THESIS FOR THE DEGREE OF LICENTIATE OF PHILOSOPHY

How communication practices shape participation for children and adults with complex communication access needs

Insights from Swedish habilitation and crisis management

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Insights from Swedish habilitation and crisis management
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Painted by students with complex communication access needs at Furuboda Folkhögskola,
on the topic of ’how you picture communication’ (October, 2025)

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1. ABSTRACT

This licentiate thesis investigates how communication practices influence participation for children and adults with complex communication access needs (CCAN) and explores strategies that can promote equitable engagement in key societal domains within Sweden. The research progresses through three interconnected stages: first, identifying communication practices that act as barriers or facilitators to participation; second, conceptualizing shared characteristics that support or hinder participation across contexts; and third, proposing strategies to enhance inclusive practices across professional settings.

Data were drawn from four papers involving children with disabilities in paediatric habilitation, and adults with CCAN participating in crisis management systems. Findings reveal that participation is shaped not only by communicative accessibility and multimodal support, but also by social accessibility, respectful and empowering dialogue, opportunities for autonomy and meaningful choice, structured inclusion, and recognition of competence. Trust emerges as a central mediating mechanism, connecting communicative practices with individuals' confidence, willingness to engage, and overall participation.

Building on these insights, the thesis proposes practical strategies for professionals, including preparation and use of multimodal supports, fostering trust and empowerment, and creating structured opportunities for participation. These strategies aim to reduce communication barriers and promote meaningful involvement for individuals with CCAN across diverse settings.

Keywords: complex communication access needs, disability, communication practices, communication strategies, participation.

Preface

This work was carried out at the Division of Design & Human Factors, Department of Industrial & Materials Science, Chalmers University of Technology. The research was conducted within two separate projects. The first, the 'HAPPY-project' (2018–2020), was funded and conducted by Halmstad University and Region Skåne. The second, 'From passive receiver to active resource in the crisis management system' (MSB No. 2021-08985), was funded by the Swedish Civil Contingencies Agency and led by Chalmers University of Technology in collaboration with Lund University.

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First and foremost, I would like to express my deepest gratitude to all participants—children and adults alike—who took part in the studies included in this licentiate thesis, as well as the many others who contributed to the broader projects from which these studies emerged. My sincere thanks also go to their families and the organisations that supported their participation. The voices of people with disabilities, especially those with complex communication access needs, are what inspire and drive my work. It is for these voices, and their right to be heard, that this research exists.

My heartfelt thanks go to my main supervisor, Professor Anna-Lisa Osvalder, who gave me the opportunity to return to research. Thank you for your invaluable guidance, countless discussions, and for making the research journey both intellectually stimulating and genuinely enjoyable.

I would like to thank Furuboda Folkhögskola for providing enthusiastic participants, valuable knowledge, and time for this research. I am especially thankful to my team at Furuboda, who have patiently tolerated my shared attention between our daily work and the demands of research.

Warm thanks to my researcher colleagues at Lund University for our collaboration in the MSB project 'From passive receiver to active resource in the crisis management system'. A special thank you to Dr. Jonas Borell for his sharp ideas, insightful suggestions, and expertise in crisis management. Heartfelt thanks also to Linda for making sure I never missed important courses, conferences, and deadlines, and for keeping me updated on everything happening in the disability field.

I would also like to thank my colleagues at Halmstad University—Ingrid, Petra, Jens, Britta, and Caroline. The HAPPY-project was my first encounter with research, and you showed me that important research can be both creative and fun—a lesson I will

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Finally, my deepest thanks go to those closest to me. Bob, who has purred faithfully beside me on the sofa through most of my academic and popular science writing. Thanks to Hasse for all the distractions, and Sven, for restoring my focus.

Furuboda, November 2025

Elin Stark

Central concepts

This licentiate thesis adopts a view of disability which combines the biopsychosocial model and the affirmative model. This means that disability is partially viewed as something intrinsic, encompassing individual physical, sensory, or cognitive characteristics (Bunbury, 2019), while also being shaped by extrinsic factors, such as accessibility and societal attitudes (Shakespeare, 2014). Additionally, the affirmative model acknowledges disability as a valid and positive identity, rejecting the notion of disability solely as a limitation or deficit (Goodley, 2024).

Participation	Includes both objective and subjective dimensions of taking part in life—not only being physically present or engaging in activities but also feeling involved and having the ability to influence one's surroundings (Adair et al. 2018; World Health Organization [WHO], 2001).
Communication	Refers to the exchange of information between two people, such as spoken dialogue, written messages and alternative communication. Communication is viewed as a means to reach participation (Beukelman & Light, 2020; Berko Gleason & Caldwell Phillips, 2024; WHO, 2001).
Communication practices	The repeated behaviors and approaches that are used to shape how communication unfolds in interactions (e.g. using picture symbols to aid comprehension) and which influence how people with CCAN are able to participate meaningfully in interactions and meetings that are important to them).
Involvement	Refers to both the opportunity to participate and the individual's active desire or ability to engage—it's not just about being allowed to take part, but also about feeling motivated and capable of contributing (Adair, 2018). Unlike inclusion, which focuses on being invited and accepted by others, involvement emphasizes the individual's active participation and engagement.
Impairment	Physical, intellectual, mental, or sensory health conditions that may cause limitations in bodily or mental functioning (WHO, 2001).
Disability	The restriction created when extrinsic environmental factors, such as physical or social environment, meet personal intrinsic factors caused by an impairment (WHO, 2001).

Abbreviations

AAC	Augmentative and alternative communication. Refers to methods, tools, and strategies used to support or replace speech, writing, or comprehension for people with communication difficulties. This includes systems like symbol boards, communication devices, gestures, and speech-generating technology.
CCAN	Complex communication *access* needs, a new adaptation from the more widely used 'complex communication needs'. Refers to people whose communication requires deliberate, explicit, and intensive interventions, and who cannot be expected to make adaptations themselves. People with CCAN often have the need for AAC.
PWA	People with aphasia. Aphasia is an acquired language disorder, often caused by stroke or traumatic brain injury. PWA often experience limitations in one or several language domains: speaking, understanding, reading, and writing.

Appended Publications

PAPER I

Vinblad, E., Larsson, I., Lönn, M., Olsson, E., Nygren, J. & Svedberg, P. (2019). Development of a Digital Decision Support Tool to Aid Participation of Children With Disabilities in Paediatric Rehabilitation Services: Explorative Qualitative Study. J*MIR Form Res, 3*(4).

PAPER II

Teleman B, Vinblad E, Svedberg P, Nygren JM & Larsson I (2021). Exploring Barriers to Participation in Pediatric Rehabilitation: Voices of Children and Young People with Disabilities, Parents, and Professionals. *International Journal of Environmental Research and Public Health, 18*(19):10119

PAPER III

Aryana, B., Stark, E. & Osvalder, A-L. (2024). Universal Crisis Information Design: A Multi-Case Study Using a Research-Through-Design Approach to Understand Vulnerable Groups' Understanding of Crisis Information. Int Conf on Universal Design Nov 2024, Oslo, Norway. *Studies in Health Technology and Informatics, Vol. 320 s. 74-81, 0926-9630 (ISSN) https://research.chalmers.se/publication/544432*

PAPER IV

Stark, E., Osvalder, A-L. & Borell, J. (2025). Supporting Communication in Crisis Preparedness: A Toolkit for Professionals Meeting People with Complex Communication Access Needs. To be submitted to Journal of International Crisis and Risk Communication Research (JICRCR).

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1. Introduction

Participation is a fundamental human right and a cornerstone of democratic society (United Nations, 2006). It means having the opportunity to actively engage in decisions and actions that affect one's life – whether in everyday interactions or during extraordinary events like crises. However, for people with communication difficulties, such as *complex communication access needs* (CCAN), participation is often restricted – not by a lack of capacity, but by the way society communicates, organizes, and provides access to support (Johnston et al., 2020).

Participation is shaped not only by a person's abilities, but also by how society provides *accessibility*, promotes *involvement*, and supports *autonomy* (Adair et al., 2018; Beukelman & Light, 2020; Leece & Peace, 2010). While these concepts are related, they are not interchangeable. *Accessibility* refers to removing barriers to participation; often understood in physical terms, like ramps or elevators to allow a person *attendance* (Adair et al., 2018; Bunbury, 2019). However, communicative accessibility is also crucial, particularly for people with CCAN. *Involvement* is about ensuring that people are not just present but feel motivated, socially connected, and meaningfully engaged in societal and social contexts (Adair et al., 2018). *Autonomy* concerns both the ability to make one's own choices (*decisional autonomy*), and the ability to do things for yourself (*executive autonomy)* (Leece & Peace, 2010). All of these require sufficient communication support for people who have CCAN (Beukelman & Light, 2020; Goodley, 2024).

In this licentiate thesis, *participation* is the central focus: specifically, how children and adults with disability-related communication difficulties, or complex communication access needs (CCAN), are enabled or hindered from participating in key areas of public life – here health care and crisis management. While much research on participation focuses on broader social inclusion or physical accessibility (Hedvall, 2017), it often overlooks how communication plays a crucial role in supporting or hindering participation, particularly for people with communication disabilities.

In Sweden, the challenge of ensuring equitable participation is evident across several public domains, including education, healthcare, cultural experiences, crisis management, and democratic practices (Stark et al., 2024; The Swedish Agency for Participation, 2023; The Swedish Agency for Cultural Policy Analysis, 2020). One explanation to these challenges is expressed in a review by the United Nations Committee on the Rights of Persons with Disabilities (2024), which found that the Swedish model of giving primary responsibility for participation to municipal and regional authorities has led to regional disparities in how accessibility and inclusion are implemented.

Despite increasing attention to participation in both national policies and disability research, a significant knowledge gap remains regarding the role of communication to promote participation—particularly for people with CCAN. In both structured settings like healthcare and more unpredictable, high-stakes situations like societal crises and disasters, studies focusing on adapting information and communication methods to promote participation for people with CCAN remain scarce compared to those addressing physical adaptations.

This licentiate thesis addresses this gap by investigating how communication practices influence participation among children and adults with CCAN in two distinct public contexts: paediatric habilitation and crisis management.

While these two contexts are vastly different, both acknowledge the importance of participation. Paediatric habilitation aims to strengthen communication and participation through structured, individualized support, helping children with disabilities engage with society on equal terms. Crisis preparedness, on the other hand, assumes a baseline of independence, self-reliance, and ability to participate in crisis management efforts —for example, the expectation that every Swedish resident can manage without societal support for seven days during a crisis.

At the heart of both contexts lies a shared concern: the risk that people who communicate in diverse ways are excluded—particularly in situations where participation is critical for health and safety. This licentiate thesis examines how communication practices either facilitate or hinder meaningful participation for people with CCAN, and how communication strategies can be used to ensure that their voices are recognized and valued in both everyday life and in times of crisis.

1.1. Communication Practices

The term communication *practices* refers to the habitual ways individuals, groups, or institutions use language, symbols, and interaction strategies to exchange information, express themselves, and make meaning in specific social contexts. These practices include verbal and non-verbal behaviours, choices of communication modes, and the ways in which communication is structured, encouraged, or constrained within relationships, institutions, or other communicative settings (Beukelman & Light, 2020). Sometimes described as *communication culture* (Marshal & Hurtig, 2019a), communication practices can include strategies such as communication partner techniques, low- and high-tech AAC, individualized communication plans, or attitudes such as addressing the individual directly.

Research shows that policy strongly shapes which practices are implemented and how, and that organizations benefit from drawing on research evidence to guide the adoption of inclusive communication practices (Oshita, 2023). Within healthcare,

effective communication adaptations require support from executive leadership and preparatory work at both clinic and organizational levels, indicating that consistent practice depends on more than individual clinician initiative (Marshal & Hurtig, 2019a, 2019b; Oshita, 2023; Oshita et al., 2024). As Marshal and Hurtig (2019a, 2019b) note, building and sustaining a hospital-wide culture of accessible communication is critical to ensuring that patients with CCAN can actively participate in their care and decision-making. Achieving this culture is a gradual process that requires collaboration across professional groups, time, resources, and organizational commitment.

In this licentiate thesis, **communication *practices*** are understood as the repeated behaviours and approaches used to shape how communication unfolds in interactions (e.g., using picture symbols to aid comprehension or slowing the pace of a meeting). They are developed contextually and are unique to each organization based on their focus and prerequisites and ultimately influence how people with CCAN are able to participate meaningfully in interactions and meetings that are important to them. In contrast, **communication *strategies*** are understood as broadly applicable, guiding principles that can be adapted across contexts to address fundamental communicative needs, regardless of the organization's specific field or focus

1.2. Aim and Research Questions

This licentiate thesis aims to contribute to a deeper understanding of how communication practices shape participation for children and adults with CCAN and to propose professional strategies that promote equitable participation in important areas of life within Swedish society.

To address this aim, the research has progressed from identifying how communication practices function as barriers or facilitators to participation for children (**RQ1a**) and adults (**RQ1b**), to conceptualizing shared or generic characteristics that support or hinder participation (**RQ2**), and finally to proposing strategies that can promote equitable participation across services and settings (**RQ3**).

1.3. Organization of Thesis

This licentiate thesis begins by providing a background on the fundamentals of communication and how communication may be affected by certain disabilities.

- Chapter 2 outlines these foundations, describing key aspects of communication and CCAN to give the reader a deeper understanding of the participant groups. It concludes with the presentation of the research questions (RQs).
- Chapter 3 introduces the research perspectives and overall process, followed by a summary of the methods used in the studies that form the basis of the four papers and the approach taken to synthesize their findings.
- Chapter 4 presents the results related to RQ1a and RQ1b
- Chapter 5 revisits the studies to answer RQ2 and synthesizes the findings from all four papers into a model that illustrates the relationship between communication practices and participation.
- Chapter 6 presents strategies to support participation for people with CCAN in response to RQ3.
- Chapter 7 discusses the findings in relation to relevant research literature and three models of participation.
- Chapter 8 provides the overall conclusions of the thesis
- Chapter 9 suggests areas for future research

2. Frame of Reference

This chapter introduces the key concepts of the thesis, including a summary of communication difficulties related to disabilities, followed by an introduction to CCAN, aphasia, and speech motor difficulties, and how these conditions may affect people during high-stakes conditions. In addition, three models to describe participation are presented, which will be used to discuss how communication practices may affect participation.

2.1. Communication and Disabilities

The World Health Organization defines the ability to communicate as being able to send and receive information, for example via speech or text, with familiar and unfamiliar communication partners (WHO, 2001). Communication is a fundamental human right and central to interaction and participation across all areas of life—including family, education, healthcare, and work. An individual's communication abilities have been found to directly influence their perceived quality of life (Bennet et al., 2016; Grönberg et al., 2022; Hanley et al., 2023; Hilari et al., 2007).

While speaking, listening, reading, and writing often are regarded as the primary modes of communication, people also communicate through gestures, sign languages, and augmentative and alternative communication (AAC) (Friedman & McNamara, 2018). For people with disabilities, communication can be limited when their preferred or necessary modes of communication are not recognized, accessible, or supported—restricting their ability to understand, be understood, and take part in daily life (Light & McNaughton, 2012; McLeod, 2018).

When we interact verbally, we don't just process the words being spoken. We also interpret tone of voice, body posture, facial expressions, eye gaze, and gestures. In addition, we draw on background knowledge—about the world, the setting, and the topic being discussed. These cues work together to help us understand each other. As a result, communication depends on the interaction between a range of systems within and between individuals, including linguistic, cognitive, and social-cognitive abilities (Sandgren, Hansson & Sahlén, 2015).

However, when a person has a communication disability, these systems may not function together efficiently. This can lead to a mismatch in how attention and mental resources are used, which in turn can make it harder to follow and understand conversations (Beukelman & Light, 2020; Sandgren, Hansson & Sahlén, 2015).

When one person experiences communication difficulties, it is the responsibility of the other(s) to help ensure that communicative meaning is not lost (Hanley et al., 2023). Thus, successful communication requires a shared effort and involves not only the skills of the person with communication disability (i.e. acting both as a sender and receiver of messages), but also the ability and willingness of the communication partner to adapt. Thus, successful communication also relies on the surrounding context and its communicative interest (Perkins, 2007). For verbal and written communication to be efficient, language skills, executive functions, and sensory and physical capacities play a vital role – all of which may be affected in individuals with disability-related communication difficulties (Himmelmann et al., 2013). These abilities are described in more detail below.

2.1.1. Language

Language is a complex human function that involves both receptive skills, such as listening, reading, and observing, and expressive skills, such as speaking, signing, and writing. A unique and important function of the human language is the possibility of *displacement talk*, meaning that humans can communicate about any part of their experiences whether in the past, present, or future; true or hypothetical (Berko Gleason & Caldwell Phillips, 2024). The ability to use displacement talk is therefore crucial in for example healthcare planning and crisis preparedness.

To communicate effectively, individuals must comprehend and produce language across several interrelated subsystems—commonly referred to as linguistic domains (American Speech-Language-Hearing Association, 2025; Berko Gleason & Caldwell Phillips, 2024; Marrus & Hall, 2017). These systems are essential for achieving communicative competence and are often described as follows:

Phonology – the ability to perceive and use the distinct sounds (or letters) of a language, and to follow the rules for how these sounds are combined.

Morphology – the understanding and use of meaningful units within words, such as grammatical markers (e.g., bake, baked, baking).

Syntax – the rules governing sentence structure, or how words are arranged to form grammatically correct and meaningful utterances.

Semantics – the comprehension and use of vocabulary, including word meanings and the relationships between them.

Pragmatics – the use of language in social contexts, which includes interpreting and applying unspoken rules such as turn-taking, tone of voice, body language, politeness, irony, and implied meanings.

The ability to use these five domains enables individuals to interact effectively in a wide range of communicative situations. However, difficulties in any one of these areas—often seen in people with communication disorders—can significantly hinder one's ability to understand or express language (Berko Gleason & Caldwell Phillips, 2024; Marrus & Hall, 2017).

2.1.2. Executive Functions

Executive functions are a set of highly advanced cognitive processes used to manage thoughts and behaviours, ultimately helping the person carry out daily tasks and adapt to changes in the environment. There are three core executive functions; all of which are of great importance to communicative abilities:

- **inhibition** (to suppress automatic responses),
- **working memory** (maintaining and using information), and
- **cognitive flexibility** (shifting focus between tasks).

From these, higher order functions are built, such as reasoning, problem solving, and planning (Diamond, 2013; Miyake et al., 2000).

Executive functions difficulties have been linked to communication impairments across ages and disabilities including specific language impairment, autism, dyslexia, aphasia, and traumatic brain injury (Kaushanskaya et al., 2017). For instance, people with intellectual disabilities may experience difficulties in all five linguistic domains (Marrus & Hall, 2017) as well as cognitive deficits in attention, learning, memory, and processes such as problems with reasoning, abstract thinking, and judgment (Hronis et al., 2017). All these aspects will ultimately affect the ability to communicate effectively.

2.1.3. Sensory and Physical Capacities for Communication

While the cognitive and linguistic abilities are the basic prerequisites for communication between people; the individual's sensory and physical capacities play a vital role in shaping *how* that communication can be carried out.

Sensory impairments—including vision loss, hearing loss, or a combination of both—can significantly affect a person's ability to access and use communication in everyday life. These impairments may limit access to spoken, written, or visual information, creating barriers to equitable participation in education, social life, and public decision-making (Crow & Wittich, 2024). For example, a person with vision impairment may not be able to read printed healthcare information such as therapy

instructions, and someone with hearing loss may struggle to follow spoken crisis information, especially in noisy environments.

Communication challenges related to sensory impairment are often compounded by limited awareness among peers and professionals. Combined sensory loss, such as deaf blindness, further restrict access to both verbal and non-verbal communication, increasing the risk of social isolation (Crow & Wittich, 2024). Sensory impairments can occur as standalone disabilities or as co-occurring conditions, commonly seen in diagnoses such as cerebral palsy and Down syndrome.

Finally, the physical requirements needed to communicate can be affected by a physical disability having impact on functions such as coordination of breath, the neurological planning, programming, and execution of speech movements, and the muscular strength and reach of muscles (Hartelius et al., 2024), thus affecting the ability to produce intelligible speech. This means that individuals can have intact language skills but be unable to speak due to severe physical limitations (e.g. individuals with cerebral palsy or neuromuscular dystrophy). Physical disabilities can also further hinder the ability to use the body to produce alternative communication such as writing, using gestures, or pointing to symbols. When a physical disability affects the vocal tract, hands, arms, face, or eyes, communication will ultimately be impacted (Himmelmann et al., 2013; Perkins, 2007).

2.2. Augmentative and Alternative Communication (ACC)

People with CCAN will ultimately experience significant limitations in communication, participation, and inclusion and in all aspects of life unless they are provided with communication supports (Beukelman & Light, 2020). AAC refers to methods and tools that support or replace spoken or written communication, either to aid expression or comprehension. AAC is *augmentative* when it is used to supplement existing speech and *alternative* when it is used to replace speech that is either absent or not functional (Elsahar et al., 2019). Solutions can vary in *technological complexity*—from high-tech devices such as eye-tracking speech-generating devices to low-tech boards with picture symbols or even single-message buttons—and in *linguistic complexity*, from single words to full language systems with grammar and linguistic nuances.

The following section introduces the most relevant AAC systems and communication-supporting methods used in the studies included in this licentiate thesis.

2.2.1. AAC Systems: Blissymbolics and Pictographic Symbols

One of the most linguistically rich AAC systems is Blissymbolics. It is an ideographic symbol-based language used to enable communication through a system of abstract symbols. Through creative combinations of symbol components, it allows for the expression of complex ideas and grammatical structures, offering linguistic depth comparable to spoken or written language (Alant et al., 2013; Nandadasa, 2021). While originally developed by Charles K. Bliss in 1949 to be a universal language to promote peace, it has since 1971 been further developed by the Blissymbolics Communication International in Toronto to function as a non-verbal symbol language for people with multiple disabilities (Nandadasa, 2021).

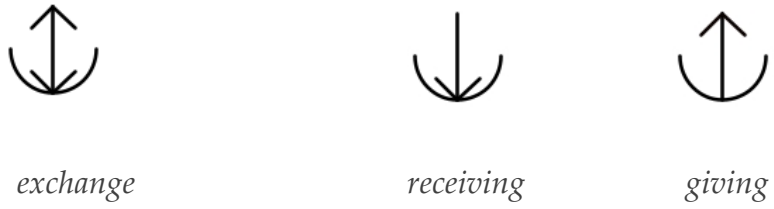
Individuals who use this system are often referred to as Bliss communicators. They are typically people with severe physical impairments with adequate cognitive and linguistic abilities to understand and use abstract symbols. While Blissymbolics has the potential to support highly nuanced communication, many users are limited to a smaller, pre-selected set of symbols due to technological constraints that make accessing the full system of over 1,400 characters and 6,000 words challenging (Nandadasa, 2021).

Below is an illustration of how Blissymbolics works (symbols from Blissonline.se). The symbol for 'communication' is made up of the combined symbols for 'exchange' and 'meaning' (Figure 1).

communication *exchange* *meaning*

Figure 1: Example of the compounded word 'communication' and its derivation in Blissymbolics

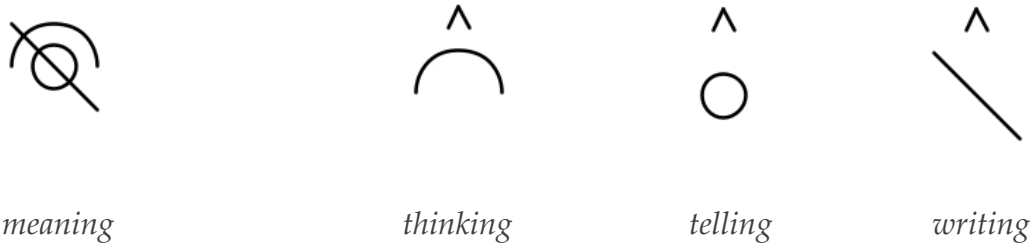
The symbol for 'exchange', in turn, is made up of the symbols for 'receiving' and 'giving'. 'Receiving' is in turn are made up of the symbols for 'down' and 'basket' (symbolizing that that which you receive is being placed in the basket). Similarly, the symbol for 'giving' is made up of the symbols for 'up' and 'basket' (Figure 2).



exchange *receiving* *giving*

Figure 2: Example of the compounded word ‘exchange’ and its derivation in Blissymbolics

The symbol for ‘meaning’ is made up of the symbols for ‘thinking’; ‘telling’; and ‘writing’; which each in turn are made up of the symbols for ‘mind’; ‘mouth’; and ‘pen’ in combination with a verb operator to indicate and action (‘mind’ becomes ‘thinking’) (Figure 3).



meaning *thinking* *telling* *writing*

Figure 3: Example of the compounded word ‘meaning’ and its derivation in Blissymbolics

While Blissymbolics is an ideographic symbol-based language with near endless linguistic possibilities, pictographic symbols (Figure 4) are more widely used in Swedish AAC interventions. Compared to Blissymbolics, pictographic symbols are considered to have a higher degree of both transparency[1] and translucency[2] (Blake Huer, 2000; Bloomberg et al., 1990; Díez et al., 2024). The picture symbols can be implemented through communication boards or software using picture symbols from different icon sets. These systems allow users to communicate by pointing, touching, or selecting symbols on boards or screens. In addition to supporting direct expression, symbols can be used as visual schedules or schematics to facilitate understanding of routines, time, and sequences of activities, providing structure and predictability for users with varying communication or cognitive needs (Beukelman & Light, 2020).

[1] The transparency of a symbol is defined as how easily it can be understood, or guessed, in the absence of the referent. The opposite of transparency is called opaqueness (Shepherd & Haaf, 1995).
[2] The translucency of a symbol is defined as how easily it can be understood, or guessed, in the presence of the referent (Hetzroni et al., 2002).

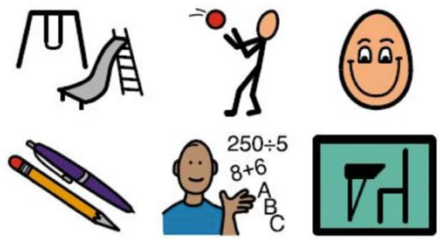


Figure 4: Examples of picture symbols from the PCS (Picture Communication Symbols)

2.3. Communication Supporting Methods

In addition to AAC systems, which individuals often use as their primary mode of communication, there are supportive methods designed to facilitate interaction with people who have reduced communicative or cognitive abilities. These approaches can help structure conversations, aid understanding, and provide multiple channels for expression. Below, I describe the communication-supporting methods that were employed in the studies included in this licentiate thesis.

Talking Mats is a visual, low-tech communication method[3] developed to support people with communication and cognitive disabilities in understanding and sharing their opinions more clearly (Murphy et al., 2007). The approach uses picture symbols that participants arrange along a visual scale to indicate their feelings or attitudes toward different topics (Figure 5), thereby helping to reveal underlying preferences and capabilities that may otherwise remain hidden (Devereux, 2016; Murphy et al., 2005). This method has been successfully applied in group research contexts (Backman, 2021; Bunning et al., 2017) and has been shown to improve both communication quality and user engagement (Stans et al., 2019). The method has also demonstrated effectiveness in helping individuals communicate preferences and make decisions (Murphy et al., 2005; 2007).

[3] Often referred to as a 'communication framework'.

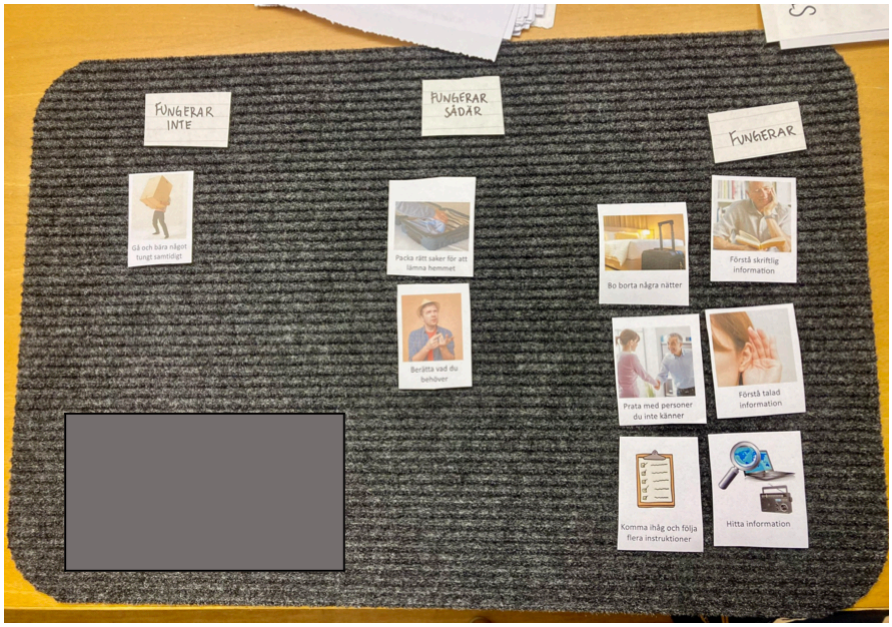


Figure 5: A laid out Talking Mat session.

Supported Conversation for Adults with Aphasia (SCA) is a method widely used to aid communication for people with aphasia (PWA). It focuses on enabling better interaction through multimodal communication strategies, such as speaking clearly, writing down key words, using gestures, and incorporating visual aids like picture symbols and photographs (Kagan, 1999). These strategies are designed to help PWA both comprehend what is being said and express themselves more effectively. For instance, a conversation partner using the SCA method might combine speech with written keywords, point to relevant images, and reinforce meaning through gestures—thus ensuring the PWA has multiple ways to engage in the conversation. Written keywords can also function as visual anchors, helping to maintain coherence and allowing the conversation to circle back to earlier topics if needed. The key purpose of the method is to help reveal the competence of the PWA. Originally developed to equip volunteers with accessible and effective tools for communicating with PWA, SCA has since been successfully implemented in community-based aphasia programs to improve everyday interactions and increase participation (LaPrade Rini & Hindenlang, 2014).

Interactive drawing (Figure 6) is a method that is scarcely described in international literature, yet it has been widely applied in Swedish practice contexts under the name '*ritprat*'. The method involves drawing simple, spontaneous sketches during a conversation in order to support mutual understanding and maintain focus on the topic at hand. Both the professional and the conversation partner can contribute to the drawing, making it a co-constructed visual record of the dialogue. The conversation partner might, for example, draw figures representing different options that are being discussed, while crossing out rejected or circling options as they are rejected or accepted.

The drawings do not aim at artistic quality but rather serve as concrete, flexible representations of what is being said. In this way, interactive drawing can make abstract ideas more tangible, help clarify complex information, and provide a shared point of reference that supports memory and comprehension throughout the interaction.

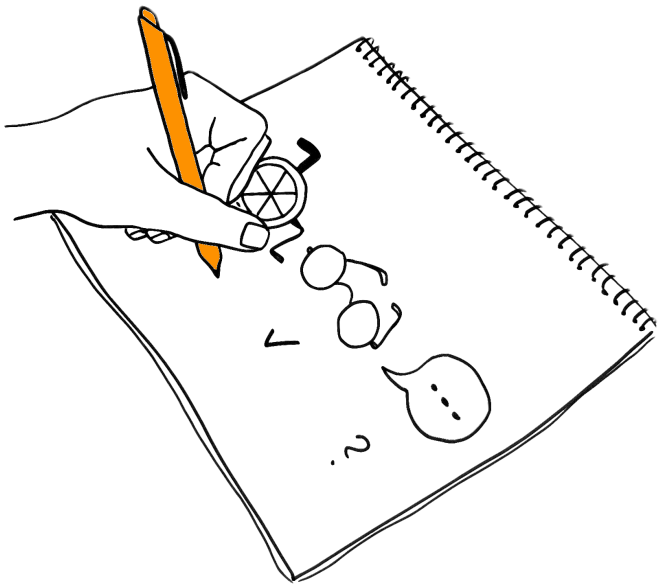


Figure 6: Interactive drawing

2.4. Complex Communication Access Needs

People whose communication requires deliberate, explicit, and intensive interventions, and who cannot be expected to make adaptations themselves, are considered having 'complex communication needs' (commonly shortened CCN) (Sigafoos & Gevarter, 2019). They often rely on AAC to support both comprehension and expression in most interactions (Beukelman & Light, 2020). In recent years, the adapted term 'complex communication *access* needs' (CCAN) has been introduced by Dee-Price (2019), to highlight the responsibility of the communication partner to make sufficient adaptations, as all individuals have the same needs: to understand and be understood. The new term also shifts focus away from the person needing to 'be fixed' in order to communicate. In this licentiate thesis, I use the term CCAN.

People with CCAN may experience communication impairments that are temporary or permanent, and either congenital or acquired. These impairments can result from a range of factors, including intellectual functioning (e.g., intellectual disability such as Down syndrome), difficulties with receptive and/or expressive language (e.g., aphasia following a stroke), structural differences affecting speech production (e.g.,

cleft palate or oral cancer), and/or motor impairments that impact the ability to speak (e.g., cerebral palsy or traumatic brain injury) (Beukelman & Light, 2020; Tönsing et al., 2024).

As the term CCAN only refers to the individual's challenges with communication, the group is extremely heterogenous. Nevertheless, many share common life experiences. In education, for instance, very few pursue post-secondary studies. They also face significant barriers to employment, with the lowest employment rates among all disability groups. Participation in recreational activities is often limited, not only due to communication difficulties but also because of other co-existing disabilities (Tönsing et al., 2024).

For people with CCAN to participate successfully in different environments, they need to meet the communication demands within those activities. This includes not only having access to the proper vocabulary, but also to understand and use social and strategic skills suitable for each particular situation. Without adequate support to develop and use their communication, people with CCAN face even greater disadvantages, as missed opportunities for interaction and learning further exacerbate the impact of their disability (Romski et al., 2005).

Relatively few interview-based studies have previously included children and adults with CCAN (Shiggins et al., 2024; Stafford, 2017; Teachman & Gibson, 2018). Suggested reasons for this are researchers lacking methods for eliciting their perspectives (Wilson & Kim, 2021) and gatekeepers protecting or judging them as unable to contribute (Taylor & Balandin, 2020). However, more recent calls for inclusive research have led researchers to investigate methods to gather data from participants who rely on AAC for communication, although there still remains a lack of information to guide the choice of methods for eliciting data from this group (Teachman & Gibson, 2018; Teachman et al., 2018).

There are numerous contexts in which professionals without formal communication training must engage with people with CCAN, where the individual's right to autonomy and privacy renders the presence of a supporting family member or assistant inappropriate. Such situations can arise in fields such as healthcare (Morris et al., 2013); crisis management and emergency responses (Blackstone & Kailes, 2015); social work (Carling-Rowland et al., 2014); legal proceedings (Volkmer, 2016), or indeed research (Brady et al., 2013). However, existing research addressing how professionals navigate interactions with people with CCAN remains scarce.

2.4.1.Aphasia

An example of a diagnosis that can cause CCAN is aphasia. It is an acquired language disorder, most commonly caused by stroke, that impacts language and communication skills. Depending on the size and location of the injury, it can cause difficulties with language comprehension, language production, and reading and writing skills. Thus, it is a condition with great variability and individual outcome for each person (Hallowell, 2023). The diagnosis only refers to injuries relating to language, while the person's intelligence is unaffected (unless other injuries were sustained as well). Most PWA know more than they can express, but the language barriers mask the individual's true competence.

Research has found people with post-stroke aphasia to report lower quality of life and participation in fewer social, societal, and recreational activities compared to other people post-stroke, even when physical abilities, access to support, and overall health are otherwise comparable. Lowered participation can in part be attributed to not feeling supported by the communication partner or disturbances in the environment (Harmon, 2020), placing a big part of the communication responsibility outside of the individual's own challenges (Herbert et al., 2018).

There are numerous treatment methods and communication strategies to help PWA become more efficient communicators. To aid in comprehension, research suggests that the use of simplified spoken and written language, announcing or highlighting key information, and using large clear fonts or clear handwriting can help people with mild-to-moderate aphasia to better understand pieces of information (Brennan et al., 2005; Jayes & Palmer, 2014; Rose et al., 2003). When it comes to aiding expressive communication, there can be a dissonance between what can be helpful to the person and what adaptations the person can tolerate. For example, many PWA can be helped by the use of picture symbols but may find them childish or patronizing, and therefor refrain from using them (Harmon, 2020).

2.4.2. Physical Disabilities with Motor Speech Difficulties

While aphasia directly affects the language areas in the brain, other communication disabilities can be the indirect effect of another disability. One example is motor speech difficulties due to a physical disability. The most common cause of congenital motor impairments is cerebral palsy (CP), in which more than half of the individuals also have accompanying intellectual, cognitive, or communication impairments (Himmelmann et al., 2013). For individuals with CP or other motor impairments, speech can be dysarthric, characterized by slow, effortful, and unclear articulation due to impaired motor control.

Since the linguistic potential is not inherently affected, many individuals with motor speech difficulties can use linguistically complex AAC methods (Ball et al., 2012; Dahlgren Sandberg et al., 2010). For these individuals, it is the physical restrictions that may limit the use of the AAC systems, for example considering operation and placement of the assistive device (Elsahar et al., 2019; Wells et al., 2023). Depending on where the most reliable muscular function is located—meaning the person can both reach and activate their assistive device repeatedly without excessive fatigue or strain—some may communicate using hand or foot activation, others may use eye-tracking devices, or a head mouse where switches are activated by tilting the head in different directions.

2.5. CCAN in High Stakes Environments

People with communication disorders, particularly those with CCAN, face significant barriers to equitable participation in high-stakes environments such as healthcare and crisis situations. Communication difficulties limit access to vital information, hinder decision-making, and contribute to increased vulnerability (Blackstone & Kailes, 2015; Eriksson et al., 2021; Simmons-Mackie et al., 2025; Volkmer, 2016).

In **healthcare**, clear communication is a prerequisite for access to safe and effective treatment. For people with CCAN, communication difficulties are associated with misdiagnosis, misunderstanding of treatment plans, and inadequate care (Hemsley & Balandin, 2014; Himmelstein et al., 2003; Morris, 2022; Morris et al., 2013). Despite often having complex health needs, these individuals frequently receive substandard care, leading to worse health outcomes compared to those without communication difficulties but with similar medical conditions (Hemsley & Balandin, 2014; Morris, 2022; Stransky et al, 2018; Sullivan & Harding, 2019). In mental health research, people with CCAN have been found to be at increased risk of mental health problems while simultaneously lacking the crucial functional communication for coping with their mental health problems (Østvik et al., 2024). In Australia, for example, adults with CCAN were found to have a 50,2 % incidence of self-reported mental health problems such as depression and anxiety (Australian Institute of Health and Welfare, 2016).

Beyond health-related risks, people with CCAN are more exposed to violence and crime, with limited ability to report or seek justice due to communication barriers. In a study from the United States, 45% of people with CCAN reported being victims of crime, and 71% of these had been victimized more than once, often by someone close to them (Light & McNaughton, 2015; Volkmer, 2016). The barriers to communicate these experiences to the police or judicial system illustrate how communication difficulties intersect with issues of personal safety, autonomy, and justice.

One contributing factor to this exclusion is that many communication systems used by people with CCAN are not designed to support displaced talk—that is, the human capacity to discuss events outside the present moment or context (Berko Gleason & Caldwell Phillips, 2024). As a result, discussions around hypothetical scenarios, such as future healthcare choices or crisis preparedness, may be inaccessible unless communication tools are tailored to support these types of conversations. This restricts their participation in both personal decision-making and broader preparedness efforts, such as crisis management (Blackstone & Kailes, 2015).

During a crisis, communication is central to ensuring citizens' safety, yet accessibility remains a challenge for people with CCAN. Standard announcements often fail to meet the needs of those with hearing, vision, comprehension, or processing difficulties (Blackstone & Kailes, 2015; Kailes & Lollar, 2021; Meltzer, 2020). People with CCAN may require plain language, multiple modalities (visual symbols, audio, easy-to-read text), and repeated information to support understanding (Howard et al., 2017; Osvalder, 2025). Timing is also critical: they need actionable information early, sometimes before the general population, yet adaptations are rarely prioritized initially (Owens, 2006; Meltzer, 2020). Adapted communication should be developed collaboratively with users and advocates (Baxter, 2021), supporting both their rights and the system's capacity to manage crises (Osvalder, 2025).

Despite these needs, there is a notable lack of accessible crisis communication both internationally and in Sweden (Cuypers et al., 2020; Gummesson et al., 2024). The Covid-19 pandemic illustrated this gap: people with intellectual disabilities experienced disproportionately severe or fatal outcomes, not because of increased medical vulnerability, but because they were left without timely and accessible information (Eriksson et al., 2021; The National Board of Health and Welfare, 2021).

A recent knowledge overview on the inclusion of vulnerable groups in Swedish crisis management (Stark et al., 2024) emphasized the importance of actively engaging people with disabilities, including people with CCAN, in co-creating preparedness strategies. Concrete measures include increasing professionals' knowledge of vulnerable groups, involving people with disabilities in testing preparedness plans, and ensuring that both physical and communicative environments are accessible from the outset (Stark et al., 2024).

2.6. Participation

In the field of AAC, the primary aim of communication support and intervention is not merely to find a technological solution to communication challenges but to empower individuals to communicate efficiently and effectively, to engage in diverse interactions, and to participate in activities of their choosing (Beukelman & Light, 2020).

In research literature, the concept of 'participation' is wide and difficult to pinpoint. In a literature review, Hedvall (2017) found that the definition of participation varied greatly, where 34 % adhered to the definition by the International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001), 26 % used 'other' definitions (such as being involved in society or the local community); and 40 % had no clear definition of participation. A predominantly large part of the articles focused on participation limited to sports and recreational activities, similar to the definition by Beukelman and Light (2020) above – '*to participate in activities of their choosing*'. As concluded by Noonan et al (2009); there is a clear lack of a gold standard in the definition and evaluation of the participation concept. Although definitions varied, Hedvall (2017) argued that having different perspectives was preferable to having no definition at all.

In Swedish society, the 'right to participate' is referenced in many situations – but without defining what that means. In 2020, the United Nation's Convention on the Rights of the Child (UNCRC) was incorporated into Swedish law, stating that all children have the right to participate in society, to have an opinion, and to be listened to in all matters affecting them (UNCRC, 1989). This, therefore, applies to all children both in healthcare and in crisis management. In healthcare, the Swedish Patient Act (*Patientlagen*) further protects the patient's right to participate in health care decisions (Swedish Parliament, 2014). How this should be accomplished, however, remains up to every institution to find an answer to.

One key approach to enhancing patients' engagement in healthcare is shared decision-making, in which healthcare professionals and patients collaboratively make choices informed by current evidence as well as the patient's experiences, taking into account various options, goals, and personal preferences (Charles et. al, 1997). While shared decision-making is consistent with the principles of the UNCRC, studies indicate that the participation of children with disabilities in healthcare and habilitation remains limited and risks focusing only on tokenistic (or superficial) choices, like being allowed to choose the toy to play with after a therapy session (Nordtröm et al., 2020).

Participation is especially challenging to achieve when communication or cognitive difficulties are present (Curran and Runs-Wick-Cole 2013; Curtis et al., 2021; Mallett and Runswick-Cole 2014)), and proper tools for involvement are lacking (Karlsson et

al., 2025). This highlights a need for strategies that actively support their involvement in important decision-making. The same is reported for adults with disabilities in healthcare (McCormick et al., 2020). Although shared decision-making aims to enhance patient participation, it typically does not include adaptations for people with CCAN, meaning that communication supports necessary for these patients to fully engage are often lacking. From the field of crisis management, low levels of participation and a lack of participation promoting methods are reported, too (Stark et al., 2024).

In order to evaluate the participation-enhancing effects of the proposed strategies in Chapter 6, I use three different models: (i) The Participation Model to understand the perspectives of AAC-users; (ii) the ICF-model to understand participation as it is viewed from the healthcare perspective, and (iii) Shier's Pathways to Participation to provide a practical tool to evaluate the level of participation. All three models are used by professionals; not by the person with CCAN to evaluate their own participation. In Swedish child and youth habilitation services, some regions apply both the ICF and Shier's model. The ICF is used through standardized forms to structure conversations and guide documentation, while Shier's Pathways to Participation is used by professionals after meetings to reflect on their practice. As Adair et al. (2018) note, assessments for individuals with limited functional communication typically rely on observations and proxy ratings.

2.6.1. The Participation Model

For people with CCAN, there are several reasons to why communication is hindered. The Participation Model (Rosenberg & Beukelman, 1987; revised Beukelman & Mirenda, 2013) is recognized as the predominant model used in AAC interventions, especially in the United States (Dietz et al., 2022). Although mainly used to identify participation patterns and communication needs to plan and evaluate AAC interventions, in this licentiate thesis, I use the model to assess the quality and relevance of the proposed strategies for increasing participation.

The model focuses on two main barriers to successful communication: *opportunity barriers*, which are imposed by the surrounding failing to provide a supportive environment where communication can happen naturally, and *access barriers,* which relate to the person's requirements of adaptations to make communication more accessible. A simplified version of the model is shown in Figure 7, focused on the parts used to assess participation.

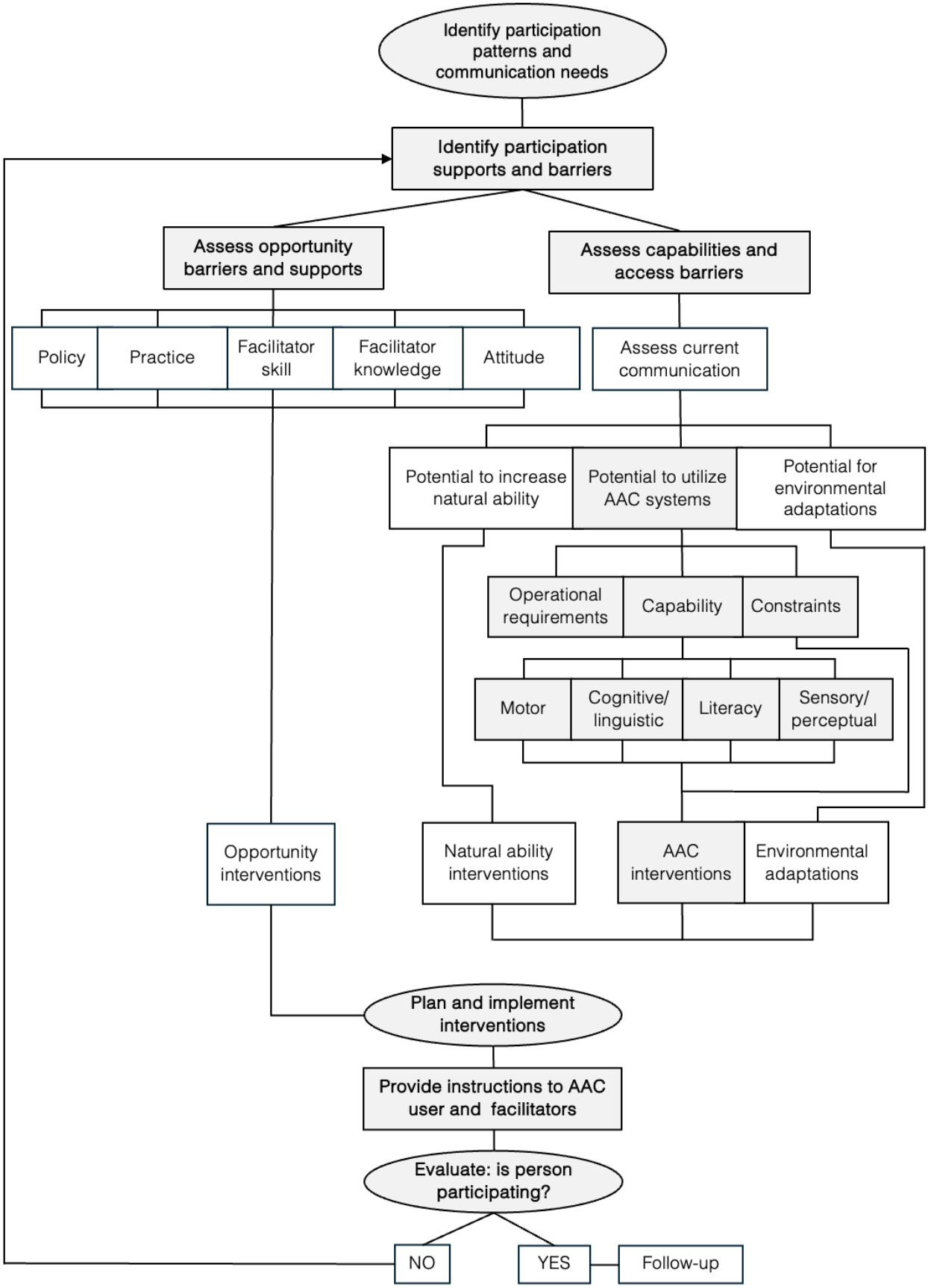


Figure 7: The Participation Model (adapted from Beukelman and Mirenda, 2013).

According to The Participation Model, there are five main barriers to participation relating to the surrounding: policy, practice, skills, knowledge, and attitudes.

- **Policy**: Legislative and regulatory frameworks can support communication access. An example of a policy support in Sweden is The Swedish Act on Support and Service for Persons with Disabilities [*Lagen om stöd och service till vissa funktionshindrade*]). In contrast, policy barriers may be limiting access to communication devices, for example regional differences in guidelines for the prescription of assistive devices.
- **Practice**[4]: Schools and workplaces may facilitate participation through the practices they choose to adopt, for example creating communication support groups. Other practices can create barriers, for example redundancies in communication supporting actions and funding of inclusive activities.
- **Attitude**: Positive attitudes encourage participation, but negative or outdated beliefs create barriers.
- **Knowledge**: Awareness of AAC options among families, professionals, and communication partners supports participation, while lack of knowledge and trainings limits opportunities.
- **Skills**: Effective communication requires both a knowledgeable and skilled communication partner. While some partners develop strategies through experience, others may struggle to become efficient in using AAC.

In The Participation Method, the use of different AAC tools or methods fall under both 'opportunity barriers and supports' depending on the communication partners knowledge and skills to use AAC; and under 'capabilities and access barriers' depending on the individual's potential to use different tools and methods.

2.6.2. The International Classification of Functioning, Disability, and Health (ICF)

ICF defines **participation** as 'involvement in life situations' (WHO, 2001), for example communicating to make friends or taking part in social activities through the use of a communication device. **Participation restrictions**, on the other hand, are the difficulties a person may encounter in engaging in these situations, such as being unable to form friendships or join social activities due to communication barriers, for

[4] note that this is a different use of the word 'practice' than the communication practices examined in this licentiate thesis, as defined under 1.1.

instance lacking a communication device or being in environments that do not accommodate their communication needs.

Participation is seen in the ICF as influenced by:

- **Body functions and structures** – such as speech, language, and cognitive impairments.
- **Activities** – such as using communication devices, understanding conversations. In ICF, activities refer to a person's capacity to perform a task, while participation reflects their actual involvement in a real-life context.
- **Environmental factors** – such as availability of AAC tools, attitudes of others.
- **Personal factors** – such as background, interests, self-confidence, which might affect for example motivation to communicate. Although personal factors are recognized as influential, they are not formally classified within ICF's coding system.

In the ICF, communication is classified under the heading 'Activities and Participation', recognizing its role in learning, social interactions, and community life. Communication challenges are not only seen as impairments but also as barriers to participation, emphasizing the importance of environmental factors (WHO, 2001). The framework is widely used in Swedish healthcare, including habilitation, rehabilitation, and speech and language pathology, where it provides a more holistic view of disabilities, including communication disorders, thus moving beyond impairment-focused assessments, to also include participation and environmental considerations (Hartelius et al, 2024).

Finally, the ICF highlights the need for the individual in question to participate in dialogue concerning them, for the dialogue to be valid – for example in the setting of social service or healthcare. While there are others who may feel qualified to make assumptions regarding a person's health or abilities, ICF stresses the importance of including the person themselves in decision-making, both for ethical and validity reason (WHO, 2001).

2.6.3. Shier's Pathways to Participation

A model to assess participation is Shier's Pathways to Participation (Shier, 2001). Based on an earlier model, 'Hart's ladder'(1992), Pathways to Participation was developed to describe the participation of children with disabilities in formal decision-making contexts. In Sweden, it is used in many settings, including habilitation and social services for both children and adults (The National Board of Health and Welfare, 2017). In research, it has been widely used in health and social sciences, as described by for example Larsson et al. (2018) as well as in relation to

children's participation in disaster management (Jang & Ha, 2021). Shier's model can be simplified to five stages of participation:

1. The person is listened to: they can express their views, but there is no guarantee those views will influence decisions.
2. The person is supported in expressing their views: they receive encouragement and resources to communicate their perspectives.
3. The person's views are considered: their perspectives influence decision-making, but others still hold authority.
4. The person is involved in decision-making processes: they actively participate in making decisions alongside others.
5. The person shares power and responsibility for decision-making: they have equal authority in the process.

2.7. Summary

This chapter has outlined the key concepts relating to communication and participation. Understanding the concepts of disability-related communication difficulties, the tools that can support communication, and models describing participation are crucial when further investigating their complex interplay and ultimately to answer the research questions. The three participation models represent three different approaches that may be relevant to professionals who meet people with CCAN: one focused on AAC-specific participation; one based on medical assessments; and one practical to guide in decision making processes.

Taken together, these perspectives provide a comprehensive foundation for the empirical work in this licentiate thesis, highlighting the necessity of combining disability-focused knowledge with participation-oriented approaches to suggest strategies to improve participation for people with CCAN.

3. Research Design and Methodology

3.1. Research perspective

The work described in this licentiate thesis is shaped in part by my professional background as a speech and language pathologist, with more than a decade of experience supporting people with disabilities and CCAN. Early in my career, I worked within Swedish paediatric habilitation services and at an intensive care unit for stroke patients, where I learned the importance of addressing individual preferences, medical factors, and environmental barriers when communicating. When my work expanded to broader disability contexts, my understanding evolved to embrace perspectives that celebrate diversity rather than focusing solely on challenges to overcome.

In my research I have adopted an approach that integrates Disability Studies, Human Factors Design, and User Centred Design, with an emphasis on user participation and equality as central values, which resonate with the principles of Disability Studies. This approach ensures that the research foregrounds users and their lived experiences and seeks to develop practical, inclusive solutions. Participation is here understood as a shared responsibility to create conditions for genuine and equitable involvement, rather than as an individual's task of adapting to fixed arrangements in the surroundings.

Disability Studies is a research field rooted in social justice that critically examines how societal structures, norms and attitudes impact the lives of people with disabilities. It advocates for rights, equality, and systemic change (Goodley, 2024; Shakespeare, 2014). Disability studies call for a more inclusive and equitable society where disability is recognized as a part of human diversity; not something to be eradicated or stigmatized (Goodley, 2024).

Human Factors Design is an approach that focuses on aligning products, systems, and environments with human abilities, limitations, and needs (Wickens et al., 2004). It integrates knowledge from psychology, ergonomics, engineering, and design to ensure that human interaction with technical systems is efficient, safe, and satisfying. The goal is to optimize both human well-being and system performance by considering physical, cognitive, and organizational aspects of interaction (Sanders & McCormick, 1993). In this sense, Human Factors Design emphasizes understanding knowledge *about* people—their capabilities, errors, and constraints—rather than people's knowledge.

User Centred Design (UCD), in contrast, places users' needs, perspectives, experiences, and expertise at the centre of the design process (Norman, 2013).

Drawing from ethnographic and participatory design traditions, UCD emphasizes processes in which users are actively involved throughout all design phases. The goal is to create solutions that are not only usable and effective but also meaningful within users' real contexts (Norman, 2013; Sanders & Stappers, 2014). A central concept is therefore **usability**, defined as the degree to which a product, system, or environment enables specific users to achieve their goals effectively, efficiently, and satisfactorily (Nielsen, 1993). In this thesis, UCD complements Disability Studies and Human Factors Design by operationalizing inclusion through concrete participatory methods.

Thus, this work is guided by principles of participation drawn from participatory design approaches and disability rights perspectives. True participation means sharing decision-making and power, valuing different types of expertise (including lived experience) and considering the organizational and social factors that can either support or limit involvement. In this sense, participation is both a research approach and an ethical commitment, ensuring that my study helps amplify the voices of people with communication difficulties and supports the empowerment of those whose communication is often overlooked.

In light of the complex interaction between linguistic, cognitive, sensory, and physical factors that shape communication for people with CCAN, understanding their lived experiences requires direct engagement with them. While proxy perspectives can shed light on external observations, for example the perspective of a parent or a caregiver, they cannot capture the nuanced meanings that emerge in real communicative situations. Speaking directly with the person with CCAN—using adapted and multimodal methods—acknowledges their communicative competence and positions them as active contributors to knowledge rather than as passive subjects to be studied. This approach aligns both with the rights-based perspective underpinning Disability Studies and generates insights that could not be accessed through second-hand reports.

3.2. Research process

This licentiate thesis is based on four papers from two research studies conducted between 2018 and 2025 (Figure 8). Both studies received ethical approvals. Study 1 was approved by the Regional Ethics Review Board at Lund University (number 2017/707), and Study 2 by the Ethical Review Authority in Sweden (number 2022-04091-01).

In Study 1, all participating children received adapted information about the study, both verbally and in written form with support from picture symbols. They communicated their consent to participate either verbally or via their AAC systems.

In addition, children who wished to do so also signed a written consent form, which the majority chose to complete. The children's parents received written information accompanied by verbal explanations and subsequently provided written consent for their children's participation. I interviewed only children who were not my patients to ensure that their participation and consent were entirely voluntary and unaffected by any existing therapeutic relationship or concerns about care.

In Study 2, all participants were provided with verbal and written information about the study and gave either written or verbal consent. Bliss communicators provided their consent using their speech-generating devices.

In both Study 1 and Study 2, different methods were used to explore how individuals with disabilities experience and navigate habilitation services or hypothetical crisis scenarios. The original papers, i.e. Papers 1-4, all include findings from a broader range of participants; however, in this licentiate thesis, only results from children and adults with disabilities are considered, while data from other participants (such as parents and professionals) are omitted. This decision was made to ensure that the voices of people with CCAN form the sole basis for understanding needs and preferences as articulated through their own lived experiences.

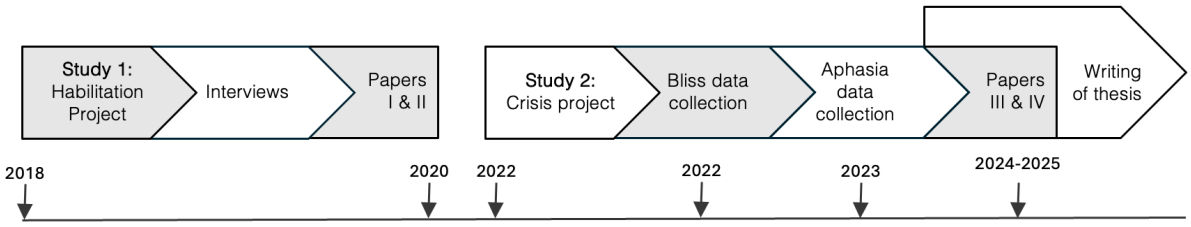


Figure 8: Timeline

The first study (2018-2020) was a research project conducted at Halmstad University in collaboration with the paediatric habilitation in Region Skåne, resulting in Papers I and II. The study aimed to develop a digital decision support tool to promote children's participation in habilitation settings. The tool was meant to support both communication and cognition for all children within the paediatric habilitation services, no matter their disabilities. In addition to the interviews reported in Papers I and II, children took part in a series of co-design workshops where they collaborated with researchers and professionals to generate ideas, test prototypes, and shape the tool's content and format.

The second study (2022-2024) was a research project funded by the Swedish Civil Contingencies Agency [Myndigheten för samhällsskydd och beredskap], resulting in Papers III and IV. The project, called *From Passive Recipient to an Active Resource in the Swedish Crisis Management System*, explored how people with disabilities and their organizations can be actively involved in Sweden's crisis management system to promote diversity, social inclusion, and equality. The study combined participatory

workshops, crisis simulations, and interviews with people with disabilities, professionals, and stakeholders. Methods and tools were developed and tested based on human factors theory, universal design principles, and participatory design, including strategies for accessible communication and trustworthy crisis information.

The research process is illustrated in Figure 9.

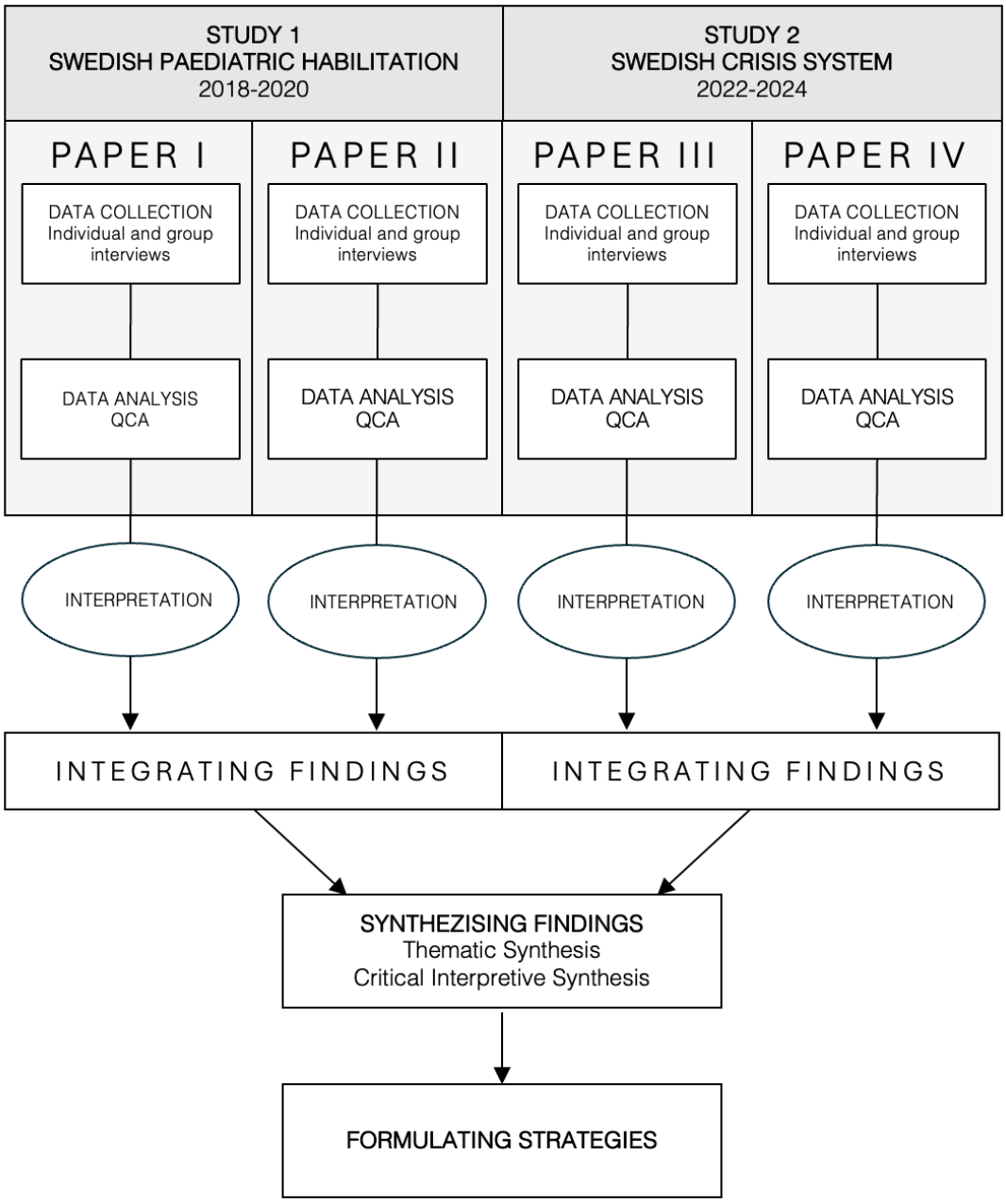


Figure 9: Research process. QCA = qualitative content analysis

3.3. The Studies

This section first outlines the data collection and analysis procedures for the components of Study 1 that led to Papers I and II, followed by the corresponding procedures for Study 2, which produced Papers III and IV.

Prior to data collection, measures were taken to establish positive rapport (i.e. developing a trusting interpersonal relationship based on their personal preferences) with all participants; children and adults (cf. Stafford, 2017; Teachman & Gibson, 2018; Teachman et al., 2018; Wilson and Kim, 2021). These steps included pre-meetings to introduce the research project and allow participants to become familiar with the researcher (the author of this licentiate thesis); allowing participants to choose the location of the research activities to create a responsive and supportive environment; asking in advance about specific needs and preferences; and, when applicable, determining the participants' preferred form of AAC. Throughout data collection in both Study 1 and Study 2, participants were encouraged to express themselves in multiple ways, including through AAC, visuals, and gestures, and were given opportunities to clarify or expand on their responses.

A summary of participants, data collection methods, and communication supports are presented in Table 1 below.

Table 1: Participants, data collection, and communication support used in the studies described in Papers 1-4.

Participants	**Number**	**Data collection method(s)**	**Communication support used**
Children with disabilities	20	Semi-structured interviews	Pre-set communication boards, interactive drawing, manual hand signs, personal AAC systems
Young adults with disabilities	6	Semi-structured interviews	
Adults with physical disabilities	5	Semi-structured interviews	Blissymbolics (personal AAC systems)
	4	Workshop	Blissymbolics (personal AAC systems); Talking Mats; interactive drawing
Adults with aphasia	3	Semi-structured interviews	SCA, manual hand signs
	3	Workshop	SCA; Talking Mats; interactive drawing, manual hand signs
	16	Questionnaire	Support from an aid person if needed

3.3.1. Study 1

Participants
Study 1 involved a total of 26 participants with disabilities, including 20 children aged 6–17 and 6 young adults who had previously received paediatric habilitation services (Table 1). The study also involved 17 parents and 9 professionals, whose data are omitted in this licentiate thesis. The participating children were recruited through staff at their local paediatric habilitation centres in the south of Sweden. Their disabilities varied, including intellectual and/or physical impairments, with some considered to have CCAN. While not all children were identified as having CCAN (a more severe communicative disability), all were considered having communication difficulties due to either intellectual disability, a physical disability affecting speech intelligibility, or autism affecting social interaction. Furthermore, they all participated in the study with the goal of finding improved ways to communicate with their therapists in order to improve their levels of participation. The young adults were recruited to reflected on their past experiences as children in the habilitation services.

Data Collection
While Study 1 involved several different data collection methods, data for Papers I and II were collected through semi-structured interviews. Children were interviewed individually using an interview guide adapted to their communication needs, asking questions about participation in services and decision-making (e.g., 'Is it important to you if you get to make decisions?'). Throughout the interviews, different communication supports were used based on the needs and preferences of each child. The young adults participated in an initial group interview (n=6) followed by individual interviews with two participants, reflecting on previous opportunities for participation and potential improvements. None of the young adults preferred using any communication supports.

Throughout data collection in Study 1, participatory and formative design principles guided the process. While Papers I and II only analysed the interview transcripts, participatory design principles ensured that children were actively involved as co-designers, while formative research enabled iterative testing and refinement of the digital decision support tool based on feedback from successive workshops and interviews (cf. Spinuzzi, 2005; Gittelsohn et al., 2006).

Participants were encouraged to communicate using multiple modalities, including AAC, gestures, and visuals. Research materials such as interview guides and visual supports were iteratively refined based on participant needs and preferences. Measures were taken to establish rapport prior to interviews, including pre-meetings and letting participants choose the location of the research activities.

Analysis
All interviews were audio-recorded and transcribed verbatim. Transcripts were coded and analysed using qualitative content analysis with an inductive approach on a latent level in Paper I with the aim to identify participation facilitators, and on both manifest and latent levels in Paper II (cf. Graneheim et al., 2017), with the aim to identify participation barriers.[5] All participants were given code names, which in Papers I and II were changed to numbers.

3.3.2. Study 2

Participants
Study 2 involved a large number of participants, including young adults with intellectual disabilities, Bliss communicators, adults with aphasia, as well as representatives from disability organizations, therapists, and crisis workers across Sweden. Data from this study formed the basis for Papers III and IV which report findings from 16 adults with aphasia, while Paper III also involved 5 adult Bliss communicators with physical disabilities.

Participants were recruited via local organizations and activity centres. Workshops required that participants lived near one another and were able to engage in interactive sessions, resulting in a smaller sample size compared to the habilitation studies. Bliss communicators also constitute a small subgroup within the population of people with CCAN, which further limited the number of participants it was reasonable to recruit for the study.

Data Collection
Data collection included semi-structured interviews, workshops, and a questionnaire to explore participants' ideas and experiences. Workshops employed the Talking Mats method (Murphy et al., 2007) to facilitate comprehension, expression, and cognition, using visual analogue scales with picture symbols to represent topics. Bliss communicators were guided by familiar personal assistants to reduce fatigue and enhance communication (Collier, McGhie-Richmond, & Self, 2010).

Analysis
Interviews and workshops were audio recorded, then transcribed and analysed using qualitative content analysis identifying both manifest and latent content (Graneheim et al., 2017). Due to the staccato nature of both aphasia and Bliss communication, utterances were combined into complete statements that took

[5] Note that these are the aims presented in papers I and II, not the aim of this licentiate thesis.

several turn-takings to reveal. In this licentiate thesis, I do not include the results generated from the Talking Mats session or the cognitively augmented questionnaire. Although included in Papers III and IV, they do not directly address the research questions.

3.4. Cross-study analysis

3.4.1. Integrating findings

To address RQ1a and RQ1b, an integration of findings was carried out for each pair of papers. For the children's context (Papers I and II) and the adults' context (Papers III and IV), the results sections were read carefully multiple times to gain a comprehensive understanding of the findings. Key communication practices, both those that facilitated and those that hindered participation, were identified and extracted from each study.

3.4.2. Synthesizing findings

To answer RQ2, a thematic synthesis (Thomas & Harden, 2008) was first conducted to identify recurrent communication practices across the four studies. To move beyond descriptions and develop a conceptual understanding of how participation could be achieved through these practices, a critical interpretive synthesis (Dixon-Woods et al., 2006) was subsequently applied.

The thematic synthesis allowed for the integration of qualitative findings across Papers I to IV while maintaining sensitivity to the context and participant perspectives in each paper.

The process involved several iterative steps. First, each of the four papers were read multiple times to gain a more in-depth understanding of the text. Next, initial codes were generated line-by-line, capturing relevant aspects of participation, communication practices, and intrinsic factors such as confidence and motivation. These codes were then grouped into descriptive themes based on similarity and conceptual overlap. Finally, analytical themes were developed by comparing themes across studies, identifying patterns that transcended specific contexts or participant groups. This approach allowed the identification of recurring practices which influenced participation while the richness and nuance of the original qualitative data was preserved.

While the thematic synthesis provided a structured account of recurring communication practices, a subsequent **critical interpretive synthesis** (CIS) (Dixon-Woods et al., 2006) was carried out to move beyond categorization. The aim of the CIS was to identify overarching patterns across contexts and participant groups, and to link these patterns to theoretical concepts, thereby developing a higher-level conceptual understanding of how participation is achieved for people with CCAN.

The process comprised several steps:

1. Compilation of findings: all barriers and facilitators to participation identified in the four papers were systematically compiled, meaning that barriers and facilitators reported in each study were extracted in a structured manner, including relevant quotations and tables, ensuring that all relevant data were captured and could be compared across studies. This included communication-related practices as well as intrinsic factors reported by participants. Summaries were constructed based on tables and quotations presented in the findings.

2. Comparison across contexts: the findings from paediatric habilitation and from crisis preparedness were examined side by side to identify similarities and differences. Particular attention was given to phenomena that appeared in both contexts, even if expressed differently (e.g., 'dominating adults' in habilitation and 'dependence on assistants' in crisis management).

3. Identification of cross-cutting patterns: through iterative reading and reflection, recurring mechanisms were identified that shaped participation regardless of setting or age group. These mechanisms included both external practices (e.g. communication supporting tools, access to adapted information) and intrinsic factors (e.g. self-confidence, motivation, sense of competence).

4. Integration with earlier research: the emerging patterns were interpreted in relation to the three participation frameworks presented earlier in the thesis, as well as to concepts of communicative accessibility, empowerment, and relational autonomy. This step ensured that the synthesis was not only descriptive but also explanatory, by linking the empirical findings to established perspectives in the field.

5. Formulation of overarching categories: the analysis resulted in six overarching areas that capture how communication practices can act either as barriers or as facilitators to participation. Each category included findings from both children and adults, demonstrating that the mechanisms were not bound to one age group or setting but reflected fundamental communicative conditions.

6. Inclusion of intrinsic factors: while the initial focus was on communication practices, the synthesis highlighted that intrinsic factors—such as confidence, motivation, and resilience—also had a significant impact, as they directly affected

the likelihood of the person striving to participate. These factors were therefore integrated into the categories, with particular attention to how they can be shaped or strengthened through respectful and empowering communicative practices.

7. From synthesis to model: finally, the six categories were consolidated into a conceptual model illustrating the interplay between people with CCAN and the professionals and organizations they interact with when talking about habilitation or crisis.

3.5. Formulating strategies

The model derived from the synthesis provided the foundation for developing a set of strategies to promote participation in response to RQ3.

Based on the synthesis, these strategies were further refined to demonstrate how they can be used and incorporated into organizations where professionals meet children and adults with CCAN. The strategies were designed to be accessible and actionable, particularly for professionals with limited prior experience of working together with people with CCAN.

4. Summary of empirical findings

In response to RQ1a and RQ1b, this chapter presents how different communication practices may act as barriers or facilitators for participation as identified by children in paediatric habilitation and adults in crisis respectively.

4.1. Participation barriers and facilitators according to children in paediatric habilitation

This section presents the communication-related barriers and facilitators derived from children within the paediatric habilitation services or the young adults who had previously attended the same habilitation services (Papers I and II).

Children and young adults highlighted several barriers that limited their ability to participate in meaningful ways. A common obstacle was the presence of overpowering adults, especially in meetings that were adult-centred, overly long, or filled with complex language. In such settings, children often felt excluded, stressed, or unsure whether their views were truly welcome. Some described discomfort or fear around sharing their honest thoughts with staff, especially when professionals spoke in a demeaning way or lacked the knowledge to support alternative communication methods like AAC.

Another important barrier was the presence of gatekeepers—adults who, often with good intentions, spoke on behalf of the child or made assumptions about their ability to participate. Unlike overpowering adults who dominate interactions without regard for the child, gatekeepers typically aim to help or protect the child, sometimes even at the child's request. Nevertheless, their actions can unintentionally limit the child's opportunity to contribute independently. Gatekeepers included both parents and professionals who were asked to assist but then took control, as well as situations where adults prioritized parental views over the child's own voice. Some children felt alienated when others discussed their health without including them, or when they weren't given enough time or clarity to understand what was being talked about. A lack of confidence, combined with not understanding the purpose of participation, also made it harder for them to engage. These experiences reflect how easily well-meaning structures can exclude children—especially when their communication or cognitive abilities are misunderstood or underestimated.

Two quotations from children exemplify how adults make decision on behalf of them. In the first quote, the child doesn't think children are allowed to make decisions:

> *Mm, children aren't allowed to do that when you're eight, aren't allowed to make decisions, it's only adults who do and make decisions.* [Child No. 12, Paper II]

In the second quote, the child would like to come forward and make decisions but been held back by low confidence:

> *I've mostly trusted the staff, and been like 'oh well, they decide', and such . . . I'd like to make decisions by myself, but I haven't really dared to speak my mind.* [Child No. 13, Paper II]

As young adults look back on their time at the paediatric habilitation services, there is a clear frustration when they reminisce on their participation in the care. One participant expressed how the professions would direct their conversation to the parent instead of them, when they were children:

> *I think they almost spoke more to my parents than me actually [. . .] I hate it when they're talking with my parents over my head as though I'm not there.* [Young person No. 8, Paper II]

The same participant also explained how the professionals made excuses to talk to the child based on time restraints:

> *They often say 'well, we have so little time'. But I don't think that I'm actually slower than the others—I might have bad hearing but I'm not slow. I think they should talk to me. I think this is why I don't attend anymore [the rehabilitation services].* [Young person No. 8, Paper II]

Regarding communication-related participation facilitators, children and young adults identified several key facilitators that supported their ability to participate meaningfully in conversations and decisions about their lives. Central to this was feeling respected, welcomed, and truly listened to—especially when their expressed opinions had a real influence on outcomes. They emphasized the importance of being encouraged to speak their mind, having the right to object, and being met with undivided attention in safe, child-centred settings.

Participation was strengthened when they had a clear understanding of the topic and their personal needs, and when they could ask questions freely—even about difficult or emotional subjects. Confidence and autonomy were also crucial; having access to reach professionals (alone if they wished, or with support chosen by them), through accessible communication methods, and being offered real choices—including the choice not to participate—helped them feel in control. Finally, children highlighted the value of supportive adults who could help them express or understand feelings, adapt information to their level, and ensure meetings were paced in a way that matched their focus and energy.

The following quote shows how understanding the information and purpose of their healthcare was aided when meetings and information were adapted:

> *They sat down and took their time to explain so that I could understand based on my prerequisites.* [Young person 3, Paper I]

Some children expressed that they understood the importance of the habilitation efforts, such as performing the recommended therapies, and how even boring tasks felt meaningful when they understood the purpose:

> *If I have to do something boring and I don't even know why I have to do it, then it will be even more boring...I have to understand it so that I'm not just showing up at the hospital and don't even know why.* [Child 8, Paper I]

All communication-related participation barriers and facilitators identified in the analysis are summarised in Table 2.

Table 2: Participation barriers and facilitators according to children

Participation barriers

	Communication practices	Negative effect on participation
Paper I	Adult-centred meetings.	Long meetings with intense conversations tha don't adapt to the child's needs.
	Adults dominating the child.	The child feels excluded from conversations. The child is not comfortable telling staff their true opinions.
	Adults protecting the child.	Adults assume too much power after having been asked to help only a little. Parents speaking on behalf of child.
	Professionals requesting the views of parents instead of the child's views.	The child feels excluded.
Paper II	Meetings perceived as stressful without time to make adaptations for the child.	The child is not given the time to understand the dialogue.
	Others discussing the child's health conditions.	The child feels alienated.
	Professionals addressing the child as if the child does not understand.	The child feels that adults are demeaning.
	Professionals not using AAC.	The child feels excluded from conversations.
	Adults underestimate the child's cognitive or communicative maturity.	The child is not encouraged to participate.
	Child avoids speaking their mind.	Non-participation becomes a norm.
	Child not being helped to understand the purpose of their habilitation services.	Low motivation to participate.

Participation facilitators

Communication practices	Positive effect on participation
The child is being listened to.	The child feels that their voiced opinions affe the outcome.
The child in encouraged to request attention.	The child feels confident enough to speak the minds.
The child is encouraged to ask questions.	The child feels confident to ask for help to understand the purpose of their habilitation services.
Adults answer the child's question.	The child gets a chance to understand their habilitation services. Understanding is a prerequisite for being able to communicate about them.
The child is allowed to object.	The child feels like their opinions matter.
Adults encourage the child to speak their mind.	The child feels like their opinions matter.
	The child feels welcomed and worth listening to.
Undivided attention to the child.	The child feels important and listened to.
The child is allowed to understand and discuss the health, even when difficult and scary.	The child gets a chance to understand their health condition.
The child is treated with the same respect as the adults.	The child feels welcomed and worth listening to.
The professionals are easy to get in contact with.	The child can access the professionals' expertise when they need it, through communication means available to them, without the help of parents.
Child-oriented adapted information.	The child gets a chance to understand their habilitation services.
Child-centred pre-meeting with only one staff.	The child feels comfortable and gets a chance to understand their habilitation services.
Meetings are paced to suit the child's needs	The child is allowed time to respond.
allowing time to respond without being overly lon or exhausting	The meetings are not too long and exhausting
Adults support the child to speak their mind when the child wishes them to.	The child's needs and preferences are communicated.
Adults explain to the child when they are unable t understand.	The child gets a chance to understand their habilitation services.
Being given a choice to participate or refrain.	The child feels autonomous.

Paper I

4.1.1. Addressing RQ1a

The findings show that children's participation in paediatric habilitation is continuously negotiated in and through communication. Barriers arose when meetings were dominated by adults, structured around parental voices, or delivered in language too complex for the child to grasp. Such practices created asymmetries that positioned the child as peripheral. Children often internalised these dynamics, reporting hesitation to express their views or resigning themselves to silence.

In contrast, communication practices that acknowledged the child as a competent participant acted as facilitators. When professionals explained information in accessible terms, adapted the pace of meetings, and created child-centred spaces, children reported increased motivation and confidence. Opportunities to ask questions, object, or meet professionals independently further supported their sense of autonomy. Importantly, participation was strongest when children felt listened to and when their contributions visibly shaped outcomes.

These findings suggest that communication practices do not merely transmit information; they configure the very conditions under which children can enact agency. Exclusionary practices reinforce dependence and passivity, while inclusive, trust-building communication practices foster children's confidence and willingness to participate.

4.2. Participation barriers and facilitators according to adults regarding hypothetical crisis

PWA and Bliss communicators described barriers relating to communication that made it difficult to access support or participate in important conversations. Many expressed challenges understanding complex or unclear instructions—especially in critical areas like healthcare or crisis situations—leading to frustration, confusion, and a lack of trust in society's ability to provide accessible information. For Bliss users, communication with unfamiliar people was only possible through personal assistants, making them heavily dependent on others to speak on their behalf.

> *With our assistants, we can do anything. Without them we can do nothing.* [Bliss communicator][6]

[6] While not included as a quote in Paper III, the statement derives from the empirical material collected in Study 2, which also formed the basis for Papers III and IV.

Technological systems were often experienced as inaccessible or confusing, particularly in healthcare contexts, where digital services and communication tools were not adapted to meet their needs:

> *Understanding societal information would be difficult for many with aphasia. Some have more extensive challenges. And I don't think many of them are very skilled at handling technology [like I am].* [Participant with aphasia]

Some also described having small social networks and feeling hesitant to repeatedly ask the same people for help, fearing to become a burden. Difficulties with comprehension, auditory processing challenges, and limited language expression further reduced the ability to engage fully, especially in high-stakes settings.

The participants highlighted key facilitators that made it easier to participate in critical conversations and feel included in crisis preparedness. A strong personal support network, especially among Bliss users, was essential—providing emotional, practical, and communication support. Clear, simplified crisis information in multiple formats (e.g., text, visuals, spoken word) helped both groups better understand and act on important messages.

For Bliss communicators, it was helpful when assistants were explicitly included in crisis strategies, ensuring that communication needs were acknowledged in advance. Participants with aphasia described how prior life experiences of capability—like having succeeded in navigating healthcare or societal systems—could continue to foster confidence even after acquiring communication difficulties.

Assertiveness and problem-solving attitudes played an important role for some, alongside self-esteem grown from successfully accessing information during the pandemic. Others appreciated having options—being able to choose among media formats increased their engagement. AAC tools were used to explain personal communication needs in unfamiliar contexts, and some relied on trusted organizations, such as disability organizations, for additional support. One participant with aphasia explained that the centre, during Covid-19, had played a key role in making sure participants were alright and had understood the directives:

> *The aphasia centre helps many. If we don't show up, they call to see if all is okay. If we are in hospital, they call to help make translations. I call them if I need to.* [Participant with Aphasia]

All communication-related participation barriers and facilitators identified in the analysis are summarised in Table 3.

Table 3: Participation barriers and facilitators in communication practices according to PWA and Bliss communicators

Participation barriers

	Communication practices	Negative effect on participation
Paper III	Complex instructions.	Struggling to understand (PWA).
	Not adapted information.	Low trust in society enabling them to find, understand, and follow instructions (both).
	Personal assistants communicate for them.	Necessary support that enable communication bus disables true autonomy.
	Societal support uses technological solutions	Cannot access if not technologically skilled.
Paper IV	PWA avoid asking questions to not exhaust their small social networks.	PWA do not always receive help.
	PWA do not have anyone to ask for help when they are unable to understand.	Questions are not being asked.

Participation facilitators

	Communication practices	Positive effect on participation
Paper III	Asking help of strong personal network (bliss).	The person is given a chance to understand and respond to important crisis information.
	Simplified crisis information (both).	The person is given a chance to understand important crisis information.
	Multi-modal crisis information (both).	The person is given a chance to understand important crisis information.
	Involving participants in crisis planning.	The persons' preparedness and participation are enhanced.
	Personalized and clear crisis information (PWA).	The person is given a chance to understand important crisis information.
	Assistant-inclusive crisis-plans (Bliss).	The person is given a chance to understand and respond to important crisis instructions when assistants are able to act.
Paper IV	Message is presented in different medias to choose from.	The person is given a chance to understand important crisis information.
	The person asks aphasia centre for help	The person is given a chance to understand important crisis information.
	The person uses AAC to explain their communication needs to others.	The person is involving themselves in the conversation.

4.2.1. Addressing RQ1b

The findings from Papers III and IV (Table 3), demonstrate that communication practices in crisis contexts can either restrict or expand adults' opportunities for meaningful participation. Barriers were most visible when information was presented in inaccessible formats—overly complex, technologically mediated, or not adapted to communicative needs. For people with aphasia, comprehension difficulties compounded the inaccessibility of crisis messages. For Bliss users, the dependence on personal assistants meant that their participation was mediated by others, restricting autonomy. Such dynamics often weakened trust in societal preparedness and heightened feelings of vulnerability.

Facilitators emerged where communication practices anticipated and respected communicative diversity. Simplified and multimodal crisis information, assistant-inclusive planning, and active support from organisations such as aphasia centres provided security and strengthened autonomy. AAC and assertive strategies allowed participants to signal their needs and to take an active role in conversations, even under high-stakes conditions.

Taken together, these findings highlight that communication practices in crisis management are not neutral channels but central determinants of inclusion or exclusion. When practices neglect accessibility, they create dependency and mistrust; when they build in clarity, multimodality, and supportive structures, they promote trust, confidence, and the capacity for participation.

4.3. Additional findings

Across both children and adults, **intrinsic factors** shaped the extent to which individuals could participate. Children frequently described low confidence and uncertainty about how to speak up, even when they wished to. Their ability to demand attention and express opinions was described as closely linked to feelings of self-esteem and security. While supportive adults were recognised as important, participants also emphasised that intrinsic factors—such as feeling capable and confident—played a decisive role. Outgoing or more self-assured children considered themselves more likely to insist on being heard or to signal when they did not understand, suggesting that personality and confidence influenced participation opportunities.

This lack of confidence was often reinforced through repeated experiences of not being listened to or not being given space, indicating that intrinsic factors were not fixed traits but dynamically shaped through interaction. Some children and young

adults accepted silence as the norm, while others sought to challenge it. Notably, no child described themselves as entirely unable to participate.

Among adults, intrinsic factors were expressed in somewhat different terms. Participants with aphasia highlighted their perseverance and problem-solving attitudes, while Bliss users underlined the resilience developed in close collaboration with personal assistants. For many, confidence also stemmed from past experiences of successfully navigating healthcare or societal systems. Yet, when communication barriers accumulated, motivation to participate was undermined, leading in some cases to withdrawal.

Taken together, intrinsic factors such as confidence, motivation, and self-esteem appear not as stable individual attributes but as outcomes of interactional histories. Exclusionary practices weakened them, while supportive and trust-building communication strengthened them, reinforcing participants' willingness and ability to take part.

5. The studies revisited: integration and synthesis of findings

This chapter brings together the findings from Papers I to IV, the conceptual and research-based perspectives outlined in earlier chapters, and my practice-based knowledge from many years of clinical and collaborative work with people with CCAN. The chapter continues to present a model that illustrates how participation can be reached through communicative practices that foster trust between people with CCAN and the professionals and organizations they encounter. The chapter concludes with answering RQ2, which also serves as a bridge to Chapter 6, where the identified practices are translated into accessible strategies to support inclusive practices across different organizational contexts.

The initial focus of the thesis was on communication practices and their role in supporting or hindering participation. However, as the analysis progressed, it became evident that intrinsic factors—such as confidence, motivation, and self-image—also significantly influence whether a person is able or willing to engage in communication. These factors are dynamic rather than fixed, shaped by lived experience, and open to change through respectful, inclusive, and empowering interactions. The synthesis therefore considers both communicative practices (RQ1a and RQ1b) and intrinsic factors, to suggest how participation can be promoted through targeted communication strategies.

5.1. Cross-cutting factors influencing communication and participation

When analysing results across Papers I to IV, several integrative patterns emerged that highlight how communication shapes participation for children and adults with CCAN alike. Although the contexts differ—habilitation focusing on everyday care and crisis management on acute societal preparedness—both groups described communication as the decisive factor for whether they could act as participants or bystanders.

A shared condition was **trust**. For children, trust was undermined when adults dominated, spoke to parents instead, or failed to adapt communication to their needs. For adults, trust was eroded when crisis information was inaccessible or when they were left dependent on assistants or digital systems. In both groups, trust in the communicative encounter appeared to reinforce intrinsic factors such as confidence and willingness to contribute, while mistrust diminished engagement. Trust thus emerges as a cross-cutting synthetising concept.

Barriers overlapped to some extent: both children and adults reported inaccessible or overly complex language, lack of time, and experiences of being underestimated. However, the form these barriers took was context-specific. In habilitation, gatekeeping adults were central, while in crisis management reliance on digital technologies and inaccessible public information dominated. Similarly, facilitators cut across both groups: respectful interaction, adapted explanations, multimodal information, and genuine opportunities to ask questions and make choices all promoted participation.

It is less clear whether disability type in itself determined these experiences. Differences between persons with aphasia and Bliss users suggest that mode of communication can shape dependency (on networks, assistants, or AAC), but the available material does not allow any strong claims. Instead, what unites the cases is that participation hinges on how communication practices acknowledge or disregard individuals' voices.

5.2. Synthesising communication practices

The synthesis process described in Chapter 4 led me to identify six areas of communication practices that facilitate participation: (1) communication accessibility and expression, (2) social accessibility, (3) respectful relationships and empowering dialogue, (4) autonomy and choice (5); structuring for inclusion; and (6) having one's competence acknowledged.

These six areas, derived from barriers and facilitators reported by children in habilitation and adults in crisis management, are also enriched by clinical experience and supported by literature. While they may appear straightforward, their significance lies in showing how participation depends on basic communicative conditions that transcend age and context. The challenge is not in recognizing their importance, but in implementing strategies that reliably meet these requirements. Below, each area is briefly justified and exemplified.

Communication Accessibility and Expression
Both children and adults emphasized that adapted, multimodal communication—such as versatile AAC support, simplified information, and the possibility to choose among different information channels—promoted participation. For children, this meant being supported in finding their own words and tools and given opportunities to build understanding; for adults, it meant being able to follow crisis information and instructions without feeling excluded. This aligns with AAC literature stressing the importance of supporting preferred communication modalities to enhance engagement and

participation (Light & McNaughton, 2012; Beukelman & Light, 2020) as well as my own experiences about the importance of being prepared to use any combination of AAC tools and to humbly ask for help when feeling unable to express or comprehend a message.

Social Accessibility

Responsive and accessible networks were identified as facilitators in both groups. Children valued when they could reach professionals independently, felt welcomed, and had their questions taken seriously. Adults emphasized the importance of having personal assistants or organizational representatives actively included in problem-solving processes. This reflects findings in the literature that social support networks are crucial for participation, both in everyday life and in crisis situations (Light & McNaughton, 2012; Brady et al., 2013). Professional accessibility was also key: showing, not just saying, that all communication modes are welcome. In my own practice, using AAC myself often encouraged the person with CCAN to engage more openly and confidently.

Respectful Relationships and Empowering Dialogue

When professionals offered undivided attention, respect, and explicit encouragement to ask questions or object, children reported feeling empowered to contribute. Adults with CCAN highlighted the importance of strong personal networks and organizations that respected their voice and ensured they were represented in decisions. Respectful dialogue thus emerged across both groups as a condition for active participation. These findings resonate with research highlighting that respectful interactions and empowerment practices enhance engagement, self-efficacy, and willingness to participate (Harder et al., 2018; Kagan et al., 1999; Kagan et al., 2001).

Autonomy and Choice

Providing genuine opportunities to make genuine choices was a central facilitator of participation. Children emphasized the importance of being able to decide how to communicate, which tools to use, and whether to engage in specific activities or not. These opportunities supported their sense of agency and encouraged active involvement in both daily routines and structured sessions. Adults highlighted that being offered meaningful choices—for instance, in how they received information or participated in planning—enabled them to maintain control over their engagement in crisis situations. These findings align with research indicating that experiences of choice foster self-determination and motivation among individuals with communication difficulties (Light & McNaughton, 2012; Ryan & Deci, 2000), and that the given choices must be meaningful instead of tokenistic (Nordström et al., 2020). Communicative practices that build trust in one's own competence and create

room for meaningful choice could benefit both children and adults. In my own experience, the key is indeed to offer *meaningful* choices. Superficial or tokenistic choices, by contrast, risk undermining participation; meaningful choices are those that influence matters of real importance.

Structuring for Inclusion

Participation was facilitators when organizations explicitly planned for inclusion, for example by offering information in multiple media, or ensuring assistants or parents were part of communication structures. Children also appreciated child-centred pre-meetings focused on the child's needs. Literature highlights that inclusive structures are crucial for participation for people with CCAN (Beukelman & Light, 2020; Hemsley & Balandin, 2014). Inclusion is therefore not only about individual encounters but about how systems and services are designed and implemented.

Having One's Competence Acknowledged

When adults recognized children's strengths, built on their existing competence, and treated them as capable, participation increased. Adults with aphasia emphasized that their competence should not be judged solely on their language abilities, but also on their past achievements and lived experience. They valued when organizations or individuals gave them time to respond and recognized them as learners who could grow into participation and helping others in the event of a crisis. These findings align closely with Kagan's SCA methodology, which stresses that recognizing and building on an individual's existing skills is a key facilitator of participation (Kagan, 1999; Kagan et al., 2001). AAC literature also highlights that recognizing an individual's skills promotes confidence and motivation to contribute, including helping others in crisis situations (Light & McNaughton, 2012; O'Sullivan et al., 2018). Across both groups, having one's competence acknowledged reinforced confidence and the motivation to contribute.

Taken together, these six areas capture fundamental conditions for communicative participation that cut across contexts. Despite differences between children in habilitation and adults in crisis management, the core prerequisites are shared. This justifies presenting them as overarching areas and forming a joint basis: both children and adults with CCAN benefit from environments where communication is accessible, respect and autonomy are fostered, and competence is recognized.

Although the empirical material was drawn from two different groups—adults with CCAN in crisis management systems and children in health care settings—the synthesis proposes shared needs for both. The barriers and facilitators identified are grounded in basic communicative conditions rather than context-specific factors. Whether in childhood or adulthood, in habilitation or crisis preparedness, individuals

benefit from environments that are accessible, socially supportive, respectful, empowering, inclusive, and competence-affirming. By articulating strategies at this level, the synthesis provides guidance that is adaptable across groups and settings while remaining firmly grounded in participants' lived experiences.

5.3. Development of a model for promoting participation

Taken together, the six areas illustrate fundamental communicative conditions that foster participation - or implicitly encourage passivity and resignation. When enacted in combination, they build a foundation of trust between people with CCAN and the professionals and organizations they encounter. The *Participation through Communication and Trust* (PCT) model below (Figure 10) illustrates how trust emerges as the outcome of accessible, respectful, empowering, inclusive, and competence-affirming communication practices which ultimately promote participation.

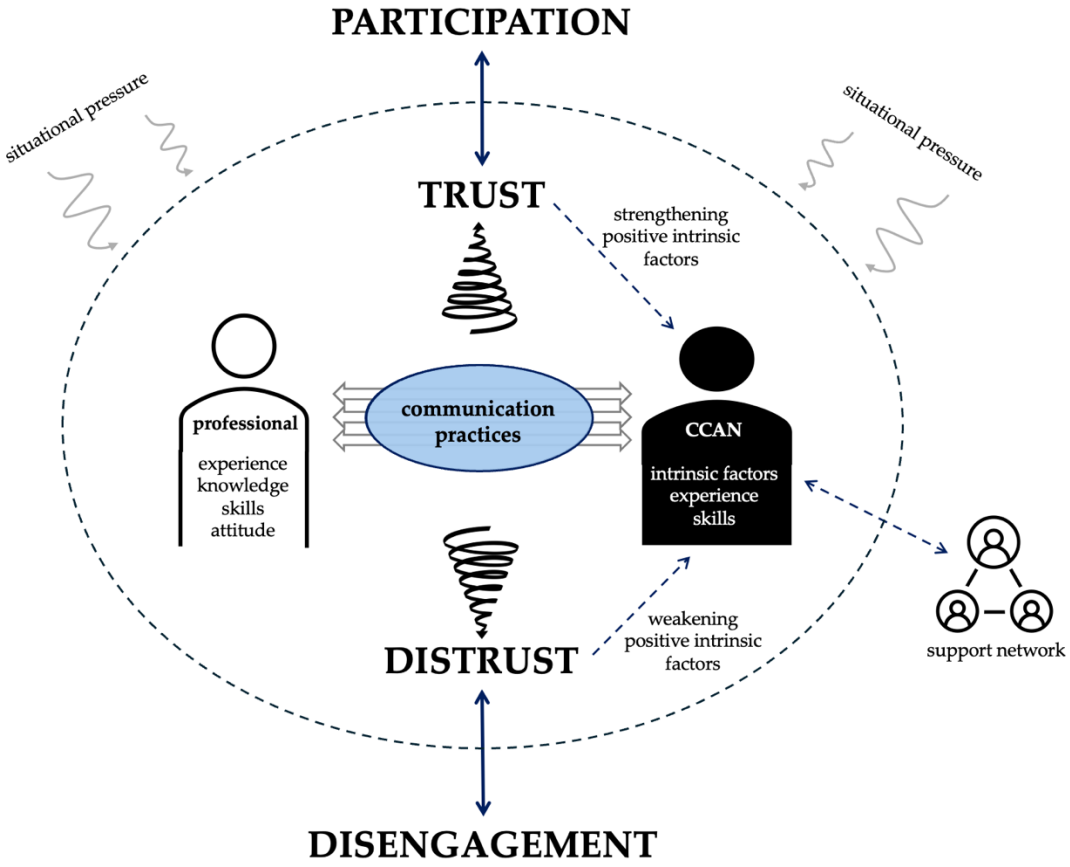


Figure 10: The PCT model

The model illustrates how participation for people with CCAN is fostered through the dynamic interaction between the individual and the professional, unfolding within a broader situation.

At the core of the model are the individual with CCAN and the professional. **The person with CCAN** contributes their interests, skills, experiences, and personality. Their lived expertise strengthens the organization they interact with by offering unique perspectives that might otherwise be overlooked. **The person's network**—such as family, assistants, or peers—may serve as a guiding support but always on the terms of the individual. Their role is intentionally placed in the background to highlight that participation should not be mediated through others unless chosen by the person with CCAN.

The **professional** (e.g. a healthcare professional or a crisis worker), in turn, carries the responsibility to ensure accessibility, fostering social support, building respectful and empowering dialogue, offering genuine autonomy and choice, structuring for inclusion, and acknowledging competence. When these strategies are applied, they strengthen the individual through empowering encounters and promote meaningful participation.

The situation itself exerts a form of **situational pressure**, influencing individuals according to their capacities and the demands placed upon them. In crises, this pressure can be acute and highly tangible, whereas in healthcare it may be more continuous yet equally demanding. Such pressure affects both the intrinsic factors of all parties involved and how communication practices are prioritized and carried out, thereby shaping their possibilities to act and determine what to focus on. For instance, healthcare professionals may face critical treatment decisions under severe time constraints, while individuals may experience fear and uncertainty concerning their health and wellbeing. Similarly, in crisis management, organizations must act rapidly and decisively, while individuals may experience intense stress in confusing or even dangerous situations. Ultimately, situational pressure influences the participants' ability and opportunity to communicate and act in ways that promote participation.

Trust lies at the core and emerges when both parties experience the exchange as positive and affirming. When professionals acknowledge the person's competence and agency, and when the individual perceives openness and genuine interest from the professional, trust begins to form. This trust is not static—it grows or diminishes depending on how communication practices are maintained under pressure. In supportive situations, trust enables both parties to share responsibility. In contrast, when communication practices fail, trust erodes to **distrust**, leading to withdrawal, passivity, and ultimately **disengagement**.

Trust therefore acts as a mediating mechanism between the individual, the professional, and the situation. It transforms potentially hierarchical encounters into reciprocal relations and shapes how each party interprets and responds to the situation's demands. Through this process, intrinsic factors are strengthened.

Participation forms the foundation of the model. It represents the outcome of a cumulative process: when communicative strategies foster trust, when situational pressure is managed constructively, and when intrinsic factors are supported rather than undermined, participation becomes achievable. Conversely, if trust breaks down or situational demands overwhelm the communicative exchange, participation is at risk.

Thus, the PCT model proposes that participation is achieved not solely through communication practices, nor solely through individual agency, but also through the establishment and maintenance of trust in communicative encounters. This trust is co-constructed in the interaction between the individual and the professional, shaped and tested by the situation, and reinforced by the surrounding network when appropriate.

5.4. Addressing RQ2

The synthesis of findings across the four studies identifies a set of shared communicative strategies that influence participation for individuals with CCAN, regardless of age or context.

Across contexts, six interrelated areas of communicative practice were identified as central to supporting participation: communication accessibility and expression; social accessibility; respectful relationships and empowering dialogue; autonomy and choice; structuring for inclusion; and having one's competence acknowledged. Together, these areas constitute a foundation for communicative participation, illustrating that the same underlying principles can either foster participation or disengagement depending on how they are enacted in practice.

6. Strategies to promote participation

This chapter revisits the identified communication practices and transforms them into actionable strategies to promote participation for children and adults with CCAN across different types of services and settings. While communication practices, as defined in section 1.1 of the thesis, are unique to each organization, shaped by its specific focus and contextual conditions, the strategies presented here are intended to be overarching and adaptable across different organizational settings.

First, the strategies are presented in a brief overview, followed by a more elaborate description of how these strategies can be applied in practice. Finally, the proposed strategies are compared to the three models of participation described in under section 2.6 to illustrate their potential to strengthen participation.

6.1. Addressing RQ3

Drawing on the identified areas of communication-related facilitators to participation and the PCT-model, the following strategies (Table 5) are presented to address RQ3.

Table 5: Identified communication practices and corresponding strategies

Identified communication practices	**Strategy**
Communication accessibility and expression	Make communication accessible and support each individual's ability to express themselves
Social accessibility	Create socially accessible environments through responsive relationships and open communication channels
Respectful relationships and empowering dialogue	Treat each person as a valued and equal partner in dialogue
Autonomy and choice	Support autonomy and confidence by offering real choices and positive reinforcement
Structuring for inclusion	Design meetings and interactions that match the person's pace, preferences, and capacity
Having one's competence acknowledged	Show recognition of strengths and capacity by expecting and supporting meaningful contribution

6.2. Strategies in practice

This section transforms the strategies by providing practical guidance for professionals who may encounter people with CCAN. The strategies are intended as a bridge between research and practice, offering concrete advice for communication, planning, and collaboration.

Printable versions are provided in Appendix 1 (English) and Appendix 2 (Swedish). These versions are slightly more elaborate and include suggestions for how the guidelines can be implemented in various organizational settings and services that work with people with CCAN.

1: Make communication accessible and support each individual's ability to express themselves

To support participation for people with CCAN, professionals need to be open, patient, and flexible in their communication. This means providing information in different ways—spoken, written, visual, and/or with symbols—so it becomes easier to understand. Some individuals use AAC tools, such as pictures, signs, or technology, to communicate. You don't need to be an expert to support AAC—what matters most is a willingness to try and to work together to find what works for the individual. Take time to help them understand what the conversation is about and encourage them to express their thoughts and needs in their own way, stressing that you want to understand them.

2. Create socially accessible environments through responsive relationships and open communication channels

Participation depends not only on how a person communicates, but also who is available and willing to listen. Professionals can promote social accessibility by being welcoming, responsive, and approachable, making it clear that questions and concerns are always valid. Make sure the individual knows how and when they can reach you and offer opportunities to connect without needing to go through others (like parents or assistants), when possible. When individuals feel seen, heard, and respected, they are more likely to ask for help, share their views, and take an active role in decisions.

3: Treat each person as a valued and equal partner in dialogue

Participation grows when individuals are met with encouragement, respect, and genuine interest. Make space for them to express opinions, ask questions, or object—even when it complicates the process. Your role is not to lead the conversation, but to invite, listen, and respond in a way that empowers. Position the individual as an active, knowledgeable contributor, and check in regularly to confirm that they feel heard and understood. A small shift in tone or body language can make a big difference in how safe and important someone feels in a conversation.

4: Support autonomy and confidence by offering real choices and positive reinforcement

When individuals are offered authentic choices—including the choice not to participate—they are more likely to engage on their own terms. Confidence doesn't grow from being pushed, but from being trusted and supported. Reinforce positive steps, however small, and avoid assumptions about ability or interest. Make it clear that participation is not about providing a right answer, but about being involved in a way that feels manageable and meaningful to both parties. Help build self-esteem by showing belief in their capability and giving space to practice agency.

5: Design meetings and interactions that match the person's pace, preferences, and capacity

Create settings that reduce stress and support focus. This might mean shorter sessions, quiet spaces, breaks, or pre-meetings with fewer people. Allow time for thinking, expressing, and clarifying, without rushing. Always consider how the structure of the interaction affects participation—what feels normal for you may be overwhelming or disengaging for someone else. Ask what works best, observe carefully, and adapt. Inclusion starts by making space in the flow and rhythm of communication.

6: Show recognition of strengths and capacity by expecting and supporting meaningful contribution

Participation is most empowering when others see and support what the person is capable of. Acknowledge their skills, preferences, and past successes—especially when those aren't immediately visible. Avoid underestimating someone based on diagnosis, speech, or the need for support. Instead, build on what they already know and can do, and invite them to contribute in ways that reflect their strengths. Equal expectations and genuine belief in their ability send the message that their opinions matter, and that their input is meaningful.

6.3. Relating the strategies to models of participation

Taken together, the six strategies align closely with established frameworks of participation. Each model described in Chapter 2.6 emphasizes slightly different aspects, but all three provide useful insights to understand and support the strategies.

The Participation Model: The strategies reflect four central components of The Participation Model—positive *attitudes* (through the promotion of openness, respect, and having high expectations); *knowledge* (awareness of AAC options); *skills* (such as learning through practice, relational communication skills); and inclusive *practices* (through adapting settings, offering choices, providing AAC access). Each strategy addresses these components in different ways:

- Strategies 1 and 2 focus strongly on *practice* and *attitudes*.
- Strategies 3, 4, and 6 emphasize *attitudes* of equality, trust, and competence.
- Strategy 5 highlights *practice*, *knowledge* and *skills* for structuring participation.

The strategies do not address how *policies* can promote participation for people with CCAN.

ICF: The strategies align with all four components of the ICF's multidimensional perspective:

- Strategies 1, 2, and 5 correspond to *environmental factors* in the ICF. They address aspects such as communication access (strategy 1), supportive relationships (strategy 2), and structuring communicative contexts (strategy 5), all of which shape the environment in which participation becomes possible.
- All six strategies relate to *activities and participation*, as they promote real-life communication, decision-making, and active engagement in everyday situations, reflecting the ICF's emphasis on participation in authentic contexts.
- Strategies 3, 4, and 6 correspond to *personal factors*, by fostering autonomy, confidence, self-esteem, and motivation—key elements for sustaining participation and self-determination. The personal factors in ICF are comparative of the intrinsic factors identified in 4.3.
- All strategies acknowledge *body functions and structures*, though this dimension is not central. Rather than focusing on impairments, the strategies

collectively shift attention toward enabling participation and communication in context.

Shier's Pathways to Participation: The proposed strategies together span multiple stages of participation:

- Strategies 1, 2, and 5 correspond to Shier's stage 1 (*being listened to*) and stage 2 (*supported to express views*) by addressing communication access, approachable relationships, and adapted pacing.
- Strategies 3 and six correspond to Shier's stage 3 (*views taken into account*) through…
- Strategy 4 supports Shier's stage 4 (*decision-making*) and 5 (*power sharing*) through the promotion of autonomy, real choices, and recognition of competence.

Strategy 6, recognizing competence, does not align with a specific stage in Shier's Pathways to Communication. However, encouraging people with CCAN to be active in decision-making (stage 4) and sharing power (stage 5) should require some belief in their inherent competence, although not specifically expressed in Shier's model.

7. Discussion

This chapter discusses the findings of the licentiate thesis in relation to previous research, my personal professional experiences and reflects on knowledgegaps and methodological considerations.

The research perspective adopted in this thesis, drawing on my clinical experience as a speech and language pathologist, Disability Studies, Human Factors Design, and User-Centred Design, directly shaped the approach and outcomes. It emphasized the social and systemic dimensions of participation, foregrounded the lived experiences of people with CCAN, and guided the development of adaptable strategies that respect individual preferences, strengthen intrinsic factors, and are applicable across professional contexts.

The studies described in this licentiate thesis involved people with CCAN as active participants and contributors in research. While such involvement may seem challenging to researchers without prior experience, it is both ethically and scientifically necessary. As Clavering and McLaughlin (2010), Shiggins et al. (2024) and Walsh et al. (2024) note, the perceived complexity of including children and adults with disabilities, particularly when flexible and tailored methods are required, can discourage researchers from doing so. This has contributed to a lack of high-quality evidence in the field (Lazarowitz et al., 2025; Shiggins et al., 2024). By demonstrating concrete strategies, I hope that this licentiate can help lower the threshold to meaningfully include people with CCAN across settings, including research.

7.1. Participation barriers and facilitators

The research presented in this licentiate thesis explored how communication practices influence participation for children and adults with CCAN in paediatric habilitation and crisis contexts. The empirical findings demonstrate that participation is not simply a matter of individual capacity but emerges through interaction, structured by the communicative environment and personal intrinsic factors unique to each individual.

For children, barriers to participation included adult-dominated meetings, gatekeeping by parents or professionals, and communication that was overly complex or poorly adapted to their needs. These practices led to exclusion, low confidence, and hesitation to voice opinions. Facilitators included child-centred communication, supportive adults who explained information at an accessible level, opportunities to ask questions, and genuine opportunities for autonomy.

Previous research has shown that the participation of children with CCAN is strongly influenced by adult attitudes and structural practices in healthcare settings (Beukelman & Light, 2020). Consistent with Hemsley and Balandin (2014), my findings highlight how well-meaning adults can unintentionally limit participation through gatekeeping or complex communication.

For adults in hypothetical crisis situations, barriers included inaccessible, complex, or technologically mediated information, dependence on personal assistants, and limited access to supportive networks. Facilitators were simplified and multimodal information, active inclusion of personal assistants in crisis planning, opportunities to use AAC to express needs, and support from trusted organizations, such as the aphasia centre and Bliss organization for the participants in my studies.

Other studies of aphasia and AAC users have similarly documented how adults with CCAN in high-stakes or crisis contexts face barriers such as reliance on support networks and technological accessibility (Brady et al., 2019; Chang et al., 2023).

Across both groups, intrinsic factors, such as confidence, self-esteem, prior experiences, and motivation, interacted with the surrounding communicative environment, shaping the opportunities and capacities for participation. This aligns with previous research indicating that intrinsic factors influence not only attendance, but also the sense of being meaningfully involved in activities (Broomfield et al., 2025; Edström et al., 2024;) and the likelihood of a person with CCAN to insist on being involved (Light & McNaughton, 2014; Olsson, 2021). As argued by Teleman (2025) from a healthcare perspective, increased participation and responsibility in one's own care tends to reinforce motivation, which in turn promotes compliance with healthcare directives and results in better care. Conversely, individuals who are not equipped or motivated to participate are at risk of receiving lower quality care (Teleman, 2025). Based on the findings of this licentiate thesis, this reasoning can be extended: the less motivation professionals are able to inspire in people with CCAN, the less inclined these individuals become to attempt participation. Over time, this can produce a 'Matthew effect'[7], whereby those who are already confident and capable are further strengthened, while those whose intrinsic factors limit participation experience a decline in both motivation and the likelihood of asserting their rights. As explained by Romski et al. (2005), people with CCAN require adequate support to develop and use their communication in social and strategic manners suitable for each situation – otherwise they risk missing out on opportunities for leaning, thereby further exacerbating the impact of their disability.

[7] *The Mathew effect* refers to the cumulative advantage, where 'the rich get richer and the poor get poorer'; see for example Rigney (2010).

In this context, intrinsic factors can be seen as partly corresponding to the ICF's concept of personal factors. While intrinsic factors themselves cannot be removed, communication strategies can mitigate those that restrict participation and promote positive intrinsic factors that encourage individuals to persist in participation despite CCAN.

7.2. Communication practices

As previously defined, communication practices refer to the habitual ways in which communication unfolds in an organization, based on the focus and prerequisites of the organization and its staff. The presence of communication practices that promote participation is crucial for people with CCAN, as they face particular challenges in engaging with key aspects of public life, as stated by Beukelman and Light (2020) and as shown in this licentiate thesis and the appended papers.

The participation promoting communication practices identified from Papers I-IV should be seen as fundamental conditions to facilitate participation for people with CCAN. While they represent basic communication needs, such as being offered accessible communication, met with respect, and having one's competence acknowledged, they still require professionals to make a genuine effort –particularly for professionals without specific training in CCAN.

While many people with CCAN may rely on relatives, assistants, or other members of their close network when communicating with unfamiliar professionals, I would argue that it should not be assumed that such support is always available or desired. As highlighted by the Bliss communicators in Paper III, they prefer to communicate with, or through, someone familiar with their modes of communication—a preference that reflects their right to choose. However, it is not the professional's right to require the presence of another person.

7.3. The PCT model

For both children and adults, trust emerged as a central, cross-cutting mechanism: where communication practices fostered trust, participation was promoted; where trust was undermined, engagement decreased.

The PCT model from Chapter 5 illustrates this by positioning trust as the mechanism linking communicative practices to active participation. The model emphasizes the co-construction of trust between the person with CCAN and the professional, highlighting that participation is promoted not solely by communication practices or

individual agency, but through relational interaction shaped within the current situation.

The six areas of communication practice identified—communication accessibility and expression; social accessibility; respectful and empowering dialogue; autonomy and choice; structuring for inclusion; and acknowledgement of competence—serve as foundational conditions for trust. Trust, in turn, strengthens intrinsic factors such as confidence and willingness to participate, creating a virtuous cycle, as reported by children in Paper I and adults in Paper IV. This aligns with Kagan's SCA framework (1999) and literature emphasizing the role of empowerment and competence acknowledgement in participation (Brady et al., 2013; Light & McNaughton, 2012). If, on the other hand, the communication practices in use cause distrust, this would lead to disempowerment and a culture of disengagement, as told by children in Paper II, who claimed to see no point in trying to participate when gatekeeping adults were present. This negative effect on trust, too, finds support in research literature from both healthcare (Clavel et al., 2021; Zhang et al., 2025) and crisis management (Badu et al., 2023; Mizrahi et al., 2019). While there are plenty of communication models (e.g. Doedens & Meteyard 2018; 2020; Light 1989; Light & McNaughton, 2014), to my knowledge the combination of CCAN, communication practices and trust is unique. Thus, the PCT-model can be used to illustrate how positive communication practices can help strengthen both the individual and the professionals' organization through a foundation of trust.

7.4. Participation-promoting strategies in a professional setting

The findings from both paediatric habilitation and crisis management highlight how exclusionary communication practices can undermine participation by creating dependency, reducing trust, and lowering confidence. The proposed strategies strive to directly target these negative effects. For instance, making communication accessible and supporting individual expression address barriers related to complex or inaccessible information, and can thereby be assumed to ensure that both children and adults can understand and respond. Creating socially accessible environments and fostering respectful, equal dialogue can be predicted to counteract dynamics where adults dominate conversations with children or where dependence on assistants restricts autonomy. Strategies that support autonomy and confidence through real choices and positive reinforcement can be assumed to reverse patterns of passivity, low self-esteem, and tokenistic participation, while structuring interactions to match pace and preferences can help prevent overwhelm or disengagement.

In Swedish habilitation, there is a real risk that participation becomes superficial, where children are offered tokenistic choices such as picking a toy after a training session, as reported by Nordström et al., (2020), Teleman (2025) as well as Paper II. Similar risks appear in crisis management, where adults with disabilities may be included on paper, yet their actual involvement in preparedness work remains minimal (European Disability Forum, 2021; Stark et al., 2024, The Swedish Agency for Participation, 2025). It is my hope that the proposed strategies can lower the threshold for professionals, making it easier for them to involve people with CCAN in ways that genuinely matter, thus avoiding tokenism. As stated by the PWA in Paper IV, they would like to contribute but don't know how.

Although the proposed strategies were developed from two distinct contexts—paediatric habilitation and crisis management—they are intended to be adaptable across a wide range of professional settings. This is because the communicative barriers experienced by people with CCAN often stem from universal challenges rather than context-specific factors (Fylkesnes & Ytterhus, 2021; Yau et al., 2024): inaccessible language, untrained communication partner, lack of communicative patience, and insufficient recognition of competence. As noted by Beukelman and Light (2020), people with CCAN encounter similar obstacles to participation regardless of setting, indicating that the principles underlying communication support are broadly applicable.

Furthermore, studies from an international context indicate that communication practices which support participation are underpinned by three interrelated principles—respect for the person, accessible communication (including adapted information and technology), and competent communication partners—each of which contributes to meaningful participation across settings that transcend specific organizations or systems (e.g., Kent-Walsh et al., 2015; McNaughton et al., 2019; Walsh et al., 2024; Wahl, 2023;). In this sense, the strategies developed in this thesis can be understood as foundational and transferable tools, capable of guiding professionals in for example healthcare, education, social services, and emergency management alike to facilitate meaningful participation for people with CCAN.

7.5. Knowledge gaps

In Chapter 1, identified gaps of knowledge included the limited understanding of how communication practices shape participation for people with CCAN. This licentiate thesis contributes to addressing these gaps by examining interactions in two distinct contexts—paediatric habilitation and crisis management.

This licentiate thesis begins to fill these gaps by exploring how communication practices influence participation in both structured healthcare settings and dynamic, high-stakes crisis situations. What still remains is a deeper understanding of how the proposed strategies can be translated to local communication practices and validated across diverse contexts to consistently support meaningful participation for all people with CCAN.

While numerous AAC resources exist for professionals who regularly work with people with CCAN, such as habilitation staff, speech and language pathologists, and social workers, there is, in my experience, a notable lack of accessible materials designed for professionals with little or no prior experience of the same. These may include individuals who meet people with CCAN only occasionally and who may not receive extensive training. For example, the University of New Mexico has developed a 'Tip Sheet for First Responders' (2021), which is referenced by the European Disability Forum (2021) as a key resource on this topic. However, while the document identifies many types of vulnerabilities, it does not address how to meet or interact with people with CCAN.

For these professionals, what seems to be needed are straightforward, practical ways to convey to the person with CCAN that they are interested, have time, value the person's contribution, and are willing to make necessary accommodations. The strategies proposed in this licentiate thesis aim to reduce communication barriers in such encounters, enabling meaningful interaction between people with CCAN and well-intentioned AAC novices. However, strategies alone are not sufficient; professionals also need concrete tools and structured guidance to apply these strategies in practice. The communication-supporting toolkit introduced in Paper IV represents an initial step in this direction, offering tangible ways to operationalize the strategies in interactions with people with CCAN.

7.6. Methodological discussion

A key methodological strength of this licentiate thesis lies in the direct engagement with children and adults with CCAN on issues that directly affect them. By centring their voices and perspectives over those of proxies, the research ensures that the findings reflect the lived experiences of the participants themselves. This approach

not only respects their communicative competence and agency but also provides insights that could not be obtained through second-hand reports or observations alone.

To support their participation in my research, a variety of methods were employed, including individual AAC devices, Talking Mats, Supported Conversation for Adults with Aphasia, manual hand signs, and interactive drawing. All data collection was conducted by the author, a trained speech and language pathologist, ensuring both professional expertise and sensitivity to the participants' communication needs.

A methodological limitation concerns the composition of the participant groups. Not all of the children had CCAN; rather, they participated in the project to co-develop a communication tool that they all would find useful. Although many were verbal, they nevertheless described communication challenges in habilitation contexts. Their perspectives are therefore highly relevant for understanding communicative barriers and facilitators, but their experiences may differ from those of children with more extensive communication needs.

For the adult participants using Blissymbolics, the presence of personal assistants was both a limitation and a strength. On the one hand, participants might have been hesitant to express sensitive opinions with their assistants present, which could have influenced the data. On the other hand, the assistants played a crucial role in facilitating communication and reducing the risk of researcher misinterpretation. This dual role highlights the complexity of conducting research with participants who rely on mediated communication. Still, as researchers Taylor and Balandin (2018) state, involving people with CCAN in research is ethically important to do, and must be done.

Another limitation is the small number of participants with aphasia. Recruitment was challenging, particularly since the inclusion criteria required participants to live independently without daily support. As a result, this group is underrepresented in the material. This limitation has implications for the generalizability of the findings: the experiences described here only reflect those of three individuals with aphasia who have relatively high levels of independence and manage daily activities without support. People with more extensive communication difficulties or daily living needs may encounter additional barriers or facilitators that are not captured in this study. Therefore, while the findings provide some insights into communication practices that can support participation, caution is warranted when extending the conclusions to all PWA.

8. Conclusion

This licentiate thesis contributes to a deeper understanding of how communication practices shape participation for children and adults with CCAN and informs professional strategies to promote participation in meaningful areas of life within Swedish society. The findings highlight patterns that are relevant across contexts, pointing to fundamental conditions for effective participation. Key conclusions include:

Exclusionary communication practices can undermine participation by reducing trust, lowering confidence and cause disengagement.

Fundamental communicative conditions, including accessibility, respect, inclusion, and recognition of competence, are shared across age groups and professional settings.

Intrinsic factors such as confidence and motivation are shaped through interaction and can be strengthened or weakened by the communication environment, rather than being fixed individual traits.

Practical strategies that target communication accessibility, social accessibility, respectful dialogue, autonomy, structured inclusion, and competence acknowledgment can promote meaningful participation.

9. Future Research

Future research should focus on further developing and validating strategies, practices, and methods that promote participation, particularly targeting professionals without prior training in AAC or in interacting with people with CCAN—those who arguably need this guidance the most.

In crisis situations, there is a pressing need to create strategies that allow individuals with CCAN to communicate complex and nuanced information about the crisis itself, rather than being limited to expressions of pain or stress, while also equipping professionals to respond appropriately and effectively.

In healthcare contexts, research should explore methods that enable professionals to communicate directly with people with CCAN, especially in situations where the presence of a family member or assistant may not be suitable.

To further understand participation, there is a need to validate tools that allow people with CCAN to rate their participation themselves, instead of relying on observations and proxy-ratings.

Regarding my own future work, I aim to build on the strategies identified in this thesis, as well as the toolkit created in Paper IV, by placing a stronger emphasis on the design dimension. My goal is to develop and validate tools that empower people with CCAN to participate meaningfully in all aspects of life that affect them, including participation in research itself.

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