

Building communication interventions  
for children with severe disabilities  
on cultural resources:  
an action research enquiry

Thesis presented for the degree of

DOCTOR OF PHILOSOPHY: DISABILITY STUDIES

in the SCHOOL OF HEALTH AND REHABILITATION SCIENCES

UNIVERSITY OF CAPE TOWN

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(September 2015)

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# Abstract

## **Building interventions for children with severe communication disabilities on cultural resources: an action research enquiry**

In South Africa, children with *severe* disabilities are often the most neglected in terms of planning and providing appropriate interventions. For those with severe *communication* disabilities, an additional lack is in the area of the basic human right to meaningful interactions and communication. Sustainable strategies to provide opportunities for basic communicative participation of these children are urgently sought.

The focus of this study, grounded in the transformative paradigm, was on culturally determined processes that can increase and enrich the communicative participation of children with severe communication disabilities in an isiXhosa language and cultural context.

The **aims** of the study were:

- to identify culturally determined non-verbal and pragmatic elements of social interaction in an isiXhosa language context.
- to identify culturally appreciative strategies to support the communicative participation of children with severe communication impairments in this context.

The **participants** were 44 mothers and/or primary carers of children with severe cerebral palsy from an under-resourced peri-urban isiXhosa speaking context in the Western Cape.

The **method** comprised an action research journey with iterative cycles of collaborative action, reflection and subsequent further planning with participants. **Data collection** included action reflection group sessions, reflective dialogues with the group facilitators, and participant observations. All data was qualitative. **Data analysis** included a process of in-group collaborative analysis and verification followed by reflective dialogues with the group facilitators and interpretive thematic content analysis.

The **findings** included 12 action learning outcomes, from which two main themes were identified, directly responding to the two main aims of the study. Findings that were considered to be new were framed as three theses:

Thesis 1: Relationships are the context and motivation for communicative participation: the social inclusion and non-ostracism of mothers need to be prioritised in order for them and their children to enjoy communicative participation.

Thesis 2: The 'Middle Ground' is a valuable positionality in implementing transformative action learning as an intervention approach.

Thesis 3: There is a need to reframe culture as a resource in supporting the communication development of children with severe communication disabilities.

In **conclusion**, implications for clinical practice, for training, for policy planning and implementation and for further research are discussed. Practical suggestions for application by mothers and others caring for children with severe communication disabilities in similar contexts are included.

## Declaration

I, *Martha Geiger*, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I authorize the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

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## Acknowledgements

Many, many people have helped and encouraged me on the research journey described in this thesis. I would like to express specific gratitude to:

all the participants; the mothers, grandmothers and other caregivers who mother the very special children who prompted this research journey.

my collaborators Pam and Nolwandle who embraced the research purpose with so much passion and taught me so much

my research supervisors Sine Duma and Theresa Lorenzo who have guided me wisely, who have personified the word 'patience' and who never gave up on the study - or on me

Shajila Singh and Harsha Karthard who assisted in getting this study started

the Western Cape Cerebral Palsy Association therapists who patiently and humbly walked part of this journey of enquiry with me

my colleagues at the Centre for Rehabilitation Studies, Stellenbosch University, who have given me space and time and encouragement to 'carry on carrying on'

the mentors who, over the years, have given key inputs which jolted me out of my blocks: Professors Roy McConkey, Usuf Chikte and Leslie Swartz

friends who have laughed and cried with me: Erna Moller, Meryl Glaser, Lyn Holness, Surona Visagie, Jess Boon, Suzette Willemse, Ingeborg Schlee, Ann Bullen and Rose Luger and all the others from The Chaeli Campaign

Mrs. Adri Winckler, manager of the UCT Health Sciences Post Graduate Office who repeatedly made it possible for me to continue even though every grace period expired over these past 11 years; Adri, thank you!

fellow PhD students Kaya Tshabalala and Vic McKinney for your inspiring encouragements – especially during the final lap

my brothers Heinz and Albert and their families (with the five nephews who rock my world!) for all your patience with my absences and your continuing love and support

my parents, Vati and Mutti; for your unconditional love, you have sacrificed more than I will ever know and you have put up with my 'bedonnerdeid'

my Heavenly Father who has placed me in the privileged business of learning with and from children with severe and profound disabilities; to unlock some of their communication potentials so that they can teach me more about Him.

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## Prologue



### Where it all began

Working as a communication therapist<sup>1</sup> in some of the multi-lingual, multi-cultural contexts of the Republic of South Africa after my professional training, I thought I was well-prepared in terms of working cross-culturally, until I relocated and spent 12 years in neighbouring Botswana (1990 – 2001). There I was immersed in the Setswana language, culture and community, and I realised that I had to embark on an extensive process of personal and professional transformation if my communication interventions were to meet the real needs of the children with whom I worked. During this time, I first encountered the concepts of reflective practice (Schön, 1991; 1995). More than merely learning from experience, reflective practice awakened the researcher in me: the critic who always asks *why* does an intervention work or not and how can my interventions become more

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<sup>1</sup> In view of the focus of my work with children who cannot speak, I prefer the term communication therapist to the term speech therapist (please see Chapter One: 1.3.3).

effective, more appropriate and more sustainable? Donald Schön (1991; 1995) – though from the very different discipline of management psychology – first ‘taught’ me the cycles of identifying a problem, finding explanations for the problem and then trialling and identifying solutions. Or conversely; recognising what works well, identifying reasons or explanations and then trialling ways of generalising and applying it in other contexts.

Meanwhile, the families of the children with severe disabilities in Botswana, whom I had the privilege of accompanying on part of their life’s journeys, had seemingly endless patience with me. They are natural researchers due to their African traditional way of observing and identifying problems, investigating causes and then trialling and applying solutions - and they patiently nurtured my learning. An example is inserted on these next pages; that is, the preliminary case study (Geiger, 2010) which describes the first, question-generating cycle of the bigger, long-term transformative action research enquiry presented in this research report.

# Using cultural resources to build an inclusive environment for children with severe communication disabilities: a case study from Botswana

Martha Geiger\*

This paper describes the first cycle of an action research project addressing severe communication disabilities *in context*. Aspects of selected African cultures are being explored as resources in supporting inclusive environments for children with severe communication disabilities. The specific cycle documented here was completed in rural Botswana. This single case study is representative of several, similar cases where collaborative problem-solving with primary caregivers of children with severe communication disabilities (resulting from Cerebral Palsy) overcame the limitations of 'conventional' western communication interventions for these children. Culturally specific non-verbal communication and contextual elements of Setswana culture were identified, enabling the communicative participation of young children with severe communication disabilities in their specific social and cultural geography. Implications are indicated for clinical practice, service delivery in communication interventions and general community based rehabilitation programmes. Research implications include the need for more participative methodologies in developing contexts and the need to address communicative participation across disciplines.

**Keywords:** action research; Augmentative and Alternative Communication (AAC); Botswana; Cerebral Palsy; communication disabilities; high context/low context culture

## Introduction

Children with severe disabilities, living in remote communities, are among the most neglected populations in terms of rehabilitation services, both globally and in southern Africa, and the quest for appropriate, sustainable and effective intervention strategies continues (Alam 1996, 2005a, Hartley and Wirz 2002, Schlosser 2003, McConkey 2005). There has also been a call for more focused research on children in developing contexts, as most published research is based in developed, Northern hemisphere contexts (Ansell and Van Blerk 2005). Moreover, the previously neglected and undefined '*other childhoods*': the minorities and/or marginalised – e.g. children with disabilities and especially those living in remote communities – need to be considered (Kesby *et al.* 2006).

Research in diverse cultures and contexts raises additional issues in the ongoing debates between the different perspectives on disability. The spectrum of theories about disability is recognised as complex and multi-faceted and ranges from the more medical, individualistic



approach to disability, its cause and intervention strategies (i.e. focussing on the impairment) all the way to the socio-cultural or socio-political approaches which offer a broader perspective on the affected person's functioning and participation in his or her specific environment or community (Helman 2002, Ross and Deverell 2004). The limitations of the medical model have been addressed at the highest levels, as the history and development of the International Classification of Functioning, Disability and Health (ICF) illustrate most clearly (World Health Organisation 2001). The importance of considering the person with a disability *within* a given context is evident – maybe nowhere more so than in environments with cultural values and resources very different from the more frequently researched, northern hemisphere ones.

The southern African context, with its diversity of languages and cultures and its limited resources in terms of service delivery options for children with severe communication disabilities, poses real challenges. In this context, the social model of intervention has been identified as the way forward, whereby the child is considered holistically in relation to his environment, and social participation in that environment is prioritised as the goal for intervention (Ross and Deverell 2004). Given a certain *impairment* (communication or otherwise), the impact of the environment on the extent of a resultant, functional *disability* in that environment, may differ (World Health Organisation 2001). Reports of the negative responses to disability, for example where children are hidden, neglected, abused or killed because of their impairments have sometimes been publicised. However, inclusive community values and the *positive* stories such as those prompting this research, may be much more prevalent than is currently documented. In Botswana, such positive clinical observations led to the investigation of culturally determined environmental factors which were optimised to enhance children's inclusion and participation in their environment by accommodating alternative modes of communicative participation, where the children had no functional speech (Geiger 2005). Cultural elements of social interactions found to be useful in communication interventions in Setswana (which belongs to the 'Sotho-Tswana' group of languages – Jones 1993) have been informally confirmed by isiXhosa and isiZulu speakers as being present in those languages too (which represent the other, Nguni, group of southern African languages; Jones 1993). While literature in the fields of Socio-linguistics, Social Anthropology and African Studies indicates the uniqueness of each African language (and dialect) in terms of its forms of social interaction, the same literature also points out the prevalence of numerous identical and/or similar contextual, non-verbal, pragmatic and idiomatic elements of social interaction common to several of the languages of southern Africa (Sandilands 1938, Jones 1993, Kaschula and Anthonissen 1995).

International and local developments in the specialised field of Augmentative and Alternative Communication (AAC),<sup>1</sup> have delivered revolutionary possibilities for people with severe communication disabilities (Beukelman and Miranda 1998, Schlosser 2003, Alant 2005a). However, services addressing any form of communication disability have historically focused on the person with the communication impairment and moreover on that person's *speech*, or rather the lack of it (Ross and Deverell 2004). Yet, communication, by definition, implies the sending *and* receiving of messages in a certain context, and for communication to be functional – and thus for communication strategies to be effective – there needs to be a good *fit* in the given context. This gives rise to two questions;

1. What is the communicative context?
2. How can the communicative context be utilised to optimise communicative participation?

The purpose of this paper is to describe the first cycle of an ongoing, long-term action research study, focusing upon valuable resources within several southern African cultures, to foster inclusive environments in which children with little or no functional speech can participate communicatively. The research questions arose out of the communication therapist-researcher's clinical reflections, which were regularly checked and developed with the members of the



multi-disciplinary team involved in the rehabilitation programme covering Community Based Rehabilitation (CBR), residential rehabilitation and home-based follow-ups (Schön 1995).

The part of the study specifically described here, was a long-term case study in Botswana, which answered the above two questions, highlighting their importance, and resulted in the identification of cultural elements as valuable resources in enhancing the communicative participation of children with severe motor speech impairments. The main focus of the case study was a young boy with cerebral palsy and his communication partners. Similar collaborative, reflective interventions occurred simultaneously with other children and their communication partners in other villages. Several of the insights gained and strategies applied with these other children, who also had motor speech impairments as a result of cerebral palsy, were then applied in the situation of the young boy and vice versa. The observations described here are strictly speaking the findings of a 'collective' case study (Stake 2003); the single case of the young boy Boiki<sup>2</sup> is detailed here as a *typical* example illustrating many of the general and repeated features of the other cases studied.

### Background

When this communication therapist-researcher began working with Boiki upon his admission to a paediatric rehabilitation centre, the following history had been recorded. Community based rehabilitation (CBR) workers first identified Boiki in his remote home village when he was 7 years old. He was diagnosed with a severe, spastic hemiplegia – the right hand side of his body being completely paralysed, and the left side weakened. He was totally dependent upon others in terms of mobility and all activities of daily living including eating, drinking and dressing etc. It was not possible to establish his levels of general development or comprehension, before AAC strategies were applied to grant him a means of expressing himself. Careful, informal observations indicated hearing and vision within normal limits. His grandmother reported that he understood 'everything' and that he participated in conversations by means of a range of unarticulated vocalisations with a range of intonations indicating agreement or objections etc. Appropriate laughing also indicated that he understood humour – including some of the deeper meanings and double entendres of the idioms and proverbs which are a common characteristic of the Setswana language (Sandilands 1953, Merriweather 1992). Some gross motor control over his left arm was noted as a potential, to be further developed as a means of expression (e.g. through pointing or rudimentary gestures).

When Boiki was initially identified in a remote, rural village in Botswana, he and his siblings had only recently been orphaned. They lived with their grandmother, who was already caring for several other, orphaned grandchildren. This is a situation which is very common in Botswana, as well as in other countries in Africa, and which is often, but not always, related to the prevalent HIV/AIDS situation and the high mortality rates, predominantly amongst the bread-winning generation (Botswana Central Statistics Office 2002). The structure and dynamics of entire village communities reflect the physical, social and economic effects of HIV/AIDS. Numerous households consist only of aging grandparents (or great-grandparents) and grandchildren (from various deceased children). Extreme poverty in such households is common; indicated by for example, observations of 2–3 days without any food whatsoever. This is related to various factors, including the receding number of adults able to engage in subsistence agriculture (constantly compounded by Botswana's recurring and increasing drought situation), the fallout of income sources through the breadwinner generation and delays in the dissemination of social welfare services and resource.

The language spoken in this remote, rural area is an old, well-preserved form of Setswana which is rich in idiomatic expressions and multiple levels of meaning. These characteristics are closely associated with traditional Setswana culture, and this older form of Setswana is



typically the language of the aging, predominantly rural generation in Botswana who is increasingly left with the responsibility of child rearing. As a result of this, it has been observed that *traditional* cultural and language norms remain more clearly defined in these households than in the decreasing number of homes where younger, urban-influenced parents are raising their children.

Traditional Setswana culture encompasses *many* beliefs about the origin of disabilities; many of which relate certain actions or neglects of the pregnant mother with the condition of the child (Merriweather 1992). The extent to which the mother is held responsible, or even 'blamed' for her child's disability, varies. As elsewhere in Africa, the role of the supernatural, or the spiritual, also plays a very significant role in beliefs about the cause and origin of disabilities such as cerebral palsy (Ross and Deverell 2004). In Botswana the belief in the power of the ancestor spirits, or '*badimo*' in such issues, is widespread (Merriweather 1992).

This does however not necessarily imply the exclusion or ostracism of the affected persons; the spectrum of social attitudes towards persons with diverse disabilities ranges to complete inclusion and full participation in society (Ingstad 1997). Extended dialogues with people in a variety of contexts in Botswana indicate that this is related to the belief that all abilities, as well as disabilities, contribute to each person's individuality. Thus, some people require more help than others, and this situation changes within each person's individual lifespan, aptly expressed in the common idiom as, '*Bokgonne bo lapiditswe ke bonsofe*' (meaning, Ability is wearied/tired out by ageing).

Inclusion and participation need to be considered in specific contexts (Wyatt 1998, Tarnusani *et al.* 2002). In the case presented here, Boiki could not attend school; but neither could his siblings, as they lived more than 10 kilometres from the closest school. In the context of this community therefore, school attendance was not significant as an indicator of social inclusion and participation. Boiki was however fully included in the daily lives of the neighbourhood in terms of typical play activities which engage multiple age and ability levels simultaneously (Geiger and Alant 2005).

### The case study

This study focused upon the case of Boiki in his real-life contexts (from village home, to residential rehabilitation centre, back home). It spanned more than 4 years, from the original identification of his needs by a CBR team who worked closely with community members and government primary health care facilities, through 3 years of multi-disciplinary interventions in the residential rehabilitation centre, to Boiki's return to his home village and quarterly follow-up home visits.

The purpose of the case study speaks to the need to generate knowledge about a specific situation (Stake 2003). While the limitation of single case studies is widely recognised, their value and their contribution to the field of AAC has been carefully described and supported (McFwen and Karlan 1990, Schlosser 2003). The intervention described here, and particularly the collaborative nature of the final phase, can have applications elsewhere within and beyond the southern African context. It can encourage more interventions '*with*' rather than '*for*' children with severe communication disabilities and their communication partners (Hartley *et al.* 2005). There is a need for more empowering research practices, especially in developing contexts, and especially in research with and about children (Holt 2004). This was recognised here, in the endeavour to understand the social and cultural geography of Boiki, and many other similarly affected children. While the final phase of this case study evolved into a productive and empowering collaboration, it cannot be described as true participatory research. It is anticipated however that it may prompt more extensive and truly empowering participatory action research (Keshy 2007).

The contributors here, were the communication therapist/researcher, other members of the multi-disciplinary team who changed over the period documented, Boiki's grandmother (and Boiki himself!). Weekly, and sometimes daily, clinical notes were gathered and analysed over the 3-year period while Boiki was in the residential programme. These were complemented by detailed field notes during home visits to his remote village during school holidays, and at least once a year for 2 years after he left the centre. Field notes were confirmed with his grandmother, with the assistance of a CBR worker who also confirmed and/or brokered language and cultural issues. A description of the progression of Boiki's rehabilitation journey, and how the collaborative phase with his grandmother evolved, follows.

### *Conventional AAC therapy in an urban residential rehabilitation centre*

Boiki was identified by CBR<sup>3</sup> workers during a routine community survey, when he was 7 years old. He was admitted to a residential rehabilitation centre in the capital, where he and other children with severe physical disabilities spent school terms, receiving individually planned intensive, multi-disciplinary treatment regimes including physiotherapy, occupational therapy and communication therapy. Boiki also participated in the beginners' group in the special education programme – together with other non-verbal children. During the school holidays (three times a year), all the children returned to their homes, many of which were in remote rural areas.

Of necessity, an AAC intervention began for Boiki before it was possible to establish his true competencies, as his minimal expressive communication abilities precluded a realistic evaluation of his comprehension and cognitive abilities. This supports other records of this repeated dilemma in AAC interventions (Goossens 1989, Sevcik *et al.* 2004). Various object–symbol relations, concepts and functional terms were taught and practiced with Boiki and the other children in individual therapy and group sessions. In this way, real household objects such as a cup and a spoon etc. were related to toy objects, then to photographs, then to realistic drawings and if this was successful, with Picture Communication Symbols (PCS) (Mayer-Johnson 1990). Boiki and his peers each received a communication board and learnt to point (by hand or eye pointing) to symbols on it (Figure 1). The teaching of PCS was complemented by verbal Setswana language, natural gestures and South African Sign Language (SASL) hand signs (Nieder-Heitmann 1980). New vocabulary was introduced according to planned, weekly themes such as 'Our families', 'Our homes', 'Food', 'Games' and themes about holidays, festivals and outings such as 'Christmas', 'Independence Day' and 'The Circus'. The weekly themes were also shared with the staff at the centre, with a brief introduction to the relevant PCS-illustrations and hand signs. This supported a general awareness of the themes with which the children were occupied and facilitated natural communication opportunities between the children and all staff including the therapists, the teachers, the house mothers, the bus drivers, the cook and the gardener. Thus, Boiki and the other children at the centre were immersed in multi-modal communication opportunities with the purpose of developing their expressive communication abilities.

Within a few weeks, Boiki had learnt to indicate certain pictorial symbols on a communication board on his lap, either by rudimentary pointing with his left arm/hand or by eye-pointing. In this manner, he also participated in naming activities in his class, he could indicate basic needs and he could initiate topics or recall events that he wanted to 'discuss' by pointing to the relevant pictorial symbol on his board. He could also invite communication partners (including staff and his peers within the rehabilitation centre) to ask him questions about an indicated topic, which he could then respond to. His functional use of the communication board with its growing number of pictorial symbols increased to the extent that he could interact quite effectively with visitors to the centre and other unfamiliar communication partners. If the picture



ntsa 	katse 	nonyane 
kgomo 	pedi 	nku 
pitse 	koko 	kolobe 
tlou 	tau 	

Figure 1. Examples of Picture Communication Symbols as represented on the children's communication boards.

communication board was not with him and he wanted to communicate something, he would request (no, demand!) it by pointing to his lap with very agitated vocalisations.

#### *Problems of carry-over from the rehabilitation centre to the home*

Like all the other children from the rehabilitation centre, Boiki always returned to his grandmother, in his home village, for the school holidays. The various therapists from the rehabilitation centre regularly visited the children in their home villages, to support the carry-over of their interventions and to assist in overcoming any challenges that arose in the home environments.

The communication therapist-researcher found that Boiki was not using his picture communication board at all at home and that he regularly became quite frustrated. These observations correspond with the previously documented findings that children often abandon their communication aids (whether high-tech or low-tech aids) in their home environments (Wasson *et al.*, 1997). Admittedly, the previously reported studies concentrate mainly on the children, the AAC users themselves. Factors pertaining to the child's *communication partners* and the *general context*, and how these impact the abandonment of communication aids, have received little or no attention (Wasson *et al.*, 1997). Repeated attempts to facilitate the functional use of his communication board with his grandmother and other communication partners were not successful. The need to thoroughly explore the communicative environment of this child was clear. Calculator (1997) emphasises the reciprocal influences between AAC users and their communication partners as well as environmental factors which either support or hinder the

communication development of the child. Cultural factors have to be included in these considerations (Soto *et al.* 2000, Alam 2005a).

### *Collaborative problem solving*

A 'dialogic' collaboration, as described by Alam (1996), began with Boiki's grandmother, in which the therapist's AAC knowledge and the grandmother's specific, cultural expertise formed a valuable synergy. Either of the elements would have been unproductive without the other. Boiki's grandmother indicated specific difficulties which unexpectedly recurred several times in similar, other contexts, in which aging grandparents took care of orphaned grandchildren with severe communication disabilities (Geiger 2002).

Most of the identified difficulties with the PCS-communication board were directly related to the fact that Boiki's grandmother, like other caregivers of the same generation, *had never learn to read*. Moreover, the majority of this aged, remote rural population in Botswana had had minimal if any exposure to two-dimensional images, let alone graphic symbols. Less transparent, or abstract, symbols were therefore problematic as Boiki's grandmother and other communication partners in this social context could not rely on the written, Setswana word accompanying each pictorial symbol, for clarification.

Additional difficulties in this context, including *the recognition of arrows or other directional indicators* in several of the PCS images, have also been observed and described previously (Huer 2000, Haupt and Alam 2002, Alam 2005a). Furthermore, Boiki's grandmother and other communication partners in this context, who had not had exposure to pictures or diagrams on paper, *struggled with some figure – ground perceptions*. This was solved, to some extent, by replacing the conventional white PCS images on a coloured background, with symbols in spot-colour on a white background, which were then identified more easily.

Symbols, which consisted of parts of figures or images, were also problematic, indicating possible difficulties with visual closure. An example was the so very familiar animal in this context, the goat, which is represented in the PCS by a goat's head, while many other animals are represented by a full animal figure. None of the collaborating communication partners in this case study could identify the goat's head. A simple line drawing of a whole goat was however accurately and consistently recognised (Figure 2).

Moreover, the grandmother and other aged communication partners could also not recognise picture symbols representing individual body parts such as an ear or an eye – let alone the more abstract symbolic additions depicting the verbs 'to hear', 'to see' or 'to speak', etc. Interesting conversations followed in which the grandmother agitatedly questioned: why does one need a picture, when a very general hand or arm movement in the direction of the ear or eye was a commonly used and understood gesture in that context anyway?



Figure 2. Simple line drawings of whole images solved the dilemma with visual closure – for example; the simple line drawing of a whole goat was immediately identifiable by all who had not been able to identify the head of the goat without context.





Figure 3. The symbol for fish in the food category was not understood while an illustration of a can of fish was immediately identifiable.

Concepts beyond the direct experiential knowledge of the people in the context of this study, posed further challenges. The picture symbol for 'fish' had no experiential reference for these desert dwellers as none of them had ever seen a fish. Canned fish was however known as a special food item, and the alteration of the symbol for fish as a can of fish in the food category, was immediately and consistently recognised (Figure 3). Other examples of concepts which Boiki had on his communication board, and which were intended to help him to relate exciting events and experiences at the rehabilitation centre to his grandmother and others in his home village, included 'swimming pool' and 'blowing bubbles'. These could not be solved as easily as the fish that became the canned fish!

In addition, the size of all the picture symbols was increased to 6×6 cm due to age-related visual difficulties in this population. As reading and literacy is not an issue for these aged, remote rural people, the provision of spectacles was not a consideration in their daily lives, and could not contribute to the solution of this dilemma.

The *learnability of symbols described* elsewhere (Huer 2000, Haupt and Alant 2002, Alant 2005b), did not provide a hopeful outcome with the aged caregivers in this context. It was evident that the same difficulties of symbol identification persisted in spite of repeated exposure and practice; which may indicate underlying issues of perception. The collaboratively developed adaptations to the picture communication symbols, some of which have been documented earlier (Bornman *et al.* 2002), were subsequently introduced to the children in the rehabilitation centre and carried over to their home environments – with slightly more success for functional communication.

### ***Mutually identified cultural resources***

Boiki's grandmother's understanding of alternative communication principles grew through this collaboration. She easily grasped the advantages of alternative communication and recognised the potential help that this could be for her grandson and others. She identified additional elements of communication which the AAC intervention was attempting to achieve with great effort but without much success, but which were already 'in use' in natural ways in the specific context. During each subsequent visit, Boiki's grandmother explained new discoveries and realisations which enhanced Boiki's communication development and competencies in this specific context.

Firstly, there were the *culturally determined non-verbal elements*, which could be utilised. Boiki's grandmother pointed out that the pictorial symbols for 'thank you' or 'sorry' on his communication board were in fact redundant. In Setswana, as well as in most of the other language and culture groups indigenous to Southern Africa, many such social functions (e.g. to thank and to apologise) are expressed non-verbally, by gestures or body language rather than by means of

words. A child expresses gratitude by accepting the given object with *both* hands, or if it is not a material item that can be accepted physically, the child shows appreciation by bowing the head and lowering the gaze. With some guidance, Boiki could soon bring his more mobile left arm to his static right arm and – accompanied by a slight head nod and lowering his gaze – this approximation of the two-handed *thank you!* was easily understood by unfamiliar communication partners. While such variations of non-verbal gestures would not be recognised in other cultural contexts, the use of non-verbal gestures in this context was so ‘normal’ that members of the community were sensitive to them and recognised and understood even such a non-standard variation as the one that Boiki used.

A second advantage for Boiki was the *social organisation and the unspoken yet clear-cut roles in his rural community* – with the associated non-verbal and pragmatic aspects which gave him a head start. As in many of the other traditional cultures in southern Africa, children have clearly defined rolls in their communication and behaviour towards adults (similarly, younger adults have clearly defined roles in relation to older adults, and women towards men). It is not expected of a child to initiate conversation, and within a conversation a child would adopt a responsive rather than an initiating role. Basically, the younger person waits for the older to initiate a conversation or to begin or change a topic. Boiki, being a child, had a specific role and this meant that the pragmatic function of initiating a conversation or a topic, did not require the same priority in the intervention as is often described in the AAC literature (Beukelman and Miranda 1998). His grandmother excitedly pointed out that this was another area in which the expectations of Boiki by unfamiliar communication partners could be identical to their expectations of other children in the community (without disabilities). She anticipated that he would master the function of communicative initiations as he grew older and, it must be added that at a later visit, 4 years after the first contacts, Boiki was observed to initiate conversations (and change topics!) at will and quite effectively.

A third, frequently repeated, observation in this rural and poverty-stricken context was that children *did not have many choices, and therefore did not need to indicate choices* in, for example, two options of available food or drink items in their everyday lives. This was another situation in which Boiki, in spite of his communication disability, was not disadvantaged in this context. These examples are consistent with the socio-linguistic features which characterise a ‘high context culture’ (Hall 1990). According to Hall, a high context culture is typified by interactions in which much of the content (or meaning) is conveyed by the context, and less meaning needs to be conveyed through specific communication as such. In a ‘low context’ culture, more of the content (or meaning) has to be specified by means of language (be it verbal or non-verbal), as less meaning is conveyed within the context. Setswana culture (and especially the tradition-bound rural Setswana culture of this context), fits the description of a ‘high context’ culture, where strong unspoken beliefs, traditions, social arrangements and practices determine many of the everyday behaviours and responses of people in, for example, Boiki’s environment.

A hasty interpretation of this situation may lead to the conclusion of a reduced communication competence or even a language paucity of the people in a ‘high context’ culture. However, in addition to the testimonies of indigenous speakers of Setswana (and other southern African languages) themselves, anyone who seriously attempts to get to know, and study, the Setswana language and culture, soon realises that there is rather a complex depth and richness here. In his definitive work Sandikands (1953) describes in depth the rich idiomatic heritage of the Setswana culture, with its *polysemy* (multiple meanings). Boiki’s grandmother pointed out that the rich symbolism of everyday idioms, proverbs and some common metaphoric expressions, would lend themselves particularly well to graphic representation for Boiki’s communication board (with consideration to size, closure etc as described earlier). A line drawing of a hornbill bird (Lat: Tuckia Nanaus; a very common bird in the area which features frequently in the local





Figure 4. A diagram of a hornbill bird; a single referent for a powerful proverb reminding Boiki's siblings to share food fairly with him.

lore and legends etc.), was added to Boiki's communication board (Figure 4). This represented the proverb '*Bana ba kgorwe ba kgaogana tlhogo ya tsie*' that is; 'the children of the hornbill share even the head of a fly'. By emphatically pointing to this diagram, Boiki could claim his rightful portion of a bowl of food which had been put down for him and his siblings to share. The siblings – who could eat much faster than the disabled Boiki and threatened his rightful portion – were rebuked through this one emphatic, and culturally powerful, reminder that siblings must share equally and justly; regardless how small the portion.

These multiple levels of meaning in the Setswana language (colloquially referred to as 'deep' Setswana) reflect a natural semantic compaction; which is the underlying principle of the very effective AAC symbol system, Minspeak (Baker 2001). In addition, Jones (1993, p. vii) has described the 'economy' of the Setswana language; that is, the ability to conjure up rich images and/or multiple meanings with just a few words. Applied here, this is what was identified as a socio-linguistic resource for a non-verbal child like Boiki, for whom a limited number of very clear picture symbols were needed to communicate 'economically' and yet with 'deep' meanings, as is usual, appropriate – and 'normal' – in his specific remote rural, traditional Setswana context.

The concept of a synergy between the interventionist's AAC expertise and the cultural experience and insights of the AAC-user and communication partners in a given context, has been described previously (Alant 1996, 2005a). The emergence of such a synergy here encouraged and empowered the stakeholders to consider their own values, traditions and culturally determined behaviours in a new light. Boiki's grandmother and other communication partners began exploring and utilising them more fully to support his interactions and communication attempts more, thereby optimising his social and communicative participation.

## Conclusions

The effects of cultural factors upon communication development in general, and more specifically upon the implementation of AAC strategies, have been recognised (Hetzroni and

Harris 1996). In fact, some early childhood interventionists have gone further and have issued the challenge to reconsider the role of the cultural environment of the child, not merely as an important effect, but as a resource or asset in the child's development (Garcia-Coll and Magnusson 2000; p. 97). Similarly, the value of identifying and building on existing assets in a child's environment (including the cultural assets) has been highlighted (Cohen *et al.* 1994, Alant 2005a). The observations in this case study supported this.

The specific cultural elements which were provisionally identified here could be explored with relevant stakeholders in other, similar contexts; they should be tested to identify whether they are 'latently' present with the potential of being more fully utilised, as in this Botswana context. Furthermore, the cultural elements which were identified as valuable starting points here, can be built upon in intervention contexts where therapeutic and professional resources are limited.

While the limitations of small case studies are widely recognised, their value and their contribution to such fields as the individualised world of AAC has been carefully described and supported (McFwen and Karlan 1990, Schlosser 2003). The intervention described here, and particularly the collaborative nature of it, can have applications elsewhere within – and beyond – the southern African context. It can encourage more interventions and research 'with' rather than 'for' children with severe communication disabilities and their communication partners, thus growing the much-needed body of participatory, empowering research (Holt 2004). Moreover, by taking this preliminary research beyond the confines of communication sciences and pathologies, (in essence, 'giving away' this knowledge – Spencer 2005) issues may be opened for discussion within other disciplines, such as Social and/or Children's Geography, which are better equipped to assist in answering the originally posed questions, about the contexts (or Geographies) within which we as communication therapists work.

## Acknowledgements

My most grateful thanks to Boiki's grandmother for her passion to share '*so that others may learn*'; to all the colleagues in Botswana who contributed to the journey of learning, to the University of Cape Town Emerging Researcher Programme (and in particular to Dr Lyn Holmes) for all the encouragement, motivation and mentoring support, to Professor Jens Boenisch (then of the University of Halle, Germany), for affirmation that earlier aspects of this study were worth publishing ... and finally to 'Boiki' and all the other children in Botswana, who, though they cannot speak, have an insatiable passion to communicate and to fill their place in their world.

## Notes

1. Augmentative and Alternative Communication (AAC) is 'an area of clinical practice that attempts to compensate either temporarily or permanently for ... people with severe speech, language and/or writing impairments' (Beutelsman and Miranda 1998, p. 3).
2. Boiki is a pseudonym, in order to protect his and other participants' anonymity.
3. Community based rehabilitation (CBR) is 'a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of people with disabilities. CBR is implemented through combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services' (U O, UNFSCQ & WHO, 2001, p. 2).

## References

- Alant, E., 1996. Augmentative and alternative communication in developing countries: challenge of the future. *Augmentative and Alternative Communication*, 12 (1), 1–12.
- Alant, E., 2005a. Cultural and socio-economic influences on communication. In E. Alant and L.L. Lloyd, eds. *Augmentative and alternative communication and severe disabilities, beyond poverty*. London: Whurr Publishers Ltd, 95–107.
- Alant, E., 2005b. Issues in graphic symbol communication. In E. Alant and L.L. Lloyd, eds. *Augmentative and alternative communication and severe disabilities; beyond poverty*. London: Whurr Publishers Ltd, 108–130.



- Ansell and Van Blerk, 2005. Introduction; children and youth in developing areas. *Children's Geographies*, 3 (2), 145–147.
- Baker, B., 2001. Semantic compaction systems. Available from: [www.minspeak.com](http://www.minspeak.com) (Accessed 15.01.08).
- Beukelman, D.R. and Mirenda, P., 1998. *Augmentative and alternative communication*. London: Baltimore.
- Bornman, J., Geiger, M., and Haupt, L., 2002. PCS adaptations for the African context. in: *Proceedings of the 10th International ISAAC Conference*, Odense, Denmark, August 2002.
- Botswana Central Statistics Office, 2002. *Population of towns, villages and associated localities in August 2001*, Department of Printing and Publishing Services, Gaborone.
- Calculator, S.N., 1997. Fostering early language acquisition and AAC Use: exploring reciprocal influences between children and their environments. *Augmentative and Alternative Communication*, 13 (3), 149–157.
- Cohen, R., Chetley, A., Mikhyo, Z., Nimpuno, P., Salole, G., and Zwitzer, L., 1994. *Building on people's strengths: early childhood in Africa*. The Hague: Bernhard van Leer Foundation.
- Garcia-Coll, C. and Magnuson, K., 2000. Cultural differences as sources of developmental vulnerabilities and resources. In: J.P. Shonkoff and S.J. Meisels, eds. *Handbook of early childhood intervention*. New York: Cambridge University Press, 94–114.
- Geiger, M., 2002. Grandparents as primary caregivers; implications for AAC implementation in Botswana. In: *Proceedings of the 10th International ISAAC Conference*, Odense, Denmark, August 2002.
- Geiger, M., 2005. Die Nutzung kultureller Ressourcen als Grundlage für UK; Anwendungen aus Afrika. In: J. Boenisch and K. Otto, eds. *Leben im Dialog; Unterstützte Kommunikation über die gesamte Lebensspanne*. Karlsruhe: Von Loeper Literaturverlag, 506–517.
- Geiger, M. and Alant, E., 2005. Child-rearing practices and children's communicative interactions; observations in a village in Botswana. *Early Years; An International Journal of Research and Development*, 25 (2), 183–191.
- Goossens, C., 1989. Aided communication intervention before assessment: a case study of a child with cerebral palsy. *Augmentative and Alternative Communication*, 5 (1), 14–26.
- Hall, E.T., 1990. *Understanding cultural differences*. Yarmouth, USA: Intercultural Press.
- Hartley, S.D. and Wirz, S.L., 2002. Development of a 'communication disability model' and its implication on service delivery in low-income countries. *Social Science & Medicine*, 54 (10), 1543–1557.
- Hartley, S., Murira, G., Mwangoma, M., and Carter, J., 2005. *Women in action; improving the quality of children's lives*. London: Institute of Child Health, University College London.
- Haupt, L. and Alant, E., 2002. The iconicity of picture communication symbols for rural Zulu children. *South African Journal of Communication Disorders*, 49, 40–49.
- Helman, Cecil G., 2002. *Culture health and illness*. 4th ed. London: Arnold.
- Hetzeroni, O.E. and Harris, O.L., 1996. Cultural aspects in the development of AAC users. *Augmentative and Alternative Communication*, 12 (1), 52–58.
- Holt, 2004. The 'voices' of children; de-centring empowering research relations. *Children's Geographies*, 2 (1), 13–27.
- Huer, M.B., 2000. Examining perceptions of graphic symbols across cultures: preliminary study of the impact of culture/ethnicity. *Augmentative and Alternative Communication*, 16 (3), 180–185.
- ILO, UNESCO, WHO, 2004. *CBR Joint Position Paper*. Geneva: World Health Organisation.
- Ingstad, B., 1997. *Community based rehabilitation in Botswana; the myth of the hidden disabled*. New York: Edwin Mellin Press.
- Jones, J.D., 1993. Preface. In: Z.I. Matumo, ed. *Setswana-English-Setswana Dictionary*. Gaborone: Botswana Book Centre, vii–ix.
- Kaschula, R.H. and Anthonissen, C., 1995. *Communicating across cultures in South Africa; toward a critical language awareness*. Johannesburg: Witwatersrand University Press.
- Kesby, M., 2007. Spatializing participatory approaches: the contribution of geography to a mature debate. *Environmental and Planning A*, 39 (6), 2813–2831.
- Kesby, M., Gwanzura-Ottmoller, F., and Chizororo, M., 2006. Theorising other, 'other childhoods': issues emerging from work on HIV in urban and rural Zimbabwe. *Children's Geographies*, 4 (2), 185–202.
- Mayer-Johnson, R., 1990. *The picture communication symbols*. Volumes I, II and III. Solana Beach, USA: Mayer-Johnson Co.
- McConkey, R., 2005. Service delivery in low income countries. In: E. Alant and L.L. Lloyd, eds. *Augmentative and alternative communication and severe disabilities; beyond poverty*. London: Whurr Publishers Ltd, 131–154.
- McEwen, I.R. and Karlan, G.R., 1990. Case studies: why and how. *Augmentative and Alternative Communication*, 6 (1), 69–75.
- Merriweather, A.M., 1992. *Puisanyo ya Bongaka ka Sekgoa le Setswana; Medical Phrasebook and Dictionary*. Gaborone: Botswana Book Centre (Pty) Ltd.
- Nieder-Heitmann, H., 1980. *Talking to the deaf; a dictionary of sign language for South Africa*. Pretoria RSA: Government Printers.

- Ross, E. and Deverell, A., 2004. *Psychosocial approaches to health, illness and disability: a reader for health care professionals*. Pretoria: Van Schaik Publishers.
- Sandilands, A., 1953. *Introduction to Tswana*. Tigerkloof: London Missionary Society.
- Schlosser, R., 2003. *The efficacy of augmentative and alternative communication: towards evidence-based practice*. London: Academic Press.
- Schön, D.A., 1995. *The reflective practitioner; how professionals think in action*. Aldershot, Hants: Ashgate Publishing Limited.
- Sevcik, R.A., Ronski, M.A., and Adamson, L.B., 2004. Research directions in augmentative and alternative communication for preschool children. *Disability and Rehabilitation*, 26 (21/22), 1323–1329.
- Soto, G., Huer, M.B., and Taylor, O., 1997. Multicultural issues. In: L.L. Lloyd, D.R. Fuller and H.H. Arvidson, eds. *Augmentative and alternative communication; a handbook of principles and practices*. Boston, MA: Allyn and Bacon, 406–413.
- Spencer, C., 2005. How can we give 'children's geographies' away? *Children's Geographies*, 3 (2), 265–266.
- Stake, R.E., 2003. Case studies. In: N.K. Denzin and Y.S. Lincoln, eds. *Strategies of qualitative inquiry*. 2nd ed. Thousand Oaks, CA: Sage Publications, Inc, 134–164.
- Turmusani, M., Vreede, A., and Wirz, S.L., 2002. Some ethical issues in community-based rehabilitation initiatives in developing countries. *Disability and Rehabilitation*, 24 (10), 558–564.
- Wasson, C.A., Arvidson, H.H., and Lloyd, L.L., 1997. AAC assessment process. In: L. Lloyd, D.R. Fuller and H.H. Arvidson, eds. *Augmentative and alternative communication; a handbook of principles and practices*. Boston, MA: Allyn and Bacon, 169–198.
- World Health Organisation, 2001. *International classification of functioning, disability and health (ICF)*. Available from: <http://www.who.int/classifications/icf/en/> (Accessed on 7 April 2008).
- Wyatt, T., 1998. Assessment issues with multicultural populations. In: D.E. Battle, ed. *Communication disorders in multicultural populations*. Boston, MA: Butterworth-Heinemann, 379–426.
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## Concluding thoughts

The purpose of this prologue was to recount, by means of the preliminary case study, what became the first cycle of the long-term, transformative action research study. The case study spanned four years and explored aspects of the Setswana language and cultural setting, which helped the child Boiki's communicative participation in his specific context. Boiki's grandmother became my teacher as we endeavoured to optimise the communicative participation of her grandson and other similarly disabled children. Her repeated reminder to me was; '*Nte ke go ruta gore wena o ka rutela ba bangwe gape*' (= Let me teach you so that you can teach others), and so this collaborative striving became a transformative journey. In the transformative paradigm, "a problem can be defined through a synergistic relationship with the important participants, with a special sensitivity to issues of power" (Mertens, 2003: 143).

We explored and identified some non-verbal, pragmatic and contextual resources and these supported earlier writings which identified the cultural environment of the child, as more than having *an effect*, but as a potential *resource* or an asset in the child's development (Alant, 2005; Cohen, Chetley, Mikhyo, Nimpuno, Salole, & Zwitzer, 1994; Garcia-Coll & Magnuson, 2000). The challenge put out by Garcia-Coll and Magnuson (2000; 97) to reconsider culture, not only as an influence but as an important resource in a child's development, challenged me to reconsider my personal and professional attitudes towards the end of the question-generating case study. During my childhood and early youth, the now generally acknowledged ethnocentric, deficit views of considering first-world or northern hemisphere cultures and norms as superior had been reinforced by South Africa's deceptive *Apartheid*<sup>1</sup> indoctrination of judging those whom one does not know. My training as a communication therapist had sadly not helped in challenging these perceptions either, but then my immersion in Botswana rural life and the lessons learnt from Boiki's grandmother and many others, revealed some of the wealth that I was missing – including the resources, to which Garcia-Coll and Magnuson refer (2000; 97).

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<sup>1</sup>*Apartheid*: the system of segregation or discrimination on grounds of race, legally enforced in South Africa from 1948, with preliminary relaxation in 1990 and until the first democratic elections in 1994. The term comes from the Afrikaans language (with original roots in Dutch), literally meaning 'separateness' (Oxford Dictionaries, 2013).



All of this learning contributed to my growing query, which was:

*How much more is there, both in Setswana language contexts and in the other southern African indigenous language contexts that can be explored together; affirmed where it is humbly not asserted and used effectively to increase the communicative participation, the quality of life and the social contribution of children (and adults) with severe to extreme communication disabilities?*

Upon my return to Cape Town, South Africa, after 12 years of living, working and learning with the people in Botswana, my next informal step included conversations with isiXhosa speaking mothers of children with similar disabilities, about specific examples of cultural elements identified as resources in the Botswana context. Without exception, the isiXhosa speaking mothers confirmed the same or very similar examples in their own cultural contexts and expressed enthusiasm to ‘test’ them. Several mothers also voiced their wonder at not having recognised these resources before – thus confirming that there was a research project needing to be explored, right here. This confirmation triggered the formalisation of what became the main study in South Africa with isiXhosa speaking participants, with the Botswana case study effectively forming the first, question generating cycle (see Figure 0.1, below).

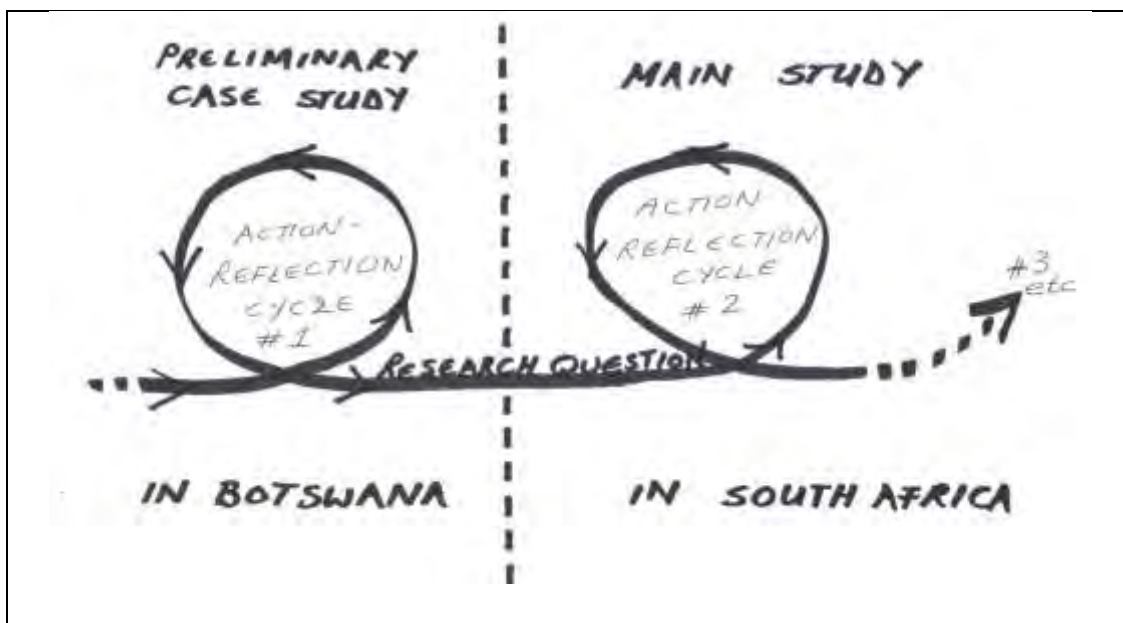


Figure 0.1: The preliminary case study became the first, question-generating cycle of the main study.

# Chapter One:

## Introduction to the study



*“If all my possessions were taken from me with one exception,  
I would choose to keep the power of communication,  
for by it I would soon regain all the rest”*

*-Daniel Webster*

*(American Statesman and Orator 1782 – 1852)<sup>1</sup>*

### 1.1 Overview of Chapter One

This chapter provides an introduction to the main study, which was implemented in South Africa and followed on from the preliminary case study from Botswana, documented in the Prologue. An explanation of how key terms have been applied in the research report is followed by the motivation for the study which comprises an overview of relevant issues in the South African context, that is, the prevalence of childhood disability; economic, social and environmental conditions and the effects of HIV and AIDS, and the policy context. A preliminary overview to the concept of communication disabilities is followed by an outline of communication therapy service delivery and its challenges in South Africa. This leads on to the problem statement, the purpose and aims of the study. A

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<sup>1</sup> Goodreads Inc. 2011. *Daniel Webster Quotes*. Accessed on 14 April 2013 from <http://www.goodreads.com/author/quotes/31180> .

declaration of my positionality, as the researcher in this study, is followed by an outline of the subsequent chapters. A brief conclusion closes the chapter.

## **1.2 Chapter introduction**

Interacting and communicating with others is part of the essence of being human. Impairments that limit a person's ability to communicate and to interact with others arguably present additional challenges of function and participation, beyond those of other disabilities. The quote at the beginning of this chapter, attributed to the nineteenth century American statesman and orator, Daniel Webster, sums it up: "If all my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon regain all the rest" (Goodreads Inc., 2011). Among those with severe or multiple disabilities, it is indeed evident that those who can *communicate* (even if they cannot speak) are less 'disabled' in terms of participation in interactive relationships and in their environments than those who cannot (or who are not given the opportunity to) communicate.

By definition, communication implies the two-way process of sending and receiving of messages (be they verbal or non-verbal) and the effective conveying or sharing of ideas and feelings (Oxford Dictionary, 2013). In the field of communication disorders, there has been a growing recognition of the need to focus not only on the person with the impairment, but also on the communication partners and the context of the communication in order to optimise this two-way process (Alant, 2005; Calculator, 1997; Hartley & Wirz, 2002; Ibragimova, Lillvist, Pless & Granlund, 2007; Kent-Walsh & McNaughton, 2005; Levin, 2006; 2013; Pepper & Weitzman, 2004; Raghavendra, Virgo, Olsson, Connell & Lane, 2011; Woodhead, 2006). For example, the reciprocal effects of primary and other caregiver responses on the child's early communication development has become a strategic focus, both in actual communication interventions and in research of the same (Ibragimova et al., 2007; Pepper & Weitzman, 2004; Rossetti, 2001; Sameroff, 2009; 2012; Strasheim, Kritzinger & Louw, 2011). An increasing body of evidence is also available on the broader ecology of physical, geographical, economic, sociological, cultural, political and/or other impacts upon children's opportunities to develop interaction, communication and, by implication participation; even if they cannot learn to speak (Alant, 2005; Battle, 2012; Hartley & Wirz, 2002; Levin, 2006; 2013; Owens, 2005).

Many communication therapists worldwide work in cross-cultural contexts and so questions about culture, culturally determined attitudes, behaviours and practices and their interrelationship with communication, have gained increasing attention over the years (Battle, 2012; Hartley & Wirz, 2002; Isaac, 2002; Taylor & Clarke, 1994). Communication therapists in the very multilingual and multicultural contexts in South Africa have also been exploring issues of language and culture and implications for communication interventions (Barratt, Khoza-Shangase & Msimang, 2012; Kathard & Pillay, 2013; Pascoe & Norman, 2011; Penn, 2000; Pillay, 2003). Related to these issues are questions of the effectiveness, appropriateness and sustainability of current and future services seeking to address the needs of those with communication disabilities in contexts shaped by specific cultures. The quest is thus on for *responsive* service delivery (Hartley & Wirz, 2002; Kathard & Pillay, 2013; Pascoe & Norman, 2011).

### **1.3 Definition of terms as applied in this study report**

The fields of health, disability and rehabilitation have witnessed a long and on-going struggle concerning the terms used to identify and describe people and disabling conditions in simultaneously clear and respectful ways – sometimes taking into account diametrically opposed views and/or purposes. The concepts below are of particular relevance here, and I would like to declare and motivate my specific usage of these terms in this research report as follows:

#### **1.3.1. Communication impairment or communication disability?**

In the international arena, the two terms most frequently used are: ‘*severe speech and physical impairments (SSPI)*’ (Beukelman & Mirenda, 1998; 2005) and ‘*complex communication needs*’ (Burkhardt, n.d.). The latter – more function or activity-centred term – has largely replaced the former, more impairment-focused term. However, in the international arena, both terms convey concepts and images of children (or adults) who cannot use speech as a means of communication, due to impairments affecting the motor, cognitive and/or psycho-social abilities of the child (Beukelman & Mirenda, 2005) – *but* who have access to alternatives such as AAC devices and supportive training and maintenance of these. I have here opted for a generally descriptive term ‘*severe communication disability*’ applied to children (and adults) who do not have the physical and/or cognitive capacity to use speech as a means of communication and who, due to

one or more additional factors (e.g. physical, cognitive, sensory and or psycho-emotional impairments and severe contextual factors such as poverty etc.) cannot access and benefit from any of the wonderful assistive technologies or strategies in the formally delineated field of Augmentative and Alternative Communication (AAC). Although the participants in this study were parents (or carers) of children diagnosed with cerebral palsy (the health condition), the complexity and interrelation of the children's structural, functional, activity and participation factors, made the concept of a severe **communication disability** (rather than an impairment) more applicable. This is discussed in greater detail within the framework of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) in chapter two.

### 1.3.2. AAC or basic communication?

**Augmentative and alternative communication** or the more commonly used abbreviation AAC refers to:

*...a set of tools and strategies that an individual uses to solve every day communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech generating devices, etc. Everyone uses multiple forms of communication, based upon the context and our communication partner. Effective communication occurs when the intent and meaning of one individual is understood by another person. The form is less important than the successful understanding of the message (Burkhart, n.d.<sup>1</sup>)*

AAC includes strategies using a range of communication aids (from homemade cardboard picture boards to high tech speech synthesisers – that is, assistive communication aids apart from the human body) as well as the whole range of ‘unaided’ systems (using only the human body) including gestures and signs. International and local developments in the specialised field of AAC have delivered revolutionary possibilities

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<sup>1</sup> No page reference for this web-citation, that is: Burkhart, L. n.d. ‘What is AAC?’ <https://www.isaac-online.org/english/what-is-aac/> accessed 2 July 2014.



for people with severe communication disabilities (Alant, 2005; Hawking, 2011). The focus here, however, was on those who cannot access formal communication systems or assistive devices, either because of the severity and complexity of their disability or because of extreme poverty and lack of access to appropriate services. For this reason, the less familiar concept of **Basic Communication**, as translated from the German *Basale Kommunikation* (Mall, 2002; 2005) as a way of interaction with no preconditions, is preferred in this context, as it is free from the connotations of technologically aided AAC.

### **1.3.3. ‘Communication therapist’, ‘Speech therapist’, ‘Speech-language therapist’, or ‘Communication Pathologist’?**

Different countries and their relevant professional bodies use these different terms (ASHA, 2004; RCSLT, n.d.; SASLHA, n.d.). Here in South Africa, my official professional registration is as a Speech therapist, but in referring to my own scope of clinical practice, I find ‘*Communication Therapist*’ most apt as non-verbal, basic communication - and not speech - is usually the focus in the children with severe disabilities with whom I work. Furthermore, with rehabilitative goals beyond medical model diagnosis, ‘therapist’ fits better than ‘pathologist’.

### **1.3.4. ‘A person with a disability’ or ‘a disabled person’?**

At risk of over-simplification, the term *person with a disability* is generally accepted in international policy contexts and is intended to reflect a respectful person-centred or people-first approach (United Nations, 1993; 2006). This term is, however, critiqued as being primarily impairment-orientated by disability activists who prefer the human rights-based term *disabled person*, which needs to be understood against the implied view that the environment or society is considered to be the disabling factor and not the person’s body or impairment (Barnes, 2003; Barnes & Mercer, 2001; Disabled People South Africa, 2001; Priestley, 2011; Priestley, Waddington & Bessozi, 2010). Both terms will be used here – depending on the context, the specific situation and the intent. Current terminology recognizes the necessity of addressing the individual, impairment-related needs (e.g. assistive devices and rehabilitative procedures, etc.) as well as the shortcomings of the society (e.g. environmental barriers to participation). This is in keeping with the bio-psycho-social model of understanding disabilities as represented in the ICF (WHO, 2001; 2011), discussed in chapter two.

### **1.3.5. ... and terminology beyond disability: the South African indigenous language names**

Nine of the 11 official languages of the Republic of South Africa are indigenous languages and the words used regarding these languages, and the people groups who use them, have a particularly riotous and emotive earlier history (Alexander, 1992). One of two language-naming conventions could be followed here.

On the one hand, one can either anglicise all the language and people group names as one does when speaking English and describing the languages of for example, Germany or France. One says ‘German’ and ‘French’ and not; ‘they speak Deutsch’ or ‘they speak Française’. In the local context this anglicised approach would thus list the nine indigenous languages (in alphabetical order) as Ndebele, Pedi, Sotho, Swati, Tsonga, Tswana, Venda, Xhosa and Zulu.

On the other hand, an alternative convention is mindful of the history of oppression of the indigenous languages and cultures and the lack of acknowledgment of these previously marginalised languages as linguistically specific and comprehensive (PANSALB, 2011). This language naming convention uses the *original* language names, acknowledging the unique prefixes, as (in alphabetical order) isiNdebele, isiXhosa, isiZulu, Sepedi (sometimes also referred to as Sesotho sa Lebowa), Sesotho, Setswana, SiSwati, Tshivenda and Xitsonga (Constitutional Court of South Africa, 1996; PANSALB, 2011; South African Translators’ Institute, 2007). Considered more in keeping with the transformative way of thinking than the first, anglicised convention, this second convention, applying the indigenous language names, has been applied in this report (thus **isiXhosa** and **Setswana**).

## **1.4 Motivation for the study**

The research journey described in this report began with questions raised during my earlier time as a communication therapist, working mostly with children who could not speak but who could communicate, in some of the remote, rural areas of Botswana (1990-2001). Working in a new environment, immersed in a different language and culture, with very limited material, human and other developed-country resources, I was challenged to explore and learn new ways of working with children with severe communication disabilities and their families. The basic cycles of reflective practice, that is, action,

reflection and adjusted planning as originally described Lewin (1946) and applied by Schön (1995) became a key to my learning and doing at that time. Furthermore, by engaging in further planning with reference to evidence from literature published in related fields, I hoped to take a step towards the much needed ‘evidence-*informed* reflective practice’ (Ng, 2012:129). One such reflective journey became the preliminary, question-generating cycle of the current study (presented in the Prologue and pre-published: Geiger, 2010). It focused on some of the valuable resources within the Setswana language and cultural setting in Botswana, and supported earlier writings which recognised the cultural environment of any child, as more than just having *an effect*, but as a potential *resource* or *asset* in that child’s development (Alant, 2000; Cohen, Chetley, Mikhyo, Nimpuno, Salole, & Zwitter, 1994; Garcia-Coll and Magnuson, 2000).

On my return to South Africa in 2002, the personal motivation to explore the presence, nature and usefulness of similar resources or assets in an isiXhosa language context, grew. Simultaneously, the calls for responsive service delivery for children with severe communication disabilities in developing or low-income contexts, including South Africa, have also been increasing (Alant & Lloyd, 2005; Battle, 2012; Department of Education, 2004; Eide & Ingstad, 2011; Hartley & Wirz, 2002; Kathard & Pillay, 2013; McConkey, 2005; Schneider & Saloojee, 2007; WCFID, 2011).

What then encompasses the needs that service delivery should address for children with severe communication disabilities in developing or low-income contexts, specifically in the Western Cape, in South Africa?

## **1.5 The South African context**

An indication of the complexity of the needs is outlined below, as several aspects of the South African context are discussed. These include matters related to disability prevalence and the reporting of it; economic, social and environmental conditions; the pervasive effects of HIV and AIDS on children, families and communities, and the international and local policies that provide directives for service delivery. Severe communication disabilities are introduced (and will be discussed in more depth within the framework of the ICF (WHO, 2001) in the literature review in chapter two); and some of the challenges of communication therapy in the South African context are outlined.

### **1.5.1 Prevalence of childhood disability**

Prevalence data on children with disabilities in South Africa has been sketchy (DSD, DWCPD & UNICEF, 2012; Kathard & Pillay, 2013; McClaren, 2013; Schneider & Saloojee 2007). General reports however confirm the increasing prevalence of severe childhood disabilities, often secondary to pre-, peri- and postnatal birth complications (ACPF 2011; WHO 2011), and cerebral palsy (CP) is widely agreed to be the biggest single contributor of childhood disability in South Africa (McLaren, 2013; Ransom, 2009). While recent local prevalence figures on cerebral palsy are lacking, two earlier studies indicated CP prevalence rates of 10 per 1000 in KwaZulu-Natal (Couper, 2002) and as high as 80 per 1000 in the Eastern Cape (Christianson, Zwane, Manga, Rosen, Venter, Downs & Kromberg, 2002); compared to between two and three per 1000 in developed countries (McClaren, 2013).

In terms of communication disabilities, it is even more challenging to establish local prevalence figures: the nature of communication disabilities is that they are often secondary to severe physical impairments (e.g. cerebral palsy), sensory impairments (e.g. deafness) or cognitive impairments (e.g. a range of intellectual disabilities) (McAllister, Wylie, Davidson & Marshall, 2013; Stuart, 2002). Even with the more descriptive, function-based question formats of the latest 2011 national census, communication disabilities are still suspected to be very under-reported, where the primary – often more visible - impairment related to, for example cerebral palsy, tends to be reported and not the secondary communication impairment (ACPF, 2011; DSD, DWCPD & UNICEF, 2012). For this reason, both the estimates of communication **disabilities** in the national census of 2001 (Stats SA, 2005) and those of communication **difficulties** in 2011 (Stats SA, 2012a; 2012b) need to be interpreted with caution.

### **1.5.2 Economic, social and environmental conditions**

High correlations between disability and poverty globally, and especially in developing contexts have been widely recognised (Braithwaite & Mont, 2009; Mitra, Posarac & Vick, 2013). In South Africa, the prevailing conditions (including poverty, limited access to health and rehabilitation services and the effects of HIV and AIDS) compound the disability for the many children and their families affected by cerebral palsy (ACPF, 2011; DSD, DWCPD & UNICEF, 2012; WHO 2011; 2013b).

South Africa's status as a middle income country (ACPF, 2011; World Bank, 2014), is supported by images of large, modern facilities, cutting-edge medical research, advanced systems of medical care, rehabilitation and education services. Yet the majority of children and families live in contexts of poverty and need, and cannot access these centralised 'first world' facilities and services (ACPF, 2011; Berry, Biersteker, Dawes, Lake & Smith, 2013; Ransom, 2009; Walker et al, 2007; 2011; WHO, 2011; 2014a; 2014b).

Despite the democratising processes in the country since 1994<sup>1</sup>, persisting economic inequality is clearly evident in the fact that the Black African majority of the country's population have a very much lower average income than the other population groups - and this 'average' represents a very large proportion who still live in abject poverty (ACPF, 2011; Stats SA, 2012; Walker et al, 2011). Disparities continue in spite of the significant increases in average *national* household income across population groups since the previous census of 2001, as indicated by the preliminary results of the South African 2011 National Census (Stats SA, 2012). Further poverty 'traps' and access barriers to services are still experienced as direct and pervasive results of the Group Areas Act (Union of South Africa, 1950) and other laws enforcing segregation during the *Apartheid*<sup>2</sup> regime, which assigned Black Africans to far outlying, poorly resourced and poorly serviced townships<sup>3</sup>. The distance of the townships from the urban centres, has meant that even after democracy, and the abolishment of the Group Areas Act and other laws of segregation, the majority of Black African families have not been able to move closer. The daily cost of transport to get to a place of work – and the time it takes to

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<sup>1</sup> 1994 marked the first democratic elections and the coming to power of the African National Congress (ANC) after the preceding white nationalist party rule with its enforced policies of racial segregation and oppression (i.e. Apartheid)

<sup>2</sup> *Apartheid* - a word from the Afrikaans language, meaning 'separateness' and referring to the system of segregation or discrimination on grounds of race, legally enforced in South Africa from 1948, with preliminary relaxation in 1990, until first democratic elections in 1994. From the Afrikaans language (with original roots in Dutch), literally meaning 'separateness' (Oxford Dictionaries, 2013).

<sup>3</sup>“In South Africa, the term township... usually refers to the (often underdeveloped) urban living areas that, from the late 19th century until the end of Apartheid, were reserved for non-whites (black Africans, Coloureds and Indians). Townships were usually built on the periphery of towns and cities.<sup>[1][2]</sup> The term *township* also has a distinct legal meaning, in South Africa's system of land title, that carries no racial connotations” accessed on 24 January 2015 from [https://en.wikipedia.org/wiki/Township\\_\(South\\_Africa\)](https://en.wikipedia.org/wiki/Township_(South_Africa))

commute from a township – comprise key factors in the vicious cycles of pervasive poverty. In addition, poorly developed and maintained public transport systems have resulted in real barriers to access the health and rehabilitation services – which are still concentrated in the urban centres (Kathard & Pillay, 2013; Mlenzana, Frantz, Rhoda & Eide, 2013). Regular therapy (be it communication therapy, physiotherapy or occupational therapy) for a child with a severe disability, living in a township, is thus an exception rather than the norm (ACPF, 2011; Kathard & Pillay, 2013; McClaren, 2013; WHO, 2014b).

### **1.5.3 HIV and AIDS**

The effects of HIV and AIDS further compound the disability for many children and their families affected by cerebral palsy (ACPF 2011; DSD, DWCPD & UNICEF, 2012; WHO 2011; 2013b; 2014b). Again, prevalence figures are scant; an estimate of the national prevalence of people living with HIV in 2012 was 9.9% of the total population of just over 50 million (Stats SA, 2013). The only large scale survey that specifically included and provided some indicators for HIV prevalence among persons with disabilities (without specifying which disabilities), indicated an HIV prevalence estimate within this vulnerable population as high as 14.1% (Shisana et al., 2010). However, the effects of HIV and AIDS are much more pervasive than any prevalence figures of actual HIV infection status can convey (Rohleder, Swartz, Schneider, Groce & Eide, 2010). Examples of such effects include very ill children (over and above the CP), and/or very ill parents and caregivers; fallout of breadwinners, further exacerbating poverty; and aged and tired grandparent-caregivers financially responsible and caring for increasing numbers of orphaned grandchildren and other, younger family members, to name but a few (Rohleder et al., 2010). For a family with a child with a severe disability and affected by one or several of these factors - it is not difficult to imagine how these added factors impact on the de-prioritisation of attending long-term therapies for the child.

### **1.5.4 The policy environment**

International and local policies provide a strong directive for adopting rights-based approaches to service delivery for people (including children) with disabilities. At the global level, the United Nations Convention on the Rights of Children (UNCRC) emphasises the rights of all children with disabilities to access all the help they need (United Nations, 1989; Article 23). Furthermore, the United Nations Convention on the

Rights of Persons with Disabilities (UNCRPD) elaborates on the rights of persons with disabilities in detail, including the right for persons with disabilities to have access to communication and to participate in their communities (United Nations, 2008). South Africa has formally ratified the UNCRPD and has therefore accepted it as legally binding.

At a national level, South Africa has some of the most progressive human rights-based legislation in the world, yet its implementation is often lacking (ACPF 2011; Dube 2006; Kathard & Pillay, 2013; Ogot, McKenzie & Dube, 2008; Schneider & Saloojee 2007). National policies detail the vision of a ‘society for all’ and one of the early fruits of our then new democracy, was the White Paper on the Integrated National Disability Strategy (INDS), which serves as a framework for the integration of disability issues in *all* governmental development strategies (Office of the Deputy President of South Africa, 1997). The practical implementation of the INDS has been conceptualised and formulated in the Disability Framework for Local Government 2009–2014 (Department of Provincial and Local Government, n.d.). However, children with severe disabilities, including those with a severe or profound intellectual disability and an IQ of less than 35, have been formally excluded from fundamental educational and training inputs for many years (WCFID 2011; Western Cape High Court 2011; Wood et al., 2009). Service delivery, including special care centres, providing for these children has not been included in any form of strategic planning or budgetary provision for appropriate educational services or even human resources for basic stimulation and training provision (Wood et al. 2009). Spearheaded by the Western Cape Forum for Intellectual Disability (WCFID), efforts to challenge and change this legislation finally reached a victory in the High Court of South Africa in November 2010 (Western Cape High Court, 2011). As part of the provincial government’s response, audits have been completed to assess exact needs and possibilities, and centre-based interventions are being piloted, but the full implementation of this positive ruling will take time.

On another front, technological and other innovations in the specialised field of AAC have delivered globally revolutionary possibilities for people with severe communication disabilities (Alant 2005; Beukelman and Mirenda 1998; 2005; Hawking, 2011; Schlosser 2003). However, the translation of these technological developments and other evidence-based AAC strategies into functional communication is still decades away in many underserved and low-income communities, where policy rollouts, financial and human

resources are lacking (ACPF, 2011; McConkey, 2005). The realities of this lack or delay are clearly evident in the population of children with severe or profound disabilities, related to cerebral palsy, and their families in the disadvantaged contexts of the Western Cape (where this study was located), and elsewhere in South Africa.

The National Rehabilitation Policy (Department of Health, 2000) was an attempt to address the provision of assistive devices in South Africa, including augmentative and alternative communication (AAC) devices and related services. In terms of implementation this has been partially replaced by the combination of the earlier, more general INDS and the multi-sectoral, Disability Framework for Local Government 2009–2014 (Department of Provincial and Local Government, n.d.). A positive aspect of this development was the integration of disability and responses to disability as a cross-cutting responsibility of all departments.

Stop Press 25 May 2014: In the most recent development of the roller-coaster history of the position of disabled persons in South Africa, the President has terminated the Department of Women, Children and Persons with Disabilities and relegated disabled persons to the responsibility of the Department of Social Development (The Presidency of the Republic of South Africa, 2014). Disabled peoples' organisations and many others are rallying to protest and counter this move which sets back hard-won developments in positioning disability as a crosscutting issue, across sectors and departments. In President Jacob Zuma's own words: 'The functions related to support for people with disabilities and children, will be transferred to the Department of Social Development' (The Presidency of the Republic of South Africa, 2014). Disability is thus once again conceptualised as an issue to be dealt with by social grants and other 'supports' rather than as a need for equalising opportunities – as per South Africa's earlier bold stances as per support of the United Nations Standard Rules (United Nations, 1993), the ratification of the UNCRPD (United Nations, 2008) and the embracing of the World Health Organisation's Community-based rehabilitation guidelines (WHO, 2010). The mandate of the UNCRPD, with the CBR as a framework for action, is discussed in Chapter 2.

## **1.6 Communication disabilities**

The focus here was on the situation of families with children who cannot use speech and moreover who, due to additional physical, cognitive or sensory impairments and/or socio-



economic, opportunity and other barriers, cannot benefit from some of the wonderful technological and other developments in the field of augmentative and alternative communication (AAC). As mentioned earlier, impairments that limit a person's ability to communicate and to interact with others arguably present additional challenges of function and participation, beyond those of other disabilities.

In reality, communication disabilities are extremely divergent, depending on several factors and at great risk of oversimplifying, three examples may illustrate this diversity. A child who has a sensory impairment and is d/Deaf might not be able to speak, but has the understanding and the capacity for learning a language system (preferably a visual, sign system) and the desire to connect and communicate with others. Children with severe cerebral palsy affecting their physical functioning more than their intellectual capacities may also need an alternative to speech that is not dependent on manual dexterity (maybe a picture communication system) to develop the potential of mastering a language system to communicate everything they want to share, effectively. In contrast, children with an impairment affecting their ability to connect with others (e.g. the autism spectrum disorders) may have the physical and intellectual capacity to speak but will need interventions which focus on the functional use of communication as a means of interaction — whether it takes the form of speech or otherwise.

Most children with severe disabilities and little or no speech have surprising potentials to communicate—even without speech. Examples, to name but a few, include facial expressions; body language; learned eye blink or eye pointing responses to spoken questions and voicing (although not being able to articulate words, the voice can express much through differently intoned sounds). Eye pointing in particular is a very powerful and often used expression, understood and developed more effectively by observant and 'listening' caregivers and communication partners than by those who are not as perceptive. In pointing out these possibilities, I do not wish to diminish or play down the impact and the frustration of communication disabilities, or the affliction of not being able to speak or communicate easily. The effectiveness of any potential forms of expression such as these depends on the people in the child's environment responding and/or providing opportunities for her to use them.

Introduced earlier, **augmentative and alternative communication (AAC)** has generally been defined as

*...an area of clinical practice that attempts to compensate either temporarily or permanently for [...] people with severe speech, language and/or writing impairments (Beukelman & Mirenda, 1998, p. 3).*

The more comprehensive and recent, formal description of AAC, presented by the International Society for Augmentative and Alternative Communication (ISAAC) adds important detail:

*AAC is a set of tools and strategies that an individual uses to solve every day communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech generating devices, etc. Everyone uses multiple forms of communication, based upon the context and our communication partner. Effective communication occurs when the intent and meaning of one individual is understood by another person. The form is less important than the successful understanding of the message. (Burkhart, n.d.)<sup>1</sup>*

The final two sentences are of particular significance to this discussion as they emphasise the *understanding of messages*, thus broadening the focus of the communication disability beyond the impairment of the child with cerebral palsy. By extending the focus to the communication partners – those who need to understand the messages and provide opportunities for messages to be sent and received regardless of the form – communicative function and participation are recognised. The roles of communication partners and the environment per se have gained increasing attention both in research and in intervention approaches (Calculator, 1997; Clarke, Newton, Griffiths, Price, Lysley & Petrides, 2011; Geiger, 2010; Ibragimova, Lillvist, Pless & Granlund, 2007; Kent-Walsh & McNaughton, 2005; Levin, 2006; 2013; Pepper & Weitzman, 2004; Popich, Louw & Eloff, 2007; Sameroff, 2009; 20012).

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<sup>1</sup> Burkhart, L. n.d. 'What is AAC?' <https://www.isaac-online.org/english/what-is-aac/> accessed 2 July 2013

## **1.7 Communication therapy service delivery**

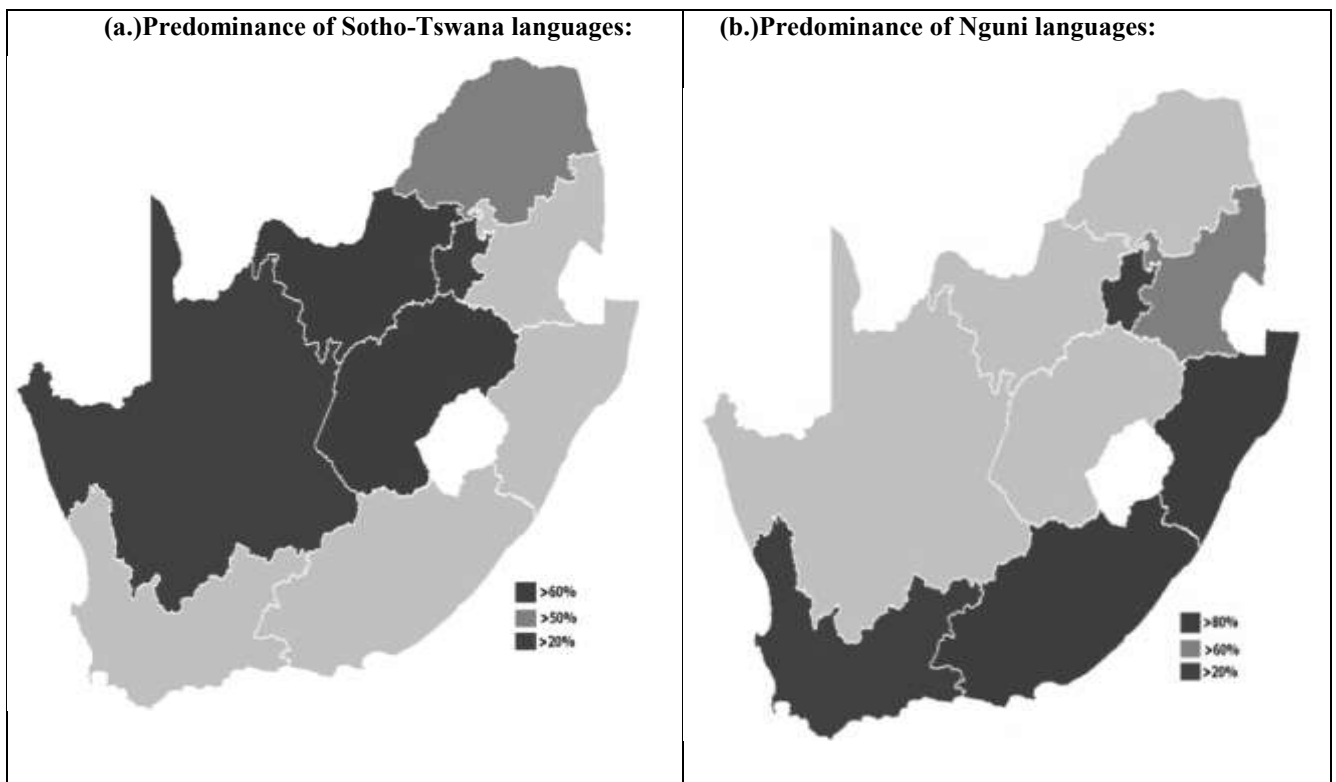
The role and scope of practice of speech-language therapists, speech-language-hearing therapists, speech pathologists, speech therapists, communication therapists etc. varies across international regions. These variations are mirrored by a diversity of professional descriptors - of which the above are only a few. In South Africa, the currently portrayed role of speech therapists, as per the official website of the professional body, the South African Speech Language Hearing Association (SASLHA) is that '*Speech Therapists... are highly trained professionals to assist ... with communication disorders*' (SASLHA, n.d.). This broad descriptor, embracing communication and not just speech and language, is a recent development. Historically, speech therapists in South Africa did not work with those without speech at all (Alant & Lloyd, 2005; Department of Education, 2004). Long-term clinical observations and self-reports by professionals in the field, confirm that 'non-verbal' children were routinely turned away – with the frequently seen note of 'Speech Therapy not indicated' in the client records. Augmentative and alternative communication (AAC) services changed some of these perceptions (Alant & Lloyd, 2005). However, for some time, AAC was considered a specialist field, technologically focused and requiring additional training over and above the primary professional degree required to register as a speech therapist (SASLHA, n.d.). This view meant that specialised AAC services were – and often are still - only available at centralised, tertiary institutions (ACPF, 2011; WHO, 2011).

The broader definition of AAC (Burckhart, n.d.) cited earlier and an expanded focus on function and participation has meant that some communication therapy services have broadened to include preverbal and nonverbal interaction and communication skills (WCFID, 2011).

### **1.7.1 Challenges in communication therapy service delivery**

In the Republic of South Africa, rehabilitation professionals in general and communication therapists in particular, face the daunting task of serving persons of 11 official and several additional, language and cultural backgrounds in this 'rainbow

nation'<sup>1</sup>. Nine of the 11 official languages in South Africa are indigenous languages and comprise isiNdebele, isiXhosa, isiZulu, Sepedi, Sesotho, Setswana, SiSwati, Tshivenda and Xitsonga (PANSALB, 2011; South African Translators' Institute, 2006). Geographical or political borders do not contain languages or define language boundaries and it is important to note that some of these languages are also indigenous in neighbouring countries (Alexander, 1992; Erasmus, 1999). One example is Setswana (or one of its dialects); it is spoken by an estimated 8% of the population within South Africa (PANSALB, 2011; Stats SA, 2012), but it is also the main indigenous and official language of the neighbouring country of Botswana. The nine official, indigenous languages of South Africa can be grouped into the two language families of the broader region; the Sotho-Tswana language group (including Setswana) with densest distributions in the northern and western parts of the region, and the Nguni language group (which includes isiXhosa), with its densest distributions in the southern and eastern parts of the region (Stats SA, 2012a) (Figure 1.1 below).



**Figure 1.1: The geographic distributions of the two main language families in South Africa: (a) Sotho-Tswana languages (including Setswana) are predominant in the northern and western regions, while (b) the Nguni languages (including isiXhosa) are predominant in the southern and eastern regions. (from <http://upload.wikimedia.org/wikipedia/en/0/0c/Sotho-Tswana.gif>)**

<sup>1</sup> Rainbow nation: a term coined by Archbishop Emeritus, Desmond Tutu (South African Nobel Peace Prize winner ) to describe the rich multiracial, multilingual and multicultural fabric of the new democracy after 1994. (<http://www.southafricaataglance.com/south-africa-rainbow-nation.html> )

Furthermore, the pervading results of the earlier, pre-democracy education system in South Africa include the facts that the training of communication therapists still occurs only in English or Afrikaans and that the majority of students accessing this training have been and still are English or Afrikaans mother-tongue speakers (Barratt, Khoza-Shangase & Msimang, 2012; Kathard & Pillay, 2013; Ntshona, 1997; Pascoe & Norman, 2011; Penn, 2000; Pillay, 2003). A small increase in the number of communication rehabilitation professionals from the nine indigenous language groups has been seen since the formal process of democratisation started in 1994, and various transformation attempts are being implemented at the training institutions across South Africa (Barratt, Khoza-Shangase & Msimang, 2012; Kathard & Pillay, 2013; Penn, 2000). However, the reality remains that there are still only a few communication therapists who are equipped or able to offer their services in one of the nine indigenous languages in South Africa. While this shortage is a challenge for *all* health and rehabilitation professionals, the challenge is amplified for communication therapists, because the very nature of their primary focus is *communication*.

Communication intervention theories have followed the evolution from individual child-based approaches grounded in the medical model to ecological, family and community-focused approaches reflecting the social and bio-psycho-social models of more recent years (Ross & Deverell, 2004; Shakespeare, 2006; Thomas, 2004, 2008; WHO, 2001; 2012a). The importance of focusing upon the child in context, as part of an ecology including family, community and broader language and cultural contexts is generally recognised – and specifically reinforced by the focus upon contextual factors in the ICF (WHO, 2001) and the directives for action of the CBR Guidelines (WHO, 2010). However, the enduring need remains for appropriate, effective and sustainable intervention approaches (Alant & Lloyd, 2005; Battle, 1998; 2012; Bronfenbrenner, 1979; Schlosser, 2003).

This need is amplified in the long-neglected arena of severe and profound disabilities which impair the communication, the interpersonal connection and the basic human interaction of children with severe communication disabilities (ACPF, 2011; WCFID, 2012).

The problem for communication therapists, working in diverse under-resourced environments in Southern Africa, includes the general shortage of communication

therapists and the even greater shortages in the under-served, more rural and remote areas (ACPF, 2011; Martin, 2010; Ransom, 2009). This situation calls for the urgent development of intervention strategies that are *appropriate* in a given context; *effective* in using available professional resources for optimal benefit and that are *sustainable*, by establishing affirming collaborations with parents, families and communities to develop and maintain opportunities and support for communicative participation and development that are culturally appropriate.

## **1.8 Problem Statement**

Both a quantifiable as well as a qualitative need are faced by communication therapists and others involved in the rehabilitation service delivery for children with severe communication impairments and their families.

Firstly, there are simply *too few human and other resources* to provide an equitable service for those most affected, that is, children with severe communication disabilities, in terms of developing their pre- and non-verbal potentials for optimal communicative participation. This shortage is a necessary focus for policy makers and planners in the departments of education, social development and health, at provincial and national levels (Kathard & Pillay, 2013).

Secondly, and more to the point for this study, there is a need to ‘stretch’ the limited human resources available by empowering professionals who *are* engaged in the field (or who are preparing to be), with (a) strategies that are relevant across language and culture differences and (b) strategies to work with mothers and families to develop culturally congruent communication strategies. There is therefore a need to affirm communities to explore and utilise the cultural and other contextual resources within, in terms of non-verbal communication practices in which children with severe communication disabilities *can* participate, and in terms of community attitudes and behaviours that are inclusive and provide such children *opportunities* to interact and participate.

So, in keeping with the transformative paradigm (Mertens 2003; 2007; 2009), the focus of the research question was developed on the initiation and request of the grandmother in the preliminary phase of the inquiry, in Botswana. The preliminary case study (see Prologue) highlighted the need to consider the communicative context in which the child

in question – ‘Boiki’ - and other children with severe communication disabilities in rural Botswana were trying to participate. Two issues were explored there, which were:

1. *What is the communicative context?*
2. *How can the communicative context be utilised to optimise communicative participation?*

The focus thus shifted from the child (with the communication disability) to the environment. The resultant collaboratively identified, culturally determined resources, which contributed to the communicative participation of the young boy in Botswana, *Boiki*, as well as other children with similar severe communication disabilities, triggered the research question for this next, main phase of the study:

*In what ways can cultural resources in an isiXhosa language context be optimised to support the communicative participation of children with severe communication disabilities?*

The **focus of this study**, grounded in the transformative paradigm (Mertens, 2003; 2009; 2010) was on culturally determined processes that can optimise the communicative participation of children with extreme communication disabilities in an isiXhosa language and culture context. The fact that the use of culturally determined non-verbal and pragmatic elements of social interaction is often broader than one specific language (described in Chapter 2), prompted the quest to explore the question in another southern African language context – that is, beyond the Setswana language context of the initial, preliminary study.

## **1.9 Purpose, aims and objectives of the study**

The *purpose* of this study was to explore an intervention approach for and with parents of children with severe communication disabilities, which reframes the cultural context as a resource (Garcia-Coll & Magnusen, 2000), especially in environments where communication therapy services are severely limited or not available at all.

There were two main aims and three objectives (or steps to achieve the aims), thus:

*Aim one* was to determine culturally determined non-verbal and pragmatic elements of social interaction in an isiXhosa language context.

The related *objective* was: to describe the presence and use of some culturally determined non-verbal, pragmatic and contextual elements of social interaction (such as those identified in the preceding case study in the Setswana language context), in an isiXhosa language context.

*Aim two* was to explore culturally appreciative strategies to support the communicative participation of children with severe communication impairments in this context.

The two related *objectives* were:

- to describe the usefulness of such culturally determined elements of social interaction in enhancing the communicative participation of children with severe communication impairments in an isiXhosa language context.
- to explore the synergy of the communication interventionists' expertise and the participants' cultural experience for the enhancement of the communicative participation of children with severe communication impairments.

These objectives were pursued through collaborative inquiry with the participants, 44 mothers and other carers of children with severe and profound disabilities, attending an outreach therapy clinic and/or an established mothers' support group of the Western Cape Cerebral Palsy Association.

## **1.10 My positionality<sup>1</sup> as a researcher**

Conventionally, this section of a research report in the qualitative paradigm seems to begin with '*I am ...*' and my quick response would be: I am a white, South African woman of German origin, with Achondroplasia<sup>2</sup> and associated musculoskeletal impairments resulting in a physical disability affecting my mobility and my social status. I am registered as a 'Speech Therapist' with a special interest in severe communication

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<sup>1</sup> I use the term positionality here as used by human geographers and others with implications of reflexivity etc. (Hopkins, 2007).

<sup>2</sup> Achondroplasia is a congenital disorder of bone growth that causes the most common type of 'dwarfism' – (Kromberg & Jenkins 2004; in Coovadia & Wittenberg, pp. 41-54).



disabilities – especially as they pertain to young children in developing contexts. I am also a person who engages in critical thinking and who does not just accept things at face value, and have awoken to the fact that research cannot remain an isolated activity, but has become a way of life. I am also a Christian and some would call me a fundamentalist. That would be the ‘short answer’ to describe myself as the researcher here.

However, it is not as straightforward as that. I find myself in-between: representing both opposites (or being the ‘neither-nor’) along several dimensions. To begin with, as a South African born, German-speaking child of German immigrant parents in South Africa, I am not fully German or South African, yet I am both.

I am a white South African, but by having been one of the last privileged volunteers in a missionary community to learn an African language by complete immersion (Brewster & Brewster, 1976) I find myself straddling cultures and enjoying acceptance in both – and also facing challenging expectations of cultural brokerage. So I am again in between.

I have a physical impairment, resulting in activity limitations but due to a privileged environment with many opportunities and facilitators, many barriers to participation have been removed (e.g. I have an adapted motor car which gives me ‘wings’) and so, in many areas of my life my physical impairment does not mean that I have functional limitations. Yet, I am disabled. An impairment of size means that I am often invisible - as children are. In fact, the positive aspect of this impairment is the acceptance by children as one of their own - a privileged and often humorous but also very sobering situation indeed. Being overlooked in a tall world, or more painfully, not being seen as fully human also means that I am often the ‘invisible observer’ - a position which develops analysis and critique like no other (Ellison, 1952; Lethbridge, 2013).

As a Speech Therapist (or rather, a Communication Therapist considering that I work with persons who do not have speech as a means of communication at all), and as a disabled person myself, I am again both and between: rehabilitation provider and consumer. I have never been at the receiving end of a *communication* intervention, but I have spent my life in the consumer position in terms of physical habilitation and rehabilitation services and this experience has undeniably shaped my analysis, critique and indeed my own clinical practice over the years.

Furthermore, as the frequent participant, no; subject and sometimes even *object* of research in the past and now more recently, as a researcher myself, I am encountering what is probably the most daunting challenge to my positionality yet. Walking the tightrope between objective researcher and participant observer, I have fallen off more often than I can honestly account for here. The position of ‘transformative action researcher’ with the scope for learning from mistakes has made it possible to get back on and continue.

I had no idea that completing the ‘*I am*’ statement of position, for the purpose of this research report, could lead to such detours about personal, cultural and disability identities - or to such bewildering existential questions. I have consequently tried to maintain the balance between keeping the focus of the study and yet addressing issues of positionality as they relate to the study in a formal space in the discussion (Chapter Five).

The advice of experienced qualitative researchers, to keep a reflective journal, became a particularly poignant part of my research journey. I frequently fled to the journal when the research process uncovered and stirred up issues which were beyond the focus and realm of the research, but which were crucial stepping stones on the journey. For the sake of completeness, I have included some of these reflective journal entries in clearly identified, boxed and shaded spaces in the research report.

## **1.11 Summary of the research report**

This research report comprises a prologue (the preliminary case study), and six chapters:

**The Prologue** includes a preliminary, pre-published case study (Geiger, 2010) which became the first, research-question-generating cycle of the main study. It was situated in Botswana, in a Setswana language and cultural setting,

**Chapter 1** (the current chapter) provides an introduction and a definition of key terms as applied in this report. The background to the study, the motivation, the purpose and the aims of the study and my positionality as the researcher, follow. The chapter continues here with a summarised outline of the research report and a brief conclusion.

**Chapter 2** comprises a review of some of the published evidence that was used to inform the current study in terms of *content* and a discussion of the theoretical framework of the *process*.

An interdisciplinary literature review of some of the published evidence that was used to inform the current study in terms of content is presented. The mandate for a human rights based approach, as well as terminology issues are outlined in terms of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), (United Nations, 2006). The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is used as an organising framework to structure this discussion and the CBR guidelines (WHO, 2010) provide a framework for action.

A discussion of the theoretical framework of the process then follows; that is, the development of the research methodology in the transformative paradigm. An appreciative inquiry approach, with iterative cycles of action and reflection to facilitate learning and change in the participants and in me, the researcher, was adopted.

**Chapter 3** comprises a description of the methods as implemented. This chapter is an account of the actual research processes I engaged in, together with two collaborators, two language facilitators and a total of 44 participants, all of whom were parents and/or primary caregivers of children with severe communication disabilities secondary to cerebral palsy. The chapter includes a description of the study settings, the participants and how they were recruited, and this is followed by a description of the data, its nature, how it was generated and how it was analysed. Thereafter, ethical considerations relating to the participants and the research processes; bracketing assumptions, issues of trustworthiness and the methodological limitations of the study are addressed.

**Chapter 4** contains the findings, framed as 12 Action Learning Outcomes (ALOs), as they relate to the aims of the study, including the voices of the participants and also the collaborative interpretation processes, with the resulting two main themes that emerged, in response to the study aims.

**Chapter 5** comprises a discussion of what were considered new contributions, in the form of three theses developed from the themes that emerged from the findings.

**Chapter 6** is the concluding chapter and contains a reflective overview of the research journey. It also contains a summary of the limitations of the study; the implications for clinical practice, for teaching, for research and for policy, as well as some concrete recommendations.

## **1.12 Chapter Conclusion**

An attempt at exploring solutions to the need for responsive service delivery for children with severe communication disabilities and their families in some of the under-resourced, isiXhosa speaking communities in the Western Cape - can at best only be a small drop in the enormous ocean of complex issues that make up this need. Yet, there is a positive expectancy that there *are* generalizable principles and strategies underpinning an approach to service delivery that is more responsive to the real needs of those whom we are trying to serve: the disabled. For example, the exploration and affirmation of resources that are already present in the given context and that are part of the cultural fabric of the given community should be a non-negotiable assumption in any context.

In terms of my positionality and who I am in relation to this study, the uncomfortable challenge was: Do I refrain from engaging in this research *because of all the baggage* that I bring with me and which will bias my interpretations? Or do I engage, *in spite of the baggage*, being acutely aware of probable biases and declaring them as I learn, possibly adding value through insights that this ‘baggage’ may add? I have opted for the latter; engaging with my subject area as a whole person – baggage and all – trying at all times to maintain my focus on the research question:

*In what ways can cultural resources in an isiXhosa language context be optimised to support the communicative participation of children with severe communication disabilities?*

# Chapter Two:

## Literature Review and Theoretical Framework



*“The real-world research problems that scientists address rarely arise within orderly disciplinary categories, and neither do their solutions”*  
- Palmer, 2001; vii.

### 2.1 Introduction to the chapter

This chapter comprises a review of some of the published evidence that was used to inform the current study, in terms of the research focus or content, as well as a description of the theoretical framework of the chosen research process. Following this introductory overview is a declaration of the scope, strategies and boundaries of the literature reviews. Then, the nature and value of the relatively young field of interdisciplinary studies as a discipline in its own right is described – with the field of Disability Studies as a ‘prime’ example. The mandate for a human rights based approach, as well as terminology issues are outlined in terms of the United Nations Convention on the Rights of Persons with



Disabilities (UNCRPD), (United Nations, 2006). The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is introduced as the framework for the subsequent discussion of severe communication disabilities in terms of the levels of impairment, functioning and participation. The discussion then focuses on the communicative participation as a level of functioning, including the consideration of environmental factors with specific reference to geographical and socio-economic factors and issues of language and culture. Disability and rehabilitation constructs, as they apply to communication, are then integrated in a discussion on community-based rehabilitation (CBR), with deference to the CBR Guidelines (WHO, 2010) as a framework for action. The CBR concept with its ‘management cycle’ of situation analysis, planning and design, implementation, monitoring and evaluation with stakeholders (WHO, 2010), guided the conceptualisation of the study process and was a good fit, in terms of the transformative paradigm in which the project was situated, as described in the last part of the chapter. Furthermore, the adoption of an appreciative approach (the anticipation of positives), applying an action research design and implementing qualitative methods, were deemed the best ways to attempt to answer the research question, as concluded at the end of the chapter.

## **2.2 Declaring scope, strategies and boundaries**

The research question prompted consideration of evidence straddling several disciplines, supporting the statement that “the real-world research problems that scientists address, rarely arise within orderly disciplinary categories, and neither do their solutions” (Palmer, 2001: vii.).

The search strategies applied here included a combination of a building block strategy (Schlosser, Wendt, Bhavnani & Nail-Chiwetalu, 2006), a simplified variation of pearl growing (Papaioannou, Sutton, Carroll, Booth & Wong, 2010; Schlosser, Wendt, Bhavnani & Nail-Chiwetalu, 2006) and serendipity, as applied to information seeking<sup>1</sup> (Foster & Ford, 2003). Applying a building block approach, the research question was divided into facets (e.g. culture AND communication; culture AND disability;

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<sup>1</sup> Serendipity in information seeking described here is considered as a separate issue from the serendipitous results/findings described later.

communication AND participation etc.), which were then used for searches. Once relevant articles had been found, a simplified variation of pearl-growing was applied by both searching the reference list of that paper (a ‘pearl’) for relevant earlier references, and also by looking for subsequent citations of that paper, across databases (Papaioannou, Sutton, Carroll, Booth & Wong, 2010; Schlosser, Wendt, Bhavnani & Nail-Chiwetalu, 2006). Serendipity, though often not considered among formal information seeking strategies (Foster & Ford, 2003), played an integral part in finding cross-disciplinary resources, which would have been missed by more exclusive strategies. The resulting tension between depth (thorough immersion in a specific topic, issue or discipline) and breadth (consideration of the broader, interdisciplinary scope of the study) was a constant challenge in this literature review.

### **2.3 Interdisciplinary Studies**

Interdisciplinary studies as a relatively new academic discipline in its own right provided a key, in the principle of *integration* of elements from diverse disciplines for the achievement of a specific goal (Newell, 2011; Newell & Green, 1982; Repko, 2012). Among the diverse conceptualisations of interdisciplinarity, noting the difference between a generalist and the integrationist views was helpful here. The *generalist* view of interdisciplinarity de-emphasises integration and accepts any form of collaboration between two or more disciplines as ‘interdisciplinary’ (Repko, 2012: 29). The other, *integrationist* view, whereby integration of knowledges is the goal of any interdisciplinary endeavour (Repko, 2012: 28-29), was attempted here.

Most fields of study have evolved over time as the product of the integration of knowledges from diverse disciplines and are by no means merely a sum of the contributing parts (Newell, 2011; Repko, 2012). The field of Disability Studies is a case in point and is in itself already an interdisciplinary field (Oliver & Barnes, 1998; Roulstone, Thomas & Watson, 2012; Shakespeare, 1996; 2006; 2014; Zola, 1994). Other fields of relevance, similarly in themselves already interdisciplinary, include Early Childhood Intervention (Shonkoff & Meisels, 2000: xviii); Children’s Geographies (Pyer, Horton, Tucker, Ryan & Kraftl, 2010; Vanderbeck & Dunkley, 2004) and Augmentative and Alternative Communication (Beukelman & Mirenda, 2005; Hourcade, Pilotte, West & Parette, 2004).

On another front, interventionists from diverse disciplines, working in the field of childhood disability and rehabilitation, have for some time increasingly adopted an ecological systems approach (Ahl, Johansson, Granat & Carlberg, 2005; Berry, Biersteker, Dawes, Lake & Smith 2013; Bronfenbrenner, 1979; Darrah, Law, Pollock, Wilson, Russell, Walter & Galupp, 2011; Garbarino & Ganzel, 2000; Sameroff, 2009; 2012; Sameroff & Fiese, 2000; Walker, Wachs, Grantham-McGregor, Black, Nelson & Huffman, 2011). The broadening emphasis of the ecological approach has developed in tandem with the development of health care approaches, of needing to address the whole continuum of care including health promotion, different levels of prevention, curative treatment and rehabilitation (Rossetti, 2001; Ross & Deverell, 2004; Sameroff 2012; Walker et al. 2011). Seeing the child in context and considering the ecology of impacts on a child is at the core of the ‘systems approaches’ (Sameroff, 2009; 2012). So, treating the medical condition or impairment of the child in isolation, has been replaced by strategies addressing the multiple impact factors of the child’s immediate and broader environment. This shift also includes the recognition of the reciprocal relationships between different aspects of the child’s ‘ecosystem’ including physical, psychosocial, geographic, political and economic aspects (McConkey, 2005; Sameroff, 2009; 2012; Walker, Wachs, Meeks Gardner, Lozoff, Wasserman & Carter, 2007; Walker et al., 2011). A systems approach, by its very nature, requires a broader perspective, beyond a single discipline (Ahl, Johansson, Granat & Carlberg, 2005; Berry, Biersteker, Dawes, Lake & Smith, 2013; Rossetti, 2001; Sameroff & Fiese, 2000; Walker et al., 2007). Prompted by evidence supporting such systems approaches, and the clinical experiences recorded in the preliminary case study published earlier (Prologue and Geiger, 2010), I embarked on an interdisciplinary quest – while anchored in Disability Studies - to attempt to answer the research question:

*In what ways can cultural resources in an isiXhosa language context be optimised to support the communicative participation of children with severe communication disabilities?*

## **2.4 Disability - changing concepts in a changing world**

Disability is a complex and multi-faceted issue, and related concepts and theories have undergone extensive changes *over time* – in addition to the wide differences *across contexts* (Devlieger, 2005). The voices from the Eurocentric worlds (notably Western

European and North America) have been the loudest in shaping published disability debates, while the developments in, for example Asia, the Middle East and Africa had been omitted from these debates for many years (Miles, 2008). This situation persists to some extent, but the winds of change are blowing; both in terms of the acknowledgement of the diversity of histories in different regions and the increasing engagement and reciprocal learning across geographical, social, cultural and economic contexts (Albrecht, Devlieger & Van Hove, 2008). ‘Global’ developments are also becoming more inclusive, with strategic endeavours such as the UNCRPD (UN, 2006), the ICF (WHO, 2001), and the CBR Guidelines (WHO, 2010) incorporating the contributions of regional working groups – although many voices still remain unheard. The surge in disability publications in recent years, together with the increased accessibility thereof through electronic media, places a comprehensive overview beyond the scope of this report, and so only a critical summary of issues as they apply to the purpose of this study, follows.

## **2.5 Seeking equal human rights for all - the mandate**

Our human history is fraught with oppression, exploitation and other terrible expressions of discrimination and inequality at various times and along various parameters, including but not limited to race, ethnicity, beliefs, gender and disability. Founded on the principle of equality for all, the United Nations affirms the dignity and worth of *every* human being and prioritises the promotion of social justice (United Nations, 1948). With the Universal Declaration of Human Rights (United Nations, 1948) persons with disabilities were implicitly included in all the subsequent human rights instruments. However, there was still a lot of work to be done in terms of raising awareness and changing attitudes and it was only the International Year of Disabled Persons, 1981, and the subsequent adoption and implementation of the World Programme of Action Concerning Disabled Persons (United Nations, 1982) that hailed the beginning of a new era. The proclamation of the United Nations Decade of Disabled Persons (1983 – 1992) provided a time frame for governments to implement World Programme of Action. In terms of disability history, this would be an era in which disability would be defined in terms of the relationship of persons with disabilities and their environment. Moreover, the need for a mandate to remove societal barriers, which hinder the full participation and enjoyment of equal opportunities by persons with disabilities, became increasingly recognized.

On another front the resistant tendency to overlook children in disability-related programmes and instruments was partially addressed in the special directives in Article 23 of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989). The emphasis on equal rights, dignity and participation and receiving appropriate support to reach their full potential, comprised a new focus in the mandates concerning disabled children – specifically also addressing the needs of children with disabilities in *developing countries* (United Nations, 1989: Article 23. 4).

A major outcome of the Decade of Disabled Persons was the United Nations Standard Rules on the Equalization of Opportunities for Persons (implicitly including children) with Disabilities (United Nations, 1993) – which saw the *actioning* of the shift from the person to the environment. Again, equal human rights, the promotion of dignity and equal opportunities to participate to the fullest potential of each individual person’s potential, were emphasised. It represented a moral and political commitment of governments to act in the quest of realising equal opportunities for all by stipulating preconditions, target areas for equal participation, implementation measures and a monitoring mechanism (United Nations, 1993).

### **2.5.1 The United Nations Convention on the Rights of Persons with Disabilities**

The rights of all disabled people, including those of children, have been restated and given new force through the unprecedented, first legally binding instrument of this scope: the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). The purpose of the UNCRPD is stated as:

*“to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”* (United Nations 2006: Article 1).

This human rights based mandate thus emphasises equality among all and respect for human dignity. Article 1 of the UNCRPD further clarifies who ‘*persons with disabilities*’ are, introducing the focus of effective participation:

*“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers*

*may hinder their full and effective participation in society on an equal basis with others” United Nations 2006 (Article 1).*

Language is powerful, and even just the use of words and terms can perpetuate discrimination and social exclusion - or promote positive values such as inclusion and opportunities for participation. For this reason, the global mandate of the UNCRPD needs to be considered together with the development of disability related concepts and terms that promote the values mandated.

## **2.6 Conceptual models and a comprehensive framework**

The earlier view of disability as a medical issue, affecting the individual, is characteristic of the earlier ‘medical model’ school of thought (Duncan, Ferguson, Geiger & Petersen, 2009; Oliver, 2009; WHO 2001; 2011). As a result, many children with severe disabilities were (and still are) cared for as ‘sick’ children with little or no stimulation, or opportunity to enjoy life stage related activities, or participate in family, peer and community life. Among disability theorists and policy makers, the proverbial pendulum then swung to the other extreme and the ‘social model’ emerged in which people were seen as being disabled by society, rather than by their bodies (Barnes, 2003; Barnes & Mercer, 2001; Oliver, 2009; Shakespeare 2006; Thomas 2004; 2008). Among the positive and lasting contributions of the social model is the recognition of the impact of environmental factors (be they physical, geographic, economic, political, social, cultural - or a combination thereof) upon the complex construct of ‘disability’ (Devlieger, 2005; Miles, 2011).

As with all theoretical models, both the medical and social models have their limitations (Devlieger, 2005; Miles, 2011; Shakespeare 2006; Shakespeare & Watson, 2001; Thomas 2004; 2008). At risk of over-simplifying the complex and critical debates in the field; disability is most certainly not merely a medical issue as there are countless environmental and social factors that can increase or decrease the impact of the disability (WHO, 2011). However, even if all the best possible environmental and social facilitators are in place to enable participation in their communities *à la* social model, persons with disabilities often still experience *disabling* problems directly related to their health condition – for example chronic pain. A helpful synergy then was the bio-psycho-social model (Ross & Deverell, 2004; Shakespeare 2006; 2014; Thomas 2004; WHO 2001;



2002; 2013). [Stop Press, 30 May 2015: the World Health Organisation has now expanded this to the bio-psycho-social-*spiritual* model to embrace the belief aspects, and the impact of these upon a person's impairment, function and participation - WHO, 2014].

While each holds value, the models and theories are context-bound, and critical thinkers have identified the evolution of models of disability as limited to predominantly Eurocentric contexts (Devlieger, 1998; 2005; Gilson & Depoy, 2000; Miles, 2007; 2008; 2011). In response to the understanding that “disabled people are a reflection of their societies” a cultural model has been proposed (Devlieger, 2005; 4). It might be added that the development of cultural models of disability appears diffuse, with considerable focus upon a “culture of disability” or “disability culture” (Barnes & Mercer, 2001; Conyers, 2003; Gilson & Depoy, 2000). Reid-Cunningham has identified that the “lens of culture may be applied to disability in a variety of ways” (2009: 99), and here, an anthropologically grounded approach, which sees that disability needs to be understood in light of existing thought and culture (Devlieger, 2005), is most congruent with the purpose of this study. Devlieger's cultural model or approach comprises three levels of focus; that is at the levels of (1) the individual, (2) the society or community, and in terms of (3) the world views and cultural processes (with conceptual, practical and ethical implications) (Devlieger, 2005; 10). The interrelationship of individual, (biological, physical or psychological) factors; social (or environmental) factors and broader contextual and cultural factors is particularly relevant in communication disabilities; the essence of communication being interaction and relating to others (Howe, 2008; Kent-Walsh & McNaughton, 2005; Kovarsky et al, 2001; Lage, 2005; 2007; Ma, Threats, & Worrall, 2008; McLeod & Threats, 2008; Raghavendra, Bornman, Granlund & Björck-Åkesson, 2007; Simeonsson, Björck-Åkesson, & Lollar, 2012; Threats, 2008).

By taking into account the contextual and social dimensions of disability, the ICF does not consider disability only as a 'medical' or 'biological' dysfunction, but includes – and emphasises - the impact of the environment on the person's functioning. Moreover, the cultural model adds valuable parameters in the otherwise sparsely defined area of ‘personal factors’ for considering communication disabilities.

### 2.6.1 The International Classification of Functioning, Disability and Health (ICF) <sup>1</sup>

According to the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) disability is perceived as the outcome of the interaction between the impairment and contextual impacts. Thus, the term ‘impairment’ refers to the loss or limitation of physical, mental or sensory function on a long-term or permanent basis. The term ‘disability’, on the other hand, describes the condition whereby physical and/or social barriers prevent a person with an impairment from practicing activities and taking part in the daily life of the community on an equal footing with others in that community.

In the context of this study, all the participants were parents or caregivers of children who had been diagnosed as having cerebral palsy (CP), which has been described as

*a disability of motor function due to a non-progressive insult of damage to the developing brain...motor manifestations may include spasticity (hypertonia)... hypotonia (or flaccidity) and/or dystonia and associated manifestations include intellectual disability, sensory impairments (deafness, blindness) and speech and language impairments (Rodda, 2004: 510-511).*

Within the framework of the ICF, cerebral palsy (CP) was the *health condition or disorder*; causing the severe speech and physical impairment (SSPI)<sup>2</sup> which affected the *activity* of communication (causing a communication disability) which in turn affected *participation* – closely and reciprocally influenced by *contextual factors* such as the presence or lack of communication opportunities offered by mothers/primary caregivers and other family members (Figure 2.1). In this study, the focus was upon how contextual factors can be enhanced by cultural variables to support participation – specifically communication related participation.

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<sup>1</sup> Implicitly included is the *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)*, as per the resolution to integrate the ICF-CY into the ICF (WHO 2012a; b).

<sup>2</sup> Severe Speech and Physical Impairment (SSPI) is an umbrella term used to describe a set of impairments that affect the motor and communication abilities of an individual (Beukelman & Mirenda, 1998; 2005). See also Chapter One; 1.3.1.

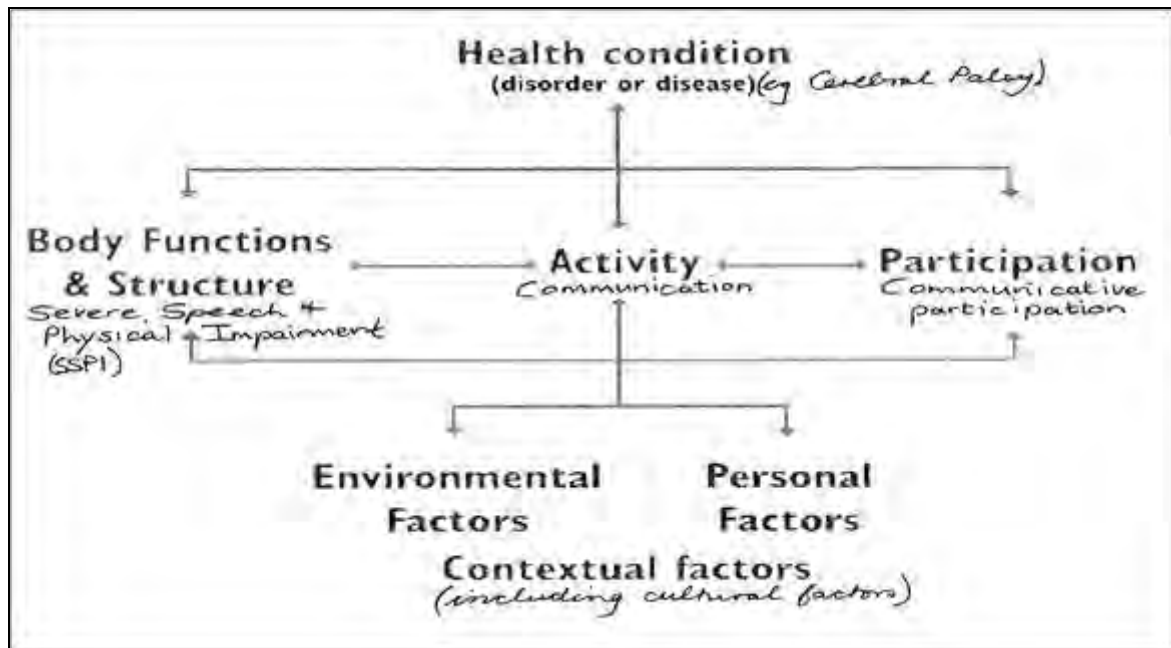


Figure 2.1: Application of the ICF to a communication disability secondary to the diagnosis of cerebral palsy (adapted from WHO, 2001: 18.)

### 2.6.2 The ICF and Communication Disability

The development and implementation of the ICF (WHO, 2001) has had an important effect upon the way that communication disabilities are seen, addressed and researched (Bornman, 2004; Howe, 2008; Lage, 2005; 2007; Ma, Threats, & Worrall, 2008; Pless & Granlund, 2012; Raghavendra, Bornman, Granlund & Björck-Åkesson, 2007; Simeonsson, Björck-Åkesson & Lollar, 2012).

Communication is by definition a collaborative process; that is; it can be described as a process of developing shared meaning between two or more persons – a process driven by the intention to communicate something to others in the environment (Alant, 2005; Owens, 2005). So, it requires a sender and a receiver of the message, which may be spoken, written, (hand)signed, gestured or expressed in any of a myriad of non-verbal ways (Beukelman & Mirenda, 2005; Howe, 2008; Owens, 2005). The broadening of the focus in the ICF from only looking at the person and her impairment and activities, to the impact of the environment and moreover, her participation in her environment, has provided a good match for communication, which is in essence all about interaction and relating to others, as influenced by contextual factors.

The distinction between **speech**, **language** and **communication** is critical in understanding a child's abilities and disabilities (Rogoff, B., Paradise, R., Arauz, R. M., Correa-Chávez, M., & Angelillo, C. 2003. Owens, 2005). Oral *speech* constitutes only one way – next to writing, etc. - of transmitting a formal *language* system such as English, isiXhosa or Setswana. Examples of non-verbal languages developed to facilitate communication where speech is not possible; these include the various sign languages developed by and for those who cannot hear speech and, for people who cannot speak *nor* form complex hand signs: picture communication systems such as PCS (Mayer-Johnson, 1990) and Minspeak (Baker, 2009) – to name but two. *Communication* is the actual interaction, the sending and receiving of messages between two or more people, whether by means of a universally understood facial expression such as a smile; a more specific gesture such as a head shake for 'no'; by a formal *language* system such as South African Sign Language; a picture communication system; or, a spoken language such as English.

## **2.7 Communication and general child development**

Amidst the fluctuating popularities of various developmental theorists, the *social* emphasis of some has earned them renewed attention in recent years. Benjamin Whorff's theory, first presented in 1956, had been glossed over for some time, but was foregrounded once again due to its recognition of the socio-cultural influences on cognitive and language development (Gopnik, 2001; Owens, 2005; Rogoff, Paradise, Arauz, Correa-Chávez & Angelillo, 2003). Vygotsky's *social constructivism* also linked the individual's development directly to environmental inputs, that is; cognitive development, thought, language and reasoning processes, which were understood to develop specifically through social interactions with others (Vygotsky, 1978). Furthermore, Vygotsky's concept of a *zone of proximal development*, describes the cyclical pattern of communication development in which a phase of adult support (e.g. a smile, a gesture or a word etc.) precedes a phase of infant attempt, and later, accomplishment. Thus, the adult or other communication partner's initiations, reactions or interpretations prompt the infant's emerging behaviours into social acts – and it is this phase of emerging communicative behaviour, dependent on social prompting, that has long been described as the *zone of proximal development* (Vygotsky, 1978). This concept was applied to the process of language acquisition in children with severe communication disabilities and the value of scaffolding or providing opportunities to enhance

participation in social interactions, was identified (Letto, Bedrosian and Skarakis-Doyle, 1994; Soto, Huer & Taylor, 2000).

Sameroff's model of transactional development (Sameroff, 2009; 2012; Sameroff & Fiese, 2000) has further strengthened the focus on children in relation to their environment. Of specific relevance is Sameroff's concept of reciprocity – that is; the responsiveness of the mother/parent/caregiver to the child, depends on the responses by the child, which in turn are fuelled by the responses of the mother/parent/caregiver. A disruption in this 'chain reaction' (e.g. if the child has a disability and responds less frequently or more slowly) can be partially countered by supporting the mother/parent/caregiver to nevertheless continue or increase responsiveness, or to empower her to recognise non-standard responses (Sameroff 2009; 2012).

Similar to Disability Studies, the interdisciplinary field of Early Childhood Intervention (ECI) with its strong focus on communication development is another history documented from a strong Eurocentric perspective (Battle, 2012; Levine, Dixon, LeVine, Richman, Leiderman, Keefer & Brazelton, 1996). The development of the field of ECI includes changes in the relative importance ascribed to culture. Briefly, in the early days of the profession, culture was considered a confounding variable, as seen in perceived dilemmas around 'minority' groups and the marginalisation of these in clinical practices, and in research, as retrospectively described by Battle (1998; 2012). Later, the recognition that cultural consideration should underpin the understanding of communication development and disorders, led to important, guiding frameworks such as that by Taylor and Clarke (1994). Models of child development increasingly 'accommodated' the role of culture and socio-cultural factors by accepting the need to understand the child and family in relation to the immediate and larger socio-cultural environment (Battle, 2012; Isaac, 2002; Westby & Ingelbrett, 2012).

Garcia Coll and Magnuson took this further and reasoned that culture should be "reframed as a resource" (2000, p 97), accepting the given that there are supportive elements in every culture which just have to be identified, affirmed and not suppressed by ideas from outside of the context. Such a resource-based worldview contrasts with previously ingrained deficit-based questions and vocabularies, and is in line with Appreciative Inquiry – a positive mode of action research grounded in the belief that the questions we ask shape the way we think (Ludema, Cooperrider & Barrett, 2001). The

positive expectation is thus so much more than a tool of inquiry, but rather an intervention in itself, identifying and strengthening positive thoughts and actions in the given context (Cooperrider & Whitney, 2005; Ludema & Fry, 2008).

## **2.8 The concept of culture**

Culture has been defined by anthropologists and others in many different ways. Definitions vary from narrow, highly distinctive descriptions to broad all-encompassing explanations. However, agreement on the following aspects is common to almost all definitions (Bailey & Peoples 2010: 18):

- culture is learned from others, while growing up in a certain group or society
- culture is shared by the members of that group or society
- culture has a profound influence on the thoughts, feelings and actions of people, that they are invariably “a product of their culture”(Bailey & Peoples, 2010: 18)
- culture largely accounts for the differences between the ways that societies or groups think, feel or act.

In line with this, the term culture is used to describe “shared, socially transmitted knowledge and behaviour” and “cultural identity comprises the cultural tradition that a group of people recognises as their own; the shared customs and beliefs that define how a group sees itself as distinctive” (Bailey & Peoples, 2010: 19). Cultural knowledge (attitudes, beliefs, assumptions about the world and other socially learned information stored in our minds) directly affects patterns of behaviour (how we typically act in various situations and social contexts).

Various constructs have been used to categorise cultures (Coleridge, 2000; Oyserman, Coon, & Kemmelmeier, 2002); and contrasting collectivist versus individualist cultures has been one of the most-used constructs over time (Hofstede, 1994; Oyserman, Coon, & Kemmelmeier, 2002; Triandis, 2001). In collectivist cultures the interests of the group – be it the family or the community – are prioritised over those of the individual person (Barry, 2012). By contrast, the individual in an individualist culture looks out for his or her own interests – even at cost to the group. This individualist culture also has implications for success and failure, and the apportioning of credit or blame either to the group or to the individual (Hofstede, 1994; Triandis, 2001). Further implications include



individual versus group responsibility for ‘burdens’ such as disabilities, where the more traditional cultures - including the southern African cultures being explored here – tend to be more collectivist in this regard (Barry, 2012; Ingstad, 1995; Ingstad & Reynolds Whyte, 2007; Merriweather, 1992; Ross and Deverell, 2004). In the context of disability, this has direct implications when considering for example the group burden versus individual responsibility. This tension will be explored further in the section entitled ‘Disability and Culture’ below (2.9).

Of particular significance here, is the continuum of ‘high context’ to ‘low context’ cultures as described definitively by Edward T. Hall (1976; 1990). In ‘high-context’ cultures, much meaning is implicit in the context, and does not need to be overtly communicated; whereas in ‘low-context’ cultures there are few ‘givens’ in the context and most meaning has to be conveyed through language (Hall, 1990). Traditional African cultures tend to be ‘high context’ where much meaning is conveyed by the context of well-defined, unspoken customs. For example, respect for seniority is expressed predominantly non-verbally in both the Setswana and the isiXhosa language contexts (including body language and less eye-contact), whereas contemporary North European cultures (e.g. German) tend to be ‘low context’ and respect for seniority would need to be conveyed by means of spoken language (e.g. the forms of addressing a person).

Another example relates to the vastly different responses elicited by, for example, a death in these two cultures. In most southern African ‘high-context’ cultures, the customs and roles of the people involved are clearly defined; relatives and neighbours rally around and there are certain tasks that are undertaken in standard ways without needing to be verbalised. By contrast, in a northern European (e.g. German) context individual preferences and less clearly defined customs call for specific choices, decisions and directives to be verbalised in order for arrangements to proceed at all. It must be said that high context-low context differences are not rigid across language or culture groups; changes such as urbanisation have contributed to customs of previously high-context groups becoming less well-defined.

While the above is only a very simplistic description of some of the differences between communities based on culture, the key issue here is that the amount of verbal communication needed in a given context, has implications for the extent to which a person with severe communication impairment can participate ‘normally’. Preliminary

dialogue with isiXhosa and Setswana speaking caregivers of children with severe communication impairments indicates that awareness of the above has implications for the social participation of the child with the disability and also for the child's family. In several cases, the redundancy of a child having to express a choice was mentioned; if choices (of what to play, where to sit, what to do when etc.) are implicit in certain contexts, then the child's 'inability' to verbally express a choice in that context, is not considered 'abnormal'; the other children also do not need to express choices, and this is at least one situation in which the child with the disability is not disadvantaged, as explored in the preliminary case study (see Prologue).

Related to this situation, is the issue of socially or culturally determined attitudes to disabilities as contextual factors which contribute to or hinder inclusion and participation.

## **2.9 Disability and culture**

In southern Africa, there are diverse concepts of and beliefs about disability, with variations determined by geography, language, culture, nature of disability and generational differences. Most attitudes and responses to disability are rooted in beliefs about the *causes* of disabilities, which in southern African indigenous cultures are predominantly ascribed to spiritual or supernatural sources (Chataika, 2013; Devlieger, 1995; 1998; 1999; 2005; Helman, 2007; Ingstad & Reynolds-Whyte, 2007; Merriweather, 1992; Miles, 2007; Ross & Deverell, 2004). In southern Africa, beliefs in the role of the ancestor spirits in responding to the activities of the living are a common denominator, with variations across diverse geographical, ethnographic, language and culture groups (Albrecht, Devlieger & Van Hove, 2008; Chataika, 2013; Devlieger, 1998; Helman, 2007; Ingstad, 1995; Ross & Deverell, 2004; Stone-MacDonald, 2012). Furthermore, the concern about causes is often stronger than the concern for solutions (Devlieger, 1995; 1998).

Reports have been published of both negative responses to disability including ostracism, abuse and even killings, as well as positive stories of non-discriminatory community values and caring inclusion of people with disabilities (Albrecht, Devlieger & Van Hove, 2008; Coleridge, 2000; Devlieger, 1998; 2005; Finkenflügel, 2004; Geiger 2010, 2012a; Ingstad, 1997; Ingstad & Reynolds-Whyte, 2007; Ross & Deverell, 2004; Stone-MacDonald, 2012). The range of cultural attitudes to disability in southern Africa is wide

and it is difficult to make generalisations about attitudes to disability – even in otherwise homogenous communities. Confirming Ingstad’s specific caution against generalisations within Botswana (Ingstad, 1995; 1997; Ingstad & Reynolds-Whyte, 2007), a first-hand observation already documented earlier (Geiger, 2012a: 107) can perhaps illustrate the extreme variations in attitude that are possible within a single community:

*While working at a rehabilitation centre in Botswana, my therapist colleagues and I did follow-up home visits to children with severe disabilities who spent school terms at the centre and returned to their home villages for vacations. During one vacation, two boys with similar forms of cerebral palsy, the same level of physical and intellectual impairment and benefiting from similar stimulation programs at the centre during term time, were visited at their respective homes in a single remote village, representing a single language, tribal and cultural community. At the first home, the son with the disability was happily included in the family circle and participated, albeit passively, in social activities such as receiving visitors — while in the second home, the disabled son was found tied to a tree behind the family hut (Geiger, 2012a:107).<sup>1</sup>*

Interventions grounded within the framework of the ICF and a the bio-psycho-social model of disability, mentioned earlier, focus on the child in context, and include environmental factors such as the issue of attitudes described above and can enhance the child’s inclusion and participation in society (Ross & Deverell, 2004). Optimising awareness of some of the advantages which a ‘high context’ culture provides for a child with severe communication impairment is another aspect of implementing a bio-psycho-social model of intervention.

## **2.10 A paradigm shift – focusing upon participation**

In the ICF (WHO, 2001) participation is described as involvement in life situations corresponding to the individual’s life phase. Life situations vary across the life span of an individual and include (amongst others) the first, predominantly mother-child interactions

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<sup>1</sup> This particular story had a good ending as the local chief became a zealous advocate for the human dignity and inclusion of the second boy and supported his family further.

of early infancy; the early school years with the big eye-openers of learning, literacy, numeracy and social rules; adolescence with its minefield of peer relations and the striving towards independence, followed by the different phases of adulthood and finally, the reduced independence of old age.

Contextual factors that interact with the activity and participation components can be qualified as barriers or facilitators. Therefore, similar impairments of body functions and structures can have different consequences for activities and participation for different individuals, depending on their individual contextual factors. First described by Bronfenbrenner (1979) ecological systems approaches in childhood development, address the child (with a disability) within the context of the family and community with specific attention also to the dynamic interactions between the various environments (Ahl, Johansson, Granat & Carlberg, 2005; Balton, 2009; Bronfenbrenner & Ceci, 1994; Garbarino & Ganzel, 2001; King, Teplicky, King & Rosenbaum, 2004). In view of the focus of this study, particular attention is given to culture as a contextual factor.

## **2.11 Communicative participation**

The construct of *communicative participation* is broad, and not at all well-defined (Levin, 2013). It has been approached from diverse perspectives and across a range of diverse impairments. What becomes clear is that communicative participation is a very different experience for those who, though they have speech and language impairments, can use some oral speech as opposed to those who cannot use oral speech at all (Levin, 2013), and moreover, have additional impairments (physical, sensory and/or intellectual), thus precluding the learning and use of a formal sign language.

For example, in the context of adults with acquired speech and language disorders, Eadie et al (2006), Yorkston et al (2008) and Baylor et al (2010), have been engaged in extended, collaborative work on developing instruments – many of them self-evaluations – to measure communicative participation in these populations. Eadie et al. have defined communicative participation as:

*taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing or nonverbal means of communication (Eadie et al., 2006:309).*

In the context of children with cleft lip and/or palate, and related speech impairments, Havstam and Lohmander (2011) have added that communicative participation can be described in different ways, for example from an individual's own perspective versus observations of how others respond to, or interact with, the child in question. Focusing upon speaking preschool children with language impairment, Crowe, Norris and Hoffman (2004) concentrated upon the training of caregivers to facilitate communicative participation during a specific activity, for example, story-book reading.

As indicated earlier, communicative participation is experienced very differently by persons who cannot use speech at all (Levin, 2013). Beukelman and Mirenda's participation model (1998; 2005) was developed specifically for those who are dependent upon augmentative and/or alternative communication (AAC). While the focus here was on contexts where formal AAC was *not* available, a contextually sensitive approach was needed. Compatible with the principles of the ICF, a communication disability model has been developed for addressing communication disabilities in low-income countries (Hartley, 1997; Hartley & Wirz, 2002).

## **2.12 The Communication Disability Model**

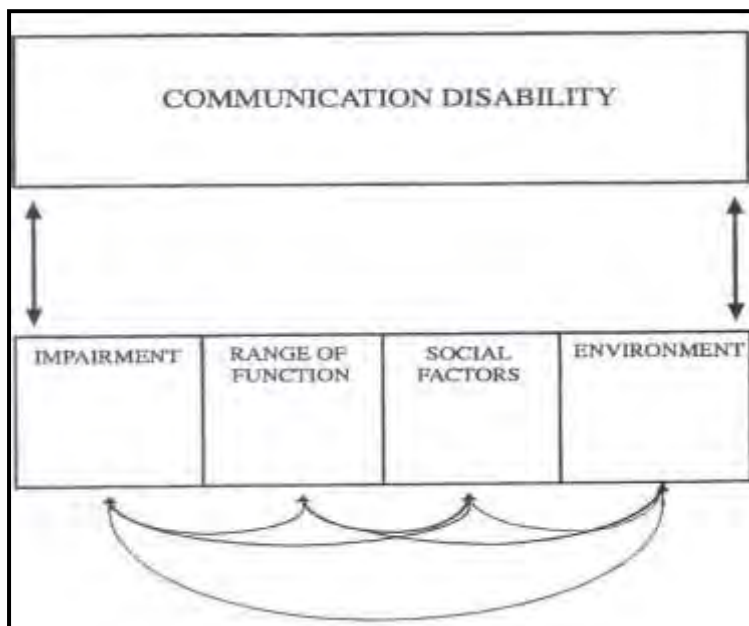
The challenges and failures of attempting to apply services developed in high-income countries in the very different situations of low-income countries, contributed to the motivation for the development of the communication disability model (CDM) (Hartley, 1997; Hartley & Wirz, 2002). Key issues included the high ratios of persons with communication disabilities to available services in low-income countries, and the poor coverage of centrally located, highly specialised services that do not meet the basic needs of these populations (Hartley & Wirz, 2002). Simultaneously, the strong, individual, impairment focus of service approaches developed in high-income countries did not meet the needs of people in low-income countries where the priority of mere survival crowded out such individual impairment-based approaches. The observation implies that interventions can be quite inappropriate - a "cultural invasion" (Paulo Freire, 1970, cited in Hope & Timmel, 1995a: 86). Interventions need to meet real needs, in contextually appropriate ways.

In these contexts of general need and poverty, approaches to human needs acknowledge aspects of human interaction and the ability to communicate as a priority – right up there with the survival needs of food, shelter and safety. Examples include 'participation' and

‘understanding’ in Max Neef’s wheel of fundamental human needs (in Hope and Timmel: 1995a: 86), and ‘love and belonging’ in Maslow’s ladder of human needs (in Hope and Timmel: 1995a: 91). In addition to this shift in conceptualising communication as a basic human need which affects communities, not just individuals, Hartley and Wirz (2002: 1544) it provides compelling information on current, and projections of future prevalence levels of general disability, including communication disability.

The logical next question then was: what kinds of intervention strategies are needed and how are these to be implemented – and by whom? The use of non-specialist personnel and alternative strategies (to the impairment focussed high-income country models) were acknowledged as potential solutions needing further exploration (and contributed to the motivation for my study, presented in this report).

Drawing together the data and analyses of a large-scale, multi-method group of studies in Nigeria and Uganda, Hartley and Wirz (2002:1548) generated the communication disability model (CDM), in which the interrelationship between *all* dimensions was the definitive characteristic – illustrated by the arrows in Figure 2.2.



**Figure 2.2: The communication disability model (CDM) (Hartley & Wirz, 2002: page 1552)**

In short, the CDM describes communication disability as multi-faceted; with contextual factors including social, cultural and environmental constraints being an inseparable part of the communication disability – and communication disability resulting from a breakdown between the individual and their environment. Furthermore, people with

communication disabilities share many common experiences, no matter what the underlying impairment is, and communication partners, not only the child with the impairment, are affected by the breakdown.

### **2.12.1 The Communication Disability Model and the ICF**

The research leading up to and culminating in the communication disability model (CDM) was conducted simultaneously but independently of the consultative development of the precursor to the ICF, which was the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2) (WHO, 1999). Hartley and Wirz (2002) outlined similarities and differences between the CDM and the ICIDH-2. In view of the subsequent development and adoption of the ICF (WHO, 2001) only key issues of mutual agreement between this newer ICF and the CDM will be highlighted as they relate to this study:

- the recognition that communication disability is broader than impairment, and involves social, cultural and environmental elements
- the implication that services need to be directed at all the elements (that is, the impairment, the activity limitations, the context including the social, cultural and environmental factors)
- the interrelatedness of all factors

In terms of the implications of the CDM identified by Hartley and Wirz (2002:1554); (compatible with the ICF) the following recommendations were included from the start in the current study:

- affirming the role of parents, carers and other non-professionals in implementing effective strategies to optimise the communication of children with communication disabilities
- challenging the process of 'labelling' which reinforces the impairment focus and underplays the *other* aspects of communication disabilities
- encouraging mothers/parents/carers in their key roles, fulfilling some of the social and environmental factors impacting on a child's communication disability and promoting active appropriate responsiveness and developmental reciprocity to support the communication development of the child in question.



A paradigm shift is thus recommended from the still dominant specialist-medical perspectives to one in which mothers, parents and carers are the empowered implementers of strategies that make a difference in the communicative participation, the basic interaction and the joy and comfort of interactive belongingness of which many children with severe communication disabilities are deprived.

### **2.13 Community Based Rehabilitation – an agenda for action**

The focus of this study was on culturally determined processes that can optimise the communicative participation of children with extreme communication disabilities in an isiXhosa language and culture context. Moving away from earlier impairment-focused rehabilitation approaches, the ICF (WHO, 2001) has provided a framework to consider and address contextual factors which affect children's participation, and more specifically communicative participation. These contextual factors include environmental factors (family and community factors, etc.) and personal factors, and an ecological approach looking at the relationships between factors both to understand a child's disability better and to facilitate positive change. The nature of communication as an interactive, relational activity blurs the lines between activity and participation and necessitates the consideration of rehabilitation approaches with an emphasis on participation. By definition, Community Based Rehabilitation (CBR) addresses the social inclusion and participation of people with disabilities (Finkenflügel, 2004; Hartley, Finkenflügel, Kuipers & Thomas, 2009; Miles, 1994; Mporu, 1995; SASLHA, 2011; Sharma, 2006; WHO, 2010).

CBR is not a separate or distinct intervention, and so it is difficult to describe – let alone quantify – its effectiveness (Hartley et al., 2005). However, summaries of published research indicate positive social outcomes such as greater communication skills for people with disabilities and enhanced social inclusion (Finkenflügel, 2004; Hartley et al. 2005). Stories of and by disabled people themselves, mothers and other caregivers of disabled children and workers in the field give further examples of positive outcomes, often most clearly defined in terms of social inclusion and participation (Coleridge & Hartley, 2010; Hartley et al. 2009; McKenzie & Müller, 2006; Mporu, 1995).

Community Based Rehabilitation (CBR) was first coined as an approach to provide rehabilitation services to people with disabilities in developing countries in the 1970s

(Finkenflügel, 2004; Miles 1994), and adopted as a strategy by the World Health Organisation at Alma Ater in 1978 (Coleridge & Hartley, 2010). In the past, health and rehabilitation comprised the main focus – and the social needs of people with disabilities were often overlooked. However, the CBR Guidelines (WHO, 2010), present CBR as a broader strategy for social inclusion and participation, which can contribute to the implementation of the Convention on the Rights of Persons with Disabilities (UN, 2006).

CBR comprises a different way of organising rehabilitation-focussed activities in communities; moreover, it distinguishes itself in the close involvement of caregivers – to the point of them being made *responsible* for the rehabilitation processes of their children (Finkenflügel, 2004). A shift of power from outside to inside the community is key (Rule, Lorenzo & Wolmarans, 2006).

The broader, more holistic CBR strategy covers the five key components of health, education, livelihood, social and empowerment components, each of which comprise five elements (WHO; 2010). The CBR matrix, capturing an overview of all of these, allows for the selection and focus upon elements either most needed, or beginning where there is a potential or resource, which can be developed by collaborating with the stakeholders in the community. Miles (1994) used the imagery of a bag of ideas which people use in different ways because of the very diverse situations in which people with disabilities and their families and others around the world live. Furthermore, it is recognised to be a process that is often comprised of many, many small and sometimes seemingly disconnected steps – but here the CBR Guidelines and especially the matrix is helpful: one can start at any point of clear need and/or where there is a resource or service in place upon which a next step can be built.

The CBR concept with its ‘management cycle’ of situation analysis, planning and design, implementation and monitoring and evaluation with stakeholders (WHO, 2010), guided the conceptualisation and theoretical framework of this transformative action study.

## **2.14 Theoretical framework**

The past three decades have seen enormous shifts in the way that research is done, and moreover, the beliefs and theoretical frameworks underpinning research paradigms. Questions of power (researcher versus participants and other stakeholders) have been at the heart of these developments (Mertens, 2007; 2010). Lincoln and Guba (1985) were

pioneers in the revolutionary break-away from positivist approaches (with the locus of power and control firmly lodged with the researcher) advocating the need and blazing trails in naturalistic inquiry (with more attempts at understanding and empowering those researched, not only as participants but as decision-makers in the research process).

#### **2.14.1 The transformative paradigm**

The implicit goal of research positioned in the transformative paradigm is the enhancement of social justice and the promotion of human rights (Mertens, 2003; 2007; 2009; 2010). This goal is closely intertwined with one's beliefs about the nature of ethics (axiology), reality (ontology) and knowledge (epistemology), as well as one's approach to methodology (Mertens, 2010). In researching across cultures and belief systems, researchers and participants may be grounded in very different meanings, realities, ways of knowing and ways of doing (Clark, Hunt, Jules & Good, 2011; Masoga, 2005; Mihesuah, 2004; Mji, 2013; Owusu-Ansah & Mji 2013; Shahjahan, 2006). Moreover, these differences have been recognised as causing power differences between researchers and participants (Clark, Hunt, Jules & Good, 2011; Mihesuah, 2004). Such power differences have been and still are evident globally and perhaps more so in the global south (McKenzie, Mji & Gcaza, 2014; Swartz, 2014), but particularly here in South Africa where the discriminatory and oppressive impacts of *Apartheid* permeated all aspects of life including the ways in which research was conceptualized, planned and carried out.

#### **2.14.2 An appreciative approach**

Davis's description of *Appreciative Transformation Learning in Action* (2005) provided guidance for the application of the chosen framework. Accordingly, the study was steeped in the sometimes controversial approach of appreciative inquiry with positive expectations and pre-suppositions (Cooperrider & Whitney, 2005; Davis, 2005; Grant & Humphreys, 2006; Ludema, Cooperrider & Barrett, 2001). This meant that challenges of positive bias needed to be systematically addressed (Grant & Humphreys, 2006), but the choice of this approach was solicitous in the bigger picture of 'deficit' expectations still dominating research in developing contexts, and especially here in South Africa.

Cooperrider and Srivastva (1987) first formulated the mode of Appreciative Inquiry which

*...distinguishes itself from critical modes of research by its deliberately affirmative assumptions about people, organisations and relationships. It focuses on asking the unconditional positive question to ignite transformative dialogue within human systems. More than a technique, appreciative inquiry is a way of...life; an intentional posture of continuous discovery, search and inquiry into conceptions of life, joy, beauty, excellence, innovation and freedom. - (Ludema, Cooperrider and Barrett, 2001; 191)*

Appreciative inquiry as a worldview within action research, is the best fit in terms of situating this study within a framework – in a context where democratisation policies have theoretically emancipated previously depreciated languages and cultures such as isiXhosa and Setswana, this framework describes an empowering way forward 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 and Barrett, 2001; 198)*

The approach of Appreciative Inquiry emboldened me to proceed with the research question in hand, and to anticipate cultural elements which could be explored cooperatively with isiXhosa mother-tongue expert-participants, as a fundamental resource in developing appropriate and sustainable communication interventions for children with severe communication disabilities.

## **2.15 Reflective chapter conclusion**

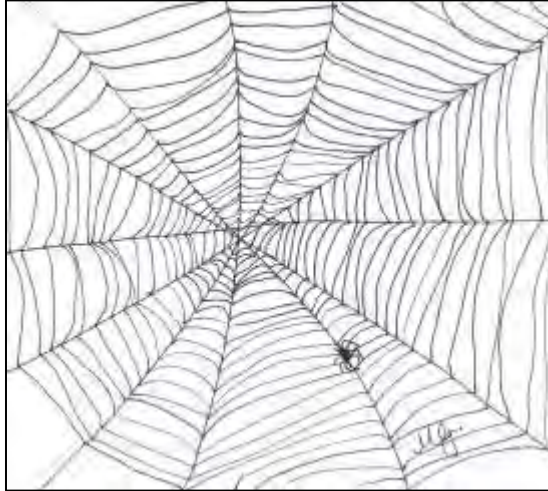
In this chapter I have endeavoured to apply a selective literature review to the research question:

***In what ways can cultural resources in an isiXhosa language context be optimised to support the communicative participation of children with severe communication disabilities?***

Moving away from earlier impairment-focused rehabilitation approaches, the ICF (WHO, 2001) has provided a conceptual framework to consider and address contextual issues which affect children's participation, and more specifically communicative participation. With the CBR guidelines as a framework for action, the communication disability model, congruent with the ICF (Hartley & Wirz, 2002) provided a functional way forward. Key elements recognised as indispensable to this inquiry were the need for action learning and collaboration. In terms of the theoretical framework relevant to the process of this study, I have endeavoured to build the case for the choices made. The study was grounded in the transformative paradigm (Mertens, 2003; 2009) which embraces some participative strategies and, moreover, learning and change on the part of the researcher (myself), the participants and other stakeholders. Furthermore, an appreciative approach, with its positive anticipation of findings was adopted, and how this was applied in an action research design with qualitative methods, is described in the next chapter (Chapter 3: Methods).

# Chapter Three:

## Methods - how the data was produced<sup>1</sup>



*Spider webs are threads of silk. Spiders can make as many as seven different kinds of silk, all with different purposes—from making egg cases to hiding. They are mainly used to catch prey... The slightest vibration of a web alerts a spider to the possibility of prey, which then rushes toward the movement*  
(- Kids' National Geographic<sup>2</sup>)

### 3.1 Introductory overview

On some levels, the planning and design of data collection and analysis strategies resemble those of a spider; from the multiple purposes of the data collection strategies (the web) to the use of everything that ‘happens’ to fly into the prepared web, including the specifically anticipated prey, the dew drops and some totally unexpected catches.

In the previous chapter (Chapter 2), I outlined the theoretical framework relevant to the process of this study, and endeavoured to build the case for the choices made. The study was

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<sup>1</sup>The concept of ‘producing data’ is borrowed from Lorenzo, 2005. Furthermore, the word ‘data’, though a plural of ‘datum’ in its original Latin form, is treated as a mass noun here (like ‘information’) and thus takes the singular verb (Oxford English Dictionary).

<sup>2</sup>Accessed from <http://kids.nationalgeographic.com/kids/photos/gallery/spider-webs/> on 4 October 2014.

grounded in the transformative paradigm (Mertens, 2003; 2009) which embraces some participative strategies and moreover, learning and change on the part of the researcher (myself), the participants and other stakeholders. While including participative strategies in which we planned and implemented certain cycles of the study, based on collaborative decisions, I remained the researcher – the spider as it were.

This chapter comprises a description of the methods *as applied*; that is, what was done in this study, with whom, how and why. It describes a transformative action research journey, during which rich and often unexpected data sources and perspectives have presented themselves. This introduction is followed by an overview of the methodology and the research design chosen to reach the aims and objectives (introduced in Chapter 1). A description of the study setting is presented, followed by information pertaining to the participants, including sampling and recruitment strategies and a description of the actual participants. An account of issues related to the data comes next; that is, the nature of the data, how it was collected and analysed; and is followed by a description of the actual research journey in five phases. Strategies that were applied to safeguard the trustworthiness and authenticity of this study are then presented, followed by bracketing assumptions. A discussion of ethical principles, implemented to protect the participants and to ensure the integrity of the study follows, and methodological and other limitations of this study are then discussed. An entry from my reflective journal concludes the chapter.

### **3.2 Methodology – briefly revisited**

The contribution of multiple perspectives, data sources and methods acknowledged in the transformative paradigm (Mertens, 2003; 2009; 2010) was a good fit with the aims and objectives of the study, which included an action agenda for change both in the participants and in the researcher (Mackenzie & Knipe, 2006; Mertens, 2010). Here, this agenda implied iterative cycles of collaborative data collection, analysis and interpretation, implemented with the participants, who were all isiXhosa speaking parents of children with severe communication disabilities in the Western Cape, South Africa. The use of several qualitative methods, with the underlying aim of action and change, complemented the transformative



paradigm overarching this study (Cresswell 2009; Cresswell & Tashakkori, 2007; Denzin, 2012; Mertens, 2009; Mertens, Bledso, Sullivan & Wilson, 2010).

The focus of the study (i.e. some of the processes involved in optimising the communicative participation of children with severe communication disorders in an isiXhosa language and culture context), was framed in the two main aims of the study, which were introduced in Chapter 1, and are reviewed in Table 3.1 below, together with the related objectives.

Table 3.1: **Overview of the aims and objectives of the study.**

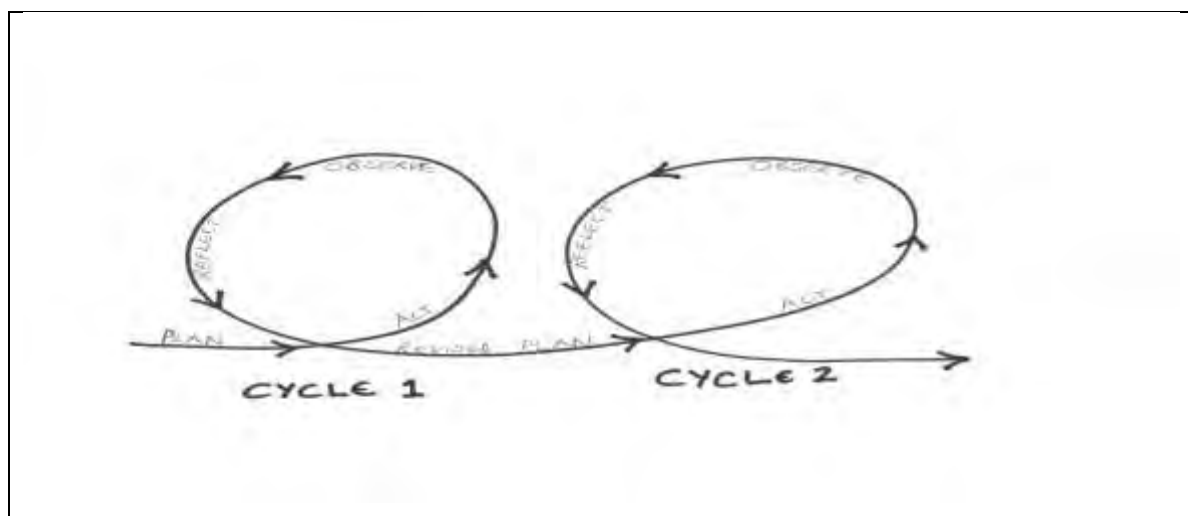
<b>Aims of the Study</b> (the goals or desired outcomes)	<b>Objectives</b> (the steps to achieve the aims)
1.) to identify culturally determined non-verbal, pragmatic and contextual elements of social interaction in an <b>isiXhosa</b> language context.	- to describe the presence and use of some culturally determined non-verbal, pragmatic and contextual elements of social interaction (such as those identified in the preceding case study, in the Setswana language context), in an <b>isiXhosa</b> language context.
2.) to explore culturally appreciative strategies to support the communicative participation of children with severe communication impairments in this context.	-to describe the usefulness of such culturally determined elements of social interaction in enhancing the communicative participation of children with severe communication impairments in an isiXhosa language context.  - to explore the synergy of the communication interventionists' expertise and the participants' cultural experience for the enhancement of the communicative participation of children with severe communication impairments.

The *unit of analysis* (or that which was placed and studied under the proverbial microscope) comprised collaboratively identified *culturally or contextually determined processes* which supported opportunities for social interaction by the participant-parents' children.

### 3.3 Research design

The theoretical positioning of this study within the transformative paradigm (with the goal of facilitating learning and change in both the participants and the researcher) was the primary determinant in the choice of research design (Mertens, 2003; 2009). Cresswell (2009) adds that the actual research question, the researcher's personal experiences and positionality and

the intended audience, are further determinants of the research design and this combination rings true of the choices made here. It is the combination of the above factors that settled the choice of a *transformative action research design*. Coined by Toomey (1997) in the field of educational action research, *transformative action research*, with its iterative cycles of qualitative data production; collaborative analysis, interpretation and action (based on changed thinking), was felt to be the best description for the design needed and applied here (Figure 3.1 below).



**Figure 3.1: A diagrammatic presentation of the design of this study, comprising iterative cycles of planning, action, observation and reflection, revised planning and renewed action (adapted from Kemmis & McTaggart, 2003; 382).**

The transformative action research design of this study, using multiple qualitative methods to produce and analyse the data, was informed primarily by the work of Hope and Timmel (1995a; 1995b; 1995c; 1999), with lessons for data production added from Hartley, Murira, Mwangoma & Carter (2005) and Lorenzo (2005). Hope and Timmel's long-term work focused upon community development *per se* and Lorenzo's study focused upon the learning and change in women with disabilities themselves, while Hartley et al. (2005) worked with mothers of children with communication disabilities in situations similar to those in this study. Even though they were from very varied geographical and social contexts, the fact that all three cited studies were also based in Africa provided valuable parallels.

### 3.3.1. Serendipity

*Reflective Journal: August 2012*

*While following up on [my supervisor] Sinegugu's cues about describing serendipitous findings, and reading about it, I wonder if serendipity is not a superfluous concept in action research.*

*Surely action research with its iterative cycles of action, reflection, planning and changed action on the basis of the preceding new findings is implicitly seeking the unexpected?*

*Yet, there were those co-incidental observations here that I was not looking for in keeping with the objectives of the study – which I did not seek with strategies but which popped up in the existing conditions – where I (and/or others) only realised a relevance afterwards and which did contribute to achieving the bigger aim or goal of the study ... with the benefit of hindsight.*

*I therefore choose to include serendipitous findings, perhaps redundantly, in an action research paradigm.*

Defined as “the occurrence and development of events by chance in a happy or beneficial way” (OED, 2014<sup>1</sup>), and has most frequently been used to describe the accidental discoveries in science (Roberts, 1989). Serendipity may be considered a redundant concept in action research with its core principle of openness to iterative developments and unexpected findings. According to Stoskopf (2005:332), “serendipitous discoveries are of significant value in the advancement of science and often present the foundation for important intellectual leaps of understanding”. Serendipitous findings did indeed prompt some leaps of understanding on my part, where they did not emerge as a result of the objectives or strategies implemented but were rather observed coincidentally – and contributed to the fulfilling of the broader aims of the research (Stoskopf 2005). From the field of information seeking, Foster and Ford (2003: 321-322) identified the ‘connection building’ role of

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<sup>1</sup> <http://www.oxforddictionaries.com/definition/english/serendipity>

serendipity. Here, this could be applied to the connections between co-incidentally observed situations, backgrounds or conditions, findings strategically sought as part of the transformative action research process and the aims of the study. Moreover, from the field of nursing, MacGuire (2006) adds that serendipity occurs not because something new has been observed but because some new relevance has been attributed to the observation.

In writing up this report, the deciding feature distinguishing serendipitous findings from those produced by fulfilling the objectives of this action research study, was *“if the relevance of an observation was only realised subsequently”* (MacGuire, 2006: 69).

### **3.4 The settings of the study**

Following the lessons learnt in Botswana as described in the Prologue, I implemented the main study in the Western Cape, South Africa. Here, the primary study site was the outdoor waiting area of the monthly outreach clinic of the Western Cape Cerebral Palsy Association (WCCPA) in a low-income area on the northern outskirts of Cape Town. Parents who brought their children with cerebral palsy to the outreach clinic sat and waited here before and between the physiotherapy, speech and/or feeding therapy sessions they attended. A second site, negotiated collaboratively with the participants later in the study, was a pre-existing, well-established parent support group which met once a month at the WCCPA head office or central clinic. Both of these pre-existing group settings had implications for recruitment (described in 3.6.4 below).

#### **3.4.1 The primary study site – Masincedane<sup>1</sup>**

The monthly outreach clinic that became the primary study site had been started by the WCCPA to provide an opportunity for multi-disciplinary therapy for children with cerebral palsy from the severely under-resourced and/or informal settlements in the area. It was a collaborative venture between (a) the WCCPA, who staffed it by providing the therapists; (b) the local Lions Club, a funding and volunteer organisation who donated and maintained a

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<sup>1</sup> Masincedane (IsiXhosa for ‘let us help one another’) was the name that the waiting parents at the monthly outreach clinic chose for what became a monthly discussion and support group.

refurbished shipping container to accommodate the monthly clinic, and (c) the South African Police Services who provided a space outside the local police station for the refurbished shipping container to be situated (Figure 3.2).



**Figure 3.2: The refurbished shipping container, which housed the WCCPA outreach clinic and which was parked outside the local police station.**

Parents and their children with cerebral palsy, who had been assessed at the central WCCPA clinic, and who lived on the far northern outskirts of Cape Town, were offered the opportunity to attend multi-disciplinary therapy sessions at this monthly outreach clinic as financial and transport constraints made it impossible for them to attend regular sessions at the central clinic. Two physiotherapists and one speech therapist (all from the central WCCPA clinic) attended to the fluctuating number of children who were brought by their parents.

At the site, basic furniture was stored inside the lock-up shipping container. When the therapy team arrived on the second Wednesday of each month, they set up the site, which included two or three therapy spaces with physiotherapy mats inside the structure (see Figure 3.3), a small table at the door for writing needs (e.g. appointments, file notes, referrals etc.) and a waiting area with chairs outside, in the shade of some trees.



**Figure 3.3: The outreach clinic in progress: Speech/feeding therapy and physiotherapy sessions with mothers and their children inside the refurbished shipping container.**

The outdoor waiting area, at the entrance to the refurbished container, in which the monthly outreach clinic took place, became the primary study site (see Figure 3.4).



**Figure 3.4: Parents waiting with their children, outside the WCCPA outreach clinic.**

A strategic factor in the nature and dynamics of the pre-existing waiting set-up was Pam<sup>1</sup>, an isiXhosa speaking woman, who regularly accompanied the therapists to this outreach clinic and played an indispensable role as translator, interpreter and cultural broker for the therapy team. Pam welcomed parent/child dyads as they arrived, noted their names in order of arrival, and also monitored whose turn was next, and with which therapist. She was often called into the container structure to translate or interpret between one or other of the therapists and the parents of the children; was responsible for keeping attendance records and offered the waiting parents and children juice or tea (depending on the season). Her involvement in this capacity meant that the parents trusted her, often asking her to explain things that they had not understood. Pam's relationship with the parents, her interest in and understanding of the positive potential of the study and her desire for the parents to benefit,

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<sup>1</sup> Her real name; used with permission. Pam's response to the concept of anonymity and a possible pseudonym are discussed in section 3.10.1 *Researching ethically*.



led to negotiations to make her a formal research collaborator in the study (please see 3.5 Facilitators and Collaborators).

The observed, pre-existing situation at this site, was that the majority of the client population was isiXhosa speaking, and tended to socialise while waiting their turns, re-joining the waiting group outside between sessions (if they had to wait for another session). Some would even re-join the socialising group after they had completed all their own therapy sessions and would only leave when the therapists packed up and closed up the shipping container at the end of the clinic morning. An observation not considered noteworthy at the time, was that the very small minority of Afrikaans-speaking clients that attended the outreach clinic (only two in total, attending several times irregularly, over the two years), arrived early, thus getting the first or second treatment opportunity with the therapists inside the clinic, and left promptly after their sessions. Therefore, they did not spend time waiting and chatting in the group with the isiXhosa speaking parents – or with each other. This matter is revisited as a serendipitous finding in the next chapter (4.6).

The outdoor location of the clinic meant that over and above all the other challenges faced by parents when bringing in their children, the weather played a key role in determining the number of attendees. Over the course of the study period, the average number of attendees on an outreach clinic day was six, with the highest number attending the clinic on any one day being 14 and the lowest number, one. On two occasions, when the outreach clinic proceeded in spite of stormy winter weather, parents waited in the benched waiting area inside the police station, between other members of the public waiting for diverse police services (e.g. laying charges, getting information, having documents certified etc.) The action reflection group process for this study could not take place on these days – for reasons expanded upon in the section on serendipitous findings (4.6) in the next chapter.

### 3.4.2 The second study site - *Iqhaya*<sup>1</sup>

The second study site, identified and explored collaboratively with some of the participants from the primary site, was a pre-existing, self-help support group for isiXhosa-speaking mothers that had been meeting once a month for several years, in one of the venues at the WCCPA offices. This group was facilitated by an isiXhosa-speaking social worker employed by the WCCPA, with a small committee elected from and by the mothers to choose topics and invite speakers – all with a self-help theme and purpose. The group was aptly named *Iqhaya*, meaning ‘self-worth’, and comprised only mothers of children with severe cerebral palsy and associated severe disabilities. As this was intended to be a monthly opportunity of respite, reflection and nurturing for the mothers, the women all made alternative caring arrangements for their children for this time and came without them. This was in contrast to the first study site where parents participated in the action-reflection groups while awaiting their clinic turns *with* their children. Differences between the two settings were noted (see Table 3.2) and were considered to add richness to the data.

**Table 3.2: Distinctive features of the two study sites, both involving pre-existing gatherings of parents of children with cerebral palsy.**

Study Site 1 – at the outreach clinic	Study Site 2 – at the WCCPA main/central clinic
Mothers, fathers and/or caregivers (who brought their children with CP) waiting for therapy services. Later named themselves the <b><i>Masinedane</i></b> group	Pre-existing <b><i>Iqhaya</i></b> mothers’ support group (i.e. Mothers of children with CP)
Outdoor waiting area at monthly Outreach CP Clinic	Indoor meeting venue at WCCPA main clinic
With children present	Without children present
Clinic/therapy focus	Self-help purpose and themes
New and emerging friendships, ad hoc support for one another.	Established relationships, social worker facilitation and support

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<sup>1</sup> *Iqhaya*: isiXhosa for ‘self-worth’ – the name of the support group for mothers meeting at the WCCPA offices.

### 3.5 Facilitators and collaborators

Four isiXhosa-speaking women assisted me in implementing the study process. Two had been formally recruited as language facilitators at the outset and two joined voluntarily as collaborators during the action research process and became indispensable to the study.

**3.5.1 Two language facilitators**, who were recruited before the first data-collection session, were under-graduate students in the BSc (Speech Pathology and Therapy) programme at the University of Cape Town. Selection criteria included isiXhosa as their first language and a good command of spoken and written English (as evidenced in their academic work). Furthermore, their ability to balance culturally appropriate reticence when speaking to, and asking questions of isiXhosa-speaking women older (and more traditional) than themselves, was carefully observed during visits to outreach clinics as part of their clinical training. Two facilitators, Essie and Bee<sup>1</sup>, were recruited in this way, to ensure that at least one of them could be available at each data collection session. Introductory training included a briefing on:

- the aims and objectives of the study
- ethical issues including confidentiality, participant autonomy and non-judgemental responsiveness to needs etc.
- the differences between literal translation and interpretation (SATI, 2012)
- cultural brokering (Jezewski & Sotnik, 2001; Penn, Watermeyer, Koole, De Picciotto, Ogilvy & Fisch, 2010)
- problem-based scenarios (e.g. “How would you approach/deal with...?”)

Further, session-by-session briefing took place before and after each session. These two language facilitators (Essie and Bee) assisted with translation and interpretation during the first five action-reflection sessions with the Masincedane participants’ group. Essie also participated in the first feedback meeting with the therapists.

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<sup>1</sup> Pseudonyms/aliases as preferred by the facilitators.

**3.5.2 Two collaborators** became involved through the transformative action research process and each of them became an integral and indispensable part of the study in the following, respective ways.

At the outreach clinic study site, **Pam** (introduced earlier in her role as the already-present outreach clinic assistant, interpreter, translator and liaison person between the therapists and the attending parents) was identified as an important gate-keeper. I informed her about the study details and she contributed much in terms of explaining the logistics and challenges of the outreach clinic and voicing her support that the study aims and objectives were relevant and that this group of parents would be able to relate to the examples to be discussed in the introductory session and would be able to contribute much. The role of the language facilitators was also explained and they were introduced. Due to her pre-existing relationship with the participants, she was an important gatekeeper in the process of introducing me, the researcher, and the language facilitators, and in explaining the goals and planned method to the waiting parents. She also relayed questions and comments from the parents to the researcher and vice versa during the preparation phase of the study. During this preparation phase (which included two introductory sessions), it became clear that she had a clear understanding of the study aims and that she was passionate in her support for the study. In light of her on-going involvement with the waiting parents and her desire to be more involved in the discussions (to which she made valuable contributions), I invited her to formally assist in the research study as a translator, interpreter and cultural broker (Jezewski & Sotnik, 2001; Penn, Watermeyer, Koole, De Picciotto, Ogilvy & Fisch, 2010). Due to the nature of this action research study proceeding simultaneously with the ongoing clinical outreach service provided by the therapists, Pam and I negotiated with the therapists that her priority would still be her role as clinic assistant. So, when needed for translation etc. by any of the therapists busy with individual parent-child dyads inside the clinic, she would leave the action-reflection group and return again when no longer needed inside the clinic.

**Nolwandle**<sup>1</sup>, an isiXhosa speaking social worker with the WCCPA, sometimes visited the outreach clinic when she had to follow up on specific clients and assist with the completion of forms for grants, assistive devices and referrals to other specialist services. During one such visit, she joined the action-reflection session with the participating parents and contributed richly in terms of eliciting additional information from the participants. She and I met the following day for a reflective dialogue and she volunteered to join the group on a regular basis. Due to Nolwandle's position and prior relationship of trust with the participants, they easily accepted her as the main facilitator of the group and I could step back into the role of participant observer (Carter, Lubinsky & Dumholdt, 2011). Regular reflective dialogues with Nolwandle followed. She also facilitated introducing three of the participants and me to a mothers' support and empowerment group which she had established several years earlier. This introduction, and subsequent establishment of the second study site (facilitated by Nolwandle), followed the participants' collaborative interest in exploring the research questions with more participants elsewhere.

## **3.6 Participant information**

### **3.6.1 The study population**

The study population comprised isiXhosa-speaking mothers, fathers and primary carers of children (under the age of 18) with severe communication disorders associated with – but not limited to – a diagnosis of cerebral palsy. More specifically, the study population comprised isiXhosa-speaking parents and primary caregivers (of children with cerebral palsy and resultant severe disabilities) who attended (a) a monthly outreach clinic on the northern outskirts of Cape Town and/or (b) a pre-existing parent support group, both run and overseen by the Western Cape Cerebral Palsy Association (WCCPA).

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<sup>1</sup> Her real name as preferred by her.

### 3.6.2 Sampling strategies

In terms of sampling logic, participants were included in this qualitative study on the basis of their relevance to the research question and availability, rather than on the basis of their representativeness of a wider population (Schwandt, 2001). Within this logic, *convenience sampling* was considered the most appropriate strategy in view of the limited number of possible participants available; a decision which was guided and confirmed by several agreeing texts (Carter, Lubinsky & Dumholdt, 2011; McMillan & Schumacher, 2001; Onwuegbuzie & Collins, 2007; Shaw & Gould, 2001; Schwandt, 2001; Strydom & Delpont, 2011). Applying convenience sampling, *all* those who attended the WCCPA Outreach Clinic and met the inclusion criteria were invited to participate.

In addition, as the study progressed, two instances of *snowball sampling* were applied (Carter, Lubinsky & Dumholdt, 2011; Onwuegbuzie & Collins, 2007; Strydom & Delpont, 2011). That is, the parents themselves (a) invited other parents to the clinic and/or to the action reflection group discussions taking place in the waiting area, and (b) sent a delegation, including myself, the researcher, to visit a previously established parent support group. The motivation for this visit was the parent-participants' desire to share preliminary results and to explore the research question with a wider group of similarly affected parents. Thus, the participants were instrumental in identifying and recruiting additional participants through their personal experience and contacts within the population of isiXhosa parents of children with cerebral palsy and severe communication disorders (Carter, Lubinsky & Dumholdt, 2011; Onwuegbuzie & Collins, 2007; Strydom & Delpont, 2011).

The eventual **sample size** was a total of forty-four (44) participants; attending action-reflection discussions at the two sites, over the duration of the data collection period from 12 October 2006 to 11 June 2008.

### 3.6.3 Selection criteria for participant inclusion and exclusion

In order to fulfil the aims and objectives of the study, participants needed to meet the following **inclusion criteria**;

- **Participants had to be isiXhosa speaking:** This was specified because isiXhosa is the most commonly spoken of South Africa's nine indigenous languages in the Western Cape Province, the geographical location of the study (STATSSA, 2012a). Due to the cosmopolitan demographics, the frequent migrations between provinces within South Africa and the resultant multilingual fluency of many black South Africans (STATSSA, 2012b), this inclusion criterion was not limited to isiXhosa *first-language* speakers. If participants were not first-language isiXhosa speakers, the other participants determined their inclusion on the basis of ease of isiXhosa language use and cultural belonging. Thus two women, whose first language was Sesotho but who were married to isiXhosa-speaking men and immersed in isiXhosa language and culture, were included and added indispensable richness to the data (more details in Chapters Four and Five).
- **Participants had to be mothers, fathers and/or carers of children with severe communication disabilities.** Carers were considered in the broader sense of including anyone who was in a situation of regularly caring for the physical, material, developmental, emotional and/or social needs of a child (with severe communication disorders), whether they were a relative, a neighbour or someone specifically employed in this role. While in western thinking the term *parents* refers only to the biological and/or legal mother and father, a more inclusive use of the term *parents*, was collectively applied here to all carers as described above. This term was in line with the widespread African indigenous understanding that it takes a whole village to raise a child (LeVine, Dixon, LeVine, Richman, Leiderman, Keefer & Brazelton, 1996; Van der Rhee, 2013). It also fit the aims of the study better than the originally planned, more exclusive participant descriptor 'mothers' would have done, as the opportunity arose to include fathers and other primary carers who brought children to the outreach clinic or attended the support group, and added rich contributions to the group discussions.



*Who are the 'parents' who raise children?*

*It seems proverbs expressing the idea that it takes a village to raise a child are commonly used – with slight variations – throughout Africa. Possibly the oldest or original one is found in the Igbo language of Nigeria, 'Oran a azu nwa' literally means it takes a community or village to raise a child.*

*But also:*

*'One hand does not nurse a child' in Kiswahili*

*'A child is a child of everyone' from Sudan*

*'One knee does not bring up a child' from Tanzania*

*... 'Collectivist' child-rearing shining through in all of these.*

- **Participants had to be parents of children with severe communication disabilities:** The umbrella term 'severe communication disabilities' (introduced in Chapter One: 1.3.1) was deemed appropriate in specifying the communication needs which, in addition to or beyond those due to impairments affecting the motor and/or cognitive abilities of the child, had not been or could not be augmented with a formal AAC system due to poverty and/or the related lack of individual interventions (outlined in Chapter One).
- **Participants had to be parents of children under 18 years:** The 18-year age-bracket was determined by the formal definitions of a child in South Africa as per the Constitution of the Republic of South Africa, (Republic of South Africa, 1996) and the Children's Act (Republic of South Africa, 2005). While a key motivation of the study was to provide inputs in the field of early childhood intervention (Shonkoff & Meisels, 2000: xvii - xviii), parents of older children – up to 18 years – were included as they could contribute valuable memories of the early childhood phase of their

children. Moreover, all of the participants' children who were older had reported developmental ages below six years due to additional intellectual disabilities.

**Exclusion criteria:** Persons who met the following criteria were excluded:

- **IsiXhosa speaking parents whose children had disabilities that did not affect their speech, language and communication development:** This exclusion was applied because the study focus was on communication.
- **Non-isiXhosa speaking parents of children with disabilities:** Parents who did not speak isiXhosa were not included as the focus was on isiXhosa language and culture.

These selection criteria resulted in the following implications: both study sites comprised pre-existent groups and, during the exploratory preparation for the study, it was found that the majority of those attending met the inclusion criteria. In terms of exclusion criteria, only two non-isiXhosa speaking parents attended the outreach clinic. However, both of these arrived early, were seen first and had often departed by the time that the isiXhosa-speaking parents started arriving and gathering in the waiting area. The case of these two mothers is re-visited later in this chapter, in terms of the ethical principle of justice (3.10.3)

### **3.6.4 Community entry and recruitment**

**Community entry** had commenced earlier, while I worked at the outreach clinic as a locum interventionist for three months, relieving the permanent speech therapist while she was away. During that time, I worked with the other therapists inside the clinic and engaged with individual mothers or caregivers and their specific children, in the assessment and intervention of communication and/or feeding difficulties. While the earlier therapy relationship with some of the parents helped in terms of trust, my changed roles from interventionist to researcher presented some challenges in terms of participants' expectations (of me, as the former interventionist), similar to those documented earlier by other researchers (Mertens, 2009; Trehan & Rigg, 2012). Factors that helped with the delineation of my new role as a researcher were the time gap of six months between my clinical involvement; my re-entry as a researcher; the explanations in isiXhosa by Pam, the outreach

clinic assistant; and my collaborator, who volunteered to assist with the study due to her interest in the aims and objectives of the study. All intervention expectations were addressed either in the group, individually afterwards, or referred to the currently responsible therapists (see also 3.10 Principles of ethics).

**Gatekeepers** in this study comprised the WCCPA board, the WCCPA chief executive officer (CEO) and the multi-disciplinary team of therapists working at various WCCPA sites in the Western Cape. Furthermore, key gatekeepers ‘on the ground’ were Pam, the isiXhosa-speaking woman who was employed to assist at the WCCPA outreach clinic and Nolwandle, the social worker who facilitated the parent support group, which became the secondary study site.

**Recruitment** of participants started after I first received approval of the study protocol by the University of Cape Town Faculty of Health Sciences Research Ethics Committee (REC. Ref.: 454/2005; Appendix A) and then organisational permission from the Western Cape Cerebral Palsy Association (WCCPA) (Appendix B) (for Principles of ethics as applied in this study, please see 3.10 below).

After I had received the WCCPA board’s permission to proceed with the study, I made an appointment with the CEO to clarify and confirm the logistics of the study and the practical details of recruiting participants. The next step was an information sharing and gathering meeting with the therapists working at various WCCPA sites, and their help was requested to identify data-rich sites. They suggested that I approach *waiting parents* at some of the therapy clinic sites and so I undertook an informal audit of the waiting areas at various WCCPA service points. Most of these shared large and noisy waiting areas with other out-patient services. The usual layout of these waiting areas comprised rows of long, unmoveable benches all facing one way, upon which the waiting patients sat in the sequence in which they arrived, regardless of which out-patient service they were waiting for. This situation was not conducive to the development of group-specific discussions – or even social conversations – and the issue is revisited as serendipitous findings (4.7)

One specific outreach clinic, held once a month on the outskirts of Cape Town was chosen because the pre-existing waiting arrangement at this site accommodated only those waiting

for the WCCPA clinic – that is, a contained group of potential participants. Moreover, the physical arrangement of chairs loosely grouped in the shade of trees outside the clinic, was conducive to developing conversations and discussions. Parents bringing their children to attend therapy sessions at the outreach clinic sat waiting and chatting outside the refurbished shipping container which housed the clinic, before, between and sometimes after their allocated therapy sessions.

At this site, the next gatekeeper was Pam; the isiXhosa-speaking woman introduced earlier, who accompanied the therapy team each month; was responsible for welcoming parents and children as they arrived; for overseeing the register and the sequence of appointments etc., and who became a vital collaborator. She was considered a key to community entry in terms of the specific group of waiting parents. After explaining the aims, purpose and planned data collection methods to her, she spontaneously volunteered several examples of why she thought that this study was important. In keeping with the co-operative, appreciative inquiry approach of this study, we negotiated her assistance in introductions, recruitment, and informed consent explanations. This assistance would involve *liaison interpreting*; encompassing specific translations, explanatory interpretations and cultural mediation between the isiXhosa-speaking participants and myself, the researcher (Du Plessis, 1999; Erasmus, 1999; South African Translators' Institute, 2007).

I then visited the waiting group of parents on two consecutive outreach clinic dates (a month apart) to observe and to get a sense of the logistics of the waiting time – including the seating arrangements, the actual waiting periods, noise levels and other distractions at this outdoor study site and, most importantly, the opportunities for group engagement. Pam introduced me and explained that I had done some research in Botswana with parents of children with cerebral palsy and she translated my brief overview of the findings of the Botswana case study, explained the aims, objectives and planned processes, the benefits and possible risks to the group in isiXhosa and encouraged questions. She translated those questions into English for me, and translated my responses back into isiXhosa for the parents. The reason that we implemented *two* such preparatory sessions was that there was some variation in attendance at the outreach clinic and I wanted to ensure that more potential participants had heard the introductory explanations and had opportunities to ask questions before we started. At the

end of both of these preparatory sessions, the parents who were present verbally and tentatively agreed to participate. A consent register (Appendix D) was shown and explained to the group to clarify the concept of written consent for the use of their contributions to the discussion. Similarly, the potential participants' right not to participate, or to withdraw at any time after initially consenting to participate, was explained and interpreted by Pam. These issues are re-visited in Section 3.10 Principles of Ethics.

Actual recruitment thus followed the identification of the whole group of attending isiXhosa-speaking parents at this outreach clinic site. A renewed invitation to participate was issued at the beginning of each action-reflection discussion session so that irregular or first-time attendees at the clinic would be informed and given the opportunity to participate – or to feel free to withdraw. The ethical implications of the recruitment process, and the collaboratively determined development of the informed consent process, are discussed later on in this chapter (3.7 Production of the data and 3.10 Principles of Ethics).

As described in sections 3.6.2 on Sampling (above), an additional site (the WCCPA *Iqhayiya* parent support group) was later identified by parents attending the outreach clinic as a place where they felt that others needed to benefit from and contribute to the research. A second group of parents who attended the *Iqhayiya* parent support group were thus added to the study by snowball sampling (Carter, Lubinsky & Dumholdt, 2011; Onwuegbuzie & Collins, 2007; Strydom & Delpont, 2011). Recruitment then proceeded through a process of translated introductions and explanations, the same as those at the first study site at the outreach clinic.

### **3.6.5 Description of the participants**

A total of forty four (44) participants were recruited and took part in the study, at either or both of the two overlapping study sites, over the duration of the data collection period from 12 October 2006 to 11 June 2008. All of the participants, except two, were isiXhosa first-language speakers. The exceptions were two mothers who were Sesotho first-language speakers, but immersed in isiXhosa language and culture by migration and marriage, and therefore included. (These two mothers also added rich information on the applicability and relevance of some of the culturally determined processes identified here, *beyond* an isiXhosa context, in other African language contexts). An overview of the numbers and the

similarities, differences and overlaps between the participant groups at the two study sites is presented in Table 3.3 below.

**Table 3.3 Overview of the participants in this study**

A. ‘Masinedane’ group - participants attending Study Site 1 (outdoor waiting area at CP outreach clinic):	B. ‘Iqhayiya’ group - participants attending Study Site 2 (Iqhayiya Mothers’ support group meeting at CP clinic headquarters):	C. Overlap - participants attending <i>both</i> Study Sites:	D. Totals (NB: A + B - C = D)
*17 mothers	22 mothers	3 mothers	<b>36 mothers</b>
2 fathers	--	--	<b>2 fathers</b>
2 grandmothers	1 grandmother	1 grandmother	<b>2 grandmothers</b>
2 aunts	--	--	<b>2 aunts</b>
2 neighbours (employed as carers)	--	--	<b>2 neighbours (employed as carers)</b>
<b>25</b>	<b>23</b>	<b>4</b>	<b>44</b>

\* this group included two mothers who were Sesotho first-language speakers, but fluent and immersed in isiXhosa language, communities and culture by marriage (see 3.6.3).

While there was some overlap of attending participants at the two study sites, they differed as follows:

At the **primary study site** at the WCCPA outreach clinic (later named ‘Masinedane’ group), the original inclusion criterion of ‘mothers’ was extended to ‘parents or primary caregivers’ of children with severe communication disorders. This change was due to the unforeseen and enriching attendance of two *fathers* and several primary carers (including two grandmothers, two aunts and two neighbours who were employed as paid carers) who were able to add valuable insights and catalysts to the discussions that would have been missed had they been excluded. Many of the participants at this study site were breadwinners or spouses in farm worker families originally from the Eastern Cape, now living in the severely under-resourced, informal settlements of Bloekombos<sup>1</sup>, Scottsdene, Wallacedene or Kalkfontein on the northern outskirts of Cape Town.

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<sup>1</sup> When naming these areas here for authenticity, the implications for confidentiality and anonymity of the participants were carefully considered. The fact that several participants came from each of these areas and the

The following micro-economic snapshot serves to emphasise the poverty-related burdens which participants from this area faced, over and above those related to the actual disability of the child in their care. Several of the parents had only inconsistent, seasonal work on the fruit and vegetable farms beyond the urban areas and relied on a social grant as their main source of income. In most cases this was a Care Dependency Grant (administered by the South African Social Security Agency within the Ministry of Social Development) which is intended to support the primary carer of a severely disabled child under the age of 18 (SASSA, 2011). The amount of this grant, has been increased slightly each year, but during the period of the study it was just under ZAR1000 per month (around USD100 at the time), which barely covers the most basic living costs. In two cases, where grandmothers were the primary carers of disabled children, the lack of birth certification for their respective grandchildren hindered these carer-grandmothers' applications for the Care Dependency Grant, and so the respective grandmother's state pension (also approximately ZAR1000 at the time), was the sole income for the household. In both of these cases the grandmother had four or more orphaned grandchildren living with her, surviving on her pension. Such situations are common, and often *but not always*, related to the high HIV/AIDS-related mortality rate among the bread-winning age group. These complex conditions of poverty were but some of the circumstances within which carers participating in the study struggled to survive, apart from the additional issues related to the disabled children in their care.

At the **secondary study site**, the pre-existing *Iqhaya* Mothers' Support Group held monthly meetings and these participants (who were included through snowballing) were all *mothers* of children with severe cerebral palsy and severe communication disorders. These mothers came from diverse parts of the greater Cape Town area including the townships of Khayelitsha<sup>1</sup>, Gugulethu, Crossroads and Brown's Farm. None of the *Iqhaya* mothers was employed, but several were engaged in income generating activities such as sewing and looking after other children with disabilities, enabling the mothers of those children to seek

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frequent movements of families within and between these specific, informal areas, were considered anonymising factors.

<sup>1</sup> Please see footnote 1 on previous page regarding considerations of confidentiality in specifically naming these areas of residence.

employment. All the participants attending the pre-existing *Iqhayiya* Mothers' Support Group regularly received the Care Dependency Grant to supplement their income.

Up to this point, the study setting, the facilitators and collaborators and matters pertaining to the participants have been described. The data production methods are presented below followed by a narrative account of the actual transformative action research journey by means of which the data was produced.

### **3.7 Data production methods applied**

The integrated concept of *data production* (Lorenzo, 2005) has been adopted here to describe *the continuity or fusion of data generation and data analysis* through collaborative reflection, action and planning cycles. In keeping with the iterative and self-generating nature and the collaboratively decided strategies of the transformative action research design, data was produced using several data collection strategies according to the need and opportunity provided by preceding outcomes, and according to the collaboratively made participant recommendations.

#### **3.7.1 Data generation strategies**

Data was generated by applying the following strategies:

- ***Narrative action-reflection groups***

Most of the data was gathered or generated by means of a series of group discussions which were an integration of group discussion approaches described earlier (Chambers, 1994; Hope & Timmel, 1995a; 1995b; 1995c; 1999; Lorenzo, 2005), with the name coined by Lorenzo (2005). A series of group discussions, featuring brainstorming about problems and collaboratively identified solutions, leading to short term aims (actions) which participants then trialled before the next discussion. Subsequent discussions then began with reflections on the respective actions that had been trialled since the previous meeting. A discussion 'trigger' was used to focus and start the discussion in each session (Hope & Timmel, 1995c; Lorenzo, 2005), and the topic of the trigger followed on from reflections on actions in previous sessions (see detailed description of action-reflection cycles in 3.7.4 'Narrative account of the actual Research Journey').



- ***Reflective dialogues***

The description ‘reflective dialogues’ conceptualised by Lorenzo (2005), best describes the meetings with the facilitators and/or collaborators, which were implemented after action reflection group meetings, whenever possible. These in-depth discussions included the reviewing of audio-visual footage, making additional and confirming observations, clarifying language and translation issues and collaboratively analysing and interpreting data. The dialogues also constituted an effective verification strategy (see 3.8).

- ***Participant observations***

A widely used strategy (Carter, Lubinsky & Dumholdt, 2011; Shaw & Gould, 2001; Strydom, 2011; Schwandt, 2001), participant observations have been described as the situation when an ‘outsider’ to the culture describes a situation from the perspective of an ‘insider’ with a key feature being learning from people rather than just studying them (Carter, Lubinsky & Dumholdt, 2011; 160). In this study, I, the researcher collected some of the data by observing the natural interactions within the participant groups, and learnt their significance through *in situ* commenting and questioning, as well as the subsequent reflective dialogues.

- ***Rapid local appraisals***

The situation of participants going and doing some of the data collection themselves, has been variously described as rapid rural appraisal (RRA) or rapid urban appraisal (RUA) – depending on the research context – or more neutrally; rapid *local* appraisals (Chambers, 1994; 2007; 2010). Here, the participants initiated and then carried out two rapid local appraisals, focusing on the presence of certain examples of non-verbal communication features in the other indigenous languages spoken in southern Africa. The participants did this informal audit, by observing, enquiring and discussing given examples with others in their community (neighbours and fellow-passengers in public transport such as combi-taxis etc.) and returning the results to the next group discussion.

- ***Reflective journaling***

The value of the reflective journal (as data) has been recognised in action research (Lorenzo, 2005; Reason & Marshall, 2001; Schwandt, 2001) and as part of the transformative process

(Mertens, 2009). In addition to the group reflections and collaborative conclusions during the meetings, my written personal (or first person) reflections and interpretive conclusions about the action research process, with emerging content issues and lessons from additional sources, added to the data (Coghlan & Shani, 2008: 644).

### **3.7.2 The format of the raw data**

As described earlier, the *nature of the data* generated by the strategies described above, was qualitative throughout, and included observed or recounted incidents or snapshots of contextually/culturally determined practices which helped or hindered communicative involvement of the participants' children.

The *format of the raw data* included audio-visual (video) recordings, field notes (of observations and scribed records of narratives), photographs and reflective journal entries.

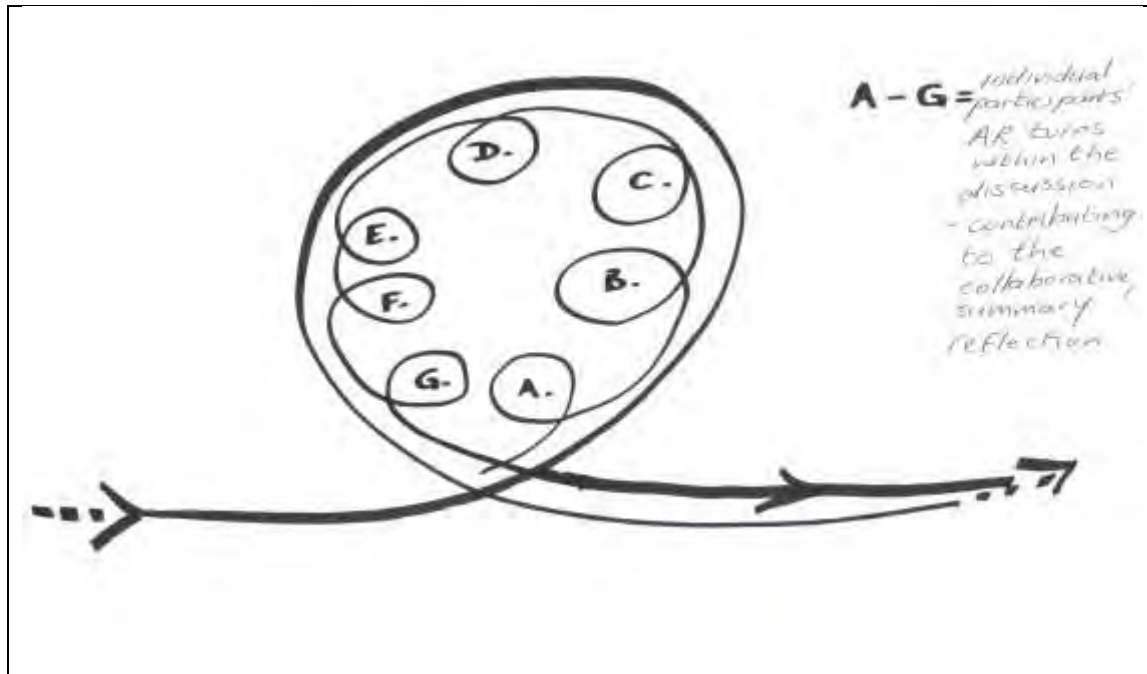
- Audio-visual recordings were made of most of the action-reflection groups and reflective dialogues, using a *Canon MV930 Digital Video Camcorder*. One of the two students assisting as language facilitators or I did the filming (when one of the collaborators, Pam or Nolwandle, were facilitating the group). The recordings were replayed and the collaborative, liaison interpreting already done during the sessions was supplemented in the reflective dialogues. Some of the reflective dialogues were also filmed (with the camcorder positioned and left in one place). In addition to verbatim data, the recordings provided some visual examples of culturally determined actions and non-verbal responses of the parents, not noticed during the session but identified and explored during the reflective dialogues. Group sessions were not recorded if one or more participant did not want themselves or their children (usually sitting on their laps) to be filmed or photographed. An additional challenge was the strong wind (typical in Cape Town) in the outdoor meeting place, and its serious interference with the quality of the sound of the recordings.
- Flip chart notes and/or diagrams were compiled during some action-reflection sessions.
- Field notes were made during the action-reflection group discussions, during the reflective dialogues and during or after participant observations. My field notes from the action-reflection group sessions included many requests for clarification which I then

raised in the reflective dialogues with the collaborators. These subsequent explanations by the facilitators and/or collaborators were then either recorded (on video) or documented as field notes.

- Scribed notes - verbatim, real-time scribing of short narratives.
- Photographs (stills) were taken of some key moments and also to serve as memory triggers for some of the discussions and dialogues.
- Reflective journal entries were mostly hand-written, and some were typed and filed, depending upon where I was at the time.

### **3.7.3 Management of the raw data**

This raw data was collaboratively identified by means of triangulated observations and accounts by the participants and/or the facilitators in the study and/or directly observed by me, the researcher, and then checked with the participants and facilitators. The transcribing and cleaning of the data was a collaborative process and was part of the iterative action-research cycles themselves. Typically, one participant would give a response or spontaneously recount something (e.g. a relevant observation) in an action-reflection discussion; a second, third and fourth etc. participant would agree, add and elaborate on the example and at some point (usually when most of the participants had added their voices about the example in question) the facilitator of that session or one of the participants would make a definitive, concluding statement and translate this into English, ‘dictating’ it slowly so that I or one of the language facilitators, could write it down. Due to the animated and lively discussions up to this point – with several people sometimes speaking at once – this summative, concluding English translation was checked and the group’s agreement sought there and then. Another practical implication of the very lively discussions (or ‘hubbub’) preceding the English summary by one of the participants or a facilitator, was that it was not possible to attribute specific contributions in the discussion, to specific participants. This cyclical, action-reflection process *within* a single action-reflection discussion session is illustrated in Figure 3.5 below.



**Figure 3.5:** The process of action and reflection by individual participants within a single discussion (A-F), contributing to an agreed summary or reflection by a ‘spokesperson’ (G) which was then translated into English and often transcribed in situ, as field notes with verbatim quotes.

A basic form of discourse analysis was applied to this collaborative response phenomenon. While there are various forms of discourse analysis, crossing diverse disciplinary divides (Johnstone, 2007), the purpose of all discourse analysis is “to understand what people are doing with their language in a given situation” (Starks & Trinidad, 2007: 1376). An in-depth discourse analysis of these collaborative summaries is beyond the scope of this report, but this collaborative response process certainly highlights the need for further research and formal analysis. My very basic discourse analysis of this repeated situation points toward its value in confirming what everyone has heard and understood and giving each person a voice to state that. As such it was a valuable strategy of collaborative analysis.

***Reflective Journal: 8 August 2007***

***With reference to my personal diary of 1990, the year I did my language and culture orientation (or ‘village live-in’) in the village of Tonota, Botswana...***

*The action-reflection group sessions remind me so much of the Kgotla-sessions (= tribal court) in Botswana! I used to attend these during my time of language*

*and culture learning in Tonota village. During these Kgotla-sessions, someone says something, and then every person present adds to (or negates, comments etc.) what has been said... and at the end the Kgosi (=chief) sums up and concludes – and his is the final word (to which everyone has contributed).*

*I used to think I can just sit and listen and learn – especially while my Setswana was still poor! - but then the Kgosi himself once said ‘Ga re itse lentswe la moeng wa rona...wa lekgoa’ (= we have not heard the voice of our white visitor; i.e. me). And he was not satisfied until I had repeated what I understood to have been said...*

*Pastor Mmolawa later explained to me that the custom is for every person present to repeat their understanding of the gist of a message. This is typical in oral cultures and seems to serve several purposes:*

- *for every person to have the opportunity to contribute (i.e. tribal democracy)*
- *for the group to hear what each person has understood – this explained the chief’s concern about my silence: he wanted to hear and confirm **what** exactly I had understood.*
- *for the decisions to be remembered – it is particularly important that decisions made, are repeated by each person present – to imprint on the individual and collective memory...*
- 

*...as Pastor Mmolawa concluded “We Batswana do not write minutes like the white people. We repeat and remember.”*

Video film from action-reflection groups was sometimes replayed in the reflective dialogues with the collaborators and clarified, analysed and interpreted in collaborative discussions – a few of these dialogues were also filmed due to the amount of valuable additional data they generated.

Thus, cleaning of the audio-visual data occurred by collaborative decision-making and consolidation of key points, which were then transcribed.

### 3.7.4 Data analysis strategies

The purpose of the data analysis was to identify themes and concepts from the diverse data sources, to guide trustworthy interpretations and conclusions in relation to the aims of the study as stated earlier:

- to identify culturally determined non-verbal, pragmatic and contextual elements of social interaction in an isiXhosa language context.
- to identify culturally appreciative strategies to support the communicative participation of children with severe communication impairments in this context.

Analysis of the data occurred in two ways. Firstly, at the collaborative, group level, implicit in the action-reflection cycles of this transformative action research study (Figure 3.5, above), and secondly, at the interpretive level of the researcher (me), with considerable overlaps between the two. At both levels of analysis, focus was maintained by loosely following Hope and Timmel's six steps of analysis (1995c: 43), which are:

- **Step 1: Observation:** answering the question; 'What is happening?' with a description of events or actions as directly observed or as recounted by the participants.
- **Step 2: Classification:** sorting these descriptions as they relate to the aims of the study, for example culturally determined processes as identified in the Botswana case study, and as confirmed and verified in the isiXhosa context – or new examples.
- **Step 3: Interrelation:** establishing the value of these culturally determined processes in relation to an extreme communication disability
- **Step 4: Insight:** identifying cause and effect, relative importance, and also recognising the value of seemingly irrelevant 'curved balls' – or unexpected serendipitous findings.
- **Step 5: Causes:** identifying why things interrelate.
- **Step 6: Hypothesis:** why do things happen (why does change happen?) and how can change be brought about.

The interrelation of the individual analysis (of myself, the researcher) and the collaborative (group) processes was often at the point of either an agreed finding and/or a new question, which was then used as a new trigger for the subsequent discussion(s). An illustrated overview of the interrelated research processes is presented in figure 3.6 below.

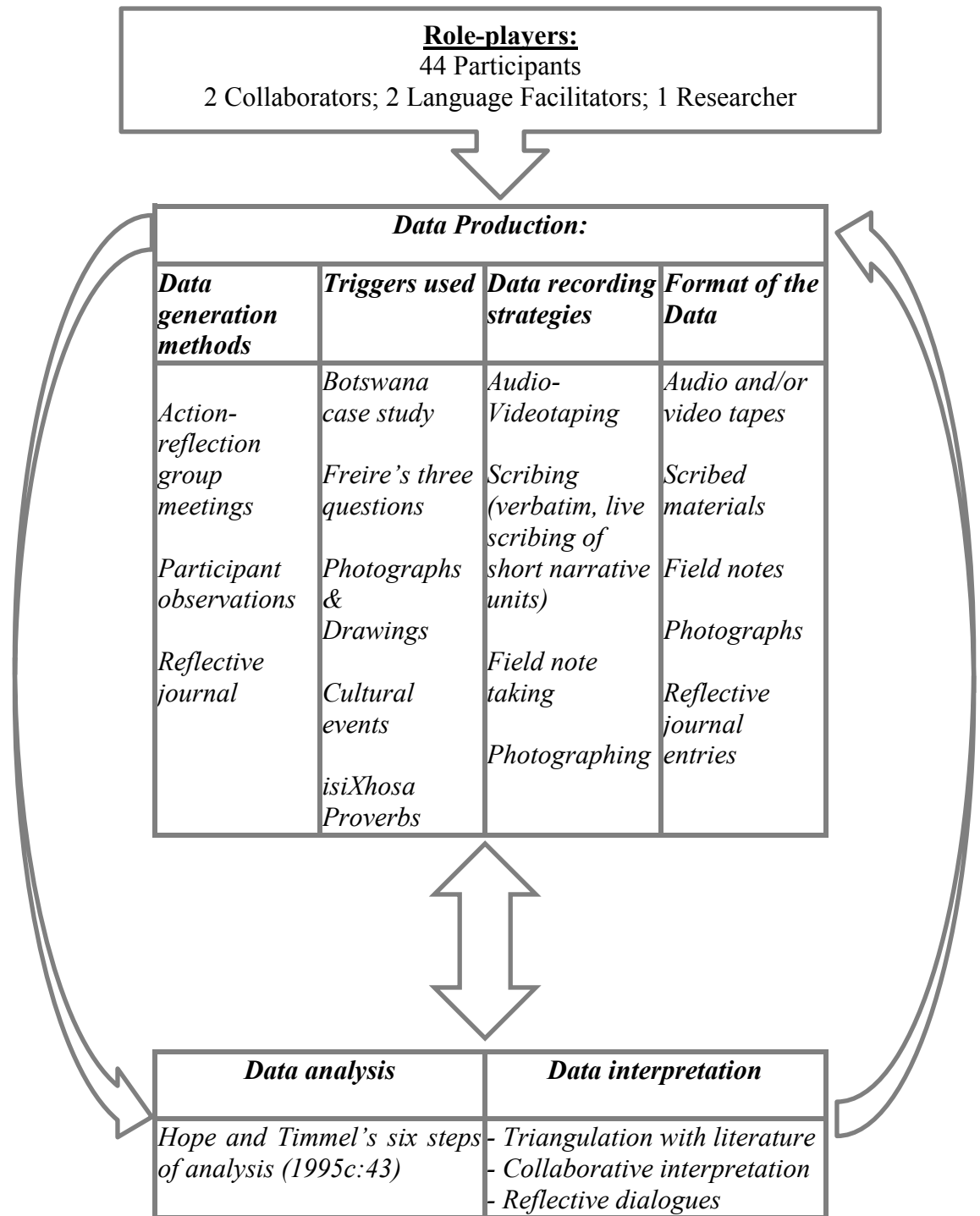


Fig. 3.6: An illustrated overview of the interrelated research processes (adapted from Lorenzo, 2005)

### **3.7.5 The actual research journey**

The actual action-research journey can best be described in five phases, each comprising at least one action-reflection cycle with various forms of data-production strategies included throughout:

- Phase One: Revisiting the earlier case study from Botswana
- Phase Two: Exploratory work in Cape Town, using Botswana triggers
- Phase Three: Confirming identified resources in Cape Town and first information feedback to interdisciplinary therapists
- Phase Four: Participants reach out to a second group of parents
- Phase Five: Wrap up and dissemination (wrap up, closure with member checking and reciprocity)

#### ***3.7.5.1 Phase One: Revisiting the case study from Botswana***

The Botswana case study, included in the Prologue of this research report and pre-published (Geiger 2010), formed a preliminary, question generating cycle which gave rise to the main study (Figure 3.7 below). In terms of its methodology, the preliminary case study included action, critical reflection and further planning with reference to evidence from literature published in related fields, thus exemplifying a step towards the much-needed ‘evidence-informed reflective practice’ (Ng 2012; 129). The work of Ng (2012) has confirmed the wider application of reflective practice in rehabilitation, and Schön’s writings (1991;1995) have been described as pivotal in the bridging of formal, academic research and learning in/from experience, or ‘action science’ (Ng, 2012; Reynolds, 2011, Schwandt, 2001).



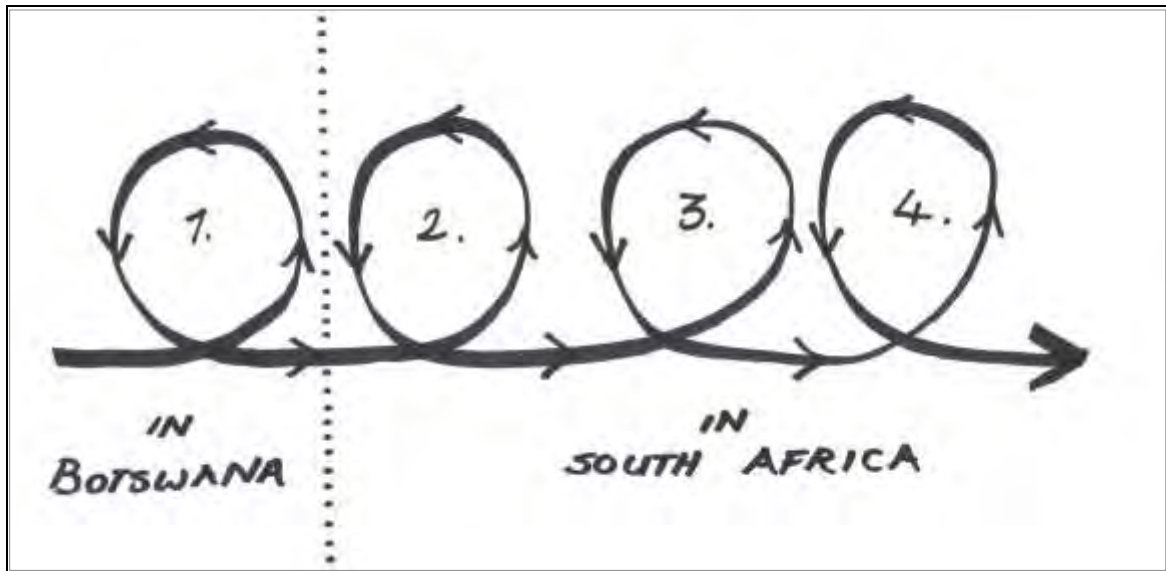


Figure 3.7 The Botswana case study can be seen as the first cycle of this enquiry.

The case study not only informed problem definition – that is, the research question – it also provided specific examples of contextually determined practises in the Setswana language setting, which were then used as ‘triggers’ to start the conversation in the discussion groups in the isiXhosa language and culture context in Cape Town.

### ***3.7.5.2 Phase Two: Exploratory work in Cape Town, using Botswana triggers***

After registering the action research project for degree purposes, obtaining the relevant approvals and permissions I identified a suitable study-setting with a relevant and interested study population, (as described in 3.4 and 3.6.1 above. Having discussed the logistics and the dynamics of the waiting group of parents with Pam, the primary collaborator and gate keeper at this site, we planned an introductory session with the waiting group. Some parents occasionally missed a monthly outreach clinic visit, and so we repeated the introductory session across two consecutive sessions in order to include more parents. The dual purpose of these two introductory sessions was recruitment and to gauge whether the parents here could identify with the examples of culturally determined resources identified earlier as being helpful in Botswana.

These two sessions followed the following format: Pam, who was of course well-known to the waiting group of parents at the outreach clinic, introduced me and conveyed my

explanation of the aims and objectives of the study to the group by real-time translation from English into isiXhosa. I presented a summary of the findings of the Botswana case study, including specific Setswana language examples as collaboratively identified by the participants in Botswana. These examples were intended as preliminary ‘triggers’, to encourage the participants’ thinking and identification of their own examples (Hope & Timmel, 1999; Lorenzo, 2005). An A4 sized ‘flip file’ with the relevant diagrams and photographs was used to illustrate the individual examples (Figure 3.8 below). The consent register (as separate from the clinic attendance register and as a means to obtain consent to use individual members’ spoken contributions and/or to obtain permission to take photographs and/or videos) was discussed. All agreed to this, with one mother stating that she felt it was unnecessary to have a consent register if what she said could help others.



**Figure 3.8 Flip-file images used to illustrate Botswana Case Study as trigger of the first action-reflection discussions.**

During both sessions, parents responded unanimously after each trigger that the same processes were present in isiXhosa. The second (repeat) introductory session, started with the parents who had attended the first session, telling those who had missed that first session,

about the project and about some of the examples from Botswana with which they could identify. After this impromptu beginning to the second session, Pam and I presented the ‘formal’ introduction, with many more comments of agreement from parents this second time around. At this point, one mother made the comment that she had been thinking and talking to others about the examples for the whole month since the first introductory meeting, and that every single one of them applied in her situation, and could help her child. Again there was unanimous agreement on the usefulness and application of each of the examples featured in the triggers, and some parents suggested inviting more parents ‘*to come and learn about this*’. One parent stated that Pam and I should go and tell more people about the examples in their culture that could help their children.

During this second meeting, the explanation of the consent register resulted in a heated discussion; the parents wanted to know why I (the researcher) was asking them for permission to use their words if they were telling me that I must go and share these lessons with others (discussed further Chapter Four: Findings).

This second phase of the study thus comprised two action-reflection discussions with the group of parents of children with cerebral palsy waiting at the outreach clinic. There were two main outcomes of this phase of the study. Firstly, there was the confirmation that the culturally determined processes identified as being helpful in the Botswana context were also present in the isiXhosa speaking context. Secondly, and very importantly, the participants’ buy-in was obtained, to further explore these and other examples.

### ***3.7.5.3 Phase Three: Confirming identified resources in Cape Town and first information feedback to interdisciplinary therapists***

The purpose of this phase was for participants to confirm and test cultural resources that had been identified as helpful in their daily contexts, and to provide collaborative feedback to the therapists in the outreach clinic in matters pertaining to therapy that had come up in the action-reflection discussions.

This phase of the study comprised four more action-reflection discussions with the participants at the outreach clinic; a verification interview with an expert in cultural issues in

mother-child interactions, and an information feedback session with the therapists working at the outreach clinic.

During the four action-reflection meetings, specific activities included

- **Discussions** which followed a basic three-phased action research pattern (Freire, 1970; Lewin, 1946) guided by the three Freirian questions of ‘*What do you think is the problem?*’, ‘*Why do you think it is a problem*’ and ‘*How can we change this?*’ (Freire, 1970) (Table 3.4 below). A discussion ‘trigger’ was used to focus the first, problem naming question in each session (Hope & Timmel, 1995c; Lorenzo, 2005), and the topic of the trigger was always followed on by reflections on actions in previous sessions.

**Table 3.4 The 3-phased pattern of each discussion session, guided by Freire’s three questions (Freire, 1970)**

<b>Session guide:</b>		
		<b>KEY QUESTION</b>
1	Naming Phase	What do YOU think is the problem?
2	Reflection Phase	Why do YOU think this is a problem?
3	Action Phase	How can WE change this?

- A **rapid local appraisal** (Chambers, 2010) was initiated by the participants. Having discussed the triggers from the Botswana study and identified similar resources in their own context, the participants wanted to confirm the common knowledge and usage of several non-verbal resources firstly in their own isiXhosa context and secondly in other southern African language contexts (this latter was just for their interest, now that their curiosity about similarities across languages had been aroused). This rapid local appraisal was completed by the participants as ‘homework’ action exercises between the fourth and fifth action-reflection sessions. A basic checklist (Table 3.5 below), which had been brainstormed on a flipchart in the sessions, guided the participants in their homework enquiries and in reporting back during the subsequent session. The unanimous responses (that all the identified

resources were present in isiXhosa as well as the other languages in the area) are further discussed in Chapter 4 (Findings)

**Table 3.5: The checklist, brainstormed in action-reflection session number four, and used by the participants’ in their self-assigned homework: a rapid local appraisal with report back in session 5.**

	isiXhosa	Setswana	isiZulu	Afrikaans	Sesotho	English	isiNdebele	SePedi	SiSwati	Tshivenda	XiTsonga
Thank you											
Sorry											
Please											
Yes											
No											

- **A validation interview** was used to clarify a few culturally specific issues in mother-infant interactions. This helped to define the trigger question for a subsequent session. Furthermore, as participants were emboldened to share some of the struggles they were having with current therapy content and processes, and simultaneously the clinic therapists were keen to learn from the preliminary findings of the study, we arranged a feedback meeting for all. This process provided a forum for open discussion (with language translation and brokering in place), and furthermore, sharing of some of the participants’ new insights with therapists; thus closing the feedback loop – or the action-reflection and planning-for-further-action cycle of Phase Three.

#### ***3.7.5.4 Phase Four: Participants reach out to a second group of parents***

Phase Four comprised three further action-reflection sessions of the *Masinedane* group of participants meeting at the monthly outreach clinic (whom I shall refer to as ‘Group 1’<sup>1</sup>) as well as the establishment of a second study site and the implementation of four action-reflection sessions with the second (*Iqhayiya*) group of participants (‘Group 2’). A second information feedback session with therapists also took place.

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<sup>1</sup> I use the terms Group 1 and Group 2 here ( rather than the group names Masinedane and Iqhayiya) for clarity of the sequence of events)

Emboldened by their discoveries and the earlier feedback session with the outreach clinic therapists, the participants from Group 1 expressed their desire to share some of their discoveries with a second, pre-existing group of parents – specifically mothers – of children with severe cerebral palsy. Group 1 ‘sent’ a delegation of four participants plus myself, to explore this. Group 2 had been meeting once a month as a parents’ support group facilitated by Nolwandle the WCCPA social worker, to engage with topics of self-help and development, including basic budgeting, sewing skills, food-gardens and/or motivational talks. Nolwandle, had shared some preliminary results with the group, and seeing their interest, she cleared the programme for a monthly meeting for the Group 1 delegation to introduce and explain the action-research process. Group 1 participants thus took the lead in introducing the concept of the study; shared some examples of useful resources from the Botswana study and added some of their own, from the isiXhosa context. Group 2 then suggested that part of their regular meeting time be dedicated to participating in the research project and four action-reflection sessions with them followed.

#### ***3.7.5.5 Phase Five: Wrap up and dissemination***

Wrap up, seeking closure with final member checking and confirming reciprocity made up the fifth and final phase of this project. This phase comprised a final meeting with Group 1 (*Masinedane*) and Group 2 (*Iqhayiya*) to review their discoveries, to encourage further personal and group exploration of resources, and to resolve any residual queries. There was also one more meeting with the therapists to give final feedback. Dissemination of personal lessons learnt, strategies for personal and group learning in the future, and dissemination strategies were addressed in these final wrap-up meetings with each group.

In summary, Table 3.6 provides an overview of the diverse kinds of events and strategies that comprised this research journey.

**Table 3.6: Overview of data production events and strategies**

Date:	Group 1: Masincedane Mothers' Group Meetings (MMG)	Group 2: Iqhayiya Mothers' Group Meetings (IMG)	Reflective Dialogues with collaborators (RD)	Validation Interviews (VI)	Information feedback sessions with therapists (IFS)
12-Oct-06	MMG 1				
08-Nov-06	MMG 2				
14-Dec-06	MMG 3				
14-Feb-07	MMG 4				
02-Mar-07				VI1	
14-Mar-07	MMG 5				
30-Mar-07					IFS 1
11-Apr-07	MMG 6				
30-May-07		IMG 1			
13-Jun-07			RD 1		
27-Jun-07		IMG 2			
05-Jul-07			RD 2		
11-Jul-07	MMG 7				
13-Jul-07			RD 3		
25-Jul-07		IMG 3			
26-Jul-07			RD 4		
01-Aug-07				VI 2	
29-Aug-07		IMG 4			
12-Sep-07	MMG 8				
13-Sep-07			RD 5		
26-Sep-07					IFS 2
10-Oct-07	MMG 9				
29-Nov-07		IMG 5			
13-Dec-07	MMG 10				
11-Jun-08	MMG 11				
25-Jun-08					IFS 3

### 3.8 Ensuring trustworthiness and authenticity

Researchers in qualitative inquiry have for a long time grappled with the identification of qualitative equivalents of the accepted, quantitative criteria of rigour (i.e. validity and reliability), (Denzin, 2012; Denzin & Lincoln, 2003; Janesick, 2003; Mays & Pope, 2000; Schwandt, 2001). The four criteria of trustworthiness, as outlined by Lincoln and Guba

(1985) in one of their seminal texts, are still widely applied. These criteria are **credibility**, **transferability**, **dependability** and **confirmability**, and Lincoln and Guba (1985) also described procedures to establish these criteria. Over the years, Lincoln and Guba's criteria have been supplemented by various concepts, all aimed at increasing the authenticity of each aspect of the research process and outcomes (Denzin, 2012; Denzin & Lincoln, 2003; Janesick, 2003; Mays & Pope, 2000; Schwandt, 2001; Shenton, 2004).

The implicit goal of research that is positioned in the transformative paradigm is the enhancement of social justice (Mertens, 2007; 2010). In this study, the enhancement of social justice applied to the goal of supporting the communicative participation of children with severe communication disabilities and moreover, appreciating and empowering parents (the participants) to facilitate this through cultural resources. Due to the historical, political and economic power imbalances in research in general and in the specific South African context, I as the researcher and initiator of the study had to take extra care in ensuring the trustworthiness and authenticity of the voices of the participants.

### **3.8.1 Credibility**

Credibility refers to the agreement, or *'fit'* between the participants' views of their lives or aspects of them and the researcher's reconstruction and representation thereof (Lincoln & Guba, 1985; Schwandt, 2001). Several strategies were implemented in the endeavour to increase credibility:

- the participants' voices were included as naturally as possible, as often as possible, as a key strategy to enhance the credibility of the reported findings (Lincoln & Guba, 1985; Shenton, 2004)
- the repeated, culturally determined in-group collaborative verification and translation process (described in 3.7.3 and illustrated in Figure 3.5), was a means of respondent validation or member checking (Mays & Pope, 2000; Schwandt, 2001).
- the action research design, with its iterative cycles of planning, action, reflection and renewed planning, allowed collaborators and participants to explore new issues arising from previous action cycles (Lorenzo, 2005); thus enabling their voices, rather than mine, in some of the decisions and directions of the research.



- the positions of the two collaborators Pam and Nolwandle as mature and understanding women in the isiXhosa language and culture, and their long-term immersion in the respective study settings, enhanced the credibility of their reconstructions and representations of participants' contributions.
- validation interviews were implemented on two occasions to confirm that my understanding and analysis reflected the participants' reality (Buchbinder, 2010; Duma, 2006).
- three information feedback sessions, for participants and therapists to engage concerning some of the issues that arose during the data production sessions, were facilitated with language translation. These provided opportunity for therapists (in the contexts where the study was implemented) to hear and respond to participants' concerns, joys and action learning outcomes directly – not just from me.

### **3.8.2 Transferability**

Transferability refers to the generalizability of the findings to other cases – it is concerned with the researcher's responsibility to provide enough detail about the case(s) studied, that readers can identify similarities with other cases (Lincoln & Guba, 1985; Schwandt, 2001; Shenton, 2004). Initial informal descriptions of the lessons learnt in the Setswana language context struck a chord with isiXhosa-speaking mothers in my clinical work in Cape Town. This transferability was confirmed when some of the earlier findings from Botswana were used as discussion 'triggers' prompting participants in Cape Town to recount and explore similar examples. Further reflexivity (Mays & Pope, 2000) and my concern about how I (the researcher) had personally shaped the research process was tested – and passed – when participants from the first study site took the same triggers to a second group and initiated similar action reflection sessions there.

### **3.8.3 Dependability**

Dependability refers to the research processes and the researcher's responsibility to ensure that the processes are logical and documented in a traceable manner (Lincoln & Guba, 1985; Schwandt, 2001). Data collection/production continued until saturation was reached. An audit trail of decisions and actions was compiled from field notes, video recordings and

journal entries; this trail is recounted in the description of the actual research journey in this chapter (3.7.5).

### **3.8.4 Confirmability**

Confirmability refers to the concern that the links between the researcher's assertions and interpretations and the data should be discernible and as objective as possible (Lincoln & Guba, 1985; Schwandt, 2001). I endeavoured to include enough data to enable the reader to see how the data supported interpretations made (Mays & Pope, 2000). Additional confirmability was sought through the member checking implicit in the collaborative, in-group verification process and the validation interviews (both mentioned above in 4.8.1 as they also address credibility).

Triangulation in qualitative research has been described as the "process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation, triangulation serves also to clarify meaning by identifying different ways the phenomenon is being seen" (Stake, 2003: 148). Triangulation was applied repeatedly throughout, to confirm findings, and moreover interpretations. The different 'vantage points' included different data sources (e.g. action reflection discussion groups AND/OR participant observation AND/OR validation interviews). Other instances included the consideration of findings in this study in the isiXhosa context AND/OR the preceding case study in Botswana AND/OR the literature.

### **3.9 Bracketing assumptions**

As the researcher in this qualitative enquiry I had to acknowledge the tensions that my assumptions or preconceptions contributed to the entire research process (Tufford & Newman, 2012). An appreciative inquiry approach with its attitude of a 'positive expectancy' (Ludema, Cooperrider & Barrett, 2001; Ludema & Fry, 2008) was the primary factor that had an impact on my assumptions on this research journey. It meant a clear bias as I presumed the presence of useful, culturally determined processes in this isiXhosa context, which merely needed identification and affirmation. While it also meant that the tensions of a positive bias needed to be considered (Grant & Humphreys, 2006; Tufford & Newman, 2012), the choice of this approach was solicitous in the bigger picture of 'deficit' expectations still dominating research in developing contexts, and especially here in South

Africa. In the real context of this study, it was observed how constructively participants respond and collaborate, given the hint of positive resources within, (in the things they were already doing) as opposed to the frequent approach of interventionists who try to help by offering new and different ways of doing things, which imply that they are better than what the participants have been doing. Reflective journaling helped me to articulate for myself, the tension, and the need for balance between thinking ‘everything is alright’ and ‘recognising the positives and building on them’ *in spite of* the other deficits I may still see in a client or community situation where I am involved.

My positively biased assumptions (and my approach to my communication interventions in general) are founded in the triangulation of three main sources of evidence. Firstly, the call to ‘reframe culture as a resource’ (García Coll & Magnuson, 2000:97) and to consider the contribution of culture to resilience in vulnerability (García Coll, Ackerman, & Cicchetti, 2000) have been welcoming challenges to see culture (*any* culture) as having positive potentials for a child born into that culture. Secondly, the underpinnings of appreciative inquiry (Ludema, Cooperrider & Barrett, 2001; Ludema & Fry, 2008) calling us to approach the topic with a positive expectancy. Thirdly, there was some clinical evidence from my own field experience in Botswana (Geiger, 2002; 2010; 2012a; Geiger & Alant, 2005) and here in South Africa (Geiger, 2012a; 2012b; Kett, Geiger & Boersma, 2008), which added diverse positive examples of the former two sources.

### **3.10 Researching ethically**

Research in general and research with human participants in particular, has had a tumultuous history of oppression and infringement of human rights. Alongside the development of research paradigms acknowledging and implementing more person-centred methodologies, the developments in research ethics within the last century include human rights-based guidelines and principles that were often a direct response to the most atrocious of the human rights violations in large-scale research (Health Professions Council of South Africa, 2008; Horn, 2011; Mertens, 2009). Examples include the Nuremberg Code of 1946, the Declaration of Helsinki of 1964 (regularly updated since) and the Belmont Report of 1979 (Horn, 2011; Medical Research Council, 2003; Moodley, 2011).

In logistical terms, the sequence of processes followed to ensure adherence to research ethics principles, were:

- the study protocol was submitted to and approved by both the University of Cape Town Department of Health and Rehabilitation Sciences Post-graduate Committee and the Faculty of Health Sciences Research Ethics Committee (REC. Ref.: 454/2005; Appendix A).
- once these approvals were confirmed, permission was obtained from the Western Cape Cerebral Palsy Association (WCCPA) to implement the study at their facilities (Appendix B),
- then the recruitment of participants started; using prepared informed consent forms (Appendix C) (please also see 3.6.4 Community entry and recruitment, above).

Moreover, basic ethical principles, or core values, in health research include (a) the core value of respect for persons (incorporating the principles of autonomy and confidentiality); (b) the core values of best interest or wellbeing (including the principles of non-maleficence and beneficence) and (c) the principle of justice (Horn, 2011; Health Professions Council of South Africa, 2008; Medical Research Council, 2003; National Department of Health, 2004; World Health Organisation, 2012c).

Transformative action research as an approach to research and as a worldview has by definition, the best interest and empowerment of participants at heart (Chambers, 2007; Mertens, 2003; 2007; 2009; 2010). In addition to the endeavour to maintain this implicitly throughout the course of this study, the ethical principles of health research, identified above, were applied as follows:

### **3.10.1. The principle of respect for persons (incorporating the principles of autonomy and confidentiality)**

The participants' autonomy was protected by ensuring voluntary participation on the basis of informed consent that is, choosing to participate on the basis of clear information about the study, translated and explained in the participants' own language – isiXhosa. In this transformative action research study, with its collaborative data collection through iterative cycles of action, reflection and planning, the informed consent process and the related issues

of confidentiality and power, took an unexpected turn when participants insisted that their contribution had to be utilised and communicated to others in the research process, (described in greater detail in Chapter Four: Findings)

Once the study site had been identified and the necessary permissions obtained, and before the first action-reflection discussion group, Collaborator Pam and I conducted two information sessions with the group of parents waiting under the trees at the outreach clinic. During the first information session, a summary of the findings of the preliminary case study in Botswana was presented, using a flipchart with pictures for illustration (Appendix E). Some of the culturally determined elements that helped the communicative participation of 'Boiki' in the Setswana context were highlighted and a preliminary discussion was facilitated on whether these isiXhosa-speaking parents thought that there may be similar or other elements in their isiXhosa language and cultural context. The general reactions of the waiting parents indicated their understanding of the issue and agreement that there were such elements in isiXhosa culture. During the second information session the flip-chart summary of the Botswana case study was repeated; this time with many supplementary interruptions from parents who had attended the first session and who were hearing it for the second time.

There was general agreement – and some excitement – about proceeding, and gathering and contributing their own examples. Thus the focus and action research process of the study was discussed. Collaborator Pam encouraged and answered questions regarding the process and also the potential benefit of the study. There was immediate agreement that the participating parents themselves would learn through the action-reflection group discussions – as expressed by one mother and affirmed by several others:

*Masinedane 6 October 2006*

*I think I will learn things that will help me to help my children.*

The planned action research process and the nature of action-reflection discussion groups was explained and interpreted into isiXhosa, including issues of consent for recording/writing down and using participants' responses; making audio-visual or audio recordings and the making and use of photographs.

Participant information and consent forms in isiXhosa and English were designed, approved and used with the participants who attended the first action-reflection group discussion (Appendix C). Although all the participants were isiXhosa speaking, the forms were offered in both English and isiXhosa, and most participants completed the English form. This action could be explained by the frequently observed phenomenon that isiXhosa speakers with only basic literacy levels, prefer and understand written English better than written isiXhosa – even if their spoken English is very poor. This practice is a residual effect of the earlier education system under the pre-1994 Apartheid regime, where – as is often the situation in colonised nations – mother-tongue education and literacy in the indigenous languages was not supported (Alexander, 1992; Eastman, 1992; Kaschula & Anthonissen, 1995). It was confirmed by Duma (personal conversation – 30 November 2013), that previously all formal documents had to be completed in English or Afrikaans as the only languages to be acknowledged as ‘formal’ at the time.

The precautions ensuring voluntary, informed participation, confidentiality and autonomy in terms of discontinuing or changing the participation agreement at any time, were to ensure that respect for the person was demonstrated at all times (Medical Research Council, 2003). All the participants agreed – and requested – that their own names be used. However, in view of possible dissemination of findings and feedback to communities, Pam, Nolwandle and I decided to anonymise stories to prevent possible family or community repercussions (Lorenzo, 2005), and we advised the participants accordingly.

As the planned, main data generation strategy was the discussion within the group, the following logistical challenges needed to be addressed:

Challenge 1: how to manage the recording of the discussion if some agreed to participate, but did not consent to the audio-visual recording and/or photographs being taken.

- In several cases field notes then had to suffice and/or collaboratively decided key sentences were recorded as summaries of more extended discussions.

Challenge 2: how to manage the transience of the group (considering that parents arrived at different times, and left the group to attend therapy with their child inside the container structure when called, and re-joined the research group again for a time if there was a time gap between say their physiotherapy and speech/feeding therapy sessions).

- There was a pattern of repetitions with variations as each participant repeated key issues in their own words and with their own variations (Figure 3.5). These repetitions meant that participants, called away for their children's therapy sessions inside the clinic for 30-40 minutes, were able to re-join and get the gist of the discussion again.

In terms of autonomy and confidentiality of their own contributions, a word is needed about the two collaborators, Pam and Nolwandle. They both requested to join the study, and offered their assistance voluntarily, and I sat with each of them to clarify informed consent, as it applied to themselves in their roles as collaborators and contributors of data. Both women understood the issues, but did not want their contributions to be anonymised and the possibility of using a pseudonym in the report was met with incredulity – and some hilarity:

*1 September 2006*

*Pam: But why? Then they won't know it's me...me, Pam! ... that says this!*

### **3.10.2. The principle of best interest or wellbeing (including the principles of non-maleficence and beneficence)**

The transformative paradigm, action research in general, and 'Appreciative Inquiry' in particular, contribute to the immediate empowerment for the participants (Mertens, 2003; 2007; 2010; Chambers, 2007; Cooperrider & Srivastva, 1987; Ludema, Cooperrider and Barrett, 2001; Ludema & Fry, 2008) – this contributed to the application of the principle of beneficence, and also distributive justice (MRC, 2003) in that the participants themselves were the primary beneficiaries of the study. There were minimal risks to the participants in this study, realising the principle of non-maleficence (HSRC, 2008; MRC, 2003). The only risks encountered were when emotive issues arose in the discussions and participants became upset and tearful, or angry. An example arose when a participant became tearful as she

shared her experiences of being abandoned by her husband and his family after the severity of their child's disability became evident. While I, as the researcher, had anticipated and briefed the research facilitator about such risks of vulnerability and we had anticipated and prepared ourselves for such situations, it was the other participant-mothers themselves who took control and supported the affected mother. In addition to expressions of understanding, comfort and shared similar experiences by the other mothers, non-verbal supports included passing her tissues (paper handkerchiefs); sitting closer; mothers on either side of her putting their arms around her and ensuring that she did not walk home alone when the group dispersed.

Another issue related to beneficence and non-maleficence and which needed explanation, was my changed role from communication therapist (previously consulting with individual mother-child dyads within the outreach clinic) to researcher (now joining the waiting group, with an isiXhosa facilitator in order to learn, through discussions with the participants, about the culturally determined processes which can support opportunities for communicative participation of their disabled children) (3.6.4: Community entry and recruitment). At this time, another communication therapist had already taken over the speech, communication and feeding therapy responsibilities on the therapy team and so parents were assured that the therapy service that I had previously provided would continue inside the clinic, and that the multi-disciplinary therapy sessions would not be interrupted or shortened by the research sessions, outside under the tree.

### **3.10.3 The principle of justice**

The infringement of justice (HPCSA, 2008; MRC, 2003) by withholding benefits of participation – considered implicit in transformative research with its immediate benefit to participants – had to be managed in the situation of excluding two non-isiXhosa speaking parents from the research group at the outreach clinic. I endeavoured to ensure justice by updating these two Afrikaans-speaking mothers each time they came to the clinic, on the progress of the research, any new findings and any useful tips that the research had been generated for the isiXhosa speaking parents. In this way, they were given the opportunity to hear, benefit from, ask questions about and try out some of the findings as they emerged, and



as they might have been relevant to them and their children, in their Afrikaans language context.

### 3.11 Chapter conclusion

In this chapter I have endeavoured to describe the methods *as applied*; that is, what was done in this study, with whom, how and why. I have described the transformative action research journey; the research design chosen to reach the aims and objectives; the study setting; information about the participants and everything about the data (that is, the nature of the data, and how it was collected and analysed). Strategies, applied to safeguard the trustworthiness and authenticity of this study, were described; followed by bracketing assumptions. Ethical principles, implemented to protect the participants and to ensure the integrity of the study, then follow and methodological and other limitations of the study are discussed.

Before I embark on presenting the findings generated by the methods described, I would like to conclude this chapter with an entry from my reflective journal:

#### ***Reflective Journal: 24 February 2011***

*As I grapple with the texts about methodologies and with my method, I am tempted to despair at having to disqualify my work on so many fronts. Until a senior researcher points me in the direction of the concept of a **bricolage\***. Several 'aha-moments' follow as I find that I can slot my patchwork of data into a credible, organisational framework, which tells a more complete and true story than any structure or framework or guiding principle I have tried previously.*

*My old patchwork quilt, which I made during a university vacation many years ago, becomes a daily object lesson. I am not an expert on patchwork as a craft: glossy coffee table books on the art of patchwork and quilting; and the section in fabric shops, helpfully labelled 'For Patchwork' leave me cold.*

*Mine is the only patchwork quilt I ever made. I pieced it together from about 600 scraps left over from childhood dresses, shirts and dungarees which Mom, and later I myself, had made as I was growing up. I did not buy a single piece of new fabric for the quilt; I only used what*

*was there...*

*Much planning and careful arrangement of the scraps was required to make a cohesive whole. This was because, of some fabrics, there was enough left over to have several repeats in the quilt, but the most treasured are those of which there was barely enough left to include only a single sample scrap in the quilt.*

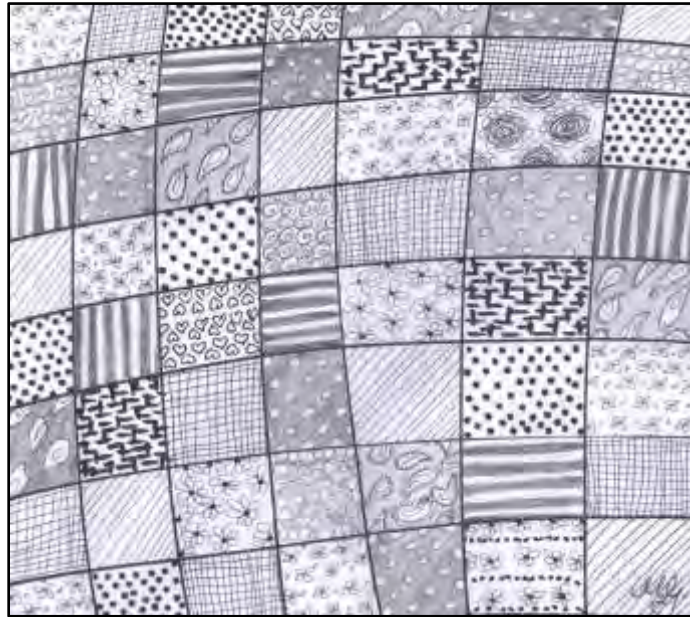
*Each scrap contributes something different in terms of memories, texture and pattern to make the quilt what it is: a surprisingly comprehensive story of my life from my birth up to my third year at university.*

*In the bricolage or tapestry of findings in this study, the aims and objectives guided the general organisation of the findings. However, in keeping with a transformative action research process, it has often been the small 'scraps', that have added real richness.*

*\* Prof. Leslie Swartz, personal conversation, 2013, February 12*

# Chapter Four:

## The findings of the study



*'The researcher...may be seen as a bricoleur, as a maker of quilts'*  
*Denzin & Lincoln, 2003: 5*

### 4.1 Chapter introduction

In this chapter, I describe the findings as they relate to the aims and objectives of the study, given the tapestry or *bricolage* of diverse data collected by means of the methods described in the preceding chapter. The analogy of a patchwork quilt, or *bricolage*, was helpful in conceptualizing the whole, and I became a *bricoleur* or 'maker of the quilt' by selecting, organizing and presenting the diverse - and sometimes extremely unexpected - findings. The interrelation of the individual analysis (by myself, the researcher) and the collaborative (group) processes was often at the point of either an agreed finding and/or a new question, which was then used as a new trigger for the subsequent discussion(s).

Here, a description of the nature of the data<sup>1</sup> that was gathered is followed by an account of the findings or ‘action learning outcomes’ (ALOs), grouped into two main themes according to the aims and objectives of the study. So, in response to the first aim, culturally determined non-verbal and pragmatic elements of social interaction identified in the given isiXhosa language context are described. These action learning outcomes were gathered into the first broad theme:

**Theme 1: “*We do it all the time but we do not know it*”**

**The recognition and appreciation of diverse forms of everyday social interaction**

Then, in response to the second study aim, culturally appreciative strategies that can support the communicative participation of children with severe communication disabilities in this isiXhosa language context are presented as the second broad theme:

**Theme 2: “*It is a way for the mother to turn the spear*”**

**Parent empowerment through culturally appreciative strategies to support communicative participation of their children with severe disabilities**

This second theme includes serendipitous findings (Foster & Ford, 2003; Stoskopf, 2005), that is, findings that were not sought according to the planned objectives of the study, but which contributed to the achievement of the aims. In conclusion, a summarised overview closes this chapter.

## **4.2 From data to action learning outcomes (ALOs)**

The *focus of this study*, grounded in the transformative paradigm (Mertens, 2003; 2009; 2010), was on culturally determined processes that can increase and enrich the communicative participation of children with extreme communication disabilities in an isiXhosa language and culture context. Thus, the *unit of analysis* (or that which is placed and studied under the proverbial ‘microscope’) comprised:

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<sup>1</sup> The word ‘data’, though a plural of ‘datum’ in its original Latin form, is treated as a mass noun here (like ‘information’) and thus takes the singular verb (Oxford English Dictionary).

- collaboratively identified, *culturally determined practices* which supported opportunities for social interaction by the participants' disabled children (in response to the first aim of the study)
- collaboratively identified *ways of optimising the above* (in response to the second aim of the study).

The *recorded format of the data* was therefore qualitative throughout (See Chapter 3 Methods: 3.7.2). Qualitative studies are generally committed to inductive analyses (Carter, Lubinsky & Dumholdt, 2011; Janesick, 2003; Schurinck, Fouche & DeVos, 2011; Schwandt, 2001). However, many qualitative studies comprise a combination of inductive and deductive analysis (Mayring, 2000; Schwandt, 2001), and this study was not exceptional in this regard. Positioning some conclusions in earlier propositions (e.g. from the preceding case study) implied some deductive analyses, while most of the findings here were arrived at by collaborative, inductive reasoning. Cleaned and tentatively defined as 'action learning outcomes' (ALOs) as also described by Cockburn-Wooten and Henderson (2006), the ALOs were grouped within the two main aims and the related objectives of the study and contributed to the two main themes. These two main themes, comprising the grouped Action Learning Outcomes (ALOs) and corresponding with the two main aims of the study, are described below.

### **4.3 Theme 1: *'We do it all the time but we do not know it'*- The recognition and appreciation of diverse forms of everyday social interaction**

The first aim, or desired outcome, of this transformative action research inquiry was to identify culturally determined non-verbal and pragmatic elements of social interaction in an isiXhosa language context. The objective – or the active step to achieve this aim – was to describe the presence and use of some culturally determined elements of social interaction (such as those identified earlier in the Setswana language context), in an isiXhosa language context. Getting the participants 'on board' during the introduction to the study, led to some preliminary findings, that is, their awareness of similarities between the examples recounted in the Botswana case study, and their own isiXhosa context.

#### **4.3.1 ‘But it’s the same in isiXhosa!’ Similarities between elements of social interaction in Setswana and isiXhosa language contexts.**

As described in the previous chapter, an illustrated summary of the main findings of the preceding case study from Botswana was presented to participants in order to introduce the study and as a trigger to encourage discussion. This process was followed with both groups of participants that is, the *Masinedane* parent group waiting at the outreach clinic and the established, *Iqhayiya* parent support group, during the first and second sessions with the respective groups (see 3.6). Photographs and diagrams depicting key issues, presented as separate flip chart pages, were used to illustrate and clarify the findings of the preceding case study (Appendix E).

Participants in both groups immediately recognised similarities with their own contexts and responded spontaneously during the presentation, sometimes unanimously. For example, during the first, introductory session with the *Masinedane* group, after the description of the non-verbal two handed ‘thank you’ in Setswana, seven participants’ responses included:

*[Masinedane group; 12 October 2006]*

- *But it’s the same in isiXhosa.*
- *We do the same.*
- *Mmmm. (Nods head).*
- *It’s the same for us.*
- *It’s the same.*
- *(Nods head)*
- *It’s the same.*

When three of the *Masinedane*-participants and I later visited the *Iqhayiya* group for the first time and together, introduced the study using examples from Botswana, participants from the *Iqhayiya* group expressed their recognition of similarities between Setswana and isiXhosa, as follows;

One mother, Nopelo<sup>1</sup>, confirmed each consecutive example spontaneously by repeating

- *It's the same in isiXhosa...*
- *It's the same in isiXhosa...*
- *It's the same in isiXhosa...*

A general hubbub followed, as all other participants mumbled agreement;

- *Ewe* [= 'yes' in isiXhosa]
- *Yesss!*
- *Mmm.*
- *General non-verbal agreement* [All nodding their heads].

At this time, a similar cyclical pattern of agreement and conclusion was observed in both participant groups, in that several (or all) participants present, made contributions (spoken or non-verbal) and then a 'spokesperson' would sum up and conclude as also described and illustrated earlier (Figure 3.5). Participants either confirmed the spokesperson's conclusion by head nodding, etc. or felt free to add more, or correct her, thus contributing to an immediate, co-operative type of member checking and ensuring a collaborative conclusion. This form of co-operative member checking was seen as a strategy to increase the trustworthiness of the findings, as discussed earlier (Chapter Three: 3.8.7: Ensuring trustworthiness and authenticity). Furthermore, the cyclical pattern of individual contributions, summarised and collaboratively confirmed (Management of the Raw Data: 3.7.3) was repeatedly observed as the discourse pattern in the action reflection discussions.

In each instance, these concluding statements confirmed a generally agreed recognition of the similarity of some non-verbal, pragmatic and contextual elements of social interaction in the isiXhosa language context, as those identified earlier in the Setswana language context. In both groups of participants, this general recognition of the similarities between the languages

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<sup>1</sup> All participant names have been anonymised: while they preferred to have their own names used rather than pseudonyms, the collaborators and I opted for pseudonyms later, in view of the possible family and community repercussions in this volatile and sensitive environment of ostracism and exclusion due to their disabled children (see also Lorenzo, 2005).

triggered the discussions, whereby the participants then began listing and describing further examples in their own isiXhosa language context.

Several participants in the *Iqhayiya* group acknowledged that they had not been aware of these communicative practices and collaborator Nolwandle summed up their hubbub as follows:

*[Iqhayiya group; 30 May 2007]*

*They say they do it all the time. But they don't know it. It is everywhere in Xhosa but they did not see it. But they are going to look now and test the kids. –  
Nolwandle*

#### **4.3.2 ‘... everyone can understand them....this can help.’ Similarities with other southern African indigenous languages.**

A supplementary topic of enquiry arose among the participants in the *Masinedane* group of waiting parents, which included two Sesotho first-language speakers, immersed and accepted in the isiXhosa language context by marriage (Chapter Three: 3.6.5 Description of the participants). These two Sesotho-speaking mothers confirmed the same non-verbal features in *their* language. For example, during the first, introductory session with the *Masinedane* group, after the description of the non-verbal examples from Botswana, and the hubbub of agreement from the isiXhosa first-language mothers, the two Sesotho-first language mothers added:

*[Masinedane group; 12 October 2006]*

- *Le rona.* (‘and us’, in Sesotho)
- *Even in Sesotho...all of these are the same in Sesotho.*

This prompted the *Masinedane* group to inquire whether the non-verbal features identified, were also present in some of the other indigenous languages, as spoken by some of their neighbours and acquaintances, where they lived in the peri-urban, northern outskirts of Cape Town. A participant-initiated rapid local appraisal (Chambers, 1994; 2007; 2010), whereby participants initiated and implemented an aspect of data collection, followed (see Chapter Three: 3.7.1). This rapid local appraisal comprised an informal survey which participants did amongst neighbours, acquaintances and fellow-travellers on public transport, who belonged to diverse



indigenous language groups. Participants started conversations and asked speakers of other regional indigenous languages, how they expressed ‘thank you’, ‘sorry’, ‘please’, ‘yes’ and ‘no’. A flipchart summary of the participants’ reported findings, compiled during the subsequent action reflection meeting, confirmed for themselves that these five main examples of non-verbal communication identified earlier, were in fact present in all nine locally indigenous languages (presented in Table 4.1 below). While ‘yes’ and ‘no’ can be expressed non-verbally in all languages including English, the point that excited the participants was that ‘thank you’, ‘sorry’ and ‘please’ are expressed or implied by a gesture or by body language – *rather* than by words - in all nine of the locally indigenous languages.

**Table 4.1: Summarised overview of the indigenous languages in which the five identified communication messages are usually expressed non-verbally (i.e. by a gesture or body language) rather than by speech.**

	Setswana	isiXhosa	Sesotho	isiZulu	Sepedi	SiSwati	isiNdebele	Tshivenda	Xitsonga
Thank you	√	√	√	√	√	√	√	√	√
Sorry	√	√	√	√	√	√	√	√	√
Please	√	√	√	√	√	√	√	√	√
Yes	√	√	√	√	√	√	√	√	√
No	√	√	√	√	√	√	√	√	√

Upon collaborative completion of the above flip-chart overview of the results of their rapid local appraisal, collaborator Pam summarised the participants’ excited hubbub conversation:

*[Masincedane group, 11 April 2007]*

*They are joyful ... because it means that all the people understand these things ... and without even speaking! ...and it’s not only the Xhosa people. Everyone can understand. If their children learn these ... everyone can understand them. They are saying this can help. (- Pam)*

While not directly fulfilling one of the objectives of the study, this activity had important implications for the participants’ understanding of and buying into the greater purpose of the study in exploring ways of supporting communicative participation. It was instrumental in helping participants to understand the wider use and understanding of non-verbal communication, including basic gestures and body language, beyond the bounds of their specific language – and the potentials for exploring it for their children. In line with Freire’s third question (Figure 3.4), my next question, as the researcher or ‘spider’ – was:

*What must we do to make this happen?*

The resultant action reflection discussions generated findings related to the second aim of the study, and are recounted in later on, but first there were other non-verbal elements of social interaction that warrant mention.

#### **4.4. Additional non-verbal elements of social interaction in the isiXhosa language context**

Following the initial recognition of the general presence of non-verbal elements of communication in their own isiXhosa contexts as described above, a further step was to identify additional specific examples in the isiXhosa context. The general questions used to trigger these discussions were: ‘Can you see communication, without speech, in your children?’ and ‘Can you give examples’.

In the category ‘additional non-verbal elements of social interaction in the isiXhosa language context’, participant responses and action reflection discussions led to the following four action learning outcomes (ALOs): ‘different cries as communication’; ‘the smile: most universal communication of all’; ‘all actions are communication’ and ‘the earliest non-verbal communication between mothers and babies during breastfeeding’.

##### **4.4.1. ALO 1: ‘different cries...for hunger...for pain...for wanting attention...’ - recognising communication without speech**

In the *Masinedane* group, responses to the above trigger-questions (‘Can you see communication, without speech, in your children?’ and ‘Can you give examples’) included:

*[Masinedane group, 8 November 2006]*

*yes, different cries  
...for hunger  
...for pain  
...wanting attention*

During the subsequent reflective dialogue with Facilitator Essie, she interpreted and summarised the recorded general isiXhosa conversation and we supplemented this with my observations, as recorded in my field notes. There were repeated confirmations of the above and Essie added that some participants – all biological mothers in this instance – added that if the tone of the cry was not enough, they considered the context to interpret the cry. An example, agreed to be common

by the mothers was: if the child has been fed and has a clean nappy/diaper and cries, then the mother knows that the child just wants to be held. Essie conveyed these mothers' agreement that they felt that this was not 'cultural' but that they assumed all mothers everywhere worked like this; although some of the mothers present had not considered cries and other vocalisations as communication. Essie also recounted an agreed commitment among the mothers at the end of this particular session that they wanted to listen more consciously to the cries and other vocalisations of their otherwise non-verbal children.

#### **4.4.2. ALO 2: *'...he pushes his plate away – that IS communication'* - all behaviour is communication**

Freire's three-question approach with its naming, reflection and action phase questions (1970) was continuously applied with slight variations, to start, guide and contain the action-reflection discussions. For example, following on from the identification of additional examples of non-verbal communication in isiXhosa, Facilitator Essie and I sought to bring the focus back to the participants' children, and the possible value of the non-verbal examples to their own children, with three questions, below:

*[Masincedane group, 14 February 2007]*

Question 1: What communication has your child learnt in this past month?

*He eats and pushes his plate away.*

Question 2: Why? How is this communication?

- *kodwa olo qhakamshwe lwano* [but that IS communication]
- *nje ngomntwana wam ongokwaziyo ukuya ngsese yedwa - akasafuni cedo konketu* [like my child; he did not know how to go to the toilet on his own - now he does not need help anymore]
- *akufanele kanga abuze* [he does not need to ask] ...
- *e o wam kunga buyisela isitya* [and mine can bring his plate].

This discussion became very lively and included much simultaneous, agitated talking. Facilitator Essie's summary and translation of this hubbub was:

*[Masincedane group, 14 February 2007]*

*Essie: They are saying you can't separate communication and general development. Whatever the child does is communication.*

The conclusion that '*everything is communication*' and that the communicative value of much behaviour is determined by mothers' (and others') perceptive and caring responses, raised the next question:

Question 3: How can we encourage this further?

This question elicited more animated and simultaneous talking – summarised by Facilitator Essie as:

*[Masincedane group, 14 February 2007].*

*Essie; 'The mothers say they must just learn to understand it more.'*

#### **4.4.3. ALO 3: '*... and ALL our children can do that – even mine*' - the smile: the most universal communication of all.**

More specific prompting ('can you give more examples, in isiXhosa culture, like the two-hand thank you?') elicited the following:

*[Masincedane group; 8 November 2006]*

*...but something not from Xhosa religion [culture]...but for **all** religions [cultures]: the smile.*

This mother's insight and statement elicited an excited and often chaotic hubbub of agreement. Some identifiable responses included;

*[Masincedane group; 8 November 2006]*

- *Bonke abantwana bethu banako ukuncuma* [All our children can smile]

- *Wonke umntu ayabaqoda xabecumile* [All people know/ understand them when they smile]
- *yiyo lonto wonke umntu eling ukuba ayenze. Labantwana!* [That's what everyone tries to get him to do. And children!]
- *lento wonke umntu ayifunayo* [this is what everyone always wants/needs].
- *amelwane abayi fanao, uTata okanye mna...* [that's what they want, the neighbours, the father...even I].
- *...abantu baya mqualasel mayehleka...* [People notice him when he laughs].
- *Maxa uthule aze ahleke mzuzwane abavakashi bamqwalase...* [When he is quiet; then he laughs... then the visitors notice him].

One particularly poignant moment was when the very shy mother of a child whose disability was particularly severe (including deaf-blindness in addition to cerebral palsy and profound intellectual disability) contributed to the conversation for the first time;

- *... and ALL our children can do that – even mine.*

From this session onwards, participants would return to the topic of the smile often: spontaneously recounting examples of increased or new observations and also implications for communicative interactions and also participation, for example;

*[Masincedane group; 14 March 2007]*

- *He is smiling more...maybe we did not see it before.*

On a later visit to the *Iqhaya* group (27 June 2007), the visiting *Masincedane* mothers recounted the above as a discussion trigger. There was some recognition and agreement ('*ewe*'... '*mmm*'), but the *Iqhaya* participants wanted time to observe and think about the value of the smile as a communication that could be optimised to help other people to engage with their children.

During the subsequent meeting of the *Iqhaya* group, one mother recounted how she had encouraged siblings, cousins and neighbour children to try to elicit a smile by doing the things that her disabled daughter enjoyed. They now spent more time with her, massaging her hands,

singing and, by hand-over-hand assistance, even helped her to ‘clap’ her hands and hold toys etc. This mother proudly recounted;

*[Iqhayiya group; 25 July 2007]*

*...now with us it is a competition, all the other children want to say ‘She smiled for me!’*

Another mother, Nopelo<sup>1</sup>, recounted how, when she walked along her street, pushing her disabled son along in his buggy<sup>2</sup>, the neighbours went indoors or continued speaking to each other and pretended not to notice her. The neighbours’ *children*, however, were intrigued and came to look and help her when the ‘Dial-a-Ride’ vehicle<sup>3</sup> with its hydraulic hoist etc. came to collect her and her son in his buggy for a hospital visit. After the discussions about the smile, she encouraged these children that they could do certain things that would elicit a smile (e.g. engage with him by name, show him things, touch his hands and above all, talk to him).

The next time Nopelo waited at the bus stop, the same children joined her and engaged with her son in more creative ways, ‘*performing*’ for him and ‘*almost fighting*’ for his attention ‘*to get that smile*’. On subsequent occasions, more of the neighbours’ children joined the waiting group at the bus stop. ‘*The big thing was to see whether they can make him smile, and then they tried other things to make him happy*’.

She went on to recount how her neighbours started greeting her, and no longer turned away when she came along. One neighbour (the mother of one of the children who regularly came to engage with them at the bus stop) also started asking after her disabled son’s wellbeing, mentioning that

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<sup>1</sup> A pseudonym. While participants consented to and even requested the use of their real names, we later discussed this and in keeping with Lorenzo (2005) agreed upon the use of pseudonyms/aliases where identifying details in the stories of some participants, could have had harmful repercussions for those participants from the community.

<sup>2</sup> ‘Buggy’ - the local term for a therapeutically customised pushchair.

<sup>3</sup> ‘Dial-a-Ride’ is an initiative by the City of Cape Town, offering a transport service with accessible vehicles and trained drivers, to persons with disabilities in the area  
(<http://www.capetown.gov.za/en/Transport/Pages/AboutDialaRide.aspx> )

her young daughter told her his name *'and that he can understand, because he smiles when you talk to him'*.

Nopelo became tearful when she told us that now all the children see her off from the bus stop;

*'...waving and making a noise to say good bye when we get on the bus and go... and all the neighbours...the other parents...greet me and him and some of the other mothers have visited me and have even offered help...like neighbours'*.

Nopelo's personal account, triggered extensive discussions about the ostracism which mothers in particular, and also families of children with severe disabilities face. The serendipitous findings about ostracism of the mother, are further discussed and linked to the second aim of this study, 'to identify culturally appreciative strategies to support the communicative participation of children with severe communication disabilities in this context' under 5.4 below.

#### **4.4.4. ALO 4: *'...I look at his face expecting the 'sorry' look – and if it isn't there I will clap again'* - remembering and reinforcing eye contact and facial expressions used in earliest interchanges**

One example came up spontaneously in both participant groups and appeared to strike a particular resonance with all the participant-mothers. This was the agreed experience of their earliest non-verbal communication with their children while breastfeeding;

*[Masincedane group; 11 April 2007]*

[one mother, currently nursing a baby – the younger sibling of her disabled child]:  
*'...like when I breastfeed and if he bites, I clap him...like this [shows how she gives her baby's diapered bottom a quick, gentle slap] ... and then I look at his face expecting the 'sorry' look – and if it isn't there I will clap again...'*

This account elicited a very excited – and chaotic - discussion in isiXhosa, which collaborator Nolwandle summarised and explained in the subsequent reflective dialogue:

[13 June 2007]

*Nolwandle - When a mother nurses her baby and the baby bites her nipple the mother will give the baby a little slap (on the nappy...on the bottom) or jerks the breast away...and looks at the baby's face, expecting a sign of "sorry". This can be eye contact and a blink... or even just eye contact and a pause in suckling... That will show the mother that the baby understands the clap. It's like disciplining. But it's communication. And it's there – even with very small babies and with their disabled children ...and all the mothers agree. This is how it is.*

In the general hubbub that followed, participant-mothers reflected on how their behaviour had continued, changed or stopped, depending on their child's responsiveness. These reflections are in line with the extensive evidence on the value of reciprocity, in encouraging and supporting the continued inputs of a caregiver and preventing the cessation of their inputs in a non-responsive child (Dunst, Trivette & Raab, 2014; Granlund, Björck-Åkesson & Alant, 2005; Rossetti, 2001; Sameroff, 2009; 2012; World Health Organisation, 1993; 1997).

The triangulation of other observations, which were strictly speaking not part of this research study, added richness. Observations during my clinical teaching in the Kangaroo Mother Care (KMC) ward at a tertiary hospital, recounted in my reflective journal at the time, paralleled the discussions in the action reflection discussion groups. Confirming Barnard's findings (Barnard, 2009) the students in the KMC ward (and I) repeatedly marvelled at how little prompting it took to help a mother to reconnect with her baby (often after a lengthy period in the incubator).



*Reflective Journal; 2 May 2007*

*Sorry...*

*This has come up several times now. It seems that a widespread and clear non-verbal expression of 'Sorry' is almost the first real communication expected of infants. If a baby bites the mum while breastfeeding, the mum gives a small slap or jerks away "and looks at the baby's eyes to see the Sorry; a humble sort of look to say I know I've done wrong..." I want to explore what makes some mums lose this kind of awareness as a child who is non-verbal grows older, and what makes it 'work' and become so much more fine-tuned in other mums....*



*Update; 22 November 2007*

*Observations from KMC\* and students; if baby does not respond, mother's inputs decrease UNLESS she is made aware of the baby's non-verbal communication abilities...the students (and I!) are repeatedly amazed at how quickly (with very little prodding, and only one or two hints about the ways in which their babies ARE responding non-verbally) the mothers respond and do connect with their babies, learning to 'read' them, respond to ... and enjoy their babies. And then, living together in the KMC ward for a while, the mothers encourage one another to look out for these things in their babies.*

*\*I was doing clinical supervision of groups of Communication Sciences final year students in the Kangaroo Mother Care ward at the time. An aim/outcome of these sessions with the students was to encourage mother-child interaction and to support and empower mothers who struggled with this with their extremely premature babies.*

Back in the *Masinedane* group of participants, this learning continued. As one mother put it,

*[Masinedane group; 8 August 2007]*

*- I must continue to 'read' my child. Even if he does not know that I am 'reading' him. I must not stop.*

The resulting reflective questions, collaboratively formulated and agreed upon by the participants, to be explored as their next pieces of 'homework' were:

- Do I still communicate like this with my child?*
- How can I do more of this and how can I encourage others?*

During the subsequent discussions, the repeated reflection of the participants was that it was relatively easy for them to increase their responsiveness to their children, with – in most cases – rewarding results. They agreed that once they focused upon ‘*reading*’ their children’s behaviour as communication and reinforced these behaviours through communicative responses, they were rewarded in terms of their children’s responses.

*[Masincedane group, 12 September 2007]*

- *I do something, he does something, I do something and then I can’t stop!*
- *Now I know how he answers and I see it all the time! [=smiling mother]*

Another participant summed it up:

- *Now there is joy.*

The subsequent reflections on how they could encourage others (family members etc.) to see and respond to their disabled children’s non-verbal communication (e.g. smiles), raised very emotional discussions. Repeated accounts of abandonment and rejection by husbands, families and others (because of their disabled children) followed. They turned out to be related more closely to the second aim of the study, that is: to identify culturally appreciative strategies to support the communicative participation of children with severe communication disabilities in this isiXhosa context. As such, these serendipitous findings are included in the discussion related to the second study aim (Chapter Four: 4.7).

#### **4.5. Pragmatic elements of social interaction in an isiXhosa language context (repetition and proverbs)**

In linguistic terms, pragmatics is “the aspect of language concerned with language *use* within the communication context” (Owens, 2005: 472). At risk of oversimplification, pragmatic elements are concerned with the ‘how’ of communication – not so much the form or the content of the communication – and the purpose that the communication serves. An example of the use of repetition as a pragmatic strategy follows, and then the use of proverbs is revisited – but with a different outcome than the examples observed in Botswana.

**4.5.1. ALO 5 He chants ‘Hêpi-hêpi-i-i-i’ (happy-happy) over and over again as he gives each child gift - repetition helps to facilitate participation and enjoyment:**

The isiXhosa-speaking ‘Father Christmas’ (Santa Claus) who officiated at the annual Christmas party held for the children, parents and therapists attending the WCCPA outreach clinic, contributed an example of how the rhythmic repetition of a single word can serve the purpose of connection, enjoyment and communicative participation for children with a severe communication disability. I include my participant-observation field notes of the event in question:

*Field Notes: 14 December 2007*

***Cerebral Palsy Outreach Clinic (Masincedane Group), Christmas Party, hosted by the junior ‘Lions Club’<sup>1</sup>***



*Mass turnout of 25+caregivers plus children, all WCCPA therapists and 6 young Lions volunteers...*

*Mothers and caregivers sit on plastic chairs in circle with their children on their laps, in buggies next to them or on rugs on the ground next to them; cassette recorder plays popular music and Lions volunteers distribute hotdogs, juice and packets of soft sweets. Variable caregiver-child interactions (lots of eye contact while seeing to feeding/basic needs)*

*A pick-up truck piled high with black plastic bags (with gifts) arrives, hooting. Father Christmas sits on top of the pile, waving, with bags of gifts, as he gets off truck; mothers get up and dance, sing and clap (some trying to include children – e.g. holding children while dancing...)*

*Father Christmas (a 60+ years old, isiXhosa gardener of one of the Lions volunteers; first time Father Christmas) didn’t know what this entails, and it is also his first exposure to children with severe disabilities. He gets briefed step-by-step as to his ‘responsibility’ of handing out gifts by the Lions chairperson (who is also his gardening employer).*

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<sup>1</sup> The Lions Clubs International – a network of volunteer community service organisations (<http://www.lionsclubs.org/EN/index.php>)

*All mothers help their children – for example;*

- *Most mothers guide child's hands to accept gift*
- *Most mothers hold child's hands (hand-over-hand) and clap in time to music*
- *Two are face-to-face with their children on their laps singing along to music (slightly exaggerated mouthing etc.)*
- *Most children on laps and moving to music...*

*Father Christmas starts handing out the gifts to circle of children sitting in buggies, on caregivers' laps etc., becomes more spontaneous, smiles at each child and moves to the rhythm of the singing. He chants 'Hépi-hépi-i-i-i' (happy-happy) as he gives each child gift...*

*This triggers imitation/ repetition...after he has repeated 'Hépi-hépi-i-i-i' in rhythm with giving gift, mothers and children chime in at different levels of ability...*

- *Verbal children (visiting siblings) chime in 'Hépi-hépi-i-i-i' in rhythm*
- *Non-verbal children vocalise variably but in rhythm and/or move in rhythm*
- *Much joyful squealing*

*Father Christmas responds to this level of reaction from the children and mothers by repeatedly and rhythmically calling 'Hépi-hépi-i-i-i' as he hands each child a gift.*

*The amazing thing is how the whole group of mothers and children sings/chants/moves almost in unison – and even the lowest functioning children are part of the excitement... and smile.*

In the subsequent reflective dialogue with facilitator Pam, I commented on the wisdom of the Father Christmas and how he had used a repeated, rhythmic chant to raise excitement and joyful anticipation; enabling even the most severely disabled children to participate communicatively. Pam responded that, in her experience, that is what grandparents, aunts, uncles and other visitors do when they bring sweets and hand them out to children in the home that they are visiting – go from child to child, and hand out the sweets saying something like 'happy-happy' (in sing-song). In contrast, I went back to members of my own and other white South African cultural communities and to my reflective journal...

*Reflective Journal Update –  
December 2011*

*Interestingly I know 4 men who regularly perform Father Christmas 'duties' in nursery schools, Sunday schools and children's homes ... all of them white South Africans.*

*I have asked each of them, what they say (or call or chant or sing etc.) in their role as Father Christmas to connect and engage with the children.*

*ALL FOUR of these 'European-origin' Father Christmases (who do not know each other and officiate across a range of contexts, including with children with severe disabilities) responded that they ask individual children whether they have been good/obedient and try to engage each child in an individual conversation.*

*This could well be originating in the European St Nicholas/Santa Claus tradition of rewarding obedient children etc.*

It seems that in their role as Father Christmas, these white South Africans reflect a common emphasis on communicating content (meaning) and this emphasis is more dependent on words (to convey meaning). The isiXhosa-speaking man and 'first-time Father Christmas', with his repeated 'happy-happy' was more concerned with the purpose of the communication – to provide enjoyment, anticipation – and intuitively facilitated the participation of these children through rhythmic repetition.

**4.5.2. ALO 6: 'It is true. The mothers know this' - the value of proverbs; agreed but not observed and a need for further exploration**

As stated earlier, pragmatic elements of social interaction include the way in which communication is used, and the purpose for which it is used. In the preceding case study in Botswana, the use of different levels of meaning inherent in the idiomatic 'deep' Setswana (including proverbs) was useful to Boiki. In spite of not having speech and only limited physical abilities, he could convey a strong rebuke to his siblings by simply pointing to the picture of a hornbill bird on his communication board. This picture represented a well-known proverb in Setswana, '*Bana ba kgorwe ba kgaogana tlhogo ya tsie*' (the children of the hornbill share even the head of a fly) – enabling Boiki to claim his rightful portion of a bowl of food set down for

him and his siblings to share. The siblings – who could eat much faster than the disabled Boiki and threatened his rightful portion – were rebuked through this one emphatic, and culturally powerful, reminder that siblings must share equally and justly; regardless of how little food there is. The premise proposed then, was that the concise, economically expressed deeper meaning apparent in proverbs could be useful to children like Boiki, who understand much more than they can express (Prologue).

When the Botswana case study was introduced as a trigger for the first two action-reflection discussions in the *Masinedane* and in the *Iqhayiya* groups respectively, this example of Boiki using the Setswana hornbill proverb to discipline his siblings immediately struck a chord. This resonance was evidenced by a general, affirming hubbub and exclamations summarised simply by Collaborator Pam as, '*It is true. The mothers know this*'. Participants in both groups agreed that proverbs were indeed very powerful expressions, and their characteristic need for very few words was discussed as an advantage in communicating without speech. However, proverbs did not come up again as a potentially helpful strategy **for the children of these participants**. Reflections on this 'negative finding' included collaborator Pam and Nolwandle's suggestion that the inclusion of proverbs should be followed up in actual communication therapy sessions (inside the outreach clinic). They both felt that communication therapist inputs, in including pictures depicting relevant proverbs on the communication boards of those children who could communicate in this manner (like my work with Boiki in Botswana), would be necessary to explore this potential further. Direct intervention (with child participants) was beyond the scope and remit of this part of the study. (This need was noted as an implication for further research, see Chapter Six: 6.5 Recommendations).

Surprisingly – or rather, serendipitously - **proverbs did emerge again in a different context**: namely in the action-reflection discussions about the ostracism experienced by participant mothers because of their disabled children, as discussed in 5.6.

#### **4.6. Interim summary of Theme One**

In summary, the first main theme, illustrated in Figure 4.1 below, comprised the six action learning outcomes which addressed the first aim of the study, that is; to identify culturally determined non-verbal and pragmatic elements of social interaction found in, but not limited to,

an isiXhosa language context. To begin with, the isiXhosa speaking participants easily recognised similarities between the examples recounted from the Botswana case study and their own contexts, and could transfer the applications to their own isiXhosa language context. They then set out to identify and ‘test’ additional examples of non-verbal communication and pragmatic features common in isiXhosa, which could support non-verbal interaction and facilitate the communicative participation of their children.

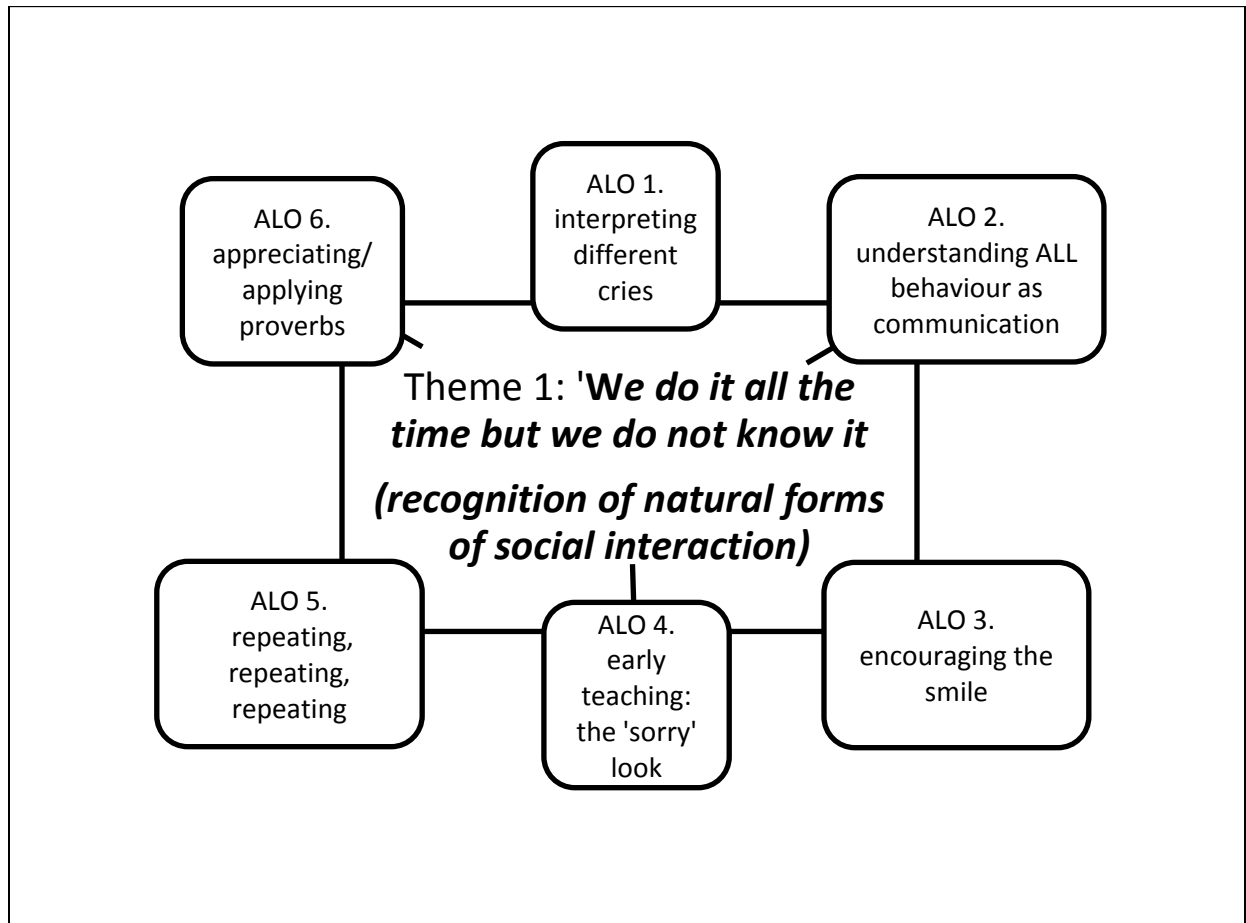


Figure 4.1: A diagrammatic overview of the six action learning outcomes (ALOs) contributing to Theme 1: the recognition of different forms of natural social interaction found in, but not limited to, the given isiXhosa context.

#### **4.7. Theme 2: *It is a way for the mother to turn the spear* - Parent empowerment through culturally appreciative strategies to support communicative participation of their children with severe disabilities**

The second aim, or desired outcome, of the study was to identify culturally appreciative *strategies* to support the communicative participation of children with severe communication

disabilities in this isiXhosa context. By this time, we had gathered most of the examples and formulated the action learning outcomes that contributed to the achievement of the first study aim (described in 4.3 – 4.6), in the action-reflection groups, supplemented by the reflective dialogues with the facilitators and/or collaborators. Subsequent triggers for discussion were guided by the two objectives – or steps to achieve this second aim - that is:

- to describe the usefulness of such culturally determined elements of social interaction in enhancing the communicative participation of children with severe communication disabilities in an isiXhosa language context.
- to explore the synergy of the communication interventionists' expertise and the participants' cultural experience for the enhancement of the communicative participation of children with severe communication disabilities.

We had been guided generally by Paolo Freire's three-question approach (1970), that is; '*What is the problem?*'; '*Why is this problem?*' and '*What can we do about the problem?*' Pam, Nolwandle and I tried to move forward to the third question, in order to fulfil the aim of identifying culturally appreciative *strategies* to support the communicative participation of children with severe communication disabilities in this isiXhosa context. However, in trying to respond to this '*why*' question, both groups of participants repeatedly returned to the challenges they experienced, in terms of rejection by family (frequently also by the father of the disabled child in question, and his family) and ostracism from their communities in general.

➤ **A clarification about the use of serendipitous findings here:**

As described earlier, some findings did not emerge as an outcome of the objectives, but in view of the aims of the study new relevance had to be attributed to certain observations *afterwards* (MacGuire, 2006). Thus, for example, the recurring accounts of ostracism and rejection experienced by the mothers of children with disability did not address the objectives, but became a key contribution in the fulfilment of the broader, second aim of the research. This second aim was to identify culturally appreciative *strategies* to support the communicative participation of children with severe communication disabilities in the given isiXhosa contexts.



Several serendipitous findings, individually identified as such, are integrated here, in acknowledgement of their relevance, among the other more ‘planned’ action learning outcomes. Thus, the serendipitous finding about the ostracism and rejection experienced by the participant-mothers became the seventh action learning outcome (ALO 7).

**4.7.1. ALO 7: ‘How can we encourage others to accept our children...and to communicate with our children if we, the mothers, are rejected?’ - the exclusion of mothers needs to be addressed as a pre-requisite for the communicative participation of their children.**

Repeated accounts of rejection and even abandonment by husbands, families and others (because of their disabled children) became the participating *mothers*’ primary topic for several sessions. While these discussions did not address the objectives of the study, collaborative reflections, and the mothers’ own appeal, indicated the central relevance of the mothers’ experience to the study aim, and it became a turning point which determined the subsequent discussions, and action learning outcomes (ALOs).

In one of our reflective debriefings, Pam and Nolwandle translated and explained a particularly emotive discussion as follows;

*[Reflective dialogue: 9 May 2007]*

*Pam: The mothers are saying, ‘It’s not only our children; it’s us that are outside in our families’.*

*Nolwandle: ... and they are asking how can we encourage others to accept our children...and to communicate with our children if **we**, the mothers, are rejected?*

In keeping with the nature of a transformative action research study, there was leeway for the participants to articulate and discuss this pain, and to encourage one another in this shared experience. Several action reflection sessions were dominated by this topic and parents – mothers in particular – needed time and space to share some of their experiences of ostracism and exclusion. I purposefully stepped back; becoming a listener only (i.e. not prompting, or asking questions) and my two experienced collaborators Pam and Nolwandle guided and facilitated these discussions in isiXhosa, mostly without translation (due to the needed shift to prioritise support over data production). They were sensitive to the emotional issues at stake, and

only sometimes tried to direct the discussions back to the research topic. Letting the mothers talk, listen to each other's stories, discover common ground and support each other was an important aspect of ensuring the ethical principles of **best interest or wellbeing** (including the principles of **non-maleficence** and **beneficence** (Chapter Three: 3.10.2). The participants themselves contributed to the support shared when topics became particularly emotional and personally upsetting to certain mothers. One particularly poignant incident was when the *Masinedane* group ensured that one mother who had cried quite a bit during one session, was walked home by other mothers, even after she had calmed down, to ensure that she was not alone.

Pam, Nolwandle and I faced the challenge of balancing the need to facilitate a forum for participants to share their painful stories of exclusion and ostracism, and the objectives of the study. We needed to acknowledge the pain of the mothers' exclusion, and yet try to move forward to the third Freirian question ('*what can we do about the problem?*') (Freire, 1970), applied more specifically to this study as:

*'What can we do to facilitate the communicative participation of our children?'*

Nopelo's story, recounted earlier (4.4.3) became instrumental in shifting the focus back to the study aim of supporting the communicative participation of their children. After starting her journey of discovering and encouraging more of her son's communicative abilities herself, Nopelo had explained these abilities to the neighbourhood children, thus facilitating their communicative engagement with him, which in turn eventually resulted in their parents, reaching out to her:

*[Iqhayiya group; 25 July 2007]*

*...the other parents...greet me and him and some of the other mothers have visited me and have even offered help ... like neighbours.*

This example of how Nopelo herself was an agent of the change – albeit slow change – in her own situation by engaging with neighbourhood children triggered more action-reflections on 'self-advocacy'. Originally coined by rights activists in the field of developmental or intellectual disability, the definition of self-advocacy has broadened and the Oxford English Dictionary

defines it as ‘the action of representing oneself or one’s views or interests’ (OED online<sup>1</sup>). Basic, important elements of self-advocacy are to know oneself and one’s needs and then to know how to communicate these effectively and assertively. Nopelo’s story exemplified an instance of self-advocacy in the situation of her own exclusion by neighbours - and also the strategy she employed – that is, engaging with the neighbours’ children.

Participants in both groups contributed additional examples of self-advocacy, having recognised their own exclusion. They were able to identify and ‘test’ strategies to support the communicative participation of their severely disabled children in their specific community and culture.

Collaboratively identified examples of strategies of self-advocacy are described in the following action learning outcomes (ALOs 8, 9 and 10).

#### **4.7.2. ALO 8: ‘They only use their children’s names... it makes the child to be known as a person’ - the words or names we use are powerful advocacy instruments**

The topic of disability-related vocabulary came up in both groups; in the Masincedane group, there was a ‘hubbub’ during which a new mother shares her experiences of ostracism and her child being labelled ‘*Isidalwa*’ ... other mothers chip in ...very emotionally and collaborator Pam summarises and translates.

*[Masincedane group, 11 July 2007]*

*Pam: ... they are telling her that she, that mother, must always, always only use her child’s name – to show people he’s human and also to remind herself never to think he’s not, she must not say or even think ‘Isidalwa’ but his name, as a person...*

*All the mothers are saying that they only use their children’s names and it is the only way to change the thinking. It makes the child to be known as a person.*

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<sup>1</sup>Accessed on 2 February 2014 from <http://www.oxforddictionaries.com/definition/english/self-advocacy>

Similarly, a particularly emotional session in the *Iqhayiya* group was summed up by collaborator Nolwandle in the subsequent reflective dialogue, as follows:

*Reflective Dialogue, Friday 13 July 2007*

*Nolwandle: A very bad example of labelling is to use the term 'isidalwa'...that means 'creature'...so people will talk about other children by name ...Lungi...uRuth<sup>1</sup>... but this one they will call Isidalwa. So what the parents experience is that the child is seen as an object with no human character...dehumanising...as opposed to the child as a human being with the condition. ...the group agreed that bad names, like Isidalwa, are used which have negative connotations especially in Xhosa. These names carry the impression that people do not accept the condition together with the child. So the parents internalise this rejection and also have difficulty in relating to the child...the parents themselves...*

*One mother mentioned that it is easy for a mother to permanently reject her own child consciously or unconsciously by just referring to the child as 'isidalwa'.*

*So they decided that they, the mothers will always only refer to their children by name, even with grandparents and others who only use 'Isidalwa' but maybe...after many times...they, others will also stop using 'Isidalwa' and leave that thinking...*

After these discussions, both groups of participants unanimously committed to refer to their children only by their given names and not to use the word *Isidalwa* when referring to their children – even if others (including respected senior relatives etc.) continued to do so. The mutually expressed hope was that this would be a way of helping others to see and accept their children as children and not as ‘creatures’ and it would also help the parents themselves – especially the mothers – not to harbour negative and rejecting emotions about their children.

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<sup>1</sup> In isiXhosa, the noun prefixes indicate a person or other category – the 'u' prefix before the name emphasises that this is the name of a *person*.

An additional reflection by Nolwandle related to siblings and other children:

[Reflective Dialogue: Friday 13 July 2007]

*But it's interesting how other children have their own way of relating to children with disabilities...they use their own words, like:*

*Mncinci-mdala* [small-big child]

*Umntwana ogulayo* [sick child]

*Although these sound negative, the moms accept them because they are not intended to be hurting, it's the child's way of showing sympathy and these descriptions by other children are original and descriptive... (Nolwandle)*

This reflection contributes both to the action learning outcome about the importance of recognising the power of the words or names we use as powerful advocacy instruments, as well as recognising the value of siblings and other children as strategic facilitators of communicative participation.

#### **4.7.3. ALO 9: 'With us it is a competition, all the other children want to say, 'She smiled for me!' Other children are strategic facilitators of communicative participation**

Nopelo's story of how her relationship with neighbourhood *children* led to greater acceptance of her child and herself (4.4.3), was but one example of mothers 'using' other children to provide opportunities for communicative participation – and enjoyment - where the beliefs and attitudes of other adults were a barrier not only for her son, but for herself. As recounted earlier, other participants told how they had prompted siblings etc. to elicit *a smile* by doing the things that their child with a disability enjoyed:

[Masincedane group; 8 November 2006]

- *yiyo lonto wonke umntu eling ukuba ayenze. Labantwana!* [That's what everyone tries to get him to do. And the children!]

[Iqhayiya group; 25 July 2007]

- ...now with us it is a competition, all the other children want to say 'She smiled for me!'

These examples of encouraging and guiding other children (a) to recognise a disabled child's non-verbal communication and (b) to provide communicative opportunities for their disabled children are not novel findings in themselves. The childrearing customs of 'collective' communities (e.g. most African cultures) lend themselves particularly to such child-to-child strategies and triangulation with earlier findings documented in the literature follows in the next chapter (6.XX).

#### **4.7.4. ALO 10 '*... because you cannot fight with a proverb... It is a way for the mother to turn the spear and say 'what about you?'* Proverbs are tools of advocacy for mothers of disabled children**

As recounted earlier (ALO 6, above) proverbs did not feature as a direct means of communicative participation for the participants' children in this context, in the way they did in the Botswana case study (Prologue). However, a series of action reflections led to insights and practical applications of proverbs as valuable advocacy tools in the contexts of the ostracism which the participant mothers (in particular) experienced because of their disabled children. It began with one participant sharing how she was repeatedly brushed-off with a well-known proverb by family when she asked for help with her disabled child.

*Akukho ndlovu isindwa ngumboko wayo* – a literal translation would be, 'No elephant is overburdened by its own trunk'. The meaning, applied to life, is something like 'Anyone should be capable of bearing his own or her own responsibilities' (Calana, 2002: 34). Other participants agreed that this proverb was sometimes used to justify situations where they (especially the biological mothers of children with disabilities among them) were shunned or avoided by family, neighbours or others. During the subsequent reflective dialogue, Nolwandle summarised the participants' agreed conclusion:

*Reflective dialogue: 11 July 2007*

*Nolwandle: In our culture, a proverb is stronger than other words. So if I tell you a proverb it is much stronger than my own words. With the elephant one, all the*

*mothers said they just have to accept it when the family tells them; the elephant has to carry his trunk ... because you cannot fight with a proverb.*

This discussion about proverbs in relation to some of the participants' painful experience of ostracism took an unexpected turn when one mother wondered how she and others could use some of the more positive proverbs – with meanings of inclusion and sharing - to advocate their own inclusion. She volunteered the well-known proverb: *Umntu ngumntu ngabantu* ['a person is a person because of other people' or 'no man is an island']. Pam summarised the conversation:

*Masinedane group: 12 September 2007*

*Pam: ...so she is not alone. She ... they are saying they can use that when they ask for help – to remind that other person ... that even with a child with a disability she is one of them. And the other people still need her...*

Both Sesotho first-language participants added that they have the same proverb, with the same meaning ('and the same power') in Sesotho, that is: '*Motho ke motho ka batho*' ('a person is a person because of other people'). From my time of living and learning in Botswana I was able to add that the Setswana version of the proverb is identical, that is '*Motho ke motho ka batho*'.

At a subsequent next meeting, another participant began the discussion by volunteering a further proverb, that she had used as a retort about the need to appreciate each other:

*Masinedane group: 10 October 2007*

*Intaka yakha ngoboya benye* [a bird builds (its nest) with another's feathers].

Pam's explanatory aside to me was that the mother in question used this as a retort when she helped a relative who was particularly harsh in the way she blamed this mother for the child's disability. In this way, the mother felt she could remind the relative in a respectful way, that even if she (the relative) judged and rejected this mother for bearing a child with a disability, they still needed one another.

A less positive retort was suggested too – one mother suggested responding to a judgemental, painful accusation about her status as a mother with a disabled child with the proverb –

*Masinedane group 10 October 2007*

- *Iqaqa aliziva kunuka* [a skunk does not smell itself. People are unaware of their own shortcomings].

Amidst an outburst of laughter (some joyful, some embarrassed), exclamations of shock – and agreement – and a hubbub of simultaneous talking, Pam’s explanation to me was:

- *It is a way for the mother to turn the spear and say ‘what about you?’*

At times like this, I could not but agree with Lipenga that “this passage hardly needs any elucidation” (Lipenga, 2014:6). Furthermore, I could not help noticing how Pam made use of yet another metaphor in her explanation – such figurative, powerful expressions are indeed a natural part of daily isiXhosa (and other African) communication.

At the end of this lively session, one more contribution was made – particularly powerful because of *who* made it (an older woman) and its timing at the end of the session, when Pam had already wrapped up and summarised the session: the only grandmother-participant present in that session literally silenced the others for a moment when she added one more saying:

- *Ithemba liyaphilisa* [Pam’s explanation: from hope you can be great one day; or hope causes one to live]

- [stunned silence, then laughter and hubbub as participants agree...several women repeat ‘*Ithemba liyaphilisa*’...start chanting it...joyous laughter...clapping of hands...]

At the end of this specific session, while the mothers and other participants were gathering their things to go, tying babies onto their backs, gathering up bags, helping to stack chairs and generally clear up the temporary clinic site, individual participants repeated this proverb to one another in agreement and turned it into the departing greeting of the day – instead of the usual ‘*hamba kakuhle*’ or ‘*bye-bye*’ departing participants said/wished one another



*'ithemba liyaphilisa' ... or simply 'Themba!' [= Hope!]*

After this session, Pam herself was moved and her parting shot to me was

*Those mothers really liked that – I think it can help. We like proverbs...they are strong and they are part of us – they make us amaXhosa...Xhosa people.*

**4.7.5. ALO 11: 'When you ask "did you practice at home?" I stay quiet. I don't know what to say' - therapists and mothers need to talk, to listen and to learn from one another.**

*Reflective journal: 15 June 2006*

*...there is a lot of frustration and even anger, that we as therapists are missing the point, mothers just say yes to our therapy recommendations and home programmes (=“those exercises”), but their real needs are not met. So they don't do “those exercises” either.*

An introductory guest-address by the then new Chief Executive Officer (CEO) of the WCCPA (she being a person living with cerebral palsy herself) to the mothers in the *Iqhayiya* group preceded one of our action-reflection sessions. Two points made during her talk proved to be emotive discussion triggers:

*[Iqhayiya, 30 May 2007]*

*...there is a need for mothers to push/raise expectations for their children with CP – which is what my parents did and what helped me to become independent...*

*...I needed different therapies and assistive devices, like orthopaedic boots, for different phases of my life... [CEO of WCCPA]*

During the subsequent meeting of the *Masinedane* group, where the members who had attended the *Iqhayiya* meeting summarised and reported the above address to the group, responses included:

[11 July 2007]

- *But they [the therapists] don't understand WHY we sometimes don't come to therapy, or why we are late and why we cannot do all those exercises. They don't know what it is like for us...*
- *She got boots and now she can walk. Why can't my child get boots?*
- *I say, the buggy makes him [her own son with CP] lazy...*
- *These buggies are stopping our children!*
- *Are the boots for white ... rich people only?*

Collaborators Nolwandle and Pam, and I tried to explain the wide range of children's different therapeutic requirements and the need for individual decisions about appropriate devices. We also recounted the mothers' sense that they were not understood and the misunderstanding about the orthopaedic boots to the therapy team.

In response to this example of differing expectations and communication breakdown between therapists and parents, the desire for a forum for open discussion was voiced – by both therapists and parents.

As a concrete action arising out of the abovementioned action reflection discussions (triggered by the CEO's life story) we began planning a combined meeting for the therapists and parents from both *Iqhaya* and *Masincedane* groups. Nolwandle, with her social worker experience at facilitating similar gatherings, organised and facilitated the meeting, and Ndileka, an experienced translator from the cerebral palsy clinic, assisted with immediate two-way translation (both from isiXhosa to English and from English to isiXhosa). This meeting was centred on the reciprocating wishes: '*what mothers would like therapists to understand*' and '*what therapists would like mothers to understand*' and contributions under each included the following:

➤ **What mothers would like therapists to understand:**

*Combined information feedback session with participants and therapists;*

*26 September 2007*

*(with Ndileka & Nolwandle translating)*

*There are reasons why we arrive at therapy sessions late, unprepared...we are unmotivated, depressed:*

- *I have to start to bath and feed and dress [child's name] at 4.30 am to get the transport to clinic – and then the transport is late. And then I come and I know he is hungry again, and his nappy is dirty because now it is ten or 11o'clock and he is unhappy but we start therapy and the therapist is angry because she says I am late. I just look away. I am so tired. Why do I come?*
- *It is a whole day to come to therapy. When I come to the clinic I am so tired.*
- *And even on the transport some people give me a hard time because of my disabled child. Now he is big so everyone can see. When he was smaller it was easier to hide his disability...but now I just hear 'isidalwa' and they look away and move away on the transport. Sometimes I can't think. Therapy...exercises...is not what I am thinking about. The grant money is not enough for transport – the father does not help. So there is less food if I use grant money for transport. I am so tired*

*We try to understand that more therapy and exercises can help our children, but sometimes we cannot do them because:*

- *When I came from Eastern Cape, to get help for [child's name] here, only my brother and his girlfriend helped me so we are living three adults and two children in that small one-room [shack]. There is no space for the exercises ... so when they show me the stretching and the exercises at the clinic I know that I can't do them that side [at home in the shack]... but I am scared to tell the therapists.*
- *It is not only physio exercises...also feeding: there is not place ... I do not have three cushions to make her sit like you make her sit here. So when you ask 'did you practice at home' I stay quiet. I don't know what to say.*

➤ **What therapists would like mothers to understand:**

In the combined information feedback session with participants and therapists, the responses of the therapists highlighted some of the issues that they implicitly wanted mothers to understand but which had not been explained because the mothers' understanding and concerns were not known:

26 September 2007

(Ndileka & Nolwandle translating)

- *Therapist 1: we will always encourage mobility, and we will never hold back a child by prescribing a buggy if the child can benefit from orthopaedic boots (and the physical training that went with them).*
- *Therapist 2: Buggies are meant for correct positioning – to prevent the back becoming worse*
- *Therapist 3: Buggies are meant to help mothers – we know you have to walk far with your children – and it is bad for YOUR backs if you carry them and all the other things, especially when they get bigger.*
- *Therapist 1: Boots are not for white rich children – if a child can benefit from boots (or AFOs<sup>1</sup> or a walking aid), we try our best to get what is best for the child at the stage that he or she is at.*
- *Therapist 3: ...the buggies are actually much more expensive.*

**4.7.6. ALO 12: ‘The reason I came back to the clinic today... and I will come again ... is the things I learnt out here...from you’ - the value of the waiting time/area**

I venture to present the following as a *definitive* serendipitous finding, that is, an observation that was not an outcome of the objectives set out: but the retrospectively realised relevance of this observation contributed to the fulfilment of the second aim of the study (MacGuire, 2006).

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<sup>1</sup> AFO: Ankle-foot orthosis – a specifically customised brace sometimes applied to stabilise the foot or to counteract drop foot or excessive flexion (Morris & Condie, 2008).

Given a space and a time to meet, these isiXhosa parents and carers supported each other; complementing and supporting the therapy services happening inside the clinic, as reinforced by the following two related observations of the *converse* circumstances:

- The same isiXhosa speaking participants, comprising mostly mothers of children with severe CP, did not (or could not) engage with each other or with others in a large, benched waiting area where many people were waiting for different purposes. This clamming up and lack of engagement among the otherwise talkative participants was observed on those occasions when bad weather forced them to wait inside the neighbouring police station (with its large waiting area and long, fixed benches together with a motley crowd of community members waiting for diverse police services). This was also the reason why one of several general community health centre waiting areas, with long fixed benches and mixed groups waiting, was not initially chosen as a study site for the action-reflection discussions.
- Given the same space and time variables (that is, informally arranged chairs under trees waiting for their therapy sessions) non-isiXhosa mothers and parents tended to keep to themselves: apart from a cordial greeting and isolated brief interchanges, they did not engage with one another.

The waiting *Masinedane* group, chatting and engaging with each other and with each other's children about progress, joys and challenges, often affirmed what was happening inside the clinic, for example, after her second visit to the outreach clinic, a 'new' mother shared the following: (in isiXhosa with Pam's translation):

*Masinedane Group: 8 August 2007.*

A newcomer-mother's story, originally in isiXhosa, translated by Pam.

*'When I was finished inside [the clinic] the first time... I was thinking I am not coming again. This is not going to help my child. But then I sat outside, here ... listening... and I was seeing you other mothers ... and your children. And just listening, I learnt that that child [pointing to one of the other children] has been coming for some years and that when she started she was like mine ...but now she is holding the cup to drink*

*and...she can't talk but she is showing you [her mother] what she wants. The reason I came back to the clinic today... and I will come again ... is the things I learnt out here...from you [sweeping hand movement to indicate all the parents sitting there]. I learnt from you, from your telling, that the lessons in there [points in to clinic] will help my child. Maybe slowly, a long time...but they will help.'*

Thus, given a regular, flexible space and time to meet as a group, the isiXhosa speaking mothers and other carers waiting for their therapy sessions, talked (a lot!), were a source of support for each other, affirmed and supported the therapy services at the outreach clinic and engaged with each other's children, creating opportunities for communicative participation.

In summary, the second main theme encompassed the collaborative identification of culturally appreciated strategies to explore culturally appreciative strategies to support the communicative participation of children with severe communication impairments in this context (as per Aim 2 of the study). The priority strategy, upon which the other strategies 'hinged' and depended, was the prerequisite need to acknowledge and address the exclusion of mothers (identified as ALO 6). An illustrated overview of Theme 2 is presented in Figure 4.2 below.

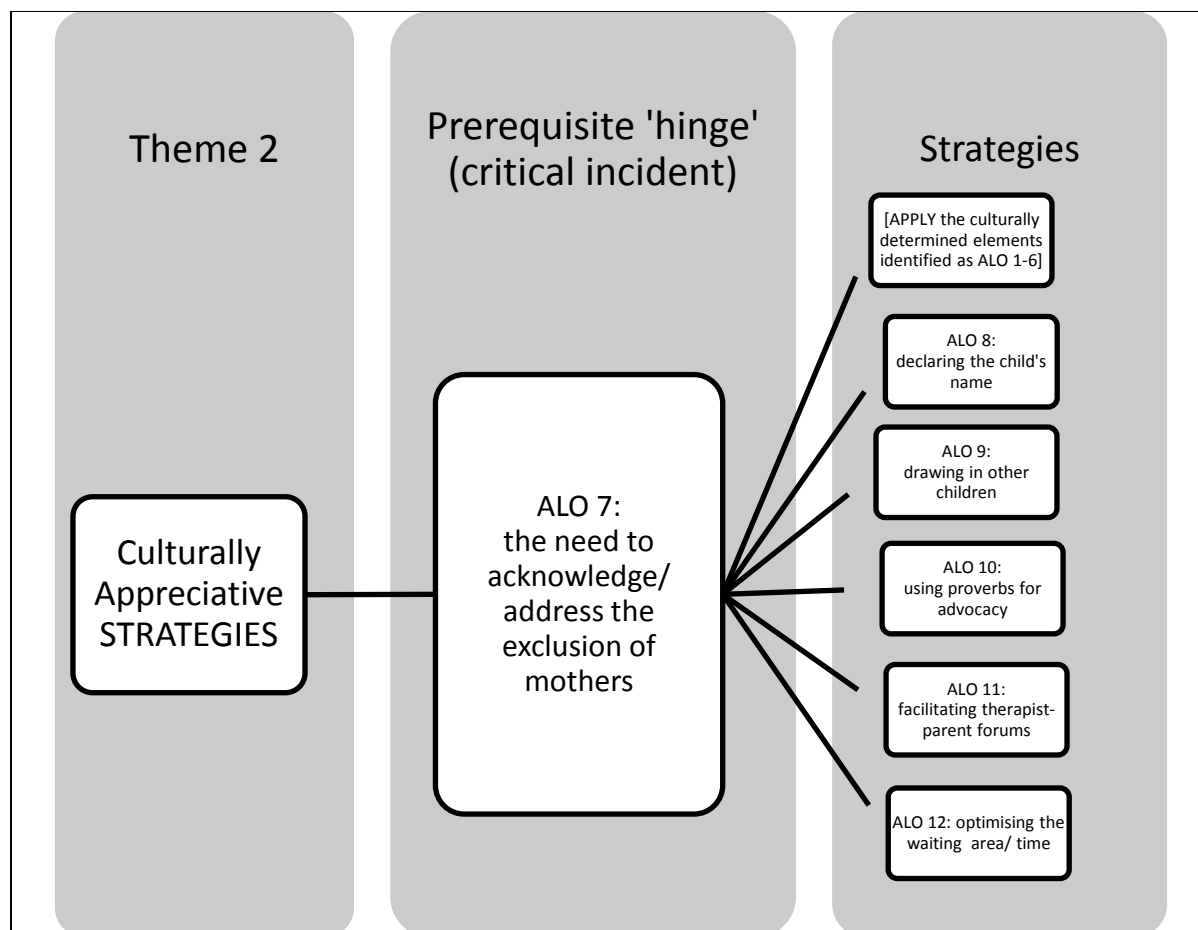


Figure 4.2.: An illustrated overview of Theme 2. six culturally appreciative strategies to support communicative participation ‘hinge’ upon the acknowledgment and support mothers in their experience of exclusion due to beliefs about and attitudes to them as mothers of children with severe disabilities.

#### 4.8. Chapter conclusion – organising the bricolage

While writing this chapter, I have experienced a tension between describing the findings as they relate to the aims and objectives of the study, and describing the *bricolage* or patchwork quilt of rather diverse data. Action research by definition implies the iterative quest for unexpected findings. Furthermore, in cleaning and interpreting the data, the relevance of some additional, ‘unsought-for’ observations – or serendipitous findings - and their implications in meeting the aims of the study, could not be omitted.

In direct response to the *first aim* - and in a satisfying, conventional ‘fit’ - several findings or action learning outcomes (ALOs) supported the presence of non-verbal, pragmatic and contextual elements of social interaction in the isiXhosa language context. Given examples from the Botswana case study, there was a generally agreed, preliminary recognition that there are similarities between elements of social interaction in the Setswana and isiXhosa language contexts and beyond. Additional aspects of social interaction that could be helpful – were then identified in the isiXhosa language context:

- the communicative value of different cries
- the smile: the most universal communication of all
- seeing *all* actions as communication
- the earliest non-verbal ‘disciplining’ of communication between mothers and babies during breastfeeding
- repetition and rhythm as facilitators of communicative participation
- the value of proverbs (with their few words and rich meanings)

As illustrated earlier in Figure 4.1, these elements of social interaction identified in (but not limited to) the given isiXhosa language context were gathered into the first broad theme; the collaborative identification and appreciation of diverse, natural forms of social interaction as articulated in a participant’s quote ‘*We do it all the time but we do not know it*’.

In response to the *second study aim*, culturally appreciative strategies that can support the communicative participation of children with severe communication disabilities in this isiXhosa language context were identified. Several serendipitous findings emerged which were not sought according to the planned objectives of the study, but which contributed to achieving the second aim and these were integrated in six further ALOs:

- a strategic need upon which much else depends, is to address the exclusion of mothers as a pre-requisite for the communicative participation of their children; an asset-based approach, that is, the mothers’ own awareness of what their children CAN do and encouraging/reinforcing/supporting the development of these assets; for



- example reinforcing the smile. Self-representation **strategies** for mothers include the awareness and enjoyment of ALOs 1-6, and to draw others' attention to them.
- stigma-laden words to describe their children need to be replaced with non-discriminatory language; a powerful advocacy strategy is to always refer to the child by name and not by means of a derogatory - albeit commonly used - descriptor
  - proverbs are powerful, culturally familiar advocacy tools
  - there is a need for forums for open communication between parents and therapists – in regular, busy clinics there are reciprocal frustrations of not being understood and not understanding both for parents and for therapists
  - other children are a valuable resource in supporting the communicative participation of their own disabled children
  - given a waiting area and a regular waiting time in a space physically conducive to chatting, isiXhosa-speaking mothers support and learn from one another.

These ALOs contributed to the second main theme: the collaborative identification of and commitment (by all participants, collaborators and myself) to practice culturally appreciative strategies to support communicative participation of our children, as expressed by collaborator Pam's powerful metaphor when she said;

***'It is a way for the mother to turn the spear'.***

## Chapter 5:

### Discussion and thesis building<sup>1</sup>



*Health care workers are the ‘experts’ on answers to the ‘what’ questions, but the communities are the ‘experts’ on answers to the ‘how’ questions.*  
-Sally Hartley (Emeritus professor, UEA)<sup>2</sup>

#### 5.1 Introduction to the chapter

This chapter comprises a discussion of the findings and what I venture to introduce as new contributions in the interdisciplinary fields of Disability and Rehabilitation Studies. The voices of the participants have confirmed that indeed, “the communities are the experts on answers to the *how* questions” (Hartley, 2004: 38), and that the way in which we as rehabilitation professionals work, can either unlock or block this resource. Inappropriate interventions have been described as a “cultural invasion” (Paulo Freire, 1970, cited in Hope & Timmel, 1995a: 86); instead, interventions need to meet real needs, in contextually appropriate and culturally appreciative ways.

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<sup>1</sup> The term ‘thesis building’ is borrowed from Lorenzo, 2005.

<sup>2</sup> Hartley, S. 2004. Bridging the gap between health care professionals and communities. *Community Eye Health Journal*. 17 (51): 38-39.

In the previous chapter, the findings were recounted as they related to the aims and objectives of the study; and framed as twelve ‘action learning outcomes’ (ALOs). The analogy of a patchwork quilt, or *bricolage*, was helpful in conceptualizing the whole, and I became a *bricoleur* or ‘maker of the quilt’ by selecting, organizing and presenting the diverse - and sometimes extremely unexpected – findings. My *bricolage* reflects some findings confirming those already presented and described by others earlier; but then there were some findings or patterns of findings and tentative conclusions which appear to be new and which will be discussed below. A description of the processes contributing to thesis-building follows. I then present three theses – that which I venture to present as something *new*. A reflective summary closes this chapter.

## **5.2 Re-confirming the purpose of the study**

As described earlier, the need for responsive service delivery for children with severe communication disabilities in developing or low-income contexts, including South Africa, was a major motivation for this study (Chapter One: 1.4).

Based upon the lessons learnt in the preliminary case study in Botswana, the problem statement for the main study in South Africa was encapsulated in the research question (Chapter One: 1.8):

***In what ways can cultural resources in an isiXhosa language context be optimised to support the communicative participation of children with severe communication disabilities?***

The *focus of this study*, grounded in the transformative paradigm (Mertens, 2003; 2009; 2010) was therefore on culturally determined processes that can support the communicative participation of children with severe communication disabilities in an isiXhosa language and culture context. Before embarking on the quest to fulfil the aims of the study, a shared understanding of the focus of the study needed to be attained together with the participants. As the researcher, I was guided by the appreciative inquiry approach (Cooperrider & Whitney, 2005; Ludema, Cooperrider & Barrett, 2001; Ludema & Fry, 2008) and the challenge put out by Garcia-Coll and Magnussen to reconsider culture not only as an influence but as an important *resource* in a child’s development (García Coll & Magnuson, 2000; 97). While I declared a

possible, positive bias (Chapter Three: 3.9), I wanted this positive expectancy to be conveyed to, and embraced by, the participants as a starting point for the research journey.

This foundation was achieved by means of reviewing examples of culturally determined non-verbal and pragmatic elements of social interaction that do not necessarily require speech, from the findings of the preliminary case study in Botswana. The presence of similarities between elements of social interaction in the recounted Setswana and in the participants' own isiXhosa language contexts was identified. Moreover, a participant-initiated rapid local appraisal served to confirm, for the participants, similarities with *other* southern African indigenous languages as well. The participants' realisation that commonalities of basic elements of social interaction between indigenous languages in the region could contribute to a means of understanding one another beyond language boundaries was agreed as a potential resource in exploring ways to encourage others to understand and engage with their children ('... *everyone can understand them....this can help*'). This foundational realisation confirmed earlier evidence that an awareness of, and a commitment to identify and promote, forms of natural social interaction are pre-requisites to engage and support basic communication as required by children with severe communication disabilities (Granlund, Björck-Åkesson & Alant, 2005; Lage, 2005;2007; Mall, 2002; 2005). Having established this pre-requisite, shared awareness, the aims of the study were pursued.

### **5.3 From aims to action learning outcomes to themes**

In the preceding chapter (Chapter 4), the findings of the study were described in terms of twelve action learning outcomes (ALOs) which contributed to the two main themes, reflecting the study aims as summarized in the illustrated overview below (Table 5.1).

**Table 5.1: Tabulated overview of the aims and objectives of the study; which led to the collaboratively identified Action Learning Outcomes (ALOs) which in turn contributed to two main themes - in response to the aims and objectives.**

Aims of the Study or desired outcomes	Objectives steps to achieve the aims	Action Learning Outcomes (ALOs)	Main Themes
<p><b>Aim One:</b> to identify culturally determined non-verbal and pragmatic elements of social interaction in an <i>isiXhosa</i> language context.</p>	<p>- to describe the presence and use of some non-verbal and pragmatic elements of social interaction in an <i>isiXhosa</i> language context.</p>	<p><b>6 +- culturally determined elements of social interaction</b></p> <p><b>ALO 1:</b> recognising communication without speech  <b>ALO 2:</b> all behaviour is communication  <b>ALO 3:</b> the smile: the most universal communication of all  <b>ALO 4:</b> remembering and reinforcing eye-contact and facial expressions used in earliest interchanges  <b>ALO 5:</b> repetition helps to facilitate participation and enjoyment  <b>ALO 6:</b> the value of proverbs; a need for further exploration</p>	<p><b>Theme 1:</b></p> <p><i>'We do it all the time but we do not know it'</i></p> <p>The recognition and appreciation of diverse forms of everyday social interaction</p>
<p><b>Aim Two:</b> to identify culturally appreciative <i>strategies</i> to support the communicative participation of children with severe communication disabilities in the given <i>isiXhosa</i> context</p>	<p>-to describe the factors that enhance the communicative participation of children with severe communication disabilities in an <i>isiXhosa</i> language context.</p> <p>- to explore culturally appreciative ways of enhancing the communicative participation of children with severe communication disabilities.</p>	<p><b>6 strategies to support communicative participation:</b></p> <p><b>ALO 7:</b> NB Address the exclusion of mothers as a pre-requisite for the communicative participation of their children. Self-representation <b>strategies</b> include: use and enjoy ALOs 1-6 and point out ALOs 1-6 to others.  <b>ALO 8:</b> avoid derogatory descriptors and USE child's name  <b>ALO 9:</b> make the most of other children,  <b>ALO 10:</b> use proverbs, as advocacy tools  <b>ALO 11:</b> create opportunities for meeting between parents and interventionists with translator  <b>ALO 12:</b> the value of the waiting area/waiting time.</p>	<p><b>Theme 2:</b></p> <p><i>'It is a way for the mother to turn the spear'</i></p> <p>- Parent empowerment through culturally appreciative strategies to support communicative participation of their children with severe disabilities.</p>

## 5.4 Interim reflection – so what is ‘new’?

My *bricolage* or patchwork of findings (the action learning outcomes or ALOs 1-12) and their analyses into the two main themes, echo some findings already presented and described by others earlier; but then there were some patterns of findings and tentative conclusions which appear to be new.

*Reflective Journal: May 2013*

### ***What is ‘new’?***

*From my results/findings there is much that is new to me, and - it appears - also to other researchers and interventionists in the field...but who am I to describe this ‘newness’ when it has long been known (whether explicitly/consciously or implicitly/unconsciously) by the participants and others from similar ethnic, cultural and knowledge backgrounds?!?*

*I realise that I’m getting into the issues with which researchers in cross-cultural research or research with and by indigenous researchers have been grappling for some time; especially also in the field of Indigenous Knowledge...but the words of one such researcher, \*Tsitsi, ring true for me here, ‘**We often don’t know what we know until someone outside picks it up because it’s new for them.**’*

*So, there seems to be a real need to engage about what I have learnt as new and valuable, **with** those to whom it is not new but also not overtly known and who are therefore not credited for its worth.*

*(\*used with permission: Dr Tsitsi Chataika is a past colleague, now senior lecturer in the Department of Educational Foundations, University of Zimbabwe).*

## 5.5 The process of thesis building

“**thesis** θi:sɪs noun (plural theses /-si:z/) a statement or theory that is put forward as a premise to be maintained or proved... (In Hegelian philosophy) a proposition forming the first stage in the process of dialectical reasoning.”<sup>1</sup>

The development of a thesis, antithesis and synthesis is the version of Hegelian dialectical reasoning that is quoted most often (Doull, 2000), but Hegel’s later version of the three-valued logical model, that is, ‘abstract - negative – concrete’ provides a better fit here. In keeping with a pragmatist approach (with which I feel most comfortable), the theses here are presented with a hope that they - and their development, modification or contradiction by others - will be *useful*. In a pragmatic evaluation of models of disability, as applied to education, Danforth (2001: 343) observes how, “woolly abstractions may fascinate us but the bottom line is how persons and communities can make use of ideas in specific contexts confronted in their lives.” As such, the concern here was to build upon past theories and theses, not with the purpose of agreement or disagreement, but in contributing to practical, concrete plans of action – thus my perhaps simplistic inclination to the later version of Hegel’s dialectical reasoning model, aiming for the concrete. Moreover, positioned within the transformative paradigm, as discussed in chapters two and three, the implicit goal of this study was the enhancement of social justice (Mertens 2007; 2010), which here took the form of optimised opportunities for communicative participation for children with severe communication disabilities in the given contexts.

The action research methodology, with its iterative cycles of action, reflection, planning and further action, repeatedly prompted examples of concrete learning for the participants, the collaborators and for me. Kurt Lewin, widely credited as the ‘father of action research’ wrote of “the tremendous pedagogical effect which these evaluation meetings, designed for the purpose of scientific recording, had on the training process” when he charted his *action, research* and *training* triangle (Lewin, 1946: 42). Furthermore, much can be learnt from the agricultural development workers in terms of making each step of the action research cycle participatory

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<sup>1</sup>Oxford English Dictionary - accessed on 21 February 2015 from <http://www.oxforddictionaries.com/definition/english/thesis?q=thesis>

(Cayster, Green & Worth, 2012; Chambers, 1994, 2007; 2010). It is this learning through evaluation – moreover, learning *together* – which was an integral part of the process that resulted in the three theses presented here. From the twelve collaboratively reached, action learning outcomes (ALOs), presented in the previous chapter, the two main themes were conceptualised to respond to the aims of the study (summarised earlier in Table 5.1). Through further reflective discussions with the collaborators and triangulation with earlier published evidence, three theses are proposed in keeping with the desire (shared by the collaborators, the participants and myself) to have concrete and practical outcomes.

- Thesis 1: Relationships are the context and motivation for communicative participation: the social inclusion (and non-ostracism) of mothers need to be prioritised in order for them and their children to enjoy communicative participation.
- Thesis 2: The ‘Middle Ground’ is a valuable positionality in implementing transformative action learning as an intervention approach.
- Thesis 3: There is a need to reframe culture as a resource in supporting the communication development of children with severe communication disabilities.

While my aims and objectives had centred on the subject matter of Thesis 3, the transformative action nature of the study revealed the first two theses as precedents.

## 5.6. Thesis 1:

**Relationships are the context and motivation for communicative participation: the social inclusion and non-ostracism of mothers need to be prioritised in order for them and their children to enjoy communicative participation.**

The transformative action research process here embraced a turning point which could have derailed the study. Instead, the turning point became a key to confront present circumstances and facilitate the development of some concrete self-representation strategies to empower the participants. At the heart of a transformative research journey is the desire for social justice and the implicit readiness to the vulnerability of changed - and possibly blurred - power relations between the researcher and the researched (Mertens, 2009). Furthermore, a transformative *action*



research journey involves an iterative agenda (Chambers, 2007; 2010; Davis, 2005; Toomey, 1997).

On the research journey comprising this study, the transformative action agenda included a crucial turning point or hinge; the collaborative identification of which fits the descriptions of critical incident stories as described by Treleaven (2001; 267). While the events and processes leading up to this revelation did not fit Flanagan's original 'critical incident technique' (Flanagan, 1954; cited by Spencer-Oatley, 2013: 1) it did fit the later broader description of critical incidents as "a critical incident is an interpretation of the significance of an event" (Tripp, 1993; cited by Spencer-Oatley, 2013: 3).

The recognition of the need to address the mothers' exclusion as identified in the seventh action learning outcome (ALO 7), happened when opportunities for open and equitable dialogue between professionals and mothers were developed (ALO 11). Mothers' repeated accounts of rejection and even abandonment by husbands, families and others (because of their disabled children) had become the primary topic of the participating mothers for several sessions. As recounted in Chapter 4, collaborator Nolwandle's explanation summed it up most succinctly:

[9 May 2007]

*... they are asking: how can they encourage others to accept their children...and to communicate with their children if **they, the mothers**, are rejected? (Nolwandle)*

This corresponds with widely documented records of the ostracism of parents, and specifically *mothers*<sup>1</sup> of children with disabilities across diverse contexts (Gona, Mung'ala-Odera, Newton & Hartley, 2010; Ingstad, 1995; Reid-Cunningham, 2009; Ryan & Runswick-Cole, 2008; Solomons, & Molefi, 2011). Until recently almost all the evidence concerned the experiences of mothers in contexts of the global north and the need for exploring experiences of mothers in developing contexts was emphasised (Gona, Mung'ala-Odera, Newton & Hartley, 2010; Ryan &

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<sup>1</sup> In this section I have consciously referred to 'mothers' in most instances, and not the more generic 'participants' as elsewhere in the study report. This is because it was the *mothers* who drove these particular discussions; the issue of exclusion and blame so specifically affects biological *mothers* of children with disabilities - more than fathers, grandmothers and other caregivers.

Runswick-Cole, 2008). Of those that have focused on developing, and more specifically African, contexts, it is clear that stigma, ostracism and exclusion of mothers are common – with variations across contexts (Barratt & Penn, 2009; Gona, Mung’ala-Odera, Newton & Hartley, 2010; Ingstad, 1995; Solomons & Molefi, 2011). In both the Setswana and the isiXhosa culture (represented here in the preliminary case study in Botswana and in the main study in South Africa, respectively) persistent beliefs about the causes of a child’s physical disability are strongly linked to actions by the mother (Ka Toni, 2008; Merriweather, 1992; Tshabalala, 2014).

This specific ostracism of mothers is in contrast to a situation further north in Africa, where, during intensive ethnographic work in a village in central Zaire, Merriam (1974) describes customs related to the birth of disabled children. A point of particular interest to this discussion was that there, in Zaire Merriam described *the father’s* role in being assigned causal blame. Furthermore, as a way forward, the father was required to declare and pay a penalty fine for the birth of a child with a disability - implying a process of admitting and compensating for the burden that he had brought *upon the community* (Merriam, 1974). This example underscores a divergence from the recurring stories of family blame, rejection and community ostracism of the *mother* of a child with a disability, which emerged here.

The concern of the participant-mothers about their own exclusion as a barrier in their attempts to facilitate the communicative participation of their children did not immediately appear to concur with the objectives of this study. In seeking to explore culturally determined strategies that could *help* their children, this barrier kept ‘interfering’ – and was thus framed as a critical (or ‘revelatory’ or ‘significant’) incident (Spencer-Oatley, 2013; Treleaven, 2001).

*Reflective journal: 1 June 2007*

*...the moms kept averting questions about how they/we could facilitate increased communicative participation for their children - it seems that many of them experience such real ostracism/blame/guilt that **THEY** are excluded and **THIS** is their primary "survival" concern.*

*It comes up repeatedly that if they (the mothers) were accepted more, the child would also be included more ...*

*Part of my transformative journey as the researcher is maybe to acknowledge **this** as a priority over the communication goals that I usually set as an interventionist.*

*...but what then?!? Where do I/we go from there? What about my study aims...?*

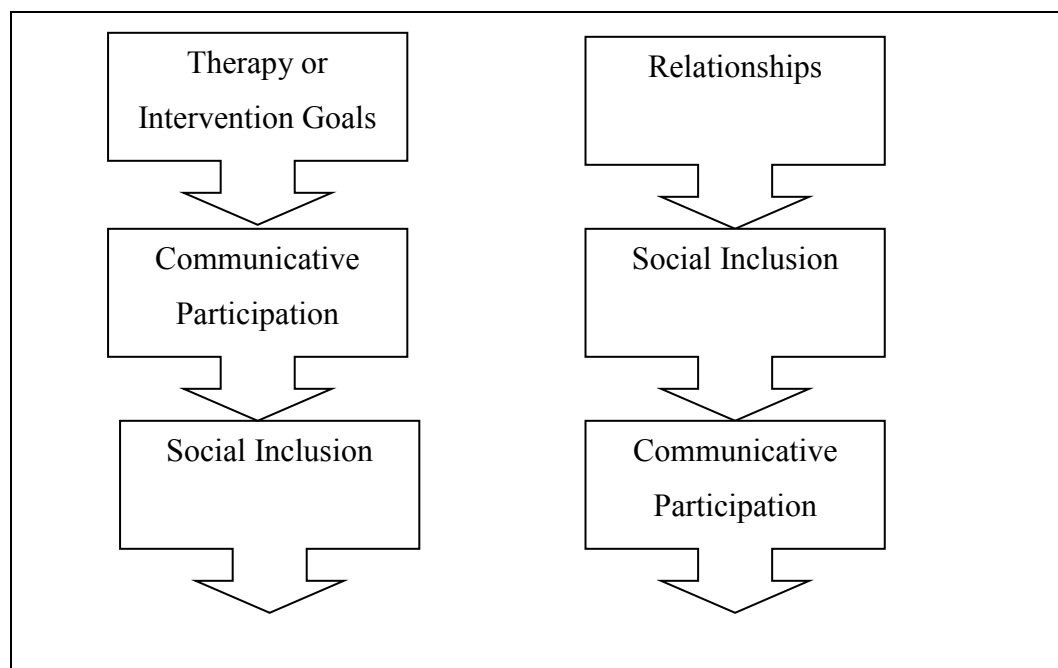
In terms of the terminology and concepts of the ICF (WHO, 2001; 2013c), environmental factors include social barriers such as attitudes of exclusion and ostracism and the resulting lack of support, experienced by the mothers (and therefore their disabled children). Not focusing specifically on *communication* disabilities, others have researched and written about some of the challenges faced by mothers, parents and/or families of children with severe disabilities (Barratt & Penn, 2009; King, Teplicky, King & Rosenbaum, 2004; Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006; McConkey et al., 2008; McKenzie & Müller, 2006; Mweshi & Mpofu, 2001; Watermeyer, & McKenzie, 2014; Watson, Thomas, Roulestone & McLaughlin, 2012). What is clear from among these accounts and highlighted by Marshall and Goldbart (2008), is that the challenges escalate if the child's disability includes a communication disability.

By allowing the transformative action progression and exploring what was at first perceived as a detour, the participant-mothers themselves indicated the need to address their own exclusion as a pre-requisite, *before* other strategies could be implemented to create opportunities for the communicative participation of their children. For us, the seventh action learning outcome (ALO 7) had been identified as: 'The exclusion of mothers *needs to be addressed* as a pre-requisite for the communicative participation of their children'.

**But how?** In the past, communication interventions tended to be impairment focussed (Hartley & Wirz, 2002), but the development and implementation of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) has had an important effect on the way that communication disabilities are seen, addressed and researched (Ma, Threats & Worrall, 2008; Simeonsson, Björck-Åkesson & Lollar, 2012; Raghavendra, Virgo, Olsson, Connell & Lane, 2011). The ICF identifies *participation* as the definitive goal of any intervention and the past decade has seen an increasing recognition of the inseparability of communication and participation (Lage 2003; Pennington, 2012; Sigurd Pilesjö, 2012; Simeonsson, Björck-Åkesson & Lollar, 2012). The broadening of the focus to include contextual factors has therefore been imperative in the study of communication (Howe, 2008; Lage, 2003; Levin, 2013; Levin & Haines, 2007; Pennington, 2012; Sigurd Pilesjö, 2012; Simeonsson, Björck-Åkesson & Lollar, 2012).

Communication can indeed not exist separately from the presence of communication partners and opportunities, and the ICF and Hartley and Wirz's communication disability model (2002) both highlight the interactions between factors. In a parallel development, the need for, and value of, ecological systems approaches have been described over time beginning with the seminal writings of Bronfenbrenner (1979) and followed by others (Garbarino & Ganzel, 2000; Sameroff, 2009; 2012; Sameroff & Fiese, 2000). Systems approaches include broadening the focus from the child with the disability to the child in the family and in the community, and moreover; considering the relationships between these levels or elements (Berry, Biersteker, Dawes, Lake & Smith 2013; Bronfenbrenner, 1979; Garbarino & Ganzel, 2000; Sameroff, 2009; 2012; Sameroff & Fiese, 2000; Walker et al. 2007; 2011). Of particular relevance to the participant-mothers' identification of their own exclusion as a barrier to the development of communicative participation by their children is the concept of transactional regulation (Sameroff & Fiese, 2000; Sameroff, 2012). Transactional regulation refers to the reciprocal adjustment of responses, by the child and/or the mother/caregiver, in reaction to the responses of the other (Sameroff & Fiese, 2000; Sameroff, 2012). An often quoted example is the reduction of interactions between a mother and child if one of them has an impairment, for example; cerebral palsy in the child or a mental health condition in the mother, which in turn reduces the responsiveness of one, and therefore also the other.

Hartley and Wirz’s communication disability model (2002), which describes the interrelationship between the diverse intrinsic and extrinsic dimensions of a communication disability (and thus concurs with the ICF on the interrelationship of factors), provided a framework to address the *exclusion* of mothers (as a pre-requisite for the communicative participation of their children – as per ALO 7), and to build the first thesis. While most communication therapy interventions traditionally begin with goal setting based on an assessment of the impairment and activity limitations of the child (ASHA, 1993; 2004; Beukelman & Mirenda, 1998; 2005; Owens, 2005; 2011; Rosetti, 2001; RCSLT, n.d.; SASLHA, n.d.), the participant-mothers prioritized their relationships as a strategic starting point for any action to support the inclusion of their children. Figure 5.1 below, depicts how the mothers’ priorities differed from traditional intervention priorities.



**Figure 5.1: The progression of traditional intervention strategies (on the left) versus mothers’ prioritisation of relationships (on the right).**

Some participants – and particularly the *biological* mothers of children with severe disabilities among them - were quite adamant that their children would not be given opportunities to interact and develop basic communication, if people around them (beginning with fathers and other family members) did not accept *them, the mothers* and therefore, by implication, their children.

Practising communication activities out of context (*those exercises* - as they perceived therapists doing) was seen as futile (please see mothers' contributions under ALO 12 in Chapter 4: Findings). As we proceeded to identify culturally determined resources which the mothers could 'optimise to support communicative participation, they were keen/willing but the 'proviso' of addressing or at least acknowledging the issues of their own exclusion wove itself through all the discussions.

In summary, the reflections of the participants – and especially the *biological* mothers among them – upon the question 'what can we do to solve the problem?' consolidated some instances of self-representation/self-advocacy, which they had either already applied and recognised as such retrospectively, or which they identified in the group and then went and '*tried out*'. The possibilities which they explored are framed under Thesis 3 ('there is a need to reframe culture as a resource in supporting the communication development of children with severe communication disabilities') in Chapter Five: 5.7 below. Mothers wanted the issue of their own relationships and their status in their families and communities prioritised – *otherwise the rest does not follow*. The transformative action process allowed this here, as indicated by the following example of turning relationships around within the research process.

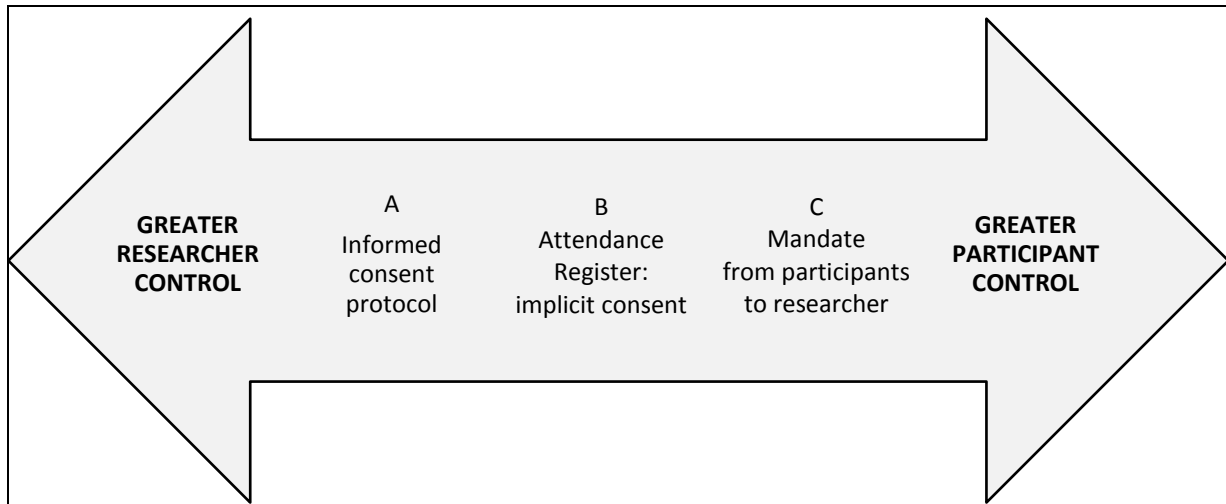
### **Changes in researcher-participant relationships**

Approaches to obtaining participant consent in participatory inquiries have traditionally ranged from formal informed consent protocols, to informed but implicit consent in the signing of participant attendance registers (Minkler, Fadern, Perry, Blum, Moore, & Rogers, 2002) (See A and B in Figure 5.2 below). In this study however, the participants insisted that what they contributed *had* to be utilised and communicated to others:

[Masincedane group, 8 November 2006]

*'...but if we say something, we **want** you to tell others. You **have** to tell others what we say' (translated by Pam)*

An additional locus, that of participants adopting the role of mandating the researcher to share and disseminate the knowledge created here (C), was thus added to the continuum of consent possibilities (Figure 5.2)



**Figure 5.2: The ‘traditional’ range of consent practices (A and B) and the addition of the mandate (C) which emerged and was embraced within this transformative action research study.**

Thus, a transformative approach may turn participant consent into a mandate. In embracing this participant mandate, I propose that transformative action research – or rather transformative action **learning** can be implemented as a strategy to allow re-prioritisation of the real needs of participants/ mothers and their disabled children. This learning contributed to the formulation of the next thesis.

*Reflective Journal*

*May 2010*

*There seems to be an increasing blurring of ‘content’ (data) and ‘process’ or is this not an issue in action research? Could be a good synergy...*

*July 2011*

*Transformative action research is just that: the process is part of the findings/outcome!*

## 5.7. Thesis 2:

### **The ‘Middle Ground’ is a valuable positionality in implementing *transformative action learning as an intervention approach.***

In the introduction to this research report I described some of the issues pertaining to my positionality as a researcher and my in-between-ness on several continua (Chapter One: 1.10). While researchers in the positivist schools need to be concerned about researcher bias contaminating their research, many qualitative researchers, and transformative researchers in particular celebrate the additional depth and richness that the ‘biases’ of insider research deliver.

By definition, a transformative action research journey implies learning and change in participants and other stakeholders, collaborators and – possibly most profoundly - in the researcher herself. Mertens (2003; 2009) explores diverse examples of researchers’ own testimonies of transformation through their research, and each experience of transformation is a journey that is uniquely different and personal.

Indigenous researchers elsewhere, including Tuhiwai Smith (1999), Mihesuah (2004), Shahjahan (2005) and Clark, Hunt, Jules and Good (2010); as well as locally in South Africa, Duma (2010), Ka Toni (2007), Mji (2013) and Tshabalala (2014) opened my eyes to some of the complexities and the advantages of being and researching between worlds. Moreover, I learnt from them just how individually different, the personal and environmental impacts on one’s positionality can be - and moreover, that these change over time (Ahmed, Lewando-Hundt and Blackburn, 2011). While I could identify with some issues identified by indigenous researchers, as described earlier, I find myself in-between: representing polar opposites (or being the ‘neither-nor’) along several dimensions.

At the beginning of this study, I became aware of my in-between position on the following six dimensions or continua (Chapter One: 1.10):

- I. As a rehabilitation service provider – and as a rehabilitation service consumer.
- II. As a person with a disability but often not disabled.
- III. Often in the position of a research participant/subject and now the researcher
- IV. In terms of my heritage and nationality: I am not fully German or South African, yet I am both



- V. On another, different, continuum I am a white, ‘Westerner’ (Setswana: *lekgoa*; isiXhosa: *umlungu*) yet having been completely immersed in African village life, language and culture for a long time, I straddle both.
- VI. Due to the way children perceive my size; they seem to see me somewhere between an adult and a child.

Grappling with this, my reflective journal became a refuge, a mirror and sometimes a window to new insights. It also helped with the ‘meta’ process of formulating this second thesis, acknowledging the middle ground as a complex and valuable positionality which I visualised as depicted in Figure 6.1 below.



**Figure 6.1: My positionality as the researcher in this study: somewhere between opposites along at least six different continua.**

I apply the term *positionality* here as it is used by human geographers and others with implications of reflexivity (Hopkins, 2007; Spry, 2001). Some basic auto-ethnographic reflections of the six continua led me to embrace the dynamic nature of the positionality I held – that as a researcher in the transformative paradigm, it was ‘okay’ to be nearer to or further from the opposites and that I needed to be aware of other dichotomies or continua which may influence the study. The number and combination of continua on which I found myself on that ‘Middle Ground’ certainly impacted this study – both in bias that needed to be addressed, but also in richness of information, which once observed, had to be shared.

During the study, I repeatedly found myself in an additional position ‘between’: as a researcher and interventionist. This second thesis concerns a meta-analysis of process and positionality rather than content. Every researcher’s positionality is unique, and embracing the middle ground, as a positionality, in which researchers can identify their own, specific dichotomies or continua may be a means of maintaining focus in implementing transformative action learning as an intervention approach.

### **5.8. Thesis 3: Cultural resources can be used to increase communicative participation.**

Finally, in direct response to the research question, the shared conclusions of participants, collaborators and me (the researcher), confirmed that:

- firstly, there are some similarities in non-verbal, pragmatic and contextual elements of communication across the isiXhosa language context explored in the main study and the Setswana language context described in the preceding case study
- secondly, ALOs 1-6 were identified as *elements* which can be used to support the communicative participation of children in the given isiXhosa language contexts
- thirdly, ALOs 7-12 were identified as *culturally appreciative strategies* that essentially answered the question ‘how can this be achieved?’

#### **5.8.1. Similarities in non-verbal, pragmatic and contextual elements of communication across southern African languages**

In order to introduce the subject matter and purpose of the study to the participants, some of the findings from the Setswana language context (from the Botswana case study) were presented to the groups (Chapter Three: 3.6.4). Subsequent discussions confirmed the presence and value of the same elements of social interaction in the isiXhosa study context as well as similarities with other southern African indigenous languages, confirming the widespread knowledge that many elements of natural non-verbal communication are not restricted to the realms of specific spoken languages but are regional (Chapter Four: 4.3.1 and 4.3.2).

Similarities in non-verbal, pragmatic and contextual elements of communication across the isiXhosa language context explored in the main study *and* the Setswana language context described in the preceding case study, confirmed earlier sociolinguistic texts (Gxilishe, 2008; Jones, 1993; Merriweather, 1992; Sandilands, 1953). Moreover some elements were identified to be present across the other southern African indigenous languages too, implying that these can be understood beyond individual language contexts. This has implications for the wider understanding and use of such elements beyond individual languages in the region, as outlined in the Findings (4.3.1 and 4.3.2). Due to the wider usage of identified non-verbal and pragmatic elements across the region, the emphasis had to shift from culturally determined (specifically within the isiXhosa language contexts of this study) to: what is culturally appreciative in the given context?

A key insight here was that the mothers recognised the wider application of the non-verbal and pragmatic. These insights empowered the participants to become more aware of, and identify additional elements of non-verbal social interaction which were accessible to their own severely disabled children.

### **5.8.2. What can facilitate communicative participation in the given isiXhosa language contexts?**

In response to some of the ‘what’ questions, ALOs 1-6 were identified as features which (in and of themselves not new findings) can be used to support the communicative participation of children with severe communication disabilities in the isiXhosa language context explored here;

**ALO 1:** *‘different cries...for hunger...for pain...for wanting attention...’* - **recognising communication without speech.** Mothers the world over respond naturally and instinctively to their babies’ cries (Barnard, 2009; Strasheim, Kritzinger & Louw, 2011) and this is an integral part of their early bonding and meaningful interactions (Pepper & Weitzman, 2004; Rossetti, 2001). The participants here described how the recognition of different cries and different meanings persists as a key to understanding the needs of their non-verbal older children.

**ALO 2:** *‘He pushes his plate away – that IS communication’* - **all behaviour is communication.** This insight of the mothers was reminiscent of Habermas’s Theory of Communicative Action, which he based upon the deliberative process where two or more individuals inter-act, based upon an agreed interpretation of the situation (Habermas, 1984: 86). The mother’s understanding of the child’s action (he has finished eating or he has had enough) meant that all three basic essentials of communication had been met; there was a sender (the child), a message (the action) and a receiver (the mother) (Owens, 2005).

**ALO 3:** *‘... and ALL our children can do that – even mine’* - **the smile: the most universal communication of all.** While the smile is not specifically determined by the cultural context, the recognition of it as a universal communication (and something that even the lowest functioning of the participants’ children could do), was an important milestone in the recognition of the value of non-verbal means of communication. In several instances in the study, this awareness of the mothers led to increased communicative exchanges both between themselves and their children and in encouraging others to engage with their children (as in Nopelo’s story – 4.4.3). Arnold Sameroff’s theory of transactional regulation (Sameroff, 2009; 2012; Sameroff & Fiese, 2000) – where a positive reinforcement prompts a repeat action which may prompt another positive reinforcement etc. – prompted the support of focusing upon the smile as a response and as a trigger for communicative interactions with the participants’ children.

A good suggestion came from an expert outside of the study: with the difficulties in presenting measurable outcomes for children with severe to profound communication

disabilities, the smile could be a valuable and do-able outcome ‘measure’ when working with these children (Jenny Hendry, CEO of Western Cape Rehabilitation Centre; personal communication 4<sup>th</sup> September 2013).

**ALO 4:** *‘I look at his face expecting the ‘sorry’ look – and if it isn’t there I will clap again’ – remembering and reinforcing eye-contact and facial expressions used in earliest interchanges.* Earliest cause and effect learning is generally accepted as an early prerequisite for communication development (Owens, 2005; Pepper & Weitzman, 2004). A particularly poignant finding here was that mothers realised that they need to maintain their responsiveness to their children as they grow older and cannot speak.

**ALO 5:** *[Father Christmas] chants ‘Hêpi-hêpi-i-i-i’ (happy-happy) over and over again as he gives each child gift... - repetition helps to facilitate participation and enjoyment:* Repetition is unquestionably a distinctive feature of oral cultures throughout the world, where it serves a key function in terms of memory and learning (Sandilands, 1953; ). The application of repetition is also a particularly important strategy in teaching and learning with children with intellectual disabilities (over and above its value for children with normal intellectual abilities) and so, it has long been identified that children with intellectual disabilities can benefit particularly in cultural contexts where there is much repetition anyway (not specifically for the child with intellectual disability) (Battle, 2012; Dunst, Trivette & Raab, 2014).

**ALO 6:** *‘It is true. The mothers know this’ - the value of proverbs; a need for further exploration.* During the recruitment sessions I had shared the story of how Boiki (in Botswana), was empowered to put his siblings in their place by pointing to a picture representing a well-known Setswana proverb (Chapter Three; 3.6.4). While the account of the value of proverbs with their inherent ‘semantic compaction’ (Baker, 1984; 2009), struck a chord with the mothers as a potentially useful strategy for *their* children, we did not identify further examples of this usage of proverbs in this study – they did re-emerge for a different pragmatic purpose, later (See 5.8.3 – ALO 10).

These six collaboratively achieved action learning outcomes were a response to the first objective of the study that is: to describe the presence and use of some non-verbal and pragmatic elements of social interaction in an isiXhosa language context. It became important to note that some of these were not exclusive to that context, but had applications beyond the isiXhosa language context and could therefore be understood beyond that context.

### **5.8.3. How can culturally appreciative strategies be applied to increase communicative participation?**

**ALO 7: ‘...how can we encourage others to accept our children...and to communicate with our children if we, the mothers, are rejected?’** The exclusion of mothers needs to be addressed as a pre-requisite for the communicative participation of their children.

As discussed earlier (Thesis One: 5.8.1) the quest to identify *culturally appreciative strategies* that answered some of the ‘how’ questions (how can communicative participation be achieved?) opened up the need to address the ostracism of the mothers in this cultural context as a prerequisite to any further strategies.

The tumultuous time around recognising this important pre-requisite for all else, was a clear turning point or critical incident (Treleaven, 2001; Tripp, 1993; cited by Spencer-Oatley, 2013: 3) during the collaborative research journey. Having recognised this, the participants went on to identify, act and reflect upon the following tools of self-advocacy which they identified, trialled and reflected upon and which we then collaboratively framed as action learning outcomes (ALOs) 8-12.

***“How can I help you to help me?”***

*These words by Vic McKinney\* during today’s Rehabilitation Think Tank, epitomise the kind of advocacy that the mothers developed.*

*It is a two-way commitment, often needing to be initiated by the mothers to help others not to exclude them (the mothers) and to help to create opportunities to optimise the communicative participation of the children...*

*\*words used with permission: Vic McKinney is a fellow PhD student and friend. He has quadriplegia and is an exceptional disability warrior.*

**ALO 8:** *‘They only use their children’s names... It makes the children to be known as people’*  
- **the words or names used are powerful advocacy instruments.** The participants decided to always only refer to their children by name in order to actively counteract the common practice of describing and referring to children with severe disabilities as *izidalwa* (creatures) – with all the stigma and rejection that accompanies that custom (Ka Toni, 2008; Masola, 2014 ).

**ALO 9:** *With us it is a competition, all the other children want to say ‘She smiled for me!’*  
**Other children are strategic facilitators of communicative participation.** Nopelo’s encouragement of neighbourhood children, to engage with her son bore the fruits that their parents, her neighbours, ceased avoiding her and ‘...greet me and him and some of the other mothers have visited me and have even offered help... like neighbours’. (Chapter 4: ALOs 3 and 9). The contributions that other children can make are many and counting on them to lead the way in inclusion and providing opportunities for communicative participation is well-documented (Child-to-Child Trust, 2003: 2009; Kritt, 2013; McConkey 2005; Sigurd Pilesjö, 2012; Pence & Marfo, 2008; Pence & Nsamenang, 2008; Ylven, Granlund & Persson, 2012; Zimmerman, 2005).

**ALO 10: It is a way for the mother to turn the spear and say ‘what about you?’ Proverbs as tools of advocacy for the mothers**

Proverbs about health – or lack of it – and disabilities have been included in some anthologies, for example in isiXhosa by Calana (2002) and in proverbs in diverse African languages by Stewart (2005). Expanding upon the nature of proverbs to state indigenous beliefs and related advice, Devlieger (1999) earlier focused upon proverbs related to indigenous beliefs about disability and its causes. Thus, rich insights were gained into beliefs about causes of disability and attitudes to persons with disabilities.

In addition, two rather different applications of proverbs emerged in the preliminary case study and in the main study described here. Firstly, in the preliminary case study in Botswana (Geiger, 2010: 59-60) as well as in current work contexts in isiXhosa language contexts, the value of proverbs with their semantic compaction in picture communication systems (Baker 1984; 2009) appeared powerful communication aids for children with severe communication disabilities (but with good comprehension). In the case of Boiki (and other children in Botswana) being able to forcefully indicate a single picture depicting a proverb on his communication board, he was able to communicate powerfully.



***Reflecting back to Boiki in Botswana***

*“Boiki’s grandmother pointed out that the rich symbolism of everyday idioms, proverbs and some common metaphoric expressions, would lend themselves particularly well to graphic representation for Boiki’s communication board (with consideration to size, closure etc as described earlier). A line drawing of a hornbill bird (Lat.; Tockus Nasutus; a very common bird in the area which features frequently in the local lore and legends etc.), was added to Boiki’s*



communication board (Figure 3).

*This represented the proverb “Bana ba kgorwe ba kgaogana tlhogo ya tsie” that is; “the children of the hornbill share even the head of a fly”. By emphatically pointing to this diagram, Boiki could claim his rightful portion of a bowl of food which had been put down for him and his siblings to share. The siblings - who could eat much faster than the disabled Boiki and threatened his rightful portion - were rebuked through this one emphatic, and culturally powerful, reminder that siblings must share equally and justly; regardless how small the portion.”*

*(From Geiger 2010:59-60)*

Secondly, during the action reflection groups with mothers in the isiXhosa language context, we identified the value of proverbs as tools of advocacy. The two pragmatic functions that proverbs were identified to serve were:

➤ **For reassuring and encouraging the mothers themselves:**

Examples included ‘*umntu ngumntu ngabantu*’ [a person is a person because of other people/ or because of their personhood] and ‘*ithemba lyophilise*’ [Pam’s explanation: from hope you can be great one day; or hope causes one to live]

Such positive and reassuring connotations aided the mothers’ own encouragement and the mothers also found them useful for conveying a positive advocacy message to others in answer to a painful question or accusation about the disabilities of their children.

➤ **For answering blame, criticism and ostracism (for bearing a child with a disability)**

An example was: *Intaka yakha ngoboya benye* [a bird builds (its nest) with another’s feathers] and a stronger retort *Iqaqa aliziva kunuka* [a skunk does not smell itself. People are unaware of their own shortcomings]

**ALO 11: *When you ask ‘did you practice at home?’ I stay quiet. I don’t know what to say - therapists and mothers need opportunities to talk, to listen and to learn from one another.***

Another aspect of relationships was identified in the need for **clear communication between interventionists and parents** (beyond instructions related to therapeutic exercises) was identified as a pre-requisite support to mothers, to empower them to support the participation of their children. Earlier published evidence identified diverse facets of the need for clear communication between interventionists and mothers (Barratt & Penn, 2009; McKenzie & Müller, 2006), as confirmed by the participants and collaborators in this study. Beyond the South African situation and nearly two decades ago already, Barrera and Kramer (1997) described the need for dialogue, in place of the instructional monologues that were found to be sadly customary.

**ALO 12: *‘The reason I came back to the clinic today... and I will come again ... is the things I learnt out here...from you [addressing the other mothers]’ - the value of the waiting time/area for the mothers, in a space conducive to informal socialization and group conversations.***

The unpremeditated **support group** (such as the one that developed in the waiting space at the outreach clinic – ALO 12) was a place where mothers established relationships for themselves and their children and where they also shared resources. The mothers raised and addressed issues not dealt with in formal interventions. Past challenges in developing formal support groups are acknowledged (Adams & Galvaan, 2010). However, the ‘organic’ and collaborative development of the support group here should be affirmed as a strategy to develop social inclusion, and as a forum where cultural resources are identified, affirmed and optimised. Both the *nature of the space* (exclusively for this group of mothers; informal seating that could be arranged in a group configuration so that participants could face one another and with space for the children’s buggies etc.) and the *regular long waiting times* contributed to the development from an ad hoc waiting situation into a peer support resource.

## 5.9. Reflective chapter summary

Interventions need to meet real needs, in contextually appropriate and culturally appreciative ways. In an attempt to contribute to solutions, the voices of the participants in this study have confirmed that indeed, while “health care workers are the ‘experts’ on answers to the ‘what’ questions, the communities are the experts on answers to the *how* questions” (Hartley, 2004: 38), and that the way we as rehabilitation professionals work, can either unlock or block this resource.

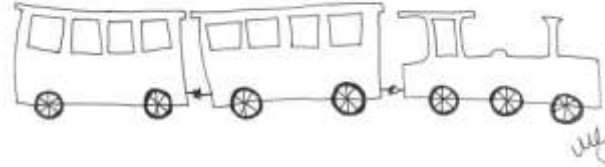
The 12 action learning outcomes (ALOs) identified and presented during the course of this study, were just that: outcomes of the action learning process whereby I, the researcher, and/or my collaborators and/or the participants learnt something. In the case of the participants it sometimes was a realisation of the value of something familiar and the need to consciously apply it for a purpose in the future. In my case as the researcher/interventionist it was the realisation of the need to become more of a listener-encourager-facilitator than an assessor-instructor.

Three theses were presented:

- Thesis 1: Relationships are the context and motivation for communicative participation: the social inclusion (and non-ostracism) of mothers need to be prioritised in order for them and their children to enjoy communicative participation.
- Thesis 2: The ‘Middle Ground’ is a valuable positionality in implementing transformative action learning as an intervention approach.
- Thesis 3: There is a need to reframe culture as a resource in supporting the communication development of children with severe communication disabilities.

These three theses may hopefully prompt *hypotheses* to be explored in future research; but more practically as a response to the needs outlined in Chapters One and Two: to inform clinical and educational practice; policy planning and implementation and other applications related to support strategies for children with severe communication disabilities and their families. Some practical implications and recommendations are discussed in the next chapter, the conclusion of this research report.

## Chapter 6: Conclusion



*“The right to search for truth implies also a duty;  
one must not conceal any part of what one has recognized to be true”  
-Albert Einstein<sup>1</sup>*

### 6.1. Introduction to the chapter

The research journey described here has been like other journeys in many ways; notably in that the point of departure was clearly defined, a destination was envisioned and then – in true action research style – events and people *en route* determined the many detours, challenges and eventually the destination itself. It seems that the ‘destination’ has become a mere pause, and a point of reflective closure for this research report, with new destinations glimpsed and planned - like most other research journeys.

An account of any journey depends upon the focus, or the perspective, of the reporter. During this journey, I have found myself to be participant observer, then passive observer; director and directed; spokesperson, interpreter and mediator; but always watcher-listener-learner. At risk of exhausting the analogy of the journey, it actually rather resembled a *train* journey and so I have drawn parallels as they enable me - the researcher - to try to report on and account for what I have come to recognise as truth(s) on this journey. There have been different landscapes passed through; people met *en route* and travelling companions; dynamics among us (within the ‘carriages’ of our train and in contact with others at our journey stopovers). The endeavour ‘not to conceal any part of what one has recognised to be true’ (Einstein, cited in Cohen 2012: 13)

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<sup>1</sup> Cited in: Cohen S. R. 2012. *My time with Einstein*. Bloomington Indiana: AuthorHouse. p. 13

meant using different ‘lenses’ or perspectives and venturing into that prickly arena in qualitative research of adopting diametrically opposing paradigms in a single study (Denzin & Lincoln, 2003; Schwandt, 2001).

Positioned within the transformative paradigm (Mertens, 2009; 2010), this framework enabled me, the researcher, to examine the underlying belief systems that guided my work with regard to ethics, reality, knowledge and methodology (Mertens, 2010: 470). The transformative paradigm is explained and illustrated as a framework for researchers who place a priority on social justice and the promotion of human rights – and the study was steeped in the sometimes controversial approach of Appreciative Inquiry with positive expectations and pre-suppositions (Davis, 2005; Ludema, Cooperrider & Barrett, 2001), as discussed in Chapter Three. The choice of this approach was made consciously, against the background of ‘deficit’ expectations still dominating research in developing contexts – and especially here in Africa.

In the advanced stages of this journey, I was pointed towards the challenging yet liberating ‘patchwork’ concept of a *bricolage* (Denzin & Lincoln, 2003; Kincheloe, 2001; Prof. Leslie Swartz, personal conversation, 2013, February 12) as an organising principle to contain this research journey and the report describing it, in an attempt not to lose any of the truths found along the way (Einstein, again). The mixing of qualitative methods, ways of thinking and reporting methodologies included the recognition of some serendipitous findings among the action learning outcomes. These serendipitous findings were the result of coincidental observations to which new relevance was attributed, by a kind of meta-reflection, rather than the result of planned strategies (MacGuire, 2006; Stoskopf, 2005).

## **6.2. A brief review of the chapters**

This research report comprises a prologue including the preliminary case study, and six chapters:

**The Prologue** includes a preliminary, pre-published case study from a Setswana language setting in Botswana (Geiger, 2010). This case study became the first, research-question-generating cycle of the main study.

**Chapter 1** provides an introduction to the thesis. It includes definitions of key terms as applied in this report; a description of the background to the study, the motivation, the purpose and the aims of the study and a preliminary description of my positionality as the researcher.

**Chapter 2** comprises a review of some of the published evidence that was used to inform the current study in terms of *content* and a discussion of the theoretical framework of the *process*.

An interdisciplinary literature review of some of the published evidence that was used to inform the current study in terms of content is presented. The mandate for a human rights based approach, as well as terminology issues are outlined in terms of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), (United Nations, 2006). The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is used as an organising framework to structure this discussion and the CBR guidelines (WHO, 2010) provide a framework for action.

A discussion of the theoretical framework of the process then follows; that is, the development of the research methodology in the transformative paradigm. An appreciative inquiry approach, with iterative cycles of action and reflection to facilitate learning and change in the participants and in me, the researcher, was adopted.

**Chapter 3** comprises a description of the methods as implemented. This chapter is an account of the actual research processes I engaged in, together with two collaborators, two language facilitators and a total of 44 participants, all of whom were parents and/or primary caregivers of children with severe communication disabilities secondary to cerebral palsy. The chapter includes a description of the study settings, the participants and how they were recruited, and this is followed by a description of the data, its nature, how it was generated and how it was analysed. Thereafter, ethical considerations relating to the participants and the research processes; bracketing assumptions and issues of trustworthiness are addressed.

**Chapter 4** contains the findings, framed as 12 Action Learning Outcomes (ALOs), as they relate to the aims of the study, including the voices of the participants and also the collaborative interpretation processes, with the resulting two main themes that emerged, in response to the study aims.

**Chapter 5** comprises a discussion of what were considered new contributions, in the form of three theses developed from the themes that emerged from the findings. .

**Chapter 6** is the concluding chapter and contains a reflective overview of the research journey. It also contains a summary of the limitations of the study; the implications for clinical practice, for teaching, for research and for policy, as well as some concrete recommendations – for mothers from mothers. An epilogue closes the chapter

### **6.3. Why did I set out on this journey?**

The purpose of this study was to explore ways in which interventions for young children with severe communication disabilities could be built on culturally determined resources in two southern African contexts. An interdisciplinary review of literature, together with reflective clinical learning over several years of work in diverse under-resourced communities, gave rise to the main research question:

*In what ways can culturally-determined resources be optimised as a foundation for interventions and to support the communicative participation of children with severe communication disabilities?*

This question was based upon the assumptions that firstly, interventions are needed and secondly interventions *can* be built on cultural resources. The collaborative, iterative action nature of this research journey soon turned these two assumptions on their heads: several challenges to the very concept of ‘intervention’ arose throughout the study. Part of the inadequacy of past communication interventions in similar contexts appears to be their very focus upon ‘intervention-thinking’: as in something needed from outside of the situation/context. A more crucial need emerged as *identifying, validating and supporting resources within*. Crystallised out of this reasoning, the main aim of the study became:

*To identify culturally appreciative strategies which support the communicative participation of children with severe and profound communication disabilities.*

Challenges in communication therapy service delivery in South Africa comprise a diverse range of factors which include – but are not limited to - the multi-lingual, multi-cultural context; predominantly centralised services and the geographical distances that children have to be transported to access them. Challenges in communication therapy service delivery are exacerbated by an ineffectual public transport system and long multi-session therapy days for already tired child-parent dyads when they do manage to travel to therapy.

Over and above the need to address challenges related to communication therapy service delivery, is the need to revisit the goals of therapy – and the participants’ identification of communicative participation as the goal of therapy meant a shift in emphasis from intervention for the child, to optimising resources in the child’s environment. This shift implied a decrease in reliance upon an intervention by a professional therapist and more reliance on the child’s communication partners. The vulnerability of changed and possibly blurred, power relations between the researcher (interventionist) and the researched (mothers of children with severe communication disabilities) echoes the desire for social justice which is at the heart of a transformative research journey (Mertens, 2009). Furthermore, a transformative *action* research journey involved an iterative agenda – a flexibility to learn and to change.

#### **6.4. Strengths of the study**

The iterative, transformative action processes of the study allowed for immediate learning on the part of the participants, the facilitators and collaborators and me (the researcher) *during* the study. Furthermore, several ‘serendipitous’ findings which were not sought according to the planned objectives of the study, but contributed to achieving the second aim (Foster & Ford, 2003; MacGuire, 2006; Stoskopf, 2005). For example, prompted by the Botswana study, the use of proverbs emerged here, not as a means of communication *for the children* (although participants and collaborators agreed that this should be explored in future), but – serendipitously - as an advocacy tool for mothers. Related to this, was the identification of the ‘power of words’ and how the vocabulary we use shapes the way we, and others, think. This resulted in a practical commitment by participants to consistently refer to their disabled children *by name* and not by any disability-focused descriptor (and especially not by the widespread term *isidalwa* – or ‘creature’), and where necessary, to use disability-related vocabulary that supports



the acceptance of their children as communicatively participating human beings. Another serendipitous observation was related to the value of the waiting time and the waiting area layout and the effect that this had upon participants' communication with and support of each other – and the resultant opportunities for communicative participation of their children.

## **6.5. Limitations of the study**

While every attempt was made to prevent *weaknesses* in the study design, method, implementation and interpretation, I declare four *limitations* that could not be prevented.

### **6.5.1. Scope of the study**

As with all qualitative research, conceptual rather than statistical generalisations were aspired to (Cresswell, 2009; Mays & Pope, 2000) and to some extent, achieved. The scope of this study for degree purposes required a containment which meant that several 'detours' could not be explored – rich though the data was that they promised. The limited context and number of participants (44) will mean that there are countless others, with different stories and different contributions to make. Conceptual generalisations of the observations and lessons learnt here are thus restricted and contribute to the rationale for more extensive research.

### **6.5.2. Language**

Much is lost in translation. As a researcher with good Setswana but limited isiXhosa language skills I can only estimate how much I 'lost' in the main study in the isiXhosa context, by comparing the richness of the direct findings in the preliminary, Setswana language cycle of the study. Mindful of South Africa's past human rights violations in the area of language translations (Alexander, 1992; Erasmus, 1999; Krog, Mpolweni, & Ratele, 2009), this limitation, known from the start, was seriously considered as a reason not to do the study at all. However, I do think that the gains made have outweighed the lacks. I trust that it would raise enough questions for other, linguistically better-equipped researchers to pursue. Two strategies were employed to counter the language limitations as much as possible:

- Two language facilitators were purposefully recruited and trained, and they assisted during the first months of the study. Then, in an iterative development, I gladly welcomed the collaboration of Pam and Nolwandle, whose understanding, buy-in and freely volunteered commitment to the study optimised the trustworthiness of their language and other contributions.
- Language translation procedures included collaborative in-group translation, interpretation and triangulation in the action reflection group discussions and translations and back-translations of all transcriptions, by neutral, bilingual community members.

### **6.5.3. Facilitator changes**

Relationships play a vital role in action research (Chambers, 2010) and even more so in research that aims to be transformative (Mertens, 2003, 2009). The two language facilitators originally recruited for this project ('Essie' and 'Bee') could unfortunately not complete their commitment to the long-term process as they had intended, due to changed schedules in their own undergraduate studies. This lack of continuity in the first few months of the study may have slowed the initial building of trust and sharing relationships. However, the iterative volunteering and enlistment of the two mature collaborators (Pam and Nolwandle) who already had trusting relationships with the participants, was an immeasurable gain.

### **6.5.4. Study site logistics (including the weather!)**

Naturalistic settings are an integral feature of qualitative research (Denzin & Lincoln, 2003; Lincoln & Guba, 1985) and the first study site at the outdoor waiting area of a monthly outreach clinic for children with cerebral palsy was susceptible to the same challenges and setbacks as the outreach clinic itself. Inclement weather often affected attendance numbers at the clinic – and therefore also reduced participant numbers in the action reflection discussion groups in the outdoor waiting area. Furthermore, if the weather was cold, wet and stormy, parents and children coming for therapy sessions fled to the neighbouring police station, to wait in the general waiting area among other community members waiting for diverse police services. This environmental factor meant that the planned action reflection discussions could not take place twice – an

observation which contributed some valuable serendipitous findings (Chapter Four). Similarly, on one occasion the wild grass had grown so high between monthly outreach clinics, that the area outside the clinic was considered unsafe to sit due to the danger of snakes and unseen, dangerous litter. Instead of the usual informal circle of chairs for parents and their children to sit (so conducive to spontaneous chats and the action reflection discussions for the study), parents and their children had to line up along the edge of the clinic structure. Again, this circumstantial change meant that the planned action reflection discussion did not take place.

Over the total data production period of 20 months, four planned action reflection sessions could not take place due to such unforeseen circumstances. These occurrences limited the data-production process; but there were rich and productive action reflection sessions subsequent to each one missed, and so contacts were re-established, topics were revisited and discussions continued.

## **6.6. Implications**

History has repeatedly confirmed that the practical implementation of research evidence is fraught with challenges (Hartley & Wirz, 2002; Kachaje, Dube, MacLachlan & Mji, 2014). There is a gap between research evidence (mostly perceived as theoretical) and strategies that meet the practical needs of different groups of stake holders in the service-delivery ecosystem. Hartley and Wirz (2002: 1553) go on to confirm that the gap between research evidence and effective implementation can be decreased by identifying implications as they apply to specific stakeholders' activities and by providing practical recommendations (See 6.7). By definition, *implications* present conclusions or assumptions drawn from something even though it is not explicitly stated, while *recommendations* comprise specific suggestions or proposals as to the best course of action.

### **6.6.1. Government action and services in low-income areas**

Local, provincial and/or national government could consider:

- extending existing services that are not only impairment focused but also focus on social factors; for example through awareness raising about causes and other information related to children with severe disabilities and their families (e.g. through schools, community channels and the media)
- specific support to fathers through information and peer-support structures, to facilitate their acceptance and care of mothers and their children with severe disabilities
- extending its coordination of government, private and/or NGO and community based service providers at a local level to address the holistic needs of children with severe disabilities and their families, and to develop local, culturally appreciative initiatives
- providing permanent posts, beyond the current one-year community service contact positions, in low-income areas and especially also in remote rural areas
- extending training and provision of culturally competent translators.

### **6.6.2. Rehabilitation professionals**

Speech therapists and other rehabilitation professionals including CBR workers could:

- adopt more asset-based and culturally appreciative approaches, especially when working cross-culturally
- listen to mothers' perspectives and partnering with mothers and others to establish intervention priorities and strategies, in which parents are not only receivers of services but play an active role,
- support the role that can be played by non-specialists in the community, including children, in supporting communicative participation of children with severe communication disabilities

- engage in community based research activities and contributing to relevant practice based evidence, for example in the area of redressing communication assessment and intervention best practices in these currently under-served areas.
- recognise speech and language as only part of the communication process and supporting other modes of communication
- develop training in which skills such as action-learning and collaborating (interdisciplinary and community based) are considered as important as specialist knowledge.

### **6.6.3. Training institutions**

Curriculum developers and teachers at facilities that train speech therapists and related professions should consider:

- a greater emphasis on the broader aspects of communication beyond speech and language
- the current content and process of teaching one of the 9 indigenous languages in the undergraduate curriculum, and possibly replacing it with a practical language and culture enskilling model that equips students to learn a language from the specific community in which they are placed during their community service year or later – thus emphasising the simultaneous building of relationships.

### **6.6.4. Non-government organisations**

Non-government organisations (NGOs) and their funders could:

- increase the involvement of disabled people including parents of children with disabilities in their planning and implementation of programmes - with real, culturally-sensitive collaborations being needed from the start for the identification of needs and the conceptualisation of programmes
- nurture the will and acquire the necessary skills to increase collaboration with other service providers
- increase the use of non-specialists and provide training in holistic (not just impairment focused) support.

### 6.6.5. Researchers

Discipline-specific and interdisciplinary research implications include the need to explore:

- non-verbal, pragmatic and other assets in local indigenous language contexts and to assess how these can be applied to optimise the communicative participation of children (and adults) with severe communication disabilities
- transformative action learning and its value as an intervention strategy

### 6.6.6. Immediate implications for participants

Immediate implications for the participants included the empowerment of participants through knowledge; through holistic support via the group of peers (fellow participants) and through the identification and action learning of:

- some self-advocacy strategies in the widespread problem of ostracism, blame and rejection of mothers who have borne a disabled child
- ‘unlocking’ existing means of communicative participation for their children with severe communication disabilities as a result of severe cerebral palsy
- ways to enhance the quality of life of their children AND their own.

## 6.7. Recommendations - to mothers from mothers

The participant mothers in this study repeatedly insisted that the lessons that *they* themselves were learning should be shared with *other mothers*. In Chapter Five (5.6) I described the transformational process of how our roles were exchanged and how the mothers instructed or mandated me to share their contributions to the action learning outcomes, rather than giving consent for me to share them with others. This was encapsulated in Pam’s summarised translation:

Masinedane group, 8 November 2006

*‘...but if we say something, we **want** you to tell others. You **have** to tell others what we say’*

So, in terms of practical recommendations, the 12 action learning outcomes are here synthesised as nine recommendations from these participant mothers to others in similar contexts. A

practical output of the study is planned to develop these recommendations into an information pamphlet in isiXhosa, for sharing with other mothers.

**6.7.1.** Mothers can take the first step in helping others to understand and learn to accept them (mothers) and their disabled children. A priority need is to address the exclusion of mothers as a pre-requisite for the communicative participation of their children (ALO 7 and also borrowing Vic's words, "how can I help you to help me?")

**6.7.2.** Proverbs are a powerful self-advocacy tool for mothers. Firstly, some proverbs are reassuring reminders of deeper life truths which can be exchanged as encouragements or used in response to prying questions of others. Secondly, some proverbs are stronger retorts to hurtful or judgemental comments or questions from others about the child or about the cause of the child's disability (*'because you cannot fight with a proverb... It is a way for the mother to turn the spear and say 'what about you?'* ALO 10)

**6.7.3.** Mothers can lead by example and use the child's personal name when talking about him or her - not any description or label by which he or she may be known (i.e. avoid *isidalwa* = creature and other common, derogatory descriptors and labels). Encourage others - especially children in the family or in the neighbourhood to do the same. This will make the children with severe disabilities be known as people – as communication partners, with likes and dislikes and personalities (from ALO 8).

**6.7.4.** Every child communicates, even if they cannot speak. Learn to interpret more and more of the child's sounds, gestures and other communicative behaviours; respond to them and show others (including other children) in the family or community how they too can respond (ALOs 1, 2 and 4).

**6.7.5.** Encourage children and other visitors (who often do not know how to engage with a child with a severe disability) to elicit a smile. Given an activity that the mother knows is soothing or pleasant to the child (e.g. singing, being silly, rubbing the child's hands or back etc.); a smile is an achievable and rewarding outcome (ALOs 3 and 9).

**6.7.6.** Use shorter repetitive communications rather than long ones - encourage participation in singing, rhymes and other rhythmic group activities by assisting the child to move or clap in rhythm (ALO 5).

**6.7.7.** Remember that children with severe communication disabilities (for example those with cerebral palsy) can understand much more than they can express - respond to any indication that the child has understood something (ALO 6).

**6.7.8.** Therapists and mothers need opportunities to talk; to clarify what the each wants the other to understand, to listen and to learn from one another. If there are no formal opportunities for therapists and mothers to talk and to learn from one another, mothers should have the freedom to ask for such opportunities (ALO 11).

**6.7.9.** Meeting with other mothers of children with similar disabilities is good for encouragement and for learning from one another - if there is no formal support group to join mothers could collaborate to start one - or even just use opportunities such as the long waiting times at the clinic or hospital visits etc. to get to know other mothers visiting the clinic, and talk about joys, challenges, resourceful ideas etc. (ALO 12).

## **6.8. Epilogue**

And finally, the following experience comes to mind as I am trying to draw together the bricolage, the patchwork quilt of lessons from this research journey. Vuyo<sup>1</sup> was a 14-year-old boy from an isiXhosa speaking family with a sharp mind and a wonderful sense of humour, who could not speak and spent his earthly life locked in a body profoundly impaired by cerebral palsy. Vuyo's mother, his caregivers and I had learnt to communicate with him by 'reading' his eye-blink responses to our normal speech communication. True to his style of concise but profound comments on what was happening around him, Vuyo made some of his strongest impacts while he was on his way out of this life.

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<sup>1</sup> The names here have been changed for anonymity and confidentiality.



***Reflective Journal: 2 April 2011***

*I am called to the hospital bedside of Vuyo, a 14-year-old boy with severe cerebral palsy (spastic quadriplegia) and now in a coma with an acute chest infection and intermittent cardiac arrest.*

*I find his mother, Zoleka, in a small room alone with him and he is attached to every imaginable and unimaginable beeping and pumping hospital machinery. Vuyo's skinny, twisted body is still breathing and his eyes are open but glazed and unblinking – it is clear that the end is near. His mother still speaks of healing.*

*Vuyo's Mom and I chat, each of us gently massaging one of his hands; we softly sing some of the songs he knows and pray with him and every few minutes one of several nurses comes in to check on one of the several machines (does each machine get looked after by a different nurse?!?).*

*I am reminded how the world sees a child such as Vuyo: almost all the nurses are surprised that Zoleka and I are speaking to him at all, and almost without exception they exclaim, "But he can't talk!"*

*The hours pass and outside, afternoon changes to evening and to night...and a new shift of nurses comes on duty and the questions begin again. I am so encouraged – Zoleka answers all the isiXhosa speaking ones bravely and boldly "Even though he could never speak he understands everything and we don't know how much he's hearing – even now..."*

*For the next few hours, we both reminisce. In contrast to the nurses' impression of the twisted, disabled young boy lying on the bed – we remember his interest in anything mechanical and we chuckle about how he would love to have tried to fathom all these machines attached to him right now!*

*...and that he has been watching the Cricket World Cup (and sadly, he's missing the Final, being decided at this moment!).*

*Zoleka tells me how her husband, the children's father, left soon after the meningitis that so severely changed Vuyo's life, when he was still an infant. Zoleka has raised Vuyo and his older sister alone. Her mother would have helped but is severely disabled by arthritis. It has indeed been a lonely road.*

*Zoleka suddenly smiles as she makes the most startling statement: "I am so glad that he has never really been a sick child – I know he has this disability, but he has not had other sicknesses..." I reel as I process her clarity of insight into the difference between medical model thinking and social model thinking: an insight that many professionals and academics do not master!*

*She continues "...and God heard my prayers. I knew another child with the fitting kind of Cerebral Palsy (with seizures) and when he (Vuyo) had the meningitis I prayed that he wouldn't have those, and he didn't..." I am overwhelmed by this woman's level of faith and thankfulness...*

*Vuyo slips away, just as some relatives arrive to support Zoleka...*

*As always, when one has had the privilege of being there when someone passes on, I feel as if the curtain to Eternity has briefly opened and I was allowed to peek in.*

*In dying, Vuyo has given us the opportunity to be reminded of the enormous and urgent need to:*

- support families to see – as Zoleka does – the difference between disability and sickness...and to get to know and nurture the development and interests of the child*
- support fathers so that they can support mothers of children with disabilities...*

- *advocate among nursing and other care-professionals to be familiar (and comfortable!) with children with disabilities, to engage with them and to see additional health needs and not to see the disability as the sickness!*

*There is such a big need for multi-level information sharing about the ability of those who cannot speak, to hear and to be included... speak to them!!! Connect with them...!*

## References

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- ACPF (African Child Policy Forum). 2011. *Children with disabilities in South Africa: The hidden reality*. Addis Ababa: The African Child Policy Forum.
- Adams, F. & Galvaan, R. 2010. Promoting human rights: understanding the barriers to self-help groups for women who are carers of children with disabilities. *South African Journal of Occupational Therapy*. 40 (1). 12-16.
- Ahl, L. E., Johansson, E., Granat, T., & Carlberg, E. B. 2005. Functional therapy for children with cerebral palsy: an ecological approach. *Developmental Medicine & Child Neurology*, 47(9), 613-619.
- Ahmed, D.A.A., Lewando-Hundt, G. & Blackburn, C. 2011. Issues of Gender, Reflexivity and Positionality in the Field of Disability: Researching Visual Impairment in an Arab Society. *Qualitative Social Work* 2011 10: 467-484. DOI: 10.1177/1473325010370188
- Alant, E. 2000. What is an asset based approach? *Proceedings of a Fogarty Maternal and Child Health Workshop on Research Priorities in Early Childhood Development in Southern Africa*. Durban, South Africa 14-18 August, 2000. 76-77.
- Alant, E. 2002. *Multicultural Issues in Graphic Symbol Research: An Overview*. ISAAC Research Presentation. Odense, Denmark. August 2002.
- Alant, E. 2005. Cultural and socio-economic influences on communication. In: E. Alant and L.L. Lloyd, eds. *Augmentative and alternative communication and severe disabilities; beyond poverty*. London: Whurr Publishers Ltd. 95-107.
- Alant, E. & Lloyd, L.L. 2005. Introduction. In: *Augmentative and Alternative Communication and Severe Disabilities; Beyond Poverty*. London; Whurr Publishers Ltd. 1-8.
- Albrecht, GL, Devlieger, P & Van Hove, G. 2008. The experience of disability in plural societies. *Alter: European Journal of Disability Research*. 2(1). 1-13. DOI:10.1016/j.alter.2007.09.002
- Alexander, N. 1992. Language planning from below. In R.K. Herbert (Ed.) *Language and Society in Africa: The Theory and Practice of Sociolinguistics*. Johannesburg: Witwatersrand University Press. 143-150.
- American Speech-Language-Hearing Association. 1993. Definitions of communication disorders and variations [Relevant Paper]. Available from [www.asha.org/policy](http://www.asha.org/policy)

- American Speech-Language-Hearing Association. 2004. Preferred Practice Patterns for the Profession of Speech-Language Pathology <http://www.asha.org/policy/PP2004-00191.htm#sec1.3.10> accessed on 7 June 2014
- American Speech-Language-Hearing Association. 2004. Knowledge and skills needed by speech-language pathologists and audiologists to provide culturally and linguistically appropriate services. *ASHA Supplement 24*, 152–158.
- ASHA (see American Speech-Language-Hearing Association)
- Bailey, G. & Peoples, J. 2011. *Essentials of Cultural Anthropology*. 2<sup>nd</sup> Ed. Belmont, California: Wadsworth, Cengage Learning Inc.
- Baker, B. R. 1984. Minspeak: An introduction to semantic compaction systems. *Speech Technology*, 168-170.
- Baker, B.R. 2009. *Semantic Compaction Systems. Minspeak™ History*. Viewed on 2 June 2014 at <http://www.minspeak.com/HistoryofMinspeak.php#.U4vnjnbNySo>
- Balton, S. 2009. *Family-based activity settings of typically developing three-to-five-year old children in a low-income African context*. Submitted in partial fulfilment of the requirement of the degree Philosophiae Doctor in Communication Pathology, University of Pretoria. URI: <http://hdl.handle.net/2263/28788>
- Barnard, P.J. 2009. Beyond the feeding relationship: mothers' descriptions of interaction within the mother-child DYAD. MSc (Nursing). Supervised by M. Coetzee and P. Mayers.
- Barnes, C. 2003. Rehabilitation for Disabled People: a 'sick' joke? Independent living institute Library <http://www.independentliving.org/docs6/barnes2003a.html>
- Barnes, C. & Mercer, G. 2001. Disability Culture: assimilation or inclusion? In (eds). *Handbook of Disability Studies*. Thousand Oaks CA: SAGE Publications. 515-534
- Barratt, J., Khoza-Shangase, K. & Msimang, K. 2012. Speech-language assessment in a linguistically diverse setting: preliminary exploration of the possible impact of informal solutions within the South African context. *South African Journal of Communication Disorders*. 59. 34-44.
- Barratt, J. & Penn, C. 2009. Listening to the voices of disability: experiences of caring for children with cerebral palsy in a rural South African setting. In MacLachlan, M. & Swartz, L. (Eds.) *Disability and International Development: Towards inclusive global health*. New York: Springer. 191-212.
- Barrera, I. & Kramer, L. 1997. From monologues to skilled dialogues; teaching the process of crafting culturally competent early childhood environments. In P.J. Winton, J. A. McCollum & C. Catlett (Eds.), *Reforming personnel preparation in early intervention:*

- Issues, models, and practical strategies*. Baltimore: Paul H. Brookes Publishing Co. 217-251.
- Barry, A. 2012. Learning from African communal values: The leadership challenge for Occupational Therapists in the 21st Century Keynote address: 5th July OTASA Congress Durban. Viewed 4 August 2012 at <http://www.otasacongress.co.za/images/stories/presentations/Thurs/Umdoni2/08h30%20barry%20plenary%20thurs.pdf>
- Battle, D.E. 1998. *Communication disorders in multicultural populations (2nd ed.)* Boston, MA: Butterworth-Heinemann.
- Battle, D. E. 2012. *Communication disorders in multicultural and international populations (4th Ed)*. Elsevier.
- Baylor, C. R., Yorkston, K. M., Bamer, A., Britton, D., & Amtmann, D. 2010. Variables associated with communicative participation in people with multiple sclerosis: A regression analysis. *American Journal of Speech - Language Pathology*, 19, 143-153. doi: 10.1044/1058-0360(2009/08-0087)
- Berry L, Biersteker L, Dawes H, Lake L & Smith C 2013. *South African Child Gauge 2013*. Cape Town: Children's Institute University of Cape Town.
- Beukelman, D.R., & Mirenda, P. 1998. *Augmentative and alternative communication: Management of Severe Communication Disorders in Children and Adults*. 2<sup>nd</sup> Ed. Paul H. Brookes: Baltimore.
- Beukelman, D., & Mirenda, P. 2005. *Augmentative and alternative communication: Supporting children and adults with complex communication needs (3<sup>rd</sup> ed.)* Baltimore: Paul H. Brookes.
- Bornman, J. 2004. The World Health Organisation's terminology and classification: application to severe disability. *Disability and Rehabilitation*, 26(3), 182-188.
- Braithwaite, J., & Mont, D. 2009. Disability and poverty: a survey of World Bank poverty assessments and implications. *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, 3(3), 219-232.
- Brewster, T. & Brewster, E.S. 1976. *Language Acquisition Made Practical (LAMP): Field methods for language learners*. Colorado Springs: Lingua House
- Bronfenbrenner, U. 1979. *The ecology of human development: experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U. & Ceci, S. J. 1994. Nature-nurture reconceptualised in developmental perspective: A bio-ecological model. *Psychological Review*, 101, 568-586.

- Buchbinder, E. 2011. Beyond Checking: Experiences of the Validation Interview. *Qualitative Social Work* 2011 10: DOI: 10.1177/1473325010370189
- Burkhart, L. n.d. 'What is AAC?' Accessed on 2 July 2014 from <https://www.isaac-online.org/english/what-is-aac/>
- Calana, Z. 2002. *Xhosa proverbs and metaphors*. Cape Town: Kwela Books.
- Calculator, S. N. 1997. Fostering Early Language Acquisition and AAC Use: Exploring Reciprocal Influences between Children and Their Environments. *Augmentative and Alternative Communication*. 13(3), 149-157.
- Carter, R., Lubinsky, J. & Dumholdt, E. 2011. *Rehabilitation Research: Principles and Applications* (4th Edition). Elsevier-Saunders.
- Cayster, K., Green, M. & Worth, S. 2012. Learning how to be participatory: An emergent research agenda. *Action Research* 2012 10: 22. DOI: 10.1177/1476750311414737
- Chambers 21st Century Dictionary (n.d.) Accessed on 1 March 2014 from <http://www.chambers.co.uk/dictionaries/the-chambers-dictionary.php>
- Chambers, R. 1994. The origins and practice of Participatory Rural Appraisal. *World Development*, 22 (7). 953-969. [http://dx.doi.org/10.1016/0305-750X\(94\)90141-4](http://dx.doi.org/10.1016/0305-750X(94)90141-4) viewed 2014, 10 January
- Chambers, R. 2007. 'Who Counts? The Quiet Revolution of Participation and Numbers', *IDS Working Paper* 296, Brighton: IDS <http://www.ntd.co.uk/idsbookshop/details.asp?id=1006>
- Chambers, R. 2010. *Paradigms, Poverty and Adaptive Pluralism*. *IDS Working Paper* 344. Brighton: Institute of Development Studies.
- Chataika, T. 2013. Cultural and Religious Explanations of Disability and Promoting Inclusive Communities. In Claassens, J., Swartz, L. and Hansen, L. (Eds.). *Searching for Dignity: Conversations on human dignity, theology and disability*. Stellenbosch: SUNMedia. 117-128
- Child-to-child Trust. 2003. *Learning together in the Mpika inclusive education project*. Accessed on 21 July 2014 from <http://www.child-to-child.org/resources/onlinepublications.htm>
- Child-to-child Trust. 2009. *Child-to-Child: An international network promoting children's participation in health and development*. Accessed on 21 July from <http://www.child-to-child.org/>

- Christianson, A. L., Zwane, M. E., Manga, P., Rosen, E., Venter, A., Downs, D., et al. (2002). Children with intellectual disability in rural South Africa: Prevalence and associated disability. *Journal of Intellectual Disability Research*, 46, 179–186
- Clark, N., Hunt, S., Jules, G. & Good, T. 2010. Ethical dilemmas in Community-Based Research: Working with vulnerable youth in Rural Communities. *J. Acad Ethics*. 8. 243-252. DOI 10.1007/s10805-010-9123-y.
- Clarke MT, Newton C, Griffiths T, Price, K, Lysley A & Petrides, KV. 2011. Factors associated with the participation of children with complex communication needs. *Research in Developmental Disabilities*. 32 (2). 774–780.
- Cockburn-Wootten, C. & Henderson, A. 2006. Sustaining competing professional identities: Measuring action learning 'outcomes' in an educational context. *Journal of Asia Entrepreneurship and Sustainability*, 2(2), 28-50.
- Coghlan, D. & Shani, A. B. 2008. Insider Action Research: The dynamics of developing new capabilities. In P. Reason and H. Bradbury. *Sage Handbook of Action Research*. 2<sup>nd</sup> Ed. London: Sage Publications. 643-655.
- Cohen, R., Chetley, A., Mikhyo, Z., Nimpuno, P., Salole, G. & Zwitzer, L. 1994. *Building on People's Strengths: Early Childhood in Africa*. The Hague; Bernhard van Leer Foundation.
- Cohen S. R. 2012. *My time with Einstein*. Bloomington Indiana: AuthorHouse. ISBN-13: 978-1477262627
- Coleridge, A., & Hartley, S. 2010. *CBR stories from Africa: what can they teach us?* Norwich: University of East Anglia.
- Coleridge, P. 2000. Disability and culture. *Selected Readings in Community Based Rehabilitation Series, 1*, 21-38.
- Constitutional Court of South Africa. 1996. *Constitution of the Republic of South Africa. Chapter 1: Section 6.1*. Accessed on 16 April 2014 from <http://www.constitutionalcourt.org.za/site/constitution/english-web/ch1.html>
- Conyers, L.M. 2003. Disability Culture: A Cultural Model of Disability. *Rehabilitation Education, Vol 17(3), 2003, 139-154*. <http://psycnet.apa.org/psycinfo/2003-10268-001>
- Cooperrider, D. L. & Whitney, D. 2005. *Appreciative inquiry: A positive revolution in change*. San Francisco, CA: Berrett-Koehler.
- Cooperrider D.L. & Srivastva, S. 1987. Appreciative inquiry in organizational life. *Research in Organizational Change and Development*. Volume1. pp129-169.



- Couper, J. 2002. Prevalence of childhood disability in rural KwaZulu. *South African Medical Journal*, 92(7):549 – 52
- Cresswell, J.W. 2009 *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. 3<sup>rd</sup> Edition. Thousand Oaks: SAGE.
- Cresswell, J.W. & Tashakkori, A. 2007. Developing publishable mixed methods manuscripts . *Journal of Mixed Methods Research* , 1, 107-111. doi: 10.1177/1558689807302814
- Crowe, L.K., Norris, J.A. & Hoffman, P.R. 2004. Training caregivers to facilitate communicative participation of preschool children with language impairment during storybook reading. *J Commun. Disord.* 37(2):177-96.
- Cruice, M. 2008. The contribution and impact of the International Classification of Functioning, Disability and Health on quality of life in communication disorders. *International Journal of Speech Language Pathology*. 10 (1): 38-49.
- Danforth, S. 2001. A Pragmatic Evaluation of Three Models of Disability in Special Education. *Journal of Developmental and Physical Disabilities*, Vol. 13, No. 4, 343-359.
- Darrah, J., Law, M. C., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D, Galupp, B. (2011). Context therapy: A new intervention approach for children with cerebral palsy. *Developmental Medicine and Child Neurology*, 53(7), 615-620. <http://search.proquest.com/docview/876959911?accountid=14500>
- Davis, C. 2005. *Appreciative Inquiry: A Tool for Transformational Learning*. Presented at the Sixth International Transformative Learning Conference, Michigan State University, Oct. 6-9, 2005. Accessed on 4 June 2014 from <http://appreciatinginquiry.wikispaces.com/file/view/AI+paper.pdf>
- DeafSA. 2009. *Frequently Asked Questions*, viewed 12 July 2012, from <http://www.deafsa.co.za/index-5.html>
- Denzin, N.K. 2012. Triangulation 2.0. *Journal of Mixed Methods Research*. 2012 6: 80 originally published online 23 February 2012. DOI: 10.1177/1558689812437186
- Denzin, N.K. & Lincoln, Y.S. 2003. Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y.S. Lincoln (Eds.) *Strategies of Qualitative Inquiry*. (2<sup>nd</sup> Ed) Thousand Oaks, CA: Sage. 1-17.
- Department of Education, 2001, *White Paper 6; Building an Inclusive Education and Training System*, viewed 27 October 2011, from [www.info.gov.za/whitepapers/2001/edu6](http://www.info.gov.za/whitepapers/2001/edu6)
- Department of Education. 2004. *The national audit of special education provision in South Africa*. Unpublished draft report. Pretoria: Department of Education.

- Department of Health, 2000, *National rehabilitation policy*, viewed 21 November 2009, from <http://www.doh.gov.za/docs/factsheets/guidelines/nrp.pdf>"  
[www.doh.gov.za/docs/factsheets/guidelines/nrp.pdf](http://www.doh.gov.za/docs/factsheets/guidelines/nrp.pdf)
- Department of Provincial and Local Government (nd) *Disability Framework for Local Government 2009 – 2014* <http://www.info.gov.za/view/DownloadFileAction?id=107417>
- DSD, DWCPD & UNICEF. 2012. *Children with Disabilities in South Africa: A Situation Analysis: 2001-2011. Executive Summary*. Pretoria: Department of Social Development/Department of Women, Children and People with Disabilities/UNICEF
- Devlieger, P. 1995. Why Disabled? The Cultural Understanding of Physical Disability in an African Society. In Ingstad, B. and Reynolds Whyte, S. (Eds.) *Disability and Culture*. California: University of California Press. 94 – 106.
- Devlieger, P. 1998. Persons with a Physical Disability at the Interstices of Classification: Examples from Africa and the United States. *Zeitschrift Behinderung und Dritte Welt* 2/98. 46-48. [Journal for Disability and International Development 1998 (2) pages 46-48].
- Devlieger P. 1999. Frames of reference in African proverbs on disability. *International J. Disability, Development & Education* 46: 439-451.
- Devlieger, P.J. 2005. *Generating a cultural model of disability*. Presented at the 19th Congress of the European Federation of Associations of Teachers of the Deaf (FEAPDA), October 14-16, 2005. Accessed on 13 May 2013 from <http://feapda.org/FEAPDA%20Geneva%202005/FEAPDA%20Geneva%202005.htm>
- Devlieger, P.J. 2010 At the interstices of classification: notes on the category of disability in sub-saharan Africa. In SN Barnartt (Ed) *Disability as a fluid state. Research in Social Science and Disability, Volume 5*. 69-102. DOI 10.1108/S1479-3547(2010)000005006
- Disabled People South Africa. 2001. *D.P.S.A Pocket Guide On Disability Equity: An Empowerment Tool In support of The Africa Decade Of Disabled Persons 1st of January 1999 – 31st of December 2009 (1<sup>st</sup> Edition)*. DPSA Parliamentary Office On behalf of DPSA.
- Doull, J. 2000. Hegel's Phenomenology and Postmodern Thought. *Animus* 5. ISSN 1209-0689. Retrieved August 9, 2011 from <http://www.swgc.mun.ca/animus>
- Dube, A.K., 2006, The role and effectiveness of disability legislation in South Africa, in B. Albert (ed), *In or out of the mainstream? Lessons from research on disability and development cooperation*, pp. 119-133, The Disability Press, Leeds.

- Duma, S. E. 2006. *Women's journey of recovery from sexual assault trauma: a grounded theory*. Unpublished PhD dissertation in the School of Health and Rehabilitation Sciences, University of Cape Town.
- Duma, S.E. 2010. Legitimate agents of knowledge, who are they? Editorial paper in *Curationis*. 33 (3). 3-4. Accessed on 14 August 2014 from <http://www.curationis.org.za/index.php/curationis/article/viewPDFInterstitial/1/1>
- Duncan, M., Ferguson, G., Geiger, M. & Petersen, L. 2009. Disability and rehabilitation in primary health care. In V. Zweigenthal, T. Puone, L. Reynolds, L. London, D. Coetzee, M. Alperstein, M. Duncan, M Loveday, S. Atkins, C Hutchings [editors] *An Introduction to Primary Health Care: Fresh Perspectives*. Pinelands: South Africa. Pearson Education. 233-264.
- Dunst, C.J., Trivette, C.M. & Raab, M. 2014. Everyday Child Language Learning Early Intervention Practices. *Infants & Young Children*. 27 (3). 207–219. DOI: 10.1097/IYC.0000000000000015
- DuPlessis, T. 1999. The translation and interpreting scenario in the new South Africa. In M. Erasmus, L. Mathibela, E. Hertog & H. Antonissen (Eds.) *Liaison interpreting in the community*. Pretoria: Van Schaik. 3-28.
- Eadie, TL, Yorkston, KM, Klasner, ER, Dudgeon BJ, Deitz, JC, Baylor, CR, Miller, RM & Amtmann, D., 2006. Measuring Communicative Participation: A Review of Self-Report Instruments in Speech-Language Pathology *Am J Speech Lang Pathol*. 2006 November ; 15(4): 307–320. doi:10.1044/1058-0360(2006/030).
- Eastman, C. M. 1992. Socio-linguistics in Africa: Language Planning. In R.K. Herbert (Ed.) *Language and Society in Africa: The Theory and Practice of Sociolinguistics*. : Witwatersrand University Press. 95-114
- Ebersöhn, L. & Eloff, I., 2006. Identifying asset-based trends in sustainable programmes which support vulnerable children. *South African Journal of Education*. 26(3), 457–472
- Eide A.H. & B. Ingstad B (Eds) 2011, *Disability and poverty: a global challenge* Bristol, UK, The Policy Press), ISBN 978-1-84-742885-1
- Ellison, R. 1952. *The Invisible Man*. New York: Random House.
- Engel, GL. 1977. The need for a new medical model: a challenge for Biomedicine. *Science*, New Series, Vol. 196, No. 4286 (Apr. 8, 1977), pp. 129-136 <http://www.jstor.org/stable/1743658>. Accessed: 07/07/2014 23:41
- Erasmus, M. 1999. Preface. In M. Erasmus, L. Mathibela, E. Hertog & H. Antonissen (Eds.) *Liaison interpreting in the community*. Pretoria: Van Schaik. p. vii - x.

- Finkenflügel, H. 2004. *Empowered to differ: Stakeholders' Influences in Community-Based Rehabilitation*. Published PhD Dissertation. Amsterdam: Vrije Universiteit Amsterdam. ISBN 90-77595-11-2
- Finkenflügel, H., Wolffers, I., & Huijsman, R. (2005). The evidence based community-based rehabilitation: a literature review, *International Journal of Rehabilitation Research*, 28, 187-201.
- Foster, A. & Ford, N. 2003. Serendipity and information seeking: an empirical study. *Journal of Documentation*. 59 (3). 321-340.
- Freire, P, 1970, *Pedagogy of the oppressed*. Continuum Publishing Company, New York.
- Gallagher, TL, DiGiorgio, C, Bennett S & Antle, K. 2008. Understanding Disability and Culture while enhancing advocacy. *Teaching and Learning*. 4 (3). Accessed 8 September 2012 from [www.isetl.org/ijtlhe/pdf/IJTLHE](http://www.isetl.org/ijtlhe/pdf/IJTLHE)
- Garbarino J & Ganzel B 2000. The human ecology of early risk. In JP Shonkoff & SJ Meisels (eds.) *Handbook of early childhood intervention (2nd Ed)*. New York; Cambridge University Press. 76-93.
- García Coll, C. & Magnuson, K. 2000. Cultural Differences as Sources of Developmental Vulnerabilities and Resources. In Shonkoff, J. P. & Meisels, S. J. (Eds.) *Handbook of Early Childhood Intervention*. (2<sup>nd</sup> Ed.) New York; Cambridge University Press. 94 – 114.
- García Coll, C.T., Ackerman, A., Cicchetti, D. 2000. Cultural Influences on Developmental Processes and Outcomes: Implications for the Study of Development and Psychopathology [Special Issue]. *Development and Psychopathology*, 12, 333-356.
- Geiger, M. 2010. African cultures as resources in supporting inclusive environments for children with severe communication disabilities: A Case Study from Botswana. *Children's Geographies*. 8(1). 51-63. URL: <http://dx.doi.org/10.1080/14733281003651016>
- Geiger, M. 2012a. Through the eyes of children: Theological lessons with and from children with severe communication disabilities. *Journal of Religion, Disability and Health*. 16(1). 102-113. <http://www.tandfonline.com/doi/abs/10.1080/15228967.2012.645615#.VeEqhSWqqko>
- Geiger, M., 2012b. Communication training for centre-based carers of children with severe or profound disabilities in the Western Cape, South Africa. *African Journal of Disability* 1(1). <http://www.ajod.org/index.php/ajod/article/view/10>
- Geiger, M. & Alant, E. 2005. Child-rearing practices and children's communicative interactions; Observations in a village in Botswana. *Early Years*. 25 (2).183-191. <http://www.tandfonline.com/doi/abs/10.1080/09575140500128079#.VeEuCyWqqko>

- Gilson, S.F. & Depoy, E. 2000 Multiculturalism and Disability: A critical perspective, *Disability & Society*, 15:2, 207-218, DOI: 10.1080/09687590025630
- Gona, J.K., Mung'ala-Odera, V, Newton, C.R. & Hartley, S. 2010. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child: care, health and development*. 37, 2, 175–183. doi:10.1111/j.1365-2214.2010.01124.x
- Goodreads Inc. 2011. *Daniel Webster Quotes*. Accessed on 14 April 2013 from <http://www.goodreads.com/author/quotes/31180>
- Goossens, C. 1989. Aided Communication Intervention Before Assessment: A Case Study of a Child with Cerebral Palsy. *Augmentative and Alternative Communication*. 5 (1), 14-26.
- Gopnik, A. 2001. Theories, Language and Culture: Whorf without wincing. In Bowerman, M. Levinson, S.C. (Eds.) *Language acquisition and Conceptual development*. Cambridge; Cambridge University Press. 45 – 69.
- Granlund, M. Björck-Åkesson, E. & Alant, E. 2005. Family-centred early childhood intervention: new perspectives. In: E. Alant and L.L. Lloyd, eds. *Augmentative and alternative communication and severe disabilities; beyond poverty*. London: Whurr Publishers Ltd. 221-242.
- Grant, S. & Humphreys, M. 2006. Critical evaluation of appreciative inquiry: Bridging an apparent paradox. *Action Research*. 4 (4) 401-418. doi: 10.1177/1476750306070103
- Gxilishe, S. 2008. African languages, linguistics, child speech and speech pathology – the connection. *Per Linguam*, 24(2), 75-87.
- Habermas, J. 1984. *Theory of Communicative Action: Volume 1. Reason and the Rationalization of Society* (Translated by Thomas McCarthy) Boston: Beacon Press
- Hall, E.T. 1976. *Beyond Culture*. New York: Doubleday.
- Hall, E.T. 1990. *Understanding Cultural Differences*. Yarmouth, ME: Intercultural Press.
- Hartley, S.D. 1997. *Development of a 'communication disability model' and its application to service delivery in less developed countries*. PhD Dissertation - Awarding Body: University of London. Accessed on 7 January 2014 from <http://ethos.bl.uk/OrderDetails.do?did=1&uin=uk.bl.ethos.264354#sthash.QAYV8Xwr.dpuf>
- Hartley, S 2004. Bridging the gap between health care professionals and communities. *Community Eye Health Journal* | VOL 17 NO. 51 | OCTOBER 2004. 38-39

- Hartley, S., Finkenflügel, H., Kuipers, P., & Thomas, M. 2009. Community-based rehabilitation: opportunity and challenge. *The Lancet*, 374(9704), 1803-1804. DOI: 10.1016/S0140-6736(09)62036-5
- Hartley, S., Murira, G., Mwangoma, M. & Carter, J. 2005. *Women in action: Improving the .* Accessed 21 February 2014 from <http://www.cehjournal.org/article/bridging-the-gap-between-health-care-professionals-and-communities/quality-of-children's-lives>. London: Institute of Child Health, University College London.
- Hartley, S., Murira, G., Mwangoma, M., Carter, J. & Newton, C.R.J.C. 2009. Using community/researcher partnerships to develop a culturally relevant intervention for children with communication disabilities in Kenya, *Disability and Rehabilitation*, 31:6, 490-499, DOI: 10.1080/09638280802061944
- Hartley, S.D. & Wirz, S.L. 2002. Development of a 'communication disability model' and its implication on service delivery in low-income countries. In *Soc Sci Med*.54 (10):1543-57. DOI: 10.1016/S0277-9536(01)00136-8
- Havstam C & Lohmander A. 2011. Communicative Participation. In S Howard & A Lohmander (eds) *Cleft Palate Speech: Assessment and Intervention*. Hichester, West Sussex UK: John Wiley & Sons. Ch 17/pp 305-316.
- Hawking, S. 2011. Foreword. In WHO, *World Report on Disability* (p. ix.). Geneva, Switzerland: World Health Organization & World Bank.
- Health Professions Council of South Africa 2008. *Guidelines for good practice in the health care professions: general ethical guidelines for health researchers (booklet 6)*. Pretoria, South Africa: HPCSA
- Helman, C.G. 2007. *Culture, Health and Illness*. 5<sup>th</sup> Ed. London: Hodder Arnold.
- Hofstede, G. 2001. *Culture's Consequences: Comparing values, behaviours, institutions and organisations across Nations*. (2<sup>nd</sup> Ed.) Thousand Oaks; Sage Publications.
- Hope, A. & Timmel, S., 1995a. *Training for transformation: a handbook for community workers, Book 1*. Practical Action Publishing, Rugby, UK.
- Hope, A. & Timmel, S., 1995b. *Training for transformation: a handbook for community workers, Book 2*. Practical Action Publishing, Rugby, UK.
- Hope, A. & Timmel, S., 1995c. *Training for transformation: a handbook for community workers, Book 3*. Practical Action Publishing, Rugby, UK.
- Hope, A. & Timmel, S., 1999. *Training for transformation: a handbook for community workers, Book 4*, ITDG Publishing, London.



- Hopkins, P.E. 2007. *Positionalities and knowledge: Negotiating ethics in practice*. *ACME: An International E-Journal for Critical Geographies*, 6 (3), 386-394. <http://www.acme-journal.org/vol6/PEH.pdf> [26 January, 2014]
- Horn, L. 2011. *Guidelines for new researchers*. Stellenbosch: Stellenbosch University Division of Research Development and Support. Accessed 1 June 2013 from [http://sun025.sun.ac.za/portal/page/portal/Health\\_Sciences/English/Centres%20and%20Institutions/Research\\_Development\\_Support/Ethics/Application\\_package/Research%20Booklet%2014%2003%202011.pdf](http://sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package/Research%20Booklet%2014%2003%202011.pdf)
- Hourcade J, Pilotte T E, West E & Parette P, 2004. A History of Augmentative and Alternative Communication for Individuals with Severe and Profound Disabilities. *Focus on autism and other developmental disabilities*. (19)4. 235–244
- Howe, T. J. 2008. The ICF Contextual Factors related to speech-language pathology. *International Journal of Speech-Language Pathology*. 2008. 10(1) 27-37.
- HPCSA 2008. Guidelines for good practice in the health care professions: general ethical guidelines for health researchers (booklet 6). Pretoria, South Africa: HPCSA
- Ibragimova, N., Lillvist, A., Pless, M. & Granlund, M., 2007. The utility of the ICF for describing interaction in non-speaking children with disabilities – caregiver ratings and perceptions. *Disability and Rehabilitation*. 29(22), 1689-1700.
- ILO, UNESCO, WHO 2004. *CBR Joint Position Paper*. Geneva: World Health Organisation.
- Ingstad, B. 1995. Mpho ya Modimo – A Gift from God: Perspectives on “Attitudes” toward Disabled People. In Ingstad, B. and Reynolds Whyte, S. (Eds.) *Disability and Culture*. California: University of California Press. 246 – 263.
- Ingstad, B. 1997. *Community Based Rehabilitation in Botswana; the Myth of the Hidden Disabled*. New York, Edwin Mellin Press.
- Ingstad, B. & Reynolds Whyte, S. 2007. *Disability in Local and Global Worlds*. Berkeley CA: University of California Press.
- Isaac, K. 2002. *Speech Pathology in Cultural and Linguistic Diversity*. London: Whurr Publishers Ltd.
- Janesick, V.J. 2003. The Choreography of Qualitative Research Design. In N. K. Denzin & Y.S. Lincoln (Eds.) *Strategies of Qualitative Inquiry*. (2<sup>nd</sup> Ed) Thousand Oaks, CA: Sage. 46-79.
- Jezewski, M.A. & Sotnik, P. 2001. Culture Brokering: Providing Culturally Competent Rehabilitation Services to Foreign-Born Persons. CIRRIE Monograph Series. Stone, J.

- (Ed). State University of New York, Buffalo: Centre for International Rehabilitation Research Information and Exchange.
- Johnstone, B. 2007. *Discourse Analysis*. 2<sup>nd</sup> Ed. Malden, Massachusetts: Wiley-Blackwell Publishing
- Jones, J. D. 1993. Preface. In Matumo, Z.I. *Setswana-English-Setswana Dictionary*. Gaborone; Botswana Book Centre. vii – ix.
- Kachaje, R., Dube, K. & MacLachlan, M. & Mji, G., 2014. The African Network for Evidence-to-Action on Disability: A role player in the realisation of the UNCRPD in Africa', *African Journal of Disability* 3(2), Art. #86, 5 pages. <http://dx.doi.org/10.4102/ajod.v3i2.86>
- Kaschula, R. H. & Anthonissen, C. 1995. *Communicating across Cultures in South Africa; Toward a critical language awareness*. Johannesburg; Hodder and Stoughton.
- Kathard, H. & Pillay, M. 2013. Promoting change through political consciousness: A South African speech-language pathology response to the World Report on Disability *International Journal of Speech-Language Pathology*, 2013; 15(1): 84–89 DOI: 10.3109/17549507.2012.757803
- Ka Toni, M. 2007. *The production of an appropriate and culturally sound isiXhosa translation of the International Classification of Functioning, Disability and Health (ICF) Checklist*. Unpublished dissertation in partial fulfillment of the research requirements of the Master of Philosophy in Disability Studies. University of Cape Town: Department of Health and Rehabilitation Sciences.
- Kemmis, S. & McTaggart, R. 2003. Participatory Action Research. In N. K. Denzin & Y.S. Lincoln (Eds.) *Strategies of Qualitative Enquiry*. (2<sup>nd</sup> Ed) Thousand Oaks, CA: Sage. 336-396.
- Kent-Walsh, J. & McNaughton, D. 2005. Communication Partner Instruction in AAC: Present Practices and Future Directions. *AAC: Augmentative & Alternative Communication*. 21 (3) 195-204. DOI: 10.1080/07434610400006646
- Kett, M., Geiger, M. & Boersma, M. 2008. CBR and Families in Crisis. In Hartley, S. and Okune, J. (Eds.) *CBR; Inclusive Policy Development and Implementation*. Norwich: University of East Anglia.
- King, S., Teplicky, R., King, G., & Rosenbaum, P. 2004. Family-centered service for children with cerebral palsy and their families: a review of the literature. In *Seminars in pediatric neurology* (Vol. 11, No. 1, pp. 78-86). WB Saunders.
- Kincheloe, J.L. 2001. Describing the Bricolage: Conceptualizing a New Rigor in Qualitative Research. *Qualitative Inquiry* 2001 7: 679. DOI: 10.1177/107780040100700601



- Kovarsky D, Culatta B, Franklin A, & Theadore, G 2001. "Communicative Participation" as a way of facilitating and ascertaining communicative outcomes. *Topics in Language Disorders*. 22(1). 1-20
- Kritt, D.W. 2013. A Vygotskian perspective on learning, culture and an education that matters. *Early Childhood Matters*. June 2013. Bernard van Leer Foundation. Accessed on 12 January 2014 from <http://earlychildhoodmagazine.org/our-focus-category/quality-early-learning/a-vygotskian-perspective-on-learning-culture-and-an-education-that-matters/>
- Krog, A., Mpolweni, N. & Ratele, K. 2009. *There was this goat: Investigating the Truth Commission Testimony of Notrose Nobomvu Konile*. Durban: University of KwaZulu-Natal Press.
- Kromberg J.G.R. & Jenkins T. 2004. Genetic and congenital disorders. In *Paediatrics and Child Health: A manual for health professionals in developing countries*. 5<sup>th</sup> ed. H.M. Coovadia & D.F. Wittenberg, Eds. Cape Town: Oxford University Press. 41-54.
- Lage, D. 2005. Unterstützte Kommunikation und ihre theoretischen Bezugssysteme - Auslegeordnung für eine behindertenpädagogische Konzeption. In: Boenisch, Jens/Otto, Katrin (Hg.). *Leben im Dialog. Unterstützte Kommunikation über die gesamte Lebensspanne*. Karlsruhe: Von Loeper Literaturverlag. S. 40-55.
- Lage, D. 2007. Was, wie, wo, welche Party? Wie lehren und lernen wir Partizipation? In: Sachse, Stefanie/Birngruber, Cordula/Arendes, Silke (Hg.). *Lernen und Lehren in der Unterstützten Kommunikation*. Karlsruhe: Von Loeper Fachbuch. S. 372-387.
- Lawlor, K. Mihaylov, S. Welsh, B. Jarvis, S & Colver, A. 2006. A qualitative study of the physical, social and attitudinal environment influencing the participation of children with cerebral palsy in northeast England. *Pediatric Rehabilitation*. July 2006. 9(3). 219-228.
- Lethbridge, L. 2013. *Servants: A Downstairs History of Britain from the Nineteenth Century to Modern Times*. New York: W.W. Norton & Company, Inc.
- Letto, M., Bedrosian, Jan. L. & Skarakis-Doyle, E. 1994. Application of Vygotskian Developmental Theory to Language Acquisition in a Young Child with Cerebral Palsy. *Augmentative and Alternative Communication*. 10 (3), 151-160.
- Levin, K., 2006, 'I am what I am because of who we all are': International perspectives on rehabilitation: South Africa. *Pediatric Rehabilitation*, 9 (3), 285 – 292. doi: 10.1080/13638490500293358
- Levin, K. S., 2013. *The communicative participation of adults with cerebral palsy*. Dissertation presented for the degree of Doctor of Philosophy; Faculty of Arts and Social Sciences: Stellenbosch University.

- LeVine, R.A., Dixon, S., LeVine, S., Richman, A., Leiderman, P.H., Keefer, C.H. & Brazelton, T.B. 1996. *Child care and culture: lessons from Africa*. Cambridge: Cambridge University Press.
- Lewin, Kurt. 1946. Action Research and Minority Problems, *Journal of Social Issues* 2 (1946): 34-46. Viewed 8 June 2014 from <http://dx.doi.org/10.1111/j.1540-4560.1946.tb02295.x>
- Lincoln Y. S. & Guba E. G. 1985. *Naturalistic Inquiry*. Beverly Hills, CA: Sage.
- Lipenga, K.J., 2014, Disability and masculinity in South African autosomatography, *African Journal of Disability* 3(1), Art. #85, 9 pages. <http://dx.doi.org/10.4102/ajod.v3i1.85>
- Lippman, L. H., Moore, K. A., & McIntosh, H. 2011. Positive Indicators of Child Well-Being: A Conceptual Framework, Measures and Methodological Issues. *Applied Research Quality Life*. 6(425-449).
- Lorenzo, T. 2005. *We don't see ourselves as different; A web of possibilities for disabled women: how Black Disabled Women in Poor Communities Equalise Opportunities for Human Development and Social Change*. Cape Town: University of Cape Town Press.
- Ludema, J.D., Cooperrider, D.L. & Barrett, F.J. 2001. Appreciative Inquiry: the Power of the Positive Question. In Reason, P. & Bradbury, H. (Eds.) *Handbook of Action Research; Participative Inquiry and Practice*. London; Sage Publications. 189 -199.
- Ludema, J.D. & Fry, R.E. 2008. The practice of Appreciative Inquiry. In Reason, P. & Bradbury, H. (Eds.). *The SAGE Handbook of Action Research; Participative Inquiry and Practice*. (2<sup>nd</sup> Ed). London; Sage Publications. 280-296.
- Ma, E.P.M., Threats, T.T. & Worrall, L.E. 2008. An Introduction to the International Classification of Functioning, Disability and Health (ICF) for speech-language pathology: It's past, present and future. *International Journal of Speech-Language Pathology*, 10 (1-2): 2-8.
- MacGuire, J. M. 2006. Putting nursing research findings into practice: research utilization as an aspect of the management of change. *Journal of Advanced Nursing* 53(1), 65–74.
- Mackenzie, N. & Knipe, S. 2006. Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research*, 16(2), 193-205.
- Mall, W. 2002. Basic Communication – an unconditional way to encounter. *Proceedings of the 10<sup>th</sup> Biennial Conference of the International Society for Augmentative and Alternative Communication, held in Odense, Denmark August 10<sup>th</sup> – 15<sup>th</sup> 2002*. . ISAAC 2002 Conference Proceedings. 496 – 497.
- Mall, W. 2005. Ein Zugang, der bleibt - auch bei Wachkoma oder Demenz: Basale Kommunikation In: Boenisch, J., Otto, K.: *Leben im Dialog - Unterstützte*

- Kommunikation über die gesamte Lebensspanne*. Karlsruhe, Germany: Von Loeper. 2005, S. 404-415
- Marshall J, & Goldbart J. 2008. 'Communication is everything I think.' Parenting a child who needs Augmentative and Alternative Communication (AAC). *International Journal of Language and Communication Disorders* 2008; 43: 77-98.
- Martin P. 2010. *Government-funded programmes and services for vulnerable children in South Africa*. Cape Town: HSRC Press.
- Masoga, M. 2005. South African Research in Indigenous Knowledge Systems and Challenges of Change *Indilinga – African Journal of Indigenous Knowledge Systems* Vol 4 (1) 15-30.
- Masola, A. 2014. On teaching 'creatures'. *Mail & Guardian Thoughtleader*. Accessed on 21 May 2015 from <http://www.thoughtleader.co.za/athambilemasola/2014/05/06/on-teaching-creatures/>
- Mayer-Johnson, R. 1990. *The Picture Communication Symbols. Volumes I, II and III*. Solana Beach, USA Mayer-Johnson Co.
- Mayring, P. 2000. Qualitative Content Analysis. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research. 1 (2)*. Accessed 3 June 2012 from <http://qualitative-research.net/fqs/fqs-e/2-00inhalt-e.htm>
- Mays, N. & Pope, C. 2000. Qualitative research in health care: assessing quality in qualitative research. *BMJ* 2000. 320; 50-52. doi: <http://dx.doi.org/10.1136/bmj.320.7226.50>
- McAllister, L, Wylie, K, Davidson B & Marshall, J. 2013. The World Report on Disability: An impetus to reconceptualise services for people with communication disability. *International Journal of Speech-Language Pathology*, 2013; 15(1): 118–126.
- McConkey, R. 2005. Service delivery in low-income countries. In Alant, E. & Lloyd, L.L. (Eds.) *Augmentative and Alternative Communication and Severe Disabilities; Beyond Poverty*. London; Whurr Publishers. 131 – 154.
- McConkey, R., Truesdale-Kennedy, M., Chang M-Y, Jarrah, S. & Shukri, R. 2008. The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies* 45: 65–74.
- McKenzie, J., Mji, G., Gcaza, S. 2014. *With or without us? An audit of disability research in the southern African region* Vol 3, No 2 (2014) AJOD: AfriNEAD 2011 Symposium Supplement – Building communities of trust.
- McKenzie, J. & Müller, B. 2006. Parents and Therapists: Dilemmas in Partnership. In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestley, M. (Eds) *Disability and Social Change: a South African Agenda*. Cape Town: HSRC Press. 311-323

- McLaren, P. 2013. *Skills development in the Cerebral Palsy (CP) sector. What exists, what existed previously and what are the possibilities for the future?* (Unpublished report for the DG Murray Trust).
- McLeod S & Threat TT. 2008 The ICF-CY and children with communication disabilities International Journal of Speech-Language Pathology, 2008, Vol. 10, No. 1-2 : Pages 92-109 (doi: 10.1080/17549500701834690)
- McMillan, J.H. & Schumacher, S. 2001. *Research in Education; A Conceptual Introduction (5<sup>th</sup> Ed.)*. New York: Longman.
- Medical Research Council. 2003. *Guidelines on Ethics for Medical Research. Book 1: General Principles (4<sup>th</sup> Ed.)*. Tygerberg; MRC South Africa.
- Merriam, A.P., 1974. *An African World: The Basongye Village of Lupupa Ngye*. Bloomington, IN, USA: Indiana University Press.
- Merriweather, A.M. 1992. *Puisanyo ya Bongaka ka Sekgoa le Setswana; Medical Phrasebook and Dictionary*. Gaborone: Botswana Book Centre.
- Mertens, D.M. 2003. Mixed Methods and the politics of human research; the transformative-emancipatory perspective. In Tashakkori, A. and Teddlie, C. (Eds). *Handbook of Mixed Methods in Social & Behavioural Research*. Thousand Oaks, California: Sage Publications, Inc. 135-166
- Mertens, D. M. 2007 Transformative Paradigm: Mixed Methods and Social Justice. *Journal of Mixed Methods Research* July 2007 1: 212-225
- Mertens, D. M. 2009. *Transformative research and evaluation*. New York: Guilford.
- Mertens, D. M. 2010. Transformative Mixed Methods Research. *Qualitative Inquiry* 2010 16: The online version of this article can be found at: DOI: 10.1177/1077800410364612
- Mertens, D.M., Bledso K.L., Sullivan M, & Wilson, A. 2010. Utilization of mixed methods for transformative purposes. In *SAGE Handbook of Mixed Methods in Social and Behavioural Research*. (2<sup>nd</sup> Edition). A. Tashakkori & C. Teddlie, Eds. Thousand Oaks, California: SAGE Publications, Inc. 193 – 214.
- Mihesuah, D.A. 2004. Preface. In Mihesua, D.A. & Wilson, A. C. (Eds). *Indigenizing the Academy: Transforming scholarship and empowering communities*. Lincoln, NE: University of Nebraska Press pp ix – xi.
- Miles, M. 1994. *What is Community Based Rehabilitation (CBR)?* Independent Living Institute. [www.independentliving.org/docs2/milesm1994.html](http://www.independentliving.org/docs2/milesm1994.html)

- Miles M. 2007. *International Strategies for Disability-related Work in Developing Countries: historical, modern and critical reflections*. Accessed 9 June 2014 from [www.independentliving.org/docs7/miles200701.pdf](http://www.independentliving.org/docs7/miles200701.pdf)
- Miles M. 2008. *Glimpses of Disability in the Literature and Cultures of East Asia, South Asia, the Middle East & Africa. A modern and historical bibliography*. Accessed 10 June 2014 at <http://www.independentliving.org/docs7/miles200807.html>
- Miles, M. 2011. Social and Educational Responses to Mental Retardation in Pakistan, India and Bangladesh: Historical and Modern Reflections. *Psychology and Developing Societies*. 23 (2) 247-275. <http://pds.sagepub.com.ezproxy.uct.ac.za/content/23/2/247.full.pdf+html>
- Minkler, M., Fadern, P., Perry, M., Blum, K., Moore, L. & Rogers, J. 2002. Ethical Dilemmas in PAR; a case study from the Disability Community. *Health Education and Behaviour*. 29 (1) 14-29
- Mitra, S., Posarac, A., & Vick, B. 2013. Disability and poverty in developing countries: a multidimensional study. *World Development*, 41, 1-18. [doi:10.1016/j.worlddev.2012.05.024](https://doi.org/10.1016/j.worlddev.2012.05.024)
- Mji, G. 2013. *Exploring the health knowledge carried by older Xhosa women in their home situation, with special focus on indigenous knowledge*. Unpublished PhD thesis, submitted to Stellenbosch University. Accessed on 22 April 2014 from <http://hdl.handle.net/10019.1/79978>
- Mlenzana, N.B., Frantz, J.M., Rhoda, A.J. & Eide, A.H., 2013, Barriers to and facilitators of rehabilitation services for people with physical disabilities: A systematic review. *African Journal of Disability* 2(1), Art. #22, 6 pages. <http://dx.doi.org/10.4102/ajod.v2i1.22>
- Moodley, K. 2011. Family Medicine Ethics. In Bob Mash (Ed.) *Handbook of Family Medicine (3<sup>rd</sup> Ed.)* Cape Town: Oxford University Press. 381-405.
- Morris C, & Condie DN, (eds) 2008. Recent developments in healthcare for cerebral palsy; implications and opportunities for orthotics. Copenhagen: ISPO. ISBN 87-89809-28-9 [Accessed from: <http://www.ispoint.org/> on 2 October 2014].
- Mpofu, R. 1995 Community based rehabilitation: A way forward in Africa. *South African Journal of Physiotherapy*. 51(3): 47 56. [No digital copy found]
- Mweshi, M & Mpofu, R. 2001. The perceptions of parents and caregivers on the causes of disabilities in children with cerebral palsy: a qualitative survey. *South African Journal of Physiotherapy*. 57 (2) 28-3.
- National Department of Health 2004. *Ethics in Health Research: Principles, Structures and Processes* HYPERLINK "<http://www.hsra.ac.za/Document-3952.phtml>" <http://www.hsra.ac.za/Document-3952.phtml>

- Newell, W.H. 2011. The Road from Interdisciplinary Studies to Complexity. *World Futures: The Journal of New Paradigm Research*, 67:4-5, 330-342  
<http://dx.doi.org/10.1080/02604027.2011.585907>
- Newell, W. & Green, W. 1982. Defining and teaching interdisciplinary studies. *Improving College and University Teaching* 30 (1): 23–30.
- Ng, S.L. 2012. Reflection and Reflective Practice: Creating Knowledge through Experience *Seminars in Hearing*. 33 (2). 117-134.
- Ntshona, M.S. 1997. Are professional interpreters needed in the South African health care services? *SAMJ*, 87 (9).
- Office of the Deputy President of South Africa, 1997, *Integrated national disability strategy (White Paper)* viewed 21 November 2009, from <http://www.info.gov.za/whitepapers/1997/disability.htm/>
- Ogot, O., McKenzie, J. & Dube, S., 2008, ‘Inclusive Education and Community Based Rehabilitation’ in S, Hartley and J. Okune (eds.) *CBR: Inclusive policy development and implementation*, pp. 160 -189. Norwich UK: University of East Anglia.
- Oliver, M. 2009. *Understanding Disability: From Theory to Practice*. 2nd edition Palgrave Macmillan. 13-26
- Oliver, M. & Barnes, C. 1998. *Disabled People and Social Policy: From Exclusion to Inclusion*. London: Longman
- Onwuegbuzie, A.J. & Collins, K.M.T. 2007. A Typology of Mixed Methods Sampling Designs in Social Science Research. *The Qualitative Report*. 12(2). 281-316. Accessed from <http://www.nova.edu/ssss/QR/QR12-2/onwuegbuzie2.pdf> on 10 July 2013.
- Owens, R. E. 2005. *Language Development: An Introduction*. 6<sup>th</sup> Ed. Boston: Pearson Publishing Company.
- Owusu-Ansah, F.E. & Mji, G., 2013. Indigenous knowledge and research. *African Journal of Disability* 2(1), Art. #30 5 pages.
- Oxford Dictionaries. 2013. OED Online  
<http://www.oed.com.ez.sun.ac.za/view/Entry/261904?redirectedFrom=bricolage&> 2014, January 15
- Oyserman, D., Coon, H.M., & Kemmelmeier, M. 2002. Rethinking Individualism and Collectivism: Evaluation of Theoretical Assumptions and Meta-Analyses. *Psychological Bulletin*. 128 (1) 3–72. DOI: 10.1037//0033-2909.128.1.3

- Palmer, C. L. 2001. *Work at the Boundaries of Science: Information and the Interdisciplinary Research Process*. Dordrecht: Kluwer.
- PANSALB (Pan South African Language Board) 2011 *An amended version of the South African Languages Act proposed by PANSALB*. Accessed from <http://www.pansalb.org.za/> on 17 December 2014
- Papaioannou, D., Sutton, A., Carroll, C., Booth, A. & Wong, R. 2010. Literature searching for social science systematic reviews: consideration of a range of search techniques. *Health Information & Libraries Journal*. 27 (2) 114–122. DOI: 10.1111/j.1471-1842.2009.00863.x
- Pascoe, M. & Norman, V. 2011 Contextually relevant resources in speech-language therapy and audiology in South Africa – are there any? *South African Journal of Communication Disorders*, Vol 58 (Editorial)
- Pence, A. & Marfo, K. 2008. Early childhood development in Africa: Interrogating constraints of prevailing knowledge bases. *International Journal of Psychology* 43(2), 78–87. <http://dx.doi.org/10.1080/00207590701859143>
- Pence, A. & Nsamenang, B. 2008. A case for early childhood development in sub-Saharan Africa. Working Paper No. 51. The Hague, The Netherlands: Bernard van Leer Foundation.
- Penn, C. 2000. Cultural Narratives: Bridging the Gap. Educating Speech-language Pathologists to Work in Multicultural Populations. *South African Journal of Communication Disorders*. 47. 71 – 78.
- Penn, C., Watermeyer, J., Koole, T., De Picciotto, Ogilvy, D & Fisch, M. 2010. Cultural Brokerage in mediated health consultations: an analysis of interactional features and participant perceptions in an audiology context. *Journal of Interactional Research in Communication Disorders*. 1(1).135-156. <https://www.equinoxpub.com/journals/index.php/JIRCD/article/view/7860/6891>
- Pepper, J. & Weitzman, E. 2004. It takes two to talk: a practical guide for parents of children with language delays. 3<sup>rd</sup> Ed. Toronto, Canada: Hanen Centre.
- Pillay, M. 2003. Cross-cultural practice: What is it really about? *Folia Phoniatica et Logopaedica*, 55, 293-299.
- Pless, M. & Granlund, M. 2012. Implementation of the International Classification of Functioning, Disability and Health (ICF) and the ICF Children and Youth Version (ICF-YC) within the context of Augmentative and Alternative Communication. *Augmentative and Alternative Communication* 28(1). 11-20.



- Popich, E., Louw, B & Eloff, I., 2007. Caregiver education as a prevention strategy for communication disorders in South Africa. *Infants & Young Children*. 20 (1) 64-81.
- Priestley, M.2011. Disability and Disadvantage. *J SOC POLICY*. 40: 198-199.
- Priestley M; Waddington L; Bessozi C 2010. “New Priorities for Disability Research in Europe: towards a user-led agenda”, *ALTER: European Journal of Disability Research* /. 4.4: 239-255.
- Pyer, M, Horton, J, Tucker, F, Ryan, S and Kraftl, P. 2010. Children, young people and 'disability': challenging children's geographies? *Children's Geographies*. 8 (1) 1-8.
- Raghavendra, P., Bornman, J., Granlund, M., & Björck-Åkesson, E. (2007). The World Health Organisation’s International Classification of Functioning, Disability and Health: Implications for clinical and research practice in the field of augmentative and alternative communication. *Augmentative and Alternative Communication*, 23(4), 349-361.
- Raghavendra P, Virgo R, Olsson C, Connell T & Lane AE. 2011. Activity participation of children with complex communication needs, physical disabilities and typically developing peers. *Developmental Neurorehabilitation*. 14(3):145-55.
- Ransom, B. 2009. *Missing Voices; Children with disabilities in Africa*. Addis Ababa; Ethiopia: The African Child Policy Forum.
- Reason, P. & Marshall, J. 2001. On working with graduate research students. In Reason, P. & Bradbury, H. (Eds.) *Handbook of Action Research; Participative Inquiry and Practice*. London; Sage Publications. 411 – 419.
- Reid-Cunningham, A.R. 2009. Anthropological Theories of Disability. *Journal of Human Behavior in the Social Environment*. 19 (1) 99-111.
- Repko, A.F. 2012. Defining Interdisciplinary Studies. In *Interdisciplinary Research: process and theory*. 2<sup>nd</sup> Ed. SAGE Publications, Inc. 3-31.
- Republic of South Africa 1996 *Constitution of the Republic Of South Africa* . No. 108 of 1996. Accessed from <http://www.info.gov.za/documents/constitution/1996/a108-96.pdf> on 17 September 2013.
- Republic of South Africa 2005 *Children’s Act, No. 38 of 2005*. Accessed from <http://www.justice.gov.za/legislation/acts/2005-038%20childrensact.pdf> on 17 September 2013.
- Reynolds, M. 2011. Reflective practice: origins and interpretations. *Action Learning: Research and Practice*, 8:1, 5-13. <http://dx.doi.org/10.1080/14767333.2011.549321>
- Roberts, R.M. 1989. *Serendipity: Accidental Discoveries in Science*. New York: Wiley-VCH.



- Rodda, J.L. 2004. Neurological and muscular disorders. In *Paediatrics and Child Health: A manual for health professionals in developing countries*. 5th ed. H.M. Coovadia & D.F. Wittenberg, Eds. Cape Town: Oxford University Press. 481 – 524.
- Rogoff, B., Paradise, R., Arauz, R. M., Correa-Chávez, M., & Angelillo, C. 2003. Firsthand learning through intent participation. *Annual review of psychology*, 54(1), 175-203.
- Rohleder, P., Swartz, L., Schneider, M., Groce, N., & Eide, A. H. 2010. HIV/AIDS and disability organisations in South Africa. *AIDS care*, 22(2), 221-227.
- Rosenbaum, P. & Gorter, J.W. 2011. The ‘F-words’ in childhood disability: I swear this is how we should think! *Child: Care, health and development*. 38 (4) 457- 463.  
doi:10.1111/j.1365-2214.2011.01338.x
- Ross, E & Deverell, A. 2004. *Psychosocial approaches to health, illness and disability. A Reader for Health Care Professionals*. Pretoria; Van Schaik.
- Rossetti, L.M. 2001. *Communication Intervention: Birth to Three* 2nd Ed. San Diego: Singular Publishing Co.
- Rothschild, N., Dhayanandhan, N., DiRito, N., Horvath, V., & Poplak, C. (2000). Behavior is Communication; a Team Approach. International Society for Augmentative and Alternative Communication - Ninth Biennial Conference for the International Society for Augmentative and Alternative Communication (ISAAC), August 2000, Washington, DC USA.  
<http://informahealthcare.com/doi/abs/10.1080/07434610012331278954?journalCode=aac>
- Roulstone, A., Thomas, C & Watson, N 2012, 'The changing terrain of disability studies'. in N Watson, A Roulstone & C Thomas (eds), *Routledge handbook of disability studies* . Routledge handbooks, Routledge, London, pp. 3-11.
- RCSLT (Royal College of Speech-Language Therapy) (n.d.) ‘What is Speech and Language Therapy?’ [http://www.rcslt.org/speech\\_and\\_language\\_therapy/what\\_is\\_an\\_slt](http://www.rcslt.org/speech_and_language_therapy/what_is_an_slt). Accessed 2014, 22 January.
- Rule, S., Lorenzo, T. & Wolmarans, M. 2006. Community-based rehabilitation: new challenges. In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestley, M. (Eds) *Disability and Social Change: a South African Agenda*. Cape Town: HSRC Press. 273 – 290.
- Ryan, S. & Runswick-Cole, K. 2008. Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society*; Mar2008, 23(3). 199-210. DOI: 10.1080/09687590801953937

- Sameroff, A.J. & Fiese, B.H., 2000. Transactional Regulation: The developmental ecology of Early Intervention, in Shonkoff, J. P. and Meisels, S. J. (eds.) *Handbook of Early Childhood Intervention*, (2<sup>nd</sup> Ed.) pp. 135-159, Cambridge University Press, New York.
- Sameroff, A.J. 2009. The transactional model of development: How children and contexts shape each other. Washington, DC, US: American Psychological Association.
- Sameroff, A.J. 2012. *Creating Futures: The secrets of human development*. Key Note Address at the 13<sup>th</sup> World Congress of the World Association for Infant Mental Health (WAIMH) held in Cape Town, South Africa, at the CTICC, 17 -21 April, 2012.
- Sandilands, A. 1953. *Introduction to Tswana*. Tigerkloof, South Africa; London Missionary Society.
- SASLHA n.d. Promo [http://www.saslha.co.za/C\\_Saslha\\_Promo.asp](http://www.saslha.co.za/C_Saslha_Promo.asp). 2014, 22 January
- SASSA: see South African Social Security Agency
- SATI (South African Translators' Institute). 2007. [http://translators.org.za/sati\\_cms/index.php?frontend\\_action=display\\_text\\_content&content\\_id=1](http://translators.org.za/sati_cms/index.php?frontend_action=display_text_content&content_id=1)
- SATI (South African Translators' Institute). 2012. Translating versus interpreting. [http://translators.org.za/sati\\_cms/index.php?frontend\\_action=display\\_text\\_content&content\\_id=1508](http://translators.org.za/sati_cms/index.php?frontend_action=display_text_content&content_id=1508)
- Scheurman, E. 1921. *Der Papalagi: die Reden des Südseehäuptlings Tuiavii* aus Tiavea. Zürich: Tanner-Stähelin Verlag 1980.
- Schlosser, R.W. 2003. *The efficacy of augmentative and alternative communication: Toward evidence-based practice*. New York: Academic Press.
- Schlosser, RW, Wendt, O, Bhavnani, S & Nail-Chiwetalu, B. 2006. Use of information-seeking strategies for developing systematic reviews and engaging in evidence-based practice: the application of traditional and comprehensive Pearl Growing. A review. *International Journal of Language and Communication Disorders*. 41(5) 567-582.
- Schneider, M. and Saloojee, G. 2007. Monitoring childhood disability. In Dawes, A., Bray, R. and van der Merwe, A. (eds). *Monitoring child wellbeing: a South African rights-based approach*. Cape Town; Human Sciences Research Council. 191-212.
- Schön, D. A. 1991. *The Reflective Practitioner; How Professionals Think in Action*. London; Ashgate Publishing Limited.

- Schön D. 1995. The new scholarship requires a new epistemology. (Cover story). *Change* [serial online]. November 1995; 27(6):26. Available from: Academic Search Premier, Ipswich, MA. Accessed June 4, 2014.
- Schurink, W., Fouche, CB & De Vos, A.S. 2011. Qualitative data analysis and interpretation. In AS De Vos, H Strydom, CBFouche & CSL Delpont (Eds) *Research at Grassroots: For the social sciences and human service professions*. 4th Ed. Pretoria, South Africa: Van Schaik. 397 - 424.
- Schwandt, T.A. 2001. *Dictionary of Qualitative Enquiry*. (2<sup>nd</sup> Ed.) Thousand Oaks; Sage.
- Sermijn, J, Devlieger P, & Loots, G. 2008. The Narrative Construction of the Self Selfhood as a Rhizomatic Story. *Qualitative Inquiry*. 14 (4): 632-650. DOI: 10.1111/famp.12119
- Shahjahan, R.A. (2005) Spirituality in the academy: reclaiming from the margins and evoking a transformative way of knowing the world, *International Journal of Qualitative Studies in Education*, 18:6, 685-711, DOI: 10.1080/09518390500298188
- Shakespeare, T. 1996. In Barnes, C. & Mercer, G. (Eds) 1996. *Exploring the divide: Illness and Disability*. Leeds: The Disability Press.
- Shakespeare, T. 2006. *Disability rights and wrongs*. Oxon UK: Routledge.
- Shakespeare, T. 2014. *Disability rights and wrongs revisited*. Oxon UK: Routledge.
- Shakespeare T. & Watson N. 2001. The social model of disability: An outdated ideology? In Barnartt SN and Barbara M. Altman BM (ed.) *Exploring Theories and Expanding Methodologies: Where we are and where we need to go (Research in Social Science and Disability, Volume 2)*, Emerald Group Publishing Limited, pp.9-28  
[http://dx.doi.org/10.1016/S1479-3547\(01\)80018-X](http://dx.doi.org/10.1016/S1479-3547(01)80018-X)
- Sharma, M. 2006. Applying Freirian Model for development and evaluation of community-based rehabilitation programmes. *Asia Pacific Disability Rehabilitation Journal*. 17 (1). 42-49.
- Shaw, I. & Gould, N. 2001. *Qualitative Research in Social Work*. London; Sage.
- Shenton, A. K. 2004. Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Education for Information*, 22, 63-75.
- Shisana, O., Simbayi, L.C., Rehle, T., Zungu, N.P., Zuma, K., Ngogo, N., Jooste, S., Pillay-van Wyk, V., Parker, W., Pezi, S., Davids, A., Nwanyanwu, O., Dinh, T.H. & SABSSM III Implementation Team. 2010. *South African national HIV prevalence, incidence, behaviour and communication survey, 2008: A turning tide among teenagers?* Cape Town: HSRC Press. Accessed 31 July 2012 from  
<http://www.mrc.ac.za/pressreleases/2009/sanat.pdf>

- Shonkoff, J. P., & Meisels, S. J. 2000. *Handbook of early childhood intervention*. Cambridge University Press.
- Sigurd Pilesjö, M. 2012 Organizational patterns of interaction between children with severe speech and physical impairment and their everyday communication partners. Ph. D. Dissertation Department of Language and Communication, University of Southern Denmark.
- Simeonsson RJ, Björck-Åkesson E. & Lollar, DJ 2012; Communication, Disability and the ICF-CY. *Augmentative and Alternative Communication*. 28(1) 3-10.
- Simmons-Mackie, N.N. & Damico, J.S. 2003. Contributions of Qualitative Research to the Knowledge Base of Normal Communication. *American Journal of Speech-Language Pathology*. Vol. 12. May 2003. 144-154.
- Snell, ME, Brady N, McLean, L., Ogletree BT, Siegel E, Sylvester L, Mineo B, Paul D, Ronski MA, and Sevcik R. 2010. Twenty Years of Communication Intervention Research With Individuals Who Have Severe Intellectual and Developmental Disabilities. *American Journal on Intellectual and Developmental Disabilities*. September 2010, Vol. 115, No. 5, pp. 364-380. doi: 10.1352/1944-7558-115-5.364.
- Solomons, F. & Molefi, S. 2011. *Child Disability In The Western Cape: A Study Of The Needs and Experiences Of Children With Disabilities And Their Caregivers, As Well As Gaps In Service Delivery In Vredendal, Beaufort West, Bellville and Gugulethu*. Department of Social Development: Provincial Government of the Western Cape.
- Soto, G., Huer, M.B. & Taylor, O.L. 2000. *Multicultural Issues*. In Lloyd, L.L., Fuller, D.R. & Arvidson H.H. (Eds) *Augmentative and Alternative Communication; a Handbook of principles and practices*. Boston; Allyn and Bacon.
- South African Social Security Agency 2011. *You and Your Grants 2011/12*. Accessed 11 December 2014 from <http://www.sassa.gov.za/index.php/social-grants>
- Spencer-Oatley, H. 2013. Critical incidents. A compilation of quotations for the intercultural field. GlobalPAD Core Concepts. Accessed on 24 June 2015 from <http://go.warwick.ac.uk/globalpadintercultural>
- Spry, T. 2001. Performing Autoethnography: An Embodied Methodological Praxis. *Qualitative Inquiry* 2001 7: 706. DOI: 10.1177/107780040100700605
- Stake, R.E. 2003. Case Studies. In N. K. Denzin & Y.S. Lincoln (Eds.) *Strategies of Qualitative Inquiry*. (2<sup>nd</sup> Ed) Thousand Oaks, CA: Sage. 134-164.
- Starks, H. & Trinidad, S.B. 2007. Choose your method: a comparison of phenomenology, discourse analysis and grounded Theory. *Qualitative Health Research*. 17(10). 1372-1380. DOI 10.1177/1049732307307031

- STATSSA (Statistics South Africa) 2005. *Census 2001: Prevalence of Disability in South Africa*. Pretoria: Statistics South Africa
- STATSSA (Statistics South Africa) 2012a. Census 2011 Statistical release <http://www.statssa.gov.za/Publications/P03014/P030142011.pdf> 08 June 2013
- STATSSA (Statistics South Africa) 2012b. Census 2011 preliminary results. <http://www.world-data-atlas.com/statssa/> 08 June 2013
- STATSSA (Statistics South Africa) 2013. Mid-year population estimates 2013. Pretoria, South Africa. Available from <http://www.statssa.gov.za/publications/populationstats.asp> [24 May 2013].
- Stewart, D. 2005. *Wisdom from Africa: A collection of proverbs*. Cape Town: Struik Publishers.
- Stone-MacDonald, A. 2012. Cultural Beliefs about Disability in Practice: Experiences at a Special School in Tanzania. *International Journal of Disability, Development and Education*. 59(4). DOI:10.1080/1034912X.2012.723947
- Stoskopf, M.K. 2005. Observation and Cogitation: How serendipity provides the building blocks of scientific discovery. *ILAR Journal*. 46 (4). 332-337.
- Strasheim E, Kritzinger A, & Louw B. 2011. The development of a neonatal communication intervention tool. *South African Journal of Communication Disorders - die Suid-Afrikaanse Tydskrif vir Kommunikasieafwykings* 58:13-18.
- Strydom, H. 2011. Information collection: participant observation. In AS De Vos, H Strydom, CBFouche & CSL Delpont (Eds) *Research at Grassroots: For the social sciences and human service professions*. 4th Ed. Pretoria, South Africa: Van Schaik. 328 – 340.
- Strydom, H. & Delpont, C.S.L. 2011 Sampling and pilot study in qualitative research. In AS De Vos, H Strydom, CBFouche & CSL Delpont (Eds) *Research at Grassroots: For the social sciences and human service professions*. 4th Ed. Pretoria, South Africa: Van Schaik. 390 - 396.
- Stuart, S. 2002. Communication, Speech and Language. In Batshaw, M.L. (Ed.). (2002) *Children with disabilities* (5<sup>th</sup> Ed). Baltimore, Maryland, USA: Paul H. Brookes Publishing Co. 229-242.
- Swartz, L., 2014, Five challenges for disability related research in sub-Saharan Africa, *African Journal of Disability* 3(2), Art. #149, 6 pages. <http://dx.doi.org/10.4102/ajod.v3i2.149>
- Taylor, O.L. & Clarke, M.G. 1994. Culture and Communication Disorders; a theoretical framework. *Seminars in Speech and Language*. 15 (2). 103 -113.

- The Presidency of the Republic of South Africa. 2014. President Jacob Zuma announces members of the National Executive, Pretoria. *Speeches: 25 May 2014. The Presidency: Republic of South Africa*. Accessed on 16 June 2014 from <http://www.thepresidency.gov.za/pebble.asp?relid=17453>
- Thomas, C. 2004. How is disability understood? An examination of sociological approaches. *Disability and Society*, 19(6) 569-583.
- Thomas, C. 2008. Disability: getting it 'right'. *Journal of Medical Ethics*. 34. 15-17.
- Threats, T. T. 2008. Use of the ICF for clinical practice in speech-language pathology. *International Journal of Speech-Language Pathology*. 10 (1-2). 50-60 doi: 10.1080/14417040701768693
- Toomey, R. 1997. Transformative action research. *Educational Action Research*. 5(1), 105-121. <http://dx.doi.org/10.1080/09650799700200022>
- Trehan, K. & Rigg, C. 2012. Critical reflection – opportunities for action learning. *Action Learning: Research and Practice*. 9:2, 107-109, DOI:10.1080/14767333.2012.687912
- Treleaven, L. 2001. The turn to action and the linguistic turn: Towards an integrated methodology. In Reason, P. & Bradbury, H. (Eds.) *Handbook of Action Research; Participative Inquiry and Practice*. London; Sage Publications. 261-272.
- Triandis, H.C. 2001. Individualism and Collectivism: Past, present and future. In D. Matsumoto (Ed.). *The Handbook of Culture and Psychology*. Oxford: Oxford University Press. 35-50.
- Tshabalala, N. 2014. *An exploration of parents' experiences of the inclusion and retention of their disabled children in public schools in the Eastern Cape Province*. Unpublished PhD dissertation presented to the Division of Disability Studies, University of Cape Town.
- Tufford, L & Newman, P. 2012. Bracketing in Qualitative Research. 2012 11: 80 originally published online 21 October 2010. DOI: 10.1177/1473325010368316
- Tuhiwai Smith, L. 1999. *Decolonising Methodologies; Research and Indigenous peoples*. London; Zed Books.
- Turmesani, M., Vrede, A. & Wirz, S.L. 2002. Some ethical issues in community-based rehabilitation initiatives in developing countries. *Disability and Rehabilitation*. 24
- Union of South Africa. 1950. *Group Areas Act, Act No. 41 of 1950*. Pretoria, South Africa: Government Printers. Accessed on 16 may 2014 from [http://www.disa.ukzn.ac.za/index.php?option=com\\_displaydc&recordID=leg19500707.028.020.041](http://www.disa.ukzn.ac.za/index.php?option=com_displaydc&recordID=leg19500707.028.020.041)

- United Nations, 1948. *The Universal Declaration of Human Rights*. Accessed on 21 June 2014 from <http://www.un.org/en/documents/udhr/index.shtml>
- United Nations, 1982. *World Programme of Action Concerning Disabled Persons*. Accessed on 21 June 2014 from <http://www.un.org/disabilities/default.asp?id=23>
- United Nations, 1989, *UN Convention on the rights of the child*, viewed 21 November 2009, from <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx> [Article 23]
- United Nations 1993. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, viewed 3 April 2013, from <http://www.un.org/esa/socdev/enable/dissre00.htm>
- United Nations, 2006, *UN Convention on the rights of persons with disabilities*, viewed 29 September 2009, from <http://www.un.org/disabilities/convention/conventionfull.shtml/>
- Vanderbeck, R.M. & Dunkley, C. 2004. Introduction: Geographies of Exclusion, Inclusion and Belonging in Young Lives. *Children's Geographies, Vol. 2, No. 2, 177–183*.
- Van der Rheede, C. 2013. *It takes a village to raise a child*. Accessed on 5.Oct.2014 from <http://www.ngopulse.org/article/it-takes-village-raise-child>
- Van Hove, G., De Schauwer, E, Mortier, K., Bosteels, S., Desnerck, G & Van Loon, J. 2009. Working with mothers and fathers of children with disabilities: metaphors used by parents in a continuing dialogue. *European Early Childhood Education Research Journal*. 17 (2). 187-201. DOI: 10.1080/13502930902951379
- Van Riel, F. & Yekani, N.V. 2004. *The Crowing of the Roosters: A story of personal courage and loss*. Cape Town: David Philip Publishers. ISBN 0-86486-654-2
- Vygotsky, L. 1978. *Mind in Society: The Development of Higher Psychological Processes*. Cambridge, MA: Harvard University Press.
- Walker S P, Wachs TD, Meeks Gardner J, Lozoff, B, Wasserman, GA, Pollitt, E. & Carter, JA 2007. Child development in developing countries 2 Child development: risk factors for adverse outcomes in developing countries *Lancet* 2007; 369: 145–57.
- Walker SP, Theodore D Wachs, Sally Grantham-McGregor, Maureen M Black, Charles A Nelson, Sandra L Huffman 2011; Inequality in early childhood: risk and protective factors for early child development; *Lancet* 2011; 378: 1325–38. DOI: 10.1016/S0140-6736(11)60555-2
- Watermeyer, B. & McKenzie, J. A. 2014. Mothers of disabled children: in mourning or on the march? *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community*. 28:4, 405-416, DOI: 10.1080/02650533.2014.889103



- Watson N, Thomas C, Roulestone A, McLaughlin. J. 2012 Understanding disabled families: Replacing tales of burden with ties of interdependency. In EDS? Routledge Handbook of Disability Studies. Xx: Routledge 402-413
- WCFID (Western Cape Forum for Intellectual Disability). 2012. *Annual Report 2011/2012*, viewed 21 November 2012 at <http://www.wcfid.co.za/>
- Werner, E.E. 2000. Protective Factors and Individual Resilience. In Shonkoff, J. P. & Meisels, S. J. (Eds.). *Handbook of Early Childhood Intervention*. (2<sup>nd</sup> Ed.) New York; Cambridge University Press. 115-132.
- Westby, C. & Ingelbrett, E. 2012. Native american and worldwide indigenous cultures. In Battle, D. E. 2012. *Communication disorders in multicultural and international populations* (4th Ed). Elsevier. Chapter 5.
- Western Cape High Court, 2011, *Western Cape Forum for Intellectual Disability v Government of The Republic of South Africa*, viewed 14 September 2014, from [http://www.fedsas.org.za/downloads/8\\_12\\_20\\_Western%20Cape%20Forum%20For%20Intellectual%20Disability%20v%20Government%20of%20The%20Republic%20of%20South%20Africa%202011%20JDR%200375.pdf](http://www.fedsas.org.za/downloads/8_12_20_Western%20Cape%20Forum%20For%20Intellectual%20Disability%20v%20Government%20of%20The%20Republic%20of%20South%20Africa%202011%20JDR%200375.pdf)
- WHO – see World Health Organisation
- Wood, T., Shaboodien, F., Kerfoot, W. & Molteno. C., 2009, ‘Education for all: constitutional rights of children with severe and profound disability in the Western Cape’, paper presented at *AfriNEAD Symposium 2009*, Lagoon Beach Hotel, Cape Town, South Africa, 30 November–4 December 2009.
- Woodhead, M. 2006. Changing perspectives on early childhood: theory, research and policy. *International Journal of Equity and Innovation in Early Childhood*, 4(2), 1-43.
- World Bank. 2014. *2014 World Development Indicators*. Accessed on 10 June 2014 from <http://wdi.worldbank.org/tables>
- World Federation of the Deaf. n.d. <http://wfdeaf.org/category/databank/information-about-deaf-issues>
- World Health Organisation, 1993. *Promoting the Development of Young Children with Cerebral Palsy: A Guide for Mid-Level Rehabilitation Workers*. Geneva: World Health Organisation.
- World Health Organisation 1997. *Let's communicate*. Geneva: World Health Organisation, viewed 29 September 2009, from [http://whqlibdoc.who.int/hq/1997/WHO\\_RHB\\_97.1\\_intro.pdf](http://whqlibdoc.who.int/hq/1997/WHO_RHB_97.1_intro.pdf) .



- World Health Organisation 1999. *International Classification of Functioning and Disability. Beta-2 Draft*. Geneva: World Health Organisation.
- World Health Organisation. 2001. *International Classification of Functioning, Disability and Health(ICF)*. Geneva, Switzerland: World Health Organisation. Accessed on 27 December 2013 from <http://www.who.int/classifications/icf/en/>
- World Health Organisation 2002. *Towards a common language for Functioning, Disability and Health*. Geneva: World Health Organization. WHO/EIP/GPE/CAS/01.3
- World Health Organisation 2010 *CBR Guidelines* viewed 7 January 2014 from <http://www.who.int/disabilities/cbr/guidelines/en/index.html>
- World Health Organisation 2011. *World Report on Disability*. Geneva, Switzerland: World Health Organisation & World Bank. [http://www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/) accessed on 7 June 2014.
- World Health Organisation 2012a. *Implementing the merger of the ICF and ICF-CY: Background and proposed resolution for adoption by the WHO FIC Council*. Accessed on 3 June 2014 from [www.who.int/classifications/icf/whoficresolution2012icfey.pdf](http://www.who.int/classifications/icf/whoficresolution2012icfey.pdf)
- World Health Organisation 2012b. *WHO Family of International Classifications Network Annual Meeting 2012. Executive Summary*. Accessed 3 June 2014 from [www.who.int/classifications/WHOFIC\\_Network\\_Annual\\_Meeting\\_2012](http://www.who.int/classifications/WHOFIC_Network_Annual_Meeting_2012).
- World Health Organisation, 2012c. *Informed Consent For Qualitative Studies*, viewed 30 September 2012, from [http://www.who.int/rpc/research\\_ethics/informed\\_consent/en/](http://www.who.int/rpc/research_ethics/informed_consent/en/)
- World Health Organisation 2013a. *Sixty-sixth World Health Assembly Resolution on Disability*. Accessed on 10 June 2014 from <http://www.who.int/disabilities/actionplan/en/>
- World Health Organisation 2013b. *Draft WHO global disability action plan 2014–2021: Better health for all people with disability*. Accessed 10 June 2014 from <http://www.who.int/disabilities/actionplan/en/>
- World Health Organisation 2013c. *How to use the ICF: a practical manual for using the International Classification of Functioning, Disability and Health (ICF)*. Exposure draft for comment, October 2013. Accessed 7 June 2014 from <http://www.who.int/classifications/drafticfpracticalmanual.pdf>
- World Health Organisation 2014a. *Disability and Rehabilitation*. Accessed 10 June 2014 <http://www.who.int/disabilities/care/en/>
- World Health Organisation 2014b. *Outcome document of the high-level meeting of the General Assembly on the realization of the Millennium Development Goals and other*

*internationally agreed development goals for persons with disabilities: the way forward, a disability-inclusive development agenda towards 2015 and beyond.* Accessed on 10 June 2014 from <http://www.who.int/disabilities/actionplan/en/>

World Health Organisation. 2014c. *International Classification of Functioning, Disability and Health (ICF) framework to facilitate Interprofessional education and collaborative practice.* Accessed on 31 May 2015 from [http://www.who.int/hrh/news/2014/hrh\\_icf\\_framework/en/](http://www.who.int/hrh/news/2014/hrh_icf_framework/en/)

Ylven, R, Granlund M & Persson, M, 2012. Problem solving in relation to resources in everyday life in families of children with disabilities: a pilot study *International Journal of Rehabilitation Research* 2012, Vol 35 No 2. 102-108. DOI: 10.1097/MRR.0b013e328351089b

Yorkston, K. M., Baylor, C. R., Dietz, J., Dudgeon, B. J., Eadie, T., Miller, R. M., & Amtmann, D. (2008). Developing a scale of communicative participation: a cognitive interviewing study. *Disability and Rehabilitation*, 30(6), 425-433. doi: 10.1080/09638280701625328

Zimmermann, R. 2005. *Small Ideas that Work.* Bernard van Leer Foundation: The Hague.

Zola, I.K. 1994. Shaping the interdisciplinary field of disability studies: the perspective of sociology. *Disability Studies Quarterly*.14. 17-20.

Zola, I.K. 1995. *Shifting Boundaries: Doing Social Science in the 1990s – A personal odyssey.* Sociological Forum. 10 (1). 5-19

Zulu, I.M. 2006. Critical indigenous African education and knowledge. *The Journal of Pan African Studies*. 1(3)

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## **Appendix A: UCT Research Ethics Committee approval**

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UNIVERSITY OF CAPE TOWN



**Health Sciences Faculty  
Research Ethics Committee  
Room E53-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
e-mail: [preaward@curie.ucl.ac.za](mailto:preaward@curie.ucl.ac.za)**

13 January 2006

REC REF: 454/2005

Ms M Geiger  
School of Health and Rehabilitation Sciences

Dear Ms Geiger

**BUILDING EARLY COMMUNICATION INTERVENTION ON CULTURAL RESOURCES: A PARTICIPATIVE ENQUIRY**

Thank you for your letter to the Research Ethics Committee dated 19 December 2005, addressing the concerns raised by the committee. It is a pleasure to inform you that the Ethics Committee has formally approved the above mentioned study.

Please quote the REC. REF in all your correspondence.

Yours sincerely

**PROF. T ZABOW**  
CHAIRPERSON

## Appendix B: Western Cape Cerebral Palsy Association permission

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### *The Western Cape Cerebral Palsy Association*

PO Box 13037  
Mowbray  
7705

Reg N° 002-936 NPO

Ph: 021 6854150  
Fax: 021 6868544  
wccerpat@iafrica.com

12 April 2007

Ms Martha Geiger  
Lecturer School of Health and Rehabilitation Sciences  
Groote Schuur Hospital  
University of Cape Town

Dear Martha:

Thank you for the correspondence and the visit to discuss the research you intend to undertake among the population of our Kraaifontein Clinic and the De Heide Special Care Centre. I understand that you want to investigate alternative methods of communication using culturally determined elements to enhance the child's inclusion in society, and that this intervention is not harmful to the child or its caregiver. It will actually benefit the child, the caregiver and anybody involved in the management of these children. I also understand that refusal by the parent to participate, or to later in the study withdraw his/her child, will not in any way adversely affect the management of that child.

All patient details will be treated as confidential and no child will be identifiable from the final paper.

Permission is hereby granted for this research to commence. It should be understood that this is a general consent for the use of our facilities, and that specific parental consent as well as, if applicable, the consent from the Manager of the Centre, is still required.

Yours sincerely

Dr S C Van Bever Donker  
Vice-chair of the WCCPA



*The WCCPA is supported by The National Lottery Distribution Trust Fund.*

## **Appendix C: isiXhosa informed consent form**

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### **Part A:**

I have heard and read the information about this research study, and I understand what it is about. *Ndivile yaye ndizifundile inkcukaca ngolufundo yaye ndiyaluqonda ukuba lungantoni.*

I understand that I will only receive money for transport to and from meetings, but that I will not be paid for attending the meetings. *Ndiyaqonda ukuba ndizakufumana imali yokuya nokubuya kwiintlanganiso kodwa andizokubhatalelwa ukuya kwiintlanganiso.*

I understand that I can stop coming to the meetings at any time, and that this will not affect any of the help that my child gets at this centre. *Ndiyayazi ukuba ndingayeka nanini na ukuba kwiintlanganiso, yaye loo nto ayizi kuchaphazela uncedo umntwana wam alufumanayo kule ndawo.*

I would like to take part in this research study. *Ndingavuya ukuba yinxalenye yolu phando nzulu.*

Name(in block letters)..... *Igama*

Signature;..... *Uphawu*

Date;..... *Umhla*

Contact phone number;..... *Inombolo yomnxeba:*

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### **Part B**

**(To be completed by Research Facilitator where verbal consent is obtained)**

I, .....have read the above letter to  
..... (potential participant's name). *Mna, Ndiyifundile le leta iya  
ku  
Igama lomntu othatha inxaxheba*

I have explained the contents, and have given clarifications where necessary.

*Ndizicacisile inkcukacha ndacacisa apho kufunekayo*

She has indicated verbally that:

*Undixelele ngomlomo ukuba*

She understands that she will only receive money for transport to and from meetings.

*Uyaqonda ukuba uza kufumana imali yokukhwela ukuza nokusuka kwiintlanganiso*

She understands that she will not be paid for attending the meetings.

*Uyaqonda ukuba akazi kubhatalwa ngokubakho kwakhe kwiintlanganiso*

She understands the potential benefits to her situation with her child.

*Uyaqonda ukuba umntwana wakhe angancedeka njani*

She understands the risks that there may be no benefit to her child and that she may feel emotional and sad during or after meetings.

*Uyaqonda ukuba umntwana wakhe mhlawumbi angancedakali yaye angadakumba emoyeni kwintlanganiso okanye emva kwentlanganiso.*

She understands that she can stop attending the meetings at any time, and that this will not affect any of the help that her child gets at this centre. *Uyayazi ukuba angayeka nanini na ukuthatha inxaxheba yaye lo nto ayizikuchaphazela uncedo alufumanayo umntwana wakhe kule ndawo(senta).*

She understands that her responses will be confidential, outside of the group.

*Uyaqonda ukuba yonke into ayithetha apha ayizi kuthethwa ngaphandle kwe- group*

She understands the need to maintain the confidentiality of other group members.

*Uyaqonda ukuba kufuneka azigcine kuye izinto ezithethwa kwezi ntlanganiso*

She agrees to the use of her anonymised responses in the write up of the researcher’s dissertation and in academic publications that may ensue.

*Uyavuma ukuba iimpendulo zakhe zingasetyenziswa ekubhaleni iphepha lethu kodwa igama lakhe lakuhlala liyimfihlo.*

She agrees to the video-recording of the sessions, and understands that these video recordings will only be used by the researcher and a second analyst to transcribe and confirm participants’ responses (and that her name will not appear on the transcriptions – only a code, which only the researcher will be able to identify).

*Uyavuma ukuba ivideo yentlanganiso ingenziwa yaye uyaqonda ukuba ezivideo ziza kusetyenziswa ngumphandi kunye nomncedi wakhe oza kubhala phantsi yonke into ethethwayo aze angqine ukuba uve le nto ibhaliweyo ( yaye uyaqonda ukuba igama lakhe alizi kusetyenziswa kule mibhalo- kuza kuvela amanani azakwaziwa ngumphandi yedwa ukuba athetha ngabani na)*

She agrees to consider consent for photographs to be taken on an ad hoc basis – with freedom to consent or decline in each individual situation. She understands that she will receive a copy of each photograph featuring her, and that having seen the photographs; she will have the opportunity to give selective consent for their use for academic presentation and/or for teaching purposes.

*Uyavuma ukuba uzakucinga ngokufotwa ngamanye amaxesha- angala okanye avume ngokuthanda kwakhe. Uyaqonda ukuba uzakuwafumana amafoto anaye, yaye ukuwabona kwakhe angakhetha afuna ukuba asetyenziswe ukubonisa abantu xa kuthethwa okanye kufundiswa.*

Research Facilitator ..... *Umphandi*

Signature;..... *Uphawu*

Date;.....*Umhla*

## Appendix D: Consent register

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### Masinedane – Kraaifontein Group

Sityikitye kulomgca ungezantsi amagama ethu kuba sisazi ukuba esikuxoxileyo namhlanje kunga setyenziswa kuvavanyo nkqubo lwe **Masinedane**

Name/Igama	Signature/ Uphawu	Date/Umhla



**Appendix E: Flip-file pictures from Botswana case study (used to introduce purpose of study to participants in Cape Town main study).**

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