



Awareness, Acceptance & Appreciation: A Road to Changing Views on Autism in South Africa

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Abstract

The idea for the thesis was born during my work placement in Autism Western Cape organisation in Cape Town, South Africa. The organisation's work is concentrating on emotional and educational support for autistic individuals and their parents and carers. At the same time the organisation is advocating its message on awareness, acceptance and appreciation towards autism. Neurodiversity and social model of disability are also important concepts in its work.

The purpose is to give the reader an understanding of autism in South Africa, how it is perceived, how are the autistic people and their families being helped and what difficulties they are facing. The situation of autism in South Africa, the lack of knowledge towards autism or the pure unawareness towards the existence of autism and the inequalities in autism assistance and access to autism care are important parts, not forgetting the professionals, their effort and the difficulties and obstacles they are encountering.

The main focus is on Autism Western Cape's work in the Western Cape area of South Africa and on its clients and service users. How the organisation is helping autistic people and their families in the area at the same time advocating its message.

The research questions are what is the situation of autism in South Africa, what is done about the situation, is this helping and what are the obstacles? Is awareness, acceptance and appreciation increasing?

The results are drawn from my findings during the work practice. The main source being Autism Western Cape, its work, staff, clients and service users. The main methods used to gather data were participant observation and semi-structured interviews. The data from these were analysed by using content analysis.

The results are that in a wider South African society there is still a long way to go changing views on autism. The situation is not very good. The organisation's work through its intervention, parental support groups and workshops helps most families that are involved. At the same time, though, the organisation's work is facing obstacles arising from unawareness, poverty and traditional belief practises. Autism awareness and acceptance have increased within most of the families involved with the organisation but not with everyone. Autism appreciation reaches part of the professional world and some of the parents of autistic children who have started to advocate themselves.

Keywords: Autism, South Africa, assistive methods, organisational work

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1 Introduction

The idea for the thesis was born during my work placement in Cape Town, South Africa in Autism Western Cape, an organisation that dedicates its work helping autistic people and their parents and carers in the Western Cape area. The practice took place between April and June 2018 for the duration of eight weeks. I chose this practice place as I wanted to concentrate on autism in my thesis. The reason I chose Cape Town in particular, was that we have family there. I went there with my spouse and our son, and it felt natural to go to a place where we would have close people providing support and local knowledge.

I have been interested in autism spectrum disorder approximately for ten years now. This was sparked up by a relationship with a person with Asperger's Syndrome, the experiences and the encounters with other autistic people at the time. It was a huge learning curve for me where I realised that autism is much more than the movie Rainman projects, which was my previous and very outdated reference to autism. I was able to see some of the key struggles autism spectrum disorder embodies and the impact they have on a person's life. Without a fail, these were to do with social interactions and relationships. I was mainly having contact with autistic people on the low support level of the spectrum. This is also called the high functioning end of the spectrum. I was also able to see the difference between the early diagnosis and late diagnosis and realise the significance of an early diagnosis in an autistic person's life.

Based on the above, my initial mindset was to explore interventions, the benefits of early intervention, how do autistic people feel about them and do interventions promote inclusion. My learning goals were to learn more about autism, interventions, how interventions have worked and any possible evidence on how they have worked. I wanted to find out whether and how these interventions might help autistic people to be more included in the society and what are the autistic people's views/feelings about these interventions. I also wanted to interact with the autistic clients and their parents and find out their thoughts on the above issues and some of their main needs. I very much wanted to learn about South Africa, the South African society and especially Cape Town where my practice took place.

Autism Western Cape seemed like a perfect place in Cape Town area to do this. During my practice, though, I soon realised that the cultural setting and the health and social care system were very different that I was used to. Access to care depends on wealth, and only a small portion of the population has the amount of wealth affording them first-class intervention programs and special schools that would have been more relevant to my original idea. Autism Western Cape is open to everyone in need, but majority of its service users come from the poorer backgrounds who have very little, or no knowledge of autism and a very limited access to care. Traditional religious beliefs also influence how autism is perceived by the community

and what kind of help is sought for the autistic person. Needless to say, after my practice period the focus of my thesis changed. Rather than concentrating on interventions and inclusion, I now had a pile of data and findings on South African society, autism in South Africa and Autism Western Cape's efforts to help the autistic people and their families and bring change to the mindsets of people via their intervention.

First of all, in chapter 1 I discuss the purpose and the goal of the thesis followed by description of South Africa and Cape Town including historical background and current facts. I also give a description of the working life partner, my work practice place, Autism Western Cape. Chapter 2 addresses the situation of autism in South Africa concentrating on the difficulties and problems that autistic individuals and their families are facing, research work on autism in the country and efforts of other organisations. Chapter 3 focuses on South Africa's disability legislation where I look into United Nations Convention on the Rights of Persons with Disabilities, White Paper on the Rights of Persons with Disabilities, Children's Act and Department of Social Development Policy on Disability. In chapter 4 I look more closely on autism, its causes and characteristics and also what is the effect of these to the wellbeing of autistic individuals and their parents. Chapter 5 concentrates more on assistive methods that are relevant to Autism Western Cape and also the advocative and developmental work of the organisation. All to do with helping the autistic people, their families and spreading the organisation's message. In chapter 6 I outline the basics of social model of disability and neurodiversity as these are important concepts for the organisation. Chapter 7 outlines the data gathering methods, chapter 8 findings of my research and chapter 9 the difficulties Autism Western Cape faces in its work.

Permission has been asked to use informants' names, and real names are being used with this permission. Otherwise participants involved are referred to as social worker 1 and 2 and staff member 1 and 2. When discussing autism, I am using autism and autism spectrum disorder, and an autistic person or autistic people. People who are not autistic are referred to as neurotypical. Autism spectrum disorder refers to the fact that there is not just one type of autism but a wide range of "autisms [...] vastly different range of behaviours" (Frith 2008, 22). For example. Asperger's Syndrome is within autism spectrum disorder. The scholars in my research have used both definitions. Autistic person/people refer to a comment I heard in an autism conference earlier this spring in Cape Town, and which I want to respect. A person said that he is an autistic person, not a person with autism.

1.1 Purpose and Goal of the thesis

The purpose of the thesis is to give the reader an understanding of autism in South Africa, how it is perceived, how are the autistic people and their families being helped and what difficulties they are facing. The situation of autism in South Africa, the lack of knowledge towards autism or the pure unawareness towards the existence of autism and the inequalities in autism

assistance and access to autism care are important parts, not forgetting the professionals, their effort and the obstacles they are encountering. All this can be very different what we are used to here in Finland, and I would imagine, countries similar to Finland. The main goal is to show the reader how in this type of setting Autism Western Cape is at the front line helping the autistic people and their families, and at the same time advocating the very important message of awareness, acceptance and appreciation towards autism. The focus is on the organisation's work with the service users that come from less privileged backgrounds. The research questions are, what is the situation of autism in South Africa, what is done about the situation, is this helping and what are the obstacles. Is awareness, acceptance and appreciation increasing?

Autism Western Cape's message is that first of all, there should be awareness towards autism, then accepting autism and finally appreciating autism. The idea advocated by Autism Western Cape is that autistic people are not abnormal and autism is not a disease that needs to be cured. The society, including family and friends should support the autistics, and embrace rather than shun the autistic qualities, and help these people to achieve their full potential.

1.2 South Africa and Cape Town

South Africa is the southernmost country in the African Continent with a population approximately of 56.5 million (Stats SA 2017) falling in into the "low and middle income" (World Bank n.d.) category. The country is divided into nine different provinces, has eleven different official languages and several different ethnicities. During the apartheid, ethnicities were divided into four different categories, these being black South Africans, Coloured South Africans, white South Africans and Indian/Asian South Africans (World Elections n.d.). The term 'coloured' is not derogatory by any means in South African context. It is an expression used for people with multi-ethnicities. According to Kolade (2016) the coloured are "neither black nor white but a mix of everything [...] blend of African, European, East Asian and South Indian". This is probably best described by the phrase "being coloured means colourful" (Adams 2018. Personal communication). In the thesis, I will be using this term when referring to this specific group. Even though, within each of the different categories there are a variety of ethnic groups, the above ones are still widely used to identify people's backgrounds. Christianity is the predominant religious belief with its many different churches, the rest is divided between Islam, Hinduism, Judaism and traditional African believes (World Trade Press 2010, 12).

Historically, the country was inhabited by diverse native African societies that "shared a structure of homestead-based pastoral and arable production, linked together in clans and presided over by a chief" (Worden 2011, 11). During the mid-17th century Dutch East India Company established itself in the today's Cape Town area and the colony that materialised from it provided the basis for later colonialization (Worden 2011, 12). The country was predominantly colonised by the Dutch and the British. The segregation between different ethnic groups that

followed colonialism is still pertinent in today's South Africa. Colonialization and racism linked to European colonialism are very familiar concepts to us. The native people and their lives had very little worth, and their lands were mercilessly reaped for profits. According to Worden (2011, 73) after the Second World War this idea started to wither away and many of the colonies started to become independent. This was not the case in South Africa, though. The segregation that is better known as apartheid, heightened to the point where it became the dominating element in the society for over forty years during the 20th century. Apartheid was the pinnacle of white supremacy which forced a complete segregation between the black, coloured and white South Africans.

The separation was complete meaning people from different backgrounds could not live in the same area, not use the same services, such as public transportation, shops, restaurants etc. Everything was separated and people were punished if they were found crossing the line to the other domain. The black and coloured population lived in more undesirable locations and poorer conditions. Their education, employment and health care were also lower standard compared to the white population. They were not allowed to vote or have any kind of representation in the government (Schulz Richard 2018). These laws that enforced the separation between the different ethnic groups were loosened during the Second World War, but after the 1948 National Party's election victory they became even more strict than before with a goal that all South Africans should be divided by their ethnic background forcing a complete "racial division" (Worden 2011, 104). The country was plunged into a decades long administration fuelled by racism that left deep scars into society that are still very tangible today.

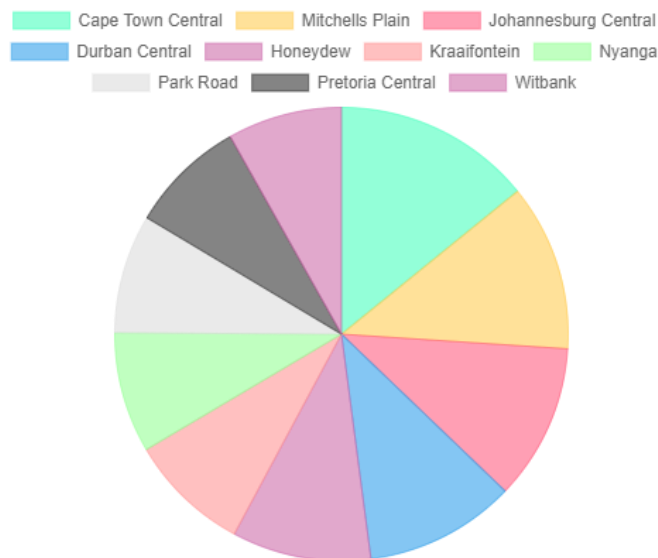
Even though, apartheid came to its official end in 1994 when African National Congress (ANC) won the elections, the separation between the different ethnic groups still exists. One very good indicator of this is the distribution of wealth. Steyn Kotze (2016, 5) states that South Africa is "one of the most unequal societies in the world". This comes down to the gap between the poor and the wealthy where the majority of the poor population is still black South African. For example, during the apartheid, masses of non-white South Africans were forcefully relocated from their homes to designated areas according to their ethnic backgrounds. This was to control people, make sure they were living in spaces allocated to them, make sure they could not own property anywhere else and prevent different ethnicities mixing (SAHO 2016). These areas are known as townships and are normally situated on the edges of cities in much less appealing areas compared to those where most white South Africans reside. For example, in Cape Town this type of area is known as the Cape Flats, also being referred by some as "apartheid's dumping ground" (Clark 2016). This is a flat basin crammed with houses and shacks with very little greenery or breathing spaces in between.

Townships still remain as the main residence for the black South Africans. Also, unemployment rates are much higher within the black South Africans (Stats SA 2015, cited in Wilkinson 2015), followed by income rates where white South Africans families have five and a half times higher income compared to black South Africans families (2010/11 Income and Expenditure of Households Survey, cited in Wilkinson 2015). It is also relevant to note that at work places high management positions are majorly held by white South Africans, this is as high as 70% (2014/15 Commission for Employment Equity Report, cited in Wilkinson 2015). This type of inequality and poverty strike up a lot of frustration. Crime rates soar especially in townships and violent protests are very common. Mamabolo (2015, 145) confirms how “poor people tends to vent their frustrations through violence”. Desperation is a driving force for crime too. People living in utter poverty are ready to do anything just to survive from day to day. As already discussed in the above, it is the distribution of wealth that is driving the deepest gap between the ethnicities.

Cape Town is situated in the Western Cape province and has approximately four million inhabitants. It consists of eight major suburbs where the Atlantic Seaboard, City Centre and Peninsula are the wealthiest ones and Cape Flats the poorest. The wealthy suburbs are located in areas captured by natural beauty, the Table Mountain National Park and the Atlantic and Indian Oceans. A lot of the housing is located in places offering breath-taking views with plenty of space and air. These areas are also very popular with the tourists. Cape Flats, as mentioned in the above, offers a very different experience with its cramped housing and lack of greeneries and nature. Parts of the area are dominated by shacks made out of corrugated metal, plastics, cardboard and wood. These belong to informal settlements where the occupants do not have any legal claim to the land (OECD 2001). They characterise the roadsides along with all kinds of waste, rubbish and litter. Lack of proper sanitation and many disease outbreaks are common in these areas too.

Due to the extreme poverty and poor conditions that many people live in, combined with high unemployment, the crime rates are soaring in Cape Town. This is relevant for the whole of South Africa, but as my work practise place took place in Cape Town, and that is where the data comes from, it is important to see the statistics from there. For example, it can be very dangerous for social workers, health care and emergency services, even police to enter high crime areas (Staff member 1 2018. Personal communication). The graph below (Crime Stats n.d.) shows ten worst districts for crime in 2018 in whole of South Africa, and four of them are in Cape Town. These are Cape Town Central, Mitchell’s Plain, Kraaifontein and Nyanga. If these segments are put together, one can see how they take up nearly half of the graph. (See Table 1 on page 10).

Table 1: Ten worst districts for crime in South Africa 2018



1.3 Working Life Partner - Autism Western Cape

Autism Western Cape is a non-profit organisation that was established in 1967 and was formerly known as Society for Autistic Children. It serves the Western Cape area in Cape Town. The main offices are based in Mowbray, an area that is part of the Southern Suburbs. (See figures 1 and 2 on page 11). Main focus of the organisation is to provide support/emotional support and education for autistic people and their parents and carers emphasising strongly empowerment, inclusion, acceptance, advocacy and awareness (Autism Western Cape n.d). Both the child and the parent are equally important. The ethos of the organisation is that autism is not something that needs to be cured, it is not a disease. The organisation advocates the concept based on social model of disability and neurodiversity where the organisation's core intervention is to let the autistic person to be the person they can be without trying to fit in the neurotypical world (Delpont 2018. Personal Communication). Definitions such as high and low functioning are not used, but replaced by low support, medium support and high support ones. This is to respect the autistic community and how it feels about the high and low functioning definitions. An article in Autistic Advocate by Rose reinforces this:

Autism is Autism, it's the same for every Autistic person. There are no degrees of Autism, one person is not more or less severe than another. Certain people are able to have better support structures and coping strategies than others, the underlying Autism is the same. It just affects different people differently, often with a co-morbid condition exacerbating the problem (2017).

The organisation's services include weekly clinics where a social worker offers support and advice after diagnosis. These clinics are at Red Cross Children's Hospital, Lentegeur Psychiatric Hospital and at Tygerberg Hospital. The clinics provide basic information on autism and advice

how to cope. There is also information given on further support groups and workshops where parents could get more in-depth knowledge and help. Autism Western Cape offers also training for schools, creches, work places and centres (Autism Western Cape n.d). This is to teach what autism is and what are its most common traits. This way professionals and employers can hopefully recognise an autistic child or an adult and provide help and assistance accordingly. There are many workshops Autism Western Cape runs that concentrate on multitude of issues, such as behavioural issues, bullying, toilet training, social interaction, sleep improvement and multisensory teaching, and also TEACCH and PECS combined with Sign Language (Autism Western Cape n.d). Monthly parental support groups take place in various locations around Cape Town and Western Cape areas. Counselling is given to any service user or parent in need and the social workers also do home visits providing the above if the service user/parent is not able to come to the offices. For adult service users, again, there has been workshops to aid them to get employment, social outings and meeting groups in the past.

The usual service user process, especially when children are in question, starts from the local GP where service users are referred to a government hospital where they are diagnosed/assessed and then informed of Autism Western Cape's clinic. Parents can come along to the clinic and get further advice. The hospital also gives forms with service user information to the organisation. In this case, a social worker makes contact and collects further information and sets up an appointment to start the process. Parents and service users can also directly contact the organisation, explain their concerns and receive assistance accordingly, e.g., meeting, counselling, support group etc. Autism Western Cape is the only organisation of its kind in the Western Cape area and the demand for the type of service it offers is huge. It is a small organisation with only eight staff members, and they are extremely busy with their work. Majority of the service users cannot afford the private sector either, and therefore, rely heavily on Autism Western Cape and its resources. The staff also has a good understanding of the service users' cultural and economic backgrounds.

Figure 1: Autism Western Cape offices

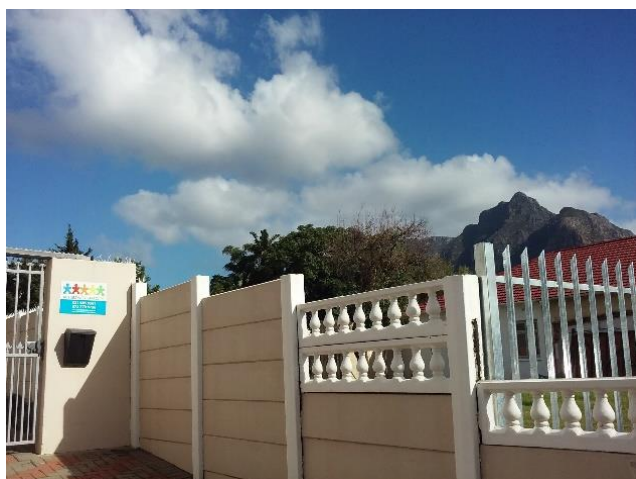


Figure 2: Front entrance to the offices



2 Autism in South Africa

Autism is still largely an unknown disability in South Africa. According to Harvey & Meyer (2018) there is “little awareness” about autism in the country, and a correct diagnosis is only given to 10% of autistic people (de Vries 2018, cited in Harvey & Meyer 2018). There are many people who have not even ever heard of the condition. In the sub-Saharan Africa the focus on children’s health care has been on diseases like Malaria, HIV, Tuberculosis and reducing infant mortality, therefore leaving no room for the study on autism and neurodevelopmental disorders alike (Boonzaier 2017).

Normally, when parent(s) notice that there is something different with their child they go to their general practitioner where the child is being referred to a government hospital where the diagnosis is done. In Western Cape, organisations like Autism Western Cape can then provide further support and information, but this might not be the case throughout South Africa. If the families live in rural areas or speak another language than English the chance of not being diagnosed is much higher (de Vries 2017, cited in Zeliadt 2018), also other support is not readily available. When there is so much unawareness towards autism it is not surprising parents not acting upon and seeking help for their autistic child. Also, cultural factors can prevent the search for assistance, i.e., social worker 1 (2018, personal communication) explained how especially in township communities people can perceive the autistic person as being possessed, thus making the parents afraid that the community does not accept the disabled child.

On a research and management level South Africa, among other African countries lacks the usage of appropriate tools when finding more about autism (Durkin et al. 2015, cited in Abubakar et al. 2016) due to “cultural appropriateness, cost of translations and adaptations, and copyright-related costs” (Ruparelia et al. 2016, cited in Abubakar et al. 2016). The truth is, though, even if the early diagnosis is done, it does not guarantee a child receiving inclusive assistance, intervention and help. The government hospitals offer speech and occupational therapy. According to Adams (2018, personal communication) a therapist who is in charge of the assessment might put the family’s needs before the autistic child’s needs if they see that the family suffers from poverty or has other problems. Also, the therapy session normally will not last for more than six months where the child goes to therapy once a month, which by far is not enough. According to Raising Children Network (n.d.) an autistic child needs 15 to 25 hours of therapy each week. Adams (2018, personal communication) also noted that if the family wants to continue with the therapy, they can be referred to their own clinic. The problem here is that many times the professionals in these clinics do not have special knowledge on autism, therefore, making the assistance and intervention pretty much non-existent.

Another problem regarding children is education. According to Autism South Africa (n.d.) there are five schools in the whole country that specify in autism spectrum disorders. There are other

schools that cater for children with special needs and may help autistic children too but inclusive help is not guaranteed. In mainstream schools teachers often do not have or have very little knowledge on the condition and do not know how to teach and manage autistic children. For this reason, main stream schools are not welcoming autistic children with open arms and autistic children are left out of education. “South Africa has failed to enforce the right to education for many children with disabilities” (2015 Human Rights Watch Report n.d., cited in Zeliadt 2017). Zeliadt (2017) continues on discussing how in Western Cape, for example, out of 1684 autistic children 940 are at schools but as many as 744 are on waiting lists. These waiting lists can be as long as three to four years. This is extremely disheartening to the parents who want their children to be educated, included in society, have contact with other children outside home and live normal lives as much as possible.

The above is predominantly considering autistic people and their families who cannot afford private health care and private education. According to a social worker 1 (2018, personal communication) only 5-10% of the population can afford to go private. On the private sector the above issues are not as dire by long shot. There are private creches, intervention centres and schools catered purely for autistic children. For example, there are lots of one to one therapies that are tailored according to each child’s needs, such as play therapy, music therapy, sensory integration and development of social and perceptual skills. (Centre for Play and Learning n.d.). Wealthy families can also have the chance to access more specific therapies, like horse riding, swimming, surfing and art.

Even though, autism is not well-known in South Africa, there are organisations, in addition to Autism Western Cape, that are working hard raising awareness on autism and helping autistic people and their families. There are also ongoing research programs that are concentrating on “screening and diagnosis, interventions ad training, understanding systems and technology” (Centre for Autism Research in Africa n.d.). Last spring, in April 2018, I had a privilege to take part in an autism conference in Cape Town organised by the University of Cape Town. The event was first of its kind and present were four researchers from Centre for Autism Research in Africa, four South African autism organisations, members of the autistic community and audience made out of other professionals and families with autistic children. It gave an overview what is happening with autism, autistic people and autism research in South Africa. The results gave an understanding that good progress is taking place but there are many challenges, such as the ones been discussed earlier. Below is brief overview on the research and the work of the organisations I was able to learn about.

The four researchers were Dr Petrus de Vries who is the founding member of The Centre for Autism Research in Africa (Centre for Autism Research in Africa n.d.), Dr Lauren Franz, Dr John-Joe Dawson-Squibb and Dr Liezl Schlebusch. Dr Franz is concentrating on improving access to

early intervention in the whole of Africa. Dr Dawson-Squibb, again, is focusing on Early Bird program that was developed in the UK in the late 1990's. Its main aim is parental training and giving parents tools how to cope with their autistic children. At the moment it is run at the Red Cross Children's Hospital in Cape Town and, according to Dawson-Squibb (2018), parents are calmer, confident, accepting and more prepared after when they have attended the program. Dr Schlebusch's project is Diamond Families Project that aims to pilot test the World Health Organisation's Caregiver Skills Training Programme for those families who have children with developmental disabilities living in areas with very little resources (Schlebusch 2018). The project aims to find out whether the training programme can work and is feasible in South Africa (Centre for Autism Research in Africa n.d.).

The organisations that took part were my work practise place Autism Western Cape, Autism South Africa, Autism Connect and Autism So What. Earlier on, I already discussed about Autism Western Cape's work and efforts. Autism South Africa is a nationwide organisation located in Johannesburg providing information, parental support, training, advocacy and lobbying (Autism South Africa n.d.). It also has a list of service providers in each of the nine provinces, the providers mostly being government and private hospitals, therapists and paediatricians. Autism Connect is a day care in Mitchell's Plain township in Cape Flats for autistic children who have not been accepted at school. The aim is that after the child completes at Autism Connect, they would stand a chance to go to a school that caters for autistic children. The organisation was founded by a mother with an autistic child who was declined a place in an autism school, and the family could not afford any other options (Autism Connect Learning Centre, Cape Town 2013). Autism So What is an internet-based community on Facebook bringing people who are touched by autism together, sharing information, advocating and in its own words "demystifying autism to increase acceptance and inclusivity" (Autism So What leaflet n.d.). The founding member also has an autistic child.

3 Disability Legislation in South Africa

In South Africa there is no specific disability act but a policy and a framework. An act is already implemented in the law whereas a policy offers objectives that are set out to be accomplished. White Paper on the Rights of Persons with Disabilities explains:

The Constitution of the Republic of South Africa, 1996 protects the rights and human dignity of persons with disabilities. The Constitution is further translated into several national policies and legislation that promotes and supports the full equalization of opportunities of persons with disabilities; and their integration into society; within a social model and human rights policy framework (2015).

Section 9 of the Constitution forbids the discrimination of disabled people (South African Human Rights Commission n.d.). I will be concentrating on White Paper on the Rights of Persons with

Disabilities, Children's Act and Policy on Disability from Department of Social Development. These documents were forwarded to me by Autism Western Cape as they should best inform the context of disability legislation. The Department of Social Development is the main governing body with responsibilities on "management and oversight over social security, [...] encompassing social assistance and social insurance policies [...] and developmental social welfare services" (National Government of South Africa n.d.). Anything to do with social welfare from legislation, policies, development and various services to funding and training non-profit organisations passes through this department. Also, the United Nations Convention on the Rights of Persons with Disabilities has been incorporated into South African legislation. In the following I summarise the above policies hoping to give a coherent overview of the South African disability legislation to the reader.

United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention defines principles and obligations that should be followed and taken into account when dealing with disabled people. This is an extensive guideline covering a broad sphere of human life. These are considering, for example, equality, disabled women and children, raising awareness, accessibility, freedom, security, independency, privacy, education, health, work and participation (United Nations Convention on the Rights of Persons with Disabilities n.d.). In South African context the main point to note here is the embedding of the United Nations Convention's obligations to its "legislation, policy and service delivery" (White Paper on the Rights of Persons with Disabilities 2015). The Baseline Country Report (2013, cited in White Paper on the Rights of Persons with Disabilities 2015) to the United Nations Convention on the Rights of Persons with Disabilities demonstrates that disabled people, especially children, are still vulnerable facing inequalities and families with disabled offspring face violations to their rights on a daily basis. It further states that each article in the United Nations Conventions should be strengthened and interventions should be better coordinated and targeted (The Baseline Country Report 2013, cited in White Paper on the Rights of Persons with Disabilities 2015).

White Paper on the Rights of Persons with Disabilities

The White Paper on the Rights of Persons with Disabilities states that all South African citizens are equal and the society inclusive regardless of person's disabilities (Bogopane-Zulu 2015, cited in White Paper on the Rights of Persons with Disabilities 2015). It is committing duty-bearers to be responsible for delivering services to all citizens throughout South Africa and making sure they have equal rights to services (UHAMBO n.d.). The White Paper is built on nine "pillars" that are specifically created to get rid of discrimination against persons with disabilities (Bogopane-Zulu 2015, cited in cited in White Paper on the Rights of Persons with

Disabilities 2015). These deal with removing barriers that prevent participation and access, protecting the rights of disabled people, supporting unified communities, supporting the empowerment of disabled people, children, women and adolescent, reducing economic hardships, ensuring a stronger voice for the representative of the disabled, building of government structures and processes that support the disabled people, promotion of international cooperation and monitoring and evaluation processes (Bogopane-Zulu 2015). Bogopane-Zulu (2015) continues that the vision is to implement White Paper on the Rights of Persons with Disabilities into South African legislation by fully checking for any gaps in current legislation at the same time as developing the new legislation. It is also important to note here the White Paper on the Rights of Persons with Disabilities view on disabled children and their access to education. The document states that parents of these children need to be empowered and supported, they should have a fair access to education that also includes an inclusive early childhood education and they have safe environments where they are cared for (UHAMBO n.d.).

Children's Act

Children's Act lays out a comprehensive set of objectives that are to ensure the promotion of reinforcing families, reception of care when own family cannot provide it, protection from neglect and making sure child and child's needs always come first, providing for services that are promoting and monitoring the overall wellbeing of children, developing structures in the community that are assisting in giving care and protection for children, protection from harm and discrimination, providing care and protection for those children who need it, recognise the special needs that disabled children have and general promotion of wellbeing, protection and development of children (UHAMBO n.d.). It also has a specific section that is concentrating solely on children with disabilities. It is very much in line with the general objectives but defines that disabled children should be able to receive special care, have inclusion and participation regardless of their disability, to be provided with needed support services, have a right to self-reliance and dignity and a disabled child should not be subjected to any religious, cultural practises that can have an adverse impact on the disabled child's wellbeing and dignity (Children's Amended Act 41 2007).

Department of Social Development Policy on Disability

This policy runs in conjunction with the above legislations pointing out that disabled people need to have a right to self-representation considering the decision-making processes and structures that involves them, and in case they are unable to self-represent they can appoint a family member to do so. Support system needs to be such, where the family is encouraged and advocated via training and information to be the main source of support. Important notions are also, all-inclusive accessibility, awareness raising, inclusion and integration in society, ensuring

independence and self-respect, access to relevant services, collaboration between different sectors in order to provide better all-round services to disabled people and making sure there are enough resources, both monetary and human, allocated.

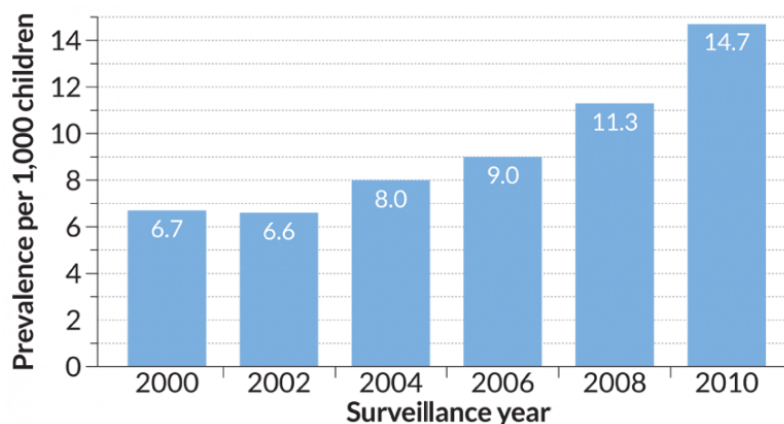
4 Autism Spectrum Disorder

For the purpose of the thesis it is important to outline the basic notions of autism spectrum disorder in order to give more information and an understanding what autism is, what can cause autism and the typical traits of autism. I am hoping this will clarify in South African context, why many times autism is misunderstood and why autistic people may find it even more difficult to integrate into South African society compared to a society where autism is very well known and autistic people receive equal assistance. It is also important to discuss the general well-being of autistic people and their parents, as this goes hand in hand with the societal awareness and assistance available.

World Health Organisation (2017) declares that every 1 child in 160 children has got autism. The estimate is that globally there are between 1%-2% of people that are autistic (de Vries n.d., cited in Jeynes et al. 2018). What comes to figures in South Africa, Lamb (n.d., cited in Jeynes et al. 2018) estimates that the figure based on worldwide measures can be approximately one million, but goes on discussing that there are not enough professionals who can diagnose autism. Zeliadt (2017) explains that in sub-Saharan Africa there were as little as 50 psychiatrist in 2015 serving children and adolescents. Also, problems discussed earlier in chapter 2 have an impact on autism diagnosis in low to middle income countries.

Figures for autism have been increasing during the past two decades. Many argue that this is due to autism awareness and better and more thorough diagnoses. Nygren et al. (2012, 1495) point that, today, professionals and the general public are more aware of autism, the criteria for diagnosing is much wider than in the past and definitions for autism have changed. Gillberg & Fernell (2014, 3274) argue, again, that autism diagnoses are given too easily to children who are showing signs of other disorders, like ADHD, language disorder or an intellectual development disorder. The authors (2014, 3275) explain that, for example, in Sweden a child can receive support at school and in a wider community when diagnosed autistic but if diagnosed with other disorder the support is not guaranteed. Even though, this could be a case regarding other countries as well, the majority of arguments point towards the fact that it is the general awareness in the society and development in diagnosis that makes it easier to detect autism today. The graph below from the US (CDC Statistics n.d., cited in Sanders 2014) shows the increase in autism diagnoses between the years 2000 and 2010, and we can clearly see how within one decade the diagnoses have more than doubled. (See table 2 on page 18).

Table 2: Increase in autism diagnoses between the years 2000-2010



4.1 Possible Causes for Autism

Autism is a neurodevelopmental disorder, which effects are predominantly seen in autistic person's social behaviour, interactions, communication and in restricted and repetitive behavioural patterns (Lathe 2006, 20). Obsessive behaviour and getting very attached to certain objects, interests, and activities are common indicators too. A lot of research has been done on autism as a whole and what causes it, but there are no definite answers to these. It cannot be defined into one category where it is a disorder caused by a one concrete factor, e.g., one extra chromosome like in Down's Syndrome. The interest lies in in the notion of what can cause the typical autistic traits, as autistic people and the levels that autism affects them can be very different.

The traditional definition is a measure from high functioning to low functioning. Where high functioning autistic person's behaviour resembles more that of a neurotypical one and low functioning autistic person's behaviour extensively exhibits the autism traits. There is controversy against these definitions as discussed in chapter 1.3 but they are still widely used in literature, research papers and in everyday language to define autistic people. Freeman Loftis (2015, 9) does argue that these labels can serve an actual purpose as they can help determining what kind of assistance could be best suited for an autistic person, but the author notes, as well, that person labelled as high functioning might live independently and communicate more verbally but a person labelled as low functioning can, again, have much higher IQ and communicate much better in writing.

For the possible causes, scholars have looked into different fields, such as genetics, the brain and environmental factors. These are the ones I concentrate on. Research in genetics has shown a strong link between autism and genes where studies concentrated on twins have demonstrated that those who come from the same egg cell have both over 60% possibility to be

autistic, whereas twins from different egg cells share no probability at all (Pérez et al. 2006, 291). According to Pérez et al. (2006, 291) this type of evidence is a high proof for genetics playing a big part in autism. Studies of families have shown that through generations there is “the possibility of an increase in the severity of the phenotype [...] due to the involvement of multiple autism genes” (Pérez et al. 2006, 292), meaning the severity of the disorder increases from one generation to the next. Pérez et al. (2006, 292) also note that due to this, autism can be more distinct between first degree family members. The heritability rate of autism has been calculated to be as high as 90% (Lathé 2006, 39).

Also, “10- 15% of individuals with Autism are estimated to have another genetic disorder, such as Fragile X or Tuberous Sclerosis” (Yapko, 2003, 65). Even though studies have demonstrated a strong link between autism and genes, Lathé (2006, 42-45) continues on arguing that such notion as gene for autism does not exist and the exact autism genes are not known. Autism does not arise from any particular gene abnormality alone but needs other factors to go with the genetic make up to fully develop itself into autism spectrum disorder.

The other contributing element to the development of autism is neurological. Here, as in genealogy extensive studies have been made to find out which parts of brain autism affects and how it affects them. Coleman & Gillberg (2011, 84) explain that the causes are “dysfunctional cortical networks”. Meaning that neural pathways and connections between different parts of the brain are not functioning as they should be. The authors (2011, 87) also argue that there are faults in both the right and the left side of the autistic brain, and also between the two hemispheres. Lathé (2006, 85-86) continues arguing that abnormalities in the limbic brain are most likely to cause autism and anomalies in the cortex and cerebellum contribute to it. Coleman & Gillberg (2011, 87-96) discuss that autistic children have been found to have larger cerebral cortex and that autism results of abnormalities in many regions of the brain. Yapko (2003, 64) sums up that “Any condition that affects the central neurological system’s development is a potential cause of ASD”.

Environmental factors are also debated having a major impact on autism. As with the above two arguments with the genetics and the brain, there are many researches done on the environment and its effects. Lathé (2006, 115-116) explains how exposure to heavy metals shows abnormalities in the same parts of the brain as autism does, and how the limbic brain, especially, is very sensitive to harmful substances. Coleman & Gillberg (2011, 291-292) explain that genetic mutations can be caused by toxins in the environment and autism exhibits mutated genes. Effects of many toxins have been researched, for example, phthalates that are being used in many products in our everyday lives, including children’s toys, have been said to increase the chance of interference with a normal brain development (Coleman & Gillberg 2011, 293). TMT is known to cause damage in the limbic part of the brain as well (Lathé 2006, 116).

Drugs, even some prescription drugs, smoking and excessive use of alcohol by the mother whilst pregnant are also associated with the development of autism (Lathe 2006, 88). Lathe (2006, 88-116) clarifies that environmental factors most probably do not have a direct cause to autism but they can trigger its development in individuals who have the genetic disposition to autism.

4.2 Typical Characteristics of Autism

The most common characteristics that distinguish autistic people are difficulties in communication, social interactions, behaviour, learning, and sensory motor skills. Yapko (2003, 35) discusses how there can be problems and delays in development and learning of language and speech. Individuals may communicate very little and instead use gestures and point at things or express a repetitive usage of same words and phrases, or only repeat words and phrases that someone else has said. Also, autistic people have often difficulties sustaining conversations, and many times they can continuously keep on a one-sided conversation unintentionally ignoring the person(s) they are talking to. An individual's spoken language might not be in sync with their body language, the tone can be monotone not matching the feelings they want to express, therefore making it hard for the listener to fully comprehend what is going on.

For an autistic person, this can be very frustrating and discouraging. Frith (2008, 72) points out the difficulties with communication also arise, as autistic people do not generally gossip or chitchat, as the information exchange is the only part that is seen necessary. Yapko (2003, 35) reaffirms that use of humour and understanding humour can be difficult. Use of language is not the same across the autistic board either. Some individuals exhibit remarkable language usage and vocabulary, whereas others use language very minimally (Arciuli & Brock 2014, 8). Understanding body language, facial expressions, and emotions is normally challenging too, and maintaining social interactions tends to become very demanding. Sarcasm, hidden social clues, and messages can go completely unrecognised.

Poor motor and uncommon sensory skills are often linked with autism too. These are typically "locomotor and object control skills" such as "running and dodging, jumping, skipping, leaping, galloping, sliding, catching, throwing, dribbling, striking an object with an implement, and rolling a ball (Todd 2012, 32). Uncommon sensory skills can include being sensitive to loud noises and sounds, or showing a complete lack of recognition, e.g., their own name (Volkmar & Wiesner 2009, 484). Autistic people can also "be preoccupied with the feel or texture of things or other sensory properties" (Volkmar & Wiesner 2009, 484). The authors give an example where children playing with a dolls house prefer to feel the different textiles and surfaces in the dolls house rather than play with it and its characters (Volkmar & Wiesner 2009, 484). Expressing empathy and putting themselves in other people's shoes and trying to understand how others are feeling is very challenging for autistic people. Therefore, they can sometimes come across as selfish and cold for those who do not understand the traits of the condition. They can also

express obsessive behaviour and get very attached to certain objects, interests, and activities. An autistic person can devote passionately to one specific matter. Routines are very important too. In *The Autistic Me* (2009) programme one of the participants explains how routines and repetition bring feelings of safety to him, whereas uncertainty and sudden changes promote chaos.

4.3 Wellbeing of Autistic People and Their Parents

The discussion above has highlighted the main traits and characteristics within the spectrum, and we can see how autism and autism spectrum disorders influence many core areas in an individual's life. By having an effect on these areas autism also has a direct effect on a person's wellbeing. Difficulties in social interactions, communication and learning contribute to social, emotional, and mental wellbeing. Poor motor and sensory skills influence the above as well, but they also contribute to physical wellbeing. Also, the older a person gets, the more distinct can the isolation feel, as they can see people around them forming relationships and families, getting jobs, and moving on with their lives. *The Autistic Me* (2009) programme showed how hard it is for an autistic person to find a partner and have a relationship due to all the difficulties with social interactions and communication. They want to have a so-called normal life, girlfriend/boyfriend, job and a place of their own etc. but a lot of the times they are incapable of maintaining conversations, rapport, or managing their lives independently. The programme also stated how only 15% of people within the spectrum are in employment (*The Autistic Me* 2009). These factors lower feelings of worth and self-confidence, and can also cause depression, further contributing to the feelings of isolation and exclusion from the rest of society.

It is not only the autistic people that are having anxieties and difficulties. Many times, their parents are equally, or even more worried for their children. Some parents may feel embarrassed for their child's behaviour if it is particularly difficult and, therefore, avoiding going out to public places, this possibly leading to feelings of anger and resentment towards the child (Volkmar & Wiesner 2009, 554). Some parents, again, may feel guilty and responsible for their child's condition, and those having high hopes towards perfection might possess feelings of disappointment their child needing extra support (Volkmar & Wiesner 2009, 552). Griffith et al. (2012, 244-245) found in their study that parents with adult children with Asperger's Syndrome felt isolated whilst supporting and assisting their offspring. Feelings of exclusion resulted from their role as a helper not being visible to anybody else outside the family unit. The authors also discovered parents being stressed out, tired and fatigued for many years as caregivers, and also struggling with their child's, sometimes, irrational behaviour. All parents wanted a comprehensive support for their children to ensure them a good quality of life once they were gone, and the possible failure for this to happen was a great concern. The authors found out that all the above combined was a great strain on parents.

5 Assistance and Support Relevant to Autism Western Cape

The above highlighted the difficult notions autistic traits can have on an autistic people and their wellbeing and, at the same time, on their parents' wellbeing. There are a variety of assistive methods and interventions to help the individuals with their difficulties. There is also assistance and help available for parents. In the following, I give an overview of the interventions and assistance that are part of Autism Western Cape's work. I concentrate on interventions and support I learned about during my stay. These interventions do not concentrate on changing the autistic person's behaviour and, according to Delport (2018, personal communication), are supported by the autistic community. These are Parent Implemented Interventions, TEACCH and PECS. The organisation's program is very much geared towards parents learning and being able to engage with their autistic child. Intervention and help come from the family. I also discuss about peer support, organisational advocacy and development. Peer support is related to the parental support groups the organisation is running and the advocacy and development to the organisation's aims to spread autism awareness and improve its services.

5.1 Interventions

The idea behind training and educating parents to help their autistic child can be linked to parent-implemented interventions where everything is entirely parent lead. Parents take charge of the activities involved and the implementation of the intervention. Hendricks (2009, cited in National Professional Development Center on Autism Spectrum Disorders 2010, 1-14) has gathered together the main elements of this type of intervention. He explains that the family works together with other possible caregivers and the professionals that are involved in the child's development. First of all, a plan is formed specific to the child and the whole family. Each parent/caregiver might have a different task where one can concentrate on routines during the day and the other on routines during the evening and the night time. Parents go through training where they are given instructions on how to implement the intervention. The ongoing intervention is monitored where parents give information on what was done, when it was done and how it was done. They need to give information on any behavioural changes and possible worries. Throughout the intervention there should be continuous supervision and support as well.

De Vries and Yeatman (2018) explain how the parent lead interventions might be more suitable in low to middle income countries, like South Africa where there is a lack of resources and other problems like discussed in chapter 2. Boettcher Minjarez et al. (2011, cited in Gena 2016 et al., 25) join in noting that autistic children's need for interventions and assistance are much greater than provided services. This enforcing the importance of parent-implemented interventions. Gena et al. (2016, 25) also discuss in their study how training parents in interaction and communication interventions and using these with their child not only had a positive impact

on their children's behaviour but also improved the relationships between the children and their parents.

TEACCH stands for Treatment and Education of Autistic and Related Communication Handicapped Children (Yapko 2003, 117). It is a method specifically concentrating on educational side and focuses on "the person, their skills, interest and needs" (National Autistic Society n.d.). Yapko (2003, 117) mentions that TEACHH is not just using one type of methodology but is more individualised and multifaceted assistive method aiming to create an environment for children with special needs that has less overstimulating, interfering or stress increasing factors. The author continues explaining that the method also uses visual schedules that are helping to organise the child's daily life. This can mean using pictures for different routines allowing the child to see and understand what needs to happen throughout the day. This is especially helpful for children who have anxieties about what is expected of them or what they should be doing. The consistency in scheduling, routines, visual instructions, activities bound in specific physical setting (Applied Behavioural Analysis Programs Guide n.d.) are the core of the TEACCH method. Yapko (2003, 117) also points out that the way TEACCH is delivered encourages child's own independence. This was also validated in a study by Van Bourgondien et al. (2003, 138-139) who found out that participants who took part in a programme based on TEACHH's philosophy and methods had positive developments in the areas of communication, social skills, behaviour management and independence. This intervention is not purely meant for children but is suitable for all ages.

Picture Exchange Communication System (PECS) is a system that uses pictures as a means of communication. Yapko (2003, 121) explains how the end goal of the intervention is for the autistic person to begin the communication process. Lerna et al. (2012, 610) describe the process as follows: The steps to reaching goal of communication initiation start from teaching the individual to exchange pictures for items that they would like to have, moving to differentiating between the pictures that they prefer and the items that they prefer, and then starting to make requests by using full sentences. This is the phase where the child is taught to use symbols and at the end make requests. The authors continue explaining that next the child enters the communication expansion phase where they learn to answer questions and make comments. The authors also argue that PECS is a valid intervention method, as their studies showed that the group of children who were given this method came out with better attention and initiation skills compared to the group who did not receive PECS. The children who used PECS also were able to play longer with other children and make requests.

5.2 Peer Support

Peer support in general is defined by "People coming together with shared experiences to support each other" (Faulkner & Basset 2012, 41). People are utilising their own experiences by

means of supporting others (Beales & Wilson 2015, 316). Faulkner & Basset (2012, 46) also explain how it developed from people in need wanting to set up their own networks of support and assistance. Peer support groups can be informal where they are formed naturally, i.e., on a voluntary basis in self-support groups, or they can be more formal where there is a peer support person in charge who is getting paid (Beales & Wilson 2015, 316). The authors explain that no matter what the case is, the support always needs to be led by service users and needs to be based on equality where everyone benefits mutually and share responsibility. Bray et al. (2016) discuss in their paper on peer support groups with parents who have disabled children how many of the them were experiencing high levels of stress and felt that life was just a day to day survival, and how they had really benefitted from peer support. The authors describe it is exactly the ability to share similar experiences that is the core of peer support, as in this case it is easy for participants to understand each other. They continue discussing that there is evidence of positive effects on wellbeing.

Faulkner & Basset (2012, 43) have also found multiple positive effects on self-confidence, skill development and stigma reduction. They are also explaining how peer support is empowering by means of feeling useful by helping others by sharing own difficulties. Beales & Wilson (2015, 321) argue that empowerment comes by transforming people from passively receiving to actively leading their own and others recovery processes. Beales & Wilson (2015, 317-318) note that it is not only the participants that are gaining on this type of method but it is also the staff of the establishment. When peer support has been implemented well, the staff's workload and the demand on them can be reduced. This method should also increase the communication between the professionals and the service users. The authors (2015, 322) stress that before setting up a peer support as an assistive method, the establishments need to very carefully establish why do their want peer support, what do they think peer support is, what do they want out of it and who will be providing it. This will ensure that no one is wasting their time and people who want to help their peers get to do exactly that.

5.3 Advocacy and Development

Both of these concepts are important in Autism Western Cape's work, as they are important when raising awareness, trying to better vulnerable individuals' situations and developing services that are more suitable for service users. Jenkins (2012, 36) discusses how advocacy is a beneficial approach when wanting justice for vulnerable people, helping vulnerable people through juridical processes, and safeguarding and representing vulnerable people. It is an act where a body, an individual or self is representing and supporting the others in need or themselves in order to either secure or exercise their rights (Dunning 2005, cited in Jenkins 2012, 32). Daly (2011, 26), again, discusses that the process of advocacy should entail a variety of methods and not just one type. The author explains that this is important as people perceive

and learn information in different ways, some of us are more visual, some of us perceive the message better by hearing whereas some of us need to be physically doing something.

When it comes people with learning difficulties, according to Walmsley (2001, 26) they are still one of those groups that are relying heavily on other people to do the advocating for them. Gray & Jackson (2001, 10) continue explaining that it is the notion of everyone's equal rights and responsibilities that drives the advocacy for people with learning difficulties. They argue that we need to fight the exclusion and discrimination that they are still facing and aid them to access their legal rights and human rights. OPAAL (2009 cited in Jenkins 2012, 33) notes that the results of various advocacy schemes have been very satisfactory and have been helpful in preventing abuse and in improving self-esteem.

Development work is vital for any organisation. Phibin & Mikush (n.d., 7) discuss of non-profit organisational development work and its connection to the staff's passion who is involved in the development. This is directly linked to the desire to better and make difference in the communities. The authors also discuss how development work can help organisations through transition and change and how it can directly be linked to the organisation's survival. This can mean a new development project transforming the organisation and its purpose to a new level. According Phibin & Mikush (n.d., 7), through development work and projects the credibility of the organisation can be also increased. This may come down to a successful project that delivered all its aims.

I encountered the concept of Asset-Based Community Development model at Autism Western Cape. This type of development work is based on the idea "what is present in the community" (Payne 2006, 29). Payne (2006, 25-30) describes this meaning the ability of the community finding solutions within itself. This is opposite to the community development work where the solutions are found through looking into the current issues and problems within the community. By doing this the service provider can create dependency, as the members of community come to believe that the service provider is the only one who can solve their problems. The focus is too much on the problems. The author explains that in asset-based community development the community members are actively interacting and collaborating with each other in order to find out if any of them have any relevant skill sets. Many times, people find out that there are various relevant skill sets within their community. Identifying these common assets and working together achieving a common goal also strengthens social ties. Therefore, it can be clearly seen how asset-based community development work empowers communities and makes them more independent.

6 Social Model of Disability and the Concept of Neurodiversity

I was introduced to these two concepts during my time at Autism Western Cape and I had a chance to learn about them, their meaning and purpose in the work of the organisation. Most importantly, I found out how important these concepts are for Autism Western Cape. Delport (2018, personal communication) said that Autism Western Cape's focus is on neurodiversity. They tie up with the idea of making it possible for an autistic person to be the person they can without trying to change themselves to fit in neurotypical society, instead having the society changing its views. "Optimising as supposed to fixing" (Delport 2018, Personal communication) was one of the ideas I learnt from the director at the time, which is referring towards the notion where autistic traits are used in a best possible way in an autistic person's life.

Social model of disability rose to oppose the medical model, which has said to victimise disabled people in a way where the disability is seen as a personal hardship and a struggle (Oldman 2002, 794), and something that needs to be cured (Freeman Loftis 2015, 5). The social model's main idea is that it is the society that acts as a disabling factor in disabled people's lives (Barnes & Mercer 2006, 35). An example of this can be care directly delivered to the disabled person instead of them choosing personal support that they can be in control of (Oldman 2002, 793). Accessibility is one important factor, as well. The better the accessibility the easier it is for a disabled person to be independent and to be included. The social model concentrates on the socio-political change instead of trying to purely concentrate on rehabilitating the individual, taking into account whole array of factors, such as the disabled person, their relationships and life histories, possible barriers, society's attitudes and the impact of policies and the welfare system (Barnes & Mercer 2006, 37). It is advocating independency, equality and inclusion and aiming to decrease dependency that leads to exclusion (Barnes & Mercer 2006, 37).

Neurodiversity promotes the idea that autism spectrum disorders are not a negative set of neurological disorders but a "positive neuro-variation" (Cascio 2012, 273). Autistic brains are just wired differently but this is nothing negative, or nothing that needs to be cured or changed. The interventions are only to assist the autistic people for them to achieve their full potential (Cascio 2012, 273). Neurodiversity also embraces the variety of characteristics in autism and the fact that each autistic person can experience autism differently and that society should accept neurodiversity by means of accepting differences and variations within us, thus reducing stigmas that are attached to those who do not act the neurotypical way (The Lancet 2016, 2479). In *What You Need to Know About Neurodiversity* (2018) video psychiatrist MacEachron talks about genetics' impact on neurodiversity. She claims that the genes for autism are not faults in our genetic make-up but rather variations that are advantageous in our society. MacEachron continues explaining that autistic genes have been positively selected in the human evolution due to their contribution to have a better memory, attention to detail and more

intensified awareness of vision, taste and smell. Polimanti's & Gelernter's (2017) study backs up the strong position of positive natural selection and autism. They argue that this is due to the cognitive abilities that the genes in question enhance.

It is important to mention here that not all autistic people or parents of autistic children support the neurodiversity movement and the ideology behind it. Even though, neurodiversity and no cure are one of the themes in the thesis, it is a good idea to let the reader know that not everyone shares the same view. Some autistic people and parents of autistic children fiercely oppose this idea. Freeman Loftis (2015, 5), an autistic person herself, argues that if autism is defined purely by neurological diversity, and the aspects that cause variety of difficulties in an autistic person's life are ignored, it may lead to lesser assistance and support, and also, reduce the autism research. Hiari (2018), an autistic herself as well, writes that autism is sickness and can be extremely disabling in some instances and needs a cure, and neurodiversity movement's views are harmful and prevent treatments.

7 Data Gathering Methods

The data was gathered by using a qualitative research methods. I did not form a detailed and specific plan before my work practise how I was to gather the data, neither did I have my interview questions ready. I went to my work practise place with the mindset that I would like to explore interventions and their effects on inclusion, as mentioned in the introduction, but I was very open how I was to carry this out. The only plan I had was to use participant observation and interviews. I already wrote in the introduction that once I started my practise, I soon realised that I was in a very different cultural setting with very different social and health care system. It was only after the work practise when I was back in Finland that I carefully studied my notes and observations and was finally able to form the basis for the thesis, thus basing my thesis purely on my findings.

Qualitative research, according to *Qualitative Research Methods: A Data Collector's Field Guide*:

seeks answers to a question, systematically uses a predefined set of procedures to answer the question, collects evidence, produces findings that were not determined in advance, produces findings that are applicable beyond the immediate boundaries of the study (n.d.).

It consists of many different approaches, such as interviews, notes, documents, observations and visual materials, and has many goals depending on the research or the project (Saldana et al. 2011, 4). My main approaches and methods within qualitative research were semi-structured interviews, participant observation with working as a member of the team, observing, ongoing topic related discussions with members of staff, phone call conversations with service users,

attending clinics organised by Autism Western Cape, home visit and a workshop organised by the organisation. At the end, after I had gathered all my data, I used content analysis to analyse the contents of my findings.

7.1 Participant Observation

Musante De Walt & De Walt (2010,12) describe how in participant observation the researcher is part of the group that she/he is researching taking part in their daily activities. The researcher becomes an active member of the community (Crane & Angrosino 1992, 64). Part of the process is to take down fieldnotes of observations, discussions and daily goings of the community. Usually, the researcher finds key informants with whom she/he can have more in depth conversations, ask specific questions and conduct interviews. After the research has been concluded, all the data is analysed and research question formed.

I used participant observation by taking part in the activities of Autism Western Cape. I was working as a member of the team with tasks that were assigned to me according to my abilities. I was able to immerse myself in the daily life of the office and observe what was going on around me. Each day I noted down the information I had obtained. At the end, I was able to define five different types of data collection methods that can be placed under participant observation. First one was ongoing topic related discussions with six staff members. According to the principles of participant observation, these staff members are called informants. I did not particularly choose my informants, as these were the members of staff that I naturally had conversations with on a daily basis. The discussed themes were varying from South African culture, society, economy, resources, belief systems and how these affect the social workers work in Autism Western Cape. Social workers methods of working and how these methods have changed were also being discussed alongside with autism in South African context and the efforts of Autism Western Cape.

Second one was the participation in autism clinics that Autism Western Cape runs at the Red Cross Children's Hospital and Lentegeur Psychiatric Hospital. (See figures 3 and 4 on page 29). Red Cross hospital picture comes from Alamy (n.d.). These clinics last approximately three hours, and each client is seen roughly anywhere between ten minutes to half an hour. To the latter I went for three times but was able to attend the first one almost each week of my stay with the organisation. These clinics offered a valuable insight into families' struggle with an autistic child, what difficulties they have, how they are taught about autism and coping tools by the social worker, how some of them are overcoming the difficulties and how some of them are at the start of their journey to learn and live with an autistic child. I also encountered parents who were denying the existence of autism or did not know what autism was.

Figure 3: Lentegeur Psychiatric Hospital



Figure 4: Red Cross Children's Hospital



Third method was phone calls to parents of newly diagnosed autistic children. The purpose is to find out the issues parents struggle with the most and to find out parental wellbeing and what kind of assistance they need and make appointments with the social worker. These were noted down in an Initial Assessment Form. (See figure 5 below). All together I made thirteen phone calls.

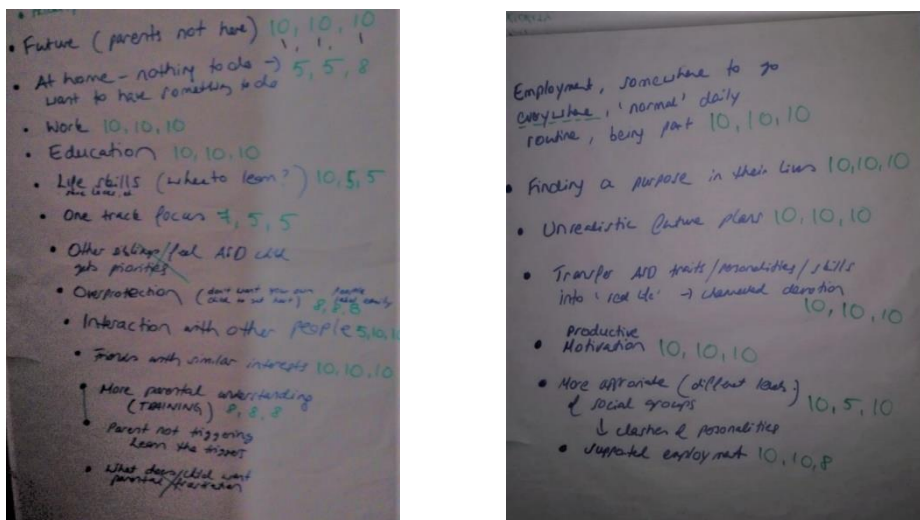
Figure 5: Initial Assessment Form

The form includes the following sections:

- Personal details:** Name of child, Date of birth, Sex, Address, Telephone, Email, School, and Other contact details.
- Medical details:** Medical history, Current medications, and Allergies.
- Living arrangements:** Living at home, Residential care, Living with others, and Living in care.
- Significant others:** Name and address, Name and occupation, Name and occupation, Name and occupation, and Name and occupation.
- Supporting people:** Name, Address, Telephone, Email, and Date of birth.
- Medications:** Name and Doseage.

Fourth method was taking part in the first stages of the development project that commenced during my stay. Via this project the organisation is hoping to offer more relevant services to its adult service users and their parents. My part was to help to organise and run the first workshop for low support autistic adults and their parents. In the end, I ended up running the parental workshop where the topic was to find out their main concerns regarding their children. These were then rated using the Schutte scale, a specific method that helps finding out any concerns within a community and the levels of importance and levels of satisfaction of these concerns. (See figures 6 and 7 on page 30).

Figure 6 and 7: Parental concerns and ratings



Fifth data collection method were home visits. Due to the social workers' busy schedules I only managed to accompany a social worker for one home visit. Home visits are organised for service users and their parents who are not able to attend the clinics or any other appointments. They also last longer than the visits at the clinics. Parental worries, coping, autistic child's and the parents' wellbeing or/and any difficulties family/child are facing are being dealt by the social worker. My task was to listen in and give opinions and suggestions when asked.

7.2 Semi-Structured Interviews

Saldana et al. (2011, 32-40) explain that interviews give a personal account of personal experiences and that it is important to select interviewees whose views best represent the environment that is being studied. There are also many types of interviews where some of them are very structured and some of them bearing very little structure, some of them are also pre-arranged whereas some of them can happen spontaneously. The topic of the research and the purpose of the research establish the basis for the themes that need to be covered, these determining the interview questions. The authors continue that each question that is being asked should be contributing to the whole of research theme, the questions should come from the research questions and that if the questions are good and appropriate, they should promote the interviewee to share more in-depth stories and perspectives. The listener should never judge but express empathy and sympathy providing a platform for the interviewees' voice to be heard.

The interviews that I conducted were more semi-structured. Whiting (2013, 36) describes that these normally are prescheduled to a specific time. The author notes that questions are predetermined but the interview is not restricted to these questions, as other questions are allowed to emerge from the dialogue between the interviewer and the interviewee. I conducted two

semi-structured interviews with social worker 1 and Keri Delpport, the director at the time. I felt that these two members of staff had very good experiences and views on the issues I wanted to discover. At the time of the interviews, my focus point was still more on interventions, inclusion and acceptance, and I got good information on interventions. I also got valuable information on the status of autism in South Africa and what is being done to help the autistic people there and what is being done to make the society more aware. I gained more information on the dichotomy between the poor and the wealthy and autistic people's views on neurodiversity vs. being cured.

The first interview with social worker 1 consisted of four core questions and lasted for 35 minutes. The second interview with Keri Delpport consisted of eight core questions and lasted for one hour. Both sets of questions can be found in the appendix. The interviews were conducted in Autism Western Cape's office and were pre-arranged. The questions were prepared beforehand but there was no specific or strict format to them. The questions acted more as guidelines to the information I wanted to receive. During both of the interviews I found out that the interviewees were very talkative and spoke widely about the issues. The interviewees themselves did not just concentrate on the questions but always gave very broad answers including many related concerns and giving out their own opinions. I also asked questions in between the core questions to get more information or guide the conversation to desired direction. There was a good rapport between the interviewees and me, the atmosphere was relaxed and the interview situations resembled more of conversations than a formal interviews. The interviews were not recorded but detailed notes were taken, and I was always able to go back and ask if anything was left unclear.

7.3 Content Analysis

Using the content analysis research method, the researcher can systematically examine text and any other type of data (Saldana et al. 2011, 10). The method uses a variety of analytical techniques in order to produce findings from the data at the same time putting them into context and deciphering 'the big picture' (White & Marsh 2006, 22). White & Marsh (2006, 35-36) also describe that the general approach when analysing qualitative data using content analysis is the researcher to read through the findings, analyse the findings and finally recognise patterns and concepts within the data. Sometimes new patterns and concepts may arise, this resulting to change of focus in the research and change of the research question. This, again, allows the researcher to pursue new direction in their research. It is, therefore, very important that the researcher is aware of the many interpretations that can come out from the findings.

My use of content analysis was to read through my findings very carefully after my work practise. I noted down all the major themes that came out from my data. After this process, I realised that my findings were very strongly pointing out to something else that I initially went

to pursue. Then I started to focus on my new direction and went through my findings again discovering a common theme that was uniting my data. I continued the process of making detailed notes that were correlating with the new-found main theme. Now I had a list of subjects under one theme and I was able to form my research questions. These were, as mentioned in the introduction, what is the situation of autism in South Africa, what is done about the situation, is this helping and what are the obstacles? Is awareness, acceptance and appreciation increasing? When I had my research questions, I picked out the relevant information from my new notes that would validate these questions. Through this process I was also able to see what would become the purpose and the goal of the thesis.

8 Road to Awareness, Acceptance and Appreciation

The concept of awareness, acceptance and appreciation manifested itself during one of my discussions with the director at the time of my work practise, Keri Delpont. We were talking about what kind of approach would be relevant for my thesis and the view that Autism Western Cape has towards autism. Delpont (2018, personal communication) noted that the organisation advocates the notion that autism does not need to be cured, autistic people have a lot to contribute to society and what is needed is the training on appreciation. (See Figure 8 on page 33). This is all very strongly linked with the notions of neurodiversity and social model of disability as discussed in the above. Delpont (2018, personal communication) said that “in order to appreciate need acceptance, in order to accept need awareness”.

After completing my content analysis this concept and theme stood out for me the most. As already mentioned in chapter 1.1, I want to give the reader an understanding of autism in South Africa, and most importantly, professional efforts to better the situation. In chapter 2 I already explained as best as I can the autism situation in South Africa. The purpose of this chapter is to present my findings and to show what is done to help the autistic people and their families and what is the effect of this to them. To start exploring these notions it is imperative to directly look at the work of Autism Western Cape. In chapter 2 I also discussed autism research and the work of other organisations in South Africa and Cape Town area, and I want the reader to know that this work and research are crucial to the cause, but as my work practise took place in Autism Western Cape, the work and efforts of this organisations are the core. Autism Western Cape has many different methods how it is delivering its intervention and assistance. This chapter looks more closely into the core interventions, parental support, advocacy and training, and development.

Figure 8: Picture in the staff room encapsulating the organisation's ethos



8.1 Autism Western Cape Intervention

The interventions that Autism Western Cape uses in its work are mostly taught in parental workshops where education and training on them are given. The core concept of Autism Western Cape intervention is educating and training parents in order for them to help their autistic child. Delpont (2018, personal communication) explained how these interventions are adopted to the South African context and environment by means of looking what do the parents have. Instead of having, for example, a TEACHH app on their phone, she said the parents take applicable pictures on their phones. She explained that PECS is similarly easily adopted. There were positive results from these interventions regarding communication between the parent and the child, following the same pattern than the studies have shown.

Social worker 1 (2018, personal communication) described how parents need to use their own intuition to find out what works best for their child. She explained that the organisation's aid is advice and providing tools and information for parents to get to know their child, as this is essential and will be the best help the child can get. Also, urging parents to find out what works and what does not, and what triggers set off aggressive behaviour. She said that it is important to educate the parents in how to modify certain behavioural patterns their children have. Delpont (2018, personal communication) explained that the organisation wants to encourage parents to come up with their own ideas to help themselves and their child. The heart of the Autism Western-cape intervention/assistance is the parent to know their child, and both the parents and the child are on focus and equally important in the organisation's work.

This is very much on par with the parent-implemented intervention where the first-hand assistance comes from the parents after they have been trained on the relevant and needed

intervention. De Vries and Yeatman (2018) statement of how this seems to be the best option in low to middle income countries, where there is a lack of resources also fits in with Social worker 1 (2018, personal communication) notions where she explains that most of Autism Western Cape's clients cannot afford private hospitals, schools or creches. She said the organisation has not got enough resources to directly help the autistic person. It can provide tools and interventions and also point to the right direction for further help. Delport (2018, personal communication) explained that in her experience, the adapted interventions like TEACCH and PECS work if the parents are persistent. She said that if there is no perseverance from the parents the interventions simply do not work. Social worker 1 (2018, personal communication) said that parents need to be consistent, as this is the only way the intervention works.

8.2 Parental Support

During my work practise I discovered the parents that Autism Western Cape is dealing with have very similar strains and worries that I was discussing about in the above. These correspond to the ones Volkmar & Wiesner (2009) and Griffith et al. (2012) describe earlier on being embarrassed, angry, disappointed, stressed and tired. These concerns came out during the telephone conversations and clinic visits. Also, the autistic behaviour the parents are experiencing correlates exactly to the most typical autism traits Yapko (2003) and Todd (2012) define, where the difficulty lies within social interactions, communication, behavioural issues, problems with speech and sensitivity to loud noises. The parents were talking about their child's behaviour where it was felt that the child is not like any other child and the behaviour is not normal and is very challenging. Examples varied from child not communicating, not having eye contact, not sleeping well, crying a lot and having a lot of temper tantrums.

One parent said that she cannot use the public transport with her child as all the sounds, loud noises and a crowd scare the child (Mother 1 2018. Personal communication). Many parents had worries over their child's toilet training, as many of the children were still in their nappies past the period when they were supposed to be already toilet trained. No connection and not having an understanding between the autistic child and the parent were also a big concerns, and majority of parents felt that they are not coping well, they are struggling, finding the situation difficult and overwhelming which, again, increased frustration. One mother also felt anger, as her child was not developing as the norm expects (Mother 2 2018. Personal communication), whereas another mother was experiencing pains and weight loss that she thought might be related to stress but concluded that she does not know how she is supposed to be feeling (Mother 3 2018. Personal communication). Parents wanted to have help with methods how they can help their child better, tools for coping and generally how they can be a better parent for their child. I was also discussing in the above about the lack of educational possibilities and the long waiting lists for schools that autistic children from especially poorer backgrounds face. 2015 Human Rights Report (n.d., cited in Zeliadt 2017) confirmed exactly this by showing how

nearly half of the children in the Western Cape area are on a school waiting lists. This was one of the major concerns within the parents I was talking to, as their child was not at school but on a waiting list.

These are the issues that the organisation is dealing with on a daily basis. Autism Western Cape's assistance most often starts from the weekly clinics where the parents of newly diagnosed children can attend. For example, after the Red Cross hospital does the diagnosis the parents are advised to go the weekly Autism Western Cape clinic. During their visit the social worker is asking how the parents are doing, how are they coping and how do they feel about the diagnosis. If the parents have never heard of autism, the social worker then explains in very simple and clear manner what autism entails. She is also giving suggestions and tools what could help the child and information on Autism Western Cape's support groups, workshops, creches, schools, any other sources where the parents can get help and information. Financial matters are also discussed and the social worker is advising on government grants that are applicable. Throughout the visit the social worker is enhancing a positive outlook on autism and specifying how there are many different methods and tools how the child can be helped and can live a fulfilling life. Social worker 1 (2018, personal communication) said that the social worker always gives advice what parents can do and they are always told that they are welcome to come back to the organisation for more advice and help. The importance of parental role is always stressed and that it is up to parents how they want to help their child. Home visits follow the same guidelines and are offered to parents who are unable to come to the clinics or visit the office. I was able to join in one home visit where the problem was the child being bullied at school for being different and child's increased behavioural problems as teenage years were approaching. In this case, the parent had a chance to share her worries and get professional advice from the social worker.

Parental support groups are an integral part of Autism Western Cape's assistance. They are running on a monthly basis in many parts of Cape Town. Delpont (2018, personal communication) explained how the support groups are based on parent empowerment model where parents are helping and teaching other parents. Social worker 1 (2018, personal communication) said that this involves a mixture of things, such as what parents have found out and learned themselves from their child, what have they learned from Autism Western Cape's training courses and what have they learned from other parents in support groups. It also includes the help and advice received from the workshops. This type of method can be linked to peer support as it follows exactly the definition by Beales & Wilson (2015) where people are using their own experiences to help others. All the parental information gets shared between parents, and the social worker 1 explained that this type of support has had a very positive effect on the parents.

The evidence from Autism Western Cape coincides with the findings by Faulkner & Basset (2012) that showed increased self-confidence, skill development, stigma reduction and empowerment. I presume finding out others having an autistic child and having similar problems most probably comes as a relief. What comes to empowerment, in support groups like this Beales & Wilson's (2015) notion of transferring from passively receiving to actively leading the recovery processes of self and others is apparent.

On the other hand, I was explained by one of the social workers at the organisation that not all parental support groups are successful. Adams (2018, personal communication) explained that a support group in a poorer area did not manage to get off the ground even with many attempts and efforts. According to her, the problem was in the very structure where considerations towards needs, dynamics, diversity and development were not met. She continues explaining that to have a successful support group there needs to be individual parental counselling after diagnosis and parental needs should be met straight away. This did not happen and the new parents got lost in the group and continued to struggle with their issues. Like Beales & Wilson (2015) explained that it is important that organisation is clear about their intentions, outcomes and who exactly is involved in providing this type of support for it to successfully take off.

As described earlier, the main parental training takes place in workshops. I did not manage to gather any specific data on these but they do have an important educational role. Many pressing issues and difficulties that are linked to autism are dealt there, and as mentioned in the above, parents do share with each other in the support groups whatever they have learned in the workshops. There is also a specific training program workshop called Autism Cares. According to Autism Western Cape's web pages (Autism Western Cape, n.d.) this is a four-day course training for "carers and caregivers in early intervention so that they are equipped and empowered to provide this much needed intervention themselves" (GivenGain n.d.). Autism Cares is also part of a research program at the Centre for Autism Research in Africa where it is being compared to the Early Bird programme that I already wrote about in chapter 2. The purpose of the comparative research "is to identify or adapt a suitable programme for scale-up in low-middle income environments" (Centre for Autism Research in Africa n.d.). This shows the organisation's importance and thrive to better the autistic people's situation in South Africa. Workshops do not normally run on a regular basis like support groups. Parents can get more information on these by asking the organisation directly or checking the organisation's Facebook pages.

8.3 Advocacy, Education and Training

Thorough its work the organisation is advocating and spreading its message and its view on autism. All three above concepts go hand in hand as at the same time as a member of staff is doing autism education, they are also advocating the organisation's point of view. These two

are also linked to training as through training the organisation advocates and educates. The organisation is also advocating the Rights of the Child, Parental rights and Education and Special Needs Child (Autism Western Cape n.d.) legislative clauses in their work. Autism Western Cape is specifically concentrating on the care of the child, child's participation and right for education. Jenkins (2012) discussed earlier how exactly in cases where vulnerable people are involved, advocacy becomes beneficial. It is exactly the vulnerable people that the organisation is dealing with. Gray & Jackson (2001) noted that the driving force in advocating people with disabilities is the idea that everyone should have equal rights and responsibilities. This idea very much driving the advocacy work of Autism Western Cape. The South African legislation is not aiding the cause of disabled people in a way that is making a huge impact, even though the intentions in legislation are good. It needs to be remembered that there is no disability act but policy and framework only. In this light, advocacy work comes up with even more purpose and importance.

In the clinics social workers advocate by telling the parents of newly diagnosed autistic children about autism in a positive way, i.e., autism does not stop the child living a good life, and even though, it is a lifelong condition, there are plenty of assistive methods and interventions available to help the child and parents, enhancing the importance of parental role in this. Autism facts are put into a context that coincides with the organisation's ethos. In Red Cross Children's Hospital, the walls of the room where the clinic is held, have posters that further enforce the positive, inclusive and acceptive view. (See figures 9 and 10 below).

Figures: 9 & 10: Posters in the Red Cross Clinic



Autism Western Cape also has autism awareness campaigns where their message is being advocated and information on autism given. One good example is an annual autism awareness walk, Fun Walk, that took place on 21st April this year. (See figures 12, 13 and 14 below). The participants were mostly autistic children and their parents, autistic adults and members of Autism Western Cape staff. The walk happened during my practise period, therefore allowing me to take part. At the start point of the walk the organisation was selling its merchandise that had positive messages about autism, thus advocating the organisation's cause. Many participants were wearing t-shirts with positive messages too, hence making autism visible in an accepting way to people who were not part of the walk. The crowd was very happy and cheery, and this also enhanced the positive outlook and view. The organisation can also advocate a single cause. Delport (2018 Personal communication) said how there was a case where a workplace tried to get rid of an autistic person as they felt this person was too different. Autism Western Cape helped the person through the process as a whole, including the legal process at the same time advocating the autistic person.

Figure 12: Autism awareness walk poster



Figure 13: Sticker



Figure 14: Autism Western Cape selling merchandise at Fun Walk

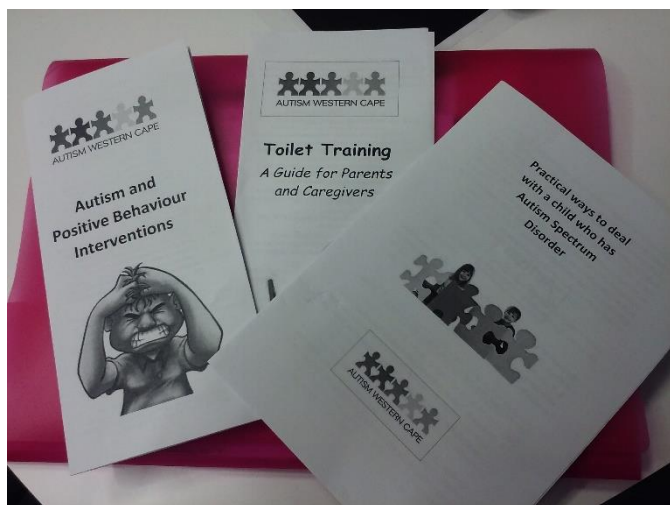


Workshops, support groups, clinics and counselling sessions are where a lot of the education and training take place. I had a chance to take part in a training session that took place in Alexandra Psychiatric Hospital this May, given by a professional from Autism Western Cape. The purpose of the training was to train the nurses to be able to recognise autistic patients. Especially those adult autistic people who have not been diagnosed, or most often have been misdiagnosed as having an intellectual disability, instead of neurodevelopmental one, have ended up in psychiatric hospitals because the family cannot cope with them anymore, or does not know how to cope with them, and the autistics have become danger to their family and themselves. The professional from the organisation started off explaining what autism is, moving onto describing the most common traits of autism and what areas the condition affects. She showed videos that gave a good understanding of autistic behaviour and what can be done to help autistic people to better communicate and express themselves. The training lasted all together four hours where after the presentation the participants were able to ask questions and talk about their own experiences. Already, during this training session there were some nurses who were able to recognise some of the autistic traits in their own patients.

Delport (2018, personal communication) explained that training can be done in work places as well, in order to make other members of staff to understand how to work with autistic people. In this case, the autistic member of staff is also invited in the training session for them to know what is being said. The former director said how in some cases a path for communication is set up between the organisation and the autistic person, in case discrimination occurs. In this case, the autistic person can always go back to the organisation with their worries and the organisation helps the best it can. Training can also be organised in schools and creches. Social worker 1 (2018, Personal communication) said that the organisation urges parents to get their autistic child into a creche even though, the staff does not know anything about autism. The parents can always let the organisation know and a social worker from the organisation can arrange a training session for members of staff in that particular creche. Same principal applies to schools and other centres, such as supported housing.

Autism Western Cape has a wide range of leaflets and pamphlets that give out all the essential autism information to autistic people themselves, parents and caregivers and teachers. (See figures 12 and 13 on page 40). For example, there is educational information on common traits of autism, on positive interventions on behaviour, on how to support an autistic child, on how to include an autistic student at school, on basic potty training for autistic children, and also information on where and how to apply benefits/grants. These are given out in all events, training, counselling, workshops and clinics. The many methods of advocacy, education and training correspond to Daly's (2011) notions on how important it is to use many different means in order to engage as many people as possible.

Figures 15 & 16: Examples of educational and information leaflets



8.4 Development

Autism Western Cape wants to develop its services to ensure that the service users have the best possible care. I was able to take part in the very early stages of a project that was just starting during my stay. Via this project the organisation is hoping to offer more relevant services to its adult service users and their parents, and through this enhance service users' independence, wellbeing and inclusion in the society. This should also increase parental wellbeing by removing at least some of the stresses and worries over their children. The aim to better service users' circumstances follows Phibin & Miksush's (n.d.) argument of development work strongly connecting to motivation and desire to make a difference.

One of the main aims of the project is to find out how to make low support, medium support and high support categories work and what needs to be done to make them work better and what would be the possible appropriate activities that could work in each category. Also, the aim is to have service users to proceed to the next category, e.g., an individual with medium support needs moving into the low support category. The method is to have workshops for the service users and separate ones for their parents. The objective of the workshops is to find out what do service users and their parents need, what needs to be done and what would work. During my practise, I had a chance to take responsibility of one parental workshop where the main task was to identify parental concerns. The ones with highest importance were autistic children's future after parents passing, work, education, finding a purpose in life, finding friends with similar interests, being part of society, having unrealistic future plans and having a productive motivation. These concerns are directly touching upon the consequences that autistic traits have on a person, as discussed in the above. The great parental worries also resembling the ones found in studies by Griffitch et al. (2012), especially ensuring a good life for their autistic offspring after they have passed on. The project manager who was responsible of the

workshop for the autistic adults informed that within the group four items rose above others. These were independent living, work, relationships and romantic relationships. These, again, coinciding with the desires of autistic people in the *Autistic Me* (2009) document where normal life, job, boy/girlfriend and place of their own were highest on the list.

In our meeting considering the project's future, the aim would be to try to organise more workshops closer to the service users and their parents, as the participation levels for the first workshops were quite low. A likely problem for the low participation levels was the difficulty for people to get to Autism Western Cape's offices. Distances in Cape Town are great, and the traffic congestion is one of the worst in the world. Also, people with lower income cannot afford the travel. The ideal is to form focus groups from which more detailed data could be collected and after that move on to the planning phase. Then again, the organisation does not have the resources to run all the focus groups. Also, some areas can be too dangerous for a member of staff to go in. As shown earlier, nearly half of the crime in South Africa takes place in Cape Town.

For this project five major Cape Town areas were picked, and ideally there should be three focus groups in each area making it all together fifteen focus groups. Numbers are important for funding purposes but according to the project manager, one member of staff can only run between two to three focus groups. She said that the solution will be to hand the responsibility to the focus groups themselves whilst the project manager is there to help and support. She would also aid with the funding applications, any further development and link the focus groups to other resources. But the main responsibility would lie within the community itself. This is how Asset Based Community Development model works. In this case, the focus groups can find out what skill sets the members of the community have and how they can be utilised to help the autistic people and their parents with the tools from the project. This follows Payne's (2006) notions where the core lies within the members of the community actively interacting and collaborating with each other finding relevant skill sets within themselves.

9 Obstacles

There are also difficulties that Autism Western Cape faces in its work towards bettering the lives of autistic people and their families and working towards awareness, acceptance and appreciation. I suppose, obstacles are natural to any establishment but the difficulties that I learned about and that stood out from my findings are quite different that I have come across before. This is why it is important to dedicate a whole chapter to them. Many of the obstacles are directly linked with the socio-economic status of South Africa. I have already discussed the inequalities in the society between different ethnic groups and how this is directly related to wealth of these ethnic groups. The trend seems to be that people with European backgrounds

have better standard of living than the people with native South African, coloured or other African backgrounds. This is all having an impact on education, employment, income and in what kind of conditions people are living in. When people lack good education, the effect does not only reach to employment and income, it also reaches to people's knowledge and awareness. Knowledge that people in higher income countries take for granted may have never been heard by poorer people in low to mid income countries like South Africa. This unawareness, and in this case, unawareness towards autism is also one of the obstacles Autism Western Cape faces a lot in its work. Poverty and its consequences are another significant obstacle. The impact of traditional beliefs on autism care is also considerable and deserves to be discussed.

9.1 Unawareness

During my stay I encountered parents and carers who did not know anything about autism or had never heard of autism. They simply did not know what autism is. They were unaware of the word and the whole concept of autism. I found out that people with the utter unawareness normally came from the less well to do communities. This directly pointing towards the lack of proper education possibilities, which again, directly pointing into the inequalities in the South African society, as pointed out at the beginning of the thesis and reinforced by Steyn Kotze's (2016) remark how South Africa is on the top of the list of world's most unequal societies. Unawareness brings a layer of problems to the autistic individuals themselves and also their families.

During one of the parental meetings in the Cape Flats area, the poorest in Cape Town, we, (social worker and me), were told how the child who was in the spectrum was bullied physically and verbally at school. During another parental meeting in the same area we were told how the autistic child in question was also bullied at school, and also, bullied by the teacher who was hitting the child in the head and calling the child stupid. During another meeting at Red Cross clinic we discovered how the parent and the carer were violent towards the autistic child, as they did not know how to cope with the child. In the background was severe sleep deprivation, stress, poor housing and illnesses. All these contributing to the difficult situation the family was in. Social worker 1 (2018, personal communication) also noted that in these types of situations there is a huge demand on social worker's abilities. Parents who are lacking awareness demand the social worker to make the autistic person better. This, again, can be very stressful for the professionals in the field.

Going back to bullying and violent behaviour, the most probable cause is unawareness. As already discussed in the above, autism is not clearly defined to one cause and one typical behavioural trait but is a sum of causes and sum of typical traits that can be placed under autism spectrum disorders. This kind of ambiguity can be scary and worrying for parents who are unaware and do not understand autism. Social worker 1 (2018, personal communication) said that

whole communities will not accept autism as they do not understand what it is. The lack of knowledge is not only dependable on education either, like Boonzaier (2017) already noted, the resources have gone to research and prevention of more acute diseases like HIV and tuberculosis.

9.2 Poverty

Poverty brings with itself a multitude of issues. The most relevant ones here are the families with autistic children and autistic people themselves and their access to care. I came across a new notion of “asset assessment” (Adams 2018, Personal communication). The social worker explained to me that the need of a service user is known, they have to identify the assets that the service users have. This determines what kind of help they can get. When there is no money the options are limited. Something as simple as going to a clinic or to an appointment can be real issues when there are no means to do so. Social worker 1 (2018, personal communication) simply said that clients do not have the money. Staff member 2 (2018, personal communication) explained that many times there are more dire issues the family is facing, such as feeding the family and finding food, than going to an appointment to discuss about their autistic child. She also explained that sometimes families in poverty can be embarrassed of their living conditions and do not want the professional to come to see them. This can be a case of having nowhere to sit down in their home.

I was able to see some of the housing and living conditions of those suffering from poverty when I was travelling with social worker Adams in the Cape Flats area, and these fit exactly as described in chapter 1.2. I found out that even if the family could make the appointment there are other issues against them. These can be a high crime and violence in the area. It can be so bad that it becomes too dangerous to try and attempt travel. There may not even be comprehensive transportation available, i.e., there are strikes or demonstrations going on or some cases, trains cannot run because the electric cables have been stolen. Adams (2018, personal communication) said that they never judge the person who does not make the meeting as they understand the problems. Clients and service users are always welcome to get back to the organisation and make a new appointment.

I already discussed the problems that poorer families have regarding access to education or even a creche with their autistic child. Schlebush et al. (2017, 1973) notes how the services that cater for people with disabilities are very limited in South Africa. The families with very limited incomes suffer from this excessively. First of all, after diagnosis the government hospital intervention scheme is not sufficient enough to really help the autistic child, Secondly, many of them have to wait for years to gain a place in the education system. The families do not have the means to seek and receive comprehensive assistance for their child. Even if they receive governmental Care Dependency Grant meant for families with disabled children

Schlebusch et al. (2017, 1973) explain that normally in traditional African families the income is shared between the members of the family making the actual amount of money much less for the services meant for the disabled. Proudlock (2014, cited in Schlebusch 2017, 1974) further notes that families who have children with mild to moderate disabilities are still being excluded from receiving the above grant. Poverty and the issues it brings are very relevant and current in South African society and directly contributes to what kind of care and assistance is available to an autistic person and how these are delivered.

9.3 Traditional Beliefs

Traditional healing was a completely new concept to me that I learned about during my practise period. UNAIDS (2001, 7) explains that this type of medical practise has been existing a long time in the African continent, and in addition to providing potential cures, it also provides a national heritage connecting the land and the people. Maware & Awuah-Myamekye (2015, 111) tell that the practitioner of the traditional healing/traditional medicine are called traditional healers. UNAIDS (2001, 7) continues explaining that in sub-Saharan Africa the traditional healers outnumber the practitioners of modern medicine providing access to treatment in places where imported and expensive medicines cannot. It says that this type of health care is also much more personalised fit to meet the patient's needs. Maware & Awuah-Myamekye (2015, 111-112) describe that this type of healing practise is most commonly used when a patient wants to prevent illness, protect themselves from illness or want treatment for illness. They explain that it can be also used to counteract witchcraft or bring back love that has withered away. Traditional healing has many different purposes. The authors note (2015, 112) that in this type of belief system it is thought that an illness has a supernatural cause, e.g., ancestral gods or evil spirits. They (2015, 126) also say that South African government is trying to increase the collaboration between the traditional and modern practitioners.

The notions in my literature research give mostly a very positive view on traditional healing. It is part of the people of the African continent and their cultures. It becomes an obstacle in the context of Autism Western Cape's work when people do not have any knowledge of autism and they believe that it can be cured by using traditional methods. Social worker 1 (2018, personal communication) said that especially within the township communities it is believed that autism is caused by possession. In this case, the parents take the child to the traditional healer in order to banish autism. Social worker 2 (2018, personal communication) was pointing to a very similar direction by telling that parents of an autistic child may contact the traditional healer as they think that demons or bad spirits have possessed child. She explained how in this case, for example, the parents can buy a cow or a goat, sacrifice it and the blood is for the ancestors, and this should cure the child. If it does not cure the child the parents can also turn to Western medicine and use this and traditional medicine side by side. I also encountered a family in Red Cross clinic where the father of the family wanted an immediate cure for their autistic child.

He did not accept the social worker's explanations, information and advice and refused any kind of support or counselling. He just wanted to social worker to cure their child. Social worker 1 (2018, personal communication) said that often in these types of scenarios where immediate solution is desired, the family in questions seeks the help of the traditional healer. It is a common practise and according to South African Medical Journal (2012, cited in Maware & Awuah-Myamekye (2015, 115) around 80% of the country's population use the traditional healers. It has positive sides and it definitely should be appreciated but it is not able to cure an autistic child, and this is the problem Autism Western Cape has to deal with. When parents want an immediate cure and do not accept the autism facts, the autistic child will suffer by not receiving the help that they deserve.

10 Conclusion

There are great efforts going into to the work improving the autism situation in South Africa. These efforts are seen on the level of research that is going into autism and also on the work of organisations like Autism Western Cape. The research is mostly concentrating on intervention and assistive methods that could work in South Africa, whereas the organisations work directly with people who are touched by autism facing them in their day to day struggles. Autism Western Cape is one of its kind in the area and is dealing with great variety of service users and those in need. The work is demanding very busy and staff is putting a lot of effort delivering their assistance.

Inequalities are one defining factor in South African society. These inequalities caused by the differences in wealth, and these differences caused by people's backgrounds. This can be traced back all the way to the colonial times from where the discrimination towards non-European ethnicities escalated into full blown racial division in the form of apartheid. Even though, now abolished, apartheid has a strong rooting in South African society affecting the way people perceive each other and how wealth is being distributed. The norm being that white South Africans having a higher income than black, coloured and other non-white South Africans. The division following exactly the apartheid pattern.

Wealth determines access to care. Throughout my stay I was repeatedly told that when the family has the money, they can offer any help they want for their autistic child, and this help can be of very high quality. Staff member 1 (2018, personal communication) pointed out how in a private centre for autistic children, that she visited, there were plenty of different spaces and learning rooms each dedicated to different activities. She said how classrooms were beautiful and sensory room was big with different things to do and explore. Each child got individual attention if required so. There were only five children in a class and the service users were mostly white South African backgrounds. This is a striking contrast to a similar centre that I

visited in Cape Flats. I have nothing but my utmost respect towards the people who are running the establishment with very limited resources, but what I experienced there with nearly 30 children confined in small space with a tiny sensory room in use, was very far from the staff member 1 description. The dichotomy between the poor and the wealthy again reinforced.

There is a policy and a framework on disability that lays out a comprehensive framework that promises a sound, equal and all-inclusive base that disabled people could rely on, and which should integrate them fully into society without any prejudices regardless of their wealth. UHAMBO (n.d.) remarks, though, that there are “problems with fragmentation; patchy implementation; weak capacity and problematic budget allocations; breakdown in referral networks; exacerbated by poverty”. Also, according to Statistics South Africa (2014) there is a strong correlation between disability and poverty that comes down to disadvantages in education, employment and income. Children who have a severe disability, especially difficulties with communication and mobility, are left outside education. Those with less wealthy backgrounds do not have access to assistive devices that further excludes them from educational and employment opportunities. Without a proper education it is difficult to enter into good employment, thus leaving those with disabilities less well-off and marginalised. When I look back to my experiences, I have to say that I did not see the impact on these policies and framework in the society. I understand that the duration of my stay was only eight weeks but, during that time, the dire need for assistance in this matter within the poorer communities was unmistakable.

Due to its nature, autism poses a problem, as it cannot be defined as a one disorder with one symptom. It has many different levels to it, autistic people having many different capabilities. It has its core symptoms with social interaction and behaviour but these, again, are in multitude of layers that affect autistic people very differently. This can pose such a problem for social workers trying to explain to a person who does not now about autism and what autism actually is. Another problem is what causes autism. As explained earlier, it is a sum of many factors. These factors are also complicated ones varying from genetics to environmental ones. For a person who has got no good education, or even a moderate one, these concepts are very difficult to comprehend. The example where one of the parents in Red Cross clinic said that there is something wrong with the brain of his child and wanted it to be immediately cured by the social worker showed exactly this.

In my experience, the staff at Autism Western Cape did a brilliant job at getting the message what autism is across to the people who were unaware of it. They did not concentrate on the scientific facts but defined the basic traits in a simple and coherent manner, at the same time advocating the message of autism not being negative and how there is assistance and help available. I experienced how most parents were relieved and wanted any help available. Some

wanted more help and some did not want any help. It must be hard to for the families who lack the knowledge of autism and an education that would support the understanding what is going on. Their need for the social worker's help is great. But then again, there are not resources for the social worker to allow too much time per service user. Social worker 1 (2018, personal communication) explained that the current trend in helping service users is to empower them, to help them realise what can they do for themselves to help themselves. This all fits in very well with the whole Autism Western Cape's intervention where the parents are the ones delivering the intervention to their autistic child and parents helping each other through support groups.

Through its intervention, assistance, advocacy, education, development, ideology and ethos Autism Western Cape is on a path changing views of those that come to contact with it. It also has an effect on the wellbeing of the parents and the autistic individuals. The organisation's work is touching those who it is helping and is able to shed light to autism and turn the negative into positive. In a wider societal sense, there is still a long way to go, but this is understandable and this is not only considering South Africa. Autistic people and neurotypical too, elsewhere in the world are demanding new concepts of understanding the condition. Neurodiversity is one of those concepts that would deliver more equality and the actual appreciation towards autism. This why it is such an important part of the organisation's ethos.

I found out that through its work Autism Western Cape is able to raise awareness and through this acceptance towards autism. I only experienced appreciation towards autism through professional and some parental accounts. Then again, the world is still working towards appreciation towards disabilities and other conditions. The obstacles that the organisation is facing are dire and have an impact on its work. All three of them, unawareness, poverty and the traditional beliefs are big ones to overcome, and I do not think they can be overcome. The issues are too huge and go too deep in the society. The only thing that can be done is understanding them and working with them, as the organisation is already doing. Make the best out what there is. Research and work of organisations such as Autism Western Cape is helping and contributing to the awareness, acceptance and appreciation.

For me personally, this was a big learning curve. First of all, I have little experience on research processes. I left for Cape Town with an idea I wanted to do, the focus of the idea shifted a bit during my work practice and after the work practice changed into something else. I had a lot of data but there was also a lot of irrelevant data. I wrote everything down because so many issues were new to me. When I did my interviews, I still had mostly interventions in my mind. I think I would have obtained more information if I had shifted my focus to South Africa and autism in South Africa already during my stay. This would have required a more careful study

of my notes earlier. I have definitely learned a lot from this process and can take it on board for any future research projects I might be conducting.

Coming back to my learning goals, I had great first-hand opportunity to find out about autism's effects on children and their behaviour and how autism can affect families and parental well-being. I was fortunate to be able to interact with so many parents who have an autistic child and learn about the issues directly from themselves. During my research and writing process I was also able to find out more about the possible causes of autism. I learned about interventions, but this was more in South African context. What type of interventions work there and why. I did not get too much insight into interventions effect on inclusion or autistic people's views on interventions but it became very clear that the earlier and more regular the intervention, the better are its effects. As I already wrote in the introduction, the focus on interventions became more secondary due to the nature of social and health care system in South Africa. On the other hand, I did learn a lot about South African culture, society its history and people. I was able to get a really good insight into autism and autism care in South Africa.

The research can benefit anybody who is interested to find out about the situation of autism in South Africa. This can also be applied to any low to middle income country, as I would imagine the resources for care are similar. The research also gives a little bit of an inside into South African society and autism and can be an engaging read to whoever is keen to find out about on these topics. For future research purposes, it would be interesting to interview the parents themselves finding out their road to either awareness, acceptance and/or appreciation and see what their next steps would be.

My practice period taught me a lot about the South African society and the struggles people face there due to inequalities and poverty. I have never experienced anything like that before, and never seen people living in such poor conditions like I did during my visits to Cape Flats. People living in utter poverty ridden areas where the desperation to get by from day to day and utter frustration of it drives people committing dreadful crimes. My heart goes out to the people who face these struggles and my respect to people who do their everything to help. I also learned about the apartheid and its damaging effects on South African society. During our visits to the Cape Flats with social worker Adams, she was showing me different parts and explained history and society to me. We had lengthy chats together and I learned so much. I did not just learn about the historical facts, I had the privilege to hear hers and her family's personal life stories and learn how apartheid had affected them. I truly appreciate this.

South Africa is a beautiful country where the Cape Town area is surrounded by stunning natural beauty. (See figure 16 on page 49). People have a lot of love and lot to give but the history is still hanging on to them and keeping its grip. I hope that future generations will resolve the

disputes and let the country and its people grow to their full potential. I also had the opportunity to work with the most wonderful people with sincere, warm and open hearts who welcomed me and made me feel as one of them. I will cherish my time I spent with them and the friendships I made. I am forever grateful for this experience they gave me.

Figure 16: Beautiful Cape Town



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Appendix 1: First appendix

Interview Questions with Social Worker 1, 11th May 2018, 35 min.

1. What are the main elements of Autism Western Cape intervention?
2. Tell me about parental support groups?
3. Could you talk about the government hospital (Red Cross) practise in regard to autism?
4. Could you talk about the differences in care between the poor and the wealthy?

Appendix 2: Second appendix

Interview Questions with Keri Delpont, 17th May 2018, 1 hour

1. What interventions Autism Western Cape uses?
2. Do the interventions work and what kinds of evidence is there to support this?
3. What type of interventions there are for adults and how are adult service users helped?
4. What type of interventions there are for adults and how are adult service users helped?
5. How do autistic people feel about interventions?
6. Are therapy/interventions given according to an individual's need, or does everyone get the same level of intervention
7. How do low support autistic adults feel about the notions of being cured? Do they advocate neurodiversity? How do they feel about it?
8. How effective is the work towards acceptance?