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RESEARCH DISSERTATION

In partial fulfillment of the requirements for the degree MSc Occupational Therapy

**A descriptive qualitative study exploring youth with intellectual disabilities’
participation in the community of Moshi**

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DEFINITION OF TERMS

Community integration: the ability of a person to live, work and enjoy his or her free time and day to day y occupations within a community setting (Radomski & Latham, 2008, p.80).

Intellectual disability: disabilities characterized by significant limitations both in intellectual functioning (reasoning learning, problem solving) and adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of eighteen years old (American association on intellectual and developmental disability [AIDD], 2017).

Occupational deprivation: *“the influence of an external circumstance that keeps a person from acquiring, using, or enjoying something”* (Wilcock, 1998, p.145).

Occupational engagement: Encompasses all that one does to involve oneself or to become occupied (Polatajko, Davis, Stewart, Cantin, Amoroso, Purdie & Zimmerman, 2007, p.24).

Occupational justice: is *“the right of every individual to be able to meet basic needs and to have equal opportunities and life chances to reach toward her or his potential but specific to the individual's engagement in diverse and meaningful **occupation.**”* (Wilcock & Townsend, 2009)

Participation: an active engagement and involvement in occupation that contributes to wellbeing (Christiansen, Baum & Bass, 2014, p.7).

Youth: refers to a person between the ages of 15 and 24 who is going through a period of transition from dependence in childhood to adulthood and more independence (United Nations, 2013). In this study, the youth age range of 18-24 will be applied.

LIST OF ABBREVIATIONS & ACRONYMS

APA: American Psychological Association

GCRC: Gabriella Children Rehabilitation Centre. [Also referred to as *the centre* or *Gabriella Centre*]

ID: Intellectual Disability

IQ: Intelligence Quotient

KCMC: Kilimanjaro Christian Medical Centre.

KCMUco: Kilimanjaro Christian Medical University College.

LMICs: Low and mid income countries

OT's: Occupational therapists.

PWD: Person with disability

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

YID: Youth with Intellectual disability

ABSTRACT

Introduction: Youth with intellectual disability (YID) in Tanzania are at an impasse, as they face potential exclusion from accessing services and participation in their community. This is due to existing negative cultural beliefs, lack of awareness of the needs and abilities, and limited government services. For youth attending the Gabriella Children’s Rehabilitation Centre (GCRC) occupational therapy services, little is known about how they engage in occupations in the community following occupational therapy intervention nor has research been conducted to date in this regard. Such insight would be important in recognizing factors that enable or hinder youth with intellectual disability participating within their communities after rehabilitation services.

Research question: *How do youth with intellectual disabilities engage in occupations in the community of Moshi Kilimanjaro and what enables their participation?*

Aim: The study aimed to describe how youth with intellectual disabilities participate in occupations in the Moshi community, Kilimanjaro Region, Tanzania.

Method: A descriptive qualitative research approach with semi-structured interviews was used to collect data from eight participants and analyzed using a thematic analysis. The ethical principles of ensuring autonomy, non-maleficence, beneficence and justice guided the research.

Findings: Two major themes were identified. The first theme; "***Becoming who I can be through what I can do***" with two sub-themes, namely, "*Opportunities at Gabriella Centre*" and "*Changes and development;*" and the second theme; "***Connecting and earning community trust through valued occupation and routines***" with three sub-themes, being; "*Valued occupational routines at home and in the community*"; "*Trusted, given responsibility and making choices*", and "*Community acceptance and support*".

Discussion: The occupational based intervention for YID offered by GCRC provided considerable practical skills that facilitated YID’s participation in community life. The youth became confident, and their abilities were recognized, bringing about more community acceptance. YID contributed to alleviating poverty through their engagement in the valued family and community routines. The person-centered approach was used to guide youth to make informed occupational choices.

Various facets of the environment were identified as enablers and barriers to community participation.

Conclusion: A well designed program that uses a person centered approach and reflects valued community occupations, such as the GCRC, is necessary for YID to learn skills and use their ability to participate and contribute to the community. However, it is essential to consider holistically the needs of YID. Existing policies and laws coupled with supportive families and communities can contribute to successful community participation for YID.

Abstract Word Count: 396

Keywords: Youth with intellectual disability; community participation; vocational skills; household chores; valued occupations

CHAPTER 1: INTRODUCTION

1.1. Introduction to study

Intellectual disability is a developmental disability that affects a person's capacity to cope with their surroundings (American Psychiatric Association [APA], 2013) and impacts the person's capacity to learn (Kazemi, Saleh, & Kheirollahi, 2016). This affects how they build their skills and talents as they grow. The United Republic of Tanzania is a signatory to the United Nations Convention on the Rights of Persons with Disabilities [UNCRPD] (United Nations, 2006) and has national laws and regulations (Tanzania Disability Act, 2010; Ministry of Labour, Youth Development and Sports, 2004) that protect and promote the rights of Youth with Intellectual Disabilities. Notwithstanding, children and young people with disabilities, including intellectual disabilities, confront multiple challenges leading to gaps in their participation (United Nations International Children's Emergency Fund [UNICEF], 2021). By exploring the experiences of youth after they participated in a rehabilitation programme, this study aims to contribute to promoting the development of more inclusive and supportive environments for young people by describing how the service provided may influence the YID engagement in their communities. This may contribute to identifying how the services and programmes could be improved. An occupational therapy lens was applied in this study to fully understand the factors that facilitate occupation and promote participation.

1.2. Background

Geographically the United Republic of Tanzania is located in East Africa and includes Tanzania mainland and Zanzibar Island with a population of about 61,741,120 people (Tanzania Bureau of Statistics, 2022). The country has 28 administrative regions with Kilimanjaro being one of them. Moshi urban and rural districts are within the Kilimanjaro region. Figure 1 illustrates this location.

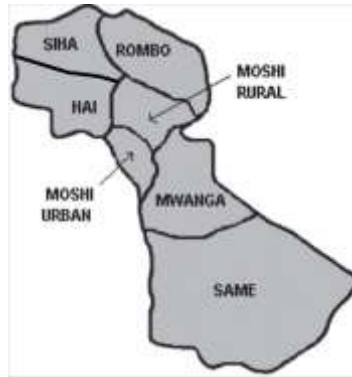


Figure 1: Google map (n.d) and map of Kilimanjaro region, United Republic of Tanzania

Numerous ministries in Tanzania hold the responsibility for delivering services to YID. These include services available through the Ministry of Health, Ministry of Education science and technology, ministry of Labour, Youth, Employment and Persons with Disability as well as ministry of Community Development, Gender, Women and Special Groups. Concerns about these services highlight that the services provided do not adequately respond to the needs and demands of persons with disabilities (PWD) (Swai, Msuya, Moshi, Lindkvist, Sörlin, & Sahlén, 2023). Only between 2-10% of PWD have access to rehabilitation services and these services are mainly provided in the urban settings, while 80% of the Tanzanian population lives in rural areas (Hansen, Chaki & Mlay, 2012; Njelesani, Couto & Cameron, 2011). According to the Kilimanjaro Christian Medical University College (KCMUco), Occupational therapy training in Tanzania started in 1998 (KCMUco, n.d.). There are less than 300 occupational therapists in Tanzania who provide services in hospital settings, rehabilitation centres and through community based rehabilitation services (The OT Hub., n.d.). As the value of the profession has become more recognized in Tanzania, the government has recently begun hiring occupational therapists in public hospitals (The OT Hub., n.d.).

However, it remains a concern that, in Tanzania, persons with disabilities are seen as a burden and may be discriminated against (Ministry of Labour, Youth Development and Sports, 2004). Existing cultural beliefs in families and communities also contribute to YID not being included in the day to day life in their communities (Tilahun, Hanlon, Fekadu, Tekola, Baheretibeb & Hoekstra, 2016). Many YID face economic marginalization, are denied employment and are viewed as though they are unable contribute to their communities (Uromi & Mazagwa, 2014). Kuper, Walsham, Myamba,

Mesaki, Mactaggart, Banks, and Blanchet, (2016) and Tiwari, Savastano, Improta, and Winters (2019) explain that people with disability in Tanzania face extreme poverty, compounded with a high unemployment rate and a lack of universal access to education and health services , which equally limits YID in their participation in occupations. This is similar to the challenges that many families in developing countries face while raising a child with an intellectual disability (Tilahun, *et al.*, 2016). These restrictions illustrate their limited access to meaningful occupation and consequently their risk of experiencing occupational injustice (Hocking 2017).

Occupational injustice occurs when barriers or constraints prevent individuals or communities from participating in meaningful occupations (Townsend & Wilcock, 2004). For youth with intellectual disabilities, this injustice can manifest in various ways.

Resource limitations can restrict access to necessary supports and services, hindering their ability to engage in desired occupations (Hammell, 2017). Societal attitudes and misconceptions about intellectual disabilities can lead to discrimination and exclusion, further limiting their occupational opportunities (Hocking, 2017). Additionally, institutional policies and practices may not adequately accommodate the unique needs and capacities of these individuals, creating additional barriers to occupational participation (Durocher, Gibson, & Rappolt, 2014). These forms of occupational injustice can have significant impacts on the health, well-being, and quality of life of youth with intellectual disabilities. They can limit their opportunities for personal growth and development and hinder their ability to participate fully and meaningfully in society (Townsend & Wilcock, 2004). Furthermore, encouraging participation and equity with regard to occupation can help achieve occupational justice for young people with intellectual disabilities (Townsend & Wilcock, 2004). This is consistent with the idea of occupational rights, which are safeguarded by recognizing and addressing the abilities, chances, and autonomy that enable people to participate in society as individuals, groups, and populations (Hammell, 2017). We can guarantee these people's full and meaningful engagement in society by creating an atmosphere that honors and supports their distinct needs and capacities (Durocher, Gibson, & Rappolt, 2014). The description of YIDs community integration and participation following rehabilitation services will offer insights into YID's experience with occupational justice. Additionally, it will highlight the distinct needs and experiences of these youth, possibly contributing to practice and policy in a way that is considerate of their rights and goals. The ultimate goal of this research is to support Tanzanian youth with intellectual disabilities in their full and active engagement in society

1.3. Gabriella Children's Rehabilitation Centre (GCRC)

One of the centres where occupational therapy services are provided for young persons with disabilities is the Gabriella Children's Rehabilitation Centre (GCRC). The clients at the centre are children and youth between the ages of 0 to 25 years with disabilities including intellectual disabilities, Autism-specific learning disabilities, Attention Deficit and Hyperactivity Disorder, and moderate physical disabilities. The GCRC is located in facilities within the Hai district, however it continues serving children and youth from Moshi urban and rural district within the Kilimanjaro region since this is where the centre originated. Most inhabitants of Moshi are part of the Chagga tribe (Madenge, 2021) and are known to be mainly involved in agricultural and small businesses to provide for themselves financially. The Moshi urban and rural districts are known as sites where the first missionaries arrived to colonise Tanzania. These districts have more infrastructure and services, such as public transport, compared to other regions of Tanzania.

The GCRC has been providing services for children and youth with intellectual disability (YID) and other disabilities since 2009 (Gabriella Children's Rehabilitation Centre [GCRC], 2023). The services are offered for persons who attend the centre daily as well as a residential service for a proportion of children and youth who live at the centre for a period of time. These services aim to ensure that their talents and abilities are identified and that they are trained to use their skills in their communities. The centre provides numerous rehabilitation services for young people and adolescents with physical and cognitive challenges as well as providing support for their parents or caregivers. These services include access to therapeutic services and training opportunities. Participants at GCRC access a multidisciplinary team that have expertise in assessing and educating caregivers on the best ways to carry out therapy at home. The services offered include intensive therapeutic intervention, transitional and integrated school, vocational & skills training, support groups and parent, teacher, and community workshops. Parent/caregivers participate in this programme during designated weeks at the beginning and end of each term. Parents/caregivers use this time to plan and support their children in making occupational choices and goals.

The multidisciplinary team includes occupational therapists, special needs teachers, artisan trainers on skills such as carpentry, agricultural, tailoring, cookery and art and crafts as well as professions

that consult such as a paediatrician, psychologist, physiotherapist, and speech therapist. In occupational therapy, interventions promote engagement in occupations, fostering social inclusion and community participation. This is done by assessing the YID's participation, providing occupation based interventions and facilitating community integration. The GCRC aims to support children and youth so that they can engage in productive and self-care based activities and lead more independent and inclusive lives.

GCRC offers a range of occupational therapy services, such as assessment of children and youth with specific learning needs includes those with intellectual disabilities, an assessment of the school environments, vocational skills needs and detailed individual reports detailing the impact on learning and any further recommendations. Occupational therapy interventions offered includes providing adapted equipment, programmes to improve fine motor skills, sensory integration, and attention and memory. The occupational therapy (OT) services offered at the center are available on a daily basis for children who attend daily. The center also offers week long therapy known as "intensive therapy week", where parents and their children from all over the country can come and receive occupation therapy services. The services offered at GCRC have not been documented before. As a result, little is known about how these youth engage in occupations and apply their skills in their different communities.

1.4. Problem statement

Many YID living in poor socio-economic conditions are mistreated and experience cultural and attitudinal barriers that leave them isolated and hidden away from the public (Tanzania Disability Act, 2010; Ministry of Labour, Youth Development and Sports, 2004) This makes it difficult for them to freely participate in occupations that they may find meaningful and also their contribution to the community is not supported. Employment for individuals with disabilities is reported to be low in Sub-Saharan Africa, including Tanzania. YID in Tanzania are mostly excluded from engaging in small income generation activities, household chores and recreational activities (Lameck, 2020; Rwegoshora, Mohamed & Mnyanyi, 2022).

A small number of YID have access to rehabilitation services. Occupational therapy services are one the services that form part of these rehabilitation services. However, the nature of the services, the interventions implemented, and the intervention outcomes have not been researched. It is

known that there is little research on services for youth with intellectual disabilities in Tanzania and other low- and middle-income countries (LMICs) (Jansen van Vuuren, Okyere, & Aldersey, 2020). Research on how youths are reintegrated into their communities after receiving services is particularly lacking. This emphasizes a critical knowledge gap and the need for research in this field.

1.5. Research question

How do youth with intellectual disability engage in occupations in the community of Moshi, Kilimanjaro and what enables their participation?

1.6. Research Aim

To describe how youth with intellectual disabilities participate in occupations in the Moshi community and to identify factors which contribute the ability to participate in their communities.

1.7. Research purpose

Promoting participation can transform community perspectives and promote participation and inclusion for YID..Since occupational therapy services are still developing in Tanzania, describing the GCRC services will provide insights that may contribute to enhancing interventions that promote community participation and disrupts possible discrimination or marginalization that YID may experience. The study findings could also inform the occupational therapy curriculum in Tanzania on how best the student can be training to promote occupational based intervention.

This study is interested in how youth with intellectual disability in Tanzania participate in the community after receiving rehabilitation services at Gabriella Children's Rehabilitation Centre. This is motivated by the reality of the situation in Tanzania where the profession of occupational therapy is relatively new and there is limited literature reporting on general occupational therapy intervention and more specifically on YID. Given the situation of the general population, there is a limited employment opportunity especially for people with disability, therefore other means of employment and engagement of occupation for YID is worth exploring. Accordingly, the use of

culturally valued activities as means of promoting participation and inclusion of YID as used at GCRC prompted the researcher to embark on this journey.

1.8. Research Objectives:

- a) To identify the occupations that youth with intellectual disabilities participate in, in their communities.
- b) To explore the factors that enable YID to engage in occupations.
- c) To explore the factors that hinder engagement in occupations for YID.
- d) To describe what meaning and purpose the community attributes to the YID occupational engagement and participation.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

This chapter describes the situation of youth with intellectual disabilities (YID) globally and in low and middle income countries (LMIC) including Tanzania. The needs and challenges YID face and their participation in occupations within their communities are outlined. It is suggested that such a description matters for mitigating occupational injustice and promoting engagement in valued occupations. Factors that contribute to community participation, as well as occupational therapy approaches and interventions towards YID, are highlighted.

2.2. Occupational right through meaningful participation and engagement.

As YID transition from childhood to adulthood, they experience challenges of instability and uncertainty, particularly in earning a realistic income suitable to sustain themselves and their families (Ellman, Sondag & Buchanan, 2020; United Nations for Youth, 2012). Young people with intellectual disabilities from high, middle, and low-income countries face difficult times and uncertainty as a result of social exclusion, lack of participation in economic activities, and limited access to employment and family activities (DuBois, Renwick, Chowdhury, Eisen & Cameron, 2019; Engelbrecht, van Niekerk & Shaw 2022).

From an occupational justice perspective, it is recognized that individuals have a unique set of occupational capacities, requirements, and routines within their surroundings (Whiteford, Parnell, Ramsden, Nott, Vine-Daher, 2021). The occupational capacities of an individual can significantly influence their ability to engage in occupations. For example, a person's physical abilities may determine what types of physical work they can do, while their mental skills may influence what types of cognitive tasks they can perform. Active engagement in occupations for YID can nurture positive occupational identities, which are developed when individuals believe that their chosen occupations are valued and supported by their families and communities. This is enhanced when, what the individual does and who they would like to be and become, is closely correlated to the community's views (Phelan & Kinsella, 2009). Occupational engagement and community participation has a potential positive impact on development, health, and well-being through allowing YID to gain skills, competence and foster meaning in life (Anaby, Bitensky, Law, &

Cormier, 2015). Occupational justice is a perspective that advocates that, regardless of their abilities or disabilities, everyone has the right to participate in meaningful and important occupations. It acknowledges that every person, including people with disabilities, has special occupational abilities and ought to be able to use these abilities in their day to day life. It brings about respect and value for persons with disabilities (PWD) which is necessary for reducing discrimination and exclusion (Christiansen & Townsend, 2010. p.7).

Engelbrecht, *et al.*, (2022), in their studies conducted in South Africa on supported employment for YID argued that occupational justice can be achieved when YID become involved in work as this is fundamental to achieving health and well-being. When YID engage in meaningful occupations it facilitates the way they participate in the community since actively engaging in doing, facilitates social connection, social growth, and social development (Wilcock, 1999). Through participating in meaningful occupations, YID are known to experience a sense of belonging, which is vital for community acceptance (Jansen-van Vuuren & Aldersey, 2020) thus promoting occupational justice. King, Okodogbe, Burke, McCarron, McCallion and O'Donovan (2017) also supported the value of community participation by proposing that people can retain a high quality of life and overall well-being while exercising their occupational rights when they actively participate in socially or personally valuable pursuits. Meaningful occupations include activities of daily living (ADL) such as self-care and instrumental ADL's (IADL) such as household work. These are known to offer structure, a sense of purpose and belonging, and a taste of community life (Ikiugu, Lucus-malitor, Feldhacker, Gebhart, Spier, Kapels, Anold & Gaikowski, 2019). Engaging in meaningful occupation varies depending on customs, traditions, social behavior, health conditions, and location (Stone-Mcdonald, 2012). When YID engage in meaningful and valued occupations, they may form interpersonal connections, develop hope, and establish structure and routines (Doroud, Fossey & Fortune, 2015). Studies have indicated that engaging young persons with disabilities in economic activities such as gardening, cooking and animal husbandry may provide them with employment opportunities whilst alleviating household poverty (Lameck, 2020). Additionally, involving young persons with disabilities in physical activity, such as sports and recreation, fosters inclusion, reduces deconditioning, optimizes physical functioning, enhances mental and academic performance, and improves general well-being (Carbone, Smith, Lewis & Leblanc, 2021).

2.3. Factors that contribute to community participation.

The International Classification of Functioning, Disability and Health (ICF) considers participation and engagement as important aspects of health and well-being (World Health Organisation [WHO], 2001). King, *et al.*, (2017) also reported that several factors outside the person contribute to community participation in YID. This includes access to appropriate services, acquiring needed skills and being given the opportunity to practice skills in an acceptable restrictive free environment. The factors explained below influence the way YID participate in the community.

2.3.1 Access to services

The World Health Organisation's (WHO) Rehabilitation 2030 initiative suggests that efforts be directed to addressing unmet needs for rehabilitation globally, by bolstering health systems to deliver rehabilitation services, making it available through all stages of the life course and in all levels of health care (WHO, 2017, p.5). Access to rehabilitation services for people with disabilities is frequently limited in low and middleincome (LMIC) countries (Bright, Wallace & Kupar, 2018; Mkabile, Garrun, Shelton, & Swartz, 2021). YID in LMIC countries, have very little access to formal education and skills training (Rwegoshora, *et al.*, 2022; Uromi & Mazagwa, 2014). According to Joel, Msuya, John and George, (2018), inadequate rehabilitation services for YID have a greater impact on families, which affects how they care for their siblings. Conversely, greater access to adequate rehabilitation services could increase productivity and decrease the time and resources spent caring for a disabled child in the family. Tanzania's policy on disability 2004, which is also in line with the Disability Act 2010 and the United Nations Sustainable Development Goal Four (SDG4) identifies the importance of having facilities that provide skills training and providing opportunities for promoting inclusion for PWD (Tanzania Disability Act, 2010; Ministry of Labour, Youth Development and Sports, 2004; United Nations, 2016).

In Tanzania and East African communities there are limited facilities, professionals and resources necessary to cater for the requirements of all persons with disabilities (Swai, *et al.*, 2023; Tilahun, *et al.*, 2016; UNICEF, 2023). YID do not have equitable and fair access to opportunities and resources as compared to their counterparts without disabilities. This disparity limits their ability

to do, be, and belong, further hindering their potential. (Hocking, 2017). More specifically, there is a dearth of rehabilitation and educational services, especially in the rural areas of Tanzania, for young people living with disabilities (Lameck, 2020; Swai, *et al.*, 2023). There is also a scarcity of competent trainers who are able to provide services for YID. Poor educational accessibility, difficult social and physical context, and preexisting unfavourable views toward individuals with disabilities all contribute to YID's marginalization (Joel, *et al.*, 2018; Rohwerder, 2020; United Nations Education Scientific and Cultural Organisation [UNESCO], 2023.). The consequence of exclusion from participation is that YID are consistently limited in their prospects and resources due to discrimination. This may contribute to restrictions in valued, meaningful occupations that are important for wellbeing (Hocking, 2017).

The lack of guidelines providing direction on how YID should engage in income generating activities in Tanzania prevents these youth from accessing financial and other necessary resources (Lameck, 2020). Uromi and Mazangwa (2014), have argued that the available skills training facilities are poorly designed to address YID needs. The few available services for PWD that exist are mostly run by non-governmental organizations and religious institutions. These organizations are few and do not have the capacity to meet the needs of all YID. The services offered by these organizations also do not offer sufficient follow up programmes (Stone-Macdonald 2012; Swai, *et al.*, 2023; UNICEF, 2021).

2.3.2 Environmental factors

In Tanzania and other low and middle income nations, environmental support is essential for young people with intellectual disabilities. In their scoping review, Anaby, Hand, Bradley, DiRezze, Forhan, DiGiacomo and Law, (2013) pointed out that environmental factors can facilitate or hinder participation for individuals with intellectual disabilities. These factors include social support from families, community support and attitudes, availability and location of services as well as policies related to disability. A situational analysis conducted by UNICEF (2021) revealed that Tanzania's legal framework for protecting the rights of children and young people with disabilities has inadequacies thus limiting their participation. King, *et al.*, (2017) propose that occupational therapists recognize that successful community participation and occupational engagement result from the interaction between the individual, the occupation they are engaging in, and the

environment where the occupation takes place. Anaby, *et al.*, (2013) indicated the connection between the environment and participation differs and depends on whether support and services provided takes place at home, school or elsewhere within the community.

Family is one crucial level of the environment that YID live in and interact with, however studies in LMIC's show that parents of children with disabilities experience higher levels of stress, sadness, family challenges, rejection, financial issues, stigma, humiliation, and prejudice, which exacerbates their situation (Mkabile, *et al.*, 2021; Malapela, Thupayagale-Tshweneagae, & Mashalla, 2020). Less time is spent caring for other children, and costs of living go up since the disabled child requires more resources (Joel, *et al.*, 2018). Perceived shame or burden that a person with a disability brings to the family is one of the major barriers limiting PWD from actively participating in occupations (Tilahun, *et al.*, 2016). For YID, improving community participation is correlated with more family involvement and available resources. Families can influence how YID access and engage in the community. Dubois, *et al.*, (2020) identified various factors that seemed to facilitate and enable participation, such as offering opportunities to engage in socially valued activities with family members, being given opportunities to make choices, as well as being guided on safety considerations whilst participating in community activities.

2.3.3 Community acceptance and belonging

Studies have indicated that community acceptance is a crucial facilitator of YID's participation (Willis, Girdler, Thompson, Rosenberg, Reid & Elliott, 2017). Jansen-van Vuuren and Aldersey (2020) showed that stigma limits the participation of YID in their communities, whilst acceptance and belonging promotes community participation for people with Intellectual Developmental Disabilities across cultures. Furthermore, developing a sense of belonging is correlated with how the community accepts an individual and provides opportunities for participation in valued community occupations (Jansen-van Vuuren & Aldersey, 2020).

Furthermore, raising awareness is an important aspect of facilitating community participation for YID. Aldersey, (2012) contended that when families on the African continent have a relevant understanding of disability, they can become key role players advocating for the rights of PWD subsequently promoting empowerment.

2.4. Creating relevant interventions

Hammel and Iwama (2012) highlight that occupational therapy is concerned with ensuring that clients have opportunities to engage in meaningful occupations that have a positive impact on their well-being. Occupational therapists work with individuals and families to determine how people with intellectual disabilities can participate in life at the family and community levels (Australiaot.com, 2021) since this is key to enabling community participation. Interventions that focus on YID's cognitive, sensory, motor, and psychosocial abilities form a part of this (Australiaot.com, 2021). A person-centered approach with YID has been shown to be beneficial for enhancing social inclusion and community engagement since it focuses on YID's talents and what matters to them in the present and in the future whilst also collaborating with their caregivers and family members (McCausland, Murphy, McCarron, & McCallion, 2021). It provides a collaborative, consultative, respectful, and inclusive approach to service provision (Brown, 2013; Mccausland, *et al.*, 2021). This would mean that YID, their caregivers, and family members as well as therapists are equal partners when involved in occupation focused interventions.

Anaby, *et al.*, (2013) argue that parental support and guidance has a positive influence on how YID participate in the community. The interventions should involve caregivers/parents and families in planning on how to involve their children in IADL's and household tasks, while taking into account their abilities, needs and interests (Johnson, Blaskowitz & Mahoney, 2019; Mccausland, *et al.*, 2021 focusing on social skills, effective communication (O'Handley, 2016); as well as addressing behavioral issues (Ali, Belckwedel & Hossiois, 2014, Jansen-van Vuuren & Aldersey, 2020). Additionally, Nuri, Ghahari, Aldersey, & Huque (2020) contend that when providing services, the families' needs should be taken into account and incorporated into the planning as this will foster acceptance and community participation.

Vocational, self-care, and independent community living skills, can influence young people's futures positively when planning for transitions from school and promoting community engagement begins early (Johnson, Blaskowitz & Mahoney, 2019). It promotes greater social inclusion and community involvement (McCausland *et al.*, 2021

). YID have to develop the necessary skills for community participation such as skills for work and small-scale income generation, self-care, and household skills. Acquiring these essential skills boost their self-confidence, self-respect, and success in community participation (Harvey, Zapt &

Groger, 2022). Additionally, it has been observed that training in daily living skills, such as taking care of one's health needs, household chores, self-care, and money management, is important for YID to have before they participate in community activities (Abaoğlu, Cesim, Kars, & Çelik, 2017; Hankle, Bluestone, Kramer, Bassi, & Goreczny, 2021).

Since YID also have a right to have intimate relationships and express their sexual needs and interests, interventions should include sexual education that helps YID with self protection as well as being able to express and manage their sexual needs. Adequate sex education can support young people with intellectual disabilities rights to make informed choices whilst participating fully in their communities (Colarossi, Collier, Dean, Pérez & Riquelme, 2023). Studies indicate that the majority of sexual education provided to YID, focus on how to protect themselves from sexual exploitation but do not offer comprehensive sexual reproductive health education, which would give opportunities for YID to freely discuss their issues related to their sexuality, (Colarossi, *et al.*, 2023; Michielse & Brockschmidt, 2021). Ngilangwa, Rajesh, Kawala, Mbeba, Sambili, Mkuwa, Noronha, Meremo, and Nyagero, (2016) indicated that there is poor access to comprehensive sexual education amongst marginalized groups in Sub-Saharan Africa, and, in Tanzania, adolescents with disabilities are more vulnerable. YID's teachers and parents perceived themselves as not competent in providing sexual reproductive health education. A study in South Africa by Kahonde, McKenzie and Wilson (2019) also described the challenges for persons with intellectual disabilities expressing their sexual desire as their caregivers utilized their cultural and social values to guide how young people should express themselves.

Youth with intellectual disabilities (YID) have the same rights to leisure activities and experiences as peers without intellectual disabilities (Heister, Zantel & Kob, 2023). Leisure time allows for the demonstration of abilities and the freedom to engage in activities, whilst fostering relationships with peers, which supports the development of identity (Heister, *et al.*, 2023). However, Heister, *et al.*, (2023) further illustrated that young individuals with disabilities may have limited access to leisure and recreational opportunities, hindering the realization of their right to human dignity. These young individuals' leisure participation is heavily dependent on outside variables including the opportunities available, the types of leisure activities they are permitted to engage in and the availability of individuals who can help facilitate access to these opportunities. Expanding community members' awareness and understanding of the value of participating in leisure and how this can be facilitated for YID can increase their participation (Hester, *et al.*, 2023). Such

services need to be prioritized by the Tanzanian government (WHO, 2021) as this would allow for the realization of the ideals reflected in the Tanzanian Disability Policy 2004 and the Tanzania Disability Act 2010.

2.5 Summary:

This literature review focused on the position of young people with intellectual disabilities (YID) globally and in low and middle-income countries (LMIC), like Tanzania. It describes the needs and difficulties that YID encounter in their community participation, highlighting concerns with employment and income generation. It describes the social marginalization, restricted occupational opportunities, and low involvement in economic and familial activities that YID frequently encounter. The review delves into the standpoint of occupational justice, acknowledging that every person possesses unique set of occupational capabilities, needs, and customs. It implies that engaging in occupations actively can foster positive occupational identities, which arise when people feel that their communities and families value and support the occupations they have chosen. It emphasizes how crucial it is to acknowledge and accept people with disabilities (PWD) in order to lessen exclusion and prejudice against them.

In order to achieve health and well-being, the review ends by discussing studies that support YID's involvement in the meaningful occupation as a means of achieving occupational justice. It highlights how crucial community involvement is to maintain a high standard of living and general wellbeing while pursuing one's occupational rights and providing YID with a feeling of purpose and belonging

CHAPTER 3: RESEARCH DESIGN AND METHODS

3.1. Introduction

This chapter details the theory underpinning and rationale for using a qualitative research design in this study, furthermore, describing the method and processes of recruitment, data collection and data analysis. The chapter concludes by explaining the principles of trustworthiness applied and outlining the ethical procedures implemented.

3.2. Research design

This study used qualitative descriptive design, which systematically provides a broad perspective on a particular phenomenon (Bradshaw, Atkinson, & Doody, 2017). It recognizes the subjective nature of phenomena and enables the researcher to explicate the detailed illustration of events and experiences (Doyle, McCabe, Keogh, Brady & McCann, 2020; Kim, Sefcik & Bradway, 2017). At one point this study was grounded on instrumental case study but due to covid 19 pandemic which paused limitation in this study another method was explored. Qualitative descriptive design was suitable for exploring how YID engage in their community and identifying the factors that enable or hinder their participation. A qualitative description (QD) design, according to Bradshaw, Atkinson, and Doody (2017), is especially useful when time and resources are limited and first-hand information from people experiencing the phenomenon being studied is needed. The experience of YID, their parents, the integration process, and community involvement were the primary focus of this study. This method allowed the researchers to collect qualitative data from interview, observation and document review which aided the analysis process. Flick, (2014) and Kim, *et al.*, (2017), highlight the importance of observation and document review in descriptive qualitative studies as it provides unique, rich and detailed contextual information which is crucial for the phenomenon under study, in this case experience of YID in community participation.

3.3. Situating the researcher and the research context

The researcher is Tanzanian and works as a local occupational therapist. He speaks and understands Chagga, English and Swahili, the latter being the national language of Tanzania. The

researcher worked for 19 years with children and youth with disabilities and tutoring at the School of Occupational Therapy at Kilimanjaro Christian Medical University College (KCMUco) in Tanzania. Informed by this experience, the researcher held an assumption that YID's lives and communities may be transformed when people are actively engaging in what is meaningful to them and what they would like to do, able to do, and what is possible to do. The researcher has also been a long-standing board member of the Gabriella Children's Rehabilitation Centre (GCRC) and was interested in this area of study since previous research had not been conducted on the participation of YID following their involvement at the GCRC. The researcher is not an employee of Gabriella centre but he is familiar with the programme offered through being a board member and as therapist he had worked with YID and occupationally therapists at the Gabriella Center previously. However, he had not worked as a therapist with any of the YID and parents who participated in the study. The study was conducted in Moshi urban and rural district, Kilimanjaro region, located under the beautiful mountain Kilimanjaro.

3.4. Study population and sampling

The study population included all youth with intellectual disabilities who had received services at GCRC from the start of the centre's services for YID in 2013. The study sample was identified as youth who had been discharged from the service over the past two years. The number of YID who had graduated since 2013 were 65. A purposive sampling method was used to recruit and select participants.

3.5. Sample selection criteria and size

Purposeful sampling is used to identify and recruit participants with diverse characteristics, allowing a study to obtain a wide range of perspectives and collect rich and meaningful data (Tong & Craig, 2019). This means selecting study participants with knowledge and experience of the topic being studied and who are amenable to contributing to fulfilling the research objectives (Doyle, *et al.*, 2020). For this study, the researcher identified that YID, their parents and therapists at GCRC would have had knowledge and experience of YID community participation.

Purposeful sampling with maximum variation approach was used to identify participants based on selected criteria (Creswell, 2007, p.74.; Patton & Cochran, 2002). Applying maximum variation

(Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2015) allowed the researcher to consider identifying factors that varied amongst participants during the selection process. These considerations included the context of their experience, their geographical location, and their relationship. The sample also intended to be convenient for the researcher with maximum variation of the study population.

The sample size included four (4) YID, three (3) parents of YID and one (1) occupational therapist.

3.6. Inclusion criteria.

The following criteria were used to select participants who were YID, parents/caregivers and an occupational therapist.

3.6.1 Inclusion criteria for youth with intellectual disability:

- The individual must have a mild intellectual disability The focus of the research was on YID with intellectual disability. Intellectual disability is often associated with specific cognitive and adaptive behavioral problems that may require targeted intervention. This increases their exclusion from the community and other services, including limited participation in the community. By focusing on these young people with developmental disabilities, researchers could gain a deeper understanding of these specific challenges and develop more effective strategies to address them.
- Aged between 18 to 24 years.
- Had participated in the GCRC programme for at least one year. The minimal period of one year of utilizing services at GCRC would mean that YID have been exposed to a range of GCRC services daily for this period and it is expected that they could reflect on this in relation to their occupations in their community.
- Have completed the GCRC programme at least two years ago as this would mean that the youth have already experienced the reality of community living for some time and also have had follow-up from GCRC.

3.6.2 Inclusion criteria for parents/caregivers:

- Parents/caregivers of YID who are taking part in the study. This are the parent of YID where the go back after the have been discharged from Gabriella centre services.
- YID had been discharged from GCRC services at least two years ago. This would mean that parents have had experience of the GCRC programme and the YID living in the community for at least two years.

3.6.3 Inclusion criteria for the occupational therapist-

Had experience working with children and youth in the community integration process for at least one year at GCRC.

3.6.4 Exclusion Criteria

- Participants who are unable to express themselves verbally as this study relied on participants' abilities to share their experiences verbally.
- Occupational therapists who are expatriates or volunteers working at GCRC since they may not fully understand the culture or have full decision making regarding working with YID at the centre at due to their given roles.
- Parents with special needs who may not be able to fully express themselves.

The Gabriella Centre's database of client records was used to verify that potential participants who met the inclusion criteria of age and had been discharged up to two years prior to data collection. The database was only accessed after YID showed interest in participating in the study.

3.7. Gaining access and recruiting participants.

Permission to conduct the research was obtained from the, Faculty of Health Sciences Human Research Ethics Committee at UCT [*see HREC NO:678/219 and ethical renewal in Appendix E1 and E2*]; Kilimanjaro Christian Medical College Research Ethics and Review Committee [*see CRERC No 2455, in Appendix F*]. Permission to conduct the study was also requested from the GCRC governing board [*see Permission Letter in Appendix C*]. Since the researcher is a GCRC

board member, he was excused from the meeting where this matter was decided. This allowed the GCRC board to make an independent, unbiased decision.

An advert inviting potential participants to indicate their interest was placed on the notice board located at the GCRC reception and main entrance as well as in various villages within Moshi. All adverts were written in Swahili. Participants were invited to contact the researcher using the information in the advert [*see the advert in Appendix B*]. Four participants were recruited following the advertisement in their villages and another three participants were recruited via the GCRC advert.

The parents of identified youth were contacted telephonically to introduce them to the research and invite their participation. If the parents were interested, an appointment was arranged for a face to face meeting where the information letter was shared with them [*see Appendix A2*]. When the parents agreed, the researcher gained their consent [*see section 3.13 Ethical Considerations*].

Four participants came from two different villages namely, *Kibosho Ndo* and *Kibosho Sinda* Village and the other three came from Moshi urban.

One of three occupational therapists working full time at GCRC met the inclusion criteria of having worked at GCRC for more than a year and this therapist was invited and agreed to participate in the research. Once potential participants were contacted by phone, permission to access their folders for the purpose of reviewing the detailed notes of their time at GCRC for the research was sought from individuals after they had understood the aim of research and consent had been obtained.

3.8. Participant characteristics

The following tables provide a brief description of each of the selected participants. A pseudonym is used for each of the participants to protect their identities.

Table 1. Youth with Intellectual Disabilities

| Name | ANNA | NEEMA | JOHN | SAMWELI |
|-------------|-------------|--------------|-------------|----------------|
| Age | 19 | 24 | 23 | 24 |

| | | | | |
|--|------------------------------------|--|------------------------------------|------------------------------------|
| Sex | Female | Female | Male | Male |
| Skills/ programmes participated in at Gabriella | Garden and chicken keeping | Gardening/cocking, chicken , goats and cow keeping | Brick making | Goat and chicken keeping |
| Year of discharge | 2019 | 2017 | 2018 | 2017 |
| Legal gurduan who Consented | Parent | Parent | Parent | Parent |
| Introduced to participant by | Gabriella’s occupational therapist | Gabriella’s occupational therapist | Gabriella’s occupational therapist | Gabriella’s occupational therapist |

Table 2. Parent/Caregiver characteristics

| Name | MAMA NEEMA | MAMA JOHN | BABA SAMWELI |
|---|------------------------------------|------------------------------------|------------------------------------|
| Age | 57 years | 62 years | 58 |
| Sex | Female | Female | Male |
| Relation to YID | Mother | Mother | Father of Samweli & Anna |
| Work/ Occupation | domestic workers | Peasant | Peasant and small business |
| Introduced to the participant by | Gabriella’s occupational therapist | Gabriella’s occupational therapist | Gabriella’s occupational therapist |

Gabriella’s occupational therapist’s characteristics

The GCRC occupational therapist selected to participate in the study has been employed in a full time capacity at GCRC since 2014. Her main responsibility has been working with children and youth with disabilities to plan and organize their community integration process and conducting follow-up home visits.

The availability of public transport in Moshi made it easy for the researcher to access the participants in their communities. The furthest distance traveled took about one hour and 30 minutes to reach a participant's location.

3.9. Data generation

The descriptive qualitative research approach afforded the researcher the opportunity to gain insight into what occupations YID participated in and how this occurred in the community of Moshi (Kim, *et al.*, 2017). Three data generation techniques were used in this study, namely semi-structured interviews, observation, and document review (Creswell, 2007). These are described in detail below.

3.9.1 Interviews

Semi-structured Interviews

Semi-structured interviews were used as a primary way of gaining information (Rubin & Rubin, 2012; Singleton & Straits, 2005) from all participants. Semi-structured interviews involve flexible one on one conversations with participants (Voutilainen, Peräkylä, & Ruusuvaori, 2011). The researcher used an interview guide to inquire into the particular phenomenon during the semi-structured interviews. The interview guide was shaped by the research objectives and information from the literature about community participation of YID. In this study one semi-structured interview was conducted with each of the participants, namely the four YID, the three parents/caregivers and one occupational therapist. The semi structured interviews took an average of forty minutes to one hour each. Each interview took place in an area chosen by the participant and comfortable, including a home, office, or their working area. Appendix D outlines the interview guide used with the YID, parent/caregivers, and occupational therapist who participated in this study. All interviews were conducted in Swahili since this is the official language in Tanzania and is understood by the citizens and local population. A special communication card was available to the YID participants to use for communicating during the interview if they felt the need for it [*see Appendix A.1.2*]. The researcher utilized communication cards (see appendix A1.2) to frequently ask the YID during the interview if they wanted or needed to take a break. One of the YID once pointed at a yellow card to request that she would like to take a break so that she

could check on the progress of her cooking. This interview was thus interrupted for a few minutes and then continued. The researcher waited patiently and the participant came back and utilized the green card to signal that it is ok to proceed. Each of the interviews was audio-recorded on an electronic device. Thereafter the interview was transcribed by the researcher. The transcriptions were captured in Microsoft Word documents and, together with the audio recordings, were kept safely in a password protected document and saved in cloud storage that only the researcher had access to. The interviews were translated into English by the researcher.

Interview procedures

The interviews took place at negotiated and suitable dates, times and places agreed upon with participants, over different days within a period of three months, which included familiarization. The following timeline outlines the order of interviews followed. 1). Neema, 2). Mama Neema, 3). John, 4). Mama John, 5). Samweli, 6). Anna, 7). Baba Samweli, 8). Gabriella's therapist. As soon as each interview was completed, the researcher documented the findings and his reflections within field notes.

3.9.2 Document review

According to Bowen, (2009) document review and analysis may be used as a method to aid triangulation on the specific research question. In this study the document review was used as supplement data to gain rich information about youth participation. The YID folders at GCRC provided information about therapeutic and occupational goals planned for the youth to engage in occupations of their choice. Other GCRC documents such as policy documents, mission statements, assessment reports, brochures, standard operating procedures, and the daily, weekly, and yearly programmes of GCRC were also reviewed. The researcher adopted a systematic way to record the information captured from the documents. This included noting the type and purpose of the document, the date of creation and author, as well as the intended audience. During the document review, data was gathered regarding the programs that were offered, the number of youth who graduated and were integrated, and the types of interventions that were used, the training that the youth with intellectual disabilities received, and demographic details of the youth who took part in the research.

3.9.3 Observation

Ryan and Cole (2009) advocate that observation is a technique that calls for the researcher to witness and experience participants in their natural environments while they go about one of their daily tasks. The study was conducted in the latter part of the Covid-19 pandemic when there were still restrictions on how people should interact. The researcher was thus constrained in the length of the observation sessions with youth. However, the researcher had the opportunity to observe each of the YID participants and follow them briefly throughout their day-to-day participation. Each observation took between three to five hours. Both the individual YID and their parents gave consent to be followed and watched as the YID worked on their duties both with and without their parents. The optimum day and time to be observed were chosen by both parties. The observation's main focus was gaining contextual knowledge while also comprehending the youth's daily routines, activities, interactions with community members, and how they fulfill their roles in the family particularly with regard to the utilization of skills acquired at the Gabriella Center

The following activities were observed

- Samweli was observed during his day to day y activities whilst he was allowing his goats to graze in the field. His interactions with his peers and how he managed his goats in the field was observed.
- Anna was observed working in her garden and thereafter was followed to different places where she took her vegetables to be sold. The researcher could witness how she interacted with her customers, how she marketed her vegetables as well as her negotiation skills.
- Neema was observed doing her daily chores at home, this included cleaning the house, feeding the cattle and preparing meals for her child and other family members. She was also observed preparing groundnuts for her business. The researcher had another encounter observing her in her business area near the primary school where she sold her product, groundnuts, to her customers. The majority of her customers were school learners. Neema was observed in these various settings over two occurrences since it was necessary to see her during her entire day's activities and routines in order to understand how she employed the GCRC learned skills in practice.

- John was observed making bricks at his work area.

Prolonged engagement throughout the data collection process allowed the researcher to build trust and allow participants to feel comfortable in the research process. The researcher considered the participants' level of interaction and community participation evident during the observation periods. The observations were recorded as field notes immediately after each session to ensure that specific aspects of the observations were not missed.

3.10. Data management

All interviews were audio-recorded and transcribed verbatim into Microsoft Word text documents. After transcription, all electronic data were saved in a password protected folder and saved in a computer with special password protection, whilst using pseudonyms for each participant. The data obtained from observation, document and field notes were also recorded and saved in password protected folder. A backup copy was stored on the cloud and on a specific flash drive. A computer software program, NVivo 12, was used for the initial data management and analysis (Creswell, 2007; O'Neill, 2013). This was followed by manual grouping of sub-themes to form themes.

3.11. Data analysis and interpretation

The interviews were analyzed using a thematic analysis (Braun & Clarke, 2019). This involved an initial reading and re-reading of the transcribed data, the field notes, and document reviews for familiarization and to initiate immersion in the data. During this process, the researcher noted ideas and questions that came to mind from reading and reflecting on the data. This was followed by an inductive analysis to identify the codes. These codes were then clustered according to units of meaning to form subthemes. The sub-themes were further clustered to generate themes. These themes were discussed, compared, and verified through iterative discussion processes between the researcher and supervisor.

3.12. The scientific rigor of the study.

Trustworthiness refers to the authenticity of the findings in qualitative research (Lincoln & Guba, 1985) and is achieved through credibility, transferability, dependability, and conformability.

3.12.1 Credibility

To ensure that this study represents the credible conceptual interpretation of participants' realities of engagement in their communities, data triangulation was applied (Lincoln, Lynham, & Guba, 2011; Stake, 1995). Triangulation involved collecting data from multiple sources, using different methods of data collection, and conducting member checking (Lincoln, *et al.*, 2011). Collecting data from YID, their parents and a therapist provided different perspectives and allowed parents and the therapist to add to the primary perspective of the youth. The methods used included interviews, observation, and a document review. Furthermore, the research supervisor served as a peer reviewer during the data analysis to ensure that the meaning of the data was accurately captured. The researcher's experience, skills and knowledge of working with youth with disabilities ensured that the research methods were applied in a fair and consistent manner with all participants. The researcher was particularly patient when interviewing YID to accommodate their capacities. The researcher kept in mind that participants may experience inattention or be inconsistent in sharing information due to their abilities. The researcher's ability to interview participants in Swahili ensured that they could express themselves in their first language. The researcher adapted accordingly to accommodate the participants including having special communication card which made it easy for the participants to communicate.

3.12.2 Dependability

Dependability refers to the extent to which the process of inquiry can be applied by another researcher and will lead to the same findings (Lincoln & Guba, 1985). It requires that the methods applied, and decisions taken in the study are well-documented. In this study the researcher maintained thorough notes and correspondence with the supervisor throughout the research procedure. These comprised the field notes, researcher's journal, which described the data collection procedure and the creation of initial codes, categories, and interpretations. Every modification made from the study's beginning to its conclusion enabling the researcher to consider his own impact on the data's interpretation in detail.

3.12.3 Confirmability

In order to ensure an accurate interpretation of the data, member checking was used to enhance the confirmability of the data (Lincoln & Guba, 1985). Member checking interviews were conducted once the main themes of the data were confirmed. This was carried out during the observation interactions with each of the YID participants and their parents, in order to ensure accuracy and determine whether the data gathered aligned with their experiences. When the themes were finalized they remained closely aligned with what had been discussed during the member checking interviews. Thus, a second round of member checking of the findings was not deemed to be necessary. The researcher also kept a reflexive research journal throughout the research process. Reflexivity includes the way researchers identify how their biases, values and experiences influence the research (Creswell, 2013). Lastly, the researcher used peer debriefing by discussing the way that the data was being interpreted and the identification of the themes and sub-themes with the research supervisor. Being more experienced, the supervisor challenged assumptions, offered insightful advice, and assisted in honing the main and supporting themes. This process helped to enhance reflexivity as the supervisor provided an alternative perspective added depth and richness to the research findings.

3.12.4 Transferability

According to Lincoln & Guba, (1985) naturalistic enquiry does not intend to make a statement about the generalization of findings. Instead, the unique research context is described so that the findings can be understood in full context. In this study, a thick description about the context and the basis of purposeful sampling and the inclusion criteria was offered. This allows researchers to consider the relevance of the findings in different settings and allows for those who wish to undertake a similar study to consider the findings in relation to their context.

3.13. Ethical considerations

The Helsinki declaration (World Medical Association, 2013) and the National Medical Research Institute (NMRI) of Tanzania's ethical principles were adhered to during this study. Permission to conduct this study was sought from the Human Research Ethics Committee at UCT, and at

Kilimanjaro Christian Medical College Research Ethics and Review Committee (CRERC) permit HREC REF: 678/219 and study renewal 2023 and CRERC 2455 respectively. The ethical principles of ensuring autonomy, non-maleficence beneficence, and justice guided the research, as described below.

3.13.1 Autonomy and informed consent

Informed consent requires that the research participants are fully informed about the research so that they can make informed decisions related to their participation (Domholdt, 2005). The YID participants in this study had varied cognitive and sensory-motor abilities that needed to be considered during data collection. Examples of abilities that needed to be accommodated for, were verbal fluency, distractedness and various forms of dyspraxia and difficulties in performing motor related tasks. Each participant was verbally informed of the study's objective, and a written format was provided for those who could read. The researcher made sure the information was explained in depth using the most used and understandable language, which is Swahili. They were issued with this information in writing [*see Appendix A1-A7 for English version of information sheet and consent form*]. For the YID because of intellectual disabilities, a verbal explanation was offered by going through the written information with them for easy communication.

Schrems (2014) defines vulnerability as the relation between a person's health status and the extent to which this person is dependent on the researcher and the research context. Participants were assured that they were free to choose to participate or withdraw from the study at any time, especially if they felt uncomfortable (Grbich, 1999). The parents were allowed to be present if the YID indicated the desire for them to be. Considering the influence on power relations, would then need to be considered. The participants were given the opportunity to ask questions and the researcher responded accordingly. YID firstly gave their assent, and then the parents/caregivers were approached to ask for their consent to the YID's participation. The youth used their fingerprint when they were unable to write to indicate their assent. As the youth have cognitive impairments, additional consent was sought from their parents. All parents as well as the occupational therapist recruited were invited to sign a consent form [*See Appendix A2 and A4.*].

The right to autonomy is the freedom for people to decide at any time whether they want to continue participating or not. The researcher ensured that the participants were given freedom of

choice after they were informed about the aim of research. The participants were made aware of every potential consequence of taking part in the study and were given freedom to choose and their decision respected.

3.13.2 Confidentiality and anonymity

Participants were assigned pseudonyms in the transcribed text to ensure that their confidentiality and identities were respected and protected. This means their names and location were changed to ensure their privacy, however, because the Gabriella Center's occupational therapist-assisted with the recruitment process, the participants were already familiar to her.

This meant that during analyzing and reporting on the data, the participants' privacy was respected. The interview took place at a place that the participants chose and one that allowed them privacy and comfort, ensuring that they could share confidential information. To further ensure confidentiality, the information collected was safely stored in password protected folders on a password protected computer. All electronic information will be permanently deleted from the storage device six months after the research has been completed.

3.13.3 Beneficence

In qualitative research, researchers must safeguard subjects from injury, uphold their autonomy and respect their welfare (Kang & Hwang, 2021, p. 5). Ensuring the principle of beneficence involved holding participants' interest central during the research process, (World Medical Association, 2013). Participants were informed about the benefit of participating in the research and sharing their experiences. The benefits shared with them was that the research findings could inform the services provided to YID, possibly offering guidance on the quality of the services and could also inform the public about the YID experiences of engaging in occupations in the community. The participants were informed that there was no direct personal gain for them, except the opportunity to share their perspectives and stories. All related research costs were covered by the researcher and no remuneration was associated with participating in the study.

3.13.4 Justice

Justice in qualitative research ensures that participants can freely have a choice to take part withdraw or continue involvement in the research process, notwithstanding the need to consider factors that could render participants vulnerable (Jelsma & Clow, 2005).

The researcher made sure that throughout the entire research procedure, the researcher visited each participant with Gabriella's occupational therapist to become acquainted whilst requesting consent, in order to establish rapport with the participant and dispel any concerns about power relationships and differences (Judkins-Cohn, Kielwasser-Withrow, Owen, & Ward, 2013). This necessitates constant consideration and reflection during the entire study process on issues such as culture where a professional is seen as an expert. Furthermore, researchers kept in mind that power dynamics are subject to change throughout time, and researchers must be flexible and sensitive to these changes. The stipulated recruitment procedure was adhered to ensuring fairness in recruitment. That included visiting the youth with someone who was familiar to them so as to lessen any anxiety which may be brought on by the researcher's presence. This was done at the outset of the research and assisted the researcher to build trust and rapport with the participants. The information letter which explained the aims of the study and the researcher's interest in the research was also discussed prior to the actual interview. This strategy facilitated putting participants at ease, allowing the participants to consider the information and ask any questions that they might have ahead of time as well as during the interview process.

3.13.5 Non-maleficence

The researcher kept in mind that YID are vulnerable and, in accordance with the Declaration of Helsinki (World Medical Association, 2013), the research should not pose or cause any harm to the participants. The researcher recognized that the participants could become distressed or anxious during the research process and thus, during the informed consent process and prior to the interview, they were informed about this risk. The researcher highlighted that the participants could possibly feel emotional distress when speaking about the limitations to their participation. The researcher arranged that, should the participant experience such distress, they could be referred to the GCRC team for the necessary support or management. None of the participants experienced

distress during the interviews or observation sessions and thus no referrals to the GCRC team were necessary.

CHAPTER 4: FINDINGS

4.1. Introduction

This chapter describes the insights generated into how youth with intellectual disabilities engage in occupations in the community of Moshi, Kilimanjaro. The data analysis yielded two themes, namely *“Becoming who I can be through what I can do”* and *“Connecting and earning community trust through valued occupations and routines”*.

4.2. Theme 1: Becoming who I can be through what I can do

This theme describes the process that youth with intellectual disabilities (YID) experienced as they grew to realize their abilities, talents and interests. It describes the opportunities that YID accessed through attending the Gabriella Children’s Rehabilitation Centre (GCRC) [sub-theme 1] and the changes that developed [sub-theme 2] through engaging with these opportunities.

The opportunities that participants accessed through the Gabriella Centre influenced their growth. Neema, one of the YID, explained how the process of becoming who she could be allowed her to make choices based on what she valued and was able to do.

... well what I remember is I learned different things, I tried different things but some were difficult for me, some I didn’t like ... example I liked cooking but not tailoring since it was not easy for me...” Neema (YID)

The YID pursued their areas of interest and activities they felt they were good at. The youth remarked that as they participated more, people in their communities recognized their capacities.

“They say I am doing well so I should put more effort to increase more goats, and I tell them I will increase...” Samweli (YID)

The YID explored their abilities to participate in occupations through their exposure and trying the different opportunities offered as part of the Gabriella Centre’s programme.

“I am glad that my parents took me to Gabriella Centre, it gave me a chance to meet other youth, we learned different things there... I have gained enough skills that would help me at home, to understand... I am grateful that I learned how to make bricks and I just want to continue with that” John (YID)

One of the outcomes of participating in the Gabriella Centre programme was that YID developed various skills to participate in occupations. As Mama Neema (Parent) continued to explain.

“ ... Right now, she [Neema] helps me on the farm. We have a better life; I thank God otherwise we would have been living outside under the banana trees”

The types of opportunities offered at the GCRC are described in detail below.

Sub-theme 1.1: Opportunities at Gabriella Centre

Gabriella Centre provides services for children and youth with disabilities which includes YID. The centre aims to equip YID to become active participating members of their communities, mainly through the provision of therapeutic intervention, vocational and life skills training. The Gabriella Centre evaluation report 2014-2018 identifies the scope of the services as.

“The centre has guidelines and specifications on how to offer four major programmes namely, therapy; transitional schooling; vocational and outreach programmes in homes of children and youth with disabilities”.

An induction week occurs at the beginning of the Gabriela programme when YID are first enrolled. The therapist conducted assessments with the YID and created an opportunity for parents/caregivers to plan together with the Gabriella team. This assists with establishing relationships between parents/caregivers and the team and contributes to forming a strong foundation for when programme evaluations are performed. A key consideration during the assessment process at the Gabriella Centre, is the consideration of how feasible and relevant the skills that YID gain while at the Centre are in relation to their home environments. The Centre’s occupational therapist (OT) explained that she aimed to match the YID interests with the potential opportunities in their home environment.

“... We also consider the environment for example if the youth have an interest in animal keeping will the environment at home allow that?”

To further understand what the YID needed in their home environments, the parents/caregivers were invited to stay at Gabriella Centre and participate in an induction week.

“...we introduce them [parents/caregivers] to different activities it helps to know the child better in that special week because we normally have an entire week for assessment and after knowing

the youth it helps us to know what kind of therapy that he/she needs so that to be able to help him/her and afterwards we work on that.” Gabriella’s occupational therapist (OT)

During the induction week, the parents/caregivers participated in the various activities offered as part of the programme. This meant that parents were actively involved in carpentry, tailoring, gardening, animal husbandry, cooking and caring for their environments. One parent described this as follows.

“...We also get time to practice with our children, different things, for example if is to wash we do together, if is garden we do participate in it... we try out different things with our children’ Baba Samweli (parent)

During this week, the programme also offers parents/caregivers a chance to get to know their child.

“...the good thing is they involve us, we work together with the centre so we understand our children well, it takes our time... it is helpful that we know what they will do.” Mama John (parent)

Some parents/caregivers had negative perceptions and expectations about what their children could do. The Gabriella team provided the parents/caregivers with relevant information and education about the nature of intellectual disabilities and the prognosis thereof.

“The process involves working in collaboration with parents/family and starting by changing parent perceptions... when they first come, some do not have the right knowledge about their child’s abilities, they are still of the opinion that my child would not be able to do anything...”

Through the parents’ involvement in the induction weeks, they improved their understanding of their children's current abilities and felt more confident that the YID could benefit from the programme. All the parents reported to leave the induction week feeling that the Gabriella Centre could care for their children. The YID parents also shared that they were very supportive of the programme after the induction week, and this continued as their children completed the programme.

“ ...they give us an opportunity to be at the Centre, ...we get time to meet other parents and see other children like ours...” Mama John (parent)

Another parent explained his experience and his opinion on meeting other parents during the induction week.

“... My advice is they should keep up providing training for youth but also for parents even if our children are no longer there but when we attended those weeks it helped me feel relieved.” Baba Samweli (Parent)

Based on the findings of the assessments conducted during the induction week, the YID are enrolled into vocational training and receive therapeutic services at GCRC. The programme is tailored to respond to each individual YID’s needs and is offered by a team of professionals in collaboration with the family, as reflected in a Gabriella Centre informational brochure.

“...This program, focuses mainly for children and youth with mild disabilities, teaches individuals different vocational, self-care, and life skills, such as gardening, crafts, and sales. The caregiver and child work with a therapist to set a joint goal, and the therapist works with the student for three months, involving the caregiver during the first and last week. The participants board at the centre for those who need it and are cared for by the Gabriella Centre.” GCRC brochure.

Most YID who joined the GCRC programme, have limited self-care skills and thus improving those skills was often a starting point before proceeding to other skills. The occupational therapist explained.

"First they start with self-care that is self-care activities, such as toileting, bathing and all those activities which are meant to build their dignity,"

The therapist continued to explain that once the YID acquired these basic self-maintenance and self-care skills, they were exposed to opportunities to develop their income generation skills and learn to perform tasks and engage in occupations which allow them to assist with tasks at home.

“... and then they learn skills for income generation... specific skills which are aimed at making them productive” Gabriella OT

The opportunity for YID to learn different skills whilst at the Gabriella Centre was also reflected in the GCRC reports.

“They do that through engaging in practical activities such as self-care, recreational activities such as dance, and productivity such as gardening, chicken rearing, goat

keeping, handcraft works, cooking, tailoring, housekeeping and environment maintenance.” GCRC annual report, 2018

One of the youth participants who learnt artwork and taking care of animals described the range of occupations and skills that he learned as the following.

"I learnt beadwork; tie-dye; how to make necklaces; bangles and other cultural art ... yes I learned how to take care of goats and that they should not be dirty, we should wash them regularly. " Samweli (YID).

In addition to income generation skills and learning to contribute to household tasks, part of the training programme also equipped YID with important skills to live in the community. This included learning about self-protection and money management, as one youth narrated.

" I learnt about money ... and how to protect myself from bad people. " Neema (YID).

The therapist elaborated by explaining the rationale behind YID learning the variety of skills.

"...also we try to look at their health issues especially around how do they protect themselves so that they cannot end up in bad groups which are dangerous for them and to protect themselves - either a girl or boy to know how they can protect themselves so that they cannot fall into bad groups and end up being a drug users; a drunkard, or having friends who can put them at risk of getting sexually transmitted diseases, so we emphasise all of that. But also, they do learn about money and money management so at least what they have [that]" Gabriella OT

The parents approved of the different skills that the YID acquired. John’s mother narrated as follows.

"When they come home on holiday you see they say do touch me here don't touch me here... which shows they have learned how to protect themselves".

The Gabriella Centre used different methods to improve the YID social and communication skills. Youth were exposed to role play, fashion shows, dance, and sport activities.

"...Although the centre has limited games for children and youth with disabilities, children get adequate interaction during group sessions which were found to be done in the

afternoon hours... dances, role play and sport days were among activities.” GCRC evaluation report document.

To prepare the home environment to be able to accommodate the shift in the YID capacities, the parents were involved in an evaluation process that occurred at the beginning and end of every term. The Gabriella OT described the purpose of this evaluation as follows.

“...if the parents are still in denial or they have not changed their perception about what their child can do it becomes difficult to integrate youth back into the community... we work together with parents/caregivers to be able to realize YID abilities and changes... so if the parents are prepared from the beginning, it becomes easier for YID to start community life.”

Another strategy that the programme used was to ensure that the YID experienced community life whilst they were enrolled as learners at the centre. This was achieved through allowing the youth time off. The YID have a one-month holiday break every three months that they participate in the GCRC programme. This provided the YID with opportunities to practice and test what they had learnt.

“...it does not happen suddenly we get prepared... While she was still on training every time they came home for holiday they were given a home package, to try at home. Sometimes they came with wheat flour and oil, sometimes seedlings to plant... so by the time they finish, we already know what is possible for her to do at home.” Mama John (parent)

The opportunity to access services offered at GCRC and develop their skills had brought changes in the lives of YID. These changes are explained in the next sub-theme namely, *“changes and development”*.

Sub-theme 1.2: Changes and development

This sub-theme describes the changes that occurred in and for YID after participating in the programme offered at the Gabriella Centre. These changes included physical and psychosocial changes to the individual YID. Their parents/caregivers expressed relief about how these changes influenced the YID participation and engagement in their homes and communities. This mattered

since their prior inclusion in activities in their families and communities was severely limited by their personal capacities to contribute.

Many of the participants had motor coordination difficulties which affected their participation in their homes and communities. Samweli's father explained the challenges that Samweli faced.

"They could not do any work since they could not even walk. Their gait was very weak. If they take two or three steps they fall ... I was very happy they got this chance. They were at home and unable to walk. They were falling a lot." Baba Samweli (parent)

Similarly, Mama Neema explained how her child's inability to pay attention affected her ability to complete and even participate in activities,

"... you can ask there [at the centre] how she used to be, she was always so fast and at speed, even people used to call her Ma-speed." Mama Neema (parent)

The therapist at Gabriella Centre described that some youth demonstrated aggressive behaviors when they first came to the centre and these concerned and confused most parents.

"...but also, they had different behavior to try to show that they can, so others were seen to be misbehaving badly, they demonstrated extremely aggressive behaviors fighting others, fighting their parents, but also some ended up doing different things of which are not okay just to get attention just to show they can do something." Gabriella OT

Historically, the YID's behavioral challenges affected the families to the extent that they sometimes gave up or lost hope of the possibility for any change, as Mama John explains.

"due to his condition, he could not attend to any activities, he could not even follow-up with school" Mama John (parent)

Mama John also explained how her son's actions before joining Gabriella Centre put him at risk.

"The challenge was he was not aware of many things, he was not settled; he could not remain still; he used to wander around, he was living in the streets and even slept there, or some other time he would come back at mid-night and when you would call him, he would not respond. He was not cooperating at all, he would not even listen to peers or other people. He was a person who was living and wandering into people's places."

The parents/caregivers described how their communities tended to judge them as having poor parenting skills and that they could not take care of their own children. They felt stigmatized and alone as they had no support.

“ -since I have more than one child with challenges, including a grandchild, my entire family left me alone. The blame fell on me as the mother and grandmother... being a widow, I felt alone.” Mama John (parent)

When the youth returned to their homes, their parents/caregivers noticed visible changes in the youths’ abilities and capacities to engage in activities. Baba Samweli described his satisfaction with the changes that he saw in his child.

“When they joined Gabriella, they stayed there and they were taught different things. They were given different exercises on how to walk - to be honest I was very happy to see they have grown.” Baba Samweli (parent)

Reflecting on her child, Mama John described how such changes resulted in the youth being able to assist with chores in their homes.

“...now you can tell him to assist on household activities such as chop the firewood, he does that now. If you send him to a place to pick things, he goes [there] and comes back and brings whatever you have asked of him; he now has become a responsible child. He has changed and he can respond,” Mama John (parent)

Anna, who was unable to physically engage activities due to her poor motor coordination challenges, was able to show the researcher how she could more easily engage in her daily routine. She explained that.

“I start working in the garden at around 8am in the morning, I water the garden, I weed the garden and if it is the day of planting, I plant new vegetables.” Anna (YID)

As YID developed their abilities, they became more able to participate in their families and communities. John described feeling proud of his accomplishments when he learnt how to make bricks.

"I am grateful that I learned how to make bricks. I want to continue doing it." John (YID)

Samweli (YID) also noticed the change in himself.

“... I didn’t know how to keep goats – now I can. I can wash myself; milk my goats; my goats give me two cups of milk for our family tea in the morning...”

Baba Samweli described this change.

“... but now I send them even to the milling machine, they do go everywhere I send them on their own, they even know the route clearly,” Baba Samweli (parent)

These changes contributed to his children being accepted for Holy Communion in their church.

” I appreciate the support from the Church, and I am happy that both of my children, in spite of having disabilities...” and he continued by explaining, *“...But with the help of GOD, they received their training [verbal] and got communion.”* Baba Samweli (parent)

The centre’s therapist explained how YID became seen for what they could do and were identified based on the occupations they participated in.

“Yes, it has brought a lot of meaning especially for the families which had gone through the entire process from the beginning to the end. They became prepared that their child had finished and were ready to go back to their community or home and he or she will be productive so it has brought so much meaning, that the family become happy that their child- some confess that they did not believe that their child could do anything but now can do and it is helpful to the entire family ...those who have accepted they are proud that their children have learned a lot of things and are people who are more independent, they have formed their individual identities; they are called a farmer; tailor; carpenter.” Gabriella OT

The YID’s parents also described how the skills that they learnt contributed to changes in the YID and how it created some ease for them. The YID’s parents were relieved that the YID no longer needed their constant support and could perform some activities on their own. Samweli’s father identified the difference that he noticed in how Samweli used his skills.

“...they are now able to use tools in the garden and know the difference between vegetables and weeds, not as it was in the past.” Baba Samweli (parent)

The outcome of participating in the multiple opportunities available at the Gabriella Centre and the changes seen in individual YID resulted in an increased awareness of what YID can do when given opportunities. The changes that occurred allowed them to start a community life where they

were integrated. The YID inability to do things before the opportunities at the centre isolated them from being connected to community activities. The following theme describes in detail how YID connected to the community, earning their trust.

4.3. Theme 2: Connecting and earning community trust through valued occupations and routines.

This theme begins with describing how YID were able to participate in community life after completing the GCRC programme. Their social environments, including family support, the friendships formed, the sense of community acceptance and sensitivity towards the YID's needs was an important part of support or barrier to participation. The YID's participation became valued as contributors to the practical routines of their families and communities. YID tended to start their days with occupations such as self-care and household chores before they started their income generating activities, such as gardening and animal husbandry. Samweli (YID) explained how he started his day.

“...When I wake up in the morning, I sweep outside; I feed my animals, and then I take my goats to graze. If the goat house is dirty, I first clean it... I like keeping goats, it helps me ... I have also gained money after selling some. So far, I have sold one.”

The development that YID experienced, [as described in Theme 1] contributed to YID becoming active and engaged in valued routines in the family. Mama Neema (parent) described the routine her daughter engaged in.

“She knows how to cook food for all. When I go out I leave her here at home and find that she has fed the cows. At the same time, she has put the beans on the stove to cook, she understands that she can put the pot of food onto the cooker¹[injika] and at that time go and feed the cows. She knows how to clean the cow shed. I leave her to tend to the chickens, where she will further feed the chickens. This child has really changed, to be very honest.”

YID demonstrated their contributions both within the family and to their communities, this allowed them to gain others' trust and lead to YID becoming recognized for what they can do.

¹ putting pot with food on top of the three stone open cooker

“... when there is a social event, [in the neighborhood] I send him to assist on my behalf as he can now do things... people now trust him, he is hardworking... you know if you don't participate in such community activities, they won't come to your event when it comes to you... but I am relieved he helps me with that.” Mama John (parent)

The YID routine participation in occupations created opportunities for them to interact with the community. The way that they interacted through what they do included when they take their animals for grazing; selling their products or assisting in the community work. Baba Samweli (parent) described how engaging in occupations specifically connected them with other youth.

“When he takes goats out for grazing, he joins other youth and they graze together and go to collect firewood - he goes with other youth, all of them - also his sister does the same.”

The above quotes highlight that the routines that YID engaged in as part of community life after being discharged from the GCRC programme allowed them to connect with their communities. These routines tended to be generally valued by all youth participants, their families and the communities. This is described in detail in Sub-theme 2.1 namely *“valued routine occupational at home and in the community”*.

Sub-theme 2.1: Valued occupational routine at home and in the community

This sub-theme identifies how the YID's acquired practical skills lead to their increased participation. YID began engaging in different valued occupations including household chores, selfcare, income generation and other community work. All YID and parents who participated in this study felt that, in contrast to before their participation in the GCRC programme, the YID could contribute to routines of everyday doing in their homes. Neema (YID) described her current daily routine,

“After I drink tea, I clean the cattle shed, I go look for food for the cattle, I cook dinner for the family, so that even when mum comes back from work, she finds food to eat... Then I go get food for the goats, then clean the goat house.”

Neema highlighted that she also ran her business, that is, making and selling small bites to eat. She distributed her products to shops for sale.

“... From there I feed the goats... afterwards I finish cooking ground nuts; doughnuts; I take them to the shop, then I take them to the shopkeeper and sell them” Neema (YID)

All the YID’s self-care and performance of household activities became an integral aspect of their daily routine. These activities were reflected as necessary and meaningful within their routines. Anna explained what she does after getting out of bed in the morning.

“When I wake up in the morning, I first brush my teeth; then I mop; then I make my bed; I wash utensils; I drink tea; I wash my clothes; I apply body lotion and I get dressed; I (then) cook dinner.” Anna (YID)

Parents/caregivers were relieved that they could focus on their own work since YID could now take care of themselves with increased independence and assist within their homes,

“I am very happy and relieved now... my children because of their disabilities, they used to stay indoors most of the time... they plant their own vegetables; they wash dishes; sweep; mop; eeh they do different types of work...” Baba Samweli (parent)

The benefit of being able to do things on their own and participating in a variety of occupations outside of their homes allowed YID the freedom to interact with other youth [sub-theme 1.2], hence YID were valued for what they do.

“I should say it has a lot of meaning to him, just going to graze his own cattle and play with other youth is one of the benefits, so he mixes himself with others, it is important.” Baba Samweli (parent)

Engaging in community work added further value since YID could earn an income. Mama John explained how her son was given an opportunity.

“These days, they take him into the cooking groups [catering team] and he takes someone else’s position [as relief work or when the team needs extra hands] and he works with them, and he does a good job. They praise him; they pay him.” Mama John (parent)

It also opened up business opportunities to sell what they produce as Anna narrates. She explains how she sells vegetables near her neighborhood, going house-to-house or to the marketplace, selling her vegetables.

"I sell them in the street, down there, up there [pointing] at people's houses, I don't have a specific place, but when they are ready, I take them and sell them." Anna (YID)

Neema also described that she took her products to the marketplace and was able to trade on her own.

"I take maize down to the market to sell them and then I buy things for my business. I am able to buy things on my own." Neema (YID)

Engaging in their business activities thus provided YID with the opportunity to meet and interact with people in their communities whilst carrying out everyday activities. The researcher observed Anna's interactions with her customers, both at home and in the marketplace, noticing how she was able to negotiate and bargain sale prices and deals in a friendly and confident manner.

"Although she hesitated [Anna] was shy but she could initiate conversation and [was] able to market and negotiate the prices of her products, she then said she was very happy that she could do that like other girls do" Researcher's field notes.

Being able to go to the marketplace, buying and selling things was important for YID as this was what most of their peers did or what young people strived to do. Their confident and successful connections with people contributed to YID's businesses becoming a resource in their communities. For Anna, it meant that some of her neighbours started to buy her vegetables directly from her at home. Neema's mother explained the shift that she witnessed between the first time that she escorted Neema to the shops to supply bites in comparison to how Neema could now go on her own and interact with her customers with more confidence.

"...although she still has challenges with counting money and understanding the value of money, now she can take her [²mandazi] to the shop alone and take new orders... she is now able to talk to them and sell the bites to school children who pass by here ... they even assist her in how to return the change when I'm not around." Mama Neema (parent)

Being able to produce and sell products resulted in YID feeling proud of themselves. For Anna, it was not only that she had successfully established her business on the streets, but she also secured a tender to supply vegetables to the GCRC. This was a significant achievement for her.

² *maandazi* is a local doughnut

"I do sell them at Gabriella and also I do sell them down there [pointing to the streets]."
Anna (YID)

Although the YID felt successful overall, they still had to navigate some challenges, such as the availability of ingredients to cook their products. Neema described how the rising costs of ingredients limited her from producing her products at times.

"Popcorn maize are inside [the house], I don't know when I will make them ...now I don't have cooking oil... because of money - there is no money to buy cooking oil, the price has increased too high" Neema (YID)

Another challenge that they faced was the competitiveness of the market, with many people who had similar businesses increasingly coming into spaces where Neema, for example, started selling her products. To work around this challenge, Mama Neema (parent) explained how she supported her daughter by trying hard to create a market for her products.

"When we started the groundnut business no one else was doing that but the neighbours - after seeing it was possible- they also started cooking and supplying at the shops - especially in areas where we had created a market. We tried hard till we got a market in the secondary school we now supply. But these people always wait till we have created a market then they go and take it up." Mama Neema (parent)

Similarly, John experienced selecting a viable place to conduct business, as a challenge. John described the limitation of his location and his difficulty with accessing a market.

"Here at home, I am doing it, I am making bricks but people do not buy it a lot. So I have not counted myself as successful in this business but also my skill's need to be improved. So my mother has not identified another suitable place for me to continue with this work."
John (YID)

The YID doing goat keeping, those growing vegetables, gardening and those making bricks faced similar challenges with establishing, sustaining, and reaching their desired business goals. Baba Samweli explained the challenges that his son faced when goat keeping.

"There has not been a major challenge except once when there was an outbreak of goat disease, he lost one goat and we were lucky that all the goats had the required vaccine. We

would have lost all of them, but I am glad the veterinarian advised us well." Baba Samweli (parent)

Anna described how her neighbours' actions affected her business. Her neighbours were not responsible enough for their animals (goats) and let them out with poor supervision. The goats then destroyed Anna's vegetable garden when they roamed about, and this caused her a financial loss.

"I get a loss when goats from neighbours eat my vegetables, sometimes I get discouraged because of the loss." Anna (YID)

Although YID learnt about money and money management during their time in the GCRC programme, they still needed assistance. YID relied on their parents to help them.

"My mother assists me to keep money. when I have money, I give it to my mother to keep for me" Samweli (YID) narrates.

"... yes, after cooking the nuts you have to pack them in small packets and get an amount enough to take to the shops, then you distribute the nuts to this shop then this shop, I leave them there and Mum goes to follow up on the money." Neema (YID)

The YID participated in routines that were expected of youth in the communities. They faced challenges related to conducting income generating activities, but this was related to market competitiveness, rather than because of their disabilities. Through their contributions, YID became more entrusted in their communities, as elaborated upon in sub-theme 2.2.

Sub-theme 2.2: Trusted, given responsibility and making choices

With time and participation in the GCRC programme, YID were able to take more responsibility for their participation. This helped them to earn the trust of others. Youth demonstrated that they were able to do things that they could not do before or that they were not expected to do before. The skills gained and changes in their capacities shifted how their families and communities at large viewed and trusted them. This enabled the YID to be trusted, given responsibility and able to make their own choices.

“actually these changes have brought a lot of respect to my family as compared to how it was before. They do not tease my children and family anymore; they see not I have support and not burden” Baba Samweli (parent).

YID explained how they not only provided relief to their families but assumed increased responsibilities. Neema described how she prepared food for the family, allowing her mother to go out to work and took care of her children by herself during the day.

“... so that even when Mum comes back from work, [she] finds food to eat... For instance, this one [pointing to her daughter] here has started going to kindergarten now; after school she comes home; she finds me here already; food prepared for her, then she sits, eats and writes - she can now write.” Neema (YID)

YID viewed the changes in their contributions as an achievement. Samweli (YID) narrated how keeping goats brought him respect in the community since he knew how to properly take care of his goats.

“I feel happy to have goats, I feel proud to have many goats ...” and *“Neighbours say I am doing well. I do take good care of my goats since they never eat their [neighbours'] vegetables, or maize or other things; they say I should raise more goats”* Samweli (YID).

Samweli (YID) ensured that his goats didn't destroy his neighbour's crops, and this led to community members encouraging him to expand his business.

The trust in the YID was evident at a family level where they became entrusted with more responsibilities. Neema's mother acknowledged this.

“So in general even when I leave her alone at home, I know I have left someone grownup... I wonder how I would manage to leave them alone if she would be as she was before. I really do not know what I would have done” Mama Neema (parent).

Apart from their involvement in their households, the YID used their income to benefit and support their families' living expenses, such as groceries for the family, paying school fees, as well as providing for their own needs.

“I use my money to buy things for my business in town and shoes for my child and smart clothes for me to go out. I also buy rice, salt, sugar and cooking oil for us to have food.” Neema (YID).

Anna (YID) described how her personal needs for hygiene products were considered such that she could use her income towards this.

"...when I sell vegetables some of money, I use for to buy body lotion and also when I visit my grandmother I braid my hair and I pay the person who does that, some money." Anna (YID)

Samweli (YID) also narrated how he used his income resulting from the occupation he engaged in to buy his personal belongings.

"I have also gained some money after selling some of my goats. I bought a bed with a mattress, a ³subwoofer, clothes for outings and going to church." Samweli (YID).

YID valued being seen as grown up. This afforded them opportunities to be involved in decisions and choices on matters that affected them, including what they can and want to do. When they engaged in the business or worked, the family did not just decide for them. The YID expressed that their needs were considered and given priority. All YID made financial decisions in consultation with their families. Samweli's father explained this.

"We normally discuss with him and his mum and I, and we decide together when he indicates that he wants something. If it is a radio; bed - then we decide together that we can sell a goat and we discuss the amount." Baba Samweli (parent)

Mama John elaborated on the choices that her son had to make with regards to how he used his income and how she guided him to plan for his life and how to spend more on his own needs.

"Now if someone calls him for work, let him go to work. He comes back home with money and shows me how much he has earned, and I tell him that if you get money you should cater for your own needs with this money because I have told him that he should keep his own money. He should not buy anything here for us anymore. Now look - take care of your own life. You are a youth now. I will try so that he can get money if he wants to buy his own things, he can do so, so that he should not spend money to buy us things now he should focus on his life." Mama John (parent)

³ subwoofer is a a music system preferred by many youth

This acknowledgement of YID as adults opened possibilities for them to be seen as adults who can contribute to their communities too.

“So now he understands he is no longer a child, he no longer needs to depend on Mum, he can live his own independent life eeh... someone to become part of the community to be someone who is confident in himself.” Mama John (parent)

John worked as an assistant masonry worker and earned the title of “⁴*fundi*” or assistant *fundi*.

“I have worked as a fundi assistant in this place called Mdoe ... We were building, we worked there, and I was paid after work, they do trust me, they allow me to do minor work. Every time they get new work, they always ask me if I would like to join, they like me.”
John (YID)

The contribution of the YID in performing household chores and generating income became seen as strong points in the family. Their families acknowledged that the youth’s improved abilities meant that they could be trusted to improve the quality of life of the family through other activities commencing in their day to day work. Neema’s mother described how Neema’s help benefited the family.

“... example right now she helps me in the farm, we have a better life [now] otherwise we would have been living outside under the banana tree” Mama Neema (parent)

Neema’s mother could rely on her because she was physically more mature and had acquired skills that enabled her to assist on the farm and thus contribute to the family’s income.

Although the YID became more trusted, their families continued to support them. Mama John narrated her experience with John who showed change in how he contributed within the household in a more acceptable manner.

“... now he can be trust, I can assign him to do something he can do it, he required few reminder ” Mama John (parent)

However, gaining trust in what they could do, based on their changed participation and the opportunities at the GCRC programme, together with the changes in their physical, cognitive and psychosocial abilities, brought hope. Mama John explained how she continued guiding her son.

⁴ *fundi* meaning builder or assistant builder

“...but as a parent I will try my best that he gets his food, I told him if he decides to buy us things, it is his choice because he used to spend and spend, there was a time he used to drink alcohol but now I am grateful he has stopped, that is all. I told him, ‘You know you are a youth, do not misuse your money, use it wisely’.” Mama John (parent)

The final sub-theme explains how the community accepted and supported the YID, showing how the YID also created connections with the community through what they could do.

Sub-theme 2.3: Community acceptance and support

This sub-theme reflects the present community perception and attitude towards persons with disabilities, as shared by participants, and the changes occurring as a result of YID’s ability to engage and participate in community life after engaging in the GCRC programme.

YID’s sense of connection with their communities was challenging because of pre-existing negative perceptions and a lack of awareness. The therapist at GCRC expressed that some parents were unsure and worried about the environment not being safe for their children upon discharge.

“...but still there are some parents who have not changed their attitude or are not ready to accept that now my child can now come back home and be self-sustainable and independent... what they wish is for their child to keep staying at the centre, because they feel it is a safe place, ...they are scared or fearful of the surrounding environment that when YID go back home, they may fall back into bad habits or join bad groups.” Gabriella OT

These worries were brought about by the experiences and challenges the families had faced whilst raising a child with disabilities, as well as the degree of support they needed to facilitate community participation for the YID.

“I used to suffer a lot especially when you send him somewhere or when he goes to the neighbours, the neighbours used to tell me. Don’t you give your child food? Why do you let him come to our house and finish our food?” Mama John (parent)

The community’s negative attitudes brought about a feeling of giving up and hopelessness in their parents and families as is seen in the experience shared by Mama Neema. She described how it was difficult to leave her daughter at home alone since Neema could not manage to do things on

her own, needing constant supervision. Moreover, she was worried for her safety and that she could be harmed by some people in the community. This limited how Mama Neema engaged in her work before.

"... before they went to Gabriella I couldn't go far from home. I had to stay near the children, as they were two of them, Ema [her son] and this one. It was really tough since I had to stay home with them all the time. If I go out to do any petty job, I would do that for a short time and come back. I had to cook for them, I would cook porridge and sit there till they had eaten it then I continued with other chores" Mama Neema (parent).

Another parent also shared,

" ...I feared that he may join a bad group or maybe conduct himself in a way that would endanger him, which caused me to wonder where he might be all the time" Mama John (parent).

The way YID behaved and responded also affected the way that YID and their families used to relate to one another, putting strain on their relationships. Mama John elaborated about how she had given up hope.

"... I was so scared even to talk to him by that time, I could not dare to talk to him. First if you talk to him it was like you are wasting your time."

As parents/caregivers went through different challenges in raising a child they would expect to have support from other community members, however due to the way YID behaved the communities did not offer support. Mama John narrated the way she expected neighbors to assist but it was the opposite.

"... he really gave me a lot of challenges, I thought I could not manage, when you tell the neighbor when they see him wondering they should try to bring him back, they said they won't do that at all, I had to keep praying, he also used to lose things a lot if you by him a slippers with no time he loses them, the same with clothes he loses them in the neighbors' houses and God answered me when I got the chance to take him to Gabriella. He went there and he started becoming calmer." Mama John (parent)

The community's attitude towards YID had an influence on their community participation. What the YID did or the way they behaved, influenced their acceptance and support. Mama John shared how her son's cognitive and behavioral challenges were a big problem.

“they used to tell me I don’t know how to take care of my children and say it is all my fault that is why my child is behaving that way.” Mama John (parent)

YID also faced discrimination when participating in their communities. John (YID) shared his experience from his place of work where, due to his condition and literacy level coworkers would tease him, which lowered his self-esteem.

“Sometimes it happens not every day... For example, because I don't know how to read and write they tease me that I am at kindergarten. So when they ask me I have to tell them that I do work... You may greet someone, and they don't respond, I end up being quiet and I continue with work.” John (YID).

Anna, who had a vegetable garden, described not being supported when her neighbor’s goats destroyed her vegetables. She reported it to the neighbour and no one seemed to care or assist to stop this from recurring.

“... but sometimes goats from the neighbour come and eat my vegetables, the goats from the neighbour sometimes destroy my vegetable garden ... I tell them but sometimes they refuse... we told them to pay, but they did not pay.” Anna (YID)

John described how, while working in catering services, he had to follow-up repeatedly as the company would sometimes take advantage of his disability and try not to pay him appropriately.

“Yes, but if you work for more than one day... without being paid you find that you yourself forget to ask. So they do not pay, you find that they don't give you your money so it is necessary that you take your money right away after work, otherwise they say they have forgotten, and I forget also. That- so again I end up using extra effort to make sure they pay me” John (YID).

Another parent shared his experience of how the community has shifted their perceptions; beginning to interact with YID after his son gained desirable skills. In this way they viewed him differently since his abilities changed.

“Because now they have the ability to do their own work without necessarily needing help - not as it was in the past. For now, if you tell them to do certain work, they do it. If you give them instructions, they do follow through. Take your goats to graze them, they do go. I think this has made our neighbours see the changes and that makes them see [them] differently... their perception has changed, they now talk to them because they know they understand,” Baba Samweli (parent)

Through engaging in valued occupations and routines [sub-theme 2.1], their connection to community members could be seen. Baba Samweli narrated how his son was included in activities and interactions with other youth in the community because they allowed their goats to graze together and engage in other chores and work tasks alongside one another.

" He has now has manage to have friends and he is more confidence as he interact with other during goat grazing and when they work together” Baba Samweli (parent)

These opportunities to participate raised the communities’ awareness and allowed the YID to become more of a part of community activities and become accepted for what they can do.

“She is now accepted, and she mingles in the society well, she even lends a helping hand to the neighbours, for example a neighbor may call her and ask her to go to the shop and buy a packet of salt, she will go. Or maybe assist a neighbour in their day to day y chores, she has become quite handy” Mama Neema (parent)

Institutions in the community such as churches were also reported to have played a role in promoting the YID acceptance in their communities. Participating in social activities such as religious events was valued by Christian believers. For example, Holy Communion was seen as an important step in life. The acceptance and opportunity for YID to participate in Holy Communion was seen as a vital connection within the community, as Baba Samweli explained.

"... and they [Samweli and Anna] cannot read and write- they both got first and second Holy Communion as any other youth in the society that really made me happy. But also, other people in the community, it was not something they were expecting, they thought it is not possible these children could get such a step in life. After seeing it, it really surprised them.” Baba Samweli (parent).

Attending parties and other community events was another way of connecting to the community. This was done with the permission of their families.

“Yes, I do go to different places. I attended parties in the neighborhood for example when one of the neighbour's children got confirmed [in the Church] they hosted a party and we did go to it like others, but we must ask for permission first.” Samweli (YID)

Community support was seen as an important aspect after integration to ensure participation is sustainable. As Gabriella's therapist explains,

“Once they graduate we do not just send them away, we do have a follow up programme, at the beginning when they just graduate we visit them frequently and then slowly reduce number of visits” Gabriella OT

The therapist further described how the GCRC programme supported the integration process,

“...after that we do follow up in order to be sure that the youth is progressing well and if there is a challenge, we work with family to solve the challenges... After integration we also have follow up in the community through community members.” Gabriella OT

Community leaders and other stakeholders in the community were key to integration and ensuring sustained participation within the community.

“And after involving the community leader, the youth start his/her project when parents are ready and village authority stand as witness.” Gabriella OT.

The Gabriella Centre continued to support the YID even after discharge from the GCRC programme. By doing so, the centre contributed to the successful integration into community life. Baba Samweli described how his son has matured and he is at the stage of developing more intimate relationships within the community.

“...I think he should be given a seminar about the life challenges to see the future; to see other things in life... like you know when youth grow up, they have certain drives in them. They start pursuing girls, as do other youth. Sometimes girls come here, and he talks to them, they chat about their things and they go, you see you cannot stop that, he is a youth, but that is why I said more seminars on how to go about it will help.” Baba Samweli (parent)

The therapist explained that they give YID an opportunity to visit the center twice a year to attend special youth camps where they have the chance to share their experiences *and* discuss the various issues that they faced within their communities.

“They do come back to the centre to attend a special youth week to remind them on issues related to youth and also it becomes easy to discuss because they have lived and experienced the reality in the community as youth... they also get time to share their experience with us and with others as well, they are also reminded of health and safety issues ... it becomes an inspiration for others” Gabriella OT.

The Gabriella Center maintained further forms of contact with the youth while they carried on with community life. This was done by making home visits to them at various stages.

The ability to meet additional demands, such as meeting health needs, having their own place to reside, and starting a family, was noted by parents of YID as a crucial requirement for future youth participation in the community. Baba Samweli expressed his worry about his child now that he was an adult.

“... you see this one [Samweli] has grown up... although he has started buying his own things like bed, clothes, radio like the peers, he will soon need to have his own life, I wish for him to have like a room of his own ... to have a house.” Baba Samweli (parent)

The routine the youth engaged in reflected their lives in their communities and how that enabled them to earn trust from the community and subsequent acceptance. However, they had to navigate the stigma and lack of community awareness initially. As the YID matured, their abilities to meet their adult social and relationship needs, and their health needs was seen as a challenge towards participation.

CHAPTER 5: DISCUSSION

5.1. Introduction

This chapter begins with discussing the benefits that YID and their families yielded through accessing opportunities at the Gabriella Children's Rehabilitation Centre (GCRC). YID had the chance to exercise their rights, make choices, and be part of their family routines while becoming recognized for their abilities and contributions in their respective families and communities. The meaningfulness and significance of the approach at GCRC for facilitating YID participation in their respective communities is also explained. This leads to a discussion about the influence of their supportive environments which included relations of family support, shifts in cultural beliefs and attitudes and services, systems, and policies.

5.2. Making and benefiting from a valued contribution

Through their participation at the Gabriella Centre, YID acquired skills that allowed them to contribute to activities within their homes and communities [theme 1]. By contributing within their homes and then visibly in the community, YID shifted from having to be looked after to assisting within their homes and communities. Rwegoshora, *et al.*, (2022) identified that most YID in Tanzania had minimal to no participation in family activities and chores. They are known to experience stigma, marginalization, and substantial socioeconomic and cultural disadvantages in comparison to those without disabilities (United Nations for Youth, 2012; Ministry of Labour, Youth Development and Sports, 2004; United Nations, 2006). The findings of the current study showed that YID could acquire skills through accessing opportunities that were well matched to possibilities for contributing within their families and to their communities. The opportunities for learning and developing skills that the YID were exposed to aligned well with the opportunities for participation in their home environments. When YID had the opportunities to take part in important family routines and occupations, their sense of identities were transformed, notably their sense of worth and trust in themselves. YID became competent and able to engage in household chores incrementally. This allowed other family members to work, which benefited the entire family. This resonates with studies that demonstrated that when YID participate in household activities, they develop a sense of belonging and are more valued as family members (Rwegoshora, *et al.*, 2022).

The opportunity for learning and developing skills also improved their possibilities to generate an income. YID participated in animal husbandry gardening, cooking, and brickmaking as part of the Gabriella program and later did this as a means of generating an income for their families. YID became breadwinners within their families and could afford to take care of their families by buying clothes and paying for important family needs. This contributed to alleviating the burdens of poverty in the family. When contributing financially, it is acknowledged that YID become able to contribute to the growth of their families and their communities (Rwegoshora, *et al.*, 2022). It also brings about occupational justice as it allows access to opportunities to actively engage and participate in meaningful occupations thus removing attitudinal, cultural and systemic barriers that contribute to occupational injustice, (Hocking, 2017).

Structured programs were required to teach youth with intellectual disabilities a range of necessary skills and to provide them with experiences of participating in a range of occupations. Being able to access different learning opportunities and skills fulfilled the YID's fundamental right to engage in meaningful occupations, as stipulated in United Nations, (2006) and Tanzania Disability Act 9 (2010). This was especially important to address their needs. Subtheme 1.1. described how YID had an opportunity to participate in specifically crafted programmes that included family members in the induction weeks. Involving parents/caregivers at this early stage, helped them to understand their children, gaining insights into their assets and needs and provided guidance towards their occupational choices. This is also reflected in the person-centered approach where people who receive services work in collaboration with the provider and have the power to make decisions with individuals and their families (Brown, 2013; Kaehne & Bayer, 2014; Ratti, Hassiotis, Crabtree, Deb, Gallagher, & Unwin, 2016). This person-centred approach assisted the YID and their parents to understand and negotiate their options, make well-informed choices and become ready for life beyond GCRC. Actively involving the family members also assisted the family to recognize the abilities of YID, to acknowledge and pay attention to their desires and to gain different insights into their support requirements. Providing YID with opportunities that match their abilities and needs leads to families being more responsive and improves the lives of everyone involved (Rwegoshora, *et al.*, 2022; Willis, *et al.*, 2017). These shifts contributed to transforming how the community perceived YID. Understanding the clients' priorities, points of views and what drives them to participate in occupations, is crucial to the success of interventions with YID (Mccausland, *et al.*, 2021). The collaborative approach used at the Gabriella Centre ensured that

YID were consulted and worked with the team as equal partners, who were respected as such. The YID gained insight into their occupations aimed at enabling their participation in community life. This approach that GCRC adopts, reflects the concept of person-centered practice (Brown, 2013) which recognizes a person's agency and ability to make decisions in matters that affect them. It also supports a view that community integration should address the needs of the families of individuals with intellectual disabilities (Machalicet, Lang, & Roulston, 2015).

5.3. Contributing to meaningful participation in the community

In this study, YID learnt a variety of skills to prepare them to participate meaningfully in their communities. Alodat, Alodat & Alodat, (2020) and Stone-Macdonald, (2012) pointed out that skills transfer is most successful when the functional skills that YID learn matches what people will do once they exit the service. The WHO (2011) Community-Based Rehabilitation (CBR) guidelines suggest that youth should have a range of opportunities for training to acquire marketable skills and decent work, either through employment or becoming self-employed. The skills include foundational skills such as self-care, technical/vocational skills and core life and social skills. These skills are described in sub-theme 1.2, in which YID learnt through the guidance provided by the YIDs' parents/caregiver and a specifically designed GCRC program, which reflected these areas of skill development. For YID, acquiring functional skills such as money management, and social skills, helped them to interact with community members. Their abilities to earn and manage money provided them with business opportunities since they were able to manage and interact with their customers. This is important for YID in Tanzania who have limited employment opportunities in the formal sector (National Bureau of Statistics [NBS], 2016). The learning and skills not only provided them with the opportunity to participate in community life but enabled them to make an income. The change and development [subtheme 1.2] connected them to their communities and disrupted the existing negative beliefs about persons with a disability known to exist in Tanzania (Anaby, *et al.*, 2013). Subtheme 2.1 described how acquiring and developing their skills enabled shifts in the community's attitudes towards YID. This occurred in the absence of a functional curriculum for YID as part of a national strategy.

The provision in Tanzania's Vocational and Education Training Act of 1994 (no.1) proposes a need to have a flexible training system that enables individuals with disabilities to adapt to the

demands of the environment including the labor market. However, the existing Technical and Vocational Education and Training (TVET) curriculum does not consider the needs of persons with intellectual disabilities. This exclusion does not reflect the goal of Tanzania's Vision, 2025, which strives to enhance human welfare and quality of life through inclusive growth in the economy that benefits, among others, youth and underprivileged groups, (UNICEF, 2021). Designing and adapting a curriculum that is client-centered, where learning reflects the needs of a person with an intellectual disability could alleviate poverty, change the community and promote inclusion in Tanzania and other developing countries (Andrew, Falkmer & Girdler, 2015; Stone-Macdonald, 2012). The importance of their contribution to the community reflected that for YID to participate socially and economically outside of their home environments, they needed to learn different skills (Stone-Macdonald, 2012).

Hammel, (2016) advocated that since engagement in occupations is a human right that is integral to wellbeing, acquiring the necessary skills to engage in occupations is a fundamental necessity. The skills learnt through the GCRC programme, reflected the culture and context of what most people in Tanzania do. Stone-Macdonald (2012) pointed out that programmes are strengthened when trainers such as teachers, therapists in Tanzania use their experience and knowledge of local and cultural practices to inform their work with persons with disabilities. For YID , promoting engagement and equity in occupation contribute in the achievement of occupational justice (Townsend & Wilcock, 2004). This includes ensuring that their rights are protected by acknowledging and addressing the capacities, opportunities, and agency that allow individuals, communities, and populations to engage in society (Hammell, 2017).

The findings revealed two gaps within the current Gabriella Centre programme. Firstly, highlighting that YID did not participate in recreational activities. There is substantial evidence that all young people, including those with intellectual disabilities, need to participate in leisure and recreational activities (Anaby, *et al.*, 2013). Participation in physical activity, such as adaptive or therapeutic sports and leisure, by individuals who have disabilities fosters inclusion reduces deconditioning, improves physical functioning, boosts mental and academic performance and increases general well-being, (Carbone, *et al.*, 2021). It appears that leisure time or recreational pursuits were less valued compared to pursuits associated with household and family routines. Auger, (2020) argued that communities must recognize how crucial it is to spend regular time outdoors, specifically for youth with an intellectual disability. Secondly, the study findings pointed

out that YID were only taught how to protect themselves from sexual exploitation and were not provided with comprehensive information about safe sexual activity and sexual reproductive health education. Colarossi, *et al.*, (2023), in a study on sexual and reproductive health education for youth with intellectual disabilities, pointed out that developmental age-appropriate sex education is recognized as a self-defense tool that can reinforce the rights of YID to make informed choices during community participation. However, this study highlighted that discussions on how to engage and navigate intimate relationships did not feature in the Gabriella Centre programme and the need to have it as part of the programme was indicated, especially as YID transitioned into adulthood. This omission is a concern since community participation can not be discussed without considering the sexual needs of persons with intellectual disabilities. Michielse and Brockschmidt (2021) emphasised that trainers and parents are often not comfortable with talking about YID engaging in intimate relationships and discussions regarding sexual experiences are seen as part of taboo with regards to cultural and religious values present in the communities and broader society.

5.4. A supportive environment enhances participation

Attaining community participation can be a challenge for YID (Perez & Crowe, 2021) due to a combination of the nature of their disabilities, and the extent of support available to them within the family and community. In this study, YID needed different kinds of support to participate in community life. This included family, community, and institutional support. These different types of support are recognized to be critical to supporting YID participation (Mbwilo, Smide & Aarts, 2010; Ministry of Labour, Youth Development and Sports, 2004; United Nations, 2006). Parents and caregivers in this study played a crucial role in ensuring their children could access services and learn skills. This is in line with the study by Anaby, *et al.* (2013) describing how parental support has a positive influence on a child's community participation. Parents' resilience is key to the journey of raising a child with an intellectual disability when there is discrimination and a lack of community support. Thus, it can be argued that better community participation for YID requires a family that is able to provide care and support and create opportunities for YID to access institutional resources. This is in line with the study by Nuri, *et al.*, (2019) who argued that services should support families as they are influential in improved social networks, greater acceptance of disabilities and strengthened family resiliency. The parents/caregivers in the current study took

full advantage of the services offered at the Gabriella Centre to address the needs of their children, thus enhancing health and well-being through the right to engage in meaningful occupations. Their support and guidance continued as YID started life in the community by providing them with supervision and support. Such support is recognized as the most common facilitator of community participation (Anaby, *et al.*, 2013).

Stigma, regardless of culture, continues to be a significant impediment to the acceptance and inclusion for persons with intellectual and developmental disabilities (IDD). However, adopting a variety of strategies can facilitate acceptance and belonging (Jansen-Van Vuuren & Aldersey, 2020). Inclusion was evident in this study when the community recognized that YIDs' abilities provided them with opportunities to access social services [sub-theme 2.3]; sell their products and freely interact with other community members. This resonates with a study by Willis, *et al.*, (2017) who argued that for someone to engage in meaningful occupation it requires them to be actively involved in those occupations; have family support and a goodness of fit with the activities available to participate in. This align with occupation justice perspective view by (Durocher, Gibson, & Rappolt, 2014) who proposed that having an environment that recognizes and supports the unique needs and capacities of individual can allow them to participate fully and meaningfully in society thus lessen the stigma around them.

Although PWD have the right to participate in productive and decent employment vocational training and essential services, the realization of these rights depends on existing policies, laws, and regulations. Tanzania has developed and implemented several laws, regulations, and standards, including the 2004 National Policy on Disability, which seeks to create an environment that is favorable for individuals with disabilities to work productively and to advance their development and better use of the resources available (Tanzania Disability Policy, 2004). In this study, institutional support was necessary to ensure follow-up and support in participating in community life. However, YID did not have many options [sub-theme 2.3] for follow-up services as there were limited public institutions that catered to their needs. The services were mostly provided by non-government organisations (NGO's) and institutions such as the Gabriella Centre. This echoes Stone-Macdonald (2012) who acknowledged that most of the services for YID are provided by NGOs and that there are few government initiatives, especially for YID.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

This study has highlighted the type of services provided by the Gabriella Children's Rehabilitation Centre, showing how the ability and needs of the YID and their families were held central to the planning and implementation of interventions to promote community participation. This could resonate with a person-centred approach (Mccausland, *et al.*, 2021; Brown, 2013). It can be concluded that, given the nature of intellectual disability and the resources available in the context, capacity development had to be tailor-made and collaborative. The GCRC's awareness of the available service opportunities and the ability to access them was crucial for enabling the YID participation. On the other hand, families needed support to build their resilience and navigate their journey of raising a child with a disability. Involvement in recreational activities appeared to be considered less important among the families and communities of YID. The need to prepare youth for relationships and sexual experiences was identified as a gap within the GCRC programme. The study also highlighted the need for ongoing support for youth as they transitioned into adulthood. Another important area was the need for well-timed follow up services. This was especially important because YID necessitate more time to master a skill and direct, gradual support is required over time as the youth successfully apply their newly acquired skills in the community. These forms of scaffolding can be reduced as YID have more experience with participating in the community. Lastly, the study revealed that parents are also challenged and must be prepared for the transition of their children back into the community since this transition is difficult for both YID and their parents/caregivers.

6.2. Recommendations

This study's objective was to describe the occupational therapy services offered and experience of YID community participation in Tanzania as part of or following the YID's intervention at the GCRC. The study therefore suggests the following recommendations.

6.2.1 Recommendation for occupational therapy practice and service delivery

In order to overcome the challenges experienced by YID, service providers and occupational therapists should take into account culturally valued ways of engaging occupations and plan programmes that reflect this. This study showed that the opportunities presented at the GCRC aligned well with the opportunities and possibilities available in the local community. Practically, including a range of categories of occupations that reflected the family and community's expectations was also important. This included self-care; housework; recreational activities and training in vocational skills.

The provision of comprehensive sexual and reproductive health education to young people in need of services will provide them the chance to make informed and educated decisions and practice self-defense. Leisure and recreational activities should be viewed as an essential component of service delivery because they can be used to identify talents and abilities and to encourage inclusion and participation.

Training and preparing parents and caregivers should be viewed as an essential component of community integration for YID at every step of service provision and follow-up.

6.2.2 Research recommendations for the future

- Further investigation is required to see how the acquired skills might be further recognised and developed, for instance through government sponsored special loans for women and persons with disabilities, or through microcredit enterprise programmes.
- Conducting specific research into how play, recreational and leisure activities might promote inclusion and challenge and transform harmful cultural beliefs amongst children and youth with intellectual disabilities in Tanzania, could be considered.
- Research should be conducted on supporting employment for YID, as well as what the barriers and facilitators might be of such supported employment.

6.2.3 Recommendation for a policy influence

- A deliberate effort should be made to raise awareness and advocate for a structured framework that facilitates follow-up through community-based intervention in order to ensure that YID have a supportive environment and hence experience inclusion within the community
- An appropriate curriculum is required for young individuals with intellectual disabilities, and for those youth who experience other cognitive impairments or challenges as the current TVET curriculum does not take these needs into account.

6.2.4 Recommendations for occupational therapy education.

- Occupational therapy education institutions in Tanzania and other developing countries who offer Diploma and Bachelor level qualifications should consider equipping their students with how to provide occupation-centred and person-centred interventions to combat poverty and exclusion as well as promote wellbeing for YID through meaningful occupations.

6.2.5 Study limitation

This study can not claim to have represented the whole of Tanzania as a sample of twenty-three regions of the mainland and five regions in Zanzibar, as it was conducted in Moshi, Kilimanjaro only. However, it offers insights into the experiences of youth with intellectual disabilities in a way that has not been documented before. The Covid-19 pandemic posed great delays in data collection. The researcher had to remain patient and persevered, waiting for the opportunity when it was safest to continue with data collection. This also made it necessary for a change of research method from early proposed instrumental case study to qualitative descriptive study. Fortunately, all participants were understanding and remained interested in being a part of the study. Additionally, the change of community leaders as a result of the election made it difficult to involve community leaders in this study as they were new in the administration, and they had not

been a part of the process of integrating YID. However, the researcher invested in re-establishing relationships with the new leaders so that the study was not compromised.

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Appendices

APPENDICES

Appendices A: Information and Informed Consent

Appendix A1.1: Information Sheet and consent form for youth with intellectual disability.



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You have been invited to take part in this study since you are one of the youth who benefited from GCRC services and you are now back to your community.

Please read/ I will read the following information carefully and then you can decide if you want to be part of this study.

This research will describe how youth with intellectual disabilities participate in occupations in the Moshi community.

During the study we will have a conversation about your experience after graduating from Gabriella. I will take pictures which will show the types of activities that you are doing and the place where you are busy. You will be shown the pictures before I use it in the research. With your permission I will look at your folder at Gabriella Centre to have more information about what skills you learned when you were there.

Discomforts/risks: The risks in this study are small in that you may for example feel shy at times, but there are no foreseeable discomforts or dangers to either you or your child in this study.

Incentives/benefits for participation: we will not give you any gift in money or favor.

Time duration of participation: There will be two interviews of one hour each. We will also spend time with you when you are engaging in you daily activities on two different days. I will spend up to five hours with you.

Statement of confidentiality: You do not need to worry about what you will tell me as everything you say will remain private because your name will not be put in any documents and all audio recorded and pictures taken will be locked safely during the time of research and will be discarded after research process.

Voluntary participation: Your participation is voluntary; you do not need to participate if you don't want to do so. Participants will have autonomy to agree or disagree to their files being accessed.

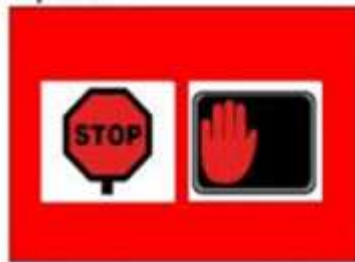
Termination of participation: If at any point during the study you feel you do not want to continue.

Appendix A1.2: Communication Card to use during interviews [part of Information Sheet and consent form for youth with intellectual disability]

You will have the following cards which you will use to communicate with researcher to indicate if you want to participate or to terminate anytime as you may wish.

At any time,
you may...

Stop for today



Take a break



Keep going



If you have additional questions regarding the research or you are not sure of your participation, you can ask your parent contact me through mobile +255713202654 or email ephant001@myuct.ac.za

The research project will be supervised by University of Cape Town, Occupational therapy Professor Roshan Galvaan (021) 406 6042. You are welcome to contact her if you have additional questions. You may also contact the UCT Human Research Ethics Committee 0214066338 or direct written concerns to E53, room 46, Old Main Building, Groote Schuur Hospital, Observatory, 7925

Thank you

SIGNING THE FORM BELOW TO INDICATE YOU VOLUNTARY PARTICIPATION IN
THE RESEARCH PROJECT



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

I, _____, YID _____ years of age, I HAVE UNDERSTOOD
THE REQUIREMENT FOR RESEARCH AND AGREE VOLUNTARILY to participation in a
program of research named above and being conducted by Anthony Ephraim a student in UCT.

_____ Signature of YID/finger print

_____ Date

_____ *please print your name here.*

Please tick the YES or NO spaces to confirm your participation in the study.

| CONFIRMATION | YES | NO |
|---|-----|----|
| <p>1. The purpose of the study has been explained to me and I have had all my questions answered.</p> | | |
| <p>2. I understand what is expected of me and know that this is a research project whose purpose is not to be of personal benefit to me.</p> | | |
| <p>3. I do not feel that I am forced to take part in this interview/field visit and I am doing so of my own free will. I have been informed that refusal to participate will not influence my access to health care and that my confidentiality will be maintained at all times.</p> | | |
| <p>4. I have received the telephone numbers of people to contact should I need to speak to someone about issues, which may arise from my participation.</p> | | |
| <p>5. In addition to the above I hereby agree to the audio recording of these interviews as.</p> | | |
| <p>6. I understand that no personal identifying information will be released in any form. I understand that these recordings will be kept in a secure, locked environment and will be destroyed six months after data capture and analysis is complete</p> | | |

Participant signature:

Signed: _____ Date: ____ / ____ / ____ Place: _____

Declaration by interviewer

I, Anthony Ephraim (ephant001)

- I have explained the information sheet of the research to the participant.
- The participant’s mental state has been assessed by an appropriate mental health care professional to determine the participant’s ability to give consent
- I have encouraged the participant to ask questions and took enough time to answer them.
- I am satisfied that the participant adequately understand all aspects of the research as discussed above

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: ____ / ____ / ____



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

INFORMED CONSENT: INFORMATION SHEET

Dear Participant parent.

My name is Anthony Ephraim and I am a student at the University of Cape Town (UCT). I am conducting research as part of the Masters in Occupational Therapy degree.

The Title of the research project is “*An instrumental case study exploring youth with intellectual disabilities participation in the community of Moshi*”

Purpose of the research: The study aims at bring an understanding of the experience of YID in activities in the community of Moshi district, Kilimanjaro region. You have been approached to participate in this study because you are one of the parents of Youth with intellectual disability and your experience is important in this study.

Procedure to be followed: You will be required to do one or two individual interviews of about 45-60 minutes. The interview will be tape recorded. I will also spend time with you at home or in your community and will take notes and pictures as part of observation. With your permission I will look at your child folder at Gabriella centre to have more information about the process, goals and the skills learned .

Your name will not be used in reporting the findings of this study. I will keep all information private and only me and my supervisor have access of the information during the research process. The digital information will be protected using password. Should you agree to take part in this

study I will ask you to give your written consent for yourself or for your child to take part in this study.

Voluntary participation: The participation is voluntary. You have a freedom to choose to stop the interview anytime and withdraw as you may wish. Your decision to participate, or not will not affect your access to Gabriella centre services. You are allowed to view the transcript after the interview sessions and the fully study report can be made available if you wish it so.

Incentives/benefits for participation: By participating in this study you will not be given money or any incentive apart from benefit of sharing your experience about youth engagement on occupation post discharge. YID will continue receiving services as per Gabriella centre process and if there is an issue to be address as result of the study we will report to Gabriella centre administration and therapist will do the follow up .

If you have additional question regarding the research or you are not sure of your participation please you can contact me through mobile +255713202654 or email [ephant001@myuct.ac za](mailto:ephant001@myuct.ac.za)

The research project will be supervised by University of Cape Town, Occupational therapy Professor Roshan Galvaan (021) 406 6042. You are welcome to contact her if you have additional questions. You may also contact the UCT Human Research Ethics Committee (021)4066338 or direct written concerns to E53, room 46, Old Main Building, Groote Schuur Hospital, Observatory, 7925

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: / /

SIGN THE FORM BELOW TO INDICATE YOUR VOLUNTARY PARTICIPATION IN THE RESEARCH PROJECT:

Please tick the YES or NO spaces to confirm your participation in the study.

| CONFIRMATION | YES | NO |
|--|-----|----|
| 7. The purpose of the study has been explained to me and I have had all my questions answered. | | |
| 8. I understand what is expected of me and know that this is a research project whose purpose is not to be of personal benefit to me. | | |
| 9. I do not feel that I am forced to take part in this interview/field visit and I am doing so of my own free will. I have been informed that refusal to participate will not influence my access to health care and that my confidentiality will be maintained at all times. | | |
| 10. I have received the telephone numbers of people to contact should I need to speak to someone about issues, which may arise from my participation. | | |
| 11. In addition to the above I hereby agree to the audio recording of these interviews as. | | |
| 12. I understand that no personal identifying information will be released in any form. I understand that these recordings will be kept in a secure, locked environment and will be destroyed six months after data capture and analysis is complete | | |

Participant signature:

Signed: _____ Date: ____ / ____ / ____ Place: _____

Declaration by interviewer

I, Anthony Ephraim (ephant001)

- I have explained the information sheet of the research to the participant.
- The participant’s mental state has been assessed by an appropriate mental health care professional to determine the participant’s ability to give consent
- I have encouraged the participant to ask questions and took enough time to answer them.
- I am satisfied that the participant adequately understand all aspects of the research as discussed above

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: ____ / ____ / _____

Appendix A3: Parent/guardian permission request for their children to participate in the research.



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

Your permission is being sought to have your child participate in this study. Please read the following information carefully before you decide whether or not to give your permission.

Purpose of the research: To describe how youth with intellectual disabilities participate in occupations in the Moshi community.

Procedure to be followed: During testing, your child will be interviewed focusing on his/her participation in daily activities. There will be two observation sessions each will last for two to five hours. There will be picture taking which will be for the sole purpose capturing the moment where your child will be engaging in activities. The pictures will not include any face or image that could identify participant. With your permission I will look at your child folder at Gabriella Centre to have more information about the process, goals and the skills learned .

Discomforts/risks: The risks in this study are minimal (i.e., no greater than those ordinarily encountered in daily life or the performance of routine). There are no foreseeable discomforts or dangers to either you or your child in this study.

Incentives/benefits for participation: There are no direct benefits to your child. The results of this study, however, will increase our knowledge about experience of YID.

Time duration of participation: Two individual interviews of approximately 45-60 minutes and two observation session which will be between 2 to 5 hours.

Statement of confidentiality: All records are kept confidential and will be available only to researchers. If the results of this study are published, the data will be presented in group form and individual children will not be identified.

Voluntary participation: Your child’s participation is voluntary. If you feel your child has in any way been coerced into participation, please contact HREC. We also ask that you read this letter to your child (if age-appropriate) and inform your child that participation is voluntary. At the time of the study, your child will once again be reminded of this by the researcher.

Termination of participation: If at any point during the study you or your child wishes to terminate the session, we will do so.

Questions regarding the research should be directed to: ANTHONY EPHRAIM

The research project will be supervised by University of Cape Town, Occupational therapy Professor Roshan Galvaan (021) 406 6042. You are welcome to contact her if you have additional questions. You may also contact the UCT Human Research Ethics Committee (021)4066338 or direct written concerns to E53, room 46, Old Main Building, Groote Schuur Hospital, Observatory, 7925

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: / /

SIGNING THE FORM BELOW WILL ALLOW YOUR CHILD TO PARTICIPATE IN THE STUDY WITH OR WITHOUT YOUR PRESENCE.

Parent Signature

Student Signature

I, the parent or guardian of _____, YID _____ years of age, permit his/her participation in a program of research named above and being conducted by Anthony Ephraim a student in UCT

Signature of Parent or Guardian

Date

_____ *Please print your name here.*

I, _____, agree to participate in the program of research named above and understand that my participation is voluntary.

Signature of YID

Date

_____ *Please print your name here.*



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

INFORMED CONSENT: INFORMATION SHEET

Dear Participant therapist.

My name is Anthony Ephraim and I am a student at the University of Cape Town (UCT). I am conducting research as part of the Masters in Occupational Therapy degree.

The Title of the research project is “*An instrumental case study exploring youth with intellectual disabilities participation in the community of Moshi*”

You have been approached to participate in this study because you are one of the therapist who is involved in in the process of integration of YID in their community.

Purpose of the research: The study aims at bring an understanding of the experience of YID in activities in the community of Moshi district, Kilimanjaro region. You have been approached to participate in this study because you are one of the parents of Youth with intellectual disability and your experience is important in this study.

Procedure to be followed: You will be required to attend one or two individual interviews of approximately 45-60 minutes. The interview will be tape recorded and also during home visits we will take notes and pictures as part of observation

Statement of confidentiality: All information will be treated with high confidentiality and your name will not be used in reporting the findings of this study. I will keep all information private and only me and my supervisor have access of the information during the research process. The digital information will be protected using password. Should you agree to take part in this study I will ask you to give your written consent for yourself or for your child to take part in this study.

Voluntary participation: Participation is voluntary. You have a freedom to choose to stop the interview anytime and withdraw as you may wish. Your decision to participate, or not will not affect your access to Gabriella centre services. You are allowed to view the transcript after the interview sessions and the fully study report can be made available if you wish it so.

Incentives/benefits for participation: By participating in this study you will not be given money or any incentive apart from benefit of sharing your experience about youth engagement on occupation post discharge.

If you have additional question regarding the research or you are not sure of your participation please you can contact me through mobile +255713202654 or email ephant001@myuct.ac

The research project will be supervised by University of Cape Town, Occupational therapy Professor Roshan Galvaan (021) 406 6042. You are welcome to contact her if you have additional questions. You may also contact the UCT Human Research Ethics Committee (021)4066338 or

direct written concerns to E53, room 46, Old Main Building, Groote Schuur Hospital, Observatory,
7925

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: ____ / ____ / ____

Appendix A5: Informed Consent for Occupational Therapist



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

INFORMED CONSENT: FOR THERAPIST

I (*your name and surname*) _____ hereby agree to participate in the research project:

Please indicate below your position

Therapist

Please tick the YES or NO spaces to confirm your participation in the study.

| CONFIRMATION | YES | NO |
|---|-----|----|
| 1. The purpose of the study has been explained to me and I have had all my questions answered. | | |
| 2. I understand what is expected of me and know that this is a research project whose purpose is not to be of personal benefit to me. | | |
| 3. I do not feel that I am forced to take part in this interview/field visit and I am doing so of my own free will. I have been informed that refusal to participate will not influence my access to health care and that my confidentiality will be maintained at all times. | | |

| | | |
|---|--|--|
| 4. I have received the telephone numbers of people to contact should I need to speak to someone about issues, which may arise from my participation. | | |
| 5. In addition to the above I hereby agree to the audio recording of these interviews as. | | |
| 6. I understand that no personal identifying information will be released in any form. I understand that these recordings will be kept in a secure, locked environment and will be destroyed six months after data capture and analysis is complete | | |

Participant signature:

Signed: _____ Date: ____ / ____ / ____ Place: _____

Declaration by interviewer

I, Anthony Ephraim (ephant001)

- I have explained the information sheet of the research to the participant.
- The participant’s mental state has been assessed by an appropriate mental health care professional to determine the participant’s ability to give consent
- I have encouraged the participant to ask questions and took enough time to answer them.
- I am satisfied that the participant adequately understand all aspects of the research as discussed above

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: ____ / ____ / ____



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

INFORMED CONSENT: INFORMATION SHEET FOR OBSERVATION

Dear Participant family/community member

My name is Anthony Ephraim and I am a student at the University of Cape Town (UCT). I am conducting research as part of the Masters in Occupational Therapy degree.

The Title of the research project is “An instrumental case study exploring youth with intellectual disabilities participation in the community of Moshi

You have been approached to give your permission to be part of the study specifically as we will observe the YID doing his/her daily routine. Since in one way or another you will interact with researcher, you may be at the place where YID have been integrated and living and thus where the observation happens and where pictures of the place is taken. Aspects that will identify people in the pictures will be omitted.

Purpose of the research: The study aims at bring an understanding of the experience of YID in activities in the community of Moshi district, Kilimanjaro region. You have been approached to participate in this study because you are one of the parents of Youth with intellectual disability and your experience is important in this study.

Procedure to be followed: There will be two observation sessions which you may be involved in as partly or full. Each observation will take from two to five hours.

Statement of confidentiality: Be sure that all information will be treated with high confidentiality where by your name will not be used in reporting the findings of this study. I will keep all information private and only me and my supervisor have access of the information during the research process. The digital information will be protected using password. Should you agree to take part in this study I will ask you to give your written consent for yourself or for your child to take part in this study.

.

Voluntary participation: The participation is voluntary. You have a freedom to choose to stop the interview anytime and withdraw as you may wish. You are allowed to view the notes and images after observation sessions and the fully study report can be made available if you wish it so.

Incentives/benefits for participation: By participating in this study you will not be given money or any incentive apart from benefit of sharing your experience about youth engagement on occupation post discharge.

If you have additional questions regarding the research or you are not sure of your participation please you can contact me through mobile +255713202654 or email ephant001@myuct.ac.za.

The research project will be supervised by University of Cape Town, Occupational therapy Professor Roshan Galvaan (021) 406 6042. You are welcome to contact her if you have additional questions. You may also contact the UCT Human Research Ethics Committee (021)4066338 or

direct written concerns to E53, room 46, Old Main Building, Groote Schuur Hospital, Observatory,
7925

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: ____ / ____ / ____

Informed Consent Form family/community member.



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

I (*your name and surname*) _____ hereby agree to participate in the research project: Family member/relative

Please tick the YES or NO spaces to confirm your participation in the study.

| CONFIRMATION | YES | NO |
|---|-----|----|
| 1. The purpose of the study has been explained to me and I have had all my questions answered. | | |
| 2. I understand what is expected of me and know that this is a research project whose purpose is not to be of personal benefit to me. | | |
| 3. I do not feel that I am forced to take part in this interview/field visit and I am doing so of my own free will. I have been informed that refusal to participate will not influence my access to health care and that my confidentiality will be maintained at all times. | | |
| 4. I have received the telephone numbers of people to contact should I need to speak to someone about issues, which may arise from my participation. | | |
| 5. In addition to the above I hereby agree to the audio recording of these interviews as. | | |

| | | |
|--|--|--|
| <p>6. I understand that no personal identifying information will be released in any form. I understand that these recordings will be kept in a secure, locked environment and will be destroyed six months after data capture and analysis is complete</p> | | |
|--|--|--|

Participant signature:

Signed: _____ Date: ____ / ____ / ____ Place: _____

Declaration by interviewer

I, Anthony Ephraim (ephant001)

- I have explained the information sheet of the research to the participant.
- The participant’s mental state has been assessed by an appropriate mental health care professional to determine the participant’s ability to give consent
- I have encouraged the participant to ask questions and took enough time to answer them.
- I am satisfied that the participant adequately understand all aspects of the research as discussed above

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: ____ / ____ / _____

Advertisement



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

Voluntary Research participation:


Anthony Ephraim is a student doing degree of Master's of Science in Occupational Therapy at University of Cape Town. His research will describe the activities that youth with *intellectual disabilities do in Moshi.*

Youth who have been at Gabriella skill training programme and now are at home, and their parents or guardians are invited to contribute. Participation is voluntary , if you are interested or you know someone who would like to share information please contact me through mobile +255713202654 or email ephant001@myuct.ac.za. Or contact Gabriella centre

Copy: Gabriella centre and Village notes boards

Appendix C. Permission letters

Appendix C.1: Permission letter to institutions

| | |
|---|---|
|  | <p>Department of Health and Rehabilitation Science Faculty of Health Sciences Division of Communications Sciences and Disorders Nursing and Midwifery, Occupational Therapy, Physiotherapy F45 Old Main Building, Groote Schuur Hospital, Observatory 7925. Tel: +27 (0)21 406 6401 Fax: + 27 (0) 21 406 6323</p> |
|---|---|

TO

RE: PERMISSION TO CONDUCT RESEARCH AT YOUR INSTITUTION:

I am an MSc in Occupational Therapy student at the University of Cape Town. As part of my studies I am doing a thesis that explores youth with intellectual disabilities participation in the community of Moshi. I am particularly interested in youth with intellectual disabilities who have completed the Gabriella skills training programme. Youth with intellectual disabilities, their parents, a therapist and a community leader of the area where youth from Gabriella have been integrated will be invited to contribute to the research.

With this letter I would like to ask for permission to conduct research at your institution. This will involve analyzing documents which may be relevant to my study. The documents access will include the folders for youth with intellectual disabilities who have consented to participate in the study; policy on programmes at the institution and annual reports available. Please find attached a synopsis of my study proposal. Should further detail be needed, please contact me.

Participation in this study is entire voluntary and there is no anticipated risks to your institution or to individuals based on participation. The only possible risk is that areas and ideas for further development of the programmes offered may be identified. All shared information will be kept in utmost confidentiality and will only be used for academic purpose. You will receive an executive summary of findings and if required full thesis can be made available through PDF electronic file.

Your approval to conduct this study will greatly appreciated.

The research project will be supervised by University of Cape Town, Occupational therapy Professor Roshan Galvaan (2721) 406 6042/roshan.galvaan@uct.ac.z

±. You are welcome to contact her if you have additional questions. You may also contact the UCT Human Research Ethics Committee (021)4066338 or direct written concerns to E53, room 46, Old Main Building, Groote Schuur Hospital, Observatory, 7925

Sincerely

ANTHONY EPHRAIM

OT Msc student at UCT

Appendix C.2: Permission letter to institutions



P .O. Box 9626
MOSHI
TANZANIA.

Phone: 0713456727 / 0754201030
E-mail: gabriellacentre@hotmail.com
<http://www.gabriellacentre.or.tz>

9/3/2020

ANTHONY THOMAS EPHRAIM

P.O.BOX 9626

MOSHI,

Dear Anthony,

RE: PERMISSION TO CONDUCT RESEARCH AT YOUR INSTITUTION:

On behalf of the Gabriella Centre Board. Permission has been granted to Anthony Thomas Ephraim who is a MSc in Occupational Therapy student at the University of Cape Town. To conduct A research with the title "an instrumental case study exploring youth with intellectual disabilities participation in the community of Moshi" particularly in the interest of youth with intellectual disabilities who have completed the Gabriella skills training programme, their parents, a therapist and other people involved coming from the area where youth from Gabriella have been integrated.

This includes analyzing documents which may be relevant to the study, however access to the individual files should have consent sought from the individual participants.

Best Regards,

S. NAIMAN

Shililiandumi Naiman

Board Chair - Gabriella Children's Rehabilitation Centre



Appendix D: Interview Guide



Department of Health and Rehabilitation Science

Faculty of Health Sciences

Division of Communications Sciences and Disorders

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital, Observatory 7925.

Tel: +27 (0)21 406 6401 | Fax: + 27 (0) 21 406 6323

Youth with intellectual disability

1. Can you please tell me about the kind of activities that you learnt from Gabriella centre?
2. What activities do you do every day? Prompt: Describe what you do from morning to the evening.
3. Since being in Gabriella centre, what activities do you enjoy doing here at your home or in the community?
4. What do you think would have been helpful during the Gabriella programme for you to be able to continue with your activities?
5. In performing your day to day activities, what part do you dislike ? **Probe:** how can it be different?
6. How has community members been helpful for you in the way you perform your activities?

Therapist/ community leader/parents and any key informants

1. How long have you been involved in the process of facilitating YID engagement in occupations in the community?
2. What has been your experience with YID engagement in the meaningful activities in their community? Follow **up question**. What changes have you seen in the life of youth after integration in the community?

3. What challenges have you experienced in entire process of YID engagement in activities that are meaningful? **Probe:** what do you think can be done to improve the situation ?

Thank you

Anthony T Ephraim

Msc OT student, UCT health and rehabilitation

Date: / /

Appendix E: Ethics Approval from HREC, UCT
Appendix E.1: Ethics Approval Letter from HREC, UCT



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



Room G50- Old Main Bldg
Groote Schuur Hosp
Observatory 7
Telephone [021] 406 6
Email: hrec-studies@uct.ac.za

Website: www.health.uct.ac.za/fhs/research/humanethics/fc

14 February 2020

HREC REF:678/2019

Prof R Galvaan
Division of Occupational Therapy
Health & Rehab Sciences-FHS

Dear Prof Galvaan

PROJECT TITLE: AN INSTRUMENTAL CASE STUDY EXPLORING YOUTH WITH INTELLECTUAL DISABILITIES PARTICIPATION IN THE COMMUNITY OF MOSHI (MSC CANDIDATE- MR ANTHONY THOMAS EPHRAIM)

Thank you for your response, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 28 February 2021.

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)

The HREC acknowledges that the student: Mr Anthony Ephraim will also be involved in the study.

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.

Yours sincerely

PROFESSOR M. BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

NHREC-registration number: REC-210208-007



This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC 678/2019sa

NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix E.2: Ethics Renewal from HREC, UCT

| | | | | |
|---|--|--|--|---|
|  UNIVERSITY OF CAPE TOWN <small>UNIVERSITEIT VAN KAPSTAD</small> | | FACULTY OF HEALTH SCIENCES Human Research Ethics Committee | |  HUMAN RESEARCH ETHICS COMMITTEE 31 MAR 2023 HEALTH SCIENCES FACULTY UNIVERSITY OF CAPE TOWN |
| FHS016: Annual Progress Report / Renewal | | | | |
| HREC office use only (FWA00001637; IRB00001938) | | | | |
| This serves as notification of annual approval, including any documentation described below. | | | | |
| <input checked="" type="checkbox"/> Approved | Annual progress report | Approved until/next renewal date | 30.03.2021 | |
| <input type="checkbox"/> Not approved | See attached comments | | | |
| Signature Chairperson of the HREC/ Designee | | Date Signed | | 31/3/23 |
| <p>Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za. Please clarify your plan for research-related activities during COVID-19 lockdown. Please use the latest form found on our website: http://www.health.uct.ac.za/fhs/research/humanethics/forms</p> | | | | |
| Comments to PI from the HREC | | | | |
| | | | | |
| Principal Investigator to complete the following: | | | | |
| 1. Protocol information | | | | |
| Date (when submitting this form) | 22.03.2023 | | | |
| HREC REF Number | 678/2019 | Current Ethics Approval was granted until | 28 feb 2021 | |
| Protocol title | A descriptive qualitative study exploring how youth with intellectual disability (YID) participate in the community of Moshi | | | |
| Protocol number (if applicable) | | | | |
| Are there any sub-studies linked to this study? | | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No | |
| If yes, could you please provide the HREC Reference number for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study. | | | | |
| Principal Investigator | Roshan Galvaan- | | | |



| | |
|--|--|
| Department / Office Internal Mail Address | Zone F45, Old Main building, Grootte Schuur Hospital |
|--|--|

| | | |
|--|------------------------------|--|
| 1.1 Does this protocol receive US Federal funding? | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
| 1.2 If the study receives US Federal Funding, does the annual report require full committee approval? Note: Any annual approvals for Full Committee review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-submission@uct.ac.za) | <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |

If yes in 1.2 please complete section 1.3 below for invoicing purposes

1.3 Ethics Renewal Fee

Please (tick ✓) appropriate box for billing purposes:

| Submission Type | Description | Now fee /Vat Incl. | tick ✓ |
|---|---|--------------------|--------------------------|
| Research funded solely from UCT departmental/divisional/group budget | Annual evaluation of research progress report for re-certification | R0,00 | <input type="checkbox"/> |
| Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges | Annual evaluation of research progress report for re-certification | R0,00 | <input type="checkbox"/> |
| Annual re-certification / Progress report (FHS016 Form) | Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Full Committee Approval | R7000,00 | <input type="checkbox"/> |
| Annual re-certification / Progress report (FHS016 Form) | Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Expedited review | R3 710,00 | <input type="checkbox"/> |
| Annual re-certification / Progress report (FHS016 Form) | National grant funded research - Annual evaluation of research progress report for re-certification for Full Committee Approval | R6000,00 | <input type="checkbox"/> |
| Annual re-certification / Progress report (FHS016 Form) | National Grant funded research for Annual evaluation of research progress report for re-certification for Expedited review | R1 500,00 | <input type="checkbox"/> |

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for invoicing, either complete section 1 or 2 :

1. Invoice billing – Directly to Sponsor

| | |
|-----------------------------|-----|
| Sponsor's name | N/a |
| Billing Address of Sponsor: | |
| Vat Number: | |



| | |
|-------------------------------------|-----|
| Contact person | |
| Telephone number | |
| Email Address | |
| 2. Internal Journal Billing: | |
| Fund Number: | n/A |
| Cost Centre Number: | |
| Account Holder Name: | |
| Division of Account Holder: | |

2. List of documentation for approval

| |
|--|
| |
|--|

3. Protocol status (tick ✓)

| | |
|-------------------------------------|--|
| <input type="checkbox"/> | Open Enrolment |
| <input type="checkbox"/> | Closed to enrolment (tick ✓) |
| <input type="checkbox"/> | Research-related activities are ongoing |
| <input type="checkbox"/> | Research-related activities are complete, long-term follow-up only |
| <input checked="" type="checkbox"/> | Research-related activities are complete, data analysis only |
| <input type="checkbox"/> | Main study is complete but sub-study research-related activities are ongoing |
| <input type="checkbox"/> | Study is closed → Please submit a Study Closure Form (FHS010) |

4. Enrolment

| | |
|--|---|
| Number of participants enrolled to date | 7 |
| Number of participants enrolled, since last HREC Progress report (continuing review) | 7 |
| Additional number of participants still required | 0 |

5. Refusals

| | |
|---|---|
| Total number of refusals (participants invited to join the study, but refused to take part) | 0 |
|---|---|



6. Cumulative summary of participants

| | |
|---|---|
| Total number of participants who provided consent | 7 |
| Number of participants determined to be ineligible (i.e. after screening) | 0 |
| Number of participants currently active on the study | 7 |
| Number of participants completed study (without events leading to withdrawal) | 7 |
| Number of participants withdrawn at participants' request (i.e. changed their mind) | 0 |
| Number of participants withdrawn by PI due to toxicity or adverse events | |
| Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance) | |
| Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up. | 0 |
| | |
| Number of participants no longer taking part for reasons not listed above. Please provide reasons below: | 0 |
| | |

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:

The data collection and analysis has been completed and the thesis is being written up.

| Date | Activities | Comment |
|------------------------------|---|--|
| March 2020 to March 2021 | Accessed Gabriella Centre document at and tried to work on | The process was interrupted by the covid-19 pandemic restrictions |
| April 2021 – July 2021 | Resumed document review | |
| August 2021 to December 2021 | Identification of participants, recruitment and arranging for data collection | Process still affected by covid-19 restrictions leading to it taking longer to identify participants |
| | | |



If yes, please describe:

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?

Yes No Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?

Yes No Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.

| | | | | | |
|-------------|--|----------------------|------------------------------|-----------------------------|--|
| Agency Name | | Report attached | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input checked="" type="checkbox"/> Not applicable |
| | | DSMB report attached | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input checked="" type="checkbox"/> Not applicable |

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?

Yes No

If yes, please explain:

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:

Increased

Decreased

Shown no change

If there has been a change, please explain:

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
Not applicable



13. Insurance

| | | |
|--|-----------------------------|--|
| Please confirm that valid no fault insurance is still in place? (tick ✓) | | |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input checked="" type="checkbox"/> Not Applicable – N/A |
| If yes, please complete the following: | | |
| Insurer's name: | | |
| Policy no. | | *Coverage Period: |
| For UCT sponsored studies please liaise the Insurance office via fhs.sponsorship@uct.ac.za regarding the required documentation and information required obtain a renewed UCT No-fault Insurance Certificate. | | |

14. Statement of conflict of interest

| | |
|--|--|
| Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓) | |
| <input type="checkbox"/> Yes | <input checked="" type="checkbox"/> No |
| If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013): | |
| | |

15. Signature

| | | |
|--|--|---------------|
| My signature certifies that the above is complete and correct. | | |
| Signature of PI | | Date |
| | | 31 March 2023 |

Appendix F: Ethics Approval from CRERC, KCMUco

CRERC 07



KILIMANJARO CHRISTIAN MEDICAL UNIVERSITY COLLEGE
(A Constituent College of Tumaini University Makumira)

RESEARCH ETHICAL CLEARANCE CERTIFICATE

No. 2455

Research Proposal No. 1239

Study Title: An instrumental case study exploring youth with intellectual disabilities participation in the community of Moshi

Study Area: Moshi

P. I Name: Anthony Thomas Ephraim

Coinvestigator: Roshan Galvaan

Institution (s): Kilimanjaro Christian Medical University College

The Proposal was approved by CRERC on: 5th March 2020

Duration of Study: One year

From 5th March 2020 to 5th March 2021

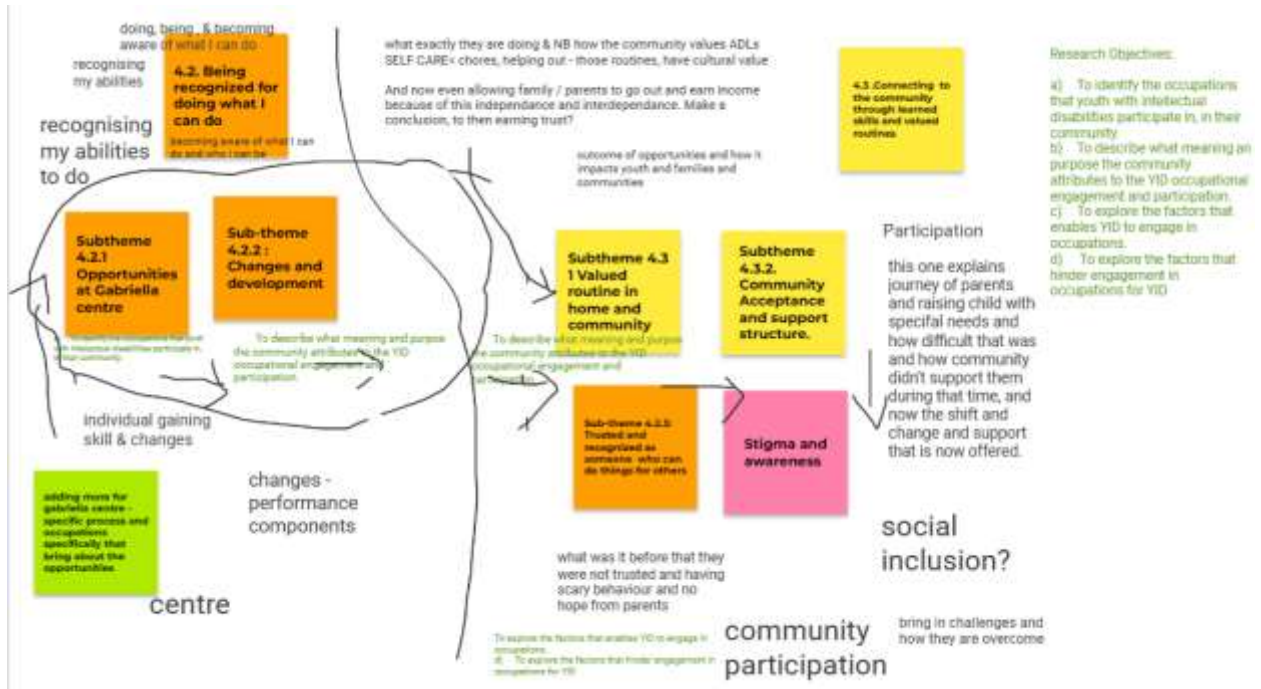
PROF. MRAMBA NYINDO

PROF. EPHATA KAAYA

Chair – CRERC

ProVost-KCMU College

Appendix G: Example of analysis



Appendix H: Tanzania and Kilimanjaro showing study area

