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The state of the art of the theory, design and analysis of longitudinal research on activity performance or participation in home and community environments of children and youth with disabilities: A systematic review

by

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ABSTRACT

The current knowledge about how children with disabilities (including those who use AAC) participate over time within home and community settings such as recreation, leisure and sporting activities is based predominantly on cross-sectional data or on studies that are limited to two measuring points and not longitudinal research that follows children over time. It is rather complex to determine causal relationships from cross-sectional studies. Furthermore, the limitations of narrow measures of participation are that they do not tell us how participation can change across important points in the lifespan of these populations. More longitudinal studies are therefore needed to examine the participation trajectories over time, although it is not yet clear to what extent longitudinal research on participation has been conducted with children with disabilities. It is also not known how well those that do undertake longitudinal research are based on the latest quality guidelines of what this type of research should consider in terms of the theory, design and analysis of longitudinal participation research. The aim of this systematic review was therefore to explore the state of the art of longitudinal research on activity performance or participation in home and community environments for children and youth with disabilities in terms of the best known theoretical, methodological and analytical guidelines available for this type of design. Twenty-two studies were identified that fulfilled the inclusion criteria. The studies were described with regard to the participants, type of design, duration of the study, country in which the study took place, the change outcome of interest, the measurement instruments used, and the child role in data collection. Furthermore, the studies were described in relation to (i) how well these longitudinal studies hypothesise a theory of change in terms of form, level, duration or predictors to guide their research (ii) how well these longitudinal studies take into account methodological and design considerations (measurement waves, timing and observations, sampling, attrition and measurement validity) when examining change in participation in home and community activities, and (iii) what analytic methods these studies use to document change. Attention is drawn to the gaps in the literature in terms of how studies are conducting longitudinal research. The importance of precision and insight to theories is discussed, as is the need for longitudinal research in LAMI countries and in the field of AAC.

Keywords: AAC, disabilities, home and community, ICF, longitudinal research, participation.

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LIST OF ABBREVIATIONS

AAC	Augmentative and alternative communication
ASD	Autism spectrum disorder
CAPE	Children’s Assessment of Participation and Enjoyment
CCN	Complex communication needs
CP	Cerebral palsy
DCD	Developmental coordination disorder
FIML	Full information maximum likelihood
GLM	General linear modeling
GMFCS	Gross Motor Function Classification System
HIC	High income countries
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health, Child and Youth version
LGM	Latent growth curve modeling
LMIC	Low- and middle-income countries
MACS	Manual Ability Classification System
PEDI	Pediatric Evaluation of Disability Inventory
PIMD	Profound intellectual and multiple disabilities
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
TD	Typically developing
UP	University of Pretoria
VABS	Vineland Adaptive Behavior Scales

1. PROBLEM STATEMENT AND LITERATURE REVIEW

1.1 Problem statement

The World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) and the children and youth version (ICF-CY) (WHO, 2007) which were integrated in subsequent years, is a useful classification framework to describe information related to a child's performance in activities and participation. Children and youth with disability, including individuals with complex communication needs (CCN) who rely on augmentative and alternative communication (AAC), experience change in their activity performance and participation patterns over the course of their lives (Engel-Yeger et al., 2009; Jarus et al., 2010; King et al., 2009). It is important to consider how this change has been measured in longitudinal studies.

One of the areas that requires more focus is to understand the extent of longitudinal research of the participation and activity performance of children and youth with disabilities within the home environment and the community. Imms and colleagues (2016) identified five themes which they describe as components of a 'family of participation constructs'. The authors identified two themes to describe the concept of participation, these being attendance (related to the concept of 'being there') and involvement (the 'in-the-moment' happening of participation). The concept of activity can be divided into three constructs, namely capacity (what the individual can do in a controlled environment), capability (what the individual can do in their daily environment) and performance (what the individual actually does in their daily environment) (Holsbeeke et al., 2009).

The reason for this focus is that the current knowledge about how children with disabilities (including those who use AAC) participate over time within home (such as self-care and mobility) and community settings (such as recreation, leisure and sporting activities) is based predominantly on cross-sectional data or on studies that are limited to two measuring points. Law et al. (2006) conducted a study on the participation patterns of children with complex physical disabilities in recreational and leisure activities. This was part of a longitudinal study that was performed in Canada and which focused on the participation of school-aged children with physical disabilities. The Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2004) was utilised to test participation. The CAPE was conducted in two phases but only one measurement was taken from which conclusions were drawn related to participation in leisure and recreational activities for this population. The limitations of narrow measures of participation are that they do not tell us how participation can change across important points in the lifespan of these populations. In another example, a longitudinal study was done by Smits et al. (2014) that explored the relations between changes in motor capacity, capability and performance among children with cerebral palsy (CP) over two-year intervals. This study only included two measuring points, i.e. baseline measurements were taken, and data was used from measurements at the two-year follow up. The authors concluded that their hypotheses, which proposed that a child's age together with the degree or severity of their CP contributes moderately to change, were confirmed, and consequently, change-related conclusions were drawn from only taking two measurements.

To determine causal relationships from cross-sectional studies is rather complex and following up of individuals over time is not possible (Wang & Cheng, 2020). Longitudinal outcomes can therefore be significantly over- or underestimated when cross-sectional approaches to longitudinal intervention are applied, and as a result, provide inaccurate conclusions (Maxwell & Cole, 2007). Moreover, the focus is too often on measuring specific developmental gains, with insufficient focus on participation of children in daily activities over time. Another issue identified is that studies which claim to measure participation do not always do so, since the outcome measure used does not consistently evaluate the construct of participation (Adair et al., 2015). A disconnection exists between the language of participation and the outcome measures utilised in research (Imms et al., 2016).

The increased pace and often different patterns of change in children with long-term health conditions or impairments (Law, 2002) therefore necessitates the assessment of change over time in terms of their functioning in activities and participation in everyday life. There are indicators that few longitudinal studies exist of everyday functioning in activity performance or participation in children and youth with disabilities. Most studies prior to the introduction of the

ICF/ICF-CY have tended to focus on body functions and developmental skills rather than functioning or participation in everyday life. More longitudinal studies are therefore needed to examine the participation trajectories over time, although it is not yet clear to what extent longitudinal research on participation has been conducted with children with disabilities. It is also not known how well those that do undertake longitudinal research are based on the latest quality guidelines of what this type of research should consider in terms of the theory (e.g. does the theory illustrate the form of change and account for the reasons why the change takes place?), design (e.g. does the study design enable detection and modelling of the hypothesised forms and predictors related to change?) and analysis (e.g. does the study describe the coding of time and was the best statistical method applied to answer the question?) of longitudinal participation research (Ployhart & Vandenberg, 2010).

According to Ployhart and Vandenburg (2010), one of these quality indicators relates to the number of measuring points. Measurements taken only at two points, for example, do not provide sufficient data for identifying the shape of change, i.e. is the functional form of the relationship constant or does it fluctuate over time? Two measurements are also not enough to measure the amount or shape of change that takes place (Rogosa, 1988, 1995). When studies do measure more than two measuring points, they may not always be conducting longitudinal research in terms of some of the latest criteria encapsulating what constitutes good longitudinal theory, design and analysis of change over time. It is therefore imperative to determine (i) how well these longitudinal studies hypothesise a theory of change in terms of form, level, duration or predictors to guide their research, (ii) how well these longitudinal studies take into account methodological and design considerations (measurement waves, timing and observations, sampling, attrition and measurement validity) when examining change in participation in home and community activities, and (iii) what analytic methods these studies use to document such change. Obtaining this information will assist in improving our knowledge to ensure that we construct better formulated theories that take temporal issues related to participation in home and community activities into consideration. This is of particular importance when addressing the activity limitations and participation constraints or barriers that many children and youth with disabilities encounter.

A systematic review will therefore be undertaken to assess the extent of longitudinal research of activity performance or participation in home and community activities for children and youth with disabilities, and to evaluate this research in line with best practice principles of what constitutes good longitudinal research as provided by Ployhart and Vandenberg (2010).

1.2 Literature review

1.2.1 ICF-CY framework

The WHO's International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) has become a universal framework for documenting disability. The ICF-CY (WHO, 2007) originated from the ICF and provides a framework specifically focusing on limitations of functioning experienced by children, and assists in identifying environmental factors that play a contributing role (Adolfsson et al., 2011). In this multidimensional framework, disability is considered the result of a person's interaction with their environment, and the documentation of such interaction can be used as the foundation for planning intervention to enhance an individual's skill, performance and participation (Simeonsson, 2009). The concept of participation as an outcome has consequently received increased interest since the establishment of the ICF, as participation is an important aspect for all humans and plays a contributing role to quality of life (Law, 2002). The ICF-CY describes participation as "involvement in a life situation" (ICF, 2001, p.10). The ICF and ICF-CY further describe two qualifiers for activities and participation, namely performance (what an individual does in their specific environment) and capacity (the ability of an individual to execute a particular task or action) (WHO, 2001).

1.2.2 Participation as defined and participation in everyday activities

The WHO clearly indicates that one of the primary goals of the ICF-CY is to enhance children's participation in day-to-day life. The constructs of 'activity' and 'participation' are, however, not clearly separated or distinguished in the ICF-CY (Granlund, 2013). Therefore, Granlund and others (2012) suggest that a third qualifier 'subjective experience of involvement' may be needed to enable such a division between activity and participation. There is also not yet a definition of participation that has been universally accepted and, as a result, concerns have been raised as to the reliability of measures used to assess participation outcomes. There appears to be a discrepancy between the language used and the applied measures (Imms et al., 2016). A study conducted by Imms et al. (2016) revealed that the language that studies and research use to describe ‘participation’ is inconsistent, as some studies would use the word ‘engagement’, or use these two words interchangeably. Imms et al. (2017) suggested that participation be defined in terms of two elements, namely attendance (relates to being in the life situation) and involvement (relates to the experience of participation while being there). This correlates with the ICF’s description of participation, being “involvement in a life situation”. Participation has been depicted as a multidimensional construct or a family of constructs (Coster et al., 2012; Granlund, 2013; King, 2013).

Participation in everyday activities can be distinguished between formal and informal everyday activities (Law, 2002). Structured activities that follow set regulations implemented by an appointed coach or leader are regarded as formal activities. Examples of these types of activities include music lessons and organised sports such as soccer. Activities that individuals begin on their own and which do not require much organisation, such as reading or playing, are regarded as informal activities. The CAPE (King et al., 2004) is a self-reporting measure that is often used to assess children’s participation in leisure and recreational activities and thus does not include activities within the school environment. Activities are divided into five types (i.e. recreational, active physical, social, skill-based, and self-improvement activities) (King et al., 2006). Recreational activities (such as playing with objects, doing crafts), active physical activities (such as doing team sports or racing), social activities (such as going to the movies or someone’s house), skill-based activities (such as learning to dance, playing a musical instrument) and self-improvement activities (such as visiting the library, reading) are good examples as to what would be considered activities in the home and community when we look at participation in these settings (King et al., 2006).

A standardised assessment that is also commonly used to assess functional abilities (such as self-care and mobility) is the Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al., 1992). Self-care is vital in every aspect of life, as competent self-care skills allow individuals to participate in a variety of activities in the home and the community (Burgess et al., 2019). Determining an individual’s functional ability provides valuable information related to how much the individual is able to engage and participate in his or her daily life (Tatla et al., 2017). Additionally, the Vineland Adaptive Behavior Scale (VABS) (Sparrow et al., 1984) survey is frequently used to measure a child's performance within four domains, including mobility performance and performance of daily activities.

1.2.3 Impact of disability on children's participation in home and community activities

Numerous benefits of participation in everyday activities for children with and without disabilities have been identified in research. Participating in community activities plays a significant role in the quality of life of children with disabilities and also assists in strengthening certain skills (Batorowicz et al., 2006). The evidence base related to the field of disability and participation is growing and there is now an extensive body of literature available (e.g. Adair et al., 2018; Anaby et al., 2017; Anaby, Avery, et al., 2020; Anaby, Vrotsou, et al., 2020; Axelsson et al., 2013; Hoehne et al., 2020), as well as research available in the South African context (Dada et al., 2020a; Dada et al., 2020b; Samuels et al., 2020). More research is consequently available to inform us of the variety of activities in which children with disabilities participate, their preferences and how much of this participation takes place in the home environment or the community.

Environmental factors often have a significant impact on the individual's ability to participate in the tasks of everyday life. The ICF views disability as "a multidimensional phenomenon resulting from the interaction between people and their physical and social environment" (WHO, 2001). Bronfenbrenner's bio-ecological system theory also highlights the importance of viewing the child within systems and focusing on the interactions between the individual and their systems/context, which consequently influences participation. In a study by Law et al. (1999), parents of children with disabilities indicated that barriers in the environment restricted participation, which further emphasised the child's disability. These parents identified attitudinal and institutional barriers as the most prominent barriers influencing their children's participation in everyday activities (including community activities, play, school and leisure), with social attitudes being the biggest handicap.

Children and youth with CCN who require the use of AAC are often faced with many barriers that limit their participation in home and community activities. Beukelman and Mirenda (2013) stated that the quintessential objective of AAC is to ensure that individuals with CCN can engage in a variety of interactions and participate in activities that they are able to choose themselves. Participating in home and community activities is often a challenge for these children, as many of them require additional support from others to be able to communicate effectively and participate in recreation, leisure and sporting activities (Batorowicz et al., 2006). Additionally, limitations in functioning in daily life increase with the severity of the disability and consequently, the ability to perform tasks such as self-care decreases (Burgess et al., 2019; Østensjø et al., 2003). Raghavendra et al. (2011) indicated, however, that the biggest handicap for children with disabilities (in particular children with CCN) appears to be in the social context of participation. The authors also indicate that the tendency exists that children with disabilities are more likely to participate in activities within their or another family member's home environment or within their immediate neighbourhood than in their community.

1.2.4 Children's participation in home and community activities over time

Imms et al. (2017) suggested that the changes in participation over time, including the variation in participation among people or settings, may be due to a combination of the following factors: developing aspects of the individual; the context or surrounding in which the individual participates in activities, as well as the type of activities; and the environment in which the individual lives. The authors believe that conceptualising change in relation to involvement could potentially be more of a challenge than conceptualising the change observed in attendance.

Axelsson and Wilder (2014) compared the frequency of, and a child's presence in, family activities for children with profound intellectual and multiple disabilities (PIMD) and typically developing children (TD). The results indicated a variation in the presence of the children when the two groups were compared, as TD children were present more often in the activities. It was also found that the occurrence of most of the family activities was lower in families that included a child with PIMD. In both groups, total family income played a role in the frequency of family activities occurring. Orlin et al. (2009) suggested that age impacts the participation of children with CP in home and community activities. The diversity and intensity of overall participation was found to be much higher for children than youth with CP. Age-related preferences may contribute to the higher participation seen in recreational activities by children. A study done by Shields et al. (2015) revealed that children with disabilities participated less frequently in active-physical and skill-based activities in comparison to other types of activities. The authors also found that personal factors such as preference played a considerable role in the participation of these children, even more than the impact of environmental factors.

The information available in relation to predictors of change over time in terms of the participation of children with physical disabilities in activities of leisure and recreation remains limited (King et al., 2009). King and others (2009) found variabilities in predictors when boys were compared with girls and when older children were compared with younger children. Notable predictors of change were, however, only for recreational and active physical activities. The type of activity, as well as the gender and age of the children, influences the factors related to the change in participation intensity. A significant decline was seen in the rate of participation in the following activities: recreational, active physical and social activities. A decline was, however, not seen in activities that were skill-based or related to self-improvement. Simpson et al. (2019) also found a decline in physical activity in a three-year study undertaken in relation to participation of children with autism spectrum disorder (ASD) in their home, school and the community. This study highlighted the change that was seen over time in the types of socialising activities in which these children participated.

Grace et al. (2019) described the process of measuring the participation experiences of children who use AAC as complex. A key factor to consider when analysing the frequency of participation and involvement of children with CCN, such as those who use AAC, is the crucial part that communication partners play in the participation of these children in activities in their home and community environment, as AAC users must have partners to communicate. These children therefore require a community that is able and willing to communicate with them and consequently support their participation in society (Huer & Threats, 2016). Providing opportunities for children who use AAC to participate in home activities allows these children to improve their communicative competence, which assists in shaping social networks with peers and consequently increases participation in the community (Raghavendra et al., 2011).

Research has shown that children with physical disabilities and children with CCN participate in a range of activities, albeit with lower frequency and reduced intensity in comparison to children with TD (Raghavendra et al., 2011; Thirumanickam et al., 2011). Research findings further indicate that children with physical disabilities and CCN have a reduced number of partners and engage in activities in restricted settings (Thirumanickam et al., 2011). Tan et al. (2016) studied factors related to the development of social participation over time in children with CP and found that children with CP also suffering from epilepsy and speech impediments are at a higher risk for limited social participation. However, children with CP but without intellectual impairment showed an increase in the extent of social participation with age.

The need exists for more extensive longitudinal research to determine how children with disabilities, including those who use AAC, participate over time (Grace et al., 2019) in home and community environments, as well as more research to support their participation in a variety of situations (Light et al., 2019; Light & McNaughton, 2015).

1.2.5 Longitudinal research and best practice guidelines

There has been an increased interest and desire for longitudinal research to build and test theories within particular fields. However, cross-sectional designs are still used in many fields for the testing of theories in the organisational and applied social sciences (Ployhart & Vandenberg, 2010). Similarly, much of the literature reviewed on participation is based mainly on cross-sectional studies that examine data from different age cohorts at a single point in time, or measure participation of individual children or groups of children with less than three measuring points. It is challenging to determine causal relationships in these type of studies as the outcome variables and the exposure variables are taken at the same time (Wang & Cheng, 2020). Additionally, predictors of activity performance or participation (such as determinants of self-care and mobility activities) are also predominantly based on cross-sectional studies over broad age ranges (Kruijsen-Terpstra et al., 2015).

Maxwell and Cole (2007) illustrated in their review that estimates of longitudinal mediation parameters will be biased if cross-sectional approaches are used to assess mediation. The authors believe that the continuous use of cross-sectional designs within a field may be the result of inadequate knowledge about the consequences that these designs may have when analysing mediation. Alternatively it is suggested that the shortage of longitudinal research may be the result of inadequate knowledge or uncertainty about how it should be done, as well as insufficient guidance to conquer the variety of challenges that accompany this type of research (Perks & Roberts, 2013; Ployhart & Vandenberg, 2010; Ployhart & Ward, 2011). Incorporating standardized checklists to assess the quality of a particular study can assist the researcher in reducing bias as a result of various variables within the study design. The Critical Appraisal Skills Programme (CASP) is a useful tool which can assist researchers to adapt a systematic approach to identify the strengths and weaknesses of a longitudinal research design (Singh, 2013). Similarly, the STARD (Standards for Reporting of Diagnostic Accuracy Studies) can also be used as a checklist to ensure that a report or study includes all the essential information which ultimately increases the transparency of a study (Cohen et al., 2016). Checklists or guidelines do not only assist in determining whether a particular study has been conducted in agreement with best practice principles but also provides the opportunity to distinguish between studies that are of high or low quality (Spencer et al., 2003).

Cross-sectional studies seldomly account for the change seen in a variable over time. Differences have also been found between the strength and the direction of the relationship between variables when comparing findings from a longitudinal study to data from a cross-sectional study (Kher & Serva, 2014). Rogosa et al. (1982, p. 744) stated that “Two waves are better than one, but maybe not much better.” This indicates that two observations are insufficient for identifying the amount of change over time. Longitudinal research is defined as research that focuses on studying change and consisting of no less than three repeated observations on a minimum of one variable (Ployhart & Vandenberg, 2010; Singer & Willet, 2003). Aside from the lack of guidance and the many analytic challenges that need to be overcome, taking measurements on multiple occasions over time does not necessarily guarantee that there will be change in the focal variables (Ployhart & Vandenberg, 2010). Ployhart and Vandenberg (2010) developed guidelines to address these theoretical, methodological and analytical issues in longitudinal quantitative designs. These can be used as a framework to evaluate the quality of longitudinal research on participation and activity performance.

1.2.6 Issues regarding change in longitudinal studies and guidelines to address these

Theoretical issues and guidance

Whetten (1989) identified four elements that are crucial to develop a sound theory. These include recognising the constructs of the theory, understanding the manner in which they are related and the reason therefore, as well as to whom they apply, and finally, to know where and when they are applicable. Pitariu and Ployhart (2010) suggested that researchers can develop stronger hypotheses when the theory includes dynamic relationships and thus explicitly incorporates the elements of time, duration and shape in detailing the relationships among the variables. "Time" refers to when the constructs are expected to change, "duration" refers to the expected length of the dynamic relationship between the variables, and "shape" relates to the functional form of the relationship over time, for example, linear or curvilinear (Pitariu & Ployhart, 2010). "Predictors" describe different sources of variations, such as overall average change or interunit differences in intraunit change (Ployhart & Vandenberg, 2010).

According to Ployhart and Vandenberg (2010), identifying the essence of the relationships between independent, dependent, and/or mediating variables (which might be either static or dynamic) presents a significant task when developing a theory of change. The way time is considered theoretically rather than methodologically presents a challenge in longitudinal research and theory in that an emphasis is often placed on the role of time in determining, predicting or causing change, rather than focusing on the variables and predictors that may cause such change, albeit it over time.

Furthermore, theoretical issues include conceptualising the functional form of change (i.e. hypothesising whether the change will be linear or nonlinear and in doing so, determining what the potential variables are that may impact the growth or change pattern), and detailing the level of change to be examined (i.e. whether there will be a focus on group mean change, where all members of the group experience the same form of change over time, vs intraunit change, which permits the form of change to vary between individual units) (Ployhart & Vandenberg, 2010).

It is therefore of utmost importance that before commencing with data collection, researchers need to have some theory about how the variables or constructs to be measured are expected to change, to provide reasons for this change, and also to clarify the nature of the dynamic relationships over time when formulating a theory of change (Ployhart & Vandenberg, 2010). It is consequently advised that researchers include the elements of time, duration and shape to ensure an accurate description of the dynamic relationships (Pitariu & Ployhart, 2010). Researchers therefore need to be as precise as possible and make sure that change is conceptualised adequately. Clearly setting out the change process assists in identifying the variables that need to be measured, as well as the timing of these measures. The number of repeated measurement observations that are required will depend on the functional form of change (Ployhart & Vandenberg, 2010).

Methodological issues and guidance

Some of the most prominent methodological issues include determining the frequency and timing of the repeated measures, confronting attrition and anticipating issues with measurements (Ployhart & Vandenberg, 2010). The number and spacing of measurements requires special attention to ensure that the inferences from the data obtained are valid. Keeping true to the purpose of longitudinal data, researchers should aim to choose samples with a high possibility of change taking place and avoid convenience samples. Furthermore, researchers need to account for attrition before the study takes place and include planned missingness approaches in the outline (Graham et al., 1996; Ployhart & Vandenberg, 2010).

Analytical issues and guidance

Issues include the challenges related to longitudinal data and coding time. Researchers must especially be cautious about violating statistical assumptions such as nonindependence and correlated residuals (Ployhart & Vandenberg, 2010). Researchers need to identify how they code time and also include their reasons. Clearly defining the reason for choosing a specific analytical method is needed, and it is necessary to include the strengths and weaknesses of such a method. To assist with evaluating the form of change, it is recommended to document all the related effect sizes and fit indices (Ployhart & Vandenberg, 2010). A better understanding of these issues will assist researchers in improving the conceptualisation, design and analysis of longitudinal research (Ployhart & Vandenberg, 2010).

2. METHODOLOGY

2.1 Aims

2.1.1 *Main aim*

The main aim of this systematic review is to explore the state of the art of longitudinal research on activity performance or participation in home and community environments for children and youth with disabilities in terms of the best known theoretical, methodological and analytical guidelines available for this type of design.

2.1.2 *Sub-aims*

The sub-aims of the review are:

i. To determine the prevalence of longitudinal quantitative research studies measuring the change in activity performance or participation in home and community environments for children and youth with disabilities or impairments 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.
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 home and community activities.
v. To determine what analytic methods these studies use to document change in participation in home and community activities.

2.2 Research design and phases

A systematic review was conducted in this study. The aim of a systematic review is to find all the available research evidence that is related to a specific question or questions. All the available research is then appraised and synthesised in order to answer the review question (Aromataris & Pearson, 2014; Grant & Booth, 2009). The systematic review of international evidence is considered as one component of evidence-based practice (Munn et al., 2018). Similarities exist between the processes used in systematic reviews and scoping reviews. There are, however, distinctive differences between a systematic review and a scoping review. In contrast to focusing on evidence related to a specific question or questions, scoping reviews are used to establish the scope of a body of literature on a specific matter. Scoping reviews are also done for the purpose of clarifying concepts or definitions in the literature, identifying knowledge gaps or to analyse how research has been conducted in a particular field (Munn et al., 2018). The Cochrane handbook states that a systematic review makes use of explicit, systematic methods that are chosen with a view to minimise bias. Consequently, more reliable findings are presented from which conclusions can be derived and decisions can be made (Chandler et al., 2017).

The aim of this systematic review was to find all the available longitudinal research related to the activity performance or participation of children and youth with disabilities in home and community environments and to evaluate this research in line with best practice principles of what constitutes good longitudinal research (Ployhart & Vandenberg, 2010). Most systematic reviews follow similar procedures. Although these processes can be classified into distinct stages, these stages are still interconnected (Newman & Gough, 2020). This systematic review followed the process as illustrated in Figure 1.

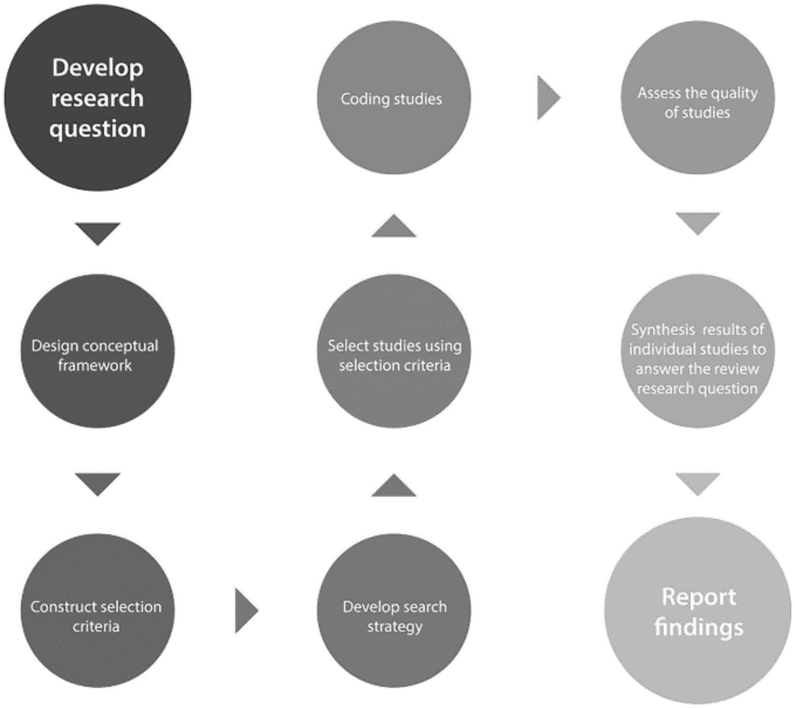


Figure 1. *The systematic review process* (Newman & Gough, 2020).

Table 1

Outline of research stages

Stage	**Description**
1. Develop research question	Specific research questions were formulated that were used to guide the systematic review. Well-formulated questions help to focus a subsequent search (Onady & Raslich, 2003).
2. Design conceptual framework	A protocol was developed before the study commenced.
3. Construct selection criteria	The inclusion and exclusion criteria that was set was shaped by the research question.
4. Develop search strategy	The search strategy was driven by the selection criteria as it indicates the studies to be included in the review. Search terms were identified to use in appropriate databases. Hand searches were also conducted.
5. Select studies using selection criteria	Studies were screened to determine if they met the selection criteria. Two reviewers independently screened on title, abstract and full text level. Any conflicts were discussed between the two reviewers. A third reviewer

Stage	Description
	adjudicated when the reviewers could not reach a general agreement.
6. Coding studies	A data extraction form was developed. Reviewers systematically identified relevant information from the study and recorded this information in the data extraction tool.
7. Assess the quality of studies	Critical appraisal of the methodological quality of the studies included in this review was conducted. Studies were also critically appraised in terms of their relevance to the study.
8. Synthesis of data	This involved collating and summarising the findings of the individual studies included in the systematic review to answer the review questions.
9. Report findings	Results were reported and implications for future research were discussed.

The PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) four-phase flow diagram (Liberati et al., 2009) was used to illustrate the flow of information throughout the various phases of the systematic review (Moher et al., 2009). The PRISMA was developed to make sure that the reporting of systematic reviews is done in a clear and transparent manner (Liberati et al., 2009).

2.3 Ethical considerations

As a systematic review identifies, critically appraises and synthesises research studies, no human participants were included. The proposed study was, however, submitted to the Ethics Committee of the University of Pretoria (UP), after which ethical clearance was granted (Appendix A).

2.3.1 Accuracy

All the steps of the systematic review were clearly documented and transparent to ensure that the study can be replicated or updated in the future (Moher et al., 2010).

2.3.2 Plagiarism

Plagiarism is a result of representing the words or ideas of others as your own. This was avoided by using quotation marks when direct words of others were used and citing all references to other sources (Comstock, 2013).

2.4 Protocol

A detailed protocol was developed before commencement of the study. The use of a protocol is vital for the rigorous execution of a review (Schlosser et al., 2007). This furthermore strengthens the transparency and replicability of the methods used in the review. The inclusion and exclusion criteria were set out in the protocol before the literature search began, which consequently reduced the opportunity for biased selection of studies (Schlesselman & Collins, 2003).

2.5 Pilot search

A pilot search was done to decide if any changes were required to the search terms or to determine if the researcher needed to make changes to the selected criteria in the data extraction form and in doing so, increase the external validity of the review (Long, 2014). Pilot studies that are well designed and conducted advise the researcher about the best research process and are therefore a critical component of a great study design (van Teijlingen & Hundley, 2001). Moreover, pilot studies assist the researcher in determining the feasibility of the study and also in identifying any logistical problems that may arise from using the chosen methods (van Teijlingen & Hundley, 2001). The refinement of search terms can be seen in Appendix B, while Appendix C indicates the yields of each pilot search that was completed.

Table 2 outlines the aims, procedures, findings and recommendations of the pilot search.

Table 2

Pilot study: Aims, Procedures, Findings and Recommendations

Aim	Procedures	Results	Recommendations
1. To determine the appropriateness of the selected search terms (Centre for Reviews and Dissemination, 2009).	Search terms were tested in different databases.	Numerous irrelevant studies were detected during initial searches, such as studies on obsessive-compulsive disorder, mental illness and sleep disorders.	The following search terms were removed: *disorder, “special need”, develop* delay*, “communication disorders”, “multi wave”, “developmental traject*”, “over time”, “follow-up”, “life span”, prospective, “interval”, functioning, “everyday life situations”, capability*, performance The following search terms were added: p*ediatric, “longitudinal stud*, “longitudinal research”, “longitudinal method”, “longitudinal trajectory*” “activity performance”, “home participation”, “community participation”, leisure, recreation*
2. To determine the efficacy of the ‘Title and Abstract Screening Tool’ (Appendix D) during the screening process and if this tool was easy to use.	The suggested tool was used to screen the titles and abstracts of studies that were chosen at random from the pilot search results. This procedure was also done by a colleague with an interest in disability studies and AAC.	During the title and abstract screening stage of the review process, it is not possible to determine if a study is published as a full text in a peer-reviewed journal. It is also not possible at this stage to determine if the full text is available through the university’s library or freely accessible on the web.	Remove: “Is the study published as full text in a peer-reviewed journal?” “Is the full text available through the University of Pretoria's library or freely accessible on the web?”

Aim	Procedures	Results	Recommendations
3. To decide if the inclusion and exclusion criteria were appropriate (Centre for Reviews and Dissemination, 2009).	The inclusion and exclusion criteria were reviewed by a colleague with an interest in disability studies and AAC.	It was not clear what would be defined as a “long term health condition”. The remainder of the inclusion and exclusion criteria were found to be relevant and appropriate to the study.	Change “Long term health conditions” to “Chronic disease (e.g. cancer, diabetes) as primary diagnosis”.
4. To determine if the data extraction form (Appendix E) is appropriate and that the extracted data are relevant to answer the research questions (Long, 2014).	Data were extracted from randomly selected articles and compared with a second reviewer.	Data related to limitations of a study were not particularly relevant to any of the sub-aims of this review. The quality assessment indicators in the data extraction form are not required as this review is essentially an exercise in quality assessment.	Remove: Quality assessment and limitations columns.

2.6 Search Strategy

Published peer-reviewed research studies measuring longitudinal change in children and youth with disabilities were used. Data collection was done through appropriate databases to obtain studies according to the selection criteria. Identifying appropriate databases and compiling the search strategies for the database searches was done in consultation with a subject librarian at UP. Hand searches were also conducted by means of forward and backward citation of included studies (Atkinson et al., 2015). Bramer et al. (2017) recommend that researchers use a combination of databases in systematic reviews, as using more specialised databases assists in retrieving more studies (Stevinson & Lawlor, 2004). Databases that index literature from the fields of health and psychology were therefore searched. The following databases were used to search for eligible studies using Ebscohost: Academic Search Complete, CINAHL, Health Source Nursing and APA psycINFO and MEDLINE. Searches were limited to English, academic and peer-reviewed journals that were issued between 2005 and 2021.

The inclusion and exclusion criteria were based on the ‘Population, Exposure (or Issue), and Outcomes’ (PEO/PIO) elements of the review question. In this review, the population refers to ‘children and youth with disabilities’. The exposure (or issue) relates to ‘longitudinal research on activity performance or participation’ and the outcomes are ‘activity performance or participation in home and community environments’.

The specific search terms that were used in the electronic databases are set out in Table 3 below.

Table 3

Boolean search terms

Criteria	**Search terms**
Disability terminology	disab* “intellectual disab*” “developmental disab*” “childhood disab*” “physical disab” “neurodevelopmental disorder” “motor disorder” AAC “augmentative and alternative communication”
Age terminology	child* youth* adolesc* teen* “young adult*” p*ediatric
Study design terminology	"longitudinal" “longitudinal stud*” “longitudinal research” “longitudinal method*” “longitudinal trajector*”
Outcome terminology	participat* engagement involvement “activity performance” recreation* leisure “home participation” “community participation” ADL

A different number of studies were yielded for each database to be compared against the inclusion and exclusion criteria. Table 4 below indicates the number of yields for each electronic database.

Table 4

Search strategies and yields for databases

Database	**Search strategy**	**Yield**	**Total minus duplicates**
Academic Search Complete (Ebscohost)	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 child* OR youth* OR adolesc* OR teen* OR “young adult*” OR p*ediatric AND "longitudinal" OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*” AND participat* OR engagement OR involvement OR “activity performance” OR recreation* OR leisure OR “home participation” OR “community participation” OR ADL	2814	2762
APA PsychINFO (Ebscohost)	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 child* OR youth* OR adolesc* OR teen* OR “young adult*” OR p*ediatric AND "longitudinal" OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*” AND participat* OR engagement OR involvement OR “activity performance” OR recreation* OR leisure OR “home participation” OR “community participation” OR ADL	1146	546
CINAHL (Ebscohost)	disab* OR “intellectual disab*” OR “developmental disab*” OR	1011	289

Database	Search strategy	Yield	Total minus duplicates
	“childhood disab*” OR “physical disab” OR “neurodevelopmental disorder” OR “motor disorder” OR AAC OR “augmentative and alternative communication” AND child* OR youth* OR adolesc* OR teen* OR “young adult*” OR p*ediatric AND "longitudinal" OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*” AND participat* OR engagement OR involvement OR “activity performance” OR recreation* OR leisure OR “home participation” OR “community participation” OR ADL		
Health Source Nursing (Ebscohost)	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 child* OR youth* OR adolesc* OR teen* OR “young adult*” OR p*ediatric AND "longitudinal" OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*” AND participat* OR engagement OR involvement OR “activity performance” OR recreation* OR leisure OR “home participation” OR “community participation” OR ADL	976	26
MEDLINE (Ebscohost)	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	2255	814

Database	Search strategy	Yield	Total minus duplicates
	child* OR youth* OR adolesc* OR teen* OR “young adult*” OR p*ediatric AND "longitudinal" OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*” AND participat* OR engagement OR involvement OR “activity performance” OR recreation* OR leisure OR “home participation” OR “community participation” OR ADL		

2.7 Inclusion and exclusion criteria

The inclusion and exclusion criteria as presented in Table 5 were used to determine the eligibility of each study. The inclusion and exclusion criteria in this review were set out in respect of the population, phenomena of interest, context, design of the study, date, language, and the publication type.

Table 5

Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Population (P)	Permanent childhood or developmental disability such as motor skills disorder Intellectual disability Communication disorders	Older than 20 years at wave 1 Older than 20 years at wave 3 or final wave Low birth weight and prematurity Population studies At risk populations e.g. children in poverty Chronic disease (e.g. cancer, diabetes) as primary diagnosis
Exposure (E) or Issue (I)	Longitudinal studies with more than two measuring points	Studies with two or less measuring points Cross-sectional research

Criteria	**Inclusion**	**Exclusion**
Outcomes (O)	Participation-based research that measures the frequency of attendance in home or community activities. Research that measures involvement or engagement in home or community activities Research that measures performance in an activity in the home or in the community	Focuses on quality of life Focuses on skills in developmental domains Measures capacity Parental or family outcomes Not in the home or community e.g. school
Study design	Prospective longitudinal quantitative designs with three or more waves of measurement Discusses change or trajectories across waves	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
Date	2005-2021	Any earlier dates
Language	Published in English	Not published in English
Publication type	Articles published as full texts in peer-reviewed journals	Abstracts, conference papers, theses, books and other grey literature
	Obtainable through the library of the University of Pretoria, or freely available on the web e.g. ResearchGate	Not accessible via the UP library or free on the internet

2.8 Selection of studies

Search results were saved in RIS format, which was then imported to Covidence (https://www.covidence.org). Covidence is an online systematic review screening platform that simplifies conducting a systematic literature review. Duplicate studies were removed once imported into Covidence. Eligibility was then assessed by means of a screening process that was based on the set inclusion and exclusion criteria as indicated in Table 5. The ‘Title and Abstract Screening Relevance Tool’ (Appendix D) was designed to facilitate identifying the studies to be included in the review. The below questions were used to screen the studies:

- Is children and youth the target population of the study?
- Does the study report a permanent childhood or developmental disability?
- Does the outcome relate to participation or activity performance?
- Is the research focused on activities or participation within the home or in the community?
- Is the study longitudinal in nature?
- Was the study published between 2005 and 2021?
- Is the study published in English?

Two reviewers (primary and secondary) independently screened studies to be included in the review during two stages i.e. title and abstract and full text review stages using Covidence. It is recommended that two reviewers conduct the screening process independently to reduce the possibility of missing studies as a result of misapplication or misunderstanding of the selection criteria, or as a result of random error of the screener (Stoll et al., 2019). During the first stage, potentially eligible studies were screened by first reviewing titles and abstracts against the predetermined inclusion and exclusion criteria. In Covidence, each reviewer could select Yes’, ‘No’ or ‘Maybe’ in response to several questions related to the inclusion and exclusion criteria, applying the Title and Abstract Screening Relevance Tool.

If ‘no’ was answered to any of the questions, the study was excluded. If a decision could not be made to include or exclude on title or abstract level, the full text was retrieved, after which it was assessed for inclusion. The full texts of the studies that were marked as ‘yes’ were retrieved, after which the final decision was made to include or exclude the study in the review. This step was also conducted in Covidence. Inconsistencies between the two reviewers were discussed and a third reviewer adjudicated for those that could not be resolved. The PRISMA diagram is illustrated in Figure 2 and indicates the flow of information throughout the various phases of this systematic review.

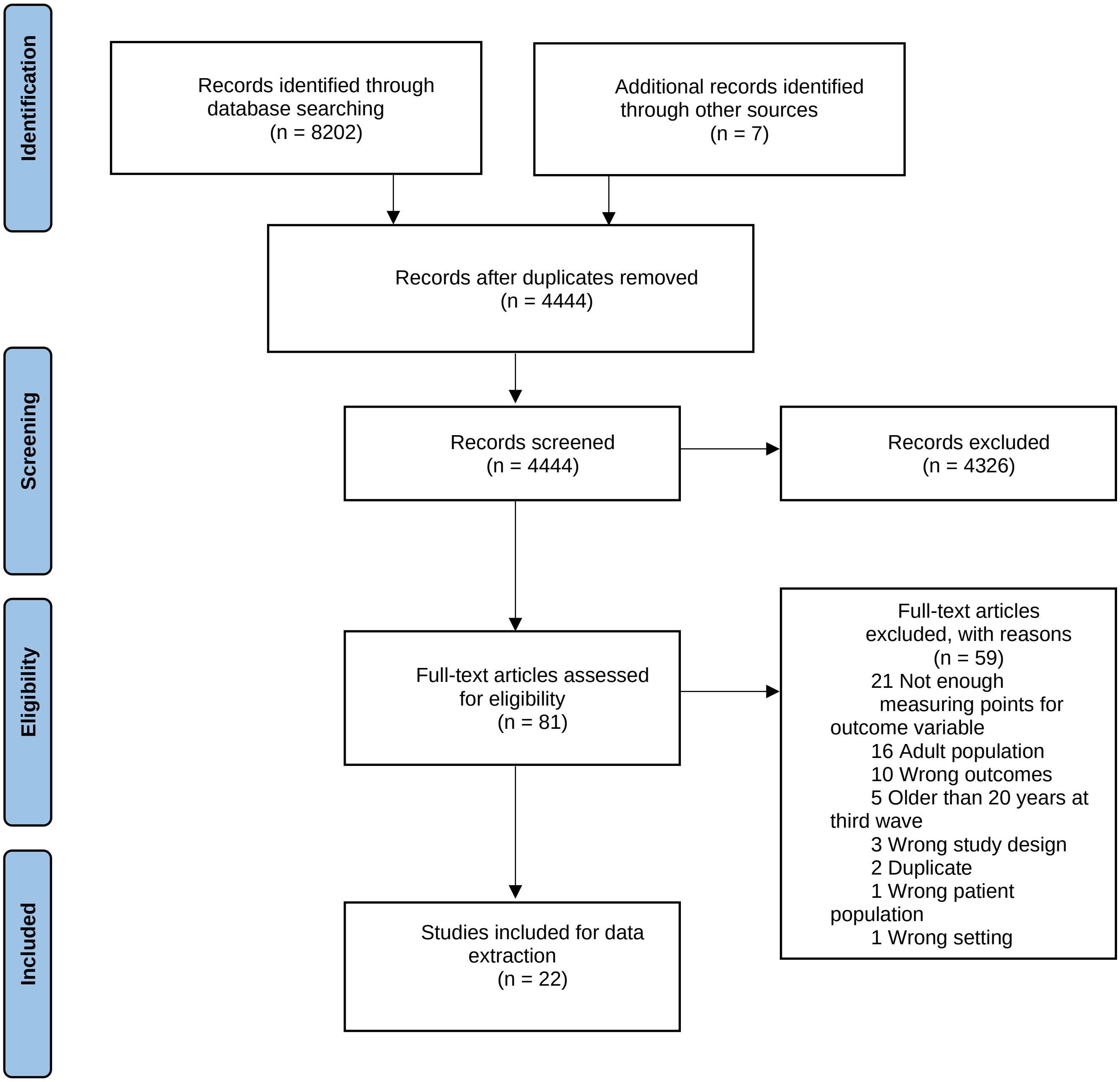


Figure 2. *PRISMA flow diagram of selection process* (Liberati et al., 2009).

2.9 Data extraction

A data extraction form was developed (Appendix E). Relevant data that can answer the review question and sub questions was extracted and imported into an Excel spreadsheet with different columns to capture different categories to answer the review question. Data was first extracted according to general study characteristics (title, authors, year of publication, where study took place, study purpose or research aims). Participant characteristics that were extracted included the focus level of the target group, the number and gender of participants, the age of the participants, and the type of disability or impairment. It was also documented if the population included children or youth who uses AAC. The change outcome of interest and the measuring instrument used to measure the change outcome variable were recorded, as were the hypothesised predictors (if any) and the measuring instruments used to measure the predictors of change. The child's role in data collection was documented (i.e. tested, self-rated, proxy rated, observed or interviewed).

Data related to the study design was extracted in terms of the type of design (i.e. quantitative or mixed), the type of longitudinal quantitative design (i.e. descriptive or explanatory), the number of measurement waves in the study, and the total duration of the longitudinal study in months or years. Data extracted in relation to the theory of change included the functional form of change hypothesis, the predictors of change hypothesis, the level of change, and whether the authors determined the optimal number of waves according to the hypothesis. The quantitative design considerations included the timing of observations, whether a convenience or purposive sampling was used and a rationale was provided. Furthermore, data extracted related to attrition included the sample at final wave, the authors' comments on attrition and whether the authors planned for attrition in their sampling procedure. Longitudinal validity was determined by assessing if the authors checked for longitudinal measurement invariance.

A quantitative data analysis was done by transcribing the analytical statistical procedures used to document change in activity or participation outcome variables, documenting whether the authors provided reasons why a particular method was preferred and how the authors documented the change results (i.e. descriptive plots/graphs of trend or tables). Additionally, it was reported whether the authors controlled for missing data in their analysis.

Finally, the results and conclusions related to the patterns or trajectories of activities or participation outcome variables were transcribed. The conclusions related to the predictors of change in these outcomes were also included in the data extraction form.

By means of extracting the particular data as described, the studies were also critically appraised comparing methodological features across studies according to best practice principles of what constitutes good longitudinal research (Ployhart & Vandenberg, 2010).

2.10 Quality appraisal of the included studies

Typically in a systematic review, a quality appraisal is conducted to evaluate the quality of the evidence presented in included studies, especially when having to synthesise the information presented in these studies. As a way of facilitating the process of quality appraisal and synthesis, numerous systematic reviews use checklists with a value assigned depending upon the number of criteria that are met or not. It is then determined if the included study is of high, moderate or low quality, which is consequently reflected in the final synthesis where high-quality studies are more important (Littlewood et al., 2010). Currently, there are no quality appraisal tools for longitudinal research. Sub-aims three to five, which is the ultimate aim of this review, looking at how well the included studies conform to best practice principals of longitudinal research as put forward by Ployhart and Vandenburg (2010), in effect then also represent the quality appraisal of this systematic review. The sub-aims of this review therefore fulfil dual functions.

2.11 Reliability

Transparency, replicability and a clear inclusion criteria are essential in conducting methodologically strong systematic reviews (Belur et al., 2021). Methods that are followed to minimise the risk of error and bias will consequently influence the quality of the systematic review. The following rigorous methods were followed to ensure reliability of the data collection and recommendations of this review (Aromataris & Pearson, 2014):

- Objectives/aims of this study were clearly articulated;
- The systematic review process (Newman & Gough, 2020) was used as a guideline to ensure that all the appropriate steps were included in this review;

- The PRISMA four-phase flow diagram was utilised to illustrate the flow of information throughout the various phases of the systematic review (Moher et al., 2009);
- A comprehensive search was done in multiple databases;
- Articles were selected to inclusion and exclusion criteria that determined the eligibility of the studies; and
- Using two reviewers (primary and secondary) to independently screen the studies to be included in the review during two stages i.e. title and abstract and full text review screening.

The interobserver agreement (IOA) was calculated for title and abstract screening. The IOA was calculated as follow: the number of agreements were divided by the number of agreements plus the number of disagreements, which was then multiplied by 100. The IOA for title and abstract screening was 98%. The disagreements that were found on title and abstract screening and full text screening were discussed until a consensus was reached to include or exclude a particular study. A second reviewer independently extracted data on 30% of the included studies, after which the data were compared to determine any differences in the extracted data. Any difficulties or queries with the remainder of the studies were also discussed with the second reviewer.

3. RESULTS

The initial database search identified 8,202 articles; 81 full texts were assessed and 22 studies were included for data extraction. The majority of the full-text articles that were excluded (n = 21) did not have enough measuring points for the outcome variable or focused on the adult population (n = 16). A total of 22 studies (Table 2) met the inclusion criteria to answer the review questions in this review. An overview of the included studies will be given with regard to (i) the study purpose, (ii) the type of design, (iii) the country where the study took place, (iv) the participant characteristics, (v) the measurement instrument used, and (vi) the child role in data collection. The studies will then be discussed in view of the sub-aims of the study by looking at (i) the prevalence of longitudinal quantitative research studies measuring the change in activity performance or participation in home and community environments for children and youth with disabilities or impairments since the introduction of the ICF/CY, (ii) the extent that children and youth who use AAC form part of the included studies on longitudinal research on participation of children and youth with disabilities, (iii) how well these longitudinal studies hypothesise a theory of change in terms of form, level, duration or predictors to guide their research, (iv) how well these longitudinal studies take into account methodological and design considerations (measurement waves, timing and observations, sampling, attrition and measurement validity) when examining change in participation in home and community activities, and (v) what analytic methods these studies use to document change in participation in home and community activities. An in-depth discussion of these results is set out in the Discussion Chapter (Chapter 4).

3.1 Study purpose, type of design, country where study took place, duration of study and number of waves

Table 6 illustrates a summary of the studies in relation to the purpose and design of the study, the country where the study took place, the duration of the study and the number of waves.

Table 6

Studies included

Study	Country	Purpose	Type of design	Duration of study in years	Number of waves
1. Anaby et al. (2012)	Canada	This study determined the changes in level of participation over one year after returning to school amongst children with a brain injury. Additionally, this study also examined if differences in rates of change in participation across children could be associated with personal (injury-related factors) and ⁄or familial characteristics.	Descriptive Explanatory	1 year	3
2. Burgess et al. (2019)	Australia	This study described the longitudinal development of self-care and its relationship to manual ability in children with CP aged 18 months to five years over all functional abilities.	Descriptive Explanatory	Not clear – part of the wider CP Child Study	6
3. Burgess et al. (2020)	Australia	This study examined the self-care developmental trajectories in children with CP over all functional ability levels, according to Manual Ability Classification System (MACS) levels.	Descriptive Explanatory	Not clear – data collected from the Australian CP Child Study and the Predict-CP study	5
4. Cairney et al. (2010)	Canada	This study examined the participation of children with pDCD in organised and free-play activities over time.	Descriptive	3 years	5
5. Chiarello et al. (2021)	Canada & USA	This study attempted to develop longitudinal trajectories and reference percentiles for frequency of participation in family and recreational activities for children with CP according to Gross Motor Function Classification System (GMFCS) level.	Descriptive Explanatory	2 years	5

Study	Country	Purpose	Type of design	Duration of study in years	Number of waves
6. Green & Carter (2014)	USA	This study examined the development of daily living skills over three years in young children with ASD. Furthermore, this study examined the predictors and course of daily living skills in young children with ASD, including the relationship between daily living skills and parenting stress.	Descriptive Explanatory	3 years	3
7. Hwang et al. (2020)	Taiwan	This study investigated the longitudinal relationship between independence (capability) and frequency of attendance in respect of the perceived mental health status in children with and without physical disabilities.	Descriptive Explanatory	4 years	4
8. Imms & Adair (2017)	Australia	The aim of this study was to add to knowledge relating to the life course development of participation patterns of children and adolescents with CP.	Descriptive Explanatory	9 years	5
9. Ketelaar et al. (2014)	Netherlands	This study described the development of mobility and self-care capabilities in young children with CP, and also examined if the development of mobility and self-care capabilities differs by CP severity with regards to five distinct GMFCS levels.	Descriptive Explanatory	3 years	4
10. King et al. (2009)	Canada	This study studied the patterns and predictors of change over three years in the participation intensity of children and youth with physical disabilities in five types of leisure and recreational activities.	Descriptive Explanatory	3 years	3

Study	Country	Purpose	Type of design	Duration of study in years	Number of waves
11. Klaiman et al. (2014)	USA	This study assessed the adaptive behaviour patterns in fragile X syndrome over time.	Descriptive Explanatory	Not clear – data collection formed part of a longitudinal study of the development and neuroimaging of people with fragile X syndrome. The mean time between measurement occasions was 3.33 years (range 2 to 9 years).	4
12. Kruijsen-Terpstra et al. (2015)	Netherlands	This study examined predictors of developmental gain in self-care and mobility activities in young children with CP.	Descriptive Explanatory	2 years	3
13. Palisano et al. (2020)	Canada & USA	This study attempted to develop longitudinal trajectories and reference percentiles for performance in self-care of children with CP.	Descriptive Explanatory	2 years	5
14. Park (2018)	South Korea	This study evaluated age-related changes in children and adolescents with CP in relation to gross motor function and ability to perform ADL.	Descriptive Explanatory	3 years	3
15. Simpson et al. (2019)	Australia	This study investigated the participation of children with ASD over three years across home, school and community.	Descriptive	3 years	3
16. Smits et al. (2011)	Netherlands	This study described the course of capabilities in self-care, mobility and social function in school-age children with CP, and investigated associations with CP-, child-, and family-characteristics.	Descriptive Explanatory	2 years	3
17. Tan et al. (2014)	Netherlands	This study determined the developmental trajectories of performance of social participation, by level of gross motor function and intellectual disability, in a Dutch population of children and youth with CP.	Descriptive Explanatory	Not clear – data collection was part of the Dutch longitudinal PERRIN+ study. In this study, the data of the four age groups of the PERRIN programme were merged into a national database of 424 Dutch individuals with CP aged one to 24 years.	4

Study	Country	Purpose	Type of design	Duration of study in years	Number of waves
18. Tan et al. (2016)	Netherlands	This study determined the factors related to the longitudinal development of social participation in a Dutch population of children and youth with CP.	Descriptive Explanatory	Not clear – part of the Dutch PERRIN programme, which commenced in 2000.	4
19. Tatla et al. (2017)	Canada & USA	This study examined and described the functional abilities of children with progressive neurological conditions over time.	Descriptive Explanatory	2 years	3
20. van Empelen et al. (2007)	Netherlands	This study examined if severity of epilepsy, motor functioning, and epilepsy-related restrictions change in children with medically intractable epilepsy who are ineligible for epilepsy surgery.	Descriptive Explanatory	2 years	4
21. Van keer et al. (2020)	Belgium & Netherlands	This study exploratively characterised the (in)variability of, and the momentary and predictive association between, parents' interactional style and children's interactive engagement over two years, in the sample group of pre-school-aged children with a significant cognitive and motor developmental delay.	Descriptive Explanatory	2 years	5
22. Vos et al. (2013)	Netherlands	This study described the developmental trajectories of mobility performance and performance of daily activities in children and young adults with CP, and explored the influence of the level of gross motor function and intellectual disability on these trajectories.	Descriptive Explanatory	Not clear – part of the Dutch PERRIN programme, which commenced in 2000.	4

Table 2 illustrates that most of the included studies were conducted in high income countries, mainly in the Netherlands (n = 8) and in Canada (n = 6). There were no longitudinal quantitative studies conducted on the activity performance or participation in home and community environments of children and youth with disabilities in low-and middle-income countries (LMICs) even though this is where the majority of the world's population of children reside (WHO & World Bank, 2011). This is consistent with the study done by Schlebusch et al. (2020) which also found that only a small number of participation research has been conducted on children with disabilities in LMICs. Demographic differences contribute to the challenge of generalising research findings from one country to the next (Dada et al., 2020a).

The majority of the studies used both a descriptive and explanatory design as indicated in Table 2. Only two studies (Cairney et al., 2010; Simpson et al., 2019) used a descriptive longitudinal design. Descriptive longitudinal research only attempts to describe how a phenomenon changes over time, whereas explanatory longitudinal research tries to determine the cause of this change process (Ployhart & Vandenberg, 2010).

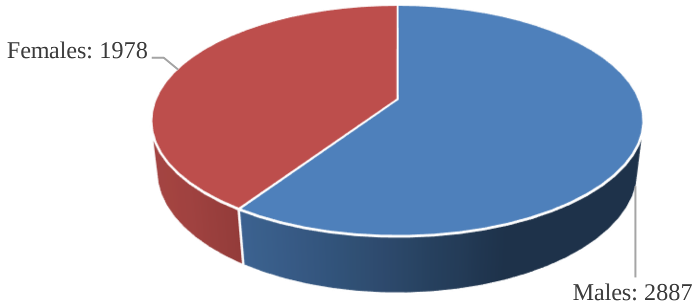
Most of the studies were performed over a period of two years (Chiarello et al., 2021; Kruijsen-Terpstra et al., 2015; Palisano et al., 2020; Smits et al., 2011; Tatla et al., 2017; van Empelen et al., 2007; Van keer et al., 2020) or three years (Cairney et al., 2010; Green & Carter, 2014; Ketelaar et al., 2014; King et al., 2009; Park, 2018; Simpson et al., 2019). Of these studies, the majority had three (Anaby et al., 2012; Green & Carter, 2014; King et al., 2009; Kruijsen-Terpstra et al., 2015; Park, 2018; Simpson et al., 2019; Smits et al., 2011; Tatla et al., 2017) or four (Hwang et al., 2020; Ketelaar et al., 2014; Klaiman et al., 2014; Tan et al., 2014, 2016; van Empelen et al., 2007; Vos et al., 2013) measurement occasions. Six studies were conducted as part of data collection for particular longitudinal studies such as the Dutch PERRIN programme (Tan et al., 2014, 2016; Vos et al., 2013).

3.2 Participants

Table 7 illustrates the characteristics of the participants included in this review. The gender, participant diagnosis and the focus level target group (age groups) are described.

Table 7

Participant characteristics

Description	Results
Gender of participants At the first point in time (T1) a total of 4,865 children and youth with disabilities participated in the 22 included studies (Figure 4). These included 2,887 males (59%) and 1,978 females (41%).	 Figure 3. *Gender of participants.*

Participant diagnosis

The majority of participants in the study had a diagnosis of cerebral palsy (CP) (*n* = 3432). Other diagnoses of the participants as seen in Figure 5 were physical disabilities (*n* = 520), Fragile X syndrome (*n* = 275), autism spectrum disorder (ASD) (*n* = 245), acquired brain injury (ABI) (*n* = 136), developmental coordination disorder (*n* = 111), progressive neurological conditions (*n* = 83), significant cognitive and motor developmental delay (*n* = 35), and medically intractable epilepsy not eligible for surgery (*n* = 28). Children and youth who use AAC did not form part of any of the included studies.

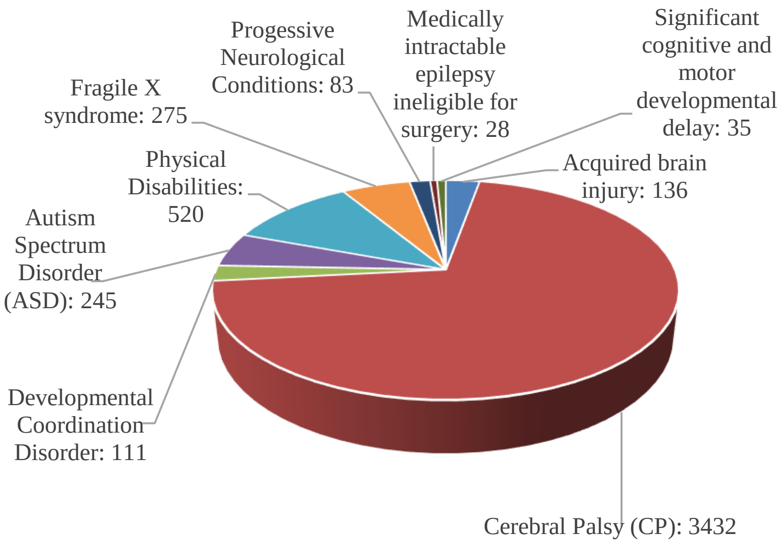


Figure 4. *Participant diagnosis.*

Focus level target group (age group)

The majority (n = 13) of the studies included only children (age range two to 12 years). Only nine studies from the total of 22 studies included both children and youth (age range 13 to 20 years).

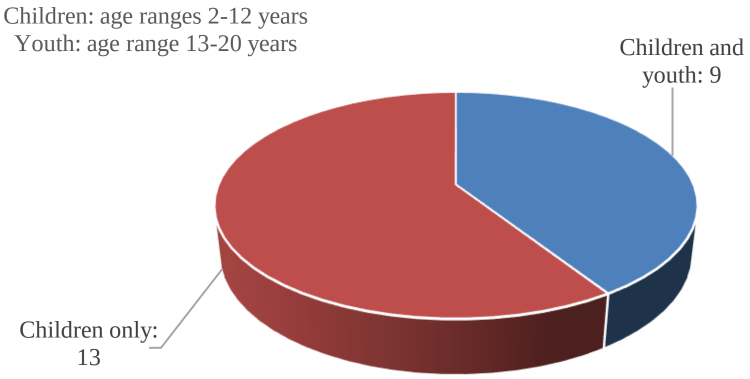


Figure 5. *Focus level target group (age group).*

The majority of the participants in this study were male. Across the globe, the prevalence of disability is higher among females than males (Mitra & Sambamoorthi, 2014). Therefore, females may thus be underrepresented in the included studies. Most of the children (n = 3432) had a diagnosis of CP and longitudinal research on the participation of children with other diagnoses is limited. This is consistent with literature, as cerebral palsy is the disability type that is most prevalent in participation research (Dada et al., 2020a).

With specific reference to sub-aim two of this review, the participant characteristics of the included studies as shown in Table 7 indicate that none of the studies focused on children who use AAC. Although most of the studies were conducted on children with a diagnosis of CP who may include children who use AAC, this was not specifically mentioned. These results therefore indicate a gap in the AAC literature on the longitudinal participation of children who use AAC. Furthermore, a gap in the literature on the longitudinal participation of youth (i.e. age range 13 to 20 years) with disabilities was also identified, as the majority (n = 13) of the studies focused only on children.

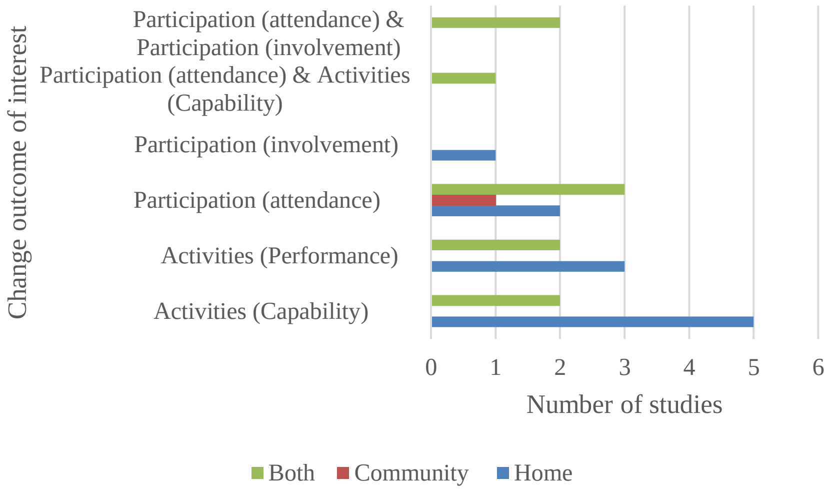
3.3 Change outcome of interest, measurement instruments used and child role in data collection

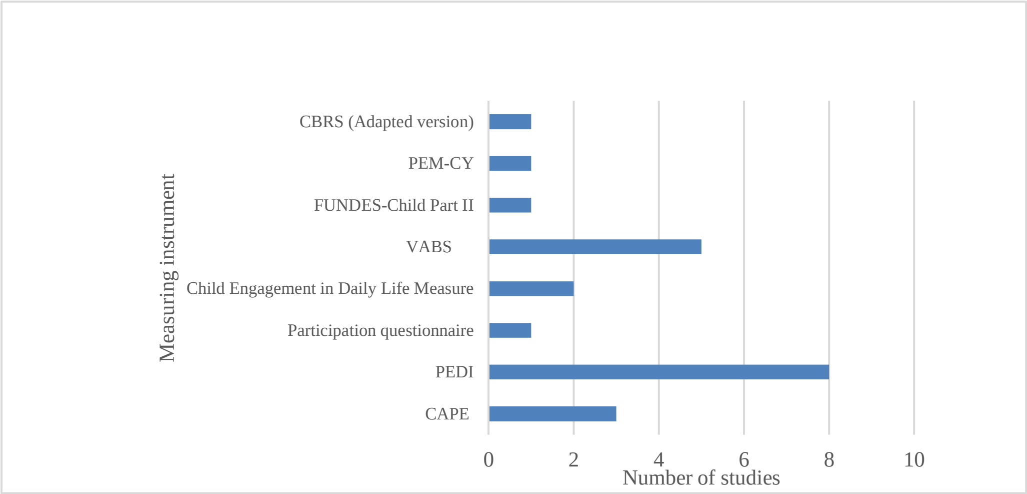
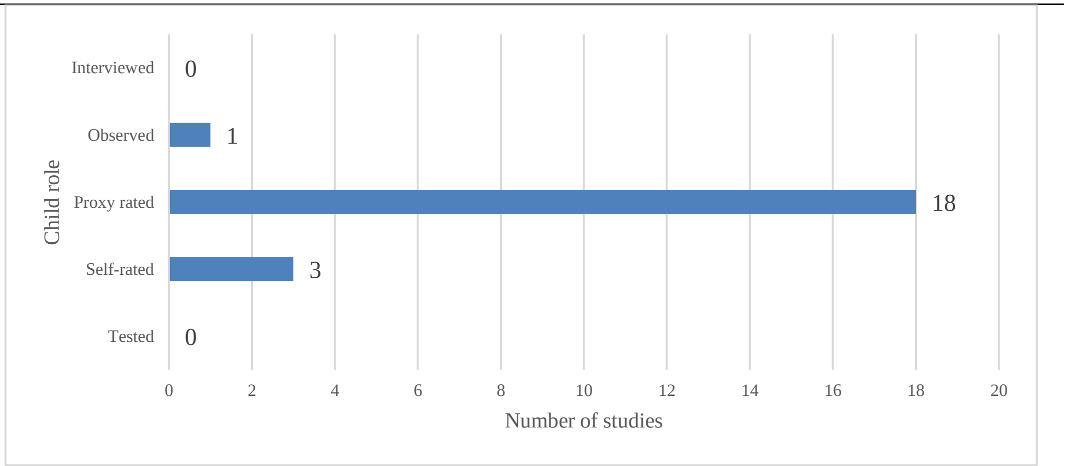
Table 8 illustrates the change outcome of interest, measurement instruments and the child's role in the data collection. It is apparent from this table that minimal research (n = 3) has been conducted measuring the involvement of children and youth with disabilities (Imms & Adair, 2017; Simpson et al., 2019; Van keer et al., 2020). It thus appears that attendance (related to the concept of 'being there') is the most prevalent dimension being measured in longitudinal research. Additionally, the majority (n = 11) of the studies focused on activity performance or participation within the home environment. As mentioned in the literature review, a tendency exists that children with disabilities are more inclined to participate in activities within their home environment than in their community (Raghavendra et al., 2011).

The PEDI was the measurement most frequently used (n = 8) and also appeared in more recent publications (Burgess et al., 2019, 2020; Kruijsen-Terpstra et al., 2015; Park, 2018; Smits et al., 2011; Tatla et al., 2017; van Empelen et al., 2007). This as opposed to the VABS, which is perhaps more reflective of measuring participation in earlier studies (Green & Carter, 2014; Klaiman et al., 2014; Tan et al., 2014, 2016; Vos et al., 2013) where the conceptual clarity of the participation construct was not as good. Furthermore, in the majority of the studies (n = 18) the participation measurement focused on proxy (typically parent) reports of activity performance or participation.

Table 8

Change outcome of interest, measurement instruments and child role in data collection

Description	**Result**
Change outcome of interest The majority of studies focused only on activity performance or participation within the home environment (*n* = 11). The remainder of the studies included both the home environment and the community (*n* = 10). Only one study included only the community. Seven studies measured activities (capability) and five studies measured activities (performance). Six studies measured participation (frequency of attendance) and one study measured participation (involvement). Two of the studies measured participation in terms of both attendance and involvement. Additionally, one study measured participation (attendance) and activities (capability).	 Figure 6. *Change outcome of interest.*

Description	Result
Measurement instruments The measurement instruments used in the included studies were the Pediatric Evaluation of Disability Inventory (PEDI) (*n* = 8), Vineland Adaptive Behavior Scales (VABS) (*n* = 5), Children's Assessment of Participation and Enjoyment (CAPE) (*n* = 3), Child Engagement in Daily Life Measure (*n* = 2), Adapted version of the Child Behavior Rating Scale-Revised (CBRS) (*n* = 1), Participation and Environment Measure for Children and Youth (PEM-CY) (*n* = 1), the Functioning Scale of the Disability Evaluation System – Child version (FUNDES-Child) (*n* = 1) and a participation questionnaire (*n* = 1).	 Figure 7. *Measurement instruments.*
Child role in data collection In the majority of the studies, a proxy-rated measurement was used to measure change in the outcome variables (*n* = 18). In three studies, children or youth completed the measuring instrument on their own or with support. In one study, the behaviour or performance of the children or youth was coded using an observational measure.	 Figure 8. *Child role in data collection.*

3.4 Hypothesising a theory of change

The first set of analysis, sub-aim 3, evaluates how well these longitudinal studies on participation in children with disabilities hypothesise a theory of change in terms of form, level, duration or predictors to guide their research. The appropriate design and analysis of longitudinal studies are directly influenced by these theoretical considerations (Ployhart & Vandenberg, 2010).

3.4.1 Form

Researchers need to hypothesise whether the expected change is linear or nonlinear as a means to conceptualise the form of change (Ployhart & Vandenberg, 2010). Understanding the form of change assists researchers in potentially knowing when certain changes are expected to occur, thus presenting important information on the timing of measurement points (Ployhart & Vandenberg, 2010). Only one study (Hwang et al., 2020) specified the expected form of change (i.e. a linear form of change). The authors did not however indicate whether the expected form of change influenced the methodology of their timing of observations. The other studies included in this review only made reference to previous research related to the change outcome of interest and provided a general theory related to the expected increase or decrease in activity performance or participation over time.

3.4.2 Level

There are two levels of interest when hypothesising the level of change. The first one being change for an entire group, where the focus is on whether the overall group changes in some manner on the variable of interest. According to Ployhart and Vandenberg (2010), group mean change regards all individuals within the group as experiencing the same form of change over time. The second form of change is *interunit* differences in *intraunit* forms of change (Ployhart & Vandenberg, 2010). This measures whether each unit or participant rather than the group may change in different ways over time, such as when one participant may show positive change and another declining change. According to Ployhart and Vandenberg (2010), intraunit change permits between-unit variability in the form of change. Articulating the level of change has implications for the type of statistical analysis that is undertaken to measure change. Testing interunit differences in interunit change prompts the utilisation of random coefficient modeling (RCM) or latent growth curve modeling (LGM), whereas testing group mean change prompts the use of the repeated measures analysis of variance

(ANOVA) model (Ployhart & Vandenberg, 2010). In 17 studies, the researchers hypothesised differences in individual change over time. Five studies (Hwang et al., 2020; Imms & Adair, 2017; Tatla et al., 2017; van Empelen et al., 2007; Van keer et al., 2020) hypothesised group mean change.

3.4.3 Duration

The duration indicates how long a dynamic relationship is expected to exist between variables. Researchers therefore need to take into consideration the duration and timing of their measurements of the independent (X), mediator (M), and dependent (Y) variables (Pitariu & Ployhart, 2010). The 22 included studies in this review did not provide a clear theory that address the duration of change. This is consistent with the findings of Mitchell and James (2001) that most theory and research does not consider 'when' the effect is most likely to take place or for what 'duration'. Furthermore, answers of researchers to questions related to 'when' and 'duration' tend to be grounded on the available data, instead of being guided by theory.

3.4.4 Predictors

Table 2 provides an overview of the type of design of the studies that were included in this review. Twenty studies incorporated both a descriptive and explanatory longitudinal quantitative design. Only two studies (Cairney et al., 2010; Simpson et al., 2019) did not include predictors in an attempt to explain the change process.

A variety of predictors were included in the 20 studies that explored variables involved in the change outcome of interest. In 10 studies (Burgess et al., 2019; Chiarello et al., 2021; Kruijsen-Terpstra et al., 2015; Palisano et al., 2020; Park, 2018; Smits et al., 2011; Tan et al., 2014, 2016; van Empelen et al., 2007; Vos et al., 2013) the authors hypothesised gross motor ability (measured by the GMFCS) as a predictor of the change outcome. Six studies included familial characteristics as predictors (Anaby et al., 2012; King et al., 2009; Kruijsen-Terpstra et al., 2015; Smits et al., 2011; Tan et al., 2016; Van keer et al., 2020). Six studies included cognition or intellectual capacity as predictors (Burgess et al., 2020; Kruijsen-Terpstra et al., 2015; Smits et al., 2011; Tan et al., 2014, 2016; Vos et al., 2013). Five studies determined the extent to which epilepsy has an influence on the change outcome of interest (Burgess et al., 2019, 2020; Kruijsen-Terpstra et al., 2015; Tan et al., 2016; van Empelen et al., 2007). Four studies considered severity or type of cerebral palsy as a predictor

(Ketelaar et al., 2014; Kruijsen-Terpstra et al., 2015; Smits et al., 2011; Tan et al., 2016). Other hypothesised predictors included in the study were manual ability (Burgess et al., 2019, 2020; Kruijsen-Terpstra et al., 2015; Smits et al., 2011; Tan et al., 2016; Van keer et al., 2020); age (Green & Carter, 2014; Imms & Adair, 2017; Tan et al., 2016; Tatla et al., 2017); problem behaviours (Green & Carter, 2014; Smits et al., 2011; Tan et al., 2016); gender (Klaiman et al., 2014; Tan et al., 2016); injury-related factors (Anaby et al., 2012); gestational age (Burgess et al., 2019); developmental level (Green & Carter, 2014), independence in activities (Hwang et al., 2020); motor type (Burgess et al., 2019); impact of school transitions (Imms & Adair, 2017); community factors (King et al., 2009); autism symptom severity (Green & Carter, 2014); child factors (such as preferences) (King et al., 2009); and selective motor control (Smits et al., 2011). Additionally, one study (Tan et al., 2016) hypothesised that factors such as pain, type of education, hearing impairment, visual impairment and speech impairment each independently add to the variability of the development of social participation for subgroups of individuals with CP. The study done by Hwang et al. (2020) is unique as it is the only study included in this review that used participation as both an outcome and as a predictor.

3.5 Consider methodological and design considerations

The implications of this sub-aim are in relation to designing longitudinal studies in a way that will enable the detection and modelling of the hypothesised forms and predictors of change. Therefore, the methodology and design of the study should be guided by the underlying theory and hypothesis that is being tested (Ployhart & Vandenberg, 2010).

3.5.1 Measurement waves

Researchers need to establish the optimum number of measurement waves and the intervals between these measurements as a way to adequately model the hypothesised form of change (Ployhart & Vandenberg, 2010). To be included in this review, the studies needed to have a minimum of three measurement waves. Eight of the included studies had a total of three measurement waves (Anaby et al., 2012; Green & Carter, 2014; King et al., 2009; Kruijsen-Terpstra et al., 2015; Park, 2018; Simpson et al., 2019; Smits et al., 2011; Tatla et al., 2017). Seven studies had four measurement waves (Hwang et al., 2020; Ketelaar et al., 2014; Klaiman et al., 2014; Tan et al., 2014, 2016; van Empelen et al., 2007; Vos et al., 2013). Six studies had five measurement waves (Burgess et al., 2020; Cairney et al., 2010; Chiarello et al., 2021; Imms & Adair, 2017; Palisano et al., 2020; Van keer et al., 2020). Only one study had a total of six measurement waves (Burgess et al., 2019). It should be noted, however, that not all the participants included in some of these studies had measurements taken or data available at all the measurement waves (Burgess et al., 2019, 2020; Chiarello et al., 2021; Ketelaar et al., 2014; Palisano et al., 2020; Tan et al., 2014, 2016; Vos et al., 2013). An example is the study done by Burgess et al. (2019), where the children in the study were observed between one and six occasions with a median of four measurements taken. While all of the studies included in this review had a minimum of three measurement waves, only one study (Imms & Adair, 2017) determined the optimal number of waves according to a hypothesis. The authors wanted to determine if significant changes in the participation profiles in activities outside of school for children and adolescents with CP are a result of key life-stage transitions (i.e. primary to secondary school, and secondary to post-secondary time points) (Imms & Adair, 2017). The authors therefore determined that they needed to collect data over three measurement waves based on the identified theory about key-life transition stages (Imms & Adair, 2017).

3.5.2 Timing and observations

The timing of the observations in most of the studies included in this review (n = 21) was according to set time points. Although all included studies specified the time points of the observations, only one study (Imms & Adair, 2017) based the timing of these observations according to theory-based transition stages.

3.5.3 Sampling

Ployhart and Vandenberg (2010) recommend that researchers select samples that are most likely to demonstrate the hypothesised form of change. For this reason, they recommend that researchers need to try to avoid using convenience samples. Eighteen studies made use of purposive sampling and only four studies (Chiarello et al., 2021; Hwang et al., 2020; Palisano et al., 2020; Park, 2018) used a convenience sample.

3.5.4 Attrition

Researchers need to determine if the participants at the final measurement wave are representative of participants at earlier points in time and also if the given sample portrays the larger sample of interest (Ployhart & Vandenberg, 2010). Therefore, researchers need to identify any significant differences which may result in possible bias in the results. Planning for attrition requires researchers to develop some sort of theory as to why missing data may come about in the study. Furthermore, researchers need to first identify the adequate sample size required at the last measurement wave and then work their way back to establish the sample size that would consequently be needed at the first point in time (Ployhart & Vandenberg, 2010). Besides this, researchers can also attempt to include “planned missingness” in the design of studies, where the participants of groups that were set up at random have measurements taken at the first and last time points but complete intermediate assessments in an alternating way (Ployhart & Vandenberg, 2010). A variety of statistical methods can then be utilised to determine the approximate missing data in the study and estimate parameters in accordance with the full sample, as suggested by Ployhart and Vandenberg (2010).

Most of the studies included in this review did not discuss planning for attrition in their sampling procedure. One study (Park, 2018) reported using convenience sampling as the sample needed to be retained for three years. Imms and Adair (2017) reported that they did not undertake a sample size calculation at the beginning of the study. The authors did, however, indicate that the loss to follow up was significant in this study.

Attritions appeared to occur in many of the studies. Reasons for attrition in the studies included the burden of the assessment (Chiarello et al., 2021; Ketelaar et al., 2014; Klaiman et al., 2014; Kruijsen-Terpstra et al., 2015; Van keer et al., 2020); the participants passing away (Chiarello et al., 2021; Tatla et al., 2017; Van keer et al., 2020); funding constraints (Green & Carter, 2014), and loss of interest, family stress or participants relocating without updating their address (Tan et al., 2014). Additionally, one study indicated withdrawal by subject, the subject did not return for more observations and medical issues/illness as reasons for attrition (Chiarello et al., 2021). One study reported limited missing data, although it was noted that 708 participants completed assessments at baseline and only 424 participants completed assessments at the final wave (Palisano et al., 2020). In three studies, the authors did not provide comments regarding attrition (Anaby et al., 2012; Tan et al., 2016; van Empelen et al., 2007). However, in two of these studies it appears that data from all the participants were collected at all the measurement waves (Anaby et al., 2012; van Empelen et al., 2007).

Three studies indicated attrition but did not provide any reasons for this (Hwang et al., 2020; Smits et al., 2011; Vos et al., 2013). Two studies reported excluding observations with incomplete data from the analysis (Burgess et al., 2019, 2020). Three studies only included and only reported data from children with three measuring points (King et al., 2009; Simpson et al., 2019; Tatla et al., 2017). Similarly, one study described and analysed data for a 'core group', which referred to the group for which data was accessible at all of the time points (Van keer et al., 2020).

When handling the missing data it is important to verify if the data are missing at random, which can require examining differences in the variables included in the study (Ployhart & Vandenberg, 2010; Ployhart & Ward, 2011). In 10 studies the authors commented on the characteristics of the study sample compared to those that dropped out or whether the sample represented the larger population of interest. Two studies (Green & Carter, 2014; Simpson et al., 2019) reported no significant difference between the participants included in the study and those who did not return for follow up. Three studies (Chiarello et al., 2021; Imms & Adair, 2017; Smits et al., 2011) reported that the GMFCS distribution of the sample was similar to reported incidence data or the total population. One study (Kruijsen-Terpstra et al., 2015) reported that the distribution of children in relation to the groups of the MACS was representative with the population seen in practice. However, in the study done by Chiarello et al. (2021), the authors indicated that the sample may not necessarily represent the demographics of the larger population of children with CP and their families in the US and Canada. Similarly, another study (Palisano et al., 2020) found that the demographic data indicated that the sample may not portray the demographics of the population of families and children with CP. Additionally, one study reported children with severe impairments being underrepresented and the exclusion of children with additional diseases (Burgess et al., 2019); one study reported the included sample not being representative of children with 'catastrophic epilepsies' (van Empelen et al., 2007), and one study indicated that using a convenience sample may have resulted in underrepresentation of the sample (Park, 2018).

Ten studies included in this review controlled for missing data in the analysis (Chiarello et al., 2021; Green & Carter, 2014; King et al., 2009; Klaiman et al., 2014; Palisano et al., 2020; Park, 2018; Simpson et al., 2019; Smits et al., 2011; Tatla et al., 2017; Van keer et al., 2020). Imputations were made in three studies (Chiarello et al., 2021; Green & Carter, 2014; Palisano et al., 2020). Two studies used full information maximum likelihood (FIML) to handle the missing data (King et al., 2009; Park, 2018). One study reported that they distributed the drop-outs and intermittent missing scores equivalently over the age cohorts and GMFCS levels (Smits et al., 2011). Missing data seemed to be controlled informally in one study (Klaiman et al., 2014), as the authors only reported conducting their analysis based on the assumption that data were missing. Additionally, three studies controlled for missing data in their analysis by only including those with three or more measuring points (Simpson et al., 2019; Tatla et al., 2017; Van keer et al., 2020).

3.5.5 Measurement validity

Measurement validity refers to whether researchers check if the same construct is being operationalised through the same set of measures at each time point as it may be that interpretation of the construct has changed over time by the participants or the data collectors e.g. in observational studies (Ployhart & Vandenberg, 2010). This can happen, for instance, when pre-test and post-test measures represent different constructs also sometimes referred to as beta change and can represent a threat to internal validity (Golembiewski et al., 1976).

Only two studies reported if they checked whether the instruments or observers measured the same construct at each measurement occasion. In the study done by Simpson et al. (2019), the Cronbach alpha coefficient for attending was recorded across all three time points for both the home and the community. Additionally, Van keer et al. (2020) reported using a variety of measures to ensure that the rating process was reliable and consequently also documented the interrater agreement for the separate scale items for each measurement wave in their study.

3.6 Analytical methods used

The last sub-aim of the study is to determine what analytic methods these studies use to document change in participation in home and community activities. Researchers should steer clear of formulating all research questions in keeping with their preferred statistical method (Ployhart & Vandenberg, 2010). Ployhart and Vandenberg (2010) provide detailed recommendations in terms of the most appropriate methods of data analysis when conducting longitudinal research. Furthermore, guidance is provided in relation to which method is best suited for the particular type of change that is being observed and the type of longitudinal data that is acquired. According to Ployhart and Vandenberg (2010), repeated measures GLM can be used when the focus is on group mean change over time and missing data is minimal.

Alternatively, random coefficient modeling (RCM) or latent growth curve modeling (LGM) may be used when the focus is on studying individual differences in change over time.

The majority of the studies included in the review used RCM (i.e. multilevel models or commonly also referred to as linear-mixed effects models or hierarchical linear models) as the analytical statistical procedure to document the change in the activity or participation outcome variables (Anaby et al., 2012; Burgess et al., 2019, 2020; Cairney et al., 2010; Chiarello et al., 2021; Green & Carter, 2014; Imms & Adair, 2017; Ketelaar et al., 2014; Klaiman et al., 2014; Kruijsen-Terpstra et al., 2015; Smits et al., 2011; Tan et al., 2014, 2016; Vos et al., 2013). Additionally, one study (Palisano et al., 2020) used a non-linear mixed effect model. Three studies (Hwang et al., 2020; Tatla et al., 2017; van Empelen et al., 2007) used repeated measures GLM (such as repeated measures ANOVA). LGM was used in two studies (King et al., 2009; Park, 2018). As a result of the sample size being small and non-normality occurring in the data, one study only made use of non-parametric tests (Van keer et al., 2020). One study only reported using median and quartile graphs to show how scores were distributed across each of the items (Simpson et al., 2019).

Ployhart and Vandenberg (2010) advise researchers to explain why they used a particular analytical method and also to document the strengths and weaknesses of this method for the particular study. The majority of the studies indicated why a particular analytic method was chosen but did not discuss the strengths and weaknesses of this chosen method in detail. The majority of the studies (n = 19) also illustrated the change results in the form of descriptive plots or graphs of trends. Only three studies (Green & Carter, 2014; Kruijsen-Terpstra et al., 2015; van Empelen et al., 2007) made use of tables to document the results.

3.7 Synthesising participation findings

While the specific aim of this review was not to evaluate the actual outcomes of what is currently known about longitudinal participation of children with disabilities, some brief discussion about the findings is warranted as these may need to be re-evaluated in light of some of the state of the art quality standards of longitudinal research that may not have been met.

3.7.1 Patterns or trajectories of activities (capability or performance)

The results from six studies indicated increases over time in self-care for children with CP between the ages of one and 12 years (Burgess et al., 2019, 2020; Ketelaar et al., 2014; Kruijsen-Terpstra et al., 2015; Palisano et al., 2020; Smits et al., 2011). Although less, change in performance was still occurring between the ages of eight and 12 years (Burgess et al., 2020). Developmental trajectories of mobility for children with CP also increased over time (Ketelaar et al., 2014; Kruijsen-Terpstra et al., 2015; Vos et al., 2013). However, one study (Smits et al., 2011) reported no increase in the mobility domain between the ages of seven and nine years. Mean functional skills (i.e. self-care and mobility) did not significantly change over time for children with progressive neurological conditions (Tatla et al., 2017). However, the opposite was observed for children with medically intractable epilepsy, as functional skills increased for the entire group (van Empelen et al., 2007).

Children with ASD and CP also acquire daily living skills over time, although at a slower rate compared to typically developing children (Green & Carter, 2014; Vos et al., 2013). Although results suggest that daily living skills increase after the age of 14 years for males with fragile X syndrome, as well as increase over time for females, the rate of acquiring adaptive behaviour slows as these individuals age (Klaiman et al., 2014). In the study done by Park (2018), the authors report that they are not able to affirm that the changes observed in the performance in activities of daily living (i.e. an increase in ADL performance) for children with CP will continue, as data collection was only conducted over three measurement waves.

In these studies, the most significant determinant of development of self-care was the participant's GMFCS level (i.e. level of gross motor function) (Ketelaar et al., 2014; Kruijsen-Terpstra et al., 2015; Palisano et al., 2020; Smits et al., 2011) or their intellectual capacity or cognition (Kruijsen-Terpstra et al., 2015; Smits et al., 2011; van Empelen et al., 2007). Development of mobility was also influenced by GMFCS levels (Ketelaar et al., 2014; Kruijsen-Terpstra et al., 2015; Vos et al., 2013), as was the growth rate of ADL performance (Park, 2018). Furthermore, preterm birth was related to better self-care scores for children with an acquired brain injury (Burgess et al., 2019) and results showed that the presence of epilepsy influenced the development of self-care (Anaby et al., 2012; Kruijsen-Terpstra et al., 2015) and mobility (Kruijsen-Terpstra et al., 2015). Two studies (Burgess et al., 2019, 2020) concluded that the severity of the manual ability impairment (i.e. MACS levels) was a significant determinant of self-care, while one study (Kruijsen-Terpstra et al., 2015) indicated it as a determinant of mobility. Family determinants was found not to be a determinant of development of self-care or mobility (Kruijsen-Terpstra et al., 2015) and problem behaviours were also not found to be predictive of daily living skills growth (Green & Carter, 2014). Additionally, age was not found to be a significant determinant of the development of functional skills over time (Tatla et al., 2017). The developmental trajectories of daily activities were, however, influenced by age and developmental level (Green & Carter, 2014). Additionally, intellectual capacity was found to be a determining factor (Vos et al., 2013). Some variation was observed between males and females with fragile X syndrome, as a significant decrease in all the domains was found for males but only in the communication domain for females (Klaiman et al., 2014).

3.7.2 Patterns or trajectories of participation outcomes

Similar to the above, the findings below on participation may need to be re-evaluated in light of some of the state of the art quality standards of longitudinal research that may not have been met. Changes in levels of participation in recreational, physical and social activities were observed for children following a brain injury (Anaby et al., 2012). Changes were also reported in participation patterns over time for children with ASD (Simpson et al., 2019). Tan et al. (2014) reported an increase in social participation for individuals with CP (without intellectual disability) over time. However, a follow-up study suggested variability in the development of social participation in children with CP (Tan et al., 2016). Considerable variability between individuals was also found by Chiarello et al. (2021), although the longitudinal trajectories illustrated a stable level of the frequency of participation in family and recreational activities of children with CP. Additionally, a stable level of participation over time was found for children with physical disabilities (Hwang et al., 2020), and a stable level of participation in skills-based activities over time for children with CP (Imms & Adair, 2017). Changes in children’s interactive engagement were observed over time; however, the study could not establish a clear group-level trend (Van keer et al., 2020).

Three studies found a decrease in the intensity or frequency of participation over time for children with CP (Imms & Adair, 2017; King et al., 2009; Simpson et al., 2019). This was particularly observed in recreational, active physical and social activities. An activity deficit is also present in children with developmental coordination disorder (DCD), which continues over time (Cairney et al., 2010). No changes were however observed in participation involvement (i.e. enjoyment scale of the CAPE) for any activity over time for children with CP (Imms & Adair, 2017).

The severity of injury was the most significant predictor of change in participation for children following acquired brain injury (Anaby et al., 2012). Although the effects were minimal and did not change with age, epilepsy and speech impairment were both found to influence the development of social participation for children with CP over time (Tan et al., 2016). Family factors were found to be a predictor of change for skill-based activities only (Anaby et al., 2012). One study (Van keer et al., 2020) did however indicate an association between a parent’s responsive behaviour and the child’s interactive engagement.

Findings indicate that intellectual disability influenced the development of social participation for children with CP much more distinctly compared to their GMFCS level (Tan et al., 2014). Another study done by Chiarello et al. (2021) also reported that participation is a personal experience that is affected by a variety of elements, as similar variability in measurement scores for children at each GMFCS level was found.

The impact of school transitions on the participation in recreational activities outside of school was found to be minimal (Imms & Adair, 2017). Variation in the participation intensity for recreational and active physical activities was attributed to a child’s gender and age (King et al., 2009). Despite difficulties in independence in activities, children with physical difficulties can still maintain a high frequency of attendance provided they receive the appropriate support (Hwang et al., 2020). Results from the study done by Hwang et al. (2020) further suggest that enhanced participation experiences could positively influence the mental status of children with and without disabilities.

4. DISCUSSION

The extent of longitudinal research on activity performance or participation in home and community environments for children and youth with disabilities was determined. Twenty-two studies met the inclusion criteria and were evaluated in line with best practice principles of what constitutes state of the art longitudinal research as set out by Ployhart and Vandenberg (2010). Eleven studies focused on activity performance or participation within the home environment. Ten studies included both the home environment and community. One study focused only on activity performance or participation in activities within the community. All the included studies were conducted in high income countries (HICs). Most of these studies were conducted in the Netherlands (Ketelaar et al., 2014; Kruijsen-Terpstra et al., 2015; Smits et al., 2011; Tan et al., 2014, 2016; van Empelen et al., 2007; Van keer et al., 2020; Vos et al., 2013) and in Canada (Anaby et al., 2012; Cairney et al., 2010; Chiarello et al., 2021; King et al., 2009; Palisano et al., 2020; Tatla et al., 2017). Table 2 highlights an underrepresentation of children and youth with disabilities from LMICs. This finding is in concordance with a study done by Plancikova et al. (2021), which indicated that the majority of research in the field of public health was conducted in HICs. There is consequently a lack of research in the everyday functioning of children and youth with disabilities in LMICs. This has implications for the generalisability of the findings to LMICs as the environment is known to have an influence on the participation patterns of children and youth with disabilities (Samuels et al., 2020). There is furthermore a need for greater awareness of participation being culturally biased (Dada et al., 2020).

More male participants (59%) were included in the studies than female participants (41%). Gender has been found to influence the participation of children and youth with disabilities (Tonkin et al., 2014). However, only two studies (Klaiman et al., 2014; Tan et al., 2016) included gender as a predictor to explore the variables in the change outcome of interest.

The majority (n = 13) of these studies focused only on children (i.e. ages two to 12 years). There is thus limited longitudinal research available related to the activity performance or participation of youth (i.e. 12 to 20 years) with disabilities. Additionally, none of the studies included children with complex communication needs who require AAC, despite the many advances in the field of AAC over the last 30 years, which include the growth of published research related to AAC (McNaughton & Light, 2015). Furthermore, AAC research predominantly focuses on younger age groups (McNaughton & Light, 2015). Consequently, many questions related to this population remain unanswered (Light et al., 2019).

When drawing inferences from the findings of these studies, it is important to consider that the majority of the studies (n = 18) made use of proxy rated measurements. This is in line with the literature that suggests that measures related to children's participation is often completed by proxy respondents (Adair et al., 2018). It is becoming increasingly apparent that how children with disabilities view their own participation may be remarkably different compared to the views of their caregivers (Dada et al., 2020; Samuels et al., 2020). It is therefore important that future research investigate the participation of children from their own perspective and that measures be developed for this purpose. Equally important is the development of measures to assess the second component of participation being involvement (which relates to the experience of participation while being there) (Imms et al., 2016), as longitudinal research predominantly measures the attendance component. As mentioned in the literature review, it appears to be more complex to conceptualise the changes in the involvement component (Imms et al., 2017).

4.1 Hypothesise a theory of change

Researchers need to be precise about which variables are assumed to change, the reasons for this change and the nature of dynamic relationships over time (if relevant) (Ployhart & Vandenberg, 2010). Developing "strong" hypotheses (i.e. where time, duration and the shape of the relationship over time are specified) is possible when dynamic relationships are integrated in the theory (Pitariu & Ployhart, 2010). Results from this study indicate that most of these longitudinal studies lack insight about the form of change (i.e. linear, non-linear or discontinuous), the duration or timing of the effects and relationships (Ployhart & Ward, 2011), and typically only provided a general theory in terms of the expected change in activities or participation over time. Consequently, the 22 included studies failed to articulate or graph the hypothesised form of change corresponding to the observed form of change (Ployhart & Vandenberg, 2010). Due to the lack of hypothesising a theory of change, it is not possible to draw conclusions about when the change will occur or for how long this change will last, as any inference related to the presence of an X,Y relationship (or its strength) relies on when X and Y are expected to occur, as well as when the measurements are taken (Mitchell & James, 2001). Insight regarding the duration or timing of relationships is required to provide prescriptive advice for practitioners and families of children with disabilities, such as advice about the maintenance of training (Ployhart & Ward, 2011).

All the studies included in this review clarified the level of change of interest. The majority of the studies (n = 17) were interested in examining *interunit* differences in *intraunit* forms of change and thus acknowledged that each unit of observation can change in different ways (Ployhart & Vandenberg, 2010). Among the five studies (Hwang et al., 2020; Imms & Adair, 2017; Tatla et al., 2017; van Empelen et al., 2007; Van keer et al., 2020) that hypothesised group mean, one study (Hwang et al., 2020) focused on children with physical disabilities. Children with an amputation, cerebral palsy, cerebral vascular accident/stroke (vascular brain disorders), congenital anomalies, hydrocephalus, juvenile arthritis, nonprogressive muscular disorders, neuropathy, orthopaedic conditions (e.g., scoliosis), spinal cord injury, spina bifida or traumatic brain injury were included, as well as those who had movement impairments or neuromuscular disabilities (Hwang et al., 2020). A focus on group average change would however be misleading when there is a such a considerable variability within the sample as it would be interpreted that all the children within this group would consequently experience the same form of change over time (Ployhart & Vandenberg, 2010).

The majority of the studies (n = 20) intended to show how the phenomenon changed over time (i.e. described the form or pattern of change over time) and also attempted to explain the change process by the use of one more or predictor variables. The identified predictors were however based on previous research or cross-sectional studies.

4.2 Methodological and design considerations

Time may add to the expected changes but may also conceal whether, how and why these changes occur (Kehr & Kowatsch, 2015). Consequently, longitudinal researchers need to attend to validity issues. Careful consideration needs to be given to the timing of measurement points and specifically when these measurement points are conducted (Mitchell & James, 2001). It is therefore imperative that researchers conceptualise the form of change to be able to make informed decisions about when measurement needs to take place. Additionally, it is important to ensure that enough repeated observations are included to adequately model the hypothesised form of change and that the duration and timing of the measurements of the variables are also taken into consideration (Ployhart & Vandenberg, 2010). Although studies required a minimum of three waves to be included in this review, data was not necessarily available for all the participants at a minimum of three measurement waves. The researchers in these studies (Burgess et al., 2019, 2020; Chiarello et al., 2021; Ketelaar et al., 2014; Palisano et al., 2020; Tan et al., 2014, 2016; Vos et al., 2013) intended to have more than two measuring points, as some children did have adequate data available at all three (or more) points in time. However these studies did not conform to best practice of longitudinal research as the researchers included participants in their analysis for which data were not available in at least three measurement waves. Only one study (Imms & Adair, 2017) determined the optimal number of measurement occasions based on key transition stages that they wanted to examine. The remainder of the studies also did not provide any reasons for the intervals between measurement occasions. As a result it is not possible to determine if the same conclusions would be drawn regarding the patterns of activities or participation, should the data collection have occurred at different points and time and with different intervals between these measuring points. Measurement occasions should be conducted at theoretically interesting times while still ensuring that the spacing of these measurements extend over a reasonable time span to allow detection of the hypothesised form of change (Ployhart & Ward, 2011).

In most of the studies (n = 18) the authors chose a purposive sample i.e. the population was based on the purpose of the study. This is in line with recommended guidelines provided by Ployhart and Vandenberg (2010) as a sample needs to be chosen that will increase the ability to detect change in the relevant variables. Nine studies (Anaby et al., 2012; Burgess et al., 2019, 2020; Imms & Adair, 2017; Klaiman et al., 2014; Kruijsen-Terpstra et al., 2015; Smits et al., 2011; Tatla et al., 2017; van Empelen et al., 2007) did however indicate limitations of their small sample sizes or recommended using larger samples in follow-up studies. The statistical power in studies with inadequate sample sizes may not be sufficient and consequently the answers to important research questions in these studies may not be reliable (Guo et al., 2013).

Additionally, many studies recommended that the analysis in future studies should be extended over a longer period of time or that the intervals between the measuring points be increased (Anaby et al., 2012; Burgess et al., 2019; Cairney et al., 2010; King et al., 2009;

Park, 2018; Simpson et al., 2019; Tan et al., 2014; van Empelen et al., 2007; Van keer et al., 2020; Vos et al., 2013). It is recommended that studies try to include more repeated measuring points in instances where the inclusion of more participants seems to be unattainable (and vice versa) (Ployhart & Ward, 2011).

Attrition is common in longitudinal research (Ployhart & Ward, 2011). Moreover, it is considered one of the prominent challenges of longitudinal research (Delva et al., 2010). The missing data is either concerned with whether the participants at a given time have the ability to represent the larger population of interest or whether the participants at a later point in time also have the ability to represent participants at an earlier point of time (Ployhart & Vandenberg, 2010). Attrition consequently poses a threat to the validity of conclusions or insights gained from a study (White & Arzi, 2005). In less than half of the studies (n = 10), the authors provided comments on whether and how those who dropped out of the study differed from those who continued to be included in the study or whether the participants included in the study sample represented the larger targeted population. Consequently, the external validity of the findings is influenced and generalisability of the results to the larger population of interest is restricted.

It is important that researchers examine why attrition took place and consequently determine whether the possibility of bias in the results exists (Ployhart & Vandenberg, 2010). Whether the missing data will contribute to bias will depend on the statistical method that was used. It is therefore recommended that researchers explicitly plan for potential attrition before commencing with the study, such as considering planned missingness approaches to data collection (Ployhart & Vandenberg, 2010). Although reasons for attrition were provided in eight of the studies (Chiarello et al., 2021; Green & Carter, 2014; Ketelaar et al., 2014; Klaiman et al., 2014; Kruijsen-Terpstra et al., 2015; Tan et al., 2014; Tatla et al., 2017; Van keer et al., 2020), the majority of the studies included in this review did not indicate any attempts to plan for attrition in their sampling procedures, and consequently a significant loss to follow up was observed in some of these studies, which ultimately reduces the reliability and statistical power of the findings. Although missing data reduces statistical power, bias is not necessarily instituted when approaches to deal with the missing data such as full information maximum likelihood (FIML) are used to account for the missing data (Ployhart & Ward, 2011). By using methods such as FIML and multiple imputation, unbiased estimates can be produced (provided that the sample size is acceptable) for both data that are missing completely at random (MCAR) and missing at random (MAR) (Mazen et al., 2019). However, in this review, less than half of the included studies (n = 10) controlled for missing data in their analysis, with only three studies incorporating imputations (Chiarello et al., 2021; Green & Carter, 2014; Palisano et al., 2020), and only two studies using FIML (King et al., 2009; Park, 2018).

Additionally, researchers need to examine the measurement properties of the variable for invariance before determining if change has occurred (Ployhart & Vandenberg, 2010). Only two studies (Simpson et al., 2019; Van keer et al., 2020) confirmed whether instruments or observers measured the same construct at each measurement occasion. Consequently, the longitudinal validity of the findings of the included studies is questioned, as the potential lack of invariance presents a level of threat to the ability to draw valid inferences from the results obtained in these studies (Ployhart & Vandenberg, 2010).

4.3 Analytical methods used to document change

The type of analytical approaches utilised and the inferences that can be made from these analyses largely depend on the design considerations (such as the spacing and timing of measurements, as well as attrition), as suggested by (Ployhart & Vandenberg, 2010). Despite uncovering that most of the studies included in this review did not adequately hypothesise a theory of change and particularly did not conceptualise the form of change, the majority of the studies did indicate why a particular method was chosen. Reporting why a particular method is used in a particular study is especially important as multiple methods can be used that may be equally appropriate to use. Some statistical methods are, however, more applicable for certain questions (Ployhart & Ward, 2011). The majority (n = 15) of the included studies that posed questions related to predicted intraunit change (i.e. differences in individual change over time) appropriately chose to use random coefficient modeling (i.e. multilevel models) as the analytical statistical procedure (Ployhart & Vandenberg, 2010).

The three studies (Hwang et al., 2020; Tatla et al., 2017; van Empelen et al., 2007) that used GLM (such as repeated measures ANOVA) adequately chose this analytical statistical procedure as these measures are particularly useful to model change when researchers aim to primarily focus on mean group change (Ployhart & Vandenberg, 2010). Furthermore, these studies had little to no missing data. Additionally, LGM that was utilised in two studies (King et al., 2009; Park, 2018) has several advantages, such as accounting for measurement error in the estimation process (Ployhart & Vandenberg, 2010). Two studies only relied on descriptive statistics. Although the majority of the studies provided reasons as to why they chose a particular analytical method, the authors did not identify or discuss potential weaknesses of using a particular method for the particular study. A general lack of awareness or uncertainty about which longitudinal data analysis method is better suited to a specific study may result in incorrect or ineffective analysis, results that are inaccurate and ultimately simplistic, or incorrect conclusions being drawn from the findings of a study (Locascio & Atri, 2011). Using graphs and visually illustrating the results obtained in these studies assisted in analysing the change results.

5. CONCLUSIONS AND RECOMMENDATIONS

More longitudinal research on participation is starting to take place, which is important for knowing the trajectories of participation in children and youth and the possible factors which may influence participation over the life course. Future research should, however, include more youth, as most of the studies included in this review focused on children under the age of 12 years. A need for longitudinal research on children and youth with CCN (such as those who use AAC) was identified, as none of the identified studies included individuals with CCN who require AAC. Additionally, there is an urgent need for research from LMICs as well as research with larger samples including a wider variety of disabilities.

Precision and insight to theories are added when temporal issues are considered (Ployhart & Ward, 2011). However, this systematic review has illustrated that the majority of longitudinal studies on activity performance or participation in home and community environments of children and youth with disabilities fail to adequately address the theoretical and methodological issues of longitudinal research. In evaluating these studies from a quality appraisal perspective of longitudinality, many of them would be considered low to moderate quality. As a result, caution needs to be taken when drawing conclusions from the outcomes of longitudinal studies in relation to the measurement of change over time in the functioning in activities and the participation in everyday life of such individuals. Notwithstanding the likelihood of the above-mentioned flaws and consequently the possibility of unreliable evidence, low-quality studies are nevertheless added in the synthesis of reviews, although caution should be taken that it can influence the general conclusions drawn in unpredictable ways (Hettinga et al., 2008). This is particularly so for our current knowledge or theories of how, when and why change occurs in activities and participation for children with disabilities.

Most of the studies included in this review did not hypothesise a theory of change in terms of the form or duration. Therefore it is not possible to determine when the change will occur or for how long the change will last (Mitchell & James, 2001). Ensuring theoretical and methodological precision in theories or research related to the participation of children and youth with disabilities will provide guidance to practitioners and families of children with disabilities to ensure that tailored support plans can be developed to optimise the participation of these individuals in a variety of aspects in life (Beukelman & Mirenda, 2013; Tan et al., 2016).

A strength of this systematic review is the transparency and rigorous methods that were followed to answer the research questions. Seven additional studies were identified and included as a result of conducting hand searches. Unpublished theses and dissertations were not included in this review. Publication bias is consequently a possibility, as unpublished studies that may have conducted longitudinal research were excluded (Schlosser et al., 2007). Furthermore, for linguistic reasons, the search strategy was confined to studies that are issued in English and therefore the outcomes of this study may be influenced by language bias (Grégoire et al., 1995). Although some studies were extracted independently by two reviewers and any difficulties in the remainder of the studies were discussed between the two reviewers, the data of all 22 studies were not extracted and compared independently by two reviewers. This may have resulted in extractor bias (Felson, 1992).

There is also not yet a definition of participation that has been universally accepted and as a result, concerns are raised as to the reliability of measures used to assess participation outcomes. There appears to be a discrepancy between the language used and the applied measures (Imms et al., 2016), which may have influenced the articles included in the search strategy. As better conceptual agreement on the concept of participation is established, more specific measures should be developed to measure the construct.

Researchers are encouraged to increase the quality of the design of their prospective longitudinal research and the reporting of their findings (Morin et al., 2018). Therefore, researchers should aim to improve the conceptualisation, design and analysis of longitudinal research (Ployhart & Vandenberg, 2010). Following best practice principles of what constitutes state of the art longitudinal research will assist researchers in developing theories that address the 'when', 'why' and 'duration' of change of their outcomes of interest (Ployhart & Ward, 2011). Additionally, carefully planned and documented longitudinal studies not only allow researchers to use the available data but can also serve as a foundation upon which to build current or new theories (Bergman, 1996). The results of this research support the idea that the state of the art criteria from Ployhart and Vandenberg (2010) should be used to develop a quality appraisal tool for systematic reviews.

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Appendix A

Ethical clearance

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

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 Mrs L Kruger
Project Title: A state of the art of the theory, design and analysis of longitudinal research on activity performance and participation in home and community environments of children and youth with disabilities: A systematic review
Researcher: Mrs L Kruger
Supervisor(s): Dr AE Samuels
Department: CAAC
Reference number: 17248125 (HUM025/1020)
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.za

Appendix B

Pilot searches

	Preliminary search 1	Preliminary search 2	Preliminary search 3	Preliminary search 4	Final search
Search concept 1	disab* OR intellectual disab* OR development* delay* OR development* disab OR “developmental disorder” OR “special need” OR “communication disorders” OR disorder* OR “AAC” OR “Augmentative and Alternative Communication”	disab* OR intellectual disab* OR develop* delay* OR develop* disab* OR “developmental disorder” OR “motor disorder” OR “special need*” OR “communication disorders” OR “AAC” OR “Augmentative and Alternative Communication”	disab* OR “special need*” OR “AAC” OR “Augmentative and Alternative Communication”	disab* OR “AAC” OR “Augmentative and Alternative Communication”	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”
Search concept 2	child* OR youth OR adolesc* OR teen* OR “young adult”	child* OR youth OR adolesc* OR teen* OR “young adult” OR pediatric OR paediatric	child* OR youth OR adolesc* OR teen* OR “young adult” OR pediatric OR paediatric	child* OR youth OR adolesc* OR teen* OR “young adult” OR pediatric OR paediatric	child* OR youth* OR adolesc* OR teen* OR “young adult*” OR p*ediatric
Search concept 3	longitudinal OR “multi wave” OR “developmental trajectory*” OR “long term traject*” OR “over time” OR “follow-up” OR “life span” OR prospective	longitudinal OR “multi wave” OR “over time” OR “follow-up” OR “life span” OR prospective or “interval” or “change” or “longitudinal traject*”	longitudinal OR “over time” OR “follow-up” OR “life span” OR prospective or “interval” or “change”	longitudinal OR “over time” OR “follow-up” OR prospective or “interval” or “change”	"longitudinal" OR “longitudinal stud*” OR “longitudinal research” OR “longitudinal method*” OR “longitudinal trajector*”
Search concept 4	participation OR “social participation” OR functioning OR “everyday life situations” OR engagement OR involvement OR “activities of daily living” OR capabilit* OR performance	participation OR “social participation” OR functioning OR “everyday life situations” OR engagement OR involvement OR “activities of daily living” OR capabilit* OR performance OR “ICF” OR “ICF-CY”	participation OR “social participation” OR “community participation” OR engagement OR involvement OR capabilit* OR performance OR “ICF” OR “ICF-CY” OR recreation OR leisure	participation OR engagement OR “activity performance” OR recreation* OR leisure	participat* OR engagement OR involvement OR “activity performance” OR recreation* OR leisure OR “home participation” OR “community participation” OR ADL

Appendix C

Pilot search results

	Preliminary search 1	Preliminary search 2	Preliminary search 3	Preliminary search 4	Final search
Academic Search Complete	7822	4039	2735	1247	2814
APA PsychINFO	12527	3508	2276	748	1146
CINAHL	7017	2739	1826	769	1011
Health Source Nursing	1694	1233	853	440	976
MEDLINE	14869	5458	3564	1278	2255

Appendix D

Title and Abstract Screening Relevance Tool

The state of the art of the theory, design and analysis of longitudinal research on activity performance or participation in home and community environments of children and youth with disabilities: A systematic review

Title and Abstract Screening Relevance Tool

General information	
Title of article	
Year of publication	
Authors	

1. Is children and youth the target population of the study?
    - ☐ Yes
    - ☐ No
    - ☐ Maybe
2. Does the study report a permanent childhood or developmental disability?
    - ☐ Yes
    - ☐ No
    - ☐ Maybe
3. Does the outcome relate to participation or activity performance?
    - ☐ Yes
    - ☐ No
    - ☐ Maybe
4. Is the research focused on activities or participation within the home or in the community?
    - ☐ Yes
    - ☐ No
    - ☐ Maybe
5. Is the study longitudinal in nature?
    - ☐ Yes
    - ☐ No
    - ☐ Maybe
6. Was the study published between 2005 and 2021?
    - ☐ Yes
    - ☐ No
    - ☐ Maybe
7. Is the study published in English?
    - ☐ Yes
    - ☐ No
    - ☐ Maybe

Outcome of the screening:

- If the answer is ‘No’ to any of the questions, the citation will be excluded.
- If the reviewer answers ‘Yes’ to all of the questions, the citation will be included in the next stage i.e. full text screening.
- If the reviewer answers ‘Maybe’ to any of the questions, the citation will also be included in the next stage i.e. full text screening.

Appendix E

Data extraction form

General information	
Title	
Date of publication	
Authors	
Study purpose	
Research questions	
Participants	
Focus level target group	☐ Children (age range two to 12 years) ☐ Youth (age range 13 to 20 years)
Number of participants (at baseline)	
Gender	Male N = Female N =
Age at wave 1	Range: Mean age (SD):
Type of disability or impairment	
AAC	☐ Yes ☐ No
Method	
Study design	☐ Quantitative ☐ Mixed ☐ Descriptive longitudinal ☐ Explanatory longitudinal
Duration of study in months or years	
Number of waves	
Theory of change	
Functional form of change hypothesis or expectation	
Predictors of change hypothesis	
Level of change hypothesis	
Determined optimal number of waves according to hypothesis? (If yes transcribe)	☐ Yes ☐ No

Quantitative change design considerations	
Timing of observations	☐ Set time points Specify set time points in months or years ____________________________ ☐ According to key transition stages based on theory (Transcribe theory)
Sampling	☐ Purposive ☐ Convenience ☐ Other *Transcribe rationale (if any) for sampling strategy
Attrition	Sample at final wave ____________________ Authors comments regarding attrition_______________________________________ Planned for attrition in sampling procedure ☐ Yes ☐ No
Checked for longitudinal measurement invariance?	☐ Yes ☐ No
Quantitative data analysis	
Analytical statistical procedures used to document change in outcome variables (transcribe)	
Reasons for analytic method (If Yes, transcribe)	☐ Yes ☐ No
Change results documented (transcribe how)	
Controlled for missing data in analysis (If Yes, transcribe)	☐ Yes ☐ No

Change outcome of interest (transcribe)	
Activities (capability)	
Activities (performance)	
Participation (being there/frequency of attendance)	
Participation (degree/level of engagement or involvement)	
Hypothesised predictors of change outcomes (if any)	
Measuring instruments for change outcome variable/s:	
Measuring instruments for predictors of change (if any)	
Child role in data collection	☐ Tested ☐ Self-rated ☐ Proxy rated ☐ Observed ☐ Interviewed
Results and conclusions	
Transcribe conclusions regarding patterns of activities	☐
Transcribe conclusions regarding predictors of activities	☐
Transcribe conclusions regarding patterns of participation	☐
Transcribe conclusions regarding predictors of participation	☐

Appendix F

Declaration of language editor

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Writer and Editor

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5 November 2021

To Whom It May Concern,

I hereby confirm that I conducted the language editing of the mini-dissertation, ‘The state of the art of the theory, design and analysis of longitudinal research on activity performance or participation in home and community environments of children and youth with disabilities: A systematic review’, by Liné Kruger

Kind regards,

Toni Ingrid Muir
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