

Supporting the Engagement of Siblings of AAC Users

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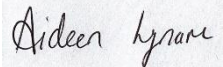
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Summary

Introduction

This research aims to increase understandings of how Speech and Language Therapists (SLT) can support sibling engagement with communication partner training interventions for children who use Augmentative and Alternative Communication (AAC). Siblings are core members of the family; they may have an close and longstanding relationship, spend a lot of time together, play a variety of roles in each other's lives, and influence one another's development. These features can lead to siblings being key communication partners for AAC users, yet they are an under-utilised resource in interventions. Siblings may benefit from training and support to become attuned communication partners effectively carrying out their sibling roles, for example that of a social play partner co-constructing communication in an interaction. Engagement with interventions is a key variable to consider when planning training interventions. Therapeutic engagement is a dynamic and co-constructed process relating to how an individual connects with a specific therapeutic intervention (e.g., communication partner training). Many factors may influence an individual's engagement with a specific intervention. These factors are specific to the individual situation, and the ways in which engagement can be supported depend on the context of the sibling, family, SLT and intervention. To the researcher's knowledge, there has been no previous research investigating sibling engagement with interventions and so not much information is known on how SLTs could best support the engagement of siblings with an intervention.

Methods

A framework of factors supporting sibling engagement with interventions was created through a review of the literature on engagement as it relates to therapeutic interventions. The framework allowed for factors to be categorised under two main principles – having a reciprocal and meaningful relationship and tailoring the intervention to siblings' needs and preferences. Additionally, the framework was surrounded by the family context, underpinning its relevance to all aspects of the framework. This framework served as the foundation for formulating research questions specific to the factors that impact engagement with a specific therapeutic intervention (i.e., communication partner training). To address these research questions and gain insights into how to support the engagement of siblings of AAC users, a convergent parallel mixed-methodology design was employed. Both qualitative and quantitative data were gathered through four distinct data collection methods: a systematic review of sibling involvement in interventions for

individuals with disabilities, a systematic review of peer communication partner training interventions, interviews with siblings of AAC users, and surveys of key stakeholders. The findings from these four data collection methods were subsequently analysed and interpreted to address specific research questions and to identify factors influencing sibling engagement in interventions.

Findings

Each of the four data collection methods rendered data which on analysis and interpretation contributed to the overall research aim of exploring how SLTs can support the engagement of siblings of AAC users in communication partner training interventions. The data from each data collection method were analysed separately and then synthesised and interpreted together to address the research questions of this study. One key finding of this research is the need for more sibling involvement in interventions – in previous studies and as reported by SLTs, siblings are often overlooked in communication partner training interventions. The findings describe several factors which may influence sibling engagement, including the nature of the sibling relationship, sibling roles, SLT beliefs and practices, individual learning styles as well as the content, setting, and timing of the intervention itself. Methods of supporting sibling engagement in practice are also outlined, with an emphasis on the need for an understanding of sibling and family experiences, needs, and preferences when facilitating interventions in order to recognise barriers to sibling engagement with an intervention. One final key finding is that sibling engagement with interventions may not always be beneficial or desired – some siblings may feel overburdened if the training gives them additional responsibilities, some may not have a close relationship with the AAC user, and some may have other demands on their time. A core underpinning of the findings is that meaningful collaboration with siblings and families is essential to effectively supporting the engagement of siblings of AAC users with communication partner training interventions.

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Abbreviations

AAC	Augmentative and Alternative Communication
ASD	Autism Spectrum Disorder
COVID-19	Coronavirus Disease 2019
HSE	Health Service Executive
IASLT	Irish Association of Speech and Language Therapists
IRD	Improvement Rate Difference
PA	Personal Assistant
PDD-NOS	Pervasive Developmental Disorder (not otherwise specified)
PDS	Progressing Disability Services
PECS	Picture Exchange Communication System
PIL	Participant Information Leaflet
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SGD	Speech Generating Device
SLT	Speech and Language Therapist
SNA	Special Needs Assistant
SPT	Stay, Play, Talk Intervention

Chapter 1: Introduction

1.1 Introduction

This chapter provides an orientation to this thesis. First, the research aim is outlined followed by a note on the terminology used in this thesis. Next, the context of the researcher and the influence of the COVID-19 pandemic on the research process are discussed. Finally, an overview of the thesis structure is provided.

1.2 Research Aim

This research aims to increase understandings of how Speech and Language Therapists (SLT) can support sibling engagement with communication partner training interventions for children who use Augmentative and Alternative Communication (AAC). There are several research questions associated with this aim which are detailed in Chapter 5.

1.3 Terminology

1.3.1 AAC User

Throughout this thesis, both identity-first (e.g., AAC user) and person-first (e.g., person with a disability) language are used. Identity-first language may be preferred by those who perceive the trait to be a core component of their identity, whereas person-first language puts the person before the disability, emphasising that a person is first and foremost a human being (Wooldridge, 2023). There is no consensus on which form of language should be used, and there continues to be some tension and debate around this (Dunn & Andrews, 2015; Vivanti, 2020; Wooldridge, 2023). The National Disability Authority recognises both terminologies (National Disability Authority, 2022) and recommends that a flexible approach is used, tailored to the preferences of the individual or group being referred to. Person-first language is suggested to be used as a default when preferences are unknown (Wooldridge, 2023). As such, person-first language is used throughout this thesis to refer to general cohorts of individuals with a disability. Identity-first language is used to refer to specific groups that have reported preferring this approach (e.g., autistic people, Botha et al., 2023; Taboas et al., 2023). The terms 'AAC user' and 'person who uses AAC' are both used across the literature (e.g., McNaughton et al., 2019; Moorcroft et al., 2019). However, little research has been completed exploring the terminology preferences of AAC users. One exception was an online survey which asked 556 people with relationships to AAC what their opinions were on 119 different words and phrases (Zisk & Konyn, 2022). It was found that the most

frequently liked term was 'AAC users', with over three-quarters of AAC users reporting to like or use the term. This term was followed by the term 'people who use AAC', with 65% of respondents liking or using the term. This survey provided the best evidence of the preference of a group of AAC users and as such, while there was not a large difference in reported preference, the most frequently used term –'AAC user' - was adopted for use in this thesis.

1.3.2. Engagement

The term engagement can mean various things, including engagement in interactions (Hahn, Brady, Fleming & Warren, 2016) or engagement (i.e., participation) with services in general (Chudyk et al., 2018). The term engagement as used in this thesis refers to, what I label as therapeutic engagement. This form of engagement encompasses how individuals interact and participate with a specific therapy intervention, for example primarily in this thesis, engagement is referred to as the process or state of a sibling participating in and collaborating with a communication partner training intervention. A greater overview of this concept is provided in Chapter 4, specifically section 4.3.1.

1.4 Researcher Context

I am a SLT, who even during my undergraduate degree always had an interest in AAC. During the initial stages of this research, I worked as an SLT in a disability service alongside many AAC users, both children and adults, and their families. There was one AAC user in particular, a teenager, whose young adult sibling was the primary service liaison for the AAC system. While the AAC user's parents were involved in other aspects of the service, they struggled to understand the high tech AAC system and so the sibling was recruited to help and support. It was the first time I encountered a sibling who occupied that role, and it caused me to reflect on my practice. Had I ever considered engaging with siblings as I would other familiar communication partners? I did not have to think too deeply, the answer was immediately 'no'. I had engaged with parents, teachers, personal assistants (PA), special needs assistants (SNA), other healthcare professionals, but never siblings. Discussions with other SLTs lead me to realise I was not an outlier. The involvement of siblings of AAC users in interventions while not unheard of, was not a common occurrence. Personally, I have two siblings who I am very close to. We have a quintessential sibling relationship; we grew up in the same household, spent a lot of time together as children, continue to keep in regular contact and look to each other for advice and support. When reflecting on my professional engagement with siblings, I also reflected on my own personal role as a sibling. I

concluded that, if either of my siblings were AAC users, I would want to help and support them however I could. This realisation led me to consider how I, and other SLTs, could support the engagement of siblings of AAC users in communication partner training interventions.

1.5 Research in the Context of COVID-19

This research journey had numerous false starts and the focus of my research shifted multiple times before settling on the current topic, due in part to the COVID-19 pandemic. The pandemic hit approximately a year and a half into my research journey. Social distancing measures were introduced, individuals were required to stay at home except for exceptional circumstances and the provision of food and exercise. As I was working as a SLT in the public health service (HSE) at the time, I was re-deployed to work as a COVID-19 tester and as a care assistant in a nursing home. This inevitably caused delays in my research. Additionally, face to face data collection was prohibited and as many staff members were re-deployed for work in essential services and others taking on the increased workload, ethical approval from external sites and recruitment of participants was postponed. When the pandemic began, I was in the process of recruiting siblings of AAC users to participate in interviews. This recruitment had to be immediately halted and re-started months later after I had received an amendment to my ethical approval to allow for online recruitment and interviews. While it was time of great worry and uncertainty, it also allowed me time to reflect on my research journey and consider what I wanted to achieve from this PhD. The COVID-19 pandemic also impacted on the decision of who could be involved in this research. While siblings of AAC users were always considered a key stakeholder to consult, AAC users were initially to be interviewed as key stakeholders also. However, during the pandemic when services were shut down and staff redeployed, there were increased barriers to not only disseminating information to AAC users, but also ensuring appropriate procedures were in place to gather informed consent and collect the data. Therefore, the decision had to be made to no longer include the voice of the AAC user in this research. Ultimately, it would not have been feasible in the timeframe of this research, especially at the time it was not known as to how long the COVID-19 pandemic restrictions would last for.

1.6 Organisation of the Thesis

The main body of this thesis is presented over three parts, separated into 11 chapters.

1.6.1 Part One- The Literature Review

The literature review comprises three chapters. **Chapter 2** provides an overview of AAC and communication partners, and the roles these partners may occupy are explored. The significance of family in the lives of AAC users is also discussed, both theoretically and in practice. **Chapter 3** introduces the concept of siblings as communication partners, exploring who is a sibling and the unique features of a sibling relationship that underpin a sibling's importance. Finally, **Chapter 4** seeks to provide an overview of communication partner training interventions, with a specific focus on sibling engagement in these interventions. This chapter also aims to explore the concept of engagement in interventions, as well as considerations to take into account when supporting the engagement of siblings.

1.6.2 Part Two – The Study

The second part of this thesis encompasses the methods and findings of this research. This part is divided into five chapters. **Chapter 5** describes the framework used for the current research, and how it was developed. This chapter also outlines the research questions and mixed methodology used to answer these questions. Four data collection methods were used to address the research questions and each of these four methods and findings are outlined in a separate chapter. **Chapter 6** presents the methods and findings of a systematic review of sibling involvement in interventions for individuals with a disability. **Chapter 7** outlines the methods and findings of a second systematic review, this one on peer communication partner training interventions. **Chapter 8** discusses the methods and findings of interviews with siblings of AAC users and **Chapter 9** reports the methods and findings of surveys of key stakeholders: adolescents, parent/guardians and SLTs.

1.6.3 Part Three – Discussion and Conclusions

In this final part of the thesis, **Chapter 10** presents a discussion of the interpretations of the findings, as described under the framework of Chapter 5. This is followed by a consideration of the practical implications of this research, summarised as guidelines, and incorporates feedback from siblings and SLTs on the guidelines. This discussion is followed by the final chapter, **Chapter 11**, which includes a summary of the main findings, an overview of the limitations of this research as well as future research suggestions.

PART ONE: LITERATURE REVIEW

Chapter 2: AAC and Communication Partners

2.1 Introduction

This chapter begins with an overview of AAC and models of communication in AAC. Next, the importance of communication partners, including their roles in the lives of AAC users is discussed. Finally, the centrality of family as communication partners in the lives of AAC users is reviewed, including both theoretical underpinnings and practical considerations in the Irish disability service context.

2.2 Overview of AAC

Communication is an essential human experience, a process by which information and ideas are exchanged between two or more individuals. In fact, it is both a basic need and a basic right of all human beings (Brady et al., 2016). Communication is vital in building relationships, developing and expressing our identity, and participating in a range of day-to-day activities (Gamble & Gamble, 2013). It allows us to share our needs, feelings, thoughts, and experiences with others and helps us understand and connect to people and the world around us. Effective communication is crucial when participating in a range of settings, for example education, personal care and employment (Beukelman & Light, 2020), and communication difficulties have the potential to increase social isolation (Kozalinski & Olmos, 2022) and reduce quality of life (Ruggero et al., 2019).

Humans start communicating from the moment they are born, and, typically, most will begin to develop a standard linguistic form of communication (e.g., natural speech, sign language) in the first year of life. This development continues over time and eventually most individuals become proficient in at least one language (Tomasello, 2003). However, some individuals may not develop a standard linguistic form of communication sufficient to meet their daily communicative needs or due to injury may lose this ability (Beukelman & Ray, 2010). These individuals may use AAC as a means of meeting their communicative needs.

AAC refers to the “*transdisciplinary field that uses a variety of symbols, strategies, technologies and techniques to assist people who are unable to meet their communication needs through natural speech and/or writing*” (Allen et al., 2023, p. 4). Examples of AAC modes include gestures, manual sign systems, vocalisations, body movements, eye pointing and graphic symbols. AAC methods can be classified as aided (i.e., communication using an aid external to the individual) or unaided (i.e.,

communication produced without an external aid) (Loncke, 2014). Aided communication includes both low-tech and high-tech tools (see Figure 2.1 for examples). AAC users, as with all communicators, may use multiple modes of communication to convey their message (i.e., a multimodal communicator) (Smith, 2023). For example, an individual may use a speech generating device, as well as gestures, facial expressions, and eye gaze to communicate a message.

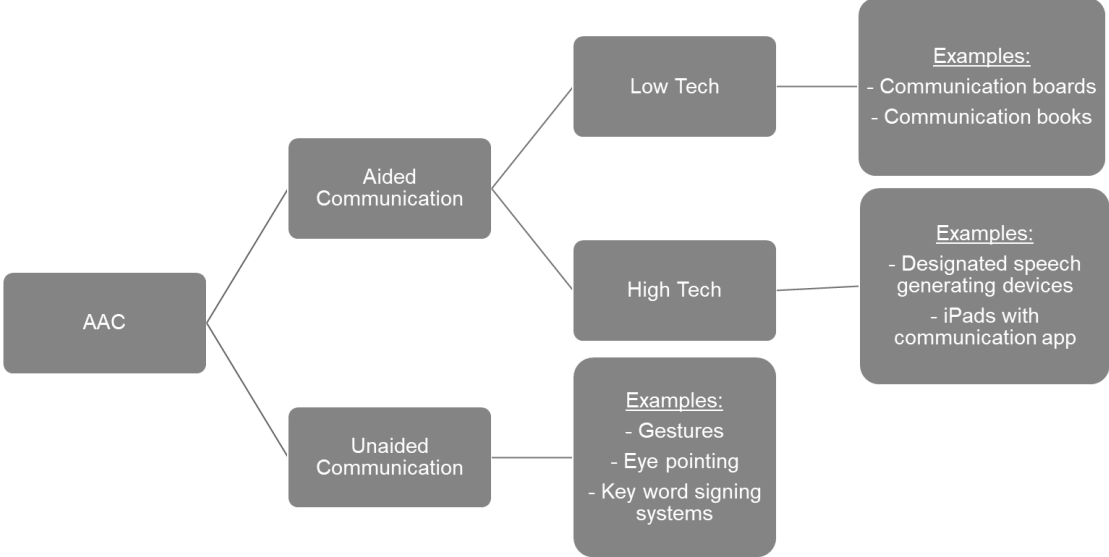


Figure 2.1 AAC Methods and Examples

AAC is an umbrella term which encompasses a wide variety of tools, strategies and purposes (Smith, 2023). It is a vital component for supporting participation and interaction for many individuals across the world. A variety of different people may benefit from using AAC and not all AAC users use the methods and tools in the same way (IASLT AAC Working Group, 2016). von Tetzchner and Martinsen (2000) describe three different groups of AAC users. First, there are individuals who use an AAC system to communicate their thoughts, ideas, and needs across environments (i.e., expressive language group). Second, there are some individuals who may need an AAC system at certain periods of their life or in certain situations (i.e., supportive language group). Finally, some individuals may use AAC to support both their comprehension and expressive communication (i.e., alternative language group). Due in part to the heterogeneity of the population of individuals who may benefit from AAC, as well as their methods of communicating, accurate prevalence figures of how many individuals use AAC have been difficult to capture. Creer et al. (2016) identified nine medical conditions which encompasses the majority (97.8%) of people who may benefit from AAC in the

UK. These conditions are dementia, Parkinson's disease, autism, learning disability, stroke, cerebral palsy, head injury, multiple sclerosis and motor neurone disease. The authors estimate the prevalence rate of those who could benefit from AAC in the UK is 0.5%. This figure equals over 360,000 individuals living in the UK as of 2023. In more recent estimates, Beukelman and Light (2020) reported a prevalence rate of 1.5%, equating to approximately 75,000 Irish and 97 million people across the world who may benefit from AAC. There have also been estimates of AAC use across specific populations. For example, it is estimated that 25-30% of Australian autistic children may benefit from AAC (Iacono et al., 2016) while Kristoffersson et al. (2020) reported that 44.4% of Swedish children with cerebral palsy used some form of AAC to communicate, either as an alternative to, or to augment their speech. Adults have also been reported to benefit from AAC, for example 46% of individuals with amyotrophic lateral sclerosis in Germany demonstrated a need for AAC (Funke et al., 2018), as did 33% of patients in intensive care units in Iowa (Zubow & Hurtig, 2013).

While recognising that AAC is an umbrella term that encompasses a wide variety of communication modes, this thesis will focus on children who may be multimodal communicators but who use at least one mode of communication that is aided. Aided communication is of particular interest due to the uniqueness of aided language learning (von Tetzchner, 2015) and the support that individuals in the environment may be expected and required to provide, as will be discussed later in this chapter.

2.3 Models of Communication in AAC

In order to better understand the concept of AAC communication, it is helpful to first explore what communication itself involves. Communication is a complex process, and different models have been developed which attempt to explain the communication process. In its simplest form, communication may be described as a linear, one-way process (Shannon & Weaver, 1949). In this basic transmission model, a sender encodes a message and sends it through a channel to a receiver who decodes it. This model of communication focuses primarily on the sender and the message; the recipient plays a passive role in the interaction. They are present only to act as a target for the message rather than as an active contributor. Lloyd et al. (1990) proposed a model to describe AAC, which is a modification of a linear general communication model. The authors added AAC-specific parameters to the model (e.g., AAC transmission processes and AAC interface) as well as expanding the existing parameters and the relationships between them. This change is to account for the potential external AAC system used by an aided language user when communicating a message. The authors describe the AAC

system as a tool used to enhance or change the signal quality so that the receiver can accurately decode the message (Lloyd et al., 1990).

However, what these linear models fail to account for is the active participation of the receiver in communicative interactions. Communicative meaning is created in an interaction between individuals (Gergen, 2015). The message is not just sent from one person to another, but rather participants engage in an active process of negotiating the meaning of an utterance between them in that specific interaction (Burr, 2015; Sperber & Wilson, 1995). Smith and Murray (2016) discuss the relevance of a constructivist perspective of communication to aided communication. In AAC interactions, meaning-making negotiations can be explicit in the interaction, with naturally speaking participants repeatedly attempting to interpret the message in a way that is both understood by the recipient and accepted by the AAC user as the intended meaning. Another advantage of applying a constructivist perspective to AAC communication interactions is that it places shared responsibilities on all participants to co-construct meaning. This perspective allows for the conceptualisation of communication success and competence, and also communication breakdown, as being shared by all individuals within an interaction. The conceptualisation of the interaction being shared between individuals has an impact on how we assess and intervene with AAC users as well as how we can understand AAC development; the AAC user is not viewed in isolation, but rather as part of a dyad in which both individuals must develop, and balance skills.

2.4 Communication Partners

Adopting a constructivist view, and perceiving aided communication as dyadic in nature, highlights the importance of both individuals in the dyad, (i.e., the AAC user and the communication partner). The term 'communication partner' can refer to anyone who interacts and communicates with the AAC user (McNaughton et al., 2019). However, for the purpose of this thesis, the term will be used to refer to familiar communication partners (i.e., those who interact regularly with the AAC user, for example parents, siblings, other family members, teachers, and peers ; Beukelman & Light, 2020) unless otherwise stated.

No two communication partners are the same. Every individual will bring different experiences, knowledge, skills, and attitudes to their interactions with an AAC user (Hanley et al., 2022) and these may impact on the role or roles they play as a communication partner; specifically what roles they are expected and have the capacity to take on (Beukelman & Light, 2020). These roles may also be impacted by the communicative context, both the purpose and the setting, and the communication

partner's role in the life of the AAC user. For example, communication with a teacher may occur in a structured, education setting with a focus on teaching the AAC user a skill, while communication with a sibling or peer may take place in a more informal situation, for example during play, with the aim of building or maintaining social closeness.

One common role for many communication partners is to communicate and interact with the AAC user, and to support the co-construction of communicative competence in an interaction. Some partners, often adults or older children, may take on additional roles such as supporting aided language learning and creating a communicatively accessible environment. Each of these roles will be discussed in detail below, however it is worth noting that not all partners will take on all roles and that the roles of partners may change over time.

2.4.1 Role 1: Supporting Communicative Competence in the Interaction

A unique aspect of interactions involving AAC users, is the role the communication partner may assume in jointly constructing meaning (Smith & Murray, 2016). As part of this joint construction, communication partners may support the demonstration of communicative competence of the AAC user.

Light (1989, p. 137) defined communicative competence in AAC as "*a relative and dynamic, interpersonal construct based on the functionality of communication, adequacy of communication and sufficiency of knowledge, judgement and skill in four interrelated domains: linguistic competence, operational competence, social competence and strategic competence*". (See Table 2.1 for definitions and examples of these competency domains). In 2003, Light further expanded this framework to include a variety of psychosocial factors (e.g., attitude, resilience, confidence) as well as environmental barriers and supports that may impact the development of communicative competence (Light et al., 2003).

Domain	Definition	Examples
Linguistic competence	Knowledge of and the ability to use the language(s) spoken and written in the individual's family and community and knowledge of and the ability to use the linguistic code (symbols, syntax, grammar) of the AAC system.	<ul style="list-style-type: none"> o Understand the form, content, and use of spoken language(s) used by others both at home and in the broader social community. o Develop as many expressive skills (content, form, and use) in the spoken language(s) of the home and broader social community as appropriate. o Code switch between different language(s) and cultures as required. o Develop literacy skills to understand and use the written language(s) of the home and broader social community; code switch between these written language(s) as required. o Develop skills in the language code of the AAC systems for home and the broader social community. o Develop lexical knowledge of the symbols used to express concepts via AAC. o Develop semantic, syntactic, and morphological skills to express more complex meanings via AAC.
Operational competence	Skills in the technical operation of AAC systems and techniques.	<ul style="list-style-type: none"> o Having the motor movements needed for unaided approaches. o Using selection techniques for aided approaches. o Navigating in and between systems. o Turning an electronic device on and off and charging it.
Strategic competence	Knowledge and skills of how to use available features to convey messages efficiently and effectively.	<ul style="list-style-type: none"> o Asking for choices due to vocabulary limitations o Using word/phrase prediction to enhance efficiency. o Using an introductory statement to explain AAC to unfamiliar communication partners. o Asking one's communication partner to write or type messages to aid in understanding and to repair communication breakdowns.
Social competence	Knowledge of what, where, with whom, when and when not to, and in what manner to communicate.	<ul style="list-style-type: none"> o Turn-taking, initiating, and terminating communication. o Topic maintenance. o Code-switching. o Requesting attention. o Requesting or providing information.

Table 2.1 Communicative Competence Domains: Definitions and Examples (Adapted from Light and McNaughton (2014))

Light and McNaughton (2014) revisited the concept of communicative competence to investigate whether Light (1989)'s framework was still applicable to modern AAC practice. They found that while the ultimate goals of AAC had not changed (i.e., goals still centred around development of sufficient communication skills to support individuals with complex communicative needs to fulfil a variety of functions), there were some changes which needed to be addressed. Due to advances in technology (i.e., access to internet, better AAC systems) and improvements in the opportunities for participation of individuals with disabilities in society, a wider set of communication demands were being placed on AAC users (Light et al., 2019). As such, the authors concluded that while the four fundamental domains of communicative competence had not changed over the previous 25 years, the range of skills needed to achieve communicative competence had grown (Light & McNaughton, 2014).

However, one limitation to this framework is the lack of emphasis on the potential role of the communication partner in relation to these competencies (Tsai, 2016). In Light's (1989) framework, the skills required to achieve communicative competence, as well as the psychosocial factors which may influence competence, are all focused on the AAC user. There is no disputing that a long-term goal of introducing an AAC system may be independence and autonomy (Smith, 2023) and as such, the skill development of the AAC user across these competencies is fundamental (Light et al., 2019). However, regardless of skill level, the AAC user alone is not responsible for their ability to demonstrate communicative competence within an interaction. While communicative competence itself is a construct specific to the individual, the level of communicative competence demonstrated within any interaction is constructed within that specific moment. It can depend on several factors, for example the communicative task itself, how familiar the partners are with one another, how skilled the communication partner is at supporting the demonstration and building of that specific AAC user's communicative competence and the overall context in which the interaction is taking place. For example, the level of competence demonstrated by an AAC user may be higher in a straightforward request to an attuned communication partner in a quiet and calm room compared to retelling an unusual event to a stranger in a noisy environment.

While both participants contribute to co-constructing meaning and in revealing communicative competence, their roles are not equal in each interaction. For example, when communicating with an individual who uses their AAC system independently, the communication partner must have the knowledge and skills to (i) respect the AAC users' communicative modes, (ii) not dominate the conversation and allow the AAC user time and opportunities to communicate and (iii) work collaboratively with the AAC user to construct meaning within the interaction and confirm they have understood the message.

However, for an individual starting out on their AAC journey who is only learning the range of skills needed to be an independent and autonomous aided communicator, the communication partner may be relied upon to (i) support the learning of the AAC user and (ii) assume some or most of the skills to support the interaction while still respecting the AAC user's modes of communicating, not dominating the conversation and co-constructing meaning with the AAC user (Beukelman & Light, 2020).

To be an attuned communication partner, able to effectively support communicative competence, individuals must have the right skills. A communication partner who does not have the appropriate knowledge and skills can be a barrier to communicative participation for the AAC user (Donato et al., 2018; Moorcroft et al., 2019). Communicative competence is learned, not innate (Tsai, 2016) and this concept applies to both the AAC user and the communication partner. Communication partners may need support in learning the necessary knowledge and skills to become a capable communication partner and fulfil their role in supporting communicative competence in an interaction (Kent-Walsh et al., 2015).

In addition to supporting communicative competence in an interaction, some communication partners may simultaneously be expected to support the AAC user's learning of aided language.

2.4.2 Role 2: Supporting Aided Language Learning

Another key role that communication partners may be expected to take on is supporting the AAC user's learning of aided language. von Tetzchner and Stadskleiv (2016, p. 19) describe aided language learning as "*an extraordinary form of language development... a 'side-track' in cultural development*". The ultimate goals of aided language learning and spoken language development (i.e., to achieve successful communication in a variety of environments and about a variety of topics), and the basic process of achieving these (i.e., individuals in the child's environment scaffolding their language skills) are similar (von Tetzchner, 2015).

However, as the word 'extraordinary' implies, aided language and the language learning contexts of aided language are unique in many ways (Smith, 2015). Aided language interactions involve explicit co-construction of meaning with a communication partner, potentially over a series of turns (Smith & Murray, 2016). It is more effortful to use, both in terms of physical and cognitive demands (Smith, 2015) and slower in pace than spoken language (Higginbotham et al., 2016). Not only must aided language users develop linguistic and social competencies as in spoken language, but they must also develop operational and strategic competencies as well (Light & McNaughton, 2014).

For example, children must learn where each individual symbol is located on an external system and the path to get there (Thistle & Wilkinson, 2013). If a symbol which is needed to communicate a certain meaning is not present on the device, the child must know how to strategically select a combination of other lexical items or phrases to communicate their intended meaning to a partner who must also have the skills to negotiate the meaning of what is being communicated (Neuvonen et al., 2022).

Furthermore, there is an asymmetry in the child's input and output modalities; they are surrounded by spoken language in the home and community but are expected to construct their utterances using aided language (von Tetzchner et al., 2018). Children learning aided language must develop competencies in both modalities (Smith, 2015). However, often the individuals who are expected to support the child's aided language development may not have the skills in the aided language modality to do so effectively (Donato et al., 2018; McNaughton et al., 2008). AAC users who are learning aided language rarely have an opportunity to interact with individuals who are proficient at using their system (Ballin et al., 2012), especially other expert communicators who use aided communication (Ballin et al., 2012). This environment differs to that of children developing spoken language who are surrounded from birth, across all language environments, by proficient spoken language users. This dearth of opportunities to observe and interact with proficient aided language communicators means young AAC users have very different language learning experiences to their speaking peers. They may have fewer communicative opportunities, with fewer competent partners especially outside of educational or other structured settings (Andzik et al., 2016; Cockerill et al., 2014; McNaughton et al., 2019). Aided language learning often take place in planned, structured interventions rather than across the range of natural environments in which spoken language is scaffolded and developed (von Tetzchner & Stadskeiv, 2016). The lack of natural communication development opportunities results in an increased reliance on trained communication partners to actively construct opportunities and scaffold language learning.

Communication partners have an important role in providing aided language input for the AAC user and scaffolding their learning. By providing input in the aided language modality, the asymmetry between input and output modalities are reduced (O'Neill et al., 2018). However, communication partners, who are expected to be the experienced scaffolders, may only be learning the child's communication system at the same time as they are expected to be the experts. Therefore, it is important to consider upskilling communication partners in using aided systems within intervention. The intervention goal may be increasing familiarity with the aided system itself, so that partners can effectively model and provide aided language input as well as using other

strategies used to promote aided language learning, for example waiting, asking open ended questions and providing meaningful opportunities for communication (Kent-Walsh et al., 2015). In addition to scaffolding aided language learning, communication partners have a role to play in promoting natural communicative interactions and language learning opportunities across environments.

2.4.3 Role 3: Creating a Communicatively Accessible Environment.

Communication partners may not only have a role in supporting aided language learning and revealing communicative competence within interactions, but they may also be responsible for creating communicatively accessible environments (von Tetzchner & Stadskleiv, 2016). At a basic level this includes the communication partners recognising the need for an AAC system (von Tetzchner & Stadskleiv, 2016). This recognition must then be followed up with the provision of an appropriate system or connecting the individual with AAC services; whichever is within the scope of the communication partner's role (e.g., SLT vs parent) (McNaughton et al., 2019). Individuals have a right to access AAC. It is one of the 15 fundamental rights listed in the Communication Bill of Rights (Brady et al., 2016). However, this right is not always guaranteed. According to a survey conducted among 220 service managers in England, it was found that at a local level, approximately 12.5% of individuals who could benefit from AAC had unmet needs (Judge & Johnson, 2017). Additionally, there were reports of an estimated one in five individuals in the catchment population who may have required a high-tech communication aid but had not been provided with one (Judge & Johnson, 2017). Communication partners, especially those who are familiar with the child, have a role in recognising the need for AAC, and in advocating for a system appropriate to the child's needs to be introduced (McNaughton et al., 2019). There is also a responsibility for communication partners to recognise when the current AAC system is no longer working and to advocate for change (Smith, 2023).

Furthermore, following the introduction of AAC, it is a role of the communication partners to ensure that the system is readily available across situations and partners (von Tetzchner & Stadskleiv, 2016). The availability of aided communication may vary across environments (Singh et al., 2017) which impacts on the participation opportunities as well as language learning across the day (von Tetzchner et al., 2018). The communication partner's role in ensuring availability of the communication aid may vary depending on the skills of the AAC user. For example, young children or those with physical difficulties may not have the cognitive or physical skills to ensure their communication aid is available, charged and brought with them across environments. As

such, a communication partner, often an adult partner, must take on this role. For example, in a case described by Allen et al. (2023) an intervention outcome was that communication partners supported the child in carrying his device between environments.

Competent and knowledgeable communication partners are vital to promoting a communicative accessible environment that support aided language use and learning, with countless opportunities for meaningful communicative interactions (von Tetzchner & Stadskleiv, 2016). Unfortunately, however, many individuals are not knowledgeable or skilled in supporting aided interactions or with AAC in general (McNaughton et al., 2019). This lack of diversity in trained communication partners can be a barrier to participation and may restrict the frequency and quality of natural interactions (Donato et al., 2018; Moorcroft et al., 2019). Communication partners should have the opportunity to engage in training in order to fulfil their roles including supporting a communicatively accessible environment. A communicatively accessible environment is one in which AAC is available and accessible at all times, and the AAC user has the opportunity to interact with different partners across a range of situations (von Tetzchner & Stadskleiv, 2016) Communication partners have a role in working together to ensure this occurs.

2.5 Significance of Communication Partner Relationships

The importance of communication partners stems not only from the roles and responsibilities they may assume, but also from their relationship with the AAC user. The profile of communication partners, and their relative importance to the AAC user, changes as the individual gets older. Similar to typical development, adults are the primary communication partners during early childhood. Parents, teachers, and other educators or healthcare professionals are crucial in supporting development and learning (McCleary & Lynch, 2023; Ronski et al., 2015; von Tetzchner & Stadskleiv, 2016). Siblings are potentially one communication partner who may be present across the lifespan, from very early until later in life (White & Hughes, 2017) and these relationships will be discussed in detail in Chapter 3. As social interactions become more important with age (Crowley, 2017), similar-aged partners, for example peers (King et al., 2020; Therrien et al., 2022), and co-workers (Lackey et al., 2023), become more significant. Yet, AAC users often encounter barriers to peer relationships (Østvik et al., 2017). Raghavendra et al. (2012), found that, between the ages of 10 and 15, both AAC users and non-AAC users reported their primary communication partner to be a close family member; however, AAC users more frequently reported a family member over a peer as their favourite communication partner. Although these findings raise concerns

regarding the social development opportunities for AAC users (i.e., less opportunity to engage in social interactions with peers to develop essential skills), they also highlight the importance of family as communication partner in the lives of AAC users, not just during childhood, but also into adolescence and beyond.

2.5.1 The Importance of Family: Theoretical Underpinnings

Families are the centre of learning for children who use AAC (Beukelman & Light, 2020). While not true for all individuals, families can provide a safe, nurturing, and rich environment for children to learn, grow, and develop (Burke et al., 2022; Spagnola & Fiese, 2007). This notion is also true of situations where additional support is required for children to learn these skills, for example aided language learning for AAC users. Understanding how a child functions as part of a family can inform AAC intervention planning.

Family systems theory is one theory which may provide a useful framework for understanding the significance of families in the lives of AAC users (Kerr & Bowen, 1988; O'Neill & Wilkinson, 2020). It posits that the child's needs cannot be understood or supported in isolation, but rather should be seen as part of the larger family unit (Turnbull et al., 2015). The theory conceptualises 'family' as a dynamic and complex system, where the behaviour of each member affects and is affected by the behaviour of other members. There can be subsystems, or smaller groups within the family system, for example parent-child or sibling relationships, each of which has its own roles and functions within the overall family system. All members and subsystems are linked, known as interdependence, and changes in one part of the system can have far-reaching effects on the entire family (Turnbull et al., 2015). The family system must adapt to the environment to maintain balance across the system, known as homeostasis (Minuchin, 1985). This theory underpins the notion that SLTs should consider all members of the family and their individual needs, as well as the family as a whole, when planning an intervention (Health Service Executive, 2020). Introduction of an AAC system can upset the balance of the family system as a whole, as well as the individual subsystems, for example through the disruption of previously established communication patterns or introduction of new roles to certain members (Mandak et al., 2017). Intervention should strive to support the entire family to adapt and return to homeostasis, as the success or failure of the intervention, and thus potentially the AAC system, will depend on its suitability for the entire family system and not just the AAC user (Doak, 2021; Moorcroft et al., 2020).

However, while family systems theory is fundamental in understanding the importance of the family in the lives of AAC users and when planning interventions, it must be noted that families do not exist in isolation. Instead, families can be seen as functioning within and interacting with other contexts, as per an ecological systems theory perspective (Bronfenbrenner, 1977). According to this theory, individuals are embedded in multiple interacting systems: the microsystem, the mesosystem, exosystem and macrosystem. These systems can be illustrated as a series of concentric circles, with the smallest one representing the individual and each subsequent ring representing progressively more distant systems of social interactions. Often the family are one component of the individual's microsystem (i.e., settings in which the individual interacts directly and regularly). The mesosystem then refers to the interconnections and interactions between different microsystems in which an individual is situated, for example family and school. The exosystem involves settings that may impact some part of the individual's life, but which they do not directly interact with and finally, the macrosystem consists of cultural and societal beliefs, values, and laws that affect the other systems (Bronfenbrenner, 1977). Ecological systems theory provides a useful framework for understanding the various systems that interact to shape individuals' lives (Biggs & Hacker, 2021; Hayes et al., 2017). This is an important factor in speech and language therapy interventions, when SLTs must consider not only working with the AAC user themselves but how also intervening at different levels of the child's ecological system, with a range of communication partners, may be of benefit.

Mandak et al. (2017), created a theoretical framework to guide family-centred AAC services incorporating elements from both family systems and ecological systems theories (see Figure 2.2 for an illustrated overview). They used the four systems from ecological systems theory, and within the microsystem layer, highlighted the interdependence and subsystems of the family members within. The authors concluded that this framework could be used by professionals to reimagine AAC services to be more family-centred and to better understand and support AAC users and their families within a variety of contexts.

There is no doubt that families are important in the lives of AAC users. Theoretically, family systems (O'Neill & Wilkinson, 2020) and ecological systems (Biggs & Hacker, 2021) theories, or a combination of both (Coburn et al., 2021; Mandak et al., 2017) have been used to highlight the centrality of family and its importance in an individual's development. Due to this significance, in practice, SLTs should strive to support family involvement as communication partners in AAC interventions.

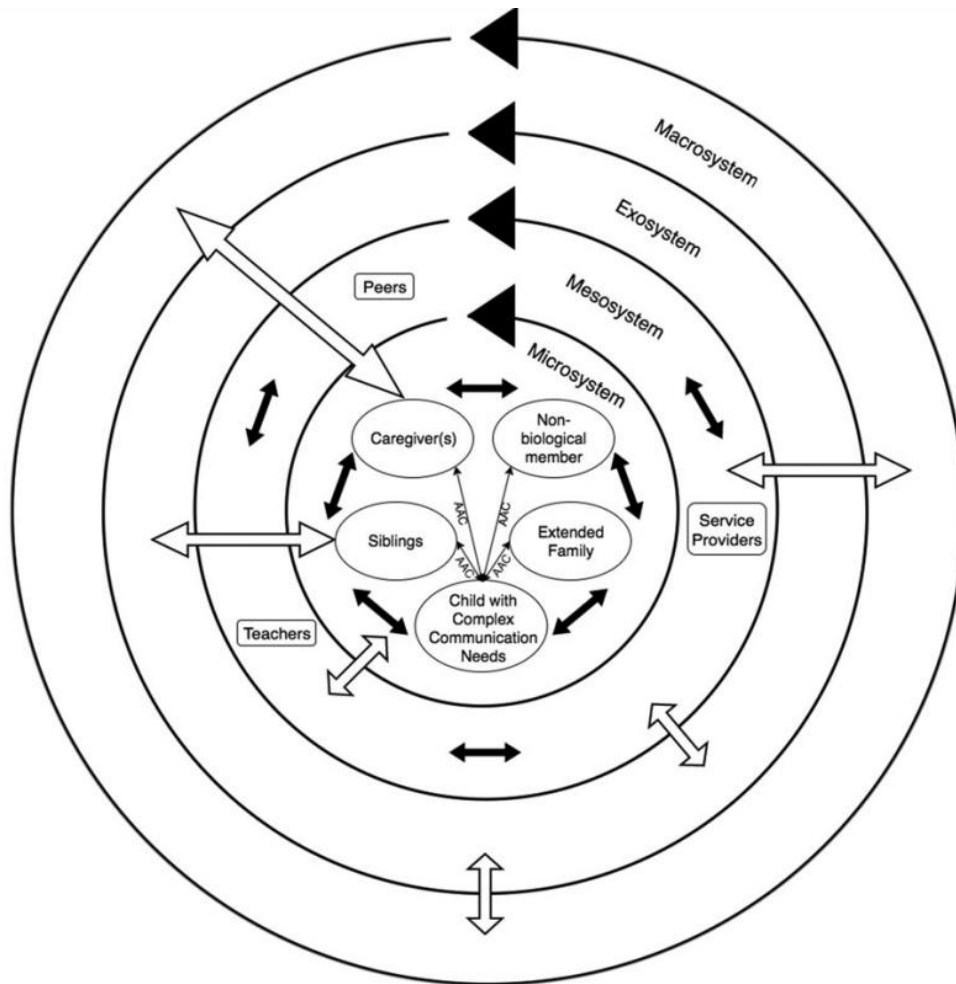


Figure 2.2 Theoretical Framework Illustrating How Family Systems Theory and Ecological Systems Theory Applies to a AAC User and Their Family, Taken From Mandak et al. (2017, p. 34)

2.5.2 The Importance of Family – Practical Considerations in an Irish Context

SLTs, as healthcare professionals, are encouraged to engage families in all aspects of their work. For example, the American Speech-Language-Hearing Association (n.d.) website notes that SLTs recognise the crucial role that families play across the lifespan, regularly acting as key decision makers with their own knowledge and skills. In Ireland, SLTs working with children with disabilities in the public health system are expected to work within a family-centred practice model of care. Family-centred practice is identified as a key principle of the service delivery model of the Progressing Disability Services for Children and Young People (PDS; Health Service Executive, 2020), the current policy setting out how public children's disability services are provided. The terms family-centred practice and family-centred care have been used interchangeably in the literature. For the purpose of this thesis, the term family-centred practice will be adopted

as this is the term used by the public health service in Ireland (Health Service Executive, 2020).

Family-centred practice is reported to be a standard model of care used in health services across the world (Fordham et al., 2012; Frakking et al., 2020; Kuo et al., 2012). However, family-centred practice can be conceptualised in many ways (Al-Motlaq et al., 2019), which has led to some difficulties with its implementation and evaluation of its effectiveness (Shields, 2015). The HSE (2020, p. 12) describes the model as “*prioritising and promoting the strengths and abilities of the family unit through recognising the family as both unique and central in the delivery of services*”. Other definitions highlight the key concepts of partnership, empowerment, individualisation and respect (Institute for Patient- and Family-Centered Care, n.d.; Dunst et al., 2007; Kokorelias et al., 2019) . Dunst et al. (2007) (see also McCarthy & Guerin, 2022) identified two main themes of family-centred practice which professionals must strive to balance: relational caregiving and participatory caregiving. Relational caregiving encompasses what is traditionally reported as good clinical skills, (e.g., active and reflective listening, compassion, empathy, effective communication, flexibility and respect). Participatory caregiving focuses on the side of participation - engaging with families and collaborating with them through equal partnership.

While there is no consensus on what exactly family-centred practice entails (Al-Motlaq et al., 2019), the core principles include collaboration to support decision making, respectful partnership, open communication, and clinical flexibility to support the family’s individualised needs (Arango, 2011; McCarthy & Guerin, 2022). Practitioners working within a family-centred practice model of care should regularly consult with key stakeholders to make decisions about goals and interventions as well as how best to support individual and family needs. Practitioners need to be flexible to provide a service which best meets the needs of each family. Practitioners must also reflect on their own interactions with family members and service users, striving to be respectful, compassionate, understanding and promoting open communication in all circumstances.

Family-centred practice offers both benefits and challenges (Dunst et al., 2007). A recent study completed by McCarthy and Guerin (2022) reported on processes and outcomes of family-centred practices in early intervention services. While only 25 of the 42 included studies made reference to outcomes, they found that positive outcomes were reported in the areas of child development (Douglas et al., 2020), parent/family development (Ely & Ostrosky, 2018), attainment of family goals (Ridgley et al., 2020), quality of life (García-Grau et al., 2019) and parent professional collaboration (Phoenix et al., 2020).

However, there have also been challenges reported with the implementation of family-centred practice. Some argue that a model of family-centred practice can take the focus away from the child and their individual needs (Coyne et al., 2016). Others report that the lack of consensus on what family-centred practice is, as discussed above, has led to difficulties implementing the practice using a standardised method which can be recorded and analysed (Shields, 2015). Additionally, Shields (2015) reported that there is limited rigorous evidence (i.e., randomised control trials and/or robust quasi-experimental studies) to support the argument that family-centred practice is effective and should be the gold standard model of care.

Family-centred practice is set out as the standard in the Irish disability services (Health Service Executive, 2020), and there is no debate that families should be involved in their child's care. The challenge is what exactly this concept of family practice entails and the potential differing of opinions of stakeholders on how it should be implemented (Mandak & Light, 2018a). Mandak and Light (2018b) interviewed SLTs about their use of family centred practices in AAC service provision. They reported that most participants agreed on the importance of families and the benefits of family-centred AAC services. However, many were also dissatisfied with their current provision of family-centred services with a variety of practices reported. In addition to inconsistency across practitioners in their understanding and implementation of family-centred services, service constraints and practitioner resources may also negatively impact on service provision. The authors reported several potential contributing factors including limited time, training, and high caseload numbers (Mandak & Light, 2018b).

These findings are relevant to the current Irish context. While the PDS model aims to support family-centred practice, there has been some criticism that it is not currently operating as was intended (Inclusion Ireland, 2022; McDonagh, 2022). Parents have been reported to be unhappy with the level and quality of services they are receiving (Joint Committee on Disability Matters, 2022). Over 50% of children are not receiving appropriate services (Inclusion Ireland, 2022) and there is an average of 34% of staff positions unfilled (Health Service Executive, 2022). As Mandak and Light (2018b) discussed, these practical challenges do not lend themselves to following a family-centred practice model, with healthcare professionals struggling to find the time and resources to manage large caseloads, let alone having the opportunity to build reciprocal relationships and collaborate meaningfully with families on decisions.

It must also be noted that while the concept is referred to as family centred practice, the focus is primarily on the child with a disability or healthcare need (e.g., the AAC user) and their parents or guardians. Discussions of the importance of collaboration and partnership, respect and communication in the literature are centred around the

relationship between the healthcare provider and the parents and decisions regarding the child with a disability (e.g. Klatte et al., 2020). This leaves other family members who may also be affected by these decisions, for example siblings, grandparents, and other extended family members, largely ignored (Gill, 2020). AAC users may regularly interact with not just parents, but also these other family members (Beukelman & Light, 2020). Therefore, the role of these family members as communication partners, and their potential to impact on the interactions and development and environment of the AAC user, must be considered.

Families are central to the lives of many AAC users, from both a theoretical and a practical perspective. While there are practical barriers to implementing family-centred practice, SLTs still have a responsibility to support the engagement of key family members in interventions.

2.6 Summary

Communication partners are central to the lives of AAC users. Aided communication is dyadic in nature, suggesting both individuals in the dyad have a role to play in co-constructing meaning within an interaction (Smith & Murray, 2016). Communication partners can play several key roles in the lives of AAC users, and no two communication partners are the same (Hanley et al., 2022). The role of the communication partner at any given time may depend on the AAC user, the communication partner, their relationship, and the context of the interaction itself. Partners may be expected to support the communicative competence of the AAC user, support their aided language learning and create a communicatively accessible environment. To be an attuned communication partner, knowing how to effectively carry out the role or roles expected of them requires skills (Berenguer et al., 2022). These skills are not innate, and training may be needed to teach individuals how to become an effective communication partner (Beukelman & Light, 2020). Family members are often reported to be key communication partners (Raghavendra et al., 2012). Research from both a theoretical (Biggs & Hacker, 2021; Coburn et al., 2021; Mandak et al., 2017; O'Neill & Wilkinson, 2020) and a practical (Kokorelias et al., 2019; McCarthy & Guerin, 2022) perspective demonstrates the importance of family and family relationships both for the AAC user, and for SLTs when AAC intervention planning. One family member who have been relatively overlooked in AAC research yet have the potential to be key communication partners are siblings.

Chapter 3: Siblings as Communication Partners

3.1 Introduction

“Sibling relationships outlast marriages, survive the death of parents, resurface after quarrels that would sink any friendship. They flourish in a thousand incarnations of closeness and distance, warmth, loyalty and distrust.” — Erica E. Goode

The importance of family members as communication partners was outlined above, both theoretically and practically. However, oftentimes when the term ‘family’ is used, it refers primarily to parents and not to other family members (Mandak & Light, 2018a; Melvin et al., 2021). According to a family systems theory perspective (Turnbull et al., 2015) and an ecological systems theory perspective (Bronfenbrenner, 1979), siblings are also important members at the centre of the child’s system. Doak et al (2021) refer to the concept of early ‘entry points’ for AAC in the home, things that may support the initial use of AAC in the home and allow for a communicatively accessible environment. It is important to consider the need for multiple entry points to allow for AAC to be supported and used across environments. Siblings, oftentimes with a wealth of knowledge regarding the AAC user, may be one specific entry point into a supportive family environment for AAC. Despite this fact, siblings are often overlooked in family-centred practice (Gill, 2020). There are few studies which focus on the experiences of having an AAC user as a sibling and the impact this may have on an individual (e.g. Dew et al., 2011). Similarly, there are relatively few studies which have engaged siblings of AAC users in communication partner training interventions (e.g. Douglas et al., 2018; Hacker et al., 2023). This chapter will examine who is a sibling and review the unique features underpinning a sibling’s importance as a communication partner for AAC users.

3.2 Who is a sibling?

At first, the question “Who is a sibling?” appears to be simple to answer; the Oxford English dictionary defines a sibling as a brother or sister (i.e., a relation to other children of the same parents). However, family structures across the world have become increasingly diverse leading to a wide range of individuals who constitute a ‘sibling’ (Hindle & Sherwin-White, 2014). The term ‘sibling’ may refer to an individual who shares at least one biological or legal parent or guardian with another individual, for example half siblings, step siblings, adopted siblings, and foster siblings (Buchanan & Rotkirch, 2021). Different ethnic and cultural groups may have a different idea of who a sibling is (Milevsky, 2021; Updegraff et al., 2010; Wu et al., 2018). Siblings are often described as

being similar aged companions, who have a shared childhood and similar family circumstances (Davies, 2023). However, even these reportedly common characteristics are not universal across all siblings. For example, in cases where there is a large age gap between siblings, where siblings have entered each other's lives relatively late in development (e.g., step or adopted siblings), or blood-related siblings who have been fostered or adopted out, individuals may not have the experience of a shared childhood or similar family circumstances (Davies, 2023). Edwards et al. (2006) used a social constructivist approach to take children's views of who they would consider a sibling. Participants included 58 children between the ages of 7 and 12 years. While there was some variation reported across participants, the majority of children highlighted both biological and social ties as being important to deciding who is and is not a sibling. Participants emphasised the importance of the relationship quality, their emotional engagement, and a deep sense of connectedness when making their decision.

For the purpose of this thesis, any individuals who are labelled, or label themselves, as siblings regardless of biological or social connection are considered as falling under the label of sibling. The primary focus will be on siblings who may be classified as familiar communication partners of AAC users, (i.e., those who have some form of sibling relationship, interact regularly and have an intimate knowledge of one another).

3.3 Siblings of Individuals with Communication Difficulties – Unique Considerations

When one sibling has difficulties communicating, for example an AAC user, this presents a unique challenge for the siblings. Communication plays an important role in the building and maintaining of relationships (Gamble & Gamble, 2013). Thus, individuals who experience difficulties in communication may encounter barriers when building and maintaining relationships with siblings. This challenge of building relationships may be evident in childhood; for example, Hansen et al. (2016) studied the attitudes of six- to ten-year-olds who had a younger sibling with a severe speech and language difficulty. Participants' attitudes to their sibling's participation in interpersonal relationships and communication were less positive than their attitudes to their sibling's participation in other situations, for example play and household tasks. Challenges communicating with a sibling is a recurring finding in studies exploring the experiences of being a sibling of an individual with a disability, even if the disability is not specific to communication difficulties (Leedham et al., 2020; Strohm, 2005). When asked about their experiences of being a sibling of an individual with profound intellectual and multiple disabilities, the

majority of children in Luijck et al.'s (2016) study discussed communicating with their sibling, either understanding and interpreting their sibling's communication or instances when they found it difficult to understand their sibling. Similarly, adult siblings have discussed how communication difficulties have affected their ability to keep in touch with siblings who do not live nearby (Dew et al., 2014). Communication difficulties may impact on the time siblings spend together. Travers et al. (2020) explored the experiences of young adult siblings (N=155) of autistic individuals or individuals with an intellectual disability. In this study, siblings of individuals who used spoken language reported participating in significantly more activities together than siblings of individuals who were nonverbal or used a communication device. However, while communication may impact on the time spent together, there were no significant differences in reported relationship quality across communication modes (Travers et al., 2020). Similarly, Smith et al. (2013) investigated the role of communication skills in sibling relationship quality and found communication difficulties were not a moderating factor in the warmth/closeness and rivalry/conflict aspects of the sibling relationship.

AAC has been reported to be one way in which individuals with communication difficulties may keep in touch and maintain their relationships, although studies of AAC users and their siblings are sparse. Dew et al. (2011) highlight the importance of siblings of AAC users through a life course approach. The authors interviewed four AAC users and their six adult siblings. Participants were reported to have active roles in each other's lives, for example acting as carer, interpreter, overseeing service provisions as well as keeping in contact. It was also reported that participants experienced an increased obligation to engage in these commitments and reliance on one another when both parents were no longer alive. The authors identified AAC as having a role in keeping siblings in contact and maintaining their relationship. However, some AAC systems may not work effectively across geographic distance, for example one participant, Betty, had a hearing impairment and used low-tech AAC which meant she could not use the telephone independently to contact her brothers (Dew et al., 2011).

Although communication difficulties may impact on the building and maintaining of the sibling relationship, there are innate characteristics of the sibling relationship itself, yet to be accounted for, which have the potential to make siblings unique and important communication partners.

3.4 Unique Features of the Sibling Relationship

Siblings of AAC users may be important communication partners in the lives of many AAC users (Dew et al., 2011). It is important to note that the sibling relationship as well

as the roles siblings play in each other's lives varies across individuals and families (McHale et al., 2012). As such, the relative importance of a sibling as a communication partner may vary depending on the individuals, their family, and their environment. However, in many families, siblings may be seen as candidates to be important communication partners because of several key features unique to siblings and the sibling relationship. These reasons include the intimate and longstanding relationship, the time spent together, sibling influence on development and the variety of roles played in each other's lives, each discussed separately below.

3.4.1 Intimate and Longstanding Relationship

Siblings have the potential to be lifelong communication partners – longer than any other relationship. The sibling relationship often spans from infancy to old age (Buchanan & Rotkirch, 2021), resulting in many years for opportunities to develop and maintain the relationship. Individuals with a disability are living longer (Coppus, 2013), potentially outliving parents and relying more on siblings later in life (Kruithof et al., 2021). This increased longevity has been represented in the literature, with the sibling relationship across the lifespan of individuals with a disability becoming the subject of more research in recent years (e.g. Avieli et al., 2019; Orsmond & Long, 2021; Rossetti & Hall, 2015). The sibling relationship itself is dynamic, changing over time. Key features of the sibling relationship reported during childhood include companionship, intimacy, knowledge of one another, emotional support and conflict (Dunn, 2015). However, as the individuals develop, so must the sibling relationship, changing and adapting to life events such as greater geographical distance when a sibling moves out of the home, starting a family of their own and in negotiating the care of aging parents (Spitze & Trent, 2018). The sibling relationship can often successfully navigate through these challenges, with many adult siblings reporting positive relationships and maintaining contact until late in life (Dunn, 2015; Jensen et al., 2020; Stocker et al., 2020; Woolley & Greif, 2020). The longstanding nature of the relationship can result in siblings whose knowledge of one another is profound and spans many years. An innate knowledge of the AAC user, knowledge of their likes, dislikes and of their communication modes supports communication partners in successfully fulfilling their roles. Siblings who have had many years to achieve and gather this knowledge may therefore have a good foundation from which to reinforce their role as an important communication partner in the life of an AAC user.

However, it is not just the longstanding and dynamic nature of the sibling relationship which promotes a good basis for a sibling to be an important communication partner, it is also the nature of the relationship itself. The sibling relationship is often

reported to be one which is characterised by warmth and closeness (McHale et al., 2012), which may support a sibling's role as communication partner. While not true for all siblings, the relationship, in general, is viewed positively overall. Siblings have reported feeling warmth and affection towards one another, wanting to spend time together, as well as being able to confide in and having frequent contact with one another (Campione-Barr et al., 2015; Tibbetts & Scharfe, 2015). However, the sibling relationship is not always exclusively positive. Conflict is described as commonplace within the relationship (Eriksen & Jensen, 2009; White & Hughes, 2017), although the level of conflict or rivalry varies across relationships (Tucker et al., 2013). Often, the positive and negative characteristics co-occur resulting in an ambivalent relationship (Campione-Barr & Killoren, 2019; Howe et al., 2022; Jensen et al., 2015), and levels of positive and negative affect within the same relationship may vary over time (Buchanan & Rotkirch, 2021; Scharf et al., 2005).

Many factors may impact on the sibling relationship, for example birth order, age difference, gender, and parental treatment (Tanskanen & Danielsbacka, 2021). Another factor that may have an impact on the sibling relationship is one sibling having a disability. Research into the sibling relationship when one sibling has a disability mirrors that of sibling relationship in a typically developing population in that both positive and negative affect have been reported within and across relationships (Guidotti et al., 2021). While there may be an assumption that having a disability results in a poorer or more negative sibling relationship, this fact is not supported by the literature (Hayden et al., 2023). In fact, some studies have reported a more positive relationship and reduced conflict in sibling dyads where one sibling has an intellectual disability compared to typically developing dyads (Floyd et al., 2009; Zaidman-Zait et al., 2020). More often, however, both positive and negative experiences are reported alongside one another (Correia & Seabra-Santos, 2022; Iannuzzi et al., 2022). In their systematic review of the qualitative literature investigating the lived experiences of siblings of autistic people, Leedham et al. (2020) reported that siblings discussed positive experiences such as love and empathy and a connection with their sibling, as well as the more negative experiences of having to take on the role of carer, experiencing aggressive behaviours and feeling overlooked within the family. The majority of studies have reported only on the perspective of the sibling without a disability, and relatively few studies have explored sibling relationships from both the perspective of the individual with a disability and their sibling (Richardson & Jordan, 2017). One exception was a study completed by Rossetti et al. (2020), who interviewed dyads; an individual who had an intellectual or developmental disability (either Down Syndrome or autism) and their sibling. Most dyads reported positive sibling relationships, describing an emotionally close relationship and

being in regular contact with one another. However, this was not consistent across all dyads with three of the eight dyads reporting not being emotionally close.

It is also worth considering that the nature of the disability itself may impact on the relationship between siblings; Tomeny et al. (2017) reported that siblings of autistic individuals may possess less positive attitudes about their sibling relationships compared to siblings of individuals with an intellectual disability. These attitudes may be due to the social difficulties which are central to an autism diagnosis (American Psychiatric Association, 2013) impacting on the relationship. Perceptions of the relationship may then change as the siblings get older and develop a better understanding and acceptance of disability (van der Merwe et al., 2017).

While there may be some level of conflict within a sibling relationship, the generally positive nature of the relationship often leads to siblings being close and in frequent contact with one another. Added to the fact that this close relationship may span a lifetime, it is no surprise that siblings may be considered key communication partners for the AAC user (Dew et al., 2011). Another aspect of a close relationship which further supports the sibling's role as a communication partner is the extended time they spend together.

3.4.2 Time Spent Together

While not true for all siblings, many siblings live together in the same household. According to the 2016 Irish census data, over 72% of children (n= 910,6356) under the age of 18 live with a sibling also under the age of 18 (Central Statistics Office, 2017). This number does not account for any adult siblings still living in the home, so the actual number of siblings living in the same house may be higher (Central Statistics Office, 2017). Living in the same house allows for many opportunities for siblings to spend time together, especially during childhood. Dunifon et al. (2017) compared the discretionary time use of children with and without siblings using time diary data. They reported that siblings spend most of their time together; about 50% engaged with one another and a further 20% present together but not engaged in an activity. Siblings, when one sibling has a disability, are also reported to spend time together in childhood (Diener et al., 2014; Paul et al., 2022). However, this finding has not always been the case. In Ireland, people with disabilities have historically been excluded from society and lived separately in institutions or group homes (Flood, 2013; Murphy & Bantry White, 2020). This exclusion has changed in recent decades, during which a more community-based approach has been implemented, allowing individuals with a disability to live in the community and have the opportunity to participate in society (Working Group on Congregated Settings, 2011).

Most children therefore have the chance to grow up in the family home, participate in family life and potentially attend school alongside their siblings (Flood, 2013). These changes allow the siblings to then spend more time together which is vital to building and maintaining their relationship. Dew et al. (2014) conducted interviews with 12 adults with moderate to severe cerebral palsy and 16 of their adult siblings. The authors reported that siblings who grew up apart were less likely to know each other well and keep in close contact as adults compared to siblings who lived together throughout their childhood.

Spending a significant amount of time together not only benefits the building and maintaining of relationships, but also provides many opportunities for the siblings to interact and communicate in a natural environment. Furthermore, the time siblings spend together is across environments. Not only do they spend time together in the home, but they may attend the same school, same extended family gatherings, and same community settings (White & Hughes, 2017). As discussed in Chapter 2, a supportive natural environment is crucial in aided language learning (von Tetzchner & Stadskleiv, 2016) and siblings may spend a lot of time interacting with one another in these environments. Home and family are key contexts for communication and aided language learning for the AAC user (Beukelman & Light, 2020). Spending a significant amount of time together across natural environments is one feature of the sibling relationship which underpins their value as an important communication partner. The intimate sibling relationship and the extended time spent together especially during childhood also allows for the sibling to have an influence on the development of the AAC user, and vice versa.

3.4.3 Sibling Influences on Development

A sizable body of research has focused on the influence that siblings may have on one another. For siblings pairs who are close in age, siblings are an important social partner, providing an early opportunity for social interactions with other children (White & Hughes, 2017). These interactions, happening regularly with the extended time siblings spend together (Dunifon et al., 2017) provide the siblings with time to learn new ideas, skills and behaviours through observation of one another (Howe et al., 2002). In addition to the direct modelling and reinforcement of behaviours, siblings may also influence one another through differentiation (i.e., a method of social comparison, where instead of looking to emulate their sibling, individuals try to differentiate themselves from them by developing dissimilar personality qualities and interests) (Whiteman et al., 2009). Furthermore, siblings may not only exert direct influence on each other, they may also indirectly influence one another through family and the environment. Sibling relationships

do not occur in isolation, but rather as part of the larger family system. As is posited in family systems theory, the individuals and subsystems may impact and be impacted by other members and subsystems (Turnbull et al., 2015). As such, parent relationships with another sibling may impact on an individual, through parental learning, parent differential treatment and resource dilution (i.e., reduced parental time and support due to parent's time being spread across siblings) (McHale et al., 2012).

The areas in which sibling influence has been recorded are wide ranging. Siblings may influence the development of socio-emotional skills, for example pro-social behaviours (Hughes et al., 2018; Smorti & Ponti, 2018) and emotional intelligence (Chandran & Nair, 2015). Siblings provide opportunities for practicing negotiation, conflict resolution, and cooperation, which are essential skills for successful peer interactions and forming friendships (Howe et al., 2022). However, sibling conflict and sibling aggression have also been linked to negative outcomes; Tucker et al. (2013) found that children who experienced sibling aggression in the preceding year reported increased mental health difficulties compared to those who had not experienced sibling aggression.

Not all siblings influence each other in the same way. There often exists a power-imbalance across siblings, with older siblings holding a position of greater power and being seen as a role model, more likely to influence younger siblings more often than the reverse (Buhl, 2009). However, the relative power between siblings is reported to often become more balanced during adolescence (Lindell & Campione-Barr, 2017). Furthermore, birth order, age difference, and gender may also impact on the relative influence one sibling has on another (McHale et al., 2012).

In addition to having an impact on socio-emotional development, siblings may also have an impact on cognitive development. Siblings have been recorded to act as teachers and mentors (Howe et al., 2016), and links have been reported between siblings' academic achievement (Bouchey et al., 2010), theory of mind and executive functioning skills (McAlister & Peterson, 2013). Siblings may also support communication skill development (Beffel et al., 2022), for example an older sibling scaffolding the communication of a younger sibling and creating shared meaning (Leach et al., 2015). Siblings' roles as a teacher and influencer of a multitude of skills underpins their importance as a communication partner for AAC users. Communication partners are reported to have roles in supporting the development of the AAC user (von Tetzchner & Stadskleiv, 2016), something which is already present in many sibling relationships. Siblings as communication partners have the opportunity to support and influence the AAC user's development in many naturally occurring interactions across a range of natural environments.

Conversely, the influence that having a sibling with a disability may have on an individual should also be considered when discussing sibling influence on development. There have been reports of a positive influence on the skills and behaviours of siblings of individuals with a disability. Siblings of individuals with a disability are reported to be more likely to have resilience, empathy, compassion and independence (Roberts, 2021) as well as increased prosocial behaviours (Orm et al., 2021). However, there have been reports of negative impacts on the mental health and quality of life of siblings. For example, sibling of individuals with a severe disability may be at an increased risk of anxiety, depression and receiving less parental support (Roberts, 2021). Another study completed by Fullerton et al. (2017) reported that siblings of children with life-limiting conditions presented with significantly higher levels of emotional difficulties, behavioural difficulties, personal strain as well as a lower quality of life compared to population norms. Evidence of the impact of having a sibling with a disability is inconclusive, potentially in part be due to the diversity across individuals with a disability, (e.g., their personalities, the type of difficulties they face and the severity of these), the siblings, the sibling relationship and the family environment. More research is needed to provide a greater understanding of this topic (Lamsal & Ungar, 2019), however given that there is evidence that siblings may be at risk of mental health difficulties and a lower quality of life, sibling wellbeing and interventions to support siblings should be facilitated (Hanvey et al., 2022). In addition to acting as a teacher and influencing one another's development, siblings of AAC users may occupy other roles.

3.4.4 Unique roles

The sibling of the AAC user may be present in many aspects of the AAC user's life as reflected in the range of roles siblings are reported to potentially occupy. Siblings, in general, are reported to assume a multitude of roles. These roles are not mutually exclusive, they may be occupied simultaneously, and they may change as the individuals grow and develop (Buchanan, 2021; Dunn, 2015). The roles of advisor and confidant (Connidis, 2007; Killoren & Roach, 2014), competitor (Hindle & Sherwin-White, 2014; Kretschmer & Pike, 2010), protector (Myers & Bryant, 2008; Serdity & Burgman, 2012), comforter (Wu et al., 2018) and a provider of support (Thang et al., 2021) have been recorded in studies of typically developing siblings. Siblings often report themselves to be friends during childhood and adolescence (Hamwey et al., 2019; Hernández-Hernández et al., 2016; White & Hughes, 2017). This role of companion is reported across the lifespan; Rosen et al. (2002) surveyed 101 young adults aged 18 to 22. When asked to describe their sibling relationships, the most common description was as a good

friend, and someone 'to hang out with'. Similarly, when Myers (2011) asked adults why they maintained their sibling relationships, friendship was one of the themes which was identified.

While not a unique role to siblings of AAC users, the role of friend may be of particular importance, especially during childhood and adolescence. While friendships between AAC users and peers have been recorded (Anderson et al., 2011), a frequent challenge for AAC users is developing and sustaining meaningful peer relationships (Batorowicz et al., 2014; Cooper et al., 2009; Østvik et al., 2017). AAC users more often interact with adults than peers (Batorowicz et al., 2014; Chung et al., 2012) impacting on the opportunities for social development. Siblings may fulfil this role, acting as a friend and providing the opportunity for the AAC user to develop a social relationship with a similar aged peer, thus supporting their social development (Batorowicz et al., 2014).

Siblings of individuals with a disability have been reported to take on additional caring and support responsibilities. Roberts (2021) completed a literature review on siblings of individuals with severe intellectual and developmental disabilities and found evidence supporting increased caregiving responsibilities across the lifespan. One study which found such evidence was Heller and Kramer (2009) who surveyed 139 adult siblings of individuals with a disability. They found that although few families reported making future plans or involving siblings in planning for the future, 36% of siblings expected to be primary caregivers for their sibling. Similarly, Kruithof et al. (2021) reported that of the thirteen siblings they interviewed, all expected to inevitably assume the responsibility of caring for their sibling with a profound disability. Mothers and typically developing siblings reported that even in adolescence siblings took on a precocious sense of responsibility, reporting to support the family when parents were tired or giving up plans to care for their autistic sibling (Corsano et al., 2017). Sibling characteristics may influence whether they take on a carer role. Sisters and lone siblings of individuals with a disability were reported to assume greater caregiving responsibilities, especially if they live close by (Burke et al., 2012). Even though taking on the role of carer may be anticipated by all stakeholders, siblings should be supported if taking on this additional role (Redquest et al., 2021). Discussion about role expectations should be initiated before siblings take on this role in later adulthood (Kruithof et al., 2021), as even those as young as 15 to 25 report worries for the future and requiring support (Rawson, 2010).

As discussed earlier in this chapter, sibling relationships can be diverse in nature, with varying levels of warmth, closeness, rivalry and conflict (McHale et al., 2012). In part due to this diversity, there is no one unified profile of roles that siblings play in the lives of individuals with a disability. Hall and Rossetti (2018) surveyed 79 participants between the ages of 19 and 72 who had a sibling presenting with a severe intellectual or

developmental disability. They found siblings of individuals with a disability reported occupying multiple roles, including roles of friend, advocate, legal representative, leisure planner and informal service coordinator. While caregiving was one of the most commonly reported roles (n=51, 64.6%), an equal number of participants reported being a friend to their sibling. Conversely, two of the participants reported having no role in their sibling's life. Using the same data set as Hall and Rossetti (2018) but broadening the criteria to include siblings of individuals who had a mild to profound intellectual or developmental disability (n=171), Rossetti et al. (2018) observed that the multiple roles siblings occupied tended to cluster in patterns. For example, the largest cohort of participants (n=65) fell into a 'companion' cluster, reporting to be a friend and sibling, but less likely to be a service coordinator or legal representative. Another reported cluster were siblings who were 'needs-focused' (i.e., occupying roles which focused on the provision of necessary and appropriate services to support their sibling's needs). These 13 siblings were reported to be a caregiver, advocate, and informal service co-ordinator. The least common cluster of roles was that of a 'professional' sibling (n=7), who did not report being a caregiver or friend, instead their role focused solely the formal and legal aspects of their sibling's life (e.g., being a legal representative, advocate and informal service co-ordinator). The final two role clusters reported were related to the number of roles siblings took on; those in the highly involved cluster were reported to occupy nearly all of the roles at a higher incidence than participants in other clusters, while those in the least-involved cluster were the opposite. In this cluster, participants were reported to occupy, on average, just two roles each (Rossetti et al., 2018).

However, it must be noted that most research on sibling relationships involving individuals with a disability have focused on the perspectives of the typically developing sibling and the parent(s), rather than the individual with a disability (Richardson & Jordan, 2017). One of the exceptions to this trend is the study carried out by Avieli et al. (2019). They researched sibling relationships involving disability through a life course perspective by interviewing 15 family units, each comprising a parent, a sibling with a disability and a sibling without a disability. Similar to Rosetti et al., (2018), the authors found that siblings could be categorised into five patterns (Table 3.1). These five patterns of involvement highlight the large differences that may exist across siblings, for example those who are close friends and have a co-dependent future, compared to estranged siblings who are reported to be unconnected to one another, two separate entities.

The range of roles siblings may occupy, and thus their involvement in the life of the AAC user, is one factor which underpins their importance as a communication partner. It is important, however, to recognise that being a communication partner may only be one of the many roles siblings are expected to play. As such, every sibling

communication partner may have different experiences and expectations of what their roles are, and their underlying reasons for assuming that role, for example out of friendship versus familial responsibility (Avieli et al., 2019). This finding further underpins the uniqueness of each sibling relationship.

3.5 Summary

There are several unique features to sibling relationships which make siblings important communication partners to consider in AAC interventions. These features are the intimate and longstanding relationship, the extended time spent together, their influence on development and the range of roles they may occupy in the life of the AAC user. Siblings can provide a vital environment for social development, especially important for AAC users in light of the challenges they encounter with peer relationships (Batorowicz et al., 2014; Cooper et al., 2009). It is important to recognise that due to this potentially close and longstanding relationship, siblings may have a very good knowledge of the AAC user's interaction and communication styles. Siblings may already have a wealth of knowledge and skills in relation to the AAC user and communication which SLTs should consider when planning an intervention. However, while these unique features may mean siblings are well positioned to be important communication partners, siblings may not always have the required skills to be an attuned communication partner. Siblings, similar to other communication partners, may require training and support to become attuned communication partners.

Pattern	Family Members' Perception of the Sibling With Disability	Shaping Family Dynamics Along the Life Course	Meaning of Siblings' Relations in Adult Life
<i>"Not a Child, but a Parent Caretaker" – The Parent Surrogate Sibling</i>	Positive and accepting perception, central figure in family life, takes priority over everything else	Reciprocity, compensation mechanism, lifelong grooming to replace the parents	Blood ties – total commitment to taking on the parental role
<i>"Somehow, We Grew Apart" - The Estranged Sibling</i>	Mixed feelings- close to parents, distant from sibling	Parents-sibling with disability coalition, the sibling without a disability is a neglected "outsider". Unbridgeable gap between the triad coalition and the sibling without disability	Two separate entities with loose ties and obligations
<i>"It is Important for Me to Maintain Some Kind of Distance" - The Bystander Sibling</i>	Intensive task that may lead to a sense of burden	Providing an intentional individuation as a means of preserving future resources for the challenge of the future commitment	Being in "standby" position to take over the caregiver role
<i>"When There's Something They Want to Tell Him, They Always Send Me" - The Mediator Sibling</i>	An "outside" who disrupts the family "we-ness"	Avoiding direct communication, using the sibling without disability as a mediator to solve family issues	Resentment, feeling that the relationship is unauthentic
<i>"I Love Him to Death" - The Friend Sibling</i>	An "entire universe"; supporting, helpful; the disability is not a factor	Lifelong partnership that goes beyond the disability	Friendship that leads to a shared destiny and co-dependent future

Table 3.1 Patterns of Siblings Growing Up with Disability Over the Life Course, Taken from Avieli et al. (2019, p. 1746)

Chapter 4: Engaging Communication Partners in Communication Partner Training Interventions

4.1 Introduction

This chapter will provide a review of the relevant research evidence on training communication partners, with a specific focus then on sibling communication partner training. Next, an overview of family engagement in interventions is presented, including what the term 'engagement' encompasses, how SLTs can support engagement and specific considerations when supporting the engagement of siblings in communication partner training interventions.

4.2 Training Communication Partners

Communication partners, especially familiar partners such as parents and siblings, play many important roles in the lives of AAC users. However, just as the use of an AAC system is not intuitive and has to be explicitly taught and learned, effectively occupying these roles, such as facilitating aided language learning and supporting communicative competence, is also not an intuitive process (Berenguer et al., 2022). Many communication partners have no prior experience interacting with AAC users and may have no knowledge of how to adapt their behaviours to effectively act as a communication partner (Beukelman & Light, 2020). While communication partners may have the best of intentions and think they are doing the right thing, studies have shown that sometimes the strategies used result in a suboptimal outcome, potentially acting as a barrier to communicative participation (Donato et al., 2018; Moorcroft et al., 2019). For example, communication partners may not recognise the communicative attempts of an AAC user (Holyfield et al., 2018). They may unknowingly dominate interactions and provide few opportunities for communication for the AAC user (Bedrosian, 1999). Communication partners may also struggle to attune their communication style to fit the AAC interaction, dominating conversations by initiating turns, while reports of the AAC user initiating turns is less frequent (Clarke & Wilkinson, 2010). This interaction style can lead to the AAC user being restricted to a passive role in the interaction and potentially developing a limited range of communication functions and linguistic forms (Kent-Walsh & McNaughton, 2005). Communication partner training interventions can help partners to become better attuned communication partners and enhance their skills to support communicative competence, aided language learning and create a communicatively accessible environment.

Communication partner training interventions have been found to effectively increase the skills demonstrated by the communication partner in interactions with AAC users. Shire and Jones (2015) reported primarily large effect sizes in studies examining communication partner strategy implementation in their systematic review of interventions designed to support communication partners of children who use AAC. Training communication partners has also been reported to benefit the aided language learning of AAC users. Kent-Walsh et al. (2015) found that communication partner trainings were highly effective for improving AAC user's communication skills. However, while the majority of studies in these reviews reported positive results, this finding was not universal. For example, Chang (2009) reported only small effect sizes and Nunes and Hanline (2007) reported mixed results. Inconsistent results may relate to variables associated with the participant, intervention and outcome characteristics of that specific training. For instance, Kent-Walsh et al. (2015) reported a smaller effect size ($IRD=.69$) for individuals with a primary diagnosis of autism spectrum disorder (ASD) as compared to other primary diagnoses (IRD range $.86-1.0$), which the authors theorised was due to the potential social challenges that autistic individuals face. Other characteristics which may impact on intervention effectiveness included participants' age, instructional strategies used, skills targeted and what outcomes were measured (Kent-Walsh et al., 2015). As such, when designing a communication partner intervention, SLTs must consider several factors, such as (i) who to engage in the intervention, (ii) who to consult when planning an intervention, (iii) what knowledge or skills to teach, and (iv) how to teach these (Beukelman & Light, 2020). These factors are considered in more detail in the next section.

4.2.1. Who to Engage

Communication partner interventions have been reported to be effective across communication partners. In Kent-Walsh et al. (2015) systematic review and meta-analysis, studies provided AAC communication partner training to caregivers, educational assistants, parents, peers, and teachers. There have also been reports of training less familiar partners in the community (Solarsh & Johnson, 2017). As discussed in Chapter 2, family are often key communication partners, and many studies report positive outcomes from training family members, either as a whole (Douglas et al., 2021; Douglas et al., 2023) or as separate individuals (Hacker et al., 2023; Timpe et al., 2021). While many different individuals may be involved in training, the roles a specific communication partner is expected to take on may differ across different partner groups. Familiar adult communication partners, for example parents and teachers/educational

assistants are more likely to take on the role of teacher, supporting aided language learning and the development of other communication skills. However, the undertaking of a teacher role is not often the case for child communication partners, for example peers or siblings. These individuals are rarely expected to specifically teach the AAC user a new skill. Instead, peers present an opportunity to engage in social interaction with individuals of a similar age and develop friendships, which is important in enhancing individual's quality of life (Bukowski et al., 2009). Communication partner interventions targeting peers reflect this difference in role as compared to parents or teachers. While some studies do have the peer in the role as teacher (Lorah et al., 2019), most studies focus on the peer's role as a friend and playmate, with the target outcomes of developing social skills and supporting interactions between the peers (Chung et al., 2012; Therrien et al., 2016).

4.2.2 Who to Consult

It is also important to consider who should be consulted when planning a communication partner training intervention. There are a number of key stakeholders who could be consulted. The communication partner themselves may already have skills or knowledge which could be built on, as well as ideas of what they would like to learn. The communication partner, especially if they know the AAC user well may have their own ways of communication which should be understood and then intervention designed to support and develop these methods (Doak et al., 2021). It may be important to consult with other professionals working with the AAC user, for example occupational therapists or psychologists, to understand any other strengths and needs of the AAC user which may impact on what the communication partner could benefit from learning (e.g., regarding challenging behaviours or sensory needs).

Another key stakeholder who could be consulted is the AAC user themselves. Over the previous decades, there has been an increasing awareness of the importance of the involvement of individuals with disabilities in decisions that impact them, for example the 'Nothing About Us Without Us' movement (Charlton, 1998; United Nations, 2004). However, this has not been reflected in the AAC communication partner training literature. Few studies have consulted with AAC users regarding what they would like communication partners training to involve. One study (Midtlin et al., 2015) did explore the opinions of AAC users. AAC users reported wanting communication partners to have the knowledge and skills to initiate communication with the AAC user, repair communication breakdowns, give the AAC user time to communicate, and take time to understand and co-construct the meaning of the message (Midtlin et al., 2015). Even

following a communication partner training intervention, few studies have gathered feedback from AAC users regarding communication partner involvement – although those that did have reported positive feedback by the AAC user (Biggs et al. 2017; Biggs et al., 2018).

4.2.3 What to Teach

Binger and Kent-Walsh (2012) discussed where to start when selecting skills to teach communication partners. They propose focusing on the AAC user skills that are closely linked to desired client outcomes. They advise identifying and teaching the partner strategies which will support these skills. One skill which has been repeatedly proven to benefit an AAC user and likely to be helpful for all communication partners to know is modelling. Sennott et al. (2016) completed a systematic review of the effects of aided AAC modelling on the language skills of AAC users. They included 10 studies in their final analysis, five of these studies focused primarily on natural communication partners, (i.e., not clinicians). The authors found that AAC modelling intervention packages completed by natural communication partners across these five studies led to meaningful gains across three linguistic areas; pragmatics (e.g., increase in communicative turns), semantics (e.g., increase in receptive and expressive vocabulary), and syntax (e.g., increase in multi-symbol AAC turns). These positive results were corroborated by other reviews of aided language modelling completed by Biggs et al. (2018) and O'Neill et al. (2018).

The knowledge and skills that may be taught during a communication partner training intervention will depend on the goals of the intervention itself. Interventions may focus on one or multiple objectives. If the purpose of the intervention is to enhance the communication partner's ability to support communicative competence, then the skills taught will be focused on changing the interaction patterns of the communication partner. For example, these may include the use of extended pause time or expectant delay, being responsive to communicative attempts, using open-ended questions and confirming understanding of the meaning (Kent-Walsh & McNaughton, 2005). A set sequence of strategies may also be taught, for example the 'Plan, Talk, Wait, Respond' strategy (Douglas et al., 2018) during which communication partners are taught to *plan* a fun activity that both they and the AAC user can enjoy and allows for a lot of communication opportunities. Next communication partners are encouraged to *talk* to the AAC user by providing choices, asking questions, and commenting about the activity. Communication partners are then taught to *wait* for at least 5 seconds after they talk to give the AAC user an opportunity to communicate. They are also instructed to repeat

the talk step if the AAC user does not communicate after this wait time. Finally, communication partners are encouraged to *respond* to every communication attempt, even if it was unclear.

Similarly, if an intervention goal is to promote a communicatively accessible environment, then skills for setting up the environment to foster communication and ensuring communication partners and AAC is accessible and available will be the focus (Beukelman & Light, 2020). Alternatively, if the intervention aim is to provide communication partners with the necessary skills to support aided language learning, then different skills may be targeted. Ultimately, the skills required for the communication partner to know will depend on the AAC user, the partner, and the context.

4.2.4 How to Teach

Similar to the variety in skills taught during an intervention, there are a range of communication partner training methods reported in the literature, with studies regularly not reporting the procedures they took in detail. One model that is well described is Kent-Walsh and McNaughton’s (2005) 8-step model for teaching strategies to communication partners. See Table 4.1 for a list and description of the eight steps.

Table 4.1 The 8 Step Strategy for Communication Partner Instruction Outlined by Kent-Walsh and McNaughton (2005, p. 198)

	Stage	Description
1	Pre-test and Commitment to Instructional Program	<ul style="list-style-type: none"> • Instructors take pre-test measurements of communication partners’ spontaneous use of the targeted strategy and the communicative participation of the AAC user in the natural environment. • Instructors introduce the targeted strategy and the training protocol to communication partners. • Instructors and communication partners discuss communication partners’ pre-test strengths and weaknesses in implementing the targeted strategy. Communication partners commit to participating in the instructional program in order to acquire the targeted strategy
2	Strategy Description	<ul style="list-style-type: none"> • Instructors describe the targeted strategy and its component skills, as well as the method for remembering the steps involved in implementing the strategy.

		<ul style="list-style-type: none"> • Instructors discuss the impact of implementing the targeted strategy with communication partners and with AAC users, and/or their parents or caregivers.
3	Strategy Demonstration	<ul style="list-style-type: none"> • Instructors model use of the targeted strategy (and its component skills) and give metacognitive explanations of all steps performed
4	Verbal Practice of Strategy Steps	<ul style="list-style-type: none"> • Communication partners practice naming and describing all steps required to implement the targeted strategy.
5	Controlled Practice and Feedback	<ul style="list-style-type: none"> • Communication partners practice implementing the targeted strategy in controlled environments with gradual fading of instructor prompting and feedback.
6	Advanced Practice and Feedback	<ul style="list-style-type: none"> • Communication partners practice implementing the targeted strategy in multiple situations within the natural environment, with gradual fading of instructor prompting and feedback.
7	Post-test and Commitment of Long-Term Strategy Use	<ul style="list-style-type: none"> • Instructors document and review communication partners' mastery of the targeted strategy and check performance against the baseline of communication partners' strategy implementation and the communicative participation of the AAC user. • Instructors elicit feedback on the impact of the communication partners' implementation of the targeted strategy from the AAC user, and/or their parents or caregivers. • Instructors assist communication partners in generating action plans for maintenance and generalization of the targeted strategy.
8	Generalization of Targeted Strategy Use.	<ul style="list-style-type: none"> • Communication partners practice implementing the targeted strategy across a wide range of settings and plan for long-term implementation of the strategy.

These eight steps have been successfully implemented in multiple studies (e.g., Ogletree et al., 2015; Rosa-Lugo & Kent-Walsh, 2008; Senner et al., 2019), and have been incorporated into the ImPAACt Programme, a communication partner instructional protocol which details skills to target and an instructional approach to take when training

communication partners (Kent-Walsh & Binger, 2013). Instructional strategies in communication partner interventions should be based on principles of learning, for example ensuring the relevance of the skills being taught, building on participants prior knowledge, and choosing strategies depending on the needs of the communication partner (Thiessen & Beukelman, 2013).

The decisions on what to teach and how to teach it will ultimately depend on the specific AAC user and communication partner. One significant partner group who have been relatively under-studied in interventions are siblings.

4.2.5 Sibling Communication Partner Training

An overview of communication partner training interventions was discussed above. However, siblings have rarely been reported to have been involved in communication partner training interventions (e.g., Biggs et al., 2019; Kent-Walsh et al., 2015) and as such information on their involvement and best practices are sparse. This section will provide a review of the existing research evidence on sibling involvement in communication partner training interventions.

Siblings have been reported to be a part of a whole family training. Douglas et al. (2021) explored the use of tele-practice as a means of delivering an aided language modelling intervention to a whole family. The target child was a 4-year-old, Ashley, who used a speech generating device, which was introduced four months prior to the study. Most of Ashley's immediate family were involved in the intervention, her mother, father, older sister and older brother. Her younger brother was 2 years old and deemed too young to take part. The training consisted of two sections, tele-based training of skills and tele-based coaching with observation and feedback. During the individual training, each family member was taught how to provide aided language modelling during a natural, home-based activity through four steps: prepare, show, wait and respond. The training was followed by individualised coaching sessions consisting of online observation of the family member and Ashley interacting together. These sessions were each preceded by a pre-observation session of reflection and planning and followed by feedback. While there was some variability in the data, the authors reported Ashley's independent communication and device use increased modestly when family members were modelling the device.

The training was effective for all family members in teaching them the aided language modelling strategy. Similar to improvements demonstrated by both parents, both Ashley's brother and sister demonstrated an immediate increase in their use of high-fidelity AAC models and in their rate of AAC models, with no overlap between baseline

and intervention data. Although as maintenance data was not recorded for the brother and only one session was recorded for the sister, it is unclear whether these improvements would be sustained over a long time period. Training the whole family was viewed as positive due to the mutual support in the process. In addition, Ashley's mother reported the intervention had a positive impact on Ashley's participation in the family, as everyone knew how to communicate with her (p.1166). The authors emphasised the importance of differentiating the sessions to support the individual participants' needs. For example, in the training intervention, the authors reported incorporating learning principles appropriate for child and adult learners (e.g., memory aid and self-reflection), and simplifying the language used during the sibling training sessions.

A similar study was reported by Douglas et al. (2023). The target child was older, Amber, aged 7, and the family members involved differed slightly to those in the Douglas et al. (2021) study (e.g., a mother, father, older brother, great aunt and aunt instead of a mother, father, brother and sister). Another difference was that a cascading model of support was implemented. The training was the same as described above in Douglas et al. (2021), however, the coaching aspect was performed by the mother in the study, who was supported by the researcher. Similar to the results in Douglas et al. (2021), training was reported to be successful in teaching family members, including the brother, to implement aided language modelling with fidelity. In addition, the brother immediately increased his rate of aided language modelling after training. This increase was variable across the coaching sessions but did not overlap with the baseline data recorded.

These studies demonstrate that whole family training and coaching can increase the fidelity and rate of sibling use of aided language modelling. In addition, to sibling involvement as part of a whole family, there have also been two studies which have reported to effectively train siblings of AAC users in a sibling-only training: Douglas et al. (2018) and Hacker et al. (2023).

Douglas et al. (2018) completed a pilot study using a single-subject multiple probe design to evaluate a sibling communication partner training programme. Three sibling pairs were involved in the intervention, each comprising an AAC user and their older, typically developing, sibling. The siblings underwent a training intervention, which lasted two sessions and followed the instructional components of Kent-Walsh and McNaughton (2005). The siblings were taught the strategy 'Plan, Talk, Wait and Respond' to use when interacting with the AAC user. This training resulted in positive outcomes for the typically developing sibling, with a reported increase in the amount of talking they did with their sibling and their frequency of responding to their sibling's communication attempts. There were also positive outcomes reported for the AAC user, with an increase in communication turns reported. However, there was variability in the

results reported across dyads, with the oldest sibling, nearly 15 years of age, demonstrating the most effective change.

Similarly, Hacker et al. (2023) also reported positive outcomes in their sibling training intervention. The authors implemented an online training and coaching programme for siblings aiming to increase their aided language modelling to support the social interactions of the AAC user. Four dyads participated in the intervention, with two dyads from the same family (i.e., AAC user and two of their siblings). The authors reported that all siblings increased their high-fidelity use of the aided language modelling strategy during training and coaching, and maintained this increase after the coaching sessions were finished. However, there were no conclusive results on the impact of the training on the AAC users' communication. The authors did find that the AAC user used AAC more as a mode of communication during the intervention than during the baseline phase (30.5% compared to 6.5%), however this outcome was not examined in detail.

Ultimately, both studies reported that siblings can learn to implement communication strategies that may impact the communication of the AAC user. However, this finding is not consistent across all sibling dyads. While social validity measures in both studies demonstrated that the majority of participants and family members found the intervention to be of benefit, interventions may need to be more specific to the individual sibling in order to promote the best outcome for the intervention. Douglas et al. (2018) suggested ensuring the training is age appropriate for the sibling, making it short, engaging and motivating for all involved. Engagement is one key variable which should be acknowledged when considering positive outcomes in an intervention. Practitioners must be aware of how best to support sibling engagement with an intervention.

4.3 Engaging Siblings in Communication Partner Interventions

4.3.1 What Constitutes Engagement?

As outlined briefly in the introduction of this thesis (Section 1.3.2), the term engagement can have a variety of meanings. For example, engagement can be used to describe how individuals engage in interactions with one another (e.g., joint engagement between an adult and child; Hahn et al., 2016), how individuals engage with health research (Chudyk et al., 2018) or how individuals engage with services (e.g., mental health services; Anderson, Howarth, Vainre, Jones & Humphrey, 2017). For this thesis, the focus is on therapeutic engagement. Therefore, the term engagement in this thesis will be considered and discussed through a therapeutic engagement lens, that of individual's

engagement with a specific therapeutic intervention (e.g., communication partner training). See Figure 4.1 for a definition and key components of engagement as it relates to engagement with interventions as discussed in this thesis.

Engagement may refer to the involvement of the individual who has a specific need for support, although in cases where a child is the service user, it is the engagement of family, or more often just parents, which may be considered (Knafl et al., 2017; Melvin et al., 2020). As such, the concept of engagement will be discussed below as it applies to service users and families. Specific factors when considering how best to support siblings to engage with communication partner training interventions will then be examined.

There is no one agreed upon definition of engagement (D'Arrigo et al., 2017). Historically, engagement has been recorded as a static behavioural concept, measured by service attendance, drop out and adherence to recommendations (Staudt, 2007). However, there is a growing consensus that these behavioural aspects alone do not encapsulate the full meaning of engagement. More recent conceptual reviews of engagement have highlighted its multidimensional nature, which includes affective, cognitive, and behavioural aspects (King et al., 2014; Steinhardt et al., 2022). The affective domain refers to the individual's emotional involvement in the process and with the professionals, the cognitive domain refers to individuals' beliefs about the need for intervention and its effectiveness, and finally the behavioural aspects are those behaviours which the individual demonstrates themselves, for example attending sessions, listening and asking questions (King et al., 2014). SLTs must therefore consider all three domains of engagement when considering how to support communication partners to engage with an intervention, as well as how to measure engagement and understand what someone who is 'engaged' may present like.

Melvin et al. (2021) identified what SLTs perceived an 'engaged' family to be. They used group concept mapping to identify seven clusters of aspects of an 'engaged' family; see Table 4.2 for a list of these clusters. The clusters all focus on what behaviours were perceived indicative of family engagement. However, the study only examined SLT perspectives and not the opinions and experiences of the family. Additionally, framing engagement in terms of what an 'engaged' family looks like may undermine the co-constructed nature of engagement and the role the SLT has to play.

Perceived Characteristics of an ‘Engaged’ Family
1. The family is reliable and ready for therapy
2. The family has an open, honest relationship with the SLT
3. The family actively participates and takes initiative
4. The family works in partnership to plan and set goals together
5. The family sees and celebrates progress
6. The family invests in intervention at home
7. The family understands intervention and advocates for their child

Table 4.2 Clusters of Statements on Perceptions of an ‘Engaged’ Family, Adapted From Melvin et al. (2021, p. 242)

A conceptual review of engagement completed by Bright et al. (2015) highlighted the co-constructed and complex nature of engagement. Following this review, Bright et al. (2015, p. 650) defined engagement as “*a co-constructed process and state. It incorporates a process of gradually connecting with each other and/or a therapeutic program, which enables the individual to become an active, committed and invested collaborator in healthcare*”. Viewing engagement as a co-constructed process shifts the responsibility to engage from the AAC user and their family alone to the individual, family, and SLT together. This view highlights the importance client-practitioner relationship in supporting engagement. In addition, perceiving engagement as being co-constructed highlights the SLT’s role in supporting the engagement of an AAC user and their family.

Engagement can also be mapped as a pathway through time. This pathway starts before the intervention sessions begin with participant awareness and then interest in attending. Next the participants make initial contact with the intervention, including responding to the recruitment invitation or enquiring further about the intervention. Following this, the intervention is started with participants attending and participating in the sessions. Engagement with an intervention continues after the intervention sessions have finished through maintenance or generalisation of skills, completing homework tasks and spreading the word to other potential participants (Nobles et al., 2018). SLTs must be aware of the ongoing nature of engagement, as well as their role in supporting, or impeding, engagement at each stage of an intervention. There have been reports of significant rates of attrition prior to enrolling in interventions. For example, Chacko et al. (2016) reported at least 25% of those identified as appropriate for a behaviour parent training program did not enrol. SLTs should not only consider how to support communication partner attendance and participation during sessions, but also how to support engagement with recruitment efforts and decisions around attending a communication partner training intervention.

Engagement as referred to in this thesis involves how an individual connects with a specific therapeutic intervention (e.g., communication partner training). It is multidimensional in nature, including affective, cognitive, and behavioural aspects. It is not static and may change over time depending on a multitude of factors. Therapeutic engagement is co-constructed between the individual and the practitioner. An individual who is engaged and who is supported to engage with an intervention, may be an active collaborator in the intervention. While collaboration is a key aspect to therapeutic engagement, the term engagement as it relates in this these encompasses more than just collaboration, for example active participation, the individual's emotional involvement with the intervention, and the individual's beliefs about the intervention.

Figure 4.1 Definition and Key Components of Engagement, as it Relates to Therapeutic Engagement as Discussed in This Thesis.

4.3.2 Supporting Engagement

Effective engagement has been linked to benefits including better quality of care, improved treatment results and increased patient satisfaction (Marzban et al., 2022). Similarly, poor engagement has been linked to limited rehabilitation benefits as measured by interventionists (Medley & Powell, 2010). In AAC interventions, engagement with the AAC user and family is vital, with a risk of AAC rejection or abandonment if engagement is not appropriately consolidated and supported (Moorcroft et al., 2019). While a system may be rejected or abandoned for a number of reasons, including personal choice (Smidt & Pebdani, 2023), abandonment or rejection of a system may leave the AAC user without a reliable and efficient communication method. In addition to promoting positive outcomes, supporting family engagement with communication partner training interventions is vital due to the centrality and interconnectedness of family members, and the roles they play as communication partners in the lives of AAC users, as was discussed previously. The more individuals who engage well in training interventions, the more skilled partners for the AAC user to interact with, thus creating an accessible communicative environment (von Tetzchner & Stadskleiv, 2016)

4.3.2.1 Factors Influencing Engagement

Many factors may influence how an individual engages with an intervention. Supplee et al. (2018) categorise engagement factors into four groups: participant, provider, programme and community. Participant level factors include participant demographics,

motivation, and alignment with the programme's design. For instance, families who perceive themselves as having a greater need for an intervention may be more likely to attend. Provider level factors are those which are related to the clinician, for example their skills and ability to be flexible and tailor the intervention towards the participants. Under this provider level, Supplee et al. (2018) also included the nature and quality of the clinician-client relationship, as well as the quality of the initial contact between clinician and client. The fact that this aspect was categorised under the provider level of factors indicates that the responsibility of developing the relationship with the client primarily falls to the clinician. Programme level factors include the programme content (i.e., ensuring it is interesting and motivating for participants) and the programme structure (i.e., timing, availability of childcare and transport). Finally, community level factors include social cohesion and support for the programme in the community. SLTs have a clear role in enacting change at both the provider and programme level, but also supporting change at an individual level and advocating for change at a community level.

Similarly, Klatte et al. (2020) identified service, parental and SLT factors in collaborative practice with parents. The authors use the phrase 'collaborative practice' rather than 'engagement with' a service in this study to emphasise the importance of working together and building relationships over the traditional view of the responsibility of engaging being solely on the parents. They identified time, skills, previous experiences, priorities and motivation, beliefs and attitudes as potential facilitators or barriers to collaborative working (Klatte et al., 2020). Many AAC users have additional difficulties, which may take priority at times over AAC training (Creer et al., 2016). Other barriers to engaging with a communication partner training intervention may be a lack of SLT skill and confidence in AAC (Barman et al., 2023) and negative beliefs around the value of AAC (Kim et al., 2021). Additionally, SLTs should recognise that every individual and family have a different journey towards engagement, and that levels of engagement can fluctuate at any given time (Hackworth et al., 2018). While SLTs may approach engagement from a predominately white, middle-class viewpoint, the culture of the AAC user and their families may not correspond with this perspective (Kulkarni & Parmar, 2017; Sun et al., 2023). The SLT's understanding of and respect for cultural difference may act as a facilitator or barrier to engagement (Fox et al., 2017).

King et al. (2022) explored engagement in interventions with children and their healthcare professionals. They completed a dyadic case analysis of interviews of three children with a disability and their SLT, occupational therapist or physiotherapist. The authors identified four common principles of engagement: the personalising principle (i.e., clinicians must know the client to know what will best engage them in intervention), the relationship principle (i.e., engagement is cultivated through relationship), the

monitoring principle (i.e., a need to be aware of the client's level of engagement). The fourth principle, the individual variation principle, is foundational to the other principles. It states that different factors will engage different clients and how individuals display engagement may vary. Engagement is individualised to the client, family, clinician and context of intervention or the service. It is important for practitioners to understand the exact barriers to engagement that each AAC user, their family and even themselves are facing. This knowledge then allows for the practitioner, for instance an SLT, to plan the communication partner training intervention with a view to mitigate the impact these barriers may have on engagement with the intervention.

4.3.2.2 How can engagement be supported?

There are no best practice guidelines for supporting individual, family and/or sibling engagement with a communication partner training intervention, but there have been numerous studies reported in the literature on supporting engagement with services in general. Some studies have focused on strategies to support engagement at different stages of the engagement pathway. For example, Gonzalez et al. (2018) completed a systematic review of methods of enhancing initial parental engagement in interventions for parents of young children. They reported that a monetary incentive and advertisement were two strategies which showed a significant impact on recruitment and enrolment in an intervention (Gonzalez et al., 2018). At the other end of the engagement pathway, Tambyraja (2020) investigated strategies which supported parents in the maintenance/homework completion phase and found that provision of handouts and verbally explaining activities were two strategies effective in supporting engagement with home activities. While it is important to recognise that specific strategies may positively impact intervention engagement at certain times, these studies are only looking at one point in the engagement pathway and did not explore the fluctuating and dynamic nature of engagement over time.

Other studies have focused on supporting engagement over the course of an intervention, with agreement that relationship, communication, and cooperation are essential for supporting engagement. In a qualitative systematic review, Melvin et al. (2020) identified three ways parents can be supported to engage with early intervention SLT: (i) by building trusting relationships with the SLT, (ii) when open, two-way communication is established with the SLT, and (iii) when SLTs work together with parents in sessions. In order to support engagement, SLTs can listen to parents and empower them, share information with them, and provide opportunities for them to be involved, both in and out of the sessions (Melvin et al., 2023). Similarly, Klatte et al.

(2020) identified four strategies used by SLTs to support collaborative working and engagement. SLTs may (i) negotiate roles with parents and support and empower them to take on new roles as well as (ii) tailoring the intervention to the child and family's needs. SLTs may also (iii) explore and discuss expectations, feelings, attitudes, and preferences to ensure shared understanding and open communication between themselves and the parents as well as (iv) actively building a meaningful therapeutic relationship.

While both Melvin et al., (2023) and Klatte et al. (2020) discuss strategies for supporting engagement, both studies focus on the engagement of parents. King et al. (2022) however, focused on the co-construction of engagement between a child and a clinician. As was mentioned previously, the authors identified four principles for service providers when co-constructing engagement; the individual variation principle, the monitoring principle, the relationship principle and the personalising principle. They concluded that there are multiple ways of engaging youth clients, and that the success of these strategies may differ depending on the client themselves. They identified eight ways in which the children in their study were supported to be engaged – ensuring the relevance and importance of the goals and activity to them, ensuring enjoyment, providing an explanation, providing a choice, ensuring success or progress and ensuring the appropriateness of the physical context, ensuring a comfortable and enjoyable interaction and taking an authentic interest in the client and in the client's conversation (Figure 4.2).

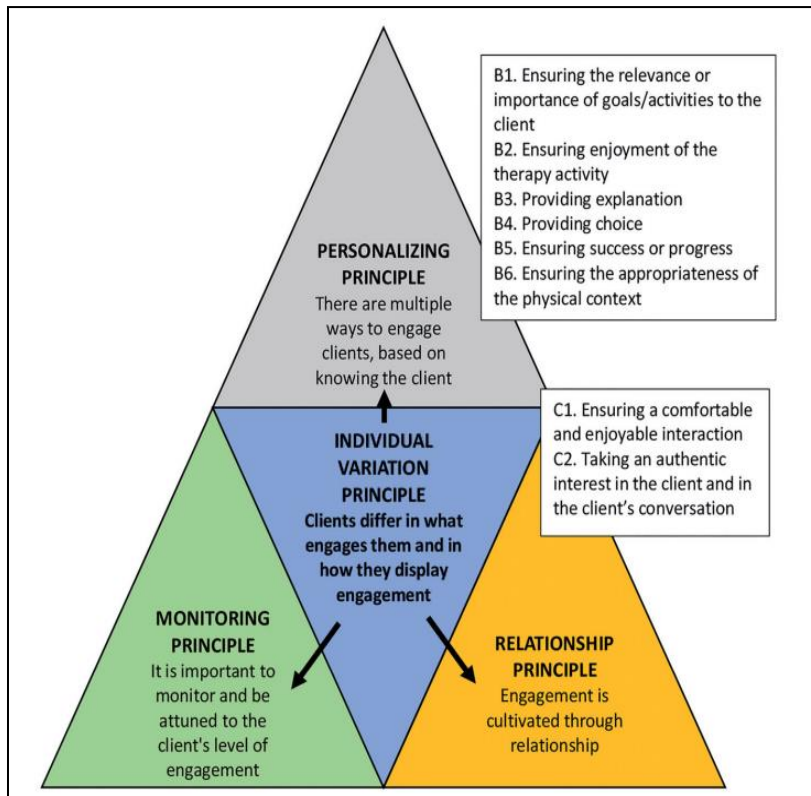


Figure 4.2 Principles of The Co-Construction of Engagement For Service Providers, Taken From King et al., (2022, p.4433)

Though there are various strategies which can be used to support engagement, these are always underpinned by a positive and reciprocal relationship between the client and the clinician (D'Arrigo et al., 2018). Building a meaningful relationship is essential in supporting engagement, and there have been many studies which have discussed the importance of a positive therapeutic relationship, as well as how to build and maintain such a relationship (e.g. Connery et al., 2022; King et al., 2022; Lawton et al., 2020). Hansen et al. (2023) completed a scoping review of empirical studies investigating the therapeutic relationship between SLTs, clients and caregivers. They identified 45 studies which met their inclusion criteria. They reported that SLTs may demonstrate professional qualities (e.g., interpersonal skills, empathy, flexibility, friendly, supportive) and attitudes (e.g., genuine interest in the client, belief in the client and the therapeutic process) which support the development of a strong relationship. Client and caregiver characteristics were less reported on, although service characteristics such as the setting and time may have an impact on the relationship. Hansen et al. (2023) also identified relational processes that SLTs used to establish and maintain relationships. Fundamental to a positive relationship was recognising personhood, (i.e., acknowledging the client as a person) as well as being responsive to the client's individual needs and preferences.

In order to support engagement, SLTs must consider open communication and collaborative working with clients and family, individualising their service to meet the needs and preferences of the client and family and most importantly, building a positive and trusting relationship (D'Arrigo et al., 2020).

4.4. Summary

Communication partners may require support and training to understand their role and become effective, attuned partners. Communication partner training interventions have been shown to facilitate the development of individual knowledge and skills (Shire & Jones, 2015), which in turn can have a positive impact on the AAC user's communicative competence and aided language skills (Kent-Walsh et al., 2015). Siblings are one such partner who may benefit from training, as their engagement with interventions have reported to lead to positive outcomes for both siblings in the dyad (Douglas et al., 2018; Hacker et al., 2023). However, there is insufficient literature available to determine the extent and consistency of these positive outcomes for all siblings, as well as the factors which may impact on these positive outcomes. Although the findings are inconclusive, it is likely there may be value in training siblings, especially in the context of their often central roles in the lives of AAC users.

It is worth noting sibling relationships vary and for many reasons, some siblings may not wish to engage with communication partner training at a certain time, or at all (Blake et al., 2023; Hank & Steinbach, 2023). Sibling attitudes towards their siblings with disabilities have been linked to the level of support they provide (Tomeny et al., 2017), and so those with more distant relationships may not be interested becoming a trained communication partner. It is important to acknowledge the autonomy of the sibling in the communication partner role. It is an acceptable outcome for siblings to make an informed decision to not attend a training, and the needs of the sibling share equal importance with those of the AAC user. Similarly, when supporting sibling engagement with an intervention, the impact of the intervention on the sibling must be considered. Communication partner interventions may increase the potential burden being placed on siblings. Siblings of individuals with a disability are already reported as having increased responsibilities (Barr & McLeod, 2010; Leedham et al., 2020) and may be at risk of mental health difficulties (Roberts, 2021) and a lower quality of life (Fullerton et al., 2017). SLTs must consider any additional responsibilities the sibling may be expected to take on, either externally (i.e., family expectations) or internally, following a training and if training will contribute to overburdening the sibling (Nuttall & Valentino, 2017). Beffel et al. (2022) outlined four suggestions to practitioners to avoid overburdening siblings.

These were to (i) assess the sibling's developmental level and ensure the intervention is developmentally appropriate, (ii) consider the bidirectional nature (or lack thereof) of the intervention, (iii) continue to assess the sibling throughout the intervention and (iv) collect information from the siblings about their perceptions of benefits and burdens as the intervention takes place.

When promoting positive intervention outcomes, appropriately supporting the sibling engagement with these interventions is vital. How SLTs can support family engagement as communication partners was discussed above. The same factors apply for siblings, including (i) open communication and collaborative working with the sibling, AAC user, and family, (ii) listening to the sibling and family preferences and individualising the intervention to meet their needs, (iii) ensuring the goals and methods are appropriate and acceptable to all involved and (iv) building a positive and trusting relationship with the sibling. Little is known about the experiences, relationships, and roles of the siblings of AAC users (except for one study by Dew et al. (2011)) and more information is needed to understand how best to support their engagement with interventions, allowing for a balance between the needs and desires of the siblings and the needs of the AAC users and families.

Siblings are a core member of the family and supporting engagement of the sibling in communication partner training interventions is paramount. However, what is not known is the specifics in what barriers and facilitators of engagement may be related explicitly to siblings of AAC users. The factors related to sibling engagement need to be explored to better understand how to support sibling engagement in AAC communication partner training interventions.

PART TWO: THE STUDY

Chapter 5: Overview of the Study

5.1 Framework for Supporting Engagement

The primary research question for this PhD was:

'How can SLTs support the engagement of siblings of AAC users with communication partner training interventions during childhood and adolescence?'

When initially considering how to answer this research question, more information was needed regarding factors that may influence engagement and so existing engagement research was reviewed (see Chapter 4 for more details). Engagement is a multifaceted, complex, and dynamic process (Bright et al., 2015; Nobles et al., 2018) and how engagement can be supported varies depending on the individual and the practitioner (King et al., 2022; Klatt et al., 2020; Supplee et al., 2018). In order to apply this existing engagement research to the siblings of AAC users, a framework was constructed detailing the evidenced-based factors that potentially support engagement with interventions (see Figure 5.1).

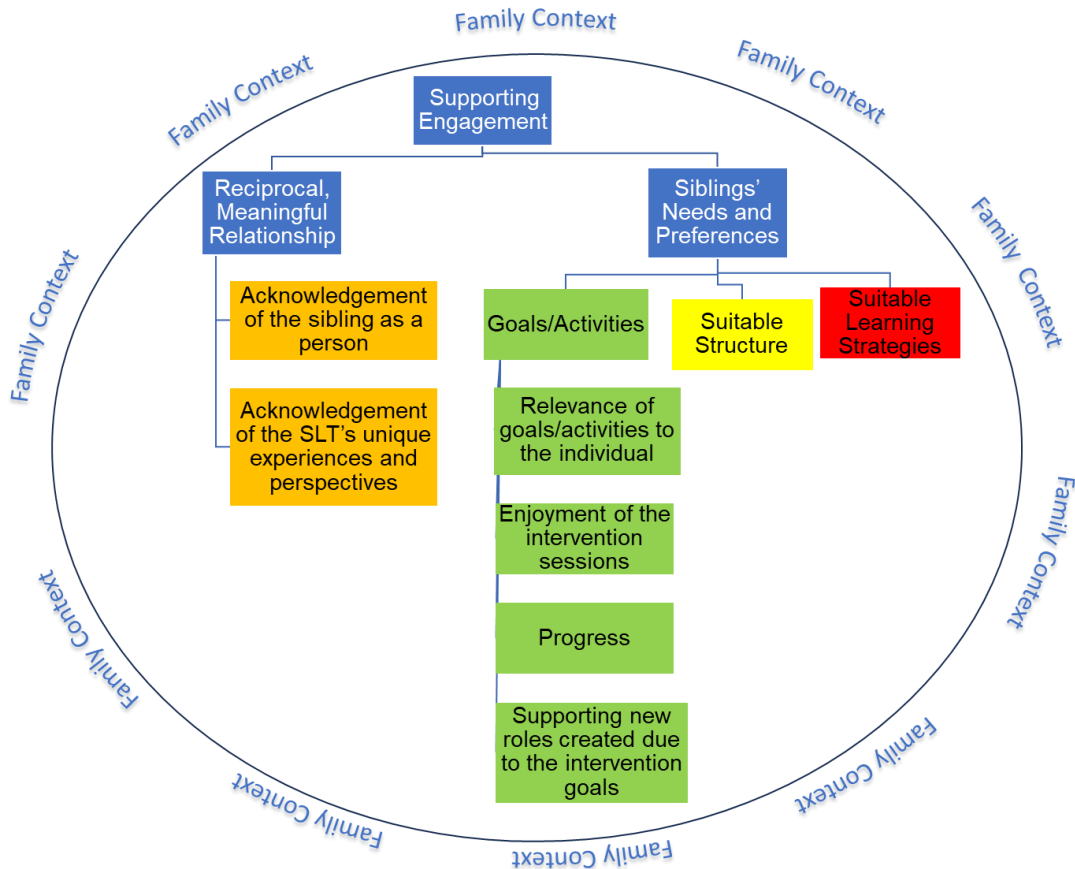


Figure 5.1 Framework for Supporting Engagement of Siblings of AAC Users

This framework (Figure 5.1) illustrates the factors that might impact sibling engagement with interventions. These factors are driven by two main principles:

1. Relationships are key to the foundation of engagement and
2. The specific needs and preferences of young people engaging in these kinds of relationships is of critical importance.

The framework itself is surrounded by the family context, demonstrating the significance of the specific family in all of engagement. The relationship principle includes approaches relating to the personhood of the sibling, and the need for the SLT to acknowledge their personal experiences and views as a sibling (R1) and the SLT's own experiences and perspectives of collaborative working with siblings of AAC users (R2). The second principle regarding the particular needs and preferences of siblings considers how to support the engagement of child and adolescent siblings as a specific group. This principle includes the relevance of the goals and activities of a training to the siblings themselves (NP1), the importance of enjoyment of the intervention for siblings (NP2), the capacity for siblings to benefit from an intervention and make progress (NP3), the consideration of new roles the sibling may take on during the intervention (NP4), the suitability of the intervention structure for siblings and their families (NP5), and the suitability of the learning strategies used during the intervention (NP6).

This framework was primarily based on King et al.'s (2022) framework (see Figure 4.2 and section 4.3.2.2 for more information on this framework) of the co-construction of engagement with youth in paediatric rehabilitation. This model was selected as it centres on the engagement of youth in interventions which aligns with this research that focuses on siblings during childhood and adolescence rather than supporting adult engagement. This model was then modified to incorporate additional aspects from other research on supporting engagement, drawn from five studies: Hansen et al. (2023), Klatté et al. (2020), Melvin et al. (2020), Melvin et al. (2023) and Supplee et al. (2018). The concept of the family as being significant to all aspects of supporting engagement was derived from family systems theory (Turnbull et al., 2015) and its importance in family-centred AAC services (Mandak et al., 2017; O'Neill & Wilkinson, 2020). Table 5.1 details the modifications to King et al. (2022) model and the research evidence underpinning each modification.

Modification	Research
Addition of <i>family context</i> as factor encompassing the whole framework.	Family is an important context for many individuals (Turnbull et al., 2015) and must be considered when supporting the engagement of a sibling. The family as a whole may be impacted by the intervention and the needs and preferences of the family must be acknowledged, in addition to those of the individual attending the training (Melvin et al., 2020).
Addition of <i>supporting new sibling roles created due to the intervention goals</i> .	Klatte et al. (2020) discusses the importance of supporting the individual to take on new roles (if applicable).
Addition of <i>acknowledgement of the SLT's unique experiences and perspectives</i> .	Hansen et al. (2023) acknowledges the importance of the therapist's attitudes, qualities, and actions on the building of a positive therapeutic relationship.
Modification of <i>providing explanation</i> (King et al., 2022) to the more general <i>suitable learning strategies</i> .	Melvin et al. (2023) identified numerous learning strategies used by SLTs to facilitate learning during sessions, rather than just focusing on providing an explanation.
Modification of <i>ensuring the appropriateness of the physical context</i> (King et al., 2022) to the more general <i>appropriate structure</i> .	Supplee et al. (2018) discussed the impact of programme level factors on engagement, for example the overall structure of the programme, rather than just focusing on the physical context.
Merging of <i>ensuring a comfortable and enjoyable interaction</i> and <i>taking an authentic interest in the client and the client's conversation</i> into acknowledgement of sibling as a person.	Both of these factors fall under a general relationship principle of acknowledging the client as a person, i.e., respecting them, listening to them and being responsive to their needs (Hansen et al., 2023).

Table 5.1 Research Evidence for Additions and Modifications to King et al.'s (2022) Framework to Create a Modified Framework for AAC User Sibling Engagement

As discussed above, engagement is an individualised and ongoing process (Bright et al., 2015). This dynamic nature lends itself to the need for consistent monitoring

of the sibling's engagement with the intervention and a knowledge of how that sibling displays engagement (King et al., 2022). These factors are treated as discrete factors in King et al.'s (2022) model, however, for the purposes of this framework they have been incorporated into the relationship principle, whereby SLTs through building a meaningful and reciprocal relationship may better understand how the sibling displays engagement and therefore what to monitor. This modified framework was first used to identify gaps in my knowledge regarding how sibling engagement may be supported. See Figure 5.2 for a diagram of the questions that arose from the different framework components.

To address these gaps, four sources of data were needed: (i) existing research evidence, (ii) insights from siblings of AAC users themselves, (iii) perspectives of SLTs and (iv) insights from other key stakeholders e.g., adolescents and parents/guardians of children (Figure 5.3). Each of these sources yielded data related to a range of existing knowledge gaps. From these general questions arising from gaps in my knowledge, specific research questions were created (Table 5.2).

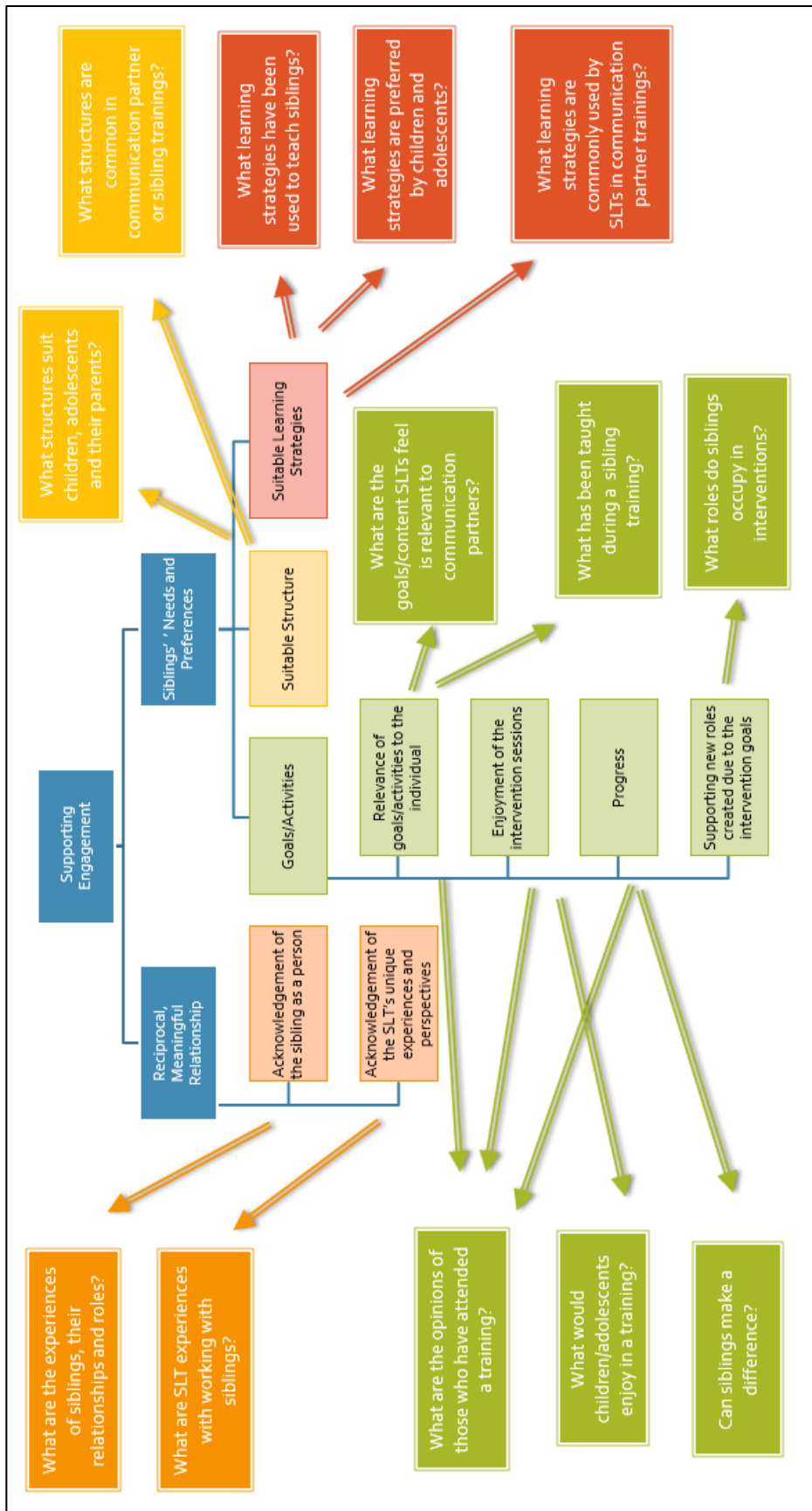


Figure 5.2 Questions Arising from Framework Components

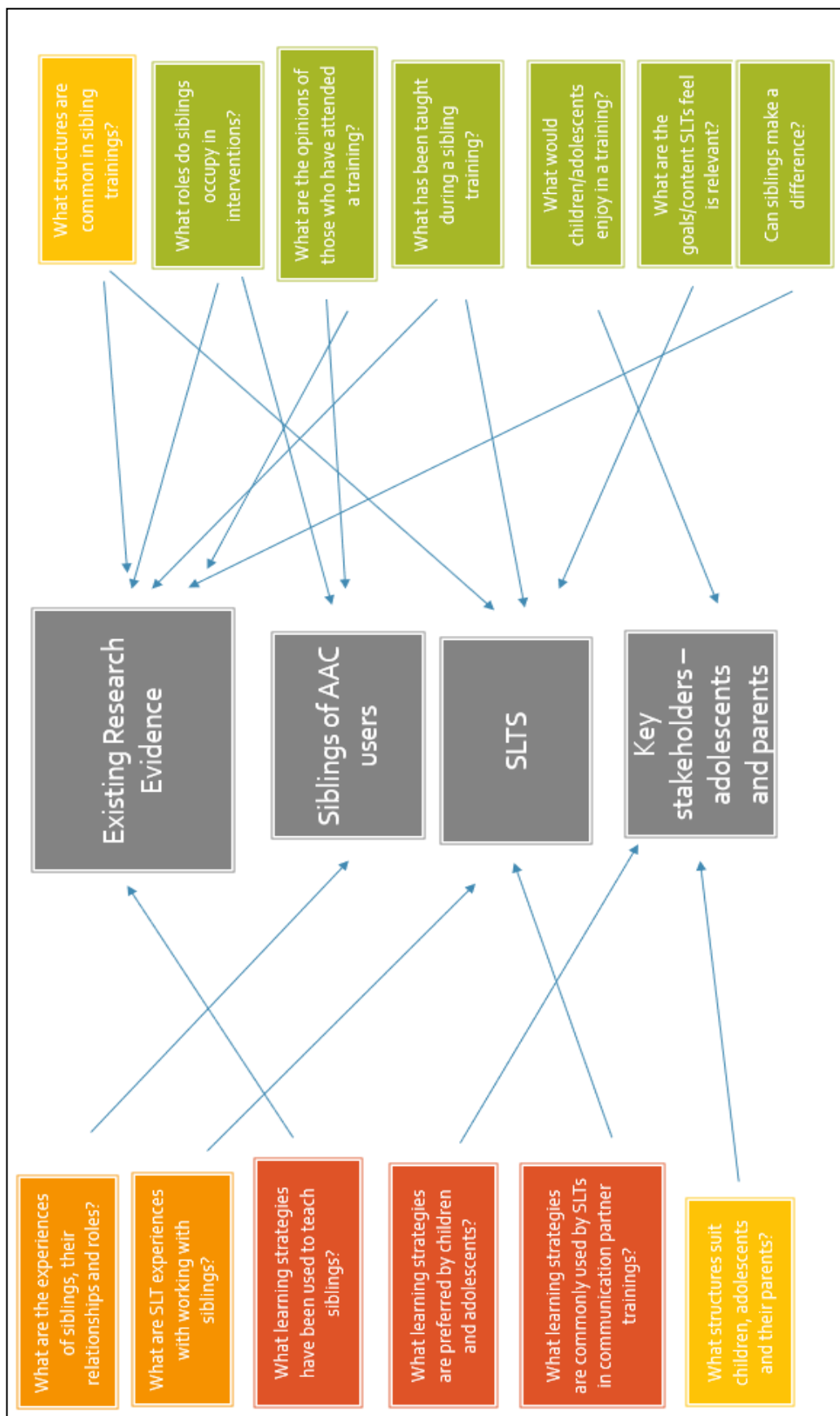


Figure 5.3 Data Sources Linked to Questions Which Arose from Framework Components

Table 5.2 Research Questions

Supporting Engagement Through Reciprocal, Meaningful Relationships: Acknowledging Sibling as a Person	
What are the experiences of siblings, their relationships, and roles?	R1a What are the experiences of individuals growing up alongside a sibling who uses AAC?
	R1b What are the characteristics of the sibling relationship when one sibling is an AAC user?
	R1c What roles do siblings occupy when their sibling uses AAC?
Supporting Engagement Through Reciprocal, Meaningful Relationships: Acknowledging SLT's unique experiences and perspectives	
What are SLT experiences with working with siblings?	R2a What are the experiences and opinions of SLTs in Ireland of working with siblings of AAC users?
Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goals/Activities	
What are the goals/content SLTs feel is relevant to communication partners?	NP1a What are the current and preferred practices of SLTs in Ireland regarding the content of communication partner interventions?
What has been taught during a sibling training?	NP1b What has been the content focus of sibling training interventions for siblings of individuals with a disability?
	NP1c What has been the content focus of peer communication partner interventions?
What would children/adolescents enjoy in a training?	NP2a What do adolescents think would aid their enjoyment of an SLT training focused on helping a sibling?
	NP2b What do parents/guardians think would aid their child's enjoyment of an SLT training focused on helping a sibling?
Can siblings make a difference?	NP3a Can siblings be effective agents of change in therapeutic interventions?
What roles do siblings occupy in interventions?	NP4a What roles do siblings occupy in interventions for individuals with a disability?
What are the opinions of those who have attended a training?	NP1-4a What are the experiences and opinions of siblings of AAC users regarding their involvement in interventions?
	NP1-4b What are the experiences and opinions of siblings who took part in a published intervention?
	NP1-4c What are the experiences and opinions of peers who took part in a communication partner training intervention?

Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Intervention Structure	
What structures are common in communication partner or sibling trainings?	NP5a What are the current and preferred practices of SLTs in Ireland regarding the structure of communication partner interventions?
	NP5b What are the common structures of interventions described in sibling training interventions?
	NP5c What are the common structures of interventions described in peer communication partner interventions?
What structures suit children, adolescents, and their parents?	NP5d What are preferences and opinions of adolescents regarding the structure of an SLT intervention which is focused on helping a sibling?
	NP5e What are the preferences and opinions of parent/guardians regarding the structure of an SLT intervention for their child which is focused on helping a sibling?
Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Learning Strategies	
What learning strategies are commonly used by SLTs in communication partner trainings?	NP6a What are SLTs in Ireland's current and preferred methods of teaching new learning during communication partner interventions?
What learning strategies have been used to teach siblings?	NP6b What instructional strategies are used in sibling training interventions?
	NP6c What instructional strategies are used in peer communication partner training interventions?
What learning strategies are preferred by children and adolescents?	NP6d What instructional strategies do adolescents believe best supports their learning?
	NP6e What instructional strategies do parents/guardians believe best supports their child's learning?

Table 5.3 Research Questions

In order to answer these questions, a mixed methodology research design was applied and the data source for each research question is outlined in Appendix A. Figure 5.4 is one extract from this appendix.

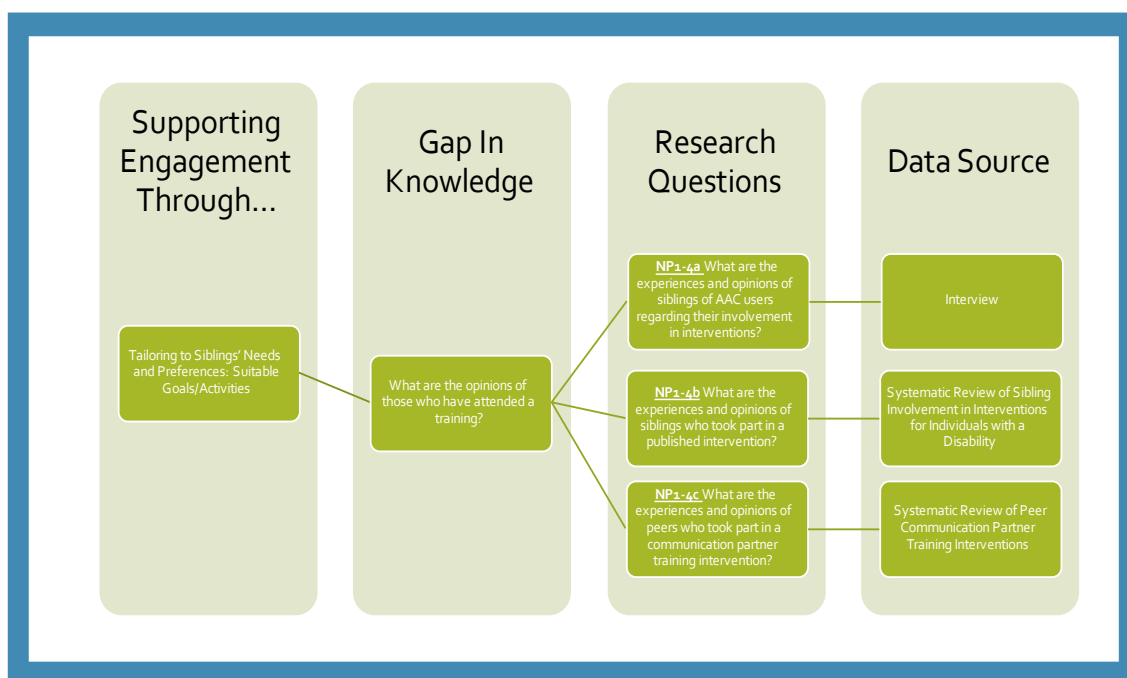


Figure 5.4 Decision Making Process from Factor Supporting Engagement to Data Source, Extract From Appendix A

5.2 Mixed Methodology

Mixed methods research is “an approach to research in the social, behavioural, and health sciences in which the investigator gathers both quantitative (closed-ended) and qualitative (open-ended) data, integrates the two and then draws interpretations based on the combined strengths of both sets of data to understand research problems” (Creswell, 2021, p. 2). Both quantitative and qualitative methods were used to answer the research questions outlined above (Table 5.2). The choice to use mixed methodologies was due to the inherent weaknesses of each approach individually: a solely quantitative approach would have allowed for generalisation of results but would not have provided the opportunity to explore the in-depth experiences of the siblings themselves and the reverse is true for a solely qualitative approach (Creswell, 2021). The different data collection methods arose from the varied research questions to be answered, and the data sources required to answer them. For example, a quantitative systematic review was chosen to collate existing research evidence on the topic of communication partner training interventions with siblings. However, due to the lack of existing research on this topic, two separate systematic reviews were completed: one

focusing on sibling involvement in therapeutic interventions for individuals with a disability and a second focusing on peer communication partner training interventions. For the siblings of AAC users, and the need to understand their experiences, relationships and roles in greater detail, a qualitative methodology was chosen to allow for greater exploration. For other key stakeholders, adolescents, and parents/guardians, as well as SLTs, there was a need to gather information from more participants to increase generalisability of the results and so surveys were used to collect quantitative data, with some qualitative data collected through open ended questions to allow participants to expand on their answers (Figure 5.5).

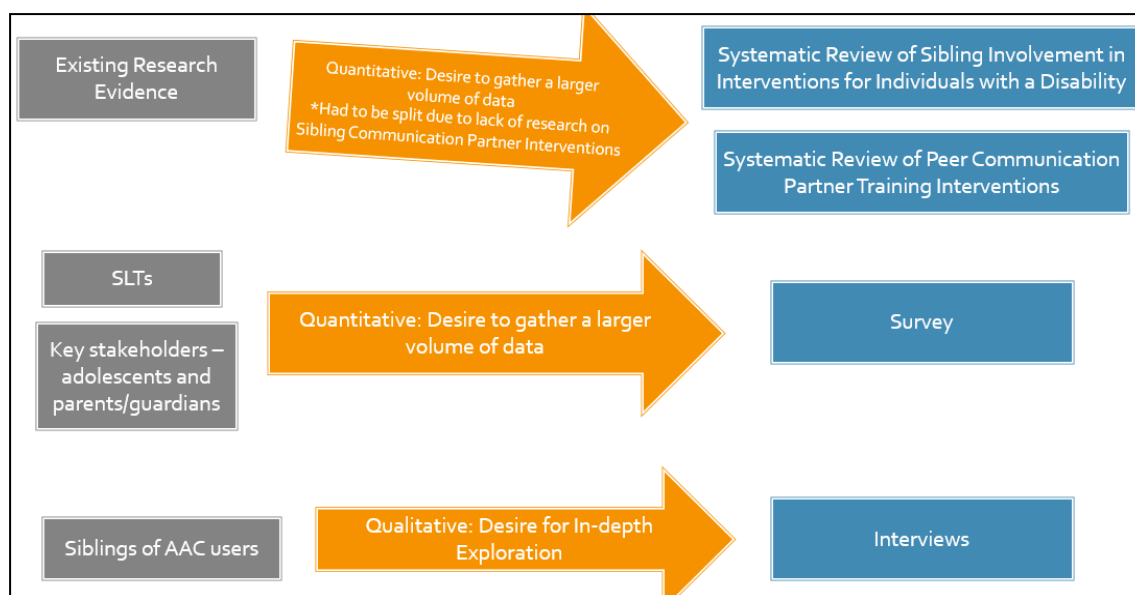


Figure 5.5 Mixed Methodology Decision Making

There is no one standard ‘mixed methods design’. The major decisions around what mixed methods design to use for any given research is (i) how to sequence the data collection and analysis and (ii) how to integrate the results (Curry & Nunez-Smith, 2015). The design used for this research was a convergent parallel design (Creswell & Plano Clark, 2017), whereby qualitative and quantitative data were collected simultaneously over the course of several years through three distinct data collection methods (systematic reviews, interviews, and surveys). The data was then analysed separately before being synthesised during the interpretation phase. The findings of one component of the research did not impact on the design of the other research components, which meant that a sequential mixed methodology design was not appropriate (Curry & Nunez-Smith, 2015). The design of each component was driven separately by the underlying theme of supporting engagement of siblings of AAC users and through the aforementioned framework (Figure 5.1). Following the data collection

and analysis of each individual component, data were synthesised through merged integration (Curry & Nunez-Smith, 2015), i.e., the results were interpreted to identify agreement and disagreement across the data sets to provide a more comprehensive understanding of supporting sibling engagement. This merged integration of the results is discussed under each component of the framework for supporting sibling engagement (Figure 5.1) in Chapter 10.

5.2.1 Methodological Considerations

A convergent parallel design was chosen for this research due to its ability to support the development of a more complete understanding of a concept, in this case sibling engagement, by integrating complementary quantitative and qualitative results (Creswell & Plano Clark, 2017). This concept is also referred to as triangulation, or the process by which a concept is explored through multiple observers, theories, methods, or data sources to generate a more comprehensive understanding of the concept itself (Curry & Nunez-Smith, 2015). This research design also provides enhanced validity: i.e., by using multiple data sources and methods, the findings can be validated across different dimensions, identifying inconsistencies and discrepancies between the data, and reducing the likelihood of drawing incorrect conclusions (Creswell, 2018).

However, there are several limitations associated with mixed methodology research designs. The process can be time-intensive, with both qualitative and quantitative phases having the potential to take considerable amounts of time (Fiorini et al., 2016). One benefit of using a concurrent parallel design is that it is more time efficient than other mixed methodology designs (Creswell & Plano Clark, 2017). Both qualitative and quantitative data are collected and analysed simultaneously, and so there is no waiting for one component to be fully complete (i.e., all data collected, analysed and interpreted) before moving on to the next piece. This was especially important during this research as the public health restrictions of the COVID-19 pandemic impacted on the recruitment and data collection for one component (qualitative interviews). Using a concurrent design meant that the delays to this component did not impact on the data collection and analysis for the other components.

Another design limitation is that analysing and interpreting multiple types of data, and the merging of these interpretations, can be challenging (Castro et al., 2010). More effort and expertise are required to understand both quantitative and qualitative methodologies and their associated data collection and analysis methods. Creswell and Plano Clark (2017) discuss the importance of mitigating this challenge by designing the study to ensure the quantitative and qualitative data address the same concept. The four

components of this research each measured different aspects (resulting from different sources) of the larger phenomenon of supporting sibling engagement. The framework outlined in Figure 5.1 provided a structure to ensure the quantitative and qualitative components fit together. A final challenge to this research design is that the different research components may have different sample sizes and as such thorough considerations need to be made regarding the relative weighting of the findings of each of the qualitative and quantitative data phases (Creswell & Plano Clark, 2017). This feature was evident in the current research owing to the different purposes of the data (i.e., quantitative for generalisability led to larger participant numbers, while qualitative for in-depth exploration of experiences resulted in a smaller number of participants). However, differing data sizes were not a limitation to this research as the data sets drew from different participant groups to answer specific research questions. As such, the findings were not weighted, compared or contrasted, but rather integrated to provide a more comprehensive picture of the concept of supporting sibling engagement (Creswell & Plano Clark, 2017).

5.3 Summary

The framework (Figure 5.1) provides a structure for the description and interpretation of this mixed methodology research. The data collection methods outlined in Figure 5.5, two systematic reviews, interviews, and surveys, are each detailed below in Chapters 6 to 9 respectively. Each individual chapter describes the methods for that specific component and then the findings are reported on under the heading of each applicable research question to that section (Table 5.2).

Chapter 6: Systematic Review of Sibling Involvement in Interventions

This chapter details the methods and findings of a systematic review of sibling involvement in interventions for individuals with a disability.

6.1 Method

6.1.1 Introduction

When identifying suitable data sources to answer the primary research question, existing research evidence was acknowledged as one source which could inform what might work or not work when engaging siblings in communication partner interventions. However, initial literature searches identified very few published studies (but see Douglas et al. (2018) and Hacker et al. (2023)). Due to this lack of published research with siblings of AAC users, it was decided that two separate systematic reviews would be completed – the first, a review of sibling involvement in interventions for children with disabilities (as described in this chapter, see also Lynam and Smith (2022) and Appendix B) and the second, a review of peer communication partner training interventions (Chapter 7). A review of sibling involvement in interventions for children with disabilities was appropriate to provide an insight into factors relevant to siblings as distinct group. For example, what structures and instructional strategies are commonly used in sibling interventions, what are sibling perspectives on being involved in interventions and whether siblings can be effective agents of change and should therefore be supported to engage with in communication partner training interventions.

Systematic reviews were chosen as a means of collecting and analysing existing research evidence data due to them being the ‘gold standard’ method of synthesising the findings of several studies (Dickson et al., 2017). Systematic reviews are a summary of the literature that employs clear and repeatable techniques to systematically search, critically assess, and consolidate findings on a particular topic (Gopalakrishnan & Ganeshkumar, 2013). Systematic reviews provide a comprehensive picture of a specific research area, that follow a transparent, verifiable and replicable approach to minimise bias and provide valid and reliable results (O’Leary, 2021). However, systematic reviews can be time intensive, and the review quality may vary depending on the reviewers and protocols followed. The timeframe for PhD research allowed for ample time to complete both reviews. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) group reporting guidelines (Moher et al., 2009) were used in both reviews to provide transparency and replicability to the process and results. See Table 6.1 for a list of the research questions for this systematic review.

	Research Question	Supporting Engagement Framework Component
NP1b	What has been the content focus of sibling training interventions for siblings of individuals with a disability?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goal/Activities</i>
NP3a	Can siblings be effective agents of change in therapeutic interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goal/Activities</i>
NP4a	What roles do siblings occupy in interventions for individuals with a disability?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goal/Activities</i>
NP1-4b	What are the experiences and opinions of siblings who took part in an intervention?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goal/Activities</i>
NP5b	What are the common structures of interventions described in sibling training interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Intervention Structure</i>
NP6b	What instructional strategies are used in sibling training interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Learning Strategies</i>

Table 6.1 Research Questions for Systematic Review of Sibling Involvement in Interventions for Individuals with a Disability

6.1.2 Information sources and search strategy

A comprehensive exploration of several databases including Medline, PsycInfo, ERIC, CINAHL Complete, EMBASE, and CENTRAL was conducted. The search strategy employed the following keywords: (sibling* OR brother* OR sister*) AND (disorder* OR disab* OR difficult* OR impair* OR injur*) AND (interven* OR therap* OR support OR train* OR teach*), with a focus on their presence within the title, abstract, and/or

keywords of the articles. The search criteria were further refined to include only articles written in English and published over the previous 21 years from when the search was completed, specifically spanning from 1999 to 2020. This timeframe was selected so that the growing trends in therapeutic interventions for individuals with disabilities could be captured while also maintaining a manageable scope. An additional search was conducted to identify articles beyond traditional publishing and distribution channels, commonly referred to as 'grey literature'. This search encompassed databases such as ProQuest Dissertation and Thesis (accessible through EMBASE) and CINAHL Plus (available through CINAHL Complete). Furthermore, Google Scholar (comprising the initial 50 results) and the Open Grey database were both employed using the same search terms. Additionally, the reference lists of five previously published literature reviews focusing on interventions involving siblings of individuals with disabilities (Banda, 2015; Ferraioli et al., 2012; Hartling et al., 2014; Shivers & Plavnick, 2015; Tudor & Lerner, 2015) were manually examined to identify any potentially overlooked studies that were not captured by the previously mentioned search methods.

All titles and abstracts identified through electronic searches were saved within a reference management system (Endnote™). Duplicate entries were recognised and removed. Following this stage, an article screening process was completed, guided by the predefined inclusion and exclusion criteria (Table 6.2). This screening procedure was initially completed on the article titles, followed by the abstracts, and ultimately through an evaluation of the complete article texts. Articles that did not align with the established criteria at a particular screening level were not progressed for consideration in subsequent screening stages. A data extraction form (Appendix C) was used to extract the data.

Inclusion Criteria	
Participants	<ul style="list-style-type: none"> • Participants can be of any age • Participants include siblings of individuals with a developmental or acquired disability.
Intervention	<ul style="list-style-type: none"> • The article must focus on an intervention. • Siblings play a clear role in the intervention.
Outcomes	<ul style="list-style-type: none"> • Outcomes include a focus on the participant with a disability • Outcomes focus on the sibling's skills and/or quality of life in relation to the sibling relationship, as measured through observations, parent report and/or both siblings report of the relationship.
Exclusion Criteria	
Participants	<ul style="list-style-type: none"> • Participants should not include siblings of individuals with a chronic illness, medical illness or mental health difficulties as their primary diagnosis.
Intervention	<ul style="list-style-type: none"> • The article cannot be a review, editorial or study protocol. • The intervention cannot be of medical or surgical nature. • The role of the sibling in the intervention must be clear. • The sibling cannot act as only a measure of generalisation of skills of the participant with a disability or as a comparison to typical development.
Outcomes	<ul style="list-style-type: none"> • Outcomes cannot solely focus on the sibling only (e.g. sibling coping, problem solving) • Outcomes cannot solely focus on the sibling relationship when the outcome measure is only reported by one sibling.

Table 6.2 Inclusion and Exclusion Criteria for Systematic Review of Sibling Involvement in Interventions for Individuals with a Disability

6.1.3 Search results

In total, 14,760 articles were retrieved through database searching and an additional 55 were identified through Google Scholar and other hand searches equating to a total of 14,815 articles. Once duplicate entries were removed (n=4,828), the total number of records reviewed was to 9,987. Following screening at title, abstract and full text level, 30 articles were deemed suitable for inclusion (see Figure 6.1 for the PRISMA flowchart). Notably, one article, Madzharova and Sturmey (2015), contained two separate studies. Thus, a total of 31 distinct studies were included in this review.

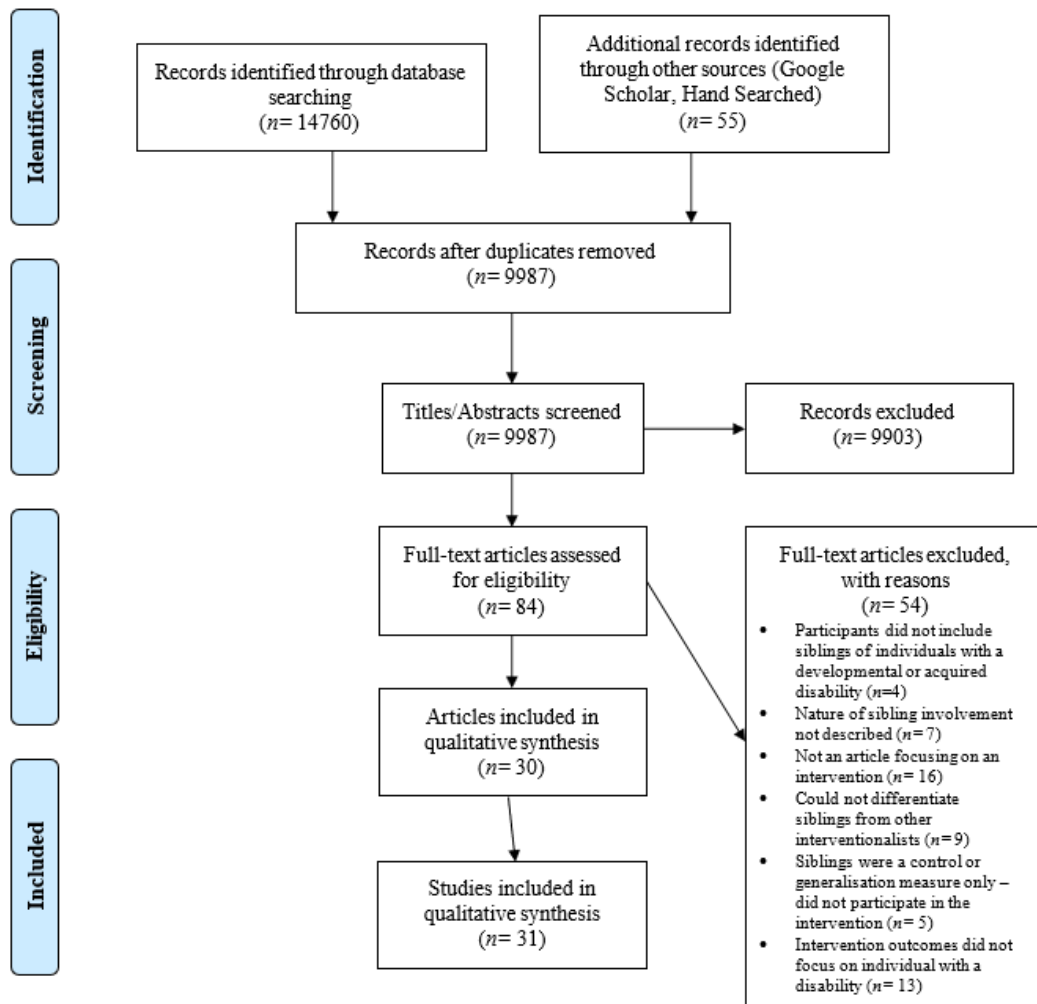


Figure 6.1 PRISMA Flowchart for Article Selection for Systematic Review of Sibling Involvement in Interventions for Individuals with a Disability (Adapted from Moher et al., (2009); Also reported in Lynam and Smith (2022, p. 4582))

6.1.4 Reliability

Three stages of inter-rater reliability checks were conducted – during title screening, abstract screening and during data extraction. A second reviewer screened 10% of the articles during both the title and abstract assessment phases to judge adherence to inclusion and exclusion criteria. Inter-rater agreement on the titles of the articles was 88.7%. Instances of disagreement were jointly reviewed by both reviewers, resulting in a unanimous consensus for all titles. The inter-rater agreement at the abstract stage was 100%.

During the data extraction phase, four research assistants, alongside the primary researcher, completed 100% of the data extraction. The data extracted matched in 100% of the cases.

6.1.5 Quality of Studies

Study quality of the 31 included studies was assessed using the Oxford Centre for Evidence-Based Medicine Levels of Evidence guidelines (Howick, 2009). Additionally, the Study Quality Assessment Tools (National Heart Lung and Blood Institute, n.d.) were used, specifically, the 'Quality Assessment of Controlled Intervention Studies' and the 'Quality Assessment Tool for Before-After (Pre-Post) Studies without a control group' (Figure 6.2). During the quality analysis, these assessments systematically considered a range of criteria used to detecting potential bias within studies. This included factors such as the sample size, presence of multiple data points, blinding of assessors, participant selection criteria, and methods of randomisation.

6.1.5.1 Results of Quality Analysis

Applying the Oxford Centre for Evidence-Based Medicine's levels of evidence framework, the majority of the studies (n=29) were assigned a quality level of evidence 4, indicative of small-scale studies lacking randomised controlled trials or cohort studies. The two remaining studies (Castorina & Negri, 2011; Chu & Pan, 2012) were rated at level 3b due to their design featuring non-randomised control groups.

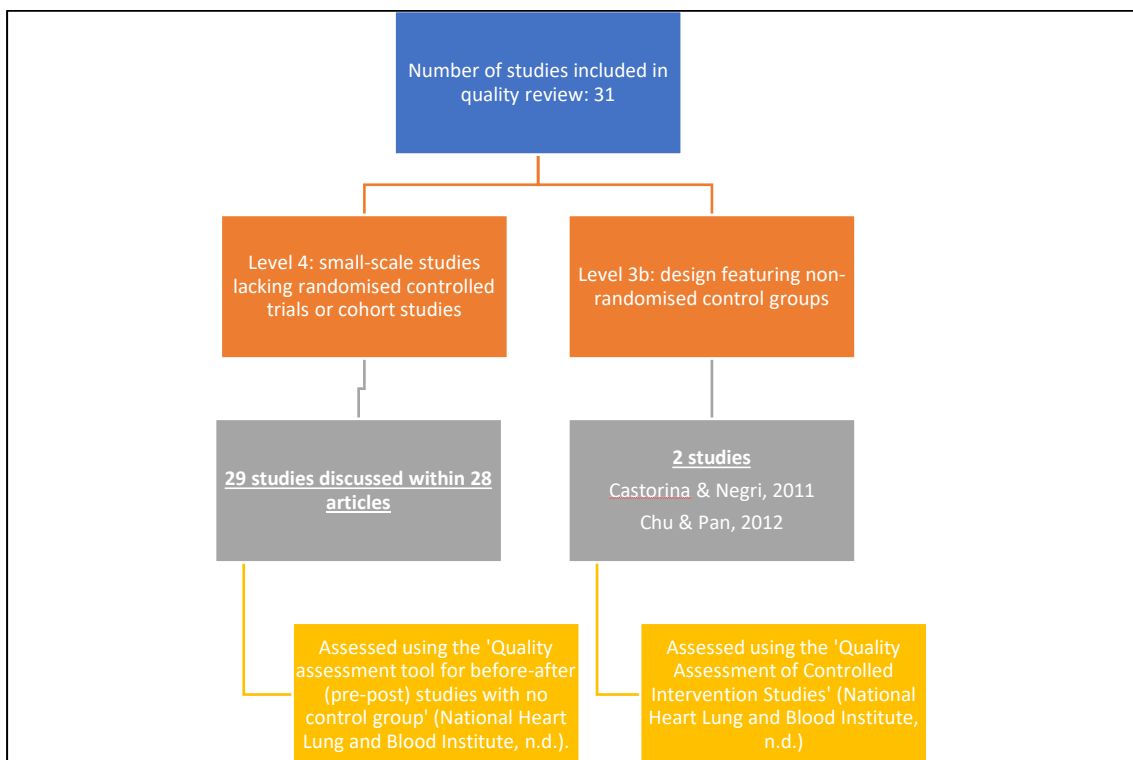


Figure 6.2 Flowchart of Study Quality Review Process

Among the 29 studies without controls, each was assessed using the 'Quality assessment tool for before-after (pre-post) studies with no control group' (National Heart Lung and Blood Institute, n.d.). The overall evidence quality across all studies was deemed to be fair, demonstrating a moderate risk of bias with scores ranging between 27% and 73% on the rating scales. Most included studies did not have a sufficiently large sample size (n=29, 100%) and did not blind assessors towards outcomes (n=24, 82.76%). Many studies also did not report using statistical measures to analyse the data (n=22, 75.86%). Nonetheless, several criteria were met by the majority of studies, including stating the objective clearly (n=28, 96.55%) and ensuring that the study participants were representative of those who may be eligible for the intervention in a clinical population (n=29,100%). It is important to note that the wide range of scores indicating a moderate risk of bias (i.e., 25%-75%) is a limitation of this tool as studies which differ in their scores by up to 50% may be given the same risk rating.

For the two studies which contained control groups., (i.e., Castorina and Negri (2011) and Chu and Pan (2012)) the 'Quality Assessment of Controlled Intervention Studies' (National Heart Lung and Blood Institute, n.d.) was used to assess study quality. Given the absence of guidance on how to categorise scores with this tool, a decision was made to classify scores of 50% or lower as weak evidence, scores ranging between 50% and 75% as moderate evidence, and scores exceeding 75% as high levels of evidence. Both studies were categorised as weak evidence due to the absence of participant randomisation and blinding procedures. However, it is worth highlighting that both studies employed reliable outcome measures and exhibited minimal dropouts from baseline.

While studies with moderate to low quality evidence might typically be excluded from systematic reviews analysing intervention effectiveness, they were included in this review due to the paucity of high-quality evidence available. Moreover, this inclusion was deemed appropriate considering the specific review focus which centred on other intervention factors (including roles, structure, opinions of participants) rather than solely assessing intervention effectiveness.

6.2 Findings

The systematic review findings are outlined below, beginning with an overview of the studies and the participants, followed by the findings as they correspond to each research question. Characteristics of the participants and the intervention in the included studies are detailed in Table 6.3 and Table 6.4 respectively.

Study	Number of Participants		Gender		Age range (in years)		Reported Diagnosis*
	Individuals with a disability	Siblings	Individuals with a disability	Siblings	Individuals with a disability	Siblings	
Baker (2000)	3	3	2 female, 1 male	3 female	0-5: 2 6-12: 1	6-12: 3	Autism
Buerger (2014)	26	26	9 female, 17 male	12 female, 14 male	6-12	6-12	ASD and comorbidities
Castorina and Negri (2011)	N= 21, n=7	7	All male	4 female, 3 male	6-12	M=12.71 (SD=0.95)	Asperger's Syndrome
Chu and Pan (2012)	N=21, n=7	7	All male	5 female, 2 male	6-12	6-12	Mild/High functioning autism and Asperger's Syndrome
Daffner et al. (2019)	3	3	1 female, 2 male	2 female, 1 male	0-5: 1 6-12: 2	6-12	Attention Deficit Hyperactivity Disorder
Dodd et al. (2008)	2	2	All male	All male	6-12	6-12	PPD-NOS
Douglas et al. (2018)	3	3	All male	2 female, 1 male	0-5: 2 6-12: 1	0-5: 1 6-12: 1 13-18: 1	Speech motor delay and emotional disability; Down Syndrome; Noonan Syndrome
Ferraioli and Harris (2011)	4	4	All male	1 female, 3 male	0-5	6-12	ASD
Hansford (2013)	20	20	Not recorded	9 female, 11 male	Not recorded	6-12	Pervasive developmental disorder e.g., ASD, autism, PDD-NOS
Huskens et al. (2015)	3	3	All male	2 female, 1 male	0-5: 1 6-12: 2	6-12	ASD and Asperger's Syndrome
Jones and Schwartz (2004)	3	3	2 female, 1 male	All female	0-5	0-5	ASD
Kim (2010)	3	3	1 female, 2 male	All female	0-5	6-12	Autism and developmental delays

Kryzak et al. (2015)	15	15	3 female, 12 male	6 female, 9 male	0-5 6-12 13-18	6-12 13-18	ASD
Kryzak and Jones (2017)	4	4	1 female, 3 male	3 female, 1 male	6-12	6-12	ASD
Lewandowski et al. (2014)	1	1	Male	Male	0-5	0-5	Asperger Syndrome
Madzharova and Sturmey (2015)	N=3 n=1	1	Male	Female	0-5: 3 (1)	0-5	ASD
AS ABOVE	1	1	Male	Female	0-5	0-5	ASD
Neff et al. (2017)	2	3	All male	2 female, 1 male	0-5: 1 6-12: 1	0-5: 2 6-12: 1	ASD
Oppenheim-Leaf et al. (2012)	3	3	All male	1 female, 2 male	0-5: 2 6-12: 1	0-5	ASD
Özen (2015)	3	3	2 female, 1 male	All male	0-5: 2 6-12: 1	6-12	ASD
Rayner (2011)	1	1	Male	Male	13-18	6-12	ASD
Reagon et al. (2006)	1	1	Male	Male	0-5	6-12	Autism
Sheikh et al. (2019)	3	3	1 female, 2 male	1 female, 2 male	0-5: 1 6-12: 2	0-5: 2 6-12: 1	ASD
Spector and Charlop (2018)	3	3	All male	2 female, 1 male	6-12	6-12	ASD
Taylor et al. (1999)	2	2	All male	1 female, 1 male	6-12	6-12	ASD
Thomas et al. (2019)	1	2	Male	1 female, 1 male	6-12: 1 6-12: 1	0-5: 1 6-12: 1	ASD
Trent et al., (2005)	2	2	All female	All female	0-5: 1 6-12: 1	6-12	Down Syndrome
Tsao (2019)	3	3	All male	All male	0-5: 2 6-12: 1	0-5: 2 6-12: 1	1 ASD, 2 developmental disabilities

Tsao and Odom (2006)	4	4	All male	2 female, 2 male	0-5: 2 6-12: 2	0-5: 3 6-12: 1	ASD
Walton and Ingersoll (2012)	4	6	All male	4 female, 2 male	0-5	6-12: 5 13-18: 1	ASD
Watkins et al. (2021)	2	2	1 female, 1 male	All female	0-5: 1 6-12: 1	6-12 years: 2	ASD

Table 6.3 Key Participant Characteristics in Systematic Review of Sibling Involvement in Interventions for Individuals with a Disability

Note: *Diagnoses are stated as reported in the article.

Abbreviations: Autism Spectrum Disorder (ASD); Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Content	Sibling Involvement	Main Reported Outcomes	Participant Reported Experiences
Baker (2000) Incorporated the autistic child's ritualistic interests/behaviours into a social game scenario with their sibling.	Untrained playmate	All participants increased their time spent in social play together as measured in 10s intervals, with this sustained during maintenance and follow up phases. Autistic children also exhibited an increase in positive joint attention behaviours.	Sibling only – interview questions focusing on perception of their own behaviours and skills of the autistic child.
Buerger, 2014 Sibling Helping Siblings psychoeducational intervention. One method of assessment used was direct observation; both children took part in interaction tasks- unstructured, puzzle construction and problem solving.	Participant in support group	Increase in positive engagement of dyads during unstructured tasks, $F(1,25)=6.91, p=.01$. No significant differences found in positive engagement during puzzle or problem-solving tasks. Increase in negative engagement during problem solving tasks $F(1,24)=8.69, p=.01$. No significant difference in unstructured and puzzle task.	Parents and sibling only – high overall satisfaction for parents and children.
Castorina and Negri (2011) Social skills training programme for autistic individuals and their siblings.	Participant in group	Ability to identify non-verbal cues – significant differences between intervention groups (with or without sibling) as compared to control group ($M=38.00, SD=12.46; M=37.50, SD=6.59; M=15.33, SD=7.47$, respectively), $F(2,18)=12.78, p<.001$, partial $\eta^2=.59$, and at follow-up ($M=34.43, SD=9.78; M=38.88, SD=10.56; M=13.17, SD=8.38$, respectively), $F(2,18)=13.02, p<.001$, partial $\eta^2=.59$) post intervention. No differences between sibling and non-sibling groups during post intervention or follow up.	Parents only – felt positive about the programme.
Chu and Pan (2012) Aquatic skills training programme for autistic individuals with assistance from peers and siblings. Sibling matched, peer matched and control groups.	Instructor	Children in the sibling matched group showed significantly more improvement on physical and social interactions with their typically developing siblings during sibling-assisted condition as compared to controls ($p < 0.01$). Also demonstrated significantly more improvement on physical interactions with their typically developing siblings ($p < 0.01$) and social interactions with their teachers and other autistic	Sibling only interview and informal parent feedback – positive and would like to take part in other activities in the future. Three parents reported increase in interactions of autistic child.

	children ($p < 0.01$) during the voluntary support condition as compared to controls.		
Daffner et al. (2019)	Sibling mediated social skills intervention with a focus on sharing, giving/asking for help and compromising.	Trained playmate	Parent and sibling only- parents reported the intervention was acceptable, suitable, and effective. Siblings reported the strategies learned were fair, easy to learn and helped them and the child with a disability be better playmates.
Dodd et al. (2008)	Social stories interventions with the aim of reducing the number of excessive directions and increasing the number of compliments provided by children with PPD-NOS to their sibling.	Untrained playmate	Parent and participant with a disability- participants with a disability "somewhat liked" reading the social story and learning something new. Parents reported positive consequences and desire for continued use of social stories.
Douglas et al. (2018)	Intervention teaching plan, talk, wait, and respond strategy for siblings of individuals with complex communication needs.	Trained playmate	Siblings and parents-siblings were positive, two-thirds reported seeing change in their communication with the child with a disability and all would recommend for others to do it. Parents reported improvements in child with a disability and sibling communication skills.
Ferraioli and Harris (2011)	Siblings training to teach joint attention behaviours to autistic child	Instructor	Siblings and parents- siblings reported moderate satisfaction with the intervention. Parents indicated high levels of satisfaction.

Hansford (2013)	Sibling support group targeting psychoeducation about autism, problem solving skills, behaviour skills training, increasing self-esteem and empowering siblings.	Participant in support group	Increase in play initiation from baseline to post intervention. Minimal change across time points on sibling prompting and praise, as well as the autistic child's rates of initiating and responding.	Parents and siblings- acceptability was rated "very satisfactory".
Huskens et al. (2015)	Robot mediated Lego therapy to improve collaborative play between siblings.	Playmate and participant in intervention	No statistically significant change in interaction initiations and responses. Two-thirds of dyads demonstrated no statistical significance in time playing together, for one-third there was a statistical decrease in time playing together ($Tau-U = -0.96$, 90% $CI -1.00$ to -0.33).	Parents, participant with a disability and sibling-treatment was acceptable as rated by the children. Parents were mixed about the effectiveness of the training.
Jones and Schwartz (2004)	Sibling, peer, and adult modelling for novel expressive vocabulary for an autistic child.	Model	No clear preference for one model was reported. Overall, correct responding in sibling/peer modelling was equal to or higher than correct responding to the adult model – all three target children reached criterion for all three phases with both siblings and peers – only one participant did so for adult model.	None reported.
Kim (2010)	Siblings' social skills strategy training for play situations.	Trained playmate	All siblings increased in play related social interactions. All siblings had low baseline in inappropriate behaviours so unable to measure significant reduction. Two-thirds of target children high variability in responding to play related social interactions. One-third increased slightly. One had no inappropriate behaviours, one decreased in inappropriate behaviours and one increased in inappropriate behaviours.	Parents and siblings- parents reported they agreed/strongly agreed that the intervention was appropriate and important. Two-thirds of siblings enjoyed the intervention and found it easy and one "did not know!" All three felt the skills they learned were helpful.
Kryzak et al. (2015)	Support group for siblings. Targeting autism knowledge, peer network development and adjustment as well as interaction between siblings.	Participant in support group	Increase in both autistic child and sibling initiations and responses- not statistically significant.	Parents and siblings- parents and siblings rated the programme as important and positive.

Kryzak and Jones (2017)	A behaviours skills training for siblings to improve their self-management of the Stay-Play- Talk curriculum in general interactions/play with their sibling.	Trained playmate	Improvements in self-management for all siblings within two sessions. Half of the siblings ($n=2$) maintained 100% across maintenance probes – two others underwent booster training at the 2 and 6 weeks follow up session. All siblings generalised improvements to home environment and three-quarters ($n=3$) generalised to outside of home in maintenance. All siblings increased in reciprocal interactions, an increase was also reported in three out of four participants with a disability.	None reported.
Lewandowski et al. (2014)	Comic strip conversation intervention to address sibling conflict between siblings.	Playmate and participant in intervention	No change for sibling across the phase of the study – high ratings in baseline. Significant difference for participant with a disability between 2 nd A phase and C phase ($Tau-U=0.54, p<0.001$). No difference between C and final A (maintenance effect).	None reported.
Madzharova and Sturmei (2015)	Mothers implemented mand training with their children.	Untrained Playmate	Improvements in non-generalisation trials and generalisation trials of mean number of correctly performed steps for mother. Variable gains for mean number of mands for autistic child	None reported.
Madzharova and Sturmei (2015) (2)	AS ABOVE	Untrained Playmate	When the mother correctly completed four steps, participant independently manded without his sister's name 90% of the time and with her name 2% of the time. When mother incorrectly completed steps, participant did not emit any mands.	None reported.
Neff et al. (2017)	Sibling training using video modelling to teach siblings how to prompt and reinforce appropriate play when engaged in cooperative play with their autistic sibling.	Instructor	Increase for two of three siblings in appropriate delivery of reinforcement of appropriate play, in prompting and in on-task behaviours. One sibling required additional aid in the form of supplemental teaching.	None reported.
Oppenheim-Leaf et al. (2012)	Sibling training to teach prompting and reinforcing social behaviours during play.	Trained playmate	Varied across dyads; Dyad 1. Increased the amount of time in cooperative and parallel play and decreased in independent play and negative interactions. Dyad 2. Higher levels of cooperative and parallel play. Dyad 3.	Parents only- very satisfied with changes in children's behaviour.

			No change – independent play in 100% of intervals across all phases	
Özen (2015)	Social skills intervention for autistic individuals using a sibling delivered iPad game activity.	Trained playmate	All autistic children demonstrated an increase in following directions, turn taking and giving appropriate responses to teaching opportunities.	Parents only- satisfied with the programme and the involvement of their children.
Rayner (2011)	Skills training for autistic individual with videos of each targeted skill modelled by two participants; one unfamiliar adult and one sibling.	Model	No significant difference in participant behaviours during sibling model vs adult model conditions.	None reported.
Reagon et al. (2006)	Pretend play skills intervention using a sibling as a video model and a play partner.	Model	Varied results – acquired 40-100% of actions and 50-100% of statements across the different scenarios. Number of contextually related spontaneous words varied across sessions.	Parent and sibling- parent highly satisfied with the programme. Sibling reported learning how to play with his brother.
Sheikh et al. (2019)	Sibling support group (learning about autism, coping skills, sharing feedback, problem solving and advocacy) alongside a parent intervention focused on helping parents learn ways to support interactions between the siblings.	Participant in support group	Variable targets across families. Family 1: increase in use of turn taking and talking ($MAP= 1$ and 0.92 respectively), family 2: increase in use of sharing and helping ($MAP=1$ for both behaviours), family 3: increase in use of orientating and prompting talking ($MAP=1$ for both behaviours). Little to no parent or sibling reported difference in the sibling relationship, however baseline levels were high.	None reported.
Spector and Charlop (2018)	Sibling training intervention to implement a natural language paradigm.	Trained playmate	Two of three participants with a disability met criterion in gains in verbal behaviour. One of three autistic children generalised across person but not setting. All three siblings learned and implemented a natural language paradigm during speech/play sessions.	None reported.
Taylor et al. (1999)	Social skills training for autistic children using video modelling.	Model	Increase in scripted play comments for both participants – One participant increased in unscripted comments also.	None reported.

Thomas et al. (2019)	Teaching an autistic child how to follow a written activity schedule containing components of Behaviour Skills Training for teaching skateboarding to his two siblings.	Untrained playmate	Among all siblings, the 10s intervals containing social interactions increased from 11.1% to 35.6%. The social interaction behaviours of the participant with a disability increased from 15% to 40%, while sibling 1 increased from 20% to 50% and sibling 2 increased from 5 to 20%.	Siblings and parents- siblings enjoyed the experience and would like to do more. Mother reported she thought outcomes were good.
Trent et al. (2005)	Sibling responsive interaction strategy training (mirroring and verbal responding)	Trained playmate	Increase in use of strategies and responsiveness for both siblings. Variable results for participants with a disability – one participant improved in mean length of utterance and vocabulary diversity with no increase in turn taking during mirroring but increase in verbal turns during verbal responding. Participant 2 decreased in verbal and related turns after mirroring.	None reported.
Tsao (2020)	Training package for siblings, including three steps of Stay-Play-Talk as well as more specific strategies such as offering to help and requesting assistance. Used stories to teach the strategies.	Trained playmate	Increase in number of social behaviours between both siblings in the dyads. Siblings expanded their use of strategies towards the participant with a disability. Intervention was likely effective for dyad 2 ($PMD=67-100\%$) and possibly effective on one participant with a disability's social behaviour ($PMD=50\%$) and one sibling's use of strategies ($PND=71\%$). The intervention had a small effect on social behaviours of both participants with a disability and their siblings ($r=0.62$, $p=0.003$ and $r=0.59$, $p=0.005$ respectively) and a medium effect on the sibling's social skills/strategies ($r=0.77$, $p=0.0002$).	None reported.
Tsao and Odom (2006)	Social skills strategy teaching to siblings of autistic individuals to increase their sibling's social participation in a play situation.	Trained playmate	Three of four siblings increased their number of their social behaviours towards their autistic sibling. All four autistic children increased their number of social behaviours directed towards their sibling.	None reported.
Walton and Ingersoll (2012)	Social skills strategy teaching (reciprocal imitation) to siblings.	Trained playmate	Variable across participants. Siblings – all six increases in contingent imitation, five increased use of linguistic mapping, four increased use of modelling and	Parents and siblings- high levels of satisfaction with the intervention.

<p>prompting and three increased use of praise. Target child- Three of four autistic children increased use of imitation and joint engagement.</p>	<p>Watkins et al. (2021) An intervention package consisting of structured and interest-based play activities, adult instruction and modelling, and response to child questions to increase interaction between siblings. Playmate and participant in intervention (NAP=.97 or above). Scores were statistically significantly ($p < .0006$). Sibling and participant with a disability- siblings reported satisfaction with the intervention as did one of two participants (other participant was non-verbal and so the authors did not collect data).</p>
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Table 6.4 Key Intervention Characteristics in Systematic Review of Sibling Involvement in Interventions for Individuals with a Disability

Abbreviations: Mean (M), Non-Overlap of All Pairs (NAP); Percentage Non-Overlapping Data (PND); Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS); Standard Deviation (SD).

6.2.1 Overview of Included Studies

This review included 31 studies originating from five different countries; the majority (n=26, 83.87%) were from the USA and the other four countries were Australia (Castorina & Negri, 2011; Rayner, 2011), Taiwan (Chu & Pan, 2012), the Netherlands (Huskens et al., 2015) and Turkey (Özen, 2015). There were 24 studies published between 2010 and 2020 compared to seven from 1999 to 2009 (Figure 6.3) .

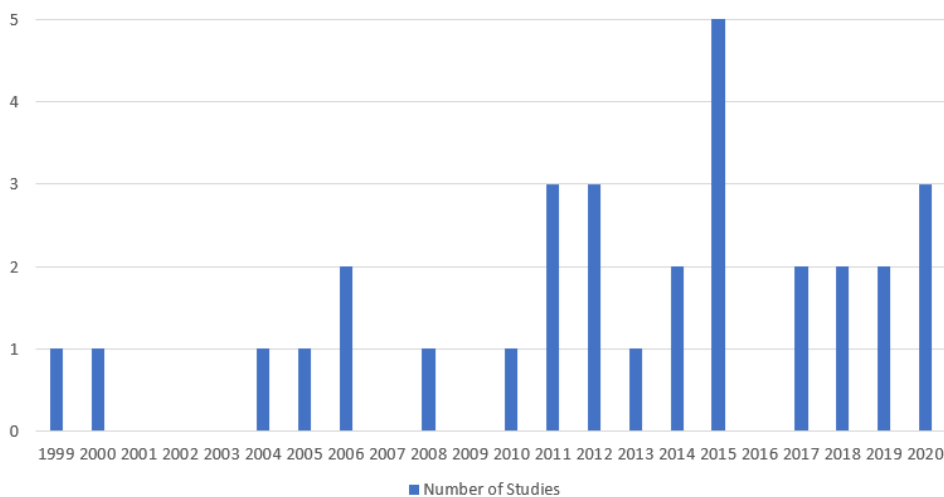


Figure 6.3 Year of Study Publication

The included studies used a variety of research designs. The majority of studies implemented a single case experimental design (n=24, 77.42%), for example Daffner et al. (2020) and Spector and Charlop (2018). Two studies Castorina and Negri (2011) and Chu and Pan (2012) used a non-randomised control design.

6.2.2 Overview of Participants

6.2.2.1 Number of Participants

Collectively, the studies reported a total of 347 participants, comprising of individuals with disabilities, siblings, parents, and peers. On average, each study had 11.19 participants (range 2 - 52). Notably, 25 studies featured 10 or fewer participants.

The total number of individuals with disabilities participating in interventions alongside their siblings was 140, with an average of 4.52 per study (range 1 - 26). Across three studies (Castorina & Negri, 2011; Chu & Pan, 2012; Madzharova & Sturmey, 2015)

there were an additional 30 individuals with disabilities who participated independently, without siblings. These participants were subsequently excluded from the analysis.

The total number of siblings was 144 (average of 4.65, range 1-26). Furthermore, there were 33 other individuals who participated in the studies, including 10 parents, three other adults, and 20 peers. It is important to note the discrepancy between the number of individuals with disabilities and siblings who participated in the studies. This is due to three studies in which multiple siblings of the same individual with a disability were engaged in the research.

6.2.2.2 Age and gender of participants

The age of siblings and individuals with a disability ranged from three years to 15 years, with the majority being between the ages of six and 12 (n=178, 62.68%). One study, Hansford (2013), did not report ages for the participants with a disability (n=20). Kryzak and Jones (2017) did not provide exact ages for participants, only an age range (participants with a disability: 4-13 years, siblings: 6-14 years). Likewise, Castorina and Negri (2011) did not report exact ages nor an age range for the siblings in their study; they only indicated that among the seven siblings, the mean age was 12.71 with a standard deviation of 0.95. No adult participants were included in any of the studies.

Of the 144 siblings, 84 (58.33%) were older than the individuals with disabilities, while 32 (22.22%) were younger, and six (4.17%) were twins. Notably, Kryzak and Jones (2017) and Chu and Pan (2012) did not report information about birth order (n=22, 15.28%).

Regarding the gender distribution, most participants with disabilities were male (n=95, 67.86%), while only 25 females were reported to be involved (17.86%). Hansford (2013) did not provide gender data for participants with disabilities (n=20). In contrast, all studies reported the gender distribution among siblings – 71 (49.31%) were male, and 73 (50.69%) were female.

6.2.2.3 Diagnosis of participants with a disability

The most prevalent diagnosis among individuals with disabilities was autism spectrum disorder (ASD), encompassing autism, Asperger's syndrome, and Pervasive Developmental Disorder not otherwise specified (PDD-NOS). Out of the 140 participants with disabilities, 120 were reported to have a diagnosis of ASD (85.71%). Furthermore, there were nine individuals who were reported to have multiple diagnoses, one of which was ASD. Other co-occurring diagnoses included attention deficit hyperactivity disorder,

anxiety, depression, and oppositional defiance disorder. Only eleven participants with disabilities did not have a diagnosis of ASD. Additional reported diagnoses included Down syndrome (n=3), Noonan syndrome (n=1), speech motor delay (n=1), attention deficit hyperactivity disorder (n=3), and developmental delay (n=3). No participants were identified with acquired or progressive disabilities. Given the predominant presence of ASD as a diagnostic group a secondary search utilising specific diagnosis terms relevant to adults and children ("cerebral palsy" OR "multiple sclerosis" OR blind OR deaf OR "amyotrophic lateral sclerosis") was conducted to identify potential studies that might not have been captured using the broad terms (disorder* OR disab* OR difficult* OR impair* OR injur*). However, this secondary search yielded no additional relevant studies.

6.2.3 Research Question NP1b: What has been the content focus of sibling training interventions for siblings of individuals with a disability?

Of the 31 included studies, 14 (45.1%) involved some form of sibling training. Within these 14 studies, the focus of the sibling training was primarily on (i) strategies for facilitating play and social interactions, (ii) strategies to support communication or (iii) both. Strategies for facilitating play and social interactions included the stay-play-talk model (i.e., Kryzak and Jones (2017); Tsao (2020)), promoting sharing and compromising (Daffner et al., 2020) and how to engage in play activities (Taylor et al., 1999). Strategies to support communication with siblings included implementing a natural language paradigm (Spector & Charlop, 2018), stay-play-talk-respond (Douglas et al., 2018) and modelling (Walton & Ingersoll, 2012). Some studies, for example Tsao and Odom (2006) included the teaching of strategies to facilitating both social interactions and communication, for example establishing eye contact, suggesting play activities, offering or asking for help, initiating conversations, and expanding their siblings' utterances (Tsao & Odom, 2006). One exception to the focus centring on facilitating social and or communicative interactions is Chu and Pan (2012) who had the siblings teaching aquatic skills as well as learning to facilitate social interactions with their sibling.

6.2.4 Research Question NP3a: Can siblings be effective agents of change in therapeutic interventions?

Overall, the included studies reported review positive results for their training and interventions. It is worth noting that this may be due to a publication bias, i.e. a tendency to publish only results that are clinically or statistically significant (Dalton et al., 2016).

While positive results were frequently reported in the studies, this was not standard across all studies; there were high levels of variability in some, with studies reporting non-significant findings (Hansford, 2013), or mixed results across participants (Walton & Ingersoll, 2012) or targets (Buerger, 2014).

6.2.4.1 Results Across Targets

Studies examined many different skills and behaviours in participants with disabilities and in their siblings, with varied outcomes reported. For instance, Buerger (2014), reported positive interactions between siblings increased post-intervention, yet levels of negative interaction behaviours remained unaffected. Similarly, in the study by Daffner et al. (2020) all participants demonstrated an improvement in positive social behaviours but no reduction in negative social behaviours was observed. While some studies reported variable results, several studies reported consistent positive outcomes: Dodd et al. (2008) reported an increase in target behaviours for both participants with a disability. The intervention reported by Chu and Pan (2012) resulted in an increase in physical and social interactions for participants with a disability. Participants with a disability who participated with a peer or sibling showed significantly more improvement in their physical and social outcomes compared to the control group ($p < 0.01$). Other studies that reported consistent positive outcomes were Baker (2000), Douglas et al. (2018), Özen (2015), and Tsao and Odom (2006).

6.2.4.2 Results across Participants

Inconsistent results were reported across participant groups. For example, Lewandowski et al. (2014) documented improvements in the target behaviours of participants with disabilities, yet no corresponding improvements were observed in sibling behaviours. Conversely, Kryzak et al. (2015) reported no statistically significant differences in targets for children with ASD but an improvement in imitations and sibling responses. In two of the studies (Chu & Pan, 2012; Jones & Schwartz, 2004), while positive outcomes were reported, there was no record of a significant benefit in involving a sibling as a key agent of change in the intervention as compared to the involvement of a peer or parent.

6.2.4.3 Summary

Ultimately, siblings may be effective agents of change in therapeutic interventions; interventions can be effective in improving outcomes for the individual with a disability and/or the sibling. However, due to the lack of consistent results across interventions,

this progress is not guaranteed when engaging a sibling in an intervention. More research needs to be completed so that the relevant variables impacting on the effectiveness of a sibling intervention (e.g., participant age, strategies taught, duration of the intervention) can be identified.

6.2.5 Research Question NP4a: What roles do siblings occupy in interventions for individuals with a disability?

Seven different roles were identified for siblings partaking in interventions (see Table 6.5). The categories were discrete, with no study reporting sibling being involved as more than one category. Across studies, trained playmate was the most commonly assigned role (n=11, 35.48%). A further three studies assigned siblings the role of instructor, whereby siblings were trained to elicit specific behaviours or responses from the participant with a disability.

Role	Description	Number of studies
Untrained playmate	Sibling did not receive any training and were present as a playmate for the individual with a disability to practice their skills learned in the intervention.	5 (16.13%)
Playmate and participant in intervention	Sibling did not receive any personal intervention. Sibling attended individual intervention with child with disability. Goals/targets of intervention were for child with disability and sibling.	3 (9.68%)
Participant in group	Sibling did not receive any personal intervention. Sibling attended group intervention with child with disability. Goals/targets of intervention were for child with disability only.	1 (3.23%)
Participant in support group	Sibling attended a support group for siblings of individuals with a disability.	4 (12.9%)
Model	Sibling acted as a model, either video model or face to face model as part of the intervention.	4 (12.9%)
Trained playmate	Siblings were trained in strategies to facilitate general interactions with the child with a disability. Siblings were not trained to elicit specific responses from the child with a disability.	11 (35.48%)
Instructor	Sibling was trained specifically to elicit a certain response from the child with a disability in relation to the goals of the intervention. Also gave feedback and specific prompts to the child.	3 (9.68%)

Table 6.5 Sibling Roles in Interventions, Taken from Lynam and Smith (2022, p.4584)

6.2.6 Research Question NP1-4b: What are the experiences and opinions of siblings of individuals with a disability who took part in an intervention?

More than half of the studies (n=18, 58.06%) reported on participant evaluations of their experiences in some form. Of the 14 studies that reported on sibling experiences, 13 included sibling reports focused on sibling satisfaction with their involvement in the intervention and their enjoyment in taking part. In contrast, Baker (2000) employed interviews to enquire about skill improvements reported by siblings. With the exception of one study (Kim, 2010), all studies reported positive feedback from siblings. Overall, most siblings reported they enjoyed their involvement in the intervention (Buerger, 2014; Daffner et al., 2020; Reagon et al., 2006; Thomas et al., 2019; Walton & Ingersoll, 2012). Chu and Pan (2012) reported siblings perceived their participation as a positive experience and expressed interest in engaging in similar activities in the future. High levels of sibling satisfaction were reported in three studies (Buerger, 2014; Hansford, 2013; Walton & Ingersoll, 2012), and one study reported moderate satisfaction (Ferraioli & Harris, 2011). The participants with a disability in the studies by Dodd et al. (2008), Huskens et al. (2015) and Watkins et al. (2021) gave positive reports of the intervention, for example reporting that they enjoyed the intervention and learning something new. No negative experiences were reported by siblings or participants with a disability in these studies.

6.2.7 Research Question NP5b: What are the common structures of interventions described in sibling training interventions?

The interventions reviewed covered a wide range of topics. The structure of these interventions varied, but just over half of the studies (n=16, 51.61%) implementing a combination of sibling training or support group sessions followed by interactive play sessions involving the individual with a disability. In addition, two studies introduced supplementary training components, targeting parents or the individual with the disability, in conjunction with the sibling support group and play sessions. Furthermore, three studies consisted of sibling training followed by intervention sessions for the participant with a disability mediated by their sibling. The structure of the sibling training varied across the studies, but generally included some form of individual or group training which incorporated aspects of modelling, in person or video modelling, role play, discussion and feedback.

Training duration varied and ranged from three weeks (Douglas et al., 2018) to 24 weeks (Jones & Schwartz, 2004). However, 14 of the studies (45.16%) did not report on the training duration in sufficient detail. Training frequency was predominantly once

or twice a week, with Reagon et al. (2006) conducting daily sessions. Session lengths were not consistently reported across all studies, but for those that did provide this information, session durations ranged from 10 minutes to 2 hours.

6.2.8 Research Question NP6c: What instructional strategies are used in sibling training interventions?

In the 14 studies that included a sibling training component, the number of instructional strategies used ranged from one to nine with a mean of four per study. The most frequently used instructional strategy was role play (n=12, 85.7%), followed by verbal description of the skill or strategy being taught (n=11, 78.6%), modelling or skill demonstration (n=7, 50%) and providing feedback (n=6, 42.9%). Other instructional strategies included video model, verbal practice or skill rehearsal, discussion about skill use, providing written materials, reading a story, PowerPoint slides, providing a rationale of why the sibling is learning the strategy and a quiz to check understanding.

6.2.9 Summary

This systematic review provided a comprehensive picture of the research evidence on interventions for siblings of individuals with a disability. One key finding from this systematic review was that siblings can be effective agents of change in interventions; sibling interventions can lead to positive outcomes for both the sibling and individual with a disability and for the most part, siblings enjoyed the experience of participating in the interventions. However, this finding was not consistent across all interventions and more research needs to be completed to understand the variables impacting on intervention effectiveness. Two examples of possible variables were the intervention structure and the instructional strategies used to teach siblings, both of which differed across the reported interventions. Another key finding was that, in the studies of this review, siblings were trained to facilitate play and social interaction and/or to communicate with their sibling. These strategies corresponded with the role of playmate that siblings were primarily expected to occupy during a training intervention. The findings of this systematic review are beneficial when considering how to support sibling engagement with an intervention, as will be discussed later in this thesis.

Chapter 7: Systematic Review of Peer Communication Partner Training Interventions

This chapter describes the methods and findings of a systematic review of peer communication partner training intervention.

7.1 Method

7.1.1 Introduction

The second systematic review focused on communication partner interventions for peers. Peers were chosen as the target participants for this review due to their similarities to siblings; for example (i) being a communication partner who is a similar age to the AAC user and may be young and (ii) occupying the role of playmate. A systematic review methodology was chosen due to the rigorous and comprehensive nature of systematic reviews as a method of synthesising existing research evidence (Dickson et al., 2017). See Section 6.1.1. for more details on the benefits and challenges of systematic reviews.

There were five research questions for this review. See Table 7.1 for a list of these research questions and their link to the factors supporting engagement principles as outlined in Figure 5.1.

	Research Question	Supporting Engagement Framework Component
NP1c	What has been the content focus of peer communication partner interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goals/Activities</i>
NP1-4c	What are the experiences and opinions of peers who took part in a communication partner training intervention?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goals/Activities</i>
NP5c	What are the common structures of interventions described in peer communication partner interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Intervention Structure</i>
NP6c	What instructional strategies are used in peer communication partner training interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Learning Strategies</i>

Table 7.1 Research Questions for Systematic Review of Peer Communication Partner Interventions

7.1.2 Information sources and search strategy

The search terms used for this review were (Peer* OR friend* OR classmate* OR Sibling* OR brother* OR sister*) AND (intervent* OR Therap* OR instruct* OR train* OR educat* OR coach* OR teach* OR support* OR peer-mediated) AND (Augmentative and alternative communication OR AAC OR Augmentative communication OR Alternative communication OR speech-generating device). These search terms represented the three main strands related to this review – peers, intervention, and AAC. The search was limited to these terms in the title and/or abstract of the articles within four databases CINAHL, ERIC, Pubmed and PsycInfo. Initially the search was completed in 2021 by a second researcher as part of another joint research project, and included articles published in peer reviewed journals between 2011 and 2021. The searches were updated to include articles published up until June 2022. This timeframe was chosen to manage the scope of the review. This current research study extended this joint project by updating the timeframe of included articles as well as answering the aforementioned research questions, with a specific focus on the content, structure, instructional strategies and participant experiences rather than the effectiveness of peer communication partner training.

In addition, reference checks of five literature reviews on increasing peer interactions in individuals with complex communication needs (Chung & Carter, 2013; Therrien, 2016), peer-mediated interventions for autistic AAC users (Bourque, 2020; O Donoghue et al., 2021) and child communication partner involvement in AAC modelling interventions (Biggs et al., 2019) were conducted to identify any studies which had been missed by the initial search. Through this additional search, there were 7 additional studies which were identified as meeting the inclusion criteria at the title/abstract level. None of these studies met the inclusion criteria at a full text level and so were not included in the final 13 studies reported on in this review.

7.1.3 Inclusion and Exclusion Criteria

All titles and abstracts that met the above search criteria were imported into a reference management database (Endnote™). Duplicates were identified and removed. Next, the articles were screened using the inclusion and exclusion criteria outlined below (Table 7.2), first by title and abstract, and then by full text. If an article clearly did not meet the criteria at a certain level, it was not passed forward for screening at the next level.

	Inclusion Criteria	Exclusion Criteria
Study	<ul style="list-style-type: none"> • The study was published in English between the years 2011-2022. • The study was published in a peer reviewed journal. • The article describes an intervention study (i.e., not a study protocol, review, or editorial). 	<ul style="list-style-type: none"> • The study was not published in English. • The study was published outside of the years 2011-2022. • The study was not published in peer-reviewed journal.
Participants	<ul style="list-style-type: none"> • The study included participants of any age. • The study included typically developing siblings of individuals who use any form of AAC. 	<ul style="list-style-type: none"> • The study included no typically developing peers. • The study included only peers of individuals who did not communicate using AAC.
Intervention	<ul style="list-style-type: none"> • The study included a description of the content of structure of any form of peer training relating to communication or AAC. • The intervention included the provision of a new AAC system. • The intervention included the training of others to facilitate peer communication/interaction. 	<ul style="list-style-type: none"> • The intervention did not include peer training. • The content and/or structure of the peer training was not described. • There were other intervention aspects within the study (e.g., AAC user receiving separate intervention from an SLT, training of others not associated facilitating peer interaction etc.).
Outcomes	<ul style="list-style-type: none"> • The outcomes of the study related to at least one of the following: <ul style="list-style-type: none"> ○ Peer knowledge, skills or attitude regarding communication, interaction or AAC. ○ AAC user's social interaction or communication skills. ○ The social interaction between the AAC user and the peer. 	<ul style="list-style-type: none"> • The outcomes of the intervention were not related to the AAC user or the peer • The outcome of the peer training could not be disaggregated from other communication partner involvement.

Table 7.2 Inclusion and Exclusion Criteria for Systematic Review of Peer Communication Partner Interventions

7.1.4 Results of Search

The search resulted in 340 citations meeting the search term criteria. Duplicates were removed ($n= 153$) and 187 titles and abstracts were reviewed. Following the screening of the titles and abstracts, 33 articles met the inclusion criteria and were accepted for further review. The full texts of the articles were reviewed, and it was found that 14 articles reporting on 13 separate studies matched the inclusion and exclusion criteria necessary to be included into this systematic review. One study was excluded as it contained an overview of two other studies included in this review. From the hand searched articles, seven references met the title criteria, but all were excluded after the full texts were reviewed. The template used to extract the data from the studies can be found in Appendix D. See Figure 7.1 for a flowchart of the article selection process.

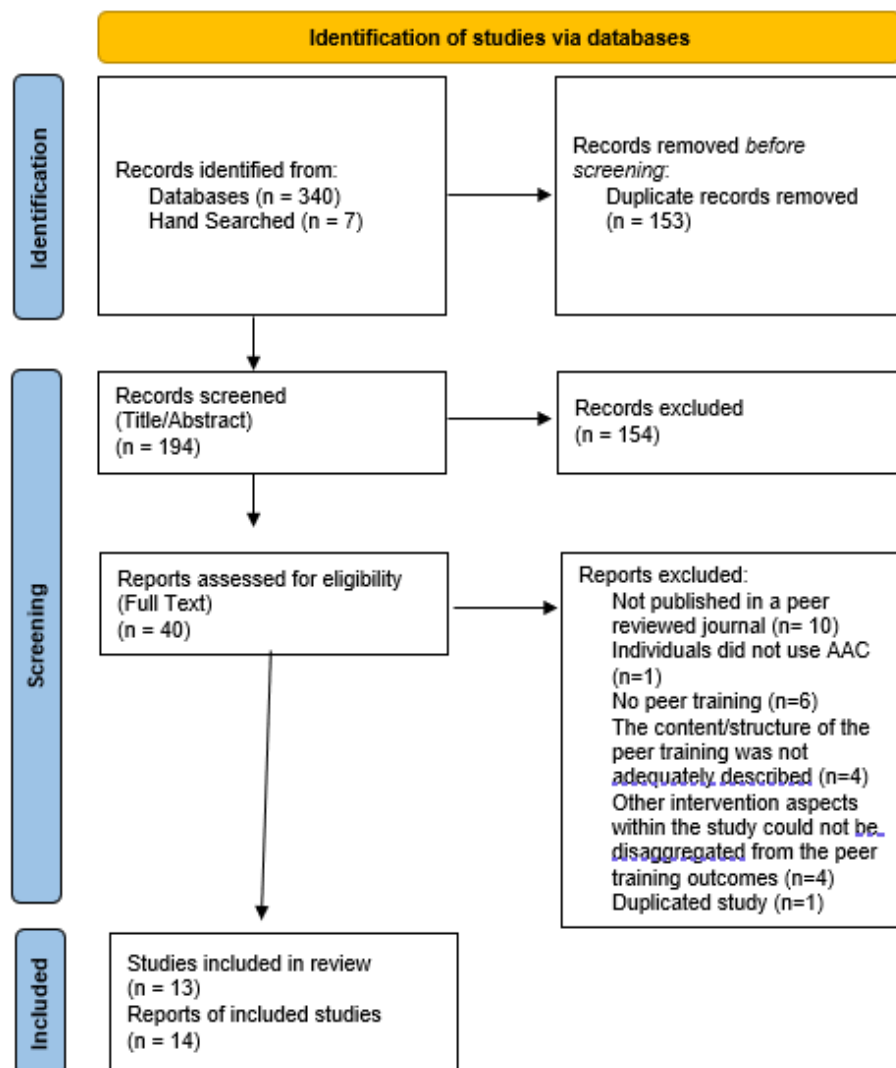


Figure 7.1 PRISMA Flowchart of Article Selection for Systematic Review of Peer Communication Partner Interventions (Adapted from Moher et al., 2009)

7.1.5 Reliability

Inter-rater reliability checks were carried out at two points – during review of titles and abstracts and during the full text data extraction. Of the 194 articles which were identified, 70% (n=134) were screened at the title and abstract level by the author and another researcher. The inter-rater reliability was 95% (n= 127).

The reliability of the full text data extraction was completed by a second researcher. This researcher was initially provided with the data extraction form and was asked to review it to ensure the headings were interpreted in the way the researcher intended. Following this review, minor changes were made to the data extraction form, specifically more detailed labels of the instructional strategies and content were introduced. The reviewer then used the form to extract data from 3 articles; 21% of those which passed the title and abstract inclusion stage. The inter-rater agreement at this stage was 100%.

7.1.6 Quality of Studies

Similar to the systematic review of sibling involvement in interventions for children with disabilities (Chapter 6), the quality of the studies in this systematic review was analysed using (i) the guidelines for levels of evidence provided by the Oxford Centre for Evidence-Based Medicine (Howick, 2009) and (ii) the 'Quality Assessment of Controlled Intervention Studies' and the 'Quality Assessment Tool for Before-After (Pre-Post) Studies without a control group' (National Heart Lung and Blood Institute, n.d.). These assessments took several factors into account when detecting potential study bias, for example the outcome measures, participant eligibility, the sample size, and dropout rate.

7.1.6.1 Results of Quality Analysis

Most studies (n=11, 84.6%) were assessed as achieving a quality evidence level of 4, suggestive of small-scale studies lacking randomised controlled trials or cohort studies (Howick, 2009). The other two studies (Holyfield et al., 2018; Thiemann-Bourque et al., 2018) were randomised controlled trials, and were deemed to be at a 2b level. Of the 11 studies without controls, each was found to have a moderate risk of bias (e.g., between 25-75% according to the assessment documents (National Heart Lung and Blood Institute, n.d.). All the studies stated the question or objective clearly as well as clearly defining outcome measures and describing the assessment. However, none of the studies blinded the assessors to the participants intervention nor have a sufficiently large sample size. Additionally, no study reported the dropout rate, however this may be due

to (i) the small sample sizes or (ii) only including the information from participants who completed the whole intervention.

For the two randomised controlled trials (Holyfield et al., 2018; Thiemann-Bourque et al., 2018) the 'Quality Assessment of Controlled Intervention Studies' (National Heart Lung and Blood Institute, n.d.) was used to assess study quality. As mentioned in Chapter 6, the lack of guidance on how to categorise scores led to a decision being made that scores of 50% or lower would be classified as having weak evidence, scores ranging between 50% and 75% as moderate evidence, and scores exceeding 75% as high levels of evidence. Using this classification, both studies were rated as moderate evidence (64.3% and 71.4% respectively). Both randomised their participant groups and had high adherence to intervention protocols. However, neither study blinded assessors to participant group nor had a sufficiently large sample size.

Similar to the previous systematic review, studies with moderate quality of evidence were included when they may not typically be included in other systematic reviews analysing intervention effectiveness. This decision was due to the dearth of high-quality evidence available as well as an interest in probing other intervention aspects, for example the common structures, content, learning strategies and participant opinions on intervention involvement.

7.2 Findings

The systematic review findings are outlined below, beginning with an overview of the studies and the participants, followed by the findings as they correspond to each research question. Key participant and intervention characteristics of the included studies are detailed in Table 7.3 and 7.4 respectively.

Study	Number of Participants		Age Range (In Years)		Gender		Diagnosis*	Type of AAC used
	AAC user	Peer	AAC user	Peer	AAC user	Peer		
Biggs et al. (2017)	4	8	10 – 16	12 – 14	1 Female 3 Male	5 Female 3 Male	Down Syndrome, Angelman syndrome, intellectual disability and severe oral apraxia	SGD - Proloquo2Go
Biggs et al. (2018)	4	13	9 – 10	Not recorded	3 Female 1 Male	Not recorded	Intellectual disability, ASD	Mix: No tech (gestures, vocalisations), communication book, SGD
Bourque and Goldstein (2020)	6	15	3;7 – 4;11	3;7 – 5;0	4 Female 2 Male	Not recorded	ASD	No tech (signs, gestures, vocalisations) and PECS
Chung and Carter (2013)	2	7	11 -12	Not recorded	1 Female 1 Male	5 Female 2 Male	Intellectual disability	No tech (manual signs, facial expressions, gestures, vocalisations), pictures and SGD
Holyfield et al. (2018)	3	24	12 - 15	11 – 14	2 Female 1 Male	Not recorded	Multiple disabilities	No-tech – facial expression, body movements and vocalisations.

Lorah et al. (2019)	3	3	3;6 – 4;2	Mean 3;6	2 Female 1 Male	3 Male	ASD	SGD
Severini et al. (2019)	2	3	3;2 – 5;3	3 – 4	1 Female 1 Male	3 Male	Down Syndrome	SGD, sign language and vocalisations
Strasberger and Ferreri (2014)	4	5	5;8 – 12;11	7 – 13	4 Male	4 Female 1 Male	ASD and cognitive impairment	No tech (gestures, manual signs and vocalisations), PECS
Tan and Alant (2018)	1	1	7	7	1 Male	1 Male	Autism and speech disorder	SGD – iPad with Touch Chat
Thiemann-Bourque et al. (2016)	4	7	3;0 – 5;1	3;4 – 11	1 Female 3 Male	Not recorded	ASD	PECS
Thiemann-Bourque et al. (2017)	3	3	4;5 – 4;7	4;5 – 4;6	1 Female 2 Male	2 Female 1 Male	ASD	Gestures and introduced to PECS
Thiemann-Bourque et al. (2018)	45	95	2;11 – 5	3;4 – 5;1	9 Female 36 Male	50 Female 45 Male	ASD	Not recorded
Trottier et al. (2011)	2	6	11;1 – 11;4	11 – 12	2 Male	2 Female 4 Male	ASD	Communication book, PECS, SGD
Wu et al. (2020)	3	9	8 – 9	Not recorded	1 Female 2 Male	Not recorded	Moderate intellectual disability, ASD	No tech (vocalisations, gestures, and facial expressions)

Table 7.3. Key Participant Characteristics in Systematic Review of Peer Communication Partner Training Interventions

Note: *Diagnoses are stated as reported in the article.

Abbreviations: Autism Spectrum Disorder (ASD); Picture Exchange Communication System (PECS); Speech Generating Device (SGD)

Study	Group/ Individual	Format of training within intervention	Duration	Instructional strategies	Content of intervention	Outcomes	Participant Feedback
Biggs et al. (2017)	Both, depending on availability of peers	Pre-intervention and concurrent support /prompting	1x 25 – 40 minute session	<ul style="list-style-type: none"> • Descriptive overview /explain rationale • Discussion/ Questions/ Feedback • Individualised plan 	<ul style="list-style-type: none"> • Expectant delay • General provision of communicative opportunities • Prompting • Contingent responses 	Functional relation demonstrated between the intervention and (i) communication with peers (Tau-U=0.94 (range: 0.81-1.0)) and (ii) with peer communication with focus student (increased across all Tau-U=0.98 (range: 0.94-1.0)). No functional relation for AAC use.	AAC user reported to like working with peers; Peers felt positively about the intervention, one reported change in attitude towards people with a disability.
Biggs et al. (2018)	Not recorded	Pre-intervention and concurrent support/ prompting	1x orientation - 25-30 minutes 1x training plus 2-4 coaching sessions - 22-30 minutes	<ul style="list-style-type: none"> • Descriptive overview/ explain rationale • Modelling/ demonstration • Oral instruction • Roleplay or rehearsal • Verbal rehearsal • Printed materials • Discussion/ Questions/ Feedback 	<ul style="list-style-type: none"> • Aided AAC modelling • General AAC education – Location of symbols • Expectant delay • Open ended questions. • General referenced partner interaction training - Offer praise and positive 	Functional relation between peer network and increased interaction with peers. Functional relation was demonstrated between the addition of peer-implemented aided AAC modelling and nonpromoted symbolic communication.	Two students indicated they liked spending time with their peer network and liked when peers used their AAC device, considered their network friends and wanted to keep spending time. Two other participant responses were unclear. Peers and paraprofessionals also rated their

<p>Bourque and Goldstein (2020)</p>	<p>Not recorded</p>	<p>Pre-intervention and concurrent support/ prompting</p>	<p>2 to 3 sessions with the length not reported.</p>	<ul style="list-style-type: none"> • Modelling/ demonstration • Roleplay or rehearsal • Printed materials. • Discussion/ Questions/ Feedback • Other - Videos of ways children communicate 	<p>g responsive</p> <ul style="list-style-type: none"> • Aided AAC modelling - • Expectant delay • General referenced partner interaction training - Stay Play Talk and getting attention 	<p>language/bein</p>	<p>experiences positively.</p>
<p>Chung and Carter (2013)</p>	<p>Individual</p>	<p>Pre-intervention and concurrent support/ prompting</p>	<p>1x 45 minute session</p>	<ul style="list-style-type: none"> • Descriptive overview/ explain rationale • Modelling/ demonstration • PowerPoint™ 	<ul style="list-style-type: none"> • General AAC education - Total communication • Expectant delay • Open ended questions • General referenced 	<p>Peer interactions:</p> <p>Increases in 3/4 classrooms from baseline to intervention (PND 90-100%). The remaining classroom had higher levels of peer interaction at baseline. Initiations of focus student also increased in 3/4 classrooms. Variable</p>	<p>Focus students: liked talking with peers. Peers: interacted with focus student more, benefits of their own learning and perceptions towards focus student.</p>

				<p>partner interaction training - Get attention and responding</p> <ul style="list-style-type: none"> • General provision of communicative opportunities • Prompting 	<p>across classrooms, but more use of SGD in interactions during intervention phase than baseline.</p>	<p>Paraprofessionals positive and beneficial. Positive changes: increased interactions and use of SGD. General ed teachers- positive experiences for focus student and peers. Parents of focus students reported positive impact, increased use of SGD.</p>	
Holyfield et al. (2018)	Individual	Pre-intervention	1x 15-minute session	<ul style="list-style-type: none"> • Descriptive overview/ explain rationale. • Modelling/ demonstration • Authentic application • Memory tool 	<p>Interpreting participant specific communication gestures, facial expressions etc.</p>	<p>Peers in experimental group improved their performance in interpreting the behaviours of the children with disabilities (M=15.5, SD=1.8, range 12-18) as compared to the Pretest (M=6, SD=3.1, range =0-12) compared to the control group (post test: M=5, SD.=2.7, range=-5-5 and Pretest M=5.6, SD=2.5, range 2-9). Significant effect of</p>	<p>Peers reported intervention was important and noticed an improvement in communication between students, would implement training in the future, children with disabilities seemed to enjoy interactions with</p>

					experimental group F(3,20)= 46.67, p<.001.	peers more and peers benefitted from the training.
Lorah et al. (2019)	Not recorded	Pre-intervention and concurrent support/ prompting	1x 30 minute session	<ul style="list-style-type: none"> • Roleplay or rehearsal • General referenced partner interaction training • Manding 	Increase in independent mands moderate to high effect in PND (84-100%).	No feedback
Severini et al. (2019)	Group with AAC user	Pre-intervention and concurrent support/ prompting	3-4 sessions x 15 minutes	<ul style="list-style-type: none"> • Descriptive overview/ explain rationale • Modelling/ demonstration • Roleplay or rehearsal • Discussion/ Questions/ Feedback 	Stay Play Talk resulted in peer staying and playing with the target child more consistently. Modified arrangement resulted in more peers staying, playing and talking. No changes for target child interactions during modified Stay Play Talk condition.	No feedback
Strasberger and Ferreri (2014)	Individual	Pre-intervention and concurrent support/ prompting	Not recorded	<ul style="list-style-type: none"> • Modelling/ demonstration - Video modelling • Other - Formal Evaluation 	All improved on manded responses. 2/4 participants demonstrated maintenance and generalisation of training.	Intervention rated as both acceptable and effective.
Tan and Alant (2018)	Individual	Pre-intervention and concurrent support/ prompting	1x 15-minute training with 2 – 3-minute reviews prior to	<ul style="list-style-type: none"> • Aided AAC modelling • Prompting • Oral instruction 	Variable increasing trend of peer prompts for first 3 sessions, remained similar for next four sessions and then much lower for last 4. Gradual increase in	No feedback

	intervention sessions	<ul style="list-style-type: none"> • Roleplay or rehearsal 	communicative acts of the AAC user. Maintained during follow up. High level of communicative acts exceeding mean for total communication acts (100%) and relevant communication acts (93%), but variable for spontaneous communication acts (57%).
Thiemann-Bourque et al. (2016)	Group Pre-intervention and concurrent support/ prompting	4x 30 – 45-minute sessions	<ul style="list-style-type: none"> • Descriptive overview/ explain rationale • Modelling/ demonstration • Roleplay or rehearsal • Printed materials • Discussion/ Questions/ Feedback • Review
		<ul style="list-style-type: none"> • General referenced partner interaction training - Stay Play Talk • PECS 	All children improved in peer-directed communication. Two children increased communicative functions to comment and share, all four improved in social engagement. All peers increased their communication with the autistic children (Tau-U= 0.98-1).
Thiemann-Bourque et al. (2017)	Group Pre-intervention	3x 30 minute sessions (1 session a day)	<ul style="list-style-type: none"> • Descriptive overview/ explain rationale • Modelling /demonstration • Roleplay or rehearsal
		<ul style="list-style-type: none"> • Expectant delay • General referenced partner interaction training - Stay, Play, Talk; 	Moderate effect sizes (Tau-U= 0.5- 0.67) for autistic children in rate of communicative behaviours and large for peer communication. Similar results for reciprocal exchanges. Higher rates of

			<ul style="list-style-type: none"> Printed materials Memory tool Review 	getting attention	communication in the added context of preferred toys and snacks.		
Thiemann -Bourque et al. (2018)	NR	Pre-intervention and concurrent support/ prompting	2 to 3 sessions with the length not reported.	<ul style="list-style-type: none"> Aided AAC modelling - Expectant delay General referenced partner interaction training - Stay Play Talk and getting attention 	Significant differences in rate of total communication for focus child compared to control group $F(4, 91)=22.53$, $p<0.001$. Significant difference in rate of total communication for peers in treatment group as compared to control group $F(4,87)=11.21$, $p<0.001$. Treatment group improved significantly more in the expressive language subtest of the MSEL ($p=.04$).	Treatment group ratings on the questionnaire grew more over time for focus children than in the comparison group when rated by teachers and parents. High acceptability of the program by school staff.	
Trottier et al. (2011)	Group	Pre-intervention and concurrent support/ prompting	1x 15 minute session	<ul style="list-style-type: none"> Descriptive overview/ explain rationale Modelling/ demonstration Roleplay or rehearsal 	<ul style="list-style-type: none"> Aided AAC modelling Prompting 	There was a change in the level of spontaneous appropriate communication acts for AAC users within one to three sessions following the initiation of Phase I intervention. AAC user spontaneous communicative acts increased (PND= 67-100%) at a fair to high level from baseline to final	Peers liked participating and wanted to do more. Felt good, more increase in confidence for Max's peers than lan's peers.

				intervention. Peers learnt to implement strategies effectively with minimal to no prompting (one trainer prompt or less per 5 minutes).
Wu et al. (2020)	NR	Pre-intervention	1x 30 minute session	<ul style="list-style-type: none"> • Descriptive overview/ explain rationale • Modelling/ demonstration • Roleplay or rehearsal • Discussion/ Questions/ Feedback <ul style="list-style-type: none"> • Aided AAC modelling • Prompting • Operational Skills
				<p>All participants used higher rates of verbal, nonverbal, and iPad SGD modes of communication following peer training, highest in use of iPad. Increased rate of communication responses by at least 1.21 per minute during peer mediated phase and 1.75 during maintenance phases.</p> <p>Nine peers - positive responses, e.g., enjoyed the training, happy to help, considered it effective and willing to do something similar in the future.</p>

Table 7.4. Key Intervention Characteristics of Systematic Review of Peer Communication Partner Training Interventions

Abbreviations: Mean (M), Mullen Scales of Early Learning (MSEL); Non-Overlap of All Pairs (NAP); Percentage Non-Overlapping Data (PND); Picture Exchange Communication System (PECS); Speech Generating Device (SGD); Standard Deviation (SD).

7.2.1 Overview of Included Studies

This systematic review identified 14 studies published between the years 2011 and 2022 (Figure 7.2). Most of the studies were from the USA (11/13, 84.6%). Two studies originated outside of the USA; Trottier et al. (2011) was published from Canada and Wu et al. (2020) was from Taiwan.

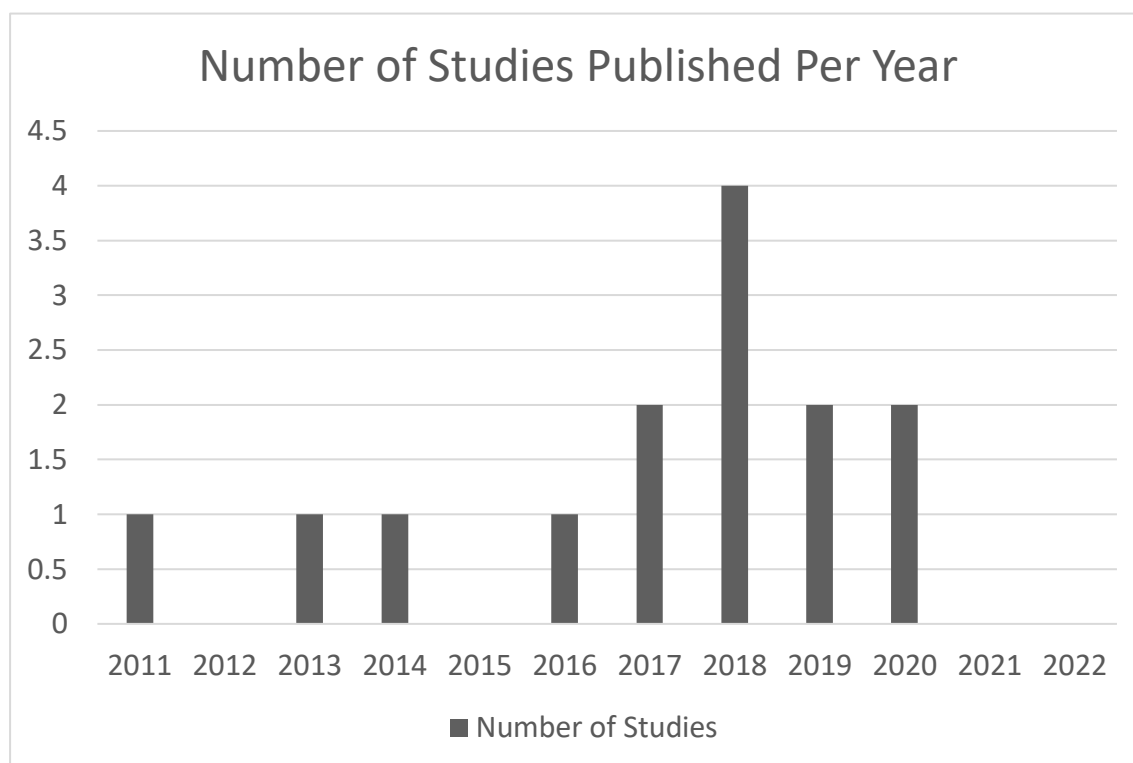


Figure 7.2 Year of Study Publication

7.2.2 Overview of Participants in the Included Studies

7.2.2.1 AAC Users

The total number of participants who use AAC across all studies was 86. The mean number per study was 6.14 (range 1 – 45). Out of the 14 articles, 12 were reported to have five or fewer participants who used AAC. One study (Thiemann-Bourque et al., 2018) included 45 participants who used AAC. If this study was excluded from the analysis, the mean number of participants per article dropped to 3.15, with a range of 1-6.

The participants who used AAC ranged in age between 2;11 and 16. The majority (n=61, 70.9%) were aged 0-5. See Figure 7.3. Only two participants were over the age

of 15. There were 60 males and 26 females participating in these studies, the majority of who had a primary diagnosis of ASD (N=73, 84.9%). Other primary diagnoses reported were intellectual disability (n=5), Down syndrome (n=4), multiple disabilities (n=3) and Angelman syndrome (n=1). Data regarding the type of AAC used by participants prior to intervention was also extracted. Of the 86 participants, 18 were reported to communication using no-tech AAC, one was reported using a low-tech communication book, four were high tech communication aids, six were reported to use PECS and two used PECS and a speech generating device. The Thiemann-Bourque et al. (2018) study containing 45 participants did not report on what form of AAC was used by participants.

7.2.2.2 Peer Participants

The total number of peers (i.e., siblings, classmates, friends etc.) across the studies was 199 (mean of 14.2 per study, range 1-95). Thiemann-Bourque et al. (2018) recorded 95 participants. If this study was removed from the analysis, the mean number of peers per study was eight. Less than 10 peer participants were reported in 10 of the studies (71.4%).

Most peers were aged 5 or under (n=126, 63.3%) and there were no peer participants over the age of 15 years. All 95 peer participants from Thiemann-Bourque et al. (2018) were aged 5 or under, and as such, if this was removed from the analysis, most peers would be aged between 6 and 14 (70/104, 67.3%). There were 65 male participants and 79 female participants, the genders of 55 participants were not recorded. A large majority of participants were classmates (n=194, 97.4%), four were similar aged peers not in the same school and one was a sibling.

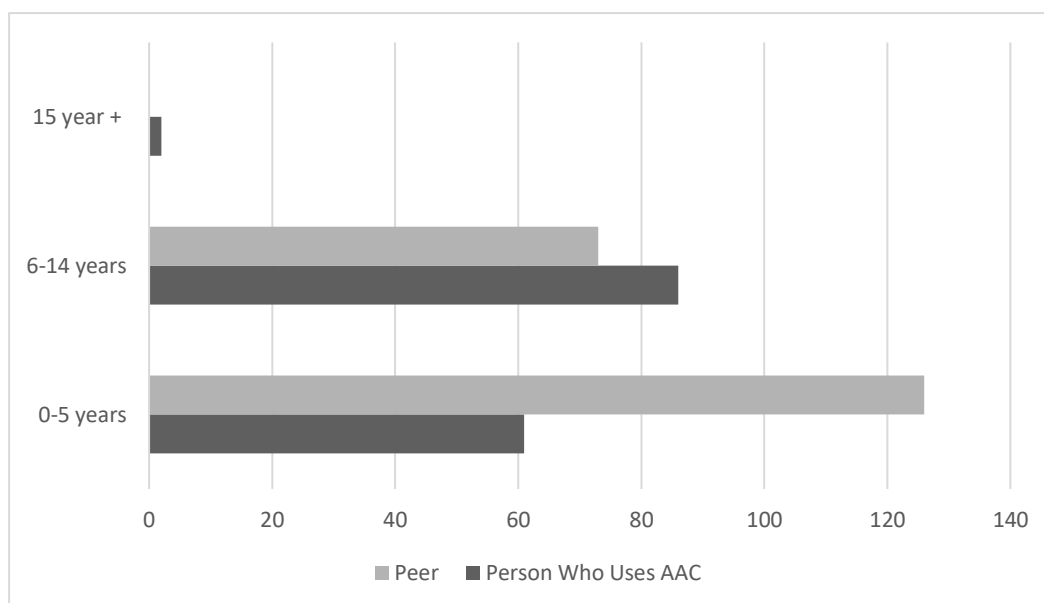


Figure 7.3 Age Range of AAC Users and Peers

7.2.3 Research Question NP1c: What has been the content focus of peer communication partner interventions?

The trainings focused on several distinct components, ranging from one to six different components per intervention (mean= 2.77). The top content item that was reported were general communication strategies (n=7), for example the stay-play-talk procedure designed to improve preschool children’s social interactions (Kohler et al., 2007). This procedure teaches peers to first ‘stay’ with the AAC user by engaging in activities or games, maintaining proximity and being present in the same space. Next peers are taught to ‘play’, i.e., selecting and participating in activities that the AAC user enjoys or finds interesting. Finally, peers are then taught to ‘talk’ with the AAC user, initiating conversations, ask questions, and responding to communication attempts (Severini et al., 2019). Other components taught to the peers were specifically AAC strategies, with studies reporting to teach peers how to prompt the individual to use the AAC system (n=6), system modelling (n=5), give time and wait for the individual to communicate (n=5) and operational strategies of how to use the device (e.g., turning it on and off, and navigating through the system etc; n=4).

7.2.4 Research Question NP1-4c: What are the experiences and opinions of peers who took part in a communication partner training intervention?

Out of the 14 studies, nine (64.3%) reported intervention feedback, or other social validity measures. Feedback was collected through questionnaires and interviews probing enjoyment, acceptability, perceived effectiveness, and intervention feasibility. Four

studies sought feedback from both AAC users and peers while one study obtained feedback from peers only. Seven studies sought adult feedback (including teachers, parents and paraprofessionals). The feedback across the nine studies was positive. Peers and AAC users reported enjoying participating and wanting to continue to do so. Others involved in the intervention reported it to be effective and acceptable. Bourque and Goldstein (2020) asked 30 graduate students, blinded to the treatment condition, to rate the social interactions of participants in videos taken pre and post treatment. The students consistently observed and reported improved social behaviours of both the AAC user and the peers in the post treatment videos when compared to those taken pre-treatment.

7.2.5 Research Question NP5c: What are the common structures of interventions described in peer communication partner interventions?

The trainings were either categorised as a group or a one-to-one training, with four studies describing a group training and four describing individual training. One study completed both group and individual training depending on the availability of the peers and four studies did not report whether the training took place in a group or one-to-one. In three studies, the training took place completely before any data collection during the intervention phase of the study. In the other ten studies, a pre-intervention training took place alongside regular support and coaching throughout the intervention phases. This coaching/support took the form of (i) a refresher of important information and strategies before the intervention data collection session, (ii) feedback from the previous session or (iii) on the spot prompting during the session itself.

The number of training sessions reported ranged from one to four (mean=2.2). The sessions were between 15 and 45 minutes long with a total duration of 15 to 150 minutes. The median duration length was 45 minutes.

7.2.6 Research Question NP6c: What instructional strategies are used in peer communication partner training interventions?

Instructional strategies were the techniques the interventionists used to deliver peer training. The studies reported using between 1 and 7 instructional strategies to train the peers, with an average of 4. Lora et al. (2019) reported using the fewest instructional strategies, only stating that roleplay was used. Biggs et al. (2018) reported using seven of the instructional strategies – providing a description/rationale, demonstrating, oral instruction of what to do, roleplay, verbal rehearsal of the strategy steps, providing printed materials and time for questions/feedback. The top instructional strategies that

were reported were demonstration of the strategy (n=11), a description or the rationale behind why the training or specific strategy is important (n=10), roleplay (n=9), time for questions or feedback from the session (n=6) and providing printed materials (n=4).

7.2.7 Summary

The findings of this systematic review summarise the research evidence relating to the content, structure, instructional strategies, and stakeholder opinions of peer communication partner training interventions. Overall, experiences of intervention involvement were reported to be positive. The elements taught to peers during a training, as well as how they were taught and what intervention structure was used varied across studies, providing an insight into factors which may be important to consider when supporting sibling engagement with a communication partner training intervention.

Chapter 8: Interviews with Siblings of AAC Users

This chapter presents an overview of the methods and findings of interviews with siblings of AAC users.

8.1 Method

8.1.1 Introduction

Literature on the experiences of siblings of AAC users is scarce (but see Dew et al. (2011)). Understanding sibling perspectives was deemed to be critical due to the significance of understanding personal experiences and opinions in building a therapeutic relationship, and thus supporting engagement (Hansen et al., 2023). To address this identified gap, four semi-structured 1-1 interviews with siblings of AAC users were conducted. Four research questions were identified for this section (Table 8.1).

	Research Question	Supporting Engagement Framework Component
R1a	What are the experiences of individuals growing up alongside a sibling who uses AAC?	<i>Supporting Engagement Through Reciprocal, Meaningful Relationships: Acknowledging Sibling as a Person</i>
R1b	What are the characteristics of the sibling relationship when one sibling uses AAC?	
R1c	What roles do siblings occupy when their sibling uses AAC?	
NP1-4a	What are the experiences and opinions of siblings of AAC users regarding their involvement in interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goals/Activities</i>

Table 8.1 Research Questions for Interviews

An exploratory qualitative approach using individual semi-structured interviews was selected for this component. Interviews were chosen as they allowed for a detailed investigation into understanding the participants' personal experiences and opinions (Tan, 2017). This in-depth exploration would not have been achievable through another method such as a survey. While focus groups were another method considered, interviews were preferable due to the small sample size, the desire to focus on the unique personal experiences of each individual and the logistics of conducting research online during the COVID-19 pandemic (Kumar, 2019).

The interviews were semi-structured (Flick, 2022); an interview schedule was followed, with general topics and prompts to cover rather than specific questions. The semi-structured interview method has been found to be successful in enabling the interviewer to improvise follow-up questions based on participant's responses and allowing space for participants' individual verbal expressions (Polit & Beck, 2010). These options were both important aspects to consider when exploring a relatively under researched topic, for which there is not a lot of background information to guide interview questions, and when personal experiences could differ widely across the participants (e.g., as demonstrated in Dew et al. (2011)).

8.1.2 Participants and Recruitment

Research ethics approval was obtained for the interviews from the School of Linguistic, Speech, and Communication Sciences in Trinity College Dublin (see Appendix E). Participants were given a Participant Information Leaflet (PIL) (Appendix F) and then provided consent through a completed consent form (Appendix G) prior to the interview. Consent was re-confirmed at the start of the interview. For individuals under the age of 16, parental consent was obtained through an online parental consent form (Appendix H) and participant assent was obtained through an online assent form (Appendix I) at the start of the interview.

Participants had to be over the age of 13 years and have a sibling who uses AAC to be eligible to take part. There was no limitation placed on the type of AAC, the length of time it had been used nor the sibling's involvement in supporting AAC use. Initially participants were recruited through services for individuals with a disability. However, due to the public health guidance and social distancing during the COVID-19 pandemic, many services were not functioning onsite in their full capacity, and it was decided to extend recruitment to an online platform (see Appendix E for research ethics amendment). The participant information leaflet (PIL) was shared on the social media sites of the researcher as well as the project. The PIL was also shared through the online newsletter and social media websites of the Irish Association of Speech and Language Therapists (IASLT) and Communication Matters in the United Kingdom.

Ultimately four participants met the criteria, provided informed consent, and completed an online interview. See Table 8.2 for their demographics. All names and other confidential information have been changed to preserve participant's anonymity.

Of interest, all participants were female, with three having female siblings. Also of note, the participants included two sets of twins.

Participant Name	Participant Age	Participant Gender	Sibling Name	Sibling Gender	Sibling Primary Diagnosis	Birth Order	Area	Occupation
Ciara	35-40	Female	Rose	Female	Cerebral Palsy	Participant Older	Ireland	Nurse
Ella	18-24	Female	Simon	Male	Severe Learning Disability and Autism	Sibling Older	England	SLT
Sarah	25-30	Female	Lily	Female	Cerebral Palsy	Twins	Ireland	SLT
Jessica	13-18	Female	Sophie	Female	Cerebral Palsy	Twins	Ireland	Student

Table 8.2 Interview Participants' Demographics

8.1.3 Materials and Procedures

In line with public health guidance at the time, the semi-structured interviews took place via Zoom™. This online format had the added benefit of allowing participants to complete the interview in a space that was familiar to them. The interviews took between 37 and 50 minutes, with a mean of 43 minutes. Each interview was audio recorded using a digital voice recorder which was placed near the computer speakers. The audio file was then transcribed and anonymised by the researcher and the subsequent word documents uploaded to NVivo (v.1.5.1), a qualitative data analysis software, for analysis.

8.1.4 Interview Schedule Development

The interviews all followed the same interview schedule (Appendix J), which outlined general topics and prompts rather than specific questions, a feature of a semi-structured interview (Tan, 2017). The prompts within these topics were adapted from an unpublished narrative literature review completed on typically developing sibling relationships by the researcher prior to the commencement of this stage of data collection.

8.1.5 Data Analysis

The interview data were analysed using the framework analysis method (Ritchie & Spencer, 1994). This method is described as existing within a broad family of thematic analysis methodologies, which seek to find similarities and differences in the data before grouping it into themes (Gale et al., 2013). The approach was originally used in applied policy research; it has more recently been used in social and health science research to explore participant experiences (McMillen, 2008; Parkinson et al., 2016; Swallow et al., 2011).

8.1.5.1 Characteristics of Framework Analysis

The approach itself comprises five distinct, but interconnected phases of data analysis: familiarisation, thematic framework, indexing, charting, and mapping and interpretation (Ritchie & Spencer, 1994). The first step is familiarisation, whereby the researcher immerses themselves in the data to become familiar with it, including listening to the interviews, reading transcripts, and studying observational notes. During the next step, a thematic framework is created by identifying key issues, concepts and themes across the data using both a priori issues identified by the researcher as well as recurring

themes identified in the data during the familiarisation phase. During the indexing phase, the thematic framework is systematically applied to the data. Each transcript is analysed and codes from the thematic framework assigned to the data. During this phase, the thematic framework may be required to be modified, for example a re-definition or re-organisation of a code to ensure the data is analysed accurately (Parkinson et al., 2016).

The fourth stage is charting which involves summarising the indexed data for each category or code and organising the summaries in chart form (Ritchie & Spencer, 1994). This chart is a defining feature of the framework analysis approach. It is in the form of a matrix structure and has the cases along the rows and each column is a different code, with the summarised data in each corresponding cell (Gale et al., 2013). This chart allows for a structure to be put on the data which is then systematically analysed both within and between the cases. The final stage is the mapping and interpretation stage. The aim of this stage is to identify key characteristics of the data to map and interpret the data set as a whole. The matrix charts are analysed for patterns or connections within the data (Parkinson et al., 2016).

8.1.5.2 Motivation for Choosing Framework Analysis

One reason why this analysis approach was chosen was that it allows for flexibility depending on the research questions; it is not aligned with a particular epistemological, philosophical or theoretical approach, nor to either inductive or deductive thematic analysis question (Gale et al., 2013). While this research regarding siblings of AAC users is exploratory in nature, much research is already available regarding sibling experiences, relationships, and roles. A literature review related to typically developing siblings was completed which resulted in numerous themes emerging which were potentially relevant to this research, (e.g., relationship maintenance centring around communication between the siblings, how this may differ if one sibling had a difficulty communicating and what this would mean for the communication partner guidelines). These preliminary themes meant that there were predefined areas of interest already identified before the interview data analysis began. The flexibility of framework analysis was as it allowed for the incorporation of these predefined codes as well as an inductive analysis to fully explore any emerging themes from the data.

Another data analysis method which was considered was interpretive phenomenological analysis (Smith et al., 2009). This is a qualitative research methodology used to explore the lived experiences of individuals by closely examining their personal narratives, perceptions, and subjective interpretations, providing insights into how people make sense of their world and their unique perspectives on various

phenomena (Smith et al., 2009). However, as the focus was on supporting sibling engagement with a communication partner intervention, and with the experiences of siblings feeding into just one piece of the overall framework, it was decided that such an in-depth examination of the participant reports was not warranted. Grounded theory analysis (Corbin & Strauss, 2008) was also considered as a potential data analysis approach. However, the presence of a priori codes and predefined areas of interest did not align a grounded theory approach, namely that analysis and development of theories emerge solely from the collected data (Corbin & Strauss, 2008). The matrix charts of framework analysis were also a benefit of the approach (Gale et al., 2013). These charts allowed for the systematic comparison of the themes both within and between cases, one aspect which is not as clear within other thematic analysis approaches.

8.1.5.3 Quality of Data Analysis Methods

When working with qualitative data, there is always a risk of bias with the research (Harding, 2018). One way to mitigate this risk is to ensure the data analysis methods are reliable, valid, and transparent (Tracy, 2019). One advantage of the framework analysis approach is that there is transparency within each step of the approach. There is an audit trail of where interpretations have come from, which allow others to link the findings back to the raw data (Parkinson et al., 2016). This audit trail is clear in the findings below, whereby the links between each stage of the process have been highlighted. In addition, both the transcribed data and codes were member checked by the participants to ensure the data and codes were valid. Furthermore, an external researcher completed validity and reliability checks on the data. When the thematic framework was completed, including each code and the explanation of what the code entailed, the external researcher read through each code and explanation to ensure they made sense and were all mutually exclusive. This researcher also coded 10% of the transcribed data to assess for inter-rater reliability of the codes. There was an inter-rater reliability of 80% for assigning codes to extracts from the data. The two researchers then met and discussed each of the coded extract segments until there was 100% agreement of the coded data.

8.2 Findings

8.2.1. Introduction

It is important to note that the demographics of the participants may have influenced the nature of the discussions during the interviews. All four siblings were females with three

of the four sibling pairs being sister-sister pairs and two of the pairs being twins. While sibling relationships are unique, there have been some trends discussed in the literature. Twins are often reported as having a particularly close relationship (Fortuna, Goldner & Knaf, 2010). There has also been some research completed on the influence gender has on the sibling relationship, with sisters being reported to have closer relationships (Spitze & Trent, 2006; Stoker et al., 2020) and engage in more conflict (Doron & Sharabi-Nov, 2016) than brother-brother or mixed gender sibling pairs. In addition to influencing the sibling relationship, gender may also impact on the roles siblings take on, or which they are expected to take on. For example, sisters, especially older sisters, are reported to take on more caring roles (Kramer & Hamilton, 2019; Weaver, Coleman & Ganong, 2003) and thus may be more involved in the lives of the AAC users. This predominance of female participants may be a result of this gender influence. If sisters are more likely to have a close relationship and be involved in caregiving roles, they potentially may have been more likely to hear about this research and agree to participate. Additionally, this predominance of sisters and twins as participants may have biased the data to relationships which are closer in nature and therefore the themes which emerged from the data may reflect this. This bias may also impact on the generalisability of results to other sibling pairs.

It is also important to note that the themes which emerged from this data are from the siblings point of view only. Although it would have been beneficial to gather information from AAC users themselves, potentially allowing for a dyadic exploration of the sibling relationship, this was not feasible due to the impact from the COVID-19 pandemic. However, this sole focus on the sibling and their experiences allowed for a greater in-depth exploration into their lives and opinions, something which has been overlooked in the literature. As discussed in section 8.1.5, a framework analysis approach was used to analyse the data. The findings at each stage of the framework analysis process are detailed in Appendix K. This section presents a short overview of the thematic framework that was created as part of this process, followed by an interpretation of the findings for each research question specific to this section of the research (Table 8.1).

8.2.2 The Thematic Framework

The thematic framework was created through the grouping of 53 inductive codes identified from the interview data, as well as 18 a priori codes identified from the literature. A second researcher examined the codes to ensure they were mutually exclusive and unambiguous. See Appendix L for a list of each code and its description. The final

thematic framework consisted of five core themes with five to 25 subthemes within each (Figure 8.1).

Following the creation of this framework, the indexed data for each code was summarised and organised into a chart form and then interpreted. The findings were analysed in order to find any relevant associations between the data. Ritchie and Spencer (1994) identify finding associations within and between cases as one of the possible aims of the mapping and interpretation stage of framework analysis. Numerous associations were identified between the participants experiences, roles, and relationships and opinions of SLT and how these may be factors to consider when supporting engagement of siblings with communication partner interventions. These interpretations will be discussed below under each of the four research questions associated with the interviews.

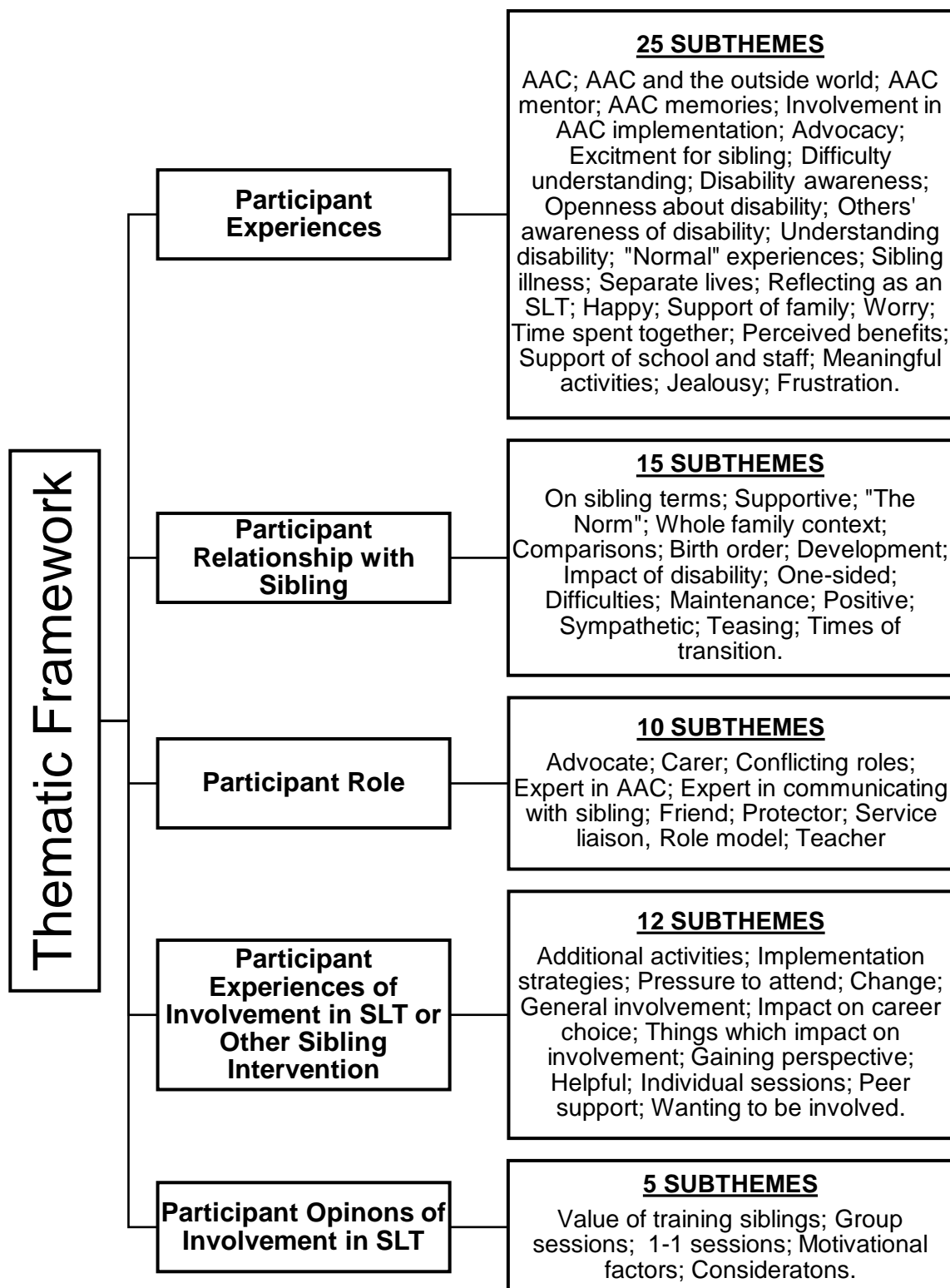


Figure 8.1 Thematic Framework Created Through Framework Analysis Process

8.2.3 Research Question R1a: What are the experiences of individuals growing up alongside a sibling who uses AAC?

8.2.3.1 Spending Time Together

The participants overwhelmingly reported positive experiences and memories of their siblings when they were younger. Three of the participants reported enjoying spending time with their sibling and described the various activities they would partake in together. Ciara discussed spending time with her sister going for walks and reading – “So we would go for walks a lot of the time, read stories. We would have done foot massages, hand massages, do her hair. A lot of the time we did a lot of reading, me and her, or I would like read to her.” Sarah also mentioned spending a lot of time with her sister when they were children. Both attended the same school, so time was spent together at school and at home. Lily “ would always have been part of everything that [they] did”.

The fourth sibling, Ella, reported having more difficulty enjoying spending time with her brother. He attended a residential school from a young age, and she spent “every third weekend with him”. She spoke about how his diagnosis of autism lead to interactions with her brother being limited and repetitive.

“Because you've got the very ASD classic thing of not being motivated to communicate beyond your wants and needs, our interactions were very much stilted to ‘I want a rice cake’ or ‘I want this DVD’ and ... so actually our interactions were limited to a kind of I want or literal need serving function....He's watching the same sort of videos and playing the same game on the computer. It was just every third Saturday and Sunday would be watching Kipper and at the time he loved rewinds, you know watching them back, but um that was what every third Sunday became and it was just a routine.”

– Ella (Extract 8.1)

Ella did also report positive feelings towards her brother, feeling protective and proud of him, especially as she grew older and began to understand his disability more.

8.2.3.2 Separate Lives

Participants reported being involved in their siblings’ lives, spending regular time with them and viewing them as someone to be protected, advocated for and cared for. Participants also discussed their lives as separate from their sibling, be it living in

different counties, going to different schools or having separate social lives. Jessica reported missing her sibling at school – *“But I do miss Sophie now. Like I’ve said it to my mam like, when I was younger I used to say could you imagine if Sophie was in the same school as me like, what it’d be like, I kind of used to always think that way.”* Both Sarah and Ciara spoke about the challenges of having separate social lives. Sarah discussed her sisters fear of missing out (FOMO).

Sarah: She has woeful FOMO so sometimes you tell her you’re going somewhere you can’t really tell her to the last minute.

Interviewer: Okay yeah.

Sarah: Because again if I’m going somewhere- I mean recently one of my friends got married and you know it was one of my friends I lived within college so she wouldn’t have been invited because she didn’t know them. But yeah she was just a bit like so put out that she didn’t get an invite to the wedding so I think she just thinks that like by association (laughs).

- Sarah (Extract 8.2)

Ciara spoke about the feelings of guilt and selfishness she felt when having a separate social life to her sister.

“Because you know, you start going out at night-time, you’re going out with your friends and, like, led by friends and stuff. And at the time, you didn’t really think of it but looking back now you sort of would feel guilty that that you weren’t there for her as much as you would be now, that you were almost nearly selfish. You were thinking of your own life. Because you know, as a teenager that’s the way you want it to be.”

- Ciara (Extract 8.3)

8.2.3.3 Worry

Participants did report feeling worry and frustration for their sibling, primarily towards the services, or lack thereof, that the sibling was receiving, as well as the lack of understanding of others when communicating with their sibling. Ciara described it as a *“constant worry”*. Three of the participants also reported that their siblings were prone to

sickness in their early years and spent time in hospital, contributing to their feelings of worry and protectiveness. Ciara discussed how she and the rest of her siblings were protective over her sister from a very early age – *“I remember when she was born and she because she hadn’t come home for about two months after she was born and all I remember from the day she was born we were all really protective of her”*.

8.2.3.4 Context of Family

The participants all discussed their experiences growing up in the context of their family environment. Jessica spoke about the closeness of her family and how they were all close with Sophie.

“Yeah, my sister, my older sister, she’s very in tune with Sophie. Claire would just know everything about Sophie. She’d just she’d just know. And then my brothers would know as well, they know what she’s saying. It just becomes normality. Like when you kind of, when you kind of live with someone with a disability, you’d kind of know. You’d become to know like.”

- Jessica (Extract 8.4)

Sarah described her parents as *“super advocates”* and reflected on the sacrifices and effort that went into advocacy. She mentioned how this impacted her and her siblings.

“Like my mam and dad would have just been very proactive and pro everything and try everything so I think in that regard it probably rubbed off on us, that we would be like of course we will embrace this or whatever.”

- Sarah (Extract 8.5)

Ella explained how her parents’ created normality for her for both herself and her brother, *“I think my parents so much wanted to almost separate it so that I could have some level of normal life and he had his”*. To Ciara, her sister Rose is the glue that holds the family together.

"I think the best thing is, is that she brings our family together. And bring us back to the family home especially. You know, she's the one person now that holds us together in our house. Because I think that if she wasn't there, we would just all have our own lives. You know, we'd have our own families and stuff. But she's just the gel that's there that we all go back to."

- Ciara (Extract 8.6)

8.2.3.5 Experiences of AAC

All participants referenced their sibling's communication and use of AAC as part of their experiences growing up. Participants spoke about how their sibling communicated, and the pathway to get to where they are now.

Jessica: She got a My Tobii at first, do you know, the ones? The big huge ones?

Interviewer: Yeah.

Jessica: She got one of them. And to start with like she was only learning so she kind of she would use it quite a lot because she was learning. And but before that, you'd just kind of know what she was saying. She used her eyes quite a lot. So say if she was looking for the telly, she'd look at it with her eyes.

- Jessica (Extract 8.7)

Sarah mentioned the excitement of Lily getting a new device *"you know it was exciting and it was new and I remember playing with the voices and changing the different like accents and like deep voices and higher voices and just doing something and then my parents being like stop messing"*. While Ella stated her brother could get his needs and wants met through his PECS system, Ciara discussed the challenges her sister faces due to having a limited communication system – *"we find that very, very hard to cope with, and it can get very, very stressful. She knows what she wants to say. And she can only say it by you asking the right question. And because she can only say yes or no, or I don't know. So like, sometimes it could take a few minutes, or it could take minutes or hours, it could take the whole day. That whole day could be spent, like with her getting really frustrated, sweating, crying, shouting, like, physically, you know, moving her hands and legs and just getting really, really, really upset by not being able to communicate what what's wrong."*

Ultimately, while there were some difficulties reported in the sibling relationships, or in the participant experiences growing up, participants reported growing up with their sibling as a positive experience with AAC and communication frequently mentioned by all participants.

8.2.4 Research Question R1b: What are the characteristics of the sibling relationship when one sibling uses AAC?

8.2.4.1 Positive and Negative Characteristics

Participants discussed their relationships with their siblings as having both positive and negative characteristics. For example, both Ciara and Sarah described their relationship with their sisters as good, and Jessica reported always being in tune with Sophie and being able to “*understand Sophie like the back of [her] hand*”. Ella described positive characteristics of the relationship on her end as “*very loving and proud*”. However, she also reported the relationship as being stilted and one-sided.

Interviewer: How would you describe your relationship with him when you were growing up?

Ella: Difficult. With a relationship probably one-sided from my point of view and also probably pretty stilted because it was just pretty impossible to have a relationship.

- Ella (Extract 8.8)

Jessica spoke about her close relationship with her sister, but also how they bicker and argue as well.

Jessica. She just annoys me when she when she rats on me. When I've done nothing wrong and she rats on me to my mam.

Interviewer: What do you do to annoy her then?

Jessica: I wind her up something terrible. If she's in her bedroom I'll go in and I'll change the programme on her and then she'll get really annoyed.

- Jessica (Extract 8.9)

8.2.4.2 Impact of Sibling Diagnosis

Sibling diagnosis, and other disabilities outside of a communication difficulty appeared to play a role in both the sibling relationship. Sarah discussed cognitive changes impacting on her relationship with her sister.

"I have a good relationship with her and as good as it can be, I suppose. Again the kind of communication barrier and I suppose more the cognitive changes mean that sometimes she you know, she sometimes is quite passive so it really has to motivate her to get her to be involved in something."

- Sarah (Extract 8.10)

Ella attributed difficulties in developing a close relationship with her brother to his diagnoses of autism and severe learning disability, as opposed solely to his difficulty communicating and use of AAC.

Interviewer: So how do you and your brother interact? What do you do together?

Ella: Yeah so not particularly so he's got severe learning disability and autism so he's very much on his own agenda.

- Ella (Extract 8.11)

8.2.4.3 Development and Maintenance of the Relationship

Ciara and Sarah also spoke about maintaining their relationships with their siblings after moving out of home. They both reported visiting their sibling regularly to spend time with them. Ciara also spoke about using facetime or phone calls to keep in contact.

"So then mammy would ring and she'd say oh Rose wants to know what it is and then I'd talk to her on the phone, even though I couldn't see her, and then I would know by her voices, her tone and stuff what she wanted to say and then mammy would say in the background 'she's saying yes, she's saying no.'"

- Ciara (Extract 8.12)

Ciara discussed the change in her relationship with her sister Rose over time. Ciara reported taking on more of her sister's care, especially after her mother passed.

"I think like I've taken on a lot, yeah a lot of her care and you know, the running of her life now. You know, the role that mammy would have had."

– Ciara (Extract 8.14)

This additional role has led to a change in their relationship and how the siblings can spend time together.

"I feel almost, now, at this part in our lives, we can't really enjoy the fun things that we do. Like we aren't as carefree. I know we're adults now, we're not children anymore but we can't be as carefree and normal, to look forward to things. There's more to, it's more so about organising and managing. D'ya know, planning ahead. That sort of thing."

- Ciara (Extract 8.15)

8.2.5 Research Question R1c: What roles do siblings occupy when their sibling uses AAC?

The participants discussed occupying a variety of roles in the lives of their sibling who use AAC, for example friend, protector, service liaison, teacher, role model and carer. Two roles were specifically linked to communication and AAC: (i) the role of being an expert in communicating with their sibling and (ii) being an AAC expert.

8.2.5.1 Expert in Communicating with Sibling

Ciara, Jessica and Sarah spoke about translating their sibling's communication so that others could understand.

"Some people might ring me if they don't understand what she is trying to communicate."

– Ciara (Extract 8.16)

"When we were younger, like people that kind of would have only seen us a couple of times would be like, oh what was she saying? And I'd be with her and I'd know, straightaway, you know oh she's saying this, or she's saying that like d'ya know?"

– Jessica (Extract 8.17)

Both Ciara and Jessica mentioned how they were happy to help translate for their sister if needed. Sarah spoke about how she was a last resort for teachers if they didn't understand her sister: *"I suppose it would be more so if they'd exhausted all sorts of yes no questions and the vocab wasn't in her Dynavox, they may have called for me. It wasn't a routine occurrence, and I think they were pretty respectful of that. But if it was something that really upset her and they couldn't figure it out they would call me"*. Jessica also discussed taking a pre-emptive approach to training others when attending a summer camp with Sophie – *"Like on the first day I'd tell the person that was helping her I'd be like oh these are her little gestures. And if she wants stuff this is the way she does it, which kind of helps having me there. If they need anything they can just call me. Like it's not no big deal."*

8.2.5.2 AAC Expert

In regard to AAC specifically, participants were reported to be involved in the AAC implementation both at home and in the school setting where appropriate. This involvement was more evident as participants got older and were in a better position to provide support for their sibling. Siblings reported experiences of explicitly teaching their sibling gestures, being involved in creating AAC materials and in advising others, within and outside of the family, how best to use and fix a high tech AAC device.

"I can't remember if she learnt or if we taught her but I remember teaching her how to say 'no' and so she shook her head to say no, like we would use to say no like non-verbally, and then she by saying yes she looks up at the light."

– Ciara (Extract 8.18)

"I remember him using [PECS] also because my mum used to get me to not necessarily pick symbols but if he was learning verbs for example my mum would take pictures of me on the swing or me drinking or me eating so I remember you know printing and cutting his little PECS symbols and taking pictures of the specific things for his PECs book."

- Ella (Extract 8.19)

"I would have been a part of a lot of the kind of things that were going on about her AAC or they'd call it me in if the battery was dead or it was frozen and I'd be like oh you just get a paper clip and you reset at the back you know (laugh)."

- Sarah (Extract 8.20)

Jessica reported being the “go to person if anything goes wrong”. She reported this was due to her knowledge of technology and resulted in her attending some SLT appointments with her sister. *“And cause you see I’m quite technical so like whereas my mam isn’t that technical. So it’d be helpful to have me there if [SLT] was doing something and to know what was happening and what was going on.”*

8.2.6 Research Question NP1-4a: What are the experiences and opinions of siblings of AAC users regarding their involvement in interventions?

8.2.6.1 Value of Sibling Training

Sibling training in AAC was universally agreed to have value. Jessica, for example, said *“I just think it’s like, it’s a different kind of world that you can see what your sibling is doing. Although you’d see it regularly, but you can see it from another perspective, like, you can see it from the Speech and Language Therapist’s perspective. You can see what they’re doing with your sibling and how you can help your sibling.”*

Participants disagreed on whether they would have preferred an individual or group training. The participants who were all involved in individual SLT sessions alongside their sibling growing up (Jessica, Sarah and Ciara) reported that they found the sessions valuable and helpful for themselves and for knowing their sibling’s AAC system. Sarah reported valuing the 1:1 involvement of siblings, *“I think being involved in the sessions where possible, you know, I think it happens in an organic sort of informal way, but I think it has value”*. In addition, Jessica also preferred individual training, reporting that she does not feel comfortable in new social situations *“I get awkward in new situations. I get really awkward. Like, I’m surprised I’m not sitting here really awkward. That’s literally, meeting new people is horrible.”*

However, Ella, who was not as involved in SLT sessions due to her brother attending a residential school and receiving services onsite, reported a preference for a group setting, particularly during adolescence. She discussed that during adolescence, when she started understanding her brother and his disabilities more, she had difficulty talking about her brother with others outside of the family.

“I think you know I almost came to this whole sibling thing too late by the time I really needed it when I was a teenager to be honest, because that was the worst. When I was younger you know you’re not really that aware, and then when I was a teenager I think I was really anxious about talking about him, I used to actively avoid that conversation because it was very difficult.”

- Ella (Extract 8.21)

Ella felt she may have benefitted from the peer support of a group situation at that time and that others might too - *"I think having experience with siblings in it would be really useful for other people to connect especially if you're at that kind of adolescent age"*.

Sibling training was reported to have value, but there was several factors that participants identified as potentially impacting on the engagement of siblings with an intervention.

8.2.6.2 Factors Impacting Engagement with Training

During the interviews, there were many important considerations for what might encourage a sibling to attend a training, either reported from the participants of why they did attend a training or why they would have attended a training.

8.2.6.2.1 Wanting to Learn and Be Involved

All four participants reported wanting to learn more to support their siblings. They reported experiencing curiosity about what the SLT was doing, as well as wanting to be involved and help their sibling to the best of their ability. Ciara mentioned the excitement in her family when the SLT would arrive for sessions.

"And I think, as children like we loved when the therapist came to the house, like we couldn't wait to see them. And when they were gone we couldn't wait to do all the stuff with Rose, to teach her the stuff. Like we loved it. You know, it was like a project for us."
- Ciara (Extract 8.22)

However, SLTs must be cautious of the sense of obligation some siblings may feel about taking on an additional role of AAC expert after being involved in SLT sessions or a communication partner training intervention. Involvement in training may put additional pressure on them to take on more of a caring or communication interpreter role that they were not prepared for. Ella broached her concerns during her interview.

"I think it depends what sort of age um you're at because I think my only hesitation with it being kind of conversation partner training is that kind of um caregiver kind of role and you know the pressure you have as being a sibling and the expectation that you have to facilitate that."
-Ella (Extract 8.23)

8.2.6.2.2 Peer Support

One aspect of group training that should also be considered is the potential benefit of peer support. One idea from Sarah was to attach the group to a regular, motivating activity to encourage involvement between the participants in a natural setting and allowing for friendships to develop.

“I think in my experience the kind of naturalistic things if you can tag team on to a Sibshop or if there was an equivalent summer camp. If it was part of a like something that's existing or part of something like the Sibshop experience or like a workshop or like something that was happening anyway, I think you probably get more buy-in and it happens in a more informal sort of supportive way.”

- Sarah (Extract 8.24)

However, not all participants felt they would benefit from peer support – as discussed above, Jessica specifically noted her reluctance to attend a group training due to her “awkwardness”. She discussed how she did not like entering a group situation with peers she did not know. This reluctance may be mitigated if siblings could attend together, or if the sibling could bring a friend along to the sessions to help them feel more comfortable.

“But I'd kind of have to have someone I know that's going along if you know what I mean? I'd be like awh who's doing that? Just cause, yeah who do I know that's there that like I could sit with, or have a chat with or because I just hate when you go into new situations and you're standing there on your own and you're just like standing there and you don't know what to do.”

- Jessica (Extract 8.25)

Sarah and Ella also discussed the impact of their sibling's disabilities on their ability to receive peer support from general group sibling interventions during childhood, but both had opposite experiences. Sarah discussed attending a group therapy and feeling her sister was “so good” and didn't have “a severe disability” due to reports from others in the group who spoke about their siblings biting or having other challenging behaviours. Ella however felt she could not relate to others in the group as her “*their siblings [were] much more able*” and “*it was still too far from [her] own experience*”. These two experiences highlight the importance of taking into account the other disabilities of the AAC user when considering which siblings to group together during an intervention,

to ensure they have an opportunity to receive peer support from others in a similar situation to them.

8.2.6.2.3 Age Considerations

Another consideration in engaging siblings in interventions is their age. As Ella mentioned above, the age of the sibling may impact on their abilities to take on a potential additional role as well as the pressure put on them to do so. Age may also impact on sibling's motivation to attend a training - participants spoke about gaining a greater understanding and perspective of their sibling's disability and communication as they grew older. They reported that they were more likely to have been involved in sessions, or having an interest in being involved in sessions, as they grew older, towards later childhood and early adolescence.

"As I got older then you see I think it was more so I'd want to do it like I'd want to know how to do it so I'd be like can I try. So yeah kind of mam and dad would have started out when we were younger but then when it went more a bit more techie with the Dynavox I got a little bit more involved."

- Sarah (Extract 8.26)

However, Ciara acknowledged that later adolescence may not be a good time to begin to involve siblings, due to other preoccupations and commitments.

"But saying that, like as an adolescent you would have been always sort of preoccupied, even though you would have been still involved. And, you know, I think up until like, say 12 and 13, as far as I remember, we were very much involved, and we definitely would have done [a training] then. And then we would have probably went through adolescence and but I think starting in adolescence would be harder."

- Ciara (Extract 8.27)

8.2.6.2.4 Parent/Family Support

The importance of parent support, especially during childhood was also discussed. All participants mentioned the support of their family towards their sibling, wanting what is best for them. Sarah discussed the importance of a parent's views on disability, AAC and the benefits of SLT, and how this may influence a child's perception of why they would attend an intervention.

"I think that that is a good thing but maybe again it depends on the sibling and how interested they are or what the family kind of dynamic and I guess it depends maybe on their age or their life stage or how involved they've been because there are other siblings who may not have. I think it depends a lot on the parents as well and their kind of attitude and acceptance to disability."

- Sarah (Extract 8.28)

Participants did not report feeling pressure to attend from their parents, as Sarah reported *"I would have gone along if you know I would have given been the option to stay at home or I would have been given the option to go along it was never imposed upon me and I think I was kind of curious to see what's happening."* However, Ciara did mention that her sister would be the one who would ask her along *"I used to go to a lot of the appointments with mammy because Rose would look for me, a lot of times to go for appointments and stuff."*

8.2.6.2.5 Timing of Sessions

Another important consideration discussed was the timing of sessions. Sarah spoke about attending sessions on a Saturday if she was free, or alongside her sister during the summer when she had nothing else on - *"It just depended on what was on. If it was during summer holidays and I wasn't doing anything sure I'd be delighted"*. Sarah also mentioned that her siblings would not have attended a training if they had sports or other activities unless it was sufficiently motivating for them - *"I don't know if my other siblings would have gone along, they'd be like uh I'm going playing camogie or football d'you know, whereas if you know if there was a day trip kayaking and it was part of it."*

Communication partner training interventions may not be a priority for the sibling, so it is important to consider when to run the sessions to ensure sessions do not clash with other important activities. For example, Jessica spoke about attending sessions with her sister, organised for a Friday afternoon when she was finished school early. *"[SLT] would do sessions on a Friday and bring me in after school like I'd have a half day on a Friday. So, she'd bring me in on a Friday after my lunch, and I'd go in."*

8.2.7 Summary

These interviews provided valuable insights into the lives of siblings of AAC users. When reviewing the literature on the topic of siblings of AAC users, there was very little evidence found on the experiences of the siblings themselves. The one exception was

the study completed by Dew et al. (2011). It was therefore vital to this research that a greater understanding of the experiences of siblings was acquired in order to inform how SLTs can support the engagement of this cohort. The experiences, roles and relationships of participants were explored during the interviews, with AAC featuring regularly in their discussions. Siblings discussed occupying many roles in the lives of the AAC user, including those of expert in communicating with their sibling and expert in AAC. The participants discussed sibling involvement in interventions, both their own past involvement and sibling involvement in general. The participants acknowledged some factors impacting on their engagement with interventions, including their age, parent/family support, the timing of sessions, the need (or lack thereof) of peer support and a desire to be involved and help their sibling. These findings were beneficial when considering the aim of this research; how to support the engagement of siblings of AAC users in communication partner training interventions.

Chapter 9: Surveys

This chapter provides an account of the methods and findings of three surveys completed with potential stakeholders in sibling interventions: adolescents, parent/guardians and SLTs.

9.1 Methods

9.1.1 Introduction

The interviews in Chapter 8 addressed the identified gap in the literature, of understanding of the experiences, roles, and relationships of siblings of AAC users. However, interviews were not suitable for addressing another identified gap, specifically that of the needs and preferences of key stakeholders regarding a sibling communication partner intervention. Data from many participants was required to produce generalisable findings, and to collect this data through interviews would have been too time consuming. Instead, three distinct online surveys were conducted to identify the needs and preferences of key stakeholders. The aim of the surveys was to get a greater understanding of the perspectives of (A) typically developing adolescents and (B) parents/guardians of typically developing 6-12 year olds as to what content, structure, and instructional strategies they would prefer in interventions offered by SLTs. A third survey (C) was distributed to SLTs to investigate their current and preferred practices around communication partner training in AAC. A number of research questions were associated with these surveys (see Table 9.1).

Survey A	
Research Question	Supporting Engagement Framework Component
NP2a What do adolescents think would aid in their enjoyment of an SLT training focused on helping a sibling?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goals/Activities</i>
NP5d What are the preferences and opinions of adolescents regarding the structure of an SLT intervention which is focused on helping a sibling?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Intervention Structure</i>
NP6d What instructional strategies do adolescents believe best supports their learning?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Learning Strategies</i>
Survey B	
Research Question	Supporting Engagement Framework Component
NP2b What do parents/guardians think would aid their child's enjoyment of an SLT training focused on helping a sibling?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goals/Activities</i>
NP5e What are the preferences and opinions of parent/guardians regarding the structure of an SLT intervention for their child which is focused on helping a sibling?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Intervention Structure</i>
NP6e What instructional strategies do parents/guardians believe best supports their child's learning?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Learning Strategies</i>

Survey C

	Research Question	Supporting Engagement Framework Component
R2a	What are the experiences and opinions of SLTs in Ireland of working with siblings of AAC users?	<i>Supporting Engagement Through Reciprocal, Meaningful Relationships: Acknowledging SLTs' Unique Experiences and Perspectives</i>
NP1a	What are the current and preferred practices of SLTs in Ireland regarding the content of communication partner interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Goals/Activities</i>
NP5a	What are the current and preferred practices of SLTs in Ireland regarding the structure of communication partner interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Intervention Structure</i>
NP6a	What are SLTs in Ireland's current and preferred methods of teaching new learning during communication partner interventions?	<i>Supporting Engagement Through Tailoring to Siblings' Needs and Preferences: Suitable Learning Strategies</i>

Table 9.1 Research Questions for Surveys

All three surveys were of a descriptive design and included both qualitative and quantitative questions. Surveys allowed for the anonymous collection of data from a wide range of participants, more than would have been possible through other data collection methods for example interviews (Tan, 2017). Surveys can be both a time and cost-effective means of answering research questions (Kumar, 2019). One of the disadvantages of using surveys is that they are not an optimal method to explore topics in detail, however for this research component, the benefit of gathering the opinions of a larger number of individuals outweighed this disadvantage (Tan, 2017). For Survey A and B, participants from typically developing populations were recruited. This decision was made due to a desire to probe the needs and preferences of these groups in a more general sense. In addition, there was a concern that it would be challenging to recruit a large number of siblings and parent/guardians of AAC users, particularly in the context of the COVID-19 pandemic.

9.1.2 Participants and Recruitment

Research ethics approval was obtained for each of the three surveys from the School of Linguistic, Speech and Communication Sciences in Trinity College Dublin (See Appendix M). Participants were recruited through a variety of channels as described below using convenience sampling (Kumar, 2019). Data collection for these surveys was carried out between May and October 2021, during the COVID-19 pandemic. In line with public health guidelines at the time, the research was conducted entirely online with surveys, participant information leaflets and consent forms all made available only through the online platform to ensure safety and convenience for the participants.

9.1.2.1 Survey A – Adolescents

Two identical surveys were created for adolescents to address research consent requirements for participants of different ages. The first survey was for 18–21-year-olds who provided informed consent themselves and did not require parent/guardian consent. The second survey was for 12–17-year-olds. This survey link was only provided to a parent/guardian to give to the adolescent once they completed a parent/guardian consent form. As the survey content was the same in both surveys, they will both be referred to as **Survey A**. Participants were recruited through social media and through post-primary schools, youth groups and sports groups in Ireland. A survey link was shared on the specific Facebook, Twitter and Instagram page of the overall project and on the personal social media pages of the researcher for participants over the age of 18.

Two post-primary schools, one youth group and two sports clubs agreed to distribute a link to an online Parent/Guardian PIL (Appendix N) and consent form (Appendix O). A gatekeeper within each setting was nominated to share this via email, text, WhatsApp or other virtual means to parents/guardians of individuals under the age of 18 in their setting.

Sixty-eight adolescents between the ages of 12 and 21 completed more than 80% of the questions in the survey (see Figure 9.1). Similar to the interview, there were majority female participants (n=45, 66.2%) compared to males (n=22, 32.4%). One participant reported being non-binary. The majority of participants were in school (n=36, 41.9%), while 27 attended a third level institution (31.4%). Seven of the participants worked full time (8.1%) and 16 worked part-time (18.6%).

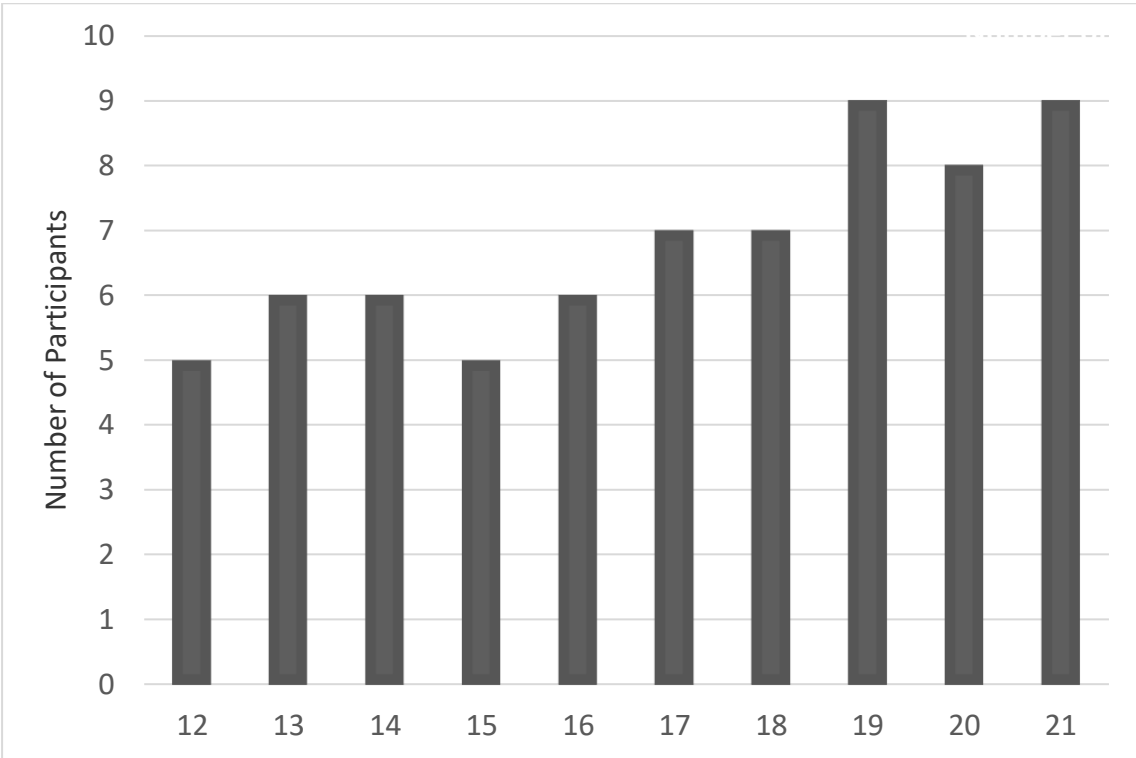


Figure 9.1 Survey A: Age of Participants

9.1.2.2 Survey B- Parents/Guardians

Participants of **Survey B** were individuals over the age of 18 who were a parent/guardian to at least one child between the ages of 6 and 12. Participants were recruited through social media websites, sports clubs, youth groups and primary schools. For social media, the survey link was posted on the specific Facebook, Twitter and Instagram page of the overall project and on the personal social media pages of the researcher. Ten primary schools, youth groups and sports clubs were contacted and asked to distribute a link to

the survey. One primary school and two sports clubs agreed to distribute the information. A gatekeeper was nominated in each setting, and they sent the survey link through email, text, WhatsApp, social media or other virtual means to parents/guardians of individuals aged 6-12.

There were 31 participants who completed over 80% of the survey questions. There were 18 (58.1%) female participants and 13 (41.9%) male participants. Nine of the participants had one child, 23 had two children and 8 had three or more children. Participants were asked to identify one child between the ages of 6 and 12 who they would think of specifically when answering the survey questions. See Figure 9.2 for the distribution of the ages of the chosen children.

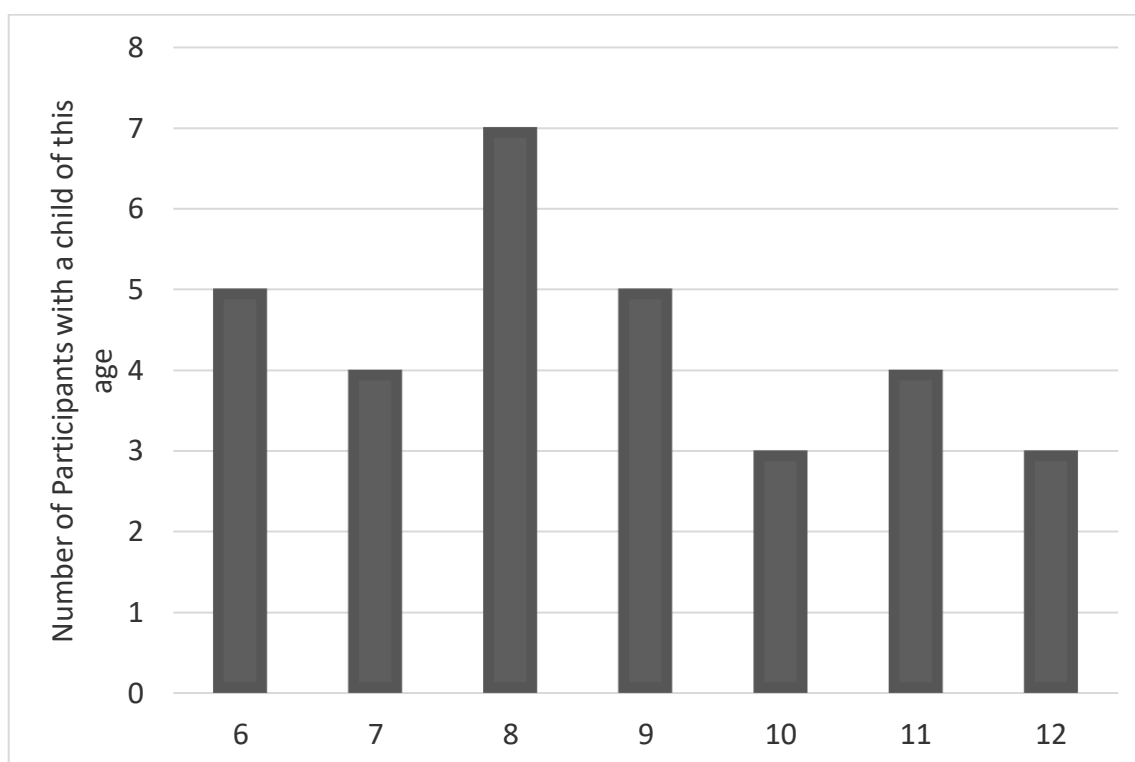


Figure 9.2 Survey B: Age of Child About Whom the Survey was Answered.

9.1.2.3 Survey C. Speech and Language Therapists

SLTs working in Ireland who had at least one year's experience of working with AAC users were recruited to complete **Survey C**. Participants did not have to be currently working directly with AAC users, as long as they had previous experience amounting to at least a year. Participants were recruited through social media posts on the specific Facebook, Twitter and Instagram page of the overall project and on the personal social media pages of the researcher. An email containing the survey link was also distributed to members of the AAC Ireland email group. This email distribution group is a forum for

individuals who have an interest in the area of AAC. The IASLT was also contacted, and they shared a Facebook and Twitter post containing the link to the survey, as well posting it to their website.

Thirty-three SLTs completed the survey, the majority of whom had 2-5 years' experience working with AAC users (n=16, 48.5%). The self-reported confidence levels of the SLTs when working with AAC users varied, but the majority reported to be 'very confident' (n=14, 42.4%) followed by 11 SLTs reporting to feel moderately confident (33.3%). See Figure 9.3 and Table 9.2 for further information on the SLT's current AAC caseloads.

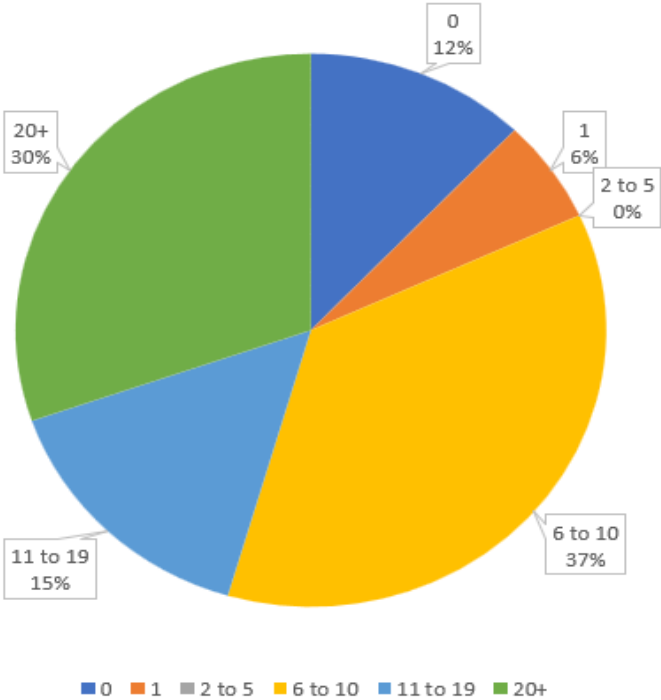


Figure 9.3 Survey C. Number of AAC Users Currently on Participant's Caseload

Age AAC User	Number of Participants	Percentage
0-5 years	20	60.6%
6-12 years	28	84.8%
13-17 years	20	60.6%
18+ years	11	33.3%

Table 9.1 Survey C. Age of AAC Users on Participant's Caseload

9.1.3 Materials and procedures

9.1.3.1 Pilot testing

All three surveys were piloted by 5 individuals who fit the participant eligibility criteria to assess the survey validity and to refine the survey administration process (Eichhorn, 2022) of the survey. These individuals completed the relevant study survey and in addition a second survey probing the survey's ease of use, formatting, and clarity of instructions and terminology. For example, participants were asked about any potential ambiguous, leading, or biased questions, or any questions that required assumed knowledge (O'Leary, 2021). Minor changes to each survey were completed after the pilot stage, including clarifying wording of some questions and instructions, incorporating some additional response options, and formatting changes to enhance clarity.

9.1.3.2 Survey Development

All three surveys had a mixture of demographic questions, yes/no questions, multiple choice questions, ranking order questions, Likert-scale questions, and open-ended questions. The surveys were hosted on the Qualtrics Online Survey software (www.qualtrics.com). The surveys were anonymous, so the software was set to not collect participants' IP addresses. Both Survey A and Survey B took approximately 15 minutes to complete. Survey A had 32 questions (Appendix P) and Survey B had 33 questions (Appendix Q).

Survey questions were centred around a hypothetical scenario, where participants had to imagine they were (A) a sibling of an individual who stutters or (B) a parent of two children, one of whom stutters. The questions then focused on what their preferences and opinions of a communication partner training intervention for the sibling within this scenario would be. Stuttering was chosen as the focus of the hypothetical scenario as it was hypothesised that more individuals may be aware of stuttering than the less well-known concept of AAC. Additionally, interventions for individuals who stutter often involve educating communication partners regarding the nature of stuttering and different communication styles. Interventions for stuttering may also involve training communication partners to modify their own interaction styles as well as teaching strategies to support the individual who stutters (e.g., Kelman & Nichols, 2020) – similar to that of interventions for communication partners of AAC users. Information regarding stuttering, including a link to a YouTube™ video, was provided to participants within the survey to ensure they were familiar with the concept.

Survey C had 46 questions asking SLTs about their experiences and opinions of interventions for communication partners of AAC users and took participants approximately 20 minutes to complete. See Appendix R for a list of survey questions.

There was some overlap between the content of the three surveys. The themes of intervention timing, frequency and structure as well as learning strategies were common across all surveys. Survey A and B also probed participant enjoyment and motivation while Survey C focused on training content and SLT experiences with siblings.

9.1.4 Data Analysis

Quantitative data was analysed descriptively, with frequencies and percentages being calculated using SPSS v.27 software. Content analysis and descriptive thematic analysis were carried out on free text responses to the open-ended questions (Harding, 2018).

9.2 Findings

The findings of the three surveys are discussed below under the heading of the research questions associated with that survey.

9.2.1 Survey A

9.2.1.1 Research Question NP2a: What do adolescents think would aid in their enjoyment of an SLT training focused on helping a sibling?

Almost 60% of adolescents reported that having clear training goals for themselves and being able to see and measure their progress towards these goals (n=40) would make the training more enjoyable, while 50.4% (n=34) reported that having similar aged peers with them doing the training would increase their enjoyment. Almost a third of adolescents (n=20) reported a theme would make the training more enjoyable for them, with 19 of those 20 (95%) reporting that they would enjoy a sports theme. This result may reflect a recruitment bias as sports clubs were one of the means of recruitment.

Two factors stood out as 'definitely motivating' respondents to engage with training: (i) the knowledge that they would learn something and (ii) a desire to help their brother/sister.

9.2.1.2 Research Question NP5d: What are the preferences and opinions of adolescents regarding the structure of an SLT intervention which is focused on helping a sibling?

Time commitment. Adolescents reported being willing to allocate 2-4 hours (n=29, 42.6%) or 4-6 hours (n=25, 36.8%) to a training to help their sibling per month. Half of the adolescents surveyed (n=34) indicated a preference for multiple short sessions while a further 14 adolescents (20.6%) indicated that either long or short sessions would suit them.

Timing of Sessions. The majority of adolescents reported a preference for training to happen outside core business hours, on weekday evenings (n=22, 32.4%) and weekends (n=19, 27.9%), although 13 adolescents (19.1%) reported that any time would suit as long as they had enough notice. The primary reasoning for these choices was so that the training did not interfere with school, college or work commitments. When asked if there was a time which would not suit at all to do the training, 53 adolescents (77.9%) reported that weekday mornings did not suit. Furthermore, 33 adolescents (48.5%) indicated that a weekday afternoon training would not be suitable for them. Again, the reasoning for these focused on work, college, and school commitments.

Session Frequency and Intensity. Adolescents preferred training to occur once a week (n=49, 72.1%). Participants were asked if the training was 4 hours in length, what structure would be their preference. The majority of both adolescents reported preferring one-hour sessions, once a week for four weeks (n=40, 58.8%). This four-hour per month commitment supports the time commitment participants reported as being acceptable to them (see above).

Group Size. The majority of adolescents reported preferring small group training in three to 10 peers (n=37, 54.4%), citing peer support and reduced pressure as the main reasons.

Online Training. The majority of adolescents indicated a preference for the training to be held in person (n=31, 45.6%). Adolescents reported this preference was for a variety of reasons including the perceived effectiveness of face to face versus online teaching, the ease of asking questions and based on their previous experiences of having to complete zoom classes for school. However, those that would prefer online training (n= 9, 13.2%) or a mix of both in person and online (n= 16, 23.5%) noted that this preference was due to the increased convenience, flexibility and safety that an online training would

offer. These results may reflect the particular context of the time. Due to the public health restrictions of the COVID 19 pandemic, students had endured many months of online classes and meetings for school, college and work with no option for face-to-face learning.

9.2.1.3 Research Question NP6d: What instructional strategies do adolescents believe best supports their learning?

Adolescents reported that seeing a new skill or competence in action (n=24, 35.5%) or having a chance to do it themselves (n=21, 30.9%) as the best ways to learn. Adolescents were also asked what instructional strategies they felt would help them learn about their sibling who stutters and how to help them and were asked to tick all the apply to them. The top strategies reported were hearing from someone who stutters about how it impacts them and how others could help (n= 46, 67.6%), having someone show them how to do the skill (n=43, 63.2%) and having a chance to practice the skill themselves (n=41, 60.3%). Knowing the goals prior to the training starting (n=3, 4.4%) and reading a book about the topic (n=4, 5.9%) were the least popular choices. See Figure 9.4 for a full list of instructional strategies and the number of adolescents who chose that strategy.



Figure 9.4 Instructional Strategies and the Number of Adolescents Who Felt That Strategy Would Be of Benefit to Them

9.2.2 Survey B

9.2.2.1 Research Question NP2b: What do parents/guardians think would aid their child's enjoyment of an SLT training focused on helping a sibling?

Parents/guardians identified that having clear goals and measurable evidence of progress (n= 16, 53.3%) and doing the training with others the same age (n=21, 70%) as the primary factors which would increase their child's enjoyment of a sibling training intervention. One-third of parents/guardians (n=10) reported that they thought a theme would increase their child's enjoyment, with sports being the most popular (n=7, 70%). Similar to the results of the adolescent survey (Section 9.2.1.1), this result may reflect a recruitment bias as sports clubs were one of the means of recruitment.

When asked what would motivate their child to attend a training the majority of parents/guardians reported that (i) knowing their friends or others they know are attending the training, (ii) wanting to help their sister/brother and (iii) thinking the training would be fun would definitely motivate their child to attend the training.

9.2.2.2 Research Question NP5e: What are the preferences and opinions of parent/guardians on the structure of an SLT intervention for their child which is focused on helping a sibling?

Time commitment. The majority of parents/guardians reported being willing to commit 2-4 hours (n=20, 64.5%) to the training per month. Almost half of parents/guardians indicated a preference for multiple short sessions as opposed to one or two longer sessions (n=34, 50% and n=15, 48.4% respectively) while another 10 parents/guardians (32.3%) indicated that either long or short sessions would suit them.

Timing of Sessions. Parents/guardians indicated their preferred times for training to take place were weekends (n=10, 32.3%) and weekday evenings (n=7, 22.6%), while five participants (16.1%) reported that any time would suit as long as they had enough notice. In line with responses from the adolescents, over half of the parents/guardians surveyed (n=15, 55.6%) reported that weekday mornings did not suit. Additionally, six parents/guardians (22.2%) reported that a weekday afternoon training would not be suitable for them. The reasons why these times would not suit were that they would clash with other work and school commitments of the child and/or parent/guardian.

Session Frequency and Intensity. When asked how often they would prefer sessions to occur, parents/guardians' preferences primarily differed between weekly sessions

(n=11, 35.5%) and fortnightly sessions (n=9, 29%). Parent/guardians were then asked if the training was 4 hours in length, what structure would be their preference. The majority of parents/guardians were split between one-hour sessions, once a week for four weeks (n=9, 29%) and one-hour sessions, once a fortnight for eight weeks (n=9, 29%). The reasons for these preferences included consistency, short sessions equating to better concentration, time between sessions to practice and a manageable time commitment.

Group Size. Parents were split between preferring 1-1 training (n=15, 48.4%) and some form of group or paired training (n=12, 38.7%). Parents/guardians who indicated a preference for 1-1 training reported the opportunity for the session to be tailored for their child as well as a lack of distraction from other children as the primary benefits. Those who indicated a preference for a group highlighted peer support and their child feeling more comfortable as potential benefits to a group training.

Online Training. Approximately half of parents/guardians (n=16, 51.6%) indicated a preference for in-person training with no online element. Participants perceived in-person training as supporting better learning and engagement.

9.2.2.3 Research Question NP6e: What instructional strategies do parents/guardians believe best supports their child's learning?

Parents/guardians reported that they felt their child would learn best by seeing a new skill or competence in action in action (n=7, 22.6%) or having a chance to do it themselves (n=7, 22.6%). Both these learning methods were reported by adolescents in Survey A as being their preference in helping them learn best.

9.2.3 Survey C

9.2.3.1 Research Question R2a: What are the experiences and opinions of SLTs in Ireland of working with siblings of individuals who use AAC?

Less than half of SLTs (n=12 of 28, 42.8%) reported actively involving siblings in SLT interventions. For those who did engage with siblings, the age of the siblings involved ranged from 0 to 18+, with 6-12 year olds being involved most frequently (n=11, 91.6%). SLTs reported involving siblings primarily in individual sessions alongside the AAC user (n= 9, 75%), rather than in groups. Only one SLT of the 12 (8.3%) reported including siblings in sibling-only communication partner training groups.

SLTs were asked to list three things that would be important for siblings to gain from attending a communication partner training intervention. The main themes which emerged were strategies to help them communicate with their sibling, understanding of AAC and their sibling's communication, how to use the AAC system and peer support. SLTs identified many advantages for involving siblings in a communication partner intervention, including more opportunities for using the system at home, siblings being better equipped to support the AAC user to communicate at home and in other environments, and encouraging the development of the sibling relationship. SLTs also reported some challenges of including siblings in communication partner interventions. These included finding a good time with siblings in school, adapting the information to the right level for the siblings, motivating the siblings and parents to attend and reluctance to add another role to the sibling, especially if they are already experiencing a burden of care.

9.2.3.2 Research Question NP1a: What are the current and preferred practices of SLTs in Ireland regarding the content of communication partner interventions?

SLTs were asked to report the topics and skills they covered during communication partner training interventions. Topics covered included general communication information (functions of communication, how children learn language, creating communication opportunities), general AAC information (myth busters, dos and don'ts, importance of communication partners, what to expect), technical knowledge (editing, programming, and navigating a system, troubleshooting and AAC company contact details) and peer support (sharing experiences, group question time, and how to include others). The skill which was mentioned most frequently was modelling, or aided language stimulation. Every SLT who answered the question mentioned modelling in their response. Other recurrent responses were pause time/waiting, creating communication opportunities, expanding, and prompting. See Figure 9.5 for a word cloud of the skills reported.



Figure 9.5 Word Cloud of Skills SLTs Report to Include in Communication Partner Training Interventions

9.2.3.3 Research Question NP5a: What are the current and preferred practices of SLTs in Ireland regarding the structure of communication partner interventions?

Timing of Sessions. SLTs were asked to rank when communication partner training sessions occurred most frequently in their service. SLTs indicated that communication partner training interventions were most frequently offered on weekday mornings, followed by weekday afternoons. Evenings and weekend sessions were ranked as the least frequent.

Session Frequency and Intensity. SLTs were asked if they had to run a training over 4 hours, what structure would be their preference. Half of SLTs reported preferring one-hour sessions, once a week for four weeks (n=17, 51.5% respectively). SLTs reported that multiple short sessions were more common in their service (n=21, 63.6%) and 19 (57.6%) reported this format was their preferred option as compared to longer sessions.

Group Size. SLTs reported primarily completing communication partner training in groups of 3 to 10 partners (n=18, 54.5%), individually (n=16, 48.5%) and/or in pairs (n=13, 39.4%). SLTs indicated a preference for training to take place in small groups of 3 to 10 partners (n=22/30, 76.7%). Two SLTs reported that their ideal group size varies depending on the training goal; for example, partners may benefit from group learning and support for general strategy learning, but that 1-1 training is better if there is a very specific goal.

Online Training and other impacts of COVID. SLTs reported preferring a hybrid approach when running a communication partner training intervention, mixing online and in person aspects (n=15, 45.5%). Participants felt the hybrid approach offered multiple benefits. The in-person training component allows for a practical approach to teaching strategies and learning about different AAC systems, as well as the opportunity for peer support. Whereas an online component supported increased attendance, was more accessible to a wider audience and provided the benefit of online follow up support.

Participants were asked about the impact of COVID-19 on their training. Of the 25 SLTs who answered the question regarding the impact of COVID on their communication partner training practices, 23 (92%) reported completing more communication partner training online. The majority of SLTs who answered the question (n=18, 72%) reported finding it more difficult to complete communication partner training and 19 (76%) reported completing less communication partner training due to the pandemic.

9.2.3.4 Research Question NP6a: What are SLTs in Ireland’s current and preferred methods of teaching new learning during communication partner interventions?

SLTs were asked what instructional strategies they use when teaching communication partners about AAC. Of the 33 SLTs who participated, 29 answered this question, and the three most popular strategies were: demonstrating in real time how to do the strategy (n=26, 89.7%); providing information sheets to take home (n=24, 82.8%); and describing the strategy in detail (n=24, 82.8%). See Table 9.3 for a full list of instructional strategies and the number of SLTs who chose that strategy.

Strategy	N	Percentage
Describe the strategy in detail (e.g. outlining steps involved)	24	82.8%
Use a PowerPoint presentation with visuals to demonstrate a strategy	18	62.1%
Having someone who has used this strategy before describe how it worked or didn’t work for them	6	20.7%
Having an AAC user discuss how it impacts them and how others could help	4	13.8%
Providing reading materials e.g. a book on the topic	7	24.1%

Providing information sheets to take home after a training to remind participants of what they learned	24	82.8%
Showing a video of someone doing the strategy in a real situation	23	79.3%
Demonstrating in real time how to do the strategy	26	89.7%
Providing participants with a chance to practice the skill by themselves	21	72.4%
Providing participants with a chance to role play the skill with you/others	20	69.0%
Setting out clear goals before the training starts	12	41.4%
Having participants complete a quiz before they start to know where their gaps in understanding are	7	24.1%
Providing participants with a chance to talk through the strategies together	14	48.3%

Table 9.2. Instructional Strategies Used by SLTs When Teaching Communication Partners About AAC

9.2.4 Summary

The surveys described in this chapter collected data from three cohorts who may be key stakeholders in a sibling communication partner intervention – adolescents, parent/guardians and SLTs. Stakeholders' needs and preferences regarding intervention structure and instructional strategies were probed, and adolescents and parent/guardians identified factors impacting on session enjoyment. The experiences of SLTs working with siblings of AAC users were also explored, with less than half reporting to actively involve siblings in interventions. The needs and preferences of these key stakeholders are a key consideration when identifying factors which may support, or act as a barrier to, sibling engagement.

PART THREE: DISCUSSION AND CONCLUSIONS

Chapter 10: Discussion

10.1 Introduction

This chapter aims to interpret the study findings and discuss how SLTs may support the engagement of siblings with AAC training interventions. First, the framework used to structure the research is discussed. Next, an interpretation of the findings is presented under three headings, engaging siblings, building a reciprocal and meaningful relationship and siblings' needs and preferences. Throughout, factors in how SLTs can support the sibling engagement in communication partner interventions are highlighted. Finally, the implications of the findings in relation to practice is discussed.

10.2. Engagement Framework Review

Therapeutic engagement is a complex, multifaceted, and dynamic concept (D'Arrigo et al., 2020; King et al., 2014; Steinhardt et al., 2022). It is co-constructed over time between the practitioner and the participant (Bright et al., 2015), beginning prior to the intervention sessions themselves and potentially lasting after the sessions have finished (Nobles et al., 2018). Thus, there is no one best method of supporting an individual to engage with an intervention. The specific individuals, their personal experiences, preferences and needs, should be considered (King et al., 2022). While these findings cannot account for every individual difference that may arise, they do provide an overview of the factors to be considered when supporting the engagement of this particular and unique group: siblings of AAC users.

As outlined in the literature review of this thesis, there is a gap in engagement research regarding sibling engagement with interventions, and how practitioners can effectively support this. While there have been frameworks and discussions of how family engagement can be supported (King et al., 2022; Klatte et al., 2020; Melvin et al., 2023), siblings have been relatively ignored in these discussions. As there was no existing framework or research evidence focusing on supporting the engagement of siblings, not to mention siblings of AAC users, a modified framework was constructed to structure this research and ensure that the key elements of supporting engagement for siblings of AAC users were explored (Figure 10.1).

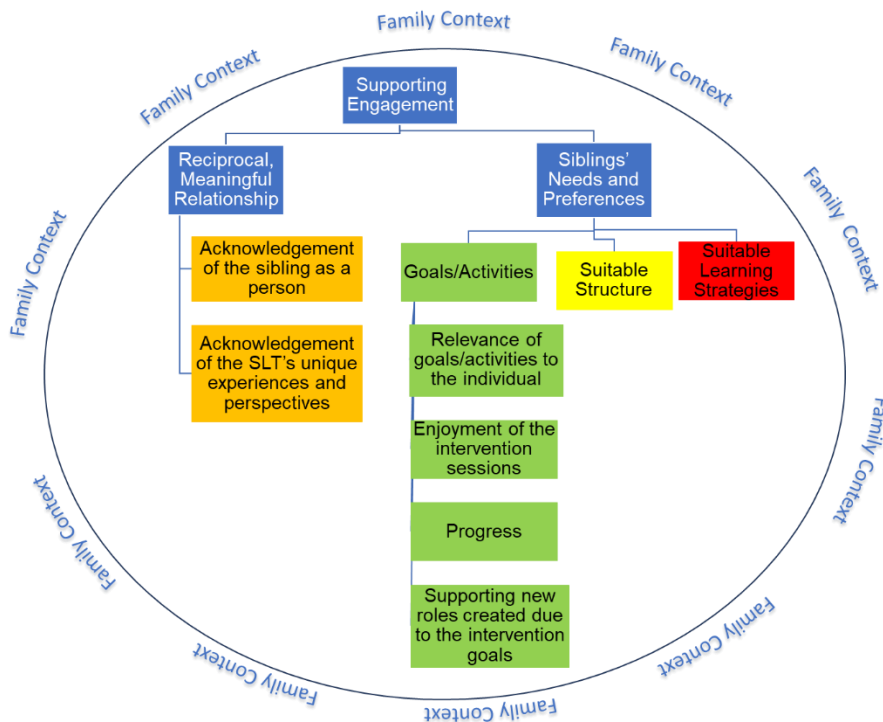


Figure 10.1 Framework for Supporting Engagement of Siblings of AAC Users (Repeat of Figure 5.1)

Frameworks have been used to understand and explain factors that influence implementation outcomes (Nilsen & Bernhardsson, 2019). Each factor comprises of individual barriers and facilitators, which independently or collectively, may have an impact on the implementation outcome (Nilsen, 2015). The current framework was used to understand and explain factors that may influence sibling engagement. A framework is beneficial when considering how to support sibling engagement with an intervention as it encourages SLTs to consider the many factors impacting on engagement, and to implement necessary changes in their practice to address each relevant factor.

The framework was based on King et al. (2022) framework of the co-construction of engagement with youth in paediatric rehabilitation, with other pertinent engagement literature informing the modifications (Hansen et al., 2023; Klatté et al., 2020; Melvin et al., 2020; Melvin et al., 2023; Supplee et al., 2018). The framework is grounded in two main principles, the first is the importance of building a reciprocal and meaningful relationship and the second is taking into account the sibling's needs and preferences when planning interventions. Under each principle there are several subsections, each highlighting an aspect of engagement for consideration (Figure 10.1). The framework is depicted as being surrounded by the family context, underpinning the relevance of family across all aspects of this framework. As the overall research methodology was not exploratory in nature, it was not anticipated that additional elements to the framework

would be identified through this research. However, as the framework was created from engagement literature not related to siblings, it was unknown whether the data would support each aspect of the findings as being relevant to siblings of AAC users. While the findings did confirm that each factor was appropriate to consider when supporting the engagement of siblings of AAC users, there was no single answer as to how best to support the engagement of siblings using each element of the framework. Evidence was identified across the findings to support each factor as a distinct valuable element in the framework, with multiple ideas of how these elements may relate to siblings discussed. This framework allowed for a concise description of the factors influencing sibling engagement, and inspired the research questions specific to each factor which were explored in this thesis. The key findings across the research strands conducted will be discussed under each element of the framework with reference to the relevant literature and illustrated in Figure 10.2.

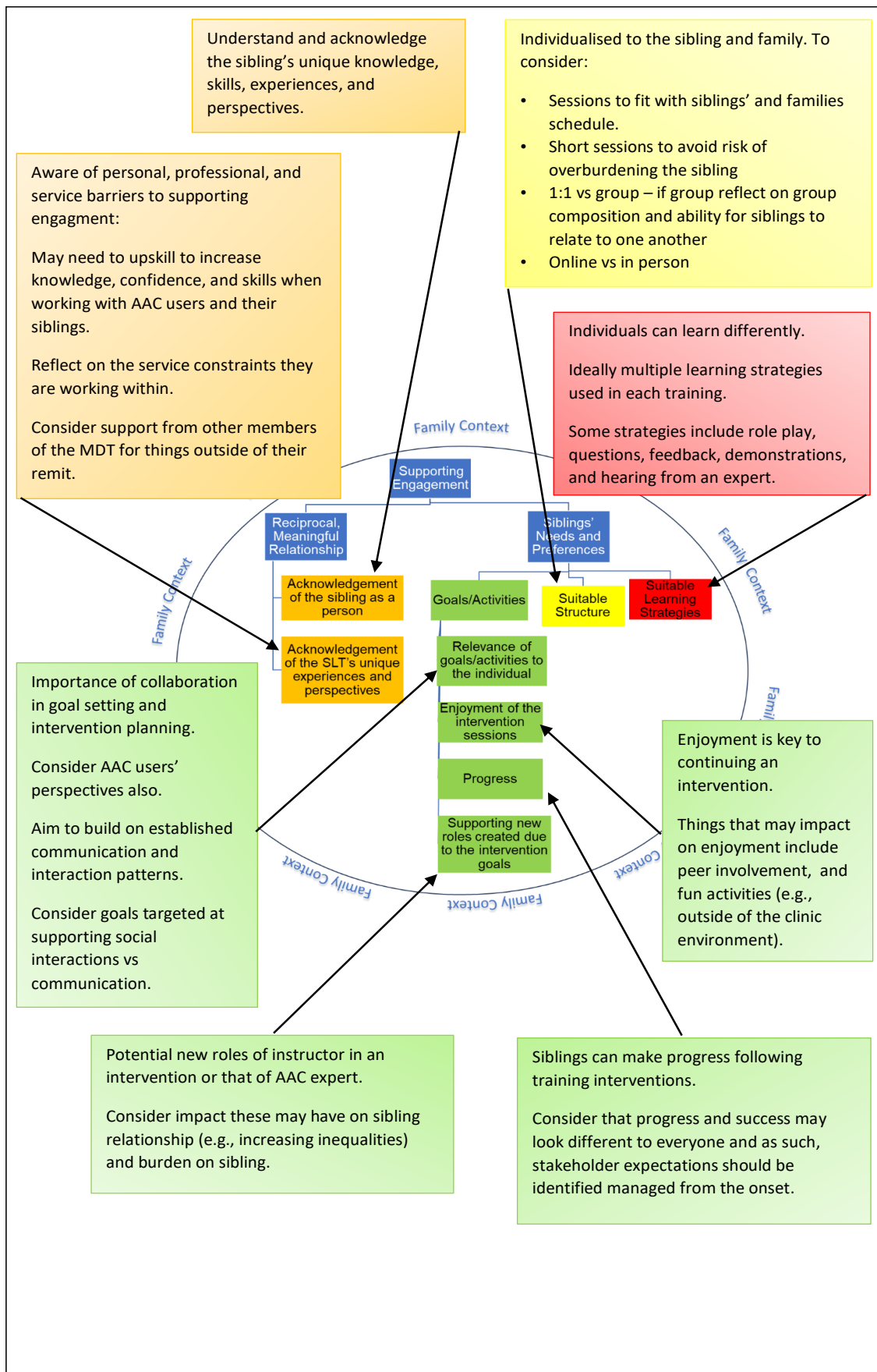


Figure 10.2 Summary of Key Findings as They Relate to the Framework for Supporting the Engagement of Siblings of AAC Users

10.3 Engaging with Siblings

Siblings are potentially a key resource to be harnessed in AAC interventions by SLTs; however, this group are currently under-utilised (But see Douglas et al. (2018); Hacker et al. (2023)). Prior to discussing how exactly SLTs can support the engagement of siblings with communication partner interventions, it is necessary to address a fundamental query – should SLTs be engaging with siblings at all?

There is no doubt that many siblings may be prime candidates for communication partner training for many reasons, siblings often spend a lot of time together (Diener et al., 2014; Paul et al., 2022), develop close, longstanding relationships (Buchanan & Rotkirch, 2021; Dunn, 2015), influence one another (Howe et al., 2022; Whiteman et al., 2009) and play many roles in each other's lives (Avieli et al., 2019; Rossetti et al., 2018). Siblings are key partners for social development during childhood and adolescence (White & Hughes, 2017) who are likely to be especially important for AAC users who may struggle to develop and maintain peer relationships (Batorowicz et al., 2014). These features of sibling relationships were echoed in the interview findings of this research (R1a-c), with participants discussing spending time together, positive and negative relationship characteristics, and the variety of roles they play in their siblings' lives.

However, while siblings have the potential to be significant communication partners, this fact does not determine if training siblings as communication partners is in the best interests of the sibling, AAC user, and/or family. Sibling relationships are varied, with some siblings reporting challenges in establishing relationships with their sibling with a disability (Tomeny et al., 2017), as Ella mentioned in her interview about her relationship with her brother (R1b). Furthermore, siblings of individuals with a disability may experience additional responsibilities, for example in caring and service liaison roles (Corsano et al., 2017; Leedham et al., 2020). Some siblings may take on more roles than others (Avieli et al., 2019; Rossetti et al., 2018); R1c) and this may be linked to the sibling's perception of the relationship (Tomeny et al., 2017). As such siblings may not want to be involved in an intervention, perceiving it as an additional responsibility for them to undertake or they may anticipate they will be expected to engage more with their sibling with a disability. While there is a general assumption throughout this thesis that engaging with siblings can be a positive aspect to an intervention, and the current research findings support this notion, it does not mean that intervention engagement is positive for every sibling. Individuals should not be expected to engage with an intervention simply because they are a sibling and are present in the home. Instead, the needs of all stakeholders should be balanced, and interventions recommended based on their alignment with the client's goals.

The concept of interventions aligning specifically with the goals of the client then raises the question of who is the client? Who should be the focus of the goals? Traditionally, the AAC user has been the client. Services have worked through a person-centred approach (DiLollo & Favreau, 2010), focusing on the client who attended the service due to an identified need – i.e., the individual with a disability who had communication difficulties and used AAC. However, with the rise in family-centred practice (McCarthy & Guerin, 2022), a reconceptualisation of the notion of who is the client is needed. Family-centred practice, as a key principle of PDS, highlights the family as a unit to be central to the service delivery (Health Service Executive, 2020). When creating collaborative goals and planning interventions, SLTs are no longer expected to consider the needs of the AAC user alone, but instead reflect on the needs of the family, and each of its individual members, as well. Interventions should focus on both supporting the strengths and needs of the individual family members, but also in supporting the relationships within the separate family subsystems (Mandak et al., 2017). Siblings are one family member who, while often overlooked (Gill, 2020), should be considered as a client. How the SLT can negotiate and balance the needs of the AAC user, the sibling and the family as whole when planning an intervention should be reflected on. Take, for example, a communication partner training intervention for siblings to train them to support the aided language learning of the AAC user (von Tetzchner & Stadskleiv, 2016). This intervention may benefit the AAC user (e.g., increasing their linguistic competence) and family (e.g., dividing the teaching responsibilities). However, the training may give the sibling, potentially one who is already struggling to come to terms with their sibling's disability (e.g., Ella (R1a)), additional responsibilities (Nuttall & Valentino, 2017). Thus, while the training would have a positive impact on some individuals, if the negative impacts on the sibling cannot be assuaged, the training is not in the best interests of the client (i.e., the whole family (Health Service Executive, 2020)) and should not proceed. Instead, the sibling could be referred to a support group with a focus on disability education, adaptive coping skills and problem-solving skills (e.g., Jones et al., 2020; Wolff et al., 2023; Zucker et al., 2022), and other appropriate communication partners trained to support the language learning of the AAC user.

Additionally, as discussed above, siblings are not perceived to be in isolation, rather the sibling relationship and the individuals themselves exist within the larger context of the family system (Turnbull et al., 2015). When discussing their experiences, each of the siblings spoke about their family environment, for example how close they all were or how supportive their parents were (R1a). The knowledge, beliefs and actions of other family members may impact on the sibling's willingness or ability to engage with a specific intervention. For example, Sarah during her interview attributed

her enthusiastic attitude towards new therapies and supports for her sister to her parents' progressive attitudes and roles as "super advocates". However, other parents who may have negative experiences with the SLT service or who may not consider intervention to be of benefit, may not support the sibling to attend an intervention. When reflecting on sibling engagement with interventions, and how to support this, an awareness of the wider family context is required. To develop their understanding, SLTs can gather information of the experiences and beliefs of the family as a whole as well as the individuals themselves when collaborating on goals and planning interventions.

Conceptualising siblings as a client within a wider family system leads to a need for those working with AAC users to have a greater understanding of how sibling engagement with interventions can be appropriately supported. Proposed guidelines for supporting sibling engagement with communication partner interventions are discussed under the practical implications of this research in Section 10.7.

10.4 Building a Reciprocal and Meaningful Relationship

10.4.1 Introduction

Building of a relationship with the sibling is a vital foundation for sibling engagement with AAC training interventions, as has been demonstrated in studies working with other key stakeholders (e.g., King et al., 2022; Klatte et al., 2020; Melvin et al., 2020). The building of a positive and trusting relationship is impacted by factors relating to both the sibling and the SLT. The experiences and perspectives of both cohorts are discussed below.

10.4.2 Interpretation of Findings: R1 Acknowledgement of Sibling as Person

Critical to building a meaningful therapeutic relationship is adopting a person-centred approach (Sylvestre & Gobeil, 2020), including recognising and respecting the personhood of the client, and showing a genuine interest and belief in them (Hansen et al., 2023). In recognising personhood of the sibling, it is important that SLTs acknowledge the knowledge and skills of the sibling prior to an intervention and seek to understand the already established communication methods between them and the AAC user. SLTs are relying on limited evidence to aid them in understanding the lived experiences of siblings of AAC users; Dew et al. (2011) is the only identified study which explicitly focused on the experiences of siblings of AAC users, providing an insight into their lives. It is important to note that individual differences across all sibling relationships are well acknowledged (McHale et al., 2012). As such, these findings are not assumed to provide a definitive account of the experiences of all siblings of AAC users. Instead, it

was important for this research to provide an awareness of what the experiences, roles, and relationships might be for some siblings of AAC users when exploring how SLTs could support the engagement of these individuals.

Similar to the findings of the only identified study on sibling experiences (Dew et al., 2011), there were individual differences in the amount of time siblings of AAC users spent with their sibling (R1a). Three of the four siblings reported spending a lot of time with their sibling, both now and during childhood/adolescence. The remaining participant, Ella, who described finding it difficult to develop a reciprocal and meaningful relationship with her brother, attributed this difficulty to extended time spent away from him, as well as his diagnosis of autism and severe learning disability leading to limited and restricted interactions between the siblings. The impact that a sibling diagnosis has on the sibling relationship has been previously acknowledged; Tomeny et al. (2017) and van der Merwe et al. (2017) both report that a sibling diagnosis of autism may impact on the negative perceptions of the sibling relationship. When considering the impact of AAC specifically, Travers et al. (2020) concluded the use of AAC itself did not impact on the sibling relationship quality in their study of siblings with intellectual disability or autism. Much of the research on sibling experiences relates to having an autistic sibling (e.g., Corsano et al., 2017; Diener et al., 2014)), and this has also been mirrored in interventions for siblings of children with disabilities (Chapter 6; and reported in Lynam and Smith (2022)). This high proportion of studies involving siblings of autistic individuals may be attributed to the belief that siblings may provide support and modelling in the area of social development (Howe et al., 2022), a common challenge for many autistic individuals (American Psychiatric Association, 2013). More consideration of other disabilities is needed in the research to provide a better understanding of the impact of other disabilities on the sibling relationship.

An awareness of the nature of the sibling relationship, and a consideration of the specific challenges of the sibling with a disability, is needed in building a meaningful and reciprocal therapeutic relationship with the sibling to support their engagement. All sibling relationships are not the same. SLTs could inquire about the nature of the sibling relationship and any specific challenges prior to an intervention, and then create goals to alleviate these challenges in collaboration with the sibling, AAC user and family. Additionally, group trainings often involve some aspect of peer support (Roberts et al., 2015; Tudor & Lerner, 2015), and so SLTs could group siblings who are experiencing similar challenges in their relationships together to allow for mutual understanding of each other's experiences.

Furthermore, when planning an intervention and supporting sibling engagement, the sibling's current and expected future roles should be acknowledged. These roles may

vary across siblings; participants reported being a friend, protector, teacher, and role models to differing degrees (R1c). Roles may vary across age as well. For example, the youngest participant, Jessica, spoke primarily about being her sister's friend, while the oldest participant, Ciara, discussed taking on more caring and service liaison roles. This finding has been mirrored in the literature with reports of siblings taking on increased caring responsibilities as they get older (Burke et al., 2012; Heller & Kramer, 2009; Kruithof et al., 2021). Sibling roles are dynamic and sibling interventions should reflect this changing context. It is suggested that intervention goals be targeted towards supporting siblings in fulfilling their current roles, for example that of a friend during childhood and early adolescence, with more consideration towards interventions providing support for caring roles later in adolescence and into adulthood. However, interventions goals may also have to consider the future roles of siblings. Siblings have been reported to anticipate caring roles (Rawson, 2010) and have concerns about the future (Corsano et al., 2017) from a young age. While siblings may be accepting of these roles (Kruithof et al., 2021; Ciara R1c), interventions targeting coping skills, problem-solving skills and education may be of benefit to support and prepare siblings for this anticipated future role (Wolff et al., 2023).

It is also suggested that SLTs be cognisant of any additional roles they may be expecting a sibling to take on following an intervention as was mentioned by Ella (NP1-4a) and by surveyed SLTs (R2a). One role which a communication partner intervention may create is that of the expert in communicating or in AAC. However, siblings may already be occupying this role prior to any intervention. As was outlined in Chapter 2, communication partners may be expected to occupy three roles; co-constructing communicative competence (Light & McNaughton, 2014), supporting aided language learning (Kent-Walsh et al., 2015) and creating a communicatively accessible environment (von Tetzchner & Stadskleiv, 2016). Siblings were found to take on all of these communication partner roles, with reports of participants interpreting their sibling's communication during conversations (e.g., Jessica), teaching vocabulary (e.g., Ciara), and adapting the environment to ensure it is communicatively accessible for their sibling (e.g., Sarah). Siblings may be the AAC expert at home or in other environments, for example school. Training can therefore support the sibling to act effectively in this role and prevent them from becoming overwhelmed. However, if the sibling is not currently occupying this role, or has no interest in being known as the AAC expert, then equally SLTs have a responsibility to ensure that this does not change. SLTs may also support the sibling in establishing boundaries around these roles. For example, as part of the intervention, SLTs could aid siblings in identifying and reflecting on their role, how to

advocate for themselves in regards to what roles they are willing to occupy and also how to direct someone to an appropriate source of advice instead of the sibling.

Some factors which may impact on the sibling's role of AAC expert include relationship, age and type of AAC. Siblings took on more of an AAC expert role as they got older and as the AAC system got more high tech and if they spent a lot of time together and had a close relationship (R1c). This finding may only be applicable to the current generation of AAC users and siblings. Each of the interview participants grew up during a time when the use of devices and technology was becoming more commonplace. Their parents, however, may have struggled to keep up with these technological advances, as Jessica mentioned in her interview. As such, due to their knowledge of technology, participants may have been relied upon to act as the primary AAC expert. Parents of younger children using AAC nowadays may be more familiar with technology, and thus more comfortable with a high tech AAC system.

Understanding sibling knowledge, skills, and experiences and recognising the personhood of the sibling are key to building a positive therapeutic relationship. However, the relationship is between two individuals, and so an understanding of the SLT's skills and beliefs need to be taken into account when considering how to support sibling engagement in that context.

10.4.3 Interpretation of Findings: R2 Acknowledgement of the SLT's Unique Experiences and Perspectives

When seeking to build a meaningful and reciprocal therapeutic relationship with a sibling of an AAC user, SLTs should reflect on their own experiences and perspectives of working with siblings. There may be barriers from a personal or professional perspective that are impacting on their ability to support sibling engagement. SLTs may not be confident working in the area of AAC. Almost half of the survey participants, most who had over two years working with AAC users, reported feeling only moderately or slightly confident working with AAC. There have been reports of varying levels of SLT confidence in AAC (Sanders et al., 2021; Ward et al., 2023) and this lack of confidence may be impacting on the services provided to AAC users and their families. It is advisable for SLTs to consider upskilling in AAC competences (e.g., National Health Service Education for Scotland, 2014) in order to increase their knowledge and skills. The onus is not just on the SLT themselves, SLT services should recognise the need for SLTs to receive guidance and instruction in the area of AAC and provide them with training and support opportunities. Additionally, it may be of benefit to individuals training to become SLTs to be provided with more AAC experiences and training opportunities and prior to

starting in their clinical role (Barman et al., 2023). The SLT could also seek the support of other healthcare professionals working with the AAC user, for example occupational therapists and psychologists to aid in their upskilling and confidence working with AAC users, for example in working with sensory needs, access methods, or challenging behaviours.

Regarding siblings specifically, more than half of the SLTs surveyed reported that they did not involve siblings in AAC interventions, a concerning statistic considering the potential importance of siblings in the lives of many AAC users (Dew et al., 2011), including those interviewed for this research (R1a-c). In addition, three-quarters of SLTs surveyed who did actively engage with siblings, involved them only in 1-1 sessions with the AAC user. These individual sessions lessen the peer support available to siblings when compared to a group intervention (Granat et al., 2011) as was reported in both the findings of the surveys (NP5d-e) and interviews (NP1-4a). When reflecting on their own practice, SLTs may consider why sibling engagement is low, a feature which is also evidenced in the literature from the difference in the amount of research available for parents and teachers as compared to siblings (Biggs et al., 2018; Kent-Walsh et al., 2015; Shire & Jones, 2015). This lack of engagement may stem from several factors. Firstly, SLTs identified barriers to engaging with siblings, for example finding a good time to run the training, adapting the information to suit siblings, and motivating the siblings and parents. On a professional level, SLTs may not have the experience nor confidence in (i) working with AAC, (ii) training with communication partners, and (iii) their knowledge of siblings to sufficiently adapt their practice to mitigate these barriers and engage with siblings. SLTs should reflect on which, if any, of these aspects they may be requiring experience and support in. As above, more training and support opportunities for SLTs in these areas would be of benefit. The implications for practice section of this discussion outlines guidelines which might also be of value to SLTs.

Moreover, who the SLT engages with may relate to their conceptualisation of who is the client, as was discussed in the previous section. SLTs working in the public children's disability service under PDS are expected to work within a family-centred practice model of care (Health Service Executive, 2020). However, siblings as members of the AAC user's family microsystem (Mandak et al., 2017) and as familiar communication partners (Beukelman & Light, 2020) are relatively overlooked (Gill, 2020; R2a). This may be associated with the SLTs conceptualisation of who is 'family' within a family-centred practice model (Health Service Executive, 2020). If an SLT does not perceive the sibling to be a client, or does not recognise a sibling's central role in the family system (Turnbull et al., 2015), then the SLT may not consider intervention to be appropriate for a sibling. However, recognising the need for sibling engagement is not

the sole responsibility of the SLT. In fact, many SLTs do have an awareness of the potential benefits of engaging siblings with an intervention. For example, the SLTs who participated in the survey mentioned more opportunities for AAC use at home, equipping siblings with skills to support the AAC user and promoting the development of the sibling relationship (a specific challenge for siblings with communication difficulties; Hansen et al. (2016)) as benefits of involving siblings in interventions. There may be barriers within the service itself associated with a dearth of sibling engagement. For example, there may be no service pathways featuring siblings or no set precedence for involving siblings in the service. Furthermore, the impact of current staffing constraints (Health Service Executive, 2022) on the time and resources available to SLTs may lead to a prioritisation of services, with those perceived as less important, e.g., engaging with additional communication partners like siblings, being removed. These service constraints also impact on the ability of the SLT to build a meaningful relationship with the sibling. Building and maintaining a therapeutic relationship takes time. SLTs must have the time to meet with the sibling, understand their experiences, have open and honest discussions about their needs and goals and build trust. However, in services where SLTs are struggling with large caseloads, long waitlists and a lack of resources, this time is not regularly available.

Additionally, the reduced availability of siblings during core SLT working hours (NP5d) may impact on the likelihood of SLTs engaging with siblings. SLTs, anticipating that the timing would not suit, may not consider inviting siblings to attend an intervention or they could be uncomfortable requesting the sibling takes time off school to attend. Alternatively, interventions which are only offered during the day may have limited enrolment, potentially resulting in less interventions for siblings being offered in the future. It is important for SLTs to be aware of their current service constraints, and how these may be impacting on their ability to support the engagement of siblings of AAC users.

In addition to a lack of experience, understanding, and service provision some SLTs reported being concerned about the risk of engaging with sibling in a communication partner training, for example assigning the sibling an additional role on top of their current role(s) they occupy as a sibling of an individual with a disability (Barr & McLeod, 2010; Leedham et al., 2020; R1c). SLTs could reflect on the nature of the intervention (e.g., developmentally appropriate, benefiting both sibling and AAC user) and the sibling themselves (e.g., sibling perceptions of benefits and burdens of an intervention), both before and during an intervention to make any necessary modifications to alleviate these concerns (Beffel et al., 2022). Gathering background information and feedback from key stakeholders is crucial to understanding how the

intervention was perceived by the siblings and family (Carter & Wheeler, 2019). Siblings may not want to engage with an intervention for various reasons (e.g., not having a close relationship; Hank and Steinbach (2023); not having the time (NP1-4a); or not wanting to be in a new social situation (NP1-4a)). In these situations, the SLT role in supporting engagement of the sibling may simply involve providing the sibling and family with the appropriate information to ensure they are making an informed decision and accepting if the sibling refuses to engage with an intervention. SLTs may benefit from support of other members of the multi-disciplinary team, for example psychologists, given the potential emotional and psychological aspects to these interventions.

Relationship building is a core aspect when supporting engagement with clients (Hansen et al., 2023). While supporting this affective aspect of engagement is important (King et al., 2014), clinicians must also support the cognitive and behavioural aspects of engagement, (i.e., making sure the client knows what they are doing and why) and also supporting the client to attend sessions and engage within sessions (King et al., 2014). In order to appropriately support all aspects of engagement, the needs and preferences of siblings must be taken into account.

10.5 Siblings' Needs and Preferences

10.5.1 Interpretation of Findings: NP1-4: Suitable Goals and Activities

10.5.1.1 NP1: Relevance of goals and activities to the sibling

The relevance of goals and intervention activities to the individual sibling is an important consideration when supporting engagement with communication partner interventions (King et al., 2022). The relevance of the intervention goals may impact on a sibling's willingness to attend. For example, wanting to help a sibling was reported to be a definite motivating factor for children and adolescents to attend a training (NP2a-b). Therefore, an intervention with goals explicitly focused on helping a sibling would be relevant and engaging for these siblings. In order to ensure the goals are relevant to the specific sibling, a process of discussion and collaborative goal setting between the SLT, sibling, AAC user, and family should occur. Individualised goal setting has been reported to support the active engagement of families with interventions (Brewer et al., 2014) and as such should be prioritised when planning a communication partner training intervention.

The intervention goals must also be considered in the context of the client as the whole family and therefore they must be relevant to not only the sibling and AAC user, but the family itself. If parents/guardians do not think the intervention relevant or

beneficial to their family, they may decide to not support their child or adolescent to engage with the intervention. For example, parents may refuse to bring their children to/from sessions or refuse to distribute information regarding the training to them. From a family systems perspective, the goals should aim to restore balance, or homeostasis, across the family system (Turnbull et al., 2015), and avoid causing any further instability. For example, the introduction or change of an AAC system may disrupt established communication patterns across the family system. A sibling communication partner training intervention could be one aspect of SLT input focusing on supporting the siblings to adapt to these new communicative changes. What the intervention should strive to avoid is introducing new roles and responsibilities to the sibling, creating a further imbalance within the sibling subsystem, potentially resulting in resistance to the inclusion of AAC in the family and thus impacting on the family system as a whole (Mandak et al., 2017).

The content of what is taught during an intervention must also be relevant to the sibling, AAC user and family. The content must also build upon the siblings' established communication methods, rather than disrupting already effective communication methods. Binger and Kent-Walsh (2012) suggest identifying the skills of the AAC user that are linked to client outcomes and teaching communication partners strategies to support these skills. The two systematic reviews completed as part of this research identified several strategies which were taught to siblings and peers during training interventions. The strategies taught to siblings in interventions for individuals with a disability primarily fell into two categories; strategies to support social interactions (e.g., play) with their sibling and strategies to support communicative interactions with their sibling (NP1b). In the peer communication partner training interventions, peers were taught to use general communication strategies, prompting, modelling, pausing, and waiting, and how to use the AAC system (NP1c). These strategies correspond to what SLTs reported to teach during communication partner interventions (NP1a) as well as what have been reported in adult communication partner training interventions (e.g., Kent-Walsh & McNaughton, 2005; Sennott et al., 2016). It is important for SLTs to understand what strategies both (i) are relevant to the goals of the sibling and AAC user and (ii) have the potential to support a positive outcome. While SLTs may be aware that these evidence-based strategies have the potential to support a positive outcome, this does not mean that this potential is obvious to the sibling. Siblings should be aided in understanding the rationale behind the strategy and how it is relevant to them and the AAC user. This information supports the cognitive component of engagement (King et al., 2014) as through understanding what they are doing and why they are doing it, siblings may be more likely to engage with the intervention.

10.5.1.2 NP2: Enjoyment of the sessions

Enjoyment is an important consideration when supporting sibling engagement with interventions (King et al., 2022). While interest in the goals or activities of an intervention may encourage a sibling to initially engage with an intervention, enjoyment of the sessions impacts on the willingness to continue to attend and actively engage with the intervention (Reeve, 1989). Adolescents reported their enjoyment of an intervention would be supported through making progress towards set goals. The importance of individualised and relevant goals was discussed above. Adolescents and parents/guardians also reported that participating in the intervention with similar aged peers would make the training more enjoyable (NP2a-b), so group trainings should be considered.

The activities within the session should also be enjoyable for siblings. For example, Sarah (NP1-4a) spoke about how interesting activities, her example was kayaking, would have encouraged her siblings to engage with a training, and may encourage other siblings as well. Organising kayaking as part of the training may not be feasible for SLTs already working within the time and resource constraints of the Irish public disability service (Health Service Executive, 2022). However, the idea that a least some of the intervention could occur outside of the traditional (i.e., clinical) intervention context should not be disregarded. SLTs could consider having a theme for the intervention sessions. Approximately a third of adolescents and parents/guardians reported that a theme would make the training more enjoyable (NP2a-b), with the overwhelming majority identifying sports as the preferred theme. This finding may be a recruitment bias, as sports clubs were one means of recruitment and so participants may be predisposed towards enjoying sports. Nonetheless, SLTs could discuss with siblings and families when planning an intervention regarding their specific likes to see if fun activities could be organised as part of the intervention to support engagement. In group interventions, activities to promote group bonding, for example a game of dodgeball, a scavenger hunt, a group art activity, Lego™ challenges or team relays could enhance the intervention and allow participants to get to know one another better in an informal setting.

10.5.1.3 NP3: Progress and Success

Making progress and experiencing a sense of achievement can be engaging and motivating for participants in an intervention (King et al., 2022). The findings from the

systematic review on sibling involvement in interventions for individuals with a disability demonstrate that siblings can make progress following an intervention. The positive outcomes reported in the studies were widespread across outcomes related to both the sibling and the individual with a disability (NP3a). It is important to note that there may be a publication bias inherent to these results; studies with measurable change are more likely to get published (Dalton et al., 2016). In addition, many of the studies reported variable outcomes across different measures or participants (e.g., Daffner et al., 2020; Kryzak et al., 2015). Nonetheless, these findings indicate that siblings have the potential to make progress through intervention. The degree of progress may vary depending on factors relating to the intervention or the specific individuals, for example the age of the participants, the content of the intervention or the instructional strategies used to teach that information. Additionally, progress and success may be impacted by the sibling's previous knowledge and skills and what they are being taught in the intervention. For example, a sibling who has no previous knowledge or skills in AAC may demonstrate more measurable progress than a sibling who is an attuned and knowledgeable communication partner. More research needs to be carried out on how these specific factors may impact on the effectiveness of a communication partner training intervention for siblings.

Regardless of the exact factors impacting on intervention effectiveness, it is critical that siblings experience some success with the intervention. This may mean matching the intervention content to the individual needs of the sibling and AAC user (Binger & Kent-Walsh, 2012), ensuring the sessions are at the right developmental level for the sibling (Beffel et al., 2022) and modifying the sessions if progress is not being made. It is also important to note that siblings and families may have different perspectives on what they recognise as progress. As such, SLTs may need to manage the expectations of the key stakeholders regarding achievable progress in an intervention and ensure that progress is being recognised by all. To aid in this management of expectations, SLTs could work collaboratively with the sibling and family from the very beginning to create well-defined and measurable goals for the intervention and then ensure the goals are clearly communicated with the key stakeholders, as was discussed above.

10.5.1.4 NP4: Supporting New Roles Created

Siblings may play many roles in the lives of an AAC user. Siblings also may be required to take on different roles in a training. As per the findings of the systematic review on sibling involvement in interventions, siblings have primarily been recorded as a playmate,

receiving training in general communication or social interaction strategies that could be then used to support an interaction with their sibling (NP4a). This corresponds with the, in general, horizontal nature of many sibling relationships, i.e., both individuals of a similar age having equal amounts of power and control (Bagwell & Schmidt, 2011). However, some interventions expect siblings to play a different role, that of instructor, in which siblings are trained to elicit a precise response, give specific prompts, and provide feedback. This role is more often attributed to individuals in vertical relationships (e.g., parent-child), characterised by inequalities in age, developmental stage and/or control (Bagwell & Schmidt, 2011). Expecting siblings to occupy a teaching role may lead to imbalances of power across the sibling relationship. AAC users may already be at a power disadvantage due to their disability (Coleman-Fountain & McLaughlin, 2013) and for the most part, interventions should aim to balance (Mandak et al., 2017) and support the maintenance of current relationship dynamics (Wright & Benigno, 2019) across the sibling relationship.

Communication partner training has the potential to create further inequalities between the siblings. A skilled sibling, perceived by others as an expert in the AAC system and the AAC user's communication, may be expected to interpret for their sibling, putting them in a position of control and creating a dependency on the part of the AAC user. This may not be perceived as a negative for some, siblings may be happy to help their sibling (R1c) and AAC users might be happy for their sibling to take on more of the communicative responsibility when co-constructing meaning in interactions (Midtlin et al., 2015). Some siblings, especially if there is a larger age gap between them, may already be experiencing inequalities across their relationship, for example older siblings being expected to act as a teacher of knowledge and skills (e.g., Buhl, 2009; Ciara, R1c). As such, in practice, the intervention should aim to support and maintain, rather than disrupt, the current relationship dynamics (Wright & Benigno, 2019). The SLT has a responsibility to ensure the intervention will not overburden the sibling (Nuttall & Valentino, 2017). The SLT may fulfil this responsibility when planning an intervention through reflection on the goals and expectations on siblings as they relate to the sibling relationship itself. SLTs could also collaborate with siblings and families to understand the current relationship and roles the sibling is occupying, set clear expectations of the roles expected of the sibling, both during the intervention and after.

10.5.2 Interpretation of Findings: NP5: Suitable Intervention Structure

The intervention structure is a key consideration when reflecting on ways in which SLTs can support engagement. For example, Supplee et al. (2018) identifies timing of the

intervention as a factor influencing engagement at a programme level. Due to service constraints, SLTs are often restricted in when an intervention can take place. SLTs working for the public health service in Ireland work 35 hours per week, generally Monday to Friday between the hours of 8.30am and 5pm. This is reflected in the finding that SLTs most frequently offer communication partner training sessions on weekday mornings and afternoons with evening and weekend sessions ranked as infrequently offered (NP5a). However, this does not match the preferences of other stakeholders, with both adolescents and parents reporting that sessions outside of core working hours (e.g., evenings and weekends) would suit them best (NP5d-e). SLTs, and the services they work in, may need to be flexible about when communication partner trainings for siblings are offered. Siblings have their own busy lives, separate to the AAC user, with school, extracurricular and peer activities all impacting on the time they would have available to attend an intervention (R1a, NP5d). Client priorities are an important factor when considering sibling engagement (Klatte et al., 2020). Siblings should not be expected to prioritise a communication partner training intervention over their own commitments. To support the engagement of sibling, the intervention should fit with their schedule. If forced to choose between regularly forgoing their own activities or education and attending an intervention aimed at helping their sibling, the intervention may not take precedence. As such, to reduce the possibility of the intervention timing acting as a barrier to attendance and engagement, SLTs could collaborate with siblings on when best would suit them to attend and organise appointments accordingly. This may mean that SLTs need to work outside of traditional working hours to offer intervention appointments that suit siblings. Services and should recognise this need and support the SLT to facilitate these appointments. Incentives such as additional time in lieu or flexible working hours may need to be offered to encourage SLTs to move away from their traditional working hours. Alternatively, a compromise could be made when consulting with siblings by identifying times that would best suit both groups, for example sessions taking place during school holidays.

It is not only when the intervention takes place which may influence sibling engagement, the time siblings may be expected to give to a training and how long the sessions themselves are may also have an impact – for example, siblings were reported to prefer short, once a week sessions, committing a maximum of 6 hours a month. Interventions which are too long or too frequent are at risk of overburdening the sibling, which practitioners should strive to avoid (Beffel et al., 2022). A consultation with the siblings prior to the intervention would provide an insight into their preferences of intervention structure. An intervention which is structured to suit the sibling's needs and

preferences is more likely to be engaged with than one which does not suit them at all (Supplee et al, 2018).

Another preference which should be taken into account is if the intervention takes place 1-1 or in a group. Adolescents reported preferring the intervention to be held in small groups of three to 10 (NP5d), while the majority of parents/guardians preferred 1-1 (NP5e). Of note, most parents acknowledged that training with others of the same age would increase their child's enjoyment and motivation to attend a training (NP2b). Thus, while some parents may recognise the benefits of a group intervention, the desire for an individualised intervention and lack of distraction takes precedence (NP5e). Peer support is a key aspect in group interventions (Roberts et al., 2015; Tudor & Lerner, 2015). However, a group intervention does not guarantee an individual will benefit from peer support. For example, Jessica spoke about being socially anxious around her peers and because of this, a group would be a barrier to her engaging with an intervention (NP1-4a). Additionally, both Sarah and Ella spoke about attending sibling groups when they were younger and having difficulty relating to the other members of the group (NP1-4a). Group composition is therefore an important consideration when planning a group intervention. SLTs could gather information from the siblings and collaborate with them to ensure that group members may relate to one another, for example by grouping siblings according to their experiences, needs, and goals. Additionally, siblings who are reluctant to attend a group intervention by themselves could bring a friend along so that they have someone familiar with them, as was suggested by Jessica (NP1-4a). Interventions can also be facilitated with a family group, i.e., all family members attending the intervention together, which has been reported to be effective (Douglas et al., 2021; Douglas et al., 2023). This structure may fit with a family-centred model of care and allow the SLT to work on both individual and family goals within the same intervention (Mandak et al., 2017).

In addition to the needs and preferences of the siblings, the needs and preferences of the family must also be considered. Framing sibling engagement in the context of whole family engagement is a recurring theme of these findings. For the most part, the siblings who SLTs will be engaging with will be children and adolescents. SLTs reported primarily working with children and adolescents who use AAC, and thus it is assumed that the majority of siblings would be of a similar age. Additionally, the systematic review of sibling involvement in interventions did not identify any interventions which targeted adult siblings. As these interventions are designed for children and adolescents, it is likely that parents or guardians would bring them to the sessions. This duty may be in addition to bringing the AAC user to interventions, bringing their children to school and extra-curricular activities, and well as other aspects of their own personal

lives such as work, their own hobbies and attending parent trainings. Interventions therefore need to fit in with the busy schedules of not only the sibling, but also the AAC user, other siblings in the family, and their parents/guardians. Collaboration with family members is key to ensuring the needs and preferences of the whole family are considered when structuring an intervention.

Facilitating an online sibling communication partner training intervention may be one method of reducing the likelihood of the intervention structure becoming a barrier to engagement. Online interventions can be more flexible and convenient (NP5d), removing the need for a parent/guardian to bring the sibling to a training. SLTs have become more familiar with online trainings following the COVID-19 pandemic (NP5a), with online trainings also being reported in the literature (e.g., Douglas et al., 2021). However, online trainings were not reported to be the preferred structure for the majority of adolescents or parents (NP5d-e). This finding must be interpreted in the context of when the data was collected. Public health restrictions of the COVID-19 pandemic had resulted in intermittent school closures over the previous year and a half. Children and adolescents had experienced months of compulsory online learning. Many adolescents and parents reported negative experiences and perceptions of online learning (Garbe, Ogurlu, Logan, & Cook, 2020; Yates, Starkey, Egerton, & Flueggen, 2021) which may have influenced their opinions of having an online component to an intervention. Participants may have been tired of online learning at the time of completing the survey, or similarly, the experiences of online learning may have highlighted to them the negatives of an online structure, for example reduced engagement, concentration, and ability to learn (Walters, Simkiss, Snowden, & Gray, 2022). A compromise may be a hybrid training, incorporating elements of both online and in-person teaching which the majority of SLTs reported to prefer (NP5a).

10.5.3 Interpretation of Findings: NP6: Suitable Learning Strategies

The way in which a topic is taught can have an impact on engagement with that topic. In the two systematic reviews (NP6b, NP6c), often multiple instructional strategies were reported to be used during each training intervention. Frequently reported strategies were ones which encouraged active participation (e.g., role play, questions and feedback) as well as a demonstration of the strategy. These corresponded to what both parents/guardians and adolescents reported, that seeing it in action or doing it themselves were the preferred strategies for a sibling when learning something new (NP6d-e). Similarly, in a follow-up question, the majority of adolescents reported having

someone show they how to do the skill and have a chance to practice the skill themselves as strategies that would be of benefit to them.

One important strategy that (King et al., 2022) specifically linked to supporting engagement was providing an explanation about the purpose of tasks and activities. This strategy reflects the cognitive component of engagement (King et al., 2014); the likelihood of a sibling engaging with an intervention may be linked to their knowledge of what they are doing and why they are doing it. Interestingly, this strategy was perceived to be beneficial by less than half of the adolescents surveyed. Participants would rather hear from 'experts' how the training has been or could be beneficial, either from individuals for whom the training would help (i.e., AAC users) or else other siblings who completed the training before (NP6d). SLTs did not attach the same importance to this strategy, with only one-fifth saying they included an individual knowledgeable in the strategy and about one-tenth reported to have an AAC user discuss the potential benefits of the strategy (NP6a). This may be related to the service constraints SLTs are working under (Health Service Executive, 2020); if SLTs are limited in the time they can allocate towards a communication partner training, it might not be realistic for them to add an additional variable to the intervention. A communication partner or AAC user acting as a co-trainer would require training and co-ordinating of schedules which would take additional time and may not be feasible for all SLTs. Regardless, some effort to include stakeholder input could be considered, for example including videos of AAC users or siblings discussing and using the strategies or recruiting other, older siblings to act as mentors and a source of information and support outside of the training.

Another notable finding is a similar number of SLTs reported providing time for participants to practice the skill by themselves as compared to providing an opportunity to role play the skill with someone else. However, there was a disparity in the number of adolescents reporting to benefit from these two strategies, with more adolescents reporting to prefer practicing the skill by themselves. This difference may be due to a number of reasons, one of which might be the social awkwardness adolescents may feel about having to interact with strangers, as was discussed by Jessica in her interview (NP1-4a). Adolescents, as a cohort, are often referred to as being heavily influenced by their peers (Santrock, 2012), sensitive to social exclusion and eager to avoid the social risk of being ostracised (Andrews et al., 2020). If role playing in front of peers is seen as a potential embarrassing action, then the risk of discomfiture may outweigh the benefits for learning for adolescents.

Differences in the strategies SLTs use and what adolescents perceive to be beneficial may arise due to the age of communication partners being trained; SLTs report primarily training adult communication partners (i.e., parents, teachers, SNAs) rather

than children and adolescents. Instructional strategies that may benefit adults may not benefit adolescents or children (Brod, 2021). The need to consider learning styles in training communication partners has been discussed for adult partners (Thiessen & Beukelman, 2013), but no equivalent research exists for younger communication partners. Individuals may have different learning styles and benefit from different instructional strategies. If the optimum strategies are not employed when teaching an individual, there is a risk of that their ability to learn and make progress will be impacted (Wilson, 2012) which may lead to disengagement with an intervention. There are many different strategies that can be used to facilitate the different learning styles. SLTs could consider using a combination of instructional strategies within the one training. One example of this is Kent-Walsh and McNaughton (2005) 8-step model. This mode incorporates description, demonstration, verbal practice of steps, controlled practice and feedback among other strategies to teach a communication partner a new skill. SLTs may also consider creating a completely individualised training with collaboration with the sibling regarding their learning style and strategies that may be beneficial to them.

10.6. Summary

There are many ways in which SLTs can support sibling engagement with communication partner interventions. One key aspect of supporting engagement is building a meaningful therapeutic relationship which requires SLTs to understand more about the experiences of the sibling, to acknowledge the sibling as their own person and to reflect on their own perspectives of engaging with siblings. Another key aspect to supporting engagement is through ensuring the intervention is individualised to the sibling's needs and preferences, specifically the goals and activities, the structure and the learning strategies used during an intervention. The findings of this research highlight ways in which sibling engagement with interventions may be supported, for example organising the intervention at a time that suits them, including fun activities that take place outside of the clinic room, and using a range of learning strategies within the one training to facilitate different individual learning styles. Furthermore, the findings of this research emphasise a number of areas which practitioners may need to investigate further prior to an intervention to support sibling engagement, for example understanding sibling relationships and experiences, exploring the roles the sibling currently occupies, and identifying sibling specific goals and expectations of progress. Next, the implications of these findings for practice will be discussed.

10.7 Contribution to Theory

This research adds to the current theoretical literature base in two distinct ways. Firstly, this research extends the current literature on therapeutic engagement. The findings of this research reinforce aspects of engagement discussed in other engagement theories, for example supporting the concept of engagement as multifaceted (King et al., 2014; Steinhardt et al., 2022) and co-constructed (Bright et al., 2015). It is important to note that most of the literature on therapeutic engagement is focused on the service user or their parents (e.g., King et al., 2022; Klatte et al., 2020). To the researcher's knowledge, this is the first study to date which has focused solely on the engagement of siblings with an intervention. Thus, this research provides valuable insights into therapeutic engagement as it relates to siblings of AAC users as well as factors which should be considered when supporting the engagement of a sibling with an intervention. The framework which highlights these multifaceted factors (Figure 10.1 and 10.2) is a novel contribution to the field of engagement. It is based off key literature in the field of engagement (Hansen et al., 2023; King et al., 2022; Klatte et al., 2020; Melvin et al., 2020; Melvin et al., 2023; Supplee et al., 2018), and the findings of this research confirm that each element of the framework is relevant to siblings of AAC users – a factor which has not been considered previously. Additionally, this framework and the findings of this research not only recognise factors that are congruent with other engagement theories, but also add to this literature by exploring aspects of therapeutic engagement which are specific to siblings of AAC users. One example is the roles that siblings may be expected to take on during or following a communication partner training intervention and the potential impact of this on the sibling relationship.

Secondly, this research also contributes to a number of the theories discussed in Chapter 2, namely family systems theory (Kerr & Bowen, 1988), ecological systems theory (Bronfenbrenner, 1977), and Mandak et al.'s (2017) theoretical framework which incorporates elements from both family systems and ecological systems theories in the context of AAC. These theories all refer to siblings as being central in the lives of individuals, and the findings of this research add to these theories by exploring siblings in the context of AAC. The findings of this study support the placement of the sibling in the AAC user's microsystem (Mandak et al., 2017). The siblings who were interviewed as part of this research discussed being close communication partners with the AAC user, potentially spending a lot of time together and knowing them very well. Similarly, the relevance of the connections between each individual in the microsystem, and not just with the AAC user, was an important finding of this research, with family dynamics being an important factor in a sibling's engagement with an intervention.

In Mandak et al.'s (2017) theoretical framework, service providers or practitioners are placed in the mesosystem, thereby assuming an interaction between them and all individuals in the microsystem. The current findings extend this theoretical assumption by highlighting the significance of the relationship between the sibling and the practitioner, as well as reinforcing the importance of considering the needs and preferences of the sibling when facilitating a communication partner training intervention, rather than just those of the AAC user, their parents, or the practitioner themselves. The findings of this research provide a novel contribution to this theoretical framework as the relationship between sibling and practitioner as well as the preferences of the sibling themselves have not been considered to date.

As described in family systems theory (Turnbull et al., 2015), siblings are a unique and distinct subsystem within the overall family system. The research findings confirm and extend our knowledge of this subsystem by exploring the sibling relationship and sibling roles when one sibling uses AAC. Another important theoretical contribution of this research is the finding that a communication partner training may cause an imbalance to the sibling subsystem through introducing new roles and disrupting previously established communication patterns. As per family systems theory, interventions should strive to maintain homeostasis, something which SLTs need to consider when planning a communication partner training intervention. Further practical implications for SLTs are discussed below.

10.8 Implications for Practice

10.8.1 Introduction

SLTs are expected and encouraged to engage families in their practice through a family-centred practice model of care (Health Service Executive, 2020). As was outlined in Chapter 2, a family-centred model of care incorporates the core principles of collaboration, respectful partnership, open communication, and clinical flexibility (Al-Motlaq et al., 2019; Arango, 2011; McCarthy & Guerin, 2022). However, while these principles have been documented when working with parents/guardians (e.g., Klatte et al., 2020), siblings have rarely been included in interventions, let alone given an opportunity to collaborate and build a respectful partnership with the SLTs. Over half of the SLTs surveyed for this research reported to not involve siblings of AAC users in interventions. The challenges of engaging siblings in these interventions were identified by the survey participants as (i) finding a good time to facilitate an intervention, (ii) adapting the information for a sibling cohort, (iii) motivating the siblings and parents to

attend and (iv) a reluctance to add an additional role to the sibling (R2a). SLTs may be reluctant to engage with siblings in interventions due to their lack of knowledge and confidence in how to manage these challenges, as was discussed under Section 10.4.3. The overall aim of this research is to explore how SLTs could support the engagement of siblings of AAC users with interventions. Therefore, the findings from this research provide SLTs with the knowledge of how to support the engagement of siblings of AAC users in their practice. The next task is how to disseminate these findings in a meaningful and practical way so that they may be of use to SLTs when planning an intervention. Bridging the gap between research evidence and its practical application is of the utmost importance in improving the quality of care.

One method of sharing these findings is through guidelines for practice. Guidelines are a set of recommendations, principles, or standards that are established to provide guidance and direction in various fields of practice, aiding individuals in making informed decisions and taking appropriate actions (Wang et al., 2018). The benefits of guidelines include consistency of practice, upholding of professional standards and better patient care (Wangler & Jansky, 2021). Guidelines are common in SLT practice, for example the IASLT provides access to several guideline documents on their website, including Guidelines for Visual Communication Displays in Playgrounds (Working Group for Visual Communication Displays in Playgrounds, 2022) and Guidelines for SLTs working with people who use or may benefit from AAC (IASLT AAC Working Group, 2016). The key findings of this research were combined into a set of guidelines, entitled '*How to support the engagement of siblings of AAC users in communication partner training interventions?*'. These guidelines are designed to be interpreted by the SLT, using their clinical expertise and knowledge of the specific context. The initial guidelines are outlined in Appendix S. To ensure these guidelines are relevant, feedback was gathered from key stakeholders- siblings of AAC users and SLTs. Given the interdisciplinary nature of communication, other stakeholders for whom these guidelines may be relevant include other professionals working with AAC users and their siblings, for example occupational therapists or psychologists. While their feedback was not gathered during this review of the guidelines, this could be beneficial in the future, along with valuable feedback from AAC users themselves. For example, psychologists could provide important insights into how best to support the affective and cognitive engagement of siblings with an intervention, especially those who may be experiencing negative emotions related to their sibling, as well as supporting the sibling to seek help themselves.

Following from this stakeholder feedback, the guidelines were revised, and the final draft guidelines are presented in Section 10.8.3.

10.8.2 Stakeholder Review of the Guidelines

10.8.2.1 Method

Following the creation of the guidelines, key stakeholders (e.g., siblings of AAC users and SLTs) were asked to review the guidelines and provide feedback regarding the social acceptability of the guidelines. Participants were asked to (i) read the guidelines through a Google Docs™ link and then (ii) complete an online survey, providing their feedback on the guidelines. The final question on the survey was optional and invited participants to leave their email if they were willing to take part in an online focus group or interview to discuss their feedback further. This form of mixed-methods research is referred to as an explanatory sequential design (Creswell, 2021), whereby the quantitative data (e.g., surveys) is collected first followed by qualitative data (e.g., interviews/focus group) collected to explore and explain the topic in more detail (Creswell & Plano Clark, 2017). Surveys and interviews were chosen as the data collection methods for this section of the research as both methods had already been undertaken as part of the main research study. As such, the researcher had recent experience with the data collection and analysis tools related to these methods and had the necessary knowledge and skills needed to complete this part of the research in a relatively short time frame.

10.8.2.1.1 Participants and Recruitment

Research ethics approval was obtained for this portion of the research from the School of Linguistic, Speech, and Communication Sciences in Trinity College Dublin (Appendix T). Participants for this study were either (i) siblings of AAC users and were over the age of 18 or (ii) SLTs who work with AAC users. Convenience sampling was used to recruit participants through five distinct channels (Kumar, 2019).

1. A link to the study was shared on the personal social media pages (Facebook and Twitter) of the primary researcher.

2. Five Facebook groups for AAC users and their families were contacted and asked to share the link. The administrator of one group, AAC Users and Allies Ireland, agreed for the link to be shared in the group.

3. An email was sent to the members of AAC Group Ireland, an email distribution group for individuals who have an interest in the area of AAC.

4. Two charities working with AAC users and their families in the United Kingdom, Communication Matters and 1Voice, also distributed the link to the study.

5. Finally, siblings of AAC users who participated in interviews during an earlier stage of this research and indicated that they would be interested in being kept informed of the project were also contacted.

A PIL and consent form was attached to the start of the surveys (Appendix U). Participants were not able to proceed to the survey without providing consent. Table 10.1 outlines the participants in this study and Figure 10.3 illustrates a flowchart from first draft guidelines to revised draft guidelines. There were 12 participants who completed the survey, eight SLTs, three siblings and one sibling who was also a SLT. Of the eight SLTs, six left an email address indicating they would be willing to take part in an interview or focus group. A PIL (Appendix V) and consent form (Appendix W) were sent to the email address provided at the end of the survey. Six participants returned a signed consent form. Due to participants' availability, two focus groups were organised, with two SLTs in each, followed by two individual interviews.

	Survey Participants	Interview/Focus Group Participants and Pseudonyms
Speech and Language Therapist	8 (66.66%)	6 (100%) Focus Group 1 (F1) – Robin and Jennifer Focus Group 2 (F2) - Catherine and Amy Interview 3 (I3) - Alice Interview 4 (I4) – Ava
Sibling	3 (25%)	0
Sibling and Speech and Language Therapist	1 (8.33%)	0

Table 10.1 Participants of Feedback Surveys, Interviews and Focus Groups

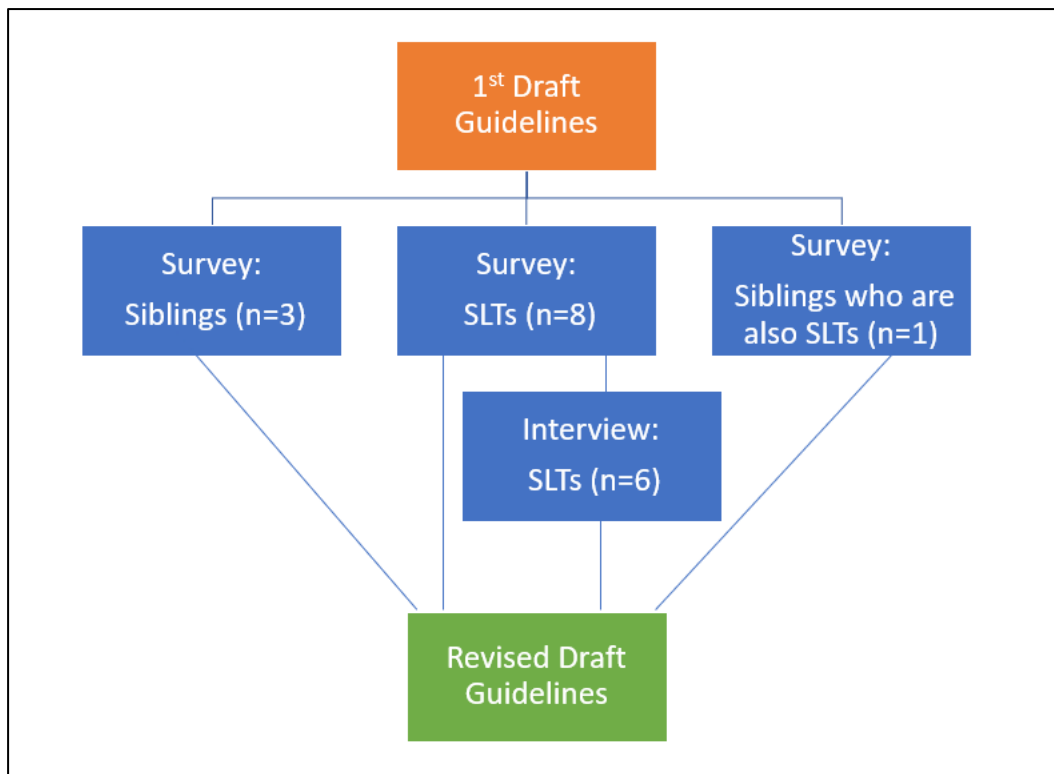


Figure 10.3. Flowchart of Process of Gathering Participant Feedback From First Draft Guidelines to Revised Draft Guidelines

10.8.2.1.2 Materials and procedures - Surveys

Survey questions were designed to probe acceptability of the content and structure of the guidelines created. Qualtrics Online Survey software (www.qualtrics.com) was used to host the survey. The software did not collect participant's IP addresses, and so was anonymous. Of note, the survey was no longer anonymous if the participant chose to leave their email at the end to be contacted for a follow up session. Skip logic was used to tailor the specific questions to participants and thus each participant answered between 11 and 17 questions. The survey took participants between 10 and 20 minutes to complete and consisted of one demographic question (Are you a Speech and Language Therapist and/or sibling), followed by a selection of yes/no questions, multiple choice questions, Likert questions and open-ended questions (Appendix X).

10.8.2.1.3 Materials and procedures - Interviews/Focus Groups

The interview and focus groups (hereafter referred to collectively as the interviews) both followed a semi-structured format based on survey topics (Flick, 2022; Appendix X). A semi-structured format was chosen as it allowed for the interviews to be guided by the survey topics but provided the flexibility for the interviewer to explore participant responses in detail and ask relevant follow-up questions (Polit & Beck, 2010). This was

important considering the aim of this section of the research was to get stakeholder feedback on the guidelines. Participants were given time before the interview to review the guidelines once again before discussing their opinions. The interviews lasted between 17 and 35 minutes. The interviews took place over Zoom™ and were audio recorded. These were then transcribed and anonymised. Pseudonyms were given to all participants.

10.8.2.1.4 Data Analysis

The survey data was analysed descriptively, using frequencies and percentages. Using the NVivo 12 Plus software, the qualitative data from the surveys and interviews were coded and organised according to the interview topics. Any ambiguous survey responses were removed from the analysis. The feedback for each interview topic was then summarised, and any changes which could be made to improve the guidelines were identified.

10.8.2.2 Findings of Stakeholder Feedback

10.8.2.2.1 Positive Aspects of the Guidelines

All 12 survey participants reported that they found the guidelines useful. When asked why they found the guidelines useful, participants mentioned the usefulness of guidelines in general. They provide a structure or starting point for an intervention, encouraging SLTs to put more thought into their preparations. One participant reported that these guidelines would be especially useful for new SLTs or SLTs new to working with AAC users. Two siblings reported that it was positive that siblings were being recognised as deserving of support.

The interview and focus group participants also described some positive aspects to the guidelines. Amy discussed how guidelines are important, especially when starting out with an intervention.

"I was gonna say that like I do think it's useful to have a guideline in areas of SLT because I just think it's so often that I go to start an intervention with somebody, and I'm thinking to myself like, how do I even do this?"

- Amy (Extract 10.1)

Ava mentioned how the guidelines would be useful to as a prompt to ensure she has considered everything prior to an intervention.

“That’s really good to have something to kind of have a look at beforehand. And to make sure, am I considering everything?” - Ava (Extract 10.2)

Other positive aspects to the guidelines that participants reported included that they are usable, practical, flexible, and universal.

10.8.2.2.2 Reflecting as a Sibling

Three of the siblings reported that they felt their needs were very well represented in the guidelines, while one sibling reported that their needs were represented slightly well. The reasons provided for these positive ratings were that the guidelines focused on explicitly on siblings and were related to life as a sibling.

When surveyed, two siblings reported that a training created from these guidelines would definitely have been beneficial to them and one sibling reported that a training would probably have been beneficial for them. The reasonings behind these positive choices were the potential for leaning and peer support.

Siblings were asked what they thought the most important guideline was. There were a variety of answers provided; one sibling felt that Guideline 2, the consideration of additional roles and responsibilities on the sibling was most important. Another sibling reported that the Guideline 13, the intervention should fit with the sibling’s schedule was most important. A sibling, who was also an SLT, reported that Guideline 11 was most important. When asked what they viewed as the most important pieces of information about siblings specifically that anyone reading these guidelines should understand, participants responded with a variety of answers including that (i) siblings want to help and that any involvement should be voluntary, (ii) siblings have their own lives and can have a lot of pressure put on them, and also (iii) siblings are experts in their own right and should be listened to.

10.8.2.2.3 Reflecting as a Speech and Language Therapist

All SLTs who answered the survey reported that the guidelines would cause them to reflect on their practice, through evaluating their previous inclusion of siblings and aiming to include them more in interventions. When asked what the most important guideline was to them, the majority of SLTs (n=6, 66.66%) mentioned the second guideline in their

answer; *The additional roles and responsibilities siblings may be expected to take on following a communication partner training must be reflected on.* Four of these SLTs reported that this caused them to reflect on the responsibilities they may encourage or ask siblings to take on. Other important guidelines mentioned once by SLTs in the survey are listed in Table 10.2.

Guideline 1	Siblings of individuals AAC users should be supported and included in interventions, if they want to be.
Guideline 8	The teaching techniques used to facilitate learning during the intervention must cater for the participant's learning styles.
Guideline 9	An expert should be recruited to act as a co-trainer.
Guideline 12	If a group training method is being utilised, the composition of the group must be carefully considered
Guideline 13	The timing of the intervention should fit with the sibling's schedule.

Table 10.2 Other Important Guidelines for Reflection as Reported by SLTs

Participants were asked again in the interviews and focus groups which guideline they felt was the most important to reflect on. Two of the participants (Ava and Alice) felt the first guideline was the most important, as sibling involvement is not common in SLT and practitioners don't often think of siblings. Three participants (Robin, Catherine and Amy) reported that they felt the second guideline was the most important, i.e., *The additional roles and responsibilities siblings may be expected to take on following a communication partner training must be reflected on.* The three participants, while taking part in different interviews and focus groups, all agreed it would cause them to reflect on what they are actually asking of the sibling. Catherine admitted that it would cause her to be more aware of ensuring the sibling is happy to engage, and it is not just the parent agreeing for them.

Finally, Jennifer reported that number 12 (*If a group training method is being utilised, the composition of the group must be carefully considered*) was important for her as the composition of the group needs to be the starting point to ensure the training is enjoyable and relatable for all participants.

Amy and Alice reported that these guidelines had already triggered them to change their practice, causing immediate reflection and consideration of how to involve siblings more if the opportunity arises.

“So this will definitely change my practice. I feel it has already changed my practice since I did the survey... I will be very cognisant of siblings, and I will put them on a par with the child, now and the parents. Everyone will be in line with each other.”

-Alice (Extract 10.3)

Robin reported that the guidelines would change her practice in small ways, but she would prefer some further prescriptive information and ideas for activities and resources before she would consider running a group training.

10.8.2.2.4 Structure of the document

Participant opinions on the structure of the guideline document were explored during the interviews and focus groups. All the participants reported liking that each guideline was separate and that you could click into them individually. A quote from both Alice and Robin below illustrate this point.

“Personally, the fact that you can click into it is wonderful. So it looks less overwhelming.”

- Alice (Extract 10.4)

“I liked that it was, it, was really clearly like categorised into those little sections, so it didn't feel overwhelming to read... You could kind of go and come back to it like you could skim, based off the heading to find something you were interested in. So I thought, like structure wise, it works.”

- Robin (Extract 10.5)

There were some suggestions on how to improve the structure of the document, for example colour coding or adding visuals to break up the text. There were also suggestions of formatting the information in different media, for example leaflets or videos to appeal to a wider audience.

“I don't know whether, like visuals or there's any other way to make the information kind of easier to absorb... like a video format, even using cartoons or something like that to explain what you should consider or the key take home messages or something that might be nice.”

- Ava (Extract 10.6)

10.8.2.2.5 Number of Guidelines

Of the survey respondents, 50% reported that there was the right number of guidelines (n=6) and while the other 50% reported too many guidelines (n=6), with two participants suggesting that some guidelines could be joined together. Similar findings emerged from the interview, participants reported the number of guidelines were perceived as the upper threshold of what might be beneficial.

"I don't think I'd want any more. I think it's enough. Um, it's not too many. But yeah, I think it's probably enough."

- Catherine (Extract 10.7)

During the focus groups discussions, Jennifer, Robin, Amy and Catherine all suggested that some of the guidelines could be joined together in order to reduce the number and make them more concise. In contrast, although Ava stated that she thought there were too many guidelines, she reported there was no repetition between the points and didn't know how it could be condensed.

10.8.2.2.6 Amount of Information Provided to Support Each Guideline

The majority of survey participants reported that the guidelines had the right amount of supporting information (n=9, 75%), while two participants reported that there was too much information (16.66%) and one participant reported there was too little (8.33%). Similarly, 75% of interview and focus group participants (n=4) reported that there was the right amount of supporting information for the guidelines. Ava's opinion was that while the information is all necessary with no repetition, it is perhaps too much for a sibling to need. It was suggested that the structure of the document allowed for the information to be broken up and read only as needed.

"I suppose with the fourteen [guidelines], you know that someone can go and read up on each one only if needed."

- Amy (Extract 10.8)

Participants in the interviews and focus groups were asked if they would like to be able to access the specific data that supported the different points under the guidelines. Five of the participants said they would. The participants provided various reasons for this choice, including for academic or research, for supporting a business case, for personal knowledge and for informing families about the guidelines. However,

the consensus was that these would be most beneficial outside of the guideline document, for example as a separate document or appendix, to avoid adding additional information to the current document.

10.8.2.2.7 Wording of the guidelines

Of the 12 survey participants, 10 (83.33%) reported that they either agreed or strongly agreed that the guidelines were clear, easy to understand and easy to read. The remaining two participants agreed that the guidelines were clear and easy to understand but disagreed that they were easy to read. Two suggestions about changing the wording were provided in the survey responses. These were to change the word ASD to autism and to remove the word diagnoses, as well as changing the wording of guideline 11 by replacing the 'but' with an 'and'; *“The training could take place in a 1-1 *and*/ or a group setting, *and* individual preferences should be considered.”*

Participant opinions on the wording of the document were probed further during the interviews and focus groups. All six participants reported positive opinions regarding the wording of the guidelines, including that they were clear, easy to understand, used reader friendly language and were self-explanatory. There were also some reported ambiguities which are outlined in Table 10.3.

Ambiguity	Participant
Guideline 6: Are the goals focused on the sibling or the AAC user?	Jennifer
Guideline 9: Who does the word 'expert' refer to?	Amy
Guideline 7: How strong the evidence needs to be to be considered appropriate to teach?	Amy

Table 10.3 Wording Ambiguities as Noted by Participants

10.8.2.2.8 Suggestions of additions to the Guidelines

Survey respondents were asked if they thought there was anything missing from the guidelines. Six (50%) reported not thinking anything was missing. Two participants reported that they would have liked specific activities or other child friendly resources. Three participants suggested the inclusion of the voice of the AAC user or getting their consent for their sibling to be involved. One participant suggested case examples would be beneficial to contextualise the information, and also for practitioners to consider including a discussion around the diagnosis of the AAC user and any expectations around their potential gains from an intervention.

This topic was also discussed in the interviews and focus groups. Like the surveys, activities/resources and the consulting with the AAC user were mentioned. Other ideas that were discussed during the interviews and focus groups were home visits, a consideration of what to do if the sibling has their own difficulties, and a sibling contract or profile prior to the intervention to gather some basic information and ensure siblings know what they are agreeing to do.

"I wonder if, as part of that, presuming that it's on a busy caseload where you don't know any siblings, if there was even like a sibling profile to be completed by the sibling themselves, something very, you know, age appropriate, like my three favourite things in the world, some something that would get their interests. And I suppose they're maturity level."

- Jennifer (Extract 10.9)

10.8.2.2.9 Summary of Findings

Participants expressed positive views and the majority of siblings reported that the guidelines represented their needs very well. SLTs reported that they found the guidelines useful, causing them to reflect on their practice. While participants overall were happy with the content and structure of the guidelines, they had several ideas on what improvements could be made:

1. While the structure of the document should remain the same, with the guidelines expanding and collapsing, visuals or colour coding would be beneficial to aid in understanding of a disseminated document.
2. The amount of information under the guidelines should remain the same in bullet point format, but additional information and statistics could be provided in an appendix in the final disseminated document.
3. Some ambiguities around specific wording of the guidelines should be resolved.
4. Information regarding the voice of the AAC user as key stakeholder should be included under Guideline 9. *An 'expert' AAC user or sibling should be recruited to act as a co-trainer.*
5. Information suggesting home visits as an alternative to in-clinic sessions should be mentioned under Guideline 13. *The timing of the intervention should fit with the sibling's schedule.*

Guidelines are a beneficial, practical method of disseminating information. The key findings of this research were summarised and structured as 14 guidelines for SLTs to consider when supporting the engagement of siblings of AAC users with interventions. These guidelines highlight the practical implications of the research findings for SLTs, and the feedback collected from key stakeholders further reinforces the benefits that these guidelines could have on SLT practice.

10.8.3 The Guidelines

These guidelines represent practical ideas for SLTs to consider when supporting engagement with siblings. As such, these guidelines are written as a stand-alone document for SLTs and contain a summary of the key, practical findings of this research. The feedback from SLTs and siblings, as discussed above, have been incorporated into these revised draft guidelines. Suggestions referring to changes to the structure of the document itself were not included into these draft guidelines as they are relevant to the final dissemination of the document rather than as part of this research.

How to support the engagement of siblings of AAC users in communication partner training interventions?’

These guidelines are designed to be flexible. There are no restrictions to who these guidelines apply, for example regarding the sibling, family, AAC user or AAC system. The numbers in brackets correspond to the information data source.

- 1: Systematic Review of Sibling Involvement in interventions for individuals with a disability
- 2: Systematic Review of Peer Communication Partner Interventions
- 3: Surveys of key stakeholders: typically developing adolescents, parents/guardians and Speech and Language Therapists (SLTs).
- 4: Interviews with siblings of AAC users

Guidelines

- 1. Siblings of AAC users should be supported and included in interventions, if they want to be.**
 - Siblings are often similar in age and may spend a lot of time together, with a relationship that can span many years.
 - Siblings have been reported to want to get involved in, as well as both enjoying and benefiting from intervention – although there are very few, if any, studies

within published literature which look explicitly at training siblings as communication partners (1,2, 3, 4).

- Similarly, few SLTs reported actively including siblings in their interventions, despite identifying potential benefits to this(3).
- Siblings of AAC users did report to have been involved in Speech and Language Therapy throughout their lives, though not necessarily in targeted communication partner interventions (4).

2. The additional roles and responsibilities siblings may be expected to take on following a communication partner training must be reflected on.

- Siblings may be expected to take on the role of 'teacher', being explicitly asked to teach the AAC user a specific word or skill. This runs the risk of increasing the difference in the power dynamic between siblings, especially if siblings are expected to evaluate and provide feedback as part of the intervention (1).
- Some interventions, rather than introducing this additional role of 'teacher' may focus on nurturing the existing roles of playmate/companion through teaching the sibling how to use general communication and social interaction strategies. These may aid the siblings to communicate and interact more effectively (1, 4).
- SLTs should reflect on how the training may impact on the mental health of the sibling, siblings should be regularly consulted with to ensure they are feeling positive and not overwhelmed by the training (1,3,4).
- Given that interventions are not consistently effective (1,2), SLTs must also plan on what to do if the intervention is not effective for a sibling pair. Siblings might feel disappointment if the AAC user does not make observable progress. SLTs can help to prevent this by setting clear expectations with the siblings and their family regarding the intervention, as well as providing time for the sibling to discuss any concerns.

3. The wider family environment should be considered when planning to include siblings in an intervention.

- Due to Speech and Language Therapy service provision in Ireland focusing primarily on children, it is reasonable to assume that siblings attending an intervention may be under the age of 18 (1,2,3,4).

- Therefore, it would more than likely be parents/guardians who are initially informed of the training, as well as them encouraging and facilitating their child to attend the session(s) (3,4). This is especially true for younger siblings.
- Parents/Guardians (and any other key stakeholders, including the AAC user and other siblings) need to be considered and consulted with when deciding on the structure, timing, and goals of the intervention (3,4).
- SLTs should also be aware of any expectations arising from family members concerning the intervention itself and the role and responsibilities of the sibling following the intervention (3,4).

4. The intervention must be motivating for siblings to be willing to attend.

- Motivating siblings to attend the training, as well as to continue to attend the training and participate in sessions is one challenge faced by SLTs (3).
- Some siblings might be intrinsically motivated to attend a training, reporting to want to help their sibling (3, 4).
- Other siblings may require extrinsic motivation to attend. Knowledge of what they would learn from the training, having friends or others they know attend the training and thinking the training would be fun were reported to be motivating factors (3).
- Age may have a factor in the motivation of siblings to want to attend a training. Some siblings of AAC users reported that they were more likely to have an interest in being involved in sessions as they grew older, towards later childhood and early adolescence (4).

5. The intervention should be enjoyable for siblings.

- Enjoyment may lead to increased motivation to continue with the intervention and a willingness to be involved future interventions, as well a willingness to generalise what they learned into day to day lives (1).
- Adolescents and parents/guardians were asked what would make a training enjoyable. They reported that completing the training alongside similar aged peers and incorporating other activities or a theme into the sessions, for example sports or group activities outside of the clinic room (3,4) would increase enjoyment.

6. The intervention goals should be specific to the needs of the sibling, created collaboratively and communicated well to key stakeholders.

- SLTs should collaborate with key stakeholders (parents/guardians, the AAC user, and especially the siblings themselves) to create the goals of the intervention. This can ensure that the training is tailored specifically to the siblings and their current strengths and needs. Goals may be focused on the sibling or the AAC user.
- Siblings will have had different experiences with AAC, and as such will have different levels of competence and confidence with the AAC system and communicating effectively with the individual using it (2, 4). The SLT should ensure to gain an understanding of the sibling's baseline knowledge, experience, and opinions of communication and AAC prior to the intervention.
- Clear goals and evident progress may aid in making a training more enjoyable and motivating for participants (3). As such, if the goals are not created collaboratively, they need to be very clearly communicated to parents/guardians and siblings, both during recruitment for the training and re-iterated during the sessions themselves.
- Individuals reported wanting to help their sibling, so it is important to ensure participants (and parents/guardians) are informed on exactly how the training could benefit them and their sibling (3,4). This also aids in setting clear expectations for the training to avoid disappointment, either with the content or the results of the training.

7. All strategies taught during the training should be based on research evidence.

- The strategies taught during the training should be evidence based, for example modelling, expectant delay, and open-ended questions.
- In a systematic review of peer communication partner interventions, researchers were reported to teach general communication strategies (e.g., the stay-play-talk procedure) and more specific AAC strategies (e.g., prompting, modelling, and waiting) (2).
- SLTs were asked about the strategies they covered during communication partner trainings. Every participant mentioned teaching the strategy of modelling, or aided language stimulation. This was followed by pause

time/waiting, creating communication opportunities, expanding, and the hierarchy of prompts (3).

- When deciding on what to teach the siblings, it is important to not only consider the research evidence as above, but also clinical expertise and the preferences of the siblings, AAC user, and their parents/guardians. SLTs should consider what the siblings already know and build from there (4).

8. The teaching techniques used to facilitate learning during the intervention must cater for the participant's learning styles.

- Different individuals can benefit from several styles of learning when understanding new information.
- When asked about learning something new, adolescents and parents/guardians reported seeing it in action or having a chance to do it themselves as the best ways to learn (3).
- The most popular instructional techniques reported by adolescents were having someone show them how to do the skill and having a chance to practice the skill themselves (3).
- SLTs reported demonstrating in real time how to do the strategy, providing information sheets to take home and describing the strategy in detail when teaching an AAC communication partner strategy (3).
- The top instructional techniques reported in studies involving peer communication partner interventions were demonstration of the strategy, a description or the rationale behind why the training or specific strategy is important, the peer participating in a roleplay, time for questions or feedback from the session and providing printed materials (2).

9. An 'expert' AAC user or sibling should be recruited to act as a co-trainer.

- One of the top techniques for facilitating learning reported by adolescents was hearing from someone who has first-hand experience of how their communication difficulty impacts them and how others could help (3).
- SLTs did not report regularly including AAC users in their communication partner interventions (3).
- SLTs could consider including an AAC user as a co-trainer during the intervention to provide an expert opinion on the topic. This may involve

meetings with the AAC user prior to the training to discuss their role in the training and programme vocabulary/messages if necessary.

- A sibling who has already underwent the training may also act as the expert co-trainer (3)

10. The training could take place online and/or in-person, and individual preference should be considered.

- Due to the recent COVID-19 pandemic telehealth facilities have become increasingly popular.
- SLTs reported a preference for a hybrid online and in person approach to communication partner training (3).
- The majority of adolescents and parents/guardians would prefer for the training to be held in person, with the perceived effectiveness of face to face versus online teaching, the ease of asking questions and the increased chance of engagement cited as the main reasons for this (3). *

*This survey data was gathered as the country emerged from a lockdown, with virtual classes being held frequently and so may impact on the results.

11. The training could take place in a 1-1 and/or a group setting, and individual preferences should be considered.

- There are no indications in the literature as to whether group or individual intervention is more beneficial for communication partners (1,2).
- Individual sessions may be utilised if there were specific goals regarding a particular individual or AAC system, while group intervention was more likely to focus on general interaction and communication strategies and peer support (1,2).
- Siblings of AAC users, while reporting seeing the value of attending a training, had different opinions on whether they would prefer a group or individual training (4).
- SLTs and adolescents reported preferring for the training to take place in small groups of 3 to 10 peers with adolescents citing peer support and reduced pressure as the main reasons (3).
- However, more parents/guardians reported preferring the training to be structured as a 1-1 training, referring to the opportunity for the session to be

tailored for their child as well as a lack of distraction from other children as the primary benefits (3).

12. If a group training method is being utilised, the composition of the group must be carefully considered.

- The opportunity for peer support between the siblings is an important consideration if the training is facilitated in a group setting.
- There are no indications in the literature regarding how best to group communication partners (1,2).
- Some important considerations (4) when grouping siblings to ensure they can relate to one another and provide genuine opportunities for meaningful peer support include:
 - siblings of similar age
 - siblings of the same birth order (e.g., being an older or younger sibling)
 - siblings of individuals who use similar AAC systems
 - siblings of individuals who have similar communicative abilities
 - siblings of individuals who have similar diagnoses (e.g., autism, cerebral palsy etc.)

13. The timing of the intervention should fit with the sibling's schedule.

- Siblings lead busy lives and attending a training might not be a priority compared to their own schoolwork or extracurricular activities (4).
- To ensure maximum attendance and participation from the siblings, the training should be organised for a time that best suits them, preferably a weekday evening or weekend (3). This was reported as being primarily due to school, college, or work commitments.
- Home visits might be an option to remove the need for siblings and parents to travel to a clinic, thus allowing more time for the intervention.
- SLTs have the responsibility to ensure the timing fits with the sibling's schedule, while still being mindful of service constraints. Evening and weekend sessions were ranked as the least frequent times offered for sessions (3).
- A compromise could be to hold the training during a school holiday (3).

14. The structure of the intervention should be flexible.

- There is no best practice or even consistent guidelines for how to structure a communication partner intervention in the literature for peers (2).
- Adolescents and parents/guardians reported that they would be willing to commit two to four hours per month to an intervention, with a preference for multiple short sessions rather than one or two long sessions (3).
- Adolescents, parents/guardians, and SLTs were asked if the training was 4 hours in length, what would be their preferred structure. The overall preference was for one-hour sessions, once a week for four weeks.
- The reasons for this preference included consistency, short sessions equating to better concentration, time between sessions to practice and shorter sessions being more manageable (3).
- Siblings and parents/guardians may have personal opinions on what would suit them best and SLTs should consult with these key stakeholders to ensure the structure of the communication partner training is the best possible for all involved (3,4).

Chapter 11: Conclusion

11.1 Introduction

This final chapter presents a summary of the research, answering the primary research question of *'how can SLTs support the engagement of siblings of AAC users with communication partner training interventions during childhood and adolescence?'*. This summary is then followed by a critical assessment of the research and recommendations for future research.

11.2 Summary of the Research

This study focused on the engagement of siblings of AAC users, which to my knowledge, is the first study to investigate this topic to date. Siblings of AAC users are a unique cohort who have, thus far, been relatively ignored in research (Gill, 2020). Past research evidence of sibling experiences has concentrated on other disabilities (e.g., Correia & Seabra-Santos, 2022; Iannuzzi et al., 2022; Leedham et al., 2020) with only one study reported exploring the experiences of siblings of AAC users (Dew et al., 2011). Similarly, the focus of communication partner training interventions has been on parents and teachers more than siblings (e.g., Kent-Walsh et al., 2015; Shire & Jones, 2015). As such, our understanding of the experiences of siblings of AAC users, the factors impacting on their engagement with interventions (and therefore how SLTs may support engagement) was limited. This research aimed to fill this gap in the literature.

A framework of factors that support engagement of siblings of AAC users was created from a review of existing research on therapeutic engagement (Chapter 3 and 5). The framework included two key principles for engagement; creating a reciprocal and meaningful relationship and tailoring the intervention to the siblings' needs and preferences. Furthermore, family context surrounds the framework highlighting the importance of the family context as it relates to all aspects of the framework. This framework was then used as a basis for forming research questions specific to the factors influencing engagement. A convergent parallel mixed methodology design was used to answer the research questions and to understand how the engagement of siblings of AAC users could be supported. This design allowed for both qualitative and quantitative data to be gathered through four distinct data collection methods: a systematic review of sibling involvement in interventions for individuals with a disability, a systematic review of peer communication partner training interventions, interviews with siblings of AAC users, and surveys of key stakeholders. The findings of these four methods were then analysed and interpreted to answer specific research questions and

identify aspects which influence sibling engagement with an intervention. The findings provided extensive contributions to knowledge, as was outlined in Chapter 10 and will be further summarised in this chapter. The findings also identified many features which would contribute to SLT practice. These contributions were structured as guidelines for dissemination to SLTs, listed in Chapter 10.

First and foremost, the findings of this research underscore the need for more sibling involvement in communication partner training interventions. Siblings are key communication partners, often spending a lot of time with the AAC user and having a close relationship with them. In both the research (Chapter 6 and 7) and as reported by SLTs (Chapter 9), siblings are not frequently engaged with in interventions, yet the potential benefits of involving siblings have been acknowledged (Beffel et al., 2022; Chapter 9). When working in a family-centred practice model of care, the family as a whole, and its individual members, are the client (Health Service Executive, 2020). Siblings are a core family member (Mandak et al., 2017) and their needs, together with those of more traditional 'clients' i.e., the AAC user and parents, should be considered when planning interventions. However, siblings may not want to be involved in an intervention or may not require support from an SLT. To facilitate sibling engagement in these situations, the SLT role may be to gather information regarding the needs and perspectives of the sibling and family and then provide appropriate information to ensure they can make an informed choice regarding their engagement.

Secondly, these research findings illuminate several influences on sibling engagement. Due to the multifaceted, dynamic, and individualised nature of engagement (Bright et al., 2015), the findings are not a complete list of aspects that unquestionably influence the engagement of all siblings of AAC users. Instead, the findings highlight aspects to be explored further within the context of a specific sibling, family, intervention, and SLT. An understanding of what may be influencing sibling engagement allows for the SLT to identify potential barriers to engagement. The SLT can then attempt to mitigate these barriers by implementing changes to their practice to support sibling engagement in that individual context. The key influences of sibling engagement are briefly summarised below, along possible actions SLTs can take to support sibling engagement for that aspect.

11.2.1 The Nature of the Sibling Relationship

The sibling relationship itself may influence the sibling's engagement. Many sibling relationships are positive, and siblings report wanting to be involved and wanting to help. However, some relationships are not as positive, with siblings of AAC users having their

own needs and challenges. Siblings may not be in the position to engage with an intervention, for example Ella in her interview spoke about struggling to come to terms her brother's disability. In order to acknowledge the potential role of the sibling relationship on engagement, SLTs could inquire about the relationships between the siblings and collaboratively create intervention goals aimed at supporting the sibling relationship and targeting reported challenges. In addition, in group interventions, the SLT may support the engagement of a sibling by ensuring they are placed in a group experiencing similar challenges in their sibling relationship so that the siblings may benefit from peer support.

11.2.2 Sibling Roles

Siblings may occupy many roles in the lives of AAC users, two of which may be expert in communicating with their sibling and expert in AAC. A communication partner intervention may be designed to support siblings in these roles. However, if siblings are not already occupying these roles, an intervention may create an expectation for siblings to take on these new roles. For example, if a sibling learns how to model on the AAC system and prompt the AAC user, individuals in the environment may expect the sibling to complete these tasks more frequently and give them an added responsibility of explicitly teaching aided language to the AAC user. SLTs can reflect on the intervention they are facilitating to understand what roles participants are being asked to take on. In order to support engagement, SLTs may gather information regarding the sibling's current and expected future roles. This information could then be considered during a collaborative goal setting process to ensure intervention goals are targeted towards supporting the sibling's current roles rather than prematurely adding others. Within an intervention, SLTs may also include strategies focused on establishing role boundaries and supporting siblings to advocate for themselves on what roles they are willing to take on. Another important action when supporting engagement is the collection of feedback from siblings throughout the intervention to ensure they are not being overburdened.

11.2.3 SLT Beliefs and Practices

The SLT's own beliefs and practices may be impacting on their ability to support sibling engagement. SLTs may not be confident working with AAC users and in facilitating communication partner training. Additionally, SLTs may not consider involving siblings in interventions, or may worry about overburdening them (see above). In order to ensure they themselves are not a barrier to sibling engagement, SLTs can reflect on their own

experiences and skills in AAC interventions, communication partner training and working with siblings to understand if they require support or upskilling in a certain area.

Furthermore, the services SLTs work in may create barriers to sibling engagement. For example, SLTs may experience a lack of time, resources, and large caseloads with reduced staff numbers. An awareness of these service barriers to sibling engagement is crucial for SLTs when considering how to support sibling engagement. SLTs may have to think creatively to work around these service barriers. Alternatively, when experiencing these barriers, management in services may be appealed to; for example, requesting protected time to work and collaborate with siblings.

11.2.4 Intervention Content

The intervention content is a key aspect which may influence engagement. The content of the intervention should be not only relevant and beneficial to the AAC user, but also to the sibling and the family as a whole. Goals should be created collaboratively with the sibling and family to ensure they are relevant to them. Additionally, the goals should be measurable and clearly communicated so that progress in an intervention can be measured and observed by all stakeholders. There are many different strategies which may be taught to siblings, for example general communication strategies, prompting, modelling, pausing, and waiting, and in order to appropriately support engagement, SLTs should be aware of which strategies are both relevant and have the potential to support a positive intervention outcome. To support the cognitive aspect of engagement, i.e., the sibling knowing what they are doing and why it is beneficial, SLTs could also explain the rationale behind the strategy.

11.2.5 Intervention Setting

The intervention setting was highlighted as an important aspect which may influence sibling engagement. Siblings may be less interested in attending a standard training in the clinic than if the training is structured around fun and motivating activities. Some examples of these which emerged from the findings were having a theme to the intervention (e.g., sport) or including fun activities outside of the clinic room, for example kayaking. While service constraints may limit what is possible for the SLT to organise, SLTs could still investigate what the siblings enjoy and collaborate with them and their families to make the intervention enjoyable and thus support their engagement.

Another aspect of intervention setting which may influence the engagement of siblings is whether the intervention is online or in person. The findings did not lead to a

definitive result of which setting is preferred by all stakeholders, although in person training was preferred by many. One way to support sibling engagement would be to investigate individual siblings' and families' preferences of online vs in person training. SLTs could then take this preference into account when planning an intervention to avoid this aspect becoming a barrier to engagement (e.g., siblings not attending the intervention because it is online or not being able to attend in person due to the travel to the clinic). Alternatively, SLTs could consider a hybrid approach to the training, with some online and some in person aspects to the intervention if they were unable to accommodate for all preferences.

11.2.6 Intervention Timing

Another aspect which emerged as potentially influencing sibling engagement is the timing of the intervention. There is a discrepancy between what suits adolescents and parents (e.g., evenings and weekends) and when SLTs work (e.g., weekday mornings and afternoons). Siblings cannot be expected to regularly forego their own activities and schooling to attend an intervention, and parents have busy lives too. Interventions should strive to suit the schedule of the sibling and family to minimise the likelihood of the intervention timing to be a barrier to sibling engagement. Clinically, SLTs could collaborate with siblings and families on what times would suit them to attend and organise appointments accordingly. SLTs may have to consider working outside of traditional working hours, or else compromising and facilitating interventions during school holidays when it might suit all stakeholders.

11.2.7 Group or Individual Training

The structure of a training, be it group or individual, may influence the engagement of child and adolescent siblings of AAC users. Group interventions may provide peer support and increase the participant's enjoyment of an intervention. However, this may not always be the case for all siblings – some may dislike participating in group situations due to social anxiety or may perceive themselves to be too different from other participants in the group. To support sibling engagement in a group training, SLTs could encourage siblings to bring a friend along if they would feel more comfortable, gather information about sibling experiences, needs and goals to ensure siblings may relate to one another or group families together.

11.2.8 Individual Learning Styles

There are different ways in which siblings may learn best, and this is one aspect which may influence their engagement. Some individuals may know how they learn best, for example hearing a description of a strategy, seeing it in action or doing it themselves. Alternatively, some individuals may have a preference in how they learn, for example hearing from 'experts' or role playing. Some siblings may feel uncomfortable in whole group discussions and taking part in role plays, while others thrive in those context. In order to support sibling engagement, SLTs could investigate sibling preferences about what they feel comfortable doing and how they learn best and strive to accommodate these. Alternatively, in a group training during which it may not be feasible to accommodate for all individual learning styles separately, a combination of strategies could be used (e.g., description, demonstration, role play, time for questions and giving feedback) to ensure all participant's learning styles are at least somewhat catered for.

11.3 Original Contributions to Theory and Practice

This research provides an original contribution to both theory and practice. Regarding the contribution to theory, this research extends the knowledge on therapeutic engagement as it relates to siblings of AAC users and provides important insight into factors which need to be considered when supporting the engagement of siblings of AAC users. A novel framework was created to structure these factors. This framework and the findings of this research reinforced important concepts in other engagement theories (e.g., multifaceted and co-constructed nature of engagement and the importance of relationship in supporting engagement), but also added to the therapeutic engagement literature by exploring aspects of engagement which are specific to siblings of AAC users. Additionally, the research findings also extend the theories of family systems theory (Kerr & Bowen, 1988), ecological systems theory (Bronfenbrenner, 1977), and Mandak et al.'s (2017) theoretical framework by considering the centrality and importance of siblings of AAC users specifically, and how family systems and ecological systems are relevant in this unique context.

This research not only provides original contributions to theory, but it also provides an important, and original, contribution to clinical practice. The practical implications of the research findings were summarised into guidelines for SLTs. To the researcher's knowledge, these guidelines for SLTs are the first which focus on engaging with any siblings, not just siblings of AAC users. These guidelines may provide valuable information for SLTs working with AAC users, and feedback was collected which

reinforced the value of SLTs having access to practical guidelines to support their clinical work.

11.4 Critiques of the Study

To my knowledge, the engagement of siblings of AAC users has not been studied to date. This study adds to the research base by exploring how sibling engagement with interventions may be supported. This mixed methodology research with data gathered from existing research and key stakeholders highlights factors which may impact on sibling engagement and ideas of how sibling engagement, in general, may be supported. However, like any research, this study is not without its limitations. First, while the framework created as part of this research was based off previous research of engagement, the studies were focused on either youth with disabilities (King et al., 2022) or with parents (Klatte et al., 2020; Melvin et al., 2023) only. There are distinct differences between siblings and both these groups. Compared to youth with disabilities, siblings do not have a clear need to engage in an intervention and the intervention goals may not be focused on benefitting them. Furthermore, compared to parents, young siblings are not often primary caregivers, a role which implies a need for support and an expectation to engage in training to help the youth with a disability. As such, there may have been some aspects specific to siblings which may not have been included in the framework. Similarly, the engagement research was not focused on AAC users and their communication partners, and so aspects unique to engaging with communication partners may also have been overlooked. A grounded theory approach (Corbin & Strauss, 2008) to creating the framework may have mitigated this limitation. However, this methodology was decided against as time constraints did not allow for both the construction of an inductive and comprehensive theoretical framework as well as answering the primary research aim of identifying ways in which engagement can be supported.

Another limitation to this research focuses on the generalisability of the findings. Due to the dynamic and individualised nature of engagement (Bright et al., 2015; D'Arrigo et al., 2020; King et al., 2014), no one framework could ever capture the array of methods in which a specific individual's engagement may be supported. While the findings of this study identified several factors in supporting engagement for siblings of AAC users, these are not universal to all siblings, families or SLTs. Instead, the findings must be interpreted further in the specific context, taking into account personal experiences, needs and preferences (King et al., 2022) to understand how best to support an individual sibling's engagement with an intervention. This perspective has implications

for the practical application of the findings of the research reported here. While guidelines were listed in Chapter 10 as a potential avenue for dissemination of the findings, these do not give a definitive answer of what to do when engaging with siblings. Instead, the guidelines provide factors for SLTs to consider, and ideas of what to probe further when engaging with siblings. Practically, this may not suit all SLTs as some may prefer a list of prescriptive steps to complete to support the engagement of all siblings (e.g., Robin feedback focus group participant).

A final limitation to this research was one which was unavoidable due to the context of when the research was carried out. As mentioned throughout this thesis, a large portion of this research took place during the COVID-19 pandemic. The public health restrictions of the pandemic led to limitations in how recruitment and data collection could be carried out. Due to the restrictions and social distancing measures, all data collection had to be completed online. While providing increased flexibility to participants, online methods may have impacted on who participated in the research. Participants needed internet access and those who were familiar with video conferencing software may have been more likely to participate than those who were not comfortable working with new technologies. Additionally, online interviews and focus groups may have limited the scope for observation of the body language of the participant (Foley, 2021). Furthermore, the public health restrictions resulted in increased time taken to recruit participants for the interviews. The mixed methodology design of this research, specifically a convergent parallel design (Creswell & Plano Clark, 2017), allowed for some flexibility in the research timeline (e.g., moving up data collection for other sections of the research not focused on collecting primary data). Nevertheless, the increased time needed to recruit participants resulted in less time available to complete the actual data collection and also impacted on the ability to complete further recruitment activities after only four participants were identified from initial recruitment efforts. Recruitment was a challenge in all aspects of this research, potentially due in part to the COVID-19 pandemic and the disruption it caused to the lives of many individuals.

One important final critique of this research is the lack of the voice of the AAC user. When making decisions regarding AAC, stakeholder opinions and preferences are only one of many considerations. Key to these decisions should be the voice of the AAC user (Lorah et al., 2021). Schlosser (1999) highlights the fact that while there is an increased emphasis on gathering stakeholder feedback on interventions, this has not been evident in the AAC literature. This article was written over 20 years ago and still for the direct stakeholder, AAC users, this hasn't changed. In the current research, it was important that siblings were given the opportunity to have their say, but AAC users should also be given this opportunity. As discussed in the introduction, the initial intention was

to gather data from AAC users as well. However, due to the COVID pandemic restrictions this data collection was not feasible in the timeframe of this research. It is hoped that future research may allow for this data to be gathered.

11.5 Future Research

This study highlights the need for further research in several areas, both theoretically and clinically. First, this research represents one of very few studies focusing on siblings of AAC users. The experiences of adult siblings of AAC users have been recorded (Dew et al., 2011), and this study adds to this research base through data collected from interviews of adults and one 17-year-old sibling. However, the experiences of younger siblings of AAC users, to my knowledge, have not been recorded in the literature. Future research could focus on understanding the experiences of child and adolescent siblings of AAC users, to better understand their particular perspectives and identify methods of supporting interventions specific to them. This information could be used to further develop the framework created as part of this research.

Another aspect of future research is gathering information from a key stakeholder – AAC users. To the researcher's knowledge, there has been no research which explores sibling relationships from the point of view of the AAC user. Future research could strive to fill this gap by gathering data from AAC users themselves regarding their experiences with their siblings, as well as their opinions on the relationship and roles within the sibling dyad. Specific to the findings of this research, future research could aim to gather the AAC user's feedback on the framework or guidelines.

Additionally, the application of this new framework with other populations could be investigated. While the framework was designed with siblings of AAC users in mind, future research could explore the applicability of the framework to other sibling groups, for example siblings of individuals who stutter, individuals with developmental language disorder or individuals with severe speech sound disorder. Furthermore, the framework was designed for sibling engagement with a communication partner training intervention, and future research could investigate the use of the framework with other sibling interventions, for example social skills groups or sibling support groups.

The key findings, as they pertain to SLTs engaging with siblings of AAC users, were outlined as practical guidelines in Chapter 10. While feedback on the guidelines was gathered from key stakeholders as part of this research, participants were asked their opinions of the guideline document. Participants did not facilitate a training for siblings based off these guidelines. Future research could investigate the guidelines as a practical resource for SLTs, exploring if they are beneficial in a clinical setting and what

changes could be made to improve their functionality. Additionally, data could be collected from AAC users, parents, and siblings themselves pre and post intervention in order to inform planning and to gather feedback from the stakeholders, similar to the data collected by Grace et al., 2023.

11.6 Concluding Remarks

Before undertaking this PhD, I did not fully expect the profound impact it would have on my life. I did anticipate that my research skills would develop. However, I didn't expect to learn quite so much – a naïve perspective in hindsight. I had never completed a convergent parallel mixed methodology study previously and it led me to develop knowledge and skills in not only conducting a mixed methodology study, but also within each of the individual components. For example, my skills in completing systematic reviews, implementing framework analysis and integrating the findings of multiple different research components and data collection methods all improved. As a researcher during the period of the COVID-19 pandemic, I learned how to adapt to, and act creatively to overcome, the unprecedented challenges that I faced.

However, this research journey had a bigger impact on my clinical practice. When reflecting on my own practice I realised I, too, engaged with siblings on a surface level, involving them in activities and games with service user if they were present in the session. I worked in a family-centred model, with family as the client, but never gave a thought to the sibling as being the client too. My practice has now changed. Unfortunately, my current role does not provide me with the opportunity to facilitate group sibling communication partner training interventions. Nevertheless, I engage with siblings individually where possible, making an effort to understand the sibling dynamics with any family that I am working with. During goal setting, when discussing family goals, I probe to identify the sibling goals rather than just parent goals. I collaborate with parents, siblings, and service users to understand what intervention structure would best fit with their lifestyles and to see how I may be able to adapt my service to suit them. I strive to provide siblings with an informed choice as to whether they want to be involved in the sessions, and if so, what role they want to occupy and what they want to learn.

This PhD has provided me with countless learning opportunities and has given me the chance to develop my knowledge, skills, and practice. It has provided me with good foundations for learning which I know I will continue build on, both as a researcher and a SLT.

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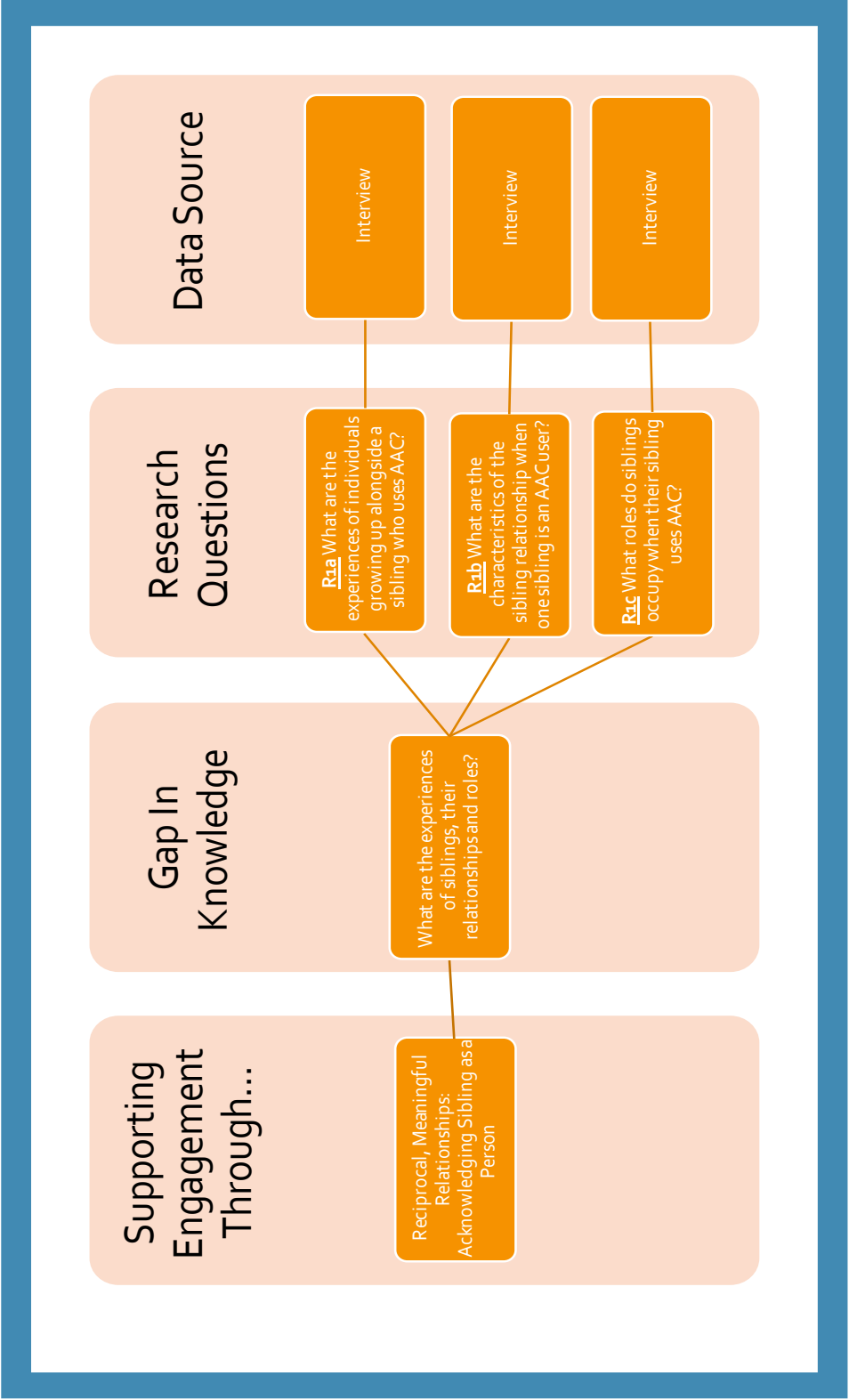
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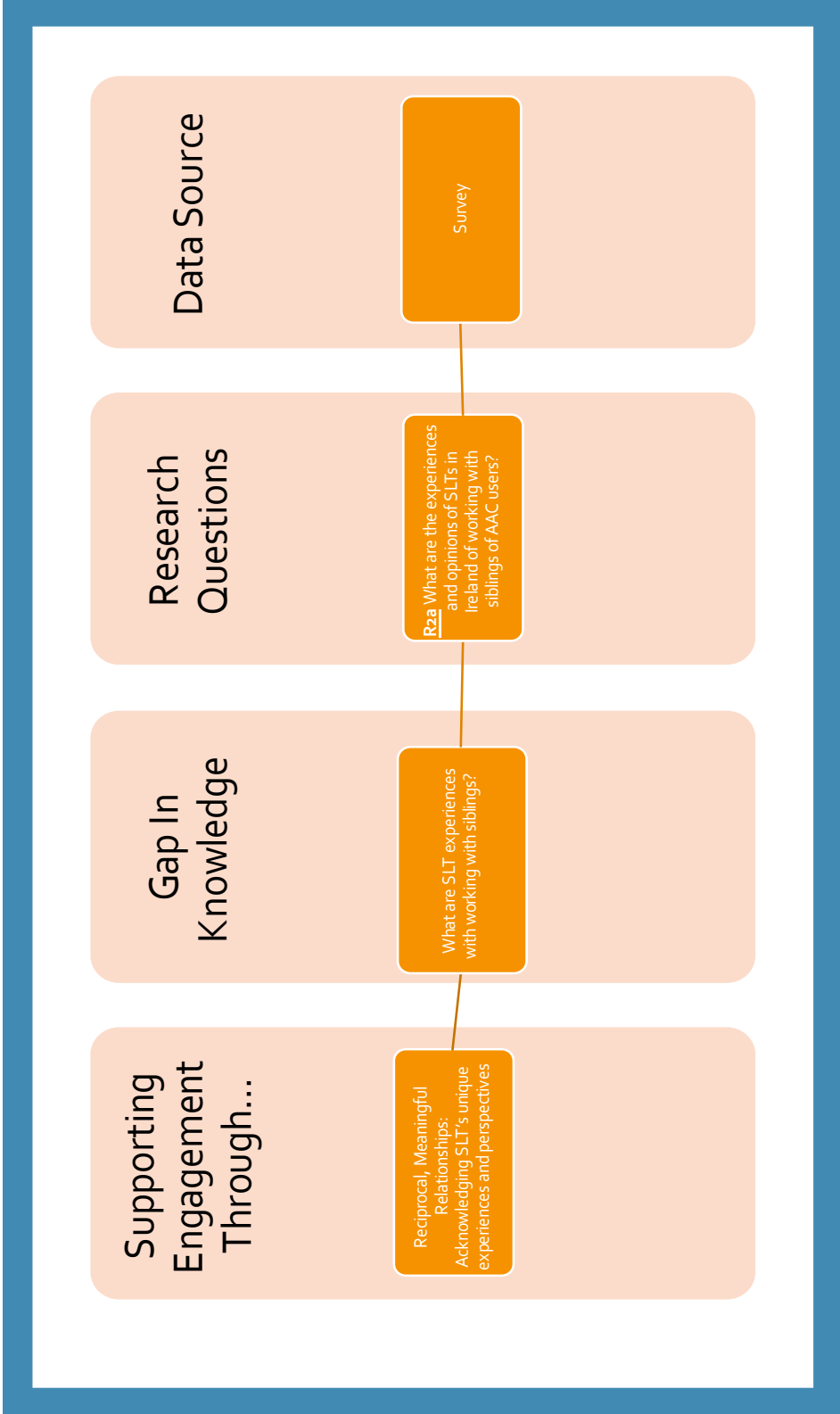
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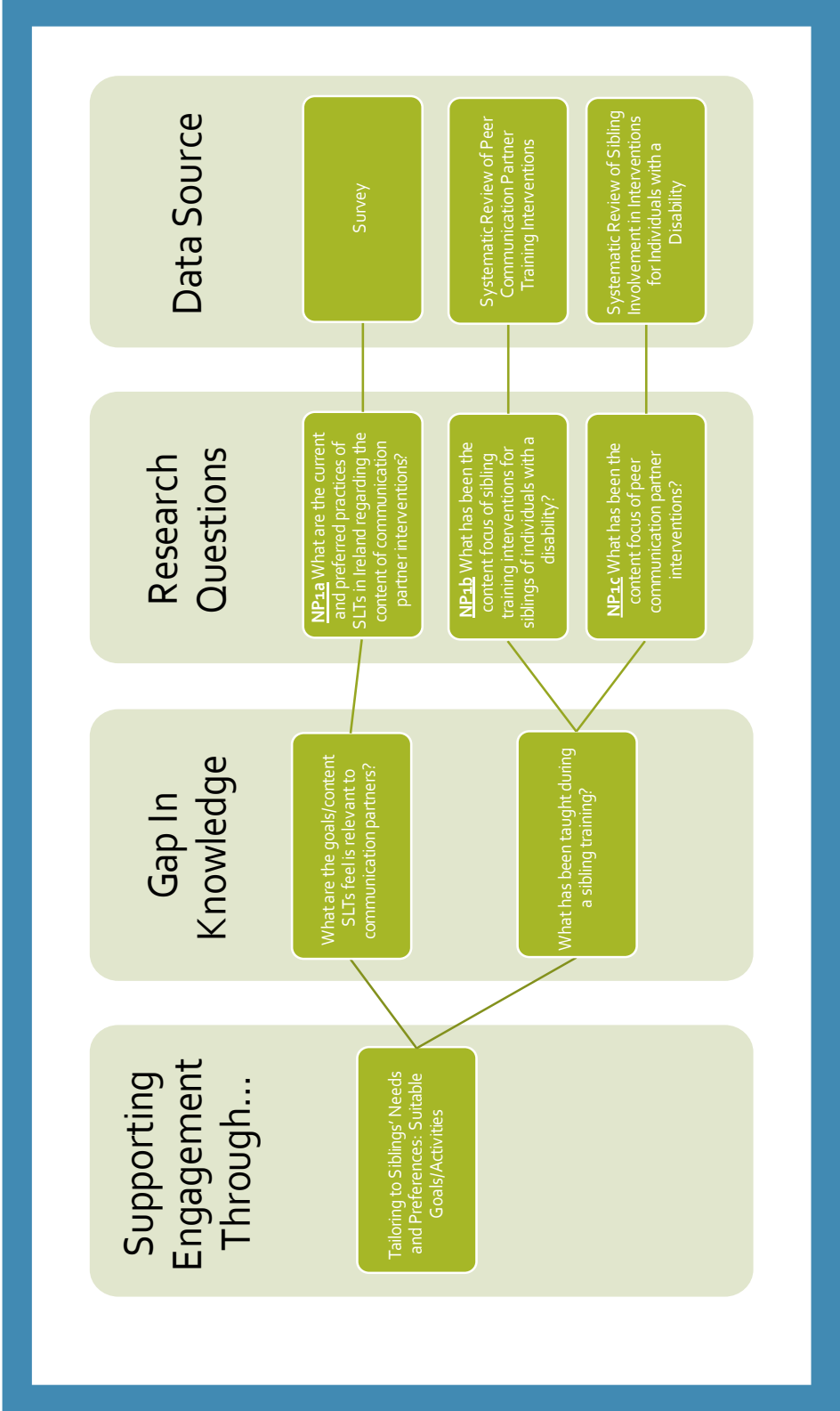
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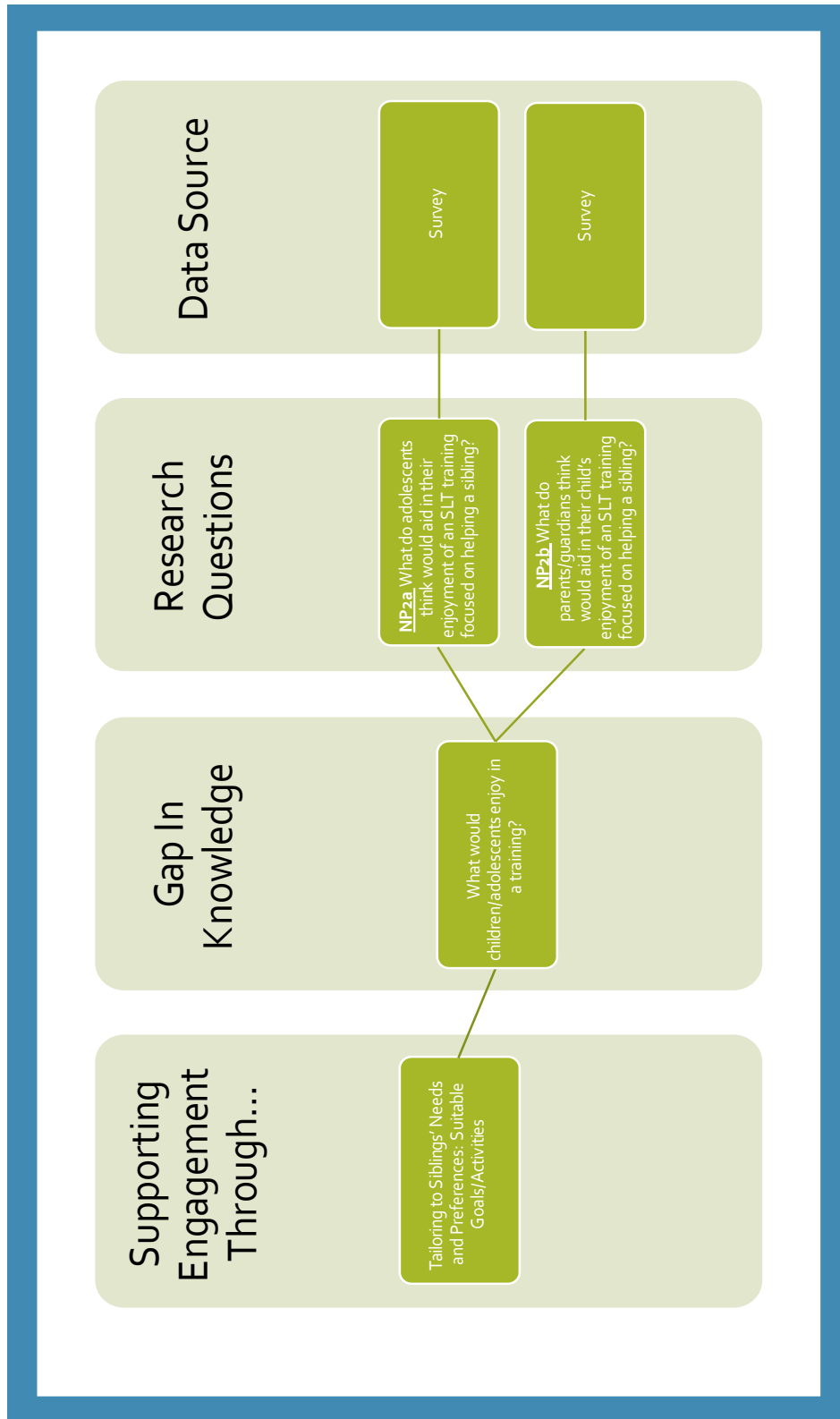
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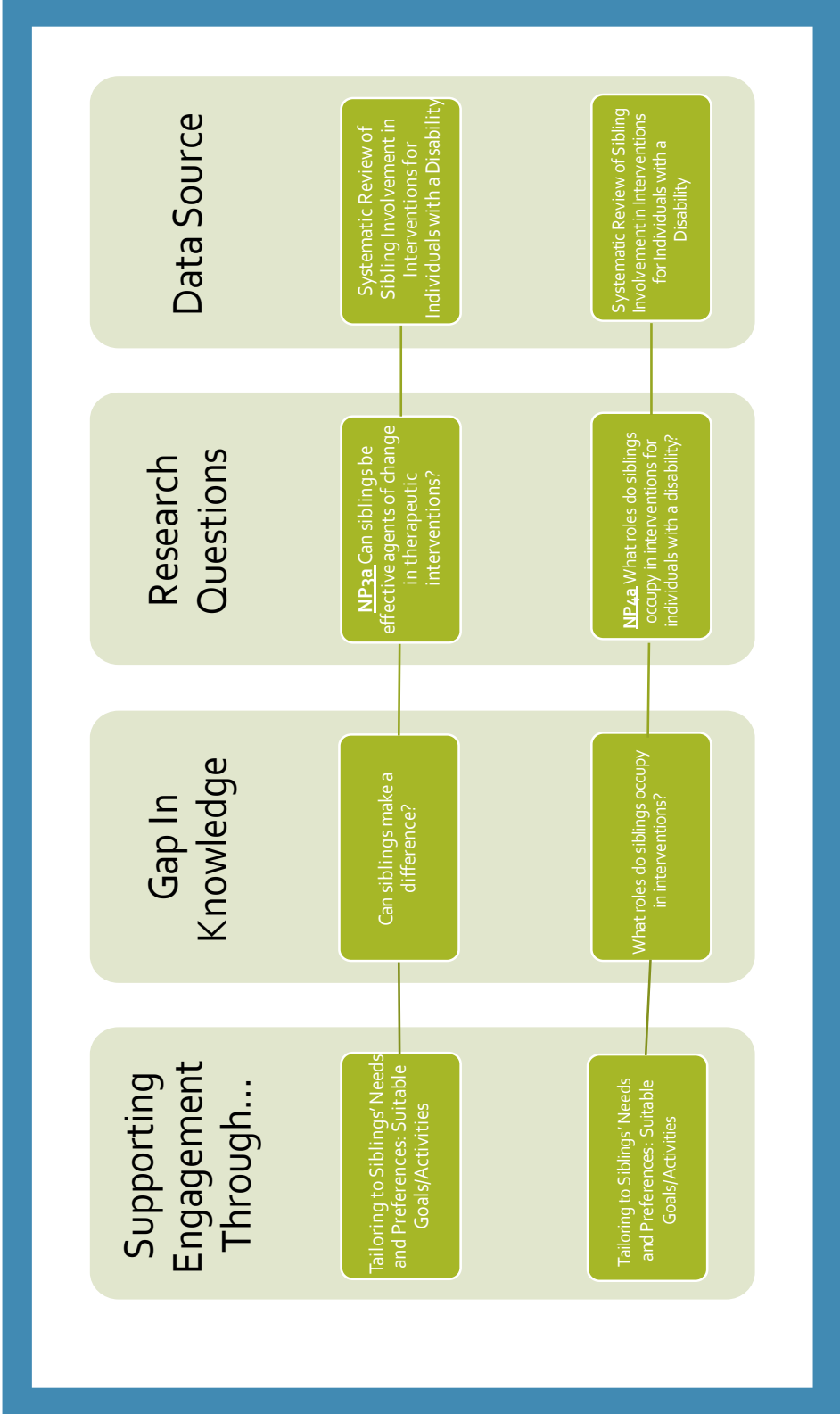
Appendix A. Decision Making Process from Factors Supporting Engagement to Data Sources

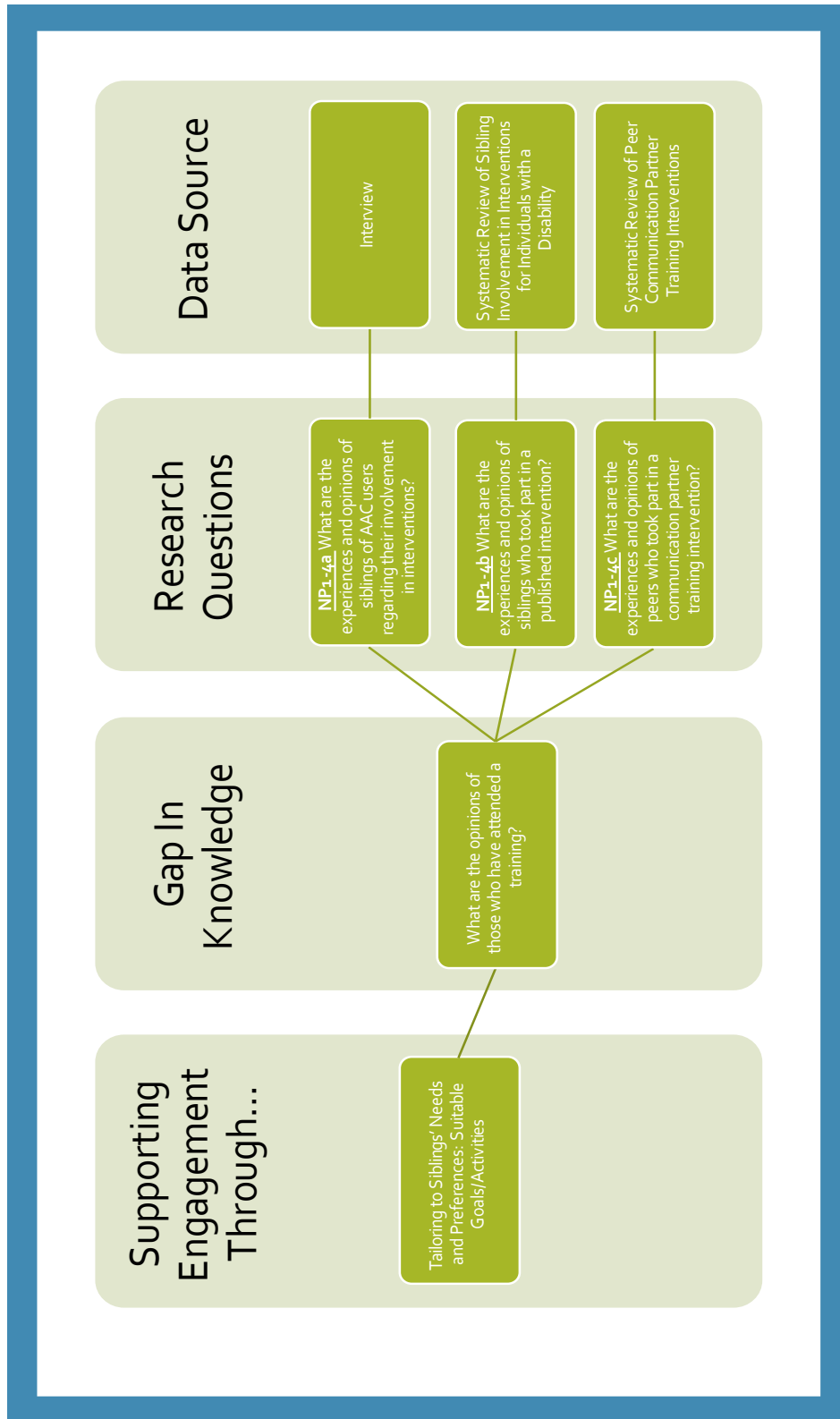


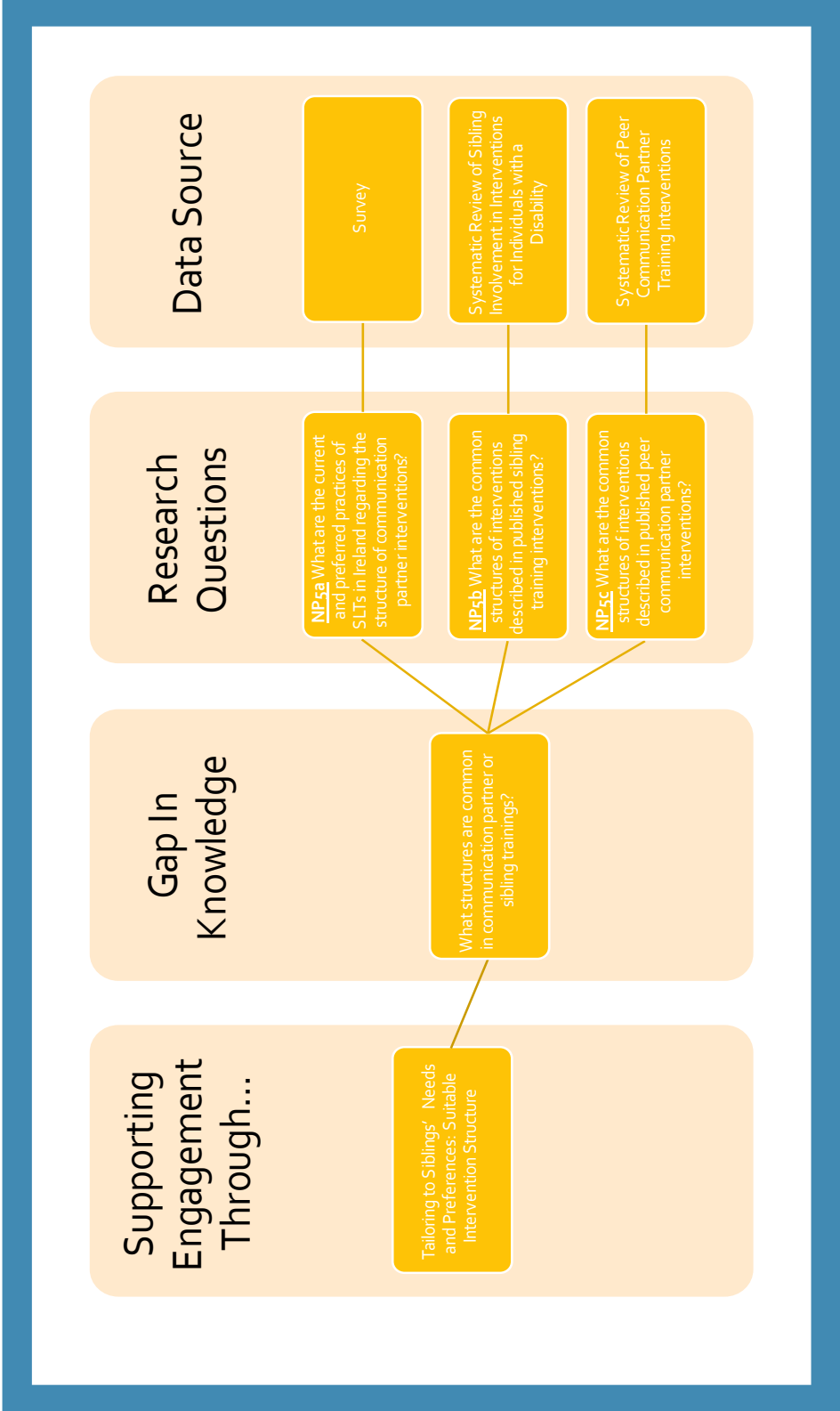


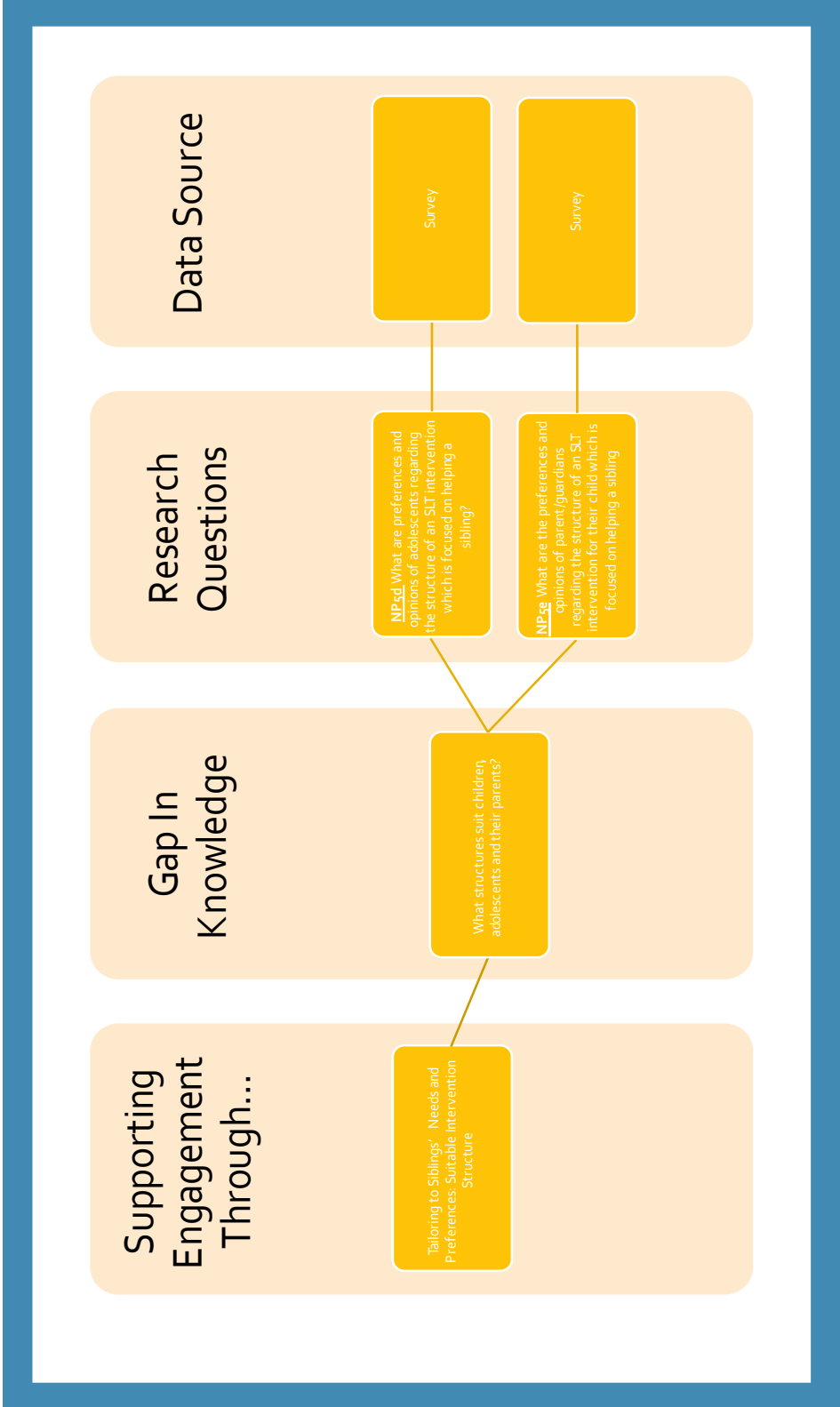


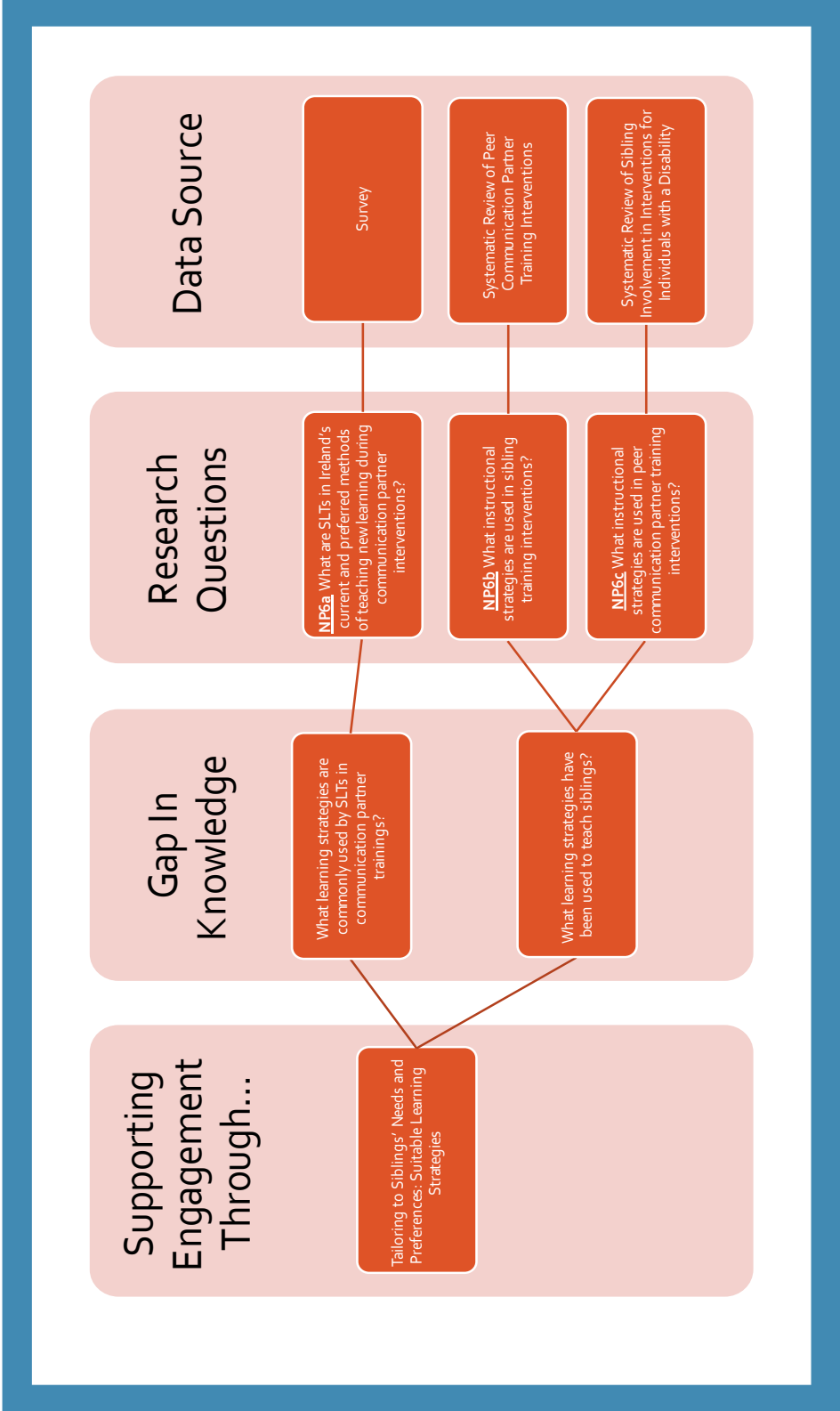


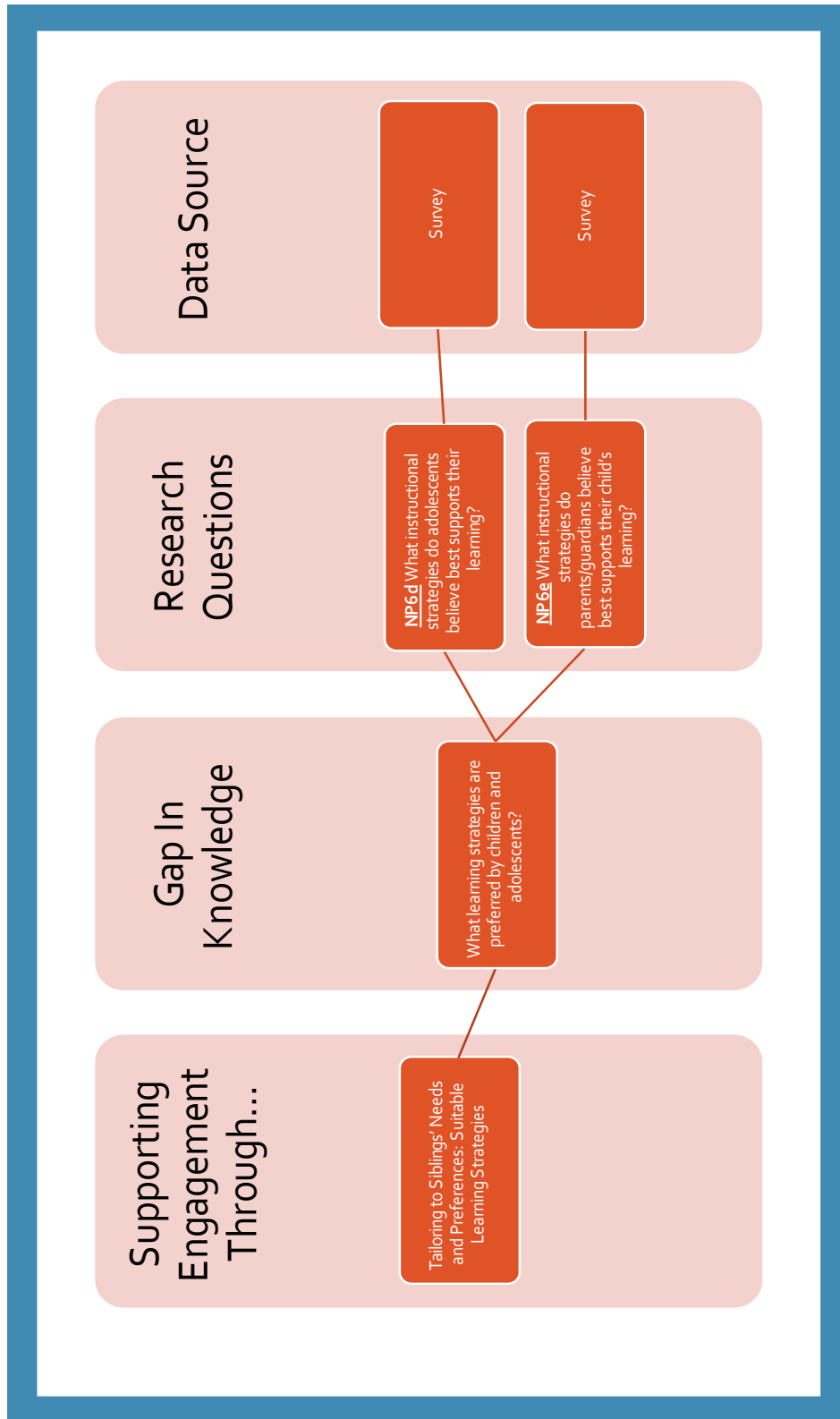












Appendix B. Approved Pre-Publication Copy of Systematic Review of Sibling Involvement (Lynam & Smith, 2022)

Introduction

For many individuals, bonds with siblings constitute their most enduring relationships, spanning infancy to old age. No two sibling relationships are the same. Differences may be attributed to individual characteristics such as age, gender and personality. In addition, external factors such as living circumstances, family size, birth order, time spent together and type of sibling (e.g. step siblings, half siblings, foster siblings) may also influence the relationship. The relationship itself is typically established and fostered in the home, within the context of the family unit as a whole. The roles that siblings may play in their relationships with each other can vary and change over time, including roles as companion, advisor, confidant, competitor, protector and carer [1-4].

The role of sibling as carer is especially relevant when one sibling has a disability. For the purpose of this review, the World Health Organization's definition of disability (i.e., "when any physical or mental impairment interacts with contextual factors (environmental and personal variables) to limit activities and participation in daily life" [5,p.213] will be adopted. A disability can be present from birth, (e.g., Autism Spectrum Disorder, Down syndrome) or develop during a person's life (e.g., an acquired disability such as Motor Neurone Disease or Spinal Cord injury). As such, the presence of a disability can shape sibling relationships from the outset, or alternatively redefine those relationships.

There are several different types of sibling relationships, including siblings who share both or one biological parent, and sibling relationships where there may be no biological relationship including step-siblings, adoptive siblings and foster siblings. For the purpose of this review the term *sibling* refers to a sibling of an individual with a disability in the context of any of these types of relationships. The terms *individual with a disability* or *participant with a disability* are used to refer to the individual within the sibling relationship who has been diagnosed with a disability.

During childhood, siblings of individuals with a disability may play significant roles in their brother's and sister's lives as playmates, friends, and teachers [6]. These roles may change as individuals progress into adulthood, with siblings taking on more of an advocacy [7] and caring role [8,9], especially when parents are no longer able to do so. With increased life expectancies for individuals with disabilities [10], caregiving needs may extend over a longer period than in previous decades, potentially increasing demands on siblings to step into this role.

Most individuals who have a disability access a variety of specialised therapeutic services, provided by professionals such as Physiotherapists, Psychologists, Occupational Therapists and Speech-Language Therapists. Planning and implementing therapeutic interventions involves identifying what the focus of intervention should be, how it should be achieved and who should act as the key agent of change [11].

Ultimately, the central aim of interventions is to improve the quality of life of the individual with a disability through modifying the environment, through changing the skills of the individual with a disability, or by enhancing the skills of individuals within their immediate social world. Individuals with disabilities often act as their own key agent of change, with their unique insight into the changes required for a positive impact on their own skills, knowledge or quality of life. However, if a child is very

young or faces significant additional challenges, another individual must assume that role. Parents, teachers, keyworkers, peers and siblings have all been reported to take on the responsibility of being the key agent of change in interventions. There are a multitude of instructional and interactional programmes documented in the literature for parents and peers of children with disabilities [12-15], highlighting the positive effect that engaging key stakeholders directly can have on the effectiveness of interventions.

Although siblings have been recognised as potential agents of change, reports of sibling-mediated interventions (i.e., interventions for an individual with a disability where siblings are the key agent of change) are not as common in the literature as parent- or peer-mediated interventions. Banda [16] completed a systematic review of 15 intervention studies which included children with autism and their siblings. He found that involving siblings can lead to positive outcomes in the social and communicative skills of the children with autism, but the review also highlighted significant methodological variations and mixed results across a number of the studies. Shivers and Plavnick [17] completed a systematic review of sibling involvement in interventions for children with autism. Their review included 17 articles and concluded that sibling involvement may have a positive effect on the skill acquisition and/or problem behaviours of the child with autism. They noted that within these 17 studies, siblings played different roles across the interventions, acting as instructors, models or co-recipients of the intervention. Both of these systematic reviews focused on children with autism and their siblings. Two other reviews have focused on siblings of children with diverse developmental or chronic disabilities [18,19]. However, both reviews focused only on the effect of the interventions on the outcomes for the siblings with typical development.

It is not surprising that there have been reports of sibling involvement in interventions for individuals with a disability. In the majority of families, siblings are familiar partners who are in frequent contact with the individual with a disability. Siblings often interact within the safe and familiar home environment, but they may also be available for interactions in other settings such as school and in the community. This relatively constant presence allows for generalisation of intervention techniques across environments and has the added benefit of involving an interaction partner of a broadly similar age. In line with the increased caring roles they may be expected to undertake as parents age [8,9], siblings may also be relied on to take on responsibility as agents of change in interventions.

Given the typical longevity of sibling relationships, harnessing sibling engagement can maximise the potential benefits of therapeutic interventions through recurring interactions over many years. However, engaging siblings as intervention partners is complex. It is vital that their own emotional and physical needs are considered in the intervention planning [17], in order to balance the needs of the individual with a disability and the specific and unique needs of the sibling and to ensure that the sibling experience is positive. Furthermore, the benefit of sibling participation in intervention may not be limited to the individual with a disability: siblings themselves may also benefit through strengthening of the sibling relationship and a sense of self-efficacy and involvement from their participation [20].

Relatively little research attention has focused on the roles siblings assume in interventions for individuals with disabilities. Reviews completed on the topic of sibling involvement in interventions [16,17,18,19] do not have an overt focus on the role the siblings play in these interventions. Additionally, two of these reviews [16,17] focus exclusively on siblings of individuals with autism while the other two [18,19] focus

only on the outcomes for the sibling without a disability. The current systematic review aims to address this gap by reviewing interventions that involve the sibling of an individual with any form of developmental or acquired disability to (i) identify the role(s) siblings played within those interventions and (ii) the outcomes of the interventions for both the individual with a disability and their sibling. In order to capture studies that include siblings of individuals with a range of disabilities, search terms similar to those used in the reviews by Tudor and Lerner [19] were used. However, due to the range of approaches and overall quality of the studies, the effectiveness of the interventions (as defined by Schlosser [21]) was unable to be reliably determined. This review aims to provide an overview of the current state of research, to aid in future research planning and may also offer guidance to clinicians who are considering involving siblings in interventions for a person with the disability.

Research Questions

The research questions were:

- (1) What role is assigned to siblings in interventions for individuals who have a developmental or acquired disability?
- (2) What are the reported outcomes of these interventions in terms of: the skills of the individual with a disability or their sibling; the interactions between the siblings; or the sibling relationship itself?
- (3) What are the reported experiences of the individual with a disability and their sibling of these interventions?

Method

Systematic Review

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) group reporting guidelines were used to structure this current systematic review [22].

Information sources and search strategy

A search of the databases Medline, PsycInfo, ERIC, CINAHL Complete, EMBASE and CENTRAL was undertaken using the search terms: (sibling* OR brother* OR sister*) AND (disorder* OR disab* OR difficult* OR impair* OR injur*) AND (interven* OR therap* OR support OR train* OR teach*) occurring within the title, abstract and/or keywords. The search was further limited to articles written in English and published in the last 21 years. The years 1999 to 2020 were chosen (i) because of the increase in therapeutic interventions for individuals with a disability over recent years, and (ii) in order to control the scope of the review.

A search for articles produced outside of conventional publishing and distribution networks, or 'grey literature', was also completed. Included in the above searches were the Proquest Dissertation and Thesis (through EMBASE) and CINAHL Plus (through CINAHL Complete) databases. Google Scholar (the first 50 results) and the Open Grey database were searched with the same search terms. Reference lists of five published literature reviews on interventions for individuals with disabilities in which siblings play a role [16-20] were hand searched to identify any further studies which had been missed by the aforementioned searches.

All titles and abstracts retrieved by electronic searching were downloaded into a reference management database (Endnote). Duplicates were identified and removed before articles were screened using the inclusion and exclusion criteria (table 1), first by

title, then by abstract and then finally by full text. If an article clearly did not meet the criteria at a certain level, it was not passed forward for screening at the next level.

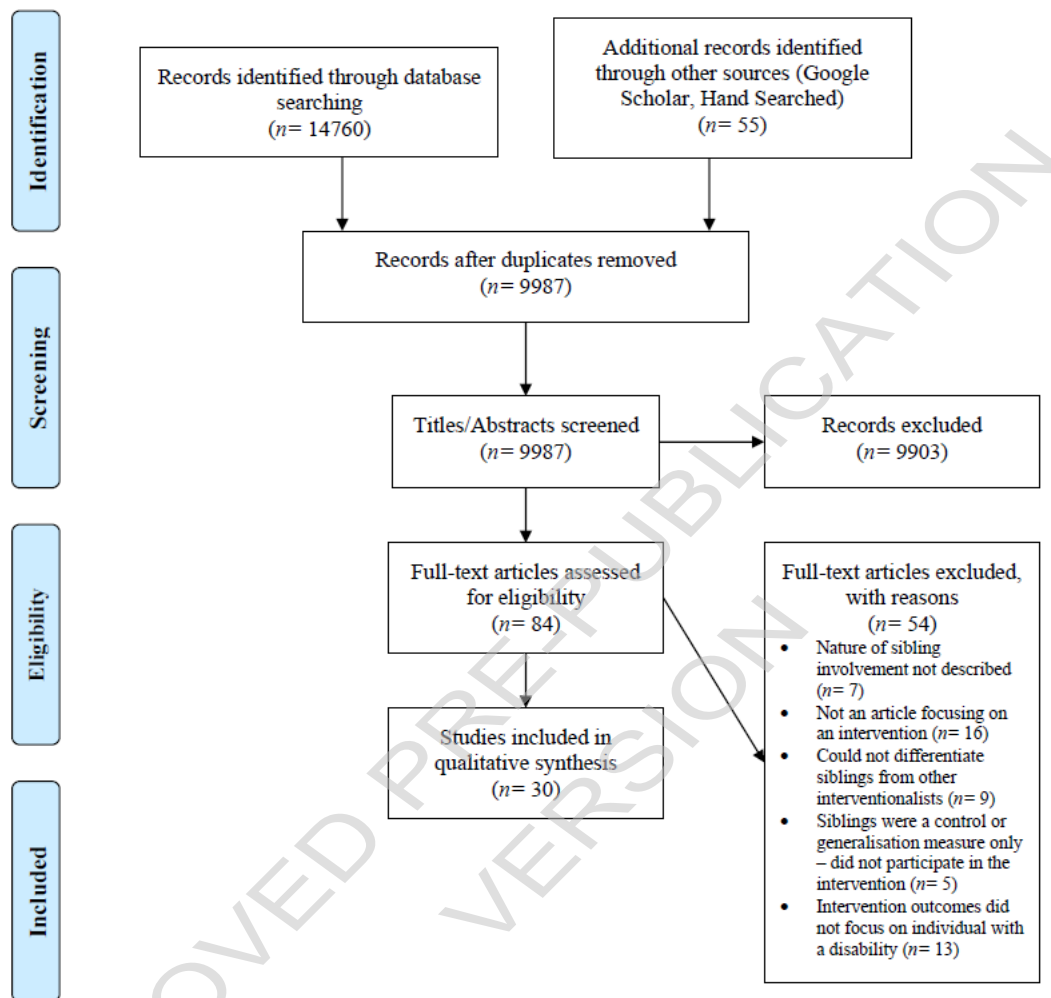
Table 1. Inclusion and Exclusion Criteria

Inclusion Criteria	
Participants	<ul style="list-style-type: none"> • Participants can be of any age • Participants include siblings of individuals with a developmental or acquired disability.
Intervention	<ul style="list-style-type: none"> • The article must focus on an intervention. • Siblings play a clear role in the intervention.
Outcomes	<ul style="list-style-type: none"> • Outcomes include a focus on the participant with a disability • Outcomes focus on the sibling's skills and/or quality of life in relation to the sibling relationship, as measured through observations, parent report and/or both siblings report of the relationship.
Exclusion Criteria	
Participants	<ul style="list-style-type: none"> • Participants should not include siblings of individuals with a chronic illness, medical illness or mental health difficulties as their primary diagnosis.
Intervention	<ul style="list-style-type: none"> • The article cannot be a review, editorial or study protocol. • The intervention cannot be of medical or surgical nature. • The role of the sibling in the intervention must be clear. • The sibling cannot act as only a measure of generalisation of skills of the participant with a disability or as a comparison to typical development.
Outcomes	<ul style="list-style-type: none"> • Outcomes cannot solely focus on the sibling only (e.g. sibling coping, problem solving) • Outcomes cannot solely focus on the sibling relationship when the outcome measure is only reported by one sibling.

Results of Search

In total, 14,815 citations were extracted from the search. After duplicates were removed ($n= 4,823$), the total number of records reviewed was 9,987. Following a review of the titles, abstracts and full texts, a total of 30 articles were included in this review (figure 1) which incorporated 31 separate studies. Mazharova and Sturmey [23] included two studies within the one article.

Figure 1: Results of Search. PRISMA flow-diagram adapted from Moher et al. [22]



Reliability

Inter-rater reliability checks were carried out at three points – during review of titles, during review of abstracts and during data extraction. A second reviewer screened 10% of the articles at both the title and abstract stages for inclusion and exclusion criteria.

Inter-rater agreement on the titles of the articles was 88.7%. The titles where disagreements arose were re-reviewed by the two reviewers together and a consensus on 100% of the titles was reached. The inter-rater agreement at the abstract stage was 100%.

During the final stage of inter-reliability checks, the data extraction phase, four research assistants completed 100% of the data extraction in addition to the main researcher. The data extracted matched in 100% of the cases.

Quality of Studies

The quality of each study was analysed with reference to the level of evidence guidelines from the Oxford Centre for Evidence-Based Medicine [24] and evaluated using the Study Quality Assessment Tools [25]. The Study Quality Assessment Tools used were the 'Quality Assessment of Controlled Intervention Studies' and 'Quality Assessment Tool for Before-After (Pre-Post) Studies with no control group'. When analysing quality, these assessments took into account various criteria relevant to identifying bias in studies, for example sample sizes, multiple data points, blinding of assessors, selection criteria for participants and methods of randomisation. See supplemental tables 1 and 2 for copies of these tools.

Results

Using the Oxford Centre for Evidence-Based Medicine's levels of evidence tool, 29 of the 31 studies included in this review were rated as having a quality of evidence level of 4 (small studies, no randomised controlled trials or cohort studies). The remaining two studies [26,27] were at level 3b, due to the 0..... (see supplemental table 3 for further details). Each of the 29 studies without controls was assessed using the 'Quality assessment tool for before-after (pre-post) studies with no control group' [25]; the level of evidence across all studies was fair with a moderate risk of bias, (i.e., scoring between 27% and 73% on these rating scales). The majority of studies did not have a sufficiently large sample size ($n=29$, 100%) and did not blind assessors towards

outcomes ($n=24$, 82.76%). Many of the studies also did not report using statistical measures to analyse the data ($n=22$, 75.86%). The conditions which the majority of studies met included stating the objective clearly ($n=28$, 96.55%) and ensuring that the participants in the study were representative of those who would be eligible for the intervention in a clinical population ($n=29$, 100%). See supplemental tables 1-3 for full details of the quality criteria scores. It should be noted that the wide range of scores (25%-75%) that are all classed as indicating moderate risk of bias is a limitation of this tool. Two studies Castorina and Negri [26] and Chu and Pan [27] were both assessed using the 'Quality Assessment of Controlled Intervention Studies' [25]. No guidance was given on how to categorise scores assigned using this tool, and so the decision was made that any study scoring 50% or less was categorised as providing weak evidence, any study between 50% and 75% as moderate evidence and anything over 75% as high levels of evidence. Both studies were assessed as having weak levels of evidence due to the lack of randomisation of participants and blinding procedures. However, it is important to note that both studies used reliable outcome measures and had low levels of dropouts from baseline.

Although studies with moderate to low quality evidence ratings might not be included in systematic reviews of the effectiveness of interventions, they were included in this review in part due to the lack of high-quality evidence available, but more importantly because a key and novel focus of the review was on identifying the roles assigned to siblings in intervention, rather than on intervention effectiveness.

Results

Study Information

Year

This systematic review was limited to studies published between 1999 and 2020.

Watkins et al. [28], Tsao [29] and Daffner et al. [30] were the most recently published studies and Taylor et al. [31] was the oldest. See table 2 for full list of publication years.

There were 24 studies published between 2010 and 2020 compared to seven from 1999 to 2009.

Country

The studies described in this review originated from five countries (See table 2). The majority, (26 studies, 83.87%), were from the USA, spanning 15 different states (e.g., [32-34]). Other countries included Australia [26,35], Taiwan [27], the Netherlands [36] and Turkey [37].

[Insert table 2 here]

Study Design

The studies included in this review used a variety of research designs (see table 2). The majority of studies implemented a single case experimental design ($n=24$, 77.42%), for example Daffner et al. [30] and Spector and Charlop [38]. A concurrent multiple baseline across participants design was used most frequently ($n=6$, 19.35%), followed by multiple probe designs across participants ($n=4$, 12.9%), multiple baselines across participants and behaviours ($n=3$, 9.67%) and non-concurrent multiple baseline across participants ($n=3$, 9.67%). Two studies [26,27] used a non-randomised control design while all other designs were only implemented in a single study.

Participant Information

Number of Participants

Across all studies, the total number of participants, including individuals with a disability, siblings, parents and peers, was 347. The average number of participants per study was 11.19 (range 2 – 52), with 25 studies reported to have 10 or fewer participants. The total number of individuals with a disability participating in the intervention with a sibling was 140 (average of 4.52 per study, range 1-26). There were an additional 30 individuals with a disability across three studies who participated without a sibling. These participants have been excluded from the results. The total number of siblings was 144 (average of 4.65, range 1-26). There were 33 other individuals across the studies – 10 parents, three other adults, and 20 peers. There is a discrepancy between the number of individuals with a disability and siblings who were participated in the studies. This is due to three studies in which multiple siblings of the same individual with a disability took part in the study.

Age and gender of participants

The recorded ages of siblings and individuals with a disability ranged from three years to 15 years, with the majority being between the ages of six and 12 ($n=178$, 62.68%).

One study, [39], did not report ages for the participants with a disability ($n=20$).

Kryzak and Jones [40] did not provide exact ages for participants, only an age range (participants with a disability: 4-13 years, siblings: 6-14 years). Likewise, Castorina and Negri [26] did not provide exact ages nor an age range for the siblings in their study, only reporting that within the 7 siblings, the mean age was 12.71 and the standard deviation was 0.95. None of the included studies had any adult participants (see

supplemental table 4 for more information). Of the 144 siblings, 84 (58.33%) were older than the participant with a disability, 32 (22.22%) were younger and six (4.17%) were twins. Kryzak and Jones [40] and Chu and Pan [27] did not provide details on birth order ($n=22$, 15.28%). The majority of participants with a disability were male ($n=95$, 67.86%) with only 25 being reported as female (17.86%). Hansford [39] did not report on the gender of the participants with a disability ($n=20$). All studies reported on sibling gender – 71 (49.31%) were male and 73 (50.69%) were female.

Diagnosis of participants with a disability

The majority of individuals with a disability had a diagnosis of autism spectrum disorder (ASD), including autism, Asperger's syndrome and Pervasive Developmental Disorder not otherwise specified (PDD-NOS). Of the 140 participants with a disability, 120 had a diagnosis of ASD (85.71%). In addition to this, there were nine individuals who were reported to present with multiple diagnoses, one of which included ASD. Other co-occurring diagnoses included attention deficit hyperactivity disorder, anxiety, depression and oppositional defiance disorder. Only eleven participants with a disability did not have a diagnosis of ASD. Other reported diagnoses were Down syndrome ($n=3$), Noonan syndrome ($n=1$), speech motor delay ($n=1$), Attention deficit hyperactivity disorder ($n=3$) and developmental delay ($n=3$). There were no participants who were reported to have a diagnosis of an acquired or progressive disability. Given the dominance of ASD as a diagnostic group within the results, additional search terms (i.e., “cerebral palsy” OR “multiple sclerosis” OR blind OR deaf OR “amyotrophic lateral sclerosis”) were used in a second search to capture any studies that might not have been identified using the broad terms (disorder* OR disab* OR difficult* OR impair* OR injur*) but no additional relevant studies were identified. See supplemental

table 4 for a full list of participant characteristics for each of the 31 studies included.

Intervention/Training Information

Structure of Intervention/Training

The interventions reviewed covered a wide range of topics. The structure of these interventions varied, but just over half of the studies ($n=16$, 51.61%) employed some form of sibling training or support group followed by a play session with the individual with a disability. On top of this, two studies involved a further training aspect – one was for parents and the other for the individual with the disability in addition to the sibling support group and play sessions. Three studies consisted of sibling training followed by intervention sessions for the participant with a disability mediated by their sibling. Sibling training across the studies varied, but generally included some form of individual or group training which incorporated aspects of modelling, in person or video modelling, role play, discussion and feedback.

The duration of the training varied and ranged from three weeks [41] to 24 weeks [42]. However, 14 of the studies (45.16%) did not record the training duration sufficiently explicitly for this to be verified in the data extraction. The majority of training took place once or twice a week, with Reagon et al. [34] conducting sessions daily. Not all studies recorded the length of the sessions. For those that did, the length of sessions varied from 10 minutes to 2 hours long.

Baseline data was collected in 28 of the 31 studies, with one to 36 data points recorded across the studies. Maintenance data for at least one participant was collected in 24 of the studies, ranging from 1 to 77 data points gathered across 1 week to 14 weeks. See supplemental table 5 for full information on duration for each study.

Content of Training

It was not only the structure, but also the content of the training which varied greatly over the studies in this review. The highest proportion of studies focused on enhancing play interactions ($n=10$) and social behaviours ($n=11$). Communication skills were the focus in four studies [38,41-43], while two studies were aimed at the reduction of negative behaviours [32,44]. Three studies focused on the development of specific skills, for example aquatic skills [27], skateboarding skills [45] and other functional skills, for example making noodles [35].

Research Question 1: Role of Sibling

The nature of sibling involvement in the studies reviewed was coded into seven different categories (see table 3). The categories were discrete, with no study reporting sibling involvement in more than one category. The role of a sibling as a trained playmate was the most commonly assigned across the studies ($n=11$, 35.48%).

Table 3. Categories of Sibling Roles.

Category	Description	Number of studies	Study References
Untrained playmate	Sibling did not receive any training and were present as a playmate for the individual with a disability to practice their skills learned in the intervention.	5 (16.13%)	[23,23,32,45,49]
Playmate and participant in intervention	Sibling did not receive any personal intervention. Sibling attended individual intervention with child with disability. Goals/targets of intervention were for child with disability and sibling.	3 (9.68%)	[28,36,44]
Participant in group	Sibling did not receive any personal intervention. Sibling attended group intervention with child with disability. Goals/targets of intervention were for child with disability only.	1 (3.23%)	[26]
Participant in support group	Sibling attended a support group for siblings of individuals with a disability.	4 (12.9%)	[39,47,51,58]
Model	Sibling acted as a model, either video model or face to face model as part of the intervention.	4 (12.9%)	[31,34,35,42]
Trained playmate	Siblings were trained in strategies to facilitate general interactions with the child with a disability. Siblings were not trained to elicit specific responses from the child with a disability.	11 (35.48%)	[29,30,37,38,40,41,43,46,50,52]
Instructor	Sibling was trained specifically to elicit a certain response from the child with a disability in relation to the goals of the intervention. Also gave feedback and specific prompts to the child.	3 (9.68%)	[27,33,53]

Research Question 2: Reported Outcomes of the Training and Intervention

Overall, the training and interventions discussed in this review reported positive results.

However, there were high levels of variability, with studies reporting non-significant findings [39], or mixed results across participants [46] or targets [47].

Results Across Targets

Studies targeted a range of different skills and behaviours in participants with disabilities and in their siblings, and in many instances, results across these different targets varied. For example, Buerger [47] reported increased positive interactions between the siblings post intervention, but no reduction in the levels of negative interaction behaviours. Similarly, in the study by Daffner et al. [30] all participants demonstrated an improvement in positive social behaviours but no reduction in negative social behaviours. Kim [48] reported that across targets, the participants with a disability were more variable in their outcomes than their siblings: for example, two evidenced high variability across the study in responding and in inappropriate behaviours. Other studies reported consistent positive results: Dodd et al. [32] reported an increase in target behaviours for both participants with a disability. The intervention reported by Chu and Pan [27] resulted in an increase in physical and social interactions for participants with a disability. Participants with a disability who participated with a peer or sibling showed significantly more improvement in their physical and social outcomes compared to the control group ($p < 0.01$). Baker [49] reported an increase in a variety of social interaction measures alongside a decrease in thematic ritualistic behaviours as an outcome of the intervention. Other studies that reported consistent positive results were Douglas et al. [41], Özen [37], and Tsao and Odom [50].

Results across Participants

There were also reports of inconsistent results for siblings versus participants with a disability. Lewandowski et al. [44] reported improvements in target behaviours of the

participant with a disability but not in the sibling, whereas Kryzak et al. [51] reported no statistically significant differences in targets for children with ASD but an improvement in imitations and responses in the siblings. In two of the studies [27,42], while positive outcomes were reported, there was no record of a significant benefit in involving a sibling as a key agent of change in the intervention as opposed to a peer or parent.

Research Question 3: Participant-reported experiences

Over half of the studies ($n=18$, 58.06%) reported on participant evaluations of their experiences in some form. While the majority of these ($n=10$, 55.56%) reported on the experiences or opinions of the sibling and the parent(s), three studies reported parent experience and opinions alone [26,37,52] and two studies included only the experiences of the sibling [27,39]. One study explored the experience of the individual with the disability and their parent [32] one focused on the individual with the disability and their sibling [28], and one study investigated the experiences of the individual with the disability, their sibling and their parent [38].

Of the 14 studies which reported on the sibling experience, 13 included sibling reports focused on sibling satisfaction with their involvement in the intervention and their enjoyment in taking part. Baker [49] instead used the interview to enquire about increase in skills that the siblings reported. All but one the studies [48] reported positive accounts from all siblings. Overall, siblings were reported to enjoy having been involved in the intervention [30,34,45-47]. Chu and Pan [27] reported that the siblings felt being involved in the intervention for the individual with a disability was a good experience and that they would like to be involved in a similar activity in the future. Three studies [39,46,47] reported high levels of sibling satisfaction, and moderate satisfaction was reported in one study [53]. The participants with a disability in the

studies by Dodd et al. [32], Huskens et al. [36] and Watkins et al. [28] gave positive reports of the intervention, for example reporting that they enjoyed the intervention and learning something new. There were no negative experiences reported by any of the siblings or participants with a disability in these studies.

Summary of Results

Across the 31 studies included in this review, siblings participated in many different interventions for the individual with a disability. The role siblings played most often in the interventions was that of a trained playmate ($n=11$), making use of newly learned general social, play or communicative strategies during play with the participant with a disability. In general, the training and interventions in this review reported positive effects on the skills of the individual with a disability and their sibling, as well as a positive effect on sibling interactions and the sibling relationship. However, the effectiveness of these interventions cannot be determined due to the moderate to low quality of evidence reported, the small sample sizes and the high levels of variability within the studies. This variability across the studies was not only in relation to the findings, but also in the participants' ages, participants' diagnoses, duration of the study, content and structure of the training, and outcomes reported. Over half of the studies reported participant experiences of involvement in the intervention, the majority reporting only on the sibling's experience; two reported on the experiences of the individual with the disability. However, for those that did include participants' feedback, experiences were reported to be overwhelmingly positive.

Discussion

Nature of Sibling Involvement

This review highlighted the varied roles that siblings may play in interventions for an individual with a disability. Across the majority of the studies, siblings were targeted as a playmate, either trained or untrained, for the individual with a disability. This reason for this may be related to the relative ages of the participants in the studies in this review. All participants were under the age of 15, with most being between the ages of six and 12. Play is a common occupation for individuals of this age. In addition, the nature of the sibling relationship itself may have impacted on the roles the siblings were required to perform. In childhood, siblings are frequently described as companions for one another and may spend a lot of their time together playing [54]. This type of relationship may lend itself better to play-based interactions during which learning can take place in a natural context. In addition, many of these studies took place in the participants' homes, once again highlighting the natural play context in which siblings often interact during childhood.

The majority of siblings in the studies reviewed received some form of training. The focus of this training ranged from how to elicit specific responses from the individual with a disability, to general interaction and social communication strategies that could be used when interacting with the individual with a disability. Siblings who performed the role of playmate in these interventions received more general interaction and communication strategy training than specific elicitation training. This focus may reflect the less structured environment of play and may have been intended to allow for generalisation to other play settings. However, the role of playmate may not be optimal if the goal of intervention is an increase in specific skills of the individual with a disability. Where specific skills were to be targeted, siblings typically occupied the role

of instructor. They were expected to give cues and provide feedback to the individual with a disability making the interaction less natural than other play-based interactions, a role more akin to that often assigned to parents in interventions: training and teaching skills [13].

Another role siblings were reported to perform was that of a model [31,34,35,42]. Research with sibling dyads who are typically developing has highlighted that siblings, especially older siblings, often act as potential models for their younger counterparts [55-57]. Across the four studies in which siblings were assigned the role of a model, siblings were reported to be effective in modelling positive social skills and interactions. Jones and Schwartz [42] compared the effect of peers, siblings, and adults as models for an individual with a disability. They found no clear preference for a particular model nor a clear difference across targets, suggesting that any model, child or adult, is beneficial and that a being a sibling was not of any additional benefit in their study.

Not all the studies focused on achieving outcomes for the individual with a disability. In four of the 31 studies, siblings participated as members of a support group (15.4%). In two of these studies [51,58] the sibling support group ran parallel to other intervention components, (e.g., a targeted skills intervention for the child with a disability), whereas in the other two [39,47] the sibling support group was the only component in the study. Although Hansford [39] reported inconclusive findings across participants, the other three studies reported an increase in positive engagement and play between the siblings and their brother or sister with a disability following the support groups. These studies indicate that a sibling support group alone, without any specific skills training targeting the needs of an individual with a disability may still benefit the interactions between the two siblings. Sibling support groups may also be

beneficial in improving coping skills and in managing any difficult thoughts and feelings siblings may have [59]. Sibling mental health is an important consideration in intervention planning when a sibling may be a key agent of change. However, as the focus of the current review was not on sibling mental health, a number of studies involving support groups for siblings with outcomes only measuring sibling mental health were not included in this review.

Siblings occupied a variety of roles in the interventions reviewed in this study. Most engaged with some form of training, and the most common environment for practising skills and measuring outcomes was through play-based interactions, a familiar interaction within most sibling relationships in childhood.

Reported Outcomes of Training and Interventions

The majority of the studies in this review reported positive results across outcomes for the individual with a disability, the sibling, sibling interactions and the sibling relationship itself. However, confidence in the extent of these effects is undermined by the variability in the results across participants, targets and/or contexts and the generally low quality of evidence across the studies. On an encouraging note, a small number of studies [6,27,32,37,41] reported consistent positive results across participants and/or targets, and no study reported consistent negative outcomes for all targets or participants. While the involvement of siblings in intervention seems to be potentially beneficial, the effect that the sibling specifically has on intervention outcomes is less clear. Few studies compared outcomes when a sibling was involved in an intervention versus when another participant (e.g., parent or peer) was involved, or when the individuals with a disability participated without a sibling. The studies that did investigate this [26,27,42] concluded that siblings did not additionally benefit the intervention outcome. However, there may have been additional benefits that were not

captured by the specific outcome measures used in these studies. In these studies, groups without sibling involvement performed to the same level as those that did. It seems therefore that the relative effect of sibling involvement in interventions remains undetermined and further targeted research is needed to understand the specific benefits of involving siblings in interventions for individuals with a disability.

Other considerations suggest a further need for caution in generalising from the studies included in this review. The majority of the studies employed a single case experimental design with only a small number of participants and only two studies included control groups. Most of the studies employed multiple baseline or multiple probe designs allowing for comparison of multiple measures. However, the number of data points was variable across the studies, not only in relation to the duration of the training or intervention but also in the baseline and maintenance phases. No study had a level of evidence which was rated above level 3 and all were assessed as having a moderate level of risk of bias using the Study Assessment Tools [25]. In order to better understand the effect of sibling involvement in interventions for individuals with a disability, further research must be undertaken which makes use of high-quality research designs.

In addition, the age range of the participants was limited. Most were between the ages of six and 12. There were no adult participants and a limited number of adolescents across the studies. This may be due to a relative lack of services provided to adolescents and adults with a disability, compared to younger children. However, research has highlighted the increased importance of the sibling relationship across adulthood, with an increase reliance on sibling support [8,9], a factor that merits consideration when offering support and training to siblings of individuals with a disability at any age. The majority of siblings in the studies were older than the participants with a disability. This

may be connected to the added responsibility and caregiving role that older siblings may be assumed to undertake more so than a younger sibling [60]. However, both older and younger siblings should be included in interventions as caregiving roles have been reported by both older and younger siblings [61]. Another possible explanation for the proportion of older siblings involved in the studies in this review is the relatively young age range of participants with a disability, the large majority of whom were under the age of 12. The cognitive and meta skills needed to take on the role of instructor or interventionist may preclude the involvement of younger siblings.

This review differed from similar reviews by increasing the span of focus from just siblings of children with autism to siblings of individuals of all ages with a developmental or acquired disability. However, even with broader search terms, the majority of studies ($n=28$, 90.32%), included individuals who had a primary diagnosis of autism spectrum disorder (ASD) as the participants with a disability and a second search targeting specific disability groups yielded no additional relevant studies. There were no participants in the studies in this review who had a diagnosis of an acquired or progressive disability. This may be linked to the lack of adult participants as discussed above, as the majority of acquired and progressive disabilities are diagnosed in adulthood. This high proportion of studies which included participants who had diagnosis of ASD is thought to be reflective of the state of the available literature. It highlights the need for future research to be focused on siblings of participants other than those who have ASD, but especially adolescents or adults and those with acquired difficulties.

What is not clear is the reason why children diagnosed with ASD were the target of most of the interventions discussed in this review. One potential reason is that siblings may have been chosen to participate in the studies alongside individuals with

ASD due to their role as a similar aged playmate, their potentially close relationship and the opportunity for extended time together [20] allowing for the frequent learning of skills in a natural environment. Alternatively, researchers interested in involving siblings in interventions may have chosen to focus on children with ASD, as the difficulties experienced by this cohort (communication and social skills) occur in domains of activity that occur frequently and naturally between siblings, compared to other intervention targets, (e.g., strengthening muscles, controlling a pencil or specific morphological development).

Furthermore, the high proportion of participants with ASD may partly explain the high proportion of males reported to be involved in the interventions (80% of participants with a disability for whom gender was recorded), as the ratio of males to females may be as high as 4:1 in individuals diagnosed with ASD [62]. In addition, the high number of participants diagnosed with ASD may have affected the intervention targets chosen by the researchers. Individuals with ASD can experience significant and specific difficulties in social interaction and social communication [63], and many of the interventions reviewed here focused on social skills, social communication and play interactions.

Experiences of Participation in the Studies

Just under half of the studies recorded participant experience of the study from the individual with a disability or their sibling. Most of the studies that recorded participant experiences only reported on the experiences and opinions of the sibling, with relatively little attention to the views of the participant with a disability (but see [28,36,49]).

Researchers have theorised that participation in interventions may benefit the sibling relationship by strengthening it and supporting siblings to recognise that they can be helpful towards their sibling [20]. The studies in this review indicated that the majority

of participants, both siblings and individuals with a disability, felt positively about their involvement in the intervention, with siblings indicating they liked helping the individual with a disability. It is important to investigate and acknowledge whether participants, (both those with a disability and their siblings), experience enjoyment during training and interventions and feel they are beneficial. Increased positive affect may lead to increased motivation [64] to continue with the intervention and a willingness to be involved future interventions alongside the individual with a disability. Enjoyment and motivation may not only affect the work completed in the clinic but also generalisation into day to day lives. Siblings are in an ideal position to promote generalisation across environments (e.g. home, school, extended family gatherings) as they are often present with the individual with a disability across multiple environments .

Interventions for individuals with a disability that have aspects of sibling involvement must ensure a balance between the needs of the sibling and the needs of the person with a disability to ensure both are satisfied and motivated to continue to work together. It is important that the experiences of the siblings and the participants with a disability are recorded, to build evidence about the elements of interventions which lead to greater participant enjoyment and motivation and that are therefore more likely to be maintained.

Limitations and Future Research

The findings from this review must be considered in the context of a number of limitations. A meta-analysis of the effectiveness of the interventions was not completed, in part because of the dual focus on the nature of the role assigned to siblings within interventions and the overall effects of those interventions. Limitations in the quality of

the studies reviewed were also noted. While these limitations did not constrain the focus on the roles assigned to siblings, they necessarily undermine confidence in reliability of the reports of effectiveness. Few studies included a control group or a sufficiently large number of participants to complete a statistical analysis and only two [27,42] studies were designed to allow for the investigation into the specific added benefit of involving a sibling rather than a peer or parent within the intervention. A further limitation is that in evaluating study quality, the quality assessment tools were non-standardised. Different tools were used depending on the study design. Despite these limitations, the review highlights the need for future research to enhance understanding of sibling involvement in interventions for individuals with a disability. The majority of participants in this review were young and were siblings of an individual with ASD, where unique needs may arise. It seems likely that research with siblings and participants of different ages and different diagnoses, both developmental and acquired, would highlight other roles and/or outcomes of involving siblings more actively in interventions. More high-quality research is needed to better understand the potential impact of involving siblings within interventions.

Conclusion

The studies captured by this systematic review were those in which siblings were involved in an intervention for an individual with a disability. Thirty-one studies were analysed, and these varied greatly in their focus, research design and quality. This systematic review differs from similar reviews by focusing on the roles assigned to siblings within interventions, as well as by extending the focus to include siblings of individuals with a range of disabilities. Although, ultimately, the majority of participants in the studies included presented with a diagnosis of ASD, this is thought to

be reflective of the state of the literature and suggests a gap in research involving siblings of individuals who have a diagnosis other than ASD. For the studies that were included in this review, siblings were found to be assigned varied roles in interventions, from a trained playmate and an instructor to an untrained playmate and a member of a support group. The role of a trained playmate occurred most frequently ($n=11$). Half of the studies reported on participant experiences of these interventions, and the results were overwhelmingly positive. However, more studies need to acknowledge sibling opinion and experiences in taking part in these interventions for individuals with a disability to ensure all participants' needs are being met. The results of interventions involving siblings were reported to be mostly positive. However, there were high levels of variability in results reported across targets, participants, or contexts as well as a small number of participants and limited statistical measures. While the overall outcomes of these interventions appear positive, what is less clear is the effect of involving a sibling specifically in the intervention.

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APPROVED PRE-PUBLICATION
VERSION

Appendix C. Data Extraction Template for Systematic Review of Sibling Involvement Interventions for Individuals with a Disability

Diagnosis of Person with a Disability									
Gender of Participants	Siblings								
	Individuals with a Disability								
Age Range of Participants	Siblings								
	Individuals with a Disability								
Number of Participants	Siblings								
	Individuals with a Disability								
	Total								
Quality Assessment Tool Risk of Bias Rating (100% = no bias)									
Level of evidence									
Main Reported Outcomes									
Duration									
Content									
Sibling Involvement									
Setting									
Study Design									
Year of Publication									
Title of Study									
Authors									

Appendix D. Data Extraction Template for Systematic Review of Peer Communication Partner Training Interventions

Participant Feedback									
Outcomes									
Content of intervention									
Instructional strategies used									
Duration									
Format of training within intervention									
Group/Individual									
Study									
Diagnosis									
Gender	Peer								
	AAC user								
Age	Peer								
	AAC user								
Number of participants	Peer								
	AAC user								
Country									
Study									

Appendix E. Copy of Ethics Committee's Approval Letters – Interview



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Application: Academic Year 2019/20
Application Code: HT 23
Applicant /Supervisor Name: Lynam, Aideen RESEARCH PG / Dr Martine Smith
Title of Research: The experiences of individuals growing up with a sibling who uses augmentative and alternative communication.
Date of this letter: 20-02-20

Dear Aideen,
Your submission for ethics approval for the research project above was considered by the Research Ethics Committee (REC), School of Linguistic, Speech and Communication Sciences, Trinity College Dublin on 20.02.20 and has been approved in full.

Please note

- (i) that on completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one signed hard copy to the School Office (Room 4091, Arts Building) as well as an electronic copy (to slscs@tcd.ie)
- (ii) the REC requests that you attend, in particular, to your commitments as regards the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research,

Best wishes,

A handwritten signature in black ink, appearing to read 'Kathleen McTiernan'.

Professor Kathleen McTiernan
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

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Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Application	Academic Year 2019/20
Applicant Code	HT23
Applicant/Supervisor Name	Aideen Lynam / Prof Martine Smith
Title of Research	The experiences of individuals growing up with a sibling who uses augmentative and alternative communication.
Date of this letter	24/06/2020

Dear Aideen,

Your amended submission (dated 22/06/2020) for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one signed hard copy to the School Office (Room 4091, Arts Building) as well as an electronic copy (to slscs@tcd.ie)
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

Dr Ciarán Kenny
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

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Application	Academic Year 2019/20
Applicant Code	HT23 (2019/20 academic year)
Applicant/Supervisor Name	Aideen Lynam / Prof Martine Smith
Title of Research	The experiences of individuals growing up with a sibling who uses augmentative and alternative communication.
Date of this letter	08/10/2020

Dear Aideen,

Your submission for ethical approval for the amended research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin on 08/10/2020 and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one signed hard copy to the School Office (Room 4091, Arts Building) as well as an electronic copy (to slscs@tcd.ie)
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

Dr Ciarán Kenny
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Scoil na nEolaithe Teangeolaíochta,
Uinbhíne agus Cumarsáide,
Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

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Appendix F. Participant Information Leaflet for Interviews

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES
Participant Information Leaflet

The Experiences of Individuals Growing Up with a Sibling Who Uses
Augmentative and Alternative Communication.

Aideen Lynam, BSc. Clinical Speech and Language Studies, School of Linguistics,
Speech and Communication Sciences. Academic Supervisor: Dr. Martine Smith.

Funded by TCD Provost's PhD. Award.

You are invited to participate in this research project which is being carried out by Aideen Lynam. Your participation is voluntary. Even if you agree to participate now, you can withdraw at any time without any consequences of any kind.

Very little is known about what it is like growing up with a sibling who uses Augmentative and Alternative Communication (AAC). This study is designed to investigate the experiences of people like you who have a sibling who uses AAC. The research is focused on what it was like growing up with a sibling who uses AAC, what the siblings do when they spend time together and the sibling's experiences of being involved (or not!) in any Speech and Language Therapy interventions with their brother or sister.

You are invited to participate in this research because you have a brother or sister who uses AAC. If you accept this invitation, you will be asked to take part in an interview, either face to face, over the phone or by Skype. The questions are designed to be non-intrusive – for example “What was it like growing up with X?” and “Do you think that siblings like you should be given the opportunity to be involved in Speech and Language Therapy with their brother or sister?”. This interview will take about an hour and a half. You will also be asked to complete a short questionnaire which will be emailed to you before your interview.

This interview is about personal matters and as such you may feel some embarrassment when talking about these topics. If you feel uncomfortable in any way, you can stop taking part in the interview at any time. If you want, you can also

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

be given the details of someone who can help support you further after the interview session has ended. If you decide to stop the interview, you can choose if you want the information, you have already given to be included in the study or else the audio recording will be deleted, and you will no longer be a participant in the study. No one will be told if you have completed the full interview or not.

You will not benefit directly from participating in this research, but health care professionals like Speech and Language Therapists might benefit from understanding your experience growing up with a sibling who uses AAC and how, in the future, siblings might be better supported to help their brother/sister who uses AAC.

Any information or data obtained from you during this research which can be identified with you will be treated confidentially. This will be done by giving you a fake name and keeping all the data password protected on a USB. Confidentiality of all information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

All information that we collect from you will be kept in the Department of Clinical Speech and Language Studies. Only Aideen Lynam and her supervisor, Martine Smith will have access to this. The data will be processed and managed in accordance with the General Data Protection Regulation (2018)¹.

The interview will be audio recorded, so that it can be written down afterwards, to make sure all the information is captured. All the interviews will be analysed to see if there are common themes across the different interviews. The recording itself will not be played to anyone else. You will have the opportunity to receive, via email, (a) a copy of the transcript of your recording and (b) a copy of the completed analysis so that you can confirm they are accurate in representing your thoughts and opinions.

1. Article 9(2)(j) of the General Data Protection Regulation, 2018.

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

Data from this research project may be published in future, however, participants will not be able to be identified. The original recording and all copies will be available only to the present investigators. The recordings will be kept in a secure location in the School.

If you have any questions about this research, you can ask Aideen (Email: Lynamai@tcd.ie, text or phone: 0877620799). You are also free, however, to contact her supervisor, Dr. Martine Smith (Email: mmsmith@tcd.ie; phone 0872886766) to seek further clarification and information. If you feel the need to make a complaint about this research at any point, you can contact X (to be confirmed).

If you are willing to participate, please return the attached consent form (for individuals over the age of 16) or the parent/guardian consent form and participant assent form (for participants under the age of 16).

Thank you for reading this and I hope you will consider participating in this research to help us understand more about the experiences of being a sibling of someone who communicates using AAC.

Appendix G. Consent Form for Interviews

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

The Experiences of Individuals Growing Up with a Sibling Who Uses
Augmentative and Alternative Communication.

Aideen Lynam, BSc. Clinical Speech and Language Studies, School of Linguistics,
Speech and Communication Sciences. Academic Supervisor: Dr. Martine Smith.

Funded by TCD Provost's PhD. Award.

I understand I am invited to participate in this research project which is being carried out by Aideen Lynam. My participation is voluntary. Even if I agree to participate now, I can withdraw at any time without any consequences of any kind.

I understand that this study is designed to investigate the experiences of people like me who have a sibling who uses AAC. I understand that I am invited to participate in this research because I have a brother or sister who uses AAC. If I accept this invitation, I will be asked to complete a questionnaire and take part in one interview over a phone or video call. I understand the questions are designed to be non-intrusive – for example “What was it like growing up with your brother/sister?” and “Do you think that siblings like you should be given the opportunity to be involved in Speech and Language Therapy with their brother or sister?”. This interview will take about an hour and a half. I will also be asked to complete a short questionnaire which will be emailed to me before my interview. This questionnaire will take me about half an hour.

I understand that this interview is about personal matters and as such I may feel some embarrassment when talking about these topics. I know if I feel uncomfortable in any way, I can stop taking part in the interview at any time. If I decide to stop the interview, I can choose if I want the information I have already given to be included

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

in the study or else the audio recording will be deleted, and I will no longer be a participant in the study. No one will be told if I have completed the full interview or not. If I feel the need to make a complaint about this research at any point, I can contact the researcher.

I understand that I will not benefit directly from participating in this research, but health care professionals like Speech and Language Therapists might benefit from understanding my experience growing up with a sibling who uses AAC and how, in the future, siblings might be better supported to help their brother/sister who uses AAC.

I know any information or data obtained from me during this research which can be identified with me will be treated confidentially. This will be done by giving me a fake name and keeping all the data password protected on a USB. I am aware that confidentiality of all information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

I understand all information I provide will be kept in a locked cabinet in the researcher's house until the data can be transferred to the Department of Clinical Speech and Language Studies. Only Aideen Lynam and her supervisor, Martine Smith will have access to this. The data will be processed and managed in accordance with the General Data Protection Regulation (2018)¹.

I understand the interview will be audio recorded. I will have the opportunity to receive, via email, (a) a copy of the transcript of my recording and (b) a copy of the completed analysis so that I can confirm they are accurate in representing my thoughts and opinions.

1. Article 9(2)(j) of the General Data Protection Regulation, 2018.

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

I understand that data from this research project may be published in future, however, participants will not be able to be identified. The original recording and all copies will be available only to the present investigators. The recordings will be kept in a secure location as mentioned above.

If I have any questions about this research, I can ask Aideen (Email: Lynamai@tcd.ie, text or phone: 00353877620799). I am also free, however, to contact her supervisor, Dr. Martine Smith (Email: mmsmith@tcd.ie; phone 0035318962027) to seek further clarification and information.

If you are willing to participate, please sign the form attached and either take a photo or scan the form and send it to Aideen on 00353877620799 or Lynamai@tcd.ie by 13/11/2020.

Contact Details

Full Name: _____

Age: 18-21
22-25
26-30
30+

My contact details are:

Phone: _____

Email: _____

I would prefer an interview over

phone call
video call e.g. through Microsoft Teams

Signature of research participant

- ❖ I understand what is involved in this research and I agree to participate in the study. I have been given a copy of the Participant Information Leaflet and a copy of this consent form to keep.

Signature of participant

Date

- ❖ I agree to allow Martine Smith and Aideen Lynam to see all the information I provide through the consent form and in the interview.

Signature of participant

Date

- ❖ I agree to allow my interview with Aideen to be audio-recorded using a digital audio recorder. I also agree to allow this audio recording to be transcribed.

Signature of participant

Date

- ❖ I agree to allow the findings of the research to be shared through journal papers and conference presentations or lectures.

Signature of participant

Date

- ❖ I would like to receive a copy of

(a) the transcription of my audio recorded interview Yes No

(b) the completed analysis Yes No

to confirm this information is representative of my thoughts and opinions.

Signature of participant

Date

Email address

- ❖ I agree to be contacted by Aideen in the future regarding similar research being conducted.

Signature of participant

Date

Email address

Signature of researcher

I believe the participant is giving informed consent to participate in this study.

Signature of researcher

Date

Appendix H. Parent/Guardian Consent Form for Interview Participants Under 16

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES
Parent/Guardian Consent Form
(Participants <16 years)

The Experiences of Individuals Growing Up with a Sibling Who Uses
Augmentative and Alternative Communication.

Aideen Lynam, BSc. Clinical Speech and Language Studies, School of Linguistics,
Speech and Communication Sciences. Academic Supervisor: Dr. Martine Smith.
Funded by TCD Provost's PhD. Award.

I understand _____ is invited to participate in this
research project which is being carried out by Aideen Lynam. Their participation is
voluntary. Even if they agree to participate now, they can withdraw at any time
without any consequences of any kind.

I understand that this study is designed to investigate the experiences of people who
have a sibling who uses AAC. I understand that _____ is
invited to participate in this research because they have a brother or sister who uses
AAC. If they accept this invitation, they will be asked to complete a questionnaire
and take part in an interview, either over the phone or by video call. I understand
the questions are designed to be non-intrusive – for example “What was it like
growing up with X?” and “Do you think that siblings like you should be given the
opportunity to be involved in Speech and Language Therapy with their brother or
sister?”. This interview will take about an hour and a half.

I understand that this interview is about personal matters some individuals may feel
embarrassment when talking about these topics. I know if they feel uncomfortable in
any way, they can stop taking part in the interview at any time. If they want, they can
also be given the details of someone who can help support them further after the
interview session has ended. If they decide to stop the interview, they can choose if

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

they want the information they have already given to be included in the study or else the audio recording will be deleted, and they will no longer be a participant in the study. No one will be told if they have completed the full interview or not.

I understand that _____ will not benefit directly from participating in this research, but health care professionals like Speech and Language Therapists might benefit from understanding their experience growing up with a sibling who uses AAC and how, in the future, siblings might be better supported to help their brother/sister who uses AAC.

I know any information or data obtained from _____ during this research which can be identified with them will be treated confidentially. This will be done by giving them a fake name and keeping all the data password protected on a USB. I am aware that confidentiality of all information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

I understand all information provided will be kept in a locked cabinet in the researcher's house until the data can be transferred to the Department of Clinical Speech and Language Studies. Only Aideen Lynam and her supervisor, Martine Smith will have access to this. The data will be processed and managed in accordance with the General Data Protection Regulation (2018)¹.

I understand the interview will be audio recorded. The recording itself will not be played to anyone else. Participants will have the opportunity to receive, via email, (a) a copy of the transcript of their recording and (b) a copy of the completed analysis so that they can confirm they are accurate in representing my thoughts and opinions.

1. Article 9(2)(j) of the General Data Protection Regulation, 2018

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

I understand that data from this research project may be published in future, however, participants will not be able to be identified. The original recording and all copies will be available only to the present investigators. The recordings will be kept in a secure location as mentioned above.

If I or _____ have any questions about this research I can ask Aideen (Email: Lynamai@tcd.ie, text or phone: 0877620799). We are also free, however, to contact her supervisor, Dr. Martine Smith (Email: mmsmith@tcd.ie; phone 01 896 2027) to seek further clarification and information.

*If you are willing to give consent for your child to participate, please sign the form attached and either take a photo and send it to Aideen on +353877620799 or scan the form and email to lynamai@tcd.ie by (date to be inserted) or send to *Gatekeeper* at X along with a Participant Assent Form.*

Contact Details

Participant's Full Name: _____

Age: 13-15

16-18

My Full Name: _____

I would like to be contacted by:

Phone: _____

Email: _____

_____ would like to complete his/her interview:

(a) On the phone Yes No

(b) Via Skype Yes No

Signature of Parent/Guardian

- ❖ I understand what is involved in this research and I agree for _____ to participate in the study. I have been given a copy of the Participant Information Leaflet and a copy of this consent form to keep.

Signature of Parent/Guardian

Date

- ❖ I agree to allow Martine Smith and Aideen Lynam to see all the information I provide through the consent form and _____ provides through the assent form and in the interview.

Signature of Parent/Guardian

Date

Appendix I. Participant Assent Form for Interview Participants Under 16

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES
Assent Form (Participants <16 years)

The Experiences of Individuals Growing Up with a Sibling Who Uses
Augmentative and Alternative Communication.

Aideen Lynam, BSc. Clinical Speech and Language Studies, School of Linguistics,
Speech and Communication Sciences. Academic Supervisor: Dr. Martine Smith.
Funded by TCD Provost's PhD. Award.

I understand I am invited to participate in this research project which is being carried out by Aideen Lynam. My participation is voluntary. Even if I agree to participate now, I can withdraw at any time without any consequences of any kind.

I understand that this study is designed to investigate the experiences of people like me who have a sibling who uses AAC. I understand that I am invited to participate in this research because I have a brother or sister who uses AAC. If I accept this invitation, I will be asked to complete a questionnaire and take part in an interview, either over the phone or by Skype. I understand the questions are designed to be non-intrusive – for example "What was it like growing up with X?" and "Do you think that siblings like you should be given the opportunity to be involved in Speech and Language Therapy with their brother or sister?". This interview will take about an hour and a half.

I understand that this interview is about personal matters and as such I may feel some embarrassment when talking about these topics. I know if I feel uncomfortable in any way, I can stop taking part in the interview at any time. If I want, I can also be given the details of someone who can help support me further after the interview session has ended. If I decide to stop the interview, I can choose if I want the information I have already given to be included in the study or else the audio

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

recording will be deleted, and I will no longer be a participant in the study. No one will be told if I have completed the full interview or not.

I understand that I will not benefit directly from participating in this research, but health care professionals like Speech and Language Therapists might benefit from understanding my experience growing up with a sibling who uses AAC and how, in the future, siblings might be better supported to help their brother/sister who uses AAC.

I know any information or data obtained from me during this research which can be identified with me will be treated confidentially. This will be done by giving me a fake name and keeping all the data password protected on a USB. I am aware that confidentiality of all information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

I understand all information I provide will be kept in a locked cabinet in the researcher's house until the data can be transferred to the Department of Clinical Speech and Language Studies. Only Aideen Lynam and her supervisor, Martine Smith will have access to this. The data will be processed and managed in accordance with the General Data Protection Regulation (2018)¹.

I understand the interview will be audio recorded. The recording itself will not be played to anyone else. I will have the opportunity to receive, via email, (a) a copy of the transcript of my recording and (b) a copy of the completed analysis so that I can confirm they are accurate in representing my thoughts and opinions.

1. Data processing under Article 9(2)(j) of the General Data Protection Regulation, 2018.

The Experiences of Individuals Growing Up with a Sibling Who Uses AAC

I understand that data from this research project may be published in future, however, participants will not be able to be identified. The original recording and all copies will be available only to the present investigators. The recordings will be kept in a secure location as mentioned above.

If I have any questions about this research, I can ask Aideen (Email: Lynamai@tcd.ie, text or phone: 0877620799). I am also free, however, to contact her supervisor, Dr. Martine Smith (Email: mmsmith@tcd.ie; phone 01 896 2027) to seek further clarification and information.

If you are willing to give participate, please sign the form attached and send to Aideen Lynam (00353877620799) or lynamai@tcd.ie by (date to be inserted) along with the Parent/Guardian Consent form.

Contact Details

Full Name: _____

Age: 13-15

16-18

I would prefer to complete my interview:

(a) On the phone Yes No

(b) Via video call (e.g., Microsoft Teams, Zoom etc) Yes No

Signature of research participant

Signature of research participant

- ❖ I understand what is involved in this research and I agree to participate in the study. I have been given a copy of the Participant Information Leaflet and a copy of this assent form to keep.

Signature of participant

Date

- ❖ I agree to allow Martine Smith and Aideen Lynam to see all the information I provide through the assent form and in the interview.

Signature of participant

Date

- ❖ I agree to allow my interview with Aideen to be audio-recorded using a digital audio recorder. I also agree to allow this audio recording to be transcribed.

Signature of participant

Date

Appendix J. Interview Schedule

Introduction

- Why the participant has been invited to participate
- What the research hopes to achieve
- Time commitment for participant
- Confirm consent/assent and confirm member checking response
- Confirm consent for interview to be audio-recorded
- Discuss format of interview – i.e., information on growing up with sibling and then information more focused on SLT interventions.

Interview

1. Information on the siblings
 - a. Can you tell me a bit about yourself (age, occupation, likes/dislikes, hobbies etc.)
 - b. Can you tell me a bit about your family?
 - c. Can you tell me a bit about your sibling X who uses AAC? (age, school/occupation, likes/dislikes, hobbies etc.)

2. Experiences growing up
 - a. What was it like growing up with X as a sibling?

Prompts:

- i. What was your first memory of X?
- ii. What is your favourite memory you have with X?
- iii. What is a stand out memory you have with X?
- iv. What is the funniest memory you have with X?
- v. What is the happiest memory you have with X?
- vi. Did you spend much time together? What did you do when you were spending time together?
- vii. How would you describe your relationship with X when you were growing up?
- viii. If you had to describe your relationship in one word what would it be?
- ix. How do you feel about having X as a sibling?

- x. How do you think having X as a sibling impacted on you as a person?
- xi. In your opinion was there any difficulties growing up with X as a sibling?
- xii. What were the aspects of growing up with X as a sibling that you found most difficult?
- xiii. Has your relationship and the time you spent together change as you grew from childhood through adolescence? How so?
- xiv. How does your relationship with X compare with your other siblings?
- xv. How has your relationship with X affected your other relationships i.e. parents, friends etc.
- xvi. How do you think others perceive your relationship with X?
- xvii. How does your relationship with X make you feel?
- xviii. How do you think X's communication difficulties have affected your relationship?

3. Current Relationship

- a. How would you describe your relationship with X now?
- b. How much time do you spend with your sibling now? What do you do when you spend time together now?
- c. What is the best thing about having X as a sibling?
- d. What do you think is most interesting about having a sibling who uses AAC?

4. Speech and Language Therapy Involvement

- a. Did X attend/ Does X attend many sessions with the Speech and Language Therapist? How much of his/her therapy were/are you aware of?
- b. Have you ever been involved in these therapy sessions?
 - i. E.g. attending group/individual sessions, helping with homework from these sessions etc.
 - ii. Did this change from childhood to adolescence to adulthood? How so?
- c. If yes: What are your opinions on your involvement in these sessions?

- i. Did you enjoy them?
 - ii. Did you feel they were of benefit to you and/or your sibling?
- d. If no: Would you have liked to have been involved/ Would you like to get involved in these sessions?
 - i. Were you ever asked to be involved in these sessions but declined the offer?
- e. Do you think that siblings should be involved/given the opportunity to be involved in therapy?
 - i. What are your opinions on a sibling only group – for support or learning techniques?
 - ii. What are your opinions on siblings being involved in therapy sessions alongside their brother/sister?

Conclusion:

- Thank the individual for their participation
- Confirm member checking process
- Confirm if consent to contact regarding further research

Appendix K. Framework Analysis

The qualitative data collected through interviews with siblings of AAC users was analysed using a framework analysis approach (Ritchie & Spencer, 1994). There are five steps to the framework analysis approach – familiarisation, creating a thematic framework, indexing, charting and mapping and interpretation (Parkinson et al., 2016). This appendix details the finding of the interview data at each stage of the framework analysis process.

Familiarisation

During the familiarisation stage of the data analysis, the researcher read through the four interview transcripts as well as listening to the original audio files multiple times. This was to ensure the researcher had a good understanding of the information which was provided during each of the interviews. The data was then coded inductively, whereby each line of the transcript was read and labelled with a code. See Table K1 for an example of excerpts from the transcripts and their corresponding codes. Following this process, 53 codes were identified across the four interviews. See Table K2 for a full list of these codes.

Transcript Excerpt	Code Assigned
Jessica: “Em. Loving, kind and laughter. Because we’re always laughing”	Happy
Ciara: “We would have done foot massages, hand massages do her hair. A lot of the time we did a lot of reading, me and her, or I would like read to her”	Time spent together
Sarah: I would have been a part of a lot of the kind of things that were going on about her AAC or they’d call me in if some of the battery was dead or it was frozen and I’d be like oh you just get a paperclip and you reset at the back you know	Acting as the AAC Expert

Table K1. Transcript excerpts and their corresponding codes during the familiarisation phase

Reflecting as an SLT	Difficulty understanding sibling experience	Meaningful activities	Support of school and staff
Advocacy of others for sibling	Excitement	One sided relationship	Sympathy within the relationship
Pressure to attend appointments/groups	Expert in communicating with sibling	Openness about disability	Teasing
AAC and the outside world	First point of contact for services	Opinion of 1-1 sessions	'the norm'
AAC memories	Frustration	Other Relationship Difficulties	Time spent together
Accommodations for sibling	Gaining perspective from other siblings	Others awareness of disability	Understanding Disability
Acting as a helper	Happy	Peer support from other siblings	Value of training siblings
Acting as a protector	Impact of Birth order on relationship	Relationship conflict	Viewing involvement in sibling groups as helpful
Acting as an advocate	Impact of disability on the relationship	Relationship with sibling within the whole family context	Wanting to be involved in therapies
Acting as the AAC Expert	Impact on career choice	Separate lives	Warmth between siblings
Acting as translator/interpreter	Involvement Additional Activities for siblings	Sibling Illness	Worry
Change in Relationship	Involvement-Change	Sibling Relationship on their terms	
Conflicting roles of being a sibling and SLT	Involvement in AAC	Social life	
Difficulty accessing services	Involvement in Individual sessions	Support of family	

Table K2. Codes which were inductively coded from the data during the familiarisation stage of analysis.

Creating a Thematic Framework and Indexing

When creating a thematic framework, the 53 codes identified during the familiarisation stage were grouped together into themes alongside the a priori codes identified from the literature. There were 18 a priori codes which emerged from a review of typically

developing sibling literature (See Table K3). Examples of excerpts from the interview transcripts where a priori codes were applied can be read in Table K4.

Aging parents	Parental treatment impact on relationship	Positive relationship (e.g. warmth, support, affection, respect)
Participant acting as a protector	Negative relationship (e.g. conflict, arguments, pressure, jealousy)	Things which impact on involvement in SLT
Relationship maintenance – contact frequency	Developing/Maturity	Participant acting as a role model
Participant acting as caretaker	Relationship maintenance – time spent together	Opinion of SLT: Considerations to be taken into account
Comparing to one another	Participant acting as friend	Relationship maintenance – shared interests
Transitions	Opinion of SLT: Motivational factors	Participant acting as teacher

Table K3. A priori codes

Transcript Excerpt	A priori code
Ciara: “I feel like yeah I think like I’ve taken on a lot, yeah a lot of her care and you know, the running of her life now. You know, the role that mammy would have had”	Participant acting as carer
Sarah: “It just depended on what was on. If it was during summer holidays and I wasn’t doing anything sure I’d be delighted with a trip to [city].”	Things which impact involvement in SLT

Table K4. Excerpts from interview transcripts and the a priori codes applied

Following the merging of the codes into a draft thematic framework, as was mentioned above, a second researcher read through the codes and descriptions to ensure they made sense and were mutually exclusive. See Figures K1 for the final framework.

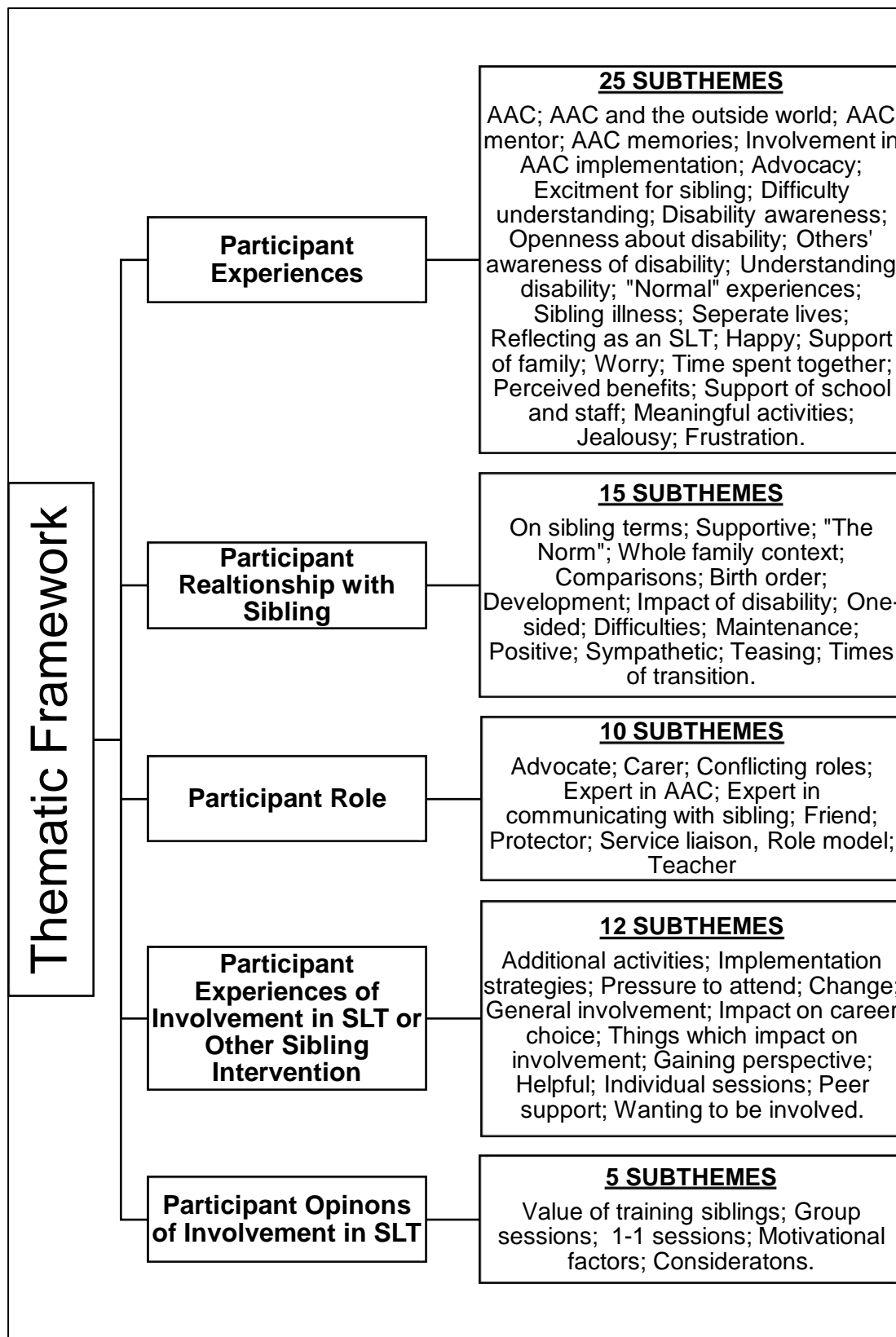


Figure K1. Thematic Framework. (Figure 8.1 in main text)

The framework consisted of five core themes with five to 25 subthemes within each. These five core themes were participant experiences, participant relationship with

sibling, participant role, participant experiences of their involvement in SLT or other sibling interventions and participant opinions of their involvement in SLT (Figures K2-K6). See Appendix L for a list of each code and its description.

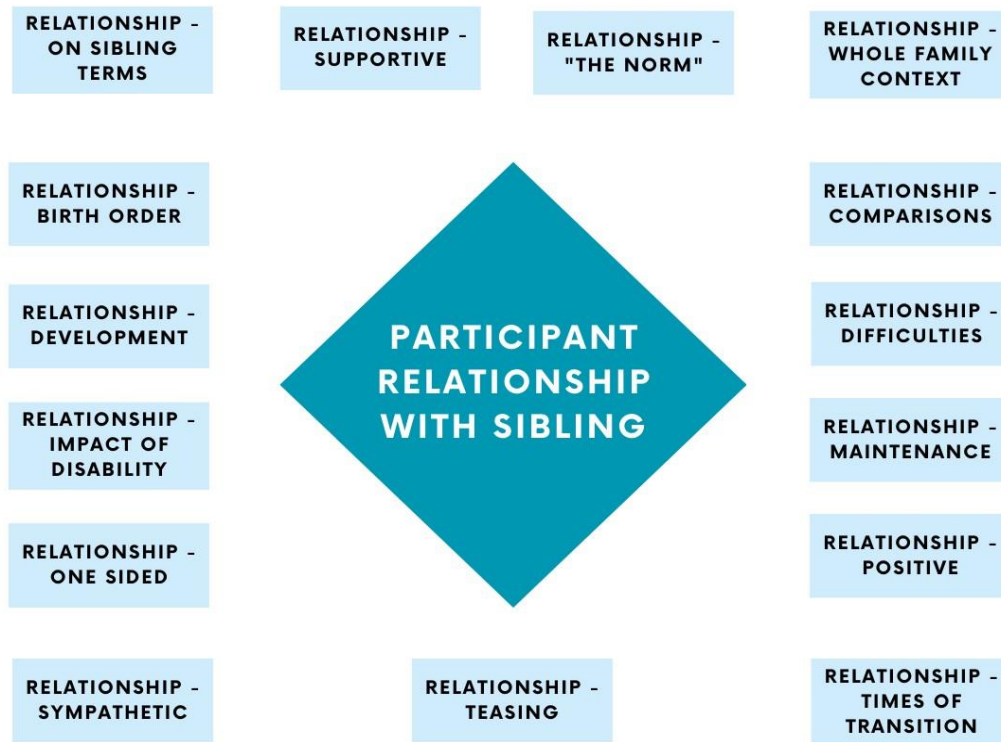


Figure K2. Thematic Framework – Participant Relationship

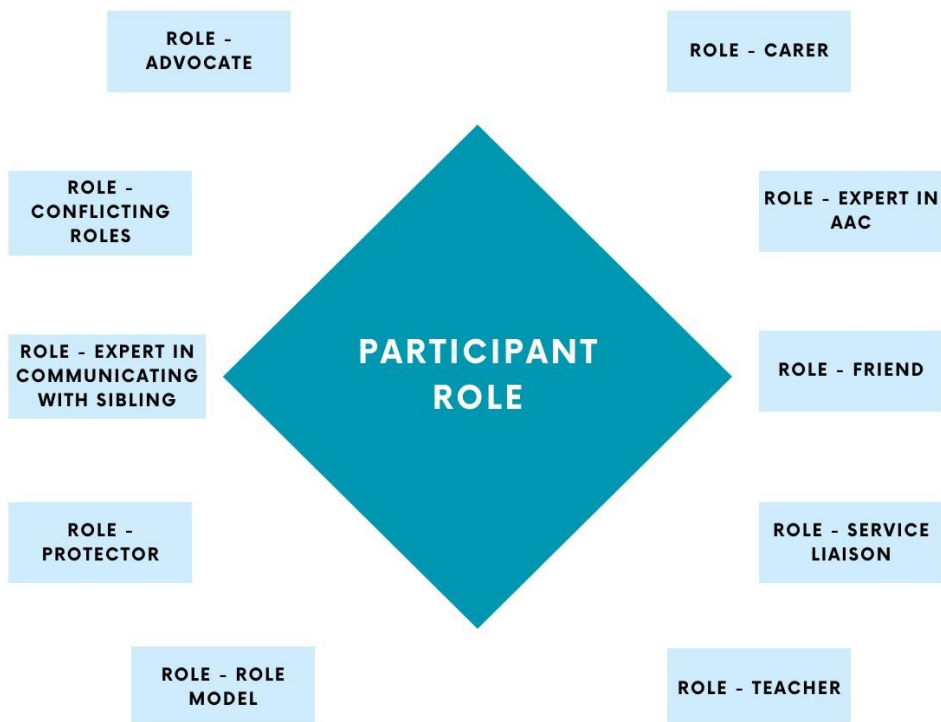


Figure K3. Thematic Framework – Participant Role

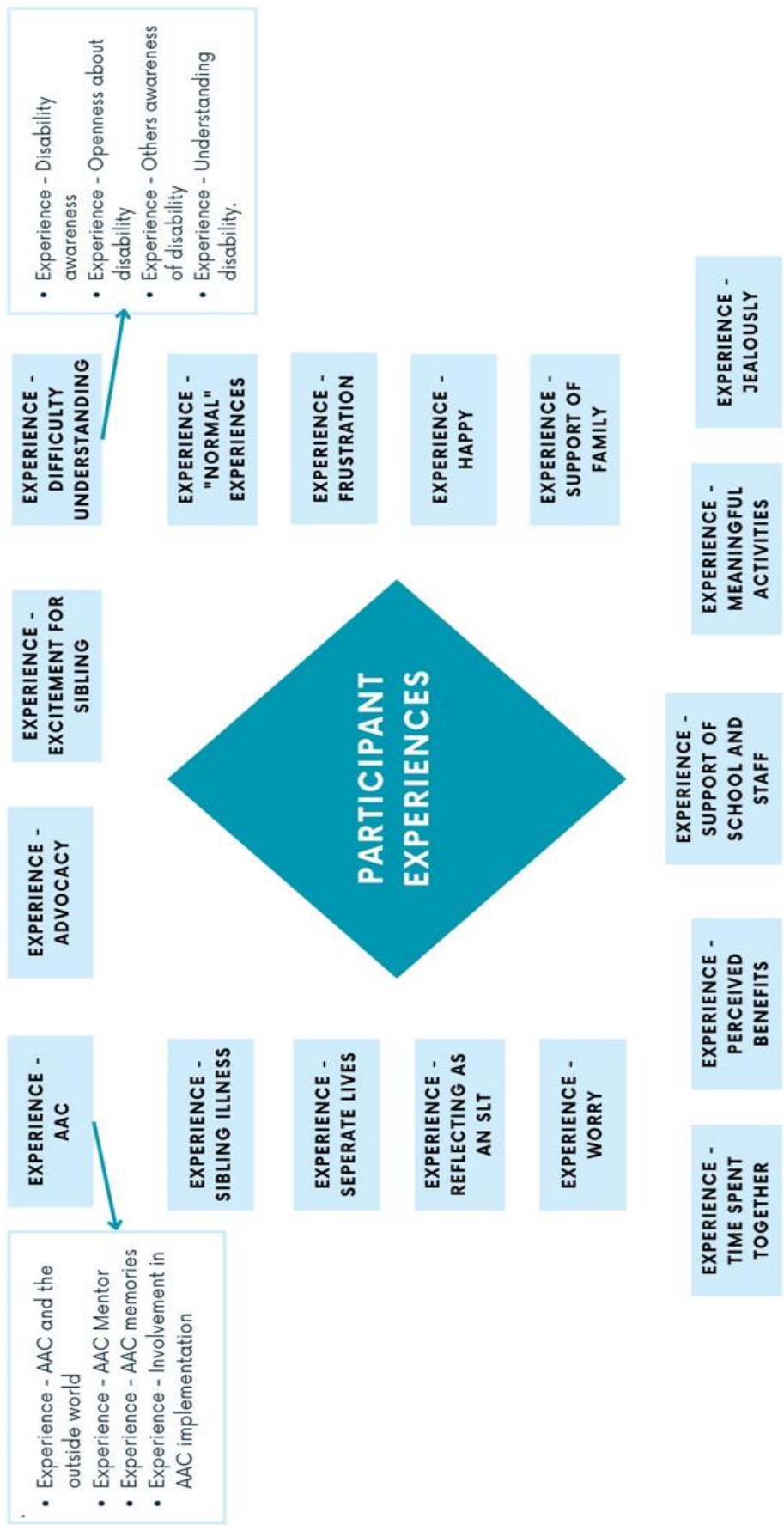


Figure K4. Thematic Framework – Participant Experience

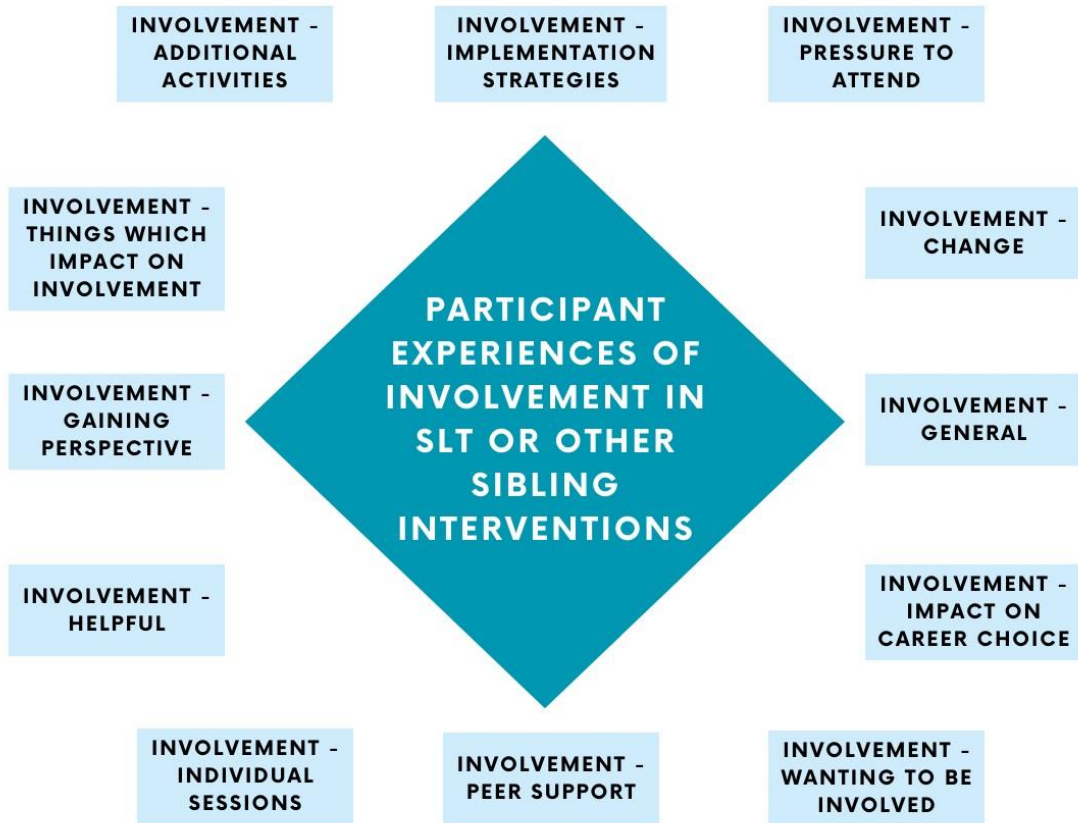


Figure K5. Thematic Framework – Participant Involvement in Interventions

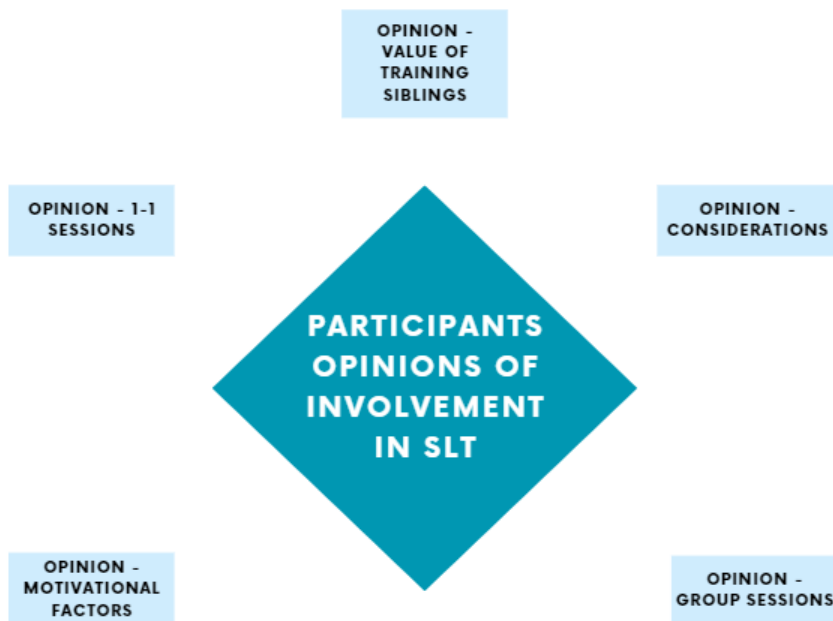


Figure K6. Thematic Framework – Participant Opinion of Interventions

Each interview transcript was then analysed once more, and the framework was systematically applied during the indexing phase. One further code, '*Experience- COVID 19*' with the core theme of participant experiences was added to the framework during this stage.

Charting

During the charting phase, the indexed data for each code was summarised and organised into a chart form. See Table K5 for extracts from the charts for the themes 'Participant experiences of their involvement in SLT or other sibling interventions'. The process from familiarisation to charting is an iterative process, with each stage being completed multiple times. See Figure K7 for an example of the process of analysis for one excerpt of the transcript.

Mapping and Interpretation

Following charting of the data, the findings were analysed in order to find any relevant associations between the data. These interpretations are discussed in Chapter Eight (Sections 8.2.3 – 8.2.6).

Participant	Involvement- Things which impact on involvement	Involvement- Pressure to attend
Sarah	Dependent on other activities (including school). Participant more likely to be involved over summer and "I wasn't doing anything"	No pressure to attend sessions. Given option to stay at home or go along. Instead, internal curiosity to see what's happening during the sessions.
	Age impacting on desire to be involved – the older she got the more she would want to do it, want to know more about how to do it. Impact of participants tech knowledge – more likely to have gotten involved with the higher tech stuff instead of parents who were more involved with the lower tech devices (e.g., big mac, alpha talker)	Participant encouraged to do what they wanted, not pressured but were told about the events and allowed to decide if they wanted to go.
	Wanting to be involved in something exciting and new for her sibling.	No pressure by family or SLT, would sometimes go and sometimes wouldn't. "I don't think that was ever sort of an issue"
Jessica	More likely to be involved with the technical aspects as mam isn't technical. Able to help and know what was happening and going on with the tech aspects of the device. Involved in other groups for sibling. Participant was just there with sibling. "I used to sit in on them with Sophie sometimes. Ehm just cause I kind of I knew Sophie."	Participant was asked to attend a session and would happily attend. "It doesn't really bother me like. Yeah, just to help with it like so."
	Not on social media, so less likely to be involved in online support groups or events.	

Table K5. Extracts from charts from theme 'Participant experiences of their involvement in SLT or other sibling interventions'.

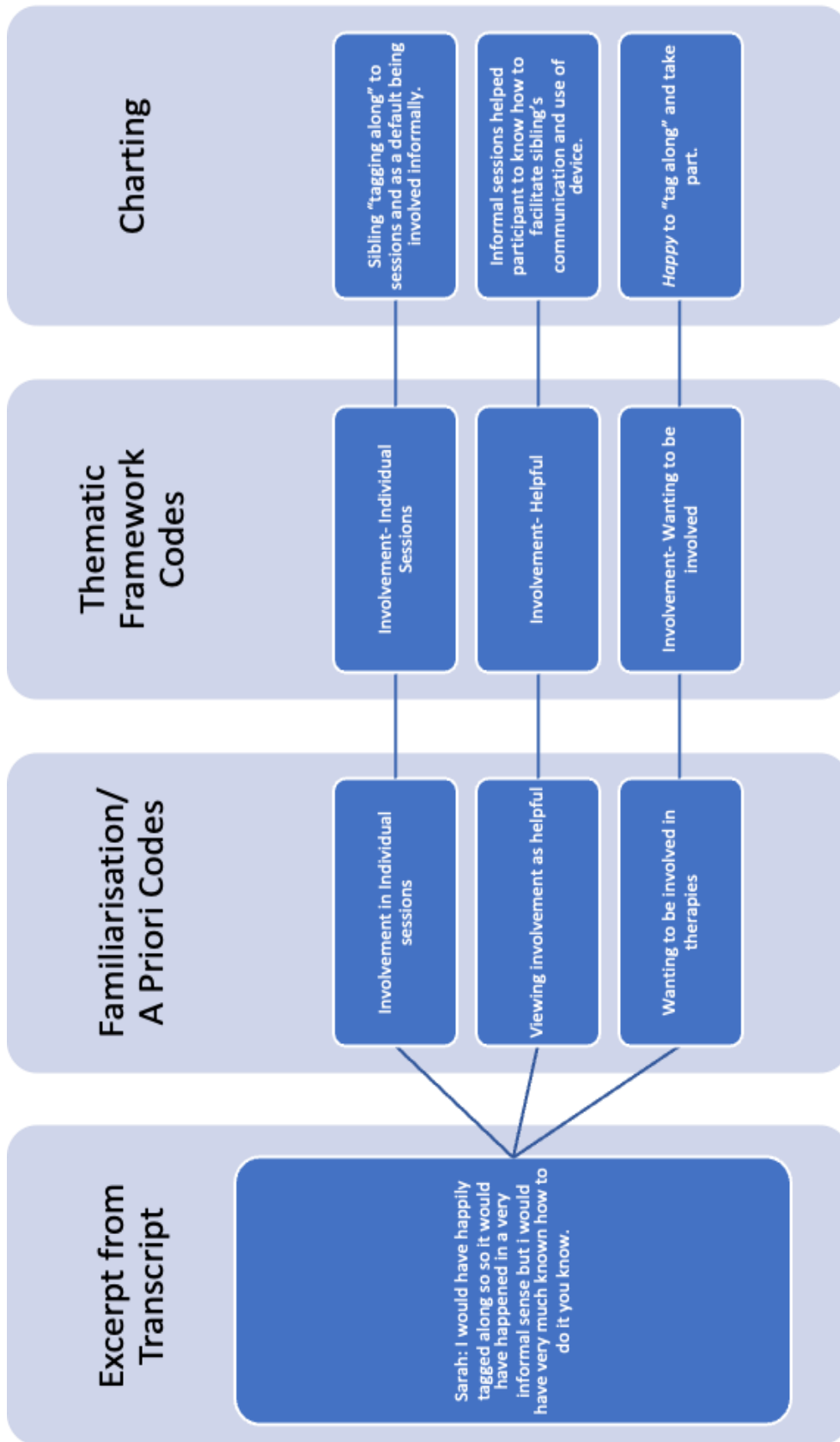


Figure K7. Analysis process

Appendix L. Thematic Code Descriptions

Participant Experiences		Participant experiences growing up with a sibling who uses AAC
1	Experience - Reflecting as an SLT	Participants who are SLTs reflecting on their sibling's communication experiences as a professional
2	Experience- AAC	Participant experiencing impact of their sibling's use of AAC in their own life
2A	Experience- AAC and the outside world	Participant modifying interactions/environments to maximise sibling's communication and use of AAC
2B	Experience- AAC Mentor	Participant teaching AAC to others
2C	Experience- AAC Memories	General participant memories of AAC being used by their sibling
2D	Experience- Involvement in AAC implementation	Participant being directly involved in AAC set up and implementation, e.g., using voice/picture as part of system
3	Experience- Perceived benefits	Participant experiences of perceived benefits directly relating to their sibling's disability
4	Experience- Advocacy	Participant experience of parents/others promoting the interests of the sibling - e.g., in relation to fighting for services
5	Experience- Difficulty understanding	Participant experiencing difficulty understanding or relating to their sibling
6	Experience- Disability awareness	Participant and others awareness of sibling's disability
6A	Experience- Openness about disability	The openness with which the disability of the sibling was/is spoken about within the family or in a wider context
6B	Experience- Others awareness of disability	The awareness that others (e.g., friends, family, strangers) have of sibling's disability
6C	Experience- Understanding Disability	Experience of understanding sibling's disability, or developing that understanding
7	Experience- Excitement for sibling	Experiencing excitement over new things or developments for sibling.
8	Experience- Frustration	Participant experiencing frustration for their sibling
9	Experience- Happy	Participant reporting happy feelings or memories with their sibling

10	Experience- Meaningful activities	Participant experiences of the meaningful activities sibling is/has been involved in
11	Experience- Separate lives	Participant and sibling having different experiences (including social experiences) either growing up or currently
12	Experience- Sibling Illness	Participant recollection of sibling being sick/in hospital
13	Experience- Support of family	Experience of support of parents/other family members towards sibling, or towards participant.
14	Experience- Support of school and staff	Support provided in an educational setting to sibling and/or participant
15	Experience- 'Normal' experiences	Participant referring to their experience as 'normal' (i.e., if no disability)
16	Experience- Time spent together	Experience of doing things together. What is done when time is spent together. Includes social experiences.
17	Experience- Worry	Participant worry for their sibling
18	Experience- Jealousy	Participant jealousy towards sibling

	Participant Relationship with Sibling	The sibling relationship from the perspective of the participant
19	Relationship - On sibling terms	Relationship is adapted to be on the siblings' terms
20	Relationship - Supportive	Providing emotional support within the sibling relationship
21	Relationship - 'the norm'	Comparison of the sibling relationship to other typically developing sibling relationships
22	Relationship - Whole family context	The sibling relationship as discussed within the context of the other relationships between siblings or within the wider family context, including aging of parents
23	Relationship- Birth order	The sibling relationship as discussed within the context of the birth order of the participant and their sibling
24	Relationship- Development	The development/change in the sibling relationship from childhood to adolescence to adulthood.
25	Relationship- Difficulties	Negative aspects (including conflict) of the sibling relationship

26	Relationship- Impact of disability	The impact that the sibling's disability (including cognition, or cognitive changes) has had on the sibling relationship.
27	Relationship- Maintenance	How the sibling relationship is maintained - e.g., regular contact
28	Relationship- One sided	Inequality of feelings or support across the sibling relationship
29	Relationship- Sympathetic	Feeling sympathy towards their sibling/ understanding the difficulties they face
30	Relationship- Teasing	Teasing between the participant and their sibling
31	Relationship- Positive	The closeness/warmth/positive aspects of the sibling relationship
32	Relationship- Times of transition	The sibling relationship during times of transition in the life of either the participant, the sibling or both.
33	Relationship- Comparisons	The participant and sibling being compared to one another

	Participant Role	The role the participants currently plays, or has played in the past, in relation to their sibling who uses AAC.
34	Role- Advocate	Participant supporting/promoting the best interests of their sibling. Eg., fighting for services, environmental adaptations etc.
35	Role- Carer	Participant acting as a carer for their sibling in activities of daily living
36	Role- Conflicting roles	Participant inhabiting two or more roles that are perceived as conflicting roles
37	Role- Expert in AAC	Participant is relied upon to know their sibling's AAC system and is called upon to demonstrate this
38	Role- Expert in communicating with sibling	Participant facilitating interactions with others, interpreting sibling communication and teaching others how to do so
39	Role- Friend	Participant acting as a friend to their sibling, e.g., catching up, spending time together, playing together as children etc.
40	Role- Protector	Participant acting to protect their sibling
41	Role- Service liaison	Participant acting as the go to person for services to contact regarding their sibling

42	Role- Teacher	Participant acting as a teacher of skills or other learning for their sibling
43	Role- Role model	Participant acting as a role model towards their sibling

Participant Experiences of Involvement in SLT or Other Sibling Interventions		The participant experiences of their involvement as a sibling in the SLT of their sibling, or else in other non-SLT interventions
44	Involvement - Additional Activities	Participant taking part in additional activities within a sibling group, but outside of the clinic setting
45	Involvement - Implementation strategies	Implementation strategies discussed - e.g., how the participant was taught the information in the groups/sessions
46	Involvement - Pressure to attend	Participant experience of (or lack of) external or internal pressure to attend SLT or other groups/sessions.
47	Involvement - Things which impact on involvement	Things that were reported to impact on participant involvement in SLT/ other sessions
48	Involvement- Gaining perspective	Participant comparing themselves/ their sibling to others in a group.
49	Involvement- General	General information regarding involvement in therapies
50	Involvement- Helpful	Participant reporting the benefits of attending appointments
51	Involvement- Impact on career choice	Impact of involvement in SLT/ other sessions on choice of career
52	Involvement- Individual sessions	Participant experience of (potentially unplanned) involvement in 1-1 sessions for sibling
53	Involvement- Peer support	Experience of meeting others in a similar situation to the participant
54	Involvement- Wanting to be involved	Participant reporting curiosity and wanting to be involved in sessions/groups etc
55	Involvement- Change	A change in the involvement of the participant in therapies for their sibling over time

Participant Opinions of Involvement in SLT		Participant opinions, in general, of the involvement of siblings of individuals who use AAC in SLT
56	Opinion- Group Sessions	Participant opinion of involving siblings in group sessions
57	Opinion- 1-1 sessions	Participant opinion of involving siblings in 1:1 sessions
58	Opinion- Considerations	Participant opinions on potential considerations to take in when involving siblings. Any potential negative factors to acknowledge.
59	Opinion- Motivational factors	The participants opinions on potential factors impacting on a person's motivation to attend a sibling training/group/session
60	Opinion- Value of training siblings	Participant opinions of the value of sibling involvement in SLT in general

Appendix M. Copy of Ethics Committee's Approval Letters – Surveys

Survey A -Adolescents



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Application	Academic Year 2020/21
Applicant Code	HT44
Applicant/Supervisor Name	Aideen Lynam / Dr Yvonne Lynch, Prof Martine Smith
Title of Research	Adolescent Opinions on The Structure of a Hypothetical Speech and Language Therapy Training
Date of this letter	14/05/2021

Dear Aideen,

Your amended submission (dated 11/05/2021) for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one electronic copy (to slscs@tcd.ie)
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

A handwritten signature in black ink, appearing to read 'Ciarán Kenny'.

Dr Ciarán Kenny
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Scoil na nEolalochtaí Teangeolaíochta,
Uíbhíne agus Cumarsáide,
Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

School of Linguistic, Speech &
Communication Sciences,
Trinity College,
Dublin 2, Ireland

T 353 (0)1 896 1560
slscs@tcd.ie
www.tcd.ie/slscs

Survey B – Parents/Guardians



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Application	Academic Year 2020/21
Applicant Code	TT54
Applicant/Supervisor Name	Aideen Lynam/ Dr Yvonne Lynch, Prof Martine Smith
Title of Research	Parent/Guardian Perspectives on The Structure of a Hypothetical Speech and Language Therapy Training for their Child
Date of this letter	09/06/2021

Dear Aideen,

Your amended submission (received 08/06/2021) for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one electronic copy (to slscs@tcd.ie)
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

A handwritten signature in cursive script, reading "Ciarán Kenny".

Dr Ciarán Kenny
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Survey C- SLTs



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Application	Academic Year 2020/21
Applicant Code	TT53
Applicant/Supervisor Name	Aideen Lynam/ Dr Yvonne Lynch, Prof Martine Smith
Title of Research	SLT Experiences and Perspectives of Communication Partner Training in AAC
Date of this letter	09/06/2021

Dear Aideen,

Your amended submission (received 08/06/2021) for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one electronic copy (to slscs@tcd.ie)
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

A handwritten signature in blue ink that reads "Ciarán Kenny".

Dr Ciarán Kenny
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Appendix N. Parent/Guardian PIL for Survey A (12-17 year olds)

Title: Adolescent Opinions on The Structure of a Hypothetical Speech and Language Therapy Training

Principle Investigator: Aideen Lynam, Ph.D. Candidate, Trinity College Dublin (lynamai@tcd.ie)

Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchyv@tcd.ie), Trinity College Dublin

Dear Parent/Guardian,

Your teenage child is being invited to take part in a research study that is being done by Aideen Lynam from Trinity College Dublin. Before you decide whether you will allow them to take part, please read the information on the next page carefully. You should understand what the survey entails so that you can make a decision that is right for you and your teenage child. You may wish to discuss it with others. You can contact me on lynamai@tcd.ie if there is anything that is not clear or if you would like more information.

Thank you for reading this,

Yours faithfully,

Aideen Lynam

Why is this study being done?

I am undertaking a PhD looking at how we can design training for adolescents to enable them to support siblings or peers with communication difficulties. I am doing this study to understand more about the learning style preferences of adolescents. This information will help us to design training for adolescents that is tailored to their preferences.

Why has my teenage child been invited to take part?

Your teenage child has been invited to take part because they are aged between 12 and 17. If you have a teenage child who aged between 18 and 21 and wishes to take part, please contact lynamai@tcd.ie. We aim to have 100 people involved in this study.

Do they have to take part? Can they withdraw? What happens if I or my teenage child changes our mind?

Your teenage child doesn't have to take part in this study. It is up to you and your teenage child to decide whether or not to take part. The information your teenage child provides in this survey is anonymous so no one will know if they have taken part. You can change your mind about your teenage child taking part in the survey and they can opt out at any time by exiting the browser. Again, no one will know they have done this. They can exit without saving any of their answers by exiting immediately. Alternatively, they can partly finish the survey by answering any of the questions they feel comfortable answering and submitting their answers. Even if you sign the consent form, this does not mean your teenage child has to take part, it only means you are allowing them to take part if they choose to.

What do I need to do if I decide to allow them to take part? If you allow your teenage child to take part, please click on the link to the consent form - [Parent/Guardian Consent Form](#). Once you have submitted this, you will receive an email or a text with a link to the survey for your teenage child. If your teenage child decides to take part, they will be asked a series of multiple choice and open-ended questions regarding their personal preferences in relation to a hypothetical training scenario. This will take them approximately 15 minutes to complete.

Are there any benefits to taking part in this research? Taking part in this study will not directly benefit your teenage child. However, research using their data and information may help us to better understand what structure of intervention would suit adolescents best and what would motivate them to take part. This is a long-term research project, so the benefits of the research may not be seen for several years.

Are there any risks to my teenage child or others if they take part? There are no identified risks if your teenage child takes part in this research. They can stop completing the survey at any point if they no longer wish to continue and their data will not be saved.

How will my data be used? Data from this research project may be published in future in medical or educational journals. The information your teenage child provides will be completely anonymous and so they will not be able to be identified in any reports or publications.

What information about my teenage child (personal data) will be used as part of this study? We will not collect any personal data from your teenage child – all their answers will be anonymous. This means that we will not know which answers are theirs and we will not be able to link the answers to them. This does mean that once they submit their answers to the survey, we cannot pick out which answers are theirs and so will not be able to find them to give them to you or your teenage child or to delete them. Please make sure your teenage child is willing to take part in the study and is happy with their answers before submitting them. Your personal data (your name, email address or phone number) that you provide on the consent form will only be used to contact you to provide you with a form for your teenage child. This data will be recorded on an excel sheet in a password protected folder on One Drive.

Who will have access my personal data? What will happen to my personal data? All the personal data that we collect about you on the consent form will be kept strictly confidential and will only be accessible to members of the research team Aideen Lynam and her supervisors, Professor Martine Smith and Dr. Yvonne Lynch. Data that can identify you will be kept for 7 years . After this time period your personal data will be destroyed by Professor Martine Smith.

Will my personal data be kept confidential? How will my data be kept safe? We take many steps to make sure that we protect your confidentiality and keep your data safe. Any information or data which is obtained during this research which identifies you will be treated confidentially. All the data collected will be stored on a secure cloud

folder accessible only to the researchers. All individual researchers involved in this project have been trained in data protection law and are bound by professional code to maintain confidentiality. It is important to note that your personal data will not be connected to your teenage child's survey responses. This means that no one, including the researchers will be able to identify which answers were completed by your teenage child and will not be able to link them to you. This means that their survey answers are completely anonymous.

What is the lawful basis to use my personal data? According to data protection legislation(1), we are required to inform you of the legal basis for using your personal data. The tasks we are performing are considered to be in the public interest(2)

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to have your data transferred to another organisation or 'data controller'
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Aideen Lynam (lynamai@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie Website: www.tcd.ie/privacy

1 The European General Data Protection Regulation (GDPR)

2 Article 6(1)(e)

It is important to note that your personal data will not be connected to your teenage child's survey responses. This means that if you request access to your data, or request deletion of your data, this will only apply to your personal data (name, email address and phone number), not your teenage child's survey responses. Once your teenage child has completed the survey it is not possible to retrieve their answers as they will be anonymous.

Has this study been approved by a research ethics committee? Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 14th May 2021.

Who is organising and funding this study? This study is being funded by the Provost's PhD award in Trinity College Dublin.

Is there any payment for taking part? No, your teenage child will not be paid for completing this survey.

Future Research *Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions about how to structure training to suit adolescents. By completing this survey, you are agreeing to allow your teenage child's answers to be available for future research.*

If you have any concerns or questions, you can contact:

Principal Investigator: Aideen Lynam – lynamai@tcd.ie

Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie Website: www.tcd.ie/privacy

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie

Thank you for reading this information.

If you are willing to consent for your teenage child to take part in this survey, please click on this link and fill in your details

[Click Here for Consent Form](#)

Appendix O. Parent/Guardian Consent Form for Survey A (12-17 year olds)

Title: Adolescent Opinions on The Structure of a Hypothetical Speech and Language Therapy Training

Principle Investigator: Aideen Lynam, Ph.D. Candidate, Trinity College Dublin (lynamai@tcd.ie)

Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchyv@tcd.ie), Trinity College Dublin

Thank you for considering your teenage child's participation in this study.

This research seeks to understand more about the learning style preferences of adolescents. This information will help us to design training for adolescents that is tailored to their preferences. This survey is part of a bigger research project looking at how we can design training for adolescents to enable them to support siblings or peers with communication difficulties.

We are a team of researchers from Trinity College Dublin. This study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 14th May 2021.

If you are interested in your teenage child taking part in this study and they are interested also, we ask you to make sure to read the information sheet for this study which can be found here: [Study Information for Parents/Guardians](#). This describes what this study is about and what is involved.

If you agree to your teenage child taking part in this study, please complete the consent form below. Once you have submitted this, you will receive a link to the survey via email or phone within 48 hours. If you have any questions, please don't hesitate to email the lead researcher – Aideen Lynam (lynamai@tcd.ie)

I confirm I have read and understood the Information leaflet for the above-named study.

Yes

No

I understand that this study is entirely voluntary, my teenage child can stop taking part in this study until they submit their anonymously completed questionnaire, without giving a reason. Even if I complete this consent form, my teenage child can decide not to complete the survey.

Yes

No

I understand consent forms with my personal details (name and contact details) will be stored separately from the completed questionnaire. There will be no link between the consent form and the study data. All study data will be anonymous.

- Yes
 No
-

I understand that personal information about me will be protected in accordance with the General Data Protection Regulation and will not be transferred outside of the EU.

- Yes
 No
-

I give permission for my teenage child's anonymous survey responses to be stored for possible future research related to how to structure training to suit adolescents without further consent being required but only if the research is approved by a Research Ethics Committee.

- Yes
 No
-

I consent for my teenage child to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet.

- Yes
 No
-

Please note

We can only send a link to the actual survey for your teenage child to you if you are their parent/guardian and have agreed to each of the above items. If you have answered 'no' to any of the above items, a survey link will not be sent to you.

Please confirm you are a parent/guardian to a teenager between the ages of 12 and 17.

- I am a parent/guardian to a teenager between the ages of 12 and 17.
 - I am not a parent/guardian to a teenager between the ages of 12 and 17.
-

Please provide your name and contact details:

(Please enter your email address OR phone number depending on how you would like to receive the survey link)

Your Name

Email Address

Phone Number

Appendix P. Survey A Questions

This is a copy of the survey for adolescents aged 18-21. The survey questions for adolescents aged 12-17 were the exact same, excepting these younger adolescents provided assent alongside parent/guardian consent.

Title: Adolescent Opinions on The Structure of a Hypothetical Speech and Language Therapy Training

Principle Investigator: Aideen Lynam, Ph.D. Candidate, Trinity College Dublin (lynamai@tcd.ie)

Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchyv@tcd.ie), Trinity College Dublin

You are being invited to take part in a research study that is being done by Aideen Lynam from Trinity College Dublin. Before you decide whether you want to take part, please read the information on the next page carefully. You should understand what this study entails so that you can make a decision that is right for you. You may wish to discuss it with others. You can contact me on lynamai@tcd.ie if there is anything that is not clear or if you would like more information.

***Thank you for reading this,
Yours faithfully,
Aideen Lynam***

Why is this study being done?

I am undertaking a PhD looking at how we can design training for adolescents to enable them to support siblings or peers with communication difficulties. I am doing this study to understand more about the learning style preferences of adolescents. This information will help us to design training for adolescents that is tailored to their preferences.

Why have I been invited to take part?

You have been invited to take part because you are aged between 18 and 21. If you are aged between 12 and 17 and wish to take part, please have a parent/guardian contact lynamai@tcd.ie. We aim to have 100 people involved in this study.

Do I have to take part? Can I withdraw? What happens if I change my mind?

You don't have to take part in this study. It is up to you to decide whether or not to take part. The information you provide in this survey is anonymous so no one will know if you have taken part. You can change your mind about taking part in the survey and you can opt out at any time by exiting the browser. Again, no one will know you have done this. You can exit without saving any of your answers by exiting immediately. Alternatively, you can partly finish the survey by answering any of the questions you feel comfortable answering and submitting your answers.

What do I need to do if I decide to take part? If you decide to take part, you will be asked a series of multiple choice and open-ended questions regarding your personal

preferences in relation to a hypothetical training scenario. This will take you approximately 15 minutes to complete.

Are there any benefits to taking part in this research? *Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand what structure of intervention would suit adolescents best and what would motivate them to take part. This is a long-term research project, so the benefits of the research may not be seen for several years.*

Are there any risks to me or others if I take part? *There are no identified risks if you take part in this research. You can stop completing the survey at any point if you no longer wish to continue and your data will not be saved.*

Data Protection

How will my data be used?

Data from this research project may be published in future in medical or educational journals. The information you provide will be completely anonymous and so you will not be able to be identified in any reports or publications.

What information about me (personal data) will be used as part of this study?

We will not collect any personal data from you – all their answers will be anonymous. This means that we will not know which answers are yours and we will not be able to link the answers to you. This does mean that once you submit your answers to the survey, we cannot pick out which answers are yours and so will not be able to find them to give them to you or to delete them. Please make sure you are willing to take part in the study and are happy with your answers before submitting them.

Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 14th May 2021.

Who is organising and funding this study? This study is being funded by the Provost's PhD award in Trinity College Dublin. Is there any payment for taking part? No, you will not be paid for completing this survey.

Future Research

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions about how to structure training to suit adolescents. By completing this survey, you are agreeing to allow your answers to be available for future research.

Future Information

If you have any concerns or questions, you can contact: Principal Investigator: Aideen Lynam – lynamai@tcd.ie Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie Website: www.tcd.ie/privacy Under GDPR, if you are not

satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie

By completing the survey on the next page, you are agreeing that:

I confirm I have read and understood the information for the above study.
I understand my answers will be anonymous – no one will be able to identify which answers are mine.
I understand that this study is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason.
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information above.
I give permission for my personal information to be stored for possible future research related to how to structure training to suit adolescents without further consent being required but only if the research is approved by a Research Ethics Committee.

Please confirm the below statements. You must agree to these statements to get access to the survey.

	Yes	No
I consent to taking part in this survey	<input type="radio"/>	<input type="radio"/>
I confirm I am aged 18-21	<input type="radio"/>	<input type="radio"/>

1. **What age are you?**
2. **What is your gender?**
3. **What is your occupation? (Choose as many as necessary)**
 - I attend school
 - I attend college/university/3rd level institution
 - I work full time
 - I work part time
 - I am unemployed
 - Other
4. **Do you know anybody who has difficulty communicating? Having a communication difficulty can affect a person's ability to speak, read, write and understand someone else's words.**

Yes, No
5. **If yes, who is this person to you? [Select multiple if you know more than one person who has difficulty communicating]**

Parent, Sibling, Friend, Classmate, Neighbour, Other

This study is researching how adolescents would prefer a speech and language training to be structured. For the rest of these questions, imagine you have a brother or sister who stutters. You are invited to attend some training. During this training you will learn more about stuttering and some strategies to help you communicate better with your brother or sister. Stuttering is a communication difficulty that can affect both children and adults. Even though the person knows what they want to say, the words don't come out smoothly. If you would like to have a better idea of what stuttering is, click on the link for a short video of people talking about their stutter - [Link to Youtube clip about Stuttering](#)

6. **Would you prefer the training to be**

Online, In person A mix of both online and in person, Whatever, I don't mind
7. **Why would you prefer this?**
8. **Would you prefer the training to be**
 - Individual 1-1 training
 - In pairs, with someone around my age
 - In small groups of people around my age (e.g., 3-10)
 - In large groups of people around my age (e.g., 11-20)
 - I don't mind, anything would suit me

9. Why would you prefer this?

10. Would you prefer to do the training with your sister or brother who stutters or without them?

- With my sister or brother who stutters
- Without my sister or brother who stutters
- I don't mind, either would suit me

11. Why would you prefer this?

11. How many hours per month would you be willing to attend a training?

1 hour or less, 2-4 hours, 4-6 hours, 6-8 hours, Over 8 hours

12. If you were asked to attend for 6 hours of training, how would you prefer the training to be structured?

One/two long sessions, Multiple short sessions, I don't mind, either would suit me

13. If you were asked to attend 6 training sessions, how would you prefer them to be spaced out?

- More than once a week
- Once a week
- Once a fortnight
- Once a month
- Less than once a month

14. If the training was to take 4 hours, how would you prefer them to be structured?

- 1 hour sessions, once a week for 4 weeks
- A once-off 4 hour session
- Two 2-hour sessions in the same week
- One 2- hour sessions, each week for 2 weeks
- A 1- hour session, once a fortnight for 8 weeks
- A 1-hour session, once a month for 4 months
- Other

15. Why would you prefer this structure?

16. When would you prefer the training to take place?

- Weekday mornings
- Weekday afternoons
- Weekday evenings
- Weekends
- During summer or school holidays
- Any time at all as long as I have enough notice
- Other

17. Why would you prefer this?

18. Is there any time which would not suit you at all to do the training? (Choose as many as necessary)

- Weekday mornings
- Weekday afternoons
- Weekday evenings
- Weekends
- During summer or school holidays
- Any time at all as long as I have enough notice
- Other

19. Why would you prefer this?

20. What do you think is the best way to learn about something new?

- By reading about it
- By reading or listening about it then having the opportunity to write notes myself
- By hearing someone talk about it
- By seeing it in action
- By having a chance to do it myself
- Other:

21. What strategies do you feel would help you learn about stuttering and how you could help your brother/sister who stutters? (Choose as many as necessary)

Hearing someone describe what I am to do

- Having someone show me a power point presentation of what I am to do
- Hearing from others who have tried this before me about what worked and didn't work for them
- Hearing from someone who stutters about how it impacts them and how others could help
- Reading a book about the topic
- Having information sheets to take home after a training to remind me of what I learned
- Watching a video of someone doing the skill in a real situation
- Having someone show me how to do the skill
- Having a chance to practice the skill by myself
- Having a chance to role play the skill with others
- Knowing what the goals are before I start training
- Doing a quiz before I start to know where my gaps in understanding are and what I have to learn
- Having a chance to talk through the strategies with others who are learning about it with me
- Other

22. Rank the top 5 strategies that help you learn something new. [1 is the strategy that helps you the best, 2 is the strategy that helps you second best etc. Type the number in the space beside the strategy.]

- Hearing someone describe what I am to do
- Having someone show me a power point presentation of what I am to do
- Hearing from others who have tried this before me about what worked and didn't work for them
- Hearing from someone who stutters about how it impacts them and how others could help
- Reading a book about the topic
- Having information sheets to take home after a training to remind me of what I learned
- Watching a video of someone doing the skill in a real situation
- Having someone show me how to do the skill
- Having a chance to practice the skill by myself
- Having a chance to role play the skill with others
- Knowing what the goals are before I start training
- Doing a quiz before I start to know where my gaps in understanding are and what I have to learn
- Having a chance to talk through the strategies with others who are learning about it with me
- Other

23. What would motivate you to agree to attend the training? (Scale: This would definitely motivate me to attend, This would probably motivate me to attend, This might motivate me to attend, This would not motivate me to attend)

- My friends/others I know are taking part with me
- I know I will learn something from it
- I know and agree with the goals of the training
- I have a chance to meet others in a similar situation to me
- I want to help my brother/sister who stutters
- I think it will be fun and I will enjoy it
- I have heard from other people who have done it and who thought it was good
- Other

24. Rank the top 5 things that would make you agree to attend the training? [1 is the biggest thing that would make you agree, 2 is the second biggest thing that would make you agree etc. Type the number in the space beside the sentence.]

- My friends/others I know are taking part with me
- I know I will learn something from it
- I know and agree with the goals of the training
- I have a chance to meet others in a similar situation to me
- I want to help my brother/sister who stutters
- I think it will be fun and I will enjoy it
- I have heard from other people who have done it and who thought it was good
- Other

25. What would make a training more enjoyable for you? (Choose as many as necessary)

- We get to go on outings as a group
- There are a range of people the same age as me doing the training with me
- There is a theme associated with the training (e.g. art, sports etc)
- I get to create something individually or as part of the group (for example a poster talking about stuttering, a video to show how I could help somebody with a stutter etc.)
- There are clear goals for the training and I can see progress every session
- Other

26. If you think a theme would make the training more enjoyable, what themes would you enjoy?

Art and crafts, Sports, Video games, Books, Music, Tv/movies, Food, Puzzles/(board) games, Other

27. What would make you want to continue to do the training? For example, you have completed one day of training and are asked to attend a second day the following week... (Choose as many as necessary)

- I enjoyed the training so far
- I got on well with the others in the group
- I got on well with the instructor/trainer
- I learned something new
- I felt what I learned would make a difference to me
- I felt what I learned would make a difference to my brother/sister who stutters
- Anything else?

28. **What would cause you to refuse to attend the training?** (Scale: This would definitely make me want to refuse, This would probably make me want to refuse, This might make me want to refuse, This would make no difference to me)

- If none of my friends or people I know are attending
- I don't think I would learn anything from it
- I don't know or agree with the goals of the training
- I don't think it will help my brother/sister who stutters
- I don't think it will be fun or I won't enjoy the training
- I've heard from other people who didn't think the training helped them
- Other

29. **What would make you want to stop doing the training? For example, you have completed one day of training and are asked to attend a second day the following week... (Choose as many as necessary)**

- I did not enjoy the training so far
- I felt I did not relate to others in the group
- I didn't like the trainer/instructor and their style of teaching
- I didn't learn anything new
- I didn't think what I learned would make a difference to me
- I didn't think what I learned would make a difference to my brother/sister who stutters
- I wouldn't have time to attend every week
- Anything else?

30. **Imagine instead this training was for a friend/classmate rather than a brother or sister. Would you change any of your answers from the survey?**

Yes, No

31. **If yes, what would you change? For example the amount of time you'd be willing to commit to the training, what would motivate you to attend the training or how you would like the training to be structured?**

Appendix Q. Survey B Questions

Title: Parent/Guardian Perspectives on The Structure of a Hypothetical Speech and Language Therapy Training for their Child.

Principal Investigator: Aideen Lynam, Ph.D. Candidate, Trinity College Dublin (lynamai@tcd.ie)

Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchyv@tcd.ie), Trinity College Dublin

You are being invited to take part in a research study that is being done by Aideen Lynam from Trinity College Dublin. Before you decide whether you want to take part, please read the below information carefully. You should what this study entails so that you can make a decision that is right for you. You may wish to discuss it with others. You can contact me on lynamai@tcd.ie if there is anything that is not clear or if you would like more information.

**Thank you for reading this,
Yours faithfully,
Aideen Lynam**

Why is this study being done?

I am undertaking a PhD looking at how we can design training for children to enable them to support siblings or peers with communication difficulties. I am doing this study to understand more about how parents/guardians would prefer a training to be structured.

Why have I been invited to take part?

You have been invited to take part because you are a parent/guardian of at least one child aged between 6 and 12. We aim to have 50 people involved in this study.

Do I have to take part? Can I withdraw? What happens if I change my mind? You don't have to take part in this study. *It is up to you to decide whether or not to take part.* The information you provide in this survey is anonymous so no one will know if you have taken part. You can change your mind about taking part in the survey and you can opt out at any time by exiting the browser. Again, no one will know you have done this. You can exit without saving any of your answers by exiting immediately. Alternatively, you can partly finish the survey by answering any of the questions you feel comfortable answering and submitting your answers.

What do I need to do if I decide to take part? If you decide to take part, you will be asked a series of multiple choice and open-ended questions regarding your personal preferences in relation to a hypothetical training scenario for your child. This will take you approximately 30 minutes to complete.

Are there any benefits to taking part in this research? Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand what structure of intervention would suit parents/guardians

best. This is a long-term research project, so the benefits of the research may not be seen for several years.

Are there any risks to me or others if I take part?

While this survey is low-risk, you might become fatigued answering the questions or may feel discomfort in relation to a certain question. You can stop completing the survey at any time, or skip a question if you do not feel comfortable answering.

Data Protection

How will my data be used? Data from this research project may be published in future in medical or educational journals. The information you provide will be completely anonymous and so you will not be able to be identified in any reports or publications.

What information about me (personal data) will be used as part of this study?

We will not collect any personal data from you – all their answers will be anonymous. This means that we will not know which answers are yours and we will not be able to link the answers to you. This does mean that once you submit your answers to the survey, we cannot pick out which answers are yours and so will not be able to find them to give them to you or to delete them. Please make sure you are willing to take part in the study and are happy with your answers before submitting them.

Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 9th June 2021.

Who is organising and funding this study?

This study is being funded by the Provost's PhD award in Trinity College Dublin. Is there any payment for taking part? No, you will not be paid for completing this survey.

Future Research

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions about how to structure training to suit parent/guardians. By completing this survey, you are agreeing to allow your answers to be available for future research.

Future Information

If you have any concerns or questions, you can contact: Principal Investigator: Aideen Lynam – lynamai@tcd.ie Supervisors: Prof. Martine Smith (mmsmith@tcd.ie) or Dr. Yvonne Lynch (lynchyv@tcd.ie) Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie Website: www.tcd.ie/privacy Under GDPR, if you are not

satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie

By completing the survey on the next page, you are agreeing that:

- I am a parent/guardian of at least one child aged between 6 and 12.
- I confirm I have read and understood the information for the above study.
- I understand my answers will be anonymous – no one will be able to identify which answers are mine.
- I understand that this study is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason.
- I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information above.
- I give permission for my personal information to be stored for possible future research related to how to structure training to suit parents/guardians without further consent being required but only if the research is approved by a Research Ethics Committee.

Q5 Please confirm the below statement. You must provide your consent to get access to the survey.

	Yes	No
I consent to taking part in this survey	<input type="radio"/>	<input type="radio"/>

1. **What age is your child/children?**
2. **What is your gender?**
3. **Do you know anybody who has difficulty communicating? Having a communication difficulty can affect a person's ability to speak, read, write and understand someone else's words.**

Yes, No

4. **If yes, who is this person to you? [Select multiple if you know more than one person who has difficulty communicating]**

Spouse, Child, Friend, Parent, Sibling, Colleague, Neighbour, Other

The aim of this research is to understand how parents would ideally like a speech and language training programme for their child to be structured. For the rest of these questions, imagine you have a child, aged 4, who stutters. Speech and Language therapists often work directly with young children who stutter, but they often also offer sessions to other family members, to help support optimal communication in the home. Imagine that another of your children (aged between 6 and 12) is invited to attend some training. During this training they will learn more about stuttering and some strategies to help them communicate better with their brother or sister who stutters. *Stuttering is a communication difficulty that can affect both children and adults. Even though the person knows what they want to say, the words don't come out smoothly. If you would like to have a better idea of what stuttering is, click on the link for a short video of people talking about their stutter - [Link to Youtube clip about Stuttering.](#) If you have more than one child aged between 6 and 12, please answer these questions with only one child in mind.*

5. **What age is the child that you will be referring to for the rest of this survey? [Must be between 6 and 12]**
6. **Would you prefer the training to be held**
 - Online
 - In person
 - A mix of both online and in person
 - Whatever my child would prefer
 - Either, it wouldn't matter to me
7. **Why would you prefer this?**

- 8. Would you prefer the training to be**
- Individual 1-1 training
 - In pairs, (i.e. with another young person of a similar age)
 - In small groups of age peers (3-10)
 - In large groups of age peers (11-20)
 - I don't mind, whatever my child would prefer
 - Other
- 9. Why would you prefer this?**
- 10. If you, as a parent, were also invited to attend a training, would you prefer to attend**
- Together as a whole family OR Separately (i.e., you would go to a parent-only group and your child would go to a siblings-only group)
- 11. Why would you prefer this?**
- 12. How many hours per month would you be willing to commit to bringing your child who does not stutter to a training programme?**
- 1 hour or less, 2-4 hours, 4-6 hours, 6-8 hours, Over 8 hours
- 13. How often would you be willing to bring your child who does not stutter to the training?**
- More than once a week, Once a week, Once a fortnight, Once a month, Less than once a month, Other
- 14. How would you like the sessions to be scheduled?**
- One/two long sessions, Multiple short sessions, Either would work for me
- 15. If the training was to take 4 hours, how would you prefer them to be structured?**
- 1 hour sessions, once a week for 4 weeks
 - A once-off 4 hour session
 - Two 2-hour sessions in the same week
 - One 2- hour sessions, each week for 2 weeks
 - A 1- hour session, once a fortnight for 8 weeks
 - A 1-hour session, once a month for 4 months
 - Other
 - No preference
- 16. Why?**
- 17. When would you prefer the training to take place?**
- Weekday mornings
 - Weekday afternoons

- Weekday evenings
- Weekends
- During summer or school holidays
- Any time would suit as long as I have enough notice
- Other

18. Why?

19. Is there any time which would not suit you at all to bring your child to the training? [Choose as many as applicable]

- Weekday mornings
- Weekday afternoons
- Weekday evenings
- Weekends
- During summer or school holidays
- Any time would suit as long as I have enough notice
- Other

20. Why?

21. What do you think is the best way for your child to learn about something new?

- By reading about it
- By reading or listening about it then having the opportunity to write notes themselves
- By hearing someone talk about it
- By seeing it in action
- By having a chance to do it themselves
- Other

22. What do you think would motivate your child to attend a training in the first place? (Scale: This would definitely motivate them to attend a training, This would probably motivate them to attend a training, This might motivate them to attend a training, This wouldn't make a difference to them)

- Their friends/others they know are taking part with them
- They know they will learn something from it
- They know and agree with the goals of the training
- They have a chance to meet other siblings in a similar situation to them
- They would want them to know how to help their brother/sister who stutters
- They think it will be fun and they will enjoy it
- They have heard from other people who have done it and who thought it was good
- They would do it to please me as a parent
- Other

23. **What do you think would motivate you to bring your child to the training and encourage them to participate?** (Scale: This would definitely motivate me to bring them, This would probably motivate me to bring them, This might motivate me to Bring them, This wouldn't make a difference to me)

- Their friends/others they know are taking part with them
- I know they will learn something from it
- I know and agree with the goals of the training
- They have a chance to meet other siblings in a similar situation to them
- I would want them to know how to help their brother/sister who stutters
- I think it will be fun and they will enjoy it
- I have attended a training in the same service and I found it helpful
- They have made it clear to me that they want to attend
- It is easy to get to and it is on at a good time for me
- I would get to meet parents of other children who stutter
- Other

24. Rank the top 5 things that would motivate you to bring your child to the training? [1 is the biggest thing that would motivate you, 2 is the second biggest thing that would motivate you etc. Type the number in the space beside the sentence.]

- Their friends/others I know are taking part with them
- I know they will learn something from it
- I know and agree with the goals of the training
- They have a chance to meet others in a similar situation to them
- I would want to know how to help their brother/sister who stutters and I think it would make a difference to my child who stutters
- I think it will be fun and they will enjoy it
- I have attended a training in the same service and I found it helpful
- They have made it clear to me that they want to attend
- It is easy to get to and it is at a good time for me
- I would get to meet parents of other children who stutter
- Other

25. What would make a training more enjoyable for your child? [Choose as many as applicable]

- They get to go on outings as a group
- There are a range of people the same age as them doing the training with them
- There is a theme associated with the training (e.g. art, sports etc)
- They get to create something individually or as part of the group (for example a poster talking about stuttering, a video to show how they could help somebody with a stutter etc.)
- There are clear goals for the training and they can see progress every session
- Other

26. If you think a theme would make the training more enjoyable, what themes would your child enjoy? [Choose as many as applicable]

Art and crafts, Sports, Video games, Books, Music, Tv/movies, Food, Puzzles/(board) games, Other

27. What do you think would make you to reluctant to bring your child to the training? (Scale: This would definitely make me reluctant to bring them, This would probably make me reluctant to bring them, This might make me reluctant to bring them, This wouldn't affect my decision)

- If none of their friends or people they know are attending
- I don't think they would learn anything from it
- I don't know or agree with the goals of the training
- I know my child wouldn't be interested in meeting new people who are in the same situation as them
- I don't think it will help their brother/sister who stutters
- I don't think it will be fun or they won't enjoy the training
- I attended a training in the same service and I didn't find it helpful
- They have made it clear to me that they don't want to go
- The time it is on at isn't good for me or it is not easy to get to for me
- Other

28. What would cause you to want to continue to bring your child to the training? For example, they have completed one day of training and are asked to attend a second day the following week. [Choose as many as applicable]

- They enjoyed the training so far
- They got on well with the others in the group
- They got on well with the instructor/trainer
- They learned something new
- They felt what they learned would make a difference to them
- They felt what they learned would make a difference to their brother/sister who stutters
- They have made it clear to me that they want to continue to attend
- Anything else?

29. What would cause you to want to stop bringing your child to the training? For example, you have completed one day of training and are asked to attend a second day the following week. [Choose as many as applicable]

- They did not enjoy the training so far
- They felt they did not relate to others in the group
- I and/or my child didn't like the trainer/instructor and their style of teaching
- They didn't learn anything new
- I don't think what they learned would make a difference to them
- They didn't think what they learned would make a difference to their brother/sister who stutters
- I wouldn't have time to bring them every week
- They have made it clear to me that they do not want to go again
- Anything else?

30. Please rank the top 5 reasons you may be reluctant to continue to bring your child to a training - For example, you have completed one day of training and are asked to attend a second day the following week. [1 is the biggest thing that would make you reluctant, 2 is the second biggest thing that would make you reluctant etc. Type the number in the space beside the sentence.]

- They did not enjoy the training so far
- They felt they did not relate to others in the group
- I and/or my child didn't like the trainer/instructor and their style of teaching
- They didn't learn anything new
- I don't think what they learned would make a difference to them
- They didn't think what they learned would make a difference to their brother/sister who stutters
- I wouldn't have time to bring them every week
- They have made it clear to me that they do not want to go again
- Other

31. Imagine instead your child is being invited to attend a training to help a friend/classmate who stutters (instead of a sibling). Do you think this would change how you would have answered the questions in this survey?

Yes, No

32. If yes, please explain how you might have answered differently. For example the amount of time you'd be willing to commit to bringing your child to the training, what would motivate them to attend the training or how you would prefer the training to be structured?

33. Who generally brings your child/children to a medial/educational appointment?

You, Your spouse/partner/the child's other parent, Another family member, It varies, whoever is available, Other

Appendix R. Survey C Questions

Title: Speech and Language Therapists Experiences and Perspectives of Communication Partner Training in AAC in Ireland.

Principal Investigator: Aideen Lynam, Ph.D. Candidate, Trinity College Dublin (lynamai@tcd.ie)

Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchyv@tcd.ie), Trinity College Dublin

You are being invited to take part in a research study that is being done by Aideen Lynam from Trinity College Dublin. Before you decide whether you want to take part, please read the below information carefully. You should understand what the study entails so that you can make a decision that is right for you. You may wish to discuss it with others. You can contact me on lynamai@tcd.ie if there is anything that is not clear or if you would like more information.

Thank you for reading this,

Yours faithfully,

Aideen Lynam

Why is this study being done?

I am undertaking a PhD looking at how we can design a communication partner training for siblings of individuals who use AAC. I am doing this study to understand more about the experiences and opinions of SLTs working in Ireland. This information will help us to design a training for siblings that is feasible and aligns with SLT goals.

Why have I been invited to take part? You have been invited to take part because you are a Speech and Language Therapist in Ireland who has worked with individuals who use AAC for at least 1 year. We aim to have 50 people involved in this study.

Do I have to take part? Can I withdraw? What happens if I change my mind? You don't have to take part in this study. *It is up to you to decide whether or not to take part.* The information you provide in this survey is anonymous so no one will know if you have taken part. You can change your mind about taking part in the survey and you can opt out at any time by exiting the browser. Again, no one will know you have done this. You can exit without saving any of your answers by exiting immediately. Alternatively, you can partly finish the survey by answering any of the questions you feel comfortable answering and submitting your answers.

What do I need to do if I decide to take part? If you decide to take part, you will be asked a series of multiple choice and open-ended questions regarding your experiences and opinions of communication partner training in AAC. This will take you approximately 20 minutes to complete.

Are there any benefits to taking part in this research? Taking part in this study will not directly benefit you. However, research using your data and information may provide us with more knowledge regarding SLT experiences and opinions of

communication partner training in AAC. This is a long-term research project, so the benefits of the research may not be seen for several years.

Are there any risks to me or others if I take part? While this survey is low-risk, you might become fatigued due to answering the questions or may feel discomfort in relation to a certain question. You can stop completing the survey at any time, or skip a question if you do not feel comfortable answering.

Data Protection

How will my data be used? Data from this research project may be published in future in medical or educational journals. The information you provide will be completely anonymous and so you will not be able to be identified in any reports or publications.

What information about me (personal data) will be used as part of this study?

We will not collect any personal data from you – all your answers will be anonymous. This means that we will not know which answers are yours and we will not be able to link the answers to you. This does mean that once you submit your answers to the survey, we cannot pick out which answers are yours and so will not be able to find them to give them to you or to delete them. Please make sure you are willing to take part in the study and are happy with your answers before submitting them.

Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 9th June 2021.

Who is organising and funding this study?

This study is being funded by the Provost's PhD award in Trinity College Dublin. Is there any payment for taking part? No, you will not be paid for completing this survey.

Future Research

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions about Speech and Language Therapist perspectives of communication partner training. By completing this survey, you are agreeing to allow your answers to be available for future research.

Future Information

If you have any concerns or questions, you can contact: Principal Investigator: Aideen Lynam – lynamai@tcd.ie, Supervisors: Prof. Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchyv@tcd.ie) Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie Website: www.tcd.ie/privacy Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint

with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie

By completing the survey on the next page, you are agreeing that:

- I am a Speech and Language Therapist working in Ireland.
- I confirm I have read and understood the information for the above study.
- I understand my answers will be anonymous – no one will be able to identify which answers are mine.
- I understand that this study is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason.
- I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information above.
- I give permission for my personal information to be stored for possible future research related to SLT perspectives and experiences of communication partner training interventions without further consent being required but only if the research is approved by a Research Ethics Committee.

Please confirm the below statement. You must provide your consent to get access to the survey.

	Yes	No
I consent to taking part in this survey	<input type="radio"/>	<input type="radio"/>

1. How many years have you worked as an SLT?

1 year or less, 2-5 years, 6-10 years, 11 years +

2. How many years have you worked with individuals who use AAC?

1 year or less, 2-5 years, 6-10 years, 11 years +

3. How confident are you with working with individuals who use AAC?

Extremely confident, Very confident, Moderately confident, Slightly confident, not at all confident

4. How many individuals who use AAC are currently on your caseload?

None, One, 6-10, 11-19, 20+

5. What are the ages of the individuals who use AAC who are on your caseload?

0-5 years, 6-12 years, 13-17 years, 18+ years

Communication partner training for individuals who use AAC can take place in many ways across clinical interactions. For the purpose of this survey, a distinction will be made between formal and informal communication partner training. Formal communication partner training refers to scheduled appointments where at least one goal is related to the training or education of one or more communication partner(s). Informal communication partner training refers to the training of communication partners that takes place outside of a scheduled appointment, or is not the intended focus of a session - e.g., a phone call from a parent about wanting to add vocabulary to a device or a teacher catching you in the hall to ask about a Lámh sign.

6. On average, how many hours (in total) do you spend on the formal training of communication partners of a specific individual who uses AAC?

1 hour or less, 2-5 hours, 6-10 hours, 11-20 hours, 21+ hours

7. On average, how many hours per month do you spend on the formal training of communication partners of individuals who use AAC across your caseload?

1 hour or less, 2-5 hours, 6-10 hours, 11-20 hours, 21+ hours

8. Do you think you facilitate more formal or informal communication partner training?

- I think I facilitate more formal communication partner training,
- I think I facilitate more informal communication partner training,
- I think I facilitate about the same amount of both formal and informal communication partner training,
- It depends -- Please explain.

9. On average, what proportion of your direct contact hours for individuals who use AAC is spent on both formal and informal communication partner training?

0-25%, 26-50%, 51-75%, 76-100%

10. How often do you include these communication partners in formal training?(Rating: Always, Often, Sometimes, Rarely, Never)

Parents, Grandparents, Teachers, SNA, P.A., Sibling, Peer, Other staff, professionals etc. working with the individual

11. How often do you include the individual who uses AAC in your communication partner training?

Always, Often, Sometimes, Rarely, Never

12. In the formal communication partner trainings that you have run, how many communication partners have you invited to each session? (Choose multiple if necessary)

SLT(s) and 1 communication partner, SLT(s) and 2 communication partners, SLT(s) and 3-10 communication partners, SLT(s) and 11-20 communication partners, Other

13. Ideally, how many partners would you prefer to have in a communication partner training?

SLT(s) and 1 communication partner, SLT(s) and 2 communication partners, SLT(s) and 3-10 communication partners, SLT(s) and 11-20 communication partners, Other

14. If you run formal group communication partner training, how do you decide which communication partners should be invited to attend a training together? (choose multiple if necessary)

- I invite communication partners of any service user who uses a certain type of AAC (e.g., LAMP, low tech communication boards, Lámh etc),
- I invite communication partners of any individual who uses AAC and has a similar communication profile (e.g., emergent, context dependent, independent etc.),
- I invite communication partners who play a certain role in the life of the person who uses AAC (e.g., parents only, teachers only etc.),
- I invite all communication partners of one individual who uses AAC,
- I invite all communication partners who may benefit from the training regardless of all of the above, I do not run group communication partner trainings, Other

15. For these individuals, how important do you think communication partner training is? (Scale: Extremely important, Very important, Moderately important, Slightly important, Not at all important)

For the person who uses AAC, For the family and friends of the person who uses AAC, For the staff/professionals who work alongside the person who uses AAC, For unfamiliar communication partners of the person who uses AAC (e.g., shopkeepers, Gardaí etc.)

16. What topics do you generally cover during a formal communication partner training? (e.g., general information about communication, general AAC knowledge, technical/device specific knowledge, information about the experience of others etc.)

17. What communication and AAC specific skills do you teach to communication partners during a communication partner training? (Please list specific skills/strategies e.g., modelling, wait time)

18. Are there any communication or AAC specific topics or skills that you feel are important for communication partners to learn, but that you do not currently incorporate into your training? If yes, please list the topic/skill and explain why you do not currently include it.

19. Do you think the content (i.e., topics and skills) of a communication partner training changes depending on the communication partner role (e.g., parents vs teachers vs siblings)?

Yes, Maybe, No

20. Please explain your answer choice.

21. Which schedule of formal communication partner training is more common in your service?

One/two long sessions (e.g., half day/ full day), Multiple short sessions (e.g., 1 - 2 hours), Other

22. Ideally, what schedule would you prefer a communication partner training to take?

One/two long sessions (e.g., half day/ full day), Multiple short sessions (e.g., 1 - 2 hours), Other

23. Formal communication partner trainings can be scheduled in many different ways. Please rank the below in order of the frequency they are offered in your service, with 1 being the most frequently offered and 7 being the least. Please put the number in the box beside the statement.

- Multiple short (1-2 hour) sessions on a weekday morning,
- Multiple short (1-2 hour) sessions on a weekday afternoon,
- Multiple short (1-2 hour) sessions on a weekday evening,
- Multiple sessions on a Saturday or Sunday,
- Multiple short (1-2 hours) sessions during a school holiday,
- Once off short session (e.g., 1-2 hours),
- Once off whole day training, Other (if applicable)

23. How often do you offer formal refresher communication partner training?

Every year, Every 2 years, When requested/as needed, Never, Other

24. Do you feel the frequency of a formal communication partner training refresher is satisfactory?

No, I think a refresher training should be offered less frequently; Yes, I think a refresher training is offered after an appropriate amount of time; No, I think a refresher training should be offered more frequently

25. How frequently do you think a formal communication partner refresher training should be offered?

26. Do you offer informal training/support for communication partners (e.g., ongoing support, but not formal training sessions)

Yes, No

27. If so, how is this initiated?

It is initiated by the SLT, It is initiated by the communication partner, It is initiated by the person who uses AAC

28. Does the type of training/support provided to communication partners vary by their role? (e.g., a set schedule of formal training sessions vs ongoing informal support)

Yes, Maybe, No

29. Please explain your answer choice.

30. When teaching an AAC communication partner strategy (e.g., modelling), what instructional strategies do you use?

- Describe the strategy in detail (e.g. outlining steps involved)
- Use a PowerPoint presentation with visuals to demonstrate a strategy
- Having someone who has used this strategy before describe how it worked or didn't work for them
- Having someone who uses AAC discuss how it impacts them and how others could help
- Providing reading materials e.g. a book on the topic
- Providing information sheets to take home after a training to remind participants of what they learned
- Showing a video of someone doing the strategy in a real situation
- Demonstrating in real time how to do the strategy
- Providing participants with a chance to practice the skill by themselves
- Providing participants with a chance to role play the skill with you/others
- Setting out clear goals before the training starts
- Having participants complete a quiz before they start to know where their gaps in understanding are
- Providing participants with a chance to talk through the strategies together
- Other

31. Do the instructional strategies you use when training communication partners vary depending on

The age of the communication partner, The time/resources available to you,
The role of the communication partner, The strategy/skill you are teaching,
Other

32. If you answered yes to any of the items in the last question, please explain how your use of instructional strategies changes for that variable (e.g., age or partners, time available, role of partners, skill being taught)

33. Has the COVID 19 pandemic changed the way you conduct communication partner training?

Yes, No

34. How has the COVID 19 pandemic changed the way you conduct communication partner training?

- I am completing communication partner more frequently
- I am completing more communication partner training online
- I think it is easier to conduct communication partner training
- The structure of my communication partner training has changed
- I am including different content in my communication partner trainings
- I am including different instructional strategies in my communication partner training
- I am completing less communication partner training
- I am finding it more difficult to complete communication partner training
- I am including different partners in my communication partner training
- I am completing more face to face communication partner training
- Other

35. If you have completed communication partner training online, do you feel the training works better....

Online, In person, A mix of both online and in person, Both work just as well as each other

36. Why?

37. Do you actively involve siblings in your SLT interventions (i.e., beyond simply permitting them to be present during a session)?

Yes, No

38. If you actively involve siblings in your SLT interventions, what form does this involvement take? (Choose multiple if necessary)

- I involve them in individual sessions with their sibling who uses AAC
- I involve them in sibling only communication partner training groups
- I involve them in group therapy with individuals who use AAC and other siblings
- I involve them in family communication partner training groups (e.g., alongside their parents, grandparents, other siblings etc.)
- Other

39. What age siblings have you included in your interventions?

0-5 years, 6-12 years, 13-17 years, 18+ years

40. If you were asked to deliver 4 hours of communication partner training to siblings of individuals who use AAC, which structure would be your preference?

- 1-hour sessions, once a week for 4 weeks
- Once off 4-hour session
- 2-hour sessions, twice a week for 1 week
- 2-hour sessions, once a week for 2 weeks
- 1-hour sessions, once a fortnight for 8 weeks
- 1-hour sessions, once a month for 4 months
- Other:

41. List three things you think would be important for siblings to gain from attending a communication partner training intervention in your service.

42. In your opinion, what are the advantages of involving siblings in a communication partner intervention?

43. In your opinion, what are the challenges of involving siblings in a communication partner intervention?

Appendix S. Initial Draft Guidelines

Where these guidelines originated from:

- 1: Systematic Review of Sibling Involvement in interventions for individuals with a disability
- 2: Systematic Review of Peer Communication Partner Interventions
- 3: Surveys of typically developing adolescents, parents/guardians and Speech and Language Therapists with at least 1 year working with individuals who use AAC.
- 4: Interviews with siblings of individuals who use AAC

The Guidelines

1. Siblings of individuals who use AAC should be supported and included in interventions.

- Siblings are often similar in age and may spend a lot of time together, with a relationship that can span many years.
- Siblings have been reported to want to get involved in, as well as both enjoying and benefiting from intervention – although there are very few, if any, studies within published literature which look explicitly at training siblings as communication partners (1,2, 3, 4).
- Similarly, few Speech and Language Therapists reported actively including siblings in their interventions, despite identifying potential benefits to this(3).
- Siblings of individuals who use AAC did report to have been involved in Speech and Language Therapy throughout their lives, though not necessarily in targeted communication partner interventions (4).

2. The additional roles and responsibilities siblings may be expected to take on following a communication partner training must be reflected on.

- Siblings may be expected to take on the role of 'teacher', being explicitly asked to teach their sibling who uses AAC a specific word or skill. This runs the risk of increasing the difference in the power dynamic between siblings, especially if siblings are expected to evaluate and provide feedback as part of the intervention (1).
- Some interventions, rather than introducing this additional role of 'teacher' may focus on nurturing the existing roles of playmate/companion through teaching the sibling how to use general communication and social interaction strategies. These may aid the siblings to communicate and interact more effectively (1, 4).
- Speech and Language Therapists should reflect on how the training may impact on the mental health of the sibling, siblings should be regularly consulted with to ensure they are feeling positive and not overwhelmed by the training (1,3,4).

- Given that interventions are not consistently effective (1,2), Speech and Language Therapists must also plan on what to do if the intervention is not effective for a sibling pair. Siblings might feel disappointment if the individual who uses AAC does not make observable progress. Speech and Language Therapists can help to prevent this by setting clear expectations with the siblings and their family regarding the intervention, as well as providing time for the sibling to discuss any concerns.

3. The wider family environment should be considered when planning to include siblings in an intervention.

- Due to Speech and Language Therapy service provision in Ireland focusing primarily on children, it is reasonable to assume that siblings attending an intervention may be under the age of 18 (1,2,3,4).
- Therefore, it would more than likely be parents/guardians who are initially informed of the training, as well as them encouraging and facilitating their child to attend the session(s) (3,4). This is especially true for younger siblings.
- Parents/Guardians (and any other key stakeholders, including the individual who uses AAC and other siblings) need to be considered and consulted with when deciding on the structure, timing, and goals of the intervention (3,4).
- Speech and Language Therapists should also be aware of any expectations arising from family members concerning the intervention itself and the role and responsibilities of the sibling following the intervention (3,4).

4. The intervention must be motivating for siblings to be willing to attend.

- Motivating siblings to attend the training, as well as to continue to attend the training and participate in sessions is one challenge faced by Speech and Language Therapists (3).
- Some siblings might be intrinsically motivated to attend a training, reporting to want to help their sibling (3, 4).
- Other siblings may require extrinsic motivation to attend. Knowledge of what they would learn from the training, having friends or others they know attend the training and thinking the training would be fun were reported to be motivating factors (3).
- Age may have a factor in the motivation of siblings to want to attend a training. Some siblings of individuals who used AAC reported that they were more likely to have an interest in being involved in sessions as they grew older, towards later childhood and early adolescence (4).

5. The intervention should be enjoyable for siblings.

- Enjoyment may lead to increased motivation to continue with the intervention and a willingness to be involved future interventions, as well a willingness to generalise what they learned into day to day lives (1).
- Adolescents and parents/guardians were asked what would make a training enjoyable. They reported that completing the training alongside similar aged peers and incorporating other activities or a theme into the sessions, for example sports or group activities outside of the clinic room (3,4) would increase enjoyment.

6. The intervention goals should be specific to the needs of the sibling, created collaboratively and communicated well to key stakeholders.

- Speech and Language Therapist should collaborate with key stakeholders (parents/guardians, the individuals who use AAC and especially the siblings themselves) to create the goals of the intervention. This can ensure that the training is tailored specifically to the siblings and their current strengths and needs.
- Siblings will have had different experiences with AAC, and as such will have different levels of competence and confidence with the AAC system and communicating effectively with the individual using it (2, 4). The Speech and Language Therapist should ensure to gain an understanding of the sibling's baseline knowledge, experience, and opinions of communication and AAC prior to the intervention.
- Clear goals and evident progress may aid in making a training more enjoyable and motivating for participants (3). As such, if the goals are not created collaboratively, they need to be very clearly communicated to parents/guardians and siblings, both during recruitment for the training and re-iterated during the sessions themselves.
- Individuals reported wanting to help their sibling, so it is important to ensure participants (and parents/guardians) are informed on exactly how the training could benefit them and their sibling (3,4). This also aids in setting clear expectations for the training to avoid disappointment, either with the content or the results of the training.

7. All strategies taught during the training should be evidence based.

- The strategies taught during the training should be evidence based, for example modelling, expectant delay, and open-ended questions.
- In a systematic review of peer communication partner interventions, researchers were reported to teach general communication strategies (e.g., the stay-play-talk procedure) and more specific AAC strategies (e.g., prompting, modelling, and waiting) (2).

- Speech and Language Therapists were asked about the strategies they covered during communication partner trainings. Every participant mentioned teaching the strategy of modelling, or aided language stimulation. This was followed by pause time/waiting, creating communication opportunities, expanding, and the hierarchy of prompts (3).
- When deciding on what to teach the siblings, it is important to not only consider the research evidence as above, but also clinical expertise and the preferences of the siblings, the individuals who use AAC and their parents/guardians. Speech and Language Therapists should consider what the siblings already know and build from there (4).

8. The teaching techniques used to facilitate learning during the intervention must cater for the participant's learning styles.

- Different individuals can benefit from several styles of learning when understanding new information.
- When asked about learning something new, adolescents and parents/guardians reported seeing it in action or having a chance to do it themselves as the best ways to learn (3).
- The most popular instructional techniques reported by adolescents were having someone show them how to do the skill and having a chance to practice the skill themselves (3).
- Speech and Language Therapists reported demonstrating in real time how to do the strategy, providing information sheets to take home and describing the strategy in detail when teaching an AAC communication partner strategy (3).
- The top instructional techniques reported in studies involving peer communication partner interventions were demonstration of the strategy, a description or the rationale behind why the training or specific strategy is important, the peer participating in a roleplay, time for questions or feedback from the session and providing printed materials (2).

9. An expert should be recruited to act as a co-trainer.

- One of the top techniques for facilitating learning reported by adolescents was hearing from someone who has first-hand experience of how their communication difficulty impacts them and how others could help (3).
- Speech and Language Therapists did not report regularly including individuals who use AAC in their communication partner interventions (3).
- Speech and Language Therapists could consider including an individual who uses AAC as a co-trainer during the intervention to provide an expert opinion on the topic. This may involve meetings with the individual who uses AAC prior to the training to discuss their role in the training and programme vocabulary/messages if necessary.

10. The training could take place online or in-person, but individual preference should be considered.

- Due to the recent COVID-19 pandemic telehealth facilities have become increasingly popular.
- Speech and Language Therapists reported a preference for a hybrid online and in person approach to communication partner training (3).
- The majority of adolescents and parents/guardians would prefer for the training to be held in person, with the perceived effectiveness of face to face versus online teaching, the ease of asking questions and the increased chance of engagement cited as the main reasons for this (3). *

*This survey data was gathered as the country emerged from a lockdown, with virtual classes being held frequently and so may impact on the results.

11. The training could take place in a 1-1 or a group setting, but individual preferences should be considered.

- There are no indications in the literature as to whether group or individual intervention is more beneficial for communication partners (1,2).
- Individual sessions may be utilised if there were specific goals regarding a particular individual or AAC system, while group intervention was more likely to focus on general interaction and communication strategies and peer support (1,2).
- Siblings of individuals who use AAC, while reporting seeing the value of attending a training, had different opinions on whether they would prefer a group or individual training (4).
- Speech and Language Therapists and adolescents reported preferring for the training to take place in small groups of 3 to 10 peers with adolescents citing peer support and reduced pressure as the main reasons (3).
- However, more parents/guardians reported preferring the training to be structured as a 1-1 training, referring to the opportunity for the session to be tailored for their child as well as a lack of distraction from other children as the primary benefits (3).

12. If a group training method is being utilised, the composition of the group must be carefully considered.

- The opportunity for peer support between the siblings is an important consideration if the training is facilitated in a group setting.
- There are no indications in the literature regarding how best to group communication partners (1,2).
- Some important considerations (4) when grouping siblings to ensure they can relate to one another and provide genuine opportunities for meaningful peer support include:
 - siblings of similar age

- siblings of the same birth order (e.g., being an older or younger sibling)
- siblings of individuals who use similar AAC systems
- siblings of individuals who have similar communicative abilities
- siblings of individuals who have similar diagnoses (e.g., ASD, cerebral palsy etc.)

13. The timing of the intervention should fit with the sibling's schedule.

- Siblings lead busy lives and attending a training might not be a priority compared to their own schoolwork or extracurricular activities (4).
- To ensure maximum attendance and participation from the siblings, the training should be organised for a time that best suits them, preferably a weekday evening or weekend (3). This was reported as being primarily due to school, college, or work commitments.
- Speech and Language Therapists have the responsibility to ensure the timing fits with the sibling's schedule, while still being mindful of service constraints. Evening and weekend sessions were ranked as the least frequent times offered for sessions (3).
- A compromise could be to hold the training during a school holiday (3).

14. The structure of the intervention should be flexible.

- There is no best practice or even consistent guidelines for how to structure a communication partner intervention in the literature for peers (2).
- Adolescents and parents/guardians reported that they would be willing to commit two to four hours per month to an intervention, with a preference for multiple short sessions rather than one or two long sessions (3).
- Adolescents, parents/guardians and Speech and Language Therapists were asked if the training was 4 hours in length, what would be their preferred structure. The overall preference was for one-hour sessions, once a week for four weeks.
- The reasons for this preference included consistency, short sessions equating to better concentration, time between sessions to practice and shorter sessions being more manageable (3).
- Siblings and parents/guardians may have personal opinions on what would suit them best and Speech and Language Therapists should consult with these key stakeholders to ensure the structure of the communication partner training is the best possible for all involved (3,4).

Appendix T. Copy of Ethics Committee's Approval Letter – Feedback on guidelines



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Application	Academic Year 2021/22
Applicant Code	TT71
Applicant/Supervisor Name	Aideen Lynam / Prof Martine Smith, Dr Yvonne Lynch
Title of Research	Social validity of intervention guidelines for a communication partner intervention for siblings of individuals who use AAC.
Date of this letter	27/05/2022

Dear Aideen,

Your submission for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin on 27/05/2022 and has been approved in full. We note that you also require approval of your DPIA by the relevant Data Protection Officer.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one electronic copy (to slscs@tcd.ie)
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

A handwritten signature in blue ink, appearing to read 'Ciarán Kenny'.

Dr Ciarán Kenny
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Scoil na nEalaíochtaí Teangeolaíochta,
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Appendix U. Participant Information Leaflet and Consent Form – Feedback Survey

Title: Assessing the social validity of intervention guidelines for a communication partner intervention for siblings of individuals who use AAC.

Principle Investigator: Aideen Lynam, Ph.D. Candidate, Trinity College Dublin
(lynamai@tcd.ie)

Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Professor Yvonne Lynch (lynchyv@tcd.ie), Trinity College Dublin

You are being invited to take part in a research study that is being done by Aideen Lynam from Trinity College Dublin. Before you decide whether you want to take part, please read the below information carefully. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others. You can contact me on lynamai@tcd.ie if there is anything that is not clear or if you would like more information.

Thank you for reading this,

Yours faithfully,

Aideen Lynam

Information about the study:

Why is this study being done?

I have created guidelines for a communication partner training for siblings of individuals who use AAC. The information I get from this survey will ensure that the content and structure of this training are acceptable to you, the people who could potentially be involved in their implementation. I am looking for Speech and Language Therapists and adult siblings of individuals who use AAC to look through the guidelines and then feedback to me about their opinions on them.

Why have I been invited to take part?

You have been invited to take part because you are either (a) a Speech and Language Therapist in Ireland who has worked with individuals who use AAC for at least 1 year or (b) an adult sibling of an individual who uses AAC. We aim to have 20 people involved in this study.

Do I have to take part? Can I withdraw? What happens if I change my mind?

You don't have to take part in this study. *It is up to you to decide whether or not to take part.* The information you provide in this survey is anonymous so no one will know if you have taken part.

You can change your mind about taking part in the survey and you can opt out at any time by exiting the browser. Again, no one will know you have done this. You can exit without saving any of your answers by exiting immediately. Alternatively, you can partly finish the survey by answering any of the questions you feel comfortable answering and submitting your answers. The only questions you must answer are the questions regarding your consent and your role. All other questions are optional.

What do I need to do if I decide to take part?

If you decide to take part, you will first read the guidelines of the intervention (here) and will then be asked a series of questions regarding your opinions of the guidelines. This will take you approximately 30 minutes to complete in total.

Are there any benefits to taking part in this research?

Taking part in this study will not directly benefit you. However, research using your data and information may provide us with more information regarding the acceptability of the treatment goals and procedures outlined in the guidelines. This is a long-term research project, so the benefits of the research may not be seen for several years.

Are there any risks to me or others if I take part?

There is a very small risk that you may become fatigued when answering this survey. You can stop completing the survey at any point if you no longer wish to continue or come back to it at a later time.

Data Protection

How will my data be used?

Data from this research project may be published in future in medical or educational journals. The information you provide will be completely anonymous and so you will not be able to be identified in any reports or publications.

What information about me (personal data) will be used as part of this study?

We will not collect any personal data from you – all their answers will be anonymous. This means that we will not know which answers are yours and we will not be able to link the answers to you. This does mean that once you submit your answers to the survey, we cannot pick out which answers are yours and so will not be able to find them to give them to you or to delete them. Please make sure you are willing to take part in the study and are happy with your answers before submitting them.

Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 27th May 2022.

Who is organising and funding this study?

This study is being funded by the Provost's PhD award in Trinity College Dublin.

Is there any payment for taking part?

No, you will not be paid for completing this survey.

Future Research

Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering future research questions about communication partner interventions for individuals who use AAC. By completing this survey, you are agreeing to allow your answers to be available for future research.

Future Information

If you have any concerns or questions, you can contact:

Principal Investigator: Aideen Lynam – lynamai@tcd.ie, Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Professor Yvonne Lynch (lynchyv@tcd.ie). Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie Website: www.tcd.ie/privacy, Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie

By completing the survey on the next page, you are agreeing that:

I have read the guidelines for the communication partner intervention for siblings of individuals who use AAC.
I confirm I have read and understood the information for the above study.
I understand my answers will be anonymous – no one will be able to identify which answers are mine.
I understand that this study is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason.
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information above.
I give permission for my survey response to be stored for <i>possible future research related to</i> communication partner training interventions <i>without further consent</i> being required but only if the research is approved by a Research Ethics Committee.
I consent to taking part in this study. Yes <input type="checkbox"/> No <input type="checkbox"/>

Appendix V. Participant Information Leaflet – Feedback Interviews/Focus Groups

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Assessing the social validity of intervention guidelines for a communication partner intervention for siblings of individuals who use AAC.

Site	Trinity College Dublin
Principal Investigator(s) and Co-Investigator(s) <i>(insert names, titles and contact details. Where relevant, give the name of academic supervisor)</i>	Principal Investigator: Aideen Lynam, Ph.D. Candidate, Trinity College Dublin (lynamai@tcd.ie) Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchyv@tcd.ie), Trinity College Dublin
Study Organiser/ Funder <i>(if applicable – remove row if not applicable)</i>	Trinity College Dublin Provost's PhD. Award
Data Controllers	Trinity College Dublin (for research data)
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 dataprotection@tcd.ie

You are being invited to take part in a research study that is being done by Aideen Lynam at Trinity College Dublin.

Before you decide whether or not you wish to take part, please read this information sheet carefully. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

This leaflet has five main parts:

- Part 1 – Information about the Study
- Part 2 – Information on how your data will be used and stored
- Part 3 – Information about Costs, Funding and Approval
- Part 4 – Future Research
- Part 5 – Further Information

Part 1 – The Study

Why is this study being done?

I have created guidelines for a communication partner training for siblings of individuals who use AAC. The information I get from this survey will ensure that the content and structure of this training are acceptable to you, the people who could potentially be involved in their implementation. I am looking for Speech and Language Therapists and adult siblings of individuals who use AAC to look through the guidelines and then feedback to me about their opinions on them.

These interviews are an extension of an anonymous survey on the same topic. The questions in the interview will be looking more in-depth into your opinions regarding the intervention guidelines.

Why have I been invited to take part?

You have been invited to take part because you are either (a) a Speech and Language Therapist in Ireland who has worked with individuals who use AAC for at least 1 year or (b) an adult sibling of an individual who uses AAC. You have read through the guidelines and have answered the survey questions.

We aim to have up to 10 people involved in this study.

Do I have to take part? Can I withdraw?

You don't have to take part in this study. *It is up to you to decide whether or not to take part.* If you decide not to take part, it won't affect you in any way.

You can change your mind about taking part in the study and opt out at any time even if the interview has started. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Aideen Lynam, Principal Investigator (lynamai@tcd.ie) who will be able to organise this for you. During the interview you can request to stop at any time and the interview will be immediately terminated.

What happens if I change my mind?

You can change your mind at any time by contacting Aideen Lynam, Principal Investigator (lynamai@tcd.ie). If you choose not to continue to take part, this will not affect you in any way. If you wish, you can ask for your data to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in research studies prior to this time.

What will happen to me if I decide to take part? What will I need to do?

The study will take place over 30 minutes. If you decide to participate you will be interviewed online at a time that is convenient to you. This interview may be 1:1 or in a group setting, depending on your

availability and your own preference. You will be asked to confirm you have read the intervention guidelines prior to the interview starting. You will then be asked a variety of questions regarding your opinions of the intervention guidelines. You can choose not to answer a question if you do not feel comfortable. This interview will be through Zoom and will audio recorded then transcribed so that the researcher can accurately capture your opinions.

Are there any benefits to taking part in this research?

Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand the opinions of SLTs or adult siblings of individuals who use AAC. This is a long-term research project, so the benefits of the research may not be seen for several years.

Are there any risks to me or others if I take part? What will happen if something goes wrong?

There is a very small risk that you may be inconvenienced and fatigued when completing this interview. To minimise the potential adverse outcomes for this research, the data collection will be completed online and at a time most convenient for you. You can also stop taking part in the research at any time.

There is a risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.

Part 2 – Data Protection

How will my data be used?

Data from this research project may be published in future in scientific or educational journals. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The original recording and all copies will be available only to the present investigators.

If you agree to your data being used in future research, or in teaching your consent form will be held until the data is no longer in use.

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Your personal information will be present on the consent form you complete, including your name and contact details. These will be stored as a PDF in a password protected folder on OneDrive. Only the researcher and supervisors will have access to the password for this. In addition, the audio recording of the interview will be stored as an M4A file in a separate password protected folder on OneDrive. This recording will be transcribed, and your name will be replaced with a pseudonym to

anonymise the information you have provided. De-identified transcribed data and analysis will be stored in a separate OneDrive in a password protected file.

Who will have access my personal data? What will happen to my personal data?

All the personal data that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team Aideen Lynam, Prof Martine Smith and Dr Yvonne Lynch. All of your personal data will be stored in Ireland. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this.

Data that can identify you as well as anonymised data will be kept for 7. After this time period your personal data will be destroyed by Prof Martine Smith.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

Any information or data which is obtained during this research which identifies you will be treated confidentially. All the data collected will be stored on the researcher's OneDrive in a password protected file. The transcribed data will be made anonymous so as to hide your identity. All files will be accessible only by Aideen Lynam, Prof Martine Smith and Prof Yvonne Lynch.

All individual researchers involved in this project have been trained in data protection law and are bound by professional code to maintain confidentiality.

What is the lawful basis to use my personal data?

According to data protection legislation¹, we are required to inform you of the legal basis for using your personal data. The tasks we are performing are considered to be in the public interest²

Some data that is defined as more sensitive (information about your personal opinions), is being used for scientific purposes³

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to have your data transferred to another organisation or 'data controller'
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting

¹ The European General Data Protection Regulation (GDPR)

² Article 6(1)(e)

³ Article 9(2) (j)

Aideen Lynam (lynamai@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 27th May 2022.

Who is organising and funding this study?

This study is being funded by the Provost's PhD award in Trinity College Dublin.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying participants to take part in the study.

Part 4 – Future Research

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions about communication partner interventions for individuals who use AAC. You do not have to agree to have your data available for future research. Future research will only take place if it has research ethics approval. You will be given an option to indicate if you are happy to have your anonymised information included in future research in the consent form.

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- Principal Investigator: Aideen Lynam – lynamai@tcd.ie
- Supervisors: Professor Martine Smith (mmsmith@tcd.ie) and Dr. Yvonne Lynch (lynchvv@tcd.ie),
- Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep. If you consent, we will contact you to arrange a time to conduct the online interview.

Appendix W. Consent Form – Feedback Interviews/Focus Groups

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

Assessing the social validity of intervention guidelines for a communication partner intervention for siblings of individuals who use AAC.

Participant code for study: _____

There are 4 sections in this form. Each section has a statement and asks you to initial if you agree. The end of this form is for the researchers to complete.

Please ask any questions you may have when reading each of the statements. Thank you for participating.

Please tick the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is entirely voluntary , and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason.	
I understand that all information will be kept private and confidential and that my name will not be disclosed.	
I understand that I will not be paid for taking part in this study .	
I know how to contact the research team if I need to.	
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researchers by email or phone as part of this research study	

Data processing	Tick box
I understand that personal information about me, including the transfer of this personal information about me outside of the EU, will be protected in accordance with the General Data Protection Regulation.	

I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me.	
I understand that I can stop taking part in this study at any time without giving a reason and this will not affect me in any way.	

FUTURE USE OF INFORMATION		
RETENTION OF DATA IN THE FUTURE	Y	N
I give permission for my anonymised interview transcript to be stored for <i>possible future research related</i> to the current study of communication partner interventions for individuals who use AAC <i>without further consent</i> being required but only if the research is approved by a Research Ethics Committee.		

Signatures

Participant Name (Block Capitals)	Participant Signature	Date
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Witness Name (Block Capitals)	Witness Signature	Date
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Participant Contact Details (please fill in one of the below)

Email

Phone

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team

Researcher name

Title and qualifications

Signature

Date

2 OR 3 copies to be made: 1 for participant, 1 for PI and 1 for clinical records if relevant.

Appendix X. Feedback Survey Questions and Interview Topics

Survey Questions

For Both SLTs and Adult Siblings

1. In what capacity are you answering this survey
 - a. SLT or Sibling of an individual who uses AAC
2. Please rate the clarity of the guidelines : very unclear to very clear.
 - a. These guidelines were clear to understand.
 - b. These guidelines were not clear at all clear and hard to follow.
3. How easy or difficult was it to read the guidelines?
 - a. Likert Scale: Very Easy to Very difficult
4. How easy to read understand the guidelines?
 - a. Likert Scale: Very Easy to Very difficult
 - b. If answer was difficult/ very difficult: Could you give some examples of where you found the wording difficult to understand?
5. How much do you agree with the:
 - a. The content/ strategies suggested: Definitely agree to definitely disagree
 - b. The instructional strategies suggested: Definitely agree to definitely disagree
 - c. The suggestions structure of the sessions: Definitely agree to definitely disagree
 - d. The suggestions for the timing of the sessions: Definitely agree to definitely disagree
6. In your opinion, what are the top 3 pieces of content/strategies suggested that should definitely be included in an intervention?
7. In your opinion, is there anything these guidelines have missed?

For SLTs Only:

1. Do you think there is enough information in the guidelines to facilitate a communication partner training for siblings of individuals who use AAC?
2. How might reading these guidelines impact on your practice as an SLT?

For Siblings Only:

1. Do you think a training developed with these guidelines would have been beneficial to you when growing up with your sibling who uses AAC?
 - Yes/No and Why
2. Rank the 2 most important pieces of information about siblings specifically that you feel SLTs should take away from these guidelines.
3. How well do think your needs as a sibling are represented in these guidelines?
4. Would having the intervention organised using these guidelines have made you more inclined to attend a training?

Interview Topics

- Clarity of Guidelines
 - How clear/easy were the guidelines to understand?
 - How clear was the wording of the guidelines?
 - What, if anything, was difficult to understand?

What are the most/least important pieces of the guidelines?
- Opinions on anything missing from the guidelines
- SLTs: Opinions on the amount of information in the guidelines
- SLTs: Reflecting on their practice as SLTs after reading the guidelines
- Different wording guidelines – sibling focused versus traditional guidelines

- Siblings: Important take aways from the guidelines for SLTs.
- Siblings: Would these guidelines have impacted their attendance of a training, or would they have been beneficial?
- Siblings: How well are the needs of the siblings represented in the guidelines