



A qualitative study into the advocacy and activism of carers of adolescents with Down Syndrome in Oshana, Namibia

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ABSTRACT

Background: Down Syndrome (DS) is a chromosomal defect known to cause intellectual disability. Adolescents with DS may need to live with their families beyond the transition period into adulthood because they require lifelong care due to the disabling consequences of the genetic condition. Evidence is lacking about the actions that carers in remote rural communities are taking to enhance the rights of their adolescents with DS as enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Aim: To describe the advocacy and activism actions of carers that promote the disability rights of adolescents with DS.

Objectives: To describe carers' understanding of 'activism' in relation to the needs of adolescents with DS; to explore what actions carers are engaging with in order to promote participation and equal opportunities for social inclusion of adolescents with DS; to describe barriers encountered and strategies used and to describe carers' advocacy priority list for social inclusion of adolescents with DS.

Methodology: A descriptive qualitative approach was used where three carers told their stories of activism and advocacy actions through a semi-structured in-depth interview method. Their stories were audio-recorded, transcribed into textual form and an inductive data analysis followed a framework approach guided by the research aims.

Findings: One overriding theme *Puuyelele* (bringing adolescents with DS into the open) emerged with four categories: namely, "Speaking for and acting on behalf of adolescents with DS", "Enabling a continuous enlightening process", "Ensuring ongoing care and services" and "Raising public awareness on human rights of adolescents with DS".

Discussion: Three concepts about DS advocacy and activism for adolescents with DS formed the discussion; first, it is a strategic process requiring togetherness, courage

and perseverance; second, it proceeds from vigilant care-giving and service provision and, lastly, it requires rising of human rights awareness.

Conclusion: A strategic and contextualised DS advocacy and activism process such as *Puuyelele* requires human rights awareness and emerges from vigilant care that enhances community participation and social inclusion of adolescents with DS. The process creates a possible and realistic conceptual framework for further strengthening of disability-inclusive development initiatives in Namibia.

Keywords: Carers, Down Syndrome, Adolescents, Activism, Advocacy, Social inclusion

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LIST OF ACRONYMS

CBR -	Community Based Rehabilitation
DS -	Down Syndrome
ID -	Intellectual Disability
IDDC -	International Disability and Development Consortium
ODSSG -	Oshana Down Syndrome Support Group
PHC -	Primary Health Care
PWD -	People with Disabilities
UN -	United Nations
UNCRPD -	United Nation Convention on Rights of Persons with Disabilities
WHO -	World Health Organization

DEFINITION OF TERMS

Down Syndrome:	Down Syndrome is a genetic condition which is the commonest identifiable cause of intellectual disability, accounting for almost one third of cases (Gupta & Kabra, 2014)
Carer:	A close person with motherly love who can be entrusted with day to day quality care of a person with intellectual disability (McKenzie, 2016, p. 72)
Adolescence:	A transitional/developmental period between childhood and adulthood with an age range of 12 to 18 years with increased hormonal, emotional, behavioural and social changes “that are influenced by both external environmental and internal factors that elicit and reinforce behaviour.” (Jaworska & Macqueen, 2015, p. 291)
Advocacy	Systematic and purposeful actions by individual/group to bring about beneficial change(s) that promotes social justice for others (Hoefer, 2015, p. 3)
Activism	A process of networking in a group/movement by advocating “more frequently and at a higher level of complexity than other parents” (Ryan & Cole, 2009, p. 44)
Social inclusion	A process for improving terms, ability, opportunity and dignity for individual/groups of those disadvantaged to take part in the society (World Bank, 2017)
Peri urban	Areas characterised by informal settlements with less governable spaces, unregulated living and working spaces that are encroached by rural migrants (Wu, Zhang & Webster, 2012)
Participation	Performing social roles such as financial, work/education, health and other domains with or for others in society, family or home (Eyssen et al., 2011, p. 984)

CHAPTER 1: INTRODUCTION

1.1 Introduction to study

Raising an adolescent with Down Syndrome in the rural context of a developing country poses challenges that may require some activism and advocacy by carers to enhance social inclusion. Down Syndrome (DS) is a chromosomal defect known to be the most common cause of intellectual disability (ID) with more health problems for these people than those without Down Syndrome (Alexander et al., 2016; Hall, 2011; Kazemi, Salehi & Kheirollahi, 2016). For the understanding of intellectual disability this study adopts the description given by the American Psychiatric Association (APA), the world's largest psychiatric organisation that publishes the Diagnostic Statistical Manual (DSM) (APA, 2013). In her review, Parekh (2017) describes intellectual disability as a problem that affects reasoning, judging and adapting to certain situations and environments. Adaptation limitations can include inability to adequately engage with societal activities and independent living (Parekh, 2017). The understanding of intellectual disability highlights the importance of why carers need advocacy and activism of adolescents with DS towards social inclusion.

Moreover, adolescents with DS are known to have more health problems like cardio respiratory ones than those without DS (Seron & Greguol, 2014). Such health problems can affect participation in activities and the quality of life of adolescents with DS (Wuang & Su, 2012). Furthermore, the ID affects the learning process that impacts on various educational and other skills development (Kazemi, Saleh & Kheirollahi, 2016). However, as enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) adolescents with DS have rights and the potential to contribute to society despite the challenges imposed by their intellectual disability.

This study aimed to describe advocacy and activism of carers of adolescents with DS in the Oshana region of Namibia by exploring their perceptions/understanding of activism, and describing actions taken towards promoting participation for equal opportunities of adolescents with DS, including barriers encountered and strategies used, and to identify what they consider as advocacy priorities.

1.2 Background

Geographically, Namibia lies on the south western side of Africa (Appendix 1: Location of Namibia). The country is divided into fourteen regions (provinces) for administrative purposes. Oshana is one the most highly populated regions in Namibia with the majority of the population consisting of the Oshiwambo speaking tribe (Namibia Census, 2014). Due to the high concentration of Oshiwambo speaking people in northern Namibia, the area is locally regarded as Ovamboland. Oshana has an administrative representative for all the government ministries. These ministries are disability stakeholders providing information and resources to benefit all people including people with disabilities according to the National Disability Policy (Republic of Namibia, 1997). However, such resources do not always focus on social inclusion, thus requiring carers to be proactive to realise benefits for adolescents with DS. Therefore, the Oshana Down Syndrome Support Group (ODSSG) forms the study population. The group consists of about fifty carers who share common problems and improvement ideas, provide peer support and advocate for the rights of persons with DS in order to improve their livelihoods. These type of actions can be rated as both advocacy and activism acts related to improving the wellbeing of their adolescents. For the purpose of this study the two words 'advocacy' and 'activism' will be considered together because they are both important experiences for carers of adolescents with DS and can both occur concurrently and in a continuum (Ryan & Cole, 2009). Considering the definition given by Farrer and others (2015), "advocacy is a deliberate attempt to influence decision makers and other stakeholders to support or implement policies that contribute to improving health equity using evidence" (p. 396). When referring to carers in this study, advocacy will not only consider improving health equity but also all other related inequalities that hinder social inclusion of their adolescents. The term 'activism for carers' in this study is borrowed from Ryan and Cole (2009) who describe it as "a process of networking in a group/movement by advocating more frequently and at a higher level of complexity than other parents" (p. 44). However, even with the above background understanding, no study has been done to investigate the carers' advocacy and activism perspectives, knowledge, resources and challenges faced by the carers in this study as they endeavour to enhance the social inclusion of adolescents with DS in the rural Oshana, Namibia.

1.3 Problem statement

Little research has been done in Namibia and Africa in general that investigates actions of advocacy and activism about people with Down Syndrome in relation to their social inclusion. There is also no documented research evidence about the activism and related actions taken by carers of adolescents with DS in Oshana, Namibia and the Southern African Development Community and Africa in general, that explores their ability to be equal partners in disability inclusive policy creation, translation and implementation. The international disability lobby slogan 'Nothing about us without us' can only be operationalized when carers, families and people with disabilities (PWD) find their voice and have it documented and translated into actions amongst their communities.

1.4 Research purpose

Empirical exploration of advocacy and activism amongst carers of adolescents with DS will provide an evidence base and a conceptual platform for further strengthening of disability inclusive development initiatives in Oshana in particular and Namibia in general. By identifying and describing the strategies used by activist role models in a Namibian context on possible and realistic actions, a framework may be created that other carers can follow to enhance participation and social inclusion of adolescents with DS.

1.5 Research question

What advocacy and activism actions are carers engaged with that enable the participation and social inclusion of adolescents with DS in a local northern Namibian community?

1.6 Study aim

The study aims to describe the advocacy and activism actions of carers that promote the disability rights of adolescents with DS.

1.7 Objectives

1. Identify what carers of adolescents with DS believe 'advocacy' and 'activism' are in relation to the needs and abilities of their adolescents.

2. Identify what actions carers of adolescents with DS are taking to promote participation and equal opportunities for social inclusion of their children at individual, family and community levels.
3. Identify barriers to activism and strategies used by carers of adolescents with DS to address barriers.
4. Identify carers' advocacy and activism priorities for social inclusion of adolescents with DS in Namibia.

1.8 Summary

This chapter has introduced the research in general. It highlighted the contextual background, problem statement, research purpose, the research question, study aim and objectives. Chapter two below concentrates on the literature review

Chapter 2: LITERATURE REVIEW

2.1 Introduction

This chapter creates an understanding of Down Syndrome (DS) as a condition and the associated social inclusion challenges in relation to the adolescence stage. Key international and national policies relevant to facilitating social inclusion are highlighted. Barriers and challenges facing care giving toward adolescents with DS are described. A description of advocacy and activism is also provided with emphasis on the need for carers' actions to engage the community for the social participation of adolescents with DS.

2.2 Down Syndrome

Down Syndrome is chromosomal disorder, generally common with the prevalence of 1 to 800-1200 and is a well recognizable condition of intellectual disability (ID) (Gupta & Kabra, 2014). Genetically every human being has 46 chromosomes but individuals with DS have an extra chromosome 21 which is the cause of physical and developmental delays in the individuals (Gupta & Kabra, 2014). Despite having intellectual disabilities, people with DS have characteristic physical features and related health problems unlike people with other intellectual disabilities (Pikora et al., 2014). Visible features like flat facial features, slanting eyes, small eyes and lingual protrusion make people with DS to be perceived as less human, a term referred to as 'infrahumanization' (Rodriguez, Mateo, Rodriguez-Perez & Rodriguez, 2016). According to Parekh (2017) intellectual disability results in mental challenges that impact on areas of intellectual and adaptive functioning. Parekh (2017) elaborates further on the intellectual functioning with examples such as learning, problem solving and judgement, while adaptive functioning includes difficulties in carrying out activities of daily life, communication and independent living.

Furthermore, the ID is responsible for language weakness and the disruption of the working memory (Dierssen, 2011). Worth noting is the fact that persons with DS present in three categories with trisomy 21 occurring in about 95%, translocation type in 3-4% and the remaining rare cases are termed mosaic (Gupta & Kabra, 2014). The interaction between the environment and the limitation of functions such as social, conceptual and adaptive can

cause social exclusion and impact on a development stage like adolescence (Rodriguez et al., 2016), thus creating a need for carers' activism and advocacy. For example, obesity is common with people with DS, while they are known to "have pleasant behaviour, are caring, affectionate and quite social. Some of them are music lovers" (Gupta & Kabra, 2014, p. 562). Therefore, with early intervention, especially with programmes such as speech therapy, physiotherapy, occupational therapy and medical attention, children with DS can have better life outcome than other intellectual disabilities (Gupta & Kabra, 2014). Life expectancy for people with DS has recently improved due to early and better medical care, but threatening factors include cardiac problems, respiratory infections and childhood leukaemia (Gupta & Kabra, 2014).

Down Syndrome is therefore a condition that needs to be well understood by not only carers, but also the individuals themselves, the service providers and the community in general in order to allow social inclusion. Such understanding may require intensive advocacy and activism from carers as part of their caring responsibility, especially during the transitional stage of adolescence.

2.3 Adolescents with DS

Adolescence is a stage of many rapid changes related to biological and social roles that impact on future health and socially related wellbeing (Sawyer et al., 2012). Strategies that focus on adolescents have important opportunities to improve on health, education and social inclusion and other factors that improve quality of life (Sawyer et al., 2012). Considering the intellectual disability of adolescents with DS, carers' advocacy and activism for social inclusion of adolescents with DS can therefore be an important intervention for their future wellbeing. For example, studies show the existence of negative attitudes and lack of information about reproductive health and sexuality for youth and young adults with intellectual disabilities (Lin et al., 2011; Scior, 2011; Stoffelen et al., 2017; Pownhall, Jahoda & Hastings, 2012). Scior (2011) also reports that attitudes towards sexuality of people with intellectual disabilities are filled with prejudice even within their own families and the general public. Therefore, there is a need for carers to be ready to learn and educate adolescents with DS and the general community about rights to sexuality through advocacy and activism.

Furthermore, the inappropriate attitude and difficulties in identifying, communicating and assisting with reproductive and sexual needs of adolescents with intellectual disabilities can create opportunities for carers, families and people with intellectual disabilities to actively engage with stakeholders for beneficial interventions (Kok & Akyuz, 2015; Martinello, 2015; Schaafsma, Kok, Stoffelen & Curfs, 2015; Lafferty, McConkey & Simpson, 2012). For example, it is possible for carers to work closely with health workers in developing health education programmes that train and monitor carers in addressing the reproductive and sexual needs of adolescents with intellectual disabilities (Kok & Akyuz, 2015).

There are more reasons as to why this study concentrates on adolescents with DS. Studies show that intellectual disabilities in adolescents with DS slow the educational process that impacts on skills development (Vaney, Khaliq & Anjana, 2015; Spangenberg et al., 2016). There exists a combination of specific health problems affecting physical and/or mental status amongst adolescents with DS such as the presence of vision and auditory sensory loss, psychotic episodes and congenital heart problems (Pikora et al., 2014; Lee, Chien & Hwu, 2016; Dykens et al., 2015; Akahoshi et al., 2012). Studies also show the existence of more increased risk of obesity and overweight in adolescents with DS than in children or adults with Down Syndrome (Krause et al., 2016).

Research also highlights that adolescents with DS have some distinct differences from typical adolescents and adolescents with disabilities but without DS (Seron & Greguol, 2014; Pikora et al., 2014). Seron and Greguol (2014) noted that, unlike others, adolescents with DS have low oxygen consumption that reduces cardiorespiratory fitness which causes a major health problem that affects involvement in exercises, sports and other lifestyle activities (Seron & Greguol, 2014). By understanding such information carers can have a good foundation for actions with their adolescents with DS and a reason to accelerate advocacy and activism for inclusive opportunities that enable activities such as regular sports and exercises for their adolescents with DS. The effect of exercise programmes such as aerobics on body composition of adolescents with DS is beneficial as it reduces obesity that can result in social isolation, depression and lack of interest for engagement in community activities (Seron, Silva & Greguol, 2014). Actions to facilitate these exercise programmes on behalf of adolescents with DS are needed. However, carers' advocacy and activism actions

and collaboration to address problems of adolescents with DS, especially in developing countries like Namibia, have not been well documented.

In addition, such health problems warrant primary health care screening and follow-ups (Lee, Chien & Hwu, 2016), a right for the adolescents with DS in line with the UNCRPD and part of carers' responsibilities to advocate for them (UN, 2006). Health problems interfere with day-to-day functioning of the individual. Bull (2011) reports that social abilities can be improved by vigilant monitoring and early intervention on such health problems through regular health supervision and check-ups at various stages in the life of people with DS. For example, Hall (2011) emphasises that adolescents often experience cardiology, cervical spinal and obesity associated problems that can interfere with sleep, behavioural and exercise norms. These problems can negatively impact on an adolescent whose stage of life requires day-to-day active and physical participation. Furthermore, interference by cardiac, cervical spinal and obesity problems, if not addressed, may cause a risk to sporting and physical exercises well known for social inclusion (Harada et al., 2011). Harada and others (2011) report that participation in community sporting activities such as Special Olympics enhances social interaction and are valued for increasing connections between individuals with intellectual disabilities, their families and the surrounding community. Therefore, carers' advocacy role in provision of the needed health services and their actions (activism) towards regular follow ups are important in promoting social inclusion of adolescents with DS. However, little is known as to how carers' actions mitigate these problems through advocacy and activism that facilitate social inclusion of their adolescents with DS.

2.4 International and national policies guiding/in support of social inclusion

Policy documents and guidelines are known to contribute towards understanding, measurement and monitoring of social inclusion for people with intellectual disabilities and challenging behaviours (Bigby, 2012; Baumgartner & Burns, 2013). Bigby (2012) argues that a greater understanding of policy guided practices that are goal oriented towards social inclusion can gain prominence in funding and support to reduce social exclusion. Therefore, it becomes crucial for carers to understand the relevant guiding policies that enable social inclusion practice in all sectors that benefit their adolescents with DS. Considering the needs and abilities presented by the Down Syndrome condition, the vibrant stage of

adolescence and the role of advocacy and activism, it becomes necessary to highlight some of the international and national policies in the Namibian context that enhance social inclusion.

The concept of social inclusion is described as a model consisting of two major themes, interpersonal relationships and community participation (Simplican, Leader, Kosciulek & Leahy, 2015). Simplican and colleagues argued that the more people get involved and participate in community activities, the more opportunities they have for widening their social networks and building stronger interpersonal relationships (Simplican et al., 2015). Involvement and participation by utilizing a broad range of activities, relationships and environments, in various settings that include private and public participation, result in social inclusion (Simplican et al., 2015). Therefore, social inclusion enables social connectedness that creates the sense of belonging to people with disabilities and is known to reduce negative attitudes, stigma and discrimination (Mahar, Cobigo & Stuart, 2013). Therefore, countries need to support social inclusion by adopting appropriate national, international policies and guidelines (Simplican et al., 2015; Mahar et al., 2013; Overmars-Marx et al., 2014).

One of the key international documents that forms the framework for national practices relating to social inclusion is the United Nations Convention on Rights of Persons with Disabilities (UNCPRD) (UN, 2006). Various researchers acknowledge that the United Nations Convention on Rights of Persons with Disabilities supports social inclusion and can be utilized as a tool to practice, monitor and evaluate social inclusion in a given society (Symeonidou, 2015; Mahar et al., 2013; Overmars-Marx et al., 2014). For example, Symeonidou (2015) reports that, despite the ratification of the UNCPRD, Cyprus did not take adequate measures between 2007 and 2014 to implement Articles 19 and 24 of UNCPRD and therefore failed to promote social and educational inclusion of people with intellectual disabilities. Namibia also realised the importance of social inclusion and the connection between national and international policies and so the country ratified and became signatory to UNCPRD in December 2007 (Amadhila et al., 2012). By ratifying the UNCPRD the country gained the benefits of guidance and support towards effective changes in lives persons with disabilities, such as empowering them, embracing their voices and promoting

their development action (like advocacy and activism) through various sectors of development (Harpur, 2012).

Another crucial document is the joint position paper on Community Based Rehabilitation (CBR), a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities as emphasised in the global action for disability (World Health Organisation, 2015). Namibia is one of the fifteen Southern African countries implementing Community Based Rehabilitation strategies in rural areas and is known to have a specific CBR policy content that guides the implementation (M'kumbuzi, Myezwa & Myezwa, 2017). The existence of CBR policy in Namibia has the potential to empower carers' endeavours to strengthen vigilant care and development of their adolescents with DS within their community while involving various stakeholders. To further complement quality health and social welfare, the Ministry of Health and Social Services (MHSS) (2010) developed the 'National Health Policy Framework 2010-2020' that emphasises health provision through primary health care services with special directions towards strategic response aimed at different issues. Notable is the emphasis given to the strategic response directions aimed at adolescent and school health that call for strong collaboration through parental involvement, community and other sectors (MHSS, 2010). The document calls for the promotion of adolescent-friendly, "provision of information and counselling, follow-up of specific condition/defects and promotion of school clubs" (MHSS, 2010, p. 10). Such directions can become opportunities for carers, families and adolescents with DS to excel in advocacy and activism towards activities that enhance their social inclusion. Namibia has disability and rehabilitation policies that are ranked high in terms of addressing human rights and social inclusion (Mannan et al., 2012). The assessment done on the Namibian National Policy on Disability (1997) showed that the document has 95% coverage of the core concepts required for human rights that favour vulnerable groups such as people with disabilities, youth, aged, suffering from chronic illnesses and those with special needs (Mannan et al., 2012). Considering the broadness of vulnerable groups, the high quality policy document attracts interest on how carers' actions are advocating for the outlined benefits leading to social inclusion of their adolescents with DS. Other relevant documents that support social inclusion within Namibia include: the Namibian constitution (Republic of Namibia, 1990), the National Disability Council Act (Government of Namibia, 2004), the

Affirmative Act (Van Rooyen, 2000) and disability grant support (Levin, Van & Yu, 2011). These and other policies from government ministries empower and enhance people with various disabilities and their carers' activism and advocacy.

2.5 Barriers and facilitators of equal opportunities for persons with DS

There is evidence of inequalities in the accessibility, availability and affordability of health care and other social services for people with intellectual disabilities (WHO, 2011). Studies from the developed world highlight structural inequalities especially in employment and health care provision that make it difficult for youth with DS to access services (Emerson & Baines, 2011; Pikora et al., 2014; Hammel et al., 2015). Little is known about inequalities for people with DS in the developing world. However, inequalities of service provision for children with disabilities can make caring become challenging. For example, in Tanzania, McNally and Mannan (2013) found that carers described objective challenges such as finance, demand for care and employment as more common barriers to social participation than subjective challenges which include negative attitudes of stigma, discrimination, isolation and pity. Meanwhile, in Ethiopia, Tilahun and colleagues reported that provision of education for children with developmental disabilities topped the list of unmet needs, followed by poor customer care by health service providers and inadequate financial support among other needs (Tilahun et al., 2016). Carers also experienced stigma that affected their efforts towards effective caring of their children, an issue that made them seek support from other carers with similar children (Tilahun et al., 2016). Similarly Spangenberg and others (2016) showed further inequalities in educational needs specifically for children with ID in South Africa. The advocacy and activism action taken by the Western Cape Forum for Intellectual Disability revealed to a South African court about educational injustices by the government department of education (Spangenberg et al., 2016). This revelation ignited the need and also called for the development of a database that would enhance access to the right to education for children with severe and profound intellectual disability (Spangenberg et al., 2016). Therefore, barriers and challenges towards equal opportunities for adolescents with DS can be diverse and intense for carers on a daily basis to the extent of them providing carers with a baseline for advocacy and activism.

Nevertheless, it is worth noting that there exist facilitators of equal opportunities for persons with DS that have become drivers and motivators for carers and their families to initiate, continue and maintain advocacy and activism for their adolescents with DS. For example, the current vigilant care and improvement in the quality of life for people with Down Syndrome can be said to have increased their life expectancy (Glasson, Dye & Bittles, 2014; Glasson et al., 2016). This allows carers to continue with caring responsibilities. Studies in developed countries show improved survival towards old age for people with Down Syndrome (Glasson et al., 2016; Lee, Chien & Hwu, 2016; Hart et al., 2017; Torr et al., 2010). Another facilitator towards social inclusion is the engagement of people with intellectual disabilities in sports, an issue adopted by Special Olympics with support from one hundred and eighty countries (Namibia included) (Harada, Siperstein, Parker & Lenox, 2011). By using unified sports inclusive programmes, the Special Olympic enables social inclusion by providing connections among and between individuals with intellectual disabilities, their families and the surrounding community (Harada et al., 2011).

Therefore, knowledge and understanding of barriers and facilitators of equal opportunities for persons with DS have the potential to motivate carers towards advocacy and activism aimed at achieving improved quality life for their adolescents with DS.

2.6 Advocacy and activism

Advocacy and activism processes in relation to disability often arise from the desire to improve the quality of life for people with disability (Test et al., 2005; Wright & Taylor, 2014; Good et al., 2017; Sauer & Lalvani, 2017). Furthermore, researchers emphasise the challenges faced by carers and family member resulting from inadequate and inequalities of service provision as major reasons that provoke advocacy and activism desire (Wright & Taylor, 2014; Good et al., 2017; Sauer & Lalvani, 2017). In their own words parents referred to the processes of advocacy and activism as “a fight for services” (Good et al., 2017, p. 107). Carers’ experiences of marginalisation in economical, educational, health and social sectors have attracted more collective rather than individual forms of advocacy and activism (Good et al., 2017; Ryan & Cole, 2008). Advocacy and activism processes are said to be a continuum where advocacy proceeds as an on-going activity that usually advances to activism (Ryan & Cole, 2008). Quite often disability advocacy and activism aim at educating

communities about disabling conditions, human rights and the rights for services (Sauer & Lalvani, 2017; Good et al., 2017; Isgro, 2015; Ryan & Cole, 2008). Thus, carers' knowledge and understanding of the disabling conditions, limiting situations, human rights and the rights to needed services serve as the background and the strength for advocacy and activism (Poon-McBrayer & McBrayer, 2014; Isgro, 2015; Sauer & Lalvani, 2017; Good et al., 2017).

Literature also shows that siblings of persons with Down Syndrome participate in advocacy and activism activities to improve the social inclusion of their brothers and sisters with Down Syndrome (Burke, Arnold & Owen, 2015; Burke, Fish & Lawton, 2015; Floyd, Costigan & Richardson, 2016). Participation of siblings can enhance good relationships with adolescents with DS. Floyd, Costigan and Richardson (2016) found that with good relationship and caring for brothers and sisters with intellectual disabilities siblings experienced strong closeness. Siblings are also able to understand the conditions, needs and abilities of their brothers and sisters and form affectionate bonding that indicates readiness for caring, educating others and acting on behalf of them (Burke, Fish & Lawton, 2015).

Burke, Arnold and Owen (2015) found that siblings did actual advocacy and activism by securing appropriate services for their brothers and sisters, educated others and took actions that caused positive changes towards their brothers and sisters. Skotko, Levine and Goldstein (2011) reported that more than 94% had affection toward their siblings with DS and expressed feelings of pride about them. Such a positive and enhancing attitude of siblings can be an indicator of readiness to advocate and act for their family member with DS (Skotko, Levine & Goldstein, 2011). However, advocacy and activism by siblings of people with Down Syndrome in developing countries is not well documented and, despite their efforts, siblings may face different challenges to improve social inclusion of their siblings with DS. Burke, Arnold and Owen (2015) report that siblings needed more information and peer support for effective advocacy and activism. Therefore, collaboration with others and even the involvement of the adolescents with DS is essential. Valuing the perspectives of persons with intellectual disabilities has recently received international attention at a summit that gave recommendations such as enabling a peer-to-peer support model that promotes advocacy and activism of groups and individuals with ID (Watchman et al., 2018). Studies also show that adolescents with Down Syndrome do participate in daily and leisure

activities that reflect aspects of self-advocacy and activism towards improving their social inclusion (MacDonald et al., 2016; Dolva, Kleiven & Kollstad, 2014; do Amaral et al., 2014; Hutzler, Oz & Barak, 2013). Persons with DS can enable self-advocacy and activism through appropriate socialization such as fully participating, learning and actively showing their skills (dancing) in the community (Becker & Dusing, 2010). By persevering through active dancing skill training a young girl with DS decreased her anxiety and fear of social settings, and increased her self-confidence, endurance and initiatives for social situations, thereby allowing her to self-advocate (Becker & Dusing, 2010). Therefore it is important for individuals and groups of persons with DS to engage with self-advocacy and activism for their own social inclusion within communities.

2.7 Need for carers' advocacy and activism for adolescents with DS

Caring for persons with Down Syndrome from birth to adolescence allows carers to have experiences that can be both enriching and challenging. With such experiences carers become skilful to tell others, talk about their children and sometimes attempt to break challenging barriers. Studies have shown that carers and family members take actions to empower and take vigilant care of DS members with the objective of ensuring provision of medical care and participation in social activities to meet their needs (Bittles et al., 2007). In another study Chadwick and others (2013) provided evidence of how advocacy and activism through promoting voices of families has become a way of rectifying and modifying services for people with intellectual disabilities. Clear understanding of healthy lifestyle needs for adolescents with DS such as addressing obesity and the on-going community activities drive the urge for advocacy and activism of parents (Curtin et al., 2013). Obesity awareness raising to community members paves the way for adolescents with DS to participate and experience a sense of belonging within a community while engaging in community healthy lifestyles activities such as exercises (Curtin et al., 2013). By advocating and being active in community sporting activities carers can make available beneficial opportunities to adolescents with DS, such as improved relationships through connectedness, being trained for desired sport codes, entertainment and taking photos for memories (Curtinet et al., 2013; Weiss et al., 2016).

Naturally, siblings often become carers especially when there is a close relationship with their family member in which case the siblings engage in positive advocacy and action that benefits their brother or sister with DS (Skotko, Levine & Goldstein, 2011). Siblings of persons with intellectual disabilities are also known to take actions and advocate for their brothers and sisters with intellectual disabilities (Burke, Arnold & Owen, 2015; Skotko, Levine & Goldstein, 2011). Siblings may have various reasons for such advocacy. Burke, Arnold and Owen (2015) found that siblings did case advocacy where they talked about the abilities, needs and aspirations of their brothers and sisters with ID. Siblings also did case advocacy where they raised awareness for changes at community level through educating others and joining broader advocacy groups for the benefit of their loved ones with ID (Burke, Arnold & Owen, 2015). Sometimes carers' advocacy and activism are need driven. For example, in Tanzania the need for better health care, financial assistance and other necessities required parents and family members to take up the role of advocacy and activism for better services (McNally & Mannan, 2013). Other needs such as prevention of abuse and cultures that foster poor practices in relation to people with learning and intellectual disabilities require carers' efforts in advocacy and activism (Dawkins, 2012). Furthermore, prompt actions from carers may be needed to acquire certain benefits. For example, in Namibia, the early conversion of the child maintenance grant to a disability grant may require some activism and advocacy to enhance earlier and better services for adolescents with DS. People with ID should also get opportunities to advocate for themselves (Levine et al., 2011). For example, the general community requires awareness of the needs, capabilities and aspirations of people with intellectual disabilities and therefore individuals and collective groups of people with intellectual disabilities can, with guidance, spearhead their advocacy and activism (Deguara et al., 2012).

While expressing their aspirations persons with ID advocate and take actions for their own social inclusion as they exercise their right to make choices and decisions but admit the need for support from carers and others who understand them, in line with the disability motto 'nothing about us without us' (Deguara et al., 2012). Contribution and support from carers, family members and others towards advocacy and activism of adolescents with DS facilitates social inclusion and has received emphasis as an obligation in accordance with the Convention on the Rights of Persons with Disabilities (United Nations, 2006). Therefore, the

ratification of UNCRPD by countries such as Namibia indicates commitments towards initiatives, support and continuation of advocacy and activism for social inclusion of persons with DS and disabilities in general. There exists a gap that shows scarcity of actual actions and strategies used by carers in their advocacy and activism role for social inclusion of their adolescents with DS. To ensure the effectiveness of carers' commitments there is a need to investigate the current initiatives and actions by carers as this may guide the development of a framework and indicate the way forward for the implementation of advocacy and activism for social inclusion of persons with DS.

2.8 Summary

Advocacy and activism for adolescents with DS is a process of learning, sharing and putting in place actions aimed at social inclusion. The process requires clear understanding of Down Syndrome as a condition. The presence of intellectual disability in persons with DS, specific health related problems and the social and economically related problems play a major role in the process of advocacy and activism for integration of adolescents with DS. The mentioned problems drive carers, family members and adolescents with DS to collectively take up the process of advocacy and activism in order to meet the needs and abilities of adolescents with DS. Therefore, clear knowledge and understanding of the existence and commitment to the international and national policy documents are needed as such documents place emphasis on strengthening and supporting social inclusion for persons with disabilities. However, little is documented about advocacy and activism towards social inclusion for adolescents with DS in Namibia. A gap therefore exists in relation to advocacy and activism of carers in rural Namibia with regard to what carers are doing to facilitate social inclusion of their adolescents with DS. Exploration into advocacy and activism of carers can provide a conceptual framework for further strengthening of disability inclusive development initiatives in Namibia. The review of literature justifies the need for the current study. The next chapter deals with the methodology used for a qualitative study to explore the advocacy and activism of carers as they endeavour to facilitate social inclusion of their adolescents with DS.

CHAPTER 3: METHODOLOGY

3.1: Introduction

This chapter explains the rationale for using qualitative methodology and methods and details the process of selecting participants, data collection, analysis and interpretation. Data management is also explained. Maintaining of research rigor and the observing of ethics and the ethical procedures are covered as well.

3.2 Research approach

A descriptive qualitative approach was used in order to explore and clearly describe the reality of activism while providing emancipatory power for carers to narrate their stories (Filck, 2014). The approach gave voice to the unfolding advocacy and activism stories of actions taken by three carers of adolescents with DS. A descriptive qualitative approach was appropriate because it enabled the participants to describe behaviours and experiences as they occurred in natural settings (Savin-Baden and Major, 2013). Participants shared their endeavours to enhance community participation and social inclusion of adolescents with DS.

3.3 Situating the researcher

The researcher is a local occupational therapist who speaks, understands and is conversant with the local language (Oshiwambo). With more than ten years' experience in disability work within a rural setting, the researcher holds the philosophical position that active individual and collective participation in advocacy is needed for change towards an inclusive society. On the basis of being a local community member, the researcher holds positive assumptions about the carers, adolescents with DS and the general community in relation to overseeing daily participation and social inclusion of persons with DS.

3.4 Research site and access

The Oshana region is rural and culturally populated by Oshiwambo people who follow an agrarian lifestyle and utilize agricultural products for social economic gains. However, there are three upcoming business orientated towns council areas called Ongwediva, Oshakati and Ondangwa that are likely to attract various businesses and employment opportunities

that will benefit the Oshana population. The reality is that the three town council areas are still very rural upcoming town areas and not yet pronounced municipality towns. Some residents may not have full town benefits and live there mainly to be near schools and the major hospital. They are actually peri-urban. It is common here for people to have an informal dwelling slightly near to a town and to use the name of this town as their residence whereas their major home is in the rural areas. The research targeted the Oshana Down Syndrome Support Group (ODSSG) members who converge monthly at a central point from the eleven political constituencies of the Oshana region. Access to the site is feasible by walking, car or by public transport except during the rainy season. The researcher considered the participants' physical and social barriers with regard to promoting an emancipatory research approach (Smith-Chandler and Swart, 2014). The participants had the opportunity to decide on an appropriate and comfortable venue to tell their stories.

3.5 Study population and sampling

3.5.1 Population

The Down Syndrome Association of Namibia, the Oshana branch - well known as Oshana Down Syndrome Support Group (ODSSG) - was approached and engaged as the research population. This is a rural group of carers and their children, adolescents, adults and relatives with DS. Their membership and leadership structure were used to reach and identify willing participants. They meet monthly to support and improve the wellbeing of their adolescents with DS by addressing service provisions such as health, safety, education and other socio-economic issues. It is estimated that the group membership of carers as of December 2017 consisted of about fifty carers. The group identifies, orientates and recruits new members with family members with DS within Oshana region.

3.5.2 Sampling, criterion and size

Due to the objectives of the study and the characteristics of the group selected, this study used purposive sampling, as recommended by Morse, Barret, Mayan, Olson and Spiers (2002), and deliberative democracy as described by Kim, Wall, Stanczyk and De Vries (2009). The purposive sampling helped to specifically identify the group members rich with information (Morse et al., 2002) while the deliberative democratic strategy allowed group

members to exercise their democracy in determining the specific active members to represent the group views and opinions (Kim et al., 2009). Group (ODSSG) members expressed their moral opinions in line with the common goals of the group to democratically determine five members in an ordered list (number one being the most active and number five the least active). The five carers of adolescents with DS who were known to be proactive in advocacy and activism within the group were therefore deliberately and democratically voted (Kim et al., 2009) by ODSSG members in one of their monthly meetings and in accordance with the criteria described below. The first three voted members were to be interviewed while the other two were to be on standby. In support of these sampling methods and the sample size of three participants, Morse and colleagues (2002) confirm that purposive selection of participants with the best knowledge enhances credibility in qualitative descriptive research. Furthermore, the democratic deliberation strategy not only allowed group members interaction in understanding the topic under question - advocacy and activism of adolescents with DS - but also enabled group members to “treat one another as decision-makers who deserve respect by being provided with reasons that they can evaluate and respond to” (Kim et al., 2009, p. 6).

3.5.3 Inclusion criteria

The ODSSG discussed activism in order to understand and proceed with a deliberative democratic voting process for suitable carers according to the given criteria (Kim et al., 2009). As a peer group, the ODSSG engaged members in deliberations over their diverse viewpoints that would lead the democratic voting process of identifying members rich with advocacy and activism information (Kim et al., 2009).

The participant must:

- be a biological or foster parent, grandparent, sibling, extended family member
- have lived with the adolescent with DS for at least three years
- be a member of the existing ODSSG
- be regarded and voted as an activist by group members (she/he should be well known to be proactive in promoting the wellbeing and inclusion of adolescents with DS)
- be able to understand and articulate well in the local language, Oshiwambo

- be willing to face the minimal potential risk that their activism story may be recognized in the research report even though pseudonyms would be used.

3.5.4 Exclusion criteria

Any carer who

- was new to the group
- was uncomfortable with the minimal potential risk that his/her activism story may be recognizable in the research report even though pseudonyms were to be used.

3.5.5 Participant recruitment

To start the recruitment process a letter was sent to the ODSSG on 10th December 2017 to introduce the research. As recommended by Coons and Watson (2013), a prior meeting in the form of workshops to familiarize potential participants with the proposed research was done on 19th January 2018 (Appendix 2). The researcher requested an agenda item on the study at one of the ODSSG monthly meetings. Members received all information on the study as given in Appendix 3 (Research Information Sheet), inclusion/exclusion criteria and the possible potential risk (that they may be recognized through their story by members of the ODSSG in spite of a pseudonym being used). After their deliberation, the three best and willing members were identified. Two more members were voted by the group as back up. Thereafter the researcher telephonically invited the three participants, explained the informed consent, the potential risk and their right to participate or voluntarily withdraw at any stage without any consequences. A date and venue for a meeting was agreed upon, and the signing of the informed consent form (Appendix 4A or B) and dates for narrating the activism story were also agreed. The researcher's knowledge of the local language was an advantage during the process of introducing the study and requesting assistance with recruitment, listening, transcribing and analysing the stories (Coons & Watson, 2013).

3.6 Data collection

3.6.1 Methods: Semi-structured in-depth interviews

The researcher used semi-structured in-depth interviews with a single open-ended question and further probing that helped the free flow narration of their personal and life

experienced stories (Baumbush, 2010). The interviews started with an introduction and obtaining the particulars of both the carer and their adolescents with DS (see Table 1 below). Use of the interview guide (Appendix 5) helped to cover general areas aligned with the study objectives. Baumbush (2010) asserts that the guiding questions allows probing and solicit descriptive stories that rich in information about the topic is provided. Although the stories narrated were given individually, participants also talked of interactive activities done in their group with other members. Use of a semi structured in depth interview with guided questions allowed each participant to promote self-advocacy and also friendship entities that participants believed existed between her and other members of the same advocacy group (Gregory, 2011; Ravitch, 2014; Perera & Standen, 2014; Berger & Lorenz, 2016). Therefore, individual stories from three carers about seeking social justice and equalities for health, education and other economically related support were audio recorded. Each interview lasted approximately 1-1.5 hours, providing a total of four hours and fifty-five minutes of data. Further probing after transcribing was done telephonically to acquire more details of the years spent with the study group and the demographics of participants. A follow up interview of approximately one hour was arranged with each participant to clarify gaps and to member check findings.

Table 1: Characteristics of participants and their adolescents with DS

Participant Code	MO	FL	RS
Relation to adolescent with DS	Biological mother	Biological mother	Biological sister
Age of participant	45 years	51 years	26 years
Duration with adolescents with DS	Since birth	Since birth	Since birth
Duration in the ODSSG	Pioneer member	Pioneer member	Five years ago
Area of residence	Rural	Both peri-urban and rural	Both peri-urban and rural
Health facility: Clinic	2km 20km - Oshakati	1km 30km - Oshakati	< 1km Private < 1km;

referral hospital	hospital	hospital	state hospital - 7km
Nearby school	1km	2km	< 1km
Nearby church	1.5km	1km	< 1km
Nearest peri urban	20km	0 km	0 km
Adolescent with DS	OB	LM	E
Sex of adolescent with DS	M	M	F
Age of the adolescent	16 years	12 years	18 years
Education of adolescent	Never attended, does not go to school	Kindergarten (3yrs) Grade 1 (six months)	Never attended, attending piano training

3.6.2 Observation/field notes

The researcher admits difficulty in observing actions of activism during the interview period because, according to Ryan and Cole (2009), observation is a process that may require the researcher to follow up the three participants in their lived environments as they network with other group members. Belonging to the same advocacy collective group enables better expression of individuals' inner views about relevant issues as they relate to the group characteristics (Gregory, 2011; Ravitch, 2014; Berger & Lorenz, 2016). Therefore, the researcher had the opportunity to just observe and listen in three of their meetings where participants were present. It is worth noting that this was not done as a group interview but just observation. Appendix 2 shows one such meeting where members talked of their 2018 activities and way forward. Such meetings lasted for about two to two and a half hours. Ethnographic observations in the advocacy environments were not done because it would have compromised the confidentiality of the participants. However, observations of speech/language expression, fluency and confidence were observed and noted during the interview and three of their meetings leave no doubt about the urge for advocacy and activism of these carers (see observational notes in Appendix 6). Writing observational field

notes helped the researcher understand the meaning attributed to activism and advocacy actions and the carers' aspirations for social change to meet the needs of their adolescent with DS (Phillippi & Lauderdale, 2017). The participants got an opportunity to decide on where the interview was conducted. This choice allowed the researcher to take notes about observation of participant interaction with the environment in which advocacy and activism for adolescents with DS unfolded in Oshana. Phillippi and Lauderdale (2017) assert that field notes help to supplement narrated data and encourage the researcher's reflection on what is observed during the interviews. Any observable information indicating actions towards social inclusion was considered and noted. For example, two participants came with their adolescent with DS health passport where some claims about health advocacy were confirmed. One participant also brought with her the photograph of her adolescent son to confirm what she was talking about. The adolescent boy had typical features of Down Syndrome, and looked healthy and well looked after in the photograph.

3.6.3 Reflection journaling

The researcher recorded in a journal the personal views and experiences that she encountered with the carers. Reflection on information gathered during the three narrative interviews and at one of the monthly group meetings was noted in the journal. These reflections included the researcher's analytical notes written on different days of this research process. For example, on 19th January 2018 the researcher provided and explained all the information concerning the research. The researcher noted that the members enthusiastically took the opportunity to understand and ask for more research related information. To the researcher this was received with eagerness and the drive to want to proceed with the identified participants from the group. Reflection notes after every story narrated allowed the researcher's biases to be bracketed so that they had limited influence during the data analysis (Phillippi & Lauderdale, 2017) (see example from the researcher's journal in Appendix 7).

3.7 Data management

The researcher utilized some of the ways to maintain confidentiality and privacy of data as discussed by Lin (2009). Therefore the following were explained to participants and done:

- data anonymity was achieved through the use of pseudonyms to avoid participants' identification
- printed data and material such as signed informed consent forms were kept safely in a lockable cabinet
- computerized material such as transcripts were secured with a password only accessible to the researcher
- participants chose a neutral but desirable, cost free, reachable and quiet venue within their local environment

3.8 Data analysis and interpretation

Braun and Clarke's (2006) step-by-step inductive thematic analysis was followed for this research. Taking of notes, and being reflexive while writing a research journal contributed towards doing simultaneous data collection and analysis. Such analysis was estimated to have taken about three hours. This enabled the establishment of a justifiable and transparent link between raw data and research objectives (Braun & Clarke, 2006).

Stage 1: The researcher listened to the recorded narratives for a number of times to gain familiarity and good understanding before starting to transcribe the recordings verbatim. Verbal utterances were accounted for resulting in the text words (Braun & Clarke, 2006). In the process of transcribing the recorded stories the researcher gained more understanding of the raw data and developed the interpretive skills that were necessary to prepare her for the analysis process (Braun & Clarke, 2006). As advised by Braun and Clarke (2006) each of the three transcripts were read and re-read, and carefully checked against the audio recording for accuracy and noting of ideas that developed. Full familiarization and understanding of the three transcripts paved the way for the coding stage.

Stage 2: The researcher did the coding manually for the entire data set (three transcripts) where segments of raw data from transcripts were copied and assigned one or more codes according to Braun and Clarke (2006). These coded segments of raw data appeared interesting and meaningful in relation to the research topic (see audit trail in Appendix 7). Coding helped the researcher to organise data into meaningful groups and to prepare for the interpretive stage of developing sub categories (Braun & Clarke, 2006).

Stage 3: The long list of different codes from the three transcripts formed the basis of this stage. Following Braun and Clarke’s (2006) advice, the various codes were sorted in terms of similarities and differences to develop the potential sub categories after which collating of the relevant extracted raw data into the identified sub categories was done (Table 2 below).

Table 2: Audit trail - Developing sub categories from codes

Who	Raw Data Extract	Code	Sub categories
P1	I understand it though with difficulties	1. it is a difficult process 1. carer admits understanding	Defining advocacy/activism
	...in the beginning it was difficult	8. can be difficult for carer especially in the beginning when bringing adolescent with DS into the open 8. it can be difficult for adolescent with DS to enter the public 8. needs courage and perseverance	
R	My understanding of advocacy is speaking for others, or on the behalf of others	47. ready to speak for the adolescent with DS 47. can speak on behalf of adolescent with DS to others 47. can help adolescent with DS to meet their needs and abilities by speaking for them 47. can help siblings to clarify the meaning	Defining advocacy/activism A difficult/hard process
	What I advocate for my sister and not only my sister, any other Down Syndrome people	51. speaks/talks for sister and others with similar needs 51. recognizes others with DS	Joint process: togetherness
P2	I think I understand because as a mother of LM who has Down Syndrome	66. advocacy helps mothers of DS to understand	Defining advocacy/activism
	and I do gather other parents of children with DS	67. can help bring other	

	to get them to understand	<p>parents with similar condition</p> <p>67. entails courage and perseverance</p> <p>67. helps to teach other parents</p> <p>67. paves way for change of understanding of other parents but not easy</p> <p>67. gathering other parents for teaching is an action of activism</p>	
P1	managed to bring our adolescents into the open <i>Puuyelele</i> (public exposure)	<p>6. involves bringing the adolescent into the open (<i>Puuyelele</i>)</p> <p>6. involves exposing the public to their adolescent</p> <p>6. managed to: process has success in exposing the adolescent to public</p>	<p>Exposure to community/adolescent</p> <p>Orientating the adolescent to environment: home, school, church, shops, rural, urban, other areas</p> <p>Dealing with stigma</p>
R	My sister and I we do shopping together	<p>90. entails exposure to communal places and activities</p> <p>90. allows the adolescent enjoy leisure time</p> <p>90. needs courage and perseverance</p> <p>90. entails learning how to use money</p> <p>90. engages the adolescent, sibling and others in shopping (community)</p> <p>90. deal with community stigma</p>	
P2	our children want to be free with their compounds, but some neighbours just don't want	<p>219. the acceptance of the adolescent by neighbours is a challenge,</p> <p>219. needs courage and</p>	<p>Requiring courage and Perseverance</p> <p>Dealing with stigma</p>

	him in their compound...am not sure what they fear	perseverance 219. the adolescent has no freedom in neighbourhood 219. entails enduring stigma	Social inclusion strategies
P1	some could separate the child or just get away from the child	21. carers observe the public avoiding or separating themselves from the adolescent, 21. carer talk of separation and rejection of her adolescent 21. advocacy/activism can address separation and rejection of the adolescent	Educate community / the adolescent for RIGHTS Public education strategies Train & Nurture life skills Promote financial gains of the adolescent
R	...and this way she gets little something for her talent	85. develop talent for equal opportunity ..work 85. allow financial benefit by talent promotion 85 train for life skills targeted for financial gain	
P1	I realized I cannot care for him alone	30. knowledge that care for the adolescent requires others 30. realising that health & safety needs and abilities of the adolescent cannot be satisfied by carer alone	Social inclusion strategies Ongoing care
R	She has her own Dr for that, who she goes and sees when there's a need	77. helps to closely monitor the health status of the adolescent 77. enables the adolescent to participate in monitoring her own health 77. enables ongoing health care for good participation.	Action for health of adolescent with DS Action for safety of adolescent with DS
P2	...when it comes to transport I do not allow	133. entails maintaining ongoing care/safety with	

	him to just go alone....he goes accompanied	transport 133. engaging family/others for ongoing care 133. together in joint process for ongoing care	
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Stage 4. Following Braun and Clarke’s (2006) advice, all sub categories were scrutinised, reviewed and refined. Some were broken down into separate sub categories in line with the research aim and objectives, while others had little data to support them and needed to be combined as they related to form more refined, meaningful and nine clear sub categories (Braun & Clarke, 2006).

Table 3: Audit trail example of reviewing and refining sub categories.

Sub categories	Refined sub categories
Defining advocacy and activism	Defining adocacy
A joint process	Defining activism
A difficulty process	<i>*Togetherness is a hard process</i>
Requiring courage and perserverance	<i>*Requiring courage and perserverance</i>
Knowing various environments (Home, school, church, shops, rural, urban, other areas)	Orientate adolescent with DS to environment
Creating/maintaing community connection for acceptance	Orientate community to adolescent with DS
Exposure to Community/adolescent with DS	<i>*Requiring courage and perserverance</i>
Dealing with Stigma	
Requiring courage and perseverance	
Maintaining safety	
Identifying and dealing with safety needs and abilities	
Making others aware of safety needs and abilities	
Understanding reproductive health	
Identifying and dealing with health needs and abilities	Actions for safety of their adolescent
Making others aware of health abilities and needs	Actions for health of their adolescent
Nurturing/training day to day skills	Action for life skills and financial gains
Orienting & enabling financial gains	<i>*Requiring courage and perserverance</i>
Dealing with stigma	
Requiring courage and perseverance	
Learning/Teaching all about DS condition	Public education strategies

Understanding normalcy	Social inclusion strategies <i>*Requiring courage and perseverance</i>
Strategy for inclusion	
Educate for rights	
Dealing with stigma	
Requiring courage and perseverance	

Table 3 shows the nine reviewed and refined final sub categories. The nine sub categories reflect, represent and relate to the whole data that tells the story of the three carers as regards advocacy and activism for adolescent with DS (Braun and Clarke, 2006). Analysis of the nine sub categories led to the development of four categories that relate to and answer the research objectives.

Stage 5: Defining the developed categories: This stage explains the analysis and interpretation steps of how the four categories were developed. Each of the four categories is defined and the description on how it relates to the research topic, aims and objectives is done in the findings chapter.

Stage 6: Summary of data analysis: This stage captures the main theme in the findings. Figure 1 at the beginning of chapter four captures the thematic essence of the findings.

3.9 The scientific rigor of the study

To maintain the scientific rigor of this study the researcher utilized descriptive, interpretive and theoretical validity (Maxwell, 1992). Description of the setting, which is the rural northern part of Namibia, the population and their culture, the study group, participants' selection process, carers' characteristics and those of their adolescents (Table 1) and data (heard and recorded) helped to increase the validity of the study (see chapter 1.2: Background). During analysis, the researcher endeavoured to accurately interpret and give meaning to advocacy and activism stories, thoughts, feeling and experiences as expressed by carers in a bid to increase interpretive validity (Maxwell, 1992). The researcher's understanding and documentation of the congruency and legitimacy of resulting concepts from theory and literature, and those given in the stories about activism and advocacy also increased theoretical validity (Maxwell, 1992). The trustworthiness of the study was determined by ensuring *credibility* (truth value); *transferability* (applicability in other contexts); *dependability* (consistency in other contexts); and *confirmability* (neutrality) of the data and findings (Guba, 1981; Shenton, 2004) as discussed below.

3.9.1 Credibility

Credibility was enhanced by the researcher familiarizing herself with the group and the use of three carers as data sources so that she could compare the similarities and differences between the data (Shenton, 2004). Member checking was done by sending the transcripts to participants for confirmation to get agreement from them regarding the truth value of the study findings (Guba, 1981). The use of direct quotes from the transcribed data of the participants helped to clarify, strengthen and confirm the meaning of carers' voices (Graneheim & Lundman, 2004). Representative quotations were identified through data analysis. Peer debriefing of the research was used to increase credibility by involving two supervisors to critique the research process (Guba, 1981). Regular presentations of this research process were done to fellow Masters' students through Skype. Triangulation occurred by using stories from the three carers as data sources as well as literature (evidence for quotations used is in chapter 4).

3.9.2 Transferability

Transferability was enhanced by describing the population context (page 19) and the topic also mentions the geographical area (Lincoln & Guba, 1988). Characteristics of carers and their adolescents (Table 1: page 22) and the use of codes (audit trail, appendix 8) helped to increase transferability (Thomas & Magilvy, 2011). The use of proper selection criteria (page 20) and appropriate methodology and methods (Chapter 3) was made to add towards transferability as recommended by Graneheim and Lundman (2004).

3.9.3 Dependability

To enhance dependability this research kept an audit trail of the data analysis process to enable the yielding of stable findings if the analysis is duplicated by someone else in the future (Shenton, 2004) (Table 1-3). Consistency was enhanced by using the same guiding questions across narrative interviews without omitting some for any of the three identified carers, a rigour strategy recommended by Graneheim and Lundman (2004).

3.9.4 Confirmability

The use of the researcher's reflection contributed not only to confirmability but also helped in developing self-understanding that can lead to the emancipation of both the participants and the researcher (Hubbs & Brand, 2005). On approval of the study the researcher kept a step-by-step audit trail to increase confirmability (Shenton, 2004) (see example of an audit trail in Appendix 8). The three different stories from three different carers formed part of triangulation and contributed towards understanding of the similarities and differences in the carers' activism (Shenton, 2004). The researcher's observations and reflective comments were noted as part of self-awareness in relation to the carers' stories (Shenton, 2004) (Appendix 6).

3.10 Ethics and ethical approval

Ethical conduct was adhered to in line with ethical approval HREC REF 698-2017 (Appendix 9) from the University of Cape Town and the permission from the Ministry of Health and Social Service in the Republic of Namibia (MOHSS - Namibia research approval Appendix 10)

3.10.1 Informed consent

A simplified research information sheet translated into the local language (Oshiwambo) was read and given to each participant to gain a good understanding of the study so as to make an informed decision about participation. On agreeing to participate the two carers were then given an Oshiwambo translated consent form (Appendix 4B) to read again and sign. However, participant R requested an English version of the consent form to read and sign. The potential risk that they may be recognized through their stories by members of the ODSSG in spite of using pseudonyms was explained. The opportunity was given to decide voluntarily to participate or withdraw at any stage from participating without consequences. None of the three persons had any objections and therefore signed.

3.10.2 Enabling autonomy

Enhancing good administration of the consent form can promote autonomy (Lange, Rogers & Dodds, 2013). Therefore, proper administration of informed consent such as listening to concerns, answering related questions, giving relevant research information, allowing

voluntary participation without coercion and consulting carers was done (Ketefian, 2015). The use of qualitative research with expressive methodologies such as narrative was used to encourage self-realization and feeling of confidence about their actions (Fisher, 2012). They made their own decisions whether to participate or not and were allowed at any time to discontinue with the research if they so wished. Using understandable ways such as local language to explain the aim, benefits and importance attached to this research triggered interest for self-expression and personal decisions (Ketefian, 2015). Respect for autonomy paved the way to enhance justice for carers during this research process.

3.10.3 Enhancing justice

Carers got an opportunity to focus on their rights as care givers and supporters of ADS within their community. They expressed human rights issues related to social inclusion and participation of their ADS (Rummery & Fine, 2012). Justice prevailed as participants had fair inclusion in the research by receiving research information and by choosing to participate in research or not (Weijer, Dickens & Meslin, 1997). An inclusion/exclusion criterion was given to ODSSG where all members (in one of their meetings) fairly and democratically decided on three participants (activists/advocates). The selected participant had further rights despite being selected by members to choose to participate or not through the signing of a consent form without being coerced (Flick, 2014).

3.10.4 Beneficence and non-maleficence

Holloway (2008) recommends maximization of benefits for participants and minimizing risks. This study gave the three carers the benefit of being chosen and regarded as activists and advocates amongst group members, an issue that provided a sense of identity. The study also offered participants, through narratives, an opportunity to express and evaluate their actions in helping with social inclusion of their ADS. Their expressions were useful for policy actions and changes in service provision necessary to benefit their ADS.

3.10.5 Confidentiality

The process of consenting increased protection of rights, freedom and confidentiality (Coon & Watson, 2013). Participants chose the place for the interview to increase confidentiality,

while the researcher used pseudonyms that kept participants anonymous and offered the freedom to continue or withdraw from the research which helped to build their confidence (Lewis & Porter, 2004). Carers were told that minimal potential risk capable of compromising confidentiality existed because their activism story could be recognized in the research report even though pseudonyms were used. They therefore got the opportunity to continue or withdraw if they so wished. They clearly understood and none opted out. They were also informed about safe keeping of data materials and information collected as described under the data management section 3.7 pages 24.

3.11 Summary

This chapter has detailed the reasons pertaining to the choice and benefits of qualitative descriptive research methodology. The chapter provides an outline of specific details on how research rigor was maintained, data was collected and analysed, and how ethical procedures were carried out and maintained. The next chapter provides details about the findings and how these findings were obtained from the data.

CHAPTER 4: FINDINGS

4.1 Introduction

This chapter details the findings from the analysis of three transcripts. The findings from the voices of the three carers revealed ‘bringing adolescents with DS into the open (*Puuyelele*)¹’ as the key driver of the advocacy process amongst the ODSSG in the Oshana region. Driven by the desire to enlighten society about DS, one overriding theme “*Puuyelele* (bringing adolescents with DS into the open) is a difficult joint process requiring courage and perseverance” emerged from the carers’ narratives. This theme answers the research question. It is also a reflection of the qualitative essence of the research aim. It is comprised of four categories. The first category, “*Speaking for and acting on behalf of adolescents with DS*” answered objective one and was comprised of two sub categories, “*Understanding advocacy*” and “*Understanding activism*”. The next two categories, “*Enabling a continuous enlightening process*” and “*Ongoing care & services*” answered objective two and consisted of five sub categories, “*Orientating ADS to the environment*”, “*Orientating the community to adolescents with DS*”, “*Action for safety of adolescents with DS*”, “*Action for health of adolescents with DS*”, and “*Actions for life skills and financial gains of adolescents with DS*”. The last category, “*Raising public awareness of DS and human rights*”, answered objective three and objective four, and was comprised of two sub categories, “*Public education strategies*” and “*Social inclusion strategies*”. The bidirectional relationships between the theme, categories and sub-categories are illustrated in table 4 below.

For authenticity of the quotations reference used in this chapter refer to the pseudonym of the participant and the page on which the quotation is found in the transcript.

¹*Puuyelele* in Oshiwambo means bringing something or issues to light or enlightening someone. Culturally the actual word is *Uuyelele* which literally means light, by using P in front it denotes light ‘at’ a place in time making it relevant to bringing adolescents with DS/issues about DS into the ‘light’ in various places/environments.

Table 4: Relationship between theme, categories, sub categories and research objectives

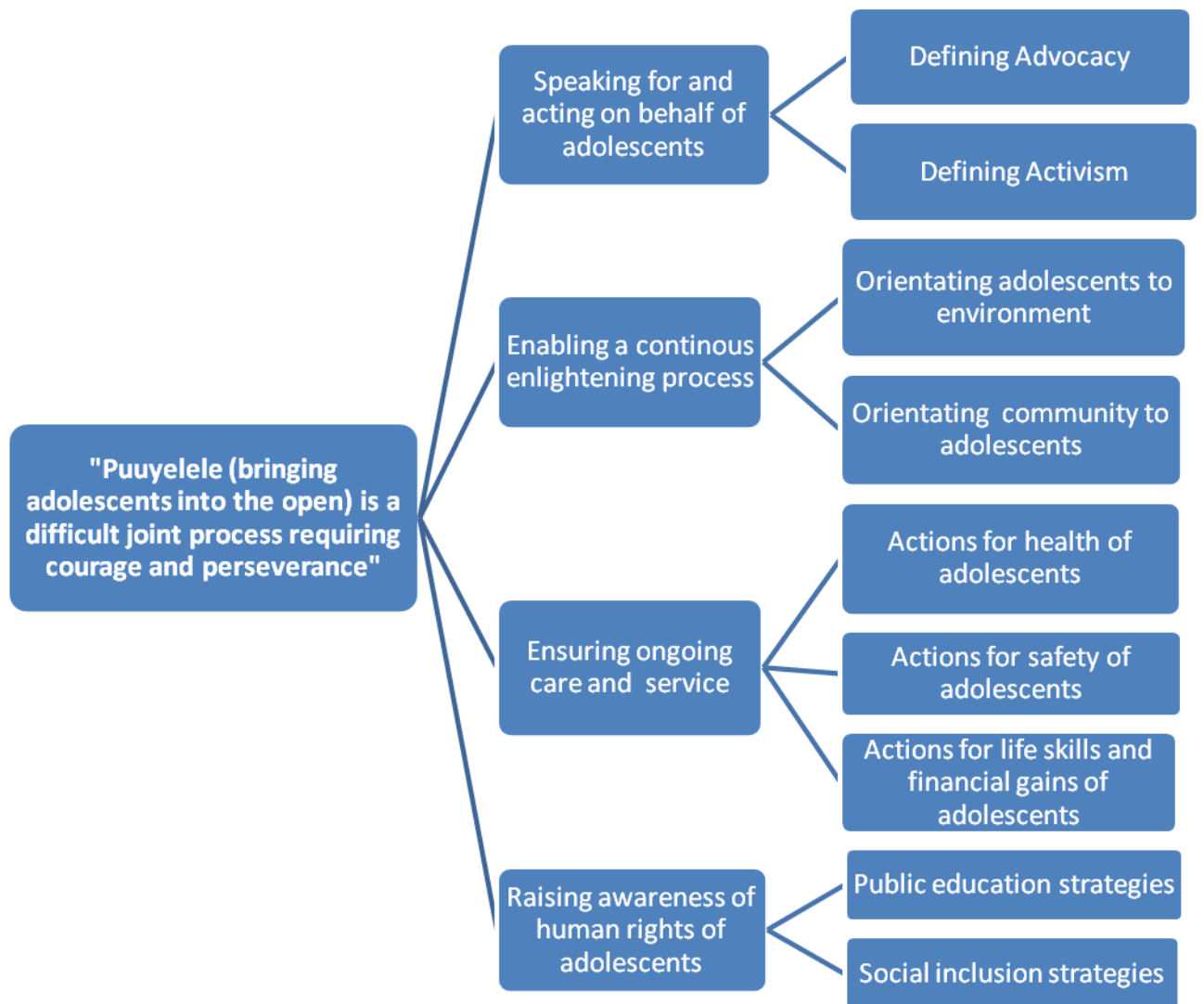
THEME	CATEGORY	SUB-CATEGORY	RESEARCH RELATIONSHIP
“Puuyelele (bringing adolescents with DS into the open) is a difficult joint process requiring courage and perseverance”	Speaking for and acting on behalf of adolescents with DS	Understanding advocacy	Answers objective one: <i>Identify what carers believe ‘advocacy’ and ‘activism’ are in relation to the needs and abilities of adolescents with DS</i>
		Understanding activism	
	Enabling a continuous enlightening process	Orientating adolescents with DS to environment	Answers objective two: <i>Identify what actions carers of adolescents with DS are taking to promote participation and equal opportunities for social inclusion of their children at individual, family and community levels.</i>
		Orientating community to adolescents with DS	
	Ensuring ongoing care & service	Action for safety of adolescents with DS	
		Action for health of adolescents with DS	
		Actions for life skills and financial gains of adolescents with DS	
	Raising public awareness on	Public education strategies	Answers objective three: <i>Identify barriers</i>

	human rights of DS	Social inclusion strategies	<i>to activism and strategies used by carers of adolescents with DS to address barriers</i> and objective four: <i>Identify carers' advocacy and activism priorities for social inclusion of adolescents with DS in Namibia</i>
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4.2 Theme: "Puuyelele (bringing adolescents with DS into the open) is a difficult joint process requiring courage and perseverance"

This theme covers the importance that participants placed on bringing their adolescents into the social space through a continuous enlightening process. It is summarized by the local word *Puuyelele* to convey the difficult but cohesive (togetherness) process of advocacy and activism that involves bringing to light DS issues and enlightening both the community and the adolescents. Respondents reported that the reciprocal processes of *Puuyelele* required courage and perseverance to get the community to understand and accept their adolescents while at the same time supporting these adolescents to get used to their community. *Puuyelele* resulted from nine sub categories and the four categories as indicated in Figure 1. The enlightening process was found to engage carers with actions that contribute to community participation and social inclusion of adolescents with DS as elaborated in the categories and sub categories.

Figure 1: Theme, categories and sub categories



4.3 The four categories of findings

The four categories reflect the whole research findings in relation to the aim and objectives. They indicate the four key carers' actions associated with both advocacy and activism. Carers' actions aimed for community participation of their adolescents with DS. The categories highlight efforts by carers to bring to light these adolescents and DS issues in order to facilitate their participation and social inclusion. The four categories with their sub categories are herewith detailed in relation to the research objectives.

4.3.1 Category one: Speaking for and acting on behalf of adolescents with DS

Findings in this category reflect research objective number one that concentrated on the carers' understanding of advocacy and activism in relation to the abilities and needs of their adolescents. The category emerged from refining of four sub categories (a difficult process, understanding advocacy and activism, requiring courage and perseverance, joint process of togetherness). Therefore the two definite sub categories that emerged from the data were *understanding advocacy* and *understanding activism*. To be precise advocacy entails "systematic and purposeful actions by individual/group to bring about beneficial change(s) that promotes social justice for others" (Hoefler, 2015, p. 3) while activism is a process by networking members that advocate "more frequently and at a higher level of complexity than other parents" (Ryan & Cole, 2009, p. 44). Essentially the whole category entails the description of what carers consider to be advocacy and activism, and how and with whom they go about the *Puuyelele* process.

Understanding advocacy

Carers felt that they understood advocacy because they knew that their adolescents had Down Syndrome and were able to talk about it for them. Carers also knew that the DS condition presents with varying levels of abilities and needs. Knowing the needs and abilities was required to help the adolescents receive varying levels of support for participation:

... one has to know these children are in three levels ... there are those who can manage to do some things on their own when taught and those who can be assisted

a little.....but there are those who may always need a carer always every time [MO, p. 2].

What I advocate for my sister and not only my sister, any other Down Syndrome people is acceptance, community should learn things about Downs, get to understand to accept Down Syndrome, we should understand that they are normal human beings like themselves, like any other kid, like any other sibling that you have at home. And they should be treated as such [RS, p. 10].

Carers had the literal understanding of advocacy as speaking for or on behalf of others. They understood it as a difficult process and acknowledged the involvement of others including the adolescents themselves:

My understanding of advocacy is speaking for others, or on the behalf of others in the....making of their community or everybody out there to understand the issues, or, anything that is going on within the community, or within that certain environment, in the person's own life [RS, p. 10].

I understand it though with difficulty because I know even them (adolescents) they take part in this process [MO, p. 1].

I have noticed, although in the beginning it was difficulty we have managed to bring our adolescents in open Puuyelele (public and adolescents enlightening) to be known by community members [MO, p. 1].

Carers' understanding on advocacy is shown by their knowledge, understanding and realization about their adolescent as special family members requiring to be well understood by others in the community. This realization gave carers the drive for advocacy:

I realized I cannot care for him alone because there is death ... God created death ... I am not on earth to live forever ... so ... I need to prepare and connect X with people,

neighbours ... first I start connecting X with family members, I must get them to understand how to care for him X [MO, p. 1].

A DS child is a gift that God gives to those who can manage. Unlike with other children one has to be strong and courageous at heart in order to care for such child [FL, p. 8].

What motivated me is to make sure he gets the correct way of life ... because if I only just stay with him at home naively he will not be free or may have fear and not know anything [MO, p. 1].

Understanding activism

For the understanding of carers' activism, it was noted in the findings that the three chosen carers were already regarded as activists in ODSSG with about fifty members. The characteristics of carers (see Table 1 page 22) showed that two of the carers were ODSSG pioneers. Findings also showed that carers understood and included creating community awareness about DS as part of activism work:

...and also to create awareness about DS to general community members ... we need to get the community to know that children with DS must be treated like other children in the community [FL, p. 8].

In understanding activism carers indicated that they gathered, trained and convinced other parents and siblings about addressing the needs and supporting the abilities of their adolescents:

I think I understand (activism) because I am a mother of X who has Down Syndrome. ... and I do gather other parents of children with DS to get them to understand because many do not understand the condition and the needs of these children [FL, p. 8].

What I would tell them, the first thing is to teach your sister about God, how to pray. The second thing is to teach your sister how to be independent, the second thing is to teach your sister self-confidence, the third thing is to teach your sister, or to identify what your sister is good at, and allow her in a certain way how to do that, because at the end of the day the moment she knows all these, she can do for herself what you have taught her, and even when you are not in this world, she will still be able to do for herself [RS, p. 17].

This action-orientated (activism) process was difficult, required courage and perseverance and went beyond the family level. To illustrate this, findings showed that carers were engaged and felt that their activism work enlightened parents on other services such as the use of the government assistance fund and procedures to get it:

... other services include government assistance which I also advice other parents how to get ... because this money helps with their health follow-up, school ... are some of the services for these youngsters [MO, p. 2].

Carers also felt that activism actions included enlightening their adolescents and other people towards improving social interaction (friendship) and related issues:

....and if you are telling him something tell the truth...children like him you must not tell them unreal things or unnecessary thing because that is what they will understand and keep forever [MO, p. 1].

Findings showed that carers understood activism because they noted changes in community behaviour towards their adolescents and therefore attributed such changes to their activism:

... my sister and I do go out very often, and the community in which we live, people have accepted, because they see her, so I recommend or advise other people out there with siblings or kids with Downs Syndrome to do the same [RS, p. 10].

... I think as time has passed by, those ones now from the village in the rural area where we go, they are getting there, they are accepting [RS, p. 17].

4.3.2 Category two: Enabling a continuous enlightening process

Findings in this category highlight how carers used *Puuyelele*, a process that helped to bring more enlightenment by orientating their adolescents to the environments within and beyond the home. Continuous enlightening involved a two way process orientating the adolescents to the community and the community to the adolescents. The process involved a steady and sustained orientation towards raising awareness about DS. Such an ongoing process of bringing DS into the light enabled carers to orientate and get the community to interact actively or passively with their adolescents. This category of findings reflects the perseverance and courage endured by carers as they took actions to face community stigma associated with DS. The category consists of two sub-categories, “*orientating adolescents with DS to the environment*” and “*orientating the community to adolescents with DS.*”

Orientating adolescents with DS to the environment

With their *Puuyelele* process of advocacy and activism carers brought to light their adolescents to various community places and activities. Such places included home and community places for specific activities - health, religious, educational, urban and rural areas. Some of the community activities included sports, travelling, shopping, neighbourhood visits, burial and wedding ceremonies:

... for my boy by going with him where people are ... and to various community service provision areas and gatherings ... like weddings (Ohango), burial (eenghali) ... shopping so that he can see where what we eat comes from [FL, p. 8].

Sports and games served as a good opportunity for community inclusion:

... as for my boy ... he has been playing soccer with neighbors before they relocated ... [MO, p. 5].

... you need to go with them to a soccer field to watch or play at home ... like my son love soccer ... he has two soccer balls bought by his big brother ... he calls others and plays soccer in the home yard with other without DS ... “you will find my home yard full of children who came to play soccer with him” [FL, p. 9].

Participation in church was important and enabled the adolescents to show off their talents:

... but I do go to church myself and we go with him ... I am a choir member so I also made a song file for him because he like singing ... so when we are called in front of church to sing, he also comes with his file and he pages the file as we page and is singing to his ability [MO, p. 5].

She knows how to pray, we go to church, she can sing, she is a very good at singing [RS, p. 13].

... you have to go with them to different festival places ... of joy and sad times ... because they can be hearing about wedding “Ohango” but have no idea about it ... you need to let the child go and watch for himself ... the child need to go to church ... a very first and important thing in church [FL, p. 9].

Travelling to do shopping brought joy, understanding of items, and the reality of finances and the act of buying to the adolescents:

... we go to town for shopping ... like when we go to Oshakati town (10KM) ... ohh ... he gets so happy ... because when we go to shopping he does not allow me to push the shopping carrier ... he takes it and push around picking all the things he like ... but I tell him no my son that one we cannot afford just take this one I will buy for you ... so when we are done he feels very happy [MO, p. 5].

Orientation of adolescents to the environment paved the way for teaching and learning. For example, most of the orientation quotations given herewith showed where, with whom and how the activities were done. A specific example is that of orienting the adolescent to

church activities. It describes what activism was involved in relation to the church environment, action to be done, when and with whom. Such exposure enabled community orientation and understanding of the adolescent.

Orientating community to adolescent with DS

The process of enabling continuous enlightening of the community was found to differ in certain areas and with certain activities. One carer (who lived in peri-urban and rural areas) commented as follows about the peri-urban community:

... but now because I already exposed him to family and community anyone can assist him ... now even him he feels comfortable free and has peace ... community know how to get him involved properly in whatever they are doing ... community members now treat him as one of their child [MO, p. 4].

I don't really find any difficulties in going out in public with her because people here are well informed when it comes to DS people [RS, p. 15].

The same carer said the following about rural area:

Yes there is a difference ... eehhhm ... It's not the same, 'cos there in the village, I think they're not well informed about DS people, you'll find that she shies away from people. Because they are staring. She doesn't really like it because she starts asking 'exactly what are they looking, why are they looking at me like that' [RS, p. 16].

Surprisingly, carer FL had a different opinion about enlightening the peri-urban community about adolescents with DS. This may be because they don't understand DS as a condition although they know the adolescent just as a neighbour's child.

... people in peri/urban have a problem ... our children want to be free with their compounds², but some neighbours just don't want him in their compound ... [FL, p. 10].

While she had this to say about the rural community:

In the village when he goes with others to play I have not seen such problems ... When I go with him in the village "ohandikalandamangulkanawa" (I feel relieved and have nice freedom) ... some go with him to the open areas "Oshana" to feed the livestock and escort him home thereafter [FL, p. 10].

The process of orientating the community to these adolescents was not always easy. Thus carers required courage and perseverance to face and change the stigmatizing attitude of community members in various places. For example, it was reportedly common for community members to stare when carers and their adolescents carried out their activities in public areas. However, the continuous enlightening process eventually led to the benefit of social inclusion. There was an attitudinal change as confirmed by carer MO:

... but now because we have created the connection we see difference in behavior between child and community members ... now community members are able to see how I or the father walk and treat our child ... so they also do the same [MO, p. 1].

Carer RS was optimistic about her rural community members getting used to and eventually stopping their gazing at her sister:

We tell her 'no, its fine, just let them look at you.' But we do tell people, that no, she's normal, she's fine. I think as time has passed by, those ones now from the village in the rural area where we go, they are getting there, they are accepting [RS, p. 17].

² Home area/environment or informally demarcated plot of home land or erf

Community fear of adolescents with DS also required carers' courage and perseverance to orientate and change community's stigmatizing attitude as commented by carer MO:

... now people have no fear if the child touches them unlike before when it seemed like that disability has "omukwayu" (a disability that can be passed on to another person) or I don't know what they were thinking ... some could separate the child or just get away from the child [MO, p. 1].

.... am not sure what their fear about this is but I have tried to assure them that he is peaceful [FL, p. 10].

... because the community member does not understand they would react differently like quickly removing a nearby baby for fear of being harmed ... but now because we have created the connection we see difference in behavior between our child and community members [MO, p. 1].

4.3.3 Category three: Ensuring ongoing care and service

Findings of this category reflect objective two that sought to identify what actions carers of adolescents with DS were taking to promote participation and equal opportunities for social inclusion of their children at individual, family and community levels. The category focused on carers' actions with the adolescents (individuals), family members and others within the community using the *Puuyelele* enlightening process. These advocacy and activism actions by the carers required courage and perseverance as they faced various challenges that included stigma. The category consisted of three sub-categories: "*actions for health of adolescents with DS*", "*actions for safety of adolescents with DS*", and "*actions for life skills and financial gains of adolescents with DS*".

Actions for health of adolescent with DS

Carers' understanding about DS (described in category one) helped to guide their actions towards addressing the health needs of their adolescents. The carers knew about health problems related to DS, and as family, adhered to continuous check-ups at health facilities:

If you talk about health to these children, they need higher health care because most of them are born with many health problems ... some have heart problems, others have hearing problems, some appear like they have asthma in their lungs [MO, p.2]³.

When it comes to health, I do take my boy with DS to hospital to be checked to see how his health is [FL, p. 8].

She has hearing problems, sometimes, not all the time, that's what we have identified, that's what the doctor has picked up because she normally goes for a normal check-up, which is a requirement for Downs Syndrome people [RS, p. 13].

Findings also revealed that carers had future preparations and plans in relation to health of their adolescents as confirmed below:

... I plan to continue with his doctor's follow ups ... I plan to open a card for medical aid for his private doctor to really care for his health ... that's my plan ... that card is what I will be using to go to his doctor with especially because of that heart problem that he has ... mmmhh [MO, p.3].

Another one is health. Of which is not much of an issue for her, because our parents are both working, and they have the medical aid [RS, p.13].

Carers advocated togetherness (shared responsibility with other family members, neighbours and sometimes other community members) in health care provision. Their realization of togetherness was evident from their activism to explain, train and work with others about the health care of their adolescents:

³ FIELD NOTE: *"The researcher has confirmed this Cardiac problem information with the MO boy's health passport, including a number of follow-ups done at both Oshakati Hospital and Windhoek Central Hospital "* (Transcript, p. 3)

That is why I decided to start connecting him with others at home, family members, neighbour and others in our community ... so that if I have to leave him I leave him freely with no doubts about his wellbeing [MO, p. 1].

... I have taught many how to check on him and notice the sign of illness like sometimes he can go quiet or not playing actively he may be unwell ... then you can take him to clinic ... I am sure I taught people his characteristics and they are able to notice [MO, p.2].

All carers were sensitive, aware and active about the adolescent's life stage of development. Actions and advocacy about issues related to reproductive health of their ADS were part of their narratives. Carers felt a need for people to learn about difficulties of caring for adolescents with DS at puberty stage:

... eeeh ... not really but you know this is the stage puberty???? or you say ... eeehhh [MO, p. 7]. ... adolescence?? [HK, p. 7] ...ooh yes adolescent ... people need to learn about them [MO, p. 7].

And these people that are hanging with them also, you should let them know also what the type of person this person is, and what sort of behaviours will not be expected from them, and any other sort of treatment, for their own protection [R, p. 18]. What protection do you mean? [HK, p. 18]. For their own protection, there is so much that is going on in their world. Contracting of viruses; pregnancy, STD's and many more things [RS, p. 18].

... the truth must be told especially about those things of rape ... you must teach them very well ... they must teach ... like the girls can be taught by their mothers and must tell everything nicely [MO, p. 6].

As you know these children grow big ... like now he is in the stage of bad years ... "Onkaloihelinawa" ... the teenage time ... you have to sit with him privately and explain to him simply [FL, p. 8].

... the boy can bath with the father ... and the father tells ... this one is called what and it is washed like this and cared for like this ... this one you don't play with it you take care because it is special to God [MO, p. 6].

Carers were also keen about reproductive health issues such as menstrual management. Menstrual care was taught to adolescent depending on their different living environments:

...oh we have different cultures, our homes are not the same. You might at home be taught, that no... dig a hole and throw it in there so it can decompose. While the other ones they put it in the dustbin, but in a dustbin you have to put it in, in a certain way. So all this you need to teach people. To suit the environment where you are' [RS, pg. 16].

...If it is a girl... the mother must tell the girl in steps...this is how you use it and you change when it is like this ... if you see this thing like this...people must not see it... put them in a plastic and every day you put in the pit toilet outside and these things ...pads...they are yours not to be seen by people...when you put them at this time and they are wet...you remove carefully put in the toilet or...if no toilet...dig a hole and burry it somewhere in the garden. ...or like us from rural area she can go to the traditional shower and dig a hole to hide it very well...it is good for them to see the real thing when you are teaching them because they may not understand very well... [MO, p. 6].

Actions for safety of adolescents with DS

This sub-category involved making the adolescents, family members and community aware and able to identify safety needs and abilities. Safety issues emerged as actions taken by carers to protect their adolescents from physical, psychological, sexual, interpersonal and other types of harm.

... when it comes to transport I do not allow him to just go alone ... he goes accompanied ...[FL, p. 10].

The above comment reflects carers' fear of transport-related problems such as her adolescent taking the wrong transport, while the comments below can be associated with increased abuse cases:

... for example like the current happenings of abuse. I mean like rape. I warn him and tell him that no one should catch your trouser to open or touch you inside there "mmmmh ... No ... No refuse you must refuse and hold it tight ... no one should remove it" if someone does that to you ... you must tell me [MO, p. 6].

And even for now, our special ones they need to know what is happening, of which we need to ... eeehh ... okay, it's more like overlook all the time, what is happening, where they are, who they hang with, the type of people they hang with, what exactly do they do, make it comfortable for them to be able to speak to you, and ask them and teach them also [RS, p. 18].

The need to be orderly so as to avoid bodily harm led carers to take actions:

... show him here you put such things ... here you don't go ... because if you don't teach him he will go even places where it is risky [FL, P.8].

Another thing I teach him is that when he goes to a festive "oshivilo" ... do not just accept food given by anybody ... only accept food and eat when it is given to me to give you ... this is because our children have been made the left over eaters because they are disabled with Down Syndrome or disabled who cannot walk [FL, p. 9].

I only cannot tell if they like him or is the soccer ball they want ... but I noted they don't harass him ... he does not come back home bitten or do bad things to him ... he comes back very happy [FL, p. 10].

These findings also indicate some aspects of community stigma that triggered carers' actions towards safety of their adolescents.

Actions for life skills and financial gains for adolescents with DS

This sub-category involved carers as they engaged their adolescents, family and the general community in actions towards abilities and needs related to life skills and financial issues. Carers identified talents and skills with longer potential economic benefits for their adolescents.

We have noticed and identified that she loves music, so that is what she is currently doing, she goes to the Multi-Purpose Centre, they have some pianos and other instruments she uses, and for now she is learning the piano [RS, p. 13].

And I also mentioned she is good at playing the piano, this will bring independence. She is independent now because she's getting something from it and she's comfortable doing it around, or surrounded by a lot of people. I believe if she continues she will not even need to get employed, and we will not even need to be funding her for life, this can become a career she can make a career out of this [RS, p. 16].

Findings also showed that carers had registered their adolescents with DS to receive a maintenance grant (Table 1, p. 22) which later changes to a disability grant at age sixteen in Namibia. One carer regarded this government money as the first priority to get because it helped to facilitate ongoing care:

I would say the first priority in terms of service is the government assistance fund "Oshikwilashepangelo" (Government cake) to all such children with DS because that is a disability where child will need care [MO, p. 2].

... she is getting a grant from the government [RS, p. 13].

Findings revealed that carers had various narratives and actions for teaching about money, how to use money for different reasons within the community and also understanding about sources of money. For example, carers taught their adolescents on how money is used to pay for services (transport) and goods rendered (shopping):

... about money when working with such children ... you do not need to start with a lot of money when teaching him ... you just give him specific amount and explain what item it can buy [FL, p. 9].

... you need to go shopping with him ... like with fifty note in his pocket that he do the buying of some things [FL, p. 9].

... sometimes we can walk to the shopping centre ... after we buy our things we get into a taxi ... the good thing is that he knows that after he is brought home he has to pay the taximan ... this one am very sure because I taught him that when you enter in people's car ... you must pay ... you cannot be carried free of charge ... sometime when we are dropped home and he has coins ... he will be the first to give taximan ... "tambula (take) Man I have paid you" ... (He tells the taximan) ... [FL, p. 10].

Carers understood the need for financial sustainability of their adolescents. This was achieved by embracing both the government support fund developing talents and skills with adolescents that could earn them some financial reward:

She actually attends events where she plays, and this way she gets a little something for her talent, even though she is registered with the ministry to get a grant, she's also receiving that, and yeah, that's about it [RS, p. 15].

Her getting rewarded, you can call it pocket money to go to town, and buy our little things that we want, we do get pocket money from our parents, so I would call it as a reward from what she does at home, she's good, she makes tea; she cleans, she makes the bed, all that [RS, p. 15].

Further actions by carers included use of money to get out into the community, enjoying leisure time and participating in youth show activities (to appreciate leisure time):

... even if there is any sort of activities which are occurring around town, and we have time, we do attend. I remember just recently we went to the Expo, Totem⁴(?) Expo, Oshakati. We bought our chicken; we ate our chicken [RS, p. 15].

Carers also advocated development of other life skills through different training opportunities. One carer suggested that their adolescents can benefit from a locally known green irrigation scheme farm Ma Etunda⁵ where they could gain some farming skills and possible employment.

... or some can join like the famous and big MaEtunda Project to work there ... for gardening or watering [MO, p. 4].

Carers' advocacy also emphasised training their adolescents in other life and vocational skills that would later enhance employment:

You know they are on different levels of intelligence ... there are those who can repair things, there are those who just like gardening, remember there those who do (work) only what they like doing ... like there those who like cleaning ... he can sweep ... sweep the home, others like watering the garden ... so when such skills are developed you may find some of these children becoming cleaners ... or some become computer repairers [MO, p. 4].

... she needs to learn something, of which she can spend the whole day at school being taught, even if its making coffee, she is being taught this at home but she can still be taught at school, how much the amount of sugar, how exact, other catering ... [RS, p. 14].

⁴ Totem is an annual community cultural show conducted in a huge stadium.

⁵ An agricultural irrigation project in a different region/province that produces fruits vegetables and cereals consumed locally.

Carers understood the intellectual ability and the increase in life expectancy of their adolescents, and therefore narrated the need and desire for these adolescents to work in accordance with their different abilities:

... about work ... we must help because many of our kids are now growing with advance ages ... years are increasing but they have no work ... some have the "Ohokwehokulonga" (love and wish to work) ... like I said some have the intellectual understanding that people at home leave and say they are going to work ... so even them they want to go and work to have money in their pockets ... eeehhhe ... they must be given "Ilongaithikengaapomthikagwao" (work that is to their level) ... [MO, p. 4].

Further findings showed that carers had advocacy actions with family members to engage adolescents with DS in becoming independent in day-to-day activities. Carers' stories confirmed the day-to-day abilities of their adolescents doing various tasks/life skills. These actions enabled the capabilities of adolescents in achieving self-reliance at home. Such achievements in turn promoted the way they presented themselves during the community enlightening process. For example, carer MO indicated relevant self-reliant actions of her adolescent that would generally enhance community acceptance:

... he can bath himself dresses himself and his clothes ... he can wash them rinse and hang by himself ... even his shoes, he will never wear wrongly even the trouser ... and his belt he knows how to put it on the trouser properly and be ready to go. What I did I gave him a separate bag for ordinary clothes and another bag for special clothes like when he comes from church he will remove church clothes and tidily put them in the correct bag ... he then gets the clothes for home or for going to neighbours ... he has separated his clothes very well [MO, p. 6].

Meanwhile, carer FL indicated the patience, perseverance and success in the step-by-step process of training her adolescent toward self-reliance:

... I started training him that after bathing he must wash his own pants with clean water in a basin ... recently I started training him to wash his clothes ... he can now wash his clothes nicely ... he can spread his bed also ... I tell him ..."see spread it like this.. go and check how I made my bed" ... he usually come and try to make his bed like mine. For bathing he does it alone [FL, p. 8].

Findings further showed togetherness of family members on aspects concerning self-independence of their adolescents.

The next one to us at home is the ability for her to learn how to do things for herself. Whether is to bathe; is to make a cup of coffee; or is to welcome somebody at home, is to open the door and say 'come in, mummy is coming; or my sister will come now,' or, which of course we hardly allow because we don't want her opening the door to anybody or everybody [RS, p. 13].

4.3.4 Category four: Raising public awareness on human rights of DS

Different from others, this category showed that carers knew about human rights entitlement of their adolescents. Therefore, raising awareness about human rights of these adolescents emerged as a strategy used by carers to address barriers and challenges faced during the *Puuyelele* process of enlightenment. Advocacy and activism actions entailed raising awareness and educating family members, other carers and the community about the human rights of adolescents with DS. However, such awareness raising depended on carers' priorities for social inclusion of their adolescents. The category therefore focuses on objective three (identify barriers to activism/advocacy and strategies used by carers of adolescents with DS to address barriers) and objective four (identify carers' advocacy and activism priorities for social inclusion of adolescents with DS in Namibia). Being a strategy for raising awareness of human rights of adolescents with DS, this category consists of two sub categories: *public education strategies* and *social inclusion strategies*. As highlighted in the major theme, this *Puuyelele* process of enlightenment about human rights of adolescents with DS also required courage and perseverance.

Public education strategies

These strategies were closely related to government policies and service provision. They are in contrast to the social strategies which are more about community action and will be explained later.

Carers' understanding of DS as a condition, human rights and priorities for their adolescents with DS spearheaded the *Puuyele* process of enlightening and educating the public. Despite their courage and perseverance in carrying out actions to ensure ongoing care (category one), carers experienced barriers and challenges in public services delivery, especially accessibility to education and health. Notably, participants' particulars (Table 1, page 22) showed that none of their adolescents received formal basic education and their long distances from the specialist state hospital was noted. In their own words, carers expressed their dissatisfaction so that the public becomes aware as anyone may be in similar situation. They had this to painfully say about the formal basic education of their adolescents with DS:

On the issue of education ... initially it was my first issue ... everywhere, every time whether sitting or sleeping, I used to think about his education always ... but unfortunately our thoughts are not the same as for others ... like these ... our children with disability ... I thought he would be in school to get some knowledge but then when we went to register him our teachers already noted about him like it is a waste of time to take him ... [MO, p. 3].

Education! ... like our children don't go to school ... like my X does not go to school but I took him to Kindergarten for three years ... and I took him to grade one ... he schooled only for six months then he was chased from school [P2, p. 9].

Findings show that at the family level the carers developed strategies to address the challenging experiences of seeking basic education by taking up various responsibilities such as educating the public and other carers on how to enlighten their adolescents despite educational challenges. As indicated below:

Now he does not go ... (to school) he does not go but I try to teach him at home...yah...so that he can somehow understand [MO, p. 3].

If he does not go to school one needs to have books at home to teach to write ... to read ... and when the other siblings come from school you must tell them how to stay with him ... you can buy learning kit and other things and put in his room with a table for him to be writing [FL, p. 8].

... but for now while he is at home I bought for him a learning kit, books and pens ... he has his books and colouring books ... we teach him to write and count but he cannot read well but he can pronounce some letters ... but teach him how to count, teach him to recognize letters, to know the alphabets [FL, p. 9].

For us education is not going to school, the normal school; even though we are saying they are normal kids like anybody else. For our sister we, yes we have taught her how to write her name, which she can now speak, she can count [RS, p. 13].

Findings showed that carers understand educational needs and abilities and are aware of the educational rights of their adolescents. Despite giving individual narrative stories carers recognized their collective responsibilities as a group and they sometime used 'we' to mean the ODSSG for shared issues. Therefore, teaming up of carers - as they say below 'we' - to raising public awareness and education on this understanding then becomes a strategy to address the educational barriers faced by their adolescents and future kids with DS:

... if it's a government school we are not asking for a special government, we are just asking for a special teacher for the DS, in a special school with a special understanding... these kids can do anything they are taught, whether it is gardening or cleaning, of which I was listing, not everything can be taught at home [RS, p. 14].

... we must talk to people to let them know a DS child is a child like any other ... is a child with rights like any other child ... [FL, p. 11].

Carers' perseverance, courage and portrayal of activists' characteristics in raising public awareness on rights of their adolescents for education were noted from their stories.

Carers' made policy related statements, a strategy capable of having future national or policy impact on the education of children with DS:

Mmmhh ... I appeal to ... Now I am speaking to the policy makers, the big fishes up there. Please create the opportunity or a platform for awareness about needs for these people, and educate the public, people need to be educated and they need to understand, and the crucial one would be education for our DS people. I believe these people can do so much for themselves because I am seeing it every day [RS, p. 18].

As for education what we were thinking ... with the government there is that word eslusive (sic) education ... meaning "Elongolyahamumweanuwakapenakatongo" inclusive education without discrimination [MO, p. 4]. You mean "Inclusive" [HK, p. 4].

... yaahh they say ... education without segregation ... they say education where they are taught together but we are saying ... it is not a matter of including ... they must just be given their specific schools that suit them in line with their intelligence ... so that they get knowledge at their level which they can understand ... they must just get their specific schools [MO, p.4].

Findings indicated that the two main featuring priorities were education and health:

... the first thing is he must have "Oundjolowele" (health) ... the second thing a child must to have "Elongo" (education) like other children ... I know he cannot have higher education but he can learn to be able to live his life [FL, p. 8].

Firstly health because I know he has DS that cause his disability for life, secondly is education ... although I know they don't get it but it is important they go to school [MO, p. 2].

Findings showed that inaccessibility of health care due to far distances (see referral hospital distances in Table 1) from the big hospital and the knowledge of complications due to DS

health related problems makes access to health services not only a barrier but also a priority requiring specific strategies to deal with it.

The issue of health is another challenge and we just have to be near or ready for hospital ... health care must be good always otherwise every week or every month you will be running heading to big hospital and you can again expect complications ... if you don't take good care [MO, p. 7].

Another barrier that needed public education was the transition stage of adolescence. Reflecting on reproductive health, carers expressed it as a challenge but used a strategy of educating/training the ADS himself/herself and other carers:

... this stage now he is fifteen years is when he likes to be with boys of his age ... it is a challenge because you have to keep warning him about being touched under the trouser [MO, p. 7].

As you know these children grow big ... like now he is in the stage of bad years ... "Onkaloihelinawayounyasha" ... the difficult period of teenage time [FL, p. 9].

We have taught her, she was explained, even I myself have explained to her that she as a woman, this is what she will experience, and we have taught her how to use the pad, where to put it, after that how to wash herself properly [RS, p. 16].

Apart from warning and training their adolescents on caring for their reproductive organs, carers also warned and educated the public such as friends and neighbours against related wrong information. Moreover, they knew and used lawful statements like reporting to the police if their adolescents' rights were violated:

Please don't give him that bad school which you may think of ... it is important to warn them ... so I tell them ... if you do it if you dooooo ... it ... I will report it and make sure the police deal with it because you have broken a law to a person of this type and you know very well his thinking ability is not like yours ... so if you do it am telling you ... It will be serious so don't try ... this must be known to the community also

because it is like breaking the law but when everyone knows it becomes easier because they tell each other [MO, p. 7].

Findings showed that carers spoke of relevant health related statements that were useful for their adolescents' health management, a strategy that can change health procedures, guidelines and policies to address the health barriers for better services:

I mean ... it should be noted when they are born with Down Syndrome they should be seen by doctor immediately ... then doctor will see at which level of care this child can be attended ... for example if they have problem with heart, eyes or ears that do not hear properly ... every time he has to have high care in health [MO, p. 2].

Regarding health now, I'm advocating for the Downs Syndrome people, not only my sister, for the government to take this as a serious, serious issue. For all the health workers to accept these people. I mean the health services are free for everyone, so it should be, they should be treated as such, as per their needs [RS, p. 11].

That is what we are advocating, we do not want to hear and see Downs Syndrome people not being helped, with general health, or any other person in this country and this is what we are voting for [RS, p. 14].

Social inclusion strategies

These are deliberate and regular ways directed to the community in which carers used the *Puuyelele* process to enable participation and social inclusion of their adolescents in their community. These strategies concentrate more specifically on the community actions. One deliberate strategy that carers used was to demonstrate individual competencies such as skills, talents and abilities their adolescents had. These allowed him/her more opportunities to be seen and interact in community activities:

... he says "let us pray first". He, on his own he can truly lead a prayer properly until he says Amen ... and people appreciate and respond Amen [MO, p. 5].

... we go out jogging [RS, p. 17].

...making the child to sit and concentrate in church listening to what Pastor preaching [FL, p. 9].

..she can sing, she is a very good at singing [RS, p. 13].

Findings show that carers also used other individual competencies that may seem trivial but very crucial in community gatherings/festivals that enhance community acceptance, participation, interaction and general social inclusion, such as proper self feeding, talking, bathing and some literacy:

... he can eat properly by himself [MO, p. 6]

... but now people are used to him and can talk to him, knowing he is like that ... they can even call the child and talk freely unlike before [MO, p. 1].

My X can bath himself [FL, p. 10].

... she can count [RS, p. 13].

It was found that carers used and encouraged the use of family members, neighbours and other loved ones (friends) as a strategy to increase relationships that in turn contribute towards participation and social integration of their adolescents:

... we go out for lunch, even with our parents, not just us [RS, p. 15].

... they come to pick him with the balls and they go to play soccer in nearby street [FL, p. 9].

My friends have accepted her, the way she is, because, I agree to do things, if we are going with her or they find her at home, and we are doing this and that, and she wants to partake or take part, she wants to sit around it, she stays. If they are uncomfortable they are more than welcome to leave [RS, p. 17].

Findings also showed that carers strategically used various service providers to maximise participation by tackling barriers that would hinder social inclusion. For example, adequate health checks, especially attending to heart problems, ensured healthy daily activities:

... we go to Oshakati Hospital because they have their own heart doctor who comes once every year and then gives them days to go to WHK for follow up [MO, p. 2].

Hearing is another barrier that can hinder day-to-day participation and social inclusion. One carer emphasised how they regularly ensured hearing by the use of an audiologist (service provider):

And she got the ear eehh ... (indicating the both ears) [RS, p. 13]

Hearing aid? [HK, p. 13].

Yes, she got the hearing aids, of which they normally check, and gives, if it needs replacement or adjustment, that they do. She has her own doctor for that, who she goes and sees when there's a need [RS, p. 13].

Carers also used experts (service providers) to develop other skills like music. Such skills would in turn promote community participation, acceptance and social inclusion through the *Puuyelele* process of enlightening both the adolescents and the community:

These people are experts; they are training her how to do this. And this is what they are teaching, she is getting now this expertise from them. I'm sure she will go very far with this [RS, p. 16].

Other strategies for social inclusion that were evident included the use of a favourable surrounding environment which was described under category two "Enabling Continuous Enlightening Process", specifically sub category "Orientating adolescents with DS to the environment" (Page 43). However, findings showed that carers had some deliberate strategies to directly engage their adolescents with direct interaction, participation and general social inclusion through the use of favourable environments. For example, through the *Puuyelele* process carers have understood that a sports stadium is one of the venues

that attracts the majority of the people, especially the youth, and is a good environment for social interaction and enlightening. Many of the community events are held here making it a favourable facilitator of social inclusion:

...when there's this inter house, for the schools we do go and watch at the stadium [RS, p. 15].

...sports are good especially boys ... you need to go with them to a soccer field to watch [FL, p. 9].

Other intentional visits to favourable environments included large community entertainment areas such as shopping malls and movies to increase youth information, chatting and interaction. The quotes below illustrate this:

... we do go with him everywhere ... get him to be free and enjoy (entertain) while doing things for himself [FL, p. 8].

Like we go to Oshana Mall, we go to the movies [RS, p. 15].

Other social inclusion strategies used by the carers and their adolescents are group meetings and networking. Background information indicates that ODSSG meets monthly (Population, page 19). The quotes below also show that the group had actions related to interaction and networking through monthly meetings:

... that is why we meet regularly to learn more about our children, get them to interact and be able to teach our community. We get various service people to enlighten us in our meetings [FL, p. 11].

I want to encourage other youth to interact with our sibling with DS ... let us meet, network and enlighten our community for the sake of our sisters and brothers with Down Syndrome. I personally represent my sister in those monthly meetings for our group where we learn and teach others about DS [RS, p. 17].

4.4 Summary

The findings chapter shows that categories and sub categories followed the *Puuyelele* process that required courage and perseverance to carry out the advocacy and activism actions. Carers' quotations showed that interactions and community participation, interpersonal relationships, enlightening and social inclusion in general are achievable through *Puuyelele*. Carers knew about DS, their needs and abilities, human rights and their environment and focused on improving the wellbeing of their adolescents. Education and health were found to be major human rights barriers and were also identified as key priorities requiring public education strategies for raising awareness of human rights. Despite various advocacy and activism actions, carers had some deliberate social inclusion strategies to enhance more community interaction and participation. The next chapter discusses the carers' *Puuyelele* process and how it relates to the existing literature.

CHAPTER 5: DISCUSSION

5.1 Introduction

The purpose of this research was to explore empirical evidence for advocacy and activism amongst carers of adolescents with DS that could provide a conceptual platform for further strengthening of disability inclusive development initiatives in Oshana in particular and Namibia in general. By identifying and describing the strategies used by activist role models in a Namibian context and disseminating this information to relevant stakeholders, it becomes possible for other carers to conceptualise, follow and enhance participation and social inclusion of adolescents with DS. The theme revealed that the carers went through the challenging process of *Puuyelele* (bringing their adolescents into the open) that required courage and perseverance from all parties, including the carer, the adolescents and the community. During *Puuyelele* the carers' advocacy and activism focussed on getting their adolescents to interact, participate and become socially included in their local community activities. Carers' drive to speak, act and advocate for their adolescents was driven by their realisation about the adolescent being a family member with special developmental needs. This entailed understanding of DS conditions, including the abilities, needs and human rights attached to people with this diagnosis. Moreover, the urge towards *Puuyelele* enabled carers to maintain a continuous process of bidirectional enlightening adolescents and the general community while ensuring ongoing care and protection of their child's human rights. This was not easy. The carers overcame difficulties in raising awareness about human rights through public education and social inclusion strategies.

This chapter will discuss three conceptual issues underpinning the *Puuyelele* process and in relation to the literature: firstly, DS advocacy and activism is a strategic process, secondly, DS advocacy and activism proceeds from vigilant care giving and, thirdly, DS advocacy and activism require human rights awareness. These three dimensions of *Puuyelele* for adolescents with DS provide the conceptual platform for disability inclusive development initiatives in Oshana in particular and Namibia in general.

5.2 Down Syndrome advocacy and activism is a strategic process

Carers in this study went about *Puuyelele* for their adolescents in a strategic manner. They were deliberate in their actions, believing that their child had the right and the potential to be socially included. In line with the principles of strategic planning (Mohammedian, 2017), carers had a general vision for their adolescents to be socially included and in particular bidirectional adolescents/community participation. They acted in deliberate ways to bring about the necessary circumstances for enhancing the wellbeing and rights of their child to social participation. Craig and Cartwright (2015) report similar strategic planning by carers determined to increase the quality of life of their family members with disabilities. These carers identified three notable strategies to enhance community participation of their adolescents that align with the findings of this study: use of information about DS and service provision, bidirectional orientation of both adolescents and the community, and use of family members and others.

5.2.1 Use of information about DS and service provision

One notable strategy used by carers is the searching, learning and providing of general information and services about DS as a condition and of the adolescent with DS as a person. Similar to the findings in category four of this study, Wright and Taylor (2014) report that carers felt empowered to act on behalf of their children's rights and special service needs when they understood the conditions, special needs and abilities of their children. Like carers in this study, Wright and Taylor (2014) assert that parents had information about the special condition affecting their children and understood their children as special family members with abilities that needed specialised attention. Furthermore, a systematic review of peer support for parents of children with chronic disabling conditions by Shilling et al., (2013) revealed that learning, exchange of information and experiences enabled parents to mentor each other by using practical information that boosted their confidence. Peer support through information and experience sharing empowered and motivated parents to continue caring (Shilling et al., 2013). Such motivation amongst carers in this study was noted to provide courage and perseverance that drove the *Puuyelele* process. However, access to information about DS and services for adolescents with DS is limited in rural areas. Even with the government commitment to the National Policy on Disability in Namibia

(Republic of Namibia, 1997), the carers from the rural locations in this study experienced challenges in learning about DS and finding suitable services. For example, findings indicated that carers were cautious and warned against possible sexual abuse but none of the carers gave information about sexuality as a right for adolescents with DS to community members or other carers. This could be attributed to lack of sexuality information; poor attitude and prejudice about sexuality for people with intellectual disabilities in general (Stoffelen et al., 2017; Frawley & Wilson, 2016; Gilmore & Chambers, 2010). Bartlett (2010) also uncovered some challenges that faced carers, especially the educational services in rural northern Namibia. She found that parents of children with disabilities lacked information on how to fully participate in the inclusive education as stipulated in the national policy on disability (Bartlett, 2010). Carers in this study also confirmed lack of information about appropriate educational services for their adolescents with DS. Similarly, in South Africa Adnams (2010) and Mckenzie, Adnams and McConkey (2013) found that carers reported limited access to information about DS and low prioritizing of intellectual disability services. Meanwhile, Mckenzie and McConkey (2016) remind us that, while locally garnered research information related to parental advocacy on intellectual disability is rare, it nevertheless has greater power and influence to effect change in families and for people with intellectual disability. Notably, carers from developed countries also experienced dissatisfaction with information and service provision for their members with intellectual disabilities (Power, 2009; Hussain and Tait, 2015). Irrespective of these challenges carers in this study continued to search for, learn and provide information to other carers and the community using their *Puuyelele* process. Community members can be said to have learnt as carers noted positive community changes towards them and their adolescents. Similar findings were reported by Robertson et al. (2005). These authors found that carers enabled exchange of information through community based care, an issue that played a role in fostering a positive attitude for people with intellectual disabilities (Robertson et al., 2005). In addition Simplican et al., (2015) assert that community members' contact with carers and people with intellectual or developmental disabilities and exchange of information consistently predict positive attitudes.

5.2.2 Use of bidirectional orientation for both ADS and the community

In their definition of social inclusion Simplican and others (2015) emphasised presence, encounter and participation as levels of involvement that enhance interaction within a community. They described 'presence' as just being physically within a community though with minimal participation; 'encounter' as meetings or interactions with people in the community that offer a sense of belonging and provide opportunities for participation; and 'participation' as engaging with community activities that enhance interpersonal relationships (Simplican et al., 2015). These descriptions resonate well with the findings of this study because carers endeavoured to counteract the community stigmatizing attitude towards their adolescents by enabling opportunities to be present, and to encounter and participate in social activities within their communities. They deliberately moved around community places and timed and attended different community activities, events and festive occasions with their adolescents using the *Puuyelele* concept of enlightenment as they orientated both the adolescents and the community in terms of space, time and person. Studies by Salmon (2013) and Foley and others (2012) support the strategic use of bidirectional orientation. Using the voices of young people with intellectual disabilities, they report that interaction within their communities created opportunities for friendships to develop (Foley et al., 2012). Elsewhere, a study by Bigby and Wiesel (2015) found that being strategic in accompanying people with intellectual disability in the public space, support workers were more effective in promoting people with ID's ability to interact with strangers and, in so doing, enabling friendships to develop. Moreover, Hall (2017) found that young people with ID had increased opportunities for social inclusion through leisure pursuit exposure to special community events, transportation and different environments such as churches and sports facilities. Furthermore, young people with ID reported that community acceptance was increased and they felt a sense of belonging by engaging with leisure and social groups which allowed them to be known by other members (Hall, 2017). Mutual and bidirectional benefits can also result from encouraging ADS to participate in community organised activities. For example, Spassiani, Harris and Hammel (2015) reported a bidirectional orientation process and community benefit in relation to practical knowledge translation for community based health initiatives. These authors found that by orientating people with intellectual/developmental disabilities to utilize the established resources, it

was possible to receive crucial feedback and suggestions (Spassiani, Harris & Hammel, 2015). In turn the feedback enabled general management, community coaches and trainers to learn and become empowered towards appropriate tailoring of future community programmes (Spassiani, Harris & Hammel, 2015). Similarly, carers in this study orientated adolescents with DS in community organised activities such as church activities that brought joy to these adolescents, while community members can be said to have accepted and enjoyed adolescents' skills such as singing and praying.

5.2.3 Use of adolescents, family members, neighbours and others in the community

This strategy entails the involvement and mobilisation of the individual (adolescent), family members, neighbours and the community in the *Puuylele* enlightenment process in order to achieve the vision of social inclusion. Simplican and others (2015) emphasised that the social inclusion model depended on the ability to move people with intellectual and developmental disabilities, their families and community members forward through fostering interpersonal relationships.

Engaging the individual adolescent with DS

Carers in this study seemed to have understood the importance of involving adolescents in their own support. Carers consulted and involved them in decision making, explained situations to them in an understandable format and supported them in learning socially appropriate behaviour including taking initiatives towards their own inclusion. This commendable decision is supported by McKenzie and others (2018) with their findings on the perceptions of people with intellectual disabilities in relation to positive behaviour support. The study highlighted the importance of including targeted individuals as active participants in all decisions pertaining to their quality of life, including how services should be presented (McKenzie et al., 2018). In addition, Hall (2017) agrees with the use of personalised guidance from young people with ID when planning and facilitating their community involvement. Furthermore, Milner and Kelly (2009) found that some of the attributes associated with the sense of belonging included self-determination, autonomy in decision making and social identity for people with disabilities to partake in community

participation and inclusion. Therefore, by engaging adolescents in their own *Puuyelele* process carers also promoted the development of these personal attributes.

However, the active involvement of the adolescents with DS is not necessarily an easy strategy to apply. Anderson and Bigby (2017) found that challenges such as stigmatizing labels restricted people with intellectual disabilities from being accepted as equal members of the community. Nevertheless, they were optimistic that, with more positive identities emerging from self-advocacy, people with intellectual disabilities had the potential to change the community's negative perception (Anderson & Bigby, 2017). Anderson and Bigby (2017) further assert that such individual and collective advocacy efforts are significant in changing community negativity and stigma about intellectual disability. Likewise, the carers in the current study confirmed that engaging their adolescents was a difficult enlightenment process that required particular attention to building a sense of 'togetherness' through continuity, patience, courage and perseverance that would change community perceptions towards social inclusion. Meanwhile, Ryan and Cole (2009) concur with the fact that courage and perseverance during a process that relates to improving social inclusion and life quality for children with disabilities does not only apply to carers but also entails encouraging those that they care for in order to meet their goals. This is in line with and relevant to the international disability motto of "Nothing about us without us" (United Nation, 2006) and must be applied with due consideration of the commitment costs to carers and the family in general. Category one entails speaking for and acting on behalf of adolescents with DS. This relates well with the slogan 'Nothing about us without us' because these adolescents may not understand or claim their right as required due to their intellectual disability. Therefore carers take the obligation to speak and act on their behalf.

Engaging family members

Carers in this study took on caring for their adolescents with courage and perseverance and as part of their family responsibility. Quite often family caring is taken as a norm shared by family members (Coyle, Kramer & Mutchler, 2014). Despite accepting the responsibility, carers expressed difficulties in their caring and enlightening *Puuyelele* process. Literature shows that caring can be a difficult task, especially when the individual has life-long mental challenges (Chang et al., 2016). Moreover, Chang and others (2016) showed that such caring

has consequences that require attention. These authors also found that primary carers experienced distress, a consequence that required appropriate and immediate support and interventions (Chang et al., 2016). In their endeavours carers in this study included other members of the family such as siblings while other family members such as father and brother were just mentioned. Coyle, Kramer and Mutchler (2014) also recommended the use of siblings as part of the aging together process that provided family continuity in a supplementary support network for people with ID. In this study one of the participants was a sibling as seen in table 1 (page 22) and the findings also indicated her positivity in advocacy and activism of her sister. For example, her voice was noted as she insisted that the reason for voting was to receive better services for all people and especially people like her sister (quote available on page 61). This courageous voice can be described as committed advocacy.

Engaging others in the community

In this study carers engaged neighbours and other community members in their *Puuyelele* process. They created and increased opportunities for interaction by enlightening neighbours and other community members about the abilities and needs of their ADS. Van Alphen et al., (2009) and Scior and Werner (2015) emphasise the importance of neighbourhood as a factor that can facilitate or inhibit social interaction of people with ID. Similar to carers' action in the *Puuyelele* process in this study, authors found that neighbours enhanced social interaction through three types of support: social support that entails superficial exchange of greetings, small talk and small favours; instrumental support requiring more commitments with mutual and reciprocal benefits such as visiting each other; and informational support such as more understanding of each other for further neighbourhood development (Van Alphen et al., 2009). However, the carers' efforts to engage neighbours in the current study were not always smooth as they encountered hostility from neighbours towards their adolescents. Carers in this study described experiences of hostility through verbal abuse and sometimes even physical abuse was encountered. This is not unique as Scior and Werner (2015) also report that hostility towards people with learning disabilities involves bullying, verbal abuse, physical violence and sometimes such people become victims of horrific hate crimes. In order to change these attitudes the authors emphasised targeting neighbours and other key community members

for educational approaches and provision of factual information (Scior & Werner, 2015). Scior and Werner (2015) also emphasised engaging people with ID in actions requiring and involving direct contact and interaction with neighbours and other community members.

5.3 DS advocacy and activism proceeds from vigilant care giving

Vigilant care giving is defined as a “flexible framework in which parents adjust their level of involvement to the warning signals they detect” (Omer, Satran & Driter, 2016, p. 298). Vigilant care entails monitoring development and also deals with bad company, alcohol and drug abuse, sexual, physical and other types of abuse (Omer, Satran & Driter, 2016). Omar and others (2016) described vigilant care as a progressive attitude in which parents change levels of open attention, focused attention, and protective steps depending on the risk signals detected during caring. The authors assert that such a caring framework embraces a collective vigilant involvement of ‘we rather than I’ that increases parental knowledge and strengthens parental shift to higher community levels (Omer, Satran and Driter, 2016, p. 298). This reflect the ‘togetherness’ actions of carers in this study whose caring efforts became strengthened towards advocacy and activism. Carers in this study provided vigilant care while accessing available services, given the attitudinal and logistical constraints such as stigma and discrimination, distance, cost and availability. Such constraints helped to form the baseline of their urge towards advocacy and activism. For example, the more they walked around with their adolescents, the more the community got used to and reduced the stigmatizing behaviour towards these adolescents; the stronger the pain of caring cost they experienced, the more they told the new group member to register for the maintenance grant earlier.

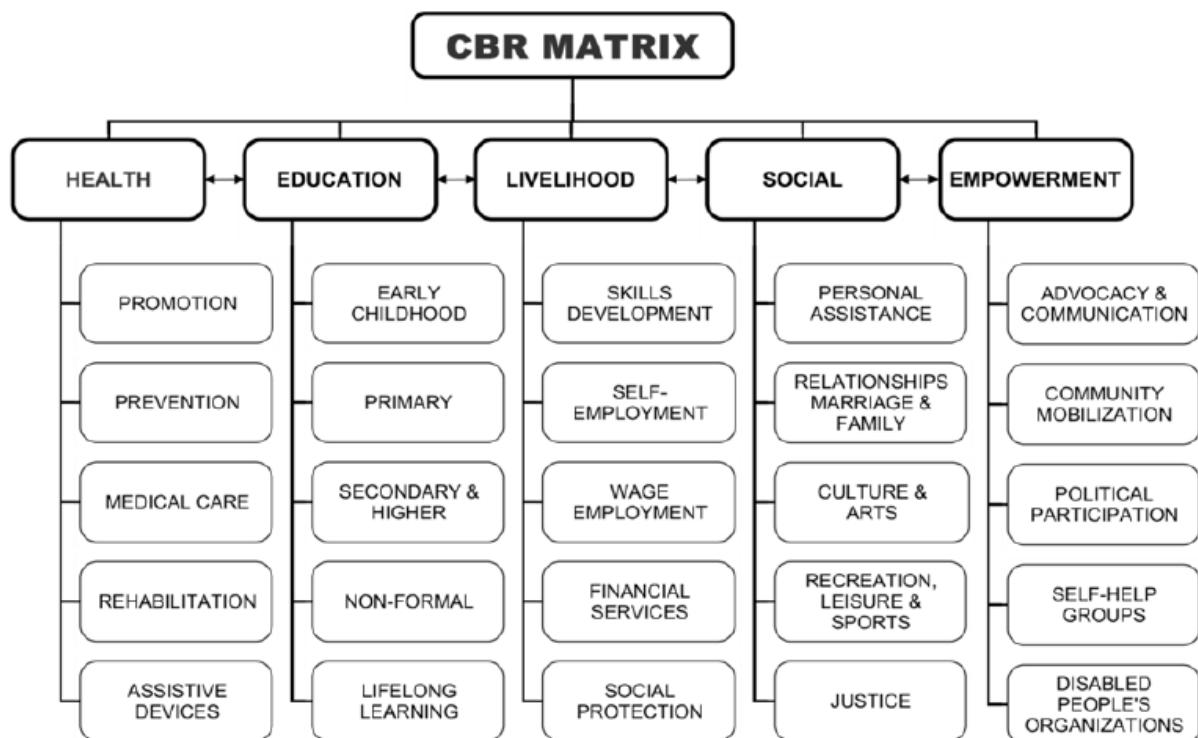
Hall (2010) argues that vigilance about stigma and discrimination is necessary for the care and protection of people with ID. He suggests that the deeply rooted structure of societies associated with stigma and discrimination may be reduced through engaging people with ID in the activities and projects alongside community ‘insiders’ so that they feel cared for and experience a sense of being valued and belonging (Hall, 2010). Similar to Hall (2010) carers in the current study were able to proceed with advocacy and activism using their *Puuyelele* process by ensuring that their adolescents were in close proximity to activities, networks and spaces close to community insiders. Vigilance was, however, necessary. For example,

the possibility of sexual and financial exploitation had to be considered. Robinson (2015) reports the need for similar vigilance. She found that abuse of children with disabilities is likely to occur at systematic levels such as disability settings like education and with social carers entrusted to such children (Robinson, 2015). Robison (2015) also reports that abuse of children with disabilities occurs on multiple occasions and is under reported with a higher rate of abuse happening to those with intellectual disabilities. It was found that carers in this study were aware that such abuse can result from leaving their adolescents under the care of others in the community. They therefore resorted to teaching and highlighting rights for their adolescents and even giving words of caution to community members. Data showed that vigilant care was empowered and connected with a community based entity, use of primary health care resources and through engagement with their own Oshana Down Syndrome support group. Thus, vigilant care strategies that preceded, prepared for and enhanced advocacy and activism by carers in this study included three community based care strategies: a community based rehabilitation strategy, a primary health care strategy and a support group strategy as described below.

5.3.1 A community based rehabilitation (CBR) strategy

With the desire to develop and progress their adolescents with intellectual disability within their given communities carers in this study embarked on the strategy of Community Based Rehabilitation (CBR). Carers choose community based type of rehabilitation in order to enhance the developmental issues of health, education, skills and other life aspects of their adolescents with DS within their community (Mckenzie, McConkey & Adnams, 2013). Through the CBR strategy carers narrated efforts to train their ADS in activities of daily living, facilitate leisure and recreation and support the development of vocational and life skills (WHO, 2010). CBR is a strategy for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all PWD, comprising of various components (WHO, 2011). The CBR matrix (Figure 2), adopted from the International Disability and Development Consortium (IDDC) (2012), shows the components.

Figure 2: Community based Rehabilitation Matrix (WHO, 2010)



Carers' perseverance and courage in their *Puuyelele* process sustained their efforts for community based services in spite of challenges that included insufficient funding. The Namibia Statistic Agency (2016) acknowledges such challenges that include inadequate rehabilitation services, low education for children with special needs and unemployment for people with disabilities in Namibia. Shumba and Moodley (2018) noted that the provision of Community Based Rehabilitation along with other public health services is a state responsibility in line with the National Disability Policy. Therefore the understanding of massive government responsibility and the desire to get their adolescents socially included may have moved the carers towards advocacy and activism for rehabilitation services within the community. Rehabilitation services through CBR have been noted to enable cohesion between people with learning difficulties, service providers and their communities (Lorenzo et al., 2015). Similarly, vigilant care giving requires partnership support between people with disability, their carers, communities and state service providers (Griffith & Hastings, 2014). This literature knowledge shows the existence of opportunities made possible for carers to utilize CBR while achieving vigilant care for their adolescents through their *Puuyelele* advocacy and activism process. Moreover, in their Meta-Synthesis review, Griffith and Hastings (2014) found that close community based collaboration with various service

providers resulted in carers' appreciation of satisfactory care support. Similarly actions by carers in this study were community based in collaboration with existing service providers towards vigilant care. CBR is known to have various community benefits (Saurabh, Prateek & Jegadeesh, 2015) and carers in this study were justified to also have such benefits alongside vigilant care. For example, the empowerment component of CBR (IDDC, 2012) was therefore enhanced through the *Puuyelele* process. Meanwhile, advocacy and activism through community based rehabilitation as set out by WHO becomes a powerful strategy to hold the state accountable for policy implementation.

5.3.2 A primary health care strategy

Primary health care has recently been described as accessibility to comprehensive, continuous and coordinated first contact care (Coleman, Wagner, Schaefer & Reid, 2016). This reflects the close similarity with vigilant care. Primary health care defined in a Namibian context entails the decentralized provision of local health care services that are accessible for both rural and urban areas, affordable with minimal to no charge to vulnerable people, with equitable resource allocation and sustainable local management within each community (Bell, lithindi & Low, 2002). This envisaged type of health care has not been fully achieved due to vast distances amongst sparsely populated communities in rural Namibia. However, carers in this study were able to access local clinics for preventative health care services within their community. Carers advised neighbours and other carers about taking their adolescents to the nearest clinic for general medical care and, if necessary, for referral to specialized services. Easy access to medical prevention and intervention made follow up appointments easier for adolescents through carers. This finding contradicts the study results by Bershinsky and others (2012). These researchers found that people with disability living with parents and relatives received less preventative health examinations and procedures (Bershinsky et al., 2012). They report that lack of specialized services, especially DS regular health check-up clinics, resulted in long distance travel and cost challenges to carers (Bershinsky et al., 2012). Meanwhile, a systematic review by Robertson and others (2011) found that at least an annual health check-up for people with ID was ideal and that the health systems needed to make this available at PHC level. Furthermore, in support of carers' sentiments, Van Rooy and others (2012) showed that people with disabilities in rural Namibia experience health service provision problems

that included distances and specialised care. Experiences of such challenges during vigilant care can be said to have preceded and propelled carers towards DS advocacy and activism for quality service care that would enhance partaking in community activities.

5.3.3 Support group strategy: Oshana Down Syndrome Support Group (ODSSG)

The carers' characteristics (Table 1, page 22) show that two of them were pioneers of the ODSSG while one (a sibling) represented parents in the group that met monthly for various activities, exchange of information, advice and training of other carers. Their persistent membership in the group seem to have some benefits for their adolescents. Wei et al. (2012) found that a social support group for people with intellectual disability and their families was effective for physical and psychological wellbeing, positive social interaction, informational and material support. Deane (1993) reports that similar activities contribute towards successful nurturing of children with special needs. In his two-page fact sheet Deane (1993) included key components necessary in support programmes for special needs groups such as information gathering, advocacy, life skills training, referrals and auxiliary support services. Findings in the current study indicated that carers were keen on such components, thus justifying the initiation and existence of their ODSSG. The findings also noted the encouragement to other siblings to join and attend group meetings to learn about DS and sibling relationships. Granat and others (2012) encouraged group interaction and other interventions that relate to the development of siblings of children with disabilities.

Findings indicated interest in music as a talent and how carers endeavoured to facilitate this skill. Culturally the Oshiwambo people value traditional dancing. This occupation creates an opportunity through which the group, including the adolescents, can explore physical participation, develop a sense of togetherness and emphasise cultural identity. Murphy and McFerran (2017) argue that musical programmes for young people with intellectual disability enhance social connectedness and foster broader socio-musical pathways.

5.4 DS advocacy and activism require human rights awareness

The understanding of one's human rights can be said to be the gateway to improving quality of life of ADS through seeking for justice by following and dealing with any violations and further promoting such rights. Chapter 3 of the Namibia constitution (Republic of Namibia,

1990) covers the fundamental human rights and freedoms, well known in the country as the 'Bill of Rights' (Mubangizi, 2006). In addition, Shumba and Moodley's (2018) review of policy and the legislative framework for disability services in Namibia confirms that Namibia has ratified the United Nations Convention on Rights of Persons with Disabilities. Awareness of these valuable documents has received attention on local community radio to which the researcher is a regular listener. Knowing the nature of the DS condition, carers in this study undertook to learn more about human rights in order to enlighten these adolescents, their own family members, neighbours and the community in general. Huus et al. (2016) report that understanding about human rights, including disability rights, is prioritised by primary carers of intellectual disabilities in South Africa as provision rights, protective rights and participation rights. How the carers in the current study learnt about human rights remains to be investigated. However, the observation and passive listening (section 3.6.2) revealed that ODSSG members were aware of rights issues for example by engaging with local radios, having fun days, commemorating yearly DS days and even collaborating in their own politically demarcated constituencies. Although none of these actions were directly tied to disability rights by the three participants the researcher found it necessary to highlight them in the discussion section. The actions were considered as conjectures about the carers' role in terms of human rights awareness. Therefore the researcher suggests the use of local radios and media, decentralisation of social networks, preparation of fun days and annual commemoration of disability days as examples of carers' role towards raising human rights awareness about people with DS and DS as a health condition.

5.4.1 Local community radio

Articles 13 and 15 of UNCRPD (UN, 2006) provides for access to justice through the use of public platforms. Various researchers also emphasise the use of radio and media by carers to raise awareness on human rights. Kivikuru (2006) in support of local community radio utilization in Namibia highlights the freedom and democratic rights enjoyed by citizens on Namibian local community radios. She reports that radio programmes such as "Namibian Peoples Parliament" make it possible for citizens, (carers included) to contribute towards raising human rights awareness (Kivikuru, 2006). However, for maximum impact they need to regularly make use of advocacy opportunities available in the local media. Robinson (2015) emphasises that "empowering children and young people with disability and those

who support them to speak up early about concerns they have on possible and actual abuse is a critical activity” (p. 477). She further recommends contextualizing the components of abuse prevention and response to suit the education and training of young people with disabilities (Robinson, 2015). O'Malley (2008) agrees that radio programmes empower the voices of persons with disability. She described how individuals can engage with media to express themselves and their rights, thus increasing self-understanding, determination and confidence (O'Malley, 2008). Such expression of spoken personal rights can enlighten others about knowledge of entitlements, the right to justice and the ability to make decisions (Blank & Martinis, 2015). Use of radio and media can therefore be assumed as one of the carers' role in human rights awareness.

5.4.2 Decentralization of support networks

Decentralization is perceived as a vehicle to accelerate power, responsibilities, capacities and resources with the aim of strengthening people's participation towards quality of life (Chigwata & Ziswa, 2018; Thede, 2009; Agrawal & Ostrom, 2001). Thede (2009) argues that with a good analysis and utilization of both decentralization and human rights through a political approach in a local context it is possible to impact on the problems of social exclusion. Namibia has ratified the African Union Charter (Packer & Rukare, 2002) on decentralization that details the empowerment of local governments and authorities for grass root level beneficiaries (Chigwata & Ziswa, 2018). It then becomes imperative that the roles of carers (in their ODSSG) initiate and strengthen the decentralization strategy using opportunities of sites as offered by their local political councillors (see chapter three: 3.4 Research site and access). In the local context decentralisation would mean utilizing *Puuyelele* to enlighten and raise human rights awareness to more people in the thirteen politically designated constituencies of Oshana region. In turn taking this strategy as a role carers would broaden network support to promote community participation for social inclusion.

5.4.3 Commemoration through disability days

International and national disability days are well known in raising human rights awareness on numerous disability issues using various ways that engage people with disabilities, their

families, service providers and community members (Mukumbuta, 2018; DeLisa, 2012; Demarzo, 2012; Meekosha & Soldatic, 2011; Ratzka, 2007; Tribiinyane, 2003). Namibia is not an exception and, although the carers in the current study did not narrate their participation in commemoration of specific disability days, the ODSSG is known in Oshana region for its Down Syndrome awareness raising activities. The 21st March (the UN declared Down Syndrome Day) is one of their special fun day meetings well-known in the country. However, carers need to increase their efforts toward their involvement with relevant local and national institutional service providers that organise, develop, supply and disseminate appropriate information on Disability Day commemorations and human rights awareness (Lazar & Stein, 2017). Therefore, DS advocacy and activism require human rights awareness arising from locally contextualised strategies that involve as many stakeholders as possible.

5.5 Summary

For strategic Down Syndrome advocacy and activism carers need to continuously learn and disseminate information about DS as a condition and their adolescents as people with DS. Such understanding will aim and enable to educate the general community for effective acceptance and participation. Contributions by the individual (adolescents with DS) is paramount as is engaging family members, neighbours, the community at large, state sector service providers and the media. Engaging many stakeholders is likely to increase the impact of the DS *Puuyelele* enlightening process by widening social support and networking. Vigilant sustained care and provision of services precedes DS advocacy and activism. Social inclusion of adolescents with DS is possible through the utilization of PHC, community based rehabilitation and local support groups using strategic integrated forms of care that engage individuals, family members, and the community. Furthermore, DS advocacy and activism are intertwined with human rights requiring awareness through contextual strategic ways such as use of local radio, decentralization of support networks and local ways of commemorating disability days.

CHAPTER 6: CONCLUSION

6.1 Introduction

This chapter highlights major recommendations to the research group so that they can benefit from their research commitment. The chapter also gives some policy recommendations and future research areas. Research limitations have also been acknowledged while the conclusion highlights the major points related to the research in totality.

6.2 Recommendations for ODSSG

- 6.2.1 This study recommends that ODSSG venture ways to team up with stakeholder in order to extend and introduce the *Puuyelele* process to DS carers in all villages of Oshana region and in the remaining thirteen regions of Namibia. Adoption of the three conceptual areas discussed in chapter five is recommended. These conceptual areas can serve as the basis for disability inclusive development training programmes not only for adolescents with DS but for other groups of carers and their children with different disabilities within Namibia in general.
- 6.2.2 Use of the local media is immensely recommended for advocacy and activism. Use of the local community radio is common and effective in Ovamboland. Therefore, activists need to take such opportunities for DS awareness raising and better public education. The three conceptual areas of being strategic, maintaining vigilant care and raising human rights awareness can serve as themes for radio talk shows.
- 6.2.3 This study also recommends the establishment of a vocation skills centre to train adolescents with DS on life skills and career related courses. Vigilant care showed that through CBR strategy (as seen in CBR matrix, Figure 2 on page 75) it is possible to proceed with skills development and social protection that enable social inclusion and also uplift the quality of life for adolescents with DS
- 6.2.4 It is recommended that ODSSG teams up and collaborates with more government service providers especially the ministries of education and health which were found to be the key areas of concern as well as major priority areas. Such collaboration will

enhance initiation of specific educational programmes and health check up guidelines for early benefits of persons with DS in general.

- 6.2.5. The confidence and courage showed by the three participants in this study indicate their readiness to be advocacy and activism role models. This study therefore recommends and encourages ODSSG to develop more carers to become local role models. The opportunity for adolescents to accompany carers in their *Puuyelele* advocacy and activism activities is also recommended. This can build adolescents' self esteem to also become role models in their capacities within the communities.

6.3 Recommendation for service delivery

- 6.3.1 ODSSG is a force to reckon with in Oshana Region. It is the group that can complement government awareness raising and carer education on DS related matters. It remains an example to be emulated by various service providers for the social integration of persons with DS. It is recommended that ODSSG be financially supported to extend their group activities to other regions within the country for the benefit of social inclusion of persons with DS in general.
- 6.3.2 In view of the benefits resulting from vigilant care by ODSSG members, this study recommends initiation and continuation of more support groups for further DS advocacy and activism that will enable social interaction and connectedness of adolescents with DS, family members and community.
- 6.3.3 Policy makers should consider adopting the ODSSG principle of advocacy and activism to formulate policies and guidelines that can be used to initiate, facilitate and monitor carer disability specific groups.
- 6.3.4 It is recommended that stakeholders in service delivery for adolescents with Down Syndrome should understand and utilize ODSSG principle of advocacy and activism in order to strengthen collaboration and monitor social inclusion within various communities.

6.4 Recommendations for future research

- 6.4.1 The absence of a male respondent in the current study creates a gap to study the advocacy and activism role of male carers of adolescents with DS in both rural and peri-urban areas.
- 6.4.2 The current methodology allowed for responses from one sibling raising a need to study advocacy and activism experiences of male and female siblings of adolescents with DS in rural and peri-urban areas.
- 6.4.3 Findings in this study highlighted carers' actions towards reproductive health. There seem to be discrepancies in terms of carers' actions towards menstruation practices in different environments. It is therefore recommended that a study be done to determine exactly what actions are done in rural and peri-urban areas in relation to reproductive health for adolescents with DS.

6.5 Limitations of the study

This study cannot claim to have represented the whole of Namibia as the sample was from one out of fourteen (14) political regions. The time was a limitation in this study as the researcher remained a full time government employee and a part time student. Such reasons contributed to the fact that pilot study was also not done. The study methodology also posed some limitation especially in terms of achieving better triangulation. Having being selected by group members one may argue that participation may not have been entirely voluntary as they probably agreed to participate so as not to let down their group members. However they remained enthusiastic in the data collection period.

6.6 Conclusion

This study has highlighted three concepts about Down Syndrome advocacy and activism. Firstly, it is a strategic process requiring courage and perseverance to educate the public and provide information on DS in a collective and bidirectional beneficial way; secondly it proceeds from vigilant care using contextual strategies such as CBR, PHC and support groups and, lastly, it requires raising human rights awareness through local resources and opportunities such as radio, decentralization

and commemoration of disability days. This conceptual framework can further strengthen disability inclusive development initiatives in Oshana and Namibia in general.

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APPENDICES

Appendix 1: Geographical location of Namibia and Oshana

Appendix 1: Geographical location of Namibia and Oshana

Namibia on the African Map (<https://www.info-namibia.com/info/namibias-geography>)



Oshana on map of Namibia https://en.m.wikipedia.org/wiki/File:Namibia_-_Oshana.svg



Map of Oshana Region <https://goo.gl/maps/awCESvqwd3A2> accessed on 20/3/2018



Appendix 2: Getting access to research participants

The Group Committee

Oshana Down Syndrome Support Group

Attention: Ms. L. lidhini (Secretary)

Tel: +264812338338

Re: Request to introduce Research and access to willing participants

I Hannah Kambowe, a student in the University of Cape Town (UCT) kindly request for time during your next meetings in order to:

1. Introduce a research that I will be undertaking in Oshana Region. The Topic of the research is: **An exploration into the activism/advocacy of carers of adolescents with Down Syndrome in Oshana, a qualitative study.**
2. Request access of suitable and willing members of your group to participate in this research. In the meeting I will also explain the selection criteria. I will then leave and allow you to select suitable and willing members whom I will contact for the research.

The research has received ethical approval from the Human Research Ethical Committee of the University of Cape Town and the Ministry of Health and Social Services in Namibia.

Thank you

Hannah Kambowe: Contact 065223315 OR 065221386

10th December 2017

Special Day: His Worship the Mayor of Oshakati Town Council commitment as a PATRON of OSHANA DOWN SYNDROME SUPPORT GROUP		
Day: 19 th January 2018	Venue: Oshakati Town Council Hall	Time: 14H00-16H00
14H00- 14H10	Prayer and Welcoming everyone- Group Chairperson	
14H10-14H20	Brief History about the Group – Group Secretary	
14H20-14H30	Introduction of related research to be conducted –Ms. H. Kambowe	
14H30-15H00	Activities of 2018 – Group Chairperson	
15H00- 15H20	His worship the Mayor of Oshakati Town - Hon. Angelus Iiyambo	
15H20 -16H00	Way forward and the closure – all	

Appendix 3: Carers' information sheet

Introduction of researcher and research:

My name is Hannah Kambowe. I am an occupational therapist. I am doing a Master's degree at the University of Cape Town. I must do a research project. The topic is: **An exploration into the activism of carers of adolescents with Down Syndrome (DS) in Oshana, Namibia: A qualitative study.**

Brief description of the study:

This study aims at understanding the actions that you are doing as carers of adolescents with Down Syndrome in order for these adolescents to be socially included and have access to services such as health, education, employment and other social amenities within your communities. Such actions will include but not limited to those that you do or..... (Name)does at individual, family and community level. The information you provide will help me describe and document your actions of activism which in turn will pave the way to identify areas that need to be strengthened in order to have full participation of these adolescents within their communities.

Expectations of participants:

You will be required to fill in a form containing your particulars and those of (Name)..... There after you will sign (or thumb stamp) a consent form if you agree to take part in this study. You will then be invited to attend an interview of approximately one hour where you will be given an opportunity to narrate the actions you have done or are doing. You have the right to choose a venue of convenience to you within the Oshana community or at the office of the rehabilitation centre. The interview will require sincerity on how you influence (Name).....and the community towards her participation. It is estimated that the study will take about one hour of your time.

Risks and benefits:

I cannot foresee major risk associated with this research. A minimal risk exists that you may be recognized through your story by members of the ODSSG in spite of a pseudonym being used. I therefore cannot fully guarantee confidentiality but everything will be done to keep

group confidentiality. Some of the benefits that may arise from this research include you being given an opportunity to highlight your actions which may be applicable and beneficial to other carers.

The reason you were chosen:

The main reason you were chosen is that you have been taking care of(Name of the adolescent with Down Syndrome).....who is now an adolescent with Down Syndrome. Secondly, it is because you are from Oshana and also a member of the Oshana Down Syndrome Support Group. You have also been noted by other carers to have great interest and concern on issues of adolescents with Down Syndrome.

Voluntary participation:

I wish to let you know that your participation is totally voluntary. You will not be forced and no one has the right to force you to participate. It is only if you agree that you will sign the consent agreement. You will be given a copy of the consent agreement and a copy of the information sheet form. Even after you sign, you have the right to withdraw at the beginning, during the process or at the end of the research. If you partake in this study and later decide that you want any data given by you to be withdrawn and not be analysed, that will be done.

Confidentiality/ privacy arrangements:

Your real name or the name of your relative will not be used but instead letters will be used to avoid you being identified. This should give you courage to talk freely, be sincere and confident in giving information. A minimal potential risk exists that your activism story may be recognised in the research report and by members of the ODSSG even though pseudonyms will be used. If you choose to withdraw from the study because of this risk, then your decision will be respected.

I promise to keep the data confidential while doing the study and any computerized material will be secured by a password. After completing my thesis data will be retained for a further one year and then destroyed.

The findings of the study:

These will be presented in the thesis. Findings will be seen by my supervisor and the examiners. The thesis may be read by future students on the course. The findings will also

be explained in a meeting to be arranged at the main hall of Oshakati hospital. You, the Oshana Down Syndrome Support Group and other community members will be informed in advance to give you opportunity to attend. I will try to use an understandable way of explaining the findings. The study may be published in a research journal.

Who has authorized this study?

The approval for this study was given by the Human Research Ethics Committee of the University of Cape Town, South Africa and the Health Research Committee of our Ministry of Health and Social Services, Namibia before interviewing you and others. Your approval is also acknowledged in this study because of your signature in the informed consent form.

Possible disadvantages of taking part and arrangements for referral:

I don't foresee any negative consequences associated with taking part in this study. However, if you experience discomfort in narrating some of the actions then you have the right to take a break until you gain courage to talk about them further or you may even decide not to continue discussing it. Moreover we can discuss your feelings about this and if need be I can arrange for you to visit our professional social worker inside the hospital for further help. If you need any further information, you can contact the researcher:

Hannah Kambowe

Disability Prevention and Rehabilitation

Oshana Health Directorate

Office Tel- 065xxxxxx Mobile – 081xxxxxx.

Location: Oshundika, Oshakati Hospital

The UCT Human Research Ethics Committee

Professor Marc Blockman

Old Main Building

Groote Schuur Hospital,

Floor E53, Room 46,

Observatory, 7925. Tel: +27 214066338

The Chairperson,

Research Management Committee,

Office of Permanent Secretary,
Ministry of Health and Social Services,
Namibia
Tel: 0612039111

Language easily understood by participants:

Some carers in the group clearly understand English while others can only communicate in Oshiwambo. Therefore translation of this informed consent form to Oshiwambo was done

If you agree to take part in the study, please write /sign/thumb sign the consent form

Signature/thumb sign

Date:

Appendix 4A: Carers' informed consent form (English)

I.....agree to participate in this research study: **An exploration into the activism/advocacy of carers of adolescents with Down Syndrome (DS) in Oshana, Namibia, qualitative study.**

The aims and objectives of this study were fully read and explained to me (a copy written in Oshiwambo was given to me). I hereby agree to voluntarily participate.

I clearly understand that I have the right to withdraw from this research without any repercussions at any time whether before the start, during the research process or at the end of this research.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that a small risk exists that my story of activism may be recognised by people in my community.

I know if I need further details about participation I can contact Mrs. Hannah Kambowe, 081xxxxxxx or visit the Rehabilitation Office, Ministry of Health and Social Service, Oshakati Namibia.

OR

Prof Mark Blockman, University of Cape Town, Human Research Ethics Committee at Tel: +27 214066338

Participant Date.....

Researcher..... Date.....

Appendix 4B: Carers' informed consent form (Oshiwambo)

Ongaye.....onditeelaokukufaombingamomapulapulogenasha
no MakonakonagaAvaliyaanyashambokayena O Down Syndrome moRegiona ha Shana

Ondaleshelwa no ondafatululilwanawaomalalakano go makonakonongaka. Onditela no
ndatokolaokwiyambakukufamoombinga.Ombapilahilingaakayashangwamoshiwamboodeyi
pewa.

Ondayelifilwakutyaondinaoufembaokuthigaponengeokuzamomomakonakonongakakapena
ondjindikiladhasha,ashikeomehalolyandjemwene,
pokatinengepeshulilolyomapolapulongaka.

Ondayelifilwakutyaotandivuluokutindilaomayamukulogandjegalongifwekonimahoiwikeiliiya
li no otandivuluokupulagadhimwepodhulu.

Onduvakokutyaoukwatyawandjeotaugamenwa no nokulekwangashitashivulika.

Onduvakononditelakutyaotashivulikandidhimbululwekuyalwemokuhokololaukwatyawandje
no womunyashagwandje

Ondishishikutyaneleondahalaouyelelewagethwapounasha no
mapulapulongakaotandivuluokumwonanengeoudhengela Meme Hannah
KambowekoNgodhoyonomolandjika 0812830596,
nengenditalelepoombelewayoNzulonkaloMuministeligwohakunuundjolowelemoshakati

Nenge

OtandivuluokudhengelaOmukoonakoniomukuluntuelikoUnivesitiyoKapagwedhina Prof
Mark Blockman, moOngodhindjika +27 214066338

Omutekuli Omasiku.....

Omukonakoni..... Omasiku.....

Appendix 5: The narrative interview guide

No.	Topic	Priority No.	Guiding questions
1.	Advocacy/activism		<p>How do you understand advocacy or activism in relation to participation and equal opportunities of(name)</p> <p>What drove you towards activism actions?</p>
2.	Knowledge on services enhancing inclusion		<p>What services do you think would enable participation and equal opportunities for(name) in the community?</p>
3.	Priority for advocacy		<p>Amongst the mentioned services which one would be or is your priority to advocate for? Why?</p>
4.	Health		<p>Tell me about the health related issues enabling or hindering social inclusion or interaction of (name)</p> <p>Please tell me what actions you have done to change or improve health issues for better participation of (name) and others with DS</p> <p>Is there anything else you plan to do in relation to change or improve health issues of(name) and other ADS</p> <p>Lastly, is there any other point or concern related to health that you may want to say or have forgotten?</p>
5.	Education		<p>Tell me about participation in education and other learning activities of (name)</p> <p>Please tell me what actions you have done for the education of (name) or any other child with DS</p> <p>Is there anything else you plan to do in relation to the education ofor other adolescents with DS</p> <p>Lastly...is there any other point or concern related to education that you may want to say or have forgotten?</p>
6	Work or financial gains of any type		<p>Tell me any ways/work in which (name) gets financial gain/ income</p> <p>Please tell me what actions you have done related to</p>

			<p>financial gains of.....(<i>name</i>) or any other child with DS</p> <p>Is there anything else you plan to do in relation to work or employment to change or improve the financial gain of(<i>name</i>) and other adolescents with DS?</p> <p>Lastly...is there any other point or concern related to work/employment/finance that you may want to say or have forgotten?</p>
7	Leisure and other community activities		<p>Please tell me what actions you have done for.....(<i>name</i>) to interact with family or other community members</p> <p>What leisure or other activities is(<i>name</i>) engaged with at family and community level?</p> <p>Do you have plans to advocate for more family and communal activities for (<i>name</i>) and others?</p> <p>Lastly, is there any other point or concern related to leisure and other community activities that you may want to say or have forgotten?</p>
8	Self-independence		<p>Tell me about self-independence of.....(<i>name</i>)</p> <p>Please tell me what actions you have done to advocate for self-independence of..... (<i>name</i>) in the family or general community</p> <p>Is there anything else you plan to do in relation to getting (<i>name</i>) experience more self-independence?</p> <p>Lastly, is there any other point or concern related to self-independence that you may want to say or have forgotten?</p>
9	Barriers and strategies to overcome		<p>What barriers and challenges have you faced in being an activist for your child? What strategies have you used to overcome these barriers? What lessons did you learn during your activism process?</p>
10	Any other issue		<p>Feel free to narrate any other issue or concern related to this study.</p>
	Thank you		

Appendix 6: Example of observational notes

Example of Observation Notes

Behaviour observed, my thoughts and on spot analysis

Day	Time period	Participant observed	What was observed
29/01/2018	11:03:35 to 12:35:10 Time taken: 1h31min33sec	P1	<ul style="list-style-type: none"> ➤ Well kempt lady walked in the venue composed. ➤ Greetings done in local language. ➤ She talks with so much confidence about her son. ➤ She is so fluent while talking(knows about her son) ➤ Came with the health passport of the son and gave it to me to confirm about particulars and health related issues of her son ➤ Talks of her rural community well – knows her village and neighbours well ➤ Has a clear understanding on son's needs and abilities and how to sort out her son's problems ➤ Very confident while talking about other family members and neighbours in relation to her son ➤ Uses high tone(like warning voice) on issues related to abuse ➤ Is not shy nor ashamed as she talks about her son ➤ Looks at me directly, sounds composed, tells from inner heart and expresses herself without fear!! <p>Impression: A real mother, I can relate to her motherhood, she just wants the best for her son.</p> <p>Personal thoughts and analysis: If I had all the necessary resources this is one mother I would want to see moving around Ovamboland talking/teaching about care of DS children and adolescents; using Oshiwambo language; I hope one day she can be on the local radio talking about DS</p> <ul style="list-style-type: none"> ➤ We are both delighted to have this interview ➤ Now I know her better than I knew her ➤ I sincerely agree with ODSSG to have selected her
27/03/2018	10:10:20 to 11:40:06 Time taken: 1h 29min 46sec	P2	<ul style="list-style-type: none"> ➤ Well-dressed smiley lady, ➤ greetings done in Oshiwambo ➤ Venue: local town council room (where they meet) ➤ Can talk English but not well fluent ➤ Came with two items to confirm her story; a photo of her son (she gave me to freely use in the report) and a health passport ➤ Fluently in local language narrates with a smile about her son

Appendix 7: Researcher's journal

Personal Comments

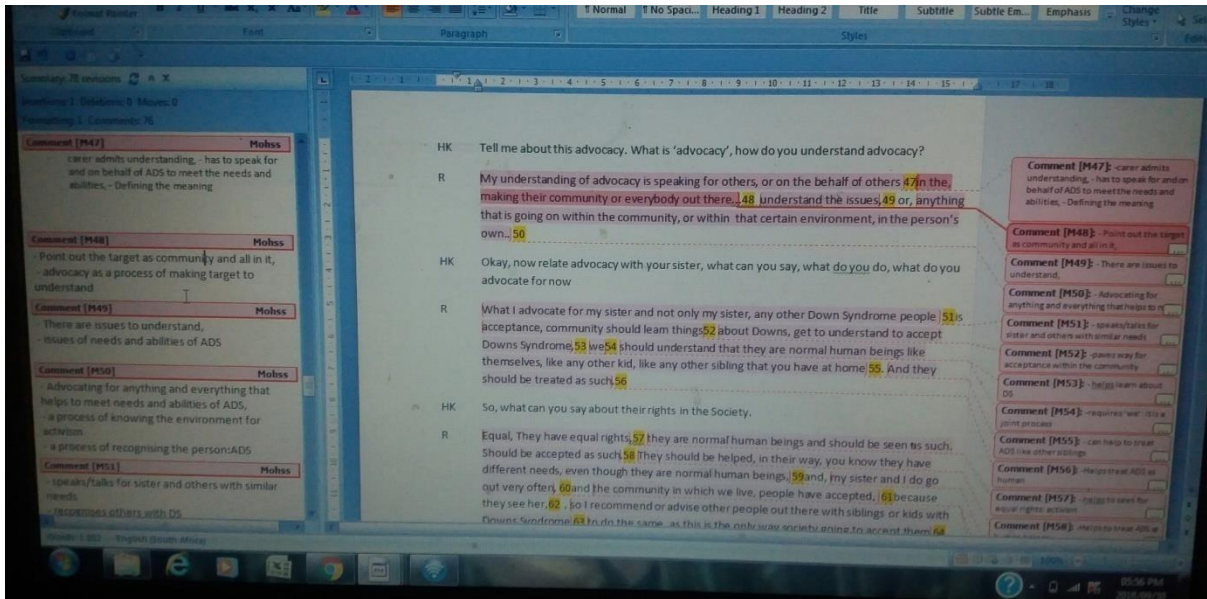
08/01/2018 Sunday. I will only be inform me that the group will have their meeting with 10/12/18 on 19th January 2018. An opportunity to introduce.

08/01/2018 Write a request letter to Secretary ODSG to be my official time to introduce my research and request for selection of participants during their forthcoming meeting on 19 January 2018.

09 January 2018 Friday
 I feel joyful and excited to have the opportunity to introduce my Research. The Cavers seem keen to know how this might help their efforts to improve the living conditions of their children.
 - I clearly explained the Research Implication.
 - I then gave details on selection criteria on participants. I had to leave them to discuss freely and give me details (contact) of selected participants to report.
 → I felt relieved as biasness feeling was subdued. However, I still wanted to know if they included anything relating their selection's.

- 20th January 2018 ODSG. The Secretary called and gave me the ~~phone~~ phone numbers of those selected for the interviews. ^{It was one to} Monday I called one of the three and she agreed to an appointment at Councilors office as she had an appointment there on 31st January. The second one said she was only available on 27 March 2018 due to planting preparations. While the 3rd one agreed to do it in April as she was doing some travelling.

Appendix 8: Example of an audit trail – Objective one: Developing codes from transcript



Appendix 9: University of Cape Town ethical approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7928
Telephone (021) 406 6626
Email: shuretta.thompson@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

26 October 2017

HREC REF: 698/2017

A/Prof M Duncan
Health and Rehab
F45, Old Main Building

Dear A/Prof Duncan

PROJECT TITLE: AN EXPLORATION INTO THE ACTIVISM OF CARERS OF ADOLESCENTS WITH DOWN SYNDROME IN OSHANA, NAMIBIA: A QUALITATIVE STUDY-(MSc-candidate-Me N Kambowe)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has formally approved the above-mentioned study subject to the following:

1. Why should being able to speak English be a criteria for selection?
2. Are three participants sufficient for the purpose of the study?
3. In the Consent Form, please make sure the language is accessible – please see Guidelines in the UCT HREC SOP for Informed Consent. The English translation should be at Grade 8 level.
4. Please also see a useful suggestion in the Guidelines – asking a few questions help to make sure the participant understands.

Approval is granted for one year until the 30 October 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

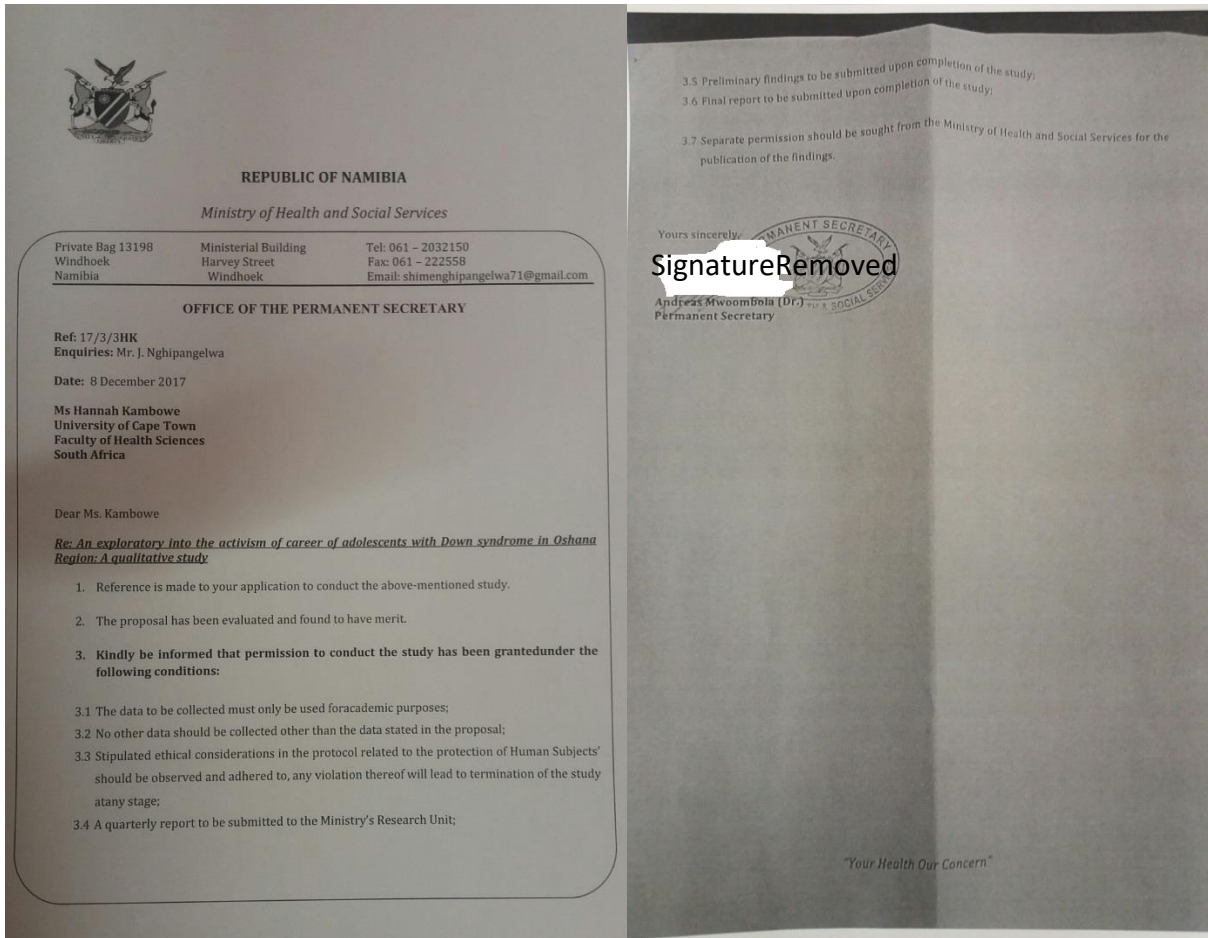
Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Hannah Kambowe will also be involved in this study.

HREC 698/2017

Appendix 10: Ministry of Health and Social Services, Namibia – Research Approval



Appendix 11: Letter confirming editing of the thesis

8 Nahoon Valley Place

Nahoon Valley

East London

5241

5 April 2019

TO WHOM IT MAY CONCERN

I hereby confirm that I have proofread and edited the following thesis using the Windows 'Tracking' system to reflect my comments and suggested corrections for the student to action:

A qualitative study into the advocacy and activism of carers of adolescents with Down Syndrome in Oshana, Namibia by HANNAH KAMBOWE, submitted in partial fulfilment of the requirements for the degree of MSc. Occupational Therapy in the Faculty of Health and Rehabilitation Sciences, University of Cape Town.

Signature Removed

Brian Carlson (B.A., M.Ed.)

Professional Editor

Email: bcarlson521@gmail.com

Cell: 0834596647

Disclaimer: Although I have made comments and suggested corrections, the responsibility for the quality of the final document lies with the student in the first instance and not with myself as the editor.

BK & AJ Carlson Professional Editing Services