#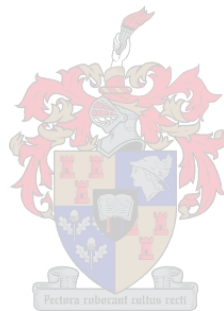 Factors facilitating completion of mainstream education in an ordinary school: reflections of young adults with cerebral palsy

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Research assignment presented in partial fulfilment of the requirements for
the degree of Master of Rehabilitation Studies
in the Faculty of Medicine and Health Sciences at Stellenbosch University.

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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Abstract

Inclusive education is supported internationally and nationally, but most children with physical disabilities are still excluded from ordinary schools in South Africa. The purpose of this paper is to add to the body of knowledge about factors that facilitate the inclusion of learners with cerebral palsy. This will complement the more widely known barriers to education, from the perspectives of teachers and/or parents and in other countries. The research question was: *What were facilitating factors within the lived experience of young adult participants with cerebral palsy, which allowed them to access mainstream education and achieve a Grade 12 pass in an ordinary school in Cape Town, South Africa?* Two in-depth interviews were conducted with each of the three participants in English. Interpretative Phenomenological Analysis (IPA) led to the identification of three superordinate themes: "Treat me the same, but treat me differently", "Good communication is vital" and "Ons gee om" [We care], each of which comprised two subordinate themes. The facilitating factors identified are discussed within the framework of the *International Classification of Functioning, Disability and Health* (*ICF*). Practical implications and recommendations are proposed.

Opsomming

Inklusiewe onderwys word internasionaal en nasionaal ondersteun, maar die meeste kinders met liggaamlike gestremdhede word steeds deur gewone skole in Suid-Afrika uitgesluit. Die doel van hierdie projek was om bestaande kennis aangaande faktore wat die insluiting van leerders met serebrale verlamming bevorder, uit te brei. Dit sal die meer algemene, reeds bekende kennis oor struikelblokke in die onderwys, vanuit die perspektief van onderwysers en/of ouers, meestal van ander lande, aanvul. Die navorsingsvraag was: *Watter ondersteunende faktore, soos ervaar deur jong volwasse deelnemers met serebrale verlamming, het hulle bemagtig om hoofstroom onderwys te betree en om Graad 12 suksesvol te voltooi as leerders van 'n gewone skool, geleë in Kaapstad, Suid-Afrika.* Twee in-diepte onderhoude is met elk van die drie studiedeelnemers in Engels gevoer. Interpretatiewe Fenomenologiese Analise het bygedra tot die identifikasie van drie hooftemas, naamlik: "Behandel my dieselfde, maar behandel my anders", "Goeie kommunikasie is lewensnoodsaaklik" en "Ons gee om"; wat elk ook in twee sub-temas onderverdeel is. Die ondersteunende faktore, soos geïdentifiseer deur die deelnemers, is bespreek binne die raamwerk van die *Internasionale Klassifisering van Funksionering, Gestremdheid en Gesondheid*. Praktiese implikasies en aanbevelings is voorgestel.

Key words

appreciative approach; cerebral palsy; facilitating factors; inclusive education; *International Classification of Functioning, Disability and Health (ICF)*; Interpretative Phenomenological Analysis (IPA); mainstream education, ordinary school; physical disability

Introduction

"Inclusive education is an education system which recognises that all children are different and all children can learn – the system changes to accommodate everyone" (Inclusive Education South Africa, 2015:4). Ideally an inclusive education system allows all children to be adequately supported in their own community school and is seen as the foundation of more inclusive societies (Mariga, McConkey and Myezwa, 2014:26). In South Africa mainstream education is currently offered in ordinary schools (the preferred term for normal or mainstream schools) and some special schools, while other special schools offer special education (Department of Education, 2015).

In addressing the situation of the small number of learners with physical disabilities who have completed mainstream education in ordinary schools to date, the focus has been on educational barriers and challenges (Danso, Owusu-Ansah & Alorwu, 2012; Lawlor, Mihaylov, Welsh, Jarvis & Colvera, 2006). Moreover, most evidence to date has been from the perspective of teachers (Geldenhuys & Wevers, 2013; Roux, 2014) and/or parents (Swart, Engelbrecht, Eloff, Pettipher & Oswald, 2004; Tshabalala, 2014). Against a growing need to hear the voices of learners with disabilities themselves, including those with cerebral palsy[1] (Moriña, Cortés &

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[1] *Cerebral palsy (CP) defines a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disturbances of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception and/or by a seizure disorder. (*Bax, Goldstein, Rosenbaum & Leviton, 2005:572)

Melero, 2014; Rosenbaum & Gorter, 2011; Shah, 2007; Sparkes & Hall, 2007), I have chosen to focus on the lived experience of a few young adults with cerebral palsy who accessed mainstream education in an ordinary school and completed Grade 12.

As Parther and Nxumalo (2013:424) assert that there is limited information available about how inclusive education can work in developing countries, the South African locality of this study is seen as valuable. In a context of scarce resources, I adopted an appreciative approach where I was specifically looking for the positives (Ludema, Cooperrider & Barrett, 2001) that have allowed success against the odds in a less than ideal system. A better understanding of the facilitating factors for inclusive education throughout schooling is anticipated to yield immediately useful information for role players wishing to focus their energy on effective support of children with cerebral palsy and possibly other physical disabilities in ordinary schools. This includes me as an Occupational Therapist working in the field of inclusive education in Cape Town.

Literature Review

The context

Internationally and locally, children with disabilities (including disabilities caused by cerebral palsy), were historically segregated in special schools or not afforded education at all. This situation was due to medical model thinking that focused on the extent of individual impairments and associated deficits, rather than on the interrelating factors comprising a disability as described in the *International Classification of Functioning, Disability and Health (ICF)* (WHO, 2001).

The World Health Organisation states that using an *ICF* framework can help one to "understand the interaction between educational environments and the participation of students [learners] with disabilities" (WHO, 2013:98). It confirms that the "physical, social and attitudinal environment in which people live influences their functioning in a substantial way" (2013:40) and that positive environmental factors have the power to boost performance beyond the capacity expected. In contrast negative

environmental factors lead to performance below the expected capacity, as has been the major focus of past studies. The environmental section of the *ICF* allows one to assess contexts in terms of how they facilitate or create barriers to participation, including in education (WHO, 2002), which can then be used to guide intervention for learners with disabilities, the ultimate purpose of this study. The *ICF* considers the following environmental factors: products and technology; natural environment and human made changes to environment; support and relationships; attitudes; and services, systems and policies along with personal factors (WHO, 2002:16).

The segregation and exclusion of learners with disabilities from education has been challenged on a human rights basis. Internationally, inclusive education is now mandated by UNICEF's Convention on the Rights of the Child (UNCRC) (United Nations, 1989), the Salamanca Statement and Framework for Action on Special Needs Education (UNESCO, 1994) and the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) (2006:16).

Locally, inclusive education is supported by South Africa's Constitution (1996:1257), the South African Schools Act (1996) and South Africa's Integrated National Disability Strategy (1997:39). The signing and ratification of both the UNCRPD and the optional protocol in 2007, make this international mandate legally binding at a local level too. In line with social model thinking around disability, South Africa adopted Education White Paper 6 in 2001. It acknowledges that barriers to learning are related to the system at various levels rather than the individual child and that, with the right support, all children can learn together. White Paper 6 thus created an environment in which children with disabilities, including cerebral palsy, could and should be included in their local ordinary school unless they have very high support needs that cannot adequately be addressed outside of a special school.

In 2001 already there were programmes to identity and attempt to remove barriers to learning experienced in mainstream education based on challenges as described in White Paper 6 (Education Department, 2001:6), namely:

> *negative attitudes to and stereotyping of differences, an inflexible curriculum, inappropriate languages or language of learning and teaching, inappropriate communication, inaccessible and unsafe built environments, inappropriate*

> *and inadequate support services, inadequate policies and legislation, the non-recognition and non-involvement of parents, and inadequately and inappropriately trained education managers and educators.*

Despite policies and laws that promote inclusive education, a cross-sectional survey of 989 South African youth aged 18 – 35 years (52.9% with self-reported physical, sensory and/or intellectual disability) found residual inequality in their access to education, with only 82.4% youth with disabilities having accessed any formal schooling compared to 99.3% of their counterparts without disabilities (Lorenzo & Murray, 2012:579). In contrast to this, according to Donohue and Bornman (2014), more than 10 years since the release of Education White Paper 6, most children with disabilities in South Africa are still not included in ordinary schools. This was largely attributed to the fact that the Department of Education had not yet held itself accountable for the implementation of the policy it created by clarifying procedures and giving directives. South Africa's first country report on the implementation of the UNCRPD admitted to challenges in the provision of inclusive education (Department of Women, Children and People with Disabilities, 2013:10).

Likewise, the 2014 International Centre for Evidence in Disability (ICED) research report by Banks and Polack found that while the UNCRPD demands of its signatories to provide inclusive practices, many countries, especially low to middle income countries such as South Africa have performed poorly. Countries evidently reported financial restrictions, but Banks and Polack highlighted that this was short-sighted as the cost of exclusion is more than the cost of inclusion. In this regard, exclusion from quality education increases long-term financial dependence on the country's resources. The Department of Basic Educations' *Report on the Implementation of Education White Paper 6 on Inclusive Education – An Overview for the Period: 2013 - 2015* (Department of Education, 2015) also acknowledges that South Africa will benefit from more effectively implementing inclusive education so that children with disabilities, including the estimated 500 000 not attending school, access quality education.

Parents' and teachers' perspectives on barriers and facilitating factors to education

Internationally, Wendelborgand and Tossebro (2010) obtained information from parents of primary school learners in Norway and found that even with progressive policy, not all children with disabilities were included in regular classrooms and even if they were, this was for less time as they got older. Interviews by Lawlor, Mihaylov, Welsh, Jarvis and Colver (2006) with families of children with cerebral palsy in England, found that participation was negatively impacted upon by uneven surfaces in the physical environment, increased dependence on adult supervision within the social environment and bullying and – in the case of deaf learners – lack of Sign Language facilities in the attitudinal environment. Lawlor et al felt that in future it would also be important to focus on the facilitating factors and barriers experienced by the children as the parents may be unaware of some of these.

In Ghana, Danso et al (2012) found that in secondary schools there were many physical barriers for learners with diverse disabilities, including obstructed paths, a lack of parking facilities, inaccessible areas within buildings, limited toilet and bathroom facilities, poor lighting and inadequate signage. As a result, few learners with disabilities are admitted and retained in these schools.

Here in South Africa, in East London, Roux (2014) found that the biggest barrier to learners with physical disabilities even applying, let alone being admitted to mainstream schools, was infrastructure inaccessibility. A sample of twenty-eight primary school teachers at ordinary schools in the Eastern Cape, South African, included in a study by Geldenhuys and Wevers (2013) suggests that implementation of inclusive education was hampered by aspects across the entire ecological system of education in South Africa, including physical restrictions and negative attitudes. Pillay and Terlizzi (2009), while being in favour of inclusive education in South Africa, described how a relatively well-resourced mainstream school could not provide adequate resources for a learner with barriers to learning and so concluded that further resources and facilities needed to be made available to ensure the successful implementation of inclusive education that really does ensure quality education for all children. Furthermore, parents of children with disabilities in ordinary schools in

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South Africa revealed to Swart, Engelbrecht, Eloff, Pettipher and Oswald (2004:80) that inclusion does not happen without long-term relationship building and support.

Learners' perspectives on inclusive education

In Canada, Pivik, McComas and Laflamme (2002:97 and 102) found that while similar findings were obtained from learners and their parents, there were also some differences in the perceptions of learners about barriers and facilitating factors to their full inclusion in mainstream schools. Focus groups with fifteen 9 – 15 year olds with mobility impairments identified multiple barriers. These related to the physical environment, such as narrow doorways and ramps, intentional attitudinal barriers such as isolation and bullying, unintentional attitudinal barriers such as lack of knowledge, understanding or awareness and their physical limitations such as difficulty with manual dexterity. The participating learners identified the following as potential facilitating factors against the identified barriers: modifications to the environment, social / policy changes and more resources.

Furthermore, in their study of experiences of university students from New Zealand who identified themselves as disabled, Bird, Claiborne, Cornforth, Gibson and Smith (2011:513) found that they highlighted a lack of access to resources and accommodation by staff, to which they felt entitled. In Spain, Moriña, Cortés and Melero's study (2014:44) reported similar findings amongst university students. In contrast, their non-disabled peers and staff were more focused on the achievement of social inclusion (Moriña, Cortés & Melero, 2014:44). Shah (2007) found that learners and students between the ages of 13 and 25 with physical impairments in the United Kingdom had insightful views of segregated and mainstream education that challenged policy and practice. It was suggested, from the young people's experiences and views, that mainstream schools in the United Kingdom at that time had not embraced full inclusion and continued to disempower learners and students with disabilities with exclusionary procedures and practices.

Locally, in a study involving fifteen 6 – 15 year olds with paraplegia attending ordinary schools in the Western Cape, Vosloo (2009) found that cognitive independence and mobility restricted participation, while resource availability, social

support and equality facilitated inclusion. A person using a wheelchair at a South African university expressed to Ntobela (2013) that able-bodied individuals must ask how they can accommodate those with disabilities if we are to avoid ongoing exclusion.

Motivation for the study

Self-representation is advocated as essential by the disability rights movement (Swartz, 2014:2). Shah (2007) challenged all educationalists to listen and provide an opportunity for young people with disabilities to take an active part in the education process, including informing practice. Sparkes and Hall (2007) did a study on the quality of life of children with cerebral palsy and concluded that there is a need for more studies that included the views of children and adults with cerebral palsy *themselves*. By 2011, Rosenbaum and Gorter continued to highlight that there was still not enough known about what intervention children with cerebral palsy themselves and their parents really value. Swartz, Van der Merwe, Buckland and McDougall (2012) from South Africa reiterated that we should seek the valuable information that can only be obtained by listening to people with disability *themselves*.

Reflections of young adults with cerebral palsy on what factors facilitated their mainstream education at an ordinary school will complement the more widely reported barriers to education, from the perspectives of teachers and/or parents and in other countries. A focus on the facilitating factors as reported by those with disabilities in Cape Town themselves, was anticipated to shed valuable insider knowledge on support strategies that can facilitate successful inclusive education for learners with physical disabilities in the future.

Accordingly, the **research question** was: What were facilitating factors within the lived experience of young adult participants with cerebral palsy, which allowed them to access mainstream education and achieve a Grade 12 pass in an ordinary school in Cape Town, South Africa?

Method

The **aim** of the study was to describe factors that *facilitated* mainstream education and a Grade 12 pass in ordinary schools in Cape Town through exploring the lived experience of participants with cerebral palsy. The applied purpose of the study in practice was to increase appropriate support for future potential learners with physical disabilities, by enhancing such facilitators.

The **objectives** were:
- To explore how the study participants successfully completed a mainstream education to Grade 12 in an ordinary school.
- To describe the facilitating factors within the individual, their family, the school, the community and the country as perceived by the young adult.
- To highlight common and contrasting facilitating factors between participants with varying personal and environmental contexts.

Study design

In this qualitative study the lived experiences of participants were explored and described through Interpretative Phenomenological Analysis (IPA). IPA allows researchers to explore how people reflect upon their experience of living in and relating to their environment (Smith, Flowers & Larkin, 2009:21; Smith, 2011:10). Pietkiewicz and Smith (2014:7) indicate that IPA is informed by phenomenology, double hermeneutics and idiography. Phenomenology is a line of enquiry that seeks to understand how individuals experience situations (O'Leary, 2014:131; Pietkiewicz & Smith, 2014:8). Hermeneutics involves interpretation (Kinsella, 2006:1) and in the case of IPA, involves dual interpretation as the researcher attempts to analyse how individuals have made sense of their own experiences (Pietkiewicz & Smith, 2014:8). IPA is idiographic in nature as it involves first analysing each case in its own context before comparing and contrasting the particulars of different cases (Pietkiewicz & Smith, 2014:8). Furthermore, an appreciative inquiry stance was adopted, which is an empowering approach taken by:

> *…continuously crafting the unconditional positive question that allows the whole system to discover, amplify and multiply the alignment of strengths in such a way that weaknesses and deficiencies become increasingly*

irrelevant…. For the questions we ask set the stage for what we 'find', and what we find becomes the knowledge out of which the future is conceived, conversed about and constructed. (Ludema, Cooperrider & Barrett, 2001: 198)

Study population, sampling and participants

I focused on young adults with cerebral palsy who have passed Grade 12 as this marks the end of secondary schooling in South Africa and hence it can be seen as an outcome measure of whether inclusive education has been successful for the specific learner with a disability. The Grade 12 qualification is also generally accepted to be the key to increasing the chance of securing productive employment and/or enrolling in tertiary education. It is expected that young adults with cerebral palsy who have passed Grade 12 can express themselves (and to an extent help to give a voice to those with greater barriers to learning) and will also be of a maturity whereby they can reflect back on their experience of schooling and share their own perceptions without undue pressure or influence from their school or family.

The study population comprised males or females with cerebral palsy between the ages of 18 and 22 years in 2015 who had attended an ordinary school in Cape Town for most of their school career and who had successfully passed Grade 12 at an ordinary school within 100km of the Cape Town Central Business District. The reason for the lower age limit is that this is usually the youngest age at which Grade 12 is completed and it is also the age of legal consent in South Africa. The upper age limit demarcates the first cohort of learners historically, who were in the foundation phase when Education White Paper 6 (Department of Education, 2001) was published. Persons who lived more than 100km outside of Cape Town, or were unwilling to share their schooling story or could not express themselves in English through written or electronic communication were excluded. These exclusion criteria were necessitated by practical reasons: firstly, the limited scope and time of this study meant that travelling times and transport costs had to be contained. Secondly, the high demand for participants to articulate their lived experiences and for direct contact with the interviewer to follow the depth and richness of their responses, as recommended in an IPA methodology (Smith, Flowers, Larkin, 2009), meant it was necessary to avoid the need for a translator.

Prior to the onset of this study I was unable to obtain an indication of the size of my study population. I sought participants indirectly through circulating a request to assist in locating participants (Appendix A) to over 100 individuals in the health, education and disability fields, including the Chaeli Campaign mailing list, Inclusive Education South Africa, the Centre for Disability Studies at UCT, the Centre for Rehabilitation Studies at US, the Cerebral Palsy Clinic at Red Cross Hospital, The Cerebral Palsy Association, Western Cape Education Department and private therapists between March 2015 and July 2015. In an attempt to reach all possible individuals who might be eligible for the study, I requested the above individuals to forward information about the study (Appendix B) to potential participants, circulate my request to their contacts or post the information on their website. The general response to this request was that the individual did not know of anyone who met my inclusion criteria.

It thus appeared that my study population was even smaller than initially anticipated; an important finding in itself as it points to the lack of inclusion of learners with cerebral palsy in ordinary schools in this age band. In a recent publication entitled *Report on the Implementation of Education White Paper 6 on Inclusive Education - An Overview for the Period: 2013 - 2015*, the Department of Education reported statistics confirming the low number of children with cerebral palsy enrolled in all schools, but especially in ordinary schools (Department of Education, 2015). While acknowledging that there were accuracy issues, it was reported that available statistics between 2011 and 2014 indicated that in South Africa there were approximately 6000 children with cerebral palsy attending special schools and of these approximately 800 were in Western Cape. In terms of children with cerebral palsy enrolled in ordinary schools for the same period, there were approximately 350 in South Africa and of these only 9 in the Western Cape.

In total I was contacted by only three young adults meeting the inclusion criteria within the 5-month period allocated for data collection. They were all included in the study as three participants is the suggested number of participants for a master's level research assignment in which IPA is implemented (Pietkiewicz & Smith, 2014:9; Smith, Flowers & Larkin, 2009:51,52,106). The first participant was sampled

purposively as I knew her personally. It was initially planned that hers would be the pilot interviews, in keeping with the increasing evidence of the value of pilot studies in qualitative research (Kim, 2010). However, as valuable information was obtained through this and no major adjustments were indicated by this 'pilot', she was included as a participant in the study, as also proposed in Visagie's study (2015:101). The second participant received the information about and invitation to participate in the study (Appendix B) from two individuals who were assisting with recruitment as described earlier. She responded to me via *WhatsApp* and was included through convenience sampling. The third participant was recruited through snowball sampling as my first participant knew her personally and informed her about the study. She contacted me via email.

It is important to note that the selection criteria did not limit gender or socio-economic background, and yet the three participants all happened to be females from middle class backgrounds, a minority group in South Africa. While this was in itself a finding (to be discussed later) this development was not deemed to be a constraint as IPA researchers support homogenous samples (Smith, Flowers & Larkin, 2009; Pietkiewicz & Smith, 2014:9) and a representative sample was never an aim in this small-scale qualitative study (Denzin & Lincoln, 2003; O'Leary, 2014; Schwandt, 2001).

The participants were aged 20, 21 and 21 years and had all been diagnosed with cerebral palsy (spastic quadriplegia – GMFC level[2] IV, spastic diplegia – GMFC level IV and spastic left hemiplegia – GMFC level I respectively) before their second birthday. They all attended government special schools until various stages in grade 3 and then went on to government quintile 5 ordinary primary and high schools[3], with one participant having transferred to a private high school for her last year and a half

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[2] Assigning a GMFC level (I – V) is the accepted way of describing the physical functioning of children with cerebral palsy with level V used to describe the most severe physical impairment (Palisano, Rosenbaum, Walter, Russell, Wood & Galuppi, 1997).

[3] Quintile ratings of 1 – 5 are used to describe the resource level at different schools by the National Department of Basic Education in South Africa with a rating of 5 used to describe schools in the wealthiest areas (South African Government, 1996a).

of schooling. Two participants were wheelchair users since at least grade 3 and one walked independently. All participants lived at home with their working parents and siblings during their schooling. They had access to private medical care and were driven by a parent or walked / rode in their wheelchair to school depending on the school's distance from the home. At the time of the study all three participants were in their third year of study at tertiary institutions in Cape Town and two drove their own cars. It needs to be emphasised that recruitment attempts had also been made to include young adults from a wider demographic spectrum including less resourced socio-economic environments, but none were found.

Data collection

Some information on personal particulars was obtained via email and *WhatsApp* while liaising in more depth about the study and then making arrangements for the first interview at a time chosen by the participants. This was added to the personal particulars page that I drew up to capture necessary contextual information (Appendix C). Each interview took place at a venue of the participant's choice with adequate privacy and where they felt comfortable to share information. Venues chosen included a room at the headquarters of the Chaeli Campaign, a family home and a room at a sports club.

Each participant was interviewed twice by me and all six interviews were audio-taped using a *Dictaphone* with the participants' consent. Initial reflective notes were made during and within 12 hours of each interview. A pseudonym ('Ashleigh', 'Christine' and 'Jess') was used for each participant in all written notes, except on the consent forms, which were stored separately to retain anonymity.

Upon first meeting, a brief casual conversation was held to help the participant feel at ease with me, and then we went through the participant information and consent leaflet together (Appendix D). As all participants were satisfied and willing to continue, the written consent forms were completed.

The initial in-depth narrative interview with each participant varied in length from 58 minutes to 106 minutes and was an opportunity for them to tell the story of their

school career. I applied the description used by Smith, Flowers and Larkin (2009:51) that a qualitative in-depth interview is like a "conversation with a purpose". Each of the first interviews began with the following open-ended question as contained in the interview schedule (Appendix C). I had also given the question to the participants ahead of time so that they could start reflecting and to give them time to collect any school reports, photographs or other items that they wished to show me:

> *I am interested to hear from your perspective what made it possible for you to attend and complete your schooling at a mainstream school. This is because in your day this was quite rare and even now it is not the norm for children diagnosed with cerebral palsy in South Africa to attend a mainstream school. Could you tell me about your journey from preschool to Grade 12 and at some stage talk me through any school reports or photographs you may have brought.*

One participant gathered together school photographs, reports, newspaper articles and awards and another participant brought school photographs, which we looked at together and which added to the conversation. During the course of their narratives I used facilitative techniques such as utterances, reflection and interpretation (Carter, Lubinsky & Domholdt, 2011:165), to show interest and encourage participants to share information. I also focused on listening carefully so that I could hear what participants had to say and probed answers with further questions or asked for explanations when required (O'Leary, 2014:217).

Four to 8 weeks after each of these first interviews, I conducted a second, semi-structured interview with each participant, varying in length from 66 minutes to 94 minutes. By this stage the participant had had time to reflect on the initial interview and I was very familiar with their story, having personally transcribed the initial interview verbatim. The focus of the second interviews was on us identifying together the factors facilitating their successful entry into, progression through and completion of Grade 12 at an ordinary school. This was roughly guided by considering the impact of personal factors, their family, the school, the community and the country and the importance of each of these at various stages in their school careers as included in the interview schedule (Appendix C).

Data analysis

Staying within the study focus of the facilitating factors to their mainstream education in an ordinary school as identified by participants, an inductive process of experiential thematic content analysis was applied, as is the norm with IPA (Smith, 2004:43). I initially listened to the interviews in full to get a holistic overview before transcribing them verbatim. I then immersed myself in the data by reading and rereading transcripts (Finley, 2014:126) making a conscious effort to cyclically 'bracket' my preconceived ideas based on prior reading and work experience, as well as initial thoughts so that my mind was neutral and the voices of the participants could speak for themselves (Lipenga, 2014:6; Pietkiewicz & Smith, 2014:1).

Each participant was assigned a font colour and transcripts were colour printed with wide margins on each side for pencil notes. As per the guidelines for IPA in Pietkiewicz and Smith (2014:9), exploratory comments (descriptive, linguistic and conceptual) were noted in the left hand margin before using these to identify and record emergent themes in the right hand margin (Appendix E contains a typed example extract). Following the guidelines for IPA, I first analysed each participant's responses individually before focusing on what they had in common, while also noting differences of experience (Smith, Flowers & Larkin, 2009:32 & 38). Emergent themes were typed into a word document in their original colours and grouped and regrouped using the electronic cut-and-paste function to get to subordinate themes for each participant (Appendix F shows a small section by way of example) using largely abstraction (Smith, Flowers & Larkin, 2009:96-99). Subordinate themes from each participant (still in their original colours) were then arranged and re-arranged multiple times using the electronic cut-and-paste function until three superordinate themes emerged, each with two subordinate themes using abstraction, subsumption and numeration (Smith, Flowers & Larkin, 2009:96-99).

Ensuring trustworthiness

A number of strategies were implemented to enhance credibility and authenticity; the main criteria of trustworthiness in qualitative research (Denzin, 2012; Denzin & Lincoln, 2003; Schwandt, 2001). In this regard, my supervisor audited my analysis to ensure that the steps and conclusions were logical. I conducted member checking

during the course of, and at the end of, the second interview to ensure that I understood what participants were explaining to me. This was particularly important in view of the varying levels of speech intelligibility of the participants, as a result of cerebral palsy (Pellegrino, 2002). I made reflective comments during and after interviews and sought peer debriefing with my supervisor to help bracket my pre-conceived ideas and remain as neutral as possible throughout (Finley, 2014:124; Kim, 2010). Two participants contributed school photos and/or reports as a form of data triangulation while the third participant had previously shared stories and documents in various ways that corroborated the information provided in the interview (Denzin, 2012). I obtained rich data and detailed information to contextualise findings and to enhance transferability.

I also followed the methodological guidelines of IPA, which is an established framework in qualitative research and incorporated the aspects found by Smith (2011:24) to result in a high quality IPA study. In this regard, I chose a clear focus for my study, obtained strong data, took into account the prevalence of emergent themes, showed convergence and divergence within themes, used verbatim quotes from each participant in each theme, used interpretation rather than just description in the analysis and demonstrated similarities as well as differences between participants' lived experiences.

Application of ethics principles

Approval for the study was obtained from the Stellenbosch University Health Research Ethics Committee 1 (Ethics ref: S14/10/209 – Appendix G). The ethical principles of the Declaration of Helsinki were adhered to (Medical Research Council, 2003). In line with the Health Professions Council of South Africa (HPCSA) *General Ethical Guidelines for Researchers* (2008), I applied the three basic ethical principles throughout my research project, namely best interest or well-being of participants, respect for persons and justice.

Best interest or well-being includes non-maleficence (minimising harm) and beneficence (maximising benefit) (HPCSA, 2008). By interviewing young adults with cerebral palsy about the *facilitating* factors in their education, the main objective was

to learn how to better support children with cerebral palsy in future. However, it appeared that those who participated gained a sense of satisfaction themselves, from reflecting on their accomplishments, feeling listened to and contributing to this cause. One participant said she found it a very liberating process to tell her story for the first time. I endeavoured to be respectful in the manner in which I interacted with participants to ensure that they felt valued and that the time and effort they invested was worthwhile. There was little risk associated with being interviewed in this non-intervention study, but I was aware that asking them to reflect back on their schooling might elicit some distressing memories and I was alert for any such signs so that I could respond sensitively. As an occupational therapist, I was able to be supportive on the occasion that two of the participants required containment. Pre-arranged referral to an experienced counsellor, who was available immediately by phone for free debriefing, was not required.

Respect for persons includes autonomy (self-determination) and confidentiality (respecting privacy) (HPCSA, 2008). While my study population was considered vulnerable in that they had a diagnosed disability, I chose to work with individuals who were 18 years and older and who had at least a Grade 12 level of education, the combination of which reduced their vulnerability (Emmanuel, 2004). My pilot participant had been involved from the outset of the planning phase and the other two participants responded to a non-direct request for volunteers based on general information (Appendix B) about the research so that replying to me in itself was a choice. I provided more detailed information in terms of what was expected of participants in plain language both in writing (Appendix D) and verbally before participants were invited to agree to an initial interview. The process of informed consent continued at the start of each of the two interviews and it was made clear that participants could withdraw from the study and have previously collected data removed from the study at any time they wished, without any negative impact. None of the participants withdrew at any stage and all three responded positively to the prospect of the results being published in an academic journal. To protect the participants' privacy, I collected only personal details that were relevant to contextualising their information. Personal details were kept separately to transcripts and appointment details and secured in a safe locked cupboard at the researcher's

house along with corresponding pseudonyms which were recorded on all other documents. All data will be kept in a locked cupboard in the researcher's house for 2 years after publication (HPCSA, 2008).

In terms of justice, the fact that only those individuals who had passed Grade 12 in ordinary schools were included in the study was not intended to discriminate against those who did not succeed in this environment. This was because the study aimed to complement the more frequently researched and more widely known barriers that explain the many reasons why inclusive education is not always successful. Upon reading about my study a mother of a child with cerebral palsy who had not been accepted to an ordinary school, contacted me and queried why I was not focusing on children like hers and the barriers they faced. I endeavoured to explain the appreciative enquiry approach applied here to supplement research already available on barriers to education, in a sensitive manner, which she accepted. As speech impairments are common in this population group (Pellegrino, 2002), I did not exclude the two individuals with slurred and sometimes indistinct speech, and instead carefully listened to their narratives repeatedly until I could record their stories verbatim. As mentioned earlier, due to the level of education of my population group, the need to be conversant, not proficient, in English to be included in this study is not considered to be discriminatory. In the case of the participant for whom English was her second language, I encouraged her to express herself in Afrikaans on the few occasions she struggled and then translated those sections in my transcriptions. Furthermore, information contained in the participant information leaflet and consent form (Appendix D) was also worked through verbally and it was not requested or necessary to translate the participant information leaflet and consent form into languages other than English.

Findings

Interpretative Phenomenological Analysis of six interviews, that is two interviews with each of the three participants ('Ashleigh', 'Christine' and 'Jess'), led to the identification of three superordinate themes. These three superordinate themes were: "Treat me the same, but treat me differently", "Good communication is vital"

and "Ons gee om" [We care]. Each superordinate theme comprised two subordinate themes, namely reasonable accommodation and physical accessibility (Superordinate theme 1); speaking up for myself and having others to assist with communication (Superordinate theme 2); and support from the family and community, and school culture (Superordinate theme 3).

Superordinate theme 1: "Treat me the same, but treat me differently"

This theme heading, quoting Christine, captures the simplicity and yet the complexity of reasonable accommodation and physical accessibility for learners with physical disability and those around them.

Subordinate theme 1.1: Reasonable accommodation

Both Ashleigh and in some instances Christine came across schools and teachers who understood that in the words of Christine: *"accommodation and special treatment is not the same thing"* and that reasonable accommodation is not about being given more, but about "*struggling to get the same"*. Talking about her second high school, Christine said:

> *all the teachers had the same expectations of me that they had of everybody else, it was just that they were more willing to, to work around my disability than before*

and

> *when I was there, there wasn't anything that made me different to the other people. I just used a laptop instead of um (pause) writing. The way that I learn is still the same and people sometimes think because I am in a wheelchair you have to change everything, but it is not like that, you have to change certain things but it is not changing the whole system around me because that also makes me feel like an outsider and that I am now making them change everything when I can fit into the system it just needs to be adapted sometimes so ja (pause).*

Practical examples of reasonable accommodation from Ashleigh, to compensate for her impaired hand and to a lesser degree impaired eye function included:

> *enlarge [the font on] my um exam papers as well as my test papers;*
> *tests on a laptop and even my um essays in the matric... the rest of the exams um I've done with a scribe;*
> *when they have something on the board or something like that they normally have it on paper as well and then they just give me the paper;*
> *I made use of the books of my fellow students to complete my notes um and biology drawings;*

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extra time.

Ashleigh explained the relief of being able to choose her subjects later in school and gave an example of how her teacher adapted the lesson content and method of assessment to make it accessible:

> *it was some sort of show but it ended in grade 10 because then you can choose your subjects yes, and so then all that nonsense of technology and all those nonsense is history, so it's ok ja…. so in life orientation in matric there was also some fancy dances and stupid stuff and then my teacher just because they can't give me marks for doing nothing (laugh) so then she just like for instance when they practically do the waltz or something she used to give me a project to do on the waltz.*

Practical examples from Christine's experience to compensate for her impaired hand function and to a lesser extent slurred speech included teachers who:

> *printed the notes for me instead of having me write them out and if we had to do 15 sums I would have to do like 5 if I was understanding the concept; getting notes;*
> *people were taking pictures on their phone of the board and sending it to me.*

In terms of making assessment accessible Christine reported:

> *with orals and things there wasn't a [voice] projection mark because cerebral palsy people have [voice] projection problems;*
> *we had to do practicals for biology which clearly (laugh) was not going to work (laugh) so what we did was I had the knowledge, I knew how to do the practical, I just can't physically do them so one of my friends who doesn't do biology she was my hands so I would tell her what to do for the practical so they would mark it as if I was doing it, as I was having her do it. It wasn't somebody who knew what we were meant to be doing so that was also like we can make it work because if your hands don't work we have many other hands that are available and willing.*

As Jess's physical disability was less obvious and she felt that she did not really need much accommodation, she only requested to be treated differently in two situations, firstly:

> *sport was a terrifying thing for me. I liked the idea of it and I really wanted to be part of it, but I maybe doubted my own abilities and thinking about what other people would say, that all frightened me a lot.*

The second situation was when it became too heavy to wear normal school shoes. In both of these situations she had letters written by her mother to negotiate exemption. With regard to competitive sport the compromised form of accommodation prevented

participation, but gave her the benefit of exemption (from the sports activity which she found "terrifying").

Subordinate theme 1.2: Physical accessibility

Christine described how both of her high schools were double storey buildings with only stairs and how she felt that this was a huge barrier for a wheelchair user at her first school, but how the negative impact was lessened at the second school by the way it was framed:

> *the stairs became a non-issue because of the attitude that the people had about me being there;*
> *I did biology in the library [biology laboratory was upstairs] and I had weekly like lessons with my bio teacher and if I had a question I could message my friends and be like what is this part of the nerve or whatever and she would then ask the teacher and she message me back the answer that was kind of like there is always a way of making it work.*

Ashleigh, a manual wheelchair user at primary school, reported how peers and a male teacher were happy to help her to access the double storey partly retrofitted primary school, which again shows what can be accomplished with the right attitude. However, she highlighted how liberating it was to then go on to a high school that had, from the start, been designed and built with wheelchair access in mind:

> *they build it in such a way that um wheelchair users can access it so there is ramps and all that sort of stuff so I manage to even been on the sports field........it was quite a fantastic experience to be able to go where I want to go [except on the stage where she was frequently required!] by myself.*

And later when offered a place at a less accessible high school she reiterated

> *I rather be in a school that is built in such a way that it is accessible in order for me to use my 'shopping trolley' [motorised mode of transport] and to go where I want to go when I want to go and with who I want to go.*

Ashleigh reflected:

> *You see when something isn't accessible and you try to make it accessible it's not as good as something that's been built to be accessible because the gradient of the ramps of all that must be, wheelchair users must be able to use it, what's use of having a ramp if not!*

Physical accessibility was less of an issue for Jess, who was an independent walker. However, it was helpful for her that the school had been built with handrails next to

the stairs as, without them, she would have been disabled by her environment and required assistance:

> *the school had stairs and all our classes were on the upper level and like even that, it was never considered, it was a concern for me at the beginning, because I wasn't used to this ...... but there were rails and I don't remember ever falling, but I wasn't running down them like every other child was (pause) I wonder if they noticed that?*

Superordinate theme 2: "Good communication is vital"

This theme heading is taken from a transcript of Ashleigh and as raised by all participants, involves timely, clear and respectful communication and open listening between learners with disabilities, peers, parents, teachers and principals. Examples demonstrated the benefit of children with disabilities speaking up for themselves, as well as the importance of having others represent them at times.

Subordinate theme 2.1: Speaking up for myself

Learning to speak up and ask for help was an important facilitating factor identified by the two wheelchair users. Christine explained that as the first wheelchair user at her ordinary primary school:

> *I had to say what I needed instead of people just knowing my needs... I had to learn a lot about helping myself to get help.*

At her second high school the principal gave her the opportunity to address the staff and her grade peers with the mandate to "*tell them what you expect of them*".

Christine reflected:

> *I think this whole experience at school has kind of, it's made me more hard-core in telling people what I need and telling people when I am not okay with stuff because in a mainstream environment you have to say when you need stuff you can't just expect people to know, so you have to have a voice, you have to be able to tell people how to help you, you have to be like this is my disability, this is why I need this....*

Describing herself as an extrovert, Ashleigh reported something similar and added how she was successful in creating a wide circle of friends at school:

> *I think the thing about being disabled is being able to communicate your needs because normally it's your environment that makes you feel disabled and that's just because of a lack of knowledge from other people so it's actually your job to inform them. And at the beginning they [peers] will walk circles around me because they don't know how to handle it [physical disability]. And I've seen it so many times in my life before when I go up to*

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them and say hi I'm [Ashleigh], it's nice to meet you and the barrier is not there anymore. And the next time they will come to me and see there is nothing to be scared of, there is actually no difference, then they is the ones who will come to me and start talking to me so if you just get out of your comfort and go out there and be a friend, then you will have a friend.

Ashleigh went on:

I had my group of friends (laugh), but when we had breaks they, it was actually, they actually joked about it (laugh). I used to visit all the groups, I used to make pit stops at all the groups, talk a little (laugh), and then I would just make a few pit stops where I see the need to make pit stops and then I go back to my circle of friends yes um, I think it is a lot about how you see yourself and the um the, in Afrikaans it's the beeld [image], the picture that you have that you send out that others react on so if you send out a positive picture, you'll get a positive reaction back ja, usually some people will walk around with that question you know (laugh) what happened what happened and why and this one will put a piece something out there and then another one will come and add something until there is a whole long story and so I started to, to talk about it um talk about it from my side and then that opened doors for them to talk about it as well. Yes, that was very helpful because I think that that's the biggest question and doing that it's also a platform for me for me to be able to share my testimony [faith experience] with them so I think it was quite good, um. I think it may sound strange but it's a brilliant platform to start a conversation with people and then to take it to a little bit deeper, when you open up to people they often open up to you as well. So I found a way to help other people as well, yes, so and to change their mind set in the hope that they will go and change other people.

As can be seen, in addition to her personality, Ashleigh's Christian faith also played a role in her communication and in fact was central in her general approach to life as will be evident in the next superordinate theme.

In contrast Jess who described herself as an introvert and whose physical disability was not obvious, did not speak out about her diagnosis and tried to blend in:

I never made it known, I tried to like hide it more than…I don't know…make it part of me.

Subordinate theme 2.2: Having others to assist with communication

When unable or unwilling to speak up for themselves, having a peer, sibling or a parent at the same school to assist with communication was helpful. Jess explains:

I didn't speak to people openly, so the friends that, that I knew [neighbours in her complex with whom she had grown up] they like spoke up [when peers commented on her ankle-foot orthosis] and said 'she had an operation, she uses a splint kind of thing'.

Jess went on to say that she appreciated that:

> *my best friend that went through school with me, at high school she would, if she heard anyone mention my name she would get so upset and she would say have you ever asked her? Whereas I wasn't that type of person, I wouldn't approach it so*

and

> *my brother was there when I started and so he was like felt that he needed to protect me in some way, so anybody being nasty in any sort of way he would get really upset.*

Christine reported: *"we [referring to her parents] had to be pushy"* to get the school to finalise her acceptance and that

> *my mom was also [teaching] at the [primary] school, it was a lot easier because if there was an issue my mom could deal with it yeah um so I think that that was helpful that my mom was there because people were more willing to kind of make a plan because my mom was plan B. (pause) (laugh). Ja.*

At primary school and for at least the initial stages at high school when multiple subject teachers added to the communication challenge, the parents of Christine and Ashleigh made a point of having direct discussions with all new teachers. Christine reported:

> *...every year we had to deal with the same issues because we had to tell people again, the same learning process had to happen again. Um and that happened constantly the whole time I was at school (laugh).*

Christine went on to express her opinion that in her case it helped when parents remained heavily involved throughout high school as well:

> *parents have to be the one that is fighting for us because sometimes when I am in a position where we can't fight for ourselves because we don't want to be different and we don't want to stand out and guys like I need this so (pause) you need your parents to be the people who are like fighting in the background for us because otherwise stuff gets lost in translation and it gets interpreted differently.*

Ashleigh said that in her case: *"then we had long meetings with [name of school] Primary"* and *"my parents was a lot more involved in primary school than in high school but they were involved in high school...".*

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What helped the more extrovert Ashleigh was having high school teachers who were able to share her concerns with other teachers as they arose. In this regard, she reported that they

> *always wanted to know my point of view and then we will work around that and see how we can um how they can assist me so I used to go and talk to one person and they will call in all my teachers and then that one person will talk to my teachers about my needs and stuff and my parents would be occasionally in that meetings as well but yes..., address it then and there rather than to wait for months to pass and then have a meeting and then no, that, it must be sorted out then and there.*

In Christine's experience she found it necessary for teachers to guide her classmates so that she was not excluded, as inclusion did not seem to come naturally to her peers. This included being explicit about the fact that they should help her:

> *It was also very blatant the expectations that the teachers [at her second high school] had of (pause) of my peers, it was um (pause) if [Christine] needs help you are going to offer help, do not wait for [Christine] to ask you,*

Moreover, being direct about why she was being accommodated:

> *She [a supportive teacher at her first high school] was also good with putting people in their place when they were moaning cos they like people like moaned about like why does [Christine] get printed notes when I have to write them and she was like very blunt with people and she was like when your hands stop working the way they are working now I will print them for you (laugh) and that for me was what we needed, we needed people to be told like you are being ridiculous, can you not moan about things that don't matter and that was in general very much what was not happening in general...*

Christine found it helpful when teachers were open with her peers as things happened:

> *[at her second high school] our teacher was like this is what we have decided to do, is everybody cool with this as a class, we got to like discuss that, so you actually got to like everybody's opinion when it was happening and there wasn't like it was dealt with head-on, they were like speaking it was very much this is happening, this is why we are doing it, what do you think about it. It was more about everybody, than just making me ok*

and in summary:

> *so I think it is so much better being open about it and to be explicitly telling people.*

Upon reflection Jess said of her situation involving a less visible physical disability:

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This might be a silly thought, but I don't know, part of me says if they just told the kids [her school experience may have been easier], but then another part of me says but does every child want that, do you want the entire school to know that, this is and she is (pause) so for me there is these pros and cons, but it is also because of the type of person that I am.

Superordinate theme 3: "Ons gee om" [We Care]

This theme heading is taken from a transcript of Ashleigh and originates from the motto of her high school. As already touched on in the previous themes, the attitude of persons towards these children with physical disability played a big role in how they viewed themselves and how included they felt.

Subordinate theme 3.1: Support from within the family and community

All participants had parents who explicitly expressed to them that they were *able* so that from a young age they internalised this. Jess stated:

I remember my dad was saying like you are no different, you are no different to your friends or your siblings

and her mom saying*: "you can do anything and everything, so do it".* Jess added that her parents taught her the importance of education which she accepted:

my mom says that my personality is also just like she says that I am her only studious child, like I want to study, um and like I am self-motivated.

Ashleigh reported that her parents

supported me in my dreams and goals and I couldn't remember once that my parents told me no that's too big or that would not be enough. So never once they told me listen here (laugh) let's get realistic. Um so um I think that is very positive a positive thing

and that her brother *"wants me to succeed".*

All three participants felt that they benefitted from the early and ongoing inclusive attitude of their families. Jess explained:

my parents said you are normal like, yes we acknowledge what you need and they have always given me that, they never said that we are not taking you to physio, just carry on and be normal, like they saw to my needs, but they didn't ever feel the need to highlight every single difference

and

they allowed me to have as normal, like a normal a life as possible [including being fully involved in extended family events and their Islamic religion as an equal], but there was always that emotional support.

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Christine commented:

> I think also for me personally, having a sister who is able bodied it is helpful because it gives an able bodied perspective to stuff

and "I think I am lucky that I have a family that includes me and stuff. Um, ja (pause)".

Ashleigh noted:

> my parents raised me and my brother the same way and sometimes when he was naughty they will ask me what happened because I am the oldest and so I must take responsibility. There wasn't ever you are different, it was you are just as um involved in this thing as your brother so there wasn't even a separation between me and my brother and I think they raised me in such a way, my pa sê altyd jou kop moet nie sag wees [my father always says your head must not be soft]. So if you set your focus on something and you go for it then you will overcome all these physical barriers and I think the struggle is big but the reward is bigger. So um then um my family also include me in everything they did so um I would never ever be sitting on my own while they were doing something. I will rather do it with them or they won't do it.

Ashleigh described how her mom assisted her at school camps

> In grade 11 um I must attend a leadership camp and I knew nobody. And I didn't want to take somebody. So my mom drove in and spent the night and just helped with the practical things. And she spent the night with my teacher. And just dressed me in the morning and went to work.

Jess and Ashleigh also mentioned the importance of supportive words from community members. In Jess's case this was largely from a lady with a disability who lived in her complex and who

> from the time she met me like she affected me in such a big way, like she would say like you can do anything.

In Ashleigh's case additional strong support came from her Christian church community which plays a big role in her life:

> my mentor as well in the youth, the words she told me the most was I believe in you, you can do this. Just, hearing I believe in you, you can do this. It's powerful, I don't think people realise the power of words because when that is all you hear you start to believe it and you go from there.

Practical support in the form of peers coming to visit her in hospital after hip surgery, neighbours coming to listen to her orals when she was bedbound and a local group donating a laptop were also reported by Ashleigh.

Jess spoke of how

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> *it did help that I had friends [from the complex where she lived] who were already at that [mainstream primary] school*

and how her best friend

> *was like a big, big help in just like I think welcoming me and making me feel like part of this and she did netball with me and so I was able to do it with her. And all those things, and she did rhythmics and so I did. She helped me interact, be a part.*

Christine commented:

> *I always interacted with able bodied kids, so it was normal for me to be going to the same school as them..., I think it is kind of weird that I had to go to a place where there were only disabled people because that wasn't the norm for me, to be surrounded by disability.*

All participants had parents who were willing and able to pay for additional support for their children, in the case of Christine and Ashleigh for the private personal assistants their ordinary primary schools initially required them to have and in the case of Jess for the live-in nanny who provided afterschool care while her parents worked.

Subordinate theme 3.2: School culture

All three participants felt that they had benefited from the early specialised services they had received at special schools between the ages of 3 or 4 years and 9 or 10 years, respectively. However, in Ashleigh and Jess's situations, the move from a special school to an ordinary school was initiated by the special school staff; providing examples of schools wanting the best for the learners when their parents did not have the experience to know when this would be beneficial. This was despite all three participants feeling that a mainstream education is what their parents initially and ultimately wanted for their children. In this regard, Ashleigh reported:

> *the teacher told my parents and I think my parents could see it that it was time for me to spread my wings and fly.*

Jess reflected:

> *if [special school] hadn't brought it to my parent's attention and said like I think that she is ready for mainstream, I don't know if they would have. I don't know if they would have battled the system like I don't know.*

The ordinary school culture was found to provide an important backdrop. Ashleigh explained:

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> *from the start I liked the culture because when you walk in [to her high school] there is like a huge billboard with the words 'Ons Gee Om' [We Care]. So they are actually interested in you as an individual.*

Likewise, Christine had the experience at her second high school, which she and her parents chose especially because of their track record of including another child with a disability who was able to pass the entrance exam that *"the whole attitude towards me was [Christine] is one of us and we help our own".* This was felt to be strongly influenced by the attitude of the principal:

> *I think it is definitely about leadership of the school. When the head of a school is like, 'this is what we are doing because this is awesome and we are doing this' they get buy-in from the teachers...*

In Jess's case, she was able to add information during the second interview after asking her mother, that the Principal at her closest primary school was open to admit her despite a diagnosis of cerebral palsy being disclosed as her report from the special school showed that

> *academically I was on par with the other kids so there wasn't any like doubt or question.*

Examples by Ashleigh of mainstream primary school teachers who went the extra mile included:

> *[after a major operation] my teacher um came every week and then she came and gave me work and then um I would do it on a plank on my lap while lying on my back and do it and then she would come back and fetch it and give me more to do it for the next week*

and while looking at a photo of a scene from a school concert, Ashleigh highlighted how teachers had always found ways to include her:

> *this was the first um show I was in at [primary school], the foundation phase programme that was presented on stage and they actually made special feathers, you know feathers for my wheelchair and all that kind of stuff and I was a mocking bird I think.*

Ashleigh described how at high school she had been assisted to participate in multiple extra-curricular and service positions of her choice:

> *the places where we must be on the school grounds, they will place me in a like for instance in the hallways, but not outside or outside but not far, close by, so I don't have to go so far and go with my wheelchair so far and all that practical stuff. I think a lot of thought go into it and then they implement it in*

such a way that was positive and that work so for instance when we had a grade 8 class that we had to look after in matric, then the teacher paired me up with someone so um I think yes another girl and I was given the same class for instance because if I can't make it in time before a bell goes because of the traffic in the hallways then she will be there and then I will go there and get the stuff from her and split the tasks so that was very considerate of them and then I think most importantly all the people in my life believed in me – they never ever ever thought it couldn't be.

Peers helped Ashleigh both at primary school and high school. She indicated:

And they were very helpful, even small ones they would take my books out of my bag and all this and do all those kind of stuff... so it's been good, it's been fantastic, the support, even from grade 3 children..., even in high school there was a joke because it was then that F1 pit stops, have you ever watched the pit stops, um (laugh), the teachers always talked about when we enter a class you know, at the beginning of each period, it's the class, before I come with my 'shopping trolley' [motorised mode of transport] the table has been moved for me, my books and pens and all is on my desk, I just have to pick up my pen and start and when the bell goes for the next period, it's been like 123 and I'm off to another class and you know and alls been packed away you know (laugh).

Table 1: Summarising overview of superordinate and subordinate themes.

Superordinate themes	Subordinate themes
1: "Treat me the same, but treat me differently"	1.1: Reasonable accommodation
	1.2: Physical accessibility
2: "Good communication is vital"	2.1: Speaking up for myself
	2.2: Having others to assist with communication
3: "Ons gee om" [We care]	3.1: Support from within the family and community
	3.2: School culture

Discussion

The *International Classification of Functioning, Disability and Health (ICF)* considers the following environmental factors: products and technology; natural environment and human made changes to environment; support and relationships; attitudes; and services, systems and policies (WHO, 2002:16). These environmental factors, along

with consideration of personal factors form a theoretical and practical framework in which to discuss the findings and provide recommendations for practice.

When it came to **products and technology (e1)** (WHO, 2003:7), the participants' families were able to provide for their immediate everyday needs, as well as accessing necessary basic assistive devices, such as manual wheelchairs and ankle-foot-orthoses (AFOs). More expensive assistive devices, such as a power wheelchair, 'shopping trolley' (motorised mode of transport) and laptop computers, were accessed by participants and their families through community support. The need for access to necessary resources was also noted by Pillay, 2009; Pivit et al, 2002 and Vosloo, 2009. Handrails next to stairs and ramps and a lift provided by the Department of Education were facilitators. Moreover, the incorporation of such facilitators was found to be especially beneficial when integrated into the original design of the school rather than being retrofitted, a finding consistent with previous reports. In the case of the wheelchair users, their families moved house and/or built ramps to allow accessibility at home. The importance of physical accessibility has been well documented globally and locally (Danso et al, 2012; Lawlor et al, 2006; Roux, 2014).

In terms of **natural environment and human-made changes to environment (e2)** (WHO, 2003:7), which considers lighting, weather, terrain etc, the only factor mentioned by participants in this study was about one school campus being easier to negotiate than another because the land was flatter. This is likely due to their impairment being largely mobility-related and highlights how it is the interaction between the impairment and environmental factor that determines an individual's level of participation.

The category of **support and relationships (e3)** (WHO, 2003:7) covers a wide range of individuals from immediate family members to health professionals. Amongst the participants, members of the immediate family played the biggest role, with the mother most often highlighted as central. This is consistent with global findings, as well as other studies in South African contexts (McKenzie & Müller, 2006; Tshabalala, 2014) where mothers were also found to be key role-players in

supporting their children with disabilities within ordinary schools. Relationships with friends, neighbours, religious organisations and community members seemed to create a second layer of support outside of school which was especially beneficial when there was an overlap of friends or siblings who also attended their school. At school, teachers and/or peers provided direct support that was valued, while the principal was seen as indirectly facilitating more helpful relationships. The positive role that support from schools, teachers and peers can play in "addressing barriers to learning, creating conducive learning environments, enhancing learners' self-esteem and improving learners' academic performance" was also reported by another group of South African teenagers in Western Cape schools (Bojuwoye, Moletsane, Stofile, Moolla & Sylvester, 2014:1).

Private personal assistants at school were initially seen as facilitators for the two learners using wheelchairs as they enabled access, but the learners found that they ultimately hindered their full inclusion and towards the end of primary school the class teachers in both cases agreed that private personal assistants were not necessary. In contrast, young teenagers with physical disabilities in Norway felt they required requested assistance from both teachers and public school aides to achieve their desired participation (Asbjørnslett, Engelsrud & Helseth, 2015). Participants in this study reported that private personal assistants / a live-in nanny at home to provide support in the afternoons when parents were at work remained a necessary support into their high school years. Private doctors, including surgeons for all participants, were mentioned as contributors to their overall functioning, as were multidisciplinary teams of state therapists when at special schools and mainly private physiotherapists later on when at ordinary schools.

When it came to **attitudes (e4)** (WHO, 2003:7), their parents' stance that they should attend an ordinary school was described as a key facilitating factor to enable mainstream education in an ordinary school. It was easier for participants when this viewpoint was supported by their special schools and later the principal and teachers at the ordinary schools chosen. This fits with the request from adults with disability in Lesotho who expressed the need for training of parents and those around them to act as a support system in mainstream environments (Sefotho, 2015:6). An attitude

of acceptance by principals and teachers was seen to positively influence the attitude of peers who otherwise sometimes defaulted to the general attitude of society towards disability which is still often negative (Department of Education, 2001) despite inclusive government policies. Likewise, a willingness to "make a plan" and problem solve was highlighted as a necessary attribute amongst teachers and one that could not be achieved by law without teachers feeling secure in themselves and wanting to find solutions with participants as they arose. This need for creativity and flexibility on behalf of teachers also came through in a study from Norway where young teenagers with physical disabilities wanted to "do things the 'regular way', as well as in their 'own way'" (Asbjørnslett, Engelsrud & Helseth, 2015:209). The importance of having teaching staff who were willing to negotiate accommodation was also highlighted by Bird Claiborne et al, 2011; Moriña et al, 2014; Ntombela, 2013; Shah, 2007 and Wendelborg et al, 2010.

With regard to **services, systems and policies (e5)** (WHO, 2003:7), parents negotiated private health care to access needed services to improve and maintain the level of their child's functioning, as is typical for middle-class families in South Africa. None of the participants knew about Education White Paper 6 until late in their schooling and did not think that their parents used it much, although felt its existence was a facilitator. It is unclear to what extent their ordinary schools knew about and applied the policy or had training around inclusive education, although the high school that was recently built with universal access and a motto of "Ons gee om" [We care] was likely informed by the changing landscape towards inclusion of learners with disabilities as led by the Department of Education. Transport to school and other activities not within walking or wheelchair pushing distance was facilitated in private cars by the parents of all three participants. Private transport cannot be taken for granted in South African contexts of lower socio-economic status than represented here where reliance is on often inaccessible public transport. This serves as an example to illustrate how the entire system and multiple government departments in the case of poorer learners, needs to work together to support the participation of learners with a disability, a widely known fact also described in Geldenhuys et al, 2013; Inclusive Education South Africa, 2015 and Sparkes et al, 2007.

In terms of **personal factors** (WHO, 2003:7) and in response to their environments, all of the participants developed an inner belief from a young age that they should be included in an ordinary school alongside their neighbours and siblings. This belief transcended their individual personalities (extrovert / introvert) and allowed them to utilise available resources and be relatively resilient in a school environment that was not always welcoming and seldom experienced in inclusive practices. Their desire for inclusion and acceptance is similar to reports of young teenagers with physical disabilities elsewhere in the world, as seen in a recent study in Norway (Asbjørnslett, Engelsrud & Helseth, 2015). Moreover, their diverse and multidimensional ways of achieving this are similar to those identified by South African teenagers challenged by poverty, namely: "self-confidence, an internal locus of control, a tough personality, commitment, being achievement-oriented, as well as positive identification of and access to social support" (Mampane, 2014:1). The middle socio-economic status of their families was an asset as this allowed for time, energy, resources and their parents multiple skills associated with education and work experience to be directed towards their individual best interests (Donohue & Bornman, 2014).

In essence, personal factors, especially their middle socio-economic status played a protective role, while products and technology were reported as beneficial to compensate for physical impairments. Furthermore, support and relationships; and attitudes could often compensate for lacks in infrastructure and gaps between policy guidelines and the actual school environment.

In fact, interpersonal factors were emphasised by participants in this research as a key to their successful completion of Grade 12 in an ordinary school. The most influential facilitating factors were sourced closest to the learners, namely from their parents and siblings, and their teachers, principal and peers. Neighbours, religious communities and health care professionals seemed to play a supportive role. What this highlights is how relationships act as a kind of social capital which facilitates a shift in attitudes and paves the way for the focus to be on how to support learners with disabilities to overcome barriers, rather than being fixated on the imagined insurmountable challenges. The need for reciprocal relationships whereby the school community is open to learn from the learner with a disability and their support

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system, as well as the realisation on the part of the disabled learner and their support system of the responsibility for them to educate the school on how to assist and change negative attitudes is also highlighted by participants in this study.

Participants did not experience any obvious direct benefits they could attribute to Education White Paper 6 and did not feel that policy in isolation had the capacity to change the way teachers related to learners with disability. Identifying facilitators and focusing on building social capital to create inclusive schools and communities as described by Mariga et al (2014:17) seems necessary to enhance the implementation of Education White Paper 6 (Department of Education, 2001). The findings of this study thus support the need for "evolving inclusive practices and creating inclusive cultures in addition to producing inclusive policies" as advocated by Booth and Ainscow (2002:8).

Conclusion

The six subordinate themes capture the key facilitating factors emphasised by the three participants in this study, with many practical examples given in the findings section that may be helpful for other learners, parents, teachers, peers and principals. In this regard, *reasonable accommodation* and *physical accessibility* were confirmed as necessary to enable participation in ordinary schooling for learners with physical disabilities. *Speaking up for myself* and *having others speak on my behalf* shows the value participants found in having timely, clear, respectful and open communication within the school environment. This is a lesser documented facilitating factor within inclusive education and is considered an especially valuable finding given the uniqueness of each learner with a disability and the novelty of inclusive education for all involved. *Support from within the family and community* and a *school culture* that was caring, corroborated previous findings about support being necessary from multiple sources to enhance inclusion and educational participation.

Limitations

Limiting factors included the scope, timeframe and resource constraints of this study for degree purposes. Due to the time-delay between life experiences and the interviews, there may be recall bias in terms of what participants remember, especially regarding primary school and before. In keeping with an in-depth IPA study, generalisability was not an aim; but the detail and depth of the reported findings may contribute to transferability within the population of learners with cerebral palsy and possibly other physical disabilities, attending ordinary schools.

Implications

- Parents and children with disabilities who have accessed mainstream education at an ordinary school have learned valuable lessons that could ease the way for the next generation if shared with all role-players through direct contact, social media and electronic communication.
- School principals who have embraced inclusive education are in a position to be role-models for fellow principals so that more ordinary school teachers and learners can be led to create supportive and inclusive learning environments.
- Children with disabilities benefit from affirmation, a focus on their abilities from a young age and early intervention to optimise their functioning in ordinary schools.
- Similar research with young adults with other disabilities and/or from other socio-economic backgrounds will provide additional useful information.

Recommendations

- Planned, new schools should be built to be universally accessible and existing schools should be retrofitted as a matter of urgency.
- Teachers can be empowered by practical training on the basics of reasonable accommodation for learners with disabilities, both during initial and later in-service training. This could include visits to special schools and visits from teachers with specialised training.
- The Department of Education is encouraged to be more proactive in educating the public and professionals about the core messages of White Paper 6 through the media so that children with disabilities and their families

get consistent information and support from all role-players and from an early stage.

- The life orientation curriculum from Grade R to Grade 12 provides a forum in which modules about different disabilities and practical lessons on how to be inclusive can be introduced and practised to decrease discrimination in schools.

- Functioning School Based Support Teams (SBST) and regular, practical individualised input from District Based Support Teams (DBST) (as described in Education White Paper 6) can be a means to provide effective support for learners with disabilities and their teachers.

- Co-ordination between the Department of Health and Department of Education should allow access to appropriate mobility and communication devices (including power mobility aids and laptop computers) for learners with disabilities who cannot access necessary technology privately.

- Schools should welcome input from parents and learners with disabilities by initiating communication to find creative solutions together.

In conclusion, I hope that this research adds to the body of knowledge about facilitating factors throughout the system for learners with cerebral palsy in ordinary schools. While country policy can set the legislative scene, it is apparent that unless those directly involved with learners with disability on a day to day basis, namely their families, schools and communities are enlightened and proactive, inclusive education will remain a theoretical ideal.

Acknowledgements

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Appendix A

PARTICIPANT REQUEST LETTER

TITLE OF THE RESEARCH PROJECT: Reflections of young adults with cerebral palsy in Cape Town on what factors facilitated their mainstream schooling and Grade 12 pass.

REFERENCE NUMBER: S14/10/209

RESEARCHER: Rosemary Luger

ADDRESS: 104 Ladies Mile Road, Meadowridge, 7806, Cape Town, South Africa

CONTACT NUMBER: 072 8311492 / 021 7124074 / rluger@hotmail.com

Dear Colleague

My name is Rosemary Luger and I am conducting a research project in partial fulfillment of a Masters degree in Human Rehabilitation Studies. The aim of the research project is to explore what young adults with cerebral palsy perceive to be the facilitating factors within themselves, their family, the school, the community and the country that enabled their successful entry into and completion of mainstream schooling. It is expected that this information can guide the relevant role-players in how best to provide more effective support within inclusive education for future generations of children with cerebral palsy. This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University (S14/10/209)** and will be conducted according to accepted and applicable national and international ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

The study is being conducted as, despite international and national policy promoting inclusive education, many children with cerebral palsy are not attending mainstream

schools or are not being adequately supported in mainstream schools. This leads to poor educational outcomes that negatively impacts on their participation in work and other adult roles. Success stories are inspiring to others and self-representation is advocated as essential by the disability rights movement. This study aims to add to the limited information about inclusive education from the learners' perspective; rather than focusing on barriers or the perspective of teachers and parents.

The study will be conducted with approximately six young adults with cerebral palsy between the ages of 18 years and 22 years who schooled and live within 100km of Cape Town and who are conversant in English. Participants who volunteer will be chosen on the basis of their ability to provide a wide range of views and experiences. Information will be gathered by myself during two 1 – 1 ½ hour interviews. In a first audio-recorded (and video-recorded if participants use a communication device) interview at their home or an alternate venue of their choice, participants will be asked to share their schooling story from the time they entered primary school until they passed Grade 12. Participants can make use of school reports, school photographs or any other items they may wish to use. In a second audio-recorded (and video-recorded if participants use a communication device) interview at their home or an alternate venue of their choice, the participant will be asked to work with the researcher to identify the factors that facilitated their successful completion of mainstream schooling by reflecting back on their experiences.

I am requesting your assistance in identifying potential participants who meet the following inclusion criteria:
- Are between the ages of 18 years and 22 years during 2015.
- Have cerebral palsy.
- Passed Grade 12 at a mainstream school.
- Schooled and live within 100km from Cape Town.
- Are conversant in English.

To maintain confidentiality, please do not send me potential participant's details. Rather forward the attached information leaflet to potential participants or post the attached information leaflet on your website along with my details so

that the young adults can choose whether or not they wish to contact me. Participation is **entirely voluntary** and potential participants are free to decline to participate. If they say no, this should not affect them negatively in any way whatsoever. They are also free to withdraw from the study at any point, even if they do initially agree to take part.

Thank you in anticipation for your assistance.

Yours sincerely

Rosemary Luger
Researcher

Appendix B

POTENTIAL PARTICIPANT INFORMATION LEAFLET

My name is Rosemary Luger and I am conducting a research project in partial fulfilment of a Masters degree in Human Rehabilitation Studies through Stellenbosch University. The research project is entitled "Reflections of young adults with cerebral palsy in Cape Town on what factors facilitated their mainstream schooling and Grade 12 pass."

If you meet the following inclusion criteria and would like to know more about becoming a participant in this research project, please read further:

-        Are you between the ages of 18 years and 22 years during 2015?
-        Do you have cerebral palsy?
-        Have you passed Grade 12 at a mainstream school?
-        Did you school and do you live within 100km from Cape Town?
-        Are you conversant in English?

This study has been approved by the Health Research Ethics Committee at Stellenbosch University (S14/10/209) and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. Your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do at first agree to take part.

What is this research study all about?

➢ The study is being conducted as, despite international and national policy promoting inclusive education, many children with cerebral palsy are not attending mainstream schools or are not being adequately supported in mainstream schools. This leads to poor educational outcomes that negatively impacts on their participation in work and other adult roles. Success stories

are inspiring to others and self-representation is advocated as essential by the disability rights movement. This study aims to add to the limited information about inclusive education from the learners' perspective; rather than focusing on barriers or the perspective of teachers and parents.

➢ The study aims to explore what young adults with cerebral palsy perceive to be the facilitating factors within themselves, their family, the school, the community and the country that enabled their successful entry into and completion of mainstream schooling. It is expected that this information can guide the relevant role-players in how best to provide more effective support within inclusive education for future generations of children with cerebral palsy.

➢ The study will be conducted with approximately six young adults with cerebral palsy between the ages of 18 years and 22 years who schooled and live within 100km of Cape Town and who are conversant in English. Participants who volunteer will be chosen on the basis of their ability to provide a wide range of views and experiences.

Why have you been invited to participate?

It is believed that you, as a young adult with cerebral palsy who has passed Grade 12, have valuable insider knowledge that can be shared to guide health care professionals, educators and parents to better support future generations of children with cerebral palsy in mainstream schools.

What will your responsibilities be?

➢ In a first audio-recorded (and video-recorded if you use a communication device) interview at your home or an alternate venue of your choice, you will be asked to share your schooling story from the time you entered primary school until you passed Grade 12. You can make use of school reports, school photographs or any other items you may wish to use. The first interview will take 1 – 1 ½ hours of your time.

➢ In a second audio-recorded (and video-recorded if you use a communication device) interview at your home or an alternate venue of your choice, you will be asked to work with the researcher to identify the factors that facilitated your

successful completion of mainstream schooling by reflecting back on your experiences. The second interview will take 1 – 1 ½ hours of your time.

Will you benefit from taking part in this research?

As the main objective is to learn how to better support future generations of children with cerebral palsy and to motivate health care professionals, educators and parents to do so, you will not benefit directly from taking part in this research. It is however hoped that contributing towards an increased understanding of how to create a more supportive mainstream school environment for future generations of children with cerebral palsy will be a satisfying and rewarding experience for you. The research findings will be shared with you should you wish to receive them.

Are there in risks involved in your taking part in this research?

This is a non-intervention, low-risk type of research that should not place you at any risk.

 If you do not agree to take part, what alternatives do you have?

Choosing not to take part in this research will have no negative consequence for you. Your decision will not be reported to anyone and so will have no negative impact on any existing relationships or future intervention needs.

Who will have access to your information?

I will collect all information personally and will treat written and audio-recorded data as confidential and protected at all times. This will be done by assigning you a pseudonym that will be used instead of your name on all documents and recordings other than the master list which will be kept in a locked cupboard at the researcher's home. Only essential personal particulars will be requested from you and information included in the thesis document and that which may be used in publications or presented orally for dissemination purposes will ensure your anonymity.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

In the event that reflecting back on your schooling elicits any distressing memories, the researcher, who is an occupational therapist, will respond sensitively. Furthermore, debriefing by another occupational therapist at no cost to you would be arranged immediately.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport to a nearby venue of your choice (if you choose not to be interviewed at home) and refreshment costs will be covered for each of the two study visits. There will be no costs involved for you, if you do take part.

What should you do if you wish to volunteer to participate?
Contact the researcher, Rosemary Luger at:
072 8311492 / 021 7124074 / rluger@hotmail.com

To protect your privacy, you need not inform the person who alerted you to this research project about your decision to participate or not.

Appendix C

<u>Personal particulars</u>

Pseudonym (linked to their name on a secured list):

Age:

Gender:

Type of cerebral palsy[1]:

Nature and extent of impairments:

Cause (if know) of diagnosis:

Gross Motor Function Classification[2] (GMFC) level:

Quintile rating[3] of schools attended:

Socio-economic status of the family during their schooling (low, middle class, wealthy):

Types of professionals involved and whether these were state or privately accessed:

List of any assistive devices:

Current studies / work / leisure activities:

Current sources of income:

Please start thinking about the following question in preparation for the first interview:

I am interested to hear from your perspective what made it possible for you to attend and complete your schooling at a mainstream school. This is because in your day this was quite rare and even now it is not the norm for children diagnosed with cerebral palsy in South Africa to attend a mainstream school. Could you tell me about your journey from preschool to Grade 12 and at some stage talk me through some of your school reports and photographs.

<u>First interview guide:</u>

Pseudonym

Date

Welcome.

Thanks for taking the time to come and share your experiences and to bring reports / photos.

Go through consent form together, sign and leave information section with them.

Opening question: "Could you tell me about your journey from preschool to Grade 12 and at some stage talk me through some of your school reports and photographs."

Prompts if required:

What stands out?

What would you like to show me first?

I would like to know what helped.

Is there anything you want to tell me first?

Maybe we could start at the beginning.

Would it be easier to tell me from the beginning or starting with your final year?

Highs and lows from school.

Same at primary school and high school?

How did it happen, why did it happen, what made it possible?

What was it like, how did you overcome that?

Could you give me an example?

Express appreciation for the sharing of their story.

Ask if there is anything else they want to share.

Remind that there is a second interview in approximately 1 month where we will look more closely at their experiences and identify together the facilitating factors within themselves, the family, the school, the community and the country.

Identify a time, date and venue for the second interview.

Ask if they have any questions. Greet.

<u>Second interview guide:</u>

Pseudonym

Date

Thank again for their time.

Get ongoing informed consent.

Last month you told me about your journey at a mainstream school. I have typed out what you said and today I am hoping that you could help me identify the factors that facilitated your successful completion of Grade 12 at a mainstream school. The areas I think we should look at are yourself, your family, the school, the community and the country.

Prompts if required:

Would you like to start with yourself and move out or at country level and move in?

Main and secondary facilitating factors.

Importance of these at various stages in their school careers.

Differences / similarities to others.

<u>Reflective Notes</u>

<u>Appendix D</u>

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:
Reflections of young adults with cerebral palsy in Cape Town on what factors
facilitated their mainstream schooling and Grade 12 pass.

REFERENCE NUMBER: S14/10/209

RESEARCHER: Rosemary Luger

ADDRESS: 104 Ladies Mile Road, Meadowridge, 7806, Cape Town, South Africa

CONTACT DETAILS: 072 8311492 / 021 7124074 / rluger@hotmail.com

You are invited to take part in a research project that is being conducted in partial
fulfilment of a Masters degree in Human Rehabilitation Studies. Please take some
time to read this information, which will explain the details of this project. Please ask
me any questions about any part of this project that you do not fully understand. It is
very important that you are satisfied that you clearly understand what this research
entails and how you could be involved. Also, your participation is **entirely voluntary**
and you are free to choose not to participate. If you say no, this will not affect you
negatively in any way whatsoever. You are also free to withdraw from the study at
any point, even if you do at first agree to take part.

This study has been approved by the **Health Research Ethics Committee at
Stellenbosch University** and will be conducted according to the ethical guidelines
and principles of the international Declaration of Helsinki, South African Guidelines
for Good Clinical Practice and the Medical Research Council (MRC) Ethical
Guidelines for Research.

What is this research study all about?

➢ The reason for this study is that many children with cerebral palsy are not attending mainstream schools or are not being adequately supported in mainstream schools, despite international and national policy promoting inclusive education. This leads to poor educational outcomes that negatively impacts on their participation in work and other adult roles.

➢ Success stories are inspiring to others and self-representation is encouraged by the disability rights movement. This study aims to add to the limited information about inclusive education from the perspective of past learners'; rather than focusing on barriers or the perspective of teachers and parents.

➢ The aim is to learn about what factors within you, your family, the school, the community and the country enabled your successful entry into and completion of mainstream schooling.

➢ It is expected that this information can guide the relevant role-players in how best to provide more effective support within inclusive education for future generations of children with cerebral palsy.

➢ The study will be conducted with approximately six young adults with cerebral palsy between the ages of 18 years and 22 years who schooled and live within 100km of Cape Town and who can share their stories in English. Participants who volunteer will be chosen on the basis of their ability to provide a wide range of views and experiences.

Why have you been invited to participate?

I believe that you, as a young adult with cerebral palsy who has passed Grade 12, have valuable insider knowledge that can be shared to guide health care professionals, educators and parents to better support future generations of children with cerebral palsy in mainstream schools.

What will your responsibilities be?

➢ In a first audio-recorded (and video-recorded if you use a communication device) interview at your home or an alternate venue of your choice, you will be asked to share your schooling story from the time you entered primary school until you passed Grade 12. You can make use of school reports,

school photographs or any other items you may wish to use. The first interview will take 1 – 1 ½ hours of your time.

➢ In a second audio-recorded (and video-recorded if you use a communication device) interview at your home or an alternate venue of your choice, you will be asked to work with the researcher to identify the factors that facilitated your successful completion of mainstream schooling by reflecting back on your experiences. The second interview will take 1 – 1 ½ hours of your time.

Will you benefit from taking part in this research?

As the main objective is to learn how to better support future generations of children with cerebral palsy and to motivate health care professionals, educators and parents to do so, you will not benefit directly from taking part in this research. It is however hoped that contributing towards an increased understanding of how to create a more supportive mainstream school environment for future generations of children with cerebral palsy will be a satisfying and rewarding experience for you. The research findings will be shared with you should you wish to receive them.

Are there any risks involved in your taking part in this research?

This is a non-intervention, low-risk type of research that should not place you at any risk.

 If you do not agree to take part, what alternatives do you have?

Choosing not to take part in this research will have no negative consequence for you. Your decision will not be reported to anyone and so will have no negative impact on any existing relationships or future intervention needs.

Who will have access to your information?

I will collect all information personally and will treat written and audio-recorded data as confidential and protected at all times. This will be done by assigning you a pseudonym that will be used instead of your name on all documents and recordings other than the master list which will be kept in a locked cupboard at my home. Only essential personal particulars will be requested from you and information included in

the thesis document and that which may be used in publications or presented orally will ensure your anonymity.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

In the event that reflecting back on your schooling elicits any distressing memories, the researcher, who is an occupational therapist, will respond sensitively. Furthermore, debriefing by another occupational therapist at no cost to you would be arranged immediately.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport to a nearby venue of your choice (if you choose not to be interviewed at home) and refreshment costs will be covered for each of the two study visits. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- ➢ You can contact Rosemary Luger, Occupational Therapist, at 072 8311492 / 021 7124074 or email rluger@hotmail.com if you have any further queries or encounter any problems.
- ➢ You can contact the Health Research Ethics Committee at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by me.
- ➢ You will receive a copy of this information and consent form for your own records.
- ➢ In the event of any changes in the research project you will be informed and your consent to participate will be re-requested.

Declaration by participant

By signing below, I …………………………….…………. agree to take part in a research study entitled "Reflections of young adults with cerebral palsy in

Cape Town on what factors facilitated their mainstream schooling and Grade 12 pass."

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....……………… on (*date*) ……………...………. 2015.

....

Signature of participant   **Signature of witness**

Declaration by investigator

I *(name)* ……………………………………………………… declare that:

- I explained the information in this document to ………………………………….
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ....…......…………. on (*date*) …………...………. 2015.

....
Signature of investigator   **Signature of witness**

Declaration by interpreter

I *(name)* ……………………………………….……… declare that:

- I assisted the investigator (*name*) ……………………………………. to explain the information in this document to (*name of participant*) ……………………………………… using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ....…......…………. on (*date*) ……...……………2015.

....
Signature of interpreter   **Signature of witness**

Appendix E

Exploratory comments	Example of Verbatim Transcript: Christine's first interview, page 5, line 1 – 28	Emergent themes
Single teacher in primary school	R: And were there like differences in the different teachers through the years?	
	C: Um (long pause) I think (pause) at primary school you have one teacher for everything pretty much so in that way	
Sporadic buy-in by school not enough	it's kind of easier because they know you and they know how like what's going on um you don't have to um deal with seven different teachers a day but also I think that every year the information we had to re-teach people because there wasn't	Time and relationships with teacher leads to understanding
Burden falls on parents to hand over information on the child with a disability	an attitude of everybody needs to know what's going on with [Christine] um because I was in one class so that teacher would need to know but then every year we had to deal with the same issues because we had to tell people again, the same learning process had to happen again. Um and that	Parents took time to prepare each new teacher
Exasperated laugh	happened constantly the whole time I was at school (laugh) but I think primary school was very different to high school um we used the I think primary school is very much more about developing the person and worrying about their self-	
Primary and high schools have different priorities	esteem and stuff and high school is more about learning what we need to learn today and kind of the focus on us as students is kind of lost a little bit I think. Um (pause) and high school was interesting (laugh)	Primary school teachers perceived as more caring
	R: I'm gathering,	
Used the word interesting with a negative tone	C: high school, because it's also got a very different set up so you have to move to the teachers the teachers don't come to where you are which creates a whole other issue so you	
Moving to teachers is challenging in a wheelchair	have to move and there are a whole lot of classes and you have to make sure you can get to all the classrooms, there are a lot more logistical issues because at primary school you stay and the teachers come to you, um, I think also because the attitude of teachers is very different at high school	Getting to multiple classes in a wheelchair is a challenge in high school
Negative stereotypes about children with disabilities	because it is more work orientated, um people assume that I am going to take more time to teach than able bodied kids um I am going to take up more space and energy	Initially high school teachers' focused on perceived challenges

Appendix F

Example of how emergent themes from Appendix E were condensed into subordinate themes
Having others to assist with communication
Parents took time to prepare each new teacher
Physical accessibility
Getting to multiple classes in a wheelchair is a challenge in high school
School culture
Initially high school teachers' focused on perceived challenges
Time and relationships with teacher leads to understanding
Primary school teachers perceived as more caring

Appendix G

Health Research Ethics Approval

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot - your knowledge partner

Ethics Letter

19-Mar-2015

Ethics Reference #: S14/10/209
Clinical Trial Reference #:
Title: Reflections of young adults with cerebral
palsy in Cape Town on what factors facilitated
their mainstream schooling and Grade 12 pass.

Dear Miss Rosemary Luger,

Your email dated 9 February 2015 refers.

The amended consent document is in order and you may proceed with your research project.

If you have any queries or need further assistance, please contact the HREC Office 219389156.

Sincerely,

REC Coordinator
Franklin Weber
Health Research Ethics Committee 1