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Behrens, Theresa Juanita

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Pilot study: Home, school and community participation of children attending a special needs school in South Africa: Barriers and supports

Theresa Juanita Behrens

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg in partial fulfilment of the requirements for the degree of Masters of Science in Medicine Child Health (Neuro-development option).

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ABSTRACT

Background:

The International Classification of Functioning, Disability and Health (ICF) is an important framework when describing disability. Participation is seen as the “ultimate goal in rehabilitation” and is a multidimensional construct. The environment has a significant influence on the participation of children and is an important aspect of intervention. Therefore measuring the participation of children in various environments is crucial. The Participation and Environment Measure for Children and Youth (PEM-CY) is a fairly new tool that was developed to determine participation in relation to certain environmental aspects. The aim of this pilot study was to describe the patterns of participation in the home, school and community of children attending a learner with special educational needs school (LSEN) in Gauteng province, South Africa.

Objectives:

To examine patterns of **home, school and community** participation and environmental factors that affect home, school and community participation of children attending a special needs school using the PEM-CY. To determine if there is a difference in participation based on whether the child attends Academic phase, Special phase or Vocational phase schooling and based on the child's primary diagnosis using the PEM-CY.

Methods:

The PEM-CY was piloted in this sample of 378 parents of children attending the LSEN school between the ages of five and 17. One hundred questionnaires were analysed.

Findings:

There were no significant differences found between the groups. The results showed that participation in the home and school was good, children participated with regular frequency and involvement. Participation in the community was fairly regular, with good involvement, however with low frequency. The results showed that the participation was lower compared to children without disabilities in some instances, similar to previous research with regards to the participation of children with disabilities. However, in some activities the children in this study participated at a level similar to children without disabilities. Parents desired changes in extra-mural type activities and special roles at schools. Barriers to participation were mainly financial, lack of programmes and services, information, social demands and cognitive demands. Parents felt supported when they received sufficient information and additional supplies for assistive devices or school supplies.

Conclusion:

The PEM-CY has been proven useful in this group of children and it is recommended that future studies validate it for use in the South African population.

DECLARATION

I, **Theresa Juanita Behrens**, declare that this research report is my own unaided work except for the help given by the persons listed under the acknowledgments. It is being submitted in partial fulfillment of the requirements of the degree of Master of Science in Medicine, Child Health (Neuro-development option) at the University of the Witwatersrand. It has not been submitted before for any other degree or examination in any other university.

Signed this day in Johannesburg

_____

Signature

2017.07.17

Date

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ADD	Attention Deficit Disorder
APS	Assistance to Participate Scale (APS)
ASKp	Activity Scale for Kids – Performance versions
CASP	Child and Adolescent Scale of Participation
CAPE/PAC	Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children
CHORES	Children Helping Out: Responsibilities, Expectations and Supports
CLASS	Children's Leisure Assessment Scale
COPM	Canadian Occupational Performance Measure
CPQ	Children Participation Questionnaire
CP	Cerebral Palsy
GAS	Goal Attainment Scaling
HESSI	Household Economic and Social Status Index
ICF	International classification of Functioning, Disability and Health
ICF-CY	International classification of Functioning, Disability and Health – Children and Youth Version
LAQ-CP	The Lifestyle Assessment Questionnaire
LIFE-H	Assessment of Life Habits
LSEN	Learner with special educational needs
MMH	Mild Mental Handicap
NGO	Non Government Organisation
PACS	Pediatric Activity Card Sort
PADL	Participation in Activities of Daily Living
PCPQ	Pediatric Community Participation Questionnaire
PD	Physical Disability
PEM-CY	Participation and Environment Measure for Children and Youth
PICO-Q	Participation in Childhood Occupations Questionnaire

PIP	Pediatric Interest Profile
Preschool ACS	Preschool Activity Card Sort
RDP	Reconstruction and Development Programme
SIAS	Policy on screening, identification, assessment and support (SIAS)
SFA-P	School Function Assessment – Participation section
SLD	Specific Learning Disability
SOM	School Outcome Measure

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CHAPTER 1: INTRODUCTION

There has been an international movement, after the publication of the International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY) towards treating children with disabilities by not only focusing on their body structures and functions but also looking at their participation in society (home, school and community). Participation is described by the ICF-CY as “involvement in a life situation” and is the ultimate goal of rehabilitation (WHO, 2007). Many factors influence participation, including both environmental and personal factors (WHO, 2007; Bult et al., 2011). Personal factors may differ in diverse cultures and are therefore not as easy to modify as environmental factors (Coster et al., 2012). According to the ICF-CY there can be barriers and facilitators in the environment that influence the participation of an individual (WHO, 2007). When considering an environment, one most often considers the physical environment first, however the social and attitudinal environment is as important when looking at a child's level of participation (Heah et al., 2007). Children with a range of disabilities including physical, cognitive and social disabilities experience barriers and supports to inclusive participation in society. These may include; the effect of technology and the natural environment, personal relationships, attitudes of others, adaptations for the child's abilities and policies on services and systems (Bedell et al., 2011; Kramer et al., 2012; Anaby et al., 2013).

Children with disabilities described “successful participation” in terms of a number of themes namely; “having fun, feeling successful, doing and being with others, and doing things myself”. The parents in this study identified that it was important for the children to be present, included, to have a sibling or a friend in the community participating with them and to have some form of independence (Heah et al., 2007). Furthermore, they emphasized the importance of the social, cultural and institutional environment in facilitating or hindering the participation of their child. The value of the link between the environment and participation was further emphasized in a study done by Bedell et al (2011). After the publication of the ICF-CY, more tools have been designed to measure participation within the environment, which are helping to bridge the gap between these two important constructs (Anaby et al., 2013).

Only a few studies conducted in South Africa looking at the participation of children with Cerebral Palsy have been published. One study which aimed at evaluating how adolescents experience being disabled in a special needs school, highlighted that children with physical disabilities don't like to be seen as disabled. They view disabled children as children who are in wheelchairs and aren't able to do anything for themselves. As these children were still able to mobilize independently, or do some things independently, they consider themselves as “different” (Bantjes et al., 2015). Another study conducted in a special needs school looked at barriers and facilitators to physical activity and identified that adolescents found that there were many physiological, psychological, social and macro-environmental factors that both facilitated and inhibited their participation in physical activity. The authors concluded that in order to change the participation of children within different environments, we would have to challenge existing practices and policies (Conchar et al., 2014).

A systematic review done by Bult et al., 2011, described what factors influenced participation in leisure activities of children and youth with physical disabilities. They described each factor in relation to the ICF-CY. Important variables identified that all contributed to participation restrictions included; the more severe gross motor function, severity of the physical disability, severity of the learning disability and severity of communicative and speech disability. Other studies have shown that increased participation leads to improved quality of life (Law, 2002; Whiteneck & Dijkers, 2009; Yeung & Towers, 2014). This further highlights the importance of describing these two constructs as together.

South Africa is a low-middle income country that is affected by poverty, poor infrastructure, low levels of literacy and belief in witchcraft. These factors all greatly contribute to environmental factors (physical, social and attitudinal) that may be barriers to children trying to participate in these communities (Maart et al., 2007). A study considering the overall participation of children in South Africa identified a number of limiting factors some being related to child rearing, expectations of children, power of adults and children's “voice” within society. It is clear from this study that there are definitely barriers to participation in the private/personal domain and in the social/public domain (Moses, 2008).

In 2001, the Department of Education issued a framework policy document called White Paper 6: Special Needs Education, Building an Inclusive Education and Training System. This policy framework is to be completely implemented by the year 2021. The main aim of this policy was to acknowledge that all children have the right to learn and should be attending schools. Children needing low levels of support would be able to be accommodated in “ordinary schools”, whereas those needing more assistance would be able to attend “full service schools”, and those needing high level of support would be accommodated in “special schools” (Department of Education, 2001). Although the implementation of the inclusive education system has been criticized, most recently by Engelbrecht et al., (2016), the need to accommodate more children with disabilities into schools is evident. The White Paper 6's aim was to transform the South African schooling system in the hope to reduce the stigma around disability and improve participation of the disabled population in society (Department of Education, 2001).

To date there have been no studies evaluating the effect of the environment at home, school and the community on the participation of children attending a special needs school in South Africa. A new measure, the Participation and Environment Measure for Children and Youth (PEM-CY), was specifically developed to assess the effect of the environment on the participation in the home, school and community for children with and without disabilities. The tool will be discussed in further detail in Chapter 2. Due to the tool being fairly new only a few studies using it have been done, however, preliminary testing has shown it to be quite useful (Coster et al., 2011). This tool can be used in large scale population studies in schools, to help identify improvements that can be made to the environment to facilitate participation.

Therefore this study will be used to pilot this measure in a special needs school in South Africa. If proving to be useful, it could be used in future studies nationally to determine whether the home, school and community environment of children facilitates better participation and for program implementation and evaluation.

Problem Statement:

In the South African context, there have been no studies to date evaluating the effect of the home, school and community environment on the participation of children with disabilities attending a special needs school.

Research Question:

What is the effect of the home, school and community environment on the participation of children with disabilities who attend a special needs school in South Africa?

Aim of Study:

To determine the factors that facilitate or inhibit participation in the home, school and community environment of children with disabilities at a special needs school in South Africa.

Objectives of the Study:

1. To examine patterns of **home** participation and environmental factors that affect home participation of children attending a special needs school using the PEM-CY.
2. To examine patterns of **school** participation and environmental factors that affect school participation of children attending a special needs school using the PEM-CY.
3. To examine patterns of **community** participation and environmental factors that affect community participation of children attending a special needs school using the PEM-CY.
4. To determine if there is a difference in participation based on whether the child attends Academic phase, Special phase or Vocational phase schooling using the PEM-CY.
5. To determine if there is a difference in participation based on the child's primary diagnosis using the PEM-CY.
6. To determine if there is a correlation between socio-economic status and participation at home, school and in the community.

Significance of the study:

This study will identify environmental factors limiting and facilitating participation in the home, school and community for children with disabilities. The information obtained from this study

may help guide principals, teachers, therapists, parents and other role-players to identify areas in the environment that are limiting the participation for all children, and may help facilitate inclusive education policy programs. This study could form the base for further studies to examine other special needs schools and mainstream schools that are implementing inclusive education policies.

Conclusion:

Despite other studies on the participation of children with and without disabilities in the home, school and community being conducted, to date no studies have been conducted in South Africa. Therefore, the aim of this study is to investigate the participation in the home, school and community of children attending a special needs school in Gauteng province of South Africa.

CHAPTER 2: LITERATURE REVIEW

This chapter will discuss the International Classification of Functioning, Disability and Health (ICF), with special attention given to the children and youth version. It will then go on to look at different aspects of childhood disability and participation. This review will discuss measures of participation and will take a closer look at the literature on the measures used in this study. It will then look at what inclusive education is, and what the Department of Education envisions for children with disabilities in South Africa. To conclude this section, the effect of socio-economic circumstances on children with disabilities will be discussed.

Literature was sourced through comprehensive searches on the following databases: Pubmed, EBSCOhost, Google Scholar, and the references of useful articles were hand searched for further studies that would be applicable to this literature review. The following are the key words that were used in searches: participation, children, disability/ies, physical disability, childhood disability, environment, home, school, community, PEM-CY, participation measures, ICF, ICF-CY, white paper 6, inclusion, inclusive education, socio-economic and HESSI. English articles from 1991 to 2015 were reviewed as presented in the section that follows.

2.1. International Classification of Functioning, Disability and Health – Children and Youth Version

The ICF is an important framework that was developed to characterise disability as a social problem and not as a medical issue that sees the individual's impairments as the cause of poor integration into society (McConachie et al., 2006) and it was used to develop a common language and approach to develop a conceptual basis that integrates the major models in the field. The International Classification of Functioning, Disability and Health – Children and Youth version (ICF-CY) was developed from the International Classification of Functioning, Disability and Health (ICF) to be specifically geared towards children, considering that they

are unique in that they are still developing. The ICF-CY is a framework which can be used to look at how a child is functioning in terms of age appropriate skills and functions. This framework can be used to identify how services can be improved to encourage better participation in life (WHO, 2007).

Participation is seen as the ultimate goal in rehabilitation, but to achieve optimal participation one needs to look at the activities that influence participation. In terms of the ICF-CY activities are further affected by body functions and structures (medical conditions) and contextual factors (personal and environmental). Body structures are the anatomical parts of a person, bones, muscles, veins, arteries, organs, etc. Body function is the physiological functioning of a person, such as the endocrine systems, cardiovascular systems, psychological functioning and so forth. Personal contextual factors are related to the person's personality, temperament, age, gender, race, relationships and any aspects relating to the self. Environmental contextual factors refers to the physical environment (accessibility), attitudinal environment (how others treat you), policies and procedures (access to schools, availability, etc.) and the social environment (cultural norms). The ICF and ICF-CY describe environmental factors as “the physical, social and attitudinal environment in which people live and conduct their lives”(WHO, 2007: 15).

The ICF and ICF-CY defines activities as the “execution of a task or action” (kicking a ball) and participation as a person's “involvement in a life situation” (playing soccer with your friends)(WHO, 2007: 12). There are nine domains in the ICF-CY referring to participation and activities.

1. learning and applying knowledge
2. general tasks and demands
3. communication
4. mobility
5. self-care
6. domestic life
7. interpersonal relationships
8. major life areas

9. community, civic and social life (WHO, 2007: 27–28)

Some debate over these domains has been raised. Chien et al. (2014) proposed that one to five refer more to activities and seven to nine refer more to participation and Whiteneck & Dijkers, (2009) shared a similar view. Coster and Khetani (2008), however, proposed that the first four domains be identified as activity domains and the last five as participation domains.

The ICF-CY focuses on the child in four important areas with regards to child development, “the child in the context of the family, developmental delay, participation and environments”(WHO, 2007: xv–xvii). The family is an important factor in influencing the child's development and what they are exposed to. The concept of participation is complex in children due to the fact that children are developing and at different stages of the child's life there will be various developmental opportunities to participate in. Children will develop certain skills as they age and experience changes in their body composition. It is important to understand what the concept of “delay or lags” is with regards to the acquisition of these skills and body structures. These “delays or lags” can manifest in a number of domains such as cognitive functioning, intellectual functioning, gross and fine motor development, speech and communication. Often the child's participation is dependent on the parent or caregivers, as there are certain activities that are dictated by adults (e.g. bath time for an adult may be an activity, whereas for a child it may be participation). A child's environment significantly affects their development. The environment is ever-changing and therefore has an impact on how the child develops, initially the child will be very dependent, slowly moving towards more independence. Altering a child's social, physical or psychological environment can have a significant impact on improving development (WHO, 2007).

Since the release of the ICF and ICF-CY, participation is seen as the ultimate goal to rehabilitation (WHO, 2007). As this is a fairly broad concept, it is difficult to measure the participation of children with disabilities. The ICF-CY has identified the environment as a key factor in contributing to a child's participation in their home, school and community. There are five potential environmental factors that can be influenced namely:

1. Products and technology

2. Natural environment and human-made changes to environment
3. Support and relationships
4. Attitudes and
5. Services, systems and policies (including health services and systems) (WHO, 2007).

2.2. Childhood disability and participation

Participation "*occurs at the intersection of what the person can do, wants to do, has the opportunity or affordances to do, and is not prevented from doing by the world in which the person lives and seeks to participate*" (Mallinson & Hammel, 2010: S30) Participation has been identified as a multidimensional concept, and is not simple to describe (King et al., 2003; Bult et al., 2011). This section will describe the current literature on participation and physical disabilities and on other disabilities. We will discuss the effect of the environment on participation and what it means to parents and children with disabilities. Lastly the effect of gender and age on participation will be discussed.

2.2.1. Participation and physical disability:

A recent scoping review done by Anaby et al., (2013) looked at the current research on how the environment affects the participation of children with disabilities in the community. Most research has been done in the domain of physical disabilities, categorizing the disabilities into neurological (cerebral palsy, traumatic brain injury, spinal cord injury, etc.) and musculoskeletal conditions (such as amputation, brachial plexus lesion, etc). There is minimal literature on the effect of the environment on other disabilities (Anaby et al., 2013) In an integrative review done by Kanagasabai et al. (2014) of high quality studies, different aspects of leisure participation and associated physical disability was studied. Most studies looked at children with cerebral palsy, however a few studies looked at children with developmental coordination disorder. There was a weak to moderate association between specific leisure participation and motor function. The six aspects considered were; diversity, context, preferences, enjoyment, quality and frequency of leisure participation. Motor function was

shown to affect the **diversity** of participation ranging from walking ability being predictive of being more actively involved, to being severely limited with decreased motor function. In terms of the **context** of leisure activities children who were more functional were involved in a broader range of activities with friends in different environments compared to children who were more affected. Motor function did have an effect on **preference** of leisure activities and children with developmental coordination disorder were more likely to choose sedentary activities. In children with cerebral palsy, leisure activities were chosen according to their motor abilities. The **level of enjoyment** in participating in a leisure activity was shown to be significantly influenced by interacting with peers. It was found that children with disabilities enjoyed interacting with other children where they felt accepted (Kanagasabai et al., 2014). In the study by Engel-Yeger et al. (2009) it was found that youth with disabilities often engage in activities alone, as the need for assistance or accessibility was an issue, whereas children of similar age participate more with peers. The **quality** of participating in leisure activities only showed moderate predictive value in terms of functional levels. The quality was affected by the degree of assistance needed from others. The **frequency** of leisure participation was the most extensively researched. The child's level of motor function was predictive of the frequency of participation, children who were more functional participated more frequently in leisure activities. Children with developmental coordination disorder were found to have no difference in frequency and motor ability (Kanagasabai et al., 2014). A systematic review done by Bult et al.,(2011), identified certain aspects that influence participation, namely having more severe motor problems, problems handling objects and the number of limbs implicated resulted in more restricted participation. Children with developmental coordination disorder had different participation patterns compared to typically developing peers, namely lower participation in social and physical activities. Children with cerebral palsy who experienced learning difficulties, suffered from seizures and communication and speech difficulties likewise had barriers to leisure participation, with more severe problems being predictive of greater restrictions (Bult et al., 2011).

Other studies done on motor ability and participation showed similar results, namely more functional motor levels resulting in greater participation (Simeonsson et al., 2001; Schenker, Coster & Parush, 2005; Maher et al., 2007; Imms et al., 2008; King et al., 2009; Majnemer et

al., 2010; Mâsse et al., 2013; Bloemen et al., 2015). One study showed that only children with a severe motor impairment had participation restrictions (Imms et al., 2008). Children with cerebral palsy with better motor ability were found to have higher diversity and intensity with overall participation when compared to children who had poorer mobility levels (Orlin et al., 2010). Children with acquired brain injury were found to be less involved or unable to participate when compared to typically developing peers. An aid or teacher providing assistance was an important factor in enhancing participation (Galvin, Froude & McAleer, 2010). Children with more complex disabilities were found to participate more in informal activities than formal activities (Law et al., 2006; Imms et al., 2008), as formal activities aren't as accessible or applicable for children with complex disabilities. Albeit, other studies have found that due to lack of opportunities and the necessary supports children with complex disabilities didn't participate in as many informal activities (King et al., 2006)

In a large study, compared to typically developing peers (354), children with disabilities (427) took part in fewer formal and informal activities (King et al., 2009). A smaller study comparing children with disabilities (22) and children without disabilities (30) didn't find many differences in participation in formal activities, however these children were all attending a school and it was hypothesized that their formal activities were arranged by teachers and therapists. They did however find differences with regards to informal activities, where children with physical disabilities had less diverse participation, and this may be due to the accessibility of participation opportunities. Youth with disabilities still experienced enjoyment in participation even though this study showed less diversity and intensity in participation (Engel-Yeger et al., 2009).

In a systematic review by Shikako-Thomas et al., (2008) children with physical disabilities had less variety in the activities that they participated in. They mostly sedentary type activities that were planned by parents and mostly took place in the home environment. These children often participated with their parents or in isolation, whereas typically developing peers were found to participate in activities with their friends. A large study conducted by Colver et al., (2011), that looked at children with cerebral palsy in the European region, found that children who were more involved, had an impaired walking ability and had a greater intellectual

impairment, had less access to physical environments which affected participation. Children with intellectual impairment and communication difficulties didn't receive sufficient social support and had less access to physical environments (Colver et al., 2011). A large study on teachers in special education found that children with neurological and physical disabilities were more restricted than children with other disabilities (Simeonsson et al., 2001).

2.2.2. Participation of children with other disabilities such as cognitive, intellectual, emotional or behavioural conditions:

Very little to no research has been conducted on the participation of children with other disabilities (Coster & Khetani, 2008; Anaby et al., 2013). A review by Bult et al., (2011) also found that most studies focused on children with cerebral palsy and few were done on other conditions.

Most research is conducted on cerebral palsy, as children with cerebral palsy often have a combination of disabilities. It was found that if children with cerebral palsy had additional communication, language, and learning difficulties they were further restricted in their participation (Schenker, Coster & Parush, 2005). Few studies conducted research on autism spectrum disorders and no studies were found that looked at the effect of visual impairment, speech and language impairment and learning disabilities and the barriers that these children and parents experience to participation (Coster & Khetani, 2008; Anaby et al., 2013).

A study looking at children with high functioning autism spectrum disorder and out-of-school participation, found that these children were limited in the activities they participated in (Hilton, Crouch & Israel, 2008). A study comparing the quality of life of children with psychiatric conditions compared to children with physical health problems (including disabilities, asthma, diabetes, and epilepsy), suggested that children with psychiatric conditions had a reduced quality of life (Sawyer et al., 2002). It is however, imperative to note that participation and quality of life are not synonymous. Following an acquired brain injury, children often experience cognitive problems, in a study by Galvin, Froude & McAleer (2010) it was found that there were barriers to participation as these children struggled to learn new skills, cope in

unpredictable environments, and communicate effectively when playing games. In a study looking at children with physical disabilities, if these children had above threshold behavioural problems they experienced additional barriers to participation (Law et al., 2007). A study looking at children with neurodevelopmental disorders and disabilities found that children with difficulties in social interaction and psychological issues, had lower participation in school educational activities (Mâsse et al., 2013).

Parents of children with behavioural, cognitive, emotional and intellectual difficulties struggled to identify what facilitated or provided a barrier to their child's participation (Bedell et al., 2011). Successful participation was evaluated by how the environment and their child interacted, these parents couldn't separate the two constructs. It is noteworthy that these parent's identified factors in the environment which related to the sensory aspects (lights and sounds), social, cognitive demands and attitudes of others that were particularly limiting in terms of participation (Bedell et al., 2011).

2.2.3. Participation and the environment:

Parents often felt they needed to describe the context in which their child was participating to be able to fully describe how they participated, this showed that the environment is important when considering participation (Bedell et al., 2011; Coster et al., 2012). It is as important as the type of cerebral palsy, walking ability and degree of intellectual impairment in determining the level of participation attained (Hammal, Jarvis & Colver, 2004).

In a review of evidence examining environmental aspects that affect participation of children with cerebral palsy, the authors described three principal levels: *“the individual’s experience of their local environment; an objective assessment of the disability-friendliness or conduciveness to participation of a local environment; and the legislative, attitudinal and regulatory framework for the environment at national level*” (Mihaylov et al., 2004: 302). These are useful aspects to consider for all disabilities. Most of the studies identified environmental factors as having an impact on disabilities, however in a review half of the included studies didn't identify environmental factors as having a significant effect on participation (Bult et al.,

2011).

2.2.3.1 Physical, social and attitudinal environment

When considering the environment the first thought is often the physical environment and the accessibility of the physical environment. This is an important consideration when looking at children with physical disabilities as it may be a major limiting factor. However one should not forget that the social and attitudinal environment has a great impact on the participation of children with all types of disabilities (Law et al., 1999; Heah et al., 2007; Shikako-Thomas et al., 2008; Whiteneck & Dijkers, 2009). Parents of children with physical disabilities identified that although the accessibility of the physical environment was important, attitudes and beliefs of others was more limiting (Law et al., 1999).

Aspects that influence participation in the environment are accessibility of the environment, attitudes of others, transportation, self-care (toileting facilities), time (planning a trip, tying shoe laces may take longer) and skills (being able to join/contribute to a team sport) (Law et al., 1999; Kanagasabai et al., 2014). A systematic review by Shikako-Thomas et al., (2008) similarly noted the importance of an accessible physical environment, the attitudes of others and social policies and procedures in facilitating better participation.

Considering the three environments, physical, social and attitudinal, this review found different barriers hindering participation in each. In the physical environment the lack of equipment and structural barriers influenced participation. Policies, segregation, lack of information and organization and peer support were aspects of the social environment. Lastly, bullying, staring and being dependent on an adult were important determinants in the attitudinal environment (Shikako-Thomas et al., 2008).

When looking at the individual's immediate environment, things like lower socio-economic status and lower parental educational level influenced participation and this also influenced leisure preferences and social support (Shikako-Thomas et al., 2008). A large European study examined what aspects of the physical, social and attitudinal environment affected participation in four developed countries. Having mobility (a wheelchair or assistive device)

and sufficient transport (private adapted vehicles or public transport) were essential to achieving participation. Often children in this study had to attend special schools which resulted in them being in schools far away from home. Organizing social activities for their children and their children's friends was often difficult. Having a supportive family was imperative to satisfying participation. Often having extra help at home, although very welcome, resulted in the family's privacy being invaded. The parents felt they lacked information and spent many hours trying to source specialized equipment for their children. In terms of the attitudinal environment, positive schools and staff resulted in better participation. However, often in public these families were subjected to staring and negative comments (McManus et al., 2006). In a qualitative study on children with developmental coordination disorder, parents describe how the effect of a negative or positive environment changed the outcome of their child's performance (Mandich, Polatajko & Rodger, 2003). Aspects that improved participation were supportive peers, family and teachers (King et al., 2006).

2.2.3.2. Participation in the home environment

Parents expressed greater satisfaction with participation at home (Law et al., 1999). Law et al., (2013) found that parents of children with disabilities experienced more barriers to participation in the home than parent's of children without disabilities. The parents in this study described environmental features such as demands of the activity and lack of availability and inadequacy of resources as participation restrictions. Children with disabilities in this study participated more in sedentary type activities (Coster, Law, Bedell, Khetani, et al., 2013).

Another study, however, found that at home more adaptations were made by parents to encourage participation (King et al., 2003). Children with disabilities were found to participate more frequently if their parents made significant efforts to encourage or provide participation opportunities (Law et al., 1999; King et al., 2003). Participation was more centered around the home, with much less participation in the community (Imms et al., 2008).

2.2.3.3. Participation in the school environment

In a South African study on teachers' attitudes and experiences towards inclusive education, it was highlighted that insufficient physical environment (facilities, infrastructure and assistive devices) and the attitudes and perceptions of teachers and learners was perceived as a barrier to inclusive education (Swart et al., 2002; Engelbrecht et al., 2005), thus participation in the school environment.

A case study found that teachers and learners perceived those with disabilities, those who speak a different language and those who are poverty stricken as “different” (Engelbrecht, 2006), this impacts the attitudinal environment. When a partnership is formed between parents and teachers, facilitation of inclusive participation is improved (Engelbrecht et al., 2005). Learners with disabilities in special schools felt they related better to their peers than learners attending mainstream schools. The authors hypothesized that to improve participation one may need to do more than just place children in close proximity to each other, opportunities for interaction may need to be created (Almqvist & Granlund, 2005). Conversely another study found that students attending a mainstream school increased participation opportunities (Bult et al., 2011).

In a large study looking at high school student's participation in certain activities, it was found that the availability of suitable resources, the age and sex of the child was important in determining participation (Garton & Pratt, 1991). In a study by Coster, et al., (2013) looking at children with and without disabilities it was found that children with disabilities had a lower level of involvement, reduced frequency and more of their parents desired a change in their participation. The parents of children with disabilities more often described features of the environment as limiting participation.

2.2.3.4. Participation in the community environment

In a South African study it was found that in the community there aren't sufficient community

support systems in poverty stricken neighbourhoods (Engelbrecht, 2006). This results in poor participation in the community. In another study, after an acquired brain injury, children struggled with participation in structured activities, that required advanced motor and cognitive skills to participate socially with others in the community, therefore the social environment significantly affected their participation (Galvin, Froude & McAleer, 2010). The children in this study experienced many barriers to participation including government agencies and policies, program design or the lack of appropriate programs, the parents expressed the lack of financial aid, and poor quality or lack of services for their children (Galvin, Froude & McAleer, 2010).

In a large study looking at children with various disabilities, reported that often cerebral palsy organisations provide opportunities for involvement, however, local support is mostly lacking (Longmuir & Oded, 2000). A study looking at the difference between two cultures, hypothesized that cultural effects have a great influence on participation in the community (Engel-Yeger, Jarus & Law, 2007). In a further study comparing children with and without disabilities, participation in the community was lower for children with disabilities, with reduced frequency and involvement and their parents more often expressed a desire for change in their participation. More parents of children with disabilities reported that features of the community environment resulted in reduced participation (Bedell et al., 2013).

The ICF-CY identifies that the environment has an important impact on a child's level of participation and is a potentially modifiable factor (WHO, 2007). The environment is easier to change than the body structure and function of a child to improve their participation goals (Law et al., 2007; Anaby et al., 2014). Barriers to participation in the home, school and community environment can be modified to improve participation and this is therefore an area of interest to develop suitable interventions (Coster et al., 2012).

2.2.4. Participation: what it means to parents and children with disabilities:

In a qualitative study parents expressed that people don't understand how it feels to be a

parent of a child with a disability. These parents often had to deal with others' comments (positive and negative) about their children. They were constantly faced with challenges related to institutions and policies and procedures (Law et al., 1999).

Heah et al., (2007), found four themes that are important regarding participation of children with disabilities and their parents, these were namely "*having fun", "feeling successful", "doing and being with others" and "doing things by myself*"(Heah et al., 2007: 44). Four important themes emerged in this study with regards to the environmental supports and barriers and these were "community program designs", "parent values and preferences", "parent vigilance" and "social and physical support" (Heah et al., 2007). Parents identify that the environment has an impact on their child's participation (Law et al., 1999; Galvin, Froude & McAleer, 2010; Piškur et al., 2012). It was highlighted in the qualitative research by Heah et al. (2007) that participation is not always significant when done alone, and that a shared experience is important. Parents identified that subtle changes in their child's behaviour and non-verbal signs indicated how well they were participating.

Successful participation isn't always measured on the child's performance (Heah et al., 2007). Parents have identified that fully integrating their children into activities would change perceptions and attitudes of others (Law et al., 1999; Piškur et al., 2012). A recent qualitative meta-synthesis identified three factors that influence participation: "adult and peer understanding of individual abilities and needs; decisions about accommodations; and the quality of services and policies". They also identified levels of participation which they described as "doing what everyone else is doing", "fringe participation", "waiting and watching" and "doing something different". These factors either made the environment less accessible for participation or more accessible (Kramer et al., 2012). A scoping review on parental strategies to enable better participation discovered two important themes namely "*1. parents enable and support performance of meaningful activities, and 2. parents enable, change and use the environment*" (Piškur et al., 2012: 6). Parents would like to see the world be better adapted to suit their child, instead of changing their child to fit into the world (Law et al., 1999).

2.2.5. Considerations of participation in child development:

Young children's participation is very dependent on the adults around them and therefore cannot be seen as a separate phenomenon (Forsyth & Jarvis, 2002; Bedell et al., 2011). That is why the ICF-CY emphasizes that a child should be viewed within their functioning in the family unit as a child moves for being completely dependent to slowly becoming more independent. Furthermore, it is important to consider that a child's body functions and structures are changing as they develop and that at different stages different skills will emerge. It is important to consider what are the age appropriate skills and functions of that child when considering participation (WHO, 2007). A change in participation is seen with increasing age. Children above the age of 12, tend to participate with lower intensity in all activity types, except social and self-improvement activities (Jarus et al., 2010). A review by Bult et al., (2011) had a similar finding showing that as children age they participate in less activities and with a lower frequency. Other studies had similar findings (Longmuir & Oded, 2000; Maher et al., 2007; Hilton, Crouch & Israel, 2008; Majnemer et al., 2008; Jarus et al., 2010; Coster, Law, Bedell, Liljenquist, et al., 2013; Bloemen et al., 2015). As children with physical disabilities age, they become more isolated (Law et al., 2006; Engel-Yeger et al., 2009).

2.2.6. Gender and participation

The pattern of participation differs for boys and girls (Engel-Yeger, Jarus & Law, 2007; Shikako-Thomas et al., 2008). Girls are more likely to participate in a greater diversity and with more intensity in skill-based activities, social and informal activities. Boys participate mainly in physical activities with a higher intensity and diversity of participation (Jarus et al., 2010; Bult et al., 2011).

Other studies likewise found similar differences in participation between genders (Posner & Vandell, 1999; Majnemer et al., 2010). Some studies found no differences between genders (Longmuir & Oded, 2000; Simeonsson et al., 2001; Law et al., 2013).

2.3. Measures of participation:

As the ICF is a fairly recent publication, not many tools have been developed to measure participation as outlined in the ICF (Forsyth & Jarvis, 2002). This is further confounded by the loose definition of participation as described by the ICF. The ICF doesn't differentiate well between the concept of activities and participation (Coster & Khetani, 2008; Mallinson & Hammel, 2010). Whiteneck and Dijkers (2009) proposed that activity is what the individual does and participation is how that individual performs in society. This however is not fully applicable to children's participation as it is often dictated by their parents. Activities that are performed by the individual as an adult may often involve engagement with others when you're a child (Forsyth & Jarvis, 2002; Coster & Khetani, 2008; Coster et al., 2012). Coster and Khetani (2008) described the definition of participation as being "flexible" which makes the development of measurable tools difficult. These authors proposed the following definitions, participation was defined as "*life situations [that] are characterized by sets of organized sequences of activities directed toward a personally or socially meaningful goal"* and activities as *"units from which such sequences may be constructed" (Coster & Khetani, 2008: 643)*.

Participation is the result of successful interaction between the following factors; *"1. disability, 2. environmental factors, 3. aids/assistance, 4. personal choices/values"(Forsyth & Jarvis, 2002: 278)*. Participation is a multidimensional and transactional aspect, tools need to reflect these properties (Mallinson & Hammel, 2010). It must be noted that participation is not the same as quality of life (McConachie et al., 2006). Most available tools test participation and environment in isolation, but this assumes that they are separate constructs. If one is only considering the physical environment this may be appropriate, but when measuring participation within the social and attitudinal environment it is important to measure the two constructs together (Coster et al., 2012). There are five environmental aspects in the ICF-CY that may influence participation namely: products and technology; the natural and built environment; support and relationships; attitudes, values and beliefs; and services and

policies (WHO, 2007). Participation covers four life areas namely: "*1. participation is essential for survival, 2. participation in relation to child development, 3. discretionary participation, 4. educational participation"* (McConachie et al., 2006: 1160–1161).

A good measure would be able to detect changes in a child's participation in different environments. A few areas that may make it difficult to develop such a tool are due to the developing nature of children, there may be individual differences in different cultures and increased frequency may not necessarily be linked to an individual's satisfaction with their participation (Coster et al., 2012). The subjective and objective dimension of participation needs to be captured within an appropriate tool (Whiteneck & Dijkers, 2009; Eyssen et al., 2011). The subjective aspect is whether the child enjoys the activity, feels included, contributes meaningfully and the value they attached to it, the objective aspect relates to the frequency, the number of activities and whether the child can access different participation opportunities (Coster et al., 2012). It is necessary to have a measure that links different aspects of the ICF-CY so that important constructs and rehabilitation outcomes can be measured (Coster et al., 2012), for "real-life" situations (Mallinson & Hammel, 2010).

Child self-report on their perception of participation would be ideal. This however poses a problem for participation measurement tool developers, as the tool would need to be developmentally appropriate. This is further complicated when considering children with severe disabilities, who have co-morbid disabilities such as, visual, communication, learning and motor difficulties (McConachie et al., 2006). A structured review done by Morris, Kurinczuk & Fitzpatrick, (2005) theorised that family report measures may be more feasible than clinicians completing lengthy assessments. This likewise makes large scale research more possible. Another review by Sakzewski, Boyd & Ziviani, (2007) cautioned against "assessment burden" of researchers and clinicians. Lastly an important aspect of a measure to consider, is whether it is applicable to all cultures (Stevelink & van Brakel, 2013).

When considering measures of participation it is important to look at what aspects of the ICF-CY are measured and to make inferences on the outcome, according to those constructs. All measures don't encompass every participation domain as outlined by the ICF-CY.

(Sakzewski, Boyd & Ziviani, 2007; Chien et al., 2014). According to the comprehensive review of 16 measures by Chien et al. (2014), which included children aged two to twelve years, with a range of disabilities the APS, CASP, PEM-CY and SFA-P covered the most participation items. In terms of the nine domains of the ICF-CY, the PEM-CY and CASP covered all of them. See Table 2.1 below for a description of the tools included in the review. Additional tools are SOM, COPM, GAS and LAQ-CP, these were described in systematic reviews by Morris, JJ & Fitzpatrick, (2005); McConachie et al., (2006) and Sakzewski, Boyd & Ziviani, (2007). Only measures of participation and tools not previously mentioned were included in the Table 2.1.

Table 2.1. Participation measures

Measurement	*Age range*	*Disability*	*Type of report*	*Domains*
ASKp	5 to 15 years	Physical disability resulting from musculoskeletal disorders	Child self-report questionnaire	7 physical functioning domains
LIFE-H	0 to 13 years	With disabilities	Child or parent questionnaire, by interview of directly	12 domains related to daily activities and social roles
APS	5 to 18 years	With disabilities	Caregiver report questionnaire	Play and leisure activities in the home and in the community, how much assistance is needed
CASP	3 to 22 years	Varied diagnoses	Parent-report questionnaire	Participation in home, school and community compared to children of the same age
CHORES	6 to 11 years	With/without disabilities	Parent-report questionnaire	Household tasks across two domains namely self-care and family care.
CPQ	4 to 6 years	With/without disabilities	Parent-report questionnaire	6 domains (activities of daily living, instrumental activities of daily living, play, leisure, social participation, education)
CAPE/PAC	6 to 21 years	With/without disabilities	Questionnaire-based measure that can be completed by child self-report or interview	Activities outside of school. Looks at 6 dimensions of participation (diversity, intensity, with who, where, enjoyment and preference)
CLASS	10 to 18 years	With/without disabilities	Child self-report questionnaire	4 domains
PEM-CY	5 to 17 years	With/without disabilities	Parent-report questionnaire	Comprehensive range of life situations across home, school and community settings
PADL	6 to 18 years	Chronic/acute health conditions	Interview-based child-report questionnaire	13 items that are rated on participation frequency and attitude to participation
PICO-Q	6 to 10 years	With/without sensory modulation disorder	Parent-report questionnaire	4 participation areas
PACS	5 to 14 years	With/without disabilities	Interview-based self-report measure	4 childhood life domains
PCPQ	8 to 20 years	With disabilities	Child-report questionnaire	Covers participation domains in activities of daily living and play or leisure
PIP	6 to 21 years (3 age versions)	With/without disabilities	Child self-report questionnaire	Play and leisure interests
Preschool ACS	3 to 6 years	With/without disabilities	Parent interview	7 preschool life domains
SFA-P	Not given	Not given	School personal directly or by interview	Participation in 6 different school settings
SOM	3-18 years	Not given	Judgement based therapist rating	Self-care and mobility, assuming student role, expressing

				learning
COPM	All ages	All disabilities	Semi-structured interview	Client rating of performance and satisfaction for identified occupations (self-care, productivity, and leisure)
GAS	All ages	All disabilities	Semi-structured interview	Individual goals expressed on a 5-point scale
LAQ-CP	3-10 years	Condition-specific for children with cerebral palsy and their families	Parent-report questionnaire	Mobility, physical independence, clinical and economic burden, schooling and social integration

ASKp = Activity Scale for Kids – Performance version; LIFE-H = Assessment of Life Habits; APS = Assistance to Participate Scale; CASP = Child and Adolescent Scale of Participation; CHORES = Children Helping Out: Responsibilities, Expectations and Supports; CPQ = Children Participation Questionnaire; CAPE/PAC = Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children; CLASS = Children's Leisure Assessment Scale; PEM-CY = Participation and Environment Measure for Children and Youth; PADL = Participation in Activities of Daily Living; PICO-Q = Participation in Childhood Occupations Questionnaire; PACS = Pediatric Activity Card Sort; PCPQ = Pediatric Community Participation Questionnaire ; PIP = Pediatric Interest Profile; Preschool ACS = Preschool Activity Card Sort; SFA-P = School Function Assessment – Participation section; SOM = School Outcome Measure; COPM = Canadian Occupational Performance Measure; GAS = Goal Attainment Scaling; LAQ-CP = The Lifestyle Assessment Questionnaire

2.4. Participation and Environment Measure for Children and Youth (PEM-CY)

The Participation and Environment Measure for Children and Youth is a parent-report questionnaire on the participation of their child within their various environments (home, school and community). The tool was specifically designed to link the participation aspect to the environment in which the child participates. The importance of this link has previously been discussed. The PEM-CY was designed to assist in large-scale population research as well as to be used with individual children and their families to identify areas of need or change. The tool can be used to facilitate changes in the environment to encourage better participation for children. It can help guide policy and program design and implementation. The tool was specifically designed to be used for children aged between five and 17 years of age, with or without disabilities and was designed to detect differences in their participation trends. This tool was seen to reflect what parents felt was important in the participation of their children (Coster et al., 2012).

The PEM-CY was designed using the ICF-CY as a guideline as well as qualitative research involving parents of children with a variety of disabilities. There are 25 different categories of activities that children are involved in (10 for the home environment, five for the school environment and 10 for the community environment). The age limit was set for five to 17 years to make sure that the activities would be applicable to this group of children. The parents are asked how frequently their child participates in the activity, how involved they are and whether they desire a change in their child's participation. The frequency was included as it is an objective indicator and can support research. How involved the child is in an activity was an important factor in participation identified by the parents, but was difficult to measure as the developers of the tool did not want this to be restricted by how the child participated and their performance in the activity. Desire for change responses were listed categorically and this was done to gauge how satisfied the parents were with their child's participation. The parents could indicate whether they wanted more or less involvement, more or less frequency or whether they wanted their child to be involved in a greater variety of

activities (Coster et al., 2012). Table 2.2 shows the responses in more detail.

Table 2.2. PEM-CY Questionnaire responses

Questions for each item	***Response options***	***Code***
Frequency: Typically, how often does your child participate in 1 or more activities of this type? Select ONE response	Daily	7
	A few times a week	6
	Once a week	5
	A few times a month	4
	Once a month	3
	A few times in the last 4 months	2
	Once in the last 4 months	1
	Never	0
Level of involvement: Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities	Very involved	5
		4
	Somewhat involved	3
		2
	Minimally involved	1
Desire for change: Would you like your child's participation to change in these types of activities? Select ALL THAT APPLY.	No, change desired	5
	Yes, do more often	4
	Yes, do less often	3
	Yes, be more involved	2
	Yes, be less involved	1
	Yes, be involved in a broader variety of activities	0

*Table compiled from information taken from the PEM-CY manual. (Coster et al., 2014)

The PEM-CY further examines how supportive the environment is. It looks at the different dimensions of the environment namely the physical layout, the sensory elements, social support, cognitive demands and the attitudes of others. It examines whether there are sufficient assistive devices or resources to facilitate the participation of their child. These are categorized under environmental helpfulness and environmental resources (Coster et al., 2012).

The reliability of the PEM-CY has been shown to be acceptable. The PEM-CY has an internal consistency of α= 0.59 to 0.91 and a test-retest reliability ICC = 0.58 to 0.95 over a period of 1-4 weeks (Coster et al., 2012). Initial construct validity analysis sought to investigate whether the PEM-CY was able to discriminate between children with disabilities and those who were typically developing. There were significant differences between the two groups across all settings and in all age ranges. Further analysis confirmed that there was a significant negative correlation between Desire for Change scores and Environmental Supportiveness (Coster et al., 2011).

2.5. Inclusive education

The right to education has resulted in a shift in the teaching practices of children with disabilities. Internationally the movement has resulted in a more inclusive teaching environment (Ehrmann, Aeschleman & Svanum, 1995). In 2001, the South African Department of Education issued a framework policy document called White Paper 6: Special Needs Education, Building an Inclusive Education and Training System. This policy framework is to be completely implemented by the year 2021. The main aim of this policy was to acknowledge that all children, regardless of race, gender, disability or ethnicity have the right to learn and should be attending schools.

Furthermore, learners with barriers to learning have a wide variety of educational needs that need to be accommodated for within the education system. The White Paper 6 was issued to be in line with international guidelines that all children have the right to education. Many children with disabilities aren't attending school and those with barriers to learning are not receiving the necessary support. Due to the previous Apartheid regime, some African children weren't allowed to attend school or the quality of schooling was poor. The “white” special schools were well resourced whereas the “black” special schools were under-resourced and the quality of education was poor. The Department of Education aims to improve education for all and redress the inequalities of the past. The policy proposed that children needing low level of support would be accommodated in “ordinary schools”, whereas those needing more

assistance would attend “full service schools” and special needs school would be for learners requiring “high-intensive educational support”. Special schools would furthermore be used as resource centres for neighbouring schools to provide support for learners with special educational needs. The White Paper 6 document's aim was to transform the South African schooling system in a hope to reduce the stigma around disability and improve participation of the disabled population in society (Department of Education, 2001).

Although the White Paper 6: Special Needs Education, building an inclusive education and training system (2001) document as a framework is in line with international goals for education, many have criticized the implementation and progress of it. Many parents struggle to find appropriate schools for their children, find it challenging to find inclusive mainstream schools and are faced with negative attitudes and resistance (Engelbrecht, 2006; Donohue & Bornman, 2014; Walton et al., 2014; Engelbrecht et al., 2016). Teachers expressed that they felt they required more training and skills, were under-resourced, infrastructure and facilities weren't available and that learner's with special needs may receive better support in “special classes” (Swart et al., 2002; Engelbrecht, 2006; Donohue & Bornman, 2014; Walton et al., 2014; Engelbrecht et al., 2016). Since the release of the White Paper 6 document, further inclusive education policy documents have been released such as the policy on screening, identification, assessment and support (SIAS), which further explains how each learner has the right to be accommodated into a school, and has the right to have an appropriate assessment of their needs, and should have these needs accommodated (Education, 2014)

Full participation in school is associated with more positive outcomes (Simeonsson et al., 2001). Children who attend regular schools had greater participation experiences (Longo, Badia & Orgaz, 2013). However merely placing children with disabilities in “regular” schools is not sufficient to encourage participation. The opportunities for interaction need to be created (Simeonsson et al., 2001).

2.6. Socio-economic status

Many aspects related to socio-economic status affect the participation of children in their home, school and community. Often the accessibility of rural homes is limiting for children with disabilities, especially those with assistive devices (Heap, Lorenzo & Thomas, 2009). Parents aren't always able to purchase the expensive equipment (standing frames, wheelchairs, alternative and augmentative communication devices, etc.) that facilitate better participation (Law et al., 1999; Morris et al., 2006; Piškur et al., 2012). In a systematic review by Shikako-Thomas et al., (2008) an included study found that parents of children with disabilities experienced the high cost of assistive devices and equipment necessary to facilitate participation as a major limitation to engaging in participation opportunities. This is further exacerbated by the finding that families of a disabled child have less earned and disposable income than those without (Mihaylov et al., 2004). Families needing to care for their children often had to make major changes to their employment (Morris et al., 2006).

A few studies in South Africa examined participation and access to education for children with disabilities. Due to South Africa being a low-income country it was hypothesized that due to financial constraints parents were more likely to send non-disabled children to school as they may in future contribute to the family's income (Donohue & Bornman, 2014). A study that looked at poverty and disability in the Western and Eastern Cape Provinces of South Africa, found that even though the economic situation was equal between families with and without disabilities, due to issuing of disability grants, people with disabilities had significantly lower access to education (Loeb et al., 2008). This by implication affects the participation in the school and the community. In future it will affect integration into society. Another study looking at intellectual and associated disabilities reported that if a child had a borderline intellectual disability the socio-economic circumstances in South Africa would most likely predispose him to developing an intellectual disability (Christianson et al., 2002). In international studies it was found that higher incomes resulted in fewer barriers, which improved participation (King et al., 2006; Anaby et al., 2014). Other variables that affected participation in activities were lower income, lower parental education level (Shikako-Thomas et al., 2008), non-Caucasian ethnicity of the parent, lower parental physical functioning, increased parental stress (Bult et

al., 2011) and single-parent status (Barbarin & Khomo, 1997).Parents of children living in high crime areas, more often sent their children to other districts for schooling, which resulted in their children spending excess time in transit, allowing less time for extramural activities (Posner & Vandell, 1999). A study conducted in Canada, found that children in lower income areas were less likely to participate in “supervised physical activity out-of-school” and “music/art lessons” (Mâsse et al., 2013).

Community participation was found to be challenging within the South African context. Public transport is mainly used in rural parts of South Africa, however the public transport system is not well developed. Often parents with disabled children are not able to access public transport, and making use of private vehicles is expensive (Heap, Lorenzo & Thomas, 2009) this by implication makes accessing the community challenging. It was further found that often public buildings are not designed to accommodate disabled individuals (Heap, Lorenzo & Thomas, 2009). In international studies income was shown to affect community participation in terms of participation frequency and level of involvement (Anaby et al., 2014). Mihaylov et al., (2004) similarly found that income influenced the use of local sport and leisure facilities. Another study found that 25 percent of families felt unsupported in their community and that only half of the people they interacted with understood their child's disability. Their child's disability further resulted in increased family stress and influenced leisure activities and vacations (Morris et al., 2006).

The Household Economic and Social Status Index (HESSI) was adapted to suit the current study and all relevant information was utilized. The HESSI scale focuses on hunger, housing, utility expenses, possession of durable consumer goods, accumulation of assets and social status as reflected in education attainment, marital status, occupation and family structure as opposed to a financial self-report as often respondents answer untruthfully (Barbarin & Khomo, 1997).

2.7. Conclusion

In summary, literature has shown that the environment has an impact on the participation of children with and without disabilities. Children with disabilities experience more barriers to participation. To improve participation, appropriate measurements need to be used, so that program implementation can be measured.

CHAPTER 3: METHODS

This chapter will discuss the locations of the study, ethical considerations, study design, subjects, materials and measurements, the procedures used to collect data, and data analysis.

3.1. Location

This study was conducted at Frances Vorwerg School in the South of Johannesburg, Gauteng. This school is a “learner with special educational needs” (LSEN) school, which accommodates children with physical disabilities and moderate to severe learning disabilities.

3.2. Ethical considerations

Ethical clearance was obtained from the University of Witwatersrand Human Research Ethics Committee (Appendix I). Permission to conduct the study was obtained from the Department of Education (Appendix II) and the principal of Frances Vorwerg School before any questionnaires were distributed.

As this study involves human participants, it is imperative that the participants rights were respected. Therefore each parent of a child attending Frances Vorwerg School received an information sheet (Appendix VI), which described the purpose of the study and the content of the study. They received an informed consent document to complete (Appendix III), which once completed indicated their participation in the study and their permission for the researcher to obtain additional information (date of birth, diagnosis and form of schooling) from their child's school medical file. Participation in the study was not mandatory and any participant wishing to withdraw from the study, at any time, could do so with no consequences. The primary researcher was the only person who had access to the

questionnaires and it was therefore completely confidential.

3.3. Study design

This study was a descriptive study: Once-off parent report questionnaire (PEM-CY) was used to collect data.

3.4. Study participants

The parents of all children attending the Academic phase, Special phase or Vocational phase schooling at Frances Vorwerg School in Gauteng province were invited to participate in the study. Children attending the Academic phase of the school follow the national curriculum statement, with reduced class size (approximately 12-17 learners in a class). This phase mostly has children with specific learning disabilities and physical disabilities, however the children are still able to follow the national curriculum statement. Children attending the Special phase follow the national curriculum statement that has been adapted and they are able to complete grade 1 to grade 4, at a pace that is adjusted to the learner's abilities. Children in this phase have the opportunity to learn adapted skills such as sewing, beading and gardening. This phase mainly has children with physical disabilities and severe mental handicap. Children in the Vocational phase follow an adult education training (AET) program, level four of this accredited program is equivalent to grade nine exit level. The children in this phase mostly have mild mental handicap and physical disabilities. Children attending this phase participate in skill classes such as cooking, metal work and wood work. Most learners are from a low to middle income background. The most common diagnoses of learners attending this school are: cerebral palsy (CP), mild mental handicap (MMH), attention deficit hyperactivity disorder (ADHD), physical disabilities (PD) and specific learning disabilities (SLD).

3.5. Inclusion criteria

- Parents of children between the ages of 5-17 years old who attended Frances Vorwerg Special needs school.
- Participants of the study had to identify themselves as parents or the primary care-giver of the child attending Frances Vorwerg Special needs school.

3.6. Exclusion criteria

- Parents under the age of 18 years of age.
- Parents of children under the age of 5 and/or over the age of 17 who were enrolled in this school

3.7. Outcome measures

- Participation and Environment Measure for Children and Youth (PEM-CY) (APPENDIX:VI) was used to assess patterns of participation in the home, school and community and identify what environmental factors affect participation in the home, school and the community for school aged children with a broad range of disabilities. The PEM-CY is divided into the three domains home (10 items), school (five items) and community (10 items). The parents of the children were then asked to describe their child's participation in terms of frequency (daily to never), level of involvement (very involved to minimally involved) and whether the parent would like to see a change in the child's participation (no or yes, and then what type of change). Parents were further asked if there were any features of the environment that helped or made it harder for their child to participate. These items were based on the ICF-CY. Parents were also asked about perceived adequacy of resources (Coster et al., 2012). (Appendix VI)

- A caregiver questionnaire was compiled based on the Household Economic and Social Status Index (HESSI), this helped identify what types of environments the children were exposed to. It was important to look at the social-economic status of children, as it can have a profound effect on the development of the child as resources are important to promote development (Barbarin & Khomo, 1997). (Appendix V).

3.8. Procedure:

1. Each child in the school was allocated a participant number.
2. Each document had a participant number on it, which coincided with a list kept by the researcher so that no personal information could be identified on the documents.
3. All parents of children who attend Frances Vorwerg School were invited to participate in the study.
4. An envelope containing the information sheet (Appendix IV), informed consent (Appendix III), PEM-CY (Appendix VI), the caregiver questionnaire (Appendix V) and an envelope for returning the documents, was sent home with each child attending Frances Vorwerg School.
5. A sealed box was placed outside the Physiotherapy department and in front at the reception area where the parents could deposit their completed or uncompleted forms, depending on their willingness to participate in the study. If they were unable to deposit them during the school term, the boxes were available during the school's parent's evening.
6. A reminder was placed in the school newsletter, however the school printer was broken and the newsletter was not distributed to the parents in time.
7. Once completed documents were received, the researcher obtained information from the child's school medical file. Information collected consisted of the child's date of birth, type of schooling and official diagnosis.
8. Results were recorded on a data collection sheet. (Appendix VII)
9. All completed forms were analysed.

3.9. Statistical Analysis

Data was analysed using STATA 14 (StataCorp USA). Basic descriptive statistics were conducted for the descriptive information collected on the participants of the study. The scores and descriptive information were assessed for compatibility with having been drawn at random from normally distributed populations by means of the Shapiro–Wilk test. The Shapiro-Wilk test is used to ascertain normal distribution for data of fewer than 2 000 observations. An unpaired t-test was used to compare the means of two groups if the data met with the requirements for a normal distribution. Where the data were not normally distributed, the Wilcoxon-Mann-Whitney test was used to compare the means of different groups. The test ranks the data in terms of closest and farthest from the median to determine if there is a difference between population medians. For comparison of scores between groups Kruskal wallis because likert data was collected. Chi square test was used to test for association between categorical variables and one way anova was used for continuous variables where there were more than two groups. Statistical significance will be accepted if $p \leq 0.05$

3.10. Conclusion

This chapter has discussed the locations of the study, ethical considerations, study design, study participants, inclusion and exclusion criteria, outcome measures used, the procedures used to collect data and the statistical analysis of the data. In the following chapter the results of the study will be discussed.

CHAPTER 4: RESULTS

This chapter will present the results of the study. The school has a total of 403 children, with an age range of between three years of age and 21 year of age. The children are mainly diagnosed with specific learning disabilities, mild mental handicap, severe mental handicap, physical disabilities or cerebral palsy. Three hundred and seventy eight questionnaires were sent out to children between the ages of five and 17, 148 were returned, of those received back 48 declined to participate, 100 parents completed the questionnaire in full or partially. All information collected was analysed. Three hundred and thirty questionnaires were not returned.

First the data on the demographics of the children and then the demographics of the participants (parents) will be presented. The data collected from the caregiver questionnaire will be presented next, this will be followed by the different sections (home, school and community) of the PEM-CY. Descriptive statistics were used to analyse the data and will be shown in tables.

4.1. Data on the participants' children

The children were 40% female with a mean age of 11.9 (±3). The participants were not evenly distributed across the three phases, Special phase (14%), Academic phase (62%) and Vocational phase (24%). Table 4.1 describes the demographics of the children.

Table 4.1. Demographics of Children

	Special phase (n=14)	***Academic phase (n=62)***	***Vocational phase (n=24)***	***P value***
Age	12.70	10.80	14.30	0.05
Gender % female	28.60	38.70	50.00	0.41

*chi square test was used for categorical variables and one way anova was used for continuous variables

Figure 4.1 shows the distribution of the age of the children. The mean age of the children in

the Vocational phase was higher, which may be due to the fact that the ages of the children accepted into this phase range from age 14 and up. The Academic phase and Special phase accept children from the age of five and eight years respectively, the Academic phase goes until grade nine and the Special phase will take young people up to the age of 21 years.

Figure 4.1. Distribution of age

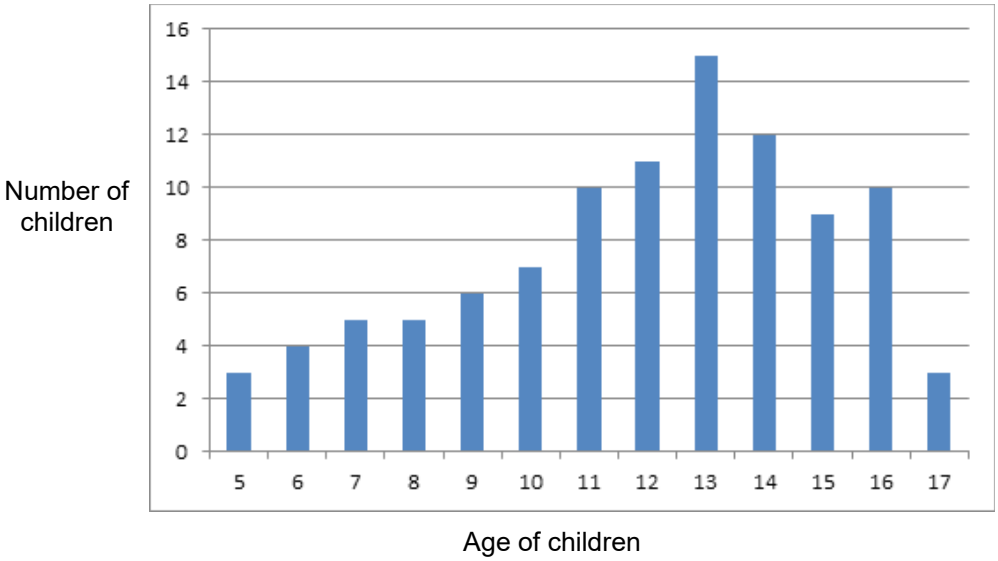


Table 4.2 shows the distribution of the primary diagnosis of the child as recorded in their school file.

Table 4.2. Demographic Primary Medical Diagnosis:

Diagnosis	***(N = 100)***
Cerebral Palsy	20
Specific Learning Disability (Speech and Language)	7
Specific Learning Disability (General)	19
Mild Mental Handicap	22
Hard of Hearing	2
Specific Learning Disability (ADHD)	10
Physical Disability (Traumatic brain injury)	5
Severe Mental Handicap	1
Specific Learning Disability (ADD)	2
Specific Learning Disability	4
Physical Disability (Medical)	1
Physical Disability (Spina Bifida)	1

Autism Spectrum Disorder	2
Physical Disability (Ehlers Danlos Syndrome)	2
Physical Disability (Neurofibromatosis)	1
Physical Disability (Muscular Dystrophy)	1

The primary diagnosis is supplied to the school for admission weighting. For further analysis these were grouped by type of disability. All children with specific learning disabilities (SLD) were grouped together, these included specific learning disabilities related to sensory impairment, speech and language (communication) disorder, attention deficit disorder, attention deficit hyperactivity disorder or a general learning disability. Included in this group were the two children who were categorized as hard of hearing. Three children with the primary diagnosis of severe mental handicap were grouped with the children with mild mental handicap (MMH), as two of the three children were attending the Vocational phase and were therefore not as likely to be severe. All physical disabilities (PD) were grouped together, including children diagnosed with Spina Bifida, Medical, Ehlers Danlos Syndrome, Traumatic brain injury, Muscular Dystrophy and Neurofibromatosis. Children with Cerebral Palsy (CP) were placed in a group on their own. The demographics of the children by primary diagnosis grouped is shown in Table 4.3 and in Table 4.4 the number of children with the grouped primary diagnosis in each phase is presented.

Table 4.3. Demographics of the children by primary diagnosis grouped

	CP	***SLD***	***MMH***	***PD***	***P value***
Age	11.4	11.1	14.2	10.6	0.05
Gender % female	40.0	34.9	52.0	33.3	0.534

As seen in Table 4.3, the age of the children according to primary diagnosis grouped is very similar except children diagnosed with mild mental handicap (MMH), this showed a significant difference (p=0.05).

Table 4.4. Diagnosis and phase of schooling of the children

Primary Diagnosis group	***Special phase (n=14)***	***Academic phases (n=62)***	***Vocational phase (n=24)***
CP	8	11	1
SLD	2	41	0
MMH	1	1	23
PD	3	9	0

The Vocational phase consisted mainly of children diagnosed with MMH, whereas 66% of the Academic phase had the diagnosis of specific learning disability (SLD). The Special phase had 57% of children with primary diagnosis of cerebral palsy (CP). Even though not all parents responded, there is not an unusual bias in the type of disability by phase as the protocol that determines what phase accepts which type of child is partially dependent on their diagnosis.

4.2. Caregiver questionnaire data

Table 4.5 reports on the demographics of the marital status of the respondents.

Table 4.5. Demographics of respondents marital status (N=90):

Marital Status	***n***	***Percent***
Married	46	51.11
Divorced	20	22.22
Widowed	2	2.22
Living with a partner	10	11.11
Single	12	13.33

Just over half of the children's parents were married and 22% were divorced. Table 4.6 presents the educational level of the mothers and the mother's partner.

Table 4.6. Mother's and mother's partner's educational level

	Level of education	***Percentage of participants***
Mother's education	Grade 11 or less	30.4%
	Matric	41.3%
	Post matric education	28.3%
Mother's partner's education	Grade 11 or less	31.0%
	Matric	32.4%
	Post matric education	36.6%

The level of education was similar for the mothers and the mother's partner. The main

difference between the mothers and their partners was that more of the mothers' education stopped at matric. It is important to note that the number who are poorly educated is the same for mothers and the mother's partners.

Most families had access to finances, however two households had no persons earning an income, 84% percent of the participants had two or less earning an income in their house. Most households (87%) had six or less people living in their house, of this 30% had five people living in the house. The vast majority of the participants had inside flush toilets, a separate kitchen and a separate bathroom. The type of house that the families lived in is tabulated in Table 4.7.

Table 4.7 Type of house

Type of house	***n***	***Percentage***
Room	1	1.04%
RDP	4	4.17%
Flat	17	17.71%
Home shared with other family	14	14.58%
Home that is not shared with other families	60	62.50%

In terms of neighbourhood safety, 68% of respondents felt they lived in a safe neighbourhood, 23% felt they lived in a dangerous neighbourhood and 8% felt they lived in a very safe neighbourhood. Most participants felt that they only sometimes had family problems (84%) and 16% felt that they often or always had family problems. Most parents (65%) felt they always had support, 28% felt they sometimes or often had support and 6% felt that they never had enough support from their family.

The parents of the children were asked what they thought was their child's most prevalent disability and they could then indicate all additional disabilities, this information is represented in Table 4.8.

Table 4.8. Diagnosis according to the children's parent's

Disability	***Most Prevalent disability***	***All Disabilities***
Developmental Delay	8 (8.9)	14 (8.6)
Intellectual delay	8 (8.9)	15 (9.2)
Hearing impairment	2 (2.2)	8 (4.9)
Speech/language impairment	12 (13.3)	18 (11.0)
Vision impairment	2 (2.2)	11 (6.7)
Emotional impairment	6 (6.7)	22 (13.5)
Orthopaedic impairment	7 (7.8)	4 (2.4)
Autism spectrum disorder	2 (2.2)	4 (2.4)
Attention-deficit disorder	10 (11.1)	18 (11.0)
Traumatic brain injury	3 (3.3)	4 (2.4)
Learning disability	20 (22.2)	29 (17.8)
Health impairment	1 (1.1)	2 (1.2)
Other	9 (10.0)	14 (8.6)
Total	90	163

The most prevalent disability was learning disability (22%), followed by speech/language impairment. When asked what the additional disabilities were, most parents indicated that their child had a learning disability (17.8%) and an emotional impairment (13.5%). More than 50% of the children had an additional disability.

4.3. PEM-CY Home Data

Analysis of the PEM-CY home section showed that 92% of parents answered the home activities question whereas 71% and 98% answered the school activities and community activities section respectively.

In this section, data on the number of activities done at home, the frequency, level of involvement and desire for change, for the whole sample will be presented for each activity (Table 4.9). This will be followed by the PEM-CY summary scores, firstly for the whole sample (Table 4.10) and then for the different groups, primary diagnosis (Table 4.11) and type of schooling (Table 4.12).

Table 4.9. Number of activities done at home by all the participants

	% of those who answered the question	*% of those who never participate*	*Frequency median (mean)*	*Level of involvement mean (SD)*	*Desire for change n (%)*
Computer and video games	90	10	6 (4.8)	4.1 (1.2)	40 (60)
Indoor play and games	86	14	6 (4.6)	3.9 (1.4)	39 (63)
Art crafts music and hobbies	97	3	6 (5.3)	4.1 (1.2)	37 (45.4)
Watching TV videos and DVD's	100	0	7 (6.6)	4.3 (1.1)	41 (64)
Getting together with others	98	2	6 (5.8)	4.2 (1.0)	31 (45)
Socializing using technology	84	16	6 (4.8)	3.7 (1.5)	37 (57)
Household chores	93	7	6 (5.4)	3.3 (1.5)	48 (69.6)
Personal care management	98	2	7 (6.6)	4.0 (1.1)	38 (54.3)
School prep	92	8	7 (5.5)	3.6 (1.3)	41 (62)
Homework	98	2	7 (6.4)	3.7 (1.2)	48 (70.6)

Analysing the activities done by the whole sample (Table 4.9), it was apparent that all the children in this sample watched TV (100%), followed by homework (98%), personal care (98%) and getting together with others (98%). Children are possibly encouraged to do these activities at home. All of the activities were done fairly frequently (4.6 – 6.6), where zero is equal to never and seven is equal to daily. The level of involvement as perceived by the parents was the highest for “watching TV, videos and DVDs”, followed by “personal care management”. Most parents desired a change in their child's homework (70.6%) and household chores (69.6%).

Table 4.10 presents the PEM-CY summary scores for the whole sample, means and standard deviations will be presented.

Table 4.10. PEM-CY summary scores for the whole sample: descriptive statistics for participation in the home environment. (Means and standard deviation)

	Min-max	***Whole sample***	***≤ 12***	***≥ 12***	***Male***	***Female***
Number of activities done at home	4.0-10.0	9.1 (1.1)	9.0 (1.0)	9.1 (1.2)	9.1 (1.1)	9.1 (1.1)
Frequency of participation	3.6-7.0	5.6 (0.7)	5.6 (0.7)	5.6 (0.7)	5.7 (0.7)	5.5 (0.7)
Level of involvement	2.8-5.0	3.9 (0.6)	3.8 (0.6)	3.9 (0.6)	3.7 (0.6)	4.1 (0.7)
Number of activities – change desired	0.0-10.0	4.1 (2.9)	4.2 (3.0)	4.0 (2.8)	3.9 (2.9)	4.4 (2.8)
Number of barriers in the home	0.0-7.0	0.8 (1.3)	0.9 (1.6)	0.7 (1.1)	0.9 (1.5)	0.7 (0.9)
Number of supports in the home	0.0-12.0	3.5 (2.3)	3.5 (2.3)	3.5 (2.4)	3.1 (2.0)	4.0 (2.7)

The children in our sample participated in nine out of 10 activities at home. The frequency of participation was a “few times a week” and the children were relatively involved (3.9, where five is very involved). The parents desired a change in less than half of the activities. Very few barriers and supports were perceived by the parents. There were no differences between age and gender, except in the domain of change, where parents of girls desired change in slightly more activities than parents of boys.

In Table 4.11 (grouped by diagnosis) and Table 4.12 (grouped by type of schooling) the PEM-CY summary scores will be presented summarized as means and standard deviations.

Table 4.11. PEM-CY summary scores: descriptive statistics and differences between grouped primary diagnosis for participation in the home environment. (Mean and standard deviation)

	CP	***SLD***	***MMH***	***PD***	***p-value***
Number of activities done at home	8.8 (0.98)	9.1 (1.0)	9.0 (1.4)	9.2 (1.2)	0.4407
Frequency of participation	5.2 (0.9)	5.7 (0.7)	5.6 (0.6)	5.9 (0.4)	0.0515
Level of involvement	4.1 (0.5)	3.8 (0.7)	3.7 (0.64)	3.8 (0.7)	0.4341
Number of activities – change desired	3.6 (2.9)	4.4 (2.6)	4.4 (3.3)	3.6 (3.5)	0.8442
Number of barriers in the home	1 (1.3)	0.8 (1.5)	0.52 (0.77)	0.8 (1.6)	0.6015
Number of supports in the home	3.3 (2.5)	3.8 (2.4)	2.76 (1.7)	4 (2.9)	0.3347

As seen in Table 4.11, children with cerebral palsy (CP) participated in slightly less activities at home. In terms of participation frequency, children with cerebral palsy had the lowest frequency of participation (5.2), which was closer to significance (p-value=0.0515) than those diagnosed with other conditions, with larger sample numbers we may have seen a significant difference. Children with all conditions were relatively involved at home (3.7-4.1 where five is very involved). Parents desired change in less than fifty percent of the activities at home. Relatively few barriers and supports were perceived by parents in the home environment. Many parents found the environment sometimes facilitating and sometimes not.

Table 4.12. PEM-CY summary scores: descriptive statistics and differences between types of schooling for participation in the home environment. (Mean and standard deviation)

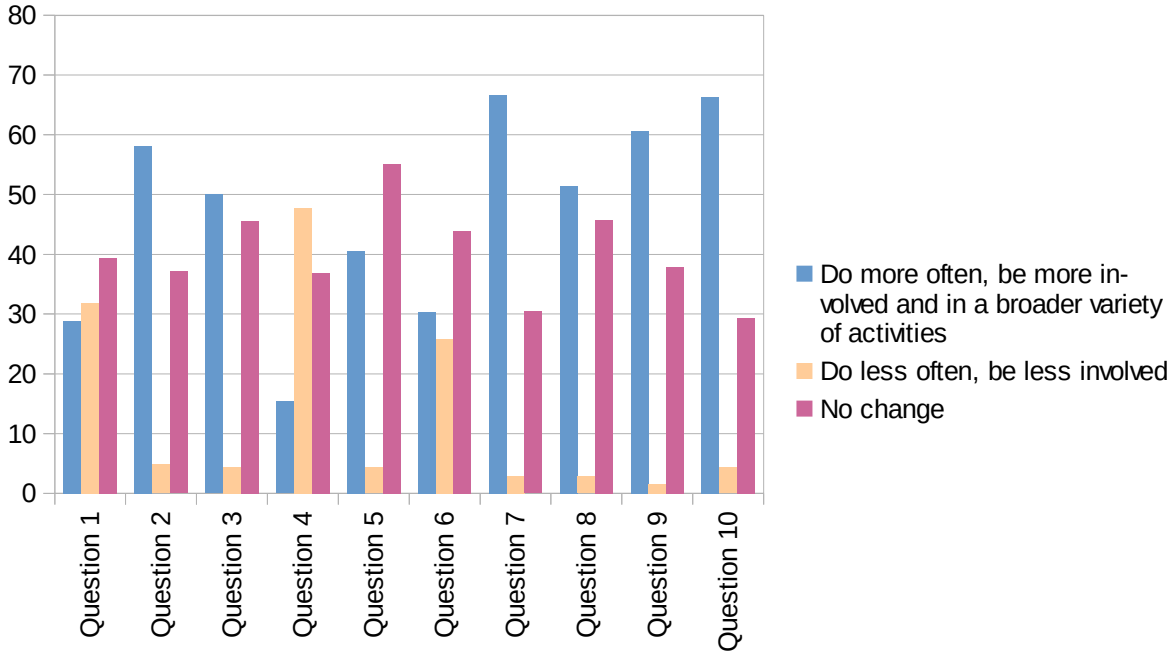
	Special phase	***Academic phase***	***Vocational phase***	***P values***
Number of activities done at home	8.7 (1.1)	9.1 (0.99)	9 (1.5)	0.3631
Frequency of participation	5.5 (1.0)	5.6 (0.7)	5.5 (0.6)	0.7377
Level of involvement	3.8 (0.6)	4.0 (0.6)	3.6 (0.64)	0.6197
Number of activities – change desired	2.1 (2.4)	4.6 (2.8)	3.8 (2.9)	0.1477
Number of barriers in the home	1 (1.2)	0.85 (1.5)	0.54 (0.78)	0.5730
Number of supports in the home	3.9 (3.1)	3.7 (2.3)	2.5 (1.6)	0.1224

In Table 4.12 the children were compared according to type of schooling. Children attending the Special phase of schooling participated in marginally fewer activities (8.7) than children in the other phases. All children participated at least “once a week” to “few times a week” in terms of frequency of participation. Children were perceived to be quite involved (3.6 – 4, where five is very involved). Again not many barriers and supports were indicated. More parents of children in the Academic phase desired a change in almost 50% of the activities.

Although desire for change was added into the questionnaire to assess how satisfied the parents are with their child's participation, if one looks at each question and the answers that the parents gave, gives one a nuanced indication of the parent's actual desires regarding change are. Figure 4.2 shows what the responses of the parents were. Positive responses such as “yes, do more often”, “yes, be more involved” and “yes, be involved in a broader variety of activities” were grouped together, whereas negative responses such as “yes, do less often” and “yes, be less involved” were grouped together, no change desired was represented on its own. From the graphs it is clear that most parents wanted to see a change in the frequency of the activity, wanted them to be more involved and in a broader range of activities, for most of the activities. However for question number four (watching TV, videos and DVDs), the parents wanted their children to be less involved and do less often. A fair number of parents didn't desire any sort of change, especially for question one (computer and video games), question five (getting together with other people) and question six (socializing

using technology).

Figure 4.2. Bar graph showing the parent's answers for "desire for change" for the home environment.



Question 1: Computer and video games

Question 2: Indoor play and games (e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)

Question 3: Arts, crafts, music, and hobbies (e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun)

Question 4: Watching TV, videos and DVDs

Question 5: Getting together with other people (e.g. interacting with peers, family, other houseguests)

Question 6: Socializing using technology (e.g., telephone, computer)

Question 7: Household chores (e.g., unloading/loading the dishwasher, cleaning room or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pet)

Question 8: Personal care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)

Question 9: School preparation (not homework)(e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)

Question 10: Homework (e.g., daily reading, homework assignments, school projects)

The parents were asked what they perceived as barriers and supports in the two domains of environmental helpfulness and environmental resources, this information is represented in Table 4.13.

Table 4.13. Support and barriers in the home environment

		Support n(%)	***Sometimes either n(%)***	***Barriers n(%)***
ENVIRONMENTAL HELPFULNESS	***Physical layout***	9 (10)	15 (16.3)	5 (5.4)
	Sensory Qualities	9 (10)	14 (15.2)	3 (3.2)
	Physical demands	21 (22.8)	17 (18.5)	4 (4.3)
	Cognitive demands	21 (22.8)	30 (32.6)	12 (13)
	Social demands	18 (19.6)	19 (20.6)	10 (10.8)
	Relationships	23 (24.7)	19 (20.4)	7 (7.5)
	Attitudes and actions	15 (17)	12 (13.6)	1 (1.1)
ENVIRONMENTAL RESOURCES	***Services***	51 (54.8)	12 (12.9)	5 (5.3)
	Supplies	50 (54.3)	33 (35.8)	9 (9.7)
	Information	43 (46.7)	35 (38.0)	13 (14.1)
	Time	60 (64.5)	32 (34.4)	1 (1)
	Money	30 (32.2)	53 (56.9)	10 (10.7)

Further analysis of barriers to participation showed that not many parents perceived that there were barriers to their child's participation in the home environment. Of those that felt there were barriers, access to information was the biggest barrier (14.1%), followed by social demands (10.8%) and finances (10.7%). However, many parents likewise felt that access to information was supportive (46,7%). Most parents indicated that the environment was supportive, some indicated that it was occasionally supportive. The highest supporting aspect (64.5%), parents felt that they had enough time to support their child's participation in the home.

4.4. PEM-CY School Data

Analysis of the PEM-CY school environment showed that not many parents (71%) completed the school section of the PEM-CY. In this section, data on the number of activities done at school, the frequency, level of involvement and desire for change, for the whole sample will be presented for each activity (Table 4.14). This will be followed by the PEM-CY summary scores, firstly for the whole sample (Table 4.15) and then for the different groups, primary diagnosis (Table 4.16) and type of schooling (Table 4.17).

Table 4.14: Number of activities done at school by all the participants

	% of those who answered the question	*% of those who never participate*	*Frequency median (mean)*	*Involvement mean (SD)*	*Desire for change n (%)*
Classroom activities	97	3	7 (6.5)	4.1 (1.1)	32 (63)
Field trips and school events	86	14	2 (2.5)	4 (1.4)	28(55)
School-sponsored teams, clubs and organizations	50	50	0.5 (1.6)	3.5 (1.4)	36 (76)
Getting together with peers outside of class	93	7	7 (6.1)	4.3 (1.2)	23 (47)
Special roles at school	48	52	0 (2.3)	4 (1.3)	37 (77)

Analysis of the activities done by the whole sample showed that 97% participated in “classroom activities”, this is encouraging in a school environment, however few children had “special roles at school” (48%). In terms of frequency of participation, the least amount of parent's answered the “school-sponsored teams, clubs and organizations”, and of those who answered their children do it almost never. Most activities had a high level of involvement (1 = minimally involved and 5 = very involved). Most parents desired a change in their child's “special roles at school” (77%) followed by “school-sponsored teams, clubs and organisations” (76%).

Table 4.15 presents the PEM-CY summary scores for the whole sample, means and standard deviations will be presented.

Table 4.15. PEM-CY summary scores for the whole sample: descriptive statistics for participation in the school environment. (Means and standard deviation)

	Min-max	***Whole sample***	***≤ 12***	***≥ 12***	***Male***	***Female***
Number of activities done at school	1.0-5.0	3.5 (1.2)	3.8 (0.9)	3.3 (1.3)	3.5 (1.2)	3.5 (1.2)
Frequency of participation	2.0-7.0	5.1 (1.2)	4.9 (0.9)	5.2 (1.3)	5.1 (1.2)	5.1 (1.2)
Level of involvement	1.0-5.0	3.6 (1.3)	3.7 (1.2)	3.5 (1.4)	3.6 (1.2)	3.5 (1.4)
Number of activities – change desired	0.0-5.0	2.8 (1.6)	3 (1.4)	2.6 (1.7)	2.8 (1.6)	2.8 (1.8)
Number of barriers in school	0.0-8.0	1.0 (1.5)	1.1 (1.3)	1.0 (1.7)	1.2 (1.7)	0.8 (1.3)
Number of supports in school	1.0-13.0	5.5 (2.3)	5.9 (3.1)	5.2 (2.8)	5.3 (2.7)	5.8 (3.3)

The children in this study participated in 3.5 activities out of a possible five at school, with a frequency of “once a week”. They were perceived to be fairly involved (3.6 where five is very involved). The parents desired a change in three out of a possible five activities at school. Few barriers were perceived by the parents at school. In terms of age, children above the age of 12 participated marginally more often than children under the age of 12. There were no differences noted between the genders.

In Table 4.16 (grouped by diagnosis) and Table 4.17 (grouped by type of schooling) the PEM-CY summary scores will presented summarized as means and standard deviations

Table 4.16. PEM-CY summary scores: descriptive statistics and differences between grouped primary diagnosis for participation in the school environment (mean and SD)

	CP	***SLD***	***MMH***	***PD***	***p-value***
Number of activities done at school	3.1 (1.5)	3.7 (1)	3.3 (0.8)	3.8 (1.4)	0.3213
Frequency of participation	5.5 (1.6)	4.7 (1.0)	5.1 (0.8)	5.2 (1.1)	0.3610
Level of involvement	3.9 (1.5)	3.7 (0.9)	3.7 (1.8)	4.8 (0.2)	0.5159
Number of activities – change desired	3.2 (1.6)	2.6 (1.6)	2.6 (1.8)	2.7 (1.9)	0.6509
Number of barriers in the school	1.4 (1.8)	1 (1.6)	0.5 (1.2)	1.3 (1.0)	0.2525
Number of supports in the school	6.0 (2.7)	5.4 (2.9)	4.7 (2.9)	6.0 (3.5)	0.5706

As shown in Table 4.16, children with physical disabilities (PD) participated in the most activities in the school environment (3.8 out of a possible five). However in terms of frequency, children with cerebral palsy (CP) were perceived as participating most frequently ("few times a week"). The parents of children with CP desired change in the most activities at school. Few barriers and supports were perceived by parents in the school environment.

Table 4.17. PEM-CY summary scores: descriptive statistics and differences between types of schooling for participation in the school environment (mean and SD)

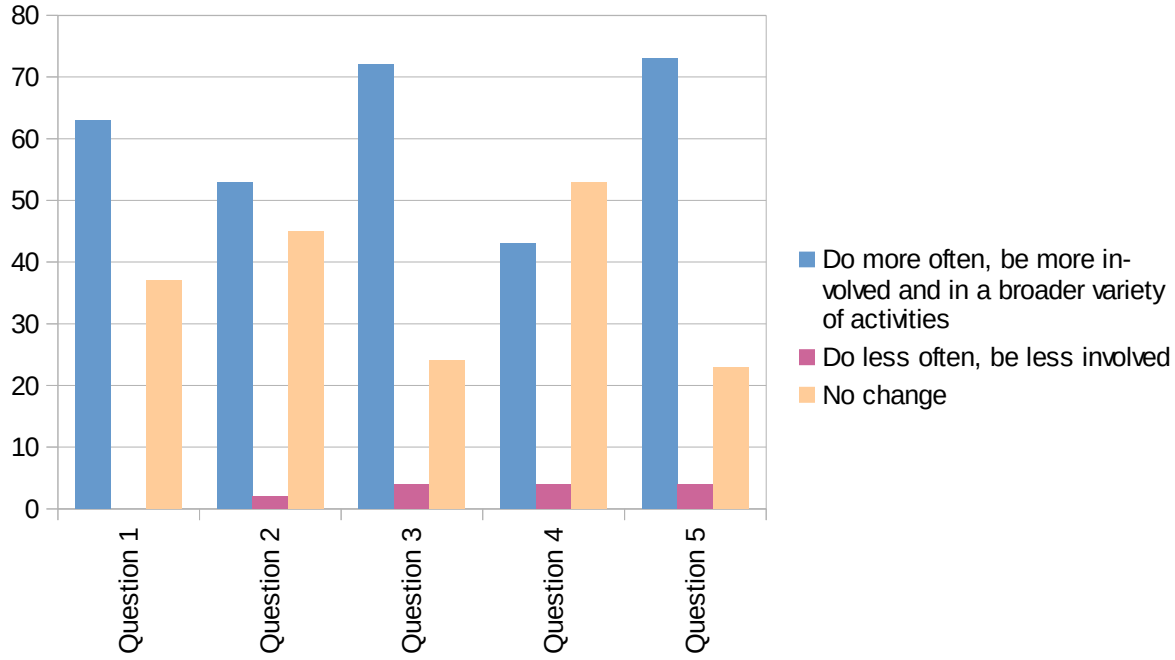
	Special phase	***Academic phase***	***Vocational phase***	***p-value***
Number of activities done at school	3.3 (1.5)	3.6 (1.1)	3.2 (0.9)	0.1938
Frequency of participation	5.3 (1.68)	4.9 (1.1)	5.3 (1.0)	0.4795
Level of involvement	4.8 (0.28)	3.8 (1.0)	3.7 (1.8)	0.3791
Number of activities – change desired	3.2 (1.8)	2.6 (1.6)	2.9 (1.7)	0.5319
Number of barriers in the school	1.5 (1.7)	1.1 (1.6)	0.6 (1.2)	0.2825
Number of supports in the school	6.1 (4.0)	5.6 (2.7)	4.8 (2.9)	0.5830

When looking at the number of activities done at school the results showed that it was fairly similar between the different groups, with no significant differences. Children in the Vocational phase participated in the least number of activities (3.2 out of a possible 5). No significant differences were noted in terms of frequency of participation (7 = daily and 0 = never)

between the phases. In terms of level of involvement children in the Special phase (4.8, where 5 is very involved) had the highest level of involvement, however this result was not significant. Parents of children in the Special phase wanted to see a change in their child's participation (3.2 activities out of a possible 5), no significant differences were noted between the phases. Few barriers and supports were indicated by parents.

Although desire for change was added into the questionnaire to assess how satisfied the parents are with their child's participation, if one looks at each question and the answers that the parent's gave, it gives you an indication of what the parent's actual desires regarding change are. Figure 4.3 shows what the responses of the parents were. Positive responses such as “yes, do more often”, “yes, be more involved” and “yes, be involved in a broader variety of activities” were grouped together, whereas negative responses such as “yes, do less often” and “yes, be less involved” were grouped together, no change desired was represented on its own. From the graphs it is clear that most parents wanted to see a change in the frequency of the activity. They wanted them to be more involved and in a broader range of activities especially in “school-sponsored teams, clubs and organizations (e.g., groups, clubs, teams, student council)” and “special roles at school (e.g., lunch room supervisor, student mentor)”. A fair number of parents didn't desire any sort of change.

Figure 4.3: Bar graph showing the parent's answers for "desire for change" for the school environment.



Question 1: Classroom activities (e.g., group work, classroom discussions, tests, in-class assignments)

Question 2: Field trips and school events (e.g., going to a museum, the school fair, spring concert or play, dances, fundraisers)

Question 3: School-sponsored teams, clubs and organizations (e.g., groups, clubs, teams, student council)

Question 4: Getting together with peers outside of class (e.g., hanging out during lunch, at recess, or other breaks during the school day)

Question 5: Special roles at school (e.g., lunch room supervisor, student mentor)

The parents were asked what they perceived as barriers and supports in the two domains of "environmental helpfulness" and "environmental resources", this information is represented in Table 4.18.

Table 4.18. Support and barriers in the school environment

		Support n(%)	***Sometimes either n(%)***	***Barriers n(%)***
ENVIRONMENTAL HELPFULNESS	***Physical layout***	6 (8.6)	4 (5.7)	0
	Sensory Qualities	11 (15.7)	13 (18.6)	2 (2.7)
	Outside weather	5 (7.1)	17 (24.3)	1 (1.4)
	Physical demands	16 (22.9)	14 (20.0)	2 (2.9)
	Cognitive demands	22 (31.8)	19 (27.5)	7 (10.1)
	Social demands	21 (30.0)	13 (18.6)	6 (8.6)
	Attitudes and actions	16 (23.2)	11 (15.9)	4 (5.8)
	Relationships	13 (18.8)	12 (17.4)	3 (4.4)
	Safety	17 (24.3)	3 (4.3)	0
ENVIRONMENTAL RESOURCES	***Personal transportation***	36 (49.3)	8 (10.9)	5 (6.8)
	Public transportation	19 (26.0)	3 (4.1)	10 (13.7)
	Programs and services	34 (46.6)	7 (9.6)	14 (19.2)
	School-related policies and procedures	40 (54.8)	10 (13.7)	3 (4.1)
	Supplies	60 (76.9)	18 (23.1)	0
	Information	63 (81.8)	11 (14.3)	3 (3.9)
	Time for support	42 (53.8)	29 (37.2)	7 (8.9)
	Money to support	24 (30.8)	38 (48.7)	16 (20.5)

Further analysis of the perceived barriers and supports in the school environment as reported by the parents showed a wide variation between supports and barriers. The most supportive aspects as described by environmental helpfulness were the “cognitive demands” (31.8%), followed by the “social demands” (30%) and the “safety” (24.3%) within the school. In terms of the environmental resources, most parents felt that the “access to information” (81.8%) was the most supportive and “supplies” such as assistive devices or technology, reading materials, sports equipment and craft supplies were similarly perceived as very supportive (76.9%). The greatest barriers perceived by parents were the “cognitive” (10.1%) and the “social demands” (8.6%) of the school. The environmental resources that created the largest barrier to participation were lack of money to support their child's participation (20.5%) and access to programs and services (19.2%) that are offered after school or additionally to the child's schooling. A fair number of parents found aspects of the environment neither limiting nor facilitating in terms of participation.

4.5. PEM-CY Community Data

In this section, data on the number of activities done in the community, the frequency, level of involvement and desire for change, for the whole sample will be presented for each activity (Table 4.19). This will be followed by the PEM-CY summary scores, firstly for the whole sample (Table 4.20) and then for the different groups, primary diagnosis (Table 4.21) and type of schooling (Table 4.22).

Table 4.19: Number of activities done in community by all participants

	% of those who answered the question	*% of those who never participate*	*Frequency median (mean)*	*Involvement mean (SD)*	*Desire for change n(%)*
Neighbourhood outings	91.6	8.4	4 (3.7)	3.7 (1.20)	42 (57.5)
Community events	66.6	33.4	1 (2.1)	3.5 (1.4)	49 (67.1)
Organized physical activities	56.5	44.5	1 (2.1)	3.6 (1.4)	58 (79.5)
Unstructured physical activities	77.4	23.6	4 (3.3)	3.7 (1.4)	57 (78.1)
Classes and lessons (not-school sponsored)	32.9	67.1	0 (1.3)	3.2 (1.5)	61 (84.7)
Organizations, groups, clubs and volunteer or leadership activities	19.7	80.3	0 (0.8)	2.7 (1.5)	52 (78.8)
Religious or spiritual gatherings and activities	77.2	22.8	4 (3.1)	3.3 (1.5)	51 (72.9)
Getting together with other children in the community	74.7	25.3	4 (3.4)	3.7 (1.3)	47 (62.7)
Working for pay	41.9	58.1	0 (1.7)	3.5 (1.3)	40 (58.0)
Overnight visits or trips	67.0	33.0	1 (1.5)	3.4 (1.4)	36 (48.7)

Most parents felt that their children were involved in “neighbourhood outings” (98%), these

are described as “shopping at the store/mall, going to a movie, eating out at a restaurant and visiting the local library/bookstore”. The activity that the parents felt their children least participated in (19.7%) was “organizations, groups, clubs and volunteer or leadership activities”. Most of the learner's frequency of participation in community activities was a few times a month (median =4). Parents felt that their children were somewhat (3) to very involved (5) particularly in “neighbourhood outings, unstructured physical activities, religious or spiritual gatherings and activities” and “getting together with other children in the community”. Children participated the least in “organizations, groups, clubs and volunteer or leadership activities” (19.7%). Most parents desired to see a change in their child's activities in the following activities, “classes and lessons (not school sponsored)”(84.7%), “organized physical activities” (79.5%), “organizations, groups, clubs and volunteer or leadership activities” (78.8%) and unstructured physical activities (78.1%). What type of change they desired will be presented later in the results section.

Table 4.20: PEM-CY summary scores for the whole sample: descriptive statistics for participation in the community environment. (Means and standard deviation)

	Min-max	***Whole sample***	***≤ 12***	***≥ 12***	***Male***	***Female***
Number of activities done in the community	0.0-10.0	6.5 (2.3)	6.8 (2.2)	6.2 (2.4)	6.5 (2.2)	6.4 (2.5)
Frequency of participation	0.0-7.0	2.3 (1.2)	2.4 (1.1)	2.2 (1.3)	2.4 (1.2)	2.1 (1.3)
Level of involvement	1.0-5.0	3.5 (0.9)	3.6 (0.8)	3.5 (1.1)	3.5 (1.0)	3.6 (1.0)
Number of activities – change desired	0.0-10.0	6.3 (2.7)	5.7 (2.7)	6.6 (2.6)	6.3 (2.6)	6.2 (2.8)
Number of barriers in the community	0.0-16.0	2.4 (2.8)	2.7 (3.3)	2.3 (2.5)	2.5 (3.0)	2.4 (2.5)
Number of supports in the community	0.0-16.0	3.4 (2.1)	3.3 (1.9)	3.4 (2.2)	3.5 (2.1)	3.1 (2.1)

The children in this study were perceived to participate in 6.5 activities out of a possible 10 in the community. The frequency of participation was low, only a “few times in the last four months”. The level of involvement was perceived by the parents as “somewhat involved”. The parents desired change in six of the 10 activities. Even though the participation frequency was low and the number of activities just over half, not many barriers were experienced by the parents. There were no differences between age and gender except for number of activities in

which change is desired. Parents of children older than 12 desired change in slightly more activities than parents of children under the age of 12.

Table 4.21 (grouped by diagnosis) and Table 4.22 (grouped by type of schooling) the PEM-CY summary scores will be presented summarized as means and standard deviations.

Table 4.21: PEM-CY summary scores: descriptive statistics and differences between grouped primary diagnosis for participation in the community environment (mean and standard deviation)

	CP	***SLD***	***MMH***	***PD***	***p-value***
Number of activities done in community	6.2 (2.2)	6.8 (2.3)	5.8 (2.5)	7.2 (2.2)	0.2626
Frequency of participation	2.1 (1.3)	2.6 (1.2)	1.8 (1.1)	2.1 (0.9)	0.0724
Level of involvement	3.3 (0.8)	3.7 (0.9)	3.2 (1.2)	4.0 (0.7)	0.0606
Number of activities – change desired	6.4 (2.7)	6.4 (2.5)	6.4 (2.8)	5.3 (3.0)	0.7246
Number of barriers in the community	2.5 (2.9)	2.4 (3.3)	2.3 (2.3)	2.5 (2.4)	0.8748
Number of supports in the community	3.6 (1.9)	3.4 (2.0)	3 (2.3)	3.3 (2.4)	0.6699

As seen in Table 4.21, children with physical disability (PD) participated in the highest number of activities in the community. Children with mild mental handicap (MMH), participated in few activities in the community (5.8 out of a possible 10 activities). The frequency of participation was low in all the groups, ranging from 1.8 to 2.6 (1 = “once in the last four months”, and 3 = “once a month”). The level of involvement was fair across the four groups, children with MMH (3.2) had the lowest perceived involvement. All the parents desired change in more than fifty percent of the activities. Once again few barriers and supports were identified.

Table 4.22: PEM-CY summary scores: descriptive statistics and differences between types of schooling for participation in the community environment (mean and standard deviation)

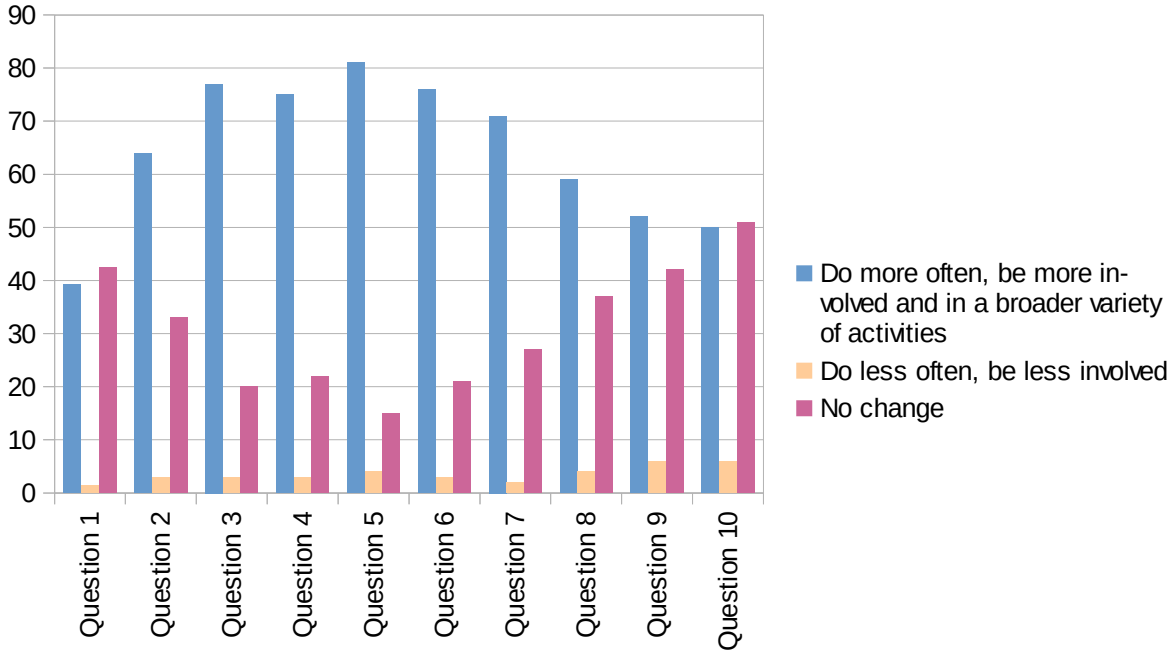
	Special phase	***Academic phase***	***Vocational phase***	***p-value***
Number of activities done in community	7.4 (2.7)	6.6 (2.1)	5.6 (2.4)	0.0816
Frequency of participation	2.5 (1.9)	2.4 (1.1)	1.9 (1.2)	0.2987
Level of involvement	3.5 (0.8)	3.6 (0.9)	3.2 (1.2)	0.3651
Number of activities – change desired	6.6 (2.7)	6.1 (2.6)	6.5 (2.9)	0.7393
Number of barriers in the community	2.8 (2.2)	2.4 (3.1)	2.5 (2.3)	0.5508
Number of supports in the community	3.3 (1.9)	3.4 (2.0)	3.1 (2.3)	0.6502

When looking at the PEM-CY summary scores for the type of schooling presented in Table 4.22 respectively, no significant differences were found in the number of activities done in the community between the groups, however the Vocational phase participated in marginally fewer activities (5.6 out of a possible 10) than the other phases. In terms of frequency of participation, children in the Vocational phase participated a “few times in last four months”, compared to the other phases who participated “once a month”. The level of involvement showed no significant differences between the groups however those attending the Vocational phase had a slightly lower level of involvement (3.2 where 3 is equal to somewhat involved). There were no significant differences between the number of activities where change was desired. In terms of barriers and supports in the environment no significant differences were noted between the different groups.

Although desire for change was added into the questionnaire to assess how satisfied the parents are with their child's participation, if one looks at each question and the answers that the parents gave, it gives you an indication of what the parent's actual desires regarding change are. Figure 4.4 shows what the responses of the parents were. Positive responses such as “yes, do more often”, “yes, be more involved” and “yes, be involved in a broader variety of activities” were grouped together, whereas negative responses such as “yes, do less often” and “yes, be less involved” were grouped together, no change desired was

represented on its own. From the graphs it is clear that most parents wanted to see a positive change (more than 50%) in all the questions except neighbourhood outings and overnight visits or trips.

Figure 4.4. Bar graph showing the parent's answers for "desire for change" for the community environment



Question 1: Neighbourhood outings(e.g. shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore)

Question 2: Community events (e.g. attending a play, concert, sports game, parade)

Question 3: Organized physical activities (e.g. sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics)

Question 4: Unstructured physical activities (e.g. nature trial walks, bicycle riding, rollerblading, skateboarding, playing hide-and-seek or chase, playing pick-up games like basketball)

Question 5: Classes and lessons (not school-sponsored) (e.g. music, art, languages, computers)

Question 6: Organizations, groups, clubs and volunteer or leadership activities (e.g. Boy Scouts, Brownies/Girl Guides, youth groups, public speaking)

Question 7: Religious or spiritual gatherings and activities (e.g. attending places of worship, religion classes, groups)

Question 8: Getting together with other children in the community (e.g. hanging out, informal gatherings outside of the home or school)

Question 9: Working for pay (e.g. babysitting, paper route, working in a store, doing chores or running errands for pay)

Question 10: Overnight visits or trips (e.g. sleepovers, vacations, camp)

The parents were asked what they perceived as barriers and supports in the two domains of "environmental helpfulness" and "environmental resources", this information is represented in Table 4.23

Table 4.23: Supports and barriers in the community environment

		Support n(%)	***Sometimes either n(%)***	***Barriers n(%)***
ENVIRONMENTAL HELPFULNESS	***Physical layout***	5(5.4)	13 (14.0)	11 (11.8)
	Sensory Qualities	5 (5.4)	16 (17.2)	15 (16.1)
	Physical demands	13 (14)	23 (24.7)	7 (7.5)
	Cognitive demands	13 (14.0)	29 (31.2)	11 (11.8)
	Social demands	17 (18.3)	23 (24.7)	11 (11.8)
	Relationships with peers	11 (11.7)	26 (27.7)	7 (7.5)
	Attitudes and actions	8 (8.4)	29 (30.5)	9 (9.5)
	Outside weather conditions	7 (7.4)	25 (26.3)	2 (2.1)
	Safety	8 (8.5)	23 (24.5)	27 (28.7)
ENVIRONMENTAL RESOURCES	***Personal transportation***	42 (44.7)	18 (19.2)	10 (10.6)
	Public transportation	27 (28.7)	18 (19.2)	13 (13.8)
	Programs and services	28 (30.1)	20 (21.5)	25 (26.9)
	Information	47 (50.0)	24 (25.5)	23 (24.5)
	Equipment or supplies	33 (34.7)	38 (40.0)	24 (25.3)
	Time for support	39 (41.5)	41 (43.6)	14 (14.9)
	Money to support	19 (20.2)	50 (53.2)	25 (26.6)

Further analysis of the supports and barriers to participation in the community showed that in terms of "environmental helpfulness" most parents perceived "social demands of typical activities (e.g., communication, interacting with others)" as a support, whereas "the safety of the community (e.g. traffic, crime, violence)" as the largest barrier to participation. In terms of "environmental resources", "information (e.g. about activities, services, programs)" (50.0%)

was seen as the biggest support whereas “programs and services (e.g., inclusive sports programs personal support worker)” (26.9%), were the biggest barriers to participation.

In the following section the results of the study will be discussed.

CHAPTER 5: DISCUSSION

This study piloted the PEM-CY in a special needs school in Gauteng province, South Africa and contributes to the research conducted on the participation of children with disabilities in various environments.

5.1. Demographics

The children represented a wide range of disabilities and there was an uneven spread across the different types of schooling. Due to the wide variation of disabilities the researcher grouped certain disabilities together for analysis. Four main groups were identified, children diagnosed with cerebral palsy, mild mental handicap, physical disabilities and specific learning disabilities. Unfortunately data on the diagnosis of children whose parents did not participate in the study could not be used for comparison in the analysis of the data. Due to the heterogeneity of the different diagnoses used for school admission in South Africa, the results are not able to be compared directly to other studies. The use of the word “handicap” is no longer used in literature since the publication of the ICF and ICF-CY, however it is still being used for admission protocols in the current South African education system.

The use of the Household Economic and Social Status Index in determining socio-economic status was not useful as the participants had very similar socio-economic status. Fifty percent of the parents were married, whereas only 13.33 percent were single. Single-parent status has been shown to be an indicator for lower socio-economic status (Barbarin & Khomo, 1997).

In our study, a third of the mothers and mother's partners had a lower educational level. As in another study very few participants obtained post-matric qualifications (Barbarin & Khomo, 1997). Lower parental educational level has been shown to influence participation of children (McConachie et al., 2006; Shikako-Thomas et al., 2008). Most of the families lived in a home

that was not shared with other families, and only 4% lived in Reconstruction and Development Programme (RDP) houses, which was lower than expected.

When asked what the diagnosis of their child was, more than 50% of the children had an additional diagnosis. Different diagnoses present with different participation restrictions and additional impairments increase a child's barriers to participation (Bult et al., 2011). A study conducted in Canada assigned children to five diagnostic groups and compared the participation of the children. Participation was lower in children with motor impairments and social interaction in physical activity. However in educational activities, children with social interaction and psychological problems had reduced participation (Mâsse et al., 2013).

5.2. Participation in the home environment

This study examined some of the trends of participation in children with a wide variety of disabilities (learning disabilities, physical disabilities, cerebral palsy and mild mental handicap) in the home environment. No significant differences were found between the different groups (primary diagnosis grouped or type of schooling), however when the entire sample is compared to studies that have conducted similar work, similarities in the participation were noted.

5.2.1. Number of activities

The activities that were perceived as “never” been participated in ranged from 2.2% (“getting together with other people”, “personal care management” and “homework”) to 15.6% (“socializing using technology”) across the 10 participation activities. This was comparable to children **with** disabilities in a study comparing the participation of children with and without disabilities (Law et al., 2013). Law et al. (2013) is one of the seminal works of the PEM-CY. The children in our study participated “never” mostly in “socializing with technology” (15.6%) and “indoor play and games” (13.5), whereas in Law et al., (2013) differences were mainly seen in their participation in “homework”, “household chores” and “school preparation”. All of

the children in our study participated in “watching TV, videos and DVDs”. This is similar to other studies that have found that more children are participating in sedentary type activities (Longmuir & Oded, 2000; Maher et al., 2007). The children in our study participated in a mean of 9.1 activities (out of 10), which was similar to the group of children **without** disabilities (9.31) in Law et al., (2013). Children **with** disabilities were found to participate significantly less than children **without** disabilities in that study (Law et al., 2013).

There were no differences noted between age and gender in our study, which was similar to children **without** disabilities in the comparative data (Coster et al., 2014). Children **with** disabilities, ages less than 12, participated in a mean of 7.8 activities, and those above the age of 12 in 8.43 activities (Coster et al., 2014). Most research on the differences in participation as children age show that older children participate less except for social and self-improvement activities (Longmuir & Oded, 2000; Maher et al., 2007; Hilton, Crouch & Israel, 2008; Majnemer et al., 2008; Jarus et al., 2010; Coster, Law, Bedell, Liljenquist, et al., 2013; Bloemen et al., 2015). There was no difference in the number of activities done at home between the groups (type of disability or type of schooling).

5.2.2. Frequency of participation

The mean participation frequency scores across all the items was 5.6 (few times a week) for this sample, whereas the study by Law et al., (2013) found children **with** disabilities participated a frequency of 4.78 (once a week) and those **without** disabilities 5.74 (few times a week). The activity least frequently participated in was “indoor play and games” and the most frequently participated in activity was “watching TV, videos and DVDs”. There was no difference between age and gender in our study for frequency of participation at home, the children in our study participated with a similar frequency as children **without** disabilities in the comparative data study. Comparative data found slightly higher frequency of participation in children over the age of 12 (5.02) **with** disabilities, than children younger than age 12 years (4.54) (Coster et al., 2014). The frequency of participation of children with cerebral palsy was lower than the other diagnoses, this result was close to significance (p-value = 0.0515); with larger numbers we may have seen a significant difference. Other studies have found that

children with more severe cerebral palsy participated less frequently (Mâsse et al., 2013; Kanagasabai et al., 2014). There were no differences between the frequency of participation for different types of schooling.

5.2.3. Level of involvement

The mean levels of involvement scores across the activities was 3.9 (out of five), this was similar to children **without** disabilities (3.9) in Law et al., (2013), notably the children **with** disabilities were marginally less involved (3.44) in their study. Involvement ratings of our study were the least for “household chores” (3.3 SD 1.5) and “school preparation” (3.6 SD 1.3), and the children were mostly involved in sedentary activities such as “watching TV, videos and DVDs”, “getting together with other people” and “computer and video games”, which is congruent with other studies (Longmuir & Oded, 2000; Maher et al., 2007). There was a slight difference in the level of involvement between boys (3.7 SD 0.6) and girls (4.1 SD 0.7), however no difference between ages was found. Some studies show similar findings with regards to gender, showing that girls tend to be more involved (Longmuir & Oded, 2000; Simeonsson et al., 2001; Engel-Yeger, Jarus & Law, 2007; Law et al., 2013). Law et al., (2013) proposed that level of involvement may be related to what the children are interested in and that may be causative of the lower involvement in certain activities. Surprisingly children with cerebral palsy had a higher level of involvement as perceived by their parents than the other primary diagnoses but this result was not significant.

5.2.4. Desire for change

In our sample the number of activities in which parents desired to see a change was 4.1 (out of ten), which is lower than both groups in Law et al., (2013), 6.39 for children **with** disabilities, and 5.03 for children **without** disabilities; our parents are seemingly more satisfied with their child's participation at home. The activities in which parents mostly wanted to see change was “household chores” (69.6%) and “homework” (70.6%), this is in keeping with the study done by Law et al., (2013). Careful analysis of what type of change was

desired revealed that many parents desired no change but those who did desire change would like their children to have less involvement in “computer and video games” and “socializing using technology” and more involvement in “household chores”, “school preparation” and “homework”. Perhaps parents require training in discipline techniques and reward systems to encourage more participation in these activities. There were no differences noted between age or gender in our study. The parents of children in the Academic phase desired change in almost 50% of the activities, surprisingly parents of children in the Special phase wanted to see change in the least amount of activities (only 2.1 out of 10). The children attending the Special phase are often “more severe” and it was hypothesized that their parents would desire more change in their participation. It may be that the parents may have low expectations of their children. The fact that our parents are more satisfied could be a reflection of perceptions of disabled people in South Africa where participation is not expected or is taken for granted. Often parents of children with severe disabilities don't receive the necessary education and support from appropriate professionals to facilitate better participation in their children. They rely on their communities for support (Maart et al., 2007).

5.2.5. Barriers and supports in the home

It was encouraging to find that not many parents perceived that there were barriers to participation in the home, this is in keeping with other studies that stated parents make adjustments to facilitate better participation in the home (King et al., 2003). The mean number of barriers in the home was 0.8 (out of a possible 12), this was much lower than children **with** disabilities (2.26) in the study done by Law et al., (2013). Parents in our study reported the number of supports were 3.5 which is higher than parents of children **with** disabilities (2.69) in Law et al., (2013). Qualitative research may be necessary to determine what is understood by barriers and supports in the home environment.

A large majority of the parents in our study felt that the environmental features sometimes facilitated participation and sometimes didn't. The environmental aspects that supported participation were having enough time to spend with their children, supplies and services. The aspects that were barriers to participation were insufficient information, lack of finances and

the social demands. Basic needs are often priority in lower socio-economic areas of South Africa, and often children are responsible for domestic tasks (Moses, 2008). It is encouraging to see that not many parents in our study experienced barriers at home, particularly the physical layout (5.4%), as other studies have shown that domestic homes aren't always accessible to persons with disabilities, particularly those with many assistive devices (Heap, Lorenzo & Thomas, 2009). Law et al., (2013) found that parents of children **with** disabilities reported more barriers than parents of children **without** disabilities, and similarly if the child had a disability the parents reported less supports than parents of children **without** disabilities. No differences were noted between age and gender. Parents of children with cerebral palsy reported the most barriers to participation in the home, and parents of children with physical disabilities reported the most supports to participation in the home, however neither result was significant. Children with cerebral palsy can be highly functional and have minimal limitations or they can have severe limitations and have struggles in multiple domains. Other studies have shown that children with cerebral palsy have more barriers to participation than typically developing peers (Engel-Yeger et al., 2009; Bult et al., 2011).

5.2.6. Summary of findings in the home environment

Children in our study take part in many activities in the home environment. All activities were participated in with good frequency and with a high level of involvement. Parents perceived few barriers to participation in the home environment. This supports research that suggests parents make accommodations at home to improve their child's participation (King et al., 2003). Children with cerebral palsy participated in less activities than children with other diagnoses, this result was close to significance. The most prominent barrier to participation was the lack of information about activities, services and programs, this however was likewise perceived as a supportive factor. Other studies similarly highlighted the importance of receiving sufficient information (Anaby et al., 2013). The most distinct support observed was having enough time to support their child's participation in the home environment. Time was identified as a predominant barrier to participation in a scoping review, especially the time required to plan outings, extra time for activities and the lack of time available (Anaby et al., 2013).

5.3. Participation in the school environment

The least number of parents completed the school section of the PEM-CY. This may have been due to them not feeling confident in their own assessment of their child's participation at school. McConachie et al., (2006) suggested that it may be necessary for teachers to complete the school section of questionnaires, as parents may not be fully aware of their child's participation at school. Learners with special needs schools are often located further from the child's community and they tend to be selective as to who may attend (McManus et al., 2006), which may have significant effects on the future outcomes of children as they aren't integrated into their community. Children tend to spend a lot of time on transportation to and from school, which reduces the amount of time available for extra-mural activities. It likewise makes it difficult to organise social events with their peers (McManus et al., 2006). In South Africa, often the LSEN schools, language of learning and teaching, are not in the child's home language or even their second language (Moses, 2008). This further impacts their chances of successful participation.

5.3.1. Number of activities

The activity which was most participated in at school was “classroom activities”, followed by “getting together with peers outside of class”. Our study showed a higher percentage of children participated in these activities than children **with** disabilities in the comparable data of the PEM-CY (Coster et al., 2014). The activity for which parents indicated that their child never participates in was “special roles at school” and “school-sponsored teams, clubs and organisations”. In terms of this, our study was similar to Coster et al., (2013) for children **with** disabilities. Children **without** disabilities participated significantly more in these activities. For the total sample the children in our study participated on an average in 3.5 activities out of a possible five activities at school, this correlates with the participation of children **with** disabilities in a similar study (Coster, Law, Bedell, Liljenquist, et al., 2013). The children under 12 years of age participated marginally more in the various school activities than those over

the age of 12 years. Coster et al., (2013) had an alternative finding that children under the age of 12 years **with** disabilities participated consistently less in the school activities. There were no differences between genders.

In terms of the groups, children with cerebral palsy participated in the least amount of activities. Other studies have found a related result for children with physical disabilities (King et al., 2009). When looking at type of schooling children in the Academic phase participated in more activities at school, than those in the Special and Vocational phases.

5.3.2. Frequency of participation

The children in our sample participated in the activities at school with an average frequency of once a week (5.1), which is consistent with the comparative data of the PEM-CY for children **with** disabilities (4.57) and those **without** disabilities (5.05) (Coster et al., 2014). Children under the age of 12 participated with a slightly lower frequency than children older than 12 years of age, this is congruent with the findings in Coster et al., (2013). Research supports the notion that participation frequency reduces with increasing age (Jarus et al., 2010; Bult et al., 2011). As children age they participate less often in formal and informal activities. Again there was no difference noted between the genders.

The frequency of participation was the lowest for individuals diagnosed with specific learning disabilities, and the highest for children with cerebral palsy. The activity in which the children most frequently participated in was “classroom activities” followed by “getting together with peers outside of class”, they participated in this daily to a few times a week. This is fairly predictable within a school environment. The children in our study participated in dramatically less “school-sponsored teams, clubs and organisations” and “special roles at school” when compared to a similar study across all the ages (Coster, Law, Bedell, Liljenquist, et al., 2013), this may be an area of opportunity for growth for this particular special education needs school in Gauteng. Research shows after-school activities help bridge the gap between children coming from lower income families and those coming from middle-class families and that children participating in after-school activities have more positive outcomes (Posner &

Vandell, 1999). This is supportive of expanding this opportunity and redressing the inequalities of the past.

5.3.3. Level of involvement

The mean level of involvement was 3.6 (5 = very involved) across the school activities, this was less than the mean level of involvement of children **without** disabilities (4.21) and slightly more than those **with** disabilities (3.35) in the comparative data of the PEM-CY (Coster et al., 2014). There were no differences between age and gender in terms of involvement in the activities at school.

It was interesting to note that children with physical disabilities (PD) parents perceived them to be the most involved (4.8) of all the primary diagnosis, parents of children in the Special phase similarly felt that their children were very involved (4.8). The activity that the parents felt their children were most involved in was “getting together with peers outside of class” followed by “classroom activities”. The children in this study had similar involvement to the children **without** disabilities in the Coster et al., (2013) study for all the activities except “school-sponsored teams, clubs and organizations”, which was the similar to those **with** disabilities. This specific school in our study, only offers a few school sponsored activities and at the time of the study, the school was practicing for a school concert which is only held every four years. However the involvement was still lower than in other studies. In Coster et al., (2013) children **with** disabilities were significantly less involved than those without disabilities. A study on children with acquired brain injury, showed that they had a lower involvement when compared to typically developing peers (Galvin, Froude & McAleer, 2010).

5.3.4. Desire for change

In our sample the number of activities in which parents desired change was 2.8 (out of a possible five activities). More parents of children under the age of 12 years, desired a change

than those over the age of 12. Parents of children diagnosed with cerebral palsy expressed the highest number of activities in which they desired change at school. The same was seen for children attending the Special phase of schooling. It is noteworthy that the activities in which the parents desired the most change were the same activities in which there was a low level of involvement, “special roles at school” and “school-sponsored teams, clubs and organisations”.

More than 50% of parents desired change in all the activities at school except for “getting together outside of class”. A closer analysis of what type of change the parents were interested in revealed that they would like an increased frequency, involvement and in a greater variety of activities, across four of the five activities.

5.3.5. Barriers and supports at school

Previous studies have shown that barriers to participation in school are related to accessibility, policies and procedures and attitudes of teachers, peers and principals (Law et al., 2007). Not many barriers (1.0) to participation were perceived by the parents in this study, this may be due to it being a special needs school, where children's needs are likely catered for sufficiently. It is possible that the parents are unaware of the challenges their children face at school and are satisfied that they have access to such a facility, as LSEN schools are few in South Africa. It was encouraging to see that more supports were indicated (5.5), however this number was still low as there were 17 aspects to report on. This may reflect that the environment is neither facilitating nor inhibiting participation.

The parents of children diagnosed with mild mental handicap (MMH) experienced the least amount of barriers to participation at school and parents of children in the Vocational phase. This is consistent with other studies that show that children with mild learning disabilities have better participation (Mâsse et al., 2013). It was encouraging to see that parents of children with cerebral palsy and physical disabilities reported more aspects of the environment were supportive than the other groups. This is contrary to the results of other studies, where it has been reported that children with physical disabilities experience the environment as less

supportive (Majnemer et al., 2010). It may be necessary to examine what aspects of the environment are not seen as supportive for children with specific learning disabilities (SLD) and mild mental handicap (MMH), and intervene at this level to improve participation. In terms of perceived supportiveness of the school environment, the parents in our study identified fewer barriers and fewer supports than parents in a similar study (Coster, Law, Bedell, Liljenquist, et al., 2013)

The parents in our study reported that “public transportation”, “programs and services” and “money” were a greater barrier than what parents in the Coster et al., (2013) study reported for both children **with** and **without** disabilities. Many of the parents in our study have to make use of public transport to get their children to school. Public transport was discussed in Heap, Lorenzo & Thomas, (2009) as being largely inaccessible to disabled people as the minibuses are overfull, and the buses aren't adapted for wheelchairs.

In terms of perceived adequacy of resources in the school, the parents in our study reported that resources were more adequate. The percentage that reported it was adequate was similar to parents of children **with** disabilities and much lower than the parents of children **without** disabilities in Coster et al., (2013), for most of the items. The parents of children **with** disabilities had significantly more barriers to participation than parents of children **without** disabilities (Coster, Law, Bedell, Liljenquist, et al., 2013). Additional resources such as assistive devices, alternative communication devices (Piškur et al., 2012) and school supplies improve the participation of children. Access to information has been identified by parents as a key factor in assisting them in improving their child's participation (McManus et al., 2006).

5.3.6. Summary of findings in the school environment

Not many parents completed the school section of the PEM-CY. This may be due to having insufficient knowledge regarding their child's participation at school. “School-sponsored teams, clubs and organizations” and “special roles at school” were identified as the two activities in which the parents felt their children didn't participate. These were likewise

identified as requiring a need for change. Previous research suggests that attending school sponsored activities improves the well-being of children, promotes friendships, and encourages social interaction (Conchar et al., 2014). A study looking at the participation of children in South Africa encourages allowing children more responsibility in facilitating necessary change (Moses, 2008). The greatest barriers to participation were money to support their child's participation, as discussed is a result of the poor social-economic status in South Africa (Moses, 2008; Conchar et al., 2014). Secondly the lack of programs and services ("after school, recreational, special resources, educational assistant/aide") was identified as a barrier. This ties in with desiring more school-based activities. An overwhelming support was receiving sufficient information. This reflects what was discussed in the home section, regarding the importance of sufficient information.

5.4. Participation in the community environment

There are significant barriers to participation especially in the community as it is not always possible to anticipate or alter the environment to suit the child. Barriers to participation can be due to the attitudes of others, accessibility and due to policies and procedures (Bedell et al., 2011; Colver et al., 2011; Anaby et al., 2014). In South Africa, the government isn't able to provide sufficient community programs for the youth to encourage community participation as budget is often allocated to providing basic needs and essential services (Moses, 2008).

5.4.1. Number of activities

The activity in which the parents perceived their children participated the most, in the community was predominantly "neighbourhood outings". None of the other activities were as well attended. Our study shows that more than 50% of the children never participated in "organizations, groups, clubs, and volunteer or leadership activities", "classes and lessons" and "working for pay". These results were very similar to the results of a similar study Bedell et al., (2013), although children **with** disabilities participated in significantly fewer activities

than children **without** disabilities. The participation of our children in the community is more similar to children **with** disabilities than those **without**.

Community participation may be lower in our sample due to socio-economic circumstances and reduced opportunity for activities such as “organisations, groups, clubs and volunteer or leadership activities” being available, and not having the financial resources for extra lessons. The crime rate in South Africa may make it impossible for children to work for pay in their communities (Moses, 2008). Twenty three percent of the parents in our sample felt that they lived in a dangerous neighbourhoods. For our total sample the number of activities in which the children participated in was a mean of 6.5 out of a possible 10 community activities. This is higher than the comparative data for children **with** disabilities (5.75), but lower than children **with no** disabilities (7.55) (Coster et al., 2014). Children over the age of 12 (6.2) participated slightly less than those under the age of 12 (6.8). This finding was contrary to the comparative data on participation in terms of age (Coster et al., 2014). However other studies have likewise discussed this finding of reduced participation with increasing age (Longmuir & Oded, 2000; Maher et al., 2007; Hilton, Crouch & Israel, 2008; Majnemer et al., 2008; Jarus et al., 2010; Coster, Law, Bedell, Liljenquist, et al., 2013; Bloemen et al., 2015). As children age they may become more interested in social activities or may limit their participation in some activities.

In terms of the groups in our study, it was interesting to note that children in the Vocational phase participated in the least amount of activities (5.6) and children in the Special phase participated in the most (7.4). Children in the Special phase often have more challenges than those attending the Vocational phase, perhaps their parents make more of an effort to integrate them in to their community activities. It has been hypothesized that individuals who participate more, become more aware of the barriers to participation (Whiteneck & Dijkers, 2009). It may be possible that the children aren't endeavouring to participate in a wide variety of activities and therefore haven't experienced any barriers. The parents have low expectations of their child's ability to participate and therefore don't perceive that the participation is lower and aren't aware of the barriers. There may likewise be few available community activities (Engelbrecht, 2006) or community activities may not be accessible

(Longmuir & Oded, 2000).

5.4.2. Frequency of participation

The children in our sample participated in the activities in the community on average “a few times in the last four months” (2.3). Children under the age of 12 and of female gender participated marginally more frequently than children over the age of 12 and of male gender. Other studies show similar findings with regards to female gender and younger age (Jarus et al., 2010; Bult et al., 2011). The activity in which the children participated the most frequently, “a few times a month” was neighbourhood outings. None of the activities were participated in more than “a few times a month”. This finding is much lower than the comparative data for children **with** (3.82) and those **without** (4.43) for community participation (Coster et al., 2014). This reflects that children aren't being integrated into their communities and don't participate in decision making processes in South African communities (Moses, 2008).

The activity in which most children “never” participated in was “organisations, groups, clubs and volunteer or leadership activities”. Children with mild mental handicap (MMH) participated with the lowest frequency (1.1) and children with specific learning disability (SLD) participated with the highest frequency (2.6), this finding was approaching significance ($p = 0,0606$).

5.4.3. Level of involvement

In Bedell et al., (2013) children **with** disabilities showed a lower involvement for the majority of the activities compared to children **without** disabilities. The mean level of involvement in our study was 3.5 (where 5 = very involved). This finding is the same as that of Bedell et al., (2013) for children **with** disabilities, in their study this was significantly lower than children **without** disabilities. The children in our study participated with the highest involvement in “neighbourhood outings”, “unstructured physical activities” and “getting together with other children in the community”. They were the least involved in “organizations, groups, clubs and volunteer or leadership activities”. There were no mentionable differences between gender

and age.

Children with physical disabilities (PD) were the most involved in community activities of all the groups (4, where 5 = very involved), and unexpectedly children with mild mental handicap were the least involved (3.2). This may be an area that requires further investigation as it has been hypothesized that children with physical disabilities struggle with involvement. Parents of children with other disabilities often found that their child struggled with participation due to attitudes of others and people not always understanding their child as you can't “see” the disability (Heah et al., 2007). The level of involvement is key to improving participation (Imms et al., 2016).

5.4.4. Desire for change

Most parents desired a change in their child's participation in community activities (6,3 out of a possible 10). Parents of children older than the age of 12 desired more change than the parents of younger children. The activities for which parents indicated the greatest desire for change was for “classes and lessons”. This was one of the activities that had the lowest percentage of those participating, and the lowest frequency of participation. When analysing the responses for each individual question, it is apparent that most parents desired more involvement and more often for nine out of the 10 activities, the only activity in which the majority of the parents indicated that they desired no change was “overnight visits or trips”. The children in our study may not be attending “overnight visits or trips” regularly, but their parents wouldn't like to see a change in this activity because they don't expect their children to be attending sleepovers. There are like wise high levels crime and abuse of children in South Africa, which further prevents parents from allowing this activity. Furthermore, being responsible for two children with severe disabilities at a sleepover, may be an enormous task for parents (McManus et al., 2006). Across the groups the parent's desire for change was the same.

5.4.5. Barriers and supports in the community

Studies focussed on changing barriers and enhancing the supportive aspects in the environment have been successful in improving participation of children (Law et al., 2015; Anaby et al., 2016). Therefore identification of barriers and supports and intervention at this level is important.

The parents perceived fewer barriers (2.4 out of a possible 16 barriers) to supports (3.4 out of a possible 16) to participation in the community. This is notable as the overall involvement in the community was relatively low. This proposes the question, what do parents in South Africa understand when asked about barriers and supports?. There were only minimal differences between parents of children of different ages and parents of children of different genders.

In terms of the perceived supportiveness of the environment, the greatest barrier to participation in the community was “safety”, which is a foreseeable finding due to the high crime rate in South Africa (Moses, 2008). The most supportive aspect was the “social demands”, which is further defined as communication and interacting with others. In terms of perceived adequacy of resources, “programs and services” in the community was an area which was lacking. There are insufficient programs offered at no charge for children in the South African community. In well-resourced areas parents pay for extra-curricular activities (Conchar et al., 2014) and drive their children to them in their own transport.

Another aspect that was seen as a barrier was not having enough finances to support the participation, sufficient equipment and supplies and information. In a country where basic needs such as having food and shelter aren't sufficient, parents don't have extra finances for extramural activities in the community (Moses, 2008). Fifty percent of the parents felt supported if they were given access to information about activities, services and programs. Bedell et al., (2013) found that parents of children with disabilities in their study reported that personal transportation, equipment/supplies, time and information were their greatest limiting factors to participation. A qualitative study in a first world country discussed barriers to participation in a number of domains namely; 1. physical environment (mobility and transport),

2. social environment (support to and by parents, bureaucracy and information), and 3. attitudinal environment (public's attitudes and inclusive schooling). This study showed how even in well-resourced countries, parents still experience numerous barriers to successful participation (McManus et al., 2006). Parents of children with disabilities have to devise innovative solutions to improve the participation of their children. They often need to "structure" their day, "educate" their child on alternative ways to achieve things, and "modify" certain activities and situations to encourage meaningful participation. Parents need to "create opportunities" for their children (Piškur et al., 2012).

Qualitative studies done in South Africa similarly discussed the limitations of not having sufficient transport (Maart et al., 2007; Conchar et al., 2014). Parents are often required to transport their children to extra-mural activities (Conchar et al., 2014). This may not be possible if both parents have full-time employment and if they don't have their own means of transportation. Public and private transportation was seen as both a barrier and a facilitating factor in our study. Although just over 10% reported it as being a barrier, the impact that this barrier has on inhibiting participation is important to consider. Families without their own transport would otherwise have no means of physically assessing such activities.

5.4.6. Summary of findings in the community environment

Community participation was moderate but attended with low frequency in our sample. A high number of children never participated in community programs and extra classes and lessons that were not sponsored by the school. It has been highlighted that community programs are not always priority when considering poor socio-economic circumstances (Moses, 2008). However the importance of community programs in developing skills, improving the integration of youth in their communities and empowering of communities is invaluable (Law, 2002; Moses, 2008). More than 70% of the parents desired change in "organized physical activities", "unstructured physical activities", "classes and lessons", "organizations, groups, clubs and volunteer or leadership activities" and "religious and spiritual gatherings and activities". These activities are all important for community upliftment. Children with mild mental handicap and those attending the Vocational phase had lower levels of participation,

this may be an area requiring more qualitative research.

5.5. Future considerations

The PEM-CY was developed and validated in Canada. It has proved itself to be useful in the South African setting, but will need to be validated specifically for the South African population. Certain items on the PEM-CY are not available or are described differently in South Africa such as “school fair”, “spring concert”, “at recess”, “lunch room supervisor”, “student mentor”, “parade”, “baseball” and “Boy Scouts, Brownies/Girl Guides”. It may be necessary to change the descriptions to make it applicable for use in the South African context. Although these descriptions aren't entirely South African, they were all part of extra descriptors of each activity and therefore would have been sufficiently understood by the parents, not limiting their ability to answer each activity. Activities such as “computer and video games” could be expanded to games on cellphones, tablets, televisions and computers. Analysis of the PEM-CY proved tedious, and it is suggested that a yes/no column should be provided prior to what type of change was desired. For future studies it is recommended that normative data for the South African population be obtained.

Further analysis may be necessary to determine how the parents understood the questionnaire and whether it is suited for the South African population in terms of layout and usability. The parent's ability in completing the questionnaire should likewise be studied, as many parents left out sections or only completed one section of the questionnaire.

Qualitative research evaluating what “participation”, “supports” and barriers” means to South Africans would add to the current knowledge on participation of children with disabilities and help determine whether the tool is reporting information reliably. Some parents left the researcher notes regarding their child or the struggles they experience in certain environments. Perhaps the tool could provide a space where parents could comment on the home, school and community section if they felt the need to highlight something. This may provide the researcher with more in-depth information about what they feel are barriers and supports, which could further enable better management of opportunities for growth and/or

intervention.

Growth areas for the school used in the study, and potentially other LSEN school using similar models are:

- Education of parents in promoting participation and increasing parental involvement
- Providing a variety of extra-mural activities at the school with no extra cost
- Extra roles in the school in which children can grow and developed
- Community programs to facilitate better community participation
- Peer to peer programs in the community
- Approaching non-government organisations (NGO's) to provide after-school support and leadership activities
- Providing parents with access to information regarding their child's diagnosis, services, assistive devices, extra-curricular activities, support groups, financial exemptions and available community programs
- Making changes to the environment to improve participation

5.6. Limitations of the study

As there were quite a few sections that were missing data on “completed” questionnaires, results need to be interpreted with caution, particularly for the school section. It is important to note that the small numbers will have an impact on the robustness of the statistical analysis. Since the survey was sent home, it may have yielded different results than a face to face interview would. The results of this study are indicative of what the parents perceive their child's participation to be in the various environments, this may not be the same as what their child's perception of their participation is or what the actual level of participation is (Imms et al., 2016).

This study was a sample of convenience, future studies should compare “mainstream” schools, “full service schools” and “special needs” schools. The current tool has not yet been validated in South Africa. Lastly it wasn't possible to evaluate objective six based on the

HESSI as the majority of families were very similar in terms of socio-economic status.

CHAPTER 6: CONCLUSION

According to the World Health Organisation, participation is seen as the ultimate goal in rehabilitation. The environment is a key factor in influencing and improving the participation of children (WHO, 2007). Since the release of the ICF-CY, tools have been developed to measure participation in various environments, factoring in what facilitates or hinders participation in those environments (Coster et al., 2012).

Internationally there has been a movement towards inclusive education. The Department of Education issued the White Paper 6 document to revolutionise the South African education system aligning it with international policies. This document outlines what the department envisions for schools and the inclusion of learners with special educational needs. The aim of the department is that all children regardless of disability, race or culture should be attending school (Department of Education, 2001).

The PEM-CY is a fairly new tool, which was designed to measure the participation of children, between the ages of five and 17 years in the home, school and community. Preliminary testing of the tool has shown it to be useful. The PEM-CY can be used on children with and without disabilities. It can be used to establish individual goals, or for measurement of program implementation (Coster et al., 2012).

The aim of the study was to determine the factors that facilitate or inhibit participation in the home, school and community environment of children with disabilities at a special needs school in South Africa.

Children in our study take part in many activities in the home environment. All activities were participated in with good frequency, with a high level of involvement. Parents perceived few barriers to participation in the home environment. This supports research that suggests parents make accommodations at home to improve their child's participation (King et al., 2003). Children with cerebral palsy participated in less activities than children with other

diagnoses, this result was close to significance. The most prominent barrier to participation was the lack of information about activities, services and programs, this however was likewise perceived as a supportive factor. Other studies similarly highlighted the importance of receiving sufficient information (Anaby et al., 2013). The most outstanding support was having enough time to support their child's participation in the home environment. Time was identified as a predominant barrier to participation in a scoping review, especially the time required to plan outings, extra time for activities and the lack of time available (Anaby et al., 2013).

Not many parents completed the school section of the PEM-CY. This may be due to not having sufficient knowledge regarding their child's participation at school. “School-sponsored teams, clubs and organizations” and “special roles at school” were identified as the two activities in which the parents felt their children didn't participate. These were likewise identified as requiring a need for change. Previous research suggests that attending school sponsored activities improves the well-being of children, promotes friendships, and encourages social interaction (Conchar et al., 2014). A study looking at the participation of children in South Africa, encourages allowing children more responsibility in facilitating necessary change (Moses, 2008). The greatest barriers to participation were finances to support their child's participation, as discussed this is a result of the poor social-economic status in South Africa (Moses, 2008; Conchar et al., 2014). Secondly the lack of programs and services (“after school, recreational, special resources, educational assistant/aide”) was identified as a barrier. This ties in with desiring more school-based activities. An overwhelming support was receiving sufficient information. This reflects what was discussed in the home section, the importance of sufficient information.

Community participation was moderate but attended with low frequency in our sample. A large number of children never participated in community programs and extra classes and lessons that were not sponsored by the school. It has been highlighted that community programs are not always priority when considering poor socio-economic circumstances (Moses, 2008). However the importance of community programs in developing skills, improving the integration of youth in their communities and empowering of communities is invaluable (Law, 2002; Moses, 2008). More than 70% of the parents desired change in

“organized physical activities”, “unstructured physical activities”, “classes and lessons”, “organizations, groups, clubs and volunteer or leadership activities” and “religious and spiritual gatherings and activities”. These activities are all important for community upliftment. Children with mild mental handicap and those attending the Vocational phase had lower levels of participation, this may be an area requiring more qualitative research.

Initial findings suggest this tool may be useful in evaluating the participation of children in a special needs school in South Africa. There were few differences between the selected groups, greater variations may be seen if the study sample is compared to children with no disabilities. When comparing our data to comparative data, in a few areas our sample corresponds with children with disabilities, however there are areas where the children in our sample perform similar to children without disabilities. Possible areas that require intervention are providing more after-school activities, community programs and improving access to information.

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APPENDIX I: ETHICAL CLEARANCE

R14/49 Ms Theresa Behrens

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160302

NAME: (Principal Investigator)	Ms Theresa Behrens
DEPARTMENT:	Paediatrics Frances Vorwerg School Physiotherapy Department
PROJECT TITLE:	A Pilot Study: Home, School and Community Participation of Children Attending a Special Needs School in South Africa: Barriers and Supports
DATE CONSIDERED:	01/04/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Joanne Potterton
APPROVED BY:	Professor P. Cleaton-Jones,Chairperson, HREC (Medical)
DATE OF APPROVAL:	20/05/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated,from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review in March and will therefore be due in the month of March each year.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX II: GDE APPROVAL

For administrative use only:
Reference no: D2016 / 436
enquiries: Diane Buntting 011 843 6503

GAUTENG PROVINCE
EDUCATION
REPUBLIC OF SOUTH AFRICA

GDE RESEARCH APPROVAL LETTER

Date:	**29 March 2016**
Validity of Research Approval:	**29 March 2016 to 30 September 2016**
Name of Researcher:	**Behrens T.J.**
Address of Researcher:	**17 Janssens Road; Constantia Kloof; Roodepoort; 1724**
Telephone / Fax Number/s:	**082 561 4156**
Email address:	**theresa.behrens@stucky.co.za**
Research Topic:	**A Pilot Study: Home school and community participation of children attending a special needs school in South Africa: Barriers and Supports.**
Number and type of schools:	**ONE LSEN School**
District/s/HO	**Johannesburg South**

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved. A separate copy of this letter must be presented to the Principal, SGB and the relevant District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted. However participation is VOLUNTARY.

The following conditions apply to GDE research. The researcher has agreed to and may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

CONDITIONS FOR CONDUCTING RESEARCH IN GDE

1. *The District/Head Office Senior Manager/s concerned, the Principal/s and the chairperson/s of the School Governing Body (SGB.) must be presented with a copy of this letter.*
2. *The Researcher will make every effort to obtain the goodwill and co-operation of the GDE District officials, principals, SGBs, teachers, parents and learners involved. Participation is voluntary and additional remuneration will not be paid;*

2016/03/29

Office of the Director: Education Research and Knowledge Management ER&KM)
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506

3. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal and/or Director must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
4. *Research may only commence from the second week of February and must be concluded by the end of the THIRD quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
5. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
6. *It is the researcher's responsibility to obtain written consent from the SGB/s; principal/s, educator/s, parents and learners, as applicable, before commencing with research.*
7. *The researcher is responsible for supplying and utilizing his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institution/s, staff and/or the office/s visited for supplying such resources.*
8. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research title, report or summary.*
9. *On completion of the study the researcher must supply the Director: Education Research and Knowledge Management, with electronic copies of the Research Report, Thesis, Dissertation as well as a Research Summary (on the GDE Summary template). Failure to submit your Research Report, Thesis, Dissertation and Research Summary on completion of your studies / project – a month after graduation or project completion - may result in permission being withheld from you and your Supervisor in future.*
10. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned;*
11. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director/s and school/s concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

.....

Dr David Makhado

Director: Education Research and Knowledge Management

DATE: 2016/03/29

Office of the Director: Education Research and Knowledge Management ER&KM)
9th Floor, 111 Commissioner Street, Johannesburg, 2001

APPENDIX III: INFORMED CONSENT

Appendix 2

Consent Form:
A pilot study: Home, school and community participation of children attending a special needs school in South Africa: Barriers and supports

Participant number:_____

I, _____ have read the information sheet provided and understand the purpose of the study.

I *consent/do not consent* to participate in this study.

I *consent/do not* consent to the researcher obtaining my child's date of birth, class information and medical diagnosis from their school medical file.

I am aware that I am able to withdraw from this study at any time without any consequences.

I understand that all the information contributing to the study will remain confidential.

_____ _____

Parent/Caregiver/Guardian Signature Date

_____ _____

Researcher Signature Date

APPENDIX IV: INFORMATION SHEET

APPENDICES

Appendix 1

Information Sheet

A pilot study: Home, school and community participation of children attending a special needs school in South Africa: Barriers and supports

Dear Parent/Caregiver/Guardian

My name is Theresa Behrens. I am currently employed as a Physiotherapist at Frances Vorwerg School. As part of my Masters Degree in Child Health (Neuro-development Option), I will be completing a research report. I would like to find out what are the supports and barriers to the participation of children in a special needs school. This study will help us to identify what factors can be improved in your child's environment, to allow them to have better participation. The information obtained from this study will be presented to the principal of the school, and the therapy team will be involved in implementing the results to improve participation within the means of the schools resources. This is a pilot study, meaning that it is the first study of its kind to be done in South Africa. As it is the first study, it will be used to test whether these questionnaires are applicable in our country and if they are able to be used in other school's to identify areas of need. There will be no financial rewards for participating in the study. I am inviting you to take part in this study.

What is involved?

You will need to complete two questionnaires, the first questionnaire (PEM-CY) will take approximately 20-25 minutes, the second one (Socio-economic questionnaire) approximately 10 minutes. Your child must be between the ages of 5-17 years at the time of completing the questionnaire. If you are uncomfortable answering any of the questions you do not need to respond to them. Should any of the questions be emotionally charged I will refer you to the nearest counselor. I will be looking at your child's medical records, if you agree to this please sign the consent form. The information that I will be obtaining from your child's file will be their date of birth, medical diagnosis and class infromation.

The questionnaires:

1. **Participation and Environment Measure for Children and Youth (PEM-CY)**: This questionnaire is meant to identify what are the barriers (things that make it harder) or facilitators (things that make it easier), for your child to participate at home, school and in the community. You will be asked to describe the frequency of your child's participation, level of involvement and whether or not you would like to see a change in their participation. Furthermore, you will be asked what factors in the environment facilitates or limits your child's participation; be it both actual and perceived and your perception of available resources (things that make it easier to participate, for example; money, equipment, etc). (Appendix 4)

2. **Questionnaire pertaining to information about your child's and your socio-economic status:** In this questionnaire you will be asked to give information about your child's disability/disabilities and the environment at home and within the community (type of house, running water, electricity, etc). (Appendix 3)

Confidentiality:

All information gathered will remain strictly confidential and safe. You will not be required to identify yourself or your child on either of the questionnaires. No names will appear on any of the questionnaires.

Withdrawal:

You may withdraw yourself, as well as the information provided, from the study at any time. You need not provide reasons for the withdrawal. There will be no effect on your child or their therapy at school should you withdraw from the study.

If you are willing to participate in this study, please sign the consent form provided and complete the attached questionnaires. Please return the questionnaires regardless of whether or not you will be participating in this study by placing them in the envelope provided, sealing it and sending it back to school with your child.

Thank you for taking the time to read this.

If you have any further questions please do not hesitate to contact me, my supervisor or the chairperson of the Human Research Ethics Committee (Medical) on the details listed below.
Warm regards

Theresa Behrens	Joanne Potterton	Prof Peter Cleaton-Jones
Researcher	Supervisor	Chair of the Health Sciences Ethics Committee
082 561 4156	084 054 8245	011 717 1234

APPENDIX V: CAREGIVER QUESTIONNAIRE

Appendix 3

Caregiver Questionnaire – Part 1

Participant number:_____

Type of disability	**Please tick your child's SINGLE most prevalent difficulty/disability**
Developmental delay	
Intellectual delay	
Hearing impairment	
Speech/language impairment	
Vision impairment	
Emotional impairment	
Orthopaedic impairment	
Autism spectrum disorder	
Attention-deficit disorder	
Traumatic brain injury	
Learning disability	
Health impairment	
Other	

Type of disability	**Please tick ALL your child's APPLICABLE difficulties/disabilities**
Developmental delay	
Intellectual delay	
Hearing impairment	
Speech/language impairment	
Vision impairment	
Emotional impairment	
Orthopaedic impairment	
Autism spectrum disorder	
Attention-deficit disorder	
Traumatic brain injury	
Learning disability	
Health impairment	
Other	

Caregiver Questionnaire – Part 2

(adapted from Household Economic and Social Status Index – HESSI)

Relationship of person providing the information, to the child: _____

Please circle the appropriate answer.

1. FAMILY STRUCTURE/HOUSEHOLD COMPOSITION

1.1) Your Marital Status
a) Married
b) Divorced
c) Widowed
d) Living with a partner

1.2) Household Membership (Please fill in on the space provided)
- How many people currently live in the household? _____
- Number 18 and older: _____
- Number 6-18 years old: _____
- Number under 6 years: _____

1.3) Are there **adult relatives** (>18 years old) now living in the household? **YES/NO**
If yes what are their relationships to the child? (e.g. sibling, aunt, grandparent etc)
_____

2. SOCIAL STATUS

2.1) Mother's Education: What is the highest level of education attained?
a) Less than Grade 5 (Standard 3)
b) Grade 5 (Standard 3)
c) Grade 6 (Standard 4)
d) Grade 7 (Standard 5)
e) Grade 8 (Standard 6)
f) Grade 9 (Standard 7)
g) Grade 10 (Standard 8)
h) Grade 11 (Standard 9)
i) Matric/High School graduate/vocational training diploma
j) 1-2 year College, Technikon
k) 3-4 years of University
l) Ph.D., M.D., J.D., D.D.S., or other doctoral degree

2.2) Education of Mother's partner: What is the highest level of education attained?
a) Less than Grade 5 (Standard 3)
b) Grade 5 (Standard 3)
c) Grade 6 (Standard 4)
d) Grade 7 (Standard 5)
e) Grade 8 (Standard 6)
f) Grade 9 (Standard 7)
g) Grade 10 (Standard 8)
h) Grade 11 (Standard 9)
i) Matric/High School graduate/vocational training diploma
j) 1-2 year College, Technikon
k) 3-4 years of University
l) Ph.D., M.D., J.D., D.D.S., or other doctoral degree

2.3) What are the jobs of the persons' earning money that live in the house?

JOBS:

2.4) Access to Finances: Who in the family earns money? Tick all that apply.
__ Mother
__ Partner
__ Parent
__ Parent Pension
__ Sibling/Aunt/Uncle
__ Grandmother/Grandfather
__ Other: Specify:_____

3. HOUSING ACCOMMODATION

3.1) In what type of housing do you live?
a) None, homeless
b) Shack
c) Room, garage
d) RDP house
e) Flat, cottage
f) Home shared with other family(ies)
g) Home that is not shared with other families.

3.2) Does your home have:
a) A **Separate Kitchen**? No / Yes
b) A **Separate Bathroom?** No / Yes

3.3) In your home how many separate rooms are there just for sleeping? (circle one number)
0 1 2 3 4 or more

3.4) What type of toilet facilities does your home have:
a) None
b) Pit or Bucket
c) Outside flush toilet
d) Inside flush toilet
e) Shared toilet in neighbours house

3.5) Do you own or rent a home?
a) Neither
b) Rent
c) Purchasing on Bond
d) Own

3.8) Does the place you live in have a ……..?
a) Refrigerator No / Yes
b) Television No / Yes
c) Telephone No / Yes
d) Car No / Yes
e) DSTV No / Yes
f) Washing machine No / Yes
g) Microwave oven No / Yes
h) Internet No / Yes
i) Computer No / Yes

3.9) In the past, have your children gone hungry because you did not have food?

a) No, never
b) Rarely
c) Often
d) All the time

4. NEIGHBOURHOOD SAFETY

4.1) In general how safe is the area in which you live?

a) Extremely dangerous
b) Dangerous
c) Safe
d) Extremely safe

4.2) How much do you worry about your child getting hurt when s/he is outside your home?

a) Never
b) Sometimes
c) Often
d) All the time

5. SATISFACTION WITH FAMILY LIFE (SUPPORT)

5.1) My family has a lot of problems:

a) Not True
b) Sometimes
c) Often True
d) Always True

5.2) My family is always there for me when I need them:

a) Not True
b) Sometimes
c) Often True
d) Always True

References:

Barbarin, O & Khomo, N. 1997. Indicators of economic status and social capital in South African townships. *Childhood.* 4(2): 193-222.

APPENDIX VI: PEM-CY

FOR OFFICE USE ONLY: _____ (ID)

Participation and Environment Measure – Children and Youth©

Wendy Coster, Mary Law, Gary Bedell

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SURVEY INSTRUCTIONS

Participation refers to a child's involvement in important everyday activities at home, in school, and in the community. The meaning of participation includes both how often a child does activities AND how involved he or she is when doing these activities.

The survey asks a set of questions about your child's participation in 25 types of activities that take place in three environments: home, school, and community. We give a few examples to illustrate each type of activity. However, you should think about all of the activities that belong to the category when answering these questions.

For each type of activity we ask:

1. **how often** your child has participated over the last 4 months
2. **how involved** your child is when participating in 1 or 2 activities of this type that he or she does most often
3. whether or not you would like your child's participation **to change**, and if so, how you would like it to change

IMPORTANT

This survey is not asking about your child's level of independence when participating in activities. "Involvement" refers to how engaged your child is in an activity, using whatever supports, assistance, adaptations, or methods he or she routinely uses or has available.

When selecting your response, please think about your child's level of attention, concentration, emotional engagement, or satisfaction (using whatever supports or assistance are usually available).

Very involved = In general, child is engaged throughout the activity. He or she shows a lot of initiative and/or interest in and attention to what he or she and others are doing during the activity.

Somewhat involved = Child is engaged in the activity some of the time. He or she shows some initiative and/or interest in and attention to what he or she and others are doing during the activity.

Minimally involved = Child is engaged in a small part of the activity. He or she only shows a little initiative and/or interest in and attention to what he or she and others are doing during the activity.

If there are things that help or make your child's participation more difficult, such as equipment or support from others, you can tell us about their impact in the home environment, school environment, and community environment sections of this survey.

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HOME Participation

	A) Typically, how often does your child participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								**B)** Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities? CHECK ONE RESPONSE ☑					**C)** Would you like your child's participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Computer and video games																			
2) Indoor play and games (e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)																			
3) Arts, crafts, music, and hobbies (e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun)																			
4) Watching TV, videos, and DVDs																			
5) Getting together with other people (e.g., interacting with peers, family, other houseguests)																			
6) Socializing using technology (e.g., telephone, computer)																			
7) Household chores (e.g., unloading/loading the dishwasher, cleaning room or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pet)																			
8) Personal care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)																			
9) School preparation (not homework) (e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)																			
10) Homework (e.g., daily reading, homework assignments, school projects)																			

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HOME Environment

Do the following things help or make it harder for your child to participate in activities at home? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space and furniture in your home				
2. The sensory qualities of the home environment (e.g., amount and/or type of sound, light, temperature, textures of objects)				
3. The physical demands of typical activities in the home (e.g., strength, endurance, coordination)				
4. The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)				
5. The social demands of typical activities in the home (e.g., communication, interacting with others)				
6. Your child's relationships with family members in the home (e.g., siblings, parent, grandparent)				
7. The attitudes and actions of babysitters, therapists, and other professionals who care for your child at home				

CHECK ONE RESPONSE ☑	Not need-ed	Usually, yes	Sometimes yes; sometimes no	Usually, no
8. Are services in your home available and/or adequate to support your child's participation?				

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HOME Environment

Are the following available and/or adequate to support your child's participation at home? CHECK ONE RESPONSE ☑	Usually, yes	Sometimes yes; sometimes no	Usually, no
9. Supplies in the home (e.g., sports equipment, crafts supplies, reading materials, assistive devices or technology, picture or word schedules)			
10. Information (e.g., about activities, services, programs)			
11. Do you (and your family) have enough time to support your child's participation at home?			
12. Do you (and your family) have enough money to support your child's participation at home?			

What are some things that you or other family members do that help your child participate successfully in activities at home? PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.

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SCHOOL Participation

	A) Typically, how often does your child participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								**B)** Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities? CHECK ONE RESPONSE ☑					**C)** Would you like your child's participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very involved	4	3 Somewhat involved	2	1 Minimally involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Classroom activities (e.g., group work, classroom discussions, tests, in-class assignments)																			
2) Field trips and school events (e.g., going to a museum, the school fair, spring concert or play, dances, fundraisers)																			
3) School-sponsored teams, clubs and organizations (e.g., groups, clubs, teams, student council)																			
4) Getting together with peers outside of class (e.g., hanging out during lunch, at recess, or other breaks during the school day)																			
5) Special roles at school (e.g., lunch room supervisor, student mentor)																			

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SCHOOL Environment

Do the following things help or make it harder for your child to participate in activities at school? **CHECK ONE RESPONSE ☑**	**Not an issue**	**Usually helps**	**Sometimes helps; sometimes makes harder**	**Usually makes harder**
1. The physical layout or amount of space in the classroom, on the playground, or on other parts of school premises (e.g., presence of sidewalks, availability of ramps or elevators in school building)				
2. The sensory qualities of the school environment (e.g., noise, crowds, lighting, etc.)				
3. Outside weather conditions (e.g., temperature, climate)				
4. The physical demands of typical school activities (e.g., strength, endurance, coordination)				
5. The cognitive demands of typical school activities (e.g., concentration, attention, problem-solving)				
6. The social demands of typical school activities (e.g., communication, interacting with others)				
7. Attitudes and actions of teachers, coaches, or staff towards your child				
8. Your child's relationships with peers				
9. The safety of the school (e.g., supervision, crime, violence)				

Are the following available and/or adequate to support your child's participation at school? **CHECK ONE RESPONSE ☑**	**Not needed**	**Usually, yes**	**Sometimes yes; sometimes no**	**Usually, no**
10. Access to personal transportation to get to school (e.g., family car, bicycle)				
11. Access to public transportation to get to school (e.g., school bus, train, subway)				
12. Programs and services (e.g., after school, recreational, special resources, educational assistant/aide)				
13. School–related policies and procedures (e.g., eligibility criteria for services, rules for behavior)				

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SCHOOL Environment

Are the following available and/or adequate to support your child's participation at school? CHECK ONE RESPONSE ☑	Usually, yes	Sometimes yes; sometimes no	Usually, no
14. Supplies (e.g., assistive devices or technology, reading materials, sports equipment, crafts supplies)			
15. Information (e.g., about activities, services, programs)			
16. Do you (and your family) have enough time to support your child's participation at school?			
17. Do you (and your family) have enough money to support your child's participation at school?			

What are some things that you or other family members do that help your child participate successfully in activities at school? PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.

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COMMUNITY Participation

	A) Typically, how often does your child participate in 1 or more activities of this type? **CHECK ONE RESPONSE** ☑								**B)** Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities? **CHECK ONE RESPONSE** ☑					**C)** Would you like your child's participation to change in this type of activity? **IF YES, CHECK ALL THAT APPLY** ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never **(skip to Question C)**	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Neighborhood outings (e.g., shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore)																			
2) Community events (e.g., attending a play, concert, sports game, parade)																			
3) Organized physical activities (e.g., sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics)																			
4) Unstructured physical activities (e.g., nature trail walks, bicycle riding, rollerblading, skateboarding, playing hide-and-seek or chase, playing pick-up games like basketball)																			
5) Classes and lessons (not school-sponsored) (e.g., music, art, languages, computers)																			

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COMMUNITY Participation

	A) Typically, how often does your child participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								**B)** Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities? CHECK ONE RESPONSE ☑					**C)** Would you like your child's participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑					
	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never **(skip to Question C)**	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
6) Organizations, groups, clubs, and volunteer or leadership activities (e.g., Boy Scouts, Brownies/Girl Guides, youth groups, public speaking)																			
7) Religious or spiritual gatherings and activities (e.g., attending places of worship, religion classes, groups)																			
8) Getting together with other children in the community (e.g., hanging out, informal gatherings outside of the home or school)																			
9) Working for pay (e.g., babysitting, paper route, working in a store, doing chores or running errands for pay)																			
10) Overnight visits or trips (e.g., sleepovers, vacations, camp)																			

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COMMUNITY Environment

Do the following things help or make it harder for your child to participate in activities in the community? **CHECK ONE RESPONSE ☑**	**Not an issue**	**Usually helps**	**Sometimes helps; sometimes makes harder**	**Usually makes harder**
1. The physical layout or amount of space outside and inside buildings (e.g., distances to stores, presence of sidewalks, availability of ramps or elevators)				
2. The sensory qualities of community settings (e.g., noise, crowds, lighting)				
3. The physical demands of typical activities (e.g., strength, endurance, coordination)				
4. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)				
5. The social demands of typical activities (e.g., communication, interacting with others)				
6. Your child's relationships with peers				
7. The attitudes and actions of other members of the community towards your child (e.g., shopkeepers, instructors, coaches, other families)				
8. Outside weather conditions (e.g., temperature, climate)				
9. The safety of the community (e.g., traffic, crime, violence)				

Are the following available and/or adequate to support your child's participation in the community? **CHECK ONE RESPONSE ☑**	**Not needed**	**Usually, yes**	**Sometimes yes; sometimes no**	**Usually, no**
10. Access to personal transportation to access community activities (e.g., family car, bicycle)				
11. Access to public transportation to access community activities (e.g., bus, train, subway)				
12. Programs and services (e.g., inclusive sports programs, personal support worker)				

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COMMUNITY Environment

Are the following available and/or adequate to support your child's participation in the community? CHECK ONE RESPONSE ☑	Usually, yes	Sometimes yes; sometimes no	Usually, no
13. Information (e.g., about activities, services, programs)			
14. Equipment or supplies (e.g., sports equipment, craft supplies, reading materials, assistive devices or technology)			
15. Do you (and your family) have enough time to support your child's participation in the community?			
16. Do you (and your family) have enough money to support your child's participation in the community?			

What are some things that you or other family members do that help your child participate successfully in activities in the community? PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.

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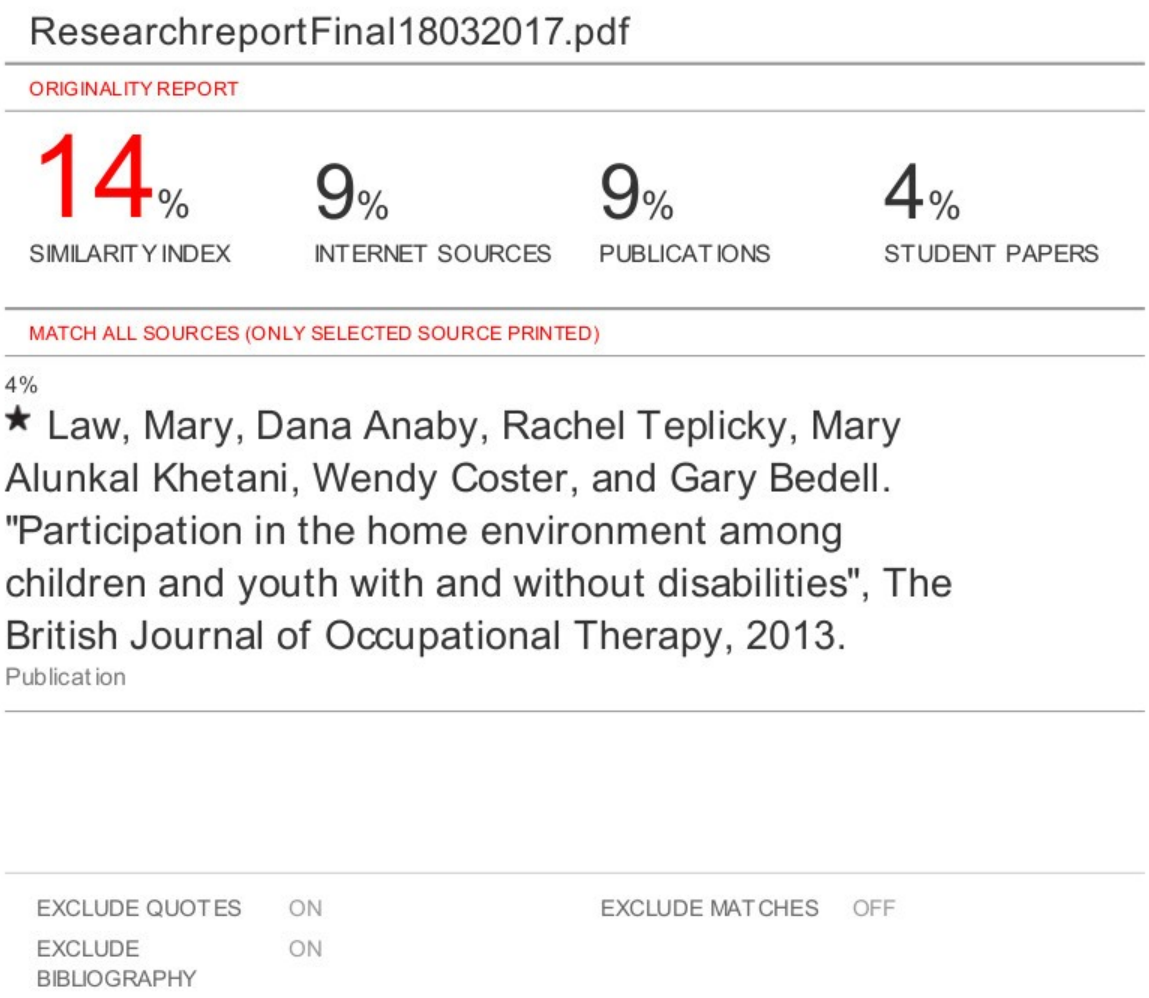
APPENDIX VII: DATA COLLECTION SHEET

A pilot study: Home, school and community participation of children attending a special needs school in South Africa: Barriers and supports

DATA COLLECTION SHEET

Participant number	Date of birth	Gender	Class	Medical diagnosis

APPENDIX VIII: TURNITIN



ResearchreportFinal18032017.pdf

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★ Law, Mary, Dana Anaby, Rachel Teplicky, Mary Alunkal Khetani, Wendy Coster, and Gary Bedell. "Participation in the home environment among children and youth with and without disabilities", The British Journal of Occupational Therapy, 2013.

Publication

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EXCLUDE BIBLIOGRAPHY	ON		

APPENDIX IX: PLAGIARISM DECLARATION

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PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Theresa Behrens (Student number: 1288038) am a student registered for the degree of MSc Child Health (Neurodevelopment option) in the academic year 2017.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this in not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: Behrens Date: 2017/03/22