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UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

A study to explore the factors that influence the aspirations of youth with Down syndrome in terms of employment

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DSSVAN001

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Masters in Philosophy (MPhil) in Disability Studies at the
University of Cape Town.

SUPERVISOR: ASSOCIATE PROFESSOR. THERESA LORENZO

FEBRUARY 2011

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DEDICATION

I dedicate this dissertation with love and pride to my son Steven who continually inspires me to strive for the rights of persons with Down syndrome and other disabilities.

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To my loving family who have supported me during this entire process. I Thank you for believing in me and motivating me to continue. Thank you for your understanding and taking care of Steven while I attended classes and worked on weekends and evenings.

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I am eternally grateful to all.

DEFINITION OF TERMS

Community Based Rehabilitation

CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. (WHO, 2010)

Down syndrome

Down syndrome is a chromosome disorder that is caused by an abnormality (excess) in the genetic material. There is an extra number 21 chromosome (Trisomy 21) which causes delays in physical and intellectual development. People with Down syndrome are considered to be mildly to moderately intellectually impaired. (Down syndrome South Africa 2010). The appropriate terminology for reference to people with this disorder is “people with Down syndrome”.

Intellectual disability

A person with intellectual disability has life-long developmental needs. Intellectual disability is a condition of slower intellectual development, where medication has no effect. Difficulties in learning and understanding lead to problems in school and working life and to difficulties in being included in the regular life of society. (Down syndrome South Africa 2010:11)

Protective workshops

Protective workshops are social welfare institutions/organisations that are registered under the Non Profit Organisations (NPO) Act and Section 5 of the Social Assistance Act No 59 of 1992. They were established to provide secondary level rehabilitation services for people with developmental disabilities. The two key areas of delivery are restorative social services and activity-based production of goods on a small scale. (Department of Social Development, 2010)

Supported Employment

Supported employment is a model that has been designed to assist people with developmental disabilities to access employment in the open labour market. Jobs are identified and matched to people who aspire to do such a job or the other way around.

Job Coach

A job coach is a person who facilitates the process to employment in the open labour market for people with developmental disabilities, working closely with both the employee and employer.

Self-Advocacy

Self-advocacy is about building self-esteem and confidence which leads to self-determination. It empowers and enables individuals with intellectual disabilities to make decisions about their lives and stand up and speak for themselves.

LIST OF ABBREVIATIONS

CBR	Community Based Rehabilitation
DOE	National Department of Education
DOBE	National Department of Basic Education
DOL	National Department of Labour
DSA UK	Down Syndrome Association of the United Kingdom
DSD	National Department of Social Development
DSSA	Down Syndrome South Africa
DWDE	Disabled Workshop Development Enterprises
NDSS	National Down Syndrome Society
SADDF	South African Disability Development Fund
SAMSA	Self Advocacy Movement of South Africa
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UK	United Kingdom
USA	United States of America

Abstract

It is a common belief that people with Down syndrome are to be considered not capable of being employed in the open labour market. Upon leaving school they are usually placed in segregated setting such as sheltered or protected workshops or are simply left at home. This study aims to establish which factors influence the aspirations of youth with Down syndrome with regards to gainful employment. This study gave the participants an opportunity to speak up for themselves and provided insight into the factors that influence their employment. The literature review encompasses a theoretical base on key concepts such as Down syndrome, aspirations, employment, education and community based rehabilitation. A naturalistic approach focusing on qualitative design was used to establish these factors using collective case studies. The studied population was the Down Syndrome South Africa (DSSA) branch in Johannesburg, Gauteng. Six young people with Down syndrome formed the sample group of which three participants were employed in the open labour market, and three were working in protective environments.

Informal interviews were done and all interviews were transcribed verbatim. A preliminary analysis was done to extract the important themes and data which were then compared. A thematic framework was developed for classification and summary of the data. Cross referencing of members was also done to ensure trustworthiness. The study focuses on the community based rehabilitation (CBR) aims as a framework. By using the actual opinions of youth with Down syndrome the following themes emerged as a result of the findings:

1. Challenges to employment.
2. Making work work.
3. Prepare and teach them well.
4. *Lift their potential.*

The study found that the resilience shown by parents and family members as well as the self-determination shown by youth with Down syndrome was a most enabling factor. It further revealed that parents can be seen as the major stakeholders in the success of the employment of their young adult children with Down syndrome. Schools and protective workshops are not adequately equipping youth with Down syndrome in preparation for work in the open labour market. Disability advocacy plays a significant role in ensuring that the rights of disabled people and their employment needs are met. The study recommended strategies for development of youth with Down syndrome and support for parents and family members.

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Putting the study into context

1.1 Introduction

As we embark on the journey into the new millennium, we must continue to foster the optimal well-being of individuals with Down syndrome in all areas of human functioning. For, when provided with appropriate health care, excellent education and offered meaningful recreational and vocational experiences, individuals with Down syndrome can live fulfilling lives. Moreover, we must convey to society that individuals with Down syndrome are people in their own right, despite their limited capacity for academic achievement, and that their value is intrinsically rooted in their very humanity and in their uniqueness as human beings. Society ought to recognize children for their abilities and their strengths, not for their limitations. We have to ensure that individuals with Down syndrome will achieve their legitimate rights as valued and productive citizens. Most importantly, we have to acknowledge the absolute fullness of their humanity as well as the value and sanctity of their lives. Our children should enjoy a status that observes their rights and privileges as citizens in a democratic society and that, a real sense, preserves their human dignity. (Pueschel 2001:321)

Not much is known about the aspirations of youth with Down syndrome regarding employment or what factors influence or hinder these aspirations. This study documents case studies of six young people with Down syndrome who live in Gauteng in order to gain information and insight into what influences their choices of employment.

This chapter provides an introductory overview of the study and covers the history and current situation of youth with Down syndrome and the political attitudes to disability in South Africa. Moreover, it provides information regarding Down syndrome and the organization, known as Down Syndrome South Africa,

employment and disability in South Africa. It outlines the purpose and aims of the study.

1.2 Background

Historically, disabled people, including people with Down syndrome, across South Africa have been discriminated against and marginalised which has led to the segregation of disabled children within the school systems and employment (Department of Education, 2001; Office of Deputy President, 1997). They are an oppressed group which have been subjected to discrimination and abuse in various forms and are often placed in segregated settings such as special schools and protective workshops and there is much evidence to support this view (Marks, 2008). In the past, parents had no choice but to place their child in segregated settings. Furthermore, people with Down syndrome have often been denied the right to live in the community, get married, have children, be employed in the open labor market or even receive a basic education and in some cases have been denied life-saving medical treatment. "They have been subjected to incarceration, sterilization, overmedication, cruel or unusual punishment" (Griffiths in Ward and Steward, 2008:26). Disabled people and especially people with Down syndrome remain in the low income bracket and access to employment is a major challenge. They are perceived as having no abilities which leads to low self-esteem and unpreparedness to access presented opportunities (DWDE 2010).

1.3 Broader context of disability in South Africa

In 1995, the South African cabinet proposed a broad definition of disability. The OSDP (2010:4) reports:

The loss or elimination of opportunities to take part in the life of the community, equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological, or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society. These barriers may be due to economic, physical, social, attitudinal and/or cultural factors.

Statistics South Africa (2005) report in their Census 2001 there are 2 255 982 disabled people with various forms of impairment in South Africa, which constitutes 5% of the total population. Of that, 12% is made up of persons with intellectual disabilities and 30% have had no education at all, compared to 13% of ordinary abled persons. Roughly 10% of the world's population has a disability and of this 10%, at least 80% live in developed countries. (WHO 2010).

1.4 Down syndrome

The incidence of Down syndrome is estimated to be one in every 1000 live births in developed countries and one in every 650 live births in developing countries. Down syndrome is characterised by a variety of unique features and a wide range of abilities in physical and cognitive areas of development. The majority of people with Down syndrome fall in the mild to moderate range of intellectual disability. However, people with Down syndrome can learn and continue to do so throughout their lives. Although it cannot be cured, people with Down syndrome benefit from loving homes, appropriate medical care, early intervention as well as educational and vocational services. Due to advanced medical care, the majority of people born with Down syndrome today have a life expectancy of approximately sixty years (Medihelp 2009) and many living much longer. Persons with Down syndrome have the same emotions and needs as any other person and deserve the same opportunities and care (DOH 2006). Most youth and adults with Down syndrome need a certain degree of support and / or supervision in their daily living activities (Wong, 2002). This support would also include access to gainful employment.

1.5 Down Syndrome South Africa

Down Syndrome South Africa (DSSA) is the national umbrella body of all Down syndrome associations in South Africa. Currently there are 12 branches and support groups that provide support and services to people with Down syndrome and their families in South Africa. DSSA has an inclusive philosophy (Dube, 2006) with the views that all people with Down syndrome can and do learn. Therefore, DSSA encourages successful transition from school to work. They extend their care, support and services to children and adults from all backgrounds that are intellectually disabled, as well as those with multiple disabilities and are committed to finding ways to improve the quality of life of all persons with Down syndrome and

other intellectual disabilities. Down Syndrome South Africa was one of the first organisations in South Africa to bring about change and introduce the supported employment model with the introduction of job coaches. However, since the introduction of this model very few people with Down syndrome have benefited as a result.

1.6 Policy Context

The United Nations Convention on the Rights of Persons with Disabilities, UNCRPD (2006), which has been signed and ratified by the South African government, is recognised as a powerful human rights tool for disabled people and their families.

Down Syndrome South Africa and many other disability organisations have given valuable input into various policies relating to disability in order to ensure that disabled people's rights are recognised and upheld in these policies. Some of these policies include the Employment Equity Act, No 55 of 1998, the Promotion of Equity and Prevention of Unfair Discrimination (PEPUDA), No 4 of 2000, the National Skills Development Strategy (NSDS) of 1998, and the White Paper 6 on Inclusive Education (2001). These policies have all been designed to ensure that disabled people are able to access the open labour market in an equitable manner without discrimination. The abovementioned legislation and White Paper can assist youth with Down syndrome in accessing their right to employment. However, Dube (2006:10) points out a fundamental necessity for people with an intellectual disability:

Despite efforts by the Government to eradicate the marginalization of persons with Intellectual Disabilities, it remains glaringly evident. This is compounded by lack of confidence in their abilities and mere partial understanding their rights by some persons with Intellectual Disabilities.

The White Paper on an Integrated National Disability Strategy (INDS), (1997) specifically condemns the segregation of persons with disabilities from the mainstream of society. It emphasises the need for including persons with disabilities in the workplace, social environment, political sphere and sports arenas. (Department of Education, 2001:10). Furthermore, a report on the Economic Empowerment of Persons with Disabilities in South Africa (OSDP, 2009) suggests

that the INDS advocates for the mainstreaming of all disability related issues across all spheres, including employment and should be supported by employment equity legislation, subsidies, training, supported work, opportunities for gaining practical work experience as well as support services for employees and employers. Various policies and guidelines have been created in an attempt to address the need for meaningful mainstreaming in employment and economic opportunities for disabled people (OSDP 2009:4). These include:

- The 2% and 4% employment and training targets set by Government.
- The Promotion of Equality and Prevention of Unfair Discrimination Act (2000) which regulates the provision of assistive devices, accessibility and barriers.
- The Labour Relations Act (1995), which regulates incapacity in the workplace.
- The Employment Equity Act (1998), requiring reports on employment distribution from organizations employing more than 50 persons.
- The JOBACCESS framework, which addresses employment and retention of persons with disabilities within government, and makes provisions for peoples with disabilities to enter training, internships, learnerships and employment.
- The Code of Good Practice on key aspects of disability in the workplace, which provides guidance about practical equality in the workplace as outlined in the Employment Equity Act.
- The Handbook on Reasonable Accommodation for Persons with Disabilities in the Public Service, which provides technical specifications regarding reasonable accommodation.

In terms of the Skills Development Act of 1999, the Government created 24 Sector Education and Training Authorities (SETA). It is the responsibility of the SETA's to develop and implement skills development plans and learnerships (South African Info, 2008).

The transformation of skills development in South Africa and the Skills Development Act (SDA) arises out of the recognition that disabled people (and other previously disadvantaged individuals) prospects of employment need to be redressed through training and education. The National Skills Development Strategy (NSDS) was

designed with this in mind and to support disabled people. The current version covers 2005-2010' (Dube, 2005).

1.7 Employment and disability

In South Africa a very small percentage of the total number of disabled people are involved in various forms of work. This varies from unpaid work in a protective setting, waged work in segregated workshops, employment in the open labor market and even self-employment. However, the majority of people with intellectual disabilities, such as Down syndrome, remain in protective workshops and absorption into the open labor market remains low despite progressive equity legislation (OSDP 2010).

1.7.1 Decent work

Not all work can be considered desirable or decent work (CBR guidelines, 2010). The International Labour Organisation (ILO) defines decent work as:

Decent work sums up the aspirations of people in their working lives. It involves opportunities for work that is productive and delivers a fair income, security in the workplace and social protection for families, better prospects for personal development and social integration, freedom for people to express their concerns, organise and participate in the decisions that affect their lives and equal opportunity and treatment for all women and men (WHO, 2010:4).

1.7.2 Supported employment in South Africa

Many family members and young people with Down syndrome are not aware of the model of 'Supported Employment' or what a Job Coach is. Since employers do not pay for this service the onus of payment then often falls on the family or on the disabled person and they are therefore less likely to access this option. The easier and cheaper option is then placement in segregated settings or just to stay at home. Schoeman (2002:5) defines supported employment as:

Supported employment enables individuals with disabilities, including those with significant disabilities to be employed in real jobs in regular settings, where training and other supports are provided on an on-going basis.

Supported employment has enabled many individuals who would not have previously been able to access employment to now be employed in the open labour market.

1.7.3 Job coach

The role of the job coach is to facilitate the process between the employee and the employer who will conduct a Person Centred Plan (PCP) and invite family members to be involved in the process which enables the job coach to get in-depth information regarding the client. The success of the placement lies with the job coach. His/her role will further involve actual training while being employed. The coach will continue to attend work with the client until such time he/she has reached their goals and are capable of maintaining their work without the support of the job coach. Meanwhile the job coach would have also enlisted the assistance of fellow workers to provide support once the coach withdraws from attending. The coach stays in contact and will visit the client when necessary to clear up any problems (Schoeman 2002).

1.8 Community based rehabilitation

The objectives and guidelines (WHO 2010) of Community-based rehabilitation (CBR) form a framework and basis for this study. CBR promotes collaboration among community leaders, disabled people, their families, and other concerned citizens to provide equal opportunities for all disabled people in the community. In addition it assists with reducing poverty, empower and affirms one's human rights and promotes quality of life and total wellbeing of disabled people and their families.

The World Health Organisations (WHO 2010:11) report the major objectives of the CBR guidelines are:

- To provide guidance on how to develop and strengthen CBR programmes in line with the CBR Joint Position Paper and the Convention on the Rights of Persons with Disabilities.

- To promote CBR as a strategy for community-based inclusive development to assist in the mainstreaming of disability in development initiatives, and in particular, to reduce poverty.
- To support stakeholders to meet the basic needs and enhance the quality of life of people with disabilities and their families by facilitating access to the health, education, livelihood and social sectors.
- To encourage stakeholders to facilitate the empowerment of people with disabilities and their families by promoting their inclusion and participation in development and decision-making processes.

The CBR principles are based on the principles of the UNCRPD (2006) Article 3. The principles of the present Convention shall be:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- b. Non-discrimination
- c. Full and effective participation and inclusion in society
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e. Equality of opportunity
- f. Accessibility
- g. Equality between men and women
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

In addition the guidelines propose two additional principles. They are empowerment, including self-advocacy and sustainability (WHO 2010:31).

Although this study is not based on researching the objectives and principles of CBR the assumption is that if all children with Down syndrome had favourable conditions during their development, more youth with Down syndrome would be able to access employment in the open labour market which would enhance their quality of life and the objectives and principles of CBR would be met.

1.9 Problem statement

The Bill of Rights found in Chapter 2 of the Constitution of the Republic of South Africa (No. 108 of 1996), specifically has a human rights approach towards addressing discrimination against disabled people. However, despite this strong rights approach, the reality is that youth with Down syndrome and other intellectual disabilities are still finding it very difficult to access education and employment.

It is common practice for people with Down syndrome to be placed in segregated settings such as special schools, which are known not to sufficiently equip them with the necessary skills that prepare them for employment in the open labour market. This contributes to and results in many being placed in protective workshops. Not much is known about their aspirations in terms of employment, be it in the open labour market or in segregated settings such as a protective workshop. Furthermore, not much is known about the factors that influence or hinder their aspirations. It is also not known if youth with Down syndrome are aware of their rights around employment. Whilst policies which are important to people with Down syndrome in assisting them to overcome barriers and to have opportunities to be employed in the open labor market exist, these policies do not always lead to them or their families to knowing about or understand their rights or desire to be employed in the open labour market. People with Down syndrome remain unrepresented in the business world. This is mostly due to the fact that businesses and service providers do not see people with Down syndrome as employable. They believe that they cannot obtain or maintain jobs in the business community (Wehman et al, 1998). Through informal discussions with its members, Down Syndrome South Africa (2008) believes that of the 1.03% of disabled people employed in South Africa, 0% are people with Down syndrome.

1.10 Research Question

What are the factors that influence the aspirations of youth with Down syndrome related to employment?

1.11 Aim

The aim of the study is to determine the factors that influence the aspirations of youth with Down syndrome in relation to employment.

1.12 Objectives

1. To explore factors which hinder the aspirations of youth with Down syndrome to employment,
2. To explore factors which enhance the aspirations of youth with Down syndrome regarding employment,
3. To identify the role of schools in providing sufficient preparation for work,
4. To identify the role of protective workshops in providing sufficient preparation for work,
5. To determine whether youth with Down syndrome know and understand their rights in respect of employment, and
6. To recommend strategies to obtaining employment.

1.13 Rationale for the study

Autonomy for youth with Down syndrome has always been difficult to achieve as parents and other people in their lives often make the decisions for them. This study will allow the participants an opportunity to speak up for themselves and inform the researcher what factors have influenced their employment choices. The findings of the study will show how much influence the participants themselves have had in where they work and what work they are doing. This will help parents, employers and others that come into the lives of the youth with Down syndrome to know what these factors are.

Furthermore, the study will determine whether or not people with Down syndrome have sufficiently been equipped with the necessary skills during their schooling years, be it in segregated settings or mainstream, in order for them to be able to be employed in the open labor market. It also aims to determine whether participants have knowledge around the various forms of legislation and skills developments. Results of this study will be disseminated to the various stakeholders for use in policy development.

1.14 Purpose

The purpose of this study is to provide insight for various stakeholders, such as parents, government policy makers, employers, schools and segregated workshops regarding what people with Down syndrome actually seek related to employment once leaving school.

Families will be more informed as to what it is their disabled children want and the various opportunities that they may aspire to. Schools and protective workshops could better prepare themselves in relations to offering skills developmental programs suitable for individuals to gain employment in the open labour market and, government and employers could align policies and put strategies into place in order to employ youth who have an intellectual disability. Down Syndrome Associations nationally and internationally will also benefit from this study by informing their communities and families of the outcomes as well as encouraging further research with universities and researchers interested in the field of Down syndrome.

University of Cape Town

Literature review

2.1 Introduction

This section reviews the literature on the models of disability, Down syndrome, family members, expectations and attitudes, special needs education, protective workshops, transition from school to work, aspirations and employment and supported employment.

“I would like to be called by my name, not by what’s wrong with me”. A plea from Anna Souza, who has Down syndrome, and who, once employed at the national office of the Down Syndrome Association (UK), is now pursuing a career as a freelance artist (Newton 2004:1).

2.2 Youth with Down syndrome

As teenagers with Down syndrome move into their ‘youth’ years they are often struck with the reality that other family members, such as siblings and cousins as well as their siblings’ friends, are going to university, starting their careers, buying cars, having relationships, getting married and having babies and yet this is not happening for them. This often leads to anxiety and depression in young people with Down syndrome (Wertheimer 2003; Wehman, Targett and Neufeld, 2006). The Foundation for Persons with Learning Disabilities in the United Kingdom (Wertheimer, 2003:6) shows that:

Low self-esteem is common at this time, especially for people with learning disabilities who may become increasingly aware of the opportunities open to them are restricted than those of other young people.

Furthermore, the authors suggest that there needs to be a closer link between families, friends and professionals in order for people with intellectual disabilities to make the most of their teenage years and early twenties. Migliore et al. (2006:8)

describes families as being the ‘important parties involved in making decisions about the future of their sons or daughters with disabilities’.

2.3 Marginalization, expectations and attitudes

People with intellectual disabilities are reportedly the most marginalised group in society and remain excluded (Butcher and Wilton 2008, Schoeman 2002). Ward and Steward (2008) suggest that people with intellectual disabilities lives are viewed as being less valuable than non-disabled people. In general, people with Down syndrome abilities are underestimated and attitudes towards them are negative. Soriano, (2006:10) informs us that ‘all documents agree on this issue, teachers, parents, employers as well as the public in general underestimate the abilities of people with disabilities’. Dube supports this statement and suggests:

Translation of legislation is a slow process and perceptions towards persons with intellectual disabilities remain negative and derogatory. There is a great ignorance concerning people with intellectual disability and too little is done that is of meaningful benefit to them (2006:10).

A report on Barriers to Employment (Williams and Watkins, 2001:14) suggests that ‘assumptions that people with learning difficulties cannot work are deeply ingrained in attitudes, policies and practice throughout Europe. This situation is not exclusive to Europe and is very much the same here in South Africa. Negative attitudes and myths inform much of the discourse surrounding Down syndrome which can have a negative impact on policies. Gable & Gostin (2008:1) says:

Unfortunately, the perpetuation of these myths has resulted in continuing misperceptions regarding the reality of persons with mental disabilities and has contributed to enduring negative stereotypes.

2.4 Education in South Africa

The UNCRPD (2006:17) Article 24 on Education states:

States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of

equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning.

In 2009 the Department of Education reported that there were 25 906 schools and 6 197 other institutions which are made up of public ABET centres, ECD centres, public FET colleges, special schools and public HE institutions (DOBE, 2010). Today children with Down syndrome are accessing ordinary schools albeit in small numbers. Previously the inclusion of learners with Down syndrome in ordinary schools meant that they attended school with no special effort made in adapting the environment or curriculum to ensure that they were able to fully participate in the education system. Inclusive education is a system that acknowledges that all children can learn and accepts that all children have diverse needs. It also focuses on overcoming any barriers that learners may have in learning (DOE, 2001).

There are 111 619 learners with special needs attending special schools in South Africa (DOBE, 2010). The estimated number of learners with special needs that do not attend school is 467 005 (DOBE, 2010). Special needs education is a system that in the past has proved not to be conducive in preparing or equipping learners with special needs sufficiently or adequately in order for them to reach their full potential that would lead to meaningful employment in the open labour market. It is also a system where the 'ravages of the apartheid system remain most evident' (Department of Education, 2001:9). People with special educational needs find themselves in a disadvantaged position regarding employment in the open labour market.

Schoeman (2002:27) refers to special schools as, 'operating from a completely different premise' and suggests that the training young adults receive is often handwork and crafts which seldom leads to any paid employment. She comments: 'It is, therefore, not a cost-effective way of making use of skilled staff and expensive facilities'. The training is also done in simulated and segregated settings, which do not adequately prepare young adults for the real world of work. It also does not prepare them to be truly included in ordinary social life as valued and productive citizens (Schoeman, 2002:27).

2.5 Transition from School to Work

Transition is described in the Salamanca Framework for Action (UNESCO 1994:34), it states that:

Young people with special educational needs should be helped to make an effective transition from school to adult working life. Schools should assist them to become economically active and provide with the skills needed in everyday life, offering training in skills which respond to the social and communication demands and expectations of adult life.

There is the recognition that once leaving school, most individuals will either want to continue further education or get a job straight out of school and for disabled people this is a difficult task (Soriano, 2006). One of the most important transitions in life is from school to work and planning what to do next will 'lay the foundations for a satisfying life after full time education (Wertheimer, 2003:6). Transition from school to work continues to remain problematic for disabled people compared to non-disabled people (Phelps and Hanley-Maxwell, 1997) and very little attention is given to people with intellectual disabilities (Hall 2005 in Butcher and Wilton, 2008).

Transition from school to employment should include the full involvement of the student, families, and co-ordination between all the services and close co-operation with the employment sector (Soriano, 2006). However, for many youth with Down syndrome this remains and an elusive task.

2.6 Employment

The UNCRPD (2006:19) Article 27 work and employment states the following:

States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation.

It is extremely difficult for disabled people to gain any form of employment in the open labour market. This is often based on the assumptions that disabled people cannot do. Migliore et al. (2007) suggests that employers will not hire disabled people due to the assumption that their conditions are too challenging for regular jobs and that by placing them into workshops is easier than finding work in the open labour market.

Research shows that paid employment is an 'elusive goal for disabled people given the persistence barriers that exist such as lack of accessible transport, discrimination, and lack of skills and training' (Blackford et al 2000 in Butcher and Wilton 2008:6). Furthermore, Grantley, Brown and Thornley's (2001:34) research concludes as follows:

If people with Down syndrome and their parents are asked their opinion about current and future employment expectations and aspirations, they are quite capable to give positive and optimistic responses that are diverse and challenging. It is suggested that the preferences of people with Down syndrome, as well as those of their parents, are given high priority when considering employment opportunities, particularly in the selection of work experience and the location of those work experience placements.

Eggleton's (1999:96) study looked at the effect that employment had on the quality of life of the participants in Australia. He reports:

A job not only provides an individual with meaningful activity and a related pay packet, but also has the potential to affect their skills, self-esteem, social competency, autonomy, and a sense of well-being amongst others.

He continued by referring to Goode's research of 1989, which shows that disabled people want the same things in their lives, have the same needs and want to fulfil the same responsibilities in the same way as non-disabled people do (Eggleton, 1999:97).

The Ntiro project in Pretoria is a supported employment project which has focused on adults with intellectual disabilities that come from poverty stricken homes. The report on the project suggests that:

The employment of people with disabilities is an extremely complicated process and even the most trained people find it hard to get placements formalised. It should be realised that the concept of employment of people with intellectual disabilities is very new in South Africa as well as the concept of job coaching (Schoeman, 2002:24).

The report goes on to define people with intellectual disability as being:

The most marginalised group within the disability sector. Only a small percentage of children of compulsory school going age have had access to special schools. The vast majority of children have stayed home, often becoming victims of rejection, isolation, neglect and, at worst, abuse. Their segregation has compounded their marginalised status in society and has consequently led to very negative opinions of their ability (Schoeman, 2002:24).

A press release by The Down Syndrome Association of the United Kingdom (DSA UK 2008) reports that recent research shows that,

Less than one in five adults with Down's syndrome of working age are in paid employment'...18% of adults aged 18-60 with Down syndrome are in paid employment, this is nearly four times less than the general population of working age. Half of adults with Down syndrome are not working at all, either on a voluntary or paid basis. Two-thirds of those who aren't working would like a job. 19% of respondents are doing voluntary work, either through choice or because they cannot find paid employment. Many respondents stated that they felt let down by employment support services, or felt that potential employers could not see past the disability.

Carol Boys, Chief Executive of the DSA UK, is quoted as saying, “We firmly believe that adults with Down’s syndrome should have the same choices and chances as the rest of the population” (Down Syndrome Association UK 2008:1).

The figures in the Annual Report for 2006/7 (Department Public Service Administration, 2007) shows that only 0.78% of disabled people have been employed. The target for 2007 was increased to 2.5% and currently 1.03% of disabled are employed. Given these statistics, one can conclude that disabled people, despite quota’s and legislation, are still finding it difficult in accessing employment in the open labour market.

Gainful employment is a crucial component of one’s every day life and often it defines who one aspires to be, establishing an identity and a place in the community. Being unemployed discounts one from roles and activities in the community (Gottlieb, Myhill & Blanck, 2011). It is common practice for most people with Down syndrome to be placed into segregated settings such as protective workshops throughout their lives (Bird, 2000 and Migliore et al, 2006) and not many are seen working in the open labour market. When looking to employ a person with a disability many companies and government departments do not think of employing a person with an intellectual disability (Soriano, 2002). People with intellectual disabilities including Down syndrome are usually excluded from employment and schools pay little attention in the transition from school to work and to move them into the workplace (Morgan and Beyer 2005). Despite all the negative beliefs regarding people with Down syndrome the reality is that they are capable of learning. Today people with Down syndrome are achieving more such as appearing on television, in movies, giving speeches at conferences, completing school and going onto tertiary education (Wong, 2002).

2.6.1 Aspirations of employment

It is the opinion of many authors (Wehman, Targett and Neufeld, 2006, Wertheimer, 2003) that young adults with Down syndrome have talents, abilities and a range of needs, likes and dislikes just like other young adults do. Furthermore, disabled people report that they want to work. Respecting the wishes or aspirations of youth with Down syndrome is important. It not only recognizes them as the key

stakeholders in the decisions they make in their life about their employment choices, but enhances their self-esteem as well (Grantley, Brown and Thornley 2001). The authors further suggest that there is a danger by parents, teachers and young people with Down syndrome in the lack of knowledge that is prevalent and which could lead to restricted opportunities and choices in terms of their field of employment field.

2.6.2 Supported Employment

A great deal of literature exists regarding supported employment. Supported employment is a rehabilitation model designed to support people with severe cognitive, physical and psychiatric disabilities in accessing meaningful and paid work in integrated settings (Wehman et al, 1998, Bekker and Drake, 2003). The model of supported employment arose in the 1980's in the USA and was then adopted by the UK. However, it is now increasingly being used across the globe. It has also been referred to as the American or job coach model and came about as a result of the lack of services provided by sheltered workshops and day care centres in moving disabled people into the open labour market (Weston, 2002). In addition, Weston (2002:87) suggests that the supported employment approach can be seen as 'focusing on the needs of the individual's desires, aspirations and needs'.

The supported employment model has been hailed as one that is certain to change perceptions and attitudes around the abilities of people with intellectual disabilities in terms of employment. It brings people out of isolation into society, thus leading to being viewed as a worthy citizen. Bekker and Drake (2003) suggest that working in the community reduces disability, and the majority of disabled people want to be employed in integrated and competitive settings. It furthermore leads to self-development (Cramm et al 2009). The model is used by employment agencies for people with developmental disabilities and parent organisations who stress the importance of job matching. This can be done by getting to know the person, identifying their aspirations, personality, individual skills and former experiences of job interests. This process is called the Person Centred Plan or PCP information. This information is important in ensuring that individuals are placed in the correct place of employment (Foundation of people with learning disabilities, 2007). Although the supported employment model has successfully been implemented in the developed countries it is still a relatively new concept here in South Africa.

Positive examples of best practice of how disabled people have succeeded at work in the open labour market may help to inspire individuals (Wehman, Targett and Neufeld, 2006).

2.7 Protective Workshops

Protective workshops were established during the apartheid era as a place for sheltered employment for disabled people who could not access employment (DWDE, 2010:3). The Department of Social Development (2007) reports that:

These workshops did little to improve the quality of life of people with disabilities and develop a sense of dignity and respect amongst, and for, people with disabilities nor did it attempt to tangibly develop the abilities and skills of people that participated in these workshops.

A study conducted in 1988 on 175 protective workshops was commissioned by the then Minister of Welfare and Population in order to guide policy and ensure developmental services be provided as well as structure and functioning. The findings showed that they were extremely expensive to operate and far from financially self-sustainable, generally not well managed, do not enable workers to earn decent income, serve only a minimal percentage of the disabled population and promote marginalisation and institutionalisation. The policy further reports that not much has changed since then and protective workshops are still functioning very much the same today (DOSD, 2007).

The Department of Social Development's policy on the Management and Transformation of Protective Workshops reports that approximately 22 000 people in South Africa make up the workforce in protective workshops and reports: 'The current approach of protective workshops is out of sync with the current dispensation or developmental approach to addressing disability' (DOSD, 2007:9). This policy is meant to reinforce the Department's commitment to fostering human rights, promoting social justice and the development of self-reliant individuals.

In general, most workshops do not sufficiently skill disabled people. These workshops do not form part of the mainstream economy as disabled people do not earn minimum wages (DWDE, 2007).

Migliorie, et al, (2007) informs us that activities in protective workshops in the USA are limited to mundane tasks which are relatively easy to learn and is repetitive. Here again, qualifications gained in such settings limits choice in accessing meaningful employment in the open labour market. He further suggests that these workshops were to support people whose conditions were 'too challenging' and therefore they could not be employed in the open labour market. Many people placed in these workshops are 'unlikely to lose that placement' which results in long waiting lists. (Migliorie et al, 2007:6). Butcher and Wilton (2008:5) suggest that 'some authors point to the potential benefits associated with this form of work organisation', which includes pride and 'training geared towards progression to employment'. However, he continues to inform us that critics put down these benefits as 'being outweighed by disadvantages' due to the fact that the workshops 'isolate the individuals from the mainstreams society.' It can be argued that workshops are exploitive, because the rate of pay is so low.

2.8 Summary of Literature Review

In summary, this chapter has provided a clear literature review of the situation of employment and Down syndrome internationally as well as nationally. It has provided information which shows that people with Down syndrome aspire to work. Using the model of supported employment youth with Down syndrome's aspirations can successfully be met. The chapter reviewed the situation of protective workshops in South Africa.

My message to all of you is to keep your minds open to the idea that we should be able to make our own choices. If young people with Down syndrome are given opportunities to have many experiences in life, we will be better prepared to make decisions for ourselves. My advice to you is to encourage children and young adults with Down syndrome to have dreams and goals and to believe that success comes from belief in ourselves. (Levitz, 1995:248)

Methodology

3.1 Introduction

This study was conducted using a qualitative research paradigm, specifically a collective case study. Data generation was done through semi structured interviews.

3.2 Research design

Qualitative methodology was used for the study due to its naturalistic approach. Broadly defined qualitative research means any type of research that produces findings not arrived at by statistical procedures or other means of quantification (Strauss and Corbin 1998:11). Furthermore, Strauss and Corbin (1998) claim that this approach can be used to better understand any phenomenon about which little is yet known. The qualitative method can also be used to gain new perspectives on things about which much is already known, or to gain more in-depth information. Denzin (2005:5) refers to qualitative research as 'attempting to make sense of or to interpret phenomena in terms of the meanings people bring to it'. This design is relevant to the research topic which is about a person's lived experiences, their aspirations, emotions and feelings.

3.3 Collective Case Study

Collective case study was done in order to provide the researcher with limited number of variables and ask 'how' and 'why' questions. Yin (2003:7) suggests that it is important to identify in the early stages of the research the type of questions that will be asked. When using 'how' and 'why' questions he suggests using case studies. 'The case study method allows investigators to retain the holistic and meaningful characteristics of real life events – such as individual life styles' (Yin, 2003:2).

Creswell (2003:15) refers to case studies 'in which the researcher explores in depth the programme, an event, a process, or one or more individuals'. Furthermore, Stake 1995 (in Creswell 2003:15) describes case studies as 'bounded by time and activity'. The case study design helped the researcher to investigate the aspirations and

experiences of youth with Down syndrome within their current work context (Yin 2003).

3.4 Population

The study was done in partnership with and the support of Down Syndrome South Africa, which is the national umbrella body of all Down syndrome associations in South Africa. Youth with Down syndrome who are members of the Down Syndrome Association of Gauteng formed the study population.

3.5 Purposeful Sampling

Purposeful sampling was used to select participants. Of the six participants, half are currently employed in the open labour market and the other half work in segregated settings such as protective workshops. They were chosen due to their ability of understanding what the research is about and willingness to participate, thus capable of giving consent. Down Syndrome Association of Gauteng was approached for names of individuals with Down syndrome, to be interviewed. Using this approach allowed the researcher the opportunity of gaining multiple perspectives of the situation (Butcher and Wilton, 2008). The parents of the participants were also invited to participate in the interviews. Their participation involved adding more in-depth information or explanation to what their son or daughter had said. This also made the participants feel more at ease. Participants met the following criteria:

- Currently working in open labour market or protective employment
- Older than 18 years of age
- Male or female
- Has Down syndrome
- Member of Down syndrome South Africa
- Resides in Gauteng

Language was not a criteria in this study. Five of the participants were English speaking and one participants home language was Afrikaans. His interview was conducted in Afrikaans and translated verbatim and simultaneously to English.

3.6 Data Generation

Data generation consisted of semi structured interviews in order to gather all data in establishing the aspirations of youth with Down syndrome in terms of employment.

3.6.1 Semi Structured Interviews

Semi structured interviews were conducted with each participant individually and thereafter follow up interviews. These methods for data generation were applied due to the nature whereby the interviews and discussions were more general and not formally structured. Barrio (1999:2) describes semi structured interviews:

As the aim is to capture as much as possible the subject's thinking about a particular topic or a practical task, the interviewer follows in depth the process of thinking posing new questions after the first answers given by the subject.

The interviews were conducted in the homes of the participants and took approximately an hour and a half per each participant. An interview schedule was used to guide the researcher with follow-up questions and probes in order to gain richer answers (see appendix F). A preliminary analysis allowed the researcher to prepare for the follow-up discussions in order to draw out more information and member checking. The researcher conducted the interviews along the format of a two-way conversation which made the participants feel at ease and helped to draw out their views, opinions and experiences. All participants were asked permission if the interviews can be recorded to which none objected (Audio recording only). This allowed the researcher to observe the participant and make note of any non-verbal expressions and gestures. This data generation was done over a two month period.

3.7 Data Analysis

All interviews were transcribed verbatim. The researcher read through all data to gain an overall feeling and meaning of the information. The objectives provided a thematic framework for manual coding of data (Cordin and Sansbury, 2006). A preliminary analysis was done of each participant individually to identify categories that were verified in follow up interview with each case i.e. the participants in the open labour market and those in protective workshops. A second level analysis was

then done and categories were collapsed to integrate findings across participants in the open labour market and protective workshops.

3.8 Rigour

The researcher applied the following methods to ensure the quality and rigour of the study:

- a) **Dependability:** - The researcher made use of field notes and a diary from the onset of the research in order to record important information, logistics, and ideas of the research. This was done in order to assist the researcher by referring to her notes and diary whilst data analysis was being done.
- b) **Credibility:** - Member verification was done through follow-up interviews to allow the participants to read and confirm the accuracy of the researcher's interpretations from the interview data. It also provided an opportunity for participants to clarify or add further information which they would like to share. Member checking helped to ensure that misinterpretation of the data was corrected.
- c) **Transferability:** - The researcher has provided a 'thick description' of context and participants so that other researchers may apply 'the findings of the study in context similar to the context in which they were first delivered' (Henwood and Pidgeon 1993).
- d) **Confirmation:** - The researcher kept a clear distinction between her values and those of the participants by being aware of her biases and preconceptions. She also had regular dialogue with her supervisor to ensure confirmation.

3.9 Ethical Considerations

Youth with Down syndrome are regarded as having mild to moderate intellectual impairment. This was taken into consideration during the research process.

The researcher included strategies applied by Stalker (1998) in the research study on people with learning disabilities. Apart from getting to know the participant beforehand, she also advises:

People (participants) should be invited to set out their own terms and conditions and, as far as possible given the power differentials involved, a genuine process of negotiation needs to take place about the implications involved on both sides (Stalker, 1998:17).

The study was conducted in a manner that complies with the ethics of confidentiality. A research information sheet, which contained information regarding the study as well as a request for permission form was given to Down Syndrome Association of Gauteng (Appendix A) and the participants (Appendix B) along with the consent form (Appendix C). The Down Syndrome Association of Gauteng signed the consent form and gave names of possible participants to the researcher. She then contacted them telephonically and explained the study to the parents and the participant. The parent then had time to further explain the study and interview process with the participant until the day of the interview, thus giving the participant sufficient time to ask questions and withdraw prior to the interview if they wished to do so. This, fortunately, did not happen and all participants were excited about being involved in the study. On the day of the interview the researcher again explained in simple language what the study was all about and gave the participants an opportunity to ask any questions pertaining to the research. Informed consent was sought from all participants (see appendix D). The participants were informed that their participation in the study was voluntary and they were further informed that should they so wish to, they could withdraw from the study at any time and the researcher would respect their choice to do so. They were also informed that they would remain anonymous and this would be guaranteed by the use of pseudonyms. Data was stored safely and was not divulged to any persons other than my research supervisor.

All interviews were done with consideration and respect of the participants. Furthermore the researcher adequately felt equipped to conduct this study (please refer to Appendix G – information about the researcher) and did not foresee any limitations. In the event of participants wanting more information regarding employment or any other information, she willingly did so.

Permission to undertake this study was sought from the Faculty of Health Science Ethics Committee at the University of Cape Town, Down Syndrome South Africa and from the Down Syndrome Association of Gauteng based in Johannesburg.

3.10 Profile of youth with Down syndrome as participants

Table 1: Summary of the participants at a glance

Name	Taylor	Sheldon	Noel	Tess	Larry	Eugene
Age of participant	26	25	27	23	26	26
Gender	Male	Male	Male	Female	Male	Male
Place of residence	At home with his mother and siblings	At home with his grand-Mother	At home with his parents	At home with her mother	Segregated residential home	Segregated residential home
Place of employment	National department store	National hardware store	Bird park	Protective workshop	Protective workshop	Protective workshop
Type of education	Ordinary for one year and special	Special only	Ordinary and special	Special only	Ordinary for one year and special	Special only
Type of employment	Cleans and packs meat in the butchery	Cleans and packs hardware equipment onto shelves	Feeds birds and reptiles and cleans cages	Packs bandages and gloves for first aid kits	Packs hose pipe fittings and cleans garden at hostel	Packing boxes and sealing plastic bags
Salary/wage	Yes	Yes	Yes	No	No	No

Taylor

Taylor is a shy 26 year old male. He lives at home with his divorcee mother and two younger siblings in Germiston, Gauteng. He attended a mainstream school for the first year of his schooling years as his mother wanted him to attend the local school. He was then placed in a special school where he stayed at this school until he was 20 years old. He works at the local supermarket of a national chain in the butchery, cleaning and packing meat. Taylor walks to and from work. He is a competitive swimmer and has won the title as Top World Male Down Syndrome Swimmer twice. He is also a Special Olympics swimmer. Taylor started swimming when he was a year old as a form of therapy and has been swimming ever since.

Sheldon

Sheldon is a 25 year old male who lives with his grandmother in Johannesburg. He has no contact with his parents. He and Taylor are close friends and swim together and spend most weekends with one another. Sheldon attended a special boarding school until the age of 22 years in Kwa'Zulu Natal, which he intensely disliked. He currently works at a local hardware store, two days per week, where he packs and cleans the shelves. Sheldon has done very well in swimming both nationally and internationally and also swims in the Special Olympics. He is independent to the extent that he locks up after himself in the mornings and walks to and from work.

Noel

Noel is a 27 year old male who lives at home with his parents in Johannesburg. He is the middle sibling of three boys. He attended both special and integrated schools. Noel loves animals and works at a bird park where he cleans the cages and feeds the animals. His parents transport him to and from work. He is a keen golfer, loves working on the computer and researching films and movie stars.

Tess

Tess is a 23 year old female who lives at home with her mother and elder sister. She attended a special school from when she was 6 months old and moved over to the protective workshop when she was 18 years old. She mostly does embroidery, sewing and baking for the fetes at the protective workshop. She also packs

bandages, etc. as contract work for the workshop. She enjoys helping with the dishes and setting the table at home.

Larry

Larry lives at a hostel and works in the protective workshop and is sometimes collected by one of his parents on weekends since they are divorced. He attended special schools for the majority of his schooling years (apart from the first year). He packs garden tools as part of the protective workshop contract work. He also does garden work at the hostel where he stays. He enjoys helping in the house on weekends when he does go home.

Eugene

Eugene lives at a hostel and works in the protective workshop. Eugene attended special school and did very well. He excelled in sports at school and was head boy in the last year of school. He went to live with his father in Cape Town for a year when he left school and worked in a restaurant and a pet shop. He then returned to Johannesburg to his mother and he was then placed in a protective workshop where he packs boxes and does woodwork. After some time he decided that he wanted to live at the hostel to be closer to his friends.

3.11 Summary of Methodology

In summary, this chapter has provided information of the structure and background information about the participants. The following chapter looks at the findings as a result of the interviews conducted with the participants.

Findings

4.1 Introduction

This chapter looks at the findings and themes which have emerged from the data analysis. Four themes emerged which are reflected in the table 4.1.1 below and are described in detail in this chapter.

Table 2: Themes and objectives

Themes	Theme name	Objective
Theme 1	Challenges to employment	Factors that hinder employment for youth with Down syndrome
Theme 2	Making work, work	Factors that enhance employment for youth with Down syndrome
Theme 3	Prepare and teach them well	Role of the school
Theme 4	<i>Lift their potential</i>	Role of Protective Workshops

4.2 Theme 1: Challenges of gaining employment

This theme reveals the challenges of gaining employments and looks at the limited prospects, administrative blocks and family matters experienced by the participants and their families in accessing employment as the factors that hinder this process. As one participant so aptly said "*It's very hard to find work*".

Table 3: Themes and categories related to factors that hinder employment

Theme 1	Categories	Subcategory	Code	
Challenges of gaining employment	Limited prospects	Misplaced job matching	<i>He would not put effort</i>	
			<i>How boring</i>	
			<i>Would be a disaster</i>	
		It's hard to find work	<i>They were adamant</i>	
			<i>Don't deal with it</i>	
			<i>Nobody was interested</i>	
			<i>They did not want to do it</i>	
			<i>It's just such a challenge</i>	
			Minimal expectations	<i>Society's way of reacting</i>
				<i>There has got to be more</i>
	<i>Sit back and accept that</i>			
	<i>You have to accept their limitations</i>			
	Administrative processes block the way	Weak policy translation	<i>Rules and regulations</i>	
			<i>The guy said Matric</i>	
		Feel disempowered	<i>Very clever</i>	
			<i>The way they word it</i>	
			<i>They are discriminating</i>	
			<i>Disabled kids are the last option</i>	
			<i>Cannot point a finger</i>	
			<i>Handled by Cape Town</i>	
Family matters		Future living arrangements	<i>Find somewhere where he could live</i>	
			<i>So far we have not managed</i>	
	<i>It is a big concern</i>			
	<i>When we get old we won't be much fun</i>			
	Stereotypical	<i>He would never get a job</i>		

preconceptions	<i>That's the limit</i>
	<i>He must have routine</i>
	<i>Stick to the same things</i>
	<i>Won't want to go on holiday</i>
	<i>Lack of expectations</i>
Parental tension	<i>A kid of that age</i>
	<i>It was dreadful</i>
	<i>He used to get so sick</i>
	<i>It was difficult</i>
	<i>Not the right option</i>
	<i>No one of his social standing</i>
	<i>Bachelor life with a child like this</i>
	<i>He sees the outside world as difficult</i>
Parental resistance	<i>Mothers seem more able with this kind of thing</i>
	<i>I was reluctant to let him go</i>
	<i>What our divorce was all about</i>
	<i>We could not agree</i>
	<i>Wanted to try an ordinary school, too much stress</i>
	<i>They are never near your home</i>
	<i>Do you uproot your entire family</i>
	<i>It used to rankle me quite a bit</i>
Being over protective	<i>I don't think I would let her</i>
	<i>She is a girl</i>
	<i>You do become over protective</i>
	<i>I have a fear</i>
	<i>She is a trusting person</i>

4.2.1 Limited prospects

The participants employed in the open labour market experienced challenges in accessing employment in the open labour market. Noel found challenges by almost being **misplaced** job matching. His mother spoke about their experience with an employment agency [service provider] for people with intellectual disabilities whilst trying to access employment in the open labour market.

They interviewed him and got....an interview for him at [national tile company], because I said it had to be fairly local for us to fetch and carry. We looked at this there and I said well what will he do there? They said well he would do filing and faxing. The more I thought of it I thought how boring and the more I thought Noel would be bored the more he would not put effort into it and then it would be a disaster from his perspective and from the employers. I thought it would not be good. (Noel's mother)

She felt that Noel would be placed in an environment that would not be suitable to him and that he would find the job boring. It was then that the supported employment agency came to spend some time with Noel and his parents to find out more about him and conducted a 'person centred plan'. It was only once the person centred plan had been done that the job matching took place and Noel was then placed in the correct working environment.

Sheldon spoke about how he could not find work and said, ***"It's very hard to find work"***. His grandmother had made several phone calls to *"[national department store... they were adamant they don't deal with it]"* [employing people with intellectual disabilities] (Sheldon's Aunt). In this instance Sheldon found that the company would not even look at the possibility of employing him because he had Down syndrome. His aunt recalls, *"nobody was interested in [employing] him"*.

Eugene's mother spoke about being in the recruiting business and the resistance she met when she suggested that a certain company employ a person with Down syndrome.

The other day we had an opportunity for a disabled person to do some shredding for a company and I phoned the director and asked him if he thinks that there is someone we can give an opportunity to get out there and maybe get a little bit of experience. They didn't want to do it because there are different sorts of situations that can come up and all that and then it made me think... about the challenges out there. Letting a person out of your sight on someone else's premises and not having the buy in and the understanding might do more damage. It's just such a challenge for society and the community to integrate.

Larry's father felt that because of **minimal expectations** by the protective workshop Larry has become withdrawn.

He used to be so outgoing, well it's the opposite now. I think it is with society way of reacting to him.

He further felt that there needs to be more for disabled people. He spoke about the lack of services being provided for people with Down syndrome as well as a lack of possibilities.

I just feel there has got to be more you know...everybody is just too keen to say okay that's it...that's the limit, sit back and accept that. (Larry's father)

4.2.2 Administrative processes blocks the way

Parents felt that there has been **weak policy translation** by employers which leads to administrative processes that block way for employment of youth with intellectual disability particularly in the open labour market. A major concern for Taylor's mother was the discrimination towards intellectual disabled youth by the way companies made "*rules and regulations*" which leave them at the bottom of the list. When Taylor's mother first approached Taylor's employer and asked what was needed to be employed by them and the "guy said Matric".

Parents **felt disempowered** by the decisions made by the companies they approached. Sheldon and his aunt spoke and related some of these barriers to employment.

They are very clever especially in the way they word it, so that you cannot point a finger at them, they are being discriminating. All they say is that employment is handled by Cape Town, and when you live in Randburg...so they just put administrative blocks in your way...Disabled kids are the last option. (Sheldon's Aunt)

It was only once Taylor's mother informed the company that he had Down syndrome and that he was prepared to do packing or cleaning that they considered employing him.

4.2.3 Family matters

Noel's mother spoke about her concern as to what will happen to Noel when they get older and his **future living arrangements**. Noel spoke about being happy to stay on with his parents, however his mother's major concern was what would happen to him once they had passed on.

It's a big concern, when we get old, we won't be much fun. We would like to find somewhere where he could live with other young people. We have tried to get something worked out with some other parents but so far have not managed. (Noel's mother)

She furthermore spoke about the **stereotypical preconceptions** that other people have of youth with Down syndrome.

Things we were told when Noel was born is that he must have routine and stick to the same things and that he won't want to go on holiday and he won't want to go to different places and so I thought no that is not going to suit us and so we made a point of doing this here and there and everywhere as much as what we could.

She also referred to the limitations which are often placed on children with Down syndrome which parents accept as the norm. These limitations did not suit Noel's mother and they continued to live their life as normal as possible.

Now it's Noel... if we are going to go out for dinner he says lets go somewhere new and I'm delighted with that because it just shows he can be flexible and that things don't have to be in a routine, and I think we have a lot of stereo type of expectations or lack of expectations and it just shows that it doesn't have to be. (Noel's mother)

Larry's father spoke about how dreadful it was to send him away and how he [Larry] continually got sick. He also spoke about how demoralised he felt having to send him away at that age and how this caused **parental tension**.

He stayed at home for a while and then his Mother found a school for him in Pietermaritzburg. It used to be a nightmare, a kid of that age...he got so sick, it was dreadful. And when we came back here to South Africa we got him into [special school] and we used to bus him in and out.

Eugene's mother explained that after he left school he went to live in Cape Town with his father for a year. During this time he worked one day a week for a short period at a bird sanctuary due to the fact that "the owner took pity on him". On the days that he did not work he would go with his father to his shop. However his mother felt that the situation was not suitable. She said,

It was difficult for my ex-husband to keep him there because he stayed in Hout Bay and he could not go over the pass and so he had to go around the mountain and it took a really long part of his day.

For a bachelor life with a child like this it did not really work out...mothers seem to be more able with this sort of thing.

It was a concern for his mother that he had no friends that he could relate to.

It was not the right option. It did not work out as there was no one of his social standing. Someone he could feel comfortable with.

It was then that he returned to his mother in Johannesburg and was placed in a protective workshop with a residential home. His mother saw that this was the best option for him as *“he sees the outside world as difficult....he feels protected here”*.

Larry's father showed **parental resistance** when his ex-wife wanted to send Larry to a protective workshop to work and live in the hostel. He felt that the protective workshop was not the best option for Larry and wanted to keep him at home with him.

That is actually what our divorce was all about, if you analyse it to the nitty-gritty, we split apart at that stage because we could not agree about it. I was reluctant to let him go. In fact our maid left here and went and worked there and she lived in the room next to his for the first six months and then she got another job. (Larry's father)

Taylor attended an ordinary school for the first year of his schooling years as it was close by from where they lived. His mother *“wanted to try an ordinary school and not to have too much stress”*. She felt that the ordinary school was not prepared to include him and that was when he was sent to a special school.

Somehow [special schools] are never near your home.....do you uproot the entire family for the sake of one child?...The fact that you wouldn't normally have to put your other child on the bus at 6am in the morning cause that was the only way of getting the child to school it used to rankle me quite a bit. (Taylor's Mother)

Sheldon's aunt explained that because of the travelling to and from school the best option was to send Sheldon to boarding school so as *“not to have the stress”*.

Tess is a girl which made her vulnerable. Her mother felt that she was **being over protective**. She preferred that Tess be in a protective environment.

I think you have parents who would like that for their children to work out in the open environment and then you have parents who would rather have their children in a protective environment. It's just a matter of choice. I don't think I would actually...you are going to have people choosing to go that route and knowing that their children are capable of going that route and then you are going to have people who prefer the protective environment for the simple reason that she is a girl...a short little girl and the mentality is there but it [she] cannot actually protect itself. I think that will just have to be up to the parents. I don't think that they are actually capable of decisions like that.

She further spoke about her reasons for being overprotective.

I don't leave her if she goes off to the toilet and things like that, 'cause I have a fear that she will get lost or someone might just walk off with her for the simple reason that she's a very trusting person and just loves everybody.

Tess's mother also believes that there are some people with Down syndrome who are very limited in their abilities, which need to be accepted.

You have very limited Down syndrome children where I believe that you have to accept their limitations and I don't say that she couldn't go out and work... but I'm just over protective maybe, especially because she is female. (Tess's mother)

She strongly felt that Tess was not capable of being employed in the open labour market as she feared for her safety.

"I have a fear that she will get lost or someone might just walk off with her for the simple reason that she is a very trusting person...and just loves everybody".

4.3 Theme 2: Making work work

The following theme explores the factors that enhance the aspirations of youth with Down syndrome and their families in relation to their experiences of employment and looks at the participants' hopes and dreams, their desire to work, gaining employment, family issues and positive handling.

Table 4: Themes and categories related to factors enhancing employment

Theme 2	Category	Sub-category	Code
Making work work	Hopes and dreams	Inspired by others	<i>I listened to that guy</i>
			<i>I was so enthusiastic</i>
			<i>There is so much that can be done</i>
			<i>She became more aware</i>
		Aspirations to work	<i>Likes to do painting and woodwork</i>
			<i>I like to work on the machines</i>
			<i>Desperately wanted to be a waiter</i>
			<i>He wanted to drive</i>
	Develop a worker identity	Self motivated and content	<i>They have to stop him from working</i>
			<i>He doesn't like to just sit and do nothing</i>
			<i>She is quite independent</i>
			<i>I have to go to work</i>
			<i>He decided by himself to come to the hostel</i>
			<i>It's time I look after myself now</i>
		Sense of responsibility	<i>He doesn't want to miss a day</i>
<i>He feels that it is important to work</i>			
<i>He is the only person that can do a certain task</i>			

			<i>It's his job</i>
			<i>He wants to do it</i>
		Desire to work	<i>He is very proud of the fact that he can do it</i>
			<i>He loves his job</i>
			<i>Close friends from the workplace</i>
			<i>All her friends are here</i>
			<i>We were delighted that he had a suitable job</i>
Social agency for change	Generates social interaction		<i>Worked in a lovely environment</i>
			<i>Thank goodness I don't have to stay at home anymore</i>
			<i>I don't have to run around anymore</i>
			<i>I have just trusted</i>
			<i>We always have a lot of fun</i>
	Being proactive		<i>It just go my back up</i>
			<i>It made me more determined</i>
			<i>What can I do?</i>
			<i>She started phoning around</i>
			<i>She tried</i>
			<i>First Gran talked to the boss</i>
	Making life easier		<i>Save me from having to take her</i>
			<i>I don't think I could have managed</i>
			<i>They helped tremendously</i>
			<i>Wanted to try a normal school</i>
Gaining employment	Prior training		<i>He did a six month course</i>
			<i>Yes the agency did help</i>
			<i>Trained all employee's and staff</i>
			<i>They started to teach him</i>

			<i>Very good about teaching him</i>
		Self determination	<i>Sheldon showed initiative</i>
			<i>I work hard</i>
			<i>What he does he does well</i>
			<i>I own key</i>
			<i>I lock door</i>
			<i>I went to ask them</i>
			<i>Can I have a job</i>
		Disability awareness	<i>The community is being accepting</i>
			<i>Keep the community aware</i>
			<i>Police community are aware</i>
			<i>Being a good swimmer has helped</i>
			<i>I explained about the whole thing</i>
		Understanding abilities	<i>They don't let him touch electronic equipment</i>
			<i>Make allowances for his personality</i>
			<i>Tolerate mistakes</i>
			<i>Wife who worked with handicapped kids</i>
			<i>He was sympathetic</i>
			<i>He was dealing with someone of less intellect</i>
			Positive handling
		<i>Keep an eye out for him</i>	
		<i>They don't let him be lazy</i>	
		<i>Don't let him get hurt</i>	
		<i>Don't let him loaf</i>	
		<i>They treat me very nicely</i>	
		<i>Tolerant of his hugs</i>	

4.3.1 Hopes and dreams

Some parents reported that they felt **inspired by others** when they saw examples of best practise to employment. Larry's father spoke about how enthusiastic he felt when he attended a seminar by an international speaker who was an expert in supported employment for people with intellectual disabilities and spoke about the model of supported employment and job coaches.

When I listened to that guy I was so enthusiastic and I thought you know, there is so much that can be done but it can only be done if the people around all acknowledge it and are there to put in the hard work and to me the rewards must be, well they are huge, I know just from little things that I have managed to make him feel more independent.

Sheldon's aunt reported that he desperately wanted to get a job in the open labour market when he saw that Taylor was working. *"I think being involved with Taylor, he became aware"*.

The participants reflected on their **aspirations to work**. When asked if Larry could do anything as a job, what was it that he could like to do, he commented *"I like to cook, wash the dishes...paint the table, I like to do woodwork"*.

His father commented,

He likes to do painting and woodwork. I think just about every table in the house has been sanded and painted. I am always trying to think of more to give him to do. His brother and I are keen on making knives and....but some of the machines are dangerous.

Larry responded by saying, *"Ya, I like to work on the machines, they are nice"*.

Eugene and his mom spoke how he desperately wanted to be a waiter as well as a driver. His mother spoke about what a good sportsman he was at school and said he also wanted to become a professional sportsman.

He desperately wanted to be a waiter and he wanted to drive, he wanted to be able to drive but unfortunately that's ... that is something he really wanted to do....he knows he cannot play rugby but he would like to play cricket for South Africa.

4.3.2 Developing a worker identity

All participants showed initiative and responsibility towards their work by being **self motivated and content**. Larry's father explained that Larry is often told to stop working and break for lunch and tea. He further expanded how he does not enjoy just sitting around doing nothing and likes to keep himself busy. When he comes home on weekends he often finds plenty of work to do such as painting and woodwork.

They say sometimes they have to stop him from working, 'cause if it's lunch time or something and sometimes he wants to keep on working hey....even when he is at home...he doesn't like to just sit and do nothing, he likes to have jobs to do.

Tess's mother spoke how she is quite independent at home and that she will not take time off and says,

She actually loves it here and I promise you I can offer her the world and she tells me I have to go to work.

Eugene showed initiative by informing his mother that it was time for him to stay at the protective workshop hostel.

When there became one place available here at the hostel he decided himself to come to the hostel, he said to me that it is time that he looked after himself now, he must carry on with his life and he's got things to do. (Eugene's mother)

Eugene has a great **sense of responsibility** towards his job and does not want to miss a day's work. He feels very protective towards his job and feels that he is the

only one that can do that job. He takes great pride in what he does and he loves his job. He also has a close friendship with all his fellow workers.

The main thing about the work is that it's always like that, even when he is home at the weekend. He doesn't want to miss a day he feels that it is very important to work. You know that feeling that it's not ethical not to work and not to stay home and that is somehow in him. He feels that sometimes he is the only person that can do a certain task here. I don't know if that is even true but that is the way he sees it. He is very jealous of his job. It's his job and he wants to do it.

The participants and parents spoke about job satisfaction and their **desire to work**. Eugene's mother said,

He is very proud of the fact that he can do it and it's really a battle to keep him home if he is sick. He loves his job.

Tess loves going to work at the protective workshop and is very happy there and does not want to do anything else or work anywhere else. She also likes the fact that all of her friends work at the protective workshop as well.

I think it also the social side of it. You know all of her friends are here and they have become very close. (Tess's mom)

4.3.3 Social agency for change

The following findings show activities which **generates social interaction**.

In Noel's case his parents were thrilled that Noel was placed in a suitable employment, which put their minds at ease. His mother said, "*We were delighted that he had a suitable job in a lovely environment*".

Since Noel always tried to keep himself quite busy during the day it was a relief for his family when he was finally employed. Noel himself said "*Thank goodness I don't have to stay at home*".

Taylor's mother spoke about the awareness of Down syndrome in his place of employment. By knowing that people are aware of her son is reassuring for the entire family.

I don't run around in a flat panic. I have trusted that... (Taylor's mother).

With the community awareness in place and the fact that they have taken it upon themselves to keep an eye out for Taylor, she trusts that he will be taken care of.

Being proactive was a fortitude shown by the participants and their parents. Here Taylor and Sheldon show what they did to gain employment in the open labour market.

Taylor was an excellent swimmer and much effort was put into that and not so much on getting him to read and write. Taylor's mother was told by a friend that because of the effort that had been put into his swimming that, *"he would never get a job"* which *"just got my back up"*. This made her more determined to find him a job and show that even though he could not read and write, he could still be employed.

Sheldon was impressed by his close friend Taylor being employed in the open labour market and he too wanted to work. His grandmother asked Taylor's mother *"what can I do"* to go about getting a job for Sheldon. Taylor's mother had informed her of what to do and also helped her by phoning around to various companies. *"First she tried at [a national department store] and some of the other shops in the centre.* Although nobody was interested in employing him they were determined to get him a job. They did not give up and kept on trying to access employment in the open labour market.

4.3.4 Gaining employment

Prior training ensured sustained employment for Noel and Taylor. Noel attended a six month skills development course which consisted of *"Dressing skills, social skills, cleaning house skills...cooking and preparing the table and those things"*. When Noel's mother was asked if she believed this helped him in his employment, she replied *"Yes it does help...it does help very much"*.

Taylor's mother spoke about the teaching and training of Taylor.

The staff at the butchery has been very good about teaching and training him what to do. (Taylor's mother)

Furthermore, she spoke about how his boss took it upon himself to teach him, but does not let him handle dangerous equipment.

He started off just cleaning meat initially and then they started teaching him how to debone the meat, but he all trained within the environment and then slowly the packing and labelling...he is not allowed to touch electronic equipment, they keep him away from that.

Sheldon showed **self-determination** which helped him to gain employment by using his own initiative. When asked how he got the job, Sheldon boldly replied, "I went to ask them". His aunt explained that he was not employed as a result of the company having to fill their scorecard or out of pity. She went onto to say,

Sheldon showed initiative, he appealed to the right person at the right time...he asked can I have a job and they said yes. He has a job to do and what he does, he does well.

Sheldon spoke about his responsibilities towards his job and said that he uses his own key to let himself in and out of home and walks on his own to work.

I own key. I lock the door. I listen to my music...walking down the road, then I go to work...I work hard.

Sheldon is proud that he has a job and said that he has fun at work, has made lots of friends and enjoys his job.

According to Taylors' mother, **disability awareness** results in communities being accepting. In his case the community and staff are very aware of him and are

knowledgeable of Down syndrome. His mother spoke about the importance of making the community aware of your disabled child and said “*because of this, the community is being accepting*” of Taylor. She spoke about how “*being a good swimmer has helped*” as he is always in the local newspapers and people recognise him. She said.

From a parents perspective keep the community as aware as possible of your family...not to make it there problem but just to make them aware that there are children of different needs, that they can all actually live together.

For Taylor, by having the community aware of him and his condition they took responsibility for him. Taylor’s mother explained how this all happened quite naturally and was spontaneous.

The police community are also very aware of Taylor and the fact that he just chats to people, so they keep an eye out for him and when they [staff at work] are opening and closing they [police] also watch and if they think he is talking to someone he shouldn’t be, they will tell Taylor and they will tell me. It has just been something spontaneous. (Taylor’s mother)

Taylor’s mother spoke about how she informed his potential employers about her son’s disability.

I explained about the whole thing, so he said....bring him around for an interview. He had a meeting with the butchery manager in between and they were discussing the possibilities, would he cope with working in a cold environment cause it is cool down there and he has been there for four years now. (Taylor’s mother)

Taylor experience positive handling at work. His mother felt that there was some sort of understanding and sensitivity towards disability. She said,

His boss’s wife worked for a nursery school that had handicapped kids. Yes, he was sympathetic to the fact that he was dealing with somebody with less

intelligence. He took him under his wing and kept an eye on him. (Taylor's mother)

Taylor's mother revealed how his boss had taken on the responsibility of having someone with an intellectual disability employed and how he was being handled in a positive manner.

He [the boss] took him under his wing and didn't let him loaf, didn't let him get hurt. They make allowance for his personality but they don't let him be lazy. They will call us in when he seems to be wondering off or not focusing on his work.

Furthermore Taylor's mother spoke earlier on how she knew of someone with Down syndrome who was fired because he hugged a customer. She said *"Taylor hugs all day and they are tolerant of it"*.

With Taylor's success as an international swimmer he regularly features in the local newspaper and television. His mother spoke about how this is good exposure for his place of employment. She felt that this positive awareness and exposure of Taylor could be a factor in ensuring that his position at work remains secure.

The fact that he has been such a good swimmer has helped I suppose. [name of national grocery store] does get good exposure when he does well with the swimming. (Taylor's mother)

Sheldon's aunt explained how the staff dealt with him and the fact that he had Down syndrome.

Because the staff are all familiar and aware with what his disability is....they make allowances....they also don't make allowances which is good, they don't just let him walk around the shop doing nothing.

She further spoke about how his employers positively handle him.

He has a job to fulfil and he must do it but if he does make mistakes they will tolerate it more than if it is another employee.

Sheldon spoke about being happy at work and explained that *“We always have a lot of fun....they treat me very nicely”*. Being happy at work is an important component of the job matching.

Noel’s mother explained how the job coach also plays an important role in the training and sensitisation of the staff members around Down syndrome and the preparation for work.

She [job coach] went in and trained all the employers to deal with him and in fact, I think, I went along as well to answer questions and talk ...just to give them a bit of a background on what Down syndrome is and what to expect and how not to be sort of fearful really. (Noel’s mother)

4.4 Theme 3: Prepare and teach them well

This theme seeks to identify the role of schools in providing sufficient preparation to work for youth with Down syndrome.

Table 5: Themes and categories related to the role of the school

Theme 3	Category	Sub category	Code
Prepare and teach them well	Influence of school environment	Happy at school	<i>Said they could do more for him</i>
			<i>One of the best things that could ever happen to him</i>
			<i>It was a wonderful caring high school</i>
			<i>Totally inclusive</i>
		Unhappy at school	<i>The more effective option</i>
			<i>I did not like it</i>
			<i>Some people bullied me</i>
			<i>Bullying happens everywhere</i>
		Achievements at school	<i>He excelled in it</i>
			<i>He was head boy of his school</i>
			<i>He did very well in school</i>
		Limited to basic skills development	What is taught
	<i>English, Afrikaans, Maths</i>		
	<i>He doesn't want to read about 'the cat sat on the mat'</i>		
	<i>Helped with the social skills</i>		
<i>I learned A,B,C's</i>			
<i>They did teach me</i>			

			<i>What is taught is sign recognition</i>
		Preparing them for employment	<i>I don't think what he learned at school equipped him for work</i>
			<i>Not do that much</i>
			<i>Programme for work at school</i>
			<i>School tried their best to prepare them for work</i>
			<i>Get distance from their parents</i>
			<i>Good way of....preparing them</i>
	<i>They are missing the picture</i>		Teacher not ready for inclusion
		<i>It is just so demoralising</i>	
		<i>It is so expensive</i>	
		<i>Should have been a joint adaptation</i>	
		<i>It didn't work</i>	
		Limited capacity	<i>She cannot read</i>
			<i>She cannot write</i>
			<i>They did try to teach her</i>
			<i>They are very limited</i>

4.4.1 Influence of school environment

The **influence of the school environment** on children can make a huge impact on their lives. Noel experienced inclusion at an ordinary school and he was very **happy at school**.

We took him out of there because the headmistress of a pre-primary observed him and said that they could do more for him at her pre-primary. He went there for three years and that is where he developed his social interaction. It was probably one of the best things that ever happened to him. He went onto a wonderful caring high school which was a technical high school. (Noel's mother)

His mother reported that the ordinary schools that Noel had attended were all “*totally inclusive*”.

Sheldon went to a boarding school for children with intellectual disabilities in Kwazulu Natal. His grandparents were concerned at that time, as they would soon be going onto pension and felt this was the best option for them.

Sheldon was very **unhappy at school** and said: “*I did not like boarding school*”. When asked the reasons he replied, “*Some people bullied me*”. Sheldon's aunt spoke about how “*bullying happens everywhere*” whether you are in segregated setting or an inclusive setting.

Bullying happens everywhere. It's almost family nature that kids might be spoiled and they might have a behaviour problem and they don't know how to handle it. So the child get tolerated and allowed to continue to bully eventually the family cannot handle it and the child get sent to boarding school and the bullying carries on.

4.4.2 Limited to basic skills development

The participants reported that **what is taught** at the special schools is **limited to basic skills developments** and which make them functionally active. Tyrone and Larry attended an ordinary school for the first year but due to the challenges they faced they were then moved into special schools. Noel initially attended a pre-primary special school. His mother felt that he was ahead of the other children as “*at home he reads newspapers, he reads magazines.....he doesn't want to read about the cat sat on the mat*”. He was then placed in an ordinary school. Noel's mother felt that by him attending an ordinary school “*helped with the social skills*”. Noel participated fully in the class and did the same subjects as the other children. “*I did*

English, Afrikaans and Maths". He continued to attend ordinary schooling and in grade four he was placed in the special class within the ordinary school. He went onto a technical high school where he learned to do woodwork, bricklaying and steelwork.

Sheldon spoke about learning to read and write at the special school and said "Yes, *they did teach me to read and write....I learned A,B,C, music and pottery*".

Taylor's mother felt that the special school did not prepare him sufficiently for employment in the open labour market. She said that by teaching them to read signs when going to the shopping centre such as where to find the men's toilet. "*They become functionally active*".

There were conflicting reports from three of the participants who attended the same school at roughly the same time in terms of **preparing them for employment**.

Sheldon's aunt felt that the school did not sufficiently **prepare him for employment** in the open labour market. "*I don't think what he learned at school has equipped him for work in the open labour market* (Sheldon's aunt).

Taylor's mother spoke about the school's role and felt that they did "*not do that much*" to assist with preparing him for employment.

Eugene attended a special school for all of his schooling years and was an achiever. His mother said,

He did very well in school. He participated in swimming and athletics and he excelled in it. He was also head boy of his school. He really enjoyed school as well. They prepared them for relationships, HIV and sex education. They had a programme for work. They also had land service, sports, and they took them on a camp so that they could go away from their parents. (To get distance from their parents.) I think it is a good way of preparing them. Yes, I think the school tried their best to prepare them for work.

4.4.3 *They are missing the picture*

The participants who had initially tried out at an ordinary school felt that the **teachers are not ready for inclusion** and that the special schools “**are missing the picture**”. They felt frustrated and disillusioned by the education system.

Larry’s first year of school was a special class within an ordinary school. There were also three other children who also special needs. This class was eventually meant to be integrated into the ordinary classes, however this never happened. Larry’s father said that the teachers were not ready for inclusion and the school felt it was too expensive to keep the special class going and so it was closed after the first year. Larry was then sent to a special school in Kwazulu Natal while his parents lived in Botswana. Larry’s father furthermore spoke about his disillusionments of the special schools and feels that such limits are placed on disabled children.

*I know they [special school] try...but **they are missing the picture** you know....there are such limits that are placed on them and their abilities.*

Taylor’s mother spoke of the challenges faced when she tried to mainstream him in the first year of school.

A lot of black kids were coming into the school and a lot of those kids I felt had as much as a language disability as Down kids have and there should have been a joint adaptation. It didn’t work. Kids get into fights and where other kids are fairly independent about rights and wrongs, whereas Taylor never ever fought.

Tess’s mother spoke about her **limitation capacity** and felt that she would never be able to cope in an ordinary school.

I think you have to analyse your child yourself and they [children with Down syndrome] are very limited. Tess is very limited. She cannot read and she cannot write....yes, they did try to teach her.

4.5 Theme 4: *Lift their potential*

The following theme seeks to identify the role that protective workshops play in sufficiently preparing youth with Down syndrome for employment and looks at independent living skills and just keeping them busy.

Table 6: Themes and categories for the role of the protective workshops

Theme 4	Category	Sub category	Code
<i>Lift their potential</i>	Independent living skills	Household chores	<i>Teach them to pack and dry dishes</i>
			<i>Give them tidy up work</i>
			<i>We clean the garden</i>
		Learning essential skills	<i>It is important for them to have their own money</i>
			<i>Learn how to work with money</i>
			<i>Can't work with money</i>
	<i>I thought they would teach them</i>		
	Just keep them busy	They do nothing to lift their potential	<i>They just try and keep them busy</i>
			<i>They don't even think like that</i>
			<i>All end up doing the same job</i>
			<i>I don't see goals</i>
		Not enough contract work	<i>To make them more independent</i>
			<i>They do need more contract work</i>
<i>There is quite a lot of children</i>			

4.5.1 Gain Independent living skills

Tess's mother felt that the protective workshop does teach them household chores such as drying and packing the dishes. Tess spoke about what she has learned at the protective workshop such as preparing her lunch for the workshop for the next day, help with getting the dinner table ready, wash and pack the dishes after supper and help her mother with the household chores.

These skills prepare youth with Down syndrome for independent living and helping around the house.

She is not academically inclined but she can sew [...] and they teach them to pack and dry dishes. So they do teach them. (Tess's mother)

Larry informed me that he does do some garden work, "When there are too much leaves, I take rake and rake up the leaves". His father further reported,

They do give them tidy up work to do, quite a lot of cleaning and sweeping on the days they don't have contract work. (Larry's father)

Tess's mother stressed the importance of youth with Down syndrome having their own money and **learning essential skills** of money management. She explained that Tess herself cannot work with money.

It is important for them to have their own money and to learn how to work with money but Tess can't work with money. So she doesn't actually know the value of money and I've tried to teach her, but she doesn't know the value of money. So that's not a good thing either but that's her limitation. (Tess's mother)

Larry's father spoke about how he thought the protective workshop would do more employment skills.

It's strange they have got this vegetable tunnel and I got all excited, I thought they would teach them how to grow all these vegetables but they just left

them...some volunteers came in and planted them and that was the end of that. (Larry's father)

4.5.2 Just keep them busy

Larry's father felt that the protective workshops **do nothing to lift their potential** [people in the workshops] and spoke about how the protective workshop **"just try and keep them busy...I don't even think that they think like that"** [about further training to get them work in the open labour market]. He further explained of how despite the different levels of potential of some of the people.

They all just land up doing the same job...they do nothing to lift their potential.... I didn't see any goals that they were working towards to make them more independent and make them able to cope with jobs in protective or mainstream environment.

4.5.3 Not enough contract work

Tess's mother felt that there were a lot of people who attend the workshop and there is **not enough contract work** to keep them all busy. She felt that the protective workshop needs to get more contract work in order to keep all disabled people busy.

They do need more contract work....because there is quite a lot of children they don't have enough contract work so if they can get more work things that can be done with hands, because they are very good with their hands, when they don't have enough work, they do puzzles, they do drawing and they do the sewing, she catches up on her own sewing and they dance like mad here.

4.6 Summary of findings

This chapter has described the findings which have emerged as a result of the interviews with the participants and the data analysis. Four themes were identified. These findings indicated hindering and enhancing factors as well as how the individual, family members, schools and employers influence the aspirations of youth with Down syndrome in terms of their employment. The next chapter will discuss these findings.

Discussion

5.1 Introduction

This chapter discusses the key themes that emerged from the findings gained from the interviews with the participants in Chapter 4, namely;

1. Challenges to employment
2. Making work, work
3. Prepare and teach children well
4. *Lift their potential*

The discussion will focus on the themes to integrate themes from the findings:

1. The role of the individual and self-determination
2. The role of the parents and family members
3. The role of education sector
4. The role of the employer
5. The role of disability awareness and advocacy

5.2 Role of individual and self-determination

Self-determination for individuals with intellectual disabilities such as Down syndrome means being able to make informed decisions for ones' self and being active in ensuing their choices or decisions. This fortitude was particularly evident in the participants who were employed in the open labour market. Many people with Down syndrome and other intellectual disabilities are not self-determined or given the opportunity of expressing their desires. People with Down syndrome rely mostly on others for support (Stock et al, 2003) but this support does not always lead to self-determination. Marks (2008:56) adds that:

Research by Michael Wehmeyer and his colleagues has provided convincing evidence that individuals with intellectual disabilities can learn and actually do want to have more opportunities for self-determination in their lives. However, they are given few such opportunities and are generally not supported in their efforts, because those around them do not believe they can succeed.

'Many people with disabilities experience barriers to communication so frequently their voices are not heard' (WHO, 2010:9). This is often due to lack of self confidence, limited communication and the lack of expressive language skills. Their expressive language often lags behind their receptive language (Feeley and Jones, 2008, Hauser-Cram et al, 1999). Although some people with Down syndrome cannot speak it does not mean that their voices cannot be heard. Alternative forms of communication can be used to express their needs and desires (WHO, 2010).

Having been given choices we begin to understand what people with Down syndrome have an interest in and what they want, which affords them more control over their lives (Brown, 2004). He suggests that choices and opportunities need to start at an early age so that opportunities can be expanded. It is never too late to start. The findings illustrated that by exercising self-determination and expressing their career choice with the support of a job coach, the participants identified and accessed suitable employment. This approach ensured long term and sustainable employment as the participants were able to do something that they wanted to do. In order to achieve self-determination Morris (2005:7) argues that the barriers to self-determination be removed and suggests supports be provided. For instance, 'they may require supports to make choices, manage their own money, and seek employment'. Lack of self-confidence is also a barrier to employment (Radar, 2006, Rose et al 2005). Self-advocacy helps to improve self confidence all which contributes to possible employment. The Self-Advocacy Movement of South Africa (SAMSA) has trained many young adults with intellectual disabilities to stand up and speak for themselves as well as raise awareness on Down syndrome and the UNCRPD (2006). In addition self-advocacy groups help to empower and build self-determination for young adults with intellectual disabilities. Self-determination can lead to independence and living independently with support. Article 19 of the

UNCRPD (2006:14) refers to living independently and in the community and states as follows:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community,

Since the majority of people with Down syndrome are living longer, so too are their parents (Wehman, Targett and Neufeld, 2006). Many people with Down syndrome are not fully capable of taking care of themselves and live completely independent lives, which remains a concern for many parents. With aging comes questions such as: What will happen to him/her when we get too old?. Although this concern was only revealed by one participant, it is widely spoken about and reported by family members of children and adults with intellectual disabilities (Heiman, 2002). Independent living empowers disabled people to take control of their own lives. In addition it enables youth with Down syndrome to make their own choices about their living arrangements. It does not necessarily mean that disabled people are left to manage their own lives. Personal assistants and other supports mechanisms are also provided if required. Youth with Down syndrome need to be seen as citizen's first and then consumers of rehabilitation and healthcare (Ratzah 2005).

5.3 The role of parents and family members

The findings provided evidence that parents or guardians play a major role in the aspirations of their children with Down syndrome, particularly regarding the decisions that they make about employment prospects and where they will work. Furthermore, the findings revealed that the issue of employment and future plans is not only a concern for the youth with Down syndrome but for their parents and other family members as well. Family remains the most predominant form of care (at least 80%) well into adulthood for people with an intellectual disability (Jockinen & Brown 2005:789). Parents expressed that having their child employed took off some of that responsibility for them. This increased independence by participants in this study would provide respite for family members and makes life a little easier for them.

Factors that influenced parents' decisions related to transport costs and traffic, safety and security of their son or daughter, unwillingness, being passive, and degree of stress encountered. Their decisions resulted in what was functionally the easiest option for the family and what they felt was best for their child.

5.3.1 Coping skills and family stress

Stress and coping skills impacted on the daily lives of the parents of the participants, affecting their choice of where their child will work or live. This factor was mainly evident in the three participants who worked in the protective workshops, but not limited to them, as parents identified issues such as transport and seeing the outside world [mainstream society] as difficult. Heimen (2002:160) reflects that:

Parents of children with disabilities experience greater stress and a larger number of care giving challenges, such as more health problems, greater feelings of restriction, and higher levels of parental depression than parents of nondisabled children.

However, the fact that the participants were happy where they worked and lived could also be viewed as a coping skill or mechanism for the parents. By doing what was best for them made it easier to cope with having a disabled child.

Interestingly, five of the six participants come from families where their parents are divorced. Besides one father who openly discussed his divorce, it is not known if the parents divorced as a result of the stress involved from having a child with Down syndrome. The difficulties related to finding agreement on the decisions that needed to be made regarding the schooling or employment possibilities of the youth.

5.3.2 Over-protective and vulnerable

The parents of the three participants who worked at protective workshops revealed some trepidation regarding their children working in the open labour market, mostly as a result of their over-protectiveness and perceiving their children to be vulnerable and at risk to abuse. Studies have shown that people with Down syndrome are particularly vulnerable to various forms of abuse such as sexual, physical, neglect

and emotional which can include bullying. This is mostly due to the cognitive deficit experienced by individuals with Down syndrome as they can find it difficult in reporting the abuse (SAHRC, 2006; Powers and Oschwald, 2004).

Gates and Edwards (2007) and the Radar (2006) report found that over protectiveness by family members can be a barrier or challenge to employment and or independent living'. Heiman (2002:160) refers to the difficulties experiences by family members who have a child with a disability as 'anxiety and overprotection'. The CBR guidelines on Empowerment component (WHO, 2010) suggests that disabled people are often strongly supported by their family, and may also be over protected as family members do most things for them.

5.3.3 Resilience and pro activity of family members

Heiman (2002:159) has described resilience as 'the ability to withstand and rebound from crisis and distress'. Many parents become resilient and proactive due to their child's disability. These responses were particularly evident in the participants employed in the open labour market. Resilience varies from family to family and may develop in the early childhood years or develop over time. However, circumstances change over time and so does a persons' resilience. The findings showed that resilience developed as the participant got older, since the parents had time to adapt to having a disabled child and facing adversity. Having the support of other family members with similar circumstances and friends and sharing information can also lead to resilience. This was particularly evident in Sheldon's case with the support his grandmother received from Taylor's mother. Taylor's mother show particular strength after being challenged.

5.4 Role of the education sector

From the findings, it appears that special schools are not sufficiently preparing youth with Down syndrome for the transition from school to work. However, all but one participant felt that the school had tried to prepare him for employment. Morgan and Bayer (2005) found that schools and colleges in the United Kingdom were not paying sufficient attention in getting people with intellectual disabilities employed. Wehmeyer's (1997:175) suggests:

One of the reasons that students with disabilities have not succeeded once they leave school is that the educational process has not adequately prepared students with special learning needs to become self-determined young people.

It is considered that teachers underestimated the abilities of the participants. By learning ABC's and teaching sign recognition, one just becomes functionally capable. This underestimation leads to barriers to learning. The CBR guidelines for Education component (2010:38, 48) suggest that,

The school is often the most effective way to train teachers rather than sending the child away'...often teachers have limited knowledge about children with disabilities' ...low and limited expectations.

After initially attending ordinary school two of the participants had to change and go to special schools. This was owing to lack of support of the teachers and schools attended. Research suggests that preconceived ideas and the lack of information regarding the potential and abilities of children with Down syndrome have caused teachers' to have low expectations of these children (Klompas 2007:12). In addition teachers' attitudes play a significant role in including learners with Down syndrome and implementing inclusive education.

5.5 The role of the employer

The CBR guidelines on Livelihoods component (2010) suggests numerous desired outcomes for disabled people in terms of employment. The role of the employer discuss' the benefits to employment, employers, supported employment, job coaches, protective workshops and the right to work and employment. One such outcome would be: "people with disabilities have access to decent work opportunities without discrimination in a safe and non-exploitive environment" (pg 3).

5.5.1 Benefits of employment

It is noted that in the general population people who are employed have better health and physical outcomes than people who are unemployed (Rose et al 2005). The findings of this study revealed that employment in the open labour market brought

about relief for the participants as well their parents. Being employed meant earning a wage or salary and gaining meaning to life. In a recent study in the Netherlands conducted by Cramm et. al, (2009) the respondents indicated that supported employment had contributed to their self-development. It also revealed that work is a way for people with intellectual disabilities to participate in society and expressed a desire for social integration.

The findings provided evidence that all participants showed initiative and responsibility towards their jobs. Kregel (1999) acknowledges that people with developmental disabilities, such as Down syndrome, are known to take their jobs more seriously than other employees and are able to get the job done. He suggests that employers rate their overall work performance favourably. Moreover, in some cases it has been reported that people with developmental disabilities are more responsible than other people when it comes to their employment. He refers to them as being reliable and having a will to succeed.

5.5.2 Social interaction and friendships in the workplace

The participants spoke about their friends and how they enjoyed the friendships that had developed at their place of employment. These friendships were one of the aspects they enjoyed most about working. In addition, they indicated that employment in the open labour market provides scope for greater social interaction with people who are not intellectually disabled.

5.5.3 Attitudes of employers

The findings suggested barriers to employment in the open labour market. It found that some employers are reluctant to employ people with Down syndrome and state that administrative processes inhibit them in the workplace. In doing so, the employers are protecting themselves against cases of discrimination. The Employment Equity Act no 55 of 1998, chapter 2 refers to: Prohibition of unfair discrimination. Point 5 states that: 'Every employer must take steps to promote equal opportunity in the workplace by eliminating unfair discrimination in any employment policy or practice'. However, having this policy does not necessarily ensure that employers will take the necessary steps to promote the employment of youth with Down syndrome. Without the knowledge or understanding of the possibilities of

people with Down syndrome and employment, employers will not usually consider employing people with developmental disabilities (Kregel,1999, Radar, 2006). In addition Kregel (1999:2) found that they 'continue to face insurmountable obstacles when attempting to pursue their dream of a rewarding self-chosen career'. Positive attitudes and awareness of the condition is a contributing factor to accessing employment. This was evident in the findings. It showed that when disability sensitising took place the reaction towards them was more positive. The reality is that for the majority of employers who employ a person with Down syndrome or similar intellectual disabilities and who know and understand the person and know what Down syndrome is, have found that they have contributed positively towards the productivity of the business (Kregel, 1999).

5.5.4 Supported employment and job coaches

The findings revealed that not many family members of/and youth with Down syndrome are familiar with the model of supported employment or what a job coach is. Although supported employment has been implemented in the USA and the UK, it is still relatively a new and unknown concept here in South Africa. The reason was that participants did not have adequate knowledge about it. Weston (2002:86) says that 'research in the USA on supported employment for people with complex needs has consistently shown success in finding people work and keeping them in work. In addition he suggests that a lack of funding can be seen as one of the barriers to successfully implementing supported employment. Only one participant used such a service that assisted him in acquiring sustainable employment in the open labour market. The participant whose parents made use of this service were fortunate enough to have the necessary resources available to them to assist their child gain employment in the open labour market with the assistance of a job coach.

Job matching forms part of the supported employment model. Incorrect job matching can lead to unsuccessful employment. It is of particular importance that people with intellectual disabilities are placed in the correct job to ensure that the job is retained. Using the supported employment model the job coach is involved from the onset to ensure that the correct PCP information is gathered. Only then can job matching or job carving begin. For the participant who made use of the employment agency the job coach only conducted a PCP once his mother informed the job coach that the

original job which they had in mind for him would not be suitable for him. Hendricks (2010:128) suggests that:

There is a need to identify jobs that are appropriate to the individual's intellectual and educational background and that match his or her skills and abilities.

A bad experience by an employee could lead to employers not employing a disabled person in the future.

5.5.5 Protective workshop

Protective workshops have a responsibility to empower disabled people in an effective and holistic manner, regardless of their degree of impairment (DOSD, 2007). In addition they are 'required to provide support services required by the individual to "exit" the protective workshops and enter mainstream economic life' (DOSD 2007:4).

The findings suggest that protective workshops are not providing an enabling environment to improve the lives of people with Down syndrome who have potential abilities to work in open labour market with support of a job coach.

The Radar (2006) report done in the UK found that the majority of people employed in a protective workshop are just being kept busy by doing the same menial activity with little or no chance of gaining employment in the open labour market. Furthermore, the Radar (2006:7) report states, 'sheltered workplaces have become increasingly criticised in recent years, as segregation can often be a barrier to moving into open employment'. One participant's father thought that the protective workshop would do more for his son and help him eventually gain employment in the open labour market. As a result of the minimal skills development he feels despondent. Furthermore he feels that since being in the protective workshop and residential home his son has withdrawn and is no longer as outgoing as he used to be.

The participants reported that they pay a monthly fee to attend and work in the protective workshops. In addition part of or their entire disability grant is paid over to

the protective workshop. This finding was supported through personal communication with the DOSD (2011). The protective workshops also receive a subsidy from the DOSD per individual attending (DOSD 2007). Furthermore, protective workshops generate income by obtaining contract work for the participants. Bearing these incentives in mind one might consider that protective workshops are viable, which means they will continue to promote that disabled people work in these places with no incentive to skill people with disabilities to assist them in accessing employment in the open labour market. The CBR Livelihood component (WHO 2010) suggests that skills development is more effective when done in an inclusive environment.

5.5.6 Right to decent work

This study revealed that none of the participants and their parents knew or understood their rights around work and employment. They were keen to know more. Disabled people's right to decent work are enshrined in numerous human rights instruments such as the UNCRPD (2006) and the CBR guidelines, Livelihood component (WHO 2010). However, knowing or understanding one's right does not necessarily lead to having access to employment. In addition, it does not mean that employers have to employ a disabled person. There have been many organisations and projects such as the Harvard Project on Disability in the USA who have developed several easy to read books on the convention. "We have human rights" (2008) and "Change your life with human rights" (2008). Disability advocacy plays a significant role in the training and awareness of such instruments.

5.6 Role of disability awareness and advocacy.

This theme discusses stereotyping of disability, raising awareness of Down syndrome and self-advocacy.

5.6.1 Stereotyping

The findings revealed that parents had to deal with stereotypes related to preconceptions and expectations of their disabled child from health and education professionals. Disability is often portrayed as homogenous. Generally it is often thought of as a person in a wheelchair (McDougall, 2006). This type of stereotyping leads to negative beliefs and a misguided notion that disabled people need to be

treated with pity as they cannot learn nor do much for themselves. In addition people with Down syndrome are seen as eternal children, special children born to special parents. These beliefs reflect and affect people's attitudes towards people with Down syndrome and their families. Block (2010:1) suggests that stereotypes are 'the image or the attitude is unconsidered, naive, the by-product of ignorance or unfamiliarity'. In instances where the mothers chose to ignore stereotypical expectations, they became more assertive and pro-active. Their resilience ensured that their children did not conform to society's expectations.

Furthermore, it emerged in the findings that negative attitudes and stereotypes also exist within the family itself by believing that they cannot achieve. This contributes significantly towards youth with Down syndrome not attempting to be employed in the open labour market. Griffiths et al, 2003 in Ward and Steward (2008:298) found that 'there is a tendency to downgrade the value of a person with intellectual disability and subject them to gross injustices'.

Kregel (1999:2) refers to the lack of confidence and awareness by employers when they are faced with employment opportunities for people with developmental disabilities. He adds:

Unfortunately, far too many individuals continue to face seemingly insurmountable obstacles when attempting to pursue their dream of a rewarding, self-chosen career. Stereotypic employer attitudes and outright employment discrimination, still deny many individuals with developmental disabilities the chance to show their skills and abilities.

The importance of awareness cannot be underestimated in order to gain and maintain employment. Prejudices, misunderstanding or ignorance about the condition can lead to people with Down syndrome not being employed at all or being dismissed from their place of employment.

5.6.3 Keep your community aware

This message came across strongly by two of the participants parents to other parents who have an adult child with Down syndrome employed in the open labour

market. Communities in general view disability as a burden and negative views about having a child with Down syndrome as a tragedy remain embedded (Cuskelly, Hauser-Cram and Van Riper, 2008). The parents felt that if the community knows and understands what Down syndrome is and they are made aware that there is a person with Down syndrome working and/or living in the area makes community members become more receptive to them and will keep a look out for them which helps to keep them feeling understood, accepted and secure.

Informing [training or sensitization] staff members and the community about the disability is an important component when a person with Down syndrome enters the place of employment. Understanding and accepting that a person has Down syndrome makes people less likely to discriminate against them and more likely to understand the situation.

5.6.1 Self-advocacy

Although none of the participants were part of self-advocacy groups. The findings showed that although none of the participants were part of self-advocacy groups two spoke up for themselves in choosing their employment. Sheldon showed self-advocacy accessing employment in the open labour market and Eugene informed his mother he wanted to live in the hostel. Furthermore, none of the participants had contacted the DSSA for support. Disability advocacy organisations such as the DSSA strive for the rights of people with intellectual disabilities and their families. In addition it can support disabled individuals in accessing their right to employment as well as raise political issues which may be discriminatory.

5.7 Limitations of the study

The number of youth with Down syndrome who are employed in open labour market was limited. Protective workshops were reluctant to let youth participate in the study. The study was limited with regard to ethnic and linguistic composition as it was difficult to find Black youth with Down Syndrome who were employed in OLM, and Black participants in protective workshops had difficulty in understanding the study due to lower educational levels.

5.8 Summary of discussion

In summary parents can be seen as the primary stakeholders in the success of their child's employment. Their over protectiveness and lack of knowledge to supported employment and their rights to work and employment hinders the possibility of employment in the open labour market. In addition schools and protective workshops are not providing sufficient skills development which leads to employment in the open labour market. The model of supported employment and job coaches plays a significant role in facilitating this process and so too does awareness raising and disability advocacy.

University of Cape Town

Recommendations and conclusion

6.1 Introduction

This chapter will provide recommendations following the discussion themes namely;

- 1) The role of the individual and self-determination
- 2) The role of the parents and family members
- 3) The role of education sector
- 4) The role of the employer
- 5) The role of disability advocacy

It will also provide recommendations to further probable studies and conclusion.

6.2 Recommendations

6.2.1 The role of the individual and self determination

The study showed that not all young adults with Down syndrome have self determination. Youth with Down syndrome should join self advocacy groups which promote self-determination and individual decision making. (DSSA's branches nationwide have self advocacy groups that meet monthly). Self-determination can increase opportunities to accessing employment in the open labour market. It also provides for personal growth.

For the participants who showed self-determination, this fortitude can be used as an advantage to encourage others who lack self-confidence/esteem. It can also be used to promote the abilities of people with Down syndrome at their place of work. Parents should encourage self-determination which leads to independence and living independently.

6.2.2 The role of parents and family members

6.2.2.1 Advocating and lobbying

Parents, family members and participants indicated that they did not know about their rights to employment. Parent and family members should take a human rights approach for their child by advocacy and lobbying for their rights more specifically in relation to the UNCRPD (2006) Article 27 on Employment. Furthermore Article 19 on Living in the community and Article 24 on Education also mentioned in this study can be used as an important tool in accessing their right to education and living in the community.

6.2.2.2 Parent and family stress

Parents and family members experienced frustration and stress in their child's education and accessing employment and many reasons were cited. Parents and family members can do much to resolve these frustrations and stresses by seeking support of other family members, friends, neighbours and the DSSA. This support can facilitate the process of inclusion in neighbourhood schools and employment in the local area. By doing so it allows them the opportunity of attending school with their siblings and not having to be too concerned about transport and traffic as well as very early mornings. Respite centres should be established with trained quality staff in order to give parents the opportunity of having very much needed 'respite' without being concerned for their child or young adult with Down syndrome.

6.2.2.3 “Keep your community aware”

Keep your community as aware as possible. This was a message the mother of one of the participants of the study. Parents play a significant role in advocacy and awareness for their child and should therefore continually raise awareness in their community by giving talks at schools and businesses. They should be encouraged to take their child out when shopping, paying accounts or family outings. Sound advice would be to support awareness initiatives by DPO's and DSSA.

6.2.2.4 Local parent organisations

The participants did not make use of the services offered by DSSA or any of its branches for assistance with employment. Parents and family members should make contact with their local parent organisation such as the Down Syndrome Association

who provide support, counselling and assist with accessing education and employment, amongst many other services. These services are provided free of charge.

6.2.3. The role of the education sector

Schools should be susceptible to the idea of having children with Down syndrome being fully included and not discriminate against them in any way. Facilitators as support for the children with Down syndrome as well as a flexible curriculum with the necessary resources are crucial. Schools can create partnerships with parent organisations such as the Down Syndrome Associations. The CBR guidelines on education suggest that 'Education is much broader than schooling' (WHO, 2010:4). Education must begin from birth and continue throughout lifetime. In doing so early intervention and developmental programmes must be accessed in order to minimise the possibility of exclusion from schools. Children who access such programmes have shown to be more advanced than those who have not (Lloyd, 2004:1) and are more likely to be included in ordinary schools. In addition schools must provide curricula in accessible format which enhances learning and development. Furthermore they must promote skills development and transitional assistance when progressing from school to work. It is also important to involve families in their child's education.

6.2.4. The role of the employer

Employers should include and cooperate with organisations such as DSSA and/or Employability in assisting with employing youth with Down syndrome. Supported employment should be promoted for youth with Down syndrome and companies open to the idea. In addition, companies can also encourage job carving. In addition have disability sensitising session with other employees will help to ease any uncertainties.

6.2.4.1 Protective workshops

The study found that protective workshops were not promoting skills development or sufficiently equipping people to work in the open labour market. Protective workshops must promote skills development and encourage work in the open labour market. The people who work in these workshops should earn job related salaries

commensurate with their skill level and ability to perform the required task within a specific job description.

6.2.5 The role of disability advocacy

The study found that disability advocacy can positively influence employment in the open labour market for youth with Down syndrome. In doing so, DSSA, the parents of/and youth with Down syndrome can mobilise communities to participate in advocacy and lobbying strategies to government. They can set up pressure groups for specific areas, such as the inclusive education, Initiative 24 (based on Article 24 on education in the UNCRPD (2006) run by Inclusion International and DSSA. Furthermore, promote and train parents and youth with Down syndrome on the UNCRPD (2006). Access easy-to-read material on the UNCRPD (2006) such as the Harvard project on disability (2008), “We have human rights” and “Change your life with human rights”.

6.2.5.2 Awareness programmes and events

The promotion of themed awareness days such as the International day of the disabled 3rd December, World Down Syndrome Day 21st March annually, and National Down Syndrome Day 20th October by the various stakeholders can have a positive impact for youth with Down syndrome. Since Down syndrome is a genetic condition DSSA celebrates ‘Genes day’ and encourages people to wear Jeans on this day in order to promote the abilities of people with Down syndrome. Stakeholder should work closely with all forms of media such as radio, newspapers, television, magazines, social networking websites and the internet.

6.2.5.3 Duty bearers

The study revealed that none of the participants were employed by government departments. The Department of Labour should encourage the model of supported employment for all people with intellectual disabilities. This will enable government departments to look at employing youth with Down syndrome. Reasonable accommodation and or assistive devices such as job coaches should be in place. Budgets and service delivery programmes should be in position, not only to merely support this model, but to improve the lives of individuals with Down syndrome and their families. The various SETA’s are to promote skills development of youth with

Down syndrome. A close working relationship with DSSA, Employability, South Africa Disability Alliance (SADA) and SADDF must be established in order to ensure success. The call in this instance would therefore be to improve policy implementation to assist youth with Down syndrome in accessing employment.

6.2.5.3.1 DSSA

The DSSA should employ more staff to enable it to further:

- Encourage and establish meaningful partnerships between stakeholders and beneficiaries.
- Promote and enhance the quality of life of people with Down syndrome.
- Share information and network with other parent organisations and DPO's.
- Fundraising and resource mobilisation to ensure the delivery of integrated programmes which benefit and empower youth with Down syndrome and their families.
- Capacity building training workshops on the UNCRPD (2006) to be done in rural areas.
- Assist rural communities to establish self-help groups. Advocate and lobby at national level for equal opportunities and equal rights.
- Further nurture partnerships with universities

6.2.5.3.2¹ South Africa Disability Development Fund (SADDF) and SETA'S

They should be encouraged to support youth with Down syndrome by funding programmes that lead to skills development and employment with the support of job coaches.

In summary the recommendations have provided us with a guide for future use by youth with Down syndrome, their parents and family members, the education sector, employers, protective workshops, government, DSSA and the SADTF.

6.3 Suggestions for future research

The following areas for further research surfaced as a result of this study.

- The feasibility of protective workshops as skill development centres.

¹ Previously known as the Thabo Mbeki Development Trust

- Quantitative research on number of people with Down syndrome and intellectual disabilities accessing employment in the open labour market from protective workshops and the success thereof.

6.4 Conclusion

This study was conducted to establish the factors that influenced the aspirations of youth with Down syndrome to employment. The literature reviewed key concepts such as Down syndrome, aspirations, employment, education and community based rehabilitation. Using a qualitative design case studies of six participants were done. Semi structured interviews explored the experiences of three participants employed in the open labour market and three participants in protective workshops.

The four themes emerged from the findings were:

5. Challenges to employment.
6. Making work work.
7. Prepare and teach the children well.
8. Lift their potential.

The discussion explored self-determination and resilience shown by participants and their parents, which resulted in them successfully being employment. In addition the discussion suggested that parent and family stress as well as overprotection are a cause for limiting their aspirations to employment in the open labour market. It was established that special schools and protective workshops are not sufficiently preparing youth with Down syndrome for employment in the open labour market. Recommendation for various stakeholders was given. Further research such as a feasibility study of protective workshops as skills development centres. Qualitative research on the number of people with Down syndrome and intellectual disabilities accessing employment in the open labour market from protective workshops and the success thereof.

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APPENDIX A - Permission letter to the Down Syndrome Association of Gauteng, Johannesburg branch and research information sheet.

4 Nisbet Place
Bedfordview, 2007
082-893-0988

The Chairperson
Down Syndrome Association of Gauteng
2nd Floor, Children's Memorial Institute
c/o Empire and Joubert Streets
Braamfontein

Dear Chairperson

I hereby request permission have access and names of members of the organisation to do interviews with six of your members, youth with Down syndrome (three of which are employed in the open labour market and three that are employed in segregated settings, between the ages of 18 and 35) for research purposes as partial fulfilment of my M.Phil. degree in Disability Studies at the University of Cape Town.

Approval from the Faculty of Health Sciences Research Ethics Committee is pending. This study will be done in partnership with Down Syndrome South Africa.

This study aims to:

Explore/identify the factors that influence the aspirations of youth with Down syndrome in terms of employment.

The objectives of the study is:

1. To explore/identify factors that influence or hinder the aspirations of youth with Down syndrome to employment.

2. To identify whether the participants feel sufficiently prepared for work in the open labour market (whether schools or protective workshops have sufficiently equipped them).

I will be selecting participants on their basis of understanding the research and who are capable and willing to being interviewed. A copy of the final research proposal will be made available to you.

I therefore request assistance by providing me with a list of possible individuals, (names and contact details) that can be approached to participate in the study. The enclosed information sheet (Addendum D) will help you in the selection possible participants. The branches will also be asked to contact the possible participants and get their permission to divulge their information to me. The selection of the specific participants will be done by me. I will meet with them face to face and explain the entire research process and what is expected of them.

The study will be conducted in a manner that complies with the ethics of confidentiality. All participants will remain anonymous and this is to be guaranteed by the use of pseudonyms. All participants parting in this study do so on a voluntarily basis and will have the right to withdraw from the study at any time. Data will be stored safely and will not be divulged to persons other than my research supervisor. The branches will be appropriately acknowledged in the research.

Attached is the Research Information sheet which gives more details regarding the study which will also be made available to the participants and their parents. Below is the consent form which I would be grateful if you could sign and return to me at your soonest convenience. Thank you for considering my request.

Yours sincerely

Vanessa dos Santos

(dssvan001)

Faculty of Health Science.

Research Information Sheet

Research Question

A study to explore the factors that influence the aspirations of youth with Down syndrome in terms of employment.

Participants' involvement

Six youth with Down syndrome will be selected to participate in this study. Interviews in the form of conversations will be held in your family home at a time that will suit you. This interview will be voice (audio) recorded. This will be done during the months of October/November 2008.

Benefits of the study

The aim of the study is to explore/identify the aspirations of youth with Down syndrome and to find out what the experiences of getting a job has been and what has helped or stopped this. It is hoped that this study will help other parents of youth with Down syndrome, disability/parent organisations, government departments, higher education institutions and more specifically school to work transition programmes in what it is that youth with Down syndrome want (aspire to achieve) when it comes to employment.

Ethical concerns

You do not have to agree to be a part of this study and have the right to withdraw at any time without any consequences. All the people who are selected and choose to be a part of this study will remain anonymous (no one will know their real names) and this will be done by using a false name. All information collected will be stored safely and will not be shown to persons other than my research supervisor.

Costs and payment

All the research costs will be covered by the researcher. You will not receive any payment for your participation in the study other than reimbursement if you have incurred any costs to participate in the study.

Researcher contact details

Vanessa dos Santos (dssvan001)

Supervisors contact details

Ass Prof. T. Lorenzo (UCT)

011-615-4234 (H)

011-252-5323 (F)

082-893-0988 (C)

Email: vanessads@telkomsa.net

082-898-8697 (C)

Email: Theresa.Lorenzo@uct.ac.za

APPENDIX B - Consent form for Down Syndrome South Africa Branch, Johannesburg for names of possible participants

- I agree to give the researcher the names and details of participants who have given me permission to do so. The names (possible participants) are from the Down Syndrome South Africa, Johannesburg branch.
- I have read the Research information sheet and have had the opportunity to ask questions about it.
- I understand that Down Syndrome South Africa, Johannesburg branch is under no obligation to allow participation in this project.
- I understand the Down Syndrome South Africa, Johannesburg branch and its participants have the right to withdraw from this project at any stage.

Signature of the Chairperson of Down Syndrome Johannesburg: _____

Signature of the researcher: _____

Date: _____

APPENDIX C - Permission letter to the possible participants in a research study.

Disability Studies Programme
School of Health and Rehabilitation Science
Faculty of Health and Science
University of Cape Town

4 Nisbet Place
Bedfordview
2007
082-893-0988

Dear _____

Re: Permission requested for participation in a research study

The Down Syndrome Association of Gauteng – Johannesburg of which you are a member has given me your contact details, to ask your permission for you to take part in my study. This study is part of the work that I need to do for me to be able to get my Masters' degree at the University of Cape Town.

I am waiting for the University's Ethics committee to give me permission to go ahead for me to do this study. This study will also be done with the permission of Down Syndrome South Africa, branch in Johannesburg.

This study aims to:

This is a study to explore/identify what your dreams or hopes are about work and what made you think this way or choose to work where you do.

The objective of this study is to:

I would also like to find out more about your work and to see if you feel that you are properly trained for you to be able to do that kind of work.

If you want to be a part of this study and agree that you are willing to speak to me about your experiences and your work, I will give you a consent form which you will need to sign to say that you are willing to help me. You will also be given an information sheet and I will go through this sheet with you and explain all the questions. You will have time to ask me any questions. You can also change your mind at any time if you do not want to carry on with the study. I will not use your real name when writing or talking about you because I will be using another name and not your real one. After I have done all the interviews I will go through all the information I have collected from you and read it back to you. This will give you a chance to change or add anything that you think will help towards my study. If you want I will give you a copy of the study when I am finished with it. I will keep all the information I collect and I will not let anyone see or have it other than my supervisor. (That is the person at the University who is helping me).

Attached is the Research Information sheet which I will go through with you and explain everything to you. Below is the consent form which I would be happy if you could sign it and return it to me as soon as possible. Thank you for thinking about being a part of my study.

Yours sincerely

Vanessa dos Santos
(dssvan001)
University of Cape Town
Faculty of Health Science

Appendix D - Consent form for participants

- I am happy and agree to be a part of this research study project.
- I have had the information sheet read and explained to me.
- I understand what this study is all about.
- I have had the time to ask questions about this study.
- My answers can be used in this study.
- I know and understand that my real name will not be used and that a false name will be used to protect me.
- I understand that I do not need to be a part of this study and this is my own decision.
- I understand and know that I can change my mind at any time and not complete the study if I don't want to.

Signature of participant: _____

Name of participant: _____

Signature of researcher: _____

Date: _____

Researcher contact details

Vanessa dos Santos (dssvan001)

011-615-4234 (H)

011-615-9406 (F)

082-893-0988 (C)

Email: vanessads@telkomsa.net

Supervisors contact details

Ass. Prof. T. Lorenzo (UCT)

082-898-8697 (C)

Email: Theresa.Lorenzo@uct.ac.za

APPENDIX E - Interview guide for Youth with Down Syndrome

Prior to the interviews the entire research process will be explained to the participants in a manner that the participants will be able to understand. This will be done 'face to face' by the researcher to the participants. This will also give the researcher and the participants an opportunity to get to know one another and for the researcher to ask them if there are any concerns that they may have. These can then all be ironed out prior to the interview process. The consent form will be signed with the researcher present and anyone else that the participant may feel they want present (e.g. parent or guardian). The form will then be handed directly to the researcher. The researcher's contact details will be given to the participants should they wish to contact her at any time during the process to ask questions for any other matters.

The interview will be conducted at the participants' home at their own convenience and will take roughly one hour for each interview. Follow up interviews will be done in order to ensure that the data has been correctly interpreted and if there is any information the participants may want to add or change. The participants can remain anonymous and use a pseudonym of their choice. All participants in this study do so on a volunteer basis and can withdraw at any time. The data collected will be stored safely and remain confidential with only the researcher and her supervisor having access to that information.

Age:

Gender:

Type of Schooling attended:

Last grade:

Age at that time:

Current situation in terms of employment

1. *Tell me about your work.*
2. *Is there something else that you would like to do, if so what is it? What or who would help you to do this?*
3. *Tell me about your experience of finding your current work.*

4. *What do you enjoy about what it is you are doing/not enjoy?*
5. *How did you get to work there? Who helped you?*
6. *Tell me how your parents/others who have supported you.*
7. *Tell me what you know about supported employment and job coaches.*
8. *Is there anything you know about the rights of disabled people and employment?*
(Would you like to know more?)
9. *Is there anything else you would like to tell me about work?*
10. *How did you feel sharing your experience with me?*

Thank you for telling me about your work and your aspirations.

University of Cape Town

APPENDIX F – Information about the researcher in relation to this study

The researcher is a mother of a child with severe physical and intellectual disability (Cerebral palsy and Down syndrome) and has been working in the disability sector for the past 15 years. During this time she has attended several training courses on counselling skills as well as having counselled many new parents (of disabled babies born with Down syndrome) and supported parents on many other issues relating to disability. She has also done research on people with intellectual disabilities in the past for the Department of Education. She therefore feels adequately equipped to conduct this study and handle any problems that may arise during the process. She also will be able to put any of the participants into contact with the necessary organisations/persons/agencies should the need arise.