A scoping review of primary caregivers' perceptions of their involvement in augmentative and alternative communication intervention of their children

by

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ABSTRACT

Background: Augmentative and alternative communication (AAC) intervention is pivotal for obtaining functional outcomes in communication and participation of children with complex communication needs (CCN). Various studies focused on the experiences and perceptions of parents as primary caregivers with regards to their involvement in AAC intervention and implementation of their child with CCN. The value of the findings of these studies lies therein that from the findings it could be derived how parents view their involvement and how their nature of involvement could possibly influence the successful and beneficial implementation of AAC intervention. Since the primary caregiver is the only constant factor in the life of a child with CCN, it has proven to be feasible to investigate the primary caregivers' perception of their involvement in AAC intervention.

Methods: A scoping review was used during which articles were screened from various databases using predetermined Boolean search terms. In a pilot study, the search terms were refined to obtain optimal selection of articles after selecting articles on abstract level, selection was done based on full text which eventually led to 10 articles being identified on a full text level using a qualitative method based on tables generated from the data. Data were extracted from these 10 articles using a self-developed data extraction tool and then organised into various tables which led to compiling the final findings and conclusion for the review.

Results: The results indicated the benefit of AAC intervention when involving the parents in AAC intervention of their child with CCN. It mainly indicated the needs of parents not involved in their child's AAC intervention, not only the influence on them as parents but on the family system and the various ecological systems of the family and the child. The knowledge and skills required by the parents are prominent needs and the lack thereof as well as not being consulted on their opinion often leaves them feeling disempowered and unvalued.

Conclusions: A family-centred approach to AAC intervention is of the utmost importance in AAC intervention of a child with CCN. If the parent as primary caregiver and the members of the family system are not included in decision making,

goal setting, and planning, AAC intervention will most likely not be successful and lead to the abandonment of the selected AAC system. This abandonment will impact on the family system as well as the ecological systems of the child which in turn, will impact negatively on the child's development and communication.

Keywords: Augmentative and alternative communication; communication intervention; family and ecological systems; involvement; perceptions; primary caregivers

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ABBREVIATIONS

AAC	Augmentative and Alternative Communication
APA	American Psychological Association
ASD	Autism Spectrum Disorder
CCN	Complex Communication Needs
CINAHL	Cumulative Index to the Nursing and Allied Health Literature
CP	Cerebral Palsy
ERIC	Education Resources Information Center
MPOC	Measures of Processes of Care
PCC	Population, Concept, Context
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
SGD	Speech Generating Device
SLP	Speech Language Pathologist

1. PROBLEM STATEMENT AND LITERATURE REVIEW

1.1. Introduction

Augmentative and alternative communication (AAC) intervention is pivotal for obtaining functional and successful outcomes in communication and participation of children with complex communication needs (CCN) (Beukelman & Light, 2020; Drager et al, 2010). Satisfactory communication and participation of children with CCN necessitate the strengthening of opportunities and removal of barriers enabled through successful early AAC intervention. These aspects required for successful AAC intervention led to various studies which focused on the experiences and perceptions of parents as primary caregivers regarding AAC intervention acceptance and its implementation for their child with CCN. Examples of studies which focused on experiences and perceptions of parents as primary caregivers regarding AAC intervention are those by Allen and Shane (2014), Bunning et al. (2014), and Moorcroft et al. (2020). The value of findings lies therein that from these findings it can be derived how primary caregiver perceptions and experiences of AAC intervention could possibly influence the successful and beneficial implementation of AAC intervention (Moorcroft et al., 2020).

Primary caregivers of individuals with CCN who use AAC are in the best position to encourage the development of the communication skills of the individuals. Since they spend a great deal of time with the individual who uses AAC, primary caregivers could play a pivotal role in AAC intervention and could build on the use the parent's natural expertise (Bunning et al., 2014; Reichle et al., 2019). Parents as primary caregivers could optimally utilise the variety of communication opportunities present in the various aspects of life to improve the communicative competency of their child who uses AAC. By applying AAC exposure and intervention as often as possible during the day, recently acquired communication skills are maximised, generalised, and maintained (Reichle et al., 2019).

A review in the AAC Journal based on 30 years of research in the field of AAC, revealed that 85% of research in AAC focused primarily on the individual or child with CCN and only 15% focused on the primary caregivers (McNaughton & Light, 2015). Research creates awareness of an existing gap between the actual practice and what

was initially expected of the attempts to actively involve and empower primary caregivers in the event of AAC intervention (Woods et al., 2011).

Primary caregivers include any person who is part of the primary circle of communication partners as defined by the Social Networks Inventory (Blackstone et al., 2003), namely parents, family members, friends or someone specially appointed to act as a caregiver. For the purpose of this study, the term 'primary caregivers' will only include biological, foster or adoptive parents. The motivation for this decision is based on the statement by Granlund et al. (2008), that parents often fulfil the role of primary caregivers with the family being the primary context. Furthermore, studies suggest that children's embracing and actual use of AAC intervention is often influenced by the attitudes and impression of parents towards AAC (Park, 2020). Accordingly, before AAC intervention starts, it is important to attend to the needs of the parents or primary caregivers as a priority (Park, 2020). This statement by Park (2020) is supported by an earlier statement by Parette and Angelo (1996) that the commitment and support of parents and family partially contributes to the success in AAC intervention.

Involving the primary caregiver in the process of assessment and intervention can be seen as the most important aspect of the holistic management of the communication of an individual with CCN (Culp, 2003; Romski & Sevcik, 2005). McNaughton et al. (2019) also support the fact that successful communication is not only based on the ability of the child with CCN, but also on the capacity of the key stakeholders of whom the primary caregivers play a significant role. The co-operation and comprehension of parents as primary caregivers play a major role in the successful implementation of AAC for their child with CCN. Specific ways to improve the parents' comprehension of AAC should be pursued to enable them to accept the AAC intervention for their children (Park, 2020). For example, Donahue (2011) emphasised the importance of educating primary caregivers on the use of available technology and resources based on the understanding of the primary caregivers' abilities and preference to learning. By considering the preferences of adults as primary caregivers and their comfort level of working with AAC systems, will enable AAC clinicians to provide the primary caregivers with the appropriate AAC systems to utilise with positive results.

Caregivers of individuals who use AAC view the relationship they have with their child as special and close and regard themselves as having expert knowledge of the child's communication and medical condition (Goldbart & Marshall, 2004). However, even though primary caregivers have such an important role to fulfil, AAC intervention is often not primary caregiver or family centred (Mandak et al., 2017) – despite the importance of primary caregivers' involvement being emphasised in literature (Parette & Brotherson, 1996; Smith et al., 2016).

The perspectives and perceptions of primary caregivers with reference to their child with CCN are often not adequately understood or acknowledged and hinders the rendering of effective services by AAC clinicians (Marshall & Goldbart, 2008). This may lead to primary caregivers often being excluded from the decision-making process regarding AAC intervention of their children with CCN (Culp, 2003). If the unique priorities of primary caregivers are not considered in AAC intervention, it may impact negatively on the primary caregivers, through impacting on their participation in support services and stress levels, their children with CCN, families as well as the effectiveness of the implementation of AAC intervention (Mandak et al., 2017; Moorcroft et al., 2020; Parette & Brotherson, 1996). For example, the study by Moorcroft et al. (2020) investigated the perceptions of parents regarding the possible contribution of other stakeholders on AAC system abandonment. These authors found that the primary caregivers of the child with CCN reported a lack of professional support and communication between them (primary caregivers) and AAC clinicians that could possibly result in the abandonment of the AAC system (Moorcroft et al., 2020). With regards to device abandonment by the primary caregivers and their child with CCN, Angelo (2000) questions the effectiveness of AAC interventions. It is further recommended that aspects such as the extent to which the device is used as well as the amount of training provided to the primary caregivers and their child who must use the AAC system, should be considered (Angelo, 2000). Since these variables could influence the child who relies on the AAC system for communication and the primary caregivers' views and perceptions of AAC, these aspects as a part of many others should be carefully considered (Angelo, 2000).

Various factors could lead to the abandonment of AAC systems by parents as primary caregivers (Moorcroft et al., 2020). These factors include parents not being emotionally ready to accept the AAC intervention, the additional workload not being part of their normal parenting tasks, the child being unwilling to use the device for communication and not being satisfied with the AAC system in general. In a survey conducted in South Korea, it was found that AAC intervention was mainly influenced negatively due to the unwillingness of parents as primary caregivers to cooperate (Kim et al., 2016). The main reason that primary caregivers did not want to accept and cooperate in AAC intervention was the fear that their child would never be able to communicate orally (Smith et al., 2016; Romski & Sevcik, 2005) .

Primary caregivers were also inclined to reject AAC intervention when it was mainly focused on the classroom environment, thus excluding the primary living context, namely the home environment where the primary caregivers are interacting with their child with CCN (Shin & Lee, 2016). Here too, even though parents as primary caregivers were aware of AAC intervention, the importance of their child being able to communicate orally been placed on them, led to rejection of AAC intervention. These findings reiterate the value of the involvement of primary caregivers in the process of AAC intervention including thorough evidence-based education on AAC intervention and the consequences thereof (McNaughton et al., 2019). When the primary caregivers are not included in the decision-making of AAC intervention, they become anxious not knowing what to expect and are often not able to express their emotions about the introduction of AAC (Culp, 2003). This leads to a lack in confidence in their own knowledge, skill and competence in AAC implementation on the part of the primary caregivers.

The involvement of primary caregivers ensures that they are part of the decision-making process regarding AAC intervention (Culp, 2003). It can thus be said that the success of AAC intervention depends strongly on teamwork amongst all stakeholders, of which the primary caregivers form an integral part (McNaughton et al., 2019). Teamwork, and specifically collaborative transdisciplinary teams, is only successful if all members are included, their value acknowledged and respected (Goldbart & Marshall, 2004; Huer & Threats, 2016; McNaughton et al., 2019; Rackensperger, 2012). For communication to

be effective, the role and function of the child with CCN and their primary caregiver within intervention should be taken into consideration (McNaughton et al., 2019).

1.2. Communication for children with CCN

Participation and communication for children with CCN in various contexts are made possible through the effective use of AAC strategies (Von Tetzchner et al., 2018). Communication is inherent to all human beings and continuously takes place in the individual's natural environment (Light & McNaughton, 2014; Romski & Sevcik, 2005). The involvement of primary caregivers contributes to the successful and positive outcomes of AAC intervention through enhancing the acquisition of communication (Hong et al., 2016; Kent-Walsh, Binger & Malani, 2010; Parette & Brotherson, 1996).

Primary caregivers, specifically parents, are regarded as the most important communication partners of their young children (Parette, Chuang & Huer , 2004). They are regarded as the key stakeholders in ensuring the development of the communicative functioning competence of their child (Starble et al., 2005). Parents also provide the evidence based upon which intervention decisions are made for their children with CCN (Romski & Sevcik, 2005). Literature confirms that primary caregiver involvement has a positive influence on the welfare and health of a child with CCN (Bruder, 2000).

Parents of children with CCN often mention that their greatest desire for their child is to be happy and have friends. To maintain current relationships and build future relationships, intensified social and communication skills are required (Angelo, 2000). As such, the primary focus of AAC intervention is to achieve communicative competence of children with CCN, thus improving their communication to enable interacting with others and their full participation in society (Beukelman & Light, 2020).

Due to various circumstances, some children are unable to use natural speech to fulfil their daily communication needs. Effective communication is crucial for expressing needs and wants, to transfer information and to have social closeness and adhere to social etiquette (Beukelman & Mirenda, 2013). Effective communication assists in development, learning, education, and employment. Furthermore, AAC intervention can lead to improved literacy and cognitive skills as well as conceptual development and access to higher levels of education and general improvement of quality of life for

children and/or individuals with CCN (Drager et al., 2010). For individuals with CCN, AAC allows them to obtain communicative competence in order to achieve the abovementioned goals of communication.

Augmentative communication supplements existing communication and alternative communication is a replacement of speech in individuals with no functional speech. As with typical communication, AAC is also multimodal. In typical communication, various modes are used such as gestures, body language, facial expressions, and speech. Similarly, AAC includes various systems such as gestures, idiosyncratic gestures, manual signing, as well as low- and high-tech devices. It is of the utmost importance that the individual relying on AAC always has access to some or all modes of AAC in their system and in all contexts (Beukelman & Mirenda, 2013).

To achieve communicative competence, the interaction of primary caregivers with their child with CCN in natural contexts is supported (Light & McNaughton, 2014; Nunes & Hanline, 2007; Woods et al., 2011). Sigafoos et al. (2004) state that AAC intervention in the home environment is promoted through the direct involvement of the primary caregiver. It can thus be assumed that AAC intervention implemented in the family's context of daily routines will result in the AAC intervention becoming part of the natural family context through involvement of the primary caregivers (Nunes & Hanline, 2007).

1.3. The role of primary caregivers in AAC intervention

Important clinical implications for the involvement of primary caregivers in AAC intervention were identified by Starble et al. (2005). These clinical implications include the provision of significant social experiences, opportunities for device practice and development of communicative functioning of the child relying on AAC for communication. Romski and Sevcik (2005) highlight the importance of training in AAC for involved AAC clinicians and the families, including communication philosophy, the assessment, and available technology and strategies for intervention. These are important areas in the complete AAC intervention where the primary caregivers must be involved.

Another clinical implication raised by Granlund et al. (2008), is the abandonment of the AAC system. AAC intervention has a multitude of advantages, but unfortunately

despite this, such interventions are not always sustained and readily accepted (Park, 2020). Granlund et al. (2008) raised the question as to who is responsible for determining the ultimate goals of AAC intervention, as primary caregivers are often excluded by AAC clinicians in determining these goals. The AAC clinicians often do not allow for or seek parents' inputs in goal settings and their opinions are often not valued. Not being involved in the goal formulation of AAC intervention may lead to primary caregivers viewing these goals as unimportant. Subsequently, primary caregivers may abandon the AAC system due to them experiencing too much stress in implementing the AAC system during intervention (Goldbart & Marshall, 2004; Granlund et al., 2008).

Adapting to an AAC device or system can be very daunting (Angelo, 2000). When a primary caregivers' child with CCN has to get an AAC device, it leads to more responsibilities for the primary caregivers. These responsibilities include learning to operate the AAC device as well as to train the child with CCN and other primary caregivers on the use of it. The primary caregiver is also responsible to ensure that the device is in a working condition and always available for communication. These extra responsibilities could lead to increased stress for the caregiver (Goldbart & Marshall, 2004). It is important to be aware of the role that each parent as primary caregiver has to fulfil to enable effective support and ensure continuous family involvement (Angelo, 2000), which is crucial for successful AAC implementation and the prevention of AAC system abandonment (Moorcroft et al., 2020).

The support from AAC clinicians to primary caregivers is important for sustained AAC intervention (McNaughton et al., 2008). Parette, Brotherson and Huer (2000) interviewed a number of primary caregivers and found that they were of the opinion that communication between themselves and the AAC clinicians was insufficient and that their family and cultural values were not understood or respected. Primary caregivers in some cases, do not always have access to professional services, (Goldbart & Marshall, 2004) be it due to the lack of transport to and from the rural areas or the difficulty in scheduling appointments with an AAC clinician. They also required more information and training on the implementation of AAC (Parette et al., 2000). A prominent factor often found in literature is that primary caregivers feel they are left to seek AAC information on their own if they were to work with AAC clinicians (Goldbart & Marshall, 2004). Most

caregivers' feelings and emotions were that of social isolation and tiredness resulting from the absence of social support structures such as support from other parents with children who have CCN or teachers at school. These aspects may cause for intervention to be seen as disturbing the family functioning (Granlund et al., 2008).

In a cross-sectional study conducted by Fewster et al. (2020) on intervention for primary caregivers of children with autism spectrum disorder (ASD) who often rely on AAC, important findings were made regarding primary caregiver intervention. Primary caregiving is marked with a high load of caring which may affect the quality of life in a negative way (Franz et al., 2017). Therefore, they should not be viewed as primary caregivers only but as users of available healthcare options to ensure quality of life, welfare, and good health (Fewster et al., 2020).

The mental health of the primary caregiver is very important as it ensures that their child with CCN can reach their maximum potential and development. It is crucial to manage the aspects contributing towards stress in the life of the primary caregiver which are related to caregiving for a child with special needs (Fewster et al., 2020). The interventions should be aimed at improving the quality of life of the primary caregiver by addressing health, emotional- and social needs. Considering these needs of the primary caregiver will lead to a more positive attitude, less stress, and an overall increase in wellbeing which will positively influence their attitude to- and interest in being involved in the AAC intervention of their child. By being actively involved in all facets of primary caregiving, primary caregivers experience value and purpose in assisting their child with CCN to be able to live a meaningful life (Law, 2002).

1.4. Family-centred AAC intervention

Traditionally, services rendered by AAC clinicians for disorders in communication focuses on the CCN of the child only (Rini & Hindenlang, 2014). AAC is not a separate action – it involves an interaction between the child with CCN and the parents (Cress, 2004). Similarly, Crais (1991) states that through family-focused intervention, the focus has shifted from only the professional and the child with CCN, to involving the whole family through inclusion in the decision-making process aiming at the development of strengths within the family and the child with CCN. Increased diversity in families

underscores the growing need for a family-centred approach (Mandak et al., 2017). By changing the focus of AAC to include the whole family in AAC intervention, the family's needs are addressed and goals for communication are integrated within the family activities (Mandak et al., 2017; McNaughton et al., 2019; Smith et al., 2016). Furthermore, other studies showed that primary caregivers have to be equipped with a certain set of skills to enable that AAC intervention be sustained and effective (Goldbart & Marshall, 2004; McNaughton et al., 2008).

By equipping the primary caregivers as part of family-centred AAC intervention, AAC clinicians must take the uniqueness of each family into account – no family is the same. Each family has its own culture and rules, varying behaviour patterns, and specific boundaries (Rini & Hindenlang, 2014). Family members are interdependent and what affects one member may have an impact on the whole family. Family members also have their own specific relationships with each other (Rini & Hindenlang, 2014). Not only does each family have its own larger social and environmental context, but also carries the ingrained ideas and traditions of past generations (Rini & Hindenlang, 2014). As different families may require different kinds of support, the characteristics of families have a significant effect on the outcome of AAC interventions and these characteristics are therefore important to consider (Granlund et al., 2008).

Part of AAC intervention involves family support, with the focus on the child with CCN to develop skills to deal with future challenges in communication (Ylvén et al., 2006). Communication of a child with CCN within the context of the family is of great value as it allows for effective functioning of the child within a natural environment (Granlund et al., 2008). Therefore, research determined that the family contexts where primary caregiving takes place, are the contexts of successful AAC intervention (Donahue, 2011; Granlund et al., 2008; Mandak et al., 2017; Moorcroft et al., 2020). AAC intervention influences the child with CCN as well as other members of the child's social network and family (Granlund et al., 2008) and is thus significantly dependent on the primary caregiver's involvement in AAC intervention. The primary caregiver, the needs of parents as well as the parents' involvement as primary caregivers have been discussed. Following is a discussion of the contexts the child with CCN and the family system have to function in.

1.5. Systems influencing AAC intervention of children with CCN

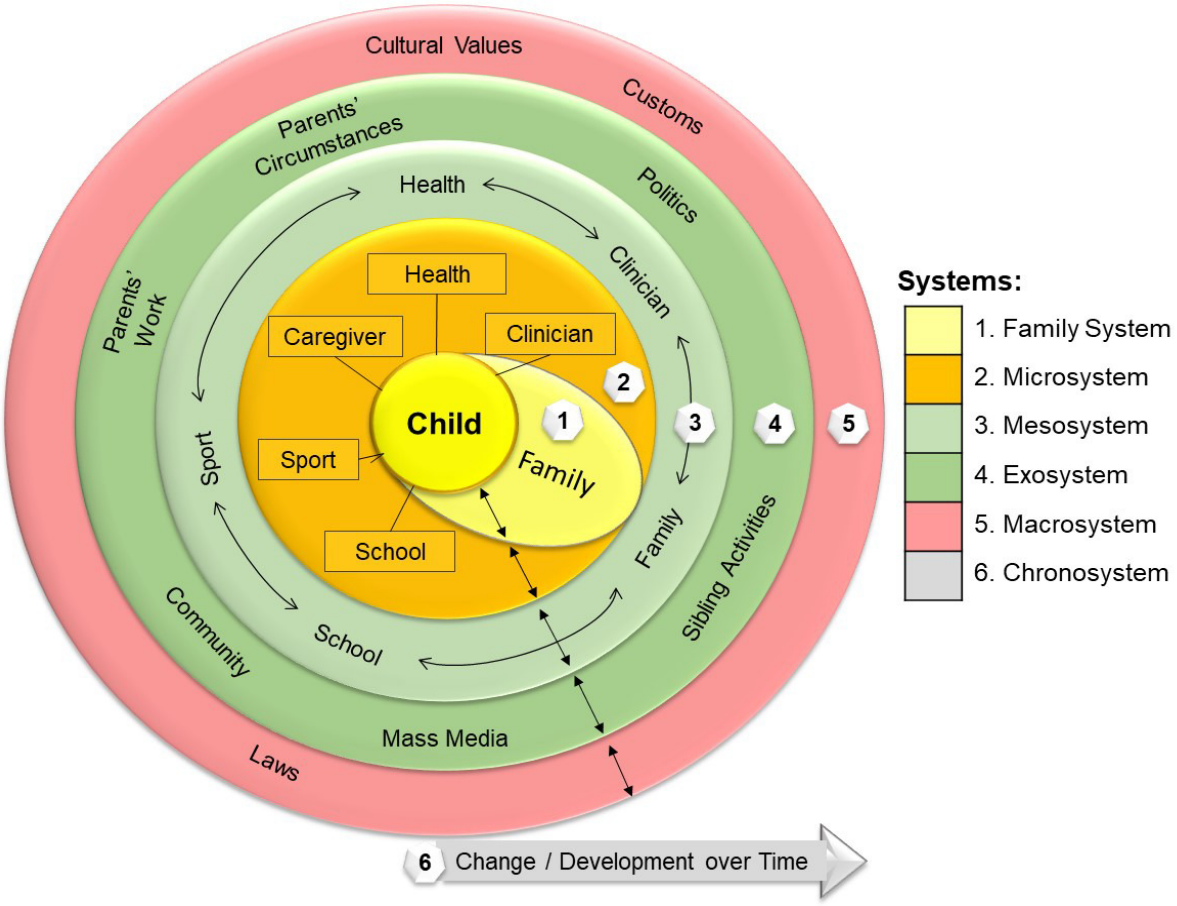
Bronfenbrenner (1979) identified five ecological systems which form part of the environment of the child with CCN and in addition, the family system which also plays a pivotal role as depicted in Figure 1 below. These systems will be the main focus of discussion for this section.

According to Crawford (2020), services to children with CCN occurring in isolation will result in change which does not always occur in the family system and thus, will eventually not form part of the family system. Families need to be empowered and provided with a supportive environment for the most appropriate AAC systems to be selected (Mandak & Light, 2018).

Mandak et al. (2017) suggested that using a family systems framework to base AAC services on, will enhance a strong family system and AAC clinician partnership through which the true communication needs and goals of the individual will be reached. The family system is professionally centred, family-allied, family-focused, and family-centred (Coburn et al., 2021). Mandak et al. (2017) consider the modern-day family and therefore, describe the family as whoever is designated by the family as family members. This forms the family system. These authors furthermore emphasise the importance of identifying relevant family members, such as primary caregivers to enhance successful family centred AAC intervention. For the current study, the family system will comprise of primary caregivers, namely parents, siblings, grandparents, and close relatives residing in the home where the child receiving AAC intervention, lives. Children with CCN and their primary caregivers do not only function within the family system – the latter can be included in the larger Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1979; Coburn et al., 2021). This theory supports the influence of various settings in which a child with CCN functions as well as other contexts relevant to the child's functioning, even though the child might not interact with the systems directly. The focus is on the development of the child within the system consisting of various relationships which influence the development of the child (Perron, 2018). Bronfenbrenner's ecological systems theory includes the microsystem, mesosystem, exosystem, macrosystem, and chronosystem as described by Pask et al. (2018) (See Figure 1).

Figure 1, depicts the interrelationship between the ecological systems and the ecological systems' interrelationship with the family (Coburn et al., 2021; Crawford, 2020; Mandak et al., 2017, Pask et al., 2018).

Figure 1: *The interrelated environmental systems of a child with complex communication needs including the family system*



The microsystem closest to the child, consists of the individuals the child with CCN interacts with directly and on a regular basis. These include the family system such as parents as primary caregivers, siblings and grandparents, other caregivers, the school environment including teachers and peers, sports environment, the neighbourhood, and healthcare providers (i.e., AAC clinicians). Key to the ecological systems theory is the interaction within each system but also the interactions between systems. The

mesosystem contains the individuals which the microsystem consists of Perron (2018) aptly describes the macrosystem as having an influence on the interactions of the other systems through a cascading effect with specific reference to their interactions with each other and with the individual with CCN. The exosystem which is the larger social system, might have an impact on the child with CCN through interacting with one or more of the members of the mesosystem, without the child directly interacting with members of this system. Examples are siblings' sport activities, parents' work environments, politics, mass media, and the community. The exosystem often has an impact through involving a member of one of the mesosystems. The macrosystem mostly consists of cultural values, laws, and traditional customs which may influence some of the other systems (Crawford, 2020). Lastly, the chronosystem depicts the child's development and change in needs, environment, and circumstances over time (Pask et al., 2018). This system has a significant influence on the family system as any change or development in the child with CCN will influence the way the family functions and also the overall modes of AAC selected and AAC intervention. In turn, the mesosystem, exosystem, and macrosystem may influence the chronosystem in the sense that any shortcoming in one of the systems will directly influence the child with CCN and thus, their communication. All ecological systems impact each other and subsequently the family system.

1.6. Justification for this scoping review

Since the primary caregiver is the only constant factor in the life of a child with CCN, it might be feasible to investigate their involvement in AAC intervention for their child (Starble et al., 2005), including the impact of their involvement with reference to the various systems of the child's environment or ecology. The investigation with regards to the influence of AAC intervention on the primary caregivers and the results of the intervention are justified for as long as AAC is being recommended by AAC clinicians (Angelo, 2000). A scoping review will assist in providing a broader understanding of the way primary caregivers are involved in AAC intervention and their needs and perceptions. The continuous investigation into primary caregivers' perceptions, which are their opinions, experiences, lessons learnt, and views of their involvement in AAC intervention of their child with CCN, will lead to an increased understanding of the

influence AAC intervention has on the primary caregivers and the family (Angelo, 2000) as well as the influence of their involvement in their child's living environment. A better understanding of these perceptions may guide AAC clinicians to ensure an improved and more successful involvement of primary caregivers in the AAC intervention of their child with CCN.

2. METHODOLOGY

2.1. Aims

To follow are the main aim and sub-aims for this review.

Main aim:

The main aim of this scoping review is to determine primary caregivers' perceptions of their involvement in AAC intervention of their children with CCN as described in literature. Primary caregiver involvement includes primary caregivers being part of the transdisciplinary team, including being part of setting goals and evaluating the effectiveness of a selected AAC mode for their child. A transdisciplinary team consists of all members from various disciplines involved in the intervention of the child with CCN including the parents as primary caregivers. A transdisciplinary team instead of an interdisciplinary or multidisciplinary team would be preferred, as knowledge and skill sharing take place amongst the members. Therefore, if the AAC clinician is not available one of the other professional team members will have acquired enough skill in the field as that of the AAC clinician to be able to assist the child and family with AAC intervention. Members of this team share information and work together to find the best possible intervention approach for the child with CCN.

Sub-aims:

To address the main aim, the following sub-aims were identified:

i. To determine how primary caregivers are involved in the AAC intervention of their child with CCN through valuing and consideration of their inputs and actively attending to their concerns through ongoing support.
ii. To map primary caregivers' involvement in AAC intervention to the family systems framework and Bronfenbrenner's (1979) ecological systems theory.
iii. To investigate the influence of the ecological systems on the family system that could result in perceived positive and negative primary caregiver involvement in AAC intervention of their child with CCN.

2.2. Research design

This study employed a scoping review design. Scoping reviews are being used increasingly with the aim being a comprehensive research on a certain topic (Levac et al., 2010). Scoping reviews do not attempt to answer in-depth research questions or evaluate the context quality of a specific study (Arksey & O'Malley, 2005), however, they provide a wider scope on a large field of literature on a specific topic (Munn et al., 2018) such as primary caregivers' perceptions of their involvement in AAC intervention. As a scoping review is broader than a systematic review, the criteria for inclusion are less restrictive (Peters et al., 2015; Levac et al., 2010), however, the review should have a clear research question. Based on the characteristics of a scoping review, it was found to be the most appropriate research design to answer the research question for the current study. Therefore, the research question for the current study will be based on the elements of population (P), concept (C), and context (C), also referred to as the PCC elements (Peters et al., 2015). The question based on the PCC elements is: '*What are primary caregivers' perceptions of their involvement in AAC intervention of their children with CCN as described in literature?'*

2.3. Search strategy

The literature searches were based on specific inclusion criteria (Peters et al., 2015). In the current review, population (P) refers to the primary caregivers, the concept (C) is primary caregivers' perception on their involvement, and the context (C) is AAC intervention. Table 1 provides a summary of inclusion- and exclusion criteria of studies according to the PCC elements, as well as the theoretical justification why these criteria were selected.

Table 1: *Inclusion- and exclusion criteria according to the PCC elements*

PCC Elements	Inclusion Criteria	Exclusion Criteria	Justification
Population	Only primary caregivers who are parents, foster parents, or adoptive parents of children and young	Any other caregivers who are not parents, for example distant family or professional caregivers even though	Although Marshall and Goldbart (2008) describe parents as the experts when it comes to their children and especially those with CCN due to their vast amount of knowledge, they found

PCC Elements	Inclusion Criteria	Exclusion Criteria	Justification
	people aged 17;11 (years; months) and younger.	Mc Naughton et al. (2008) regards the above as part of the family.	that all parents were not equally involved with AAC intervention. Hence the importance of finding out what literature says regarding parents and why some of them are less actively involved. As stated by McNaughton and Light (2015), between 1985 and 2014 most research was conducted on the population with CCN aged 17 years and younger.
Concept	Primary caregivers must be involved in the implementation of the AAC intervention through participation and engagement and not only in primary care.	If no primary caregivers are involved or if they are involved but do not have to take any responsibility for the AAC intervention, those studies will be excluded.	For communication to be effective, the role and function of the primary caregiver within intervention should be taken into consideration (McNaughton et al., 2019).
Context	AAC has to form part of the intervention plan. Articles dated from 1980–2021 will be included.	If AAC intervention is not implemented studies will be excluded.	The main aim of the review is to determine the nature of the primary caregiver's perception on their involvement in AAC intervention of their children with CCN to enable communication competence (Light & McNaughton, 2014)

Before commencing with the full review, a pilot study search was conducted in collaboration with the supervisor and two library subject specialists at the University of Pretoria to ensure optimal results in the searches and refined search terms. The Cumulative Index to the Nursing and Allied Health Literature (CINAHL) database was used for the pilot study. During the pilot study, initial search terms were amended.

Table 2 shows the various search strings used and the number of searches it yielded. Considering the search strings, it was concluded that the first two strings were too wide as they yielded mostly irrelevant results. With the input from the library subject specialists, the search string was refined further to the final one proposed for the main study as more relevant results were obtained.

Table 2: *Search terms evaluated in the CINAHL database during the pilot study*

Searches	Search Terms	Number of Searches Found
First attempt of search terms	involv* OR participat* OR collaborat* OR perception AND famil* OR parent* OR primary OR primary caregiv* AND augmentative and alternative communication OR AAC AND implement* OR intervent* AND child* OR adolescent OR teen*	60509
Refined search terms	involv* OR participat* OR perception AND famil* OR parent* OR primary caregiv* AND augmentative and alternative communication OR AAC AND intervent* AND child* OR teen*	10011
Final terms	involv* AND parent* OR primary caregiv* or family AND augmentative and alternative communication OR AAC AND intervent*	395

Table 2 shows how the final Boolean search term string resulted from the pilot study yielded studies more relevant to the research question.

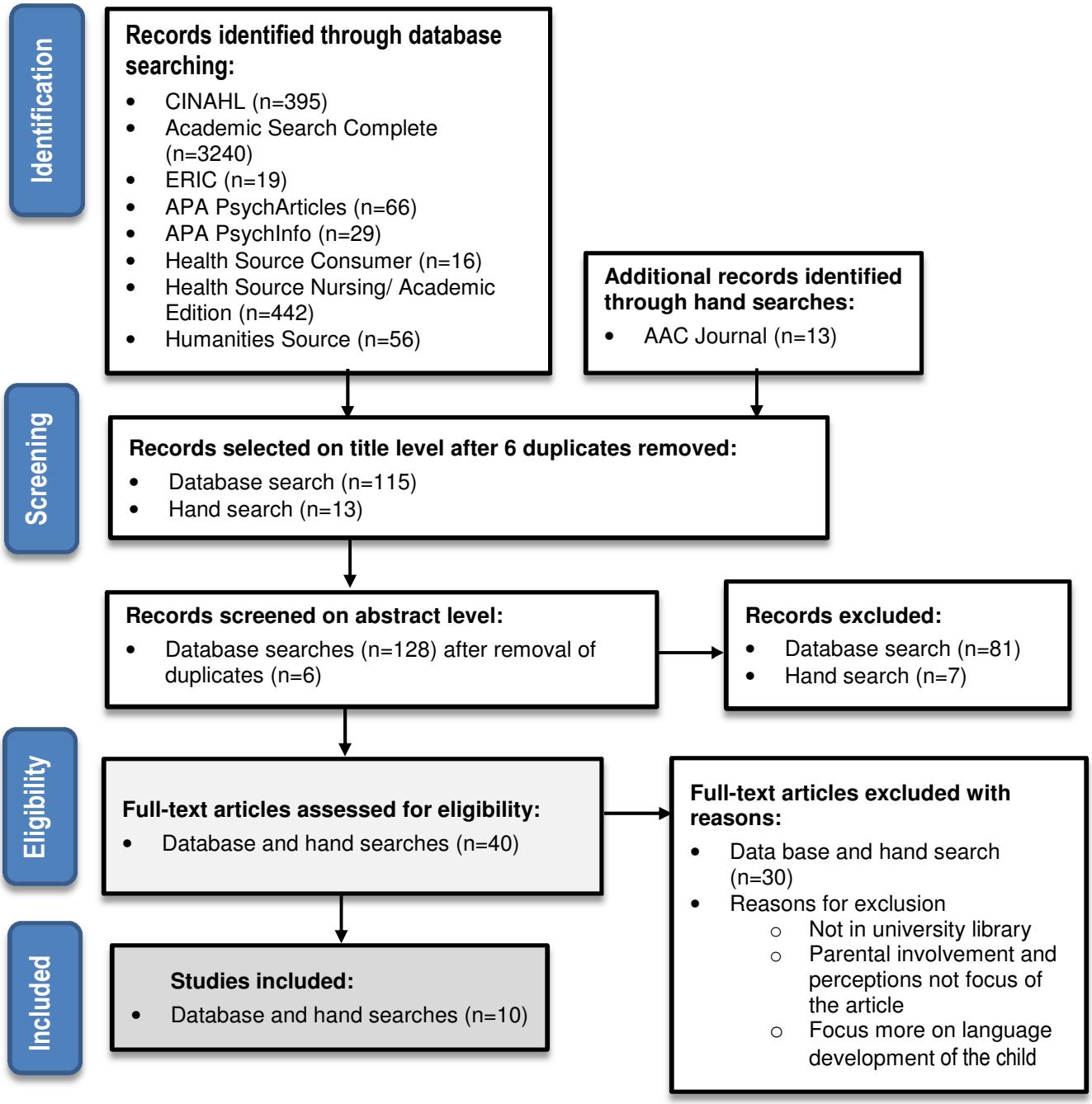
2.4. Selection procedure for main study

Once the search terms were finalised in the pilot study, they were used to do the literature search for the main study in the following eight electronic databases: CINAHL, Academic Search Complete, ERIC, APA PsychArticles, APA PsychInfo, Health Source Consumer, Health Source Nursing/Academic Edition and Humanities Source. These databases were selected as they were found to be most relevant to the field of AAC intervention. To ensure that no study was excluded or overlooked in the database searches, hand searches were done in the index of the AAC journal as this journal was found to contain recent and relevant articles. Apart from the PCC elements used to identify the inclusion- and exclusion criteria of studies for this review (See Table 1), the following other selection criteria were added: (i) only articles written in English were included as it is too costly to translate studies written in other languages; and (ii) only peer-reviewed articles in accredited journals were included and all grey literature such as newspaper articles, webpages, dissertations, or theses were excluded.

Figure 2 illustrates the selection procedure followed according to the Preferred

Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram for scoping reviews to identify the studies for this review (Moher et al., 2010; Peters et al., 2015).

Figure 2: *The PRISMA flow diagram for scoping reviews (Peters et al., 2015)*



A total of 4 263 studies yielded from the eight databases with 13 more studies identified by means of a hand search in the AAC Journal. Figure 2 gives a summary of the number of studies identified per database. From the total of 4 263 studies that were screened on title level, 128 studies were selected to be screened on abstract level. Reasons for exclusion were duplications, abstracts indicated that the articles were not topic-related and did not cover all keywords in the search string. These selected studies' abstracts were uploaded onto Rayyan, an online platform designed for collaborative systematic reviews (Ouzzani et al., 2016). Regular Microsoft Teams meetings were held between the researcher and supervisor to confirm selection criteria. The Microsoft Teams platform was found to be most user-friendly for the researcher and supervisor alike. After a discussion between the two reviewers of the 128 articles screened on abstract level, a 100% consensus was reached and from the abstract level screening, 40 studies (Appendix A) met the inclusion criteria to be reviewed on full text and were uploaded onto Rayyan to enable more multiple reviewers to conduct blind reviews. From the full text review, five discrepancies (88% agreement) between the two reviewers (the researcher and supervisor) were observed. A 100% agreement was reached in another Teams meeting between the reviewers to confirm the inclusion of 10 studies for data extraction.

2.5. Materials and equipment

Citations were screened using Rayyan Qatar Computing Research Institute software (Ouzzani et al., 2016). Through the process of blind screening, objectivity was increased and selection bias minimised. An interrater agreement was enhanced through this process (Ouzzani et al., 2016). A self-developed data extraction tool (see Appendix B) as recommended by Levac et al. (2010), was used to extract data based on the author, year, title, country in which the study took place, the study aim, the study design, and adult or child participants. Materials used, type of AAC interventions, caregiver perception and outcomes/key findings were included as well as the various bio-ecological systems against which data were extracted.

2.6. Data extraction and analysis

Data extraction in a scoping review is charting and summarising the results in such a way that it correlates with the main- and sub-aims of the review (Peters et al., 2015). The data extraction tool was used (Refer to Appendix B) and alterations were made to the tool by the reviewers as the review on full text level progressed.

Table 3 indicates the data extraction topics that were applied as well as the theoretical justification for each topic.

Table 3**:** *Data extraction topics*

Area of Extraction	Data	Theoretical Justification
Demographics	Authors	There are a number of leading authors in the field of AAC intervention who have varying and joint viewpoints which could influence the choice of aims and sub-aims of their studies and thus have varying results and conclusions. This is evident from the growth which was exponential in AAC research and publications between 2005–2014 (McNaughton & Light, 2015) and to date.
	Publication year	The field of AAC is relatively young and started to emerge as a field in its own right in the 1980s (McNaughton & Light, 2015). Although it is best practice to include recent literature, some of the important core statements serving as motivation for this study were made as early as 1980. Therefore, literature from 1980 to May 2021 was included.
	Study title	The study title is important as a key word, indicating the relevance to this scoping review occurs in the title.
	Country where study was conducted	The main context in which the individual with CCN lives plays a significant role in communication and AAC intervention (Granlund et al., 2008). Contexts vary in different countries and therefore the country where the research was conducted is regarded as key information.
Methodology	Type of study design	The study design was noted as it might have influenced the results.
	Aims and sub-aims	The aims and sub-aims of the studies will be extracted to indicate their underscoring of the aim and sub-aims of this scoping review.
	Participants	The population included in the research is important as the context might influence the responses and involvement of primary caregivers, for example the degree and nature of

Area of Extraction	Data	Theoretical Justification
		the child's cognitive and physical impairment directly influences the reality surrounding speech production (Wilkinson & Hennig, 2007) and hence the AAC system. Each population has different cultural values.
Results	Type of parental involvement	How parents were involved in AAC intervention would directly affect their perceptions on their involvement in AAC intervention.
Outcomes / Findings	Outcomes/relevant key findings	The outcomes of each study are crucial in answering the sub-aims of this scoping review in order to give a conclusion to the main aim.

A thematic analysis was followed. The reason for this being that it is a method more widely used in qualitative contexts, it has flexibility within various theoretical frameworks and a wide range of research questions can be addressed (Terry et al. 2017). After the inclusion- and exclusion factors were determined, specific data extraction topics were identified (Table 3). The deductive analysis was done using the operational definitions and themes identified by McNaughton et al. (2008), namely (i) AAC device selection; (ii) knowledge and skills needed to use AAC technology; (iii) barriers to learning, (iv) teaching the individual; (v) educating society and (vi) recommendations to others. The extracted data were linked to Bronfenbrenner's ecological systems as well as the family system of the child with CCN and are depicted in Table 4 – a theoretical framework in which this study took place Refer to Section 3.5. for more information on how the linking was done.

Table 4: *Settings against which data were extracted*

Systems	Environments	Theoretical Justification
Systems in which extracted data were placed	Environments in which parents were involved in AAC intervention.	Based on Bronfenbrenner's (1979) ecological systems, theory environments (systems) are important for the functioning of a child within the everyday settings as well as in their related contexts to be considered when planning and implementing AAC intervention (Coburn et al., 2021). The family system is referred to as part of the microsystem by Bronfenbrenner (1979) and is a tight knit system wherein the family functions. The microsystem that includes the family system is influenced directly or indirectly by events in all other systems (Refer to Figure 1).
	Specific circumstances in the mesosystem, exosystem, macrosystem, and chronosystem which might influence the parents' involvement in AAC intervention.	Members of the child's microsystem and mesosystem might have an indirect influence on the parents' involvement in AAC intervention, for instance the circumstances of a close friend or a sibling or parents' work-related circumstances (Coburn et al., 2021).

2.7. Trustworthiness

In qualitative data analysis, external- and internal validity are not used, instead trustworthiness is used (Leedy & Ormrod, 2015), implying that the findings should be credible, transferable, dependable, and confirmable (Shenton, 2004).

Credibility

Macnee and Mc Cabe (2008) define credibility as being sure that the research finding is true. Credibility determines if the findings are believable information determined from the findings of the research article and was correctly interpreted in this case, the scoping review (Graneheim & Lundman, 2004). To ensure credibility, only peer reviewed articles were selected for this study.

Transferability

Transferability determines the extent to which the findings of qualitative research can be conveyed or made applicable to different contexts with different participants, in other words generalised (Bitsch, 2005).

Dependability

Findings are dependable when they remain stable over time and do not change (Bitsch, 2005). To ensure dependability of data for the findings of the present research study, the interpretation and recommendations following from the findings were evaluated, in this case by the researcher and the supervisor, to ensure that the data gathered in the study support the findings (Cohen, Manion & Morrison, 2007).

Confirmability

Confirmability implies that the findings and the interpretation of research data should be true and not manipulated by the researcher to comply with the research aim and should be able to be confirmed by other researchers (Tobin & Begley, 2004). Confirmability for this study was ensured through assessment by the supervisor and an external examiner.

To ensure that the scoping review as well as the selected research articles adhered to the requirements of trustworthiness, the supervisor and the researcher depended on interrater reliability.

2.8. Ethical considerations

Ethics approval was received from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria (HUM027/0920). Although the current study does not entail any humans, the use of human participants in research such as in the field of AAC, is general practice. When research involves human participants, adherence to strict ethical practice is crucial (Leedy & Ormrod, 2015). These ethical considerations include protection from harm be it physical or psychological, participation that is informed and voluntary, with informed consent given by participants and the protection of the participants' privacy (Leedy & Ormrod, 2015). It should also be clear that the authors did not manipulate any data or misinterpret it (Leedy & Ormrod, 2015). In the current scoping review, the considerations mentioned by Leedy and Ormrod (2015) together with the other inclusion- and exclusion criteria, determined inclusion or exclusion of an article. If it was clear on the full text level of articles involving human participants that the study did not adhere to the abovementioned considerations, it was not considered for the present scoping review.

In this scoping review no manipulation of data to enhance a specific viewpoint took place and neither were articles that promoted a specific viewpoint selected (Wager & Wiffen, 2011). Plagiarism was avoided at all times throughout the scoping review and the authors of articles used were correctly acknowledged (Wager & Wiffen, 2011). To prevent researcher bias, the articles included were independently selected by the researcher and the study supervisor based on the specific inclusion- and exclusion criteria determined to ensure focus of the review on the research question at hand.

3. RESULTS AND DISCUSSION

3.1. Introduction

This study aimed to determine primary caregivers' perceptions of their involvement in AAC intervention of their children with CCN and to link caregivers' perceived involvement in AAC intervention to the family systems framework and Bronfenbrenner's (1979) ecological systems theory. The results and discussion are offered according to the three sub-aims of the study. Firstly, how primary caregivers are involved in the AAC intervention of their child with CCN through valuing and consideration of their inputs and actively attending to their concerns through ongoing support. Secondly, mapping of primary caregivers' involvement in AAC intervention to the family systems framework and Bronfenbrenner's (1979) ecological systems theory. Thirdly, how could the influence of the ecological systems impact the family system that may result in perceived positive and negative caregiver involvement in AAC intervention of their child with CCN.

3.2. Demographic features

A summary of the demographic features (i.e., authors, year, title, country where the study was conducted, study design, aim of study, and participants) of the included studies is depicted in Table 5. The adult participants as primary caregivers included either both parents, mother, father or single parents. Data of children included their age and type of disability resulting in CCN. Study aims as well as study designs were also included as these aided in the selection of the studies to be reviewed.

Table 5: *Demographic description of included studies (N=10)*

#	Author, Year, Study Title	Country	Study Aim	Study Design	Participants: Adults	Participants: Children
1	Allen & Shane (2014). Autism spectrum disorders in the era of mobile technologies: Impact on caregivers	USA	To give a review of the literature on parental stress in children with ASD, as well as the involvement of caregivers and their attitudes towards AAC intervention in using mobile technology.	Literature review	Parents of children with ASD requiring AAC intervention.	Children with ASD requiring AAC intervention through use of mobile technology (No ages mentioned).
2	Anderson, Baladin & Stancliffe (2014) Australian parents' experiences of speech generating device (SGD) service delivery	Australia	To examine parents' experiences of current service access and coordination and to explore their experiences of the relationship between parents and AAC clinicians. These results were aimed at developing a new SGD support and training programme after the study.	Narrative analysis	Parents (N=6) of children with CCN.	Children 2–18 years using a SGD or used one in the past.
3	Bunning et al. (2014). Caregiver perceptions of children who have CCN following a home-based intervention using augmentative and alternative communication in rural Kenya: An intervention note	Kenya	To study the outcomes of home-based caregiver-implemented intervention through AAC methods involving children with CCN and their primary caregivers.	Within group design investigating reported impact associated with home-based AAC intervention. A pre-test post-test design investigated the changes in print perceptions after following a home-based intervention.	Number of parents not mentioned.	Children (N=9) 4–12 years were recruited. They were children with ASD, cerebral palsy (CP), intellectual disabilities.
4	Douglas et al. (2021). The effects of tele practice to support family members in modelling a speech-generating device in the home	USA	To investigate if tele practice is an effective and socially valid way of teaching more than one family member to implement aided language modelling in the home.	Single-case multi-probe design	Both parents (father and mother) with intervention based on the baseline and consisted of tele based training and thereafter, coaching.	Siblings (N=2) and the child with CCN.

#	Author, Year, Study Title	Country	Study Aim	Study Design	Participants: Adults	Participants: Children
5	Fäldt et al. (2020). "All of a sudden we noticed a difference at home too": Parents' perception of a parent-focused early communication and AAC intervention for toddlers	Sweden	To describe the breadth of parent perceptions on AAC interventions based on the ComAlong Toddler programme.	Qualitative design: Telephonic interviews	Parents (N=16) (15 married; one single parent).	Children (N=13) with CCN (18 months–3 years) from 13 families who took part in the ComAlong Toddler courses. Causes of the CCN were not provided.
6	Gona et al. (2014). A home-based intervention using AAC techniques in rural Kenya: What are the caregivers' experiences?	Kenya	To explore the effects and development potential of home-based AAC intervention for children with CCN in rural Kenya by looking at experiences of caregivers and their experiences when homebased intervention is introduced.	Qualitative single case study design	Caregivers (total not mentioned).	Children (N=9) 4–12 years were recruited. Their diagnosis included ASD or CP or intellectual disability or hearing impairment.

#	Author, Year, Study Title	Country	Study Aim	Study Design	Participants: Adults	Participants: Children
7	Mandak & Light, (2018). Family-centered services for children with ASD and limited speech: The experiences of parents and speech-language pathologists	USA	The main aim of this study was to determine the degree of family centredness and the identification of specific family-centred behaviours as observed by parents as opposed to the perceptions of the speech language pathologist (SLP). The sub-aim relevant to this review was to determine what the experiences were of parents whose child had ASD and CCN regarding the family-centredness of the speech and linguae services of their child with CCN.	Web based survey	Parents (N=99) of children with ASD and CCN.	Children (N=99) 2–20 years with ASD and having received speech and language services for at least one year.
8	Marshall & Goldbart (2008). Communication is everything I think'. Parenting a child who needs AAC	United Kingdom	To get more insight on the lived experiences of families with children in the early stages of using a formal AAC system.	Qualitative design: semi-structured interviews (at home; one telephonic)	Parents of families (N=11) participated, two being foster parents.	Children (N=11) 3–10 years with either CP, intellectual disabilities or hearing impairment.
9	McNaughton et al. (2008). "A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies	USA, Greece	To gain a better understanding of parents' perspectives on the technology learning experiences of children who use AAC.	Qualitative study: Online focus group	Parents (N=7).	Children 6 – 30 years (of whom four were older than 17:11 years) with CP.

#	Author, Year, Study Title	Country	Study Aim	Study Design	Participants: Adults	Participants: Children
10	Moorcroft et al. (2020). 'We were just kind of handed it and then it was smoke bombed by everyone': How do external stakeholders contribute to parent rejection and the abandonment of AAC systems?	Australia / USA	To explore parents' perceptions on the contribution of external stakeholders to the rejection or abandonment of the AAC system of their child with CCN.	A qualitative descriptive design: Semi-structured interviews	Parents (biological mothers) (N=12).	Children (N=12) 3–16 years Diagnoses: five ASD, one CP, one intellectual disability, three various syndromes, and two other causes.

In Table 5 the demographical data of all 10 of the included studies were presented. It was noted that two (n=2) of the studies were conducted in 2008 and the remaining eight studies were conducted over the past ten years, that is 2014 (n=4); 2018 (n=1); 2020 (n=2); and 2021 (n=1). This increase in studies reporting on primary caregivers' perceptions on their involvement of their child's AAC might show the shift to family-centred intervention. The countries in which the studies were conducted included six countries from four continents (Africa, Australia, Europe, and North America): Five studies were conducted in the USA, two in Australia and Kenya respectively, and one each in Sweden, Greece, and the United Kingdom – indicating that AAC intervention is being employed in developed as well as low-and-middle income countries. The study designs varied across all studies with a different number of adults (primary caregivers) and children with CCN with different disabilities being included. These aspects could have contributed to the adherence of trustworthiness as mentioned earlier. The variety of authors, dates, countries, study aims, number of primary caregivers, and children of varying ages as well as the fact that the caregiver's perceptions correlated across studies, be it that the studies accentuated negative or positive perceptions, all contributed to trustworthiness as the data obtained from the 10 studies showed applicability in various contexts, were stable or similar over time and because of similarity could be assumed confirmable.

3.3. Intervention methodology, primary caregivers' perceptions and key findings

A comprehensive summary of the intervention methodology, primary caregivers' perceptions, and key findings of each study is reflected in Table 6. The materials used, type and form of AAC intervention methods, and the involvement of caregivers are described. Once again, a significant variation is noted indicating adherence to trustworthiness. Six themes are presented with reference to primary caregivers' perceptions regarding their involvement in AAC intervention of their child with CCN , namely (i) AAC device selection; (ii) knowledge and skills needed to use AAC, (iii) opportunity barriers to learning, (iv) teaching the individual, (v) educating society and other factors as based on the study by McNaughton et al. (2008).

Table 6: *Intervention methodology, perceptions of primary caregivers, and key findings*

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
1.	Various articles on children with ASD depending on AAC by using mobile technology.	High technology non-dedicated devices; Form of AAC: Mobile technology	Parents were involved in AAC intervention in the included studies (the various ways of how parents' opinions were obtained were not mentioned in the specific review).	AAC DEVICE SELECTION: • Use of mobile technology for AAC may be more normalising and could also reduce stress levels of parents with a child with CCN. KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Parents of children with CCN have a need to gain knowledge and skills to reduce their stress levels. • Parental stress amongst parents with children with CCN is significant if compared to parents with children with disabilities without CCN. By reducing their stress levels, the parents feel that the outcomes for their child with CCN will improve. OTHER: • Communication and social skills are ranked as pivotal by parents. Expression of needs and wants and the ability to make choices for their child with CCN are very important. • There is a lack of research on the expectations and attitudes of parents towards knowledge and skills regarding mobile technology.	• Communication behaviours have either increased or stayed the same when mobile technology was used for communication instead of communication cards. • Mobile technology used as an SGD allowed for a higher rate of independent responding as opposed to other AAC modes. • Parents can be successfully trained in the use of AAC for their children which will lead to improved communication with their children and thus reduce parental stress.
2.	Semi-structured interviews were used. Interviews were conducted face-to-face, by phone or via videoconference.	High-technology dedicated devices; Form of AAC: Speech generating devices (SGD)	Parents were involved in assisting their child with the use of the SGD.	AAC DEVICE SELECTION: Parents felt that: • The initial responsibility of teaching how to use the device was the responsibility of the SLP and the SLP also had to guide them gradually into taking over some of the responsibilities. • The intervention role transfer from the SLP to the parent should be a guided process where the parents' participation had to be	• Families required a high degree of initial support, ongoing needs are the programming, vocabulary selection and goal setting, and find inaccessible support systems as well as poor quality disempowering. • Their ideal of intervention was that it should take place once a week at home and be on-going.

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
				observed and commented on by the SLP. • They were disempowered when they were excluded from decision-making and intervention dominated by the AAC clinicians. • Their goals and priorities for intervention were met sufficiently. • Goal setting was not family-centred and the parents had to almost fight for the services they wanted. • Very often the preference of device selection led to conflict between the AAC clinicians and the parents. KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Access to services for parents, knowledge and expertise of the therapists, consistency and continuity of the services, roles and responsibilities, and the influence of parents had been included. • Some parents (n=5) had positive experiences towards the services, with consistent weekly in-person support. • The therapy team abandoned the parents from the start after the SGD was introduced. • Three parents abandoned the SGD as they felt there was no steady guidance and encouragement from the AAC clinicians. OPPORTUNITY BARRIERS: Parents felt that: • AAC clinicians could not provide the support needed as they were not trained in the use of the communication systems.	• Device abandonment was mainly due to a lack of support to the families. This could be overcome by tele-health, group intervention for families, and family networks. • Although some therapists were experienced and very equipped, lack of experience in therapists caused a great deal of frustration and forced parents to do everything on their own. • Parents also noted that there was a lack of consistency in services with regards to coordination and communication. • Parents felt that team goals should be made according to family capacity and on transdisciplinary practices. • Almost all parents felt that parents have to play a pivotal role in facilitating the use of the device in the home environment. • It was felt though that initial training and programming should be the responsibility of the professional. • Clear and consistent messages were not received from all AAC clinicians. • The knowledge gap between parents and AAC clinicians was expanded as AAC

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
				• Technical assistance in the case of device failure was not always readily available. • Policy barriers, for example age and eligibility restriction caused concern. • Families in rural areas have less access as they had to travel far to meet with the professional team. • Funding on a long-term basis was seen as a significant barrier. • Coordinating appointments with the AAC clinicians is difficult. TEACHING THE INDIVIDUAL: • Parents turned to online forums for help, but some still preferred face-to-face access for help and advice. OTHER: • Parents emphasised their role as primary facilitator in the implementation of SGD use. • Lack of proper support network resulted in parents feeling they had sole responsibility to do the programming, maintaining of the device. • Parents felt AAC clinicians overwhelmed them with advice and instruction leading to feelings of disempowerment and failure. • To empower parents, they needed to be included in the whole intervention process as part of the AAC intervention team. • Families often felt that their concerns went unheard.	clinicians believed certain information should be withheld from parents. • Training in the use of SGDs could empower parents and allow for appropriate access
3.	The Communication Profile-Adapted was used in pre- and post-	Low technology options, aided and unaided,	Parents were involved in AAC intervention of	KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Apart from two parents, parents' views of	• Home-based AAC intervention involving, and equipping parents resulted in a number of positive outcomes.

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
	intervention to assess caregiver perception of the abilities of the child with CCN. For the children with hearing impairment total communication was used – an approach emphasising flexible use of communication across modalities.	were used; Form of AAC: multi-sensory objects, communication boards with photos and line drawings such as picture communication symbols supplemented by unaided modes such as gestures, facial expressions, and signs.	their child after receiving training from the SLP. The SLP gave feedback after each session on the positive aspects of the intervention.	their child's abilities were much more positive after the intervention. • Intervention built on the parents' relationship with their child using their natural expertise. • Intervention increased parents' skills and helped them to facilitate the child's strengths. • Communication forms were introduced which were compatible with the child's abilities. EDUCATING SOCIETY: • The supply of AAC modes resulted in more outings and thus more opportunities for participation. There were more people the child could communicate with and acceptance of their child by the community was higher.	• The home-environment, the child's skills and the caregiver's natural expertise as well as local AAC materials contributed significantly to successful AAC intervention.
4.	Aided language modelling was used to demonstrate through training and coaching using an SGD device in a specific activity. The SGD device was used to provide a choice, ask a question, comment, or facilitate a response.	High technology dedicated devices; Form of AAC: Parents and siblings were involved in tele practice training of modelling aided language with a SGD in the home environment and then method	Parent involvement comprised of an interview via Zoom during a target activity.	KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Parents as well as other family members found the goals, procedures and outcomes socially valid. • Both parents showed a higher commitment towards AAC intervention training in the post study interview. • Parents expressed their hopes that their child would communicate their needs, wants, and feelings using the SGD.	• Tele based training can be effective when teaching more than one family member how to use aided language modelling in the home environment in everyday routines. • A family consists of subsystems and relationships among and the inclusion of these subsystems in AAC intervention success is important. • Family members responded at different rates to the training and coaching and these differences also have to be considered.

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
		coaching			
5.	Audio recordings of telephonic interviews and an interview guide.	ComAlong Toddler programme. Specific modes and forms of AAC intervention were not mentioned. SLPs were involved in the training.	Parents participated on two ComAlong Toddler courses to guide them in adapting their communicative behaviours when communicating with their child with CCN as part of parent-centred intervention. Parents' involvement also included their feedback on benefits from this training.	KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Initial home visit served as an affirmation of the parents' worries and need for a deeper understanding. • SLPs' description of the child's communication difficulties during the first home visit, including lack of eye contact, was helpful for the mother's understanding of her child's difficulties through the intervention. • Parents gained insight into the importance of communication and language comprehension as well as the importance of being clear and distinct when communicating with their child	• Families prefer home visits by SLPs. They feel that when AAC intervention is parent-focused they gain insight, the child's communication develops, team relations are strengthened. • AAC tools are acquired, peer learning takes place through home assignments, learning is modelled during the home visit, knowledge is shared with other parents, and intervention is structured.
6.	Intervention was based on the developing child's ecological view in a natural context. Intervention was based on a completed Communication Profile and goals based on the International Classification of Functioning, Disability and Health. Interviews with parents were	Low technology aided and unaided AAC was used; Form of AAC: Total communication, communication boards, Picture Exchange Communication System and manual signing were used.	Parents were trained in AAC intervention of their child and the application of their training was observed and commented on by the AAC clinicians involved. Thereafter they were interviewed on the results of the intervention of	KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Parents felt that they became familiar with their child's behaviour. • They recognised the important role they play in their child's unique communication. • Through intervention, new ways of understanding and communicating with their child were learnt. • Parents showed a clear desire for their child to be able to communicate the same as typical children. • Parents realised that learning was a key	• Major changes were noted by the caregivers after the home-based intervention. They were able to show a new interest in their child with CCN. • Caregivers felt that because their voice was heard by the therapists, these positive results were noted. • The interaction and novel materials used in intervention attracted positive attention from the community towards the child. Intervention was tailor made for each child's needs as known by the caregivers, resulting in the acknowledgement of the caregivers as experts. • Caregivers were empowered through the

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
	digitally recorded.		their child.	component in this aspect. After intervention they had a different view of the term normality. OPPORTUNITY BARRIERS: • The lack of clear communication was found to be difficult by the parents as they could not always understand the child's needs and wants. • Parents mentioned the feeling of isolation in raising their child, but the intervention helped them to connect with other parents with similar problems. • After intervention parents were less tired as the burden of caring had disappeared. • Intervention of their child improved the well-being of the parents. EDUCATING SOCIETY: • Post intervention superstition towards the cause of their child's inability to communicate became less as the parents' experiences of their child's new means of communication replaced those beliefs.	pivotal role they played in intervention. Intervention was focused on what the child could-and could not do. • This created awareness of the positive aspects with the parents and siblings. • Learning opportunities were created through intervention and associated with a cure for the disability. • The influence of superstition was also replaced by the positive effects of intervention.
7.	Two self-report web-based questionnaires were used, the Measures of Processes of Care (MPOC)-20 for parents and the MPOC-SP for the SLP.	Specific types and forms of AAC intervention were not indicated.	Parents were involved in this study by completing an online questionnaire regarding their perceptions of the services they received from the SLP involved with	KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Parents perceived family centred services as not being delivered frequently enough. • Parents of younger children with CCN experienced the services being more family centred than what parents of older children with CCN perceived it. • Parents of younger children rated enabling and partnership and	• According to parents in this study, family-centred services were not received frequently enough from their SLP. • It is suggested that multiple skills sets have to be adjusted as the lack of family-centred services may result in negative outcomes of the child with CCN and the family. • The various domains mentioned in the MPOC can give an indication where improvement is required. In participatory

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
			their child's AAC intervention.	coordinated and comprehensive care as higher than the other areas they had to rate. • Parents regard SLPs as having consistent strengths and weaknesses regarding family centred services.	practices, families are encouraged to use existing knowledge and capabilities and engage in informed decision-making. • Parents of children with CCN have a desire for intervention to be collaborative where therapists use their knowledge and parents contributing by setting their goals for the intervention and the knowledge regarding their child.
8	Briefing [interview] guide	Low technology aided and unaided AAC Form of AAC: Signing, , communication books and boards and Picture Exchange Communication System. High technology communication devices were also used although the specific form of AAC was not specified	Parents were involved in communication efforts with their child with CCN. They gave feedback on the child's level of communication, comprehension and intelligibility difficulty, communication choices, societal attitudes towards AAC, and financing of AAC. This was all done by means of semi-structured interviews.	AAC DEVICE SELECTION: Parents felt that: • AAC clinicians also had to consider the extent to which they [parents] should be involved in decision-making and to what extent they wanted to be involved. • The amount and time they were provided with information varied. • None of the parents were concerned about the introduction of AAC. • Difficulties were experienced with the use of high-tech communication aids as well as the implementation. KNOWLEDGE AND SKILLS NEEDED TO USE AAC: Parents felt that: • They were expected to be experts in various fields regarding their child. • AAC clinicians were hesitant to provide information as they thought that parents might not be able to cope with too much information. • They were often expected to gain their own knowledge about their child's AAC intervention.	• Family-centred practice is important in introducing AAC. • Most frustration was caused when parents felt that the SLP did not value their input (values, ideas, and concerns). • This eventually led to the abandonment of the AAC device. Involvement in the use of an AAC system by their child was influenced negatively by attitude, orientation, knowledge, lack of support and ineffective communication of the AAC clinicians.

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
				• AAC intervention was not explained clearly to them by the AAC clinicians and they had to be forceful if they wanted to obtain knowledge and access services. EDUCATING SOCIETY: Parents felt that: • They needed support from other parents. • AAC clinicians needed more insight into the burdens parents carried with their children with CCN.	
9.	Phorum 3.3.2.2 a password-protected Internet bulletin board system; interview guide; biographical questionnaire.	The children used various high technology AAC devices; Form of AAC: speech generating AAC devices.	Parents' input obtained through online video conferencing.	AAC DEVICE SELECTION: • Lack of family involvement. • Difficulty obtaining services. • Difficulty obtaining funding. • School involvement. • Family members assuming a leadership role. OPPORTUNITY BARRIERS: • Lack of trained AAC clinicians. • Limited knowledge and experience of AAC clinicians. • Failure to create communication opportunities. • Challenges to support the ongoing use of the device. • Difficulty mounting the device. • Physical fatigue. • Inefficient access techniques. • Device breakdowns. • Negative attitudes of others. • Lack of communication opportunities. • Poor communication skills of partner.	• AAC clinicians should form partnerships with the parents, do relevant and ongoing information sharing, and communicate in a way that is beneficial for all team members. • Families should take a leadership role in decision-making. • Parents need to acquire more skills and knowledge. • Barriers to learning AAC should be addressed. • There is a lack of trained AAC clinicians as well as challenges in support of ongoing device use, communicating in the community, and cost of AAC devices. • Outside the home environment the child has no means of communicating if the parents are not with them. • AAC clinicians are expected by the parents to work as part of a team which includes the parents.

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
				• Time and effort needed to learn device. TEACHING THE INDIVIDUAL: • Trial and error. • Increased self-confidence. • Model device use in play activities. • Independent practice with manuals. • Support in setting up instructional materials. • Need for parents to learn how to programme the device and to assist their children in using it. • Importance of mentors. • Help in learning vocabulary and grammar • Help in promoting social interaction. • Assistance in identifying other instructional opportunities. • Use of icon predication. • Benefits of training. • Use of telephone technical support. EDUCATING SOCIETY: • Insufficient support received from the AAC clinicians. • Stakeholder communication not effective. • Parents not involved in decision-making and planning. • Parents' input and feedback was not valued. • No community support present.	
10.	Interview guide (specific key prompts retrieved from AAC research questions in literature).	High technology AAC was used. The form of AAC was not	Parents' opinions were obtained through interviews - face to face, telephonically and	AAC DEVICE SELECTION: • Parents felt pressurised to use the AAC system and that AAC clinicians did not listen to them or their child. • Limited interdisciplinary actions took	• Family-centred practice is key to introducing AAC systems for children with CCN. • The main parent frustration was caused by the fact that parents felt that AAC

#	Materials	Type of AAC Intervention	Caregiver Involvement	Caregivers' Perceptions (Subsections based on McNaughton et al., 2008)	Study Outcomes/Key Findings
		specified	with video conferencing. Professional involvement took place as well.	place. KNOWLEDGE AND SKILLS NEEDED TO USE AAC: • Parents felt that the SLP did not support them. • They did not receive a clear intervention plan. • Ongoing support for implementation was lacking. Individualised support through coaching, resources and encouragement was lacking. • Communication between the various stake holders was insufficient. Inadequate explanations were received. OPPORTUNITY BARRIERS: • Parents felt that the beliefs and advice from AAC clinicians influenced the use of an AAC system. • When AAC clinicians only relied on their own inputs, parents felt devalued. • The training and experience of the professional had an influence on AAC implementation. EDUCATING SOCIETY: The community did not utilise the AAC system constantly or optimally.	clinicians did not consider their ideas, opinions, or concerns. This eventually led to AAC abandonment.

In summary of Table 6 a few key aspects can be highlighted according to the mentioned themes as portrayed in the study by McNaughton et al., 2008. The researcher derived conclusions form the ten studies analysing the studies according to these themes.

With regards to AAC device selection, the initial role of AAC device teaching of the SLP guides role transfer to the parents. If parents are excluded from the decision making in device selection they feel disempowered. Goalsetting for device selection should be family-centered therefore the SLP should strongly consider how to involve parents and family in device selection. The parents and family should take a leading role in the selection under guidance of the SLP and the rest of the interdisciplinary team. Parents should be consulted regarding funding available as the latter will have an influence on device selection.

Considering knowledge and skill required for AAC intervention, it was evident that knowledge and skills gained through AAC intervention were the most prominent factors. Firstly it reduced parental stress. Being part of intervention led to positive attitudes by parents and a better relationship between the parents and their child with CCN. Parents' skills improved and they gained more insight into their child's skills and needs when included in the intervention process. They were also more committed to the whole process of AAC intervention. Intervention including the parents also led to them having more appropriate expectations of their child with CCN. Initial home visits by the professionals revealed the parents' need for understanding and guidance. Without training, though the parent is the expert in their child with CCN, the parents' skills and knowledge are not sufficient.

Various opportunity barriers were experienced by parents as primary caregivers. The main issue was a lack of trained AAC clinicians and their limited knowledge. Ongoing support of AAC device use was another barrier as was transport to and from home to the therapy centre. Beliefs and advice from AAC clinicians influenced device use.

Under the theme, educating society, there was very little community support present which left the parents feeling that they were not receiving enough support from other parents with children with CCN. There was a significant amount of post intervention superstition from the community but often the child's new mode of communication replaced those disbeliefs.

For teaching them as individuals parents often turned to online forums but face-to-face training was preferred as it promoted social interaction.

The theme ‘’other’’ was not that well defined but included that the expression of parents’ needs and wants and their ability to make choices were regarded as important. It was evident that a lack of research on parental experiences on the use of mobile technology. Parents need to be included in the whole intervention process to enable empowerment. Including the family as part of the family system is crucial and it was felt that family concerns were not heard.

When considering the perceptions of parents as primary caregivers on their involvement in the AAC intervention of their child with CCN as contained in Table 6, it is important to take note of the following: Intervention aims at gaining insight into the child’s communicative needs, the disability, and how the parents as primary caregivers should communicate with their child (Fäldt et al., 2020). Many factors contribute both positively and negatively to various aspects of involving the parents as primary caregivers in AAC intervention. Parents as primary caregivers have the desire for their child with CCN to communicate in a similar manner to that of a neurotypical communicator by being able to express their needs and feelings regarding their AAC device (Douglas et al., 2021).

3.4. Parent’s perception on their involvement in AAC intervention

Not all experiences regarding primary caregivers’ involvement in the AAC intervention of their child with CCN are negative as seen in the included studies as indicated in Table 6. Through being involved in their child’s AAC intervention to an extent, primary caregivers realised the importance of their role in their child’s communication. Being involved in their child’s AAC intervention in their home environment, primary caregivers’ perception regarding AAC intervention has changed positively. The most prominent factors resulting in the negative perceptions of primary caregivers on their child’s AAC intervention are when primary caregivers are excluded in the AAC device selection and intervention planning processes. Another factor contributing to primary caregivers’ negative perception is the lack of knowledge and skills of AAC clinicians which cause primary caregivers to rely on their own knowledge or to seek information themselves by consulting other resources (e.g., social media). The factors included in Table 6 lead to a

significant amount of stress experienced by primary caregivers of children with CCN during the AAC intervention process. Primary caregivers often feel isolated and not part of the community as their children with CCN are not included in the community. The exclusion by the community might be due to prejudice or stereotyping by society or opportunity barriers, for example policy barriers (Beukelman & Mirenda, 2013). However, the study conducted by Bunning et al. (2014) emphasises the importance that primary caregivers take the children with CCN on outings in the community so as to educate the community.

3.5. Influence of the ecological systems on the family system

The child with CCN is part of a family system and lives in an environment or ecology with specific systems. Bronfenbrenner (1979) identified the five ecological systems (Refer to Figure 1) in which an individual with CCN functions. Within these systems, the family system plays an important role as it provides the pivotal context wherein the children's language skills are built (Coburn et al., 2021). Similar to what Bornman and Granlund (2007) refer to as the systems theory that provides a framework within which the different units function and interact with and upon each other to bring about change, the relationships within the systems of Bronfenbrenner's ecological system indirectly result in changes within the family system. This change does not only occur within systems themselves but also in the relationship between members within the different systems, for example the children with CCN, their family, and the AAC clinicians. Furthermore, as successful AAC intervention aims to enhance active participation of the child with CCN, other system levels may become more relevant. The ecological systems theory as advocated by Coburn et al. (2021), argues that the functioning of a child and the family in the various settings should be considered in clinical supervision. This aspect may influence the perception of the parents' involvement in the AAC intervention of their child with CCN.

By way of illustration, in AAC intervention, the chronosystem plays an important role as it takes into account the change or development of the child over time which will influence the family system and members of other systems. The subsequent changes that occur within the child as they become a competent communicator and active participant due to AAC intervention will necessitate a follow-up AAC assessment to inform future intervention. Should the need for the introduction of more advanced AAC systems be

identified in the follow-up assessment (i.e., because the current AAC device may not have the capacity to accommodate increased vocabulary needs), the decision-making process and future AAC intervention might be directly or indirectly influenced by other ecological systems. For example, the availability of funds within the macrosystem (i.e., to buy AAC devices and pay for AAC support) as well as factors within the mesosystem (i.e., AAC clinicians' knowledge and skills on the suggested AAC device), could impact parents' perception on their child's AAC intervention as well as their perception on their involvement on AAC intervention.

The family system is a good example of how change can be brought about with positive or negative results depending on specific characteristics. These characteristics include culture, age, socioeconomic status, education, and beliefs of the family. The type and the degree of disability of the child could also have an influence on the family system and subsequent AAC intervention. Due to the diversity of the family system and the individual needs of the child with CCN, AAC clinicians should prioritise family-centred AAC intervention. According to McNaughton et al. (2019), awareness has to be created for the inclusion of the family and the wider community in AAC intervention, thus the ecological systems theory (Bronfenbrenner, 1979) is very relevant. It is furthermore important to keep in mind that change which occurs outside the context of the family, reflects directly as well as indirectly on the family system (Crawford, 2020).

The lack of family-centred services is one of many barriers which occur in various systems. Beukelman and Mirenda (2013) describe aspects preventing intervention success as barriers. The current review highlights, for example a number of opportunity barriers (i.e., barriers not inherent to the child with CCN). Some barriers mentioned in the included studies include: (i) the lack of knowledge and skills from the AAC clinicians (Anderson et al., 2014; McNaughton et al., 2008); (ii) AAC clinicians who provided insufficient support to primary caregivers (Moorcroft et al., 2020); (iii) goal setting that was not family-centred (Allen & Shane, 2014; Mandak & Light, 2018), and (iv) age of the child with CCN and eligibility to qualify for an AAC device (Anderson et al., 2014.). All of these barriers form part of the mesosystem, whereas: (v) insufficient funding from state and medical aids (Anderson et al., 2014); (vi) lack of community support especially other parents (Gona et al., 2014; Marshall & Goldbart, 2008); (vii) insufficient access to transport

to and from the therapy site (Anderson et al., 2014); and (viii) insufficient technical assistance (Anderson et al., 2014; McNaughton et al., 2008) are barriers which are mainly present within the macro- and exosystems.

Due to the barriers mentioned above, primary caregivers feel abandoned and disempowered (Anderson et al., 2014) which implies that their opinions and contributions are not valued resulting in subsequent influencing of the chronosystem, microsystem, and the family system. According to Allen and Shane (2014), stress levels in primary caregivers with children with CCN are higher than stress levels of primary caregivers with children with other disabilities. These authors also found that access to AAC reduces stress levels in primary caregivers (Allen & Shane, 2014). In another study by Sivberg (2002) on the coping behaviours of family systems with a child with ASD, it became clear that the higher the level of coping abilities of the child was, the lower the pressure and stress was on the family system. As such, barriers influence various bioecological systems even if the barrier arises in another system.

Another example of barriers mentioned earlier, is the lack of transport and funding which occurs in the exo- and macrosystems but impacts the micro- and mesosystems: Primary caregivers often have to leave their jobs to care for their children, resulting in a decrease of financial resources and subsequent lack of access to medical aids due to their low socio-economic status. Insufficient funding or no access to transport within the macrosystem results in no AAC intervention. Without intervention, clear communication between the various members of the systems will not be possible confirming the ripple-effect on the other systems due to changes in some systems (Perron, 2018). Therefore, in AAC intervention, it is important to consider both the immediate environment (micro- and mesosystems) as well as the influence of the larger environment (exo- and macrosystems) on the child with CCN and their family (family system).

In the same vein the lack of professional knowledge and skills that originate in the microsystem and mesosystem is found. This review highlighted that often AAC clinicians do not have the necessary knowledge and skills when interacting in the microsystem and as a result neither do they have the ability to transfer this knowledge and skills to other members of the mesosystem, thus impacting on both the micro- and mesosystems.

As can be seen in the examples mentioned above, barriers often result in negative changes on other members within various systems. Many barriers that occur in the AAC intervention process which the primary caregivers could not alter, influenced their perception on their involvement in the AAC intervention. For example, due to inadequate knowledge and skills of the AAC clinicians, primary caregivers often have to join online forums (e.g., social media platforms in the exosystem) to gain information that is not provided in the mesosystem.

The success of AAC intervention is thus influenced by the interaction between the various ecological systems. Should any of these systems not function adequately or assist in involving the parents in AAC intervention, intervention might be unsuccessful and could further lead to AAC device abandonment.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1. Summary of main findings

Findings from this study emphasise the importance of a holistic approach to AAC intervention within the various ecological systems of the child with CCN of which the child and parents play a pivotal role. The involvement of parents in their child's AAC intervention form the base of successful AAC intervention within the family system and the five ecological systems identified by Bronfenbrenner (1979). As illustrated in Figure 1, the child with CCN does not function in isolation, but within the family system which is impacted by the interaction of the various ecological systems forming part of the environment of the child with CCN. Parents as primary caregivers play a pivotal role within the family system, however, the malfunctioning within any of the ecological systems may negatively influence primary caregivers' involvement in AAC intervention, that is, the feeling of disempowerment due to reactional relations by other members within the mesosystem and by barriers which may occur within the meso- or macrosystems.

It is concluded that based on the 10 studies reviewed, parents do not perceive their involvement in their child's AAC intervention as adequate. Primary caregivers believed that the use of devices should initially have been taught by the AAC clinician and that a role transfer should gradually take place. However, in reality primary caregivers were often excluded from decision making and intervention. Goal setting was perceived not to be family-centred as AAC clinicians often relied on their own insight and disregarded the input from primary caregivers who are in fact experts in their knowledge of their children with CCN. However, in some cases, family-centred services were provided to a certain extent – especially for younger children. Ongoing support after selection of the device was not provided to the primary caregivers. When training was provided it was often perceived as inadequate due to AAC clinicians' lack of knowledge and skills about a variety of technical aspects regarding the devices. Opportunity barriers existed within various systems and had a definite influence on the parents' perceptions regarding their involvement in AAC intervention.

Although many negative aspects were identified, some of the included studies highlighted the importance of primary caregivers' involvement in AAC intervention. Support provided by the AAC clinician in person to primary caregivers was viewed by the caregivers as having positive results. Children's improved abilities were viewed more

positively after intervention. Primary caregivers' skills improved after intervention and led to them being able to facilitate their child's strengths. In the family system, some goals for intervention were found socially valid and primary caregivers became committed when involved in their children's AAC intervention. By involving the primary caregivers in AAC intervention, the caregiver gained insight to the importance of language and communication and being connected with other families in the macro system. Learning opportunities were created and aspects such as myths surrounding CCN were replaced by the positive effect of intervention. The pivotal role parents as caregivers played in the intervention empowered them.

Parents felt that community support in the use of their child's AAC system was lacking. The community was not aware of- or informed on AAC intervention. This specific concern has implications for the programming of the AAC device informing persons from the community about the child's communication modes and instructions on how to use the system or device.

In the study by Gona et al. (2014), parents became aware of the important role they play after involvement in intervention. Being involved in intervention helped parents to connect with other families in the macrosystem and aided in lowering their stress levels. In the study of Bunning et al. (2014), parents described their perception of involvement in AAC intervention as positive with major changes being noted in their child. The reason for this was that their 'voice was heard' by the AAC clinician. These parents felt empowered. With the intervention being family-centred, the siblings also became aware of the positive aspects of AAC intervention. Learning opportunities were created and aspects such as superstitious myths surrounding the CCN were replaced by the positive effect of intervention.

4.2. Implications for practice

AAC intervention should be seen as the process of gathering insight regarding the child's communicative needs incorporating the needs of the family. The positive influence of primary caregivers' involvement in AAC intervention has been highlighted. As such, implications for practice are multiple. Firstly, primary caregivers should be a valued member of a transdisciplinary team with a family-centred focus taking the family system into consideration. Secondly, intervention should further consider the operational aspects of the family as well as the direct or indirect impact which may occur due to changes within the ecological systems. For example, in the exosystem, aspects outside the family

system could influence the involvement of the primary caregivers and subsequently, have successful AAC intervention. Thirdly, care should be taken not to overwhelm and burden primary caregivers during AAC intervention within the natural home environment. For example, planned intervention strategies should support current communication practices within the family system. Therefore, transdisciplinary teams should not only consider the child's disability and focus on what the child is able to do within the ecological systems, but also consider primary caregivers' needs throughout their involvement in the AAC intervention of their child with CCN. For instance, during the decision-making and planning for AAC intervention, the transdisciplinary team should acknowledge the primary caregivers' current communication and support with their child and how these communication interactions could be addressed and improved during intervention. AAC intervention decision-making should also consider primary caregivers' expectations of their child's ability for future communication. Lastly, primary caregivers should not be expected to gather information regarding AAC on their own – AAC clinicians should equip the primary caregivers in order to facilitate and support their child's skills and needs. The goals and procedures should be socially valid through minding the ecological systems as well as the impact of the chronosystem on the family and child with CCN. Home visits are preferred and could also serve as a basis to understand the primary caregivers' needs and create a deeper understanding of the family within its ecological systems. Intervention should create awareness with the primary caregivers regarding the importance of the role they play in the AAC intervention of their child.

By addressing the barriers, it might be difficult and not viable for AAC clinicians to try and change them, especially the barriers in the macrosystem. However, barriers that could be minimised are the lack in knowledge and skill of AAC clinicians. Where technical assistance is not available, a technician could do home visits or give online support where necessary.

4.3. Critical evaluation of the study

As with all studies, the strengths and limitations of this review should be acknowledged.

Strengths

The 10 studies included in this review were conducted in four of the five continents comprising of both developed and low-to-middle income countries that may assist AAC

clinicians from diverse contexts to acknowledge parents' perceptions on their involvement in AAC intervention of their child with CCN. A significant strength of this study is the fact that the findings include both negative and positive aspects regarding primary caregivers' perceptions on their involvement in AAC intervention. Furthermore, the direct and indirect impact of the different ecological systems on the implications of primary caregivers' perceptions on their child's AAC intervention is highlighted in this study.

Limitations

A limited number of 10 studies met the criteria for this review. Only studies published in English were included in this review which could have limited the scope of the review to a certain extent affecting the reliability of findings. As part of the inclusion criteria, primary caregivers included only biological, adoptive, and foster parents; however, it might be that by expanding the primary caregivers to include, for example grandparents and close relatives, it might have generated other contributing findings that were not obtained in this review.

4.4. Recommendations for further studies

Allen and Shane (2014) indicate a lack of research regarding the expectations and attitudes of primary caregivers towards their gaining of knowledge and skills regarding mobile technology. To get a more in-depth review of studies, studies in other languages or cultures should also be reviewed using translators. A follow-up study on this review could be done to determine if the selection criteria of primary caregivers were expanded to include, for example grandparents and siblings in the AAC intervention, might result in further findings which were not obtained in the current review. Considering the impact of culture, future studies conducted on primary caregiver involvement in AAC intervention, could be continent or culture specific. To promote the importance of family and the home environments perceptions of primary caregiver involvement, studies performed in the home environment could be compared to studies of therapy conducted in the therapy room.

A comparison could be made of the influencing involvement of primary caregivers in AAC intervention on the various systems. One study should include primary caregiver involvement and another where no primary caregiver involvement is present.

The influence of sound AAC intervention, with good knowledge and skill of the AAC clinician as a foundation, on the interactive functioning of the various ecological systems could be investigated. How will successful involvement of the parents in AAC intervention of their child with CCN for instance, influence the interaction of all the members of the mesosystem positively?

Another suggestion is an investigation of the nature of the interrelationship of members of a specific system, for instance the macrosystem's various stakeholders on the successful implementation of AAC intervention on the child with CCN.

4.5. Conclusions

For family-centred services in AAC intervention to be effective, AAC clinicians have to be loyal towards the parents as caregivers, equipping them with the correct knowledge and skills and include them in all decision-making. The family system has to be recognised as pivotal. This statement is based on the research question and the perceptions of the primary caregivers.

Realising and honouring the importance of the involvement of parents as primary caregivers in AAC intervention will also influence the ecological systems within the lives of children with CCN positively, contributing to successful AAC intervention and thus successful communication not only in the family system but in the community as well.

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APPENDIX A: ARTICLES SELECTED FOR FULL TEXT REVIEW

This Appendix presents the accepted and declined studies based on a full texts review with consideration of the inclusion factors and the exclusion factors.

#	Author	Date of article	Title of article	Included	Excluded
1	Alant et al.	2012	Exploring interagency collaboration in AAC intervention		X
2	Allen & Shane	2014	Autism spectrum disorders in the era of mobile technologies: Impact on caregivers	X	
3	Anderson et al.	2014	Australian parents' experiences of speech generating device (SGD) service delivery	X	
4	Barry	1987	Strategies for involving parents in programs for young children using augmentative and alternative communication		X
6	Bunning et al.	2014	Caregiver perceptions of children who have complex communication needs following a home-based intervention using augmentative and alternative communication in rural Kenya: An intervention note	X	
7	Chung & Snodgrass	2016	Understanding communication intervention for young children with autism and their parents: Mixing behavioural and social validity findings		X
8	Douglas et al.	2021	The effects of tele practice to support family members in modelling a speech generating device at home	X	
9	Fäldt et al.	2020	"All of a sudden we noticed a difference at home too": Parents' perception of parent-focused early communication and AAC intervention for toddlers	X	
10	Ferm et al.	2012	Patterns of communicative interaction between a child with severe speech and physical impairments and her caregiver during a mealtime activity		X
11	Gona et al.	2014	A home-based intervention using augmentative and alternative communication (AAC) techniques in rural Kenya: what are the caregivers' experiences?	X	
12	Granlund et al.	2008	AAC interventions for children in a family environment: Implementing evidence in practice		X
13	Greenberg	2011	Applying an effectiveness research model to the picture exchange communication system		X
14	Kent-Walsh, Binger & Malani	2013	Fundamentals of the ImPAACT program		X

15	Lai et al.	2020	Evidence based support for autistic people across the life span: Maximising potential, minimising barriers and optimising the person environment	X
16	Mandak & Light	2018	Family-centred services for children with ASD and limited speech: The experiences of parents and speech language pathologists	X
17	Marshall & Goldbart	2008	'Communication is everything I think': Parenting a child who needs augmentative and alternative communication (AAC)	X
18	McNaughton et al.	2008	"A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies	X
19	Moorcroft et al.	2020	'We were just kind of handed it and then it was smoke bombed by everyone': How do external stakeholders contribute to parent rejection and the abandonment of AAC systems?	X
20	Myers	2007	''Please listen, it's my turn'': Instructional approaches, curricula and contexts for supporting and increasing access to inclusion.	X
21	Nunes & Hanline	2007	Enhancing the alternative and augmentative communication use of a child with autism through parent-implemented naturalistic intervention	X
22	Parette	1997	Family-Centred Practice and Computers for Children with disabilities	X
24	Parette & Marr	1997	Assisting children and families who use augmentative and alternative communication (AAC) devices. Best practices for school psychologists	X
26	Pennington & Noble	2009	Acceptability of usefulness of the group interaction training program It takes two to talk to parents of children with motor disorders	X
27	Pennington et al.	2009	Effects of it takes two to talk - Hannen program for parents of pre-school children with cerebral palsy. Findings from an exploratory study	X
28	Reichle et al.	2019	Implementing aided augmentative communication systems with persons having complex communicative needs	X
29	Romski, Sevcik& Adamson	2010	Parent perceptions of the language development of toddlers with developmental delays before and after participation in parent coached interventions	X
30	Romski, Sevcik et al.	2010	Randomised comparison of augmented and non-augmented language interventions for toddlers with developmental delays and their parents	X
31	Senner et al.	2019	Effects of parent instruction in partner augmented input on parent and child speech generating device use	X
32	Sevcik, Romski, &	2004	Research directions in augmentative and alternative communication for pre-school children	X

	Adamson			
33	Shaw	2005	Grandparent Involvement in the communication development of children who are deaf –blind	X
34	Shire et al.	2015	Parents' adoption of social communication intervention strategies: Families including children with autism spectrum disorder who are minimally verbal	X
35	Shugda	2017	Involvement of family communication partners in using an iPad to enhance the communication skills and appropriate behaviour of youth with severe/multiple disabilities in Saudi Arabia	X
36	Smith et al.	2015	AAC and early intervention for children with cerebral palsy: Parent perceptions and child risk factors	X
37	Snell et al.	2008	Communication breakdown at home and at school in young children with cerebral palsy and severe disabilities	X
38	Stadskleiv	2017	Experiences from a support group for families of preschool children in the expressive AAC user group	X
39	Wadnerkar et al.	2010	A single case study of a family-centred intervention with a young girl with cerebral palsy who is a multimodal communicator	X
40	Yung-Ching Chung et al.	2016	A meta synthesis of team members' voices: what we need and what we do to support students who use AAC	X

APPENDIX B: DATA EXTRACTION TOOL

This Appendix presents the data extraction tool used to extract relevant data from the 10 finally selected studies.

DATA EXTRACTION TOOL			
Demographics			
Variable	Category		
Authors			
Publication year			
Study title			
Country where study was done			
Type of design		True experimental	
		Quasi experimental	
		Single subject	
		Group	
		Other (Specify)	
		Qualitative	
		Quantitative	
Aim of study	Describe		
Participants: Adults	Both parents	n=	
	Single parents	n=	
	Father	n=	
	Mother	n=	
	Grandparents	n=	
Participants: Children	Children	n=	
		Age =	
	Diagnosis of child		
Methodology			
Materials used	Describe		
Type of AAC intervention	Unaided		
			Gestures

			Manual signs
			Vocalisations
	Aided		
		Low tech	
		Type	
		High tech	
		Type	
			Dedicated
			Non-dedicated
	Type of AAC specified		Yes / No
Caregiver involvement			
How were opinions obtained			Face-to-face
			Telephonically
			Questionnaires
			Video conferencing
Part of transdisciplinary team			Yes
			No
If yes, who are members:			
Was support received			Yes
			No
Effective stakeholder communication			Yes
			No
Community support present			Yes
			No
Involved in decision making and planning			Yes
			No
Involved in implementation of AAC			Yes
			No
Input/ feedback form parent valued			Yes
			No
Intervention environment			
	Specified	Yes	
		No	
	Home		
	School		

	Other
How are ecological systems involved?	
Micro-	
Meso-	
Exo-	
Macro-	
Chrono-	
Family system	
Caregivers' perceptions	

APPENDIX C: ETHICS APPROVAL

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100 Since 1919

7 October 2020

Dear Mrs G Olivier

Project Title:	Involvement of Primary Caregivers in their Children's AAC Intervention: A Scoping Review
Researcher:	Mrs G Olivier
Supervisor(s):	Dr E Johnson
Department:	CAAC
Reference number:	85567095 (HUM027/0920)
Degree:	Masters

Thank you for the application that was submitted for ethical consideration.

The Research Ethics Committee notes that this is a literature-based study and no human subjects are involved.

The application has been **approved** on 1 October 2020 with the assumption that the document(s) are in the public domain. Data collection may therefore commence, along these guidelines.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. However, should the actual research depart significantly from the proposed research, a new research proposal and application for ethical clearance will have to be submitted for approval.

We wish you success with the project.

Sincerely,

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Research Ethics Committee Members: Prof I Pikirayi (Deputy Dean); Prof KL Harris; Mr A Bizos; Dr A M de Beer; Dr A dos Santos; Ms KT Govinder Andrew; Dr P Gutura, Dr E Johnson; Prof D Marais; Mr A Mohamed; Dr L Ntombé; Dr C Puttergill; Prof D Reyburn; Prof M Suen, Prof E Taljaard, Prof V Thebe; Ms B Tsebe, Ms D Mokalapa

APPENDIX D: DECLARATION FORM LANGUAGE EDITOR

JANINE ELLIS

LANGUAGE EDITING / TRANSCRIPTION / TYPING

janine.ellis4@gmail.com

Cell: 083-6563660

Client

Gonda Olivier
Mini-dissertation
Student No. 85567095
University of Pretoria

P O Box 28164
Sunridge Park
6008

08 June 2022

DECLARATION

To whom it may concern,

I hereby declare that I fully language edited the mini-dissertation of Ms Gonda Olivier titled: ***A scoping review of primary caregivers' perceptions of their involvement in augmentative and alternative communication intervention of their children.*** All aspects of this mini-dissertation were carefully looked at, corrections made and suggestions given with regards to content wording and sentence structure, however, the academic content was not influenced in any way. The layout, presentation, and referencing of this mini-dissertation were edited as per the referencing and technical/style template/guide provided by the client. Final acceptance of all proposed corrections/changes/comments is at the personal choice/discretion of the client.

This service was rendered from 23–30 May, with final checks been made 08 June 2022.

Kind regards

Janine Ellis