

Recovery-oriented work with adolescents facing complex needs

Exploring participation through the triad of adolescents, parents, and staff in psychiatric inpatient care

Jennie Moberg



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Abstract

The promotion of youth participation in healthcare and welfare services has gained global attention, particularly for those with complex care needs. In 2020, Sweden took a major step toward strengthening youth participation by incorporating the UN Convention on the Rights of the Child (UNCRC, 1989) into national law. Yet, challenges remain in translating these commitments into practice. In mental health care, user involvement is recognized as essential, but structural barriers often limit its realization. Adolescents in psychiatric inpatient care frequently report low participation in treatment decisions, highlighting the need for models that enhance agency and engagement.

This dissertation examines youth participation in Swedish Child and Adolescent Psychiatry (CAP), focusing on the relational dynamics between adolescents, parents, and staff. It explores Patient-Initiated Brief Admission (PIBA), an intervention enabling adolescents to independently initiate short enrollments, thereby promoting autonomy and care accessibility. Grounded in recovery-oriented practices, the dissertation delves into how youth participation is operationalized and understood to influence recovery among adolescents with complex mental health problems. Two theoretical frameworks – epistemic injustice (Fricker, 2007) and ecological systems theory (Bronfenbrenner, 1979) – serve as the main analytical lenses. Epistemic injustice is applied to analyze the credibility and knowledge hierarchies in psychiatric inpatient care, particularly how young people's lived experiences are valued in clinical decision-making. Ecological systems theory offers a multi-level perspective on participation, considering the broader socio-structural and institutional influences shaping interactions in psychiatric inpatient care.

The research comprises four interrelated qualitative studies: a scoping review of youth recovery literature (study I), and three interview-based studies exploring staff experiences with the implementation of PIBA (study II), staff perspectives on balancing parental involvement with adolescent autonomy (study III), and the views of adolescents and parents on participation during PIBA enrollment and its influence on recovery (study IV).

The findings indicate that youth recovery is a relational and non-linear process, shaped by trust, agency, and identity development. They point to the importance of care environments that can adjust to adolescents' evolving needs. The results further highlight systemic barriers, including credibility deficits and the 'admission game' phenomenon, which can undermine trust and restrict genuine involvement. Staff face challenges in balancing protection and participation, especially where parental involvement is believed to complicate adolescents' autonomy. While PIBA appears to offer potential for enhancing participation and fostering autonomy, its effectiveness seems dependent on trust-based collaboration among adolescents, parents, and staff, as well as on adequate staff knowledge and support.

Ultimately, the dissertation highlights youth participation as a dynamic, context-sensitive process influenced by supportive ecological systems and balanced with protective structures. It suggests that youth participation in psychiatric inpatient care is shaped by integrated approaches aligning provision, protection, and participation – the three pillars of the UNCRC. Strengthening adolescents' credibility as knowledge holders appears important in addressing epistemic injustice. Revisiting care models to support collaborative decision-making and integrate recovery-oriented principles with participatory practices emerges as valuable. These insights contribute to developing participatory, recovery-oriented mental health care, with implications for staff training, improved communication, and flexible, youth-centered approaches that support adolescents' active roles in their recovery.

Keywords: *Adolescents, child and adolescent psychiatry (CAP), ecological systems theory, epistemic injustice, mental health, Patient-Initiated Brief Admission (PIBA), participation, recovery, inpatient care.*

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*Till Annika, Catherine
och Inger*

*You can laugh, It's kind of funny
The things you think at times like these
Like I haven't seen Barbados
So I must get out of this.*

Tori Amos, "Me and a Gun"

*Den här resan
i något slags landskap efteråt –
där allt var så otroligt starkt vid liv.*

Linda Boström Knausgård

Förord

Tiden är en förunderlig faktor: den utmanar och straffar, uppmuntrar och lindrar, den tar och den ger. Efter en lång livskamp gav den mig access till ett av mina mål – att bli doktorand och att få sätta erfarenheter i ett sammanhang där deras mening kunde växa bortom det initiala.

De som kommit i kontakt med återhämtning vet att den inte kan eller bör tas för given, samtidigt som den är någonting man själv genomgår, men med stöd av andra. För mig har avhandlingsarbetet varit ett viktigt fundament i denna process, och i kombination med att regelbundet få dela sina funderingar med två kloka och engagerade handledare har gjort dessa fyra år till något av ett äventyr. Tack Lisa Skogens för lugnet och stabiliteten och för att det har känts så självklart att slå mig ner inne hos dig med frågan ”har du fem minuter...?” och traska därifrån först en timme senare. Ulla-Karin Schön, jag är djupt tacksam för att du lotsade in mig i akademien och för din osvikliga förmåga att få mig att tänka ett, två, tre varv till. Ni två, Lisa och Ulla-Karin, har kompletterat varandra på ett sätt som fått mig att stortrivas på institutionen. Gång efter annan har ni utmanat mitt sätt att resonera och guidat mig rätt de gånger jag slirat runt bland metodval och analysprocesser. Era skarpa genomläsningar har drivit mig till nya intellektuella nivåer och det har varit ett privilegium att få utvecklas tillsammans med er.

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Bromark, jag har värdesatt våra många och *långa* (telefon)samtal om allt möjligt. Tack för gapskratt, schackprat och broccoli på Proviant. Vårt kommande samarbete präglas av devisen ”kul, kul, kul – klart!”. Jag vill även tacka Evelina Fridell Lif och Mira Sörmark för allmän omtanke och guidning i undervisningssammanhang. Tack också till Annika Jemteborn, Ingrid Tinglöf, Ulrika Engström och Ingeborg Hasselgren för teknisk och administrativ support genom åren – stort som smått.

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Stockholm, april 2025

Jennie Moberg

List of studies

- I. Moberg, J., Skogens, L. & Schön, U–K. (2022). Young people’s recovery processes from mental health problems – a scoping review. *Child and Adolescent Mental Health*, Volume 28, Issue 3 pp. 393–407.
<https://doi.org/10.1111/camh.12594>
- II. Moberg, J. & Schön, U–K. (2022). Staff’s experiences of implementing patient-initiated brief admission for adolescents from the perspective of epistemic (in)justice. *Frontiers in Psychiatry*, 13:1054028.
<https://doi.org/10.3389/fpsy.2022.1054028>
- III. Moberg, J. (2024). “It’s an extra twist that’s a bit tricky to solve”: Staff balancing parental involvement when supporting the participation of adolescents in a family-oriented practice. *Child & Youth Services*, 1–26.
<https://doi.org/10.1080/0145935X.2024.2426120>
- IV. Moberg, J. (2025). “The idea of not having to prove anything in the way I needed, that would be really helpful” – Exploring adolescents’ and parents’ understanding of youth participation during patient-initiated brief admission enrollment in psychiatric inpatient care. (Manuscript accepted for publication in *Qualitative Health Research*).

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Introduction

In recent years, global interest has grown concerning the promotion of young people's¹ participation in healthcare and welfare services, particularly for those with complex care needs (Cuevas-Parra, 2023; Watson et al., 2023; WHO, 2018). This focus reflects broader societal shifts in recognizing youth agency (Carter et al., 2024; Ford et al., 2018). In 2020, Sweden took a major step toward strengthening youth participation by incorporating the UN Convention on the Rights of the Child (UNCRC, 1989) into national law. Despite this progress, challenges remain in ensuring that these legal commitments are fully upheld (Barnombudsmannen, 2022).

Scholars emphasize the right to participation, including the recognition of young people as key actors in care and support contexts (Bromark, 2024; Carlsson et al., 2017). In contemporary social and psychiatric work, there is an understanding of user involvement as essential (Askheim et al., 2016; Bjønness et al., 2022; Jeindl et al., 2023; Markström et al., 2023). Systematically adopting user involvement has practical implications for the design of care and support (Bee et al., 2015; Beresford & Boxall, 2012; Omeni et al., 2014). Consequently, user involvement has become an integral part of developing evidence-based practice (EBP) and is recognized internationally and in Sweden (Jobling & Sayuri Ii, 2024; Le Boutillier et al., 2011).

User involvement in mental health care has gained prominence over time and is closely linked to increased participation (Millar et al., 2015; Viksveen et al., 2021). Framed as a human rights issue and a cornerstone of health and social care, participation also carries legal and democratic significance (National Board of Health and Welfare, 2024). However, its definition remains ambiguous across age groups

¹ Henceforth, young people and adolescents are used synonymously, and in this dissertation, the terms refer to people between the ages of 13 and 17.

(Hoffmann et al., 2023; Kristjánsson & Thórarinsdóttir, 2024), contributing to challenges faced by professionals² in child and adolescent psychiatry (CAP), social services, and general healthcare. Moreover, these challenges are often attributed to resource shortages and structural barriers (Coyne & Harder, 2011; Tambuyzer et al., 2011).

While society generally upholds the belief that participation positively impacts young people, especially when they require care and support (Coyne & Harder, 2011; Swedish Government Official Reports, 2021; UNICEF, 2022), a majority of adolescents report low levels of participation (Davies et al., 2022; Health and Social Care Inspectorate [IVO], 2015). For example, this includes exclusion from mental health care planning and evaluation (Bjønness et al., 2024). A range of strategies and interventions have been introduced to address this, including user involvement coordinators and peer support workers to foster youth participation in inpatient care (de Beer et al., 2024; Malla et al., 2020; cf. Bakke Åkerblom, 2024; Spencer et al., 2024).

Research highlights the importance of agency and participation in mental health recovery, regardless of the origin of mental health problems (Bjønness et al., 2024; Coates & Howe, 2014; Leamy et al., 2011). Growing evidence underscores these elements as paramount for adolescents in vulnerable situations (Heimer et al., 2018; Michelson, 2023; Munford & Sanders, 2015; Strømmland et al., 2022), and this perspective has gained increasing traction within broader social discourse (Alexanderson et al., 2014; cf. Christensen & Prout, 2002).

However, the application of recovery principles in CAP remains debated. While some studies address recovery needs identified by young people (e.g., Barbic et al., 2019), there is limited research on implementing recovery-oriented practices with young people and their families (Reid et al., 2024; cf. Swart et al., 2023). For adolescents with complex mental health problems, accessible inpatient care plays an essential role in supporting recovery (Holland et al., 2023; Wallström et al., 2021; cf. Ashworth et al., 2024). However, residing alongside other young people who have mental health problems can negatively impact adolescents, meaning that inpatient care may sometimes hinder recovery (Edwards et al., 2015; Wallström et al., 2021). Additionally, young people in this setting often struggle to have their experiences and knowledge valued by parents and staff (Carel & Györffy, 2014;

² Henceforth, professionals and staff are used synonymously.

Greenblatt et al., 2023). Consequently, research show that supporting recovery requires a shift in power and knowledge dynamics between mental health users and professionals, recognizing individuals with mental health problems as credible sources of knowledge (Crichton et al., 2017; Grim et al., 2022; Kidd et al., 2022).

Nevertheless, parents and professionals might disagree on how to best support a young person in inpatient care, an environment often characterized by rapid decisions that raise moral and ethical concerns (Eder et al., 2025). When applying this reasoning to adolescents with mental health problems, it becomes clear how complex the care system is. Accordingly, the ‘triad’ of adolescents, parents and staff (cf. Basic, 2015), faces challenges with balancing protection and participation, reflecting the three Ps – provision, protection, and participation – that are central to the UNCRC (1989). Such dynamics require acknowledging adolescents, parents, and staff as epistemic “knowers” (Fricker, 2007 p. 1) in managing mental health problems (cf. Cuevas-Parra, 2023; Jörgensen et al., 2023). Building on this, youth participation is best understood as a relational and dynamic process (Cahill & Dadvand, 2018), shaped by context and dependent on careful negotiation of the three Ps.

This dissertation explores participation in CAP, often described as complex and elusive, requiring a continuous balance between ensuring both protection and participation (Coyne & Harder, 2011; Viksveen et al., 2021). It focuses on the implementation of *Patient-Initiated Brief Admission* (PIBA) as a means to enhance participation in psychiatric inpatient care (Värnå et al., 2024). By providing rapid access and empowering adolescents to take an active role in their treatment, it simultaneously leverages their expertise (cf. Eckerström et al., 2019), which is why PIBA aligns with broader efforts to deliver integrated, holistic, and recovery-oriented mental health care for young people (National Board of Health and Welfare, 2019; cf. Harris & Holman Jones, 2024).

The interest in this topic is not merely theoretical. In my previous professional roles as a user involvement coordinator and children’s rights advocate (barnrättsombud) within CAP, I encountered the structural barriers that, at times, impede young people’s participation. These experiences provided both the impetus and the practical grounding for this research, which seeks to contribute to a deeper understanding of participation as a relational, negotiated, and context-dependent process embedded in complex care systems.

Rationale

Participation in CAP occurs at the intersection of complex care requirements and diminished autonomy, all surrounded by the triad of adolescents, parents and staff. The staff operate within a highly regulated practice – shaped by laws and policies – the requirements of EBP, expectations of effectiveness in terms of ‘production’, and the obligation to implement participatory approaches such as PIBA. Against this backdrop, balancing the provision of essential care and protection with safeguarding young people’s agency emerges as a central challenge. Within the context of inpatient care in CAP, the concept of participation thus becomes intricate, prompting reflection on its meaning, how it is understood by young people, parents, and staff, and ways of fostering it in a meaningful way. A recovery perspective further underscores the significance of participation as a means to promote empowerment, autonomy, and hope during the care process. Due to the contrasting views on this issue, it demonstrates the importance of carefully considering the role of participation in young people’s recovery from mental health problems.

Aim and research questions

This dissertation aims to explore experiences of participation during enrollment in child and adolescent psychiatric inpatient care and its influence on recovery. It examines young people’s and parents’ understanding of PIBA, an intervention designed to enhance participation in care, and investigates staff perspectives on its implementation in CAP.

The following research questions have guided the dissertation:

- I) How does existing research characterize young people’s recovery processes from mental health problems, and what role do agency and participation play in these processes? (Study I)

- II) How do staff conceptualize participation within the framework of PIBA, and what are their experiences of the implementation process? (Study II)

III) How do staff strike a balance between encouraging parental involvement and engaging in recovery-oriented practices with young people in psychiatric inpatient care? (Study III)

IV) How do young people and parents perceive their experiences of participation during enrollment in psychiatric inpatient care, and how does participation contribute to recovery from mental health problems? (Study IV)

Disposition

The dissertation is organized in six chapters. Following the introduction, chapter two reviews the state of knowledge and research on participation and recovery. Chapter three presents the theoretical frameworks, while chapter four outlines the methodology of the four studies. Chapter five synthesizes the core findings, while the concluding chapter contextualizes these insights within broader practice, explores practical implications and proposes areas for future research.

Conceptual definitions

Delineations

In this dissertation, ‘young people’ refers to individuals between the ages of 13 and 17. Further, they have, or have had, mental health problems that have required psychiatric inpatient care.

The present study examines PIBA as a means to support participation in psychiatric inpatient care. However, it does not focus on a detailed evaluation of PIBA’s implementation, on measuring its overall effects, or examining the everyday experiences of care during admission. Instead, the focus is on exploring staff experiences of balancing PIBA with the routine work conducted in CAP, as well as understanding the specific contributions PIBA is perceived to offer in this context.

Children vs. young people

The target group of this dissertation is young people, and thus children in the legal sense. However, because they face quite different

challenges compared to younger children, especially in terms of their overall emancipation process from their parents, I will refer to them as *young people* and *adolescents*.

Mental health problems and vulnerability

In order to avoid adopting biomedical language, *mental health problems* (cf. Häggström Westberg et al., 2022) will be used as the main term throughout this dissertation. This reflects a broader understanding of the psychological and emotional challenges that have a significant impact on the well-being, functioning, relationships, and development of young people. While the focus is on the participation of adolescents with mental health problems, it does not center on specific diagnoses. Instead, it seeks to generate insights into how participation can be operationalized in practices encountering adolescents in vulnerable situations.

This broader perspective allows for generalizations regarding the participation of young people in institutional care, such as facilities run by the Swedish National Board of Institutional Care (SiS), and participatory work in similar contexts. While young people with complex care needs are often associated with vulnerability (Almqvist & Lassinantti, 2018; Cuevas-Parra, 2023; Lin & Guo, 2024), this view risks overshadowing their inherent resilience and coping strategies (cf. Enell & Wilinska, 2021; Friesen, 2007). As such, the dissertation addresses vulnerability not only as an *individual* experience but also as a *systemic* issue, highlighting how inadequately adapted systems may exacerbate the challenges faced by this group (cf. Carel & Kidd, 2024; Radu et al., 2022).

Recovery

Understanding recovery is regarded as a complex task (Stuart et al., 2016). Beyond recognizing recovery as not just a process but a perspective, recovery is framed in this dissertation as an overarching concept encompassing knowledge, power, and participation. Recovery-oriented work with young people adopts a holistic approach, focusing on their individual abilities, goals, and strengths (Hughes et al., 2016; Naughton et al., 2020; Rayner et al., 2018). While Swedish national policy promotes recovery-oriented care, its practical implementation faces various obstacles (Bejerholm et al., 2022). Drawing on the

complexity and individual nature of recovery, this dissertation emphasizes *personal* recovery over *clinical* recovery (cf. Bentley et al., 2019). Personal recovery prioritizes the expertise of those with lived experience, emphasizing the pursuit of a meaningful and fulfilling life despite mental health problems, without necessarily aiming for symptom elimination (Ballesteros-Urpi et al., 2019; Dallinger et al., 2022). In contrast, clinical recovery relies on professional expertise, emphasizing symptom reduction, and “a return to a level of functioning prior to the development of an illness” (Rayner et al., 2018 p. 331). Yet, evidence suggests that recovery is often possible without psychiatric intervention, as many people recover on their own (Roach et al., 2023; Slade & Longden, 2015).

Participation, agency, and autonomy

The literature on participation highlights a plethora of overlapping terms, including agency, codesign, cooperation, involvement, person-centeredness, autonomy, and user involvement. Consequently, participation is a multifaceted concept that spans a continuum, from tokenism to active collaboration and shared decision-making (cf. Eiroa-Orosa & Roura-Roca, 2025; Shier, 2001; Sinclair et al., 2019). Due to its wide-ranging and interchangeable nature, participation can be difficult to define or differentiate (Kylén et al., 2022). In inpatient care for adolescents, participation involves moving from being a passive recipient of information to an active collaborator in decision-making (Bjønness et al., 2020). It emphasizes the development of environments that enable young people to contribute their knowledge meaningfully while responding to their specific needs.

Adding to this, Cahill and Dadvand (2018) and Malorni et al. (2022) stress the centrality of *relational* practices in fostering youth participation. Coyne and Harder (2011) further highlight that youth participation is *situated*, and shaped collectively through practical activities. Rikala (2020) also defines agency as an individual’s capacity to act and influence society, exercised within social relationships that can enable or constrain action. Agency and autonomy are frequently seen as interchangeable; Brisson et al. (2021) explain that autonomy can refer to independence in certain contexts, while in others, it represents agency – the genuine capacity to make choices.

The present study views agency as key to allowing young people to actively pursue participation, including the right to choose *not* to

engage. Agency is thus seen as an overarching umbrella concept that encompasses related ideas, recognizing young people as agents capable of making their own decisions about their care. As regards PIBA, participation is believed to be shaped through relational negotiations (Kanthi, 2024), where adolescents engage in recognizing their own needs and, with appropriate support from parents and staff, make autonomous decisions regarding inpatient care enrollment. Here, PIBA might offer a way to promote active involvement by giving young people a real say in their care. This approach is further assumed to support epistemic justice by recognizing adolescents as credible contributors to their own treatment (cf. Fricker, 2007) – when their perspectives are taken seriously, they are more likely to feel respected and included in the care process (cf. Nesrallah et al., 2023).

Complex care needs

The focus of this dissertation is on young people with complex mental health problems, often resulting in equally complex care needs. Conditions such as trauma and anxiety disorders, frequently prompted by internal or external events, generate a substantial need for comprehensive support across multiple care systems (Broersen et al., 2020; Van den Steene et al., 2019). Addressing these complex needs requires youth-adapted, person-centered interventions, emphasizing continuous planning and evaluation involving multiple stakeholders (Attard et al., 2025; Castle et al., 2022; Radu et al., 2022; Stanhope et al., 2021).

The CAP context – outpatient care and inpatient care

Outpatient and inpatient care in CAP, one of the largest specialist child and adolescent psychiatric services globally, is explored in relation to its impact on young people with mental health problems. In Stockholm, CAP employs over 1,000 staff members who annually serve around 22,000 children, adolescents, and their families (CAP, 2023; psykiatriforskning.se). CAP primarily supports individuals aged 0–17 with more complex mental health problems, such as severe anxiety, depression, self-harm, and suicidal ideation. Referrals typically come from primary care or school health teams. CAP operates under a mandate from the Health and Medical Services Administration (HSF), overseen by the Health and Medical Services Board.

While most care is delivered by outpatient facilities, inpatient care faces accessibility challenges due to high demand (National Board of Health and Welfare, 2024; cf. Roe et al., 2024; Truscott et al., 2024). Outpatient treatment often suffices, but inpatient care is required for certain young people, most commonly during their teenage years. Each year, approximately 2,500 young people are admitted to inpatient care in Sweden, typically voluntarily and for short durations, although some stays may extend to months. In some cases, the care is involuntary, provided under the Compulsory Psychiatric Care Act (LPT), which may involve coercive measures.

CAP emphasizes a family-oriented approach, requiring staff to balance the perspectives of young people and their parents to foster participation in recovery-oriented care while maintaining alliances with both parties. Parents often stay with their children during inpatient care and act as proxies for accessing care and advocating for their needs. With regard to PIBA, it presents an opportunity for both outpatient and inpatient staff to identify young people who might benefit from this intervention. Its implementation relies on collaborative efforts among the care teams to enhance participation and recovery.

Background and previous research

This chapter explores youth participation and recovery from both international and Nordic perspectives. It begins with an overview of children's rights and how they shape participation. The discussion thereafter considers the connection between participation and recovery in research and practice. Additionally, it introduces PIBA as a potential recovery-oriented approach for adolescents receiving psychiatric inpatient care. Finally, the chapter concludes with reflections on this dissertation's contributions to the broader research field.

The emergence of a children's rights perspective

Throughout history, children have been regarded as holding a subordinate position in society (Bessell, 2011; Westerlund & Westerlund, 2012). In essence, this has hindered collaborative actions and impeded their ability to be heard. While this historical perspective has often silenced children, recent decades have seen significant progress in advancing youth participation in healthcare (Swist et al., 2022), education (Lundy, 2007), and the political sphere (Kitanova, 2019). Central to this progress is the UNCRC (1989), which has been instrumental in establishing and advancing children's and young people's rights to participation (cf. Barnombudsmannen, 2020; Worrall-Davies, 2008).

These developments have influenced person-centered care, legal frameworks, and guidelines, including the Care of Young Persons (Special Provisions) Act (1990:52, LVU), the Compulsory Mental Care Act (1991:1128, LPT), and the Social Services Act (2001:453, SoL). Evelius (2017) argues that participation, privacy, and legal certainty must be central in compulsory care. These principles need to be adapted to meet children's specific needs and circumstances, while also ensuring that young people in care and their support systems have full access to their human rights as outlined in the UNCRC (1989). As mentioned in the introduction, the UNCRC (1989) is built on three key

principles – provision, protection, and participation (Cuevas-Parra, 2023; Jörgensen et al., 2023; Kirk, 2019; cf. Skelton, 2007). *Provision* emphasizes the responsibility to provide necessary resources and services for children’s and young people’s well-being and development. *Protection* ensures they are safeguarded from harm, abuse, and exploitation, while *participation* underscores their right to have their voices heard and considered in decisions affecting them (cf. Bartnick et al., 2024; Eiroa-Orosa & Roura-Roca, 2025; Lundy, 2007; McLeod, 2007). The UNCRC (1989) further underscores the importance of recognizing children and young people as active rights-holders rather than passive recipients of care. As such, its goal is to enhance their legal standing and prioritize their best interests.

The Convention also requires their involvement in decisions that impact their lives (Axelsson et al., 2020; Coyne & Harder, 2011; Markström, 2024; Shier, 2001). While research indicates a paradigm shift from prioritizing protection to fostering participation (e.g., Hayes et al., 2021; Toros, 2021), it simultaneously highlights challenges in facilitating meaningful involvement and credibility in decision-making (Fylkesnes et al., 2018; Kennan et al., 2018; Martin, 2019; Watson et al., 2023). These barriers are particularly pronounced for vulnerable adolescents, who rely on parents and staff to balance participation with protection. Mental health problems are described as further constraining participation (Bjønness et al., 2024; Sallnäs et al., 2010), compounded by knowledge hierarchies that may hinder the realization of the UNCRC’s (1989) human rights objectives (Yamaguchi et al., 2023; Greenblatt et al., 2023).

Defining youth participation

Research consistently identifies youth participation as essential (Sylte et al., 2023), particularly in decisions directly affecting them, including those made by social services and CAP professionals (McCabe et al., 2022; Yamaguchi et al., 2023). As such, participation is said to play a key role in ensuring accurate and effective interventions, and improving satisfaction and outcomes (Kennan et al., 2018; Salamone-Violi et al., 2015; Shahnaz et al., 2025). Furthermore, participation reduces the risk of intervention breakdown (Skoog et al., 2015; Skoog, 2016) and fosters stronger self-esteem among vulnerable adolescents (van Bijleveld et al., 2015). In contrast, inadequate or tokenistic participation may have negative consequences for young people with mental health problems

(Bower et al., 2023), where such approaches might lead to interventions being perceived as punitive and irrational (cf. van Bijleveld et al., 2021; Skoog, 2016). This perception often triggers feelings of uncertainty, frustration, and a sense of powerlessness, which may manifest as norm-breaking behaviors when individuals engage with social or mental health care systems (Bjønness et al., 2020; Haug & Stallvik, 2024; Mossberg, 2016; Wallström et al., 2021).

Despite evolving frameworks for participation (Arnstein, 1969; Hart, 1992; Shier, 2001), the concept remains ambiguous and difficult to measure (van Bijleveld et al., 2020; Viksveen et al., 2021; Woodman et al., 2023). Youth participation is often linked to *autonomy* (Daly, 2018; Holmqvist et al., 2023), *actorship* (Michelson, 2023; Sallnäs et al., 2010), and *agency* (Bjønness et al., 2022; Munford & Sanders, 2015). As such, youth participation is described through various lenses, emphasizing its multifaceted nature (cf. Bjønness et al., 2024; Kriz et al., 2017; UNCRC, 1989). When reviewing these definitions, youth participation is seen as a spectrum that underscores the significance of listening to young people, considering their perspectives, and encouraging open dialogue. Dogra (2005) found that young people want care that is accessible, with professionals they can trust, and who have good listening skills. Nearly 20 years later, Kirk et al. (2023) and Viksveen et al. (2021) confirm these findings, showing that adolescents desire to be actively involved in decisions about their mental health care. However, these studies also point out that *how* user involvement is practiced varies, ranging from simply asking for opinions to truly including young people in decision-making.

In summary, participation is an evolving, relational, and context-dependent process shaped by interactions between young people, parents, and staff, as well as structural and systemic factors (Lundy, 2007; Mampane, 2019; Yamaguchi et al., 2023). Its complexity means participation is not static, requiring adaptable structures and sensitivity to the unique challenges of all involved. Although participation is widely recognized as critical, its implementation is often hindered by insufficient practical guidance and established frameworks (Kennan et al., 2018). With growing awareness of children's rights under the UNCRC (1989) (Heimer et al., 2018), professionals are expected to move beyond narrow interpretations of Article 12 (Kennan et al., 2019) and work toward meaningful implementation.

Navigating participation – integrating family-centered and person-centered approaches

There is growing recognition that incorporating the unique experiences of service users and caregivers is vital for designing targeted interventions, and deepening the understanding of participation and mental health problems (Karlsson & Börjesson, 2011; Lynch et al., 2024; Maiese, 2024). This shift has transformed power dynamics and knowledge production within mental health research, emphasizing the value of user perspectives (Bjønness et al., 2020; Lloyd et al., 2024).

In the literature on sociology of childhood, young people in need of social or medical interventions are sometimes – albeit as a simplified starting point – viewed through two contrasting lenses: “becomings” and “beings” (Heimer et al., 2018 p. 317; Huang, 2019; Uprichard, 2008). The becomings perspective sees young people as dependent on adults. It believes that young people are not yet able to understand their circumstances fully. The beings perspective recognizes young people as individuals with rights, while valuing their experiences in the present. These lenses shape how professionals engage with young people, influencing whether and how their voices are included in decisions.

Efforts to embed youth participation into practice, guided by frameworks such as the UNCRC (1989), face persistent barriers. Participation often appears conditional, constrained by adult-led agendas and competing demands within organizational structures (cf. “bounded agency” in Munford & Sanders, 2015 p. 618). Professionals may prioritize safety and protection over young people’s knowledge, which can contribute to what has been described as a credibility deficit, where young people’s perspectives are perceived as less reliable (Skoog, 2016; Toros, 2021). This deficit risks fostering self-censorship among young people, especially when they anticipate that their views might be dismissed (Fylkesnes et al., 2018; Kennan et al., 2018). Furthermore, ideas about age, maturity, and disability can influence perceptions of young people’s ability to participate, often leading to a greater focus on adult decision-making (van Bijleveld et al., 2015).

Several factors can make the implementation of participatory practices more complex. For instance, mental health and social care services often use family-centered approaches (e.g., Linderborg et al., 2024; cf. Coyne et al., 2016; Sharrock et al., 2013), which focus on involving the family unit in treatment (cf. Martin et al., 2023). While

these approaches highlight the role of families in supporting adolescents, they may sometimes underemphasize individual, child-centered perspectives (Heimer et al., 2018; Wissö et al., 2018). Family-centered practices typically view the family as a unit of care, where support is extended not only to the adolescent but also to the parents and siblings (slo.se). Parents are often seen as key figures in promoting their child's well-being and recovery (cf. Badour et al., 2023; Bratt et al., 2019; Beckman & Hellström, 2021; Wirehag Nordh et al., 2024). However, integrating person-centered approaches into family-oriented frameworks risks creating tensions, especially when navigating the demands of adolescents' growing autonomy with parental involvement in their care (cf. Miller, 2019; Shalem & Attar-Schwartz, 2022; Pine et al., 2024). Such dynamics have also been identified as challenges in implementing PIBA in CAP, where fostering adolescent independence needs to be managed alongside maintaining family involvement (cf. Lantto et al., 2023; Lindkvist et al., 2022).

Other organizational factors can also affect how consistently participation is supported. While high staff turnover and gaps in care risk rendering support for young people less consistent (Eder et al., 2025; Salamone-Violi et al., 2015), these factors also complicate or hinder their collective understanding of what participation entails. In the absence of clear and structured frameworks, participation practices may vary across settings and depend on individual practitioners' approaches (Henriksen et al., 2021; Kennan et al., 2018; Rasmusson et al., 2010). While these factors contribute to inconsistent experiences of participation, they simultaneously highlight opportunities to refine and deepen child-centered approaches in mental health care.

Protection vs. participation – a dualistic mindset?

The ambition to ensure young people's safety and stability can paradoxically hinder their agency (Sallnäs et al., 2010), reinforcing the perception that vulnerable young people lack the skills to participate in decision-making. As Sallnäs et al. (2010) argue, it is problematic to assume that young people are "incompetent *because* they are in social care" (p. 128). This tension – between prioritizing protection and fostering participation (cf. van Bijleveld et al., 2015; Clark & MacLennan, 2023; Woodman et al., 2023) – reflects the everyday challenges professionals face, where decisions about young people's

well-being are often made without the opportunity to make nuanced assessments (cf. Eder et al., 2025; Moell et al., 2025).

A common issue among staff is balancing the need to protect young people while ensuring they are included in decisions, and not giving them responsibilities they may not be ready to handle. This difficulty frequently arises in the care of adolescents with complex needs. The underlying, sometimes paternalistic, power structures inherent in the child-adult relationship (Godwin, 2020; Sundhall, 2018) thus grant adults a privileged yet responsible position to shape young people's lives. To address this, professionals are tasked with refining their ability to move beyond a rigid dualistic mindset (protection vs. participation). The age-based power dynamic often results in young people being viewed as lacking epistemic credibility (Fricker, 2007), a perception that, at times, is reinforced by societal associations between vulnerability and the need for adult protection. Challenging this tendency seems imperative to ensure young voices are not only valued but meaningfully integrated. Addressing this dynamic hinges on repositioning young people as epistemic agents, and fostering participatory spaces where their lived expertise actively informs decision-making.

‘Doing’ participation

Research consistently shows that while young people in health and social care settings wish to be involved in decisions affecting their lives (e.g., van Bijleveld et al., 2015, 2021; Skoog, 2016; Viksveen et al., 2021), their participation is often limited (Granlund et al., 2021). Studies indicate that young people may encounter barriers in assuming adult decision-making roles, whether due to inability, restriction, or hesitancy (cf. Bjonness et al., 2020; Lundy, 2007). This can arise from concerns about protecting childhood innocence, organizational norms, or uncertainty about the purpose of participation, potentially leading to reduced involvement.

Key elements of participatory work include being provided with adequate information, active listening, ongoing dialogue, and fostering relational dynamics among stakeholders (Fylkesnes et al., 2018; Haynes et al., 2011; Hultman et al., 2020; Naughton et al., 2020). However, Daly (2018) argues that listening is insufficient on its own, emphasizing that the child's views “must be seriously considered” (p. 69) for participation to move from theory to meaningful action. With

meaningful action, this, for example, refers to “autonomy support” (p. 65) and that autonomy should only be restricted if there is a significant risk of harm arising from a child’s preferences. As a result, these actions highlight the need for a human rights approach, where the responsibility for fostering authentic participation is placed on the adults. In essence, the focus shifts from just listening to genuinely involving young people in decisions about their lives – unless there is a serious risk.

Valuing young people’s experiences has the potential to transform theoretical participation into meaningful contributions to their lives. However, participation may, according to research, burden or confuse young people, influenced by factors such as organizational cultures, and misunderstandings of its purpose (cf. van Bijleveld et al., 2020; Toros, 2021). These notions are likely to contribute to low participation levels, despite participation being recognized as a preventive strategy for supporting vulnerable young people (Garcia-Quiroga & Salvo Agoglia, 2020; Hultman et al., 2020). Youth participation does not exist in isolation but emerges from relational dynamics involving reciprocal actions among stakeholders with varying degrees of power and decision-making authority (e.g., Toros, 2021; cf. LeFrancois, 2008). Interactions between young people and care systems naturally involve power imbalances, making it important to find ways to support real participation instead of token gestures.

Within the dynamic between young people, parents, and professionals, understanding what helps or hinders participation warrants close consideration. Given its significant role in supporting mental health and recovery, the discussion will now focus more specifically on youth participation in psychiatric inpatient care and other locked facilities.

Participation as a core concept in youth recovery

Adolescents with mental health problems are often regarded as particularly vulnerable (Häggström Westberg et al., 2022; Lin & Guo, 2024). Their interactions with care and support systems – such as mental health care and social services – frequently present obstacles to meaningful participation and the opportunity to express their experiences and perspectives (the Swedish Agency for Health Technology Assessment and Assessment of Social Services [SBU], 2017). Such obstacles can make it harder for adolescents to take part in

their own recovery, demonstrating the need to encourage their agency and voice in shaping the trajectory of their own healing. Because the environment plays a pivotal role in young people's participation (cf. Coster et al., 2012), creating inclusive surroundings where they feel heard and have a say in their recovery is key. Consequently, rather than merely receiving care, young people can benefit from being actively involved in the process.

Comprehending youth recovery

Adolescence is a critical developmental phase marked by significant physical, emotional, and cognitive changes, as well as the onset of mental health problems (Chandra-Mouli et al., 2015; Hellström & Beckman, 2021; Jaworska & MacQueen, 2015; Scheiner et al., 2022). Early intervention and preventive measures during this period are essential for fostering personal recovery and promoting long-term positive outcomes (Baetens et al., 2024; Colizzi et al., 2020; Hamson et al., 2023). While youth recovery research is expanding, understanding the factors young people consider vital for their recovery remains limited (John et al., 2015; Kelly & Coughlan, 2019; Swart et al., 2023). The 'CHIME' framework – a synthesis of the five interwoven recovery components *connectedness, hope, identity, meaning, and empowerment* – was originally developed for adults and has become a widely used model for understanding and operationalizing personal recovery in mental health (Leamy et al., 2011). Although said to be universal across age groups and mental health problems (Lases et al., 2024; Salamone-Violi et al., 2015), scholars have identified the need to adapt CHIME to adolescents (Ballesteros-Urpi et al., 2019; Naughton et al., 2018).

By demonstrating how developmental changes and family support structurally inform recovery, Reid et al. (2024) and Ward (2014) question whether traditional recovery models truly capture the complexities of adolescent mental health (cf. Hess et al., 2014). Similarly, Ballesteros-Urpi et al. (2019) demonstrate that applying existing recovery-focused interventions to younger populations poses distinct challenges. For example, connectedness for adolescents in mental health care is often rooted in their relationships with their parents and family (Kelly & Coughlan, 2019), alongside their reliance on daily routines, social interactions, and other aspects of their everyday lives. Additionally, the current recovery approach does not fully capture the impact of peer relationships on the development of identity and the

meaning of life. For this reason, research indicates that while the core components of CHIME align with young people's recovery processes, modifications are necessary to better account for youth-specific factors (Naughton et al., 2018; Schneidtinger & Haslinger-Baumann, 2019).

Youth recovery processes are uniquely shaped by developmental maturity, identity exploration, and the need to balance parental support with growing independence (Naughton et al., 2020; Rayner et al., 2018; Storm et al., 2023). An ecological systems perspective also highlights the interplay between family and social and environmental factors in adolescent recovery (Halsall et al., 2022; Lindstedt et al., 2018). Recovery during adolescence is increasingly recognized as a non-linear process, marked by ambivalence, fluctuations, and moments of self-discovery (Kelly & Coughlan, 2019; Schneidtinger & Haslinger-Baumann, 2019). This challenges traditional linear models and underscores the importance of empowerment and resilience in recovery-oriented care (Kelly & Coughlan, 2019). Researchers advocate for a youth-centered paradigm that prioritizes the *person* over the patient (Biering & Jensen, 2018), and underscores the necessity of recognizing and reinforcing individual recovery trajectories in mental health care (Larvik et al., 2018; Palmquist et al., 2017; Uhlhaas et al., 2023).

Additionally, parental involvement is described as “common practice” (Thulin et al., 2014 p. 185), thus playing a pivotal role in adolescent recovery by fostering collaborative, emotional, and practical support, which enhances help-seeking behavior and active participation in treatment (Haine-Schlagel & Walsh, 2015; Hasset et al., 2018; Pine et al., 2024). However, parental involvement can also create tensions, as family-focused interventions may conflict with the autonomy of a young person (Bjønness et al., 2022). These challenges become even more pronounced for young people with complex care needs, particularly those in inpatient care, where hierarchical structures and limited independence bring additional layers of complexity in balancing family and individual priorities (cf. Clark & MacLennan, 2023; Walker & Logan, 2019). In this context, professionals navigate intricate dynamics to ensure that care is both participatory and recovery-oriented. This involves respecting the autonomy of the young person while integrating family perspectives, all within the limitations of the care setting.

Participation among young people with complex care needs – a Nordic outlook

All the Nordic countries have observed a decline in self-assessed mental health among children and adolescents, accompanied by a rising demand for child and adolescent psychiatric services (Bjønness et al., 2024; Häggström Westberg et al., 2022). Concurrently, there is a documented increase in referrals to and utilization of CAP services (Nordic Council of Ministers, 2011). Youth participation in psychiatric inpatient care represents a key concern in Nordic healthcare systems, where laws, and child rights perspectives are closely linked (Roy, 2020).

As seen in all the Nordic countries, psychiatric inpatient care and other restrictive facilities for adolescents often involve strong coercive and controlling measures (Biering & Jensen, 2018; Henriksen, 2021; Pålsson et al., 2023; Sallnäs et al., 2024; Sourander et al., 2002; Turunen et al., 2010; Viksveen et al., 2024). At times, these facilities are seen as a “last resort” (Ponnert & Johansson, 2024 p. 1), focusing on urgent assessments and paternalistic approaches to maintain safety (Bjønness et al., 2022; Vogel, 2012; cf. Eder et al., 2025; Moell et al., 2025). Focusing on protection may, however, unintentionally limit meaningful participation, especially when mental health problems make it harder for adolescents to engage (Westerback, 2016). The tension between protection and participation highlights the inherent complexity of clinical work in psychiatric and social care settings, where professionals are expected to navigate competing priorities in supporting adolescents with diverse needs (Pelto-Piri et al., 2013; Sallnäs et al., 2024; Storbjörk, 2007).

The participation of adolescents in psychiatric inpatient care reflects similar complexities to those observed in other institutional settings, including facilities managed by the Swedish National Board of Institutional Care (SiS), treatment centers, or care homes (HVB). Adolescents in compulsory care provided by SiS often face a combination of social problems, mental health problems, and substance abuse (Sallnäs et al., 2024; Vogel, 2016; 2017), leading to their portrayal as a particularly challenging group. As demonstrated in Danish and Swedish studies, these institutions function as sites for assessment, scrutiny, restriction, and control (Henriksen, 2017; 2021; Mattsson & Enell, 2023), reinforced by inherent power imbalances between staff and residents (Enell et al., 2018).

Despite, or perhaps because of these dynamics, the relationship between staff and adolescents is critical for effective care. As shown by Icelandic, Finnish, and Swedish researchers, collaborative and respectful relationships can build trust in authorities and enhance intervention outcomes (Biering & Jensen, 2018; Kaasinen et al., 2020; Pålsson & Wiklund, 2024). Here, showing consideration means treating adolescents with care and attentiveness, especially when they are in vulnerable situations (Biering & Jensen, 2018). However, in locked and restrictive settings such as SiS, their vulnerability is similar to that in CAP, where coercion is often a key part of care. In essence, research highlights low levels of participation in these settings, which are strongly shaped by power and control (Swedish National Board of Institutional Care [SiS], 2013; Swedish Government Official Reports [SOU], 2006; cf. Pelto-Piri et al., 2013).

In two Norwegian and Swedish studies, adolescents under involuntary psychiatric care – particularly girls with self-harming behaviors – are described as being an “extreme challenge” (Holth et al., 2018 p. 605) and frequently report feeling less safe and treated differently compared to peers in voluntary care (Eriksson & Åkerman, 2012). Even adolescents in voluntarily care in Sweden, Denmark and Norway report experiencing coercion, including informal coercion, which raises concerns about legal certainty and recovery (Engström et al., 2020; Henriksen & Øye, 2023). Such coercion, whether formal or informal, has been linked to weakened therapeutic alliances and poorer staff relationships, ultimately impeding recovery (Nyttingnes et al., 2018; cf. Moell et al., 2025). Adopting recovery-oriented principles and being sensitive to developmental phases in adolescents (cf. Lavik et al., 2018; Ruiz & Yabut, 2024) are depicted as vital to addressing these challenges, promoting effective care and fostering better outcomes for young people in institutional care.

PIBA as a means to enhance participation in the recovery process

As noted in the introduction, efforts to enhance adolescent participation in CAP include various models and interventions, with PIBA as one such initiative. However, implementing innovative interventions in this complex setting presents significant challenges. To ensure an efficient implementation process, it is crucial to explore both barriers and facilitators (Peters-Corbett et al., 2023). Overall, the effectiveness of

service delivery models for children and young people remains poorly understood (Prymachuk et al., 2024), and the same applies to PIBA in CAP, which, to my knowledge, lacks international parallels.

Originally designed for adults requiring extensive care, PIBA has demonstrated positive outcomes in areas such as care utilization and suicide prevention, as well as regarding an improved care climate in the Netherlands (Helleman et al., 2014; 2018), Denmark (Ellegaard et al., 2017), Norway (Heskestad & Tytlandsvik, 2008; Nytingnes & Ruud, 2020; Tytlandsvik & Heskestad, 2009), and Sweden (Eckerström et al., 2019; Liljedahl et al., 2017; Strand et al., 2017; Trysell, 2018; Westling et al., 2019).

From a Nordic perspective, studies highlight benefits such as fewer serious relapses, increased satisfaction and user involvement, reduced care days and compulsory care, and greater feelings of control (cf. Lindkvist et al., 2021). However, criticism includes concerns about reduced decision-making capacity during acute mental health episodes, which may hinder the use of PIBA (Strand & von Hausswolff-Juhlin, 2018; cf. Crichton et al., 2017). In addition, a study by Thomsen et al. (2018) shows ambiguities as regards reduced coercion and self-harm, suggesting that more research is needed in order to determine PIBA's clinical significance.

In Stockholm, PIBA has been available to adults since 2014, and in 2019, a political decision (sometimes referred to as 'top-down') expanded its provision to young people. Implementation in CAP began in 2020, marking what has been described as a new era of person-centered care in CAP (National Board of Health and Welfare, 2023; psykiatriforskning.se). Given its recent introduction in CAP, but also its somewhat slow implementation process, experiences with PIBA and the role of parental involvement in the intervention remain largely unexplored (Lantto et al., 2023; Lindkvist et al., 2022).

PIBA in CAP is designed for adolescents between 13 and 17 with complex mental health problems, including self-harming behavior, suicidality, and psychotic episodes. The intervention involves a contract drawn up jointly by the adolescent, the parents, and the outpatient and/or inpatient care staff, outlining shared decisions. This contract allows adolescents to independently initiate up to three care periods per month, each lasting a maximum of three days, without requiring parental or staff approval. By bypassing mandatory visits to psychiatric emergency departments, PIBA aims to enhance participation and

accessibility, both central to recovery-oriented care (van Amelsvoort & Leijdesdorff, 2022; Richter Sundberg et al., 2021).

Mental health professionals have traditionally decided who receives inpatient care through the principle of “gatekeeping” (cf. Dawber, 2014 p. 53; Systema et al., 2002), making sure limited resources go to those most in need. However, this approach can restrict young people’s involvement in their care and recovery, which contradicts the emphasis on self-determination in PIBA. While increased participation may present ethical trials (Sobode et al., 2024), PIBA challenges entrenched care cultures rooted in general paternalism and the notion that “the doctor knows best” (Pilnick, 2023 p. 1786; cf. Bjonness et al., 2022; Koivisto, 2017; Peltto-Piri et al., 2013; Sjöstrand et al., 2013). For PIBA to be implemented in a meaningful manner, this work is closely linked to the rethinking of professional roles, power dynamics, and decision-making structures (cf. Damsgaard & Angel, 2021). Unlike traditional admission, PIBA allows the individual, rather than the doctor in charge, to make the decision. In CAP, this means adolescents choose their care instead of relying on a professional assessment. As such, the goal is to give young people more control over their treatment.

While research on PIBA for adults is generally positive, there is a need to examine how it applies to young people, especially regarding power dynamics and user knowledge. In addition to its impact on youth participation, the challenges faced by parents and staff also warrant attention. In CAP inpatient care, participation is often defined as the ability to identify your own needs and take ownership of your own healthcare and treatment (Bjonness et al., 2022). However, given CAP’s family-oriented and system-focused approach, participation can be a challenging concept to apply to adolescents with severe mental health problems.

In their practical work, staff continuously balance encouraging youth participation while managing the risk of mental health deterioration, including serious self-harm and/or suicide. During traditional admission, parents are typically involved, providing support and enabling ongoing care. Prior to admission, they often act as primary caregivers and advocates on behalf of their children (Greally et al., 2024; Oruche et al., 2012; Sarrio-Colas et al., 2022). Upon admission, they may experience emotional distress, such as anxiety and worry, seeing the situation as a crisis (Bjonness et al., 2022; cf. Martin et al., 2024). As regards PIBA, parents are encouraged to trust the staff to provide compassionate care while also relying on their child’s ability to

make informed decisions and use the contract effectively (cf. Lindkvist et al., 2022).

Summary

A growing number of studies emphasize children's rights and the importance of involving them in the care and support system. The view of the role of young people has shifted from seeing them as passive recipients of care to recognizing them as active participants. The adoption of the UNCRC (1989) has been a key step in strengthening children's rights, highlighting their right to protection, care, and participation. A clear focus has been on youth involvement in decision-making, especially in mental health services, where these rights are still often overlooked. While participatory approaches are gaining more attention, challenges remain. Hierarchical structures often fail to fully value young people's perspectives, and there is still an ongoing tension between ensuring their protection and respecting their autonomy – particularly for those in vulnerable situations. As such, finding the right balance between family-centered and person-centered care is essential to support young people while they are in the care and support system.

In addition, this chapter has explored youth participation in restrictive settings, such as inpatient psychiatric care, where coercive practices may prevent meaningful involvement. The concept of recovery-oriented care is introduced as a framework that emphasizes shared decision-making and power redistribution in clinical settings. As regards this dissertation, PIBA is examined as a model for enhancing youth participation in mental health care by allowing young people to initiate their own inpatient admissions. However, its implementation in the care of adolescents presents challenges, including power imbalances, parental involvement, and professional responsibilities. These complexities highlight the need for a rights-based approach that not only acknowledges young people's voices but also ensures meaningful participation in decision-making. Taking it further, it seems equally essential to ensure that their perspectives genuinely shape decisions in institutional settings.

This dissertation explores the intersection of social work and mental health care, focusing on the experiences of young people, parents, and staff in fostering participation within a complex care environment. It also examines how participation is addressed during admission to

psychiatric inpatient care. As such, it makes a practical contribution to various fields, such as recovery research, (psycho)social work, child social care, nursing science and implementation research. With regard to inpatient care and the means to enhance youth participation in such a setting, the dissertation advances the understanding of a rather unexplored practice. Its contribution primarily addresses increased user knowledge – i.e., how young people and parents experience participation during enrollment in psychiatric inpatient care, as well as the experiences of staff in implementing novel interventions such as PIBA.

Theoretical frameworks

This dissertation is grounded in two primary theoretical frameworks – *epistemic injustice* (Fricker, 2007) and *ecological systems theory* (Bronfenbrenner, 1979) – each highlighting essential components for participation and recovery. In essence, these frameworks emphasize: (1) the critical role of participation in designing care and support efforts, (2) the importance of generating knowledge and meaning from the experiences of vulnerable groups, such as adolescents receiving mental health care, and (3) the significance of supportive relationships in recovery-oriented work. Epistemic injustice informs the analysis in studies II and IV, while ecological systems theory underpins studies III and IV. Furthermore, *Normalization Process Theory* (NPT; May et al., 2018) guided staff interviews in study II, serving as a model rather than a comprehensive theoretical framework, and is expanded on in the methods section. Although the studies are not explicitly anchored in a specific theoretical framework of participation, the dissertation frequently draws on the contributions of Lundy (2007) and Shier (2001). These concepts are examined in detail, as they align with the core principles of epistemic justice and ecological systems theory.

Epistemic injustice – analyzing power and credibility

Historically, the psychiatric field has been shaped by power and knowledge hierarchies, which have led to dynamics of superiority and subordination (Foucault, 2010). Moreover, psychiatric inpatient care has been criticized for its paternalistic approach, which can limit the ability of individuals with mental health problems to participate in their own care (Crichton et al., 2017). These people often experience epistemic (knowledge) injustice, driven by cultural stereotypes and systemic power imbalances in healthcare (Carel & Kidd, 2014; Newbigging & Ridley, 2018). For example, such individuals are frequently perceived as cognitively impaired or emotionally unstable, further undermining their accountability (Fisher, 2024). This tradition

often leads to the systematic dismissal, silencing, and devaluation of care users' knowledge, testimony, and interpretations – practices that can occur unconsciously without intent to harm (Dotson, 2011; Fisher, 2024). Nevertheless, whether conscious or unconscious, epistemic injustice restricts the epistemic agency and influence of mental health users.

Fricker (2007) defines epistemic injustice as “a wrong done to someone specifically in their capacity as a knower” (p. 1), occurring when individuals are mistreated or dismissed in their role as knowledge bearers. Stefanello (2023) highlights that individuals with mental health problems and older adults are often excluded from the category of “trustworthy knowers” (p. 175) due to social biases tied to age and/or health. Epistemic injustice raises critical questions such as “Who do we believe and why?”. It can take two forms. The first is *testimonial injustice*, where a person's credibility is undermined due to prejudiced assumptions (based on factors such as gender, class, race, or health). The second is *hermeneutical injustice*, which arises when social knowledge gaps prevent individuals from fully understanding or articulating their experiences due to the absence of relevant conceptual frameworks (Fricker, 2007; Hookway, 2010)

Adolescents in CAP are described as being vulnerable to epistemic injustice, as they rely on both parents and staff (cf. Carel & Györfy, 2014). Due to their age and mental health problems, they face epistemic limitations that affect their credibility and recognition as epistemic agents during care. Parents may also face epistemic injustice when their understanding of their child's mental health is dismissed or undervalued by staff (Hultman & Hultman, 2023). Their knowledge of their child's emotions, behaviors, and needs can be an instrumental part of the care process. However, due to staff prioritizing clinical assessments or standardized guidelines over parental input, it risks creating a credibility deficit which can result in parents feeling unheard and disempowered in an already difficult situation.

Similarly, epistemic injustice might affect staff, particularly at an organizational level. Due to the inherent hierarchical structure of the professions in CAP, frontline staff expertise and experience may be devalued when organizational decisions about new practices or guidelines overlook their practical insights (cf. Bueter & Jukola, 2025). For example, staff observations of the daily realities of working with adolescents and families may be considered less significant compared to decisions driven by administrative goals, financial concerns, or

external demands for standardization. This can leave staff feeling powerless and overlooked, which not only affects their motivation to engage meaningfully in care practices but may also compromise the quality of care (cf. Kidd & Carel, 2018).

Epistemic injustice among young people in institutional care

Epistemic injustice manifests itself in contexts such as education, legal systems, and healthcare (Burroughs & Tollefsen, 2016; Crichton et al., 2017; Hanna, 2023; Harcourt, 2021; Miller, 2018; Schües, 2016; Scrutton, 2017). Carel and Györfy (2014) emphasize the importance of addressing epistemic injustice in healthcare involving young people, as they hold valuable information critical to decision-making processes. However, power imbalances between adults and adolescents often lead to this information being diminished or lost, with dialogues primarily occurring between professionals and parents (Greenblatt et al., 2023).

Young people with mental health problems, as part of an exposed group, face challenges in institutional settings, described as “vulnerabilizing forces” (Carel & Kidd, 2024 p. 2). These challenges include being ignored, disbelieved, or having their knowledge dismissed, which can undermine their sense of credibility. Although adults aim to protect young people, this can sometimes come at the expense of recognizing their perspectives and experiences – that is, at the cost of their epistemic value. To address the impact of epistemic injustice, Carel and Kidd (2024) stress the need to examine how vulnerability is shaped by individuals, organizations, and social systems.

From a participatory and children’s rights perspective, addressing epistemic injustice is essential to ensuring that young people’s knowledge and experiences are respected by adults (Greenblatt et al., 2023). Mental health problems are often associated with stereotypes about impaired decision-making capacity, which makes young people in institutional settings particularly vulnerable to power imbalances and knowledge hierarchies (Carel & Kidd, 2014; Klyve, 2019). Klyve (2019) highlights how adolescents in psychiatric care risk having their perspectives dismissed due to the attitudes of both staff and parents. Parental involvement, for example, may lead staff to prioritizing parental accounts over those of adolescents, resulting in a credibility deficit that undermines the value of young people’s insights (cf. “double denial” in Lundy, 2007 p. 935).

Long-term effects of epistemic injustice

Fricker (2007) suggests that epistemic injustice is linked to structural discrimination, limiting the recognition of individuals as credible sources of knowledge and affecting their sense of self. When people are repeatedly denied the opportunity to share and make sense of their experiences, it restricts their ability to understand their place in a broader context, which goes against principles outlined in laws and policies such as the UNCRC (1989). For young people, repeated epistemic injustice can harm emotional and psychological well-being (Elicor, 2020), diminish self-esteem and self-confidence (Carel & Györfy, 2014), and erode trust in authority figures (Fieller & Loughlin, 2022). Houlders et al. (2021) further highlight the negative impact of epistemic injustice on long-term outcomes and recovery. When adolescents feel ignored or disbelieved, they may start to see their perspectives as unimportant (Okoroji et al., 2023). This can lead to disengagement from treatment and ongoing mental health problems. Addressing epistemic injustice in CAP and similar settings therefore appears essential for improving long-term outcomes and ensuring youth-friendly services.

Research shows that adults often attribute a lower level of knowledge to young people, leading to self-censorship and the internalization of an unknowing identity (Carel & Györfy, 2014; Dotson, 2011; Greenblatt et al., 2023). Stereotypes about the decision-making capacity of individuals with mental health problems further distort their credibility. As such, epistemic injustice may hamper recovery, making participation important to ensure fairness in how knowledge is valued. Supporting young people's involvement in inpatient care and addressing these challenges may lead to a more inclusive mental health care, stronger therapeutic relationships as well as personal growth.

Final remarks on epistemic injustice

This dissertation explores epistemic injustice by recognizing the credibility and knowledge of everyone involved. Acknowledging these perspectives is fundamental to building genuine collaboration and meaningful participation (Grim et al., 2022). Within a triadic model of epistemic justice – including adolescents, parents, and staff – attention is drawn to both individual and systemic factors that influence how knowledge is recognized and valued. From a reflective stance, however, recognition of knowledge does not inherently lead to improved well-

being. When knowledge does not produce a desired outcome, it might deepen frustration and feelings of powerlessness. For instance, a young person or parent may feel heard, but this does not always translate into having an influence over care or treatment decisions (cf. Aarthun et al., 2018). Effective communication is key – clearly explaining the reasoning behind decisions and how different perspectives have been considered can help reduce feelings of marginalization. Epistemic *justice*, therefore, encompasses both the recognition of knowledge and a critical understanding of its limitations and contextual applicability.

If frontline staff feel that their expertise is undervalued within the organization, they may experience a similar sense of vulnerability as the adolescents and parents they work with. This creates a dual challenge – while staff are expected to support and include others, they may not receive the same recognition from those in higher positions. As such, exploring both the relationships between adolescents, parents, and staff, as well as the organizational and systemic factors that sustain knowledge hierarchies, is essential (cf. Bueter & Jukola, 2025).

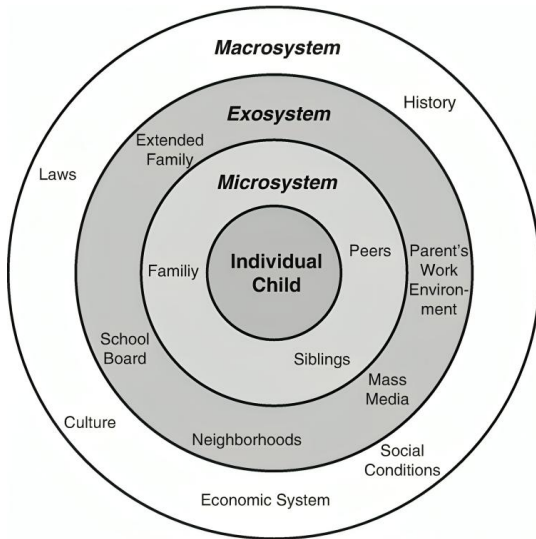
To conclude, recognizing knowledge does not mean simply agreeing with every perspective. Instead, epistemic justice is about creating dialogue where individual experiences are considered alongside professional expertise, clinical guidelines, and institutional limitations. Transparency and respect in this dialogue are crucial for demonstrating how different sources of knowledge contribute to achieving optimal outcomes. Addressing both organizational and relational dimensions appears vital for developing a just and inclusive practice in CAP (cf. Burns & Emon, 2023), where all actors are recognized as epistemic agents (Kidd et al., 2022), thereby fostering a more equitable and responsive mental health care environment.

Ecological systems theory

This dissertation conceptualizes participation as a continuum, aligning with Shier's (2001) model that delineates with its varying levels of engagement. This perspective provides a structured framework for an analysis of how hierarchical social relationships and systemic influences shape adolescent participation in care (cf. Savaglio et al., 2023). To explore youth participation, Bronfenbrenner's ecological systems theory (1979; see Figure 1) offers a multi-layered analytical lens, emphasizing that individuals develop within a network of interdependent systems – micro-, meso-, exo-, macro-, and

chronosystems – each playing a unique but connected role in shaping behavior and development.

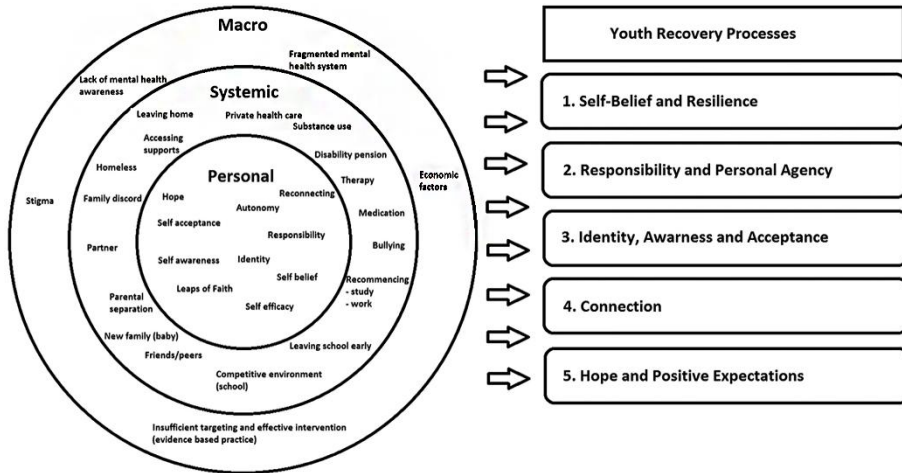
Figure 1. A model showing Bronfenbrenner's (1979) ecological system



The *microsystem* is at the center of this framework, representing the close, everyday interactions that shape adolescents' experiences in care. This includes direct relationships with parents, peers, and staff, all of whom can either support or limit participation. Moreover, adolescence, as a period of increasing autonomy, may pose a challenge to the traditional power dynamics within the microsystem, which usually leads to tensions between adolescents and authority figures (Rayner et al., 2018; see Figure 2). The *mesosystem* focuses on how different environments, such as home and inpatient care, interact. For example, communication between parents and staff in CAP can strongly shape an adolescent's experience of participation. A cooperative relationship between parents and professionals may strengthen a young person's sense of agency, while conflicting expectations could create obstacles (National Institute for Health and Care Research, 2021). Beyond these direct interactions, the *exosystem* encompasses broader influences, such as hospital policies, healthcare regulations, and staff training, which shape the extent to which adolescents are involved in decision-making (Walker & Reibel, 2013). Structural barriers, such as rigid care protocols or insufficient staff training in participatory approaches, can

restrict adolescent agency despite intentions to promote involvement (Eriksson et al., 2018; McDonald-Harker et al., 2021).

Figure 2. The ecological youth recovery model by Rayner et al. (2018)



The macrosystem, in turn, situates participation within a larger socio-cultural and ideological framework, reflecting dominant attitudes toward adolescent autonomy in medical decision-making. As Kemp et al. (2016) acknowledge, ecological models consider wider contextual factors and how they influence both the onset and progression of development in general, as well as mental health outcomes in particular. In addition, cultural norms regarding youth competence and mental health problems (Moses, 2009; Stanton et al., 2020) may be understood as influencing the degree of recovery of a young person.

Finally, the *chronosystem* emphasizes how participation evolves over time, greatly influenced by personal growth, policy changes, and shifts in institutional practices (Bronfenbrenner, 1979). Adolescents' involvement in care decisions can change during the course of their recovery. Their past experiences of healthcare, shifting self-image, and changing relationships with caregivers all play a role in how willing and able they are to participate (Rayner et al., 2018). Viewing participation as a dynamic, context-dependent process thus necessitates adaptive care models capable of responding to these temporal shifts.

Empirical research highlights the significance of fostering trust-based interactions within the microsystem to facilitate meaningful participation (cf. Dewan et al., 2024; Quaye et al., 2019). Taking this

further, the National Institute for Health and Care Research (2021) considers that inpatient admission creates new interactional networks between adolescents, parents, and staff, thus reshaping the mesosystemic structures that mediate participation. This aligns with Bronfenbrenner (1974; 1979; 1986), who highlights the various interconnected systems and how they affect families, drawing attention to the complexity of developmental processes. This complexity can give rise to conflicts between different systems, e.g., disagreements about treatment goals or differing views on adolescents' maturity and ability to manage their mental health. Such conflicts can hinder young people's participation, particularly when they are in vulnerable situations, such as being admitted into inpatient care.

In addition, the structure of healthcare systems often prioritizes adult authority, making it harder for young people to have a say in their care, even when policies support their involvement (cf. Coyne et al., 2016). Overcoming these barriers necessitates an ecological approach that integrates systemic, environmental, and interpersonal considerations. A family-oriented model of care aligns with this perspective, emphasizing collaborative partnerships between adolescents, parents, and staff (cf. Jacobs & Lekganyane, 2024). Research suggests that co-constructing care plans, facilitating transparent communication, and recognizing adolescents as competent decision-makers can enhance their participation (Kelly & Coughlan, 2019; King et al., 2014; Liverpool et al., 2021). In this approach, participation is understood not merely as being present, but as a temporal process that unfolds over time. As part of this process, young people take an active role in their networks, influencing their surroundings just as much as they are shaped by them.

In summary, and in order to understand how adolescents participate in psychiatric inpatient care, an ecological lens considers how both their personal relationships and broader social structures shape their opportunities for involvement. This dissertation underscores the need for participatory care models that are both contextually adaptive and developmentally attuned by recognizing the critical role of interpersonal relationships, institutional structures, and socio-cultural influences. By viewing participation not as an isolated event but as a relational and temporally dynamic process (Cahill & Dadvand, 2018; Kanthi, 2024; Price-Robertson et al., 2016), new avenues open for constructing inclusive, recovery-oriented care environments that genuinely empower young people in their mental health journeys.

Participatory models as presented by Shier and Lundy

Several participatory models emphasize the inclusion and influence of children and young people, as outlined in Article 12 of the UNCRC (1989). These models build on established concepts of participation. Shier's (2001) model, inspired by Arnstein (1969) and Hart (1992), outlines five levels of youth participation in decision-making: (1) young people are listened to, (2) young people are supported in expressing their views, (3) young people's views are taken into account, (4) young people are involved in decision-making processes, and (5) young people share power and responsibility for decision-making. At each level, Shier identifies three key components: *openings* (readiness to operate at a level), *opportunities* (meeting the conditions needed to support that level), and *obligations* (formalizing it as the organizational policy). According to Shier (2001), it is essential to follow these steps to empower young people and to ensure that their voices are heard.

However, Lundy (2007) cautions that equating participation with merely 'giving' a voice risks reinforcing passivity and neglecting critical reflection on how voices are managed and how they influence decision-making. To address this, Lundy (2007, p. 927) proposes that "voice is not enough" and expands on Shier's work through the Lundy Model of Participation (Lundy, 2007; cf. Grace et al., 2024; Kennan et al., 2018; 2019). This model outlines four interconnected components:

- (1) *Space*: Children must be given the opportunity to express a view
- (2) *Voice*: Children must be facilitated to express their views
- (3) *Audience*: The view must be listened to
- (4) *Influence*: The view must be acted upon, as appropriate.

This framework provides a comprehensive approach to ensuring that young people's participation is both meaningful and impactful. Unlike simplified interpretations of the right to be heard or narrow readings of Article 12, the Lundy Model of Participation underscores that genuine involvement depends not only on expression (voice) but also tangible impact, primarily facilitated by adults (cf. Lago & Elvstrand, 2022). However, Lundy (2007) identifies three main barriers that may hinder adult commitment to Article 12: (1) scepticism about young people's ability to contribute significantly to decision-making, or the conviction that they are incapable of doing so, (2) concerns that giving young people more say could weaken adult authority, and (3) apprehension that getting them to comply might entail too much effort.

To summarize, the models by Shier and Lundy focus on involving young people in decision-making and offering ways to engage them in a fair and effective manner. These models are particularly useful in this dissertation as they connect with concepts such as epistemic injustice and ecological systems theory. Together, they provide a framework for examining social dynamics, power relationships, and the challenges of making youth participation meaningful and sustainable. In the context of inpatient care, CHIME (Leamy et al., 2011) offers a complementary perspective by emphasizing how participation contributes to recovery. While Lundy (2007) ensures that young people have space, voice, audience, and influence, CHIME highlights connectedness, hope, identity, meaning, and empowerment as core components. By integrating these frameworks, participation (Lundy) becomes a mechanism for fostering recovery (CHIME), ensuring that youth participation is not only a right but also a vital part of their recovery.

Critical reflections

The phrase ‘all models are wrong, but some are useful’, coined by the British statistician George Box (1976), highlights the dual nature of models. While they serve as important tools, they are also simplified versions of reality. According to Box, even the most sophisticated models inevitably omit certain details and simplify complex situations. Despite their flaws, however, models remain valuable for understanding and predicting various phenomena. In a similar way, the theoretical frameworks used in this dissertation are not flawless representations of reality and have been subject to critique over time.

For instance, Halldenius (2020) critically examines Fricker’s (2007) concept of epistemic injustice. She agrees that Fricker’s work is valuable for highlighting overlooked injustices but calls into question what the theory actually means in practice. Halldenius also points out that Fricker’s focus on *individual* character and self-reflection on prejudice shifts the attention from the bigger picture, such as the larger, systemic political power dynamics affecting marginalized groups. This shift, Halldenius contends, risks individualizing and depoliticizing the concept of injustice (cf. Bufkin, 2024). Medina (2017) also criticizes Fricker’s framework, particularly for its limited scope in defining hermeneutical injustice. He argues that injustice can still occur even when the right concepts are present, but are misunderstood or

misapplied. Taking a pluralist approach, Medina highlights that society is made up of different interpretive groups, and that injustices affect individuals in various ways depending on their community affiliations (Medina, 2012). These critical perspectives (Greenblatt et al., 2023; cf. Carel & Györfy, 2014) not only provide a theoretical foundation for understanding why young people's voices are often marginalized, but also offer a framework to analyze participation barriers through the lens of epistemic injustice. By applying this concept, both individual (e.g., preconceived notions about youth capacity) and systemic obstacles (such as structurally inaccessible decision-making processes) can be highlighted.

Bronfenbrenner's (1979) ecological systems theory has faced criticism for potential reductionism, as it focuses primarily on the influence of environmental systems while underemphasizing individual agency and cognitive processes. Critics argue for a more integrative approach that includes multiple levels of study to better capture the complexities of human development (Kaushik et al., 2023). Notably, Bronfenbrenner himself acknowledged the model's potential overemphasis on context at the expense of considering the individual's active role in their development (Tudge et al., 2009).

Despite its applicability across age groups, CHIME (Leamy et al., 2011) has also faced criticism, particularly for its "overly optimistic" perspective (Stuart et al., 2016 p. 1; cf. Jagfeld et al., 2021). As put forward in this study, this perspective might overlook the everyday struggles of people with mental health problems. Further, having an overly positive view of recovery risks homogenizing individual experiences rather than empowering them. Instead of focusing solely on the five core components presented by Leamy et al. (2011), Stuart et al. (2016) advocate for a broader perspective on recovery – one that includes diverse experiences rather than "celebrating only the strengths of those who appear successful" (p. 12). This is particularly relevant when applying CHIME to young people. To avoid individualizing recovery, emphasis is placed on acknowledging the environments and key figures that support recovery. This shifts the focus from measuring a young person's 'success' to fostering connectedness with others who provide hope, support, and related relational resources.

Cuevas-Parra (2023) criticizes Lundy's Model of Participation for not fully capturing the complexities of children's daily activities or considering how socioeconomic status, gender, and disabilities influence their participation. Reflecting on this is particularly relevant

for understanding the obstacles young people with mental health problems may face when seeking to enhance their participation during enrollment in CAP. By drawing on Cuevas-Parra's (2023) criticism, this underscores the complexity of participation – not just as a theoretical concept but as a practice shaped by real-world constraints. Further, Lundy's (2007) Model of Participation has also faced criticism for potentially promoting tokenism, which refers to the superficial or symbolic inclusion of underrepresented groups to give an illusion of fairness (Lundy, 2018). While Lundy highlights the importance of initiating participation, even in imperfect forms as a step toward progress (Mikkola, 2021), this approach risks being perceived as prioritizing symbolic gestures over genuine inclusion. Shier (2001) takes a stronger position, linking tokenism directly to non-participation, which he compares to manipulation (using children to make things seem child-led when they are not) or decoration (putting children in support roles without acknowledging their ideas). However, some researchers argue that Shier's Pathways to Participation model is overly complex (Hartung, 2017), making it difficult to apply in practice – especially when adults lack the preparation needed to use it effectively (Grace et al., 2024).

To conclude, this dissertation synthesizes theoretical frameworks and practical models to advance a relational, systems-oriented mental health perspective, illuminating how participation and recovery are co-constructed within power-layered contexts (e.g., therapeutic hierarchies and institutional policies). The integrated analytical lens not only identifies barriers – such as epistemic marginalization or resource inequities – but also reveals emancipatory opportunities to redesign care ecosystems. However, transparently engaging with these limitations – particularly methodological challenges in balancing macrolevel structural analysis with microlevel lived experiences – is crucial for maintaining the study's scientific integrity. This reflexive stance not only clarifies the framework's scope but also highlights fertile ground for future research on participatory praxis in mental health care.

Methods and materials

This dissertation comprises four studies, each addressing the previously outlined research questions. In this chapter, I will detail the study design, data collection methods, and analytical approaches employed in each study. To acknowledge my role as a researcher and its influence on the research process and outcomes, a methodological and ethical discussion is presented. Summaries of the studies are provided in Tables 1–4.

Study design

The dissertation has an overall qualitative approach to explore participation during enrollment in CAP and its impact on recovery from the perspectives of young people, parents, and staff. Each perspective contributes to a comprehensive understanding of the complexities involved in participatory work within this setting. The dissertation is cumulative, as knowledge is progressively built through the interconnected studies (cf. Donner, 2021), with each study adding to the existing research landscape.

The research began with a scoping review (study I) to systematize knowledge about young people’s mental health recovery, emphasizing the roles of participation and parental involvement. These findings influenced the direction of later studies, which explored staff actions to promote participation (study II), staff–parent interactions (study III), and the perspectives of young people and parents on participatory practices (study IV). As the dissertation developed, it became apparent that parental involvement, alongside young people and staff, was a key factor in the enrollment process for inpatient care, emerging as a more significant aspect than initially anticipated. As such, the cumulative development of this idea is particularly evident in studies III–IV.

Methodologically, a qualitative design was chosen for its capacity to uncover the complexities of human experiences, thoughts, and feelings (Kvale, 1997). This approach assumes that knowledge and reality are

socially constructed (cf. Rose & Kalathil, 2019), rejecting the positivistic notion of universal “truths” (Galbin, 2014, p. 84; cf. Sohlberg & Sohlberg, 2019). A social constructionist perspective (cf. Gergen, 2018) is therefore central to this dissertation, as it allows for an exploration of how participation and recovery are shaped by cultural, social, and institutional contexts.

This theoretical position is directly relevant to the study’s aim and research questions, which focus on how young people’s knowledge, experiences, and relationships are negotiated and legitimized in psychiatric care settings. In line with Berger and Luckmann (1991), reality is understood as continuously co-constructed through social interactions and shared agreements, rather than as an objective, fixed entity. Consequently, participation and recovery are seen as encompassing multiple subjective truths rather than a single objective reality (cf. Rose, 2006). Furthermore, the epistemological foundation of this study acknowledges that knowledge emerges through researcher–participant interaction. The researcher’s influence on knowledge production is thus an integral consideration throughout the dissertation (Shaw & Gould, 2011; Uggerhøj, 2011).

Interviews, central to three of the four studies, offer valuable insights into behaviors, motivations, and individual experiences (Bryman, 2018; Kvale, 1997). Rather than striving for generalizability, the focus is on enriching understanding through strategic sampling and achieving theoretical saturation (Glaser & Strauss, 1967; cf. Hennink & Kaiser, 2022). This methodological emphasis aligns with the overarching aim of the dissertation and leverages the perspectives of young people, parents, and staff to deepen the understanding of participation and mental health recovery, in line with the three Ps of the UNCRC (1989).

Table 1. Summary of the studies in the dissertation

	Study design	Participants	Data collection	Material	Theoretical framework	Analysis³
Study I	Qualitative	*	Scoping review	Data from 33 articles	*	Qualitative thematic analysis
Study II	Qualitative	Staff (n=27) from outpatient care and inpatient care in CAP	Five focus group interviews and one individual interview	Interview transcriptions	Epistemic injustice and Normalization Process Theory (NPT)	Thematic content analysis
Study III	Qualitative	Staff (n=27) from outpatient care and inpatient care in CAP	Five focus group interviews and one individual interview	Interview transcriptions	Ecological systems theory	Abductive thematic analysis
Study IV	Qualitative	Adolescents (n=5) and parents (n=5) with experiences of inpatient care in CAP	Individual interviews	Interview transcriptions	Epistemic injustice and ecological systems theory	Thematic analysis

³ This study follows Braun and Clarke's (2006) thematic analysis approach as outlined in their earlier works. However, it is crucial to acknowledge their more recent reflections, where they emphasize the diversity within thematic analysis methodologies and caution against treating thematic analysis as a monolithic approach (Braun & Clarke, 2022). They advocate for researchers to 'own' their perspectives, recognizing both personal and theoretical influences on the analysis. In line with this, I have adopted a reflexive and deliberate approach, aiming to move beyond rigid procedural adherence and engage deeply with the data and its contextual meanings.

Table 2. Summary of participants in studies II–III

	Focus groups	Units	Inpatient care units	Outpatient care units	Individual interview	Participants
Studies II-III	5	Units involved in implementing PIBA	1	4	1	27

Table 3. An overview of the focus group participants and their professions

	FGI 1	FGI 2	FGI 3	FGI 4	FGI 5	Individual interview
Psychologist	2	3	2	2	*	*
Psychiatrist	*	1	1	2	*	*
Counsellor	1	1	*	*	*	*
Nurse	*	*	2	1	*	*
Designated staff⁴	*	*	1	*	*	*
Care worker	*	*	*	*	4	*
Unit manager	*	1	1	1	*	1

⁴ At each unit, a designated staff member was assigned to oversee and have insight into the implementation process.

Table 4. Summary of participants in study IV

Adolescents	Type of care	Parents	Type of care
<i>Ester</i>	Voluntary and PIBA	<i>Christoffer</i>	Compulsory and PIBA
<i>Olivia</i>	Voluntary and compulsory	<i>Iris</i>	Voluntary
<i>Jacob</i>	Voluntary	<i>Ingrid</i>	Voluntary and compulsory
<i>Mika</i>	Voluntary	<i>Agnes</i>	Voluntary
<i>Gabriel</i>	Voluntary	<i>William</i>	Compulsory

Data collection and material

This section outlines the settings, participants, and data collection procedures for the four studies. The themes detailed in the results sections of these studies will be presented more comprehensively in the following chapter. Although the dissertation primarily focuses on adolescents between the ages of 13 and 17, different age ranges appear in various parts of the dissertation, making them context-dependent. To avoid excluding studies exploring young people's recovery, the age range in study I was extended to 12–25 years of age. In study IV, the participants were between 15 and 19, as they were required to have experienced inpatient care at some point during the past two years, meaning they were between 13 and 17 years old at the time of their admission.

Study I

There is limited knowledge on young people's recovery from mental health problems, despite its increased recognition. The overall understanding is that recovery among young people is complex as well as nuanced with certain characteristics that need consideration. To better understand recovery as experienced and expressed by young people, it is important to consider a range of perspectives, including those of adolescents, parents, and professionals. This study employed a scoping review methodology to map existing research on the recovery experiences of individuals aged 12 to 25 facing mental health problems. The review identified the lack of sufficient data on this topic, especially when compared to adult populations. In all, 33 articles were analyzed, focusing on the perspectives of young people, parents, and professionals regarding their understanding of recovery. The concepts of agency and participation were critically examined, with particular attention to their portrayal across the articles and their perceived significance in the recovery process.

Data collection

This study explored various forms of recovery knowledge, making a scoping review especially useful for gaining a wide range of insights in the field. Scoping reviews are designed to provide a comprehensive overview of a specific area and its existing empirical work (Arksey &

O'Malley, 2005), including “gray literature” (Paez, 2017 p. 233) such as unpublished studies, evaluations, reports, and working documents. Preparations for material collection involved consultations with a librarian to discuss search processes, to develop search strings, and to identify relevant keywords. After identifying the research question, the following search string was constructed (‘recovery process’ OR ‘mental health recovery’) AND (adolescen* OR teen* OR young* OR youth*).

I (being the first author) filtered the articles retrieved from the search and performed an initial review to determine their relevance, excluding those that did not meet the study’s inclusion criteria. Thereafter, the articles were categorized more systematically and reviewed by the supervisory team. Together, we engaged in discussions to critically evaluate the relevance and quality of each study, ultimately reaching a consensus on which articles would be included in the final analysis.

The total number of articles included was 33, and the majority (n=21) had a qualitative design. A quantitative design (n=2) and a mixed-method approach (n=3) were also conducted. Most of the studies originated from Australia (n=15) and other Anglo-Saxon countries (n=12), while one study included three countries (Australia/the USA/Belgium). Nordic and European countries made up the remaining studies (n=5). A total of 25 of the studies involved young people through interviews, blogs, online forums, and literature reviews (n=4). The remaining studies focused on the experiences of parents (n=5) and health professionals (n=3) in young people’s recovery.

Analysis

A qualitative thematic analysis, guided by Braun and Clarke’s (2006; 2019) framework with an emphasis on *reflexive* thematic analysis, was conducted to synthesize existing knowledge on recovery in adolescents with complex mental health problems, ensuring depth and flexibility in data interpretation. The first step was a thorough review of the selected articles to become familiar with the content. Initial findings and patterns with regard to youth recovery were observed throughout this process. As the analysis progressed, codes were grouped into more general categories that brought attention to similarities, contradictions, and gaps in the literature. The final themes reflected both shared and differing recovery experiences, highlighting the complexity of youth recovery and the broader systemic influences at play. In total, eight distinct themes emerged: (1) ‘Recovery as an individual journey’, (2)

‘Ambivalence and acceptance’, (3) ‘The role of family and peers’, (4) ‘Hope, optimism, and connectedness’, (5) ‘Facilitating agency and participation in an adolescent’s recovery’, (6) ‘Aspects of being involved and heard: a ‘youth-friendly’ mental health service’, (7) ‘Barriers to recovery’, and (8) ‘Recovery and future’.

Study II

Study II explored how staff in CAP Stockholm navigate the challenges of putting PIBA into practice, a novel intervention supporting adolescents with complex care needs. At the start, five units were chosen to implement PIBA, and the study focuses on the readiness of the staff, and the obstacles they encountered along the way. As noted earlier, the introduction of PIBA stemmed from a top-down political decision (Johansson, 2010; cf. Dawson et al., 2021). Such decisions, made with limited input from frontline staff, can lead to misunderstandings or resistance during implementation.

The study applied Normalization Process Theory (NPT) to better understand this process (Elf et al, 2018; May et al., 2018). NPT comprises four core components: (1) *Coherence* (the sense-making done by staff individually and collectively during the implementation of PIBA in their units), (2) *Cognitive Participation* (the relational work staff do to build and sustain a community of practice around PIBA), (3) *Collective Action* (the work staff carry out to enact and implement PIBA), and (4) *Reflexive Monitoring* (explores the appraisal work of staff to assess and understand the ways that PIBA affects them and the adolescents). These components helped explain how interventions become part of the routine in clinical settings by looking at both individual and group behaviors. NPT guided the interview questions in studies II and III, offering a framework to further explore the details of how the implementation process works. Moreover, NPT had the potential to identify barriers to integrating lived experience and diverse knowledge systems into practice and research (cf. Newbigging et al., 2024). It also highlighted processes that promote care for those receiving support (Damsgaard & Angel, 2021) and helped dismantle epistemic hierarchies (cf. Besson, 2022).

Data collection

The material was collected through five semi-structured focus group interviews conducted with staff from both outpatient and inpatient care settings (see Tables 2–3). Between December 2021 and April 2022, a total of 27 staff members with diverse professional roles participated. A combination of purposive and convenience sampling was used to recruit participants (Etikan et al., 2016). Purposive sampling ensured the inclusion of staff with relevant experience from both care settings, while convenience sampling was reflected in the reliance on the availability and willingness of staff to participate.

To recruit participants, unit managers at relevant clinics were contacted and asked to pass along information about the study to staff who might be interested in joining the focus group interviews. Those who wanted to participate informed their managers, who then shared the number of staff interested in participating with the researcher. The focus groups were then set up using this information. This approach made it possible to include staff from different professional roles while also considering practical factors like availability and interest.

Analysis

The material included approximately six hours of recorded interviews and 140 pages of transcribed text. The analysis started with a detailed transcription, providing an initial opportunity to engage with the data. I (being the first author) then carefully reviewed the material to gain a broad understanding of the content and identify initial patterns. This was followed by a detailed coding process, focusing on key discussions about the conditions needed for PIBA to be implemented and how it functions in practice within CAP settings.

The transcripts were carefully examined using thematic content analysis (Braun & Clarke, 2006; 2019). Initial codes were created and refined in a step-by-step process, where relevant sections were condensed and grouped into broader categories. Through this procedure, main themes as well as subthemes were identified revealing both surface-level insights and latent patterns.

In order to understand how new practices are put into action and to identify factors that influence the adoption of PIBA, the analysis was guided by the main principles of NPT (May et al., 2018). This framework offered a clear way to look at the process of integrating PIBA into current clinical routines. The concept of epistemic injustice

(Fricker, 2007) was applied at a later stage in order to comprehend aspects of power and knowledge in the dataset. In this way, the analysis was reinforced, demonstrating how PIBA was put into practice but also reflecting on relational aspects brought by this intervention. Through this process, two main themes emerged: (1) ‘Staff experiences of PIBA’, reflecting how staff perceived the intervention, including its challenges, and (2) ‘Managing clinical PIBA work’, exploring the strategies used and the complexities involved in integrating PIBA into everyday clinical practice.

Study III

Study III built on the focus group interviews conducted for study II, which examined multiple facets of PIBA implementation. While study II focused on specific aspects of the implementation process, the material from study II contributed to study III by offering insights from a distinct perspective and addressing different research questions. The interviews underscored the complexities of managing parental involvement in CAP, highlighting the significant impact parents have on adolescents’ participation in inpatient care. Recognizing the pivotal role parents play in supporting young people’s recovery, study III focused on how staff navigate and balance parental involvement while engaging in recovery-oriented work with adolescents enrolled in inpatient care.

Data collection

For a comprehensive description of the procedural protocol, please see the methodology delineated in study II.

Analysis

This study used an abductive qualitative thematic analysis (Braun & Clarke, 2006; 2019; Thompson, 2022) alongside Bronfenbrenner’s (1979) ecological systems theory to better understand how youth participation is influenced by the interconnected social environments around them. This framework focused on how adolescents interact with various systems (e.g., family, school, healthcare, and community

services), thus highlighting the different contexts in which their participation develops.

The analysis started with a verbatim transcription of the recorded interviews to accurately capture the participants' words and expressions. I then read through the transcripts without applying any theoretical framework at first, which meant that I was able to get a sense of the material and note emerging patterns. This allowed for an open and inductive exploration of the data. Later, the analysis shifted to an abductive approach, where I examined the preliminary findings through the lens of Bronfenbrenner's (1979) ecological systems theory. This iterative process enabled a dialogue between the empirical data and the theoretical framework, allowing for both data-driven and theory-informed interpretations. Key content was systematically coded, with particular attention to elements reflecting the requirements and practicalities of PIBA implementation within CAP.

Next, the codes were categorized according to Bronfenbrenner's (1979) ecological levels, such as microsystems and mesosystems, showing the complex relationships between adolescents and the social structures that affect their participation. In line with the abductive thematic analysis, key concepts such as 'microsystems' and 'cooperation' were identified and explored in detail. This helped create a deeper understanding of how personal experiences connect with larger systemic factors. Through this comprehensive analysis, two overarching themes emerged: (1) 'A family-oriented mindset', which explores how familial dynamics and parental involvement shape adolescent participation, and (2) 'Balancing the complexities', which highlights the challenges staff face in navigating competing demands between promoting youth participation and maintaining structured, recovery-oriented care.

Study IV

Research highlights the importance of involving young people with lived experience in youth mental health studies (Lloyd et al., 2024; Mawn et al., 2015; McCabe et al., 2022; Prior et al., 2022). Similarly, parents with experience of having a child in inpatient care also offer valuable insights (von Wirth et al., 2023; cf. Aarthun et al., 2018; de Melo et al., 2014). Building on this premise, study IV was designed as an interview study involving young people and parents. The

overarching aim was to explore their experiences of enrollment in inpatient care in CAP, and to understand how participation during this process impacts recovery. While the original intent was to recruit individuals specifically familiar with PIBA, the pandemic delayed its implementation, resulting in few signed contracts. To address this, the inclusion criteria were broadened to encompass general experiences of participation during inpatient care in CAP. Interviews also examine how young people and parents perceive PIBA and its potential to enhance participation during inpatient care enrollment.

Data collection

The inclusion criteria required respondents to be between 15 and 19 and to have been admitted to psychiatric inpatient care in CAP within the past two years. To explore their participation experiences, respondents were asked about their knowledge of PIBA and their views on its core components. The recruitment of adolescents occurred between February 2022 and December 2023⁵, while the recruitment of parents took place from October to November 2023. Parents, like adolescents, needed to have experienced a period of inpatient care involving their child within the last two years. With regard to adolescents as well as parents, the need for inpatient care arose from self-harming behavior, emotional instability, anxiety, manic episodes, suicidal thoughts and actions, eating disorders, compulsive behaviour and post-traumatic stress.

Participants were recruited by using a combination of purposive and convenience sampling (Etikan et al., 2016) to specifically identify respondents with experiences of inpatient care in CAP. Recruitment efforts were broad, utilizing flyers in outpatient care waiting rooms, digital platforms of user organizations (NSPH⁶, SHEDO⁷, and the OCD⁸ Association in Stockholm County), LinkedIn, and a national family network coordinator (SNAPH⁹). Interested participants initially

⁵Appendices 2 and 3 state that the adolescents would be interviewed on two occasions. However, as the project shifted direction – placing a greater emphasis on the parents than originally intended – no follow-up interviews were conducted due to time and resource constraints.

⁶NSPH stands for The Swedish Partnership for Mental Health.

⁷SHEDO stands for Self-Harm and Eating Disorder Organisation.

⁸OCD stands for ‘obsessive compulsive disorder’.

⁹SNAPH stands for Stockholm Mental Health Action Network.

contacted the researcher via text or email and received additional details during a follow-up call. If they remained interested, interviews were scheduled at locations selected by the participants. However, some individuals who had initially shown an interest decided later not to participate in the study. In total, 10 semi-structured qualitative interviews were conducted – five with adolescents and five with parents¹⁰ – all of whom had experience with CAP in three Swedish cities. Despite my previous work in CAP, I had no prior relationship with any of the adolescents or parents participating in this study. This helped ensure objectivity during the interviews and minimized the risk of bias in the data collection phase.

The interviews took place in various settings, including participants' homes, in cafés, libraries, schools, and via Zoom or Google Meet (see Appendices 8 and 9 for interview questions). To show appreciation, the adolescents received two cinema tickets and refreshments (e.g., coffee or soft drink) for participating in in-person interviews. This was funded by a research grant from the Swedish National Association for Social and Mental Health (RSMH), aimed at encouraging user participation and knowledge-sharing in research.

Analysis

The data consisted of about 20 hours of recorded interviews and more than 300 pages of transcriptions, which offered a substantial basis for in-depth analysis. Although some parts of the interviews provided valuable insights into inpatient care from a broader perspective, they did not align with the focus of the dissertation. Consequently, these sections were excluded to maintain a focused and manageable analysis.

The study applied thematic analysis (Braun & Clarke, 2006; 2019) to find both clear and hidden meanings in the data. This was combined with Bronfenbrenner's (1979) ecological systems theory, which helped explain how different factors – such as family and larger institutions – affect how adolescents participate in their recovery during inpatient care. This approach provided a deeper understanding of participants' experiences, highlighting how parents, adolescents, and staff interact and adapt within the complexities of the care environment. To add more depth to the analysis, Fricker's (2007) concept of epistemic injustice

¹⁰ None of the respondents were related to one another.

was used to explore how power dynamics and credibility influenced whether participants were seen as trustworthy and valued for their knowledge.

The analytical process followed Braun and Clarke's (2006; 2019) six-phase approach, beginning with familiarization through repeated readings of the transcripts, followed by systematic coding to identify significant patterns. The coding process was data-driven, and as the analysis was being refined, six connected subthemes took shape, capturing the nuanced experiences of inpatient care. These subthemes ultimately led to the main interpretative theme, 'Togetherness in inpatient care', which highlights the challenges and relationships involved in creating a supportive and participatory environment in a psychiatric setting.

The subthemes were as follows: (1) 'Care on different terms', highlighting the varying expectations and realities of inpatient care, (2) 'It is all about trust', emphasizing the foundational role of trust in facilitating participation, (3) 'Not having to fall apart to receive help', reflecting on accessibility and preventive care, (4) 'Participation as holding on and letting go', exploring the delicate balance between adolescent autonomy and parental involvement, (5) 'A joint relief', illustrating moments of shared understanding and emotional release among families and staff, and (6) 'Being addressed directly', underscoring the importance of adolescents being seen and heard in their own care processes. These themes collectively illustrated the interactions between systemic structures, relationships, and individual actions in shaping experiences of inpatient care. The combination of ecological systems theory and epistemic injustice offered a comprehensive understanding of how participation is both supported and constrained in this setting.

Methodological reflections and limitations

This dissertation employs a qualitative design, with most data collected through focus groups and individual interviews. Studies II and III involve staff interviews about their experiences of implementing PIBA. Focus group interviews are valued for generating rich, in-depth insights into participants' opinions and attitudes while fostering interactive discussions (Leung & Savithiri, 2009; Morgan, 2013). In a group setting, people often spark new ideas off each other, leading to insights

that might not come up in one-on-one conversations. This going back-and-forth can enrich the discussion and bring out different perspectives (Gundumogula & Gundumogula, 2020). But focus groups also have their challenges. Certain individuals may monopolize conversational dynamics, thereby marginalizing others and limiting their opportunities for meaningful participation (Leung & Savithiri, 2009), and the lack of anonymity can make it harder for participants to be completely honest (Sim & Waterfield, 2019). A skilled moderator is key to making sure everyone gets a chance to contribute and that the discussion stays relevant and balanced. With this in mind, my prior experience of managing group dynamics as a user involvement coordinator in CAP proved valuable during the interviews, helping me navigate the challenges of focus group discussions.

Since most of my previous work occurred in inpatient care, I was more familiar with inpatient staff, which influenced the planning of the focus group interviews. To mitigate potential biases or hesitation among staff due to my former role, it was decided that my supervisor, rather than I, would conduct the inpatient interviews. Notably, these staff interviews took place early in the implementation phase, and discussions were marked by apprehension, contributing to the dual perspectives presented in studies II–III. Additionally, study II primarily employed the concept of agency. Initially, my analysis insufficiently explored the interconnected dynamics of agency, autonomy, and participation. With deeper theoretical engagement, I would now emphasize participation's pivotal role in recovery-oriented practices, reflecting my evolved perspective on participatory frameworks

As previously outlined, the implementation of PIBA in CAP progressed slowly at the outset. About two years into the project, the focus of the dissertation changed. The only interview conducted in those two years was with a young person who had actively used PIBA. Because of this, the approach was adjusted, and study IV was expanded to include experiences of inpatient admissions in general, rather than focusing only on a specific care model. Thus, all the adolescents in study IV have experience of attempting to access inpatient care. In relation to the overall hypothetical discussions surrounding PIBA, they were able to draw on their own experiences to reflect on and discuss what they believe would be the difference between being admitted through traditional procedures and being admitted according to the core principles of PIBA. Despite this methodological refinement, study IV relies on a partially speculative framework (Meskus & Tikka, 2024),

which could be seen as one of the major limitations of the dissertation as a whole. However, having two participants (one adolescent and one parent) with firsthand experience of PIBA strengthens the dissertation by offering real-life perspectives. Their insights help shed light on how participatory approaches such as PIBA influence the admission process, especially in terms of how young people are involved in decisions about their care. These firsthand accounts offer a more nuanced understanding of how PIBA operates in practice, illuminating both its potential benefits and inherent challenges. By integrating these perspectives with reflections from participants who have engaged with traditional care pathways, the study presents a more comprehensive and layered exploration of youth participation during enrollment in inpatient care.

In study IV, adolescents and parents were interviewed individually, either in person or online, to explore their experiences of inpatient care admissions. Unlike group interviews, one-on-one conversations do not allow participants to generate ideas from each other, hear different viewpoints, or develop a shared understanding. Without the chance to interact with peers, participants miss out on the kind of support that can be especially helpful when discussing sensitive topics (Hassler et al., 2024). In one interview, a young person asked if a friend could join remotely for support while scrolling through their phone during the conversation. I had not anticipated this situation, but I understood that honoring the adolescent's choice was more important than doubting their request. It thus required flexibility in following ethical guidelines – what Wästerfors (2019, p. 181) refers to as “improvising” – to make sure the interview was conducted in a manner that was comfortable for this respondent.

The young people and parents who participated in this study might be those who were not entirely satisfied with their inpatient care. While some did talk about positive experiences, the study's focus may have unintentionally drawn in more participants with critical perspectives. Conversations often delved into difficult experiences, requiring me to navigate and interpret complex emotional responses. To manage these sensitive discussions, I drew upon my previous professional role in CAP, as a school counselor, and in social services, leveraging my experience in supporting individuals through pain and suffering. The stability and sensitivity fostered by this background were likely important in enabling the interviews, aspects that will be further reflected upon in the ethical considerations section.

Ethical considerations

Throughout the dissertation process, I have encountered ethical challenges that warrant a detailed discussion to ensure transparency and uphold scientific rigor. Additionally, it is pertinent to reflect on how my personal experiences have shaped my interpretations of the data underpinning this work. I have spent several years enrolled in inpatient care, and I have also worked as a user involvement coordinator and children's rights advocate in CAP. Due to this, ethical considerations were central to this dissertation, whether involving young people, parents, or staff, each presenting distinct 'dilemmas' and complexities. Consequently, this section outlines how these considerations were addressed.

The studies included in this dissertation were approved by the Swedish Ethics Review Board (Dnr: 2021–02790; 2023–05055). Ethical principles, including the Declaration of Helsinki (World Medical Association, 2024) and Guidelines for Social and Medical Research (Swedish Research Council, 2017), were strictly adhered to. Informed consent was obtained from all the participants prior to the interviews conducted in studies II–IV. They were explicitly advised of their right to skip questions or withdraw from the interview at any time without consequences. During the interviews, I used a semi-structured guide but allowed participants to steer the conversation toward topics they felt were most important. To create a supportive environment, I reassured them that there were no right or wrong answers. Anonymity and confidentiality were guaranteed, and all interview data were securely stored, accessible only to myself and two senior researchers. Together, these measures helped ensure ethical rigor and prioritized participant welfare throughout the process.

From shared experience to scholarly inquiry – navigating positionality in research

Acknowledging my shared experiences with the study participants underscores the necessity of reflexivity in research (Berger, 2015; Ide & Beddoe, 2024; Olmos-Vega et al., 2022; Taquette & Borges da Matta Souza, 2022). My background as a mental health user and my familiarity with psychiatric inpatient care raised ethical concerns about potential biases. Reflecting on these experiences was therefore crucial to preserving analytical neutrality. While an insider perspective –

‘having been there’ – may provide valuable insights (Berger, 2015) and bridge the gap between theory and practice, it simultaneously risks blurring boundaries and introducing subjective bias. Writing this dissertation thus meant integrating my user perspective with enough distance to consider diverse viewpoints.

During the data collection and analysis phases of study IV, some material had a deep emotional impact on me. To manage this, I engaged in discussions with my supervisors and kept a reflective work diary, emphasizing the need for self-ethics (Tullis, 2021; cf. Sparkes, 2024) and situated ethics (Dembele et al., 2024) to address the emotional challenges of research. However, leveraging personal experience of the subject also provided distinct advantages, such as fostering mutual understanding and bringing authenticity to the interviews. This “expert by lived experience” perspective (cf. Guerrero et al., 2024, p. 2) enabled a more empathetic approach, which might have been harder to achieve had I been perceived solely as an outsider probing sensitive topics. A majority of the adolescents participated because they wanted their voices to be heard, reflecting their dissatisfaction with being ignored and marginalized as knowledge holders (cf. Eriksson & Näsman, 2008). Youth rights, as outlined in the UNCRC (1989), stress the need for both protection and the opportunity for young people to express and shape their voices (Cohen et al., 2007; Quennerstedt et al., 2014; Rutanen et al., 2021). This becomes particularly significant in contexts where young voices may be overshadowed by the agendas of others (cf. Åkerlund & Gottzén, 2017). As Björklund (2024) argues, greater participation disrupts traditional notions of expertise, fostering an exchange between lived and formal knowledge.

In the interviews, I aimed to treat the adolescents as competent individuals and experts in their own experiences (cf. Bodén, 2021; Petersen et al., 2012; Samuelsson et al., 2015). This avoided framing them as merely fragile or passive (cf. Koelch & Fegert, 2010). In line with Romsland et al. (2019), I sought to move beyond tokenistic involvement by fostering a research environment where adolescents felt their insights genuinely influenced the study. Following Råheim et al. (2016), I prioritized creating a safe, anti-authoritarian space that equalized power dynamics, encouraging them to share their unique insights (cf. Cohen et al., 2007; Hoop et al., 2008; Sobočan et al., 2019). In terms of CHIME, this might have facilitated connectedness as well as meaning, cultivating a deeper engagement with their experiences. The following interview excerpt illustrates this approach:

Adolescent: *Talking to you was easier than I expected.*

Jennie: *Could you elaborate on that?*

Adolescent: *I thought it might feel a bit stiff, but you actually understand this on a real level, unlike someone who's only mildly interested. It turned out to be the opposite – talking to you felt easy and relaxed.*

Since all the parents preferred to meet online, that option was provided. Unlike the group discussions with staff, these one-on-one interviews allowed the parents to remain completely anonymous and speak more freely. The experience of having a child in psychiatric inpatient care can be deeply emotional, any many parents find themselves torn between wanting to support their child's needs and dealing with the emotional strain of the situation (cf. Merayo-Sereno et al., 2023). Additionally, navigating a fragmented healthcare system can be overwhelming, and discussing these experiences may trigger stress and anxiety (cf. Leung et al., 2022).

Conducting interviews digitally made it more challenging to detect emotional cues and to offer support when needed. Nonetheless, my background in CAP likely supported my ability to stay engaged, listen with empathy, and facilitate a natural flow of conversation. Although parents initially expressed frustration and disappointment with the quality of care, my ability to navigate these emotions helped redirect the interviews toward more nuanced discussions of participation during the care episodes.

My prior professional roles in CAP involved promoting youth participation and ensuring staff adhered to related guidelines. While these roles emphasized one of the three Ps (participation) of the UNCRC (1989), this focus may have led to an overemphasis on participation or a less objective perspective on the topic. Regarding focus group interviews with staff, my former role might have made participants feel scrutinized, particularly in inpatient care, my primary area of work. To reduce the risk of bias and conflicts of interest, one of my supervisors conducted the focus group on inpatient care as well as a one-on-one interview with a managerial staff member. I carried out the four focus group interviews in outpatient care, where I had less direct experience. Reflecting on the distinction between working within a practice and observing it externally underscored the importance of reflexivity throughout the dissertation (cf. Adams & Manning, 2015; Berger, 2015; Olmos-Vega et al., 2022).

Consent, resistance, and power

In the broader social discourse on adolescent mental health, it is essential to acknowledge the roles of various actors – parents, mental health professionals, teachers, and others – in shaping the understanding of these issues. At times, there is uncertainty about how to address mental health problems, which can lead to a fear of making the situation worse. For example, adults sometimes worry that bringing up the topic might increase anxiety, encourage self-destructive behavior, or even contribute to suicidal thoughts – a concern that mirrors what Sparrman (2014, p. 123) describes as a form of “moral panic”. This raises a significant question: Is it justifiable to explore someone’s difficult experiences for the sake of gaining knowledge? From my perspective, this ties into broader questions of power dynamics, interpretive authority, and the positioning individuals assume when negotiating their lived experiences (cf. Foucault, 2003; Fricker, 2007) – themes that form a foundational pillar of this dissertation

Källström and Andersson Bruck (2017) advocate for actively involving children and young people in research, promoting a shift from studies *about* them to studies conducted *with* them (cf. Totzeck et al., 2024). Some of the adolescents in this dissertation have faced coercion – whether informally, through parental persuasion, or formally, through coercive measures in inpatient care. Given their experiences of the mental health system, questions concerning consent, resistance, and power take on a particular significance. Drawing on this, young people might need some degree of choice and control over their participation, especially since many decisions affecting their lives have been, and still are, made by parents, doctors, and/or social services.

Control, inherently tied to power, was a critical consideration during the data collection phase. I reflected on this while informing the participants about the study and conducting interviews. Properly informed, the adolescents held the power to decline to answer questions or opt out of participation if they felt uneasy. A hesitant response or silence could signify resistance – either to the research process as a whole or to specific questions – demonstrating their autonomy in deciding what knowledge to share. As this dissertation emphasizes young people’s participation in inpatient care and its role in their recovery process, allowing them the freedom to share diverse perspectives during interviews enriches our understanding, but also underscores the importance of their active participation in shaping their recovery journey.

In the context of CAP, parents and staff occupy often unequal positions of power. Parents, here understood as actors navigating the system on behalf of their children, may feel subordinate to the institutional hierarchy and hesitant to voice criticism or concerns, fearing repercussions or judgment. Conversely, staff, as internal stakeholders, may feel a sense of loyalty to the institution or a need to safeguard their professional identity, leading to defensiveness or a reluctance to acknowledge systemic shortcomings (cf. Chatten, 2022). As a researcher, it was crucial to remain aware of these dynamics in order to provide spaces where participants felt comfortable sharing their experiences. This involved building trust, fostering openness, and demonstrating respect in every conversation. Whether in group settings or one-on-one interviews, it was equally important to recognize and manage the inherent power imbalances present in these interactions (cf. Berger, 2015). For parents, this meant feeling listened to and respected. For staff, it was important to create an open environment where they could speak freely without worrying about being judged or facing negative consequences at work (cf. Kvale & Brinkmann, 2015).

To achieve this, I strived to adopt a neutral stance, avoiding alignment with either group, while actively acknowledging the different pressures and vulnerabilities each faces. By demonstrating empathy, ensuring voluntary participation, and prioritizing participant agency, I sought to encourage both parents and staff to engage honestly and collaboratively, enriching the study with diverse perspectives.

Risk vs. benefit and ‘mess in ethics’

This dissertation seeks to address the limited knowledge of how participation in inpatient care influences recovery from mental health problems, driven by an inherently empathetic aim. However, research ethics often involve navigating unpredictability, requiring moral decisions within complex, real-world contexts. Factors such as risk, protection (Faruqui et al., 2024), and the inevitable “messiness” of research (Rutanen et al., 2021 p. 2; Sparrman, 2014; Thomas-Hughes, 2018; cf. Billett et al., 2020) shaped my role as a researcher. Acknowledging this messiness included recognizing the emotional complexities and conflicts (cf. Kousholt & Juhl, 2023) that surfaced during certain interviews, compelling me to assess whether a conversation was likely to do more harm than good. The following extract illustrates this challenge:

Jennie: *Earlier, you mentioned “getting well”. Do you consider yourself ‘ill’?*
Adolescent: *I usually say I’m...broken in some way, like a glass that’s been shattered and hasn’t been put back together. I feel like I’ve lost parts of myself that I can’t recover. I don’t feel ‘ill,’ but I don’t feel ‘well’ either. I’ve met people who’ve lost all hope, and I think that’s why I hold on to mine – I don’t want to fall into hopelessness. I’ve also seen two people who’ve taken their own lives. Once, on my way to CAP, I saw a man jump in front of a train.*
Jennie: *Was that recently?*
Adolescent: *No, it was a long time ago. I was 12.*
Jennie: *And you’ve been carrying that with you since?*
Adolescent: *Yes. That event has stopped me from attempting suicide. I’ve thought about it a lot – it really affected me.*
Jennie: *Mmm. How do you feel talking about this?*
Adolescent: *I’m used to talking about it.*
Jennie: *Because otherwise, we can change the subject.*

This extract highlights the balance between risk vs. benefit (Helgesson, 2015; Hiriscau et al., 2016; Hoop et al., 2008) and demonstrates my awareness of the adolescent’s efforts to steer the conversation. By offering an alternative approach, I aimed to enhance their participation through a form of ‘consent check’, fostering an interview environment rooted in mutual respect (cf. Mayne & Howitt, 2015). Active listening to both content and tone allowed the research to be conducted *with*, rather than *on*, the adolescent (Bodén, 2021; cf. Sheikh et al., 2024). Attentiveness to the adolescent’s emotional state reflected my recognition of their vulnerability without making unilateral decisions about the next step. Their proximity to adulthood at the time of the interview arguably legitimized the decision to proceed. However, critical reflection raises the question of how the approach might have differed with a younger participant, such as a 13-year-old. While it is likely that a younger age would require a distinct ethical framework, this cannot be stated with certainty, as ethical considerations depend on the unique circumstances of each situation.

Ending interviews – maintaining boundaries and respect

During the data collection phase, I sought to remain conscious of my role in the lives of the young participants, aware of the risk of becoming a transient figure who comes, interviews, and leaves (cf. Bodén, 2021). To foster a permissive interview environment, I actively avoided a mechanical approach to our interactions. My goal was to conduct the interviews ethically and to ensure that the young persons were left in apparently good state, which warranted heightened ethical sensitivity.

This approach, however, prompted several critical questions: How do you read a young person accurately? Could a misinterpretation occur? Did I risk assuming a role beyond that of researcher, and was this appropriate? Navigating the balance between proximity and distance, as Michelson (2023) so delicately puts it, necessitated managing the transient nature of the interview setting, particularly when concluding interviews in an ethically considerate way. The excerpt below features an interview with an adolescent who started crying when talking about painful memories. This illustrates the ethical hurdles in trying to manage their emotional state when simultaneously striving to end the interview in a respectful way (cf. Eldén, 2020).

Adolescent: I've never had the chance to really share what it was like for me being enrolled. No one's been willing to listen.

Jennie: Thank you for trusting me and allowing me to be the first person you share this with.

Adolescent: (Laughs) I was SO nervous before coming here today.

Jennie: I understand, and I'm truly grateful for your trust. As you've seen, hearing your story affects me too – I'm only human. It's a privilege to listen and talk to you. Thank you for being willing to share.

The next day I sent her a text message while trying to get a sense of the aftermath of the interview. I wrote:

Hi! Thanks for meeting me yesterday! Just wanted to check if you're ok?

The answer came a few hours later and read:

Yeah, I'm good!

Following an “ethical radar” approach (Skånfors, 2009 p. 1), I sent this message to check that our conversation had not caused any harm. While my intentions were good, it makes me question whether I might have overstepped the line separating researcher and participant (cf. Berger, 2015). Could my concern have caused confusion or been seen as something similar to a therapeutic follow-up? What prompted me to send the message, and what expectations could this have raised for the adolescent? The brief response also makes me wonder about its honesty and how I would have reacted if the message indicated a worsening mental state. In essence, I believe these ethical considerations to be closely linked with the methodology. For instance, conducting focus group interviews might have reduced the perceived need for individual

follow-up by allowing participants to support one another before, during, and after the interview session. Ultimately, while reflection cannot predict alternative outcomes, it can heighten awareness of these complexities and their potential implications.

Just as with the young participants, parents and staff in CAP also bring unique emotional and psychological experiences to the interview process. Given the sensitive nature of the topics discussed, it was essential to ensure that interviews with them ended in a way that respected their emotional states and upheld appropriate boundaries. For both parents and staff, closing the interview required a careful balance – acknowledging their experiences, the emotional weight of the discussion, and the vulnerability inherent in sharing such personal matters, while avoiding any overstep as a researcher. In this context, I took extra care to express my gratitude for their participation, reinforcing the value of their contributions to the study. My aim was to offer closure in a way that was compassionate yet non-therapeutic, ensuring that participants felt respected and safe as the conversation came to an end.

Main results

This chapter provides a synthesis of the main findings from the four studies, emphasizing both their distinct insights and their collective contribution to advancing knowledge in the field.

Study I: Young people's recovery processes from mental health problems – a scoping review

The aim of study I was to synthesize existing research on young people's recovery processes from mental health problems and to explore the role that agency and participation can play in these processes. The study combined the perspectives of young people, parents, and professionals, emphasizing recovery as a deeply personal, non-linear, and dynamic process that fluctuates over time and depends on youth-friendly mental health care (Hense & McFerran, 2017; McCann & Lubman, 2012; Rickwood et al., 2019; 2024). A key finding was that young people often perceive their mental health problems through a biological lens, potentially undermining confidence in the feasibility of recovery and contribute to shifting perceptions of what recovery means in both clinical and social contexts. Accepting ongoing challenges and learning to manage them emerged as part of recovery, though this acceptance also generated uncertainty regarding long-term well-being.

The study highlighted the pivotal role parents play in youth recovery, both by motivating young people and helping them access care. It showed that when parents and professionals offer guidance and encouragement – rather than pressure or control – adolescents feel more supported in their recovery process. However, the precise mechanisms of family involvement remain unclear, with maladaptive family dynamics potentially hindering progress. Helping young people recover from mental health problems, as shown in the study, supports the relevance of the adult CHIME framework (Leamy et al., 2011).

Nevertheless, it needs to be adapted to fit the specific needs of young people, taking into account their stage of development, the influence of peers, and the key role of family dynamics (Ballesteros-Urpi et al., 2019; Naughton et al., 2018). For young people in inpatient care, the study suggested that parents and staff play an instrumental role in encouraging them to set goals such as returning to school or finding a job, both of which are key factors for long-term recovery and social reintegration. Finding the right balance means acknowledging their need for independence while ensuring recovery goals are personalized to their needs. The findings further highlighted the tension between professional guidance and self-led recovery, and emphasized the need for collaborative decision-making models that prioritize participation and youth participation.

Fostering hope and optimism emerged as a central cornerstone of recovery, emphasizing that mental health problems need not define or dictate young people's future. Central to nurturing this hope is the active participation of adolescents in decisions about their care, which empowers them and strengthens their sense of control and self-confidence. The empowerment component of the CHIME framework underscored the importance of giving adolescents a voice in their care, the ability to make informed decisions, and ensuring that they play an active role in their recovery journey.

To conclude, study I highlighted the need for a holistic, system-oriented approach that integrates agency, participation, and the complex interplay of individual, family-related, and structural factors. To better support young people's mental health recovery, future research should investigate how family dynamics and systemic barriers – such as limited access to care, stigma, and socioeconomic inequality – shape their recovery trajectories. It is likely that developing effective youth-centered interventions will require sustained collaboration between policymakers, clinicians, and researchers to ensure that young people receive the support they need to navigate their mental health journeys.

Study II: Staff's experiences of implementing patient-initiated brief admission for adolescents from the perspective of epistemic (in)justice

Study II explored how staff in CAP understand participation within the PIBA framework and their experiences of the implementation process,

with a particular focus on how youth participation is viewed in care and support systems. This was especially relevant given that PIBA, initially designed for adults with complex psychiatric needs, had been adapted for adolescents. While youth participation continues to gain momentum, the study revealed persistent systemic challenges at every stage – preparation, execution, and post-implementation – emphasizing the need for adaptive structures that embed sustainable, youth-centered practices into routine care frameworks (May et al., 2007; cf. Ørjasæter, 2023). The study showed that staff generally viewed PIBA as a promising intervention for adolescents with complex needs, offering them greater involvement in their care. However, there were concerns that PIBA might reinforce the identity of adolescents as ‘patients’ and risk trapping them in a cycle of care dependency.

While recognizing both the individual benefits and disadvantages of PIBA, staff also faced challenges during its implementation, particularly in bridging the gap between PIBA’s theoretical framework and its practical application in the CAP setting. These challenges were largely attributed to the top-down nature of the implementation process and a lack of organizational readiness, particularly in inpatient care. Staff reported feeling that they had minimal control or influence over how PIBA was introduced, leading to an implementation process marked by uncertainty and ambiguity. Consequently, staff felt excluded from decision-making, resulting in diminished ownership and engagement.

The study applied Fricker’s (2007) concept of epistemic injustice to show how staff’s credibility and contributions were undervalued (testimonial injustice), and how they lacked interpretive resources to make sense of their experiences (hermeneutic injustice). This disempowerment not only affected staff but also risked undermining adolescents’ participation, as staff who were unable to advocate effectively could not fully support youth agency. Adolescents, who are already in a vulnerable position in CAP, may therefore face additional barriers if staff feel unheard or disempowered. When staff are unable to advocate effectively due to their own lack of voice, young people risk being overlooked or misrepresented in the planning of care. This may perpetuate an imbalance where institutional priorities take precedence, making it more difficult for young people’s voices to be truly heard and valued in their recovery.

In addition to Fricker (2007), the study applied Normalization Process Theory (NPT) to analyze key barriers within its four core components, weaving them into the findings. *Coherence* emerged as a significant challenge, as staff had different levels of understanding regarding the purpose and goals of PIBA. This inconsistency in interpretation led to fragmented implementation efforts, with some staff viewing PIBA as a valuable resource for empowering adolescents, while others struggled to grasp its relevance within the CAP setting. *Cognitive participation* was hindered by the lack of ownership and involvement in the initial planning stages. Staff reported feeling excluded from decision-making processes, which limited their commitment to the intervention. This disconnect contributed to difficulties in building a cohesive community of practice around PIBA, weakening the foundation necessary for successful implementation. *Collective action* faced obstacles due to practical challenges such as unclear protocols, inadequate training, and resource constraints. These issues impeded the integration of PIBA into day-to-day care, leaving staff uncertain about their roles and responsibilities. The absence of clear guidelines also exacerbated tensions between outpatient and inpatient units, further complicating collaborative efforts. Finally, *reflexive monitoring* was limited, as staff had few opportunities to evaluate and adjust the implementation process. Without a clear system for feedback, staff struggled to evaluate the effectiveness of PIBA, and to identify areas for improvement. Consequently, not being able to reflect on this work made it difficult for staff to integrate PIBA into everyday care.

In summary, this study advances research on person-centered mental health care, offering insights into recovery-oriented interventions such as PIBA. Key takeaways include the importance of collaborative implementation, addressing power dynamics, and centering staff perspectives.

Study III: “It’s an extra twist that’s a bit tricky to solve”: Staff balancing parental involvement when supporting the participation of adolescents in a family-oriented practice

Building on data from study II, this study explored how staff navigate parental involvement while fostering youth participation in recovery-

oriented inpatient care. Evidence increasingly highlights the significant role parents play in supporting young people's recovery, particularly in shaping whether and how recovery is facilitated (DeCarlo Santiago et al., 2020; Kelada et al., 2018; Rayner et al., 2018; cf. Sheerin et al., 2023). Drawing on Bronfenbrenner's (1979) ecological systems theory, the study illuminated how interactions across individual, relational, and systemic levels shape youth recovery.

Staff generally supported the involvement of parents as partners in family-oriented work in CAP. However, within the context of PIBA, they described challenges in balancing adolescents' autonomy with parental involvement. The PIBA contract, as explored in this study, was intended to address this challenge by clarifying expectations, specifying treatment goals and conditions, and fostering communication between the ecological systems influencing adolescents' situations. While the contract aimed to empower young people and guide staff to promote youth participation alongside parental involvement, staff also perceived it as underdeveloped in relation to adolescents. They identified this as a critical area for improvement, emphasizing the need to strengthen cross-system communication and collaborative practices.

At the same time, staff noted that PIBA can disrupt traditional notions of partnership by shifting decision-making power toward adolescents. This shift may foster a binary view of participation, where it is seen as belonging either to the young person or the parents. Staff often described parents as a potential 'risk,' leading to tensions and contradictions in how participation is enacted. Rather than being understood as a dynamic, negotiated process (cf. Michelson, 2022; Munford & Sanders, 2015), participation was frequently described in either-or terms.

The study also introduced the concept of the 'twist,' referring to situations where family difficulties – such as parental mental health problems or substance abuse – affect adolescents' care needs. In some cases, inpatient care was explained to provide an escape from challenging home environments. Staff underscored the complexity of circumstances arising at the intersection of mental health care and social work – particularly challenges in delineating responsibilities between CAP and social services (Barnhoorn-Bos et al., 2025) – and called for strengthened inter-agency collaboration to address systemic gaps.

In conclusion, study III offered important insights into how staff approach parental involvement when implementing participatory work within PIBA in CAP. The findings suggested that for participation to

meaningfully support recovery, parental involvement should be seen as an asset rather than a barrier. More broadly, the contractual framework of PIBA has the potential to strengthen links between ecological systems and foster structured collaboration between staff, adolescents, and parents in support of recovery.

Study IV: “The idea of not having to prove anything in the way I needed, that would be really helpful” – Exploring adolescents’ and parents’ understanding of youth participation during patient-initiated brief admission enrollment in psychiatric inpatient care

Study IV explored how adolescents and parents perceive participation during the enrollment process for psychiatric inpatient care and how participation influences recovery from mental health problems. Drawing on interviews with five adolescents and five parents, the study valued lived experience alongside professional expertise (Beames et al., 2021; Honey et al., 2020; Watson et al., 2023). The findings were analyzed using the concepts of epistemic injustice (Fricker, 2007) and ecological systems theory (Bronfenbrenner, 1979).

This study showed that both adolescents and parents struggle to have their needs recognized and met during enrollment. Participation was closely linked to adolescents’ ability to express their care needs without feeling compelled to exaggerate or dramatize their situation to gain access to inpatient care. Viewed through the lens of epistemic injustice, the study emphasized the critical role of adults in taking adolescents seriously, listening attentively, and recognizing them as credible ‘knowers’. When microsystems such as parents and staff actively supported adolescents in articulating their care needs, participation was strengthened, contributing positively to their recovery journey.

The study further illustrated participation as a dynamic process shaped by interpersonal and systemic relationships. This dynamic allowed adolescents to navigate the tension between dependence on others and the desire for greater responsibility regarding their mental health. Both adolescents and parents described the pressure to amplify symptoms to gain care access, often resulting in feelings of being an ‘imposter’ or taking resources from others with seemingly greater needs. This experience rendered inpatient care unwelcoming and

contributed to feelings of anxiety and disconnection. Frustration and isolation during enrollment led adolescents to question whether PIBA could truly benefit them. More specifically, they viewed PIBA as a conceptually promising intervention but emphasized that, without systemic reforms, its practical application faced significant barriers.

Findings also demonstrated the necessity of avoiding tokenistic participation and overcoming organizational barriers that hinder recovery. Respecting adolescents' capacity to define their care needs shifted the balance of power and knowledge between adolescents, parents, and staff, positioning participation as an integral part of care rather than a mere policy formality. Furthermore, the study underscored the importance of parents and staff reflecting critically on their own epistemic assumptions regarding adolescents with mental health problems. These beliefs significantly influenced adolescents' access to care and their ability to participate meaningfully in the recovery process.

Addressing these knowledge dynamics is essential for fostering a more inclusive, participatory approach in psychiatric inpatient care. Overall, study IV offered valuable insights into how adolescents and parents experience participation during enrollment in CAP. The findings underscored the necessity of creating structures that empower adolescents, value their experiential knowledge, and support their individual recovery journeys. By applying epistemic injustice and ecological systems theory, this study provided a deeper understanding of how agency, systemic influences, and participatory practices intersect in psychiatric inpatient care.

Discussion

The aim of this dissertation is to explore experiences of participation during enrollment in child and adolescent psychiatric inpatient care and its influence on recovery. It examines young people's and parents' understanding of PIBA, an intervention designed to enhance participation in care, and investigates staff perspectives on its implementation in CAP. Along with insights and questions raised by the dissertation as a whole, this chapter summarizes and discusses the main findings from the studies, with the aim of deepening the understanding of certain patterns and orientations. These themes explore both the challenges of implementing youth participation in CAP and how it is experienced by adolescents and parents. The chapter concludes with a brief discussion of the key implications of the findings.

Youth recovery as a multifaceted journey

The findings in this dissertation reinforce the understanding of youth recovery as complex, non-linear, and deeply relational (Kelly & Coughlan, 2019; Schneidinger & Haslinger-Baumann, 2019). Adolescents with complex care needs face fluctuating levels of agency and vulnerability, influenced by relationships with parents and staff, institutional structures, and societal expectations (Halsall et al., 2022; Lindstedt et al., 2018). Recovery emerges as a dynamic process, in which hope, trust, and empowerment evolve through continuous interaction with care environments. This underscores the need for recovery-oriented work that is responsive to these fluctuations and support adolescents as active participants in shaping their care (Rayner et al., 2018).

Study I builds on this by illustrating the complexity, unpredictability, and individual nature of youth recovery. Consistent with recovery-oriented frameworks, connection with staff, family support, and identity development form interconnected pillars supporting young

people’s mental health recovery. A youth-centered mental health approach that recognizes these dimensions is understood as essential (Khoury, 2020; Liao Siling et al., 2021). The CHIME framework (Leamy et al., 2011; cf. Ballesteros-Urpi et al., 2019) provides a valuable structure for comprehending how supportive relationships within the microsystem – especially with family and staff – facilitate recovery and participation (Bronfenbrenner, 1979; Green et al., 2019; Kelly & Coughlan, 2019). Importantly, adolescents’ trust in staff, nurtured through feeling heard, believed, and safe, plays a critical role in strengthening participation and aligns with the CHIME principles (cf. Andrews et al., 2024; Hartley et al., 2022; Lynch et al., 2020).

Study IV identifies systemic barriers where adolescents and parents report pressure to exaggerate symptoms for care access. This practice perpetuates mistrust and undermines participation as well as recovery (cf. Hultman et al., 2017). Referred to as “the admission game” (Sydor et al., 2024 p. 5), this phenomenon diminishes adolescents’ ability to express genuine needs and contributes to epistemic injustice, where young people question their own credibility (Carel & Györfy, 2014; Greenblatt et al., 2023). The study further underscores that introducing participatory models such as PIBA in environments where trust is absent risks reducing them to performative gestures, thereby undermining their potential. Moreover, adolescents’ reluctance to engage in care appears rooted in prior experiences of exclusion and compromised dignity, pointing to the need for respectful care practices that involve young people in decision-making and support recovery outcomes (Burnand et al., 2024; Jamalimoghadam et al., 2019).

Together, the findings from studies I and IV demonstrate that young people need youth-friendly, accessible care without having to perform distress or magnify their situations (Barari et al., 2024; Lindkvist et al., 2022; cf. Wittevrongel et al., 2023). Addressing these challenges can lead to more effective interventions that support young people’s individual recovery trajectories.

Striking a balance – fostering participation while maintaining protection

Studies II–IV highlight the complexities faced by parents and staff in supporting young people’s participation in mental health care. A key challenge lies in balancing adolescents’ right to participate with the

need for protection in vulnerable situations (cf. Clark & MacLennan, 2023; Ruiz-Casares et al., 2016; Woodman et al., 2023). Drawing on Lundy (2007), achieving this balance calls for structures that ensure that adolescents' input translates into meaningful impact (cf. Leamy et al., 2011).

Study II reveals staff concerns about young people becoming overly accustomed to the ward environment (cf. Sherbersky et al., 2023), potentially reinforcing a patient identity. Additionally, parental influence might limit adolescents' autonomy, particularly regarding decisions about PIBA contracts. This raises questions about whether young people feel genuinely acknowledged as capable decision-makers (Baumtrog & Peach, 2019; Burroughs & Tollefsen, 2016; Fricker, 2007). Study III further illustrates these complexities, demonstrating that staff, at times, conceptualize participation in binary terms – as either fully present or absent (cf. Clark & MacLennan, 2023; Davies & Wright, 2007; Woodman et al., 2023). Such a rigid perspective inadvertently positions parents as barriers to care, sidelining their potential role as allies in recovery (Kelleher & Hoagwood, 2015; Mackova et al., 2022; Radovic et al., 2015).

Findings from study IV challenge this binary understanding by addressing how 'togetherness' shapes meaningful interactions in inpatient care. In this study, participation emerges not an individual trait but a relational process shaped by 'yo-yo transitions' – the dynamic interplay between dependence and independence inherent to adolescent development (Biggart & Walther, 2006; Skogens et al., 2017; Spånberger Weitz, 2011). This perspective aligns with understanding participation and recovery as interdependent processes shaped by CHIME components such as meaning and connectedness within broader ecological systems (Kemp et al., 2016; Leamy et al., 2011; McDonald-Harker et al., 2021). Bridging the gap between participation in theory and practice – that is, the discrepancy between how participation is conceptualized and how it is implemented in real-world settings (cf. Askheim et al., 2016) – involves promoting supportive attitudes within the ecological microsystems surrounding adolescents (Bronfenbrenner, 1979). This approach thus underscores the essential role of parents and staff in fostering young people's participation.

To conclude, moving beyond the binary between protection and participation is understood as beneficial for youth participation and systemic accountability. A developmental perspective could further help illuminate how adolescents' capacity for participation evolves over

time, shaped by supportive relationships (Cahill & Dadvand, 2018). Additionally, a trust-based approach to participation may offer a more comprehensive understanding of young people's experiences. In contrast, overlooking these relational dynamics risks reducing the effectiveness of care or, in some cases, making it counterproductive (cf. Hyde, 2017; Reavey et al., 2017; Wallström et al., 2021).

Advancing epistemic justice in ecological systems

The findings from studies II–IV shed light on how adolescents, parents, and staff navigate care systems structured by laws and institutional guidelines. Each party seeks recognition of their knowledge and epistemic authority, adding to the complexity of inpatient care (Clark & MacLennan, 2023; cf. Lindgren et al., 2015; Molin et al., 2016). The concepts of epistemic injustice (Fricker, 2007) and ecological systems theory (Bronfenbrenner, 1979) offer valuable lenses for understanding these dynamics.

Credibility deficits can lead to frustration and disengagement across all stakeholder groups (Greenblatt et al., 2023; Grim et al., 2022). Study II particularly underscores the challenges faced by frontline staff, who may experience epistemic injustice due to their professional roles. Despite being integral to implementing PIBA, staff lacked the conditions necessary to do so effectively. Most staff members lacked familiarity with PIBA's goals and implementation strategies, reflecting a fundamental gap in their understanding of the model's framework and intended outcomes (cf. Elf et al., 2018; May et al., 2009; Weiner, 2009). This gap was exacerbated by feelings of exclusion from key decision-making processes, fostering frustration and resistance to PIBA's implementation (cf. Mikołajczyk, 2021). These findings highlight the need for improved systemic communication between frontline staff and decision-makers to support the long-term integration of PIBA. Achieving sustainable change in implementing participatory models requires both individual commitment and collective engagement, ensuring epistemic justice by recognizing the voices and expertise of all stakeholders (cf. Fricker, 2007; Hitchcock Noël et al., 2014; Weiner et al., 2017).

The ecological systems lens further reveals that these dynamics are shaped not only by individual attitudes but also by organizational structures and societal norms. For instance, the absence of involvement

in decision-making processes made it difficult for staff to perceive their role in youth recovery as meaningful, as highlighted through CHIME terminology (Leamy et al., 2011). Therefore, addressing staff exclusion, deepening their understanding of the model, and fostering ownership are understood as critical steps for successfully implementing PIBA in inpatient care settings. This aligns with findings from Banwell et al. (2023) and Parolini et al. (2019), who identify collaboration between researchers, practitioners, and care users as integral to model development and refinement.

As shown in study III, fostering participation requires cultivating epistemic recognition at all ecological levels (cf. Thoresen et al., 2025). The PIBA contract exemplifies this approach, structurally enabling participation through clearly defined responsibilities. Drawing on Bronfenbrenner (1979), the contract operates at the intersection of microsystems, helping to create a collaborative framework essential for recovery-oriented work in CAP. Serving as a shared point of reference, it aligns with ecological systems theory, which posits that interconnected systems – from familial to institutional – significantly shape adolescents’ opportunities for meaningful participation (cf. Law et al., 2020; Rayner et al., 2018). When operationalizing participation and addressing the division of responsibility in the PIBA process, the contract was considered important for stipulating what participation entails, and what is or is not expected of parents during PIBA enrollments. This highlights the need for communication within and between microsystems to ensure both participation and protection. Positioned within the mesosystem, the contract serves as a boundary object, negotiating competing priorities between adolescents, parents, and staff while redistributing decision-making authority.

Study IV similarly demonstrates how hierarchical knowledge structures can impede epistemic justice across various ecological systems. Adolescents face epistemic injustice when their perspectives on care are disregarded or undervalued during enrollment. In this context, PIBA emerges as a potentially transformative approach if implemented in a way that genuinely integrates young people’s lived experiences. Advancing participation in both policy and practice involves reconsidering power dynamics within youth care systems, where embedding participatory principles in organizational policies and cultures appears essential (cf. Shier, 2001).

Participation in the realm between childhood and adulthood

Study I and study IV provide key insights into youth participation in mental health care, emphasizing its fluid, relational, and collaborative nature. While adolescents nearing adulthood are neither children nor adults, they often face role ambiguity, struggling to navigate their social and legal status between childhood and adulthood (cf. Alderman et al., 2019; Beal et al., 2017; Keller et al., 2007). Study I demonstrates that conceptualizing youth participation as a developmental process – supported by parents and staff – enhances its effectiveness through alignment with adolescents’ evolving capacities (cf. Bronfenbrenner, 1979). Adolescents, particularly those with complex needs, express a desire to be involved in decisions impacting their care but often recognize the limitations of their capacity to engage fully as adults (cf. van Bijleveld et al., 2021; Shin & Ahn, 2023; Skoog, 2016). The findings illustrate that participation is enhanced when seen as a dynamic process, with parents and staff providing tailored support to navigate age-specific challenges and opportunities.

Study IV builds on this by revealing that adolescents shows that adolescents prefer participation structures that are flexible and context-sensitive, accommodating their evolving capacities. A key insight from study IV is that participation is not a fixed state. Rather, adolescents shift between non-participation and active involvement based on their readiness, the demands of any given situation, and the level of adult support they receive (cf. Spånberger Weitz, 2011). Parents serve as vital allies, supporting young people in navigating clinical decision-making while balancing guidance with growing autonomy (cf. Ellison et al., 2022; Medforth & Boyle, 2023; Skogens et al., 2017).

Both studies underscore the need to translate theoretical frameworks such as the UNCRC (1989) into accessible, actionable practices. Failing to include adolescents in decision-making processes risks leading to epistemic injustice, where young people’s perspectives are dismissed or undervalued (cf. Carel & Györfy, 2014; Greenblatt et al., 2023). Such exclusion erodes trust and diminishes participation, ultimately weakening the collaborative foundation essential for effective and respectful care. Taken together, these findings support a collaborative, context-sensitive approach to youth participation, one that balances autonomy with guidance and adapts to the dynamic transitions inherent in adolescence (cf. Cahill & Dadvand, 2018; Malorni et al., 2022).

Participation and recovery through the lenses of CHIME and Lundy

As outlined in this discussion, the interplay between participatory structures and recovery-oriented practices shapes adolescents' experiences in psychiatric inpatient care (cf. Bjønness et al., 2022; Lynch et al., 2023). In light of systemic challenges and the need for trust-based collaboration, theoretical models can help address these tensions. The CHIME framework (Leamy et al., 2011) and Lundy's (2007) Model of Participation offer complementary lenses for analyzing key dynamics shown in this dissertation. The following section explores how these frameworks collectively enhance the understanding of participatory structures in psychiatric inpatient care and inform recovery practices responsive to adolescents' fluctuating needs.

Table 5. Participation through CHIME and Lundy

CHIME component	Lundy component
Connectedness	Space, voice, audience
Hope	Voice, influence
Identity	Voice, audience
Meaning	Audience, voice, influence
Empowerment	Space, influence

Participation in CAP is inherently relational (studies I and IV), relying on *connectedness* among adolescents, parents, and staff in a dynamic triad. When facing vulnerability and uncertainty about accessing inpatient care, PIBA may foster trust by providing adolescents with *space* to *voice* their needs while balancing autonomy with parental support (studies II–III). When young people distrust the system, engagement declines, reinforcing the importance of professional connectedness (study IV). Across all studies, findings indicate that participation in vulnerable situations depends on having supportive adults (*audience*) who actively listen and respond, and maintaining trust-based relationships that strengthen collaboration.

Hope, central to youth recovery (studies I and IV), is nurtured when adolescents feel their *voices* are heard and their *influence* over care

decisions is real. However, hope can be undermined when mental health problems are viewed only through a biological lens, creating uncertainty about recovery. Feelings of abandonment and a lack of recognition as knowledgeable individuals can further contribute to feelings of hopelessness and self-doubt (study IV). This is compounded when staff are unclear about PIBA principles, how they differ from traditional inpatient care, or their own role in facilitating youth participation (studies II–III). PIBA appears to foster hope by offering adolescents opportunities to take part in decisions about their care and to experience that their perspectives are valued. However, recognizing adolescents as ‘knowers’ involves more than allowing them to speak – it also includes staff who are attentive and responsive, taking adolescents’ experiences into consideration throughout the care process. In this context, staff awareness and understanding of PIBA’s principles may play an essential role in supporting hope.

Identity formation in adolescence is shaped by recognition, respect, and the opportunity to develop autonomy (study I). Feeling believed in and taken seriously by adults aligns with the concept of *voice*, suggesting that mental health care benefit from approaches that acknowledge young people’s evolving needs and growing independence. Moreover, adolescents need adults who not only listen (*audience*) but also encourage them to take responsibility for their recovery (studies II–IV). Through PIBA, adolescents are thus seen as active participants in their recovery journeys, strengthening their commitment and independence.

Youth recovery, often marked by ambivalence and uncertainty (study I), is dependent on adults that help adolescents understand the *meaning* of their experiences. Parents and staff serve as key *audiences*, ensuring that adolescents’ *voices* are not only heard but *influence* decision-making (study IV). At the same time, however, staff navigate the challenge of balancing young people’s participation with the need for protection, sometimes at the expense of voice and meaning-making in inpatient care (studies II–III). Here, PIBA seems to offer a potential mechanism to manage this balance, while ensuring necessary support from adults.

Finally, *empowerment* is fostered when adolescents are provided with both *space* and *influence* in their care decisions (study IV). Accordingly, PIBA supports empowerment by offering adolescents opportunities to make meaningful choices. However, organizational barriers and unclear parental involvement can limit these efforts

(studies II–III). While staff highlight the importance of fostering young people’s sense of responsibility, parental involvement can sometimes constrain their actual decision-making power. Parents therefore play a dual role: providing close support while gradually fostering their children’s autonomy, enabling young people to exercise agency and responsibility in their care.

Altogether, this section suggests that meaningful participation in psychiatric inpatient care is built on trust, recognition, and supportive relational structures. When guided by the principles of CHIME and Lundy’s Model of Participation, frameworks such as PIBA may help balance participation and protection, fostering adolescents’ agency in their recovery.

Comprehensive understanding: Situated participation as an impetus for mental health recovery and epistemic justice – adherence to the three Ps

The findings in this dissertation illustrate key factors that are necessary to translate theoretical understandings of youth participation into practice, particularly within the framework of the three Ps of the UNCRC (1989) – provision, protection, and participation.

Although all stakeholders agree on the benefits of increased participation for young people, they encounter different obstacles in making it happen. The three Ps, fundamental to youth rights, sometimes conflict with one another, complicating participation efforts. While such conflicts may persist, centering the context-sensitive needs of adolescents – and explicitly acknowledging their liminal position between childhood and adulthood – may help mitigate these challenges by aligning care practices with developmental realities and systemic barriers.

In this dissertation, youth participation in inpatient care is understood as a situated and relational process – one that evolves through social interactions and practical activities (Coyne & Harder, 2011). This perspective, rooted in Lave and Wenger’s (1991) concept of situated learning, frames participation as contextual rather than a static right or obligation. In mental health care, this means balancing participation with protection in ways that align with the best interests of young people (cf. van Bijleveld et al., 2015; Clark & MacLennan, 2023; Viksveen et al., 2021). This approach is consistent with the CHIME

framework (Leamy et al., 2011), which suggests that participation fosters connectedness, enhances empowerment by enabling influence over care, and creates meaning by allowing young people to define their recovery journey. CHIME's emphasis on identity and hope further supports a flexible approach to participation, allowing young people to engage at their own pace while maintaining a sense of control.

In the context of CAP, situating participation within relational settings such as enrollment processes may enhance recovery potential. Moreover, the triadic relationship between adolescents, parents, and staff rely on ongoing negotiations to balance knowledge and power in ways that promote epistemic justice. However, study findings point to tensions regarding staff perceptions of parental involvement in youth participation during PIBA. Study II highlights staff concerns about navigating adolescent and parental roles, while study III shows that participation is sometimes viewed as a separate effort by *either* adolescents *or* parents. In contrast, study IV underscores that genuine participation develops through *joint* interactions among adolescents, parents, and staff, emphasizing the need for a more integrated approach. Rather than viewing participation as an all-or-nothing state, it seems essential to recognize its nuanced and evolving nature. A rigid or binary approach – where participation is seen as either fully achieved or absent – can limit involvement. Instead, the findings support a situated perspective that acknowledges how participation shifts across different moments and contexts, aligning with CHIME's focus on connectedness and meaning.

In summary, meaningful participation involves structured yet adaptable frameworks that respect adolescents' evolving capacities while ensuring support from parents and staff. A promising pathway lies in adults operationalizing the UNCRC's (1989) three Ps through a critical lens that not only but also facilitates meaningful participation (cf. Mathews, 2023; Sallnäs et al., 2024).

Implications for practice and future directions

This dissertation highlights the need for inpatient care that is tailored to adolescents' needs (cf. Barbic et al., 2019; Storm & Edwards, 2013). A values-based approach strengthens recovery-focused care and provides meaningful support for young people experiencing mental health problems (Williams et al., 2015; cf. Fisher, 2024). The findings offer

valuable insights for both social work practice and research with several practical implications.

First, advancing youth participation calls for an “*epistemic shift*”¹¹ (Kragh, 2019, p. 1; cf. Greenblatt et al., 2023; Grim, 2023) in how institutions conceptualize knowledge and expertise, thus moving beyond tokenistic inclusion to recognize young people as legitimate co-producers of knowledge. As such, recognizing young people as ‘knowers’ challenges traditional power structures, and prompts a reevaluation of adult-youth dynamics. When participation is recognized as relational (Cahill & Dadvand, 2018), it enables a more inclusive and supportive care environment, essential for mental health recovery. All actors – adolescents, parents, and staff – seek epistemic recognition, making the extension of epistemic justice crucial. Achieving systemic balance through mutual recognition enhances youth participation, a goal that closely aligns with the CHIME framework, particularly in its focus on fostering empowerment and connectedness. (Ballesteros-Urpi et al., 2019; Leamy et al., 2011; Schneidtinger & Haslinger-Baumann, 2019).

Second, achieving epistemic justice involves *joint* efforts across ecological systems involving young people, parents, and staff. Participation in CAP is influenced not only by individual factors (cf. Halldenius, 2020; Jagfeld et al., 2021; Stuart et al., 2016) but also by relationships within the microsystem (e.g., family, peers, and educators) and broader institutional structures within the macrosystem (e.g., cultural norms and policies). To transcend tokenistic participation (Lundy, 2018; Shier, 2001), systemic changes would need to address proximal interactions in the microsystem, mesosystem linkages between settings, and macrosystem-level ideologies (Bronfenbrenner, 1979). Viewing participation as dynamic and pluralistic allows it to evolve in supportive environments, balancing the needs of young people, their families, and societal structures. This calls for schools, healthcare providers, and social services to work together and embed participation as a core principle in line with the UNCRC (1989), safeguarding it from resource or knowledge constraints.

¹¹ “Epistemic shifts” refer to claims that the fundamental methodological and epistemological principles of science need revision (Kragh, 2019).

Third, *collaboration* between adolescents and their support systems is paramount during intensive interventions such as inpatient care. Strong collaboration encourages mutual recognition and active listening, which supports a youth-centered approach to mental health care. In turn, this ensures that adolescents' voices are heard throughout their treatment while valuing the perspectives of the parents. Without this synergy, recovery can be hindered, impeding hope and future-oriented thinking, as emphasized in the CHIME framework (Leamy et al., 2011; cf. Gísladóttir & Svavarsdóttir, 2011). Effective inpatient care involves providing staff with practical tools for family engagement (Hawke et al., 2019), ensuring a broader perspective that surpasses medical diagnoses.

Inclusive, youth-friendly care fosters participation and positive treatment experiences. Moreover, increasing participation levels during enrollment relies on parents and staff to trust young people's capacity to engage, even in crisis situations. This shift can transform CAP from a "last resort" (James et al., 2018 p. 348; Ponnert & Johansson, 2024) into an accessible, recovery-focused practice that enhances well-being and prevents further decline (cf. Kelly et al., 2024). This approach aligns with CHIME's emphasis on meaning, enabling young people to define their vision of recovery within structured participatory frameworks.

Finally, moving from *professional control* to a *user-centered approach* is essential in inpatient care for young people (cf. Damsgaard & Angel, 2021). Such an approach emphasizes active involvement in recovery, bridging theoretical ideals and practical frameworks (cf. Law et al., 2020). Providing young people with meaningful decision-making opportunities in psychiatric and social care settings fosters their development and sense of agency (cf. Lundy, 2007). Addressing these challenges allows policymakers and practitioners to prioritize mental health recovery and epistemic justice while supporting young people's transition to adulthood.

These findings are relevant not only for adolescents in CAP but also for professionals working with young people facing complex needs. The findings shed light on participation in institutional care settings, including CAP, SiS, and residential care homes (HVB), where adolescents with psychological or behavioral difficulties receive support. Enrollment in CAP and SiS is often involuntary, and while both institutions strive to encourage participation, various challenges may hinder it (cf. Bjønness et al., 2020; Enell et al., 2023; Mattsson,

2008). While there are certain similarities between CAP and SiS, their differences must be considered, as these unique contexts and challenges require tailored participation initiatives to be effective.

Importantly, there is no ‘one-size-fits-all’ solution for youth participation or mental health recovery (cf. Tambuyzer et al., 2011), making it necessary to critically evaluate methods presumed to enhance participation. Revisiting Box’s (1976) axiom that ‘all models are wrong, but some are useful’, theoretical frameworks offer critical leverage for examining participation and enriching our conceptualization of participatory work in recovery-oriented practice. The central challenge involves systematically operationalizing these theoretical insights into practice within CAP, SiS, and HVB settings.

Drawing on this, future research should explore strategies to optimize care structures that foster recovery and ensure that young people are admitted to meaningful inpatient settings where they are valued as epistemic ‘beings’ rather than ‘becomings’. Additionally, examining the role of imposter syndrome in inpatient care and its impact on mental health (Barari et al., 2024) could yield deeper insights into how self-perceived fraudulence among young people interfere with recovery principles. Moreover, investigating how imposter syndrome intersects with hierarchical knowledge structures and staff perceptions may reveal systemic barriers to authentic youth participation in decision-making processes. Understanding these dynamics may inform more inclusive, youth-centered approaches that empower adolescents and reinforce their role as active agents in their recovery.

A finding not fully addressed in this dissertation is the portrayal of ‘dysfunctional families’ in study III. Staff discussed the difficulties of ensuring young people’s participation in families marked by negative dynamics. This blurs the boundary between mental health care and social work, raising questions about where the responsibility for supporting these families lies (cf. D’Angelo et al., 2023; Powell et al., 2025). Given that participation in inpatient care emerges through collaboration among the triad of young people, parents, and staff, future research should explore how these dynamics affects participation and recovery outcomes.

Concluding remarks

Writing this dissertation and exploring youth participation and its role in recovery has been both an academic and personal journey. I am sincerely grateful to the adolescents, parents, and staff who shared their experiences and perspectives. Their openness and commitment to improving mental health care for young people have strengthened and expanded this research and served as a valuable source of inspiration. Their voices are at the heart of this work, and for that, I am truly thankful.

This work is also a reminder of the fact that knowledge is relational, and that progress emerges when diverse perspectives are brought into the conversation. My hope is that these conversations will continue across disciplines and care settings for the benefit of those who need them most.

Svensk sammanfattning

Unga med olika former av komplexa (vård)behov möts ofta av vård- och stödsystem som har svårt att tillgodose delaktighet. Den barn- och ungdomspsykiatriska vården (BUP) är inget undantag, och präglas av en generell balansgång mellan att säkra de ungas liv och hälsa samtidigt som vården ska präglas av respekt för autonomi. Personalen förväntas dessutom arbeta aktivt för att involvera unga och deras föräldrar i olika vårdrelaterade beslut, något som i praktiken kan vara svårt att genomföra.

Den här avhandlingen undersöker delaktighetens betydelse i ungas återhämtningsprocesser från komplexa psykiska problem, och på vilket sätt delaktighet kan stärkas i relation till föräldrar och personal vid inskrivning i BUP:s heldygnsvård. I fokus står interventionen självvald inläggning (SI) vilken beskrivs utmana befintliga maktstrukturer genom att tillskriva unga med psykiska problem ett ökat beslutsmandat. Det innebär att när behovet av heldygnsvård uppstår ska ungdomens kunskap om sitt mående styra beslutet om inläggning, och behovet ska därmed inte ifrågasättas av personal. Genom detta förhållningssätt är tanken att ta tillvara de ungas kunskap och upplevelser, samtidigt som möjligheten för ett reellt partnerskap mellan unga, föräldrar och personal förväntas stärkas.

Såväl internationell som nationell forskning om SI fokuserar i stor utsträckning på vuxnas erfarenheter, medan endast ett fåtal studier undersöker SI:s tillämpning och effekter specifikt riktade mot unga med psykiska problem. Dessa unga möter andra utmaningar än vuxna – deras handlingsutrymme formas ofta av begränsningar i omgivande system såsom föräldrars inflytande och vårdens byråkratiska strukturer. Dessutom måste de navigera i en kontext där omgivningens attityder till psykisk ohälsa (t.ex. stigmatisering eller misstro) kan undergräva deras upplevda beslutsförmåga och trovärdighet i vårdkontakter. Forskning visar att det kan vara direkt kontraproduktivt för återhämtning att regelbundet ifrågasättas eller ges lägre trovärdighet. Det riskerar att

leda till upprepad epistemisk orättvisa eftersom individers kunskap om sin situation inte erkänns som legitim.

Syftet med avhandlingen är således att belysa den komplexitet som unga ställs inför i mötet med psykiatrin, och särskilt vid inskrivning i heldygnsvård. Avhandlingen tillämpar två huvudsakliga teoretiska ramverk: 1) *Epistemisk orättvisa* som adresserar ojämlikheter i kunskapsproduktion och –spridning, samt 2) *Ekologisk systemteori* som betonar samspelet mellan individen och dess omgivande miljö i ett utvecklingsperspektiv. För att förstå *hur* delaktighet kan skapas används även Lundy-modellen som lyfter fram att unga behöver ett konkret utrymme (space) att uttrycka sina åsikter, möjlighet att göra sin röst hörd (voice), någon som lyssnar (audience), samt faktisk möjlighet att påverka beslut (influence). Avhandlingen anlägger också ett återhämtningsorienterat perspektiv och ser återhämtning som en djupt personlig och individuell process. CHIME-ramverket (connectedness, hope, identity, meaning och empowerment) bidrar med en värdefull lins för att bättre förstå de processer som underlättar återhämtning för unga med psykiska problem.

Avhandlingen bygger på en kumulativ design där fyra sammanhängande delstudier, var och en med ett eget fokus, tillsammans genererar ett helhetsperspektiv avseende ungas delaktighet och återhämtning. Studierna belyser såväl strukturella möjligheter som praktiska hinder när detta helhetsperspektiv ska omsättas i klinisk verksamhet och/eller stödinsatser. Delstudie I (artikel I) är en litteraturoversikt och sammanfattar det internationella kunskapsläget avseende ungas återhämtningsprocesser. Det huvudsakliga kunskapsbidraget visar på vikten av att förstå återhämtning som en komplex och icke-linjär process som är unik för varje individ. Den lyfter fram behovet av holistiska, ungdomscentrerade metoder i den psykiatriska vården som också behöver ta hänsyn till den mångfacetterade karaktären av unga människors återhämtning. Artikeln understryker även vikten av att involvera familj och vårdgivare i processen, och att dessa aktörer i stor utsträckning kan både facilitera och hindra ungas möjlighet till delaktighet och återhämtning.

I den andra delstudien (artikel II) riktas fokus mot hur personal i BUP resonerar kring att implementera SI i den ordinarie praktiken. Via fokusgruppsintervjuer diskuteras de utmaningar personalen ställts inför under detta arbete, och hur dessa utmaningar har hanterats. I denna delstudie analyseras resultaten utifrån teorier om epistemisk orättvisa – d.v.s. en hierarkisk förståelse av kunskap – och implementering. Trots

strukturella hinder för implementering tyder resultaten på att införandet av SI i BUP har potential att främja mer rättvisa kunskapsrelationer och stärka ungas återhämtning. Samtidigt framträder vikten av att förstå de faktorer som underlättar och försvårar implementeringen, samt att stödja personalens roll och handlingsutrymme i denna process.

I den tredje delstudien (artikel III), som bygger på samma material som artikel II, undersöks hur personalen ser på balansen mellan föräldrainsflytande och ungas självbestämmande i samband med SI. Här används ekologisk systemteori för att analysera hur olika system – individ, familj, organisation – samspelar. Resultaten visar på en till viss del dualistisk syn på delaktighet när SI aktualiseras, d.v.s. delaktighet beskrivs som något som man antingen har eller inte har, och merparten av personalen betraktar föräldrar som potentiella hinder snarare än resurser för att uppnå delaktighet.

I den fjärde delstudien (artikel IV) intervjuas unga och föräldrar med erfarenhet av BUP:s heldygnsvård. Några har dessutom använt sig av SI. Respondenterna ombeds reflektera kring hur inskrivningsprocessen upplevs, hur deras egen kunskap om sitt mående tas till vara och vilka för- och nackdelar de ser med SI. Utifrån syftet används teorier om epistemisk orättvisa och ekologisk systemteori för att analysera makt- och kunskaps-hierarkier, samt hur ekologiska system hanterar sådana strukturer när ungas beslutsmandat i vården stärks. Resultaten visar att delaktighet förutsätter förtroendefulla relationer och att unga kan använda föräldrar som stöd under inskrivningsprocessen utan att deras delaktighet äventyras eller helt omöjliggörs. Respondenterna diskuterar också, om än på olika sätt, ett underförstått behov av att förstärka de psykiska problemen för att optimera access till heldygnsvården. Detta beskrivs skapa känslor av att vara en inkräktare ("imposter") snarare än en legitim vårdsökande, vilket kan förstås gå emot intentionerna i en personcentrerad och ungdomsanpassad psykiatri. Möjligheten att själv definiera sitt vårdbehov och att kunna växla mellan beroende och självständighet framträder som viktiga faktorer för delaktighet och återhämtning.

Sammanfattningsvis betonar avhandlingen vikten av att förstå delaktighet som en situerad och dynamisk process i ungas återhämtning. Den belyser samtidigt den komplexitet som uppstår när strategier för delaktighet ska implementeras och hur de system som omringar en ung person därmed utmanas avseende makt- och tolkningsföreträden. Ungas möjligheter till delaktighet påverkas av relationer till både föräldrar och vårdpersonal, samt av organisatoriska

faktorer såsom kunskapshierarkier. En central utmaning handlar om att bygga tillitsfulla relationer där ungas perspektiv ges legitimitet utan att de behöver förstärka sina psykiska problem för att bli hörda.

Avhandlingens implikationer tyder på att de vård- och stödsystem som möter unga med komplexa behov kan behöva omstruktureras för att tillsäkra unga meningsfull delaktighet. Det innebär att synen på makt och kunskap behöver göras synlig och reflekteras över, särskilt om målet är att unga ska kunna betraktas som trovärdiga kunskapsbärare. Att uppnå epistemisk rättvisa bör också förstås som en *gemensam* angelägenhet som utvecklas inom ungas ekologiska sammanhang. I dessa sammanhang betonas vuxnas roll i att främja en utvecklingsinriktad och tillåtande syn på delaktighet där den förstås som en dynamisk färdighet som formas och tränas progressivt under de ungas väg mot vuxenlivet. Inom de verksamheter där Barnkonventionen ska styra beslut och riktlinjer behöver delaktighet dessutom ges högre status och inte förstås som något som kan förhandlas bort.

Slutligen finns det ett behov av att adressera delaktighet som en del av återhämtningsinriktat arbete, där vården går från professionell kontroll till brukarorientering. För att återhämtning ska bli mer än ett abstrakt ideal krävs att samhällsstrukturer – och i synnerhet professionella som möter unga med komplexa problem – utformar system som aktivt främjar delaktighet i återhämtningsprocessen. Detta innebär att unga, oavsett vårdkontext (psykiatri, socialtjänst etc.), behöver ges säkra utrymmen att träna på delaktighet genom progression och meningsfullt inflytande. Genom att beakta dessa implikationer kan vård- och stödsystem samt beslutsfattare utveckla mer inkluderande och stärkande strategier som bidrar till att främja både epistemisk rättvisa och återhämtning hos unga med psykiska problem.

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Appendices

Appendix 1

Just nu pågår det en forskningsstudie som intresserar sig för ungas erfarenheter av att använda sig av metoden självvald inläggning (SI). Det innebär i korthet att du som ung patient får möjlighet att själv lägga in dig på BUP:s heldygnsvård för en kortare period med avlastning och stöd i ditt mående.

Om du har en överenskommelse om SI med din behandlare och om du är intresserad av att delta i studien är du varmt välkommen att kontakta mig. Jag som håller i studien heter Jennie Moberg och jag har tidigare jobbat som brukarinflytandesamordnare på BUP. Nu är jag doktorand i socialt arbete vid Stockholms universitet och ska skriva en avhandling om hur unga i BUP berättar om hur det är att ha tillgång till SI. Jag letar efter ungdomar som vill bli intervjuade av mig på valfri plats (fysiskt eller digitalt). Du behöver inte ha hunnit använda dig av SI för att kunna intervjuas, det går lika bra ändå. Som tack för din medverkan får du två biobiljetter.

Vill du veta mer eller är nyfiken på vad detta kan innebära för dig när du mig på telefonnummer 0764–961986 (det går också bra att sms:a) eller via mailadress jennie.moberg@socarb.su.se. Är du under 15 år behöver du föräldrars samtycke till att delta. Detta är dock inte nödvändigt om du är över 15 år. Anledningen till detta är att du som ung i vården ska säkerställas en god forskningsetisk ställning, vilket är reglerat i lagstiftning.

Jag tror och hoppas att studien ska bidra med kunskap om hur ungdomar med SI berättar om sin situation, samt hur och om SI påverkar vardagen på något särskilt sätt. Det finns väldigt lite skrivet om just unga med denna vårdform, vilket innebär att just din kunskap är viktig att lyfta fram i forskning.

Välkommen att höra av dig!

Hälsningar,
Jennie

Appendix 2

Information till ungdomar om forskningsstudien ”Att implementera patientdelaktighet och främja återhämtning i barn- och ungdomspsykiatri, –exemplet självvald inläggning”.

Vi vill fråga dig om du vill delta i ett forskningsprojekt. I det här dokumentet får du information om projektet och vad det innebär att delta.

Vad är det för projekt och varför vill ni att jag ska delta?

Studien vänder sig till dig som ung patient (mellan 13–17 år) som har tillgång till självvald inläggning. Självvald inläggning handlar om att du har möjlighet att själv bestämma om och när du vill använda psykiatrisk heldygnsvård som stöd för att må bättre. Eftersom självvald inläggning inte har utvärderats för barn och unga tidigare tycker vi att det är viktigt att även denna målgrupp lyfts fram i forskning. Därför vill vi fråga dig om deltagande i studien.

Ansvarig för projektet är Institutionen för socialt arbete och studien görs i samarbete med barn- och ungdomspsykiatri (BUP) i Region Stockholm.

Vilka kan delta i studien?

Alla ungdomar som har en överenskommelse om självvald inläggning tillfrågas om de vill delta i studien. Du kan delta vare sig du aktivt har använt dig av vårdformen eller inte.

Hur går studien till?

Om du tackar ja innebär det att du kommer att intervjuas två gånger om hur du tycker att självvald inläggning fungerar samt om och hur vårdformen påverkar ditt mående. Intervjun kommer att ta ca en timme per tillfälle.

Vid intervjutillfällena får du själv avgöra på vilken plats du vill ses (t.ex. skola, fik, öppenvårdsmottagning, hemma m.m.). Du kan också välja att ses digitalt (t.ex. Skype, Teams, Messenger m.m.). Det som är viktigt är att du känner dig bekväm med den plats du väljer och att du inte behöver stressa vare sig till eller från intervjun. Jag som intervjuar dig är socionom och doktorand i socialt arbete. Jag har stor vana av att

prata med barn och unga. Om du är intresserad av att delta är du välkommen att kontakta mig, Jennie Moberg (se kontaktuppgifter längre ned). Du avgör själv om du vill ringa eller sms:a.

Finns det några fördelar med att delta i studien?

Om du väljer att delta i studien tror vi att du kan hjälpa oss att förstå hur unga tycker och tänker om självvald inläggning.

Finns det några risker med att delta i studien?

Om du väljer att delta i studien ser vi inga uppenbara risker. Om du under intervjuerna ändå känner att det är jobbigt att prata är det du själv som bestämmer om du vill pausa eller avbryta. Att välja att vara med i studien påverkar inte den vård du redan får.

Vad händer med mina uppgifter? Hantering av data och sekretess

Projektet kommer att samla in och registrera uppgifter helt anonymt. Ljudinspelningarna kommer att skrivas ut och utskriften anonymiseras, d.v.s. om uppgifter från intervjuerna går att härledas till dig så kommer dessa att tas bort ur utskriften.

Ditt namn, personnummer, var du bor, vilka behandlare du har eller vilken avdelning du har varit på kommer inte på något sätt att uppges i studien.

Allt som samlas in om dig hanteras enligt regler som Institutionen för socialt arbete har för forskningsdokumentation. Dessutom har endast forskare som ingår i projektet tillgång till materialet från intervjuerna. Det insamlade materialet kommer att krypteras, lagras i 10 år i ett låst arkiv och endast vara tillgängligt för auktoriserade personer i enlighet med PUL (personuppgiftslagen).

Det kommer att finnas kodlistor med namn från forskningspersonerna i projektet. På kodlistorna kommer kodnummer, personens namn samt datum för intervjun samt att dokumenteras. Dessa kodlistor kommer projektets forskare att fylla i för att ha kontroll över materialinsamlingen. För att förhindra att forskningspersonernas identitet kan komma att kopplas med någon av de uppgifter som sammanställs inom ramen för studien kommer kodlistorna att förvaras inlåsta i låskåp vid Institutionen för socialt arbete och endast hanteras

av forskningsledaren. Vid analys kommer materialet att digitaliseras och endast kodnumret kommer att finnas med i det bearbetningsprogram som används för att koda den kvalitativa datan. Inga personnummer redovisas dock.

Resultaten av forskningsstudien kommer att beskrivas både på gruppnivå och individnivå. Resultaten kommer att presenteras i rapporter, artiklar och på konferenser.

Ansvarig för dina personuppgifter är Institutionen för socialt arbete, Stockholms universitet. Du har enligt EU:s dataskyddsförordning rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i projektet, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om du vill ta del av uppgifterna är du välkommen att kontakta mig, Jennie Moberg.

Dataskyddsombud på Institutionen för socialt arbete nås via mailadress ingrid.tinglof@socarb.su.se. Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att ge in klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

Hur får jag information om resultatet av studien?

Du får självklart ta del av dina intervjuutskrifter, men om du inte vill är det också helt okej. Om du önskar ta del av materialet är du välkommen att kontakta mig, Jennie Moberg. När forskningsstudien är klar kommer du även att kunna be om en rapport om resultatet genom att antingen fråga din behandlare eller genom att kontakta mig.

Försäkring och ersättning

Att vara med i forskningsstudien innebär att du, genom att vara patient och ha tillgång till självald inläggning, är försäkrad via den så kallade patientskadeförsäkringen. I och med det behövs ingen ytterligare försäkring för att kunna delta i studien. Ingen ersättning ges för att vara med i forskningsstudien.

Deltagandet är frivilligt

Ditt deltagande är frivilligt och du kan när som helst välja att avbryta deltagandet utan att det påverkar din vård eller din möjlighet till självvald inläggning. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför, men det är då bra om du kontaktar den ansvariga för studien (se nedan).

Ansvariga för studien

Jennie Moberg, doktorand vid Institutionen för socialt arbete.

jennie.moberg@socarb.su.se, telefonnummer: 0764–961986

Ulla-Karin Schön, professor vid Institutionen för socialt arbete.

ullakarin.schon@socarb.su.se

Appendix 3

Information till vårdnadshavare kring forskningsstudien ”Att implementera patientdelaktighet och främja återhämtning i barn- och ungdomspsykiatri, –exemplet självvald inläggning”.

Vad handlar projektet om och varför är mitt barns deltagande viktigt?

Du får den här informationen eftersom ditt barn har fått möjlighet att använda sig av en vårdform som kallas självvald inläggning. Studien vänder sig till unga mellan 13–17 år som, tillsammans med vårdnadshavare, läkare i öppen- och heldygnsvård, har upprättat en s.k. ”överenskommelse” kring självvald inläggning. Överenskommelsen handlar om att ditt barn har möjlighet att själv bestämma om och när hen vill använda psykiatrisk heldygnsvård som stöd för att må bättre. Eftersom självvald inläggning inte har utvärderats för barn och unga tidigare tycker vi att det är viktigt att även denna målgrupp lyfts fram i forskning, varför ditt barn erbjuds att delta i denna studie.

Ansvarig för projektet är Institutionen för socialt arbete och studien görs i samarbete med barn- och ungdomspsykiatri (BUP) i Region Stockholm.

Vilka får vara med i forskningsstudien?

Alla ungdomar som har en överenskommelse om självvald inläggning tillfrågas om de vill delta i studien. De kan delta vare sig de aktivt har använt sig av vårdformen eller inte.

Hur går forskningsstudien till?

Om du som vårdnadshavare godkänner ditt barns deltagande, samt om barnet själv tackar ja, innebär det att hen kommer att intervjuas två gånger om hur hen tycker att självvald inläggning fungerar samt om och hur vårdformen påverkar det psykiska måendet. Intervjun kommer att ta ca en timme per tillfälle.

Vid intervjutillfällena får ditt barn själv avgöra på vilken plats intervjuerna ska genomföras (t.ex. skola, fik, öppenvårdsmottagning, hemma m.m.). Hen kan också välja att ses digitalt (t.ex. Skype, Teams, Messenger m.m.). Det som är viktigt är att ditt barn känner sig bekväm

med platsen och att hen inte behöver stressa vare sig till eller från intervjun. Jag som intervjuar är socionom och doktorand vid institutionen för socialt arbete. Jag har också lång professionell erfarenhet av att prata med barn och unga med psykisk ohälsa.

Om ditt barn är intresserad av att delta är hen välkommen att kontakta mig, Jennie Moberg (se kontaktuppgifter längre ned). Barnet avgör själv om det passar bäst att ringa eller sms:a.

Finns det några fördelar att vara med i forskningsstudien?

Genom att delta i forskningsstudien bidrar ditt barn med till ett nytt kunskapsunderlag som vi hoppas kan fungera som vägledning inom det barn- och ungdomspsykiatriska fältet. Vår ambition är att studiens respondenter kan bidra till att samhället, sjukvård, socialtjänst m.fl. får ökad kunskap om målgruppens behov och vad de tycker om den vård de erhåller via självvald inläggning.

Finns det några risker att vara med i forskningsstudien?

Om ditt barn väljer att delta i studien ser vi inga uppenbara risker. Om det under intervjuerna ändå visar sig vara jobbigt att prata är det hen själv som bestämmer om vi ska pausa eller avbryta.

Samtliga respondenters uppgifter hanteras med sekretess (se avsnittet ”Hantering av data och sekretess” nedan). Att välja att vara med i studien påverkar heller inte den vård som redan planeras eller ges.

Hantering av data och sekretess

Projektet kommer att samla in och registrera uppgifter om ditt barn, men ditt barns deltagande är anonymt. Med ditt barns tillåtelse kommer intervjuerna att ljudinspelas. All denna information tas sedan omhand så att ingen annan än berörda forskare kan komma åt den. Ljudinspelningarna kommer att skrivas ut och utskriften anonymiseras, d.v.s. om uppgifter från intervjuerna går att härledas till barnet så kommer dessa att tas bort ur utskriften.

Vare sig namn, personnummer, var barnet bor, vilka behandlare hen har eller vilken avdelning hen har varit på kommer inte på något sätt att uppges i studien. Allt som samlas in om barnet hanteras enligt regler som Institutionen för socialt arbete har för forskningsdokumentation. Dessutom har endast forskare som ingår i projektet tillgång till

materialet från intervjuerna. Det insamlade materialet kommer att krypteras, lagras i 10 år i låst arkiv och endast vara tillgängligt för auktoriserade personer i enlighet med PUL (personuppgiftslagen).

Det kommer att finnas kodlistor med namn från forskningspersonerna i projektet. På kodlistorna kommer kodnummer, personens namn samt datum för intervjun samt att dokumenteras. Dessa kodlistor kommer projektets forskare att fylla i för att ha kontroll över materialinsamlingen. För att förhindra att forskningspersonernas identitet kan komma att kopplas med någon av de uppgifter som sammanställs inom ramen för studien kommer kodlistorna att förvaras inlåsta vid Institutionen för socialt arbete och endast hanteras av forskningsledaren. Vid analys kommer materialet att digitaliseras och endast kodnumret kommer att finnas med i det bearbetningsprogram som används för att koda den kvalitativa datan. Inga personnummer redovisas dock.

Resultaten av forskningsstudien kommer att beskrivas både på gruppnivå och individnivå. Resultaten kommer att presenteras i rapporter, artiklar och på konferenser.

Ansvarig för personuppgifter är Institutionen för socialt arbete, Stockholms universitet. Ditt barn har enligt EU:s dataskyddsförordning rätt att kostnadsfritt få ta del av de uppgifter om hen som hanteras i projektet, och vid behov få eventuella fel rättade. Barnet kan också begära att uppgifter om sig raderas samt att behandlingen av sina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om ditt vill ta del av uppgifterna är hen välkommen att kontakta mig, Jennie Moberg.

Om du inte är nöjd med hur personuppgifter tas omhand har du möjlighet att kontakta Datainspektionen som är en tillsynsmyndighet går att nås på telefonnummer 08-657 61 00, eller via mailadress datainspektionen@datainspektionen.se

Dataskyddsombud på Institutionen för socialt arbete nås via mailadress ingrid.tinglof@socarb.su.se. Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att ge in klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

Hur får jag information om forskningsstudiens resultat?

Du och ditt barn får självklart ta del av intervjuutskriften, men om ni inte vill är det också helt okej. Om du önskar ta del av materialet är du välkommen att kontakta mig, Jennie Moberg. När forskningsstudien är klar kommer du även att kunna be om en rapport om resultatet genom att antingen fråga din behandlare eller genom att kontakta mig.

Försäkring och ersättning

Att vara med i forskningsstudien innebär att ungdomen, genom att vara patient och ha tillgång till självvald inläggning, är försäkrad via den så kallade patientskadeförsäkringen. I och med det behövs ingen ytterligare försäkring för att kunna delta i studien. Ingen ersättning ges för att vara med i forskningsstudien.

Deltagandet är frivilligt

Ditt barns deltagande är frivilligt och hen kan när som helst välja att avbryta deltagandet utan att det påverkar vården eller möjligheten till självvald inläggning. Om barnet väljer att inte delta eller vill avbryta sitt deltagande behöver hen inte uppge varför, men det är då bra om du eller barnet själv kontaktar den ansvariga för studien (se nedan).

Ansvariga för studien

Jennie Moberg, doktorand vid Institutionen för socialt arbete.

jennie.moberg@socarb.su.se, telefonnummer: 0764–961986

Ulla-Karin Schön, professor vid Institutionen för socialt arbete.

ullakarin.schon@socarb.su.se

Appendix 4

Personalens samtycke till deltagande i studien

Jag har fått muntlig och skriftlig informationen om studien och har haft möjlighet att ställa frågor. Jag får även behålla den skriftliga informationen.

Jag samtycker till att delta i studien ”Att implementera patientdelaktighet och främja återhämtning i barn- och ungdomspsykiatri”. Jag samtycker även till att mina uppgifter behandlas på det sätt som beskrivs i forskningspersonsinformation.

Plats och datum	Underskrift personal

Appendix 5

Ungdomens samtycke till deltagande i studien

Jag har fått muntlig och skriftlig informationen om studien och har haft möjlighet att ställa frågor. Jag får även behålla den skriftliga informationen.

Jag samtycker till att delta i studien ”Att implementera patientdelaktighet och främja återhämtning i barn- och ungdomspsykiatri”. Jag samtycker även till att mina uppgifter behandlas på det sätt som beskrivs i forskningspersonsinformation.

Plats och datum	Underskrift ungdom

Appendix 6

Vårdnadshavares samtycke till deltagande i studien

Jag har fått muntlig och skriftlig informationen om studien och har haft möjlighet att ställa frågor. Jag får även behålla den skriftliga informationen.

Jag samtycker till att delta i studien ”Att implementera patientdelaktighet och främja återhämtning i barn- och ungdomspsykiatri”. Jag samtycker även till att mina uppgifter behandlas på det sätt som beskrivs i forskningspersonsinformation.

Plats och datum	Underskrift vårdnadshavare

Appendix 7: Interview guide (staff), study II and III

”Coherence” (sammanhang/begriplighet kring SI)

- Hur presenterades SI för er? I vilket sammanhang och på vilka grunder? – Finns det en gemensam förståelse för syftet med SI? – Hur skulle ni beskriva SI?
- Vad innebär det att (i den kliniska vardagen) arbeta med SI? – Har ni ändrat rutiner och struktur på avdelningen? – Om ja, hur/på vilket sätt? – Om nej, varför? – Hur skulle ni sammanfatta kärnkomponenterna i SI?
- Vilka förutsättningar har ni gett/fått (beroende på vem jag intervjuar) för att SI ska förstås som en del i det vardagliga arbetet? – Hur mycket tid vigdes åt förberedelser? – Vilka förutsättningar finns för reflektion av de nya rutinerna? – Hur har utfallet blivit i den kliniska vardagen? – Är SI tydligt beskrivet för er? – Känns SI relevant att införa i BUP och i sådana fall på vilka grunder?
- Hur skiljer sig SI från ordinarie praktik, d.v.s. vad är det ”nya” som SI förväntas generera för de som är inblandade?
- Vad tror ni är hjälpsamt med tillgång till metoden? – Hur bidrar SI till återhämtning och delaktighet? – Finns det exempel på hur ungdomars agens framträder i genomförandet/kontraktskrivning etc.? – Är det något som är problematiskt med SI (ge exempel)?
- Utforska: vilken målgrupp menar ni att SI riktar sig till? – Vad tror ni att man behöver ha med sig för att kunna klara av en sådan insats? – Vilka förutsättningar krävs för att få SI? – Finns det någon/några ni tänker att det inte fungerar för? Hur kommer det sig?

”Cognitive participation” (aktivt deltagande i SI)

- Är SI som möjlighet för ungdomarna förankrat hos er? – Ser ni möjligheter/risker med SI? Hur yttrar sig dessa? – Vad menar ni är behållningen med SI för ungdomarna (och personal)?
- Behövs det en särskild kompetens för att arbeta med SI? – Arbetar några utvalda med metoden, eller åligger det samtliga? – Vem styr arbetet med SI och på vilket sätt?

- Beskriv gången kring inläggningen för mig. – Hur identifieras ungdomarna och på vilka grunder? – Är det ett gemensamt beslut i personalen eller kan det även ske på individuell nivå? – Hur ges info samt hur beskrivs SI för ungdomen?
- Hur bevakas ungas vilja och delaktighet i ett sammanhang som också involverar föräldrar? – Kan ni/vi veta vems vilja som gör att ungdomen nyttjar SI? – Vems röst är ”drivande”? Märks detta om/när ungdomen kommer till avdelningen?
- Finns det unga som tackar nej till SI? – Vad tror ni får dem att fatta detta beslut?

”Collective action” (det gemensamma arbetet kring SI)

- Hur axlas ett ägandeskap av metoden, vad krävs, vilka (organisatoriska) förutsättningar ges? – Upplevs SI som en (självklar) del i BUP/alt. upplever ni att SI kan bli det? – Finns det några organisatoriska svårigheter/hinder med SI?
- Hur skapas engagemang för SI och hur görs SI legitimt och relevant? – Är arbetet med implementeringen av SI en social process eller hamnar det hos var och en att integrera det nya arbetssättet?
- Vad görs för att få SI att passa in och säkerhetsställa resurser, kunskaper och uppföljning?
- I vilka forum/konstellationer kan ni diskutera implementeringen, metoden och andra frågor som väcks i denna process? – Har ni några diskussionsforum där ni aktivt reflekterar kring metoden eller gemensamt utvärderar arbetet med den? – Vem har sanktionerat det? – Vad har ni fått ut av det? – Är det värdefullt?
- Är SI ”valbart”, d.v.s. kan det väljas bort? – Har ni möjlighet att påverka detta och på vilket sätt? – Vad kan ligga bakom en sådan bedömning och vem diskuteras man den med?
- Finns det någonting ni behöver som ni i dagsläget saknar i arbetet med SI?

”Reflexive monitoring” (organisatorisk uppföljning av SI)

- Kan man som medarbetare påverka och/eller anpassa det nya arbetssättet? – Skulle någonting behöva förfinas eller justeras för att optimeras än mer?
- Finns det en plan för och känner personalen till rapportering om effekter av SI, och hur kan resultaten värdesättas? – Känner chefer/personal ägandeskap i uppföljningsprocessen?
- Har ni sett några ”risker” med SI?
- Hur kvalitetssäkras SI? (Enkäter, samtal med ungdomarna?)
- Vad behövs för att metoden ska bli självgående i BUP, d.v.s. vad behövs för att SI permanentas, upplevas som en naturlig ”rutin”, leva kvar och bli en självklar del i vårdutbudet?
- Är SI värt att satsa på och investera tid i?

Eventuella tillägsfrågor

- Har ni fått någon feedback från ungdomar (och/eller föräldrar) och vad säger de i sådana fall? – Hur ser nyttoeffekten ut? – Ser organisationen vinster med att involvera ungdomarna i uppföljningsprocessen, d.v.s. försöka mäta/avgöra nöjdhet etc.? Hur bevakas ”kundnöjdheten”?
- Vad är återhämtning för dig/er? Hur yttrar sig den? Kan den påverkas, på vilket sätt? – Hur tänker ni kring återhämtning och hur uppfattar ni att organisationen BUP arbetar med den?
- Beskriv gärna hur återhämtningsdiskursen är aktuell på BUP – Hur yttrar den sig – I vilka forum diskuteras den – Hur pratar ungdomarna om detta (vilka begrepp, språkkonstruktioner etc.)?
- Hur tänker ni kring SI i framtiden, var befinner ni er om t.ex. fem år?
- Kan ni beskriva en typisk situation som leder till att en ungdom erbjuds SI?

Appendix 8: Interview guide (adolescents), study IV

Inledning

Ramarna för intervjun beskrivs (intervjun spelas in, den tar ca 1–1/2 timme och du kan när som helst och utan förklaring avbryta eller pausa). Har du blivit intervjuad/berättat om dina erfarenheter tidigare? Ett samtal, inga rätt eller fel svar utan det är dina erfarenheter som är i fokus. Är det någonting du funderat på sedan vi hördes sist som du vill berätta innan vi börjar?

Bakgrundsfakta om ungdomen

- Tjej/kille/annan könstillhörighet? Ålder? Etnicitet? Familjekonstruktion? Skola/jobb/annan sysselsättning?
- Hur lång kontakt med psykiatrin? När var den senaste inläggningen?
- Hur ser din nuvarande vårdkontakt ut?

Tidigare erfarenheter av psykiatrisk HDV

- Kan du berätta hur det gick till när du senast blev inlagd? Följdfrågor om det behövs (vilka var inblandade, var dina föräldrar involverade, typ av vårdform, bemötande, grad av delaktighet etc.)?
- Om du tänker tillbaka, var HDV utformad så att den passade dig? Önskade du något som inte fanns där?

Delaktighet (att bli lyssnad på, självbestämmande, bli konsulterad, informerad m.m.).

I dag pratar man om att psykiatrin ska stärka patienternas delaktighet i sin vård. Att man som patient ska ha inflytande, ha tillgång till information och kunna vara med och bestämma. Är det något du har hört talas om?

- Om du funderar, vad innebär delaktighet i HDV för dig?
- Fick du vara med och bestämma något när du var inlagd? Om nej, vad hade du velat bestämma över? Vad är viktigt för dig när du är i HDV?

- Uppstod det någon situation där du inte fick eller kunde vara med och bestämma?
- Finns det situationer då du *inte* ville vara med och bestämma? Finns det saker som kan vara skönt att andra bestämmer om i HDV? Kan du berätta om en sådan situation?
- Har dina föräldrar varit med och påverkat något när du mått dåligt och behövt HDV (vårdinnehåll, önskat bemötande, kontaktperson m.m.)?

Återhämtning

Introducera begreppet.

- Om/när du har börjat må bättre, hur skulle du beskriva den processen för mig? (Hur märker man om man är i återhämtning/är återhämtad)?
- Om du tänker tillbaka, var HDV utformad på ett sätt som passade dig som ung? Om inte, vad behövs för att vården ska kunna stötta dig när du mår psykiskt dåligt?

Info om SI

Introducera vårdformen (kort inläggning som initieras av den unga, ökad access till HDV, akuten undviks, 1–3 vårddygn, att föräldrar inte förväntas vara på avdelningen) och att det finns ett särskilt kontrakt där den unga, föräldrar och personal tillsammans bestämmer innehållet.

- Har du hört talas om vårdformen SI?
- Om du skulle få möjligheten att själv bestämma när du vill bli inlagd, tror du att det skulle ha någon betydelse? På vilket sätt? Hur skulle det vara för dig att ha ett sådant kontrakt?
- Om du hade tillgång till den här vårdformen, skulle du vilja att någon stöttade dig i beslutsprocessen att lägga in dig? Vem och på vilket sätt (ringa avdelningen och kolla om platsen är ledig, hjälp med skjuts etc.)?
- Om du funderar, vad skulle du vilja stod i kontraktet?
- Vad skulle bli viktigt för dig för att du skulle vilja använda en sådan vårdform? Skulle det krävas något speciellt av dig för att du skulle kunna hantera den?

- Om du funderar på hur det har varit vid tidigare inläggningar, finns det risker med att få bestämma mer när du mår dåligt?

Om ungdomen har tillgång till och/eller har använt SI

- Hur länge har du haft SI? Har du använt dig av SI hittills?
- Vill du berätta hur processen fram till att du fick SI såg ut? (Vad gavs du för information, fick du vara med och bestämma något i upplägget kring SI, hur såg dialogen ut mellan dig, föräldrar och personal)?
- Vilken betydelse har SI haft för dig? Har tillgången till SI påverkat din skolgång, relation till familj och kompisar etc.?
- Vad tycker du krävs av dig för att du ska kunna hantera SI?
- Om du har använt SI, var du ensam om att fatta beslutet att åka till avdelningen? Vill du berätta om hur den processen såg ut?
- Har det uppstått några konflikter mellan dig och personal/föräldrar under vårdtillfället? Kan du berätta vad de handlade om?

Följdfrågor om de inte redan har besvarats

- När du har varit inlagd, har relationen till personalen varit viktig för dig då? Vad tycker du är viktigt för personalen att tänka på för att du ska kunna få bestämma mer i HDV?
- Vad tror du har påverkat hur personalen resonerat/beslutat om din möjlighet att bestämma under inläggningen?

Övrigt

- Tycker du att jag har glömt att fråga någonting viktigt, eller vill du lägga till någonting som du tycker att jag bör veta?

Appendix 9: Interview guide (parents), study IV

Inledning

Ramarna för intervjun beskrivs (intervjun spelas in, den tar ca 1–1/2 timme och du kan när som helst och utan förklaring avbryta eller pausa). Har du blivit intervjuad/berättat om dina erfarenheter tidigare? Ett samtal, inga rätt eller fel svar utan det är dina erfarenheter som är i fokus. Är det någonting du funderat på sedan vi hördes sist som du vill berätta innan vi börjar?

Bakgrundsfakta

- Mamma/pappa/annan vårdnadshavare? Ålder? Etnicitet? Sysselsättning?
- Hur lång kontakt har familjen haft med psykiatrin? När var den senaste inläggningen?
- Hur ser ditt/dina barns nuvarande (vård)situation ut?

Tidigare erfarenheter av psykiatrisk HDV

- Kan du berätta hur det har gått till när ditt/dina barn blivit inlagd? (Vilka var inblandade, typ av vårdform, bemötande, grad av delaktighet etc.)?
- Om du tänker tillbaka, var HDV utformad så att den passade dig och ditt/dina barn? Önskade du något som inte fanns där?
- Vilken betydelse tänker du att möjligheten till HDV har för ditt/dina barns mående?

Delaktighet (att bli lyssnad på, självbestämmande, bli konsulterad, informerad m.m.).

I dag pratar man om att psykiatrin ska stärka patienternas och deras närståendes delaktighet i sin vård. Att man som patient ska ha inflytande, ha tillgång till information och kunna vara med och bestämma.

- Om du funderar, vad innebär delaktighet i HDV för dig?
- Fick du och ditt/dina barn vara med och bestämma något när ni var inlagda? Om nej, vad hade du/ni velat bestämma över?

- Fanns det tillfällen då du och ditt/dina barn ville olika saker? Vad hände då?
- Fanns det situationer då du *inte* ville att du eller ditt/dina barn skulle vara med och påverka/influera eller finns det saker som kan vara skönt att andra beslutar om i HDV? Kan du berätta om en sådan situation?
- Utvecklar man/krävs det några specifika strategier som förälder för att säkra delaktighet i HDV?
- Har du som förälder varit med och påverkat vården i någon riktning när ditt/dina barn har behövt HDV (vårdinnehåll, önskat bemötande, kontaktperson m.m.)?
- Vad är viktigt för dig som förälder för att kunna vara delaktig när du är med ditt/dina barn i HDV?

Info om SI

Introducera vårdformen (kort inläggning som initieras av den unga, ökad access till HDV, undvika akuten, vigd plats på avdelningen, att föräldrar inte förväntas vara på avdelningen, kan funka i preventivt syfte innan måendet blivit akut) och att det finns ett särskilt kontrakt där den unga, föräldrar och personal tillsammans bestämmer innehållet.

- Vad skulle krävas för att du som förälder skulle samtycka till en sådan vårdform?
- Om ditt/dina barn skulle få möjligheten att själv bestämma när hen vill bli inlagd, tror du att det skulle ha någon betydelse för er situation? På vilket sätt?
- Hur tror du att det skulle vara för dig som förälder om ditt/dina barn hade ett sådant kontrakt?
- Hur tror du att beslutsprocessen kring att använda SI eller inte skulle se ut i er familj och hur kan man stötta den unga i en sådan process (dialog med barnet om inläggning, ringa avdelningen och kolla om platsen är ledig, hjälp med skjuts etc.)?
- Om du funderar, vad skulle du vilja stod i kontraktet, d.v.s. vad blir viktigt för dig som förälder att säkerställa under en SI-inläggning?

- Vad skulle bli viktigt för dig för att du skulle låta ditt/dina barn använda en vårdform som SI? Skulle det krävas något speciellt för att er familj skulle kunna hantera den?
- Om du funderar på hur det har varit vid tidigare inläggningar, finns det risker för ditt/dina barn med att få bestämma mer när hen mår dåligt?

Om föräldern har erfarenhet av SI

- Hur länge har ditt/dina barn haft SI? Har hen använt dig av SI hittills?
- Vill du berätta hur processen fram till att hen fick SI såg ut? (Vad gavs familjen för information, fick ni vara med och bestämma något i upplägget kring SI, hur såg dialogen ut mellan ditt/dina barn, dig och personal)?
- Vilken betydelse har SI haft för dig som förälder?
- Vad skulle du säga krävs av ditt/dina barn för att kunna hantera SI?
- Om ditt/dina barn har använt SI, hur har inläggningsprocessen sett ut?
- Har det uppstått några konflikter mellan dig, ditt/dina barn och personal under vårdtillfället? Kan du berätta vad de handlade om?

Följdfrågor om de inte redan har besvarats

- När du som förälder har varit med ditt/dina barn i HDV, har relationen till personalen varit viktig för dig då? Vad tycker du är viktigt för personalen att tänka på för att ett barn ska kunna få bestämma mer i HDV?
- Vad tycker du är viktigt för HDV-personalen att tänka på i kontakten med dig som förälder?
- Kan det uppstå några (specifika) svårigheter i HDV som du som förälder har reagerat/funderat på under vistelsen där?
- Vad uppfattar du har påverkat hur personalen resonerat/beslutat om ditt/dina barns möjlighet att bestämma under inläggningen?

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