planning in CAP is usually guided by psychiatric diagnostics, typically guided by the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013; van der Mheen et al., 2024). While this classification-based model may provide a structured approach to identifying symptoms and determining treatment strategies, it is ill-suited for youth with SEMHP. Their difficulties often encompass shifting, co-morbid, and context-dependent symptoms that do not fit neatly into standard diagnostic categories (Bansema et al., 2023). As a result, the medical model and its reliance on DSM-based classifications fail to provide a coherent foundation for their treatment.

Youth with SEMHP frequently cycle through multiple treatment attempts, diagnostic reassessments, and transitions between outpatient and inpatient settings. These fragmented care trajectories may fail to address the persistent

and contextually embedded nature of their difficulties, and can contribute to feelings of rejection and misunderstanding (Broersen, Frieswijk, Kroon, Vermulst, & Creemers, 2020; Woody et al., 2019). One critical consequence of this process is the loss of epistemic trust: the ability to regard others as reliable sources of knowledge (Fonagy & Allison, 2014). Many youth with SEMHP already struggle with epistemic trust due to their earlier experiences of trauma, family instability, social exclusion, and insecure attachment (Bevington, Fuggle, & Fonagy, 2015). Repeated treatment failure may further undermine this trust, creating a downward spiral in which meaningful therapeutic relationships, and thereby effective care, are increasingly difficult to establish.

These structural and relational challenges also raise a broader fundamental question: what should treatment for youth with SEMHP aim to achieve? Psychiatric care has traditionally prioritized symptom reduction from a medicalized model of illness management (Gillard, 2019; Huda, 2021; Tempel, van Dijk, & de Castro, 2022). While this approach may be appropriate for people with singular or well-defined diagnoses, it falls short for youth with SEMHP. Their symptoms frequently shift due to developmental changes and may be masked until expressed in high-risk behaviors, such as self-harm or suicidality (Woody et al., 2019). As a result, interventions often prioritize acute safety and symptom reduction rather than long-term well-being, despite evidence suggesting that symptom reduction does not necessarily translate into improved quality of life (Stige, Barca, Lavik, & Moltu, 2021; Tempel et al., 2022). To better serve youth with SEMHP, it is therefore essential to reconsider not only how care in CAP is organized, but also what treatment should aim to achieve.

The role of the practitioners and caregivers

Providing care for youth with SEMHP in CAP places high demands on practitioners. These youth often display high-risk behaviors that require immediate decisions under pressure and challenge professional boundaries (Kaijadoe et al., 2025; Offringa et al., 2024). At the same time, youth's histories of treatment failure and the aforementioned lack of epistemic trust may lead to disengagement or resistance, complicating the therapeutic relationship, despite strong evidence that such alliances are essential for effective treatment in CAP (Baier, Kline, & Feeny, 2020; Elvins & Green, 2008; Horvath, Del Re, Fluckiger, & Symonds, 2011). Repeated setbacks can lead to practitioner fatigue, self-doubt, and moral distress, especially when restrictive measures are needed that may clash with professional values or with the youth's autonomy. Over time, such experiences may contribute to burnout and trauma (Kaijadoe et al., 2025; Maslach & Leiter, 2016) while also influencing clinical decision-making and the ability to maintain connection. These challenges can

be further compounded by the role of caregivers. In their efforts to protect their children, caregivers may advocate for restrictive interventions, which can place additional emotional and ethical strain on the clinical team (So, Nooteboom, Vullings, Mulder, & Vermeiren, 2024).

The involvement of caregivers is a crucial yet often underexamined factor in the treatment of youth with SEMHP. Caregivers play a dual role: they are important sources of support for youth and, at times, partakers in the systemic difficulties that affect treatment outcomes. Their emotional responses to their child's distress, previous experiences with mental health care, and perceived efficacy of interventions shape how they interact with practitioners (Baker-Ericzén, Jenkins, & Haine-Schlagel, 2013). While collaborative engagement between caregivers and practitioners can enhance the quality of care (Hoagwood, 2005), tensions may emerge when caregivers, driven by concern for their child's safety, advocate for restrictive measures that conflict with practitioners' preferred approaches. (So et al., 2024). Furthermore, caregivers themselves experience significant stress, often feeling isolated, exhausted, and unsure of how best to support their child (So et al., 2024).

These complex dynamics underscore the need for a more systemic understanding of care in the context of youth with SEMHP in CAP.

The role of care service in CAP

In recent years, the mental health needs of children and adolescents have received growing attention in public discourse, as concerns about rising prevalence, long waiting lists, and inadequate service capacity have become more urgent. In the Netherlands, approximately 8% of youth require long-term psychiatric care, highlighting the considerable demand placed on the care system (Systema et al., 2006).

These systemic challenges play a crucial role in shaping the experiences of youth with SEMHP. In the Netherlands, CAP services currently face a range of structural encounters that hinder the delivery of effective care. These include long waiting lists, particularly for youth with severe and complex mental health problems, an increase in acute crisis situations, and a shortage of personnel, all of which place growing pressure on care teams (Inspectie Gezondheidzorg en Jeugd, 2021). Moreover, recent reforms and budgetary constraints have further undermined continuity in care. One critical point is the transition from youth to adult care at the age of 18, a process that frequently results in fragmented trajectories and loss of support for vulnerable youth (Markoulakis et al., 2023).

International research underscores the urgency of addressing these systemic issues. Structural aspects such as referral procedures, financial policies, and eligibility criteria directly influence whether and how youth can access the care they need (Gulliver, Griffiths, & Christensen, 2010; Rickwood, Deane, & Wilson, 2007). Without adequate infrastructure and alignment across services, critical gaps in care persist.

The way safety is managed within care settings is another structural factor that affects how youth experience treatment. In the Netherlands, CAP services are embedded within a system that permits the use of restrictive measures in situations of acute risk, even when youth are treated in open residential settings. These measures, such as seclusion or forced feeding, are intended to ensure immediate safety for the youth and their surroundings (de Valk, Kuiper, van der Helm, Maas, & Stams, 2016; Inspectie Gezondheidszorg en Jeugd, 2022; Van de Koppel et al., 2022). However, their use also raises ethical concerns, particularly when such interventions undermine youth autonomy or damage trust. Over time, these experiences may impact treatment engagement and hinder recovery (de Valk et al., 2016; Ryan & Deci, 2000; Stein & Dumaret, 2011; van Dorp, Nijhof, Mulder, & Popma, 2021).

These findings suggest that the care environment itself, its legal, ethical, and relational dimensions, play a key role in either supporting or undermining youth safety and autonomy. For youth with SEMHP, who often have prolonged and complex trajectories in care, these dynamics deserve closer attention.

Current developments in the field of CAP

Shortcomings in care to meet the needs of youth who struggle with severe mental health problems have led to growing interest in alternative frameworks, such as the recovery movement and the positive health approach, which reframe health not as the absence of disease, but as the ability to adapt and self-manage in the face of adversity (Huber et al., 2011; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). While such strength-based models have influenced adult mental health care, they remain underdeveloped in CAP. Initiatives like Youth Flexible Assertive Community Treatment (Youth Flexible ACT) illustrate promising efforts to broaden treatment goals and provide more personalized, recovery-oriented care for youth with SEMHP (Broersen, Creemers, Frieswijk, Vermulst, & Kroon, 2020). Nevertheless, in practice, care for youth with SEMHP continues to be shaped by a DSM-oriented framework and goal-setting procedures that reflect system-based pressures, such as classification-based funding structures, rather than individualized recovery trajectories. The same diagnostic rigidity is mirrored in research, where most intervention studies target narrowly defined groups, thereby excluding youth

with SEMHP due to their complex, co-occurring, and high-risk presentations. Consequently, these youth are not only underserved in practice but also underrepresented in evidence-based research, despite their high level of need.

Dissertation

This dissertation aims to explore the treatment needs of youth with SEMHP within CAP by examining the perspectives of youth, caregivers, and practitioners. In doing so, it seeks to foster a better understanding of how care can be more effectively tailored to this group. To address this aim, this dissertation adopts a predominantly qualitative design, allowing for an in-depth exploration of the perspectives of those directly involved in care (Braun & Clarke, 2013).

Methodological orientation

The overall DevelopRoad research project followed a grounded theory as methodological orientation, complemented by the principles of Patient-Oriented Research (POR) (Nelson, Bally, Spurr, Foulds, & de Padua, 2023). This combination was chosen to bridge the gap between academic research and clinical practice, ensuring that knowledge generation is both grounded in real-world experience and practically applicable.

Grounded theory

Constructivist grounded theory methodology was adopted to allow theory inductively form a framework in different stages rather than starting from a predefined theory (Corbin & Strauss, 2014). This approach was particularly suited to the aims of DevelopRoad, which sought to build a practice-oriented framework from scratch to describe the characteristics and needs in treatment for youth with SEMHP, a group that has been rarely studied before. In line with Charmaz's constructivist perspective, this methodology acknowledges the co-construction of knowledge between researchers and participants, emphasizing reflexivity and contextual understanding throughout the research process (Charmaz, 2017). The choice of constructivist grounded theory as the methodological orientation results in studies that build on the results of the previous study.

Patient-Oriented Research

Central to DevelopRoad and in line with the principles of POR is the value of co-creation. Meaningful and sustainable improvements in care can only be realized when all stakeholders (e.g., youth, caregivers, and practitioners) are actively involved throughout the research process. POR is giving voice

to stakeholders as research team members, ensuring the topics studied and outcomes generated are relevant in practice (Forsythe et al., 2019).

Throughout the project, we collaborated with various experts by experience, often in partnership with the National Youth Council (Nationale Jeugdraad; NJR). This youth panel draws on personal experiences with mental health challenges to improve care and support for their peers. This allowed us to align the experience and expertise of the youth experts with the research phase, ranging from designing the study and formulating research questions to conducting research, including participant recruitment, interpreting results, and ultimately translating findings into practice. In addition to their substantive input, this collaboration fostered personal growth and empowerment among the youth involved (de Beer et al., 2022).

Of particular importance was the involvement of caregivers, a stakeholder group often underrepresented in youth mental health research, despite their vital role in supporting youth across systems of care (Haine-Schlagel & Walsh, 2015). Their perspectives enriched the project and strengthened its grounding in the lived realities of families.

By integrating scientific, clinical, and experiential knowledge, we aimed to develop an evidence-informed practice model that genuinely reflects the needs of youth with SEMHP (Kuiper, Munten, & Verhoef, 2016). Embedding the POR methodology in DevelopRoad enabled the creation of practice-based knowledge that is both theoretically sound and practically applicable.

Outline

This dissertation consists of four parts, each contributing to a better understanding of the needs of youth with SEMHP in CAP, from the perspectives of youth, caregivers, and practitioners.

Chapter 2 presents a systematic literature review of drop-out and ineffective treatment in youth with SEMHP. This chapter maps out what is currently known about the factors associated with treatment failure in this group of youth. In total, 36 studies were included, and through a descriptive thematic analysis, factors were divided into three main categories: client, treatment, and organizational factors. This chapter demonstrates the added value of focusing on treatment factors in relation to treatment failure. However, it also highlights that little research has been conducted on organizational factors within this target group. Therefore, understanding how these factors are understood in practice was an essential next step.

Building on this foundation, *Chapter 3* explores how treatment factors, such as treatment services and accessibility of care, are experienced by youth with SEMHP, caregivers, and CAP practitioners. This qualitative study uncovers barriers and facilitators in the care process, emphasizing the importance of trust-based relationships and continuity in care. The chapter demonstrates how current systems often fall short in addressing the complexity of SEMHP in treatment, and it foregrounds the voices of those directly affected.

Whereas Chapter 3 highlights the tensions within current care trajectories, *Chapter 4* delves deeper into the objectives of treatment in CAP for youth with SEMHP. This mixed-methods study examines the current and preferred treatment foci as perceived by youth, caregivers, and practitioners. Using a sequential exploratory mixed-method design, this study showed variations in ratings on current and preferred treatment focus within and between groups.

Chapter 5 zooms in on one of the core tensions identified in earlier chapters: the balance between promoting autonomy and ensuring safety in the care of youth with SEMHP. Drawing on qualitative data, this chapter explores how autonomy and safety are understood and navigated in residential CAP by youth with SEMHP, caregivers, and practitioners.

Finally, the General discussion (*Chapter 6*) synthesizes the findings across all chapters, reflects on their implications for theory, policy, and practice, and outlines directions for future research. Particular emphasis is placed on how the perspectives of youth and caregivers can contribute to more responsive, relational, and sustainable approaches to care.