

Educating Learners with Down Syndrome Successfully: A Narrative Journey

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Abstract

The aim of the article is to illustrate the important role that parents can play in the development of the education of learners with Down syndrome (DS). A literature review was done to obtain background information on the concept DS and on the history and possibilities of education for learners with DS, as well as on the role of the parent in the management of the education of learners with DS. A qualitative case study, focusing on the narrative approach was implemented to illustrate the management of the educational opportunities and thus, the self-actualisation of all learners with DS. The educational history of an academically successful girl with DS was followed in order to establish what lay behind her success. From the findings it can be deduced that parents and educators should collaborate to enhance the educational opportunities of learners with DS. The contribution this article makes is to convey to educators and parents the important role they can play in the advancement of the education of learners with DS, as a possible way to give these learners a better chance to live a meaningful life. The assumption is that if learners with DS receive optimal stimulation and encouragement from their parents and teachers in collaboration with one another, from an early age, their educational skills and self-actualisation will benefit to a large extent. This will improve their opportunities to become valued human beings.

Keywords: Education; Down syndrome; early childhood interventions; Down syndrome education

1. Introduction

Parents play an important role in the development and education of learners with Down syndrome (DS), which is one of the most common congenital syndromes and is caused by one extra copy of chromosome 21 (Livingston & Strydom 2012). It occurs once in about every 700 births, but this number may vary from one in 500 to 1 000 (Hovorka & Naznin Virji-Babul 2006; Laws & Millward 2001; Selikowitz 2008; Shiver 2010). If one looks at the overall picture, it affects around 5.8 million people worldwide and is the most common inherited cause of learning difficulties. This fact stresses the importance of this study (Hanney, Jones, Francis & Ballard 2012).

Scientific improvements and pre-natal screening have decreased the incidence of DS by only about 1% in the last 20 years in the United Kingdom (Hanney, Jones, Francis & Ballard 2012). These findings and also the fact that people with DS tend to reach a much older age than was expected previously (Hanney, Jones, Francis & Ballard 2012) necessitates research into their educational needs and potential. This kind of research may help them to become adults with skills and competencies that can add value to their own lives, as well as that of the communities in which they live. Unfortunately, many disabled people might remain uneducated and unemployed because their potential is not acknowledged. Parents and people who are in decision-making positions need to be aware of the benefits that lie in the inclusion of educated people with disabilities in a diverse workforce (Kleinhans & Kotze 2010).

Learners with DS have many similar characteristics, but they also have unique features and abilities in the physical and cognitive areas of their development (DSSA 2011). The specific abilities of each child are best known to her/his parents and this should indicate the education opportunities, which would be able to meet their child's individual needs optimally (Shiver 2010). Although many western countries provide a number of services, including educational services to people and families with DS, there is still an enormous amount of work to be done in many countries internationally (Robertson 2009) and especially in Africa (International Down Syndrome Conference 2011). Education planners and parents must take cognisance of the fact that learners with DS have educational rights and a right is not what someone gives you; it is what no one can take from you (Guernsey & Stein 2008).

The contribution of this article is that it might help to give learners with DS the best possible chance to develop their educational skills to become valued human beings who can contribute to society. If a parent is actively involved in the development of her/his child with DS, the child may have a much better chance to develop with regard to his/her educational and social skills. Research on the educational needs of learners with DS can make a significant contribution

towards the self actualisation of these learners (Goodley 2009; Mittler 1984).

In the following section the theoretical background of learners with DS and their possible educational problems and strengths are discussed. The aim of the article is to establish what the underlying reasons for the educational success of learners with DS can be. The results of a case study of one learner with DS who excelled above the others in a country, such as South Africa will be reported on in a narrative way. The article concludes with guidelines to parents/ carers and educators so that they will be able to manage and improve the educational opportunities of learners with DS.

2. Theoretical Framework

In the sixteenth century people who were seen as different, did not fit into society and had to be removed. Martin Luther himself was quoted on the need to remove *deviants* from the community (Luther 1652, quoted in Kanner 1964). Although Luther might have been misquoted (Blatt 1987), it is clear that there was a shift in the discourse on deviancy brought about by the Reformation. This can be the reason why so many parents decided to keep their children from sight or sent them to asylums at that time. This deprived them of educational opportunities and may still have an influence in some societies today. The words of Foucault (1956:26): "Madness no longer lies in wait at the four corners of the earth, it insinuates itself within man" convey the general perceptions of that time. To those people, man had a moral obligation to work; little did they realise that parents and society itself deprived people with disabilities of the ethical value of labour at that time. One may ask whether these attitudes have really changed in the general population today when so many countries, policy makers, educators and even parents continue to deprive people with disabilities of educational opportunities that best suit their needs.

It was only in the nineteenth century that certain educators and social thinkers started to resist the banishment of people on the grounds of their differences (Kliwer 1998). It was then realised that people with intellectual disabilities could be taught and the best way would be in association with non-disabled learners (Seguin 1866 in 1907). In this article, the role parents can play in preparing a child socially and academically for her/his best educational opportunities is emphasised (Merrick 2006; Parker 2010). So many DS learners still receive education because of the 'generosity and goodwill' of individuals or charity groups and they are still judged to be incapable of benefiting from existing education (Green & Engelbrecht 2009).

After the Department of Education (DoE) published the *White paper 6* which gazetted the Policy on 'Building an Inclusive Education and Training system' in South Africa (RSA 2005) and the *Children's Act* (RSA 2006), the DoE selected and supported a number of ordinary schools to become full service schools. These schools accommodate learners with DS, as well as many other learners with learning disabilities (Schoeman 2009).

Research clearly shows that there is variability in the population sharing the genotypic feature of Trisomy 21. More targeted educational planning to address the variability in a population of individuals with DS might make it possible to focus on the individual educational needs relating to the complex profile associated with DS, with more success (Fidler & Nadel 2007). Most teachers feel that when they start teaching they do not feel prepared to include learners with disabilities, although teaching strategies, consistent with good teaching practices, also seem to be effective when teaching in an inclusive environment (Wolpert 2001). Parents can play an important role in helping prepare these teachers and the abled learners informally, when a child with DS attends their classes (Wolpert, 2001).

Although many learners with DS lag far behind in their reading levels, many do acquire the skill between 9-13 years (Trenholm & Mirenda 2006). One must keep in mind that some learners need more extensive practice to become automatic fluent readers (Otaiba & Hosp 2004). When letter knowledge is taught to a child, phonological awareness (a conscious level of understanding about the sound structure of words) improves and this is associated with better reading outcomes (Curenton & Justice 2008; Van Bysterveldt, Gillon & Foster-Cohen 2010). Reading accuracy and phonological skills, strengths in visual and verbal short-term memory, articulation and speech fluency is not always an indication of the learner with DS's knowledge-based reading comprehension (Groen, Laws, Nation & Bishop 2006). The problem with most of these learners is that they do not understand what they read (Fidler & Nadel 2007; Reynders 2005). More research needs to be done to explore the development of comprehension skills of learners with DS (Burgoyne 2006).

Generally, these learners show stronger receptive language skills and weaker expressive language skills, which is an important aspect when education is planned for them (Fidler & Nadel 2007). Because the determinants of the successful education of learners with DS are complex and involve many factors, it is also not a straightforward process to establish what constitutes educational success for a child with DS (Laws & Millward 2001). This is why this article aims to illustrate some of the underlying reasons for one learner's success.

3. Research Methodology

This research was undertaken from an interpretive framework, because it refers to a deeper search for meaning which incorporates feelings (Henning, Van Rensburg & Smit 2011; Waghid 2003). This approach involves the opinions and experiences of people who are familiar with their own or the situations of others (Patton 2002). The above research was done from a narrative approach by charting my life journey with my child, by means of an in-depth explanation of the educational road that I have travelled with my DS daughter. I then explained my perspectives by using my own story structures (Sinclair Bell 2002). I used a narrative research perspective to try to present a richer understanding of the issues involved, as this approach allowed me to obtain information that I did not consciously know myself, and more importantly, it allowed me an in-depth understanding of the educational development of my daughter. In this article the role parents can play in preparing a child socially and academically for their best educational opportunities is emphasised (Merrick 2006; Parker 2010).

I focused this study on the activities according to which I have raised my daughter and I compared them to the literature on the research that has been done on the effective education of learners with DS. Qualitative research helps the researcher to gain insight and understanding into the life of the research participants; in this case it was my own life (Henning, Van Rensburg & Smit 2011; Mouton 2003). Qualitative research seeks to understand phenomena without the researcher attempting to manipulate the phenomena (Patton 2002). This approach emphasises the role of the researcher's experience of and insight into the phenomenon under investigation (Henning, Van Rensburg & Smit 2011), which in this case, is appropriate. I (the researcher) have a daughter of 32 years old with DS. Therefore, the method of research is appropriate to my ontological (what is reality?) and epistemological (how does one know something?) assumptions about DS (Harriss 2001).

4. Narrative Discussion

In the management of the education of learners with DS, the parent should become an effective partner with the professionals to maximise their support of the learner. They should become an ad hoc professional who is prepared to become involved in the development and implementation of programmes to support their child.

The following narrative will be written in my own words and will convey the deeper feelings and insights that I developed during my educational journey with my child. The narrative will be divided into certain important developmental stages in the life of my daughter with DS.

4.1 Birth and first impressions

"Sheri was born 32 years ago. A little baby girl, playing with her tongue, lay next to me that morning, only minutes after her birth. My whole life was about to change dramatically, although I did not realise it at that stage. Jerry, my husband immediately saw the features that reminded him of the features of a baby with DS he had once seen. He asked the doctor whether our baby was okay and he replied that the baby was fine. The doctor thought it best to leave the sad news for the next morning when we had all rested after my night in labour. The next morning, Jerry's fears were proved correct when the paediatrician told me that my baby had low muscle tone and we realised that he suspected Down syndrome. Although I was only 25 years old, I had gained enough knowledge during my studies at University to know that this meant intellectually impaired, not being able to help yourself, looking different and being mocked by other people. This was in 1982. People with disabilities or who looked and acted differently were marginalised and excluded from society at that stage. We were led to believe that all people were the same and fitted into a perfect mould. Disabled people or their parents were punished for something they or their forefathers had done wrong. That is why so many parents left their babies in institutions or locked them away in their homes.

I felt different and although I felt unsure and a little scared, I felt blessed! I loved my little daughter. To me she was the most beautiful baby I had ever seen, although I could see the features, which distinguished her from the other babies in the maternity ward. I felt sad for her, not for myself. I immediately realised how lucky I had been to be able to attend a normal school and go to university. Before that morning, it was something I just took for granted. Without my knowing it, this little girl had already changed my perception of life and she started to open my mind.

Although I feared the unknown, I decided there, in hospital, that I would give her every possible opportunity to develop and I asked all the people who wanted to pray for her "to become normal" to rather pray that she would get the support to reach her full potential. I loved her for what she was and was determined to provide her with all the opportunities she would have received if she had been born a normal baby. I realised that she would need more caring from me, but I decided that she was not going to be a burden. She was just as human as any other person and she deserved the same opportunities. I accepted her being different and never tried to pretend that she was or could become normal.

From that time in my life I started to embrace the differences between people, without knowing it. That morning I decided to teach this little baby everything I knew, but it turned out that she taught me much more”.

The role parents can play in the development of their children with DS can never be underestimated. The more readily parents adopt and accept the disabled identity of their children, the smoother the process of dealing with assisting professionals appears to be. These parents will feel more in control and their improved relationships with the professionals, as well as their acquired skills, may help them to carry out the interventions from which the child will benefit (Rix & Paige-Smith 2008).

I accepted my daughter as being different and realised that we have to respect the differences in people, without my grasping the fact that respecting the differences in people adds to one's knowledge and understanding of reality (Niemann 2006).

It is also important to note that the mother's exposure to higher education is usually associated with positive literacy concepts, to the benefit of the learner with DS (Curenton & Justice 2008). In my case, I was fortunate to have had the opportunity to attend university.

4.2 Home and acceptance

“We went home amidst flowers and love provided by all our family, friends, colleagues and even people we did not know. I looked at my little baby with her almond eyes and realised that she had changed so many people's hearts and lives and I prayed that someday, her life would mean something more than just receiving from others. This was part of my dream for her, to become a worthy human being. I hoped that she would give back some day, whatever she has, to the society who accepted and loved her from birth. I chose not to see any negativity around her or any rejection. Sometimes I did feel the urge to be afraid and sorry for myself, but then I immediately changed my thoughts into thankfulness for the special opportunity I had received, to walk a path less travelled”.

The literature endorses the fact that the active, rational coping mechanisms of parents raising children with DS may relate to a feeling of reward, thus making it easier for them to contribute positively to the nurturing of their children with DS. The fact that the parents cope with the fact that their child has DS will thus be beneficial to both the parents and the children (Lyne & Roger 2000). The focus on positive perceptions as a coping mechanism can also be used as an intervention to help families accept and adapt to a child with disabilities (Hastings & Taunt 2002).

4.3 The need for knowledgeable support

“Because the path that I followed was different from what most parents did, it was unclear to me where I was heading. Early childhood interventions were unheard of and therapies and support were either non-existent or very limited at the time Sheri was born. Apart from Sheri's doctor, who supported us tremendously, we had very little knowledgeable support in the developmental aspects of Sheri's life. When she was about three years old an occupational therapist started to give me guidance, but before that, I had to rely on medical and child development literature to guide me to support my baby. I wished in my heart that Sheri's life would help to make this path easier for the people in the same position. Many doctors told me that children with DS do not live long because of medical problems normally associated with them. They gave me a vague indication that it was highly unlikely that she would reach the age of 30. You can imagine the celebration when she did turn 30 as a healthy, happy and strong young woman, with an occupation and dreams of her own.

Some doctors also said that people with DS develop intellectually only until the age of 7, if they are lucky. I was so confused by things people told me that I decided to try to meet and talk to parents with older children with Down syndrome living in Bloemfontein to find out from them what they experienced. I was able to talk to only three mothers. Somehow, nobody could give me names of more parents. I discovered that most parents never showed their children to the outside world, which made my task more difficult. I decided this would not happen to babies still to be born and I gave my name to the nurses at the clinic and to many doctors. I told them to tell parents of children with DS that they could contact me at any time and this resulted to many special friendships in the years to follow”.

The primary physician who acted as a coordinator of care for my daughter helped us to support her to achieve the highest level of independence (Urkin 2006). The independence of learners with DS relates directly to their educational needs and vocational dreams. Although I did not know it at that stage, research also indicates the importance of parents who experience more positive perceptions of having a child with DS, to help other parents who are struggling to accept their child with DS (Burke, Fisher & Hodapp 2012). By helping other parents, parents may benefit because it gives them a sense of meaning to the birth of their child with disabilities.

It is necessary for parents and educators to take cognisance of the most common characteristics of children with DS, such as their low muscle tone, their delayed motor, speech and language development; to be able to best address their educational needs (Selikowitz 2008; Laws & Millward 2001). Some learners with DS may have a number of the above-mentioned problems and others may have none. There is also a large variation in the severity of these conditions in different children. Knowledge about the possible medical problems these children may have can help parents and teachers to handle them with the necessary caution (Schneider, Wedgewood, Lewellyn & McConnell 2006).

4.4 First few months

"Amidst all these feelings, I breastfed Sheri for more than a year and believed it would be good for the muscle tone in her mouth and later her speech development. I had to wake her every so often because it took so much energy for her to suck. This was the beginning of her life, which was already characterised by hard work to achieve that which normal babies do with ease. Everything she had to do took effort, but that did not mean that she would not be stimulated to do things. She only needed more time and support and that she got from me, Jerry, my mother and all the people who loved her. We did not permit her to give up before trying her best. I never showed her that I was sorry for her, because I believed that would have given her the opportunity to quit. I tried to teach her that effort is part of life. We applauded every effort and she loved the positive attention and happiness that resulted from her achieving some or other competency.

In time, this little baby girl became an integrated part of my life. Today, I call her 'my shadow', although I know I stand in her shadow because of what she has accomplished and the fortitude she possesses. I resumed my post as teacher and the learners and colleagues were wonderfully supportive. They provided me with articles on how to stimulate Sheri and with books about DS from the medical library. I appreciated this, because it was scientific and researched information. One particular book indicated the development areas in normal children and that helped me to know on what I had to focus. At that stage very little support was available in the city where we lived. The parents of DS children, whom I visited, could also not help much, except the parents of one boy of 20 who seemed much brighter than the other children in the school that I visited. This boy gave me hope for my little baby and was the start of a miracle journey with Sheri".

I sought scientific knowledge concerning the developmental and educational needs of children with DS and I knew that it could make a significant contribution towards the self-actualisation of my child with DS (Goodley 2009; Mittler, 1984).

The goals of early childhood development programmes are to provide therapeutic and developmental help to children with DS and their parents (Lloyd 2009). Studies have shown that the progressive slowing of the intellectual development of children with DS can be minimised by the provision of early educational interventions (Fidler 2005; Russell 2013). The early intervention programmes for children with DS are important because they can promote the development of literacy skills, as well as enhancing the child's spoken language development. In this way the parent can assist a child with DS to commence school with stronger underlying skills that will encourage greater engagement and success in classroom-based reading programmes (Van Bysterveldt, Gillon & Moran 2006).

4.5 Three months and older

Sheri was a healthy, happy baby. I kept on teaching and the learners were wonderful. They accepted my little baby for who she was, a baby with DS, because they could see I was proud of her just the way she was. People don't always know how to handle people with disabilities and I decided to make it easier for them by talking about her and explaining to them what her genetic disorder implied. I did however focus on the fact that everything this little person was to know I would have to teach her. I felt that it was all up to me as the mother, to stimulate and teach her what a normal baby would pick up by herself. I tried to stimulate her every free minute that I had, by talking, reading and playing stimulating games with her. Learning had to be fun and we had a lot of fun learning; it was never a sacrifice for me or for her. My mother also looked in on her nearly every morning while I was at work, to play stimulating games with her for an hour or so. Jerry played and joked with her, bringing normality into our house. I was the teacher, outside and inside the house. Although it kept me busy, it wasn't an effort to raise Sheri. I enjoyed my little 'slant-eyed angel', as we often used to call her, after reading a book with the same name.

We played classical music to Sheri as much as we could and she related to the music with enthusiasm, although she liked music with a beat much more. I used every opportunity to teach Sheri to speak and understand words. I would put my lips on hers and speak the words, trying to teach her and began by showing her how the sounds are made. It was fun and also helped her to realise that her tongue should be in her mouth and not protrude. Her first word was "daddy", which she uttered before she was a year old. It was not only a sound; she looked away from me, at Jerry, when he entered the room. After that "mamma" and other easy words followed. It took a whole weekend to teach her to say

"hello" and before she turned one, she could greet people with a "hello"! We applauded all her efforts and she loved it, jumping up and down and clapping our hands when she mastered something new. She started to get the thrill of accomplishment.

The one mistake I made was comparing Sheri to other babies of her age. I could see the gap growing and at times, it made me sad. I believed it was up to me to help Sheri to develop to her full potential and I often felt I failed her. Nevertheless, I never lost hope or faith; I would try only harder and pray more. Later in her life she took this determination over from me when she had to adapt to being among normal learners who teased her, as well as having to study much harder than her sisters. Somehow she learned not to give up easily and she was determined to do the things she wanted to do, although she was slower in everything she did".

It is important for all parents or carers to prepare a child with DS socially and academically for the best educational opportunities possible (Merrick 2006; Parker 2010). The parent specifically, has a very important role to play in the development of language of a child with DS. Research indicates that there is a definite correlation between early language experience and the development of speech processing efficiency later on in the child's life (Curenton & Justice 2008; Fernald & Weisleder in Neuman & Dickenson 2010).

The quantity and quality of the mother's speech is a prediction of the child's language proficiency later, while maternal talk is also closely associated with the child's vocabulary growth and the development of fluency in the understanding of the spoken language, in time. This understanding helps the learner to remember previous information which can enhance academic achievement and perceived intelligence (Fernald & Weisleder in Neuman & Dickenson 2010).

Another factor which can influence pre-schooler's oral and literacy skills is the oral and written language skills of the parents (Taylor 2011). The home literacy environment of 3 to 5 year olds with no or less severe disabilities is a significant predictor of their receptive vocabulary and reading comprehension in later years (Carison, Bitterman & Jenkins 2012; Roberts, Jurgens & Burchinal 2005).

The importance of increased family interaction to improve phonological awareness cannot be stressed enough. Children with DS become consciously aware of the sound of spoken words through reading and talking with adults. Parent's attitudes to literacy and their engagement in literacy-related activities, including book reading with their children, seem to be of the utmost importance (Van Bysterveldt, Gillon & Moran 2006). Instinctively, I did these things because I wanted to stimulate Sheri, so as to give her the best developmental opportunities she could receive.

4.6 *The birth of a sibling at 21 months*

"When Sheri was 21 months old her sister Marisa was born. This was one of the highlights of her life. She loved her tiny sister and tried to tend to her needs. She was the big girl now. She could walk at that stage and I could send her to fetch things, which helped her to develop a feeling of responsibility. Marisa grew and developed much faster than Sheri as could be expected and when Sheri was about four years old the gap between the two became very small. Sheri accepted this and later on the roles changed, with Marisa looking after Sheri and helping her in her development. I would sit with them, reading stories and teaching them to read and Marisa would start to read the words before Sheri could. This helped Sheri because Marisa explained concepts to her on her own level of understanding. Sheri could read with comprehension from the age of 5 and that is one of the skills, which helped her most in her intellectual development. She loves reading and this skill opens the doors of knowledge.

I also started to teach the children to write to develop their fine motor skills, when they became a little older. They enjoyed writing their names and later they started to write me short letters that I would find under my pillow or in my handbag. When Sheri was seven years old and her youngest sister was born, she wrote me letters while I was in hospital. Reading and writing is still an important activity in Sheri's life, especially now that she is writing her own book.

Evidence suggests that the home literacy environment is an important factor in the development of the DS child's speech and language skills, especially when the child actively participates during joint story reading (Bracken & Fischel 2008; Van Bysterveldt, Gillon & Moran 2006). However, this environment is not the only significant predictor of the receptive vocabulary and reading comprehension of learners with moderate to severe disabilities (Carison, Bitterman & Jenkins 2012).

Parent-child reading interaction and the child's reading interests are significantly related to the child's early literacy skills (Bracken & Fischel 2008; Van Bysterveldt, Gillon & Moran 2006). Some children need more extensive practice to become automatic and fluent readers (Otaiba & Hosp 2004). When letter knowledge is taught to a child, phonological awareness improves and this is associated with better reading outcomes (Curenton & Justice 2008; Van Bysterveldt, Gillon & Foster-Cohen 2010). Parents should focus on comprehension and higher order reading skills, which could

increase the learner's ability to learn to "read to learn" (Trenholm & Mirenda 2006; Reynders 2005). The importance of increased family interaction to improve phonological awareness cannot be emphasised enough. Children with DS become consciously aware of the sound of spoken words through reading and talking to adults. Parents' attitudes to literacy and their engagement in literacy-related activities, including book reading with their children, is of utmost importance (Van Bysterveldt, Gillon & Moran 2006).

With regard to writing, research indicates that only a minority of children with DS has in-depth skills (Trenholm & Mirenda 2006). Writing requires sophisticated arm and finger movements, a fine motor skill that is difficult for many children with DS (Reynders 2005), but increasing the frequency of home writing can alleviate this problem. It seems that parents rather prioritise communication, self-help skills and making friends, than reading and writing skills (Trenholm & Mirenda 2006).

4.7 Pre Primary school

"As Sheri grew up, schooling became the next concern. Once a week she went to a mainstream pre-primary school. They would not take her every day and actually Sheri needed more stimulation. The classes were big and although it helped to develop her social skills, which is very important, it did not provide the stimulating activities to which she was used. The special school near us decided to start a pre-primary class, which only Sheri (3years) and a boy of 6 years attended. The number of learners increased, but only to six. Sheri received a lot of attention and stimulation and in the afternoons I would reinforce the work of the teacher. A few months later, I saw something strange. Sheri started to adopt negative behavior, such as bumping her head against the wall, which she picked up from the other learners. She became reluctant to go to school and would not play with the other children. I decided to make an appointment at another school, which followed a mainstream curriculum, but catered for learners with physical disabilities. I did not mention that she was a learner with DS, but only that she might need extra help".

The choices that parents have to make with regard to school placement can be a source of great concern (Johnson 2006). The attitudes of the parents can also play an important role. Parents, who feel involved in the education of their child with DS, may feel more appreciative of the education provided (Laws & Millward 2001), but they may also identify problems within the educational context of their child.

4.8 Mainstream schooling

"When the headmaster saw her, he immediately declined her enrolment, telling me that she would not be able to attend his school. He did not even want to evaluate her. According to him, learners with DS could not attend his school. They would give his school a bad name because it is not a "special school" and that is where he believed she had to go. I was sad, but accepted his decision and took her back to her "special school". Before we went home, I asked the principal one last time to please rethink my request and give her a chance, if possible only for a day or a week. I told him that learners with DS in America attended mainstream schools. A few weeks later the principal phoned me and said I could bring Sheri for evaluation, without any obligation from his side, to accept her. After two days of in-depth evaluation, we were called in by the vice principal of the school. The principal was out of town that day. This wonderful man accepted Sheri at the school for a trial period. Her IQ was high enough and they would have accepted her if she were not a learner with DS. The next week, Sheri started at her new school and the principal warned me that if she did anything out of line she would have to leave immediately. I thanked him for giving her a chance and promised my full cooperation. The trial period became 15 years, with Sheri passing her grade 10 National Certificate when she was 18 years old. In her final year she was awarded the school's highest honour for Drama accomplishments on National level and she also received the prize for the highest marks in Biology. She was the first and only learner with DS who had attended the school and the first and only in the country, to receive a National Grade 10 Certificate, without any concessions. The road she had to travel was full of challenges. She was the only learner who looked different from the other learners. She had to endure mockery, little social acceptance and she had to show the principal that she could fit in. The teachers were very supportive; they were strict with her and set boundaries within which she knew she had to function. They did not give her much leniency or allowed her any manipulation. I supported the teachers and we worked together to the benefit of Sheri's development. Every year a committee at the school decided on the future of every learner and I was always so worried about the outcome. She was held back and started mainstream Grade 1 a year later than her peers at the age of 8. She also had to repeat Grade 2, but she was never asked to leave the school, although many of the so-called 'normal' learners had to go to special schools along the way. For this, I have to thank the teachers for being strict and not feeling sorry for her, which would have had detrimental effects on her".

Howell (2000) stresses the importance of the development of inclusive schools for learners who can benefit from it (Laws & Millward 2001) because research supports the fact that people with intellectual disabilities can be taught and the

best way would be in association with non-disabled learners (Seguin 1866 in 1907). Parents can also play an important role in helping to prepare teachers informally with written material and personal information on their children, as well as talking to the child's classmates before the onset of inclusion, so as to help prepare them (Wolpert 2001).

Although a lot of work on inclusive education has been done on the first years of schooling, less has been researched on later years and in particular, the secondary schooling years, in which intellectually demanding tasks and peer pressure magnify the presence of the child's special needs. Another problem faced in the later years of learners with DS is the fact that their IQs often diminish as they grow older. Although they still learn and develop, the gap between them and abled learners tends to become bigger (Reynders 2005).

4.9 Leaving the safe haven of school

"After leaving school we again had a problem. She was 18 years' old, very small in stature, very used to stimulation and without any future prospects. She decided that she would like to work at a nursery school, where she could work with small children. A school gave her a chance to work there but some parents took their children from the school because of her working there. The school was very supportive but we did not want the school to be at a disadvantage because of her and took her away. We also realised that that she could benefit from structured knowledge about teaching small children. I had to look for new educational opportunities for Sheri. I went to the National Further Education and Training College and asked them whether Sheri could attend the college. She had the necessary certificate (National Grade 10) and they accepted her. Again, Sheri was the only learner who looked different from all the other learners but this time, there were many more students and they spoke different languages and were from different cultural backgrounds. In this institution she had a lot of freedom and socialisation became very important. During her time at school, she developed so well socially that she was chosen as class captain in her last year. My focus at home was always: "Look what normal learners do and do the same". Sometimes she would get in trouble and then she would use this as an excuse for being naughty. Her friendships with more abled learners were very special in her life and most of her school and college friends are still her friends today. She has been a bridesmaid for many of these friends in the last few years".

As in Sheri's case, it is clear that factors outside the family, such as mainstream schooling, can benefit learners with less severe disabilities academically, if the mainstream communities accept and support these learners (Turner, Alborz & Gayle 2008). Parents should give a lot of attention to the socialisation of learners with DS if they are to be incorporated into a mainstream school. Positive social interactions with learners with disabilities are not only the responsibility of learners without disabilities; parents of learners with disabilities also play an important role in this regard (Reynders 2005).

4.10 National Tertiary College

"Sheri started her college educational road, without special assistance or adjustments to the courses, subjects and evaluations. She enjoyed the classes; her friends and lecturers were very supportive and at home she had to study on her own, just as she had to do during her last years at school. She had to take responsibility for her education because my own program as lecturer at university and mother of three very busy daughters became very hectic. She had to write 3-hour papers which were set and marked nationally. She had to fit in and do exactly what the other students did. A big problem Sheri had was that the study material and lectures were in English and her knowledge of English as a 2nd language, was not sufficient. Luckily, one of her friends also had this problem and her mother started to translate the material, so we bought translated study material from them".

Sheri had to adapt to a different inclusive learning environment with a heterogeneous group of students. Each of the students functioned differently and it was clear that having the same rights do not necessarily mean having to benefit from the same interventions (Nota 2006). In a diverse group of students the needs of every student differs and it is impossible for a lecturer to accommodate every need. The fact that Sheri had a language barrier was not the problem of the lecturers or the institution; we had to look for ways to solve this problem on our own. Sometimes parents have to assist their children in their educational needs. It is very difficult for teachers to attend to the needs of every learner in a mainstream environment, although all educators should try to keep abreast with the latest developments in special education and be given opportunities to attend training in this regard (Olivier & Williams 2005).

4.11 Sheri lost a very important stabilising factor and the person she loved most

"Then Sheri received a huge blow. Jerry tried to retrieve his cell phone, which fell at the top of the Augrabies Waterfalls.

He slipped and fell down the falls. His body was found nearly a month later. Sheri, like her sisters, loved her father unconditionally and missed him tremendously. Her work deteriorated at the college and she failed her first year. I also went through a tough time, looking after my three daughters and my very ill mother on my own. My youngest daughter became head girl of her primary school soon after her father's death and needed a huge amount of support and Marisa finished secondary school that year. She was one of the top 15 Grade 12 learners in the province and the next year she started at university. They all needed my support and I still worked full time. I say this to illustrate the fact that our house did not revolve around Sheri. She was not more or less important than her sisters. This was the way in our house all through her time at school and college. Her sisters loved her because she did not take all my time and attention and she had the same responsibilities as they had. The one positive thing that resulted from this sad event was that Sheri had to become stronger and more independent. There just wasn't enough time for her to be a passenger. I expected more of her and this helped her to believe in her own abilities".

The role parents can play in preparing a child for their best educational opportunities and also for the realities of life is of utmost importance (Merrick 2006; Parker 2010). Often, we as parents tend to do things for our disabled learners without realising that we are taking away their independence by taking away their responsibilities.

Life skills, like taking some responsibility for one's actions and standing up for oneself, reflects positively on the community (Pennell 2001; Self Advocacy Association of New York state 2011; Mintz 2011). Responsibility is a principal of self-advocacy and it can facilitate self-expression, highlighting the ability to represent one and others and in context, it can also mean self-development (Goodley 2009). The fact that Sheri was forced to become more independent and to take on more responsibilities was beneficial to her development and later, her self-actualisation.

4.12 Assistance, motivation and success

"The next year I asked a friend of Marisa who studied to become a teacher, to help Sheri with her studies twice a week for an hour. This helped Sheri very much and it made me feel better about her education. It left me with enough time to look after her emotional needs since the death of her father. She had to accept it and it was my aim to give her enough security and I told her that she had an important role as the oldest sister in our new family structure. It worked and at the end of the next year she passed most of her subjects. We were all so proud of her. We applauded her efforts as we always did. At the end of the next year she passed all the subjects to acquire her N3, which equals Grade 12. She went on to pass the N4, N5 and N6 courses, although she failed some of her subjects from time to time, sometimes failing them more than once. She never gave up but only tried harder. When the course changed to a part-time course only presented in English, by Sotho (African language) lecturers, she still persisted. She continued with a tutor twice a week. N6 is the highest qualification at a National College. She also had to do some practical teaching and after completion, she was awarded the National N6 Diploma in Educare in May 2009".

The provision of educational support to educators and learners with disabilities can result in a climate of trust and effective teaching (Billingsley 2007), as in Sheri's case where the tutor assisted her. Teachers and parents should realise that learners with disabilities need more support to develop educationally (Westling, Herzog, Cooper-Duffy, Prohn & Ray 2006).

The importance of motivation can never be stressed enough because children with DS tend to be reluctant to persist in a task when they are challenged or if they are not immediately successful and this can influence their learning abilities (Kasari & Freeman 2001). Research has emphasised the role of motivation in the achievement of individuals (Maehr & Midgley 1991) and intrinsic motivation to promote internalisation, leading to the desired educational outcomes for many years (Deci, Vallerand, Pelletier & Ryan 1991).

4.13 Educational success

"This was an amazing event, a highlight in the lives of both Sheri and me. The city hall was packed with students and parents. When Sheri took her turn to walk to the podium, wearing a robe and mortarboard, silence fell over the people. They respected this small girl with her obvious intellectual disabilities, acquiring a diploma without any exemptions made for her. The academics on the stage and then the audience in the city hall stood up to applaud her and she was awarded a special prize for being the first and only person with DS to receive a tertiary qualification in South Africa (to date). She was also the first and still is the only qualified teacher with DS in the world".

Curriculum choices, the characteristics of the learner, classroom support and the attitudes and behaviour of the other pupils, staff and parents may determine the success of the learner with DS (Laws & Millward 2001). Because the determinants of the successful education of learners with DS are so complex and involve so many factors combined, it is

not straightforward to find out what exactly constitutes the educational success of these learners (Laws & Millward 2001).

4.14 Occupation

"This brought me to another crossroad. Although Sheri had the necessary qualifications there were no guarantees that she would be appointed at a school. I was very grateful when the headmaster of the Lettie Fouche School for learners with special needs decided to give her a chance as an assistant teacher in the pre-primary classes at the school. She had done her practical teaching at the school and they already knew her. This was another dream come true. She had a real occupation with a qualification as background. Helping the teacher with class activities, presenting some lessons and assisting the learners with activities, was part of her job description. Sheri still assists at the school today and works with small children with different kinds of disabilities, which gives her so much satisfaction. She has developed into a responsible citizen with rights and responsibilities. Her social skills are very good and she can handle herself in most social structures".

The fact that Sheri has an occupation improves her self-esteem and this is a clear indication that by satisfying the educational needs of learners with DS, they can make a significant contribution towards their self-actualisation (Goodley 2009; Mittler 1984).

Self-actualisation should be the main goal of education because the main reason why we learn is to further our knowledge of ourselves and of the environment in which we function. The purpose of education should be to give students the necessary tools they need in order to reach self-actualisation (Emmerson sa). The main fear that parents of children with DS have is their positive future outcomes and financial independence. Parents feel more satisfied when their children are more independent and reach self-actualisation (Burke, Fisher & Hodapp 2012).

4.15 She has become a respected person in her own right

"Sheri's educational success resulted in many new opportunities for her to develop and to become a respected person in her own right. People started to ask her to speak at events after word got around that she had gained a tertiary diploma. This escalated and at this stage, we have had to decline many invitations. She tells her audience how it feels to be disabled and the road that she has had to travel without structured help or interventions. She goes on to tell the people to make the best of circumstances that cannot be changed. She has spoken at many schools, conferences, community functions and educational occasions. Four of the highlights of these motivational speeches she gave nationally and internationally was when she spoke to nearly 15 000 people in three days, during nine sessions at graduations at the University of the Free State. She walked with the main procession, sat on the stage; a person with DS has never been given a better opportunity to change perceptions about the abilities of people with DS. Then she was invited to speak at a function that was held on International Disability day. The function was attended by the State President of South Africa There were more than 3 000 people present and when she started to speak, silence fell. After her speech, the State President and all present gave her a standing ovation and that evening parts of his and her speeches were broadcast on national television. Sheri also had the opportunity to address the Down Syndrome International conference in the United Nations building in New York. Her latest invitation was to present the keynote speech at the gala function of the World Child conference in Wales.

Sheri has been honored by Down Syndrome International for the work she is doing for people with DS. The Hamlet Foundation in Johannesburg has also lauded Sheri as the person in South Africa who has done most to change perceptions about people with intellectual disabilities. She was also chosen as "Shoprite Checkers Woman of the Year for the category Youth Movers" in 2012. Both of these were national awards, presented, for the first time to someone with a disability. Sheri has really addressed many challenges with what she has accomplished educationally. She has also acquired more self-confidence because of the respect she receives from so many people nationally and internationally. Educational success really gave her the opportunity of self-actualisation. One can only hope that her success will play a role in the optimal self-actualisation of many other children with DS."

One cannot pinpoint what exactly determined the educational success Sheri has achieved. It is also not a straightforward process to determine the educational success of any child with DS (Laws & Millward 2001). Knowledge about the determinants of educational success can make a significant contribution towards the self-respect and self-actualisation of these learners (Goodley 2009; Mittler 1984).

5. Conclusion

From this study the following guidelines for parents, carers and educators can help children with Down syndrome to reach their full potential:

1. All children with DS are not the same and they do not all have the same developmental potential. Parents, carers and teachers should always try to determine each child's individual potential and also to respect and embrace their differences.
2. After the birth of a baby with DS, the parents should try to obtain as much information on the subject as possible. It is necessary for parents and educators to take cognisance of the most common characteristics of learners with DS so as to be able to best address their educational needs. In-depth knowledge can equip parents with the management skills required to raise their children in the best possible way to enable them to reach their full potential.
3. The thread that runs through this study is acceptance by the parents. True acceptance will not only make it easier for the parents, but also for the child with DS. Parents who have to manage their own acceptance issues will have less time and energy to support their child. The child may experience rejection when the parent compare and get hurt every time the child's backlog is evident. Acceptance by the parent will also help the educators to collaborate with the parents to assist the child to succeed in reaching his/her potential.
4. Stimulation should start as soon as possible after birth and it will most probably never end. Stimulating speaking, reading, writing and the understanding of words are of primary importance in the early life of a child with DS.
5. The parents of learners with DS can play a very important role in the management of their children's education. Parents can share this responsibility with educators, tutors and medical support teams, but their input is of primary importance because of the knowledge parents have regarding their own children.
6. Parents and educators must take cognisance of the fact that there is a clear indication that some parents and educators experience uncertainty and have insufficient knowledge when they teach children with DS. If they support each other, the knowledge of both the parents and educators will improve, to the benefit of the learner.
7. The coordination of care between parents and educators is imperative and will help the child to develop socially and intellectually. Parents and educators should try to provide a safe environment within which the learner with DS can function. The parents should manage the discipline and boundaries at home, as well as supporting the educators in appropriate disciplinary actions. The parents and educators should constantly focus on what the child *can* do, not on where he/she is lagging behind; rather expect more than less.
8. Stigmatisation may have a negative effect on the educational opportunities of learners with DS. Because stigmatisation may be part of a learner with DS's whole life, parents and educators should manage this with the necessary tact and should possess enough knowledge and self-confidence to try to change the negative perceptions people may have.
9. Motivating the child with DS is a lifelong management task of the parents. It may become more important in secondary education because, at that stage, the differences in the abilities of abled and disabled learners become more obvious. The parents should also try to combine and balance all the roles expected of him/her with the role as a parent of a learner with DS.
10. Parents and educators should not allow the child with DS to manipulate them and if they feel sorry for the child, they should not show it. Parents and educators should always keep in mind that only by means of their input and management of the education of a child with DS, will this child reach self-actualisation and become a responsible, worthy citizen with self-confidence. The best way to change misconceptions about people with DS is to enable people with DS to act in a socially acceptable way in everyday life.
11. If the parents can remain positive about all the challenges that life has in store for his/her child, it may be easier for the parents to actively manage the circumstances and the possible preconceived ideas of other learners and parents.

The case study and underlying theory clearly indicates the positive effect a dedicated parent- educator combination can have on the education and self-actualisation of a child with DS. The child's right to receive the best possible education can have a direct influence on his/her ability to become a respected citizen with the rights and responsibilities associated with it. The role parents can play in the development of their child with DS is of utmost importance. It is crucial that every parent realises this responsibility as soon as possible after the birth of her/his DS child.

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