A systematic review of the theory, design and analysis of longitudinal research on participation in education related activities for children and youth with disabilities

by

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ETHICS STATEMENT

The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research ethics approval.

The author declares that he/she has observed the ethical standards required in terms of the University of Pretoria's Code of ethics for researchers and the Policy guidelines for responsible research.

ABSTRACT

Most research done on children and youth with disabilities are cross-sectional designs. Good, quality longitudinal research designs in terms of theoretical, methodological and analytical considerations are recommended for this population as it will examine the change outcome regarding the ICF domains, specifically the participation trajectories in education-related activities. A three-pronged approach (including an online hand search of the *Augmentative and Alternative Journal)* was used to search for studies that met the inclusion criteria. Studies yielded from online databases were screened at the title and abstract level (IRR = 92%) and full text level (IRR = 85%) by two independent reviewers in COVIDENCE. Included studies were extracted in EXCEL using a data extraction form specifically made for the purpose of the study. A total of 10 studies met the inclusion criteria. The studies were described in terms of participants' characteristics, change outcomes of interest, and longitudinal research considerations. None had all recommended longitudinal considerations. No studies meeting the inclusion criteria were found in the *Augmentative and Alternative Journal.* Participation trajectories are highlighted in terms of capability, performance and attendance. Trends and gaps in the literature are highlighted. Longitudinal participation research of children and youth with disabilities in education-related activities needs to increase and improve in standard to meet state of the art criteria for this method of research. Quality longitudinal research for children and youth who use AAC in education-related activities is also needed.

Keywords: Longitudinal research, capability, performance, attendance, participation, education-related activities.

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AAC	Augmentative and alternative communication
AF	Adaptive functioning
ASD	Autism spectrum disorder
DD	Developmental delay
DS	Down syndrome
EOS	Early onset schizophrenia
ICF	International classification of functioning, disability and health
ICF-CY	International classification of functioning, disability and health – children and youth version
IEP	Individualised education plan
LMIC	Low- and middle-income countries
QOL	Quality of life
WHO	World health organisation

1. PROBLEM STATEMENT AND LITERATURE REVIEW

1.1 Problem statement

The World Health Organisation's (WHO) International Classification of Disability, Functioning and Health (ICF: WHO, 2001) and its version for children and youth (ICF-CY: WHO, 2007) is a framework created to treat disability within a social model and ultimately aims to improve participation in the daily lives of children and youth. It aims to provide a common language that can be used by practitioners to assist with rehabilitation (WHO, 2001). For children and youth, participation in daily life can include participating in activities within the home, family and community but also in education-related activities (Mâsse et al., 2012). Education is an important part of their lives (WHO, 2007) where they take part in activities that form part of the school setting and the curriculum. Children and youth with disabilities, especially those from low- and middle-income countries (LMICs), have most often been excluded from participating in the educational setting (Bines & Lei, 2011). When children are able to participate adequately in this setting, it contributes significantly to their development of essential life experiences and skills (McConachie et al., 2006).

However, within education-related activities such as time on the playground, children with disabilities have been found to participate less frequently in social interaction with their peers (Simeonsson et al., 2001) as well as in school sports, that may ultimately decrease mobility issues (Murphy & Carbone, 2008).

With particular interest to the author and the field of Augmentative and Alternative Communication (AAC), children and youth with severe communication disabilities who use AAC have also been found to experience lower levels of participation in the educational setting, due to the lack of opportunities to practice their social and communication skills (Thomas-Stonell et al., 2015). This in turn further exacerbates their communication development and therefore their participation levels. A study by Pufpaff (2008) observed a young learner with complex communication needs and found that he had less opportunities to participate in group educational activities, such as literacy instruction, as his teacher expected him to struggle and therefore did not give him as many opportunities as his peers.

To understand how participation can change over the education years, it is best seen in studies with a longitudinal methodology (Smits et al., 2014), as factors that affect the level and experience of participation may change over time (Holsbeeke et al., 2009) . Cross-

sectional data may not capture the level or form of change of participation (Ployhart & Vandenberg, 2010) at critical time points in a child's educational trajectory.

However, most of the current research on the participation of children with disabilities (Ladd & Dinella, 2009) and most likely those who use augmentative and alternative communication (AAC) (King et al., 2020), only measures participation at specific points in time or in cross-sectional studies (Ladd & Dinella, 2009) rather than how their participation in education-related activities changes over time. This is problematic since these types of studies do not examine the influence time may have on participation. Cross-sectional studies are therefore static in nature and are not recommended for examining causal relationships in research (Caruana et al., 2015). Understanding the way in which participation of children and youth with disabilities and those who use AAC changes over the course of the educational years can guide interventions to support and promote participation in education-related activities at various points where they may be vulnerable or at risk (Eriksson et al., 2007).

Longitudinal research designs have been recommended as the best way to measure change over time, specifically with children participating in education-related activities (Ladd & Dinella, 2009). Research evidence regarding this population appears to be mostly from cross-sectional data (Ladd & Dinella, 2009). Currently we do not know the extent of longitudinal research participation in education-related activities for children and youth with disabilities including those who use AAC. If this research does exist, we need to evaluate also whether it conforms to the state of the art guidelines for this type of research in terms of the theory, design and analysis as proposed by Ployhart and Vandenberg (2010) in a landmark publication on this methodology. These guidelines can also be used as a basis to evaluate the quality of participation-related longitudinal quantitative studies (Ployhart & Vandenberg, 2010). Without good quantitative longitudinal research that take these aspects into account, inaccurate conclusions can be drawn about how and the extent to which participation changes over time, which may affect how and when interventions are chosen, implemented and the effects measured (Ployhart & Vandenberg, 2010).

The purpose of this mini-dissertation is therefore to review the extent to which quantitative longitudinal research on participation in education-related activities has been conducted with children and youth with disabilities including those who use AAC, and how well this research conforms to best practice longitudinal research guidelines.

1.2 Literature review

1.2.1 *The ICF and the concept of participation for children and youth with disabilities*

The World Health Organisation's (WHO) International Classification of Disability, Functioning and Health (ICF: WHO, 2001) and its version for children and youth (ICF-CY: WHO, 2007) is a framework created to understand and treat disability within a social model and ultimately aims to improve participation in the daily lives of children and youth.

Within the ICF, functioning and disability are framed within the domains of Body Functions, Body Structures and Activities/Participation. Within this framework, activity is defined as 'the execution of a task or action by an individual' and participation as 'involvement in a life situation' (WHO, 2001, p. 12), and these life situations relate to the child's participation in educational, social, recreational and physical contexts (Mâsse et al., 2012; Raghavendra et al., 2012). Children and youth participate in these various contexts according to the social roles they play (for example, being a learner in the school setting) and their levels of involvement may change across different contexts (Coster & Khetani, 2008). For children and youth to experience full participation, they must develop various roles across their contexts (Eriksson et al., 2007).

An example of not being able to participate is to not have the means or access to the environment in which that life situation takes place (Coster & Khetani, 2008), for example, when children and youth with disabilities are excluded from the education environment. Inclusion in these life situations are important for development and creating social relationships (Eriksson et al., 2007). Inclusion in a variety of activities in school is also important for development. These can include formal (curriculum-related activities such as language studies and mathematics) as well as informal activities on the playground or in leisure time (Thomas-Stonell et al., 2015).

1.2.2 Clarifying the boundaries between activity and participation

Although the ICF and ICF-CY provide distinct definitions of activity and participation, they do not clarify how to separately operationalise the two concepts into measurable constructs (McDougall et al., 2013). This has resulted in difficulties in measuring it accurately (Granlund, 2013). Since its conception, the activity and participation constructs has been better operationally conceptualised (Badley, 2008; Whiteneck & Dijkers, 2009), with Granlund and colleagues (2012) recommending including involvement as a subjective experience as an additional qualifier in the ICF/ICF-CY. The activity constructs can then be

further differentiated into ‘capacity’ (what an individual can do in a controlled or ideal setting), ‘capability’ (what an individual can do in their natural settings in daily life), and performance (what an individual actually does in their natural settings in daily life) (Holsbeeke et al., 2009).

1.2.2.1 Capacity, capability and performance within the domain of activities

Coster and colleagues (2013) reported that the most common environmental barriers on participation for children and youth with disabilities were the demands of the activities on their physical, cognitive and social skills. As participation of children and youth can be enhanced by adapting the environment (Coster & Khetani, 2008), and environmental factors are stronger determinants of participation than the child’s and youth’s intrinsic factors (Murphy & Carbone, 2008), one can see the importance of the environment when discussing participation. The ICF’s/ICF-CY’s interactive domains of body structures and functions, activity and participation, and the environment implies that a change in one domain (for example, body structures) will cause a change in the other domains (for example, activity). For example, by providing a hearing aid and aural rehabilitation to a child with a hearing deficit, the range of activities they can take part in will increase. However, this is not always the case as a change in one domain does not always cause a change in the other, and any form of change depends on a variety of factors and interactions between the environment and the child and youth (Smits et al., 2014). For example, Holsbeeke and colleagues (2009) found in their study that the motor performance of children with cerebral palsy was not entirely affected by their motor capacity and capability skills, as personal and social factors may cause differences. They found that personal factors, such as motivation, play a more important role in motor performance (Holsbeeke et al., 2009). For example, a child may have the skills (e.g. request with photographs) in a therapeutic setting but may prefer not to use the skill in a natural setting (e.g. pointing for a desired item). Their study also found that social factors affect motor performance more than they affect motor capacity and motor capability, as social factors are generally absent in standardised settings (Holsbeeke et al., 2009). This shows the importance of social factors and social roles, as performance levels can change if the capacity and capability levels does not match the social role (for example, a child dressing a doll in therapy versus actually taking care and dressing their younger sibling).

The scholastic environment is also important for when discussing participation as education is one of the important life situations children and youth experience (Coster & Khetani, 2008).

1.2.2.2 The two dimensions of participation

While it may be difficult to determine the exact point where activity performance becomes participation, Granlund and colleagues (2012) and Imms and colleagues (2016) recommends differentiating the participation construct into additional constructs of 'being there' (measured as a frequency of attendance) and 'involvement' (the experience of participation during attendance and also known as 'engagement'). Both 'attendance' and 'involvement' are related to the factors of the environment of the specific life situation (Granlund, 2013). In terms of measuring these two domains, 'attendance' would be measured by frequency counts, whereas 'involvement' can be considered as a qualitative measure and is therefore more complex to measure (Granlund, 2013).

Minimal research has been done to measure 'involvement' (Granlund, 2013). Adair and colleagues (2018) include aspects such as motivation, persistence, affect and social connection in their operational definition of 'involvement'. Imms and colleagues (2016) further adds activity competence, sense of self, and preferences in operationally defining participation, with Badley (2008) reporting that participation consists of two characteristics, namely role performance and interacting with others. Therefore, objective measures would fail to correctly acknowledge subjective aspects that affect participation (Coster & Khetani, 2008).

Participation can be achieved in more than one way, in various contexts and with various supports. Therefore the way participation is measured should account for this variability and should strive to be measured in the individual's specific environment (Coster & Khetani, 2008). Measures should also include the child and youth as the main respondent if their experience of involvement is being researched (Coster & Khetani, 2008) instead of only relying on responses from proxies such as parents, caregivers and teachers. For example, a study by Claes and colleagues (2012) found discrepancies between self-reported scores and proxy scores when measuring quality of life (QOL) outcomes in persons with intellectual disabilities.

When participation is investigated as the independent variable, participation is seen as the process. When it is investigated as the dependent variable, participation is seen as the outcome (Schlebusch et al., 2020). Participation should therefore be viewed as a way to change aspects in the body structures and functions domain as well as functioning in the activities domain (Imms et al., 2016).

1.2.3 Participation and communication

The WHO describes someone as a full participant in their communities if they are able to communicate and socially interact with others (WHO, 2007). Therefore, the ability to communicate is an important factor when determining levels of participation. Peers and teachers in a study by Egilson and Traustadottir (2009) termed children full participants if they had good social interaction skills, implying that in the educational context at least, communication skills and social inclusion are included in determining participation levels of learners (Raghavendra et al., 2012). Children and youth are therefore required to develop language and communication skills needed for participation in the school environment (Granlund, 2013).

Participation as an outcome is important for treatments for children and youth with communication needs, as communication skills are required in all their contexts (Klang et al., 2016). A study done by Thomas-Stonell and colleagues (2015) (although it was done on a small sample) found that augmentative and alternative communication (AAC) intervention improved their participants' communicative participation skills, which is essentially communication in natural settings. The study by Klang and colleagues (2016) found that four out of their five participants with ASD using AAC achieved various educational settings based skills, such as academic, social and language skills. AAC intervention therefore assists with social interactions and participation (Beukelman & Mirenda, 2013), and will therefore be included in discussing participation.

1.2.3.1 AAC and participation

Children and youth with communication difficulties can use AAC to communicate and therefore participate (Beukelman & Mirenda, 2013). Due to new research and technological advances, AAC users have the ability to access a wider range of contexts and therefore more opportunities for participation (Light et al., 2019). For example, social media has become an integral part of participating in society as it assists with developing social networks (Light et al., 2019) and high technology AAC systems are able to provide access to this type of participation for AAC users, creating the expectation for learners who use AAC to be able to participate in social media applications. This in turn raises the expectations of those who use AAC to communicate and exposes them to communication partners that may not be familiar with their AAC system (McNaughton & Bryen, 2007), reiterating the need for AAC skills to be generalised into the class, home and community environments.

McNaughton and Bryen (2007) stress the importance of a supportive environment for individuals who use AAC, as a lack of support and inappropriate educational activities are associated with low participation. It is also possible that an AAC user's participation level can differ between contexts (Light et al., 2019). Children and youth who use AAC to communicate should be supported in their communication interactions in their daily life activities (Raghavendra et al., 2012). With support, their confidence in communication increases, which in turn positively impacts on participation levels (Batorowicz et al., 2006) as the 'involvement' experience of children and youth with disabilities can include levels of anxiety and low self-esteem (Murphy & Carbone, 2008).

Training of parents in AAC intervention has been suggested to increase AAC usage in natural settings, further explaining the importance of not only measuring communication progress in standardised settings (capacity) but also that external factors (for example, communication partners) play a role in participation levels (Trudeau et al., 2003). However, again, a change in one qualifier does not imply a change in the other and the interaction between the individual and their environment is an important aspect in examining participation (Holsbeeke et al., 2009). In a study by Koppenhaver and Yoder (1993), learners who use AAC were found to receive less support in literacy activities and often completed these activities in isolation from their peers. This could be due to the extra support needed for them to complete a task, as found in Klang and colleagues' (2016) study where teachers reported that learners with ASD using an AAC device required more time to complete an assignment. It is important for children who use AAC to develop skills in literacy, as this not only assists with educational and future vocational opportunities, but also with participation (Pufpaff, 2008; Trudeau et al., 2003).

However, merely introducing an AAC system may not increase participation, and learners may still experience low participation even with an AAC system (Trudeau et al., 2003). A study by Pufpaff (2008) which observed a young learner with complex communication needs found that he required adult support to use his AAC device, which reduced his interaction time with his peers. This is echoed in a study by Hunt-Berg (2005), which found that AAC users were dependent on their communication partners for programming and maintaining their device, showing that learners who use AAC require adult support to operate their devices, consequently changing their participation style. This need for adult support and other environmental support makes participation more challenging (Raghavendra et al., 2012).

In terms of the ICF, an AAC device is considered a contextual factor under the environmental domain (Raghavendra et al., 2007). There are various other factors under the different domains of the ICF to consider for a change to occur.

1.2.3.2 Children and youth who use AAC and participation over time

While there has been research examining the outcomes AAC interventions have on communication and participation (Alsayedhassan et al., 2016; Ganz et al., 2017), not many studies research the impact of the AAC system on the child's performance, i.e. their communicative participation in their natural settings. Studies that research participation levels should be able to capture more than the child's attendance (i.e. frequency or duration of activities) (Thomas-Stonell et al., 2015), and this should extend to the AAC population.

A single case study done by King and colleagues (2020) found that an AAC user's device and system changed over the years as his language and literacy skills developed, changes in social settings occurred, and technological advances of AAC systems took place. They found his AAC usage was not linear. The study by Thomas-Stonell and colleagues (2015) specifically mentioned their results of improved communicative participation skills were due to AAC intervention, as well as natural developmental change (although the full impact of natural change was hypothesised to be small). This raises the issue of natural growth that occurs over time, and the importance of correctly measuring outcome measures (Thomas-Stonell et al., 2015).

Research on long term outcomes of using AAC in the school setting is therefore needed (Granlund et al., 2008), as changing technological systems, expected change in growth development and development of skills, can all affect the participation trajectory of children and youth who use AAC.

1.2.4 Participation in education-related activities of children and youth with disabilities

Simeonsson and colleagues (2001) listed common school activities under overarching themes such as social activities (e.g. sports), recreation (e.g. art classes), communal activities (e.g. playground time), creative activities (e.g. music classes), civic activities (e.g. assisting with school administration), and academic activities (e.g. Mathematics, Literacy). In this study, education-related activities will be considered as any activity or task done within a school setting. Participation in school activities is necessary for learning and academic achievement (Eriksson et al., 2007; Simeonsson et al., 2001). Children and youth with disabilities may experience difficulties with cognitive skills that are important for schooling

(Anaby et al., 2019). In the United States of America (USA), it is the school's responsibility to put modifications in place that assist the individualised child (Murphy & Carbone, 2008). However, merely attending school does not ensure active involvement in the curriculum (Pufpaff, 2008), as children need to be active participants in the classroom to be academically successful (Ladd & Dinella, 2009).

Children and youth with disabilities often participate in activities that occur in their home settings and experience difficulties with activities that take place in other settings (such as school) or participate more in activities with fewer social interactions, such as watching TV or music lessons (Mâsse et al., 2012). This could be due to the extra support that children and youth with disabilities need in order to participate. Research has shown that having adult support can be a causal factor for reduced peer interactions (Raghavendra et al., 2012).

Pufpaff's (2008) study found their participant to have had less opportunities to participate in group educational activities as his teacher expected him to struggle and therefore did not give him as many opportunities as his peers. Beukelman and Mirenda (2013) termed this low expectation as an 'attitudinal barrier'. In Pufpaff's (2008) study we see that the attendance domain of participation was appropriate, but the learner's ability to be involved in the classroom was lacking. In another study, Kurth and Mastergeorge (2010) found that learners with ASD's individualised education plans (IEPs) focused more on their diagnosis than on adapting the way instructions were given to them. These can further exacerbate the learner's isolation and restrictions to participation.

During storybook reading activities in school, learners are asked various questions about the story that assist in engaging with the story and therefore is a participation activity. However, a study by Light and Smith (1993) found that children and youth with disabilities experienced less opportunities to participate in literacy based activities. Simeonsson and colleagues (2001) also found reduced participation experienced by children with disabilities. They found that a total of 33% of their sample of children with disabilities participated in playground activities. A similar result was found by Eriksson and others (2007) where children with disabilities experienced lower participation levels when activities were less structured.

A study by Mâsse and others (2012) found that when comparing children with neurodevelopmental disorders (NDD) to children with chronic medical conditions (CMC), children with NDD were found to participate in physical activities more in school than children with CMC. This may be due to the co-morbidities and health restrictions of children with CMC. In this case it is characteristics of the child's condition that hinder participation,

or perhaps their parents' and caregivers' fears, or a lack of motivation to participate in those activities. The severity of the disability was therefore an important factor that resulted in reduced participation in school activities (Mâsse et al., 2012).

Another important factor that hinders participation is financial resources, as children and youth with disabilities require specialised and extra activities (Mâsse et al., 2012) and equipment (Murphy & Carbone, 2008). An inability to afford supports and the individual's motivation and perceived self-competence (affected by attitudinal barriers from their communication partners), can reduce participation levels in children and youth with disabilities (Murphy & Carbone, 2008). Children and youth with disabilities, especially those from low- and middle-income countries (LMICs), have most often been excluded from participating in the educational setting (Bines & Lei, 2011).

Children and youth with disabilities that attend 'regular' schools have been found to think negatively about school, have less social interactions, are affected by environmental barriers (perceived and otherwise) and depend more on adults (Eriksson et al., 2007). Clark and MacArthur (2008) found that reduced participation in activities on school grounds occurred with reduced participation in school outings. A high percentage of schools in the USA allows exemptions from physical activities due to cognitive and physical disabilities (Murphy & Carbone, 2008), which could further add to reduced participation and shows how policies can impact on participation.

Due to their fewer social interactions, children and youth with disabilities may not get the practice needed to fulfil common social roles in life situations. Overall, children and youth with disabilities participate in less activities, and participate for decreased amounts of time. They also experience lower engagement than children and youth without disabilities (Eriksson et al., 2007). These restrictions may continue as the child continues over his/her educational journey while transitioning to adulthood (Murphy & Carbone, 2008).

1.2.4.1 Participation of children and youth in education over time

Due to their lower levels of participation, children and youth with disabilities may not reap the benefits of participation (Mâsse et al., 2012), such as participating in sports that may ultimately decrease mobility issues (Murphy & Carbone, 2008). Research on this population has commonly been using cross-sectional (Ladd & Dinella, 2009) methodologies. The interplay of changes of capacity and performance (participation) is best seen in studies with a longitudinal methodology (Smits et al., 2014), as factors that affect capacity and performance may change over time (Holsbeeke et al., 2009). Cross-sectional data may not capture the

level or form of change (Ployhart & Vandenberg, 2010). There is therefore a gap in the literature for longitudinal research that studies participation in the same group of learners and how their participation affects and predicts their progress in education (Ladd & Dinella, 2009).

Not much is known about how participation of children and youth with disabilities changes over time as they progress through the education years, however it has been reported that learners may achieve academic success if their participation levels increase as they develop (Ladd & Dinella, 2009). Bifurcation points are expected (but otherwise unpredictable) changes that will occur, and it is at these points where change is more likely to occur with intervention input. (Bornman & Granlund, 2007). More research therefore is needed on the impact of developmental factors on participation (Coster et al., 2013), such as age, but also keeping in mind the individual nature of bifurcation points for children and youth with disabilities (Bornman & Granlund, 2007)

Ladd and Dinella (2009) suggests that specific changes in participation may be dependent on the child's characteristics, the school setting, and how the child participates in school. Their study of typically developing school-going children found that sometimes the child's level of 'engagement' (involvement), specifically behavioural or emotional, is generally maintained as they continue their schooling. Other times, their patterns of engagement are not maintained and can show discontinuity and fluctuations by either increasing, decreasing or stabilising for a period. A study by Coster and colleagues (2013) found a pattern of decreased participation of children with disabilities as they aged, however the sample was cross-sectional and used differently aged groups of children with disabilities. They however found that the policies and routines of the school can determine the frequency (attendance) of participation, but not necessarily the involvement aspect of participation. These studies show the importance of describing forms of change and having reasonably distanced – and an appropriate amount of – measurement points when doing longitudinal research (Ployhart & Vandenberg, 2010).

1.2.5 Longitudinal research and best practice guidelines

Cross-sectional studies are observational studies that describe a population at a certain point in time and depicts the relationship between outcomes and exposures (Wang & Cheng, 2020). Due to its static nature as the outcomes and exposures are measured together, cross-sectional studies may not depict causal relationships very well (Wang & Cheng, 2020). A type of cross-sectional study that can be used to show changes over time is a repeated cross-

sectional study, where researchers measure the same population at different points in time. However, this type of design may not show individual change such as a cohort study (Wang & Cheng, 2020).

Research following a longitudinal design implements repeated measures of outcomes over a period of time. They are often observational studies in that no extra or unnatural factors are introduced to the phenomenon being studied (Caruana et al., 2015). Longitudinal research that is observational is useful for researching the outcomes that an intervention may bring over a period of time (Caruana et al., 2015).

Cross-sectional studies, on the other hand, may assist with studying multiple variables at one point in time, but does not convey the influence time has on the targeted variables. This makes cross-sectional studies quite static and not recommended for researching cause-and-effect relationships (Caruana et al., 2015). However, cross-sectional studies are easier to design and implement than longitudinal studies, and can be useful for preliminary or pilot studies of cause-and-effect relationships before a longitudinal study is done (Caruana et al., 2015).

There are various advantages when using a longitudinal prospective design. This type of design allows researchers to determine how events are associated and the sequence of these events, as well as depicting the change over time within the sample (Caruana et al., 2015). More time and financial resources are needed for longitudinal research designs. Losing participants as the study progresses (which in turn affects data that can be extracted) is a common disadvantage of conducting longitudinal research (Caruana et al., 2015). Other disadvantages include complications with separating the effect the variables (exposure and outcome) have on each other as the study progresses and the risk of drawing inaccurate conclusions due to the usage of inappropriate statistical techniques (Caruana et al., 2015). Undertaking a longitudinal research study requires careful thought to be made for the study to retain its validity during the duration of the study and to reduce the risk of attrition (Caruana et al., 2015). Ployhart and Vandenberg (2010) recommended certain considerations to be done for longitudinal research that has been lacking in previous research, namely: theoretical considerations, methodological considerations, and analytical considerations.

1.2.5.1 Theoretical considerations

Researchers should first operationally define the construct they are measuring to ensure the measurement tool they select is appropriate, as constructs being measured by researchers may change due to time, but rather they change over time due to exposure to a variable. Time

is therefore a way to measure a construct that changes, evolves or develops. When designing a longitudinal study, albeit descriptive or explanatory, there must be a clear theoretical understanding of what variables are expected to undergo a change, and why this change is expected (Ployhart & Vandenberg, 2010).

The hypothesis is an important part of the research process as it assists with being more precise with what is being measured. Therefore, in longitudinal research, it is recommended that the form of change (i.e., will the change be expected to be linear or nonlinear) is conceptualised in the variables of interest before the first measurement point takes place, and that a theory of change is developed describing the expected change process. This would in turn allow for better testing of the theory (Ployhart & Vandenberg, 2010).

The effect time would have on change as well as the form of change would determine the variables that would need to be measured as well as when they should be measured and the frequency of measurement points. The theory of change would guide the way participants are chosen and tested, how many measurement points to have and the duration of time between them, and ultimately what statistical analyses one would use (Ployhart & Vandenberg, 2010).

1.2.5.2 Methodological considerations

Typically, longitudinal research begins with a measurement point by measuring variables, known as the first wave, and after an amount of time has passed another wave or measurement point occurs to see if there has been any change in variables. It is recommended that longitudinal research has at least three measurement points, and that an adequate amount of time passes between waves (Ployhart & Vandenberg, 2010). If there are too few waves, the process of change may not be correctly captured (Ployhart & Vandenberg, 2010). For example, between wave 1 and wave 2 where the interval between waves are 3 weeks, a learner displays no change in literacy skills and the intervention is deemed unsuccessful and therefore abandoned. However, perhaps the lack of change was due to the methodological issue of the timing and spacing of the measurement points. There could have been an increase in literacy skills (linear), followed by a plateau of improvement, which then lead to regression (non-linear). At wave 2, the learner presents as having the same skills even though there may have been improvement, a plateau, and then regression. It is therefore important for longitudinal research studies to carefully consider the timing and spacing between measurement points in their methodological design, and should not base measurements due to practical reasons only (Ployhart & Vandenberg, 2010).

A theory of 'missing data' should also be developed before conducting a longitudinal study. Attrition, the phenomenon of losing participants and therefore missing out on data, may occur and can affect the significance of the results. If a theory is developed to identify potential reasons why data would be lost, practices can be implemented to prevent the effect of attrition. For example, perhaps a larger sample would be needed at wave 1 if the participant population is expected to decrease in size. Missing data can also be deemed 'ignorable' if it does not affect the results of the study and is due to the purpose of the study (Ployhart & Vandenberg, 2010).

1.2.5.3 Analytical considerations

As mentioned before, the theory of change would indicate the kind of statistical analysis that will be used. Ployhart and Vandenberg (2010) describe three models that can be used for various conditions present in the study: i) the repeated measures general linear model (interested in group differences), ii) the random coefficient model and iii) the latent growth curve (interested in individual differences over time). The type of model chosen would be determined by the need for individual or group differences change over time, how many repeated observations has been conducted, whether the residuals correlated, as well as the presence of attrition as well as whether any missing data is ignorable (Ployhart & Ward, 2011). Without the careful planning of the theory of change and methodological design, an inappropriate model of change can be chosen that will not necessarily represent the data in the best way possible. For example, the general linear model may not be the most appropriate model if the expected form of change is non-linear (Ployhart & Vandenberg, 2010).

Therefore, while it is important that more longitudinal research is done on children and youth with disabilities in educational settings (Ladd & Dinella, 2009) as well as children and youth with disabilities who use AAC to participate in education (Granlund et al., 2008), it is equally important that they follow good longitudinal research guidelines as recommended by Ployhart and Vandenberg (2010).

2. METHODOLOGY

2.1 Aims

2.1.1 Main aim

The purpose of this systematic review is to examine the extent and conformity to best practice guidelines of longitudinal research in studies measuring change in activity performance or participation for children and youth with disabilities in education-related activities.

To address the main aim, the following sub-aims will be investigated.

2.1.2 Sub-aims

The sub-aims of this review are:

i. To determine the prevalence of longitudinal quantitative research studies measuring the change in activity performance and participation in education or educational activities for children and youth with disabilities since the introduction of the ICF-CY.
ii. To determine to what extent children and youth who use AAC form part of the included studies on longitudinal research on participation of children and youth with disabilities in education or education-related activities.
iii. To determine how well these longitudinal studies hypothesise a theory of change in terms of form, level, duration or predictors to guide their research.
iv. To determine how well these longitudinal studies consider methodological and design considerations (measurement waves, timing and observations, sampling, attrition and measurement validity) when examining change in participation in education-related activities.
v. To determine what analytic methods these studies use to document change in participation in education-related activities.

2.2. Research design

Systematic reviews aim to document and synthesise available research and to identify any research gaps (Schlosser et al., 2007). Therefore, a systematic review design was used as the method for this study to address the research aims.

The Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) (Moher et al., 2009) was used to guide this study. The PRISMA-P ensures that transparency is observed by documenting the research process (Liberati et al., 2009), and was

therefore used to document articles that had been identified for screening, how many were excluded against criteria and/or was a duplicate, and how many met the eligibility criteria and could therefore be included for analysis and synthesis.

The PRISMA-P checklist supplies various items that are required to be included in a systematic review (Liberati et al., 2009) that links to other guidelines of conducting these types of reviews, such as stages provided by the Centre for Reviews and Dissemination (2009).

The first stage was doing an extensive search of the available literature pertaining to the research aims to get familiar with previous work, so that the terminology for search terms and a search strategy can be generated (Centre for Reviews and Dissemination, 2009). This was done during the protocol phase, as well as when conducting the literature review for this study. The next stages were carefully creating eligibility criteria for study selection, designing a data extraction tool that extracts relevant data from the included studies that answers the research questions, assessing the quality of included articles, and analysing and synthesizing the extracted data (Centre for Reviews and Dissemination, 2009). These stages will be discussed further below.

2.3. Protocol

The protocol of this review was developed as a research proposal submitted to the Research Ethics Committee of the University of Pretoria. It is an important step in a systematic review as it allows for transparency for readers to understand the process of this study and for replication (Schlosser et al., 2007). The protocol is also crucial for the planning stages of a systematic review, as this is where the study's search terms were generated based off current literature and, subsequently, the specific inclusion and exclusion criteria was decided (Siddaway et al., 2019). Therefore, the protocol was used as a basis to develop the pilot search for the study.

2.4 Pilot search

A pilot search was conducted to determine the appropriacy of generated search terms and inclusion and exclusion criteria, which assisted with guiding this study to yield relevant research that correlates with the research aims. Appendix B illustrates how the search terms were used and refined in the pilot search process.

Table 1 is a summary of the pilot search and illustrates the aims, procedures, findings and recommendations. The recommendations gained from the pilot search was included in the study.

Chapter 3: Methodology

Table 1

Pilot Study

Aim	Procedures	Findings	Recommendations
To determine if the search terms were appropriate	Searches were conducted in the chosen databases	Many irrelevant articles were found with certain search terms, such as 'performance' being associated with business related articles. Some of the two-word terms were being searched by the databases as one word and not the two-words as a phrase, for example, 'learner engagement' was being interpreted as any article with 'learner' and 'engagement'. The population search terms may not have included all children with special needs, such as cerebral palsy. Not all databases had an age limiter, resulting in the need for age specific search terms.	Make use of the databases' built-in thesaurus. Terms removed: -'disab*'. 'disorder', 'developmental delay', 'communication', 'multi wave', 'ICF', 'participat*', 'performance', 'experience', 'educational activities', 'pupil', 'individualised education plan', 'IEP', 'class', 'student', 'learner' Terms added: -'developmental disab', 'childhood disab*', 'disabilities', 'disability', 'disabled', 'impairment', 'impaired', 'longitudinal studies', 'longitudinal research', 'longitudinal method', 'cohort', 'participation', 'icf-cy', 'inclusion ADJ2 classroom', 'capability', 'activity performance', 'education system', 'learner engagement', 'student engagement', 'learner ADJ1 participation', 'children', 'adolescents', 'youth', 'child', 'teenager', 'young', 'adult', 'pediatric', 'paediatric'

Aim	Procedures	Findings	Recommendations
To determine if selection criteria is appropriate	Before an account for COVIDENCE was set up, a screening tool (Appendix C) in Microsoft Excel was created using the search criteria and piloted with 5 articles. One article was randomly selected from each of the chosen databases during the Pilot Search conducted on the 7th of February 2021. All 5 articles were screened by both reviewers.	Although ICF-CY reports children and youth to be up to 18 years of age, children in special needs education may stay in the education system until 20 years of age.	Population should not be older than 20 years old at wave 3.
To determine whether understanding and usage of selection criteria for Title and Abstract screening was uniform between the two reviewers	As above	Some articles would not explicitly report number of waves in abstract, therefore one reviewer would say ‘no’ for that criterion while the other reviewer would say ‘maybe’.	Reviewers should choose ‘maybe’ when article is not clear about eligibility criteria.

2.5 Search Strategy

An extensive search of the literature was done so as to avoid a source bias (Schlosser et al., 2007). Therefore, the search occurred in three steps: 1) search of chosen relevant databases (in consultation with the subject librarian) that index literature pertaining to the research aims, 2) hand searching the online *Journal of Augmentative and Alternative Communication*, and 3) the use of forward and backward citations of included articles on Google Scholar. Articles found were downloaded as an RIS file and imported into COVIDENCE, an online systematic review platform.

In consultation with a subject librarian, the following online databases were accessed: APA PsychInfo, APA Articles, Academic Search Complete, Cumulative Nursing and Allied Health Literature (CINAHL), and Education Resources Information Centre (ERIC). These databases were chosen as they index literature from the fields of education, allied health and psychology. All databases were accessed via the EBSO Host online platform. The search was conducted on the 5th of May, 2021.

Forward and backward citations of included studies was another step used to ensure that an extensive search of the literature was done. For backward citations, each reference list of the included articles was scanned to see if there were relevant article titles that were not in the yield of results. For forward citations, the details of each included article were put into Google Scholar to use its 'cited by' function, to see which studies had cited the included study. This step is to ensure recent literature is not missed. The new articles from the forward and backward citations method were screened at the abstract and full text level. Forward and backward citations searches were completed on the 11th of August, 2021.

Hand searching journals can be another significant way to retrieve studies that may not have been indexed by online databases (Centre for Reviews and Dissemination, 2009), therefore the *Augmentative and Alternative Communication Journal*, the leading AAC journal, was hand searched online from the year 2005 through to 2021. Hand searches were completed on the 11th of August, 2021, and yielded no studies meeting the inclusion criteria.

Table 2 illustrates the search strategies used, yield for different databases, and the amount left after duplicates were removed.

Table 2
Search strategy and yields for databases

Database	Search strategy	Yield	Total after duplicates removed
Academic Search Complete (EBSCO Host)	child* OR youth* OR adolesc* OR teen* OR "young adult*" OR p*ediatric AND disab* OR "intellectual disab*" OR "developmental disab*" OR "childhood disab*" OR "physical disab*" OR "neurodevelopmental disorder" OR "motor disorder" OR AAC OR "augmentative and alternative communication" AND longitudinal OR "longitudinal stud*" OR "longitudinal research" OR "longitudinal method*" OR "longitudinal trajector*" AND participat* OR engagement OR involvement OR inclusion OR "activity performance" OR "learner engagement" OR "student engagement" OR "classroom engagement" OR "academic engagement" AND school OR education OR classroom OR curriculum OR "special education" OR preschool OR kindergarten OR "early childhood education" OR playground	1 279	869
APA PsychArticles (EBSCO Host)	child* OR youth* OR adolesc* OR teen* OR "young adult*" OR p*ediatric AND disab* OR "intellectual disab*" OR "developmental disab*" OR "childhood disab*" OR "physical disab*" OR "neurodevelopmental disorder" OR "motor disorder" OR AAC OR "augmentative and alternative communication" AND longitudinal OR "longitudinal stud*" OR "longitudinal research" OR "longitudinal method*" OR "longitudinal trajector*" AND	28	28

Database	Search strategy	Yield	Total after duplicates removed
	participat* OR engagement OR involvement OR inclusion OR "activity performance" OR "learner engagement" OR "student engagement" OR "classroom engagement" OR "academic engagement" AND school OR education OR classroom OR curriculum OR "special education" OR preschool OR kindergarten OR "early childhood education" OR playground		
APA PsychInfo (EBSCO Host)	child* OR youth* OR adolesc* OR teen* OR "young adult*" OR p*ediatric AND disab* OR "intellectual disab*" OR "developmental disab*" OR "childhood disab*" OR "physical disab*" OR "neurodevelopmental disorder" OR "motor disorder" OR AAC OR "augmentative and alternative communication" AND longitudinal OR "longitudinal stud*" OR "longitudinal research" OR "longitudinal method*" OR "longitudinal trajector*" AND participat* OR engagement OR involvement OR inclusion OR "activity performance" OR "learner engagement" OR "student engagement" OR "classroom engagement" OR "academic engagement" AND school OR education OR classroom OR curriculum OR "special education" OR preschool OR kindergarten OR "early childhood education" OR playground	632	626
ERIC (EBSCO Host)	child* OR youth* OR adolesc* OR teen* OR "young adult*" OR p*ediatric AND disab* OR "intellectual disab*"	283	259

Database	Search strategy	Yield	Total after duplicates removed
	OR “developmental disab*” OR “childhood disab*” OR “physical disab*” OR “neurodevelopmental disorder” OR “motor disorder” OR AAC OR “augmentative and alternative communication” AND longitudinal OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*” AND participat* OR engagement OR involvement OR inclusion OR “activity performance” OR “learner engagement” OR “student engagement” OR “classroom engagement” OR “academic engagement” AND school OR education OR classroom OR curriculum OR “special education” OR preschool OR kindergarten OR “early childhood education” OR playground		
CINAHL (EBSCO Host)	child* OR youth* OR adolesc* OR teen* OR “young adult*” OR p*ediatric AND disab* OR “intellectual disab*” OR “developmental disab*” OR “childhood disab*” OR “physical disab*” OR “neurodevelopmental disorder” OR “motor disorder” OR AAC OR “augmentative and alternative communication” AND longitudinal OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*” AND participat* OR engagement OR involvement OR inclusion OR “activity performance” OR “learner engagement” OR “student engagement” OR	229	225

Database	Search strategy	Yield	Total after duplicates removed
	"classroom engagement" OR "academic engagement" AND school OR education OR classroom OR curriculum OR "special education" OR preschool OR kindergarten OR "early childhood education" OR playground		

2.6 Inclusion and Exclusion Criteria

The process of inclusion of studies in a systematic review is guided by pre-determined eligibility criteria (Moher et al., 2015). Table 3 gives a description of the inclusion and exclusion criteria that was used to determine eligibility in terms of population characteristics, study design, outcome, and limiters.

Table 3
Eligibility criteria

	Inclusion Criteria	**Exclusion Criteria**
Population	Children and youth (0-20 years) with disabilities and long-term health conditions including children and youth who use AAC	Typically developing children and youth Older than 20 years at wave 3
Study design	Longitudinal research measuring change over time consisting of 3 or more measuring points	Other systematic reviews, literature reviews or meta-analysis Experimental designs Quantitative: case study or case series or single-group studies Single subject designs Follow-up studies mainly measuring follow-up outcomes Qualitative longitudinal studies Two waves of measurement Cross-sectional studies Instrument validation studies Intervention studies
Outcome	Participation based research that focuses on being in education or education-related activities (i.e., anything done in the context of the education system) Research that focuses on involvement or engagement in education-related activities Research that measures activity performance in educational activities (anything done in the context of the education system)	Participation-based research that focuses on being in activities at home or in the community Capability
Date	2005 – 2021	Earlier
Language	English	Other
Publication type	Articles published as full texts in peer review journals Obtainable through the library of the University of Pretoria, or freely available on the web, e.g. ResearchGate	Abstracts, conference papers, theses, books and other grey literature Not available via the UP library or free on the internet
Design	Longitudinal research designs	Any other design

2.7 Materials and equipment

A laptop with internet connection to the online library of the University of Pretoria was used as hardware to complete this review. Software used was COVIDENCE and Microsoft EXCEL for data extraction and data analysis.

2.8 Selection of records

Harrison and colleagues (2020) found COVIDENCE to be one of the most used software tools by healthcare professionals for abstract and full text screening when conducting a systematic review. Articles found from the online search was imported into the user's COVIDENCE account, where screening (guided by the selection criteria) was conducted independently by 2 reviewers.

A two-phase process was undertaken to screen articles obtained through data base searches. Firstly, screening at the title and abstract level was done independently by each reviewer using the inclusion and exclusion criteria (see Table 3).

Articles that met all inclusion criteria were included. Articles that had at least one exclusion criteria were excluded. When decisions could not be made at a title and abstract level due to insufficient information, they were included for full text screening.

Articles that were included at the title and abstract level were reviewed at the full text level as well. Two reviewers again independently screened articles at full text level to reduce bias. The reviewers then compared their findings and, if there were discrepancies which could not be resolved by discussion, a third reviewer (the supervisor) adjudicated. Full text screening was guided by the eligibility criteria as seen in Table 3.

After both reviewers had completed full text screening and all discrepancies were resolved, the hand search phase commenced using the forward and backward citations method on the included articles. Here the reference lists of the included articles were scanned to see if any relevant studies were missed, as well as inputting the included articles into Google Scholar to see if it had been cited in relevant studies.

The process of including and excluding studies was documented and reported below (Figure 1) as a PRISMA-P diagram (Moher et al., 2009).

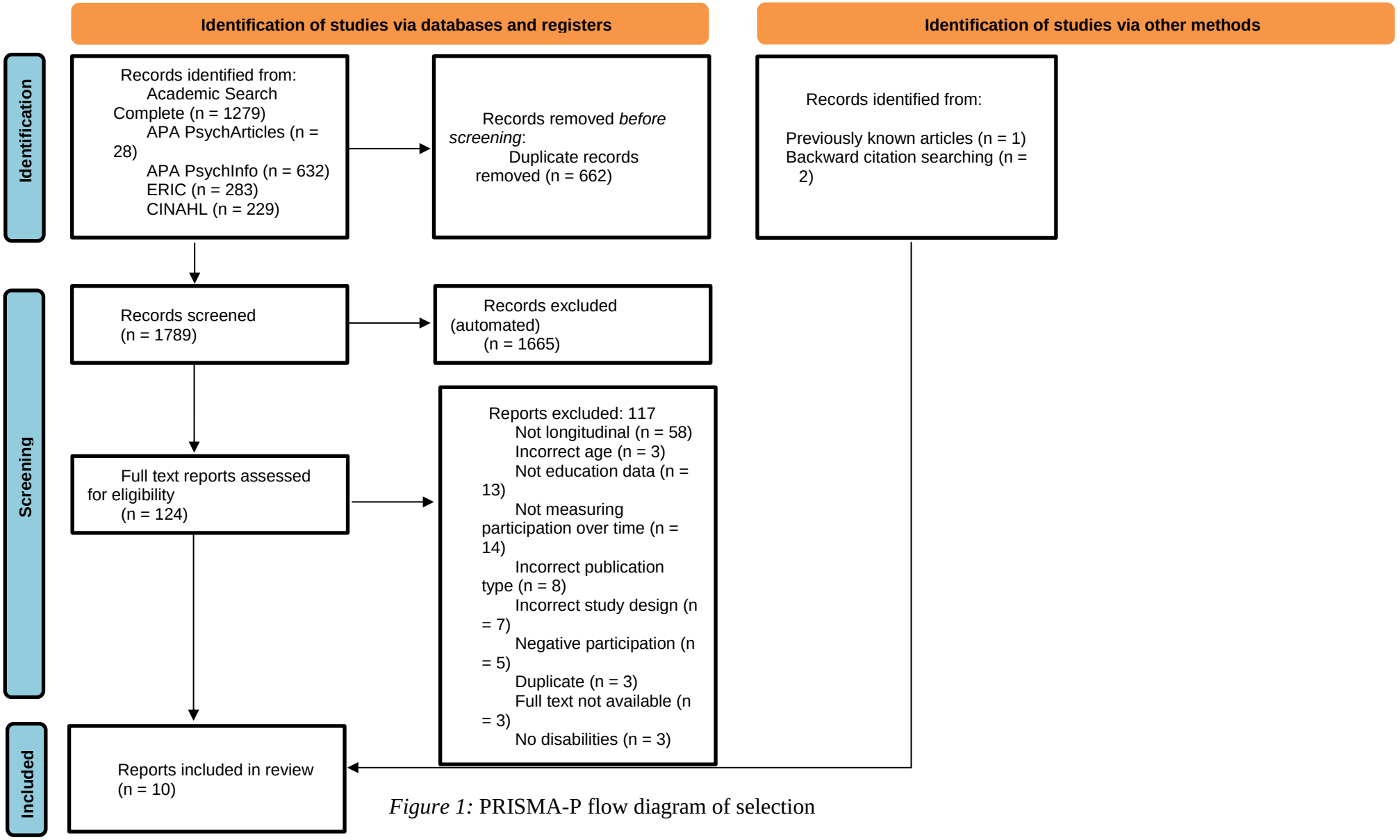


Figure 1: PRISMA-P flow diagram of selection

2.9 Data extraction and analysis

A data extraction form using Microsoft Excel was developed specifically for this study (Appendix D). Relevant extracted data from articles was transcribed into the data extraction form. The type of data extracted is summarised in Table 4. Extracted data was analysed manually using a thematic analytic approach (Braun & Clarke, 2006) to search for emergent patterns and themes guided by the research questions.

Table 4
Summary of data extraction

Criteria	Justification
General information	To determine the trend of number of publications since the implementation of the ICF-CY and to note any geographical tendencies
Methodology	To determine the frequencies of types of study designs and the average amount of waves
Participants' characteristics	To determine a trend in certain age groups, gender groups and diagnosis groups, as well as the frequency in which children and youth are primary sources for data collection
Participants' role in child/youth's education	To determine the frequency where caregivers and/or teachers comment on intrinsic aspects of participation
Change outcome of interest in context/subject/activity	To determine frequency of change in participation observed in studies
Theoretical, methodological and analytical considerations	To determine how researchers hypothesise a theory of change in participation in terms of form, level and duration, and how they considered measurement waves, timing, sampling, attrition and measurement validity

2.10 Ethical considerations

Systematic reviews make use of available research that can be extracted, synthesised and extracted (Schlosser et al., 2007). The participation of human participants was therefore not required and, as such, ethical clearance for human subjects was not needed. However, in accordance with the Research Ethics Committee of the University of Pretoria, ethical clearance was granted from the Faculty of Humanities (Appendix A). The following ethical considerations were followed:

2.10.1 Accuracy

To ensure accuracy, the study followed a systematic process that was documented to ensure transparency (Liberati et al., 2009) and replicability of the study (Schlosser et al., 2007). Data reported in this study was not made up nor falsified.

2.10.2 Plagiarism

Plagiarism is the act of using another researcher's work without acknowledgement. All studies used for this review was referenced using referencing software (Mendeley). This

review was also submitted to the Faculty of Humanities via online plagiarism detection software (Turnitin).

2.11 Reliability

Inter-rater reliability (IRR) refers to the level of agreement between two reviewers working on the same data independently, to ensure consistency is ensured during the study process (Schlosser & Raghavendra, 2004). The following steps were followed to ensure the study was done in a rigorous manner and bias was reduced:

- The PRISMA-P (Moher et al., 2009) diagram was completed to illustrate steps taken during the study process
- Searching multiple online databases
- Using eligibility criteria to include and exclude articles
- Two reviewers to independently screen at the title and abstract level, as well as the full text level, with a third reviewer to adjudicate

The IRR was calculated for the title and abstract level, as well as the full text level of screening. This is calculated by dividing the number of agreements between reviewers with the total number of articles screened at each level. COVIDENCE's built-in tool was used to export the inter rate reliability data.

$$\frac{Total\ number\ of\ agreements}{Total\ number\ of\ articles\ screened} = Percentage\ agreement$$

At the title and abstract screening level, the following totals were calculated:

$$\frac{1646}{1789} = 0.92007$$

At the full text screening level, the following totals were calculated:

$$\frac{106}{124} = 0.85484$$

For the title and abstract screening, the agreement percentage was 92%. For full text screening, the agreement percentage was 85%.

3. RESULTS

A total of 10 studies met the inclusion criteria of this systematic review. An analysis of the included studies will be reported in terms of (i) participants' characteristics and (ii) change outcomes of interest. Thereafter, the included studies will be discussed by answering the sub-aims of this review, such as the (i) theoretical considerations, (ii) methodological considerations, and (iii) analytical considerations.

Table 5 is a summary of the included studies. Three of the included articles were published before the year 2010. Most of the included articles (7) were published after the year 2010. The year 2010 is used as a reference as this was the year Ployhart and Vandenberg's (2010) seminal work on best practice guidelines for longitudinal research guidelines was published. All studies had both a descriptive and explanatory research design. Two studies (Studies 2 and 5) did not specify the length of their study. Of the eight studies that did, the duration of the included studies ranged from two years six months to 10 years. The range of number of waves is three to six, with an average of 3.9 waves. Half of the included studies (*n* = 5) had a total of three waves, which is the minimum amount of time points recommended for longitudinal research (Ployhart & Vandenberg, 2010).

As can be seen from Table 5, seven studies were published in the United States, one in Sweden and one in Australia. One study did not specify where the study took place; however, the existing data set used by the study was performed in the United States. None of the included studies were conducted in LMICs.

Section 3: Results and Discussion

Table 5
Included studies

	Study	Country	Purpose	Type of design	Number of waves	Duration of study in months/years
1.	Ball et al. (2018)	USA	To augment the knowledge about the impact of IEPs on school outcomes in youth diagnosed with early onset schizophrenia (EOS) and to better understand the problems they face in community-based schools.	Descriptive Explanatory	3	2 years, 6 months
2.	Barnard-Brak & Lechtenberger (2010)	Not specified (however existing data set used was done on USA population)	To examine the association of student participation in the IEP process with academic achievement across time using a nationally representative sample of elementary school - school aged children with disabilities.	Descriptive Explanatory	3	Not specified. Used an existing data set, the Special Education Elementary Longitudinal Study (SEELS) which was initiated in the year 2000
3.	Goldfeld et al. (2015)	Australia	To examine the learning and academic pathways of children with special health care needs (SHCN) across the elementary school period.	Descriptive Explanatory	4	4 years
4.	Guralnick et al. (2008)	USA	To characterise the possible shift from full-inclusion placements over time, and to determine the extent to which specific child characteristics within this group of children with mild delays were associated with any	Descriptive Explanatory	3	3 years

	Study	Country	Purpose	Type of design	Number of waves	Duration of study in months/years
			placement changes across the transition to the early elementary years.			
5.	Heyman & Hauser-Cram (2019)	USA	To explore trajectories of school-based adaptive functioning (AF) over time. This study also investigates relationships between experiences at home and with family members during early childhood and AF in the classroom, where task demands undoubtedly differ from the demands within the home and family context.	Descriptive Explanatory	5	Not specified. Used an existing data set, the Early Intervention Collaborative Study (EICS) which was initiated in the year 1985.
6.	Hibel & Jasper (2012)	USA	To explain longitudinal variation in special education placement among children in immigrant and native families.	Descriptive Explanatory	4	5 years
7.	Hurwitz et al. (2020)	USA	To examine whether special education programs provide students with supports that allow them to advance academically, as intended by the law, to a greater degree than they might have advanced without the supports.	Descriptive Explanatory	6	3 years
8.	Kelly (2009)	USA	To investigate the extent to which US students who are visually impaired use assistive	Descriptive Explanatory	3	4 years

Study	Country	Purpose	Type of design	Number of waves	Duration of study in months/years
		technology, the change in the use of assistive technology as time progressed, and several predictor variables that may have played a role in the use of assistive technology.			
9. Kelly (2011)	USA	To assess the use of assistive technology by high school students with visual impairments through a secondary analysis of the National Longitudinal Transition Study-2 (NLTS2).	Descriptive Explanatory	3	10 years
10. Lundqvist et al. (2015)	Sweden	To investigate the educational pathways of a group of children with and without special educational needs.	Descriptive Explanatory	5	3 years

Section 3: Results and Discussion

3.1 Participants' characteristics

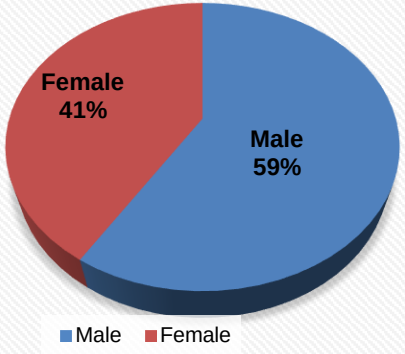
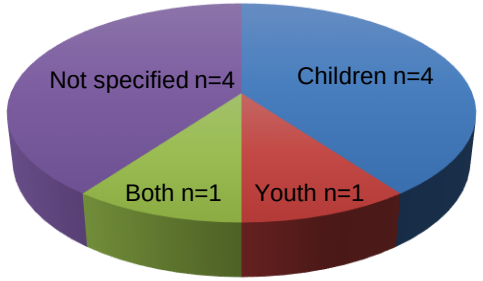
Table 6 is a summary of the learners' characteristics in the included studies. In terms of gender (Figure 2), more studies (n = 4) had more males than females. Three studies did not specify the gender of the participants. All studies did not specifically set out to recruit one specific gender.

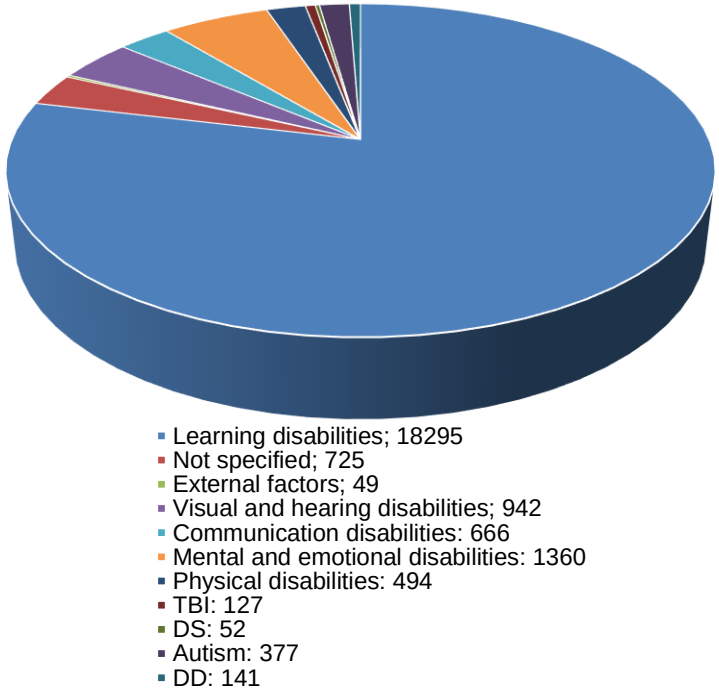
Children were characterised as being 0 to 13 years of age. Youth were characterised as being over 13 years of age to 21 years old. Five of the studies aimed to use children, four out of 10 of the studies aimed to use both children and youth, and one study aimed to use youth. This implies that there is less research on the high school years of youth with disabilities. Figure 3 shows the age focus groups of included children and youth with disabilities. It is important to note that authors of the included studies used different language terms for possibly the same diagnosis, e.g. orthopaedic impairment versus motor impairment. Similar conditions were therefore coded together. Of the 10 studies, four focused on only one diagnosis. The remaining studies (n = 6) had more than one diagnosis. Figure 4 represents a summary of diagnoses included. Figure 5 depicts the participants' role in data collection. Five studies used proxy reports to collect data on change outcomes. Five studies used the child as well as their caregiver and/or teachers to collect data. No studies used self-rated and observation methods to collect data from the children and youth with disabilities.

No studies were found that met eligibility criteria and was concerned with AAC during the online hand search of the *Augmentative and Alternative Communication Journal*. Only one study (Study 10) gathered AAC information but it was not the change outcome. In fact, only two of the included studies (Studies 8 and 9) were concerned with the usage of assistive technology by children and youth with disabilities in schools.

Section 3: Results and Discussion

Table 6
Participants' characteristics

Description	Result
Gender of participants A total of 23 570 children and youth with disabilities were participants in the included studies. Four studies (Studies 2, 6, 8 and 9) did not specify the gender of the learners, resulting in 21 830 participants with unknown gender. Of the six studies (Studies 1, 3, 4, 5, 7 and 10) that did specify the gender of their participants (*n* = 1 740), 1 024 were male and 716 were female. Of the six studies that specified the gender of participants, more studies (n = 4) had more males than females. All studies did not specifically set out to recruit one specific gender.	 **Figure 2. Gender distrubution**
Age of participants The ages of learners ranged from 3 years to 20 years of age. Children were characterised as being 0 to 13 years of age. Youth were characterised as being over 13 years of age to 21 years old. Four studies (Studies 4, 6, 7 and 10) did not specify their age ranges. Of the six studies (Studies 1, 2, 3, 5, 8 and 9) that did specify age, all studies reported on age ranges instead of individual ages. Four studies used children under 13 years of age (Studies 2, 3, 5 and 8). One study (Study 1) used both children and youth, and one study (Study 9) used youth.	 Figure 3. *Age groups*

Description	Result
Participant diagnosis Study 10 did not specify the total participants per diagnosis group and therefore was not included in the diagnosis distribution of Figure 4. Most participants (*n* = 18 294) were classified as having learning disabilities. Seven hundred and twenty-five of the participants' diagnoses were not specified, and 49 participants had external factors that impeded on academic achievement. Other diagnosis included were: visual and hearing disabilities (*n = 942)*, communication disabilities (*n* = 666), mental and emotional disabilities (*n = 1360)*, physical disabilities (*n* = 494), traumatic brain injury (TBI) (*n* = 127), Down syndrome (DS) (*n = 52)*, autism (*n* = 377), and developmental delay (DD) (*n* = 141). Children and youth participants who use AAC was not found in the included studies.	 Figure 4. *Participant diagnosis*

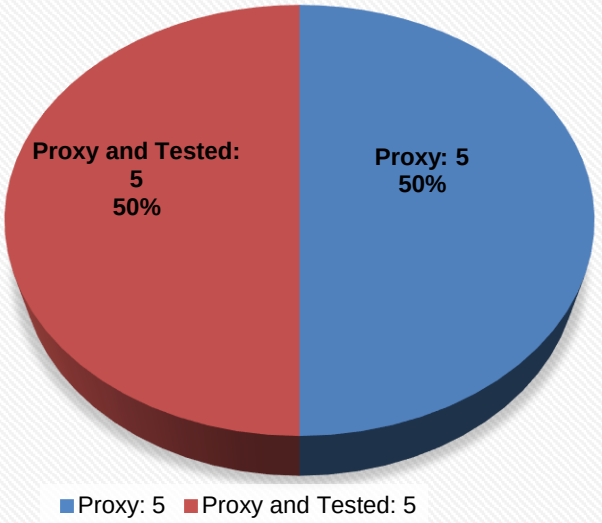
Description	Result
Participant's role in data collection Five studies (Studies 2, 3, 4, 7 and 8) obtained data from the child through testing as well as from their caregiver and/or teachers. The remaining 5 studies only used proxy ratings.	

Figure 5. *Role in data collection*

3.2 Change outcome of interest

Table 7 is a summary of the change outcomes of interest and the measurement instruments used. The included studies made use of more than one measurement instrument, and would have either gathered data from directly testing the learner and gathering information from their caregiver/teacher, or only using caregiver/teacher reports and/or school records. Educator reports (n = 5) were the most common measurement instrument used, with School records (n = 3) and Assessments (n = 3) being the least common measurement instruments.

Figure 6 is a representation of the domains and constructs measured. There was a total of 14 change outcomes accumulated from the included studies, as some studies measured more than one change outcome. More studies (n = 4) focused on the attendance aspect of participation, with the special education services (such as inclusive settings, partially inclusive settings, and the hours per day learners spent receiving special education services) and provisions being the most (n = 5 out of 14) measured change outcome. One study (Heyman & Hauser-Cram, 2019) only measured the capability construct of the Activities domain, where they measured learners' adaptive functioning in school and whether this affected their academic scores. Another study (Ball et al., 2018) measured progress in academic skills (language studies, mathematics and sciences, and social studies) over time under the performance construct of the Activities domain. The performance construct also had codes of AT usage (Braille readers and large print books) for progress of academic achievement. The attendance construct had school attendance, IEP presence, and attendance in special education services and provisions, and authors aimed to investigate whether attendance affected academic achievement over time.

Table 7

Outcomes measured

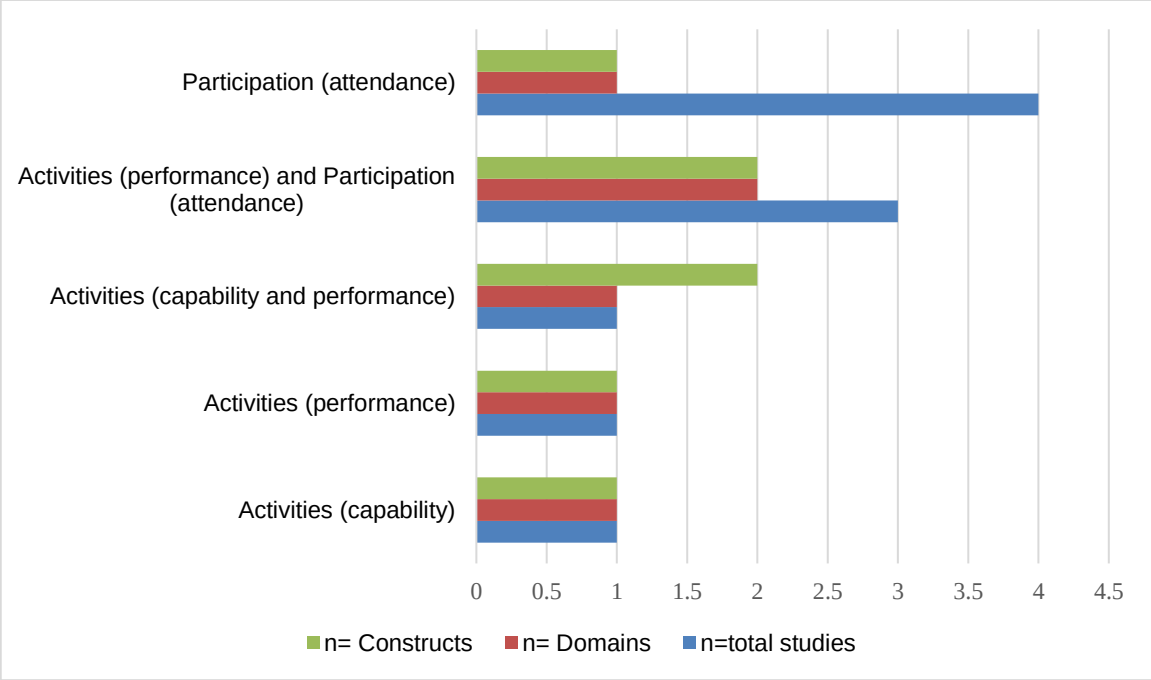
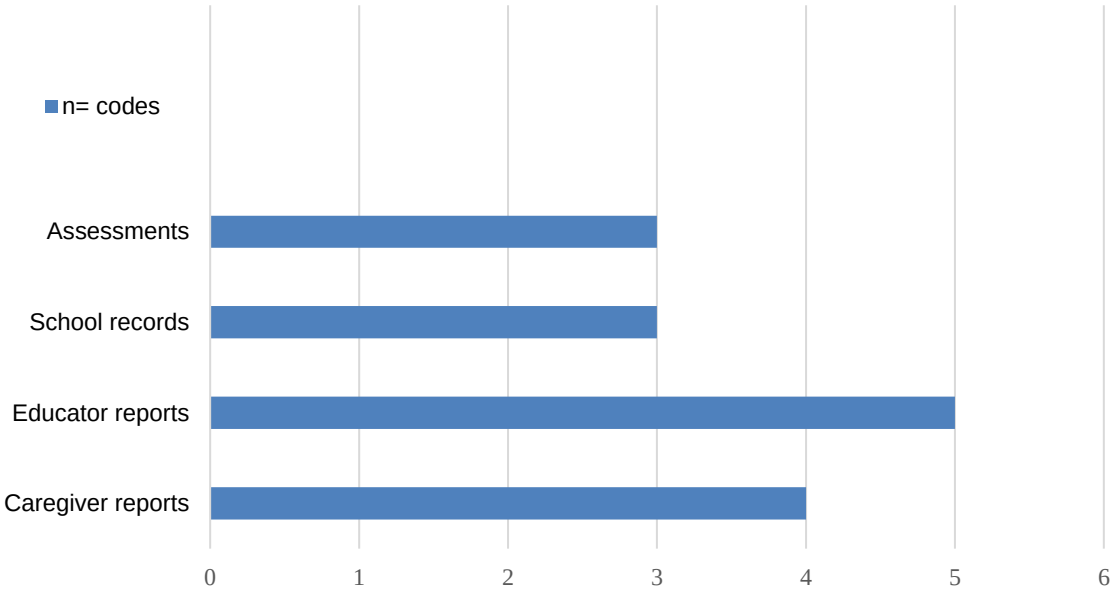
Description	Result
Change outcome of interest Of the 10 included studies, three studies measured outcomes in the Activities domain, three studies measured outcomes in both the Activities and Participation domains, and four studies measured outcomes in the Participation domain. One study measured both the capability and performance constructs in the same domain (Activities), and three studies measured two different constructs (capability and attendance) in different domains (Activities and Participation). More studies (*n* = 4) focussed on the attendance aspect of participation. One study (Study 5) only measured the capability construct of the Activities domain. There was a total of 14 change outcomes accumulated from the included studies. Within the capability construct, adaptive functioning (*n* = 1) and academic skills (*n* = 1) were measured. In the performance construct, academic performance (*n* = 2) and using AT for academic achievement (*n* = 2) were measured. In the attendance construct, "not present" (*n* = 1), IEP presence (*n* = 2), and special education services and provisions (*n* = 5) were measured.	

Figure 6. *Change outcomes*

Description	Result
Measurement instruments The following measurement instruments were found: • VABS (*n* = 1), WAI (*n* = 1) and ARS (*n* = 1). These were coded as 'Assessments'. • Informal interviews held with caregivers (*n* = 4). These were coded as 'Caregiver reports' • Informal interviews held with educators (*n* = 3), LSAC educator interview (*n* = 1), and questionnaire administered to school administration (*n* = 1). These were coded as 'Educator reports' • NAPLAN (*n* = 1), State-wide MAP (*n* = 1), and school records (*n* = 1). These were coded as 'School records'.	 Figure 7. *Measurement instruments*

3.3 Longitudinal research considerations

The results are now presented in terms of answering sub-aims iii to v, which deal with how well the included studies conformed to the requirements of good longitudinal research. Ployhart and Vandenberg (2010) have recommended various theoretical, methodological and analytical considerations for good, quality longitudinal research. Of the 10 included studies, none had all of their longitudinal research considerations.

3.3.1 Theoretical considerations

Sub-aim iii considers how well the included study took into account theoretical considerations. When designing a longitudinal study, albeit descriptive or explanatory, there must be a clear understanding of what variables are expected to undergo a change, and why this change is expected. It is therefore recommended that researchers formulate a theory of change in terms of form (expected trajectory pattern of change), level (expected change at the individual and/or group level), duration (planned duration of study to examine variables of interest and their impact on each other) and predictors (variables expected to impact on change outcome) (Ployhart & Vandenberg, 2010). The theory of change guides the sampling method used, which measuring instruments would be most suitable, wave management, and which statistical analysis to use (Ployhart & Vandenberg, 2010).

3.3.1.2 Form

The expected form of change can be linear or nonlinear and assists researchers to place measurement points where change is most likely to occur (Ployhart & Vandenberg, 2010), such as a bifurcation point (Bornman & Granlund, 2007). The form of change assists researchers in knowing when a change is expected to occur and therefore can time their measurement points correctly (Ployhart & Vandenberg, 2010). Very few studies (n = 2) (Guralnick et al., 2008; Hurwitz et al., 2020) hypothesised their form of change. Of these two studies, Guralnick and colleagues (2008) expected a linear change and Hurwitz and colleagues (2020) expected a nonlinear change (i.e. their predicted change would not follow a straight line growth pattern). This implies that there may be breaks in change and varying rates of change over time.

3.3.1.2 Level

The level of change can measure either group mean change, which sees all individuals in the group as having the same form of change over time, whereas *interunit* differences in

intraunit forms of change measure whether each participant changes over time relative to each other rather than the group (Ployhart & Vandenberg, 2010). Specifying the level of change has implications for the type of statistical analysis that is undertaken. Group mean change requires repeated measuring of analysis of variance (ANOVA). Testing *interunit* differences in *intraunit* change requires statistical analysis with respect to random coefficient modelling (RCM) or latent growth curve modelling (LGM) (Ployhart & Vandenberg, 2010).

Half of the studies had a level of change hypothesis. Most studies (n = 9) measured group level of change, except the study by Hurwitz and colleagues (2020) which measured change at the individual level.

3.3.1.3 Duration

Duration within a theory of change considers how long a dynamic relationship is expected to exist between the independent (X), mediator (M), and dependent (Y) variables. This determines the most appropriate amount of waves as well as the time lag between waves to capture change (Ployhart & Vandenberg, 2010).

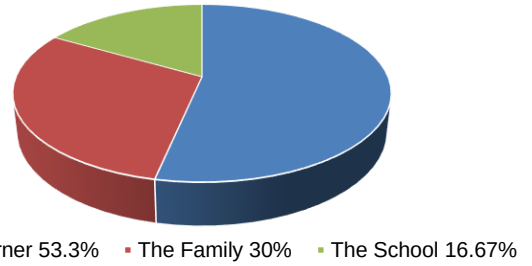
As seen in Table 5, the range of the length of studies was from two years six months to 10 years. Only two studies (Guralnick et al., 2008; Lundqvist et al., 2015) specified their theory of change in terms of duration of change. They used theory from previous research regarding transition stages to signify when they expected change in inclusion status (change outcome) to occur.

3.3.1.4 Predictors

Predictors are the variables present that are hypothesised to facilitate the change in some way. While time can be a variable, there are other variables that have the potential to influence a change in the outcome variable (Ployhart & Vandenberg, 2010).

Most studies (n = 7) had more than one hypothesised predictor. Two studies (Barnard-Brak & Lechtenberger, 2010; Hurwitz et al., 2020) had only one hypothesised predictor, and one study (Lundqvist et al., 2015) did not specify their predictors. Table 8 and Figure 8 represent a summary of predictor variables reported on from the nine studies that had predictors.

Table 8
Predictor variables

Description	Result
A total of 30 different predictor variables were accumulated from the included studies. The following predictors were prevalent in the included studies: • 'The Learner'. This included variables pertaining to learner demographics, intrinsic factors and education participation skills. • 'The Family'. This included variables pertaining to SES, mother-child interaction, parental involvement, and immigrant status. • 'The School'. This included variables pertaining to school type, level, and environment.	 Figure 8. *Predictors*

As shown in table 8, most hypothesised predictors (53.3%) were focused on the learner and included the learners' demographics, intrinsic factors and education participation skills (social and adaptive functioning skills, cognitive skills, and behaviour). The least hypothesised predictors were focused on the school (16.67%) and included the school type (partial or fully inclusive school setting), school level (government or private sector) and the school environment.

3.3.2 Methodological considerations

Sub-aim iv considered how well the included studies considered methodological and design considerations. This includes the frequency and timing of measurement points, planning for attrition, and measurement validity (Ployhart & Vandenberg, 2010). The implications of this sub-aim are that longitudinal studies should be designed in a way that will allow the detection and modelling of the hypothesised form and predictors of change (Ployhart & Vandenberg, 2010). These should be guided by the aforementioned underlying theory or hypothesis that is being tested.

3.3.2.1 Frequency of measurement waves

Having at least three waves is the minimum recommended amount of measurement waves for longitudinal research (Ployhart & Vandenberg, 2010) and was an inclusion criteria for this study (as seen in Table 3). As previously mentioned (Table 5), the number of total waves ranged from three to six. Most studies (n = 5) had three waves (Ball et al., 2018; Barnard-Brak & Lechtenberger, 2010; Guralnick et al., 2008; Kelly, 2009, 2011), two studies had four

waves (Goldfeld et al., 2015; Hibel & Jasper, 2012), and two studies had five waves (Heyman & Hauser-Cram, 2019; Lundqvist et al., 2015). One study had six waves (Hurwitz et al., 2020).

Two of the studies (Guralnick et al., 2008; Lundqvist et al., 2015) determined the amount of the waves according to their hypothesis. Of the two that did, Guralnick and colleagues (2008) measured annually according to the academic transitions of learners, and Lundqvist and colleagues (2015) used a similar rationale but linked it to previous literature as well.

3.3.2.2 Timing

Careful planning of when to measure the outcome of interest is needed to ensure change is not missed (Ployhart & Vandenberg, 2010). All of the included studies had set time points, with only Guralnick and colleagues (2008) and Lundqvist and colleagues (2015) who aligned their time points according to theory. Most studies (Goldfeld et al., 2015; Guralnick et al., 2008; Hibel & Jasper, 2012; Kelly, 2009, 2011; Lundqvist et al., 2015) measured annually, and Ball and colleagues (2018) as well as Hurwitz and colleagues (2020) measured every six months for the duration of their studies. One study (Heyman & Hauser-Cram, 2019) had time points according to age groups (ages 3, 5, 8, 10 and 15 years) but did not specify why these ages were chosen and did not specify the timing of waves.

3.3.2.3 Sampling

Purposive sampling is recommended for longitudinal research so as to ensure the theory of change is relevant for the chosen sample. All included studies used purposive sampling. Eight of the studies were secondary analyses of existing data sets and therefore the authors did not conceptualise the way in which data was collected. These eight studies did not have a sampling rationale other than that they used an existing data set to answer their research aims. Two of the studies (Guralnick et al., 2008; Lundqvist et al., 2015) collected their own data and did not rely on previous data sets. Guralnick and colleagues (2008) however did not specify their sampling rationale, while Lundqvist and colleagues (2015) purposely sampled participants based on SES, geographical location, and pedagogical variation.

3.3.2.4 Planning for attrition

It is expected that a certain amount of attrition (i.e., the loss of participants) will take place in longitudinal research. However, even if there is a loss of numbers, the sample of respondents at the last wave of measurement should be representative of respondents at earlier

measuring points. If a large amount of attrition is expected over the course of the data collection period, researchers should consider the optimal number of participants needed at the last time point and oversample at the first measurement point to accommodate for the expected drop in numbers over time (Ployhart & Vandenberg, 2010). None of the included studies planned for attrition. It is important to reiterate that eight studies did not use their own participants and examined existing data sets and therefore could not plan for attrition. Of the two studies which collected their own data, Barnard-Brak and Lechtenberger (2010) did not specify their optimal sample number at the final wave. Four studies (Hurwitz et al., 2020; Kelly, 2009; Lundqvist et al., 2015) had a decrease in participants from the initial wave, and four studies (Ball et al., 2018; Goldfeld et al., 2015; Heyman & Hauser-Cram, 2019; Hibel & Jasper, 2012) had the same amount of participants from the initial to the final wave. One study (Kelly, 2011) had a fluctuating amount of participants (i.e. *n* at T1 = 80, *n* at T2 = 40, *n* at T3 = 90) and therefore had an 'increase' in the amount of participants from the initial to the final wave.

Four of the studies (Ball et al., 2018; Goldfeld et al., 2015; Guralnick et al., 2008; Hurwitz et al., 2020) did not have complete data sets available and no reason was given as to why. Of these four, only Guralnick and colleagues (2008) compared the data of missing participants to other participants with full data sets in the last wave and found differences insignificant. Ball and colleagues (2018) combined all waves to construct a new data set, and Goldfeld and colleagues (2015) and Hurwitz and colleagues (2020) only used complete data sets. Of the remaining six studies, Kelly (2009) had no comments regarding attrition, two studies (Kelly, 2011; Lundqvist et al., 2015) had attrition as participants naturally aged out or did not fit the study's parameters anymore, and three studies (Barnard-Brak & Lechtenberger, 2010; Heyman & Hauser-Cram, 2019; Hibel & Jasper, 2012) used some form of imputation analysis to control for missingness. Analysis used to control for missingness was full-information maximum likelihood (FIML) (Barnard-Brak & Lechtenberger, 2010) and pooling of results (Heyman & Hauser-Cram, 2019; Hibel & Jasper, 2012).

3.3.2.5 Measurement validity

Measurement validity is concerned with whether researchers check if the same construct is being measured with the same set of measures at each time point (Ployhart & Vandenberg, 2010). Rather than real change occurring, it could be that the change may have resulted from a change in interpretation of the construct in the minds of raters, i.e., participants or observers. When measures at different time points represent different constructs, this is referred to as

beta change and can represent a threat to internal validity (Golembiewski et al., 1976). None of the included studies checked for measurement validity.

3.3.3 Analytical considerations

The final sub-aim of the review determined what analytic methods the included studies used to document change in participation in education-related activities.

The analytical methods are determined by the theoretical and methodological considerations. Put simply, growth linear modelling (GLM) is recommended for when the level of change is group mean change, and attrition is low (Ployhart & Vandenberg, 2010). When the level of change focused on individual differences in change over time, then random coefficient modelling (RCM) is recommended as various variables can be analysed within the model (including time). The reasoning for the analytical method used should be clearly seen (Ployhart & Vandenberg, 2010).

3.3.3.1 Analytical methods used

Ployhart and Vandenberg (2010) advocate that researchers should explain their reasons for using a particular analytical method to change. Additionally, they advise that the strengths and weaknesses of the analytic method chosen should be documented as well. Seven of the studies (Ball et al., 2018; Barnard-Brak & Lechtenberger, 2010; Guralnick et al., 2008; Heyman & Hauser-Cram, 2019; Hurwitz et al., 2020; Kelly, 2009, 2011) gave reasons for their chosen analytical method. RCM was the most common (n = 6) analytical method used (Ball et al., 2018; Heyman & Hauser-Cram, 2019; Hibel & Jasper, 2012; Hurwitz et al., 2020; Kelly, 2009, 2011). Other analytical methods used were: latent class analysis (Barnard-Brak & Lechtenberger, 2010; Goldfeld et al., 2015; Guralnick et al., 2008), only frequencies and percentages using ANOVA software (Lundqvist et al., 2015), descriptive analysis (Kelly, 2009) Chi-square analysis and a Schiff test (Guralnick et al., 2008).

The different types of ways the included studies depicted their change outcomes were in tables, graphs, and figures. All studies made use of tables, while four (Ball et al., 2018; Goldfeld et al., 2015; Hibel & Jasper, 2012; Hurwitz et al., 2020) also included graphs, and three (Barnard-Brak & Lechtenberger, 2010; Guralnick et al., 2008; Lundqvist et al., 2015) used figures.

3.3.4 Synthesising participation in education findings

It should be noted that the aim of this review was not to evaluate the actual outcomes of what is currently known about longitudinal participation of children and youth with disabilities in education-related activities or settings. However, some brief discussion about study findings is warranted as these may need to be re-evaluated in light of many of the included studies not meeting Ployhart and Vandenberg's (2010) standards of quality longitudinal research.

3.3.4.1 Activities (capability and performance) trajectories

School-based adaptive functioning in children with developmental delays appears to positively change over time at individualised rates, and this is associated with mother-child interaction. Heyman and Hauser-Cram (2019) hypothesised that children and youth gain perseverance and self-determination skills during nurturing interactions with their caregivers, and this affects how they participate in other settings such as school. Murphy and Carbone (2008) reported similar findings by noting that low self-esteem can affect participation. Intrinsic factors of children and youth with disabilities therefore play an important role in participation (Murphy & Carbone, 2008).

Another intrinsic factor to consider is the age and grade of children and youth with disabilities to appreciate the impact natural development has on functional skills (Coster et al., 2013). By considering these intrinsic factors, researchers can plan the most effective time of when to introduce an intervention practice that would cause a positive change (Bornman & Granlund, 2007). Goldfeld and colleagues (2015) saw a strong association between overall academic achievement and achieved foundational skills, such as emergent literacy and numeracy skills in early educational years. The implications of this are that children and youth with disabilities require early intervention at a younger age to ensure future academic success. Results from Hurwitz and colleagues (2020) add to this discussion as their participants developed academic skills at individualised and varying rates.

Academic skills were inclusive of the subjects of Mathematics, Literacy, English, Arts and Social Studies (Ball et al., 2018; Heyman & Hauser-Cram, 2019). Merely having an IEP may not necessarily play a vital role in academic achievement across time (Ball et al., 2018); however, actively participating in one’s IEP has been associated with academic achievement over time as well as improved self-determination skills (Barnard-Brak & Lechtenberger, 2010). This further reiterates Ladd and Dinella's (2009) point that only attending school is not

good enough as learners are required to engage with the curriculum to reap the most academic benefits.

3.3.4.2 Participation (attendance) trajectories

Children and youth with disabilities were found to have improved in academic skills after attending special educational services (Hurwitz et al., 2020). Children and youth in need of special education services require varying levels of support as they progress through school, meaning their need for supports may change. There appears to be a trend whereby learners requiring low support provisions attend partially inclusive schooling, whereas learners requiring high support provisions may begin their education in segregated schooling systems and remain in that type of placement over their education life span (Lundqvist et al., 2015). However, as support provisions for children and youth with disabilities can be costly (Murphy & Carbone, 2008), information regarding how children and youth with disabilities with high support needs attend schools in LMIC is still needed. In fact, even in the USA, Kelly (2009) and Kelly (2011) found that less than half of visually impaired learners had access to AT (for example, braille readers) to assist them with access to the curriculum.

Contextual factors therefore play a vital role in how children and youth with disabilities participate in educational settings (Coster et al., 2013; Murphy & Carbone, 2008). Guralnick and colleagues (2008) highlighted additional contextual factors for consideration, such as language. They found that language (together with cognition levels) was an important factor considered when placing learners in special education services. Similarly, the study by Hibel and Jasper (2012) found that learners with learning disabilities who did not speak or understand English very well (due to language barriers and not necessarily a language disability) were delayed in being referred to special education services. As mentioned previously, early intervention and attending special education services allow for a greater chance of academic achievement (Goldfeld et al., 2015; Hurwitz et al., 2020).

3.3.4.3 Engagement (or involvement) in education

None of the included studies measured engagement by children and youth with disabilities in education over time. The construct of engagement is the complex Participation construct defined as the experience of an event, and is therefore more difficult to measure accurately (Granlund, 2013). Aspects such as motivation, persistence, affect, social connection, activity competence, sense of self, and personal preferences has been associated with the engagement

construct (Adair et al., 2018; Imms, Adair, et al., 2016). Although Heyman and Hauser-Cram (2019) used self-determination skills of their participants as a predictor for academic achievement, it was not a participation outcome. Therefore, none of the included studies aimed to measure these aspects relative to educational outcomes.

As engagement is a qualitative (Granlund, 2013) and subjective (Coster & Khetani, 2008), data should then be collected from the children and youth with disabilities themselves and not from proxies, such as teachers and caregivers. All the included studies used proxies to gather information on the targeted outcomes. Of the ones that used proxies as well as directly testing their participants, the testing instruments did not measure engagement.

4. DISCUSSION

A total of 10 studies met the inclusion criteria of this systematic review. The analysis of the participants' characteristics showed more males were recruited than females, and there were more children under the age of 13 in the samples. Foundational skills are important (Goldfeld et al., 2015), and may be the reason why the included studies tended to research a younger age cohort. However, while the included studies do give a view of how children with disabilities participate in education-related activities, less is known about how youth with disabilities, i.e., those over the age of 13 years, participate in education-related activities and settings and indicates a gap in the literature.

The majority of the total participants in the included studies were diagnosed with learning disabilities. This can be quite a heterogeneous group as there may be co-morbidities causing a learning disability (Mâsse et al., 2012). This can cause confusion with conceptualising variables across different studies. It was also noted that while there was a small percentage of children and youth with communication disabilities (2,82%) included in the total amount of participants, no mention of AAC for academic participation was reported. An online search through the *Augmentative and Alternative Communication Journal* also did not yield any studies that met the inclusion criteria. AAC can assist an individual with complex communication needs to participate more effectively in education-related activities (Beukelman & Mirenda, 2013) and is considered a contextual factor influencing participation in the ICF (Raghavendra et al., 2007). Future research should aim to address this gap.

The outcome measuring instruments used to measure activity performance and participation were mostly reports from the educators of learners. These studies then used mainly proxy ratings for data collection or tested children's and youth' academic achievement. None of the included studies used self-rated ratings by children and youth with disabilities themselves of their own participation. For the complex experience of engagement to be measured, children and youth with disabilities must be the main respondents (Coster & Khetani, 2008) as there can be a discrepancy of rating between proxies (educators, caregivers) and self-raters (children and youth) (Claes et al., 2012).

That being said, it is appropriate that educators were used as proxies since the inclusion criteria for this study was for change outcomes to occur in education-related activities. However, school records were the least used measuring instrument (n = 3) and this may be the actual performance (at least in academics) of children and youth with disabilities.

The construct of attendance under the Participation domain was the most common construct measured. This could be due to the fact that frequency calculations are generally

easier to complete than the more complex engagement construct of participation (Granlund, 2013). This indicates a potential gap in the literature.

None of the included studies had all the longitudinal research considerations as recommended by Ployhart & Vandenberg, 2010). Also, none had planned for attrition or checked for longitudinal invariance. It must be mentioned that eight of the included studies used existing data sets and therefore did not conceptualise their study, which made it difficult to align their studies to the theoretical, methodological and analytical considerations. Nevertheless, besides planned attrition and checking longitudinal validity, all included studies had at least one of the longitudinal considerations. While this is a positive for literature, it shows the need for improvement in quality longitudinal research in the field of educational participation for children and youth with disabilities.

Even though the conclusions drawn from included studies show positive growth in learners' academic achievement over time, the majority of these studies failed to adequately address the theoretical and methodological issues of longitudinal research. Their results should therefore be interpreted with caution as the exact point of where the change occurred could not be ascertained. It has been reported that rate of change is specific to the individual (Heyman & Hauser-Cram, 2019) and is affected by the interplay of intrinsic factors and environmental factors (WHO, 2007). Longitudinal research in children and youth with disabilities in education-related activities should therefore consider these factors so as to draw accurate conclusions regarding their participation in education over time.

5. CONCLUSIONS AND RECOMMENDATIONS

None of the included studies had all the theoretical, methodological and analytical considerations. This is congruent with a report by Caruana and colleagues (2015) as longitudinal studies are more difficult to design and implement. However, longitudinal research is needed to see the changes in activities and participation (Smits et al., 2014), as predictors that affect these outcomes may change over time (Holsbeeke et al., 2009). These considerations are needed for accurate conclusions to be drawn from studies to guide future practice (Ployhart & Vandenberg, 2010).

Good, quality longitudinal research is needed to understand the participation trajectories of children and youth with disabilities in educational settings (Ladd & Dinella, 2009), as well as how children and youth who use AAC in education-related activities participate over time (Granlund et al., 2008). There is also a gap in the literature regarding how children and youth with disabilities from LMICs participate in school over time.

A strength of this systematic review is the rigorous methodological processes followed as stipulated by the Centre for Reviews and Dissemination (2009). The study's objectives, eligibility criteria and process of study selection are clearly stated. Study selection was also done via two independent reviewers so as to ensure reliability.

Certain limitations of this review should also be noted. This study was limited to studies only published in English, which may have resulted in a language bias (Schlosser et al., 2007). The full texts of three articles were not available via the University of Pretoria's library and it is not clear whether these articles may have altered the results. This review did not use a quality assessment tool as recommended for systematic reviews (Schlosser et al., 2007). However, as the aim was to evaluate the state of the art of longitudinal research in children and youth with disabilities in education-related activities, the analysis gives insight as to the quality of the included studies in terms of their theoretical, methodological and analytical considerations as recommended by Ployhart and Vandenberg (2010). A quality assessment tool for longitudinal research is therefore needed.

REFERENCES

Adair, B., Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs : a systematic review. *Developmental Medicine and Child Neurology*, 1–16. https://doi.org/10.1111/dmcn.13959

Alsayedhassan, B., Banda, D. R., & Griffin-Shirley, N. (2016). A Review of Picture Exchange Communication Interventions Implemented by Parents and Practitioners. *Child and Family Behavior Therapy*, *38*(3), 191–208. https://doi.org/10.1080/07317107.2016.1203135

Anaby, D., Avery, L., Gorter, J. W., Turner, L., Levin, M. F., Teplicky, R., Cormier, I., & Hanes, J. (2019). Improving body functions through participation in community activities among young people with physical disabilities. *Developmental Medicine and Child Neurology*, 1–7. https://doi.org/10.1111/dmcn.14382

Badley, E. M. (2008). Enhancing the conceptual clarity of the activity and participation components of the International Classification of Functioning, Disability, and Health. *Social Science and Medicine*, *66*, 2335–2345. https://doi.org/10.1016/j.socscimed.2008.01.026

Ball, A., Rittner, B., Chen, Y.-L., & Maguin, E. (2018). Impact of individualized education plans on academic success of youth with early onset schizophrenia. *Journal of Evidence-Informed Social Work*, *15*(5), 534–549. http://10.0.4.56/23761407.2018.1487356

Barnard-Brak, L., & Lechtenberger, D. (2010). Student IEP Participation and Academic Achievement across Time. *Remedial and Special Education*, *31*(5), 343–349. http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ897719&site=ehost-live&scope=site

Batorowicz, B., Mcdougall, S., & Shepherd, T. A. (2006). AAC and community partnerships: The participation path to community inclusion. *Augmentative and Alternative Communication*, *22*(3), 178–195. https://doi.org/10.1080/07434610500468498

Beukelman, D. R., & Mirenda, P. (2013). Beukelman & Mirenda 2013.pdf. In *Augmentative and Alternative Communication. Supporting Children and Adults with Complex Communication* (pp. 3–15). Paul H. Brookes.

Bines, H., & Lei, P. (2011). Disability and education: The longest road to inclusion. *International Journal of Educational Development*, *31*(5), 419–424. https://doi.org/10.1016/j.ijedudev.2011.04.009

Bornman, J., & Granlund, M. (2007). Facilitating change in early childhood intervention by using principles from systems theory: An interventionist's perspective. *SA Journal of Occupational Therapy*, *37*(3), 4–7. http://137.215.9.22/handle/2263/6235

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101. http://www.ncbi.nlm.nih.gov/pubmed/11752478

Caruana, E. J., Roman, M., Hernández-Sánchez, J., & Solli, P. (2015). Longitudinal studies. *Journal of Thoracic Disease*, *7*(11), E537–E540. https://doi.org/10.3978/j.issn.2072-1439.2015.10.63

Centre for Reviews and Dissemination. (2009). *Systematic Reviews: CRD's guidance for undertaking reviews in health care*. Centre for Reviews and Dissemination.

Claes, C., Vandevelde, S., Hove, G. Van, Loon, J. Van, Verschelden, G., & Schalock, R. (2012). Relationship between Self-Report and Proxy Ratings on Assessed Personal Quality of Life-Related Outcomes. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(3), 159–165.

Clark, P., & MacArthur, J. (2008). Children with physical disability: Gaps in service provision, problems joining in. *Journal of Paediatrics and Child Health*, *44*(7–8), 455–458. https://doi.org/10.1111/j.1440-1754.2008.01327.x

Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation*, *30*(8), 639–648. https://doi.org/10.1080/09638280701400375

Coster, W., Law, M., Bedell, G., Liljenquist, K., Kao, Y.-C., Khetani, M., & Teplicky, R. (2013). School participation, supports and barriers of students with and without disabilities. *Child: Care, Health and Development*, *39*(4), 535–543. https://doi.org/10.1111/cch.12046

Egilson, T. S., & Traustadottir, R. (2009). Participation of Students With Physical Disabilities in the School Environment. *American Journal of Occupational Therapy*, *63*(3), 264–272. https://search-proquest-com.proxy.cityu.edu/docview/231968980/fulltextPDF/C580F521C3314320PQ/1?accountid=1230

Eriksson, L., Welander, J., & Granlund, M. (2007). Participation in everyday school activities for children with and without disabilities. *Journal of Developmental and Physical Disabilities*, *19*(5), 485–502. https://doi.org/10.1007/s10882-007-9065-5

Ganz, J. B., Morin, K. L., Foster, M. J., Vannest, K. J., Genç Tosun, D., Gregori, E. V., & Gerow, S. L. (2017). High-technology augmentative and alternative communication for

individuals with intellectual and developmental disabilities and complex communication needs: a meta-analysis. *AAC: Augmentative and Alternative Communication*, *33*(4), 224–238. https://doi.org/10.1080/07434618.2017.1373855

Goldfeld, S., O'Connor, M., Quach, J., Tarasuik, J., & Kvalsvig, A. (2015). Learning trajectories of children with special health care needs across the severity spectrum. *Academic Pediatrics*, *15*(2), 177–184. https://doi.org/10.1016/j.acap.2014.09.001

Golembiewski, R. T., Billingsley, K., & Yeager, S. (1976). Measuring change and persistence in human affairs: types of change generated by OD designs. *Journal of Applied Behavioral Science*, *12*, 133–157. https://doi.org/10.1177/002188637601200201

Granlund, M. (2013). Participation- challenges in conceptualization, measurement and intervention. *Child: Care, Health and Development*, *39*(4), 470–473. https://doi.org/10.1111/cch.12080

Granlund, M., Arvidsson, P., Niia, A., Björck-Åkesson, E., Simeonsson, R., Maxwell, G., Adolfsson, M., Eriksson-Augustine, L., & Pless, M. (2012). Differentiating activity and participation of children and youth with disability in Sweden: A third qualifier in the International Classification of Functioning, Disability, and Health for Children and youth? *American Journal of Physical Medicine and Rehabilitation*, *91*(2 (Suppl)), S84–S96. https://doi.org/10.1097/PHM.0b013e31823d5376

Granlund, M., Björck-Åkesson, E., Wilder, J., & Ylvén, R. (2008). AAC interventions for children in a family environment: Implementing evidence in practice. *AAC: Augmentative and Alternative Communication*, *24*(3), 207–219. https://doi.org/10.1080/08990220802387935

Guralnick, M. J., Neville, B., Hammond, M. A., & Connor, R. T. (2008). Continuity and Change From Full-Inclusion Early Childhood Programs Through the Early Elementary Period. *Journal of Earl*, *30*(3), 237–250.

Harrison, H., Griffin, S. J., Kuhn, I., & Usher-smith, J. A. (2020). Software tools to support title and abstract screening for systematic reviews in healthcare : an evaluation. *BMC Medical Research Methodology*, *20*(7), 1–12.

Heyman, M., & Hauser-Cram, P. (2019). The influence of the family environment on adaptive functioning in the classroom: A longitudinal study of children with developmental disabilities. *Research in Developmental Disabilities*, *86*(January), 20–30. https://doi.org/10.1016/j.ridd.2019.01.001

Hibel, J., & Jasper, A. D. (2012). Delayed Special Education Placement for Learning Disabilities Among Children of Immigrants. *Social Forces*, *91*(2), 1–27.

http://10.0.4.69/sf/sos092

Holsbeeke, L, Ketelaar, M., Schoemaker, M. M., & Gorter, J. W. (2009). Capacity , Capability , and Performance : Different Constructs or Three of a Kind ? *Arch Phys Med Rehabil*, *90*, 849–855. https://doi.org/10.1016/j.apmr.2008.11.015

Holsbeeke, Laura, Ketelaar, M., Schoemaker, M. M., & Gorter, J. W. (2009). Capacity, Capability, and Performance: Different Constructs or Three of a Kind? *Archives of Physical Medicine and Rehabilitation*, *90*, 849–855. https://doi.org/10.1016/j.apmr.2008.11.015

Hunt-Berg, M. (2005). The Bridge School: Educational inclusion outcomes over 15 years. *AAC: Augmentative and Alternative Communication*, *21*(2), 116–131. https://doi.org/10.1080/07434610500103509

Hurwitz, S., Perry, B., Cohen, E. D., & Skiba, R. (2020). Special Education and Individualized Academic Growth: A Longitudinal Assessment of Outcomes for Students With Disabilities. *American Educational Research Journal*, *57*(2), 576–611. https://doi.org/10.3102/0002831219857054

Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016). ‘ Participation ’: a systematic review of language , definitions , and constructs used in intervention research with children with disabilities. *Developmental Medicine and Child Neurology*, *58*, 29–38. https://doi.org/10.1111/dmcn.12932

Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2016). Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine and Child Neurology*, 1–10. https://doi.org/10.1111/dmcn.13237

Kelly, S. M. (2009). Use of assistive technology by students with visual impairments: Findings from a national survey. *Journal of Visual Impairment and Blindness*, *103*(8), 470–480. https://doi.org/10.1177/0145482x0910300805

Kelly, S. M. (2011). The Use of Assistive Technology by High School Students with Visual Impairments: A Second Look at the Current Problem. *Journal of Visual Impairment & Blindness*, *105*(4), 235–239. http://10.0.4.153/0145482X1110500405

King, M., Romski, M. A., & Sevcik, R. A. (2020). Growing up with AAC in the digital age: a longitudinal profile of communication across contexts from toddler to teen. *AAC: Augmentative and Alternative Communication*, *36*(2), 128–141. https://doi.org/10.1080/07434618.2020.1782988

Klang, N., Rowland, C., Fried-Oken, M., Steiner, S., Granlund, M., & Adolfsson, M. (2016).

The content of goals in individual educational programs for students with complex communication needs. *AAC: Augmentative and Alternative Communication*, *32*(1), 41–48. https://doi.org/10.3109/07434618.2015.1134654

Koppenhaver, D. A., & Yoder, D. E. (1993). Classroom literacy instruction for children with severe speech and physical impairments (SSPI): What is and what might be. *Topics in Language Disorders*, *1*, 1–15.

Kurth, J., & Mastergeorge, A. M. (2010). Individual education plan goals and services for adolescents with autism: Impact of age and educational setting. In *Journal of Special Education* (Vol. 44, Issue 3). https://doi.org/10.1177/0022466908329825

Ladd, G. W., & Dinella, L. M. (2009). Continuity and Change in Early School Engagement: Predictive of Children's Achievement Trajectories From First to Eighth Grade? *Journal of Educational Psychology*, *101*(1), 190–206. https://doi.org/10.1037/a0013153

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., Clarke, M., Devereaux, P. J., Kleijnen, J., & Moher, D. (2009). The PRISMA Statement for Reporting Systematic Reviews and Meta-Analyses of Studies That Evaluate Health Care Interventions : Explanation and Elaboration. *PLoS Medicine*, *6*(7), 1–28. https://doi.org/10.1371/journal.pmed.1000100

Light, J., Mcnaughton, D., Beukelman, D., Fager, S. K., Fried-oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative communication : Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication*, *35*(1), 1–12. https://doi.org/10.1080/07434618.2018.1556732

Light, J., & Smith, A. K. (1993). Home literacy experiences of preschoolers who use AAC systems and of their nondisabled peers. *Augmentative and Alternative Communication*, *9*(1), 10–25. https://doi.org/10.1080/07434619312331276371

Lundqvist, J., Mara, A. W., & Siljehag, E. (2015). Inclusive Education, Support Provisions and Early Childhood Educational Pathways in the Context of Sweden: A Longitudinal Study. *International Journal of Special Education*, *30*(3), 3–16. http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1094947&site=ehost-live&scope=site

Mâsse, L. C., Miller, A. R., Shen, J., Schiariti, V., & Roxborough, L. (2012). Comparing participation in activities among children with disabilities. *Research in Developmental Disabilities*, *33*, 2245–2254. https://doi.org/10.1016/j.ridd.2012.07.002

McConachie, H., Colver, A. F., Forsyth, R. J., Jarvis, S. N., & Parkinson, K. N. (2006).

Participation of disabled children: How should it be characterised and measured? *Disability and Rehabilitation*, *28*(18), 1157–1164. https://doi.org/10.1080/09638280500534507

Mcdougall, J., Bedell, G., & Wright, V. (2013). The youth report version of the Child and Adolescent Scale of Participation (CASP): Assessment of psychometric properties and comparison with parent report. *Child: Care, Health and Development*, *39*(4), 512–522. https://doi.org/10.1111/cch.12050

Mcnaughton, D., & Bryen, D. N. (2007). AAC technologies to enhance participation and access to meaningful societal roles for adolescents and adults with developmental disabilities who require AAC. *Augmentative and Alternative Communication*, *23*(3), 217–229. https://doi.org/10.1080/07434610701573856

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, T. P. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, *6*(7), 1–6. https://doi.org/10.1371/journal.pmed.1000097

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P., Stewart, L. A., & Group, P. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, *4*(1), 1–9. http://www.systematicreviewsjournal.com/content/4/1/1

Murphy, N. A., & Carbone, P. S. (2008). Promoting the participation of children with disabilities in sports, recreation, and physical activities. *American Academy of Pediatrics*, *121*(5), 1057–1061. https://doi.org/10.1542/peds.2008-0566

Ployhart, R. E., & Vandenberg, R. J. (2010). Longitudinal Research : The Theory , Design , and Analysis of Change. *Journal of Management*, *36*(1), 94–120. https://doi.org/10.1177/0149206309352110

Ployhart, R. E., & Ward, A. K. (2011). The "Quick Start Guide" for Conducting and Publishing Longitudinal Research. *Journal of Business and Psychology*, *26*(4), 413–422. https://doi.org/10.1007/s10869-011-9209-6

Pufpaff, L. A. (2008). Barriers to participation in kindergarten literacy instruction for a student with augmentative and alternative communication needs. *Psychology in the Schools*, *45*(7), 582–599. https://doi.org/10.1002/pits

Raghavendra, P., Bornman, J., Granlund, M., & Björck-Äkesson, E. (2007). The World Health Organization's International Classiffication of Functioning, Disability and Health: Implications for clinical and research practice in the field of augmentative and alternative communication. *AAC: Augmentative and Alternative Communication*, *23*(4),

349–361. https://doi.org/10.1080/07434610701650928

Raghavendra, P., Olsson, C., Sampson, J., Mcinerney, R., & Connell, T. (2012). School participation and social networks of children with complex communication needs, physical disabilities, and typically developing peers. *Augmentative and Alternative Communication*, *28*(1), 33–43. https://doi.org/10.3109/07434618.2011.653604

Raghavendra, P., Olsson, C., Sampson, J., McInerney, R., & Connell, T. (2012). School participation and social networks of children with complex communication needs, physical disabilities, and typically developing peers. *AAC: Augmentative and Alternative Communication*, *28*(1), 33–43. https://doi.org/10.3109/07434618.2011.653604

Schlebusch, L., Huus, K., Samuels, A., Granlund, M., & Dada, S. (2020). *Participation of young people with disabilities and/or chronic conditions in low- and middle-income countries: a scoping review*. https://doi.org/https://connect.up.ac.za/https/doi-org.uplib.idm.oclc.org/10.1111/dmcn.14609

Schlosser, R. W., & Raghavendra, P. (2004). Evidence-Based Practice in Augmentative and Alternative Communication. *AAC: Augmentative and Alternative Communication*, *20*(1), 1–21. https://doi.org/10.1080/07434610310001621083

Schlosser, R. W., Wendt, O., & Sigafoos, J. (2007). Not all systematic reviews are created equal: Considerations for appraisal. *Evidence-Based Communication Assessment and Intervention*, *1*(3), 138–150. https://doi.org/10.1080/17489530701560831

Siddaway, A. P., Wood, A. M., & Hedges, L. V. (2019). How to Do a Systematic Review : A Best Practice Guide for Conducting and Reporting Narrative Reviews , Meta-Syntheses. *Annual Review of Psychology*, *70*, 747–770.

Simeonsson, R. J., Carlson, D., Huntington, G. S., McMillen, J. S., & Brent, J. L. (2001). Students with disabilities: A national survey of participation in school activities. *Disability and Rehabilitation*, *23*(2), 49–63. https://doi.org/10.1080/096382801750058134

Smits, D., Gorter, J. W., van Schie, P. E., Dallmeijer, A. J., & Ketelaar, M. (2014). How Do Changes in Motor Capacity , Motor Capability , and Motor Performance Relate in Children and Adolescents With Cerebral Palsy ? *Archives of Physical Medicine and Rehabilitation*, *95*, 1577–1584. https://doi.org/10.1016/j.apmr.2014.04.013

Thomas-stonell, N., Robertson, B., Oddson, B., & Rosenbaum, P. (2015). Communicative participation changes in pre-school children receiving augmentative and alternative communication intervention. *International Journal of Speech-Language Pathology*, *July*, 1–9. https://doi.org/10.3109/17549507.2015.1060530

Trudeau, N., Cleave, P. L., & Woelk, E. J. (2003). Using augmentative and alternative communication approaches to promote participation of preschoolers during book reading : a pilot study. *Child Language Teaching and Therapy*, 181–210.

Wang, X., & Cheng, Z. (2020). Cross-Sectional Studies: Strengths, Weaknesses, and Recommendations. *Chest*, *158*(1), S65–S71. https://doi.org/10.1016/j.chest.2020.03.012

Whiteneck, G., & Dijkers, M. P. (2009). Difficult to Measure Constructs: Conceptual and Methodological Issues Concerning Participation and Environmental Factors. *Archives of Physical Medicine and Rehabilitation*, *90*(SUPPL. 1), S22–S35. https://doi.org/10.1016/j.apmr.2009.06.009

World Health Organization. (2001). The International Classification of Disability, Functioning, and Health: ICF. In *International Classification of Functioning, Disability and Health: Children and Youth Version ICF-CY*. https://doi.org/10.1017/CBO9781107415324.004

World Health Organization. (2007). *The International Classification of Functioning, Disability and Health-Child and Youth: ICF-CY*. World Health Organization.

Appendix A
Ethical Clearance

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100
Since 1919

2 November 2020

Dear Miss M Parker

Project Title:	A systematic review of the theory, design, and analysis of longitudinal research on participation in education related activities for children and youth with disabilities
Researcher:	Miss M Parker
Supervisor(s):	Dr AE Samuels
Department:	CAAC
Reference number:	20751207 (HUM026/1020)
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 29 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.z
a

Appendix B

Search term refinement

Date of Search	Resource Used (database, search engine)	Years Searched	Strategies used	Limiters	Yield	Notes/recommendations/irrelevance
01-02-2021	ERIC via EBSCO Host	2005-2021	"Disab*" OR "Disorder*" OR "special needs" OR "developmental delay" OR "augmentative and alternative communication" OR "AAC" OR "communication" AND "Longitudinal" OR "interval" OR "multi wave" OR "life span" OR "prospective" OR "over time" OR "follow up" OR "change" OR "ICF" AND "Participat*" OR "involvement" OR "engagement" OR "performance" OR "experience" AND "Education" OR "educational activities" OR "pupil*" OR "school*" OR "individualized education plan" OR "IEP" OR "class" OR "curriculum" OR "student" OR "learner"	English, peer reviewed, full text	5023	Include subject narrowing: student participation, learner engagement, disabilities, longitudinal studies, intervention,
01-02-2021	ERIC via EBSCO Host	2005-2021	"Disab*" OR "Disorder*" OR "special needs" OR "developmental delay" OR "augmentative and alternative communication" OR "AAC" OR "communication" AND "Longitudinal" OR "interval" OR "multi wave" OR "life span" OR "prospective" OR "over time" OR "follow up" OR "change" OR "ICF" AND "Participat*" OR "involvement" OR "engagement" OR "performance" OR "experience" AND "Education" OR "educational activities" OR "pupil*" OR "school*" OR "individualized education plan" OR "IEP" OR "class" OR "curriculum" OR "student" OR "learner"	English, peer reviewed, full text	1745	Add ICF with participation search concept. Add: parenthesis and 'experience'
01-02-2021	ERIC via Proquest	2005-2021	("Disab*" OR "Disorder*" OR "special needs" OR "developmental delay" OR "augmentative and alternative communication" OR "AAC" OR "communication") AND ("Longitudinal" OR "interval" OR "multi wave" OR "life span" OR "prospective" OR "over time" OR "follow up" OR "change") AND ("Participat*" OR "involvement" OR "engagement" OR "performance" OR "experience" OR "ICF") AND ("Education" OR "educational activities" OR "pupil*" OR "school*" OR "individualized education plan" OR	English, peer reviewed, full text	3839	Include subject narrowing: intervention, disabilities, student participation, longitudinal studies, learner engagement. Add document type: Journal articles

			"IEP" OR "class" OR "curriculum" OR "student" OR "learner")			
01-02-2021	ERIC via Proquest	2005-2021	("Disab*" OR "Disorder*" OR "special needs" OR "developmental delay" OR "augmentative and alternative communication" OR "AAC" OR "communication") AND ("Longitudinal" OR "interval" OR "multi wave" OR "life span" OR "prospective" OR "over time" OR "follow up" OR "change") AND ("Participat*" OR "involvement" OR "engagement" OR "performance" OR "experience" OR "ICF") AND ("Education" OR "educational activities" OR "pupil*" OR "school*" OR "individualized education plan" OR "IEP" OR "class" OR "curriculum" OR "student" OR "learner")	English, peer reviewed, full text	161	Remove subject narrowing as not all articles index their relevant subjects
02-02-2021	ERIC via EBSCO Host	2005-2021	("Disab*" OR "Disorder*" OR "special needs" OR "developmental delay" OR "augmentative and alternative communication" OR "AAC" OR "communication") AND ("Longitudinal" OR "interval" OR "multi wave" OR "life span" OR "prospective" OR "over time" OR "follow up" OR "change" OR "ICF") AND ("Participat*" OR "involvement" OR "engagement" OR "performance" OR "experience") AND ("Education" OR "educational activities" OR "pupil*" OR "school*" OR "individualized education plan" OR "IEP" OR "class" OR "curriculum" OR "student" OR "learner")	English, peer reviewed, full text	3973	Do not limit to full text as title and abstract screens will take place first, then exclude those that are not available at full text. Use subject headings as search terms such as: Intervention, Longitudinal studies, Student attitudes, Learner engagement, Student participation, Communication skills, Educational environment, Learning disabilities
02-02-2021	ERIC via EBSCO Host	2005-2021	("Disab*" OR "Disorder*" OR "special needs" OR "developmental delay" OR "augmentative and alternative communication" OR "AAC" OR "communication" OR "communication skills" OR "learning disab*) AND ("Longitudinal" OR "longitudinal stud*" OR "interval" OR "multi wave" OR "life span" OR "prospective" OR "over time" OR "follow up" OR "change" OR "ICF") AND ("Participat*" OR "student participation" OR	English, peer reviewed, full text	95493	Do not limit to full text. Remove: subject headings, experience, multi wave, interval, performance, experience, educational activities, pupil, class, curriculum, learner, student. Add: impairment, special, longitudinal studies, longitudinal research, cohort, learning, teaching, classroom, education system,

			"intervention" OR "student attitudes" OR "learner engagement" OR "involvement" OR "engagement" OR "performance" OR "experience") AND ("Education" OR "educational activities" OR "educational environment" OR "pupil*" OR "school*" OR "individualized education plan" OR "IEP" OR "class" OR "curriculum" OR "student" OR "learner")			individualized education program (based off database thesaurus)
03-02-2021	CINAHL via EBSCO Host	2005-2021	(disability or disabilities or disabled or impairment or impaired or special or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge or discharge planning or patient discharge) AND participation or engagement or involvement AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan)	Age limiters: 0-18 years, English, peer reviewed	541	Remove: special. Add: capabilit*, inclusion, ICF-CY, learner, longitudinal method. Replicate search in another database
03-02-2021	Academic search complete via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability or performance) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement)	Scholarly (Peer Reviewed) Journals, English	14667	

03-02-2021	CINAHL via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability or performance) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement)	Scholarly (Peer Reviewed) Journals, English, age limiters: 0-18 years	3506	Remove: 'learner engagement', 'student engagement', 'performance', 'longitudinal method' Databases yielding any articles with 'learner' in it, and not necessarily with 'engagement'. 'Performance' is being linked to business articles.
03-02-2021	CINAHL via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan)	Peer reviewed, English, age limiters: 0-18 years	602	Add: learner engagement, student engagement
03-02-2021	CINAHL via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement)	Peer reviewed, English, age limiters: 0-18 years	604	Note: performance was linked to other subjects, longitudinal method was being picked up as method only

03-02-2021	ERIC via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement)	Peer reviewed, English	1948	Add: children or adolescents or youth or child or teenager
03-02-2021	ERIC via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement) AND (children or adolescents or youth or child or teenager)	Peer reviewed, English	913	Replicate in another database
03-02-2021	APA PsychArticles via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan)	Peer reviewed, English	29	Replicate in another database

			OR (learner engagement or student engagement) AND (children or adolescents or youth or child or teenager)			
03-02-2021	APA PsychInfo via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement) AND (children or adolescents or youth or child or teenager)	Peer reviewed, English	1602	Replicate in another database
03-02-2021	Academic search complete via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up NOT (discharge planning or discharge process or discharge management) AND (participation or engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement) AND (children or adolescents or youth or child or teenager)	Peer reviewed, English	2409	Continued to yield articles with 'discharge' even though it is a NOT. Remove: ‘Discharge’
03-02-2021	Academic search complete via EBSCO Host	2005-2021	(disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research) OR (longitudinal or prospective or cohort) OR (over time or change) OR life span OR follow up AND (participation or	Peer reviewed, English	2286	Note: yields single words, like “system”. For the next search in all databases: Add: school participation, curriculum, activity performance, learner participation, classroom participation. Use ADJ1 or ADJ2. Add in age search terms to be

			engagement or involvement) OR icf-cy OR inclusion OR (capability) AND (education or school or learning or teaching or classroom or education system) OR (iep or individualized education program or individualized education plan) OR (learner engagement or student engagement) AND (children or adolescents or youth or child or teenager)			consistent in all databases. Remove: IEP-children not participating in creating IEP. Reason: adding in more education participation related terms to note relevancy of articles
07-03-2021	ERIC via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR life span OR (over time or change) OR follow up AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager	Peer reviewed, English, Academic Journals	512	Note: ERIC holds 'ERIC documents' which are education policies, therefore 'academic journals' was chosen as a limiter
07-03-2021	Academic search complete via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR life span OR (over time or change) OR follow up AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager	Peer reviewed, English, Academic Journals	1605	Replicate in another database

07-03-2021	APA PsychInfo via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR life span OR (over time or change) OR follow up AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager	Peer reviewed, English, age limiters: 0-18 years	23	Replicate in another database
07-03-2021	APA PsychArticles via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR life span OR (over time or change) OR follow up AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager	Peer reviewed, English, age limiters: 0-18 years	758	Replicate in another database
07-03-2021	CINAHL via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR life span OR (over time or change) OR follow up AND (education or school or	Peer reviewed, English, age limiters: 0-18 years	420	Age limiter changed to 0-20 years, as children with special needs stays longer in the education system than typically developing children

			learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager			
14-04-2021	Academic Search Complete via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR life span OR (over time or change) OR follow up AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager	Peer reviewed, English, no age limiter	1681	Add in non-Mesh terminology for population as medical conditions may not be covered by the term disab* (librarian consultation via email). Discussion with co-reviewer lead to: Add intellectual disab*, developmental disab*, childhood disab*, young adult, pediatric, paediatric,
14-04-2021	Academic Search Complete via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND intellectual disab* OR developmental disab* OR childhood disab* OR (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND interval or (longitudinal studies or longitudinal research or longitudinal method) OR (longitudinal or prospective or cohort) OR life span OR (over time or change) OR follow up AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager or young adult or pediatric or paediatric	Peer reviewed, English, no age limiter	28	Only use 'interval' and 'longitudinal' for study design criteria

14-04-2021	Academic Search Complete via EBSCO Host	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND intellectual disab* OR developmental disab* OR childhood disab* OR (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND interval or longitudinal AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager or young adult or pediatric or paediatric	Peer reviewed, English, no age limiter	67	Replicate in another database
14-04-2021	APA PsychArticles	2005-2021	(participation or engagement or involvement) OR icf-cy OR inclusion ADJ2 classroom OR capability OR activity performance AND intellectual disab* OR developmental disab* OR childhood disab* OR (disabilities or disability or disabled or impairment or impaired or special needs) OR (augmentative and alternative communication or aac) AND interval or longitudinal AND (education or school or learning or teaching or classroom or education system) OR (learner engagement or student engagement) OR school ADJ1 participation OR curriculum OR classroom ADJ1 participation OR learner ADJ1 participation AND children or adolescents or youth or child or teenager or young adult or pediatric or paediatric		2	Too small a yield. Remove ADJ1 and ADJ2

Appendix C

Pilot Screening Tool

Article number	Article title	Inclusion Criteria	Yes	No	Needs a third opinion
		Children (0-18 years at wave 1) with disabilities AND/OR children (0-18 years at wave 1) who uses AAC			
		Longitudinal research design with 3 measurement points			
		Study measures change in participation (involvement, engagement, activity performance) in educational settings.			
		Published between 2005 and 2020			
		Published in English			
		Published as full text			
		Full text is obtainable through the University of Pretoria's library or freely accessible			

Appendix D

Data extraction form

Variable and Key		Reporting objectives
General information	○ Author/s ○ Year published ○ Title ○ Location	To determine the trend of number of publications since the implementation of the ICF-CY and to note any geographical tendencies
Methodology	○ Study design ○ Duration of study ○ Number of waves ○ Age at wave ○ Gender ○ Total participants	To determine the frequencies of types of study designs and the average amount of waves
Participants' characteristics	○ Diagnosis ○ AAC user ○ Role in data collection ○ Total at each wave	To determine a trend in certain age groups, gender groups, and diagnosis groups, as well as the frequency in which children are primary sources for data collection. To determine the frequency where caregivers and/or Teachers comment on intrinsic aspects of participation
Change outcome of interest in context/subject/activity	○ Attendance ○ Capability/capacity ○ Activity performance ○ Engagement ○ Involvement ○ Participation	To determine frequency of change in participation observed in studies
Theoretical considerations	○ Theory of change ○ Form of change ○ Level of change ○ At least 3 waves	To determine how researchers hypothesizes a theory of change in participation in terms of form, level, and duration, and how did they consider measurement waves, timing, sampling, attrition, and measurement validity
Methodological considerations	○ Description of timing of waves ○ Description based off theory of change ○ Sampling method ○ Attrition preparation	
Analytical considerations	○ Growth model used ○ Reason for growth model ○ Reason for chosen statistical analysis	
Results and conclusions		

Appendix E

Declaration by Language editor

TO WHOM IT MAY CONCERN

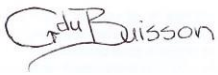
DECLARATION: TEXT EDITING

Herewith I, the undersigned, declare that I have edited the following document (excluding appendices and reference list) regarding language, spelling and punctuation:

Mini-dissertation:

A systematic review of the theory, design, and analysis of longitudinal research on participation in education related activities for children and youth with disabilities

by Malikah Parker



Gertruida du Buisson

APEd (SATI), APTrans (SATI)*

Member of South African Translators' Institute (SATI) – National and Free State/Northern Cape Chapter Member number: 1002232

*Accredited Professional Text Editor (SATI), Accredited Professional Translator (SATI)