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Shaping trust

*Facilitating user participation in coordinated
planning for individuals with comorbidity*

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Abstract

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In support planning and decision-making processes within social work and healthcare, user participation is emphasised as a core principle. However, the concept of user participation remains ambiguously defined, and a gap persists between the intentions outlined in the literature and policies on the one hand and practical implementation on the other. This dissertation focuses on adults with comorbidity of substance use problems and mental illness/ADD/ADHD or autism within the context of establishing a coordinated individual plan (CIP) – a process that involves collaboration among social service and healthcare staff and the user (i.e. the individual receiving support). The aim of this thesis is to explore how user participation is understood and can be facilitated in CIP.

In the thesis, a predominantly qualitative approach supplemented by questionnaire data is used. In the first study, a grounded theory approach based on individual interviews with users is used to explore how adults with comorbidity perceive participation in social services. In the second study, data from future workshops and present-and-future stories workshops is analysed to explore staff perspectives on challenges and potential solutions related to user participation, shared decision-making and support coordination in CIP. Following the first two studies, an innovation designed to increase user participation through shared decision-making – namely, a revised CIP process with a new form for documentation – was introduced to staff via training sessions across three sites. In the third study, barriers to and facilitators of the implementation process of this innovation are explored using an approach inspired by explanatory mixed methods that combines staff questionnaires with individual and focus group interviews with staff. Finally, in the fourth study, individual interviews are conducted with users and staff to explore their experiences of the revised CIP process.

This thesis contributes to an understanding of user participation as a relational process characterised by mutual trust, knowledge-sharing and working together over time. This understanding applies to the shaping of mutual trust not only between users and staff but also among staff members, as this thesis supports an understanding of the importance of staff relations in facilitating user participation in the CIP process. Knowledge sharing and working together over time are shown to be facilitated by the revised CIP process and new form for documentation. Despite these promising experiences with the revised CIP process, several barriers to the implementation are identified, including perceptions of the complexity of the innovation, time constraints and challenges in communication across organisational boundaries. This thesis stresses the importance of prioritising relational processes, with knowledge sharing being built on mutual trust between users and staff and among staff members, in order to unlock CIP's full potential for coordinated support with user participation.

Keywords: user participation, trust, coordinated individual planning, substance use, mental health, shared decision-making, social services, healthcare

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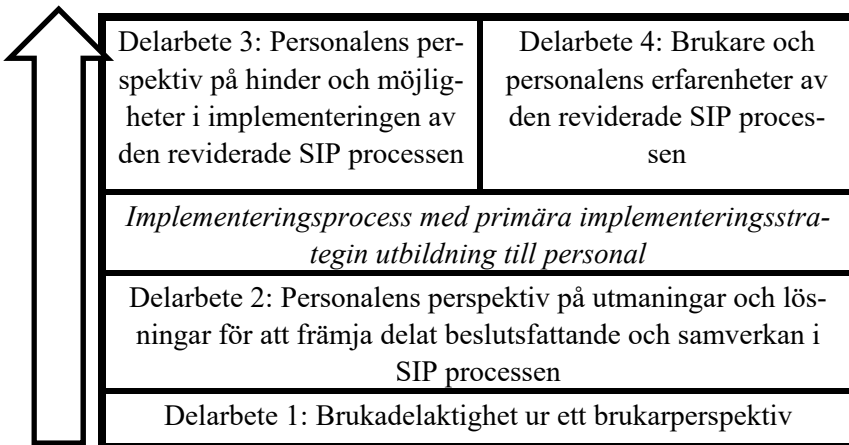
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Svensk sammanfattning (Swedish summary)

Brukardelaktighet är en grundläggande princip i beslutsfattande och planering av stöd inom socialtjänsten samt hälso- och sjukvården. Vikten av brukardelaktighet betonas i policyer och forskning. Studier har visat att brukardelaktighet kan ha flertalet positiva följder, såsom att stödja individens återhämtningsprocesser och minska avbrott i behandlingen. Omvänt kan bristande delaktighet, såsom att inte känna sig lyssnad på eller informerad, leda till en negativ uppfattning av personalens bemötande och det erhållna stödet. Fokus för avhandlingen är brukardelaktighet i kontexten samordnad individuell plan (SIP) och målgruppen är vuxna med samsjuklighet av skadligt bruk eller beroende i kombination med psykisk ohälsa, autism, ADHD eller ADD. SIP är lagstadgat sedan 2010 och syftar till att främja en samverkansprocess mellan individen själv, socialtjänsten och hälso- och sjukvården när individen kan ha behov av stöd från båda aktörerna. Brukardelaktighet har en central roll i SIP processen och det är den enskildes behov och önskemål som ska vara utgångspunkten i planeringen. Forskning indikerar dock att SIP inte har uppnått målen avseende brukardelaktighet och samverkan. Forskning visar även att det finns ett behov av ökad kunskap om hur brukardelaktighet förstås, särskilt ur ett brukarperspektiv, och hur brukardelaktighet kan främjas i processer såsom SIP. Syftet med denna avhandling är därmed att undersöka hur brukardelaktighet kan förstås och främjas i kontexten SIP för personer med samsjuklighet. Den här kunskapen kan bidra till att brukardelaktighet i SIP realiserar som avsett.

Avhandlingen består av fyra delarbeten. Det första delarbetet utgörs av en kvalitativ intervjustudie med brukare, personer som varit i kontakt med socialtjänsten utifrån samsjuklighet, där deras perspektiv på brukardelaktighet och dess innebörd undersöktes. Denna förståelse av brukardelaktighet utgör grunden för de efterföljande delarbetena. Logiken avseende hur delarbetena byggs på varandra visas i Figur 1.

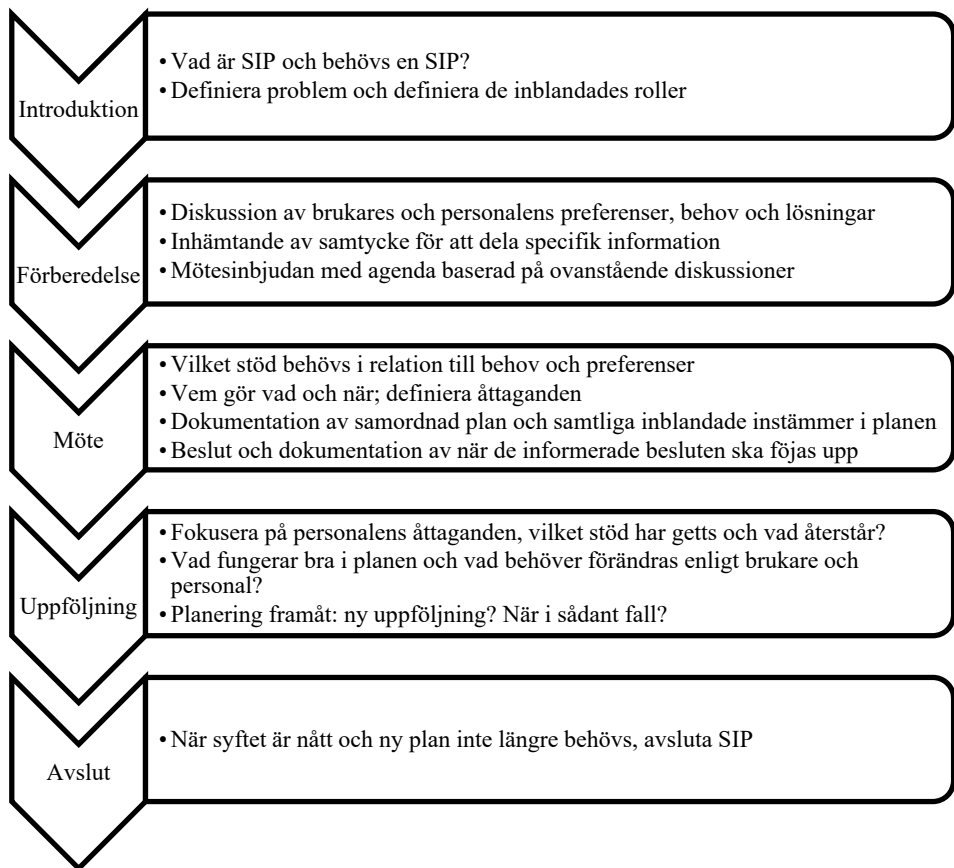
Figur 1. Illustration av hur delarbetena bygger på varandra.



I det andra delarbetet användes data som tidigare samlats in i workshops, *framtidswerkstäder*, med personal som i sin roll inom socialtjänsten eller sjukvården möter brukare med samsjuklighet. Syftet var att undersöka personalens perspektiv på utmaningar och potentiella lösningar för att främja delat beslutsfattande (DBF) och samverkan inom SIP. Därefter introducerades en reviderad SIP process till personal på tre orter i en region. Den reviderade SIP processen innehåller DBF och var sedan tidigare framtagen i workshops med personal och brukare inom samsjuklighetsområdet. Stegen i den reviderade SIP processen illustreras i Figur 2.

För att underlätta användningen av den reviderade SIP processen introducerades en ny dokumentationsblankett för SIP. Blanketten stödjer SIP som process och uppmuntrar till diskussioner och kunskapsdelande över tid mellan brukare och personal, och mellan personal. Den primära implementeringsstrategin bestod av en halvdagsutbildning för personal, där de även rollspelade den reviderade SIP-processen och använde den nya blanketten. Utöver detta fick personalen en lathund som stöd i arbetet och erbjöds externt stöd från oss som ansvarat för utbildningen. De uppmuntrades även att utse *facilitare* – personer som stödjer implementeringen lokalt inom arbetsgrupperna. I den tredje studien undersöktes personalens perspektiv på hinder och framgångsfaktorer i implementeringsprocessen. Personalens perspektiv undersöktes genom en enkät som delades ut vid två separata tillfällen och därefter genomfördes individuella intervjuer och fokusgruppsintervjuer för att få en djupare förståelse för de initiala resultaten. Den fjärde studien undersökte erfarenheter av den reviderade SIP processen, och data samlades in genom individuella intervjuer med brukare och personal.

Figur 2. De fem stegen i den reviderade SIP processen



Resultatet i delarbete ett visar att brukardelaktighet förstås som en social process som involverar att forma ett ömsesidigt förtroende mellan brukare och personal. Deltagarna beskrev i intervjuer att de har haft ett lågt förtroende till socialtjänsten och upplevt detta låga förtroende som ömsesidigt. Vidare beskrevs olika förutsättningar för delaktighet. De här förutsättningarna involverar att själv ha motivation och vilja att ta emot stöd och att det finns tillgängligt stöd när man är motiverad samt att ses som en kunskapsbäare och att personal har kunskap. Vidare framkommer vikten av att personal tar hänsyn till brukares beslutsfattande förmågor samtidigt som personal stödjer brukardelaktighet genom att lyssna och involvera brukaren i beslutsfattande processer.

I delarbete två identifierades utmaningar och lösningar inom tre områden, *organisation och personals kunskap, samordning mellan personal samt personalens attityder och brukardelaktighet*. De föreslagna lösningarna involverar bland annat förbättrat samarbete mellan personal samt att personal får mer

kunskap om SIP och varandras roller. Lösningar avseende brukardelaktighet involverar att använda strategier för att stärka brukardelaktigheten såsom att förbereda SIP mötet med brukaren och annan personal för att kunna skapa en tydlig agenda för mötet. Genom en noggrann förberedelse och tydlig agenda kan alla komma förberedda till SIP mötet. Vidare diskuteras i delarbete två om SIP är det bästa sättet att samordna stöd, eller om det behövs andra strategier såsom att arbeta i team.

Hinder i implementeringsprocessen som framkom i delarbete tre involverade hög arbetsbelastning, bristande strukturer för kommunikation mellan socialtjänst och sjukvård och att personal är tveksamma till hur brukardelaktighet i SIP kan realiseras. Exempelvis framkommer i resultatet osäkerhet till att diskutera olika alternativ med brukare. Personal beskrev även att brukare inte kan sätta agendan, vilket gör att personal lyfter andra saker på SIP mötet än överenskommet med brukaren i förberedelsen. Möjligheter i implementeringsprocessen inkluderar det omvända, att det finns strukturer för samverkan mellan de involverade verksamheterna och att se brukare som experter som behöver involveras genom SIP processen.

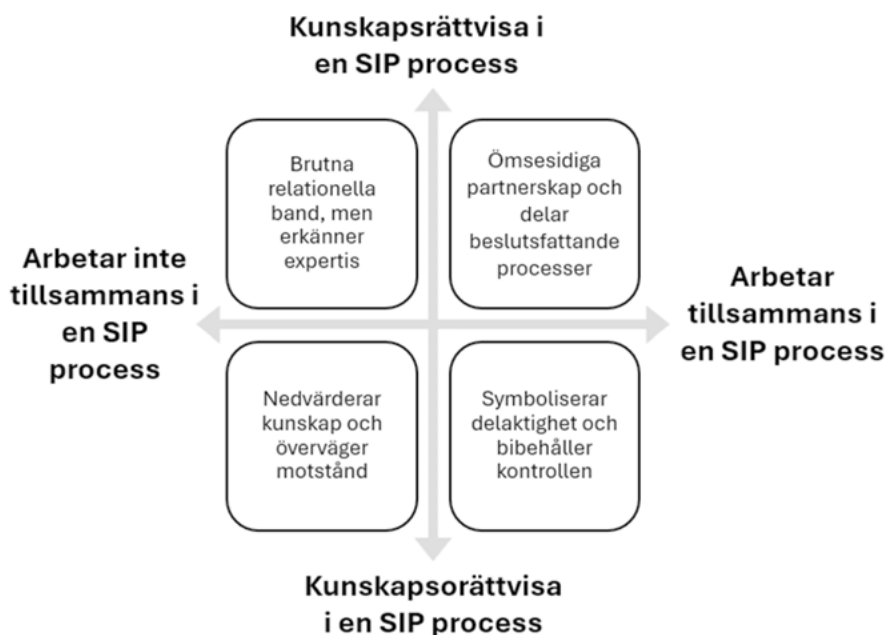
I delarbete fyra beskrev både brukare och personal att de upplever att den reviderade SIP processen ökar tryggheten genom SIP processen genom att man visste vilka som skulle delta och vad som skulle diskuteras utifrån att SIP mötet förberetts, vilket upplevdes som viktigt. Att brukare och personalen förberedde SIP mötet tillsammans gjorde att de involverade upplevde att brukardelaktigheten realiserades genom hela SIP processen, särskilt då det brukarna lyft i förberedelsen togs upp vid SIP mötet. Att arbeta tillsammans över tid upplevdes även öka förtroendet mellan de inblandade i SIP processen. Vidare framkom en ökad struktur i brukarnas liv generellt sett. Användandet av den nya dokumentationen för SIP upplevdes leda till den ökade strukturen och gemensamma förståelsen genom SIP processen.

Sammanfattningsvis bidrar denna avhandling till en förståelse av brukardelaktighet som en social process där ömsesidig tillit formas. Detta gäller inte bara formandet av ömsesidig tillit mellan brukare och personal, utan även de relationella banden mellan personalmedlemmar, då avhandlingen belyser vikten av personalrelationer för att främja brukardelaktighet i SIP-processen. Ömsesidig tillit formas genom att arbeta tillsammans över tid för att etablera relationella band och är också avgörande för att uppnå kunskapsrättvisa, eftersom det kräver tillit till varandra som kunskapsbärare. Att navigera relationella band och kunskapsrättvisa beskrivs vidare som centralt för att främja brukardelaktighet i SIP för individer med samsjuklighet. *Kunskapsrättvisa*

förstås här som att erkänna varandra som kunskapsbärare som är kapabla att aktivt delta genom hela SIP processen. Det handlar därmed även om *deltagar-rättvisa*, att ses som en kompetent deltagare genom SIP processen. För att brukare ska kunna känna kunskapsrättvisa behöver de även ha tillit till att personalen förser dem med viktig information, kunskap, genom hela SIP processen, vilket benämns som *kunskapsförtroende*.

Processerna med att arbeta tillsammans över tid och etablera kunskapsrättvisa illustreras i Figur 3.

Figur 3. Interaktioner mellan brukare och personal, och mellan personal i SIP processen



Att brukardelaktighet förstås som en process illustreras genom användandet av presens-form i Figur 3. De olika *rutorna* i Figur 3 förstås som olika *element* som SIP processer kan innehålla. Samtliga rutor illustrerar både relationer mellan brukare och personal, och mellan personal. I avhandlingen diskuteras olika exempel på de här elementen. Exempelvis, när personal och brukare förbereder SIP-mötet tillsammans och planeringen följs upp, förstås det som *element av ömsesidigt partnerskap och delande av beslutsfattande processer* (övre högra hörnet i Figur 3). Av resultatet framkommer att den reviderade SIP processen främjar de här elementet. Dock, när personal inte delar med sig av information till brukare gällande exempelvis olika alternativ etableras istället *element av symbolisk delaktighet där personal bibehåller kontrollen* (nedre

högra hörnet i Figur 3). När brukare upplever att de nekas stöd och inte ses som kunskapsbärare motverkas processer av att arbeta tillsammans och resultatet visar att det kan medföra att brukare förvärrar sin situation medvetet för att få stöd. Det här förstås i avhandlingen som element av *nedvärderar kunskap och överväger motstånd* (nedre vänstra hörnet i Figur 3), brukare reagerar inte endast på personalens beslut utan överväger hur de ska gå vidare och agerar. Av resultatet framkommer även att det finns svårigheter för personal att nå varandra över organisatoriska gränser, vilket ses som *element av brutna relationella band, men erkännande av expertis* (övre vänstra hörnet i Figur 3). Det här elementet påverkar brukares möjligheter till delaktighet då personal exempelvis inte kan inhämta olika alternativ och diskutera med brukaren. Den här avsaknaden av möjlighet att förbereda SIP mötet tillsammans med annan personal medför risken att nya ämnen som brukaren inte samtyckt till lyfts på SIP mötet. Resultaten visar intressant nog på att en och samma SIP process kan innehålla flertalet element, och det är viktigt att reflektera över hur brukardelaktighet i SIP processer kan främjas – kanske med hjälp av Figur 3 som kan användas som en karta för att navigera reflektionen.

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I. Jones, A., Jess, K., & Schön, U.K. (2021). How do users with comorbidity perceive participation in social services? A qualitative interview study. *International Journal of Qualitative Studies on Health and Well-Being*, 16(1).
- II. Jones, A., Knutsson, O., & Schön, U.K. (2022). Coordinated individual care planning and shared decision-making: Staff perspectives within the comorbidity field of practice. *European Journal of Social Work*, 25(2).
- III. Jones, A., Fjellfeldt, M., & Schön, U.K. (n.d). Barriers and facilitators during the implementation process of shared decision-making in the comorbidity field: Staff perspectives. [Submitted]
- IV. Jones, A. (2025). User and staff experiences of a revised process for coordinating support with shared decision-making in the comorbidity field of practice: A qualitative interview study. *International Journal of Qualitative Studies on Health and Well-Being*, 20(1).

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Abbreviations

AIM	Acceptability of Intervention Measure
ADD	Attention-deficit disorder
ADHD	Attention-deficit hyperactivity disorder
CFIR	Consolidated Framework for Implementation Research
CGT	Constructivist grounded theory
CIP	Coordinated individual plan
EBP	Evidence-based practice
FIM	Feasibility of Intervention Measure
IAM	Intervention Appropriateness Measure
PTSD	Post-traumatic stress disorder
SDM	Shared decision-making
SOU	Swedish Government Official Reports (<i>Statens offentliga utredningar</i>)
SUP	Substance-use problems

Introduction

The aim of this dissertation is to explore how user participation is understood and can be facilitated in social services and healthcare, with a focus on adults with comorbidity in the context of coordinated planning. Herein, the term *comorbidity* is used to refer to the co-occurrence of substance-use problems (SUP)¹ along with mental illness, attention-deficit hyperactivity disorder (ADHD), attention-deficit disorder (ADD) or autism. In the Swedish Government Official Reports (*Statens offentliga utredningar*, SOU), these conditions are identified as common, severe or a combination of both when co-occurring with SUP (SOU, 2021:93). The complexity of comorbidity, which is characterised by interaction between at least two conditions, often leads to greater severity compared with either condition alone (Morisano et al., 2014; Najt et al., 2011).

Various terms are used in the literature to refer to user involvement in decision-making processes, including *user participation*, *influence*, *collaboration* and *partnership* (Egilson et al., 2018; Levin, 2012). Distinctions have been made between these concepts, such as the view that ‘participation’ involves a hierarchical structure with one person leading, whereas ‘collaboration’ is based on mutual knowledge sharing and power (Levin, 2012). This thesis embraces a broad definition of *user participation* that refers to both involvement in decision-making processes and the influence users have throughout the process. However, a lack of consensus remains regarding how user participation is understood in the field of comorbidity (Selseng et al., 2021), and it is this ambiguity that this dissertation seeks to explore in greater depth. In this thesis, user participation is explored in the context of coordinated planning, more specifically in the context of coordinated individual plan (CIP). CIP has been legislated since 2010 in Sweden and should be established when an individual requires, or might require, support from both social services and healthcare (Lindström, 2019), in order to prevent fragmentation (Matscheck et al., 2019). A CIP is established through a coordination process between the individual in

¹ Previous research illustrates that substance misuse has a variety of concepts and definitions (Rehm et al., 2013). In this dissertation, *SUP* refers to substance misuse that has led to problems in other aspects of the person’s life.

need of support, social services and healthcare. As such, the CIP process involves support planning and decision-making with user participation (Lindström, 2019).

This thesis begins by seeking to explore how user participation is perceived and understood from the perspectives of those with lived experience of comorbidity and of using services provided by social services and healthcare (referred to herein as *users*). Thereafter, staff perspectives on problems and solutions in the CIP process regarding user participation, shared decision-making (SDM) and collaboration are explored. The *staff* referred to in this dissertation work in social services or healthcare. Taken together, perspectives from users and staff are used to gain a deeper understanding of user participation and its facilitation in the context of CIP. In this dissertation, the term *facilitate* refers to actions that promote, encourage and/or ease user participation. An implementation process is used in the dissertation to further explore how user participation can be understood and facilitated. The particular implementation process relates to an innovation: a revised CIP process that incorporates SDM (Knutsson & Schön, 2020). SDM emphasises knowledge sharing between users and staff, with the goal of fostering greater user involvement in decision-making processes (Elwyn et al., 2010). By exploring these elements of SDM and coordination, this dissertation aims to deepen our understanding of user participation and how it can be facilitated.

In this thesis, the Background chapter explores policies and previous studies. Next, the Theoretical framework chapter provides an overview of the framework used in this dissertation, which focuses on epistemic (in)justice and its application. The Methods chapter then outlines the research approach, followed by the Results chapter. In the Discussion chapter, the results are discussed in relation to prior research and the theoretical framework. However, before proceeding with the thesis, a brief description of the scope is provided. User participation, coordination and collaboration among staff members, and implementation processes intersect with multiple research fields, including organisational structures, staff conditions and inter-organisational collaboration. Research on individuals with comorbidity also draws on perspectives and theories beyond those utilised in the present dissertation, such as recovery and those within the field of neuroscience. To refine the focus, this thesis examines user participation *within* coordinated planning, specifically within CIP. While coordination, collaboration and staff conditions are considered in relation to user participation, they are not explored in depth as standalone topics.

Background

This chapter outlines the context in which the thesis is situated. It begins with a brief overview of key policies in Sweden regarding user participation and the organisation of support for individuals with comorbidity. Swedish social services and healthcare operate in a manner specific to Sweden, as the responsibility for SUP is shared between both organisations. In most countries, healthcare manages SUP treatment, while social services focus on supporting individuals' social needs, such as housing, financial aid and vocational support (SOU, 2021:93). Therefore, it is important to provide information on policies within the unique Swedish context. In Sweden, social services are municipality-based, whereas healthcare is managed at the regional level; thus, one region encompasses several municipalities, with specialist services being concentrated in specific areas. The policy overview is followed by an overview of previous research relevant to this thesis, positioning the thesis within both national and international contexts.

Key policies

Several policies highlight the importance of user participation in services, as it is rooted in citizen rights, equality and democracy. Participation is incorporated in human rights legislation and forms part of Sweden's constitutional laws. Notably, the Instrument of Government (SFS, 1974:152) states that 'public institutions shall work to promote the opportunity for all to attain participation and equality in society' (c. 1, Art. 2). Besides being part of broader legislation, user participation is embedded in both the Social Services Act (SFS, 2001:453) and the Patient Act (SFS, 2014:821). These laws assert that services should respect individuals' rights to self-determination and integrity (SFS, 2001:453, c. 1, § 1; SFS, 2014:821, c. 4, § 1). The Social Services Act (SFS, 2001:453) further specifies that social support should be designed and delivered in collaboration with the individual (c. 3, § 5). It also mandates that information be provided on the harmful effects of substance use and available treatment options (c. 3, § 7). Similarly, the Patient Act (SFS, 2014:821) decrees that individuals have the right to information about their health,

treatment options, expected outcomes and timelines for support (c. 3, §, 1) and the possibility to choose treatment and providers (c. 3, § 2). It also declares that healthcare should be easily accessible (c. 2, § 1). User participation is also highlighted in ethical guidelines for social workers and healthcare personnel (Akademikerförbundet, 2017; International Council of Nurses, 2021). For social workers, these guidelines stress the necessity of dialogue, participation and influence for the individuals receiving support (Akademikerförbundet, 2017). In healthcare, the focus is on person-centred care, informed consent and respect for patients' values and integrity (International Council of Nurses, 2021).

Policies also specify individuals' right to support. Under the Healthcare Act (SFS, 2017:30), healthcare is obliged to prevent, assess and treat diseases, including comorbidity (c. 8, § 1; c. 2, § 1). Under the Social Services Act (SFS, 2001:453), social services are responsible for preventing SUP (c. 3, § 7) and providing support to individuals with SUP (c. 5, § 9). They must also contribute to vocational support and supported living to individuals facing substantial challenges in daily living (c. 5, § 7) and promote individuals' rights to work, housing and education (c. 3, § 2). To foster coordination between social services and healthcare, CIP was legislated in 2010, with formal requirements outlined in both the Social Services Act (c. 2, § 7) and the Healthcare Act (c. 16, § 4). User participation crucial in establishing a CIP. The CIP process involves preparation, meeting and follow-up meeting(s), with mandatory staff attendance. Both organisations must adhere to confidentiality laws, requiring user consent before initiating CIP and sharing information. Through the CIP process, the required support, who will provide it and when are discussed, planned and documented, with adjustments based on the user's evolving needs. While no universal CIP documentation form exists, recommendations for its content are provided. This documentation complements, rather than replaces, other required records within social services and healthcare (Lindström, 2019).

Within this legislative structure, the division of responsibilities for substance-use treatment has long been debated in Sweden. Over the years, reports have recommended that healthcare take responsibility for substance-use treatment, while social services focus on social support, such as housing, vocational support and family assistance. These reports have also emphasised the need for user involvement in decision-making (SOU, 2011:35, 2021:93). In addition, the 2021 report highlighted CIP as a means of coordinating support, although it further suggested the use of integrated teams with joint management for users with needs requiring long-term coordinated care (SOU, 2021:93).

Previous research

This section provides an overview of research related to individuals with comorbidity, the role of user participation and research on the implementation of SDM as a method to strengthen user involvement in services. Next, the section presents research on support needs among individuals with comorbidity, with a specific focus on coordination of support.

Individuals with comorbidity

Depending on population and the measures used, the prevalence of comorbidity varies (Daigre et al., 2021). Nevertheless, research indicates that comorbidity is common. For example, in a U.S.-based population study covering a 12-month period, 18% of adults with mental illness had a substance-use disorder as well, while 38% of individuals with a substance-use disorder also had a mental illness (Han et al., 2017). Moreover, reviews have shown that approximately 25% of individuals with major depression also have a substance-use disorder (Hunt et al., 2020); 50% of individuals with lifetime drug dependence also have anxiety disorders (Lai et al., 2015); and 42% of individuals with schizophrenia also have a substance-use disorder (Hunt et al., 2018). Moreover, about a fifth of individuals with a substance-use disorder have ADHD, according to a review by Rohner et al. (2023). The prevalence of autism is uncertain, due to limited research and conflicting results. However, a review reported that most studies found a vulnerability among individuals with autism towards developing substance use, although some studies disagreed with this link (Haasbroek & Morojele, 2022).

Reviews report that comorbidity has a greater negative impact on physical health, leads to more social consequences and results in worse treatment outcomes compared with having either condition alone (Morisano et al., 2014; Najt et al., 2011), as the conditions intensify each other (Drake et al., 2020). For instance, in a retrospective cohort study, a severe mental illness in combination with a substance-use disorder was found to shorten an individual's lifespan more than a severe mental illness alone (Iturralde et al., 2021). The consequences of comorbidity have been elaborated on in both qualitative and quantitative research; they include a weak economic situation, homelessness and unemployment (Zoric et al., 2024), increased risk of suicidal considerations (Onaemo et al., 2022) and early death (Iturralde et al., 2021). Also, a deteriorating everyday life is shown, with passivity or impulsiveness, little structure (Kronenberg et al., 2014) and loss of daily routines such as sleep, food and taking care of the home (Zoric et al., 2024). Individuals with

comorbidity are heterogeneous, and their needs and the severity of their situation vary (Carroll, 2021; Daigre et al., 2021). Thus, user participation is essential throughout the coordination and deciding of support, as described in the following sections.

Uncertainties in conceptualising user participation

The definition and scope of user participation and related concepts remain uncertain. For example, some researchers describe user participation on a spectrum ranging from no participation to full citizen control, with Arnstein's ladder of participation (1969) being one of the most prominent models (Cornwall, 2008). However, this model has been criticised by scholars such as Tritter and McCallum (2006) for neglecting the dynamic, relational aspects of participation and focusing primarily on power dynamics. While these frameworks offer valuable insights into user participation, neither Arnstein nor Tritter and McCallum address individual-level involvement, which is the focus of this dissertation.

Selseng et al. (2021) synthesised research on the perspectives of user involvement among users with SUP, including individual-level decision-making, and found ambiguity and a fluid understanding of user involvement in the literature. Overall, the users with SUP understood user involvement as a partnership, working together with staff and having one's knowledge acknowledged and valued in the decision-making process. To ensure user involvement in practice, the researchers (ibid.) emphasised the importance of users feeling listened to, valued, cared for and treated with respect. Selseng et al. (2021) also described the relational, dynamic processes of individual-level decision-making through co-production, while recognising the uncertainty surrounding what user involvement truly entails. The review further emphasised the need to continuously 'examine how user involvement is understood and include service users' perspectives when investigating and defining user involvement' (Selseng et al., 2021, pp. 15–16). Lastly, the scholars stressed the importance of research that focuses on the *processes* of user involvement, rather than limiting the scope to specific decisions.

Arguments for user participation

Previous research within the field of mental health has established the principle of 'no decision about me, without me' (O'Brien, 2022) or, similarly, 'nothing about me, without me' across healthcare settings (Wise, 2011). The importance of user participation is also central to evidence-based practice (EBP), which

integrates the knowledge of users and staff with evidence (Sackett et al., 1996), alongside organisational considerations (Haynes et al., 2002).

Quantitative studies on users' preferred participation have shown that most users – whether having SUP or mental health conditions – wish to be involved in decision-making (shared or informed). However, it is necessary to consider individuals' preferences for participation (Friedrichs et al., 2018; Liebherz, Härter et al., 2015; Liebherz, Tlach et al., 2015). Qualitative research has also indicated that users generally want to be involved in decision-making processes. For example, Wenaas and Bahl et al. (2021) found that most participants emphasised their desire to be involved in the decision-making processes before and during treatment. Nevertheless, research has also shown that users with SUP devalue their own knowledge in favour of staff knowledge, limiting their will to engage in decision-making (Fischer & Neale, 2008).

A review of randomised clinical trials within the mental health field involving substance use demonstrated that providing user-preferred support reduces drop-out rates (Windle et al., 2020). A quantitative study also found that user participation increased satisfaction and perceptions of achieving treatment goals among individuals with drug use (Brener et al., 2009). As shown in the review by Selseng et al. (2021), it is important for staff to foster users' feelings of being heard, respected and informed in the decision-making process. Feeling heard and respected can help users understand difficult decisions, such as those related to involuntary treatment, as shown in a qualitative interview study (Thomas et al., 2018). User participation also supports the recovery process, with one review indicating improved wellbeing for individuals with alcohol-use disorders (Hell & Nielsen, 2020). Wenaas and Bahl et al. (2021) also showed that, when users are involved in decision-making regarding their own treatment, they are likely to take more responsibility for their recovery process. In addition, a qualitative interview study showed that participation can empower users with comorbidity (Bendtsen Kronkvist et al., 2023). Furthermore, experiences of not feeling heard, respected or informed can negatively impact users' perceptions of the support they receive and their interactions with staff (Bendtsen Kronkvist et al., 2023; Thomas et al., 2018; Wenaas, Andersson et al., 2021).

User experiences of their participation in services

A significant body of qualitative research with users as participants has revealed paternalistic attitudes towards users and a lack of involvement in decision-making and support planning for individuals with comorbidity (Bendtsen

Kronkvist et al., 2023; Wenaas, Bahl et al., 2021; Wenaas, Andersson et al., 2021; Fischer & Neale, 2008). The review by Selseng et al. (2021) described users reporting that staff often displayed negative or unsympathetic attitudes, held stereotypical views or made the users feel judged, dismissed or ignored. Bendtsen Kronkvist et al. (2023) also showed that there were limited instances of systematic user involvement in support decisions, with power imbalances and staff making decisions without user input. Even when users felt understood, they reported lacking a ‘real role’ in decision-making and perceived tokenism, with staff asking for preferences for appearances’ sake but not considering such preferences when planning support.

Research has shown that users feel ‘lucky’ when they encounter staff members who truly listen to and involve them (Bendtsen Kronkvist et al., 2023). Users perceive their knowledge and inputs to be undervalued, with staff knowledge dominating the support planning process (Wenaas, Andersson et al., 2021) and decision-making processes (Fischer & Neale, 2008), and they often sense a lack of trust from staff (Bendtsen Kronkvist et al., 2023). A lack of staff knowledge and insufficient information on treatment options are also experienced by users, which limit users’ opportunities to make informed decisions and engage meaningfully in decision-making and treatment (Wenaas, Bahl et al., 2021; Wenaas, Andersson et al., 2021).

Barriers to the realisation of user participation

In line with the above reports of users’ experiences, the literature highlights both structural and individual barriers to user participation. Structural barriers include time constraints (Bromark et al., 2022; Laitila et al., 2018) and conflicts between user participation and organisational demands (Bromark et al., 2022; Matscheck & Piuva, 2022a). In the context of CIP, discussions about responsibilities and costs between providers may take precedence, limiting users’ opportunities to influence the coordinated planning. However, staff also have a responsibility to advocate for user support (Matscheck & Piuva, 2022a). Bromark et al. (2022) used future workshops to explore obstacles and co-create solutions together with staff in social services. The scholars demonstrated how legislation and routines can limit staff discretion in advocating for user participation, restricting staff’s ability to involve users in decision-making processes. In addition, Björk (2019) reported that decision-making within social services is often shaped by organisational rationales – particularly financial considerations. As a result, staff are constrained by organisational priorities, which can prevent them from making certain decisions independently.

Other researchers have pointed out that a lack of available and accessible treatment options, due to limited financial resources, reduces user participation in decision-making (Fischer & Neale, 2008). While increasing resources could increase user participation, it would not ensure improvement as long as users and staff are not actively engaged (Fischer & Neale, 2008). Recent research has emphasised the importance of staff commitment in facilitating user participation (Bendtsen Kronkvist et al., 2023). Thus, meaningful participation requires the commitment of both users and staff, emphasising the need to address individual-level barriers as well as organisational-level ones. Grim (2019) has illustrated that staff attitudes can serve as a barrier to user participation in services if they, for example, lack trust in users as knowledge bearers and in their ability to participate.

The impact of comorbidity on decision-making abilities can be another individual-level barrier to user participation. While addiction is sometimes viewed as a brain disease with compulsive traits (Heilig et al., 2021), most individuals with addiction can make good choices most of the time. However, the risk of making harmful decisions – including those with life-threatening consequences – remains, even when better options are available (Heilig et al., 2021). Qualitative studies with users as informants have shown that comorbidity can impair users' ability to process information, evaluate alternatives and make decisions (Thomas et al., 2018; Wenaas, Bahl et al., 2021; Wenaas, Andersson et al., 2021). Therefore, users may need support to participate in decision-making processes. For instance, Grim (2019) demonstrates that the willingness and ability to participate largely depend on receiving sufficient opportunity, encouragement, and support. Furthermore, it is necessary for staff to have strategies for providing information, since receiving information is vital for active user participation (Wenaas, Bahl et al., 2021; Wenaas, Andersson et al., 2021). This involves both using 'plain language' (Wenaas, Andersson et al., 2021) and having alternative ways of providing information (Wenaas, Bahl et al., 2021).

Other barriers to user participation include emotional manipulation by users linked to substance cravings, as users may place their personal needs above those of other people or lie (Khedr et al., 2023). However, users may also fear judgment or negative consequences when they are honest about their substance use, underscoring the importance of clear communication from providers (Farber, 2020). Research has shown that users may withhold information; this may be a consequence of meeting several members of staff at the same time, for example, which can lead to users feeling overwhelmed. Users have also been reported to

express fear of potential consequences for speaking up, which can limit their engagement in decision-making (Wenaas, Andersson et al., 2021).

Ethical dilemmas can arise when determining whether an individual requires temporary mandatory care, which some suggest may support an individual's autonomy during periods of limited decision-making abilities due to substance use. The autonomy of individuals with substance dependence has also been questioned, as their condition may influence their choices and behaviour (Caplan, 2006). Nevertheless, research has demonstrated that users with comorbidity are often insightful and aware of their periods of reduced decision-making capacity (Thomas et al., 2018) and their difficulty processing information (Wenaas, Bahl et al., 2021). Fischer and Neale (2008) have argued that, while some constraints on user participation in decision-making are inevitable and perhaps even necessary within the comorbidity field, user participation is still important in these processes. An article by Nykänen (2020) described a need for more knowledge on how user participation can be implemented in services.

Shared decision-making as a method to promote user participation

In a randomised controlled trial, Hell et al. (2021) positioned decision-making on a spectrum from paternalism (i.e. providers decide for users) to informed decision-making (i.e. users choose based on provided information). SDM lies between these extremes. Elwyn et al. (2010, p. 971) have described SDM as follows:

Shared decision making is an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them. Shared decision-making respects patient autonomy and promotes patient engagement.

Elwyn et al. (2012) have stressed that SDM involves collaborative discussions, in which both staff and users share knowledge and evaluate options together. In their later work, Elwyn et al. (2014, 2017) underscored that SDM should be seen as an ongoing process rather than a single event. Other scholars have emphasised that SDM recognises users as equal contributors of

knowledge alongside staff in the decision-making process (Knutsson & Schön, 2020).

Fisher et al. (2021) noted that research on SDM for users with comorbidity is an emerging area, particularly in comparison with its more established application in mental health or cancer treatment settings. Their review synthesised 10 qualitative and quantitative studies, highlighting that SDM can enhance user involvement, support user autonomy and encourage a more active user role in decision-making, ultimately improving the quality of the decision-making process and decisions made. These findings align with those in reviews by Friedrichs et al. (2016) and Marshall et al. (2022), who identified promising results for SDM in the context of substance use but stressed the need for further research in this field. Chmielowska et al. (2023) have also identified the need to explore SDM in broader contexts beyond the patient-doctor relationship in the field of mental health research, including substance use. In addition, Andersson et al. (2024) described a need for more knowledge of frontline staff perceptions of using SDM in CIP.

Thomas et al. (2018) have highlighted SDM as a crucial element for quality care in crisis situations related to comorbidity. In their work, users valued clear information on next steps, discussions on treatment options and the opportunity to feel heard and respected, while striving to reach a shared understanding. However, crises could limit users' ability to consider treatment goals and options. Nevertheless, transparent communication and ongoing discussions were viewed as key strategies to support decision-making outside of crises. In addition to its promising outcomes in practice, SDM has been advocated for based on other rationales, such as adherence to legislation on user participation (Nykänen, 2020), ethical principles (Elwyn et al., 2012; Nykänen, 2020) and the integral role of SDM in EBP. Since there is some concern that research uptake may be overemphasised when applying EBP (Davies & Gray, 2017; van der Zwet, 2018), it has been proposed that SDM and EBP complement each other, with SDM helping to counterbalance the focus on research by placing a greater emphasis on individuals and their needs (Hoffmann et al., 2014; Páez et al., 2021).

Implementation of shared decision-making

In their review, Verwijmeren and Grootens (2023) explored barriers to implementing SDM in psychiatric care, identifying challenges at the micro, meso and macro levels. At the micro level, users' decision-making abilities and low self-esteem can hinder participation, as uncertainty about one's abilities may reduce one's motivation to participate in the decision-making process. The

relationship between staff and users is also important, with mutual trust and a shared understanding of problems and goals being essential. Additional barriers include time constraints, staff turnover disrupting continuity of care, and staff's limited knowledge of treatment options, which can restrict the information available to users. At the macro level, stigma surrounding mental illness and restricted access to support services further impede SDM. Fisher et al. (2021) examined implementation outcomes besides the impact on the decision-making process and concluded that, while SDM appears to be feasible, acceptable and beneficial, further research is needed within the comorbidity field.

A process evaluation from a staff perspective of SDM within services showed that community mental health staff aimed to protect users from making self-destructive decisions or facing information overload, often by limiting users' options to just one and thereby reducing the opportunity to realise user participation (Schön et al., 2018). Grim (2019) described this protective approach as a 'logic of care' in which staff members restrict users' choices to prevent false expectations, excessive responsibility or overwhelming information. However, this logic acts as a barrier to staff and user collaboration. Furthermore, a randomised factorial survey that included five vignettes with staff showed that staff could be less willing to support user autonomy and SDM during the decision-making process in cases of users with comorbidity. Hence, the severity of a user's condition affects staff's support for the user's autonomy and engagement with SDM. Moreover, staff attitudes towards user autonomy play a significant role in the use of SDM, indicating that both user and staff characteristics influence SDM use in practice (Lukens et al., 2013).

Andersson et al. (2024) conducted a stakeholder analysis prior to SDM implementation in CIP, revealing both supportive and hindering factors. Management staff viewed SDM positively, particularly for enhancing user participation and structure. However, they also identified significant challenges, including the complexities of CIP, difficult working conditions and collaboration barriers. Key obstacles included staff's lack of knowledge, confidence, time and continuity, alongside differing organisational cultures and mandates. The literature on implementation in collaborative settings involving social services and their partners highlights both barriers and facilitators. At the organisational level, longitudinal mixed-methods studies have identified challenges such as poor collaboration within and between organisations, high staff turnover and limited financial resources (Bergmark et al., 2018, 2019). A process evaluation of SDM in services also reported a lack of structural support during implementation (Schön et al., 2018). At the individual level, barriers included a

perceived lack of incentive to change established practices when current methods were yielding positive outcomes (Bergmark et al., 2019). Facilitators for translating knowledge into action in collaborative settings comprise thorough preparation, including plans for internal and external collaboration, networking and supportive structures (Bergmark et al. 2018, 2019; Schön et al. 2018). The presence of external experts and internal facilitators with dedicated time has also been identified as a facilitator (Bergmark et al. 2019; Schön et al. 2018). Moreover, the importance of organised collective reflection on practice – more specifically, critical reflection to challenge taken-for-granted knowledge and routines – has been identified as important in relation to integrating knowledge in practice (Avby & Melke, 2023).

Support for individuals with comorbidity

Given the severity of comorbidity, the need for ongoing support has been emphasised in previous research. For example, a retrospective cohort study by Watkins et al. (2016) demonstrated that sustained support reduced mortality rates, while a longitudinal cohort study by Costello et al. (2019) showed that continued engagement after inpatient substance-use care increased the likelihood of abstinence. Additionally, a 16-year follow-up by Drake et al. (2020) showed that evidence-based integrated treatments improved users' health, despite the severe initial nature of their comorbidity. Nevertheless, a discrepancy exists between the number of individuals with comorbidity and those receiving support for it (Han et al., 2017). A review by Priester et al. (2016) identified both user-related and structural barriers to treatment for individuals with comorbidity. User characteristics included vulnerability due to mental illness, cognitive impairments, psychosocial instability, distress and a lack of motivation, energy or ability to seek support. A lack of trust in institutions and fear of seeking help also play a role. Structural barriers include the absence of specialised services, insufficient staff knowledge, long waiting times and a failure to identify and treat both conditions.

A continuum has been identified from the separation of support to its integration, with coordination and collaboration as intermediate stages (Grell et al., 2013). *Integrated care*, in which users receive simultaneous treatment for both mental illness and SUP from the same team, has long been regarded as the best practice for individuals with comorbidity (Mueser et al., 2003). However, falling closer on the continuum to separation than to integration, *coordination* involves organisationally separate actors jointly planning support while maintaining their distinct responsibilities (Grell et al., 2013). In Sweden, CIP is a legislated process for coordinating support, and it has been suggested that CIP

can be used to address fragmentation due to separation between service providers (Matscheck et al., 2019).

The implementation of CIP in practice has brought challenges. In Sweden, research on CIP involving users with comorbidity has primarily been conducted by Matscheck and Piuva and their colleagues, focusing on the roles of staff and users in the process. For example, these scholars have highlighted that staff without formal decision-making authority often participate in CIP meetings (Matscheck et al., 2019) and have pointed out, along with other researchers, the lack of a structured process, with insufficient attention being given to preparation and follow-up (Knutsson & Schön, 2020; Matscheck & Piuva, 2022b; Matscheck et al., 2019). Additionally, CIP is inconsistently applied in practice, depending on professional discretion (Matscheck et al., 2019), and the literature reports a lack of knowledge about CIP (Andersson et al., 2024). Furthermore, Larsson et al. (2019) investigated staff perspectives on inter-organisational collaboration for individuals with complex needs and found that municipalities, primary care and hospitals rated their own collaboration abilities more highly than those of others, often attributing poor collaboration to external parties.

Research indicates that the legislation of CIP has not achieved its intended outcome of enhanced user participation (Matscheck & Piuva, 2022a, 2022b; Matscheck et al., 2019). It also shows that users' needs are often seen as secondary to providers' responsibilities and costs. The dual role of staff – who support individuals while gatekeeping organisational resources – affects users' opportunities to actively participate in the CIP process and increases the risk of users being caught between providers (Matscheck & Piuva, 2022a). This lack of user involvement has also been observed internationally. For example, Wenaas and Andersson et al. (2021) described a similar absence of user involvement in interprofessional meetings in Norway. Overall, there is a recognised need for more knowledge of user and staff perceptions of how the user participation that CIP is intended to facilitate can be realised in practice (Matscheck & Piuva, 2022b). Matscheck et al. (2019) have questioned whether CIP can address the challenges of supporting users with complex needs, or whether insufficient organisational support and other factors will limit its effectiveness. They suggest that alternative strategies – such as working in multi-professional teams – may be needed for users who need integrated support, rather than just having their support coordinated. However, the scholars also noted that CIP can facilitate essential processes for successful collaboration.

Rationale

The importance of user participation is well established in both policies and research, along with the need for coordinated, individualised support for users with comorbidity who face multiple risks of deteriorating health and social situation. Despite these intentions, the implementation of user participation in decision-making processes remains limited in the field of comorbidity, with research highlighting challenges at both the organisational and individual levels.

Hence, there is a gap between the intention to promote user participation outlined in policies and research and how it is implemented in decision-making processes in practice. This applies to intentions about user participation in social services and psychiatric care in general and in the context of CIP more specifically. However, it is unclear what user participation actually entails and how it is understood in the comorbidity field of practice. It is especially important to include users' perspectives in order to expand the understanding of user participation. There is also a need for more knowledge on users' and staff's perceptions of how the user participation that CIP is intended to support can be realised in practice. SDM is a promising approach designed to enhance user participation in decision-making processes. However, research on SDM in the context of comorbidity remains in its early stages, and there is a particular need for insights beyond traditional doctor-patient interactions. It is also necessary to focus on the broader decision-making process rather than on isolated decisions. It should be noted that CIP is a decision-making process that involves several members of staff in addition to users.

To narrow the gap between policy and research on the one hand and practice on the other in services directed towards users with comorbidity, this thesis aims to explore how user participation is understood and can be facilitated in the context of CIP. A deeper understanding of user participation and its facilitation advances knowledge in the field of comorbidity and is essential for a realisation of user participation in practice.

Aim and research questions

The overall aim of this dissertation is to explore how user participation is understood and can be facilitated for adults with comorbidity, in the context of CIP.

The following questions are explored:

Study 1: How do people with comorbidity perceive participation in social services?

Study 2: What were staff members' perspectives on problems and solutions regarding user participation, SDM and coordination of support in CIP processes?

Study 3: What barriers and facilitators did staff perceive during the implementation of the revised CIP process that involves SDM?

Study 4: How did users and staff experience using the revised CIP process that incorporates SDM?

Theoretical perspectives

Aligning with a social constructionist perspective (Burr, 2025), this dissertation explores how user participation is understood and can be facilitated. Burr (2025) has emphasised that a core aim of social constructionism is to deconstruct power hierarchies and dismantle the structures that sustain them. Similarly, this dissertation seeks to challenge power imbalances between staff and users by addressing structures that enable injustice, in order to promote the realisation of user participation. Power asymmetries in services – such as staff controlling resources while users remain dependent on resources – have long been recognised (e.g. Hasenfeld, 1992; Lipsky, 1979/2010). Even well-intentioned professionals may unknowingly reinforce these imbalances by prioritising institutional agendas and their own expertise as the most valid understanding of a situation. This often marginalises user perspectives and excludes users as knowledge contributors (Lee et al., 2019). Such dynamics reflect Fricker’s (2007; Swedish translation, 2018) concept of epistemic injustice, which highlights how individuals or groups are systematically denied recognition as knowledge bearers.

Several scholars have expanded on Fricker’s ideas, including Hookway (2010) on participatory injustice and Grasswick (2018) on epistemic trust injustice. This section outlines these perspectives as a theoretical lens for this thesis.

Epistemic (in)justice: Users as knowledge bearers

Fricker (2018) defines *epistemic injustice* as wrongs done to an individual in that person’s capacity as a knower, where prejudice prevents the individual from being recognised as a knower. The two initial forms of epistemic injustice outlined by Fricker are testimonial injustice and hermeneutical injustice. Initially, these injustices were linked to factors such as gender and ethnicity (Fricker, 2018). However, recent literature has expanded this understanding to include individuals with mental illness (Grim, 2019). Within the field of mental health, other researchers have also highlighted the importance of users

being heard, viewed as credible and taken seriously (Kurs & Grinshpoon, 2018). In other words, users need to be perceived as reliable sources of knowledge and capable ‘epistemic subjects’ (Fricker, 2018; Nouf & Ineland, 2023), in line with epistemic justice.

When an informant’s trustworthiness is unfairly judged based on that person’s social identity, this constitutes a *testimonial injustice*, in which members of marginalised groups are more often perceived as less trustworthy. Testimonial injustice involves an informant’s capacity to share and provide knowledge not being recognised or valued and the individual not being taken seriously. This lack of trust can undermine the informant’s confidence in future interactions (Fricker, 2018). Individuals from marginalised groups may also experience *hermeneutical injustice* when their ability to interpret and communicate their experiences is obstructed by a collective lack of appropriate concepts or hermeneutical resources. This occurs when the experiences of these groups are excluded from broader sense-making practices, while those of dominant groups are prioritised (Fricker, 2018). Mason (2011) argues that hermeneutical injustice can take two forms: either there is a collective lack of hermeneutical resources, preventing marginalised groups from fully understanding and articulating their experiences, or these groups do possess the necessary resources but find their interpretations dismissed by others who privilege dominant frameworks. Kidd and Carel (2017) link the latter to situations in which individuals with mental illness, for example, describe their condition in non-medical terms and are disregarded as merely being subjective or complaining.

Over time, various forms of epistemic injustice have been elaborated on. One such variation is discussed by Hookway (2010), who examined an injustice in which individuals are prevented from participating in knowledge-enhancing practices due to prejudice. Kwong (2015) terms this type of injustice *participatory injustice*. Hookway (2010, p. 156) explains that participation is not merely about exchanging information but involves asking questions, proposing ideas and considering alternative possibilities. He argues that participatory injustice differs from testimonial and hermeneutical injustice because it does not occur during ‘testimonial exchanges’ (ibid., p. 153). For instance, asking a question is not an act of knowledge expression *per se*, but it can move the discussion forward, enriching the knowledge and understanding of a topic. Being recognised as a competent participant, therefore, also involves being trusted to carry out activities that contribute to the solution of a problem.

When individuals experience participatory injustice, their contributions to discussions are dismissed due to prejudice, preventing them from collaboratively

exploring, discussing and enhancing knowledge and understanding. This type of injustice silences individuals by failing to recognise them as valuable contributors to the conversation. Like testimonial injustice, participatory injustice can diminish an individual's confidence in participating in such discussions, further marginalising that person (Hookway, 2010).

Another scholar that draws upon Fricker's theory of epistemic injustice is Grasswick (2018), who expands on the concept of epistemic trust. *Epistemic trust* refers to an individual's willingness to place trust in another person's knowledge claims. Interpersonal trust is essential for gaining knowledge, as it allows us to rely on others' expertise and insights. Epistemic trust is built over time through interactions that involve a broad spectrum of knowledge; it is significant to our understanding of ourselves, our wellbeing and life in general. However, this trust makes us vulnerable, which is why it must be placed responsibly; one should not trust indiscriminately or without critical evaluation (Grasswick, 2018).

Grasswick (2018) argues that key aspects in establishing epistemic trust are the informant's competence and sincerity/care. Competence goes beyond having the relevant expertise; it encompasses qualities such as gathering and filtering information, making informed judgments, managing public resources responsibly and avoiding unethical practices in the pursuit of knowledge. In other words, trusting someone's knowledge claims also involves trusting that person's competence in acquiring and conveying knowledge. Sincerity/care refers to the ethical dimension of the relationship and the attitude towards the trusting party. For example, in a physician-patient relationship, the patient trusts not only that the physician is sincere in sharing information but also that the physician will provide all the necessary and relevant details to support the patient in making an informed decision, with the patient's interests being prioritised over other possible competing interests (Grasswick, 2018).

When a trust-based relationship has been successful in the past, knowledge can be shared without needing to question the other party's competence and sincerity. However, when there is a history of negative interactions, it can shape present and future dynamics, leading the trusting party to be more cautious or distrustful. In this case, the trusting party may either reject the knowledge claims or continue to trust in hope of improving the relationship. If there is a history or present lack of competence or sincerity/care, there is insufficient basis for responsibly placing trust, which hinders the trusting party's ability to gain significant knowledge in a responsible way. Epistemic trust injustice occurs when the conditions for responsible trust are not met,

resulting in the trusting party being obstructed from acquiring valid and meaningful knowledge (Grasswick, 2018).

The application of the framework of epistemic (in)justice in this dissertation

The framework of epistemic (in)justice underscores the importance of viewing users as trustworthy collaborators, with their perspectives and understanding being integrated into decision-making processes. For this to happen, users must receive significant knowledge from staff, which requires users to be able to trust in the competence and sincerity/care with which staff members provide this knowledge. It also involves users being recognised as participants throughout the CIP process, trusted to carry out activities that can contribute to solutions, such as gathering information and asking questions. In this dissertation, the concept of *participatory injustice* is understood as a user being prevented from being an active participant in the CIP process, whereas *testimonial injustice* is understood in relation to a user being devalued within informational exchanges. *Hermeneutical injustice* is understood in terms of a user being excluded from contributing to a shared understanding of that user's situation, and *epistemic trust injustice* is understood in relation to staff members' competence and sincerity/care in providing users with information. The various forms of epistemic (in)justice described are applied in this thesis in the discussion of the results in order to gain a deeper understanding of how user participation is understood and can be facilitated throughout the CIP process.

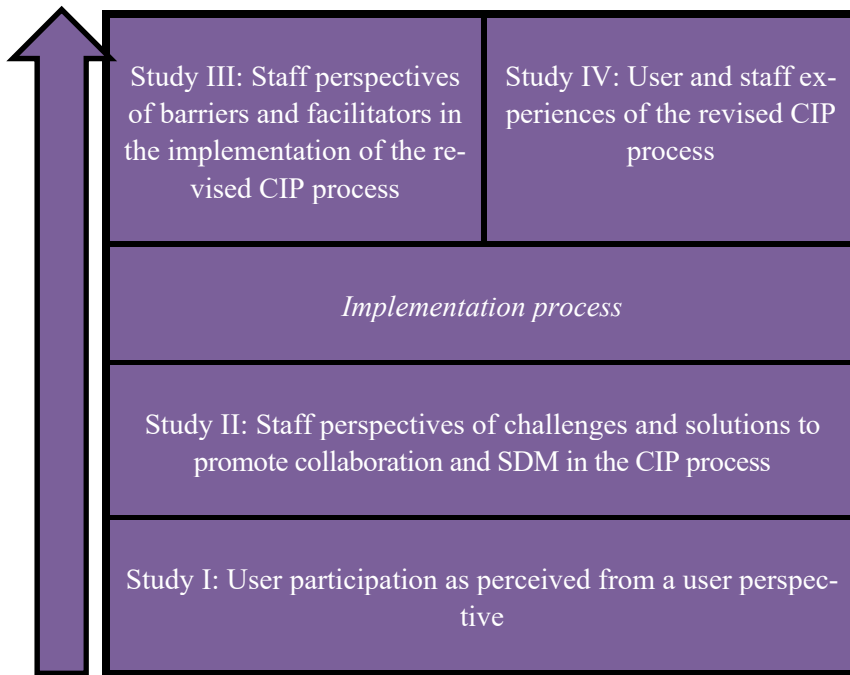
Methods

This chapter presents the design and methods used throughout the dissertation. It begins with an overall description of the studies, followed by an outline of the settings and design. Thereafter, it describes the recruitment of participants, data-collection strategies and analysis procedures. The chapter concludes with a discussion on methodological considerations, including my position and knowledge view and the trustworthiness of the findings. It also describes the limitations and strengths of the research procedure.

The studies

This dissertation consists of four studies and a cover story (*kappa*). As the overall aim of the dissertation is to explore how user participation is understood and can be facilitated, the first study (Study I) explored how user participation is perceived from a user perspective. Next, the focus shifted to the specific context of CIP and how user participation is understood and can be facilitated in this context. First, staff perspectives of challenges and solutions to promote collaboration and SDM in the CIP process (Study II), followed by an exploration of the implementation of a revised CIP process (Studies III and IV). In addition to exploring how user participation can be facilitated, the implementation of the revised CIP process provided knowledge on how user participation is understood. Overall, carrying out the studies was a cumulative process, in that the earlier studies influenced the design and research questions of the later ones. The connection between the studies is best understood by considering Study I as a basis upon which Studies II–IV were built (Figure 1).

Figure 1. Illustration of the logic of the relation between the studies.



The different aims and methods of each study are elaborated in Table 1.

Table 1. Overview of the studies included in this dissertation.

	Study I	Study II	Study III	Study IV
Aim	To explore how users perceive participation in social work encounters through a grounded theory approach	To examine what staff identify as challenges and solutions to promote collaboration and SDM in the CIP process	To explore staff perceptions of contextual barriers and facilitators in the implementation process of SDM within CIP	To explore user and staff experiences of using a revised CIP process that involves SDM
Design	Constructivist grounded theory	Future workshops; present-and-future story workshops	Inspired by qualitative dominant sequential explanatory mixed-methods (quan→QUAL)	Individual interviews with users and staff
Recruitment and participants	Convenience sampling; 12 participants, users	17 participants, staff who participated in the workshops	Convenience sampling; 101 + 36 questionnaires, staff 27 participants in interviews, staff	Convenience sampling; 5 users and 8 staff
Data collection and analysis	Qualitative semi-structured interviews: an inductive approach to analysis was used, as recommended in grounded theory	Data consisted of staff perceptions, written on sheets of paper during workshops carried out previously by Knutsson and Schön (2020); the collected data was analysed using inductive content analysis	<i>Quantitative:</i> Questionnaires were given at two time points and analysed descriptively <i>Qualitative:</i> Semi-structured individual and focus group interviews; collected data was analysed using deductive content analysis	Semi-structured individual interviews with users and staff; collected data was analysed using thematic analysis

Settings and designs

All studies were conducted in Sweden and involved individuals with comorbidity and/or staff within social services and healthcare who provide support to users with comorbidity. The specific settings varied across the studies. In Study I, interviews with users were conducted in different parts of Sweden.

The workshops providing the data used in Study II were carried out by other researchers (Knutsson & Schön, 2020) in a single region and involved two municipalities. The implementation of the revised CIP process in Studies III and IV was carried out in a different region and involved three municipalities. The sites in Studies II and III/IV were recruited by emailing management within social services to inquire whether they would be willing to participate in the research. Next, the management of healthcare was emailed to inquire about participation at the same locations the social services had already agreed to participate. At all the locations the management of social services had agreed to participate, the management of healthcare also agreed to participate.

In line with a social constructionist perspective (Burr, 2025), qualitative methods were primarily employed in the studies in order to explore how user participation is understood and can be facilitated in the context of CIP. Study III incorporated questionnaires to give broader insight into staff perceptions. As the studies had different designs and two involved an implementation process that requires further elaboration, the studies, their designs and the rationale behind these choices are outlined below.

Study I

To explore how people with comorbidity perceive user participation in social services, a constructivist grounded theory (CGT) approach (Charmaz, 2014) was used in Study I to construct a model of users' perspectives on user participation. CGT was chosen because it permits a deep exploration of processes and the construction of frameworks of topics that have been the subject of limited research (Charmaz, 2014).

Study II

Prior to this study, workshops had been held by the co-authors of Study II, Knutsson and Schön (2020), among staff members of social services and healthcare in the context of comorbidity. To explore staff perspectives on challenges and solutions regarding user participation, SDM and collaboration in CIP processes, data from these workshops was used as the empirical material

for Study II. Among the various types of workshops that exists, future workshops (Kensing & Madsen, 1992) and present-and-future stories workshops (Knutsson & Schön, 2020) produced the data used in this study. *Future workshops* involve future users of a product and capture their perceptions of problems and solutions – in this case, regarding the different steps in the current CIP practice and user involvement in this practice. In *present-and-future stories workshops*, researchers share their interpretations of the participants' views on problems and solutions with the participants. These two workshop formats complement each other well, as the data collected during future workshops can be shared with participants in subsequent present-and-future stories workshops and checked for accuracy. Hence, the workshops were held on two occasions by Knutsson and Schön (2020): first, a future workshop in which data was collected; and second, a present-and-future stories workshop in which Knutsson and Schön's (2020) interpretations of this data were presented and the participants undertook further discussion on problems and solutions for an improved CIP process.

Studies III and IV

To gain a deeper understanding of how user participation is understood and can be facilitated throughout the CIP process, Studies III and IV explored the implementation process and experiences of using the revised CIP process with SDM.

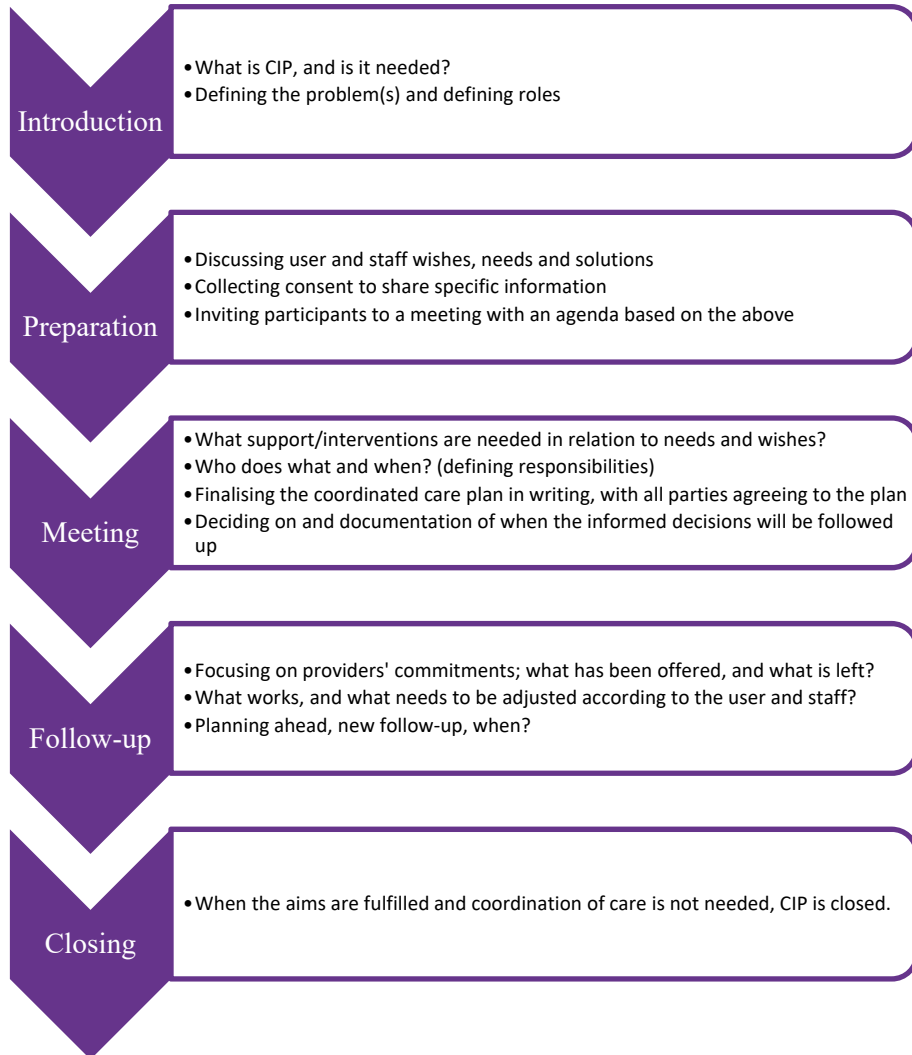
The innovation and implementation

Prior to the implementation process in this dissertation, Knutsson and Schön (2020) worked with users and staff within the comorbidity field of practice to co-create a CIP process that involves user involvement and SDM. In this dissertation, this CIP process is referred to as 'the revised CIP process'. The revised process adjusts the way in which CIP is applied in practice by addressing problems with the current application of CIP such as the lack of user participation and deprioritisation of preparation and follow-up. Figure 2 provides an overview of the steps in the revised CIP process.

The key adjustments made in the revised process highlight the importance of preparing for a CIP meeting in order to facilitate user participation and of ensuring a follow-up. During the preparation, staff members engage in discussions with both the user and each other. Ongoing discussions among all parties are central to this revised CIP process; in these discussions, information and knowledge regarding topics such as treatment options are shared to support

SDM. Thus, the core component of the revised process is continuous knowledge sharing through every stage of the process.

Figure 2. The revised CIP process incorporating SDM



The revised CIP process also incorporates a new documentation approach: a co-created CIP form designed both to facilitate the core components of SDM and to document the CIP process. This new form for documentation states that staff should provide users with information on different options and encourages a discussion of these options with the user. This information is written

down and shared with the user. For details on the development of the CIP process and the CIP form, see Knutsson and Schön (2020).

Three different sites participated in the implementation of the revised CIP process, with staff drawn from both social services and healthcare. The implementation strategy included joint staff training, external support, distribution of a visual step-by-step guide of the revised CIP process and encouraging each site to appoint an implementation facilitator. The training involved a presentation of CIP and SDM, and staff roleplaying the revised CIP process. The staff participating in the training varied: at two sites, both management and front-line staff took part; at the third site, only front-line staff were involved. The front-line staff held various roles, including social workers, housing supporters, nurses, assistant nurses and physicians. Management staff determined which staff and units would participate in the training, based on the criterion of working with individuals with comorbidity.

Study III focused on the barriers and facilitators staff perceived during the implementation of the revised CIP process, while Study IV explored the experiences of users and staff in using the revised CIP process. More specific descriptions are provided below.

Study III

To describe and explore barriers and facilitators during the implementation of the revised CIP process, Study III employed a design inspired by a qualitative dominant sequential explanatory mixed-methods (quan → QUAL) design (Creswell & Plano Clark, 2017). A mixed-methods design was chosen because it allows for both describing staff's perceptions of the implementation process over time and deeply exploring these perceptions. However, specific cases could not be explored, despite being recommended in a quan → QUAL design, due to collected data not allowing for this.

Study IV

To explore user and staff experiences of using the revised CIP process, a qualitative study was conducted using semi-structured individual interviews with users and staff. These interviews permitted data collection on specific topics while offering flexibility in the process (Polit & Beck, 2021).

Recruitment and participants

Participants for all studies were recruited through convenience sampling (Polit & Beck, 2021), meaning that participants who were available and eligible were recruited to participate. The sampling was therefore based on users' and staff members' willingness to participate rather than on a purposive selection of individuals. Table 2 shows the number of participants in each study and their workplace, if staff.

Table 2. Number of participants in each study

Study	Users	Social services staff	Healthcare staff	Total
I	12	—	—	12
II	—	12	5	17
III, first questionnaire	—	76	23	101*
III, second questionnaire	—	34	2	36
III (Qualitative data collection)	—	21	6	27
IV	5	6	2	13

*Two participants did not answer the question regarding which organisation they worked at.

As shown in Table 2, users participated in Studies I and IV, with 12 users participating in Study I and five in Study IV. The eligibility criteria for users were being between 18 and 65 years old, having comorbidity and not actively engaging in substance use. Having a formal diagnosis was not set as an inclusion criterion. As noted in previous research, there is a risk of comorbidity being unidentified (Priester et al., 2016), so the decision was made to include individuals based on self-assessment, staff assessment and/or formal diagnoses.

In Study I, users were recruited with the help of staff in social services and healthcare and through user organisations. Participants were sought based on their experience of having had contact with social services or healthcare due to comorbidity, such that they could share their views on user participation in this context. In Study IV, users with experience of the revised CIP process were recruited by staff, who asked them after a CIP meeting whether they

were interested in participating in the study. In both Studies I and IV, the contact details of users who expressed interest in receiving more information regarding the study were forwarded to me. When the users were contacted for the first time, they were provided with information, and a time for an interview was scheduled, if the user agreed to participate.

The participating users had extensive experience with inpatient treatment, outpatient treatment and housing support. Some had a formal diagnosis, while others were suspected by both themselves and staff to have a condition. The types of (diagnosed or suspected) mental illnesses reported varied and included depression, anxiety, post-traumatic stress disorder (PTSD) and bipolar disorder. Participants also experienced ADHD, ADD and autism. Additionally, some had a comorbidity of mental illness and ADHD or ADD and substance use. There was variation in substance use related to drugs and/or alcohol.

As shown in Table 2, staff members participated in Studies II, III and IV. The eligibility criteria for staff were working within social services or healthcare and engaging with adult users who have comorbidity. The staff involved in the studies had worked in various units across social services and healthcare. For example, the staff in social services had worked in units for SUP, financial assistance and domestic violence, while the staff in healthcare had experience in primary care and specialised psychiatric care. Due to ethical considerations and the risk of identifying individual staff members, given the low number of staff members from some units, specific details about the number of staff members from each unit are not provided.

In Study II, a total of 17 staff members (12 from social services and five from healthcare) participated in the workshops. During the workshops, the participants were divided into groups, and an iterative process of individual work and group discussions took place. The staff participating in the workshops had different roles, such as social workers, housing supporters and nurses.

Study III involved questionnaire data and interviews. The first questionnaire was distributed at the staff training for the revised CIP process, and the follow-up questionnaire was sent out 6 months later, with the assistance of facilitators and managers (i.e. contact people). Reminders were sent until 8 months after training. Of the 118 staff members who participated in the training, 101 responded to the questionnaire. However, the response rate for the follow-up questionnaire was relatively low ($n = 36$) of which 11 only answered the

follow-up questionnaire. Most participants were from social services compared with healthcare, as shown in Table 2.

In Studies III and IV, all staff working at the three sites implementing the revised CIP process were invited to participate in focus group or individual interviews. Staff were recruited through the contact person at each site, who arranged the time and location for the focus group interviews. These interviews included all staff members willing to participate; thus, both staff members who had used the innovation and those who had not could take part in the focus group interviews. A total of 27 staff members from social services and healthcare participated in interviews for Study III – nine in individual interviews and 23 in focus group interviews. Some staff took part in both individual and focus group interviews.

Staff who participated in individual interviews for Study III and had used the revised CIP process were also included in Study IV, as they had experience and knowledge of its practical application. Of the nine staff members who took part in individual interviews for Study III, eight had practical experience of the revised CIP process and were asked about it in the interview. The staff interviewed in Studies III and IV had worked as social workers, nursing assistants, nurses and rehabilitation coordinators.

Data collection

Data for the dissertation was collected through interviews (Studies I, III and IV), workshops (Study II) and a questionnaire (Study III). A description of the intentions behind these data-collection strategies and how they were conducted across the studies is provided below.

Individual and focus group interviews

A combination of individual (Studies I, III and IV) and focus group interviews (Study III) was used to capture rich, complementary data. Individual interviews are known to provide depth and detail about individual participants' experiences and perceptions (Morgan, 1997), which was the aim of the individual interview studies. The research focus was on users' perceptions of user participation and what it entails (Study I); staff perceptions of barriers and facilitators in the implementation process (Study III); and user and staff experiences of using the revised CIP process (Study IV). Individual interviews were conducted both at locations chosen by the participants (Study I) and over

the telephone (Studies III and IV). The locations chosen by participants included offices, their place of residence and a user organisation. I conducted all individual interviews.

Focus group interviews are designed to collect data through the interaction between participants. In such interviews, participants are encouraged to ask each other questions and follow up on each other's statements, rather than only responding to questions posed by the researcher (Kitzinger, 1994). In Study III, the goal was to capture data through the interactions among individuals involved in the implementation process, as implementation is considered a collective undertaking. Therefore, focus group interviews were conducted, with the individual and focus group interviews in Study III being viewed as complementary. The individual interviews captured personal perceptions, while the focus groups facilitated a collective discussion.

Focus group interviews are known to capture more sensitive information than individual interviews (Guest et al., 2017). In Study III, the focus group interactions allowed the staff members to generally agree with one another, while also challenging each other's views and initial thoughts, thereby providing different perspectives on SDM and user involvement. The focus group interviews were conducted face-to-face at the participants' workplaces, and I conducted all but one of them alone. Ideally, a focus group should consist of four to eight participants, and there are benefits to working with pre-existing groups, as the participants will be familiar with each other and can relate in a different way (Kitzinger, 1995). In this study, all focus groups involved staff from the same workplace, although some worked in different units (e.g. financial support and the substance-use unit within social services). The groups typically consisted of four or five participants, with one group having three participants due to illness.

All interviews (Studies I, III and IV) were semi-structured, using interview guides with open questions to capture participants' perspectives. In a semi-structured interview, the interviewer can ask follow-up questions and encourage participants to elaborate on certain aspects. An interview guide provides structure, ensuring that key topics are covered, while allowing participants the freedom to express themselves in their own words (Polit & Beck, 2021). This flexibility makes semi-structured interviews ideal for capturing participants' perspectives, which was the intention in this dissertation. The interview guides used in the studies were designed to capture participants' perspectives in a structured yet flexible way.

In Study I, the initial interview guide (Appendix 1) focused on four central topics: participation, information, response (*bemötande*) and assessment; each topic was introduced with an initial broad question, followed by follow-up questions as needed and concluded with an open question to allow participants to add anything relevant to the central topic under discussion. Based on the analysis of the first interviews, the interview guide was revised. This arrangement is in line with CGT (Charmaz, 2014). The revised interview guide (Appendix 2) covered the same topics as the initial guide but incorporated additional questions within each topic to explore these further. Interviews 1–7 were conducted using the initial interview guide with central topics, and interviews 8–12 were held with a revised interview guide based on the coding of interviews 1–4.

In Study III, the interview guides for individual (Appendix 3) and focus group interviews (Appendix 4) were both guided by the Consolidated Framework for Implementation Research (CFIR), which includes five domains with several constructs (Damschroder et al., 2022). The domains of ‘innovation’, ‘individuals involved’ and ‘inner setting’ were selected as the basis for data collection and analysis in this dissertation. In addition, the interview guide was informed by the initial analysis of the quantitative data. During the individual interviews, staff with practical experience of the revised CIP process were asked about their experiences and the impact on themselves and users; this data was used in Study IV. In Study IV, the interview guide (Appendix 5) for the user interviews included questions on how the innovation was perceived and experienced, with follow-up questions about the different steps of the process and what the revised CIP process had led to for them.

After the interviews, they were transcribed verbatim either by me or a professional transcriber and subsequently analysed, as discussed later on.

Workshops

Workshops serve at least a threefold purpose within research: as a means, a practice and a research methodology (Ørngreen & Levinsen, 2017). The workshops that collected the data used in Study II were both used as a means to co-create the revised CIP process (Knutsson & Schön, 2020) and as a research methodology to collect data from staff regarding how they perceived challenges and solutions in CIP regarding collaboration, user participation and SDM. During the workshops, staff members were instructed to write down their individual thoughts on the different steps of the CIP process on sheets of paper and then discuss these in groups to further work on the challenges and

solutions in the CIP process. These discussions were jointly documented on large sheets of paper. All this written material constitutes the empirical data for Study II. Hence, the data for Study II was collected elsewhere (Knutsson & Schön, 2020).

Questionnaires

In this dissertation, a questionnaire was developed and distributed to staff at the beginning (Appendix 6) and during the implementation process (Appendix 7), allowing quantitative data to be collected at two different time points. Questionnaires are used to gather self-reported data (Polit & Beck, 2021). Questions in the questionnaire that were intended to assess the respondents' perceptions of the innovation's acceptability, appropriateness and feasibility (to capture the 'innovation' domain) were inspired by the Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM) and Feasibility of Intervention Measure (FIM) questionnaires developed by Weiner et al. (2017). Questions on capability, opportunity and motivation (to capture the 'individuals involved' domain) were derived from the Behaviour Change Wheel (Michie et al., 2011), which is referenced in the CFIR. Questions on the overall CIP collaboration and on the staff members' perceptions of users' readiness were also included (to capture the 'inner setting' and 'individuals involved' domains). In total, the questionnaires contained 11 Likert-scale questions, ranging from 1 (*Don't agree at all*) to 5 (*Agree completely*). In addition to the questions outlined above, the follow-up questionnaire included questions about whether the respondent had participated in the training and if the CIP form had been used.

Analysis

The different strategies used in this dissertation to analyse collected data are presented one by one below.

Study I: Grounded theory

In grounded theory, data collection and analysis are an iterative process in which data is collected and analysed in parallel (Charmaz, 2014). The grounded theory approach was used in this study, which allowed the interview guide to be revised during the data-collection processes to facilitate rich and illustrative categories. The software program NVivo was used for the analysis. During the coding process, I constantly moved back and forth between being

close to the data and considering the theoretical level. First, an initial coding was conducted based on the first interviews; this coding was mostly done *nvivo* (i.e. using the participants' own words), and small, tentative categories were constructed. When subsequent interviews were coded, re-categorisation was carried out, with new, tentative categories being constructed. The first interviews were then recoded based on this new coding. After that, the whole coding process was reviewed again for consistency, before the last interviews were coded.

A continuous memo-writing process and discussions with co-authors were carried out throughout this analysis process, in which categories and sub-categories were examined to determine whether (and how) they are linked, and some former sub-categories were combined. All interviews were read repeatedly to determine whether anything needed to be adjusted or any codes were missing. This process of memo writing and discussions shaped the model constructed in the analysis.

Study II: Inductive content analysis

As mentioned above, the data used in Study II was collected earlier by Knutsson and Schön (2020). After they collected data on paper in workshops, Knutsson and Schön entered it into a Word file and sorted it based on where in the CIP process staff had encountered challenges and proposed solutions. However, when I conducted an inductive content analysis (Elo & Kyngäs, 2008) on Knutsson and Schön's material in Study II, I found the information regarding where in the process staff had encountered challenges and solutions to be irrelevant. Instead, my analysis aimed to examine the staff members' overall perspectives, regardless of the stage of the CIP process. During the inductive content analysis, the material was coded and categorised using the software program NVivo. Initially, open coding was applied to all aspects of the material. During this process, codes were grouped into sub-categories based on their similarities. These sub-categories were then organised into main categories. This was an iterative process, with open coding being conducted concurrently as the categories were developed. Subsequently, all codes, sub-categories and main categories were discussed and revised together with Knutsson and Schön, who were the co-authors of Study II.

Study III: Descriptive statistics

Collected quantitative data can be analysed in several ways (Polit & Beck, 2021). In this dissertation, the analysis was descriptive, with a focus on the

proportion of staff within each group, and comparisons were made between the first questionnaire and the follow-up to capture these staff members' perceptions over time. The 5-point Likert-scale responses were divided into three groups: 1 (*Agree*), 2 (*Neither agree nor disagree*) and 3 (*Disagree*). The data from all sites was analysed together.

Study III: Deductive content analysis

Interviews were recorded, transcribed verbatim and analysed using deductive content analysis (Elo & Kyngäs, 2008), based on the chosen domains in the theoretical framework, the CFIR. Data that did not fit into the existing constructs was coded inductively, as described by Elo and Kyngäs (2008). Domains from the theoretical framework were established prior to the analysis in an unconstrained matrix (Elo & Kyngäs, 2008). The constructs were not chosen before the analysis; rather, they evolved during the analysis. After an initial sorting process of the qualitative data into domains, the material within each category was coded in relation to constructs. However, it was sometimes clear that data belonged to a certain construct during the initial analysis process. For example, staff descriptions of the innovation as complex were directly coded into the construct 'Complexity' under the domain 'Innovation'. Lastly, all data within the constructs was coded to ensure that different aspects of each construct could be recorded. For example, under the construct 'Complexity', data was coded as 'good in theory', 'the old way is easier', 'feasibility in practice', 'complicated CIP process', 'perceptions of the innovation as being more complicated than it is' and 'takes time'. These codes were then illustrated with quotations and used to report the material.

Study IV: Thematic analysis

Data was analysed following the six phases of reflexive thematic analysis (Braun & Clarke, 2022): (1) developing familiarisation with the data; (2) coding the data; (3) generating initial themes from the codes and coded data; (4) reviewing and developing themes; (5) defining, naming and refining themes; and (6) writing the report. Study IV generally involved an iterative process of going back and forth between the phases during the construction of themes and discussions with supervisors for improved clarity on how the themes could be understood.

The analysis of the collected data was data-driven, in that that no categorisation matrix based on a theoretical framework was constructed prior to the analysis. Nevertheless, after the analysis was done, the written text was linked to

concepts related to epistemic injustice (Fricker, 2018) in order to gain a deeper understanding of users' and staff members' experiences.

Methodological considerations

This section provides a brief overview of my views of knowledge and my position as a doctoral student conducting research on social work practice while simultaneously being employed in social work practice. It then discusses criteria for quality in research in relation to the results of this dissertation, including the strengths and limitations of the research process and methods used.

Based on my social constructionist epistemological stance, I view knowledge as something that is contextually constructed through participant interactions, interviews and analysis. The aim of this dissertation was not to uncover an 'objective, unbiased observation' (Burr, 2025, p. 3) of phenomena such as user participation, the implementation process or CIP; rather, the focus was on exploring participants' perceptions and experiences of how user participation is understood and can be facilitated, while acknowledging my influence on the construction of this knowledge (see e.g. Burr, 2025). Therefore, I consider it important to acknowledge my position as both a social worker and a PhD student conducting research on social work practice.

My employment has been co-financed by academia and practice. I consider the advantages of my situation to include a decrease in the gap between academia and practice and an understanding of the organisational and structural conditions my research findings will be intertwined with. Marsh and Fisher (2008) have pointed out that practitioners undertaking research often leave practice to do so and that researchers have little to do with practice. My co-financed employment allows me to remain in practice while conducting research on practice. Marsh and Fisher (2008) have stated that the benefits of having a practice-based understanding when conducting empirical research include knowing the system and how to navigate it. In my case, I have an experience-based pre-understanding of working in social services, coordinating support and interacting with users that have comorbidity. However, there are methodological and ethical dilemmas related to being a practitioner conducting research about practice. The methodological considerations are further discussed below, while the ethical considerations are discussed in the section after that.

Quality in research: Strengths and limitations in this dissertation

This dissertation employed a variety of qualitative designs and methods, alongside a questionnaire, to explore participants' perspectives and experiences. While quality markers in quantitative research are generally well-established, the criteria for assessing quality in qualitative research remain under some debate (Burr, 2025; Tracy, 2010). Tracy (2010) proposed eight universal criteria to evaluate research quality that are applicable across qualitative disciplines. This section discusses the criteria relevant to the strengths and limitations of this dissertation. The mixed-methods approach used in Study III will be considered within the framework of *crystallisation*, integrating the quality of the quantitative data collection into the broader discussion of research quality.

Tracy (2010) has defined *rich rigour* as thoroughness in data collection and analysis, with clear descriptions of the methods used to support claims. Rich rigour is enhanced through systematic planning, detailed documentation of procedures, and the use of quotations to demonstrate how interpretations are grounded in the data. Thus, the use of diverse data-collection methods strengthened the rigour of this dissertation. It is my aim to provide sufficient detail on the data-collection and analysis procedures, including the number of interviews, questionnaires, the participant descriptions and by attaching interview guides and questionnaires (Appendix 1-7). Transparency regarding procedures, limitations and challenges is also key in ensuring *sincerity* (Tracy, 2010).

Recruitment challenges in this dissertation may have reduced its rich rigour. Grounded theory recommends theoretical sampling, in which data collection and analysis occur simultaneously, enabling the researcher to select participants based on the concepts constructed during the initial analysis (Charmaz, 2014). Moreover, the aim of qualitative research is to recruit diverse participants representing a range of experiences of the phenomenon being explored. The use of convenience sampling limits participant diversity, as it does not guarantee the inclusion of those who can provide the most information-rich and varied perspectives (Polit & Beck, 2021). Due to recruitment challenges, theoretical sampling in Study I and purposive sampling in Studies III and IV were deemed unfeasible.

A pragmatic decision was made to include participants based on willingness and eligibility, which may have influenced the results. For example, the experiences of using the revised CIP process gathered in Study IV were relatively

uniform, with limited contradictions, suggesting a lack of diversity in the perspectives from both users and staff. The users generally expressed positive views towards their social workers, which may reflect a more favourable outlook on the services and revised CIP process they interacted with, compared with the outlook a more varied group of users might have had. Similarly, the staff members who participated in Study IV and had used the innovation may have been individuals eager to embrace new approaches and may thus have championed the approach by offering a positive perspective. In contrast, the interviewed staff in Study III provided a more nuanced view of the implementation of the revised CIP process. The absence of a selection strategy in Study IV likely contributed to the overrepresentation of relatively positive participants. However, Study III provided a more diverse picture of the implementation process by capturing a broader range of perspectives. Aside from the relatively uniform perspectives of the revised CIP process obtained in Study IV, a variety of experiences and perceptions among both users and staff were elaborated across the studies in this dissertation. For instance, the users had different types of comorbidities, varying support experiences and diverse perceptions of services, while the staff members came from different backgrounds and had varying years of experience, contributing to the range of perspectives in the dissertation.

A limitation of the data collection in this dissertation is that except for one focus group interview, I conducted the interviews independently. Although the interview guides were discussed with my supervisors prior to the interviews, and ongoing discussions were held throughout the data-collection process, having a co-interviewer could have provided broader perspectives and encouraged more in-depth discussions, particularly in the focus group interviews, where the presence of both a researcher and a facilitator is recommended (Kitzinger, 1995; Polit & Beck, 2021). In particular, a co-interviewer could have improved the results by making up for any of my shortcomings as an interviewer due to my position as a social worker. For instance, during the interviews, I sometimes had to remind myself to ask follow-up questions, even when I anticipated the response, to ensure that the participants expressed their own views. Moreover, I have sometimes felt frustrated with the lack of appropriate coordination in social services and healthcare, resulting in the users not receiving the support they needed, and this frustration could have influenced the interviews. To mitigate the effect of my personal feelings, I made a conscious effort to remain open-minded and curious without influencing participants with my views or directing the interviews based on my pre-

understanding. Still, a co-interviewer could have facilitated the areas where I experienced limitations, thereby enhancing the rigour of the results.

To ensure *sincerity*, it is essential to be self-reflexive, as well as being transparent with one's position (Tracy, 2010). My position, preconceptions and pre-understanding required careful management. To maintain self-reflexivity throughout the process, I employed strategies such as mind mapping and memo writing (Charmaz, 2014), alongside ongoing discussions with supervisors and co-writers during data collection and analysis. Discussions throughout the analysis process are one strategy to enhance credibility (Tracy, 2010). According to Tracy (2010), *credibility* refers to the trustworthiness of research findings and can be achieved through crystallisation, among other methods. *Crystallisation* involves using multiple data types, sources, researchers, theoretical frameworks and methods to gain a deeper understanding of a phenomenon, rather than seeking a singular valid truth. In this dissertation, credibility was increased through discussions between researchers, participation from both users and staff, and the use of various qualitative methods in addition to quantitative data collection. However, the questionnaires were only inspired by the validated instruments by Weiner et al. (2017). This limitation may have affected the validity and reliability of the results in Study III, as we did not control for how the questions were perceived (which could impact reliability) or whether they accurately measured what we intended to measure (which could impact validity). Also, the interpretation of the quantitative data, due to the low response rate in the follow-up questionnaire is a limitation. Despite this limitation, reporting these perceptions and exploring them further with qualitative data was deemed important. The integration of both qualitative and quantitative data for example enhances credibility as described above.

However, since crystallisation involves using diverse data types, it is worth considering whether incorporating additional data could have further increased understanding. A limitation in the implementation process is the absence of observational data on fidelity, particularly regarding how the revised CIP process was applied in practice. As a result, it remains unclear whether the collected experiences of the revised CIP process related to utilising CIP as a process or to the incorporation of SDM in the CIP process. Nevertheless, the interviews revealed perceptions aligned with SDM principles, such as establishing a shared understanding of the user's situation and emphasising the use of user-provided knowledge throughout the CIP process.

In sum, steps were taken to improve the quality of the results, including ongoing discussions during the systematic planning, execution and analysis of the

studies; transparency; self-reflexivity; and the crystallisation of perspectives, sources and methods. However, the results should be considered within the context in which they were constructed and in light of limitations related to participant recruitment and data collection. Overall, the knowledge constructed in this dissertation can be viewed as valuable puzzle pieces that contribute to a deeper understanding of user participation and how it can be facilitated within the context of CIP. It offers a foundation for future research and supports practice in fostering ongoing discussions on user participation in this complex setting.

Ethical considerations

This dissertation involves and includes people with comorbidity, who are often viewed as vulnerable. Grasswick (2018) states that scientific communities have historically been incorrect when gaining knowledge of marginalised groups or knowledge important to such groups. There is also a history of scientific communities mistreating members of marginalised groups when including them in research. Ongoing ethical considerations are therefore essential in research. Relevant types of ethical considerations identified by Tracy (2010) include procedural, situational and relational ethics.

Procedural ethics are achieved by following ethical principles such as doing no harm, providing participants with informed consent, ensuring that participants understand their voluntary role and protecting participants from undue exposure. To ensure this dissertation met procedural ethics, it was ethically approved (No. 2019-00657 and its complement, No. 2019-03971). The study followed the ethical principles listed above: information was provided to all participants, who were informed that their participation was fully voluntary and that they could terminate their participation in the study at any time. The material collected in the interviews and questionnaires was stored according to current routines and was not disclosed to unauthorised people. Written consent or a recorded verbal consent was collected from everyone who took part in the studies, including users and staff.

Situational ethics are specific to the field and go beyond procedural ethics by emphasising the possible harm to participants in relation to the goals – that is, whether the means justify the ends (Tracy, 2010). In this thesis, situational ethical decisions included the exclusion of individuals in active substance use. This decision involved a dilemma: excluding these individuals' perspectives on behalf of ensuring informed consent. This decision required repeated reflection (Tracy, 2010) on how the exclusion criteria could be maintained during the research process. Since users were recruited by either staff or user organisations, it was judged that these staff members' and organisations' knowledge of the user and the user's current substance intake, in conjunction

with the users' own statement on being sober, was sufficient to ensure informed consent.

According to Tracy (2010), *relational ethics* relate to the relationship between the researcher and participants. My position as a social worker, both before and during this dissertation, necessitated reflection, as I interviewed users about their experiences with social services. To avoid role conflicts or power imbalances, I have not included users I had previously engaged with as a social worker. However, perceived power dynamics may still have influenced participants' openness, particularly regarding sensitive or critical information, if they viewed me primarily as a social worker. To mitigate this, I clarified that the interviews would not be disclosed to unauthorised persons and that the information given in the interviews would not affect their support, as I was conducting the research solely in my role as a doctoral student. The staff members were also informed that participating in interviews would not affect their working conditions.

One limitation of this dissertation is its lack of user involvement in planning and conducting the research. Including users throughout the research process could have made the explored areas more relevant to users' experiences. While user knowledge is emphasised as vital in practice, it is equally important in research, where it enhances both ethical integrity and quality (Askheim, 2020). This absence also relates to epistemic injustice (Fricker, 2018), as users were not included as knowledge contributors in the research design. However, besides staff also users were involved in developing the innovation explored in this dissertation (Knutsson & Schön, 2020), and users participated in the interviews in this dissertation. In line with Fricker's (2018) concept of hermeneutical injustice, involving users in research helps establish concepts grounded in their experiences. Although users were not part of the research process itself, their perspectives have shaped how user participation is understood in this dissertation.

Main results

In this chapter, the main results from the studies are introduced one by one. To place the studies in their contexts, a brief background and aim for each study are presented before the results. The chapter ends with a summary of the main results.

Study I

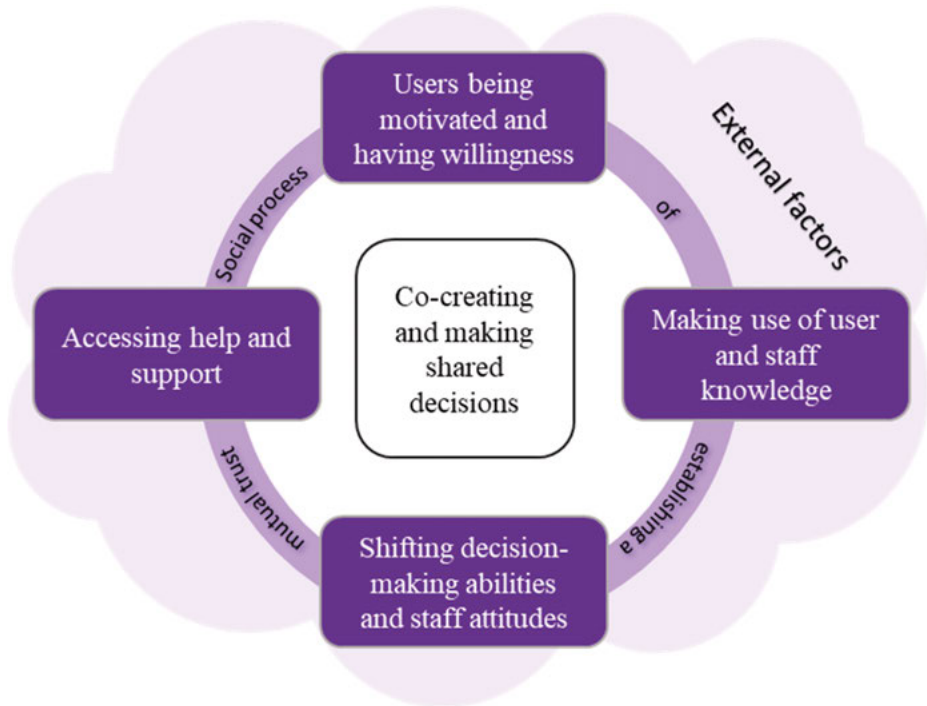
Title: ‘How do users with comorbidity perceive participation in social services? A qualitative interview study’

Amanda Jones, Kari Jess, Ulla-Karin Schön

In policies and previous research, there is a lack of consensus on what user participation entails, and its definitions can vary, depending on who is asked (Eriksson, 2015). The aim of Study I was therefore to explore how users perceive participation in social work encounters through a constructivist grounded theory approach (Charmaz, 2014). Participants also gave explanations of their views on coordinated support and participation in the context of social work encounters.

The main finding from Study I was how users described their understanding of user participation as a social, relational process in which the establishment of mutual trust was essential. Overall, users described low initial trust towards social services and perceived themselves as ‘lucky’ when they met a ‘good’ member of staff. They also initially perceived the staff member’s trust towards them as low. The social process of establishing mutual trust cuts through the whole process of establishing user participation and shared decisions, as illustrated in Figure 3.

Figure 3. The constructed framework in Study I.



The four core categories illustrated in Figure 3 are understood as prerequisites for establishing user participation as a social process with mutual trust. Taken together, these four prerequisites – namely, *user’s motivation and willingness*, *using user and staff knowledge*, *users’ shifting decision-making abilities and staff attitudes*, and *accessing help and support* – contributed to a perceived co-creation and to shared decision-making processes. There were also external factors that influenced user participation in the decision-making process, such as limited budgets, a hierarchical system that meant that the person the users encountered might lack the mandate to make a decision, high caseloads, staff turnover, laws and routines.

It was recognised that, in the decision-making process, users and staff are co-creators and therefore have a joint responsibility throughout the process. For example, users recognised that their own sometimes manipulative behaviour could lower staff trust towards them. This manipulative behaviour was especially evident when users did not have the will or motivation to receive support. When they did have the necessary will or motivation, users described how they ‘laid all their cards on the table’ and were honest. In such cases, trust enabled the users to share their views, thoughts and preferences while enabling

staff to take user statements into consideration in the decision-making process. To facilitate mutual trust, users highlighted the need for staff to be humble, empathetic, understanding and patient in terms of waiting for users to want support rather than pushing them to accept it. Receiving support beyond the perceived formal obligations of staff was also emphasised as something that increased trust.

Users described how substance use and mental illness, during certain periods, could make it difficult for them to acknowledge their needs, consider different alternatives and make decisions. Trust in staff was described as crucial for users to give staff the authority to make decisions on behalf of the users during these periods of decreased decision-making ability. This was described not as an expression of power by the staff but rather as a source of security (*trygghet*). However, the study also emphasised the importance of involving users in the decision-making process by drawing on their experience-based knowledge through discussions. When staff listened to users, it fostered a sense of being heard, regardless of the outcome of the decision-making process. This increased feelings of respect, being taken seriously and having a voice that influences decisions. It also reflected the importance of staff attitudes of viewing users as bearers of valuable knowledge.

Staff seeking out users' experiential knowledge and having a general understanding of comorbidity were identified as key factors throughout the decision-making process according to users, as this allowed staff to provide support tailored to the individual needs of each user. Since a user's will and motivation could be brief, having quick access to help and support was viewed as important. Nevertheless, users described instances of being denied support, for reasons such as staff not trusting the users and users having an SUP – which was paradoxical, since they sought support in order to get sober. When denied support, users described intentionally worsening their situation as a strategy to obtain the needed support, which illustrates the risks of users not being listened to. Having access to support also involved receiving coordinated support when more than one service was needed. In meetings with several members of staff, adjustments might be required, based on the user's situation and needs.

Study II

Title: 'Coordinated individual care planning and shared decision-making: Staff perspectives within the comorbidity field of practice'

Amanda Jones, Ola Knutsson, Ulla-Karin Schön

There is a gap between the intention of providing coordinated support with user participation and how this coordination is actually implemented in practice, where user participation is often lacking (Matscheck & Piuva, 2022b; Wenaas, Andersson et al., 2021). To bridge this gap, it is important to explore the challenges that persist and to identify potential solutions for how to support user participation and SDM in CIP. Thus, Study II aimed to explore the perspectives of staff involved in a CIP process with users with comorbidity. The study focused on the challenges the staff faced and the solutions they proposed to improve collaboration and promote user participation and SDM within the CIP process.

Staff identified several challenges in the CIP process related to organisational aspects (e.g. staff turnover and time constraints), a lack of functional collaboration and insufficient knowledge of each other's responsibilities and the overall CIP process. They also perceived challenges in the CIP meeting itself, which was often given priority, with less emphasis on preparation and follow-up. As a result, CIP meetings and follow-ups frequently lacked a clear agenda and structure. Staff members also stated that they were often unclear about what was expected of them in CIP meetings and follow-ups, that too many people were involved and that plans were not followed or followed up on.

The staff encountered difficulties in overall collaboration, including poor communication, members of staff from other organisations not attending CIP meetings or not inviting others to a CIP meeting – despite the need for it, and perceived unwillingness to collaborate from individuals in other organisations. Furthermore, staff identified several challenges related to user participation in the CIP process. These included a focus on organisational needs and limited resources, instances when users did not consent to a CIP and perceptions that users' varying health statuses could influence their ability to participate in and understand the CIP process. Although the workshop specifically asked how staff members present their views on users' problems, needs and wishes, little information was provided. This result suggests that expressing views is complex and requires further reflection from staff.

Overall, the proposed solutions emphasised the need for greater knowledge of the CIP process and how to utilise each step in practice, as well as better understanding of colleagues' roles. In addition, remembering that the CIP process could save time in the long run was suggested as a solution related to time constraints. Strengthening the collaborative culture was also highlighted, with suggestions including joint activities such as staff training, a shared CIP process calendar or even co-locating staff in the same building. Staff believed it was important for the management to support the improved CIP process by, for example, allowing sufficient time for staff to carry out the process and participate in joint activities. At the same time, staff members themselves had to ensure they took enough time for the entire CIP process.

Improving the CIP process involved adequate preparation, such as discussions with users and colleagues beforehand, setting a clear agenda and structure so everyone could come prepared, and offering alternatives to users during the preparation stage. Clear documentation from the CIP meeting, along with scheduling a follow-up during the meeting itself, was deemed crucial to ensure meaningful follow-up meetings for which all participants arrived prepared.

Solutions related to relational aspects between staff were also suggested, such as attending meetings, adhering to plans and supporting each other by sharing knowledge and discussing different options. Similarly, solutions for improving user participation were put forward, such as adapting communication, providing clear written and verbal information, using motivational interviewing, fostering mutual understanding of the user's situation and sharing decision-making. All these solutions include listening, providing information and options, asking questions, gathering information collaboratively and discussing the options. It was also considered essential to build trusting relationships and to recognise that this process takes time.

Study III

Title: 'Barriers and facilitators during the implementation process of shared decision-making in the comorbidity field: Staff perspectives'

Amanda Jones, Maria Fjellfeldt, Ulla-Karin Schön

There is limited knowledge about the implementation of SDM in decision-making processes involving multiple participants beyond the user and physician (Chmielowska et al., 2023) and within the field of comorbidity (Fisher et al., 2021). The aim of this study was to describe and explore staff members

perceptions of contextual barriers and facilitators during the implementation process of a revised CIP process that involves SDM. The implementation took place within the comorbidity field of practice.

This study explored barriers and facilitators in the three domains of ‘innovation’, ‘inner setting’ and ‘individuals involved’, in accordance with CFIR (Damschroder et al., 2021). Overall, staff perceived the *innovation* – that is, the revised CIP process – as complex, time consuming and difficult to implement. However, they also perceived a relative advantage of the innovation compared with previous CIP processes, since they perceived it to focus the CIP process on the user and improve the structure in the CIP process. Also, experience with the innovation was a facilitator, since the staff who tried the innovation were positive overall.

However, a major barrier in the implementation process was in the *inner setting* domain; more specifically, the relational connections between staff from different organisations became a barrier to implementation. Overall, it was deemed difficult and time consuming to contact other staff to gain knowledge from them during the preparation, since there was a perceived lack of communication channels between organisations. However, it was also evident that communication channels were actually in place. A lack of collaboration between staff therefore acted as a barrier to using the revised CIP process. Staff perceived other barriers in the ‘inner setting’ domain as well, such as constrained settings with staff turnover, which made it difficult to find time to learn something new. Nevertheless, facilitators regarding relational connections between staff were also evident, such as having functional collaboration before the implementation. For example, having regular formal network meetings between staff members, along with informal connections and knowledge of each other, facilitated the implementation of the revised CIP process.

The complexity of CIP was brought forward as both a barrier and a facilitator. In interviews, staff commented that they sometimes invited other staff members to a CIP to support users in receiving support from other organisations, but found the agenda for the CIP meeting to be one-sided, since it was only relevant for the other organisation. Other barriers in the implementation process included not knowing what a CIP is or when a CIP process should be planned, while wishing for an improved CIP process was a facilitator since it enhanced staff members motivation. The study also shed light on an implementation process in a collaborative setting, where it was discussed whether one setting could take the lead in the implementation process or whether everyone needed to have the same approach and values in the CIP.

Other factors influenced the implementation process in the domain of *individuals involved*. For example, staff attitudes influenced the implementation process. Staff generally emphasised user participation as important. However, conflicting views were shared regarding users' readiness to participate in the CIP process, and staff members were unsure whether important topics would be brought up in the CIP meetings if the users specified the agenda. They noted that, at times, other topics that arose or seemed important were discussed during the meeting. This was perceived as important if needed, although this way of conducting the CIP process was also questioned.

Additionally, the interviews illustrated that – despite a focus on the revised CIP process – there could be an organisational focus during the CIP process, pertaining to questions such as who needed the CIP (i.e. staff or user) and whether options were being discussed. For instance, staff expressed uncertainty about discussing options with users, as they felt it might create false expectations for the users. User knowledge was mostly mentioned in relation to having knowledge regarding what could be expected in terms of support. However, a small amount of reflection focused on the staff perceiving the users as experts on their own situations and therefore being aware that the users needed to be involved in the decision-making process. Staff also discussed the importance of the management having knowledge of the innovation in order to facilitate its usage in practice.

In sum, the results indicate that some alterations to how CIP was conducted in practice were made during the preparation for a CIP process in which the users were more involved than prior to the implementation. However, due to barriers in the 'inner setting' domain, a persistent organisational focus and uncertainty regarding users' involvement throughout the CIP process, the revised CIP process was not used in all CIP processes across all settings, and some staff noted that they did not use the new CIP process as intended.

Study IV

Title: 'User and staff experiences of using shared decision-making in coordinating care planning in the field of co-existing substance use and mental illness: A qualitative interview study'

Amanda Jones

There is a paucity of knowledge on user participation in CIP and how it can be facilitated (Matscheck & Piuva, 2022b). Thus, the aim of this study was to

explore the experiences of users with comorbidity and staff regarding the revised CIP process incorporating SDM.

Users described how the CIP was important for them to establish a joint plan and receive coordinated support. The main result in this study was how users and staff experienced the revised CIP process as structured, which gave them a feeling of safety (*trygghet*) and trust. Both users and staff found that the new form for documentation facilitated this structure and the users' active participation. Overall, the preparational part of the process, which involved user participation in setting the agenda and deciding who to invite, allowed for active user participation throughout the process. It also facilitated a shift from discussions on the staff's situation to discussions on the user's situation during CIP meetings. Mutual trust was described as being facilitated by the predetermined structure in which users and staff worked together over time. Facilitating trust was noted as important, since users described having trust issues due to their comorbidity and therefore being hesitant regarding the information they gave to others. The interviews with users also revealed that they needed this predetermined structure, since it made it easier for them to understand the CIP process; this was deemed important due to their comorbidity and/or need for control over their life situation.

The predetermined structure was also found to increase the structure in users' lives in general, both in attending meetings and in gaining increased stability regarding work and sobriety. Both users and staff described how the predetermined structure enabled everyone to be prepared for CIP meetings and – importantly – clarified what was expected from everyone during the CIP process. The preparational part with the users made it possible for the right staff to be invited to the CIP meeting based on the agenda, instead of inviting everyone the users had contact with, as doing so could be perceived as chaotic.

The follow-up made it possible to see that other participants in the CIP process were following through on their commitments, which was described as important to enable mutual trust between staff and users and among staff from different organisations. Overall, users and staff found that the revised CIP process 'went somewhere' when the follow-up part was used. Having this clear planning process with follow-up also meant that there was a plan to be followed even in instances of staff turnover, which was experienced as beneficial.

Aside from the more stringent experience of the revised CIP process related to the structure, the importance of partnership was emphasised in the interviews, including partnership between staff and users, and partnership among

staff. Overall, users and staff described experiences of users as contributors, equal partners and credible epistemic subjects in the revised CIP process. For instance, users commented that they had felt listened to and were seen as active participants throughout the CIP process. However, they also had experiences of staff needing to validate the users' situation to other staff in order for the users to feel that they were being taken seriously, which can be understood as users not being viewed as trustworthy knowledge bearers. Overall, utilising the revised CIP increased the possibility of reaching a shared understanding of the user's situation through the ongoing discussions. Using the same procedure and form for documentation also meant that staff from different organisations had a joint understanding of the CIP, which enabled their collaboration. Overall, the users believed that it was important for staff to talk with each other without the user being present, since this helped staff be prepared for the CIP meeting, lessened the burden on users to coordinate their own support and made it possible for everyone to have a shared understanding. However, staff could not discuss everything without the user's presence. From a staff perspective, being prepared was described as important to foster a functional collaboration in which no one had to enter 'defence mode' when participating in CIP meetings.

Discussion

The overall aim of this dissertation was to explore how user participation is understood and can be facilitated for adults with comorbidity, in the context of CIP. This thesis depicts user participation as a social process that involves the shaping of mutual trust – not only between users and staff but also among staff members. Thus, this thesis provides an understanding of the importance of staff relations in facilitating user participation in the CIP process. Mutual trust is shaped by working together over time to establish relational bonds; it is also crucial for achieving epistemic justice, which requires trust in each other as bearers of knowledge. Navigating relational bonds and establishing epistemic justice are demonstrated in this thesis to be essential in facilitating user participation in CIP among individuals with comorbidity.

This section discusses relational processes and knowledge exchange between users and staff (user-staff) and among staff members (staff-staff) in relation to previous research and theoretical frameworks. By doing so, it positions the results of this dissertation within a broader context and enhances the interpretability of these findings. The section begins with an overview of the relational bonds within the CIP, before discussing relational processes between users and staff that involve users being recognised as contributors to the CIP process and staff providing users with significant knowledge. Thereafter, the focus shifts to staff members' collaboration, emphasising the potential of CIP to facilitate user participation and the relational bonds among staff. A reflection on the implementation of the revised CIP process is then provided and offers valuable insights, although this thesis primarily focuses on understanding and facilitating user participation rather than on the implementation itself. Lastly, the conclusions, implications for practice and suggestions for future research are addressed, highlighting areas for further inquiry.

User participation as a relational process

The results show user participation to be a social process that involves the shaping of mutual trust both between users and staff and among members of staff. Mutual trust enables users to share their views, thoughts and preferences and allows staff to credibly recognise this knowledge throughout decision-making processes such as CIP. Thus, this dissertation contributes to an understanding of the importance of knowledge sharing between users and staff in facilitating user participation. Such knowledge sharing includes how staff perceive user knowledge during the CIP process and how staff members' own knowledge is shared with users. By ensuring that users are seen as both credible and competent collaborators who can provide and receive knowledge throughout the decision-making process, the element of mutual partnerships between users and staff can promote a CIP process with sharing decision-making. The results of this dissertation also demonstrate the importance of staff-staff relations, knowledge sharing and of staff acknowledging other staff members' knowledge throughout the CIP process. Hence, this dissertation supports an understanding of user participation as an ongoing process of *working together* and *recognising each other as competent collaborators and knowledge bearers*. These processes occur both in the interactions between users and staff and in the interactions among staff members throughout the CIP process.

The findings align with the relational aspects of user participation that have been highlighted in previous research (Selseng et al., 2021) and contribute to the literature an understanding of the importance of staff-staff relational bonds in facilitating user participation in the CIP process. The interviewed users and staff also expressed views on key aspects of their interactions, such as staff being empathetic, understanding and patient – findings that are supported by previous research (Selseng et al., 2021). Moreover, the results amplify Tritter and McCallum's (2006) ideas about the importance of relational processes, while placing less emphasis on the power dynamics expressed in frameworks such as Arnstein's ladder of participation (Arnstein, 1969). In particular, this dissertation shows that certain elements of user-staff and staff-staff interactions in decision-making processes such as CIP do not align with the so-called 'rungs' in Arnstein's ladder of participation (Arnstein, 1969). These elements of user-staff and staff-staff interactions are illustrated in Figure 4.

Figure 4. Key elements of user-staff and staff-staff interactions in the CIP process.

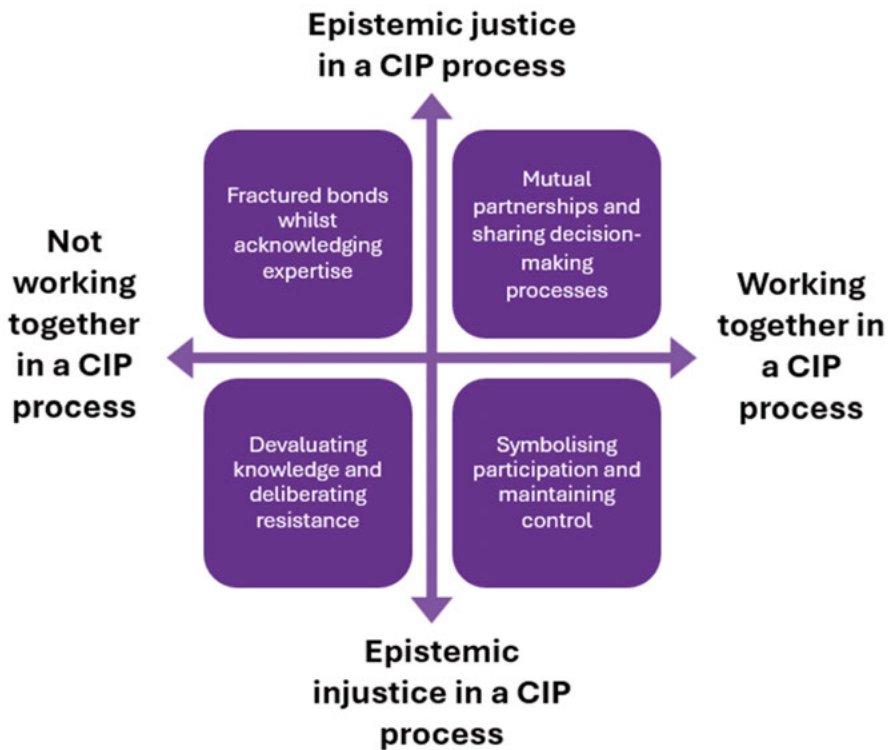


Figure 4 visualises key elements of the CIP process, providing a clearer understanding of how users and staff can navigate knowledge exchange and work together over time to facilitate user participation. This understanding of user participation is a dynamic, iterative and relational process and not a fixed state; in Figure 4, this is reflected by the use of the gerund (-ing) form. Each element in the figure illustrates the intertwined roles of users and staff in facilitating participation, as described in the following sections with examples of how these different elements are revealed in the results.

Mutual partnerships between users and staff

This thesis portrays user participation as a mutual partnership between users and staff, with knowledge sharing and a sharing of decision-making processes. In this partnership, users become epistemic subjects who are trusted as knowledge bearers throughout the CIP process and as collaborative partners who can receive knowledge from staff. The results underscore the importance of staff listening to users and recognising them as knowledge bearers and

credible epistemic subjects, in line with previous research (Kurs & Grinshpoon, 2018; Nouf & Ineland, 2023). The findings also emphasise the significance of epistemic justice (Fricker, 2018) in realising user participation in practice. Thus, feeling heard and listened to is an essential part of user participation – as emphasised in both this dissertation and previous research (Selseng et al., 2021) – and is crucial for building users’ trust towards staff. User and staff experiences with the revised CIP process indicate that the users felt heard and listened to and that their chosen topics were raised at the CIP meetings. Thus, the revised CIP process supported testimonial justice (Fricker, 2018) by enabling user knowledge to be valued and users to contribute as equal knowledge bearers. The revised process also promoted participatory justice (Hookway, 2010) by supporting users in being recognised as equal contributors throughout the CIP process and thus being trusted to contribute to the CIP process. Hence, both users and staff perceived users as being more involved in the revised CIP process compared with previous CIP processes, which was emphasised as one of the main benefits of this approach. Moreover, according to the users’ and staff members’ experience, the users were active participants throughout the revised process, and their knowledge was acknowledged; thus, the revised process contained the element of mutual partnership between users and staff (top right corner of Figure 4), which involves working together over time and users being recognised and trusted as knowledge bearers.

Nevertheless, the results indicate that users also had interactions with staff in which the users did not feel heard, and that they experienced situations in which staff members had to validate the users’ situation in order for the users to receive support. This finding is understood as users’ knowledge being devalued in relation to staff knowledge (bottom left corner of Figure 4). Previous research in the field has similarly reported paternalistic views towards users, users feeling unheard and judged, and users not being acknowledged as knowledge bearers (e.g. Bendtsen Kronkvist et al., 2023; Selseng et al., 2021; Wenaas, Andersson et al., 2021). Such experiences can give users negative perceptions of their interactions with staff and the support they receive (Bendtsen Kronkvist et al., 2023; Thomas et al., 2018), which was illustrated in the results when users who were denied necessary support were unable to shape trust in the staff. As highlighted in previous research, barriers to receiving support still exist in social services and healthcare (Priester et al., 2016). Still, the importance of ongoing support over time is emphasised in the literature, which shows that such support can reduce mortality rates (Watkins et al.,

2016), increase the likelihood of abstinence and improve users' overall health (Drake et al., 2020).

In this dissertation, users described how they might take action to worsen their situation in order to be heard and receive the support they needed. Such actions can be understood as the element of deliberated resistance (bottom left corner of Figure 4). Rather than being an unconscious reaction, resistance is understood as a deliberate action in response to decisions made by staff; it reflects the user-staff power imbalance and shows how users – who are dependent on receiving support – cannot withdraw from such encounters. Users also described instances of lying or manipulative behaviour, especially when avoiding support, further demonstrating negotiated resistance. They were aware that their actions could impact staff trust. Previous research supports this finding; for example, Khedr et al. (2023) linked drug cravings to emotional manipulation and lying. Other studies have also shown that fear of judgement or consequences can affect honesty, underlining the importance of staff providing users with clear information about what will happen next (Farber, 2020). As described in the results, this dissertation contributes to the field by showing that users are more honest when seeking support, complementing research (Selseng et al., 2021) about the importance of staff not judging users.

Being subjected to testimonial injustice or participatory injustice can lead to decreased confidence and a reduced willingness to share knowledge and participate in collaborative processes in the future, resulting in epistemic silencing (Fricker, 2018; Hookway, 2010). In this dissertation, users and staff showed that users' willingness to participate in decision-making processes could be low. When viewed through this theoretical lens, such a lack of willingness can be understood as stemming from previous experiences of feeling unheard that led to epistemic silencing. This understanding aligns with research showing how staff attitudes can negatively influence users' self-esteem (Bendtsen Kronkvist et al., 2023). Overall, the literature illustrates how most users want to be involved in decision-making (Friedrichs et al., 2018; Liebherz, Härter et al., 2015; Liebherz, Tlach et al., 2015).

Nevertheless, in the results of this dissertation, user participation is portrayed in relation to staff listening to users and valuing their contributions, rather than staff providing users with relevant information, even when using the revised CIP process. This situation is understood as a process that incorporates symbolic elements of user participation while staff maintains control (bottom right corner of Figure 4). In this process, users work together with staff over time but are not recognised as equal contributors and partners throughout this

process. For instance, the interviewed staff members were unsure about sharing treatment options with users, as they did not want to create expectations that could not be met. This reluctance to provide information aligns with previous research, which shows that comorbidity can lower staff's willingness to engage in SDM with users (Lukens et al., 2013). Staff's failure to provide essential information regarding treatment options and overall courses of action limits users' ability to make informed decisions and fully participate in the decision-making process (Schön et al., 2018; Selseng et al., 2021; Wenaas, Andersson et al., 2021; Wenaas, Bahl et al., 2021). This situation exemplifies epistemic trust injustice (Grasswick, 2018), as it involves the systematic withholding of crucial information that would enable users to trust staff as reliable sources of knowledge. This withholding of information undermines the ethical dimensions of the relationship and further limits user participation in the CIP process.

Grim (2019) describes users experiencing a lack of information, stemming from the logic of care and staff members aiming to protect users from consequences such as false expectations, too much information or responsibility, and the potential for self-destructive decisions. However, a lack of information acts as a barrier to partnership between staff and users in the decision-making process. In alignment with participatory injustice (Hookway, 2010), this situation can be understood as staff not recognising users as competent collaborators and potential contributors in the decision-making process. To facilitate participatory justice in practice, discussions of different alternatives are important. Yet, this dissertation shows that users risk being prevented from being part of these discussions, exemplifying participatory injustice in the CIP process.

The results contained other examples of staff not providing users with information as well. For example, staff members prepared the CIP meeting together with users but then raised additional topics at the actual meeting – topics that had not been consented to by the users, even though confidentiality laws require the user's consent before information is shared with staff from other service providers (Lindström, 2019). Preparing the CIP meeting together with the user and then introducing additional topics in the CIP meeting can be viewed as a decision-making process that features symbolic user participation, while the staff maintains control (bottom right corner of Figure 4). Similarly, the literature describes instances of users lacking a 'real role' in decision-making processes (Bendsten Kronkvist et al., 2023). This symbolic user participation constitutes participatory injustice (Hookway, 2010), as the users are excluded from equally collaborating with staff throughout the CIP process. This exclusion of users shows that the staff members retain ultimate control over the

agenda in the CIP meeting and that the ownership of the CIP process lies with the staff, rather than with the users as intended. This finding aligns with research showing that staff knowledge dominates the care-planning process, while user knowledge is devalued (Wenaas, Andersson et al., 2021).

It is worth considering why staff member(s) do not raise these different topics earlier, during the preparation with the user. Of course, one reason might be that new events occurred between the preparation of the meeting and the actual CIP meeting, and the staff member(s) felt that this new information needed to be discussed. The choice to bring up different topics during the CIP meeting might also be a reflection of staff members viewing themselves as experts and knowing best what needs to be addressed in the meeting, while devaluing users by not viewing them as competent collaborators throughout the CIP process. This possibility aligns with previous research that revealed paternalistic views among staff members regarding individuals with comorbidity (Bendtsen Kronkvist et al., 2023; Wenaas, Andersson et al., 2021; Wenaas, Bahl et al., 2021; Selseng et al., 2021). Perceiving users in this way can contribute to participatory injustice (Hookway, 2010) by preventing users from being trusted as collaborative partners throughout the CIP process. However, the results also showed that the staff found it difficult to describe how they viewed users' situations and problems, which might be why they did not bring up certain topics during the preparation; instead, they waited for the CIP meeting to raise these issues with other members of staff. This may reflect a more passive form of participatory injustice in which staff do not intentionally exclude users; rather, staff members' hesitation in describing users' issues to the users themselves limits the users' participation throughout the CIP process. Regardless of the reason, such staff actions constitute hermeneutical injustice (Fricker, 2018), since it prevents users from contributing to an understanding of their situation during the preparation. As a consequence, staff perspectives take precedence in the CIP meeting. This situation was shown in the results, which revealed that an organisational focus could persist throughout the CIP process, even when the revised CIP process was used. Based on these findings, the coordination of support is understood to influence the conditions for user participation in practice, as discussed in the following section.

The potential promise of user participation in CIP

The results show that the CIP context can influence the facilitation of user participation in practice. CIP was originally legislated in order to improve coordination among social services, healthcare and individuals requiring support from both providers; it has been described as 'the user's plan' and emphasises

user participation (Lindström, 2019). However, several challenges associated with CIP have been identified in both this dissertation and previous research. These issues include a lack of preparation and follow-up (Knutsson & Schön, 2020; Matscheck & Piuva, 2022b; Matscheck et al., 2019) and insufficient knowledge among staff regarding what CIP entails (Andersson et al., 2024). Moreover, research has shown that user participation in CIP remains low and that users' needs often play a secondary role to those of service providers (Matscheck & Piuva, 2022a, 2022b; Matscheck et al., 2019; Wenaas, Andersson et al., 2021). Matscheck & Piuva (2022a) have also explained that staff members collectively hold power in the CIP process, potentially placing the user at risk of being caught between providers. Taken together, these challenges illustrate the tangled context of an actual CIP process. The findings of this thesis reinforce concerns regarding a lack of user participation and emphasise the need to facilitate user participation in CIP so it can function as originally intended.

User participation in the CIP process involves participating in decision-making, since the aim of the CIP is to establish a coordinated individual plan that describes decisions regarding the support that will be provided to the user (Lindström, 2019). However, the users interviewed in this dissertation described how their ability to make decisions, which involves acknowledging their needs and considering different alternatives, could be temporarily decreased. These results align with previous research in this field similarly showing that users' abilities to process information and evaluate options can be temporarily decreased due to comorbidity (Thomas et al., 2018; Wenaas, Andersson et al., 2021; Wenaas, Bahl et al., 2021). Deficiencies in decision-making abilities such as processing information and considering alternatives may affect users' opportunities to participate in the CIP process, unless they receive support to participate. The results also indicate that staff perceived that users' decision-making abilities could be decreased both within general services and in the specific setting of CIP, resulting in the need for a balancing act between facilitating user participation and considering users' individual capacities. This way of thinking reflects staff perceptions of the complexities of user participation in the context of comorbidity. However, participatory injustice (Hookway, 2010) may arise if staff members fail to recognise users as competent collaborators throughout the CIP process due to generalised assumptions about decreased abilities. If staff members – whether consciously or unconsciously – dismiss users as contributors throughout the CIP process, power imbalances can be reinforced and user participation can be limited in practice. Working together over time without recognising users as competent partners

in this process can be understood as symbolic user participation, while staff members maintain control (bottom right corner of Figure 4).

Regarding users' abilities to process information and evaluate options, the literature highlights the importance of staff using wording that users understand (Wenaas, Andersson et al., 2021) and having alternative strategies for providing users with sufficient information (Wenaas, Bahl et al., 2021). In other words, the solution to users' possibly limited ability to make decisions is not to exclude them from decision-making processes such as CIP but rather to provide them with the necessary support to participate. The revised CIP process gives some hints on how this support can be provided by facilitating discussions over time; this gives users and staff the experience of meeting over time, having a clear structure and knowing what will happen – all of which are viewed positively by users and staff and in relation to the user's health. Hence, the revised CIP process yields promising results related to user participation and structure throughout the CIP process. The new form of documentation in the revised CIP process also encourages staff to provide the user with information on different options and prompts staff to discuss these options with the user, demonstrating how staff can support users throughout the CIP process. Since this information is written down and shared with the user, it can enhance the provision of sufficient information and the use of different strategies to provide users with information (both verbally and in writing). Since the revised CIP process involves meeting over time, it supports participatory justice (Hookway, 2010), as users are involved as participants throughout the CIP process. In addition to supporting the user throughout the CIP process, the revised form for documentation was described as supporting staff; for example, it increased user and staff mutual understanding of the CIP process, which was perceived as beneficial.

Nevertheless, it is necessary to mention that some users described their ability to make decisions as being decreased to such an extent that it was necessary for them to trust staff to make decisions on their behalf during periods of decreased health. The users perceived this type of staff decision-making as a form of security (*trygghet*) rather than paternalism. The results show that the users initially perceived the trust between themselves and social services as reciprocally low, which can be understood as a barrier to mutual partnerships and the sharing of decision-making processes. For example, some users described feeling 'lucky' when meeting a 'good' member of staff – an attitude that has been noted in previous research (Bendtsen Kronkvist et al., 2023). Thus, shaping trust between users and staff is an ongoing process that often begins with perceptions of low trust. Grasswick's (2018) exploration of

epistemic trust (in)justice views the shaping of trust as a mutual, ongoing process. Epistemic trust is developed over time through interactions. If users are expected to trust staff members and their knowledge in decision-making without the opportunity to critically assess or negotiate trust throughout this process, epistemic trust injustice may occur. Likewise, if users are expected to comply with staff decisions and not challenge them, this could be seen as epistemic trust injustice, as users would not have the opportunity to critically evaluate staff's sincerity/care and competence in the decision-making process. Hence, trust must be mutually shaped and not assumed. That said, users trusting staff to make necessary decisions on their behalf is not the same as users being excluded from decision-making processes such as CIP; rather, it relates to the actual decisions being made. Hence, users being listened to, involved over time and acknowledged as contributors in the CIP process do not contradict user perspectives of appreciating staff taking the lead in decision-making during certain periods. These processes incorporate elements of mutual partnerships with sharing decision-making processes (top right corner of Figure 4), as users are involved in and trusted to contribute to the processes over time. In addition to these interactions between users and staff, the results of this dissertation acknowledge the importance of relational bonds among staff in facilitating user participation, as discussed below.

Mutual partnerships among staff as a condition of user participation

The results highlight the significance of relational bonds and epistemic justice among staff members – not only for strengthening coordination but also for enhancing user participation throughout the CIP process. Even though epistemic (in)justice was first explored in relation to marginalised groups in society (Fricker, 2018), the concept involves aspects such as recognition, respect and validation of knowledge that are relevant in the current context. In this thesis, these aspects are applied to staff members' contributions to the CIP process as well. The results point to staff members' desire to have more knowledge about each other's responsibilities, which could be facilitated by working together to prepare the CIP meeting. This preparation, which includes contacting relevant staff from other organisations to gather their perspectives, was suggested as a solution to challenges in the CIP process (Study II). Thus, in addition to recognising users as knowledge bearers, staff must acknowledge each other's knowledge and their own need to learn and be open to learning from colleagues. This attitude is understood as promoting epistemic justice among staff, as it involves acknowledging

others as valuable knowledge bearers throughout the CIP process (top right corner of Figure 4). However, in practice, staff engagement in knowledge sharing throughout the whole CIP process, starting with the preparation for the meeting, remained limited (Study III).

The lack of communication channels between staff members from different service providers presented a challenge to working with the revised CIP process. This situation illustrates how organisational barriers can prevent knowledge sharing beyond individual organisations, fracturing the bonds among staff (top left corner of Figure 4). While staff members may acknowledge each other's expertise, organisational silos can hinder them from consulting colleagues across organisations throughout a process. As a result, staff may lack the necessary knowledge to discuss different options with users, limiting the users' opportunities to prepare for the CIP meeting. In this way, fractured bonds among staff members can impede users' ability to actively participate throughout the CIP process. From a user perspective, it is important to note that, when staff members contact each other before a CIP meeting, their aim should be to increase their knowledge, such as by better understanding treatment options, rather than to make plans without the user. This suggestion aligns with previous research emphasising the principle of 'no decisions about me, without me' (O'Brien, 2022). Users highlighted the importance of staff communicating with each other to reduce the burden on users to coordinate their own support, while simultaneously stressing that certain discussions should not take place without user involvement.

The results revealed other challenges in collaboration among the staff; for example, staff described how members of other organisations sometimes failed to invite others to a CIP meeting, even when there was a clear need for it, and how some failed to attend meetings, even when invited. These views can be linked to the concept of *organisational hybris* in which staff members believe their own organisation to be superior to others in the collaborative process (Larsson et al., 2019). This attitude causes staff members to assign the responsibility for uncoordinated actions to their partners rather than themselves. On the other hand, the act of not inviting others to a CIP meeting – despite the need for it – can be understood as a form of participatory injustice (Hookway, 2010), in which the perspectives of other staff members are dismissed or devalued (bottom left corner of Figure 4), undermining collaborative decision-making and user participation. This, in turn, could lead to users not receiving the coordinated support they need. Similarly, the act of not attending a CIP meeting when invited can be seen as a devaluation of the knowledge of both the user and the staff members attempting to facilitate the CIP process.

Another challenge brought forward in the results relates to staff inviting others to a CIP meeting to advocate for the user to receive support from the other organisation involved. However, when doing so while using the revised CIP process, the staff reflected on how the agenda became unilateral, as they had nothing to contribute themselves. The agenda thus focused solely on the other organisation and the requests for support from its staff, rather than focusing on coordinating support, which is the overall intention of CIP. This situation can be seen as a result of the absence of structures for supporting the user in receiving support in other ways. It can be understood as a result of the element of fractured bonds among staff (top left corner of Figure 4), even while staff acknowledge the expertise of both the user, in knowing the user's own support needs, and other members of staff. This example highlights a broader challenge in the CIP process: the risk of meetings becoming one-sided rather than collaborative, shifting the focus away from coordination and towards securing support from other organisations. This dynamic may lead to epistemic trust injustice (Grasswick, 2018), if securing support from other providers is caused by staff members' wish to safeguard their own organisation's resources, since it prevents users from trusting the staff members to prioritise the user's interests above competing interests such as safeguarding organisational resources. In addition, when staff balance such competing responsibilities, users may find their perspectives and needs reduced to symbolic inputs while staff members maintain control (bottom right corner of Figure 4), rather than users sharing the decision-making with members of staff throughout the CIP process.

Furthermore, this dynamic among staff touches on other challenges in collaboration, such as joint and diverse responsibilities being placed on different organisations. As described in previous research (Matscheck et al., 2019), a key question is whether CIP alone can sufficiently support users in receiving the necessary support, or whether other methods, such as multiprofessional teams, are needed. The findings in this dissertation echo this question; and, in alignment with suggestions in the SOU report (2021:93), multiprofessional teams and integrated care are viewed as essential. Integrated treatment has long been recognised as the most effective course of action for users with comorbidity (Mueser et al., 2003).

Nevertheless, social services and healthcare have joint and diverse responsibilities (SFS, 2001:453, 2017:30). Hence, it is necessary to coordinate support from different organisations in order to counteract fragmentation (Iturralde et al., 2021; Matscheck et al., 2019). Previous research has acknowledged CIP as an important process to facilitate collaboration between service providers (Matscheck et al., 2019). In line with this, CIP was deemed crucial from a user

perspective in the present dissertation, as it enables participation, shared information, coordinated plans and access to coordinated support. Staff also believed that CIP was an important aid to coordinated planning and wished for improved CIP processes. However, in order to effectively promote coordination as intended in legislation and CIP-related policies (Lindström, 2019; SFS, 2001:453, 2017:30), improvements are greatly needed in how CIP is implemented in practice. This dissertation provides insights into how the revised CIP process can help address some of the challenges related to user participation, staff collaboration and the facilitation of CIP as a process instead of a focus on the CIP meeting.

The revised CIP process is therefore understood as contributing to the element of mutual partnerships involving users and staff in sharing decision-making processes, as shown in the top right corner of Figure 4. For instance, the participants experienced the revised CIP process as improving the collaboration among staff because it prompted them to work together over time. This collaborative work over a period of time was also experienced as shaping trust among staff and allowing staff to work in the same way with the same form, which facilitated a shared understanding of the CIP process and each other's roles. This dynamic can contribute to epistemic justice (Fricker, 2018) by ensuring that both user and staff knowledge is valued and incorporated into the decision-making process. By using the revised form for documentation, users and staff are encouraged to share all relevant knowledge, which is important in relation to epistemic trust (Grasswick, 2018). However, to attain these potential benefits, the revised CIP process must be sustainably implemented with fidelity to its core functions. Challenges related to the implementation of the revised CIP process remain, as discussed in the following section.

A reflection on the implementation of the revised CIP process

The results demonstrate how limited resources – including budgets and staffing – were perceived to hinder the implementation of the revised CIP process. These findings regarding barriers to the implementation process align with those of previous studies (Andersson et al., 2024; Bergmark et al., 2018, 2019; Verwijmeren & Grootens, 2023), which have identified similar obstacles within service implementation. The perceived complexity of using the revised CIP process, which was exacerbated by time constraints, was identified as another barrier. These identified barriers to the implementation are brought forward in the CFIR as barriers in the 'inner setting' domain (i.e. time

constraints) and related to the ‘innovation’ domain (i.e. complexity) (Damschroder et al., 2021).

Matscheck et al. (2019) described significant staff discretion in how and when to utilise CIP overall. In alignment with this, the revised CIP process was not adopted by all staff in the present research, raising the question of why some staff utilised the revised CIP process while others did not, despite working under the same conditions – especially since those who had tried it perceived it as a positive experience. Lukens et al. (2013) demonstrated that staff who believe in the importance of user autonomy are more inclined to support SDM in practice. Similarly, Fischer and Neale (2008) highlighted that increased resources do not necessarily ensure enhanced user involvement if staff attitudes are not supportive of it. Based on these findings, it can be inferred that the staff members in this dissertation who used the revised CIP process had more positive attitudes towards user participation and autonomy than those who did not, demonstrating how staff attitudes influence the implementation process.

In addition to staff attitudes, the results revealed another precondition in the implementation of the revised CIP process: the presence of a strong collaborative culture prior to implementation, with relational connections among staff. The ‘inner setting’ domain in CFIR also references the importance of relational bonds in implementation (Damschroder et al., 2021). In the results, this precondition included both informal and formal collaboration, such as regular interprofessional meetings, which fostered mutual partnerships and supported the implementation of the revised CIP process. Grell et al. (2013) described collaboration and coordination as being on a continuum, with coordination being closer to separation and collaboration leaning towards integration. The focus of this dissertation is on coordination; however, the results show the importance of functioning collaboration in facilitating the implementation process. Thus, collaborative structures among staff are viewed herein as a precondition for the successful implementation of the revised CIP process. The importance of such structures for sustained implementation has been emphasised in previous research (Bergmark et al., 2018, 2019; Schön et al., 2018). Given the significance of these structures before implementation, it is also worth considering whether we, as researchers, could have done more to establish supportive conditions. For instance, could we have worked more closely with management and staff to better prepare for implementation? Recruitment was carried out through members of the management, who were informed about the innovation. However, the perceptions among the staff suggested that the management needed to be more actively involved and well-informed; moreover, not all managers were present at the training sessions

across the sites, which may have negatively impacted the implementation. Would greater engagement and commitment have been fostered by requiring sites to develop their own implementation strategies?

Avoiding the use of the revised CIP process or not using it as intended can be understood as strategies to manage a lack of resources. However, as put forward in this dissertation, using the revised CIP process as intended can save time in the long run. Research has indicated the positive outcomes of user participation, which include lower drop-out rates (Windle et al., 2020) and increased perception of achieving treatment goals (Brener et al., 2009). Additionally, it has been noted that users who are involved in decision-making are likely to take more responsibility for their recovery process (Wenaas, Bahl et al., 2021). This thesis demonstrates how using the revised CIP process enabled users to achieve greater overall structure in their lives, such as improving their attendance at meetings and increasing their stability regarding work and sobriety – improvements that can be viewed as users taking responsibility for their own recovery process in the context of CIP. Increased user participation and greater structure in the user's life, discussed both in previous research and in the present dissertation, can be hypothesised to be a way to save time (and resources) in the long term. Thus, even if staff members perceive time constraints as barriers to implementing the revised CIP process, this process could ultimately save them time. The importance of reflection when integrating and enhancing knowledge has been described by Avby and Melke (2023); perhaps the implementation process (and user participation) would be facilitated if staff members were able to take the time to stop and critically reflect on their current practice and on how the CIP process and user participation could be improved. In fact, the interviewed staff in this dissertation expressed the wish to try the new CIP process and reflect on how much time it actually took.

Conclusions

This thesis contributes knowledge on how users and staff within the comorbidity field of practice understand user participation and how user participation can be facilitated within CIP. In this dissertation, user participation is understood as a social process that involves the shaping of mutual trust between users and staff members and among staff members. In CIP, these mutual processes can be facilitated by working together over time and by acknowledging and trusting each other as trustworthy collaborators and knowledge bearers. The revised CIP with the new form for documentation can facilitate this work over time by encouraging knowledge sharing and discussions between users

and staff and among members of staff. However, the implementation processes of the revised CIP process revealed that other features in the CIP process may influence user participation, such as staff being unsure about providing users with significant information. Another feature involves staff members being hindered from working together over time due to organisational barriers, such as a lack of communication channels between staff members from different service providers. Such factors may limit the realisation of user participation in practice. Interestingly, a single CIP process can involve several of the elements illustrated in Figure 4 over time. For instance, preparing a CIP meeting together with the user can support the staff member(s) and user in working together over time and sharing decision-making. That said, even in a jointly prepared CIP meeting, the staff member(s) could raise undiscussed topics during the meeting itself, thereby hindering the user from participating in a shared understanding of the user's situation and SDM and instead establishing elements of symbolic user participation. Moreover, when staff members are hindered from contacting each other, relational bonds cannot form among staff members, impeding user participation by limiting staff members' opportunities to discuss options with the user, for example. Hence, collaboration among staff is important in facilitating user participation throughout the CIP process.

Implications for practice and policy

This dissertation offers suggestions for practice regarding how user participation can be understood and facilitated for users with comorbidity in the context of CIP.

- **The role of trust and collaboration:** In the context of CIP, user participation is understood as a relational process involving the shaping of mutual trust. Meeting regularly over time can support the shaping of mutual trust, thereby establishing a foundation for user participation.
- **Knowledge exchange and communication:** Communication practices such as listening, showing respect and recognising users as knowledge bearers can facilitate user participation in practice. Viewing users as competent collaborators in receiving knowledge also promotes user participation. Finally, collaboration among staff – both within and across organisations – is a necessary prerequisite for user participation throughout the CIP process.
- **Reflection and development of practice:** Reflecting on current practices can offer insights into how participation is understood and facilitated. The revised CIP process and new documentation form are

potential tools for supporting knowledge exchange and long-term collaboration. Taking a structured approach to reflect on a specific CIP process could provide opportunities for both staff and users to reflect on their experiences. Figure 4 can be used by staff and users as a tool to navigate this reflection on the CIP process, along with questions such as, *Which of the elements in this figure are present in our CIP processes? What can be done to strengthen the elements of mutual partnerships and sharing decision-making? How was the CIP process experienced by all the individuals involved?*

Suggestions and implications for future research

There are still gaps in research regarding user participation in services that require further exploration. For example,

- Research on user participation in services remains limited, particularly regarding SDM in social services and contexts beyond the patient-doctor relationship.
- Further exploration of how users experience trust in relation to user participation and knowledge sharing could provide deeper insights into the role of trust in service interactions.
- This dissertation illustrates how staff attitudes can influence user participation in practice; however, more knowledge is needed regarding how staff attitudes can be adjusted. The importance of critical reflection might give some clues to this issue, but further exploration is required.

This thesis also provides insights into conducting research in practice, and the lessons learned could be valuable for future research to build upon. For example,

- Involving users in research is essential, as their perspectives are valuable. This involvement can make the subject being researched more relevant and trustworthy, while enhancing methodological procedures, such as reaching out to potential participants. Additionally, involving staff in research processes can increase the sustainability of the implementation, as a plan for implementation can be developed together with staff.
- Conducting research in practice requires flexibility and pragmatism, especially during data collection, while still ensuring trustworthiness.

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Appendix



Appendix 1: Interview guide 1, Study I

Delaktighet

Jag är intresserad av att delaktighet i kontakten med socialtjänsten. Vad innebär delaktighet för dig?

Har du några erfarenheter av delaktighet i kontakten med socialtjänsten?

Finns det något mer du vill nämna vad gäller delaktighet i kontakten med socialtjänsten som jag inte frågat om?

Information

Hur ser du på den information du har fått och får?

Vilken information och kunskap önskar du bidra med när du träffar socialsekreterare?

Finns det något mer du vill nämna vad gäller information som jag inte har frågat om?

Bemötande

Hur upplever du bemötandet från personal vid socialtjänsten?

Finns det något mer du vill nämna vad gäller bemötandet som jag inte har frågat om?

Bedömning

Har du tillsammans med personal på socialtjänsten kommit fram till vilka behov av stöd som du har? Hur?

Finns det något mer du vill nämna vad gäller att kartlägga behov och anpassa insats utifrån behovet som jag inte har frågat om?

Appendix 2: Interview guide 2, Study I

Tema 1, delaktighet

Att vara delaktig är något som beskrivs som viktigt, samtidigt som det kan uppfattas som något oklart vad delaktighet innebär. Vad skulle du säga är viktigt för att du ska känna dig delaktig när du har kontakt med socialtjänsten?

Kan du ge något exempel på ett tillfälle då du känt dig delaktig? Vad ledde detta till?

Vad skulle du säga är utmärkande för de gånger du inte har känt dig delaktig?

Kan du ge något exempel på ett tillfälle då du inte har känt dig delaktig? Vad ledde detta till?

Kan det finnas skäl för socialtjänsten att ”fatta beslut över huvudet”, dvs att frångå princip om delaktighet? Vilka skulle dessa kunna vara isf?

Vilka faktorer inom socialtjänsten tror du kan möjliggöra för dig att vara delaktighet?

Vilka faktorer hos dig tror du underlättar för dig att vara delaktig?

Andra faktorer som kan underlätta delaktighet?

Vilka hinder för delaktighet kan föreligga inom socialtjänsten som organisation?

Vad tror du kan försvåra för dig att vara delaktig?

Hur kan man underlätta delaktighet vid sådana tillfällen? Vilket stöd kan socialtjänsten ge?

Hur ser du på maktrelationen som föreligger med socialtjänst och brukare?

Har du erfarenhet av att ha efterfrågat mer stöd från socialtjänsten än vad de har beviljat? Vad leder det till för din del?

Vad är din erfarenhet av väntetid från ansökan till att beslut tas?

Finns det något mer som gäller delaktighet du vill ta upp och som jag inte har frågat om?

I en annan intervju berättade personen att man i perioder inte kan delta i beslutsfattandet och att man då behöver "sätta sig i baksätet och låta någon annan köra ens beslut" är detta något du kan relatera till? Vad är isf viktigt för att man ska "våga" låta någon annan ta ens beslut?

Tema 2, information

Hur ser du på den information du har fått och får?

Vilken information och kunskap önskar du bidra med när du träffar socialsekreterare?

Finns det något mer du vill nämna vad gäller information som jag inte har frågat om?

Tema 3, bemötande

Hur upplever du bemötandet från personal vid socialtjänsten?

Hur tycker du att ett bra bemötande från socialtjänsten sida är?

Kan du ge något exempel på bra bemötande? Vad ledde detta till för din del?

Har du något exempel på dåligt bemötande från socialtjänsten? Vad ledde detta till för din del?

Finns det något mer du vill nämna vad gäller bemötandet som jag inte har frågat om?

Tema 4, anpassa insatser efter behov

Har du tillsammans med personal på socialtjänsten kommit fram till vilka behov av stöd som du har? Hur?

Finns det något mer du vill nämna vad gäller att kartlägga behov och anpassa insats utifrån behovet som jag inte har frågat om?

Appendix 3: Interview guide individual interviews, staff, Study III and IV

Frågor om interventionen

Vad jag förstår har du genomfört en SIP-process enligt det något förändrade arbetssättet? Hur upplevde du att det var?

Vilka fördelar ser du med denna SIP-process?

Vilka nackdelar ser du med denna SIP-process?

Hur gick du tillväga? Hur genomfördes SIP-processen?

I samband med utbildningen besvarade ni en enkät om kunskap, motivation och förutsättningar bland annat att SIPpa på det nya sättet. Nu har det gått ett tag sedan utbildningen, hur ser du på din

Kunskap, har du tillräckligt med kunskap, behövs mer kunskap?

Motivation

Och förutsättningar att använda den nya SIP-processen?

Har dessa aspekter förändrats över tid? Hur?

Frågor om implementeringen

Om jag förstått det rätt har det varit lite svårt att komma igång med att använda detta arbetssätt, vad är din upplevelse?

Vad var det som gjorde att du kunde SIPa på det förändrade arbetssättet vid detta/dessa tillfällen?

Har du haft SIPar efter utbildningen som inte är utifrån nya arbetssättet?

Finns det situationer där du inte kan använda det förändrade arbetssättet?

Resultat av att jobba med DBF i samband med SIP

Hur ser du på brukardelaktighet i samband med SIP nu, jämfört med tidigare SIP?

Hur påverkas brukardelaktigheten- om den påverkas?

Hur ser du på brukardelaktighet i de olika stegen av processen?

Hur ser du på brukarens roll i samband med SIP nu jämfört med tidigare?

Hur ser du på samverkan med andra huvudmän, har det skett någon förändring i samarbetet sen ni började SIP på detta sätt?

Hur ser du på förtroendet mellan er personal och brukare, har förtroendet ändrats iom denna nya SIP-process?

Hur ser du på förtroendet mellan er och andra huvudmän, har förtroendet ändrats iom denna nya SIP-process?

Något annat som du vill tillägga som berör implementeringen, arbetssättet eller resultat av arbetssättet?

Appendix 4: Interview guide focus group interviews, Study III

Interventionen

Inledningsvis kommer några frågor gällande att jobba med DBF inom ramen för SIP och hur ni upplever detta arbetssätt.

Hur upplever ni detta arbetssätt?

Vilka fördelar ser ni med detta sätt att genomföra SIP på?

Vilka nackdelar ser ni med detta sätt att genomföra SIP på?

Hur ser ni på möjligheterna att genomföra SIP-processen på detta sätt?

Hur arbetar ni med processen?

Hur ser ni på brukares möjligheter att delta i SIP-processen?

Implementeringsprocessen

Frågor som berör att förändra arbetssätt

Hur har det varit att börja jobba med delat beslutsfattande inom ramen för SIP?

Vilka hinder för att jobba på detta nya sätt har ni stött på?

Vilka lösningar har ni själva tagit fram för att kunna jobba med delat beslutsfattande inom ramen för SIP?

Jag är också lite nyfiken på vad som händer efter en utbildning, utifrån enkätsvaren har vi information om att man överlag var positiv till ens kunskap, motivation och någorlunda kring förutsättningarna, men vad jag förstår har det varit lite svårt att komma igång när man kommer tillbaka till verksamheten. Hur ser ni på det här?

Var kommer motivationen/viljan att jobba med SIP på detta sätt ifrån?

Svaren avseende organisatoriska förutsättningar var något lägre än motivation och förmåga, hur ser ni på de organisatoriska förutsättningarna idag? Har det förändrats över tid?

Vad är det som gjort att ni har kunnat SIPpa på det förändrade arbetssättet när det har gjorts?

Vad är det som gör att ni inte har kunnat SIPpa på det förändrade arbetssättet vid andra tillfällen?

Vad är era intentioner framåt – hur vill ni arbeta med SIP framleds?

Hur upplever ni SIP-blanketten?

Frågor som berör implementeringsstrategin

Vilket stöd tänker ni är viktigt att man får från faciliteraren?

Vilket stöd är det viktigt att man får från extern, t.ex. forskare som håller i projektet.

Hur upplevde ni utbildningen?

Hur ser ni på er kunskap idag? Behövs mer kunskap – om vad?

Hur är er motivation idag gällande det nya arbetssättet?

Har erat sätt att se på brukares förmågor påverkats av denna SIP-process?

Hur upplever ni rollspelen i utbildningen?

Hade ni behövt något mer för att jobba i enlighet med DBF i SIP? Vad?

Ni som har sippat på detta sätt – vilka utfall har det lett till?

Appendix 5: Interview guide, individual interviews users, Study IV

Frågor om upplevelser av denna SIP-process

Har du deltagit i en SIP förut,

Om ja, skillnader mot nu?

Beskriv övergripande de olika stegen i SIP-processen som du deltagit i

Hur gick SIP-förberedelsen till?

Hur gick SIP-mötet till?

Har du haft uppföljning – hur gick den till?

Hur upplevde du att SIP-processen var?

Vilka fördelar ser du med att SIPa på det sätt som ni gjorde denna gång?

Vilka nackdelar ser du med att SIPa på det sätt som ni gjorde denna gång?

Resultat

Hur upplever du din delaktighet i SIP-processen?

Har du kommit till tals, blivit lyssnad på, varit med och tagit fram agenda

Hur ser du på dina egna kunskaper i SIP-processen, har de kommit till användning? hur?

Hur upplever du samarbetet mellan hälso-och sjukvården och socialtjänsten?

Upplever du att SIP-processen gett dig något?

- kommit framåt vad gäller stöd, behandling

Har SIP processen påverkat förtroendet mellan dig och personal? Hur?

Något du vill tillägga?

Appendix 6: The first questionnaire, Study III

Bakgrundsfrågor

Kön	<input type="checkbox"/> Kvinna <input type="checkbox"/> Man <input type="checkbox"/> Annat <input type="checkbox"/> Vill ej svara
Arbetsplats	<input type="checkbox"/> Socialtjänst <input type="checkbox"/> Öppenvårdspsykiatri <input type="checkbox"/> Primärvård <input type="checkbox"/> Annan: _____
Yrkesroll	<input type="checkbox"/> Behandlare <input type="checkbox"/> Boendestödjare <input type="checkbox"/> Läkare <input type="checkbox"/> Sjuksköterska <input type="checkbox"/> Skötare <input type="checkbox"/> Socialsekreterare <input type="checkbox"/> Annan: _____
Antal år inom yrket	
Grundutbildning	
Vidareutbildning	

Frågor gällande delat beslutsfattande i SIP-processen

Nedan följer några frågor gällande hur du initialt upplever SIP-processen som innefattar delat beslutsfattande och därefter blanketterna som presenterats här idag. SIP-processen med delat beslutsfattande syftar till själva tillvägagångssättet med exempelvis förmöte med brukare där alternativ diskuteras, SIP-mötet och uppföljning. SIP-blanketterna syftar till själva blanketternas användarvänlighet, både SIP-mötet och uppföljningen.

Frågor gällande accepterande av interventionen, interventionens lämplighet och interventionens användbarhet

	Instämmer inte alls	Instämmer inte	Varken eller	Instämmer	Instämmer helt och hållet
1. Jag tycker att SIP-processen med delat beslutsfattande verkar bra.	①	②	③	④	⑤
2. Jag ser fram emot att arbeta med SIP-processen med delat beslutsfattande	①	②	③	④	⑤
3. SIP-processen med delat beslutsfattande verkar lämplig	①	②	③	④	⑤
4. SIP-processen med delat beslutsfattande verkar möjlig att implementera.	①	②	③	④	⑤
5. SIP-processen med delat beslutsfattande verkar möjlig att genomföra	①	②	③	④	⑤
6. SIP-processen med delat beslutsfattande verkar enkel att arbeta med.	①	②	③	④	⑤

Frågor gällande kunskap, förutsättningar och motivation

	Instämmer inte alls	Instämmer inte	Varken eller	Instämmer	Instämmer helt och hållet
1. Jag har tillräckligt med kunskap för att genomföra SIP-processen med delat beslutsfattande	①	②	③	④	⑤
2. Jag har organisatoriska förutsättningar för att genomföra SIP-processen med delat beslutsfattande (ex. tid, stöd från kollegor, stöd från ledning)	①	②	③	④	⑤
3. Jag är motiverad att genomföra SIP-processen med delat beslutsfattande	①	②	③	④	⑤

Appendix 7: Follow-up questionnaire, Study III

Bakgrundsfrågor

Kön	<input type="checkbox"/> Kvinna <input type="checkbox"/> Man <input type="checkbox"/> Annat <input type="checkbox"/> Vill ej svara
Arbetsplats	<input type="checkbox"/> Socialtjänst <input type="checkbox"/> Öppenvård psykiatri <input type="checkbox"/> Primärvård <input type="checkbox"/> Annan: _____
Yrkesroll	<input type="checkbox"/> Behandlare <input type="checkbox"/> Boendestödjare <input type="checkbox"/> Läkare <input type="checkbox"/> Sjuksköterska <input type="checkbox"/> Skötare <input type="checkbox"/> Socialsekreterare <input type="checkbox"/> Annan: _____
Antal år inom yrket	
Grundutbildning	
Vidareutbildning	

Frågor gällande delat beslutsfattande i SIP-processen

Nedan följer några frågor gällande hur du initialt upplever SIP-processen som innefattar delat beslutsfattande och därefter blanketterna som presenterats här idag. SIP-processen med delat beslutsfattande syftar till själva tillvägagångssättet med exempelvis förmöte med brukare där alternativ diskuteras, SIP-mötet och uppföljning. SIP-blanketterna syftar till själva blanketternas användarvänlighet, både SIP-mötet och uppföljningen.

Frågor gällande accepterande av interventionen, interventionens lämplighet och interventionens användbarhet

	Instämmer inte alls	Instämmer inte	Varken eller	Instämmer	Instämmer helt och hållet
1. Jag tycker att SIP-processen med delat beslutsfattande verkar bra.	①	②	③	④	⑤
2. Jag ser fram emot att arbeta med SIP-processen med delat beslutsfattande	①	②	③	④	⑤
3. SIP-processen med delat beslutsfattande verkar lämplig	①	②	③	④	⑤
4. SIP-processen med delat beslutsfattande verkar möjlig att implementera.	①	②	③	④	⑤
5. SIP-processen med delat beslutsfattande verkar möjlig att genomföra	①	②	③	④	⑤
6. SIP-processen med delat beslutsfattande verkar enkel att arbeta med.	①	②	③	④	⑤

Frågor gällande kunskap, förutsättningar och motivation

	Instämmer inte alls	Instämmer inte	Varken eller	Instämmer	Instämmer helt och hållet
1. Jag har tillräckligt med kunskap för att genomföra SIP-processen med delat beslutsfattande	①	②	③	④	⑤
2. Jag har organisatoriska förutsättningar för att genomföra SIP-processen med delat beslutsfattande (ex. tid, stöd från kollegor, stöd från ledning)	①	②	③	④	⑤
3. Jag är motiverad att genomföra SIP-processen med delat beslutsfattande	①	②	③	④	⑤

Frågor avseende de andra aktörerna i SIP

	Instämmer inte alls	Instämmer inte	Varken eller	Instämmer	Instämmer helt och hållet
1. Jag tror att brukarna är redo att delta i SIP-processen med delat beslutsfattande	①	②	③	④	⑤
2. Jag upplever att SIP-arbetet mellan socialtjänsten och regionen fungerar bra när det gäller brukare som har samsjuklighet (missbruk/psykisk ohälsa).	①	②	③	④	⑤

Frågor kring SIP-utbildningen och användandet av nya blanketterna

Jag deltog i utbildningen i SIP och delat beslutsfattande i September 2022	<input type="checkbox"/> Ja <input type="checkbox"/> Nej <input type="checkbox"/> Delvis, behövde gå tidigare/kom sent
Jag har använt nya SIP-blanketten	<input type="checkbox"/> Ja, vid ett tillfälle <input type="checkbox"/> Ja, vid flera tillfällen <input type="checkbox"/> Nej, har använt tidigare SIP-blankett <input type="checkbox"/> Nej, då jag inte har deltagit i någon SIP-process sedan utbildningen <input type="checkbox"/> Annat: _____

Om ja, hur upplever du användandet av SIP-blanketterna?

Ex. vad gäller användarvänlighet och struktur

Om nej, vad skulle du säga att det beror på?

ex. vilka utmaningar föreligger för att börja använda enkäten?
