IMPROVING AUGMENTATIVE AND ALTERNATIVE COMMUNICATION USE BETWEEN MOTHERS, SIBLINGS, AND CHILDREN WITH COMMUNICATION DISABILITIES

by Marica Gatt

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Supervised by Dr Jill Bradshaw, Professor Glynis Murphy and Dr Nicola Grove.

Tizard Centre

School of Social Policy, Sociology and Social Research

University of Kent

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Abstract

Siblings are essential communication partners within the family support system with longest-lasting relationships within a family structure (Howe et al., 2015). However, there is limited research about the inter-relationships between mothers, siblings, and children with intellectual and developmental disabilities (IDD) who benefit from augmentative and alternative communication (AAC). This thesis explores the communicative interactions between mothers, siblings and children with IDD who use AAC to support their comprehension and expression of spoken language (Ganz et al., 2014). Thus, a systematic review of the literature of family-led interventions was conducted. A total of 21 studies, including 6 group studies and 15 single-case experimental designs, were included in the coding and analysis stage. A range of interventions, including parent and sibling training programmes, storybooks and speech generated devices, were reported. The need for more research in mother-sibling-focal child interactions where a child has a communication disability was highlighted. Therefore, the first study consisted of a Pilot study involving three families of children with communication disabilities. Two independent small-scale studies involved six families of typically developing children (study 2a) and six families of children with communication disabilities (study 2b). The researcher aimed to understand behaviour patterns in mother-sibling-focal child interactions for typically and atypically developing children. A mixed-methods study design involving both qualitative and quantitative methods was used. Mothers and siblings presented with a range of behaviours that were in synchrony with the mothers' and children's responsivity and their emotional capacity to respond to each other. Despite the benefits of using AAC in the home, it was evident that no consistent and functional use was observed. In view of this, a final study was

conducted to evaluate the effects of sibling-mediated interventions using existing modes of communication within the home environment. A pre/post-test research design of three phases was chosen: baseline, instructional, and post-instructional. Observational data were collected on reciprocal sibling-focal child interactions, use of prompts directed towards the sibling or focal child, and levels of proximity. Results suggested an increase in sibling-focal child initiations and responses while parental prompts decreased following the intervention. These results confirm that siblings may be excellent co-interventionists in the intervention process, and with the right level of support, the use of a communication system may be successfully implemented within the home environment. Finally, implications and recommendations for further research were discussed for improving the social interactions of siblings and the focal child within the home environment.

Keywords: family-led interventions, sibling mediated interventions, siblings as co-interventionists, mother-sibling interactions, intellectual and developmental disabilities, communication disabilities, Augmentative and Alternative Communication, maternal responsivity, supportive directives, goal setting in AAC, Video Interaction Guidance.

Acknowledgements

Dedication

I want to dedicate this thesis to my eldest son and my mentor, Samuel, who has inspired me to explore this area of research and sustain my interest for the past eighteen years. I developed a unique role through him, that of a 'parent turned AAC practitioner'. Unknowingly, Samuel opened so many avenues and opportunities for others who eventually benefitted from AAC services on the island.

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

Over the past three decades, several contributions have described communication intervention research with children with communication disabilities and their family members (e.g. Shire & Jones, 2015). These interventions aimed to increase the social participation and overall quality of life of these children who benefit from augmentative and alternative communication (AAC) (Granlund et al., 2008). Family members, including parents and siblings, are the primary interventionists and main communication partners (Moorcroft et al., 2021). Indeed, as the children approach formal schooling, other communication partners (e.g. classroom teachers and peers) take up meaningful roles as interventionists and communication partners. However, parents and siblings remain the main communication partners across the lifespan, caring for their child and family member.

While the literature has addressed the critical role families have in supporting children with intellectual and developmental disabilities (IDD), only a few studies address the issue of communication partners instruction, specifically for family members of children with expressive language difficulties (e.g. Kent Walsh et al., 2015; Romski et al., 2015). Siblings are essential communication partners within the family support system, but little is known about the inter-relationships between mother-siblings, sibling-sibling interactions, and one dyad's effects on the other during joint activities with family members. In addition, very little is known regarding optimal sibling relationships and the effects on family functioning and well-being. The limited literature available focuses on family members of individuals on the autism spectrum. These studies address sibling behaviour, attitudes, coping strategies and quality of life issues whilst sibling interactions and communication were somehow overlooked. (Howe et al., 2010; Smith & Elder, 2010).

Some studies focus on sibling relationship quality and psychosocial outcomes, particularly for adult siblings of individuals on the autism spectrum and individuals with intellectual disability and show that sibling relationship attitudes were related to various sibling outcomes. (Critchley, 2021; Tomeny et al., 2017). There needs to be careful consideration of sibling relationship attitudes when conceptualising sibling relationships in families where one of the siblings has IDD (Tomeny et al., 2017).

Studies imply that focal children tend to gain from conversations between mothers and their siblings. Similarly, siblings have not been participants in these communication partner instructions since the focus is more on mother-focal child interactions. Assuming that siblings are interconnected to the family subsystem where all family members are impacted somehow, the parent-child interactions play a crucial role in the quality of sibling relationships (Howe et al., 2014). Sibling studies indicate that these relationships tend to remain asymmetrical regardless of whether the typical sibling is older or younger. For older siblings of children with intellectual disabilities (ID), sibling relationships remain asymmetrical as older siblings tend to teach, help, and manage their younger siblings with ID (White et al., 2014; Howe & Recchia, 2014). Typically developing children younger than their older sibling with a disability assume 'role dominance', leading the interaction. They take on dominant roles involving helping, teaching, and behaviour management (Howe et al., 2014; Brody et al., 1991).

The directive approach to interaction exhibited by mothers and the acclaimed detrimental effect on parent-child interactions is also reported in the literature on mother-focal child interactions. Mothers tend to take a dominant role since they must interpret and expand on the child's utterance, leading to a passive role for the child with a communication disability.

Because of the time taken to produce an utterance, the total amount of language used by the child is more limited than that of a natural speaker. Perhaps the dominant role exhibited in parent-child interactions also prevails in sibling relationships, which could become a potential research question. Stoneman (2005) claimed that while there has been an increased number of sibling disability studies, the conceptual frameworks and research methods have remained the same. The author suggested applying a guiding theory, offering an alternative conceptualisation, referring to the typically developing children's relationships to compare it to siblings of disabled children.

In the process of challenging this *alternative conceptualisation*, the researcher (MG) raised pertinent questions which informed the literature review thorough search:

i. Are sibling relationships similar in quality to those of siblings with IDD?

ii. How different are these relationships for siblings of children who also present with communication disabilities?

iii. How does the mother's communication style impact on sibling relationships?

iv. How can siblings become better communication partners and co-interventionists in the process?

1.2 A Conceptual Framework to study family and sibling interactions.

As in other research areas, one would expect studies to utilise conceptual frameworks to identify aims, questions and methodology. Traditionally, family and sibling interactions research was generally considered "theory-free" (Stoneman, 2005). In this thesis, the conceptual framework adopted by Romski et al., (1997) reflects the Vygotskian view of the relationship between intrinsic and extrinsic influence on language competence.

This framework is extended to justify the role of more competent others, i.e. siblings as interventionists in the process, who collaborate (interact) with the focal child. Siblings model the use of an AAC system in a joint activity. This collaboration between the sibling and the focal child leads the latter towards internalising the method used to achieve the goal. The social constructivist model put forward by Vygotsky (1978) claims that infants do not develop in isolation but through interaction with more competent others (such as caregivers, siblings, more able peers, teachers). According to Vygotsky, learning is achieved through social mediation, with the child internalising what he/she had learnt in a social context. The parent reacts to the infant's behaviour as though it is intentional and meaningful, and, in this manner, the parent lays the framework for the baby to learn how to interact socially. To understand the relationship between development and learning, one must distinguish between two developmental levels – the actual and the potential levels of development. The actual level of development refers to those accomplishments an individual can demonstrate alone or perform independently. The potential level of development is what the individual can do with assistance. The zone of proximal development (ZPD) is the difference between what the learner can do independently and what the learner can accomplish cognitively with support from more knowledgeable partners. It describes the process of internalisation in the teaching/learning process. According to Vygotsky (1978), it provides the scaffold to reach a range of skills which the child can master with minimal support. Romski et al., (2007) argue that what the child brings to the learning process, 'intrinsic factors', is crucial. Intrinsic factors include biological factors such as neurological and neuromotor status and psychological competencies such as cognitive skills, communication, and language abilities.

Such a process is developmental since what starts as extrinsic for the focal child (e.g. the more knowledgeable person uses aided language stimulation pointing to pictures of a communication book) is then internalised and becomes intrinsic (e.g. an improvement in expressive communication levels). Launonen (2019) elaborated on the child's intrinsic factors, including personality, level of engagement, interest and skills, and persistence. These factors are what the focal child brings to the task during the intervention. Extrinsic factors are what the more knowledgeable person brings to the process. These may include modalities, devices and naturalistic or structured instructional approaches. The family's social-economic status, social environment, poverty, and societal attitudes are also included within a broader perspective.

1.3 Overview of the studies

This thesis involves three studies; the first study consisted of a **Pilot study** involving three families of children with communication disabilities. This was followed by two *independent small-scale studies* involving six families of typically developing children **(study 2a)** and six families of children with communication disabilities **(study 2b)**. The aim was to understand behaviour patterns in mother-sibling-focal child interactions for typically and atypically developing children. A final study (**study 3**) was conducted to evaluate the effects of sibling-mediated interventions using existing modes of communication within the home environment. A pre/post-test research design of three phases was chosen: baseline, instructional, and post-instructional. Observational data were collected on reciprocal sibling-focal child interactions, use of prompts directed towards the sibling or focal child, as well as levels of proximity. Table 1 provides an overview of the studies described below.

Study number	Name	Type of Study	Participants	Quantitative Measures	Qualitative Measures
1	Pilot Study	Observational study	3 families of mothers-siblings-focal children with communication disabilities	Level of responsivity. Emotional Availability. Frequency of Directives	Maternal Questionnaires Sibling Interviews Narrative Transcriptions
2a	Study of typically developing children	Observational study	6 mothers-siblings-TD children dyads/triads	Level of responsivity. Emotional Availability. Frequency of Directives	Maternal Questionnaires Sibling Interviews Narrative Transcriptions
2b	Study of atypically developing children	Observational study	6 mothers-siblings-focal children dyads/triads with communication disabilities	Level of responsivity. Emotional Availability. Frequency of Directives	Maternal Questionnaires Sibling Interviews Narrative Transcriptions
3	Study on sibling mediated interventions	Pre-post-test research design	8 siblings-focal children dyads with communication disabilities	Sibling-focal child initiations. Modes of communication. Caregiver prompts. Proximity to the aided system, siblings and caregivers.	Maternal Questionnaires Sibling Interviews Narrative Transcriptions Communication Goal setting Post-intervention questionnaires & interviews

Table 1: Overview of the studies

1.4 A Definition of Augmentative and Alternative Communication

Augmentative and alternative communication (AAC) is the umbrella term for the different methods used to enhance a person's receptive and expressive language skills when interacting with other people. Such persons cannot meet their communication needs by using their natural speech alone. AAC users have diverse needs varying in motoric and sensory abilities, cognitive and linguistic skills (Romski et al., 2015). AAC systems include unaided systems such as gestures, manual sign systems, eye pointing and facial expressions and aided systems such as real objects, communication passports, communication books, boards, graphic signs, photos, orthography as well as voice output communication aids (VOCAs) and speech generated devices (SGDs).

Such technologies range from low-tech systems such as communication books and boards to high-tech devices. Some AAC devices may use synthetic or digitised speech and may particularly enable non-speaking individuals and children whose speech is unintelligible to participate in classrooms and the community (Beukelman & Mirenda, 2017).

It is somewhat challenging to quantify the need for AAC for several reasons. First, potential AAC users often present with complex conditions and additional needs making the sample heterogeneous and varied (Teachman & Gibson, 2014). Second, the needs of AAC users change over a lifespan. Advances in medical care have led to a better quality of life for individuals with severe learning disabilities, not to mention the phenomenon of an increasingly ageing population. The latter increases the prevalence of acquired or progressive neurological disorders such as stroke or Parkinson's Disease. According to Beukelman & Mirenda (2017), around 97 million individuals worldwide have significant disabilities that compromise functional speech development. The authors argue that the wide variance in prevalence reported in the literature may be due to differences in terminology, target populations, sampling techniques and age rather than an actual variation in prevalence. The prevalence of significant communication difficulties in America is about 1.3%, whereas, in the UK, it is approximately 1.4% of the total population (Beukelman & Mirenda, 2017). Enderby et al., (2013) identified nine top disorders which may lead to requirements for short or long-term use of AAC strategies, e.g. congenital disabilities including cerebral palsy, profound, multiple and complex disabilities, intellectual disability and physical difficulties. Developmental disorders include autism spectrum disorders, developmental delays, speech and language impairment. Progressive neuromuscular disorders encompass complex syndromes, muscular dystrophy and Freidrich's Ataxia. Acquired neurological disabilities usually comprise traumatic brain injury, stroke and spinal cord injury.

According to Enderby et al., (2013), acquired disorders make up for 56.8% (Alzheimer's/Dementia, Parkinson's disease, Motor Neurone Disease, Stroke); Autism spectrum disorder 18.9%, Learning disabilities 13.3%, Cerebral Palsy 4.5%, Head/brain injury 2%, PMLD 2%, Other 2.5% (e.g. Prader-Willi, Williams Syndrome, Multiple Sclerosis, Angelman Syndrome, Rett syndrome). A systematic review approach was used to identify the literature related to the prevalence of aetiological conditions which would benefit from AAC in the United Kingdom (Enderby et al., 2013). The researchers estimated that over 0.5% of the UK population (529 per 100,000) would benefit from AAC. In addition, the researchers estimated that 0.05% of the UK population might benefit from medium-tech and high-tech communication aids (single recorded message output devices to complex voice output communication aids). Minimal information is available for AAC sub-populations categorised by geographic region, race and ethnicity. More data is required to inform the evidence base for AAC assessment and intervention and improve AAC users' overall quality of life (Romski et al., 2015).

1.5 Intellectual and Developmental Disabilities

The terms intellectual disability (ID) and developmental disability (DD) are terms applied when individuals are characterised by a lack of various skills concerning daily functioning. Individuals may share similar causes, such as chromosomal abnormalities and prenatal infections. Intellectual disability pertains to intellectual and adaptive deficits, whereas developmental disability includes intellectual disability and other disabilities, such as autism, evident during childhood. Developmental disabilities affect one or more areas of development, such as cognitive, sensory, or physical (Beukelman & Mirenda, 2017). Based on parental reports in the USA, about 1 in 6 (17%) children aged 3–17 were diagnosed with a developmental disability (Centres for Disease Control and Prevention, 2020).

Communication skills are often one of the affected difficulties, and AAC techniques are often used with people with developmental disabilities to enhance language learning and use. This section provides the context wherein each condition within the umbrella term is defined and described briefly in terms of prevalence and implications related to the selection and use of AAC systems.

Theoretically, approximately 2.5% of any population will have an IQ below 70 (two standard deviations below the mean). Severe ID (i.e. IQ below 50), with a prevalence of 3-4 per 1000 of the general population in developed countries, may be lower in developing countries due to increased mortality due to fewer medical advances. Nevertheless, administrative prevalence is often lower than so-called 'true' prevalence, and international studies have suggested that approximately 10.37/1000 (1.04%) of the population worldwide has a diagnosis of intellectual disability (Maulik et al., 2011). Down syndrome, Fragile X syndrome, and foetal alcohol syndrome account for at least one-third of all known causes of intellectual disability. A follow-up meta-analysis found the overall population with ID between 0.05 to 1.55% (McKenzie et al., 2016).

The National Joint Committee for the Communication Needs of Persons with Severe Disabilities (2020) advocates for individuals with significant communication support needs resulting from intellectual disability and states that individuals with intellectual disabilities may benefit from some form of AAC regardless of the degree of impairment. An individual with intellectual disabilities (ID) has an IQ under 70 with significant limitations in adaptive behaviour as expressed in conceptual, social, and adaptive skills (Association for Individuals with Developmental Disabilities AIDD, 2020).

Rather than describing the individual according to his IQ, the preferable emphasis is more on the level of support required to access the community at large. Persons with intellectual disabilities may present with other difficulties such as cognitive impairment, sensory impairment, seizures, behavioural difficulties, and syndrome-specific conditions, including other physical disabilities. In the past, intellectual disability was known as 'mental retardation' (US) and 'mental handicap' (UK), which are not used nowadays. Disability movements deemphasise the IQ classification of ability levels (profound, severe, moderate, mild). According to Rosenbaum et al., (2007), cerebral palsy encompasses a group of permanent disorders of

> *"movement and posture attributed to a non-progressive disturbance that occurred in the developing brain. This is often accompanied by difficulties with perception, cognition, communication, and behaviour; epilepsy; and secondary musculoskeletal problems."*

It is estimated that the incidence of cerebral palsy is 4 per 1,000 live births (Centres for Disease Control and Prevention, 2020). Dysarthria is estimated to occur in 31% to 88% of individuals with cerebral palsy (Beukelman & Mirenda, 2017). Central to their support is the importance of a trans-disciplinary team and a balanced therapeutic approach to intervention. The selection of multimodal systems and adequate training for the individual and their communication partner should be encouraged and supported. Another group of individuals who often benefit from an AAC system are persons on the autism spectrum. Approximately 1 in 54 children are identified with Autism (Centres for Disease Control and Prevention, 2020). ASD used to be said to have three diagnostic features i) impairment in social interaction, ii) impairment in communication iii) unusual social and behavioural characteristics.

The American Psychiatric Association (2013) proposed new, highly controversial diagnostic criteria for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The group recommended a new category called 'Autism Spectrum Disorder', implying that the previously separately diagnosed conditions, including Asperger syndrome, would now be incorporated within Autism Spectrum Disorder. Instead of the previous triad of impairments, two core difficulties were described: deficits in social communication, repetitive behaviours, and restricted interests. Individuals on the autism spectrum often experience a wide range of additional complex issues related to intellectual disability, language and communication. For example, it is estimated that approximately 50% of persons on the autism spectrum do not develop functional speech (National Institute on Deafness and Other Communication Disorders, 2010). AAC systems are often used to help facilitate language acquisition for persons on the autism spectrum. However, incorporating an AAC system for individuals on the autism spectrum or other developmental disabilities can be challenging due to difficulties in social reciprocity (Kent Walsh et al., 2015).

1.6 Prevalence of Persons with IDD in Malta

Several working documents and databases were evaluated to determine the number of AAC users in Malta. The two relevant databases were the National Statistics Office (2014), and the other is the National Commission Persons with Disability (CRPD) register, the latter being a voluntary register. Both databases present their limitations; the former is based on families filling in a questionnaire, and the latter is based on the voluntary registration of individuals in the disabled person register. Therefore, both data sets are unreliable, although they may indicate the local situation of disabled people on the island.

Based on the 2011 Census in Malta, the total population of persons between 0-19 years was 87,910, with 4,148 disabled persons (4.7%), 410 had an "intellectual disability" (0.46%), 685 had a "developmental disorder" (0.78%), and 374 had a "physical disability" (0.42%) (National Statistics Office, 2014). At the time of the writing of this thesis, the Maltese Government was preparing for the 2021 Census (Malta Census, 2021).

Type of Disability	0-9 years	10-19 years	Total	% of the student population n=87,910
Mental Health condition	29	123	152	0.17
Deafness or partial hearing loss	46	108	154	0.17
Blindness or partial sight loss	54	255	309	0.35
Intellectual disability	160	250	410	0.46
Specific learning difficulty	487	1552	2039	2.32
Development disorder	397	288	685	0.78
Physical disability	132	242	374	0.42
Other disability	15	10	25	0.03
Total			4,148	4.7%

Table 2: Type of Disability (NSO 2011)

Based on 2004/2005, the NSO determined that out of 85,864 students, there were 766 students with a "mobility problem" (0.89%) and 135 with "severe learning difficulties" (0.16%) (page 109). A research study conducted by the National Commission Persons with Disability (2014) reported that out of a sample of 600 disabled persons, 487 had a "physical impairment" (81.2%), and 71 had an "intellectual disability" (11.8%) (KNPD, 2014). By the end of 2020, 19,705 disabled persons were registered with the Commission for the Rights of Persons with a Disability (CRPD, 2021). Of these, 15,268 had physical disabilities (77%), while 3,438 had an intellectual impairment (17%). One must note the different terminologies used, which makes the data difficult to interpret and compare. Not all individuals with physical disabilities, intellectual or 'other' disabilities included in the sample, have a communication disability and require some form of AAC. A rough estimate of potential school-aged AAC users in Malta is 1.4% (Gatt, 2015).

1.7 Terminological Considerations

In writing this thesis, the researcher consulted with various stakeholders, including academic staff from the Department of Disability Studies, Faculty of Social Wellbeing, University of Malta; the National Commission Persons with Disability (NCPD), and the National Parents Society with Disability (NPSPD). The consultative document proposing a Maltese National Strategy on the Rights of Disabled Persons 2021-2030 referred to the term 'disabled persons', 'disabled children', in Maltese *'persuni b'dizabilita`', 'tfal b'diżabilita` (*Ministry for Inclusion and Social Wellbeing, 2021*).* Malta's 2021-2030 National Autism Strategy refers to the term 'children on the autism spectrum', in Maltese, '*tfal fuq il-firxa wiesgħa tal-awtiżmu'* (Autism Advisory Committee, 2021). In the absence of guidelines for other disability groups, a People-first Language was used for children with intellectual/developmental disabilities; in Maltese, this term is used for children with intellectual disability '*tfal b'diżabilita` intelletwali'.* From a syntactical and semantic point of view, the rules of the Maltese language do not allow the morpheme 'intelletwali' preceding the term 'diżabilita`'. People-first language refers to how "we speak, write, and portray people with disabilities that eliminates disparagement or pity" (Clarke et al., 2017 p.74). The Social Model of Disability rejects a People-first language on the basis that it is a result of the Medical Model of Disability.

The term 'Siblings' refers to the brothers or sisters of the focal child who live in the same household. The term 'focal child' refers to the child with an intellectual/developmental disability and a communication disability who may benefit from AAC use. The term *complex communication needs is* not used in this thesis since the term is unclear and confusing. The term implies a static relationship between a child's needs and his/her interactions with the surroundings.

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From a pragmatic point of view, one may argue, whose communication needs are not considered complex? The needs of a child with a disability and those without disabilities may be more "complex" or less "complex" depending on the tasks presented, the context and whether the focal child has access to AAC. Rather, the term 'communication disability' is used during this thesis.

The term "disability" in the literature is used to refer to children's restrictions in the performance of communicative and physical actions in different activities promoting the Medical Model of Disability. Throughout this thesis, the Social Model of Disability is used where the person is disabled by society (for example: a child with a communication disability with no access to a communication aid). The word "interactions" refers to any unaided or aided communication that may be executed by both the mothers and the siblings. According to Dunst et al., (2013), "interventions" refers to the "methods, procedures or activities used to promote improvements or changes in outcomes of interest" (p. 87). "Implementation" practices refer to the "methods, procedures or activities used to promote adoption and use of intervention practices" (p.87). The researcher used the international literature available on AAC proposed by von Tetzchner & Martinsen (2000). Likewise, the notation presented by von Tetzchner & Jensen (1996) was used in the case of representations of manual, graphic signs and SGD messages.

1.8 Outline of the remainder of the thesis

The remainder of the thesis is organised as follows:

Chapter 2 is concerned with the functions of communication, language and social participation of individuals with IDD to establish the basis for understanding the nature of communicative exchanges between mothers and siblings.

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Chapter 3 is concerned with family and sibling interactions summarising studies on family and typically developing sibling interactions concerning communication, language and sibling quality relationships. This is followed by a review of mother and sibling interactions of individuals with IDD to identify gaps in the literature and suggest further directions for the research on family and sibling interactions. This chapter focused on mainstream Anglo-western models of parenting since families from other cultures may have a different philosophy of parenting. **Chapter 4** aimed to evaluate several family-led communication interventions for children with IDD through a systematic review. Findings from these interventions were analysed to identify the factors influencing the success of an intervention. The results revealed very few studies focusing on mother-sibling and sibling-focal child interactions where a child with an intellectual disability could benefit from AAC. **Chapter 5** presented the methodology of the subsequent studies. **Chapter 6** presented a pilot study (study 1) involving three families of children with communication disabilities. **Chapter 7** involves a small-scale study involving six families of typically developing children (study 2a). **Chapter 8** involves six families of children with communication disabilities (study 2b). The studies investigated how two different interaction styles, responsive and directive, are employed by mothers and siblings in their encounters with children with intellectual disabilities. In summary, a responsive communicative style was evident across dyads and, in some instances, even across triads. Despite the body of research demonstrating the benefits of using AAC systems in daily interactions, neither the pilot study nor the small-scale study found consistent and functional AAC use. For this reason, a final study was conducted to investigate the use of AAC systems with family members, including siblings (Study 3). **Chapter 9** consisted of a study of 8 families of children with IDD and communication disabilities.

This study evaluated the impact of an intervention aimed at promoting sibling-mediated interactions using existing modes of communication within the home environment in sibling-focal child dyads. A pre/post-test research design made up of three phases: a baseline, instructional phase and post-instructional phase were utilised. Siblings discussed how these interactions might be improved based on the initial goal setting task and using the principles of video interaction guidance. Finally, **Chapter 10** gives a general discussion, main conclusions, contributions of the thesis, and future research. The study's significant findings are summarized along with the limitations and suggestions for future research.

CHAPTER 2: THE DEVELOPMENT OF FUNCTIONAL COMMUNICATION

2.1 Introduction

This chapter is concerned with the theoretical underpinnings of the development of functional communication and the difficulties encountered by individuals with intellectual and developmental disabilities to develop communicative exchanges with significant others. The chapter commences with a definition of communication, establishing the purpose of communication and giving an overview of some of the models of communication. Next, there is a reference to relevant studies that discuss caregiver/child interactions and inter-relationships between communicative intent and pragmatic functions. Research reveals how adult caregivers control the conversation by initiating topics, issuing commands, and asking questions. Children respond using one utterance, often characterised by a restricted range of communicative functions.

2.2 The Purpose of Communication

The purpose of communication is for individuals to engage in social interactions and participate effectively and efficiently in activities of their choice (Beukelman & Mirenda 2017). Light (2003) identifies four purposes that communicative interactions fulfil i) communication of needs and wants, ii) transfer of information, iii) social closeness, and iv) social etiquette. The first type of interaction consists of the expression of needs and wants, where the listener's behaviour is regulated towards an action-oriented approach, e.g. ordering food from a takeaway, asking for directions. The second type of interaction is the transfer of information wherein the goal is to share information, e.g. a youngster telling his peers what he did during the weekend, a girl telling her friends about her upcoming trip. The third area of interaction is social closeness which relates to establishing and maintaining personal relationships, e.g. a group of youngsters cheering for their disabled peer during a game.

The fourth type of interaction is social etiquette which is the ability to conform to the social conventions of politeness, e.g. a child expressing 'please' and 'thank you' to the teacher.

2.3 Models of Communication

One of the earlier models of communication is based on information processing. This model is like telephony since meaning is assigned following the signals or behaviour produced by the individual. The sender encodes a message transmitted to the receiver within an environment of physical, physiological or psychological noise, and the latter then decodes the message for its meaning (Shannon & Weaver, 1969). Following this definition of an early model of communication, recent studies of human interaction have advocated a continuous process model. Within this model, the sender and the receiver interact more closely by modifying and responding to each other's behaviour in a manner where the sender and the receiver's roles become unidentifiable.

Lloyd et al., (1990) present an augmentative and alternative communication (AAC) model that is a modification of the General Communication Model (GCM). A schemata of the AAC model is presented, and ten parameters are discussed, including sender, message, transmitters, transmission processes, AAC interface, internal feedback, transmission environment, communication environment, receiver, and external feedback. A critical feature distinguishing this model from other GCMs is the focus on the changing character of the transmission processes when using aided AAC. The model is proposed as a conceptual framework to stimulate the generation of specialised models.

The Social Constructionist view proposes communication to be the product of the interactants sharing and creating meaning. The Constructionist View assumes that ideas are constructed through the social process of communication.

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It is a more realistic view of communication because it involves human interactions and the free sharing of thoughts and ideas. The Transactional Model (Sameroff, 2009) is based on the concept of co-operation, a mutual relationship between the child and the environment where the child and the events in the environment influence each other rather than the child being influenced by events in the environment, e.g. parental style (Von Tetzchner & Grove 2003, p65). Children bring about their skills, knowledge and attributes in the environment whilst the latter has 'certain qualities' (p 8). The environment may manifest itself on the child's skills, knowledge and abilities, which manifests itself in the environment, e.g. a non-speaking individual who has no means of communication, and the parents introduce a manual sign system in the environment. Therefore, the child has influenced the parents to start using an alternative mode of communication, which otherwise was not required if the child did not present with a communication disability.

Another example to explain the manifestations of the transactional model is the phenomenon of the dominant role taken up by the parent of a child using an alternative means of communication and the passive role exhibited by the child. While one suspects that this could be due to the child's passive disposition or the parental style, there may be other reasons. The child has a limited means of expressing needs and wants, and parents try to intervene to keep the communication interaction going. This parental style may rebound on the child by increasing one's passivity, subsequently leading to learned helplessness (Basil, 1992; Calculator, 1997).

Theories of Language Acquisition	Relevance to typical language development	Relevance to individuals with communication disabilities.
Behaviourist approach (Skinner, 1957)	Learning a language is like learning any form of behaviour (stimulus, response, conditioning, reinforcement). Unfortunately, behaviour analysis has little to offer to promote understanding of cognitive, social and cultural processes.	Behavioural strategies alongside other strategies may have some practical use in an intervention (especially conditioning). This approach, however, still does not explain how and why language develops. Neither does this approach explain what goes on in the brain.
Nativist approach (Chomsky, 1968)	Species-specific neurological module perceives specific experiences as linguistic and categorises and structures what is perceived according to inborn linguistic rules and categories.	Exposure to linguistic input is limited outside 'specific' training situations. The child cannot set parameters or calibrate the language naturally, e.g. the quality of linguistic input is inadequate for a person who depends on a manual sign system for input.
Emergentism/ Connectionism	Learning a language is a dynamic process involving many underlying processes focusing on social and cognitive processes.	Language learning may be understood as constituting distinct developmental paths. Impairment constrains the normal processes in such a way that hinders typical language development.
Constructivism (Piaget, 1971)	Language results from the constructions of sensorimotor intelligence, where the child investigates the physical world as a primary motivator of development. Therefore, children cannot handle grammatical structures such as the passive until they have coped with the cognitive concept of reversibility.	This model does not allow linguistic behaviour to change due to maturational factors. Children need to have achieved the sensorimotor stage to build mental structures (structures of knowledge). It is unclear how this model relates to persons with physical needs, where manipulating objects is problematic.
Social constructivist model (Vygotsky, 1978)	Words and sentences gain meaning through social interchanges and activities that the child participates in. The human brain and human culture both are necessary for the development of language. To this extent, language is internalised through the joint construction of meaning.	The understanding of alternative language forms needs to be reflected in the design of intervention strategies. Activities may differ from activities involving spoken communication. This perspective needs to take an eclectic approach rather than a pure social constructivist approach.
Usage-Based Theory (Tomasello, 2003)	how language is used to direct people's attention to events and entities in the current joint attentional frame. Units of language acquisition are considered as whole utterances and constructions rather than isolated words. Children hear and store concrete utterances and then find patterns in these stored utterances.	This theory may have implications in intentionality and the theory of mind framework. Research has determined that individuals on the autism spectrum fail to achieve this theory of mind. The usage-based theory needs to be tested against the input/output asymmetry argument.

Table 3: Summary of the theories of language acquisition

2.4 Theories of language acquisition

There have been extensive studies and numerous debates towards language studies ranging over nature versus nurture, innateness versus language learning and more recently, the social versus the cognitive properties of language. Table 3 summarises language acquisition theories according to environmental input, cognitive development, and social factors.

A significant contribution to social constructivist theory is 'scaffolding'. This means that adults participate in activities with children with joint engagement, over-interpretation, and generally supporting the child to communicate effectively. Letto et al., (1994) used the Zone of Proximal Development (ZPD) to develop an appropriate methodology for the longitudinal study of language acquisition in a male child aged 2.6 years with cerebral palsy. Over ten months, the child was engaged in collaborative interaction with an adult partner providing prompts to elicit certain prelinguistic communicative functions. Findings indicate an increase in the frequency of the child's communicative function initiations with the adult partner across time, as evidenced by the child's progression through the ZPD. The later elaboration of Vygotsky's approach offers a broad view of typical and atypical language development worth exploring further (Bøttcher, 2019). Vygotsky's theory asserts that words and sentences gain meaning through social interchanges in which children take part. Language is learnt through the guidance of more competent language users, not from pre-wired neurological structures or behaviour reinforcement (Von Tetzchner & Grove, 2003). Language competence is seen as a joint construction with other communication partners before it is internalised. The social constructivist theory offers various options on how alternative language forms can develop, posing significant implications for the design of intervention strategies (Solomon-Rice, 2010).

The usage-based theory of acquisition put forward by Tomasello (2003) describes sets of skills that are of importance in the acquisition of language. The first set involves *intention reading,* concerned with how language directs people's attention to events and persons in the current joint attentional frame. Intention reading emerges around 9 to 12 months of age and includes:

i.   the ability to share attention with others on objects and events of mutual interest;

ii.   the ability to follow the attention and deictic gestures to objects and events outside the immediate interaction;

iii.   the ability to direct the attention of others by pointing or by using other gestures;

iv.   the ability to imitatively (or culturally) learn the communicative acts of others, including their intentions.

Tomasello (2003) claims that infants' early language is concrete and item-based, implying that their speech is based on lexical items within their immediate environment and caregivers. Infants cannot produce any utterances because they were not exposed enough to the native language. Such exposure plays a critical role in a child's linguistic competence and not only their innate abilities. Tomasello (2003) argues that prelinguistic infants do not understand linguistic symbols or how these work, and therefore language does not have any meaning, and spoken language is perceived as 'noise'. He maintains that children acquire language around twelve months of age because the learning process is dependent on joint attention, intention reading and cultural learning. He claims that although children would have acquired the concept of things around the age of five months and start to recognise sound patterns in association with distinct objects, they do not yet comprehend or produce any language.

The second set of skills involves *pattern* finding (also known as categorisation). Such skills are necessary for children to decipher linguistic symbols across different utterances and construct human linguistic competence. Linguistic symbols are used referentially in utterances to direct the mental and attentional states to the outside world. Linguistic symbols are also used as declaratives to inform persons of things and events.

Thirdly, this approach is *usage-based,* wherein children hear and store concrete utterances and then find patterns in these stored utterances, which are later abstracted to form general-purpose rules. This process depends on the type of input, the rate and the child's developmental age. Finally, the process of symbolic integration requires an item-based construction with the insertion of novel items, and the child needs to focus on the form and function of language.

2.5 Intentionality of Communicative acts and caregiver style

Intentional communication is thought to develop at around the age of nine months, wherein a shift occurs from pre-intentional (perlocutionary) to intentional (illocutionary) communication (Bates, 1976). To understand this phenomenon, let us, for the sake of argument, assume that all behaviour is considered communicative and that distinguishing between pre-intentional and intentional communication is context-dependent. The communication partner's sensitivity and responsiveness towards that communicative act determine whether the behaviour is pre-intentional or intentional. The communication partner must be responsive and consistent when responding to such signals if such behaviours become contingent. The development of intentionality may have a direct effect on the caregivers' style. Caregivers provide learning opportunities by encouraging communicative signals through eye contact, gestures, and vocalisations to signal attention. As their child's signals become more established, caregivers can start assigning intentions to their child's communicative attempts. Directing attention towards the caregiver increases the possibility for the former to produce a symbol in the form of a sign or spoken word, reflecting the meaning of that behaviour or intention, otherwise known as linguistic mapping (Quinn & Kidd, 2019).

In intentional communication, the individual uses a range of behaviours to involve the interlocutor and communicate a message. In the early stages, this is directed either to a person or the object. In an established three-way communication, the individual may use a range of recognisable communicative behaviours to gain the adult's attention and directs it to what he wants them to do or look at. This is when an individual is said to have developed total intentional communicative behaviour. Various researchers have recognised direct and sharing attention, including Tomasello (2003), as a crucial prerequisite to communicative competence.

A few studies on early communicative functions, including one conducted by Bates et al., (1975), identified a number of communicative acts in their sample of Italian children's language identifying two communicative acts' proto-imperatives' and 'proto-declaratives'. Bruner (1983) discusses the role of proto-imperatives (using the adult to obtain the desired object) and proto-declaratives (use of an object to gain the adult's attention). Proto-declaratives and proto-imperatives are early requests and comments which regulate the behaviour of others and establish joint attention. According to Bruner (1983), these early pragmatic skills are present as infants move from prelinguistic to linguistic and eventually to multi-word utterances and advanced language forms. These early functions, as defined by Bruner (1983), fall under three categories:

i. Behaviour regulation: requests for objects, actions and protests.

ii. Social interaction: requests for social routines, greeting, asking permission, acknowledging.

iii. Joint attention: commenting, request for information, and clarifications.

Joint attention is a state in which the caregiver's and the child's attention states are focused on the same object (Clark & Berman, 2008). For most researchers, joint attention includes the notion that the participants are both aware that the focus of attention is shared. This is demonstrated in early infancy through gaze shifting patterns. Eye gaze shifting for typically developing children between the caregiver and the object starts at the age of 6 months. At 13 months, children demonstrate triadic gaze shifts coordinating their attention between the adult and the object. According to Clark & Berman (2008), joint attention is critical for successful reference, whether by a child or an adult. By definition, joint engagement occurs when a child actively attends to the same event or object as the communication partner., who may stimulate the child's experience with actions and symbols that are not observed during solitary object play (e.g. Zampini et al., 2015). It can be argued that if the adult and child are looking at the same object of interest, this cannot be taken as evidence of joint attention. The child must alternate his gaze towards the object of interest and the adult to show that he/she coordinates this joint focus with joint engagement.

Adamson et al., (2010) claim that typically before 15 months of age, infants can sustain periods of *supported joint engagement*, which is defined as a state when the infants and caregivers can share attention on an object if the adult scaffolds this interaction, the child will be able to focus his attention exclusively on the object. By the middle of their second year of life, infants will sustain periods of *coordinated joint attention,* where the infants can focus on the shared object or event and their partner. When the infant and the partner communicate during periods of joint engagement, it is thought that this facilitates the emergence of symbolic understanding. Studies have documented a positive correlation between early word learning and joint attention (Tomasello & Farrar, 1986).

It is argued that joint attention provides the foundation for representational strategies and symbol formation, underpinning developing theory of mind and narrative skills in 3 to 4-year-old children. Symbol infused joint engagement can be *symbol-infused supported* where the child and partner are actively involved with the same object or event and attending to symbols, but the child does not acknowledge the partner's participation, e.g. the partner is assisting the child as he/she focuses on a naming task, but the child does not attend to the partner. On the other hand, in *symbol-infused coordinated joint attention*, the child and partner are actively involved with the same object or event and attending to symbols. In addition, the child repeatedly acknowledges the partner's participation, e.g. the partner is assisting the child as he/she focuses on a naming task, and the child constantly acknowledges the partner (Adamson et al., 2014).

While this developmental scenario seems appealing, there is limited research on how infants between 18 to 30 months and their partners share attention during social interactions. The frequency and quality of *symbol-infused joint attention* and how it facilitates the development of language acquisition needs to be fully addressed (Adamson et al., 2010). As previously discussed, the significance of symbol-infused joint attention is compatible with Vygotsky's (1978) social constructivist model. According to Arens et al., (2005), the quality of joint attention with adult communicators influences the later communicative development in disabled children. The establishment of joint attentional frames and the understanding of communication interaction is crucial for pragmatic skills development. The communication partners must look at the object or 'referent' and share the same focus of attention. For a successful conversation to occur, the two communication partners must agree on what is being 'talked' about. To ensure this, there needs to be the same locus of attention.

Referential communication is an area of pragmatics where the speaker conveys information to enable the interlocutor (hearer) to identify a referent in some shared set of objects (Clark & Marshall, 2003). The interlocutor identifies the referent from the shared set of objects and indicates this to the speaker. Reference also requires mutual knowledge, also known as shared knowledge or common ground. Conversation, therefore, proceeds in an orderly manner as long as the speaker and the hearer have established common ground (Clark & Marshall, 2003). The ability to help the listener understand what the hearer is referring to depends on mind reading. In other words, referential communication involves the following steps:

i.   Establishing attention on an object.

ii. Communicating the identity of this object through a sign, gesture, symbol, vocalisations, or other modes of communication and thereby

iii. Drawing the interlocutor's attention towards the object.

According to Light (2003), individuals with communication disabilities need to learn to engage in basic referential skills by:

i.   attending to the communication partner,

ii. pointing to request an object or a person,

iii. pointing to an object to clarify the referent when commenting,

iv. gesturing deictically to request information or indicate another's turn,

v.   searching for information when responding to questions.

Young children with developmental disabilities may have difficulties establishing joint attention with caregivers with fewer opportunities to engage in meaningful shared interactions.

Cress et al., (2008) demonstrated that children with developmental disabilities initiate fewer joint attention communicative acts than typically developing infants. They also demonstrated fewer triadic gaze shifting patterns and impaired engagement behaviours. This is typically evident with children who have physical disabilities and instances where there is a cognitive load, including planning and controlling physical movements. This phenomenon has not been only documented for children with physical disabilities but also children with developmental disabilities, including those with ASD. Children on the autism spectrum, for instance, do not follow a typical developmental path in terms of the development of joint attention, which may be due to the theory of mind state (Kristen et al., 2015). This framework, developed by Baron-Cohen (2001), describes how children develop the ability to form a perspective of what other people think and feel and their intentions. Baron-Cohen concluded that children with autism cannot represent mental states and are at a disadvantage to predict the behaviour of others. Baron Cohen's mindreading system emerges between 9 to 18 months and is the shared attention mechanism. Infants at this age start experiencing a sense of sharing the world with the added awareness that they and the communication partner attend to the same object. Baron-Cohen claims that the shared attention mechanism allows infants to interpret the partner's intention to distinguish a referent from a non-referent. Baron-Cohen also stressed that the establishment of joint attention in infants is a clinical precursor to developing a theory of mind. Benigno et al., (2011) declare that two joint attention states are *passive* or *coordinated.* When two communication partners share attention on an object either verbally or non-verbally (partner-object gaze shifts), this is said to be coordinated. On the other hand, passive joint attention states involve mutual sharing of attention with no indication of the communication partner's shared attention.

The caregiver's style is affected by joint attention engagement, mainly a *follow-in* behaviour where the caregiver follows into the child's current focus of interest. On the other hand, the caregiver's style can be *directive* - where the adult attempts to shift the focus away from their interest. When the adult follows into the child's focus of attention and labels the object to which the child is attending, the child is more likely to extract information from this interaction. However, if the adult attempts to direct the child's joint attention away from the object of interest, it is less likely for the child to learn from this interaction.

Triadic Joint Attention   Quadratic Joint Attention
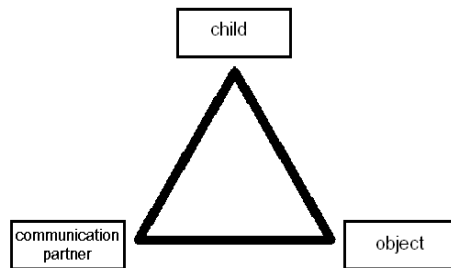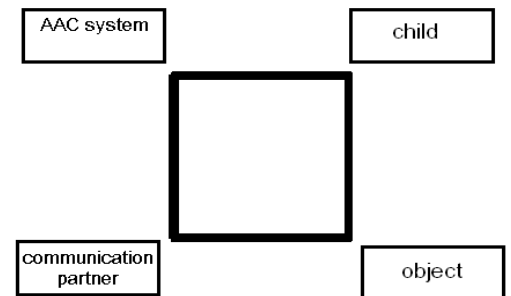
Figure 1: Triadic and Quadratic Joint Attention

Quadratic interaction involves coordinating attention between the child, the communication partner and the activity and coordinating the AAC system (see Figure 1). There has been prior research in the development of joint attention between adults and infants and the strategies developed to enhance the use of an AAC system (Smith et al., 2009). The latter study suggests that the AAC system should be near the communication partner, close to their face and that the activity itself be embedded into the system. This reduces the attention demands for the children and allows them to minimise attention to the partner, the AAC system, and the activity at once without having to shift attention.

Smith et al., (2009) analysed the frequency and duration of coordinated and passive joint attention episodes in a storybook task. The system with the aligned condition resulted in greater frequency and duration of coordinated joint attention than when the experimenter's gaze was divided from the system. It was also concluded that age was significantly related to joint attention frequency and duration in the aligned condition only.

Benigno et al., (2011) examined how the caregiver and child interaction style and psychosocial variables in relation to joint attention engagement with the AAC systems are related across two different conditions. These consisted of the system aligned to the experimenter's eye gaze or divided from the experimenter's gaze. It was found that joint attention skills, infant age and features related to temperament and joint attention engagement during caregiver-infant free play are significantly related to typically developing infants' joint attention with the AAC system. The experimenters concluded that both intrinsic and extrinsic factors need to be examined in light of minimising attentional demands and safeguarding the success of joint attention interactions with AAC systems. Several studies by Tomasello (1999) have established a relationship between language, temperament, communication partner engagement and interaction skills, and the children's joint attention skills. Tomasello & Farrar (1986) found an association between developing language skills such as early vocabulary acquisition and the capacity to coordinate one's attention with the activity/object and initiate and respond to joint attention with others. The quality of engaging in joint attention can be affected by the communication partner or caregiver's interaction. This form of engagement can be child-directed, where the adult follows in on the child's interest or adult-directed, where an adult leads the child. The child is more likely to extract information when the adult tunes in to the child's focus of attention and labels the object that the child is attending or following.

When the adult tries to direct the child's joint attention to an object of the adult's attention, the child is less likely to gain from this interaction (Tomasello & Farrar, 1986); Benigno et al., 2011). Cress et al. (2008) have reported that disabled children experience a higher degree of parent interaction when compared to typically developing children because of the nature of their communicative skills. Studies have examined the relationships between parent behaviour (contingent and directiveness) and children's skills (language and motor) during undirected incidental play. Consequently, free play open-ended tasks have elicited less adult directive behaviour and more frequent child initiation (Girolametto et al., 2000). More research needs to be conducted to investigate the link between caregivers' styles and joint attention with children with developmental disabilities. The developmental trajectories noted in language and communication may have an onset in the prelinguistic period since it is a fundamental prerequisite to acquiring a language. Before the onset of language, the prelinguistic period consists of typically developing infants using gestures, vocalisations, and eye gaze to convey communicative intentions. These communication contexts consist of requesting (pointing to the object and looking at the adult) and commenting (pointing and vocalising to get the adult to attend to an object, person or event). The literature highlights the difficulties persons with intellectual disabilities face when producing messages that make their intended referents clear to their communication partners (Smith, 2015). This problem lies in the fact that messages result from a failure to encode or attend to the dimensions that the speaker is referring to (the referent versus the non-referent). Research also suggests that while persons with intellectual disabilities engage in non-face to face tasks producing referential descriptions, at times they fail to use these skills without being prompted by the adult.

2.6 Development of Pragmatic skills.

There is no generally accepted definition of pragmatics since the field itself is broad and diverse. Dewart & Summers (1996) define pragmatics as "the study of the use of language in context by real speakers and hearers in real situations" (p.10). There are three major aspects of the development of pragmatics. The first one is the development of communicative functions, such as requesting, greeting and giving information. A variety of communicative behaviours may be used, such as gestures, vocalisations and verbal language. The second aspect is concerned with the child's response to communication, the way the child reacts to and understands communication from others. The third aspect relates to how the child participates in interaction and conversation, where the child participates in social interactions, initiation, turn-taking and repair. This is affected by variations in context, such as time, place, and people involved (Dewart & Summers, 1996). Tomasello (2003 p.37) describes how young children use language to request or indicate the existence of objects, request or describe the recurrence of objects or events (more, again), request or describe events involving objects (up, down, on, off, open, close), request or describe actions (eat, drink, sleep), comment on the location of objects and people (here, there), ask questions (what, where), attribute a property to an object (wet, pretty) and use of performatives to mark specific social events and situations (bye, thank you, no). Halliday (1973) put forward a school of thought which emphasises the social aspect of language by observing his son's language development and monitored his use of language till the age of 20 months. He developed a taxonomy of language functions documented in chronological order as his son developed his language skills.

These were listed as: the *Instrumental,* which enables the child to obtain an object he/she desires; the *Regulatory* which allows the child to exert control over other persons, the *Interactional* which allows the child to use language during social interaction and the *Personal* Functions which allows the child to realise his/her characteristics. These were documented to occur between the age of 9 to 12 months. Halliday identified another set of language functions between the age of 12 to 18 months being the *Heuristic* where the child asks questions and shows an interest in learning, the Imaginative where the child creates his/her own niche of make-believe, and the *Representational* functions where the child shows an ability to give information about something.

Speech Act	Type	Description	Example
Assertives	affirming, alleging, announcing, answering, attributing, claiming, classifying, commenting, concurring, confirming, denying, disagreeing, disclosing, disputing, identifying, informing, insisting, predicting, reporting, stating, stipulating, suggest, hint.	Speakers express their belief/commitment to what they are saying (p304).	Daniel was asleep yesterday.
Directives	advise, admonish, asking, begging, commanding, dismissing, excusing, forbidding, instructing, ordering, permitting, requesting, suggesting, urging, warning, pleading, providing information in response to asking, REQUESTS, Question.	The speaker gets the conversational partner to carry out an action or provide information in response to asking, ordering etc.	Do you know where Daniel is? Go to sleep, I said!
Commissives	agreeing, guaranteeing, inviting, offering, promising, swearing, volunteering, vowing, pledging, threaten.	Speaker commits to future course of action.	If you don't go to your bedroom, I will get angry. I'll promise you. I'll be in bed by nine o'clock.
Expressives	apologizing, welcoming, congratulating, greeting, thanking, accepting, deploring	Speakers convey utterances expressing their feelings.	I'm sorry for keeping you waiting. Thank you for your kindness.
Declarations	Utterances related to conventional ceremonies in religion, law and government	The speaker brings about a new state of affairs.	I name this child Daniel. I am resigning with immediate effect. I sentence you to five years imprisonment.

Table 4: Types of Illocutionary Acts
Adapted from Clark & Berman (2008)

The study of pragmatics can provide valuable information about the individual's communication on a day to day basis; however, it is challenging to investigate systematically without observations and analyses that could be detailed and time-consuming. According to Searle (1976), the five basic kinds of illocutionary acts (or speech acts) are assertives, directives, commissives, expressives, and declarations (see Table 4). Nevertheless, language assessment and intervention that does not consider pragmatic considerations of function and use would seem severely limited. Therefore, other methods and approaches to the study of pragmatics may be seriously considered. There have been studies that observation of the child in specific naturalistic situations would be of value. Such observational data helps to support the information gained from the interview concerning a particular child. The child's responses may alternatively be observed in elicited communicative situations.

Turn-taking is thought to develop from a form of scaffolding, where speakers present a scaffold of information about the event and then prompt the child to contribute towards the conversational exchange even with one utterance (Clark & Marshall, 2003 p.307). Children become more proficient by participating in this conversation and start taking turns with their conversational partners. This requires the skill of waiting for your turn and adding common ground to what has mutually been pre-established in the conversation. This could be done by acknowledging what the speaker has said or building on what has been agreed as common ground. When a typically developing infant is around ten months of age, pointing gestures emerge together with an urge to reach towards a desired object. Bruner (1983) has regarded this as the precursor of assertives (pointing towards an object) and directives (reaching for an object). It is typical of one-year-old infants to rely on gestures by pointing, looking and reaching and whining or vocalizing. They typically pull the adult towards the object they want, out of reach or the shelf they want opened.

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2.7 Maternal Responsivity

Parental responsiveness, or as it is commonly referred to, maternal responsivity, is one of the major social-environmental influences on the development of young children (Tamis-LeMonda et al., 2001). It is defined by the contingent and prompt reactions that parents demonstrate to their children in everyday interactions. Cress et al., (2013) identify two factors that may affect the quality of contingent responsivity, these being a communicative function (intentionality) and communication mode (type of communication behaviour). 'Professional' judgment calls for how one distinguishes between pre-intentional to intentional communication and how this is manifested. Such communication acts may be difficult to establish for typically developing individuals and even more complicated for those with severe, profound and multiple learning disabilities. If parent responsiveness is necessary for the development of communication, parents must be able to recognise a range of behaviours as being potentially communicative. Cress et al., (2013) argue that if parents recognise potentially communicative attempts and respond in a timely manner, children will recognise that their behaviour affects the environment. It is more complex for parents of children with PIMD to recognise and respond in a timely manner where such potential communication attempts remain idiosyncratic, and the level of intent is often difficult to establish.

According to Landry & Smith (2006), there are four aspects of responsivity: contingent responding, emotional-affective support, joint attention, and receptive language input. These are not mutually exclusive and have been reported to correlate with each other. At a molecular level, parent responsivity is referred to as contingent responding by following the child's lead and providing input and support, which builds on the child's interest.

A highly responsive maternal style maintains the child's focus of attention and expands on the child's initiations. This style has been positively correlated with enhanced child language development and enhanced cognitive, emotional, and social development (Landry et al., 2001). On the other hand, directive behaviours are less responsive and negatively correlated with language development (e.g. Smith et al., 2019; Tomasello & Farrar, 1986). According to Medeiros & Cress (2016), one needs to distinguish between responsive and directive communication. In a responsive communication interaction, the adult responds contingently to the child's focus of attention and acknowledges the communication as being intentional. In a directive communication interaction, the adult redirects the child's focus of attention to match the adult's own intent. Failure from the caregiver to interpret communicative attempts may result in **non-contingency** for the child with learning disabilities, potentially resulting in a long-term effect of learnt passivity and failure to develop intentional communication (Basil, 1992). Consequently, caregivers utilize a directive style to engage their children whose signals are difficult to interpret. Research has shown that parents of children on the autism spectrum tend to exhibit more directive than responsive behaviour (Wan et al., 2012).

2.7.1 Maternal Directiveness

Directive use is frequently measured in studies of maternal responsiveness. The frequent use of imperatives characterizes a directive maternal style. Historically, directive use of language has a detrimental effect on a child's language outcomes (Nelson, 1973). Directives have been associated with intrusive and insensitive maternal interactions that do not facilitate language growth in children. Directives may be detrimental to language acquisition because they do not provide a rich language model. Directives are generally short and do not typically use a rich vocabulary (e.g., "Stop that", "Come here", "Put that down").

Additionally, a directive maternal style has been associated with less child engagement, an essential factor in the social interactionist model of language acquisition (Mahoney et al., 1998). The literature only partially supports the conceptualization of maternal directiveness as a negative interactional style. Whereas some studies suggest that directives are non-facilitative (Nelson, 1973; Murray & Hornbaker, 1997), other studies have shown no correlation between directives and child language outcomes (Tomasello & Todd, 1983; Carpenter et al., 1998). Still, other researchers have found positive relationships between directives and child language outcomes (Shimpi et al., 2011). These conflicting findings in the literature may be due partly to a lack of a consistent definition of what constitutes a directive. Combining all commands into a single category of directives may not be useful to determine the role of directives in the language acquisition process.

Close evaluation of maternal directives in mothers' interactions with their young children has yielded interesting findings (Flynn & Masur, 2007; Pine, 1992; McCathren et al., 1995). McCathren et al., (1995) posit that directives that follow the child's attentional focus (i.e., refer to objects, activities, and referents that the child is currently attending) increase the number of utterances and facilitate language growth. In contrast, other types of directives may be less facilitative in the language acquisition process because they contain referents the child is not currently attending to. Studies regarding outcomes of directive maternal speech for children with developmental disabilities have reported inconsistent findings (Landry et al., 2001; Gilmore et al., 2009). Inconsistencies regarding the effects of directive maternal speech on language and communication development may be partly due to how directives have been conceptualized and defined.

For example, Flynn & Masur (2007) differentiated between directives that follow the child's focus of attention or ongoing activity (i.e. supportive behavioural directives) and those that lead the child's attention away from his or her current focus (i.e. intrusive directives). This pattern of behaviour was explored by looking at all the directives within the broad descriptive analysis based on Table 5 below.

Category	Subcategory	Description	Example
Supportive Directive Utterances (SDU)		Seek to control the physical behaviour of the child by suggesting, commanding or encouraging the child while following the child's attentional focus.	The child is putting the square in the shapes box, and the mother says, "Put the square on top!"
Intrusive Directive	Intrusive Behavioural Directive (IBD)	Attempts to modify the child's behaviour and *does not consider* the child's attentional focus.	The child is playing with a puzzle, and the mother says, "Put the horse in the stable!"
	Intrusive Attentional Directive (IAD)	directives that attempt to modify the child's current attentional focus.	The child is looking at a toy horse, and the mother points to a toy sheep and says, "Look at the sheep!"

Table 5: Coding of Maternal and Sibling Directives
Adapted from Flynn & Masur, (2007)

A study conducted by Flynn & Masur (2007) provides additional support for dividing directives into separate sub-categories based on the child's attentional focus. Supportive directives were defined as commands that followed the child's attentional focus (e.g., saying "turn the square around" while the child was attempting to fit a square piece into a shape puzzle). Conversely, intrusive directives were defined as directives that do not consider the child's attentional focus. Intrusive directives were further subcategorized into two types of intrusive directives: intrusive behavioural directives and intrusive attentional directives. Intrusive behavioural directives seek to modify the child's behaviour and do not consider the child's current attentional focus (e.g., the child is stacking blocks, and the mother says, "put the cow in the barn").

Intrusive attentional directives seek to modify the child's current attentional focus (e.g., the child is playing with a toy cow, and the mother points to a pig and says, "look at the pig"). In line with the social interactive model, the supportive directives, which follow the child's lead, would be considered maternal responsivity. These types of directives are beneficial in the language acquisition process as they provide a direct connection between the child's focus and the words the child is hearing. Conversely, intrusive directives do not follow the child's lead or provide a link between the child's focus of attention and the words heard. Behavioural and attentional intrusive directives are theorized to be adverse to language development by these researchers.

Flynn & Masur (2007) examined maternal interactions with their typically developing children at 10, 13, 17, and 21 months of age in two naturalistic settings (i.e., free play and bath time). Their study indicated that high rates of responsive language were negatively associated with the use of intrusive directives. In contrast, supportive directives were found to occur frequently in the language of mothers that were highly responsive in their interactions with their children. Their findings justify separating directives into distinctive categories. Masur et al., (2005) studied the relationship between directives and later expressive language achievement at 10, 13, 17 and 21 months. The use of supportive directives by mothers during play was positively associated with reported expressive vocabularies. This positive association was found only for the children between the ages 13-17 months of age. The authors argued that the children were in a period of rapid vocabulary development and may be more sensitive to maternal verbal interactions at this age than at previous ages. The use of intrusive directives was found to be negatively associated with reported expressive vocabularies.

Paavola-Ruotsalainen (2018) re-examined the role of maternal responsiveness and directive speech towards their children by applying an analysis procedure based on the Flynn & Masur (2007) study. Maternal verbal utterances were divided into four categories: *Responsive Utterances, Supportive Directive Utterances, Intrusive Behavioural Directives, and Intrusive Attentional Directives*. There was a positive correlation between responsive utterances and the total number of utterances at 0;10 and 2;0 and between supportive directives and the total number of utterances at 0;10. A positive correlation was noted between maternal intrusive attentional directives and the amount of speech at 0;10 and 2;0. No relationship was found between responsiveness and directiveness and children's later linguistic capacities. These studies provide further validation for separating intrusive and supportive directives into two distinctive categories in future research of maternal directive use.

2.7.2 Video Interaction Guidance as a means of establishing Maternal Attunement and Sensitivity

Video Interaction Guidance (VIG) is a video-based intervention that highlights the positive aspects of a person's existing skills and resources. It helps identify the person's relational strengths through the shared review of video clips that show successful interactions, video reviews, and goal setting. There are three cycles of VIG, comprising making a film followed by a shared review. Stern (2004) proposed that intersubjectivity, the moment when mother and baby share an understanding, is hard-wired into the brain at birth. The attachment between parent and child keeps individuals close so that intersubjectivity and intuitive recognition of intentions can develop with deepening attachments (Stern, 2004). The mother's attunement and sensitivity to the child's needs are essential for the child's emotional and cognitive development.

Bowlby & Ainsworth (2013) define maternal sensitivity as understanding the child's communicative intent, responding to the child's affective signals, and sharing. Stern (2004) argues that this 'affect attunement' is an essential aspect of intersubjective relatedness. Trevarthen & Aitken (2001) define intersubjectivity in that infants need two skills to share mental control with other persons. Subjectivity is defined within the principles of individual consciousness, and intentionality needs to be established. For infants to communicate, they need to adapt this subjective control to the subjectivity of others, thereby exhibit 'intersubjectivity'. Primary subjectivity is the communication between two persons where emotions are communicated and received in the "communicative dance". Secondary intersubjectivity involves a joint focus between parent and child on an object related to the theory of mediated learning (Bruner, 1983). Mediated learning refers to the role of the parent in scaffolding the child's learning in situations where the child cannot perform the task alone (Vygotsky, 1978). The parent mediates and provides meaning to the child's actions and emotions with a response attuned to the child's level of understanding. Once the child's initiatives have been received and understood, the attunement is deepened when the parent can provide explanations and opinions further, deepening the discussion and helping to manage conflict. The cycles of interaction between parents and their children are known as 'attunement'. Attuned communication consists of cycles of initiating contact and response between the child and parent—other variations of video feedback interventions incorporated additional parenting support and behavioural instruction (Fukkink, 2008). Studies have shown that when family-based interventions incorporate video feedback as a central intervention component, they become more skilled and experience more enjoyable parenting interactions.

Fukkink (2008) suggested positive effects of video feedback interventions with increased parental sensitivity, increased pleasure in their roles, improved parent behaviour and attitudes, and stress reduction. Studies also positively impact the child's behaviour and cognitive functioning (Kennedy & Underdown, 2017).

2.8 The Social Participation of Children with Communication Disabilities and use of AAC.

In its broadest sense, the concept of AAC is relatively old, with types of body language, gestural communication, and drawings reported in the communication literature for decades. A case in point is the account in the New Testament of Zachariah, the High Priest who failed to believe that his ageing wife, Elizabeth was to bear a son. Punished by God's wrath, he could not use his voice and temporarily reverted to the written mode of communication. The field of AAC emerged as an academic discipline in the late 1960s and early 1970s. This was brought about by the changing roles of disabled people and electronic equipment to provide independent communication options for non-speaking individuals (Romski et al., 2015). The AAC field embraces a number of controversies of the candidacy model, the advancement in digital technologies, the provision of AAC services to persons with developmental disabilities, and AAC users' inclusion in the school and the community. The initial base of AAC was very multidisciplinary, and the fractioning in the field is a relatively recent phenomenon. The intervention in AAC was largely therapist-led rather than research-led. This intervention process and the efficacy of instructional strategies aimed to support persons with communication disabilities in need of AAC. Pioneers in the AAC field struggled to develop communicative competence for persons with severe communication disabilities and facilitate participation in their daily lives (Donato et al., 2018).

The expectations and attitudes of communication partners in the environment may influence the child's language development. AAC users depend heavily on the opportunities and means provided by paid professionals working with them. If the professional supporting the individual introduces a restricted range of communicative functions due to a lack of awareness about AAC systems, communicative opportunities may be compromised (Donato et al., 2018). For example, if AAC users use graphic symbols, they are often constrained to use whatever symbols have been prepared for them by their caregivers or paid professionals. It also follows that AAC users may be using symbols that had been taught only in a structured environment, and they may be unable to transfer or generalise skills taught in a clinical setting into a naturalistic setting such as the home, school or community. AAC users may find the system confusing and difficult to generalise in naturalistic environments. Since paid professionals generally drive communication systems, parents feel 'disempowered' to use an AAC system in a natural environment (Von Tetzchner & Grove 2003; von Tetzchner et al., 2018).

In an international survey, Von Tetchner et al., (2018) found that professionals had limited knowledge of the AAC users' aided communication system outside the school context, suggesting more support for aided communication in the community. The authors implied that late access to a communication system as well as the lack of availability and use of the system in everyday use "may contribute to the widening gap in language competence between individuals who use aided communication and those who use natural speech" (p.89). Light et al., (2019) argue for developmentally appropriate approaches to support children with communication disabilities in promoting language learning, social interaction and literacy competence.

Opportunities should include the social participation of children with communication disabilities and instructional supports for families and other communication partners. Historically, AAC interventions with children have rarely targeted naturalistic interventions within families. Snell et al., (2010) maintained that in almost half of the reviewed studies, the intervention was delivered in unnatural settings, with researchers delivering the interventions. Light et al., (2019) claim that despite advances in the field of AAC, the development of adequate AAC supports and interventions for children with communication disabilities and their communication partners is still lacking. Despite the critical role of AAC technologies, these supports alone are not enough; instead, children with communication disabilities also require evidence-based instruction to learn the linguistic, operational, social, and strategic skills required to develop communicative competence. There must be a commitment to ensure the fundamental right of *all* children to have the opportunity to participate fully in society and reach their full potential.

2.8.1 Multi-modal means of communication

Lonke et al., (2006) describe how human communicators typically use a combination of modes to generate a message, a phenomenon known as multimodality. The authors designate multimodality as an explanatory framework for AAC, which may be analysed from a communication, psycholinguistic, and cognitive perspective. The multimodality framework can be utilised to consider iconicity, simultaneous communication, lexical organization, and compatibility of communication modes. When understanding the underlying processes in AAC users and their communication partners, multimodality should not be excluded. The use of multimodal communication and its benefits in developing functional communication have been documented in the literature.

Brady et al., (2015) argue that multimodal systems allow individuals to access communication through all channels available to them, promoting functional and effective communication across more contexts than one modality alone. The individual and the system should be adaptable to all environments by incorporating different AAC forms or languages for code-switching (Soto & Yu, 2014). A few single case studies have reported the successful implementation of multimodal means of communication. AAC users in these studies have been reported to present with developmental apraxia of speech, ASD, cerebral palsy and developmental disabilities (e.g. King et al., 2013; Wadnerkar et al., 2012). AAC intervention approaches using speech, gestures, manual signs, low technology aids (topic-based communication boards, PECS, and communication books) and high-technology aids (VOCAS and static overlay communication aids) were used during these various intervention studies. These case studies describe how AAC aids and strategies were successfully supplemented and provided greater opportunities for facilitating language development, communicative competence, and academic success. The children had greater opportunities to initiate and maintain interactions and repair communication breakdowns in various communication situations. In a longitudinal study of children with Down Syndrome, Launonen (2019) found that the children using manual signs as part of a total intervention program had more spoken words than another group of children provided with the same intervention program but without any manual signs. In a study with aided AAC users, Binger et al., (2008) investigated the effect of AAC interventions on different modes of communication, including speech. Research findings indicate that the use of aided communication interventions can be used to develop functional communication. There were no proven adverse effects on speech production, and in some situations, multimodality had positive outcomes on speech development (e.g. Romski et al., 2010).

While multimodal communication has been documented in the literature as successful in intervention, studies demonstrate that children with developmental disabilities seem to have their preferred mode of communication, e.g. Van der Meer et al., (2012). Results suggest that children's preferences to their choice of AAC may influence acquisition and maintenance of requesting responses. The researchers further compared the acquisition of, and preference for, manual signing, PECS, SGDs in four children on the autism spectrum. Preferences for using the former modes of communication were noted. All children learnt how to make requests using at least one of the three communication modes and preferred one mode. PECS is reported to enhance children's spontaneous communication for requests using pictures, speech, or a combination of both modes (Gordon et al., 2011). While AAC systems such as manual signs and PECS have been successful with individuals with DD, others require specific and tailor-made communication systems to meet their daily communication needs (Wadnerkar et al., 2012).

Gatt (2015) conducted a survey that found that Maltese AAC users utilise a wide range of multimodal techniques and strategies as part of an AAC system in interactions with their caregivers and educational and community settings. Most users do not use medium to high tech AAC technologies with their most familiar communication partners but rather use AAC technologies in a school setting or formal situations. The data indicate that AAC users seem to opt for unaided communication means such as facial expression/body language, gesture and vocalizations in their repertoire of expressive modes rather than aided communication modes. However, aided communicators prefer to use VOCAs. The same modes are reported to be their preferred use in the context of their homes with their primary caregivers. More than 50% of the participants used vocalisations and speech, mostly with their primary caregivers, while AAC devices were used with paid professionals and unfamiliar partners.

Although many individuals used manual signs, they used very few and did not combine them in multi-sign utterances. Whilst AAC devices were perceived as useful in some contexts; they were not used in other situations with familiar partners because they preferred unaided means of communication. Studies from culturally and linguistically diverse backgrounds reported gestures and natural speech as preferred communication modes, especially when creating and supporting a bilingual AAC system (e.g. Soto & Yu, 2014).

The survey also indicated that 70% of mothers of AAC users in Malta used speech as the main mode of expression with their children. Mothers reported varied behaviours, ranging from pre-intentional and pre-symbolic behaviour to more symbolic and conventional communication systems. AAC users convey messages in recognisable communicative behaviours that caregivers understand and interpret as intentional, but their behaviours depend on physical and verbal prompts. Interactions have been described as 'fossilized' with early patterns of behaviour persisting (Pennington & McConachie 1999, p.393). Unsurprisingly, emergent communicators exhibit a mixture of pre-intentional communication or earlier behaviours to make their needs known. This is typical of individuals with profound and multiple learning disabilities who may be using a limited number of communicative behaviours to express needs, wants and communicative functions. Parents' perceptions of intervention in the immediate environment are related to the degree and type of disability, affect (emotional expression) and behaviour style of the child (Carr & Wilder, 2016). Parents have indicated how they interpret their child's communicative behaviours using verbal and non-verbal modes to get their caregiver's attention, even if these are dependent on a higher level of prompting.

AAC users have been reported to be using attention-getting strategies, both non-verbal and verbal, to get their caregiver's attention. Parents mentioned instances when the child grabs the food item, which means he/she wants 'more food'. Every so often, mothers interpret their son's/daughter's communicative intent and establishing them as assertives or directives. For pre-intentional communicators, this may be an early attempt to interpret the use of language. Mothers have also explained the role they take when their child communicates any of these intentions. Children take up a passive role since they respond only when prompted by their caregivers (Cress et al., 2013). Therefore, individuals with communication disabilities must learn how to initiate by starting an interaction themselves.

2.8.2 Creating the need and opportunity for communication

Light (2003) argues that creating the need and the opportunity for communication is central to effective communication intervention. Therefore, partners need to identify such opportunities for communication. To such an effect, communication partners need to be trained to become effective communicators. Sigafoos & Drasgow (2001) put forward several reasons why individuals with developmental disabilities have limited opportunities for communication. One of the reasons may be the inability of the communication partner to respond to a communicative exchange. Another reason might be that the communication partner may anticipate what the individual may require and therefore provide beforehand their needs and wants, reducing opportunities for initiations and requests. For instance, the desired cereal bar is put within reach, so the individual reaches out for it, or worse, the caregiver gives the child the cereal bar without creating the opportunity to request it. Another typical example is the caregiver ordering food from a restaurant for a child with a communication disability without empowering the child to do this independently using his/her preferred mode of communication.

The communication partner needs to be supported to orchestrate the environment for optimal communication to be incorporated daily. Interventionists need to know how to facilitate social interactions and plan intervention techniques to support various social contexts and communication partners. Blackstone & Hunt Berg (2003a, 2003b) designed the 'Social Networks' communication inventory for AAC users and their communication partners specifically to understand the social inclusion of AAC users in the education and community setting. It helps identify individuals who interact with AAC across 'Circles of Communication Partners', namely, life partners (family members, caregivers), close friends or relatives, acquaintances, paid workers (therapists, teachers, carers) and unfamiliar communication partners. The inventory can collate data related to the individual's mode of communication, representational strategies, interaction styles, and conversational topics. Areas of skills are identified within each circle of communication partners, and specific intervention goals can then be devised accordingly.

2.8.3 Outcomes of AAC intervention

Iacono et al., (2016) have reported a wide range of AAC systems and variability in evidence-based practice in relation to AAC. The authors report effective to highly effective use of AAC in increasing the ability to seek needs and wants. Schlosser et al., (2009) put forward three approaches related to outcome measures in AAC; namely, goal attainment scaling (GAS), participation and quality of life (QoL). Firstly, outcomes usually attributed to AAC intervention can be defined as positive, negative or unplanned. Secondly, outcomes measurement presents itself as a continuum for efficacy research by demonstrating intervention effectiveness (Calculator, 2002) and outcomes research by monitoring differences before and during the intervention.

There is a body of research that has investigated the communicative interaction skills of individuals with communication disabilities. Research is available across a wide range of individuals, from infants to adults. Regardless of the individual variations characterised by communicational exchanges, there are similar patterns of interaction related to discourse status, communicative functions and linguistic competence. Discourse status is characterised by asymmetric turn-taking patterns, with AAC users taking up half the turns and communicating only when necessary (e.g. Pennington & McConachie 1999). AAC users seldom initiate during a communication interaction but attempt to maintain a conversation. This body of research similarly notes that AAC users follow a question and answer using yes/no and supply information specific to wh- questions.

Light et al., (1985b) report that most pre-schoolers who are AAC users utilise limited communicative functions when communicating with their caregivers. While children use a wider range of communicative functions during elicitations with their therapists, there is still a limited range of functions. For example, the children rarely asked for clarifications or asked questions. There were limited studies conducted to evaluate the long-term outcomes of AAC intervention (Lund & Light, 2006; Lund & Light, 2007a; Lund & Light, 2007b). The Lund & Light study involved seven male participants between 19 and 23 diagnosed with cerebral palsy with communication disabilities who used partner assisted scanning. Participants had all used AAC since preschool, and six of them had previously participated in a study by Light et al., (1985 a,b,c). The study investigated the long-term outcomes of AAC interventions based on the World Health Organisation International Classification of Functioning, Disability and Health (ICF). Schlosser & Lloyd (2003 p.484) define the constructs of the ICF as body functions, body structures, impairments, activities and participation.

Lund & Light (2006, 2007a; 2007b) applied this model within the following domains: (a) receptive language; (b) reading comprehension; (c) communicative interaction; (d) linguistic complexity; (e) functional communication; (f) educational and vocational achievement; (g) self-determination; and (h) quality of life. As mentioned earlier, each of the areas was measured based on language samples, standardised tests, interviews, and questionnaires. The participants' results demonstrated that domains relating to interaction were like those regarding participation. In contrast, results related to the language domain were less analogous to results related to participation. The importance of the evidence-based practice (EBP) approach in integrating reliable research evidence in AAC decision-making processes have been addressed several times in the literature (Thistle & Wilkinson, 2015; Schlosser & Raghavendra, 2004). For example, Hill (2006) proposes a basic case study format for documenting AAC intervention to ensure a valid and reliable measurement of performance and outcomes for evidence-based practice.

2.8.4 Quality of Life issues

AAC implementation is intended to facilitate communication and improve the overall quality of life (QoL) of individuals with communication disabilities. There are many widely accepted definitions of QoL, although it is viewed as individualised or unique, interacting with individual characteristics and the environment. The following definition of QoL based on seven domains was put forward by Cummins et al., 1997 p.9.

> *"Quality of life is both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Objective domains comprise culturally relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by their importance to the individual".*

Several research papers have attempted to identify what is meant by QoL for individuals with communication disabilities. (Hamm & Mirenda, 2006). According to Beukelman & Mirenda (2017), successful outcome evaluation and QoL measures are dependent upon the individual's AAC intervention and one's participation in the environment. The AAC intervention would be measured in important life domains such as participation in the community, educational inclusion, social inclusion, self-determination and gainful employment. In addition, structured interviews may be used to elicit information related to QoL measures. Measures such as the Quality of Life Profile: People with Physical and Sensory Disabilities instrument (QOLP-PD and the American Speech-Language-Hearing Association Quality of Communication Life Scale (ASHA QCL) have been used to measure long term outcomes for people who use AAC (Hamm & Mirenda, 2006; Hrad, 2016). While the use of AAC strategies has had positive effects on the individuals' educational and communication skills, there is no guarantee that when the student leaves formal schooling, he or she will still uphold these achievements. Hamm & Mirenda (2006) studied the post-school outcomes of eight Canadian individuals who used AAC during their schooling years. The measures mentioned above were used to collate data (Quality of Life Profile: People with Physical and Sensory Disabilities instrument QOLP-PD) and a communication survey. Post-school outcomes for these individuals were discouraging, with several practices and policy barriers identified. Nevertheless, there is a positive correlation between the quality of life and the quality of communicative competence. This study seems to replicate the results from the study by Lund & Light (2006), wherein a positive relationship exists between communication ability and QoL. However, one must note that the Lund and Light study participants seem to be more satisfied by their overall life outcomes and communication abilities than the Hamm and Mirenda participants.

This could be due to the Lund and Light participants being subjected to a sustained period of AAC interventions for most of their lives, unlike the Hamm and Mirenda participants. In a study by Lee McIntyre et al., (2004) of 30 mothers of young adults with a severe intellectual disability regarding their son or daughter's quality of life. They were asked to describe what quality of life means for their child and evaluate their QoL. Mothers mentioned recreation, activities, and hobbies as essential components of their young adult child's quality of life (73%), of having their child's basic needs met (53%), having their child belong to a social network (40%), having their child to be content (37%), gainful employment (7%), communication skills(10%), health (13%), and consistency in their child's lives (17%).

2.8.5 AAC use in the local context

During the past decade, there have been significant developments in the AAC field in Malta, with initiatives taken up by governmental and non-governmental organisations. However, local studies about the social participation and educational inclusion of Maltese AAC users are limited. For this reason, due importance was given to the study, which focused on the barriers to providing AAC systems to Maltese school-aged children with communication disabilities (Gatt, 2007; Gatt, 2012). Service providers and service users were interviewed through face-to-face and focus groups to identify common barriers to effective participation. An imminent need to develop competent, collaborative AAC related practices to provide effective intervention services and implement legislative measures, policies and funding possibilities was highlighted. Practice barriers stemmed from role boundaries and responsibilities as a source of potential conflict. Role ambiguity seemed to be another factor on who should ultimately be responsible for device initiation, implementation, monitoring and ongoing assessments.

Respondents appreciated the involvement of AAC teams and families in developing and implementing AAC systems and called for team collaboration, information, and adequate training. When considering findings involving decisions against an AAC system, interviewees generally agreed that this was due primarily to the families' negative attitudes and concerns, lack of resources, and expertise in AAC. Furthermore, professionals unfamiliar with the recent research and theories about communication development may fail to recognize the potential benefits of AAC. Professionals decided against an AAC system since the child was at a pre-symbolic level of language development. Considerations of AAC strategies may be postponed due to common misconceptions about presumed "entrance skill" requirements for AAC intervention.

2.9 Conclusion

The focus of this chapter was to describe theoretical underpinnings of the nature of communicative exchanges between family members and children with IDD who have a communication disability. I was interested in how the theories of language acquisition were relevant to individuals with communication disabilities, particularly the adaptation of the Social Constructivist model and how these can be reflected in the design of an intervention strategy for my studies. I realised that a more eclectic approach needs to be taken rather than a pure Social Constructivist approach. I felt that the *Transactional model* appears to be appropriate for understanding early cognitive and language development, caregiver-child interactions, and the use of an AAC system. I was interested in how the Transactional model can be used to explain the dominant role taken up by the caregiver and the passive role exhibited by the disabled child.

Caregiver (or maternal) sensitivity is crucial for the understanding of the child's communicative intent and responding to the child's affective signals. I understood that if the caregiver is attuned and sensitive to the child's needs this may impact positively on the disabled child who benefits from AAC.

I learnt that Video Interaction Guidance may be an effective tool to increase caregiver sensitivity and attunement and could impact on the child's behaviour and cognitive development. Interestingly, this video-based intervention encompassed an aspect of subjectivity which is related to the theory of Mediated Learning (Bruner, 1983) influenced by the Social Constructivist Model (Vygotsky, 1978).

This chapter also provided an overview of the international literature related to AAC users' characteristics, including prevalence, and intervention techniques that may enhance the social competencies of AAC users. The importance of multimodality as a mode of communication was also implied with emphasis on the local situation of AAC use. A number of shortcomings were identified in this literature review, which was systematically addressed in subsequent chapters concerning family relationships and interventions. From this review, I realised that I wanted my studies to focus on children with communication disabilities who benefit from AAC. I also wanted to learn more about the interactions between mothers, siblings and AAC users and how this acclaimed 'dominant' caregiver style may impact on mother-sibling-child relationships.

I felt that it was best that a review of family interactions should be addressed for typically developing children and also for disabled children. This was followed by the role of siblings as potential partners in AAC interventions as addressed in the next chapter.

CHAPTER 3: FAMILY AND SIBLING INTERACTIONS – A NARRATIVE REVIEW.

3.1 Introduction

Before the 1980s, studies on family and child interactions dominated the research scene, with considerable research channelled towards mother-focal child relationships. There was a lesser emphasis on siblings with learning disabilities and how these impact on family interactions. It was not until the late 1980's and 1990's that a substantial number of studies on siblings of disabled children were published. Notably, there was a development of theoretical frameworks addressing sibling relationships. Several longitudinal studies on sibling relationships over time and qualitative approaches include perspectives of individuals with developmental disabilities within the sibling relationships framework (Cebula and Kovshoff, 2020).

This chapter summarises the studies on family and typically developing sibling interactions concerning communication, language and sibling quality relationships. This is followed by a review of mother and sibling interactions of disabled individuals to identify gaps in the literature and suggest future directions for the research on family and sibling interactions. Finally, this chapter focuses on mainstream Anglo-western models of parenting since Malta, being an EU member state and part of the British colony for over 150 years shares an Anglo Western culture, which privileges child-centred approaches to rearing. Those families from other cultures may have a different philosophy of parenting. For example, an authoritative and authoritarian parenting style is usually associated with Asian Cultures, although studies have indicated that Eastern parenting was positively associated with positive parenting but not with rejection and negative discipline (Xu et al., 2005).

3.2 Models of Disability

There was much debate about the different models of disability through the past three decades, emphasising a child-centred approach to service delivery (Oliver & Barnes, 2013). The focus and planned outcomes of interventions differ according to which disability model is adopted by families and interventionists alike. There are four major models of disability the medical model, the social model, the transactional model, and the ecological or systems model. Within the medical model, the child's impairment and the parents need to be 'fixed'. Interventions have focused on the child's impairments while the family's inability to fix the child's problems has been highlighted (Oliver & Barnes, 2013).

The social model of disability focuses on social and environmental interventions in challenging attitudinal barriers and inadequate service provision. Whilst the social model of disability calls for a trans-disciplinary approach to service delivery, there is a tendency for professionals to control the parent-professional relationship, assuming the expert role rather than involving parents in the decision-making process. As a result, parents may become marginalized and disempowered with reduced opportunities for parental involvement and participation. The transactional model proposes a framework for conceptualizing how such dynamics affect the experience of disability for the child and the support system (Llewellyn & Hogan, 2000). Finally, the system analysis model integrates the medical model, the social model and the transactional model. Llewellyn & Hogan (2000) suggest the systems analysis model places the child with a disability in an environmental context that can produce developmental changes. Parents can be most effective if they understand the underlying models and develop partnerships to ensure support services meet the child's needs.

Dunn (2005) highlights novel perspectives on family processes related to multilevel modelling, in which siblings play a central role. The author also pointed to different theoretical perspectives on families, for instance, Volling's systems perspective (2005), which presents a developmental ecological systems model for examining changes in family life and the older child's adjustment following the birth of a younger sibling. Whiteman et al., (2011) propose four psychologically-oriented perspectives to inform research on variations in sibling relationships. These perspectives consist of (a) psychoanalytic-evolutionary, (b) social-psychological, (c) social learning, and (d) family-ecological systems.

3.3 Family Theories and frameworks

Researchers turn to other family models to inform evidence-based practice. Three commonly cited theories in family relationships are the family systems perspective, the social ecology theory and the Siblings Embedded Systems Framework (see figure 2).

3.3.1 Family Systems Theory

Bowen (1966) penned the family systems theory, which suggests that individuals should not be understood in isolation but as part of a family system of interconnected individuals. Research on the family systems theory suggests that each family is conceptualized as a system comprised of various subsystems interacting in reciprocal ways (Mandak et al., 2017). Families relate to the subsystem to which they belong using the subsystem concept. These subsystems include the spouse-partner, the parental dyad, children, sibling subsystem, father-son subsystem. Subsystems and roles may overlap and change over time and according to the family circumstances. Minuchin (1985) postulated that the systems theory could address studies related to family-child interactions.

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A meta-analysis of 47 studies confirmed that help-giving and family-systems intervention practices directly affected parents' self-efficacy beliefs and well-being and indirectly affected parent-child interactions and child development in an enabling manner (Trivette et al., 2010).

3.3.2 The Social Ecology Theory

The Social Ecology Theory put forward by Bronfenbrenner (1986) postulated that to understand the framework of human development, the entire ecological system in which the individual functions needs to be considered. This consists of five socially organised subsystems that support the individual's development (i.e. the individual, the microsystem, the mesosystem, the exosystem and macrosystem). This model works in parallel with the family systems theory and emphasizes that development must always occur in context. While the family systems model focuses on the individual (e.g. age, gender, health) and microsystem subsystems (the immediate surroundings), the social-ecological theory also considers the meso, exo and macrosystem as the overall patterns of the larger social system, the ideology and organisation.

The family systems theory and social ecology theory stress the importance of not looking at an individual in isolation, as every person influences and is influenced by family members and society (Carpenter and McConkey, 2012; Carpenter, 2010). Interventionists using the family systems theory need to address the subsystems or interconnecting units and cannot assume that the individual will change without considering the other family members. This means that intervention programs need to consider the surrounding environment unless the intervention is also aimed at adjusting the child's environment.

Similarly, the Social Ecology Theory does not account for the individual's development or relationships without considering the levels of influences surrounding that individual. Interventions based on this theory need to recognise that change must address the different levels. For change to occur, this depends on the resources available in the community. These theories are beneficial when considering the focus and planned outcomes of family-led interventions but do not emphasize enough the biological and cognitive factors that the child brings to the task at hand. Similar models have included a 'bioecological theory' that acknowledges that the individual plays a role in the environment and influences the individual (Saxena & Adamson, 2013). The authors use the revamped model known as person-process-context-time to focus on developmental outcomes over the life course. This theory recognizes the interconnected nature of all the factors impacting the child over a lifespan, the person (sibling), microsystem (family, school, community), mesosystem (connections between microsystem), exosystem (heath, community resources), macrosystem (laws, culture, social policy), and chronosystem (the influence of chronological/developmental time).

3.3.3 The Sibling Embedded Systems Framework

The Sibling Embedded Systems Framework (Kovshoff et al., 2017) builds on the family systems model (Minuchin, 1974), the diathesis-stress model (Bauminger & Yirmiya, 2001), the Double ABCX model (McCubbin & Patterson, 1983) and the bioecological systems approach (Bronfenbrenner, 1986). It illustrates some of the key factors at each level. Individually, each model has been used in family research to conceptualise the family as a dynamic integrated system. Kovshoff et al., (2017) argue that these models were not explicitly designed to examine sibling relationships. The Sibling Embedded Systems Framework was designed to understand siblings of children on the autism spectrum.

The framework adopts the bioecological systems approach where it incorporates a series of levels from micro-systems (experienced by the sibling), the mesosystem and the exosystem, which is broader and determined by cultural and societal factors. Within this framework, the child is seen as an active participant in the environment. Figure 2 illustrates the 'event' who may be the child with a disability who is not presented as a 'stressor' within the family but rather a positive impact on the family structure. The 'within siblings' factors consist of the demographic variables (e.g. gender, age), internal challenges (e.g. language disorder) and internal resources (e.g. resilience), as well as the sibling's interpretation of the results.
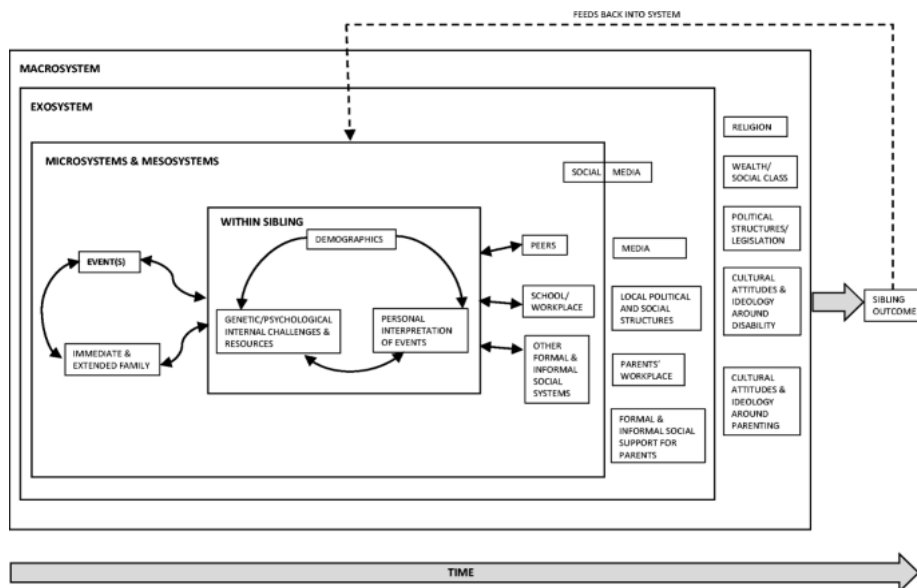
Figure 2: Sibling Embedded Systems Framework
(adapted from Kovshoff et al., 2017 p.39)

Within the micro-and meso-level, sibling outcomes are affected by the 'event' and the 'within siblings' factors. The development of this framework may guide this field of research to include a wider participatory framework and evidence-based interventions (Tudor & Lerner, 2015). This framework may potentially lead to understanding the factors that affect siblings and involve families from different cultural and socio-economic backgrounds (Kovshoff et al., 2017).

3.3.4 Service Delivery models

Several service delivery models are considered beneficial by early interventionists and practitioners concerning families (King et al., 2004). One must note that the terms 'parents' and 'families' are used interchangeably in the literature to refer to the family perspective of service delivery. King et al., 2004, p79 define a family-centred service as endorsing the following: (i) that parents are experts on their child's needs and abilities, (ii) families are unique, and (iii) families work together with service providers to ensure informed decisions are taken about the child's support services. Family-centred approaches based on the family systems theory focus on the knowledge and skills necessary to effectively interact with the child and develop positive outcomes for the family and the child (Dempsey et al., 2009). The parent partnership model is perhaps one of the most effective since it involves a paradigm shift from the professional as 'expert' to acknowledging the parent as a valued partner in the intervention process (Sloper, 1999). The author suggests that such models provide a consistent reference point for the families by assuming parent empowerment and acknowledging parents' expertise and knowledge.

Two types of programs may be directly associated with this proposed parent partnership model: a) family-focused home-based programs and b) a combination of family-focused home and centre-based programs. Parents may partner with professionals, providing various therapies across various services and strategies. Parents may serve as co-interventionists and partners in implementing family interventions. There are encouraging reports that parental participation in their child's early intervention programme is beneficial in the child's social and cognitive development, as amongst other things, their participation increases parental confidence in carrying out their various roles and responsibilities (Guralnick, 2017).

Several studies have evaluated the success of home intervention programs and their effects on other family members, including siblings. Results suggested that changes in the home environment resulting from early intervention programs were beneficial to all the family members, confirming that family-focused programs produced efficient intervention strategies. Guralnick (2017) also refers to the family patterns of interaction that significantly influence the child's competencies. These three major components are parent-child transactions, family-orchestrated child experiences and children's health and safety. These components are also influenced by the families' resources, including the parents' characteristics (e.g. parental style) and resources (e.g. financial resources). An effective early intervention programme necessitates attention to all the components within the family patterns of interaction and the families' resources.

3.3.5 Family interactions and typically developing children

Chapter 2 gave an overview of parents' early interactions and responsivity with their typically developing children. Learning occurs within a socio-cultural context in which more able individuals scaffold the learning of young children to higher levels of thinking. Children who experience stimulating home environments early in their development are advantaged in the learning process (Bruner, 1983; Vygotsky, 1978). Researchers into child development have turned to developmental models based on the work of Sameroff (2009). Three models of child-environment interactions consist of the main-effect model, interactive and transactional model. The transactional model is the most complex as it considers that the environment changes as a function of the child's characteristics, and the child changes due to the environment. While the role of family interactions has been associated with children's cognitive development and social interactions, it is yet unclear how family interactions influence child development and how child and family factors work in combination.

The transactional model is a useful framework for understanding how highly responsive parenting may impact cognitive and language development and how low responsive parenting may hinder further cognitive and language development. This process can be observed early in infancy with mutual gaze between the infant and caregiver and contingent responsiveness related to infants' state of hunger, pain and distress. A responsive caregiver modifies his/her behaviour towards the child to support and scaffold further language, cognitive and emotional development in the child. Studies endorsing child-driven or transactional models may be useful in understanding early cognitive and language development and the interactions between the child and the caregiver (Warren & Brady, 2007). There has been extensive documentation of different maternal styles related to early language development over almost 50 years. Snow (1972) indicated that speech addressed to children differed from speech addressed to adults. Child-directed speech was described as having shorter utterances, raised pitch, and simpler sentence constructions. A notable study by Nelson (1973) found that maternal directiveness was related to the child's vocabulary development. The mothers' directive style seemed to impede the child's vocabulary progress, whilst a nondirective style facilitated vocabulary building. Studies by Tomasello and colleagues (e.g. Tomasello & Farrar, 1986) indicated that the time children spent in joint attention episodes with their mothers was positively correlated with increased vocabulary size.

3.3.6 Family interactions in children with additional needs

Some studies have addressed parent responsivity and children with additional needs, including children at risk due to premature birth and varying degrees of biological risk (Muller-Nix et al., 2004; Landry et al., 2001).

Environmental factors, such as parental stress and SES and the increased risk of motor, language, and cognitive delays in children born preterm, have important implications when considering the formation of high-quality, responsive interactions between the caregiver and a child with additional needs (Potharst et al., 2012). These studies suggested that mothers were less sensitive and more controlling due to post-traumatic stress reactions. In addition, studies determined that mothers who had experienced stress in the perinatal stage were less sensitive and more controlling with their children.

Other studies analysed the role of early or ongoing maternal responsiveness in predicting cognitive and social development for full-term children, low-risk and high-risk premature children (Landry et al., 1997). Premature children showed faster cognitive growth when mothers were consistently responsive. Social growth was similar when mothers were consistently responsive and inconsistently early-responsive—however, a more significant deceleration by four years among children whose mothers did not demonstrate early responsivity. Interestingly, in a study by Younesian et al., (2021), mothers of pre-term children were more intrusive and directive than mothers of full-term children. Mothers of full-term children were more responsive and used supportive directives in their interactions. Moreover, in full-term children, maternal supportive directiveness and responsiveness were significant predictors of language development. In the pre-term group, maternal supportive directives and supportive and intrusive directiveness were significant predictors, with intrusive directives negatively associated with language development. Less sensitive parental responsiveness and maternal directiveness were evident with children with attention-deficit/hyperactivity disorder (e.g. Johnston et al., 2002), oppositional behaviour and anxiety disorders (e.g. Hudson & Rapee, 2001).

The framework within the transactional model can be used to understand the children's oppositional behaviours and diminished maternal responsiveness and the reciprocal relationship between parenting and increased oppositional behaviour.

3.3.7 Family interactions in children with developmental disabilities.

Several studies have reported maternal responsivity in families of children with developmental disabilities, particularly the influence of maternal responsivity and language growth in children with Fragile X syndrome (e.g. Brady et al., 2020; Brady et al., 2014; Sterling et al., 2013), parent-mediated interventions with children on the autism spectrum (Siller et al., 2013) and parenting models of developmental intervention and Down syndrome (Lorang et al., 2018; Sterling & Warren, 2014; Mahoney & Nam, 2011). These studies have demonstrated that highly responsive parenting may reap benefits in language, cognitive, social, and emotional development in the early years. Conversely, an unresponsive and directive parenting style is associated with low gains in terms of language and overall developmental areas.

A commonly reported finding is that mothers tend to be more directive when interacting with children with DD than with typically developing children (e.g., Spiker et al., 2002). Despite the caregivers' best intentions, children with developmental delays such as children on the autism spectrum, Down syndrome, and Fragile X syndrome are more likely to experience reduced environmental input, in part due to their low responsivity and initiations (Brady et al., 2014). Slonims & McConachie (2006) argued that by eight weeks of age, infants with Down syndrome were less communicative than their typically developing infants, and by 20 weeks, mothers were less sensitive and more remote than mothers of typically developing children.

This suggests that the development of early social interactions, particularly gene-environment interactions between mothers and their children with Down syndrome, is likely to follow adifferent transactional process. Indeed, children with Down syndrome need to be directed to engage in opportunities for learning because they tend to be passive (Warren & Brady, 2007; Spiker et al., 2002). Mothers of children with Down syndrome accommodate their children's passive behaviour by becoming more controlling (e.g., Landry et al., 1998; Spiker et al., 2002). Lorang et al., (2018) compared maternal responsivity of gestures of 22 infants with Down Syndrome and typically developing infants based on age and diagnosis. The participants were aged between 22 and 63 months and were matched on chronological age. Children with DS used more gestures than their typically developing chronologically age-matched children. There were no differences in maternal responses for mothers of children with DS based on child age. There was a negative relationship between the percentage of maternal responses and child age for typically developing children. A longitudinal study by Sterling and Warren (2018) examined maternal responsivity and directive behaviours for mothers of 55 children with Fragile X and Down Syndrome. Both groups of mothers demonstrated a responsive style of parenting and the use of language skills such as commenting. Mothers of children with DS used more commenting and more gestures, similar to what Lorang et al. (2018) reported. These studies suggested that early intervention should focus on increasing parent responsivity in response to the child's gestures as early as possible to aid language learning and capitalise on their strengths. In a narrative review, Crowell et al. (2019) stated that parents of children on the autism spectrum tended to be less sensitive and more directive in their interactions.

It appears that fathers and mothers differ in how they interact with their children, with fathers being less active when engaging with their young children on the autism spectrum. According to Konstantareas et al. (2008), fathers are reported to be more directive than mothers. These studies of parental sensitivity and emotional attachment were cross-sectional, and one needs to consider that higher functioning children on the autism spectrum are more capable of showing attachment behaviours and, therefore, eliciting more responsive parenting. In a   cross-sectional study by Flippin & Watson (2015), those fathers who were sensitive, positive and contingent towards their children on the autism spectrum had children with higher language scores.

In another study by Flippin (2019), a father of a child with ASD mastered three of the strategies (follow-in comments, follow-in directives, responsive physical play). The child's use of single words and multi-word utterances increased. A study by Bentenuto et al., (2021) showed that fathers of children on the autism spectrum demonstrated child-directed language with descriptions, which was higher than fathers with typically developing children. They used more verbal scaffolding by commenting and explaining what was happening during the play activities. Interestingly, the fathers in this study did not show a directive style often reported for mothers of children on the autism spectrum and ID.

Parents of children with cerebral palsy produced more initiations and were more directive to their infants during free play when compared to mothers of typically developing children (Hanzlik, 1990). However, in studies that involved goal-directed behaviours (e.g. puzzles and toys), parents of children with severe speech and physical impairments were no less responsive or more directive than parents of typically developing children (Tamis-LeMonda et al., 2001).

Findings that parental responsiveness is associated with higher levels of developmental functioning among children with DS and children with ID suggest that parents accommodate their higher-functioning children by being more responsive and supportive of their children's initiations. While the research indicates that parents are highly directive, they are responsive to their child's developmental level and needs and show a warm parenting style (Warren et al., 2010; Sterling et al., 2013).

A longitudinal study by DeVeney et al., (2016) investigated whether parent responsiveness towards their children with communication disabilities changed during object and social play and whether this was influenced by the child's overall receptive and expressive language development level and motor development or different play tasks. All the 37 parents of children with physical or neurological disabilities participated in three activities. Results indicated that parents who were responsive before the study continued to interact in the same manner. These findings are consistent with Yoder & Warren's (2002) and Broberg et al., (2012) studies, which both reported an increase in parent responsivity or else parents maintained their levels of responsivity after the program. Those parents who were directive before the study, mainly during object play, were more responsive during social play than object play. In conclusion, the results suggested that parents used responsive styles during social play activities rather than goal-directed object play activities.

Mothers of disabled children face many barriers to the development of mother-focal child interactions. These include maternal factors such as the anxiety and stress of raising a child and child-related factors with a higher risk of language delays and attention deficit. Mothers tend to provide more intrusive directives, allowing them to control and guide the child's play without considering their attentional focus.

Traditionally, directives have not been considered facilitative of language learning in young children, as these do not provide a rich language model, resulting in less child engagement (Prizant et al., 1993). However, other researchers argue that certain types of directives, particularly those that follow the child's attentional focus, provide a relevant connection between their words and their referents and facilitate language growth (Flynn & Masur, 2007). This issue has been thoroughly discussed in Chapter 2.

In summary, there have been consistent findings that mothers' responsivity directed to children supports early language development in three ways, i) the amount of maternal speech directed to the child facilitates early language development, ii) maternal directive style is negatively correlated to the child's language development and iii) a responsive non-directive style has been positively correlated with the child's language development. Understandably, one would ask whether sibling interactions would mirror the same characteristics of a directive maternal style and to what extent these features are similar.

3.4 Introduction to Sibling Relationships

According to Buhrmester & Furman (1990), parent-child relations are the foundation of the family framework. Parent and child characteristics have been shown to affect the quality of sibling relationships (Petalas et al., 2012b). Sibling perspectives, family resources and coping styles seem to determine the nature of sibling relationships (Johnson et al., 2020). Investigations on sibling adjustment have found a combination of fixed and modifiable variables. Fixed variables include family size, socioeconomic status, and sibling ages and age differences. Factors related to sibling relationship qualities have focused on the family structure or constellation variables, namely gender, birth order, and siblings' spacing.

However, a focus on constellation variables does not help us understand the processes underlying differences among sibling relationships (Dunn, 2005). Modifiable variables include depression, conduct and self-concept. A study by Marquis et al., (2020) asserted that the type of developmental disability, sex, birth order, characteristics of the non-disabled sibling and family income are associated with depression and siblings' mental health outcomes.

Furman & Buhrmester (1985) developed the Sibling Relationship Questionnaire (SRQ) to assess the qualitative features of sibling interactions. Children's perceptions of the qualitative features were factor analysed, and four factors were derived. These factors were identified as (1) warmth/closeness, (2) conflict, (3) rivalry, and (4) relative status/power. According to this model, there are three primary determinants of sibling relationships: family constellation variables, child characteristics, and parent-child relationships. Constellation variables for age, gender, birth order and birth spacing exert their influence on sibling relationships. The most consistent result for gender is that females report higher social closeness and warmth levels than their male counterparts (White et al., 2014). There does not seem to be a relationship between gender and rivalry or conflict (Furman & Buhrmester, 1985). Birth order does not affect the level of warmth and closeness, but there seems to be an effect of birth order on rivalry and conflict, moderated by parental differential treatment (Volling, 1997). Birth spacing seems consistent across warmth, closeness, conflict, rivalry and relative power (Buhrmester et al., 1992). The best birth spacing for quality sibling relationships was five years, and the narrowest spacing was one year or less, with a spacing of two or three years being the most negative on sibling relationships (White et al., 2014).

While these constellation variables play a role in the quality of sibling relationships, the size of these effects is relatively small compared to the effects of child temperament, parent behaviour, and child age (Brody, 2004). These variables are reported to impact the more significant amount of variance in sibling relationships' quality. This chapter addresses these three primary determinants of sibling relationships to unpick the research evidence regarding sibling quality interactions in typical and atypical family and sibling studies. This section also highlights the untapped areas of research concerning sibling relationships and Bronfenbrenner's bioecological model (see Table 6).

Levels of contextual influence				
Person	**Microsystem/mesosystem**	**Exosystem**	**Macrosystem**	**Chronosystem**
Perceptions of care	Type of relationships among family members	Community resources for disabled children	Family ethnicity	Sociohistorical events
	Parental coping mechanisms	Parent programs and support groups	Cultural beliefs about disability	Change in beliefs about disability over time
	Stage of parent reaction to disability		Expectations of survival and social participation	Family life stage
			Funds for sibling support programs	

Table 6: Untapped areas of Research
Adapted from Saxena and Adamson, 2013.

3.4.1 Typically developing Sibling interactions

Mannle et al., (1992) conducted an in-depth study comparing preschool sibling-infant and mother-infant conversations. When siblings were compared to their mothers, they were noted to engage in shorter and fewer conversations with infant siblings. They asked fewer questions and used more directives than their mothers did. Infants tended to be more responsive to their mothers rather than their siblings. This study showed differences in the pragmatic abilities of siblings and mothers in interactions with younger children.

It suggested that sibling interactions with their younger siblings portray a directive style and lack of responsivity. It seems too that later-born children may develop language at a slower rate than their older siblings. Volling et al., (2010) claim that second-born siblings become more cognitively, linguistically and socially competent over the early years, with early power imbalance becoming less relevant as age and interactions become balanced. Mother-sibling interactions must be studied by examining other family dyads to understand the complex relationships between siblings. Studies suggest that role asymmetries are likely to exist between older and younger siblings, but this is discussed further in this chapter (see Brody, 2004).

Previous research on typically developing siblings highlights that siblings seem to influence each other's development (Howe & Recchia, 2014). Therefore, teaching strategies have also been identified in typically developing siblings wherein they can understand other children's perspectives through direct instruction and demonstrate scaffolding skills used to explain and demonstrate complex tasks. Although it is unclear how the older sibling may affect the younger ones and vice versa, the presence of a sibling plays a crucial role in the development of each sibling alike (Taunt & Hastings, 2002). Several studies investigate the link between the quality of relationships, parenting style and management of sibling relationships (e.g. Gau et al., 2012). Dunn & Kendrick (1981) examined the relationship between sibling relationships and mother-focal child relationships. They found that while mothers' interactions with their elder girls were intense and playful, their interactions with their younger siblings were not that positive. Similar results were reported in the study by Brody et al., (1996), who found qualitative and quantitative differences in mother interactions with their school-aged children associated with less positive sibling interactions and increased agonistic behaviour between siblings.

A study by Yaremych & Volling (2020) indicated that supportive and non-supportive emotion socialization strategies used by fathers with the older sibling accounted for a significant amount of variance in older siblings' rivalry, aggression, and avoidance. The same cannot be claimed for mothers. Older siblings' rivalry/aggression and avoidance were linked to fathers' non-supportive reactions to both the older *and* younger siblings' negative emotions. A within-family approach is essential in clarifying parents' and siblings' emotional socialisation.

Despite many studies on mother-focal child-sibling interactions, there is little research into triadic interactions and how mothers influence their siblings during social interactions. The available research focuses on studies related to twins (e.g. Oshima-Takane & Robbins, 2003). These studies confirm that triadic interactions are longer than dyadic ones, and as previously observed in past research, children benefit from overhearing conversations with their mothers and siblings (Barton & Tomasello, 1991). Other studies have indicated that when mothers divide their attention with all the children during triadic interactions, they provide fewer language models. According to Warren & Brady (2007), maternal responsivity and the child's behaviours can disrupt the fine line of optimal parent-child interactions. These factors include the cognitive and physical abilities and the functions and modes of the child's communicative behaviour (Cress et al., 2013; Slonims & McConachie, 2006; Warren & Brady, 2007). Similarly, low and high maternal responsivity is multifaceted and depends on maternal education, stress, depression, anxiety, poverty and history of child abuse. In addition, maternal responsivity interventions may enhance the child's language, social, emotional and cognitive development (Yoder & Warren, 2002). More research is desirable to establish how these factors influence the success of an intervention.

3.5 Siblings and disabled children

Various inherent factors influence sibling interactions, and this is related to birth order, gender and developmental trajectories, parenting, family characteristics, and the community. Considerable research has focused specifically on mother-focal child relationships; however, the impact of a disabled child on sibling interactions and the family is not well researched, results are conflicting, and the findings are often confusing (Saxena & Adamsons, 2013; Stoneman, 2005).

While older siblings of typically developing children serve as leaders in sibling interactions and support their younger siblings in the early years, these relationships become well balanced as both siblings enter adulthood. The same cannot be said for siblings of individuals with DD who, regardless of their birth order, spend more time in caregiving activities throughout adulthood (Hannah & Midlarsky, 2005). Reportedly, more females than males report the long-term positive impact of having a brother or sibling with DD (Orsmond & Seltzer, 2007). The literature reported the dominant roles of siblings of children with developmental disabilities, who assume various roles with their disabled sibling (Stoneman, 2005). This results in role asymmetry between sibling pairs compared to typically developing sibling pairs (Gordon-Pershey & Hodge, 2017). Siblings typically take up asymmetric but reciprocal roles to instruct their younger siblings while capitalising on their social, emotional and cognitive development (Stoneman, 2009). The role of the parents is crucial when assigning specific roles to the siblings. Siblings often take up the parents' roles in the everyday care of their sibling with a disability as they often manage, help and teach their disabled brother or sister (Kramer et al., 2019; Stoneman, 2005).

Older and younger siblings, particularly sisters of disabled children, tend to take more leading and nurturing roles (White et al., 2014). Some studies suggested that age causes issues of power and control, rivalry and jealousy between siblings (Della Porta & Howe, 2012; Kolak & Volling, 2011; Miller et al., 2000). Age differences were also shown to provide the context for more teaching, helping and caregiving interactions (Kramer et al., 2019; Howe & Recchia, 2014). Regardless of the birth order, children with Down syndrome behaved in patterns similar to second-born children, and their siblings behaved in patterns similar to firstborn children. Although some differences were noted, children with Down syndrome received more nurturing behaviour from older siblings and more prosocial requests from younger siblings. Prosocial behaviours such as sharing and talking with their sibling with ASD increased after siblings participated in a sibling support group as part of a parent sibling training program (Sheikh et al., 2019). Siblings teach one another while playing together with second-born children benefitting from the older sibling interactions (Volling et al., 2010).

Stoneman (2005) reported that the role of asymmetry was evident with siblings of children with Down syndrome who tended to lead the interactions. Older siblings of children with intellectual disabilities spent more time with their siblings than siblings of children without a disability. They also engaged in more frequent caretaking activities (Volling, 2014). Siblings with a learning disability were responsive toward their siblings, but children on the autism spectrum established less frequent interactions and imitations. Siblings of individuals with Down syndrome were more optimistic about their relationship than siblings of children on the autism spectrum (Orsmond & Seltzer, 2007). Siblings of individuals on the autism spectrum find it difficult to be primary caregivers for the child with ASD, as they have less emotional closeness.

They are more pessimistic about their sibling's future than siblings of individuals with DS (Critchley et al., 2021; Orsmond & Seltzer, 2007). Sibling participants of children on the autism spectrum experienced significant difficulties with their mental health, although there was also a process of adjustment, including empathy and acceptance (Johnson et al., 2020; Leedham et al., 2020).

Older sisters of both siblings without disability and those with intellectual disability exhibited more managing and teaching roles than older brothers (White et al., 2014). Despite contradictory reports about the nature and complexity of the disability which influence sibling relationships, siblings may be valuable interventionists and potential communication partners even though siblings are more associated with caring responsibilities such as monitoring, babysitting, physical care and day-to-day help (Volling, 2014; Kramer et al., 2019; Stoneman, 2005). A list of factors impacting family and sibling relationships were compiled (see Table 7). The table portrays the inherent factors that impact communication and language development and family and sibling interactions. Where relevant, pertinent studies were identified.

3.6 Sibling relationships and children with communication disabilities.

Despite difficulties related to developmental disabilities, sibling relationships are generally positive and allow warm and close relationships throughout the lifespan (Stoneman, 2005). Developmental disabilities are associated with communication difficulties and problems with social closeness. Communication and language skills are essential variables in the development of family and sibling relationships.

Factors	Impact on communication and language	Impact on family and sibling interactions
Child characteristics		
Age	High – important variable affecting communication and language development. (NIDCD, 2016)	High–sibling relationships change developmentally over time (Stoneman, 2005).
Gender	High - gender is an important factor in the rate of early vocabulary growth (Huttenlocher et al., 1991).	High – older sisters are more likely to engage in caretaking and helping roles than older brothers (White et al., 2014).
Birth history (including chronic disease, illnesses, language delays)	High - prematurity may be associated with long term neuropsychological morbidity in childhood and adolescence (Caravale et al., 2005; Forcada-Guex et al., 2006).	High – heterogeneity of conditions and child behavioural/learning patterns affect sibling relationships (Stoneman, 2005).
Age difference	High - Younger siblings often imitate older children's language during play (Howe et al., 2014)	High – causes issues of power and control and rivalry and jealousy between siblings (Della Porta & Howe, 2012; Kolak & Volling, 2011; Miller et al., 2000). It also provides the context for more teaching and helping and caregiving interactions (Kramer et al., 2019; Howe & Recchia, 2014).
Birth order/birth spacing	Low - Second born siblings become more cognitively, linguistically and socially competent over the early years, with early power imbalance becoming less relevant as age and interactions become more equitable (Azmitia & Hesser, 1993). Birth order, family size, parents' anxiety and negative comparisons by parents of hearing and deaf siblings are key factors in sibling relationships (Bat-Chava & Martin, 2002).	High - Siblings teach one another while playing together with second-born children benefitting from the older sibling (Perner et al., 1994). Birth order may have a differential effect on siblings' emotional and behavioural adjustment (Petalas et al., 2009). High–best birth spacing is five years, and the narrowest is one year, with a spacing of two to three years being the most negative (Kidwell, 1981).
Temperament	low – individual differences in pretend play are linked to feelings and temperament (Youngblade & Dunn, 1995).	High–high warmth and low agonism is associated with supportive and democratic parenting and positive family expressivity (Gamble & Yu, 2014).
Social/adaptive skills/problem behaviours	High – children with specific language impairments have poor social skills and fewer peer relationships (Fujiki et al., 1996)	High-sibling conflicts are frequent, poorly resolved, at times aggressive, violent, and abusive. This is often associated with a poorer adjustment later in life (Dunn & Munn, 1986). Like parental stress, parental attitudes regarding the child with a DD can be a powerful influence on the sibling's adjustment (McHale et al., 2012). High - Low self-concept and increased behaviour problems for siblings of disabled children (e.g. aggression, anxiety) (Cuskelly et al., 1998).
Type of disability	High – individuals with intellectual and developmental disabilities are likely to experience communication/language delays (Warren & Brady, 2007).	High – types of disabilities affect parent sensitivity and interactions (e.g. Howe & Recchia, 2014).

		High - different developmental disabilities appear to affect family processes and siblings differently.
Bilingual language acquisition	high – Paradis (2001) proposed that bilingual children have two separate phonological systems, but those two systems can influence one another. Bilingual children's phonological acquisition differs from monolinguals of either of the languages spoken indicates that having two phonologies affects acquisition.	High – Gatt et al., (2015) found that children use Maltese and English in their expressive vocabularies and develop bilingual proficiency per input levels.
Parenting skills		
Parent styles	High-maternal sensitivity and cognitive stimulation were significant partial mediators of the relation between SES and verbal comprehension, expressive language, receptive verbal, conceptual abilities (Raviv et al., 2004).	High–mothers of children with LD are more likely to use directives and reprimands with siblings. (Flynn & Masur, 2007).
Level of education	High - fathers' education and income were uniquely associated with child measures, and fathers' education consistently predicted the quality of mother-child engagements (Tamis-Lemonda et al., 2004) High - children's spontaneous speech and language differed according to the educational level of the children's mothers (Dollaghan et al., 1999)	High-maternal responsiveness during infancy, particularly in the verbal mode, is influenced by the mother's cultural background and school attendance (Richman et al., 1992).
Sibling socialisation goals and practices	High - Siblings with a disability and their siblings spend large amounts of time interacting with each other (Stoneman, 2005).	High-warmth, conflict and sibling management had different implications depending on the sibling's gender (Floyd et al., 2009). However, positive relationships were reported for siblings of disabled children (Cuskelly & Gunn, 2003).
Childbearing	High - children of teenage mothers perform significantly poorer than children of comparison mothers on expressive language and language comprehension (Keown et al., 2001).	Parents' experiences with older children contribute to younger children's rearing, contributing to the younger children's development (Brody, 2004).
Role assignment	low – younger siblings catch up and advance their older siblings with intellectual disabilities in terms of role dominance (Stoneman, 2005).	High - Role relations between children with ID and older siblings are asymmetrical, with older siblings assuming managing, helper, teacher roles while non-disabled siblings' roles' are playmates (Brody et al., 1991).
Differential parenting	Rauer and Volling (2007) study revealed that receiving differential parental affection, regardless of whether the participant or sibling was favoured, is associated with more negative self-image models associated with developing interpersonal relationships.	High – differential parental treatment is a result of age differences (Volling, 1997). Many complex processes and relationships are involved, sometimes leading to differential parenting of siblings within the same family unit (Rivers & Stoneman, 2003)
Family		

Family size	High – children from large families tend to score lower on vocabulary and IQ (Pan et al., 2005).	Medium - Large family size appears to facilitate healthy adjustment in siblings of children with autism; children from large families sought and received more help (Kaminsky & Dewey, 2002; Cicirelli, 2013).
Religion		Low: strong Roman Catholic beliefs which may affect family decisions to the type of schooling, values & attitudes towards disabled persons (Selway & Ashman, 1998).
Ethnicity	High: Ethnic identity influences their mother language, retaining it throughout their lives (e.g. McCoy, 1992).	Medium to low: immigrants are increasing even though immigrant children with learning disabilities are relatively low (McCoy, 1992).
Stress	High - Targeting early parent-child interaction and perceptions of parenting stress may improve child language development (Magill-Evans & Harrison, 2001).	High–family stressors such as illnesses, accidents, problems bring siblings closer together (Dunn, 2013). Medium - siblings experience more family conflict and negative affect than do children in general. Low family conflict and parental stress can lead to positive developmental outcomes (Rivers & Stoneman, 2003), whereas parental depression and higher levels of conflict negatively affect adjustment, leading to greater behaviour problems among siblings (e.g. Cuskelly et al., 1998).
Depression	High - Exposure to maternal depressive symptoms, during the prenatal, postpartum period, or chronically ill, increases children's risk for later cognitive/language difficulties (Sohr-Preston & Scaramella, 2006)	High - increases in sibling conflict were linked to increases in depression symptoms (Kim et al., 2007).
Coping skills		Positive perceptions function as strategies for families to cope with raising a child with a disability (Hastings & Taunt, 2002).
Marital adjustment		Low - Marital adjustment seems to play a role in the child's emotional security (Davies & Cummings, 1994). Higher marital satisfaction, lack of parental depression, and presence of nonconflictual sibling relationships are protective for siblings of children with Down syndrome but not for siblings of children on the autism spectrum, which emphasizes the complexity of family process variables (e.g. Nuttall et al., 2018).
Emotional climate		Low-secure attachment relationships support children's emotional understanding by promoting mother-focal child discussion of emotions. Emotion understanding in pre-schoolers is

		compromised by maternal depression (Raikes & Thompson, 2010).
Resources (e.g. socioeconomic status)	High - based on the study of Hoff (2003), where children whose families with low socioeconomic status (SES) differ in their productive vocabulary development because of different language-learning experiences. A positive relationship between language and high SES (Miser & Hupp, 2012).	High - Martinelli & Raykov (2015) found strong associations between student reading achievement and their socio-economic background, the type of school, and the dominant language that students use at home and school. High - social environment, the educational background of the mother and the mode of interaction does influence child language development (Maltese study)
Community		
Extended family/peers		Medium – can be a source of emotional and physical support, but literature is scarce (Saxena & Adamson, 2013)
Support systems/services		High - Families experiencing high marital stress who sought support from external services had typically developing siblings who reported a high level of negative sibling behaviour (Rivers & Stoneman, 2003).
School		High - Type of schooling contributes to high socioeconomic status, e.g. child attending independent schools rather than a state school (free).
Culture		
Beliefs about disability		medium – Families of children with LD experience a range of inequalities where the whole family unit becomes affected (Dowling & Dolan, 2001).
Values and attitudes		
Norms and practices		
Siblings roles and expectations		medium – siblings of individuals with DS were more optimistic about their relationship than siblings of children on the autism spectrum (Orsmond &Seltzer, 2007)
Environmental context		High - Factors in the family environment can compromise parents' effective strategies to support siblings (Stoneman, 2005).

Table 7: Factors impacting family and sibling interactions

Barr et al., (2008) examined the experiences of siblings of children with communication disabilities. They interviewed six siblings and their typically developing siblings. Positive relationships were noted when siblings were together, and they enjoyed various activities. When siblings were together with outsiders, they took up the role of interpreter and protector. Nuttall et al., (2018) implied that siblings of individuals on the autism spectrum had a lesser intention of protecting and providing future care when compared to siblings of children with Down Syndrome. They often protected their siblings when they experienced bullying and interpreted their communication attempts when they were unintelligible to others. They expressed resentment, worry, concern and jealousy towards the child with communication disabilities. Siblings noted less parental attention to themselves and were concerned about the impact of the child's difficulties on their parents and adopted a parent-like role towards their disabled sibling and parents alike. The authors noted that the roles exhibited by the siblings in this study were not found in the general disabilities literature and maybe unique roles for children with communication difficulties. Summers et al., (1997) studied the conversational patterns of older children with their younger siblings, including preschool non-disabled children and children with hearing impairment, Down syndrome, developmental disabilities, and their older, non-disabled siblings. Siblings of disabled children appeared to be less responsive to their brothers and sisters than the siblings of nondisabled children. Differences were observed in conversations between different types of disabilities. Smith et al., (2013) examined the role of communication skills in the quality of sibling relationships in thirty sibling dyads were there was a child with DD. Varying levels of power and relative status were noted. Warmth, closeness or rivalry were not impacted by communication status and siblings generally engaged in more managing and helping roles.

In summary, these are the key issues identified in this narrative review:

i. Various inherent factors influence sibling interactions which are not only related to birth order, gender and developmental trajectories but also sibling characteristics, parenting, family characteristics and the community at large.

ii. Despite contradictory reports about the nature and complexity of the disability, siblings may be valuable interventionists and potential communication partners.

iii. Siblings tend to take asymmetric but reciprocal roles when interacting with the focal child. This suggests that siblings tend to imitate their mothers' directive style.

iv. Siblings are essential communication partners within the family support system, but little is known about the inter-relationships between mother-siblings, sibling interactions, and one dyad's effects on the other during joint activities with family members. Studies suggest that disabled siblings tend to gain from conversations between mothers and their siblings.

v. During mother-focal child interactions, mothers adjust their language according to their child's linguistic competencies, suggesting that siblings also adjust their language use when interacting with a child with a disability.

3.7 Conclusion and Implications for further research.

This review emphasised the importance of caregiver responsivity and contingent responding by following the child's lead and providing more input for support. I have learnt that parents of children with communication disabilities tend to be less responsive and more directive as a consequence to missing communicative initiations. A directive style is considered to be less responsive and may restrict the child's social development and participation.

The literature partially supports a directive style as being negative, due to the lack of consistent definition of what constitutes a directive. There are two types of directives; supportive directives which follow the child's attentional focus unlike the use of intrusive directives. I wanted to address this issue in my studies to understand patterns of behaviour in mother-focal child and sibling interactions, particularly the levels of responsivity between mothers, siblings and children with communication disabilities.

From the summary of points i-v on page 85-86, I concluded that siblings are essential communication partners within the family support system however little is known about the inter-relationships between mother-siblings, sibling interactions. It is evident from the literature that sibling studies targeting communication skills are scarce and have some limitations. The available studies examining communication skills between siblings and children with communication disabilities are similar to the role asymmetry present in the typical sibling literature except for study by Smith et al. (2013). Disabled children tend to take a less active role in communicative interactions while their typically developing siblings take more dominant roles, which is also evident in other studies (e.g. White et al., 2014).

In order to address the paucity of knowledge in this area, I decided to conduct a systematic review of family-led communication interventions for children with IDD. Findings from these interventions were analysed to identify the factors influencing the success of an intervention. Implications of results and directions for further research are presented in the concluding section of this chapter.

CHAPTER 4: A SYSTEMATIC REVIEW OF FAMILY-LED COMMUNICATION INTERVENTIONS

4.1 Introduction

This chapter describes the process of a systematic review of family-led AAC interventions and identify factors that determine the success of an intervention. The review encompassed randomized controlled studies, non-randomized controlled studies and single-subject experimental designs (Pearson et al., 2015). However, significant findings have also emerged from a series of observational studies, summarised hereunder. Such studies have demonstrated positive changes in interaction styles between parents and AAC users, which were beneficial in increasing the effectiveness of AAC users' communicative interactions (McNaughton et al., 2008).

In summary, the observational studies present two sets of findings: one concerning infants and preschool children with *severe expressive communication difficulties* and the other concerning school-aged children with physical disability and severe communication disabilities who use aided means of communication. The studies representing infants and preschool children with a physical disability, developmental delay, mild to severe cognitive impairment, and limited speech suggest that while children are responsive and compliant during free play situations, mothers seem to initiate conversations and use directive behaviour with their children (Hanzlik, 1990). When children with severe expressive communication difficulties and developmental delays were exposed to a goal-directed interaction (e.g. requesting) during structured play, they responded more frequently to their parents, often associated with increased parent responsivity and low parent directiveness. However, parent directiveness is often high when involved in a non-goal directed interaction (e.g. commenting). Parents also consistently responded to intentional and pre-intentional behaviours (Cress et al., 2013; Cress et al., 2008).

It is encouraging that parents can be trained to recognize and respond to pre-intentional behaviours, intentional and symbolic communication. For school-aged children with physical disabilities and severe communication difficulties, studies have mainly focused on communicative modes, functions of communication and discourse status. Studies also show an asymmetry between communication partners and children in the balance of contributions. Adults tend to dominate the conversations with an increased number of turns, initiate conversations, ask questions and use high levels of directiveness (Light et al., 1985 a,b). Parents dominate the conversation interaction in a manner not found in caregiver/typically developing children dialogues. This can lead to an asymmetry in the role of the communication partner where the caregiver inflects the child's utterance and adds function words. Although the children had access to aided communication, they preferred to use vocalisations, gestures, eye gaze and body movements (e.g. Light et al., 1994).

4.1.1 The Mechanisms for Change

Despite the growing recognition of the importance of family-centred intervention services in AAC, there has been little guidance on how professionals may establish successful collaborative relationships with families (Mandak et al., 2017). While there is an emphasis on child-focused interventions, these do not consider the family systems model. The intervention design depends mainly on the interventionists' professional judgment and the theoretical knowledge concerning the intervention process. The intervention process referred to as the mechanism for change establishes the approaches used (Bunning, 2004). Therapists may include a combination of these mechanisms as part of a process of change. However, without planned consideration of these mechanisms and how they interact (e.g. environmental changes & individual changes), the intervention/therapy process is incomplete, and any outcomes become hard to identify.

It is precarious to have therapists pick and choose their preferred mode of conducting the therapies, moving in and out of the centres of influence without considering the mechanism for change. The implications of these mechanisms of change, in other words, how the change has been brought about, cannot be verified unless these conditions are respected. While a continuum of direct and indirect approaches within the centres of influence allows flexibility, still, there should be a focus on the individual factors of influence. Given the above, a systematic review was undertaken to clarify the evidence base addressing family communication interventions, including parents and siblings and individuals with IDD and communication disabilities. The review was also meant to address the theoretical approaches and conceptual frameworks identified in the selected studies and whether planned considerations of the mechanisms for change support the process and outcomes of the interventions. With respect to the researcher's studies described in Chapter 6,7,8 and 9, the review gave more information about the different research designs, methods, procedures and tools that could be used for the studies.

4.1.2 Aims and Objectives

The Aims and Objectives were as follows:

i.   Identify family intervention programs and teaching strategies designed to improve communication of children with intellectual/developmental disabilities and communication disabilities.

ii. Identify the theories and frameworks underpinning these interventions and whether they support and uphold the outcomes of the interventions.

The following Research Questions were addressed:

i. What effective intervention programs and approaches are reported in the literature for families of children with intellectual and communication disabilities?

ii. Which models and approaches underpin these interventions?

4.2 Method

The methodology for conducting this systematic review comprised the following strategies

i. identifying the existing research and organizing it into themes and sub-themes where relevant;

ii. selecting the identified studies according to specific inclusion and exclusion criteria;

iii. organizing and assimilating the intervention strategies as discussed within the literature;

iv. analysing the data and interpreting the results following the NJC Evidence-based Data Entry Instrument (June 2008).

A systematic review aims to identify, describe and synthesize all the relevant research according to pre-established inclusion criteria in a rigorous, replicable and accountable manner (Gough et al., 2017). The findings of this systemic review are then brought together as a synthesis of all the evidence. Systematic reviews are very useful in compressing the amount of research knowledge available into a single review article, presenting the researcher with precise conclusions and results, helping them make better clinical decisions.

Systematic reviews are considered valuable as they are directed towards acquiring all possible knowledge from the available literature without bias. All possible data is collected concerning the identified research question or topic, and the relevant data is filtered and synthesized. The resulting knowledge may then be used in clinical practice, teaching or future research studies (Cook et al., 1997). Systematic reviews also have several limitations. Bias is one of the main known limitations of a systematic review. The researcher who selects the articles may consciously or subconsciously select articles or studies that seem relevant. Other articles might be discarded due to perceived irrelevance. Also, the quality of the systematic review itself depends on the research available. There is also the possibility of the reviewer not conducting a thorough literature review. The limitations set by the inclusion criteria might interfere with reviewing all possible literature published. Given the limitations of any study, the search might not have been comprehensive and systematic enough to guarantee a high-quality review (Moher et al., 2009).

Systematic reviews tend to draw on quantitative studies, typically randomised controlled trials (RCT) using meta-analysis to synthesise the data. Randomised controlled trials related to augmentative and alternative communication and family interventions are relatively few due to the varied methodologies, sampling techniques, participant characteristics and specific outcome measures. This may pose challenges to researchers who wish to undertake systematic reviews and include quantitative data for statistical purposes. When identifying systematic reviews, the researcher needs to consider randomised controlled trials, experimental and quasi-experimental studies and case studies that include multiple baselines or similar systematic interventions (Shire & Jones, 2015).

4.2.1 Retrieval of Research literature

Three different techniques (Databases, Hand Search and Ancestor Search) were applied consecutively to retrieve the research literature, since if each procedure is applied alone, a biased sample of studies results. For instance, computerized database searches under-represent the most recent research and unpublished research. On the other hand, using the 'ancestor search' may over-represent the results compatible with that particular research paradigm by which the journal network represents (Cook et al., 1992). The databases used were LLBA, Psych Info, Cochrane Collection, Web of Science, Scopus, BEI, CINAHL, ERIC and PubMed (see Table 8).

Database	*Total number of results*
LLBA	674
British Education Index	298
Psych Info	499
Cochrane	1,881
Web of Science	607
Scopus	1,494
PubMed	NIL
ERIC	2,498
CINAHL	3,203
Psych INFO	499
Total	11,653
Total number of duplicate articles	2,312
Total results after duplicates were removed	9,341

Table 8: Database results

The number of articles found using the search terms and the inclusion and exclusion criteria are described in the following pages. Relevant articles may be present in journals that were not abstracted by the electronic search system being used and, therefore, following the electronic search, a hand search of applicable journals may be useful.

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This strategy permits a systematic search of relevant journals, including those not found in any of the above-listed databases. It also minimizes limitations arising from predetermined search items and provides added support to the databases if the particular article is not retrieved by the electronic search (Gough et al., 2012). A hand search involves a systematic search of tables of contents for relevant titles. In cases where titles appeared relevant to the subject area, the abstract was read, and the articles were included in the systematic review. In this review, once a number of articles were identified using the databases and hand search, an ancestry search was implemented. Reference lists of the obtained documents were systematically searched for relevant articles. This allowed articles that could not be found through keyword strategies because authors of original articles may not have used the same keywords used in the initial search. The keywords by which these articles were identified, were noted and the new keywords were used to find further articles. For instance, keywords such as 'home interventions', 'parental responsiveness' 'parent training' and 'family-based interventions' were used. A number of systematic reviews (10) have also been consulted, and an ancestry search was conducted accordingly for relevant titles. These included reviews by Chung et al., (2012); Gökçe et al., (2019); Shire et al., (2015); Shivers et al., (2015); Te Kaat-van den Os et al., (2017); Tudor et al., (2015); Pennington et al., 2004; Smith et al., 2010.

4.2.2 Search Terms

The search terms used were combined by 'AND' and 'OR' in the search fields as follows:

1st line: symbol* OR sign* OR PECS OR "picture exchange communication system" OR gestures OR "keyword signs" OR "aided AAC" OR communication AND (board* OR "augmentative and alternative")

2nd line: (interven* OR interact* OR relation*) AND (sibling* OR parent-child OR parent-mediated OR Mother* OR home* OR family-based OR "parent-based language" OR parent* OR sibling* OR child*)

3rd line: (disabil* OR disorder* OR delay) AND (developmental OR severe* OR intellectual)

Due to the amount of search results often resulting in over 14,000 search results, the term "TOPIC" was selected for the 1st line while "All Fields" was selected for the 2nd and 3rd line. For Psych Info and Web of Science databases which rendered over 16,000 searches when "TOPIC" was used, the term "Abstract" was selected for the 1st Line. The next step was selecting studies for inclusion in the review. Articles meeting the following inclusion criteria were selected:

i. Articles from January 1985 to June 2019 were included.

ii. Articles published in peer-reviewed journals.

iii. They are written in the English language.

iv. Child participants aged from birth till 18 years of age.

v. Child participants with intellectual or developmental disabilities and communication difficulties.

vi. Studies involving the use of AAC such as the use of manual signs, PECS or VOCAs

vii. OR studies involving sibling interactions.

viii. Studies applied intervention strategies addressing communication messages with a familiar communication partner (a family member/caregiver – father, mother, sibling, close relative) using any mode of communication (unaided or/and aided).

ix.   Intervention studies related to communication, language, and literacy outcomes, with interventions in a naturalistic environment (home or home/clinic/school/community set up).

x.   RCTs, non-RCTs and SSED studies.

Articles meeting the following exclusion criteria were discarded:

i.   Individuals with sensory impairment/dual sensory impairment as a **prime** diagnosis.

ii.   Individuals with physical impairment and no intellectual disability.

iii.   Adult AAC users from the age of 19 upwards.

iv.   Acquired disorders such as ALS, Locked-In syndrome, acquired aphasia.

v.   Studies conducted exclusively in schools, intensive care, nursing homes or residential care without generalization in the family homes.

vi.   Book chapters, book reviews, reviews, systematic reviews, comments, dissertation abstracts and other electronic collections.

vii.   Articles focusing on pre-verbal skills (pre-linguistic skills) such as matching tasks, picture identification, categorisation, or focusing on developing linguistic skills were discarded unless these skills were used to communicate with a family member.

viii.   Observational studies, case studies, case series.

RefWorks was used to collate all the data gathered from the different sources and organise it into themes/folders and subfolders. Duplicate articles were removed so that they only appeared once.

Where data were replicated because they had the same participants (ID: 8,10,13,16), these were not included in the quantitative analysis to avoid duplication of data. In order to ensure whether the participants were duplicated across studies, I contacted the respective first authors in all four of the above cases (Koppenhaver, Romski, Skotko and Thunberg). There were also instances where authors had omitted or failed to report participant characteristics such as age, gender, IQ scores or communication skills. In each case, the first author was contacted for further details. Thus 17 studies were included in the quantitative analysis.

4.2.3 Inter-rater agreement

A group of 1868 articles (20%) were randomly selected and assigned to an independent reviewer, a trained speech-language pathologist specializing in AAC, from the articles selected after the duplicates were removed. Both this second-rater and the main author (MG) separately selected relevant studies for the review. Inter-rater agreement was calculated by dividing the total number of agreements by the number of agreements and disagreements and multiplying by 100. Inter-rater reliability for inclusion criteria was 91%. Disagreements were discussed with the primary researcher on a case by case basis. In addition, the Inter-rater agreement was assessed on all the final 21 studies to ensure that all studies qualify for the quantitative analysis. An inter-rater agreement of 97% was obtained. Again, disagreement was discussed with the primary researcher and resolved. Figure 3 shows the flow of information through the different systematic review phases adapted from the PRISMA model (Moher et al., 2009).
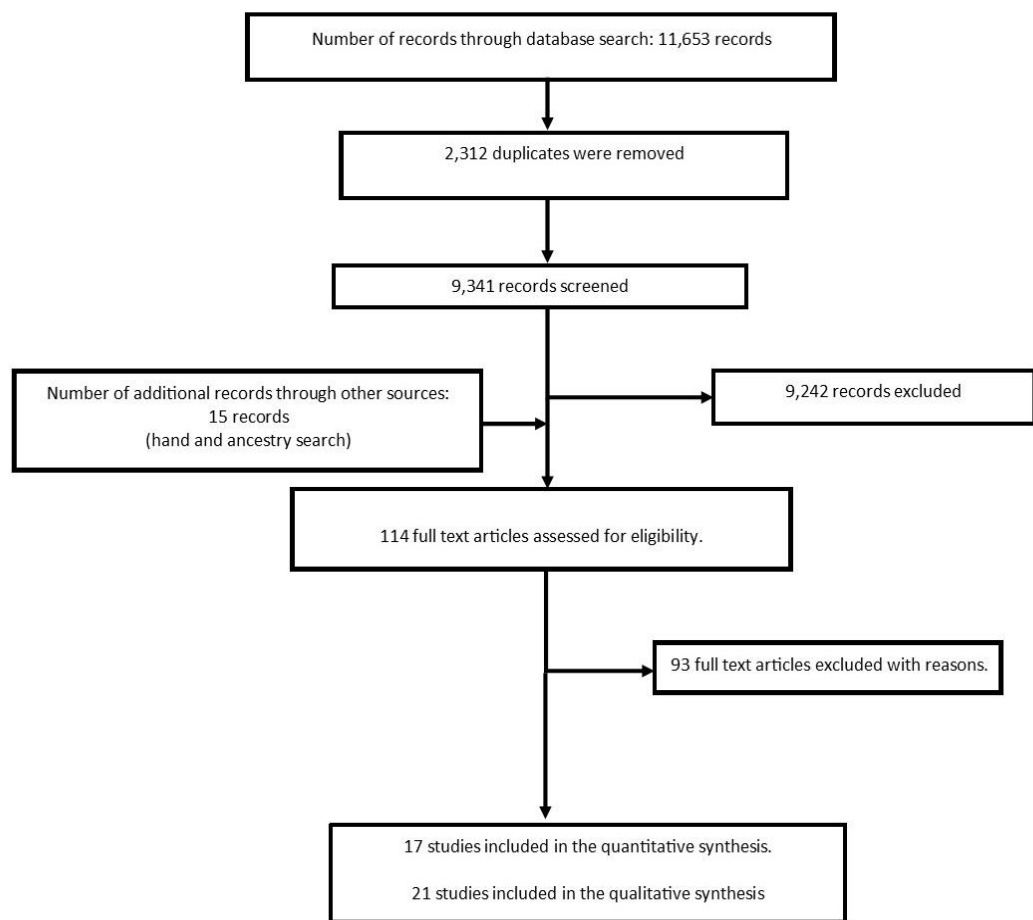
Figure 3: Flow of information through the phases
Adapted from Moher et al., 2009.

4.2.4 Quality appraisal tools

For the sake of this review, the NJC Evidence-Based Practices Data Entry Instrument was used together with a summary of the studies similar to the Cochrane Handbook (refer to Appendix A for an overview of the different quality appraisal tools considered). Additionally, the EVIDAAC adapted PEDRO scale examined the quality of evidence in terms of internal validity of the studies and provided a global score that could be compared to similar studies (a score of 12 for RCT studies and a score of 10 for non-RCTs and SSEDs). More details are available in appendix A.

4.2.5 Synthesis

Synthesis consisted of three phases. The first phase provided a descriptive summary of the studies (quantitative analysis) based on criteria from the NJC Evidence-Based Practices Data Entry Instrument (e.g. search results, participant characteristics, persons conducting the interventions, tools utilised, details of intervention and a section on research design and validity). The second phase categorised the interventions according to common themes (e.g. parent training, sibling mediated intervention, language interventions, storybooks). The main outcomes of these groups of studies were identified and summarised as main points. At this stage, relevant theories and approaches were drawn upon to determine how they were operationalized in this group of studies. The last phase of the synthesis was to analyse the theories and approaches underlying the group of studies and whether these theories support or extend these interventions. This last phase of the systematic review informs the discussion section and highlights shortcomings related to family intervention studies.

4.3 Results

4.3.1 Search Results

After considering the total number of articles, including hand-searched articles and ancestry search, 21 articles were found to meet all the inclusion criteria and were considered in the qualitative analysis. Seventeen studies were considered in the quantitative analysis since four of the studies had the same participants. As illustrated in Table 9, the Journal of Speech, Language and Hearing Research and the American Journal of Speech-Language Pathology contributed the largest percentage (14%) of the included research articles.

Journal Title	N=21	%
Journal of Speech, Language and Hearing Research	3	14
American Journal of Speech-language Pathology	3	14
Journal of Positive Behaviour Interventions	2	9
American Journal on Intellectual and Developmental Disabilities	2	9
Topics in Early Childhood Special Education	1	5
Journal of Applied Behaviour Analysis	1	5
Augmentative and Alternative Communication	1	5
Disability and Rehabilitation	1	5
Communication Disorders Quarterly	1	5
Exceptional Children	1	5
Early Childhood Services: An interdisciplinary Journal of Effectiveness	1	5
Journal of Special Education Technology	1	5
Clinical Linguistics and Phonetics	1	5
International Journal of Disability, Development and Education	1	5
Journal of Early Intervention	1	5

Table 9: Source of Reviewed Studies

The publication dates of included studies ranged from 1985 to 2019, with most of the studies

published between 2010 and 2019 (Table 10). The majority of the studies (81%) were carried

out in the USA (see table 11).

Dates of Studies	n=21	%
1985 – 1989	1	5
1990 - 1999	3	14
2000 – 2009	8	38
2010 - 2019	9	43

Table 10: Dates of Reviewed Studies

Location of studies	n=21	%
USA	17	81
Sweden	2	10
Spain	1	5
Israel	1	5

Table 11: Location of reviewed studies

There were 15 (71%) parent training programs and interventions studies, whilst 6 (29%) comprised sibling interventions and interactions. In total, 268 family members were involved, including 123 mothers (46%), eight fathers (3%), 42 parents (16%) and 95 siblings (35%). The six sibling studies did not involve the direct participation of parents in the interactions. Over 40 interventionists involved in all the studies included the first authors, university students, speech-language therapists and special educators. Data involving non-disabled children or control groups with typically developing children were not considered in the quantitative analysis.

4.3.2 Participant characteristics

The researcher identified the number, chronological ages, and gender of the participants in each study. There was a total of 241 child participants with intellectual and communication difficulties. The number of participants per study ranged from 2-62 (mean: 14; median: 5; Std deviation 18.2). In addition, 155 were boys (64%) and 86 were girls (36%). The average chronological ages of the children at the time of recruitment to the study ranging from 12 months to 18 years. The age groups for participants were 12 months-5 years (67%), 6-10 years (25%) and 11-18 years (8%).

4.3.3 Aetiology and participants' communication skills

Table 12 presents the number of studies reporting the characteristics of individuals with intellectual disabilities. This table was adapted from the NJC Evidence-based Practices Data Entry Instrument (June 2008). The aetiology and primary disabilities of the participants in each study, including genetic disorders and specific syndromes, were noted. Studies reporting aetiologies as 'other' may overlap between different disability groups. It may include individuals with a dual diagnosis or comorbidity who do not fit into one specific category (e.g. individuals with a physical disability, sensory impairment and epilepsy). There may also be an overlap between 'developmental and intellectual disability' since the terminology has different interpretations in different countries. Sixteen per cent (16%) of all the studies recruited different disability groups (four studies). Where available, the communication skills of the children, including receptive and expressive language skills, were reported. Not all studies included baseline and pre-treatment data of the communication skills of the children. Where these were reported, they were presented as a mean, with two standard deviations below the mean. However, studies reported that the children were functioning at a pre-linguistic stage and single-word level with descriptors such as 'less than ten words or signs' or 'uses fewer than 20 words'. Receptive language skills were also documented in this manner, with the common descriptors to explain this consisting of 'can understand one-word phrases' or 'early two-word relations'. Not all studies reported the communication modes used by the participants. The participants' modes of communication included vocalisations, gestures, eye contact, keyword signs, and natural speech. These may have been used in combinations by some participants.

Characteristics[1]	Number of Studies reporting participants with ID (n=17)[2]	%
Chronological Ages		
0-5yrs11mths	12	70
6yrs 0-10yrs 11 mths	9	53
11yrs0-18yrs 0mths	2	12
Diagnosis		
Intellectual Disability – degree unspecified	9	53
Severe to Profound ID (IQ 0-35)	4	23
Mild to Moderate ID (IQ 35-70)	4	23
Developmental delays/disabilities	4	23
Cerebral Palsy	5	29
Autism Spectrum Disorder	4	23
Specific genetic disorder/syndrome	7	30
Unspecified	1	6
Expressive communication levels		
Pre-linguistic	4	23
Emerging	8	47
Multiple non echolaliac words >50	7	41
Other (e.g. echolalia)	2	12
Expressive communication modes		
Speech	11	65
Signs and gestures	8	47
Aided without speech output	9	53
Aided with speech output	8	47
Vocalisations	13	76
Receptive communication levels		
Not responsive (RLA≤9 months)	unclear	
Simple directions (RLA 9-18months)	3	18
Single words (RLA 18-30 months)	6	35
Grammatical constructions (RLA>30months)	2	12

Table 12: Characteristics of participants with ID

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[1] These categories have descriptors that are not mutually exclusive and therefore add to more than 100%.
[2] studies considered in the quantitative analysis

Participants using aided means of communication were reported to use communication books, boards, low tech aids, Speech Generated Devices (SGDs) and Voice Output Communication Aids (VOCAs). Symbols used in communication boards included Clicker symbols™, Picture Communication Symbols™ (PCS), Widgit Rebus™ and Bliss symbolics™. Where available, cognitive skills were reported, generally recording IQ scores as one or two standard deviations below the mean ages (see table 12). Some studies used the terms 'mild to moderate intellectual disability; severe to profound intellectual disability (e.g. Calculator, 2002). See Table 13 for more details.

Diagnosis	number of participants = 241	%
Developmental disability	123	41.6
Angelman syndrome	27	9.1
Intellectual disability	26	8.8
Autism spectrum disorders	22	7.4
Down syndrome	20	6.8
Cerebral palsy	13	4.4
Rett syndrome	4	1.4
Unspecified	6	2

Table 13: Diagnosis of study participants according to the number of studies

Nevertheless, it was challenging to obtain percentages or means since there was either missing data or otherwise, different assessment tools were used, making it difficult to obtain a standardised mean of all the participants.

	Study	Design	Participants	Intervention type	Training delivered by	Outcome measures
1	Adamson et al., (2010). USA	Randomised controlled study	57 toddlers 53 mothers 4 fathers	Augmented language intervention using SGDs	SLP	Vocabulary acquisition and use.
2	Basil, 1992 Spain	Controlled group before and after study	3 mothers 1father 4 children with CP	Aided language stimulation through the use of communication boards	Trainer (not specified)	Parents' contingent responses versus child responses
3	Calculator, 2002 USA	Multiple baseline design	9 Children with Angelman Syndrome Nine parents	Enhanced Natural Gestures	investigator	Parent use of 4 teaching techniques
4	Calculator, 2016 USA	Quasi-Experimental design "B"	18 children with Angelman syndrome. 18 parents.	Enhanced Natural Gestures	SLP Self-administered parent programme	Child initiated messages/is understood when using ENG. Parents self-administer ENG training procedure
5	Hancock & Kaiser, 1996 USA	Multiple baseline design	3 Children with CP, ID and William Syndrome 3 siblings (8-12 years)	Milieu teaching procedures	First author	Modelling and mand modelling
6	James & Egel (1986) USA	Multiple baseline design	3 Children with CP and ID 3 siblings (6,10-8,1)	Sibling training procedure through modelling and feedback	experimenter	Positive initiation
7	Kent-Walsh et al., (2010) USA	Multiple probe design	6 children with CP and DS 6 parents	IMPAACT program through a storybook task	First author	Communicative turns and semantic concepts
8	Koppenhaver et al., (2001) USA	Multiple baseline design	6 girls with Rett syndrome 6 mothers	Storybook reading	The first author explained the program. The other authors conducted literacy assessments	Child interactive engagement

9	Koppenhaver et al., (2001) USA	Multiple baseline design	4 girls with Rett syndrome 4 mothers	Storybook reading	The first author explained the program. The other authors conducted literacy assessments	Communicative turns and semantic concepts
10	Romski et al., (2007) USA	Contrast group design with random assignment	30 children with DD 27 mothers and 3 fathers	Augmented language interventions	3 female interventionists	Child outcomes: MLU & % child initiations.
11	Romski, et al., (2010) USA	Contrast group design with random assignment	62 children with DD 58 mothers and 4 fathers	Augmented language interventions	6 female interventions (Psychology/Communication)	independent picture exchange and child's word vocalisations
12	Rosa-Lugo, & Kent-Walsh, (2008) USA	Multiple probe design	2 children with DD 2 mothers	Storybook reading	SLP and researcher discussed the program with parents	Parent perception of language development
13	Skotko et al., (2004) USA	Multiple baseline	4 girls with Rett Syndrome mothers	Storybook reading activity	Individual sessions in clinics before home sessions.	Child measure: number of augmented and spoken words
14	Smith et al., (2013) USA	Non-randomized controlled trial	30 children with DD 30 siblings	Semi-structured activities with siblings	First author	MLU , the total number of turns, utterance rates
15	Stiebel, 1999 USA	Multiple baseline	3 children on the autism spectrum parents	Problem-solving intervention during family routines using Natural language Teaching Paradigm (NLP)	therapist	parents' accurate strategy implementation
16	Thunberg et al., (2007) Sweden	Pre-test post test multiple case study designs	4 children on the autism spectrum parents	System for Augmenting Language (SAL) using a Speech Generated Device (SGD)	Research leader	Child behaviours (modes, acts, communicative behaviours)
17	Thunberg et al., (2009) Sweden	AB-type single-subject design	4 children on the autism spectrum parents	Use of a Speech Generated Device (SGD) during family activities	Research leader	Parent behaviours
18	Trent-Stainbook,	Multiple baseline	3 children on the	responsive education	First author Research assistant	Increased use of mirroring &

	Kaiser & Frey, (2007) USA		autism spectrum 3 siblings			verbal responding. Increased intentional communicative behaviours.
19	Tzuriel & Hanuka-Levy, 2014 Israel	Non-randomized controlled trial	25 children with ID 50 siblings	Sibling-mediated intervention	We (authors)	child spontaneous card use
20	Walton & Ingersoll, 2012 USA	Multiple baseline	4 children on the autism spectrum Six siblings	Sibling implemented reciprocal training	First author	intervals of opportunities provided by the parent
21	Wright et al., 2013 USA	Multiple baseline	4 toddlers with DS 3mothers, one father	Enhanced Milieu Teaching (EMT)+JASPER	Therapist + Authors assessed generalization at home	a rating of perception of parent and child skill.

Table 14: Study design characteristics

4.3.4 Specific outcomes of intervention

All the studies were reviewed individually to determine the goals and outcomes of the interventions (see Table 14). Whenever studies investigated several aspects of an AAC intervention, these were only noted once for what was counted **as the major goal of the study** (as emphasised by the authors).

Table 15 indicates the dependent variables (measures taken) used by the 21 studies and the corresponding outcomes of intervention. Table 16 shows that the most frequently targeted outcome was an improvement in expressive communication levels and modes of communication (52%), followed by improved interactional and conversational skills (38%). No information was available on outcome measures in receptive language skills following interventions.

Study	Intervention type	Theory /Suggested Approach	Dependent variables (measures taken)	Outcome of intervention	Limitations/Implications
Adamson, 2010	Augmented language interventions using SGDs	Aided language modelling	Social interaction, requesting and commenting.	Gains in symbol use during intervention generalized to symbol use in non-intervention context.	Maturation effect in the contrast group
Basil, 1992	Augmented language interventions using communication boards	Learned helplessness theory (Seligman, 1965)	Parents' contingent responses versus child responses	Learned helplessness decreased but learnt dependency did not.	The Control group was inadequate. Parent training should target contingent social responsivity to address the issue of learnt dependency.
Calculator, 2002	Enhanced Natural Gestures (teaching techniques: environmental sabotage, mand-model, expectant delay, and molding)	Direct language teaching approach Environmental approach	Parent use of 4 teaching techniques	Acceptable teaching program	parents were not monitored when they used the approach
Calculator, 2016	Enhanced Natural Gestures (teaching techniques: environmental sabotage, mand-model, expectant delay, and molding)	Direct language teaching approach Environmental approach	Two teaching methods, Mand-Model with time delay and Molding-Shaping	Acceptable teaching program	Same parent and SLP were asked to evaluate the effectiveness of the programme & parent bias.
Hancock, 1996	Milieu teaching procedures	Natural modelling and incidental teaching in sibling relations	Modelling and mand modelling	Sibling responsiveness to child verbal initiations increased	Some level of generalization to a snack setting
James, 1986	Sibling training procedure through direct prompting and modelling	Direct prompting training strategy	Positive initiation	Direct prompting increased interactions (reciprocal interactions)	Long term effects of sibling programs have not been assessed.

Kent-Walsh, 2010	IMPAACT program through a storybook task	Aided language stimulation (Storybook based communication intervention)	Communicative turns and semantic concepts	increased communicative turn-taking and use of different semantic concepts	Use of wh-questions, expectant delays, and contingent responses promoted the development of the children's turn-taking skills Study lacks generalisability
Koppenhaver, 2001	Storybook reading	Aided language stimulation (Storybook based communication intervention)	Coding of communication modes and functions	a wider range of communication modes & increased the frequency of their labelling and commenting	Appropriate switch use suggesting parent-child preferred switch technology.
Koppenhaver et al., 2001	Storybook reading	Aided language stimulation (Storybook based communication intervention)	Same as above	Increased frequency labelling & symbolic communication	Small sample
Romski, 2007	Augmented language interventions	Parent implemented language intervention	Parent perception of language development Child measure: number of augmented and spoken words	Parent-reported more positive perceptions, especially the ones using an SGD	The parent sample was not representative of the population (limited presence of families from lower social backgrounds)
Romski, 2010	Augmented language interventions	Aided language modelling Parent implemented interventions	MLU, the total number of turns, utterance rates	Children in the augmented group demonstrated positive effects	Maturation effect in the contrast group Unable to generalise results to less educated parents
Rosa-Lugo, 2008	Storybook reading	Aided language stimulation (Storybook based communication intervention)	parents' accurate strategy implementation children's communicative turns Measures of the children's overall frequency of turns taken and novel semantic concepts expressed	Increase in turn-taking rates and semantic concepts	It cannot be generalised to other activities.

Skotko, 2004	Storybook reading activity	Aided language stimulation (Storybook based communication intervention)	Child behaviours (modes, acts, communicative behaviours) Parent behaviours	Positive change in reading and interactive behaviours	Mothers need to engage in different strategies to facilitate better use of augmentative strategies
Smith, 2013	Semi-structured activities with siblings	Theory free: Sibling interactions and relationships	Five measures of communicative interactions (e.g. MLU, MLT, number of different words)	Confirms asymmetric nature of sibling communication noted highest in the independent group.	Parents present in the room may have influenced the interactions. Use of unvalidated communication categories (emergent, context-dependent, independent) to group participants. The study suggests that when a child with a disability is more independent, TD siblings interact more with them and take a more leading role. This is contrary to what the literature found.
Stiebel, 1999	Problem-solving intervention during family routines using Natural language Teaching Paradigm (NLP)	Generalisation/maintenance /problem-solving tasks	child spontaneous card use percentage of intervals of opportunities provided by the parent a rating of perception of parent and child skill.	Increase in card use and increased parent opportunities	Parents should be given more assistance when they present from high-risk groups.
Thunberg, 2009	System for Augmenting Language (SAL) using a Speech Generated Device (SGD)	ToM (conversational topic and sharing of information)	Conversational topics analysis/analysis of topic segments	Irrelevant speech decreased, and topic length increased through SGD	Not all activities (e.g. mealtime) were motivating for the child. This led to the negative development of interaction. Small sample/no follow up.
Thunberg, 2007	Use of a Speech Generated Device (SGD) during family activities	Parent responsivity	Level of engagement, turn-taking and communicative functions	Increased conversational interaction and topic maintenance	The limited number of participants across three different settings. No, follow up observations were included. Parents level of engagement and training are important variables to be considered

Trent-Stainbrook, 2007	Sibling-mediated intervention	Responsive interaction	responsive interaction, nonverbal mirroring and verbal responding,	older siblings increased their use of mirroring and verbal responding. Intentional communicative behaviours increased among their younger siblings	assessing maintenance at a later interval and have someone other than the interventionist conduct follow-up assessments
Tzuriel, 2014	Sibling-mediated intervention	Mediated learning experience theory Metacognition and Self-regulation – Piaget and Vygotsky (1978) Shared intentionality (Tomasello, 2005)	Measures of 5 MLE strategies	ID group scored high on mediation strategies and low on activation and antimediation behaviours.	There may be other variables that affect mediation, e.g. aetiology and cognitive development.
Walton, 2012	Sibling implemented reciprocal training	Sibling mediated and reciprocal imitation (modelling, praise and prompting)	Contingent imitation and linguistic mapping	Increased contingent imitation and linguistic mapping in some of the siblings	Not all siblings generalised one of the skills in play or other settings. The parents may consolidate maintenance.
Wright, 2013	Enhanced Milieu Teaching (EMT)+JASPER Naturalistic sign intervention	Naturalistic communication intervention strategy.	Child, parent and joint engagement measures	increased spontaneous use of signs and a smaller increase in spoken words	Measures of joint attention and joint engagement are unreliable. The relationship between JE and child measures could not be determined.

Table 15: Intervention type and outcomes of intervention

Type of outcome measure used in each study	*n=21*	*%*
Improvement in expressive communication levels/modes of communication (e.g. the number of augmented/spoken words/enhanced gestures, use of multi-symbol utterances, MLU, independent picture exchanges/spontaneous card use/ use of communication boards).	11	52
Improvement in interactional/conversational skills (e.g., turn-taking-reciprocal interactions, joint attention-shared focus, imitation skills, initiations, topic maintenance, use of different semantic concepts).	8	38
Increased frequency of communicative functions (e.g. regulate the behaviour of others – request/mands; establish joint attention-commenting; engage in social interaction – greeting/commenting).	2	10

Table 16: Type of outcome measures used in each study

4.3.5 Details about the Intervention

The section below gives details of the interventions below:

4.3.5. 1 Location of the interventions

Most of the interventions took place in the participants' homes (97%). However, some of the interventions in the homes also included a variety of other places, such as schools, clinics, after school behaviour management centres, labs, day-care or the community, to ensure generalisation of the skill being taught (total of 33%). Sessions in the homes included those held in the kitchen, dining room, playroom and bedroom. Places in the community included the café, park, the school playground and church playground (3%).

4.3.5. 2 Individual or group interventions

Interventions consisted either of parent training interventions or/and a combination of direct and indirect interventions. Interventions involving parent-child, sibling-sibling, child-interventionist were delivered on an individual level. Parent training interventions also consisted of one-to-one sessions in groups with other parents or the presence of their respective educators or speech-language pathologists.

4.3.5.3 Persons delivering the interventions

A variety of persons delivered the interventions at different stages of the studies. Speech-language pathologists, special educators, and researchers were involved in 40% of the studies. Parents and siblings were also involved in the interventions after they were themselves trained to teach the skills. Only siblings were involved in the six sibling studies, as parents were not involved in the interventions when siblings interacted with the child with communication disabilities.

4.3.5. 4 Frequency and duration of training

A total of 18 studies (86%) reported the number of sessions and minutes per session ranging over weeks or months. Not all studies provided this information, and at times, graphs had to be consulted to detect the duration of training sessions. The duration was reported in weeks or months, and where reported, this varied from 10 weeks to 9 months. The total number of sessions varied from 2 sessions to 24 sessions. The duration of the sessions ranged from 10 min to 90 min. Duration of the actual treatment was calculated based on the interventions, e.g. two sessions at 60-90 minutes each (180 minutes); 12 sessions at 20 minutes each (240 minutes) (See Appendix A for more details).

4.3.5.5 Methods of collecting data

A variety of tools were utilised; some studies used mixed methodologies to ensure triangulation of data. Tools included questionnaires, observations, surveys, logbooks, workbooks, video recordings, behaviour schedules and semi-structured interview schedules. Some examples include the Mullen Early Learning Composite, Vineland Adaptive Behaviour Scales, Sibling Relationship Questionnaires, Questionnaire of resources and stress.

4.3.5.6 Programs and Approaches

Interventions consisted of specific programmes, made up of a combination of different approaches such as Keyhole™ (TEACCH, Hanen and PECS; McConkey et al., 2011); Language and Play Every day (LAPE; Moore et al., 2014); System for Augmenting Language (SAL; Romski & Sevcik, 2018); Enhanced Milieu Teaching (EMT; Hancock et al., 2016) blended with Joint Attention, Symbolic Play, and Emotional Regulation (JASPER; Kasari et al., 2015) and IMPAACT (Kent Walsh, 2003). See Appendix A for more details.

Stand-alone strategies were also utilised including, visual supports, storybooks, enhanced natural gestures (ENGs; Calculator, 2002), Milieu Teaching (Kaiser et al., 2000), mediated learning experience (MLE) strategies (Tzuriel et al. 2014), Reciprocal Imitation Training (Ingersoll, 2012), Com Along Boards (Ferm et al., 2011), TEACCH (Mesibov et al., 2005), Responsive Education (RE)/ prelinguistic milieu teaching (PMT; Yoder & Warren, 2002), Responsive Teaching (RT; Mahoney & MacDonald, 2007), scripts, Natural Language Teaching Paradigm (NLP; Koegel et al., 1999); and video modelling. In addition, aided modes of communication were presented, including PECS (Frost & Bondy, 1994), symbol charts, light tech aids, SGDs and VOCAs (an appendix of each of these approaches and a brief description is available in Appendix A). Activities consisted of games (Connect 4, Guess Who), role plays, physical play, use of manipulatives (Lego), free play, social tasks, daily living activities, joint book activities, mealtime and snack activities (cracker, juice, decorating biscuits). Resources included pictures, popular children's book series and toys (stickers, spinning top, magnetic blocks, cars, trucks, trains, puzzles, Tricky Fingers, mazes and completion of face drawings).

4.3.6 Research design and validity

This section reports the results separately for single-subject experimental designs and group designs; see Tables 17. The researcher consulted the algorithm by the National Institute for Health and Care Excellence (NICE) 2014 to distinguish between experimental and observational study designs. Several design hierarchies were considered while assigning a level of evidence to individual primary studies. These included the categories of evidence put forward by the National Health and Medical Research Council (NHMRC); Evidence-Based Nursing Practice EBPN; The Centre for Evidence-based Medicine (CEBM) and the pyramid of evidence provided by Salmond (2007).

The hierarchy of study design suggested by the NHMRC (2000) was preferred over the latter hierarchies due to its focus on assessing clinical evidence in intervention studies and the detailed explanatory notes accompanying the guidelines. Naturally, this level of assessment of research quality is not enough on its own, and as previously discussed, more detailed quality appraisal tools need to be utilised.

Type of Design	n=21	%	Level of Evidence NHMRC (2008)
Randomized controlled trial	3	14	II
Non-randomized controlled trial	3	14	III-1
Single subject experimental design	15	72	III-2

Table 17: Type of Design

From the six group studies reviewed, only three studies made use of randomized controlled trials. The National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (NJC) focuses on the need for more evidence-based practice and what constitutes high-quality research evidence. Randomised controlled trials are known to be the 'gold standard' for evidence-based practice. Randomised Controlled Trials yield a Level 1b of evidence, and that with each descending level, the chance of bias increases and the strength of evidence decreases (Salmond, 2007 p. 119). Because of the heterogeneous characteristics of individuals using AAC and the limited number of individuals available to participate in experimental studies, it is not easy to utilise Randomized Controlled Trials as a research design. This is due to some practical, scientific and ethical reasons (APA, 2005). Although single-subject research methodologies may not be the first choice, they may still provide potential evidence-based practice research (Schlosser & Raghavendra, 2004). Additionally, the research characteristics that contribute to the credibility of the results must be carefully considered, regardless of the research design (Odom et al., 2005).

Therefore, while RCT designs involving individuals with ID may be challenging, the credibility of single-subject research methodology may be confirmed against some elements of threats to internal and external validity.

4.3.6.1 Inter-rater and intra-rater Reliability

Inter-rater reliability data was measured for 87% of the studies. Three studies (14%) utilised Cohen's Kappa coefficient as a statistical measure of inter-rater agreement, with Kappa being 0.73 and greater (0.73-0.97). Intra-rater reliability, which measures researcher consistency over time, was not explicitly reported.

4.3.6.2 Social and ecological validity

Social validity is a measurement of other participants' perspectives of the success of an intervention (Schlosser & Raghavendra, 2004). Several studies utilized elements of social validity to gauge the success of the intervention program. For example, in the study by Rosa-Lungo & Kent-Walsh (2008), a family member viewed several randomly selected videotapes to determine functionality and child participation. Ecological validity is the degree to which behaviours manifested in interventions can be generalized to natural settings. All the studies were carried out in natural settings, i.e. in the participants' homes, and the materials used were familiar to the participants. Some studies also determined whether the behaviours manifested during the interventions were typical of the behaviours exhibited daily. Some family members confirmed this in the studies by Calculator (2002).

4.3.6.3 Fidelity of treatment (treatment integrity)

This provides evidence that the experimental conditions were implemented as described in the study. Measures of treatment integrity were measured in 3 studies (14%).

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Some studies referred to the term 'procedural integrity', which were considered to have implemented fidelity treatment for the sake of this review.

4.3.6.4 Generalization

The studies were examined for any generalizations that may have occurred, including transferring the target skills across different settings and communication partners and tools. The following contributions may be attributed to some form of generalisation, i) more than one interventionist including a family member delivering the intervention, e.g. parent, sibling, educator, speech therapist (21 studies), ii) different settings used to conduct the interventions, e.g. home, school, clinic, café (7 studies) iii) use of different routines, e.g. snack, toy, game, free play. (6 studies).

4.3.6.5 Maintenance

Most of the studies (16 studies) did not report a follow-up, i.e., measuring the effects of the intervention on the child after the intervention finished. For this item to be logged, the target skill must be measured at least three months after the intervention has been concluded. Only five studies reported measuring maintenance of effects three to six months following the interventions. One study reported successful language outcomes a year after parent-child interventions were measured.

4.3.7 Family training programs and interventions

In compiling this section, several options in presenting these data were available. One of the options was to report studies according to the main emphasis of the study. In their systematic review, Pickstone et al., (2009) categorized the projects as four types of studies i) systematic adjustment of environment, ii) parent interaction, iii) language enrichment and, iv) books.

This study categorized the interventions according to the study's main goals since some studies reported secondary outcomes that could also be classified elsewhere. Five categories or themes were identified, these being i) storybooks, ii) parent training programs, iii) language stimulation and pragmatic functions, iv) aided language modelling, and v) sibling training programs. In hindsight, however, it was more complex and difficult to justify why sibling training programs and parent training programs should not be in the same category or appertain to the same typology of aided language modelling since some of the specific approaches which addressed micro-level interactions were present in both parent and sibling programs. There was a continuum of interventions ranging from the broad use of storybooks and speech generated devices to micro-level interactions. Interventions reportedly focused on developing pre-verbal skills such as symbolic play, imitation, turn-taking and joint engagement. Other studies report specific language outcomes such as the development of pragmatic functions (e.g. requests, comments, protests, choices). Some studies targeted parent interaction styles such as responsivity, engagement, modelling, use of pause time and expectant delay. Thus, it was decided to report the studies according to the primary outcomes of the intervention. The three categories broadly identified were i) improvement in interactional and conversational skills, ii) improvement in expressive communication levels and modes of communication, and iii) increased frequency of communication functions.

i)   Interactional and conversational skills (n=8)

This refers to turn taking-reciprocal interactions, joint attention-shared focus, imitation skills, initiations, topic maintenance, use of different semantic concepts. Six studies investigated the interaction patterns of children with cerebral palsy, developmental delay and Rett syndrome through storybook reading interventions (Kent Walsh et al., 2010; Koppenhaver et al., 2001; Rosa Lungo & Kent-Walsh, 2008; Skotko et al., 2004).

Three of these studies have documented the efficacy of using the guidelines outlined in the eight-step model during communication partner instruction programs (Rosa-Lugo & Kent-Walsh, 2008). The interaction strategy incorporated aided AAC modelling, expectant delay, open-ended questions, and increased responsiveness to communicative attempts. These studies demonstrated that communication partners developed the skills necessary to effectively implement interaction strategies with AAC users with a small amount of instruction. In addition, after instruction, the AAC users increased their use of multi-symbol messages and started using various symbol combinations. Another strategy used to support positive communicative interactions with AAC users and individuals with communication disabilities was pause time, where communication partners adapted their interaction style, and AAC users increased their multi-symbol messages. Similar outcomes were achieved in studies where children could communicate in meaningful ways through familiar storybooks and the availability of communication displays. The children were reported to be more active and successful in storybook reading tasks subject to the scaffolding of symbols, single switch use and use of VOCAs. Through these supports, the children were able to establish a wide range of communicative attempts, various communication modes and functions of communication. In conclusion, studies found that mothers needed to engage in different strategies to better facilitate augmentative strategies. This group of studies was also represented by a small sample of children with limited opportunities to generalise the skills across different contexts. Several parent training programs reported in this section were used separately or in conjunction with other programs to improve the child's communication skills. Interventions that have focused on training parents to become more responsive communication partners have been addressed.

Specifically, the levels of responsivity, affect, levels of engagement, face to face contact, reduction of directiveness and increasing opportunities for communication were targeted. This group of studies reported specific approaches such as introducing direct prompting techniques, making short, simple sentences, slowing down the speech rate, and questioning techniques. The studies made use of modelling, practising and pause time (expectant delay). The majority of the studies reported increased parents' responsivity while the children increased their mean length of utterance, vocabulary skills and initiations. Basil (1992) reported an increase in learnt dependency, lower levels of engagement of the children and increased parent directiveness in free play activities. Whilst learned helplessness decreased, learnt dependency, however, did not improve. This may be due to how the parent training program was devised, and further research could target contingent social responsivity to address this shortcoming. Six studies [3] investigated the effects /impacts on sibling interactions of training procedures, consisting of prompting and modelling, mediation exercises and imitation training procedures, and sibling communication interaction patterns, including the number of turns and mean length of utterance. Three of them included participants presenting different aetiologies. As previously explained, siblings' characteristics were not documented, but the studies used older and younger siblings and siblings of the same or different gender. Positive outcomes reported included sibling implemented and reciprocal imitation training, increased joint engagement states, responsiveness to mediation, imitations targeted utterances and balanced interactions between sibling dyads (Tzuriel & Hanuka-Levy, 2014; Walton & Ingersoll, 2012).

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[3] Studies 5,6,14,18,19,20

These siblings mediated interventions have been used in improving interactions (e.g., Walton & Ingersoll, 2012), such as improving imitation and joint engagement with children on the autism spectrum. While the studies showed some improvements during treatment, skill gains were found to be inconsistent across children. Positive changes during free play were observed where sibling pairs increased their positive reciprocal interactions and retained this level of reciprocal interactions after the instruction (Hancock et al., 2016; James & Egal, 1986; Trent-Stainbrook et al., 2007). A study by Smith et al., (2013) examined the characteristics of sibling communication interaction patterns of 30 sibling dyads, this being the most extensive sibling dyad study. This was the only study where children were placed in three communication status groups, *emerging*, *context-dependent* and *independent* communicators. Scripts were provided to help in initiating, maintaining and terminating the conversations while preparing a snack. An overall asymmetry in sibling communication was noted, supporting previous studies that children with developmental disabilities have difficulties initiating and maintaining communicative interactions. Typically developing siblings dominated the interactions and engaged in longer communicative turns whilst their disabled siblings maintained passive roles and exhibited a lower mean length of turn (MLT). However, surprisingly, asymmetry was more evident in the independent communication group (Smith et al., 2013). A reason for this was because typically developing siblings have more opportunities to communicate with their disabled siblings, who are independent communicators but still tend to take over the interactions and establish dominant roles in conversations. The disparity may be due to the framework chosen to group the children according to their communication skills. The researchers used the social communication inventory devised by Blackstone & Hunt Berg (2003).

Unfortunately, these scales have not undergone measures of reliability to assess accuracy and dependability due to technical issues in accessing the Communication Assistance for Youths and Adults (CAYA) database (Patricia Dowden, Personal Communication, 19th February 2015). This could be rectified by using inter-observer agreement to provide an indication of reliability over time. Furthermore, future studies should utilize the social communication inventory in isolation as well as the available standardised assessment tools to categorise children according to their existent communication skills. The same study also utilised the Vineland Adaptive Behaviour Scales, scales of adaptive functioning commonly used by psychologists based on parent reports/interviews and are not detailed on developing early communication skills. Ideally, these scales should not be used in isolation because otherwise, this would lead to maternal social desirability bias.

ii)   Expressive communication levels/modes of communication (n=11)

These studies used various enhanced natural gestures, communication boards, books, picture exchange systems and speech generated devices (SGDs) through augmented language intervention or a variation of this approach such as aided language stimulation (e.g. Adamson et al. 2010). This strategy provides a functional model similar to the mode of communication the child is expected to use. These studies reported increased vocabulary selection on the screen, single switches, and vocabulary selection and availability on the devices. The results highlight that parents could implement augmented language interventions through aided language stimulation programs and speech generated devices and boards. Fair results were reported to develop target spoken vocabulary, although a few children produced fewer target words after several sessions. This implies that regardless of common myths, AAC does not hinder language development. This includes signing, which does not stop speech from developing but also seems to enhance it (Launonen, 2019).

Possibly, establishing augmented language intervention at such a young age helps ease the child's frustrations whilst exposing them to an alternative language form. Further studies are needed to look at the effects of using speech generating devices on comprehension and expression in infancy. There should be careful considerations of the claims of the additional benefits of the exclusive use of speech-generating devices in early years. Additionally, using speech generated devices as an augmentative input in early years should be compared to the effects of using natural communication modes (such as gestures) during typical interactions with familiar partners.

iii) Use of communicative functions (n=2)

These studies report a range of language-based interventions representing a continuum of interventions ranging from strategies to instil joint attention, joint engagement, symbol-infused joint engagement (Adamson et al., 2010), symbolic play, imitation skills, and turn-taking (e.g. Kent Walsh et al., 2010 also reported in storybook reading strategies). Additionally, these studies also addressed the development of pragmatic skills such as requesting, commenting and protesting. One study targeted requesting (improvisation of mands) and environmental sabotage (Hancock, 1996). A functional relationship between the parent-implemented training and improvisation of requests (mands) was reported. Both studies also demonstrated that parents could implement improvisation training. Maintenance is crucial to support the long-term outcomes of successful parent interventions even if parents increased their responsivity and language enhancing strategies after participation in the programs.

4.3.8 Summary of Results

A range of interventions, including parent and sibling training programs and approaches, the use of storybooks, speech generated devices and micro-level interactions, were reported. Some studies focused on pre-verbal skills development such as symbolic play, imitation, turn-taking and joint engagement. Other studies included specific language outcomes such as the development of pragmatic functions (e.g. requests, comments, protests, choices). Parent and sibling interaction skills included aided AAC modelling, pause time, expectant delay, open-ended questions, and increased responsiveness to communicative attempts. Descriptive communication partner interventions included modelling, scripts, visual supports, joint activities, video modelling and role play. By far, the most frequently targeted outcome was an improvement in expressive communication levels and modes of communication (52%) followed by an improvement in interactional and conversational skills (38%) followed by an increased frequency of communicative functions (10%). Only two studies explicitly identified a theoretical framework or approach to explain how changes have occurred in the intervention (see table 15). The rest of the studies either implicitly referred to several conceptual frameworks or overlooked the need for a conceptual framework. The review indicated limitations related to the reporting of interventions, participant data and coded reliability measures on specific elements of internal validity, including experimental design, treatment fidelity, inter-rater agreement. Most studies scored relatively low on the adapted PEDro (EVIDAAC) quality scale (Schlosser et al., 2009) – see Appendix A for a detailed review.

4. 4 Discussion

This systematic review has brought to light the complexities involved in family interventions and children with communication disabilities. At a glance, all studies reported positive outcomes of intervention based on the different approaches and programmes put forward. However, this has to be treated with caution due to the heterogeneity of the population, the sample size, different research designs, and the methodological flaws of some of the studies. Other issues arose from the low-quality scores obtained from the quality appraisal checklists and limited information related to the 'how' and 'why' of the different interventions. All these factors mentioned previously pose challenges for researchers when designing, synthesising, and replicating such interventions.

4.4.1 Limitation of these studies

Generally, all studies reported immediate positive outcomes of family training and intervention strategies. However, Snell et al., (2010) suggest that such positive outcomes may be due to selection bias. When the articles are presented for publication to scholarly journals, authors submit studies that highlight positive outcomes rather than those which fail to produce encouraging results. This leads to selection bias since only the studies rendering positive outcomes are presented for scholarly journals publications. Another limitation is due to most studies being conducted without a control group (15 studies). This makes it difficult to examine how much of the change reported in the child's behaviour was due solely to increasing developmental maturity. Additionally, the child may also have been attending interventions in a clinical setup or day centre (as some of the studies portrayed), so it may be premature to claim that gains were due to the family interventions and approaches conducted at home.

Thus, future studies should include non-treatment groups to address this shortcoming. Another complication is that while studies reported changes in parent-child interaction and positive outcomes in the child's language, researchers may not assume that changes in the environment may have caused changes in the child's language. Pickstone et al., (2009) clarified that changes in the child's language influenced family interactions (p 74). An explanation for the positive outcomes of intervention may also be due to the Hawthorne Effect due to response-consequence contingencies. These are behavioural changes brought about by participants being aware that they are being observed, resulting in parents and siblings being more responsive or the children themselves performing to please their communication partner when both perform under experimental conditions. A case in point is one of the sibling studies where parents were still present in the room even if they were not involved in the communication exchanges (e.g. Smith et al., 2013). It is argued that the Hawthorne effect should be avoided and not used as a cover-up to mask the confounding variables which may have affected the outcomes of the study, variables that were not monitored during the studies (Wichstrom & Bendix, 2000). One suggested strategy to avoid the Hawthorne effect is to have a randomized control study with control and experimental groups, so both groups are exposed to the same variables. The high attrition rate reported in some studies was another limitation. Firstly, some programmes spanned over a long period, and parents perhaps could not take up this commitment for so long. Studies have revealed that parents who dropped out were significantly younger and had lower IQs. Drop out families had lower family incomes and the mothers had a lower level of education. In addition, there were three studies (Adamson et al., 2010; Romski et al., 2007 and Romski et al., 2010) where the parent sample was not representative of the population since there was a limited presence of families from lower-income social backgrounds.

This could create a subset of a sample that does not represent the population, posing problems with generalising the results to the larger population. The heterogeneity of the sample and small sample size may have compromised the effectiveness of some studies. For example, on the one hand, studies can be externally validated across different disability groups, but on the other, only 16% of the studies recruited different disability groups. This means that external validity (which should ensure generalization of the skills or interventions across different disability groups) cannot be claimed for the studies. Additionally, the small sample size (mode=3) may not generalise interventions across larger populations.

4.4.2 Quality of Evidence

This review reported low scores on the EVIDAAC reporting scale (Schlosser et al., 2009), with scores as low as 4. Other systematic reviews (e.g. Marshall et al., 2015; Snell et al., 2010) coded reliability measures on specific elements of internal validity, including experimental design, treatment fidelity, inter-rater agreement. A serious limitation was identified in these studies concerning treatment fidelity. Only 14% of the studies reported in this systematic review defined measures of treatment fidelity (treatment integrity). This is similar to findings reported in other systematic reviews (Snell et al., 2006; Snell et al., 2010). Snell et al., (2010) reported that 32.2% of the studies assessed whether the experimental conditions were targeted as explained in the research methodologies. Not all studies reported treatment intensities, including intensity of interventions and duration of interventions, including the timing of interventions. Additionally, the use of multiple component interventions to address interventions may pose difficulties of not knowing which component (single or in combination) was responsible for the outcome of the intervention (Wetherby et al., 2002). Often, treatment integrity is not reported when studies are based on single-component treatment.

The studies in this database used multiple component treatments (natural/unnatural context; adult and child-directed interventions; direct and indirect interventions). Consistent measurement of treatment fidelity should be given due consideration in future research, particularly independent variables that could be measured over time to ensure consistency in implementing the target skills.

Generalization was reported to be relatively low across three parameters (settings, persons and activities); for example, one of the studies by Trent-Stainbrook et al., (2007) reported that it was challenging to maintain generalization sessions consisting of siblings making peanut butter sandwiches to last 10 minutes. So, the generalization sessions had to be reduced to be made comparable to the 5-minute treatment sessions. This is similar to other reviews, which report that generalization was not implemented in 50% of the studies of individuals with severe intellectual and developmental disabilities (e.g. Snell et al., 2010). Hence, more studies need to be directed to ensure generalization across different disability groups, communication partners and settings. Also of importance is the maintenance of skills across time to assess long-term impact. For long term effects to be noted, this has to be maintained for six months or longer (Snell et al., 2006). This is problematic if families are involved in the decision-making process and implement interventions and training in using the AAC system when there are difficulties maintaining skills learnt across time. Like other systematic reviews (e.g. Snell et al., 2006), most of the studies included in the database did not elaborate on how families were involved in the decision-making process accounting for poor generalization and maintenance of skills. Future studies could examine family support systems that promote the maintenance of skills learnt and the availability of parent support groups and intensive individual support if necessary.

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As previously discussed, it has been difficult to report participant characteristics across studies either due to inconsistencies in reporting data or missing data. Specifically, data related to receptive and expressive language skills, chronological ages and cognitive abilities were sometimes either missing or otherwise reported as a mean or in ratios. This made collating and interpreting data problematic and laborious. This has been reported elsewhere in other systematic reviews by Snell et al., 2010; Pennington et al., 2007). It is highly recommended that future investigations should follow a standardized procedure of how participants' characteristics are reported to ensure details are consistent across studies (Snell et al., 2010). Where possible, detailed descriptions of the participants should be included, including chronological age, cognitive function, receptive and expressive language skills and modes of communication. Additionally, more information related to the settings and characteristics of communication partners is critical. In the systematic review by Pennington et al., (2007), specific guidelines were proposed that consider the participants' data, including skills and attitudes of communication partners and the physical environment where the interactions took place. The International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY) (WHO, 2021) is an ideal tool to analyse the goals of AAC intervention studies. While time-consuming, the NJC Evidence-Based Practices Data Entry Instrument (2008) may also be used to address this shortcoming.

4.4.3 Models and approaches underpinning the intervention studies.

Not all the studies presented in this systematic review commented on the theoretical frameworks underpinning their work. Only two (7%) studies explicitly identified a theoretical framework or approach to explain how changes have occurred in the intervention (Appendix A for a more detailed explanation).

The approaches/frameworks referred to explicitly are the Learned Helplessness Theory (Seligman, 1965), Mediated Learning Experience Theory (Feuerstein et al., 1979), Shared Intentionality (Tomasello, 2003) and metacognition and self-regulation theory (Vygotsky, 1978). These approaches and frameworks are based on some of the key theories of child development. Thus, shared intentionality, mediated learning experience, metacognition and self-regulation would be related to the social development theory (Vygotsky, 1978). Conversely, the Learnt Helplessness theory is influenced by the operant conditioning/ behavioural development theories (Skinner, 1957) and social learning theories (Bandura, 1977).

The Tzuriel (2014) study utilized the mediated learning experience, metacognition and self-regulation, and shared intentionality theories, i.e. social development theory. The authors hypothesized that with these mediated strategies, children would internalize these learning mechanisms and become self-autonomous. The authors introduced five of the twelve mediated learning experience strategies based on the mediated learning experience theory to teach sibling mediated interventions. Results confirmed that children with ID scored high on mediation strategies (such as intentionality, reciprocity, transcendence, self-regulation). Furthermore, mediation for self-regulation was related to adapting to the pace of the task and providing scaffolding strategies as necessary. The study supports the notion that mediators adapt to the child's cognitive abilities, interest level, and attention span of their younger siblings, endorsing the Vygotskian approach, which emphasizes scaffolding the learners' needs and capabilities. Other studies implicitly referred to the approaches mentioned above as well as the Behaviourist Approach (Skinner, 1957), Social Constructivism (Vygotsky, 1978), Social Cognitive Model of Joint Attention (Tomasello, 2003) and the Parental Sensitivity Attachment Theory (Bowlby & Ainsworth, 2013).

These studies either implicitly referred to a number of conceptual frameworks or otherwise overlooked the need for a conceptual framework. Therefore, concerns are raised about how these studies have determined intervention outcomes without a conceptual framework. For example, a number of studies referred to parental sensitivity and parent responsivity (Thunberg et al., 2007; Thunberg et al., 2009). The attachment theory derived from the psychoanalytic model is based on the joint works of Bowlby & Ainsworth (2013). The theory maintained that for a child to grow mentally healthy, s/he needs the warm, intimate and continuous relationship of his mother, or substitute mother, assuming the mutual enjoyment from both partners (Bretherton, 2000). Bowlby & Ainsworth (2013) claim that the mother functions as the ego and superego of the child, developing the capacity for self-regulation. The mother performs functions for the child until the skill is transferred onto the child and becomes autonomous, similar to the Vygotskian rather than Freudian ideology. For instance, a study by Jonsson (2011), which had to be excluded from the review because it was on parent perceptions on communication aids, embraced two approaches, the Vygotskian Approach and the framework put forward by Tomasello (2003). Both frameworks suggest that the child needs to be presented with the social means he/she could master to be adequately challenged. Therefore, according to the frameworks, the child had to be exposed to more symbols on the communication boards than s/he had internalized linguistically. Together with the boards and the training provided to the parents, the study hypothesized that the parents would model AAC using the boards. To this extent, the increase in the frequency of use of the communication boards and the increased use of multi-symbol utterances supported both theoretical frameworks.

4.4.4 Gaps in the Research

The results from this review's descriptive and qualitative analysis highlighted several missing gaps that have not been adequately addressed in the literature of family-led interventions. The researcher identified three main areas of concern i) sibling interactions and individuals with profound intellectual and multiple disabilities (PIMD), ii) the role of mothers in sibling-focal child interactions, and iii) the role of fathers in family interactions.

Concerning the first issue of sibling interactions and individuals with profound intellectual and multiple disabilities (PIMD), to the researcher's best knowledge, there is no evidence of any scholarly articles of siblings and children with PIMD. The only study is the doctoral dissertation by Nijs (2015), where it is evidenced that children with PIMD felt motivated more when they interacted with their siblings rather than peers. Nonverbal attention directing behaviours were presented mainly by the siblings manifested by touching the child with PIMD. The study concluded that verbal and nonverbal attention directing behaviours were most effective while increased peer-directed behaviour was observed.

The second issue concerns the interrelationships between parent-child-siblings interventions and the need to acknowledge siblings as co-interventionists. However, little is known about the inter-relationships between parent-siblings, sibling interactions, and one dyad's effects on the other during joint activities with family members. The only relevant study to date is Singh et al. (2015), conducted to compare dyadic and triadic interactions of mothers, siblings, and children performing at the pre-symbolic level of communication. Results showed that mothers and siblings need to recognize the children's pre-symbolic behaviour and engage in triadic interactions where adults can provide more competent models.

Some methodological issues were also noted, including a discrepancy between the groups of children (e.g. developmental ages, language skills), a small sample and the short duration of intervention. Different sibling characteristics may also be confounding variables that may influence the intervention results.

Concerning the third issue, the role of fathers in family interactions, to the best of the researcher's knowledge, there is limited data on fathers' role and involvement in interactions with their children with ID. The only study to date is the qualitative study on the personal impact of Down syndrome on fathers (Marshak et al., 2018), which demonstrated that while fathers experienced positive changes in personal growth, these often co-existed with anxiety and loss. This systematic review reported several intervention studies involving mothers and fathers but not specifically fathers in isolation. Spiker et al., (2002, p36) declared that findings related to mother-focal child interventions could be replicated for fathers and other family members, an observation that may be speculative and hypothetical. Mandak et al., (2017) imply that the child may communicate more frequently or more successfully with the mother or with the father in a two-parent family, which could be attributed to the family's cultural background. It may be culturally appropriate for the mother to assume all caregiving responsibilities, while in some cultures, the role of fathers may be equally, less, or more involved than mothers as caregivers. Future research could address triadic interactions using AAC systems to determine whether interaction patterns vary after unaided or aided means of communication are introduced. Studies may also focus on addressing other age groups (e.g. 11 to 16 years) to determine the quality of interactions between family members and children with communication disabilities. Finally, studies within this age group could establish new methodologies and interventions emphasising outcome measures, particularly in adolescence and young adulthood.

4.4.5 Limitations of the systematic review

Several limitations should be noted. Firstly, the review does not cover all family interventions for children with ID and communication disabilities. The journals identified in the hand search were selected based on their research focus; additional studies might have been identified if other journals not abstracted in the database search were included. Likewise, using the 'ancestor search' may over-represent the results compatible with that particular research focus. For instance, the concentration of studies from Sweden may have been brought about by the over-representation of results obtained from the ancestor search of the same authors or co-authors.

Secondly, the large number of variables extracted from the quantitative data increases the probability of human error. This could have been minimized if a second researcher independently coded all the variables in the studies according to the NJC item checklist and then compared results on an item by item basis and checked for inter-rater reliability. Thirdly, studies were conducted predominantly in the USA. The search strategy may have instigated this since only studies in the English language were included in the search criteria. Nevertheless, only one study was reported from the United Kingdom. Some studies from the United Kingdom had to be excluded because they did not qualify for inclusion in the systematic review. One of the main reasons was that they were systematic reviews, narrative reviews, or observational studies, whilst other studies addressed parent perceptions and views rather than family interventions.

A final point is family interventions in other cultures considering various studies from various countries, including Spain, Israel, Sweden and the USA. Mandak et al. (2017) imply that cultural background may affect the family's perceptions of disability.

For example, there is a stigma associated with disability in some cultures, where it is believed that parents were punished for their sins or disability is seen as a blessing or gift from God. Besides the family coping strategies, families use resources and social support, which vary based on culture. For example, families from collectivist cultures (such as Asia, America and South America) may rely heavily on family social support, sharing responsibilities among siblings and extended family members. They are then less likely to rely on professional support, and this may influence AAC service delivery.

4. 5 Conclusion

The main findings of this systematic review confirmed that family interventions could have positive outcomes across a range of participants and interventions. The findings complement some systematic reviews conducted over the past decade (Granlund et al., 2008; Pennington et al., 2004; Schlosser & Sigafoos, 2006; Smith & Elder, 2010; Snell et al., 2010). The present review differs from other systematic reviews since a) it included some sibling studies which otherwise were not reported in other reviews, b) drew upon interventions happening in naturalistic conditions, which again were not necessarily within past systematic review inclusion criteria. In addition, the inclusion of reviews over the past nine years (2010-2019) sustains the growing trend in family interactions and interventions, contributing to the richness of systematic reviews. This systematic review is one of the first to analyse the theories embraced by the studies and suggest that it is needed to consider a conceptual framework that is needed to consider and that may support studies that failed to address the mechanism for change.

4.5.1 Implications and directions for further research

Few studies have been identified which address sibling communication and AAC interventions. Since these studies have only addressed one specific context, this limits the efficacy of siblings' communication strategies in other contexts (e.g. mealtime, reading and leisure activities). This poses a threat to external validity since communication interventions may not be generalised across different activities. There is a paucity of research including older children with communication disabilities, and therefore more research involving older children with their family members is necessary. Research needs to be more systematic and rigorous when reporting intervention studies and participant data. Family-led intervention studies need to be addressed using mixed research methods, which consider confounding variables, such as the different environmental approaches undertaken, the amount and type of training given, family dynamics, and the relationships between families and interventionists involved.

Considering these shortcomings, more studies may be designed to address sibling communication and AAC interventions in different contexts. Having siblings as co-interventionists may potentially strengthen AAC interventions (Mandak et al., 2017). In view of this systematic review I decided to construct my studies by referring to mothers, siblings and children with communication disabilities within the family home. This review helped me to construct my studies as described in Chapter 6,7,8,9 since it provided information about the different research designs, methods, procedures and tools that are used in family-mediated AAC interventions. The next chapter looks at the methodological implications of this thesis and the possible methods and tools considered in the process.

CHAPTER 5: METHODOLOGY

5.1 Introduction

The purpose of this chapter is to explain and justify the methods used to investigate the research questions for sub-studies 2a, 2b and Study 3 as reported in Chapters 6, 7, 8 and 9. Moreover, this chapter outlines the sampling procedure, the data collection, the tools, and the form of data analysis used. It also features ethical considerations, which heighten the validity of the study. An overview of the different approaches to quantitative and qualitative data analysis and research involving people with communication disabilities is documented. The researcher must be clear about what kind of data collection and analysis is undertaken because this is significant to the purpose of the analysis and how it is written up. The researcher needs to determine the research questions and consider whether the aims are to describe, summarize, interpret, note patterns of behaviours, generate themes, explore, discover commonalities, similarities or differences, or explain or seek connections. Researchers assemble groups of data at a theoretical level together, putting them together coherently and then aggregating and comparing field notes. This process intends to move from a description to an explanation and then eventual theory generation.

5.1.1 Research Perspective

Several perspectives were used to help guide and interpret this study. These consisted of the 'New Sociology of childhood' (Prout & James, 2015) and the application of the 'Vygotskian developmental theory of language acquisition' (Romski et al., 1997). The 'new sociology of childhood' framework acknowledges children being active in constructing and determining their own lives (Prout & James, 2015). Within a typical family unit, children are empowered and may share their lives with their disabled siblings.

The Vygotskian developmental theory of language acquisition is another perspective of this study. The focal child gains autonomous control over the skills whilst the more competent communication partner guides the child until these skills become internalised and mastered by the child (Romski et al., 1997). This chapter also describes the use of Video Interaction Guidance (VIG) through the principles of attuned interaction in guidance (Kennedy & Underdown, 2017), used in all the studies described in Chapter 9. A characteristic of VIG is 'mediated learning', which provides the underpinning of attuned guidance when the sibling is required to lead the focal child by using all means of communication possible, including keyword signing, communication books or voice output communication aids. For attunement to occur, there needs to be a Zone of Proximal Development (ZPD) for the focal child. The communication partner's role is critical in scaffolding and providing the necessary assistance in co-constructing meaning through AAC.

5.1.2 Researcher Position

The researcher is at an advantage since she works with children who have severe and profound disabilities and is also the head of the primary education resource centre on the island. She is a visiting lecturer delivering modules on AAC and disability issues at the University of Malta. In addition, since she is a mother of a youngster with a communication disability, she is in contact with parents whose children have a communication disability. Previously, she set up and led the island's education-based AAC assessment unit and was aware of the opportunity and access barriers to social participation, having conducted her postgraduate studies in AAC (Gatt, 2007).

5.2 Research Design

Sarantakos (2012) claimed that before choosing what study design to use, the researcher must first define and make explicit the aim of the study to be carried out. To do so, the researcher must identify and create the research questions. Corbin and Strauss (2014) argued that the research approach adopted for the studies needs to be problem-oriented, aiming to answer the research questions. The existing literature must be considered before formulating and defining the research questions for the Pilot study (1), sub-studies 2a, 2b and 3. Specific research questions are addressed in Chapters 6,7, 8 and 9. Creswell & Clark (2017) clarify that the contrast between qualitative research and quantitative research is based on theoretical open-ended questions (qualitative) as opposed to numerical (quantitative) or close-ended questions (quantitative hypotheses). Qualitative and quantitative approaches have pros and cons with which the researcher should be acquainted (see Table 19).

5.2.1 Qualitative Research

Qualitative research is an approach that explores and understands individuals' ascribed meaning through

> *"emerging questions and procedures, data typically collected in the participant's setting, data analysis inductively building from particulars to general themes, and the researcher making interpretations of the meaning of the data." (p32)*

Cohen et al., (2017) indicated that some kinds of observations focus groups and interviews are various methods used to assemble and explore qualitative data. This approach is sometimes referred to as a qualitative description (Sandelowski, 2000) and interpretative description. Furthermore, this approach, also known as "inductive reasoning, is often referred to as a "bottom-up" approach to knowing" (Lodico et al., 2010 p.10).

According to Merriam & Tisdell (2015), such an approach is methodologically flexible because it seeks to discover and understand a phenomenon, a process, perspectives and worldviews of the people involved. Additionally, it provides an easy-to-use systematic process for examining qualitative data, generating valid and credible findings (see Table 18).

	General Inductive Approach	Grounded Theory	Discourse Analysis	Phenomenology
Analytic strategies and questions	What are the core meanings evident in the text, relevant to evaluation or research objectives?	To generate or discover theory using open and axial coding and theoretical sampling	Concerned with talk and texts as social practices and their rhetorical or argumentative organization	Seeks to uncover the meaning in lived experiences and to convey understanding.
Outcome of analysis	Themes or categories most relevant to research objectives identified	A theory that includes themes or categories	Multiple meanings of language and text identified and described	A description of lived experiences
Presentation of findings	Description of most important themes	Description of the theory that includes core themes	A descriptive account of multiple meanings in the text	A coherent narrative about the experience

Table 18: Comparison of qualitative analysis approaches
Adapted from Thomas (2006)

Qualitative research requires the use of qualitative data, such as that derived from interviews. According to Creswell & Clark (2017), qualitative research starts with a philosophical assumption or a theoretical/interpretive framework and examines the connotations people give to their narratives. Data should be gathered in a natural environment to aid the interviewee to feel comfortable. The use of a qualitative approach is an advantage when the researcher searches for deep and detailed insights into the experiences, in this case, of mothers and siblings of children with a communication disability. As Thomas (2006) stated, the generic inductive/qualitative description approach compresses raw written data into a short, brief descriptive structure. It also intends to create explicit connections between the evaluation or research objectives and synopsis findings obtained from the raw written data.

In addition, it aims to create a model about the core components of experiences, procedures, or perceptions stemmed from the transcribed data. Taylor (2005) defines semi-structured interviews as one of the primary techniques for gathering data in qualitative research. The interviewees' perspectives and experiences are known as phenomenology. The primary aim of the **phenomenological** study is to comprehend a person's understanding and perception of a situation and the way they decipher it (Van Manen, 1990).

5.2.2 Quantitative Research

Quantitative research looks at establishing and validating a connection among variables by obtaining numerical data, which can be analysed using statistical procedures from a selected group while ensuring confidentiality. Quantitative research incorporates either a true experimental design or non-experimental form of research such as a survey.

	Quantitative Research	*Qualitative Research*
Strengths	Useful for obtaining data that allow quantitative predictions to be made.	Data is based on the participants' categories of meaning.
	Data collection can be quick.	Useful for describing complex phenomena.
	Provides precise, quantitative, numerical data.	Useful for in-depth studies
	Data analysis is relatively less time-consuming.	Provides understanding and description of peoples' personal experiences.
	It is useful for studying large groups of people.	Data are usually collected in naturalistic settings
	Can generalize research findings when the data are based on random samples of sufficient numbers.	Qualitative approaches are especially responsive to local situations.
	Can generalize a research finding when it has been replicated on many different populations.	Qualitative data from the participants lend themselves to exploring why and how phenomena occur. Provides individual case information.
Weaknesses	The researchers' categories that are used might not reflect local understandings.	Knowledge produced might not generalize to other people or other settings.
	The researcher might miss phenomena occurring because of the focus on theory or hypothesis testing rather than on theory or hypothesis generation.	It is challenging to test hypotheses and theories with larger populations.
	The knowledge produced might be too abstract and general for direct application to specific local situations and individuals.	It might have lower credibility.

Table 19: Strengths and weaknesses of quantitative and qualitative research

5.2.3 Mixed Method Research (MMR)

Mixed methods research (MMR) utilises both qualitative and quantitative approaches in one empirical study (see Table 19). MMR is more complex than one single research method since it brings about a distinct epistemological stance and conceptual framework (Creswell & Clark, 2017) . This type of inquiry is more time consuming, and the researcher has to have a strong understanding of qualitative and quantitative research. MMR has been used to understand aspects of a phenomenon and resolve a problem using different types of information. Methods in MMR can be used sequentially, concurrently, or transformatively. When used concurrently, quantitative and qualitative data converge as they are both gathered simultaneously. Concurrently, the researcher also integrates and interprets qualitative and quantitative information. Creswell & Clark (2017) portray mixed method research as an approach that incorporates qualitative and quantitative data in a single study better to understand a research problem than either approach alone. Different types of data can be gathered, utilising more than one technique, approach or strategy as part of the same study. Therefore, a *mixed-methods* approach was adopted for all three studies. Qualitative and quantitative data were gathered simultaneously by blending and consolidating the quantitative data with the qualitative data to clarify the general outcomes.

5.3 Ethical Considerations

Before data collection, an ethics pack was submitted for review and approval to the Research Ethics Committee of the University of Kent and the University of Malta Research Ethics Committee. Following approval from both bodies, all potential volunteers were contacted through a Maltese NGO that provides services to persons with IDD.

Finally, following signed consent, the participants were visited (and videotaped) in their homes when convenient for them.

5.3.1 Beneficence

The researcher was aware that the participants took part in this study (in part of her doctoral studies) and ensured that families, in turn, benefitted from some communication goals that could be used for assistive technology and IEP reviews. The ultimate aim of this research was to empower families, particularly siblings as co-interventionists in the process. Additionally, families were encouraged to use different modes of communication to model an aided communication system with the focal child.

5.3.2 Non- maleficence

The principle of non-maleficence ensures research does not cause harm, difficulty or inconvenience to any participants. The researcher was aware that she was working in family homes with children who had an intellectual and developmental disability, which could be a potential source of anxiety for the families. The researcher was also aware that the focal children needed to be portrayed with dignity, especially if they are not fully clothed during the filming process. Therefore, the researcher decided not to film the children during such periods. She also stopped filming when there was an indication that the situation was getting stressful for the families or the children needed help with personal care.

5.3.3 Informed Consent

Informed consent presents as a challenge when working with children who have an intellectual and developmental disability with additional communication needs, making it difficult for the child to assent or ask to withdraw from the study at any time.

The researcher designed age-appropriate information sheets using simple language, easy to read formats, graphic symbols and digital photos. The families were given copies of the information sheet and consent forms. Siblings were also presented with age-appropriate and easy to read assent forms. The consent form guaranteed full confidentiality, and participants had the option to withdraw from the study at any time without giving any reason, as clearly stated in the project information sheet. Some families whose children attend the researcher's school/centre were interested in participating in the project. However, as informed consent requires that participants feel no pressure to participate (Farrimond, 2013), ethical approval was granted provided these families were excluded from the study. Furthermore, participants were informed that they could stop the interview at any point if they wish to take a break from questions or to stop altogether.

5.3.4 Confidentiality & Anonymity

The principles of ethical research require consideration of individual's autonomy in deciding to participate in the research and considerations of how best to protect their anonymity following data collection and analysis (Farrimond, 2013). Participants were reminded about their rights under the General Data Protection Regulation (GDPR) and the Malta Data Protection Act, 2018 to access, rectify, and, where applicable, erase any data concerning them. To safeguard the anonymity of the interviewees, all the information gathered and stored complies with the Data Protection Act (DPA) 2018. The data collected was stored in a locked cabinet in the researcher's home. Transcriptions were labelled with a code, and the names of participants were not added to the transcripts. The signed consent forms were kept separate from the transcripts in another locked case within a compartment in the cabinet. All the transcripts, questionnaires and recording sheets were given a code corresponding to the participants' names.

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The corresponding code and names sheet was kept locked separately. All the digital information, including the videos, was stored on a removable hard drive that was password-protected. Participants were informed that data was seen by the researcher, the research assistant, the supervisors and examiners if necessary. All data used in the thesis has been duly anonymised. All identifying material will be kept for five years following the PhD completion, after which time the data will be destroyed.

5.3.5 Impartiality

Tizard Centre, University of Kent partly funded the research, and the researcher had no known conflict of interest.

5.4 Data Collection Methods and Tools used

5.4.1 Sampling Procedure and design

The sampling phase is crucial to the study. It is not viable nor effective to study the entire population (Dhivyadeepa, 2015). Hence, for this study, the use of a convenience sampling technique has been adopted. Convenience sampling, also known as, Haphazard Sampling or Accidental Sampling, is a non-probability or non-random sampling approach that qualitative researchers use to enlist readily available and convenient participants (Rahi, 2017). A specific criterion was adopted when selecting the participants to be part of the study (Cohen et al., 2018). The selection of participants is described in more detail in Chapters 6, 7, 8 and 9. Essentially the study in Chapter 9 also used a case series. Case series can also be seen as a cohort study without a control group or 'an uncontrolled before-and-after study' (if a pre-intervention measure is available).

In the absence of a concurrent control group, it is difficult to conclude effectiveness, as it is difficult to ascertain whether any observed effect is a 'true' intervention effect since the contribution of the natural course of the condition, placebo/Hawthorne effect, or the effect of other concurrent treatment cannot be ruled out. In addition, it is the weakest kind of experimental design since it focuses on a single unit, and generalisability is an issue. A biographical case study is an alternative method. It may be most suitably written as a descriptive narrative, often in chronological order. While this is not necessarily a requirement, some narratives may report critical events, decisions, outcomes and evaluations. Narratives cannot record all events but rather a selective account based on the researcher's criteria. This could include key areas in the narrative, or events, themes, behaviours, and actions. After the key areas are identified, then the text can be interpreted and analysed. In the current studies, broad narrative transcriptions were provided following video observations for all of the studies. A narrative process was used to discuss the data and capture the participants' interactions in a particular time, place and setting.

5.4.2 Data Collection

This section describes qualitative and quantitative approaches to data collection and which approaches were chosen for the current studies.

5.4.2.1 Qualitative approaches

The principle of the qualitative approach is to gather rich information for interpretation until the data saturation level (that is when no new themes arise) is achieved. There are several approaches to the analysis of qualitative data. Qualitative data emerges from several sources, including transcribed or non-transcribed interviews, participant or non-participant observations, accounts, field notes, audio, video recordings and diaries.

This poses several challenges since the data is so rich and that eventual analysis requires selecting and ordering. As a result, this may pose internal validity issues since the researcher may have a personal bias. The researcher must adopt an objective role at this stage of the research. Grounded theory, content or thematic analysis will follow, which address coding and categorisation of the data. Qualitative data focuses on smaller numbers of people being studied, and the data is usually richer and more detailed than quantitative data analysis. Data is then either presented individually (individual by individual), and then if necessary, key issues can be combined, which emerge across individuals. Several qualitative studies focus on individuals and often quote verbatim responses in the discussion stage. Direct conversations can be very rich in data and detail, and verbatim data can be used. Other studies address common themes which summarise issues across different individuals.

In interview and questionnaire studies, the questions are considered a core element because, through questions, valuable and rich data from the participants is collected. Hence, when formulating the questions, the researcher must ensure that the choice of questions should reflect what the researcher is trying to investigate regarding the researched topic (Cohen et al., 2017). After an extensive literature review, the researcher in this thesis planned a sequence of questions. These questions targeted the aim and objectives of the study, using a funnel approach. Through this approach, the researcher began to explore issues through open-ended questions. Then, using focused but not suggestive questions, the researcher gradually narrows the topic area to the subject matter of paramount significance to the research objectives. Initially, the researcher sought to use the most common traditional form for generating data in qualitative research (Creswell & Clark, 2017), in-person interviews. Such interviews are often considered the 'gold standard' within qualitative research.

5.4.2.2 Video calling and video recording

Due to the current COVID situation in Malta and following the Health Authorities guidance, the researcher also considered using another type of interview, video calling (Jowett, 2020). Video calls are an internet-based technology that allows recreating that in-person experience much like the in-person, face-to-face interviews, whilst physically separate. Video calls allow a flexible and focused conversation between the researcher and the interviewee. Furthermore, video calls help the researcher understand the participants' perceptions of the subject researched. Besides, video calls are a tool that can also help obtain other additional unforeseen information that was not originally in the researcher's frame of mind. In this thesis, these video call interviews comprised a focused conversation based on a set of open-ended questions. This type of interview enables the researcher and the participants to discuss in-depth specific topics without strictly following a formal, rigid list of questions. Video calling offers advantages as a research tool for interviewers. These advantages include easing the scheduling burden, cost-effectiveness as it saves travel costs, time, personal safety, especially with the current pandemic, and securing data generation and storage. The disadvantages of video calling interviews include technical issues and missed opportunities to respond to body language and cues, though this is debatable. The general outline for qualitative methods in research projects usually entails getting and making recordings of some kind, transcription, analysing selected parts and reporting research. Recordings can be audio or audio-visual. The latter may analyse selected visual details as face-to-face interaction and complement the audio recording (ten Have, 2007). The recorded interaction may involve non-vocal exchanges or non-vocal accompanying activities that may not be accessible on audio, and therefore video recording is usually preferred over audio recording. Video recordings may also be useful for quantitative data collection.

They can be transcribed and coded for specific behaviours: communication (speech and vocalisations, eye gaze, gestures and actions, graphic signs, aids, body posture and facial expressions). For example, Sterling et al., (2013) included video observations of mother-focal child interactions in four different contexts, coded for child communicative acts whilst maternal responsivity was coded at two levels: a general and code-by-code behaviour measure. Video recording also allows the possibility of transcribing conversations for analysis.

Several studies have reported video feedback intervention following unstructured free play interactions of parent-child interactions and are an effective tool for observing individuals within a process of change (Kennedy et al., 2017). This process involves goal setting, filming sessions and shared review sessions of short video clips. Participants take part in a goal-setting conversation, and they set a goal where they would like to see a change. Then the interventionist takes a video that depicts the particular goal which needs to feature. Participants use the principle of microanalysis to discuss which behaviours provided successful communication supports with their children. Following the filming session, the interventionist analyses the film using Video Interaction Guidance (VIG) (e.g. eye-gaze and attentiveness, initiative and reception of verbal and nonverbal initiatives, and turn-taking behaviours that foster attuned responses) to select short clips of positive communication. Barlow et al., (2010) quote evidence of the effectiveness of Video Interaction Guidance (VIG) in improving parental sensitivity. Meta-analysis of studies using video feedback concludes that parents become more skilled in their interactions with their children. As a result, they have a more positive perception of parenting which helps the overall development of their children (Fukkink, 2008).

For this thesis, all the studies utilised the process of VIG, where families were asked to specify their own goals, which helped the researcher know how to organise the films and which clips to select. Families observed themselves on video and experienced feedback about their communicative interactions and identifying their strengths while identifying goals for changes in communication. Then there were three shared review sessions of 1 hour each where the parents and the researcher micro-analysed and reflected on the behaviours exemplified in video clips.

5.4.2.3 Quantitative Approaches: direct observational methods

There have been many observational studies that have described interactions between persons with communication disabilities and their partners. These studies range from observational studies that include triangulation of data, such as interviews, questionnaires, behaviour rating scales, and observations. This section discusses direct observation techniques, including event recording, interval sampling and momentary time sampling, and which methods were used for this study (see Table 20). A method of evaluating behaviour that provides the researcher with a precise picture is behavioural recording. There are three basic behavioural recording methods: event (frequency) recording, interval and duration recording.

a) *Event (frequency) Recording*

Event recording documents the number of times a target behaviour occurs during a specific time. The data gathered during event recording is documented as a rate. The frequency of the behaviour is calculated by dividing the number of occurrences by the number of minutes. The advantage of event recording is that it is easily implemented and is effectively used when the behaviour occurs briefly and discreetly (Murphy, 1987).

However, event recording is inappropriate when the behaviour occurs at a very high rate (uncountable) or occurs over extended periods, especially for behaviours that last more than a few seconds. The researcher utilised frequency recording in Study 3 to record each occurrence of the communication modes used by the focal child within a 10-minute set time frame since this did not occur frequently. Frequency recording was also used for studies 1, 2a, and 2b to determine the amount of supportive and intrusive directives in mother-focal child and sibling-focal child dyads and mother-sibling-child triads. The rate was calculated by counting the total number of times the behaviour occurred and dividing by the total amount of time (10 minutes) to get the frequency/rate.

b) Whole Interval Recording

Interval recording documents whether a behaviour occurred during a particular period. The three types of interval recording are whole interval recording, partial interval recording and momentary time sampling. Whole interval recording is one type of interval recording method where the observer marks down whether a behaviour occurs throughout the entire interval by placing an "X" for occurrence and an "O" for non-occurrence. The number of intervals in which behaviour is observed is counted, and the percentage of intervals is documented. The advantage is that it provides the duration of behaviour and the occurrence or absence of a particular behaviour. The behaviour is measured by counting the number of time intervals in which the behaviour occurred. Unfortunately, behaviour is not easily counted when: i) it is difficult to tell exactly when the behaviour begins or ends, or ii) it occurs at such a high rate that it is difficult to count. For Study 3, whole interval recording was used to record the occurrence of sibling-focal child initiations and caregiver prompts throughout the whole ten-minute interaction.

Whole interval recording was chosen since it was expected that sibling-initiated interaction behaviours would be too high compared to focal child interactions and would be difficult to keep count. The observation period made up of 10 minutes was divided into equal intervals of 10 seconds each. At the end of each interval, the researcher recorded whether the behaviour occurred or not. After the session is over, the number of intervals were counted during which the behaviour occurred. This was divided by the total number of intervals and multiplied by 100 to determine the percentage of intervals during which the behaviour occurred.

c) Partial Interval Recording

Partial Interval recording is a data collection method involving recording whether a behaviour occurs or does not occur during a specific interval. It does not have to occur throughout the entire interval, unlike whole interval recording. The advantage of the partial interval recording method is that it estimates the frequency and duration of behaviour and provides information about where behaviours occur across observational sessions. Partial interval recording documents whether behaviour occurred or not but will not provide information about frequency within the interval. If the behaviour happens quickly or does not last long, one may use the partial interval recording method. Partial interval recording was not considered in the studies because it tends to overestimate and overinflate the behaviours, especially when the siblings take more turns than the focal child.

d) Momentary Time Sampling (MTS)

An observation period is divided into intervals in momentary time-sampling, and a behaviour occurrence or non-occurrence is noted at a specific moment in time.

MTS provides a percentage of an observation period during which a target behaviour occurs by dividing intervals scored as occurrences by the total number of intervals. MTS is used to estimate the frequency of a target behaviour. MTS can be used with several interval lengths, observation durations, and target behaviours like interval-recording procedures.

Name	Definition	Advantages	Disadvantages
Continuous procedures			
Event (frequency) recording	The observer records the number of times a target behaviour occurs during a specific time	Effective to record brief and infrequent behaviours	Event recording is inappropriate for behaviours that last more than 2 seconds or behaviours of variable duration. Inappropriate for very fast behaviours because the observer will be unable to count them.
Duration recording	The observer records the total length of responses	Effective to record behaviours that last more than 2 seconds, especially those which vary in length	Inappropriate to record brief and infrequent behaviours
Discontinuous procedures			
Whole interval recording	The observer records a behaviour during the entire interval (5, 10 or 20 seconds long).	Good for high rate behaviours that cannot be counted.	The observer has to observe the entire interval. The occurrence of the behaviour is often underestimated since it is only counted when it occurs throughout an interval
Partial interval recording	The observer records the occurrence or absence of behaviour that occurs during any time interval	The observer does not need to observe the rest of the interval after the behaviour occurs.	This measure underestimates the frequency of behaviours occurring at a high rate. It overestimates the total duration of the behaviour
Momentary time sampling	The observer records a behaviour that occurs/or is absent at a specific moment of time.	The observer does not need to attend to the behaviour except at the end of the interval. More accurate to reflect the per cent of behaviour than is interval recording.	This measure is very accurate with short intervals (e.g. of around 10-20secs). It is inaccurate when the time intervals are greater than 2 minutes

Table 20: Advantages and disadvantages of direct observation methods
(adapted from Murphy, 1985)

Regarding Study 3, Momentary time sampling was used to determine the dependent variables related to proximity to the sibling or adult and proximity to the aided communication system. This was based on a momentary time sample, at the end of every 20 seconds, over a 10-minute sample. This system was chosen over other observational measures since the recorded behaviour tends to last for a while, for example, proximity to sibling and proximity to an aided communication system.

The researcher does not need to look throughout the entire interval but only at the end of each 20 seconds interval to determine whether the behaviour is occurring at that specific moment in time. Table 20 discusses a number of advantages and disadvantages of these types of observational methods.

5.4.3 Other quantitative tools (rating scales)

Several tools are used to measure communicative style, including predefined behaviours such as gestures, request for verbal compliance, commenting, recoding, request for behavioural compliance, redirecting and restricting the child's behaviour in some way but not always negatively (Warren et al., 2010). In addition, rating scales have been used in similar studies; see table 21 below.

	Scale & authors	*Subscales and variables measured*
RAACS	Responsivity Augmentative and Alternative Communication Scale Broberg et al., (2012).	i) attend to and confirms the child's communication, ii) adjust physically to the child, iii) give the child space to communicate, iv) clarify communication, v) communicate according to the child's focus of interest /conversational topic, vi) expand on the child's communication, vii) use AAC, viii) adapts and is engaged, and ix) adjusts to the communicative level of the child
S-DMM	Scale for Dialogical Meaning Making (Hostyn et al., 2009a)	Mutual openness Joint embedding context Non-manipulative negotiating Joint confirmation Non-evaluativeness
CARE-Index	Crittenden, P. M., Der, C. A. R. E., & Früherkennung, I. (2005)	The measure assesses mothers on three scales: sensitivity, control and unresponsiveness. There are also four scales for infants: cooperativeness, compulsivity, difficultness, and passivity.
EAS	Emotional Availability Scales (Biringen et al., 2005),	Adult: sensitivity, structuring, non-intrusiveness, and non-hostility, child: responsiveness to adult and involvement of an adult. The EA Scales measure two dimensions: child qualities—child responsiveness to the caregiver and the child's involvement with the caregiver.
MBRS	Maternal Behaviour Rating Scale (Mahoney et al., 1986)	Child Oriented/Maternal Pleasure reflected the orientation of mothers toward their children, as well as the mother's apparent enjoyment. Quantity of Stimulation reflected the quantity of maternal stimulation during the play session. Control reflected maternal control, such as directiveness, achievement orientation, and sensitivity towards the child

Table 21: Rating Scales

Before proceeding with the respective ratings, the terms "responsivity" and "emotional availability" were operationalized.

Landry et al. (2006) define responsive communication as encompassing such characteristics as being attentive, adjusting one's communication to the child's communicative level, giving prompt responses to communication signals from the child, and communicating according to the child's attentional focus. Biringen (2008 p.7) cited that emotional availability refers to the "individual's emotional responsiveness and affective attunement to another person's needs and goals". Two scales, the RAACS and the EAS, were used for coding episodes of responsivity, emotional availability, and the frequency of social interaction behaviours during the three 10-minute sessions of activities recorded to gain an understanding of mother, sibling and focal child interactions. These are described below.

(a) The Responsivity Augmentative and Alternative Communication Scale (RAACS) Version 3 (Broberg et al. 2012)

Before 2012, there was no coding scheme to assess the responsivity of parents when interacting with AAC users. Therefore, the Responsive Augmentative and Alternative Communication Style Scale (RAACS) was developed to assess parents' communicative styles with children with communication difficulties. The RAACS resulted from a seven-year project developed for assessing parents' communicative styles for children with communication disabilities. This was part of Broberg et al. (2012) more extensive evaluation of the *ComAlong Course* targeting parents of children with communication disabilities and aims to enhance their knowledge and different kinds of communication supports. The scale was used by Broberg et al. to analyse 105 play interactions based on 43 parents and 28 children with different disabilities. The scale demonstrated an acceptable intercoder agreement of 0.89 and an internal consistency of 0.85. Thus, the scale has been found adequate to assess responsive communication styles and behaviours and parental strategies for using and implementing AAC with satisfactory scale psychometric properties.

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For the pilot study's purpose, the RAACS instrument was used to measure the responsive style for both mothers and siblings. This scale specifies the following 9 categories of interaction: i) parent/sibling attends to and confirms the child's communication, ii) parent/sibling adjusts physically to the child, iii) parent/sibling gives the child space to communicate, iv) parent/sibling clarifies his or her communication, v) parent/sibling communicates according to the child's focus of interest /conversational topic, vi) parent/sibling expands on the child's communication, vii) the parent/sibling uses AAC, viii) parent/sibling adapts and is engaged, and ix) parent/sibling adjusts to the communicative level of the child (refer to appendix). The scores are based on nine statements. A global score of the total responsivity is provided for statements 8 and 9. The overall RAACS score is provided by adding the total means for statements 1-7 to the sum of statement 8+9. This gives an overall RAACS score out of 20 (see Appendix for more details).

(b) The Emotional Availability Scales Middle childhood/Youth version (4th Edition: Birigen, 2008)

The EAS is a tool that can score the quality of relationships between children and their caregivers. Biringen et al. (2014) report a whole body of empirical research with over 125 studies using the EA scales examining child-caregiver relationships across a spectrum of adult-child relationships, including children with DD (Down Syndrome and ASD). There are two versions of the scale: one operationalized for young children and one for school-aged children and youths. Acceptable validity and reliability scores have been demonstrated with the scales. The scales have been used in intervention studies, and so sensitivity to change has also been documented.

The EAS assesses dyadic interactions between an adult and a child/youth. The scales consist of six dimensions, 4 for the adult's emotional availability towards her child: sensitivity, structuring, non-intrusiveness, and non-hostility; and 2 for the child, namely responsivity towards involvement with the mother and the child. The mutual emotional signalling between the mother and the child is essential when both the adult and the child interact. The scales also allow the coder to score the adult's behaviour based on four variables, whereas the child's behaviour is scored on two variables. The EAS scores the quality of interactive congruence shown by the mothers and children. A global score is rated for each of the six dimensions using a 7point scale (a score of 1 indicating a non-optimal level and a 7 for the most optimal level). Generally, scores above "4" are not considered to require any form of intervention, but dyads with the range of 3 to 5 may suggest a better potential for intervention over lower scores.

Secondly, direct scores for each construct compare to the first 2 key elements of each construct. Thus, for the adult sensitivity construct, the total score would compare to the affect and clarity of each key characteristic. The parental EA allows the parent's awareness of and response to the child's emotional cues and a range of emotions in interaction. A key aspect of child EA is the child's readability of emotional signals and his or her positive emotional presence. The EA scales were chosen for study 2a and 2b since it provides six unique dimensions with a thorough description of each construct. Unlike other approaches that use frequency counts of specific behaviours, emotional availability is based on global judgment where the researcher uses contextual cues and a global judgment through a final score. The EA scales were used to code the maternal dimensions and the child dimensions separately.

5.4.4 Questionnaire and Interview Design

A baseline questionnaire for mothers was used to identify participant characteristics, which have been shown to impact communication and language development (e.g. socio-economic status, parent style, the use of language and bilingual situation, parent stress, family constellation, intrinsic factors such as genetic disorders, illnesses). The development of this questionnaire was based on an extensive literature review as well as similar questionnaires conducted. A Sibling Communication interview (refer to Appendix E) was used to address variables such as warmth and closeness, roles within the family, level of responsivity, rivalry, birth order and gender. The interview was also based on an extensive literature review, and similar sibling communication interviews were consulted in light of the research aims and objectives.

5.4.5 Piloting

The Pilot Study (Study 1) is described in Chapter 6.

5.4.6 General Overview of the Studies

Table 22 details the studies conducted in this thesis and their respective research designs, measures, data collection tools and analysis. Detailed information about each study is found in each respective chapter.

5.5 Data Analysis

A method of organising data is by research instruments often used in conjunction with other approaches, such as groups or themes. This has several disadvantages since the connection between different forms of data can be absent since data is presented instrument by instrument rather than across instruments creating fragmented and contrasting modes of analysis.

					Data collection		Analysis
Study	Name	Research design	Measures taken	Rating scale	Direct observation	Questionnaires & Interviews	
1	Pilot Study	MMR	i) Frequency of directives, ii) responsivity / EA ratings	EAS and RAACS	Frequency count of supportive and intrusive directives	Maternal Questionnaires Sibling Interviews	Frequency count of directives
2a	Study of typically developing children	MMR	i) Frequency of directives, ii) responsivity / EA ratings	EAS	Frequency count of supportive and intrusive directives	Maternal Questionnaires Sibling Interviews	Thematic analysis using attunement principles of VIG
2b	Study of atypically developing children	MMR	i) Frequency of directives, ii) responsivity /EA ratings.	EAS	Frequency count of supportive and intrusive directives	Maternal Questionnaires Sibling Interviews	Thematic analysis using attunement principles of VIG Descriptive statistics
3	Study on sibling mediated interventions	MMR	i) sibling-focal child initiations /responses, ii) caregiver prompts to-wards the sibling & focal child, iii) AAC modes/ aided communication messages iv) the level of proximity of sibling, caregiver and system		Interval recording of sibling-child initiations and caregiver prompts. MTS for the level of proximity of siblings, caregivers and aided system Frequency counts of communication modes	Maternal Questionnaires Sibling Interviews Communication Goal setting Post-intervention questionnaires & interviews	Thematic analysis using sibling embedded framework Descriptive statistics

Table 22: Overview of the studies

Case studies represent data analysis where exclusive features of case studies can be drawn together with common findings across the different case studies. Another way of organising the data analysis is by constructing a narrative in a story. Narrative analysis may help the researcher understand how participants construct stories and narratives from their own experiences, creating a dual-layer of interpretation. Participants interpret their own lives through narrative, and then the researcher interprets the construction of that narrative. Narratives may be extracted from in-depth interviews, transcriptions, focus groups, or other types of narrative qualitative research (Nasheeda et al., 2019).

5.5.1 Thematic analysis

As discussed earlier in the chapter, although ontologically, this project acknowledges that "real" or "material" structures impact the social world, understanding these structures is a socially constructed process. Thematic analysis was chosen for the qualitative data collected since it is a flexible approach not tied to a particular ontological or epistemological position compared to commonly used qualitative analysis methods such as interpretative phenomenological analysis (Braun & Clarke, 2019). This thematic analysis approach seeks to categorise the meaningful patterns discovered within the research data and analyse the significance of these patterns concerning the research aims (Guest et al., 2012).

Other qualitative analysis methods may include grounded theory which seeks to identify repeated ideas or concepts occurring in the data using a precise coding method. It seeks to develop micro-level theory through data analysis deriving theory directly from the gathered evidence(Walsh et al., 2015). The first stage of the analysis is to become familiar with the data. Once the data was read and transcribed, the researcher progressed to the second analysis stage to generate initial codes. Within thematic analysis, themes can be developed using one of two processes. First, the data can be interpreted through a semantic approach that seeks to identify patterns at a surface or literal level or a latent process where data is interpreted for the underlying ideas, assumptions, and beliefs discussed (Braun & Clarke, 2019). Next, the researcher used broad transcriptions to transcribe the data to ensure a reliable and accurate source is needed for thorough analysis. The researcher followed Braun & Clarke's (2019) six-stage process for conducting a thematic analysis.

i.   Familiarisation with the data: The researcher becomes familiar with the data that has been obtained, whether this involves verbal data via transcriptions or some other form.

ii.   Generating initial codes: The generation of initial codes occurs, followed by collating the codes and all relevant data extracts.

iii.   Searching for themes: Once the initial coding has finished, searching for themes within data may occur.

iv.   Reviewing themes: The researcher reviews the data and identifies themes, while interesting, not substantive enough to constitute a 'theme'. Consequently, themes can be refined so that the final themes provide a clear picture of the data.

v.   Defining and naming themes: Once the researcher is satisfied with the resulting themes, a more detailed analysis of each theme can occur and can name the themes.

vi.   Writing up: This phase can only occur once the researcher has a complete set of clear themes, which are then analysed using evidence from the data to support the researcher's position.

5.5.1.1 Attunement evidence from narrative accounts.

The principles of attunement were used to describe and analyse the descriptive narratives found in the appendices (Table 23). A thematic analysis approach was used to analyse these qualitative data, which involved identifying themes. Video Interaction Guidance (VIG) (e.g. eye-gaze and attentiveness, initiative and reception of verbal and nonverbal initiatives, and turn-taking behaviours that foster attuned responses) were used when analysing the films. These are described in the principles of attunement in Table 23 (Kennedy et al., 2017).

Being attentive	Looking interested with friendly posture.
	Giving time and space for the other.
	Turning towards the other.
	Wondering about what they are doing, thinking or feeling.
	Enjoying watching the other
Encouraging initiatives	Waiting.
	Listening actively.
	Showing emotional warmth through intonation.
	Using friendly and/or playful intonation as appropriate.
	Naming what the child is doing might be thinking or feeling.
	Naming what you are doing, thinking or feeling.
	Looking for initiatives.
Receiving initiatives	Showing you have heard, noticed the other's initiative.
	Receiving with body language.
	Being friendly and/or playful as appropriate.
	Returning eye contact, smiling, nodding in response.
	Receiving what the other is saying or doing with words.
	Repeating/using the other's words or phrases.
Developing attuned interactions	Receiving and then responding.
	Checking that the other understands you.
	Waiting attentively for your turn.
	Having fun.
	Giving a second (and further) turn on the same topic.
	Giving and taking short turns.
	Equally contributing to the interaction or activity.
	Co-operating or helping each other.

Table 23: Principles of attuned interactions
Adapted from Kennedy et al., (2017)

5.5.2 Descriptive Statistics

Descriptive statistics relate to the analysis, summary, and presentation of findings from a quantitative data set within a sample or entire population. It may be used to summarise quantitative data using tables and graphs. Descriptive statistics comprise three main categories Frequency Distribution, Measures of Central Tendency, and Measures of Variability. In terms of the current research, studies 2a, 2b, and 3 utilised these three categories to understand the outcome measures.

a) Frequency distribution

Frequency distribution is used for quantitative and qualitative data by depicting the frequency of the different outcomes in a sample. The frequency distribution may be presented in tabular or graphical form.

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Each entry is accompanied by a frequency of the values' occurrences in an interval, range, or specific group. Thus, the frequency distribution summarises grouped data categorized based on mutually exclusive classes and the number of occurrences in each class.

 b) Central Tendency

Central tendency refers to the data set descriptive summary using a single value reflecting the data distribution centre. The mean, median, and mode are the measures of central tendency. The mean refers to the average in a data set. The median is the middle value in a data set when the data is arranged in ascending order. The mode refers to the value that is most frequent in a data set.

c) Measure of Variability

A measure of variability depicts the range and width of the distribution of values in a data set. The range, standard deviation, and variance depict different components and aspects of the spread. The range depicts the degree of dispersion between the highest and lowest values within a data set. The standard deviation determines the average variance in a data set and provides the difference between a value in a data set and the mean value of the same data set. Finally, the variance reflects the degree of the spread as an average of the squared deviations.

5.5.3 Inter-rater reliability

The researcher (MG) served as the primary observer for studies 1, 2a, 2b and 3. A second independent researcher working with disabled students served as a second observer. Before collecting all the data for the studies, the researcher and the second independent researcher reviewed the coding definitions and discussed the questions and disagreements.

The observers practised coding using video clips which were not utilized during the studies until an 80% interobserver agreement (IOA) was reached. Interobserver agreement (IOA) was checked by randomly selecting 20% of observations from each video clip. The second observer coded the data according to the pre-assigned coding procedures according to each study. Data were collected on the reliability or interobserver agreement (IOA) associated with each dependent variable and the intention that IOA levels meet the minimal standard (lOA = 80%). The point-by-point total agreement (IOA) was calculated by dividing the total agreed intervals by the total agreed and disagreed intervals, multiplied by 100%. Cohen's Kappa was also calculated for each behaviour using an online calculator (https://www.easycalculation.com/statistics/cohens-kappa-index.php). McHugh (2012 p.281) argued that researchers should calculate both the percentage agreement and kappa since they have their strengths and limitations. While percentage agreement is easy to calculate and interpret, it may overestimate the true agreement among raters due to guessing. The kappa was designed to consider the possibility of guessing, but it is difficult to interpret directly and may lower the estimate of agreement. The Kappa result is interpreted as follows: values ≤ 0 no agreement; 0.01–0.20 none to slight; 0.21–0.40 fair; 0.41– 0.60 moderate; 0.61–0.80 substantial, and 0.81–1.00 as almost perfect agreement (McHugh, 2012).

5.6 Conclusion

This chapter describes the general research approaches adopted for the studies reported in Chapters 7, 8 and 9, including the theoretical perspective of the research, the methods used for data collection, data analysis and ethical considerations.

The following two chapters describe the Pilot study (Study 1) and draw on the specific approaches, methods, sampling, data collection and findings from the study on mothers, siblings and children who are typically developing (study 2a); mothers and siblings of children with a communication disability (study 2b) and the final study 3 on sibling mediated interventions (Chapter 9).

CHAPTER 6: PILOT STUDY (STUDY 1)

6.1 Introduction

Previous chapters have highlighted challenges that families face daily in initiating communicative attempts with individuals with communication disabilities. The systematic review chapter has demonstrated that mother-focal child interactions have dominated studies involving families, but studies focusing on understanding the social interactions between AAC users, particularly children with severe communication disabilities and their siblings, are scarce. The review also established minimal research in triadic interactions involving child, sibling and mother. Siblings are essential communication partners within the family support system, but little is known about the inter-relationships between parent-siblings, sibling interactions, and one dyad's effects on the other during joint activities with family members. Before proceeding to the main study based on the recommendations of the systematic review, the researcher conducted a pilot study as described below.

This chapter gives an overview of the pilot study's goals and outcomes and the implications for the main study. Ultimately, the objective of the main study is to understand patterns of behaviour in mother-focal child and sibling interactions, particularly the levels of responsivity between mothers, siblings and children with communication disabilities. The aims of this pilot study, before the main study, are

i.   to investigate whether the methodology and the analytical tools used are adequate and can be used in the main study.

ii. To provide a preliminary analysis to determine whether the data could answer the proposed research questions.

Pilot studies allow the researcher to detect any flaws in the measures and operationalise the independent variables. In addition, the pilot study can also help identify unclear and ambiguous items in the questionnaires and the interview schedule. Therefore, the following research questions were proposed:

i) What patterns of behaviour are observable in mother-sibling-focal child interactions in families where a child has a communication disability?

ii) What are the similarities and differences in these behaviours between and within families?

iii) How valid are the selected measures at capturing these patterns of behaviour?

6.2 Methodology

6.2.1 Design

This pilot study is a mixed-methods design applying both qualitative and quantitative methods. It involved observing dyads and triads in communication 'activities' complemented by structured interviews, questionnaires and field notes. The 'activities' included a 10 minutes caregiver-child free play session within the home environment. This session was conducted so that the experimenter could observe the interaction between the mother, siblings and the child with communication disabilities. Mother-focal child, sibling-focal child and mother-sibling-focal child interactions were videotaped in their homes during these activities. The interventionist asked what activities were preferred, and these were videotaped for eventual analysis. The room was set up to allow the mother and sibling to sit near the child.

6.2.2 Ethics, access and consent

Ethics approval was sought from the Research Ethics Committee of Tizard Centre and the University of Malta research committee, and approval was granted (see Appendix D). See Chapter 5 for a more detailed overview on ethics, access and informed consent.

6.2.3 Participants

Inclusion criteria

Mother participants

i.   Have a child with a developmental disability who presents with delayed or impaired communication.

ii.   Have typically developing children over the age of 7 years.

iii.   They were willing to participate in the study.

Child participants (Focus dyads)

i.   Presented with a developmental disability according to a psychological report conducted within two years of the onset of the study.

ii.   Had a communication disability due to physical, neurological, or cognitive difficulty/impairment, and cannot use speech independently as their primary means of communication unless through aided means

iii.   Had **achieved** at least level III of the Communication Matrix (Rowland, 2004).

Sibling Participants

i.   Typically developing sibling/s over the age of 7 years.

ii.   Are willing to participate in the study.

iii.   If the child with a communication disability had more than one typically developing sibling, the sibling closest to the AAC user's age was asked to participate.

6.2.4 Description of participants

Three focal children were participants in this study, two girls and one boy. Table 25 represents the participant data (children's and young adults' names have been anonymized), including the child's age and gender, the siblings' age and gender, and the child's disability. All three target participants had physical and neurological impairments associated with cerebral palsy. Siblings were typically developing children/young people (Table 27). All the three target children met risk criteria for nonspeaking children, such as no more than ten spoken words (Warren & Brady, 2007), and the congenital risk factors described for children with developmental disabilities who rely on AAC (Beukelman & Mirenda, 2017). The Communication Matrix (Rowland, 2004) was used to gauge their expressive communication skills. The Matrix is suitable for children with severe or multiple disabilities, including sensory, motor and cognitive impairment. All children met Level III: unconventional pre-symbolic behaviour used intentionally to communicate, including body movements, vocalizations, facial expressions, and simple gestures. The families participating in the study were recruited from an NGO providing services for children with developmental disabilities. All children were receiving services through school-based and non-governmental organisations. According to the inclusion criteria, the target families were then identified on a case by case basis since all criteria had to be met. Assessment reports of the children's speech, language, cognitive functions and communication skills assessed by speech and language pathologists and a developmental psychologist were collated. In addition, the researcher had the families' permission to contact the speech and language pathologists for further questions about their receptive and expressive language skills if needed.

Categories	Description
AB	Persons exercising a profession, persons in managerial and administrative grades.
C1	Persons in the higher clerical, clerical supervisory grades; skilled craftsmen and technicians; owners/managers of small businesses.
C2	Skilled manual workers and foremen.
DE	Semi-skilled, unskilled workers, labourers and casual workers; persons whose income is provided by the state.

Table 24: List of categorical social grading of occupations

All three families are made up of four persons, the father, mother and two siblings. All families lived in the southern part of the island, two in apartments and one in a semi-detached villa. All parents completed compulsory education, and both worked 30 to 40 hours per week. Parents held teaching posts, executive positions or were self-employed (Table 26). The work of Vassallo et al., (1994) was referred to in terms of the categorical social grading of occupations (Table 24).

Child's Name	Age	Gender	Child's disability	Communication Matrix Level	Type of AAC system used.
Tina	11	F	Global developmental delay with perinatal asphyxia	Level V concrete symbols	Medium tech aid with auditory scanning
Sara	11	F	Hemimegaloencephaly and developmental delay	Level VI abstract symbols	Tablet PC
Steve	18	M	spastic quadriplegia	Level IV conventional gestures and vocalisations	Tablet PC

Table 25: Pilot study child participant data

Family	Mother's Age group/years	Mother's occupation	Level of Education	Social Grading Category	Type of household	Locality	No of people living in the same house
1	36-45	Executive officer	Completed compulsory education	C1	maisonette	central	4
2	36-45	teacher	degree	AB	maisonette	south	4
3	46 -	homemaker	Certificate/diploma	N/A	Semi-detached villa	central	4

Table 26: Pilot study mother participant data

Family	Sibling's Age	Gender	Learning difficulties	School	Before/after school programme
1	8	F	Nil	Church school	Nil
2	9	F	Nil	State school	Nil
3	20	M	nil	N/A	Nil

Table 27: Pilot study sibling data

6.2.5 Measures and Procedures

In this pilot study, observations of activities with three sessions were made of mothers with the focal child and sibling. In addition, EAS and RAACS scales were completed, and a frequency count of types of directives. Further details, including procedural guidelines, baseline questionnaires and sibling interviews, are available in Appendix B, D and E.

Video data

Data collection was undertaken using video recordings with the mother-focal child, sibling-focal child, mother-sibling and mother-sibling-focal child interactions. The families chose activities because they were considered the main interventionists in the process. Recordings were obtained using a smartphone, later transferred onto a laptop for eventual analysis. Video data ranged from 2.01-11.57 minutes per session. Table 28 indicates the average amount of minutes for each dyad and triad across the three families. Since families were free to choose their activities, it was difficult to balance structured and unstructured activities. Participants engaged in 92% structured activities and 8% unstructured activities.

	Family 1	*Family 2*	*Family 3*
Mother-focal child	6.39	7.46	6.25
Mother-sibling	6.31	4.41	4.18
Sibling-focal child	6.23	8.33	6.56
Mother-focal child-sibling	11.39	7.15	5.25

Table 28: Pilot study average amount of minutes across activities

Activities

When discussing the activities with the families, the researcher left it up to them to decide which activities they would like to choose, so activities captured what the families like to do together, and it would not look like a staged activity. Also, it gave the families more autonomy and control over the activities they wanted to choose. Families are crucial in the intervention process, and therefore, they should determine what constituted a good interaction in their opinion. Activities can be structured or unstructured (open-ended) games and activities in and outside the house. Games help develop practical skills, serve as physical exercise, or perform an educational or psychological role. Table 29 distinguishes the difference between structured and unstructured activities, namely determined by i) whether they occur in a specific time or place, ii) whether they are goal-oriented or spontaneous and self-motivated, iii) whether they are adult or child-led and (iv) whether they follow specific rules or follow a script. Structured activities have a set of rules with specific objectives. Examples of structured activities are board games, card games, puzzles, assembling toys and outdoor games such as football and tennis. When one engages in structured activities, this is usually an efficient way to achieve specific objectives. On the other hand, unstructured activities are open-ended with unlimited possibilities where one develops his/her objectives in the process. Examples of unstructured activities which can be creative and child-led include playing with blocks, colouring, drawing or painting, and playing with toys. It is hypothesized that different types of activities and whether these are structured or unstructured may directly affect the different interactional styles. Therefore, a structural continuum is suggested to place the activities in different parts of the continuum from high structure to low structure.

Structured activity	Unstructured activity
Occurs at a specific time and place	Requires no specific time or place
Specific (follow the rules) and pre-defined goals. Goal-oriented	Self-motivated and spontaneous
specific objectives	Objectives are developed during the activity.
Organized and directed by an adult or elder sibling	Led by children
Children may feel they have failed the adult's expectations if expectations are too high.	Less pressurized as the child feels responsible, more creative and in control.
Examples include board, card, strategy games; dice games, puzzles following directions (e.g. Simon Says), instructions when building Lego themes, outdoor games, watching TV, using technology, listening to music, life skills activities, everyday tasks (sorting laundry, gardening, around the house).	Examples include free play, building blocks creatively, inventing games, water play, inventing songs, free drawing, painting, play dough, dressing up and role play.

Table 29: Difference between structured and unstructured activities
(Adapted from Tassoni & Hucker, 2000)

The table below shows how the structural continuum could be represented for different activities. However, one needs to allow fluidity in setting up these categories due to the different constructs that ultimately determine whether activities should be structured or unstructured or anywhere in between (Table 30).

High structure						Low structure
Board games	Card games	Strategy games	Activities at home		Free play	
Battleship	Uno	Kerplunk	Decorating biscuits/cakes	Gardening	Playdough	Roleplay
Scrabble	Bingo	Jenga	Cooking pancakes	Potting	Art and craft	Playing with dolls/cars
Monopoly	Snap	Greedy Gorilla	Making sandwiches	planting	Lego	Water play
Guess Who			Baking a cake	Table soccer	Blocks	Inventing games
Snakes and ladders			Cooking pasta	Reading a book	Playing musical instruments.	
Rummikub			Making soup	massage		

Table 30: Continuum of activities

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6.3 Video Coding and Analysis

A total of 36 video clips were processed (3 families x 3 activities x 4 dyad/triads). Episodes of maternal-child interactions were coded from 167.3 hours and consisted of structured and unstructured activities in the house. In addition, RAACS and Emotional Availability Scales were used (see Chapter 5).

6.3.1 Directives

As suggested in the literature, narrative accounts have previously revealed that mothers and siblings were directive towards children with developmental disabilities. First, the level of directiveness was taken manually over a ten-minute sample or less (according to the number of minutes filmed) as a frequency count based on the number of directives from the film and verified from the narrative transcriptions. Then the average number of directives per minute was calculated, i.e. mother and focal child, sibling and focal child, and mother, focal child and sibling. The results from this section are meant to complement the results drawn from the narrative transcriptions, and EAS enabling more triangulation of data.

6.4 Inter-rater reliability

Inter-rater reliability data was measured as a statistical measure of inter-rater agreement on 20% (n=7) of the videos of the EAS data and RAACS scores. The independent researcher coded 20% of each transcript for the use and type of directives (see Table 31).

Behaviours	Interobserver Agreement %	Kappa κ
Maternal Responsivity Score	87.06	0.87
Sibling Responsivity Score	85.71	0.71
Maternal EAS Scores	82.3	0.82
Maternal Supportive Behaviour Directives	89.25	0.88
Maternal Intrusive Behaviour Directives	78.44	0.74
Sibling Supportive Behaviour Directives	85.43	0.85
Sibling Intrusive Behaviour Directives	85.6	0.81

Table 31: Inter-observer reliability data for Pilot study (Study 1)

First, the independent researcher determined if the utterance was a directive. Second, if the utterance was a directive, the independent researcher determined whether it was a Supportive or Intrusive directive. Third, the number of agreements and disagreements was calculated, and coding inter-rater reliability was determined (Table 31). More details are available in Chapter 5.

6.4.1 Ecological validity.

Ecological validity is how the participants manifest behaviours during data collection and whether these behaviours can be transferred to natural settings. All studies were carried out in natural settings, i.e. in the participants' homes, and the materials used were familiar to the participants since the families chose them. Furthermore, the researcher discussed the behaviours manifested during data collection with the mothers and which they said were, in fact, typical of the behaviours exhibited daily.

6.5 Results

This section presents an analysis of three families, each with a child with a communication disability. First, the quantitative data is presented, followed by the narrative accounts related to responsivity by the RAACs and the EAS and the quality of attunement and the levels of directiveness. Finally, data from the interviews and questionnaires are also considered concerning the family quality of life issues.

6.5.1 Responsivity

6.5.1.1 RAACS Scores

A mean percentage score was calculated to clarify the degree of responsivity (see table 32 and figure 4) for families 1 to 3 across three different baseline measures.

For family one over three baseline measures, the mother scored 14.5, 15.0 and 14.8 with a mean percentage score of 73%. The sibling scored 10.8, 11.2 and 11.3 with a mean percentage score of 55%. For family two over three baseline measures, the mother scored 15.0, 15.4 and 15.2 with a mean percentage score of 76%. The sibling scored 15.4, 15.0 and 15.5 with a mean percentage score of 76%. For family three over three baseline measures, the mother scored 14.7, 14.0 and 14.8 with a mean percentage score of 72%. The sibling scored 10.0, 10.3 and 10.5 with a mean percentage score of 51%.

Overall RAACS score for families 1-3 (out of 20).			
	Family 1	*Family 2*	*Family 3*
Baseline measure 1			
Mother-focal child	14.5	15.0	14.7
Sibling - focal child	10.8	15.4	10.0
Baseline Measure 2			
Mother-focal child	15.0	15.4	14.0
Sibling – focal child	11.2	15.0	10.3
Baseline Measure 3			
Mother-focal child	14.8	15.2	14.8
Sibling-focal child	11.3	15.5	10.5
Overall means across activities			
Mean mother-focal child score	14.7	15.2	14.5
% mother-focal child score	*73%*	*76%*	*72%*
Mean sibling-focal child score	11.1	15.3	10.2
% sibling-focal child score	*55%*	*76%*	*51%*

Table 32: Overall mean RAACS Scores across activities

Figure 4 shows the total RAACS scores for mother-focal child and sibling-focal child scores across three baseline measures. The graphs also show total responsivity across baseline measures even when the activities were slightly different from each other.
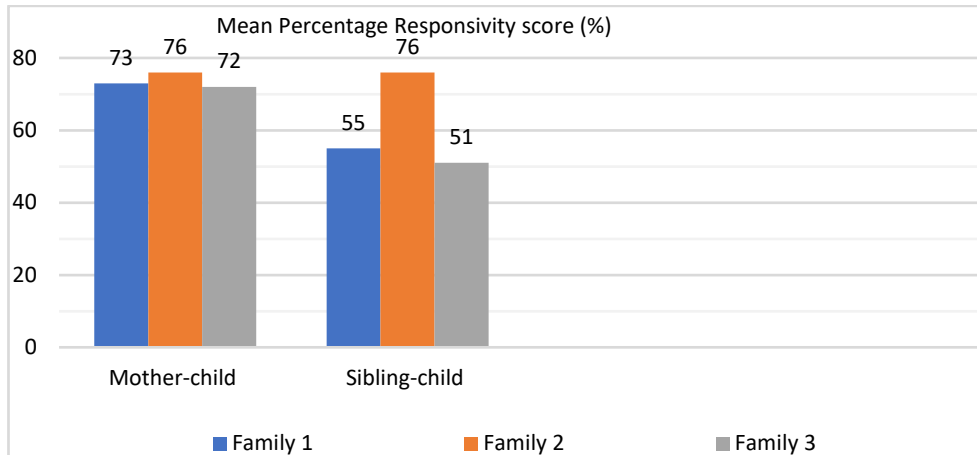
Figure 4: Mean percentage responsivity scores across activities

The overall scores for Family 1 indicate a slightly greater responsivity between the mother and the child than the child and the sibling. Specific statements indicate that scores were higher when the mother gave the child more space to communicate and attend to the child's interests. The mother also could adapt and be engaged with her daughter. She was also more able to adjust to the child's communication level in comparison to the sibling. Family 2 shows that both sibling-focal child and mother-focal child dyads scored an overall 6/6 on the total responsivity, showing that both siblings and mothers scored similarly on statements 8 and 9. This means that both the mother and the sibling show consistency in adjusting, adapting, and engaging with the child. The graph in figure 4 also shows a consistency of responsivity across baseline measures even when the activities were slightly different from each other. There were instances when the sibling and child dyads showed higher responsivity scores than the mother and child dyads. There were more instances of positive interactions when the child with a disability responded warmly to her sister. It was noted that the sibling could attend and confirm the child's communication and give the child space to communicate. She was able to communicate according to the child's focus of interest.

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It could also be that the choice of activities chosen by the siblings was more engaging; for instance, in the role-play games involving Tweetie, the sibling could communicate and expand to the child's communication since the child showed genuine interest and enjoyed the activity. This suggests that noting the type and choice of activity may also influence the interpretation of the results. Family 3 shows that both sibling-focal child and mother-focal child dyads scored an overall 5/6 and 6/6 on the total responsivity across dyads. The graphs also show a consistency of responsivity across baseline measures even when the activities were slightly different from each other (Figure 4). However, although there is a consistency in the scores, it is evident that child-sibling total responsivity scores are considerably lower than the mother-focal child scores. This was evidenced with statements such as "the parent/sibling attends and confirms child's communication" with baseline measures for families typically the mother-focal child and sibling child dyads with similar scores, e.g. a sum of 14 and a mean of 1.4 for families one and two and with lower scores for family 3. This is also evident with the total raw scores for RAACs across all statements. Figure 4 demonstrated that family three sibling-focal child dyads scored relatively lower when compared to the mother-focal child dyads. While this data suggests that the sibling in family 3 tries to adjust to the child's focus of interest by being responsive, the mother reported that the child does not seem interested in his brother. The mother had mentioned this as a limiting factor when discussing communicative interactions with the researcher. She expressed concerns that the child prefers his mother since his brother is not much around in the house. The child's interests seem to affect the interactions between child and sibling, respectively. It seems that this lack of motivation could have a ripple effect on social interactions within the family. This phenomenon was not noted with the other families, but the sibling was considerably older, which may make a difference.

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The RAACs scores also verified this with statements such as "parent attends and confirms child's communication" with baseline measures for families, typically the mother-focal child and sibling child dyads with similar scores (sum of 14 and mean of 1.4 for families one and two with significantly lower scores for family 3. This was evident with the total raw scores for RAACs across all statements. Sibling-focal child dyads for family 3 scored relatively lower when compared to the mother-focal child dyads. All three families seldom used any form of AAC system as addressed in statement number 7 on the scale "the parent/sibling uses AAC". Families 1 and 2 obtained 'nil' scores across dyads and triads, except for family 3 (sum of 12, mean of 1.2; 11 and a mean of 1.1 and 12 and 1.2) respectively between the mother and her son. This is important when comparing this score with that of the other families. Typical scores for this statement was 0.0 for family one and two across all baseline measures.

6.5.2 Emotional Availability

Table 33 indicates that emotional communication is mostly positive and appropriate, with the adult showing pleasure in interacting with the child, suggesting that both mothers and children are emotionally connected. Generally, the adult's facial expressions and tone of voice were pleasant where dyads showed enjoyment with each other. Mothers use statements to and regarding their child and others, rather than sarcastic or critical, in an accepting manner. They are also flexible, varied and creative according to the demands of the situation. However, there were brief moments when one of the mothers expressed some preoccupation, perhaps looking her best for a videotaped session. Some behaviours were inconsistent, and where the scales would establish this as "apparently sensitivity".

Sensitivity

Total Score	7	7	3	3	3	3	3	29	7
	Affect	*Clarity of Perceptions*	*Timing*	*Flexibility*	*Acceptance*	*Amount of Interaction*	*Conflict*	*Total Score*	*Direct score*
1	4	6	3	3	2	3	3	24	6
2	5	6	3	3	3	3	3	26	7
3	5	5	3	3	3	3	3	25	6

Structuring

	Guidance	*Success*	*Amount of Structuring*	*Limit Setting*	*Firm in Pressure*	*(Non)verbal structuring*	*Peer vs Adult*	*Total score*	*Direct score*
1	6	4	3	3	3	3	3	25	4
2	6	6	3	3	3	3	3	27	6
3	6	4	2	3	2	3	3	23	4

Non-intrusiveness

	Following C leads	*Ports of entry*	*Commands*	*Talking*	*Didactic Teaching*	*Interferences*	*Feel Intrusive*	*Total score*	*Direct score*
1	1	1	1	2	2	1	2	10	1
2	4	4	2	3	3	1	2	19	3
3	1	1	2	2	2	1	2	11	3

Non-Hostility

	Lack negativity	*Lack ridiculing*	*Lack threats of separation*	*Loose cool*	*Frightening*	*Silence*	*Themes*	*Total score*	*Direct score*
1	4	3	3	2	2	3	3	20	5
2	5	6	3	3	3	3	3	26	5
3	4	3	3	3	3	3	3	22	5

Child responsiveness

	Affect	*Responsiveness*	*Autonomy*	*Physical Positioning*	*Role-reversal*	*Lack of avoidance*	*Task-oriented*	*Total score*	*Direct score*
1	4	4	1	2	3	2	3	19	4
2	6	6	3	3	3	3	1	25	5
3	5	5	2	2	3	2	2	21	3

Child involvement

	Simple Initiative	*Elaborative Initiative*	*Use of Adult*	*Lack of over-involvement*	*Eye contact*	*Body positioning*	*Verbal involvement*	*Total score*	*Direct score*
1	1	1	1	3	1	2	1	10	4
2	4	4	2	3	2	2	2	19	6
3	2	2	2	3	2	2	1	14	3

Table 33: Mean EAS scores across activities

Through the application of the EA Scales, it was possible to evaluate qualities of the interactions which would not have been apparent through other means. Lower levels of non-intrusiveness were recorded for all families (direct scores: 1-3), where higher levels of non-intrusiveness are optimal (total direct score is 7). Structuring was noted to be moderate to satisfactory for all families (total score 4-6). The findings indicate lower levels of non-intrusiveness with higher structuring. The EA system is designed for viewing higher structuring attempts as positive attempts if the child receives these attempts positively and is likely to contribute to the child's socioemotional development. The scales suggest that mothers tended to over-structure and over-direct. Children were unable to receive such structuring bids due to their internal characteristics. Likewise, higher levels of non-intrusiveness are recommended. The child's level of responsiveness was moderate, which indicates that they were generally positive and emotionally available, even in their affective responsiveness. Mothers were able to read their child's emotional signals and respond to their children appropriately. The child would show some emotional responsiveness and anxiety at this level, implying that the young person depends on the mother. The EA also looked into the observation of the child's initiation of interaction. For example, the child or youth may be responding to the mother when the mother initiates, but he/she may not be involved on his/he own. This is described as somewhat non-optimal in involving behaviours. For example, in family 1, the adult may have attempted to engage the child and received some response, but there was no attempt to elaborate on these exchanges or initiate new ones. In conclusion, none of the three families is seen to be at risk of emotional disconnectedness due to the moderate baseline scores on the sensitivity, structuring and non-hostility dimensions of the EA scales. Mothers were generally emotionally available to their children and sensitive to their needs.

They were able to structure interaction and play to provide support without being overly intrusive or hostile. Individual differences in adaptation are noted for children with severe disabilities, such as the challenge to adapt parenting style, be sensitive and responsive to whatever cues the children offer, structure play and interaction, and have higher non-intrusiveness levels and structuring techniques. The EAS has been specifically designed to assess dyadic interactions between the caregiver (adult) and a child/youth. It has never been used to assess dyadic interactions between siblings and the younger/older child with a disability. A responsive communicative style was noted across dyads and, in some instances, even across triads. Mothers and siblings alike in two families responded contingently and attempted to build on the child's focus of attention even across different contexts while they were in the kitchen, bedroom, or sitting room. It was noted that mothers took the lead and waited while the child responded. They showed emotional warmth by using varying intonations while talking (see appendices). Siblings in families 1 and 2 generally waited and listened actively. They looked for interactions and repeated what their siblings were feeling or doing as if they were trying to clarify what the disabled sibling is trying to communicate. Mothers in the study generally took the lead during triadic interactions, which all happened around the kitchen table. They all assigned them different roles in the kitchen while also involving the elder sibling in the activity. Both mothers and siblings generally showed emotional warmth using varying intonation while they are talking. It was evident that mothers exerted an effort to involve both siblings equally. However, variables such as physical disability, sensory issues and the child's attention and interest in the tasks could have played a part in having the children participate more functionally in the interactions. A high level of dependency and a lower level of engagement was evident, especially in Family 1.

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In both dyadic and triadic interactions, highly asymmetric interactions in all families were evident following broad transcriptions. This asymmetry is more dominant when families present with more complex physical and sensorial disabilities. For instance, in family 1, one could notice the shift in attention between the mother and the sibling with more attention for the sibling rather than the child with a disability. The mother provided a higher level of support and used some directives like "press the switch" "come on". In family 2, while there was some evidence of asymmetry in interactions, the mother tried to tune in to the other children. Asymmetric interactions were also evident in Family 3 between the mother, sibling and child. This suggests that when the child presents with physical and intellectual disabilities and sensory impairment, the level of interaction is highly asymmetric. These families provided a good number of **turns**, taking many turns between the mother and sibling and allowing lesser opportunities for communication. When the child did not answer, the mother repeated the same question and kept probing for more. For example, in Family 1, the child takes more than 3.5 minutes to respond, with the sibling getting bored and started to fidget. It was noted that mothers were providing good role models to the siblings as well. In some instances, siblings were acting as good role models as their mothers. For example, mothers typically showed them how to interact with the disabled sibling and provide attuned moments of interactions (e.g. during massage activities and joint cooking activities).

6.5.3 Directives

This section addresses the levels of directiveness determined by analysing the narrative accounts and a frequency count for the two main types of directives (supportive and intrusive). Previous research confirmed that separating these two types of directives is critical since they serve different functions (Pine, 1994; Flynn & Masur, 2007).

The narrative transcriptions indicated that mothers generally provided higher physical prompts when children were physically more compromised and used several directives. For instance, the mother in Family 1 had to physically support the child by turning the pages and handling the utensils during cooking activities. This was also evident with the other families, where the child could still not participate actively during the sessions although they had less physically challenged children. This could have reduced interaction levels since family members were focusing on providing physical support. It was also evident that mothers portrayed a directive style rather than contingent responsivity where the child presented with complex physical and multiple disabilities suggesting learnt dependency.

Narrative transcriptions revealed common phrases included (family 1) "*head up*", "*Come on Tina*", "*Let's listen*", "*let's laugh*", "*Come on Sara*", (family 2) "*Ejj Ejja*" (come on, come on, come on), "*ħa, ħa, ħa aqbadhom*" (come on pick them up), "*għollieha l-ħobża*" (pull out the bread), "*niżżilha*" (put it down), "*oħrog l-ħobż*"(put the bread out), "*dellikulu naqa'*" (spread it), (family 3) "*u aqtagħlhom naqa' zokk*" (and cut their stem), "*Agħmel kollox*" (do everything), "*Ejja Steve hit the ball*", "*Ejja hit it forward*", "*Ejja Steve turn it round*", "*Ejj' ilgħab*" (come on play), "*Ejja dawwar*", "*oħrog t-tazzi*" (take out the plates), "*Ejja, mur ġibli l-pala*" (go and get me the spade), "*Isa*" (come on). Most of these examples are all supportive directives since they are all supporting an ongoing activity. For instance, '*let's play*' and '*let's laugh*' are typical examples of supportive directive behaviours. Table 34 below provides a frequency count of the two types of directives (supportive, intrusive directives) based on mother-focal child dyads and sibling and focal child dyads across all three activities. The level of maternal directiveness during mother-focal child-sibling interactions was also noted.

Category	Family 1			Family 2			Family 3		
Behaviour	*M+C*	*S+C*	*M+C+S*	*M+C*	*S+C*	*M+C+S*	*M+C*	*S+C*	*M+C+S*
Supportive	8	1	10	5	18	5	2	10	1
Intrusive	0	0	0	0	0	0	0	0	0

Table 34: Mean Directive utterances across activities

The frequency count demonstrated that types of directives consisted exclusively of supportive behavioural directives for the mother-focal child, sibling-focal child and mother-sibling-focal child triads. Interestingly, maternal supportive directives remained the same across dyads and triads for the three families, suggesting that maternal interactional styles and supportive directives remained unchanged. For families 2 and 3, the level of supportive behaviour directives between the sibling and the child may have been due to the higher demand in the task at hand. These activities allowed more instructional directives as well as directives to support an ongoing activity. For family 1, supporting behaviour directives was higher due to prompts and encouragement addressing physical posture and positioning.

6.6 Summary of Findings

The responsivity scores demonstrated that both mothers and siblings were emotionally connected with the child with a disability with an appropriate responsive style and emotional warmth in all three families. Both the mothers and siblings were seeking pleasure in the interaction. This was also evidenced from the broad narrative transcriptions and accounts where a responsive communicative style was evident in mother-focal child and mother-sibling-focal child dyads and triads. Both mothers and siblings responded contingently and attempted to build on the child's attention in different contexts and use different activities. It was noted that mothers took the lead and waited while the child responded.

Mothers generally showed emotional warmth by using varying intonations while talking and demonstrated emotional connectedness. The EAS scales and the results from the frequency of directives confirmed that the mothers presented with numerous directives across different activities and games, but these were supportive rather than intrusive. This was accompanied by higher physical and verbal prompting from the mothers. The children with communication disabilities presented with higher levels of dependency on their mothers. The EAS scales tended to be directive and use structure. From the narrative accounts and the EAS scales, mothers seemed to be overcontrolling with their children, possibly unconsciously perceiving these opportunities for interaction as a learning experience for their children. During activities together, the focal children were prompted to name objects to retrieve naming words, turning them into an instructional activity rather than functional communicative interactions. They perceive themselves as tutors and even mentors. However, it does not mean that the child remained passive during interactions because the mothers were overprotective or intrusive. The types of directives taken from the frequency counts for all dyads and triads demonstrated that the types of directives consisted predominantly of supportive behavioural directives. The frequency counts confirm that maternal interactional styles and supportive directives remain unchanged, suggesting that maternal interactional styles remained unchanged irrespective of whether mothers were involved in dyadic or triadic interactions.

6.7 Interactive style and choice of activity

Families chose the activities they wanted to play and preferred highly structured activities, but some activities still allowed for free conversations suggesting a structural continuum of dynamic activities.

Such activities were cooperative and interactive (e.g. making pancakes) compared to games that are typically highly scripted (e.g. Uno, Snap). Only one family chose to play Uno, but this was between mother and sibling. These games aim to establish a winner and the winner "takes it all" model. Families chose structured activities in the kitchen; others used the child's bedroom to do some reading sessions and massages. One family also used the child's bedroom to play on the computer and read books. Another family chose to go to the basement where the soccer table was, or the courtyard to play football. Interestingly, all families had activities around the kitchen table with highly structured but cooperative activities, such as making sandwiches, decorating biscuits, preparing smoothies, cooking pasta, or making pancakes. There seemed to be a particular preference for mothers, siblings and children to choose a cooking activity, possibly because more role release and turn-taking was involved. What seemed problematic was that some of the kitchen activities required complex motor planning which was undermined by the children's physical and sensory challenges. All children found it physically difficult to manipulate pots and pans. Also, kitchen activities require fine motor skills like stirring the batter, pouring it in the pan, spreading butter on the bread, and putting ingredients in the blender. Possibly due to this, mothers presented with supportive directives and higher physical and verbal prompts. The children with communication disabilities presented with a high level of dependency on their mothers.

6.8 General Discussion

This pilot study examined mothers' behaviours towards the focal child and how siblings interact with their disabled brother/sister. Additionally, the study examined responsive interaction styles focused on attunement principles, specifically attentive, encouraging initiatives, receiving initiatives, and developing attuned interactions.

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Finally, the study looked specifically at the patterns of behaviour observable in mother-sibling-focal child interactions and the similarities and differences in these behaviours between and across families. This study showed evidence of the use of both verbal and non-verbal communicative and emotional behaviours. This was evidenced by the use of gestures and signs, facial expressions, vocalizations, tone of voice, use of speech and eye gaze and friendly physical postures. There was synchrony encompassing both the mother's and the child's responsivity and emotional capacity to respond to each other. Mothers showed they had noticed their child's initiatives shown by body language and being friendly and playful. They returned eye contact while smiling and nodding in response to music, playful songs, and role-play activities. Siblings likewise showed that they had heard and responded to their siblings' initiatives while playing together and initiating vocalisations and single words, especially in families 2 and 3. The mother led the siblings to give them specific roles in the kitchen during triadic activities, but both mothers and siblings were friendly and playful. They returned eye contact, smiled and nodded in response to the activities at hand. The literature does delineate that parents of children with communication disabilities tend to become less responsive and more directive due to missed opportunities to develop interaction (Pennington et al., 2004; Pennington & McConachie, 1999). Other studies show that parents introduce most topics in conversation, ask closed questions, and ask for already known information (Ferm et al., 2011; Pennington et al., 2004). Breakdowns in these early interaction patterns between the child with a disability and the parent and the development of a less responsive parental communication style may restrict social participation and the development of necessary social, cognitive, and communicative skills (Rasmussen et al., 2011; Delarosa et al., 2012; Landry et al., 1997).

Developing attuned interactions were evident within the mother-focal child and sibling-focal child and mother-focal child-sibling triads. This was also similar across families. For instance, mothers were looking for opportune moments where they could receive feedback during different activities. They could respond as soon as the child interacted while they waited attentively. There was an element of cooperation from the mothers towards their children, which was also evident between the siblings across families. There seems to be an association between engagement levels of mother-focal child, sibling dyads, respectively, as indicated in the responsivity scales (RAACS) and the narrative accounts. In mimicking their parents, typically developing siblings seem to be taking over a dominant role, providing more communicative turns, using more assertives and directives and predominantly taking over the number of turns as evidenced in the narrative transcriptions and the frequency of directives. However, siblings also offered participation opportunities when the parents presented with higher engagement and participation opportunities (e.g. involving their sibling in cooking activities, joint activities during leisure play, gardening activities). It was noted that the families rarely use AAC with their children who have communication disabilities in daily interactions. International studies indicate that if AAC is introduced in the homes, parental responsivity can be positively improved. Ferm et al., (2011) reported that aided language stimulation helped parents tune with the child. Jonsson et al.; (2011) noted that parents used a wider range of communicative functions and expanded on their children's utterances after the introduction of aided language stimulation. Thunberg et al., (2011) noted more responsive interactions between the parent and the child when a speech generated device was introduced in different contexts at home. The RAACS specifically indicated limited use of medium or high-tech aids during dyadic and triadic interactions.

Notably, there were only two instances when the mother used a low-tech aid (an italk2) in triadic interactions during storytelling. The device was used to elicit questions and answers following a listening comprehension. Thus the AAC system was used specifically within an educational context rather than to elicit functional communication and naturalistic social interactions. In the other instance, the mother encouraged her son to use a tablet PC (Sahara tablet PC with The Grid 2) to indicate what ingredients he needed to put in his sandwich. Nevertheless, he was just pressing the screen just for the cause and effect of it. The device had a very low sound, and thus the child could not gain immediate auditory feedback from the device. Thus, the parent could not expand on the child's utterances due to the low auditory feedback, losing the scope of the use of the system. Neither was she checking on the screen to see what the child had pressed. Instead, her attention was more drawn towards the activity at hand and provided some conversation starters to her son.

The emotional availability indicated higher levels of directiveness with lower levels of non-intrusiveness. Structuring and non-intrusiveness scores are both influenced by the mother's and child's reactions. The mother can structure within the zone of proximal development. However, she cannot do so without considering the child's cues and attending to them. Adult intrusiveness can be very complex because the mother can consciously or unconsciously control her child. The mother may be perceiving herself as the tutor or the mentor, and her role is for the child to learn new skills, which are mainly educational. Biringen et al., (2014) suggest that Structuring and Nonintrusiveness should address maternal directiveness and learned helplessness. One would argue that maternal directiveness should be seen as a positive characteristic to support scaffolding and complement structuring within the zone of proximal development. Directiveness, which is intrusive for a typically developing child, may benefit a child with severe disabilities.

Likewise, maternal directiveness is seen as negative as it is perceived as being intrusive. Perhaps if mothers use a more directive style without being too intrusive, this might support the young child's growth and development with opportunities for the child to direct himself or herself. Children with developmental disabilities tend to be less active and responsive and avert their gaze and bodies more during interactions than typically developing children (Flynn & Masur, 2007). To date, it is unclear whether redirecting the behaviour or attention of children with developmental disabilities would positively or negatively influence their development. Redirecting an unfocused child to the task at hand may increase productive play and encourage task mastery. Alternatively, providing too many directives for a child with developmental disabilities might decrease the child's ability to develop independent skills and self-efficacy. This study has indicated that in mother-focal child and child-sibling dyads and mother-focal child-sibling triads, both mothers and siblings provide more supportive directive utterances rather than intrusive behavioural or attentional utterances. This suggests that parents and siblings are using these behavioural directives to support and direct the child in the course of the activity itself in which they are already engaged. Similar studies (e.g. Flynn & Masur, 2007) have also indicated increases in frequencies of maternal responsiveness and supportive directive utterances during play activities. These directives followed the child's focus of attention rather than utterances to redirect the child's attention or behaviour. This finding highlights the importance of making clear distinctions between supportive and intrusive behaviour directiveness and, more importantly, reconceptualizing the idea of directiveness. Families chose various activities and games, which were mainly highly structured. There were very few unstructured activities or games involving child-led activities. Games were highly scripted and associated with highly predictable speech acts and forms (Uno, Bingo, Snap).

In such circumstances, the language was more prescriptive, with the activities being more goal-directed according to a set of rules. However, it does not mean that all structured activities are necessarily prescriptive and with highly scripted language. It is to be noted that there were instances when structured activities allowed for more free conversations and flexibility, especially when there were no particular set rules that players had to focus on. Seemingly, the quality of interactions and the interactional style varied according to the different activities and contexts, as evidenced by the broad transcriptions and narrative accounts. Some of the games expected the participants to be more focused on the structure of the game, and their attention was more focused on the rules of the game. However, one could still notice the non-verbal behaviours and dynamics during the games, such as eye contact, smiles, and exaggerated facial expressions. Notably, the families used buzz words or scripted words expected to be used as part of the game's rules. Most of the time, the games were reduced to minimal verbal exchanges and fewer conversational opportunities. While this could seem a disadvantage for families, it does not provide dynamic interactions since they are highly scripted. These highly scripted games in themselves provide ready-made phrases such as "it's my turn; give me five; change colour to -----; snap, uno". These phrases can then be pre-recorded on the child's communication device, such as a big mack, and these can, in turn, be introduced during sessions. With the proper support at the intervention phase, families would implement family-led interventions to instil better interactions. This could take visual scripts or pictorial examples of phrases or sentences that could be used as a simple reminder to get support during an activity or suggestions to initiate a conversation. This could help children to increase their spoken language and their vocabulary using socially appropriate phrases. So these could be introduced by choosing a target activity such as a game which the student enjoys.

It is suggested that similar activity is observed for typically developing children, so the vocabulary and typical phrases used during the activity are noted. So conversations such as the comments used, the initiations used, the questions they ask, and the topics are transcribed verbatim. So while playing a board game, the learning objective could be asking for a turn or commenting. The learning objective could be social greetings, offering a toy, asking for help, and commenting during constructive play. While preparing a snack or a meal, the learning objective could be commenting, offering to help, responding to comments or questions and responding to past and present events. In conclusion, therefore, when looking within and across families for the patterns of behaviour, it is suggested that maternal responsivity is dependent on: i) the nature of the activities, ii) the context, iii) the persons involved and their level of interest and iv) the child's physical, cognitive status and level of interest. One would also suggest that the interplay between these variables may affect the quality of interactions between the mother, sibling and the child. For example, when it comes to sibling interactions, they mimic their mothers when they respond and interact with their disabled brother or sister. They also tend to establish more caregiving roles and imitate their mothers by using more supportive behavioural directives rather than intrusive behavioural directives during everyday activities.

6.9 Methodological adequacy

This section examines the reliability, validity and replicability of the methods used to capture the responsive styles of behaviour. The research tools using qualitative and quantitative methods have allowed between-method triangulation as a contrasting method of gathering data. This was made possible through structured interviews, questionnaires, field notes and 10-minute video recordings of prescribed activities.

The use of methodological triangulation as a contrasting method of gathering data may help increase the study's validity. However, the purpose of triangulation was not to cross-validate the data but rather to capture different dimensions of the same phenomenon. Observations and coding were done using the principles of attunement developed through the Video Interaction Guidance, the methodology described in the previous chapter. This coding poses a limitation, possibly since directiveness is not included in attunement principles and was not coded. The reader had to read between the lines to understand whether minimal responsivity automatically meant more directiveness, which is not necessarily the case. Every effort was taken to control the variables in the studies; however, it did not allow for control over other variables. These included individual differences between participants and the different activities chosen by the families, whether these were structured or unstructured. Families may sustain good interactions over short periods and with an observer implies an element of social desirability bias. This study does not indicate what may happen when the observer is not present or if the behaviours are exhibited over longer periods.

6.9.1 Analytical tools

RAACS has been used to code behaviours following the videoing. More work needs to be developed to validate the effectiveness and usefulness of this instrument in qualitative studies. There are no further studies that establish RAACS as a tool to evaluate the effectiveness of this instrument as part of a single case study. This scale may not be appropriate in gauging the effects or changes in behaviour is due solely to the intervention itself once the main study is conducted. Furthermore, RAACS has been developed to look into parent responsivity only and does not consider the child's behaviour in the process. The RAACS has been tentatively applied for sibling dyads, and the nine statements are easily adapted within the sibling-focal child context.

However, the scale has not been assessed for validity and reliability, and therefore results are indicative and have to be treated with caution. The Emotional Availability Scales may be used to assess relationships between mothers and their children and the specific EA dimensions. From an ecological perspective, the use of the EA Scales may need to be analysed within the Maltese context. One should note that the EAS has been specifically designed to assess dyadic interactions between the caregiver (adult) and a child/youth. It has not been validated to assess the dyadic interactions between siblings and the disabled child. See Table 35 for applications of outcomes of the pilot study.

Pilot Study	*Outcomes for the Main Study*
The percentage level of directiveness was based on a 1-minute random sample based on different activities.	The percentage level of directiveness may be over 10 minutes of the sample and ideally based on the same activities.
Maternal and sibling responsivity were measured quantitatively using the RAACS scale only, and the scores were compared within and between family dyads and triads.	The Emotional Availability Scale (EAS) may be used to consider all aspects of dyadic and triadic interactions.
Inter-rater reliability for RAACS was not checked.	Inter-rater reliability for RAACS will be checked for 30% of the sample.
Inter-rater reliability for EA was not checked.	Inter-rater reliability will be obtained by a second coder on 30% of the video recordings randomly selected from pre-post and follow up visits. Inter-rater reliability will be obtained on all six dimensions of the scale (r>.80)
The time allocated for the questionnaires, interviews and video taking activities was around 2 hours.	Due to the length of the questionnaires, interviews and the video taking activities, more time needs to be allocated to these sessions. A minimum of 4 hours is needed for each visit. This needs to include looking into psychological reports, which was not calculated in the original pilot study.
Research questions do not address the intervention stage.	A research question addressing the intervention and post-intervention stage will be included in the main study.

Table 35: Applications of the outcomes of the pilot study

6.10 Limitations and implications for future research.

This present pilot study is limited to a very small sample of participants, and the results are to be treated with caution. The generalization of the results is also limited to the sample itself due to the heterogeneity of the sample. Children with communication disabilities also present with additional physical, sensory, cognitive and language difficulties—the children presented with various impairments within this sample and were highly homogeneous.

A second limitation is the limited standardization of activity sampling lengths and a wide range of activities. The researcher deliberately encouraged spontaneous and naturally occurring interactions with activities chosen and led by the families. As a result, it was difficult to standardize the type and amount of activities across families, and activity samples per family averaged 6.7 minutes per sample, a sample lesser than other parent responsivity research (Haebig et al., 2013). In addition, the study did not control for the type of activities, whether they are structured and goal-directed or whether they are unstructured and non-goal directed. It may be likely that mothers and siblings may show differing amounts of responsivity and directiveness, increasing opportunities for more unstructured activities (e.g. social play). However, implementing standardized directions for families regarding types of activities will defeat the purpose of allowing autonomous mother-focal child and sibling activities. Additional research may be extended by contrasting different activities (structured or unstructured) to determine whether structured activities encourage more directive interactive styles. It would also be interesting to examine whether responsivity and directiveness are associated with the children's motoric, cognitive and language skills.

6.11 Conclusion

The results from the pilot study suggest that a responsive communicative style was present across dyads and, in some instances, even across triads. Mothers and siblings alike in two families responded contingently and attempted to build on the child's focus of attention even across different contents. There does not seem to be any specific pattern as to why in particular families, the siblings were more responsive than others and, in some instances, even as much as their mother. However, various intrinsic factors may determine the quality of interaction and a responsive communicative style.

In one of the families, the younger sibling seemed to have the innate ability and unique disposition and warmth to respond and expand on her sister's communicative intent. The RAACS scale indicated that mothers seemed to be reluctant to use AAC with their children. One of the reasons may be the lack of professional support in implementing the system in the home environment and empowering parents to be more proactive in the intervention process. Some parents find it more convenient and easier to interpret their child's communicative needs rather than set up their AAC system for them. Others might find the use of the AAC system to be too invasive or alien for them. They might also need more support to understand the benefits of using AAC systems in daily interactions.

6.11.1 Implications for the Main Study

This pilot project addresses some of the main issues already highlighted in the literature. The main study now hopes to address specific research questions, including the effect of using a more directive style with lower levels of intrusiveness for increased social interactions. While the focus is on the level and quality of responsivity, the EAS scale is a more defined scale to examine how the level of directiveness and non-intrusiveness function within the context of the activities.

Despite the body of research depicting maternal directiveness as a negative characteristic, maternal directiveness may be a positive characteristic supporting the child's zone of proximal development. It is also suggested that the mothers use a directive style but without being overly intrusive. To establish whether maternal directiveness is typical for Maltese families of children with communication disabilities, one needs to look at what patterns of behaviour/responsivity are observable in mother-sibling-focal child interactions in typically developing families.

Secondly, similarities and differences in these behaviours between and within TD families (Chapter 7) and families of children with communication disabilities (Chapter 8) need to be noted. The proposed studies may shed light on whether the nature of the activities may affect the patterns of responsivity. This is crucial when looking at the role of specific behaviours, especially maternal directiveness and the potential role of directiveness within the context of the activities and the nature of the disability. It is difficult to have similar family structures or constellation variables such as gender, birth order, and spacing of siblings, and this poses a challenge across the different study phases.

CHAPTER 7: A STUDY OF THE LEVELS OF RESPONSIVITY AND DIRECTIVENESS BETWEEN MOTHERS AND TYPICALLY DEVELOPING CHILDREN (STUDY 2A)

7.1 Introduction

Results from the pilot study suggested the need to look at typically developing Maltese families to understand the patterns of behaviours, namely responsivity and directiveness and how mothers and siblings respond during everyday interactions at home. This study was necessary to understand these patterns due to limited research in the Maltese context. In addition, it was also indicated that another study should be conducted to draw similarities and differences with families of children with communication disabilities.

7.2 Aims of the study

The current study explores how the levels of responsivity of mothers, siblings and children who are typically developing manifest themselves across different activities and contexts. The following research questions are proposed.

i) What are the patterns of behaviour in mother-sibling-focal child interactions during everyday activities?

ii) How do maternal patterns of responsivity and directiveness manifest themselves with siblings during everyday interactions?

iii) How do siblings interact with each other during everyday activities?

7.3 Methodology

7.3.1 Design

This study was a mixed-methods design applying both qualitative and quantitative methods.

It involved observing dyads and triads in communication activities complemented by structured interviews, questionnaires and field notes. The activities included a 10 minutes caregiver-child free play session within the home environment. This session was conducted so that the experimenter could observe interactions between the mother, siblings and the child.

7.3.2 Ethics

Ethics approval was sought from the Research Ethics Committee of Tizard Centre and the University of Malta research committee, and approval was granted. See Chapter 5 for a more detailed overview on ethics, access and informed consent.

7.3.3 Participants

7.3.3.1 Description of participants

There were six families involved; twelve children were participants in this study, four girls and eight boys (see table 36). One sibling in each family was termed the focal child. Only two families have same-sex siblings participating in the study, both with three-child families.

Child's Name[4]		Age	Gender	Sibling's Age	Gender	Age difference (years)	No of Siblings
1	Kai	8	M	16	F	8	2
2	Albert	12	M	15	M	3	3
3	Lorenz	8	M	11	F	3	2
4	Mark	10	M	7	M	3	3
5	Yvette	8	F	6	M	2	2
6	Simon	7	M	13	F	6	2

Table 36: Study 2a-child participant data

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[4] Names have been changed

The other four families were made up of mixed-sex dyads with two-child families (see Table 36). Where there were three children in the family, the two closest in age were chosen. There was an age difference of 2 to 8 years (mean=4; median=3; range 6) between the siblings. The families participating in the study were recruited from personal contact. The families lived in the central and southern parts of the island. All parents completed compulsory education, and all worked 30 to 40 hours per week. Mothers held teaching posts, executive positions or were learning support educators (see Table 37).

Family	Mother's Age/years	Mother's occupation	Level of Education	Social Grading	Type of household	Locality	Number of people living in the same house
1	36-45	Executive manager	Completed compulsory education	C1	maisonette	central	4
2	36-45	teacher	degree	AB	Terraced house	south	5
3	36-45	Learning support educator	diploma	AB	maisonette	central	4
4	36-45	teacher	degree	AB	apartment	central	5
5	25-35	Learning support educator	diploma	AB	maisonette	central	4
6	36-45	University lecturer	Post graduate qualification	AB	townhouse	south	4

Table 37: Study 2a-Family participant data

Criteria for selection of participants:

Child participants:

   i.   no history of communication disabilities,

   ii.   age-appropriate receptive, expressive language skills and cognitive capabilities,

Mother Participants:

   i.   Mothers were matched by chronological age wherever possible. As far as possible, the baseline comparison should resemble the focus triads concerning the home environment and social status.

Sibling participants:

   i.   typically developing sibling/s over the age of 7 years.

   ii.   no history of communication disabilities,

   iii.   age-appropriate receptive, expressive language skills and cognitive capabilities,

7.4 Measures

Observations of activities with three sessions each were made of mothers and siblings. In addition, the EAS scale was completed as well as a frequency count of types of directives. Narrative transcriptions and video observations were also used (see appendix B for detailed profiles about these families). Further details, including procedural guidelines, baseline questionnaires and sibling interviews, are available in Appendix D and E.

7.5 Procedures

Data collection was undertaken using a total of 72 video recordings of the mother-focal child, sibling-focal child, mother-sibling and mother-sibling-focal child interactions. Recordings were obtained using a Samsung Galaxy smartphone, later transferred on a laptop for eventual analysis. Video data ranged from 4.37-13.20 minutes per session. Table 38 indicates the average amount of minutes for each dyad and triad across the six families.

	Family 1	Family 2	Family 3	Family 4	Family 5	Family 6
Mother-target child	10.17	8.00	10.28	5.29	5.22	11.23
Mother-sibling	11.26	5.44	10.06	4.51	5.35	9.09
Sibling-target child	13.20	6.50	11.24	6.59	5.02	10.14
Mother-target child-sibling	10.57	8.08	10.04	7.49	4.37	10.31

Table 38: Study 2a-Average amount of minutes across activities

As in the pilot study, when discussing the activities with the families, the researcher left it up to them to decide which activities they would like to choose, so activities capture what the families like to do together. Thus, it gave the families more autonomy and control over the activities they wanted to choose.

7.5.1 Coding and Analysis

Episodes of maternal-child interactions were coded from a total of 199.45 hours.

7.5.1.1 Attunement evidence from narrative accounts.

A thematic analysis approach was used to analyse these qualitative data which involved identifying themes. Thematic coding and analysis followed the identifying themes of the principles of attunement through video interaction guidance.

7.5.1.2 Directives

This pattern of behaviour was explored by looking at all the directives within the broad descriptive analysis and videos. In addition, the average number of directives per minute was taken from the videos for each dyad and triad, i.e. mother, focal child, sibling-focal child, and mother. The results from this section are meant to complement the results drawn from the narrative transcriptions, and EAS enabling more triangulation of data.

7.5.2 Inter-rater and intra-rater reliability

Inter-rater reliability data was measured as a statistical measure of inter-rater agreement on 20% (n=14) of the videos of the EAS data, RAACS scores and types of directives (Table 39). More details are available in Chapter 5.

Behaviours	Interobserver Agreement IOA %	Kappa κ
Maternal EAS Scores	88.8	0.77
Maternal Supportive Behaviour Directives	84.6	0.76
Maternal Intrusive Behaviour Directives	85.2	0.86
Sibling Supportive Behaviour Directives	87.3	0.82
Sibling Intrusive Behaviour Directives	78.4	0.74

Table 39: Inter-observer reliability data for Study 2a

7.5.3 Ecological validity

All studies were carried out in the participants' homes, and the materials used were familiar to the participants since the families chose them. The behaviours manifested during data collection were discussed with the mothers to confirm that these behaviours were typical of daily behaviours.

7.6 Results

7.6.1 Interactive style and choice of activity

Most of the interactions happened around the kitchen table, with four of the families opted for cooking activities, two opted for decorating pebbles, and the other family opted for a strategy game. Mother-focal child and sibling-focal child dyads generally chose highly structured activities, although activities still allowed for free conversations, suggesting a dynamic structural continuum of activities that allowed fluidity.

Family		Structured activities				Unstructured
		Board games	Card games	Strategy game	Activities in the house	Free play
Family 1	Mum – child 1[5]			Kerplunk		
	Mum-sibling		Uno	Rummikub		
	Child1 – sibling		Uno			
	Mum-child1-sibling				Making pancakes	
Family 2	Mum – child 1				Decorating pots with seashells	
	Mum-sibling				gardening	
	Child1 – sibling				Making appetizers	
	Mum-child1-sibling				Making a jelly cake	
Family 3	Mum – child 1					Water play using plastic pipes
	Mum-sibling				gardening	
	Child1 – sibling					Inventing obstacle games
	Mum-child1-sibling				Preparing a fruit salad	
Family 4	Mum – child 1				Feeding the birds	
	Mum-sibling				Making a sandwich toast	
	Child1 – sibling		Snap			
	Mum-child1-sibling				Making soup	
Family 5	Mum – child 1				Making fruit kebabs	
	Mum-sibling				Decorating fingernails	
	Child1 – sibling				Watering plants	
	Mum-child1-sibling				Decorating pebbles	
Family 6	Mum – child 1					Playdough
	Mum-sibling		Uno			
	Child1 – sibling			O-X-O Tic-tac-toe		
	Mum-child1-sibling			monopoly		

Table 40: Study 2a-Choice of Activities

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[5] Child 1 is the younger child.

Such activities were cooperative and interactive (e.g. making pancakes, making soup, decorating pebbles) compared to games that are typically highly scripted (e.g. Uno, Snap). The scope of these games was to establish a winner and the winner "takes it all" model. (see Table 40). The games chosen by the families were board games involving counters or pieces moved or placed on a board according to a set of rules. Rules were simple like Tic-tac-toe (OXO) to others more complex and thematic such as Monopoly. These complex games were role-playing games where the board serves to help visualize the game scenario.

7.6.2 Emotional Availability

The EAS established that the emotional communication was mostly positive and appropriate, with the mother expressing pleasure in interacting with the focal child, suggesting that both the mothers and their children were emotionally connected. Generally, the adult's facial expressions and tone of voice were pleasant and with dyads showing enjoyment with each other. Mothers used statements to and regarding their child and others in an accepting manner, and they were also flexible, varied and creative according to the demands of the situation.

High levels of sensitivity and structuring were obtained except for the amount of interaction in the sensitivity subscale for family 6 (see Table 41). The mother exhibited a lower score on the amount of interaction (score: 1), showing apparent sensitivity, which was well-meaning but rather mechanical. Likewise, affect was bland and neutral most of the time (score:5). Higher levels of non-intrusiveness were evident for all families (total direct score is 6 to 7).

Structuring was noted to be suitable for all families (direct score 6-7). High levels of non-hostility were also recorded except for family six, where the mother scored 1 point on silence in the non-hostility subscale (direct score: 5), portraying a business-like, even longsuffering approach.

This score indicated that the mother talked so little that the tone of interaction seemed deadened. The child's level of responsiveness was moderate to high for most of the children, which indicates that they were generally positive and emotionally available, even in their affective responsiveness, except for Simon, who lacked responsiveness (score 2). Child involvement was high for all children except Simon, who scored 3 and 1 point respectively on simple and elaborative initiatives. Simon did not display clear signs of pleasure in interaction or an eagerness or willingness to engage with the adult, possibly over-reliance, which may not lead to optimal emotion regulation. Simon was not likely to respond at that time since he was focused on his task and seemed oblivious when his mother was initiating.

In conclusion, all six families demonstrated emotional attunement due to the moderate to high baseline scores on the sensitivity, structuring and non-hostility dimensions of the EA scales. Mothers were generally emotionally available to their children and sensitive to their needs. They were able to structure interaction and play to provide support without being overly intrusive or hostile. Notably, family 6 confirms how the child's behaviour affects the interaction between the mother and the child, specifically in interaction and silence.

Sensitivity Score

	Affect	Clarity of Perceptions	Timing	Flexibility	Acceptance	Amount of Interaction	Conflict	Total score	Direct score
Total Score	**7**	**7**	**3**	**3**	**3**	**3**	**3**	**29**	**7**
1	7	7	3	3	3	3	3	29	7
2	7	7	3	3	3	3	3	29	7
3	7	7	3	3	3	3	3	29	7
4	7	7	3	3	3	3	3	29	7
5	7	7	3	3	3	3	3	29	7
6	5	6	3	2	3	1	3	23	4

Structuring Score

	Guidance	Success	Amount of Structuring	Limit Setting	Firm in Pressure	(Non)verbal structuring	Peer vs. Adult	Total score	Direct score
1	7	7	3	3	3	3	3	29	7
2	7	7	3	3	3	3	3	29	7
3	7	7	3	3	3	3	3	29	7
4	7	7	3	3	3	3	3	29	7
5	7	7	3	3	3	3	3	29	7
6	7	7	3	3	3	3	3	29	6

NonInstrusiveness Score

	Following C leads	Ports of entry	Commands	Talking	Didactic Teaching	Interferences	Feel Intrusive	Total score	Direct score
1	7	5	2	2	3	2	3	24	7
2	6	5	2	2	3	2	3	23	7
3	7	6	3	3	3	3	3	28	7
4	7	5	2	2	3	2	3	24	7
5	7	6	3	3	3	3	3	28	7
6	5	6	3	3	3	3	3	26	6

Non-hostility Score

	Lack negativity	Lack ridiculing	Lack threats of separation	Loose cool	Frightening	Silence	Themes	Total score	Direct score
1	6	6	3	2	3	3	3	26	7
2	6	6	3	2	3	3	3	26	7
3	7	7	3	3	3	3	3	29	7
4	6	6	3	2	3	3	3	26	7
5	7	7	3	3	3	3	3	29	7
6	6	6	3	3	3	1	3	25	5

Child Responsiveness Score									
	Affect	*Responsive ness*	*Autonomy*	*Physical Positioning*	*Role-reversal*	*Lack of avoidance*	*Task-oriented*	*Total score*	*Direct score*
1	7	7	3	3	3	3	3	29	7
2	7	7	3	3	3	3	3	29	7
3	6	7	3	3	3	3	3	28	7
4	7	7	3	3	3	3	3	29	7
5	7	7	3	3	3	3	3	29	7
6	4	2	2	3	3	3	1	18	4
Child Involvement Score									
	Simple Initiative	*Elaborative Initiative*	*Use of Adult*	*Lack of over-involvement*	*Eye contact*	*Body positioning*	*Verbal involvement*	*Total score*	*Direct score*
1	7	7	3	3	3	3	3	24	7
2	6	4	3	3	3	3	3	25	6
3	6	4	3	3	3	3	3	25	6
4	7	6	3	3	3	3	3	28	7
5	7	7	3	3	3	3	3	29	7
6	3	1	3	3	3	3	3	19	3

Table 41: Study 2a-Total mean EAS scores across activities

7.6.3 Attunement

A responsive communicative style was evident across dyads and triads, as evidenced by the narrative transcriptions and video footage. Mothers and siblings responded contingently to the child's focus of attention even across different contexts. Both mothers and siblings showed emotional warmth by using varying intonations while talking. Siblings generally waited and listened actively. Mothers in the study generally took the lead during triadic interactions around the kitchen table with all families. They all assigned them different roles in the kitchen while also involving the elder sibling in the activity. It was evident that mothers exerted an effort to involve both siblings equally, particularly when there was an age gap between siblings.

7.6.4 Dyadic and triadic interactions

This section includes observations from the narrative transcriptions and narratives and observations for each dyad and triad based on the video footage. Additionally, the quality of interactions of mothers and siblings and the factors about age, sex, birth order, sibling roles, rivalry and power are also discussed in this section. The latter information has been extracted from the maternal questionnaires and sibling interviews, and triangulation was obtained from the narrative transcriptions and video observations (see appendix B for detailed profiles about these families).

7.6.4.1 Dyadic InteractionsThere was evidence of turn-taking occurring between the mother and elder children. In highly scripted games, the communication partners tended to argue and challenge each other. However, there seemed to be more opportunities for cooperation in dyadic interactions where there were more "free conversations" in unstructured games. Younger siblings tended to use '*backchannelling*' (e.g. used items such as yes, okay) to signify attention. Words like "iva'' (yes) are all back channels and were used frequently by the younger siblings to gain the attention of their mother or older sibling. These types of backchannels are not considered as turns and do not involve speaker shifts. Instead, they were used to contribute or encourage the other partner. Feedback from the siblings and mother in dyadic interactions was not only verbal but also silent. This was in the form of eye gaze, gestures, facial expressions, grimacing and laughter. Silent feedback was evident during card games which are considered highly scripted and involved less verbal feedback. In all interactions, there was spoken language evidenced.

In some script games, for instance, card games, there was an amount of non-verbal communication: funny faces, grimacing, eye contact, vocalisations, gestures. Participants

were also vocal at times and giggled and laughed. Mothers used many questioning sequences to elicit an answer, and yet again, this was more evident with the younger siblings to elicit an answer and keep the conversations going. Sibling rivalry was evident when playing highly scripted games (e.g. Snap and Uno), but more collaborative interactions were noted when triadic interactions were in place. Eye contact was more dominant when tasks/activities were highly scripted, especially when one participant waited his/her turn or expected the other partner to make his/her move. At times, the younger siblings were using nonsense words during highly scripted games (e.g. boboj; booboo, boohoo); buzz words "take that", and mannerisms while saying "ha, ha, ha" while slamming the cards at the same time to create more effect and assert power over the younger sibling.

7.6.4.2 Triadic Interactions

It was noticed that communication partners waited for each other to stop talking before starting to speak again. This resulted in a smooth speaker shift. When one of the siblings took over without waiting for the other sibling to finish off, some moments resulted in a less smooth speaker shift. The transcripts showed an overlapping in the conversation when both siblings were talking with their mother. Whilst the mother tried to involve all siblings, there was a tendency for the older sibling to dominate the conversation, especially where there was a more significant age gap. All mothers tried to involve both siblings in interactions and tried to be attentive, encourage and receive initiatives and develop attuned interactions. The younger the siblings were, the more verbal prompting the mother had to initiate. Mothers seemed to use more questioning sequences to elicit an answer rather than more instructional directives, giving suggestions, prompting and assertives.

Other primary acts included accepting, acknowledging, agreeing, alert, answering, apologising, checking, confirming, disagreeing, questioning, reacting, rejecting, requesting, suggesting, and thanking. All interactions generally started with an opening where the different communication partners exchanged information and spoke about the task at hand, evidence of phatic talk. There was also evidence of speech-in-action in all conversations where speakers spoke about other events that had nothing to do with what was discussed. This was evident both in dyadic and triadic interactions where for example, while they were preparing pancakes and beating an egg, the elder sibling recounted how a chick came out of the raw egg. There was also evidence of asides, especially in triadic interactions when the mother and the children discussed methods for ameliorating their culinary skills. All conversations commenced with a single topic that the participants were participating in. There was evidence of a topic drift, where the topic shifted from one related topic to the next. For instance, in a dyadic interaction involving the mother and younger sibling, they fixed shells onto the pots using a hot gun. The child told his mother that his friend hurt his finger with a hot gun. In another conversation involving a triad, the conversation drifted from eggs to when they once went on a farm and found hatched eggs. In another conversation between the mother and her daughter, the latter recounted how she used to do hand massages to her grandmother.

7.6.5 Level of Directiveness

Levels of directiveness within and across families seemed to vary according to the activity at hand and the person's temperament. The frequency of directives increased slightly when mothers had to give instructions or issue reprimands during kitchen tasks and in situations where there were more risks of health and safety issues (e.g. when using the toaster, using the hot glue gun, filling up a jug with boiling water).

Examples included *"itfa' l-misħun"* (pour hot water), *"biżżejjed"* (enough), *"mela ħu tiegħek"* (take yours), *"aqta' fuq l-injam"* (cut on the board), *"attent ħabba s-sikkina"* (be careful of the knife). Minimal levels of directiveness were observed when mothers and siblings were involved, for instance, with board games (e.g. Uno), which requires the players to follow the rules and are more scripted. Interestingly, maternal supportive directives remained the same across dyads and triads for all the families, suggesting that maternal interactional styles and supportive directives remained unchanged (see table 42).

Category	Family 1 - Kai			Family 2 - Albert			Family 3 - Lorenz		
	MC	SC	MSC	MC	SC	MSC	MC	SC	MSC
Supportive directives	3	1	3	4	5	5	0	0	1
Intrusive directives	0	0	0	0	0	0	0	0	0
Category	Family 4 - Mark			Family 5 - Yvette			Family 6 - Simon		
Supportive directives	4	2	2	2	2	1	1	2	1
Intrusive directives	0	0	0	0	0	0	0	0	0

Table 42: Study 2a-Mother sibling child mean directives across activities

7.7 General discussion

This study examined mothers' behaviours towards their children and how siblings interact with their younger brother or sister. Additionally, the study examines responsive styles of interaction and the level of responsivity and directiveness for both the mothers and siblings. There was synchrony encompassing both the mother's and the child's responsivity and their emotional capacity to respond to each other as determined from the EAS scores. For example, during triadic activities, the mother leads the siblings to give them specific roles in the kitchen, but both mothers and siblings are friendly and playful. They returned eye contact and smiled and nodded in response to the activities at hand.

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The EAS score also indicated that mothers (notably family 6) might have found a moderate level of accessibility during verbal interactions with comfortable breaks for both communication partners and could be described as healthy within the emotional availability. The findings generally indicated higher levels of non-intrusiveness as well as higher structuring. The EA system is designed for viewing higher structuring attempts as positive attempts if the child receives these attempts positively and is likely to contribute to his/her socioemotional development. Likewise, higher levels of non-intrusiveness are recommended. Mother-focal child and sibling-focal child and mother-focal child-sibling triads developed attuned interactions, evident across all families. For instance, mothers were looking for opportune moments where they could receive feedback during different activities. This study has indicated that both mothers and siblings provide more supportive directives than intrusive behavioural or attentional utterances. This suggests that the mothers and siblings use these behavioural directives to support and direct the younger child during the activity itself. Despite previous research which argues that directiveness is a negative feature, the findings from this study suggest that this is not the case. The critical issue is the appropriateness of the directives towards the child and how the directives are given (Moore et al., 2010).

7.8 Limitations

This study is limited to a small sample of participants, and the results have to be treated cautiously. Also, grouping families according to the home environment, social status, maternal and sibling ages, and age differences was challenging. A second limitation is the range of activities and activity sampling lengths.

It was difficult to standardize the type and amount of activities across families since the aim was to encourage naturally occurring interactions chosen by the families. The study did not control for the type of activities, whether they are structured or unstructured. Furthermore, implementing standardized directions for families regarding types of activities would defeat the purpose of allowing autonomous mother-focal child and sibling activities.

7.9 Conclusions

This study found a responsive communicative style between mothers and siblings in typically developing families. Mothers used higher levels of non-intrusiveness and higher structuring in their interactions within the emotional availability scales. Structuring and non-intrusiveness scores were influenced by both the mother's and child's reactions. Mothers tended to use assertives and questioning techniques to prompt and interact with the children. When maternal and sibling directiveness was used, this was of a more supportive behavioural type. Mothers used lower-order thinking questions that scaffold the child's Zone of Proximal Development. There was mutual bidirectionality with collaboration between siblings even when there was an age difference indicating power dynamics and sibling rivalry. While this is a small-scale study with a relatively homogenous group, the quality of interactions between mothers and siblings and the interactional style varied according to the different activities chosen by the families.

CHAPTER 8: A STUDY OF THE LEVEL OF RESPONSIVITY AND DIRECTIVENESS BETWEEN MOTHERS, SIBLINGS AND CHILDREN WITH COMMUNICATION DISABILITIES (STUDY 2B)

8.1 Introduction

Following the results of the pilot findings, the three Maltese families of children with communication disabilities demonstrated that both mothers and siblings were emotionally connected with the child with a disability with an appropriate responsive style and emotional warmth. Mothers presented with several directives across different activities and games. This was accompanied by higher physical and verbal prompting in some instances, creating a situation of commands. In some instances, this was observed with siblings during role play where independent and self-help skills were targeted. The types of directives consisted predominantly of supportive behavioural directives. The pilot study indicated the need to extend the number of families to establish whether these patterns of behaviour are present in a larger sample and determine the type and level of directiveness in mothers and during everyday interactions at home.

8.2 Aims of the Study

The current study explores how the responsivity of mothers, siblings, and the focal child (a child with communication disabilities) manifests themselves across different activities and contexts chosen by the families. The following research questions were proposed.

i.   What are the patterns of responsivity and directiveness in mother-sibling-focal child interactions during everyday activities?

ii.   How do maternal patterns of responsivity and directiveness manifest themselves with siblings during everyday interactions?

iii.   How do siblings interact with each other during everyday activities where there is a child with communication disabilities?

8.3 Methodology

8.3.1 Design

This study was a mixed-methods design applying both qualitative and quantitative methods. It involved observing dyads and triads in communication activities complemented by structured interviews, questionnaires and field notes. The activities included a 10 minutes caregiver-child free play session within the home environment. This session was conducted so that the researcher could observe interactions between the mother, siblings and the focal child.

8.3.2 Ethics

Ethics approval was sought from the Research Ethics Committee of Tizard Centre and the University of Malta research committee, and approval was granted. See Chapter 5 for a more detailed overview on ethics, access and informed consent.

8.3.3 Participants

Inclusion criteria

Mother participants

i.   Mothers of a child with developmental disability resulting in delayed or impaired communication.

ii.   Have typically developing children over the age of 7 years.

iii.   They were willing to participate in the study.

Child participants (Focal child)

i.   presented with a developmental disability according to a psychological report conducted within two years of the onset of the study.

ii.　had a communication disability due to physical, neurological, or cognitive difficulty/impairment, and cannot use speech independently as their primary means of communication unless through aided means.

iii.　had **achieved** at least level III of the Communication Matrix.

Sibling participants

i.　typically developing sibling/s over the age of 7 years[6].

ii.　are willing to participate in the study.

Six families were involved; twelve children were participants in this study, seven girls and five boys (see Table 43,45). Five of the families had same-sex siblings participating in the study. Four families had two children, one with four children and one with five children.

Focal Child [7]	Age	Gender	Age difference from sibling	Child's disability	Communication Matrix	Means of communication
Tina	11	F	+3	Global developmental delay with perinatal asphyxia	V	Medium tech aid
Laura	11	F	+2	Hemi-megalocephaly and developmental delay	VI	VOCA
Steve	18	M	-2	spastic quadriplegia	IV	VOCA
Mario	6	M	-2	Down syndrome & epilepsy	IV	Medium tech aid
Maria	14	F	-2	Down Syndrome	VI	VOCA
Faith	11	F	-1	Cerebral palsy and hearing impairment	III	Objects of reference

Table 43: Study 2b-Child participant data

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[6] If the focal child had more than one sibling, the sibling closest to the focal child's age was asked to participate.

[7] Child's names have been changed

There was a siblings age difference of 1 to 3 years (mean=2; median=2; range 2). Two of the families had the eldest child with a disability and both siblings. The families lived in the central and southern parts of the island (Table 44). All parents completed compulsory education, and three of the mothers held teaching posts or executive positions while the other three mothers were homemakers.

Family	Mother's Age/years	Mother's occupation	Level of Education	Social Grading	Type of household	Locality	Number of people living in the same house
1	36-45	Executive officer	Completed compulsory education	AB	maisonette	central	4
2	36-45	teacher	degree	AB	maisonette	south	4
3	46 -	homemaker	Certificate/diploma	N/A	Semi-detached villa	central	4
4	36-45	Sales manager	Completed compulsory education	AB	maisonette	central	7
5	36-45	homemaker	Completed compulsory education	N/A	maisonette	central	4
6	36-45	homemaker	Completed compulsory education	N/A	maisonette	south	6

Table 44: Study 2b-Family participant data

Family	Sibling's Age	Gender	No of siblings	Learning difficulties	Before/after school programme
1	8	F	2	nil	nil
2	9	F	2	nil	nil
3	20	M	2	nil	nil
4	8	M	5	nil	sometimes
5	16	M	2	nil	nil
6	12	F	4	nil	nil

Table 45: Study 2b-Sibling participant data

8.4 Procedures

Observations of activities with three sessions each were made of mothers with the focal child and sibling. In addition, the EAS scales were completed as well as a frequency count of types of directives. Narrative transcriptions and video observations were utilised (see appendix B for detailed profiles about these families). Further details, including procedural guidelines, baseline questionnaires and sibling interviews, are available in Appendix D & E. For more detailed information, please refer to Chapter 5.

	Family 1	Family 2	Family 3	Family 4	Family 5	Family 6
Mother-focal child	6.39	7.46	6.25	1.97	4.7	6.26
Mother-sibling	6.31	4.41	4.18	8.18	9.33	10.06
Sibling-focal child	6.23	8.33	6.56	2.2	7.34	5.10
Mother-focal child-sibling	11.39	7.15	5.25	3.42	10.26	8.46
Total amount of minutes	48.53	73.42	45.55	32.06	36.32	29.88

Table 46: Study 2b-Average amount of minutes across activities

Video Data

There were 72 video clips with video data ranging from 2.2-11.39 minutes per session for a total of 266.16 minutes (mean 44.29 minutes). Table 46 indicates the average amount of minutes for each dyad and triad across the six families.

8.4.1 Coding and Analysis

Episodes of maternal-child interactions were coded from 266.16 hours, consisting of structured (58%) and unstructured activities (42%) in the house.

8.4.2 Responsivity ratings

For more information about the responsivity ratings, including the Emotional Availability Scales Middle childhood/Youth version (4th Edition: Birigen, 2014), see Chapter 5 for more details.

8.4.3 Attunement evidence from narrative accounts.

A thematic analysis approach was used to analyse these qualitative data which involved identifying themes. Thematic coding and analysis followed the identifying themes of the principles of attunement through video interaction guidance.

8.4.4 Directives

The directives were coded based on the criteria established by Flynn and Masur (2007). See Chapter 6 for more details.

8.4.5 Inter-rater and intra-rater reliability

Inter-rater reliability data was measured on 20% (n=14) of the videos of the EAS data, RAACS scores and types of directives. Percentage occurrence and non-occurrence are shown for each behaviour (Table 47). More details are available in Chapter 5.

A comparison of reliability measures was performed on two occasions by the primary researcher to establish intra-rater reliability. An 89% reliability coding for EAS scores and 81.4% for Directive scores were obtained, indicating a strong level of agreement (0.8-0.9).

Behaviours	Interobserver Agreement IOA %	Kappa κ
Maternal EAS Scores	83.2	0.88
Maternal Supportive Behaviour Directives	81.5	0.71
Maternal Intrusive Behaviour Directives	79.4	0.78
Sibling Supportive Behaviour Directives	78.8	0.75
Sibling Intrusive Behaviour Directives	79.2	0.74

Table 47: Inter-observer reliability data for Study 2b

8.4.6 Ecological validity

All studies were carried out in the participants' homes, and the materials used were familiar to the participants since the families chose them. The behaviours manifested during data

collection were discussed with the mothers to confirm that these behaviours were typical of daily behaviours.

8.5 Results

8.5.1 Emotional Availability

All families except one obtained a direct score of 6 or over on the adult sensitivity construct (see Table 48), implying apparent sensitivity to a more emotionally available, warm, sensitive and appropriately responsive interaction. Sensitivity refers to various qualities that tap the adult's ability to be emotionally connected and warm, and responsive to the interactive partner. The maximum score is 7, and the acceptable score is from 4 upwards. The section on clarity of perceptions and appropriate mother responsiveness indicated awareness of signals and communication and a willingness to respond appropriately with scores over 5. The majority of the families scored 3 points on flexibility, variety, and creativity, implying that the mothers are flexible and enjoy fun and creative play. The structuring construct demonstrated that all families used proactive guidance or suggestions to make subtle or varied suggestions and comments, leading the child to the task at hand.

	Affect	Clarity of Perceptions	Timing	Flexibility	Acceptance	Amount of Interaction	Conflict	Total score (29)	Direct score (7)
1	4	6	3	3	2	3	3	24	6
2	5	6	3	3	3	3	3	26	7
3	5	5	3	3	3	3	3	25	6
4	7	7	3	3	3	3	3	29	6.5
5	6	7	3	3	3	3	3	28	6
6	5	5	3	2	3	3	3	22	4

Table 48: Study 2b-Sensitivity score

Notably, families 1,3 and 6 success of attempts were not always ideal even if they were plentiful, with the adult losing the child during the activities. Less structure than ideal was observed in some instances, even if the level of interaction was good (Table 49).

	Guidance	Success	Amount of Structuring	Limit Setting	Firm in Pressure	(Non)verbal structuring	Peer vs. Adult	Total score (29)	Direct score (7)
1	6	4	3	3	3	3	3	25	4
2	6	6	3	3	3	3	3	27	6
3	6	4	2	3	2	3	3	23	4
4	6	5	3	3	3	3	3	26	5
5	6	7	3	3	3	3	3	28	6
6	5	4	2	3	3	1	3	19	4

Table 49: Study 2b-Structuring score

The score on the non-intrusiveness construct indicated that generally, the mother tends to lead, over-direct, over parent and expects the child to follow the lead. Families also generally interrupt the interactions with some evidence of occasional to constant use of commands and directives. Families 2 and 5 use verbal means of communication during social interaction as part of a dialogue. Families 1,3, 4 and 6 use talking to overreach and overpower the child. All the families except for family 1, scored 1 point in verbal versus physical interferences meaning that interferences are physical.

Additionally, families 1,2,3,4 and 6 scored 1 or 2 points in the section where the adult is made to feel or seem intrusive, meaning that the child is indicating nonverbally by his/her behaviour that the mother is being too intrusive (Table 50).

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	Following C leads	Ports of entry	Commands	Talking	Didactic Teaching	Interferences	Feel Intrusive	Total score (29)	Direct score (7)
1	1	1	1	2	2	1	2	10	1
2	4	4	2	3	3	1	2	19	3
3	1	1	2	2	2	1	2	11	2
4	5	5	2	2	2	1	2	19	1
5	6	6	2	3	3	2	3	25	5
6	3	5	2	1	1	1	1	14	3

Table 50: Study 2b-Nonintrusiveness score

The non-hostility construct indicates that the mothers used subtle signs of irritation, impatience, and slight anger. Generally, mothers-maintained composure during stressful times such as tiring times or when the child presented with behavioural challenges. The silence subscale indicated that all families except one were not silent at all. The mother in family six scored one point, indicating that there was very little verbal communication. This may be due to the child's hearing impairment and the possibly learned helplessness from the mother and siblings when communicating with their daughter (Table 51).

	Lack negativity	Lack ridiculing	Lack threats of separation	Loose cool	Frightening	Silence	Themes	Total score (29)	Direct score (7)
1	4	2	3	2	2	3	3	19	5
2	5	6	3	3	3	3	3	26	5
3	4	3	3	3	3	3	3	22	5
4	5	5	3	2	2	3	3	23	5
5	6	6	3	3	3	3	3	27	6
6	6	6	3	3	3	1	3	24	6

Table 51: Study 2b-Non-hostility score

The child-responsiveness construct indicated that child affect is generally positive, but they may over-rely on their mother. There were instances when the children seemed distressed, or distressed and underregulated, but otherwise connected to the adult.

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Generally, all the children were responsive; children in families 2, 3, 4 and 5 responded verbally or nonverbally when the adult initiates. The child in family 6 was not likely to respond, and the mother did not initiate. Generally, the children show some signs of autonomy seeking even if it was not age-appropriate; however, child 1 and 6 seemed very passive and physically stayed close to the mother. Children generally seek a physical position that is positive and age-appropriate, but child 1 seemed to seek physical contact or physical proximity seeking, indicating that the child may be over-connected. Generally, the children did not seem avoidant but were not necessarily always connected. The child in family 6 seems avoidant to the adult, but this could have been due to her hearing impairment. Additionally, child 4 and 6 were focused on their activity and seemed to exclude their mother. This could be due to joint attention difficulties where the child cannot demonstrate triadic gaze shifts co-ordinating their attention between the adult and the object (Table 52).

	Affect	Responsiveness	Autonomy	Physical Positioning	Role-reversal	Lack of avoidance	Task oriented	Total score (29)	Direct score (7)
1	4	4	1	2	3	2	2	18	3
2	6	6	3	3	3	3	3	27	5
3	5	5	2	3	3	2	2	22	3
4	7	6	2	3	3	2	1	24	6
5	6	6	3	3	3	3	3	27	6
6	3	1	1	3	3	1	1	13	3

Table 52: Study 2b-Child responsiveness score

The last construct in this scale is 'child involvement'. Child 1 and 6 use their mother more as a tool than to have their emotional needs met. Additionally, children 2,3 and 4 seem to be using the adult both emotionally and instrumentally. The construct generally indicates that most of the children seem to have difficulties initiating eye contact.

All children except child 5 rarely involved themselves through the positioning of the body towards the adult. Overall, the scores indicate that the children show some emotional responsiveness with some inappropriateness of social responsiveness and less than optimal behaviour for development (Table 53).

	Simple Initiative	Elaborative Initiative	Use of Adult	Lack of over-involvement	Eye contact	Body positioning	Verbal involvement	Total score (29)	Direct score (7)
1	1	1	1	2	1	2	1	9	2
2	4	4	2	3	2	2	2	19	5
3	2	2	2	3	2	2	1	14	3
4	4	2	2	2	2	2	1	15	4
5	5	5	3	3	2	3	2	23	5
6	3	1	1	2	1	2	1	11	2

Table 53: Study 2b-Child involvement score

8.5.2 Attunement

While responsiveness is a key feature, the EAS score is more inclusive of other qualities described previously and not only based on the adult's ability to be responsive. Thus, a thematic approach was utilized to understand the quality of attunement, which also incorporated responsivity. The themes extracted from the attunement principles indicated a responsive communicative style across dyads and triads between mothers and siblings of children with communication disabilities. Mothers and siblings generally responded contingently and built on the child's focus of attention. Both the mothers and siblings were seeking pleasure in the interaction. Mothers showed emotional warmth by using varying intonations while talking. Siblings generally waited and listened actively. They looked for initiatives for interactions and repeated to clarify or confirm what their disabled brother/sister was indicating. Mothers took the lead and waited while the child responded.

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Mothers generally showed emotional warmth and emotional connectedness by using varying intonations while talking. Mothers tried to include all siblings during triadic interactions through physical disability, sensory issues and the child's attention and interest in the tasks compromised the child's participation in the activities. This was evident by a marked higher level of dependency and lower level of engagement shown by the disabled children. Mothers generally provided higher physical prompts while using commands and directives rather than short order questioning techniques. While not all children in the study were physically challenged, they could not participate actively during the sessions all the time. This could have reduced interaction levels since family members focused on providing physical support and expecting them to follow their lead.

8.5.3 Level of Directiveness

Levels of directiveness within and across families seemed to vary according to the activity at hand, the level of attention and the nature of the disability. For example, the frequency of directives increased slightly when mothers had to give instructions or issue reprimands. Common phrases included "*head up*", "*Come on Tina*", "*Let's listen*", "*let's laugh*", "*Come on Sara*", "*Ejj Ejj Ejja* (come on, come on, come on)", "*ħa, ħa, ħa aqbadhom*" (come on pick them up), "*għollieha l-ħobża* (pull out the bread)", "*niżżilha* (put it down) *", "oħrog l-ħobż* (put the bread out)", "*dellikulu naqa'* (spread it), (family 3) "*u aqtagħlhom naqa' zokk"* (and cut their stem), "*Agħmel kollox*" (do everything), "*Ejja Steve hit the ball*", "*Ejja hit it forward*", "*Ejja Steve turn it round*", "*Ejj' ilgħab"* (come on play), "*Ejja dawwar*", "*oħroġ t-tazzi*" (take out the plates), "*Ejja*", "*Mur ġibli l-pala*" (go and get me the spade), "*Isa*" (come on), Mario – "*now ejja do it, tell me B, you have to tell me B, ejja isa with the noise,*" (Table 54).

Category	Family 1			Family 2			Family 3		
	MC	SC	MSC	MC	SC	MSC	MC	SC	MSC
Supportive directives	6	1	8	5	18	5	2	10	1
Intrusive directives	2	0	2	0	0	0	0	0	0
Category	Family 4			Family 5			Family 6		
	MC	SC	MSC	MC	SC	MSC	MC	SC	MSC
Supportive directives	3	1	3	1	nil	3	8	nil	10
Intrusive directives	0	1	1	0	0	0	0	0	0

Table 54: Study 2b-Mother-focal child mean directiveness across activities

Levels of directiveness within and across families vary according to the activity at hand and the persons involved. For Family 2 and 3, the level of directives was greater, possibly due to the higher demand for role play and table soccer, respectively. In family 1, the level of directiveness of when the mother and child were involved, was higher and the quality of directives noticeably were prompts related to physical posture and positioning. Some intrusive behaviour directives were also noted and related to the adult or sibling attempting to modify the child's behaviour and not necessarily follow the attentional focus.

8.5.4 Interactive style and choice of activity

Most of the interactions happened around the kitchen table, the sitting room or the child's bedroom. Two families opted for cooking activities, two opted for messy play, and two for reading activities. Mother-focal child and sibling-focal child dyads generally chose highly structured activities, although activities still allowed for free conversations, suggesting a dynamic structural continuum of activities that allowed fluidity. Such activities were cooperative and interactive (e.g. making pancakes, making a sandwich) in comparison to games which are typically highly scripted (e.g. Uno, Snap) (See Table 55).

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Both mothers and siblings showed evidence of commands and directives which were supportive. Increased supportive behaviour directives were mostly linked with role play (unstructured activities) and structured activities in the house (namely life skills activities).

		Structured activities				Unstructured activities
		Board games	Card games	Strategy game	Activities in the house	Free play
Family 1	Mum – focal child				Computer games using switches	
	Mum-sibling			Jenga		Stretching and massage. Walking.
	Sibling-focal child					Massage and relaxation.
	Mother-sibling-focal child				Reading a story	
Family 2	Mum – focal child		Greedy Gorilla		Singing and playing musical instruments	
	Mum-sibling	Snakes and ladders. Uno.				
	Sibling-focal child					Roleplay
	Mother-sibling-focal child				Making pancakes. Reading a story.	
Family 3	Mum – focal child				Preparing a sandwich. Helping in the house, sweeping and doing the clothes.	
	Mum-sibling				Preparing the table for dinner.	
	Sibling-focal child				Practising climbing the stairs/using a walker. Playing table soccer. Playing football.	

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	Mother-sibling-focal child				Preparing pasta carbonara.	Walking. Kicking the ball.
Family 4	Mum – focal child		Drilling of flashcards			Singing Row the boat.
	Mum-sibling			Cheek retractor/ Watch ya mouth		
	Sibling-focal child					Rough play
	Mother-sibling-focal child					Messy play
Family 5	Mum – focal child	Ludo				
	Mum-sibling		Football card game			
	Sibling-focal child	Ludo				
	Mother-sibling-focal child				Making a sandwich	
Family 6	Mum – focal child					Playing with noisy toys
	Mum-sibling					Messy paint
	Sibling-focal child			Jenga		
	Mother-sibling-focal child					Messy dough with water

Table 55: Study 2b-Types of activities

8.5.5 Sibling interview

All siblings report that they enjoy activities together, ranging from going out as a family for walks, taking the dog for a walk or swim in the pool. They all share hobbies such as reading or listening to music, playing frame football and attending swimming sessions. Siblings tend to fight over toys or schoolbooks. They all reported their sibling needs help during the day with dressing, feeding, washing and walking. They are reported to take more caregiving roles. They have different perceptions of how they see themselves concerning their disabled brother or sister; some see themselves as a caring sister or brother, others feel they are best friends or helpers to the younger brother.

They all have dreams for their siblings and want them to live a good life and improve their quality of life.

8.5.6 Comparison of results of Study 2a and 2b

The responsivity scores demonstrated that both mothers and siblings in Study 2a and 2b were emotionally connected with the child with a disability with an appropriate responsive style and emotional warmth (See Table 56 and 57). Mothers generally showed emotional warmth by using varying intonations while talking and demonstrated emotional connectedness. Siblings in both studies likewise showed that they had heard and responded to their siblings' initiatives while playing together and initiating vocalisations and some single words. During triadic activities, the mother led the siblings by giving them specific and clear roles. The responsivity scores in both studies demonstrated that both mothers and siblings were emotionally connected with the child with a disability with an appropriate responsive style and emotional warmth (see Table 57). Both the mothers and siblings were seeking pleasure in the interaction. This was also evidenced from the broad narrative transcriptions and accounts where a responsive communicative style was evident in mother-focal child and mother-sibling-focal child dyads and triads. Both mothers and siblings responded contingently and attempted to build on the child's focus of attention in different contexts and use different activities. It was noted that mothers took the lead and expected the child to respond. Mothers generally showed emotional warmth by using varying intonations while talking and demonstrated emotional connectedness. Siblings likewise showed that they had heard and responded to their siblings' initiatives while playing together and initiating vocalisations and some single words. During triadic activities, the mother led the siblings by giving them specific and clear roles.

STUDY 2a	STUDY 2b
Families of non-disabled children	*Families with a disabled child*
Emotionally attuned and available mothers.	Emotionally attuned and available mothers.
Mutual enjoyment between mothers and children.	Mutual enjoyment between mothers and children.
Mothers involved siblings in interactions equally	Mothers tend to over-direct and over-parent. They seem to overpower the focal child.
Mothers used higher levels of non-intrusiveness (low intrusivity) as well as higher structuring in their interactions.	Mothers showed lower levels of non-intrusiveness (i.e. high intrusivity). At times there was less structure than ideal .
Mothers generally took the lead during triadic interactions around the kitchen table.	Mothers expect the child to follow their lead during triadic interactions around the kitchen table.
Mothers show commands and directives during kitchen tasks and in situations with health and safety risks.	Mothers show increased use of commands and directives. In addition, they demonstrate higher physical and verbal prompting, particularly during activities in the kitchen.
Mothers and siblings provide more supportive directive utterances rather than intrusive behavioural or attentional utterances.	More supportive behaviour directives were used rather than attentional or intrusive behavioural utterances.
SBD for mothers and siblings were similar in frequency. However, mothers used more questioning sequences to elicit an answer rather than more instructional directives, giving suggestions, prompting and assertives.	SBD in mothers and siblings (SBD – 18) varied according to the task at hand (e.g. role-play, physical activity), attention and child temperament.
The younger the siblings were, the more verbal prompting the mother had to initiate.	Focal children rely more on mothers and their siblings, showing higher levels of dependency.
Children were attentive; they encouraged and received initiatives and develop attuned interactions.	Focal children remain passive and seek physical contact.
No difficulties were noted with maintaining triadic gaze shifts.	Some children have difficulties with maintaining triadic gaze shifts. This was evident by an increase in more attentional directives.
Child affect is positive.	Child affect is positive.
Children show emotional responsivity with the appropriateness of social responsiveness and behaviour.	Children show emotional responsivity but with some inappropriateness of social responsiveness and behaviour.
Mothers involved both siblings in interactions, and all tried to be attentive, encourage and receive initiatives and develop attuned interactions.	Mothers led the siblings by giving them specific and clear roles. Both mothers and siblings responded contingently and attempted to build on the child's focus of attention in different contexts and use different activities.
Older siblings dominated the conversation, especially where there was a more significant age gap.	Siblings demonstrated higher levels of engagement and participation opportunities in joint activities.
There is an indication of power dynamics and sibling rivalry, particularly when there was a much older sibling.	Siblings establish more caregiving roles and imitating their mothers in providing their disabled siblings with more support.
Mothers tended to use more assertives and questioning techniques to prompt and interact with the children. In addition, lower-order thinking questions were used.	Mothers tended not to use aided means of communication with the focal child, and when it was used, it was more to elicit multiple choice answers/closed-ended questions.

Table 56: Summary of the main issues between studies 2a and 2b

From the narrative accounts and the EAS scales, mothers seemed to be controlling with their children, possibly unconsciously perceiving these opportunities for interaction as a learning experience for their children. The children presented with higher levels of dependency on their mothers. The EAS scales and the results from the frequency of directives confirmed that the mothers presented with numerous directives across different activities and games. This was accompanied by higher physical and verbal prompting from the mothers.

The types of directives taken from the frequency counts for all dyads and triads demonstrated that the types of directives consisted predominantly of supportive behavioural directives.

EAS Score	Study 2a Mean Scores /7	Range	Study 2b Mean Scores /7	Range
Sensitivity	6.5	4-7	5.9	4-7
Structuring	6.8	6-7	4.8	4-6
Non Intrusiveness	6.6	6-7	2.5	1-5
Non-hostility	6.7	5-7	5.3	5-6
Child Responsiveness Score	6.5	4-7	4.3	3-6
Child Involvement Score	6.0	3-7	3.5	2-5
Directives	Study 2a Mean Scores	Range	Study 2b Mean Scores	Range
Maternal Supportive Behaviour Directives	2.3	1-4	4.2	1-8
Maternal Intrusive Behaviour Directives	0	0-0	0.3	0-2
Sibling Supportive Behaviour Directives	2.0	0-5	5.0	1-18
Sibling Intrusive Behaviour Directives	0	0-0	0.2	0-1
Mother-sibling-child supportive directives	2.2	1-5	5.0	1-10
Mother-sibling-child intrusive directives	0	0-0	0.5	0-2

Table 57: Summary of mean responsivity and directiveness scores for Studies 2a and 2b

Table 57 shows that mothers in study 2b seemed to be controlling with their children possibly unconsciously, perceiving these opportunities for interaction as a learning experience for their child even when the AAC system was used in some instances. The children presented with higher levels of dependency on their mothers. Mothers and siblings in study 2b presented with more directives across different activities and games. This was accompanied by higher physical and verbal prompting from the mothers, creating a situation of commands. In some instances, this was observed with siblings where independent, and self-help skills were targeted. The types of directives consisted predominantly of supportive behavioural directives and some intrusive directives.

8.6 Discussion

In summary, results from both studies (chapters 7 and 8) suggest that mothers and siblings of children with communication disabilities engage in more directive behaviours than mothers and siblings of typically developing children.

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In addition, mothers and siblings of children with communication disabilities utilize more supportive behaviours than mothers and siblings of typically developing children. Mothers and siblings of typically developing children did not differ in the frequencies of their directives or supportive directives, unlike mothers and siblings of children with communication disabilities who exhibited varied frequencies in their supportive directives. These results support other studies (e.g. Sterling & Warren, 2014), suggesting differences between mothers' interactive styles of mothers of typically developing children and mothers of children with Down syndrome. This may be due to mothers' adaptations or strategies with their children by using more supportive behaviours attuned to their developmental capabilities. This is also evident with siblings of children with communication disabilities who utilize more supportive interactive styles than siblings of typically developing children. This suggests that siblings typically mimic their mothers in how they interact and support children with communication disabilities. The focal children all benefitted from a means of communication as part of the inclusion criteria. Despite the body of research demonstrating the benefits of using AAC systems in daily interactions, no consistent and functional AAC use across families was found.

Mothers and siblings were reluctant to use keyword signing, gestures or aided means of communication. This may be attributed to various causes. First, family members may find it more convenient and easier to interpret the child's communicative needs rather than set up their AAC system for them. Second, they might find the use of the AAC system to be too invasive or alien for them. Third, there may be a lack of professional support in implementing the system in the home environment. They may need more support to understand the benefits of using an aided AAC systems in daily interactions (e.g. Cress et al., 2013; McNaughton et al., 2008).

When unaided means of communication such as manual signing is introduced, scholarly research confirms that signing does not stop speech from developing but rather seems to enhance it (Launonen, 2019). One of the common myths or misconceptions is that manual sign systems' introduction may hinder verbal language development, suggesting why Maltese families were reluctant to use manual signing with their children (Gatt, 2015).

8.7 Limitations and Implications for Further Research

This study is limited to a small sample of participants, and the results have to be treated with caution. Another limitation is the range of activities and activity sampling lengths since it was difficult to control the type and amount of activities across families. The aim was to encourage naturally occurring interactions chosen by the families, and as a result, the study did not control the type of activities, whether structured or unstructured. Furthermore, implementing standardized directions for families regarding types of activities would defeat the purpose of allowing autonomous mother-focal child and sibling activities. Future studies that utilize a larger sample size would benefit from using statistical methods such as multiple regression that would allow researchers to examine further the relationship between important maternal and child-related characteristics, emotional availability and maternal directive use.

8.8 Conclusion

This study found a responsive communicative style between mothers, siblings, and the focal child indicated mutual enjoyment and emotional warmth. However, mothers used lower levels of non-intrusiveness (i.e. high intrusivity) with a tendency to over-direct, over-parent and overpowered the child with a disability.

While child affect is generally positive, they tended to over-rely on their mother and sibling, and most of them remained passive with the inappropriateness of social responsiveness behaviours. They also had difficulties establishing triadic gaze shifts coordinating their attention between the adult and the object. At times, mothers had to use intrusive behaviour directives to gain the child's attentional focus. This study highlights the importance of making clear distinctions between supportive and intrusive behavioural directiveness. When assessing the mother's interactional style, interventionists should consider the types of directives used to plan intervention goals. It was also clear from this study that families, including siblings, were not promoting AAC use. Therefore, the next chapter describes a study of sibling-mediated interventions for children with a communication disability to investigate the current use of AAC in the home.

CHAPTER 9: THE EFFECTS OF SIBLING-MEDIATED INTERVENTIONS ON THE SOCIAL INTERACTIONS OF CHILDREN WITH COMMUNICATION DISABILITIES (STUDY 3)

9.1 Introduction

The results of the systematic review highlighted several missing links not addressed in the literature of family-led interventions. Very few studies focus on mother-sibling and sibling-focal child interactions where a child has intellectual and communication disability. A pilot study of three families of children with communication disabilities (see chapter 6) followed by a small-scale study involving six families of typically developing children (see chapter 7) were then conducted to explore the interrelationships between mothers and siblings. A stand-alone study involving mothers, siblings and focal children (children with communication disabilities) was conducted (see chapter 8). The studies investigated how two different interaction styles, responsive and directive, are employed by mothers and siblings in their encounters with children with intellectual disabilities. A responsive communicative style was evident across dyads and, in some instances, even across triads, and all the children with developmental disabilities in the study presented with high levels of dependency. Both groups' mothers and siblings responded contingently and built on the child's focus of attention across different contexts. There was no apparent reason why some siblings were more responsive than others and, in some instances, even as much as their mothers. In families with focal children, it was also evident that mothers presented with several directives and higher physical and verbal prompts than mothers of non-disabled children. The focal children presented with high levels of dependency on their mothers compared to the children from typically developing families. Siblings from atypically developing families mimicked their mothers when they responded and interacted with their disabled siblings. They also took over a dominant role where they dominated most of the conversation by providing more communicative turns and more directives and assertives than the other dyads from the typically developing children.

They also established more caregiving roles (e.g. feeding, dressing up, caring for their disabled brother/sister) and imitated their mothers in their directive styles. They demonstrated a higher level of engagement in comparison with siblings for the typically developing children.

Although there is substantial literature on mother-focal child interactions, the research into the role of siblings and their impact on each other's development has been limited. More recently, research has focused on sibling relationships in early childhood to adolescence, with a recent shift to sibling relationships and individuals on the autism spectrum and DS (e.g. Hastings & Petalas, 2014). Howe & Recchia (2014) argue that there has been a shift from studying the role of structural variables (e.g., age, birth order, age difference, socio-economic status) towards more process variables (e.g., understanding of their social and cognitive worlds and influencing each other's learning). According to Howe & Recchia (2014), while sibling studies provide a perspective for learning and development, several methodological and conceptual challenges need to be addressed.

The research evidence establishes the role of siblings as an integral component of family systems, and sibling relationships are likely to play a fundamental part in the lives of families (Mandak et al., 2017). Sibling relationships may last longer than any other relationship in one's lifetime (Howe et al., 2015). Developing positive sibling relationships may create an opportunity for siblings to learn how to interact, engage in social interactions, and regulate both positive and negative emotions in socially acceptable ways (Howe & Recchia, 2014). There may be many opportunities for siblings to use their cognitive skills to teach or model the functional use of an AAC system. Having siblings as co-interventionists may potentially strengthen AAC interventions (Mandak et al., 2017).

From a Family Systems Perspective, Mandak et al., (2017) argue that professionals often overlook the sibling subsystem, although siblings have the potential to strengthen AAC interventions. The role of siblings as AAC interventionists may potentially relieve some of the caregiver responsibilities of parents (Hancock et al., 2016). As discussed in chapter 3, some recent studies were published on sibling relationships and children with IDD, particularly siblings of children on the autism spectrum (e.g. Johnson et al., 2020; Leedham et al., 2020). A few systematic reviews have evaluated the impact of sibling and peer-mediated interventions for children on the autism spectrum who attend mainstream schools (e.g. Chung et al., 2012). However, there is limited research about the effectiveness of sibling-mediated interventions for children with ID who also use AAC (Douglas et al., 2018; Banda, 2015; Kim & Horn, 2010, Shivers & Plavnick, 2015).

A limited number of studies have focused on the role of siblings in interventions with children on the autism spectrum (Oppenheim-Leaf et al., 2012), for instance, teaching joint attention (Ferraioli & Harris 2011); facilitating social skills (Tsao & McCabe, 2010); targeting play skills (Shivers & Plavnick 2015; Walton & Ingersoll 2012). Sibling interventions have also been effective for children with developmental delays such as Down syndrome, William's syndrome and intellectual disabilities (Kim & Horn, 2010). Research has suggested that sibling interventions do focus on naturally occurring activities, such as play (Ferraioli et al., 2012), content-based supportive interactions with choices, questions, comments, and waiting time for the child with communication disability (Douglas et al., 2018).

In the context of the use of AAC, strategies used for promoting siblings to be effective interventionists may include (i) involving siblings from the beginning for their ideas, (ii) including siblings during home routines; (iii) providing them with developmentally appropriate toys and books for their disabled brother/sister, (iv) involving siblings when asking and answering questions, and (v) considering goals for the sibling as well as the child with communication disabilities (Bass & Mulick, 2007; Ferraioli & Harris, 2011).

9.1.1 The Purpose of this Study

There is limited data on sibling relationships where there is a child with a communication disability. To the researcher's knowledge, no such data exists for the local situation. This study occurred within a local context, and it was essential to keep the local situation in perspective. See Chapter 2 for more details.

9.1.2 The Study

This study follows Chung & Douglas (2015), which evaluated the impact of an intervention on interactions between students with ASD who used speech generated devices (SGDs) and their peers in inclusive classrooms. This study was replicated in families to examine i) the determining factors in sibling-focal child interactions and ii) the effects of a sibling-mediated intervention using existing modes of communication within the home environment. The ultimate aim is to understand how siblings could become better communication partners and potential co-interventionists when introducing or sustaining AAC use. The research questions were:

i.   What factors do mothers and siblings perceive as important in sibling-focal child interactions where there is a child with a communication disability?

ii.   Will the child with a communication disability increase AAC use with his/her sibling following the intervention program?

iii.   Will siblings increase their reciprocal interactions following the intervention program?

9.2 Method

9.2.1 Design and Study Conditions

A pre/post-test research design across eight families was used to evaluate the effectiveness of the intervention program. The design was made up of three phases: a baseline, instructional and post-instructional phase. Data was collected using video recordings of sibling-focal child interactions across three home-based activities at baseline and post-intervention. During the baseline and post-instructional phase, siblings were asked to participate in everyday activities together, and they took part in a goal-setting task with the researcher (MG). During the instructional phase, siblings watched the video footage and discussed how these interactions might be improved based on the initial goal setting task and using the principles of video interaction guidance. All baseline and post-instructional phases were video recorded. See 9.2.4 Procedure for more information.

9.2.2 Participants

The study included eight sibling-focal children pairs in which one child had communication disabilities and intellectual disabilities (Table 58). For this study, the children with communication disabilities are referred to as 'focal children' (FC). The inclusion criteria were as follows:

a) Focal children

i.   Aged 5 to 16 years.

ii.   Presented with an intellectual/developmental disability according to a recent psychological report within the last two years from the commencement of the study.

iii.   Met risk criteria for nonspeaking children, such as no more than ten spoken words (Warren & Brady, 2007) and the congenital risk factors described for children with developmental disabilities who rely on AAC (Beukelman & Mirenda, 2017).

iv.   They achieved at least level III of the Communication Matrix (unconventional pre-symbolic behaviour). This is considered the stage where intentional communication commences. At this level, "the child uses pre-symbolic behaviours **intentionally** to express his/her needs and desires to other people" (Rowland, 2004 p.3). Behaviours at this level may include body movements, vocalizations, facial expressions and simple gestures.

b) Sibling participants

i.   They are typically developing sibling/s (of the focal child) between the ages of 7 and 16.

ii.   Are willing to participate in the study.

c) Parents

i.   Mothers of a child with IDD and a communication disability.

ii.   Have a child who is typically developing between the ages of 7 to 16

iii.   Are willing to participate in the study

	Focal Child (FC)	Age	Gender	disability	ID	Communication Matrix	Means of communication	Sibling
1	Tina	14	F	Global developmental delay with perinatal asphyxia	Severe - profound	III	Medium tech aid – Tobii with scanning.	Paula (12)
2	Mario	8	M	Down syndrome & epilepsy	moderate	IV	Medium tech aid	Lorian (10)
3	Louis	9	M	Down syndrome	Mild - moderate	V	Communication book /PECS	Michael (9)
4	Jade	8	F	Global developmental delay	moderate - severe	III	Tablet with Avaaz software	Miriam (12)
5	Massimo	9	M	Down syndrome	Mild-moderate	IV	keyword signing	Ian (8)
6	Leone	8	M	ASD	Mild-moderate	IV	PECS – Communication book	May (12)
7	Jeremy	7	M	Glass syndrome-SATB2	Moderate - severe	IV	SGD – Accent & some keyword signs (more, finished, bye)	Karen (12)
8	Bruce	5	M	Cerebral palsy	Severe-profound	III	iTalk2	Elaine (9)

Table 58: Study 3-Participant Data

9.2.3 Measures

9.2.3.1 Participant Characteristics

These included age and gender of children, parental characteristics, and sibling-focal child intrinsic factors such as genetic factors. In addition, other sibling relationship qualities are known to influence sibling-focal child interactions, such as conflict, rivalry, warmth and closeness. More information regarding the description, procedures, & tables for each recording system is available in the Appendix.

   a) Demographic data from parents

Before participation in the study, mothers completed a baseline questionnaire (see Appendix E and a detailed description in the Methodology chapter). As reported in Chapter 3, previous studies have used similar measures, including questionnaires and interviews, to address such factors.

b) Demographic data from siblings

Following the procedural guidelines in the Appendix C , the researcher also administered a Sibling Communication interview with the siblings identified in the study before the intervention. More information is available in the Methodology and appendices sections.

9.2.3.2 Dependent variables

Interval recording systems, event (frequency) recording and momentary time sampling were used to collect the data through direct observation. The dependent variables were a) sibling-focal child initiations and responses, b) prompts provided by the adult caregiver towards the sibling or focal child, c) the use of AAC and number of aided communication messages and d) the level of proximity of the sibling, adult caregiver and aided communication system.

a) Sibling-focal child initiations and responses.

These are initiations or responses provided by the focal child toward the sibling or the sibling toward the focal child through interval recording. This may include a range of verbal (e.g. vocalizations, speech, use of a communication book or speech generated device (SGD) and non-verbal (e.g. key-word signs) behaviours.

b) Prompts provided by the adult caregiver towards the sibling or focal child

Interval recording was used to record the number of prompts for initiations/responses provided by the mother or father who remained in the room. Prompts were also noted as occurring towards the sibling or the focal child (displayed as a percentage of intervals and range at baseline and post-intervention).

c) Communication Modes

The communication mode used by the focal child to initiate or respond to the sibling was recorded each time an interaction occurred using event recording. These modes included keyword signing, vocalizations, communication book or SGD. If the focal child used a communication book or SGD during sibling interaction, the number of messages produced during the 10-minute sample was also recorded. If the message was recorded as a whole phrase on a medium or high-tech aid, this was considered one utterance. For example, the phrase 'green car' generated by a VOCA was recorded as one utterance.

d) The level of proximity of the siblings, adult caregiver and aided communication system

Momentary time sampling was used to code the level of Proximity if the focal child was (i) within physical reach of an aided means of communication in case of a communication book or SGD (ii) near his sibling (iii) near his mother or father. Nearness is defined as being not more than a meter (1m) away from the sibling. If mothers, fathers or other members of the family (e.g. younger siblings) were present in the room but more than one meter away from them, this occurrence of proximity was coded as not present/not proximal. In an aided communication system such as a communication book, symbols, flashcards, SGD, the following terms were used: NTO: aided system available but not taken out for activities; NA: system not yet available for the family.

e) Parent and sibling pre-intervention interviews

The maternal questionnaires and sibling interviews at the pre-intervention stage were designed specifically to identify the factors that may influence the intervention outcomes. The questionnaire and the interviews complemented each other in providing insight into the context and the intrinsic factors involved in daily sibling-focal child interactions. The maternal questionnaires also helped in triangulating the data obtained from the sibling interviews. The interviews focused on the tasks and activities that siblings enjoy doing together. This section also gave an overview of the frequency of each activity that was carried out.

f) Mothers and siblings' post-intervention interviews

Post-intervention, a maternal and sibling interview was conducted to determine the intervention's social validity and understand the families' experiences during the partial lockdown. An in-depth interview is a qualitative data collection method that involves a direct engagement with participants. In-depth interviewing can occur face-to-face or in other circumstances using online platforms, such as Microsoft Teams. The in-depth interview questions consisted of the following 1. Can you describe how your child has responded to being at home during the lockdown? 2. Has your child's communication changed during this time? (If yes, can you describe how?) 3. What else might have contributed to these changes during the lockdown period? 4. What would you have changed from this training?

The focal children were encouraged to participate using their preferred mode of communication through a brief individual interview. The questions for the focal child included: 1) Did you enjoy talking & doing activities with your brother/sister? (Yes/No) 2. Would you like to do more activities with your brother/sister? (Yes/No).

Siblings completed a brief questionnaire after the post-intervention phase (see Appendix). The questionnaire consisted of four questions to determine whether the goals set during the baseline phase were achieved post-intervention. Questions were answered using a Yes/I don't' know/No statement rather than a Likert scale since, according to Mellor and Moore (2013), internal feelings may be difficult for children in the stage of concrete operations (7–11 years of age). During this stage, children develop the capacity to make judgments and reason about the physical world. Children at the stage of formal operations (11–16 years) can think in abstract terms.

9.2.4 Procedure

a) Ethics

Ethics approval was sought from the Research Ethics Committee of Tizard Centre and the University of Malta research committee, and approval was granted. See Chapter 5 for a more detailed overview on ethics, access and informed consent.

b) Recruitment

See Chapter 5 for a detailed description of the recruitment process.

c) Baseline phase

This session included three activities of not less than 10 minutes within the home environment (Table 59). This session was conducted so that the experimenter could observe the interaction between siblings, analyse observed behaviour samples, and use a total communication approach in an interactive setting. No changes were introduced during the baseline condition. The researcher did not prompt the use of AAC or the sibling's proximity, other siblings, their mother/father, or the AAC system itself.

		Baseline 1	*Baseline 2*	*Baseline 3*
Family 1	Pre-intervention	Cooking activity (baking a cake) (structured)	Reading activity (Structured)	Massage (unstructured)
	Post-intervention	Cooking activity (baking a cake) structured	In the bedroom (unstructured activity)	Working on the computer (structured activity)
Family 2	Pre-intervention	Rough and Tumble on the sofa (unstructured)	Messy play (unstructured)	Pool activity (unstructured)
	Post-intervention	Rough and tumble on the sofa (unstructured)	Playdough (unstructured)	Rough and tumble on a slide using a makeshift mattress (unstructured)
Family 3	Pre-intervention	Rough and tumble on the trampoline (unstructured)	Rough and tumble play on the sofa and spontaneous storytelling using soft toys (unstructured)	I spy games using flashcards (unstructured)
	Post-intervention	Playing mini billiards (unstructured)	Playing and running	Playing a card game
Family 4	pre-intervention	Making fruit kebabs (unstructured)	Language activity with wooden shapes (structured)	Numeracy activity (structured)
	post-intervention	Outdoor play in the pool (unstructured)	Playing with animals and using the device (structured)	Introducing yes/no with the device (structured)
Family 5	pre-intervention	Treasure Hunt in the house (unstructured)	Charades – word guessing game for kids (unstructured)	Dressing up game (unstructured)
	post-intervention	Reading a book (structured)	Making toast (structured)	Simon says… (unstructured)
Family 6	pre-intervention	Cooking activity – making chips (structured)	Reading activity with Dinosaurs (structured)	Game activity on the iPad + threading (structured)
	Post-intervention	Outdoor activity in the pool (unstructured)	Reading activity (structured)	Game activity on iPad (structured)
Family 7	pre-intervention	Cooking Nutella pancakes (structured)	Floor play with the cars (structured)	Playing with different blocks (unstructured)
	Post-intervention	Cooking Nutella pancakes (structured)	Reading activity (structured)	Playing with different blocks (unstructured)
Family 8	pre-intervention	Cooking activity – making cookies & jam tarts (structured)	Dressing up activity and pirate story (unstructured)	Massage (unstructured)
	Post-intervention	Choosing activity using the iTalk2 (structured)	Choosing an activity with flashcards and iTalk2 (Structured)	Playing with toys

Table 59: Activities at pre-and post-intervention stage

Most of the filmed interactions happened around the kitchen table, the sitting room or the child's bedroom. Four families opted for cooking activities, one family opted for messy play, and two for reading activities. Siblings often chose highly structured language and numeracy activities, iPad activities and cause and effect games, and playing with toys. Unstructured activities seemed to be more popular amongst some families and included trampolining, swimming, rough and tumble, massages, dressing up (role-play). Such activities allowed for free conversations suggesting a structural continuum of dynamic activities and allowed fluidity such as rough and tumble play, pool fun, role play, dressing up, and a Treasure Hunt. Most activities were cooperative and interactive (e.g. making Nutella waffles, kebab sticks, making a sandwich, making jam tarts) compared to games that are typically highly scripted.

d) Intervention phase

Following the filming session, a discussion with the sibling ensued using visual aids to aid comprehension (if necessary) about what they mean by communication and what communication target they will be working on. All these communication targets were documented for each family. This task then helped siblings identify communication goals they wanted to reach for their siblings. They then participated in a goal-setting conversation, and they set goals where they would like to see a change (See Appendix C for more details). The intervention used video feedback of sibling-focal child interactions. Three sessions were held once a fortnight with a maximum of one hour shared review session. During the first session, the researcher guided the siblings towards a discussion on their experiences during the lockdown period and what they think about the process of communication. A goal setting task was then presented, and the siblings filled in the sections accordingly.

During the second session, siblings shared some of the video clips from the baseline data and the researcher (known as the guide in the VIG process) via Microsoft Teams. Through the support of the researcher, the siblings used the principle of microanalysis to discuss which behaviours provided successful communication supports. Siblings observed themselves on video and experienced supportive feedback about their communicative interactions. The researcher supported them to identify their strengths, taking note of examples of positive interactions, concerns, worries and hopes for change. During the third session, the feedback drawn up from the second session was then compared to the original goal setting task, which also served as a self-monitoring exercise for the siblings. The siblings' mother or father was present and were asked for their views following the intervention process. The VIG process necessitates the guider to choose specific examples of successful interactions by selecting and editing video clips before the shared review session. However, this study modified this process to empower the siblings to choose what they think were good examples of AAC goals. In this manner, siblings autonomously reflected on their practices and communication goals rather than influenced by the researcher-led edited video clips.

e) Post Intervention Phase

After the three intervention sessions, the post-intervention observations were conducted with activities of not less than 10 minutes within the home environment, conducted in the same way as the baseline, and used the same measures. Following these observations, a discussion and a review of the initial goals took place to determine whether the goals set by the siblings were successfully achieved. Finally, a sibling questionnaire (see Appendix E) was used to determine how effective the intervention was.

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f) Post Intervention Follow Up

The plan was to apply the observational procedures identical to the baseline and post-intervention stage, three months after the children's last intervention session. Unfortunately, this was not possible due to several constraints concerning the Covid Pandemic, which caused two partial lockdowns in the country and consequently delayed the study phases considerably.

g) Inter-rater reliability

The researcher served as the primary observer for all the sibling-focal child interactions. The second independent researcher (experienced in working with students with disabilities) served as a second observer. Before collecting the data, the second observer reviewed the coding definitions through direct video observations. Before the baseline phase, the researcher and the second independent researcher reviewed the coding definitions and discussed the questions and disagreements. The observers practised coding using video clips which were not utilized during the study until an 80% interobserver agreement (IOA) was reached. Interobserver agreement (IOA) was checked by randomly selecting 20% from each sibling dyad across all six sessions. The second observer coded the data according to the pre-assigned coding procedures for the sibling interactions, focal child initiations/responses and communication modes. Data were collected on the reliability or interobserver agreement (IOA) associated with each dependent variable and the intention that IOA levels meet the minimal standard (lOA = 80%). The point-by-point total agreement was calculated by dividing the total agreed intervals by the total agreed and disagreed intervals, multiplied by 100%. The below table shows the percentage of IOA across the dependent variables and the different activities (Table 60).

Dependent Variable		Mean (%)	Range	IOA (%)
Initiations				
	Sibling initiations	94.3	87-100	82
	Focus-child initiations	96.1	84-100	86
Prompts				
	Prompts by mother	100	100-100	85
	Prompts by father	100	100-100	87
Communication modes				
	vocalisations	99.4	96.1-100	80
	Manual signs	99.6	95.2-100	87
	Speech (single words)	97.5	91.5-100	86
	Use of aided communication	98.6	88.6-100	87
Proximity to				
	Aided system	98.2	90.0-100	90
	Sibling	100	100-100	91
	Mother	100	100-100	85
	Father	100	100-100	92

Table 60: Study 3-Percentage of IOA across activities

h) Ecological Validity

All studies were carried out in the participants' homes, and the materials used were familiar to the participants since the families chose them. The behaviours manifested during data collection were discussed with the family members to confirm that these behaviours were typical of daily behaviours.

i) Generalization

Generalization included the transfer of the target skills across different settings, across different communication partners and tools. The following were noted, i) more than one 'interventionist' involved, e.g. mother, father or sibling; ii) different settings in the home, e.g. kitchen, living room, bedroom iii) different routines/ (structured or unstructured) activities, e.g. snack, toy, game, free play.

j) Treatment Fidelity

To ensure that the siblings carried out the shared review sessions as planned, the researcher used a procedural checklist to self-record the completed steps (i.e. discuss communication goals, write goals, view videos, revise goals, conduct post-intervention interview,

questionnaire). The adherence was calculated by dividing the number of steps conducted by the total steps planned and multiplied by 100%. Thus, a range of 96-100% of the planned steps was obtained. In addition, the researcher also measured whether sibling interaction was a result of the mother's or father's prompting. A checklist was also devised to determine whether the siblings used several initiation strategies when communicating with their siblings. These strategies were adapted from McConachie & Pennington (1997), which included the following: i) getting the child's attention, ii) use multi-modal means of communication where possible, iii) questioning, iv) waiting for the focal child to respond while looking at him/her, vi) provide help (whether it is physical or verbal) and vii) respond. A checklist partly adapted from Carter et al., (2009) was also devised for the adult caregivers (mothers/fathers) to ensure that the following strategies were adhered to: i) enable proximity to siblings, ii) empower siblings to create opportunities for social communication, and iii) provide additional support as needed. Not all the seven strategies from the original Carter et al., (2009) were implemented since the researcher did not want to emphasize the use and access to the aided communication system, neither did she want to make the caregivers aware of the level of encouragement or prompts directed towards the focal child or sibling. The final strategy that the researcher purposefully left out from this checklist was reducing support for the caregivers at the post-intervention stage to investigate whether the caregivers faded prompts and direct support naturally while allowing the siblings to take up a more natural and autonomous support system.

9.2.5 Analysis

a) Quantitative observations analysis

The percentage of intervals during which the focal child used AAC (unaided or aided) to interact with his/her sibling was displayed for both baseline and post-intervention phases.

It was expected that an increase in the percentage of intervals indicated the success of the intervention programme. The percentages of intervals in which focal children used different modes of communication (e.g. vocalisations, signs, communication book) were also included. The percentage of intervals where the focal child initiated towards his/her sibling and when the sibling initiated towards the focal child was recorded for baseline and post-intervention phases. Prompts for initiations both from the mother or father towards the focal child and sibling were calculated for both phases. Changes were also observed in the siblings' proximity towards the focal child, proximity to their mother or father, and an aided communication system (range and percentage).

b) Qualitative pre-intervention interviews

Thematic analysis was chosen as a qualitative analytic approach to understand the factors affecting sibling relationships. Thematic analysis is a qualitative method for identifying, analysing and reporting themes within the data (Braun and Clarke, 2019). More information about this method is available in Chapter 5. Data were analysed according to the six phases of Thematic Analysis. Initially, interviews were audio-recorded and transcribed in detail. Next, transcripts were read and re-read until the researcher familiarized herself with the data. Next, initial codes were generated through a coding process, and common themes were extracted from the coding process. Finally, the themes were reviewed, and key themes were named and defined. Finally, the data was analysed and gathered given the research questions and the extensive literature on family-sibling relationships.

c) Qualitative post-intervention interviews

Thematic analysis was chosen as a qualitative analytic approach for mothers and siblings' semi-structured post-intervention interviews.

Since the parents and siblings were interviewed together, the themes were analysed as a whole. More information about this method is available in Chapter 5.

9.3 Results

9.3.1 Description of participants

Eight families contributed to this study, and sixteen children were participants, seven girls and nine boys. Six families had two children (the focal child and the sibling), but one family had three children, and one had five children, so the sibling closest in age to the focal child was chosen in these latter two cases. Five of the families had same-sex siblings participating in the study. The age range of all the children was between 5-14 years (mean=9.5; median=9). The age range of the siblings was between 8-12 years (mean=10.5; median=11). The age range of the focal children was (mean=8.5; median=8; range=9). There was an age difference of 0 to 5 years (mean=2.6; median=3; range 5) between the siblings.

Focal child's name	*Mother's Age range /years*	*Mother's occupation*	*Level of Education*	*Category*	*Type of household*	*Locality*	*Number of people living in the same house*
Tina	36-45	Executive officer	Certificate/diploma	C1	maisonette	south	4
Mario	36-45	Sales manager	Certificate/diploma	C1	maisonette	central	6
Louis	36-45	Pharmacist	degree	AB	Terraced house	central	4
Jade	36-45	clerk	Certificate/diploma	C1	maisonette	south	4
Massimo	46 years over	Nurse	degree	AB	Apartment	north	4
Leone	25-35	homemaker	Completed compulsory education	N/A	maisonette	south	4
Jeremy	36-45	homemaker	Completed compulsory education	N/A	maisonette	central	4
Bruce	25-35	taxi driver	Completed compulsory education	DE	apartment	south	5

Table 61: Study 3-Family participant data

Thus, of the eight families, four siblings are older than their brother/sister with a disability; one family had twin boys, one of whom was the focal child and one the sibling; and three families had an elder child with a disability. Demographic data were obtained from the maternal questionnaires: age, gender, birth history, age difference, birth order, and type of disability. In addition, the section also includes the child's communication skills, temperament, social and adaptive behaviour. The families participating in the study were all recruited from non-governmental organisations. The families lived in the northern, central and southern parts of the island. All parents had completed compulsory education, and three worked 30 to 40 hours per week. Three mothers were educators or work in the caring profession; two held executive positions, while three were homemakers. The parents' professions or occupations were provided in the questionnaire to identify their socio-economic category (Table 61).

In order to determine the siblings' communication skills (question 10), "Tell me how you communicate with each other?", the choices were "speech", "signs/gestures", "eye pointing/eye gaze", "bodily movements", "objects, pictures, symbols", "tablet, iPad", "physical communication-hugs, tickling, rolling around together, and "I don't think we really communicate at all". Siblings were told that they could tick more than one option. None of the siblings reported that they did not communicate with the focal child. Only one sibling reported using a tablet or iPad to communicate with their sibling. The rest of the participants ticked several options such as signs, gestures, objects, and physical communication.

Sibling	Sibling's Age	Gender	Age difference compared to the focal child	No of siblings	Before/after school programme
Paula	12	F	-2	2	sometimes
Lorian	10	M	-1	5	sometimes
Michael	9	M	nil	2	sometimes
Miriam	12	F	+4	2	sometimes
Ian	8	M	-1	2	sometimes
May	12	F	+4	2	nil
Karen	12	F	+5	2	nil
Elaine	9	F	+4	3	nil

Table 62: Study 3-Sibling participant data

9.3.2 Qualitative Pre-intervention interviews

9.3.2.1 Parent interviews: themes

The common themes extracted from the questionnaires and the interviews were categorized according to overarching themes and themes (Table 63). The four main overarching themes for the mothers were i) family life, ii) relationships, iii) the community and iv) my hopes and dreams. The following table gives an example of each theme data extract for mothers.

	Over-Arching Theme	Themes	Theme Data extract
a	Family life	Activities in the house & Leisure activities Coping with Stress	"he loves to sleep in the morning, so I have chance to clear up. After we go swimming or walking for a ride with the car". "I spend many nights awake because of her acid reflux attacks."
b	Relationships	Relationship with my son/daughter. Relationship between the sibling and focal child	"Jeremy is very attached and loves hugs and playing with me." "can get frustrated with Massimo because of his lack of play skills". Ian is jealous of attention from outsiders to Massimo. Massimo looks up to Ian a lot and after tries to engage but is not sure how."
c	The community	Support services	"We have had a lot of support from Embrace. They are so dedicated".
d	My hopes, my dreams for…	I wish….	"I only wish is for my son to be happy and independent".

Table 63: Study 3-Overarching themes for mothers

a) Family life

This overarching theme comprises two sub-themes: activities in the house and leisure activities and coping with stress.

    i)   Leisure activities

The researcher asked the mothers what the siblings enjoy doing during the day and how they spend the week. Mothers reported that the children like to listen to music, do their daily stretching, join their mother in the kitchen to watch her cook, engage in messy play, play in the ball pool, watch movies, go out, dance and sing, and dress up and role play. In addition, some mentioned how they manage to organise their week

> "*he loves to sleep in the morning, so I have chance to clear up. After we go swimming or walking for a ride with the car.*" (Leone's mum)

    ii)   Coping with Stress

The maternal questionnaires pinpointed the major issues encountered as a family, including frequent hospitalization and major surgeries, including hip surgery and other interventions such as removing adenoids and tonsils, glue ear, grommets, and an endoscopy. In addition, they reported sleepless nights due to acid reflux, hip pain, epileptic seizures, respiratory difficulties and frequent bedwetting: "*I spend many nights awake because of her acid reflux attacks.*" (Tina's mum)

b) Relationships

This overarching theme comprises two sub-themes: relationship with my son/daughter and relationship between the sibling and focal child.

i)   Relationship with my son/daughter

Mothers gave due importance to the family relationships, and that they try and act as role models towards the focal child. Their situation as mothers of a child with a disability offered them the opportunity to appreciate diversity and teach them to become independent and responsible. This positive parental attitude is reflected in the way mothers talk about their child with a disability. For example, Bruce's mother reports that: "*me and my son we are a lot attached. He doesn't do nothing when I am at home.*" Jeremy's mother remarked how attached her son is to her and the need to communicate with her "*Jeremy is very attached and loves hugs and playing with me.*"

Mothers spoke about the positive attitude towards the focal child: "*Jeremy is a lovely boy who seek mum's attention most especially when he needs to communicate.*" They describe the focal child as happy and trusting with a "*secure and firm relationship*" (Tina and Paula's mum). Mario's mum describes her son as: "*a very joyful person, very cheeky and very stubborn.*" Some families described the child as calm and happy, while others described them as highly strung, stubborn or agitated.

> "*My son and I have a great relationship, and now I can understand him more. My son is a great boy; he fulfils our lives. He's very sensitive and very stubborn, but we always manage to complete each task with a lot of patience and hard work.*" (Mario's mother)

> "*We have positive relationships although we do argue a lot.*" (Massimo's mum)

ii)   Relationship between sibling and focal child

In this section, mothers reported the siblings' roles concerning the focal child. For example, some parents described the siblings as caring, amusing, attentive and loving towards the

focal child. The mother also commented that the focal children look up to their brother or sister. For example, Massimo's mum pointed out that Massimo looks up to his brother a lot and often tries to engage in activities but is not sure how to do so:

> "The relationship is good in general. Ian can get frustrated with Massimo because of his lack of play skills." (Massimo's mum)

Jeremy's mother stated that Jeremy loves his sister and seeks her attention: "Jeremy loves his sister so much, and they don't play quite often, but when they do, they enjoy it a lot." Not all mothers mentioned or were aware that they might be giving more attention and assistance to the focal child and only Massimo's mum pointed this out. She stated that the sibling gets jealous of the attention from outsiders about the focal child.

> "Ian is jealous of attention from outsiders to Massimo. Massimo looks up to Ian a lot and after tries to engage but is not sure how." (Massimo's mum)

Mothers reported that siblings are generally optimistic about their focal child. They feel that although the impairment exists, the families have learned to appreciate the child's achievements: *"Ian is quite protective of Massimo and is proud of his achievements."* (Massimo's mum). Mothers hinted that the siblings feel embarrassed when their brother or sister acts up and thought they get *"embarrassed by certain behaviours in public."* (Massimo's mum). Bruce's mum reported that Bruce is happy to be around his siblings at home:*"my son understand everything what is going on in our house. He is totally happy when they are at home.*"

Mothers describe the siblings to be supportive and caring. For example, Tina's mum thinks that Paula is very supportive: *"Paula is supportive, protective and caring.*" Jeremy's mother described Jeremy's and Karen's relationship to be strong and fulfilling:

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"*Jeremy seeks for his sister Karen he loves her so much. He likes to play with her especially roughly he likes her company and likes to see a friend of Karen on video call.*"*(Jeremy's mum).*

Mothers generally reported the siblings to be supportive, protective and caring. Mothers report that: "*He gets along well with his siblings; they love to interact.*" (Mario's mum). One of the mothers reported that her daughters' relationship was "*happy, trusting, secure and fulfilling.*" (Paula and Tina's mum) while Mario's mum describes him as "*a very joyful person, very cheeky and very stubborn.*" Massimo's mother described her child as "*very tactile, and the relationship is very close because they hug a lot.*" She described the relationship as good in general, but she also highlighted the sibling's frustration with the focal child because of "*his lack of play skills.*"

c) The community

i) support systems

Mothers mentioned weekly therapeutic sessions such as physiotherapy, therapeutic horse riding, Padovan therapy, hydrotherapy, speech therapy, private tutors, occupational therapy, and behavioural therapists. They added that the siblings had built good social networks that the siblings built with their peers, school, and community. As a result, they have good connections with the wider community, and siblings enjoy weekly sports activities, drama classes, gymnastics, dancing and singing lessons. Massimo's mother stated that they have alot of support from an NGO: "*We have had a lot of support from Embrace. They are so dedicated*". Mothers describe the support systems available for their child, including weekly hours of physiotherapy, occupational therapy, horse riding, behaviour therapy, music, private tuition, swimming and ICT.

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Mario's mother claimed that her son improved with weekly occupational therapy and feels more relaxed when he has his horse-riding sessions. Massimo's mother describes a non-governmental organisation that offers respite and after school activities as *"easily his favourite."*

d) My Hopes and dreams

Towards the end of the questionnaire, mothers were asked about their wishes and dreams for the focal child. Most mothers had realistic expectations for their child hoping they would be happy, independent and with a small circle of friends. Mario's mum wishes for her son to be happy and independent: *"I only wish is for my son to be happy and independent."* (Mario's mum). Other mothers wished that their children could learn how to walk and communicate verbally: *"My dreams are that he will be partly independent at least at home and to manage to communicate his feelings."* (Leone's mum).

> *"I dream that he will be able to achieve semi-independence and function as a contributing member of society. I dream that he will have a small but good social network". (Massimo's mum).*

Bruce's mother wants her son to be able to walk and talk: *"my dream is to see him walking, and he will speak. My son is a big fighter for his life, and I always be there for him until I die."* (Bruce's mum). Jeremy's mum would like her son to be more independent and loved:

> *"My dreams are that my son can be more independent, hope he will be able to say few words, and live a happy life where he is surrounded by love." (Jeremy's mum)*

9.3.2.2 Sibling pre-intervention interviews: Themes

Siblings expressed their feeling and perceptions given the qualitative pre-intervention sibling interviews were made up of three over-arching themes a) my everyday life, b) my connections, and c) the way I see it (see Table 64).

	Over-Arching Theme	Themes	Theme Data extract
a	My everyday life	The way I feel about ….	"It is nice when Jade uses her tablet to talk to me."
		What my role is …	"I think I am a caring sister." 'I think I'm like a helper. Mario learns a lot from me as I am very patient'. (Lorian)
		Leisure Activities	"we love to jump on the trampoline together".
b	My connections	My family My social network	"there is a positive relationship, although we do argue a lot". "I enjoy going for drama lessons and singing".
c	The way I see it	The way I perceive my brother/sister. My hopes, my dreams for	"He is smart and loving." "I wish she could communicate with her voice." "I wish he can live a good life and be happy."

Table 64: Study 3-Overarching themes for siblings

a) My Everyday Life

i) The way I feel about:

Siblings described several qualities that they were able to identify and learn to appreciate life circumstances. Some siblings hinted that they feel embarrassed at times when their brother or sister acts up. Siblings seem reluctant to bring some friends for a sleepover because they become embarrassed with the focal child's particular "*behaviours*". They reported that they are not always invited to birthday parties, even if they enjoyed them. They said it would be nice that their brother/sister was also invited to birthday parties. Some siblings reported that it is more fun to speak to the focal child and reply by signing or using the device "*It is nice when Jade uses her tablet to talk to me.*" (Miriam). They reported that they enjoy playing with their siblings, and they frequently help them during the day.

ii)What my role is:

Siblings also reported taking up more caregiving roles. They reported that the focal child needs help during the day with dressing, feeding, going to the bathroom, washing and walking. They have different perceptions of how they see themselves in relation to the focal child. Some see themselves as a caring sister or brother: "*I think I am a caring sister.*" (Paula). Others feel they are best friends or helpers to the younger brother. Finally, some try to be role models for the focal child. For example, one of the siblings commented that he helps his mother clean up, help his brother with his homework, and blow his nose. *'I think I'm like a helper. Mario learns a lot from me as I am very patient'.* (Lorian). Others think they are also caregivers and need to help their brother or sister with their basic needs, especially when they have a physical impairment. They said that even though they have such roles in their lives that their peers do not experience, they are still very happy in their roles.

iii)   Leisure activities

Apart from additional roles and responsibilities, siblings were asked about leisure activities at home and in the community. In addition, the researcher asked the siblings what they enjoy doing during the week and the frequency of such activities. Listening to music was one of the most favourite activities; other activities include playing with the sibling pretending to be the teacher. Other weekly activities included helping in house chores, visiting family members, going for a swim and going shopping. Monthly activities included going out in the playing fields, visiting cafes and restaurants. The least common joint activities mentioned were going to the cinema and special trips abroad with family. They didn't play with electronic games such as the XBOX and PlayStation. Siblings preferred to play independently however, were unable to do so when the focal child was around.

However, one of the twin boys loved to engage in rough play and indicated their favourite activity *"we love to jump on the trampoline together."* (Michael). Siblings enjoyed each other's company, from simple activities such as taking the dog for a walk to a more complex structured activity, such as reading. For example, one of the siblings loved reading stories to her sister at bedtime or offer her a massage.

b) My Connections

This over-arching theme comprises two themes, i) my family and ii) my social networks.

i)   My family

Siblings reported fulfilling and supportive relationships with their families. In addition, siblings reported ending up taking responsible and independent roles. Siblings described what they do with their families: *"during the week, we go to school and do homework and during weekends we go out as family and we have fun."* (Paula)

One of the siblings reported that sometimes it is difficult to find a place to enjoy family time. It was more flexible in leaving the focal child in respite care while the rest of the family enjoys a weekend break in a resort. However, some siblings commented that it would have been much better if their disabled siblings had been with them and enjoyed themselves more. Paula reported that their family sometimes chooses a resort with a heated indoor pool so that her sister could also use the facilities and enjoy themselves as a family.

> *"sometimes we go to Luna and take her with us because there is a heated pool there and we can all have fun together as a family." (Paula)*

ii)   My Social Networks

Siblings were generally positive about the social networks with their peers, in school and the community. They have good connections with the wider community, and siblings enjoy weekly sports activities, drama classes, gymnastics, dancing and singing lessons. Ian reported that: "*I love to go to drama and singing lessons, and sometimes Massimo comes with me as well.*"

c) The Way I See It….

This final overarching theme comprises two themes i) the way I perceive my sibling and ii) hopes and dreams.

i)   The way I perceive my brother/sister

When asked how they perceive their disabled brother or sister, siblings opted to draw them. Ian described his brother who has "*dark brown hair, small ears, chochalate eyes, smooth skin with tiny hairs, tall, frechals (freckles), big nose and loves to stimm.*"
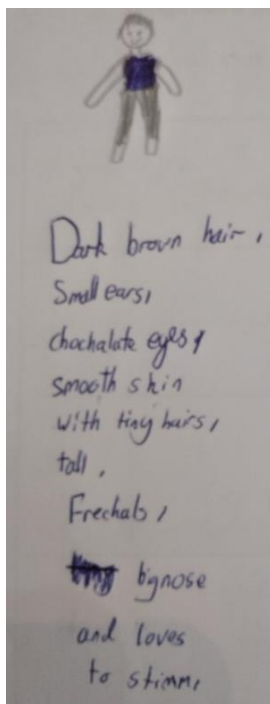
Figure 5: Ian's drawing

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Some siblings described their brother or sister as fun, special, amusing, and even annoying. Generally, siblings positively described their focal child, and some of the siblings highlighted their characteristics "*he is loving, caring, smart and fun to be with.*" (May). Siblings generally were very enthusiastic to highlight all the strengths that the focal child has. For example, one of the siblings mentioned that his brother tends to scratch him, but then he corrected himself "*he likes to scratch but a little bit, he loves his music.*" (Lorian). When asked what they fought about, siblings mentioned food, toys, tablet and schoolbooks "*We fight when my sister wants my mobile or dolls.*" (Miriam). Ian reported that at times his brother takes his food: *"Sometimes Massimo takes my food and sometimes eats and drinks my food and water."* (Ian). All siblings are very proud and protective of their brother and sister. They said that they "*would not change a thing".* Other siblings felt that their brother or sister could do everything with some support. Siblings generally were proud of their disabled siblings, and some described them as "*smart*" and "*clever*", "*he loves to tell people what to do and where to go.*" (Ian). Both Paula and Miriam think their sisters are adorable "*My Sister is adorable and very friendly*" (Miriam); "*..she is so beautiful. She always smiles, she could take the sadness out of you with her laugh*" (Paula).
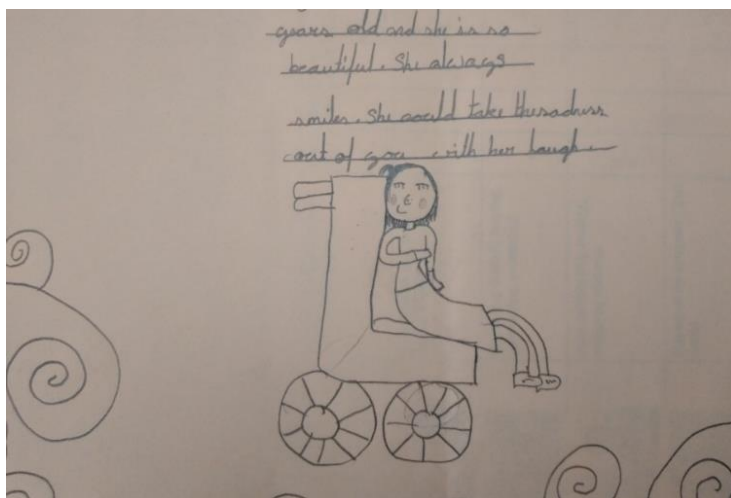

Figure 6: Paula's drawing

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ii)   hopes and dreams for…

Having a brother or sister with whom the sibling can communicate easily is the sibling's dream. They are very keen to learn how they can teach the focal child to communicate better. They did not take it as an extra task but can improve their relationship with their sister or brother. Siblings perceive the focal child's physical and communication needs as a barrier, and one of the siblings was very vocal in her wish to have their brother or sister talk like them "*I want Jade to start talking and communicate.*" (Miriam). Most of the siblings' expectations are to have a better quality of life and become as independent as possible; "*I want Leone to manage to live as normal as possible.*" (May); "*when he grows up, he lives happily with me.*" (Ian); "*I wish that he will succeed be strong, happy, and have a good life.*" (Lorian).

9.3.3 Communication Goals

During the intervention phase, the researcher shared examples of the videos taken during the baseline phase and both siblings, and their parents were free to comment and take notes of what went well and what needed to improve. The parents present during these sessions were predominantly the mothers. This was expected since they were primarily involved in the caregiving process, and the sessions were conducted whenever the mother was also available. Both siblings and mothers contributed to this phase either separately or jointly. Sessions were held in the kitchen, at the kitchen table.

Mothers and siblings both set communication goals, which they had written beforehand or developed during the mutual discussions, and these were then shared with the researcher. After the first intervention session, the goals were written, read and shared.

Siblings and their mothers were also allowed to modify their communication/AAC goals if they felt the need to do so, and this typically happened by the third session. Table 65 represents the Communication Goals for the family, the siblings and the focal children. After completing the baseline measures, such goals were devised and designed during the goal-setting phase (see Figure 7). The communication goals were further discussed in terms of inner, middle and outer circles. These circles were compared for each of the eight families with the main aim of extracting the opportunity and access barriers to active participation for these families at generic (outer), sibling-set (middle) and highly specific (inner) circles.

	Outer Circle *(Generic goals for the family)*	*Middle circle* *(Specific Goals for the sibling)*	*Inner circle* *(highly specific & explicit goals for the focal child)*
Tina	Tina will participate and will initiate more during simple choice-making activities and daily activities in the house. Tina will reply to simple 'yes' and 'no' questions during lunchtime Tina will greet familiar people as she feels them by her side.	Paula will hold the iTalk 2 in the middle and support Tina's arm before making a choice. Paula will physically and verbally prompt Tina to press the switches on the iTalk 2 before a choice-making activity or to say "hello". Paula will ask Tina questions related to food and drink: 'Do you want to drink?' She will then present the device and physically prompt her to press the switch accordingly.	Tina will select the correct answer from the iTalk2 with 80 % accuracy. Tina will use the device appropriately to reply to 'yes' and 'no' questions during lunchtime 4 out of five consecutive times. Tina will greet familiar people with minimal verbal prompts as they come near her 4 out of 5 times.
Mario	We would like Mario to increase his sitting tolerance and maintain eye contact. Mario will understand signs showing simple commands: stop, wait, come here, sit down.	Lorian will present two flashcards for the basic signs, so Mario can point to them during activities. Lorian will present two flashcards showing the number represented in keyword signing, and Mario matches the flashcard to the number. Lorian will encourage Mario to do the sign of a named number. Lorian will sign the command and carry out the command himself while physically and verbally prompting Mario when necessary.	Mario will spontaneously select the correct flashcard in 4 out of 5 attempts. Mario will match the keyword sign representing the number independently 4 out of 5 times. Mario will sign the named number up to 5 independently in 3out of 5 times. Mario will carry out the commands given to him through signing in 4 out of 5 occasions.
Louis	Louis will use some keyword signs and flashcards to indicate his needs. Louis will use some keyword signs and visuals to choose everyday activities. Louis will communicate 'I want more'/'I don't want more' through flashcards or by signing.	Michael will present four flashcards so that Louis can indicate a need. Michael will provide opportunities to Louis where he can make choices during everyday tasks Michael will encourage Lorian to communicate want/don't want more' during various activities.	Louis will spontaneously use five words/keyword signs to indicate his needs and wants without verbal and physical prompts. Louis will make choices by signing and/or using visuals on 4 out of 5 occasions. Louis will communicate want/do not want by signing or using the correct

			flashcard during everyday activities 80% of the time.
Jade	Jade will be introduced to her new tablet with Avaz software during numeracy and literacy games. Jade will use her tablet to greet familiar people Jade will use her tablet to communicate everyday needs: eat, drink, toilet	While navigating through the screen, Miriam holds Jade's hand and helps her press "stop" and "finished". Miriam will expose Jade to the greeting page on the tablet to greet family members during the day. Through hand on-hand support, Miriam will show Jade how to use her tablet during lunchtime and toileting.	Jade presses "stop" and "finished" spontaneously and without prompts 80% of the time. Jade will use the tablet with minimal verbal prompts to greet family members 4 out of 5 times. Jade will communicate eat, drink and toilet with minimal verbal prompts with her tablet 4 out of 5 times.
Ian	We would like Massimo to be able to use more single words and short phrases. We would like to teach him communication skills through music and activities. We would like Massimo to wait for his turn during a simple game	Ian will provide Massimo with flashcards, and with the help of his mother, use some signs to teach Massimo. Ian will show Massimo flashcards of happy and sad, and Massimo must choose the card that best matches his feelings. Ian will say, sign and expose Massimo to the flashcard showing 'wait' during simple games.	Massimo will express five single words/signs spontaneously without any prompts, 4 out of 5 times. Massimo will communicate basic emotions through flashcards independently, 4 out of 5 times Massimo will wait for his turn without prompting when he shows the flashcard 80% of the time.
Leone	We would like Leone to use speech like us. We wish Leone to learn words like 'more' ', stop', 'enough', and 'no more so that he will say them to us instead of getting frustrated.	May will help Leone spell some words on Clicker 7 using predictive text. May will help Leone familiarize himself with the favourite activities page on Clicker 7. May will help Leone familiarize himself with these words on the device and use them appropriately during activities.	Leone will spell five words on Clicker 7 with minimal support, 4 out of 5 times. Leone will use his device to choose the favourite song independently 4 out of five times. Leone will use these words with minimal verbal prompting on 4 out of 5 occasions.
Jeremy	Jeremy will use his tablet to participate in daily activities We would like Jeremy to retrieve basic colours and shapes. We wish that Jeremy will use his device to tell us what he wants to do while playing with blocks.	Karen holds Jeremy's hand so he can select the cells on the device through physical and verbal prompting. Karen will present the flashcard with a shape or colour, and Jeremy will be encouraged to name it using his tablet. Karen helps Jeremy familiarize himself with these keywords; more, on, put, make, big, colours when playing with his blocks.	Full physical prompting of the device is reduced to partial physical assistance 80 % of the time. Jeremy will use the tablet to identify basic colours and shapes with minimal prompts 4 out of 5 times. Jeremy will use these words while playing with blocks 80% of the time.
Bruce	We would like Bruce to initiate more and participate during storytelling sessions We would like Bruce to participate during daily activities We would like Bruce to indicate 'more' during lunchtime and massage sessions It would be nice if Bruce can choose a favourite object	Elaine will hold Bruce's iTalk 2 in the middle so Bruce can press the correct button. Elaine will help Bruce familiarize himself with his device during cooking to name the ingredients Elaine will help Bruce familiarize himself to ask for 'more' during lunchtime and massage sessions with full physical and verbal prompting. Elaine will help Bruce choose a favourite object from a choice of 2 using his device during favourite activities with full physical prompting.	Bruce will use iTalk two and read a short sentence during storytelling activities 4 out of 5 times. Bruce will name the ingredients during cooking activities with full physical prompting 80% of the time. Bruce will ask for 'more' during lunchtime and massage sessions with minimal physical support 4 out of 5 times. Bruce will choose his favourite object using iTalk 2 during a favourite activity with minimal assistance 80% of the time.

Table 65: Study 3-Communication goals for each family
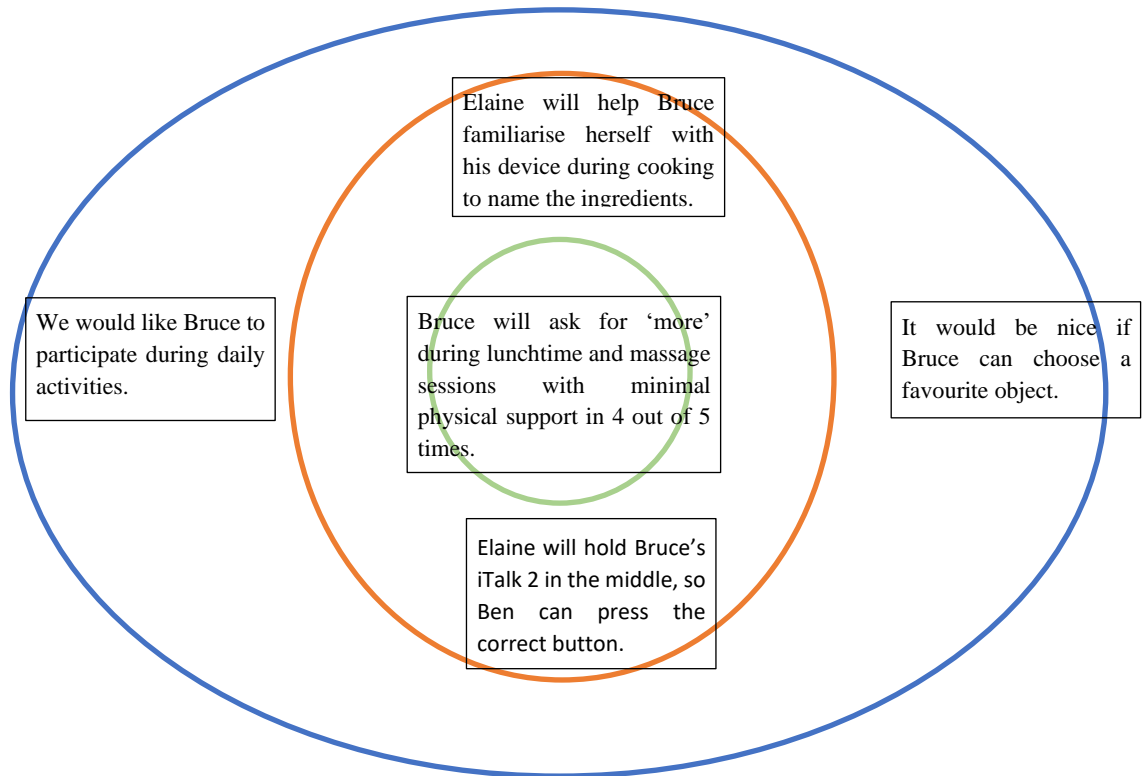
Figure 7: An example of Bruce's inner, middle and outer circle

a. The Outer circle

The outer circles AAC/Communication goals were contributions by the family and consisted of generic goals. There were several differences and some commonalities amongst these goals. Most families mentioned that they wish their son/daughter could participate more or initiate more during everyday activities. In two families, the siblings came up with goals that were either very ambitious or unrealistic. These consisted of statements such as "*I wish my brother could talk just like me.*"

b. The Middle Circle

Within the middle circle, these would be the siblings' goals with the researcher's help. Some of these goals are common, such as Bruce's & Tina's sister, who placed the switch in the middle and offered physical support.

Similarly, Jeremy's & Jade's sisters had similar goals based on access issues, where they had to make sure the focal child isolates his/her finger and be physically guided towards the correct grid cell on the VOCA.

<u>*c. The Inner Circle*</u>

The inner circle were goals set for the focal child were very specific and highly explicit. Due to the specificity of the goals, it was very unlikely that the focal children shared the same goals, but there was a common theme for all of the children. All focal children were working to become communicators who were more functional and participated actively in daily activities. Some of the children's specific goals involved reducing physical prompts to not rely on the more *competent* communication partners leading to learned helplessness. Possibly the main emphasis in these inner (and middle circle) communication goals was the presence and availability of the AAC system, exposure to the system (VOCA, signs, flashcards, medium-tech aid) and access to aided language stimulation strategies which provided a scaffold for the focal child. In this case, the more competent communication partner (the sibling or the sibling and parent) provided the proper scaffold for the focal child, which helped address the inner circle goals.

9.3.4 Quantitative Results

The results below show below represent an average of the three baseline measures for both pre-and post-intervention data.

 a) Initiations

Table 66 shows the number of initiations by focal children toward the siblings and siblings initiated toward the focal child. All focal children at the pre-intervention level demonstrated a lower mean percentage of initiating (mean 47.6, range 10-100, SD 32.1) than the siblings

(mean 75.7, range 50-10, SD 18.8). At the post-intervention level, focal child initiations were very similar to pre-intervention (mean 50.6, range 13-86, SD 22.8) and remained lower than sibling-led initiations (mean 75.6, range 26-100, SD 23.8). There was a very slight increase in the means for the focal child at the post-intervention level with a reduced range and SD. At the post-intervention level, the sibling initiations means were the same while the range and SD increased.

Interactions	F1	F2	F3	F4	F5	F6	F7	F8	Mean	Range	SD
Focal child-initiations (baseline) (%)	10	23	100	50	86	50	46	16	47.6	10-100	32.1
Focal child-initiations (post-intervention) (%)	57	13	73	86	53	40	50	33	50.6	13-86	22.8
Sibling-initiations (baseline) (%)	50	70	97	80	76	50	83	100	75.7	50-100	18.8
Sibling-initiations (post-intervention) (%)	83	26	100	80	100	60	80	76	75.6	26-100	23.8

Table 66: Study 3-Mean percentage of intervals of sibling-focal child interactions by condition

Overall, there was an improvement in the number of initiations for four focal children (family 1,4,7, and 8), but a reduction in the other four (family 2,3,5 and 6). The number of sibling initiations decreased at the post-intervention stage for families 2, 7 and 8). Families 7 and 8 experienced an increase in focal child initiations and a decrease in sibling initiations. The number of sibling initiations at the post-intervention level increased for families 1,3,5 and 6.

b) Communication modes

Table 67 indicated the total frequency count for communication modes averaged across all three baselines and post interventions.

	Mode	F1	F2	F3	F4	F5	F6	F7	F8	Mean	Range
Pre-intervention	signs	0	3	0	1	6	0	3	0	1.6	0-6
Post-intervention		0	0	0	0	0	0	0	0	0	0-0
Pre-intervention	Vocalizations	0	3	16	16	0	13	0	5	6.6	0-16
Post-intervention		0	0	0	5	3	15	0	4	3.4	0-15
Pre-intervention	Speech (single words)	0	0	25	4	45	4	0	0	9.7	0-45
Post-intervention		0	0	27	0	28	6	0	0	7.6	0-28
Pre-intervention	Use of aided communication	2	0	0	0	0	0	22	0	3.0	0-22
Post-intervention		17	4	0	28	0	5	15	6	9.4	0-28
Pre-intervention	Number of SGD messages	2	0	0	0	0	0	22*	0	3.0	0-22
Post-intervention		17	0	0	28	0	5	15	6	8.9	0-28

Table 67: Study 3-Total frequency count of communication mode

Concerning unaided means of communication, signs were used by four focal children at the pre-intervention stage (F2, F4, F5, F7) initially, which were not present at the post-intervention stage. Five children used vocalisations (F2,3,4,6,8) with a marked decrease for three families (F2,3,4), and two families remain the same at the post-intervention stage (F6, F8), and one focal child showed a slight increase (F5). Four children used single words at the pre-intervention level, mostly unintelligible (F3,4,5,6). There was a slight increase in single words in focal children (F3 and F6) at the post-intervention level and a marked decrease in focal child 5. Regarding the use of aided communication, only two children used it at the pre-intervention stage (F1, 7). At the post-intervention stage, six children used an aided means of communication (F1,2,4,6, 7,8). There is a relatively high user (F7) at the pre-intervention stage, but this was physically prompted and assisted by his sister, and there were no spontaneous attempts from the focal child's end.

At the post-intervention level, while this user decreased the number of attempts, these were all spontaneous. For the others, there was a marked increase for two children (F1, F4) and slight increases for three children (F2,6,8). Aided communication increased at the post-intervention stage for five children, but overall, the range of communication modes reduced pre-post intervention except for aided communication and the number of SGD messages. This can be determined from the total frequency count during which the focal child used their SGD to interact with their sibling. Before the intervention, only two of the focal children used their SGD to interact with siblings (F1 & F7). The other focal children used several vocalisations and single words, which were at times unintelligible. The focal child in Family 3 used single words mostly in repetition and not necessarily spontaneously in response to his brother's initiations. He also used some single words in repetition to show protest and defiance, for example, using 'no'. The focal child in Family 5 used single words and some keyword signing, especially when highly structured activities were introduced, for instance, during a Charades game. This was similar to the focal child in family 3, where the siblings were involved in more structured activities such as I spy. No manual signs were noted from the focal children at the postintervention stage; however, one child reverted to single words and an aided communication system (F6). Table 67 represents the total number of SGD messages generated during an activity. Five children generally showed an increase in the communication mode, mainly when an aided communication system was introduced (focal child 1,2,4,6 and 8). The number of messages for the focal child at the pre-intervention stage in Family 7 was not spontaneous but all physically prompted by his sister. He showed a slight decrease in the use of the speech-generating device (from 22 to 15 attempts); however, he had more spontaneous initiations at the post-intervention stage rather than having his sister physically prompting him to touch the screen and select the correct cell.

c) Prompts from parents

Table 68 presents the percentage of prompts for mothers or fathers' initiations as an average across the three activities directed to siblings or focal children. Such prompts included "*come on Tina.*", "*What colour is this Jeremy*?" Both mother and father were present during the interactions, and on two occasions with two different families, both parents used words of encouragement and positive reinforcers.

Phase	Mothers' & Fathers' Prompts	F1	F2	F3	F4	F5	F6	F7	F8	Mean	Range
Pre-intervention	father's total prompts (%)	NP	NP	33	NP	NP	53	13	NP	33	13-53
Post-intervention		NP	NP	NP	NP	NP	NP	NP	NP	NA	NA
Pre-intervention	Father's prompt to sibling initiations (%)	NP	NP	23	NP	NP	6	NP	NP	14.5	6-23
Post-intervention		NP	NP	NP	NP	NP	NP	NP	NP	NA	NA
Pre-intervention	Father's prompt to focal child initiations (%)	NP	NP	10	NP	NP	47	13	NP	23	10-47
Post-intervention		NP8	NP	NP	NP	NP	NP	NP	NP	NA	NA
Pre-intervention	Mother's total prompts (%)	99	49	32	89	90	26	30	62	59.6	26-99
Post-intervention		0	73	36	99	19	20	40	26	39	0-99
Pre-intervention	mother's prompt to sibling initiations (%)	13	16	16	6	40	3	10	26	16.2	3-40
Post-intervention		0	33	20	3	6	0	0	20	10.2	0-33
Pre-intervention	Mother's prompt to focal child initiations (%)	86	33	16	83	50	23	20	36	43.3	16-86
Post-intervention		0	40	16	96	13	20	40	6	28.8	0-96

Table 68: Study 3-Mean percentage of parent prompts according to condition

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[8] Not present during the interactions

Alternatively, words of praise were used towards the focal child with phrases such as "*good boy*", "*well done*" while clapping their hands and vocalising with pleasure. The fathers present in all activities at the preintervention stage were Families 3,6 & 7.All mothers were present in the room for all activities at the pre-post-intervention stage. The mean percentage of maternal prompts addressed to focal children at pre-intervention across families was (mean=43.4, range=16-86), and at post-intervention, this was (mean=28.8, range=0-96). This indicates that mothers directed more prompts towards focal children at the pre-intervention stage. The mean percentage of maternal prompts directed towards the siblings across families at the pre-intervention stage was mean=16.2 (range=3-40). This was mean=10.2 (range=0-33) at the post-intervention stage, indicating a slight decrease in the mean percentage. The number of maternal prompts directed towards the focal child decreased considerably at the post-intervention level (from 43.3% to 28.8%), indicating that siblings were more proactive and were making more initiations without the necessary prompts or commands from the mothers. This result also implies that siblings were taking over their mother's style of initiating and responding. Siblings used words of encouragement and paused to allow the focal child to respond. One of the parents (F8) reminded the sibling to pause by saying *"Tih ċans" (*give him time to respond) during one of the sessions at the post-intervention phase.

d) Proximity

Table 69 presents the percentage proximity of the AAC system, siblings, and parents. Only three families had an aided communication system in close proximity, which was not for all the sessions (Family 1,4,7). For some families, there was no access to an aided communication system at the pre-intervention stage.

This was not because the system was not taken out and used during the session but because the families had no access to the device at home for some reason or other. Due to the Covid measures taken at a national level, families could not access the local assessment AAC team (ACTU), and those families who were in the process of trialling a device had their device trial on hold. All focal children were in proximity to their siblings during the baseline condition (mean=95.5%, range=90-100). This was also the case for siblings during the post-intervention condition, where they were in close proximity for all the sessions (mean=97.7%, range=90-100).

Phase	Level of Proximity	F1	F2	F3	F4	F5	F6	F7	F8	Mean	Range
Pre-intervention	Proximity to the aided system (%)	33	NA	NA	66	NA	NA	66	NTO[9]	55	33-66
Post-intervention		66	66	33	66	33	33	66	66	53.6	33-66
Pre-intervention	Proximity to sibling (%)	100	100	90	96	96	90	96	96	95.5	90-100
Post-intervention		100	100	100	96	100	90	100	96	97.7	90-100
Pre-intervention	Proximity to mother (%)	33	33	0	96	66	30	96	35	48.6	0-96
Post-intervention		100	66	100	100	66	30	100	66	78.5	30-100
Pre-intervention	Proximity to father (%)	NP[10]	NP	NP	NP	NP	23	96	NP	59.5	23-96
Post-intervention		NP	NP	NP	NP	NP	NP	NP	NP	NA[11]	NA

Table 69: Study 3-Proximity to aided system, sibling, and parents

Not all mothers or fathers were in close proximity to the focal child during the pre-intervention stage; however, they were always in the room where the activities were taking place. Fathers of families 6 and 7 were in close proximity during some of the sessions (e.g., cooking chips or spreading Nutella on waffles).

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[9] Aided system available but not taken out during the session
[10] Caregiver not present during activity
[11] System not yet available to the family

One of the fathers (F7) was present in the room and in close proximity during two baseline sessions (Nutella and shapes activity). None of the fathers was actively participative at post-intervention stage. Mothers were involved in filming some of the post-intervention data, and therefore, while they were not in close proximity all the time, they were still present in the room and could be heard prompting the siblings or whispering and encouraging the focal child to respond.

9.3.5 Qualitative Post Intervention interviews

The post-intervention interview consisted of questions about the intervention (see Appendix E. A research assistant not involved in the intervention study conducted the questions relating to social validity, so the main researcher would not influence the families and cause a social desirability bias. The research assistant was experienced in the field of severe disabilities and worked in the early intervention service. The research assistant interviewed the mother and siblings to determine whether they thought the intervention was beneficial and whether the success was due to other factors.

These interviews were conducted online via Microsoft Teams. The mothers were present throughout the interview and helped clarify any misunderstandings between the siblings and the research assistant. Common themes were extracted for the mothers, siblings, and focal children. The themes were analysed together since the participants were interviewed together (see Table 70). The themes were as follows:

	Over-arching Theme	Theme	Theme extract
A	Training sessions	Sometimes the sessions worked well	"I liked it that I could teach him communication skills through music and activities like the ones at Embrace". (Ian). "We have learnt some signs, and we can use sign language" (Vale). "Sometimes it was a bit hard because when we tried to communicate, he pushes us away. But sometimes he obeys". (Lorian). "The training wasn't a waste of time because now we can use the goals, we wrote for Jeremy's IEP meeting". (Jeremy's mum) "I know I cannot look him in the eye because you can provoke him, but I could use Clicker with him, which was good." (May)
B	Communication and use of AAC	We can communicate better	"it wasn't easy-he improved a lot in communication-mummy is understanding you more, Mario. More time for Mario." (Mario's mum). "he chooses the pictures that he likes. Like he did with Mummy." (Vale). "Sometimes you cannot communicate with him, and it is frustrating. It is really hard to learn his language." (May) "I would say wrong guesses on purpose to make it more fun. Sometimes I use all of them" (pictures and signs) (Ian)
		We are using the tablet more	"I think Mario can communicate better; he has the communication, iPad and flashcards. With the iPad, he can choose what he wants, we don't need to ask him all the time, and with the flashcards, we can ask him for school, and he chooses." (Lorian)
C	Experiences during lockdown	Lockdown wasn't easy	"I felt a bit helpless at times because we lost our routine, and Massimo became very oppositional". (Massimo's mum) "I didn't like lockdown because I couldn't go to the beach. He stayed on the TV, and I helped him." (Vale) "May ħaditha bi kbira għax kellha ħafna HW u ma setgħetx tmur l-iskola u ddejqet ġewwa. Dawra bil-karozza biss". (May's mum) "It improved when we were together most of the time and playing more creatively now. Even his speech has improved. Last year that had improved, but then it regressed, and he decreased his language skills, but now it is improving." (Ian) "Social interaction was hard because Massimo was not able to follow 'meets and greets' online. Having said that, it was nice to be able to focus more on everyday skills, washing, dressing himself." (Massimo's mum) "Lockdown wasn't bad, I still met my friends, but I stayed at home. It wasn't the easiest with Mario because when he wants to watch TV, we do a tiny tantrum." (Lorian)

Table 70: Study 3-Common Themes for mother -sibling-focal child post-intervention interviews

a) Sometimes the sessions worked well.

During interviews, families generally responded positively about their experience of video interaction guidance and goal setting tasks. Siblings found video interaction very interesting and requested more information on creating more opportunities for the focal child. Leone's mum felt that her son has benefitted from the training:

> *"at that time, he didn't used to follow that much. He doesn't scream that much now. He doesn't get that angry now. He vocalises to attract your attention.*" (Leone's mum)

They were given access to several educational resources based on what they had initially indicated as part of the communication goals the siblings had identified with guidance from the researcher. As a result, they were able to indicate positive social interactions and identify opportunities for further improvement.

> *"I know I cannot look him in the eye because you can provoke him, but I could use Clicker with him, which was good.*" (May)

Some siblings also confirmed that the baseline videos shown during the intervention phase were indeed what happens daily.

> *"There is nothing different in these videos from what we experience every day; this is all normal for us*!" (May)

When focal children were asked whether they enjoyed interacting with their siblings, Jeremy responded using his device "*yes*", Mario chose "*yes*" from a yes/no flashcard system, Louis said "*yeah*", and Bruce smiled and vocalised "*eeee*". Families generally appreciated the value of the study; they perceived the input of the intervention as an interesting process.

In addition, they reported that the communication goals they set together with the siblings could potentially be used in their upcoming individual educational program (IEP) review:

"The training wasn't a waste of time because now we can use the goals we wrote for Jeremy's IEP meeting." (Jeremy's mum)

For example, Mario's mum noted increased interactions for Mario and that both the focal child and the siblings enjoyed the social interactions. She also reported an improvement in sitting tolerance, turn-taking and self-help skills. The same was reported for Jade, Massimo, and Louis.

    b) We can communicate better, and we are using the tablet more

Siblings reported that the device was being used more after the intervention, and there was an improvement in their relationship as the number of activities they were able to do together increased.

> *"it wasn't easy-he improved a lot in communication-mummy is understanding you more, Mario. More time for Mario."* (Mario's mum)

> *"he chooses the pictures that he likes. Like he did with Mummy." (Mario's sister)*

> *"I would say wrong guesses on purpose to make it more fun. Sometimes I use all of them (pictures and signs)."* (Ian)

At the pre-intervention stage, the siblings were not always aware of the benefits of the device or signing and how they could use such strategies during the daily activities with the focal child.

> *"I think Mario can communicate better; he has the communication, iPad and flashcards. With the iPad, he can choose what he wants, we don't need to ask him all the time, and with the flashcards, we can ask him for school, and he chooses." (Lorian)*

Not everyone found it easy to communicate with the focal child. May was finding it hard to communicate with Leone using AAC: "s*ometimes you cannot communicate with him, and it is frustrating. It is really hard to learn his language."*

Despite mothers reporting challenges with the AAC system, or the unavailability of the AAC system due to restricted visits to ACTU, siblings were keen to continue using the strategies and explore alternative possibilities as discussed during the interventions. Leone's, Jade's, and Mario's mothers reported that they are still waiting for the new AAC system or tablet from ACTU. Massimo's mother said, *"We have Clicker 7, and I managed to get Clicker 7 installed on the hybrid tablet until his new system arrives."*

Miriam and her mother managed to install Avaz software on Jade's tablet. May, Miriam, and Karen indicated they would like further training on navigating their sibling's AAC system. Mario's and Louis's mother felt that following the intervention, the siblings felt surer of themselves, and with their support, they were guided to experience more fun interactions with the focal child.

> *"he played more with her; even his communication skills improved. He was copying her; he was making simple requests. We have a pool on the roof. I ask him, 'shall we go downstairs?' and he answers 'no'. But then, when he got tired, he wanted to go down."* (Leone's mum)

Additionally, siblings approached their mothers more often with ideas on adding more vocabulary to the system and creating more opportunities for interaction. For instance, Karen and Miriam were more interested in trying to program and navigate through the new AAC device, and Miriam was keen to explore how she could use the recording features of the system to record some new phrases in Maltese: *"I wanted to know how I can record some Maltese words on Jade's tablet. It was so cool."* In the absence of a compatible Maltese text-

to-speech engine, some families used the recording features of their tablets to create novel messages, especially where the main language spoken at home was primarily Maltese.

c) Lockdown wasn't easy

When asked what their experiences were during the first and second partial lockdown, participants agreed that the focal child improved their communication and social skills such as self-help skills, sitting tolerance, attention, and turn-taking. In addition, parents reported favourable outcomes with home-schooling and opportunities for more social interaction (Jade, Louis, Mario). Likewise, siblings felt that they had more time to play together and interact with each other with so much time on their hands.

> "*it improved when we were together most of the time and playing more creatively now. Even his speech has improved. Last year he was saying some single words but then it kind of regressed, and he decreased in his language skills, but now he is improving. We also had more time to play Simon Says and Sly Fox.*" (Massimo's Brother)

Even if the measures were so strict, which limited access to crowded areas, some families found the time to go out and enjoy some quality time with their children, like fishing and swimming.

> *"at the moment, a lot of it is free time, unfortunately with Massimo stimming or on a tablet. So we try to fit in a walk, a swim, some reading, some clever time and some playtime, but it doesn't always work, also some board games with Ian."* (Massimo's mum)

Mario's mum reported circumstances when the situation was highly stressful since all the support services were closed. At times she found online teaching too stressful and inaccessible since parents had to work around the clock to support the other siblings as well.

> "online teaching for Mario was a nightmare. I also had Vale's and Leone's online sessions to attend to. It was a real struggle." (Mario's mum)

Massimo's mum felt that the sessions were too hard to follow due to Massimo's difficulties with social communication.

> *"Social interaction was hard because Massimo was not able to follow 'meets and greets' online. Having said that, it was nice to be able to focus more on everyday skills, washing, dressing himself."* (Massimo's mum)

Likewise, Massimo's mother reported that they lost the daily routine and did not find enough support from Massimo's learning support educator (LSE). However, she claimed that during the lockdown, they could focus more on developing self-help skills. They also found more time to interact and socialise.

> *"I felt a bit helpless at times because we lost our routine, and Massimo became very oppositional. Most of the work being sent by his LSA was inappropriate for Massimo as it involved printouts. Having said that, it was nice to be able to focus more on everyday life skills, washing, dressing. We had more time to interact."* (Massimo's Mother)

Lockdown was stressful for some of the siblings because they could not go out:

> *"I didn't like lockdown because I couldn't go to the beach. He (Mario) stayed on the TV, and I helped him."* (Mario's sister)

> *"May ħaditha bi kbira għax kellha ħafna HW u ma setgħetx tmur l-iskola u ddejqet ġewwa. Dawra bil-karozza biss."* (May's mum)

> *[May took it badly because she had a lot of HW and could not go to school and got bored indoors. Only a drive in the car]*

May, for instance, did not enjoy the lockdown period because she had too much homework to do, and she got bored indoors. The only outing was a drive in the family car with her brother.

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9.4 Discussion

As discussed in the introductory chapter, there are limited studies on sibling-mediated interventions for a child with a communication disability. A few studies have looked at sibling mediated interventions when there is a child with ASD, see Ferraioli et al., (2011); Tsao & McCabe (2010); Siller et al., (2013). However, there are very few studies on sibling relationships and children with communication disabilities. Wright & Benigno (2019) suggested that developing family-centred sibling intervention programs for individuals on the autism spectrum is an area of research that needs to be tapped. The authors propose using the Family Systems Framework, which considered the unique features of the family to improve outcomes for the focal child, the relationships between siblings and the family unit as a whole. In addition, the Family systems framework may examine key features such as communication skills to promote positive sibling involvement and family functioning. A meta-analysis study of peer-mediated interventions to promote social interactions for children on the autism spectrum suggested that peer-mediated interventions can be highly effective (O'Donoghue et al., 2021; Chung et al., (2012), Chung & Carter (2013). Chung & Douglas (2015) conducted several studies evaluating an intervention involving peers and professionals with students with IDD who used SGDs. They received training and facilitating strategies on proximity to peers, access to the device, creating opportunities, monitoring, and encouraging students by praising to encourage future interactions and reducing support. These studies documented an increase in peer interactions and a slight increase of SGD in the classrooms. The dependent variables used were similar across the studies and included peer interaction behaviours, the SGD and other communication modes, and contextual variables such as proximity to the SGD and peers.

As discussed previously, the researcher based this study 3 partly on the study by Chung & Douglas (2015), which evaluated the impact of an intervention on interactions between students with ASD who used speech generated devices (SGDs) and their peers in inclusive classrooms. This study was replicated in families to examine the effects of sibling-mediated interventions using existing modes of communication within the home environment in sibling-focal child dyads. This section describes some of the changes that needed to be made. The use of contextual variables mentioned in Chung & Carter (2013) and Chung & Douglas (2015) was clarified in this study by referring specifically to proximity to the sibling, mother/father and the aided communication system rather than a broader term such as "contextual variables". Additionally, this study advocated the broader use of an aided communication system such as symbols and medium-tech communication aids. Manual sign systems were considered a form of unaided means of communication that could be taught to the siblings. The studies addressed peers and professionals in inclusive classrooms. The students involved had an intellectual disability or presented with ASD. Therefore, it is not easy to compare the data reported in those studies with the data here. This was because the study participants (focal children) did not always present with the same aetiologies, the communication partners were not similar (they were peers in comparison to siblings), and the context was different (classrooms) whilst this study presented with activities that the families wanted to have (mainly structured and unstructured activities). Whilst considering these limitations, the researcher still attempted to draw some similarities or differences with the data where this was applicable.

This study indicated that the intervention stage was generally successful for four families and that the sibling pairs increased their communicative attempts (see Senner et al., 2019). For one of the families (F7), the child increased the number of spontaneous attempts on his

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device while the sibling did not need to prompt him physically. For family 1, while the sibling provided more prompts at the post-intervention level, the focal child also increased the number of attempts on her device. However (family 2,3,5,6), four families made no particular progress in focal child-sibling interactions (Table 66). Maternal prompts for family 3 remained unchanged for the pre-and post-intervention stage, while maternal prompts decreased for both sibling and focal child in families 1, 5 and 8 (Table 68). The current study indicated an increase in aided communication, and one of the children showed an increase in the number of utterances even if these were a series of "No". There is an indication that when the siblings are exposed to the intervention program, they give the focal child the opportunity to access the system, the level and the quality of interactions increase. Similar studies indicated that none of the focus students used their SGD to interact with their peers before the intervention. These studies indicated ranges very similar to Table 67 with "0" signs, speech and SGDs at the pre-intervention stage. There was an increase in aided communication use at the post-intervention stage in this study, evident in other studies (see Chung & Carter, 2015; Senner et al., 2019). The focal children were encouraged to use multimodal means of communication, including vocalisations, symbols and speech generated devices. One of the focal children, Tina, used her Tobii device with auditory scanning, her italk2, and her laptop with switch scanning. Chung & Carter's study and this study differ because other studies only allowed the participants to use one unaided or aided communication system.

In fact, following the intervention, one of the focal children, Louis, increased his single word utterances which was the ultimate goal for the family and the therapists involved (Table 67). The proximity of the aided system is a limiting factor to the success of the intervention for an aided communication user.

The Chung & Carter study indicated an increase in the proximity of the SGD (70% to 100%). This could not be documented in the local study since aided systems were not present in the room for all the families, particularly in the baseline phase (see Table 69). Only Family 1, 4 and 7 had access to an aided system. More families had access to an aided system at the post-intervention stage, which was available and switched on during the session. One of the siblings had also learnt how to program the iTalk 2, and she provided the opportunity for the child to access it. Both at baseline and post-intervention levels, siblings maintained close proximity with the focal child. None of the focus students was in proximity to their peers during baseline conditions in the Chung and Carter study, though they increased their proximity following the intervention phase. In the local study, siblings maintained their close proximity at all times, both at baseline and post-intervention. The level of proximity of the fathers and mothers decreased over time.

Focal children must be in close physical proximity to their siblings to participate in sustained interactions at home. Being at home but not in close proximity to their siblings may limit the opportunities focal children might have to communicate and practise social skills. It may be difficult for some focal children who depend on a more experienced partner to access the aided communication system. The device has to be available and in close proximity to the child. It needs to be charged, fully functional and switched on. It has to be programmed with the vocabulary needed for the activity.

For some of the focal children, the siblings helped to provide physical and verbal prompts. For others, the siblings helped them position their hand and the device at times, e.g. Tina and Bruce needed support with their switches and their physical position.

Sibling interviews, maternal questionnaires and direct observations of focal child-sibling interactions were used to determine an increase in the number of interactions between the sibling and the focal child (see table 66). At the pre-intervention stage, some focal children had limited interactions with their siblings despite their proximity. The mothers and fathers had to provide several prompts to ensure that the focal child may interact with the sibling and vice versa. This is similar to the results obtained by Chung & Carter (2015), where students with severe disabilities were socially isolated despite being in an inclusive setting. The interactions remained stable at the post-intervention phase or improved drastically for some sibling pairs (Table 66). This suggests that the training component introduced at the intervention phase followed by the setting of communication goals and video interaction encouraged the siblings to increase their interactions. In addition, the introduction of an unaided or an aided communication system (where this was available) helped the focal child interact more with his/her sibling. It should also be noted that the mother and father (if applicable) at the pre- and post-intervention stage helped the sibling pairs work on their communication goals and set tangible examples that the siblings could copy.

This study was intended to study the interaction between the siblings and the focal children. The intervention indirectly involved the fathers and mothers who tended to address the focal children to prompt them. This was most evident during the pre-intervention stage, wherein, in some instances, Jade's mother also physically assisted her while the sibling was interacting with her.

There is a clear indication that the mothers decreased the number of prompts towards both siblings (focal child and sibling) (see Table 68). Siblings felt more autonomous and empowered to lead the focal child and provide the necessary scaffolding. Only one parent

took over the session because the sibling was feeling unwell, and the mother was providing physical support (i.e. hand over hand to press the screen). Other siblings continued to provide access to the child in various ways; for instance, siblings 1 and 8 ensured that the focal child had access to the aided communication system and physically supported them. They allowed them more time to respond or initiate.

The study reported similar results in sibling and focal child interactions, where the baseline measures for the focus students demonstrated relatively low levels of interactions towards the siblings (see Table 66). Interestingly in the Chung & Carter (2013) study, peer-initiated interactions were in the range of (0-11) at baseline phase whilst student-initiated interactions were in the range of (0-1) at baseline phase represented as a percentage of intervals (Chung & Carter, 2013). These studies did not elaborate further than disclosing that changes in trend direction vary according to the activity following the intervention. In previous studies, nearly no prompts (0 prompts) were provided by any of the professionals involved in directing the focal child or directing the peer to initiate towards the focal child.

9.5 Limitations of the study

This study is limited to a small sample of participants who were heterogeneous in their needs, and results must be treated with caution. A second limitation is the range of activities and activity sampling lengths. It was difficult to standardize the type and amount of activities across families since the aim was to encourage naturally occurring interactions chosen by the families.

Furthermore, the study did not control the type of structured or unstructured activities since families chose whatever they wanted to do and what they felt comfortable doing daily. For

instance, when the researcher suggested an activity in the kitchen such as cooking, one of the families objected to this, claiming that the child is not interested in food. Furthermore, implementing standardized directions for families regarding types of activities would defeat the purpose of allowing autonomous mother-focal child and sibling activities. Additionally, families may only sustain good interactions over short periods and with an observer present. This study does not indicate what may happen when the observer is not present or if the behaviours are exhibited over longer periods. There were instances where families were asked to film their activities due to COVID restrictions, which could have posed technical issues in filming and transferring data to the researcher. Some families also found it challenging to complete the study requirements due to various stressful situations they found themselves in during partial lockdown. At times this proved to be more stressful for families to complete some of the video recordings in time, and it was not the researcher's intention to create undue pressure on the families. More information is available in the Limitation section in Chapter 10.

9.6 Conclusions

This chapter examined the effects of sibling-mediated interventions using existing AAC within the home environment in sibling and focal child dyads. The results showed that during the intervention process, siblings were highly motivated to support the focal child. They actively interacted with the focal child, and the parents hardly prompted them at the post-intervention phase.

Thus, the intervention was partly successful because it facilitated more social interactions between some of the focal children and the siblings with the least prompts from the parents. In addition, the focal child increased his/her initiations whilst the siblings allowed the focal

child to be an active participant in the learning process. This was facilitated by increased aided AAC use at the post-intervention stage and the siblings' keen interest in actively participating in implementing the system. The final chapter gives a general overview of the studies conducted as part of this thesis and discusses the implications of the results, drawing on the international literature.

The conceptual framework used throughout this thesis is a consolidation of the Vygotskian developmental theory of language acquisition. This consolidation is due to the focal child gaining autonomous control over the skills whilst the sibling guides the child until these skills become internalized and mastered. This chapter also attempts to draw some general conclusions and provides recommendations and implications for further research.

CHAPTER 10: GENERAL DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

10.1 Introduction

The systematic review reported in Chapter 4 highlighted the complexities of family interventions and children with communication disabilities. At a glance, all studies in chapter 4 reported positive outcomes of intervention based on the different approaches and programmes put forward. However, the heterogeneity of the population, the sample size, different research designs, the methodological flaws and the low-quality scores obtained from the quality appraisal checklists added to the complexities of the task. Notwithstanding the limited information related to the 'how' and 'why' of the different interventions, the number of maternal and sibling intervention studies drawn facilitated the researcher to inform and plan the main studies.

In the course of this thesis, three experimental studies were conducted within a timeframe of three years. Study 1 consisted of a pilot study involving three families of children with communication disabilities. The pilot study investigated how two different interaction styles, responsive and directive, are employed by mothers and siblings in their encounters with children with intellectual disabilities. The second study addressed two mini studies reported simultaneously in Chapters 7 and 8. Chapter 7 examined the interactions of typically developing families and the behaviours of mothers and siblings in natural conditions. It was important to investigate what behaviours were evident for mother-sibling interactions and responsivity, emotional availability and directiveness in families with typically developing children. Chapter 8 looked at the patterns of responsivity and directiveness for mother sibling interactions where the child presented with IDD and had a communication disability.

The third and last study reported in chapter 9 addressed sibling mediated interventions with the focal child with IDD and communication disabilities.

10.2 Revisiting the Conceptual Framework

The Systematic review in Chapter 4 addressed the mechanisms of change and the different centres of influence (i.e. individual, partnerships, environment and societal). Not all of the studies in the systematic review considered the importance of these individual factors of influence as affecting the overall performance of an intervention. Bunning (2004) proposed a practical framework that considers the child, the social environment and the interventions within the individual factors of influence.

Research studies should give more importance to reporting the child's characteristics, skills, abilities, and use of the AAC system. The social environment should be given due consideration regardless of whether the centre of influence is individual, on a partnership basis, environmental, a combination of all three mechanisms or a mixture of direct and indirect interventions. In Calculator's (2002 p341) study, where the parent was the primary interventionist, the therapist's role was briefly affirmed: providing the "initial directions and methods for change and monitoring both the process and the progress". While parents were taught different strategies such as environmental sabotage, mand-modelling, and expectant delay, these were not monitored after the data collection, contradicting the author's commitment to monitor the change process. There needs to be a parent support system in place where the role of the interventionist is to offer support and monitor the mechanism for change.

Another point concerns the philosophical implications addressed previously in the systematic review, which seriously questions the conceptual framework of intervention. Some studies in the review seem to be implicitly motivated by one particular model, namely the medical model. These studies seem to challenge the internal processes of the individual.

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The underlying behaviourist approach in some of the studies related to PECS training, for instance, fails to address the reciprocal influence of the environment and the role of the communication partners in the process, unlike the social development theory, which gives importance to the role of the communication partners and the environment.

Adopting a particular ideology in interventions does not necessarily guarantee a successful intervention. According to Llewellyn & Hogan (2000), different disability models indicate different intervention approaches, and no single model can adequately support the wide range of intervention approaches. Often, interventionists choose an intervention without a clear understanding of the disability model on which the intervention is based. A better understanding of the disability model or a combination of models underlying interventions may improve the design of interventions and choice of intervention.

The communication partner's role is critical in scaffolding and providing the necessary assistance in co-constructing meaning. By applying the Vygotskian developmental theory of language acquisition, the child gains autonomous control over the skills whilst the more competent communication partner guides the child until these skills become internalised and mastered (Letto et al., 1994). This theory has been directly addressed in one of the studies (Tzuriel, 2014).

Other studies, by Kent Walsh et al., 2010; Koppenhaver et al., 2001; Rosa Lungo & Kent-Walsh, 2008 and Skotko et al., 2004, while not embracing any particular theoretical framework, all implied that the social participation of children through interactive storybook tasks might support the development of language and emergent literacy skills especially if

the mothers had implemented different strategies to facilitate better use of AAC. The Vygotskian concept may be used to uphold storybook tasks that scaffolds and offers a continuum of progression with the support of the more able communication partner. Several longitudinal studies have utilised the Vygotskian theory and a model of typical language acquisition to elicit some communicative functions (requests) (Letto et al., 1994). More studies investigating the effectiveness of instructional programs utilising the Vygotskian theory are highly recommended. Piagetians would argue that the Vygotskian model has several disadvantages (Fox & Riconscente, 2008). Several similarities and differences between Vygotsky's and Piaget's theories are noted. Piaget's theory was epistemological, explaining how knowledge develops rather than how the child develops. The Vygotskian framework, while cooperative, emphasizes the competence of the adult or more capable peer. Furthermore, perhaps there is a need to move away from this adult authoritarian role allowing the individual to become more autonomous. One of the goals of Vygotskian followers is to recognise the role of the individual in constructing meaning and cognitive tools. The study by Tzuriel & Hanuka-Levy (2014) references the Mediated Learning Experience Theory (Feuerstein et al., 1979), which has similarities to the Vygotskian's concept of the zone of proximal development. This study addressed metacognition and self-regulation, which commences with internalising children's interactions with family members in the home context (Vygotsky, 1978).

It could be asked what happens if the home context is different or if children are exposed to different types of language-based interactions which are different from those of the school environment. How would the process of self-directed learning change, and how would the child utilise questioning techniques and requests for help to rise to the demands of a given task? Given these challenges, scaffolding for the learners must be internalized so positive

behaviours are externalised. Studies addressing the development of metacognition and self-regulation have to be more rigorous in establishing the internalization of skills that will lead to self-autonomous learning.

The systematic review presented in this thesis is one of the first to analyse the theories embraced by the included studies. The application of the 'Vygotskian developmental theory of language acquisition' (Romski et al., 1997) was suggested as a Conceptual Framework in that it may support studies that failed to address the mechanism for change. The framework suggests that the interplay between these intrinsic and extrinsic factors may play a crucial part in the success and effectiveness of intervention programs. This conceptual framework merits further research and could be utilised to understand how children with intellectual disabilities acquire language through augmented means. Using this framework, the factors leading to the success of an intervention could be analysed by measuring the outcomes, such as an increase in communicative interactions (the dependent variables / intrinsic factors) and manipulating the independent variables, such as the use of the AAC system (the extrinsic factors). The framework may help address shortcomings brought about by the design of interventions and the eventual internalisation of skills.

10.3 Maternal and sibling directiveness

The study (2b) examined mothers' behaviours towards their children with communication disabilities and how siblings interact with their disabled brother or sister. The study also looked specifically at the patterns of behaviour observable in mother-sibling-focal child interactions and the similarities and differences in these behaviours between and across families. The literature suggests that caregivers of children with communication disabilities

tend to be less responsive and more directive due to missed opportunities to develop interaction (Pennington et al., 2004).

This study indicated attuned interactions within the mother-focal child and sibling-focal child and mother-focal child-sibling triads where mothers and siblings alike looked for opportune moments to receive feedback during different activities. The study also demonstrated emotionally available mothers and children who generally show emotional responsiveness; however, their social responsiveness and behaviour were inappropriate. The emotional availability scores indicated high levels of directiveness where mothers tended to lead, over-direct and over-parent, with lower levels of non-intrusiveness (i.e. high intrusivity). The children tended to remain passive and over-reliant while seeking physical contact with their mothers.

The EAS scale is a more defined scale to examine how the level of directiveness and non-intrusiveness function within the context of the activities. Although conceptualised differently, the attachment theory greatly influences maternal structuring, non-intrusiveness and nonhostility constructs (Biringen, 2008).

In summary, optimal non-intrusiveness refers to the ability to be available to the child without being intrusive to him/her. Biringen (2008) suggests that focus should be on structuring and non-intrusiveness when positing the relationship between maternal directiveness and learned helplessness.

Commands and directives are targeted in two of the subcategories of the scale, i.e. in the "non-interruptive ports of entry or natural breaks" as well as "commands and directives". This construct looks at different dimensions compared to the frequency of directives

measure as defined by intrusive behaviour directives (IBD), attentional behaviour directives (ABD) and supportive behaviour directives (SBDs). Conversely, the EAS sub-categories refer to the "don't" phrases and how the adult seems to be creating a situation of "constant commands". Directiveness considered intrusive for a typically developing child may benefit a child with severe disabilities, particularly when the directives were mainly supportive. Likewise, maternal directiveness is seen as negative as it is perceived as being intrusive. It is suggested that if mothers use a more directive style without being too intrusive, this may be more beneficial for the child's growth and development with opportunities for the child to become autonomous. Children with developmental disabilities tend to be less active and responsive and avert their gaze and bodies more during interactions than typically developing children (Flynn & Masur, 2007). Providing too many directives for a child with developmental disabilities might decrease the child's ability to become autonomous. A directive interaction style by mothers of children with Down Syndrome showed greater control and directive behaviour (e.g. Stoneman, 2005). Most research has also suggested detrimental effects of maternal directiveness on developing language, cognitive and social-emotional outcomes of typically developing children (e.g. Tomasello & Farrar, 1986).

However, some evidence suggests that if mothers balance their directive behaviour with supportive behaviour and use interactive strategies linked to the child's behaviours, these are appropriate adaptations in different parenting situations (e.g. Landry, et al., 2001). Study 2b indicated that both mothers and siblings provided more supportive directives than intrusive behavioural or attentional utterances. This suggests that parents and siblings are using these behavioural directives to support and direct the child in the course of the activity itself in which they are already engaged. Supportive behaviour directives may provide the

critical impetus for optimal development if responsiveness is not compromised. Similar studies (e.g. Flynn & Masur, 2007) have also indicated increases in frequencies of maternal responsiveness and supportive directive utterances during play activities. These types of directives followed the child's focus of attention rather than utterances which were aimed at redirecting the child's attention or behaviour, although there were some instances where this was observed. The child's ability to maintain joint attention episodes is a child-related factor that may affect maternal directiveness.

Study 2b indicated that some children had difficulties maintaining the focus of attention where the child was unable to demonstrate triadic gaze shifts and coordinate their attention between the adult and the object. When a child frequently diverts his or her attention away from an episode of joint attention, the mother may use intrusive attention directives (i.e., "look", "watch") to regain the child's attentional focus (Masur & Turner, 2001). The child's level of engagement plays a central role along with caregiver responsiveness, and using intrusive behavioural directives (e.g., "put that down" or "stop banging that toy") may result in less engagement by the child (Prizant et al., 1993). The child is more likely to extract information when the adult tunes in to the child's focus of attention and labels the object that the child is attending or following.

When the adult tries to direct the child's joint attention to an object of the adult's attention, the child is less likely to gain from this interaction (Tomasello & Farrar, 1986; Benigno et al., 2011). Future research may assess supportive directive behaviour by the siblings at the baseline phase, followed by an evaluation of mutual sibling-focal child engagement during the intervention phase and beyond the post-intervention phase. Such measures would have considerable effects on generalised outcome measures as well as treatment fidelity. In

addition, future research may consider collecting comparative data on sibling interactions to evaluate the extent to which the sibling-focal child dyads reflect the typical interactions of typical sibling-sibling dyads. This may also be extended to research involving triadic interactions involving the mother, sibling and focal child. Expanding the role of mothers and fathers as support role models for siblings of children with communication disabilities has not been adequately explored yet. This is similar to adult facilitation in mainstream schools and the effect of adult support in peer interaction. The importance of adult facilitation has not been given enough empirical support and should be encouraged to continue refining and promoting peer interaction outcomes beyond the home environment (Chung & Carter, 2013).

10.4 Sibling-focal child relationships. What do we know?

Past sibling developmental disability research reviewed the research on sibling relationships, using a mixture of self-reporting and parent interviews, and reported that children with developmental disabilities have more positive relationships with their siblings (Rossiter & Sharpe, 2001). Smith et al., (2013) looked at the characteristics of sibling communication interaction patterns and the quality of sibling relationships.

This study aimed to examine the characteristics of sibling communication interaction patterns when one sibling had IDD and the unique role that communication skills played in the quality of sibling relationships. Several variables had been identified in the literature, such as child characteristics, aetiology, adaptive behaviour and temperament, which could influence the relationship between siblings and the focal child. Smith et al., (2013) claimed that communication and language skills are essential variables when studying sibling relationships. Studies of sibling interaction have indicated that disabled children take a less

active role due to difficulty initiating social interaction (Smith, 2013; Knott et al., 1995). This finding is consistent with the quantitative data of Study 3, where siblings engaged in more initiations than the focal child, indicating the tendency for more able communication partners to take over the conversation.

Though siblings felt that they understood what their sibling was saying most of the time from the sibling interviews, they could solve communication breakdowns with the focal child, play together and share several activities. The study seems to indicate that siblings have found ways to communicate and understand each other. Some of the participants described how they managed to find a means to communicate with the focal child. They shared their feelings about their relationships with the focal child. Despite the child's communication difficulties, they gave examples of how they interpret their non-verbal behaviour and communicate using vocalisations and aided means of communication such as flashcards and tablets. These findings are similar to Baltor et al., (2014), where children with cerebral palsy communicate using different communication systems. The international literature perceived communication difficulties as a challenge in sibling-focal child relationships.

In a study by Rossetti et al., (2020), adult siblings of people with severe disabilities identified limited functional communication barriers to positive relationships. The local study did not find such considerations that the focal children could not communicate with the siblings. Although the focal children had difficulties with verbal communication, siblings reported that their relationship with the focal child is generally positive and meaningful (Cuskelly & Gunn, 2003).

The literature discusses the implications of being born first or second, being far apart or close in age, and having an identical or opposite-sex sibling. The effects of sibling status are often described as resulting from some aspect of sibling interactions. Factors such as the sex and age of the individual children, the sex composition of the dyad, and the age interval between siblings may affect patterns of interaction (Howe & Recchia, 2014). Notwithstanding such studies claiming that age, sex, age spacing, and birth order may affect the patterns of interaction between siblings, the studies conducted here do not particularly indicate that one or more variables may adversely affect the patterns of interaction. It was not the aim of the studies to test whether such variables affect sibling interactions since the researcher was more interested in describing the naturalistic patterns of interaction within this context. Some studies confirmed that older siblings serve as a model to the younger child, which was also evident when analysing the sibling interviews and maternal questionnaires. The literature suggests that older siblings are considered more physically, socially, and cognitively advantaged over their younger siblings. Younger siblings are expected to match the capabilities of their older siblings as they grow older, so the interactions become equalised (Dunn, 2013; White et al., 2014). There was noted to be turn-taking and equal participation during sibling interactions (Dunn, 2013).

While older siblings tended to influence their younger siblings, collaborative and mutual interactions were also noted between siblings. Studies have also highlighted the power struggles in sibling birth order. Campione-Barr (2017) adds that sibling power dynamics impact how control and influence are exerted within the dyad and the quality of the sibling relationship. Older siblings are more likely to win arguments or control interactions by expert power, for instance, when the elder sibling has more knowledge over the other. Younger siblings are then more likely to use teasing as a strategy to irritate older siblings or

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gain the support of parents during disagreements (Campione-Barr, 2017). Evidence of power struggles in study 2a was noted for families with typically developing children during scripted games since greater demands on the elder sibling were placed to win the game. There were instances when the younger sibling was teasing his much older sister and using several topic conflict modes. A range of issues was noted, including information, controlling behaviours, possessions, and rule violation (game rules) (Della Porta & Howe, 2012).

More capable older siblings are often responsible for caring for their younger siblings. This was evident in the study where siblings were sometimes perceived as babysitters or helpers to their younger siblings. Siblings in Study 3 perceived themselves as a helper or carer, babysitter, playmate, or simply as a friend or brother or sister. In addition, siblings identified specific roles with the focal child primarily related to basic care needs, speech and communication. This is similar to the study conducted by Smith et al., (2013) and the local study by Vella Gera et al., (2020), where siblings reported that they helped with reading, homework, sports and behaviour management. It is reported in the literature of sibling relationships that siblings engage in helping and teaching and babysitting and day-to-day physical care activities of feeding and dressing (White et al., 2014).

Study 3 indicated that siblings wanted to teach, model and also support the focal child's attempts, even assigning meaning to a particular behaviour: "*if he goes like this* [while Mario was squishing the playdough]*, he means yes"* (sibling from family 2). Participants mentioned that they frequently help the focal child with their self-help skills, toileting, dressing up and eating. Some of the siblings also added that they help them to eat and accompany them to bed. Two participants added that they help them program and input the new vocabulary on the AAC device and play games that enhance their reading vocabulary.

Families in the study chose a variety of activities and games, which mainly were highly scripted. There were very few unstructured activities or games involving child-led activities. Games were highly scripted and associated with highly predictable speech acts and forms (Uno, Bingo, Snap). In such circumstances, the language was more prescriptive, with the activities being more goal-directed according to a set of rules. However, it does not mean that all structured activities are necessarily prescriptive and with highly scripted language. It is to be noted that there were instances when structured activities allowed for more free conversations and flexibility, especially when there were no particular set rules that players had to focus on. Some of the games expected the participants to be more focused on the game's structure, and their attention was more focused on the rules of the game. However, one could still notice the non-verbal behaviours and dynamics during the games, such as eye contact, smiles, and exaggerated facial expressions. Particularly sibling participants from study 2a used buzz words or scripted words expected to be used as part of the game's rules. Most of the time, the games were reduced to minimal verbal exchanges and fewer conversational opportunities. Generally, participants enjoyed household chores and accepted that they need to help in their daily roles. The literature suggests that siblings take up various roles in the home, depending on age, gender, and culture.

In Dervishaliaj & Murati (2014) study, adolescent siblings commented that they carried out their responsibilities with pleasure even if this allowed less time for leisure activities. This is evident in the literature where siblings engaged in more helping, teaching, and managing behaviours while the focal child identified with his/her sibling. This indicates an asymmetry between typical sibling relationships and those involving disabled individuals (Stoneman, 2005). Siblings tend to engage in more teaching and scaffolding behaviours with the focal child. For example, "*You want to tell me if you want yoghurt or no?"* (sibling in family 1

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while the focal child was using auditory prompts to access the device); "*Biex ħa nilagħbu issa Bruce biż-żugraga jew bir-robot?"* (what do you want to play with now Bruce, is it the spinner or the robot?) (sibling of family 8 to child using iTalk 2).

The studies here highlight the positive characteristics that siblings of children with communication disabilities portray towards the focal child. In addition, several sibling qualities emerged from the research, such as being patient and caring for their disabled sibling. This is synchronous with the literature of sibling relationship qualities, including the studies by Howe et al., (2014) and Kramer et al., (2019). Furthermore, the helpful characteristic that the local participants portrayed in their interviews was similar to the findings in the survey conducted by Skotko et al., (2011). More than 96% of the siblings in this study expressed feelings of affection and pride for their sibling with DS, with 90% wanting to be involved in their lives as they approached adulthood. In addition, positive feelings emerged from the interviews with siblings (study 3), highlighting the joy of playing with their disabled siblings, helping them with their homework, and developing their abilities.

Warmth and closeness were another characteristic which featured in the interviews. Despite admitting that it is very stressful, siblings did not feel the need to consider their sibling as not having a disability and could not imagine things being otherwise (Smith et al., 2013; Vella Gera et al., 2020). Instead, they felt proud of the focal child and indicated that they tried their best. Siblings generally think highly of their brother or sister with a disability, which may imply a level of acceptance and that they can see beyond the disability (Vella Gera et al., 2020). They identified good qualities and characteristics when describing their sibling. This is congruent with the literature where siblings have perceived strengths

concerning the focal child (Petalas et al., 2012b), positively impacting social activities and focal child-sibling relationships (Kao et al., 2012; Petalas et al., 2009, 2012b). These studies also portrayed moments where the siblings felt uneasy or frustrated, similar to the local studies.

The local participants also reported some feelings of frustration and elements of embarrassment. This was also evident in the study (study 3), where one of the mothers said, "*Ian sometimes feels embarrassed due to the inappropriate behaviours of his brother in public.*" Similar feelings of embarrassment were reported in the literature (Barr & McLeod, 2010; Stalker & Connors, 2004). However, participants in the local study also report occasions when they feel they need to protect the focal child. This sense of embarrassment is mixed with a shared feeling of needing to protect the focal child. This may stem from the fact that siblings portray a caring attitude and possibly see their brother or sister as more vulnerable and needing more care and protection. The literature also mirrors such attitudes where siblings of children with a disability showed a need to protect them (Dervishaliaj & Murati, 2014).

The participants here mentioned leisure activities in the home and the community, which mirrors findings from other studies. They mentioned daily, weekly and monthly activities, including music, drama, sports and arts. They drew on to solitary activities such as reading and playing with their computers. They also mentioned that they could not play with their siblings because of the focal child's limited play skills. One of the siblings, Paula, mentioned that when the whole family tries to include Tina in their outings, "it *takes longer, it is worth it.*" Sometimes they have to leave Tina in respite to enjoy a weekend break "*without interruptions*", but then they miss her and wish they were with her (Vella Gera et al., 2020).

Siblings spend large amounts of time playing together and engage in pretend play. Siblings generally spoke highly of their disabled brother. For instance, Ian complemented Massimo on his signing of 'balloon'. "*I didn't guess that one, but you did very well.*" Likewise, Michael to Louis, "*I didn't even know it was there. He's smart*". This is what Paula thinks of Tina "*my sister Tina is so beautiful. She always smiles. She could take her sadness out of you with her laugh.*"

Participants shared their views and perceptions of their relationship with the focal child through various means, using drawings and the written mode. For example, two of the siblings decided to draw how they perceive their brother or sister. They described the focal child as happy, smart, caring, and special. Two of the sisters described their disabled sister as unique and perfect. Zaidman-Zait et al., (2020) studied sibling relationships through drawings of typically developing children and siblings of those with ID. Findings indicated higher levels of positive relationships for children who have siblings with ID. The drawings portrayed positive relationships, and such qualities were significantly associated with children's adjustment.

Positive perceptions are also synchronous in the study carried out by Stalker & Connors (2004), which found that the disabled brother or sister was not thought of as different from the siblings and unique in every sense. They also felt proud of their disabled siblings' efforts and achievements, describing them as "smart" and "clever". Similarly, Petalas et al., (2009) reported siblings' accounts recounting the focal child's positive qualities, efforts and achievements.

Finally, siblings were asked about their dreams and wishes for the focal child. All the siblings wished the focal child could live a fruitful life, be happy, learn more and be more

independent. The local study by Vella Gera et al., (2020) voiced similar wishes for the disabled siblings, specifically that some siblings understand the non-verbal communication that the sister uses and that she communicates better. Some siblings indicated that they wished the focal child could communicate using their voice, just like them. This is also congruent with the results from the current literature on sibling relationships (Smith et al., 2013; Vella Gera et al., 2020). Vella Gera concluded that while siblings expressed acceptance and siblinghood, most participants wished that the disabled sibling was 'normal' and could talk just like them.

10.5 The Challenges of Implementing AAC systems at home: Myths and Misconceptions?

While assistive technology may be perceived as a vehicle to obtain more independence, caregivers seem to encourage unaided means of communication, preferring continued dependence on them (Gatt, 2015). Parents seemed reluctant to use AAC systems with their children in the home environment, indicating that they may not support a conducive environment for functional AAC use.

There are indications that there have been situations of device abandonment due to either the device not being used and needs updating or, otherwise, parents are not trained to use the system (Anderson et al., 2016). Parents expect professionals to take the responsibility to teach the use of the aided communication system and for the child to generalise what he/she has learnt (von Tetzchner et al., 2018). Parents find it more effective and practical to communicate with their children using natural speech modes. Some parents were found to reportedly oppose the use of medium and high-tech aids (Gatt, 2015). Moorcroft et al., (2021) claim that this is considered a barrier to AAC when parents interpret their child's idiosyncratic behaviour and refuse aided means of communication. However, Marshall &

Goldbart (2008) argue that the interpretation of idiosyncratic communication has many advantages for families because it supports simple, quick, and emotional closeness.

A study by Doak (2021) found that systems such as Picture Exchange Communication System (PECS) and keyword signing (Makaton) were limited in family homes. The author pinpointed three areas: i) the communicative aspects and the emotional and relationship-building of family dynamics; ii) having to bring up a disabled child and juggle family life; and iii) the child's existing means of communication, including objects of reference. According to Doak (2021), parents experience a wide range of emotions ranging from guilt to self-blame concerning their child's communication. A range of communication strategies was available in the homes, including eye gaze, facial expression, vocalisation, posture, proxemics and objects of reference. The lack of interest in using aided means of communication at home was possibly "an act of self-preservation in the face of considerable demands and few supports with families learning to anticipate their child's needs in order to prevent problems before they occur." (Doak, 2021 p 11).

Caron (2015) argues that parents have to juggle different roles, parents, teachers, advocates, and technicians for the AAC system. Mandak et al., (2017) assert that families also have to face financial and health struggles and deal with high-stress levels, fatigue and stress. Families need to be supported and taught about the various forms of communication and how these can be used to elicit functional communication in the home environment. Professionals working with families need to emphasise the potential benefits of the use of AAC systems. Mandak et al., (2017) argue that while speech-language therapists think they are using a family-centred approach by providing them with information and obtaining their agreement to collaborate, such practices lack the features of family-centred service

provision. The authors argue that reluctance and resistance to AAC use should be seen from a family centred perspective to understand the issues. Families should be empowered to make informed decisions that consider the needs, wishes, concerns and fears that the family might have about AAC intervention and implementation in the home environment (Gatt, 2015; Gatt, 2007; Stephenson & Dowrick, 2005; Smith et al., 2016).

10.6 The Influence of COVID-19 on family relationships

The coronavirus disease 2019 (COVID-19) pandemic has influenced the lives of many families, and the long-term effects are still unknown. Families were subjected to working and living in the same environment, experiencing a lack of community support while raising awareness and teaching their disabled children about the virus (Critchley et al., 2021; Mutluer et al., 2020; Bellomo et al., 2020). Some families made a case for their children to be considered high risk from COVID-19 due to associated comorbidity factors (Rose et al., 2020).

Alexander et al., (2020) described the crucial role that families play in supporting people with IDD. While many families reported positive aspects of supporting their disabled children, they also experience significant stress levels imposed by social distancing and several imposed measures by the Health Authorities (Rose et al., 2020). This is of particular concern for caregivers of children with IDD who are more likely to have additional burdens. Some families in the local study reported additional benefits for positive interaction with their children. Critchley et al., (2021) reported that families expressed positive outcomes with increased family time, maintaining a structured routine, and increased safety within the home. However, these benefits may be easily marred by continuous care, support, and work commitments around the clock. Community support such as schools and after school

therapeutic centres had to remain closed, and support was provided remotely. Rose et al., (2020) identified potential stressors for families, and these included the fact that essential services were closed. Some of the family members also lost their jobs. Others have ended up caring for their child without any support from respite care or care workers. Other family members worked in establishments where they had to deal with daily rising Covid cases. Since access to after-school activities, such as physical and therapeutic programs, were not available, a few NGOs have reached out to the families through their websites by giving remote support.

When writing this thesis, the Government of Malta has just started releasing some of the measures and offering relaxation in social distancing rules (Government of Malta, 2020). Prime et al., (2020) have attempted to conceptualise the risk and family resilience during the pandemic. They suggest that longstanding effects of Covid-19 are expected due to the high-stress levels of the caregivers. They implied that differential treatment by the parents towards the siblings might pose a difficulty with sibling relationships.

Critchley et al., (2021) argued that the dyads in their study gave mixed responses given the pandemic and its influence on family dynamics. Therefore, this may indicate that some families may thrive, suggesting an element of resilience. More research needs to be conducted to understand the long-term effects of family relationships and sibling coping strategies.

10.7 Limitations and Directions for Further Research

The researcher encountered several challenges during this research and the data collection process. One of the most significant challenges was possibly collecting data during the Covid

19 Pandemic amidst two partial national lockdowns and so many uncertainties for the researcher and the participants of the studies. The external validity of this study would have been improved if maintenance data was collected three to six months post-intervention to determine whether there was any generalization of the skills taught. Unfortunately, this was very difficult to achieve due to the stressful situation that families found themselves in. This factor seriously affected the study's external validity and limited the conclusions drawn from the study's findings. As a result, some questions may remain unanswered. For example, i) would parents continue to prompt as needed and fade support if the focus students or siblings demonstrate spontaneous initiations or responses? ii) Would siblings continue to support the focal child's communicative attempts? iii) Would the family continue to support using an AAC system (both unaided or/and aided)?

Every effort was taken to control the variables in the studies, such as having the researcher and the research assistant independently analyse the data and using known and validated tools. Indeed, there are limitations of the pre-post intervention design with challenges related to naturalistic interventions.

This design did not allow for control over other variables, such as individual differences between participants and the different activities chosen by the families, whether these were structured or unstructured. The small number of participants and use of convenience sampling, while common when persons using AAC, limits the generalization of findings to this population (Grace et al., 2019). The additional problem is that families may sustain good interactions over short periods and with an observer implies an element of social desirability bias. This study does not indicate what may happen when the observer is not present or if the behaviours are exhibited over longer periods.

The outcomes of these studies may have been strengthened by considering other measures to better understand the intervention's effectiveness. The study used both quantitative and qualitative measures to collect data, such as rating scales. There are advantages and disadvantages of using rating scales that also need to be considered in the process. The same may be argued for direct observation measures such as event and interval recording. Such advantages and disadvantages were discussed in Chapter 5 of this thesis. The results from the systematic review and the narrative review by Biggs & Meadan (2018) suggest that researchers need to be attentive to the type of research designs and the intervention models used. Specific factors about participants, their cultural backgrounds, SES and types of interventions need to be appropriately reported. These should include i) generalisation and maintenance regarding parent-related and child-related outcomes, ii) implementation and intervention fidelity, and iii) social validity of the goals, procedures and outcomes of the specific interventions.

All the parents who were contacted had agreed to participate in the study. The non-governmental organisations who provided the researcher with the contact details of the families may have been chosen on the premise that these are more cooperative and responsive. However, having handpicked parents rather than randomly selected may not guarantee a representative sample of the population. The variety of aetiologies and age ranges highlighted the inconsistency of children's physical, receptive/expressive language skills, pragmatic competencies, cognitive abilities and social communication skills. In addition, children with profound and multiple disabilities were part of the sample being studied. Due to the complexity of their needs, one would expect intra-group variations.

Consequently, research presenting group results may disguise individual performance (Light, 1999). An alternative would be providing in-depth descriptions and data at individual and group levels to provide a clearer picture of their needs. Given the variety in the AAC population and the limited sample, trends should always be treated with caution. The results may not necessarily represent the perceptions of the whole AAC population since it is a non-representative sample.

All the parent participants in the studies were mothers, and therefore the results contributing to this study were based mainly on maternal perspectives of the relationship between siblings and the focal child. This might have been different if the fathers had actively participated in the studies. More awareness needs to be created of fathers' involvement within the family systems framework, which guides the process. There needs to be more research on the role of fathers in sibling relationships and the use of AAC. Additionally, a comparison of paternal and maternal language styles may be researched, particularly their directive style and role in parental-based interventions (Flippin & Watson, 2015; Flippin, 2019; Bentenuto et al., 2021).

Recruiting families was highly challenging due to various factors concerning the set inclusion criteria. It was difficult to find families who matched all the inclusion criteria without compromising structural variables reported previously in the literature, such as birth order, age differences, type of disability and socioeconomic background. Recruiting families with children, especially from larger families and collecting data at home, may be time-consuming, yet it provides rich naturalistic data. Another limitation is family closeness during the pandemic influenced by the fathers' and mothers' occupations. One of the mothers in the study was an intensive care nurse, and she did not have the same level of time

as other families. This could have affected the overall family dynamics and family cohesion (Critchley et al., 2021). On the other hand, other families had more time since they either lost their jobs or worked from home. Mothers considered homemakers had to care for their children around the clock, especially when schools and essential services were closed. As a counterargument, some families may have felt over-stressed having to cope with their families and the child with a disability, distorting the study results.

Most sibling studies in the past have examined Western cultures and typically white, middle-class, and US families (Campione-Barr, 2017). However, there may be cross-cultural issues in mother and sibling interactions when examining other cultures since family dynamics may be similar or different and may affect the quality of mother and sibling interactions. The impact of more than one language and different cultures has been raised in the literature of AAC users (e.g. Bunning et al., 2014). Romski et al., (2015) stress that it is essential to address the roles of more than one language and diverse cultures on the use of AAC for infants and young children. The authors argue that socioeconomic status and its role in implementing AAC interventions need to be considered in the process.

Despite results drawn from the current literature and the results from these studies, little is known about the potential significance of sibling relationships and positive outcomes for children with a developmental disability or siblings (Hastings, 2014). Additionally, the children who participated in the studies also attended other programs such as after school therapeutic programs and speech-language therapy. It was difficult to determine whether the outcome of the intervention was due to the video interaction package or to other programs that the child was attending at the time of intervention. Several questions may remain unanswered or may need to be further investigated:

a) Will mothers/fathers fade support (verbal/physical prompting) if the siblings or the focal children demonstrate spontaneous initiations/responses? The post-intervention data in Study 3 suggests that mothers fade support, mainly physical or/and verbal prompting and that siblings, in general, demonstrating more spontaneous initiations and responses.

b) Families, including siblings, need the skills and support to implement AAC in their homes. What kind of training and support can be identified for families, especially after an aided communication system is recommended? Who is responsible for the assessment and intervention?

c) Can training be presented in a manner where families (including siblings) can explicitly refer to the goal-setting tasks and help siblings reflect on their practices, and in turn, they become better communication partners?

d) Are fathers underplayed in the research? Why is there so little research on fathers and children with communication disabilities who use AAC?

e) Does a positive relationship with a sibling lead to better outcomes for the focal child who uses AAC? Similarly, does a positive relationship with the focal child augur better developmental outcomes for siblings?

An intervention study could create opportunities for siblings and focal children in familiar everyday situations using aided means of communication. Specific strategies may be targeted, for instance, i) initiating wh? questions ii) minimising communication breakdowns iii) providing aided language stimulating techniques to enable children to talk about their needs, aspirations iv) introducing pause time to allow children to take the initiative and be more proactive. Another study may be conducted to determine contingent family members'

interactions and the quality of life issues of individuals with developmental disabilities. Family members' responsivity may be associated with positive outcomes in children's language development, academic success, participation in the community and self-determination.

10.8 Implications for Policy, Practice and Service Provision

There are several implications for policy and service provision and families of children with IDD and communication disabilities. First, there should be an emphasis on parent education and sibling intervention programs to assist families in developing more functional AAC teaching strategies. Second, intervention programs may be developed to improve sibling relationships regarding support groups for adult siblings of disabled people (Agenzija Sapport, 2020) and AAC service delivery and Policy provision. Due to recent COVID measures and the fact that families could not physically access the local AAC service delivery team, ACTU started provided online sessions and webinars.

Topics addressed included helping families support AAC users and practical activities and examples of setting up an AAC users implementation plan at home. These webinars are now available online and easily accessible. The role of ACTU in the selection, assessment and trailing of equipment needs to be made clear, and all stakeholders need to clarify which entity has to provide for the intervention and training of the system. This would ensure that while there should not be any duplication of services, the speech-language therapists should not end up in a tug of war with ACTU to provide training and intervention. Finally, the importance of team collaboration needs to be recognised, and future research may explore the role of transdisciplinary teams in supporting family intervention programs. Families should be more involved as they work with other professionals, including speech-language

pathologists (SLPS) and take up interventionist roles. As Hodge & Runswick-Cole (2008) argue that parent-professional relationships should allow *fluidity* and *"respond to changing perspectives and shifting perspectives as parents, and professionals engage with new experiences and influences."* (p19-20). Davies et al. (2017) suggest that families should negotiate roles in the partnership before the intervention begins, and families should be empowered to adopt an interventionist role. Future research may include a replication of the study by Gatt (2007) by conducting a large-scale survey and in-depth interviews with different stakeholders to examine the opportunity and access barriers when implementing an AAC system within the family environment.

Secondly, siblings need to be considered primary communication partners and the therapists involved in providing the interventions need to involve siblings in the development of the focal child's communication and social goals. Unfortunately, there is limited research on the role of siblings in AAC intervention, and the evidence-based practice is drawn from studies in peer-mediated interventions in inclusive classrooms (e.g. Chung & Carter, 2013).

The studies conducted as part of this thesis show that siblings were willing to participate in naturalistic interactions with the focal child. They showed supportive and emotional availability towards the focal child and were particularly interested in using an aided communication system when this was available. These results augur well for sibling interactions since they can serve as effective communication partners with rewarding mutual experiences for the siblings and the focal child.

Finally, intervention goals have to be set in such a manner to ensure that the focal child can develop the skills and opportunities across different communication partners (i.e. the immediate family and peers) and in different contexts (i.e. at home and school). Finally, as

a previous local study suggested (Vella Gera et al., 2020), there should be a sibling support group where siblings of disabled children can meet and share their experiences and concerns in a safe place. This service could easily be under the guidance of Agenzija Support.

10.9 Conclusion

This chapter has given an overview of the studies conducted in this thesis and has considered the systematic review results in planning the remaining studies. These studies, although preliminary, may give a view to gaining a better understanding of how mothers and siblings interact with the focal child in a manner that supports a positive communicative environment. In addition, there are positive benefits in establishing warm and positive sibling-focal child relationships since sibling relationships are long-lasting, ensuring better developmental outcomes (Howe & Recchia, 2014). Siblings are natural co-interventionists for focal children who may benefit from unaided and aided communication systems. This is evidenced by the fact that siblings were highly motivated when actively involved in the training process as communication partners.

They actively interacted with the focal child, and at post-intervention phase, they were rarely prompted by the mothers/fathers. The intervention consisting of video interaction guidance and the development of communication goals suggested that the process facilitated more social interactions between some of the focal children and their siblings. In addition, with the introduction of an unaided or aided communication system, the focal child increased his/her initiations whilst the siblings allowed the focal child to be more autonomous and actively involved in the process.

This thesis attempted to identify the salient features and pave the way for future studies in caregiver-focal child-sibling interventions. As Cebula & Kovshoff (2020 p.2) claim, future research needs to focus on the extent to which current sibling theories enable high-quality research, leading to positive outcomes in terms of sibling quality relationships. As a parent turned AAC practitioner, this research journey has been enriching in so many aspects of my personal and professional life. I have been empowered with such knowledge and skills, while conducting thorough, rigorous literature reviews based on a robust conceptual framework that has informed my research. The systematic review was a painstakingly disciplined process which enriched the evidence-based practice in relation to AAC family led interventions. While maternal/sibling interactions and interventions have been so much prioritised in the literature, this PhD has shed light on so many possibilities for future research. I was personally struck by the presence of fathers in the family homes and how they interacted as part of a family support system. While I understand that this area is so much under researched, it is interesting that while the research refers to 'parental responsivity', researchers would be referring to 'maternal responsivity'. This aspect needs to be challenged and if necessary, re-addressed in the light of mainstream Anglo-western models of parenting.

Lastly, I learnt so much from the families themselves particularly from the siblings and their unique role in AAC interventions. Both siblings as well as the focal child may benefit from these mutual interactions and as researchers we have so much to learn from how siblings can be better communication partners when an AAC system, whether unaided or aided is introduced. As much as the literature attempts to emphasise the importance of mother-child interactions, one can never look at an individual in isolation since every person influences and is influenced by the other family members. Definitely, this PhD paves the way to more

opportunities in terms of designing high-quality research with better outcomes for sibling-focal child interactions.

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