

**Access to schooling spaces for my child with  
Down syndrome: an autoethnography**

Pushpagandhi Gramanie

Student Number: 8421423

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Promoter: Professor Reshma Sookrajh  
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## DECLARATION

I, **Pushpagandhi Gramanie** declare that this thesis is my own work. It is being submitted for the degree of **Doctor of Education** at the **University of Kwa-Zulu Natal**, South Africa. It has not previously been submitted for examination at any other university. Sources used have been acknowledged in the bibliography.

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Pushpagandhi Gramanie  
Researcher

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Date

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Professor Reshma Sookrajh  
Promoter

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Date

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My late mum, Mariamma Pillay, from whom I learnt that reading aloud advantages the listener. I used to read to her because she could not read; now I read to my daughter for the same reason.

## DEDICATION



*To my daughter, Tiara Gramanie  
Thank you for the privilege of being  
your mother.*

## MY CROWN

(for my daughter, Tiara)

She who wears the crown is Queen

So I guess my daughter with Downs must be the ONE:

She reigns in our heart with kindness so pure.

She reigns in her manners so meek, I adore.

She reigns in her smile, so sincere and loving,

She reigns in disposition so forgiving and adoring.

She's takes time to know you and make you feel welcome;

Her hugs are so warm and lingering, never in a hurry.

She still can't write her name but rest assured,

She discerns your lies, your fake smile and put on graces,

And shows more love than all words you may assemble.

It sits so well on her, to wear the crown daily

I swear she was born to be a queen, any day and unrivalled.

(Pushpa Gramani, 2014)

## ABSTRACT

As part of the Indian diaspora whose ancestors were indentured labourers brought to South Africa to work in the sugar plantation (Mishra, 1996) with little scope for education, I repeatedly heard the expression ‘the only way to escape poverty is through education’ from my grandparents and parents. The access I had to schooling, and the opportunity to complete, provided me with a passport to tertiary education, a privilege only a few of my siblings had. The importance of education was instilled in me from my childhood and it was a natural expectation when I became a parent, to want access to good quality education for my own children. My pursuit of access to schools for my daughter with Down syndrome was an immense challenge with no guarantees in the South African context.

I have undertaken this study to reflect on nearly fifteen years of formal and informal schooling for my daughter, Tiara. In an effort to purposefully engage the reader on the subject of schooling spaces and access to it, I considered autoethnography most suitable for the task. It offers me the scope of using personal experiences as principal data and the latitude to express those experiences in a mosaic format by intersecting and sometimes collapsing it with those of others. These ‘others’ consisting of four women, are part of a community of practice, and predominantly parents of children with Down syndrome who interact within my social space. This allowed a wider interpretation of my experiences in relation to others. Their cameos which emerged from semi structured interviews conducted at a time and place at their convenience are captured alongside mine as episodic nodal moments. In choosing autoethnography as the methodology, greater consideration was given to the issue of ethics to ensure confidentiality and respect of all informants. Three of the informants each have a child with Down syndrome. The fourth informant is an academic who is a prolific researcher in the field of Inclusive Education. Her input is from a dual perspective of having a sibling with disability and being a key role-player in the crafting of policies pertaining to inclusive education in South Africa.

These reflective accounts were excavated predominantly through qualitative method of memory work. While memory-work is broadly recognized as a profoundly felt emotional experience, it is first and foremost a research tool (Cadman, Friend, Gammon, Ingleton, Koutroulis, McCormack, Mitchell, Onyx, O'Regan, Rocco & Small., 2001). Memory work entailed chronicling past events in as much detail as possible with occasional stimuli to trigger recall. A coalescing of all chronicles and cameo accounts pertaining to access to schooling spaces for children with Down syndrome is followed by thematic analysis. This is discussed in a mosaic format with all chronicles and cameos interwoven. A created multidimensional model of access, influenced by Nind and Seale (2010) helped unpack the enabling and disabling aspects of experiences of accessing schooling spaces for children with Down syndrome. This is done to shed insight on the state of South African segregated schooling in public education, in both mainstream and special needs and the challenging experiences of access to inclusive schooling spaces for children with Down syndrome.

The data suggests that despite enabling legislation, implementation of inclusive policies reflects gaps, primarily in lack of political will and sustained effort. Physical access into a school did not necessarily mean that Tiara had enabling access to and meaningful participation in the spectrum of schooling experiences: systemic, curricular, social, pedagogical, spaces and practices. Parental advocacy has historically contributed to the evolution from medical deficit model to social justice but the need for endurance to continue the fight for accessible inclusive spaces continues to be unyielding.

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## LIST OF ABBREVIATIONS

DS	Down syndrome
ID	Intellectual Disability
CWDS	Child/Children with Down syndrome
CWDD	Child/Children with developmental delays
BTL	Barriers to learning
VBTL	Visible barriers to learning
DSEI	Down Syndrome Education International
DSA- KZN	Down Syndrome Association - Kwa-Zulu Natal
DSSA	Down Syndrome South Africa
SAHCR	South African Human Rights Commission
CWSN	Children with special needs
EWP6	Education White Paper Six
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNCRC	UN Convention on the Rights of the Child
MDG	Millennium Development Goals
SEN	Special Educational needs

# CHAPTER ONE

## *COBBLESTONE FACADE*

### **1.1 Introduction**

The cobblestone image is scorched into memory since early childhood. It prompts a reminder of the meandering uncemented cobblestone pathway I had to take to the entrance of the emblazoned school gate. During my high school days, my friends and I played games of hopscotch or tic-tac-toe on cobblestone pathways to distract ourselves from the long and arduous uphill walk to school. The face brick façade with small manicured flowerbeds belied the age of the school and the occasional broken or missing part behind the wall: its loose door and window hinges, leaking taps, flaking paintwork and uncollected rubble of irreparable desks and chairs piled up on the far end of the school grounds. The walls masked the catalogue of burgeoning activists desirous for change in government policies. That was back then, in the 1970s and 1980s framed by rolling mass action with urgency and agency for change. Now, the expressive images of nearly thirty earlier, seep into my mind as I contemplate schooling spaces for my child, born in 1995, about to step into the portals of schooling at the age of three. I begin this study from the premise that my interest is in education and its associated potential to provide opportunities (in various schooling spaces) for my child to engage with spaces, places and people and from those interactions, learn. Getting into the spaces meant getting onto a different ‘cobblestone’ path and walking and sometimes, stumbling to the gate.

*Private, mainstream, special school, home-school?*

*Which is the right answer for my child at this time? Will it be the answer for ALL TIME? I do not know. I will keep evaluating and adapting to her needs. I cannot say if it is working so far. Issues I initially considered in my choice of schooling included: is this schooling choice a good fit for my child’s learning style? Can this schooling option meet my child’s academic needs? Can this choice meet my child’s social needs? It is not a case of one size fits all: the choice of private schooling for my firstborn may not suit the second born.*

In my mind the catalogue of questions looked like a puzzle, a mosaic of sorts, and each unprepared and unknown piece, a part of the ‘gestalt’ of formal schooling: how will I get her in, when can I do that, who will let her in, are there gatekeepers who can refuse her entrance, when she is in, who will she share the spaces and places of learning with; what will she learn, will it be in a classroom, school ground, sports field, swimming pool, excursion, overnight trips? Will she learn, who will teach her, what they will teach her, will she enjoy going there, how will she get there, where will I get her shoes? I feel reassured by researchers Grossman, Kuhn-McKearin and Strein (2011) and Yamamoto & Holloway (2010) that parental expectations and aspirations have substantial, or even great, effects on the achievements of their children.

Pause.

Education! Schooling! I enter the study acknowledging that processes of schooling and education can occur anywhere but position this study into the domain of formal schooling. Schostak (2008) defines schooling as a process of shaping and transforming minds and behaviour, which is what I envisaged for my daughter. Colleagues and commentators suggest education and schooling appear to be the same thing, only suggesting that on deliberating on the idiosyncrasies of both disciplines, they take on different meanings and outcomes.

In May 2013, I was forwarded an article (see Appendix E) which appeared in a local newspaper which reported a meeting of a young lady with Down syndrome (hereafter abbreviated as Ds) with Professor Jonathan Jansen. I remember that Professor Jonathan Jansen was formerly Dean of Education of University of Durban-Westville in 1997, now renamed as University of Kwa-Zulu Natal after amalgamation in 2006<sup>1</sup>. My study is located at the same university. I recall the waves of political unrest and instability through which he commanded the faculty at the time, hence he comes to mind. He is the current rector and Vice Chancellor

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<sup>1</sup> Prior to democracy, universities in SA were divided along racial lines which also added to a bloated administration to run separate universities. In 2005, several universities were merged, In the province of Kwa-Zulu Natal, the former University of Durban Westville, University of Natal (Howard and Pietermaritzburg campuses), and Edgewood College of Education were merged under the banner of University of Kwa-Zulu Natal.

of the University of Free State, an acclaimed academic from South African soil, renowned for his incisive comments on the state of education, its policies, policy makers and learners, often critiquing educational changes as ‘changes for the sake of change’. In a podcast on 6 May 2013, titled ‘[A]re you schooled or are you educated?’ He contended that while ‘most ... have been schooled, few... have been educated’ and underpinned his comments on the preface that schooling entrenches mechanical routines and a form of institutionalization. He is on record for saying the following:

An educated person, as opposed to one merely schooled, is guided by values such as humility. It is this deep understanding that you are not better than the person you despise or curse, and that very often you are subject to the same weaknesses (such as prejudice) as the one who offends you. When education teaches and nurtures a humble spirit it prepares the ground for reconciliation; it creates, further, a foundation for leadership that acknowledges mutual vulnerability and therefore prepares leaders who are capable of solving complex human problems.<sup>2</sup>

Research from children’s geography regarding the “institutionalization and commercialization of learning places” (Leander, Phillips & Taylor, 2010, p. 354) resonates with Professor Jonathan Jansen’s comments and accelerates my need to understand more of the current state of children’s places and spaces of learning. Further discussion on the subject of children’s geography will be offered in Chapter four.

I value Professor Jansen’s comments even more because he displayed these very humbling characteristics he espouses, when he met a young lady who has Ds. Notwithstanding the reference to her as ‘Down syndrome girl’ rather than ‘girl with Down syndrome,’ he referred to the impact of this meeting with the following words: “I have sat in audiences where I have listened to and interacted with Edward Said, Jurgen Habermas, Oprah Winfrey, Nelson Mandela and a half-dozen Nobel Laureates in the sciences but never before have I heard a

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<sup>2</sup> Jansen, J. (2013) Are you schooled or are you educated?. Accessed on 15 June 2014 from [Ehttp://www.ufs.ac.za/docs/default-source/timeslive-documents/2013-05-16-are-you-schooled-or-are-you-educated-1243-eng.pdf?sfvrsn=0](http://www.ufs.ac.za/docs/default-source/timeslive-documents/2013-05-16-are-you-schooled-or-are-you-educated-1243-eng.pdf?sfvrsn=0)

speech with the intelligence, insight and compassion of a Down's Syndrome girl who came to my office three days ago”.<sup>3</sup> This interaction heightens the impact of self and parental advocacy, access and appropriate support can make to a child with Down syndrome (CWDS).

I choose to place schooling and education not in tandem but more often intertwined, and sometimes adjacent to ‘spaces’ to suggest an interrelatedness, yet distinctly mindful that this study lies in the vortex of a legacy of apartheid that “continues to frame the schooling experiences of the majority of South African”(Smith, Case, Walbeek, 2014, p. 624). In considering the relationship of learning to space and place, the focus is not exclusively on the classroom-as-container (Kevin, Leander, Phillips & Taylor, 2010, p. 333), though it is considered a dominant discourse of the field. Foucault (1972) suggests that it constructs not only particular ways of speaking and writing in educational research, but also systems of rules concerning how meaning is made. This discourse functions as a microcosm, an ‘imagined geography’ (Kevin, et al, 2010, p. 329) of education, constituting when and where teachers assume learning to take place. I adopt the position as Foucault recommends, to disrupt this view and expand the notion of schooling space to incorporate “in school” and “out of school”, without borders.

The school and its classrooms are not just “material locations but also as a conceived or imagined space- an imagined geography of a particular kind” (Kevin et al. 2010, p. 331). Schooling is to be looked at as an active process that occurs within these material and imagined locations. Lefebvre (1991) critiques how people hold container-like perspectives on the material and social locations of everyday life (which can be applied to schooling) through an analogy of a house.

Consider a house, and a street, for example. The house has six storeys and an air of stability about it. One might almost see it as the epitome of immobility, with its concrete and its stark, cold and rigid outlines . . . Now, a critical analysis would doubtless destroy the appearance of solidity of this house, stripping it, as it were, of its concrete slabs and its thin non-load-bearing walls, which are really glorified screens,

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<sup>3</sup> [http://anisa.org.za/category/news\\_free\\_tagging/jonathan\\_jansen?page=1](http://anisa.org.za/category/news_free_tagging/jonathan_jansen?page=1)

and uncovering a very different picture. In the light of this imaginary analysis, our house would emerge as permeated from every direction by streams of energy which run in and out of it by every imaginable route: water, gas, electricity, telephone lines, radio and television signals, and so on. Its image of immobility would then be replaced by an image of a complex of mobilities, a nexus of in and out conduits (pp. 92–93).

In visualising schooling as something which occurs within spaces with invisible screens rather than closed in places with walls, then the container-like perspective is replaced by an almost transient location (of spaces and places) in which activity occurs. After all, no two days can be identical nor two visits to the same place elicit the exact same response. Lefebvre's image of in and out channels then represents (social) space as produced through ongoing movements. Access is then the unrestricted and unobstructed movements with 'in' and 'out' patterns created through human mobility in space. I am inspired and struck by the idea of conceived spaces (Lefebvre, 1991) as representations of space that powerfully shape our attempts at new visions and productions of education. This background of schooling and spaces nudges me towards the core aspects of this study: access, schooling spaces and Down syndrome.

Adjacent to reading on access and schooling, I identified varied ways in which terms pertaining to 'learning disabilities', 'impairments', 'mainstream' are used in conjunction with schooling. Given the span of literature across the terminologies and its association with inclusion I have selected to use the terms intermittently, as and when relevant. I have entered into the discourse without rigidity but it does not detract from the core idea that access to schooling is affected by how these terms are interpreted and applied. The inward outward gaze also pushes me to understand the inward-outward gaze of terminology. As and where literature availed itself, impairment and disability is discussed in that context, and, at times seems to be used interchangeably by different researchers and authors. To avoid terminological confusion and maintain consistency, my use of the term 'impairment' signifies an intrinsic medical predisposition and 'disability' as the social construct, disabling a person with impairments from access and participation. DS is referred to as a disability not to contradict but underline the reality for me: that the complexities of language usage has shaped and created this reality of which I write. The essence is to capture and drive home the

disadvantage that CWDS are caught in and detracts from what is normalcy. Greater discussion on inclusion occurs in Chapters Two and Four. As an indicator to the reader, 'inclusion' is used slightly different from 'mainstream' as it refers to deliberate placing of 'learners with disabilities' with 'non-disabled learners' in general schooling, and classroom setting. By doing this, learners have access to and attend schools they would have attended if they did not have a disability, among their peers and receiving relevant support to participate fully. 'Mainstream' setting refers to regular classroom which does not accommodate children requiring high level of support. 'Special needs school' is one that takes in children requiring high level of educational support. Chapter two gravitates towards more discussion on these concepts.

## **1.2 Rationale for my study**

### **1.2.1 A personal imperative**

'Nothing about us without us' has been a significant and memorable slogan of the people with impairments (sometimes referred to as differences or challenges) movement in England (Campbell & Oliver, 1996) and adopted by non-governmental organisations, advocates and agencies throughout the world. In capturing and retelling the stories, the voice of the disabled is reclaimed and foregrounded. It may be construed that if there is some level of controversy over first-person telling of the history, then the second-person telling of the story of disabled as an outsider is even more controversial. I wish to insert my study into this very space of my previously untold, unpublished narrative. My research takes the antithesis of the very perspective described in this preamble, in that I am not telling the story of a disabled person, as an outsider. By recording the living and personally transforming story of having a child who is born intellectually impaired, I provide a dual perspective of outside/insider. She has a voice through the chronicles of the mother-cum-researcher. As the mother I have the insider perspective of daily living, and from interacting almost daily with other parents of children with DS, who attend the same school, or socialising through common membership of DSA. I am able to elicit their perspective and apply my outsider viewpoint to the phenomenon of schooling or experiences of access.

For me, this research topic made a discreet appearance. When it did, it kept knocking at my heart, coaxing me that it needed to be written, simultaneously urging me to let go of my cradle of angst, joy, heartache and bitterness, and to revisit each nodal incident and related facets of getting to know what I know. This study foregrounds my subjectivity as researcher as recommended by Mauthner & Doucet (2003). It cannot be neutral as it carries epistemological, ontological and theoretical assumptions of me as the researcher. Through the myriad experiences selectively distilled nodal incidents, offered as chronicles, I adopt a personal yet critical and academic lens towards specific situations and incidents related to schooling.

I hope to disentangle schooling choices best suited for children with DS by examining my own experience of accessing schooling spaces for my child with DS with the relevant international and National frameworks and policy guidelines for inclusive education in hand namely: the *Salamanca Statement and Framework for Action on Special Needs*, (1994) to which South Africa is a signatory, the *UN Convention on the Rights of Persons with Disabilities*, (2006), in which Article 19 states that “persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live” and indeed, the *South African School’s Act of 1996*. This reminds me of a sculpture of Janus, a two-headed carving, with each face poised in opposite directions. In its original denotation, the two-headed god meant vigilance and new beginnings<sup>4</sup>. This study hopes to be that Janus, epitomising vigilance and new beginnings: that watchful threshold where concerned people can enter the space of critical engagement and advocate for unrestricted schooling as a new beginning for all children with DS. In the past, the historical and political apartheid policies entrenched education and social separation of all races (Maharaj, 1994) with the tier system of Whites at the top (receiving most favour) and Blacks at the bottom (receiving least consideration). In the present dispensation, segregation policies are scrapped and tier systems replaced by a Constitution promising equal opportunity. The future must see a structure where separate systems of ‘special needs’ and mainstream coordinated to coalesce into a singular indiscriminate inclusive system where the spirit of

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<sup>4</sup> <http://www.janushead.org/JHSummer98/jhedit.cfm>

*Ubuntu* becomes pervasive and a norm. *Ubuntu* is an abbreviation of a proverb of isiXhosa origin from Southern Africa. In its entirety it reads “*Umuntu ngumuntu ngabantu*; ‘a person is a person through their relationship to others. *Ubuntu* is recognized as the African philosophy of humanism, linking the individual to the collective through ‘brotherhood’ or ‘sisterhood’.” (Swanson, 2007, p. 55)

A notable Nobel Prize laureate of South Africa is Archbishop Desmond Tutu, one of the architects of the post-apartheid democracy, in “*The Truth and Reconciliation Commission*” (1999) explained the term using the following words “I am a human because I belong. I participate. I share. In essence, I am because you are” (cited in Swanson, 2007, p. 58). This principle means we build, sustain and nurture each other through people partnerships because society gives human beings their humanity.

As further pedagogic discourse occurs amongst the body of partnerships with educational researchers, policy-makers, parents, non-governmental organisation and politicians from different parts of the political spectrum there is potential for new beginnings. The shape of schooling and access to it for children with DS will depend upon the path which is opened through the dialogue within the community of parents, policy designers and implementers, non-governmental organisations, advocates for inclusion, educators, community of practice and interested stakeholders that extend beyond the ‘watchful threshold’. This is one of the intentions of this study. Through a first person account, the reader will journey with me into the crevices of ignorance, through the labyrinth of knowing, and with each chapter will resurrect a *mosaic* past (between moments of sheer joy and dollops of sorrow, of being a mother, of a CWDS), and lean into the foundation and pillars of the future under construction, but first, I must unfold that past! The meandering, yet rigorous, reflexive format will allow both the researcher and reader to navigate the core of this autoethnographic account with its own sense of agency. Sharing the chronicles of my experiences and the cameo nodal accounts of informants in this study, has the potential to benefit the research community (Piwowar & Chapman, 2010).

This autoethnographic account appropriates and incorporates predominant voices of key informants as well as my own voice. These voices nestle and feel right together as they form part of my natural, everyday space. They are people I have interacted with, travelled with, supported and received support from, laughed and cried with and shared the trials and tribulations of the journey of raising a child with Down syndrome. I remember the journey all too well. Now as I read for this PhD, the journey takes on a texture and nuance of its own. I am reminded of an apt quotation from one of my readings, “When you are preparing for a journey, you own the journey. Once you’ve started the journey, the journey owns you” (Slope, 2006, p. 165). It is now time for the reader to interact with the journey.

The phrase ‘a millstone or a milestone’ paradoxically provides me with a key to unlock the chronicles I share with you, the reader. Allow me to lead you into the caverns of the past and travel with me to unearth and compact the layers of experiences that have paved the way to the present.

I have been a teacher in a public co-educational school for twenty years and had experience in variety of roles- as a teacher, university tutor, author, social welfare volunteer, playwright, poet and parent. In the first six years of teaching I experienced first-hand how easily people label and lower their expectation of success for children with visible barriers to learning (VBTL) which will be described in detail later. I found it difficult to bear some of the terms used by people in general when describing learners who experienced challenges in learning, reading, listening, writing or counting. These experiences challenged me to question how I taught, what I taught and how learners learnt. The more I engaged with the parents of children with barriers to learning (BTL) the more I realized that the challenge for parents was to ascertain how much meaningful participation their child received from the classroom context, curriculum, peers, educator, extra and co-curricular programmes offered. Learning to differentiate my strategies in my classroom to enable all learners to participate meaningfully was sometimes hindered by lack of resources, large classes and limited floor space. I persevered nonetheless in the hope that respecting and valuing my learners as people is important and helping each achieve their optimum will equip them with skills to cope in the real world. Sadly though, my personal journey with my daughter did not enjoy the same acknowledgement and acceptance.

In 1995, a year after the birth of our democracy in South Africa, our daughter Tiara was born. A week later she is diagnosed as having Down syndrome (DS), a diagnosis I did not bother to know about prior to that day. Since that announcement and following a confirmed blood test result, Michael (the father) and I, as parents, were catapulted into a paradigm of advocacy for Tiara, in an effort to secure access to meaningful participation in the formal mainstream inclusive schooling system. Her inclusive schooling experiences at two private pre-primary schools before she turned seven offered promise that she would make an easy transition into public education system. We were initially hopeful as South Africa's democracy was in its infancy and policies were drafted gradually. The simultaneity of the events (her growing up at the same time as papers were drafted, re-drafted and then legislated into policy) meant that the chance of intersecting policy with praxis was yet to be achieved. Now, twenty years after our first gasp and 'what now' expression I am rerouting myself to that place and time, to revisit, and analyse what worked or did not work in accessing schooling spaces for inclusion in, but not exclusively, public education for my child with DS.

### **1.2.2 A broader construct**

I share my personal story with others, stories which in the eye of the reader may capture pictures of resilience, chronicles which poignantly convey the magnitude and intensity of human pain, the effort, resolve and diligence needed to face adversity, chronicles that attest to the qualities of tenacity. Or it may be received as a chronicle of despair and hopelessness. I am reminded that each individual interpretation is subject to personal context and individual socio-political constructs (Lalvani & Polvere, 2013; Amelina, 2010). This study is not one of those one-person anecdotal, self-indulgent 'twin-saver tissue' autoethnographic accounts that expose strengths and vulnerabilities and no more. Tears have been replaced by the act of telling. It is an exposé spanning eighteen years, which map significant learning experiences and challenges in the effort to secure access to schooling spaces for my child with Down syndrome (CWDS). The aim of my study primarily is to scrutinise personal chronicles of eight extrapolated nodal incidents and critically review these to determine whether access to schooling spaces for my daughter was enabled or disabled. This intersects with cameo

chronicles of informants, those within the community of practice: parents and academic informants. By being situated socially and emotionally in the centre of this study allowed me to interact and respond to informants which is an important element of reflexivity.

This study is done employing autoethnography with sharing, as a facet of autoethnography, well documented by Foster, McAllister & O'Brien (2006); Chang (2008) and Wall (2006; 2008). Through the process of sharing my chronicles with informants, it fostered their openness as well and generated empathy and rapport. Whilst this study is focussed primarily on my own experiences of access for my daughter with DS, the 'self' does not exist in isolation or as vacuum as suggested by Ngunjiri, Hernandez, & Chang (2010). To this end, the variety of others with similar, different or opposing experiences to my own are present in this study about self (Chang, 2008). In my reality, a multiplicity of "others" exists in the context where the self, lives.

The uniqueness of my story is that it hovers over a phenomenon of access to schooling spaces for child with DS. I took issue of access for granted when I sought admission for my typical, non-disabled first-born child. The contrast of my own experience with my second child with intellectually impairment was stark and challenging. The similarities or dissimilarities of experiences of the same phenomenon are exposed when the narratives of multiple informants are placed parallel to mine. The unbridled pathos weeps from the chronicles of self and others, and shines a light for others stepping onto a similar or uncharted pathway. The sharing is expanded as it joins the platform of researchers who have employed autoethnography because it provided them with opportunities to study subject areas that would not be as effortlessly and intensely expressed with other methods.

As an autoethnographer I want to build a context for the study acutely aware of academic requirements. This study shows how I reconciled the components of the personal with the academic, as it has evolved with the passage of time. When I launched myself into the PhD journey I had to ask myself what constitutes a PhD (substantive literature review, finding an appropriate methodology and justifying choice thereof, theorising experiences and providing a way forward)- and strove to fulfill those requirements. I wanted to get the personal thread to

weave with the academic and it happened that I often ‘stumbled’ on appropriate readings as I proceeded from the established topic.

I now proceed to present the key questions and sub questions upon which this study revolves. The need to keep my gaze or surveillance on the core purpose of this study, inspired critical questions.

### **1.3 Key research question**

The key question guiding and informing my study is as follows:

How and why can my experiences of searching for schooling spaces for my daughter with Down syndrome be explained through autoethnography?

The above question ostensibly includes attention to the following: what policy has to say about access to schooling spaces for children with Down syndrome, and, an interrogation of inclusive education against current mainstream practices in providing for children with DS, incorporating legislation.

The next section focusses on the structure of the thesis with an overview of each chapter of this study framed to facilitate discussion, transitions and highlights.

### **1.4 Structure of the thesis**

Chapter one, *Cobblestone façade* used a metaphor to focus on what I thought existed compared to what really was. The nostalgic reminiscence of my past years of schooling creeps into the present search of schooling. The parallels are of the veneer, stony pathway leading to the school and the face-brick walls but also that no-one on the outside, knew what unfolded within the gates of schools. The 1970s and 1980s for me were robust years flagged by 1976 Soweto uprising, stone throwing and apartheid protest songs ‘we don’t need no education’ drummed from a learner perspective. The present era is a stony pathway, a struggle to find inclusive schooling spaces and access to it. Policy restructuring, curriculum changes and protest demands for services dim the vigorous parent advocacy. The contrasts lie in that,

parents of then, had limited choice of where to school their children with the government policies. Now, with new democratic government parents still have limited choice of where to school their children. Just as persistent dripping can make a stubborn hardened surface reshape, so too was my expectation of access to inclusive settings.

The overview is meant to help the reader to orientate towards the study by looking through the lens of a mother and researcher. This perspective allows the personal imperative and broader construct to offer dialogic entrance for the reader.

Chapter two, *Touchstone* is synonymously the litmus test of how South Africa is positioned next to its neighbouring countries in Africa and its global players. The successes and shortcomings in both domains are contextualised through its researchers and their findings. Chapter two sets the foundation by presenting discussion on aetiology and prevalence as a springboard for the concentrated discussion on access, schooling spaces, and the legislative framework of the inclusion debate. Literature review of Chapter two is compacted with an outline of what discourses within this study entails: surrounding and focussing on the issues of access, inclusion and social justice. The multi-layered, complex and inter-linked nature of understanding these facets and the ways in which they are visible in policy is intersected it with logistics and practicalities in implementation. I then consider carefully the information from my reading and how that evidence and the scope of the system of education in South Africa can be evaluated against social principles of: impartiality, openness and democracy. I draw on data from research within the borders of this country and considered whether South Africa is on track to reach 2015 to reach its Millennium Development Goals <sup>5</sup>and its various policy initiatives to redress unequal status that preceded democracy. The focus then swings towards access, schooling spaces, DS and autoethnography.

Chapter three shifts to a more personal gear with *Writings on tablets of stone* which unwraps ways of knowing, what I came to know. These incremental layers, from ‘not knowing’ (ignorance) to ‘knowing’ to ‘knowledge’ has both an explicit academic and spiritual dimension. To analyse my journey of knowing and knowledge, I ‘stand on the shoulders’ of

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<sup>5</sup> Listed as Goal two, is access to primary schooling for all children.

established researchers and unlock the multidimensionality of my learning.

Chapter four, *Leave no stone unturned* highlights my struggle with the research design until a niche is found in autoethnography. The methodological, epistemological and ontological basis of the study is positioned interfacing the interpretivist framework. Extracting relevant information from the past, using memory work is challenging work primarily because it must address the key research question. The relevance of memory work and the tools used to access it, is explained. Extracting information from the past necessitated excavation of details through recall. I provide as much detail as possible to the chronicles so the veracity of what is presented can be authenticated. Providing depth to nodal moments developed from general impressions to clarified detail. The option to incorporate a multiplicity of voices which autoethnography includes in its description meant that nodal persons could be selected. Details of the nodal persons, referred to as key informants, are outlined. The serious ethical dilemma I faced and how situations are weighed and decisions taken are substantiated. Next, justification for the choice of analytical framework is provided. This leads on to deep consideration of ethical issues pertaining to this study as it involves references to children, internationally ‘categorised’ as vulnerable and thus to be protected.

Chapter five is *Sticks and rolling stones* begins with a metaphorical reference to insecure pieces of information (*sticks*) and the solid enduring pieces of learning (*stone*) from the beginning of life with Tiara and its growth through the study. The canvas is broad and empty at first, and gradually enveloped with knowing and knowledge with each of the eight chronicles. This develops into a commingling of personal episodes and cameos with key informants and captured metaphorically as *rolling stones*. The coined ‘sticks and rolling stones’ has no bearing on the proverb. ‘A rolling stone gathers no moss’ proverbially refers to person who is always on the move, not wanting to settle in any particular place and avoiding responsibilities. On the contrary, this study involves parents in partnership, in motion (*rolling*) to shift ideology and spaces from exclusionary to inclusionary and taking full responsibility for the schooling of CWDS. There may be a pause in the journey, but no stagnation. Unlike Sisyphus in Greek mythology who was condemned to push the rock up the mountain only for it to roll back down, parents’ in this study exert themselves toward accomplishing access. The

data is presented in an iterative writing style of *my turn* (personal chronicles) and *your turn* (a collage of cameo chronicles of all informants). Applying thematic analysis identified the common themes that emerge from the cameo narratives. A discussion of the collated data is done using an adapted model of Dunn (2003) 'ways of knowing' model. This discussion is extended with the analytical framework developed from stimulus of Nind and Seale (2010) multidimensional model related to access. Discussion of some highlighted findings are contextualized. The analysis process is explained and the meaning making is elaborated. Chapter 5 concludes with recommendations emanating from my experiences and the interactions with key informants and concludes with some implementable strategies in the South African context.

The final Chapter 6, subtitled, *Gathering stones*, is a gathering and presentation of solid ideas emerging from the study which are practical and implementable. Charting a way forward for education in a post democracy for our CWDs must continue as we 'stand on the shoulders' of advocacy giants, both national and international. *No stone in my shoe* is the culminating metaphor of the thesis. The reflectivity, lessons, ruminations on access to schooling spaces for my CWDS comes to a close but the discourse continues beyond the pages and words. The thesis culminates with the spiritual anchorage, a return on my part, to God's Word and how that stop-over helps release the *stone in my shoe*. Chapter 7 ends with concluding thoughts on the subject of access of schooling spaces for my child with DS.

## CHAPTER TWO

### *TOUCHSTONE*

“Every [child] can learn, just not on the same day, or the same way.”- George Evans (n.d.)

#### **2.1 Introduction**

The above, George Evans quotation, was a *touchstone* to me for the duration of my teaching career. Now it touches a personal chord with me in my experiences of access and schooling of my CWDS. The intimacy of the notion that she can learn is what drove me to do this study. The reality that she is profoundly deaf in the right ear, meant that she could not learn the same way in any case as her non-disabled peers, at least not on the same day.

This Chapter is presented in the format of the ‘outward, inward gaze’ then an ‘inward, outward gaze’, which supports the intentional reflexivity (Lim, 2012) embedded in my choice of autoethnography. This bears direct link to ‘touchstone’ in the opening line. Touchstone (an assaying tool), is a stone used to identify precious metals. It is used as a metaphor in this Chapter Two. I use it to help explain the process of scrutinizing multiple contexts and experiences to highlight those that become the chronicles in this study and informed by the research question. I take time to ruminate on them. By gazing (more intently than intermittently) on each experience of access, filtering each one through research of national and international scholars, the discourse on access gains clarity. The ‘outward, inward gaze’ consequently offers a stepping stone outline and enables me to present my work in layers of personal and academic discourses.

I begin the literature review by offering a compressed synopsis of the ability of babies to learn instinctively and purposefully, without pre-judgement of their capability at birth. This is wedged with a concertina of ‘images’ that are interspersed in the chapter with my looking back on the trajectory of eighteen years. These flashback ‘images’ referred to as episodic or nodal moments allowed me to capture reflectively and engage critically with experiences from medical diagnosis through to layers of access *to* and *in* schooling spaces, Down syndrome and

autoethnography. Each of these key areas is punctuated with rigorous discussion, though at times this merges into an interwoven academic mosaic. This mosaic will be noticed in the discussion of access as it is always coupled with schooling spaces and DS. I have chosen access to be centralized and embedded with schooling spaces and DS. An awareness that the kernel of this study is personal meant that I needed to check my writing continually that my position as an autoethnographer with its inherent subjectivity is weighted judiciously against academic frameworks. Autoethnography contributed meaningfully towards directing the intent: making this study of a personal nature, academic, whilst being mindful of creating the balance between the two. In its final presentation I tried to maintain a semblance of a normal thesis with all components (literature review, methodology, data analysis, and conclusion). By making it academic, I make what is private and personal, universal.

To explain this mosaic further I draw on the expertise of researchers, particularly Priya Lalvani (2011, 2012), who has explored various topics related to my study which include models of disability, personal experiences borne by families of CWD, mothers' perceptions of educational environments for their children with Down syndrome, segregated and inclusive schooling, parents participation, and the influence of educational ideologies and socio-economic status on children with Down syndrome. Medical practitioner Brian Skotko (2005; 2009; 2011) has engaged with the topic of DS less from a personal perspective (of having a sibling with DS) but more from a medical perspective. His insights have changed my view of medical personnel who are often classified as impersonal and detached. Education policies, academics and local, national and international research (Muthukrishna, 2011; Engelbrecht, 2006; Buckley, Bird, Sacks & T. Archer, 2006; Lalvani, 2011; 2012) also add texture and depth to the points of discussion. I provide discussion on interpretations of disability before exposing and merging personal experience with those of medical practitioners', in order to trace the historical frames of reference used in social and medical practice.

This is followed with etiology and prevalence of DS. Gathering information and understanding more about DS prepared the way to consider realistic schooling options for my child with DS. Using the background of international trends and practices, I embark on a discourse on schooling, contextualizing it in the period prior and following the dismantling of

apartheid. Research findings do not argue for separate systems (medical model) for children with DS to optimize their life skills as those who champion a singular system (inclusion) where CWDS learn alongside their peers to optimize holistically their social, physical, emotional, recreational and academic skills (Archer, Bird, Buckley & Sacks 2006; Gobel, 2010). The inclusion or special needs schooling is fraught with controversy (Lindqvist & Nilholm, 2013; Lyons & Arthur-Kelly, 2014) and localising it (Engelbrecht, 2006; Klompass, 2008; Anderson, Boyle & Deppeler, 2014; Meltz, Herman & Pillay, 2014) provides a niche from where the critical engagement for myself was initiated. This discussion incorporates the national imperatives with the legislative framework. The timeline from pre-democracy to contemporary post-apartheid tracks parents' expectations of schooling spaces in South Africa, including salient issues that link with access and Down syndrome.

The choice of autoethnography is the liquid, invisible thread that runs through the work and offers texture in its presence, permeating all chapters and pages of this study. Chang (2008) identifies autoethnography as a self-narrative and Ellis & Bochner (2003) provided me with key focus areas that should be addressed in a study using autoethnography as a methodology.

The Nind and Seale (2010) model of access is the tool used to measure the level of access in past and current practices and will often be explicitly stated. This allows one to determine if set targets for inclusive practice has been realized- or is realizable both nationally and internationally, given the legislative framework to which many countries that are signatories to related policies, are expected to adhere.

## **2.2 The genesis and axis of schooling**

Access. This is where it all starts.

Newborn babies display some common behaviour characteristics though the timing and frequency of each varies from one baby to another. The *World Health Organization* (2001) and the *United Nations International Children's Emergency Fund* (1946) recommends immediate physical 'skin' contact between mothers with their newborn babies should occur

promptly following a natural or Caesarean section birth. Stevens, Schmied, Burns and Dahlen (2014) who undertook a review of papers to assess data on the facilitation process of physical 'skin' contact shortly after birth and not exceeding one hour identified enablers, hurdles and related mother and child outcomes as well as identified nine instinctive newborn behaviours: "birth cry, resting, awakening, activity, crawling, resting, familiarisation, suckling and sleeping" (Stevens, et al, 2014, p. 456). These appear as common behaviours, yet through these behaviours babies indicate signs of accessing parent attention. Mothers may rely on instinct and intuition to learn how to respond appropriately to these instinctive behaviours. As a baby develops and maternal care progresses, neither child nor mother will rely entirely on instinct for learning but will progressively in that timeline consider additional responsibilities to child, one of which is schooling options: private, public, Montessori or home. The choice may be influenced by personal, social, economic, financial, political and environmental factors, but largely it is a cocktail: access, cost, suitability to child's needs, school religious ethos, geographical location, facilities, extra-mural activities, though it is also not uncommon for parents to simply seek placement at the local public school without particular consideration for any of the factors. The continuum from birth through schooling and post-schooling requires further deliberation if the child has a disability which requires additional and specific educational support, more than the norm. It is when what is considered 'different' is defined more as a medical difficulty, responses are initiated and actions taken which should ordinarily not be the case (Conrad, 2004; Foucault, 1965). In other words Conrad (2004) indicates 'medicalising' the deviancy which depicts a shift from the norm affects the approach. I will return to discuss this notion shortly.

Allow me to ruminate for a moment on Michel Foucault. I am selective in quoting Foucault and his inserts are epiphanic moments for me. In trawling through his readings I find his writing bewildering yet his name is common to scholars in my surround. My fascination with Foucault's work that explore implications and insights concerning spatiality, power and knowledge, urged me to read more, though I admit it is complex and comprehension is difficult. The following quotation suggests that spatiality (within geography) occurs as a central part of a greater disquiet, that to understand one it should be interpreted in relation to the other components. "It is somewhat arbitrary to try to dissociate the effective practice of

freedom by people, the practice of social relations, and the spatial distributions in which they find themselves. If they are separated, they become impossible to understand” (Foucault, 1984, p. 239).

I extracted further sections from Crampton & Elden (2007) on Foucault, which lends themselves to my study. Space is prudently expressed as a “vital part of the battle for control and surveillance of individuals, but it is a battle and not a question of domination” (p. 2). My interpretation of Foucault may be superficial but relevant. Foucault perceives power as both productive and negative; and in an abbreviated comment about space as power he writes “the vertical is not one of the dimensions of space, it is the dimension of power” which in its application to this study, may be looked at in this way: government situates itself in a position of power by designing policies and expecting it to be implemented. My child is a consumer of this product through exposure to the implementer (educator) and the parent becomes an indirect consumer of this product. In the context of this study as I understand it, to apply Foucault’s interpretation translates into the following: that government through its policies has power to control what a child learns and the parent and child who does not question this linearity, are all in a space of captivity. Foucault suggests that this can be reversed: the ‘inside outside’ (Crampton & Elden, 2007, p. 8). The most memorable quotation to me on this subject is to “recognize that ethics requires us to risk ourselves precisely at moments of unknowingness, when what forms us diverges from what lies before us, when our willingness to become undone in relation to others constitutes our chance of becoming human” (Butler, 2005, p. 136). South Africa’s pre-1994 colonial practice configured geography of schooling spaces in unequal ways (Christie, 2012). The effects of those spatial relationships of power may be manifested even in current practices. Encountering Foucault through this study has forced me in a way to deliberate about spatiality, power and knowledge positions, ask more questions, to configure possibilities and reappraise schooling continually.

### **2.3 Unlatching access**

As you can see I am a person with Down's syndrome, which means that I have one extra chromosome in every cell in my body. My grandmother's friends wanted to

pray for me to become 'normal' but my mother asked them rather to pray that I would receive the support to reach my full potential as a Down's syndrome person.

(Sheri Brynard: Extract 1 from her speech at her graduation, 2012).

I take my cue from Davis and Sumara (2006) who state that “a knower’s knowledge necessarily affects the ways a phenomenon is perceived and how the knower acts in relation to that phenomenon. (p. 15). In trying to gain an understanding of school as a social system necessitates my simultaneous consideration of the multiple and complex layers of dynamic nested activities that are continually at play. Whilst working through the intricacies of my child’s abilities, I was exploring the uncharted terrain of discourse on disability, access, and schooling identifying for myself the various layers of dynamic interrelated nested activity. To inform myself, I initially started reading about ‘*one extra chromosome*’ of DS (Davis, 2008; Buckley, 2000; Skotko, 2005) which led me to interpretations of disability (Terzi, 2004), inclusion (Buckley and Bird, 2000; Muthukrishna, 2011) and incrementally brought me to access (Ribot & Peluso, 2005; Nind & Seale, 2010). It was Ellis and Bochner (2000) who offered me the avenue of autoethnography through which the ensemble can be compiled and presented as a personal and academic offering to the reader.

My raising a child with a disability involves negotiation, part of which is adaptation. The greater and more demanding concerns were about her future. The primary concern was located in admission into an inclusive mainstream schooling context. For me, inclusive education meant full immersion in a mainstream school, with frequent occupancy in a regular mainstream class, accessing partial or full benefit of allotted instructional time as recommended by Rynders (2005), whereas special schools tend to focus on skills of self-care and independence and minimising the academic expectations of learners. Inclusion within education implies that children who were formerly trained and educated in special schools are now allowed to attend any ordinary school and participate in classes with their ‘normal’ peers (Klompas, 2008, p. 3). Clearly, abilities vary from one child to another and it is no different with DS. CWDS are not a homogenous group, although most tend to be within the mild to moderate learning disability range. CWDS “are capable of learning in the mainstream

classroom but they often advance at a slower level” (Davis, 2008, p. 271). This is reinforced by George Evan’s expression that “every [child] can learn, just not on the same day, or the same way”.

This leads me to consider in greater detail the notion of access and explicit participation.

It is necessary to contextualize and expand what the concept ‘access’ means in order to measure its efficacy in practice. It must be understood that in this study, it is more as an implementable rather than a political idea. Access, as a concept, has been functional or implicit in many contexts including economics, politics, technology, medicine and education, but explicit research dealing specifically with CWDS participation in inclusive setting is concentrated in the UK. In tandem with access is the issue of participation. ‘Participation’, as a term is considered as having multiple meaning including ‘taking part’, ‘being present’. Additionally, it may refer to contexts of consultation or transference of power. In such a context, the participant can affect the outcome in decision making by being provided with relevant information, (Franklin & Sloper, 2007). When contemplating ‘participation’ for CWDS in a mainstream inclusive setting, it should be characterised by meaningful involvement: being present, taking part, being consulted and allowed as the learner to be instrumental in the outcome processes. In unlatching the practicality of implementing this idea, Franklin and Sloper (2006) offer the following explanation that resonated with my expectation, “meaningful participation must be seen as a process, not simply an isolated activity or event” (p. 726). The research work of Rabiee, Sloper, and Beresford (2005) with children of youth who do not use speech for communication draws sharp attention and alignment to issues of access, schooling spaces and DS, the main issues on which this study focusses. A crucial element in achieving the overall aim of participation, is the need to “develop communication methods, which can maximize children’s communication potential to express themselves and address the barriers they face. The other key component for effective participation is to recognise the fact that communication is a two way process requiring others to learn and understand how a child expresses herself/himself.” (Rabiee, Sloper & Beresford, 2005, p. 386).

In synchrony with the notion of ‘participation’, is the element of learning. Lave and Wenger (1991) critique the association of learning ‘situation’ with a ‘simple location in space and time’ in their model of learning as ‘legitimate peripheral participation’ in a ‘community of practice.’ These theorists consider their views on situated learning as involving a much more multidimensional and relational perspective in which “agent, activity, and the world mutually constitute one another” (pp. 32-33).

The forgoing insights highlight the need for me to look more deeply into the issues of access, the principal theory upon which this study is constructed. A better understanding of what I mean by access, and how access can be promoted or achieved, is fundamental to all children and their geography of schooling. The composite group of CWD are tacitly incorporated within this particular study focus of CWDS. This segmentation could increase understanding of what specific target group experiences and possibly increase generalisability of CWDD. Having broader and deeper understanding will provide the rationale for promoting it. ‘Access’ is a useful concept and term that gets right at the heart of calls for the dismantling of a disabling society. It is about people, their families, their allies and advocates, their potential and their ambitions. I will return to this discussion later in this Chapter. At this juncture, it is necessary to position interpretations of disability with schooling ahead of that detailed consideration of access, so that the related questions of *how* and *why* may coalesce to a mosaic of understanding their overlaps and interconnectedness, when looked at collectively.

## **2.4 Evolution of interpretations of disability**

I live among these people ... me, a girl with Down's syndrome, a condition that makes people abort their babies and lock them in institutions or at the back of their homes so others can't see them!

(Sheri Brynard: Extract 2 from her speech at her graduation, 2012)

I was intrigued to read that the term ‘disability’ was selected as a polite alternative for previous use of the term ‘handicap’, given that the prefix *dis* emerged from DIS, the name given by ancient Roman civilization to the ruler of Hades, or the underworld. DIS was

portrayed as effecting harsh treatment on mortals by reducing their health, well-being and capacity to function in their environments (Daly, 2009). Some of these perceptions are manifested in the twenty-first century but not always in discernible forms. What is visible is its emotional manifestation. These emotions and attitudes (more of negativity and condescension) that I have witnessed are challenging to overturn.

DePoy and Gilson (2011) underscore the view that “disability is a judgment about authenticity and worth” (p. 7). I thought it a good starting point to unpack “how bodies come to be understood and have different degrees of worth, by different services, institutions and cultures” (p. 7). Martin and Volkmar (2007, p. 12) assert that “those who were mildly atypical [mild disabilities] experienced a range of support and inclusion in community life from none to full but that in many areas, extreme deviations from the typical [severe disabilities] were considered inhuman” a consideration assigned, especially in newborns.

At present, there is no uniform interpretation that is applied consistently in all literature with the result that description of disability to some, is impairment to another. To be sensitive to the advocates and human rights activists and the gains made for CWDD the term impairment will be used to refer to all categories (mild, moderate or severe). It was difficult to fix a description or explanation that will suit all types of diagnosis. For this reason, the term ‘children with disability’ (CWD) will be used specifically instead of ‘disabled children’ having been made aware of the arguments for people-first terminology. Support for the latter is provided by Ngwenya (2010). In his study of disability equality in the South African workplace, he motivates that such usage is an affirmation of the reality that disabled persons are part of human diversity; CWD implies a marginalised, identifiable social category.

I base my notion of disability on Oliver’s (1990) social model, distinguishing *impairment* as a medical predisposition of a human body and *disability* as the prejudices and discriminatory practices in society that marginalise CWDS. In using the terms *impairment* and *disability* interchangeably confuses and weakens the social model. As a political principle CWDS should also be treated equally as non-disabled people and offered opportunities to be included rather than excluded. It is not a case of semantics but of determining what aspects require

intervention, developing the policies and implementing those policies to address the need.  
This

Through my reading I started to re-think my own understanding of certain notions of disability. One such notion that surfaced is that concepts are somewhat ‘time’ and ‘culture’ bound: different interpretations of disability have historically led to different methods of dealing with it (Smart, 2009). Foucault’s (1976) seminal work on the government of disability was informative from the point of view that it questions the very label of ‘disability’ that constitutes power relations. His view is that it contributes to silencing the affected and reducing their moral agency. I did encounter the reference to ‘models of disability’ when reading about the evolution of the disability discourse (Oliver, 1990; Barnes, 1997; Terzi, 2004). Over the years there have been many models defined. The most regularly and selectively cited, are the social and medical ones. These frames of references become tools which in the impaired/disabled debate helps define impairment/disability. They could be used as levers to provide a foundation for government to design or review programmes and strategies to address the ones affected.

The reality of people’s attitudes, visible in their speech and practices towards DS and DS with other severe impairments, is succinctly encapsulated in the comment by “*abort their babies and lock them in institutions or at the back of their homes so others cannot see them*” is encountered in people’s speech and practices. I recall an incident of a little boy, about six years old, in a local community, who was chained daily to a stake and left outside the home for the day while the family attended to daily chores. He was unable to hear or speak except for expressing guttural sounds. His parents uninformed on how to support his muteness, convinced themselves that chaining him was to ‘keep him safe’. He was intermittently offered a modest meal and spent most of the day outdoors with the family pets. Incidents of neglect, abandonment and abuse of CWD is associated with societal perception of reduced individual worth as alluded to earlier. It was a while before a relative, visiting the family, witnessed this and acted decisively by ‘adopting’ the boy and offered him intervention and support services to address his needs. This incident illustrates that disability is pathologised, even to the

ordinary person, and the affected suffers further from being excluded in everyday activities (Lalvani, 2012).

Disability has historically been seen through the lens of medical science and framed by pathology and impairment (Bricout, Porterfield, Tracey & Howard, 2004, p. 48). The medical model couches disability as residing within the individual body and requiring prolonged individualised medical treatment by professionals. Byrom (2004) is averse to this interpretation which absolves the conscience of human beings and their responsibility towards the consequences for people living and sometimes struggling with disabilities. DePoy & Gilson (2004) explain that “variations of the human condition were identified in contrast to what was typical, and some explanations for extreme variations were met with legitimate acceptance and positive responses while others were not tolerated” (p. 13). The example of servicemen returning from battlefields, who were maimed in the process were looked upon as heroic figures (where the circumstances and explanation was known). This [deficit] model of disability is accused of ‘legitimated individualised and personal tragedy perspectives’ (Barton, 1997, p.12) and controlling or attending to the disability is directed to be curative or as close to being cured. As a result, medical treatment is central, and politically, the foremost reaction is to amend and restructure health-care practices and guidelines.

The model which emerged later, from the disability rights movement in 1970s and in contrast to the medical model, is the social model. This model suggests that individuals are not disabled by individual impairments, but through obstructions and disabling barriers in society (Oliver, 2013). This perspective points toward disability ‘not only in need of individualised medical treatment, but changes in social society is [considered] essential’ (Siebers, 2011, p. 73). The responsibility then, shifts away from the individual (de-individualised) and is seen as a shared responsibility of society (Llewellyn & Hogan, 2000, p. 159). Those who support and campaign for social justice do not repudiate the necessity for expertise of medical knowledge to address specific impairment matters. On the contrary, they promote that medicine is not the sole catalyst to resolve discriminatory matters concerning disability. , (DePoy & Gilson, 2011). Harlan Hahn expresses a similar sentiment, from a North American context: “the failure of a structured social environment to adjust to the needs and aspirations of citizens

with disabilities rather than from the inability of the disabled individual to adapt to the demands of society” (Hahn, 1986, p. 128).

With this perspective at hand, I was not surprised to encounter an echo of this interpretation of disability when reading an article by Finkelstein (2001) entitled “*The Social Model of Disability Repossessed*”. In his paper, he explained the view of the physically impaired community, commencing by citing “*UPIAS Fundamental Principles of Disability*” (1975:

It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (*UPIAS Fundamental Principles of Disability*, 1975)

The message Finkelstein conveyed is for people with impairments to be researched from a social justice standpoint where impairment is considered as a contextually situated problem. In this model, disability is perceived, not a characteristic feature of an individual, but rather a multifaceted assemblage of circumstances, mostly shaped by the surrounding social environment. Addressing the issues requires social action. This can be manifested through shared accountability as society effects changes to the environmental which are crucial for meaningful participation of PWD in every aspect of social life. The problem is approached from a cultural and ideological angle, with a scaffold approach to social changes: from individual, to community, then to a comprehensive agenda. Finkelstein argues that access that is alike for a person with or without an impairment or disability should fundamentally reside and operate from human right viewpoint. He proposes that people with impairments be considered within the social model where society and environmental factors affect the individual. This interpretation rejects the notion of deficiency or inadequacy, which places blame on the individual rather than on society through the undifferentiating reference to impairments as disabilities. Looking at disability from and within the ‘social model’ lens, is adopted internationally as an approved approach. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) has expressed its approval and underlined its paradigm shift. This transformation attends to attitudes and approaches to

persons expressly with disability disquiets. From the time Hahn (1986) commented, nearly thirty years later, countries around the world are still discussing definitions and models of interpretation which is an indication of the slow rate of address and progress for people with disabilities.

To move forward from gazing at terminology the suggestion from Terzi (2004) is that it is more important to consider disability or impairment as a specific human variation (p.167), an aspect of human heterogeneity and beyond simplistic notions of personal deficits. I am inclined to agree with Terzi (2004) whose argument was also expressed by Corker in 1999 for a ‘dialogic relation between impairment and disability, not an analytical privileging of one over the other.’ Further discussion on each of these models will be offered later in this Chapter to determine the level of marginalisation of CWDS in accessing schooling spaces and more so with inclusive schooling spaces.

I now share with you the context where the words ‘normal’ and ‘abnormal’ entered into my repertoire of unsavory epithets.

## **2.5 A world of peculiarities**

*I remember Jasper! We were in the same primary school though in separate classes. He went to the special needs class which had a designated teacher for the year. Jasper had an awkward walk because of the disproportionate length of his legs. I did not know his diagnosis. He also stuttered severely and as a result was often unable to complete a sentence in a conversation, allowing the listener to do that for him as he also struggled to find words to express what he meant. I remember Jasper on Sports Day. He was always entered to participate in the ‘sack race’. Everyone cheered for him. It did not matter to the crowd that he did not finish the 25 m race on the programme, only that he got as far as he could. Either I or Tinnie was always on standby with water and an orange to offer him on his ‘completion’ of the race. He smiled! I smiled!*

In my childhood every person was accepted for who he or she was. The children did not refer to Jasper as ‘handicapped’, ‘disabled’ or ‘challenged’ but I did sometimes hear educators refer to him as ‘abnormal’. It did not matter to me then because he was one of us whether on the sport-field, on excursions or just walking leisurely on the ground during recess periods. Now as I reflect on him, as I often did since Tiara was born, I replay in my mind the kaleidoscopic images of Jasper on the track, in his sack, hopping and pausing in-between as he made his way down the track with his eyes fixed on the finish line. I think to myself now how peculiar it is that people stop, stare and look away when they ought to run and help, as we did as children.

I now ask myself, why did the educators sometime refer to Jasper as ‘abnormal’? The answer emerges in the discussion that follows.

Perception of what constitutes ‘normal’ operates in most social contexts and the place where one is most likely to be born - a hospital - is no different. At its birth it is not uncommon for the attending doctor to pronounce: ‘it’s a normal healthy baby’, to suggest the baby is free from any infection, disease or malformation referred to as “normative narrative” by Carrington (2002). Subsequent visits to a medical practitioner offers enhancement and embedding of what constitutes a norm. ‘Your baby is growing normally’ or ‘your baby is well within the range of milestones for her age group’. Society marks the arrival of a CWD or impairment as one who is ‘different’ since by its own norms (determined predominantly by non-disabled adults) the baby does not conform within the range of socio-cultural norms of expectation. Doctors have the authorizing power to certify not just disablement but, often, an individual’s functional capacity (Campbell, 2009) and inadvertently become tacit agents of social control (Lalvani & Polvere, 2013).

Campbell suggests that society’s beliefs and attitudes form an intricate system that is projected where disability “is cast as a diminished state of being human” (2001, p. 44). This translates into the child being classified in a genre different to ‘normal’ and with this ‘different’ label comes associated stigmatization (Green, 2003). This medical deficit model may be perpetuated in prenatal, and antenatal classes and linger throughout the child’s

growing up years. Adults, in a position of power by virtue of their training, qualification and experience, determine what is appropriate for children with disabilities and their families, using their own constructs and definitions of 'normal'.

The purpose of foregrounding experience of the corridors of the hospital (also a place of learning), is to reignite the discussion on interpretation of disability and access to knowledge either withheld or restricted. In this context the professional medical personnel are deemed to be in a position of power. At this moment, in this study context, I am interpreting and applying Foucault's notion of power in the following way: I would say its existence is palpable only when put into action. I observe the parallel between Foucault's explanations and my own context of how subtle the technique of power translates from procedure of 'individualization' to exclusion practiced in the nineteenth century and exists today, in various spaces including to some extent, the hospital (Foucault, 1977). The divide of normal and abnormal is the binary to which every person is subjected, then and even in our time. I recall the excitement when the doctor did a house visit, it was traditional to rush out and assist with the medical bag and escort him to the patient. All eyes would gaze on the doctor, his every move, his assessment of the patient, the plastic sachet into which he drops the prescribed tablets. There was complete reverence and awe of his social and academic credentials. I identify with Gallagher (2008) that there is no desire on the part of the parent to remove the power relations altogether as the medical practitioner is viewed as the bearer of knowledge but rather to re-configure these power relations by imparting what he knows to those who do not know and negotiating the final understanding. I have respect for the position any medical practitioner holds in society but as a bearer of knowledge, the manner in which this knowledge is imparted needs to be humane, even empathetic, adopting a disposition that conveys that he/she cares.

*The paediatric cardiologist stood briefly at the foot of the hospital bed on which I lay and quite nonchalantly said to me, "your child may have DS". No sooner had the words left his lips, than I was upright on the bed, gesticulating and thinking that my retort would cancel his statement and blurted out, "She has ten fingers and ten toes. She looks like any ordinary child. Why do you think she is different?" Pause. "I am only in my twenties. What went*

*wrong? Whose fault is this?” All he did was shake his head and say “It is not the end of the world. In any case a blood test will confirm whether she is or not” and he walked out leaving behind a devastated mother, shattered. Thinking ... my daughter is different!*

In my case, the attending paediatric cardiologist displayed a detached, impersonal and clinical approach. This was my first-hand experience of the medical deficit model in action. I later read of studies conducted by Skotko, Capone and Kishnani (2009), located in the medical field, who have in their record elucidated the medical practitioners dispassionate or empathetic manner in which the disclosure of DS diagnosis particularly with post-natal context. My experience resonates with sentiments expressed by Skotko, et.al. (2009, p. 751) where the manners of the professional dispensing the diagnosis was ‘abrupt, unsympathetic’ nor emphasized the positive aspects of the condition resulting in “feeling anxious, frightened, guilty, and angry after learning the diagnosis for [my] child”. This is categorised as predominantly deficit-based. Such attitudes on disability which add to pressure on the family unit increases deleterious reactions (Lalvani & Polvere, 2013). My understanding of DS, its characteristics and issues related to raising such a child, developed later as my understanding of the subject grew. I shall explore these components in greater detail in Chapter four.

My first piece of information pertaining to how to refer to persons with DS, was from a brief chance conversation with a visitor at a local library. As I sought books on the subject of DS, a lady said to me during a brief conversation about my child: “*She is a baby first and foremost. It so happens that she has a condition called DS*”. That means to privilege her, not the condition; that she is a person first. This affirmation is supported by Broderick, Mehta-Parekh & Kim -Reid (2005) who asserted that “disability resides in the context, not in the person” (p. 200). Nind and Seale (2010) concur with this view and add that the human rights perspective foregrounds the individual, not the disability.

DS receives extensive coverage in medical research, ranging from prenatal screening to postnatal support, chromosomal abnormalities and breaking the news to parents. It was whilst trawling through the internet that I read an article by Brian Skotko entitled “*Mothers of Children with Down Syndrome Reflect on Their Postnatal Support*” (2005) that touched a

chord with me. The objective of his study contextualize in United States (US) was to record the thoughts of mothers when they received diagnoses of their CWDS. Skotko (2005) dealt with medical practice of imparting diagnoses to parents. Most of the mothers interviewed expressed distress, fear or concern on hearing the diagnosis, with a small number rating the interaction positively. Mothers reported that their attending doctors spoke little on positive aspects of DS and seldom offered resources or contact details of other parents of CWDS. I identified immediately with this context, not only of inappropriate handling of sensitive information by professionals but also the disinterest in recommending avenues of support.

There are other researchers who have engaged with work on emotional repercussions of DS on the family structure. Studies by Peralta and Arellano (2010) focus on the impact of disability on parents, whilst Dykens (2006) examine the pathology of labelling on the disabled and non-disabled members of the family showing the need for positive psychology. Extending the idea, Wright (2008) focusses on contexts when news of a child's disability is disclosed correlating with the notion of positive psychology. Keen (2007) considers fruitful and dynamic relations and how this affected the affected individual and their families holistically, encouraging and promoting a family-systems approach of support.

From their studies conducted in Spain, Peralta and Arellano (2010) assert, "what the disability means to parents, and how they react to it, has to do with the historical reality and social context in which they live" (p. 134). They also re-articulate the view that between 1820 and 1910, during the gradual specialisation of the medical and educational professions, parents bore the burden of moral guilt about the disability of their child. Such a child was viewed as a tragic event, and required that parents go through a stage of mourning the loss of the ideal child. Later (1920-1980) an intrinsic connection was made between the birth of a child with disability and family pathology (siblings were also considered maladjusted or maladapted); that is, the disability in itself inevitably hurt the family, labelling it as a "pathological family" (Dykens, 2006, p. 185). As a contrast to these ideas, both Keen (2007, p. 339) and Wright (2008) in their findings, motivate for facilitation of sensitive communication and in promoting positivity. My own frame of mind is echoed by Vacca and Feinberg (2000): that a home that

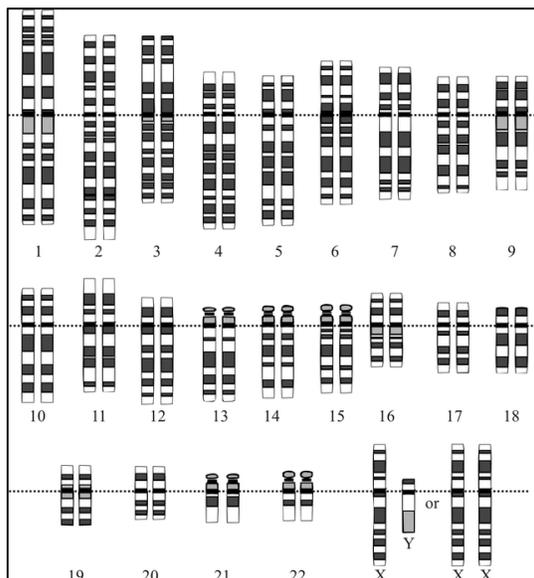
has a child with disability is not a predictor or predominantly a narrative forecast of ‘gloom and doom’.

In an effort to dispel notions of ‘gloom and doom’ and understand DS characteristics, mortality, the incidence of DS both nationally and globally and what schooling options were available, I turned to Down Syndrome Association Kwa-Zulu Natal, a non-governmental organisation established to support and promote the rights of persons with DS. Lang and Upah (2008) have contended that the major reason for the existence of non-profit and non-government organisations is advocacy for improvement and implementation of ‘rights’ as a social justice issue. A careful reading of the book, *Expecting Adam* by Martha Beck (2001), and researched articles by Sue Buckley (1999), “*Improving the speech and language of children and teenagers with Down syndrome,*” available from the DSA office, nudged me to enter into the foray of literary knowledge. The first position was to answer for myself the question of what Down syndrome is. It was challenging to trawl through the physiology and anatomy information of what happens at the time of conception that affects the formation of Trisomy 21.

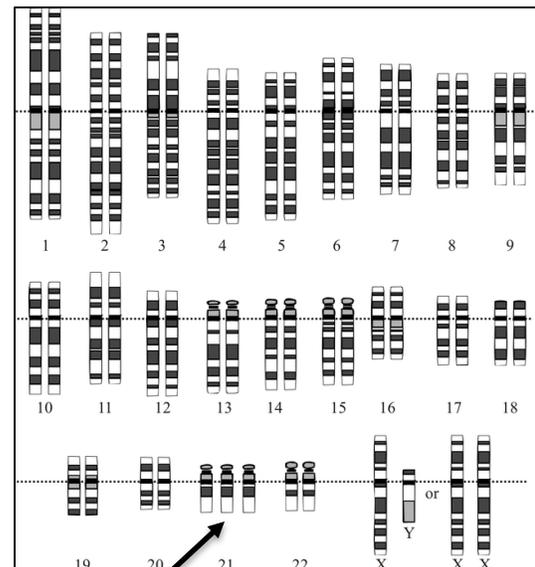
### **2.6.1 Etiology of Down syndrome**

A brief discussion of the etiology of DS is necessary to convey my narrative of access to information that would allow the reader to travel vicariously with me through from inertia (from not knowing what DS is) to the ‘fast-track of eighteen years’ to bring me to my present place and space as researcher in this study. This may be misconstrued as presumptuous and ostentatious. I was immersed into a paradigm of re-thinking and re-consideration. The inclusion of this aspect (description of DS medically) is to illustrate how I was enlightened through my research.

My understanding of the etiology of DS is gleaned from reading of Davis (2008). *Here begins my science of understanding what DS meant.* There are 46 chromosomes in a normal or typical cell. The configurations of our genes is within the structure of the chromosomes. The blueprint to the body's development and functioning is captured in the genes. The genes also determine an individual's physical attributes, medical profile, expected hair color, potential blood type and predisposition to certain disease. CWDS have 47 chromosomes instead of the typical 46 (Gardiner & Costa, 2006). Over and above that 23 chromosomes from each of the parents the CWDS has an extra one (Figure 1). This extra copy of chromosome is referred to as Trisomy 21 (Figure 2). Davies explains that DS is a chromosomal disorder where there is no manipulation of the genes but rather, it is prearranged before conception. DS is located within the spectrum of developmental disabilities. The level of intellectual impairment is said to be measurable using medical investigative techniques (Bricout, Porterfield, Tracey & Howard, 2004).



**Figure 1: Typical human Karyotype**<sup>6</sup>



**Figure 2: Three copies of chromosome 21, Karyotype for Down syndrome, Trisomy 21.**

<sup>6</sup> Figure 1 and 2: <http://commons.wikimedia.org/wiki/File:Karyotype.png>

Further reading on the condition provided the following information related to epidemiology: DS is identified as the most common genetic disorders with the last accessible record indicating that it affects 1 in 650-1,000 (Engelbrecht, Swart & Eloff, 2001, p. 256) with the primary genetic deficiency of trisomy 21 ... in 94% of cases, mosaicism (2.4%) and translocations (3.3%)". The risk factors pertaining to family history is the maternal age- with the ration increasing from 1:385 for the age group of 35 years, to 1:30 in the age category of 45 years (Tidy, 2013)<sup>7</sup>.

A chromosome anomaly may be reflected in a particular arrangement or number of the chromosome. Most chromosome anomalies are either numerical or structural. Numerical as the name suggests is applicable to the absence of a chromosome (monosomy) or additional chromosome to the existing pair (trisomy). An example of a condition caused by numerical abnormalities is Down syndrome, also known as Trisomy 21. Some anomalies are identified to have occurred after conception. The resultant type is mosaicism. With this type of DS, some cells (not all) have anomalies. Whilst some chromosomal anomalies is genetically transmitted which describes 'translocation', it could also be a case of 'de novo' meaning a new occurrence. Parents are advised to undertake chromosome tests when there is a positive identification of a chromosomal anomaly (Ghosh, Feingold & Kumar Dey, 2009).

In mosaicism, if all the cells do not have the additional chromosome, the child is considered not as severely affected. Such a chromosomal defect results in a cluster of physical and neurological impairments. Persons with DS present physical and communication impairments to varying degrees (Davis, 2008, p. 271). The causes for DS are unknown and indiscriminate because such a child can be born into any religious, social, racial background or context, or age of the mother.

In the next section I highlight the debate on definition of disability and include discussion on educational status of CWDS internationally. The reason for this is to locate how constructs of

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<sup>7</sup> <http://www.patient.co.uk/pdf/2071.pdf>

disability and impairments, addressed from either medical deficit or social, human rights paradigms leads to its just or unjust classification affecting prevalence data which in turns affects government financial allocation.

### **2.6.2 Prevalence of Down syndrome disability**

The disability and impairment binary is central to the social model and Patston (2007) adds that this binary ‘fuels discrimination’ unnecessarily (2007, p. 1627). Whilst disability can at times be severe enough to impair optimal daily activities, disabled people experience impairment, as well as disability, though not in separate Cartesian compartments (Hughes & Paterson, 1997). The social model with its disabled/non-disabled comparison is criticised for preserving and promoting a dualistic view of society by looking at the feature of function, with disability constructed as a “lack of wholeness” (Hughes, 1999). Lalvani (2014) adds that the medical model paradigm equates disability with impairment. My experience of accessing schooling spaces for my child illustrated how implementers of policy (principals and educators) view of how functional a person is influenced the assigned label of ‘disabled’ or ‘impaired’ with the latter receiving a more lenient treatment. To change the social mind-set means that society must adopt the view suggested by Patston (2007) that “everyone has different capacity to function at different times and in different situations” (p. 1626). This idea articulated by Patston existed in 2007 yet the dominant model of either medical or social prevailed. I am influenced to use the disability/ impairment binary prevalent at that time to articulate my discussion.

The World Health Organisation (2001, p. 19) definition of impairment is used when referring to the term. Impairments are described as “problems in body function or structure such as a significant deviation or loss”. *Impairment* as I learnt to understand it from trawling the internet and reading on various related topics, can be congenital, such as mental impairments or spinal bifida; it can also be acquired during life, due to injury or disease. Lalvani and Broderick (2013) refer to impairment as particular physical or sensory experience. This is dissimilar to De Poy and Gilson (2011) who describe impairment as a physical condition

which presents a body as aesthetically or functionally different, while disability is regarded as a social construct in which impaired bodies are treated with discrimination and exclusion. Lalvani and Broderick on the other hand, do not strictly follow person-first syntax usage and in unity with a growing section of the disability rights community “often use ‘identity-first’ syntax (e.g., “disabled people”), which positions disability as a central, integral, and valued facet of a person’s identity, rather than as a separate—and possibly negative—entity or appendage” (Lalvani & Broderick, 2013, p. 482). What is important to me is that impairment is not to be equated with disability and the focus should be primarily on the person and secondary, the impairment or disability.

UNCRPD (2006) define disabled people by inserting that they “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”. CWDS are not a homogenous group; there are variations within each of the three types (Trisomy 21, translocation and mosaicism). The characteristics of DS are noticeable but Corker (2001) cautions that to view disability as ‘visible’ not only generates an oxymoron, but is also exclusionary. Lalvani and Polvere (2013) indicate that meaning of disability is embedded in socio-cultural contexts adding that disability is not an absolute condition (Lalvani, 2008, p. 437)

I use the term ‘disabled’ judiciously, to describe children or young people or adult who have intrinsic or inherent learning disability associated with intellectual impairment. The condition of DS is a long term impairment which coupled with social barriers can restrict access to participate in all aspects of society.

Disability is a normal phenomenon ....it should be possible to estimate the sizes of the various disability populations, determine their needs and develop appropriate and cost-effective strategies to meet those needs. This is yet to be accomplished however, largely because disability is a complex interconnected bio-medical, social and environmental phenomenon that is yet to be fully analysed and understood (Metts, 2004, p. 2).

‘Estimate size’, ‘determine needs’ and ‘accomplish’ are key words and phrases in determining the nature of support by obtaining relevant data at the outset. Croft (2012) asks a pertinent question in her research title “*Do we need to know how many disabled children there are?*” and goes on to provide a detailed explanation of the merits of statistics. This advances the discourse on provision of accessible schooling spaces for CWD to which I subscribe. Data on disability has the prospect to aid throughout the phases of processing inclusion of CWD in formal schooling: advocacy, policy development, monitoring and evaluating.

Accessing comparative record of statistics, during advocacy for non-discriminatory laws, procedures and finance, can galvanise and accelerate (Albert, Dube, Hossain & Hurst, 2005) disability onto national and international political agendas (Fujiura, Park & Rutkowski-Kmitta, 2005). This is useful when comparing the status of educational opportunities of children with disabilities to their non-disabled peers. Such information can contribute to discourses of prevalent inequalities at an international and intra-national level. This may also incorporate movements in access opportunities for and between diverse populations based on culture, constituency or specificities of impairment (UNESCO, 2010). During the policy development phase, specific data on background characteristics can identify potential children at risk. This information can contribute to appropriate and targeted strategies of intervention. (UNESCO, 2010). When assembled data is disaggregated it can provide further information on specificities: of disabilities and of inequality correlated to gender (Rousso, 2003), language and context (Muthukrishna, 2011) or ethnicity (de Beco, Hyll-Larsen & Balsera, 2009). In the monitoring and evaluating phase, the effect of interventions (UNESCO, 2004; Modern, Joergensen & Daniel, 2010) is measured. The cornerstone of these phases of data is to enable improved provision of accessible and quality education for CWD.

Down syndrome is a well-researched and documented genetic condition with over 12 000 publications worldwide (Christianson, 1996). Multidisciplinary related topics to DS are accessible through a range of nursing, medical, psychiatric, educational, anthropological, journal articles and books. Despite the availability of information on diagnosis, risks, treatment of related illnesses and teaching resources, Statistics South Africa record that

discussions issues related to disability by important participants, have progressively tracked the absence of adequate and correct information on prevalence of the condition.

Sifting through various websites reveals figures across the world suggesting an increase of DS cases and a quick overview indicates this. In the USA, “approximately 1 in 830 babies are born with Down syndrome”.<sup>8</sup> From 1979 to 2003, “the prevalence (total number of cases of a disease in a population at a specific time) of DS at birth increased by 31.1%, from 9.0 to 11.8 per 10 000 live births in ten US regions” (Shin, Besser, Kucik, Lu, Siffel, & Correa, 2009). The National Down Syndrome Cytogenetic Register in UK, which has collected statistics on prevalence of DS births since 1989, showed general increased numbers in diagnosis with approximately 840 cases throughout the UK each year. Worldwide, it is estimated by Down Syndrome Education International (DSEI) that 220,000 babies with DS are born annually.<sup>9</sup> In UK presently, it is estimated there are 12 800 persons with DS below eighteen years of age. Longevity with DS is to live beyond 60 years which is achieved in developed countries due to their enhanced medical care, an improvement from 1970s, in which life expectancy of those with DS was only 30 years.

To attest to the growing population of DS worldwide and the incidents of mild to moderate learning difficulties, DSEI noted that it affects 1 in 400 babies born in various parts of the world, depending on maternal ages, and availability and accessibility of prenatal screening policies. In countries including Ireland and United Arab Emirates, where it is considered illegal to abort a foetus with DS, its occurrence is greater. On the contrary, France records lower incidents in DS prevalence due to early pregnancy terminations for the same diagnosis (Collins, Muggli, Riley, Palma & Halliday, 2008).

Access to Down Syndrome South Africa (DSSA) national website, indicates that the incidence of DS has steadily increased since 1979. From 9.5 between 1979 and 1983 the number has risen to 11.8 between 1999 and 2003. In South Africa, the incident statistics of

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<sup>8</sup> <http://www.who.int/genomics/public/geneticdiseases/en/index1.html>

<sup>9</sup> <http://www.dseinternational.org/en-gb/about-down-syndrome/>

persons with DS persons is proportionally higher<sup>10</sup> compared to the rest of Southern Africa. A study over a twenty year period on prevalence of DS in Cape Town between 1 January 1974 and 31 December 1993 showed 784 Down syndrome pregnancies, of which 95% were trisomy 21 (Molteno, Smart, Viljoen, Sayed & Roux, 1997). A similar sentiment is expressed by Irvin, Basu, Richmond, Burn & Wren (2008) who note that numbers of Down syndrome births are still surprisingly high.

The trends, internationally, is a signal to me that advocates for CWDS cannot retreat while there is much work still to be done.

The South African Census (2011) and other national household surveys, locate disabilities within category with general questions. In 2011, when the most recent Census was conducted, disability was referred to as impairment, and listed generic categories in the question on type(s) of disability a person may have:

- 1 = Sight, described as being blind or having severe visual limitation;
- 2 = Hearing, as deaf or profoundly hard of hearing;
- 3 = Communication, (speech impairment);
- 4 = Physical, need of wheelchair, crutches or prosthesis, limb hand usage limitations;
- 5 = Intellectual noted as experiencing severe problems with learning;
- 6 = Emotional associated with behavioural or psychological challenges.

The next question following from this is: “Does the disability seriously prevent (the person) from full participation in life activities (such as education, work, social life, etc.)”? (n. p.)

Category- ‘5 capturing ‘Intellectual’, has bearing on CWDS; however, it is too broad a category to address the variations within the types of DS. The non-specific design of the questionnaire cannot yield statistics specifically about prevalence of genetic condition such as DS as it is not designed for that purpose. The United Nations Children's Fund (2010) noted that it is a greater challenge to measure disability in children than adults because the natural

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<sup>10</sup> [http://www.rightdiagnosis.com/d/down\\_syndrome/stats-country.htm](http://www.rightdiagnosis.com/d/down_syndrome/stats-country.htm)

growth process cannot predict uniform pattern of characteristics due to its evolving nature. UNICEF (2012) estimate that such fluidity, complicates the task of estimating function specifically in differentiating significant restrictions from variations in typical developmental processes. In the absence of accurate recorded statistics, in my opinion, national planning to address specific needs of children with DS will remain substantially unachieved. I share the same concern of Modern, Joergensen and Daniels (2010) that ‘relatively positive’ legislation drafted at national and international levels are inadequate in effecting transformation to existing education systems deliver sufficient change in education systems.

In South Africa, on websites where statistics are available, the disclaimer is that it is not reliable. Unreliable data may be attributed to a variety of reasons, including that DS is incorporated in an all-encompassing category of disability. The other reason may be with the varying definitions of disability. The medical approach to issue of disability equates disability to be one and the same as impairment and cases of impairment are counted as disability which skews the result. Any survey instrument that is structured on the premise of impairment will yield reduced prevalence data than if it focussed on limitation of activity (Mont, 2007). According to Statistics South Africa, other factors which affect results include methodology of data collection; condescending attitudes towards those affected by impairments; inadequate service delivery particularly to those in rural or underdeveloped areas and places with incident of violent incidents. Statistics South Africa (2011) states that these listed factors militate against effective gathering of data, thereby affecting the overall representation.<sup>11</sup> In deliberating on the information, I have surmised that the broad categorisation of disabilities, lack of definitive records at birth and unavailability of estimated statistics specifically of persons with DS in South Africa, means that “a credible needs assessment based on a national survey of the prevalence of disability” (UNESCO, 2010, p. 203) remains unachieved.

From the information I did locate I was able to extract the following international trend: that compared to the occurrence rate of other genetic conditions, DS is considered to be quite common (Buckley, 2000) with the frequency of live births with this condition, increasing in

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<sup>11</sup> <http://www.statssa.gov.za/publications/Report-03-02-44/Report-03-02-44.pdf>

UK and many other countries (Morris & Alberman, 2009). With research showing that life expectancy for people with Down syndrome is improving with medical care and support (Fernhall, Mendonca & Baynard, 2013), it has become more important that target research be conducted to determine the social benefits (Knowles, 2013)). In addition consideration should be given to post schooling as it does have financial implications for inclusion. It is preferable to be a contributing member of society with potentially independent living against the alternative of indefinite financial dependency on social welfare.

The gaps identified in accuracy of statistics and classification affect government macro planning strategies. My concern now rests on how do parents proceed to access schooling spaces against this deficit background. The next section focuses on national and international efforts on gaining admission into inclusive settings and the outcomes.

### **2.7.1 International discourses in schooling children with Down syndrome**

In this section I argue that educational outcomes depend on schooling settings and offering CWDS the opportunity to access inclusive mainstream will precipitate meaningful participation.

Reed and Osborne (2014) articulate a parallel viewpoint to Warnock (2005) on appropriate education procedures, underscore this concern and augment the argument about which (and how) children should access schooling [curricula]. In *“Education for Individuals with Down Syndrome: An Overview”* (2000), Sue Buckley and Gillian Bird raise a concern that there are projects undertaken in various countries and contexts, yet published data on the educational findings is sparse and suggest that such data is required to build a case to present to educators and parents about the benefits of accessing curriculum through inclusive education for children with DS (p. 2). In the same overview the authors mention that historically, children with DS on diagnosis were pathologised as unfit to benefit from schooling and this medical deficit model reduced and in many cases obstructed access in the last 30 years. It is added that data before 1980 will reflect that CWDS in the UK received little or no education and were excluded from meaningful participation in community activities.

In 1971 CWDS in the UK were placed in special schools as all were categorised as being ‘educationally subnormal’ (Osborne, 2014, p. 3). DS was then referred to in medical research synonymously ‘with mongolism’ (a medically deficit interpretation). The prevalence at that time, was identified to be present in about 1 in 600 neonates of all races (Beighton, 1978, p. 19). In 1981 through advocacy and lobbying, terminology of ‘subnormal’ was replaced with ‘difficulty’ and legislation that year allowed for CWDS to learn together with their peers in mainstream inclusive spaces. An understanding of the variation amongst CWDS is taken into consideration and the thinking that CWDS are educable enables such a child to meet the goals of participation, skills acquisition and where possible, independent living. Buckley and Bird (2000) have noted the gradual progression, of children with DS in the UK through to inclusive settings. In cases where the Local Education Authorities (LEA’s) have been mostly reluctant, parent advocacy has advanced the call for inclusion.

It is worth reviewing the dominant discourses in schooling children with disability to link and explain how inclusion has come to be a “contested territory” with gains unequally sustained in different countries and contexts.

Andrews and Lupart (2000) provide a summative description of societal perceptions and systems of education that has undergone changes concomitant with the changing philosophies of the time, in Canada. Looking back at the practice of institutionalization of people with disabilities in the early 1900 which escorted the medical model based on identification and recommendation of the practitioner, showed me the harshness of policies and practices. Segregated schooling was pronounced in the 1900s through to 1950s with categorisation of high, middle and low functioning. This bears testimony of CWD taught in separate schools altogether. It was encouraging to read that the 1970s saw a gradual consent for placement of CWD into separate classes, not separate schools, in the integration plan which stressed education in the least restrictive environments. The social/human rights model of mainstreaming of the 1980s endorsed placement of CWDD in regular classes. This practice suggests that dialogic nature of policy and practice had occurred.<sup>12</sup> The present philosophy of

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<sup>12</sup> <http://bctf.ca/diversity/reports/InclusionJourney/report.pdf>

inclusion is principally promoted in many schools in many countries throughout the world. However, the idea of inclusion continues to be a ‘contested territory’ with some arguing that the “destination will never be reached” (Naylor, 2005, p. 5) primarily because of the challenge in sustaining the effort.

There is considerable research on general inclusion of CWDD. Sources consulted to gauge current perceptions and attitudes to inclusion of CWDS in specific countries reveals a range from extensive in UK to minimal in South Africa. With increasing numbers of CWDD world-wide, I was expecting to identify enrolment rates to be parallel to the occurrence. Instead, the enrolment rates of children with disabilities “variance of 1% to 3% is hard to ignore” (Jonsson and Wiman, 2000, p. 1). Internationally, “parent advocacy has been a driving force in the move towards including learners with disabilities in mainstream education in many schools in several countries” as discussed by (Klompas, 2008, p. 3).

Within this international domain, the options for schooling children with DS have been researched by several past and contemporary scholars such as Kliewer (1998), Buckley, Bird, Sacks and Archer, (2006), Buckley, (2006, 2007), Turner, Alborz and Gayl, (2008) and Gobel (2010).

Kliewer (1998) conducted a 2-year study in UK that followed ten CWDS (ages 3-10) across 13 classrooms and accounts of high-school aged students with DS, in order to provide a detailed picture of schooling, DS, and disability. His findings discuss how establishing valued community connections lead CWDS towards citizenship and recommend that segregated schooling be abolished. The extensive work done by Buckley, Bird, Sacks, and Archer, (2006) in England covers a range of issues relevant to DS including inclusive education. Turner, Alborz and Gayle (2008) assert that the sustained effort in research and advocacy that has resulted in educational policies undergoing substantial revision and subsequent changes to address the fate of learners with intellectual impairments. As Sue Buckley (2002 c) suggested earlier, it is the evidence that is needed to show skeptical parents and authorities that CWDS and non-disabled children benefit from the inclusion. This view is supported from research in another context in Australia. An investigation by Gilmore, Campbell and Cuskelly (2003)

looked at how educators and parents felt about the inclusion of CWDS into mainstream classroom settings. Katz and Mirenda (2002) conducting similar research focus, found that non-disabled learners were unaffected adversely through the inclusion of learners with special needs (LWSN). In reviewing literature of the same phenomenon of inclusion of learners with disabilities with non-disabled, Sparling (2002) observed that there was greater acceptance of CWDS by their peers in earlier or primary phases of schooling than in secondary phase of schooling. If there was partial acceptance then it was due to the specificity type of disability. Other factors include limited or not knowing about disabilities, the gravity of peer influence, overall culture and attitude of concerned stakeholders.

Prior to this inclusion movement individuals with DS were regarded as uneducable and were either kept “at home or placed in training centres, which offered day care and relief for parents, instead of education for their children” (Buckley et al, 2000, p. 60). Riddel (2009) comments on the extensive research with DS children in the UK by Sue Buckley, where “reducing social exclusion and promoting inclusion have been major preoccupation” (p. 287). In one study in the UK conducted by Buckley, Bird, Sack and Archer (2006), a comparison of the consequences of special and mainstream systems of schooling. This was conducted with learners with DS formatted into two groups. The sample was similar in terms of circumstances and capability was done. The focus was on key aspect of communication, language facility, ability to read, social participation skills, ability to live independently and general behaviour characteristics. The results of the study show improvement for CWDS, in most aspects, except communication. This outcome was in contrast to a study of special needs education captured over a prolonged 13 year period in the UK (between 1986 and 1999) in which no improvements in school achievements was recorded. The results of a repeat survey confirmed their hypothesis that the children with DS were underperforming and generally isolated from social activities due to segregated schooling which describes special education.

In another study, Buckley, Bird, Sacks and Archer, (2006) in UK found improvements in skills of literacy and expressive language in eighteen teenagers diagnosed with DS schooled in mainstream classrooms in comparison to twenty-eight schooled in segregated special schools. Their findings suggest that learners are not provided optimum learning opportunities within a

special school context. They propose that learning alongside their non-disabled peers is important to enable optimal progress. The reasons cited are as follows: Firstly, CWDS who are included would be more likely to have friends in the neighbourhood and improved socialisation. Secondly, their educational accomplishments would be more likely to increase, in comparison to CWDS schooled in separated systems.

Turner, Alborz, and Gayl, (2008) in their research aimed to identify indicators of educational accomplishments through an illustrative group of CWDS in UK, found that mainstream education benefitted the sample, albeit modestly. Non-disabled were positively affected from the inclusive programming as they demonstrated development in social awareness, self-esteem, improved their empathy and recognition of diversity. Parents of the non-disabled confirmed the findings of improved results due to the inclusive context of learning: that of severe disabilities within the regular education classroom (Kochhar, West, & Taymans, 2000). Working in the context of USA, Smith, Polloway, Patton and Dowdy (2004) offer implementable strategies to reach learners who have specific needs, and to work effectively in an inclusive environment without denying the other learners their reward. Buckley and Bird explain that understanding the levels of cognitive or social development CWDS may attain can when allowed full participation through inclusion into the geographical spaces where their lives are lived, with access to optimal services in education, health and support. While progress in school accomplishments is associated mainly with cognitive development, mainstream schooling had some influence during and post- school years. The steady increase over the last decade of CWDS in mainstream schools is due to enforced legislation and children who enter at age five or six, remaining in that schooling space for more years. There is variation among Local Education Authorities in the implementation of inclusion policies.

The statistics provided by The Audit Commission in UK, stipulate that “87 per cent of learners permanently excluded from primary schools and 60 per cent from secondary schools, have special physical and educational needs” (Russel, 2003, p. 220). Research in subsequent years has refuted some of the long-held views of earlier years. The present scenario in the UK illustrates once again continuous research yields positive results for CWDS.

One of the most insightful articles I engaged with was that of Gobel (2010) who looked at the variance of academic accomplishments when a CWDS participant in a regular, mainstream context compared to separated, special needs classroom. Gobel's focus is directed to three aspects: daily living, socialization, and communication. He concludes that it was more beneficial for CWDS in the long term to engage and participate with non-disabled peers whose progress is regular, as they too are inclined to advance further and positively compared to those who were enrolled in a special education school. Learners who were in an inclusive setting had better communication skills and general approval from their parents.

Whilst there are great strides made in research to bring the discussion to the level of policy changes, attitudes of implementers of policy and relevant stakeholders can present obstruction and thwart progress made in the domain of schooling spaces. Naylor (2002, 2005), Rieser (2006), Dhillon (2008) and Allan (2008) share their reservations and identify the potential systemic and attitudinal obstructions to full and meaningful participation in inclusive settings for CWDS.

Commitment of staff meeting learners' special needs takes precedence to curriculum matters in successful inclusive mainstream placements in the UK (Cuckle, 1999). This view has been corroborated through ongoing research on related topics. Rieser (2006) argues that inclusion has more to do with attitudes and commitment of educators. Where it is planned and resourced with whole staff capacitated, "inclusion would have greater opportunity to succeed" (p. 163). Nind and Seale (2010) add their voices to the argument in stressing that meaningful participation which inclusion should be, is affected by "the ethos, community of the school, teaching approaches, attitudes of the staff and relationship between staff and learners" (p. 106). Similar results on the attitudes of teachers to inclusion is documented by Shade and Stewart (2001), Killoran, Woronko and Zaretsky (2014), Gordon (2002) and Varcoe and Boyle (2014) amongst others. Their views reiterate the results of many other researchers that the attitude of educators is central to successful implementation of inclusion. To this end Naylor (2002) compiled a report on positive attitudes among all learners towards learners with exceptionalities. He also recorded affirmative educational advantages for learners with different requirements, although in fewer topics. With educator willingness to support the

philosophy of inclusion coming through in additional research (Pudlas, 2003; Martinez, 2004) it is unfortunate that the positivity is not matched with preparation and training educators for inclusive schooling spaces. There are texts offering guidelines on inclusion to educators. However, there is inadequate or negligible backing to fulfill that responsibility (Naylor, 2005). In a research paper on exclusion in some public schools in Canada, Dhillon (2008) presented his view considering ideologies and practices that affect the successful inclusion of CWSN in the education system and in summary stated CWDD are excluded from having meaningful participation with their non-disabled peers. Allan (2008) researching the Netherlands context noted that there are fewer opportunities for CWDD to exercise their children's rights as they have greater control exerted over them as they are considered 'less able to achieve academically, underachieve and socially excluded' (p. 40).

### **2.7.2 South African discourses in schooling children with Down syndrome**

Each of these international studies nudged me to examine discourses closer to home, the South African context. By its own admission, the South African Department of Education (2007, p. 3) acknowledges the shortcomings of special schools to offer quality education for its learners stating, "there are few special schools that offer appropriate, quality education and many learners never progress beyond Grade one". Swart, Engelbrecht, Eloff and Pettipher, (2002) alert me to the fact that during the 1990s there existed limited research on inclusion in South Africa (p. 178). Although I am concerned, I am not alarmed to read that there have been few studies in South Africa on the issue of attitudes of teachers to inclusion, and much less on inclusion itself (Engelbrecht, Oswald and Forlin, 2006, p. 178) than in the UK, USA, Canada and Australia explored earlier. Researchers who have considered these attitudes of teachers to inclusion, in the South African context (rural and urban) include Swart, Engelbrecht, Eloff, and Pettipher (2002); Engelbrecht, Swart, Oswald, and Eloff (2005); Jabulani and Muthukrishna (2011); Ntombela (2011); Christie (2014) and Donohue and Bornman (2014).

Engelbrecht, Eloff and Pettipher (2002) considerations of teachers' viewpoints and attitudes to inclusivity necessitates certain crucial modifications to the undertaking and fulfillment of significant resolutions to transformation from segregated (mainstream and special needs) to a

unitary system (inclusion) in South African education. They identified three main themes that affect inclusion in the South African context: insufficient capacity of knowledge, training and skills to execute educational inclusivity; absence of appropriate and ongoing educational and teacher support; inadequate amenities and teaching and learning material.

In a later study Engelbrecht, Swart, Oswald, and Eloff (2005), in reporting on the experiences of parents of placing their CWD in ordinary schools within Gauteng and Western Cape provinces of South Africa, explain that parents recognise the attitudes of schools towards inclusion of CWDD (with CWDS implicitly included in this category) as an important factor in creating successful inclusive experiences of schooling. These studies have established that parents recognised the scholastic, social and emotional advantages of the inclusive education context for both learners with and without disabilities. Almost in contradiction of this finding, the majority of parents felt that special education classes would serve their needs better. Generally, the group that supported inclusive practices had fewer negative assumptions about DS (Gilmore, Campbell & Cuskelly, 2003).

A paper that made me think more about rural contexts of Kwa-Zulu Natal was authored by Jabulani and Muthukrishna (2011). The paper explored a school-based initiative in a semi-rural township that has included learners with disabilities. The findings indicated that although learners with and without disabilities were together in the classroom, educators' understandings of inclusion operated from a deficit model. In pathologising the lived experiences of the disabled learners with disabilities, educators were attempting to change the learners to fit into mainstream and were referred to in terms of difference. Their comments included the condition of oppression that prevailed with disabled children subjected to prejudice, stigmatization and labelling. In homogenising the disabled learners, their individuality was repudiated. One of the critical areas of attention was teacher professional development.

On another aspect related to inclusion, Donohue and Bornman (2014) identified that in South Africa, "up to 70% of children of school-going age with disabilities are out of school. Of those who do attend, most are still in separate, special schools for learners with disabilities" (p. 1). This statistic is incongruous to expectations outlined in Education White Paper 6,

which has raised just concern from researchers because the urgency for implementation was initiated twelve years ago when the paper was crafted and put in place (Department of Education, 2001). The recommendation is that “the more children with disabilities are included in education and elsewhere in their communities, the sooner they can become productive and contributing members of society” (p. 12).

Data collected from research at three primary schools in in Kwa-Zulu Natal by Ntombela (2011) presented findings from considering two districts, that educators had minimal understanding and experience of inclusion expectations in South Africa. She asserts that one of the contributing factors to this limitation is insufficient and ineffective skills improvement plan in disseminating information within education structures of the Department.

All of these studies cited adopted a general over-arching approach to inclusion research whether it is urban or rural in context with no specific medical diagnosis focus. Western Cape and Kwa-Zulu Natal with a combined total of thirty-one percent of the total population are two provinces out of nine represented in the research and in papers. This is a third of an estimated population of fifty-four million. This information released as recent as 31 July 2014 by Statistics South Africa<sup>13</sup> indicates that inclusion is under-researched. It reflects that study on attitudes towards inclusion of specific groupings of CWDS is even less researched, especially in South Africa. I wanted to know more about the background to segregated education systems and Lomofsky and Lazarus (2001) provided me with useful insights. Ethnicity determined the separate facilities and the possibility existed that the proportion of Black learners was double compared to White schools. The entrenched discrepancies ensured ‘White’ learners received mandatory education. It was optional for ‘Non-White’ racial groups (Asmal & James, 2001).

Historically, the existence of regular and special schools (within segregated education) attest to the prevalent discriminatory practices entrenched in the period prior to democracy in 1994. This exclusionary system was perpetuated for decades and resulted in obstruction of access to mainstream education for many learners (Naicker. 2006). Special schools for special needs practices reflected the operationalised medical deficit interpretation. Learners with disabilities

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<sup>13</sup> <http://beta2.statssa.gov.za/publications/P0302/P03022014.pdf>

were routed to special schools which, compared to mainstream, “were under-resourced and for the most part were recognised to have provided sub-standard education that both reflected and entrenched the marginalised status of their learners” (Du Plessis, 2013, p. 204). Special schools were further segregated according to race, with Whites receiving the largest portion of budget allocation and amongst the non-white comprising Black, Coloured and Indian. The Black children, received the smallest portion of the budget allocated for education (Department of Education, 2001), and support was uncommon for CWD who attended schools accommodating their own race. Separate education departments and disproportionate allocation split along racial demarcations, reinforced partitions in the education system (Engelbrecht, Howell & Basset, 2002). Post 1994, when the National government made significant increases on allocation towards Black learners, “the amount spent per pupil in White schools was more than two and a half times that spent on behalf of Black students in the urban townships” (Fiske & Ladd, 2006, p. 95) This consternation is underlined by DuPlessis (2013) stating that Black learners admitted to special schools were exposed to double discrimination, first on account of their disability and secondly on account of their race (Du Plessis, 2013) Another consequence of the segregated systems of education for different race groups meant that many teachers as products of unequal systems of educations have not received adequate training in all aspects of teaching CWDD. This implies that many of the teachers in the current system of education who are products of disparate training systems are without the necessary skills to teach CWDS (Donohue & Bornman, 2014).

The existence of dual system of regular and special needs created a dichotomy and the ‘common referent’ (Graham & Slee, 2008, p. 281) or norm to which special needs is contrasted, is the regular mainstream school. Mainstream schools, prior to admission, show preference for learners perceived to be fitting the norm by scrutinizing application forms. Evidence of deviancy of those not meeting the expectations meant rejection or diversion, to special needs schools. Tisdall and Riddel (2006) refer to classifications and suitability prerequisites which could have inclusionary or exclusionary intentions for children (and parents).

The deficit interpretation which viewed the disability as residing in the individual translated into attempts to ‘cure’ or ‘treat’ the ‘condition’ with the expectation that the individual

limitations could be ‘cured’ or ‘restored’ to a level comparable to developmental norms (Hodkinson & Vickerman, 2009). With the ideal person viewed through the lens of ‘ableism’ (a devaluative attitude of disability) where those who deviated from the view of being capable, were classified as disabled and assigned the ‘lesser’ status, with lowered expectation to accomplish tasks (Terzi, 2004). It was perceived that a cure for this diminished state was possible and if not repairable then the increased negative perception relegated the individual to social categories of deviancy and silenced (Campbell, 2008). Such conviction resulted in the special education ensconcing the discourse of ‘deficiency’ and in that way excluding children who were not able to fit into the ‘norm’ (Soudien & Baxen, 2006). Research on inclusive education by Meltz, Herman and Pillay (2014) showed that disability is seen as “enforced on disabled people in addition to their impairment by a repressive and discriminating social structure” (p. 2).

According to Solorzano and Yosso (2001) the increasing challenge is that diversity among learners is not valued due to attitudes related to power, privilege and status. Learners who are categorised economically disadvantaged, English Second Language, as well as the marginalised and vulnerable, may be at greater risk of exclusion. These labels and the stereotypical perspective associated with them, contribute to the expansion of the deficit model. This perspective attaches CWDD with negative descriptors such as anti-intellectual implying he or she cannot or is unable to achieve. In recent years these deficit theories have been criticised for attributing liability to the individual, perpetuating stereotypes, and disregarding institutional causes for learner not thriving but underachieving. However, such negativity is pervasive especially related to the education of CWDD. Du Plessis (2013) noted that “there are various reasons for the exclusion of children with disabilities from mainstream education. In most instances, exclusion from education is but one facet of the broader social exclusion of people with disabilities” (p. 203). She goes on to elaborate that there are some areas that are under-resourced and lacking basic service infrastructure to access piped water, electricity and indoor toilet facilities. With the social model locating disability as a social phenomenon in society the inference I draw is that CWD are sometimes more severely affected by personal restrictions resulting from impairments as well as environmental and social factors which complicates the chances of access to schooling spaces.

South Africa has had a past perforated with injustice, inequality and inaccessibility with regard to children's access to best practices in education. Post-apartheid 1994 saw the ushering in of a new era and a deftly designed dispensation to redress the imbalances of the past. The Bill of Rights, which is embedded within The Constitution of South Africa, is commended worldwide. It underscores the rights of its citizens, one of which is basic education. The rules of equitable access and opportunities are protected by legislation, such as the South African Schools Act 84 of 1996 and the Constitution (1996). The Bill of Rights, considered a the foundation of equal opportunity and fairness is preserved in the Bill of Right in The Constitution of South Africa which is constructed with an acute awareness of the injustices of the past. The overhauling of the legislative framework created widespread policy development and subsequent legislation in social, economic, political and educational domains. The concluding paper informing the education policy, "*Education White Paper 6: Special Needs Education, Building an inclusive education and training system*", was released in 2001. Inclusive Education, as outlined in the Education White Paper 6 (EWP6) is designed on the premise of establishing a society that is caring, humane and democratic. The emphasis is also to restore the human rights of all marginalised and vulnerable groups and entrench the rights of all South Africans to access basic education (RSA, 1996)

As I contemplated what forced this shift from an oppressive and dominating stance to one of social justice in a post-democracy, I thought of one of our revered heroes, Nelson Rolihlahla Mandela, whom we called *Tata*<sup>14</sup>. One of his beliefs, which fit so aptly into this study, is "there can be no keener revelation of a society's soul than the way in which it treats its children". With our new democracy under his sturdy leadership the pride of its first time voters increased, and collectively, expectations of free and accessible schooling for all children were lifted. This potential route of meaningful participation and developing necessary societal and educational changes, (Loebenstein, 2005) signalled a new era. Increased mobilisation and political engagement of disabled people's activities worldwide injected a shift in sociopolitical philosophy from the medical deficit or individual approach to

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<sup>14</sup> *Tata* is a isiXhosa word which means "father" and is a term of endearment that many South Africans use when speaking of the late, Mr Mandela.

the social approach based on principles of social justice. These changes to education for CWDD in South Africa are said to be underpinned by the international and domestic shift. Various policies and legislation were put in place to provide the course on how to re-configure the unequal education system towards an inclusive, humane, egalitarian one. Branson and Zuze (2012) indicate that access to quality education, which includes higher education, can assist in replacing the pattern of inequity of South Africa (Branson & Zuze, 2012).

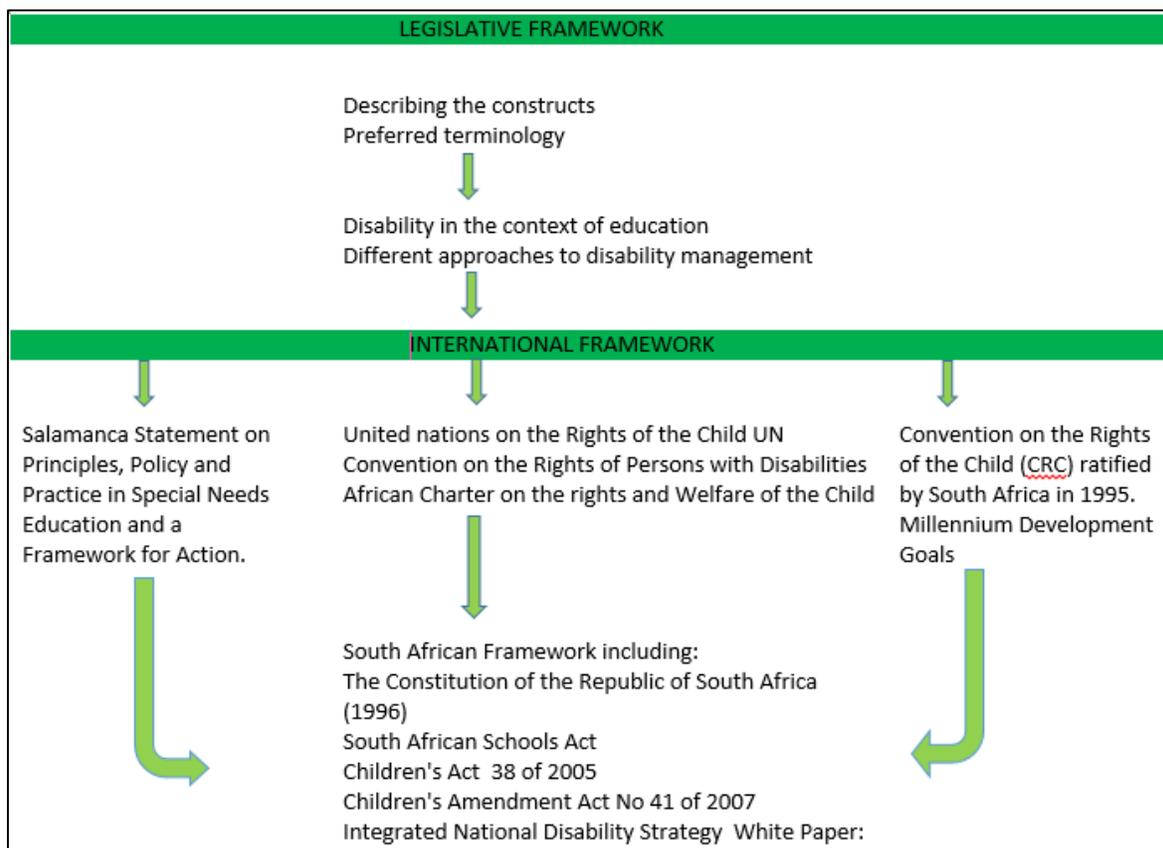
*“South Africa’s Children – A Review of Equity and Child Rights”* ( March 2011), a review “undertaken by the South African Human Rights Commission and UNICEF South Africa” offers the following insights: South Africa is cited as “one of the most unequal countries in the world”. The concluding remarks made in the review are an appeal for hastening the plan of reducing imbalances to meet the realization of children’s right. As a moral command, it is regarded as a crucial reflection of progress for a developing country. Noting that 30 000 children are absent from a classroom, within South African population of nearly 5 million children, must prompt focused consideration from policy makers, to prioritise their rights in government planning of events, spending and checking systems. Policy makers need to apply greater urgency in the move to attend to imbalances of the past and the present challenges faced by children who are poor. Inclusion then comes to be considered within an agenda of justice and fairness embodied in human rights. Seclusion and exclusion is then viewed as “morally wrong” (p. 193)

The new democratic government of 1994 committed itself to the transformation of education. One of the tenets of Education White Paper 6 was intended to address the gaps of inequity and inaccessibility in schooling. The policy envisaged a three-tier system of educational support services which meant that all learners could be accommodated, irrespective of the developmental delay and according to the level of support required.

Learners who require lower levels of support will get that at mainstream or regular schools; those needing moderate support can be accommodated at what are termed “full service schools” and those “who require high levels of support” will be enrolled in “special schools” (Du Plessis, 2013, p. 204)

Availability and accessibility of schools (mainstream or special needs) to serve the needs of communities in urban and rural contexts is inconsistent or varied in districts and provinces. South African researcher and advocate for social justice, Nithi Muthukrishna has conducted sustained research in rural and urban contexts. Her individual and collaborative research projects have generated persuasive reasons for inclusive education to be enclosed in a “human rights discourse” conveyed in” Education White Paper 6: Special Education — Building an Inclusive Education and Training System” (Department of Education, 2001). In South Africa, as with most parts of the world, research pertaining to access to education covers a broad spectrum of disabilities including autism, cerebral palsy, epilepsy, deafness and learning (Ngcobo & Muthukrishna, 2011, p. 359).

## 2.8 Reviewing the legislative framework



**Figure 3: Created representation of the legislative framework aligning national with international policies.**

As outlined (Figure 3), in 2006, all countries were called upon by “United Nations Convention on the Rights of Persons with Disabilities” (UNCRPD) to immediately effect and monitor the implementation of policies and legislation pertaining to education (Watkins, Ebersold & Lénárt, 2014). At an international level the expectation and pressure to map out such developments are very clear and justified within a human rights legislative framework. Countries who are signatories to the “Salamanca Statement of Principles, Policy and Practice in Special Needs Education and the framework of action”, are also expected to fulfill the promise to provide equal opportunity to access schooling for children with disabilities and non-disabled children.

Salamanca World Conference on Special Needs Education endorsed the idea of inclusive education (UNESCO, 1994). The “Salamanca Statement of Principles, Policy and Practice in Special Needs Education and the framework of action” fundamentally presented and underlined the intention of promoting an inclusive society (Lindsay, 2003; Ainscow, 2005). The shift was not merely a linguistic one but possessed a vision for the global context addressing diversity, access and opportunity for all learners. The key principles contained within policy documents created by UNESCO (1994) offered an expectation and challenge to the signatories, through statements: “challenge all exclusionary policies and practices in education”; “the right of all children to a common education in their locality regardless of their background, attainment or disability”; and, “good-quality education for learners and a community-based education for all”. Explicitly, this human rights approach was a departure from ‘integration’ “embedded in the western European history of segregation of disabled people” (Vislie, 2003, p. 18) which did not meaningfully address the ideal of equal opportunity, post 1980, as the right of disabled persons to an appropriate education gained momentum. The term ‘inclusion’, encompassing a broader vision, became a global descriptor used initially by its representative of 92 governments and 25 international organizations and gradually adopted and embraced by the wider international context as it was orientated and familiarized with core practice of inclusion. ‘Support for inclusion is perhaps the strongest ever but tensions arise from different understandings of the inclusion process and from different value systems’ (Shaw, 2001, p. 2). Although many countries currently have policy

imperatives pertaining to inclusive education, in reality the vision of inclusive education has yet to be achieved in most countries.

There is ample legislation in place with researched support in the UK (Clay, 2014; Lindsay, 2007; Slee & Allan, 2001), Australia (Forbes, 2007; Whitburn, 2014), Canada (Gordon, 2010; Loreman, 2014) Netherlands (Graaf, 2002), and US (Holsinger & Jacob, 2009; Graves, 2012), that optimization of development of CWDS and improving speech and language skills is ensured by being placed within mainstream settings. The construct of wanted policy results being attached to authorised judicial trends, have contributed to design of support and services delivered to individuals with intellectual disabilities, is evidenced in some first world countries.

Research conducted by Porter (2004), Gordon (2010), Holsinger and Jacob (2009) and Graves (2012) indicate that inclusive education is beneficial for children with DS confirming that the benefits outweigh the challenges. Canada has catalogued “more than two decades of inclusive education practice” (Gordon, 2010, p. 1) which overturned previous research done by Porter (2004) who noted that no Canadian province practiced full inclusion and an estimated 40% of learners with intellectual challenges were schooled in special needs classes or separated schools. During the same period the British Columbia regulation had no directive for full integration (Lupart & Pierce, 2003), but placed the responsibility for decision making an access and placement on School Boards. The practice was placement of learners in combined inclusive settings except when the specialised needs requirement was of such a nature that it warranted a different arrangement (Naylor, 2005)

In the United States, programs of an inclusive bias have increased exponentially (Holsinger & Jacob, 2009), where inclusion programmes are implemented in all states, at all grade levels, involving students across the entire range of disabilities. Graves (2012) explains that Public Law 94-142 was passed in 1975, ensuring the rights of children with disabilities to a “free, appropriate, public education in the least restrictive environment” (LRE). This LRE facet is explicitly stated in law that “children with disabilities must be educated with their non-disabled peers to the maximum extent possible with necessary supports provided”. Similarly,

Australian policy designers are very supportive of inclusive practice, whilst aware that there are teachers who have reservations about teaching learners with a disability within their regular, mainstream classes. The Australian government endorses the choice of mainstreaming CWD legislatively, as it too wished to adhere to international agreements of the same (Forbes, 2007).

Other studies in countries like India reflect the struggle to making inclusive education pervasive. Giffard-Lindsay, 2007 and Ainscow, 2005 found in their research in India that whilst there are issues and constraints, the reconceptualisation of inclusive education as an issue of quality is needed to benefit all children. In India disabilities are often forgotten, emphasising their invisible status. In some countries definition of disability has excluded CWDS from accessing formal education (Kliwer, 1998). Nonetheless, “their educational exclusion and right to education are now receiving more policy attention”, states (Bines and Lei, 2011, p. 420). Ashima’s (2010) study results show support for inclusive education through adaptation, with physical support structure to enhance the mobility and accessibility for children with differing physical needs by installing elevators and ensuring accessibility to the toilets. Access, in this context, is possible for children with physical challenges. Ashima (2010) surmises that “apart from these provisions and the help the children sought from their non-disabled peers, there were no good practices reported” (p. 212).

Research shows that CWD amongst many other groups of children remain outside of enrolment to elementary schooling in developing countries (Giffard-Lindsay, 2007). Ajodhia-Andrew (2007), examined inclusive education with children with special needs in Guyana and identified four factors which were possible obstacles to executing inclusive education: “attitudes/perceptions towards those with special needs”, “change agents”, “resources” and “experiences with children with special needs”(p. 53). Although legislation may be in place in many countries, its implementation and monitoring of its status is neglected as shown by the body of current research.

I now enter the foray of access and allow Thomas and Loxley's (2007, p. 1) argument that thinking about inclusion and inclusive education which has extended into new terrains, sometimes so overused as to lose meaning, to lead the course of the discussion.

## **2.9 Access: its place and spatial consideration together with legislative framework**

I have used the term 'access' in conversation and in general writing, and brought it into my study to navigate my own understanding of access, which I associated with an enabling process or to be allowed to enter, participate, to be part of, included. In my journey of accessing schooling spaces for my CWDS or striving to do that, I encountered other terms associated with access: 'equal' and 'equitable opportunities' to 'take full advantage' and its applicability to my study broadened the spectrum. Undertaking the PhD prompted me to engage deeper and further. In coupling access with schooling and inclusion, the notion of elimination of barriers was implicitly suggested.

Devas (2003) helped me to place access and inclusion as concepts in relation to each other by explaining that inclusion is what happens when society is accessible. Using the social model of disability and the way it has positioned society as disabling, Devas argues that "although it is the individual who make choices, it is down to society to create access" (p. 234). It's necessary to understand the import of access to unlock its position as an enabling or obstructive human construct particularly in its juxtaposition with schooling.

I will now arch my discussion of schooling spaces with the concept of access as extrapolated from Nind and Seale (2009) multidimensional model of access. Nind and Seale explain that the issue of access is frequently recognised as being "at the forefront of the practical challenges facing people with learning disabilities and the people working with or supporting them" (p. 273). Despite the seriousness of the practical challenge of accessing inclusive education, especially for CWDS, it receives little consideration with researchers. In lacking thorough research and theoretical attention, it is relegated to casual discussion between affected persons and people working with or supporting them. Nind and Seale (2009, p. 273) endorse these sentiments in stating that access has been much less picked over by academics

than inclusion or participation. Like inclusion, access has become part of the fabric of our discourse about education and community, pervasive and often unquestioned. The word 'access' has not been on this scope of journey and it has acquired less baggage along its way. The concept of access, pertinent to schooling for children with DS has being relatively under-researched under the umbrella of learning disability therefore it warrants further and deeper insights: not exclusively 'what it is' but includes 'how it is experienced'

Access is interpreted differently depending on subject and perspective: medical (Martin, Roy & Wells, 1997); environmental resources (Ribot & Peluso, 2003); sports (Devas, 2003); curriculum (Peter, 1992); leisure (Thompson & Emira, 2011) and education (Buckley & Bird, 2006; Lalvani, 2012; Nind & Seale, 2010). Nind and Seale contend that access touches upon all aspects of human and social networks including physical access, knowledge, power, relationships, advocacy and participation. This study focuses predominantly on schooling spaces and the impact access has for my CWDS and is considered in conjunction with Nind and Seale multidimensional model.

Research was conducted by Martin, Roy and Wells (1997) in an effort to establish experiences of health-care services for people with intellectual impairments and carers, with a follow up after a year showed that there were improvements in health through screening but the challenge was with transport to get to the service provider.

Ribot and Peluso (2003) consider access in the context of US, to be comparable to 'a bundle of powers' than to its association with 'bundle of rights' as used in property. The distinction is that the former can be applied to a broad spectrum of social relationships which contribute or restrict benefits from resources, which they argue is not the case with property relations. They submit that power arises from or courses through the 'intended and unintended consequences', an expression, which I found very useful in the context of schooling as it also has intended and unintended practices effected through various strata of government, policies, implementers, designers, management personnel, with potential to affect social relationships They define access as the facility to gain advantage from resources "including material objects, persons, institutions, and symbols" (p. 3) which have bearing on learners and parents

as ‘consumers’.

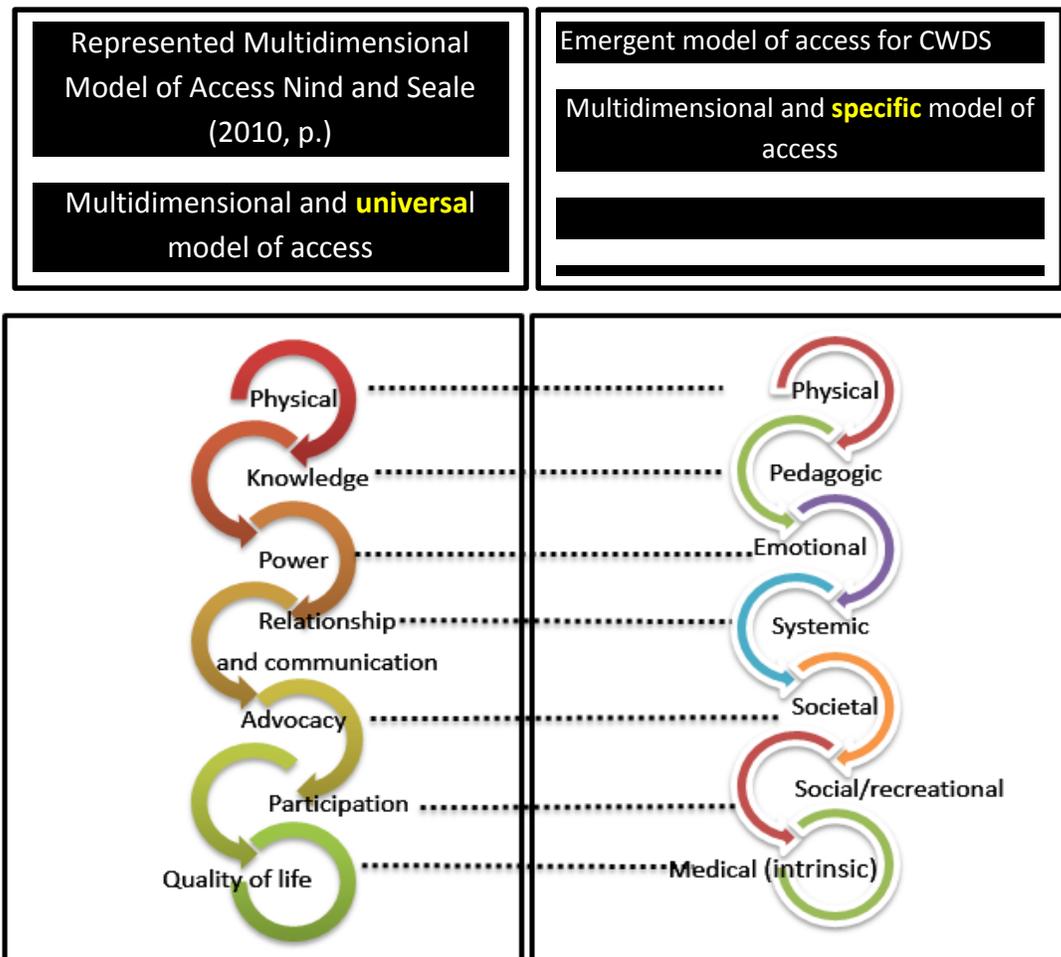
Devas (2003), offers a detailed description of support for people with learning impairments. The suggestions include individualised programmes to specific facilities depending on specific needs and abilities. The emphasis is to make available broad access by paid personnel and general administration staff and understanding by support staff on skills they need to have to accommodate any adjustments that people with learning impairment may require.

My personal experience of limited access to leisure activities for my CWDS found connection with Thompson and Emira’s (2011) study in the UK with focus on parental and caregivers’ experiences and perceptions in securing opportunities for children with Autistic spectrum disorder (ASD) to access and participate in leisure activities. He recommends further research into inclusive practices to consider aspects of leisure activities to encourage parental engagement. A telling statement of the attitudes of people in authority to CWDD is captured in this quotation I came across on the internet. It reads: “They say every child matters, but they do not” is an indictment on adults, if the needs of all CWD are not treated with equal care as their counterparts.

Nind and Seale (2010) endorse the view of Ribot and Peluso (2003) who explain that access is often discussed in terms of “getting to somewhere”, “being part of something” and, crucially, being able “to derive benefit from things”. This takes the concept beyond the simplistic notion of merely getting through the door to somewhere or something, and into the realm of what happens thereafter. Access, like inclusion, is more than about place. It is more ambitious than the integration notion of being allowed in (as long as one fits and behaves). It carries the notion of rightful and active participation. May (2004) problematised the notion of participation by suggesting that the term is used in different ways implying different levels of participation from simply taking part (superficial, being here) through to involvement (integral, active). Participation is defined by Treseder (1997) as a process “where someone influences decisions about their lives and this leads to change” (p. 4) In synthesising insights of participation from various sources, the key elements I extracted are: reciprocity, views are heard and valued, consultative decision making, support, positive contribution to school and local community. To me these phrases and expressions collectively imply inclusion and

agency: more than hearing and listening but willfully seeking to convert gestures and exercises into tangible processes. In my discussion, participation will be subsumed as part of access. Nind and Seale (2010) do not focus their theorising on specific developmental delays or diagnosis but offer a universal model.

On reading of “advocacy”, “physical”, “knowledge”, “participation”, “power”, “relationship and communication”, and “quality of life”, as factors to unlocking meaning of access, I saw its value to my study as it started to form part of the theoretical understanding. For the purpose of this PhD study, an emergent model focusing specifically on access to schooling spaces for CWDS, is adapted from information available from Nind and Seale (2010).



**Figure 4: Representation of Nind and Seale’s, multidimensional UNIVERSAL model of access alongside emergent multidimensional SPECIFIC model of access.**

Nind and Seale (2010) multidimensional and universal model of access speaks to all categories.

The UN Convention on the Rights of the Child (UNCRC) formally acknowledged in international law that children are the subjects of rights, not merely beneficiaries of adult defense (Lansdown, 2001). Article 12 of the Convention acknowledges that learners who are able to articulate their points of view should be provided platform in which to do so. As consumers of services, more than goods (Sinclair, 2004) learners have a right to indicate their predilections and influence the type and value of what is issued to them. This indicates that the quality of service provided does not fully address learners' needs. In an expression of commitment to increase children's participation, the UNCRC Article 12 acknowledges children's participation and views, 'where possible' to be considered in conjunction with age and understanding. The qualifying statement 'where possible' is subject to age, maturity and level of understanding, which are factors for "conditional participation". Tisdall, Gadda & Butler (2014) in being mindful of children and young people's involvement and its transformative possibility noted that "it's not up to the child to prove his capacity, it should be presumed he has". Why this is important is that professionals may decide for children. May (2004, p. 70) is of the view that this is "crucial to issues of access [because] if participation is conditional, the access to community will also be conditional". This extends into addressing context of children with profound intellectual impairment where adults are consulted to interpret on the child's behalf as a proxy. Access and inclusion are not just concepts for academics, politicians and practitioners. These concepts are understood by parents of CWDS and young people through phrases 'nothing without us' and 'count us in' in slogan or phrases in mission statements of many DSA nationally and internationally.

### **2.10 Autoethnography: offering a voice**

As I deliberated more on these phrases, I searched for scholarly work incorporating children and young people with DS that could reinforce the ideas of inclusion explicit in 'nothing without us' and 'count us in'. There is growing body of research referred to as inclusive research, where the voices of the disabled are considered central to the research. That is

important in the human rights/ social justice model and is acknowledged. However, with the focus of this study being my experiences intersected with parents and their experiences I dabbled into the general scholarly work related to autoethnography. Although some reading did not relate to access, schooling or DS, but most helpful in understanding autoethnography (Keefer, 2010; Starr, 2010; Ellis & Bochner, 2000; Wall, 2006; Chang, 2008; Butler, 2009)

It is Ellis and Bochner (2000), who explain three central aspects of autoethnography: the “research process - ‘graphy’, culture - ‘ethnos’ and the self - ‘auto’” and Reed-Danahay (1997) who indicates that writers of autoethnography may vary their emphasis on these aspects. This method of inquiry, as Ellis and Bochner (2000) continue to explicate, is “usually written in first-person voice, and autoethnographic texts appear in many forms – short stories, poetry, fiction, novels, photographic essays, personal essays, journals” (p. 739).

Autoethnography is becoming the research method of choice for those extending what constitutes the qualitative borders through concentrating on a singular focus “in the life of the researcher, as the central aspect of study” (Keefer, 2010, p. 207) emphasising the personal and intimate (Butler, 2009) and chronicling self as a way to understand self and others (Chang, 2008). To understand the intricacies of this further, Starr (2010) helped me with comparative characteristics when she outlined with its qualitative method bias, autoethnography is embedded “where the individual’s study of one’s self within a culture replaces the researcher-as-observer stance present in more traditional ethnographic forms” (p. 4). I was persuaded that this method would allow me to incorporate my views, thoughts, and story as a valid part of the study (Denzin, 1989; Reed-Danahay, 1997). My intention in this study resonates with Sarah Wall (2006) that, “the intent of autoethnography is to acknowledge the inextricable link between the personal and the cultural and to make room for the nontraditional forms of inquiry and expression” (p. 146)

My initial hesitation was to express personal stories, feelings and emotions knowing that I am potentially exposing myself up to criticism with the reflexivity, inward made outward, the private made public. Reassurance to persevere came from Ellis and Bochner (2000) who express that “vulnerability can be scary, but it also can be the source of growth and understanding” (p. 752).

I am aware that this in itself may be limiting yet also believe that as the individual undergoing the experiences with Tiara, I am in a favourable position to describe my personal encounters and experiences more intimately and accurately than anyone else. In a comment about the value of inner knowing Duncan (2004, p. 4) affirms the subjective view presented in autoethnographic research. This sentiment is supported by Kleinknecht (2007) who states that “the auto-ethnographer’s intimate knowledge of the cultural and social setting in which he/she is situated can help the audience to ‘understand human group life through the lens of one individual’s experience’” (p. 243). It offers me an opportunity to present detailed or “thick description” of life experiences within the context of accessing schooling spaces for my child with DS and liberate the experience which was until now, cloistered (McNeil & Chapman, 2005). ‘Thick description’ as described by Ponterotto (2006) is presented in this study. I will strive to capture the emotions, thoughts, senses, context and motivations that will lend believability to its occurrence as the reader is able to cognitively and emotively ‘place’ themselves within that context.

The discussion that follows, point towards the researchers who offered me inroads towards improved understanding of my research focus.

I found Holt (2001) fascinating from the perspective of using a reflective logbook as his primary data for his course. He incorporated his individual philosophy with previous experience to negotiate the contextual expectations that he had of the university and the university, of him. Duncan (2004) offered insightful ideas on methodological rigour and offered me reassurance through guidelines in answering some of the problematic aspects I was encountering and of times when I found myself having inner dialogues as I reflected on aspects I was contemplating, including or omitting. Duncan emphasized rigour in the research process. I came across Couser (2005) who provides an analysis of a one first person narrative expressing capability of self-representation “*Count Us In: Growing Up with Down syndrome*”, “a collaborative narrative by two young men with the syndrome in question. Not only is the title cast in the imperative mood—”count us in”— the subtitle puns on “up” and “down” in a way that challenges conventional ideas about mental retardation, such as that those with it never really mature” (p. 107)

In trying for a closer synchrony of my experiences on access, schooling and Down syndrome collectively, from an autoethnographic perspective, I located John Quicke (2008). In *Inclusion and Psychological Intervention in Schools: A Critical Autoethnography*, he describes schools as “complex, social, cultural context” (p.V) where inclusive thinking is a struggle. Through various narratives he excavates inclusion using critical autoethnography. In summation he suggests that understanding what barriers to inclusive access exist, the reason for their presence and then work to remove them will contribute towards creating an inclusive environment. I found his work engaging and found his passion for inclusion so endearing and believable. Hanekom (2012), undertook an autoethnographic study to reflect on the physical and emotional journey two parents experienced in finding a suitable schooling context for their child who was medically diagnosed with “Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS), an Autism Spectrum Disorder”. She employed co-constructed narratives and followed a chronological sequence of events though the discussion was more thematic. It was easy to identify with her struggles and the poetic yet realistic manner in which she expresses her experiences. Her use of metaphors tapped into my appreciation for the English language. The idea of co-constructed narratives reinforced and extended from the personal into the broader social context. Murray’s (2000) autoethnographic account connected on a personal level with me as I read of her transparency in sharing with the reader her vulnerabilities as she writes of her son and the secrets of mothering. Her son has DS, and on this maternal level, I found kinship.

These examples go beyond telling stories. They provide academic accounts with defensible interpretations. The work “does not consist solely of the researcher’s opinions but are also supported by other data that can confirm or triangulate those opinions” (Wall, 2008, p. 5). Beyond these limited examples, I struggled to locate an autoethnographic study on access to schooling specifically for a child with DS. This very gap allows for my study to be inserted as a contribution to the body of knowledge. I return to elaborate on autoethnography as my preferred methodological choice, in Chapter four.

## **2.11 In conclusion**

Meaningful participation is described as a multi-layered concept but in its core expectation, the participant's view is represented through consultation as suggested by (Franklin & Sloper, 2007). To allow learners with DS effective participation means access to express himself/herself and the listener, to actively process what is expressed as an ongoing process of interactions. In addition, organisational arrangements, which are non-disabling are required to enhance the involvement process (Cavet & Sloper, 2004).

Research, reflecting on twenty years of democracy, portray a bleak picture of inclusion as practices of 'ableism' and 'normalcy' are perpetuated (Hamre & Oyler, 2004) although in different formats. The report of SAHRC and UNICEF (2014) attest to the outcome of deficiency as a result of inequality: "the unequal provision of education under apartheid has persisted beyond the transition to democracy and continues to contribute to inequalities in the school system and schooling outcomes, despite the new government's considerable channelling of resources into education. Poor quality education is unquestionably a poverty trap mechanism". Poor quality is implicit in support for the three-tier system in any format or practice, which limits the range of possibilities for inclusive education to be realised (Slee, 2001). To add her voice of consternation, Engelbrecht (2006) indicates that complex modification in various strata of society, surrounding educational restructurings and contextual changes, related to expected diversity in schools and the management thereof, have had an adverse effect on the roll-out of inclusive education. An observation recorded by Fulcher in 1989 holds true even in 2014, that of a noticeable propensity within the arena of SEN, for policy to shift yet practice remains unchanged.

One of the difficulties faced in South African education system is that of decentralization where resources and decision making are transferred to local authorities of District and Province. With this shift and perceived flexibility to adapt to local circumstances, there are disparities in value and quality in services rendered. The Millennium Development Goals (MDG) outline eight goals with a predicted timeframe of achievability to be 2015. It is supposed to reflect an answer to the global central growth and expansion challenges. The MDG embodied in the Millennium Declaration, outline specific activities and objectives. One

hundred and eighty-nine (189) nations accepted it and 147 leaders from various governments signed acceptance during the “UN Millennium Summit” of September 2000. Goal two of the eight MDG is ‘to achieve universal primary education’. The UN issues an annual report assessing a country’s progress towards the preset goals. The report records that South Africa intention to fulfill this objective by 2015, is realisable.<sup>15</sup>

In this chapter, the insertion of comments and first person narration is determined by choice of autoethnography. It also afforded me the latitude to traverse and roam freely through the field of experiences, dwell on few and yet fulfill PhD expectations of conceptualising and theorising the core phenomenon of this study and fulfilling the literature review function.

I outlined the prevalence of DS both within and outside South Africa to indicate the increasing number of live births of DS and identified the gap in service provision to meet this growing demand due to unreliable data on prevalence of DS condition nationally and internationally. This was followed by discussion of discourses in education in their general reference to disabilities and specific reference to DS and consideration was also given to legislative frameworks that inform policies at school, district and provincial levels. In many contexts, including the UK, a frequently cited critique is inadequate funding, lack of adequate training of teachers and negative attitudes of implementers of inclusion policies.

The transition was seen to be towards theory of access. It is argued that focus on access to schooling spaces is critical because it sheds light on important aspects of CWDS participation. CWDS who require additional support want recognition and support for their individual needs, as well as for the collective needs as a community. The need for policies to be articulated from a perspective of human rights (social model) instead of an individual needs standpoint (medical paradigm), was addressed. I then provided an overview of the national imperatives emanating from policies and current practices that are sometimes disjointed. The concluding comments present insights to building an understanding of the transformations expected. The perception of consumers, like ourselves, of services from government is that accessible schooling spaces should be the norm rather than the exception.

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<sup>15</sup> <http://www.sustainabilitysa.org/GlobalResponse/SAGovernmentsResponse/SAandtheMDGs.aspx>

I now proceed to Chapter Three, which is the canopy of my journey by theoretically exploring different types of knowing.

## CHAPTER THREE

### *WRITING ON TABLETS OF STONE*

#### 3. 1 Introduction

*“The time has come,” the walrus said,  
To talk of many things: of shoes—and ships—and sealing-wax—  
Of cabbages—and kings. . .”<sup>16</sup>*

Lewis Carroll

This section embodies Lewis Carroll’s “the time has come” expression as it is the ‘now-ness’ that is grounded within an intimate expose of how this study has evolved personally, professionally and academically. “Shoes—and ships—and sealing-wax—of cabbages—and kings” may not all literally feature in the discourse but they represent the many facets stitched together. I ask readers to appreciate the openness and vulnerability, especially of this section in context of their own parallel experiences.

I was drawn into reading the complete thesis of Murray (2010) *Secrets of mothering* after perusing the abstract online. She speaks openly of placing the private in the public domain. I realised that the reader may, as I did with her work, enter and travel with the researcher through the pages of the narrative, if he or she so chooses. The focus in this section hinges on ‘ways of knowing’. I asked myself the following questions: How did I come to know what I know? Who decided what I should know? How did I come to construct my knowledge about DS? How has this affected the process of becoming? These seemingly philosophical opening questions will set the tone for what will unfold in this section. My answer becomes a fusion of Cross’s (2001) suggestion, “‘knowing how’ is more important than ‘knowing that’” with ‘knowing how’ referring to that which precedes ‘knowing that’

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<sup>16</sup> <http://www.brokenheartquotes4u.com/quotes/shoes/>

Computations of 'knowing' was evident in Donald Rumsfeld's ( United States Secretary of State ) speech in 2003 at a press conference on the invasion of Iraq in which he adopted a philosophical stance:

There are known knowns; there are things we know we know. We also know there are unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns, the ones we do not know we do don't know (cited in Norris, 2005, p. 18)

The views he presented were debated in that context as he needed to justify actions within a political field. Within the parameters of this autoethnography I see the relevance of some of what he said but discharge them on a social justice, human rights field. I will refer to Donald Rumsfeld's homily predominantly to flag salient issues that have arisen from this reading and discuss its epistemological import within the context of this study.

It is now time, for me to unfold a personal and vulnerable part of myself. I choose to insert into the public space, '*my knowing*', which encapsulates what was fearful and uncomfortable to me both 'before' and 'during' my study, a disclosure which resonates with being true to myself.

### **3.2 My knowing**

It is in the admission of ignorance and the admission of uncertainty that there is a hope for the continuous motion of human beings in some direction that does not get confined, permanently blocked, as it has so many times before in various periods in the history of man. Richard P. Feynman (1998)

"Ignorance" and "uncertainty", as used by Feynman, were two words which leapt off the page for me. They crystallised the early emotional and psychological attitude I had when faced with the prospect of raising my child with DS. These blocks which reduced functionality did not remain forever, but long enough to alter events for the future. Despite what seemed like a

stagnant state of action, I was in continuous motion - though more emotional than physical. The transition from this has to do with ‘knowing’.

To help develop the discussion I consider it necessary to differentiate ‘knowing’ and ‘knowledge’ for which I turn to Amin (2008) to incorporate a slice of her study. Through judicious extractions and discussion of her views and that of Kivinen and Kaipainen (2007) and Dewey (1988), it is my hope that their relevance to this study is conveyed to the reader.

Undertaking this PhD study offered me an opportunity to think critically on the intricacies of ‘knowing’. Amin’s PhD thesis (2008) focused on *teachers’ knowing* about their learners. Her study was centred on a post-apartheid secondary school in South Africa. In intersecting teachers’ knowing with learners’ knowing she extracted ways of teacher knowing as solicited, unsolicited and common, and five kinds of teacher knowing: racialised, gendered, cultural, classed, and professional. According to Dewey (1988, pp. 124-125), if we say we ‘know how’ it would be on account of our habits, whilst ‘knowledge that’, involves more mindful consideration. Kivinen and Kaipainen (2007) reaffirm this view with the statement that ‘knowing how’ does not originate in ‘knowledge that’ and cannot be reduced to it (p. 5). I ruminate that the approach I adopted to accessing schooling would have been vastly different then, had I access then to what I know, now. Albert Einstein (n.d.) reassures me with the observation that “the significant problems we face cannot be solved at the same level of thinking we were at when we created them”<sup>17</sup>. The articulation of experiences in this study does not lend itself to apply the depth and layers of knowing, articulated by Amin (2008). I do however, make use of Amin’s (2008) ‘paradox of knowing’ later in this chapter as it has bearing on the context explained. I use phrases to ‘know of’ and ‘knowledge of’ instead of ‘knowing how’ and ‘knowledge that’ of Dewey (1988) and Kivinen and Kaipainen (2007) to reflect the shift in understanding within the timeline of experiences. I present this chapter of my study with the following contextual reference: ‘Knowing’ as the superficial, outward layer, with ‘knowledge’ and understanding as the inward layer. To me *knowing* of access is the outward layer (past) and *knowledge of* access the inner layer (present) is discussed from with a sensory, cognitive focus.

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<sup>17</sup> [www.alberteinstein.com/quotes/einsteinquotes.html](http://www.alberteinstein.com/quotes/einsteinquotes.html)

How I framed my understanding of my child's disability was indicative of the level of my (lack of) knowledge. Now as I look at myself and look back with an analytical gaze the scales seem to fall from my eyes. I hope the reader will be able to gauge how and when this happened. The English proverb, "Where ignorance is bliss, 'tis folly to be wise" may be considered an ironical yet useful expression to illustrate my introduction to my daughter, her diagnosis and the subsequent unpredictable journey that unfolds with her. The proverb learnt in early education, has its genesis in Thomas Gray's *Ode on a Distant Prospect of Eton College*. I probably quoted this proverb a few times in my teaching of English lessons over the years. Written in 1742, the poem is a dignified and somewhat nostalgic capture, in the first-person point of view, the perspective of a worldly-wise former Eton student as he contemplates the unforgiving, severe, unpredictable and daunting realities that the now-carefree young Etonians will one day face. This sentiment is conveyed in the Stanza 6:

Alas, regardless of their doom,  
The little victims play!  
No sense have they of ills to come,  
Nor care beyond today:  
Yet see how all around 'em wait  
The ministers of human fate,  
And black Misfortune's baleful train!  
Ah, show them where in ambush stand  
To seize their prey the murtherous band!  
Ah, tell them, they are men! (From "*Ode on a Distant Prospect of Eton College*" by Thomas Gray) <sup>18</sup>

The students may be catapulted from a world they know and have knowledge of to one that is unknown. Similarly, my sense of uncertainty on having and raising a CWDS is mirrored within the tone of this poem. When I read the lines closely, they also mimic the shifting paradigms of what I thought I knew, not knowing what needed to be known, not wanting to

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<sup>18</sup> <http://www.thomasgray.org/cgi-bin/display.cgi?text=odec>

know, and then having to know. Truly then it would be apt to adapt the proverb to read as “where ignorance is not bliss, ’tis folly not to be wise”.

*I wish I had known more about Down's syndrome before I got the amniocentesis. Down's syndrome is made out to be an AWFUL thing, much worse than it really is and the general level of ignorance that is common just fuels that.*<sup>19</sup> (A mother referring to the news of her child with DS)

Mothers are commonly considered as ‘experts’ about their own children given the intimate contact they have, particularly in the period immediately after the birth of the child. Maternal knowledge, which develops in the ‘private’ domain of intimate contact, assigned me pre-knowing status of a condition I really knew nothing about. Thus began the journey of knowing listed as ignorance, knowing and knowledge. The transformation emanates from an admission of ignorance of what DS is and with its myriad uncertainties. For me the proverbial ‘wheels which had come off’ needed to be reset and rerouted. My embarking on this study attests to the prospect conveyed through one of Feynman (1998) quotes that “there is a hope for the continuous motion of human beings [*myself*] in some direction that does not get confined, permanently blocked, as it has so many times before in various periods in the history of man” (n. p.). I was overladen with questions arising out of knowing about ‘not knowing’ as an academic exercise. I turned to various sources to glean and present a more informed position.

An understanding of how ignorance is construed and constituted requires attention to the following particulars. First, what claims are made regarding who is ignorant about what? Second, how do these claims match on aspects of what knowledge and ignorance are, and what can and cannot be known? Third, how are stakeholders using and responding to their own and others’ aims about ignorance? What are the consequences of these notions about ignorance in social interaction? (Smithson, 1985, p. 213).

Social theories addressing ignorance are preoccupied with ascriptions about psychological conditions and practices. Drawing from key ideas of Smithson (1985), and to help myself

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<sup>19</sup> [http://www.nbcnews.com/id/44703812/ns/health-health\\_care/t/down-syndromes-rewards-touted-new-test-looms/#.Uk3HLdJHKSo](http://www.nbcnews.com/id/44703812/ns/health-health_care/t/down-syndromes-rewards-touted-new-test-looms/#.Uk3HLdJHKSo)

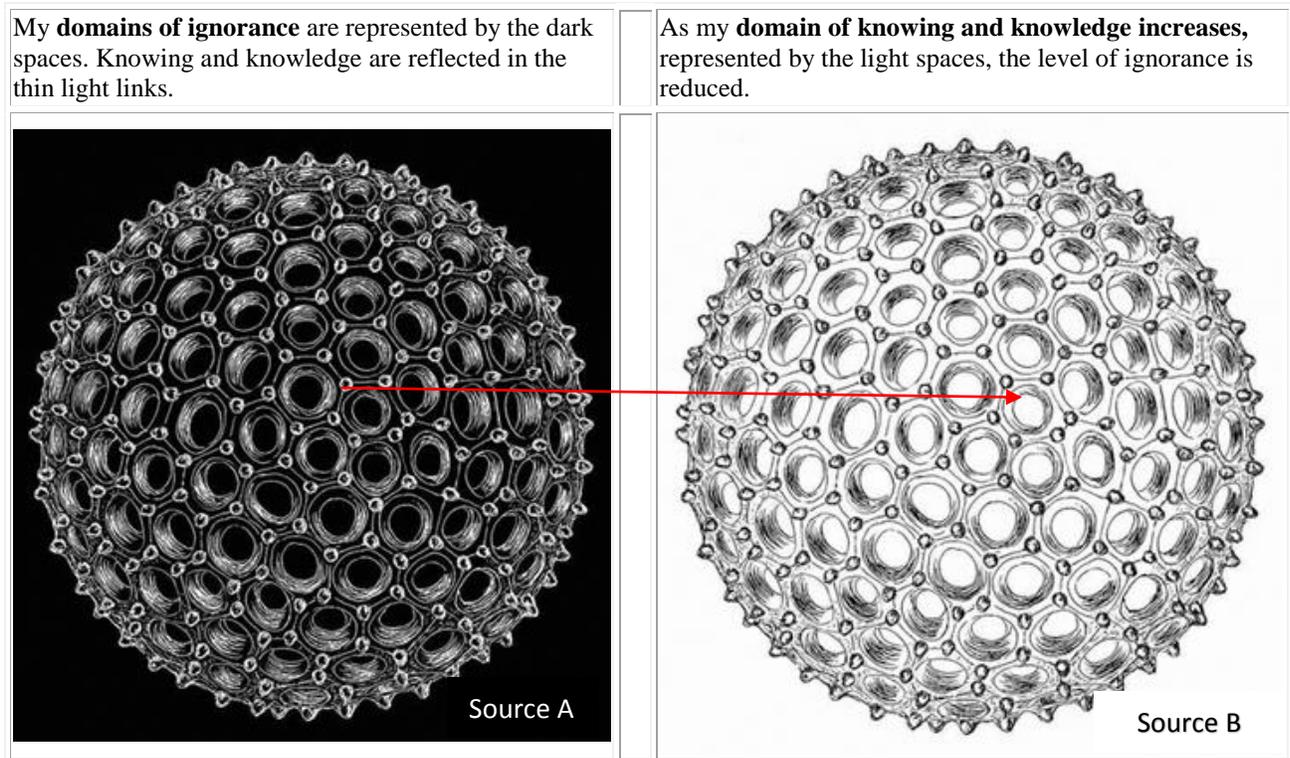
understand the connection between ignorance and significant occurrences, I assembled words such as “selective attention”, “denial”, “forgetting and delved into further reading. I was intrigued by Laberge, High, Kelly and Maid (2013) tentative definition of ignorance as “knowledge denied or denigrated” (p. 2). On the contrary, ignorance in my experience was not knowledge denied but simply an absence of knowledge having a substance of its own. Essentially it fitted the description used by American Former Secretary of State, Donald Rumsfeld quoted earlier, “There are known knowns; there are things we know we know. We also know there are unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns, the ones we do not know we do don’t know” (cited in Norris, 2005, p. 18)

It will make sense to explain how the term ‘knowing’ is used in this study to differentiate it from ‘knowledge’. As a student and force-of-habit I turn to the New Elizabethan Reference Dictionary (third edition, n. d.) which delivers broader definitions. It describes knowing in the following terms: ‘to be acquainted with, to have personal experience of, to be on intimate terms with, to be aware of, and to understand from learning or study’. This suggests one should have generally reliable information about the world. From this premise, then, emerges knowledge which is defined as, “the result of knowing, that which is known, certain or clear apprehension of fact or truth, learning, erudition, science, sum of what is known (n. d. p. 820). In the light of these dictionary definitions, “knowledge” can construed to be precise, whilst “knowing”, more tentative. To rephrase, “knowing is pre-knowledge”, and “knowledge is post-knowing”. Although not considered an authentic academic source, in my state of ignorance, it is not uncommon to turn initially to an accessible and convenient source. From this point, I proceeded to lift off the veil of ignorance for myself.

Using different phraseology, Tekippe (1998) sees knowledge as conceptual knowing, and knowing as primordial knowing. Conceptual knowing is a clarifying process where thoughts and ideas are distilled and primordial knowing is a precursor of conceptual thinking. This suggests a linear progression. The veracity of this statement may be tested in applying this explanation to my study. My thinking that there is the possibility of a medical condition but not knowing any details about it may be described as primordial knowing. When information

and details of what it is, its characteristics, whom it affected, who was at risk and the long term impact for the person, family and the society it may present, will be considered as conceptual knowing. Somehow, it did not satisfy my understanding. Information is gathered piece-meal: little bit at a time. When one establishes understanding of an aspect then additional information can be placed to embed that and build further or enhance. To me it meant that this realm of meaning has layers. Polkinghorne (1988) refers to it as strata and describes this realm of meaning as an activity which reiterates my earlier reference to ‘motion’. That it is not static.

I did find clarity in reading Anderson (2006) on multi-modal theory of epistemic access. He states that “human knowers are open to the world via multiple channels, each operating for particular purposes and according to its own logic” (p. 18). I use this viewpoint to argue for the different types of knowing presented in this study. Embracing this view meant that I could enter into the domain of knowing at different times and phases and for different purposes. It is this premise that offers me the avenue to articulate my journey, of unlocking different types of knowing at different phases and in different consistencies through multiple channels (books, magazines, television, medical waiting rooms and shopping aisles conversations, to name a few). It is for me, a precept upon precept journey. As the consequence of new information being accrued gradually, and more about the condition is unlocked, I moved closer to the marrow of searching to access schooling spaces. These perceptions came to be formatted as fragments and segments, codified to be in the world “out there”. I carried prognostic propositions of the outer world and of Tiara. It seemed all arbitrary until I consciously decided to delve further and deeper towards knowing and knowledge. This may be metaphorically encapsulated in the following illustration:



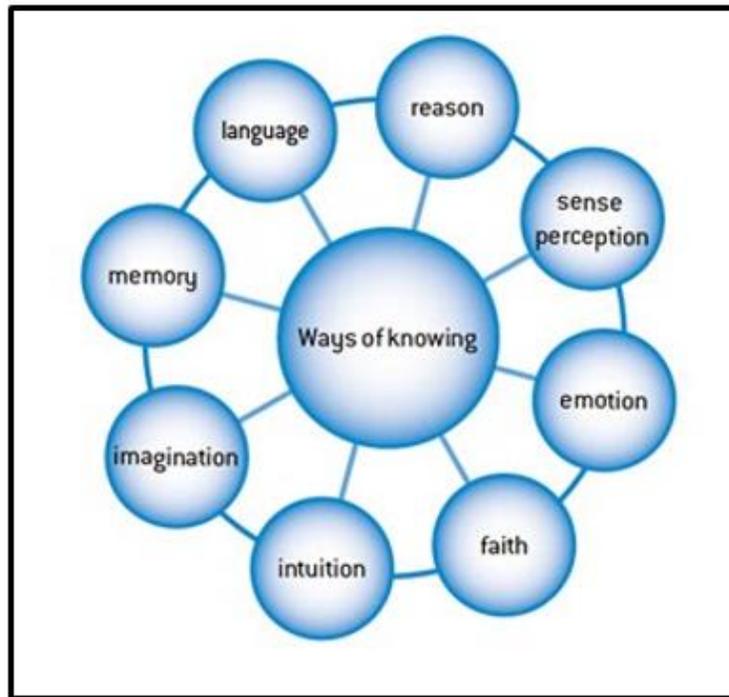
**Figure 5: Domains of ignorance, knowing and knowledge** <sup>20</sup>

This was a most interesting find (Figure 4) to represent ignorance and knowing. The image on the left (Source A), metaphorically, captures the beginning of my journey from ignorance, and the journey towards ‘enlightenment depicted by the red line moving from Source A to Source B. This is applied particularly with information of the condition of DS, represented by the dark space pockets and dark background. Admittedly the level of knowing and knowledge has accrued and can be described as ‘illuminated’, as illustrated by the light spaces pockets. This contrast illustrates that knowing about Down syndrome, access and schooling spaces did not necessarily mean I have reached a state of saturation, but suggestive that more knowledge can be added (as reflected by the thin grey lines outside the white space pockets in Source B). The body of knowledge accrued over eighteen years now places me in an improved position to interact with the characteristics, predictability and risks of condition of Down syndrome in a more informed manner, identify the types of access that affect Tiara and the

<sup>20</sup> Image extracted from <http://www.laetusinpraesens.org/docs10s/univigno.php>

options of schooling spaces available for CWDS. I stand at a ‘vantage point’ of eighteen years’ experience to critique the position I assume within this study.

I was puzzled at how hard it was to find an adequate representation of ‘ways of knowing’ which could be adapted to suit specific fields of study. There were various images I could access that represented ways of knowing specific subjects of Mathematics, Science, and Technology; however, I was unable to find any images reflecting maternal knowing. Dunn (2013) offers eight aspects to the state of being aware or informed: “language, sense perception, emotion, reason, imagination, faith, intuition, memory” (Dunn, 2013). Using an adaptation of Dunn’s model of knowing, I will explain its suitability to this study focussing on mothers’ ways of knowing.



**Figure 6: Ways of knowing, reflected in 8 generic dimensions, according to Dunn (2013)<sup>21</sup>.**

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<sup>21</sup> Image extracted from <http://blogs.osc-ib.com/wp-content/uploads/2013/10/wokwheel300.jpg>

While alternate means of knowing exists, I have elected to explain Michael Dunn's 8 dimensions of knowing before adapting them for the purposes of this study.

*Faith* is explained within a religious context and is imbued with an element of trust which is not necessarily evidence-based. *Intuition* is described as immediate understanding or immediate awareness without previous suggestion. The contrast of reason with intuition because it is regarded as "knowing" without using cogent methods. Carl Jung (1964)<sup>22</sup> notably talked about intuition as perception through "the unconscious", with an accent on the idea that intuition is knowing not necessarily "understanding how they are known". The association is sometimes made, of intuition, with the notions of nature and inherent knowledge. I take cognizance of Lampert's (1986) reference to intuitive knowledge as 'resulting from and context bound in which the knower is confronted with personally relevant problems to solve'. *Sense perception* traditionally refers to the five senses of sight, touch, smell, taste and hearing and through these processes information about the external world accrues. *Imagination* is considered as ability to create an image without the impetus of sensory experience. In a broader application it is associated with creativity, problem-solving using various ideas, to resolve a problem. It can be construed to be subjective. *Reason* extends the immediate sensory experience and links to rationality. This leads to valid deductive thinking stemming from hypotheses. I have used inductive reasoning in this study through offering specific statements to reinforce general ones and is by this process, inferential. *Emotion* has sometimes been regarded as an unreliable way of knowing. Emotions as I understand it, is not an illogical impediment to achieving knowledge, misrepresenting reality. Instead, emotions enable meaning-making of diverse experiences and can inform "social, ethical and political" dimensions of knowledge, through equipping one with techniques to understand the world. Much of the knowledge is captured and resides as *memory*. Understanding the process of storage and recall informs how personal knowledge is constructed. This aspect will be discussed further in Chapter four.

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<sup>22</sup> <http://www.rlwclarke.net/Courses/LITS3303/2008-2009/08BJungApproachingtheUnconscious.pdf>

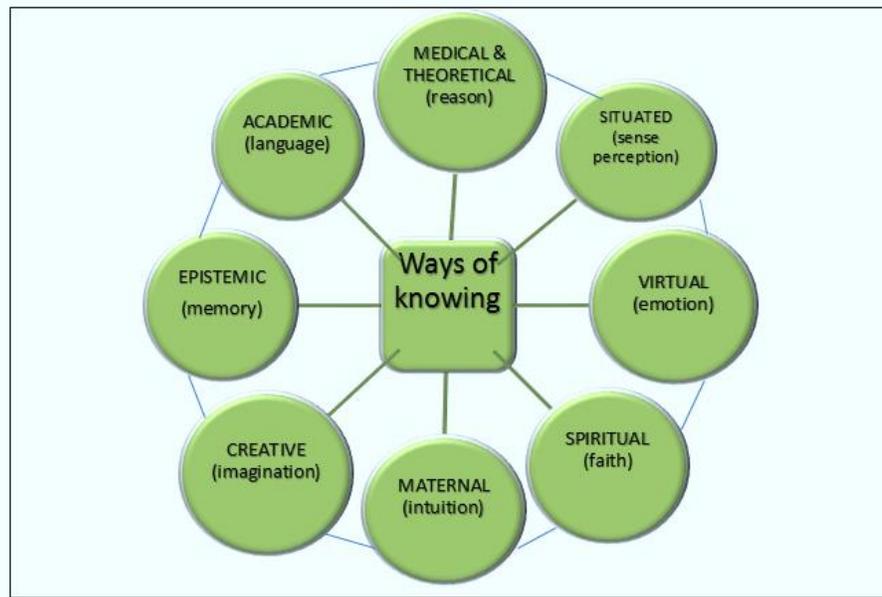
*Language* can denote intellectual ability which permits people to absorb and activate systems to communicate. For this purpose of communicating knowledge, language plays an important role. It can help describe our experiences of the world and structures those experiences.

As elucidated in the brief explanation of the eight ways of knowing, each aspect does not function in a detached manner. For this reason it should not be considered in compartments, disconnected from each other. They interrelate in diverse ways, enabling the building of knowledge and the creation of knowledge assertions.<sup>23</sup>

The discussion that will follow on is based on an adaptation of Dunn's (2013) eight ways of knowing. Each term has been adapted to suit the specifics of this study, although it retains its original meaning. This original diagram illustrates ways of knowing within the following categories: "emotion, reason, language, sense perception, imagination, faith, memory and intuition". These terms are inserted within brackets to aid connection of meaning offered earlier. The adapted format is as follows: spiritual knowing, maternal knowing, situated knowing, creative knowing, medical and theoretical knowing, virtual knowing, epistemic knowing, and academic knowing. Each of these ways will be illustrated with a short narrative. The overarching premise here, too, is that each way of knowing is not compartmentalized and isolated, but is like a helix, interrelated.

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<sup>23</sup> [https://ibpublishing.ibo.org/exist/rest/app/tsm.xql?doc=d\\_0\\_tok\\_gui\\_1304\\_1\\_e&part=2&chapter=3](https://ibpublishing.ibo.org/exist/rest/app/tsm.xql?doc=d_0_tok_gui_1304_1_e&part=2&chapter=3)



**Figure 7: Ways of knowing reflected in 8 specific dimensions, with stimulus of Dunn (2013) ‘Ways of knowing’.**

### 3.2.1 Spiritual learning

When told by the attending physician that my newborn may have Down syndrome before a blood test confirmed it, I recall feeling weak, shocked and angry. I heard myself screaming, ‘My God will not do this to me!’ I recount how much I worried when I heard our child had DS, my reaction was to worry about what my family will think, the shattered dreams of her future, even thinking about her prospect for marriage. I was naïve, ignorant of what DS was and filled with fear.

The imagined and unrealistic prediction of the future for my child with DS, prompted by how I thought people around me may react to my child meant that accurate, logical, rational and unambiguous knowledge was needed to replace this closet of doubt. It was crucial to enable informed decision making. In my chosen state of ignorance I focused on God helping me cope with the emotional turmoil.

In highlighting my quest for spiritual upliftment, I situated myself exclusively to finding answers and healing to my unwelcome situation. I believed that if I focused intensely on God this situation will be overturned, miraculously and through persuasion. I was hoping that

through fasting, playing popular gospel songs frequently so that it permeated the house and reading the Bible regularly I would receive a breakthrough, according to my terms. I memorized Biblical passages and recited them often, entreating the Almighty to reverse the situation of pain and heartache. I attended crusades, allowed senior members of the church to intervene in prayer and petition God, and wrote letters of my own hoping that by declaring it on paper I could secure a better result/outcome. This whirlpool of pleading went on incessantly with many uncontrolled and emotional outbursts.

The passage that I latched onto was “For verily I say unto you, That whosoever shall say unto this mountain, Be thou removed, and be thou cast into the sea; and shall not doubt in his heart, but shall believe that those things which he saith shall come to pass; he shall have whatsoever he saith” (Mark 11:23). In this context Peter said to The Lord Jesus Christ, “Rabbi, look, the fig tree which you cursed has withered.” “And Jesus answered saying to them”, “Have faith in God. Truly I say to you, whoever says to this mountain, ‘Be taken up and cast into the sea,’ and does not doubt in his heart, but believes that what he says is going to happen, it will be granted him.” The diagnosis of DS felt like an insurmountable mountain. I wanted it to be like a withered tree which I could overturn it if I had enough faith. In order to increase my faith I surrounded myself with God’s word, reading and reciting repeatedly, became a ritual. By strengthening myself spiritually I believed I had more power to negotiate with God.

### **3.2.2 Maternal instinct**

News that my child has DS was not received positively at the beginning. My joy was corroded by anxiety, fear, guilt and anger (Falik, 1995; Woodman, 2014). I was experiencing what Glidden (2012) describes as a joy-grief paradox of emotions. Without any reading material or referral to support organisation, the process of bonding and working through the emotional uncertainties was a rollercoaster. ‘Knowing something is always arrived at through direct personal experience’ (Patterson)<sup>24</sup> and I observed the physical for cues. It was a while before the attitude would change.

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<sup>24</sup> <http://www.vision.net.au/~apaterson/spiritual/knowing.html>

### **3.2.3 Situated coordination**

Situated knowing applies to but is unrestricted neither by geographical immediacy nor prevalent spatial form. The coordination of the interest group (DSA-KZN) served an important purpose in the accrual of individual contacts which expanded into groups and then into an association of large membership that could support one another. This group is unrestricted to geographical proximity. It is through this membership, interaction and active participation that the informants came to participate in the study. On occasion, academics from various institutions have the platform to present a paper or workshop to members or simply attend as an interested individual. On one of these occasions I met and engaged with Patricia Krishna. She has contributed to inter provincial DSA initiatives, some of which are replicated in all provinces, on the same day. ‘Down syndrome awareness’ is one such initiative that is managed nationally, with provincial coordinators in charge of such portfolios expected to liaise and support one another. On one such occasion, Patricia Krishna addressed parents on a formal and informal basis, concerns pertaining to parenting and schooling. Since then, she has maintained contact with the organisation and has offered services and shared her expertise at information sharing meetings.

### **3.2.4 Creative realm**

Alertness and compassion are useful characteristics in the foundation of adapting or implementing therapies, intervention programmes and activities to address holistic development of the child. An impetus to tap into the creative realm was stimulated from reading Fuller’s (1972) *Intuition*:

Because the brain's TV prime resource  
Consists of images,

We may call the total brain activity  
Image-ination.

All we have ever seen

Is and always will be  
In the scopes of our brain's TV station.  
All that humanity has ever seen  
And will ever see  
Is his own image-ination;  
Some of it is faithfully reported new,  
Some of it is invented fiction or make believe;  
Some of it is doggedly retained "want to believe."  
(R. Buckminster Fuller, Intuition, 1972, p. 122)

It was inadequate to simply copy and paste worksheets from any source before understanding what my child's specific needs were. I tried to design tasks with images then words thinking she is a visual learner and the use of images, variety of pictures, attention to color and other visual media to aid her learning. Collaborating with a friend who was at the time, a junior-primary school teacher, helped provide appropriate focus, to sourcing material, adaptation and differentiation. We incorporated fine and gross motor co-ordination, developed through skills of colouring within the lines, writing patterns to help hand-eye co-ordination, physical activities that offered 'make-believe and fantasy play to encourage speech and found the children's channel on television helpful too. This lasted few months until my friend relocated and the home intervention stalled. The professional was initiated and sustained through regular one-on-one sessions. This will be expanded in Chapter five.

### **3.2.5 Theoretical and medical meaning**

The initial image conceived when the words 'Down syndrome' were uttered in the same sentence with my child, was of a child in a wheelchair and incontinent. I left the hospital with a dreaded fear which I could not immediately reconcile with the baby I cradled in my arms, who was beautiful, with soft hands and facial features and a delicate placid nature, sleeping blissfully. Gradually, I undertook to reading about the condition to better relate to her and engage others about her care. The value of accessing scholarly research of Buckley (2006),

Skotko (2005, 2009) and Sapon-Shevin (2013), to name a few, provided me with some information which was theoretical, and medical, valid and reliable.

### **3.2.6 Virtual space**

The area of virtual space was only recently acknowledged as an area that can generate knowledge. It was accepted as a space where information is learnt through exchange. It has now expedited contact, communication, exchange of information irrespective of distance and time. This interaction has improved and increased the highway of information and access is augmented through improved technological software. One could find online a range of social and academic communities. Ellis and Vasconelos (2004) indicate that the investigation into how the knowledge of online communities' and its nuances contrast with communities reliant on shared knowledge through face-to-face interaction. The existence of an open and unstructured online support group of parents of CWDS provided a forum where virtual interaction generated knowledge through Facebook and question and answer links on various DSA websites or blogs. The Facebook closed group provided immediacy in access to information. Members of this group interact virtually, with no restrictions on when or how long one remains in the group. I benefitted from the written contributions of members which range from medical and academic to experiential (anecdotal accounts).

### **3.2.7 Epistemic communities**

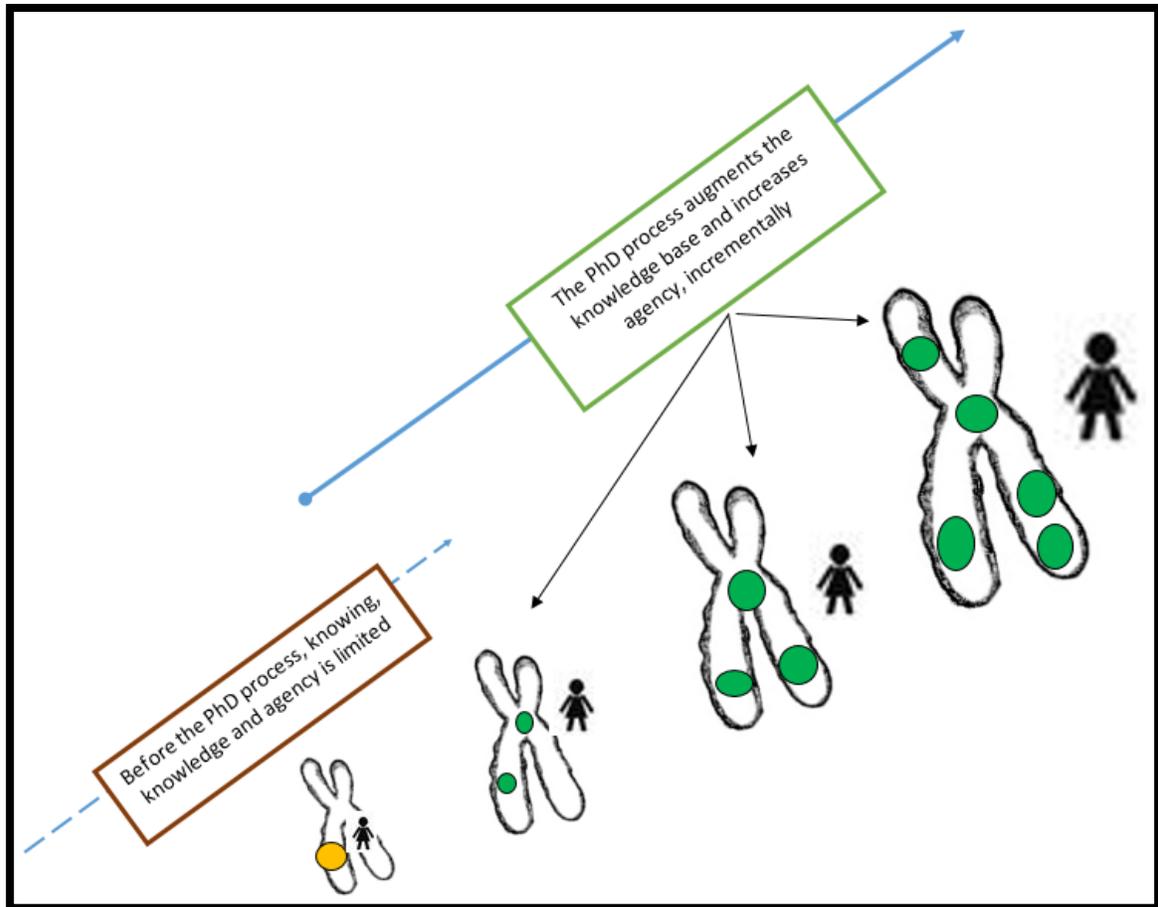
In this sliver of the study I scrutinised the subtleties of collaboration when diverse people with in-depth knowledge edge towards and into “new knowledge” that challenges a shift in thinking (Buckley & Bird, 2006; Skotko, Capone & Kishnani, 2009; Engelbrecht, Oswald & Forlin, 2006; Lalvani & Polvere, 2013). These researchers have explored and expressed deep insights on topics related to schooling, access and DS through their collaborative efforts. My access to their ideas and new thinking through the virtual space, has contributed significantly to my knowing more on these aspects of my study.

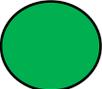
### 3.2.8 Academic whirlpool

A characteristic, that is broadly common to professional communities and relate to the type of knowledge that is acquired for their specialisation, is referred to as ‘codified knowledge’. This codified knowledge is absorbed through individual academic study. It is noticeable in written or verbal communication that the individual has a level of mastery a body of knowledge (Engelbrecht, 2006; Skotko, 2009; Muthukrishna, 2011; Lalvani, 2012). In this context I also refer to health science professionals I have interacted with: speech therapist, physiotherapist, orthotist, cardiologist, paediatrician, ear-nose and throat specialist and specialist physician. This professional body of individuals possesses knowledge which at most times facilitated my understanding, particularly with intervention strategies. The benefits from these interactions and exchanges enabled me to draw on information in the specific context of interaction and translate it into words in this academic study. Parents of other children with DS also provided opportunities of acquiring situational relevant information

I now use Amin’s (2008) *Paradox of knowing* to explain my paradox. For at least a year what I experienced through the senses fitted into a fluid, unfixed tenuous frame of reference. Up to this point there is deliberate use of *knowing* as opposed to *knowledge*. This stance may seem odd because the word ‘*knowledge*’ is inextricably bound to the word education. Education, supposedly, deploys *knowledge* to advance *knowledge*. Though *knowledge* and knowing are both derivatives of the same root, ‘know’, *knowledge* is the culmination of *knowing*, organised, structured, and essentialised whilst *knowing* is tentative and fluid and, as theorised by Skovsmose (1994), dynamic. Furthermore, *knowledge* is a body of information that is often impersonal, abstract, and imposed (Belenky, Clinchy, Goldberger & Tarule 1986), whilst *knowing* is internalised belief informed and influenced by relationships existing between knowers and the known.

Distilling from this discussion, the start of this journey to access schooling spaces to the present circumstance of my PhD journey is represented (Figure 8) to convey how knowledge influenced my agency.



	Represents knowledge base prior to the PhD journey in engaging with access to schooling spaces for Tiara.
	Represents knowledge base at the end of the PhD journey in engaging with access to schooling spaces for Tiara.
	As the knowledge base accrues (indicated by blue arrow) and increasing size of chromosome image, so does the agency of researcher, represented by the increase in size of 

**Figure 8: Diagrammatic representation of the impact of PhD on knowing, knowledge and issues of access to schooling spaces for Tiara**

### **3.3 Conclusion**

My awareness of the fast pace in which knowledge is becoming available and how it impacts on the highway of knowledge generated, has led me to think contrarily at times around how the subject of knowing is constituted. Legitimising the multiple ways one may “know” ensures that one is not privileged over another and grants equal value to its place in the spectrum of knowing, knowledge, known and unknown. It lends support to my researcher bias in interpreting ways of knowing and knowledge in an ever- present, personal voice.

The next Chapter shifts towards a more intimate and personal space in framing the intimacies of my knowing, and progresses to explain how autoethnography chose me as the appropriate methodology. I consider extensively ethical issues central to the undertaking of this study and how I address some of the ethical challenges faced during the journey of writing.

## CHAPTER FOUR

### *A ROLLING STONE GATHERS NO MOSS*

One writes out of one thing only - one's own experience. Everything depends on how relentlessly one forces from this experience the last drop, sweet or bitter, it can possibly give. This is the only real concern of the artist, to recreate out of the disorder of life that order which is art. (James Baldwin)<sup>25</sup>

#### 4.1 Introduction

James Baldwin, a writer and civil rights activist in the 1950s and 1960s, explored concerns about race and society through his writing. He earned his reputation for writing extensively on Black people experiences in America. He wrote of his personal experiences of being “Negro” and American. In his effort to write contextually relevant texts, he had to unlock the subject of how it felt to live the life of a “Negro” before he could hope to write about anything else. This meant an awareness of the general social fabric of history, traditions, customs and moral assumptions (Jones, 1966). In his novel “*Go Tell It on the Mountain*” (1953) the narrative hinged on a young man raised in Harlem wrestling with unresolved issues with his father, and religion. He defended his writing from a personal perspective. “Mountain is the book I had to write if I was ever going to write anything else. I had to deal with what hurt me most. I had to deal, above all, with my father,” he said<sup>26</sup>. From reading critiques of his work I am struck by how noticeably poignant his writing is when the context and personal experiences of racism and injustice are read as unhealthy, destructive interwoven threads, yet an inextricable part of his life. Baldwin protested through his writing about racial injustice (Miller, 2000). In his subsequent work he chose to write on subjects that did not always get the support of the society he wrote to and about. The themes that he dealt with included sexuality, family, homosexuality and interracial issues, with experience as the impetus for the writing. The bold

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<sup>25</sup> <http://www.goodreads.com/work/quotes/125495-notes-of-a-native-son>

<sup>26</sup> <http://www.biography.com/people/james-baldwin-9196635#early-works&awesm=~oi0hTlnSuF3wVv>

tone of his writing reflected his response to issues and experiences unfolding in his life personally and within society.

Pathos!

I was drawn to his writing because of the defining angst and pathos. Resonance.

It was the opening quotation that leapt out at me from the page and had me transfixed, provoking a response. The words ‘experience’, ‘bitter’, ‘sweet’, ‘re-create’ ‘disorder’, ‘order’ all resonated with me, but from a different perspective to that which James Baldwin wrote about. Within this punctuated continuum of recollected experiences, lies the paradox for both him and me. Some are bitter; some are sweet; some cause disarray; some re-establish order and priorities. As with James Baldwin’s storytelling, my reflective narratives numbed or intensified the experience as it is indelible personal experiences.

My study emanates from the need to turn the stones, to tell, not to an unmoved ‘mountain’ of people that James Baldwin experienced and wrote about, but to the community I live in and interact with in the hope of increasing awareness to the issues surrounding access to schooling for children with DS. I want people to have an insight into *my* experiences of access to schooling that they did not have before. In pondering over the past eighteen years, scrutinising the catalogues of memories and selecting those moments that connect with the purpose of this study, it was unavoidable that the past (context and experiences) jostled for space in words. The objective of the scrutiny is to allow the reader to be led to recreate the incident as it is unveiled and to relive it with the researcher- moment by moment. The research questions that drive the research method, I surmised, can be addressed with one of two methodologies: ethnography or autoethnography. The note to myself was that this is a study on DS, which makes the approach exceptional. Thus began my earnest search to work out which would be better suited. “Insider research is not faultless, nor should one presume that as an insider, one necessarily offers an absolute or correct way of seeing and/or reading the culture under investigation” (p. 6) I agree with Wolcott (1999) that “every view is a way of seeing, not [the] way of seeing” (p. 137).

I struggled to chart a plan that will allow me the flexibility to articulate my experiences clearly without infringing on ethical considerations central to the study. In my writing I wanted to portray a picture of access to schooling for my daughter with DS which must unravel the complexities yet the immediacy of the experiences presented a problem because of a perceived lack of neutrality and objectivity (Dyson, 2007).

#### **4.2 Arriving at the intimacies of my world**

I started reading on ethnography and Down syndrome and was struck by the work of Kliewer (1998). This ethnographic study examined school literacy experiences of ten young learners with Down syndrome over two years. Menear (2007) conducted a study on individuals with Down syndrome in the UK, focussing on parents' insights, of levels of fitness and quality of health of their CWDS. It was identified that "fitness levels and obesity in individuals with Down syndrome may be related to sedentary lifestyles, social and recreational opportunities, or low motivation to be physically active" (p. 67). Another ethnographic qualitative study on the college experience of an individual with Down syndrome was conducted at a Jesuit University in the Midwest in USA, by Hamill (2003). The finding was that irrespective of the cognitive disabilities of a person with DS, his or her qualification academically for entrance into a university is secondary to the experience and opportunity provided for the person to have a college experience. This study addressed related issues of access from a higher education standpoint. It delighted me to see an oasis of opportunity available to young people with DS (p. 351). Trenholm and Mirenda (2006) conducted an exploratory survey to ascertain literacy experiences of various age groups of CWDS in the contexts of home and community. Collaborative research by Kliewer, May Fitzgerald, Meyer-Mork, Hartman, English-Sand, and Raschke (2004) focused on "*Citizenship for all in the literate community: An ethnography of young children with significant disabilities in inclusive early childhood settings*". This study showed that educators who exploited the learning technique of children's personal narratives were successful in developing "literate citizenship" for all learners collectively, in inclusion classrooms. This was based on the premise that learners with disabilities had ability to create and make meaning of written texts.

I went on to reading a few scholarly work that employed autoethnography, starting with Ellis and Bochner (2000). Adopting a free flowing conversational style, the story itself captures the method. It was focused on an individual keen on pursuing dissertation using the methodology of autoethnography. My choice of autoethnography allowed for a free flowing piece of personal writing imbued with reflection. I contemplated the highly interactive therapy sessions and thought about how this could work for my own study. It was Murray (2012) who unobtrusively helped me see the value of my study as she too sought to promote appreciation for the human experience and challenge, and shift practices around the subject of developmental disabilities where DS is also situated. When I perused the autoethnographic study of Lazarsfeld-Jensen (2014), who explored disability by incorporated the “genealogical approach”, which Foucault was associated with, concentrating on issues of deafness and blindness. It is explored from multiple perspectives: “historical, social, and personal”. I did not deliberate on the prospect of a genealogical approach for my own study as the context was far removed from my own.

I was in a quandary about which would be the most suitable and began to ask myself questions presented at the outset of my study, my critical questions. I read more voraciously and after what seemed like unremitting gestation I was drawn to Sparkes (1996, 2000). He presented a balanced approach and allowed me to engage with his writing style and genre. He initially considered his work as narrative and later categorized it as autoethnography as it does meet the description of what constitutes autoethnography with its connection of personal and cultural components. His writing flows in a fluid, seamless and inviting manner to me: I, as he suggests “attempt to take you as the reader into the intimacies of my world. I hope to do this in such a way that you are stimulated to reflect upon your own life in relation to mine” (p. 467).

I found a niché.

I felt relaxed and reassured, more so through reading subsequent comments about his misgivings and gradual development as a researcher using autoethnography until he was able to frame his personal story with substantial and relevant theory. This strengthened his confidence to tell his story and weave it into pertinent theory. The insights gleaned, from a

reading, of his work and critiques of it, encouraged me to attempt autoethnography. My intent on utilising personal experiences as the impetus led me to find rapport with Sparkes's (1996) handling of autoethnography. I position myself to connect the personal lived experiences whilst netting and weaving to integrate the stories of other role-players into that lived experience. My journey of experiences is coloured by what I observed, what I now choose to write on, and how others will interpret and respond to what I write. Readers, too, may relate or identify with my experience in so far as interpreting my work will be subject to their own experiences. Jointly, or independently, meaning is generated from the words I have used to capture these experiences. Admittedly, there were fleeting moments when I doubted myself. This was due to exposure and focus on traditional research and writing conventions I employed in a previous study, which for a long time I considered the only legitimate way to gain acceptance from the reader and academia.

I surrendered and embraced that autoethnography will allow me the latitude to express realistic issues, which may be construed ordinary by some but contribute to authenticity I needed for the study. I have not followed a chronological pattern; instead, the incidents are piece-meal and details may not be structured or linear but they are drawn from experiences that are real and captured as believably as possible. Patton (2002) alludes to the same format when he states that "autoethnography speaks to the reality and importance of the seemingly mundane because rich details excavated are essential to the authenticity of autoethnographic study; those details are not structured, linear or even logical, but they are very much drawn from the reality of practice" (p. 111).

I then plunged myself into the world of research that principally used autoethnography as the vehicle to inquire and probe. I took time to read *what* was placed under the microscope and *how* they went about doing that. As I was a teacher for over twenty years and as a teacher of English who enjoyed the variety of ways in which ideas were expressed, I also slid under the layers of meaning that were couched within each journal article and book I read.

The phenomenon of the 'what' of my study was 'access', 'schooling spaces' and 'Down syndrome'. I leaned on autoethnography as a developing qualitative research inquiry practice to ask: "How does my own experience of this culture connect with and offer insights about

this culture, situation, event, and/or way of life?” (Patton, 2002, p. 84). According to Glense (2006), “the autoethnography begins with the self, the personal biography. Using narratives of the self, the researcher goes on to say something about the larger cultural setting” (p. 199). Increasingly, researchers (Smith, 2005; Wall, 2006) see a need to better incorporate self into research as a means of exploring sociocultural issues, as well as relieve the researchers from having to speak for others, because self is the source of data.

I examine the focal aspects by looking outward at the schooling system and its enabling or disabling policies, and inwardly at the experiences I have had with my daughter to access schooling. The benefit of adopting autoethnography as the preferred approach is borne by the avenue it offers for “doing something meaningful for myself and the world” (p. 672).

The rewards and ramifications of this type of approach are many. As the researcher “I am not trying to *become the insider* in the research setting. In fact, *I am the insider*” (Duncan, 2004, p. 3). Autoethnography provides that space for my own ideas and experiences as researcher, mother and activist to be included. Autoethnography “acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist” (Ellis & Bochner, 2010, p. 122). This study will present a record of the world of Tiara I have been a part of (the lived experience) and express how I gradually make sense of that world of schooling or lack thereof. It will document and analyse critical incidents as I purposively engage with what I have come to know.

Autoethnography involves the researchers' recollection and reflection. One of the ways of recalling is through memory work. Alerted by Chang (2008) that memory is both a friend and foe. I will proceed to expound how the arriving at the intimacies of my world had to be unhurried and, bearing in mind that when it is assembled, the triadic balance of “research process (*graphy*), on culture (*ethno*), and on self (*auto*)” is met.

### **4.3 Methodology of Autoethnography**

#### **4.3.1 Memory unlocked**

As James Baldwin illustrated in his work, coaxing one's memory to release the memories can be both sweet and bitter. For me, reflecting on these eighteen years that have passed is challenging primarily because there are a multitude and sometimes a clutter of negative and positive experiences. Painful experiences did not rush out to be written but needed gentle coaxing. Delving into past incidents seemed easier with distance because the immediacy of the incident has passed and is beneficial to the writing process. Ellis and Bochner (2000) recommend that establishing distance from the lived experience helps provide clarity and avoid getting too caught up. Frank (1995) endorses this view with the comment "lived chaos makes reflection, and consequently story-telling, impossible" (p. 98). Though the lived experiences were not altogether chaotic, there were moments when the challenges seemed insurmountable. On reflecting on some of those moments, the details elude me. Muncey (2010) argues that data analysis begins with memory work: selecting memories connecting to the focus area, entails examining, evaluating and analyzing which ones fit. For this autoethnographic study, I deliberated on nodal moments that inform the research questions pertaining to access, schooling in South Africa, legislation, inclusive education, Down syndrome and autoethnography. The experiences that needed to be captured had to be excavated from memory as it required deep consideration and reflection and then once unearthed, needed to be subjected to further probing and reflection. Through this journey I have compiled a record of incidents, events and encounters excavated from memory that resonates with my research focus on access to schooling spaces for my child with Down syndrome.

#### **4.3.2 The act of remembering**

This study uses my individual memories and intersecting them with memories of other mothers of children with Down syndrome, which coalesce into a collective mosaic or ensemble though not done collectively or collaboratively. Halbwach (1966) offers a distinction between individual and collective memory in saying that it is only individuals who

remember, even if they do much of this remembering together. Olick (1999) concurs with this view. This in practice for me meant that reconstruction of the memories lay in my individual access to it. The same principle then lay in how other mothers reconstructed the memories each had on the similar phenomenon of access to schooling for their children with Down syndrome. I am reminded of an apt observation of Toni Morrison (1996) cited in Mitchell and Pithouse-Morgan (2014), which I discovered between reading and writing this segment of the chapter: “Memory (the deliberate act of remembering) is a form of willed creation. It is not an effort to find out the way it really was ... The point is to dwell on the way it appeared and why it appeared that way” (p. 215). I could not replicate the exactness of place, word, gesture of the narrative in my study. Instead, I questioned why it was that way, at that time, which would provide greater value to the study. “One can understand such accounts as productions of meaning in the act of remembering” (Kuhn, 2002, p. 9). The imperative I adopt is that of Monaco (2010), that memory work- of remembering-is contextually positioned.

Theorists, Deleuze and Guattari (1994) make a fleeting entrance into my world and my fascination with them is nested in the harmony of their ideas. Deleuze demote memory stating that it is always the present (and that the future), not the past, which is at stake: 'We write not with childhood memories but through blocs of childhood that are the becoming-child of the present' (p. 168). The montage of memory, of past and present co-existing simultaneously is captured in this central idea:

We cannot represent a former present (that is, the past) without also making the present itself represented in that very representation. He adds, that each time we remember, there will be two core facets to this: firstly, the ‘actual’ memory of that past; but also a representation of the present (or the self) as itself being engaged in remembering. Deleuze describes these two aspects as memory and understanding. (p. 168).

The relevance of Deleuze and Guattari commentaries and value for this study is that I too do not hold memory as a modest issue of signifying the history (or past-ness) of the experience, admitting that memory facilitates the construction of that past.

Memory is the tool by which I construct my chronicles. I associated several events in my experiences of access for schooling spaces, with images which now help to mediate memories. Bergson (2004)<sup>27</sup> offers a useful explanation to extend the utility of memory to this study. He asserts that memory does not represent the past to us. It acts it. This thesis attests to this truth. Not only does it preserve long-gone, past images but it has also prolonged its usefulness into the present context of inclusion into this thesis. The transformation of memory from images into words, gives voice also to those within the cameo experiences of the informants. This becomes the vivification of my experiences long gone, but brought to the fore allowing it the prospect of being prolonged.

### **4.3.3 Accessing the field of data**

The data collection process for this autoethnography is characterized by two features: (1) the data collection framework (non-chronological, non-sequential model in this case); and (2) flexibility, built into the data-collection plan to allow me to decide subsequent data collection topics based on reading and re-reading of narratives. This combination of features helped me create a loose structure and format to the written work.

At the beginning, my supervisor, posed a writing prompt: describe the nodal moments connected to schooling, such as when Tiara was offered an opportunity to be at David's Private School. I drew a mind map and plotted possible topics to consider in relation to the critical question. The familiarity with reading qualitative research requirements helped identify possible topics that could contribute to the data.

The narratives were written intermittently over a period of six months and each narrative was re-visited if and when further details extending or clarifying the incident surfaced. I initially selected a broad topic. I wrote a general response to the selected topic. Once my words were on paper I revisited it to select one strand to focus and expand on it. The first prompt and a series of discussions around it with my supervisor and fellow students in the Doctorate cohort triggered further consideration of the depth of the discussion. Once I felt the topic was

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<sup>27</sup> <http://immanentterrain.wordpress.com/2012/04/03/democracy-affect-and-enter-activity-in-zoe-strauss/>

saturated I went on to another topic. This resulted in a reduction from ten to seven non-chronological/ non-sequential narrative pieces with each one aligned to the researched focus of access to schooling. It appeared like a quilt with multiple patches. I was always aware that the data when reassembled after analysis may need to be reattached meaningfully so that there are no loose threads for the reader.

All topics did not yield the same outcome as some were not directly relevant to the study. It required sifting each one for its appropriateness to the topic of access to schooling by reading each narrative in conjunction with the research question and sub-questions. There were ten topics: Crying into my teacup; I'm not a stranger at the gate: let me in; My child is talking, is anyone listening?; Tracking the milestones; Intervention strategies; If the shoe fits; Schooling apocalypse: the beginning...the end; What choice do I have?; Exclusion in Inclusion; The gate is opened wide... The gatekeeper has left.

I wrote personal narratives of about two pages on each topic. These helped me create a broad frame of reference. This will be the first layer of the data, which I call narrative analysis. Once the data is written I set it aside. The benefit of using the non-sequential model was two-fold: it allowed me to stay focused on one sub-topic at a time if I chose to, with the option to the revisit it whenever I needed to expand what was already written, and provide more depth to the original narrative until I was satisfied.

Typically, autoethnographical writing highlights action, discourse, feeling, epithets, piety and a sense of self-awareness (Ellis, 2004; Spry, 2001). This constituted the discourse analysis layer of the data. It will be crafted, weaving both story and theory. Once the narrative of each nodal moment is presented, I will use a magnifying glass over the lived experience (which is the third layer of content analysis). It is analysed for its immediate and wider application, with a 'then' and 'now' timeline interface, offering insights for myself and the readers (Creswell, 2007; Goodall, 2000). The range of nodal moments traumatic and negative, as well as joyous ones, incorporated in this study, include emotional, medical, professional, spiritual characteristics. These are recalled moments which had an impact on my life (Ellis, Adam & Bochner, 2011) and connected to the purpose of this study, allowing the reader to get up-

close-and-personal as he/she interacts with the exposed information. It has the potential to allow the reader to re-examine their own lived experiences and share its discourse.

The next phase was to interact with the key informants who were part of the nodal moments, participants with whom I interacted from the same community of practice. In this study context the ideas generated within the community of practice has delivered a worthwhile view to understand knowing, and extended to, learning (Wenger, 1998). In belonging to the same domain (Down Syndrome Association) we share a common interest and commitment. We enjoy meeting with each other on social and educational initiatives, offering support. We have shared best practice ideas on parenting, health, education, possessions, skills, stories, and recurrent problems.

Having considered autoethnography as my research methodology, a feeling of restlessness nagged me for a while. This restlessness remained buoyant as I contemplated the issue of ethics and how best to handle it for my study.

#### **4.4.1 Issue of ethics: Possibilities**

*“It could be **unethical** [my emphasis] to exclude people with more severe learning disabilities from studies that could provide insight into their experience and help to shape more sensitive care in the future”* (Tuffrey-Wijne, Bernal, & Hollins, 200, p. 188)

This statement, together with my increased awareness of inclusive research where people with learning disabilities are participative, as co-researchers. This approach which is gaining momentum, accelerated my impetus to persevere with this study. Walmsley (2001) created the term ‘inclusive research’ to signify “research involving people with intellectual disability as more than just subjects or respondents” (p. 188) and Bigby, Frawley, and Ramcharan (2014) adopt a similar approach. My reading of Kellett and Nind (2001), “*Ethics in quasi-experimental research on people with severe learning disabilities: dilemmas and compromises*” and the discussion on some ethical apprehensions through suggested models of including people with profound learning disabilities as actual and important team members in

related research, has shown me that there is currently a favourable trend in representing and including the voice of those with learning disabilities especially if they are able to represent themselves and the community of which they are a part.

Conventionally, people with learning disabilities (considered as vulnerable) have been considered as incapable or having minimal capability of engaging and understanding research ethics, particularly if it is classified as severe. This aspect of the process then is assigned conveniently into the hands of the researcher who is considered as an “academic expert”. As works adopting inclusive research approach enters into public areas of access, we read and see how people with learning difficulties have been engaging with ethics. Atkinson (2007) contends that gate-keepers’ preoccupation to shield the defenseless and weak as co-researchers or participants may inadvertently contribute to their omission or exclusion. This will renounce their voices in research practice. I endorse the view of Atkinson that “ethical scrutiny of research is not only to prevent harm to the vulnerable, but also to provide a framework to empower such people to take part in research. To do otherwise is to further stigmatise and marginalise them” (Atkinson, 2007, p. 134). He argues that to safeguard the vulnerable from perceived maltreatment if they were involved in research can ironically be detrimental. He raised concern of stigmatisation where labels, as descriptors are assigned to the person rather than consideration of the external factors. He also mentioned gate-keeping strategies of capacity criteria which filters and inevitably excludes learners.

The challenge is presented when one probes the level of inclusivity in research for persons with intellectual impairment, specifically for persons with Down syndrome. Here too the level of impairment ranges from mild to severe. The difference is that intellectual impairment is understood as incapability of learning certain tasks which affect daily living, whereas learning disability suggests that the person has difficulty in learning certain things while coping well or even excelling in certain areas, whether it be sports or the arts. Despite being categorised as intellectually impaired, a few members of Down Syndrome International (DSI), have self-advocates within their ranks who are cognitively able to engage as co-researchers, participate with insight and express what their feelings are about issues in research and have their voices heard, subject to the methods employed by the researcher. Whilst such advocacy and agency

is encouraged, there also exists the category of individuals with Down syndrome who are cognitively unable to engage in research ethics dialogue by virtue of possessing skills, but not those required for research practice. It then becomes incumbent upon those who adopt the responsibility of articulating the thoughts of the ‘voice-less’ children with Down syndrome to be mindful of the charge entrusted to them, and to me.

As a sensitive researcher I admit that this study has made an impact on me on a personal level. The drive to engage with the research was also increased by the community of CWDS and their families who call me regularly to check how my studies are progressing. I think to myself quite often that I owe it to the children, my daughter and others like her, and their families to deal with the issues, particularly on vulnerability, with respect and care. Whilst researchers express the difficulty in pinning a specific definition to the term ‘vulnerable’ due to it being conceived as a social construct (Moore & Miller, 1999) and may include broad categories of people (Flaskerud & Winslow, 1998, p. 69), I was comforted by the voice of Liamputtong (2007) that conducting research with and for the vulnerable gives them a voice provided it handled with care. I lean on Liamputtong (2007) in my discussion of ethics in greater detail in the next chapter.

#### **4.4.2 Assembling the moral maze**

At the earliest stages of my thinking of (what? why? who? when? and where) of my research, the consideration of ethics was high on my own agenda and I was thinking critically of the sensitivity of the persons, context and content that I would be unpacking in my study. I considered ways in which to avoid at best or minimise at least the number of ‘informants’ in the study so that the intent is still engaged and forwarded and the moral sheathing remains intact. What constitutes good social research and the complexity of a human subject had to be carefully considered, then measured against established principles of ethics even before thought and writing processes were operationalised. Protocols focused on how boundaries would be maintained, as research including vulnerable persons makes examination of this dimension paramount.

The term ‘vulnerable’ as alluded to in Chapter One, is a socially constructed term to include “individuals who experience diminished autonomy due to physical/psychological factors or status inequalities” (Silva, 1995, p. 15). The vulnerable individuals are those who may experience real harm and require protection to guard their welfare and rights (Moore & Miller, 1999, p. 1034), of being abused physically, emotionally or both. Some individuals are more vulnerable than others such as those with disabilities. Stone (2003) refers to these groups of people as the ‘marginalised’ and hence invisible populations in society. The reason for their invisibility could be varied but includes lack of opportunity to be heard, fear of being disrespected or having stigma attached to their condition (Fisher & Ragsdale, 2005; Wenger 2002). For this reason Liamputtong (2007) on researching the vulnerable states that “they need special care from the researcher” (p. 3).

Categorisations of vulnerability are varied and debated, as there are many reasons why research participants may be disadvantaged. Vulnerability may result from factors such as physical or mental infirmity, language difficulties or membership of a minority group. This research places children with intellectual impairment as vulnerable, the foremost being my own daughter. Adhering to ethical principles is of immense importance in this study.

#### **4.4.3 Ethical consideration**

The word ‘ethics’ is derived from the Greek word *ethos*, meaning ‘character’. In my reading I have come across statements ‘ethics must be considered within a social context, not in a vacuum’ (King, Henderson & Stein (1999) and ‘norms or rules for conduct that distinguish between acceptable and unacceptable’ (Resnik, 2011) that reinforce why ethical considerations in my study is particularly important. These statements are the stems that hold my study upright and informed the ongoing consideration through my research process.

A central premise in research ethics is the ethical treatment of others, particularly participants in the research. I have adopted protocols that protect the person or institutions, the details of which are expounded in this Chapter. Research that involves people with disabilities is important in uncovering issues requiring attention: in informing existing or new plans and

policies; assessing packages offering services; trailing changes on social and economic levels that touch lives of those with disabilities. The need for research, data and strategic plans have been underscored in “the Report of the Commission on the Status of People with Disabilities” (1996), and in the “United Nations, Convention on the Rights of Persons with Disability” (2006), adopted in December 2006.

Ethics, applicable to research in disability is situated inside the broad ethics framework of research. These principles are a cornerstone when incorporating human participants. It affects how they are included and framed to respect their human rights. The UN Convention offers guiding principles related to this focus. The UN underlines dignity and autonomy. This allows for individuality to be respected. Additional central principles highlighted in “Article 3 of the UN Convention” and fundamental to ethical appraisal comprise: “equality, full and effective participation and inclusion in society, respect for difference and accessibility”<sup>28</sup>

I have entered into this domain of autoethnographic research study being mindful that the very existence of moral principles guidelines is intended to minimise (or at best eliminate) room for errors or possible abuse in the course of research. This is applicable internationally. I have benefitted from familiarising myself with the Code of Research Ethics (2006) as outlined by the Human Social Science Research Council of South Africa and the UNCRPD. As a researcher focusing on people (and institutions managed by people) the well-being of individuals included in my study is my priority.

#### **4.4.4 The core values**

Three core values which make up the collectively acceptable foundation for research ethics is extrapolated from Gostin (1991) and Weijer (1999), is centralized in my study: Respect for persons, Anonymity, Beneficence and Justice

*Respect for persons* entails an alertness and pledge to affording participants protection from manipulation of their sensitivities, where autonomy may be diminished. *Anonymity* to be

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<sup>28</sup> [http://www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/\\$File/ethicsfootnotes.html](http://www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/$File/ethicsfootnotes.html)

implemented. *Respect for communities* places a duty on the researcher to uphold, preserve and respect tenets and securities and minimising potential for harm. *Beneficence* requires an obligation on the part of the researcher to minimise risks and capitalize on benefits that could be added to participants. *Justice* is associated with reasonable spread of both risks and rewards arising from research. The idea is that those who participate, with the inherent risk and responsibility of participation, should inherit and share in profits of knowledge grown.

In articulating my study with these core values, I adopted the following approach.

*Respect for persons*: The dignity of all persons participating in this study is valued. Appreciation of the core values ensured that people were not used as a means to accomplish research purposes. I remain open and available to allow informants to interrogate my views, and for my morals to be probed by others. The commitment to respect persons participating in the study is to implement informed consent and ensure confidentiality (Patton, 2002). All schools and persons associated with the institutions are presented anonymously. The same applies to direct or indirect references to medical persons.

*Anonymity* referring to guarding the privacy of informants is a key principle in this autoethnography and qualitative research; however, handling it, in action, was far more complex. The views of Walford (2005), Swain, Heyman and Gillman (1998) and Tuffrey-Wijne, Bernal and Hollins (2008) were carefully considered as they expressed the diversity of concerns that are possibilities in the context I faced and each one with valid reasoning. Walford (2005) questioned whose interest is served and whether liberties may be taken by researchers when participants are undisclosed. I found the sentiments of Swain, Heyman and Gillman (1998) resonate with this study. They say that persons with any form of learning difficulties may be filled with pride on account of their involvement and may desire to take ownership of their contribution and be willingly identified. The cautionary voice emerges from Tuffrey-Wijne et al. (2005) that careful consideration must be assigned on decisions and consequences since anonymity of the broader association and relationship to the participant, cannot always be effectively and securely predicted. Attending to “*Respect for communities*” placed the obligation on me to maintain integrity, values and wellbeing of the DS community

central to this study and, as strive to offer shelter from hurt. *Anonymity* and confidentiality with vulnerable persons will contribute to the intent which is to focus on issue of access from personal perspective whilst including its effect on others in similar circumstances..

At the end it was my carefully considered decision to disclose the name of my child for the following reasons:

She is a vulnerable child. She is unable to read or write but when told that Mommy is telling a story about her to her friends, she responds with rhythmic clapping. She needs some personalized attention with managing herself and cannot take care of herself or all of her needs independently.

She is of the group of marginalised people in our society. This study is an acknowledgement of our only daughter who is important to us. She has a distinct identity by which she must be recalled and remembered.

She may not be able to read for herself (as yet) but we know her contribution is immense for the community of fellow travellers. Her silence at times or limited speech facility at most times is perhaps more powerful alongside the words I have used to articulate this journey. Her story may be etched for posterity, living in the words which she may never be able to construct in her lifetime.

I was reliant on the “Health Professions Council of South Africa” (HPCSA) for guidelines on all aspects related to ethics since this study is located in the South African context. I will now explain how informed consent within the approved code of practice was achieved. Informed consent is the instrument indicating participants informed decision to be or not to be involved. Informed consent is a valuable process, safeguarding and upholding respect of persons and their contribution during research. The process of participation is limited to parents of children with Down syndrome, agents and non-profit organisation representatives. Details of what my research entailed, incorporating a balanced perspective of possibilities and advantages, are explained verbally and clarity is offered where required. A form capturing the details of the research is read and signed when the participant is satisfied. Further signatures of the researcher, and witnesses, completes the written procedure. Informed consent was necessary for this particular qualitative autoethnographic study. The actuality of being both

mother and researcher necessitates the insertion of an impartial critical ‘co-researcher’ via informants, to avoid positioning myself as the only knower of the experiences described. I admit the need for proxy consent on behalf of my daughter who is central to the chronicles disclosed. “Consent of a parent or legal guardian is legally required for children and may also be sought where the potential participant is determined not to have the mental capacity to consent” is advised by Strode, Lack and Essack (2010). Tiara has limited capacity to consent. Proxy consent is rarely considered ideal, but rather a necessary compromise. To address purposefully this aspect of the process in my study, I submitted a letter of motivation to the family specialist physician (see Appendix B) to give consent or assent to her being mentioned in this study, in first person and not as a non-de-plume. The letter of motivation sent to him, was returned with his approval. The doctor’s approval suggests that every reasonable step be taken to ensure that her personal dignity or right to privacy is not violated.

Conducting consent procedure with key persons, whose comments and views are inserted in this study, was done one-on-one in an agreed upon place and time. The language used was English and pitched at a level that the participant could understand. All participants were notified that they were free from compulsion or undue pressure to participate. Informants could agree to a written or oral permission. The requirement for informed consent, however, is not waived.

The aspects that will be elaborated upon include the following:

- Explain the purpose of the research.
- Explain expected risk and not just tout the advantages
- Emphasise, that voluntary involvement, implies the option to withdraw without negative consequences.
- Clarify how privacy might be protected.
- Provide my personal information and details of the processes should any person require clarity about the pre-, during-, and post- participation in the period of the study.

I recall one of the processes in place prior to formal acceptance as a PhD candidate was to defend my proposal (subsequently renamed as peer review), which I did with a power-point presentation. At the conclusion of my presentation I waited for more than an hour before I was invited in for feedback compared to other candidates who waited no more than twenty minutes. I was told that my proposal is flagged 'red' to denote area of focus, a vulnerable child, intellectually impaired. It was during this waiting period that I deliberated on aspects which I may be asked to elaborate. Ethics was central to the feedback and discussion. Following this university defense process I had to await communication from the review process and, when I received the letter of approval (see Appendix A) to proceed with the study, I foregrounded the critical nature of ethics throughout the writing process, emerging from the review.

#### **4.4.5 How I protect confidentiality**

By its very design, this autoethnographic qualitative research is conversational. As the researcher I maintained clear a professional interaction with participants. Conversation with each person will be kept on the topic of access to schooling and if the informant volunteers to divulge or elaborate on related but personal or sensitive information, it would not be disclosed in any form. To ensure confidentiality all electronic storage of material is password-protected.

*Beneficence* is explained in the following way: Individuals are afforded agency during and post-research processes by my committing to ongoing dialogue on access to schooling with them. Each will be allowed to participate in the increased agency for Down syndrome education in South Africa to maximize benefits that may accrue to the vulnerable group of Down syndrome. *Justice* is addressed by putting into place, the following process. In order to maintain mutually beneficial relationship, an invitation will be extended to key informants to attend a presentation on completion of this study where they will be allowed to engage further on the topic of access to schooling for children with Down syndrome. Individuals, who are most likely to draw advantage by way of knowledge, are asked to participate. Currently, members of the Down syndrome association and its stakeholders (children with Down syndrome, parents, agents and advocates) will be engaging more intensively and intimately

and, in the incremental process of acquiring knowledge, increase advocacy for access to mainstream education for children with Down syndrome.

Access to supervision has helped me develop reflection on the process, which is helpful for maintaining sound ethical practice. Further to this, the practice of ‘reflexivity’, where I as a researcher place myself and what I am writing in my study under closer examination, recognise potential “ethical dilemmas that permeate the research process and impinge on the creation of knowledge” (McGraw, Zvonkovic & Walker, 2000, p. 68). Constant reflection reflected my exercise of self-regulation.

The intricacies of knowing and knowledge, highlight the complexities and converse simplicities, which reside, side by side. While my academic engagement on various aspects of how I got to know, and continuing through the PhD, I occasionally tried to explain to Tiara that she lies within these pages and how easily she points to her name. I accessed different accounts of ethics and finally realised that considering Tiara and all the informants for their own sake and not because they may benefit me, underpins this study. I acknowledged how vulnerable Tiara is and the need to protect her would not be compromised. Reading widely on the importance of ethics clearance in researching vulnerable children provided me with a moral framework which I have used, to negotiate difficult decisions when settling on chronicles. Finally, the extensive and necessary space dedicated to ethics in this Chapter is not reduced to informed consent only but permeated all reflection, discussion and assignation related to my study.

#### **4.5 Key informants**

Chang (2008) refers to ‘others’ in an autoethnographic text as subjects, while Muncey (2010) privileges the terms participant and informant. I choose to use the term informants as it incorporates the academic voice of one person. Taylor (2011) indicates the necessity of negotiating the ethics of friendship when working with participants in research. All of the informants were known personally, prior to commencing this study. Four persons (and it was

co-occurrence that they were all women) were selected from the four major ethnic groups in South-Africa (White, Indian, Coloured and African), three of whom were from the province of Kwa-Zulu Natal and one from the Western Cape. These are two provinces out of nine in the country. The women range between the ages of 58-63. The criteria used to select them were: (1) parent of child or adult with Down syndrome and (2) the child or adult with Down syndrome had to currently be nineteen years of age or as close to it for historical context purposes.

There are many agencies advocating human rights of CWSN, in general and, specifically, DS. One such organisation is DSA-KZN. The chairperson of the organisation Carol Dellis, shared her account of events from her experience with institutions on the subject of access to schooling. The next informant is a retired domestic servant, Joy Nxumalo who resides in Umlazi, in Durban. She has a twenty-one year old daughter, Lindiwe who was born with DS. The next informant is Estelle Adams, a mother of a twenty-year old son with DS. She lives in Belville, Cape Town, and is currently an outreach coordinator of the DSA-Western Cape branch. One informant, Patricia Krishna, with whom I have had consistent association through her writings, is a highly acclaimed academic in South Africa. She was intimately involved in the crafting of policies pertaining to South African education focusing on special needs.

Data was collected through face-to-face individual interviews at a date, time, and place that suited the informant. I relied mainly on the semi-structured interviews format with the informants during times of discussion. The flow of a conversation between the researcher and informant was guided by three open ended questions or points to cover within the frame of diagnosis, access, schooling spaces and experiences. I guided the conversation through questions but allowed the informant to cover specific aspects and allowed the conversation to evolve and progress overall (Merriam, 1998). The broad questions were to allow the informants the space to express themselves freely. Data was analysed on two levels: firstly, to get an overview of the experience of schooling and secondly, re-look at the experience by focussing on what was said (specific words and phrases) and how it was said.

This study will principally have a first person account presented by me. The use of the first person voice in autoethnography is well documented (Holt, 2003; 2013 Wall, 2006; Ellis,

2010). Writing in the first person, making myself the subject of the research and breaking from the conventional separation of researcher and subject places this study as autoethnography (Bochner, 2012). Within the principal narrative will be ‘dialoguing voices’ in the form of commentary or narratives of other persons that relate directly to this study. This includes the voices of members from the community of practice: an academic and four parents. Tedlock (2000) acknowledged that the feature of autoethnographic study that is beautiful is that the self and the participants “appear together within a single narrative that carries a multiplicity of dialoguing voices” (p. 471). This study is inextricably linked to a community of other parents of children with DS which is part of the motivation for this sample. Much of the trauma of journey of accessing schooling spaces was buffeted by parents having similar experiences as myself and generating knowledge which may be considered emotional, from their subjective experiences and unshared until now. Paradoxically, it was ‘comforting’ to know that I was not the only one undergoing what I did. An argument offered by Monaco (2010) in favour of autoethnography is that “it teaches as it challenges the limitations of knowledge production and social science research practices that often attempt to separate the detached intellectual realm of the objective from the highly emotional realm of the subjective, which is silenced or rationalised in empirical work” (p. 102).

#### **4.6 Organising data**

I analysed the data in two ways and in two parts. Part one entailed reading my own chronicles and applying a critical lens to it. I read the chronicled individually and highlight key words and phrases then placed them adjacent to each other to identify if there were any overlapping ideas. These emerging ideas translated into themes and will be discussed intensively. Part two will reflect a similar pattern. I will read the cameo chronicles of each informant, fully and repeatedly, to identify any pronounced themes that are similar or dissimilar particularly because each individual is representing the perspective of experiences that may be unique to self, race and culture. Each level of analysis required a reordering of the data to recognize developing and entrenched themes that gravitated towards the following assertions: what options were available for the child’s schooling; how did parents access schooling for their child with Down syndrome; to what extent was access enabled or impeded; how would they

describe the child's experience of schooling. These four cameo chronicles of the informants will coalesce into a single discussion though with various themes. This thematic discussion may overlap with discussion of theory of access as extrapolated and adapted from Nind and Seale (2010). The summary discussion will allow the reader to see a tapering or merging of ideas of Parts One and Two, if and where similarities or differences related to critical questions are identified.

One cannot embark on such research without careful and considered processes related to ethics particularly when involving children with disabilities considered as the vulnerable. A deep consideration of ethical issues permeated the process of this study. I have explain how I resolved some of the dilemmas faced.

#### **4.7 In conclusion**

In this Chapter I have allowed the reader entrances into the intimacies of my world. Focussing on the process of remembering and memory work (from a personal, non- medical perspective), and how it is to be represented in the study, was important in terms of particulars: chronology, geography, characters and setting to benchmark the common standpoint from which all voices are blended. Inviting community of practice informants into the field expands the discussion. Insights into an analytical framework to be deployed was described in detail and focused on how the data is to be organised and analysed. Then the reader considers with the researcher how ethical issues pertinent to this study are balanced against the requirements of a PhD.

Chapter Five is arguably the most subjective of the thesis as it allows the reader to pause more often between each chronicle for the emotional weight it bears. The array of chronicles is not compartmentalized into restrictive timeframes or sequence but braids itself as cameos. There is some indication of time if one looks closer at the compendium presentation in chronicle entitled, 'Exclusion in Inclusion'. The use of the writing style "My turn, your turn" allows the reader to follow the iterative nature of autoethnographic writing. The circle of informants

articulate their experiences on access to schooling spaces within the same discussion as mine and gravitated towards discussion of ideologies and practices.

## CHAPTER FIVE

### *STICKS AND STONES*

#### 5.1 MY TURN

##### 5.1.1 Introduction

The data for *my turn* section of autoethnography consists of eight chronicles all varied in length. Exploring the new epistemology of autoethnography, I have reduced the risks inherent in the representation of others primarily through non-de-plume, allowing for new knowledge through creative construction from a situation of being mother and researcher. Whilst it is an offering on a small scale, it has the potential to advise salient and specific challenges within specific circumstances and contexts (Denzin & Lincoln, 1994), related to access to schooling for children with Down syndrome. I am constantly mindful of what I remember, how I remember and convey it through the discourse of reflexivity. As Amanda Coffey asserts: “The craft skills of reconstructing and reproducing the field pivot on how we remember and what we remember. Our (re)construction is temporal and evokes the past in the present” (1999, p. 110) as alluded to earlier in Chapter four with Bergson (2004) comment on the same. It reminds the reader that my understanding and explanations of information intersects imagination of memory and specifically applied theories, for analysis, whilst still maintaining the genre of autoethnography. I review my own interpretation, constantly bearing in mind that it was a difficult process to spell out my own views and separate from them for purpose of analysis, in order to keep in check that I do not take liberties.

Each of my chronicles may be considered self-standing as they are episodic and do not follow on from each other. These are presented in substantive detail at the beginning of the chapter. *My turn* is followed by *Y/Our turn*. This offers space to the voices of informants (particularly mothers of CWDS) belonging to the community of practice to be incorporated. Once *my turn*, *y/our turn* discussion is completed, the next consideration is of themes that emerge collectively from all chronicles and cameos. These themes will be synchronized and subsumed into the discussion at the end of the Chapter with ‘auto’ and ‘ethnography’ cradled together at the conclusion of this Chapter.

### 5.1.2 Naming the chronicles

The chronicles are as follows:

	<b>Chronicle</b>	<b>Estimate time-frame</b>	<b>Access</b>
1	Ten fingers, ten toes	At birth, 1995	Homeschooling with creative and mainstream adapted learning tasks.
2	Tracking the milestone	From birth, 1995 onwards	Interventions: physiotherapy
3	Lend a hand or book	End of 1996 until 1999	Interventions: speech therapy
4	Going Down - under	1999	Open access to inclusive schooling setting
5	If the shoe fits	1998 onwards	Medical intervention: appropriate purpose-made shoes meant increased physical balance, which equaled to safety in varied geographical spaces
6	The beginning...the end	1998 onwards	Physical access
7	Whose choice is it anyway?	1998 onwards	Physical access
8	‘Walls of inclusion’	Fifteen years	Physical, basic amenities,

**Table 1: Eight Chronicles captured with estimated timeframe of occurrence and notion of access.**

The leading narrative *ten fingers, ten toes*, an idea echoed in Lalvani (2009), introduces Tiara: to me as a mother, to her dad who waited with bated breath for her first cry, to her (then) two year old brother who wanted to share a slice of his birthday cake kept aside from his second

birthday party the day before, to her doctor who delivered her as he did her brother, to the world of family and friends ... waiting. This is an academically sentimental chronicle. The paradox of joy and sadness may be palpable in its reading but eighteen years later is not tinged with sorrow, at all. The thoughtful selection of seven from ten chronicles was done solely to concentrate on the issue of access to schooling spaces rather than emotive accounts of incidents which though they are important, do not extend the focus of this study. *Tracking the milestone* outlines the need to put in place procedures to address challenges faced in delayed milestones. *Lend a hand, book, whatever* speaks of speech therapy and physiotherapy and the responsibilities entrusted to us all as her care-givers. *Going Down- under* underscores motivation for emigration and the variables that played out on the canvass of our lives, before and after that phase of 'running to' rather than 'running from' battle. *If the shoe fits* is a reminder that there are no small matters relating to raising and fulfilling the basic necessities for a CWDS. The lesson was to attend to detail of design and material and its match to her height, weight, sandal gap with no-arch feet. *The beginning ... the end* presents the dilemma of mainstream or special needs schooling. *Whose choice is it anyway?* captures the encounter that informed our decision-making. *Excluding in inclusion* is a concertina of the nearly 15 years she has spent in the schooling system. It is in the form of a table to allow the reader a quick overview of the schools, time spent there, her age at each stage and the holistic consideration of access. The symbolism of the wall will be clarified in the discussion. This is the most substantive narrative as it hones in to address the key research question: How and why can my experiences of searching for schooling spaces for my daughter with Down syndrome be explained through autoethnography?

#### **5.1.2.1 Chronicle 1: 'Ten fingers, ten toes'**

*I have been told the pathway to a baby's entrance into the world begins long before it actually happens. The path is not always a familiar trodden path. Sometimes it's a 'road less travelled'. From the very moment a baby arrives into the world, family and friends, even distant relatives, clamour to get a glimpse of the baby. One glance is all it takes for many to start forecasting the potential of success for the baby. The eyes, the hair, the size, weight,*

*complexion are all inescapable traits that help forge a plethora of possibilities in their estimation. It's a phenomenon that is not unique. It was my experience as well.*

*I had to do wait for further three days after I brought my baby home from the week-long stay at hospital before I would hear any results. During this waiting window-period I didn't allow myself to engage with any other professional except the attending paediatrician/cardiologist.*

*My child has ten fingers and ten toes, a head and eyes and could breathe on her own. What could be the problem?*

*"Your child has DS".*

*I remember feeling numb. The doctor, recalling my defensive outburst in the hospital earlier in the week and, because he was also a Christian thought it necessary to 'reassure' me, that my circumstances of a CWDS was in no way an indication that I lacked faith. He went on to share his own story of having a child with an eye condition (I don't recall the exact term) that may result in blindness in one eye at some time in her life. This didn't comfort me then. What kind of reassurance is that, when a doctor tells you of his problem when you can barely understand your own.*

*I learnt much later that my husband was aware of the result prior to this visit to officially hear the news from the family doctor. Looking back, I can see how unfair a burden it was because he was as shocked as I was yet had to be strong for me.*

*Here I was with a son only two years old and having to negotiate an additional responsibility without a manual, no guidelines, no trial run, and no option to exit. How am I supposed to navigate a terrain without a map of what to avoid, what to do and what to be wary of. Where do I start? In the emotional turmoil, reason deserted me. This was all too unfamiliar, fearful and altogether, paralyzing. That's what happened! I was in a pit of emotional paralysis. The utopia I lived in until this moment was suddenly and without warning, disintegrating. A dark ominous cloud hovered over me, my home, my family...*

*My pathway was strewn with emotional debris. I needed everyone to stay away so I detached myself from everyone outside my home, to help me cope better-until I could forge a plan of*

*action. Instead of action, I wallowed in self-pity, self-loathing and unbridled anger. It took me many months before I could muster the courage to share this reality and face the truth with my extended family.*

*My first source of advice was the Bible. I needed answers! I didn't have a plan so I was hoping God had one. The one verse I clung to was 'speak to the mountain and say, "be thou cast into the sea" and "it shall be done". One week of agonizing, waiting for results of the blood test felt like a lifetime. It was emotionally exhausting and spiritually barren. There was unbridled anger. I felt like God was punishing me for something I had done or not done in my life am. Was I being punished for the sins of my parents? It was illogical to think this way. Whichever way I looked at it, there was no immediate answer.*

In his research of families who have CWDS, Skotko (2005) noted that the majority of parents "do not learn of their children's diagnosis until after the children are born" (p. 64). Hook, Cross and Schreinemachers (1983) note that prenatal testing (as recently as 1983) allowed practitioners to elicit a fairly accurate diagnosis within two months of pregnancy, yet such procedures were not commonly shared with prospective mothers unless over the age of 35. This age group and higher are considered at high risk of conceiving a child with possible chromosomal abnormalities (p. 249). Back in 1995 prenatal testing was not an option that was discussed with me by the attending doctor, primarily because I was considered a low risk individual taking into account factors such as age (twenty-seven), no family history of chronic diseases or anomalies, healthy medical profile and easy pregnancy of my previous child-factors considered as important in the medical field in diagnosing abnormalities.

### **5.1.2.2 Chronicle 2: Tracking the milestones**

*As parents, we waited with much anticipation to welcome a smile-even half a smile, vocalisations of any kind, gestures and the arrival of first words as we tried to track whether our child would be able to engage in any form of meaningful communication. This development was delayed and the wait was so worth it when we heard the first word that sounded like 'dada' when she was eight months old. From my incidental reading on the*

*subject I learnt that language development in children with DS is quite varied, and it is important to consider expressive and receptive language separately.*

*In Tiara's case the progress on both was slow and they developed at different rates. On beginning with speech therapy as early as possible, we had raised expectations as she acquired and developed her language skills. The intervention programmes, while they developed her-albeit slowly-did not provide for rapid or substantial progress because the interval of two weeks between the first session and the next was wide. Either the interest in the task was limited or the technique used in the practice at home programme was not properly administered and monitored by my husband, the care-giver/s or myself when we worked with Tiara during the day.*

*It didn't occur to us nor was it recommended to us by the regular paediatrician, Dr Karim whom we visited so frequently in her infancy, that we should have had her hearing tested. It was only in 2005 that we were advised by him to take her to an Ear, Nose and Throat (ENT) specialist because Tiara did not breathe properly during sleep and we were concerned that this was making her restless and disturbed her sleep, especially at night. The problem was thought to be her adenoids.*

*He subsequently requested a hearing test when he examined her ears and saw the buildup of wax in both her ears. He asked us if she could hear us well. We were for the first time alerted to the behaviour patterns preceding this comment and shared incidents with the specialist. For example, when she transferred the telephone earpiece from her right ear to her left. He recommended an auditory assessment. The speech discrimination test designed for typical children couldn't be administered without modification. Tiara did not necessarily have the vocabulary to identify all sound that would be played to each ear, one at a time showing that to 'test' her hearing using this traditional methods was inappropriate.*

*It was resolved to do a "bone conduction audiogram", through which the level of hearing is measured. This was not conclusive as Tiara needed to be absolutely still during the procedure. She was 8 years old.*

*Her age and weight were factors taken into consideration to determine the strength and dose of medicine to be administered. The dosage didn't work. She was wide awake and started to show her restlessness by tossing and resisting our touch as she sensed the unusualness with which she was handled.*

*Finally it was suggested that we have a procedure (under general anaesthetic) of inserting grommets into her ear at the same time that her adenoids would be removed. The hearing test was repeated after two weeks. The objective of inserting the grommets was to amplify the sound level she was able to hear. Whilst her sleep pattern improved after the adenoids were removed the result of the repeat auditory test concluded that Tiara is profoundly deaf in her right ear, and has 90% hearing in the left ear. Prior to this test, it seemed that she compensated for the hearing loss by adapting her body posture to listen when she was spoken to. She often wanted to look at our face when we spoke and often read facial expressions to support what she thought she heard. The speed of our speech also affected her understanding. We spoke normally. To her, lip reading was challenging. Only then did we recall that she didn't sustain any conversation telephonically and she swapped the hand grip of the telephone from right to left. This was the reason. She couldn't hear!*

*I was angry at the school teacher who worked daily and extensively with her yet did not identify this serious impairment. The hearing test report was forwarded to the school and the recommendation of re-seating her to be on the right side of the teacher's teaching posture was effected. The greater concern is that the teachers to whom the information was available did not read the progressive historicity report when receiving her from the previous year's teacher and different teachers had to be reminded each year of the report. It is not possible to know now how she would have progressed had she been diagnosed earlier. I was more regretful that I didn't use sign language to equip her to communicate with us. If we did she might have alerted us through more frequent signing than vocalising that she had hearing impairment. I was utterly disappointed at the delay in this diagnosis, though who is to be blamed I cannot say. However, I accept partial blame because the responsibility was also mine.*

Research conducted by Shott, Joseph and Heithaus (2001) within the DS population estimated that 38–78% of children with DS have a hearing loss, a three times greater risk than children with other developmental delays. Chronic otitis media as he explains it to me, is a primary cause for hearing impairment and children with DS are at increased risk due to facial structure differences related to DS. The anatomy of the midface specific to children with DS causes the child's eustachian tube to be more cylindrical in shape and smaller in width and predisposes the children to chronic ear disease. In addition, stenotic ear canals can cause cerumen impaction, and hypotonia can leave the tube more likely to collapse and restrict air flow to the middle ear causing buildup of middle ear fluid and chronic otitis media (Shott, 2006).

CWDS experience cognitive delays, with language identified as one of the most impaired domains.<sup>29</sup> It stands to reason that language opportunities provided within the environment can influence a child's facility in development of language (Price, Roberts, Vandergrift & Martin, 2007). For that reason, parents should be provided guidelines of best practice to boost the opportunities for their children to learn language (Roberts, Chapman, Martin & Moskowitz, 2008). The relationship between hearing ability and support of speech and language development has been emphasised by research conducted by Moeller, McCleary, Putman, Tyler-Krings, Hoover and Stelmachowicz (2010) in a longitudinal study with four children focusing on “late-identified mild-moderate sensorineural hearing loss” (p. 53). A similar focus is available of study done by Hendershott, Woods, Jackson and Lakey (2012). They state that children with developmental delays and disabilities, such as Down syndrome, may develop communication skills at a slower rate as compared to their typically developing peers. As noted above, CWDS present increased possibility for communication deficits, especially with expressive language, and these language deficits can be further affected by hearing (Shott, 2006). Receptive language is described as the skill to simultaneously listen and comprehend language conventions. Expressive language expands to include external communication, by means of language. It places greater importance on having to know if a child has impaired hearing as this process will be affected.

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<sup>29</sup> [http://digitalarchive.gsu.edu/cgi/viewcontent.cgi?article=1095&context=psych\\_theses](http://digitalarchive.gsu.edu/cgi/viewcontent.cgi?article=1095&context=psych_theses)

Language is one of the most impacted abilities for a CWDS, with deficits in expressive language, vocabulary production, and speech intelligibility (Kumin, 2012). Previous research found that competency in expressive language skills amongst CWDS is less than in receptive language skills. Ypsilanti, Grouios, Alevriadou, and Tsapkini (2005) conveyed the notion that CWDS are under-developed in aspects of expressive language, whereas their receptive vocabulary and comprehension are less impaired. They stated that children with DS produced significantly more errors on expressive vocabulary than mental age-matched controls.

For CWDS, expressive language generally progresses through the same milestones as typically developing children but at a delayed rate; the period of canonical babbling is often extended, with first words delayed. It is not uncommon for a child with DS to produce his or her first words at 21 months or later (Abbeduto, Warren & Conners, 2007). In another study, Berglund, Eriksson, and Johansson (2001) found overall a 36-month-old child with DS paralleled the language performance of a 16-month-old typically developing child, and the language development of a 48-month-old child with DS was close to a 20-month-old typically developing child's language development.

*As parents we waited eagerly for our baby's utterance of her first word. Whilst acknowledging the possible imperceptibility of receptive language we focused on her response to the sound of our voice, which is one of the ways the beginnings of receptive language is indicated. When she cooed in response to a familiar voice, we knew she was commencing with expressive language. This signalled that she was starting to appreciate the usefulness and importance of communication.*

### **5.1.2.3 Chronicle 3: Lend a hand, lend a book**

*We often spoke to other parents who awaited their turn in the queue for speech therapy for their child with Down Syndrome (DS). We became regular visitors to the Down Syndrome Association (DSA) situated on the same premises as the municipal local clinic. Andrea, the speech therapist, was highly recommended for her skills in working with children with special needs. She offered insightful comments and tailored programmes for each child to work at his or her own pace and often issued us, as parents with 'homework'. These exercises were*

*practiced with our child at home to build on vocabulary and establish sequences to simple life skills, for example, brushing one's teeth. The following week the therapist would consolidate these activities and add to them. I believe she was training us as parents to develop effective strategies to enhance the opportunities for Tiara to learn language. One of the key techniques was to teach by Tiara taking turns and doing all activities using eye contact and with repetition of activities to consolidate its understanding. The one characteristic that often amused us was Tiara's ability to imitate what we did. On occasion this resulted in much hilarity, for example, when she intentionally dropped the box of crayons because I accidentally dropped one.*

*Ria (the speech therapist) was always prepared. She had a formal structured programme with specific guidelines of work – concentrating on simple tasks and concepts. Often, I took Tiara myself. It was often coupled with a meet-and-greet session with other parents and their children with DS. There was little available time between sessions to engage on matters pertaining to intervention programmes, therapy ideas or general coping skills. Despite their friendly nature, our children rarely interacted with each other. If we did chat our conversation hinged on activities we were working with at home and we 'assessed' its meaningfulness. My focus was primarily to get Tiara to read/recognise words and pictures and to be able to form a sentence in conversation. I knew this would be a long term commitment and teaching and learning, for Tiara, couldn't be rushed. The intervention and support programmes had an impact, albeit very little and very slowly. What troubled me is that learning new information often displaced prior learning.*

*During one of these many visits, I talked with another parent, Rachel, about her choice of schooling for her son Tom, who was much older than Tiara. She openly expressed how limited the options were and how reluctant principals of schools were in offering schooling space for her child. During one of these conversations the Chairperson of the DSA was close by and overheard our conversation. I thought it an ideal opportunity to get her input and I chatted with her view on available options for our children. She shared with me that another parent was negotiating with a mainstream, private school in Hilltop Mainstream for his daughter, but described his struggle in persuading the School Governing Body to offer access for his child. He was asked to sign multiple 'on condition' forms. Further into this same conversation*

*Sunset, the school for children with special needs in Durban North was suggested. Bella's daughter, Jennifer, schooled there. Whilst I listened attentively to what was shared I was convinced that Tiara was adequately equipped to enter into mainstream schooling. A special needs school would be the very last option, if at all.*

*After months of contact sessions/ activities, the therapist offered a very positive verbal report on Tiara's progress. She was persuaded, and convinced us, that Tiara had the appropriate and adequate vocabulary and social skills to learn alongside her peers in a mainstream inclusive context.*

It is suggested by researchers that due to delays and intervals in realising several developmental milestones for CWDS prompt mediation with speech, occupational and physical therapy commence and be sustained for prolonged period to ensure optimal long term results (Davidson 2008). Research findings of Colleen Oliver indicate that exposure to timely intervention, even from age of one month helped performance in language assessment when eighteen months old compared to babies who received intervention when three to six months old. Martin, Klusek, Estigarribia and Roberts (2009) agree with these findings, as they found that timeous intervention is beneficial for CWDS. Kumin (1996) states that although there is extensive research on receptive and expressive language disorders in children with DS, the information on intelligibility problems of children with DS is sparse. Intelligibility is explained as "the capability of the speaker to produce an understandable spoken language" (p. 307) and in the case of DS it is described as reduced. There has not been sufficient research to support this.

#### **5.1.2.4 Chronicle 4: Going 'Down-under'**

*As Tiara began to grow, we noticed the slow development and the milestones were just not there. This created an instinct to pay increasingly more attention to Tiara and less to our son. He would be working with two sets of puzzles or building blocks at the same time whereas Tiara would struggle to put a few words together. Her first sentence was 'Yes Jesus loves me'. She learnt this from a musical video which was given to her by one of our friends.*

*We knew that schooling Tiara was going to be a challenge and the Down Syndrome Association – Kwa-Zulu Natal (DSA- KZN) recommended a few schools, but we were not pleased with any of them. We felt that children with learning disabilities were being too isolated, and we wanted her to be educated in an environment where she would benefit more from interacting with other children with all levels of aptitude. There was no such place in South Africa and we began to investigate the availability of schools for inclusive education in other countries. We knew of families that had emigrated to Australia and New Zealand, and they spoke highly of learning spaces for children with Tiara's needs. We decided that we would emigrate to Australia, via New Zealand as the waiting period, at the time, for Australia was about 3 to 5 years. After a lengthy and expensive application process, interviews and medicals we were granted visas for New Zealand in May 1999. Thereafter, we began to have doubts as we would be leaving behind our family members, our immediate support from my mother-in-law, who used to take care of our children whilst we were at work. We would also be leaving our jobs and venturing into uncharted waters as the economy in New Zealand revolves around approximately 4 million people and a lot more sheep. We decided, however, that the need for Tiara to be in a learning environment suitable for her was of paramount importance and the decision was made to visit New Zealand in the winter of 1999. There was a lot made about the 'harsh' weather conditions to that of South Africa and we agreed that if we could handle the winter there we would be comfortable. Michael had arranged for interviews with three of the major construction companies, and I had arranged interviews with two schools in Auckland for a teaching position. We spent three weeks in New Zealand and were impressed with the learning spaces they had for children like Tiara. Furthermore, all children from the age of five have a right to free education until they turn nineteen. Children having special intervention and support needs continue to receive free schooling until age of twenty-one. Things were looking very promising and we felt that it would be an ideal place for our little girl to develop.*

*The weather was manageable and Michael was offered employment by one of the largest construction companies there. The New Zealand Teacher registration organization was extremely impressed with my CV and did not foresee any difficulties in me securing suitable employment in any one of their schools. Things were moving rapidly and Michael needed to*

*respond to the employment offer within a few days. We decided that he would accept and that he would commence on the 1 of September that year. We returned home with mixed feelings but the driving need to access suitable learning spaces for Tiara was the motivating force behind our decision to emigrate. Michael resigned from his job, cashed in his pension, and we sold all our assets, but could not sell our house. I was tasked with this responsibility as Michael would return to accompany the family for the great trek in December of that year.*

*Within a few weeks of Michael being in New Zealand he could sense from the tone in our telephonic conversations that all was not well back home. I was having second thoughts and my health began to suffer. I was concerned about the close family ties that we would leave behind, and the loss of the support structure in the care and love of my mother-in-law for our children. Michael returned home in November 1999 and we decided against emigrating. Tiara would have to make do with the schooling spaces that South Africa had to offer children like her. But we would endeavour to find the most suitable. We would do everything in our power to ensure that we give her every available opportunity to develop to her full potential.*

Gothard and Ford presented a paper, at the eight World Down Syndrome Congress, held in Singapore in April 2004, in which they related their treatment by the government officials in their planned emigration application. They identified discriminatory practices when they received a negative report from the Health Assessment Service citing the probability that the needs of their CWDS will include additional educational resources over and above what is provided in mainstream education. An additional reason for the decline was that the child will in the future most likely require supported employment which is considered as a cost to the Australian community. The final outcome set aside the ruling of exclusion based on independent and substantial medical evidence submitted by the parents. The advice offered to prospective applicants for emigration was that they would encounter more stringent selection through application process than would otherwise be the case. It is for this reason that we chose to go to New Zealand which was less stringent, rather than Australia.

### 5.1.2.5 Chronicle 5: If the shoe fits

*We were cautioned by the physiotherapist that children with DS often display delayed onset of independent walking. This did concern us because one of the key observations of the nurse attending to Tiara at the hospital was that she had low muscle tone called hypotonia. It is a muscle condition where the muscles have a deficiency in their tone (the amount of tension or resistance to stretch in a muscle) and strength. This assuaged us primarily because we thought intensive therapy would address this weakness. We had noticed the flat-feet at birth and with time, we were concerned that if the hypotonia was not addressed satisfactorily, the impact will be on an important milestone: her ability to walk. What most people take for granted, we struggled with: getting the right pair of shoes. The readily available commercial shoes didn't meet her needs. To address this issue we had to visit a specialist: an orthotist and a shoe company based in the Midlands (approximately 107 kilometers from home). We felt that by identifying corrective measure for flat-feet through regular x-rays and visits to the orthotist we would also increase the chances of Tiara successfully balancing when upright, walking and participating in various co-curricular activities that may be available to her.*

“Children’s foot conditions are a frequent cause of parental concern, especially flat feet is a dominant concern. Indeed, the foot has been found to be the most common musculoskeletal region presenting to general practice in the UK” (Evans, 2012, p. 1). On hearing professional people express the sentiment that several foot maladies experienced in adulthood, commenced in childhood, I wanted to be proactive.

A sandal-gap malformation is identifiable in prenatal ultrasound. This characteristic is identifiable with its noticeable interspace between the largest toe on the foot and the one nearest to it. It is equated to the gap evident when wearing a pair of sandals. While considered a typical variant in circumstances of it being the only finding, it is correspondingly thought of as a soft indicator of other fetal anomalies (Davidson, 2008). For safety reasons I wanted Tiara to be fitted with appropriate shoes. To most people buying a pair of shoes is so elementary that one does not think long and hard about it. The basic shoe is easy to find. The range of styles, colours, texture is secondary to comfort. To us, finding the right pair of shoes

was nearly impossible. There were no outlets that catered for flat feet with no arch; it had to be purpose-made.

Childhood-valgus flat foot with marked pronation of the foot created problems of stable gait. In early years Tiara's walking was affected and her balance on her feet compromised by this condition of her feet which required various specialists' advice. The first was an orthopedic surgeon who recommended we visit an orthotist to have a mould made of her foot and a purpose made shoe created to offer more support with a detachable in-sole to create an arch for the flat feet and help stabilise her walk. (Her walk until then was a swaying and imbalanced with a tendency of swaying from side to side.) Year after year, and at great cost, Tiara had to be taken to the orthotist to have a new mould made each time she outgrew her shoes. Specific height, weight, material and strapping had to be carefully deliberated.

There is not much research available to me on suitable shoes for school children. Illingworth (1978) appealed to the medical profession, if they could, to put pressure on shoe manufacturers to design and manufacture suitable shoes, emphasising the risk of disfigurements in children wearing unsuitable footwear. Beyond this comment I struggled to find research on design and manufacturing of suitable walking and running shoes for CWDS.

I accessed information on children's footwear from a website promoting their range of shoes, which offered the following information: Children spend hours of their school lives in shoes, it is important for them to fit properly. I took particular notice of a website promoting a particular brand of school shoes which, in its marketing statement, state that "in the first eleven years of a typical child's life, feet will grow through around 17 shoe sizes, up until they are 18 years of age, and ill-fitting shoes can lead to problems in adulthood, such as ingrown toenails, corns and bunions, which may even require surgery later in life".<sup>30</sup>

To ensure we were obtaining the appropriate fitting school shoes, both feet were measured and it was found that one foot was slightly longer and broader. To avoid injuries by wearing shoes larger than the feet, Tiara's shoes had to be purchased twice a year. Velcro fastening on genuine soft leather uppers was considered an appropriate choice. The orthotist took into

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<sup>30</sup> [www.kidspot.com.au](http://www.kidspot.com.au)

account the following aspects in the design of the custom-made shoes: a comfortable fit offers the wearer's thumb-width space at the back of the shoe and at the front of the longest toe; the widest part in the shape of the foot should match with the width in the shoe; the clasp on the shoe must allow for the heel to be firmly positioned at back of the shoe and made of velcro as she could not do lace-up; the sole needed to be non-slip in case of inclement weather, and thick enough to give stability; the shoe heel needed to be comfortable and secure whilst the rear, durable and offering a steady balance when walking; insoles had to be designed to be inserted into the shoes to compensate for the flat feet and create an artificial arch; the light weight of the shoes had to be comfortable and genuine leather material was chosen to meet this requirement.

I was mindful that her feet had bones in continual growth. We were advised by the orthotist that if she wore shoes larger than her feet, it would cause damage to her bones and balance. Having flat feet meant that only custom-made shoes designed uniquely for her feet would do. Her shoes needed to be stable when she set on the floor to avoid a swaying gait, with sufficient cushioning, whilst offering all-round support. If her shoe wore off unevenly, it could lead to superficial irritation of the skin so it had to be inspected intermittently. One style of shoes did not suit all purposes and therein lay our next challenge. Extra-mural activities required children to wear takkies. This battle we could not win. We compromised by buying takkies off the store shelf of a reputable store and inserted the purpose made insoles into them.

This is the starting point that prompted me to think of schooling access as not just entrance through the front gate but the issue of navigating the geographical spaces within the school. According to Calvo (2013) "shoes can allow children to spend more time performing more recreation activities, such as playing" (p. 2). Guzian, Bensoussan, Viton, De Bovis, Ramon, Azulay and Delarque (2006) add that shoes can prevent foot diseases and improve walking speed and gait when worn. In a study conducted by Terrier, Lithi and Deriaz (2013) on 25 patients in a rehabilitation facility in Switzerland to analyse their gait and foot stability, on account of their chronic pain through ankle or foot injury, noted that foot orthotics or purpose-made footwear are commissioned to address malformations. In the design these individualities have to be accommodated in order to reduce or remove discomfort caused by factors each

person experiences. We observed that orthotic insoles in custom made footwear improved Tiara's gait symmetry, and hence ambulation.

#### **5.1.2.6 Chronicle 6: The beginning, the end**

*We scheduled an appointment to meet with the acting principal Mrs. DuPlessis who was in charge of admissions. The cobblestone expansive car park, well-maintained lawns and trimmed gardens, conveyed an image of an institution that prides itself on appearance. In partial view is a jungle -gym with a few swings, roundabout and sandpit all brightly coloured and the hint of use was a spade in the sandpit.*

*We enter through multiple security gates into a corridor that led to the boardroom cum principal's office. The elongated ebony wooden table and high-back chair smelt of long history. Many important decisions would have taken place in this very space. Surrounding the boardroom were a few pictures of artwork produced by the children. In the far end stood a smaller table, sprawled with books and letters of correspondence. Opposite the table were tiers of shelves with files; admission, budget, staffing, evaluation and policies. These were indicative of the attention given to detail and the need to access information speedily.*

*Three days into the first week Michael (I have permission to use his name) called the school requesting to speak with the management person who oversees admissions to the school. He was advised to complete an assessment form prior to our visit with her. Really! We didn't have one. She recommended we have one done and she recommended a psychologist whose services had been used before. It was done.*

*On our arrival, we introduced ourselves and indicated our preliminary interest in enquiring about the facility and what it offers children with special needs. She requested the psychological report. She peered over her spectacles as she read the report. We filled in an application form just asking for the following personal particulars: birth, milestones, intervention, support, biological details of both parents, sibling. Our intention was primarily to compare a special needs facility with a mainstream facility and decide which would best serve our child's needs. We enquired about classroom size (ratio of teacher to learner), curriculum, and teachers (and we were told that each class had an assistant teacher). Our*

*questions were answered scantily and unconvincingly. Our request to see the classroom was rebuffed with “they are all the same. You are a teacher (looking at me) so you know what a classroom is like.” We didn’t pursue this point thinking it to be too mundane to be persistent about.*

*My husband expressed our gratitude for the information that was shared and remembered her dismissing us with “You will be back! You may have ideals but she would not fit in anywhere else”. This perplexed and disappointed me as inclusive mainstreaming was our first choice.*

### **5.1.2.7 Chronicle 7: Whose choice is it anyway?**

*I sat with application forms of at least three residential schools and painstakingly filled each section. It was easy when completing parent details and profile of self. It was the section pertaining to the child (the prospective learner) that was not straight forward. This dilemma presented a challenge because exposing all personal details about our child, especially her Down syndrome medical profile bothered me. However, without declaring all of these details may limit her chances of acceptance. All had to be revealed: pregnancy details, birth details (where? when? how?), milestone from birth onwards (even wanting to know whether she suckled well as an infant), medical history of all visits to the doctor, all that she can and cannot do had to be fully disclosed. The irrefutable truth is out: Tiara has DS. All original reports from speech therapists, psychological assessment had to be attached to validate the statements made.*

*I returned all of the completed forms within the specified window period. The year is 2002. It is legislation that recommends her placement at school. It is the people who interpret the legislation who will determine if she gains access. The response from two of the schools is an empathic “No!” The third school requested contact meeting with us. We seized such a rare opportunity and presented ourselves soon after the invitation was extended. We did this without Tiara, to determine the attitude of the personnel. We met with the principal and Head of Department who were both warm and welcoming. We spoke frankly and openly about our journey with Tiara and our voice were confidently asserting that she was adequately equipped to enter the domain of formal mainstream schooling.*

*We were informed that the large learner intake increased the ratio of teacher to learner. The average ratio was 1:35. The skills to cope with large classes depended on experience and qualification. We were uncertain of any teacher's adequacy to cope conjointly with large classes and our child with DS. The determination to see our child interact in a reasonably inclusive mainstream classroom prompted us further to surrender emotionally.*

*It was evident from our conversations that neither the principal nor Head of Department had any previous experience of working with children with DS or other special needs. However, the information we shared with them on what Tiara had achieved with her previous schooling, and in her life skills reassured them that she would be accommodated into the inclusive context. We accompanied her on the first day, attending the morning assembly, escorting Tiara to the classroom and when she was settled, made our way discreetly back to work.*

*Our stay, expected to take about an hour extended into three hours because of the lack of adequate preparation on the part of the school to accommodate late applicants (which delayed the start of the school day). For the first time I stood on edge looking at the brisk business-like manner in which returning learners moved from one space to another : classroom to school grounds to assembly area. They were well rehearsed it seemed with the space wherein they learnt and played. They have been in this space many times before and familiar with the routine. There was nothing strange to them on this day.*

*Tiara too will learn this routine, I told myself. We randomly stood at the back of the assembly line as the prayer, welcome and announcement were conducted. We awaited our turn to be advised on where to take our child. On receiving this information, we proceeded to the junior block of classrooms. We identified an unoccupied chair close to the teacher's table and sat Tiara there. We were also pleased that the numbers were fewer than expected. This was so because the school did not take in the maximum number which it had the capacity to hold; hence late applicants were always considered. From the gradual trickle of parents lining the office corridor, the completion of the process would be prolonged. Some parents do not take advantage of early application and expect to be accepted due to demographics of residing close to the school.*

*We left Tiara in the care of her female teacher and nervously left, hoping that care would be taken of her. When the day ended, much earlier for her, our housekeeper was awaiting her at the classroom exit. Tiara's books were untouched. Her lunch was partially eaten. Her appearance was undisturbed except for her ponytails undone because of her silky hair. She showed no particular sign of distress or discomfort and I interpreted that calm demeanor as a promising indicator of the days to come. She did not of her own accord say anything particular to us. However, she offered responses to our promptings: "Did you have fun at school today?" "Do you have new friends?"; "Do you like your new school?" to which her ready answer was "Yes"*

*It was the third day now that Michael arrived at the school. It was a Friday when the school day is shorter for religious reasons. It was earlier than the finish time of 12 h 30 when the entire school would be dismissed. The principal informed him about what had happened over the previous two days and expressed her optimism that 'things would work out'. The class teacher was called and on request Tiara would be allowed to leave with him. Minutes passed, no one returned to the office area, where he was asked to wait for her. When the teacher did return she in panic indicated that she did not know where Tiara was. The toilets, school grounds, entrance and exits were scoured. Tiara was nowhere to be found. PANIC set in!*

*More personnel were dispatched to help in the search. After much searching within the school premises she was finally located in the caretaker's quarters. No one could explain how she ended there. Or why she was found sitting on the bed. She didn't understand the fear that was struck in the heart of her father that day when he held her firmly and walked out to the car, never to send her there again.*

The potential of people with learning difficulties will not be realised until they have many more opportunities to develop it. Offering an opportunity, yet placing a descriptor label on a child with Down syndrome, blinds and limits educators' perceptions of the learning capacity of children described as intellectually impaired (Delpit, 2001): Inclusion is a reality in countries such as the United States in some way, shape or form. Children of most categories of disabilities (except deaf-blind) are incorporated within regular classrooms through diverse means and in inordinate numbers (Ysseldike, Algozzine & Thurlow, 2000) ought to

encourage us in our South African context to do likewise. Research by Ngcobo and Muthukrishna (2011) and Engelbrecht (2006) document how far we are in South Africa, from realising this dream and the teacher is key role-player in implementing transformation through acceptance of children with Down syndrome into their inclusive classroom. Whilst the directive to “include” is noble, it competes with other variables which shapes and exerts pressure from outside and within. Building from foundation is preferable to renovating an existing building to prepare for inclusion. Either way, inclusion should be seen as a positive stimulus.

Chronicle 8: Exclusion in inclusion		ACCESS TO SCHOOLING SPACES FOR MY CHILD WITH DOWN SYNDROME						
PLACE OR INSTITUTION		Informal	Formal	Formal	Formal	Formal	Formal	Post school
		HOME	DAVIDS PRE-SCHOOL	MIND THE GAP	DURBS PRIMARY	SUNSET	HILLTOP TRAINING COLLEGE	HOME
TYPE		Home school	Private	Montessori	Mainstream Public	Special Needs Public	Special needs Private	Home school
AGE		0-3	3-4	4-6	7	7-12	13-18	18 onwards
YEARS SPENT		3	2	2	2 weeks	6	5	ongoing
SCHOOL ACCESS PREREQUISITE	Entrance	NIL	INVITED	APPLICATION	APPLICATION	APPLICATION	APPLICATION	NIL
	Medical evidence of condition and report	Not applicable	Not applicable	Not applicable	Applicable	Applicable	Applicable	Not applicable
CHILD ACCESS REQUISITE	SYSTEMIC	Learning and teaching support material						
		facilities at school						
		classroom size						
		mother tongue instruction						
		school ethos						
		intervention programmes						
	SOCIETAL	Basic amenities- water, electricity, toilets						
		Transport services						
		Extra curricular: Swimming						
		Recreation: outings/stayover						
	PEDAGOGICAL	Teaching methodology						
		Curriculum						
		Assessment						
	MEDICAL Educator Awareness	of learner's Hearing impairment						
		of learner's Visual acuity						
		of learner's medical profile:Hypothyroidism						
	INTRINSIC: Educator awareness	of learner intellectual ability						
		of learner level of mobility						
		of learner's ability to remember						
		of learner's attention span						
EMOTIONAL	Child self-concept							

KEY:

DESCRIPTOR								
SUITABLE	OFTEN							
	SOMETIMES							
	RARELY							
UNSUITABLE	NEVER							
	NOT APPLICABLE							
			CLASS SIZE	<table border="1"> <tr> <td>L</td> <td>MORE THAN 30</td> </tr> <tr> <td>S</td> <td>LESS THAN 20</td> </tr> </table>	L	MORE THAN 30	S	LESS THAN 20
L	MORE THAN 30							
S	LESS THAN 20							

**Table 2: A compressed view of the fifteen years spent in different systems of formal schooling in KZN, South Africa.**

A compressed overview of schooling spaces (Table 2) which Tiara was in includes, home, Montessori, private mainstream, public mainstream, special needs private, special needs public. Each system had school access requisites of application first, open policy where anyone was accepted but the high cost of being in that school limited applicants or invited as in the case of David’s preschool. The invitation was extended by the educator who in the previous year had taught my son who attended the same school. Table 2 depicts six child access requisites: systemic, societal, pedagogic, medical, intrinsic and emotional. Each of the schooling systems is rated using self-designed colour coded descriptor with green equated to ‘often’ or suitable options and purple ‘not applicable’ and dark blue with ‘unsuitable’. Each block of colour is counted as one unit to identify the dominant characteristics associated with each schooling system. The analysis will be incorporated into the discussion section of this Chapter.

*Tiara was exposed to six choices of education systems, each with its peculiarities. It was the years of speech and language therapy that complemented the three years of informal home schooling. The focus was on extending what was presented at the sessions of therapy. Neither I nor the caregivers followed a rigid structure or routine but adapted activities to the child’s disposition and health. Lacking specialist knowledge on suitable programmes that could be implemented meant that activities were unplanned and informal on some days.*

*With each of the formal schooling systems thereafter routine and repetition was the catchphrase. It seemed that there was no formal curriculum policy for special needs offered by government to the schools or the school did not implement what was given. I was a teacher at a government public high school and had to follow a prescribed curriculum. I assumed it*

*was the norm. Apparently not so. My child did not bring any 'homework'. I assumed it was because most of the learners lived in the school hostel and after-care supervision would be difficult to monitor.*

*I also assumed that every educator had a teaching qualification, until I served on the governing body of Sunset. I learnt then that sometimes a teacher assistant was allowed to be a full time educator while studying part-time through correspondence. This meant that the School Governing Body undertook to pay the educator. On reflecting on these years I admit that I depended on the full time educators entrusted with the schooling of my child to develop her to her optimum. Each parent-educator meeting was bursting with positive comments about her good behaviour and animated interaction with her peers. Use of 'she can,' 'I'm so proud of her' and 'thank you for letting me teach your child' distracted me from asking the important questions each time.*

*In the later years when I did ask about the curriculum, I was sarcastically told by the principal of Sunset that I should come in and show them what to do, since I knew so much. I backed off. My mistake!*

*No sign of Reading, Writing, Arithmetic!*

*Most of the schools focused on skills: baking (where all ingredients are measured out and the sequence almost completed for the learners). Perhaps she had a chance to sprinkle the candy on top of the cupcakes); gardening; sewing (each item so perfectly stitched, it had to be done with adult assistance for most of the product. Once again, it was not my child's work) as she was not taught to thread a needle. She would not know what to do with a needle if she held it; art (all templates perfectly coloured within the line or all sequins equidistant on the border of the painting. It would have been wonderful, if she did it on her own. I did not doubt her ability except from activities done at home, I knew this skill was not developed to level of adequate competency.*

*There were annual sports days and Christmas school plays where the entire school participated. To me these events simply mimicked mainstream activities where the learners with mild impairments were cheered and congratulated for 'breaking the records in the sporting event or encouraged to pursue an acting career for speaking so articulately and*

*portraying character with such confidence. These were once off events! It was not the compliments that disconcerted me. Tiara loves music and at home, often played the single drum with its cue stick in perfect timing to the point of emphasising the accent beat. She never played a musical instrument at school. There was no nurturing of the talent or skill of individual learner's potential to prepare her for post-schooling opportunities of employment. Tiara took part. Period.*

*She had a few opportunities in the last four years of formal schooling with day-visits to animal farm or a museum and stay-overs at various local farming destinations. She enjoyed the friendships more than the activities because she was so accustomed to spending most of her time behind a desk that she wished she did not have to do the physically demanding tasks.*

*She had no option and being supported and motivated by her peers, she surrendered. The focus was on the physical (as the teacher was a fitness fanatic. I remember one parent saying to me as we shuffled our kids into the car of the lift club. She frowned: "why does the educator always insist that Riri do aerobics and running round and round all on the same day when my child suffers with exercise induced asthma? Riri is not going to take part in the Comrades Marathon."*

*I could not offer a response. All I could think of at that moment was Tiara, with her flat feet and struggling balance, low metabolism on account of her hypothyroidism, impaired hearing medical predisposition, trying to execute the same. I sighed, as I did many times before that day, and after.*

*Schooling offered troubled days too. I recalled one incident when Tiara was being treated for an abscess under her arms. She was on doctor's advice allowed to go provided the small abscess was treated daily. It was just two nights. The abscess was treated and dressed at home according to medical advice with an additional medical kit for the weekend needs. When she returned from the trip, the abscess was oozing and the additional medical kit of supplies, untouched. It took months of treatment to restore her health. The discomfort of these months was not commensurate to the weekend where she did not participate fully in the outing.*

This final narrative has more of the information compressed and tabulated to allow the reader to have a composite visual overview of the spectrum of approximately fifteen years of schooling at one glance. The analysis and discussion of this narrative in particular and the other chronicles in general will be merged with *Y/our story* in the data discussion in the latter part of this Chapter.

In considering the geographies of access, I identify five public mainstream primary schools within a five to ten kilometre radius of my home, to service children from the neighbourhood yet attempts to enter these schools prove futile. At the time that I was making applications for admission for formal schooling, I was not aware of any child with intellectual impairments, being accepted into mainstreaming, within the community. 'No place' or 'we are full' were subtle reasons for decline. In 1998, faced with such open reluctance, we opted for private schooling (15 kilometres away). This was considered as an interim measure, whilst we pursued efforts to gain admission into a public mainstream school. Tiara was three years old. In 1998, South Africa was four years into its new democracy. This showed to me that custodians of schooling spaces were unprepared and wanting in implementing policy of inclusive education.

One of the seven schools was for physically challenged and the other four were public mainstream, not inclusive schools, less than a radius of five kilometres from our home, yet none offered to accommodate CWDS. *Sunset*, a school catering for special needs, outside the residential area, had to be sought. Lack of free or public transport meant that my child had to be transported at private cost.

## **5.2 YOUR TURN**

### **5.2.1 Introduction**

Each of us has our own individual life, our own hopes and dreams, our own relationships and decisions achievements and failures. At the same time, each person lives in a particular society at a particular time. What happens to us often happens to other people as well. We fit into social categories (sometimes without knowing it) and

we experience ‘structures of opportunities’ that are similar to others like ourselves. In fact, we cannot really make sense of our own experiences and chances in life until we are aware of other individuals who are in the same circumstances as we are. The sociological imagination helps us to see relationships between our own lives, the lives of others, and the times in which we live. (Adapted from Christie, 2008, p. 4)

Christie’s (2008) notion of ‘sociological imagination’, with the emphasis on the narrative, helps crystallise the choice of autoethnography for this study. She suggests that there is a synchronicity about experiences and is better understood with awareness of similarity to that of other people. This reflective narrative supports and complements the array of qualitative research techniques of describing, decoding, clustering and translating (Frey, Anderson & Friedman, 1998) employed in this study. The objective was to come to specific terms of understanding of informants’ perspectives on negotiation of access of schooling spaces for our children with Down syndrome (a social category) when juxtaposed with my account.

### **5.2.2 Structure of analysis: assigning meaning**

This section will provide the informant data analysis in the following format. Part 1 will concentrate on a synopsis of each informant interview presented in the first person. It will incorporate their first person utterances. Part 2 will follow with an interpretation and discussion of the data of all informants, constructed thematically using an interpretivist approach which was discussed in detail in Chapter Three. The research process I have followed resonates with the following three key dimensions: *ontology, epistemology and methodology* as outlined by Terre Blanche and Durrheim (1999).

The three parts, which have been explained in Chapter Three, are interconnected in this study in the following way. To reiterate, I have taken what I hold to be my truth (my ontology) and understanding that truth and the nature of knowledge (my epistemology) to select the appropriate methodology. How I understand my truth, my ontology, is important for my research because situating it in autoethnography warrants clarity about how I know my truth to be true, my epistemology. In foregrounding these positions, I can catapult myself into

finding out more about the world of experiences of other parents (pertaining to access, schooling, Down syndrome) whilst connecting my own place within it.

The way in which I go about unearthing information, my methods, and the suitability of these methods resonates with my methodology. Once I had collected information about parents 'or guardians experiences of access to schooling for their children with Down syndrome, I interpreted to make meaning of what was shared by drawing inferences between the information and some (abstract) pattern alluded to by Aikenhead (2008). I aimed to understand the phenomenon of access to schooling spaces further through the meanings that parents assign to them in their chronicles using an interpretivist lens. I was searching for meaning, particularly the social and historical meaning informants assigned to their experiences of the phenomenon of access to schooling retrieved from memories, of experiences of places and spaces situated in the past but articulated in the present.

In the main, chronicles are understood as stories that comprise a temporal ordering of events and within this transient context; I endeavour to signify the experiences in a personal, cultural coherent and plausible manner. The time and place and space in which informants tell their chronicles linking features from different timeframes (past, present, future ) and a capsule of a fleeting moment, is referred to as a 'threshold'(Churchill & Churchill, 1982) in that it captures and crystallises an interpretation in that moment in time. My decision to look at the transcripts of the informants as filial narratives with an interpretivist lens afforded me the following: access to maternal kinship with mothers of children with Down syndrome; emotional connectedness of anger, joy, frustration; humanness of experience of time, order and change; acceptance that it is a representation of a life experience at a given moment. With the context of a common phenomenon, which is access to schooling, the particulars of human experience of how parents negotiated that process, is illuminated in my qualitative autoethnographic study using an interpretivist approach (Ayres, Kavanaugh & Knafl, 2003). It was through this process of additional encounters and perspectives that I extended, knowing more about the phenomenon.

Each informant's explanation of her experience occurred on a unique timeline and setting,

none in the same year, place nor in the same suburb. All children represented by the informants were born between 1989 and 1995, a period marked by significant political changes in South African history as people prepared for the milestone first democratic elections the following year, on 27 April 1994 as illustrated in Table 3.

Between 1989 and 1995	Political Event
1989	“Nelson Mandela responds to a memorandum from President P.W. Botha in which he states that the ANC would end the armed struggle if the organization was unbanned, political prisoners released and troops are withdrawn from the townships”.
	“13 December, Nelson Mandela and F.W. de Klerk meet for the first time to discuss the country’s political future”.
1990	“Nelson Mandela is released from prison”.
	“The government puts forward the 'Clase Models', which set out the conditions under which white state schools can admit black students”
	“2 February, President F. W. de Klerk makes a speech at the opening of Parliament, announcing among other measures, the lifting of a 30-year ban on the ANC, the PAC and other anti-apartheid organisations, the suspension of the death sentence until further review, the release of some political prisoners and the partial lifting of restrictions on the media and on some detainees”.
1991	“European countries end sanctions against South Africa (April 15). The South African Parliament repeals apartheid laws (June 5)”.
1992	“Most European sanctions lifted; UN General Assembly ends restrictions on cultural, academic exchanges”. “Whites support political reforms in referendum”.
1993	“Constitution of the Republic of South Africa ratified on December 22. Transitional Executive Council (TEC) established” Nobel Peace prize is awarded jointly to F.W. De Klerk and Nelson Mandela.
1994	“27 April marked the first democratic elections in South Africa”.

**Table 3: Highlights in South African political history between 1989 and 1994<sup>31</sup>.**

<sup>31</sup> Information adapted from of <http://www.sahistory.org.za/1900s/1980s>

Bearing in mind this political landscape, I had to cultivate a suitable response in interpreting the data to reflect each person's experience closely remembering to apply it similarly to all cameo accounts which comprised the data collage. In processing the analyses, I needed to discriminate concerning information applicable to all informants from those components that were specific and limited to a particular informant. According to Ayres, Kavanaugh and Knafel (2003) "those aspects of an experience that were unique to one individual have limited usefulness outside the interpretation of that individual's experience" (p. 871). However these unique characteristics and nuances might be necessary when considering that person's account of event. In the main, this Chapter will elucidate the informants' content and context and draw parallels to my own experiences where it is applicable. The centrality of children to this study presented from the informant perspective is not veiled but is a different viewpoint. I am reliant on the parents understanding of the social and historical context and first-hand experiences inserted as nodal moments in the study. I bring in other voices in my curiosity to know whether others experienced difficulties, new, same or different and to what extent to make commentary on the particular versus the general and universal. Contextual grounding of the meanings of human action and language which can provide particular commentary is vital to our everyday understanding of our own and others' behavior. In this study, the objective is also to locate meaning in context (Mishler, 1979).

*My meeting with Patricia Krishna was an unforgettable nodal moment. Prior to meeting her, I have been avidly reading articles and publications related to inclusion, authored or co-authored by her. They include "Transforming professional development programmes into an inclusive education system" (2000). "In Meeting Special and Diverse Educational Needs. Making Inclusive Education a Reality" (2000); and "The geographies of inclusion of students with disabilities in an ordinary school" (2011).*

*That one-on-one engagement with her facilitated and offered me further tools to penetrate into deeper issues of schooling and access, when she introduced me to the notion of 'children's geographies'. This critical discourse in that liminal space and time extended my thinking on inclusive education particularly with the concept of children's geographies. I read*

*further. I surmised that the notion of children's geography would go beyond place and space and reading on the subject confirmed this.*

In the absence of theorising earlier in the study, I was drawn to the ideas of Nind and Seale (2010) and children's geography to frame my response by key informants in the study. I am motivated to apply children's geography as an analytical frame for some of the data generated by all informants and conjoin this analysis with the theory of access as expounded by Nind and Seale (2010). Children's geography offers the notion of spaces (and places) of the children's lives. The theory of access helps to review experiences of those spaces (and places) to question the how and the why of it and recast it to answer the research question: how did parents' experience issue of access to schooling spaces for their children with Down syndrome in the South African context, post- apartheid period.

I will now proceed to offer snapshots of the informants of this study, ranging from an accomplished international academic to domestic worker, with each presenting personal experiences related to disability and access of education for their children and loved ones. Interspersed within the snapshots are actual, first person quotes from the key informants.

### **5.2.3 Snapshot of informants**

Patricia Krishna's involvement in dialogue and policy formulation was first read when I did a certificate course on Learning Impairments as a correspondence course through distance learning through the university in South Africa, Unisa. It whet my appetite on inclusive education and exposed me to 'barriers to learning' identification and intervention strategies. Her academic writings were encountered more prominently during this and subsequent post graduate work on special needs.

Carol and I are both currently serving as board members on DSA-KZN. She has over the years, shared experiences of raising her daughter with DS and I often found I could identify with what she said. There is a two-year difference between Tiara and her daughter, Jennifer so it was possible to compare notes at times, on parenting matters. During the time she served as

Chairperson of DSA-KZN, parents of CWDS benefited from her holding this portfolio as she had access to pertinent information particularly on health and social welfare and made it available to members.

Board meetings for DSA-KZN are held once a month and during the year there are several meetings for members of the DSA-KZN to hear talks from specialists on issues affecting CWDS and during these meetings I met Joy Nxumalo. She is a regular attendee and often brings her daughter, Lindiwe with her. We often get to talk about our experiences of raising CWDS and related social, medical, educational matters. She participates in group discussions and offers insights that help address access to CWDS in the township of Umlazi where she lives.

I met Estelle Adams during the World Down Syndrome Conference in 2012, when South Africa hosted it, in Cape Town. Opportunities to meet professionals, during the conference was possible during group sessions and intervals for tea and lunch. She showed me some pictures of her son, John, and I reciprocated with pictures of Tiara. We talked about our children's common interest in music. Estelle is the outreach programme coordinator in Western Cape Province. We talked about the challenges parents face when choosing schooling options (if they have a choice) which her experience qualifies her to advise. We shared equal concern on hearing statistics of the number of CWDS who are unable to access basic services of education and disability grants, especially in the rural areas and planned to stay in touch. Fortunately, with technology, we stay in touch via e-mail.

These five people constitute the group of informants who exist in my world and were ever so willing to allow me to include their chronicles in conjunction with mine. The reader is reminded that the motif of the cross is used to introduce each informant. It underlines the ascent and remount of the slope of our past, with each person finding nascent action, spiritually. Whether it is intended or incidental does not negate the need to cope, overcome or positively accept responsibility.

### 5.2.3.1 Patricia Krishna: *The crossroad*

Patricia Krishna recounted her life experience with a sibling. Her personal, intimate and moving narrative is a tribute to a remarkable young man who shared fifty-one beautiful years with her. Her account weaves nostalgic memories that thread her life's journey as a sister and mentor to the embodiment of multiple roles of academic, activist, researcher, expert informer, advisor, keynote speaker and teacher. On a personal note, she shared the family's journey on access to schooling for a sibling with cerebral palsy. "*He was born with a cleft and during the surgery he suffered anoxia as a 10 month old baby. His major disability thereafter became deafness*". His hearing was affected profoundly by the brain injury he had during the surgery.

Apartheid laws of the time affected the search for appropriate schooling. Laws such as The "Group Areas Act, Act No 41 of 1950" prevented non-whites from attending the same school as whites. The chief purpose of this Act to ensure compulsory separation in residential areas, was achieved. The Acts specified and restricted zones or spaces where various races were permitted to own property, live, study or work.<sup>32</sup> Because of his collaborative work between faculties, Professor B. Maharaj, a senior professor in the Department of Geography has engaged in co-supervision of education based theses. His several publications entail the Group Areas Act and related work. In reading his account of "*The group areas act and community destruction in South Africa*" (1994), I learnt how the machinery of apartheid worked to oppress non-white people.

Group Areas Act was used to enforce ideology of apartheid. It served as a powerful tool for state intervention in controlling the use, occupation, and ownership of land and buildings on a racial basis. In terms of the Group Areas Act, separate residential areas, educational services, and other amenities had to be provided for the different race groups. The overriding goal was racial segregation (Maharaj, 1994).<sup>33</sup>

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<sup>32</sup> <http://www.sahistory.org.za/politics-and-society/apartheid-legislation-1850s-1970s>

<sup>33</sup> Maharaj, B for further debates on group Areas Act. He is an expert in Group Areas Act discourse and analysis.

Krishna recalled her stint at Spes Nova, a school including children diagnosed with CP, as the “special need”. Her higher education (Honours degree) training as a psychologist pushed her to register for courses, like many others, in order to acquire skills to teach children with CP. It is at this school that she observed how effective a few teacher aides were in engaging the learners. The encouragement from the principal that teachers should receive in-service training meant that teachers were upgrading their skills to serve the needs of the learners.

On a broader trajectory and larger scale, Patricia Krishna was part of the dialogue on inclusion for the South African context. This engagement informed the drafting process with Education White Paper 6. While papers and publications attest to the strides she has made in personal and professional capacity to empower stakeholders at school, district and provincial levels to implement policy aligned to the country’s Constitution, she expressed that the goal of inclusivity has yet to be realised on a national scale. *“In our region children should be given a chance. Put them in Grade 1 and see what happens,”* reflects the need to see inclusive education succeed but she quickly adds that *“but you got to get a teacher who’s trained in curriculum differentiation”*. Her quest to see schools for special needs develop more substantially than perceived *“babysitting institutions”* is printed on paper, but translating into practice will require *“leadership; “accountability”* and *“raised expectations”*. These issues on inclusion and barriers to access learning have been on the research agenda for a while as evident from these publications: Muthukrishna (2000); Muthukrishna & Schoeman (2000, 2005) Muthukrishna (2003 a, 2003 b); Muthukrishna & Ramsuran (2007).

### **5.2.3.2 Carol Williams: *Criss- cross, living on both sides***

Carol William’s opening statement *“Jennifer is now 21 and was born with Down syndrome”* gave me my first glimpse of the pre-democracy period in which she was born - 1993. Jennifer is the second of two children with an age gap of thirteen years between them. Caroline remarked: *“I think she was 3½ - 4 weeks old when I decided that I had to get on with it because it was a new life for us and I had to find out about it”*. Caroline mentioned that she contacted Down syndrome Association and gradually started to participate in all activities planned by the association. She did resign from her secure job in a bank with a 30 year service

reward .When management of the association changed due to retirement, Caroline, being available, volunteered. Her entry was opportunistic and she needed to keep busy yet accessible to the school personnel whilst Jennifer was there. Thirteen years of service to the association earned her the position of Branch Manager of Down Syndrome Association - Kwa-Zulu Natal (DSA- KZN).

Her determination and positive outlook to her daughter's education opportunities, in the earlier year, is conveyed in her various statements: "*From the time she was one day old I was rooting that she will be going to mainstream*"; "*I knew my plan. I knew Jennifer's plan from the time she was born. I still know her plan*". "*We now had a foot in the door*"; "*I was available*".

Caroline adopted a positive approach to motherhood and this in itself may be interpreted "as an act of resistance against linear medicalised models that tend to promote the notion that it is essentially tragic to be the parent of a disabled child" (Russel, 2003).

*Jennifer* had the experience of two different schooling systems. The one school offered her opportunity to be with her peers with *whole school support* where she earned *two 'A' ratings one of which was for sums*.

### **5.2.3.3 Joy Nxumalo: *Crossing the road, carrying the cross***

The third informant was Joy Nxumalo, a Black woman who lives in Umlazi, a township with an estimated population of 404,811 <sup>34</sup> It is located on the east coast of KwaZulu-Natal, South Africa, and south-west of Durban. Joy has facility in expressing herself in English, for which she credited her White employers, although her home language is isiZulu. To Joy Nxumalo, who worked as a domestic servant until her retirement, the tragedy of losing two babies in her early twenties did not dim the passion she had to serve the needs of her daughter, Lindiwe. This was conveyed in the following sentiment: "*I have only Lindiwe, only one child delivered*

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<sup>34</sup> [www.durban.gov.za/Documents/Invest\\_Durban/.../5.pdf](http://www.durban.gov.za/Documents/Invest_Durban/.../5.pdf)

*through Caesarean section. I had two boys before her. They died. After those boys I got her. Lorraine is 25 years old*". Joy was 37 years old when she had Lindiwe and is now 63. She explained that the first baby died during child- birth and to this day does not know the details of the incident. The second baby was stillborn at six months. When the nurse at the hospital told her that her third child Lindiwe was '*not well*' she assumed this was only because she did not cry immediately when she was born. She later came to understand that the new-born unaccustomed to breathing on its own, was prompted through a gentle pat on its buttocks. It instinctively responds to the pain with a yell, which automatically opens the nose and the lungs to start conveying oxygen. When the matron who visited her at home said: "*if you leave the child on the bed she's going to sleep forever*", she assumed the child would die imminently or some misfortune will befall the child. Both these statements would turn to be pivotal in her raising Lindiwe to ensure that the predicted gloom 'to sleep forever' did not happen. She referred to the manner in which the father of the child responded to the birth. He said: "*I do not give birth to such children*". Such an impersonal statement reflects a broader cultural and gender stereotype that exists in society where blame for conception of disabled children is apportioned to mothers rather than fathers. Joyce felt a greater urge to protect her vulnerable child from the father who abandoned them despite having the resources to do differently: "*He was a shop steward at work. He had the money to look after us but he did not want to*". Cultural factors influence and inform parents' responses to their CWD and greater pressure is on fathers, in Black patriarchal society.

#### **5.2.3.4 Estelle Adams: *Cross it out, and get in***

The fourth informant was Esther Adams, a Coloured female whose home language is Afrikaans and who lives in Bellville, Cape Town. Esther Adams was the only parent who had the option of mainstream schooling from the age of eight (8) but chose to place him in a school for children with special needs. She accepted that "*they* (referring to the teachers) *did not put pressure on these children and allowed them to learn at their own pace, for which I was satisfied*"

Estelle's fourth child, John, is 22 years old. John has Down syndrome. She refers to him as 'laat lammetjie', an informal term in the Afrikaans language which refers to a child born

many years after his or her siblings<sup>35</sup>. In this case, he was the last born after thirteen years of the third child. With three daughters to help with the caregiving, Estelle did not experience stress about caring or raising him. The girls were twenty-one, twenty and thirteen, self-sufficient and largely independent. They were very proud of their brother. *“John was everyone’s responsibility”*. This space of joy was very different to the anxiety she silently felt during her pregnancy. She did not tell anyone, but within herself, she knew the risks of giving birth at the age of forty (the age risk factor will be discussed further in the next chapter)

Estelle was very satisfied with John’s first school, Cheré Botha Special School. The School was established by Mike and Gloria Botha in 1981. It was named in honour of their daughter, Cheré, who was born on 17 September 1976 with DS but less than four years later died of leukaemia on 27 June 1980. The school opened its doors on 17 September 1981 and has been in operation for 33 years. The school was originally part of the Down’s syndrome Association of the Western Cape, but is now under the auspices of the Western Cape Department of Education<sup>36</sup>. The Cheré Botha Facebook page explains that for the last few years the school has extended services by including children with autism. The school occupies three premises, closely situated to each other. Western Cape Department of Education has intentions to build a school with a potential to provide learning and accommodation space for 300 learners with autism, intellectual disabilities and Down syndrome.

Estelle said: *“For me it was very easy because at the age of about three I put him into Cheré Botha School and he has been there until the age of 6 or 7”*. Placing her son in this school gave her peace of mind for a few years while she contemplated ‘big school’. She expressed repeatedly the joy John brought to the family. While some choices, especially with schooling, were difficult to make, she did not regret them. As the Down Syndrome Association Outreach coordinator, she says *“I work with the community and parents and I always tell them it’s your choice it’s where you want to place your child*. She explains the choices available and guides parents to make decisions that suit their needs. The irony is that she guides other parents to make choices which she found to be a struggle.

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<sup>35</sup> <http://dictionary.reference.com>

<sup>36</sup> [www.cherebotha.co.za](http://www.cherebotha.co.za)

The chronicles of the informants are clustered on a few commonalities: the children have disability of Down syndrome (except for the academic informant, whose sibling had cerebral palsy and profound deafness); all had experiences of attending a ‘brick-and-mortar’ school; birth is between 1989 and 1993, pre-democracy; they are all South African citizens. This leads me to explain why the concept of children’s geographies is a useful tool to unpack broadly how South Africa treats its vulnerable children with disabilities, and position Down syndrome in that continuum. My interest in learning about children’s geography forces the inclusion of the next section.

## **5.2.4 Children’s geographies**

### **5.2.4.1 Analytical framework**

Human geography is a sub-field of geography and an area within social sciences that focuses on cultures, people, and the world, with accent either “across” or “of” both “space and place”. Whilst human geography focuses on studying human activities (Holloway, 2014), children’s geographies is described as a branch of that. It zooms into places and spaces “of” or “across” children’s lives and concentrates on the social, cultural and political spectrum considered important and a strong stimulus for study. The pluralisation of “children’s” is intentional as it implies how vastly different children’s lives would be if the changed circumstances including ability/disability and contexts of time or place shifted. Holloway (2014) suggests that current research is trying to link a multiple perspective framework when analysing children’s experiences. In so doing, it acknowledges the diversity of their lived geographies. Exploring this facet means a particular or vested interest relationships of power encompassing children and the spaces wherein they live (Weller, 2006).

Ngcobo and Muthukrishna (2011) state the centrality of space in an educational context of schooling, which has exercised the right to include CWD. Using a geographic focus in their South African case study, they highlighted the experiences of inclusion for CWD in a regular public school. They examined the procedures and mechanisms that sustain or test spatial

arrangements within which individual identity is formed, particularly for CWD, and how understanding of inclusion is produced. Horton and Kraftl (2005) have stirred the contemporary discourse of children's geographies further and interrogated practices unfolding within schooling contexts. They have argued the need for continued exploration and specific to spaces of and for education

#### **5.2.4.2 The concept of children's geographies**

Understanding of geography has evolved over the last two decades focussing on the "places and spaces of children's lives in their experiential, social, political and ethical formations" (Ngcobo and Muthukrishna. 2011, p. 358). The view suggested through researchers of the field is that children's lived experiences would be significantly different in contexts different to the current one with regard to school, family, class gender and ability/ disability (Ngcobo and Muthukrishna. 2011). The period pre-and post-1994 in South African history attests to that. The period pre-1994, where one schooled, worked played, ate or socialised, was affected by the political context of apartheid (as discussed in Chapter One). Post 1994, when apartheid was dismantled after the first democratic elections, areas where people were previously prohibited from entering were accessible without fear of prosecution. The same is true of schools especially access 'non-whites' had to previously 'Whites-only' schools. It is a shared view that schools are sites of preparation for future roles and a part of the organisation of everyday routine for many families. As such, every child has a right, and obligation, to be in spaces where they may receive appropriate preparation for adult life.

The idea of children's space is essential when looking into children's geography (Wyness, 2003) and a useful context to unlock an understanding of geographies of power. Sharing a parallel view, Lefebvre (1991) has stressed that schools are peppered with pockets and shades of power. Van Ingen and Halas (2006) also submit a similar viewpoint of schools: "richly textured, power laden spatialities of everyday life" (p. 382) and argue further that "schools are 'contact zones' - places where the values, ideologies and practices intersect in often highly unequal relations of domination and subordination" (p. 380)

### **5.2.5.1 Analysis process**

Chang in Pierce (2008) offers a suggestion on how to engage with the autoethnographic data by using a zoom in-out technique that I have employed for this study. This translated into action as follows: I looked at my own data set and highlighted key words and phrases that may contribute to possible themes. I then took one data set at a time of each informant and did the same. When I adopted the bird's-eye view of the collated data it enabled me to see *if* and *how* my case of access to schooling spaces for my child with Down syndrome related to that of other parents in experiences of access to schooling spaces for their children with Down syndrome. This shifting of gaze from self to others is done to attend to personal and broader social contexts, always mindful of the “visible and invisible participants” (Chang, p. 69) within the chronicles. The motivation in collecting multiple accounts of experience of access to schooling for children with a Down syndrome was not for the purpose of generalisation but to offer contextual plausibility: personal, social and historical. I am reminded of “*Not My Way, Sesha, Your Way, Slowly: Maternal Thinking in the Raising of a Child with Profound Intellectual Disabilities*” (Narrative, 2002). It felt like déjà vu as each episode unfolded like a parallel narrative to my own.

### **5.2.6 Unpacking the mosaic of the chronicles**

To extend the discourse on access to schooling, six themes which are highlighted within the chronicles, are contextually elucidated. They are as follows:

5.2.6.1 Definitional issues

5.2.6.2 My knowing

5.2.6.3 Barriers to learning

5.2.6.4 Inclusion versus exclusion

5.2.6.5 Ecology of space

5.2.6.6 Post-schooling

### 5.2.6.1 Definitional issues

The issue of disability and inclusive education needs to be underscored in the context of all interviews to ensure consistency of meaning and to enable the reader to follow its discussion in conjunction with CWDS geographies rather than the broader discourse. I was really keen to push beyond the academic discourse of the concepts to a deeper, richer and more contextual meaning of disability and DS. The motivation for asking questions on concepts was to gain an understanding of how informants engaged with the term. My need to insert this theme is borne from the discussion with informants where understanding of what is disability and its intersection with DS was problematic for most informants at the point of the diagnosis. It is for this reason I decided to work through this theme to ascertain informants' ideas about it.

As alluded to in Chapter One, disability is a label, a generic term that refers to limited competence in performing certain actions or inability in varying degrees to complete ordinary and everyday responsibilities. In context of medicine, it refers to a diagnosed condition that describes difficulty one experiences in engaging in the activities of daily life. As a generic term of reference it matches concrete skill to typical functioning and in some cases, is used synonymously to refer to a range of impairments including physical paralysis and intellectual delays.

Disability is sometimes classified as visible (disability that is noticeable) or invisible (disability not immediately apparent) as discussed in Chapter Two. DS is characteristically distinct and visible yet it was not always possible for parents to identify their child as disabled because the appearance of "*head, hands, feet and body*" as I initially understood it, were indicators that the child was typical and non-disabled. It was the trained eye and experience of medical personnel who knew details of characteristics associated with specific disabilities, to alert parents of the differentiation or to verify through blood test. "*Your baby is not okay*" or '*different*' expressions from nursing staff, conjures notions of fear as illustrated by Joyce's request: "*I want to see her whether she's in a bad condition or not*".

“People who are blind or deaf, or who use wheelchairs, have chronic pain, or learn at a slower pace than others have vastly different experiences and perspectives; yet they share society’s definition of them as ‘*disabled*,’ with consequences for how they are viewed and treated by the majority, presumably non-disabled ” (Willet & Deegan, 2001, n. p.).<sup>37</sup> Disability, with its construct and embedded meaning also found within community and traditional context is reflected in the comment by Mandla (Jennifer’s father): “*I do not father children like this*” when was told of his child’s diagnosis. There is a vast difference when one refers to ‘disabled person’ or person with disability. Expressing the term as “disabled persons” focuses ones gaze and positions disability as central whereas “person with disability” correlates with the human rights, person first identity, as illustrated in Chapter One. It was my first introduction to the human rights perspective of raising a child with disability. The next issue that needed to be understood, was Down syndrome.

It was Jérôme Lejeune who discovered the cause of DS to be an extra chromosome. It was later identified as chromosome 21. It is common for most people to have 23 pairs of chromosomes, making it 46. People diagnosed as having DS possess 47 chromosomes. The additional chromosome attached on the 21<sup>st</sup> changes the make-up of the person referred to having Trisomy 21. What medical research has identified is that there are various levels to learning abilities amongst CWDS (Buckley, 2000). The ability of each child with Trisomy 21 is not the same, with neither translocation nor mosaicism. Globally, about ninety-five to ninety-nine percent of people diagnosed with Down syndrome “have ‘non-mosaic’ Down syndrome, where every cell has an extra 21<sup>st</sup> chromosome” (Epstein, 1995)

“*Why is my baby not crying nurse*” asked Joyce of the mothers of the nurse, is indicative of mother’s intuition and she probes “*tell me, is anything the matter with my child*”. Being older than thirty-five, and having had other children prior to the child with Down syndrome, two of the three mothers were aware of the risks that came with conception after the age of 35 but the third did not hear of the condition before until a home visit from the hospital matron, and was perplexed when it was mentioned.

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<sup>37</sup> <http://disabilitystudies.syr.edu/what/whatis.aspx>

For Caroline and Estelle, exposure to their children's disability is innocuously expressed as "*your child is unwell*", implying that the child requires "professional intervention to be restored" (Conrad, 2004) or openly "*your child has Downs*". In my case it was the cautious phrase: "*your child may have Down syndrome, but only a blood test can tell conclusively*". None of these expressions bore any meaning for nor prepared us as mothers for the responsibility of raising a child with Down syndrome. The absence of explanation of the condition is indicative of assumptions or limited knowledge of nursing personnel, about parent's cognitive inability to understand medical terminology of the biological condition and the terms of reference may be unfamiliar; to reduce the initial shock of 'expectation not met' for the parent; that the gradual understanding of the condition may lessen the feeling of shock and increase the acceptance; withholding facts approach will allow parents to persevere with the raising the child until they either reject or embrace the child.

I wanted to establish the informants' knowledge about Down syndrome prior to the diagnosis. For Estelle, the delay in bringing her baby to her concerned her. Both Joyce and Estelle deduced the nursing staff's truth-delaying strategies were to some extent, a consolation. I have no history of the condition in my extended family and with no interaction with parents or CWDS, had no idea what the condition was or its implication for a family. The characteristic of withholding of information on the part of the nursing staff, as if it was a secret, of something to be scared or avoided, instilled more fear rather than the condition itself. Although the gathering of information was slow and incremental, and initiated by self, it offered respite and lessened the fear factor.

Physiologically, I have noticed Tiara to have loose muscles and very flexible joints, with poor muscle tone and tended to grow more slowly than her typical non-disabled sibling. As observed by the informants, "*the baby was not strong*" (Estelle) like their other children, and one informant added that the baby "*didn't want to breastfeed*" (Joy). In my case, the nursing staff observed her "*low muscle tone*" but she did breastfeed well. This suggests that the characteristics are defining features but they are not applicable to the same degree in each case. People with DS have some level of intellectual impairment with common corporeal

characteristics which were identified by the parents, especially features of the remarkably round face and distinct small chin. The most pronounced feature, as I have noticed with Tiara, is the flat bridge of the nose. To all parents, including myself, the characteristic of “epicanthic folds (folds over the inner corner of the eyes)” and “shorter arms and legs” (Davies, 2008) was identified only from later reading of the condition. Parents noticed that their children with Down syndrome were generally prone to infections as evident from comments: *“I take her to the clinic 3 or 4 times a week because of her asthma”*; *“she was always getting a cold so the doctor put her on preventative treatment in taking the pump (Asthavent) administered with a spacer as the child cannot inhale in large gulps”*; In my case, in addition to recurrent chest infection my daughter had *“thyroid problems (hypothyroidism) diagnosed at ten years of age which resulted in chronic medication prescription of Eltroxin at 0.5 mg daily since then.”* Some of these descriptions may not be applicable to all children with Down syndrome but to the interviewed informants. What was also quite noticeable is how mothers became more conversant with medical terms and description of medication.

It was necessary to start to know what the condition entailed and each informant began the journey of ‘knowing’, differently: Joy, through clinic visits and Estelle, Carol and I, through reading. The various ways parents came to ‘know-what-they-know’ about DS is a piecemeal manner.

#### **5.2.6.2 My knowing**

Research on the experiences of families serving the needs of a CWD indicates that, although there may be shared ideas in parenting experiences, the impression varies greatly among families (Hanson, 2003). Some of the commonalities and differences of parenting a child with Down syndrome is presented through spiritual knowing, theoretical/medical knowing, and intuitive maternal knowing as deduced from conversations with the informants in this study. Academic input could only be offered by one informant who was situated in the domain of academia and has researched, written and presented papers on the subject of inclusion, barriers to learning, disability, children’s geographies and related fields.

### 5.2.6.2.1 Spiritual Knowing

Joy and Patricia indicated that their family spiritual reliance helped channel the negative emotions towards a positive one by focusing on the task of raising the child, as a blessing from God and “*there is a purpose for God to give this child to you*”. According to Johansson (2014) turning to God is described as a strategy for coping. Research indicates that one of factors which enables parents to cope with raising children with disability is resilience (Muthukrishna & Ebrahim, 2014), which is expressed as reliance on God in (Littrell & Beck, 1999) and well-defined faith lives, (Bachay & Cingel, 1999). These expressions of spiritual comfort enable parents to cope and in some cases emerge stronger. ‘*Cope*’ reflected my own experience. From my initial, spiritually barren outburst, “*This cannot be happening to me! It is not possible. I am only in my twenties. I shouldn’t have been at risk. What went wrong? Someone is to be blamed. Certainly not me!*” it took a long while to regain my focus. The weeks and months that followed were a rollercoaster of spiralling emotions of denial, none of which were good. Within days I was in a pit of utter despair, shutting out the world and everyone with it and consumed with dreaded possibilities. Numb, unwilling and unable to engage with people at all. More attempts at analysing the circumstance led to intensifying this pain- and what I later came to understand as ‘denial’.

### 5.2.6.2.2 Theoretical and Medical knowing

Estelle and Carol were aware from visits to the gynaecologist that the risk of a CWDS was high due to their age group (over thirty-five). This propelled me to read about DS and older women. I read of a study in the UK conducted by Professors Joan Morris and Eva Alberman of *Barts and London School of Medicine and Dentistry*. It was accessible from a British Medical Journal.<sup>38</sup>The *NHS Fetal Anomaly Screening Programme* funded the *National Down Syndrome Cytogenetic Register* with the mandate to gather data on DS and maternal age groups, until March 2009. The results indicated an increase in DS diagnoses. The link is to age of the mother showing that women who delay pregnancies until later in life (past thirty-

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<sup>38</sup> [specialpost.org/2013/03/12/down-syndrome-birth-trends](http://specialpost.org/2013/03/12/down-syndrome-birth-trends)

five) increase their chances of having a CWDS- with risks higher with older age group. Australia records a shift of delayed pregnancies, correlating with international trends. The inclination towards delayed motherhood increases the risk of live births of DS children. Research in the UK approximates risks of 40-year-old mother with a 25-year-old mother, to be 16 times likelihood to have a CWDS than the latter age group.<sup>39</sup>

In both cases the mothers were informed of pre-natal testing that was available, accessible and affordable to them. One informant chose to pursue that route and the other did not. Recent research conducted in Western Cape, South Africa showed that women were positive about pre-natal testing and added that it allows the mother time to prepare for the arrival of the baby with DS (Scott, Futter, & Wonkam, 2013). Both were anxious during the pregnancy as they awaited the birth, one hopeful that the baby will defy medical research and will be born non-disabled; the other hoped that with no birth defects in the family history, the risks will be reduced. That interim period was filled with silence. Both did not share their fears with their spouses or attending doctor. *“They [the doctors] asked me if I knew what DS was. I said yes but I didn’t really know. I knew they were funny little children. I became scared. This was unknown to me”* While Joy and Estelle heard of the condition prior to the diagnosis being confirmed, they were not contented with the scientific description of the condition that was provided as it offered no frame of reference to understand the scope or depth of the maternal responsibility. It was a case of little knowing (as they only heard of the word before) and not knowing (as they did not know the details of the condition of DS).

To Joy, the simplistic and vague terminology (*“unwell”*) and expressions (*“we want to see the baby”*) to justify the frequent ultra-sound sessions she had undergone during her pregnancy-instilled further nervousness. She did not learn of the diagnosis until the matron visited her home and even then had no idea what that meant. *“It was the first time I hear the name, Down syndrome”*. She was preoccupied with the possibility that she may not carry the baby to full term as both her previous pregnancies were unsuccessful. When she was informed of the diagnosis, her lack of medical understanding of condition did not matter as much to her as the

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<sup>39</sup> <http://www.nhs.uk/news/2009/10October/Pages/Down-syndrome-termination-rate-screening.aspx>

need to protect the baby and ensure her growth. Estelle's anxiety is conveyed in the following: *"I could see they were very uncomfortable and I knew something was wrong because everyone else in the hospital got their babies but for me. I did not get my baby"* "Initial experiences with health professionals have a major, lasting influence on the parents' ability to cope with their child's condition" proposed by Graungaard and Skov (2006, p. 296) is evident in this context. "Women appear to adjust well if they use both emotion-focused and problem focused coping, and therefore, health professionals need to provide accurate information" is the recommendation from Horsch, Brooks and Fletcher (2013, p. 8)

To further this discussion I consider whether access, a matter of choice in the remaining discussion on this aspect.

The core focus of the interview regarding parents' consideration of schooling indicated the effect historical, social and contextual factors played in the choices available and accessible. Being unfamiliar with the South African schooling landscape at the time, for their children with disabilities, parents made emotionally guided decisions. Parents have fears that their pre-school children on entry, will face social isolation, rejection, or mockery by their non-disabled peers (Rafferty, Boettcher & Griffin. 2001). Estelle elected to enter the child into special needs schools without consideration of mainstreaming, citing the recreational programme as a satisfactory reason: *"They had swimming lessons and horse-riding. Had I put him into a mainstream school this would not have happened?"* Informants generally perceived teachers at mainstream to be less competent to teachers of children with special needs such as Down syndrome, by saying *"Mainstream teachers are not qualified enough to teach our children"* They preferred special needs schooling to mainstream schools perceiving that although *"educators do not have adequate qualification and training"* *"the teachers know the condition of our children"* and were therefore more likely to be more relaxed in the approach. These statements are made against the background of having other non-disabled children who attended mainstream schooling. It may be that informants were generalizing about both mainstream and special needs schooling options based more on general conversations with parents of other children with Down syndrome (who chose special needs schooling options for their children with Down syndrome, 3-5 years earlier). Parents were influenced by contextual

factors as prevalent options were unknown and reliance on hear-say and experience of other parents determined their choice of schooling. Heiman concurs with this view in his study with parents on coping, expectations, and resilience. He surmised that “parents shared their feelings or thoughts about their child’s disability with the people from whom they expected understanding, rather than according to the severity of the child’s disability” (Heiman, 2002, p. 164). Having access to appropriate information helped parents plan ahead and feel more in control (Pain, 1999, p. 306) and add that information from healthcare professionals helped to accept the child’s disability and adjust their expectations accordingly.

### **5.2.6.2.3 Intuitive and maternal knowing**

*“I go to the nursery. The nurses say ‘which one is your child here?’ I just go to my baby and pick her up. They say ‘how do you know it’s her. It is your first time here?’ I tell them I cannot forget about my child”* Parents tend to focus on the abilities and skills their child may develop and show forth; health-care professionals, on the other hand, have a tendency to highlight the disability. Parents express this experience as a “misinterpretation of their child”, and add that they were treated dismissively, as a case and statistic, than a person (Graungaard & Skov, 2007).

As parents progress with taking care of the child and growing in their understanding of how to do that with their spiritual, theoretical and intuitive knowledge, the observation of milestones and comparison with non-disabled children of their own, opens up the aspect of challenges or barriers the child faces in many forms. The following discussion is couched within the domain of access, schooling and implicit references to children’s geographies. Ngcobo and Muthukrishna (2011) combine these components, underscoring “that schools are about *providing quality education* for all children and youth, regardless of differences in respect of race, class, culture, language, gender, ethnicity, ability versus disability” (p. 357). It is the point of entrance into the next phase of discussion.

### 5.2.6.3 Barriers to learning

‘After getting in’, was a persistent concern. Physical access of securing a place for my CWDS at a school did not mean objective achieved, parent satisfaction and withdrawal. There are numerous means by which managing educational achievement can become unequal. I wanted to learn more about the ways this is manifested. I wanted to learn about obstacles or barriers to learning (BTL), a term used to describe anything whatsoever that may present an obstruction or preclude the learner to participate wholly, and learn successfully ( (Ngcobo & Muthukrishna, 2011). It is of added importance to note that obstacles do not necessarily prevail continuously, but can appear unexpectedly, with variation in conditions, emotional disturbances and a host of other dynamics. Discussion of BTL, in great depth, occurred in Chapter Two but for the purposes of this context a brief summary is offered noting that “White Paper 6 on Inclusive Education” grasps the urgency of identification, followed by analyses of prevalent obstacles to learning within the current schooling system. A broad overview of BTL, which was discussed in detail in Chapter Two, is revisited, synthesized and presented with input of Patricia Krishna to help the reader navigate its importance in the domain of children’s’ geographies.

According to Patricia Krishna, four significant BTL were listed and described as follows:

- *Systemic barriers include the whole issue of classroom, unsafe school environment and inaccessible school buildings for the disabled. School level policies and procedures e.g. child protection policy.*
- *Societal barriers include poverty, impact of HIV and AIDS, abuse.*
- *Pedagogical barriers refer to specific barriers related to learning- underqualified teachers, overcrowded classrooms, and inappropriate teaching and assessment strategies to cater for diversity. It is one of the biggest issues in the curriculum.*
- *Medical or Intrinsic barriers indicate children with neurological problems, sensory problems, and physical problems*

Inclusion would be addressing those barriers, making schools more responsive to those barriers and offering an opportunity for the child to negotiate spaces and places of learning

(Muthukrishna & Schoeman, 2000). The inclusive approach encompassing the Revised National Curriculum Statement policy on education, sought to address barriers to learning that learners. As a parent and outsider to the classroom interaction, I have expressed the sentiment that to ensure learners succeed it is incumbent on the educator to engage with them to create opportunities for optimized participation. The four over-arching barriers to learning (Muthukrishna & Schoeman, 2005) are significant enough for a trained and vigilant educator to detect to some extent, the social, emotional or physical, and sometimes a combination of challenges, faced by learners.

The following discussion will intersect a collective parents' view and experiences with the fundamental barriers to learning: systemic, pedagogical, societal, access to basic services, intrinsic/medical, lack of access to the curriculum.

#### **5.2.6.3.1 Systemic barrier**

Carol, too, always wanted to mainstream Jennifer to such an extent that she resigned from her job of thirty years to accommodate the adjustment. *“My son had gone to Tito Primary school and I knew they had a special class in that school. Government had closed down special classes in schools (around the year 2000) but Tito kept it and that’s where she went...into the special class so that she could work at her own pace.”* This scenario portrays one of the BTL to be pedagogical. Whilst Jennal was in the mainstream school, she attended a class exclusively for children with intellectual and learning disabilities with a teacher *“specially trained in special needs”*. *‘Specially trained’* is a conflated term as its varying differences are not factored in. The additional barrier was systemic emanating from this description: *“Jennifer was coming home with fingernail marks on her arms as if someone had grabbed her. This isn’t working now”*. This occurred during her later years at the school when a new teacher was assigned to the class in 2005. A school Safety and Security or Child Protection Policy should have been in place to prevent such incidents from occurring. Carol was unaware of the South African Schools Act (SASA) 84 of 1996 and the Employers Equity Act (EEA) 55 of 1998 which outline acceptable and unacceptable conduct of teachers. She opted to remove Jennifer and with few choices available, secured a place at Golden Hours (school for children with

special needs. The absence of protocols and infrastructure to help parents navigate through the maze of schooling for CWDS leaves the parent helpless). After eight years at this school Caroline says “*I don’t think my child can read anymore. She could read but now I’m not sure. The books she was reading when she left Tito Primary is the same level books she looks at now*”. I guess Carol was not aware that it is not unusual for children with Down syndrome to regress when moved from early intervention and sustained programmes in mainstream schooling to special needs schooling.

Tiara had experience through various systems of schooling in the hope of finding one that will optimize her development. *David’s pre-school* offered her place to be amongst children of her age but without personalized attention at three years of age, struggled to be independent. *Mind the gap* had a Montessori approach and she had a space where she could settle herself and work through puzzles and building blocks, rather than baby dolls and fantasy play. There was little to no written work as the educator said she was allowing Tiara to develop gross and fine motor skill and communication skills. She was introduced to swimming and enjoyed it very much. The limited provision for her academic growth is witnessed in her ability to complete age appropriate puzzles in good time but skills in writing, dissociated with her communication skills. The trend of focussing on skills continued into the remaining years of her schooling and remained a core focus at *Durbs Primary* and *Sunset*. She was thirteen when she went into Hilltop Training College. A small class and a lot of personalized attention could not reduce the gaps set in her formative years. Now she is receiving personalized one-on-one tutelage at home. My expressed desire to see her write her name, T i a r a, is yet to be achieved.

#### **5.2.6.3.2 Pedagogical barrier**

Estelle contemplated mainstream but decided against it based on unpleasant experiences shared with her by other parents of children with Down syndrome. On reflection, she has no regrets in making that choice. John was placed in a school that catered specifically for DS and over time the school accommodated children with other disabilities and impairments. “*They didn’t put pressure on these children*” is indicative of pedagogical and systemic barriers because the gentle approach to academic programmes transferred learning to parental

responsibility with the general pace at school not dictated through any formal curriculum. Low expectations experienced by learners with DS contribute further to their breakdown of learning. This is evident from the parent affirming “*he got the rest at home. We had him working hard at home. He can read though not like other child his age.*”

#### **5.2.6.3.3 Societal barrier**

One of the BTL for her child, which Joy faced, was societal: the lack of professional and sustained early intervention programmes. These programmes which could have increased the capacity of her child to learn was not available, except for the occasional instruction from the clinic of what Joy could do with her at home. It was not monitored or supervised at all. Joyce went directly with her daughter, Lindiwe, to a school which offered instruction in the home language. At Phezulu School for CWSN, a combination of inappropriate pedagogy with limited curriculum access meant that learners were exposed to life and self-sufficiency skills, to a greater degree, than core curriculum. “*No reading! No writing. She can’t do that at all!*” Lindiwe was at the school for fifteen years and emerged with minimal self-sufficiency and cooking skills and no coherent reading or writing skills.

#### **5.2.6.3.4 Negotiating access**

For a developing country like South Africa, where inclusion is gaining momentum slowly and staggered in various provinces, and implementation is still evolving, access is partial or restricted (Shakespeare, 2006). It is dependent upon the type, severity, number of disabilities and the level of additional support available to the learner. Joy’s attempt at gaining access was uncomplicated as evident from her comment: “*The principal looked her [Lindiwe] up and down and said ‘she’s looking well’* and with a brief conversation with her, a place was secured.

Gaining access to special needs schools for John, was equally unproblematic for Estelle. The Cherie Botha School originally catered specifically for CWDS so securing a place for her son John was effortless. For Carol, the mainstream scenario was different. An interview with the

principal, followed by monitoring Jennifer at her pre-school over a few days and from their observational notes determined that she would cope in the mainstream school albeit a special class. No psychological assessment report was required. Carol's comment: "*You have to get that principal on your side*" and "*I was friends with the special class teacher because she taught my son*" are indicators that previous positive interactions and with management and staff is more likely to result in a favourable application.

In my case, I knew no-one on the staff of the schools applied for. Applications sent to four schools with attached psychological assessment reports did not yield the expected outcome. Instead, three principals indicated that they had intake to full classroom capacity and could not take more learners. An interview at one school secured a combined meeting with the principal and management. The discussion ended with an offer of a trial period of three months when school opened in the following year. Due to safety compromise, Tiara was not there for less than a week when she was removed (for safety reasons) and with no other choice I was forced to place her in a special school, which we deferred in order to give her the opportunity of mainstream inclusive setting. The application was scrutinised against the psychological assessment report and after much deliberation, Tiara was allocated a place for formal schooling. The deputy principal's words that we would be, reverberated when we explained our desire for mainstream, adding that mainstream schools would not accept her. These dismissive statements echo some of the negativity that parents are faced with when making difficult choices.

Each nodal moment on access captures the following commonalities: space and negotiation. The perspective of space as suggested by Soja (1989) that it should not be seen as "fixed, dead, undialectical" (p. 11), is applied in this study. In determining the most suitable education space for CWD, the opinions of the affected children and that of their parents are less likely to be given credence as long as the frame of reference is 'disability' rather than 'ability'. Access, as extrapolated from the work of Nind and Seale (2010), indicates the following precepts: mainstream education has its own policy of access and is a struggle. To counter this struggle, every school should have an accessibility plan detailing how the school "will improve the physical environment, make improvement in the provision of information

and increase access to the curriculum” (Nind and Seale, 2010, p. 7). In other words, access should be facilitated, not frustrated.

Having secured a place, a seat in a class for the child, the engagement of principal, management or teacher with each informant varied from minimal to hardly any feedback. I wanted more interaction, involvement, and feedback on a regular basis as a partner and parent. Ainscow, Howes, Farrell and Frankham (2003) acknowledge that recognition in the shift of parental involvement paradigm (primarily through their own advocacy) allows them to be collaborative partners instead of passive clients. Parents do have insider information of their child’s strengths whether it is academic or arts, as well as their challenges from intrinsic or extrinsic factors. With this information, they are in a unique position to offer insight into the areas of needs and the best ways of supporting children with disabilities in schools.

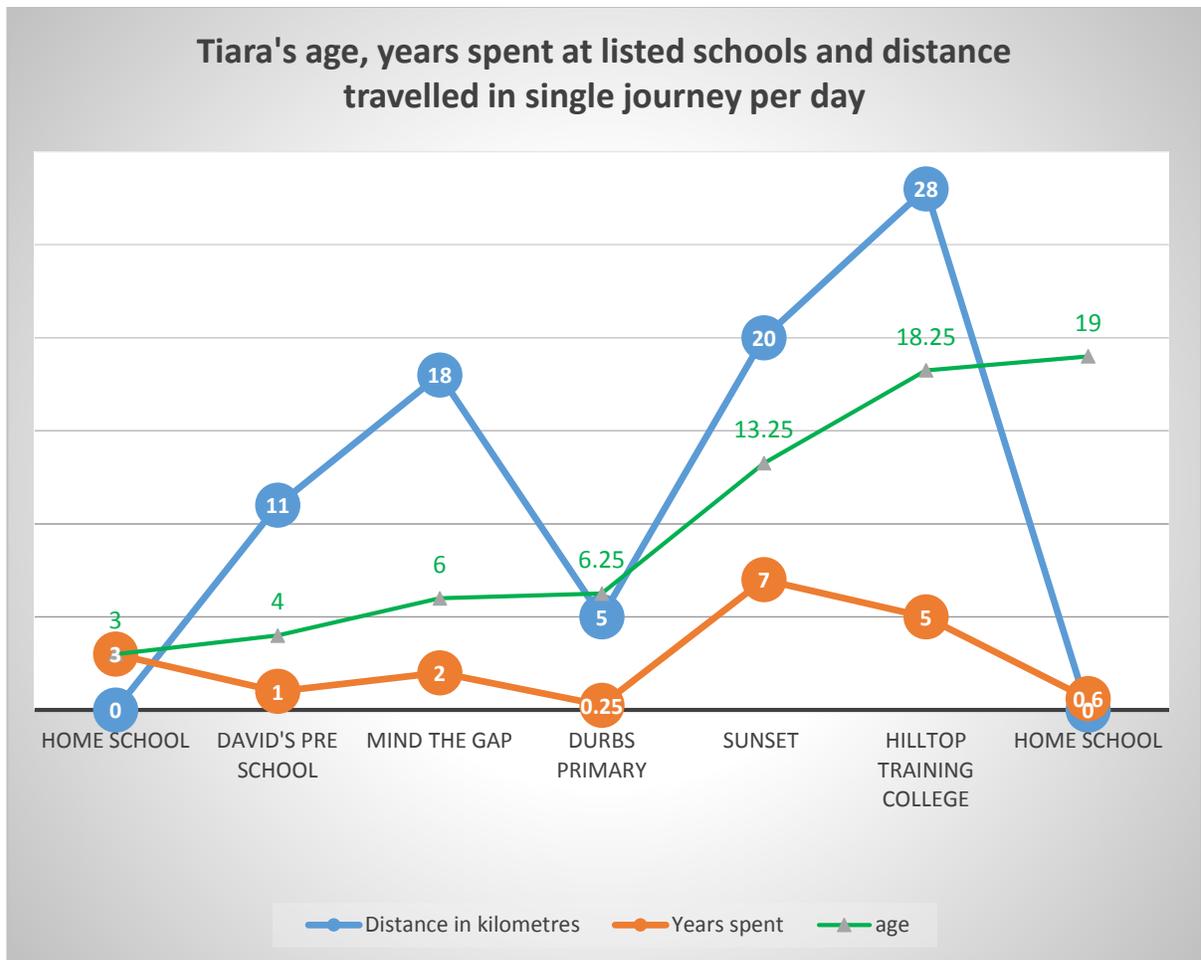
In thinking back of the fifteen years she spent in one system or another and what she has to show for it, the incongruence is troubling. At the end of each year at Sunset and Hilltop Training College, Tiara brought home a report of her performance and evidence of the work she had done. Within the file would be sheets of paper, the marks on each page indicative of her having worked on it. At the corner of that page would be her name, written by the educator. In any given year, the pages show similar activity: colouring of pictures.

#### **5.2.6.3.5 Access to basic services**

*Tiara has to be up at 5 h 30 in the morning to prepare herself on time to catch the bus at 6 h 30. She gets to the pick-up point accompanied by the nanny, boards the school bus and travels with fellow scholars through a circuit of stops to pick up other learner. She gets to school approximately 7 h 45. The return trip sees the same amount of time spent on the road before she gets home at approximately 14 h 30. The mainstream schools within a five kilometer radius of our first home refused admission on grounds of inadequate space or personnel citing the Department of Education policies that restrict the intake capacity of each school. There was no other choice. We moved home from the Riverhorse Hills to West Villa as the driver of the school bus was not authorised to deviate half a kilometre off the regular*

bus route to pick Tiara up, despite our appeal. Now that we relocated to be closer to the bus route, it meant an early start to the day for all of us. Riding on a school bus resulted in longer hours in transit. The alternative was to use private transport but work commitments ending at 14 h 30 and no aftercare at school meant limited options.

Consideration of the travelling distances from home to school for each of the children with Down syndrome in this study indicates the limited number of schools available to service the needs of the children that forces parents to transport them privately or public transport. If the option of the school bus is selected, geographical residence is important. “*I had to relocate in order to be located on the bus route*” because the driver was not authorized to make any deviation from the established route. Caroline travelled 34 kilometres from Amanzimtoti to Durban North on a single journey to school to fetch her daughter. Parents electing to transport children to school privately relate to concerns over traffic safety and personal security. This configuration of travel plan is “in itself a result of the interplay between existing social, geographic, economic and environmental factors” (Morris, Wang & Lilja, 2001, p. 2). In an effort to reducing time spent travelling and the associated risks with that, parents were prompted to transport their children privately. Lindiwe and Tiara travelled with the school bus which meant long journeys twice a day, every day.



**Figure 9: Composite representation of geographies of access. Indicates age, distance in single journey to schools attended in the approximately 15 years and duration of stay at each school.**

Part of the reason for increasing travel distances is dispersed location of schools servicing special needs, caused by deliberate policies of Apartheid. Caroline had the option of a school half the distance to the one selected but chose not to because of its general appearance. The school in Durban North appealed more to her because it had a neat façade and well maintained structure. *“A special school is a special school. It does what it does, so I looked at pretty as opposed to which one is actually going to be better. Sunset was neatly kept. It is lovely, painted and beautiful whilst Willowton was falling to pieces. It is not so bad now. Totally wrong”. I could have taken her to Willowton because I worked close by but I thought half a dozen years, just leave her where she is”*. An additional contributory factor is of parents

exercising their right to quality education. The perception that better schooling opportunities exist elsewhere, lead parents to search and secure access to schools outside the place of residence, snubbing local schools. Morris, Wang and Lilja (2001) referred to a study by Godfrey, Mazzella, Cabrera & Day (1998) conducted in Australia, where parents transported their children regularly because of distance from home to school. The likelihood that learners would walk to school if they lived more than 2.4 kilometres away from the school, is minimal (Morris & Wang & Lilja, 2001). That study did not specify disabled or non-disabled children. In South Africa, where most non-disabled learners walk daily between twenty minutes to half an hour to school twice a day, parents have to make personal arrangement to transport their children with disabilities (sometimes through lift-clubs, at other times through private transport companies), is indicative of the absence of suitable mobility programme by government for its school going population of both disabled and non-disabled learners.

#### **5.2.6.3.6 Intrinsic and Medical**

Hearing loss is a sensory disability classified as medical or intrinsic barrier to learning. *“My daughter was in a special needs classroom for three years seated with the teacher speaking to the right of her. With three different teachers in three years, not one of them picked up that my child was profoundly deaf in the right ear”*. How does one reconcile meaningful participation with schooling, curriculum engagement or recreational benefits when the child only received deferred sound, undetected for three years? “Unilateral hearing” describes typical auditory sense in one ear and permanent loss in the other. “Learners’ who experience unilateral hearing loss, can usually function normally and will only have problems locating the direction of sound”. Tiara was profoundly deaf in the right ear at birth but was only diagnosed when she was nine years old. Tiara was probably pre-lingual deaf (that is deaf at birth) but only diagnosed after formal schooling had commenced. It is very difficult for me to estimate the level of impact it had on her learning.

I recalled browsing through an information booklet on hearing loss in the waiting room of a local hospital (where we were having Tiara’s hearing tested) and was startled to read that currently as early as one month, babies can have auditory tests. In case of positive screening

infant diagnostic audiologic evaluation is advised, preferably before three months of age. Individuals recording hearing loss (subject of the degree of loss) have access to early intervention services before six months of age. Why this information was not available to me earlier is inexplicable. The paediatrician, the cardiologist, the gynaecologist, specialist physician and general practitioner had consultations with Tiara from birth yet not one of them advised me to conduct a hearing test.

When I read Bess (2004) dictum that ‘minimal is not inconsequential’ I see its aptness to this discussion. He conducted research on hearing loss and understands the profound difference hearing can have on learning outcomes. One of the research projects conducted in the UK to establish children’s level of hearing indicates that “children with mild and unilateral hearing loss score lower on tests of speech, language, school achievement, and behavior than do children without hearing loss” (p. 11) and shows that “unilateral sensorineural hearing loss is the predominant form of loss” (p. 18).<sup>40</sup>

#### **5.2.6.3.7 Lack of access to the curriculum**

Although the child may be in a classroom with a teacher, curriculum access denied can be manifested in various forms. The most recent research, in 2014, by SAHRC and UNICEF shows that “Teachers’ content and pedagogical knowledge, the availability of textbooks, teacher discipline and school management” (SAHRC and UNICEF, 2014, p. 14) affect schooling outcomes. When Caroline says: “*my child brought home a file of worksheets she had randomly coloured, at the end of the year*”, it show that in the classroom context learners with disabilities who are considered incompetent would have fewer opportunities to engage or participate meaningfully regardless of their disposition of interest and eagerness, and are to some extent excluded. The paradigm of child incompetence intersected with low expectation on the part of parents (“*if you said she must write her name she just make marks like this*”). This extends into and exists in the schooling of children with disabilities (“*I had to read*

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<sup>40</sup> Workshop Proceedings: National Workshop on Mild and Unilateral Hearing Loss. Beaver Run Resort, Breckenridge, Colorado July 26–27, 2005. Accessed from [http://www.cdc.gov/ncbddd/hearingloss/documents/unilateral/Mild\\_Uni\\_2005%20Workshop\\_Proceedings](http://www.cdc.gov/ncbddd/hearingloss/documents/unilateral/Mild_Uni_2005%20Workshop_Proceedings)

*between the lines of what one teacher told me. I cannot remember exactly but she suggested, 'put your child in a special school'") in South Africa as it does in other contexts despite explicit policy changes and shifts towards inclusion. Overturning this dichotomy of theory and praxis warrants further investigation especially on the feasibility of inclusion of CWDS into mainstream schools (Kitchin and Mulcahy, 1999).*

The sample of special schools referred to in this study is not listed as providers of any formal academic accreditation. On completing approximately eighteen years of schooling and exiting the system without any certification represents marginalization. Following on from this context, the disabled are often marginalised from formal participation or contribution to the labour sector, resulting in a multitude of “marginalised positioning” (Gleeson, 1999), performing mundane repetitive tasks at workshops in the periphery of society, with little to no stimulation. Through teachers’ lack of understanding, knowledge and training in how to teach disabled children (Mkumbo, 2008) and a random, arbitrary curriculum, special schools denote and underline variance, negatively (Thomas, 1997). In addition, some authors maintain that any average experience within special education is penurious. This is manifested in restrictive access to holistic curriculum with limited chances for the building of children's beliefs and values (Alderson & Goodey, 1998).

It is worth offering the reader a smidgen by way of explanation, on the curriculum offered in South Africa. There is only one nationally prescribed curriculum per subject, per grade. Children in mainstream setting access the National curriculum and used in its entirety in preparation for various examination sittings. Children in special needs schools do not necessarily follow the National curriculum in its entirety and in some contexts it is adapted and referred to as a differentiated, but school-based curriculum. In other words, there is no uniformity of curriculum in all schools catering for children with various disabilities. At the schools Tiara attended, the emphasis was on skills, with adaptation of the core curriculum, an exception rather than a norm. In 1997 the National Curriculum Statement (NCS) signalled a post-apartheid design. With Outcomes Based Education (OBE) as its methodology, it was hoped it would address the need for quality education for all. It was criticised from many quarters and subsequently reconstructed (Jansen, 1998; Botha, 2002). The outcome was

Curriculum and Assessment Policy Statement (CAPS) introduced in 2010. It offered guidelines and recommendations for inclusive practices rather than a prescribed alternate or differentiated curriculum, and assessment for children with special needs. Being optional, meant that it is not taken seriously. As a result children in special schools are not exposed to an adequate curriculum commensurate with their age.

The perception created from such contexts reflect practices of ‘ableism’ which is defined by Neely-Barnes, Graff, Roberts, Hall & Hankins (2010) “to include overt discrimination against people with disabilities, the notion that people with disabilities are inferior to non-disabled people” (p 245). It is suggest that the primary school education system Tiara engaged in designed and implemented an ableist framework through its policies, curriculum and personnel attitudes, and in so doing did not cater for children with a range of intellectual capacities.

Minister for Women, Children and People with Disabilities, Ms Lulu Xingwana (Member of Parliament), in “*A Review of Equity and Child Rights*” done collaboratively with UNICEF and the Department of Women, Children and People with Disabilities of South Africa, expressed the following sentiments about her Ministry in 2011: “committed to create an enabling environment to ensure the facilitation of constitutional obligations, policies and legislative frameworks to realise all children’s rights”; “ensure that no child is left behind”; “that children with disabilities experience a society that values them and respects their rights”. In the same report, Commissioner Lindiwe Mokate of the South African Human Rights Commission (SAHRC) made the following statements: “More attention should be given to children’s meaningful participation”; “gaps in policies and service delivery programmes”; “improve the situation of children, especially vulnerable children” and “inequalities in the provision of and access to basic needs”.<sup>41</sup>

It seems that the Ministry expectations by Ms Lulu Xingwana is deemed as not met as expressed by Lindiwe Mokate showing us that such discrepancies that existed in 2011, when

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<sup>41</sup> [http://www.unicef.org/southafrica/SAF\\_resources\\_factschildrens11.pdf](http://www.unicef.org/southafrica/SAF_resources_factschildrens11.pdf)

the publication in which it occurred was merely three years ago, and South Africa was estimably seventeen years into its democracy. Therein lies one of the barriers to learning: dichotomy between intended and implemented policies and frameworks.

*“Curriculum policy is very good. CAPS is really good and some of the insertions made there as part of the Department guidelines on how to cater for diversity, children functioning at different levels even regarding the curriculum, and assessment at Foundation Phase and is not implemented”* says Patricia Krishna. The consequence of this lack of implementation and monitoring of implementation by government is that many of these learners will become dependent on state subsidy, have little to no independence and have their chances of gainful employment reduced.

#### **5.2.6.4 Inclusion versus Exclusion**

Inclusion is generally described as the practice of "educating children with disabilities in regular (or what we generally refer to as mainstream) classrooms of neighbourhood schools- schools which they would attend if they did not have a disability- and providing them with necessary services and support" (Rafferty, Boettcher, & Griffin, 2001, p. 266). Grove & Fisher (1999) present the view that it is a challenge to find suitable schools with educators adequately capacitated in knowledge, inclusive educational goals, relevant teaching practice and qualification to provide for the schooling needs of children with additional, educational needs. The disquiet about qualification of educators in special needs institutions is expressed by two informants: *“teacher will know there’s potential there if they were qualified”* stressed Caroline. Estelle reinforced this perception with her comment: *“Even at the special school they don’t have teachers equipped (qualified) enough to know our children”*

Recreation (social) and curriculum exclusion are two domains where CWDS more often, experience exclusion more often than inclusion. Smith –Chandler and Swart (2014) suggest that individuals with disabilities experience open or discreet exclusion from mainstream settings amongst perceptions of disability as an inferior status. Joy indicated that she was advised by friends not to bring her child when visiting as they felt they would be judged as

having an ‘abnormality’ by association and the child would bring misfortune to them if she entered into the same space of the home. Joy was told, “*Please leave your child at home. I don’t want to get sick.*” She added her concern: “*no one wants to play with my child*” to show that non-disabled children, too, may mimic adult attitudes and behaviour by excluding children with disabilities from involvement in recreational activities.

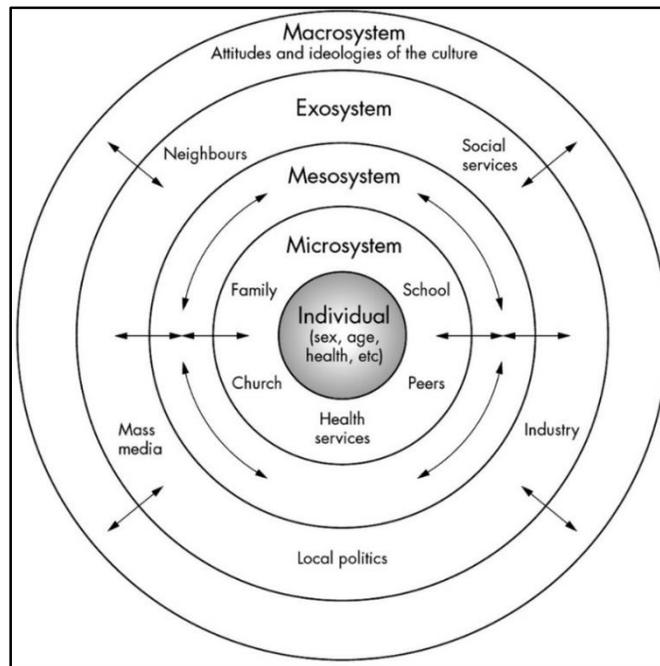
Carol was concerned that the children “*never went on outings*” suggesting that the children’s geography was predominantly within the confines of the school for the duration of every school day. For children who have Down syndrome (who are by nature very sociable) restriction of activity and association with only classmates (at most) or schoolmates (on occasion) limit the frame of reference for living when de-schooled. Nespor (2000) research on school fieldtrips exploring ‘curriculum of public spaces’ in the US raises concern over children being progressively restrained in urban settings. Extra-curricular activities are considered invaluable instances for familiarising them with and creating a framework of their involvement and interaction in public spaces. His view is that schools are not just places and spaces regulating children’s movements within their boundaries, but vehicles, which *should* [my insertion] contribute to social cohesion by physically and symbolically offering a passage of experience into and across shared physical landscapes (Nespor, 2000).

Ballard (2013) expressed his view about the processes of inclusion and exclusion in the following words: “inclusion and exclusion reflect ideas about how the world is to be seen and understood, about who is to be attended to and who ignored, and about how institutions are to be organised” (p. 762). Transformation heading in the direction of inclusive and socially fair provisions necessitates thoughtful examination of philosophies informing further policies and revised practice. In tandem with this thoughtfulness, there is need for serious scrutiny of the traditional or educational beliefs and values from which ideas develop their sway and control. It may be one of the reasons that the comparative value of segregated schooling to inclusive mainstream schooling, remains a debatable topic (Holt, 2003; Kitchin and Mulchay, 1999). Research shows that schools as education institutions are “underpinned by normative assumptions of ‘appropriate’ childhood development, whereby childhood is viewed as a period of preparation for ‘productive’, conforming adulthood. Such norms are (re)produced

through the everyday spaces of the school. Children who do not concur with these expectations are frequently ‘Othered’ ” (Holt, 2004).

#### **5.2.6.5 Ecology of space**

Schools have distinct spatial expressions or geographies depending on whether they have ‘special need’, ‘mainstream’ or ‘inclusive’ specific component and purpose. In the UK the inclusive context for disabled children’s primary schools is characterised by ‘de-segregated geographies’ (Holt, 2004). As a result, children classified with a range of disabilities (couched as “mind-body” variances) are more and more favourably considered within mainstream, instead of disconnected and isolated special schools (Holt, 2004). In reading on de-segregated schooling spaces, I was interested to know more about the holistic schooling of children with Down syndrome. To gather further understanding about sustained human interaction, which schooling is, I came across the word ‘*ecology*’. The explanation that it is a division of biology which looks at the inter-relationship of organisms to each other as well as their physical environments, interested me. Through investigation of this topic, I was led, from my wide reading, to the specific work of Urie Bronfenbrenner. He is considered the forerunner in exploring the natural conduct of children within their family, school, amongst peers and public. Bronfenbrenner’s research emphasizes the authority implicit or explicit in human interaction, conceptualised as the ecology of human development through informed research and practice with children and youth. Bronfenbrenner has urged the need to look at the environment or setting in which a child develops, as well as at the child him- or herself. (Bronfenbrenner 1979). He advocated that research with children should be in naturalistic settings for ecological validity and added that it must be engaged and sustained for a while to estimate congruence to chain of events in real life, paying attention to subject and setting.



**Figure 10: Bronfenbrenner's ecological systems theory**

Bronfenbrenner's ecological model appeals decidedly for firm conceptualisation of settings and interactions as systems. For the purposes of this analysis in this section of my study I utilise select details of the “micro-system” which speak of the connection concerning an evolving individual (subject) and the direct milieu of school and family (setting).

Bronfenbrenner (1976, p. 58) states:

Whether and how people learn in educational settings is a function of sets of forces, or systems, at two levels; the first comprises the relations between the characteristics of the learner and his or her surround in each of the principal environments in which he lives out his life (e.g., home, school, peer group, work place, neighborhood, community). The second encompasses the relations and inter-connections that exist between these environments (Bronfenbrenner).<sup>42</sup>

To unlock parents experiences of schooling for their children with Down syndrome, necessitated reflectively tracking the characteristics of the learners and the environments in

<sup>42</sup> <http://files.eric.ed.gov/fulltext/ED131025.pdf>

which the learners lived out their lives. There were two incidents that are distinctly compatible in this context of discussion. In the first incident “*Tiara broke her ankle whilst at school. When we asked how it had happened the feedback from the receptionist was that Tiara was on the playground and slipped without provocation. No statement was asked of the teacher, no inquiry followed. Instead we were reminded that we signed an indemnity form absolving the school of any injury to her person. Tiara was in plaster-cast for six weeks.* In the second incident, *Tiara underwent a hysterectomy, she was out of school for six weeks. During both times there was no telephone call to find out how she was doing.* These occurrences testify to the dispassionate manner in which some individuals executed their duties.

Bronfenbrenner asserts that “ecology of education is not and cannot” be limited to studies within stringently or exclusively instructive, educational locations .This suggests that happenings or failed happenings of this context affects and is affected by events and exchanges external to the scope. “ In contrast to most educational research, the ecology of education is not and cannot be confined exclusively to conditions and events occurring within a single setting of home, school, peer group or work place. Equal emphasis must be given to relations occurring between settings” (Bronfenbrenner, 1976, p. 11). These ideas resonate with the work of Jan Nesper, who describes the phenomenon as “constellation of ongoing relations and everyday, materially-embedded and enmeshed practices, which extend beyond the school in space-time” (Nesper, 1997). The application of this framework to the context of geographical spaces implies that access to schooling for CWDS warrants looking at the environments where they spend their time: with parents, school and society. Carol’s comment of her experience with mainstream compared to special needs school shows the contrast in ecology at the different school. In referring to the mainstream school she said: “*She [the principal] got her teachers together. She worked with them. ...to make sure this was going to be a success. I went there and gave talks to the children*” in contrast to “*we were not allowed to go into the school unless you invited. You pick your child up from outside*” in reference to special needs school. The assemblage of each creates conflict rather than support and enhance the schooling experience for the child. How these facets relate and inter-connect with each other will reflect their response to the call for unrestricted access to schooling for children with Down syndrome.

### 5.2.6.6 Post schooling

*“Lindiwe has a part time job. She is paid so little for the hours she spends at work that it saddens me”;*

*“Jennifer is at home. She watches television most of the day”;*

*“John is at home. We are hoping to start a workshop soon where he can go a few times a week”;* *“Tiara is at home. We have a part time tutor once a week for two hours. She has started the Grade R curriculum for literacy with her. During the week she has a flexible programme of exercise, listening to music, working with puzzles, blocks and outdoor activities of gardening”*

Except for Lindiwe, all of the others, who are now between nineteen and twenty-one years of age, are homebound for most days. Their lack of participation in the labour market may be viewed as social exclusion. To overturn this scenario merits creation of opportunities for gainful employment. Critical engagement on issues of social participation to accelerate inclusion and diminish exclusion, even within education, co-exists in diverse spaces of policy documents. The challenge, once again, lies in effective implementation. Teese and Polesel (2003) state that presently, “practically all avenues to economic advancement are linked to schools” (p. 12) but Christie (2008) offers the corollary as well, that schools also “provide avenues to failure and marginalisation” (p. 26). The vision of schooling with a ‘production factor’ (Christie 2008, p. 26) in design will in time add value and contribute to economic growth. This would see more learners employed rather than the disconnected status portrayed in three learners staying at home, ill-equipped with skills to participate in the economy. One needs to question the quality of activities with which learners are engaged within the special needs system, to shed new light.

Tiara is now eighteen. When I consider what post-schooling options would be available for Tiara, I sigh! She returns to home-schooling. She is now learning by personally engaging and ‘doing’ and while she is ‘doing’ she learns more about herself and her relationship to her surroundings. It is not uncommon to find her working on a puzzle, or building a tower with blocks or playing her favorite compilation of music for equal lengths of time and sometimes,

simultaneously. Presently, her learning programme does not follow a fixed curriculum, is not directed by a traditional teacher, and occurs within the milieu of family and community.

This phase of our journey was also an imperative I had to heed: Tiara was terrified of going to school because of the barking and frisky dogs on the school premises that galloped to the gate when school was dismissed or did the same in the morning when the gate opened for me to drop her off. My husband and I contemplated whether the disbanding of the lift club was a 'blessing in disguise'. We thought long and hard about how she would occupy her days at home when she is not routinely up at five-thirty in the morning. It took time and with the passage of time we accepted that private homes schooling was the only option. Compulsory institution based schooling was over. A new chapter was about to begin.

I have come to design her daily programme not in complete rejection of the authoritative structure of schools but to be flexible to her needs to access all aspects of schooling. On a typical day her routine includes exercise in the home gym with her favourite music, reading and being read to, developing vocabulary through flashcards and pictures, doing activities on her tablet which has programmes on numbers, shapes, colours, differences, similarities, completing puzzles, identifying sounds to objects and animals, matching, preparing a simple meal for herself, learning to answer the telephone and holding a conversation. She enjoys storytelling and fantasy play as she puts on her apron and sets the table for two at tea-time to serve her 'friends', Milly and Minnie. We have days in the month assigned to gardening, recreational visits to park, social responsibility visit to old age homes or orphanages, movies and restaurant treat, and have a friend sleep-over. It is about building relationships between people, between adults and children, and between children and their natural environment. I see post-schooling being about learning that takes place anywhere and everywhere, not solely within the four walls of our home but extending to the community. I want for her to be engaged in real, purposeful, meaningful tasks with real people working and playing in real life situations: an embodiment of schooling spaces I envisaged before she entered into her first school at the age of three.

### 5.2.7 Enabling or dis-enabling access

*“After leaving school I went to the Motheo College, a technical college, and was also the first, and only student with Down's syndrome, to be accepted there. With the grace of our dear Lord, a lot of hard work and an ulcer because I stressed so much, I passed the N3 course, which equals 'matric', and after that I passed the N4, N5 and N6 courses. The N6 course is the highest qualification at the college. I was awarded the Education Diploma in Educare, in May 2009.*

*“When my mother and sister received their degrees, I started to dream about wearing a robe and mortarboard and walking across a podium. When I did eventually walk across a graduation podium all the people in the City Hall stood up for me. I was also awarded a special prize for being the first Down's student to receive a National Diploma. That was the most amazing moment of my life. I looked at all the people and saw my mother and sisters crying”.* Sheri Brynard graduates and become the first person with DS to obtain a degree.

Sheri Brynard: Extract 3 from her speech at her graduation.

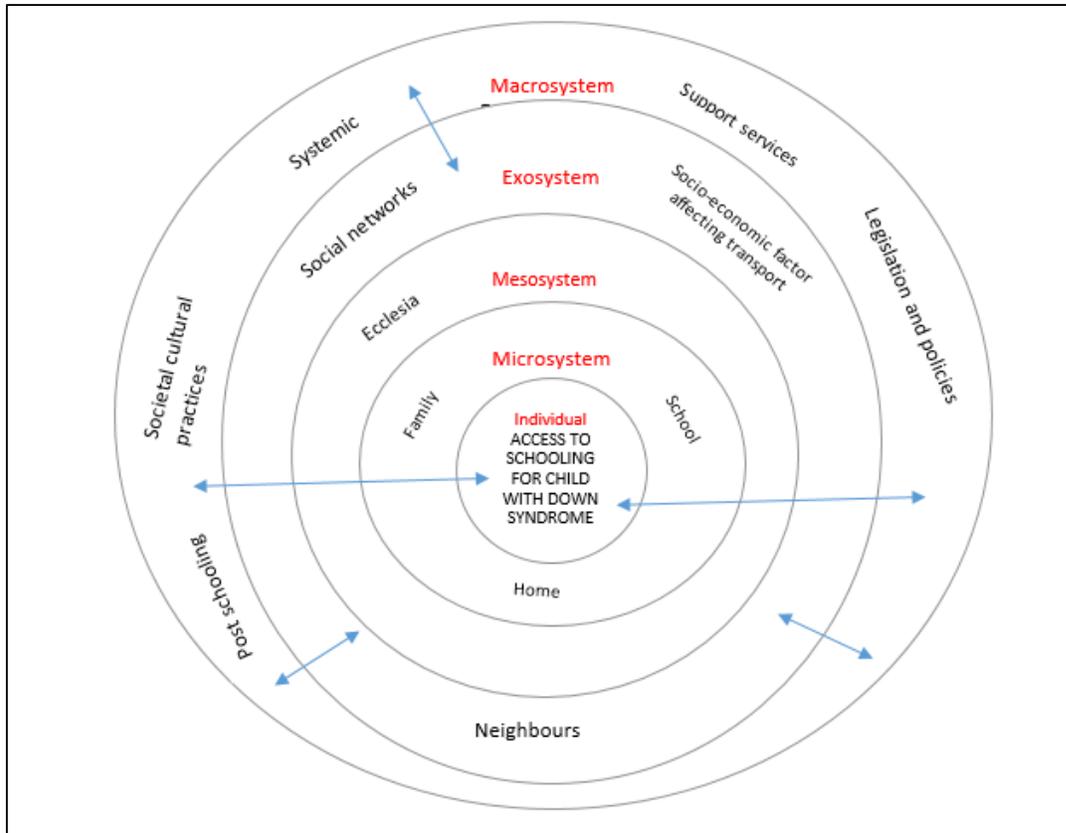
The paradox of our education system is played out in the contrasting outcomes for CWDS. Sheri Brynard is one of South Africa's few success stories. She is recorded to be the first, “and still is, the only person in South Africa with Down's syndrome who has received a tertiary qualification when she graduated from the National Technical College in Bloemfontein”. This qualification acknowledged and celebrated a victory for CWDS. She attended and completed schooling in a mainstream setting. Her entrance and exit from the schooling system occurred in an apartheid system as it happened 23 years ago. This success story exemplifies how disparate education favoured some CWDS and excluded others.

In reflecting of construction and implementation of post-apartheid plans, in 2001, Professor Kader Asmal outlined objectives in a report on South Africa's progress towards the inclusive society that was envisaged. He said,

I hold out great hope that through the measures that we put forward in this White Paper we will also be able to convince the thousands of mothers and fathers of some 280,000 disabled children – who are younger than 18 years and are not in schools or colleges - that the place of these children is not one of isolation in dark backrooms and sheds. It is with their peers, in schools, on the playgrounds, on the streets and in places of worship where they can become part of the local community and cultural life, and part of the reconstruction and development of our country. For, it is only when these ones among us are a natural and ordinary part of us that we can truly lay claim to the status of cherishing all our children equally (p. 4).

In reflecting on the thirteen years since this comment was made, policy implementation does not articulate favourably with expectation. Tiara spent that same thirteen year period he referred to, with peers with similar impairments in an enclave, separated from mainstream society. Her interaction with non-disabled people was predominantly family and friends in community of practice. Policy designers expect people to embrace its instructions but the reality is that to share in the cultural life of the local community, feel a sense of belonging and participate in the country's transformation and growth requires willing and ongoing participation of non-disabled people extending and including CWDS in social activities.

The synthesis of the discussion of access to schooling spaces for CWDS thus far, is represented in an adaptation of Urie Bronfenbrenner's Ecological Systems Theory.



**Figure 11: A composite illustrative summary of the study of access modelled on Bronfenbrenner's Ecological Systems Theory**

### 5.2.8 In conclusion

Autoethnography affords me the space to articulate chronicles that speak pointedly to access, schooling and DS without embellishing any of the information. Revisiting the various contexts and people and the diversity in experiences confirm that schools are not homogeneous. There are broad variations, in terms of lack and affluence distribution, geographic locations of distant and close, characteristics of the population dynamics, language of teaching and learning, cultural diversity, and religious beliefs in the range of schools to which Tiara had physical access. The same can be said of the key informants whose unpretentious chronicles affirm the challenge to get physical access. The discussion that follows in the next chapter will peel off the layers to identify if there are discreet or overt layers of exclusion even within special school context.

## CHAPTER SIX

### *GATHERING STONES*

#### 6.1 Introduction

Albert Einstein words, “I don't know how man will fight World War III but I do know how they will fight World War IV with sticks and stones<sup>43</sup>” is a pre-emptive warning that we are in a state of regression irrespective of the era we live in. In an attempt to prevent such a catastrophe, each nation need to gather collectively and strategise. His Excellency Jacob G Zuma, President of the Republic of South Africa, in addressing strategies and collective responsibility in his state of the nation address in Cape Town on 13 February 2014<sup>44</sup>, drew focus to his presentation with his uncharacteristic use of poetic and emotive words. “We have a good story to tell” accentuated select aspects of development which assigned credit to his administration.

This study reflects on the past twenty years and it seems apt to incorporate extracts of a ‘good story’ of a well written speech. The irony is that whilst the speech expounds achievements across the socio-economic-political spectrum its dedicated space to education, underscored the following aspects of the social transformation programme:

Education is a ladder out of poverty for millions of our people; We are happy therefore that there is a huge increase in the enrolment of children in school, from pre-primary to tertiary level; The number of children attending Grade R has more than doubled, moving from about 300 thousand to more than 700 thousand between 2003 and 2011; A Draft Policy Framework towards Universal Access to Grade R has been gazetted for public comment, with a view to making Grade R compulsory; The matric pass rate has gone up from around 61 percent in 2009 to 78 percent last year and the bachelor

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<sup>43</sup> Source: In an interview with Alfred Werner, *Liberal Judaism* 16 (April-May 1949), 12. Einstein Archive 30-1104, as sourced in *The New Quotable Einstein* by Alice Calaprice (2005), p. 173.

<sup>44</sup> <http://www.thepresidency.gov.za/pebble.asp?relid=16912>

passes improve each year; Through the Annual National Assessments, we keep track of improvements and interventions needed, especially, in Maths and science; **To promote inclusivity** and diversity, the South African Sign Language curriculum will be offered in schools from next year, 2015. We have increased our numbers of literate adults through the Kha Ri Gude programme from 2, 2 million in 2008 to 3 million people; We have also been investing in teacher training and are re-opening teacher training colleges to meet the demand; To produce a decent learning environment, we have delivered 370 new schools replacing mud schools and other unsuitable structures around the country. The programme continues.

I will make direct reference to snippets of this ‘story’ in the following discussion on access to schooling spaces for CWDs.

### 6.2.1 Measure of access

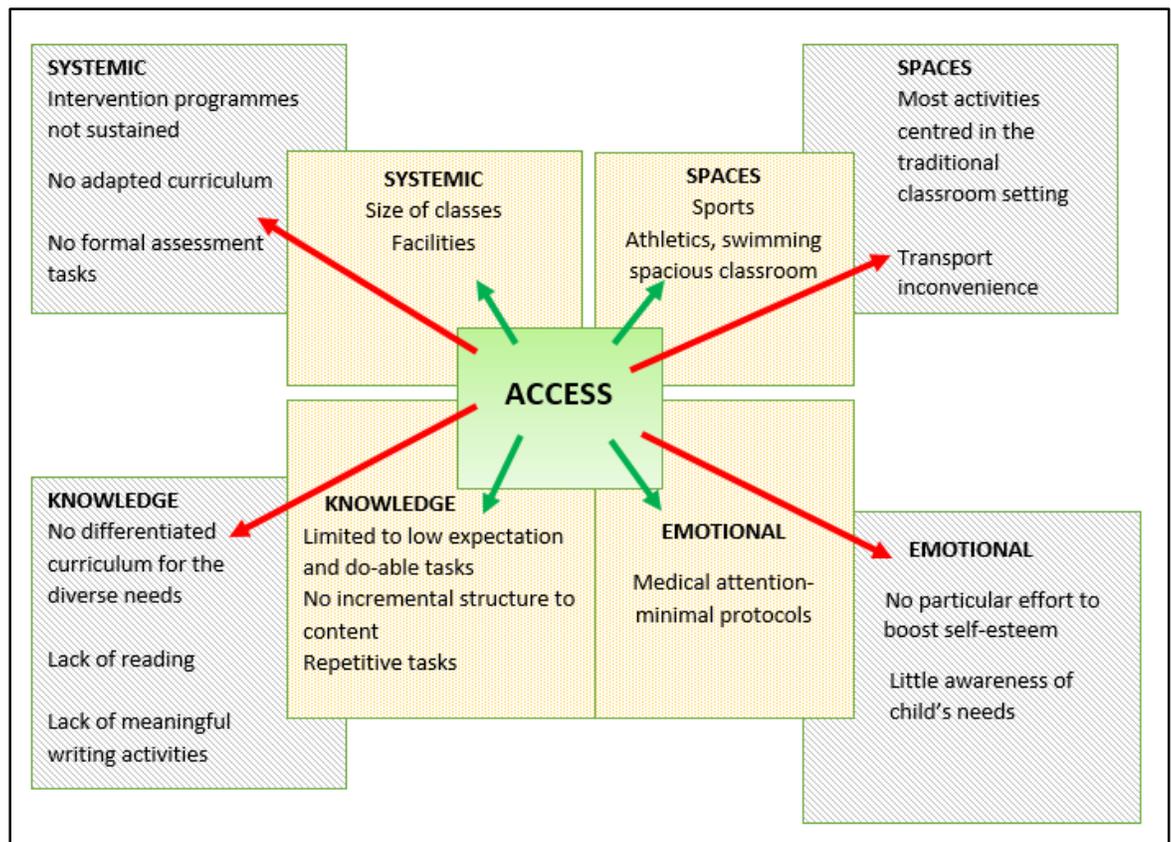


Figure 12: Measure of access to formal schooling as experienced by parents of CWDs.

I have found that most parents' experience of access to schooling spaces for their CWDS is located in the deficit model with limited access to education and schooling spaces restricted to pre-school and primary school. Parents' experiences of access through placement of children was not always the parents' choice. In some cases the choice is pre-determined through the 'sifting' process of application prior to admission. Application also did not guarantee admission. It is found from the various chronicles that CWDS were deviated to segregated schooling setup regardless of their ability. In some cases the professional routed the parent towards special needs schooling (segregated schooling) without meeting or interacting with the child and presenting that option as more suitable to the child's needs. Once again, professional assumptions about the child inability to cope coupled with 'easier', 'manage better' phrases led parents into believing that it is the preferable option without offering the child a chance to try it out. Nind and Seale listed negative expectations and attitudes as a factor in CWDD lacking skills development quoting comment from one the participants in the research: "They always tell us we can't do it, without giving us a chance to try" (Nind & Seale, 2009, p. 280).

This observable practice suggests that preconceived negative notions of CWDS is lodged within the medical model with stereotyping and prejudices manifested and reinforced in 'discreet' practices. In cases where parents voluntarily chose the option of segregated schooling it reflected the indirect influence of the educator whose 'professional' opinion reinforced parent insecurities. Parents in doubt of choice were offered what seemed like a reasonable explanation to make them feel justified in their choice of segregated schooling. The need for the child's safety was paramount and parents used that as the important criterion in their final decision, where options were available.

In the context of my study, parents' experiences converge with points of view of scholars who have identified that parents limited knowledge and access to legislation available for CWD affected their scope of advocacy for inclusion. It may be what parents would like but without the appropriate understanding of legal processes, they capitulate to the authority of the professional. Parent understanding that advocacy is required for better schooling experiences is supported by research (Lalvani, 2011; Wang, Mannan, Poston, Turnbull, & Summers,

2004). Of immense value to the parents is my forwarding one article a month to members of the board. At the monthly meeting we allocate twenty minutes discussion time to coincide with the coffee break. The first article was by Lalvani entitled “*Eye on the Prize: Parents, Privilege, and the Politics of Inclusive Education*”. It was most interesting to hear what parents identify as important to them and for their CWDS. So far it has been advocacy, social justice, choice of inclusion or not, how is special school faring with regard to access to pedagogy and curriculum. The discussion is generally friendly and edifying with parents asking questions and sharing experiences. It is my hope that this will be sustained in the ‘informal’ programme.

### **6.2.2 Advocacy for access**

Parents of children in the mainstream schooling setup do not necessarily have to advocate access compared to parents of CWD; admission is assumed whereas parents of CWD have to provide strong motivation and medical evidence to build a case for inclusion. In the process, parents who do not have the endurance for prolonged struggle with systemic resistance, withdraw. With the Salamanca Statement and Framework for Action on Special Needs, (1994) and the UN Convention on the Rights of Persons with Disabilities, (2006) in place, offering the foundational principles of access and the right of all children to it, Lalvani (2012) questions the need for advocacy at all. Lalvani asserts that there are international laws that protect children’s right to access free and fair education yet parents have to embark on individual advocacy campaigns to access schooling spaces. The important issue here is that access gets negotiated in some instances and then it is about what happens **inside** schools after access ( addressing personal care, curriculum, progress monitoring, developing reading and writing skills)

The discrepancies inherited from the previous apartheid era have not been eradicated. Instead, they seem to have morphed into other fragmented policies and systems. The policy of inclusion enshrined in law is contradictory in practice. This is not by accident but by design. The loophole which professional’s use as a weapon of exclusion is located in legal documents governing education. Non-committal neutral statement of ‘inclusion where possible’ provides

gatekeepers (school leaders and administrations) the room for exclusionary and ‘ableist’ practices with little to no recourse for parents. From the host of discussion and policy documents (available in the public domain or government websites), there is adequate understanding amongst stakeholders of how to catapult inclusive education from an ideal into a reality in the South African mainstream education system. The reality shows a portrait of large numbers of CWD being schooled separately, isolated, in a set up far removed from mainstream. In the case where CWDS had the experience of temporal placement within regular school, the child did not receive adequate or considerate inclusion in many of the educational or social dimensions of schooling.

Special needs education is the sector that bears witness to the twofold disadvantage that permeated the system during apartheid: “first segregation” was on account of race then extended to “second segregation”, of disability. Current demographics reflect all races within mainstream and special school contexts though not necessarily commensurate to population specifics. More importantly, there exists largely disproportionate opportunities of access pre- and post-apartheid period with non-whites still bearing the brunt of the legacy of apartheid.

Parents of CWDS reported immense discontent and overriding concern with services provided by schools and adamant that the arduous journey onwards and towards inclusion arguably is no closer in public schools than it was twenty years ago. Parents have articulated strongly in this study that systemic access is hampered by professionals and administrators assigned the responsibility of managing special schools and its resources. I have also added my voice to the murmuring parents who accuse custodians of schooling, employing an undisclosed, unwritten (‘hidden’) dual operating systems: visible and invisible ideology. That which is visible to the public ( sports day, art exhibitions, school concerts) portray the image of a access, equal opportunity, maximum participation by all all learners on the field and stage. This visual of each child included lulls the majority of the parents into thinking that all is as it should be. The invisible aspects is what happens behind the façade of the school and within the boundaries of the school and classroom where the public has restricted or no access. In this study, what comes to the fore from parents interpretation of human and material products is that schooling paints a picture of barriers rather than access.

The following is indicative of minimal or inadequate curriculum, epistemic, pedagogical access: I have identified a curriculum which is arbitrary with generic programmes unsuitable to specific individual needs yet critical to the contribution and development of citizenship; participation in superficial and largely deficit with learners occupying their time doing mundane ‘colouring’ activities on a regular basis; lack of educator qualification, training and experience resulting in inaccurate observation of learner specific needs; range of disabilities in one class means that some disabilities may be unnoticed and become ‘invisible’ with the educator paying no attention to his or her presence or need to be engaged meaningfully. In other words, learners are excluded in already segregated practices of special needs schooling.

Education White Paper 6 quotes World Health Organisation to have estimated “between 2.2 % and 2.6 % of learners in any school system could be identified as disabled or impaired. An application of these percentages to the South African school population would project an upper limit of about 400,000 disabled or impaired learners”<sup>45</sup>. The evidence has yet to be reflected in how education and training systems is preparing for teaching of CWDS or CWDD in the teacher training programmes. Inadequate training and absence of upskilling or reskilling results in barrier to pedagogical access.

### **6.2.3 Aligning political will to paradigm shift**

National policies and legislation theoretically espouse inclusion. I am reminded of government intention to create a unitary system for all its learners inclusive of disabilities captured in “Education White Paper 6: Special Needs Education, Building an inclusive education and training system” (July 2001). Significance of equality outlined in the Constitution of the Republic of South Africa reads as follows: “Every person shall have the right to basic education and equal access to educational institutions”(Department of Education, 1996, p. 16) and enabling legislation of South African Schools Act (1996) and National Plan of Action for Children (1996). As a parent of a CWDS seeking access to

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<sup>45</sup> Department of Education, 2001

inclusive schooling system I was expecting the infusion of these policies into school admission policies and practices. I was hoping to find a school that “in both its design and its effect continually strives” (MacKay & Burt-Garrans, 2004, p. 6) to ensure that each CWDS has unquestioned admission. That is, full access and support to contribute to the school community, to belong, to be involved, to take, as well as contribute. What was noticeable in practice is an extension of segregation with the dual system approach of special needs and mainstream embedded further with full service, . Furthermore, in South Africa the full service schools are modelled to cater for children with severe disabilities, the dispersion of which does not meet community access.

Continuation of special schools remodelled as resource schools does not change the historical deficit discourse that is inherent and perpetuated, and, it does not contribute to minimizing devaluing characteristics. Instead, it escalates it in the form of internalised oppression where parents of CWD, and the children, have internalised this persistent oppression and do not have raised expectation. Low expectations from professionals and reduced opportunities to participate reduce the self-esteem of the already emotionally vulnerable children.

Despite what Russel (2003) coined “double jeopardy” encountered by many CWD from predominantly previously disadvantaged communities which was discussed in Chapter Two, parents are persevering to advocate for their inclusion in mainstream schools hoping that the tide will turn favourably with the years of advocacy, and reward their active participation.

‘To promote inclusivity’ needs to go further than political rhetoric. Millennium Development Goal 2 (MDG 2) states that all boys and girls of entrance age “must achieve **universal** [my emphasis] primary education by 2015, or must have completed primary education, regardless of their age” (p. 37). Universal is euphemistically applied in the report for nowhere within the report on education is there any mention of children with disabilities. Once again, broad-based generic programmes do not address specific and marginalised group needs. Inclusion needs priority on the political agenda and leadership needs political will to initiate, monitor and ensure the plans are implemented. Shifting time-frames from ‘now’ to ‘sometime in the future’ delay service deliver. Additionally, the increased rather than reduced presence and

visibility of monitoring and accountability structures, from district and provincial levels, on an ongoing basis, will curtail or eradicate ineffective and unproductive structures and personnel at school level.

Outcomes Based Education (OBE) was replaced with Curriculum and Assessment policy Statement (CAPS) with the notion that inclusivity is implicitly stated. Re-conceptualising pedagogy as inferred in the design of CAPS, should translate into ‘recognizing the different needs of every learner’, ‘help each one become personally competent’, and educators enter into the schooling space with the expectation that ‘every child can learn’. It must become the everyday diction. To borrow an analogy from Steve Hargadon (an education blogger) to illustrate the approach to schooling of CWDS: “No one says that from age six to seventeen, we will give you all the same food, at the same time, regardless of your individual circumstances or needs”. New and flexible models designed for CWD will provide an adaptive rather than prescriptive proviso. In this way it will be a model that will best suit the needs of the learner. It is not a one-size-fits-all model currently in practice where the learner has to fit into the system rather than one where the system is designed to accommodate the learner’s specific needs. “Living in a democracy means involving people in decision making,” Hargadon says. “You cannot just create a new system to implement top down; you have to provide the opportunity to talk about it and build it constructively.”

#### **6.2.4 Conceptual lens consideration**

Schooling and learning are meaningful to the extent that they provide skills for a distant future, for adulthood and for the labour market of the future (for those atypical persons able to access them). A popular quotation of John Dewey argues that education “is a process of living and not a preparation for the future”. A compromise would be to prepare learners fully, now, especially because schooling in contemporary society is a complex, dynamic and diverse phenomenon. In order to show the significance of education in the lives of people, it is necessary to broaden the conceptual lenses through which schooling and learning are studied. Dewey suggested that there is a need to include and consider seriously, issues of how children’s opportunities for participating and contributing to activities are organised and what

the implications of their involvement are, in terms of their future life, and what arenas for learning and active engagement are created in schools and classrooms. These are equally significant for children with intellectual challenges whose capacity for engaging with curriculum matters differs from one to another.

“Adequate and appropriate resources, support for both learners and educators, relevant training, planning time, and a commitment to a vision of success for all students is vital to the success of inclusion” (Sapon-Shevin, 1995, p. 7). At a societal level, advocacy with interpersonal mediation and ‘capability’ framed approach, are two processes that could advance the discourse on inclusion. Self-advocates, with their own challenges, like Sheri Brynard, are generally considered as suitable mentors, to assist others experiencing difficulties. Interpersonal mediation involves creating networking connections of people in positions of influence (leaders who are respected, individuals, selflessly advocating for the less fortunate) to organisations in need of enhanced support. These individuals can champion the cause of inclusion and access to inclusive schooling that could make a big difference. Non-profit and non-governmental organisations, which have close interactions with the people they represent, should be offered a forum to engage with policy designers in order to contribute to ‘inclusivity-capability’ framework. Terminology referring to CWD needs to be reviewed with the starting point being CWDS referred to as learners with ‘specific needs’, as opposed to ‘special needs’ which has connotations of inadequacy. Referring to learners with intellectual or learning impairment as ‘disabled’, is considered ‘spoiled identity’ (Goffman, 1990). It is my view that to replace the word ‘special’ in special needs with ‘specific’, is more aligned with the social justice and human rights model of access.

At school-level, curriculum, methodology, resources, time and communication are elements that enrich the passage to inclusion. Teaching CWDS, utilising curriculum and methodology that is enabling, will help them to help themselves towards independence and provide scope for employability. Technology as a resource can help CWDS to participate in their own learning more meaningfully with access to explore the potential of technology. Designing suitable material to accommodate diversity of learning styles and capabilities warrants allocation of differentiated tasks and time on task. Allowing sufficient time on task, time to

express oneself verbally and non-verbally, and time to practice are equally important. For CWDS allowing more time on task to complete tasks at a pace appropriate to their cognitive levels will enable them to access and achieve curriculum consistently.

Improving teacher qualification and upskilling through in-service programmes could strengthen the approach to teaching in diverse contexts and varied abilities. The “use of a collaborative or co-teaching model, in which two to three (qualified ) educators share the responsibility of meeting the diverse needs of all students, results in better academic and social outcomes for those learners” (Clearinghouse, 1993, n.p.).<sup>46</sup> Access to everyday communication can be enriched by including CWDS in conversation on ordinary day-to-day activities. Nind and Seale (2009) referred to a turn-of-phrase used by participants in one of their studies which stressed “not being able to speak does not mean not having anything to say” (p. 282) and underlining that access must be considered a two-way process. Educators should create opportunities for CWDS to express themselves and not necessarily, verbally.

The concept of “access” need be understood as intersecting with the idea of “social inclusion”, which entails having community acquaintances, undertaking fruitful work, having cash to use and making choices. Cascading earlier research of Abbott and McConkey (2006), Roy McConkey reasoned that CWDD are more included, or belong more, if they have opportunities to meet and interact with. Schooling is the beginning of that process. Being in an environment that allows and nurtures relationship and communication builds self-confidence and skills for both the typical and atypical. Engaging meaningfully provides opportunities to maximize potential and prepare CWDS for scope of entering post-schooling spaces. For this reason, access, activism through advocacy and social inclusion should be calibrated as interwoven components. Multi-disciplinary, inter-agency, engaging within the public and close interaction with organisations is also recommended (Franklin & Sloper, 2007). The profit of partnership embraces sharing of expertise, new concepts and ideas, funding possibilities and general information (Franklin & Sloper, 2007).

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<sup>46</sup> ERIC Clearinghouse on Disabilities and Gifted Education (1993). Including students with disabilities in general education classrooms. Arlington, VA: Author. (ERIC EC Digest No. E521)

Our society has reached a turning point where we must make decisions about values, direction and costs. We no longer have the luxury of modifying ideas from abroad without examining the context: an African solution for an African identity. Presently we have pieces to solutions which camouflage the fact that we are not answering the hard questions about values - what do we believe in? What kind of future do we want for our children? How do we get there? I have reflected on these questions based on my own experiences, which also resonated with the views of informants. The two opposing trends of inclusion versus exclusion have created many dilemmas. To address inclusion meaningfully warrants a review of current practices. The more people believe in inclusion (egalitarian opportunity as the predominant value) that get into the debate, then the more the supporters of exclusionary practices will reconsider their standpoint based on empirical evidence.

### **6.3 'Crossing the border'**

As an autoethnographer, I am both the author and the focus of the story, the one who tells and the one who experiences, the observer and the observed, the creator and the created. I am the person at the intersection of the personal and the cultural, thinking and observing as an ethnographer and writing and describing as a storyteller (Ellis, 2009, p. 13).

I have asked myself several questions in the journey to completing this study and some have been answered in the process of writing, reading, rewriting. A few questions linger, answered only partially for myself, for the submission of this thesis is not the end. The chronicles which commenced at the start of this study will continue to be written and rewritten, probably indefinitely. I had no idea when I started about how it will be collated. What I can remember clearly is the reassuring voice of my Supervisor encouraging me with motivational phrases: 'keep writing', 'we will work out what goes where later' and 'surge ahead'. The adopted gestalt image, of the pieces coming together to make the whole has prevailed during the process. Admittedly, writing and rewriting about my experiences took much longer and at times the process was more intense than the lived experience. Each recollection and the act of

remembering allowed the transition from the personal domain to sharing in the public domain and shift with the different lens and positions. The chronicles have become a representation and reproduction (Denzin, 1991). In choosing me, autoethnography has allowed me to look purposefully at schooling from a retrospective and reflexive position. I took myself to specific places and spaces and allowed myself to write from there.

#### **6.4 Re-imaging schooling, reducing deviancy**

The conundrum is whether access to education, employment and health-care is worth having as I reflect over the experiences of access to schooling spaces over the last eighteen years, fifteen of which were spent in the schooling matrix of contexts: private, private special needs, Montessori, public mainstream, public special needs and home. Special needs, a sub-system of public schools, produces dependency. Presently, mainstream public and private schooling systems perpetuate the impression that the intelligent learners soar to the pinnacle of success, inconsequential of factors such as family and social conditions. The remaining learners receive a subliminal message that they are losers. A professed belief in the intrinsic worth and ability of all children is sidestepped to create more competitive spaces and opportunities for a focused, small and elite group. Steve Hargadon, (2014) a blogger, explains that one of the reasons for this is that “adults find the situation tolerable’ and this attitude may be because they are products of the system and, as such, find it difficult to envision an alternative. They do not question schooling”<sup>47</sup>.

In order to maximize value-added characteristics the reverse- minimizing devaluing characteristics-should be installed. Challenging hegemonic ideas that exclude, separate and subordinate CWDS (and CWD) and dilute chances of accessing inclusive schooling spaces is a precursor to promoting actively the imperative: mainstream school setting is superior only if it includes, not excludes. New construction rather than modifications of pre-existing approaches to teaching and learning will witness redistributive opportunities for the CWDS considered as requiring additional support. Improvement will be possible with active participation and meaningful learning.

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<sup>47</sup> [blogs.kqed.org/mindshift/.../steve-hargadon-escaping-the-education-matr](http://blogs.kqed.org/mindshift/.../steve-hargadon-escaping-the-education-matr)

## 6.5 Alleviate rather than perpetuate

The South African Human Rights Commission (SAHRC) indicates that it is vital for the schooling system to try and alleviate instead of perpetuating social inequalities. Combat strategies for reducing discriminatory practices should be our main priority. The notion of imperfection that fosters perceptions of unworthiness is historically ingrained in our society. It has manifested in products such as dual systems of schooling. Embracing that notion that disability, with its variances, is an ineradicable facet of human circumstances, and accepting that no amount of antenatal diagnosis will eliminate disability, will prepare society for an inclusive society. After all, it is in knowing that discourses must change, not the person who is disabled or impaired. Definitions must be human-rights based as a means of mitigating the consequences of impairment, to place the person in a space where, through access, quality of life is improved. Looking at capability rather than incapability opens and privileges agency (Reindal, 2009; Terzi, 2005) advances and augments the discourse beyond the installation of ramps for the physically impaired or providing assistive devices to the hearing impaired. As Nind and Seale (2010), suggest “living and experiencing access to participation and community is not just about adapting structures and systems and removing barriers but also about principles, ethical relationships”.

“What did my child get out of nearly 15 years of schooling?” I asked myself.

For most part, she learnt to follow, and to a greater extent, depend. Beyond schooling disclosure, this study ‘articulates her voice’ implicitly in the chronicles that exemplify how disabling certain spaces can be. Left unchecked society demonstrates its abdication of responsibility. To limit unnecessary suffering and enable access through provision of appropriate social support and professional interventions, it is crucial for the government, surrounding community (including the family and friends), service -providers, and policy-makers to have a deep understanding of the challenges that affect parents of CWD (Algood, Harris & Hong, 2013, p. 132; UN, 2013 a: 5-6).

Inclusion is the major challenge facing educational systems around the world.

Reflecting on evidence from a programme of research carried out over the last ten

years, it provides a framework for determining levers that can help to ease systems in a more inclusive direction. The focus is on factors within schools that influence the development of thinking and practice, as well as wider contextual factors that may constrain such developments. It is argued that many of the obstacles experienced by learners arise from existing ways of thinking. Consequently, strategies for developing inclusive practices have to involve interruptions to thinking, in order to encourage an exploration of overlooked possibilities for moving practice forward (Ainscow, 2005, p. 109).

Over the past twenty years, we have seen the South African government translate its concern over quality of education by identifying new ways in which the standards can be raised to compete with its global partners. A proliferation of measures from National Curriculum Statement (NCS), Outcomes Based Education (OBE) to National Curriculum Statement, Curriculum and Assessment Policy Statement (CAPS) is perceived to be a contribution to that objective. Whilst new ideas are drafted and implemented, teachers (sometimes untrained or undertrained) are overwhelmed by the administrative requirements and are not always ready to embrace change.

My child entered the schooling system when South Africa was in the throes of implementing changes and steering itself through its newly found democracy. The question I have after eighteen years, nearly fifteen of which were spent in a schooling environment, might seem trivial to some, but turns out to be central at this point of reflection. I ask, ‘Can I aggregate years of schooling into a measure of schooling capital?’ My momentary foray into the genre of economics tells me that in the world of commerce, each year spent in education increases earning capacity: the higher the qualification, the greater the earning potential. Studies traced in this vein to Gradstein & Justman (2000) accentuate the potential benefit of “government intervention as a means of internalizing the external benefits of education” (p. 880). In other words, public schooling is not only intended for instilling knowledge and skills, but for building social capital which is cited as a “prominent motive for developing public education systems” (Gradstein & Justman, 2000, p. 881). With the largest sector of the school-going

population residing within the public system, more consideration should be accorded to inclusive education and the role it can play in nation building. Research into the proposition that public schooling prioritises social capital (cohesion) whereas private schooling prioritises economic capital urges one to wear the breastplate of advocacy for equal access opportunity for CWDS as well as typical, non-disabled learners.

Our twenty-year democracy can look elsewhere for best practice. Singapore is one such example, aside from the UK, Canada and USA. “Under colonial rule, education in Singapore was racially segregated, its level and content varying across population groups, but after independence the government unified the different education streams and aggressively promoted universal public schooling, with English as a common official language”(p. 882). The common national Curriculum and Assessment Policy Statement (CAPS), is primarily designed for an inclusive mainstream teaching and learning setting. LWSN who may require support to access this curriculum are dependent on the educator’s discretion to select and adapt content for teaching. Individual learners who present academic challenges may not necessarily receive the individualised attention to access the same curriculum as their peers in mainstream schools.

I began this study with a different assumption to where I stand now, because mapping the years of schooling and estimating the schooling capital generated from it, is minimal compared to what could have been achieved. My view is steeped in the knowledge that full access to inclusive schooling spaces could have contributed to more than the output of independence and self-sufficiency and into the scope of employability, adding value for Tiara to be recognised as a contributing member amongst disabled and non-disabled people. The present model of special education and my opportunity to interact within it, and perceived as an operation in bad conditions. “In bad conditions schooling is accumulated but this accumulation cannot, in and of itself, create growth”. In such conditions, schooling is accumulated, but the quality of that accumulation cannot, in and of itself, create growth without further intervention and support. The current status of Tiara being home-bound is a case in point.

What is evident after engaging with other parents of CWDS is that schools commit one of the cardinal sins of assuming ignorance on the part of children and to discount the insight that CWDS can bring into the schooling environment. It is in the interface between who teaches and who listens, where the one who is listening is often ignored or marginalised into silence by the attitudes of educators. CWDS are expected to pilot an increasingly hazardous geographical and social terrain. Parents, 'bringing up' CWDS and facing unequal opportunities of access for their children, require tenacity and endurance on the 'battlefield' of negotiation as they try to win the 'war' on access.

## **6.6 In summary**

The opening thoughts of Chapter One provided the canvas upon which the writing of this thesis would occur. The explanation of the carefully chosen subtitle was to engage the written word in duality on a natural and spiritual plane, and at times, on a literal and metaphorical level. In establishing this thought-pattern as a foundation, the reader is able to transport himself or herself into the spaces and places put forth and apply the option of interpreting information from his or her own perspective. In doing so, the intention of this autoethnography, to engage critically with the reader on issues presented. When this engagement is activated as it allows the reader to step inside and sometimes, walk alongside the study juxtaposing his or her interpretations and experiences, to add resonance or dissonance.

Chapter One, subtitled '*COBBLESTONE FACADE*' offered a personalised and conversation-style entrance into the thesis with a cameo personal reflection on my own schooling memories and how I was drawn into the present study focus. This was followed by the key question underpinning this study, which asked the question of 'how' and 'why' could my experiences of access to schooling spaces for my child with DS be explained using autoethnography. The subject questions included area of inclusion, mainstream, policies on inclusion, legislation and what the condition of DS is and the potential for inclusion of CWDS. The Chapter concluded with outline of focus in the following chapters.

Chapter Two called ‘*TOUCHSTONE*’ honed in on the hospital corridor, considered a sterile environment and reflective of the impersonal and indifferent manner in which medical practitioners disclose diagnosis to parents, which is dis-enabling rather than enabling. From this sometimes dis-enabling corridor, parents’ pursuit of access to schooling spaces is fraught with challenges from indifferent principal, management staff and educators. Their own prejudices and attitudes increase or minimize the chances of acceptance of CWDS in a mainstream or inclusive public school. The evolution of interpretation from the medical deficit model to the social justice/ human rights model has not been fully implemented in all countries or all contexts (even when it is legislated). The lack of accurate information on the etiology of DS and the potential of children with DS to succeed in inclusive settings has resulted in some countries such as the UK, Canada, USA and Australia, adopting and implementing inclusive practices, although there are still some inherent challenges, while South Africa is lagging behind despite being a signatory to many international policies, including the *Convention on the Rights of Persons with Disabilities* (2007) and *UN Convention on the Rights of People with Disabilities* (2006), which make provision for all children to have access to participate and be supported in the chosen schooling system. *Education White Paper 6* (2001) and the *South African Schools Act* (1996) are enabling legislations. However, dispersed priorities away from CWD have led to unsustainable or unmonitored practices. The suitability of autoethnography to communicate the intentions of this study is explained, including the issues of ethics surrounding research with or of CWD.

Chapter Three, ‘*WRITING ON TABLETS OF STONE*’ considered implicit spiritual knowing (with echoes of Moses receiving the Ten Commandments from God written on two tablets of stone) that permeates all knowing. A theoretical understanding of Dunn’s (2003) ‘eight ways of knowing’ led to an ‘adapted multidimensional model of knowing’ that is situated within the context of access and schooling. Each of these concepts are illustrated with reflective anecdotes or elaborated in context of engagement with community of practice.

Chapter Four, used the metaphor of ‘*STICK AND STONES*’ to illustrate the weak and strong moments of searching for a suitable methodology. Whilst ethnography would suit some research ideas it was inadequate to address my needs. I wanted the flexibility of articulating my voice and incorporating others as part of my world, my chronicle, my choice.

Autoethnography addressed my needs. The act of remembering posed challenges, as distilling what pertains to the study was sometimes clouded by other memories. A hint of how Nind and Seale (2010) theory of access would be unpacked in Chapter five was given. Excavating memories from the past needed time and patience. In my moral gaze I considered the position of researcher I adopted and the caution I needed to exercise without spoiling the objective of the study, in attending to the issue of vulnerability. This was followed by descriptions of five informants of the community of practice. Ethical considerations relevant to this study are prioritised and explained with reference to respect, beneficence, justice and anonymity.

Maintaining a conversational style with navigation tool '*MY TURN, Y/OUR TURN*', Chapter five delves deeply into eight personal chronicles and these are followed by intersecting the chronicles of the informants in the joint discussion of its implications for access, schooling and CWDS. The expanded consideration of children's geography, inclusion and exclusion, ecology of space and its South African context draws similarities and differences to international trends.

Chapter Six, '*GATHERING STONES*' knitted all the chapters together as multiple discussion points are raised and recommendations for a way forward was proposed. The concluding thoughts to the thesis are personal evaluation points of schooling after almost fifteen years, and whether it was worth it. The resignation and the truth bearing statements leave one feeling disappointed with the landscape of opportunity for CWDS, both at school and at post schooling level. Having completed the journey on paper, the advocacy (urgency and agency) would be accelerated in the hope that future CWDS are offered a better promise than the one Tiara had.

## **6.7 Closing thoughts**

Tiara has been home since the beginning of 2014. The silence of her not engaging or wanting to participate in activities troubled me. We sought long and hard, and finally secured a tutor who comes home to teach her. Within months of bonding with Tippy, her new teacher, Tiara is able to participate in learning, in a 'school' she calls home. The structured programme of reading, writing, Mathematics and skills that are sustained on a daily basis, has seen her laugh

more, want more, play more, learn more and sing more. She is energized to such an extent that she is up early and gets ready to receive her teacher Tippy. The journey for Tiara continues in a different time, place and space, but what remains as an irksome truth is that access denied is immoral.

It is strategically the best time to allow you to read this poem, penned by Emily Kingsley entitled, "**Welcome to Holland**"

*"I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this ...".*

*"When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting".*

*"After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says",*

*"Welcome to Holland."*

*"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."*

*"But there's been a change in the flight plan. They've landed in Holland and there you must stay".*

*"The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place".*

*"So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met".*

*"It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around .... and you begin to notice that Holland has windmills .... and Holland has tulips. Holland has Rembrandts".*

*"But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say" "Yes, that's where I was supposed to go. That's what I had planned."*

*"And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very, very significant loss. But ... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland".*

This celebratory mood of this piece of writing is in sharp contrast to my **initial** experiences and indeed of most parents who have to face the indefinite prospect of raising a CWDD. Having Tiara was like planning for a trip to Italy but arriving in Holland, except it was not the romanticized perspective inherent in this text of Emily Kingsley. My lesson was crisp: expect the unexpected. That was eighteen years ago.

During that time I have interacted with many mothers of CWDS. In having the baby, some lament the lack of free time and the loss of their 'old lives' while others relish the chance to face the day-to-day challenges involved in raising any child. Personally, raising a CWDS is different to raising a typical child on many levels. What I have learnt is that I may never have known the joys of having Tiara, if I remained in my prison of grief focusing on her inabilities rather than her capabilities. By breaking the deficit paradigm I have opened my heart and mind to the possibilities that exist. I still yearn for the day when she would write her name, not just recognise it or spell it orally, but it is not the destination I covet.

For now, I temporarily suspend this search to access schooling spaces for my CWDS as I find comfort in the words of Khalil Gibran:

“The Moving Finger writes; and, having writ,  
Moves on: nor all thy Piety nor Wit  
Shall lure it back to cancel half a Line,  
Nor all thy Tears wash out a Word of it”.

For me the journey continues, as I gather my stones, from a spiritual point of view. I think on the man (Christ Jesus) who walked this earth 2000 years ago. He did not attend school or the universities of his age, but was educated in the ways of God. He practiced and taught divine principles, whereby there would be “glory to God in the highest, and on earth, peace and goodwill toward man” (Luke 2: 24)<sup>48</sup>. He will return as promised and all the nations of the earth will learn of His ways and walk in His paths. When he establishes God’s Kingdom upon this earth there will be righteousness and peace in abundance, and no more war. There will be food, in abundance for everyone. Children like Tiara will be healed and made whole, “for the blind shall see and the deaf shall hear. The lame shall leap like a springbok and the dumb shall sing” (Isaiah 35: 6). This Kingdom will commence like a little stone but then grow into a huge mountain and fill the entire earth. All the families of the earth will benefit from it, for none shall be excluded (from its blessings). Perhaps we may have been denied access in this lifetime, to earn an entrance into eternity. It is the Creator’s prerogative, at whose feet I place my altar of stones, asking for His mercy, grace, favour and longsuffering, and surrender what remains of my journey unto His plan and purpose.

The story of Tiara will be emblazoned forever.

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<sup>48</sup> biblehub.com/luke/2-14.

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# APPENDICES

## APPENDIX A



24 October 2012

Mrs Pushpagandhi Gramania #421423  
School of Education  
Edgewood Campus

Dear Mrs Gramania

Protocol reference number: HSS/1128/0120  
Project title: An autoethnography: Schooling spaces for my child with Down Syndrome.

### EXPEDITED APPROVAL

I wish to inform you that your application has been granted Full Approval through an expedited review process.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Professor Steven Collings (Chair)

/pm

cc Supervisor: Prof Reshma Sookraj  
cc Academic leader: Dr MN Davids  
cc School Admin.: Ms S Nalcker

Professor S Collings (Chair)  
Humanities & Social Sc Research Ethics Committee  
Westville Campus, Govan Mbeki Building  
Postal Address: Private Bag X54001, Durban, 4000, South Africa  
Telephone: +27 (0)31 260 3367/3330 FAX/989898; +27 (0)31 260 4659 Email: smp@ukzn.ac.za / syc@ukzn.ac.za  
Funding Centres: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville



INSPIRING GREATNESS

## APPENDIX B

### PERMISSION TO CONDUCT RESEARCH

1A Kinloch Avenue  
Westville  
3629

24 October 2014

Medical Centre  
Sydenham  
4067  
Contact:

Dear Sir

### PERMISSION TO CONDUCT RESEARCH

I am currently enrolled as a Phd (Education) student at the University of Kwa-Zulu Natal (Student Number 8421423). The title of my doctoral thesis is as follow: *Access to schooling spaces for my daughter with Down Syndrome: an autoethnography*

The primary aim of my research is to explain my personal journey focussing on schooling spaces for my child with Down Syndrome. I intend broadening the scope of my explanation by including the experiences of other parents' efforts to gain access to schooling spaces for their children with Down syndrome. My secondary intention is to use the information gathered to inform policy designers and school admission policy gatekeepers to develop a framework of access for children with Down Syndrome (one which is inclusive and holistic).

This study is intended for academic purposes.

Every effort is made to protect sensitive information related to my daughter, Tiara. However, I do wish to include her name in the study for the following reasons:

1. She is of the group of marginalised people in our society. This study is an acknowledgement of our only daughter who is important to us. She has a distinct identity by which I wish for her to be remembered.
2. She is not quoted in the study.
3. To affirm her real personhood (without diminishing her worth or tarnishing her value).

In order to maintain protocols of ethics suitable to this study, I request your written permission (proxy consent) to be allowed to use her name (and not pseudonym) in the study. Her father has also granted permission for her name to be used in the study.

Your favourable consideration of this request will be most appreciated.

You are assured anonymity and confidentiality throughout the process.

Once the study is completed, a copy of my findings will be made available to you.

Yours faithfully

  
PUSHPA GRAMANIE

Dr  
Accepted:

Date: 24 October 2014

## APPENDIX C

APPENDIX C:

### PERMISSION TO CONDUCT RESEARCH

1A Kinloch Avenue  
Westville  
3629

24 October 2013

Michael Gramanie

Dear Sir

### PERMISSION TO CONDUCT RESEARCH

I am currently enrolled as a Phd (Education) student at the University of Kwa-Zulu Natal (Student Number 8421423). The title of my doctoral thesis is as follow: *Access to schooling spaces for my daughter with Down Syndrome: an autoethnography*

The primary aim of my research is to explain my personal journey focussing on schooling spaces for my child with Down Syndrome. I intend broadening the scope of my explanation by including the experiences of other parents' efforts to gain access to schooling spaces for their children with Down syndrome. My secondary intention is to use the information gathered to inform policy designers and school admission policy gatekeepers to develop a framework of access for children with Down Syndrome (one which is inclusive and holistic).

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2. She is not quoted in the study.
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Your favourable consideration of this request will be most appreciated.

You are assured confidentiality throughout the process.

Once the study is completed, a copy of my findings will be made available to you.

Yours faithfully



PUSHPA GRAMANIE



Michael Gramanie (father)

Accepted: YES

Date: 24 October 2013

# DOWN'S GIRL MAKES SPIRIT SOAR

I have sat in audiences where I have listened to and interacted with Edward Said, Jurgen Habermas, Oprah Winfrey, Nelson Mandela and a half-dozen Nobel Laureates in the sciences

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**Cheri Brynard making a speech during the most recent graduation ceremony at the University of the Free State**  
Photo: Hannes Pieterse





**Prof. Jonathan D. Jansen**  
Rector and Vice-Chancellor  
UFS

BUT never before have I heard a speech with the intelligence, insight and compassion of a Down's Syndrome girl who came to my office three days ago. This is what she said:

"As you can see I am a person with Down's Syndrome, which means that I have one extra chromosome in every cell in my body. My grandmother's friends wanted to pray for me to become 'normal' but my mother asked them rather to pray that I would receive the support to reach my full potential as a Down's Syndrome person.

"I always knew that I was different. My mother explained

to me that the reason why I have more difficulty studying and doing things is because I am a person with Down's Syndrome.

"I wondered why people admire Nelson Mandela. When my mother explained that he was in jail for 27 years and stayed positive and loving, I immediately identified with him. Sometimes I feel as if I am in the jail of my own body because I cannot always say how I feel and many people talk to my mother about me, but not to me, as if I am invisible or cannot speak for myself.

"I learn new things every day and sometimes feel sorry for myself because I cannot

get married or leave the house in the same way that my sisters do. I know Gustaaf, my Down's friend for the past 12 years, will not be able to look after me. He cannot look after himself.

"He cannot even send me an SMS, even though I tried to teach him one whole afternoon. So I have decided to get married in heaven one day, where we will all be the same.

"I need dreams, just the way you do. But I adjust my dreams to my abilities.

"That was one difficult thing about going to a school with only 'normal' children

**CONTINUES ON PAGE 2**

#### CONTINUES FROM PAGE 1

- you have problems fitting in. So I started to ask the boys whether they wanted my extra chromosome and, because they could not understand what I was saying, they left me alone.

"My stepfather tried to teach me to drive, but I am too short. When my feet touch the pedals, I cannot see, and when I sit on cushions, my feet cannot reach the pedals.

"I received a Grade 10 certificate before leaving Martie Du Plessis High School. In my last year at school, I received a prize for the highest marks in biology and I received the highest honour of the school for drama accomplishments on National level among 'normal' learners.

"After leaving school I went to the Motheo College, a technical college,

and was also the first and only Down's Syndrome student to be accepted there.

"With the grace of our dear Lord, a lot of hard work and an ulcer because I stressed so much, I passed the N3 course, which equals 'matric', and after that I passed the N4, N5 and N6 courses. The N6 course is the highest qualification at the college. I was awarded the Education Diploma in Educare, in May 2009.

"When my mother and sister received their degrees, I started to dream about wearing a robe and mortarboard and walking across a podium. When I did eventually walk across a graduation podium all the people in the City Hall stood up for me. I was also awarded a special prize for being the first Down's student to receive a National Diploma. That was the most amazing moment of

my life. I looked at all the people and saw my mother and sisters crying.

"I am so happy to work at Lettie Fouche, a special school for learners with learning problems, as an assistant in the pre-primary classes. I enjoy every day and I help the teacher to prepare her lessons and to stimulate the learners.

"Vanessa Dos Santos of Down's Syndrome South Africa asked me to 'open' the international conference for Down's Syndrome in 2012. She also asked me to be on the International Board for Down's Syndrome.

"I live among these people. Me, a girl with Down's Syndrome, a condition that makes people abort their babies and lock them in institutions or at the back of their homes so others can't see them!

"May you also be blessed with happiness and a heart full of compassion for those in need."

# APPENDIX F

2014 EDCS912E1 PhD Subs Yr C... TURNITIN Assignment - Part 3 (Moodle...)

Originality GradeMark PeerMark

Access to schooling spaces  
BY PUSHPAGANDHI GRAMANI

turnitin 2% SIMILAR -- OUT OF 100

### CHAPTER ONE

#### COBBLESTONE FACADE

##### 1.1 Introduction

The cobblestone image is scorching into memory since early childhood. It prompts a reminder of the meandering uncentred cobblestone pathway I had to take to the entrance of the emblazoned school gate. During my high school days, my friends and I played games of hopscotch or tic-tac-toe on cobblestone pathways to distract ourselves from the long and arduous uphill walk to school. The face brick facade with small manicured flowerbeds belied the age of the school and the occasional broken or missing part behind the wall: its loose door and window hinges, leaking taps, flaking paintwork and uncollected rubble of irreparable desks and chairs piled up on the far end of the school grounds. The walls masked the catalogue of burgeoning activists desirous for change in government policies. That was back then, in the 1970s and 1980s framed by rolling mass action with urgency and agency for change. Now, the expressive images of nearly thirty earlier, seep into my mind as I contemplate schooling spaces for my child, born in 1995, about to step into the portals of schooling at the age of three. I begin this study from the premise that my interest is in education and its associated potential to provide opportunities (in various schooling spaces) for my child to engage with spaces, places and people and from those interactions, learn. Getting into the spaces meant getting onto a different 'cobblestone' path and walking and sometimes, stumbling to the gate.

*Private, mainstream, special school, home-school?*  
*Which is the right answer for my child at this time? Will it be the answer for ALL TIME? I do not know. I will keep evaluating and adapting to her needs. I cannot say if it is working so far. Things I initially considered in my choice of schooling, is this schooling choice a good fit*

#### Match Overview

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## APPENDIX G

18 Winchester Drive  
RESERVOIR HILLS  
Durban  
4091

Telephone: 082 449 9099 (c)  
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Fax:         086 555 8223  
E-Mail: [sharrybsingh@gmail.com](mailto:sharrybsingh@gmail.com)

25 November 2014

### CONFIRMATION OF EDITING

I hereby confirm that I have edited the following thesis for errors in language and general layout:

**TITLE:** Access to schooling spaces for my child with Down syndrome: an autoethnography

**CANDIDATE:** Pushpagandhi Gramanie



**B. SINGH**  
BA (Hons) (Unisa), MA (Natal), LSTD (UDW)

## APPENDIX H



**S. M. Ramson**

Contact number: 0844020251

Annotated profile: BA, UHDE, Psych Hons, MA, Certificate in Computer Studies. Educator, Lecturer, PGCE, NPDE, Bed Honours. Editor – Honours, MA and PHD students (Detailed profile available on request)

To: The Supervisor: Prof R. Sookrajh

Cc: Pushpagandhi Gramanie

### **EDITOR'S CONDITIONS**

Editing to be undertaken for student Pushpagandhi Gramanie . UKZN Edgewood  
Student number 8421423

The above student has verbally requested my services as editor of her PhD dissertation titled:

*Access to schooling spaces for my child with Down syndrome: an autoethnography.*

The student is hereby informed that editing will comprise of the following:

- Reading of the entire document for language, spelling and grammar usage in accordance with SA language
- Examining the continuity between sub-sections and between chapters.
- Checking referencing in relation to APA 6<sup>th</sup> standards, unless otherwise directed by supervisor/institutional requirements.
- Checking the sequence of numbering in headings and subheadings
- Checking layout / design and formatting of chapter titles and font type and size for consistency. This includes checking of pagination and margins.
- While students may have the freedom of creativity, content will be examined for meaning and sense, and requests for clarification where confusion exists will be made.
- An overall technical edit will be undertaken
- Obvious or noticeable inconsistencies will be brought to the attention of the student

Remuneration for the editing has been discussed with the supervisor

**WAIVER:**

**Any substantive changes made, are only to CLARIFY the meaning, NOT to change the meaning of the student's work.**

**The student has engaged my services as editor for the purposes of examining and correcting the technical aspects of the work. It is assumed that at this stage the student's supervisor(s) has sufficiently examined the thesis and advised the student with reference to research, research methodology, data generation, reporting, knowledge production and content. It is also assumed that the student is sufficiently proficient in these matters. The editor waives any claim of responsibility regarding the student's type of research, research process, research methodology, data generation, reporting of data, knowledge production and content, and cannot be held accountable for any plagiarism by the student or the examiner's final assessment of the student's effort.**

**S.M. Ramson.**

The student is requested to respond via email to this letter as follows:

I.....(Name and student number) have read and understood the contents of the EDITOR'S CONDITIONS and agree to the editing of my thesis under these conditions.

This email serves as a contract between both parties.

\_\_\_\_\_  
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