Enhancing communicative participation

by integrating children's contexts into speech and language therapy

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Enhancing communicative participation by integrating children's contexts into speech and language therapy

Verbetering van communicatieve participatie door de integratie van de context van kinderen in de logopedische behandeling

(met een samenvatting in het Nederlands)

Proefschrift

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CONTENT

Chapter 1

General introduction

In recent years, there has been a shift in pediatric healthcare from a strong focus on the disease towards a focus on participation in important life situations (Rosenbaum & Gorter, 2011). Within speech and language therapy, too, this shift is emerging (Westby & Washington, 2017). For children with developmental language disorder (DLD) this means that their treatment increasingly focuses on promoting communicative participation (Cunningham et al. 2017). However, speech and language therapists (SLTs) have limited tools to understand how DLD may affect children's communicative participation, or how to tailor their treatment to the unique context and needs of children in order to optimize their communicative participation.

This thesis focuses on how SLTs can improve the communicative participation of children with developmental language disorder (DLD) through shared decision making with parents and by taking children's contexts into account. The thesis is grounded in the International Classification of Functioning, Disability and Health, Children and Youth Version (ICF-CY) Framework (WHO, 2007), and concentrates on the concepts DLD, communicative participation, shared decision making (SDM), and contextual (personal and environmental) factors.

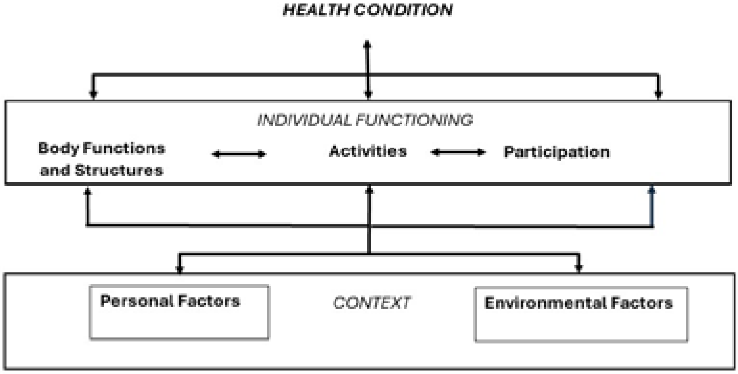
DEVELOPMENTAL LANGUAGE DISORDER

DLD is a neurodevelopmental condition that emerges in childhood and is characterized by unexplained, yet significant, and on-going difficulties in learning, understanding, and using language (Bishop et al., 2017). DLD is a heterogeneous disorder. Symptoms can be either expressive, receptive, or a combination of the two. Phonology, syntax, semantics, and pragmatics may be affected and the specific language problems can change over time (Conti-Ramsden & Botting, 1999; Leonard, 2014). The prevalence of DLD is estimated to range from 3% to 10%, depending on age, measure and definition (Law et al., 2000; Norbury et al., 2016; Tomblin et al., 1997; Weindrich et al., 2000). The language difficulties of children with DLD limit their ability to communicate and interact with other people, and restrict their participation in everyday life at home, at school, with peers, and in the community (Bishop et al., 2017; Dubois et al., 2020; Eady et al., 2018; Feeney et al., 2012; Lloyd-Esenkaya et al., 2020). Children with DLD are more prone to being bullied, have fewer friends, engage in fewer leisure activities, and obtain lower academic and vocational qualifications (Beitchman et al., 1986; Roulstone et al., 2012; Snowling et al., 2001; Van Agt et al., 2010). Even though DLD has been known to be a risk factor for social-emotional development, health, well-being and quality of life, therapy has long focused only on remediating children's specific linguistic problems.

THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH, CHILDREN AND YOUTH VERSION

In the field of DLD, views on communication limitations have been strongly influenced by approaches taught and practiced in biomedicine, with a major focus on the biomedical aspects of a disease or disability, rather than a more holistic view of the functioning of the individual. Since the introduction of the International Classification of Functioning, Disability and Health, Children and Youth Version (ICF-CY; WHO, 2007) the World Health Organization has called on pediatric SLTs to provide care that impacts all aspects of children's experience, including their participation in valued life situations (Westby & Washington, 2017).

Figure 1
The International Classification of Functioning, Disability, and Health—Children and Youth version (ICF-CY) Model of Functioning and Disability (WHO, 2007)



The ICF-CY (Figure 1) is a biopsychosocial model of functioning that visualizes how a child or young person's level of functioning ('Body functions and structures', 'Activities' and 'Participation') emerges from the interaction between the child health condition ('disorder or disease') and contextual factors ('Environmental factors' and 'Personal factors'). It offers a conceptual framework and a common language for researchers, clinicians, educators and policy makers.

Health condition in the ICF-CY is an umbrella term for disease, disorder, injury or trauma. Body functions are defined as the physiological functions of body systems, including psychological functions. Body structures are the anatomical parts of the body, such as organs, limbs and their components. Problems in body functions are referred to as impairments (e.g. phonological impairment). Activity is the execution of a task or action. Participation refers to the involvement in everyday situations and in society. Difficulties at the activity level are referred to as activity limitations (e.g. limitations in talking), and problems children may experience in being or getting involved in everyday situations and in society are denoted as participation restrictions (e.g. restrictions in interpersonal interactions and relationships) (WHO, 2007).

Contextual factors represent the background of a person's life and living situation. Among the contextual factors, the environmental factors make up the physical, social and attitudinal environment in which people live. These factors are external to the person and can have a positive or negative influence, i.e., they can serve as a facilitator or a barrier for a person's functioning. Personal factors are the particular background of a person's life and living situation and comprise features that are not part of the primary health condition. These may include but are not limited to gender, age, lifestyle, habits, and social background and they define the person as a unique individual. Like environmental factors, personal factors can have a positive or negative impact on a person's body functions and structures, activities, and participation (WHO, 2007).

Practical uses of the ICF-CY have demonstrated its effectiveness in realising a more holistic and person-centred type of care, with the focus on children's possibilities of participation, instead of resolution of disease or disability (Cunningham et al., 2017; Holsbeeke et al., 2009; Imms et al., 2017; Rosenbaum & Gorter, 2011). ICF-CY thinking breaks away from the idea that only the treatment of impairments can lead to functional gains. Instead, the different components within the ICF-CY - Body Functions and Structures, Activities and Participation, Environmental Factors, and Personal Factors - are thought to be interrelated and interacting dynamically. This interaction is crucial because it captures the complexity of a child's functioning within his or her environment. For example, children who can participate in life situations through communication (ICF-CY component Participation) gain practice in speaking and understanding language (ICF-CY component Activity), which then leads to a larger vocabulary and more syntactic knowledge (ICF-CY component Body Structures and Functions). Which life situations are important, and how children and their families engage in them is influenced by contextual factors (ICF-CY components Personal and Environmental), some of which can be positively influenced to promote communicative participation.

COMMUNICATIVE PARTICIPATION

Communicative participation is embedded in the ICF-CY model and it includes all forms of verbal and non-verbal communication required for participation in life situations. Eadie et al. (2006) first introduced the term communicative participation in a review of instruments for assessing communication in social contexts. They defined communicative participation as "participation in life situations in which knowledge, information, ideas or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication" (Eadie et al., 2006, p. 309). The term ‘life situations’ corresponds to the participation situations where communication occurs, while the term ’exchange‘ reflects the nature of two-way communication (Yorkston & Baylor, 2010). Participation is a broad construct, encompassing many life domains, such as mobility, self-care, and interpersonal interactions and relationships. Some life situations allow children to participate without communication, such as getting dressed or eating breakfast. However, many participation domains encompass communication. Like a situation where a child discusses the rules of a game while playing with a sibling at home, for example. Or when a child asks the teacher a question because he or she doesn’t understand the instruction. Situations like these, when communication happens within the context of participation, can be referred to as communicative participation.

At the outset of this project, the term "communicative participation" as introduced by Eadie et al. (2006) in scientific literature, was not yet used in Dutch speech and language therapy practice. Therefore, we first focused on the related participation-based construct (Imms et al., 2017), of ‘communicatieve redzaamheid’ (roughly translatable as communicative self-reliance), that emerged in the Netherlands primarily in a legal context related to special education funding for children with speech, language and communication needs (Rijksoverheid, 2005). This concept emphasized the importance of describing children's communication problems in everyday life situations to determine eligibility for specialized educational services. However, a clear definition was lacking as well as behavioural examples that include the perspectives of parents, SLTs, and other professionals involved in the care for young children with DLD. This has led to the use of different idiosyncratic approaches for assessing children's everyday communicative functioning.

COMMUNICATIVE PARTICIPATION AS A RESULT OF SPEECH AND LANGUAGE THERAPY FOR CHILDREN

For children with DLD and their parents, communicative participation is the most important therapy outcome (Baylor & Darling-White, 2020; NVLF, 2022; Prelock et al. 2008). Parents value the development of their child’s language and communication skills, because they see them as necessary for fostering independence, acceptance, and inclusion as well as realizing academic success (Roulstone et al., 2012). Therapy can help children overcome barriers in communication with other people in daily life (Cunningham et al., 2017; Hidecker, 2010; Lyford Jones, 2010; Prelock et al., 2008) and parents value outcomes that help children to participate in life situations (Roulstone et al., 2012).

Speech and language therapists (SLTs) recognize the importance of improving communicative participation for young clients and their parents (Baylor & Darling-White, 2020; Eadie et al., 2006; Prelock et al., 2008), because the ability to communicate is essential for interpersonal contact, which is a basic human need (Baumeister & Leary, 2007). Despite this, SLT interventions for children with DLD in general do not focus on communicative participation (Cunningham et al., 2017). Instead, therapy tends to focus on improving language competence, such as forming grammatically correct sentences, learning vocabulary, or understanding narrative structures. The implicit expectation is that communicative participation increases when a child has better language skills. However, while language proficiency and communication are correlated, their relationship is far from linear or straightforward (Cunningham et al., 2019; Gerber et al., 2012). Growing evidence suggests that language competence alone cannot explain why some individuals with DLD experience more communicative participation restrictions than others (Conti-Ramsden & Durkin, 2015; Cunningham et al., 2019; Gerber et al., 2011;). Moreover, evidence suggests that improved language skills do not automatically lead to better communication performance skills and participation in everyday life (Cunningham, 2017; Westby & Washington, 2017). Targeting communicative participation outcomes is thought to bridge the current gap between treatment of a DLD at the impairment level and a children's actual participation in important life spheres where communication is needed.

UNDERSTANDING COMMUNICATIVE PARTICIPATION OF CHILDREN WITH DLD

The concept of 'communicative participation' as an outcome in therapy has been well established in adult communication disorders (Eadie et al., 2006; Jin Jingyu, et al. 2021) but is relatively new in the context of DLD. Traditionally, DLD has been assessed and treated predominantly at the level of language functioning and activity, which are easily observable and objectively testable (Cunningham et al, 2017; Eadie et al., 2006; McCormack & Worrall, 2008). However, focusing solely on a child's language abilities does not fully capture their functional communication skills and their ability to participate in everyday life situations in a meaningful way (Cunningham et al., 2017). Various constructs such as social communication, life participation, and quality of life have been proposed, but none of them align closely with the objective of language therapy, which is to enhance everyday communicative functioning. This misalignment has led to measurement instruments that are not well-suited for assessing the outcomes of speech and language therapy.

The implementation of the ICF-CY has highlighted the need for the development of outcome measures for assessing communication in daily life (Cunningham et al. 2017; Izaryk et al., 2015). Valid and reliable instruments can provide information on the everyday communication of children with DLD, which can help SLTs to plan and evaluate their treatments using patients' experiences with everyday communication (Greenhalgh et al., 2017). In recent years, some instruments have been developed and are now being used in clinical practice. For example, the Focus On Communication Under Six (FOCUS) parent questionnaire for measuring real life change as a result of therapy has been translated into multiple languages, highlighting the growing importance of measuring participation outcomes globally (FOCUS, Thomas-Stonell et al., 2010). Despite this progress, recent critical appraisals of paediatric social communication assessments concluded that none of the available instruments adequately represents all the relevant social communicative contexts that are distinguished in the ICF-CY (Alons et al., 2024; Izaryk et al., 2015). Recently, efforts have been made in developing a comprehensive pediatric communicative participation item bank, signalling advancements in this area (Alons et al., 2024).

THE INFLUENCE OF CONTEXTUAL FACTORS ON COMMUNICATIVE PARTICIPATION

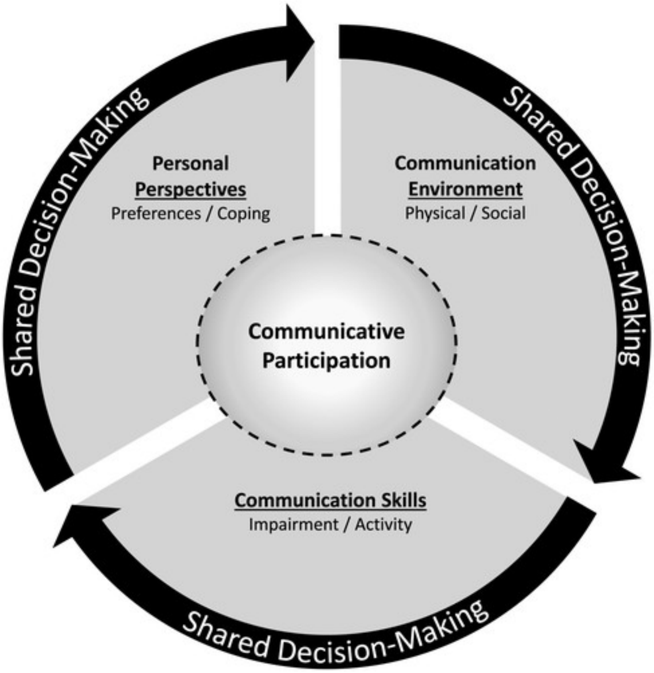
Variations in communicative participation of children with DLD cannot be wholly explained by their language difficulties alone (Conti-Ramsden & Durkin, 2015; Cunningham et al., 2019; Gerber et al., 2011), and are likely influenced by contextual factors (Dempsey & Skakaris-Doyle, 2010; Howe, 2008). The Children & Youth version of the ICF (ICF-CY; WHO 2007) conceptualises functioning and disability as a dynamic interaction between a child’s health condition and contextual factors. Contextual (personal and environmental) factors can be barriers to or facilitate communicative participation of children with DLD. SLTs may aim to minimise barriers by tailoring interventions to individual children’s and families’ needs (WHO, 2007). Contextual factors that facilitate communicative participation can guide the development of individualized goals and care plans for children with DLD that aim to boost resilience (Luthar & Cicchetti, 2000). However, insight into which contextual factors are relevant to address in therapy is currently lacking in SLTs.

SHARED DECISION MAKING WITH PARENTS

Baylor and Darling-White (2020) proposed a framework to support participation-focused interventions through shared decision making (SDM) (Figure 2). The authors restructured elements of the ICF-CY (WHO, 2007) to aid clinical practice and help clinicians provide more person-centered care. In this framework, communicative participation is placed at the centre as the primary focus of therapy. Specific communication skills, environmental factors, and personal perspectives support communicative participation. The circular design of the figure symbolises the absence of an inherent hierarchy between communication skills, the communication environment, and personal perspectives, emphasising that each deserves equal consideration and that they can influence each other. The dotted boundary between communicative participation and the surrounding elements signifies the interactions between these components and the constant exchange of influences. Finally, the outermost circle with the words 'Shared Decision-Making' signifies the importance of discussing the different elements with parents of young children with DLD and reaching a collaborative decision about the most appropriate goals for communicative participation (Baylor & Darling-White, 2020).

Figure 2

The framework proposed by Baylor and Darling-White (2020) to guide participation-focused intervention practices



SDM is an important element of family-centered care (FCC), which is the current standard of practice in pediatric healthcare (American Academy of Pediatrics Committee on Hospital Care, 2003). Shared decision making (SDM) has been defined as 'an approach where clinicians and patients [parents] share the best available evidence when faced with the task of making decisions, and where patients [parents] are supported to consider options, to achieve informed preferences' (Elwyn et al., 2012). Although this definition applies to all aspects of treatment planning and evaluation, SDM models have neglected goal setting as an explicit step (Elwyn et al., 2020). Despite the strong case for engaging parents in speech and language therapy, research indicates that SLTs currently have a central role in the goal-setting process, rather than parents and children (Roulstone, 2015; Watts Pappas & McLeod, 2009). SDM is a prerequisite for addressing communicative participation in speech and language therapy, because SLTs cannot evaluate or observe a child's communicative participation directly in a clinical setting and rely on information from parents and child instead. However, SLTs lack knowledge and tools for including the parents' perspective in participation focused interventions for young children who cannot yet advocate for themselves.

CENTRAL PROBLEM AND RESEARCH GAPS ADDRESSED IN THIS THESIS

Little is currently known about the impact of DLD on communicative participation, and the personal and environmental factors that may impact on communicative participation. This thesis tackles three research gaps stemming from this central problem.

Firstly, we currently do not know how children and their parents conceptualize communicative participation, and neither do we know whether consensus exists on the construct between families and professionals involved in the care for young children with language and communication problems. A practice-based definition and operationalization can clarify what parents and professionals see as the ultimate goal of therapy for children with DLD.

Secondly, SLTs cannot evaluate or observe a child's communicative participation directly in a clinical setting. Instead, they need to ask parents for information on a child's communicative participation in order to develop personalized goals for therapy. Currently, there are no instruments that engage both parents and SLTs in the goal setting process and the evaluation of therapy goals. It is unclear how SLTs can include parents in the decision making on therapy goals for communicative participation. Clarifying this issue can help SLTs to place parents in the centre of the goal setting process, a step towards using SDM in clinical practice.

Thirdly, to attain personalized goals through therapy SLTs need to know how a child's and family's context influences communicative participation. Insight is lacking on the associations between contextual factors and communicative participation (Threats, 2008) and communicative participation as an outcome of therapy has not been researched enough (Cunningham et al., 2017). A better understanding of how contextual factors influence communicative participation can help to tailor therapy to the needs of children and their families.

AIM AND RESEARCH QUESTIONS

The general aim of this thesis is to improve communicative participation by developing knowledge and tools that can bring the contexts of children with developmental language disorder and their families into speech and language therapy. We wanted into gain insight in what communicative participation of young children with language problems entails from the perspective of different stakeholders, explore how contextual factors shape communicative participation outcomes, and how parental perspectives on communicative participation outcomes can be taken into speech and language therapy.

The research questions addressed in this thesis are:

1. How does a panel of parents, teachers, SLTs, and other professionals define and operationalise communicative participation (CP) of 2-to-8-year-old children with language disorders? (chapter 2)
2. How did a co-design process with SLTs lead to the development of a shared goal setting tool for SLTs (the ENGAGE tool) to use with parents of children with DLD? (chapter 3)
3. How can the TIDIeR checklist and guide be used to describe the tool ENGAGE for use in clinical research and practice? (chapter 4)
4. What is known in existing literature about risk and protective contextual (personal and environmental) factors present in early childhood associated with communicative participation in school-aged children with DLD; and which possible gaps in knowledge about this subject can be identified? (chapter 5)
5. What are SLTs' perceptions of contextual factors associated with the communicative participation of children with DLD? (chapter 6)

OUTLINE OF THIS THESIS

Chapter 2 of this thesis describes consensus development in a Delphi study with parents and professionals on the definition and operationalization of the concept of communicative participation (research question 1). **Chapter 3** describes the development through co-design of a tool for shared decision making on personalized therapy goals to be used by SLTs with parents (research question 2). **Chapter 4** describes the tool for shared goal setting (ENGAGE) using the TIDIeR checklist and guide (research question 3). **Chapter 5** describes a systematic scoping review on contextual (personal and environmental) factors associated with communicative participation in language impaired children (research question 4). **Chapter 6** describes the results of a focus group study on SLT's perspectives on contextual (personal and environmental) factors that impact on the development of communicative participation in children with DLD (research question 5). **Chapter 7** presents a general discussion, where the results of the studies are integrated, the main findings are discussed, methodological considerations are presented, suggestions for future research are made and clinical implications are provided.

The data used in this thesis were partly collected in the research project ENGAGE (Singer et al., 2019), funded by FNO under grant 101.353.

This thesis is written in British English. However, some chapters consist of previously published articles that appear in US English, as per the conventions of the journals in which they were published. These articles have been reproduced without alteration.

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Chapter 2

A multidisciplinary Delphi consensus study of communicative participation in young children with language disorders

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ABSTRACT

Purpose

Our aim was to develop consensus on the definition and operationalization of communicative participation (CP) in 2- to 8-year-old children with language disorders (LDs). A clear definition and operationalization can facilitate the discussion about children's communication problems in daily life between parents and professionals.

Method

In an online Delphi study, anonymized thoughts and opinions were collected on the definition and operationalization of CP in young children with LD. The 47 Delphi panel members were Dutch parents, young adults with LDs, teachers and assistants, speech-language pathologists, clinical linguists, and clinical researchers. Thematic content analysis was used to develop a concept definition and items operationalizing CP. The Delphi panel rated the suitability of concept definitions using a 7-point Likert scale. Concept definitions were revised with feedback from the Delphi panel until consensus was achieved. The Delphi panel rated items on how well they operationalize CP, using the same Likert scale.

Results

The majority (79%) of the Delphi panel indicated that the essence of CP was captured by the definition: "CP is understanding and being understood in a social context, by applying verbal and non-verbal communication skills." In addition, 33 behavioral items were developed.

Conclusion

This study resulted in strong consensus on the definition of CP between Dutch parents and professionals. Items were developed that can inform speech-language pathologists on the type of questions to ask a child's parents or teacher when discussing CP. Further research is needed on how the items can best be used in clinical practice.

INTRODUCTION

Children with language disorder (LD) have difficulty understanding language and producing words or sentences. Signs and symptoms of LD vary across children, depending on the language domain(s) affected, the severity of the problems, the age of the child, and the stage of linguistic development (Conti-Ramsden & Durkin, 2015). LD can be associated with intellectual disability (ID) or autism spectrum disorder (ASD), but in many cases, no underlying cause is known (developmental language disorder [DLD]; Bishop et al., 2017). It is one of the most common types of childhood developmental problems (Law et al., 2000; Tomblin et al., 1997). Although children with LD fall within different etiological and clinical classifications, a common denominator is that their limited linguistic abilities disrupt communication in everyday interactions with their parents, peers, and unfamiliar persons (Bishop, 2004; Catts, 1993; Conti-Ramsden & Botting, 2004; Dempsey & Skarakis-Doyle, 2010; Fujiki et al., 2005; Hart et al., 2004; Snowling et al., 2001; Van Agt et al., 2010). Language and communication are fundamental for a child's cognitive, social, and emotional development and well-being, and LDs can have a profound impact on a child's development (Roulstone et al., 2012). Parents value the development of their child's language and communication skills, because they feel they are necessary for fostering independence, acceptance, and inclusion as well as realizing academic success (Roulstone et al., 2012). Parents, speech-language pathologists (SLPs), teachers, and other professionals who work with children with LD consider successful communication in everyday interactions as the ultimate goal of interventions for children with LD (Cunningham, Washington, et al., 2017; Hidecker, 2010; Lyford Jones, 2010; Prelock et al., 2008; Roulstone et al., 2012).

In recent years, therapy focus has shifted away from the impairment and increasingly includes participation outcomes. Traditionally, language therapy interventions targeted impairments in language form (phonology, syntax, and morphology), content (semantics), and language use (pragmatics; Bloom & Lahey, 1978; Ingram, 1976; Leonard, 1975). Clinicians acting within the traditional biomedical perspective assumed that communication problems reside within the child with LD and that therefore the SLPs' job is to remedy the client's knowledge of linguistic and pragmatic language rules (Duchan, 2011). However, functional gains cannot not be assumed when improvement of body function is the target of intervention (Rosenbaum & Gorter, 2012). Over the years, it has become clear that knowledge of language structures and rules does not automatically transfer to better communication outcomes for children in everyday life (Westby, 2007; Westby & Washington, 2017). Implementation of the World Health Organization's (WHO's) International Classification of Functioning, Disability and Health-Children and Youth (ICF-CY; WHO, 2007) as a framework allows clinicians to develop a comprehensive view on of health, integrating biological and social perspectives (Ma et al., 2008; WHO, 2007). The ICF-CY has been developed as a framework that can deal with functioning, disability, and health, independent of the etiology of a child's impairment, and it implies greater emphasis on participation outcomes (Dempsey & Skarakis-Doyle, 2010; McLeod & Bleile, 2004; Prelock et al., 2008; Washington, 2007; Westby & Washington, 2017). Since the introduction of the ICF-CY, clinicians' approach in treatment of young children with LD has shifted from solely targeting children's language knowledge and skills toward improving children's actual participation in real-life communicative activities (Dempsey & Skarakis-Doyle, 2010). With that, improving communication in everyday life has become the ultimate goal of speech and language therapy (Prelock et al., 2008).

Consulting parents or others who know the child well helps identify goals that are relevant and grounded in a child's daily life (Glogowska & Campbell, 2000; Watts Pappas et al., 2008; Westby & Washington, 2017). Research in other fields of allied health care has provided evidence for the necessity for including the child's environment in service provision. For example, in a study on occupational therapy, children and parents valued functional outcomes, while professionals tended to focus more on the improvement of physiological functions of the body (Costa et al., 2017). The collaboration between the health care professional and the parent or patient forms part of shared decision making (SDM), which has been described as two-way communication and information exchange (Charles et al., 1997). In SDM, patients, families, and professionals are all considered key partners who should contribute to the clarification of intervention goals (Kokorelias et al., 2019). The success of SDM depends on the level of joint understanding of the child's problems between the clinician and the parents or caregivers and requires communication processes that respect individual agency and autonomy and that support an empathic approach to practice (Elwyn et al., 2014). However, engagement and effective communication with parents throughout the goal-setting process appear to be complex (Oien et al., 2010). Although SLPs usually discuss the area(s) of the child's language deficits with parents and work with them to develop treatment goals, studies reveal that they tend to overestimate the level of actual parental engagement in the decision-making process (Watts Pappas et al., 2008). How well parents understand the treatment goals and see their relevance has an impact on their capacity to take an active role in the goal-setting process. This means that the SLP should clarify the many aspects of everyday communication that parents can consider, giving them the vocabulary to describe their child's communication problems in detail. Without this, there is the potential for a mismatch between what professionals and family see as desirable treatment outcomes. In addition, clinicians may steer decisions toward therapy aimed at remediating structural language skills when information about the impairment is more readily available than information on participation problems. The extent to which the therapist is able to support parents during the goal-setting process therefore affects the extent of collaboration between them and the parent (Forsingdal et al., 2013).

Agreement on communicative participation (CP) is critical for the goal-setting process. A shared frame of reference between parents and service providers is a necessary condition for parental engagement in the therapy process and for accomplishing improved service delivery and functional outcomes for the individuals served (American Speech-Language-Hearing Association, 2016; Lyon et al., 2010). Currently, such a shared frame of reference is lacking with regard to CP for young children with LD, because CP has not yet been defined and operationalized for this group. Eadie et al. (2006) proposed a definition of CP in adults for research purposes. This definition states that CP is “taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication” (Eadie et al. (2006, p. 309). Researchers interested in child LDs have adopted Eadie et al.’s definition (e.g., Cunningham, Hanna, et al., 2017; Thomas-Stonell et al., 2013). However, it is currently unclear whether parents of children with LD, SLPs, and other professionals recognize this conceptualization.

The aim of the current study is therefore to develop a definition and operationalization with behavioural examples using an online Delphi study with a panel of parents, teachers, SLPs, and other professionals. In this study, we focus on CP of children aged 2-8 years, because we invited parents in the CP Delphi panel as their representative assuming that children up to the age of 8 years are likely to experience barriers to self-report on their health problems (Morris et al., 2009; Rebok et al., 2001). The operationalization adds to the definition in that it provides behavioral indicators of CP in young children with LD that can empirically observed. This information can be used for developing decision support materials and for training, which in turn can inform and engage parents from all walks of life and educational backgrounds (King et al., 2011; O’Connor et al., 2009).

METHOD

The Delphi study technique is a widely used method for transforming individual opinions on a specific topic into group consensus by exchange of written information, which makes it particularly well suited to reach our aim (Hasson et al., 2000; Keeney et al., 2001). The findings are presented according to the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

Delphi panel members

Since no consensus exists on the optimal size of a Delphi panel (Okoli & Pawlowski, 2004), the aim was to create a Delphi panel that was large enough to represent the views of different stakeholders but small enough to enable group discussion and the exchange of views and information. We aimed to establish a panel consisting of 40-50 participants, all native Dutch speakers. The Delphi panel members were recruited via letters on social media, including professional, parental, and patient networks. Clinical researchers in the LD domain were personally invited based on their research interests and experience. Selection criteria were the following:

- Dutch clinical researcher on language or language development on one of the patient groups (DLD, ASD, ID);
- not connected to author's university; and
- have at least one article published after 2010 in a (Dutch) scientific journal on language and communication in children with DLD, ID, or ASD.

For each patient group, two researchers published most frequently on the subject were selected. When the first selected experts did not reply or did not wish to participate, we invited the next one on the list until two experts per LD group were included. Due to the linguistic and cognitive complexity of the subject, young children with LD were not included in the study. Instead, parents of children with LD participated to serve the interests of their children. In the original design of the study, we aimed to include young adults with LD, because they could reflect from personal experience on which aspects of CP are important. However, in consultation with the young adults, their participation was set out to be limited to the part of the study where items were rated, as they did not feel comfortable to be involved in the discussion about a definition. In addition, face-to-face support was provided by one of the first two authors, who are both SLPs, to help them whenever necessary. Professionals were included who work with children with LD, such as SLPs, children's psychologists, teachers and teaching assistants, clinical linguists, and researchers involved in clinical research on children with LD. In total, 105 SLPs, 14 teachers and teaching assistants, seven clinical linguists, four children's psychologists, 22 parents of children with LD, six clinical researchers, and five young adults with LD expressed an interest in participating in the study. All clinical researchers were trained as SLPs, and four of them were also trained as clinical linguists. Two of them had a PhD degree, and two were PhD students. The response in some groups of participants was higher than anticipated. In order to obtain optimal heterogeneity in the sample, maximum variation sampling was used in these groups by looking at work setting, geographic location, and years of working experience with children with LD. The selected parents varied in the diagnosis of their child (DLD, ID, and/or ASD), their child's age, and the region where they live. The characteristics of the Delphi panel are displayed in Table 1.

Ethical approval

This research was approved by the HU University of Applied Sciences Institutional Review Board (Reference Number 41_002_2016). All Delphi panel members gave their written consent, and feedback to other panel members was provided anonymously. Panel members' names and contact details were known to the first two authors only.

Table 1

The Delphi panel

	Number of participants	**Working with children with/ having children with/involved in research on children with[a]:**			**Years of working experience, child age, age M (*SD*)**	**Work setting**
		DLD	**ASD**	**CI**		
Children's psychologists	4	3	2	1	20.2 *(8.4)*	Early & special education (n=4)
Clinical linguists	4	4	2	1	13.8 *(6.1)*	SLP practice (n=2) Early and special education (n = 2)
Clinical researchers	6	5	2	1	n.a.	Early & special education (n=3) Universities (n=3)
Speech and language therapists	11	10	7	4	13.9 *(6.5)*	SLP practice (n=5) Early & special education (n=6)
Teachers and teaching assistants	7	5	4	1	16.6 *(11.8)*	SLP practice (n=2) Special education (n=5)
Parents	10	7	2	3	5.6 *(1.7)*	n.a.
Young adults	5	3	3	0	25.4 *(0.5)*	n.a.
Total	47	37	22	11		

Note. N.a. is Not Applicable.

[a] Some professionals have experience in working with children with comorbidity, some clinical researchers are involved in research with different groups of children, some parents reported having children with comorbidity, some young adults reported comorbidity.

Procedure

No clear guidelines exist regarding the optimal number of rounds for a Delphi study (Hasson et al., 2000). In order to limit the burden for panel members and to prevent sample fatigue, we restricted the maximum number of rounds to five within a time frame of 4 months. The Delphi process was cyclical, with panel members giving input and opinions repeatedly and moderators feeding back summaries of opinions within the group, while allowing for interaction and engagement between panel members (Hasson et al., 2000). Throughout the Delphi process, the first two authors acted as moderators and were responsible for survey development, data analysis, and communication with the Delphi panel. The first round consisted of open-ended brainstorm questions. For each subsequent round, controlled anonymized feedback was provided to the Delphi panel by presenting summaries of the data from the previous round and a new survey that was developed based on collected data. Reflexivity was addressed through regular discussion of notes from the moderators during data collection within the last two authors, ICC and EG. All researchers are experienced allied health care professionals (four SLPs and one physiotherapist). The study flowchart is displayed in Figure 1. The aim of the data collection and analysis after Round 1 was twofold: developing the definition for CP (left) and developing items to operationalize CP (right).

Topic identification

Data collection. Round 1 consisted of a survey with open-ended questions developed to identify topics on CP (see Table 2). Delphi panel members were asked to describe CP in their own words and to provide real-life examples of adequate or lacking CP in children with LD. Colleagues of the moderators pilot-tested the survey, which resulted in minor changes in wordings to remove possible ambiguity of the questions and to make questions easier to understand. For example, instead of describing "limitations in CP," the Delphi panel was asked to describe "problems with CP."

Data analysis. Round 1 data consisted of written answers to the survey questions about CP from the Delphi panel. A realist approach guided the thematic analysis, as escribed by Braun and Clarke (2006). Analysis was performed in order to capture important themes in an inductive way, at a semantic level. The first two authors (IS and ISK) coded the first two surveys independently and compared their codes. Slight differences in the wording of codes were resolved by choosing the code that followed the wording used by panel members most closely. This resulted in one codebook. First, all odd-numbered surveys were coded by IS, who added new codes to the codebook. Next, ISK coded all even-numbered surveys using existing codes and adding new codes as they were identified within the data set. In addition, the coding process was discussed during regular peer feedback sessions with the last two authors (I. C. C. and E. G.) in order to promote consistency in interpretations and codes in the codebook. These feedback sessions resulted in minor revisions in wording of codes and themes, until agreement was reached. A logbook was used to record decisions on codes. Ultimately, the analysis resulted in themes for defining CP and a list of the different behavioral aspects of CP. MaxQDA Qualitative Data Analysis Software, Version 4, was used throughout the process for qualitative data management. Data were stored anonymously at a secured data server with access for the authors only.

Table 2

Survey questions round 1

1. What is communication when you think about children with LD?
2. Can you describe in your own words what communicative participation is when you think about children with LD?
3. Is CP about understanding others and/or being understood? Please explain.
4. Please describe in your own words what communicative participation is when you think of a[a]/your[b] child with LD.
5. In which situations is communicative participation of importance for a[a]/your[b] child with LD? Why do you think so?
6. Please think about a[a]/your[b] child with LD and give three examples of concrete observable behavior indicating problems in CP.
7. Please think about a[a]/your[b] child with LD and give three examples of concrete observable behavior indicating adequate CP.

Note. LD = language disorders; CP = communicative participation.

[a] Questions for professionals. [b] Questions for parents.

Definition of CP

Data collection. Concept definitions were developed with the themes from Round 1. In Round 2, panel members were asked to rate concept definitions using a 7-point Likert scale. A score of 1 indicated that the definition was “very good,” and a score of 7 indicated the definition was “very poor.” In addition, panel members were asked to give feedback on each definition. Ratings and feedback were analyzed, and questions were developed to clarify any conflicting feedback that was given on the concept definitions. Next, in Round 3, panel members answered the clarifying questions. In addition, they were asked to substantiate their answers. Round 4 consisted of controlled feedback (i.e., summaries of Round 2 and 3 data). In addition, three redrafted definitions were rated by the Delphi panel with the same 7-point Likert scale (1 = very good to 7 = very poor). Again, panel members were asked to provide feedback on the redrafted definitions.

The following criteria were used for consensus:

1. At least 75% of the Delphi panel rates the definition as "very good" or "good" (score of 1 or 2), which is an indication for acceptability (Von der Gracht, 2012), and equals the median threshold for consensus reported in Delphi studies (Diamond et al., 2014).
2. The definition is rated as "very good" or "good" more frequently than alternative definitions, which indicates preference for one of the definitions by the Delphi panel.
3. The interquartile range (IQR) of the ratings is no larger than 1 point on the 7-point Likert scale, meaning that 50% of all ratings fall within 1 point of the scale. This indicates a limited degree of variation within the Delphi panel (Murphy et al., 1998).

Data analysis. Ratings of definitions by panel members in Rounds 2 and 3 were used to calculate percentages of "good" and "very good" for each definition, and ratings were compared with each other. As a measure of dispersion, IQRs were calculated for each concept definition.

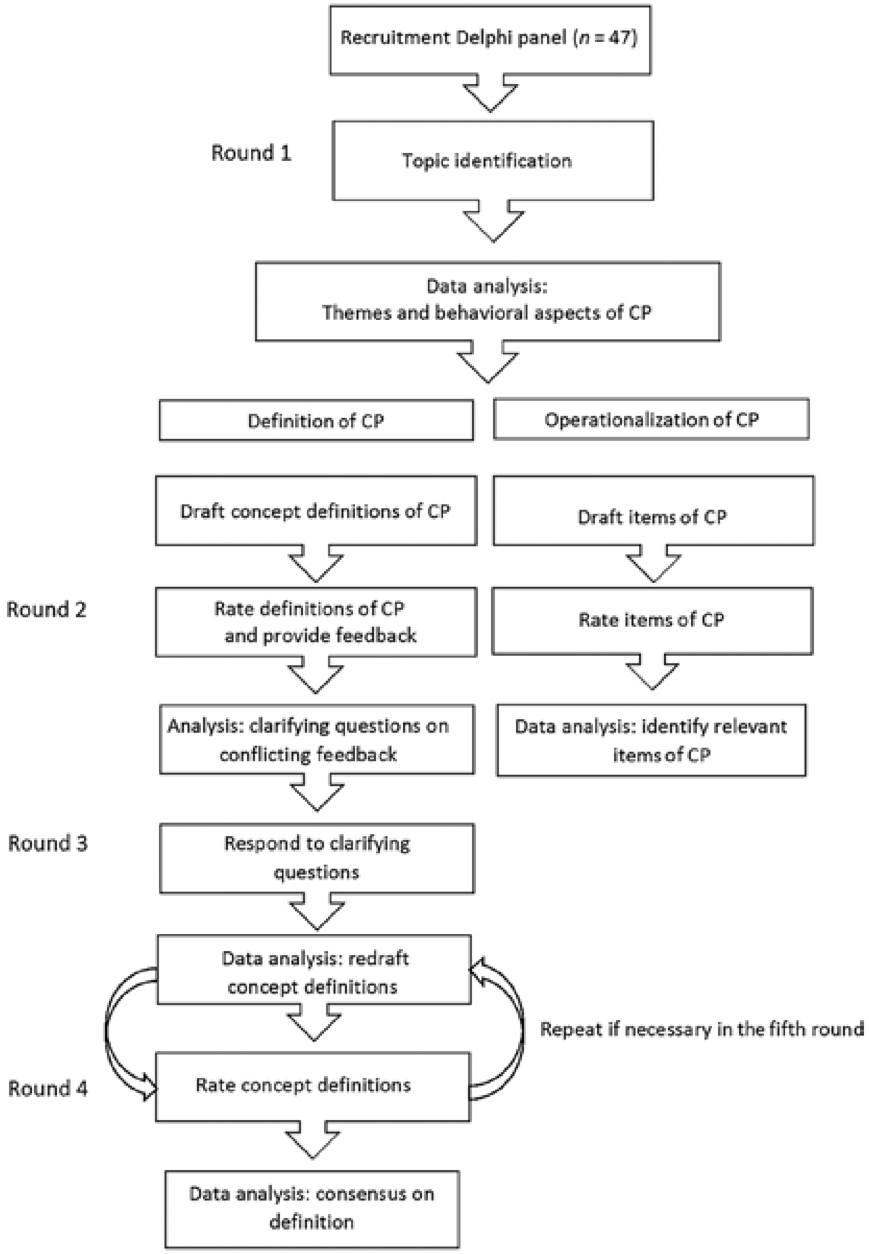
Comments on concept definitions were summarized by the first author, and points of conflicting feedback were identified and discussed in the research team, in order to explore possible new ways to improve consensus. Answers on the clarifying questions were analyzed by calculating the percentage of the panel members who chose each predefined answer category. For quantitative data analysis, we used IBM SPSS Statistics for Windows, Version 23.

Operationalization of CP

Data collection. Several quotes were drawn from the data for each behavioral aspect that panel members had mentioned in Round 1. Using panel members' quotes as examples, the first two authors (IS and ISK) drafted items that describe different aspects of CP. The items were discussed and clustered in three categories in consultation with the last two authors (ICC and EG). In Round 2, the list of items was presented to the Delphi panel, as part of a larger research project where an additional 189 items from existing questionnaires on language and communication were rated on face validity. The Delphi panel, including the young adults with LD, rated how well each item matched with the construct CP on a 7-point Likert scale (1 = matches the construct very well to 7 = matches the construct very badly). In order to help the young adults with LD with understanding the questions and provide answers that reflect their true opinions, extra support was provided to them (Coad, 2007). They were invited to the research facilities, where they practiced the line of questioning and could ask for clarification on any item they did not understand and discuss their opinions with one of the researchers.

Figure 1

Flowchart study consensus of communicative participation (CP)



Data analysis. After the second round, the percentage of the panel members who rated an item as "very good" (score = 1) or "good" (score = 2) on the 7-point Likert scale was calculated, as well as the IQR for each item. Items were considered valid indicators of CP when they met the following criteria:

1. At least 50% of the Delphi panel considers the item to match the construct "good" or "very good" (score of 1 or 2 on a 7-point Likert scale). We deemed this liberal "absolute majority" cutoff score (Von der Gracht, 2012) appropriate for the development of an operational definition, because some of the items might be relevant for a subgroup of children with LD only.
2. Score dispersion lies within a predefined limit with an IQR of 2 or smaller, meaning that 50% of all ratings fall within 2 points of the scale. This indicates a limited degree of variation within the Delphi panel (Murphy et al., 1998).

The Delphi study was conducted in Dutch. The first author translated the definitions, items, and participants' quotations into English and discussed the translations with the other authors.

RESULTS

Response rates

Table 3 contains a summary of response rates per round. In Round 1, one parent and one professional decided to withdraw, due to personal circumstances and lack of time. Both were replaced by a panel member with similar characteristics. Response rates varied between 75% and 100% in most rounds and respondent groups, except for the children's psychologists and young adults. The reasons for nonresponse in children's psychologists were heavy workload, illness, and holidays; however, all expressed a wish to stay involved in the project and receive the next survey. During the face-to-face interviews, two young adults with LD were unable to finish the questionnaire. Of the total of 225 items to be rated in the larger research project, one young adult had to withdraw after Item 135, and the other had to withdraw after Item 185, because they could no longer concentrate on reading the items, thinking about them, and rating them. The response rate for this group is therefore limited to 60%.

Table 3

Response rates in Delphi survey rounds

Member	Round 1		Round 2		Round 3		Round 4	
Children's psychologists	3/4	75%	3/4	75%	2/4	50%	2/4	50%
Clinical linguists	4/4	100%	4/4	100%	3/4	75%	3/4	75%
Clinical researchers	5/6	83%	6/6	100%	5/6	83%	5/6	83%
Speech and language therapists	10/11	91%	10/11	91%	9/11	91%	10/11	91%
Teachers and teaching assistants	7/7	100%	6/7	86%	6/7	86%	5/7	86%
Parents	9/10	90%	9/10	90%	10/10	100%	9/10	90%
Young adults	n.a.	n.a.	3/5	60%	n.a.	n.a.	n.a.	n.a.
Total	38/42	90%	41/47	87%	35/42	83%	34/42	81%

Note. n.a. = not applicable.

Definition of CP

Themes and codes

Round 1. This round involved the identification of six themes (a-f) for defining CP.

a. Communication. Panel members often use the word "communication" when they describe CP. They view communication as the transferring, processing, and understanding of messages between sender and receiver: "*Communication is the transfer of a message between two or more people, independent of the codes used…. There must be an exchange of a message between a sender and a receiver*" (parent of an 8-year-old child with LD)."*Communication is a dynamic exchange of ideas, thoughts or feelings between two or more people, who intend to get a message across that is understood and they intend to understand the other. Roles shift between sender and receiver and according to the type of exchange*" (teacher and teacher trainer in special education for children with DLD).

b. Receptive and expressive communication. Results show that CP was described most often with a focus on expressive communication of the child. A minority spontaneously mentions receptive communication as part of CP. One panel member explains this phenomenon:
"*I think that most people would think CP is about being understood, because expressive language disorders are more striking to the environment*" (clinical researcher with 20 years of working experience with children with DLD and ASD). The Delphi panel

expresses that both understanding someone and being understood are part of CP, when asked explicitly. For example: "*CP is both about understanding and being understood. A conversation will come to an end if you're not being understood or when you don´t understand the other*" (parent of a 6-year-old child with LD)."*If you don't understand others it's impossible to act and respond properly (for example in conflicts, but also during daily activities). The same applies the other way around. If others don't understand you because you are unable to express what you mean through verbal or non-verbal means, it's impossible to participate in daily activities*" (SLP with 5 years of working experience with children with LD in a diagnostic center).

c. Verbal and nonverbal. Many, but not all, panel members pointed out that all means for conveying a message can be used: language, nonverbal communication, sign language, or assistive devices: "*CP is being able to express yourself—in whatever way—to convey what you want, mean, need or wish to say. This can happen using any means or aid, as long as it doesn't require specific skills, knowledge or adaptations from the receiving party (except from some patience and empathy)*" (parent of an 8-year-old child with LD)."*The way it [establishing a connection] happens is irrelevant. All codes can be used, both verbal and non-verbal" (teaching assistant with 15 years of working experience with children with DLD and ASD).*"*Communication is conveying your thoughts, intentions and ideas through verbal and non-verbal means such as eye contact, mimicry, pointing, gesturing and spoken language*" (clinical researcher on DLD and ASD).

d. Social context. Panel members think CP is important in many different social situations:
"*Actually, I think CP is important in every situation. Communication is so important, especially for children with an impairment*." (parent of a 6-year-old child with LD)."*CP is important in all situations where a child interacts with its environment*" (children's psychologist with 10 years of working experience with children with cognitive impairment).

e. Participation. According to a number of experts, CP is an important aspect of participation in society: "*CP is important in order to participate in society. For a child the school is important, but also at home, in a shop, on the streets etc*" (SLP with 5 years of working experience with children with LD in a diagnostic center)."*When a child grows older, it [CP] also means being able to ask for help in a shop, asking directions from strangers, making a phone call, making appointments*" (clinical linguist and SLP with 21 years of working experience with children with DLD in a special education setting).

f. Positive connotations. Panel members used different positive words to describe CP as communication with positive attributes, such as independent, socially acceptable, and effective: "*A child demonstrates CP when it is able to act independently, even when situations differ (to an extent) from regular or standard, by adapting to the*

> *situation or circumstances. It is more than performing routines*" (parent of an 8-year-old child with LD)."*It's important that she is able to communicate with other people she interacts with daily, without help. For her to respond adequately to others and to express herself in such a way that she's being understood*" (parent of a 6-year-old child with LD)."*CP means being able, and having the courage, to stand up for yourself and to move and express yourself freely. Being able to and daring to set boundaries in a socially acceptable way. Taking initiative when this is desired*" (teacher with 5 years of working experience with children with DLD and ASD)."*CP means having the necessary skills to express yourself and to get across what you wish or mean. That you can listen to someone's story or question and respond adequately*" (SLP in a school setting with 16 years of working experience with children with DLD).

The words used in the examples differed somewhat between respondent groups. As may be expected, parents, teachers, and teaching assistants tended to give examples from their personal experience with their child, while SLPs, children's psychologists, clinical linguists, and clinical researchers preferred to use general terms and sometimes used jargon. Although there was some variation between individual panel members, no structural differences were observed in the themes that were brought up by the different respondent groups. Therefore, the six themes (communication, receptive and expressive, verbal and nonverbal, social context, participation, and positive connotations) were used to develop three concept definitions:

1. CP is transferring, understanding, and processing verbal and nonverbal communicative messages, by use of available language and pragmatic skills.
2. CP is adapting to the social environment through flexible and purposeful use of acquired language and pragmatic skills in daily life.
3. CP is transferring, understanding, and processing verbal and nonverbal communicative messages in daily life, independently and in a socially acceptable way.

The first concept definition captured receptive and expressive as well as nonverbal and verbal communication. In the second concept definition, social context and participation in real-life situations were added. In the third concept definition, two frequently mentioned positive markers (independence and social acceptance) were added. This resulted in three concept definitions. The three concept definitions and more detailed results of the thematic analysis were presented to the Delphi panel in Round 2.

Consensus development

Round 2. None of the concept definitions were rated as “good” or “very good” by at least 75% of the respondents, and there was a large degree of variation within the Delphi panel. Analysis of feedback from the panel showed that this variability was caused by a lack of consensus on the following subjects:

- The need to specify social contexts or situations in the definition (18 comments).
- CP is communication in a broad sense, not only language (10 comments).
- CP is not only about language but also about thinking, use of compensation strategies, and resilience (four comments).
- Whether or not CP should be related to developmental level or age (eight comments).
- Whether CP is about applying skills in daily life (performance) or should be seen as skill level (capacity; seven comments).

In addition, the Delphi panel provided feedback on word choice:

- It is better to use understanding and being understood instead of language and pragmatic skills (31 comments).
- Whether or not to use the terms “socially acceptable” and “independently” (19 comments).
- The definitions are too complex, with ambiguous terms (27 comments).

Opinions within the Delphi panel differed substantially on five specific topics. Clarifying questions were drafted in order to provide direction on

1. whether CP is about verbal communication only or both verbal and nonverbal communication;
2. whether CP should be viewed as a capacity (to be observed in a standardized situation) or as performance (to be observed in real life);
3. whether use of strategies to resolve communication failure is essential for defining CP;
4. whether comparison with a reference group or criterion is essential for defining CP and, if so, which reference group or criterion this should be; and
5. to what extent adequate CP may be expected in complex or novel social situations from young children.

After answering the clarifying questions, panel members were asked to provide arguments substantiating their choice.

Round 3. Analysis of the answers on the clarifying questions revealed the following opinions within the Delphi panel, with similar distributions of the answers for different groups of participants:

1. Eighty-six percent of the panel members think CP is about all forms of communication, both verbal and nonverbal.
2. One hundred percent of the panel members think CP is about performance—using communication skills in real-life situations.
3. Fifty-two percent of the panel members think it is important to include a child's use of compensation strategies (in case of communication failure) in the definition. All respondents stress, however, that the most important thing is to understand others and to be understood, independent of how this is achieved.
4. Fifty-two percent of the panel members feel it is important to take individual (language, cognitive, and developmental) strengths and limitations into account, while 46% of the panel feel it is also important to take the child's calendar age into account.
5. Thirty-six percent of the panel members think CP is relevant in frequently occurring social situations, and 29% thinks CP is relevant in every social situation (also in rare or new situations), while 17% thinks CP is relevant only in situations that are important from the child's point of view.

Answers reflecting the majority opinion on Questions 1 and 2 were incorporated in the redrafted concept definitions. Opinions differed on whether CP should be related to a calendar age or to certain developmental aspects; therefore, we decided not to specify a norm group in the definition. In addition, opinions differed in the extent to which CP is relevant in rare or new situations for younger children. Several respondents stated that the social contexts in which CP is relevant depend on age, developmental level, personal circumstances, and the environment of the child. Therefore, we decided not to specify the type of context in the definition. Incorporating the views of the majority resulted in three redrafted concept definitions:

1. CP is understanding and being understood in a social context, by applying verbal and nonverbal communication skills.
2. CP is communicating independently in a social context, using verbal and nonverbal means, in such a way that the child is understood and understands others.
3. CP is applying language and communication skills and strategies in a social context in order to understand others and to be understood.

Definition 1 reflects the opinions of the majority outlined above. Definition 2 adds independence, which was a term that received mostly positive but some negative feedback in Round 2. Definition 3 adds use of strategies in order to resolve communication failure, which was an unresolved topic of discussion in Round 3.

Round 4. Definition 1 met the predefined criteria for consensus, with 79% of the Delphi panel rating the definition as “good” or “very good.” In contrast, Definitions 2 and 3 were rated as “very good” or “good” by only 50% and 47% of the panel, respectively. In terms of score dispersion, Definitions 1 and 2 met the predefined criterion with an IQR of 1, while Definition 3 had an IQR of 2. In conclusion, the Delphi rounds resulted in consensus on the definition: “CP is understanding and being understood in a social context, by applying verbal and nonverbal communication skills.”

Qualitative analysis of Round 1 data resulted in 36 codes, which were subsequently categorized in three broad themes: understanding others (five codes), being understood (14 codes), and interacting with others (17 codes). Table 4 provides an overview of the three themes and a list of the accompanying codes.

Table 4
Three themes and listing of accompanying codes

Theme	**Codes**
Understanding others	Understanding instructions Asking for a clarification Paying attention to what someone else is saying Checking whether you have understood a message correctly Understanding non-verbal communication
Being understood	Conveying desires and wishes Being understood Being able to tell stories Being able to compensate Communicating without help from others Asking for help Conveying thoughts and feelings through language Being considerate of the communicative partner Asking questions Conveying thoughts and feelings non-verbally Being able to formulate a message within reasonable time Offering an opinion Clarifying, explaining Repeating a message when it hasn´t been understood

Table 4
Continued

Theme	Codes
Interacting with others	Connecting with someone Holding one's own in a social context Solving problems with language Reciprocity Taking initiative Responding appropriately Standing up for yourself Working together well with other children Exchanging information Setting boundaries Being able to use communication skills flexibly in different situations Taking part in conversations Playing well with other children Discussing/ arguing Explaining communicative needs Understanding your own limitations Inviting others to play

Item development

In total, 36 items were developed. Table 5 provides an example of a code, a quote from the first survey, and the item that was developed within each of the three themes.

Table 5
Illustration of translation from quote to item

Theme *Code*	Quote	Item
Understanding others *Understanding instructions*	"An indication of CP is when a four year old starts to clean up after I tell him "we're going to clean up" while simultaneously making the sign" - professional (31)	The child understands instructions that match his/her developmental age.
Being understood *Conveying desires and wishes*	"Children need to have the skills to express themselves during interaction with others so they can express what they want or mean" - professional (27)	The child expresses his/her desires and wishes.
Interacting with others *Exchanging information*	"Children with communication needs may succeed often or regularly, but sometimes they fail in effectively exchanging verbal information with their environment" - professional (3)	The child exchanges information effectively with its environment.

Rating items

Ninety-two percent of the items were rated as matching the construct CP "very good" or "good." Of the 36 items, 28% have a median rating of 1 (very good), 64% have a median rating of 2 (good), and 8% have a median rating of 3 (fair). Sixty-seven percent of the items have an IQR of 1 point, and 33% have an IQR of 2 points. Using the predefined criteria, the Delphi panel considers 33 items to be valid indicators of CP in children with LD aged 2-8 years. The items and the percentage of the panel members who rate an item as "good" or "very good," as well as the medians and IQR for every item, are displayed in Table 6. The three items that did not meet the criteria are marked with an "*" in Table 6.

Table 6

Items, percentage of panel members rating the item as matching the construct CP "good" or "very good," and median rating/interquartile range (IQR) of items

Theme: Item	Percentage rating item 'good' or 'very good'	Median rating / IQR per item
Understanding others		
The child understands instructions that match his/her developmental age.	62%	2 / 2
The child asks for an explanation when he/she does not understand someone.	95%	1 / 1
The child pays attention to what someone else is saying.	84%	2 / 1
The child checks whether he/she understood the message correctly.	78%	2 / 1
The child understands someone's non-verbal message.	73%	2 / 2
Being understood		
The child expresses his/her desires and wishes.	87%	1 / 1
The child can express him/herself verbally and non-verbally in such a way that he/she is understood.	84%	1 / 1
The child tells a clear story about something it did.	86%	2 / 1
The child conveys its message in a different way when he/she is not understood.	84%	1 / 1
The child communicates without help from others.	76%	2 / 2
The child asks for help when he/she needs it.	92%	1 / 1
The child expresses his/her thoughts and feelings through language.	86%	2 / 1
The child is considerate of the communicative partner.	76%	2 / 1

Table 6
Continued

Theme: Item	**Percentage rating item ‘good’ or ‘very good’**	**Median rating / IQR per item**
The child asks questions when he/she wants to know something.	92%	2 / 1
The child conveys his/her thoughts and feelings non-verbally.	76%	2 / 2
The child formulates his/her message before the other person loses interest.	59%	2 / 1
The child offers his/her opinion.	62%	2 / 2
The child clarifies what it means when he/she is not understood.	87%	1 / 1
The child repeats its message when he/she is not understood.	78%	2 / 1
Interacting with others		
The child connects with other children and adults.	76%	2 / 2
The child stands firm in social situations.	84%	1 / 1
The child resolves conflicts by using words.	76%	2 / 2
The child's (non-)verbal communication is reciprocal.	89%	1 / 1
The child initiates communication.	86%	2 / 1
The child listens and responds adequately.	84%	2 / 1
The child stands up for him/herself.	70%	2 / 2
*The child works well together with other children.	19%	3 / 1
The child exchanges information effectively with its environment.	84%	1 / 1
The child sets boundaries in a socially acceptable way.	70%	1 / 2
The child makes sure its communication matches with the situation.	84%	2 / 1
The child takes part in conversations.	86%	2 / 1
*The child plays well with other children.	24%	3 / 1
The child can discuss an issue with others.	57%	2 / 2
The child can clarify to others what he/she needs in communication.	76%	2 / 2
**The child has an understanding of its own communicative capabilities and limitations.*	46%	2 / 2
The child invites other children to play together.	54%	2 / 2

Note. *Item was not considered a valid indicator of CP.

DISCUSSION

This study resulted in a definition of children's CP from the perspective of parents, SLPs, teachers, and other professionals. In addition, CP was operationalized in 33 items reflecting CP in children with LD aged 2-8 years. The high level of agreement with the definition and the lack of variation in ratings indicate that individual Delphi panel members' opinions were effectively combined into group consensus. Eadie et al.'s (2006) research definition of CP closely resembles our definition. Both refer to receptive and expressive communication, but different words are used. While Eadie et al. use the words "speaking, listening, reading, writing," our Delphi panel reached consensus on the words "understanding and being understood." Both Eadie et al. and our definition include verbal and nonverbal forms of communication as part of CP. Our panel did not make a distinction between verbal and written communication, a distinction that perhaps was considered irrelevant for young children. Finally, our Delphi panel places CP "in a social context," while Eadie et al. placed CP in "multiple life situations or domains." The latter wording closely resembles the terminology used in the ICF-CY and will be understood by most researchers and SLPs for whom Eadie et al.'s operationalization is intended. However, parents and teachers are not familiar with the ICF-CY, which is why we opted for the more colloquial "in a social context" in the definition.

Two sets of definitions were developed before the criteria for consensus were met. The first set of definitions generated many comments from the Delphi panel on choice of words. This implies that a lack of clarity in wording in the first set of definitions resulted in ambiguity in the definitions, which is likely to have contributed to the lack of consensus on a definition in the second round. Further points of discussion within the panel were whether or not to mention a norm group in the definition and deciding on the proper norm reference: calendar age, language level, or developmental level. Advocates for including a norm group in the definition stressed that it is important to assess whether the behavior of a child is developmentally appropriate or not. However, a definition serves the purpose of describing the construct, not the patient. The discussion resulted in agreement that including developmental comparisons in a definition is unwarranted, since a definition is merely a statement explaining the meaning of a word or a phrase and including developmental comparisons in a definition would imply that it can be used to identify deviant or delayed CP. Still, the fact that part of our Delphi panel stressed the need of including a norm group in the definition of CP reveals a wish to classify the level of a young person's overall functional communication skills. An interesting difference in the preference of a norm group was notable. On the one hand, parents of and professionals and clinical researchers working with children with ASD and ID preferred referencing against developmental level. On the other hand, parents of and professionals and clinical researchers working with children with DLD strongly preferred referencing against calendar age. This difference may be explained from a long tradition of using scores from standardized language assessments and cognitive referencing in the diagnosis of DLD, while participation restrictions, which are unique for every individual, are viewed as a fundamental part of an ASD or ID diagnosis. Although the push for norming CP in children with DLD is understandable, it would mean reverting back to biomedical thinking and would hamper a focus on a child's abilities and problems.

The second result of this study, the operationalization of CP, gives clinicians and parents clear examples of children's communication in daily life. On the basis of many examples of the panel members, a list of 36 skills was developed representing CP of children aged between 2 and 8 years. The large majority, 33 of these items, were considered to be valid indicators of CP by the panel. The items concern a broad range of behaviors, from understanding someone's nonverbal messages to clarifying one's communicative needs to other people. This indicates that CP is both a broad and abstract construct. The majority of the items concern expressive communication and interaction, as opposed to receptive communication. This may reflect how difficult it is for both parents and professionals to recognize receptive language problems in daily life and stresses the importance of addressing this explicitly. The value of this operationalization lies in the fact that it is now clear which aspects of CP need to be considered in order to gain a comprehensive view of what parents and professionals value as possible treatment outcomes.

Strengths and limitations

The main strength of this study lies in the inclusion of SLPs, teachers, teaching assistants, clinical linguists, children's psychologists, clinical researchers, parents, and young adults with LD in the Delphi panel. Including parents was especially important because parents can observe their child's functioning extensively and in many different social contexts. In order to facilitate participation of many different stakeholders, we made an effort to use language that is easy to understand when writing items and drafting definitions. The parents' and young adults' ratings were in line with the ratings from other participants in this study. We therefore think that the results are a valid representation of the opinions of the different stakeholders in this project.

Another strength of this study lies in the fact that a Delphi process is anonymous. Feeding back opinions anonymously allowed panel members with different backgrounds to have an equal voice. Despite the variety of views and opinions, consensus on the definition was established after four rounds, which is an acceptable number for a typical Delphi process (Hasson et al., 2000). The lack of consensus in Round 3 indicated that Round 4 was necessary, while adding a Round 5 would likely have caused sample fatigue (Hasson et al., 2000).

The Delphi method poses some limitations as well. The fact that a Delphi study runs online prevents direct interaction. Questions during a face-to-face interview or interaction during a focus group might have triggered panel members to think of other defining aspects and other examples of CP than the ones they wrote down in the online survey. However, face-to-face methods would have limited the number of, and variation in, panel members due to practical and time constraints. In addition, anonymous participation would have been impossible. A limitation in this particular study was the relatively small panel size for the quantitative rating of concept definitions and potential items. However, the IQRs of the final definition were very small (within 1 data point) as well as those of the items (all within 2 data points), indicating a high degree of agreement within the Delphi panel. Because the definition and 33 out of 36 items were rated as highly relevant by a large proportion of the Delphi panel, we feel confident that the definition and items reflect the opinions of many different people involved in the care and education of children with LD.

Despite our efforts to facilitate participation of young adults with LD in this study, two of five young adults were unable to complete the survey due to difficulty concentrating for a long time and problems with understanding complex language. We tried to facilitate their participation by reading items aloud and offering room for discussion and questions, but still, rating many different items proved too cumbersome for two of them, who dropped out before they were able to rate the items that were developed in this study. For future studies, we would suggest to consult with participants with LD in every phase of the study in order to optimize feasibility and facilitate their participation (Miskelly & Roulstone, 2011). In addition, using nonverbal methods such as storyboards and providing further extra support and time when verbal methods are used could improve the chances to participate for young people with LD (Coad, 2007).

Recommendations for further research

In future research, we would like to explore the usability of the items developed in this study to support parents in reflecting on CP of their child, because none of the existing measurement instruments for describing communicative functioning, such as Communication Function Classification System and Focus On Communication

Under Six (Hidecker et al., 2011; Thomas-Stonell et al., 2010), have been developed to open up discussions between parents and professionals. CP is a broad and somewhat abstract concept, which makes it difficult to discuss clearly with parents who may lack words to describe what goes well in everyday communication and with which aspects their child is struggling. Discussing the communication problems of an individual child with parents is important for developing individualized care plans that target functional outcomes and for setting shared goals with parents. In addition, as CP is something that takes place in the social domain, further research is needed on contextual factors that influence its development in order to create optimal conditions for children with LD to communicate in daily life.

Clinical implications

The definition and operationalization of CP that was developed in this study deliver a clear framework and a common language for professionals and parents to use when discussing CP of children with LD. The items on CP may be used by SLPs in their dialogue with parents or teachers in order to identify possible intervention targets.

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Chapter 3

Using co-design to develop a tool for shared goal-setting with parents in speech and language therapy

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ABSTRACT

Background

Despite the compelling case for engaging parents in speech and language therapy, research indicates that speech and language therapists (SLTs) currently have a leading role in the goal-setting process of therapy for children with developmental language disorder (DLD). Therefore, we set out to develop a tool that aims to support the dialogue between SLTs and parents and enhance shared decision-making about children's communicative participation goals. We used co-design techniques with SLT-practitioners to include their perspectives throughout the design process. Although co-design has been used for some years in healthcare research, it is still a relatively new research methodology in the field of speech and language therapy.

Aims

To provide a detailed description of the co-design process that led to the development of a physical artefact that can support SLTs to engage parents of children with DLD in collaborative goal-setting.

Methods & procedures

The Design Council's Double Diamond model was used to develop a tool in co-design, together with eight SLTs, who participated in all stages of the development process. Usability was tested in actual goal-setting conversations between four SLTs and 11 parents of a child with DLD resulting in stepwise improvements. In addition, usability of the first and final prototypes was tested with five usability criteria that were rated on a 10-point scale by 64 SLTs.

Outcomes & results

The co-design process resulted in the development of a physical prototype of the tool called 'ENGAGE', consisting of a metal 'tree trunk' on which parents can stick magnetic 'leaves' containing potential participation goals for their child. The 'tree' shape represents a child's development and opportunities for growth. This first prototype received marks between 7.0 and 8.0 out of 10 on attractiveness, user-friendliness, safety, functionality and affordability. After several iterations, there were significantly higher marks for attractiveness, user-friendliness and safety in favour for the final prototype. Marks for functionality and affordability did not change significantly.

Conclusions & implications

As researchers we usually develop pen-and-paper tools, interview protocols, apps or questionnaires to support clinical practice. Including the SLTs' perspectives in the design process resulted in a tree-shaped physical artefact that, according to the SLTs, helps to order information and encourages and guides their dialogue with parents. We strongly advocate the inclusion of end-users in developing innovative user-centred tools for speech and language therapy and we hope that this will become widespread practice.

Keywords: assessment, children, developmental language disorder, outcome, parents, speech and language therapists

WHAT THIS PAPER ADDS

What is already known on the subject

Collaborative goal-setting is at the heart of family-centred speech and language therapy. However, research indicates that goal-setting processes for children with DLD are currently predominantly therapist-led, instead of family-centred. Reasons for the lack of parental engagement are that effective communication with parents throughout the goal-setting process appears to be complex, and parents are not always invited and supported to engage in this. We used co-design to develop a tool that aims to support SLTs in their dialogue about therapy goals with parents.

What this paper adds to existing knowledge

This paper provides an example of applying a co-design approach for the development of a shared goal-setting tool for SLTs and parents of young children with DLD. The co-design approach enabled us to incorporate needs, experiences and ideas of SLTs in the design process. We report the four stages in the co-design process from (1) discovering the needs, wants and desires of the people involved, (2) defining the problem that SLTs experience, (3) developing several solutions and selecting the best solution, and (4) developing and testing the prototype. The detailed description of this process can add to an understanding of the advantages and disadvantages of a design process that includes the perspective of end-users. The result is a physical artefact representing a tree, which aims to support the conversation between SLTs and parents about a child's communicative participation. Items describing facets of communicative participation are printed on 'leaves' that can be hung on a tree trunk by parents. The tree shape is a positive metaphor for the growth and development of a child.

What are the potential or actual clinical implications of this work?

This study describes how SLTs can be meaningfully involved as partners in a co-design research approach. Incorporating experience from clinical practice was highly relevant since our study aimed to create a solution that would support goal-setting and service delivery by SLTs. We want to show that it is inspiring and beneficial for SLTs to partner with researchers in innovation of their own clinical practice and provide examples of co-design activities that illustrate the involvement and influence of end-users in a design process. Including the perspective of SLTs in the development of a new tool to facilitate the dialogue between SLTs and parents of children with DLD regarding therapy goal-setting is expected to add value and enhance its implementation in clinical practice.

INTRODUCTION

Children with developmental language disorder (DLD) have language problems enduring into middle childhood and beyond, with a significant impact on everyday social interactions or educational progress (Bishop et al., 2017). DLD affects 7% of all 5-year-old children (Tomblin et al., 1997), which means that on average two children in every classroom have DLD. Intervention for children with DLD consists of speech and language therapy delivered by speech and language therapists (SLTs), often in collaboration with professionals in preschools and schools. Since the family is the child's primary source of strength and support, it is important to deliver interventions in partnership with parents. Partnership is characterized by mutual understanding, a respecting and trusting relationship, shared decision-making, and processes that incorporate family beliefs, needs and preferences (An & Palisano, 2014). A strong partnership between therapist and parent is thought to improve the quality and impact of the services provided, because it helps parents and children to receive the care they need when they need it (Law et al., 2012). In addition, parental involvement is expected to lead to improved decision-making (Stevens et al., 2013), which is in turn associated with a better parent-therapist relationship (Stacey et al., 2017), more parent engagement (Klatte et al., 2019), and with better intervention outcomes for children (Coulter & Collins, 2011; Haine-Schlagel & Escobar et al., 2016; Roberts & Kaiser et al., 2011; Van Voorhis et al., 2013). Our study focused on parental involvement in goal-setting, because shared goal-setting connects the therapy process with the child's and parents' personal perspective and their communicative home environment, thus leading to relevant intervention outcomes (Baylor & Darling-White, 2020; Paul & Roth et al., 2011; Wilcox & Woods et al., 2011; Woods et al., 2011). Setting goals for communicative participation draws heavily on the client values and preferences aspect of the evidence-based practice triangle (E3BP) (Dollaghan et al., 2007). Parents of the client are most knowledgeable about their families' preferences and coping style, as well as their specific physical and social communication environment (Baylor & Darling-White, 2020).

Shared goal-setting

Scobbie et al. (2011) have identified four components of a goal-setting and action-planning practice framework: (1) goal negotiation, (2) goal identification, (3) planning and (4) appraisal and feedback. In the goal-negotiation stage, parents consider the current situation and identify the main problem(s) they want to address. In the goal-identification stage, the problem is refined into a specific, challenging goal agreed by both parents and the SLT. In the planning stage, parents are involved in translating goals into timely action. Finally, in the appraisal and feedback stage, parents receive support and feedback from the therapist. In our study we focused on the first two stages in Scobbie's framework: (1) goal negotiation and (2) goal identification, because we think that establishing a dialogue between SLTs and parents is essential here. An example of goal negotiation and identification could be an SLT asking parents what they would like to see their child accomplish over the next 2 months of therapy. Parents may start with a goal that refers to development of language skills, such as for their child to use more words. The therapist can then probe deeper into parents' underlying values. She may discover that the parents' priority is to foster their child's independence. Then, through discussion, the parents and therapist can discover what independence means for a 3-year-old child. Parents may indicate that this involves a degree of autonomy, for example, being able to ask for a preferred play activity or toy. Next, the SLT can discuss which situations offer opportunities to develop the target behaviour and explain to parents what this behaviour would look like. She could also explain which levels of support can be offered to the child to scaffold the development of the behaviour. This conversation may result in an example goal such as: 'In 2 months, Sam can tell his preschool teacher which familiar play activity he would like to engage in during free play time.'

Despite the positive impact of engaging parents in speech and language therapy, research indicates that goal-setting processes are currently predominantly therapist-led, instead of family-centred (Roulstone, 2015; Watts Pappas & McLeod, 2009). This seems particularly problematic when the aim of therapy is to improve communicative participation. Parental engagement in the articulation of communicative participation goals is key because only parents can tell which situations are most relevant for their young child's life (Baylor & Darling White, 2020; Grootens-Wiegers et al., 2017). Yet, effective communication with parents throughout the goal-setting process appears to be complex (Øien et al., 2010). What contributes to the complexity is that for parents it may be difficult to articulate participation goals because they draw on values, hopes and priorities in life which are often not clearly defined (Elwyn & Vermunt et al., 2020). In addition, parents may not know right away what their desired level of involvement in therapy is, and thus in goal-setting (Epstein & Gramling, 2013). This complexity can result in SLTs not actually inviting and supporting parents to engage in the decision-making and goal-setting process. At the same time, SLTs tend to overestimate the level of actual parental engagement (Watts Pappas et al., 2008). This suggests that SLTs may be unaware of their dominant position in the decision-making process.

To support SLTs in their collaboration with parents of children with DLD, we set out to develop a tool that can support SLTs and parents in the goal-negotiation and goal-identification stages of the shared goal-setting process (Scobbie et al., 2011). The tool should be able to assist SLTs in their dialogue with parents about their priorities and concerns, as well as in setting and evaluating specific goals for communicative participation, together with parents.

Decision support aids

Decision support aids, such as shared goal-setting tools, can facilitate the exchange of information in an open conversation between client and service provider (Alston et al., 2014). They aim to help the client making informed choices about healthcare that reflect their personal values and preferences (Elwyn et al., 2010). Decision support aids encourage parents' active participation in healthcare decisions affecting their child and improve partnership between the parent and the SLT (Barry & Edgman-Levitan, 2012; Coulter & Collins, 2011; Holmes-Rovner et al., 2007). In addition, decision support aids are considered important vehicles to achieve better healthcare outcomes and higher client and provider satisfaction (Van der Weijden et al., 2012). Decision support aids can be classified in three categories, depending on the context of use: use during face-to-face encounters, independent use by the patient, and use during remote client-to-coach and peer-to-peer encounters. Our study focused on use during face-to-face encounters. This type of decision support aid typically displays a limited amount of information that can easily be shared across a desktop (Elwyn et al., 2010). It aims to support shared decision-making by making options visible and by organizing information in a way that a patient can understand. These tools are designed to improve the decision process by promoting dialogue and helping the clinician to engage the patient in a discussion about preferences (Elwyn et al., 2010). Although decision support aids have been available since the early 1980s, evidence suggest that their implementation into routine practice has been limited (Gravel et al., 2006). Many different cognitive (e.g., lack of knowledge), affective (e.g., motivation), social (e.g., patient acceptance) and environmental (e.g., reimbursement) factors may act as barriers for implementation (Holmes-Rovner et al., 2007; Michie et al., 2005).

Although standards for decision support aid development do not prescribe specific ways or frequencies with which users must be involved (Coulter et al., 2013; Witteman et al, 2015), adapting tools to the needs of those who use them is expected to support successful implementation of decision support aids (Coulter et al., 2013; Vaisson et al., 2021; Witteman et al., 2015). This means that optimizing feasibility of actual use in clinical practice cannot be achieved without the input of the users of a decision aid (Vaisson et al., 2021). Therefore, we chose to develop the tool for shared goal-setting together with SLTs and with researchers having a design or SLT background, and subsequently testing its usability in real life conversations with parents.

Co-design

Co-design refers to the collective creativity of designers and people not trained in design working together in a design development process (Sanders & Stappers et al., 2008). It can be used to address a specific problem by bringing together the views, input and competencies of different stakeholders using a range of tools and exercises to optimize collaboration. According to Steen et al. (2011) co-design can be beneficial for users, projects and organizations. User benefits include a better fit between the innovation and the user needs, a better user experience, and higher satisfaction. Projects benefit because co-design improves the creative process, the central problem is better defined, and the project is organized more efficiently or effectively. Finally, organizations benefit through an improved focus on user needs, more creativity, better interdisciplinary cooperation, and more capabilities and enthusiasm for innovation (Steen et al., 2011).

Co-design is thought to impact on participants directly (Robert et al., 2015), as it facilitates their empowerment, foster trust, and develops their autonomy, self-determination and choice (Bowen et al., 2013; Palmer et al., 2019). It can reshape professionals' work and make a meaningful contribution to realizing family-centred care (Østergaard et al., 2017). Furthermore, the impact of co-design is thought to reach beyond those who are directly involved, and lead to improvements in healthcare service delivery for the whole patient community (Boyd et al., 2012). Systematic research indicates that the level of end-user engagement influences the outcomes of service redesign: structural outcomes, such as enhanced care, service delivery and governance, are associated with high-level (co-design) engagement (Bombard et al., 2018). However, there are also challenges associated with a co-design approach, such as differences in power between participants, commitment to the co-design process in terms of time and energy, use of appropriate methods for collaborative gathering and interpreting of experiences, involvement of participants not only in the experience gathering stages but also in the design of improvements, and finally moving a project forward towards actual implementation and subsequent impact (Dimopoulos-Bick et al., 2019). Unfortunately, research on the impact of co-designed tools within healthcare settings is currently lacking, and within the field of SLT no co-design studies were found. Since co-design with end-users appears to lead to more useful and positive outcomes, we chose to use this methodology in our study. We report this co-design approach to illustrate the benefits and challenges of this approach in developing new tools or resources for speech and language therapy.

Aim

The aim of this paper is to provide a detailed example of the co-design process in which a shared goal-setting tool was developed for speech and language therapy. The content of the tool was developed prior to this co-design project, in a Delphi Study with parents, young adults with a language disorder, SLTs, teachers and teaching assistants, child psychologists, clinical linguists and clinical researchers (n = 47) (Singer et al., 2020).

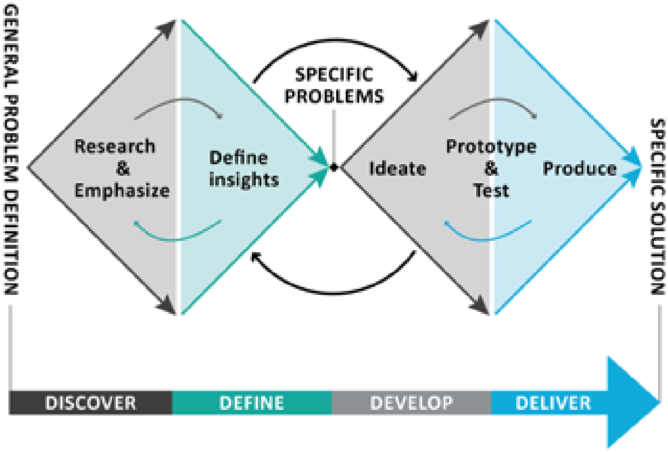
This Delphi panel developed 36 items indicating communicative participation of 2-8-year-old children with language disorders. Examples of items are: 'the child asks for an explanation when he/she does not understand someone', or 'the child tells a clear story about something it did' (for the full list of items, see Singer et al., 2020). We could have stopped at this point, and the SLTs might use the items as a topic list for a dialogue with parents on goals for therapy. However, to optimize actual implementation in clinical practice we decided to use the list of items to create a 'tool', which at that point, could be anything from an app, leaflet, questionnaire, interview protocol, game, framework, etcetera, to a physical artefact, which was the result of co-design together with SLT end-users.

METHOD

Design

The present study is a case study in which we used a co-design approach and actively involved SLT-practitioners to develop a tool that can support their dialogue with parents about goal-setting.

Figure 1
The Design Council's Double Diamond model (2007)



The Design Council's Double Diamond approach guided our design process (Design Council, 2007). The model, developed to describe how the design process takes place in practice, consists of two diamonds (Figure 1) representing the two base points of the design process. Whilst the first diamond aims to 'design the right thing', the second diamond is directed to 'design the thing right'. This process contains four stages: 'Discover', 'Define', 'Develop', and 'Deliver', starting with exploring an issue more widely or deeply and then taking focused decisions and actions, shifting from divergent thinking to convergent thinking. Although these stages appear to be successive steps, the real design process is not linear in nature. Rather, it can be seen as a dynamic and iterative process that allows designers to jump back and forth between the four stages in a way that complies with what is needed according to the current state of the design, and what is needed to advance the design most effectively (Dorst & Cross, 2001).

We used co-design research activities such as brain writing, dot voting, persona development, mind mapping, sorting tasks and more (e.g., Digital Society School, n.d.; Lewrick et al., 2020; Van 't Veer et al., 2020). The output of the activities was used as input for new activities or stages. For clarity, we have chosen to present these activities and the output in the results section of this paper. Figure 2 displays which activities were planned in the various stages of the Double Diamond model.

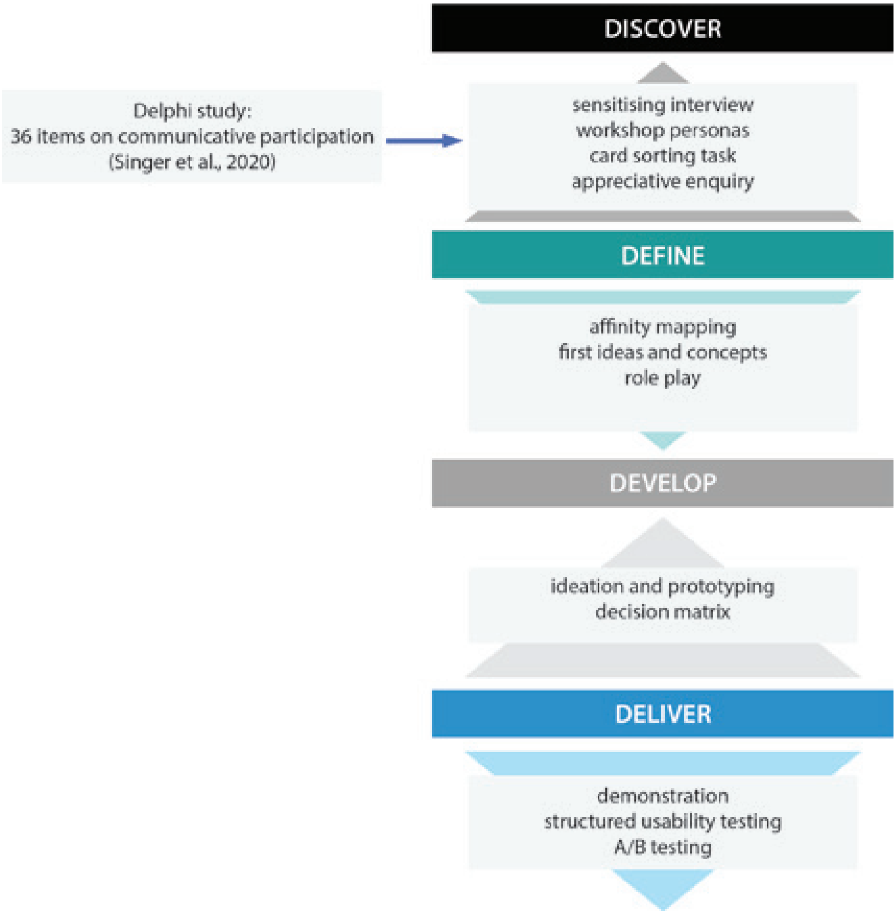
Table 1
Overview of participants in the various design stages

	N	**Discover**	**Define**	**Develop**	**Deliver**
SLTs in co-design workshops	8	✓	✓	✓	
Parents who filled in sensitising poster	48	✓			
SLT researchers	3	✓	✓	✓	✓
Co-design researchers	4	✓	✓	✓	✓
Co-design students	4	✓			
SLTs in usability study	4				✓
Parents in usability study	11				✓
SLTs graded first and final prototypes	64				✓
Total	145				

Note: Each row represents unique individuals who participated in one or more stages of the research project.

Figure 2

Stages of the Design Council's Double Diamond (2007) connected to activities in the present study



Participants

Participants were Dutch SLT-practitioners, SLT-researchers, co-design researchers, co-design students and parents of children with DLD (Table 1).

The project was initiated and coordinated by three SLT-researchers (authors IS, IK and EG), while the three co-design researchers (RdV, RvdL and a third researcher who is not an author) were responsible for the planning and organization of the co-design activities. Both SLT and co-design researchers participated in all the stages of the project. The co-design researchers had backgrounds in design and engineering, but their primary role in the project was that of researcher.

Eight SLT-practitioners participated as co-designers in the Discover, Define and Develop stages. They were recruited via social media. Five of these eight SLT-practitioners worked in SLT practices in primary care, two in special education and one in a diagnostic centre. All SLT-practitioners worked with children with DLD and their parents. They had an average of 16 years of working experience as an SLT (range = 2-41 years). These eight SLT-practitioners each invited six parents of a child with DLD (in total 48) from their caseload to participate in a short interview. There were no selection criteria used. All SLTs gave their written informed consent to participate in the study. Parents gave verbal informed consent to the SLT to take their (anonymous) answers to the workshop.

The four co-design students were recruited via a tutor of an international co-design minor at our university. The students voluntarily selected our project for their co-design assignment. They were majoring in communication and multimedia design at different universities in the Netherlands, South Korea and Ireland.

A new group of four SLT-practitioners was recruited via social media for the usability study in the Deliver stage. Of these four SLT-practitioners, three worked in primary care and one in special education. All SLT-practitioners worked with children with DLD and their parents. They had an average of 24 years of working experience as an SLT (range = 13-39 years) and gave their written informed consent to participate in the study.

Parents in the usability study were recruited via the SLT- practitioners and asked to use a prototype of the tool during their scheduled intake. Parents gave their written informed consent to participate in the study. Each SLT-practitioner tested prototypes with one to three parents, in two rounds. In total, 11 parents were involved in the usability testing. Because parents participated anonymously, demographic data on parents' background was not collected. There were no selection criteria used.

Finally, two groups of SLT-practitioners graded the first (n = 22) and final (n = 42) prototype at two stakeholder meetings organized by the research group speech and language therapy. They were informed that their rating would be used for this study and handing their rating and feedback was voluntarily and anonymous.

This study was conducted following the principles of the Declaration of Helsinki (World Medical Association, 2013), and it was reviewed by the Internal Review Board of Health Sciences, HU University of Applied Sciences Utrecht, which concluded that the study is not subject to the Dutch Medical Research Involving Human Subjects Law (reference number 52_000_2017).

All data were processed anonymously and stored at a secured research server of our university with limited access, by authors IS, IK and EG.

RESULTS

In this section we use the structure of the four stages of the design model to describe the various co-design activities and their outcomes (Figure 2).

Stage 1: Discover

The objective in this stage is to uncover users' needs, which they may or may not be aware of and to discover who the users are, and which emotions guide their behaviour (Design Council, 2007). In our study the primary users were SLT-practitioners, and our primary focus was on their needs. Via the SLT-practitioners we also explored the views of the parents that are involved in their service delivery. Several co-design activities were used which are described in detail in the paragraphs below.

Sensitizing interview

Sensitizers are appealing assignments to prepare and inspire participants for an upcoming co-design workshop. This way, they already can start thinking about the subject of the session, doing some research or interviewing stakeholders (Sleeswijk Visser et al., 2005). To encourage the SLT-practitioners to explore aspects of their personal context before coming to the workshop, they were asked to have a short interview with at least five parents about their child's well-being and the importance of certain values in life (e.g., health, relationships and education). Parents' views on speech and language therapy and responsibilities in the therapy process were also incorporated. The questions were informed by research on parental perspectives of preferred outcomes for children with DLD (Law et al., 2015; Roulstone et al., 2012). The co-design researchers developed visually attractive interview posters in A3 format, to guide SLT-practitioners and parents in the interview process and collection of responses. The interviews helped SLT-practitioners to build up an understanding of, and empathize with, parents' needs, emotions, motivations and ways of thinking. After each interview, SLT-practitioners were instructed to take 10 min for self-reflection on what was shared during the interview, to note their thoughts and observations on a dedicated space on the poster, and to bring the parents' answers and their notes to the workshop.

Workshop personas

In the first co-design workshop, SLT-practitioners (n = 8) were engaged in the development of personas. Personas are fictional 'characters' created in design research, with the intention to simplify communication and project decision-making by a design team during the design process. They provide a context for designers of usage of an innovation (Lewrick et al., 2020: 97-102). In our study, personas were developed to help designers understand how diverse the parents are that SLTs encounter and to gain insight into how SLT-practitioners and parents' may differ in their needs, experiences, behaviours and goals. The personas were used to help the designers recognize the diversity in parents that SLTs encounter when using the tool. In total, 48 interview posters containing parents' answers and SLT-practitioners' reflections on them, were brought to the co-design workshop. SLT-practitioners were divided into two groups in which they talked about their interview posters. They reflected on similarities and differences between parents and constructed a mind map of the perceived differences between parents. After this assignment, the two groups presented their findings to each other.

SLT-practitioners described eight experiences with parents from their SLT practice. These descriptions, together with the interview posters and workshop notes taken by the co-design researchers, constituted the input for the creation of four personas that were given fictitious names (Lewrick et al., 2020: 97-102). These four personas are fictitious characters based on observations, interviews and notes that represent the diversity of parents that can be encountered within an SLT practice.

Card-sorting task to categorize communicative participation items

The structure of the content of the tool was explored with a card-sorting task (Wood & Wood, 2008). The objective was to learn how SLT-practitioners organize and categorize the content of the tool, the 36 items on communicative participation previously developed in the Delphi Study by Singer et al. (2020), for use in the next design steps so that the tool could be structured in a way meaningful for SLTs. The eight SLT-practitioners were randomly divided into three groups. In addition, the three SLT-researchers formed a group. Each group was handed 36 cards with one item from the Delphi Study (Singer et al., 2020) indicating communicative participation written on each card. The groups were asked to sort the items into one of four models familiar to many SLTs: Bloom and Lahey's (1978) model of language development, Gleason's model of language development (Gleason, 2005), the International Classification of Functioning, Disability and Health, Children and Youth Version (ICF-CY; World Health Organization (WHO), 2007) and the United Nations Children's Fund's (UNICEF) (2009) developmental domains. Alternatively, groups could develop their own categories. Groups presented and explained their categorization after which all participants were asked to vote on their favourite categorization using dot stickers (dot-voting; Tabaka et al., 2006). In total 33 stickers were used, and the number given for each categorization was counted. Subsequently, the four categorizations were presented and discussed at meetings with other experts such as the SLT research group, and SLT-lecturers of our university and several individual SLT-practitioners who were not involved in the previous workshop. This resulted in developing new categories, rewording categories and combining categories in a total of nine iterations.

Table 2

Categorization of the items on communicative participation

Item no.	Original items (from Delphi study[a])
1	The child expresses his or her desires and wishes.
2	The child conveys its message in a different way when he or she is not understood.
3	The child exchanges information effectively with its environment.
4	The child asks for help when he or she needs it.
5	The child conveys his or her thoughts and feelings nonverbally.
6	The child expresses his or her thoughts and feelings through language.
7	The child stands up for himself or herself.
8	The child checks whether he or she understood the message correctly.
9	The child offers his or her opinion.
10	The child connects with other children and adults.
11	The child sets boundaries in a socially acceptable way.
12	The child asks questions when he or she wants to know something.
13	The child resolves conflicts by using words.
14	The child asks for an explanation when he or she does not understand someone.
15	The child tells a clear story about something he or she did.
16	The child's (non)verbal communication is reciprocal.
17	The child can discuss an issue with others.
18	The child takes part in conversations.
19	The child initiates communication.
20	The child pays attention to what someone else is saying.
21	The child repeats its message when he or she is not understood.
22	The child is considerate of the communicative partner.
23	The child listens and responds adequately.
24	The child understands instructions that match his or her developmental age.
25	The child understands someone's nonverbal message.
26	The child communicates without help from others.
27	The child clarifies what it means when he or she is not understood.
28	The child makes sure its communication matches with the situation.
29	The child understands its own communicative capabilities and limitations.
30	The child can clarify to others what he or she needs in communication.
31	The child can express him- or herself verbally and nonverbally in such a way that he or she is understood.
32	The child stands firm in social situations.
33	The child plays well with other children.
34	The child invites other children to play together.
35	The child works well together with other children.
36	The child formulates his or her message before the other person loses interest.

[a] *Singer* et al., 2020

Group 1 (SLT-researchers) Heading **Items under heading**	**Group 2** (SLT-practitioners) Heading **Items under heading**	**Group 3** (SLT-practitioners) Heading **Items under heading**	**Group 4** (SLT-practitioners) Heading **Items under heading**
Resilience 1, 6, 7, 9, 13, 17, 30 **What to do when your conversation partner does not understand you?** 2, 8, 15, 21, 27, 31 **Insight and effective communication** 3, 23, 26, 29, 36 **Initiative** 19, 34 **Non-verbal communication** 5, 10, 16, 20, 24, 25, 33, 35 **Social situation** 11, 18, 22, 28, 32 **Clarifying** 12, 14	**Contact** 10, 33, 34, 35 **Telling something** 2, 14, 15, 17, 18, 30, 31, 36 **Understanding** 23, 24, 25 **Initiative** 4, 12, 19 **Adjusting** 3, 8, 16, 20, 21, 22, 26, 27, 28, 29 **Feelings** 1, 5, 6, 7, 9, 11, 13, 32	**Create conditions** 5, 22, 23, 24, 25 **Create opportunities** 6, 15, 28, 33, 35, 36 **Use opportunities** 10, 16, 18, 20, 30, 31, 34 **Carry out communicative acts** 1, 4, 8, 9, 12, 14, 26 **Managing situations** 2, 3, 7, 11, 13, 17, 19, 21, 27, 29, 32	**Satisfying own needs** 1, 19 **Conscious communication and contact** 4, 10, 18, 20, 21, 23, 24, 27, 31, 33 **Self-awareness and reflection** 29, 30 **Purposeful communication** 2, 3, 5, 6, 7, 8, 9, 11, 12, 13, 14, 15, 16, 17, 22, 25, 26, 28, 32, 34, 35, 36

Appreciative enquiry to develop design guidelines

Appreciative enquiry was used to enable the SLT- practitioners to develop design guidelines. Design guidelines are used across the co-design cycle, whenever the team gets into situations where decisions must be made. At these critical points, design guidelines can support the team (Lewrick et al., 2020: 53-56). Appreciative enquiry was first developed in the field of organizational psychology as a method of generating innovative ideas about a topic of enquiry (Cooperrider & Whitney, 2005). The approach does not start with a predefined 'problem' that needs to be fully understood to remediate it but enables those involved in the process to focus on the 'ideal' situation instead. SLT-practitioners were asked to share their dreams about what an ideal tool would do, and how it would look, feel and work. One of the co-design researchers facilitated this discussion, while two others took notes. After the workshop, the co-design researchers translated their notes into seven ideas that could guide the design (Lewrick et al., 2020: 53-56).

Output stage 1: Discover

The output of the first co-design activities were four personas with fictitious names 'Wesley and Gina', 'Carine and Tim', 'Michaela', and 'Isaac and Miriam'. For an example of a persona, see Figure 3.

Table 2 shows the categories that three groups of SLT- practitioners and SLT-researchers developed to structure the 36 communicative participation items. The example models, such as ICF-CY, that were provided by the research team where not used. Instead, each SLT group developed their own unique categorization. While groups 1 and 2 developed headings that could be interpreted without a specific order, groups 3 and 4 ordered the items from easy to complex. Furthermore, group 4 placed the items in a tree shape, with easy items in the root, moderate items in the trunk and difficult items in the branches. The result of the dot voting task is displayed in Table 3 and shows that the categorization by group 4 was favoured. For each categorization, one SLT-practitioner volunteered to explain what she saw as a key advantage of this solution. A quote from their explanation is displayed in Table 3.

The SLT-researchers used the output in Tables 2 and 3, four categorizations, the outcomes of the dot-voting and discussions with stakeholders to sort the 36 items of the tool into three categories named 'communicative intention' (four items), 'understanding others' (seven items) and 'being understood' (25 items) that were used in the further development of the tool.

Table 3

Results of dot-voting

Group number	**1**	**2**	**3**	**4**
Percentage dot- votes	**21%**	**27%**	**15%**	**38%**
Key advantage of a classification according to one of the participants	Resilience and non-verbal communication are strong categories	Most categories are recognizable for parents	This categorization sorts items from 'easy' to 'difficult'	The process of growth is visualized well by placing the cards in a tree

Figure 3

Example of a persona: 'Wesley and Gina'

WESLEY & GINA

AGE:
36 YEARS
PROFESSION:
SOFTWARE
ENGINEER

AGE:
33 YEARS
PROFESSION:
HELPDESK
ADVISOR
(PART-TIME)

CHILDREN:
LEIA (5) FINN (2)
RESIDENCE
LELYSTAD

"TO BE HAPPY IS MORE IMPORTANT THAN HAVING A GOOD JOB"

WHAT IS IMPORTANT?

The most important thing is their children's happiness. The children should feel proud of themselves with every step they take. They want their children to feel free to make their own choices.
During their leisure time they spend much time together as a family. They like to go out as a family on day trips, like the zoo or take a nice walk in the forest with their dog Sparky.

SOME KEYWORDS:

trust
accepted
teamwork
involved
positive

WHO SHOULD HAVE THE LEAD IN THERAPY?

ABOUT THERAPY

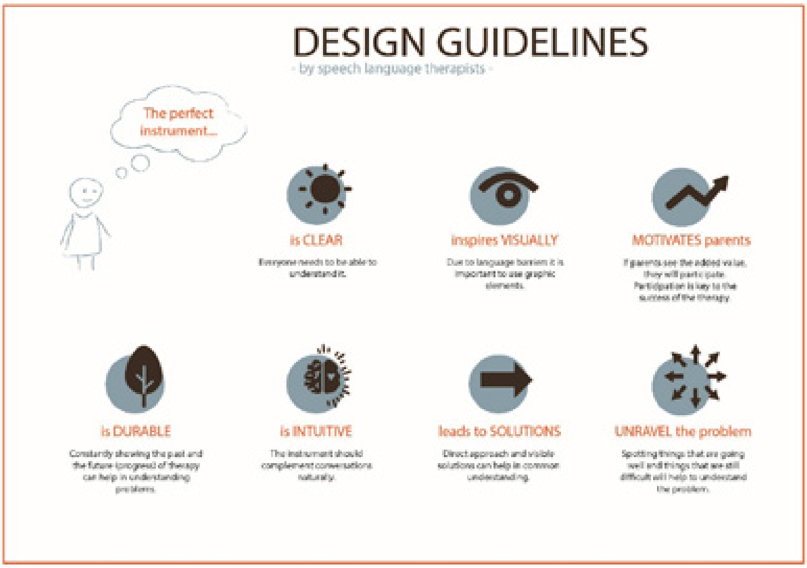
They have been to many different therapists with their child. They know the drill and what to expect from a therapist. And also what is expected from parents.
They are aware that therapy is not an easy task, but it will benefit their child. They want their child to feel secure and comfortable.
They feel that cooperation brings the best results.

The SLT-practitioners responded to the appreciative enquiry with ideas such as: ‘I would like to have a tool that motivates the parents to contribute to the conversation.’ The results from the appreciative enquiry were translated into seven design guidelines (Figure 4). In summary, the most important requirement according to SLT-practitioners was that the tool should have tangible, interactive and visual components to stimulate participation and engagement of the parent during the conversation with an SLT.

A team of co-design students at our university used the personas, categories and items, and design guidelines to develop a first concept. The student team developed an ‘SLT collectible puzzle’, consisting of 36 pieces with the communicative participation items written on each piece (e.g., the child pays attention to what someone else is saying, the child communicates without help from others). The puzzle pieces had three colours that represented the three categories: communicative intention, understanding others and being understood. On the back of each puzzle piece there was room for notes, for example, a description of a goal or skill that the child could develop and more detailed and personalized assignments for a child. The idea was that parents could take a puzzle piece as a reminder of a particular language stimulating activity they can do at home, and that the child earns the puzzle piece as a reward when a goal is accomplished. According to the students, completing the puzzle illustrates children’s growth and this will motivate parents to stay involved in therapy. This student-concept was used as input for the next co-design steps.

Figure 4

Design guidelines developed by the speech and language therapy (SLT) practitioners in the workshop



Stage 2: Define

The objective in this stage is to state, explicitly and clearly, which problem keeps users from reaching their objective (Design Council, 2007). In our 'Define' stage, working mechanisms were explored and usability criteria were set up to inform development of prototypes.

The function of concept development and prototyping in this phase is for understanding the problem, whereas in the subsequent Develop phase, the focus shifts towards developing a fitting solution. Several co-design activities were used, which are described in detail below. The activities were part of a workshop at our university and were facilitated by the co-design researchers. The same eight SLTs as in Stage 1 participated, except for two SLTs who were unable to attend this second time. The workshop lasted for 4 h including several breaks.

Affinity mapping of product requirements

SLTs were asked to reflect on the 'SLT collectible puzzle' concept developed by the student team. While participants commented on the student-concept, a co-design researcher noted their positive and negative feedback (Van 't Veer et al., 2020: 188-191). This researcher categorized these comments together with the participants into an affinity map with five categories of product requirements. Affinity mapping is the collaborative process of organizing output from a discussion or brainstorming session into clusters or categories of similar items (Van 't Veer et al., 2020: 188-191).

First ideas and concepts

Six SLT-practitioners and two SLT-researchers individually developed a tangible concept, departing from the requirements just formulated. These concepts were early, sketchy and incomplete drafts intended to quickly illustrate potential working mechanisms (Lewrick et al., 2020: 199-202; Van 't Veer et al., 2020: 249-252). Participants used scrap materials, such as paper, wool, marbles, markers, containers and trays. The process was facilitated by the three members of the co-design research group. After 20 min, a moment of reflection was built in to share individual results and to facilitate the combination of concepts into a maximum of three concepts in total. A total of 30 min were left to improve and strengthen the concepts in small teams.

Role play to identify working elements

Participants selected two concepts for exploration in terms of working elements during a role play with two SLTs: one in her own role and one in the fictitious role of a parent with characteristics matching one of the personas. The role play was used to further explore and validate the product requirements of the tool, while also allowing the SLTs to experience the solution and to interact with it. They experienced which mechanisms could work in the context of a conversation with a parent. The co-design and SLT-researchers analysed the video recordings of the role plays to identify basic working elements for the solution (Lewrick et al., 2020: 199-202).

Output stage 2: Define

All observational workshop data, such as photographs of the whiteboard with product requirements, videos of the role plays, and individual research journal notes were reviewed and discussed with the SLT-researchers and codesign researchers. This resulted in a final set of product requirements for the tool: functionality, user-friendliness, attractiveness, safety and affordability. Two important insights were gained from the concepting and role play activities. First, SLTs noted that handing the 'parent' a physical artefact resulted in the SLT to lean back and listen to the parent and thus seemed to facilitate parents in a dialogue with the SLT. Second, the SLTs playing the parent role predominantly talked about their child's skills and accomplishments, rather than about their experienced barriers and problems. These insights revealed that the biggest challenges in engaging parents in the goal-setting process were to put parents in the lead and to focus on growth and development instead of focussing on barriers and problems.

Stage 3: Develop

In this stage, as many ideas as possible are generated, prototyped, tested and iterated, all aiming at solving the users' problem.

Ideation and prototyping

This stage started with a brainstorm to generate ideas (Lewrick et al., 2020: 151-154), building on insights from the earlier phases. We refer to the act of generating ideas, with the term 'ideation'. When ideating, it is important to keep an open mind, and to retain, and build on, ideas that may seem too trivial and easy or too far-fetched and complex (Isaksen et al., 2011). A multidisciplinary approach to ideation is encouraged, as it brings together varied perspectives which can lead to better outcomes (Van 't Veer et al., 2020).

Two members of the co-design research group were also product and graphic designers, and they changed their roles during this stage from research facilitators to designers. Together with two SLT-researchers, ideas for prototypes were explored and developed. Two co-design researchers and one SLT-researcher combined several ideas into three concepts and built a prototype for each concept.

Decision matrix

The three prototypes were presented and evaluated within the research team. To make a well-grounded choice between the three concepts, they were evaluated against the design guidelines developed in Stage 1, using a decision matrix (Van ‘t Veer et al., 2020: 217-220). Consensus on the best prototype was reached through discussion between two co-design researchers and two SLT-researchers.

Output stage 3: Develop

The first prototype was a board with five jigsaw puzzle pieces. Each puzzle piece had a red-coloured side which indicated barriers in communicative participation, and a green-coloured side for positive items (Figure 5). The second prototype was based on the game ‘Guess who?’ (Figure 6). In this prototype the user had to eliminate information to get to the core of the problem. The third prototype was a tree depicting the growth of the child’s communicative abilities (Figure 7). Leaves could be placed high or low on a ‘tree trunk’ to indicate the performance in a communication skill.

Figure 5
The ‘Jigsaw puzzle’ prototype

Figure 6
The 'Guess who' prototype

Figure 7
The 'Tree' prototype

The decision matrix is presented in Table 4. In both the 'Jigsaw puzzle' and 'Guess who' prototypes, a large amount of information was shown simultaneously, which made it harder to funnel the results. The jigsaw puzzle also contained too much text that was not supported by icons or images, which contradicted with the requirements of visual support. 'Guess who' was less intuitive than the other two prototypes; instead of getting more information during the use of the tool, the information had to be eliminated from an extensive amount of information to begin with. The 'tree-concept' was evaluated as the best prototype, because it had an excellent match with the design guidelines. Overall, it was the most intuitive product, and the SLT-researchers thought it was inspiring, as the tree shape visualizes the concepts of growth and development. Another advantage was that the tool facilitated a structured and gradual way of sharing information in a conversation, and that pieces of information could be handed to parents, in order to elicit active participation.

Table 4
Decision matrix where prototypes are evaluated against design guidelines

Design guidelines	Jigsaw puzzle	Guess who?	Tree
The tool is clear	-	+/-	+
The tool inspires visually	+/-	+/-	+
The tool motivates parents	-	+	+
The tool is durable	-	-	+
The tool is intuitive	+/-	+	+
The tool leads to solutions	-	+/-	+
The tool dissects the problem	-	-	+

The research team evaluated the fit and function of the winning 'tree' prototype using the four personas. For example, we reasoned that the parents in our example persona, Gina and Wesley, who were described as very capable in expressing their concerns and needs, still might benefit from using the tool, because it marks the process of shared goal-setting and decision-making. For the SLT the expected advantage of using the tool was the opportunity to share observations in a dialogue with parents.

Stage 4: Deliver

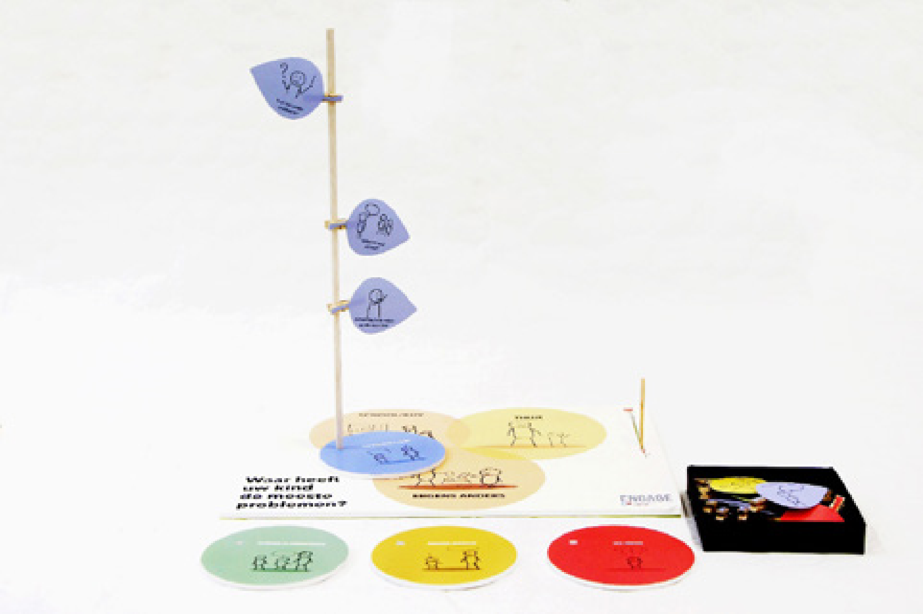
The last stage of the Double Diamond model is the delivery of the project, resulting in the finalization of the outcome, for example, a product or a service. This stage revolves around developing and testing the final concept, prior to actual production and implementation (Van 't Veer et al., 2020). In our deliver stage, we used the results of the structured usability testing to develop multiple iterations of the tree-prototype (Lewrick et al., 2020: 229-232), and conducted an A/B test to verify whether the adaptations had been successful (Lewrick et al., 2020: 233-235).

Demonstration

To receive feedback on the first tree prototype (Figure 7), it was demonstrated in a workshop on a continuing education symposium for SLTs. The participating

SLTs had not been involved in previous stages of the present study. After a live demonstration of the tool, SLTs (n = 22) filled in a feedback form that included the product requirements as usability criteria. Comments and suggestions mentioned by more than one SLT were fed back to the co-design researchers who adjusted the tool accordingly (Figure 8).

Figure 8
First iteration developed in the testing stage



Structured usability testing

Four SLTs invited parents to discuss their child's communicative participation problems. First, the SLTs prepared the conversation by reading a draft instruction manual, while commenting aloud on any vagueness in how the tool could be used. Their comments were used to improve the manual. Remaining questions from the SLTs were answered by the SLT-researchers. In the next step, three SLTs used the tool (Figure 8) together with five parents. SLTs' findings were reported in a feedback form that included the product requirements as usability criteria. SLTs discussed their answers with an SLT-researcher. In addition, the SLT-researchers interviewed the parents about their experiences with the tool, focusing on the same criteria. After the first test round, the comments of the SLTs and parents, as well as parts of the video recordings of the conversations were fed back to the co-design researchers who adjusted the tool (Figure 9), while the SLT-researchers adjusted the user manual and texts in the tool. The updated version of the prototype and manual was used in a second test round that was performed with the same procedure. The three participating SLTs invited six other parents to participate in this round and obtained their informed consent. The tool was adjusted again after this round of usability testing (Figure 10).

Figure 9

Second iteration developed in the testing stage

A/B testing

To evaluate whether the usability of the first (Figure 7) and the final prototype (Figure 10) had changed, an A/B test was conducted. A/B testing is a user-experience research methodology wherein two versions, A and B, of a product are compared (Lewrick et al., 2020: 233-236). The first (A) and final prototype (B) were demonstrated at two separate occasions at a workshop of a continuing education symposium for SLTs. None of the attending SLTs had been involved in previous stages of the present study. Each SLT rated either the first (n = 22), or the final (n = 42) prototype on the five usability criteria using a 10-point Likert scale, with a score of 1 indicating the worst possible performance and a score of 10 for the best possible performance. To test the tool for 'affordability', we asked participants to rate two different selling prices for the first and the final prototype. This way we wanted to determine whether an increased production value (i.e., robustness, level of detail and finishing) of a prototype was reflected in a higher perceived value by SLTs. Affordability was marked against a fictious selling price of €50 for the first prototype and €75 for the final prototype.

Figure 10
The final 'Tree' prototype developed in the testing stage

Output stage 4: Deliver

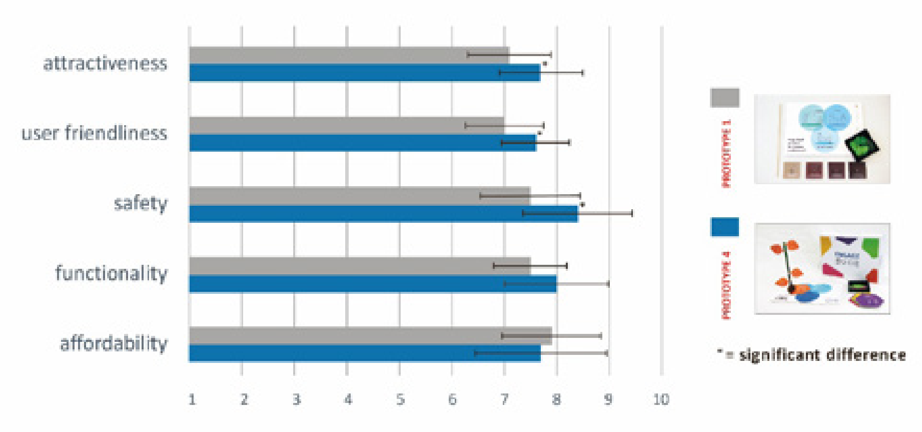
Structured usability testing resulted in several iterations leading to a final prototype (Figure 10): a physical artefact that we called 'ENGAGE'. It consists of a metal 'tree trunk', on which parents can stick selected 'leaves', with items representing relevant participation goals for their child. Parents place the trunk on a board with three circles referring to participation at 'home', 'school/day care centre' and 'somewhere else', to indicate in which context(s) their child needs support. Tree leaves that are placed higher in the tree represent the child's acquired competences, and tree leaves placed lower in the tree are potential goals for therapy. Together with the tool, a form was developed for writing down a personalized goal for communicative participation. On this form, parents can score a 10-point Likert scale, indicating how well the child is performing on this goal at the start of a therapy period. Scoring can be repeated after working on that goal for some time. A higher score in an indication of progress.

SLTs commented on the prototypes concerned the colour scheme, the choice of materials, its safety and robustness, the clarity of categories of items, understandability of texts in the tool, the need for a form to write down and evaluate goals, and the comprehensiveness and coherence of the text in the manual for the SLT. Whilst the first prototype contained 36 items in three categories (communicative intention, understanding others, and being understood), the final version had 17 items and four categories (likes to communicate, understands others, is understood and uses language in conversations). Feedback on the complexity of the items resulted in items being reworded from C and B2 language levels into the less complex A2 or B1 Common European Framework of Reference for Languages language levels (CERF; Council of Europe, 2001). As a result of rewording the items, some were merged, reducing the total number of items in the tool from 36 to 17. The extra category 'uses language in conversations' was created, because SLTs thought that the category 'is understood' had too many items and the set of skills that it described was too broad. They suggested to create an extra category for complex language use in conversations. Based on their feedback we also added a separate information sheet with examples illustrating each item in the manual of the final version. Feedback from parents resulted in in changing the visual analogue scale for goal evaluation into a Likert scale, which parents found easier to understand and use, and adding space on the form for describing activities that they can do with their child to work towards the goals.

The first (Figure 7) and final (Figure 10) prototypes were rated using a 10-point Likert scale (Figure 11). The first prototype received marks between 7.0 and 8.0 out of 10, while the final prototype received marks between 7.5 and 8.5 out of 10, indicating sufficient usability for both prototypes.

Figure 11

Speech and language therapy (SLT) practitioners ratings of the first and final prototype



The A/B testing results were further analysed with independent-samples t-tests comparing the ratings of the first and final prototypes (Table 5). In summary, there were significant differences in the scores for attractiveness, user friendliness and safety in favour for the final prototype. Differences between marks for functionality and affordability were not significant.

Table 5

Results of an independent samples t-test on usability ratings of the first and final prototypes

	First prototype M; SD	Final prototype M; SD	T-test(df), *p*
attractiveness	7.1; 0.82	7.7; 0.78	$t(61) = -2.87$, $p = 0.006$ [a]
user friendliness	7.0; 0.74	7.6; 0.67	$t(60) = -3.26$, $p = 0.002$ [a]
safety	7.5; 0.97	8.4; 1.07	$t(53) = -2.95$, $p = 0.005$ [a]
functionality	7.5; 0.68	8.0; 0.98	$t(60) = -1.81$, $p = 0.075$
affordability	7.9; 0.93	7.7; 1.25	$t(59) = 0.415$, $p = 0.680$

Note: [a] significant with a Bonferroni corrected *p*-value of 0.01.

DISCUSSION

This study describes the co-design process in which a shared goal-setting tool was developed that we named ‘ENGAGE’. Co-design partners were SLTs working with children with DLD and their parents in Dutch school settings or in SLT practices. We started with a list of items describing communicative participation of children with language disorders according to parents and professionals (Singer et al., 2020). We envisioned that a checklist of items would not be the best instrument to facilitate goal-setting that is less therapist-led. Instead, including SLTs perspective and needs and reflections from parents of children with DLD resulted in the co-design of a physical artefact called ‘ENGAGE’, which we regarded to be more in line with family-centred care and shared decision-making. The tree-like shape of the tool provides a positive metaphor for the growth and development of a child. Use of the tool allows the gradual introduction of items, and hence new information about the child’s communicative functioning by both parents and the SLT. The tool supports the dialogue, shared decision-making and goal-setting process, and is flexible and intuitive in use. After several iterations performed in a usability study, the ratings on attractiveness, user-friendliness and safety increased significantly, while the ratings for functionality and affordability remained at a satisfactory level.

From the role play session and the first ideating workshop it became apparent that the SLTs had a strong preference for developing a physical artefact. They expressed that this would serve their own needs and those of parents by facilitating dialogue and interaction. This result corresponds with the observation of Elwyn et al. (2010) that in face-to-face encounters sharing an artefact encourages dialogue because it typically requires both patient and clinician to shift body position and fix their gaze on the same information.

Some advantages of using co-design are a better fit between an innovation and the user's needs, a better user experience, and higher user satisfaction (Steen et al., 2011). In this project, SLT-practitioners, SLT-researchers, and co-design researchers were equally involved in the creative thinking and design process. Involving SLT-practitioners had the advantage that understanding how they feel, think, and act in the context of goal-setting with parents provided insights in how to develop and optimize prototypes that would meet their needs (Sleeswijk Visser et al., 2005). We started with needs and wishes related to the organization of the content of the tool (i.e., the items) and during the project this focus shifted towards ideas and needs related to the format and functionality of the tool (i.e., how the items can be used to stimulate dialogue and interaction).

A key component of co-design is that it builds on unique and individual experiences but it includes collaboration and collective perspectives too. Only eight SLT-practitioners participated in the first three stages. This low number of participants constitutes a risk of developing a solution that is not recognized as such by the larger group of end users. To test this, we invited new groups of SLT-practitioners to rate and usability test the prototypes. Their positive ratings and feedback confirmed the usability of the prototype and implies that the impact of the solution can reach beyond those who are directly involved (Boyd et al., 2012).

A strength of our project is that the co-design researchers who prepared and conducted the co-design workshops were also the designers of the tool. Usually, a co-design researcher's involvement ends after the 'Discover' and 'Define' stages. Insights gained from these stages would typically be used to brief another designer, who would then develop prototypes. In this project however, the 'Develop' and 'Deliver' stages were integral parts of the process, mainly because we had limited funding and therefore limited time available to reach a practicable end-result. The 'Develop' and 'Deliver' stages were therefore conducted without hiring an external design studio. Instead, the co-design researchers assumed a different role, which led to a 'designer understanding phase' that was much more elaborate than a traditional briefing could be (Sleeswijk Visser et al., 2007). Their involvement from the beginning of the project ensured a deep understanding of the problem to be solved, the functionality to be delivered, and the design and user requirements to be met.

A risk associated with having the same (co-)designers involved throughout a project is that it may invite unwanted or preliminary control from the co-design researchers towards a particular solution. However, we do not think this occurred because the co-design researchers were asked to start design no earlier than at the end of the

Discover and Define stages. Another risk might be that the intensive interaction between co-design researchers and participants leads to positive of negative bias towards the ideas and input of one or more participants. In this case, we do not think that this happened, because the input was regularly reviewed and discussed with all participants. In addition, bias may still be translated into the content of the briefing for an external designer. Furthermore, from the perspective of the SLT-researchers, having the same co-design researchers involved in all the stages in the design development process proved to be extremely efficient for the project; the first prototype was already highly usable and needed only minor revisions during the 'Deliver' stage when it was tested in a real care setting. This observation is in accordance with Steen et al. (2011) who conclude that co-design helps to organize projects more efficiently.

Challenges in collaboration across research disciplines were discussed in two evaluation sessions with the co-design and SLT-researchers, halfway and at the end of the project. We observed differences in research language and traditions between health sciences and design researchers. For example: SLT-researchers used the term 'prototype', referring to the prefinal version of the product, while the co-design researchers thought of a tangible version of an early design idea. Similarly, SLT-researchers expected structured agendas and protocolled activities within co-design workshops, whereas the co-design research group allowed for flexibility in the choice for specific creative techniques. In addition, timelines and deadlines within the project were perceived differently between the two research groups. The SLT-researchers were focused on the end-product and tried to direct the project towards a tangible product. The co-design researchers, on the other hand, tended to focus on the insights gained from the workshops, and refrained from skipping stages or jumping to conclusions. While both research groups acknowledged that there were marked differences between the research traditions, both agreed that SLT-practitioners proved to be excellent candidates for participation in a co-design project, because they easily understood co-design techniques and participated fully in the different creative workshops. When working as a cross-disciplinary team we think it is important to address differences in approaches and expectations openly, preferably both before the start and during the project (Stickdorn et al., 2018). This way, co-design can help to improve interdisciplinary cooperation within organizations, which has been described as one of its benefits for organizations (Steen et al., 2011).

In addition to the challenges identified in our evaluation sessions, previous studies mention several other potential problems when using co-design methodology, such as lack of project management skills, and difficulties in establishing, building, and maintaining relationships with many different stakeholders (Groenevelt et al., 2019). In the present project, we think that these risks were minimized because the co-design researchers were experienced in the collaboration with allied health professionals, while the SLT-researchers had previous experience conducting research with SLT-practitioners.

This study adds to the increasing number of initiatives that use co-design in the development of health care interventions. With this paper, we wanted to provide an example of a co-design development process in the field of SLT. The detailed description of the process may give the reader insight in what a co-design process entails and what the distinct roles are of the actors involved. We hope that other researchers in the field of SLT can benefit from this example when they wish to develop new products together with end-users, whether they are patients or professionals. Methods and co-design techniques are dependent on the specific problem addressed and the stakeholders involved. It is therefore important to note that the example as outlined in this paper should be seen as a source of inspiration only, rather than as a procedure or methodology.

Limitations and suggestions for further research

A limitation in this study lies in the fact that SLT-practitioners were not directly involved in the actual selection of one of the three prototypes. Instead, the research team evaluated the three prototypes against the design guidelines and usability criteria that were developed with the SLT-practitioners. Including SLT-practitioners directly might have yielded different insights, or even a different solution. We chose not to do this, because the three prototypes had diverse levels of detail and sophistication, which may have influenced SLT-practitioners' decision. When evaluating the project, we felt that including SLT-practitioners in the selection process would have been more appropriate because it again brings different perspectives together. However, this would only have been possible if all prototypes had the same level of detail, which required additional time from the designers. This limitation highlights the importance of carefully considering which decisions at what point in the process are made jointly or by subgroups only, and to plan the project accordingly. Another limitation is that we did not inquire if and how participation in the project changed SLT-practitioners' perspectives on shared goal-setting and collaboration with parents.

A significant limitation of our co-design process is that parents' input on the development of tool was not sought. Our focus was on SLTs because we felt that the SLTs held the key to change of their own behaviour in service delivery, and hence to the change from therapist-directed to shared goal-setting. While the tool sets out to enhance a dialogue between parent and SLT, parents' involvement was limited to an interview on their children's wellbeing and values in life via participating SLT-practitioners, and in the usability testing. In retrospect, we should have included parents as equal partners in the co-design process. Based on experiences in other projects where parents are part of the research team, we are now convinced that parents could have made a valuable contribution in any co-process aimed to improve the care for their children. Including the parents' perspective in therapy is an essential component of evidence-based practice (E3BP, Dollaghan, 2007). Similarly, parents' participation in a co-design process can be very empowering and can break down barriers to participate in society (Sleeswijk Visser et al., 2005), while it can also be challenging to involve non-professionals in a design process (Groeneveld et al., 2019). However, more systematic research is needed that evaluates patients' actual experiences of the co-design activities (Bombard et al., 2018). ENGAGE was developed for use with parents of young children (aged 2-7 years) with (or at risk for) DLD, which is the typical age when children are identified in the Netherlands (Wiefferink et al., 2020). These children are too young to participate in a co-design process with written instruction and communication, but we think that there is an urgent need to develop tools and methods for shared goal-setting with children that incorporates their unique perspectives, aspirations, and challenges. Methodologies that are tailored to engage (young) children in research, for example, through drawing, are increasingly being developed, tested and applied in SLT (e.g., Holliday et al., 2009).

A final limitation is that our description of the co-design process ends with testing of several prototypes. Two additional steps must be taken before a tool is ready to be used in clinical practice: valorization and implementation. Future research could focus on how co-design can help with the implementation of project results. In addition, research is needed on how SLTs, parents and children experience use of the tool, and how shared goal-setting with a tool like ENGAGE impacts on therapy outcomes.

Conclusions

The co-design approach resulted in a shared decision-making tool that was quite different from a traditional pen-and-paper questionnaire or test. Inclusion of the needs, experiences, and perspectives of SLTs in each stage of the development process resulted in a physical artefact that we named ENGAGE. The tool is aimed at supporting shared goal-setting with parents, and also providing a positive metaphor for the growth and development of a child. Our project is an example of co-design research with SLT end-users. We hope that inclusion of professionals, but also children or adults with communication disorders and their families, will become best practice in the development of new tools, instruments and interventions for speech and language therapy.

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Conflict of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper. All authors read, edited and contributed to the manuscript.

Data availability statement

Data are available upon request from the authors.

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Chapter 4

Enhancing shared decision making in paediatric speech and language therapy: A description of the ENGAGE intervention

Singer, I., Luinge, M., Gorter, J.W., & Gerrits, E. (2024). *Enhancing shared decision making in paediatric speech and language therapy: A description of the ENGAGE intervention*. ResearchGate. https://www.researchgate.net/publication/387167556_Enhancing_shared_decision_making_in_paediatric_speech_and_language_therapy_A_description_of_the_ENGAGE_intervention

ABSTRACT

Background

Children with developmental language disorders (DLD) face ongoing challenges in language and communication, impacting their learning, literacy, social interactions, and emotional well-being. Speech and language therapy interventions have been shown to positively influence the language abilities and communication skills of children with DLD. However, these interventions are often not described in full detail, hindering effective implementation, replication, and the advancement of knowledge.

Method

We used the Template for Intervention Description and Replication (TIDieR) checklist and guide to describe the ENGAGE tool, which supports shared decision-making between parents and SLTs about communicative participation goals for children with DLD. The description was based on the development process, the ENGAGE user manual, and an interview study on its impact on SLT practice.

Results

We provide a detailed description of the ENGAGE intervention using the 12 items from the TIDieR checklist and guide, facilitating easier implementation and replication.

Discussion

Reflecting on our findings, we discussed the evolution of shared decision-making models, comparing Elwyn et al.'s (2012) model with the updated goal-based model by Elwyn & Vermunt (2020). This new model highlights the importance of collaborative goal setting in speech and language therapy. Our findings suggest that the ENGAGE tool aligns well with the latest theoretical advancements in shared decision-making.

INTRODUCTION

Children with developmental language disorders (DLD) experience persisting problems with language and communication that affect their learning, their ability to read and write, friendships, and emotional well-being (St. Clair, Pickles, Durkin & Conti-Ramsden, 2011; Conti-Ramsden & Botting, 2004). Speech and language therapy interventions have a positive effect on the language abilities and communication skills of children with DLD (Cirrin & Gillam, 2008; Rinaldi et al., 2021). In recent years, speech and language therapy has evolved to take a more holistic view of the treatment of DLD, focusing not only on treatment of the language impairment, but also on support for children's societal participation through communication. Communicative participation has been defined as "taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication" (Eadie et al. 2006, p. 309). It is now considered the primary outcome of speech and language therapy (Cunningham et al., 2018; Prelock et al., 2008).

Since the family is the child's primary source of support, speech and language therapists (SLTs) are encouraged to involve children's parents/caregivers in all aspects of therapy, including goal setting. Parental involvement is expected to lead to strengthened decision making (Stevens et al., 2013), which in turn is associated with more collaboration between parent and SLT (Klatte et al., 2019), an improved parent-therapist relationship (Stacey et al., 2017), and with superior outcomes for children (Coulter & Collins, 2011; Haine-Schlagel & Escobar et al., 2016; Roberts & Kaiser et al., 2011; Van Voorhis et al., 2013). However, research suggests that goal setting processes are currently predominantly therapist-led, instead of family-centred (Roulstone, 2015). To support shared goal setting we developed a tool called ENGAGE. The aim of the tool is to facilitate the dialogue between SLTs and parents about children's communicative participation goals.

The need for the ENGAGE tool and its development has already been reported (Singer, Klatte, De Vries, Van der Lugt & Gerrits, 2022), but the tool itself and how it can be used in clinical practice has not been described yet. Academics in the field of DLD have highlighted concerns that descriptions of language interventions in the published literature tend to report generic approaches and materials rather than details about specific tasks and techniques inherent to the intervention (Law et al., 2003; Roulstone et al., 2015). The lack of consistent and transparent reporting of speech and language interventions hinders effective implementation, impedes replication, and limits the advancement of knowledge on the treatment of DLD (Law et al., 2003; Roulstone et al., 2015; Frizelle et al., 2023). To enhance transparency in healthcare research reporting, an international coalition of experts developed the Template for Intervention Description and Replication (TIDieR) checklist and guide (Hoffmann et al., 2014). This tool complements the EQUATOR (Enhancing the QUAlity and Transparency Of health Research) guidelines. However, no study has yet utilised the TIDieR checklist to describe developmental speech and language therapy (SLT) interventions (Shobbrook, Young, Beeke, & Best, 2024). Although specific guidelines for applying the TIDieR checklist in speech and language therapy are still under development, its use is anticipated to improve the consistency of reporting interventions for children with developmental language disorder (DLD) (Frizelle et al., 2023).

We want to set an example and emphasise the vital role of accurate intervention descriptions in shaping evidence-based practice. The TIDieR checklist and guide are used here to describe the intervention ENGAGE (Figure 1) in detail. Our aims are to contribute to the understanding of the ENGAGE intervention, and to transparent reporting in speech and language therapy in general.

Figure 1
ENGAGE, a tool for shared goal setting for SLTs and parents of children with DLD (Dutch language version)

METHOD

We used the TIDieR checklist (Hoffmann et al., 2007) to describe how ENGAGE can be used to support shared decision making between parents and SLTs about communicative participation goals for children with DLD. The primary aim of the TIDieR checklist is to guide authors to provide comprehensive details of interventions, thereby facilitating their replication. It includes the essential items recommended for describing an intervention, with the assumption that information may be added if deemed necessary for the successful replication of the intervention. The twelve items in the TIDieR checklist are: 1) brief name of the intervention; 2) the rationale, theory, or goal of the intervention; 3) intervention materials; 4) intervention procedures; 5) who delivered the intervention; 6) mode of service delivery; 7) site of delivery; 8) intervention planning; 9) tailoring (i.e., personalisation); 10) modifications (i.e., unanticipated changes during the course of the trial); 11) fidelity assessment; and 12) actual intervention adherence (Hoffmann, et al., 2014).

The description of ENGAGE is based on information from the development process (Singer et al., 2022), the ENGAGE user manual for SLTs (Singer, Klatte & Gerrits, 2019) and an interview study on the impact of ENGAGE on speech and language therapy practice (Klatte, Luijten, Singer & Gerrits, 2019).

RESULTS

This section describes the ENGAGE intervention using the items of the TIDieR checklist.

Name of the intervention

TIDieR item 1: Provide the name or a phrase that describes the intervention

The name of the intervention is ENGAGE. This acronym stands for ENgaging parents in Goal Articulation and Goal Evaluation. To engage means ‘to take part in or be involved in’. As the name suggests, the tool aims to involve parents in goal setting and goal evaluation. For ease of reading, the word 'parents' is used throughout this report. However, ENGAGE can be used in a discussion with one or both parents, as well as with one or two regular caregivers of the child who are not the parents. The tool can also be used by professionals who are familiar with the child instead of the parents, when the focus of the intervention is on a specific context such as school. In section 4 (Procedure), where 'parents' is mentioned, 'professionals' can also be used as a substitute.

Rationale

TIDieR item 2: Describe any rationale, theory, or goal of the elements essential to the intervention

The aim of ENGAGE is to support SLTs in engaging parents of children with DLD in a discussion about priorities and concerns that can serve as input for specific therapy goals that will enhance communicative participation. Essential elements of the intervention are shared decision making by parents and SLTs, and communicative participation as the desired outcome.

Active parental involvement in goal setting for children with DLD is easily overlooked as an explicit component of shared decision making (Elwyn & Vermunt, 2020). Engagement of parents as primary caregivers is essential for connecting the therapeutic process with the communicative home environment (Wilcox & Woods et al., 2011). Therefore, collaboration between SLTs and a child's family is essential (An & Palisano, 2014). Collaboration means that therapy is responsive to the needs of families, that SLTs and parents share responsibility for choosing and implementing interventions, and that families feel empowered to make informed decisions. Yet, research suggests that goal setting processes for children with DLD are predominantly therapist-led, rather than family-centered (Roulstone, 2015; Watts Pappas et al., 2008).

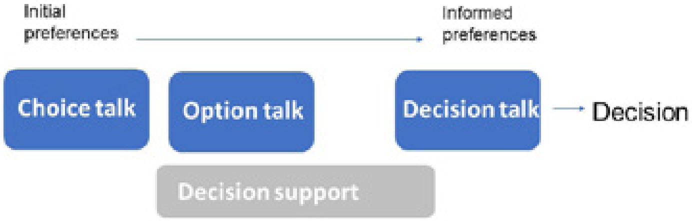
Elwyn et al. 's (2012) shared decision making model (Figure 2) suggests an approach to achieving shared decision making (SDM), that may also be applied to shared goal setting. SDM aims to explore initial personal preferences of a patient and subsequently develop well-informed preferences that can guide decision-making. According to the model, SDM can be achieved in three steps: (1) Choice talk, (2) Option talk, and (3) Decision talk. Choice talk involves ensuring that patients are aware of the availability of reasonable options. Option talk entails offering more comprehensive information about these options, while decision talk involves supporting the process of considering preferences and determining the most suitable course of action. The model also includes the use of decision support interventions that can be used during encounters to support SDM (Elwyn et al., 2012).

ENGAGE has been designed as a tool to support SDM on communicative participation goals, by eliciting choice talk, option talk and decision talk into a discussion between parents and SLT.

Communicative participation has been defined as "taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication" (Eadie et al., 2006, p. 309). This definition has been validated in a Delphi study with parents of children with DLD, SLTs, and other professionals such as teachers and child psychologists who stated that communicative participation means understanding and being understood by using communications skills in a social context (Singer et al., 2020). In addition to this definition, 34 items were developed in the Delphi study that represent behavioural aspects of communicative participation in young children with language disorders (Singer et al., 2020). These 34 items provided the basis for the content of the tool.

Figure 2

Elwyn et al.'s (2012) shared decision-making model



Materials

TIDieR ITEM 3: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL)

ENGAGE (Singer, Klatte, Gerrits, 2019) is a physical box containing the following items (Figure 1):

- o 5 round cards with broad categories of communicative participation problems (Figure 3). The categories are:
  - My/the child does not like to communicate (green)
  - My/the child does not understand others well (orange)
  - My/the child is not well understood (pink)
  - My/the child finds it difficult to use language well in conversations with others (purple)
  - My/the child needs help with something else (yellow)

The round cards can be turned over to read 'The child' instead of 'My child', for use with a professional such as the child's teacher.

- 17 magnetic leaves with specific communicative participation skills, each belonging to one of the categories of communicative participation problems, and five blank spare leaves on which specific acts can be written (Figure 4).
- An appendix with examples of communicative participation situations that illustrate the communicative participation skills on the tree leaves. The examples come from the Delphi study with parents and professionals on the definition and operationalisation of communicative participation (Figure 5 and Figure 6) (Singer et al., 2019).
- A base sheet with different contexts where communicative participation problems may occur: at home, at school or day care centre or elsewhere (Figure 7).
- A metal tree trunk with a stand.

Not visible in Figure 1, but included in the pack are:

- A response form (Figure 10).
- A user manual, including a score interpretation table (Table 1).
- A wipeable marker.

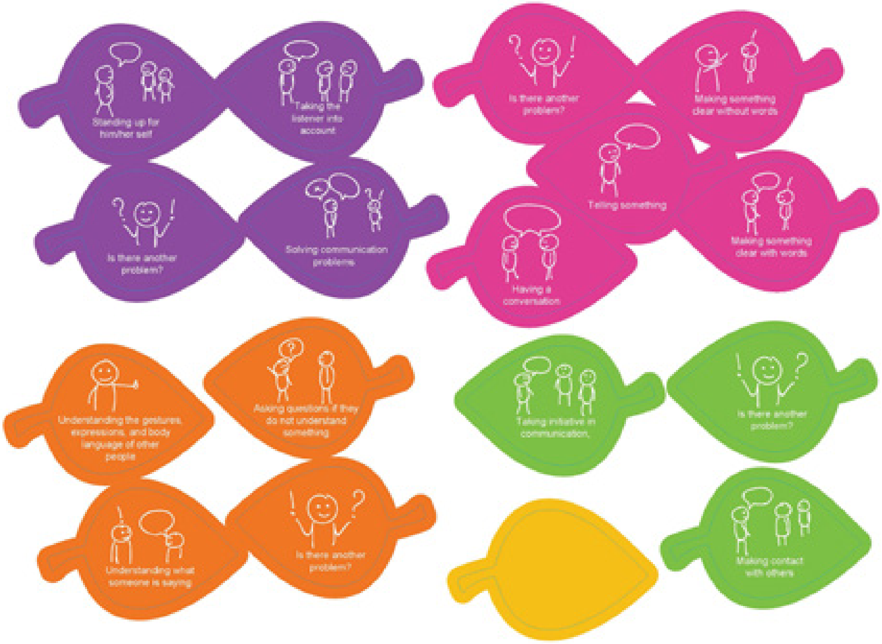
The Dutch language version ENGAGE materials are shown in Appendix 4.1.

Figure 3

Round cards with categories of communicative participation problems

Note. Four round cards with categories of communicative participation problems and a yellow round card that can be used when a difficulty suggested by a parent does not fit into one of the categories. The coloured cards with white text describing "My child" are intended to be used with parents. The white cards with coloured writing describing "The child" are for use with professionals, such as the child's teacher.

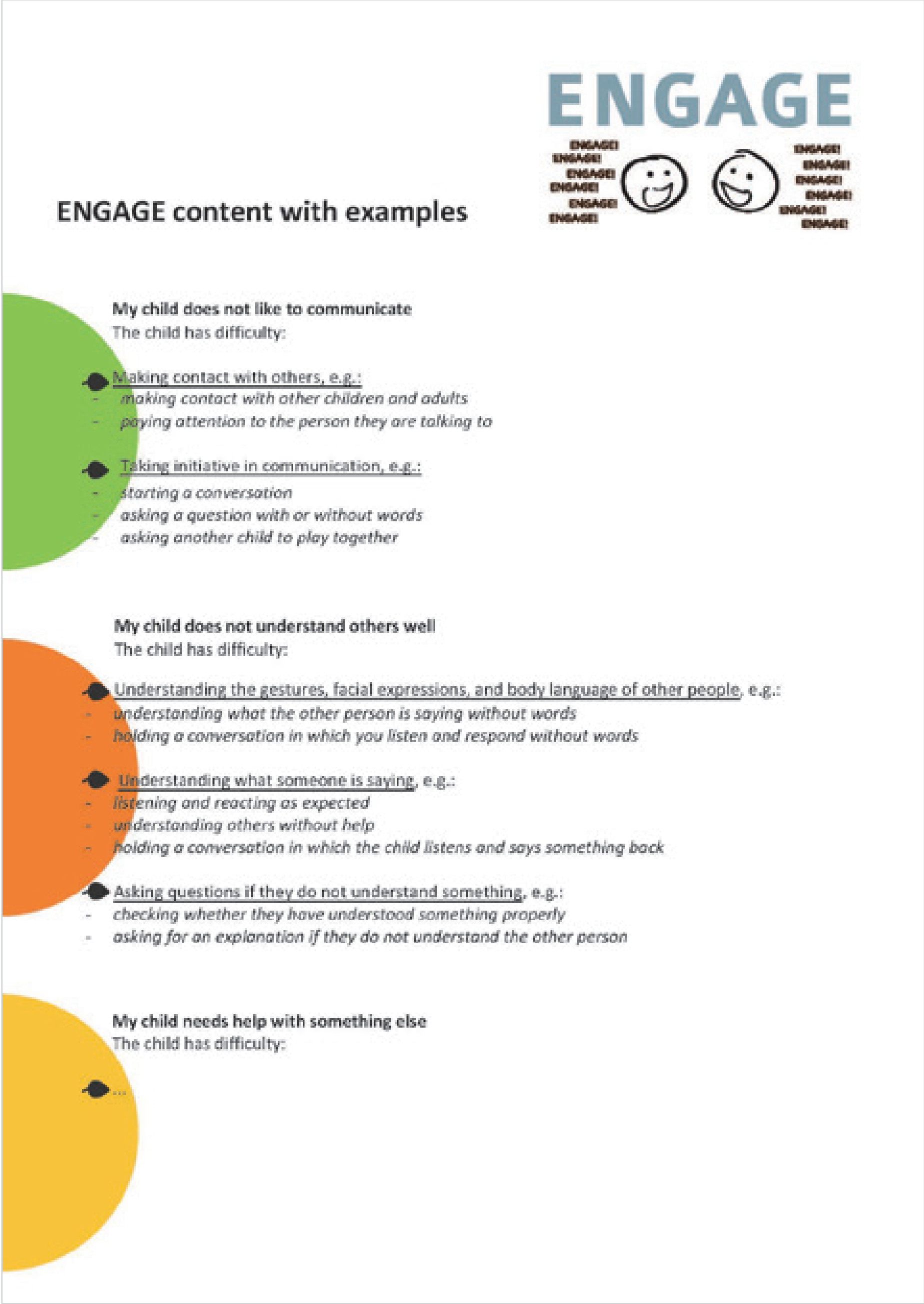
Figure 4
Tree leaves



Note. Tree leaves indicating specific communicative participation skills within the four categories of communicative participation problems, and a yellow leaf for noting a specific difficulty suggested by a parent that does not fit into any of the categories.

Figure 5

Appendix for SLTs, page 1



ENGAGE

ENGAGE content with examples

My child does not like to communicate

The child has difficulty:

- Making contact with others, e.g.:
  - *making contact with other children and adults*
  - *paying attention to the person they are talking to*
- Taking initiative in communication, e.g.:
  - *starting a conversation*
  - *asking a question with or without words*
  - *asking another child to play together*

My child does not understand others well

The child has difficulty:

- Understanding the gestures, facial expressions, and body language of other people, e.g.:
  - *understanding what the other person is saying without words*
  - *holding a conversation in which you listen and respond without words*
- Understanding what someone is saying, e.g.:
  - *listening and reacting as expected*
  - *understanding others without help*
  - *holding a conversation in which the child listens and says something back*
- Asking questions if they do not understand something, e.g.:
  - *checking whether they have understood something properly*
  - *asking for an explanation if they do not understand the other person*

My child needs help with something else

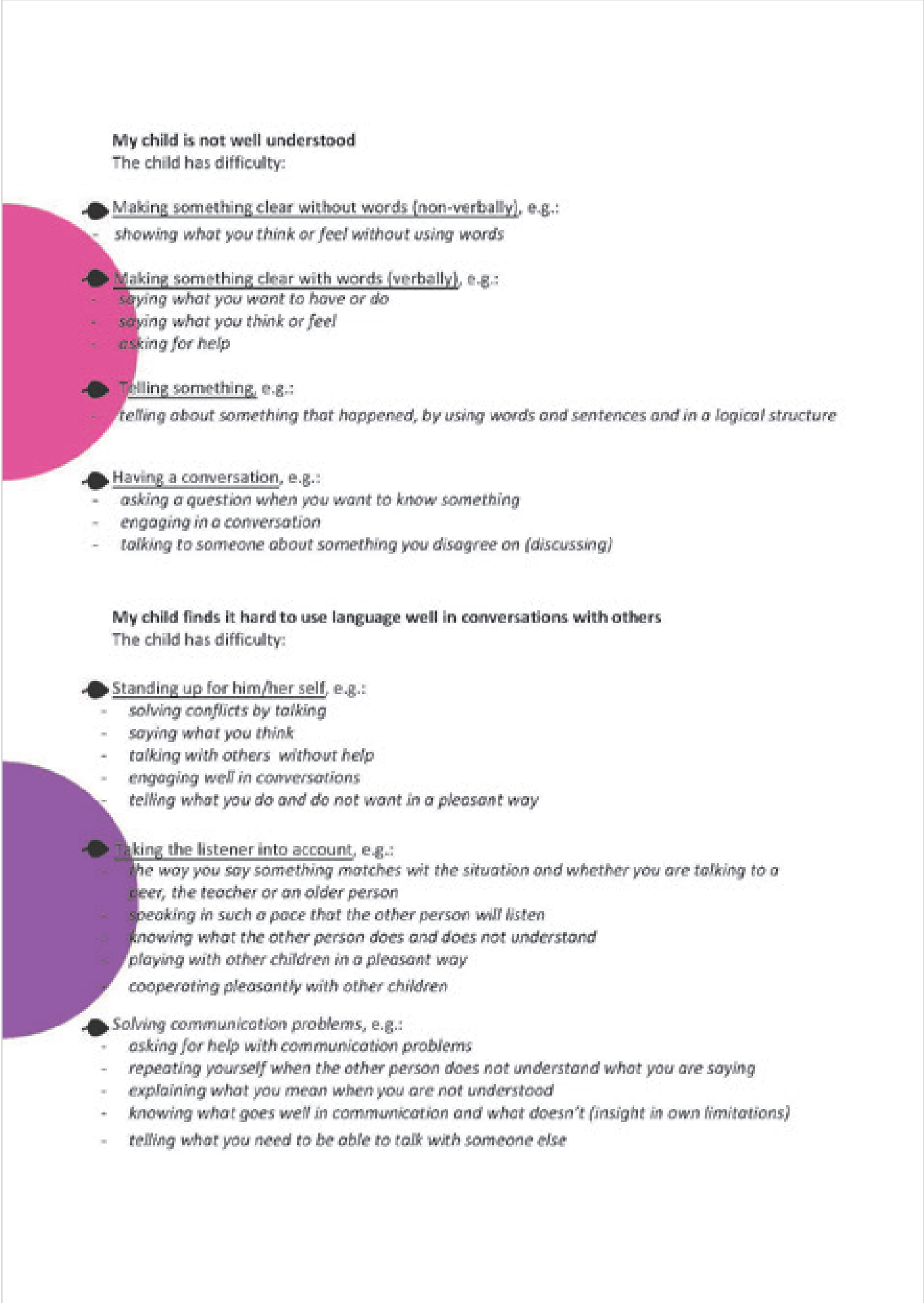
The child has difficulty:

- …

Note. Page 1 of the appendix for SLTs with the main communicative participation categories 'Does not like to communicate' (green), 'Does not understand others well' (orange), specific communicative participation skills on tree leaves (underlined), and examples of situations.

Figure 6

Appendix for SLTs, page 2



My child is not well understood
The child has difficulty:

- Making something clear without words (non-verbally), e.g.:
  - *showing what you think or feel without using words*
- Making something clear with words (verbally), e.g.:
  - *saying what you want to have or do*
  - *saying what you think or feel*
  - *asking for help*
- Telling something, e.g.:
  - *telling about something that happened, by using words and sentences and in a logical structure*
- Having a conversation, e.g.:
  - *asking a question when you want to know something*
  - *engaging in a conversation*
  - *talking to someone about something you disagree on (discussing)*

My child finds it hard to use language well in conversations with others
The child has difficulty:

- Standing up for him/her self, e.g.:
  - *solving conflicts by talking*
  - *saying what you think*
  - *talking with others without help*
  - *engaging well in conversations*
  - *telling what you do and do not want in a pleasant way*
- Taking the listener into account, e.g.:
  - *the way you say something matches wit the situation and whether you are talking to a peer, the teacher or an older person*
  - *speaking in such a pace that the other person will listen*
  - *knowing what the other person does and does not understand*
  - *playing with other children in a pleasant way*
  - *cooperating pleasantly with other children*
- Solving communication problems, e.g.:
  - *asking for help with communication problems*
  - *repeating yourself when the other person does not understand what you are saying*
  - *explaining what you mean when you are not understood*
  - *knowing what goes well in communication and what doesn't (insight in own limitations)*
  - *telling what you need to be able to talk with someone else*

Note. Page 2 of the appendix for SLTs with the main communicative participation categories 'Is not well understood' (pink), 'Finds it hard to use language well when talking to others' (purple), specific communicative participation skills on tree leaves (underlined), and examples of situations.

Procedures

TIDieR ITEM 4: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities

ENGAGE is a decision support aid that can be used during face-to-face encounters with parents of children with DLD. During the session, the parents build a three-dimensional 'life tree' that illustrates what has been discussed. The tree-shape was suggested as a metaphor for children’s growth and development by SLTs who participated in the co-design development process (Singer et al., 2020). Parents can stick tree leaves in the top of the tree, indicating communicative participation skills that the child has mastered already or position the tree leaves in the middle or at the bottom of the tree if they think that their child needs support in mastering these communicative participation skills. A base sheet (Figure 7) is used to specify the context in which communicative participation problems are most prevalent.

When ENGAGE is used in a discussion about children's communicative participation restrictions, a number of steps can be taken, depending on the preferences of SLTs and parents:

1. Preparation
2. Starting the discussion
3. Determining where the problem arises
4. Identifying and prioritising problems
5. Summarising the discussion
6. Shared decision on one or more SMART communicative participation goals
7. Baseline measurement of goal
8. Write down ideas for practice at home
9. Follow-up measurement
10. Discuss goal measurements with parents

Elwyn et al.'s (2012) 'choice talk' takes place in steps 2 - 5. The discussion between clinician and parents shifts to 'option talk' in steps 4 - 8, while 'decision talk' takes place in steps 7 - 10. Elwyn and Vermunt (2012) describe SDM as a non-linear and iterative process in which goals may evolve and priorities may shift as consequences become clearer or as personal preferences and possibilities become apparent. This evolving and shifting is evident in the step-by-step description of shared goal setting using ENGAGE: several steps address more than one talk in Elwyn et al.’s (2012) model.

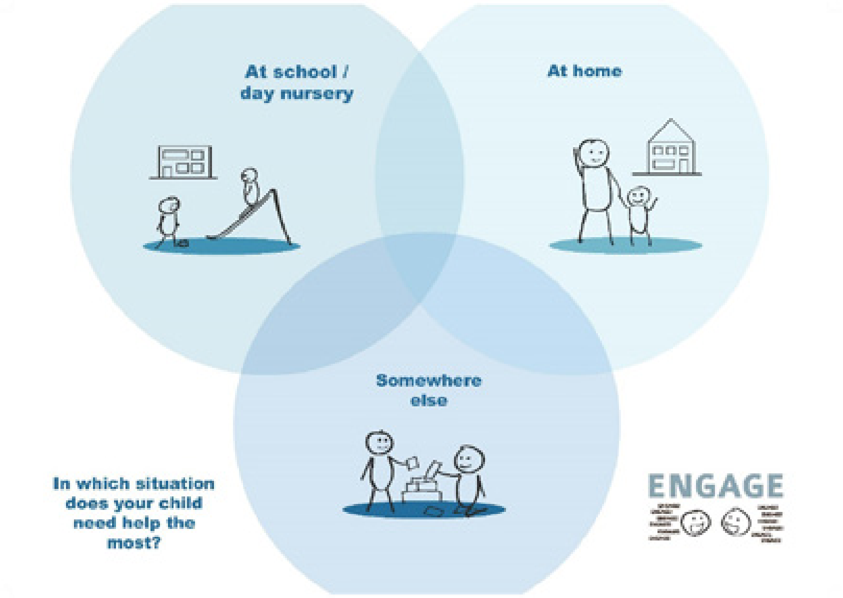
Step 1: Preparation

SLTs who have not used ENGAGE before are advised to read the manual and watch the tutorial video. Scan the QR code below to view the tutorial video. The video is recorded in Dutch. English subtitles are available via the 'gear icon' > subtitles > automatic translation > English.

edu.nl/mexjc

Before a goal-setting discussion, the SLT places the stack of five round cards on the table. With parents, the coloured side with the text 'My child ...' should be used. For the discussion with the child's teacher, the white side with the text 'The child ...' should be used. The SLT places the leaves with specific difficulties in communicative participation under each corresponding colour card. Finally, the base sheet (Figure 7) is placed on the table next to the cards.

Figure 7
Base sheet



Note. Base sheet with different contexts where communicative participation problems may occur: at home, at school or day care centre or elsewhere.

Step 2: Starting the discussion

The SLT explains that the aim of the session is to talk about communicative participation problems experienced by the child that the parents would like to address in therapy. The SLT asks a general question to open the discussion. Examples of such questions are:

- What is your main concern?
- Why have you referred your child for speech and language therapy?
- What results do you hope to achieve through speech and language therapy?
- What is the biggest barrier to your child's communication?

Next, the SLT introduces the round cards with the main categories of communicative participation problems one by one. The green card (my child does not like to communicate) can be used when there are problems with communicative intention. The orange card (my child does not understand others well) can be used when there are language comprehension problems, while the pink card (my child is not well understood) can be used when there are language production problems. The purple card (my child finds it difficult to use language well in conversations with others) can be used if there are problems with pragmatics. The SLT reads out what each card says and explains the main categories of communicative participation problems to the parents. The SLT ends with the card that says, 'My child needs help with something else'. The parents choose a card that best describes the child's communicative participation restrictions. Some parents may find it easy to describe their child's communication difficulties, while others may find it more troublesome. These parents can be supported by suggesting specific communicative participation skills written on the leaves of the tree (Figure 4), and with an appendix listing examples of situations as well (Figure 5 and Figure 6). SLTs can use the appendix with examples of situations when talking to parents to clarify the communicative participation skills described on each leaf. Figures 5 and 6 show the English translation of the appendix with the main communicative participation categories (bold), the communicative participation skills on the tree leaves (underlined) and the examples of situations for the SLT (italics).

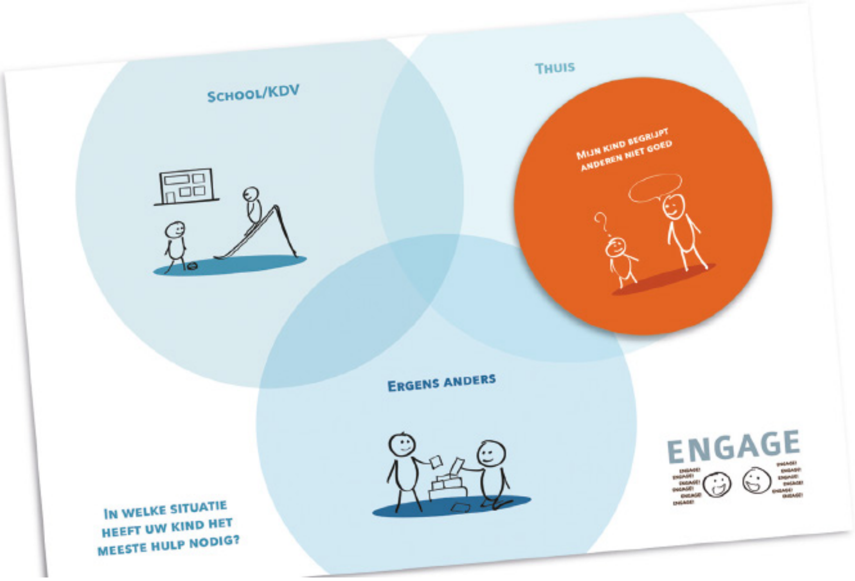
Obviously, parents may have needs that are different from those listed on the tree leaves. Therefore, for each round card there is a leaf that states that the child has a different problem. This leaf can be used if the problem described by parents does not match any of the communicative participation skills on the leaves. If the parents describe more than one problem, the SLT may ask them to prioritise which problem is the most important now. The SLT checks whether she has understood the problem correctly. She then proceeds to step 3. If more than one card fits the problem, or if the SLT and the parents find it difficult to choose one, it is possible to go through steps 2-4 with several cards.

Step 3: Determining where the problem arises

The SLT hands the parents the round card that best describes the child's communicative participation restrictions and the base sheet (Figure 7). Next, she asks the parents in which context the problem is most noticeable (the question on the base sheet is: "In what situation does your child need the most help?) There are circles on the base sheet to indicate whether the problem occurs mostly at school/nursery, at home or elsewhere). The SLT invites the parents to place the round card on the circle/context where the communicative participation problem occurs (Figure 8). If the problem occurs in more than one place, the parents can place the round card on two or three circles with different contexts.

Figure 8

Example use of base sheet



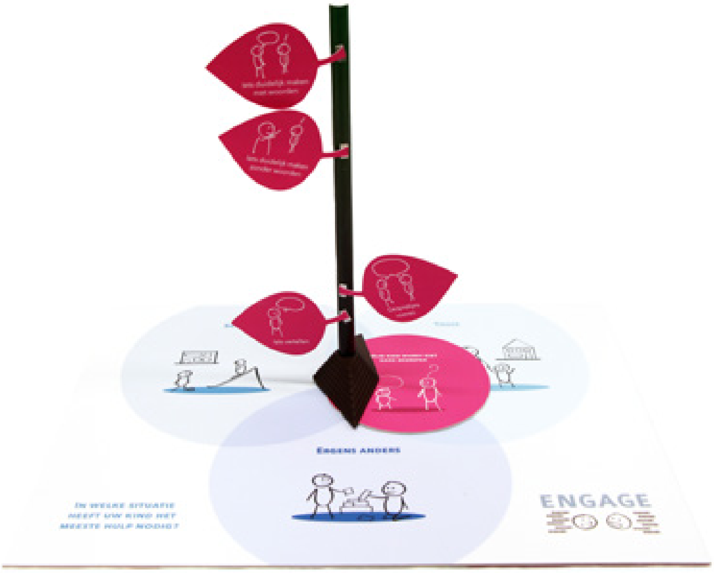
Note. Base sheet with an example round card (photo of the Dutch language version) positioned to indicate that the problems are present at home ('thuis').

Step 4: Identifying and prioritising problems

Next to the identification of the category of communicative participation problems the parents wish to focus on and where the problem occurs, the SLT may invite the parents to elaborate on a specific difficulty that needs to be addressed in therapy. For example, she might ask, "How do you/your child notice this in everyday life?" or "How can you tell that this is difficult for your child?”

If the parents clearly identify a specific difficulty (e.g., asking for something he/she wants) prioritisation is not necessary. In this case, the tree trunk should not be used and the SLT can proceed to step 5. If the parents do not mention a specific difficulty, the SLT places the tree trunk in the stand and places it on the round card (Figure 9). She introduces and explains the text on leaves that match the colour of the chosen round card one by one. The SLT can use example situations from the appendix if necessary. The SLT asks the parents to hang the leaves on the tree trunk using a magnet. If the parents think that the child is experiencing difficulties with the communicative participation act described on a leaf, the parents place that leaf at the bottom of the tree trunk. If a child has some difficulty, the parents place the leaf higher up on the tree trunk. Leaves describing skills that the child does not have difficulties with at all, are placed at the top. The SLT finishes with the leaf that says: 'Is there any other problem?' The SLT can use the wipe-off marker to write down a communicative participation act that the parents have mentioned if it does not match any of the leaves.

Figure 9
Example use of tree trunk



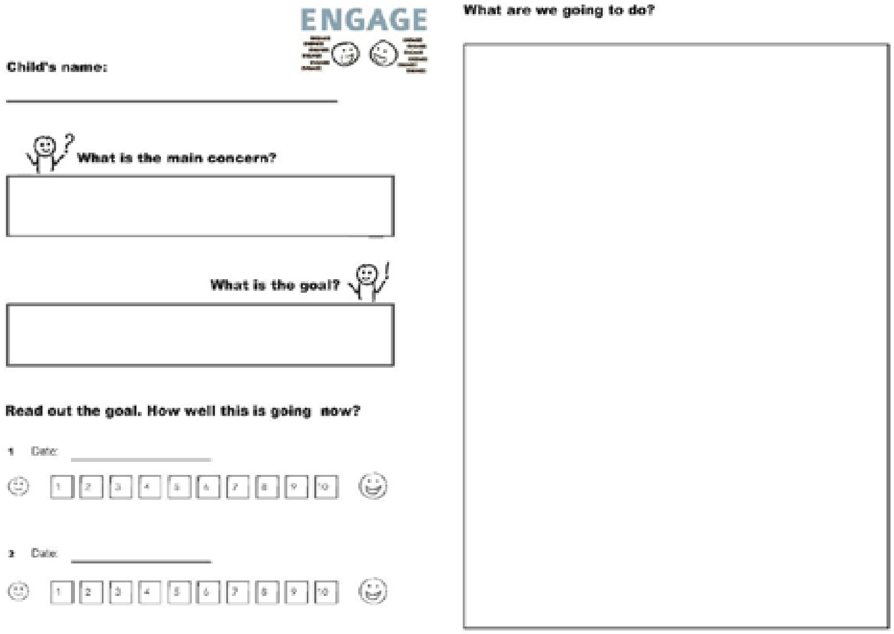
Note. Parents place coloured leaves with specific communicative participation skills belonging to one of the main categories of communicative participation on the tree trunk (photo of the Dutch language version).

If the parents have selected more than one round card, the SLT will repeat this process with leaves from the other category. In addition, the SLT may feel that leaves from other categories are important to discuss. She can select as many leaves as she feels are relevant. Finally, the SLT asks the parents which leaves placed at the bottom of the trunk indicate a difficulty that needs to be addressed first in speech and language therapy. The SLT can advise on the best sequence if more than one difficulty needs to be addressed.

Step 5: Summarising the discussion

The SLT summarises the information that was shared. She repeats what the parents consider the main concern, using the parents' own words as much as possible. She checks that she has summarised the parents' input correctly and records the main concern on the response form (Figure 10). The SLT and parents can photograph the ENGAGE result for inclusion in the child's file or for keeping at home.

Figure 10
Response form



ENGAGE

Child's name:

What is the main concern?

What is the goal?

Read out the goal. How well this is going now?

1 Date:

1 2 3 4 5 6 7 8 9 10

2 Date:

1 2 3 4 5 6 7 8 9 10

What are we going to do?

Note. The front of the form includes the child's name, the parent's main concern, the goal, and a baseline and scoring measure using a 10-point Likert scale. The back has space for ideas on how to address the goal at home.

Step 6: Set one or more SMART communicative participation goals

To ensure that the speech and language therapy treatment is consistent with the parents' goals, the SLT collaborates with the parents to develop a SMART (Specific, Measurable, Achievable, Realistic, Timely) personalised communicative participation goal. The SLT discusses the participation goal with the parents, including the question whether the goal is realistic and acceptable for the parents. The SLT records the participation goal in the (digital) patient record and on the response form (Figure 10). The parents and SLT decide together how much time will be spent working towards the goal. SMART goal setting is part of the SLT training curriculum and will therefore not be explained in detail.

Step 7: Baseline measurement

After the goal is set, the SLT may ask the parents to rate the child's goal performance before treatment begins (baseline measurement). A baseline measure is useful for evaluating the goal with the parents. The SLT notes the date of the baseline assessment on the response form. She also notes when the follow-up measurement will take place. She then reads out the communicative participation goal and asks the parents to indicate on the top scale (1) of the response form (Figure 10) how well this is going by putting a cross in one of the numbered boxes (1 being the lowest score, 10 being the highest score). She explains and points out that a cross in the box next to the neutral face means that the communicative participation act needs further development, while a cross next to the laughing face means that the communicative participation act is well developed. Finally, the SLT records the date and result (the score [1-10]) of the baseline measurement in the (digital) patient record.

Step 8: Write down ideas for practice at home

During the agreed period, the child will receive therapy directed towards the communicative participation goal. The SLT and the parents can now consider how, when and with what support they can actively contribute to achieving the goal. Ideas about activities parents and child can do at home can be recorded on the back of the response form under 'What are we going to do?

Step 9: Follow-up measurement

In the follow-up meeting, the parents assess whether the goal has been achieved (follow-up measurement). The parents rate the child's goal performance after the treatment period. For a reliable assessment it is important that the same parent(s) complete(s) both the baseline and the follow-up measurement. The difference between the two measures indicates the extent to which the parents feel the goal has been achieved. The follow-up assessment consists of five steps:

i. The SLT discusses with the parents what the main difficulty was that needed to be addressed in therapy and reads out the personalised communicative participation goal and the parents' indication of the child's ability at the time of the baseline measurement (described on the response form).
ii. The SLT asks the parents to indicate on the lower scale (2) how the child currently performs in relation to the communicative participation goal that has been set. She explains and indicates: a cross in the box to the right of the neutral face means that the communicative participation act needs further development, whereas a cross in the box to the right of the smiling face means that the communicative participation act is well developed.
iii. The SLT records the outcome of the follow-up assessment (score 1-10) in the (digital) patient record and calculates the change in score by subtracting the baseline score from the follow-up score.
iv. The SLT looks up in the manual how to interpret the score change. The score interpretation table is shown in Table 1. The SLT discusses the interpretation of the score change with the parents.

Table 1

Change in score interpretation table

-1, 0, 1	No progress
2	80% of the parents find this to represent real progress in daily life
3 or more	90-100% of the parents find this to represent real progress in daily life

Note. The justification of the score interpretation table is reported in Appendix 4.2.

Step 10: Discuss goal outcome with parents

The SLT discusses with the parents whether the main concern is still present and whether the parents wish to set a new communicative participation goal to address this difficulty in therapy. If this is not the case, the SLT can repeat the first steps of ENGAGE to find out if a new main concern has arisen and develop a new personalised participation goal together with the parents. If there are no further difficulties, this may support the decision to stop treatment.

Service delivery

TIDieR item 5: For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.

ENGAGE is developed by and for SLTs but can also be used by ambulant Special Educational Needs (SEN) teachers for children with DLD. In the Netherlands, SLTs are qualified to provide speech and language therapy after completing their bachelor's degree. SLTs are experts in the field of children with communication difficulties and often have expertise in motivational interviewing, a skill required for the use of ENGAGE. Ambulant SEN teachers ('ambulant dienstverleners') in the Netherlands are usually experienced primary or secondary teachers with a bachelor's degree. ENGAGE can be used by ambulant SEN teachers who are trained in assisting children with DLD in their home environment.

TIDieR item 6: Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.

Typically, ENGAGE is used in a 30-minute face-to-face therapy session between SLTs (or another competent professional who aims to support the development of communicative participation of children with language disorders) and one or both parents or the child's teacher.

TIDieR item 7: Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.

ENGAGE was specifically designed for use in face-to-face SLT-parent interactions. When the focus is on the child's communicative participation in a school setting, the tool can also be used with a professional such as a teacher who knows the child well in the school setting, rather than with parents.

ENGAGE is ideally used in a private and quiet SLT therapy room with chairs and a table or desk. ENGAGE can be used in all care and educational settings where children with communication problems are receiving treatment. ENGAGE can also be used in the parents' home. One or both parents can be present, depending on their preferences and availability. To avoid distraction, the child is ideally not present during the discussion, but the SLT and parents may decide otherwise.

Intervention planning

TIDieR ITEM 8: Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.

Although ENGAGE has been evaluated for usability and use in practice, it has not yet been the subject of an intervention study. SLTs involved in usability testing chose to use ENGAGE after history taking, but prior to language assessment (Singer et al., 2020). The SLT and parents can decide on the communicative participation goal immediately after the discussion or after concluding the language assessment. ENGAGE includes a baseline and follow-up assessment of personalised treatment goals. The time between baseline and follow-up depends on how quickly the SLT and parents feel the goal can be achieved. In the experience of SLTs and parents, using ENGAGE to decide on a goal takes a session of 20-40 minutes. Any follow-up discussion can also be expected to be within this timeframe. The baseline and follow-up measures take approximately 2.5 minutes each. In total, completing one round of goal setting and evaluation takes between 25 and 45 minutes.

Tailoring

TIDieR ITEM 9: If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.

SLTs are encouraged to use ENGAGE and its materials in a way that suits their needs and the needs of the parents during the discussion. The steps outlined in section 4.4 (Procedures) can be changed, skipped, repeated or modified if the SLT or parents feel this will better support the discussion. The shared goal-setting process is successful when the SLT and parents together prioritise a goal that is consistent with the parents' main concern and available intervention options.

Modifications

TIDieR ITEM 10: If the intervention was modified during the course of the study, describe the changes (what, why when, and how).

TIDieR ITEM 11: Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.

TIDieR ITEM 12: Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.

In this case, the TIDieR checklist is completed for a protocol. These items are not relevant to the protocol and should only be described if an intervention study is completed.

DISCUSSION

In this paper we gave a detailed description of the intervention ENGAGE. We used the Template for Intervention Description and Replication (TIDieR) checklist and guide (Hoffmann et al, 2014). This checklist and guide was developed for reporting details of interventions in clinical trials and intervention studies. The TIDieR checklist and guide provide clear guidelines on information to include when describing an intervention. The description of ENGAGE aims to contribute to the understanding of the intervention by clinicians and researchers, and aids to transparency of reporting in the field of speech and language therapy.

In describing TIDieR item 2 (describe any rationale, theory, or goal of the elements essential to the intervention), we presented Elwyn et al.'s (2012) shared decision making (SDM) model as a theory underlying the intervention ENGAGE. The studies that led to the development of ENGAGE took place between 2016 and 2018. Since then, thinking about SDM has evolved. The absence of goal setting as an explicit step in SDM models has been criticised by clinicians because goals play a vital role in treatment planning (Elwyn & Vermunt, 2020).

ENGAGE was designed to support collaborative goal setting, whereas the SDM model of Elwyn et al. (2012) was more general in nature. Although the SDM model was only used as a general background in the development of ENGAGE, the detailed description of ENGAGE presented here, encouraged us to reconsider the exact fit of the Elwyn et al.'s (2012) SDM model. We reasoned that, like other shared decisions described in the Elwyn et al. (2012) model, a shared decision about participation goals would need to include raising awareness of the possibility of personalised choices for treatment goals (choice talk). In ENGAGE, this took the form of taking time to talk about goals. Next, different goals should be explored and discussed (option talk). In ENGAGE this was operationalised by the SLT introducing the various categories of communication problems, providing information about language and communication development, and the SLT and parents clarifying their concerns by discussing the child's mastery of different communicative participation skills. Finally, according to the SDM model preferences should be explored, in terms of the parents' priorities, the feasibility of achieving potential goals, and the subsequent course of action (decision talk). In ENGAGE this step involved using the tree trunk to prioritise concerns, and the response form to write a SMART participation goal, evaluate it, and set a course of action.

In 2020, Elwyn and Vermunt have published an updated SDM model that explicitly focuses on collaborative goal setting, for use with people with multiple, complex, or long-term clinical conditions such as DLD. This new model has been developed because the authors recognise that collaborative goal setting is an essential part of SDM. The new goal-based shared decision making model describes an approach for shared decision making by eliciting and prioritising goals and aligning prioritised goals with interventions. Like the earlier SDM model by Elwyn et al. (2012), it consists of three steps, or 'talks'. However, the need for collaborative goal setting is more explicit in the newer model (see table 2). The 2020 model on shared goal setting distinguishes (1) goal team talk, (2) goal option talk, and (3) goal decision talk. The steps in the two models are summarized in Table 2.

Table 2
Comparison of steps in Elwyn et al.'s (2012) shared decision making model and Elwyn and Vermunt's (2020)

SDM model (2012)	**1. Choice talk** Convey awareness that a choice exists - initiated either by patient or a clinician.	**2. Option talk** Patients are informed about (treatment) options in more detail.	**3. Decision talk** Patients are supported to explore what matters most to them, having become informed.
Goal-based SDM model (2020)	**1. Goal-team talk** • Introduce goal setting in relation to problems • Set goals (fundamental, functional, disease specific) • Make goal interdependency explicit and prioritize goals	**2. Goal-option talk** • Compare options for achieving prioritized goals • Pay attention potential results: benefits and harms • Consider impact on other goals and reprioritize if necessary	**3. Goal-decision talk** • Agree on decisions to be made • Make goal-based decisions • Plan evaluation of goal attainment

Goal-team talk involves establishing a partnership between clinician and client to support decision making. It includes agreement on the nature of the problems, accurate identification and prioritisation of goals, and a shared understanding that goals shape the search for effective solutions. The first step in the 2020 model differs from the 2012 model, in that it does not only introduce the concept of shared goal setting, but also includes the exchange of information between patient and clinician. In the 2012 model, information sharing was included in the second step. In addition, the 2020 model no longer assumes that the clinician knows all the options. Rather, it emphasises that discovering the nature of problems and possible solutions is a process that clinician and patients or parents engage in together. The new model better fits with the procedure of ENGAGE as described in steps 2-5, where parents and SLT look into specific communicative participation difficulties together. Compared to the 2012 model, the goal option talk in the 2020 model is more focused on identifying treatment options that will help to achieve the goal. Although the response form in ENGAGE provides space for writing down ideas on how to work on the goal at home, we still have too little knowledge within speech and language therapy to link communicative participation goals to interventions in a substantiated way. More research is needed to allow for comparison of intervention options, consideration of the sequencing of interventions, the benefits and harms, and the necessary efforts from parents, child and SLT. Finally, the 2012 and 2020 models both address understanding the client's preferences for deciding therapy goals. However, the key difference is that the 2020 model includes an evaluation of goal attainment, which the 2012 model lacks. This evaluation is a crucial component of the ENGAGE tool, featuring a scale that parents can use to track changes in their child's performance.

The comparison between Elwyn et al.'s (2012) shared decision-making model and Elwyn and Vermunt's (2020) goal-based shared decision-making model highlights the parallel evolution of SLTs aspirations and theoretical thinking regarding SDM. Because ENGAGE was developed in co-design with SLTs and subjected to usability testing involving SLTs it can be expected to reflect SLTs' desires for shared goal setting with parents. These aspirations align remarkably well with the evolving understanding of SDM within Elwyn's research group.

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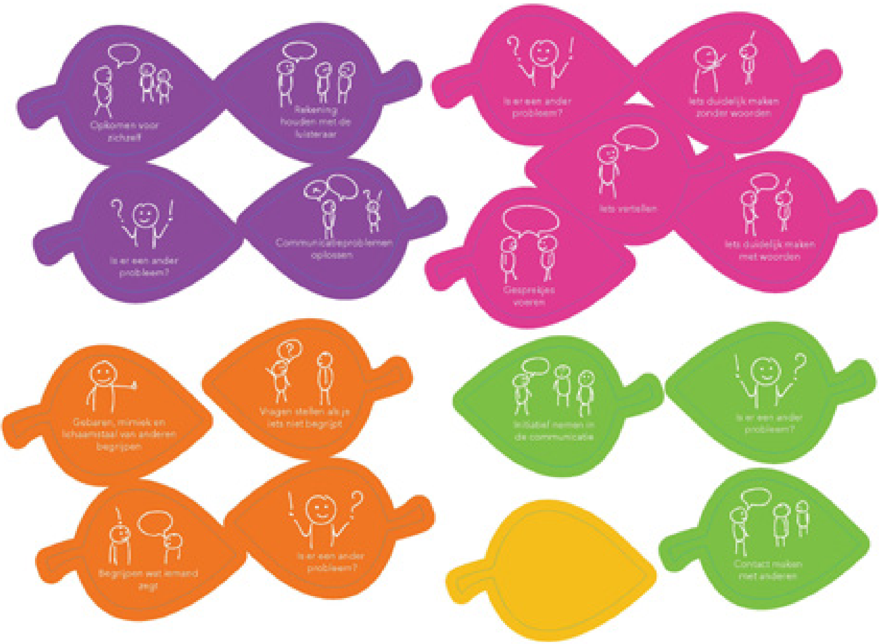
APPENDIX 4.1

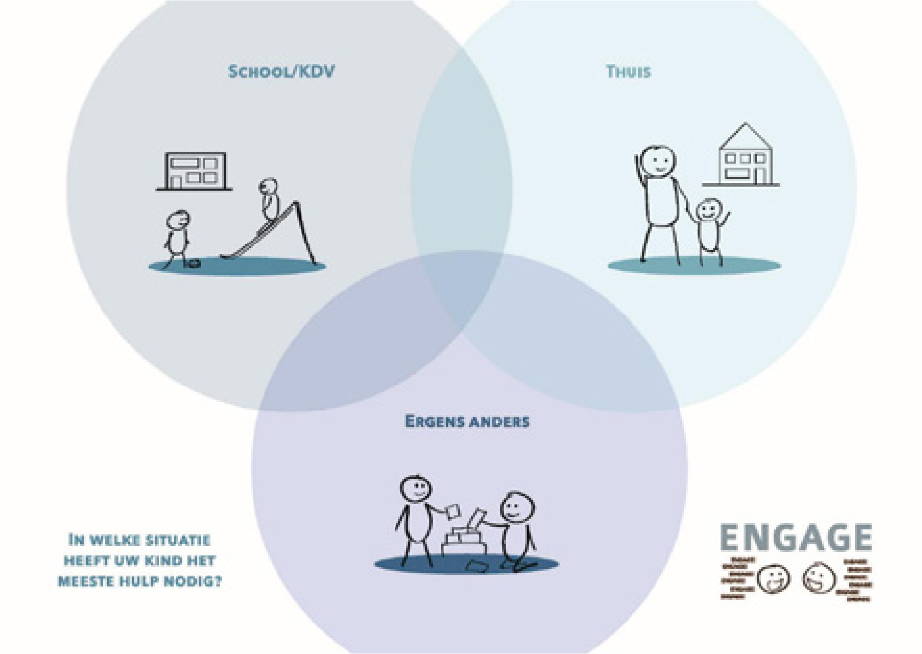
Dutch language materials

Five Dutch language round cards with categories of communicative participation problems. The coloured cards with white text describing "My child" are intended to be used with parents. The white cards with coloured writing describing "The child" are for use with professionals, such as the child's teacher.

Dutch language tree leaves indicating specific difficulties within the four categories of communicative participation problems, and a yellow leaf for noting a specific difficulty suggested by parents that does not fit into any of the categories.



Dutch language base sheet



The front of the Dutch language appendix for SLTs with the main communicative participation categories 'Does not like to communicate' (green), 'Does not understand others well' (orange), specific difficulties on tree leaves (underlined) and examples of communicative participation situations illustrating the difficulties on the tree leaves.

ENGAGE

INHOUD ENGAGE MET VOORBEELDEN

Mijn kind communiceert niet graag
Het kind heeft moeite met:

- Contact maken met anderen, bijvoorbeeld:
  - contact maken met andere kinderen en volwassenen
  - letten op de persoon met wie je praat
- Initiatief nemen in de communicatie, bijvoorbeeld:
  - een gesprekje beginnen
  - een vraag stellen met of zonder woorden
  - een ander kind vragen om samen te spelen

Mijn kind begrijpt anderen niet goed
Het kind heeft moeite met:

- Gebaren, mimiek en lichaamstaal van anderen begrijpen, bijvoorbeeld:
  - begrijpen wat de ander zonder woorden wil zeggen
  - een gesprekje voeren waarbij je luistert en reageert zonder woorden
- Begrijpen wat iemand zegt, bijvoorbeeld:
  - luisteren en reageren zoals verwacht wordt
  - anderen begrijpen zonder hulp
  - een gesprekje voeren waarbij het kind luistert en iets terug zegt
- Vragen stellen als je iets niet begrijpt, bijvoorbeeld:
  - checken of je iets goed begrepen hebt
  - vragen om uitleg als je de ander niet begrijpt

Mijn kind heeft hulp nodig bij iets anders
Het kind heeft moeite met:

- ...

The back of the Dutch language appendix for SLTs with the main communicative participation categories 'Is not well understood' (pink), 'Finds it hard to use language well when talking to others' (purple), specific difficulties on tree leaves (underlined) and examples of communicative participation situations illustrating the difficulties on the tree leaves.

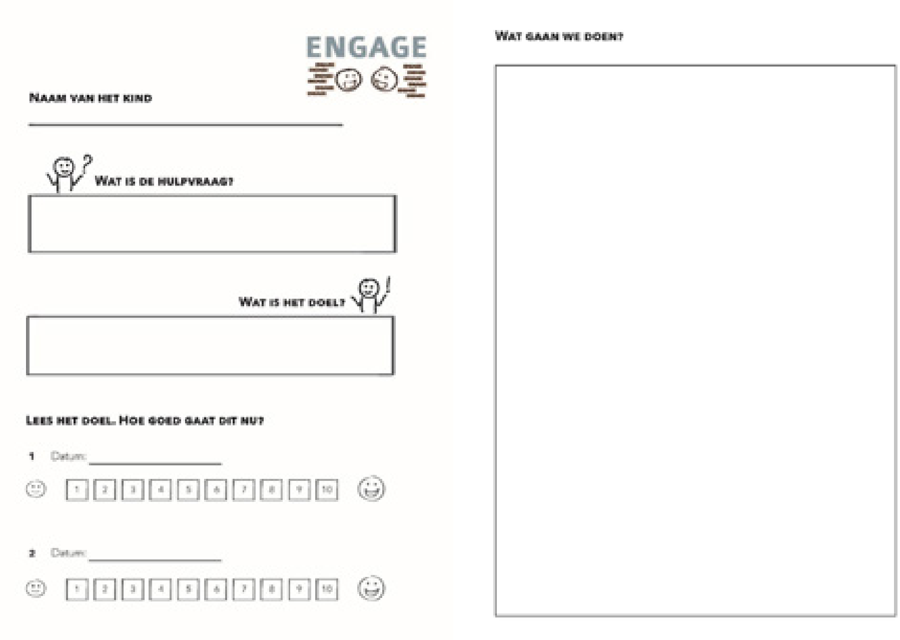
Mijn kind wordt niet goed begrepen
Het kind heeft moeite met:

- Iets duidelijk maken zonder woorden (non-verbaal), bijvoorbeeld:
  - laten zien wat je denkt of voelt zonder woorden te gebruiken
- Iets duidelijk maken met woorden (verbaal), bijvoorbeeld:
  - zeggen wat je wil hebben of doen
  - zeggen wat je denkt of voelt
  - vragen om hulp
- Iets vertellen, bijvoorbeeld:
  - duidelijk vertellen wat je hebt meegemaakt, door goed gebruik te maken van woorden, zinnen en een logische opbouw
- Gesprekjes voeren, bijvoorbeeld:
  - een vraag stellen als je iets wil weten
  - meedoen aan gesprekken
  - met een ander praten over iets waar je verschillend over denkt (discussiëren)

Mijn kind vindt het lastig om taal goed in te zetten in gesprekken met anderen
Het kind heeft moeite met:

- Opkomen voor zichzelf, bijvoorbeeld:
  - ruzie oplossen door te praten
  - zeggen wat je vindt
  - zonder hulp met anderen praten
  - goed meedoen aan gesprekken
  - op een prettige manier aangeven wat je wil en niet wil
- Rekening houden met de luisteraar, bijvoorbeeld:
  - hoe je iets zegt, past bij de situatie en of je bijvoorbeeld praat met een vriendje, de leerkracht of een ouder iemand
  - vlot genoeg vertellen, zodat de ander blijft luisteren
  - weten wat de ander wel en niet begrijpt
  - prettig samen spelen met andere kinderen
  - prettig samenwerken met andere kinderen
- Communicatieproblemen oplossen, bijvoorbeeld:
  - om hulp vragen bij communicatieproblemen
  - jezelf herhalen als de ander het niet verstaat
  - uitleggen wat je bedoelt als je niet begrepen wordt
  - weten wat er goed gaat en wat er niet goed gaat in de communicatie (inzicht in mogelijkheden)
  - zeggen wat je nodig hebt om met elkaar te kunnen praten

Dutch language response form. The front of the form includes the child's name, the parent's main concern, the goal, and a baseline and scoring measure using a 10-point Likert scale. The back has space for ideas on how to address the goal at home.



ENGAGE

Naam van het kind

Wat is de hulpvraag?

Wat is het doel?

Lees het doel. Hoe goed gaat dit nu?

1 Datum: ______________

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

2 Datum: ______________

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Wat gaan we doen?

APPENDIX 4.2

Results from interpretability study ENGAGE

Ingrid Singer, Inge Klatte, Marlies Welbie & Ellen Gerrits (13-04-2018)

Research was conducted on the interpretation of the Likert scale for evaluating participation goals developed with ENGAGE. 124 parents of children with DLD participated in this study. The study shows that difference scores from 2 points onwards are outside the 95% confidence interval of the scale. A difference score of -1, 0 or 1 point is not significant and should be attributed to the imprecision of the Likert scale (measurement error).

At a difference score of two points or more, 80% of parents in the sample report clinically relevant progress in daily life, while 20% of parents indicate that their child is not functioning better in daily life. This means that the SLT who uses ENGAGE with other parents who report a change score of two points, can be reasonably confident that this difference indicates clinically relevant progress. At a difference score of 3 points, another 10% of parents in the sample indicate that there was clinically relevant progress, while at a difference of 4 points all parents reported clinically relevant progress. This means that with a difference score of 3 points or more over 90% parents in the sample indicate that a meaningful change has occurred.

SLTs who use ENGAGE with parents of children with DLD can be confident that the parents feel there is real progress in daily life when the change score is 3 or higher. No information is available on the interpretation of difference scores of -2 to -10. With a large negative difference score, the speech therapist should discuss with the parents what meaning they attach to this.

Table 1
Interpretation Likert scale ENGAGE

Difference score	Interpretation
-1, 0, 1	No progress
2	80% of parents think this is relevant progress
3 or more	90-100% of parents think this is relevant progress

Examples interpretation:

A. is a 3;11-year-old boy. His mother gives him a score of 3 points on the Likert scale at the start of the treatment episode. At the evaluation four months later, she gives him a score of 4 points. The difference score is 1 point: there is no progress on the set goal. The SLT can discuss with mother what is causing this and what policy is desired.

B. is a 4;8-year-old girl. Her father gives her a score of 5 on the Likert scale at the start of the treatment episode. At the evaluation three months later, he gives her a score of 7 points. The difference score is 2 points: there is likely to be relevant progress. The SLT can discuss with the father whether it is useful to continue working on the goal, whether another goal should take priority at this time, or whether treatment is completed.

C. is a 6;5-year-old boy. His mother gives him a score of 2 on the Likert scale at the start of the treatment episode. At the evaluation six months later, she gives him a score of 8 points. The difference score is 6 points: there is relevant progress. The SLT can discuss with the mother whether there is another issue where a participation goal needs to be set, or whether treatment is completed.

Chapter 5

A systematic scoping review on contextual factors associated with communicative participation among children with developmental language disorder

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Singer, I., de Wit, E., Gorter, J. W., Luinge, M., & Gerrits, E. (2023). A systematic scoping review on contextual factors associated with communicative participation among children with developmental language disorder. *International Journal of Language & Communication Disorders, 58*, 482-515.

ABSTRACT

Background

Variations in communicative participation of children with developmental language disorder (DLD) cannot be wholly explained by their language difficulties alone and may be influenced by contextual factors. Contextual factors may support or hinder communicative participation in children, which makes their identification clinically relevant.

Aims

To investigate which contextual (environmental and personal) factors in early childhood are protective, risk or neutral factors for communicative participation among school-aged children with DLD, and to identify possible gaps in knowledge about this subject.

Methods & procedures

A scoping review was conducted based on a systematic search of studies published from January 2007 to March 2022 in Pubmed, Embase (without MEDLINE), CINAHL and PsycINFO. In total, 8802 studies were reviewed using predefined eligibility criteria, of which 32 studies were included for data extraction and critically appraised using the Critical Appraisal Skills Programme (2021) tools.

Main contribution

The methodological quality of included studies was adequate to strong. Personal protective factors identified are being a preschool girl, reaching school age and being prosocial, while personal risk factors are becoming a teenager or adolescent, having low socio-cognitive skills and experiencing comorbid mobility impairment or behavioural problems. Gender after the preschool years and non-verbal abilities were not found to be of influence, and the role of socio-emotional skills is inconclusive. Receiving therapy is an environmental protective factor, while the association between socio-economical family characteristics with communicative participation is inconclusive.

Conclusions & implications

Limited research has been conducted on which risk and protective factors present in early childhood are associated with later communicative participation of children with DLD. The influence of co-occurring health conditions, social background variables, individual psychological assets, interpersonal relationships and attitudes of other people represent knowledge gaps. In addition, knowledge about the comparative effectiveness of different types of interventions and service delivery models, and the impact of administrative control, organizational mechanisms and standards established by governments on children's communicative participation is lacking. More longitudinal research is needed focusing on the identification of relevant personal and environmental factors and the interactions between them in relation to communicative participation outcomes.

Keywords: communicative participation, contextual factors, developmental language disorder, ICF-CY, scoping review

WHAT THIS PAPER ADDS

What is already known on this subject

Children with DLD experience varying degrees of communicative participation restrictions. Insight into contextual factors that influence communicative participation can help to identify children at risk and inform family and child-centred therapy. Systematic research on contextual factors that facilitate or hinder communicative participation in children with DLD is currently lacking.

What this paper adds to existing knowledge

Knowledge of protective factors can guide the development of interventions for children and young people with DLD that boost resilience and facilitate communicative participation, while insight into the risk factors can help professionals identify the most vulnerable children and develop interventions that can lift or neutralize barriers present in the life of these children. Specific groups potentially at risk are young boys, children with co-morbid mobility impairment, children with conduct problems, and children reaching adolescence. In contrast, potentially protective factors are reaching school age and being prosocial. In addition, the development of socio-cognitive skills may be beneficial for the communicative participation of children with DLD.

What are the potential or actual clinical implications of this work?

To support communicative participation, it is important that professionals who work with children with DLD understand which groups are at risk for communicative participation restrictions, and which factors can foster resilience. In the absence of evidence-based instruments for the systematic assessment of personal and environmental factors, consulting parents and children on the contextual factors that they perceive as important remains critical.

INTRODUCTION

Children with developmental language disorder (DLD) show severe delays in their language development, often in several language domains (Bishop et al., 2017). Tomblin et al. (1997) report that DLD affects 7% of monolingual English-speaking kindergarten children. DLD has a lasting impact on the daily communicative functioning of affected children. The language difficulties and communication breakdowns of children with DLD limit their ability to communicate and interact with other people, and restrict their participation in everyday life at home, at school, with peers and in the community (Bishop et al., 2017; Dubois et al., 2020; Lloyd-Esenkaya et al., 2020).

Eadie et al. (2006) introduced the term communicative participation to acknowledge the importance of both language and communication for people's participation in daily life situations. They defined communicative participation as 'participation in life situations in which knowledge, information, ideas or feelings are exchanged' (Eadie et al., 2006: 309). This definition was validated by a Delphi panel in the Netherlands consisting of parents of a child with language disorder (LD) and professionals including teachers, speech and language therapists (SLTs), and psychologists, who agreed that communicative participation is 'understanding and being understood in a social context by applying verbal and/or non-verbal communicative skills' (Singer et al., 2020: 9). Examples of communicative participation are initiating a conversation with a friend or family member, being involved in school and community activities, and engaging in play with others (Washington et al., 2012). Several instruments have been developed that aim to capture aspects of communicative participation, and their use is increasing (Cunningham et al., 2017b). However, no gold standard for measuring communicative participation currently exists. Available instruments measure aspects of communicative participation, but also aspects of other constructs such as confidence, coping skills or peer relations. In reverse, instruments developed to measure functional communication, communicative competence, pragmatic language, social communication, social skills, or peer and family interactions, also measure aspects of communicative participation. For this paper, we have chosen to refer to this broader range of outcomes when we use the term 'communicative participation' since they all assess children's participation in life situations in which knowledge, information, ideas, or feelings are exchanged.

As a group, children with DLD experience more communicative participation difficulties than their typically developing peers (Botting & Conti-Ramsden, 2008). However, the impact of DLD on children's communicative participation varies considerably between individuals (Cunningham et al., 2021; Dempsey & Skakaris-Doyle, 2010). Many SLTs will recognize that some children are good in supporting their incomplete sentence production with gestures or other non-verbal communication. These children are understood easier than children who have not developed usable skills to solve communication difficulties, or who do not have an understanding and supportive environment.

Although variations in communicative participation outcomes between individuals with DLD are well known in the clinical field, they are poorly understood and not well described in the literature. There is growing evidence that language competence alone cannot explain why some individuals with DLD achieve better communicative participation outcomes than others (Conti-Ramsden & Durkin, 2015; Cunningham et al., 2019; Gerber et al., 2011). In fact, it has been established that at-risk preschoolers' language skills are only moderate predictors for social skills at age 8, explaining 29% of the variance (Aro et al., 2012). In addition, receptive or expressive language skills at age 7 do not significantly predict the development of problems with peer relationships in children with a DLD diagnosis at age 7 or 11 (Mok et al., 2014). These findings suggest language skills are among other factors that explain variation in communicative participation between children with DLD. However, it is currently unclear which risk and protective factors should be considered when the objective is to improve communicative participation outcomes in children and young people with DLD (Dempsey & Skakaris-Doyle, 2010; Howe, 2008).

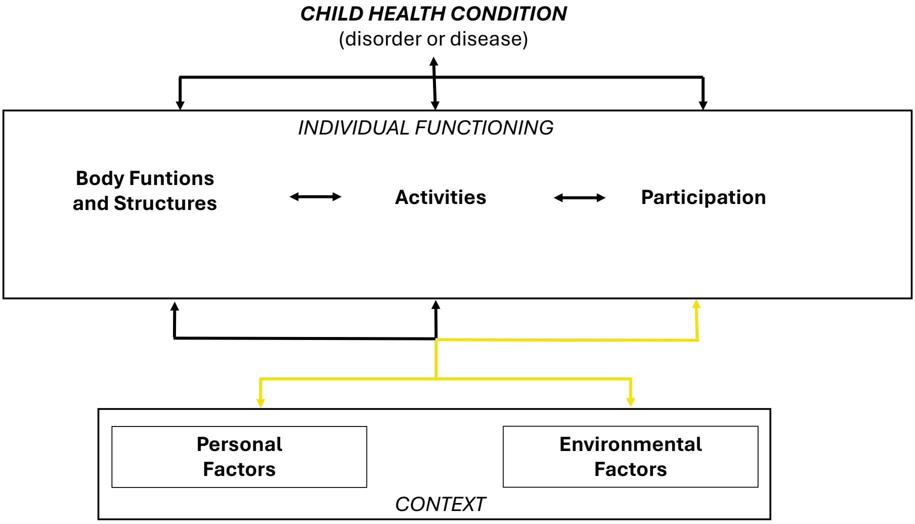
The International Classification of Functioning, Disability and Health—Children and Youth version (ICF-CY) (WHO, 2007) provides a common language and terminology for describing health and disability of infants, toddlers, children and adolescents within three domains of functioning: body functions and structures, activities and participation (WHO, 2007). The ICF-CY organizes information in two parts. Part 1 deals with individual functioning, while Part 2 covers contextual (personal and environmental) factors related to individual functioning. Table 1 gives an overview of the ICF components and their definitions.

Table 1
ICF-CY components and definitions

Component	Definitions
Part I: Individual functioning	
Body Functions and Structures	Body functions are the physiological functions of body systems (including psychological functions). Body structures are anatomical parts of the body such as organs, limbs, and their components.
Activity and Participation	Activity is the execution of a task or action by an individual. Participation is involvement in a life situation.
Part 2: Context	
Personal factors	N/A
Environmental factors	Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives.

Note. From 'ICF-CY Beginners Guide' (WHO, 2007: 228, 242, 246), with permission of the World Health Organization (WHO). n.a., Not available. Personal factors are not defined in the ICF-CY. They are described as the particular background of an individual's life and living and comprise features of the individual that are not part of a health condition or health states.

Figure 1
The International Classification of Functioning, Disability, and Health—Children and Youth version (ICF-CY) Model of Functioning and Disability (WHO, 2007) visualizes how individual functioning ('Body functions and structures', 'Activities' and 'Participation') emerges from the interaction between the child health condition ('disorder or disease') and contextual factors ('Environmental factors' and 'Personal factors'). The interactions between the components' contextual factors and participation are highlighted, as they are the central focus in this review.



The ICF-CY model (Figure 1) illustrates how a young person's functioning results from complex interactions between the Personal and Environmental factors components and the components of Body functions and structures, and Activity and Participation (WHO, 2007). While Activity and Participation both address the domain of communication, Activity refers to the highest probable level of functioning that a person may reach at a given moment in a standardized environment (capacity), while Participation refers to what an individual does in his or her current environment (performance). Since 'communicative participation' refers to participation in life situations in which knowledge, information, ideas, or feelings are exchanged (Eadie et al., 2006), this construct fits within the Participation component of the ICF-CY. The yellow line in ICF-CY model in Figure 1 visualizes the potential relationship between contextual factors and communicative participation, which is the focus of this scoping review.

The relevance of the relationship between ICF-CY contextual factors and participation for speech and language therapy is illustrated with several examples. Howe (2008) described the training of family members to communicate better with an individual with LD as an environmental factor with impact on communicative participation. Other examples of environmental factors are provided by Dempsey and Skakaris-

Doyle (2010), who describe that the culture that children grow up in influences the way children tell stories, that peer acceptance fosters communicative participation, and that the attitude towards, and experience of teachers with children with DLD impact on the support teachers can offer. In addition, Dempsey and Skakaris-Doyle describe personal factors that affect a person's health state, for example, that child temperament interacts with the emotional content of parent-child conversations, and that a child's gender relates to conversational style. However, systematic research on contextual factors that facilitate or hinder communicative participation in children with DLD is currently lacking (Threats, 2008).

Contextual factors may be modifiable and can either support or hinder communicative participation in children, which makes their identification clinically relevant. Knowledge of protective factors (e.g., positive teacher attitude towards children with DLD) can guide the development of interventions for children and young people with DLD that boost resilience and facilitate communicative participation (Luthar & Cicchetti, 2000). In contrast, gaining insight into the risk factors (e.g., experiencing negative attitudes of peers) can help professionals identify the children most at risk and develop interventions that can lift or neutralize barriers present in the life of these children (WHO, 2007). More specifically, it can help SLTs to adapt therapeutic approaches according to the personal characteristics of children, and to the environments in which those children live (Dempsey & Skakaris-Doyle, 2010; Westby, 2007). Since optimal communicative participation is the ultimate goal of therapy for children with DLD (Prelock et al., 2008), addressing contextual factors adequately in therapy will aid the transfer of language and communication skills to use outside the clinic (Threats, 2008). To date, the literature on contextual factors that influence communicative participation of children with DLD has not been reviewed systematically. Therefore, the present scoping review aims to answer the following research questions: (1) Which risk and protective contextual (personal and environmental) factors present in early childhood are associated with communicative participation in school-aged children with DLD; and (2) Which possible gaps in knowledge about this subject can be identified?

METHOD

We conducted a scoping review following the six scoping review framework stages described by Arksey and O'Malley (2005) and Levac et al. (2010): (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarizing and reporting the results; and (6) consultation. In addition, we used the guidelines of the Preferred Reporting Items for Systematic

Reviews and Meta-Analyses Extension for Scoping Reviews checklist (PRISMA-ScR; Tricco et al., 2018). At the start of the scoping review, a research protocol was developed for each stage of the framework, which was subsequently adapted as the review progressed (Peters et al., 2020). A summary of the protocol was registered with the Open Science Framework.

Stage 1: Identifying the research question

The Population-Concept-Context (PCC) mnemonic was used to develop the research question (Peters et al., 2020). Population refers to important characteristics of participants, including age and other qualifying criteria. Concept refers to the core phenomenon of interest. Finally, the Context-element includes the specific factors and/or setting of interest in the scoping review. Our scoping review's aim was to map contextual factors present during early childhood (Context) of children at risk of, or diagnosed with, DLD (Population), that exert an influence on the children's communicative participation (Concept).

Stage 2: Identifying relevant studies

After conducting an initial limited search in the PubMed database combining the terms 'children with DLD', 'communicative participation' and 'contextual factors', keywords from selected key papers and their synonyms were placed in a search strategy concept map, following the PCC mnemonic (Peters et al., 2020). For each element in the PCC mnemonic, eligibility criteria were determined. Table 2 summarizes the eligibility criteria for each element of the PCC concept map.

Table 2

Population, Concept, Context elements and summary of eligibility criteria

POPULATION	Children with developmental language disorder (DLD) (Bishop et al., 2017), children with late language emergence, or at risk for DLD.
CONCEPT	Communicative participation (Eadie, et al. 2006) measured between the ages of 2 to 18 years.
CONTEXT	Environmental or personal factors identified when the child was between 0 and 8 years old.

Population

In this scoping review, the focus was on children (at risk of) DLD aged 2 to 18 years. We applied Bishop's (2017) definition of DLD as an inclusion criterion and searched and included studies where (at least a part of the) participating children were identified with DLD. We used a broad set of terms in the search stage, including DLD, specific language impairment (SLI), speech language and communication needs (SLCN), LD and language impairment (LI). We included these search terms because we wanted to include children labelled as SLCN, LI or LD that have no associated biomedical condition or intellectual disability and therefore meet the criteria of DLD in Bishop et al. (2017). We searched for and included studies with children who were at risk of DLD by using search terms that refer to children under age 5 with moderate language delays, sometimes referred to as 'late talkers'. These children generally have a good chance of catching up. However, some children in this group do not catch up, and are later diagnosed with DLD (Reilly et al., 2010). In addition, parental concern about language development (Law & Roy, 2008), and having a parent with DLD or dyslexia (Snowling et al., 2016) are indicators that a child is at risk of DLD. The age range was chosen because language problems may first become apparent from age 2 and can be diagnosed reliably from age ≥ 5 (Bishop et al., 2017), while the age of 18 years typically marks the end of child centred care and the transition into adulthood (Gorter et al., 2014).

Concept

The primary outcome of our review was communicative participation, as defined by Eadie et al. (2006) as 'participation in life situations in which knowledge, information, ideas or feelings are exchanged'. A gold standard for measuring this construct in children is currently lacking. Therefore, we included instruments, observations tools, protocols, and (proxy) patient-reported outcome measures (PROMs) intended to measure participation-related constructs targeted in speech and language therapy, such as pragmatic language, communication in everyday life, social communication, social skills, and family or peer communication and relations. These are all outcomes of speech and language therapy that refer to communication in daily life, or communicative participation. We therefore included all participation outcome instruments that were identified in the scoping review of Cunningham et al. (2017b) who used ICF-CY (WHO, 2007) to frame the measures that are used to evaluate speech language outcomes of children with communication disorders. Instruments and protocols that were not identified in Cunningham et al.'s review were reviewed by the first and second author and evaluated on face validity for measuring communicative participation, by verifying whether at least half of the items in an instrument or scale addressed communicative participation. Studies that used an outcome measure for communicative participation or a related construct that had not previously been published, and was not included in the study itself, were excluded. Psychosocial outcomes such as bullying, emotional difficulties and psychiatric difficulties were not included in this review, as they are usually not directly targeted in speech and language therapy and have been reviewed elsewhere (Durkin & Conti-Ramsden, 2010).

Context

We searched for studies describing environmental and personal factors present from birth to age 8, because this is a time of accelerated growth across all areas of development, including language and communication (Britto et al., 2016). In addition, most children with DLD who receive speech and language therapy are under the age of 7 (Law et al., 2003; McKean et al., 2019). At this young age, children are very much dependent on the environment and the people that surround them. In addition, the early childhood period lays the foundation for many aspects of functioning later in life, including language (Pinker, 2007), and social skills (Hart et al., 2004; Jones et al., 2015).

Additional search limits

Additional search limits were defined a priori, except for the study design, which was added after the initial search. The year limit was set at 2007, the year of the introduction of the ICF-CY (WHO, 2007). Moreover, 2007 also marks the moment when the original ICF started to be accepted and used as a standardized disability framework across the diverse areas in speech and language therapy (Ma et al., 2007). To guarantee a minimal quality of the evidence, we limited the review to peer-reviewed research publications and did not search grey literature. We only included publications in English, as this is the primary language used for scientific communication. Studies were excluded when the focus was on a range of syndromes, mental disorders, congenital diseases and developmental disorders distinct from DLD. Finally, we only included study designs that allowed to determine developmental associations, that is, randomized controlled trials (RCTs) and longitudinal studies (including studies with a pretest-post-test follow-up design), as we were interested in which contextual factors present in early childhood influence later communicative participation outcomes. The additional search limits are summarized in Table 3.

Table 3

Additional search limits

Limit	>2007 Peer reviewed English Not about other childhood disorders Randomized controlled trial (RCT) or longitudinal study design	The study was published between January 1, 2007 and March 17th, 2022, it was a peer-reviewed study, and written in English. Studies with key words containing specific childhood disorders or syndromes other than DLD were excluded. The study design was a RCT or a longitudinal study (including studies with a pretest-post-test follow up design).

Search

A first search, conducted in August 2018, used Pubmed, Embase (without MEDLINE), CINAHL and PsycINFO, and included studies published between 1 January 2007 and June 2018. Supplementary searches were carried out in June 2020 and March 2022 to locate studies published from June 2018 to March 2022 in the same databases. All searches were performed together with an expert information specialist. Search terms reflecting the same concepts were combined with 'or' and search terms reflecting different concepts were combined with 'and'. 'Advanced keyword' search options were used wherever available. The Pubmed query is available for review (see Appendix A).

Stage 3: Study selection

Study selection was conducted in two phases: (1) title and abstract screening; and (2) full-text screening of the articles that remained after step 1. Authors were contacted when the full-text article was not available.

Title-abstract screening

The first author (IS) developed draft inclusion criteria based on the research question and refined them in consultation with co-authors ML and EG. To establish consistent decision making and to optimize the inclusion criteria, they were tested and reviewed during an initial reliability trial run in which three authors (IS, ML, EG), and an undergraduate student completed screening of a random sample of 10 titles and abstracts. Next, the updated inclusion criteria were practiced during a second trial run with 10 new randomly selected abstracts, and further optimized by the project group until everyone followed the same line of decision making. The final inclusion criteria, as described in Table 2, were outlined in an instruction document, which was used to include or exclude references in an online Refworks account.

The first author (IS), SLT and PhD candidate, completed the screening of all titles and abstracts (TIABs) that were identified. When abstracts lacked necessary information to decide on inclusion or exclusion, the study was included for full text review. There were two different second TIAB reviewers who screened every 10th title and abstract: TIABs from 2007 until 2018 were screened by an undergraduate student majoring in Clinical Language, Speech and Hearing Sciences (Utrecht University). TIABs from 2018 until 2022 were screened by second author (EdW), an SLT researcher, PhD with experience in Systematic Reviews. Ambiguities were discussed and resolved with the second reviewer and, if necessary, with the entire research team.

Full-text screening

Full-text screening of all selected studies was conducted by two reviewers (authors IS and EdW) independently. To support consistency of coding and decision-making, both reviewers independently recorded in a datafile which inclusion criteria were met by each study. In addition, comments or queries regarding the papers that required further discussion were noted. The two reviewers conducted an initial trial of five full-text articles, compared the results, and resolved any disagreements. Remaining issues or ambiguities were discussed with senior members of the research team (authors JWG, ML and EG), until consensus was reached.

Stage 4: Charting the data

In this phase, key elements from the included studies were recorded in a charting form that was developed by the first author in consultation with the research team. The form was tested by the first author (IS) by extracting relevant data from three included studies. Extracted data were presented by the first author (IS) and usefulness and completeness of the form was evaluated with the entire research team. Data extraction was conducted by the first and second author (IS and EdW) independently. General information about the study (author, title, year of publication, study location, method), specific information relating to study (aim, population, measurement instruments used), and its findings (environmental and personal factors and their relationship with communicative participation) was recorded. IS and EdW compared their results and developed consensus on final data extraction.

In studies that reported data on children with DLD and other groups, for example, healthy children or children with other learning disorders, we only charted the data of the DLD group. Studies were excluded from this review if participating children had speech difficulties (such as a speech sound disorder), other developmental disorders (such as autism spectrum disorder, intellectual disability or attention deficit hyperactivity disorder), specific learning disorders or cerebral palsy.

Stage 5: Collating, summarizing and reporting the results

An interrater reliability analysis using Cohen's kappa statistic was performed to formally determine consistency between the two reviewers in the title-abstract and the full-text screening phase (Belur et al., 2018). McHugh's (2012) interpretation was used to evaluate the level of agreement between reviewers: 0-0.20 = none; 0.21-0.39 = minimal; 0.40-0.59 = weak; 0.60-0.79 = moderate; 0.80-0.90 = strong; > 90 = almost perfect.

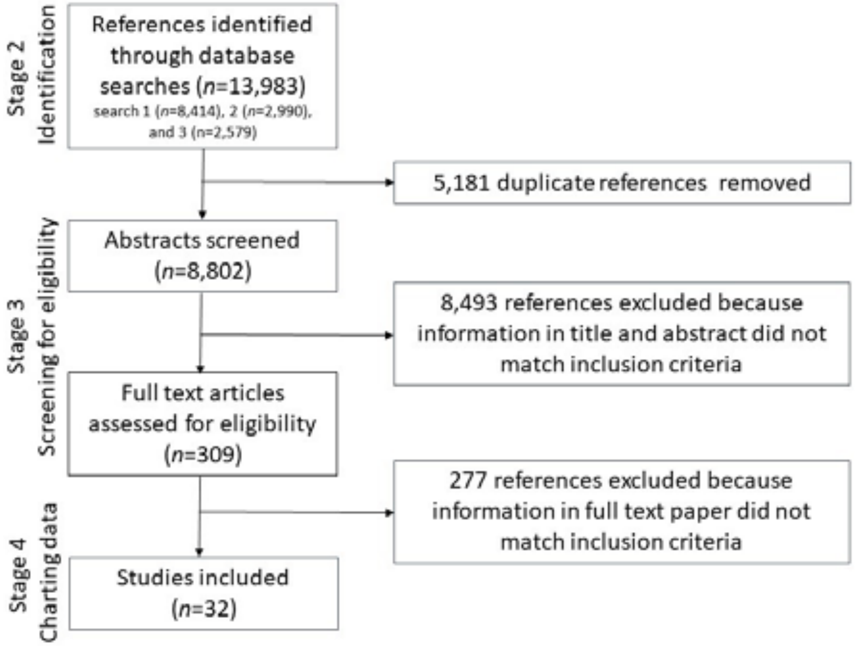
We summarized general characteristics of the included studies in a table with the study location, diagnostic labels used, terms used for addressing communicative participation or related constructs, and outcome measures. After collating and summarizing the included studies, a critical appraisal using the Critical Appraisal Skills Programme (CASP) Randomised Controlled Trial (RCT) (CASP, 2021a) or Cohort Study appraisal tools (CASP, 2021b) was performed to establish the quality of the studies and to judge the trustworthiness of the outcomes. The appraisal was conducted independently by the first and second author (IS and EdW) and disagreements were resolved in a consensus meeting. The first six items from the CASP RCT tool (CASP, 2021a) and the first six items from the Cohort Study appraisal tool (CASP, 2021b) addressing design and methodological quality were scored with 0 (= no or can't tell), 1 (= yes), or n.a. if not applicable. Because item 5 and 6 in the Cohort Study appraisal tool consists of an a- and b-question, and item 4 in the RCT appraisal tool consists of an a-, b- and c-question, the maximum possible raw score for both checklists is 8. We converted raw scores to percentages, and categorized study quality as strong (> 80%), good (70-80%), adequate (50-69%) or limited (< 50%) as suggested by Lee et al. (2008). Contextual factors that were identified were presented in a table together with the outcome of the critical appraisal. Factors were described in terms of personal versus environmental factors and risk versus protective factors and a description of the factor's relationship with communicative participation was provided. For both personal and environmental factors, a summary was written. In addition, possible knowledge gaps were identified by comparing results with the domains and descriptions in the ICF-CY. Personal factors are not specifically coded in the ICF-CY because of the wide variability among cultures. However, the ICF-CY states that these factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience, overall behaviour pattern and character style, individual psychological assets, and other characteristics (WHO, 2007: 15). The personal factors identified in this study were compared with this list. Within the ICF-CY environmental component five chapters can be distinguished: (1) Products and technology; (2) Natural environmental and humanmade changes to environment; (3) Support and relationships; (4) Attitudes; and (5) Services, systems, and policies (WHO, 2007). The environmental factors identified in this study were compared with these chapters.

Stage 6: Consultation

The sixth stage was carried out as an integral part of the activities in stages 1 to 5. We invited stakeholders to contribute to knowledge translation by providing insights about the research question, the inclusion criteria, the relevance of the results, and the identification of knowledge gaps. The primary stakeholders for this review were SLTs and speech-language researchers. To optimally address stakeholders' needs, the research question, PCC mnemonic, and inclusion criteria were presented, discussed, and refined in two workshops with six SLTs and five SLT researchers. The SLTs suggested that the review should not only focus on contextual factors that affect communicative participation in early childhood, but also in middle childhood and adolescence. The inclusion criteria were revised accordingly. In addition, two workshops were organized with 32 SLTs and teachers in total where preliminary results from the screening phase were presented, used in case work, and discussed in terms of clinical relevance. The stakeholders indicated that interactions between personal and environmental factors were of relevance. This input was translated into an item in the data chart: Interactions personal and environmental factors. Finally, the main findings were presented during two research meetings with eight (first meeting) and nine (second meeting) SLTs and researchers of our research group. These stakeholders provided suggestions to further clarification of the results in the table and offered suggestions for structuring the results. In addition, they supported the identification of knowledge gaps in the personal factors component by reflecting on how the examples of personal factors provided in the ICF-CY relate to the findings in this study. Finally, they gave feedback on the results paragraph of the manuscript.

Figure 2

PRISMA flowchart of study selection process



RESULTS

Selection of the sources of evidence

Number of included studies

In the three searches a total of 8802 studies were identified. In total, 32 studies were included for data extraction. A flowchart outlining the study selection process is shown in Figure 2.

Interrater reliability

The interrater agreement for inclusion/exclusion of the 10% reliability sample in the title and abstract screening phase was 95% (n = 937), and interrater reliability was moderate with $\varkappa = 0.65$ (95% confidence interval (CI) = 0.54-0.76), $p < 0.001$. Interrater agreement for inclusion/exclusion in the full text screening phase was 93% (n = 309), and interrater reliability was moderate with $\varkappa = 0.69$ (95% CI = 0.59-0.80), $p < 0.001$.

Characteristics of the sources of evidence

General characteristics of included studies

Table 4 displays the general characteristics of included studies. All studies in this review originated from Western countries, with the majority coming from English speaking countries. The diagnostic labels ‘at risk’, DLD, SLI, and late talkers were used most often. In addition, LD, (speech and) LI, speech, language, and communication disorder, expressive and/or receptive language scores < 1.25 SD, language problems, and social communication impairments or pragmatic LIs were used. Communicative participation (skills) or (real world) communication skills was the term used to refer to the primary outcome in eight studies. Alternative terms used for communicative participation in included studies were classified into three categories, each addressing different aspects of communication in real life contexts: peer interactions, social communication and competence, and pragmatic language.

Communication in everyday life was measured most often with the teacher, self- and parent report versions of the Strengths and Difficulties Questionnaire: Peer Problems subscale (SDQ-PP; Goodman, 1997), followed by the parent report version of the Focus on Communication Under Six (FOCUS; Thomas-Stonell et al., 2010), and the teacher and parent report versions of the Children’s Communication Checklist (CCC; Bishop, 1998, 2003). In total, 13 different instruments were used for measuring communicative participation.

Table 4

General Characteristics of Included Studies (n = 32)

Characteristic	Number (*n*=32)	Percentage (%)
Origin of included studies		
UK	12	37,5
Canada	7	21,9
Australia	4	12,5
Finland	2	6,3
USA	2	6,3
Austria	1	3,1
Germany	1	3,1
Norway	1	3,1
Spain	1	3,1
The Netherlands	1	3,1
Diagnostic label used (see appendix B for details)		
At risk	6	18,8
Developmental language disorder (DLD)	5	15,6
(Speech and) language impairment (LI)	5	15,6
Specific Language Impairment (SLI)	4	12,5
Late talkers	4	12,5
Language disorder (LD)	3	9,4
Other	5	15,6
Term used for communicative participation [a]		
Social (communication) skills, -difficulties, -competence, -withdrawal	14	43,8
Peer problems, -difficulties, -relations, -interactions	12	37,5
Communicative participation or (real world) communication, -skills	8	25,0
(Pragmatic) language skills, -difficulties or conversational coherence	7	21,9
Instrument used for measuring communicative participation[b]		
SDQ[c]	13	40,6
FOCUS[d]	6	18,8
CCC[e]	5	15,6
Other	11	34,8
Study design		
Longitudinal study (including pretest-posttest follow up designs)	27	84,4
Randomized Controlled Trial	5	15,6

Notes.

[a] In some papers more than one term is used to refer to communicative participation, which is why the total adds up to more than 100%.

[b] In some studies more than one instrument is used to measure communicative participation, which is why the total adds up to more than 100%.

[c] SDQ, Strengths and Difficulties Questionnaire (Peer Problems and/or Prosocial subscales) (Goodman, 1997).

[d] FOCUS, Focus on Communication Under Six (Thomas-Stonell et al., 2010).

[e] CCC, Children's Communication Checklist (Bishop, 1998, 2003).

Study designs

We found 27 studies with a longitudinal design, including studies with a pretest-post-test follow-up design, reporting on a total of unique 21 cohorts/groups of children. Five RCTs were included.

Identified personal and environmental factors

Table 5 provides an overview of the personal and environmental factors that were identified in the 32 included studies. For each factor that was identified we report whether it is a personal factor or an environmental factor, and whether is it a risk factor, a protective factor or whether no statistically significant impact of the factor on the outcome was reported (n.s. = not significant).

Papers that report on the same cohort are clustered in Table 5.

Personal factors in early childhood that facilitate or hinder communicative participation

Child characteristics: age, gender and mono- or multilingual status

Results indicate that communicative participation skills increase in children from preschool to school age (Cunningham et al., 2017a, 2018). However, when children with DLD grow older, they subsequently experience increasing levels of peer difficulties from middle childhood to adolescence (Conti-Ramsden et al., 2019; Lindsay et al., 2007; Lindsay & Dockrell, 2012; Mok et al., 2014; St Clair et al., 2011), although one study reports stable peer problems from age 7-9 to 11-13 years (Helland et al., 2022). Being a boy or a girl only seems to affect communicative participation at a very young age. In children aged under 6, girls have better communicative participation skills than boys (Cunningham et al., 2017a, 2018), but equally adequate social communication (Chiat & Roy, 2008) and communication skills (Määtta et al., 2012). In middle childhood and adolescence, social difficulties and peer problems are found to be equal for boys and girls (Chiat & Roy, 2008, 2013; Conti-Ramsden et al., 2019; Goh & O'Kearney, 2015a, 2015b; Lindsay et al., 2007; Lindsay & Dockrell, 2012; Mok et al., 2014; St Clair et al., 2011). Finally, multilingual children who have a low level of communicative functioning show more growth in the development of communicative participation skills than monolingual children, which could mean that they catch up with monolingual children over time (Cunningham et al., 2017a, 2018).

Cognitive skills: non-verbal abilities and socio-cognition

Included studies do not report an association between the non-verbal abilities of children with DLD and social difficulties in middle childhood and adolescence (Conti-Ramsden et al., 2019; Lindsay et al., 2007; Lindsay & Dockrell, 2012; Mok et al., 2014; St Clair et al., 2011), or pragmatic language difficulties in middle childhood and adolescence (Mok et al., 2014). However, in preschoolers with better socio-cognitive skills, which includes responsiveness to others, joint attention, and symbolic understanding, are found to predict better social communication in at age 4-5 years (Chiat & Roy, 2008) and age 9-11 years (Chiat & Roy, 2013).

Social-emotional skills and behaviour: self-concept, emotional difficulties, emotion regulation, prosociality, social skills, conduct problems, friendships and social play

Studies about the impact of social-emotional competence on communicative participation yield mixed results. First, no associations are reported between self-concept and peer problems in middle childhood and adolescence (Lindsay et al., 2007; Lindsay & Dockrell, 2012). In addition, while emotional difficulties are found to be unrelated to peer problems in middle childhood and adolescence in some studies (Conti-Ramsden et al., 2019; Mok et al., 2014; St Clair et al., 2011), in another study emotional difficulties pose a risk factor for preschoolers and adolescents but not in middle childhood (Forrest et al., 2020). Furthermore, emotion regulation difficulties in preschoolers and school children do predict peer problems in middle childhood and adolescence (Forrest et al., 2020). Similarly, the association between social skills or prosociality, which included being considerate of other people's feelings, being kind and sharing with others, and communicative participation is not straightforward. While peer problems in all age groups predict peer problems at a later age (Forrest et al., 2020), children with lower prosocial skills tend to experience more peer problems (Conti-Ramsden et al., 2019; Mok et al., 2014; St Clair et al., 2011; Toseeb et al., 2020), and pragmatic language difficulties (Mok et al., 2014) in middle childhood and adolescence. On the other hand, being prosocial in middle childhood is reported to be protective against concurrent social difficulties (Toseeb & St Clair, 2020), but it does not protect against social difficulties in later childhood (Toseeb & St Clair, 2020). Furthermore, the absence of prosociality in early childhood does not seem to make social difficulties in middle childhood inevitable (Toseeb & St Clair, 2020). In addition, preschoolers with lower social skills scores showed larger gains in communicative participation than peers with better initial social skills (Washington et al., 2015). Besides, one study reports that a higher level of conduct problems is not associated with more peer problems in middle childhood and adolescence (Lindsay et al., 2008; Lindsay & Dockrell, 2012), while another study indicates that the

Table 5

Factors that influence communicative participation, arranged in alphabetical order by first author name.

Author(s) (year)	Study design	Participants with/at risk of DLD	*Term used for communicative participation* **Measurement instrument used (author, year)**	Personal			
		n; Gender; Age Range; Mean age (M)		Factor	R	P	NS
Aro, Eklund, Nurmi and Poikkeus (2012)	Longitudinal study: Jyväskylä Longitudinal Study of Dyslexia	107 children at risk of DLD (family history of dyslexia); 54 boys, 53 girls; 2;6 - 8;0 years	*Social skills* Social Skills scale of the PRS-Children of the BASC, parent reported (Reynolds & Kamphaus, 1992)	Weak behavior regulation skills	●	○	○
Chiat and Roy (2008) Chiat and Roy (2013)	Longitudinal study	*Chiat and Roy (2008):* 163 children at risk (concerns about language and referred to clinical services); 2;6 - 3;6 years at time of referral and 4;0 - 5;0 years at follow-up *Chiat and Roy (2013):* 93 children at risk, 9;0-11;0 years at follow up	*Social communication*[b] SDQ, parent reported (Goodman, 1997) and CCC, parent reported (Bishop, 1998, 2003)	Low socio-cognitive skills	●	○	○
				Gender	○	○	●
Chiat and Roy (2013)	See Chiat and Roy (2008)						
Conti-Ramsden, Mok, Durkin, Pickles, Toseeb and Botting (2019)	See St Clair, Pickles, Durkin, and Conti-Ramsden (2011)						
Cunningham, Hanna, Oddson, Thomas-Stonell and Rosenbaum (2017) Cunningham, Hanna, Rosenbaum, Thomas-Stonell, and Oddson (2018)	Observational longitudinal study: Ontario, Canada’s publicly funded Preschool Speech and Language Program (PSLP)	*Cunningham et al. (2017)*: 46,872 preschool children with speech and language impairment; 31.404 boys and 15.467 girls; *Cunningham et al. (2018)*: 21,998 preschool children with speech and language impairment; 15.179 boys, 6.819 girls; 1;6 - 5;7 years; mean age 3;5 years. Re-assessed every 6 months.	*Communicative participation skills* FOCUS, parent reported (Thomas-Stonell, et al. 2010)	Being a girl	○	●	○
				Multilingual status	○	●	○
				Age: reaching school age	○	●	○

Environmental				**Summary of findings**	**Critical appraisal**
Factor	R	P	NS		**Study quality** [a]
				The combination of weak language and poor behavior regulation skills is associated with poor social skills, while the social skills of children with weak language only, are age appropriate.	Strong
				Some preschoolers had primary deficits in socio-cognition that contributed to their later social communication problems	*Chiat and Roy (2008):* Strong
					Chiat and Roy (2013): Good
Multilingual children with a low level of communicative functioning had significantly better (growth in) communicative participation skills than monolingual children in the same level of functioning. Older children had better communicative participation skills than younger children.				Girls had better communicative participation skills than boys across all ages.	*Cunningham et al. (2017)*: Adequate *Cunningham et al. (2018)*: Good
Starting speech language interventions	○	●	○	Starting intervention was associated with better communicative participation skills compared to not starting intervention for all except children in the lowest level of communicative functioning.	
More time spent in intervention	○	●	○	Communicative participation skills increased with time spent in intervention.	
Participation in an early learning environment	○	●	○	For children with higher levels of communicative function, participation in an early learning environment was beneficial for developing communicative participation skills.	

Table 5
Continued

Author(s) (year)	**Study design**	**Participants with/at risk of DLD**	***Term used for communicative participation*** **Measurement instrument used (author, year)**	**Personal**			
		n; Gender; Age Range; Mean age (M)		Factor	R	P	NS
Cunningham, Hanna, Rosenbaum, Thomas-Stonell, and Oddson (2018)	See Cunningham, Hanna, Oddson, Thomas-Stonell and Rosenbaum (2017)						
Cunningham, Kwok, Earle and Cardy (2019)	Pre-post-follow-up design	24 late-to-talk toddlers; 15 boys, 9 girls; 1;4 - 2;4 years, mean 1;8 years	*Communicative participation* FOCUS, parent reported (Thomas-Stonell, et al. 2010)				
Forrest, Gibson, Halligan, and St Clair (2020)	Longitudinal study: Millennium Cohort Study	891 children at risk of DLD (6.3% of the total sample of 14,262 at 5 years); 629 boys, 261 girls; assessments at 9 months and 3, 5, 7, 11, and 14 years	*Peer problems* SDQ, parent reported (Goodman, 1997)	Poor emotion regulation	●	○	○
				Emotional problems	●	○	○
				Peer problems	●	○	○
Galagher and Chiat (2009)	RCT	24 children with SLI; 18 boys, 6 girls; 3;6-5;0 years	*Language skills* Questionnaire on parent perceptions of the child's language and communication skills (published in the article).				
Goh and O'Kearney (2015a) Goh and O'Kearney (2015b)	Longitudinal study: Longitudinal Study of Australian Children (LSAC; Soloff et al. 2005)	439 children with LI (parental concern or <13th percentile on PPVT, no parental report of biomedical condition, normal IQ); 280 boys, 159 girls; 4;3 - 5;7 years; mean 4;9 years at inclusion, followed-up at ages 4-5, 6-7, 8-9 and 10-11 years	*Quality of peer interactions* SDQ, parent reported (Goodman, 1997)	Gender	○	○	●
Goh and O'Kearney (2015b)	See Goh and O'Kearney (2015a)						
Gregg, Hart, Vaquerano, Cuervo, Suarez, and Graziano (2021)	Pre-post- design	91 children with language impairment and at-risk or clinically elevated levels of externalizing behavior problems; 69 boys, 22 girls; mean age 4;9 years	*Social functioning* Social Skills scale of BASC-2, parent reported (Reynolds & Kamphaus, 2004)				

Environmental				**Summary of findings**	**Critical appraisal**
Factor	R	P	NS		**Study quality** [a]
Participation in Target Word™, The Hanen Program® for Parents (Earle & Lowry, 2015)	○	●	○	75% of the children made clinically meaningful progress in communicative participation after intervention.	Adequate
				Poor emotion regulation at ages 3, 5, and 7 years predicted peer problems at all later time points (ages 5, 7, 11, and 14 years).	Strong
				Emotional problems at age 3 predicted peer problems at age 5 and emotional problems at age 11 predict peer problems at age 14.	
				Earlier peer problems predicted peer problems in later childhood and adolescence.	
Intervention type and status (intensive therapy vs nursery-based therapy vs no intervention)	○	○	●		Adequate
					Goh and O'Kearney (2015a): Strong *Goh and O'Kearney* (2015b): Strong
Intervention: an 8-week (30 min/4 days a week) summer treatment program for Pre-Kindergarteners	○	●	○		Adequate

Table 5
Continued

Author(s) (year)	**Study design**	**Participants with/at risk of DLD**	***Term used for communicative participation*** **Measurement instrument used (author, year)**	**Personal**			
		n; Gender; Age Range; Mean age (M)		Factor	R	P	NS
Helland, Posserud, and Lundervold (2022)	Longitudinal study: Bergen Child Study (BCS) (Stormark et al. 2008)	311 children with language problems and 3.199 control children without language problems; 7-9 years (T1) and 11-13 years (T2)	*Peer problems* SDQ, parent (T1 and T2), teacher (T1 and T2) and self (T2) reported (Goodman, 1997	Age	○	○	●
Kim, Carlson, Curby and Winsler (2016)	Longitudinal study	192 children with SLI; 135 boys, 53 girls in a total study population of 898 children with learning disorder; 3;3 -5;7 years, mean 4;6 years	*Social skills* Devereux Early Childhood Assessment (DECA), subscales: Initiative, Self-Control and Attachment, teacher reported (LeBuffe and Naglieri, 1999)	Gross and fine motor skills	○	○	●
Kwok, Cunningham and Cardy (2020)	Pre-post- follow up design	76 late talking children; 51 boys, 25 girls; mean age 2;0 years	*Communicative participation* FOCUS, parent reported (Thomas-Stonell, et al. 2010)				
Lindsay, Dockrell and Strand (2007) Lindsay and Dockrell (2012)	Prospective longitudinal study	*Lindsay, Dockrell and Strand (2007):* 69 children with LI; 52 boys, 17 girls; mean age 8;3 years, range 7;6 - 8;10 years at enrollment and 10;0 - 12;0 years at follow-up *Lindsay and Dockrell (2012):* 56 children with SLI followed until their last of compulsory education at age 16 and 17	*Social difficulties / peer problems* SDQ, parent and teacher reported (Goodman, 1997)	Age: reaching teenage and adolescence	●	○	○
				Gender	○	○	●
				Non-verbal ability	○	○	●
				Self-concept	○	○	●
				Conduct (problems)	○	○	●
Lindsay and Dockrell (2012)	See Lindsay, Dockrell and Strand (2007)						
Määttä, Laakso, Tolvanen, Ahonen and Aro (2012)	Longitudinal study	93 children at risk (before second birthday); 0;6 - 2;0 years at recruitment and 4;7 years at follow up	*Communication skills* FTF communication subdomain, parent reported (Kadesjö et al., 2004)	Gender	○	○	●

Environmental				**Summary of findings**	**Critical appraisal**
Factor	R	P	NS		**Study quality** [a]
					Adequate
				Neither gross motor nor fine motor skills predicted improvements in social skills for children with SLI.	Good
Participation in Target Word™, The Hanen Program® for Parents (Earle & Lowry, 2015)	○	●	○	Communicative participation increased significantly after intervention, but there were no additional gains during follow-up.	Adequate
				One third of the 8 - 12-year-old children and half of the 16-year-old children experienced peer problems.	*Lindsay, Dockrell and Strand (2007):* Strong
					Lindsay and Dockrell (2012): Strong
					Strong

Table 5

Continued

Author(s) (year)	Study design	Participants with/at risk of DLD	*Term used for communicative participation* **Measurement instrument used (author, year)**	Personal			
		n; Gender; Age Range; Mean age (M)		Factor	R	P	NS
Marschik, Einspieler, Garzarolli, and Prechtl (2007)	Prospective longitudinal follow-up study with retrospective classification	15 late talkers; 10 girls, 5 boys; mean age 1;6 years at enrollment, mean age 2;0 and 5;7 years at follow-up	*Social competence* German version of Griffiths Developmental Scales, subscale personal—social competence B scale, parent reported (Brandt, 1983)				
Mok, Pickles, Durkin, and Conti-Ramsden (2014)	See St Clair, Pickles, Durkin, and Conti-Ramsden (2011)						
Murphy, Joffe, Donald, Radley, Sunthararajah, Welch, Bell, Messer, Crafter, Fairhurst, Corbacho, Rodgers and Torgerson (2021)	Cluster-randomised controlled trial	50 children with social communication impairments or pragmatic language impairments attending mainstream schools; 37 boys, 13 girls; age 4-7 years; mean age 6;2 years.	*Communication* CCC-2, teacher reported (Bishop, 2003)				
Senent-Capuz, Baixauli-Fortea, and Moret-Tatay (2021)	Pre-post design	10 late-talking children/ families and 7 control children/families; age 1;6 - 3;4 year, mean age 2;5 years The first assessment was carried out the month immediately before starting the intervention (Time 1); the second assessment took place about 6 months later, after the therapy was finished (Time 2).	*Social communication abilities* Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP), Social composite scale, clinician reported (Wetherby & Prizant, 2003)				

Environmental				Summary of findings	Critical appraisal
Factor	R	P	NS		Study quality [a]
Small family size	○	●	○	Children from smaller families were more socially competent than children from larger families.	Strong
Low householder's vocation and education	●	○	○	Lower householder's education and vocation was associated with lower social competence at age 2.	
Low family income	●	○	○	Lower family income contributed to lower social competence in children at age 2.	
Low maternal education	●	○	○	Lower maternal education was associated with lower social competence at age 2.	
E-PLAYS intervention: dyadic collaborative computer game (8 30-min sessions with teaching assistant and 4 15 min sessions with classmate) vs usual care.	○	○	●		Adequate
Intervention: ITTT Hanen Intervention vs Conventional clinician-directed therapy without the ITTT component	○	●	○	Parents' perception of their children's communication development was significantly better in the intervention group.	Strong

Table 5
Continued

Author(s) (year)	**Study design**	**Participants with/at risk of DLD**	***Term used for communicative participation*** **Measurement instrument used (author, year)**	**Personal**			
		n; Gender; Age Range; Mean age (M)		Factor	R	P	NS
St Clair, Pickles, Durkin, and Conti-Ramsden (2011) Mok, Pickles, Durkin, and Conti-Ramsden (2014) Conti-Ramsden, Mok, Durkin, Pickles, Toseeb and Botting (2019)	Longitudinal study: Manchester Language Study	*St Clair et al. (2011):* 234 children with a history of SLI; 179 boys, 56 girls; *Mok et al. (2014):* 171 children with a history of SLI; 128 boys, 43 girls; *Conti-Ramsden et al. (2019):* 242 children with a history of DLD at inclusion, 232, 200, 113 and 139 at follow up; 6;6- 7;9 years (original cohort) 11 and 16 years at follow-up in St Clair et al. (2011); 8, 11 and 16 years in Mok et al. (2014); 8, 11, 14 and 16 in Conti-Ramsden et al. (2019)	*Social (peer relations) difficulties*[c] SDQ, teacher reported and self-reported (Goodman, 1997) CCC, teacher reported (Bishop, 1998; 2003)	Age: reaching middle childhood	●	○	○
				Prosociality	○	●	○
				Performance IQ	○	○	●
				Gender	○	○	●
				Emotional (difficulties)	○	○	●
Thomas-Stonell, Oddson, Robertson and Rosenbaum (2013)	Prospective longitudinal study	Sample 1: 97 children with a speech, language, or communication disorder on a waiting list for SLT; 68 males, 29 females; 0;10 - 4;11 years; mean age 2;8 years Sample 2: 28 children with a speech, language, or communication disorder; 16 males, 12 females; 3;1 - 4;9 years; mean age 3;11 years	*Real-world communication skills*[d] FOCUS, parent reported (Thomas-Stonell, et al. 2010)				
Toseeb and St Clair (2020)	Longitudinal study: Millennium Cohort Study	738 children at risk of DLD at age 5 (487 boys, 250 girls); mean age at inclusion in DLD group was 5;3 years; reassessed at 7;0 and 11;0 years	*Peer difficulties* SDQ, parent reported (Goodman, 1997)	Prosociality (in middle childhood)	○	●	○
				Prosociality (in early childhood)	○	○	●

Environmental				Summary of findings	Critical appraisal
Factor	R	P	NS		Study quality [a]
				Peer problems increased from childhood to adolescence in part of the children (St Clair et al., 2011; Conti-Ramsden et al., 2019). Peer problems increased significantly from 7 to 11 years, and then further increased, but not significantly from 11 to 16 years (Mok et al., 2014).	*St Clair et al. (2011):* Strong *Mok et al. (2014):* Good
				More prosocial children had less difficulty in developing peer relations and more prosocial children had less pragmatic language difficulties (Mok et al, 2014).	*Conti-Ramsden et al. (2019):* Strong
Family income	○	○	●		
Maternal education level	○	○	●		
Receiving therapy (individual; group; home programming + consultation; parent training) vs waiting list (general communication strategies only)	○	●	○	All children made significant gains in communicative participation, but gains were larger in the groups receiving therapy than in waiting list group.	Adequate
				Being prosocial in middle childhood was protective against concurrent social difficulties.	Strong
				Being prosocial in early childhood was not protective against later social difficulties nor did the absence of prosociality in early childhood make social difficulties in middle childhood inevitable.	

Table 5
Continued

Author(s) (year)	**Study design**	**Participants with/at risk of DLD**	***Term used for communicative participation*** **Measurement instrument used (author, year)**	**Personal**			
		n; Gender; Age Range; Mean age (M)		Factor	R	P	NS
Toseeb, Gibson, Newbury, Orlik, Durkin, Pickles, and Conti-Ramsden (2020)	Longitudinal study: Avon Longitudinal Study of Parents and Children (ALSPAC)	394 children with DLD (in total sample of 6531), age at inclusion in DLD group was 8-9 years	*Peer problems* SDQ, parent reported (Goodman, 1997)	Social play	○	○	●
				Prosociality	○	●	○
				Friendship skills	○	●	○
Van Balkom, Verhoeven, Van Weerdenburg and Stoep (2010)	RCT (a randomized controlled group design with follow-up measures)	22 children with DLD; 2;2 - 3;1 years pre-treatment; 2;8 - 3;7 years at follow-up	*Appropriate conversational coherence* Video segments rated on appropriateness of the child's conversational contributions with a published rating scale, researcher reported (published in article)				
Wake, Levickis, Tobin, Gold, Ukoumunne, Goldfeld, Zens, Law and Reilly (2015) Wake, Tobin, Levickis, Gold, Ukoumunne, Zens, Goldfeld, Law and Reilly (2013)	Randomized trial nested within a cross-sectional study: Language for Learning	200 children with expressive and/or receptive language scores > 1.25 SD below the mean at age 4 years entered the trial (132 boys, 68 girls), with 179 children at follow up at age five (91 intervention and 88 control); mean age at inclusion in intervention group: 4;2 years and control group: 4;1 years, children were reassessed at age 6	*Pragmatic language skills* CCC, parent reported (Bishop, 1998; 2003)				
Wake, Tobin, Levickis, Gold, Ukoumunne, Zens, Goldfeld, Law and Reilly (2013)	See Wake, Levickis, Tobin, Gold, Ukoumunne, Goldfeld, Zens, Law and Reilly (2015)						

Environmental				**Summary of findings**	**Critical appraisal**
Factor	R	P	NS		Study quality [a]
					Strong
				Higher levels of prosociality were associated with fewer peer problems in middle childhood.	
				Better friendships were associated with fewer peer problems in middle childhood.	
Early language and communication environment	○	●	○	A positive early language an communication environment is associated indirectly with less peer problems, through higher levels of prosociality.	
Socio Economic Status	○	●	○	Higher SES is associated indirectly with less peer problems, through higher levels of prosociality.	
Participation in a parent-based video home training program (vs direct child intervention)	○	●	○	The parent-based video home training program had a positive effect on conversational coherence, while the direct child intervention had a negative effect.	Adequate
Participation in 18 1-hour home-based therapy sessions (vs 'usual care')	○	○	●	There was no effect of intervention on pragmatic language skills directly after the intervention (Wake et al, 2013) and at 2 year follow-up (Wake et al, 2015) compared to a control group not receiving an intervention.	Wake et al. (2015): Good
Maternal education	○	○	●		*Wake et al. (2013):* Good

Table 5

Continued

Author(s) (year)	Study design	Participants with/at risk of DLD	*Term used for communicative participation* **Measurement instrument used (author, year)**	Personal			
		n; Gender; Age Range; Mean age (M)		Factor	R	P	NS
Washington (2013)	Pre-post-follow-up design (Washington et al., 2011 cohort)	34 children with DLD; 27 boys, 7 girls; 3;0 - 5;0 years; mean 4;4 years at inclusion; 22 children in intervention group, 12 in control group	*Social skills* (Socialization domain of the Vineland Adaptive Behavior Scales (VABS), Interview Edition Survey Form, parent reported (Sparrow, Balla, & Cicchetti, 1984)				
Washington, Thomas-Stonell, McLeod and Leeper (2015)	Pre-post- follow-up design	61 children with DLD; 3;2 - 6;0 years Intervention groups: 26 children with DLD; 24 boys, 4 girls and 20 children with additional motor impairments; 8 male, 12 female. Control group: 15 children with DLD; 13 male, 2 female.	*Communicative participation* FOCUS, parent reported (Thomas-Stonell, et al. 2010)	Low initial social skills	○	●	○
				Co-morbid mobility impairment	●	○	○
Wettig, Coleman and Geider (2011)	Study 1: controlled longitudinal study Study 2: pre-post-follow up design	Study 1: 22 children with social anxiety and developmental language delay; 14 boys, 8 girls; 2;6 - 6;11 years Study 2: 167 children with social anxiety and language delay; 107 boys, 60 girls: 2;5 - 6;11 years	*Shyness/timidity and social withdrawal* Questions from the Clinical Assessment Scale for Child and Adolescent Psychopathology (CASCAP-D), SLT-reported (Doepfner, Berner, Flechtner, Lehmkuhl, & Steinhausen, 1999)				

Notes. R = risk; P = protective; n.s. = not significant; • = yes; o = no.

[a] Raw score 4 or 5 = adequate; 6 = good; 7 or 8 = strong.

[b] In Chiat and Roy (2013) social communication was measured with the Social Responsiveness Scale parent reported (SRS; Constantino & Gruber, 2005) at ages 9;0-11;0.

[c] In the Manchester Language Study SDQ scores at ages 7, 8 and/or 11 years were calibrated using multiple imputation from the Rutter Behavioural Questionnaire—Teacher Report (Rutter, 1967).

[d] In Thomas-Stonell et al. (2013) parents also filled in the Ages and Stages Questionnaire—Social/ Emotional (Squires et al., 2003) at assessment, start and end of treatment. Change measured by the FOCUS correlated with change measured by the ASQ-SE communication questions.

Environmental				**Summary of findings**	**Critical appraisal**
Factor	R	P	NS		**Study quality** [a]
Participation in (10 20-minute expressive grammar intervention sessions (vs no intervention)	○	●	○	Only the intervention group made clinically meaningful changes in social skills.	Strong
				Preschoolers with lower social skills scores had more 'room to grow', demonstrating larger gains in communicative participation compared to preschoolers with higher social skills.	Strong
				Co-morbid mobility impairment was associated with lower communicative participation change scores between post- to 3-months post-intervention.	
Participation in a range of interventions provided by SLTs in different community settings (vs. waitlist control)	○	●	○	Only children in the intervention group experienced clinically meaningful change in communicative participation over time.	
Participation in "Theraplay" intervention (18 attachment based play therapy sessions) (Jernberg, 1979)	○	●	○	Shyness, timidity, and social withdrawal decreased after the Theraplay intervention in both studies.	Strong

combination of weak language and poor behaviour regulation skills is associated with poor social skills (Aro et al., 2012). In addition, children with better friendships at age 7 childhood, experience less peer problems at age 9 (Toseeb et al., 2020). However, there is no association between social play skills at age 7 and peer problems at age 9 (Toseeb et al., 2020).

Motor skills: mobility impairment and gross and fine motor skills

Co-morbid mobility impairment is associated with lower communicative participation change scores in early childhood (Washington et al., 2015), while neither gross nor fine motor skills predicted improvement in social skills in otherwise healthy children with DLD (Kim et al., 2016).

Environmental factors in early childhood that facilitate or hinder communicative participation

Family characteristics: social economic status, family income, maternal education level, paternal education and vocation level, family size, and the early language and communication environment

The association between familial socio-economic factors and communicative participation varies between studies. One study reports that a higher family income is associated with better social competence in preschoolers (Marschik et al., 2007), while other studies find no significant effect of family income on social difficulties for school-aged children and adolescents (Conti-Ramsden et al., 2019; Mok et al., 2014; St Clair et al., 2011). One study found an indirect association between higher social economic status, via prosociality in middle childhood, with less peer problems age 9 (Toseeb et al., 2020). Several studies report that maternal education level is not associated with pragmatic language skills at age 5 and 6 (Wake et al., 2013, 2015) or with peer relations at ages 8, 11, 14, 16 (Conti-Ramsden et al., 2019; Mok et al., 2014; St Clair et al., 2011). In contrast, lower maternal education and lower parental education and vocation are found to be risk factors for social competence in preschoolers (Marschik et al., 2007). Furthermore, one study reports that children from smaller families are socially more competent than children from larger families (Marschik et al., 2007). Finally, a positive early language and communication environment, that is, what parents do to promote the language and communication skills, and the resources they have to facilitate their child's language and communication, was associated with more prosociality in middle childhood and less peer problems at age 9 (Toseeb et al., 2020).

Receiving intervention

In general, receiving therapy seems to have a positive effect on communicative participation in children with DLD. Several studies describe a positive impact of engagement in an intervention (Gregg et al., 2021) per se, or compared with no intervention on communicative participation of young children with DLD (Cunningham et al., 2017a, 2018, 2019; Senent-Capuz et al., 2021; Thomas- Stonell et al., 2013; Washington, 2013; Washington et al., 2015; Wettig et al., 2011). Other studies report no (Murpy et al., 2021; Van Balkom et al., 2010) or mixed effects (Galagher & Chiat, 2009; Wake et al., 2015) of therapy on pragmatic language and communication skills. There are no clear effects of dosage of therapy. Spending more time in intervention is associated with better communicative participation (Cunningham et al., 2017a, 2018), but no difference in improvement of communication skills can be observed between children who receive 12 one-hour SLT group sessions over the course of 24 weeks, versus children who receive 24 four-hour SLT group sessions over the same period (Galagher & Chiat, 2009). The results from comparisons of intervention type and model of intervention are also mixed. Three studies describe a positive effect of the parent directed Hanen programme (Earle & Lowry, 2015) on young children's communicative participation compared with waiting list controls (Cunningham et al., 2019; Kwok et al., 2020; Senent-Capuz et al., 2021). Van Balkom et al. (2010) also report a positive effect of indirect intervention via parents, but not of direct child intervention. Other studies, however, report no significant difference between the effect of individual direct child therapy and parent training (Thomas-Stonell et al., 2013), nor from collaborative computer play with a teaching assistant on young children's communicative participation (Murphy et al., 2021). Enrolment in an early learning program, such as preschool or kindergarten is associated with better communicative participation outcomes in young children, particularly for children with a higher level of communicative functioning (Cunningham et al., 2017a, 2018). Finally, a positive association was found between children's participation in an intensive 8-week summer treatment programme on their social functioning (Gregg et al., 2021).

Knowledge gaps

To identify knowledge gaps in personal factors we compared our outcomes with the examples of personal factors described in the ICF-CY and discussed them with stakeholders in the consultation phase of this review. Compared with the list of personal factors mentioned in ICF-CY we only found a limited set in our included studies: gender, age, other health conditions (i.e., motor impairment, behavioural problems), social background (i.e., mono-/multilingual status), and individual psychological assets (i.e., cognitive, social and emotional skills). The influence of co-occurring health conditions (e.g., dyslexia), social background variables (e.g., birth order), and individual psychological assets (e.g., motivation) have not been investigated and therefore represent knowledge gaps. Two aspects of fitness (gross and fine motor skills) were not found to have an impact on communicative participation, but many other potentially relevant aspects of fitness have not yet been investigated, and therefore represent knowledge gaps. Results are mixed for social-emotional competence, prosociality and social skills. This means that it is currently unclear how these factors relate to communicative participation, which is a knowledge gap. During the consultation phase of this review, stakeholders indicated that every other factor mentioned in the ICF- CY (lifestyle, habits, upbringing, coping styles, education, past and current experience, overall behaviour pattern, and character style) are relevant for communicative participation, except for profession and race. None of these factors is mentioned in the studies included in this review.

To identify knowledge gaps in environmental factors we compared our outcomes with the descriptions of environmental factors in chapters 1-5 of ICF-CY. Chapter 1-5 are: (1) Products and technology; (2) Natural environmental and human-made changes to environment; (3) Support and relationships; (4) Attitudes; and (5) Services, systems, and policies. We found one study (Toseeb et al., 2020) that is related to ICF-CY chapter (3) Support and relationships, and we found several studies on the effectiveness or efficacy of interventions, that relate to the ICF-CY environmental factors chapter (5). A knowledge gap exists on comparative effectiveness of different types of interventions and service delivery models on communicative participation of children with DLD. Another noticeable knowledge gap relating to this chapter is the impact of administrative control, organizational mechanisms, and rules, regulations, conventions, or standards established by governments on children's communicative participation. Furthermore, several studies included in this scoping review report on family characteristics, such as family income, parental education level, and family size. While family size may be related to chapter 3: Support and relationships, these factors are usually included in studies as estimates of socioeconomic status. As such, they cannot be related to a specific chapter in ICF-CY, because summary terms are not themselves found in the classification (WHO, 2007). Finally, no studies were identified that report on factors mentioned in chapters (1) Products and technology; (2) Natural environmental and human-made changes to environment; and (4) Attitudes.

Critical appraisal of study designs

The last column in Table 5 summarizes the results of the critical appraisal of the 32 included studies. The quality of 17 studies was categorized as strong, six were of good quality, and another nine studies were categorized as of adequate quality. No

RCTs were categorized as strong because in none of the RCTs the participants and investigators were blinded for group allocation, and in three of the included RCTs the intervention and control group were not treated equally. While study quality in most of the cohort studies was strong or good, in some cases we identified risk of bias, due to lacking information on recruitment of the participants, incomplete follow-up (e.g., high proportion of missing data, a missing analysis of participants who are lost to follow-up), and a short (less than 1 year) follow-up period. In eight cohort studies confounding factors were not accounted for in the study design and/or analysis. However, no RCT or cohort studies were categorized as of limited quality.

DISCUSSION

The aims of this scoping review were to investigate which contextual (environmental and personal) factors in early childhood are associated with communicative participation among school-aged children with DLD, and to identify possible gaps in knowledge about this subject.

In this review, 32 studies were included, which were of adequate to strong quality. We identified a limited set of personal factors that are associated with communicative participation of children with DLD: gender, age, other health conditions (i.e., motor impairment, behavioural problems), social background (i.e., mono-/multilingual status) and individual psychological assets (i.e., cognitive, play, social and emotional skills). Furthermore, socio-economical family characteristics and receiving intervention were identified as environmental factors that impact on communicative participation of children with DLD. Children of parents who have the necessary skills and resources to promote their child's language and communication (i.e., who provide a positive early language and communication environment), were found to be more prosocial as school children, meaning they are kind, sharing and considerate of other people's feelings. Their prosociality is associated with better peer relations in middle childhood. These factors may explain some of the interindividual variation that can be observed between children with DLD with comparable language skill. Although socioeconomic variables, age, gender, and nonverbal skills have emerged as important factors influencing communicative participation, caution should be exercised as these factors have only been identified as relevant factors in a limited number of studies.

We used the ICF-CY and consultation with stakeholders to identify knowledge gaps. ICF-CY provides a list and classification of environmental factors in chapters 1-5. However, a comparison with the personal factors found in the present review turned out to be complicated since ICF-CY only gives a limited set of examples of personal factors, while a taxonomy of codes as well as guidelines for its application are currently lacking. This omission makes it difficult to identify knowledge gaps on personal factors objectively and transparently (Simeonsson, et al., 2014). The large social and cultural variance associated with personal factors complicated the development of this ICF-CY component (WHO, 2007). In addition, the debate on whether an objective taxonomy of personal factors in the ICF-CY is needed and feasible is still ongoing (Simeonsson et al., 2014). Meanwhile, several categorizations have been developed that cover a total of 12 broad content areas: socio-demographic factors, behavioural and lifestyle factors, cognitive psychological factors, social relationships, experiences, and biography, coping, emotional factors, satisfaction, other health conditions, biological/physiological factors, personality, and motives/motivation (Müller & Geyh, 2015). Each personal factor that was identified in this review can be placed within one these broad content areas, but none of the factors provides complete coverage of an area. In fact, Müller and Geyh's (2015) overview of content areas reveals additional knowledge gaps that we did not identify via our comparison with the examples of personal factors from the ICF-CY. These include the impact of social relationships, satisfaction, motives or motivation, and emotional factors on communicative participation.

To identify knowledge gaps in the relation between environmental factors and communicative participation we compared our results with chapters 1-5 of the environmental factors component of the ICF-CY. Our outcomes show that the number of studies investigating the relationship with communicative participation has remained limited since the introduction of the ICF-CY in 2007. Threats (2008) remarked that 'other persons' are an important factor in the environment of people with communication problems but very little research has been conducted on how people in a child's environment influence its communicative participation since then. In fact, we only found one study that addresses this factor (Toseeb et al., 2020). Similarly, Dempsey and Skakaris-Doyle (2010) have argued for the development of a contextual component of the ICF-CY, to help SLTs to understand why children may respond differently to interventions, and to help them to adapt approaches to the context in which those children live. While communicative participation of children with DLD is likely to be influenced by the amount of practical and emotional support they receive from the people in their lives, including parents, teachers, SLTs and peers, research on interpersonal relationships, and attitudes of other people in the child's environment is only starting to emerge.

Communication necessitates an interplay between the child (i.e., personal factors), and environment (i.e., environmental factors) (Threats, 2008). However, we found no studies that reported on interactions between personal and environmental factors in relation to communicative participation. In response to a presentation of preliminary results of this scoping review, SLTs and teachers indicated that possible interactions between personal and environmental factors had their particular interest, and that it is of great importance to gain insight into how these interactions relate to developmental trajectories for children with DLD. They said that information on child-environment interactions is useful for understanding what works when for whom. Further research in this area could lead to a better understanding of how personal and environmental factors shape communicative participation outcomes in individual children. More specifically, it can help SLTs to adapt therapeutic approaches according to the personal characteristics of children, and to the environments in which those children live (Dempsey & Skakaris-Doyle, 2010). This is essential for realizing personalized care, which does not consider language function alone, but also takes into account the personal and environmental factors that influence communicative participation (Westby, 2007). Currently, it remains unclear which interactions are relevant for children with DLD, and this represents a substantial gap in knowledge.

A structured assessment of contextual factors can support the identification of barriers that need lifting to increase communicative participation and can capitalize on facilitators that could enhance communicative participation (Westby, 2007). However, the development of evidence-based instruments for addressing contextual factors in speech and language therapy is still in its infancy. This scoping review provides a first indication of contextual factors that are expected to be relevant for early identification of children at risk for DLD, and for speech and language therapy for these children. Further research will have to show whether including these factors are clinically relevant for the optimization of the communicative participation of children with DLD.

Limitations

Some limitations should be considered when interpreting the results of the present study. First, since there is no gold standard measure of communicative participation part of this review was an evaluation of the measures used in the studies. This resulted in inclusion of studies reporting outcomes of 14 different measures that often addressed only a specific part of communicative participation, for example, in a specific context such as in school of with friends, or addressed more than communicative participation alone, for example, language performance or social inclusion. For example, the FOCUS outcome measure aims to measure communicative participation, while it also captures other positive outcomes of intervention, such as having clear speech and being able to change between activities. In fact, two FOCUS validation studies (Thomas-Stonell et al., 2013; Washington et al., 2013) report considerable convergent validity between the FOCUS and two outcome measures included in this review: the Ages and Stages Questionnaire (ASQ) (Squires et al., 2003) and Vineland Adaptive Behaviour Scales (VABS) (Sparrow et al., 1984). This implies that these instruments address related or overlapping constructs, but it gives no indication which instrument best captures the construct of communicative participation. In contrast, some other included measures (e.g., Strengths and Difficulties Questionnaire—Peer problems subscale; Goodman, 1997) intend to measure peer difficulties, while in fact several items address communication with peers in daily life. This makes the outcome relevant for this review. In addition, studies that used the Children's Communications Checklist (CCC-2; Bishop, 1998) aim to report on social communication, defined by the American Speech-Language-Hearing Association (ASHA), n.d.) as 'the use of language in social contexts'. The CCC-2, however, includes items on structural language, pragmatic skills, and on communication in a life situation. We believe that all these outcomes are relevant for answering the research question in this scoping review, and we therefore included all studies that had as an outcome children's participation in life situations in which knowledge, information, ideas, or feelings are exchanged. A second limitation is that we chose to exclude qualitative studies, because we were interested in retrospective or longitudinal designs that can link factors present in early childhood to later communicative participation outcomes. We do recognize, however, that longitudinal qualitative research could provide further insight into additional contextual factors. It could be beneficial to review the body of qualitative research when new longitudinal or experimental studies are conducted on associations between personal and environmental factors and communicative participation. Third, despite our systematic search methods, some relevant publications may not have been identified because we limited our search to publications dating from 2007 onwards. Relevant publications may have been published prior to 2007 and therefore been missed.

Clinical implications

Insight into risk factors can help professionals with the identification of children at risk and with tailoring interventions to individual children's needs (WHO, 2007). In addition, knowledge of protective factors can guide the development of interventions for children and young people with DLD that boost resilience and facilitate communicative participation (Luthar & Cicchetti, 2000). This review identified both modifiable (e.g., socio-cognition, receiving therapy) as well as unmodifiable (e.g., age, gender, comorbid conditions, mono-/multilingualism, socio-economic conditions) factors. Knowledge about unmodifiable factors can be used by clinicians to identify children at risk who may need help urgently. For example, young boys and children with co-morbid mobility impairment are more likely to experience barriers in communicative participation. Moreover, adolescents with DLD are at risk for developing difficulties in peer relations. Adequate support should be provided for these at-risk groups. Socio-cognition, social play skills and friendship skills are modifiable factors that were found to be associated with communicative participation. Assessment of these factors can help to identify children who may benefit from therapy that addresses social skills. This review established that access to speech and language therapy services throughout early and middle childhood is likely to be beneficial for children with DLD. More specifically, it shows that providing family- and child-directed therapy, as well as access to early learning programs and day care, are supportive for the development of communicative participation of children with DLD. Furthermore, we found that having parents provide an environment that supports language and communication contribute to communicative participation. Our results regarding other modifiable contextual factors are inconclusive (e.g., social emotional skills), or lacking (e.g., motivation, interpersonal relationships, attitudes). It is currently unclear whether screening for and treating potential problems in these areas is likely to impact on communicative participation. This scoping review indicates that addressing contextual factors in speech and language therapy, in addition to addressing language problems has the potential to prevent and remediate communicative participation restrictions in children with DLD. More research on contextual factors is needed to develop valid instruments that will enable SLTs to address contextual factors routinely, and provide a holistic approach to intervention for children with DLD. We therefore conclude that it remains critical to consult parents and children on the perceived relevance of their context, in particular on the factors identified in this study.

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Conflict of interest

The author(s) declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Data availability statement

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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APPENDIX A

(("Language Disorders"[Mesh:NoExp] OR "Articulation Disorders"[Mesh:NoExp] OR "Language Development Disorders"[Mesh] OR DLD[Title/Abstract] OR SLI[Title/Abstract] OR LI[Title/Abstract] OR LD[Title/Abstract] OR language disorder*[Title/Abstract] OR language impairment*[Title/Abstract] OR language development disorder*[Title/Abstract] OR phonological impairment*[Title/Abstract] OR phonology impairment*[Title/Abstract] OR phonological disorder*[Title/Abstract] OR phonology disorder*[Title/Abstract] OR communication needs[Title/Abstract] OR SLCN[Title/Abstract] OR communication impairment*[Title/Abstract])

AND

("Child"[Mesh] OR child[Title/Abstract] OR children[Title/Abstract] OR preschooler*[Title/Abstract])

AND

("Language Development"[Mesh] OR language[Title/Abstract] OR "Communication"[Mesh] OR "Play and Playthings"[Mesh] OR functioning[Title/Abstract] OR "Social Participation"[Mesh] OR "Narration"[Mesh] OR communication[Title/Abstract] OR communicative[Title/Abstract] OR participation[Title/Abstract] OR conversation*[Title/Abstract] OR interaction[Title/Abstract] OR play*[Title/Abstract] OR storytelling[Title/Abstract] OR narrative*[Title/Abstract] OR narration[Title/Abstract])

AND

("Risk Factors"[Mesh] OR "Language Therapy"[Mesh] OR "Schools"[Mesh] OR "Multilingualism"[Mesh] OR "Resilience, Psychological"[Mesh] OR "Mental Processes"[Mesh] OR "Stress, Psychological"[Mesh] OR "Object Attachment"[Mesh] OR "Attention"[Mesh] OR "Personality"[Mesh] OR "Child Rearing"[Mesh] OR "Parenting"[Mesh] OR "Sociological Factors"[Mesh] OR "Protective Factors"[Mesh] OR "Social Skills"[Mesh] OR "Adaptation, Psychological"[Mesh] OR factor*[Title/Abstract] OR influenc*[Title/Abstract] OR predict*[Title/Abstract] OR relat*[Title/Abstract] OR effect[Title/Abstract] OR effects[Title/Abstract] OR role[Title/Abstract] OR associat*[Title/Abstract] OR cause*[Title/Abstract] OR circumstan*[Title/Abstract] OR element[Title/Abstract] OR component*[Title/Abstract] OR ingredient*[Title/Abstract] OR medium[Title/Abstract] OR impact[Title/Abstract])

NOT

("Attention Deficit and Disruptive Behavior Disorders"[Mesh] OR "Child Development Disorders, Pervasive"[Mesh] OR "Intellectual Disability"[Mesh] OR "Learning Disorders"[Mesh] OR "Schizophrenia, Childhood"[Mesh] OR "Tic Disorders"[Mesh] OR "Chromosome Disorders"[Mesh] OR "Fetal Alcohol Spectrum Disorders"[Mesh] OR "HIV Infections"[Mesh] OR "Epileptic Syndromes"[Mesh] OR "Brain Diseases"[Mesh] OR "Cleft Palate"[Mesh] OR "Hearing Disorders"[Mesh] OR "Cochlear Implants"[Mesh] OR "Anemia, Sickle Cell"[Mesh]))

AND

((2007/1/1:3000/12/12[pdat]) AND (dutch[Filter] OR english[Filter] OR german[Filter]))

APPENDIX B

Diagnostic labels

Children ‘at risk’ of DLD, n = 6

1. Chiat and Roy (2008)
2. Aro et al. (2012)
3. Määttä et al. (2012)
4. Chiat and Roy (2013)
5. Forrest et al. (2020)
6. Toseeb and St Clair (2020)

Developmental language disorder (DLD), n = 5

1. Van Balkom et al. (2010)
2. Washington (2013)
3. Washington et al. (2015)
4. Conti-Ramsden et al. (2019)
5. Toseeb et al. (2020)

Specific language impairment (SLI), n = 4

1. Galagher and Chiat (2009)
2. St Clair et al. (2011)
3. Mok et al. (2014)
4. Kim et al. (2016)

Late talkers, n = 4

1. Marschik et al. (2007)
2. Cunningham et al. (2019)
3. Kwok et al. (2020)
4. Senent-Capuz et al. (2021)

Language disorder (LD), n = 3

1. Wettig et al. (2011)
2. Goh and O’Kearney (2015)a
3. Goh and O’Kearney (2015)b

(Speech and) language impairment (LI), n = 5

1. Lindsay et al. (2007)
2. Lindsay and Dockrell (2012)
3. Gregg et al. (2021)
4. Cunningham et al. (2017a)
5. Cunningham et al. (2018)

Other diagnostic label, n = 7

1. Speech, language and communication disorder: Thomas-Stonell et al. (2013)
2. Expressive and/or receptive language scores < 1.25 SD: Wake et al. (2013, 2015)
3. Language problems: Helland et al. (2022)
4. Social communication impairments or pragmatic language impairments: Murphy et al. (2021)

Chapter 6

Speech and language therapists' perceptions of contextual factors associated with communicative participation in children with developmental language disorders

Singer, I., Gerrits, E., Gorter, J. W., & Luinge, M. (2024). Speech and language therapists' perceptions of contextual factors associated with communicative participation in children with developmental language disorders. *Child Language Teaching and Therapy,* 40(3), 297-314.

ABSTRACT

Children with developmental language disorders (DLDs) may experience barriers to communicative participation. Communicative participation is defined as 'participation in life situations in which knowledge, information, ideas or feelings are exchanged'. Barriers experienced in communicative participation cannot be explained by language competence alone and are thought to be influenced by contextual factors. A better understanding of these factors will contribute to tailored speech and language therapy services for children with DLD. We conducted a focus group study with 13 speech and language therapists' (SLTs) to explore their perspectives on contextual (environmental and personal) factors in early childhood that are associated with communicative participation in children with DLD. The personal factor of child well-being, and the environmental factors of familial support and SLT service provision were developed through thematic analysis. The potential mediating role of these factors on communicative participation implies that it is important to address contextual barriers and facilitators in speech and language therapy services.

Keywords: developmental language disorder, communicative participation, contextual factors, practice-based research, speech and language therapy, focus group study

INTRODUCTION

Children with developmental language disorder (DLD) have difficulties with understanding and using language. DLD is relatively common, affecting approximately 7.5% of children aged 4 to 5 years (Norbury et al., 2016). Children with DLD often experience severe restrictions in everyday communication (Bishop et al., 2017). Their participation restrictions may vary across contexts and cannot be attributed solely to differences in children's language skills (Dempsey & Skarakis-Doyle, 2010; Eadie et al., 2006).

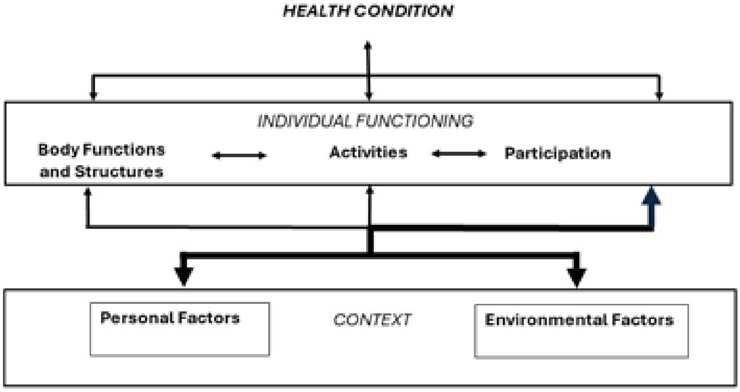
The ability to engage in everyday communicative situations or communicative participation is an important skill for children with DLD (Jensen de López et al., 2021). Optimising communicative participation is considered as the ultimate goal of speech and language therapy for children with DLD (Hidecker, 2010; Lyford Jones, 2010; Prelock et al., 2008; Roulstone et al., 2012). Communicative participation is defined as 'participation in life situations in which knowledge, information, ideas or feelings are exchanged' (Eadie et al., 2006, p.309). This definition has been validated by parents of children with speech and language disorders and professionals, including teachers, speech and language therapists (SLTs) and psychologists, who agreed that communicative participation is 'understanding and being understood in a social context by applying verbal and/or non-verbal communicative skills' (Singer et al., 2020, p.9).

The World Health Organisation's (WHO) International Classification of Disability Functioning and Health - Children and Youth version (ICF-CY; WHO, 2007), conceptualises functioning and disability as a dynamic interaction between a person's body functions and structures, activities and participation, and their contextual factors (Figure 1). Contextual factors, that is, personal and environmental factors, influence children's communication in social contexts (Conti-Ramsden & Durkin, 2015; Cunningham et al., 2021; Gerber et al., 2011). Contextual factors may pose a risk or protect against communicative participation restrictions (WHO, 2007). Knowledge of risk factors, such as having low socio-cognitive skills, can help professionals identify children at risk and develop interventions that can remove or neutralise barriers present in their lives (Singer et al., 2022). In contrast, knowledge of protective factors, such as prosociality, can guide the development of interventions for children and young people with DLD that build resilience and facilitate communicative participation (Luthar and Cicchetti, 2000).

In a recent systematic scoping review (Singer et al., 2022), we identified several risk and protective factors for communicative participation in children with DLD. Only studies with a (quasi) experimental design and cohort studies were included. The review found that receiving therapy, a positive early language and communication environment at home, and a higher level of parental education level are protective environmental factors. No environmental risk factors are known. Personal protective factors include being a pre-school girl, reaching school age and being prosocial. Personal risk factors include being an adolescent, having low socio-cognitive skills, and having co-morbid mobility impairments or behavioural problems. However, significant gaps in knowledge were identified, such as the impact of life-satisfaction, motives or motivation, and emotional functioning, as well as the role of interpersonal relationships, and attitudes of other people in the child's environment (Singer et al., 2022).

Figure 1

The International Classification of Functioning, Disability, and Health - Children and Youth version (ICF-CY) model of functioning and disability (WHO, 2007) visualises how individual functioning ('body functions and structures', 'activities' and 'participation') emerges from the interaction between the child health condition ('disorder or disease') and contextual factors ('environmental factors' and 'personal factors'). The interactions between the components' contextual factors and participation are highlighted using a thicker line, as they are the central focus of this study.



Note. From 'ICF Beginners Guide' (WHO, 2002, p. 9), with permission of the World Health Organisation.

In order to better understand the many factors and the interplay between them, qualitative research can provide the perspectives of children with language and communication disorders and their parents. Parents have been shown to consider their child's understanding of social situations as a relevant personal factor (Lloyd-Esenkaya et al., 2021; Myers et al., 2011). In addition, parents and children mention several other factors that were not yet identified in the scoping review. These include the child's confidence as a communicator (Markham et al., 2009), their understanding of and ability to regulate emotions (Lloyd-Esenkaya et al., 2021), the development of coping strategies (Lloyd-Esenkaya et al., 2021), practicing communication and putting in an effort (Merrick & Roulstone, 2011), feeling comfortable in the environment, having things in common with others, and feeling accepted by peers (Brinton et al., 2010; Lloyd-Esenkaya et al., 2021; Merrick & Roulstone, 2011; Myers et al., 2011). A protective environmental factor identified by parents, and also found in the scoping review, is the availability of support and therapy (McCormack et al., 2018). In addition, parents mention that informal support at home and in the community has a positive impact on communicative participation (Jensen de López et al., 2021; Markham et al., 2009; McCormack et al., 2018). Focus groups with children with communication difficulties show that a calm and quiet learning environment is helpful for their communicative participation in school (Markham et al., 2009). Finally, other people's attitudes towards the child and their communication problems can have an impact on a child's communicative participation, according to children and their parents (Jensen de López et al., 2021; Merrick & Roulstone, 2011). These insights into the perspectives of children with DLD and their parents highlight what is important to them. Addressing these needs in speech and language therapy is essential to providing family-centred care.

Even when the perspectives of children and parents are known, they may not coincide with those of SLTs. Potential discrepancies may have an impact on the therapeutic process (Marshall et al., 2007). The extent to which SLT perceptions of factors associated with communicative participation align with children's and parents' perspectives and research evidence, is currently unknown. SLTs provide services to a diverse group of children and families. Exploring SLTs perceptions may broaden insight into contextual factors. Furthermore, their perceptions may be more applicable to practice than evidence from tightly controlled quantitative research studies (Lof, 2011). Therefore, the central research question of this study is, 'What are SLTs' perceptions of contextual factors associated with the communicative participation of children with DLD?'

We decided to conduct a focus group study, because focus groups provide opportunities for interaction between participants, which allows SLTs to reflect on each other's contributions from their own experience (Hennink et al., 2010). SLTs insights can complement the research literature and ensure that all relevant barriers and facilitators can be addressed. Ultimately, this may contribute to the optimal communicative participation of children with DLD.

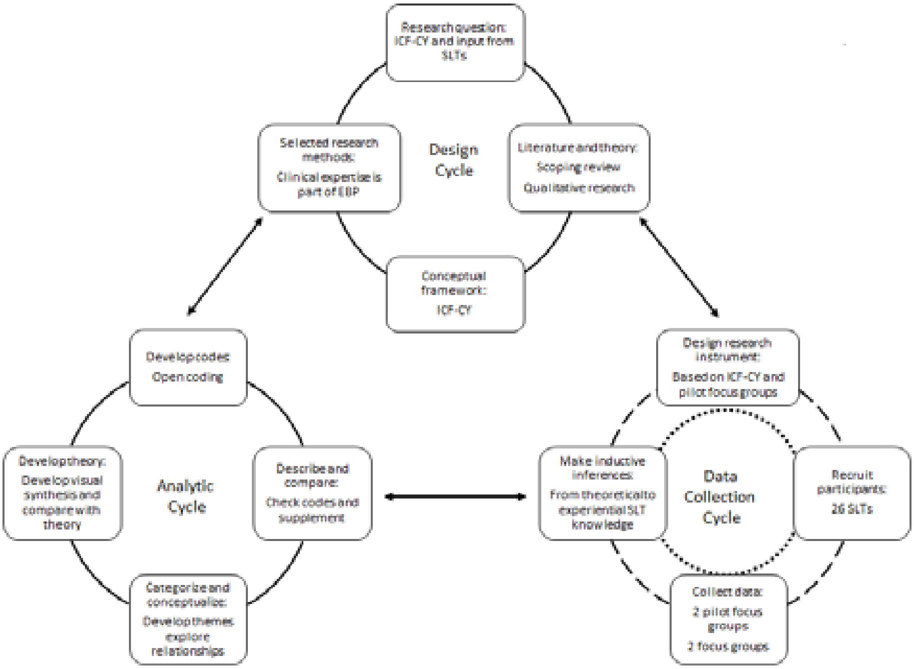
METHODS

Design

We conducted focus group discussions with SLTs to explore which contextual factors are associated with the communicative participation of individual children with DLD. We used the Hutter-Hennink qualitative research cycle approach (Hennink et al., 2010, p. 5). The cyclical research design is illustrated in Figure 2, and consists of the interrelated design, data collection and analytic cycles. In the design cycle, the ICF-CY was used as a conceptual framework for the development of the research question and the initial topic guide and prompts. In the data collection cycle, we first conducted two pilot focus group discussions to find out which topics were most relevant according to the SLTs and discover how SLTs talked about and reflected on factors that influence children's communicative participation. This cycle is illustrated by the dotted line in Figure 2. The cycle of data collection in the pilot focus groups (circle with the dotted line) is explained in Supplemental appendix A. Following the first pilot discussion, several changes were made to the list of topics and the procedure to improve the natural flow of the conversation. These changes included removing an introductory topic from the list and replacing prompts with more general ones such as 'Can you tell me more?' and 'Can you give me an example?'. The moderator's introduction to the ICF-CY framework was shortened in the second pilot group, allowing for more time for discussion. Talking cards and brainstorming exercises were omitted due to time constraints. Instead, an observer recorded and clustered the factors on a whiteboard. After the second pilot focus group, the SLTs were asked to discuss real cases. These adaptations aimed to gather specific experiential knowledge from SLTs working with children with DLD and their families, as distinct from theoretical knowledge gained from training and literature. Next, we conducted two focus groups in which we specifically asked about SLTs actual experiences. The objective was to delve deeper into SLTs' perceptions, generate richer data and identify relevant concepts. This cycle is illustrated by the dashed line in Figure 2. Finally, in the analytic cycle, the themes generated during inductive analysis of the focus group data were examined for interconnectedness, and a visual representation of the data was developed. Data analysis of the first and second focus groups resulted in code saturation, and therefore no new focus group discussions were initiated (Hennink et al., 2019). The data collection cycle of the focus groups (outer circle with the dashed line), as well as the analytic cycle will be further explained in the following section.

Figure 2

Current study design in the qualitative research cycle (adapted from Hutter-Hennink (2010), in Hennink et al. (2010)). The dotted inner circle in the data collection cycle represents the pilot focus groups, the dashed outer circle represents the focus group discussion for data collection.



Ethical considerations

The study was approved by the Ethical Review Board of HU University of Applied Science in Utrecht, the Netherlands (reference number 89_000_2019) and was conducted in accordance with the tenets of the Declaration of Helsinki (World Medical Association, 2013).

Research team and reflexivity

The first author, IS, is trained as a developmental psychologist and as an SLT. Her doctoral research is on developing knowledge and tools to support SLTs in shifting their focus from language skills alone to everyday communicative functioning in children with DLD. EG, is an SLT and a senior researcher specialised in research on communicative participation of people with language and communication difficulties. JWG has training in rehabilitation medicine and is a senior researcher on physical health, family empowerment, and cognition in children and youth with disabilities. ML is a senior researcher with expertise in pedagogy and neurolinguistics. She recommended the use of the Hutter-Hennink's qualitative research cycle approach in this study. Two SLTs assisted with data collection: IKW, with over 30 years of experience, and EDW, who has a PhD. in childhood language disorders. ADG assisted with data analysis. She is an experienced SLT with over 25 years of practice.

Data collection cycle main focus groups: Dashed circle

a Design research instrument

The list of topics prompts and materials that were used in the focus groups are shown in Table 1.

Table 1

List of topics, prompts and materials used in two focus groups

List of topics	Prompts used	Materials used
Think of a child you have had under your care whose communicative participation did not match with his or her language competence: What factors influenced this child's communicative participation? Which factors do you think were most important? How are the factors related? How do the factors interact?	Can you tell me more? Can you tell me about the way this factor exerts its influence? Can you tell me how you noticed the influence of this factor? Do you think that this factor can be changed? Can you give an example of how the factors are related?	The moderator used a PowerPoint slide to introduce the research question, the ICF-terminology (contextual, environmental and personal factors) (WHO, 2007) and the definition of communicative participation (Eadie, 2006, p. 309) Post-its and pens Whiteboard for taking notes during the focus group

b Recruit participants

The focus group participants were SLTs recruited through convenience sampling via social media platforms. They were required to have at least 2 years' experience of providing services to children aged 3 to 8 years with DLD. The characteristics of participants are shown in Table 2.

Table 2

Focus group discussion participants

Activity	Total number of participants	Number of participants working in school setting*	Number of participants working in care setting*	Years of work experience (M; range)
Focus group discussion 1	9	6	5	16.6; 3-28
Focus group discussion 2	4	1	3	10.6; 2-25

* Some participants work in both settings.

c Collect data

One focus group took place in a school meeting room, and the second focus group was conducted online due to the COVID-19 pandemic restrictions. Both focus groups lasted for 120 minutes. The discussions were video recorded.

Data analysis

a Describe and compare

Data from the focus group discussions were transcribed verbatim. The ICF-CY framework served as the primary lens through which we analysed our data, therefore we organised our data into personal and environmental factors using the ICF framework (deductive) (WHO, 2007). Next, reflexive thematic analysis was used to develop themes relating to communicative participation in children with DLD (inductive) (Braun & Clarke, 2021). The development of codes and themes was driven by the recognition that SLTs' perceptions are social constructs, and that the way SLTs talk about factors associated with communicative participation is shaped and sustained by training, SLT practices and shared professional beliefs.

b Develop codes

The first author (IS) read the transcript of the focus groups and developed codes through open coding using Atlas.ti (version 22) (ATLAS.ti Scientific Software Development GmbH, 2022). The first deductive step in data analysis was to organise data into two subsets (personal and environmental), followed by an inductive reflective thematic analysis of the fragments falling within each subset. Apart from personal factors (P), environmental factors (E), the outcome of communicative participation (O) was marked in the dataset. Quotes were coded as belonging to personal factors if they described an aspect of the child as a unique individual, whereas quotes were coded as belonging to environmental factors if they described the physical, social and attitudinal environment in which the child lives. If a quote described a positive influence, it was coded with a plus (+) sign, and if it described a negative influence, it was coded with a minus (-) sign. ADG independently coded the transcripts using the same codes. Differences, and additional codes were then discussed and changes were made until consensus was reached.

c Categorise and conceptualise

IS and ADG grouped similar open codes together into second-order open codes in Atlas.ti for Windows version 22 (ATLAS.ti Scientific Software Development GmbH, 2022). This was done separately for open codes relating to personal factors and those relating to environmental factors. No further analysis was conducted on open codes relating to the outcome, as these specified aspects of communicative participation, rather than contextual factors. We used Excel version 2021 (Microsoft Corporation, 2021), to cluster second order open codes into subthemes, and to group subthemes into themes. The results were discussed with all authors until consensus was reached. The subthemes and themes were positioned within the ICF-CY framework. Next, the themes and subthemes were described as closely as possible to the participants' words. Quotes were extracted from the data to illustrate each subtheme.

In order to explore how factors are related in SLT perception, we identified which open codes were mentioned together in the transcripts. We then aggregated the relationships between open codes at the subtheme level (Hennink et al., 2010, p. 250). Clusters of subthemes that were related in a similar pattern were then categorised into a theme. The last step in data analysis was a visual synthesis of the data, which illustrates how themes and subthemes are related.

Quality measures

In the design phase, we used the ICF-CY framework (WHO, 2007) and stakeholder consultation to inform the research question and the choice of research methods. In the data collection phase, we started with a deductive approach and used the experience of the pilot focus groups to make (inductive) inferences about the line of questioning that would yield the most informative data. Member checks were conducted by sending a summary of the discussion to the participants immediately after each focus group. The majority of the participants confirmed that the summary reflected the discussion well, while some highlighted the importance of particular issues (e.g. responsive caregivers) in their responses. The responses informed the naming of some (sub)themes. Data collection was conducted by two researchers (IS and IWK or EDW). Data analysis was conducted partly jointly and partly independently by two researchers (IS and ADG). The last author (ML) supervised the data analysis. In addition, sensitive issues raised in the focus groups were discussed in meetings with senior members of the research team. The Consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007) was used as a framework to ensure comprehensive and transparent reporting of the study design, data collection and analysis processes.

RESULTS

Three themes and nine subthemes were developed. These themes and subthemes are illustrated with SLTs' quotes. The study positions them in the ICF-CY framework, discusses relationships within and between themes, and provides a visual representation of how contextual factors impact communicative participation in young children with DLD, according to SLTs. All participant names mentioned in this section have been replaced with pseudonyms to protect their privacy and confidentiality.

Personal factor: Child well-being

Child well-being is a crucial theme for communicative participation, according to SLTs. This theme includes the subthemes of 'mental and physical health', 'past experiences with communication', 'coping style' and 'self-image'. Child well-being is considered a personal factor within the ICF-CY (WHO, 2007), and is not necessarily tied to the child's language problems. The subthemes and their interconnectedness are explained below.

Mental and physical health

Mental and physical health are both important aspects of overall well-being. Mental health encompasses emotional, psychological and cognitive well-being, while physical health pertains to the body's well-being, including factors such as nutrition, exercise, sleep and overall physical condition. According to SLTs, children's communicative participation can be negatively impacted by physical or mental health issues.

> *When a child is tired, not in good health, or otherwise unwell, that will have an impact on their total functioning. And that includes communicative functioning ... Obviously, there will be children with DLD and co-morbid neurobiological disorders, which may already make them less focused on communication. This is an additional barrier to their [gaining] communication skills.* Focus group 2, Hannah

Past experiences with communication

According to SLTs, a child's history of communication experiences significantly influences their interactions with others. Positive experiences can enhance communicative participation, while negative or limited experiences may lead to communication challenges, such as difficulty expressing oneself or understanding others.

> *I also think that due to the DLD, a sort of vicious cycle is created... If you're very verbal and you constantly come up with all sorts of things, and have the ability to ask questions or to express things, and the other person responds to it ... the communicative patterns develop very differently compared to those of children*

> *who don't know what to say or how to name things, they keep quiet, and then the other person doesn't respond…* Focus group 1, Ellen

Coping style

Coping style refers to how individuals deal with stress, adversity and challenging communicative situations. Some children will use problem-solving strategies, while others may resort to avoidance or emotional coping.

> *How does the child learn and how does the child cope when things don't go well? What kind of coping response do you get? Does the child get stressed? Will they try again? And what I see a lot with the young children I work with is that when things don't work out, they immediately go 'boom' into the red zone … How do you deal with it effectively when a child becomes very upset or very sad when something they're trying doesn't work out? I find that to be important.* Focus group 2, Amber

Self-image

Self-image refers to an individual's perception of themselves. In the context of speech and language therapy, self-image relates to how a child evaluates their communication skills in relation to their environment. Negative self-perception in this area can have a significant impact on mental health, potentially leading to anxiety, depression or behavioural challenges.

> *If they have a younger sibling who verbally outperforms them, this really has an impact. When they realize this, they might think, 'Why can't I do that? Why is he or she better than me?' Those kinds of thoughts could come into play. Of course, you can't look into their minds, but sometimes you can tell from the children's behaviour. This can cause conflicts at home or arguments. Yes, it can.* Focus group 2, Julie

SLTs suggest that the subthemes are interconnected. For instance, children who have a negative self-image may experience challenges with their mental health and encounter difficulties in effective communication. Their coping mechanism may involve avoidance or negative behaviour, which can further impact their well-being. Conversely, children who have good mental and physical health may be better equipped to manage communication challenges and maintain a positive self-image. Additionally, positive prior experiences with communication may enhance children's coping abilities and self-image. Understanding these connections can be helpful in addressing communicative participation problems of children with DLD.

Environmental factor: Familial support

SLTs suggest that the communicative participation of children with DLD is significantly affected by the support they receive from their families. This support includes the physical, social and attitudinal environment in which children live and conduct their lives. Therefore, it can be classified as an environmental factor within the ICF-CY (WHO, 2007). The familial support theme can be divided into three subthemes: 'stimulating and rich environment', 'knowledge and acceptance of DLD' and 'responsive caregivers'. These factors can either facilitate or hinder progress.

Stimulating and rich environment

A stimulating and rich environment refers to the surroundings and experiences that provide many opportunities for communicative participation. According to SLTs, this includes access to age-appropriate books and regular dyadic reading sessions, engagement in social interactions and conversations both in one-on-one and in group settings, and participation in play, games and activities with others. SLTs believe that exposing children to a variety of sounds, sights and experiences can enhance their comprehension of the world and encourage communication.

> *It does help if a child has wider experience. Children who do many things with their parents have a much broader world view. They can converse about many different things.* Focus group 1, Sara

A stimulating and rich environment also encompasses the network of parents and the level of support they can provide for their child.

> *Early intervention is important. When parents have a small network, children with communication problems may only be identified later on and …then it's very difficult to do anything.* Focus group 1, Petra

Responsive caregivers

SLTs emphasise the importance of parents or caregivers providing a safe environment and responding positively to a child's attempts at communication. This involves being attuned to the child's needs, emotions and cues, even if the child's verbal communication is limited. SLTs believe that parents should create opportunities for their child to communicate by asking open-ended questions or offering choices. They should also provide positive feedback and reinforcement for the child's attempts to communicate. It is important to maintain an objective and balanced approach to encourage the child's communication development. SLTs acknowledge that progress in communication skills may be slow and requires consistent support from parents without undue pressure.

> *I also know some mothers who are really on top of it. The more speech therapy the better. They are very enthusiastic, but also somewhat one-track. I mean, they are not so much interested in what the child has to say or in talking together, but rather they want them to study hard, do well [in school], learn vocabulary … That is what they consider to be of paramount importance…* Focus group 1, Ellen

> *Safety … These kids must feel safe first, otherwise nothing is possible. [Without that] you can't ask anything.* Focus group 1, Martha

Stressors such as parental illness, poverty and strong sibling rivalry can adversely affect parental responsivity, especially when multiple problems exist. This can impact how the family relates and communicates.

> *Families where several things are going on, poverty … or another sick sibling in the family… a whole lot of issues can pile up and the child is snowed under.* Focus group 1, Jane

Knowledge and acceptance of DLD

According to SLTs, it is essential for parents and caregivers to have knowledge of and accept DLD. This includes a clear understanding of DLD, including its causes, characteristics and potential impacts on a child's development, as well as accepting the child's diagnosis. SLTs emphasise that it is crucial for parents to understand that the child's language difficulties are real and not due to laziness or lack of effort.

> *The knowledge about DLD that either the parents, teacher, or the entire environment has, plays a really significant role. It affects how the environment treats the child.* Focus group 2, Julie

SLTs believe that a stimulating and rich environment for children with DLD involves providing opportunities for language exposure and practice. Informed and supportive caregiving requires knowledge and acceptance of DLD, while parental responsivity involves responding to the child's communication attempts with understanding, encouragement and patience. These aspects of familial support contribute to the child's communicative participation, according to SLTs.

Environmental factor: SLT service provision

SLTs emphasise the importance of timely engagement in therapy services for the development of communicative participation in children with DLD. Two key aspects of intervention in relation to children's communicative participation are highlighted by SLTs: preparation for real-life situations and a child-centred approach.

Preparing for real-life situations

SLTs emphasise the significance of equipping children with the necessary skills to participate in real-life situations. To achieve this, they suggest integrating social skills training into speech therapy sessions and practising fundamental communication skills, such as asking questions and engaging in discussions. Debate is recognised as an effective method for teaching children how to navigate communication challenges, including enhancing the clarity of their thoughts and resolving misunderstandings.

> *We practise in small groups when possible. For example: How can you ask each other questions? How can you discuss views on a topic? Yes, the really basic skills.* Focus group 2, Julie

> *Debating provides a very pleasant structure for children. I notice that children like this structure where one stands up while others sit down, and they have all the time and attention to express their opinion.* Focus group 2, Jo

Child-centred approach

SLTs emphasise the importance of placing the child at the forefront of the learning process. They suggest tailoring communication activities to the unique needs, interests, and developmental stage of each individual child to nurture their individuality and autonomy.

> *I mean that you connect, that you talk to, not over, the child, that you give the child plenty of time and don't talk too fast, that you establish a connection with the child, so that what you say, do, explain, or read, registers with the child.* Focus group 1, Ellen

> *For him, it is particularly important that he can suggest a topic, something that he wants to talk about. That suddenly makes him more communicative.* Focus group 2, Amber

> *If you show a sincere interest, I think the child will also be able to talk about emotions.* Focus group 1, Jo

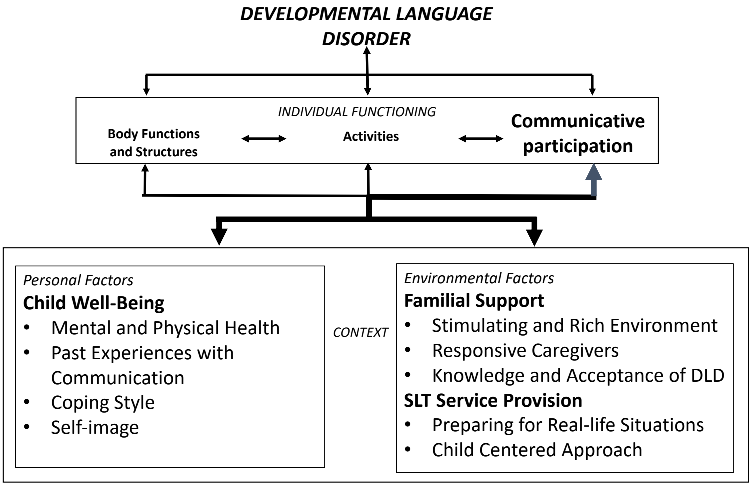
SLTs believe that therapy should be tailored to the individual needs and interests of the child. This approach enables the child to practice communication skills in real-life situations, leading to meaningful progress in their ability to communicate and participate in everyday interactions.

Themes placed within the ICF-CY

Figure 3 presents an overview of the themes within the ICF-CY framework.

Figure 3

The themes and subthemes identified in this study are positioned within the environmental factors and personal factors components of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) model (WHO, 2007).



Note. From 'ICF Beginners Guide' (WHO, 2002, p. 9), with permission of the World Health Organisation.

Interactions between themes

According to SLTs every theme was found to be related to at least one other theme through codes that were mentioned together. Some associations were described positively. For example, the association between the open code 'opportunities to communicate' (subtheme 'child-centred approach' and theme 'SLT service provision') and the open code 'taking initiative' (subtheme 'coping style' and theme 'child well-being') is framed positively in this fragment:

> *He always brought something to therapy for me. We had to talk about that for about five minutes. It could be a hand puppet, a soccer ball, or a Pokémon. And then you would suddenly see that he could talk quite well about it, that he dared to. But it had to align with his interests. I found it very impressive that he took the initiative, connecting to his experience. And because he took the initiative himself, he gained more confidence to talk about it.* Focus group 1, Amber

Other interactions are phrased negatively. For example, the open code 'parents do not accept DLD' (theme 'knowledge and acceptance of DLD') is negatively associated with the open code 'child well-being' (theme 'self-image') in the fragment:

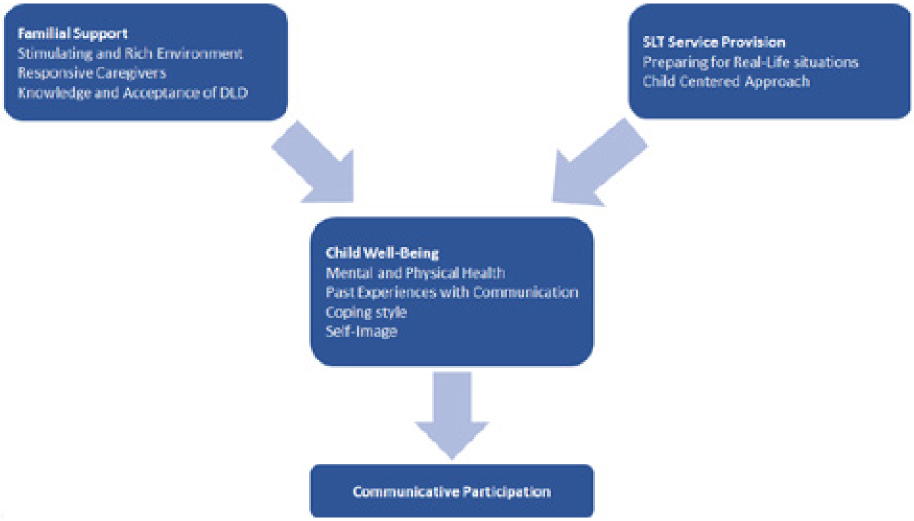
> *His parents denying his DLD turned out to be a huge obstacle for his ability to communicate. It gave unrelenting stress. Seeing this one-to-one link between the parents' lack of acceptance of the problem and their level of stress when communicating with the child has really impressed me. It had a massive impact on how that boy felt about himself and on his communicative participation.* Focus group 2, Hannah

The analysis of interactions between themes shows that some have a direct connection with communicative participation, while others are associated indirectly with the outcome, through other themes. In the example above, the theme 'child well-being' is directly associated with communicative participation, while the theme 'familial support' and 'SLT service provision' are associated indirectly with communicative participation through the theme 'child well-being'. On the level of subthemes, a child's self-image and coping style are associated directly with the child's communicative participation, while an indirect influence was mentioned for mental and physical health and past experiences, as well as the subthemes within the environmental factors' domain. Finally, SLT service provision is directly associated with the child's self-image and coping style, and indirectly though shaping the child's past experiences with communication, according to SLTs. The interaction between themes is visualised in Figure 4 and illustrated in the following quote:

> *We suspected that it was due to really intense perfectionism, that he only wanted to talk if he was sure he was saying it right. That was a huge barrier for his communication at the time. Everything had to be nonverbal, and that didn't always go well either. But the great thing was that, once he knew that he could do it, then he immediately talked in full, or almost full, sentences. He seemed to skip all the in-between steps, because he wanted to be able to perform well straightaway. So, perfectionism was important. But I also think that the environment played quite a role because, if you receive a negative response when you make a mistake, you will become more afraid of letting yourself be heard. So that's a trade-off. And once you dare to communicate, even if you make mistakes, and there is a positive response, then that gives positive reinforcement of course. So, I cannot see one separate from the other.* Focus group 2, Julie

Figure 4

Interrelations between themes, and their relationships with communicative participation according to SLTs



Note. The direction of the arrows in the figure indicates the direction of the relationships between themes as perceived by speech and language therapists.

DISCUSSION

The study identified three themes and nine subthemes that illustrate personal and environmental factors associated with communicative participation in children with DLD. The analysis of interactions between themes suggests that communicative participation is directly associated with child well-being, which is, in turn, affected by familial support and SLT service provision.

Personal factors

There are many similarities between the theme child well-being identified in the present study with SLTs, and personal factors identified in qualitative studies on the perceptions and experiences of children and parents. These include the child's understanding of, and ability to regulate their emotions (Lloyd-Esenkaya et al., 2021), development of coping strategies (Lloyd-Esenkaya et al., 2021), confidence as a communicator (Markham et al., 2009) and practicing communication (Merrick & Roulstone, 2011). These factors align with the subthemes 'coping style', 'self-image' and 'past experiences with communication' in our study. It is important to note that there are differences in perceptions between SLTs and parents/children. Firstly, the subtheme 'mental and physical health' was identified in our study with SLTs but not in studies with parents or children. While parents are likely to be aware of any health problems their child experiences, they may not necessarily associate them with communicative participation. Secondly, parents and children mention that feeling at ease in the environment, having shared interests with others, and feeling accepted by peers (Brinton et al., 2010; Lloyd-Esenkaya et al., 2021; Merrick & Roulstone, 2011; Myers et al., 2011) have an impact on communicative participation. Parents and children consider a child's understanding of social situations as a relevant personal factor (Lloyd-Esenkaya et al., 2021; Myers et al., 2011), but this is not the case for SLTs. This difference may be due to the limited insight that SLTs have into the child's daily life, including their social relationships. This could be because the SLTs who participated in this study primarily work with children in individual sessions.

The subthemes 'coping style' and 'self-image' identified by SLTs in this study have not yet been linked with communicative participation in quantitative studies (longitudinal and RCT) (Singer et al., 2022). Limited evidence suggests an association between 'mental and physical health', and communicative participation, which is consistent with SLT perceptions. Research has established a co-occurrence of emotional difficulties and peer problems in children with DLD (Conti-Ramsden et al., 2019). Furthermore, Singer et al. (2022) found no available data on the influence of other aspects of child health on communicative participation. Lastly, the impact of 'past experiences with communication' has not yet been investigated in longitudinal quantitative research (Singer et al., 2022). However, research shows that a positive early language and communication environment at home as an environmental factor, is associated with better communicative participation in children with DLD (Toseeb & St Clair, 2020).

Environmental factors

The environmental factors that emerged from the current study with SLTs are consistent with those identified in previous quantitative and qualitative research with parents and children with DLD. Regarding the theme of 'SLT service provision' and the subtheme of 'preparing for real-life situations', numerous quantitative studies have shown that engaging in functional therapy has a positive impact on the communicative participation of children with DLD (Cunningham et al., 2018; Singer et al., 2022). The significance of receiving assistance and aid has also been recognised in a qualitative study that sought the opinions of children with communication disorders (McCormack et al., 2018). In contrast, the subtheme 'child-centred approach' discovered in this study has not been identified in quantitative studies as a factor that affects communicative participation (Singer et al., 2022), but rather as an approach to stimulate language development (e.g. Rinaldi et al., 2021). This difference may reflect SLTs specialised knowledge and skills in stimulating language and communication development. Furthermore, the theme of 'familial support' and its subthemes, including 'stimulating and rich environment', 'knowledge and acceptance of DLD' and 'responsive caregivers', may be linked to the results of a longitudinal study on children with DLD. The study found that a positive language and communication environment at home is crucial for promoting communicative participation (Toseeb & St Clair, 2020). Qualitative research has also mentioned themes related to the early language and learning environment, including children with DLD and their parents. Examples are a calm and quiet learning environment (Markham et al., 2009), other people's attitudes towards the child and their communication problems (Jensen de López et al., 2021; Merrick & Roulstone, 2011), and the positive effect of informal support at home and in the community (Jensen de López et al., 2021; Markham et al., 2009; McCormack et al., 2018). This study's findings suggest that 'familial support' and other factors may contribute to a positive early language and communication environment at home. Focusing on these aspects could be a valuable approach in indirect therapy.

Interactions between the child and their environment

Our study found that both familial support and SLT service provision have an impact on child well-being, which is in turn associated with communicative participation. These influences are unidirectional. However, the view of socialisation as a bidirectional process has gained wide acceptance. For instance, in the ICF-CY (WHO, 2007), interactions between personal and environmental factors, and the participation component of functioning are reciprocal. The visual synthesis of our findings does not represent the influence of 'child well-being' on 'familial support' and 'SLT service provision'. Only one SLT mentioned that the child's response to communication problems (i.e. 'coping style') may influence how parents react (i.e. 'responsive caregivers'). Furthermore, we did not find any mention of the influence of child or family factors on SLT service provision. Furthermore, the graphical representation of the data indicates a lack of consideration for the impact of SLT service provision on familial support. This may be due to the focus group questions being solely directed towards identifying factors that affect the communicative participation of children themselves. Alternatively, it could suggest that SLTs may not fully recognise the role of the family and community in intervention. To achieve optimal collaboration with parents in therapy, SLTs need to become more aware of parents' perspectives. This will enable them to adopt a family-centred approach to therapy.

Limitations

Although research suggests that data saturation can be achieved in relatively few focus groups, a minimum of three groups has been suggested instead of the two that we conducted (Hennink et al., 2019). This small number of focus groups means that some themes may have been missed. However, the associations between subthemes within each theme indicate a satisfactory degree of data saturation. In addition, we conducted two pilot focus groups. The pilot focus group participants' responses aided in the development of a topic list and approach that generated rich narratives on how personal and environmental factors influence communicative participation. These narratives provided valuable insight into the experiences of speech and language therapists. One limitation of this study is that only four SLTs participated in the second focus group, while the intention was to include six to eight SLTs (Hennink et al., 2010). The COVID-19 pandemic led to the implementation of a lockdown, which resulted in the second focus group being conducted online instead of in person. Conducting a focus group online was a new experience for both the moderators and participants. Therefore, before commencing the focus group, we paid attention to the etiquette for online discussions. In hindsight, the smaller number of participants did not impede group discussion. It is noteworthy that the participants in this online focus group took longer speaking turns than the SLTs in the pilot focus and the first focus group. We now believe that conducting online focus groups with four to five participants may be an appropriate way to include a wider range of experiences and perspectives of professionals with busy schedules.

Clinical implications

To support communicative participation, it is crucial for SLTs working with children with DLD to comprehend that personal and environmental factors can facilitate or hinder communicative participation. Our study on SLTs identified several themes and subthemes that are also perceived as relevant by children with DLD and their parents in qualitative research. These themes and subthemes include: 'child well-being', 'coping style', 'self-image', 'past experiences with communication', 'SLT service provision', 'preparing for real-life situations' and 'familial support'. The current SLT service delivery in the Netherlands focuses on individual children. The results from this study illustrate that SLTs need to embrace family-centred care and collaborate with both parents and children. Based on our study, we recommend a comprehensive approach to treating children with DLD. This approach should address all relevant contextual barriers and facilitators to achieve optimal communicative participation for children with DLD.

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Data availability statement

Data available on request due to privacy/ethical restrictions.

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Chapter 7

General discussion

The main goal of this dissertation is to generate knowledge and to develop tools that strive to include the context of children with developmental language disorder (DLD) into speech and language therapy. This aligns with a paradigm shift in speech and language therapy, that moves the focus from a child's impairments to an emphasis on their communicative participation in meaningful contexts at home, school, and in the community. We explored this topic by investigating three touchpoints between the contexts of children with DLD, and speech and language therapy. In a Delphi study, we examined the concept of communicative participation from the perspectives of parents and professionals, aiming to clarify which participation goals can be effectively addressed by speech and language therapy. Next, we developed a tool that could help speech and language therapists (SLTs) to include parents in the decision making on therapy goals for communicative participation. Finally, we investigated the personal and environmental factors that may affect the attainment of communicative participation goals in a scoping review and in focus groups with SLTs. This general discussion provides an overview of the main findings of each chapter, a discussion of those findings, methodological considerations, recommendations for implementation and further research, and final conclusions.

MAIN FINDINGS

Chapter 2 reports on a Delphi study in which a multidisciplinary panel reached consensus on the definition of communicative participation. Parents, young adults with DLD, teachers and assistants, SLTs, clinical linguists and clinical researchers agree that communicative participation means “*understanding and being understood in a social context using verbal and nonverbal communication skills.*” The results of the Delphi study suggest that our panel conceptualises communicative participation in the same way as the international research community that uses Eadie's (2006) definition of communicative participation: "*Taking part in life situations in which knowledge, information, ideas or feelings are exchanged. It may take the form of speaking, listening, reading, writing or non-verbal means of communication*". In addition, thirty-three behavioural items were developed to describe specific aspects of communicative participation that reflect potential therapy goals. The definition and operationalisation of communicative participation resulting from this study provide a clear framework and a common language for professionals and parents to use when discussing children's communicative participation.

Chapter 3 describes the co-design development of a tool to support SLTs in engaging parents of children with DLD in collaborative goal setting. The behavioural items from the Delphi study are incorporated into a prototype of the tool, called ENGAGE, which is an acronym for ENgaging parents in Goal Articulation and Goal Evaluation. The tool consists of a metal 'tree trunk' onto which parents can stick magnetic 'leaves' containing potential communicative participation goals for their child. ENGAGE is a conversation tool that facilitates discussions between SLTs and parents about their child's language and communication in various contexts by offering a systematic approach using a 'development tree' and items on leaves. The tree shape symbolises children's growth and development and is based on a drawing of a tree made by SLTs during a co-design workshop. The drawing shows basic communication skills at the root of the tree and more complex skills higher up in the branches. The magnetic leaves are inspired by findings from another co-design workshop, which gave us the insight that handing parents a card with a specific topic, encourages SLTs to sit back and listen more attentively to the parents' input. This study provides an example of co-design research, emphasising the involvement of stakeholders in the development of new tools for speech and language therapy.

While chapter 3 discusses the need for, and development of the ENGAGE tool, **chapter 4** focuses on its application in clinical practice. Experts in DLD have raised concerns that language intervention descriptions in research reports often are too generic, lacking specific details about tasks and techniques (Law et al., 2003; Roulstone et al., 2015; Shobbrook et al., 2024). This inconsistency in reporting hampers implementation, replication, and knowledge advancement in DLD treatment (Frizelle et al., 2023; Law et al., 2003; Roulstone et al., 2015). To address this, **chapter 4** provides a detailed description of the ENGAGE tool using the twelve items from the Template for Intervention Description and Replication (TIDieR) checklist, aiming to enhance transparency and understanding for clinicians and researchers. In this chapter, we present Elwyn et al.'s (2012) shared decision making (SDM) model as a theory that forms the basis of the intervention ENGAGE. The absence of goal setting in this and other SDM models has been criticised by clinicians for its importance in treatment planning (Elwyn & Vermunt, 2020). The development of ENGAGE, from 2016 to 2018, coincided with evolving SDM thinking. In 2020, Elwyn & Vermunt introduced an updated SDM model emphasizing collaborative goal setting, especially for complex conditions such as DLD. This shift reflects the essential role of goal setting in SDM. ENGAGE, co-designed and usability-tested with SLTs, aligns with SLTs' aspirations for shared goal setting with parents, mirroring the evolving SDM understanding within Elwyn's research group.

Chapter 5 describes a scoping review of contextual factors associated with communicative participation. Knowledge of these factors can help SLTs to understand how the child's and family's context influences communicative participation. Examples of personal risk factors identified in research studies are reaching adolescence, having poor socio-cognitive skills, and having comorbid mobility impairments or behavioural problems, while personal protective factors are being of preschool age (for girls only), reaching school age, and being prosocial. Non-verbal IQ and gender after the preschool years are not associated with communicative participation, and the impact of social-emotional functioning is inconclusive. Speech and language therapy and participation in early learning programmes are protective environmental factors, as is a positive early language and communication environment at home. The evidence on the impact of socio-economic family variables is inconclusive. There are gaps in understanding how co-occurring health conditions, social background variables, individual psychological strengths, interpersonal relationships, and other people's attitudes affect outcomes. There is also a lack of information on the comparative effectiveness of distinct types of intervention and service delivery models, and on the influence of administrative control, organisational mechanisms, and government standards on children's communicative participation.

Chapter 6 describes a qualitative study with focus groups with thirteen SLTs to explore their perspectives on contextual (environmental and personal) factors affecting communicative participation in children with DLD. SLTs identified the child's wellbeing as a key personal factor, and family support and SLT service provision as key environmental factors. SLTs emphasised the importance of the interaction between the child and their environment, and they also advocated a holistic approach to therapy and case management. The study suggests that recognising the potential mediating role of contextual factors is essential and highlights the importance of addressing both personal and environmental barriers and facilitators in speech and language therapy services.

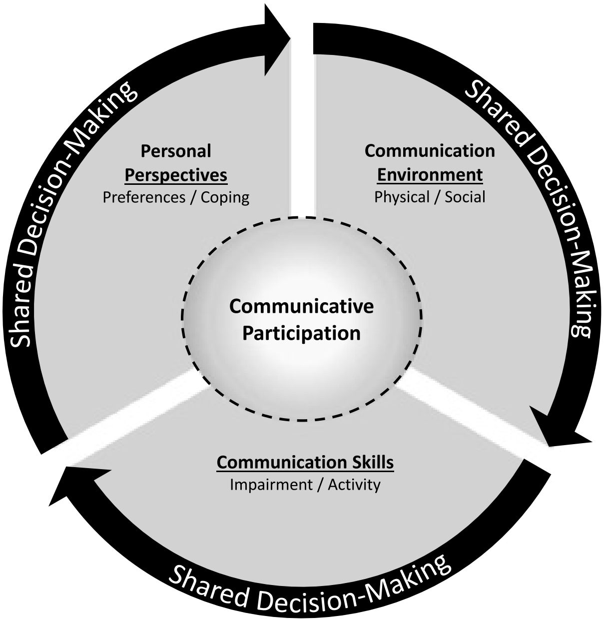
DISCUSSION OF THE MAIN FINDINGS

A shift towards participation focused speech and language therapy

Our studies were conceptualized using the ICF-CY framework (WHO, 2007), which links participation to the components body functions and structures (the child's physical and mental health functions), activities (the execution of tasks or actions), and contextual factors (personal and environmental influences). The different components interact to shape the level and quality of a child's participation. The ICF-CY (WHO, 2007) was developed to provide a universal language for documenting health and disability in children and youth. However, the ICF-CY has been criticized for being overly complex and difficult to use in practical settings. Health professionals may find it challenging to clarify distinctions between activities and participation, which can lead to a default focus on impairment without incorporating clients' personal viewpoints and taking the role of the environment in account (Baylor & Darling-White, 2020). Different authors have tried to disentangle the constructs of activities and participation, while accounting for the role of the environment. Holsbeeke et al. (2009) distinguish between the concepts of capacity (what a person can do in a standardized, controlled environment), capability (what a person can do in his/her daily environment), and performance (what a person actually does in his/her daily environment). This distinction is intended to guide decision making towards the focus of the intervention, while emphasizing the importance of contextual factors that influence participation in daily life (Holsbeeke et al., 2009). Likewise, the Family of Participation-Related Constructs (FPRc), developed by Imms et al. (2017), was created to further clarify the activities and participation component of the ICF-CY for research and clinical practice. Imms et al. (2017) distinguish between two aspects of participation: attendance and involvement in life situations. Attendance is necessary for involvement, but the level of involvement can vary in terms of engagement, sense of belonging, and the perceived importance of the activity. Recently, the FPRc has been used to explore the relationships between participation, interventions, and outcomes. Granlund and Imms (2024) emphasize that achieving sustainable participation outcomes through intervention requires creating a learning experience in which children and families actively engage at every stage. This includes shared decision making on intervention goals, intervention planning, delivery, and evaluation (Granlund & Imms, 2024). The ideas of Imms et al (2017) and Holsbeeke et al. (2009) are further explored in the participation focused intervention framework developed by Baylor and Darling-White (2020), which employs the ICF-CY concepts to guide participation-focused intervention practice. Communicative participation has gained increasing interest in speech and language therapy internationally and is now recognized as the primary therapy goal for children with DLD (e.g. Cunningham et al., 2017; NVLF, 2022). Baylor and Darling-White (2020) place communicative participation at the core of therapy. They emphasize that specific communication skills, environmental factors, and personal perspectives collectively support communicative participation. The role of shared decision making in the framework is similar to Granlund's and Imms' (2024) idea of active involvement of children and families in every stage of intervention planning to achieve lasting outcomes. The circular design of the Baylor and Darling-White (2020) model symbolizes the absence of a hierarchical structure among communication skills, the communication environment, and personal perspectives, highlighting that each element warrants equal consideration and can mutually influence one another (Figure 1).

Figure 1

The framework proposed by Baylor and Darling-White (2020) to guide participation-focused intervention practices



The studies in this thesis support five important assumptions underpinning the Baylor and Darling White (2020) model. Firstly, communicative participation is central to the model and informs therapy goals. This assumption is in line with the general aim of this thesis (chapter 1) to improve communicative participation of children with DLD through shared goal setting with parents. This overarching aim is based on the premise that parents often seek professional help because they are concerned about how their child's DLD affects the activities they want and need to do in their daily lives (Cunningham et al., 2017; Hidecker, 2010; Lyford Jones, 2010; Prelock et al., 2008; Roulstone et al., 2012). Understanding these wants and needs regarding communication in daily life should be the starting point of therapy for children with DLD. This also supports the placement of communicative participation at the heart of the Baylor and Darling-White (2020) model.

Secondly, the definition from our Delphi study (chapter 2) emphasises the supportive role of language and communication skills for communicative participation as suggested in the Baylor and Darling-White (2020) model. The communication skills element in their model combines the ICF-CY concepts of body function and structure (e.g., language impairment) along with activity (the ability to communicate and to perform cognitive tasks). In our Delphi study, parents, young adults with language disorders, and professionals reached a consensus on defining communicative participation as: ‘understanding and being understood in a social context, by applying verbal and non-verbal communication skills’ (Singer et al., 2020). Both in this definition, and in the Baylor and Darling-White model (2020) communication skills sustain communicative participation outcomes. Traditionally, the communication skills component, including language skills, has been a major part of speech and language therapy work. While this work remains important, SLTs may mistakenly expect that skill improvements will automatically enhance communicative participation (Baylor & Darling-White, 2020). However, research shows the relationship between language skills and communicative participation is neither straightforward nor linear (Cunningham et al., 2019; Conti-Ramsden & Durkin, 2015; Gerber et al., 2011; Rosenbaum & Gorter, 2012). Rather than targeting a broad range of language skills, focusing on specific language functions that complement and support individualised communicative participation goals can help transfer skills for use in everyday life.

Thirdly, our tool ENGAGE (chapters 3 and 4) links parents’ perspectives with communicative participation goals through SDM. This aligns with a key message in the Baylor and Darling-White (2020) model, which emphasizes the importance of SDM for participation-focused intervention. While studies on SDM have been increasing over the years, the absence of goal setting as an explicit step in SDM models has been criticised by clinicians because goals play a vital role in treatment planning (Elwyn & Vermunt, 2020; Lu, Li, & Yang, 2019). Developing SDM strengthens the idea that supporting effective communication between parents and clinicians about treatment goals is crucial for guiding participation-focused intervention in speech and language therapy. In our co-design study, the tool ENGAGE was developed to support collaborative goal setting for children with DLD by providing a structure for discussing the abstract concept of communicative participation with parents while supporting parent engagement in goal setting. Co-designed with SLTs, it incorporates SLTs view of SDM for realising participation focused therapy. This is a strong indication of the relevance of the SDM component in the Baylor and Darling-White (2020) model.

The fourth assumption in the Baylor and Darling-White (2020) model that is supported in this thesis, is that environmental factors influence communicative participation. Baylor and Darling-White (2020) describe how environmental factors relating to the physical and social communication environment may affect communicative participation. In our focus group study (chapter 6), we found supporting evidence of the importance of family support, and surroundings and experiences that provide opportunities for communicative participation for children with DLD. In addition, our scoping review (chapter 5) identified a positive early language and communication environment as a positive factor for communicative participation. However, it also identified substantial knowledge gaps regarding the role of interpersonal relationships and attitudes of other people for communicative participation of children with DLD.

The fifth and final assumption in the Baylor and Darling-White (2020) model is that personal factors influence communicative participation. The personal perspective as outlined in Baylor and Darling-White (2020) is a reinterpretation of the personal factors' component of the ICF-CY (WHO, 2007) that draws attention to the importance of understanding an individual's response to the communication disorder. Like Baylor and Darling-White (2020), SLTs in our focus group study (chapter 6) highlighted the importance of adequate coping skills and a positive self-image for communicative participation. However, in our scoping review (chapter 5) we also identified substantial knowledge gaps about the influence of individual psychological assets.

The findings from the different studies in this thesis highlight the importance of considering children's contexts in therapy in order to optimise communicative participation for children with DLD. Participation-focused interventions should extend beyond addressing language deficits by including children's contexts. Our research can help to identify potential intervention targets related to communicative participation, as well as to the communication environment or the personal perspectives that support communicative participation in children with DLD. Due to the lack of standardised measures for environmental factors, these aspects cannot be easily measured in a reliable and valid way. However, they can be discussed with parents. Similarly, given the diversity of personal responses to communication difficulties, and the absence of standardized measures, SLTs will continue to use non-standardized methods for assessing personal perspectives. Unfortunately, our ENGAGE tool does not explicitly address personal perspectives or the communication environment into the SDM process for setting communicative participation goals. In retrospect, it would have been better to develop the ENGAGE tool after we had explored and identified the critical role of contextual factors (chapters 5 and 6). This would have made it possible to include contextual factors, such as optimising the communication environment at home or increasing the child's confidence as a communicator, in a discussion of goals with parents. The fact that contextual factors are not included in the ENGAGE tool needs to be addressed in the further implementation of ENGAGE in clinical practice. Therefore, after identifying a specific communicative participation goal (e.g., asking questions in class), SLTs and parents could collaboratively examine how the communication environment and personal perspectives function as barriers or facilitators towards achieving this goal.

In summary, in the Baylor & Darling-White (2020) framework, communication skills, communication environment, and personal perspectives are arranged around communicative participation to indicate their supportive function in participation-focused interventions. Our work substantiates this framework, while the findings from the studies in this thesis provide specific insights into which contextual factors may influence communicative participation and how SLTs can collaborate with parents to set communicative participation goals. These results may prove valuable in training SLTs and SLT students to implement participation focused intervention.

Adopting a participation-focused approach to assessment and intervention involves shared decision-making at every stage of an intervention and requires SLTs to consider the child's context. Based on the findings from the studies in this thesis we hypothesize that therapy tailored to the unique needs and circumstances of each child is more likely to lead to more relevant outcomes. However, this hypothesis needs to be tested through further research.

The relation between family-centered care and communicative participation

A strong focus on communicative participation in assessment and intervention cannot be realised without collaboration between SLTs and the parents and children whom they serve. Often, clinicians regard child-centered work as a priority, dedicating their limited time to engage directly with children (Klatte, et al., 2024). This implies that the transition to a participation-focused approach cannot happen without the transition to family centered care (FCC). FCC operates on the principle that a child's well-being is most effectively addressed within the family context, recognizing parents as experts on their child's abilities and needs (Kokorelias et al., 2019; McCarthy & Guerin, 2022). Therefore, it is essential to include parents in therapy, as their involvement ensures a more comprehensive and effective approach to addressing the child's needs.

The lack of SDM between SLTs and parents regarding treatment choices in general, and goals in particular, has been a significant challenge for participation-focused intervention planning in speech and language therapy. A systematic review suggests that family-centered, collaborative methods of selecting therapy goals can clarify family priorities and improve engagement (Burney, McCann, & Arnold-Saritepe, 2024). Open conversations with families during goal setting are essential for building collaborative relationships, while involving parents in intervention planning allows treatment goals to be integrated into daily routines, providing frequent, meaningful practice opportunities (Cunningham & Rosenbaum, 2015). FCC is also critical for considering relevant personal and environmental factors in treatment. Daily routines within the family, the type of activities they engage in, the toys and games their child takes an interest in, and parents' views on language and communication development are examples of potentially relevant contextual factors that can best be understood through and with the parents. Therefore, information from the parents is necessary to tailor the therapy to the abilities and needs of both the parents and the child.

Another principle of FCC is involving parents in SDM (King & Chiarello, 2014). By including parents in SDM, SLTs can ensure that the therapy goals are not only clinically appropriate but also aligned with the family's priorities and daily life. This collaborative approach fosters both decision-making, and the active involvement of parents in the therapy process, leading to more meaningful and sustainable outcomes.

In summary, a prerequisite for achieving participation-focused, context-aware speech and language therapy for children with DLD is for speech therapists to embrace the principles of FCC.

METHODOLOGICAL CONSIDERATIONS

There is an increasing emphasis on stakeholder involvement throughout the entire research process, highlighting the importance of co-creation from the very beginning to the end of a project. Patient and public involvement in research enhances the quality and applicability of studies by incorporating valuable insights from patients' experiences, identifying barriers and facilitators to treatment adherence, meeting their needs and preferences, and improving the dissemination of findings, ultimately leading to more effective interventions, and reduced healthcare costs (Arumugan et al., 2023).

A methodological consideration relating to patient and public involvement concerns our effort to give all relevant stakeholders a voice. We had varying degrees of success in the different studies. Young people with DLD participated in the conceptualisation of the Delphi study and the co-design study, but parents and SLTs did not. The Delphi study involved parents, professionals, and young people with DLD as participants, but not in the design and implementation of the study. The co-design study involved SLTs as co-design participants, but not parents. Parents were only involved in usability testing. Neither parents nor SLTs participated in study design and implementation. SLTs engaged in the conceptualisation and study design of the scoping review and in the conceptualisation of the focus group study, but not parents or young people with DLD. SLTs, teachers and SLT researchers reflected on the findings of the scoping review, but parents and young people with DLD did not do this. Finally, SLTs were included as participants in the focus group study. The relevance of the findings was discussed with parents of children with DLD, but not with SLTs or other professionals.

Since the inception of the first study in this thesis in 2016, health care research has evolved significantly. Moreover, our understanding of the importance of facilitating patient and public involvement has evolved, which resulted in co-creation with stakeholders. Over time, we have developed a better understanding of co-design methods versus qualitative research methods. We now understand that while co-design or other participatory research methods may require considerable time from participants and researchers, and may feel like a detour, it is crucial to include parents and children in future research. We have experienced that relevant stakeholders can be involved in every research study or project, from design to implementation. If we were to undertake comparative research now, it is hard to imagine doing so without extensive involvement of SLTs, parents and young people with DLD. Setting up an independent advisory panel of parents, young people, SLTs and other professionals can be an effective way of representing stakeholders throughout a research project.

A related methodological consideration is that, despite our intentions to give equal voice to SLTs and parents, opportunities to hear parents' voices may have been missed in our studies. An example of this is the use of the Delphi method in a consensus building process. Whilst this method is valuable, it is highly language dependent and seems less suitable for involving parents who may themselves have language difficulties. It seems more appropriate for use with professionals, as surveys can be answered at the convenience of the respondent but require considerable effort to read and formulate arguments. The advantage of using an interactive method such as an interview over a survey is that you can tailor the conversation to every specific interviewee, check whether they understand and ask deeper questions. Parents' involvement in defining terms was highly valuable in our Delphi study, but future research could seek their input through interactive methods such as interviews. Moreover, by exclusively focusing on quantitative research designs in our scoping review of factors influencing communicative participation, we may have inadvertently overlooked the perspectives of parents. Although we identified studies on parents' and children's perspectives, we excluded them to focus on retrospective or longitudinal designs linking early childhood factors to later outcomes. Eventually, we did review the qualitative literature, that highlighted parents' and children's views on child well-being and familial support. In quantitative studies, parents and young people were respondents filling out questionnaires, and they did not identify which factors were most relevant for parents and children. We now believe that excluding qualitative studies may have obscured important insights from parents and children and including it would have been beneficial. A final example of parents' voices being overlooked in the way in which we conducted the co-design process that led to the development of ENGAGE. Particularly in the field of communication disorders, involving parents, young people and SLTs together in a highly language-dependent research project can be challenging. Co-design is an effective approach to design issues, tapping into implicit knowledge and using less language-dependent methods, making it suitable for involving people from diverse backgrounds. The co-design method, which has not previously been used in this context, demonstrates that co-designing interventions with practitioners can be effective in influencing behaviour and practice. By demonstrating this approach, we hope to inspire other researchers to involve end-users in the development process, thereby creating more relevant and user-centred tools.

While children's and young people's voices are largely absent in this work, we aim to give them a voice in future research projects whenever their linguistic and cognitive abilities allow them to do so. Although it is challenging to define an exact age at which children can self-report, it has been suggested that children from the age of 5 years are able to do that (Varni et al., 2007), although this age limit may be slightly higher for children with language problems (Alons et al., 2024). In addition, we wish to explore how we can collaborate with young people with DLD and their parents as co-researchers. Both aspirations lead to unique ethical challenges about roles, expectations, and inclusion (Aussems et al., 2022) and both researchers and young people with DLD and their parents might benefit from training to develop knowledge, confidence, and skills to work together as research partners (Dong et al., 2023). Developing new and tailored approaches to involve young children with DLD in research is crucial. Successful inclusion of children with communication difficulties in research has been realised by carefully adapting interview methods to meet the needs of young children (Ponyzovsky-Bergelson et al. 2019), and by combining talk-based methods with visual or art-based methods such as drawings, photo- and videography, and techniques such as rank sorting tasks (Lyons et al., 2022).

In conclusion, integrating diverse stakeholder voices, especially those of parents and children, is essential for creating more inclusive and effective research methodologies in the field of communication disorders.

WHAT IS NEEDED TO INCLUDE CHILDREN'S CONTEXTS IN SPEECH AND LANGUAGE THERAPY?

Insight into contextual factors enables SLTs to tailor interventions to address specific barriers and facilitators in a child's environment, thereby increasing the effectiveness of therapy. SLTs can be supported in including children's contexts through the development of practical interventions and tools, such as ENGAGE. ENGAGE has been developed to support SLTs in collaborating with parents by discussing relevant therapy goals and promoting an active partnership. The tool has been available for clinical practice since 2019 and has since then been purchased (at a retail price of € 98,50) by more than three hundred Dutch SLT practices.

The service design approach utilized in the development of ENGAGE has been linked to improved implementation in clinical practice, because it thoroughly analyses the entire decision-making process and comprehensively addresses the needs of all stakeholders involved (Sañudo et al., 2024). In addition, the co-design development of ENGAGE included testing the tool in practice, which has been identified as a strategy associated with successful implementation (Van Beest, et al., 2022). However, implementation of the tool has been fragmented and is likely to have reached practitioners who are already at the forefront of delivering FCC and participation-focused interventions. The extent to which tools such as ENGAGE can encourage inclusion of children's contexts in therapy needs further research. In addition, tools are needed to measure and evaluate communicative participation. Recent developments towards this goal are the development of a parent- and teacher-reported instrument to measure communicative participation in children aged 6-12 years with DLD (Auris, n.d.) and an item bank to measure self-reported communicative participation in children aged 6 years and older (Alons et al., 2024). Finally, tools are needed to help SLTs gain insight into the personal and environmental factors that shape a child's communicative participation. Currently, no tool or method identifies the environmental factors relevant to DLD, because existing tools such as PEM-CY (Coster et al., 2011) focus on the physical environment rather than the social communication environment. Tools to identify personal factors are completely outside the realm of speech and language therapy.

The F-words framework (Rosenbaum & Gorter, 2012), based on the ICF, can be used as a stepping stone for translating the evidence on contextual factors associated with communicative participation into clinical practice. It can help SLTs and parents to address all aspects necessary to incorporate the child's context into therapy. The F-words framework provides a holistic perspective that encompasses key areas of child development: Function, Family, Fitness, Fun, Friends, and Future (Rosenbaum & Gorter, 2012). Five F-words were plotted on the ICF-CY (Figure 2): Friendships, Fun, Family, Fitness, and Function, while the sixth' F-word has been added to the figure.

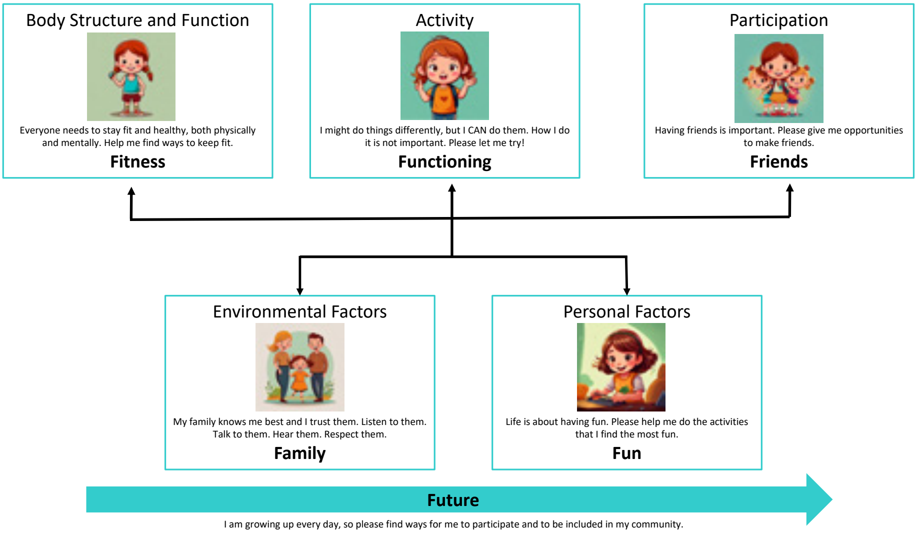
Our first F-word, Friendships, is closely related to the ICF-CY component of participation, or communicative participation for children with DLD. The definition that we developed with parents and professionals emphasises that communicative participation takes place in a social context, including friendships with peers. This finding is supported by qualitative research with parents and children which highlights the importance of belonging and inclusion. Our second F-word, Fun, refers to the ICF-CY component of personal factors. It refers to what the child enjoys doing, and it is closely related to the well-being factor identified in the focus group study with SLTs and to the social-emotional skills factor identified in the scoping review. Our third F-word, Family, refers to an environmental factor, as the family is an important context in young children's lives. This is supported by the results of our focus group study, where SLTs identified familial support as one of the most important contributors to communicative participation of children with DLD. This is further supported by the scoping review which identified the early language and communication environment as an environmental factor influencing communicative participation. Our fourth F-word, Fitness, refers to the ICF-CY component of body functions and structures. Discussing fitness with parents can shed light on the child's mental and physical health, a personal factor identified by SLTs in our focus group study as important for communicative participation.

The F-words Function and Future do not relate directly to children’s context. Our fifth F-word Function (or Functioning) is connected to the Activity level of the ICF-CY. For children with DLD this means language and communication skills. As suggested in the Baylor and Darling-White’s (2020) participation focused intervention framework and supported by SLTs in our focus groups study and the results of the scoping review, developing relevant language and communication skills can be beneficial for children’s communicative participation. Finally, our sixth F-word, Future, is not included in the ICF framework. It refers to growth and development across the lifespan. This idea connects perfectly with shared goal setting, as supported by the ENGAGE tool that was developed in this project.

The F-words framework could serve as an accessible way to provide a contextualised approach to speech and language therapy. The F-words have been translated into Dutch, as favourite words (Gorter, 2019). They cover the most key factors that influence communicative participation of children with DLD, while allowing for a flexible incorporation of new research results. They are easy to remember and easy to use in open conversations with parents. We propose that applying the 'F-word' framework at the clinical level will enable service providers to integrate each child's unique issues and strengths into therapy, thereby personalizing interventions. SLTs can integrate the F-words into their clinical work with families by using it to guide assessment and goal setting, ensuring that therapy is holistic and considers the child's overall wellbeing. They could involve families in planning interventions that address relevant F-words, document progress in these areas, and familiarise families with the framework to support their child's development. A new tool, grounded in the F-words framework, could be developed in co-creation with stakeholders to translate the findings from our scoping review and focus group study to practice (Ketelaar et al., 2024). More than ten years of implementation efforts using multiple strategies in partnership with families and service providers have supported the use of the F-words worldwide (Cross et al., 2022).

Figure 2

The F-words plotted on the ICF framework. Adapted from Rosenbaum & Gorter (2012)



Everyone needs to stay fit and healthy, both physically and mentally. Help me find ways to keep fit.

I might do things differently, but I CAN do them. How I do it is not important. Please let me try!

Having friends is important. Please give me opportunities to make friends.

My family knows me best and I trust them. Listen to them. Talk to them. Hear them. Respect them.

Life is about having fun. Please help me do the activities that I find the most fun.

I am growing up every day, so please find ways for me to participate and to be included in my community.

TOWARDS CHANGE OF PRACTICE

The shift towards participation-based practice and FCC in everyday practice of speech language therapists does not happen by itself. It requires carefully planned strategies to change practice and sustained monitoring. This can be achieved by conducting an implementation project informed by implementation science.

The primary implementation strategy of training for (future) professionals is to develop the necessary knowledge, attitudes, and behaviours. Implementation in SLT training and education can be achieved by co-creating useful materials and playful reminders to support SLTs in adopting a family centered and participation focused approach. New course material can be developed, or new knowledge can be added to existing bachelor courses. Training may also include the use of tools that have already been developed to support FCC and participation focused interventions, such as ENGAGE. Training and implementation strategies could be continuously updated to include tools and knowledge that have yet to be developed, such as participation-based measurement instruments and knowledge (products) based on the F-words framework. Deepening students' and SLTs' understanding of SDM, FCC and participation focused intervention as guiding principles, can help to reshape professional identities and attitudes necessary for providing contextualized speech and language therapy.

Another implementation strategy includes raising awareness of FCC among (future) SLTs. While FCC principles are still absent in the 2017 evidence-based guideline on DLD (NVLF, 2017), the professional standard for Dutch SLTs emphasises the importance of collaboration with clients and parents and highlights the importance of communicative participation as an outcome (NVLF, 2022). Similarly, the inclusion of family-centered and participation-focused approaches in disorder-specific guidelines, such as the forthcoming monodisciplinary guideline on DLD in 2025, can help SLTs see these practices as best practices.

Policy makers need to support (future) SLTs to work in a family-centered way and to optimise collaboration with parents by emphasizing the importance of collaboration and implementing necessary changes. Policy changes would preferably allow for flexible service delivery models, enabling effective collaboration between SLTs and parents. This could include lobbying for health insurance recognition and funding for family-centred SLT approaches, such as reimbursing SLTs for parent-focused sessions. To support these efforts, the monodisciplinary DLD guideline could be adapted to emphasise FCC as a guiding principle, incorporating the child's context and collaborative goal setting with parents.

A final implementation strategy concerns the empowerment of parents. Parents could be empowered to the extent that they find it acceptable and helpful to be involved in treatment. This can be achieved by highlighting the importance of their involvement in reliable sources of information on DLD for parents, and by working with parent associations for children with DLD.

Implementation efforts can be effectively guided by the Knowledge-to-Action (KTA) framework (Graham et al., 2006). This framework provides a systematic process for translating research findings into practical applications that promote behaviour change. The KTA framework integrates elements from over 30 theories of planned action, forming what is known as the action cycle. It also includes a knowledge creation component: the knowledge creation cycle. Importantly, it adopts a systems perspective, placing knowledge creators and users in a dynamic, adaptive, and unpredictable knowledge system. Consequently, the transition from knowledge to action is a complex, iterative, and dynamic process.

An implementation project should monitor both proximal and distal outcomes. Proximal outcomes include awareness, knowledge, attitudes, and behaviours among (future) speech therapists regarding family-centered care and participation-focused intervention. Distal outcomes can be evaluated by assessing communicative participation, family empowerment, and adherence to DLD guidelines in a longitudinal cohort study with baseline and follow-up assessments, e.g., every six months over the course of 2-4 years. Data could include parent- and child-reported measures of communicative participation (COPE, Alons et al., 2024; COMPARe, Auris z.d.), parent-reported questionnaires on family centeredness (e.g., Measure of Processes of Care, MPOC; Woodside, Rosenbaum, King, & King, 1998), family empowerment (Family Empowerment Scale, FES; Koren, DeChillo, & Friesen, 1993), attitudes and behaviour of healthcare providers (e.g., through interviews, video interaction analysis or intervision), and care plan reviews, with both quantitative and qualitative analyses conducted to assess the outcomes.

FURTHER RESEARCH

This thesis has focused on bringing the children's contexts into speech and language therapy. We developed a definition of communicative participation with parents and professionals (chapter 2) and a tool for shared goal setting that SLTs can use with parents (chapter 3 and 4). We identified personal and environmental factors that may influence communicative participation in children with DLD (chapter 5 and 6). However, our scoping review (chapter 5) also revealed significant knowledge gaps in the impact of context factors, such as individual psychological assets, co-occurring health conditions, social background variables, interpersonal relationships, and the attitudes of others on outcomes. Additionally, there is a lack of information on the comparative effectiveness of various intervention types and service delivery models, as well as the influence of administrative control, organizational mechanisms, and government standards on children's communicative participation. These gaps highlight the need for further research.

Furthermore, SLTs identified the child's well-being as a crucial personal factor, while family support and SLT service provision were seen as key environmental factors (chapter 6). They also emphasized the importance of the interaction between the child and their environment and advocated for a holistic approach to therapy and case management. The findings from this study suggest that recognizing the potential mediating role of child well-being and familial support is essential.

Based on the findings from our scoping review and focus group study we hypothesize that therapy tailored to the unique needs and circumstances of each child is more likely to lead to more relevant outcomes. However, further research is needed to test this hypothesis.

Our project emphasized the critical role of parents and SLTs in integrating children's contexts. However, it is imperative to conduct more research on how the voices of (young) children with DLD can be effectively incorporated into both research and clinical practice. Lyons et al (2022) advocate for practices and methodologies that prioritise children's voices in both research and clinical practice. Their work highlights the ethical and practical imperatives of giving children a voice in matters that affect them, leading to more effective and respectful therapeutic interventions. Developing methods and tools to include the voices of young children with DLD in research and clinical practice can have clear benefits. Including children's perspectives empowers and engages them, making them active participants in their treatment, which can increase motivation and engagement, leading to more effective interventions. In addition, understanding children's experiences and preferences allows for more personalised and contextually relevant therapeutic strategies, improving the overall impact of therapy on communicative participation. However, there are potential pitfalls with this approach. Developing methods to effectively incorporate young children's voices can be complex, particularly when children have communication impairments (Lyons et al., 2022). In addition, children's perspectives can vary widely and be influenced by their developmental stage, making interpretation and integration of their input challenging. Methods for incorporating children's views have tended to focus on older children and those who can communicate verbally. Recently, however, this gap has been addressed by researchers exploring methods to facilitate the voices of young children with and without developmental delays. Promising approaches focus on creative, participatory and arts-based qualitative methods, such as drawing and photography, combined with co-constructive exchanges to engage young children in research (Lewis-Dagnell, Parsons, Kovshoff, 2023; Tay-Lim & Lim, 2013) and care (Lambert, Glacken, McCarron, 2013; Lyons, et al., 2022; Schweiger, 2024). Ensuring the reliability and validity of innovative methods requires careful evaluation and reflexivity on the part of researchers and clinicians.

FINAL CONCLUSIONS

This research highlights the importance of including the child's context in therapy to achieve optimal communicative participation for children with DLD. Three main conclusions can be drawn:

1) Collaborating with parents of children with DLD involves setting joint goals for communicative participation, considering the child's language abilities, and addressing both personal and environmental factors.

2) Relevant contextual factors for children's communicative participation are their communicative environment, the support they receive and their well-being.

3) The integration of parents' and children's perspectives is crucial to enhance participation-focused interventions and family-centred care, and sets a precedent for future innovations in speech and language therapy.

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Appendices

NEDERLANDSE SAMENVATTING

Dit proefschrift richt zich op hoe logopedisten de communicatieve participatie van kinderen met TOS kunnen verbeteren door middel van gezamenlijke besluitvorming met ouders en door rekening te houden met de context van het kind. Het onderzoek is gebaseerd op het *International Classification of Functioning, Disability and Health, Children and Youth Version* (ICF-CY) raamwerk (WHO, 2007) en richt zich op de kernbegrippen taalontwikkelingsstoornis (TOS), communicatieve participatie, gezamenlijke besluitvorming en contextuele (persoonlijke en omgevings-) factoren. De verschillende studies richten zich op drie hoofdthema's, gerapporteerd in hoofdstuk 2 tot en met 6.

1. **Definitie van communicatieve participatie**
   Hoofdstuk 2 beschrijft een Delphi-studie waarin ouders en professionals overeenstemming bereikten over de definitie van communicatieve participatie: "*begrijpen en begrepen worden in een sociale context met verbale en non-verbale vaardigheden.*" Daarnaast werden 33 gedragsitems ontwikkeld om therapiedoelen te beschrijven. Dit biedt een gemeenschappelijke taal voor ouders en logopedisten om doelen voor communicatieve participatie van kinderen te bespreken.

2. **Samen doelen stellen met gesprekstool ENGAGE**.
   Hoofdstuk 3 beschrijft de ontwikkeling van ENGAGE, een tool voor het samen opstellen van gepersonaliseerde doelen voor kinderen met TOS. Dit hoofdstuk geeft een voorbeeld van co-design onderzoek, waarbij belanghebbenden intensief betrokken worden bij de ontwikkeling van nieuwe hulpmiddelen voor logopedie. Het resultaat van het beschreven co-design proces is ENGAGE; een metalen 'boomstam' met magnetische 'bladeren'. Deze tool kan logopedisten en ouders helpen bij het samen stellen van doelen voor de communicatieve participatie. **Hoofdstuk 4** geeft een gedetailleerde beschrijving van hoe de gesprekstool ENGAGE kan worden ingezet. Deze complete beschrijving aan de hand van de TIDieR checklist vergemakkelijkt het inzetten van de tool in de praktijk en in onderzoek.

3. **Invloed van contextuele factoren**
   Hoofdstuk 5 beschrijft een systematische scoping review naar contextuele factoren (persoonlijke en omgevingsfactoren) die de communicatieve participatie van kinderen met TOS beïnvloeden. Kennis van deze factoren helpt logopedisten te begrijpen hoe de context van het kind de communicatieve participatie bevordert of belemmert. Persoonlijke risicofactoren zijn adolescentie, zwakke

sociaal-cognitieve vaardigheden en bijkomende mobiliteits- of gedragsproblemen. Beschermende factoren zijn voorschoolse leeftijd (alleen voor meisjes), basisschoolleeftijd en prosociaal gedrag. De invloed van sociaal-emotioneel functioneren is onduidelijk. Omgevingsfactoren zoals een positief taal- en communicatieklimaat thuis, logopedie en deelname aan vroeg- en voorschoolse educatie zijn ook beschermend. De invloed van sociaaleconomische gezinsvariabelen is onduidelijk. Er zijn hiaten in kennis over de impact van bijkomende gezondheidsproblemen, psychologische karakteristieken, sociale achtergrond, interpersoonlijke relaties en de houding van anderen. Ook ontbreekt informatie over de effectiviteit van verschillende interventies en beleidsmaatregelen. **Hoofdstuk 6** beschrijft een kwalitatieve studie met focusgroepen met dertien logopedisten over factoren die de communicatieve participatie van kinderen met TOS beïnvloeden. Logopedisten benadrukten het belang van het welbevinden van het kind, gezinsondersteuning en logopedische diensten. Ze pleitten voor een holistische benadering van therapie, waarbij zowel persoonlijke als omgevingsfactoren worden meegenomen.

Conclusies

Dit onderzoek benadrukt het belang van het includeren van de context van kinderen met TOS in hun logopedische behandeling om de communicatieve participatie te optimaliseren. Er kunnen drie belangrijke conclusies worden getrokken:

1. Het samenwerken van logopedisten met ouders van kinderen met TOS omvat het samen stellen van doelen voor communicatieve participatie, rekening houdend met de taalmogelijkheden van het kind, en met persoonlijke en omgevingsfactoren.
2. Relevante contextuele factoren voor de communicatieve participatie van kinderen zijn hun communicatieve (thuis)omgeving, de ondersteuning die ze krijgen en hun welbevinden.
3. Het integreren van het perspectief van ouder en kind in de behandeling is noodzakelijk om participatiegerichte interventies en gezinsgerichte zorg te realiseren en geeft richting aan toekomstige innovaties in de logopedie.
4. Voor logopedisten betekent dit zij effectievere en meer op maat gemaakte therapie kunnen bieden door samen te werken met ouders en het perspectief van ouder als kind te integreren, wat leidt tot betere communicatieve participatie en welbevinden van kinderen met TOS.

Referentie

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ABOUT THE AUTHOR

Ingrid Singer was born on April 3rd, 1974, in Hoorn, the Netherlands. In 1992, she finished secondary school at RSG-West-Friesland in Hoorn (VWO). She completed her master's in communication science at the University of Amsterdam in 1997. Next, she worked in marketing communication and fundraising for profit and non-profit organisations in The Netherlands and in South Africa. She completed the BSc Developmental Psychology program at the University of Amsterdam and the BSc Speech and Language Therapy program at HU University of Applied Sciences Utrecht between 2008 and 2011. She has worked in the residential care setting for children and young adults with communication and cognitive impairments, and she worked also as an SLT in a primary care and in Special Education settings.

In 2014, Ingrid joined the HU research group Speech and Language Therapy - Participation through Communication as a junior researcher. In 2016, she received a grant from FNO - Zorg voor Kansen for her proposal for the Delphi study on communicative participation and the co-design development of a tool for shared goal setting with parent. In 2018 she received a PhD voucher from HU University of Applied Sciences Utrecht, which allowed her to become a PhD candidate at Utrecht University and to start her research project on contextual factors associated with children's communicative participation.

Throughout her doctoral research, Ingrid completed various courses and training, including the training 'Family Engagement in Research' at the University Medical Centre Utrecht, the Netherlands. She received a 2019 Comenius teaching fellow grant to develop an educational digital practice management game for speech therapists in training. She has since been the coordinator and a lecturer in this course. She is an extraordinary member of the Network of Amsterdam Speech Therapists, which focuses on collaboration between speech therapy organisations in primary healthcare. Her international network focuses on the topic of communicative participation.

Ingrid is driven by a passion for better care for people with communication disorders. She is committed to continuing her work in this field to improve education, policy, and practice.

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Award

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