The Extent to which Children and Young People with Disabilities are Involved in the Design of Assistive Technology: A Scoping Review

by

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ABSTRACT

Background: Assistive Technologies (AT) are often abandoned. As technology is an expanding and vast field, it should be utilised optimally for vulnerable populations. Research shows that to address this, there is an increasing need to involve end-users in the design process of AT. This study aimed to investigate the extent of research available pertaining to the involvement of children and young people with disabilities in the design of ATs and further analysed the extent of their involvement.

Methods: A scoping review of the literature was therefore conducted. Limitations included a risk of publication bias on English articles, and accessibility from 2007 to 2020.

Results: The results revealed that minimal research was available that actively involved children with disabilities in a Participatory Design (PD) framework in the field of AT development including Augmentative and Alternative Communication (AAC). Children and young people's levels of involvement were mainly at a symbolic level in terms of the type of participation. This research highlights the need for intensified efforts towards increasing the participation and engagement of the children and young people as they voice their opinions, which could then be considered by the decision-makers.

Conclusions: The findings shed light on the disparity in the research which may hinder the effective implementation of ATs. Future research is needed to establish optimal methods of involvement of children and young people with disabilities in AT design.

Keywords: assistive technology, Augmentative and Alternative Communication (AAC), children with disabilities, the extent of involvement, involvement, participatory design

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LIST OF ABBREVIATIONS

AAC	Augmentative and Alternative Communication
AT	Assistive Technologies
CCN	Complex communication needs
CINAHL	Cumulative Index to Nursing and Allied Health Literature
ERIC	Educational Resources Information Center
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health: Children and Young People version
LMICs	Low-and-middle income countries
PD	Participatory Design
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
TYPE	Typology of Young people Participation and Empowerment
UCD	User-centred Design
WHO	World Health Organization

1. PROBLEM STATEMENT AND LITERATURE REVIEW

1.1. Introduction, Problem Statement and Literature Review

Assistive technology (AT) is a term used that encompasses various forms and systems (MacLachlan & Scherer, 2018). Assistive technologies (ATs) are extensively associated with devices that assist individuals with disabilities (Edyburn, 2004). The range of disabilities that can be improved with AT include visual, hearing, physical, communication, or cognitive impairments – as Raghavendra and Oaten (2007) described disability to be a "multi-dimensional phenomenon" existing within interactions between an individual and their health status with their physical, social, and attitudinal environments. Assistive technology (AT) aims to empower individuals with disabilities, to participate in or complete tasks that they might not be capable of doing otherwise (Buehler et al., 2015). Hurst and Tobias (2011) reported on how using available technology to make modifications to existing AT devices and create novel designs is a growing area of interest. It provides the facility to personalise devices and empowers end-users of AT to design their own assistive solutions.

To date, in the clinical setting, speech therapists and children with complex communication needs (CCN) are presented with numerous Augmentative and Alternative Communication (AAC) AT options to use. Although still limited and challenging within the South African context, technologies are becoming more accessible and aesthetically appealing as a result of the rapid developments of mobile technologies (Dada et al., 2017; Foley et al., 2012; Light et al., 2013). However, when analysing their efficacy in augmenting speech and language development and/or acting as an alternative to speech, they lack what research suggests as optimal for AACs. This includes characteristics such as product features, appeal, minimal learning demands, increased opportunity and design for functional use, feature matching, and what may practically be more beneficial and personalised for the user. The absence of many of these characteristics can result in clinicians and end-users of AT experiencing less optimal use of ATs that are available which can lead to device abandonment and limitations of the vast and expanding development of ATs (Hurst & Tobias, 2011; Light et al., 2013; Light & Drager, 2002). Device abandonment suggests that adopting AT within the clinical setting is not as optimal as it could be, and this thesis further explores how developers are not those utilising the technologies clinically. Furthermore, it shows how the involvement of individuals with disabilities, as the end-users, in the design and development of AT is not being implemented.

Allsop (2010) argued that there appears to be little research available that includes children with disabilities in the design of AT and concluded that there is an increasing need and emphasis for user involvement in the field. Conventionally, technicians develop AT and user input is only considered when the prototypes or existing technologies are tested or reviewed (Flodin, 2007). Not only does this lead to an increased risk of device abandonment, but further demonstrates how work is often done surrounding individuals with a disability, without their participation and inclusion (Gelderblom, 2014; MacLachlan & Scherer, 2018). Participatory Design (PD) is suggested as a way to address this, which represents a paradigm shift from designing for users, to designing with them (Sanders, 2002). Participatory Design (PD) has been and continues to be applied outside the field of technology (Kensing & Blomberg, 1998). The concept dates back to as early as the 1960s when societies demanded an increased say in decision-making about their lives and were prepared to participate in these processes (Simonsen & Robertson, 2013). Light et al. (2013) were some of the first authors in the field of AAC to highlight the importance of PD when they asked children without disabilities about their ideas pertaining to the design of AAC devices; this was so that they could focus on the needs of users of AAC, who might be children, rather than focusing on the technology itself. However, it is not yet clear to what extent the field of AAC has incorporated these recommendations or even adopted PD into the field of AAC technology development.

To bridge this gap, it is thus proposed that involving end-users within the design process of AT is crucial through the use of PD as it can prevent, amongst others, device abandonment (Allsop et al., 2011). Hurst and Tobias (2011) reported that many ATs selected for individuals with disabilities are abandoned for various reasons which include a failure to consider user opinion in the selection, ease in obtaining the device, poor device performance and, finally, changes in user needs and priorities. Similar reasons have also been found in the South African context (van Niekerk et al., 2019). These findings allude to the importance of taking users' opinions into account not only in the selection but also in the design of AT to address their needs. However, the extent to which this has been done is not known. Furthermore, there also does not appear to be a set of methodologies or strategies as to how children and young people with disabilities can be involved optimally in the design of AT in general. A preliminary scoping of the AAC field suggests that apart from Light et al's. (2007) work with typically developing children, there appears to be very little research done since, concerning the involvement of children and young people with CCN in the design of AAC AT.

However, we cannot be certain about this until the field of AT which includes AAC is scoped systematically. It is thus beneficial to consider, organise and analyse the extent of involvement of children and young people with disabilities in the design of AT in general and critique the applicability of findings to the involvement of children and young people with CCN's involvement in AAC technology design.

The aim of this study is therefore to scope the research on the PD of AT and to evaluate the extent to which children and young people with disabilities are involved in the design of AT especially AAC technologies. Moreover, an attempt will be made to analyse the degree of their involvement according to a PD framework and from this extrapolate strategies or methodologies by which children and young people with CCN can also be involved in the design of AAC technology.

1.2 Literature Review

1.2.1 Assistive Technology

Assistive Technology (AT) is seen as "any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customised, that is used to increase, maintain or improve the functional capabilities of individuals with a disability," and was coined in an American Act (The United States of America, 2004, p. 1710) and further adopted as an international definition after the World Health Organisation referenced it in their World Report on Disability (WHO, 2011). Referring to AT within the South African context, the White Paper on the Rights of Persons with Disabilities suggests that "it is an umbrella term that includes assistive, adaptive, and rehabilitative devices and services for persons with disabilities, which enable the persons with disabilities and learning differences to attain independence" (Department of Social Development, 2015, p. 3).

1.2.2 A post-modern approach to the participation and involvement of children with disabilities in AT design

The International Classification of Functioning, Disability, and Health and the version for Children and Young people version (ICF-CY) (World Health Organization, 2007) highlights the concept of the involvement of children with disabilities in various life situations. The ICF-CY in particular, emphasises that involvement enhances the development of children, amongst others, their language, learning to read and write, play and socialise (Raghavendra et al., 2007) which AT aims to facilitate in those with disabilities. Involvement can take different forms and

PD is complex. Often, researchers use the term in different ways (Benton & Johnson, 2015). Hart (1992) introduced a prominently used ladder of participation which was adapted from an earlier introduction by Arnsterin (1969) as cited in Benton and Johnson (2015). Hart's (1992) ladder represents a hierarchy of participation in that at each rung of the ladder, the extent of participation increases from the bottom to the top.

The progression and development of PD approaches remain complex and evolving (Kensing & Blomberg, 1998; Simonsen & Robertson, 2012.). Participatory Design (PD) is not a new phenomenon and appears to have been introduced and researched for many years, although it may not have been named as such. Many other design approaches, methods, and techniques appear to share similar characteristics to PD. These include methodologies such as user-centred design (UCD) which although similar, has an alternative philosophy (Benton & Johnson, 2015). User-centred Design (UCD) adheres to the end-users needs, and users are involved in a series of design and prototyping sessions but are not considered as part of the design team (Benton & Johnson, 2015). In recent years, PD has also been referred to as co-operative or co-design (Carroll et al., 2000) and since then, there has been a need to further conceptualise a model of participation.

Following a critique of the medical versus the social model of disability, Mankoff et al. (2010) noted that disability studies' models are generally not evident in the AT literature. Therefore, they highlight the importance of including participatory methods from disability studies into the field of AT. Briefly, they recommend merging a medical model focused on the correction of impairment with a social model which includes the 'patient' / user being key stakeholders in their management (Clark, 2003; Goering, 2010; Mankoff et al., 2010; Shakespeare, 2006). This is also consistent with the International Classification of Functioning, Disability and Health (ICF). Although there are positive aspects to these approaches, there are limitations as well. Mankoff et al. (2010) and Oliver (2017) asserted that both medical and some social models are driven by the assumption that the goal for disability is normality which strives to eliminate disability. Mankoff et al. (2010) proposed a third approach, a post-modern model. They explained that medical and social models should not be abandoned (for example, some conditions may need medical attention), however, the goal should be a shift towards an individual's unique experience, strengths, and weaknesses within their specific activities of daily living with a cultural understanding of avoiding 'the norm' as the ultimate goal. They recommended that researchers within AT research must understand these complex models within the literature.

The literature above highlights the shifting trend where an individual with a disability should be considered as a key stakeholder. For the individual to be actively involved, they need to be participating optimally. Involving end-users, especially young people with disabilities, in the design process will assist in gaining insight as to what the populations' specific strengths, weaknesses, and needs may be, and to design AT with those considerations, accommodations, and preferences in mind.

A typology of participation that was developed by Wong et al. (2010) appears to take on a post-modern approach required for AT design recommended by Mankoff et al. (2010).

Wong et al's. (2010) conceptual model specifically focuses on the participation of younger people with disabilities, and could therefore be applied to children and young people in PD research. In their model, referred to as the Typology of Young people Participation and Empowerment (TYPE) pyramid, they identify varying levels of participation and empowerment (see Figure 1). An empowerment approach is important since it values the intrinsic strengths of stakeholders such as AT users and seeks to actively involve them in issues that they deem important (Dada et al., 2021).

There are five levels to Wong et al's (2010) pyramid with the peak of the pyramid, the 3rd level, being the pluralistic level where in relation to AT design, it is suggested that both designers and users could together, play an active role. Although research studies differ, the pluralistic level is the preferred level for studies with specific groups such as children and young people. Before this level are adult or designer-driven participation levels. In the first position, the vessel level, children and young people stakeholders may be used merely for testing already developed AT prototypes but do not give any individual input. In the second position, the symbolic level, designers still maintain control but seek to include some perspectives of stakeholders or users, for example, by asking their opinions about certain design characteristics of AT. At the preferred pluralistic level, the 3rd and peak position, designers and users may have shared control where users may be included from the very beginning when conceptualising or designing new AT. They may, therefore, be asked to give input about certain design features that they require in a particular device, as was seen in the Light et al. (2007)

study where children (although they did not have a disability) were asked by AAC researchers to give their ideas about designing an AAC device for children with disabilities.

Beyond pluralistic control is the independent level (4th position), where direct AT users themselves control the design with some input from AT designers or researchers. This can be seen for example, when users design their own AT and get input or are mentored by more experienced AT designers. The final and 5th level is the autonomous level where there is no designer involvement at all and users have all the control of the AT design (Wong et al., 2010). The levels beyond the pluralistic level may be quite rare in participatory AT design studies especially for children and young people with disabilities.

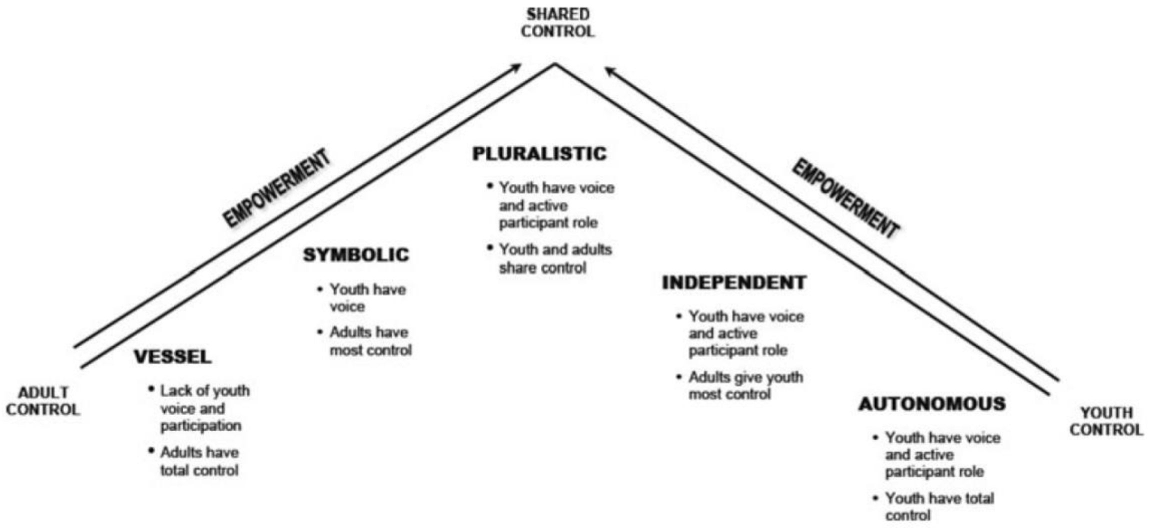


Figure 1: The TYPE Pyramid (Wong et al., 2010 p. 105)

When considering the participation of children and young people with disabilities in the design of AT, The TYPE pyramid can therefore be used to define the various types and levels of participation. This allows for a shift to a post-modern model which includes children and young people with disabilities, while still considering and acknowledging the medical model and at the same time incorporating an individualistic social model.

1.2.3 Participatory approaches to assistive technology design

Gelderblom (2014) stated that because there is a lack of end-user involvement in AT, it still follows a top-down approach that does not allow for proper testing before implementation. This involvement approach is then more similar to the philosophy of UCD rather than that of PD, which increases the chances of device abandonment and the issues of user opinion, poor device performance, and adaptations are still relevant (Hurst & Tobias, 2011; Light et al., 2007; Light & Drager, 2007; Prior, 2011). Furthermore, Hurst and Tobias (2011) motivated for custom and individualised designs and argue that empowering users by involving them in the design process can improve the adoption and, ultimately, the efficacy of the AT. The authors further reported how participants who they interviewed in their study, had an interest in being involved in the design process for their own individual ATs. Additionally, this framework gives people with disabilities a voice within academia and design regarding work that is usually done “about them and not necessarily with them” (Mankoff et al., 2010, p. 3), an important consideration supported by Gelderblom (2014). Participatory Design (PD) is an approach to design that actively involves users with disabilities in the design process to optimally recognise their requirements and preferences (Sampath et al., 2013). Although this approach is the gold standard in AT and product design, the population at hand is still a vulnerable group and prominent challenges remain for including children and young people with disabilities due to the nature of their impairments. Sampath et al. (2013) discussed how involving users with disabilities can be a challenging process as they may not have the skills to contribute effectively; this might be why they are only included at the level of testing ATs’ efficacy (Flodin, 2007) rather than including them in the design process from the beginning. Sampath et al. (2013) suggested that learners with special needs are an assorted group in terms of their skills and that their motor skills, sensory abilities, or cognitive skills may be a barrier in shared designing of AT. It appears that including children and young people with disabilities in AT design has not yet been extensively studied (Adams, 2011; Allsop et al., 2010b) and one needs to consider that those different disabilities may have varying requirements and might require different AT designs or accommodations that would make the AT more appealing for the specific disability. Therefore, there is a need to carefully scope and critique the available research relating to the participation of children and young people with disabilities in AT design.

1.2.4. Involvement of children and young people in the AT design process

Allsop (2010) deduced that emerging methods of accommodating the unique characteristics of children with disabilities is not a straightforward process, and applications of methods and approaches which are typically suited for adult populations are not necessarily satisfactory.

Allsop et al. (2011b) suggested that the fundamentals for developing an assistive device for children are to include them as early as possible in the design method. Furthermore, children of this millennium are born into a society with knowledge of and experience with technology and this can result in a relationship different to those which adults have with technology (Mallan et al., 2010). Mallan et al. (2010) made this statement a decade back; but with the progress in development and accessibility, as reviewed by Foley et al. (2012) and Miangah and Nezarat (2012), it may be truer now than ever for children today. Additionally, Gelderblom (2014) suggested that because of children's more "natural relationship" with technology, they may have an advantage over adults in technology design. Fortunately, the development of technology is expanding rapidly, and devices are becoming smaller, faster, cheaper, and easier to use and procure. It is also becoming more and more accessible in both urban and rural areas, internationally (Foley et al., 2012; Miangah & Nezarat, 2012). Frauenberger et al. (2019) further discussed how individuals with autism engage positively with technology as it resonates with their often safe and predictable preferences. Their insight, influence, and perspective may therefore be beneficial when incorporated into the process of the design and development of AT and could be an opportunity to address some of the reasons for discontinuation and device abandonment as previously mentioned.

Recently, researchers including Allsop et al. (2010a), Benton and Johnson (2015), Sanders (2002), Light et al. (2007), and Light and Drager (2007) have shown an increased interest in PD and the involvement of children and young people with disabilities in the design of AT. Allsop et al. (2010a) stated that there has been little research directed towards the design and development of rehabilitation technologies involving children with disabilities. Additionally, Allsop's (2010) research indicated that there is little guidance and few methods available for designers of healthcare technology on how best to include children in the design of AT as well as which methods would be most suitable and effective.

1.2.5 Involvement of children and young people with disabilities in the AT and AAC design process

Although some research on rehabilitation technologies involving children with disabilities appears to be available (Allsop et al., 2010a), the extent of this involvement is as yet not well known and even less so in the field of AAC.

Because of the high rate of device abandonment, Light and Drager (2002) proposed that AAC technologies for children should be re-designed and aimed at increasing their appeal, expanding the function of the device, and reducing their learning demands. Re-designing AAC technologies to incorporate these functions and features may, in turn, increase their appeal and make it easier for young children with CCN to use, learn, and develop communicative competence as well as motivate their utilisation of the device with peers (Allsop et al., 2010a; Light et al., 2007).

Light et al. (2007) acknowledged the need to include end-users in the design and development of AAC technologies and provided the groundwork for future research by obtaining children's ideas for the design of AAC AT for young children with CCN. In their study, typically developing children (without disabilities) were asked to develop low-tech prototypes of AAC. Being one of the few known PD studies in AAC that have involved children, albeit children without disabilities, their work showed that there is limited research available that includes children in the design and development of AAC AT. The results from their study revealed that the ideas of children without disabilities differed significantly from what had been incorporated into the then-current designs of AAC. The authors speculated that if AAC encompassed features such as bright colours, lights, transformable shapes, popular themes, and humour, AT might be more appealing to CCN (Light et al., 2007). Children might also have been more motivated to use them, and they might have maintained children's engagement over time.

Promoting end-user participation in the design and development process increases the likelihood of the product being usable, safe, clinically effective, and culturally appropriate (Bridgelal Ram et al., 2008). Furthermore, it meets the need to facilitate the participation and inclusion of children with CCN. Light et al's. (2007) study, however, did not include end-users of AAC or even the perspectives of other children with disabilities who may not have communication impairments. It is crucial to do this as children with disabilities may have differing opinions compared to children without disabilities (Allsop, 2010). Such research would intend to minimise design exclusion, capitalising on the user's capabilities to develop optimal AAC technologies (Allsop et al., 2010b). As mentioned, Sampath et al. (2013) discussed how involving users with CCN can be a challenging process due to their impairments as they may not have adequate speech, language, or communication skills to contribute effectively. Fortunately, Gelderblom (2014) and Nilsson et al. (2015) provided guidelines that may compensate for such challenges. These authors suggested that the method by which children with disabilities as research participants are interacted with, and their responses elicited and encouraged, should be age-appropriate and encouraged (Gelderblom, 2014; Nilsson et al., 2015). Furthermore, the instrument tools used to elicit their responses should be easy to use and should make use of visual aids. For example, Talking Mats ® may be used to accommodate children with CCN (Murphy & Bornman, 2006).

Participatory Design (PD) methodology has been used effectively in the development of children's educational software (Druin et al., 1999) and could be applied to the design of AAC. Although demanding, involving users (namely children with disabilities) in the design and development of AAC and broader AT is an area of growing importance (Allsop et al., 2010b) and by AT adopting 'users' preferences, appeal and efficacy are likely to increase.

It is acknowledged that involving children or young people with disabilities is often formidable, and their views are often overlooked or mistaken for the information their proxies (i.e., parents or teachers) provide. Additionally, there is growing recognition that information obtained from proxies do not always reflect those of the individuals in question (Manset-Williamson et al., 2008; Rabiee et al., 2005 as cited in Allsop et al., 2011). Duysburgh et al. (2012) reflected on a process of developing interactive applications for children with hearing loss and suggested the importance of designers having an understanding and empathy for the target population. This is further supported by Koskinen and Battarbee (2003 cited by Duysburgh et al., 2012) who reiterate that empathy is a key concept in design theory and understanding the experiences of the end-users is essential in design processes. Unfortunately, even when designers were encouraged to "get-to-know" the end-users for the proposed AT, many still failed to orientate themselves to the end-users' lives, lifestyles, needs, and wants which is of concern, as these designers and developers are often relied upon to produce AT and devices for children with disabilities.

Research design techniques are also often based on a mutual or shared verbal or visual language or communication system; these are skills which children with disabilities often have difficulty with, further impacting how these participants are included and involved in the design process (Duysburgh et al., 2012).

Caution should additionally be observed when including vulnerable populations in PD due to perceived power imbalances between researchers and collaboration partners. Allsop et al. (2010b) outlined how participatory designs that involve children collaborating with researchers can potentially limit and influence what children do, thus eradicating the proposed benefit of using this method. Children may be influenced by the adult's mere presence within a data collection session and as Sims (2018) concluded, adults may even assume a position of power when asking questions and in turn, influence the participation and data collected from the participants. To evaluate the extent of the involvement of children and young people with disabilities in the design of AT, one would then need to find an adequate balance between researcher and participants to obtain their optimal level of involvement.

From the above, it can be deduced that there appears to be a need to investigate approaches that have been useful in other participatory AT fields, which may allow children and young people with CCN to be involved in the research and design pertaining to AAC technologies. Methods from other fields which have included children with disabilities could then be adapted to facilitate research with children and young people with CCN.

This study, therefore, will undertake a scoping review to analyse what research is available in terms of the participation of children and young people with disabilities in the design and development of AT and to determine their level of involvement in the process. By consolidating the available literature, this study aims to also show how the findings could potentially be extrapolated to children and young people with CCN, and thereby be applied to participatory research in the field of AAC design.

2. METHODOLOGY

2.1 Research Aims

2.1.1 Main aim

The main aim of this study was to undertake a scoping review to analyse what research is available in terms of the participation of children and young people with disabilities in the design and development of AT, including AAC technology, and to determine their level of involvement in the process.

2.1.2 Sub-aims

To address the main research aim, the following sub-aims were investigated.

i. What current published research is available that includes children and young people with disabilities in a PD framework in the design of AT?
ii. To what extent are children and young people with communication disabilities, or those who use AAC, part of the available research?
iii. What is the extent of involvement of children and young people with disabilities in the design of AT in these studies in relation to the TYPE pyramid model?

2.2 Research Design

A scoping review was the most appropriate method for this study (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Grant & Booth, 2009; Peters et al., 2015). Arksey and O'Malley (2005) suggested that it is a method that is used to review available literature addressing a broad topic, especially when not much is known about a topic. This evidence-based, methodology synthesises knowledge (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Peters et al., 2015) which Colquhoun et al. (2014) suggested can be influential for policy and practice. Grant and Booth (2009) reviewed the characteristics of a scoping review and further suggested the following, which applies to why a scoping review is the chosen methodology for this research. According to them, a scoping review identifies the nature and extent of evidence-based research. It is typically tabular with additional narratives, and it attempts to specify a viable review of the literature (Grant & Booth, 2009).

The phases of this scoping review are shown in Figure 2.

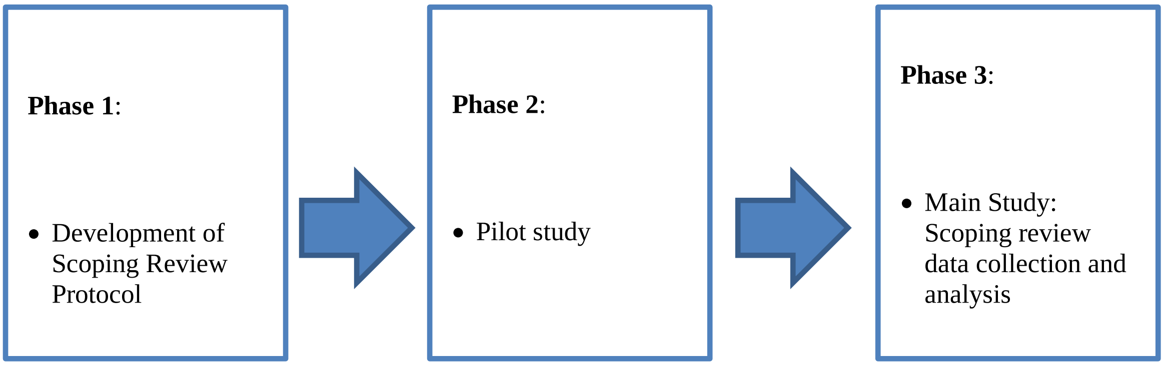


Figure 2: Phases of the Review

2.3 Protocol

A protocol was established before the data collection phase of the research. According to Schlosser et al. (2007), this increases the methodological transparency and facilitates the potential for the replication of the systematic search. The inclusion and exclusion criteria were determined before the systematic search to reduce study selection bias for inclusion in this research (Schlosser et al., 2007).

2.4 Pilot Search

A pilot study was conducted to ensure that the methodology of this scoping review was appropriate to the study. The preliminary search terminology, inclusion and exclusion criteria, and selection of studies (according to Appendix A), data extraction (by using Appendix B), and data analysis were completed and adjusted to ensure appropriacy. Table 1 provides an overview of the aims of the pilot study, the materials and procedures used, the results, and the subsequent recommendations. Changes and adaptations resulting from the pilot included not using abbreviations in the search terms and including additional databases.

Table 1: Pilot Searches: Aims, Materials, Procedures, Results and Recommendations

Aim	Materials	Procedures	Results	Recommendations
To determine whether the search terms were effective.	University of Pretoria Library platform and databases.	Search terms for Population, Exposure and Outcome sections explored and adjusted.	No abbreviations i.e., AT or AAC to be used in search terms. Manipulated, added, and removed search terms.	Year of publication adjusted to 2007 and thereafter. Language limited to English research.
To assess the appropriacy of the inclusions and exclusion criteria.	Appendix A Rayyan online review platform.	Trialed the inclusion and exclusion criteria and software with an appropriate study.	Appendix A is appropriate. Rayyaan is compatible software.	Refine AT definition for the study.
To review data extraction options.	Appendix B. Rayyan online review platform.	Adapted Appendix B. Trialed the appendix and software with an appropriate study.	Appendix B is appropriate. Rayyaan is compatible software.	NA
Data analysis attempts to review efficacy of proposed methodology.	Appendix B.		Appendix B suitable for methodology and study.	NA

2.5 Main Study: Search Strategy and Terminology

Online databases were searched to collect relevant research for this review. The following online databases were used: Academic Search Complete, The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Educational Resources Information Center (ERIC) (at EBSCOhost), Medline, and Web of Science to ensure a comprehensive search. A subject librarian at the University of Pretoria was consulted to assist in selecting appropriate electronic databases. Databases selected for consideration were compatible with AAC and assistive devices and/or ATs. Published and English research was searched dating from 2007 to 2020 which might have limited the selection of research to temporal bias (Schlosser et al., 2007), however, this was done to accommodate for participatory research since the introduction of the ICF-CY. The search was completed in April 2021. The Population Exposure Outcome (PEO) framework was used to guide the search. This framework was selected as it is used most frequently for qualitative questions (Khan et al. (2003) as cited in Bethany-Saltikov & McSherry, 2016). The comprehensive and specifically framed (PEO framework) research question had three elements, as suggested is optimal in a scoping review, and facilitated searching all relevant papers pertaining to the topic (Bethany-Saltikov & McSherry, 2016; Flemming, 1998). This framework was appropriate for this study as it was focused on a specific population, children and young people, their involvement and level of participation, and the outcome thereof as illustrated below in Figure 3.

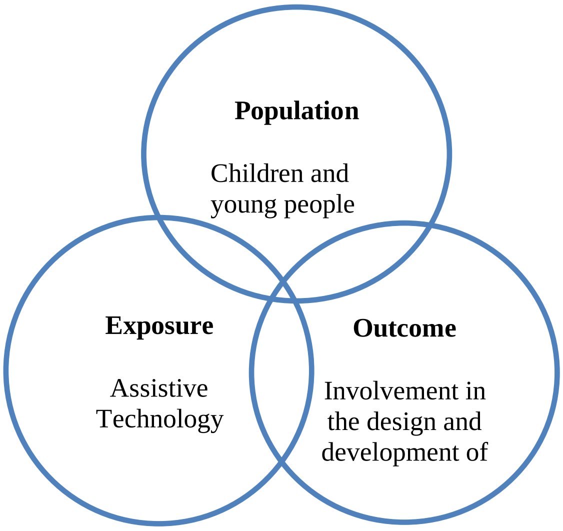


Figure 3: Illustration of the Population, Exposure and Outcome Framework

The following search terms (Table 2) were used consistently in all of the above-mentioned online databases.

Table 2: Search Terms

Criteria	Search Terms
Participant Terminology (Age)	child* OR young people OR adolescen* OR teenage*
	AND
Participant Terminology (Disability)	disab* OR "special needs" OR impair* OR "developmental delay" OR handicap* OR "complex communication needs"
	AND
Exposure Terminology	"assistive technology" OR "Augmentative and Alternative Communication" OR "adaptive technology"
	AND
Outcome Terminology	"design" OR "participatory design" OR "design process" OR "involvement in design" OR "co-design" OR "co-production" OR "inclusive design" OR "user-centred design" OR "participatory research"

2.6 Inclusion and Exclusion Criteria

Table 3 presents the inclusion and exclusion criteria considered when screening at the title, abstract, and full text. Some important inclusion criteria required the population of children and young people to be in the age range 0 to 18 years, have an identified disability, and that the participatory research that they were involved in be specific to AT design. It was important, therefore, to constantly refer to the definition of AT for this purpose (Department of Social Development, 2015; The United States of America, 2004; WHO, 2011).

This review aims to determine the coverage of available literature pertaining to the extent of which children and young people with disabilities are involved in the design and development of AT. Study designs that did not include raw data related to the design of such devices, such as systematic reviews, were then excluded based on the premise that studies of this nature also review available research (albeit for different reasons) (Munn et al., (2018)) and this scoping review aims to consolidate and identify initial data of designing AT, identifying and analysing characteristics based on the initial studies/research that display how a particular device was designed and developed.

Table 3: Inclusion and Exclusion Criteria

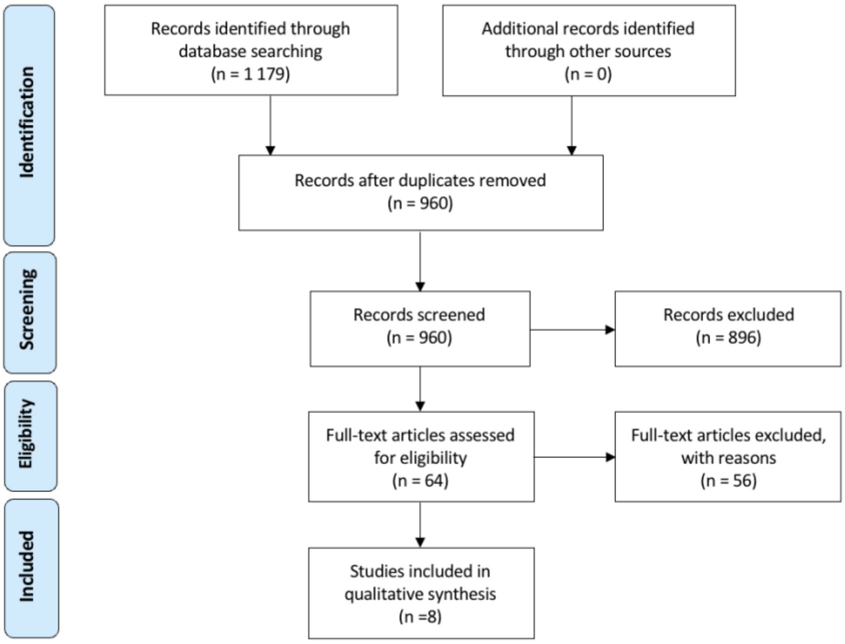
	Inclusion criteria	**Exclusion criteria**
Population	Participants include children or adolescents, up to the age of 18 with a disability.	Participants are adults or young people older than 18 years and studies will be excluded should the participation group be children or adolescents without a disability.
Study Design	Qualitative, quantitative, and mixed-method study designs were included in this research.	• Systematic reviews • Meta-analysis • Literature reviews • Descriptive reviews • Conceptual article
Source Type	Articles published within peer-reviewed academic journals.	• Journals • Dissertations • Technical or research reports • Conference papers • Committee reports • Government documents • Institutional repositories • Preprint materials • White papers • Blogs and newsletters • Podcasts • Policy reviews • Institutional guidelines • Book chapter
Availability	Article’s full texts are available from The University of Pretoria Library or freely available on the internet.	Articles are unobtainable via the library’s database or free online.

2.7 Procedures and Selection of Studies

Studies retrieved from the databases were uploaded to the Rayyan, an online systematic review platform (Ouzzani et al., 2016). Screening at the title and the abstract level was undertaken independently by the researcher and the researcher's supervisor and was guided by the inclusion and exclusion criteria (Table 3). The Title and Abstract Screening Tool (see Appendix A) was developed based on the set inclusion and exclusion criteria displayed in Table 3. This form assisted in organising the data of articles found based on the search criteria. When a decision could not be made at a title and abstract level due to insufficient information, it was included for full-text screening. Studies had to meet all inclusion criteria and were excluded if there was at least one excluding reason. After independent review, the inclusion of the studies at all levels was discussed by the reviewers to improve reliability and to resolve any uncertainties or conflicting decisions until 100% agreement was reached (Peters et al., 2015).

This review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Peters et al., 2015) (Figure 4) and was completed according to findings in this study:

Figure 4: PRISMA Flow Diagram



The PRISMA is a standardised guideline that assisted this research by outlining the review process in an evidence-based manner. Although this guideline is an established one, it should be considered that it is designed to guide systematic reviews and meta-analyses. Munn et al. (2018) illustrates the differences between systematic reviews and scoping reviews and how they serve different purposes, using different methodological differences such as critically appraising and synthesising results versus demonstrating and providing an overview of the available evidence. These authors then express the need and benefit of applying and considering an extension to the PRISMA when conducting scoping reviews when Tricco et al. (2018) presented the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). This extension guides the reporting of scoping reviews and is in line with the reporting structure of this paper. This study undertook a scoping review as preliminary searches indicated that there appeared to not be much published research in this area. It was thus important to scope the extent of the work in terms of participatory design in the development of AT.

From this scoping review, we could determine the extent of research that involved children with disabilities in a PD framework in the design of AT. Furthermore, data were extracted that determined the level of their involvement, that can be observed on a continuum, in these projects according to the TYPE pyramid proposed by Wong et al. (2010) (refer to Figure 1).

2.7.1 Data extraction and analysis

The data analysis process focused on extracting relevant data relating to the review question. Specifically, data such as i) methodology: the specific study design of the research, ii) participants: the age, disability, communication impairment, type of AT, and strategies for the involvement of children and young people with disabilities, and finally iii) conclusions: the level of participations relating to the TYPE pyramid.

Data were then extracted from the included articles by the researcher and reviewed by the supervising researcher, using Appendix B which was specifically designed for this study in order to answer the review questions. The main points of data extraction were to determine the varying research that involved children and young people with disabilities in a PD framework in the design of AT, whether children and young people who used AAC were part of this research, and furthermore the degree of participation or involvement according to the TYPE typology of children or young people’s involvement. After reviewing at a full text level, 56 additional articles were excluded. Many of these evaluated existing designs of AT rather than including people with disability from the very beginning in the design while others did not meet all existing inclusion criteria as indicated in Table 3.

2.8 Ethical Considerations

The nature of this research was that of a scoping review that identified, appraised, and synthesised specific literature and research. Human participants were not directly involved and, therefore, ethical issues were reduced. This research proposal was however submitted to the University of Pretoria Ethics Committee and ethical clearance (see Appendix C) was obtained to continue with the review. To ensure the accuracy of the data obtained, precise methods have been provided for future replication. A Declaration of Originality has been completed and provided in this thesis which guarantees that no plagiarism was committed.

3. RESULTS AND DISCUSSION

In this section, an overview of the included studies will first be provided in terms of participants' characteristics and the outcomes of interest. Thereafter, the included studies will be discussed by answering the sub-aims of this review. Table 4 shows a summary of the eight articles that were included in the study, in terms of the country publication, study designs, disabilities, methodologies used, and level of participation according to Wong et al's. (2010) TYPE pyramid framework.

Table 4: Studies Included

Article	Authors	Date	Country	Study design	Age of participants	Disability	Communication disability	Users of AAC	Methodologies	Types of AT being designed	Level of participation
Involving children in the development of assistive technology devices.	Allsop et al.	2011	United Kingdom Including participants from a lower-middle income socio-economic background.	Survey	04 - 11	CP, hearing impairments, GDD and Down's Syndrome.	yes	yes	Usability testing.	An interactive web-based survey interface.	Symbolic: Relevant participants were used in the final informal usability testing phases of the development of the interface.
Interactive Design – the desire for autonomous upright mobility: A longitudinal case study.	Flodin.	2007	Sweden	Single subject design, longitudinal case study.	1 participant through infancy, childhood, and early teens (aged birth – 13)	Spinal Muscular Atrophy (SMA II).	No	no	Interactive process.	Walking aid.	Pluralistic becoming Independent in later years, Developers observed the participant who provided input toward the design of the aid while considering her expressed desires. As she became older, she started to

Article	Authors	Date	Country	Study design	Age of participants	Disability	Communication disability	Users of AAC	Methodologies	Types of AT being designed	Level of participation
											direct the process of design.
Thinking Outside the Box - Designing Smart Things with Autistic Children.	Frauenberger et al.	2019	Austria	Case Study	06 – 08	ASD	no	no	Interactional model, co-design, and co-operative inquiry, participatory design.	Smart objects of digital technology.	Pluralistic: Technologies were designed with relevant participants that led them to drive the process with their ideas and desires and then consolidated, implemented and materialised by developers.

Article	Authors	Date	Country	Study design	Age of participants	Disability	Communication disability	Users of AAC	Methodologies	Types of AT being designed	Level of participation
An interactive serious game to target perspective-taking skills among children with ASD: A usability testing.	Ghanouni et al.	2020	Canada	Longitudinal study	Children’s mean age was 10 (SD = 1.8), and the young people’s mean age was 15;16 (SD = 1.8)	ASD	no	no	Think aloud method and usability testing.	An interactive game.	Symbolic: Relevant participants tested initial version of product designed by developers. They shared their thoughts of the product as they were using it, observed by developers who then discovered technical issues and bugs not previously observed.
Inclusive design - assistive technology for people with cerebral palsy.	Heidrich & Bassani.	2012	Brazil (LMIC)	Qualitative study	“Children” - specific ages not specified	CP	Not specified	Not specified	User-centred design.	An expanded mouse and a keyboard.	Vessel: The technologies were designed based on the perceptions of designers of children with disabilities.

Article	**Authors**	**Date**	**Country**	**Study design**	**Age of participants**	**Disability**	**Communication disability**	**Users of AAC**	**Methodologies**	**Types of AT being designed**	**Level of participation**
The design and evaluation of electromyography and inertial biofeedback in hand motor therapy gaming.	MacIntosh et al.	2020	Rural France and Urban Canada (LMIC)	Mixed methods study	10 – 23	CP	Not specified	Not specified	Participatory design.	A hand motor therapy game.	Symbolic: Developers considered the relevant participants' natural function when further designing the game.
"Bursting the Assistance Bubble": Designing Inclusive Technology with Children with Mixed Visual Abilities.	Metatla & Cullen.	2018	United Kingdom	Quantitative study	7 – 16	Visual Impairments.	no	No	Co-design.	Various materials.	Pluralistic: Participants were observed and interviewed with structured flexible questions. Themes were then deduced and refined by researchers. Workshops were then further held where a facilitator and participants could co-design materials.

Article	Authors	Date	Country	Study design	Age of participants	Disability	Communication disability	Users of AAC	Methodologies	Types of AT being designed	Level of participation
Design of a Braille Learning Application for Visually Impaired Students in Bangladesh.	Nahar et al.	2015	Bangladesh (LMIC)	Mixed-method study	Children in grades 1 – 5 Age not specified	Visual Impairments.	No	No	PD	A Braille learning application.	Symbolic: Participants were interviewed, a prototype was then designed and evaluated by adults with visual impairments.

3.1 Characteristics of Participants in the Included Studies

From Table 4 it can be seen that most (6) of the included studies were conducted in high-income countries. No studies were conducted in South Africa or on the African continent although two studies were conducted in other low-and-middle income countries (LMICs) namely Bangladesh (Nahar et al., 2015) and Brazil (Heidrich & Bassani, 2012b) as shown in Table 4. Table 5 shows the disability status of participants in the included studies, in order of the most frequent disabilities evident within the eligible studies, to the least.

Table 5: Disability Status of Participants

Disability status	**Number of studies including these disabilities**	**References**
Cerebral Palsy	3	Allsop et al. (2011); Heidrich & Bassani (2012) and Metatla & Cullen (2018)
Autism Spectrum Disorder	2	Frauenberger et al. (2019) & Ghanouni et al. (2020)
Visual Impairments	2	Metatla & Cullen (2018) and Nahar et al. (2015)
Down Syndrome	1	Allsop et al. (2011)
Global Developmental Delays	1	Allsop et al. (2011)
Hearing Impairments	1	Allsop et al. (2011)
Spinal Muscular Atrophy	1	Flodin (2007)

3.2 Types of Assistive Technologies

Table 6 shows the different types of AT focused on in the various studies.

Table 6: Assistive Technologies Focused on in Included Studies

Reference	AT
Allsop et al. (2011)	An interactive web-based survey interface
Flodin (2007)	Walking aid
Frauenberger et al. (2019)	Smart objects of digital technology
Ghanouni et al. (2020)	An interactive game
Heidrich & Bassani (2012)	An expanded mouse and a keyboard
MacIntosh et al. (2020)	A hand motor therapy game
Metatla & Cullen (2018)	Various materials
Nahar et al. (2015)	A Braille learning application

None of the ATs focused on the development and design of AAC technologies, although people with CCNs who may have additional sensory or motor comorbidities might derive some benefit from these devices too. For example, Flodin's (2007) research, which focused on the development and design of a walking aid, does not aim to develop an AAC technology, but a person with CCN who might also have a motor disability, could potentially benefit from the AT used by the participants in the study.

3.3 The Extent to Which Children With Communication Disabilities Are Part of the Research on Participatory AT Design

Allsop et al.'s (2011) research was the only study that included a sample of participants with CCN who were communication aid users. However, further information and details on the nature of their communication disabilities or their communication devices were not reported. Their research was also not specifically focused on the design and development of an AAC technology but investigated children with and without disabilities' personal preference for pre-developed joystick designs (Allsop et al., 2011). Since this study was one of testing usability, it therefore required a low level of involvement from participants with CCN and as a result, methodological adaptations for their participation were not really necessary. Participants did not need to rely on expressive communication to participate but rather were offered a series of forced-choice decisions from which they manually selected their joystick preference from two presented options. After this process, participants were then asked a series of questions and provided with a list of five possible responses from which they could select a suitable response. Throughout this phase of the study, the reliability of their own independent communication or skills was not considered and they were also not really allowed to add additional or different responses other than the closed set with which they were provided.

Some of their participants also had hearing disabilities and sign language was used. However, this was not considered a form of AAC as it is considered an independent language. López-Ludeña et al. (2013) reiterated that sign language encompasses the same language properties and constructs as other languages and is not considered a form of AAC since it is more advanced than a related AAC strategy such as key word signing, for example (Grove & Woll, 2017).

While children with severe motor disabilities also tend to have concomitant communication challenges, both Heidrich and Bassani (2012) and MacIntosh et al. (2020) included participants who presented with CP, but they did not report on whether they were users of AAC. However, the low level of participant involvement in their studies (symbolic and vessel) did not require them to communicate extensively which is possibly why this information was not deemed important to report.

3.4 The Extent of Children and Young People With Disabilities' Involvement in the Design of AT in These Studies Based on the TYPE Pyramid Model

Table 7: Level of Involvement of Children and Young People in the Included Studies

Level of Involvement	Number Of Studies	References
Vessel	1	Heidrich & Bassani (2012)
Symbolic	4	Allsop et al. (2011); Ghanouni et al. (2020); MacIntosh et al. (2020); Nahar et al. (2015)
Pluralistic	3	Flodin (2007); Frauenberger et al. (2019); Metatla & Cullen (2018)
Independent	1	Flodin (2007) (towards latter stages of their longitudinal study)

The eight studies included in this review all claimed to include children and young people in the design of AT to various extents. Table 8 however, shows that the most common level of participation was symbolic. These studies, while often calling them co-designed, almost always were usability designs, where participants were asked to give input retrospectively to already designed prototypes and where input was used for refinement rather than development. Consistent with the literature that has advocated for more active involvement for true PD and which acknowledges the importance of children and young peoples' opinions in AT design, this result appears to be less than desirable.

In contrast, in terms of Wong et al.'s (2010) framework, three of the studies (Flodin, 2007; Frauenberger et al. 2019; Metatla & Cullen, 2018) were ideally pluralistic, although they did not consider participants with CCN or users of AAC. Within these pluralistic studies, participants were observed and interviewed before the design and development started and thereafter, guided in the process of design. For example, even at the young age of one year and nine months, Flodin's (2007) participant with a motor disability "strongly expressed what she wanted and that the upright posture was an exploring posture to her" (p. 216) in a longitudinal study which she called an interactive design. In a further acknowledgement of a shift in power in the design relationship over time, Flodin

(2007) reported that as her participant grew older and matured "she was able to verbally express her points of view, and this resulted in her increasingly becoming the director of the process" (p. 215). This is the only example where the child participant appeared to have more control than the designers which according to Wong et al's (2010) framework could be classified as an independent level of participation. Similarly, the pluralistic Frauenberger et al. (2019) study included designing a corresponding alarm system after establishing an effective communication system between the participant, Mia, and the researchers, after Mia reportedly "suggested that we create a cushion that wakes her up by vibrating next to her instead of the disturbing sound made by her then-current alarm clock" (p. 672). Additionally, although Metatla and Cullen (2018, p. 10) concluded that they "interviewed and observed educators and children living with visual impairments to identify challenges", they moved from a vessel level of participation to that of a pluralistic one, as they collected their observations and then facilitated co-designing workshops which allowed for participants' opinions and preferences to be shared and considered.

3.5 Strategies Used to Include Children Within Participatory Designs

The highlighted reportedly effective strategies of including children and young people with disabilities should be considered and then be further extended into the design of AAC AT bearing in mind these end-users. For example, Flodin (2007) considered their participant's verbal expressions in the design of the walking aid, and Frauenberger et al. (2019) used co-operative inquiry and observed the participants' preferences in a flexible method to engage them according to their abilities and interests. Metatla and Cullen (2018) further used PD to facilitate engagement by exploring co-designing with participants as they administered an interview and observation session, followed by a workshop that structured the design process of materials. These strategies encouraged and enabled an optimal level of participation as deduced by the researcher, according to Wong et al. (2010). Strategies could then be incorporated for children and young people with CCNs.

Additional approaches to consider could be to conduct research within the participants' familiar school environment as Metatla and Cullen (2018) did. They hosted sessions within the premises in addition to incorporating content from the curriculum into their design activities. This reportedly facilitated the comfort of the participants as they progressed from a familiar activity into the design space with the unfamiliar researchers. They further adopted a collaborative approach where participants and researchers were considered as a collective team, as mentioned by the authors, "with our inventor hats on, participants and the researcher explored the design of a tool (p. 6)". This illuminates what was discussed earlier, as Gelderblom (2014) and Nilsson et al. (2015) suggested that to include this population, interactions need to be age-appropriate and encouraged.

In summary, there are currently not many AT design studies that include children and young people with disabilities in the design process. The fact that only eight articles were included in this review highlights the paucity of research in this area. It should be noted that many studies that were excluded from this review did, in fact, use the term PD to describe their methodologies, but the extent of involvement of the users was not consistent with the level deemed to be participating, as it relates to the TYPE framework (Wong et al., 2010). In these studies, children with disabilities participated in terms of user-testing where they often only tested the efficacy of an already designed AT or prototype, rather than obtaining their ideas before the start of the design or during the design process (Flodin, 2007).

Another significant gap was that children with CCN are also included less often in AT designs and no studies were identified involving children with communication disabilities in the design and development of AAC AT. The latter is of concern since it has been 14 years since Light et al. (2007) first identified this as a significant deficit in the design of AAC technology. Furthermore, although research reiterates the importance of PD and the need for children with disabilities to be involved in the process, much of the definitions of PD were unclear in these studies and appeared to be open to interpretation.

Some of the above-mentioned strategies should be considered in future research with children with disabilities and especially those with CCN for example, including an interaction model, co-designing, and co-operative inquiry methods. Optimal participation of inclusion will enable expression of opinions and preferences from the end-user population which can then be incorporated into the results. Provisions should be made (such as the previously suggested Talking Mats ® that might be used to accommodate children with CCN) (Murphy & Bornman, 2006) to facilitate the independent expression of users of AAC in the design and development of AT end products. This would be more optimal than the Allsop et al. (2011) study that included users of AAC but limited to what extent and what could be communicated.

4. CRITICAL EVALUATIONS, IMPLICATIONS AND CONCLUSIONS

4.1 Critical Evaluation of the Study

This scoping review excluded various publications based on availability/accessibility and language and was limited to the end of 2020. Publication bias can therefore not be disregarded (Schlosser et al., 2007).

The search was further limited to a few databases that were deemed appropriate by the researcher and librarian regarding the specific field. Future reviews might benefit from searching across additional databases for more comprehensive results to be obtained.

Determining the outcomes of a study that involved children with disabilities in the design and development of AT and to what extent their involvement was used according to the TYPE pyramid (Wong et al., 2010), was a subjective judgement and future studies may benefit from a larger assessors/researchers component.

Included studies were not scrutinised for quality. Quality criteria did not influence whether articles were included within this study as this is not a requirement for a scoping review (Franz et al., 2017). Studies might have been excluded should their methodologies have been deemed as less than desirable.

Upon screening articles identified in the systematic search, categories should have been allocated to show the reasons why the articles were not included. This might have been beneficial in displaying results and could have illustrated what research was available within the search.

4.2 Clinical Implications

This research showed that minimal studies are available that included children with disabilities in the design and development of AT, even less so children with CCN (Light et al., 2007). Although children with CCN were often included in user-testing and to study the effectiveness of ATs or AAC, no research was found that included children with CCN in the design and development of AAC AT, despite numerous researchers and literature suggesting it. This research proposes the need to rethink what a PD encompasses and how to consider PD when determining children and young peoples' level of involvement. Furthermore, it is suggested that to reduce the risk of device abandonment the need for involvement must be responded to. Device abandonment might take precedence when attempting to implement AAC if the needs and preferences of end-users in the design of these technologies are not addressed and incorporated.

Previous research has made advances in the field of defining participation and desirable methodologies when including the participation of children with disabilities, further encouraging their involvement in the field. This research adds to the notion using further encouragement and defining the involvement of this target population.

If strategies can be acknowledged for the involvement of children and young people with disabilities and CCN, then these findings can be used to benefit the design and development of AAC AT. Although a challenging population to work with, capitalising on their established mode of communication and using approaches that have been mentioned such as end-user expression, might mean their optimal level of participation in participatory research in the field of AAC design in terms of the design and development of AT. The level of participation, as per Wong et al.'s (2010) typology, should incorporate the children and young people's preferences and opinions in a collaborative and shared role with designers.

4.3 Recommendations for Further Studies

It is recommended that future studies consider involving children with disabilities in the design and development of AT. Children and young people with CCN should likewise be considered when designing AAC technologies. Failure to do this will result in ATs continuing to be abandoned and not being optimally effective for the end-user.

4.4 Conclusion

This research aimed to identify available research that involved children with disabilities in the design of AT and further classify their involvement. Based on the analysis of a systematic search, it can be concluded that few ATs involve children and young people with disabilities, as end-users, in the design process. Children with CCN are even less considered in devices that are aimed for their benefit, such as AAC technologies. The results indicate that the extent of involvement is not optimal in this design process. This research clearly illustrates that there is a disparity in how different research understands what involvement and PD mean. Based on these conclusions, developers of ATs should consider optimally involving end-users, specifically children with disabilities and CCNs in designing processes so that technologies follow a specific UCD, incorporating their preferences for enhanced appropriacy and usability. To better understand the implications of these results, future studies could address methodologies to optimally involve this vulnerable population. Findings confirm a lack of available ATs that include end-users, being children with disabilities, in the design process and further challenge how the involvement of these participants within PD is considered or established. Children with disabilities are capable, innovative, and key in the development of systems that will most probably become an extension of themselves, and it is, therefore, essential that they have some degree of input into how these technologies are developed.

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APPENDICES

Appendix A: Title and Abstract Screening Tool

Appendix A - Title and Abstract Screening Tool Reviewer: ______________________

Review Question:

What are the various levels of participation in current research involving children with disabilities in the design of AT?

Article Title	Authors	Publication Date	Population: *<18;00 *disability	Outcome: children with disability involved in design of AT?	Design: Is the design of the study listed in the inclusion criteria of this study?	Publication: *English, *2007 -2020 *Available online and / or UP library	Answers and Plan			Conclusion		Comments
							Yes → read full text	No → Exclude	Unsure → read full text	Include	Exclude	

Appendix B: Data Extraction Form

Title	
Date of publication	
Authors	
Aims of study	
Country, where the study took place	
Method	
Study Design	☐ Pre-experimental design ☐ True Experimental design ☐ Quasi-experimental ☐ Single subject design ☐ Descriptive design ☐ Comparative design ☐ Correlation design ☐ Narrative research design ☐ Survey design ☐ Secondary data analysis ☐ Mixed-method design ☐ Qualitative study ☐ Quantitative study ☐ Phenomenological design ☐ Grounded theory ☐ Case study ☐ Unpublished paper
Participants	
Age of participants: (<18;00)	
Number of participants	
Disability	
Do the participants have any form of communication impairment reported in the study	
Are the participants users of AAC	
Type of AAC used: High tech, low tech or both (Describe)	
Type of AT being designed	

Methodologies and strategies for the involvement of children with disabilities used within this study	
Conclusions	
Type of involvement described in words	
Level of Participation:	☐ Vessel ☐ Symbolic ☐ Pluralistic ☐ Independent ☐ Autonomous
Barriers and facilitators to the involvement of children with disabilities (CWD) in PD methodologies	Facilitators:
	Barriers and Disadvantages:
Comments on cultural and context appropriacy. i.e. diversity of participants, cultural aspect to the design and participants, socio-economic status, high vs low tech AAC used, how the research fits in to a South African context.	
Additional Comments	
Additional Articles to review sourced from this article’s reference list	

Appendix C: Ethical Clearance

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100.
Since 1919

4 June 2020

Dear Ms A de Jager

Project Title:	The Extent to which Children and Young People with Disabilities are Involved in the Design of Assistive Technology: A Scoping Review
Researcher:	Ms A de Jager
Supervisor:	Dr AE Samuels
Department:	CAAC
Reference number:	12045587 (HUM031/0619)
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 28 May 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.

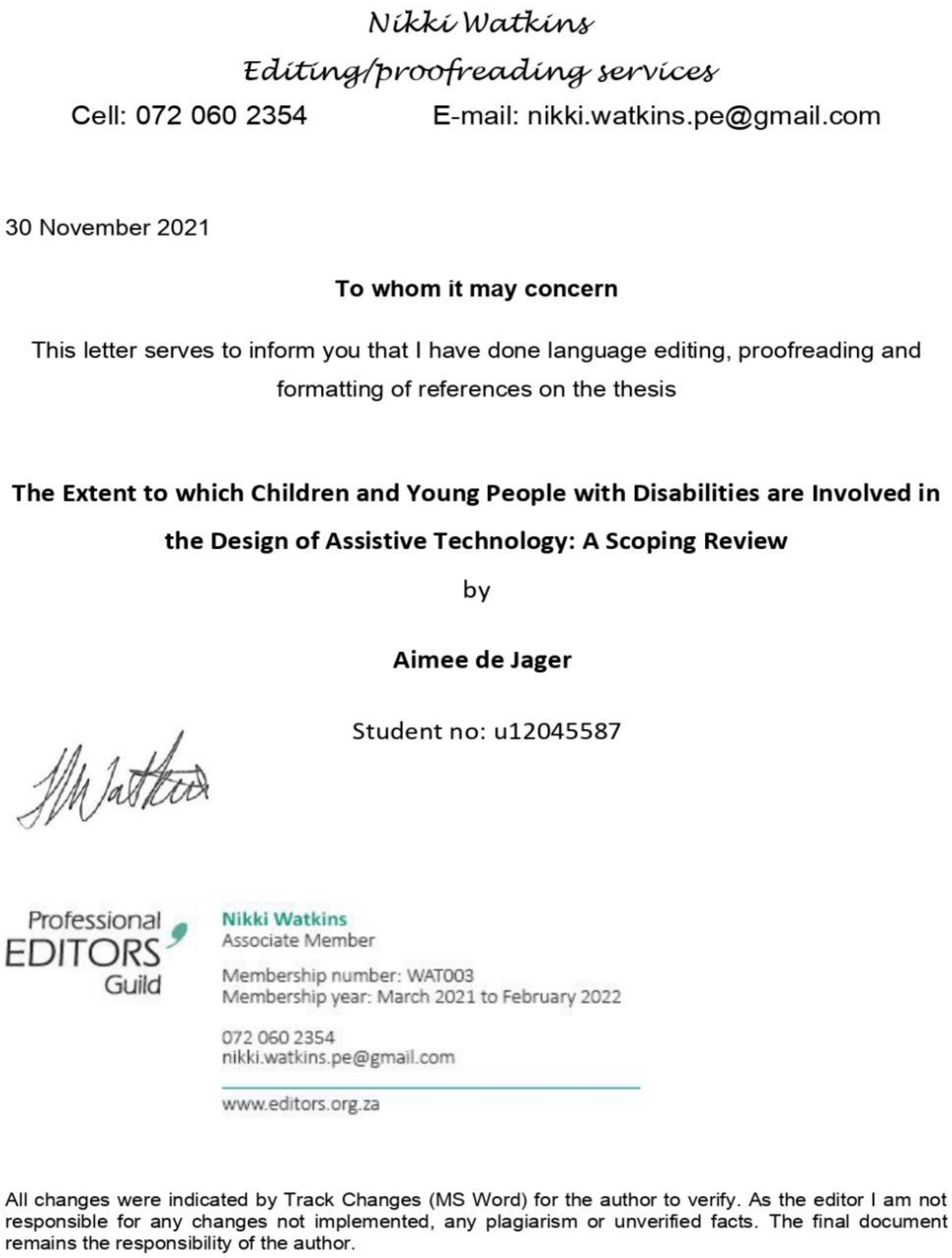
Sincerely,

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 Maree; Mr A Mohamed; Dr I Noomè; Dr C Puttergill; Prof D Reyburn; Prof M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

Appendix D: Editor's Letter



Nikki Watkins
Editing/proofreading services
Cell: 072 060 2354 E-mail: nikki.watkins.pe@gmail.com

30 November 2021

To whom it may concern

This letter serves to inform you that I have done language editing, proofreading and formatting of references on the thesis

The Extent to which Children and Young People with Disabilities are Involved in the Design of Assistive Technology: A Scoping Review

by

Aimee de Jager

Student no: u12045587

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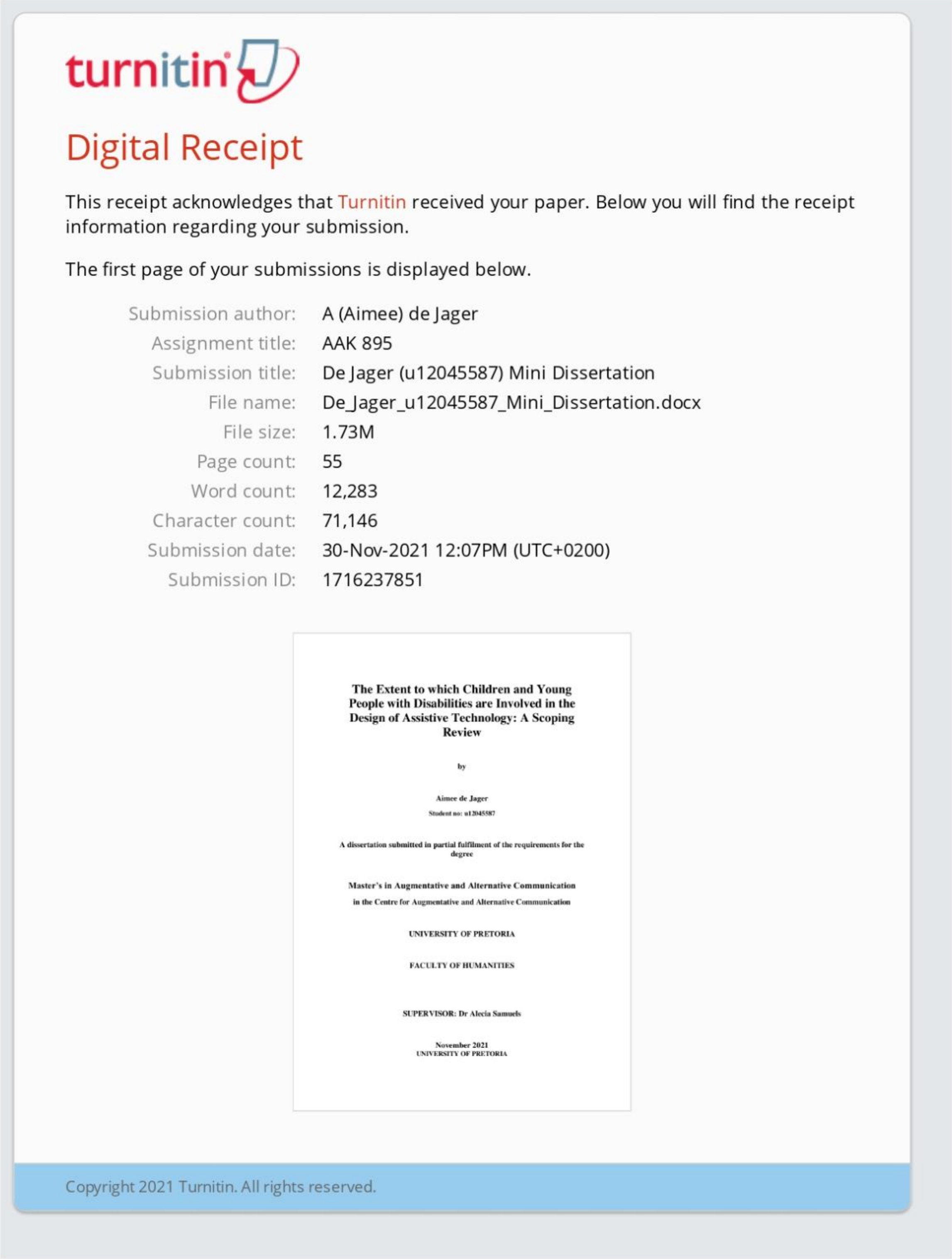
Appendix E: Turnitin Report



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The Extent to which Children and Young People with Disabilities are Involved in the Design of Assistive Technology: A Scoping Review

by

Aimee de Jager

Student no: u12045587

A dissertation submitted in partial fulfilment of the requirements for the degree

Master's in Augmentative and Alternative Communication

in the Centre for Augmentative and Alternative Communication

UNIVERSITY OF PRETORIA

FACULTY OF HUMANITIES

SUPERVISOR: Dr Alecia Samuels

November 2021
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