

A SPECTRUM OF EXPERIENCE: PERSPECTIVES ON AUTISM FROM MOSHI,
TANZANIA

by

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Dedication

I dedicate this thesis to Mama G, Mr. K and the myriad other local champions dedicating themselves to improving the quality of life of children and adults living with disabilities in Tanzania, while also working to create a world in which autistic people are acknowledged, accepted and celebrated. You are truly inspiring.

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Abstract

There are two ways of viewing autism: as an affliction, or as an identity. The first, biomedical perspective is most common, but communities of self-advocates are lobbying for a more socio-cultural approach, arguing for the societal recognition and celebration of “neurodiversity.” The limited research on autism *outside of a western context* is almost exclusively epidemiological, assuming ignorance on the part of least developed countries in addressing issues of disability. This paper explores the lived experience of autism in Moshi, Tanzania through a 2.5 month multi-sited ethnographic study to identify and validate socio-cultural perspectives of autism and to determine whether a parallel concept to neurodiversity might exist, arguing that Tanzania’s lack of medical infrastructure and social supports may be advantageous in creating the conditions for acceptance of neurodiversity, and suggesting that this potential may be harnessed by increasing the visibility of autism through informal social channels such as media and religion.

List of Abbreviations Used:

ACT – Autism Connects Tanzania

ASAN - Autistic Self-Advocacy Network

ASD – Autism Spectrum Disorder

CBR – Community Based Rehabilitation

LDC - Least Developed Country

NGO – Non-Government Organization

NSAC – National Society for Autistic Children

WHO – World Health Organization

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Chapter One: Introduction

“Africa is a large continent with many diverse peoples and cultures. Any attempt to treat it as one homogenous whole is doomed to fail. With only a few exceptions however, the continent is united in the paucity of information on the subject of intellectual disability” (Njenga, 2009, p.457).

Autism is known to exist cross-culturally, yet little is understood about how the disorder manifests outside of a Western context (Grinker, 2007). My research seeks to help remedy this lack of knowledge by exploring the experience of autism in Moshi, Tanzania. Right now, in the global north, there is a polarized debate between two ways of thinking and talking about autism; one which takes its cues from biomedical discourse, viewing autism as a loathsome illness that destroys lives and robs parents of their children (Kras 2010; Waltz, 2012), and the other influenced by socio-cultural discourse, claiming that autistic people possess a unique cognitive profile and a “different way of being” that is no less valuable than any other (Grinker, 2007; Murray, 2008; Solomon, 2012). The former perspective has its roots in individualized illness models and is the hegemonic lens through which autism is publicly viewed, while the latter belongs to the latest branch of the disability rights movement which lobbies for the recognition of autism as an identity (Solomon, 2012; Silberman, 2015). The goal of this movement is the societal recognition and celebration of neurodiversity, a term used to describe the vast differentiation in the ways that people are cognitively “wired.”

Autistic characteristics have been identified in children around the world, often appearing as curious, or shocking behavioural differences which unsettle accepted cultural conventions surrounding child-rearing practices, developmental expectations, and social inclusion (Shaked, 2005; Grinker, 2007). However, the limited research exploring autism outside of a western context is overwhelmingly epidemiological in focus and the few services offered to autistic children and their families in developing countries are predominately based on western knowledge and experience. International aid tends to focus on alleviating the assumed stigma of the ‘disabled’ by supplying alternative discourses and conceptions based on the assumption of local ignorance about the causes of disability and the supposed mistreatment of disabled people, a belief which Ingstad (1995) terms “the myth of the hidden disabled.” In contrast, Kisanji (1995) claims that this “north-south myth” is sensationalist and has little bearing on the actual experience of disability in non-western countries, despite its frequent invocation by Non-Government Organizations (NGOs) and other development programs eliciting support and funding for their various projects.

This myth saturates the website of EdPowerment, a U.S based registered public charity dedicated to providing educational opportunities to “neglected teenagers and youth with special needs through grassroots, thoughtfully administrated, hands-on programs in the villages outside of Moshi, Tanzania” as these children are often “outcasts, kept hidden in homes and even thrown out or deserted” (EdPowerment, 2014). One of the projects implemented by EdPowerment is Autism Connects Tanzania (ACT), which aims to “educate families, organizations and schools about intellectual disabilities, create a national network of supporters, and protect children with intellectual disabilities

from harm” (EdPowerment, 2014). It does so by offering public seminars, disseminating informative materials and partnering with the Gabriella Children’s Rehabilitation Center to offer education and support to the developmentally disabled.

Hence, there appears to be a contradiction between the work of scholars studying disability cross-culturally and charitable organizations such as EdPowerment, which seek to remedy the dire situation of people living with disabilities in impoverished nations.

What is really going on? To what degree does the myth of the hidden disabled represent reality for autistic people in Tanzania? Do popular Western representations and debates accurately capture experiences of autism, or do they fall somewhere outside of this rubric? My research explores the lived experience of children with autism and their families in Moshi, Tanzania through a 2.5 month ethnographic study, in order to understand the role, if any, of western-based discourses, diagnostics and treatments in influencing local interpretations and understandings of autism. My pre-fieldwork investigation and initial contact with collaborators in Tanzania led me to hypothesize that in Moshi, due to foreign influence, biomedical conceptions of autism are privileged over more social, rights-based conceptions of neurodiversity. This study allows for the possibility of uncovering local or regional aspects of the autism experience which do not easily fit within the previously outlined positions and perspectives of popular debate.

My research attempts to answer the following questions:

- 1) How is autism experienced by families in Moshi whose children have been identified as autistic?
- 2) What is the relationship between biomedical and socio-cultural discourses and explanations of autism in Moshi?

3) Does a parallel concept to neurodiversity exist in Tanzania, and if so, how is it articulated and from where does it originate?

In addressing these questions I hope to contribute to the growing body of family-focused, child-centric research coming out of global disability studies and disabled children's childhood studies (Ingstad & Whyte, 2007; Curran & Runswick-Cole, 2013) as well as to facilitate a deeper understanding of autism across contexts, potentially aiding in the development of more culturally appropriate forms of treatment and engagement.

Chapter Two: Literature Review: Global Disability Research

Talking Disability: The Impact of Discourse

Since disabilities are culturally and socially defined – through a process of evaluation against cultural assumptions, societal norms and expectations - dominant ideas about specific disabilities arise out of popular discourse. Discourses can be thought of as codified systems of language in a given field of inquiry or on a certain topic which can reveal the relationships between language, structure and agency (Rogers and Swadener, 2001). Discourses with the most cultural cachet and widest exposure become dominant, acting as lenses through which large numbers of people conceptualize certain issues. Curran (2013) offers a Foucauldian definition of discourse as “the disciplines, practices and techniques we are all subject to and to which we subject ourselves... at the level of the body, the local and global” (p.123). We are not always aware of the subtle, yet instrumental role discourse has in shaping our subjectivities (Reynolds-Whyte, 2009, p.14). Both scholarly and lay discourses on disability usually fall into one of two categories: biomedical or socio-cultural. Conceptions of autism are filtered through this binary framework, creating sub-discourses and narratives which attempt to represent autistic experience and which profoundly impact how autistic children are understood by parents, peers, communities and society at large.

Autism Spectrum Disorder (ASD) is a developmental disorder which manifests in developmental delays (according to biomedically prescribed “milestones”) such as impaired communication, difficulty forming social relations, and repetitive or stereotyped behaviour, before a child reaches age three (Shaked, 2005, p.2191). The severity of a

child's symptoms determines where they are deemed to fall along the spectrum, categorizing them as either high or low functioning autistic. Consequently, the label of autism is stretched-thin; one word attempting to describe vastly differing personalities and experiences.

Research suggests that autism is neurobehavioural in nature and that 75% of cases are accompanied by intellectual disability, but there is no agreed upon cause (Ravindran & Myers, 2012). An upsurge in diagnoses in the past decade is believed by some to be evidence of an "autism epidemic," spurring a search for possible biomedical, environmental or genetic causes. However, scholars such as Grinker (2007) and Ennis-Cole, Durodoye and Harris (2013) argue that this increase may be attributable to the evolution and expansion of diagnostic criteria, as well as the easy and widespread dissemination of information through the internet. Autism is behaviourally defined, as Norbury and Sparks (2012) explain, there are no biological markers or medical tests for ASD. Diagnosis is based solely on observed behaviour and parental report, meaning that "the point at which normal variation converges on disorder is largely an arbitrary decision and is highly likely to be influenced by cultural values and expectations" (p.45). Evidence points to the importance of early detection and treatment of autism, yet there is little consensus on the efficacy of treatments for individual children (Ravindran & Myers, 2012, p.315). Autistic characteristics have been identified in children around the world, in varying degrees of severity, often appearing as curious, or shocking behavioural differences which unsettle accepted cultural conventions surrounding child-rearing practices, developmental expectations, and social inclusion (Shaked, 2005; Grinker, 2007). The ways in which ASD is framed within discourses shapes the way that people

think about autism, and subsequently the ways in which they treat autistic people. Autism is a particularly salient example because, unlike conditions with a definitive cause, its ontology is prone to shifts, leaving it especially susceptible to interpretations influenced by various discursive constructs. Murray (2008) argues that this lack of scientific consensus makes autism an open topic for interpretation and representation, and that rather than trying to reflect the essence of the condition, these competing discourses create a new idea altogether, overlaying the disorder with an aura of mystery and fascination, rather than understanding (p.4). Most people learn more about autistic experience from books and media sources, with questionable authenticity, than they do from firsthand interaction with autistic people. Further, Murray (2008) claims that despite the recent proliferation of conversations and publications about autism across all genres and fields of study, we still know very little about how “specifically *cultural* versions of disabilities influence their various subject matters” (p.4) as “organized thinking about autism and culture is still very much in its infancy” (p.16). The information available about autism is inherently biased toward a western perspective.

Rogers and Swadener (2001) argue that dominant discourses, “assumed to be at the center of human experience, ... are actually located in exclusive and privileged margins” (p.2). In their edited volume *Disabled Children’s Childhood Studies*, Curran and Runswick-Cole (2013) advocate for a discipline which foregrounds a ‘child first’ approach to research, attempting to develop a counter-hegemonic voice and an alternative form of authority to dominant discourses of childhood and disability which consistently exclude the perspectives of those who they claim to represent (p.121). As Waltz (2005) explains, the most prolific narratives of autism are written from a position of power,

using an authoritative voice to construct an official discourse of autism and rarely incorporating autistic perspectives (p.421). Rogers and Swadener (2001) use an applied semiotics approach to show how the label of “disability” acts as a “created state, status, symbol, process, construction, definition and metaphor” in reference to human interaction and discourse, a view which allows for the recognition of the term’s malleability according to economic and social conditions (p.4). This view maintains that although humans use language and categorization to represent understandings and to order our world, sometimes these discursive constructs claim more representative authority than they deserve in determining how certain individuals are known to others. An applied semiotics approach is intended to expand and elaborate limited, marginalizing discourses, adding more voices to the conversation.

According to Curran (2013), the individual model and the social model of disability guide most enquiries and interventions into disabled childhoods (p.123). Biomedical discourses are based on the individual model and have been highly criticized by disability scholars and activists alike. This approach locates the ‘problem’ of disability within the individual, consistent with the scientific method, thus producing a view of the disabled person as suffering from an illness alleviated through medical intervention. This perspective continues to hold worldwide authority in presenting disabled children negatively, in terms of deficits (Curran, 2013, p.12; Murray, 2008). The binary opposition of the normal and the abnormal is integral to medical discourse. It is particularly salient in the language of childhood development within which ‘normal’ development is measured in age-based stages or “milestones” that outline a particular, normative path through life (Curran, 2013, p.125; Cooper, 2013, p.140). Disabled children often fail to

follow this rubric of development in the expected timeframe, or even to follow it at all, and thus stand out in juxtaposition to the notion of a 'normal child' which it seeks to produce. The idea of the "normal child" which emerges out of this framework is integral in shaping conceptions of childhood disability. According to Cooper (2013), in this age of ever-increasing scientific advancement, the 'abnormal child' has replaced the 'sick child' as the "parameters of the normal" are constantly being defined, and re-defined in medical terms, hugely increasing the risk of parents being informed that their child is 'abnormal' (p.145). She argues that contemporary culture may be mistaken in treating scientific and medical advancements as positive progression on the grounds that the construct of normalcy produced through medical knowledge can act as a restrictive and oppressive force in the everyday lives of disabled children (p.148). Rogers & Swadener (2001) agree that while there can be advantages to being labeled in a certain category, for instance, moderately learning disabled or deaf, because of the social support it affords, the designation of an individual as disabled, without their active participation and collaboration in that labeling, may in itself be disabling by subjecting them to a reduced field of expectation, potential and opportunity (p.2). This assertion is complicated by the fact that many autistic individuals are non-verbal and cannot act as self-advocates, however, supporters would argue that all efforts should be made to allow for autistic people to express themselves by any means possible, even simply pointing to a picture or a symbol to convey their preference. In order to understand and respect the difference of autism, Murray (2008) argues, we must challenge the dominant medical framework which permeates public consciousness about disability and supports the idea that bodies either work, or contain flaws that prevent them from functioning "normally."

The social model of disability, incorporated into the subversive approach of disabled children's childhood studies, produces socio-cultural discourses which hold that disability is not a direct result of biology, but rather of social processes of disablement inscribed on to certain bodies. As Curran (2013) explains, "Disabled children, like everyone, are embodied, not as a result of 'nature,' but specific social practices of embodiment" (p.122). Thus, a child can be "dis-abled" or "enabled" in correlation with a culture's particular construction of disability (Mutua, 2001, p.103; Ennis-Cole, Durodoye, & Harris, 2013). This approach underpins attempts to resist the dominant forms of authority embedded in specific discourses of childhood disability by creating space for disabled children's views and voices. It highlights the contextual nature of disability and the ductility of the term as a social construct, rather than a biomedically determined category. Employing this framework, disability rights activists have redefined disability as a socio-political issue, using it as a platform to lobby for disabled persons' rights and the equalisation of opportunities (Grech, 2009). While this may seem like a shining alternative to the individual model, Grech (2009) notes that it is just as much a western construct as the individual model, making it highly problematic in a cross-cultural context as it represents the experience and articulates the concerns of a particular population: white, middle class, educated, western, disabled academics (p.772). Furthermore, it also promotes a singular, universal discourse, likely to prove inappropriate when transferred across cultures (Grech, 2009, p.775). Rogers and Swadener (2001) believe that any attempt to create a universal discourse representing the experience of disability, regardless of its alignment with either individual or social models, creates an "us" and an "other," condensing the lives of disabled people into

reductive narratives of “marginalized voices” and strengthening binary oppositions between conceptions of the ‘normal’ and the ‘abnormal’ (p.2).

In the global north, at this particular historical moment, there is a fundamental tension between two ways of thinking and talking about autism; one which takes its cues from biomedical discourse, viewing autism as a loathsome illness that destroys lives and robs parents of their children, and the other influenced by socio-cultural discourse, claiming that autistic people possess a unique cognitive profile and a “different way of being” that is no less valuable than any other (Grinker, 2007; Murray, 2008; Solomon, 2012). The former perspective has its roots in individual, illness models and is the hegemonic lens through which autism is publicly viewed, while the latter belongs to the latest branch of the disability rights movement which lobbies for the recognition of autism as an identity (Solomon, 2012). The goal of this movement is the societal recognition and celebration of neurodiversity, a term used to describe the vast differentiation in the ways that people are cognitively “wired.” Within disability studies, treating autism as a disease highlights the individual’s deficits, while an approach that encourages neurodiversity highlights society’s deficits in accommodating the individual (Grinker, 2010). In the autism community, it is often parents of disabled children who engage biomedical discourse, searching tirelessly for a cure for their children and fundraising for medical research with this goal (Sousa, 2011), while disabled adults are often offended by the notion that autistic ways of being need to be “fixed” (Murray, 2008; Solomon, 2012).

A number of sub-discourses on autism have emerged out of the standard biomedical framework. Autism used to be blamed on poor parenting. Historical

psychoanalytic literature claimed there to be a link between mothers' behaviour and their children's developmental outcomes, namely that cold, insensitive, "refrigerator" mothers were the cause of autism and similar neurological differences (Sousa, 2011; Ennis -Cole, Durodoye, & Harris, 2013, p.280). While this notion has long been discarded, Sousa (2011) argues that it has been replaced by a new discourse of good mothering in which women are encouraged to act as "warrior-heroes" who will fight against any number of social or political barriers, no matter the personal or financial costs, in order to gain access to medical and educational interventions for their children (p.220). Surprisingly, the "warrior-hero" concept is not being imposed upon women from above, but rather has emerged from within as educated, middle-class mothers of children with intellectual disabilities document their experiences in memoirs, a process which Sousa (2011) claims is an attempt to undermine the professional domination of discourses on mothering disabled children. This effort makes sense in light of the fact that "Even today much of the public discourse about people with disabilities and their primary caregivers continues to be structured by the medical, educational, legal and social work professions, while mother's relationships have been 'speculative' in the professional literature" (Sousa, 2011, p.223) Using discourse analysis of mother's memoirs, Sousa (2011) discovered that this attempt to counteract dominant discourses largely adheres to the individual model and promotes a biomedical perspective - the mothers must work to solve the problem located in their child and although they may struggle to come to terms with diagnoses, receiving a label is also comforting because it offers hope for a cure, or at least a mitigating treatment, while allowing mothers to channel their energy into making said cures and treatments available to their children (p.227). This discourse is very class-

based, produced mostly by western women of high socioeconomic status with the time and social capital that allows them to engage in such an endeavour, and thus can serve to create yet another instance of mother-blaming when other mothers fail to champion their children's interests so fiercely.

Other parents reject biomedical discourse and its conception of autism as an illness, instead taking their cues from disability rights activists who focus on identity. When parents see their child's disability as resulting from an illness that can be eradicated, they focus on battling disease in order to free the 'normal' child it has captured. Conversely, in an identity model, parents recognize their children as fundamentally intertwined with their disability, so that being autistic is not so much something a child *has*, but rather an integral part of who they *are*. Global autism research organizations publish public service announcements which personify autism as a kidnapper that steals children away and ruins families, while the neurodiversity movement and its supporters object to the offensive goal of creating a world in which autism, and thus autistic people, do not exist (Solomon, 2012, p.258). Unfortunately, it is the former, more sensational and biomedical, message that seems to have the widest audience and the greatest influence on public opinion.

Reynolds-Whyte (2009) emphasizes the important role of comparative ethnography in realizing the impact that social and political conditions can have on the possible formations of health identities (p.6). Solomon (2012) found that people of higher socioeconomic status struggled more than those of lower socioeconomic standing, finding it more difficult to deal with children's perceived shortcomings and going to great lengths to change them (p.36). He claims that adherence to one model or the other is

often contingent upon this class difference: “Fixing is the illness model; acceptance is the identity model; which way any family goes reflects their assumptions and resources” (Solomon, 2012, p.37) The identity model has the potential to improve public attitudes toward disabled people, and is doing so already in developed countries. Identity politics are about reevaluating differences that have been devalued, calling attention to discrimination and advocating for social justice, a process which Reynolds-White (2009) notes always has the potential to fetishize difference, but may also generate positive discussion and action among commonly allied groups (p.8). Unfortunately, the identity model is less accessible in so-called developing countries, having been founded and communicated largely on the internet, and rarely being incorporated into development agendas which operate almost exclusively from an individual, biomedical approach using an illness model. This has significantly slowed the disability rights movement in the global south, yet Reynolds-Whyte (2009) notes that groups of disabled people around the world are beginning to connect and rally around a shared experience of disability, yet she notes that identity may not always be articulated so explicitly. It can also be formed in the absence of social movements, without conscious actors and specific intentions, and may be a norm in certain cultures.

While the above discussions of autism are popular among affluent, western, white parents, biomedical and socio-cultural discourses of autism are engaged differently across cultures, influencing beliefs about the causes and treatments of a child’s disability. Some accept the biomedical view of autism as biological, seeking medical treatment, while others adopt a more socio-cultural perspective and may eschew professional/scientific answers in favour of lay or “folk” conceptions, often referred to as supernatural, magical,

metaphysical or religious (Danseco, 2006, p.44). Ravindran and Myers (2012) highlight the importance of investigating parent's beliefs about the causes of disability, as these influence the attitudes of family members and the larger community toward the disabled individual (p.312). In his research, Danseco (2006) found that parents were influenced by both the more hegemonic, globally disseminated and biomedically structured discourses as well as lesser-known, more locally specific socio-cultural discourses regarding their children's condition. Parents were found to have a duality in beliefs: able to explain their child's autism in terms of medical etiology, but also clear about their personal beliefs regarding the causes of disability (p.45). Chinese-American, Mexican-American and Jewish-Oriental parents cited many alternative causes for their children's disabilities including fate or punishment, mother's behaviour, and marital difficulties (Danseco, 2006, p.45). Parents were likely to follow prescribed biomedical treatment plans, but also to seek alternative, more culturally relevant forms of healing. In their research in Puerto Rico, Gannotti et al. (2001) found that biomedical explanations coexisted with a strong belief that disabilities run in the family, acting either as an avenue to acceptance, or afflicting the family with guilt and shame (p.1520). Socio-cultural views are not necessarily negative, sometimes disabled children are seen as gifts from God, deserving of the utmost care and reverence. Yet a misconception that disabled children are systematically mistreated in "Other" cultures circulates in the west, creating a pervasive discourse which Ingstad (1995) calls "the myth of the hidden disabled" (p.139). This recently created "north-south myth" stereotypes the behaviour of cultural others by suggesting that all people from non-western, supposedly "under-developed" nations, hide disabled people away out of shame, ignorance or heartlessness, undermining the various

efforts these people make to support disabled individuals despite significant obstacles, and ignoring the complexity of cross-cultural experiences of disability. A discussion of how this myth operates in relation to Tanzania specifically, as well as how it is incorporated into development discourses and agendas can be found in the discussion section of this thesis.

Discourses serve to dictate the expected reactions and behaviours of parents, peers, and cultures to a child's disability. Presently, discourses describing disability in deficit terms and advocating for the eradication of autism reign supreme, and alternatives have limited circulation, mostly in the Global North, among privileged groups of wealthy, white parents who, ironically, tend to ignore them, pinning their hopes on scientific paths to a cure (Sousa, 2011; Solomon, 2012; Murray, 2008). As Jabery et al.'s (2012) work in Jordan highlights, many parents depend on the internet and other media sources for information on the etiology of autism and the location of services, gaining access to biomedical discourse and tending to adopt its attitude toward disability (p.8). While discourses emanating from the west have served to heighten global *awareness* of autism, arguably, they have not managed to generate further *understanding* of the disorder, but rather increased public fascination with a topic that seems to elude full comprehension (Murray, 2008, p.4). In order to develop a deeper, and more holistic understanding of autism beyond that extolled in dominant discourses, Murray (2008) suggests we take an "inside-out" approach, looking to autistic individuals to supply narratives of their own lives, offering stories and worldviews which differ from those promulgated by majority culture and honouring the Foucauldian call to seek out desirable alternatives to dominant discourses (Curran, 2013, p.124). Rather than try to universalize

autistic experience in a singular discourse, adhering to only one framework or perspective of disability, these more culturally specific and nuanced accounts may be the only way to truly understand the place of autism in the world, possibly challenging the supremacy of illness models and creating space for new identities to form.

Disability and Personhood

Tanzania is an East African country of approximately 45 million people and more than 130 ethnic groups which established independence from British rule in 1960 (Stone-Macdonald, 2014). It is a post-socialist country with cultural values that still reflect the legacy of former president Julius Nyerere whose government centered on the concept of “ujamaa,” a Kiswahili word meaning “familyhood” or “socialism,” which foregrounds communal cooperation and dictates that all members should have equal rights and opportunities (Stone-Macdonald, 2014, p.10). Tanzania still has a socialist-based education system that aims to be all-inclusive, but its goals are consistently jeopardized by the country’s economic instability. The education budget is hugely dependent on foreign aid and there are few educational opportunities for children whose disabilities prevent them from attending mainstream schools. Although some schools for children with disorders such as autism have been set up with help from NGOs and other donors, access is often limited by financial constraints and their western-influenced curriculums emphasize academics over more practical and beneficial vocational skills. Children with disabilities are expected to be cared for by their families, and are often kept sequestered at home out of concern for their safety and lack of access to means of support, facilitating

western assumptions of mistreatment and sometimes preventing them from being considered full and equal members of society.

In 2004, Tanzania ratified its first National Policy on Disability which acknowledges the needs of people with disabilities and the desire to provide them with access to education, but requests help from the international community and NGOs in doing so (Stone-Macdonald, 2014, p.9). As Stone-Macdonald (2014) explains, many African governments instate policies which aim to improve the well-being of disabled people, but lack the resources to actualize these promises (p.9). The term “autism” and the characteristics it describes have only recently become popular in Tanzania. The disorder is still largely undifferentiated from other forms of intellectual disabilities. This is not unusual, as Muyinda and Whyte (2011) explain, in most African countries even disabled person’s organizations (DPOs) at both grassroots and national levels downplayed, or were unaware of, the many disparities among people with disabilities, perhaps in an effort to attract more membership and to avoid concentration of resources on one condition. As a result, the nuances of disabilities and disabled experiences are generally unavowed, leaving all disabled people lumped together in one reductive category of being.

As Murray (2008) iterates, any discussion of disability also necessitates a discussion of the human condition and the cultural variability of personhood. Ingstad and Reynolds-Whyte (1995) agree, noting that all forms of impairment bring to the surface moral and metaphysical questions of personhood, responsibility, and the meaning of difference, while also stressing that “cultural assumptions about the body and personhood must be seen in the context of ordinary social interaction” (p.4). As opposed to the

western conception of individuals as bounded wholes (Fowler, 2004; Rose, 1998), a more collective understanding of personhood is common across the African continent. As Hansen and Sait (2013) explain, the concept of “ubuntu” (a zulu term, in Tanzania the same idea is called “undugu”) symbolizes a particular form of sociality in which perceptions and ideas are shared through a practice of togetherness, emphasizing such cultural values as helping others in need by sharing food, money or knowledge (p.101). These practices give birth to a modality of being in which the self is constituted in conjunction with others. The zulu explanation is simple and poignant: “a person is a person through other persons” (Hansen & Sait, p.102). According to Muyinda and Whyte (2011), “personhood is about the cultural recognition of an individual’s social value and dignity” (p.128). They found that in Uganda the doubly-disenfranchising combination of disability and poverty impinged on personhood in many ways. Those who could not support themselves or provide for others, travel to social functions, or in some cases, have a spouse, were considered less worthy of respect and seen as having less dignity than others (Muyinda & Whyte, 2011, p.128).

Childhood is also an unstable, culturally dependent category. In the west, childhood is generally thought of as a carefree period in which children are not subject to the burdens of adult life and parents provide unconditional love and support, striving to make their offspring as happy as possible. On the contrary, in many developing countries there is a less distinctive separation between adulthood and childhood. Children are expected to perform tasks such as cooking, cleaning, and childcare, as well as to contribute to the household income whenever possible (Curran & Runswick-Cole, 2013). Having a child with a disability can place an extra burden on families living in poverty,

and parents may become frustrated when these children do not automatically emulate the behaviour of their siblings (Stone-Macdonald, 2014). Ingstad and Eide (2013) maintain that quality of life and integration into society are closely linked to work in developing countries, affecting one's acceptance into social life and acting as powerful determinants of social inclusion more than in the global north (p.5). In western countries, work is undertaken by individuals as a means to achieve success and improve class status, more than it is to secure a sense of belonging. Communities and families throughout sub-Saharan Africa generally take responsibility and provide care to the best of their ability for disabled members, yet people with disabilities still face discrimination based on their ability to participate in the daily social and economic activities of the community (Stone-Macdonald, 2014, p.9) Not participating in these activities signifies a failure to uphold the social contract, limiting social membership, and potentially impeding personhood. As such, individuals who make positive contributions to their community, both physically and economically, are more likely to be accepted and respected, regardless of their disability status (Stone-Macdonald, 2014, p.9).

Based on her ethnographic work in Tanzania at a school for children with disabilities, Stone-Macdonald (2014) argues that autistic presence in the community and the acquisition of "tacit cultural knowledge" (Ochs and Solomon, 2004) is key to student's future success. For children with disabilities, proving their physical and intellectual capabilities by conducting themselves in a respectful manner, fulfilling such cultural expectations as using appropriate greetings or participating in rituals, and contributing to daily subsistence activities, went a long way toward reducing stigma and securing them a place in the social fabric. In rural Tanzania, where most families' income

is largely dependent on agricultural production, it is important that disabled children cultivate and demonstrate skills such as weeding gardens, or harvesting corn, to be considered valuable members of society (Stone-Macdonald, 2014). Stone-Macdonald (2014) found that autistic children often excelled at these tasks, but needed extra teaching. However, the Tanzanian curriculum has colonial roots, meaning that academic knowledge is privileged over more hands-on, everyday intelligence and little time is spent on more vocational instruction.

In order to understand historical and contemporary attitudes toward disability in Tanzania, Kisanji (1995) analysed a number of proverbs that he determined have been circulating in Tanzania for at least the last 60 years, striving to counter dominant discourses that use the myth of the hidden disabled to paint a negative picture of traditional African cultures (p.6). In oral cultures such as those in Tanzania, proverbs encompass cultural values instructing personal conduct and are used to teach younger generations, and remind the older ones, of what it means to be a “good” Tanzanian citizen. In his analysis, Kisanji (1995) found that many proverbs spoke to issues concerning disability, while very few of them expressed negative or rejective attitudes. The proverbs encouraged fairness and equal opportunities for all, including the disabled, while urging everyone to contribute to community welfare to the best of their ability. Some proverbs illustrated a fear of disabilities in the form of metaphors which reminded community members to behave in socially accepted ways (Kisanji, 1995, p.15). While some disabled people in Tanzania and other African countries have indeed suffered mistreatment, both historically and presently, Kisanji (1995) notes that this mirrors global experience, in all cultures reactions to disability can be seen to form a continuum,

therefore specific negative instances should not be taken to represent the non-western status-quo.

Contrary to the attitudes embodied in the myth of the hidden disabled, historically, beliefs about disability in sub-Saharan Africa have been both positive and negative (Stone-Macdonald, 2014; Kisanji, 1995). Religion is a major influence on conceptions of disability in Tanzania. Historically, there have been a number of explanations which African populations have used to understand the cause of disability, while those that blame disabilities on curses have been most popularized in western discourse. Consistent with the work of Danseco (2006) and Gannotti et al. (2001), Stone-Macdonald (2014) documented both biomedical and socio-cultural views of disability in East Africa, with a recent shift towards a melded model in which disabilities are seen as the result of a multitude of factors combining both medical and non-medical explanations (p.8). While the myth of the hidden disabled tends to concentrate on “bizarre” socio-cultural explanations such as witchcraft or sorcery, Stone-Macdonald’s (2014) Tanzanian informants rarely mentioned curses and insisted that those beliefs were a thing of the past (p.123). Instead, both Muslims and Christians cited religious beliefs that disabilities are a part of God’s plan. Although they understood and believed biomedical explanations, they were also convinced that medical and health issues were additionally influenced by deities and other religious forces (p.123). Religion has had a positive impact on the treatment of children with disabilities, however, while the doctrines of both Islam and Christianity stress the importance of familial care and support for disabled children, they do not necessarily postulate that these children deserve to be active members of the community (Stone-Macdonald, 2014, p.124). Shaked (2005) found that in ultra-orthodox

religious communities in Israel, the behavioural difficulties that often accompany autism made it difficult for autistic children to participate in religious rites, a key aspect of community life, while Stone-Macdonald (2014) cited a debate in rural Tanzania over whether to allow children with intellectual disabilities to attend church. Disabilities like autism present certain barriers to full participation in daily life, compromising social inclusion, and preventing autistic individuals from qualifying for ‘personhood’ as it is defined in their community.

Defining Disability Across Cultures: Poverty and Aid

World Health Organization (2012) statistics claim that the presence of a physical or intellectual impairment for a child in Tanzania doubles the likelihood that they will not attend school. Since 2008, the Tanzanian government has been working with local organizations and outside donors to address issues of disability and to create more inclusive practices and strategies. Education programs have been set up in Tanzania for children with disabilities, including those with autism, by western donors and NGOs using a community based rehabilitation model; one that has been criticized for its cultural insensitivity. Although stigmas surrounding disability still exist to some degree, these actions suggest that it is not intentional disregard, but financial constraints, that prevent most disabled children in Tanzania from accessing the same opportunities awarded to their non-disabled peers. Lack of economic stability makes it difficult for any children to receive adequate schooling, let alone those who may require extra assistance. In developing countries, more immediate and life-threatening problems, such as HIV/AIDS,

conflict, and political instability usually take priority over disability, which is considered more of a long-term, rehabilitation issue (Muyinda & Whyte, p.125).

Eide and Ingstad (2011) argue that the complex relationship between disability status and dire poverty is often ignored. There is little knowledge about the impact of impairments on daily life when combined with poverty in resource-poor settings or the coping strategies adopted by individuals in these situations, but “there is sufficient knowledge to conclude that people with disabilities are at risk of being the poorest of the poor” (Grut, Olenja, & Ingstad, 2011, p.154). Ingstad and Eide (2011) found that in Somalia, children with disabilities from poor families were treated worse than those from more affluent backgrounds, suggesting that class status offered some reprieve from stigmatization and elicited more positive reactions to children’s impairments. Grut, Olenja and Ingstad (2011) recognize that the parental behaviours deemed cruel by outsiders, and lambasted in north-south myths, are actually the result of forced choices constrained by the overbearing presence of poverty. It is significantly more expensive to have a disabled child. These children may not be accepted at the local school, necessitating costly travel to special donor-dependent schools, which are few and far between. Parents make the tough, but most economically feasible decision to send their non-disabled children to school instead (p.161). According to Grut, Olenja and Ingstad (2011), in a harsh environment in which every penny counts and survival is a serious concern, these parents are not callous or cold, but practical.

Even when parents do decide to send their disabled children to school there can be complications. Grut, Olenja and Ingstad (2011) offer the example of an autistic boy in Kenya who was able to attend the local school, but who needed assistance to disembark

the bus at the right stop. His parents were busy at work, and in a display of apathy that runs contrary to the values of community generally upheld in East Africa, neither the driver nor his fellow passengers offered to help. When he got lost one day, his parents decided to discontinue his schooling out of fear for his safety. Further, in the occasion that the barriers of transport and limited finances are surmounted, most schools are ill-equipped to serve the needs of disabled children, leading parents to make very realistic assessments of their child's learning environment, concluding that attendance is just not worth the risk (Grut, Olenja, & Ingstad, 2011, p.162).

Special western-funded boarding schools for children with disabilities are seen as the most appealing solution. However, Stone-Macdonald (2014) notes that while these schools are tailored to address disabilities, they may not serve the child's best, long-term interests, as children's absence from the community does not allow for integration, awareness, and acceptance. This is consistent with Murray's (2008) argument that it is "autistic presence that resists the many discourses that would simplify or ignore the condition," as the physicality of this presence forces communities to reconsider what constitutes 'normal' human behaviour. The presence of autistic people, displaying a variety of personalities and ways of being, defies reduction to "simple narratives - medical, social or cultural - that might seek to contain it without reference to its own terms" (Murray, 2008, p.3). Further, the academic focus of these schools deemphasizes "tacit cultural knowledge" which Ochs et al. (2004) argue is critical to successful navigation of social life, especially for children with autism. Stone-Macdonald's (2014) work in Tanzania revealed an increasing acceptance of disability in rural communities, but also a persistent need to bolster social integration of children with disabilities into the

social fabric by increasing their presence, facilitating opportunities for them to be seen and heard interacting positively with other members of the community. This cannot be accomplished by sending them off to schools where they may become more academically inclined, but will eventually return to live out the remainder of their lives in a community in which they lack the practical skills and social history to be considered full persons.

Community Based Rehabilitation (CBR) is an initiative developed in 1978 by the World Health Organization (WHO) as a strategy to improve access to rehabilitative services for people living with disabilities in low-income and middle-income countries. In the decades since, it has been adopted and adapted by several UN organizations, non-government organizations (NGOs) and disabled persons organizations (DPOs). CBR serves as a framework for developing programs that are integrated into local communities, promoting the inclusion of disabled people and which aim to facilitate individuals' achievement of the freedoms outlined in the Convention of the Rights of Persons with Disabilities (WHO, 2010). Additionally, CBR aims to reduce poverty through access to health, education, livelihood and social sectors, while empowering people with disabilities and their families by including them in decision making processes. The guidelines for implementing CBR encourage regular evaluations of their effectiveness in meeting community needs and improving the well-being of people with disabilities (WHO, 2010; Pollock, 1992; Mitchell, 1999). CBR is currently practiced in over 90 countries using guidelines developed in consultation with over 180 different people, mostly from low-income countries. CBR claims to be a "bottom-up" strategy with the ability to make a real impact in fulfilling the aims of the Convention. In a case study from India, Chatterjee et al. (2003) have shown how the CBR model can be

extremely effective in rural settings by encouraging local community participation, utilizing low levels of technical expertise to deliver services and improving patient compliance rates, yet these results cannot be generalized. There is always a considerable gap between official protocol and actual practice. Despite the noble goals outlined in the CBR framework, individual programs vary in their ability to address local concerns in a culturally respectful and appropriate way; many rely on western discourses and specialists unfamiliar with the cultures of their patients. Thus, it is important to acknowledge the possible shortcomings of CBR strategies, noting how programs “on the ground” differ from the ideal models outlined in the CBR guidelines, and how these programs may serve as a means through which western discourses, particularly those concerning autism spectrum disorder (ASD), are exported to the rest of the world.

Defining disability across cultures is increasingly complex. It has no universally adopted definition and its meaning is contingent on its placement in unique socio-cultural contexts. The category itself is a western construct borne out of a particular historical moment in Europe (Grech, 2009, p.772). Whether a particular condition constitutes a disability in a given setting depends on the skills and abilities that are valued in that culture. Dyslexia, for instance, is unlikely to be considered a disability, or even acknowledged to exist, in a country that places little value on literacy (Ingstad & Whyte, 2007). Thus, “it is a mistake to assume that treatment approaches developed in the west can be blindly generalized to children (or adults) with disabilities across the world” (Ravindran and Myers, 2011, p.312). Grech (2009) claims that the process of definition is a decidedly western endeavour, serving power functions closely linked to development agendas and focusing on labeling cultural others as “abnormal” according to western

norms. Ingstad and Whyte (2007) argue that instead of focusing on developing universal definitions and categories of disability, scholars and advocates should pay attention to what is specifically disabling for individuals in their worlds (p.14). Additionally, in countries where families act as social security systems, Grut, Olenja & Ingstad (2011) suggest a shift of focus away from diagnosing individuals, to addressing the needs of disabled households (p.167).

Frustrated by health professionals' tendencies to focus solely on their subject of clinical expertise, ignoring the socio-cultural context in which patients live, Leavitt (1999) argues for a blending of the fields of rehabilitative medicine and medical anthropology, creating the subspecialty of cross-cultural and international rehabilitation in an attempt to address and rectify the lack of cultural competence among most rehabilitative health care workers. She believes that health professionals can only be effective in working with diverse populations if they make a concerted and genuine effort to understand their clients' socio-cultural backgrounds (p.3). Additionally, they must be self-reflexive, willing to assess the impact of their own cultural influences on their views and actions, recognizing that it is not only the "other" who is a product of a unique cultural context and taking care not to overlook intra-cultural diversity (Leavitt, 1999, p.3). Leavitt (1999) plots rehabilitative efforts along a continuum of cultural competence beginning with cultural destructiveness and ending with cultural proficiency, determining that most critiques of CBR focus on its cultural incapacity: when a system fails to operate effectively within another culture, maintaining biases, supporting stereotypes and assuming a paternal stance; or its cultural blindness: when programs attempt an unbiased philosophy, assuming all people are the same, but in doing so ignore the need for cultural

specificity, thereby offering ethnocentric services which invalidate the strengths of local cultures (Leavitt, 1999, p.4; O'Toole, 1987). As Miles (1996) elucidates, the term rehabilitation is itself problematic, hinting at the underlying tendency to empower professionals at the expense of locals.

Two major classificatory systems endorsed by the WHO are used to produce standard diagnoses of diseases and disorders and to plot their distribution around the globe: The International Classification of Diseases (ICD), now in its tenth revision, and the Diagnostic and Statistical Manual (DSM), currently in its 5th edition, which offer categorical approaches to disabling disorders like autism based on specific criteria (Florian et al., 2006). The label of autism is quickly accumulating cultural currency on a global scale. Grinker (2007), one of the few scholars to study autism cross-culturally, argues that autism predates its terminology, suggesting that people who have historically been considered slightly odd, or were even revered for their unique abilities, are now clinically diagnosed as autistic. He views autism as a social construct subject to the instability of diagnostic criteria that is constantly evolving in correlation with new medical and scientific advancements. The American Psychiatric Association periodically produces DSMs which dictate what is considered a disorder and serve as standardized diagnostic measures. In his cultural constructivist critique of DSMs, Gaines (1992) argues that “professional psychiatric classification expresses an underlying cultural psychology” which relies on western conceptions of personhood (p.3). According to Gaines (1992), the DSM and similar standardized diagnostic formats developed in the west are articulations of a particular “cultural voice” (white, western, male) which seeks to assert a “positive notion of self” through a discourse of disease classification (p.3).

The medical model at the core of psychiatry assumes that diseases, disorders, and mental illnesses can be “discovered” using diagnostic tools, while Gaines (1992) claims they are “created” through the same means. He argues that conditions like autism are cultural constructions borne out of “interpretations of defined abnormality” encountered in both medical and non-medical contexts. While Grinker and Cho (2013) agree that psychiatric diagnoses are social constructions, they contend that it does not follow that “symptoms or constellations of symptoms were not real or disabling before they were named,” as historical analyses will show, but that the meanings and labels attributed to these symptoms or behaviours change over time (p.47). Behaviours which are presently seen to comprise ASD used to signify a diagnosis of “childhood schizophrenia,” a condition which is now considered largely obsolete, not because children’s behaviours changed, but because ideas of what constitutes a particular disorder evolved (Grinker and Cho, 2013, p.47). Rather than disputing whether actual biological phenomena underlie the conditions that the psychiatric community names and classifies, the focus of these critics is to examine how “psychiatric concepts and the institutions that support them evolve and change the way one understands human thought and behaviour” (Grinker and Cho, 2013, p.48).

CBR is an example of an institution through which this process can be observed. Western health professionals, mainly psychologists, are sought as volunteers through CBR programs to diagnose and explain autism to local families in biomedical terms. This process was explained to me by Ashley Johnson, a U.S. based psychologist who volunteers at a rehabilitation centre in Tanzania (personal communication, Oct.12, 2013). She claims that formal diagnostic evaluations in the region are virtually non-existent,

however in Stone-Macdonald's (2014) work, she found that local teachers had developed their own checklist for diagnosing autism, suggesting that informal, culturally significant methods do exist, but remain under the radar due to lack of ethnographic knowledge.

Further, none of the dominant, western affiliated diagnostic measures have been translated for use in local languages. In some countries assessment tools have undergone cultural adaptation and translation procedures, yet Ravindran and Myers (2012) explain, empirical investigations of the clinical utility of these carefully adapted instruments in different communities are very rare (p.49). Norbury and Sparks (2012) urge researchers to examine the exportation of diagnosis and treatment models for neurodevelopmental disorders from western countries, questioning whether it is helping children and families from other cultural backgrounds, or pathologizing people who are otherwise well adjusted within their own communities (p.52).

Johnson noted that she tried her best to modify standard protocol to improve cross-cultural validity, but her main objective was still to define Tanzanian children as autistic based on symptoms that have been designated as abnormal according to western norms. The symptoms of autism such as social aloofness, unusual play, or poor eye-contact which in western terms are taken to signify developmental delays, may not be applicable in different social contexts. There are huge cultural variances in expectations of social-communication behaviour, as Norbury and Sparks (2012) explain, in China eye contact with adults and pointing with the index finger are considered inappropriate for children, yet the ability to master these tasks is weighted heavily in many western diagnostic algorithms (p.49). Likewise, the ages at which parents expect children to reach so-called "developmental milestones" vary both inter-culturally and intra-culturally, for

instance, Gannotti et al. (2001) found that Puerto Rican parent's expectations of children's functional skills such as feeding oneself with a spoon, or smiling at a face were expected to occur later than American children due to strong cultural values of interdependence and overprotectiveness (p.1515). Thus, according to the American norms institutionalized through medical and psychiatric discourse, all Puerto Rican children may be diagnosed as having a developmental delay. Norbury and Sparks (2012) add that disorders may manifest in locally specific ways. Of the few studies on autism in Africa, two reported that certain stereotypical behaviours observed in children with ASD in western countries (e.g. hand flapping or rocking) were uncommon among African children with the same diagnosis (p.49). Setting aside the fact that behaviours taken to exemplify symptoms are being analyzed out of context, the very process of diagnosing autism may be culturally inappropriate. A foreign psychologist conducting a one on one session with a child may have a significant impact on the child's demeanor, as this sort of encounter is very unusual in many cultures. Further, the reliance on a translator may cause important linguistic nuances to be lost. Therefore, Gannotti et al. (2001) argue that while standardized measures are necessary for diagnosing and treating disorders, the results cannot be adequately interpreted if the social and cultural context in which they operate is not understood, thereby seriously compromising or even negating their efficacy, (p.1513). Therefore, clinical assessments should be attuned to determining whether a child would be described as having pragmatic deficits by members of their own cultural community, according to its unique norms and expectations of behaviour (Norbury and Sparks, 2012, p.49).

In their work on the cross-cultural implications of assigning children into diagnostic categories of disability, Florian et al. (2006) offer a more benign interpretation than those noted above, viewing the process as part of a long practiced attempt to understand human differences. While they concede that labeling children in an educational context may reinforce the differences that specialized programs are intended to address, they nevertheless maintain the belief that systems of classification are an important and crucial component in developing a framework to guide intervention (p.37). To negate the risks associated with classification, Florian et al. (2006) stress the importance of recognizing and examining childhood disability in a relational context, a process which Grech (2013) agrees is crucial in determining the cross-cultural appropriateness of disability discourses that are largely borne out of a western individualistic perspective. Florian et al.'s (2006) version of classification attempts to counteract the tendency for such systems to locate the difference of disability within the individual. As an example, they discuss a collaborative project undertaken by the Organisation for Economic Development (OECD) which attempts to improve international data collection on disability in education systems by creating three broad categories into which all national conceptualizations of "special needs" students can be slotted, reflecting data from 36 countries in a common format (Florian et al., 2006, p.40). However, in an attempt to condense information, this tripartite model fails to illustrate the complexity of children's experiences and differential interpretations of characteristics across cultures. This is because the policy frameworks employed in national special education initiatives are founded on discourses that describe and reinforce a particular worldview; one that dictates student's experiences in the language of special education

and continues to be influenced by a medical model of impairment (Florian et al., 2006, p.40). As someone who grew up with a disability in Africa, Kisanji (1998) argues that the western emphasis on inclusive policies of special education assumes the pre-existence of exclusionary practices and ignores the history of valuable and inclusive practices of indigenous customary education in which the curriculum focused on cultural transmission and the acquisition of functional skills (p.59). Kisanji (1998) claims that development projects such as CBR often strive to fulfill a perceived need for academic instruction, while dismissing more traditional and practical vocational education.

CBR programs often perpetuate the myth of the hidden disabled to justify their presence. The CBR guidelines provide a historical overview of the concept of disability, beginning with the assertion that many traditional societies still believe in mythological or religious sources of disability such as devils or spirit possession. The guidelines claim that the disability rights movement has caused a shift away from medical models that focus on individuals being cured, to the more appropriate human rights approach (WHO, 2010). I identify two issues with this narrative: first, in the case of autism, as I have explained above, the medical model is still dominant, and second, it assumes that the individually focused human rights approach is universally appropriate and beneficial. As Grech (2009) contends, what is considered oppressive in one society may not be so in another. Depicting a person as oppressed when they do not conceive of themselves as so “may only serve to marginalize and stigmatize the person in a way not dissimilar to medicalisation” (Grech, 2009, p.777). In this way, the supposed “solution” can also become the problem, as attempts to confer individual rights through service provision may cause people to be singled out as “special cases,” detaching them from the rest of

their community (Grech, 2009). Miles (1996) believes that CBR does need to have a rights-based agenda, but that it should be formulated through direct engagement with local adaptations of the disability rights movement. She attests that CBR programs need to create relationships with local DPOs (helping to facilitate their growth if none exist) so that children will have positive role models who serve as tangible representations of future possibilities. Further, CBR programs should establish a collaborative relationship with parents and DPOs in which roles are re-evaluated, and decisions are made through dialogue.

Conversely, Grech (2009) disputes this position, even though the UN's commitment to anti-discrimination legislation has been undeniably instrumental in shifting global attention away from disability as a medical issue and redefining it as a political concern. Her critique centers on the fact that human rights are a distinctly western invention and that while a number of DPOs and NGOs in the global south have adopted powerful slogans such as "rights not charity" from the disability rights movement, ideas, money, and resources still invariably flow from north to south (p.778). Grech (2009) maintains that the language of disability rights is unevenly adopted by urban elites, rather than the rural poor, in low-income countries and stems from "the western obsession with and idealisation of individualism and autonomy" (p.778) This discourse, like any dominant discourse, paints with a broad stroke, overlooking the complexities of context and the unique challenges of people living with both poverty and disability (Ingstad & Whyte, 2007). Further, in cultures where strong community ties and relationships of mutual obligation are critical to survival, individual rights may present a serious threat to economic stability and social cohesion (Grech, 2009, p.778). Thus, while

CBR tries to attend to local differences at a surface level, the assumptions at its core may render it fundamentally inappropriate for use in collectivist cultures. Further, there is an obvious power imbalance when autism is targeted through CBR initiatives, as western expertise and diagnostic protocols are privileged over local knowledge. It remains to be seen whether careful consideration from a cultural relativist position and genuine consultation with disabled children, their parents and their communities can make it possible to avoid these pitfalls

Chapter 3: Background Information and Theoretical Framework: A Context for Inquiry

A Brief History of Tanzania: Culture, Social Structure and Governance

The nation of Tanzania dates formally from 1964, having been a faction of German East Africa from the 1880s to 1919 when it became a British mandate. The country served as a military outpost during World War II, existing as a United Nations Trust Territory under British administration from 1947 until its independence in 1961, when Julius Nyerere, “the Father of Tanzania,” initiated his decades of leadership. In Tanzania’s infancy as an independent nation, Nyerere developed and implemented a unique ideology of African socialism called Ujamaa – Kiswahili for “relationship, kin, or brotherhood.” Ujamaa was his version of a socialist philosophy of development based on “the principles of freedom, equality and unity” (Human Rights Watch, 2013, p.22). Nyerere was an ardent proponent of equality, establishing Kiswahili as the national language to prevent ethnic conflict, and drafting a national constitution in which discrimination is emphatically renounced, while human dignity and justice are passionately upheld. In searching for an appropriate political formula for his part of the world, Nyerere looked to the small, kinship-based societies of the past. He recognized qualities in traditional African versions of equality, democracy, and socialism that “could be adapted to serve the collective needs of the present” (Yeager, 1989, p.31). The subsistence cultures that inspired Nyerere commonly believed that their environments contained a finite amount of resources to sustain and advance human life. Following this belief, one family or social group could not accumulate an excess of basic resources without jeopardizing the well being of another. In villages, “harsh geographical

surroundings, labour-intensive technologies, and familial social organizations” necessitated a dependence on sharing resources and created high levels of cooperation amongst both individuals and groups (Yeager, 1989). Loathing inequality, Nyerere noted that within a political structure based on this principle, “the different shares of different members of a family can never get very unequal; all the customs operate to bring them constantly back toward equality” (Yeager, 1989, p.31). Nyerere’s visions of equality harkened back to pre-colonial times, where “...presumably inequality did exist between the sexes and among the generations of different descent groups,” but which he imagined was far more egalitarian, whereas “...the colonial experience had joined African kinship segments into new and broader sets of relationships, introducing wider and deeper inequalities and an ethic of interpersonal and intergroup competition” (Yeager, 1989, p.32).

To Nyerere, this inequality was seen to have significantly weakened the unity of Tanzanian society, thereby impeding its functionality; he saw this capitalist model as distinctly un-African. Nyerere identified democracy and democratic socialism as the solution to healing his nation and restoring equality, looking toward the traditional values and customs of previous generations to inspire his political actions. After spending the better part of the 1960s and 1970s devising ways to establish socialism in Tanzania, Nyerere was confident that ujamaa would catalyze the development of a national moral code that would foster economic equality and a democratic society (Yeager, 1989). Within ujamaa, resources are shared equally based on one’s needs and their willingness to work. This concept forms the basis of Tanzania’s development ideology. Indeed, Yeager (1989) posits that the country’s focus on ethical, rather than material,

foundations, is perhaps the reason behind its continued financial struggles. Nyerere's ideal for independence was not unanimously supported, as both colonial and local politicians put forth different strategies, placing far greater emphasis on disciplined political organization. When Nyerere's goals for Tanzania were finally manifested in policy form in 1967, they were punctuated by these dissenting ideas (Yeager, 1989) Throughout the 1960s and 70s, Tanzania implemented policies of self-reliance, including extensive compulsory viligization (ujamaa), nationalization, and price controls, which Reed (1996) describes as s catalyst for "short-run growth, but long-run economic downturn" (p.108). By the 1980s, Tanzania was the world's second poorest country in terms of GDP per capita, and its natural resource base became noticeably threatened, initiating "a movement towards more market-oriented policies and a change of political leadership" (Reed, 1996, p.108). In 1985, Nyerere relinquished some power, becoming chairman of the ruling party until 1990, when he handed over that responsibility as well. However, his unique socialist ideology has had a lasting impact on the nation he so passionately "fathered."

Nyerere's model of unity and non-discrimination has been highly effective in quelling political and ethnic conflict. Tanzania is the only East African country whose history is not marred by such violence (Human Rights Watch, 2013). However, as documented in a Human Rights Watch (HRW) (2013) report, social exclusion is certainly not a foreign concept: "Due to either their immutable characteristics or their general social status, there have always been outsiders in Tanzania" (p.22) These "outcasts" include people with albinism, refugees and street children (HRW, 2013, p.22). Interestingly, the report contends that Nyerere's emphasis on social cohesion is perhaps

antithetical for the progression of human rights in Tanzania, arguing that in a country that reveres calm and peaceful consensus, “discussion of human rights can seem provocative” (HRW, 2013, p.23). Nyerere’s ujamma can be seen to have created a country in which societal harmony is prioritized over the resolution of individual injustices. An activist from Dar Es Salaam explains, “There were no human rights organizations before because of the community system... When we started to talk about human rights, for many in Tanzania, it was a strange thing” (HRW, 2013, p.23).

During the early and mid-sixties, when most African countries achieved independence, planners subscribed to human capital and modernization theories which held that the most profitable form of investment, for both societies and individuals, was education (Sifuna, 2007, p. 691). Education became a primary target of global development initiatives, the general consensus being that education is essential to economic and social development, and that schooling would improve the quality of the workforce by equipping labourers with the necessary skills and knowledge to participate more ably in the modern economic sector (Sifuna, 2007). Sifuna (2007) writes:

The optimistic decade of the 1970s witnessed high rates of economic growth and rapid ‘development’...without any appreciable improvement in the condition and life chances of the world’s poor, especially women and children...by the late 1980s, the world’s economies were already mired in recession and decline, huge foreign debts were accumulating in the poorer nations (holding them hostage to the United States and Brussels), and the World Bank was insisting, rather highhandedly, on structural adjustment policies (p.692).

Schepher-Hughes (1996) provides a broad overview of global development, characterizing the 1980s as “a decade of neoliberalism and structural adjustment programs,” while the 1990s represent a period of “radical transitions to democracy and the pursuit on a global scale of individual and human rights” (p.7) In her opinion, this “Western-based but international discourse on human rights – including women’s and children’s rights – underwrote the reformist spirit of the times (Schepher-Hughes & Sargent, 1996, p.7) Consequently, the human and political rights of women and children have been formally recognized in new constitutions and in universal documents such as the *United Nations Convention on the Rights of the Child* which was ratified in 1990. During this time, education was viewed as the preeminent global solution. The twentieth century modernization thesis, Stambach (2006) argues, presupposed that “state-sponsored education would produce common structures and practices across different national systems” (p.288), yet this theory fails to capture the whole picture. The World Bank’s narrow focus on quality through cognitive achievement has faced serious criticism by those who argue that the goals of schooling should encompass more than just academic success, and that a purely academic model ignores issues which deal with overall human betterment (Hawes and Stephens 1990; Smith 1993; Sifuna, 2007). Further, such development strategies have had a fundamental impact on the social relations and familial practices of the places in which they are implemented. As Stambach (2006) contends, “...under modernist visions of governance, communities were supported in part through the services of state agencies, [however] neoliberal policies implemented in recent years conceive of individuals as financially and socially responsible for themselves. This

reconceptualization has had important implications in Africa, affecting how extended families operate and cooperate in sharing expenses and distributing resources. It has contributed to a sense of autonomy among younger generations, who, compared with previous cohorts of secondary school graduates, have fewer prospects for employment and, when employed, tend to send comparatively little money to family members living back home (Stambach, 2006, p. 289).

This shift away from collectivity and toward a more individualistic social structure is necessary to complement a capitalist economic model. However, it has profoundly influenced not only the education system, but Tanzanian society and its national psyche as a whole. While ujamaa called for self-reliance, social cohesion, social consideration and the sharing of communal resources, the introduction of neoliberalism in Tanzania has placed an emphasis on an economic and individual liberalism in the form of rights and obligations, self-reliance and self-management, and a turn away from community dependence and regulation” (Ong 2006, p.50). Further, I believe it has been instrumental in shaping present-day attitudes toward persons with disabilities, affecting their quality of life and their ability to enjoy the full benefits of personhood, as individual achievement takes precedence over cooperation. Colonization, and now modernization and globalization, have spurred a societal movement away from communal structures, which by default may be taken to represent progress, but which have created environments that are much less hospitable for people with disabilities, creating another obstacle to their acceptance. Critically, the status of a society’s disabled cannot be extricated from the socio-economic and political conditions in which it operates.

Moshi: Formation of ACT

Moshi is a Tanzanian municipality with an estimated population of 184, 292 nestled at the foot of Mt. Kilimanjaro, Africa's highest mountain (National Bureau of Statistics, 2013). Its proximity to this majestic peak, coupled with its relative closeness to the famed Serengeti desert, makes Moshi a bustling hub for tourists and local entrepreneurs alike. I was hard pressed to find an individual whose livelihood was not somehow linked to "the mountain" or the plains -most conversations with young men inevitably lead to them offering me a discounted deal on a climb, or a Kili-Safari combo – and the town was consistently crawling with foreigners kitted out in stereotypical outback garb. This unique geographical locale makes Moshi an ideal location for NGO headquarters, as "voluntourists," (those wishing to attach a brief stint of humanitarian work to their vacation time), can easily transition into a climb or a wildlife tour. Moshi's economy, originally centered on the coffee industry in the 1970s and 80s, has become less robust in recent years due to global decline in coffee prices, loss of acreage, and prolonged drought, thus, tourism now forms the basis of most economic activity (Moshi Municipal Council, 2013).

The majority of people in the Kilimanjaro Region belong to the Chagga tribe, Tanzania's third largest ethnic group (Yeager & Ofcansky, 1997). The Chagga people are known for their business acumen, having formed the Kilimanjaro Native Cooperative Union (KNCU) in 1931, a system of organizing coffee marketing that became a model of African progress revered throughout the nation (Yeager & Ofcansky, 1997) and financed the enrollment of Chagga offspring in secondary schools and universities (O'Brien et al.,

2008). The Chagga are viewed as a relatively wealthy group by other tribes and are recognized for their entrepreneurship. Colloquially, they are referred to as having two main concerns: money and education. Indeed, education was a primary concern for the Chagga with whom I spoke, as well as a source of great pride. Figuring out ways to fund one's education and that of one's children was of paramount importance, as education is seen as an investment in the future, highly likely to deliver a satisfying return, and guaranteed to significantly elevate one's social status.

As such, Moshi is an ideal location to base an autism awareness organization that encourages schooling for disabled children. In fact, it was the existence of just such an organization, Autism Connects Tanzania (ACT) that brought me to this special town in the first place. ACT is a local program founded by a U.S. based charitable organization called EdPowerment and operated in collaboration with both local and American stakeholders. The organization was born after a chance meeting between Mama G, a former nurse for the Peace Corps then working at a hostel catering to volunteers, and one of her guests, Kerri Elliott, a special education teacher from Chicago, Illinois in 2008. Mama G had noticed "strange" things about her son, Erick, beginning in his toddlerhood. She had long suspected an intellectual disability, but had no label for his condition. She was confused about how to care for him and worried about supporting his development. Naturally inquisitive and fiercely maternal, she constantly sought answers. Eventually, she landed in the waiting room of a German doctor, "a specialist," refusing to leave until he saw Erick. She left his office with a label, "autistic," but little insight into what that word meant, and how it could help her to better understand her son. Throughout Erick's childhood, Mama G searched for ways to support his success, visiting various schools

and consulting several health programs, but found none of these avenues to be fruitful. Taking matters into her own hands, Mama G assembled a team of parents and government leaders who together built a special needs education unit at a local teacher's college and then another in a government school. The intention was to provide Erick and other local children with intellectual disabilities with a learning space that catered to their unique needs, yet by the time Mama Grace met Kerri in 2008, her son had reached adolescence and again she was faced with the problem of finding a "space" for him. At 19, Erick and several of his classmates were too old to attend primary school, yet were re-enrolled year after year. These students were not challenged academically, nor were they taught basic life skills, or encouraged to develop independence, thus they had made little collective progress, despite years of schooling. Hearing that Kerri was a special needs teacher in the United States, Mama G seized the opportunity to engage her as an ally, asking for assistance in creating a program that could advocate for the needs and rights of children, youth and young adults like Erick. In 2010, this vision came to fruition as a community based organization (CBO) called Autism Connects Tanzania (ACT). Its mission was to educate Tanzanians about autism by hosting seminars and workshops, training educators, and circulating information, with the ultimate goal of reducing the stigmatization of the intellectually disabled. The bulk of the information they distribute stems from a bio-medical approach, outlining the individuals characteristics in terms of deficits and suggesting ways in which their behavior can be adapted to better facilitate their acceptance in society, while also encouraging kindness and acceptance of these individuals, despite their eccentricities.

They hosted their first workshop at the Gabriella Rehabilitation Center. It was on the verge of closing its doors for lack of patronage. Stigma surrounding disability kept families from utilizing its services and prevented community support. However, ACT's involvement and endorsement spurred a dramatic turn-around. The center is now a bustling hub, well known and respected in the region. Families travel from afar to seek support and training, and dozens of children board full-time, proving that attitudes toward disabilities are in fact, mutable. ACT brought in two psychologists, one local and one American, who diagnosed several cases of autism using Western diagnostic measures, as a local adaptation has yet to be constructed. Suddenly, there was a label for what might have otherwise been regarded as strangeness, or craziness. A label that some experts, including Grinker et al. (2012) argue does not reflect an increase in the prevalence of the disorder, but merely provides a system of categorization - a language for measuring difference - that did not formerly exist.

This label has been ardently adopted by Mama G, who finally has a word without negative connotations with which to describe her son, and ACT, which introduced the word "autism" to teachers and local community leaders in their educational seminars. Subsequently, a Swahili translation, "usonge," was developed, although it has yet to be incorporated into the lexicons of those not directly involved in the cause. When I mentioned either autism or usonge to the average Tanzanian, they looked at me quizzically, assuming I was referring to someone who was "artistic," in English, or politely dismissing what they interpreted as a gaffe in my Swahili. Thus, Tanzania provides us with the unique opportunity to witness the introduction of a diagnostic label, to observe the "birth" of autism by that name.

Understanding the Neurodiversity Movement

When I heard about ACT and its efforts to improve the lives of children with autism and other intellectual disabilities, I began to wonder if any parallels could be drawn between their work, and that of Western disability rights activists focusing on autism. In my research on autism activism, I uncovered significant controversy. The biggest organizations, Autism Speaks being the most visible, are very vocal and very well funded. They receive billions of dollars to be put toward scientific research aiming to uncover the root cause of autism and to eradicate it for future generations. On the contrary, there is a legion of autistic self-advocacy organizations, most notably the Autistic Self Advocacy Network (ASAN), which take a radically different stance. These autistic individuals and their supporters lobby for their rights and emphasize the intrinsic value of the autistic mindset. The community was formed largely on the internet, where people on the spectrum could connect, creating what Silberman (2015) calls “autistic space.” Self-advocates prefer to be referred to as autistic, not as people with autism, claiming that to remove their autistic characteristics would be to lose their essential “selves.” In their view, using “person first language” such as “people with autism” or “people who have autism,” suggests that autism is something that can be removed, rather than an integral part of their identity.

Self-advocates actively protest against Autism Speaks, lampooning their lack of autistic board members and their dogged focus on bio-medical, disease-focused research. ASAN members and their supporters are proponents of neurodiversity: the belief that while some brains may be configured differently than what is considered “normal,” they are no less valuable, and do not require “fixing.” ASAN organizes and stages protests

against Autism Speaks, publishing a joint letter in January 2014 which urged sponsors, donors and supporters to end their affiliation with the organization, referencing their reliance on “offensive and outdated rhetoric of fear and pity,” and their “history of supporting dangerous fringe movements that threaten the lives and safety of the autism community,” which directly undermines the efforts of ASAN to “empower and support people with all disabilities, including adults and children on the autism spectrum, to be recognized as equal citizens in our society and to be afforded all the rights and opportunities that implies” (<http://autisticadvocacy.org/2014/01/2013-joint-letter-to-the-sponsors-of-autism-speaks/>). Both a website and a Facebook page entitled *Boycott Autism Speaks*, are devoted to outing the organization, with detailed breakdowns of their budgetary expenditure (a 2014 audit of their financial statements shows 43.91% of their budget directed toward advertising, marketing and donated media, while a mere 3.84% is used to support family services, grants and awards), a list of high profile anti-Autism Speaks supporters including Home Depot and Toys R Us, and a petition to be signed by new collaborators (<http://www.boycottautismspeaks.com/home.html>).

Ari Ne’eman founded ASAN in 2006. In 2010, he became the first autistic person to be elected to the National Council on Disability. The New York Times described Ne’eman as “a lightning rod for a struggle over how autism will be perceived” (Harmon, 2010, March 27). He has been widely criticized by those who oppose his views. Jonathan Shestack, co-founder of the advocacy group Cure Autism Now, devotes his time to financing research that will terminate future instances of autism and castigates Ne’eman for not appearing “to represent, understand, or have great sympathy for all the people who are truly, deeply affected in a way that he isn’t” (Harmon, 2010, March 27). In

response, Ne'eman argues that those most severely impacted by autism actually benefit the least from the pursuit of a cure, as it detracts attention and diverts funding from accommodations and services that could drastically improve their quality of life. In his testimony to the U.S Committee on Oversight and Government reform (2012), Ne'eman cited statistics from the National Institute of Health's (NIH) 2010 budget: of the \$217 million spent on autism research, a paltry 2.45% went toward improving support and services for autistic people and their families, while a meager 1.5% was reserved for research that addresses the needs of autistic adults. By contrast, the big money gets funneled into research with causation, etiology, biology or diagnosis as its focus. While Ne'eman is not anti-research, he maintains that the research agenda needs to be recalibrated to include exploration of "both causation and quality of life" and to address the "actual needs" of autistic people at this moment (Congressional Oversight and Government Reform, 2012). ASAN's slogan "Nothing About Us Without Us" epitomizes their collective desire to help shape how autism is perceived by larger society, including governments, researchers and policy makers. I was eager to see if a similar community had formed in Tanzania, a flourishing or fledgling group whose ideas and opinions could be translated to align with the concept of neurodiversity. Based on my preliminary research and my initial contact with local stakeholders, discussions that continuously reiterated the lack of awareness and routine mistreatment of autistic people in Tanzania, I hypothesized that if such a concept did exist, it would not be immediately evident. It would have to be teased out.

From a Theoretical Perspective

I begin by acknowledging my positionality as a researcher, entering the field not as a “blank slate,” but as an open mind, shaped by my particular life experiences and the preconceptions they create, but willing to consider alternatives (Haraway, 1988; Charmaz, 2006). Unlike positivism, which attempts to deny our fundamental susceptibility to bias, believing that empirical and universal truths can be discovered using research processes that actively work to eliminate the researcher’s subjectivity and placing faith in the ability of systematic study and documentation to overcome the intrinsic “messiness” of social phenomena (Gergen, 2001; Morawski, 2001; Stanczak, 2007; Tolman & Brydon-Miller, 2001), I align myself with a social constructionist approach. From this standpoint, a neutral or unbiased opinion is considered unattainable. Instead, social constructionists continuously ratify the existence of the researcher-participant relationship and its impact on the data, incorporating an awareness of this rapport into both the research process and the data analysis (Tolman & Brydon-Miller, 2001; Anastasiou & Kauffman, 2011).

As a complement to this perspective, I employ “grounded theory” as articulated by Charmaz (2008), a perspective that is framed by the following assertions:

“1) reality is multiple, processual, and constructed - but constructed under particular conditions; 2) the research process emerges from interaction; 3) it takes into account the researcher’s positionality, as well as that of the research participants; and 4) the researcher and researched co-construct the data - data are a product of the research process, not simply observed objects of it” (p. 402). Researchers ascribing to this rubric prioritize the understanding of their participants’ points of view and consider their voices

as integral to their analysis. Any theory they produce does not simply “emerge” immaculately from the data, but is constructed by the researcher, according to the categories they choose to create and the theories they decide to apply. At its core, this methodology involves the examination of “meaning in context,” presupposing that all findings are forged from a particular social and theoretical setting (Charmaz, 2008).

A social constructionist approach to grounded theory is especially useful to studies like mine that examine differences in perception and explore the variances in heterogeneous discourses (Clarke, 2005). According to Ungar (2004), this approach enables a “critical deconstruction of the power that different health discourses carry” (p.345). Although useful in some ways, both biomedical and socio-cultural models of autism and their subsequent discourses emerged in a Western context, and tend to promote a singular, universal discourse, which may prove inappropriate when applied cross-culturally. While discourses emanating from the West have served to heighten global awareness of autism, arguably, they have not managed to generate further understanding of the disorder, but rather have “increased public fascination with a topic that seems to elude full comprehension” (Murray, 2008, p.4).

In order to develop a deeper, and more holistic understanding of autism beyond that extolled in dominant discourses, I adopt Murray’s (2008) “inside-out” approach by looking to autistic individuals and their families to supply narratives of their own lives. These stories and worldviews may differ from those promulgated by majority culture. I incorporate standpoint epistemology, as explained by Harding (2004), by examining knowledge as socially situated, taking everyday life as problematic, and building my thought process *up* from marginalized lives, rather than *down* from academia (p.40).

Feminist standpoint theory objects to the common conceptualization of the experiences and lives of marginalized peoples as providing “particularly significant *problems to be explained*, or research agendas” for which the answers can be found not “in those experiences or lives, but elsewhere, in the beliefs and practices of people at the centre who make policies and engage in social practices that shape marginal lives” (Harding, 2004, p.43). Charmaz (1990) supplies an antidote to this critique, suggesting that “[b]y starting with the data from the lived experience of the research participants, the researcher can, from the beginning, attend to how they construct their worlds. That lived experience shapes the researcher’s approach to data collection and analysis” (p. 1162).

Following this approach, I hold families of autistic children, as communities of knowledge production, to be the ultimate authorities on their experience and the starting point from which I begin thinking about autism. Harding (2004) argues that this strategy of “strong objectivity” counteracts the incentive for less powerful groups to understand perspectives other than their own, assimilating their views with those who belong to a more powerful group, and can produce more holistic, and in a sense, more objective, research by elucidating little known perspectives. Rather than try to universalize autistic experience in a singular discourse, adhering to only one framework or perspective of disability, these more culturally specific and nuanced accounts may be the only way to truly understand the place of autism in the world, possibly challenging the dominance of illness models and creating space for new identities to form.

Chapter 4: Methodology

Entering the Field:

Throughout the planning stages of my project, I had been in touch with Kerri Elliott, the principle spokesperson for ACT. She had arranged for me to station my ethnographic study at The Gabriella Rehabilitation Center. I would serve as both a volunteer and a researcher, conducting participant observation in the Center's many activities throughout my stay. However, despite this pre-arrangement, I was forced to adjust my research agenda immediately upon arrival in Moshi when the Gabriella Center revoked their invitation to host me.

As a result, my subsequent research was much more transient; a multi-sited project rather than a stationary one. While this approach may have cost me some depth, it more than made up for it in breadth. My research spanned a total of 3 months. I spent two weeks each at two of the Moshi School District's Special Education Units, Amani and Bushira. During my tenure at the latter, I met Mr.K, a passionate and curious special education teacher who took it upon himself to expand my research horizons by facilitating meetings, asking questions, and coordinating day trips to various sites engaged in, or related to, disability work. Mr. K became a trusted friend, primary informant, and invaluable research assistant who collaborated with me throughout the remaining 2 months of my study. Through a combination of Mr. K's networking, engagement with Mama G and Kerri's contacts, and participation in their various meetings and events, as well as my own exploration, I was able to cobble together a multi-faceted picture of disability in Moshi which not only helped me to address my

original research questions, but also allowed me to identify several more topics of inquiry.

Participant Observation and Interviews

My macro-level analysis of autism in Moshi is informed by an amalgamation of micro-level interactions and observations. On Fridays, Tanzanian special education teachers conduct home visits to check in on families and to assess their living situations. I was invited to accompany them, visiting the homes of ten students. Additionally, I visited 8 schools, 6 centers for disabled children, and one special education teacher's college. I met with three district educational officers, spoke with one local psychologist, and attended many of ACT's meetings, including its Annual General Meeting (AGM). I interviewed a minister in training, a disability rights activist in a wheelchair, and an exceptionally kind neighbour who takes it upon herself to look out for disabled kids in her community. According to Solomon (2012), "Anthropology can make important contributions to the understanding of human conditions and the social processes positioned at the intersections of biomedicine and social science" (p.244). My ethnographic fieldwork is intended to facilitate a deeper understanding of the lived experience of autism in Tanzania by delving beneath the layers of biomedical discourse and development rhetoric to examine the extent to which discursive constructs such as the myth of the hidden disabled can be corroborated with the stories of those whose lives they attempt to describe.

At Amani and Bushira, and within ACT, I occupied a dual role of both researcher and volunteer. My 8 years of experience working with children, including two years with

an autistic child and additional training in Applied Behavioural Analysis (ABA), qualified me to fill this role and allowed me to engage more deeply in the community. As Schneider (2006) explains, researchers can become an unobtrusive part of an organization by providing a useful function, and that “the participant role allows the researcher to understand the agency from the inside out, become an asset to the agency, and develop rapport with the people in the research project” (p.417). Through this type of “on the ground” research, I became a part of the autism conversation in Moshi, witnessing firsthand the collision point of local and global interpretations.

When my original plan to conduct a stationary ethnographic study at a single site was compromised, my research was enhanced. I gained access to a more representative sample of people from diverse backgrounds with varying perspectives, all converging around the issues of autism and disability. To complement my participant observation, I used a snowball sampling strategy to conduct 6 one-on-one semi-structured interviews. These were conducted in English and recorded with the interviewee’s express permission and informed consent. Further, I facilitated a series of “focused group interviews” which Grim, Harmon and Gromis (2006) define as “a qualitative method in which researchers interactively question a group of participants in order to test a theory-driven hypothesis” wherein survey type questions are integrated with questions that probe participants’ subjective experiences (p.517). In these sessions, Mr. K took on an assistant position, clarifying any miscommunications due to the language barrier and translating when necessary. My queries of all interviewees attempted to elicit responses which explained how they view autism, how they believe it should be treated, and where this knowledge comes from, as well as how they think autism is interpreted in society more broadly.

Interviews followed a rough interview-guide, but were flexible to allow for the interviewee to partially direct the process. I use pseudonyms for all the people and organizations referenced in my study, unless requested otherwise. Interviews were recorded on a handheld recorder after interviewees gave permission. Many of my participants had limited literacy and were intimidated by the introduction of formalized consent forms, thus I obtained verbal, not written, consent before conducting interviews.

Data Analysis

All recordings from interviews were transcribed and all data, including fieldnotes, was carefully inspected in order to conduct a thematic analysis. The term discourse has a tendency to be used so frequently and generally that it loses its meaning. I wish to avoid this pitfall. For the purpose of this analysis, I will separate the term into two categories, Discourse with a capital-D, and small-d discourse, as explained by Alvesson and Kärreman (2000). Discourses with a capital-D are dominant, institutionalized and organizational ways of speaking about and understanding an issue, in this case autism, while small-d discourses are those that are more localized, lesser-known and narrower in scope. My analysis sought to explore the relationship between these two types of discourses in Moshi, to see if and how they interact or influence each other. In addition to looking for this relationship in everyday speech within the data gleaned from participant observation and interviews, I also analyzed the formal documents and educational materials supplied by EdPowerment, the websites of both organizations, local newspapers and any other local publication which discussed autism, of which there were few. Not only was I looking to identify discourses, but also themes within them, such as the myth

of the hidden disabled, neurodiversity, and disability rights. Using a combination of both deductive and inductive content analysis, words were selected for significance and divided into content related categories representing a number of key concepts (Elo & Kyngas, 2007). To be considered a theme, the content had “to represent some level of patterned response or meaning within the data set that captured something important with relation to the research questions” (Robertson, Lang and Schaefer, 2014). This process allowed me to determine whether there was a differential dissemination of biomedical or socio-cultural views, or perhaps a complex melding of the two, and if the concept of neurodiversity exists in Moshi. Additionally, I was able to identify a number of common concerns and issues that can serve as targets to be addressed by policy makers and activists in the future.

Ethical Considerations

Nyambedha (2008) suggests that “researchers should take personal responsibility for addressing the problems of their study population” (p.776), doing so by explaining their informant’s opinions and situations to relevant NGOs, or helping to attract funds for grassroots organizations through such actions as helping to draft better proposals or linking them to appropriate donor agencies, not merely as afterthoughts, but as formal components of research design. In undergoing the important work of deconstructing possibly overly-naïve images of charitable organizations, I do not wish to jeopardize the potential for them to affect future positive change. As Murdock (2003) has noted, nakedly critical evaluations can compromise funding, or even destroy organizations (p.509). Although I may at times critique the work of EdPowerment, my ethnographic contributions are intended to facilitate changes that allow them to continue to support

community-based programs in ways that are more culturally sensitive. For instance, my work may help to generate the formulation of a culturally adapted diagnostic measure for autism, or to incorporate the concept of neurodiversity into their educational materials and seminars. My goal is not to determine whether Autism Connects Tanzania is a “good,” or “bad,” project, instead I follow Murdock’s (2003) lead in focusing on the lived experience of NGOs: “Our job as researchers may not be to ask whether they are ‘doing good,’ but rather to ask what are the constraints and affordances under which they attempt to ‘do good’ as they define it” (p.508).

Chapter 5: Disability in Tanzania: Case Studies

While in the field, some sites stood out as particularly rich loci for analysis in which common issues could be condensed, captured and communicated. Below, I present these spaces as case studies for your consideration.

Amani: Donor Influence, Parental Apathy, and Local Leadership

My first two week long placement was in a small special education unit at Amani Primary School, a well-funded and well-kempt unit about 10 kilometres outside of “downtown” Moshi and just a short walk from my place of residence.

My time there was initially quite discouraging. My first impression was of lazy, disengaged and uninspired teachers, sharing space with bored, often confused, and generally unstimulated students. I spent my first day - I was told it was “not typical” as students had just returned from a mid-term break - sitting on the floor playing Lego with the kids, none of whom were believed to have autism. The second day was much the same; this time one of the unit’s three teachers taught a lesson, using a repetitive call and response format and lasting approximately 15 minutes, throughout which she consistently and distractedly fiddled with her cell phone. Despite explicitly agreeing to my largely observational, researcher role, the teachers still seemed to expect me to step in and take over, calling me a “teacher,” and instructing me to lead the children in their lessons.

When I reiterated my position, they acquiesced, but still showed supreme lack of initiative. I was skeptical about the potential for meaningful engagement and data collection in that environment and felt apprehensive about the execution and ultimately, the success, of my study. However, I soon began to see my experience and the interactions I observed as illustrative of a common problem plaguing special education

initiatives in Tanzania, identifying an area worthy of greater attention and in great need of improvement.

Unlike most other government schools in the Moshi Municipal district, the special education unit at Amani receives outside support from a European aid group. As such, the space is much larger than average and far better equipped, the Lego alone is demonstrative of this fact. The walls are painted in cheery colours and accented with depictions of various Serengeti dwelling animals. The tables and chairs are sturdy and new. They have several books and colouring books - none written in Swahili or intended for an African audience - and other teaching materials, yet most of them sit locked up and unused. The resources are abundant, but the motivation to utilize them is nil. The unit has the unique privilege of financial assistance and access to teaching tools, highly unusual by Tanzanian standards, yet rather than stimulating and enlivening the teachers, this foreign influence in the classroom seemed to foster a sense of detachment and apathy. Why? The head of the donor group happened to be visiting throughout my stay, throwing into sharp relief the complicated social dynamic involved in donor-recipient relations and catalyzing a series of interesting events.

The Rafiki Group is a Belgian NGO headed by a well meaning, but inexperienced, and in my opinion, culturally insensitive couple. Penny speaks only a few words of Swahili and conversed mostly in heavily accented, choppy English. Her male partner, silent by her side, spoke neither, simply nodding and smiling at regular intervals. They had instigated and financed the building of the unit and felt very emotionally invested in the community. As an outsider, I immediately detected a tension between the teachers and Penny, a sort of turf-war, if I may. At the most basic and obvious level, I

noticed these strong, out-spoken Tanzanian professionals markedly alter their behavior in Penny's presence. They were more active in the classroom, working to create an illusion of structure where none existed, and essentially "performing" their roles. There was a palpable sense of disdain on the part of the teachers when Penny talked, emanating especially powerfully from Marie, the most charismatic of the three. They nodded and indulged her, feigning submission, while radiating contempt. It was almost painful to watch, their obvious distaste, and her oblivious reception.

Mama G stepped in to confirm my interpretation of this relationship. When questioned, the teachers freely aired their grievances. They were indeed flummoxed and frustrated by Penny; they felt usurped by her. The women explained that Penny had not deferred to their authority as teachers and as local community leaders, going around them to communicate directly with parents, thereby jeopardizing their jurisdiction. As a result, teacher-parent relations were fractured. Some parents had stopped sending their kids to school, except when Penny happened to be in town. A community meeting was to be held the following week, and Penny had already begun going door to door to recruit parents, rather than allowing teachers to have a principle organizational role. Mama G and Kerri were asked to step in as mediators, to try to heal the strained relations of all parties involved.

Promptly thereafter, they began to uncover several layers of resentment and conflict due to miscommunication and lack of cultural awareness. From things as simple as what to have for lunch – Penny had planned to order Pizza, a dish that would certainly not appeal to older villagers – or when to have the meeting – it cannot interfere with market times, and you must request that parents arrive approximately two hours before

you intent to start. It was clear that donor and recipient expectations were not aligned. In the past, Penny had provided food and gifts, such as t-shirts, creating suspicion regarding whether parents were attending out of genuine concern for their child's education, or for less altruistic reasons. Penny was aware of this, but had established her role as gift-giver, and did not know how to reverse it. The teachers were fed up. They felt ignored, resenting Penny for rendering them impotent.

The Rafiki Group's influence had tangible benefits in the form of better facilities and resources, yet these may not have outweighed the negative repercussions of teachers' apathy and community disengagement. In a study of NGO engagement in Ghana, Bawole and Hossain (2015) found that local governments resented NGOs for "spoiling local communities by lavishly doling out programmes and money to communities which discourage and kill self-help spirit" (p. 2075). Likewise, foreign aid has often been critiqued, albeit amidst much controversy, for creating a "dependency syndrome" which serves to prevent locals from "taking ownership" of their problems (Brautigam and Botchwey, 1999). In keeping with decades of development literature, Moss, Pettersson and van de Walle (2006) maintain that "certain types of aid could undermine long-term institutional development, despite donors' sincere intentions" (p.4), referencing the "resource-curse" which posits that aid without local involvement and investment "undermines incentives to build local institutions and perhaps a social contract with the population" (p.4). While such negative views may not be appropriate when used to delegitimize the practice of foreign assistance writ-large, they do prove applicable in this case, creating understandable concerns from ACT regarding the sustainability of the Rafiki groups' involvement and the future of the Amani special needs unit.

Mama G, ever perceptive, astute and socially aware, was highly attuned to this problem, and she intended to address it. She recognized the domino effect that would ensue should the Rafiki Group suddenly withdraw their support. A dynamic speaker and respected leader, she took control of the meeting, urging parents to take responsibility for their children with disabilities, just as they would for those without. After a Rafiki Group representative stood to speak about the new uniforms she planned to finance, Mama G spoke out: “We are supposed to provide for our children. It’s great that we have been given new uniforms, but we are supposed to feed our children, to care for them. We should not depend on these donations.” She employed the language of human rights, telling parents to *own* the problem and to *own* their child. Acknowledging that they can ask for help in doing so, but should not pass off responsibility: “You know you have to buy a uniform for your non-disabled kids. You know that’s what you have to do and that they have to go to school, but you wait for someone to donate it for your disabled child. They need to be treated equally. It is their right. ”

It must be acknowledged that Mama G is not a typical Tanzanian parent. Unusually, she embodies Sousa’s (2011) warrior-hero trope of upper-middle class mothers in the Global North, advocating tirelessly and sacrificially for her son’s well being. Her unique background and high levels of socio-economic and cultural capital precipitate such a stance. The fact that Mama G is highly educated, has been exposed to many new ideas and perspectives while nursing in the Peace Corps, and is relatively affluent, directly impacts her reaction to her son’s behaviour and her willingness to devote unlimited amounts of time and energy fighting for his success and his rights. Thus, she has a hard time relating to these village parents and grandparents, finding it

exasperating that she should have to instruct them in something as seemingly innate as loving their children.

Additionally, while human rights rhetoric can be extremely effective in articulating fundamental ideas of freedom and equality, it also has a tendency to be highly ethnocentric, articulating western ideas of personhood and childhood. Human rights activism sometimes “detaches violations of human rights from the political, economic and social contexts which make them possible and even rational” (Marks, 2011, p.59). Ideas about and expectations of children and notions of childhood are highly context dependent. As Stephens (1995) questions: “How can [we] celebrate a ‘universal’ code of children’s rights when the notion of ‘the child’ is so dependent on local meanings and practices?” (p.37) Schepher-Hughes and Sargent (1998) caution against the possible unintended consequences that may stem from a universal approach to human rights, suggesting that this “rhetoric could serve as a screen for the transfer of Western values and economic practices dependent on a neoliberal conception of independent and rights-bearing “individuals” as opposed to ideas of social personhood embedded in, and subordinate to, larger social units, including extended families, lineages, clans and village (or ethnic) communities” (p.21).

As such, it is important to advocate for children with disabilities in Tanzania to be afforded the rights that will allow them to flourish in their present locale and which are similarly experienced by their non-disabled siblings and peers, rather than to align with a prescriptive model that has little bearing on their actual experience. In his analysis of the anatomy of civil society in postcolonial Africa, Mutua (2009) “links the explosion of human rights NGOs in the region to the rise of the dominant Western-based human rights

movement, an association that foretells the deficit of ideological and conceptual originality in African human rights groups” (p.5). He decries “the thin social base of human rights NGOs and challenges them to exercise more independence from Western donors and cultivate local moral and financial support” (Mutua, 2009, p.5) In Mutua’s (2009) opinion, it is only by paying attention to the particular social, economic and cultural rights and issues, as discussed by “universities, analysts and think-tanks in the region,” moving away from a dominant focus on “the norms of a liberal democratic state,” that can help human rights NGOs in the region to “avoid a paralyzing crisis of legitimacy” (p.6). Mama G walks the fine line between donors and recipients, possessing the unique ability to relate to both, and serving as the perfect conduit for translating and relaying discourses and ideologies in terms that can be understood and accepted locally. With Mama G as its figurehead, ACT manages to avoid many of the problems that the Rafiki Group has encountered. She has an insider perspective and deep understanding of local customs that cannot be replicated by outside forces, thus she is able to relay human rights concerns in a manner and vocabulary that is colloquial and culturally salient.

As an anthropologist, it is my instinct to avoid blaming individual parents for their insensitivities, or perceived cruelties, instead looking to explain their actions with reference to structural and cultural conditions. My first line of defence is to argue that it is unfair to characterize these parents as heartless or callous, or to assume that they lack some essential nurturing gene, given that treating disabled children with indifference is a norm in Tanzania. Attributing little value to their education, and failing to envision a future in which they make quantifiable contributions to their communities is expected. Conversely, Schepher-Hughes and Sargent (1998) caution against this predisposition,

taking a hardline approach that is mirrored in Mama G's public admonishment of parents. They write that in our desperate attempts to avoid mother-blaming, we are vulnerable to "...the deadly consequences of an uncritical overattachment to the idealization of maternity and mother love, an attachment that can prevent family, friends, and even well-seasoned professionals from perceiving" the ill intent of some parents who are consciously harming their children (p.22). Adding that, all of these parties "try to see such high-risk women as flawed and imperfect, but still potentially "good mothers," (p.22) which in many cases may be true. Yet, the point remains that the unexamined perpetuation of this pattern exemplifies " a misguided political correctness that avoids assigning responsibility to parents – especially if they are poor- for the preventable injuries and deaths of their children" (p.22). Schepher-Hughes and Sargent (1998) argue that anthropologists have been reluctant to critique parenting, failing to analyze the actions of adults as they pertain to the well-being of their children, and very rarely entertaining the possibility that some parental actions may be willfully detrimental to their offspring, stating that: "strong ideologies of unconditional mother love and maternal bonding have contributed to the naturalization of maternal sentiments and the failure to see parenting as analogous to any other intentional and willful human action" (p.21).

Unlike myself, political correctness is not a rubric to which Mama G ascribes. Cultural relativity is not on her radar. She has no qualms about reprimanding her fellow parents and demanding that they rise to the occasion. While this approach may serve her well, it is not one that I can readily adopt, or that would be appropriate for me, or any other outsiders to express. It is a powerful illustration of the critical importance of local

leadership in community-based organizations and the principle force behind the success and respect that ACT has achieved.

Bushira: All of the Motivation, None of the Support

In sharp juxtaposition to Amani, Bushira, another of Moshi's special education units, has very few resources and no outside support, yet the teachers and students are significantly more engaged. I was warmly welcomed into their shabby classroom, its barren walls adorned only with a few faded calendar pages, several years outdated; introduced to every child - only 12 out of 30 total registered pupils were present; and provided with a short explanation of each of their conditions and backgrounds. They were shaky on the number of kids who had autism, guessing there to be 4 or 5 registered, and pulling two aside, Glory and Wilson, to work separately, stringing lines of colourful plastic beads, while the others worked with paper and pencils. The head teacher, Mr.K, stood out right away as an exceptionally kind and devoted educator. Glory is clearly the apple of his eye. He gives her candies "to keep her busy," gently guides her back to the classroom when she strays, which is often, and is clearly amused by her antics. Although she is non-verbal, Glory is a born entertainer, managing to convey immense amounts of information and emotions through body language, using various sounds, and directing attention with her powerfully expressive eyes. Mr. K has a degree in special education. His three female colleagues, Alice, Irene and Editha have special education certificates. All of them are engaged in the classroom activities and very eager to "share ideas with me." They are very interested in "special education in my country," especially inclusive education policies, and are driven to create change and to introduce new concepts, asking

“how can we make a connection with people in your country, maybe by email, to share ideas about autism.” Their ambition and dynamism stood in stark contrast to the Amani teachers’ detachment and lassitude. They wanted very badly to have a donor, pointing out the classroom’s dilapidated appearance, caused partially by the absence of window coverings. They ached to provide the kids with more educational opportunities, explaining: “We want to take the kids places, to visit the national park, to go to the soda industry, to the airport and to get a balance beam that is lower so they won’t fall off, but the government won’t pay.” Instead, they wrote letters to Moshi’s biggest corporations asking for donations, requests that have been either denied or ignored. They told me that parents pay for their “normal” kids to partake in such activities, but would not finance fieldtrips for a child with special needs.

In our two weeks together, we exchanged a wealth of information and became great friends. They asked me to make some posters for the walls, repeatedly suggesting that I utilize the slogan: “Disability is Not an Ability.” I was not keen to comply, perceiving a derogatory tone, and asked questions instead. They learned the slogan in English in college. When I probed deeper into its meaning, they admitted to some confusion, asking me to explain the word “ability:” “We understand the word ‘disability,’ but not this one ‘ability.’” This illustrates the effects of memorization without understanding, and the recitation of sentiments they are taught to view as right and just, but do not necessarily believe. The way they were using the slogan suggested that they wished to elicit pity for children with disabilities, more than compassion, and certainly not respect, encouraging people to feel sorry for these kids, but not suggesting that they possessed strengths and qualities worthy of equal consideration. The predominant

language they used in discussing their students was victimizing. Despite their obvious affection, the teachers did not seem to view disabled children as full “persons.”

The Autism Community in Moshi: Other Stakeholders

In an exemplary display of true Tanzanian hospitality, several of my contacts took it upon themselves to help me get a “bigger picture” understanding of autism in Moshi and the surrounding areas. Bushira’s infectiously curious head teacher, Mr. K, was my most invaluable networking tool and research assistant. Passionate about generating information that could support his efforts to attract government attention and allocate funding for his unit, he took it upon himself to be my escort and translator. He would leave work early, or otherwise rearrange his day, to accommodate our busy travel schedule. On our first trip, I proposed via text message that we meet at a mosque in the center of town, offering a description of its exterior colours when he asked for further clarification. From that point on, he would message me several times a week to coordinate our schedules, always addressing me as “Madam,” and invariably referring to our meeting spot as: “the place known as green and white mosque.” We traipsed around the region, squeezing onto crowded dala-dalas (vans), zipping around on the back of “boda-bodas” (motorbikes), taking buses and bumping down dirt roads in a bajaji (a motorized cart with three wheels). We visited every special needs unit in the region, several private organizations dealing with children with autism, and many government offices. When I was not travelling with Mr. K, I was utilizing Mama G’s network, tagging along on their trips, and sitting in on their meetings with various stakeholders, both local and international. At each site, I sat with the teachers, organizers, or

government officials and asked for their opinions and their suggestions. The summation of these micro-level interactions helped me to gain a more nuanced understanding of how disability and autism are perceived in Tanzania, forming a patchwork compilation that serves as a macro-level analysis. From these discussions and interactions, I was able to identify several key themes that I discuss in the following section.

Chapter 6: Themes: Common Experience of Disability

Throughout my research and across all sites of inquiry, certain experiences and explanations emerged as representative, having been expressed repeatedly and emphatically by multiple informants. I compiled these discussions into five distinct thematic categories presented below.

Disabled Children as a Bad Investment

It is not a wise financial move to spend money on a child that is seen to have no potential to improve the lot of an impoverished family, leading me to adopt the attitude that in conditions of poverty, children with disabilities are what I call a “bad investment.” My informants attributed this mass disengagement to parents’ awareness that “these children will never become doctors or lawyers.” They will never be able to lift them out of poverty. Over and over again, teachers expressed frustration stemming from the lack of parental involvement and general familial apathy surrounding the social and financial support of children with disabilities. Teachers complained that parents were unwilling to attend meetings at special education units, provide contributions of firewood or manual labour, pay for uniforms, or ensure their child’s consistent attendance, all tasks that would be considered par for the course in the education of a “normal” child. Mr. K cited parents as the biggest barrier to the success of special education units: “They are not involved. They do not come to talk about their child’s progress, to analyze, because they do not get profits from their disabled children. Normal children can help them and contribute to the family. They can give them profits.” Parents willingly contributed to “the normal school,” but not to the special education unit, “Not one single cent,” Mr. K lamented, “They say ‘we will do this and we will do that,’ but they never do.” When framed in economic terms, the decision not to invest in the future of a child with disabilities seems sensible. The guarantee on their return is low, if I am being generous,

and non-existent, if I am being honest about the conditions I witnessed. Sheila, a member of a local charitable organization for disabled children and a minister in training, put it this way: “If you compare two people, maybe the parent has a normal one and a disabled one, she is caring for the normal one because she knows in the future, he or she will help me.”

Parents’ reluctance to spend money on children with disabilities is compounded by Tanzania’s deep-rooted culture of foreign assistance and the prevalence of charitable organizations in the region, as was clearly evidenced in the case of the Amani special education unit. Parents come to rely on outside support, and in turn, their sense of culpability diminishes. In my experience, it was only those families that were affluent and highly educated that saw potential in their disabled children and wished to explore opportunities to educate and support them, to truly “invest” in their future. For these parents, with funds to spare, it was less critical that their income be focused entirely on the avenue with the greatest potential for remuneration. For them, survival is not the foremost concern. Thus, it is unfair and inaccurate to attribute the apparent neglect of children with disabilities, and the assumed disregard for their welfare, entirely on ignorance or apathy.

This reluctance to invest in disabled people extends to Tanzania’s leadership. Its economic challenges as a nation, and its ambitious desire for development, do not incentivize governmental spending on disabled children and adults who are unlikely to be key players in advancing Tanzania’s global status. The heads of the Kilimanjaro region’s only special education teacher’s college were shocked when I mentioned having worked with an autistic child whose favourite activity was to play on his iPad, telling me: “If you

bought a child with autism an iPad here, it would be a court case! They would call it a misuse of funds.” They elaborated, complaining: "Even if you go to the municipality to ask for a scholarship to learn more about autism, they say, 'Huh, that's a waste of our money.' They are talking very negatively."

Hierarchies: Disabilities and Education

In Moshi, some forms of disability are viewed more positively than others. Physical disabilities, most notably, blindness and deafness, are more widely acknowledged than intellectual impairments, and far more resources are allocated for supporting individuals with these conditions. As one teacher explained, "Here in Tanzania a good number of people are aware of the blind and the deaf, but not intellectual impairment. Even the government doesn't think much about these people. They think about blind and deaf a little, but not these (intellectually impaired) because they think they are worthless. Most schools are supported by missionaries." I pondered aloud in one group interview, "If I had an intellectual impairment and I worked in a shop, would people shop there?" After much chatter, some laughter, confusion and deliberation, Mr. K supplied a collective response: "Madam, in our country there is not even a single person with autism or an intellectual disability who has a shop, so that's why we fail to answer. If they had a physical disability, that is not a problem, that is common, but not intellectual, that doesn't happen."

In a discussion of funding distribution with a district education officer, she explained that the district receives a set amount of funding, and that the special education budget is split between two different government boarding schools: one for the blind and

one for the deaf. Special education units within “normal schools” like Amani and Bushira receive their funding as an excerpt from government grants that are afforded to the heads of these schools. Formal regulations dictate that children with disabilities receive twice as much funding as those without, but practice rarely aligns with policy. In actuality, directors of “normal schools,” dole out money to special education units at their discretion, generally prioritizing the needs of “normal” classrooms.

My interviews with special education teachers revealed a deep-seated sense of resentment and offence at not having their profession validated by their colleagues in the “normal schools,” highlighting a hierarchy among teachers. They told me that because children with disabilities “lag behind, most people think they are useless,” and that devoting one’s career to educating these kids is seen as foolish and futile: “People say, ‘Why are you doing this? You think you can change them? You are mad.’” Special education is not taken seriously within the teaching profession. In some schools, special education teachers are asked to fill in for sick colleagues in the normal classes, but the favour will not be returned: “You get pulled out to teach normal when the normal teachers are sick, but maybe if we are sick, they do not come to teach here, they think it is just playing.” Tasks such as toilet training that may be involved in special education are looked down upon and not considered “real” teaching.

This lack of respect also translated to the general public, parents included, as Mr. K relayed: “If the normal school sends a letter to parents about a meeting, they will all come. But if we do, nobody will come. Only one parent showed up.” When I asked a district education officer why she thought parents didn’t send disabled children to school, she replied, “They think they won’t get good teaching. Even that one,” she pointed at Mr.

K, "They will not accept him." I spoke with another teacher who had worked in special education classrooms for many years, and who less experienced teachers identified as a senior authority on autism. She had recently been transferred to a "normal" kindergarten class, as school officials thought her talents were being squandered on disabled kids. She explained, "Now that I am here teaching in the normal class, people say it is great for me, because it was a waste of time and money before. Now people are quiet." As a potential means by which to elevate outsiders' perceptions and to entice more professionals to the field, teachers suggested that if facilities were improved, "more teachers would be interested in working with special needs kids," but as it was, a career in special education was widely deemed undesirable.

The Government Doesn't Care: Lack of Resources and Ageing Out

My informants were very frustrated by their government's perceived incompetence. After home visits one Friday, special education teachers from seven different districts gathered at a conference, during which they emphasized the need "to write and go to local education officers" to draw attention to their students' rights and to educate government officials, explaining "Disability has been an issue here only for about 5 to 10 years. Our leaders don't know about it, even the president, that's why he doesn't talk much about it. The leaders don't know about rights for these kids. They know about normal (the rights of normal kids), but the rights are different."

Both Mr. K and Mama G had a tumultuous relationship with local government education officers. Mama G claimed to incite fear in Moshi's officer, Beatrice. Indeed, when Mr. K and I set out to interview her, she proved incredibly evasive. When I finally

sat down with her, she alleged that her boss, with whom I had already consulted and who happily engaged in a lively interview, would disapprove. A former special education teacher herself, Beatrice loosened up as we chatted. Her reluctance seemed to stem more from self-consciousness about her limited knowledge of autism, than it did from indifference. The hardest part of her job, she told me, was “lacking human resources and facilities. Their needs are many, as you know, but what we receive for them is very little... what you have from central government is very meagre. You give them all that you have, but it is insufficient, so it is a challenge.” Referencing parents’ reluctance to invest, she added, “You expect the difference to come from the parents, but from the communities it's not forthcoming. This is a big problem”

Beatrice maintained that disabled children still receive double the funding of other children, but Mr. K was not convinced: “Twice as much for special education, but for what? Her boss said it was for learning materials, but we don’t have any!” When we visited education officers in two different districts, Mr. K was exasperated by Moshi’s shortcomings. In both, the government provided lunches for special education units, while his kids get only porridge mid-morning - many having traveled great distances on empty stomachs - and then are sent home before noon. “It is the *same* government,” he bemoaned, “but those places get food.”

The government in Tanzania is habitually regarded as corrupt. Government officials regularly accept or demand bribes and are not held accountable for illegal actions. Corruption is a commonly acknowledged social issue in Sub-Saharan Africa and corrupt public officials within developing states are blamed for reducing economic growth and hindering the benefits of foreign aid by diverting funds for personal use

(Odemba, 2012, p.21). The introduction of official policies and government bodies to combat corruption has had minimal impact in Tanzania. In 2009, it ranked 126 out of 180 countries on a Transparency International corruption measurement index (as cited in Odemba, 2012, p.22). Systemic corruption has precipitated a widespread mistrust of the government and undermined citizens' confidence in governmental leadership.

Nearly all of the teachers with whom I spoke expressed resentment toward the government, claiming in one form or another that "they just don't care about these kids." Just as reliance on foreign aid, NGOs, and volunteers dissuades parents from investing in disabled children, it also detracts government attention from their plight. Outsiders step in and the government escapes accountability. As one teacher summarized: "These children are not supported by our government, all of this (she pointed around the classroom) is from volunteers, the government is not concerned to even build a toilet, but when you go into the normal school, they build kitchens even." The teachers at one unit described the arduous process of obtaining government support for the construction of a playground: "We started with a fence. The government paid for the fence, but it was a tough job to get the fence. The government paid, but only after crying a lot." They hoped to finance the building of the actual playground within the fence through a combination of private donors and government assistance, anticipating the latter to be most challenging. The only teachers who did not actively protest the government's apparent neglect were those, Amani being the principle example, whose units were generously supported by an NGO. They were markedly more complacent, not articulating the desire to "fight" for government attention that was so common amongst teachers in other units.

Another major concern that emerged in my discussions was the government's deficiency in supporting children with disabilities into adulthood. At 18, students age out of the schooling system and are expected to fend for themselves. After they grow up, "They go to their village and just go around, not doing anything, because the government doesn't care. The village government doesn't even care." Subsequently, many adults with disabilities end up homeless, presumed to be "mad" by onlookers. This is one of Mama G's biggest grievances: "We are shaping the schools and pushing the government for special education schools, but then they turn 18 and they are pushed back into the world. The government says 'we are done,'" she mimes washing her hands of them, "It is like making a cup of tea and then pouring it in the dust bin."

At some units, a few students were permitted to keep attending well into adulthood. Dominicki, 40, was a class charmer, cheerfully greeting everyone each day and approaching all activities with great enthusiasm, and Nnema, 26 kept the classroom tidy and impressed me with her artistic talents. Nearly all of the children had unique skills and interests that could be developed, but instead, the colonial curriculum had them focusing on repeating alphabet and number sequences, rarely with any success. As one teacher pointed out, "There is this problem in Tanzania where mentally retarded children, their syllabus, their curriculum, they are supposed to get training to enable them to help themselves, but in Tanzania it is not developed. We don't have trainings to enable them to help themselves in life, unlike where you come from, such children are helped better than we do here." Although some vocational schools exist in the Kilimanjaro region, they are mostly filled with students who failed secondary school entrance exams, or are otherwise vulnerable, with a few physically disabled students, mostly blind or deaf, and very rarely

those with an intellectual disability. I was frequently asked about Canada's inclusive education policies, which teachers viewed positively and hoped to one day replicate: "Inclusive education is not here. It is a new trend in our country. We are just trying, but it is not really functioning. The policies are there, but they are just policies."

Mama G's dream is to create an opportunity for those, like her son, who are too old for school, and who rely on parents and relatives (if they have not already been abandoned) who will eventually pass away, leaving them defenseless. She has already set aside a plot of land where she hopes to build a group home for Erick to live with his peers, each of them fulfilling a specific role, such as cooking or tending to livestock, based on their interests and abilities. The home would double as a hostel for visiting volunteers, creating income, and young adults with disabilities would fill the management positions. But this is a long-term goal, in the interim she has to focus on raising awareness and trying "to teach the local government." Sheila cited a similar objective for her church affiliated organization: "The goal is to make those with intellectual disabilities to be independent, to help them to do something, because in the future those parents will disappear, even us, we can disappear, so to help them to have something to do." To create change, one teacher suggested, "Policy makers and government first of all need to help adults once they leave school, guide them, recognize their problem and help them, so they are not just wandering the street looking crazy. The government needs to protect these children and adults, help them and give them support." Another agreed, "If the government provides more resources, I think we can improve."

No Culture of Psychology: Diagnosis, Labeling and Class Stratification

On a tip from Mr. K, I was able to locate a psychologist who diagnoses autism at a small hospital in Arusha, about an hour's drive from Moshi. After a lengthy game of phone tag, I finally got her on the line. Originally from India, Dr. Gupta had been working in Tanzania for 8 years. In all that time, she had diagnosed only 7 or 8 cases of autism. "They don't come," she told me, "They come only when a general practitioner refers them and that doesn't happen very often." Psychology is not a culturally recognized branch of medicine. "In general practice, they don't even think of going to a psychologist," Dr. Gupta informed me, "Awareness of mental health is very poor. They know something is wrong, but they don't know where to go. They end up going to religion."

Medicine is not the default response to health issues in Tanzania. Traditional Health Practitioners (THP) or Traditional Healers (TH) are people recognized by their communities "as competent to provide health care by using plants, animal and mineral substances and other methods based on socio-cultural and religious background as well as knowledge, attitudes and beliefs that are prevalent in the community regarding physical, mental and social well being and causation of disease and disability" (Mbwambo, Mahunnah and Kayombo, 2007, p. 115). Since colonial times, traditional and conventional health care systems have co-existed, attempting to serve the same population, but "operating in parallel circles" (Mbwambo, Mahunnah and Kayombo, 2007, p.115) and within very different paradigms. "To the traditional African healer," Busia (2005) elaborates, "There is no clear conceptual distinction between the physical

worlds and the supernatural world. Health, illness and healing are part of this integrated worldview wherein religion plays a major determinant” (p.919).

A study by Ngoma, Prince and Mann (2003) documented there to be high rates of usage of traditional healer services in an urban Tanzanian setting and Kromberg et al. (2008) found that mothers and other caregivers in Tanzania turn to both local traditional healers and Western medical systems for their children with intellectual disabilities (as cited in Njenga, 2009, p. 459). Even among orthodox healthcare workers in Nigeria, Bakare et al. (2012) found a significant proportion subscribed to supernatural explanations for neuropsychiatric disorders and behaviours, a trend which they claim is representative of the general African population and which “negatively affects help-seeking behaviour, help generally first being sought from spiritualists, traditional healers, other non-orthodox practices” (Bakare and Munir, 2011, p.119). Njenga (2009) views this situation positively, being that traditional healing is already well established in Africa, it creates an exciting opportunity to cooperate with biomedical practitioners, initiating “new partnerships in the care of persons with intellectual disability in Africa” (p.459). He asserts: “An understanding of different cultures can help healthcare professionals to understand how and why families make decisions concerning healthcare and rehabilitation,” adding that “an understanding of and respect for the roles of both health professionals and traditional healers in relation to disability should be incorporated in the training of healthcare professionals (Njenga, 2011, p.459).

Bakare and Munir (2011) argue that late presentation to orthodox health care, a common occurrence in African countries, is a negative repercussion of this “tortuous help-seeking pathway” (p.118). Because spiritual beliefs about the cause of neuropsychiatric

disorders are so prevalent, psychiatric clinical practice is not the first avenue for care, thus the age at which children are eventually diagnosed is older than is typically recommended in Western medical circles, a significant setback, being that early intervention is widely upheld to be critical for a child's future prognosis (Bakare and Munir, 2011). Dr. Gupta mentioned that her autistic patients have all been diagnosed at a late age: "I have never seen a young child with parents asking, "Why isn't my child developing? No, they are all over 5 because as they grow older the symptoms are more visible."

Although many teachers, especially those who had attended ACT seminars, understood the definition of autism and its key characteristics, they still struggled to parse its differences from the more general category of intellectual or mental disability. This is consistent with the work of Mankoski et. Al. (2006) who found that ASD in Africa is rarely diagnosed exclusive of intellectual disability. Only one teacher distinguished autistic children from mentally disabled children by saying, "What is different about autism, is that they are intellectually fit. Intellectually impaired people could not know that about themselves (to be self-advocates), but autistic people can." In an extensive review of the literature on ASD in Africa, Bakare and Munir (2011) found much to be desired, concluding that, across the continent, "more policy-making attention needs to be directed at child and adolescent mental health service provision, especially regarding the issues of childhood development disorders and intellectual disability (p.210).

Many of my informants mentioned that people with autism or other intellectual disabilities are assumed to be "mental," or "crazy" (kichaa) by Tanzanian terms. When

families hide their children in an effort to protect them, it only increases this perception: “It is seen as a mental illness, people think they are crazy because they isolate themselves,” Dr. Gupta asserted.

I asked Dr. Gupta if she thought that having the specific label of autism to describe their child’s persona was helpful for families: “The label helps because the culture here, if something is wrong, the first thing that comes to mind is they are bewitched. Then after they seek those (religious leaders/witch doctors) resources, they go to medical practice.” The label proves that they are not, in fact, bewitched. Mama G confirmed that when Erick was young, everyone thought he was cursed. Slowly, she has been able to adjust these attitudes by advocating for Erick, and through her work with ACT.

Mama G’s experience with Erick is perhaps the most poignant example of the potentially affirmative effects of receiving a diagnostic label. She first noticed something was different about Erick when he was an infant. He wasn’t interested in being cuddled or held after breastfeeding and was very “hyperactive.” She took him to the doctor at 7 months and again at a year, because he hadn’t developed any simple language skills. Each time she was reassured there was nothing wrong, “He is just hyperactive.” At three years old, he was speaking only in oddly constructed sentences and exhibiting destructive behaviour, jumping from windows and breaking household items. “He would jump from the bed, to the chair, back and forth,” she recalled, “He didn’t mind who is an adult...you come home and he would just come jump on you. He didn’t care if it was a stranger.” In Tanzanian culture, politeness, reservation and respect for one’s elders are highly valued, making this behaviour especially disturbing and disruptive. “I felt very bad, like, he

shouldn't be doing that, and the bad thing was we were punishing him," Mama G told me regretfully, "especially my husband. He would just..." (She holds up her hand here, miming a hitting motion). Mama G was told to medicate Erick daily for "child psychosis," but she refused. After a German pediatrician at the university hospital again sent her home with her "hyperactive" son, she asked a fellow nurse and her pediatrician husband to come over, "I said, just come and watch my son." They sent her back to the hospital, where, after 2 days of observation, the doctors told her conclusively: "This one is an autistic." Of course, she didn't know what that meant, "I was like, what is autistic? I didn't know what is autistic. They told me, this is autistic. He cannot communicate well, is hyperactive, he doesn't like to touch, he doesn't have eye contact with anybody." The doctors prescribed Ritalin. She had to send someone to Nairobi to get it.

The years following his diagnosis are a perpetual saga of trying and failing to find a place where Erick might "fit." Bouncing from school to school, too hyperactive for some, too advanced for others. Eventually Mama G built her own unit where Erick stayed for 9 years, all the while, continuing her quest for assistance: "I was going with him to different places, specialty places, talking to them, calling them to come and see him." She took him off Ritalin when he became "numb," unable to sleep day or night, and "flabby because he couldn't do anything." Most doctors didn't know anything about autism. When he was 18, he aged out of the school system and faced a new set of problems: integrating into the neighbourhood.

A tall, energetic teenager with a passion for electronics, Erick would frequent the shops in his housing complex, one barber's shop in particular: "He goes there and they abuse him with bad language. They think he is deaf, he is kichaa (crazy) and he gets very

angry... When he goes somewhere they want to get rid of him, they make shooping noises and shout 'Get out!' and he doesn't like that, so he was a menace in that place... If they come to get Erick, he can run, so once he throw the stone at them, or if he wants something and they don't give it to him, he throws the stone. He breaks a lot of windows. I've been paying to repair a lot of windows." Mama G received endless calls from neighbours complaining, "Your son did that, your son did that." Eventually those neighbours reached a consensus, "They were going to go to Erick and kill him. They were going to poison him. They hired some young people to give him drugs in his soda." Fortunately, a friend caught wind of this plan and tracked down Mama G, who called the police. She reported the plan to the chairperson of her complex and called a community meeting. To entice people to attend the meeting, Mama G spread the word that she would be paying reparations for all the damages Erick had caused:

So everybody came, with lots of claims. Some were true, some were not true. Everybody was trying to say why Erick is very nonsense? Why Erick is doing marijuanas? Why Erick doesn't speak to anybody? Why he is hyperactive? Why he runs away? Everybody was complaining. After they talk, I say, let me tell you, Erick is not a marijuana person. He has a problem called autistic. He cannot communicate well. If he comes to want to greet you, he come and touch you. But sometimes he touch them and they beat him.

As it turned out, the Mama who had initiated the plan also had a child with autism, "She's a very educated person. She has been in the States. She did her PhD

there... but she didn't know that Erick was autistic." This Mama was angry because Erick has broken her salon windows and scared away her high paying UN employed patrons. "So I explained what autistic is, how he was born with it, and it was not what they expected," Mama G told me, "And I didn't know that that lady had a child like that and she started crying. She cried a lot." The Mama was full of remorse. She said, "Today I have been educated about autism, I'm sorry, you don't need to pay me anything." But she still had an issue with Erick scaring away her customers. They hatched a plan, taking a photo of Erick to the police and "putting up posters all over to educate people." They made Erick t-shirts that read, "I'm autistic. Please don't hurt me," and added his family members' phone numbers underneath. "He wears them to this day," Mama G chuckled, "even when he goes to church in a nice shirt, he puts another t-shirt inside." Now her neighbours treat him well. They have changed their minds.

In this case, being able to rely on a label, to distinguish Erick from a "mad man," or a "crazy person," saved his life. Unfortunately, on another note, it also highlights the acceptability of aggression toward those with mental illnesses and the general dearth of mental health literacy in Tanzania. Being recognized publicly as autistic opened up avenues of awareness, acceptance and empathy for Erick. In treating his autism as an identity, as is common amongst advocates of neurodiversity, Erick was afforded an unprecedented level of respect.

However, autism in Tanzania, at least as a label, is a class-stratified condition. As I have previously argued, those with no expendable income are not apt to invest what precious little they have in a child with a disability. Thus, it is primarily members of the upper-middle class, Mama G being a perfect example, who seek outside assistance, and

who receive a diagnosis. To have that label applied to one's child, or even to recognize the term, implies that a family has the cultural capital necessary to acquire such information – they send their child to school, they understand English, they can afford to explore therapeutic opportunities. For the average Tanzanian parent, seeking psychological labeling and diagnosis is not a natural reaction to their child's perceived differences, instead they turn to long established local authorities such as religious leaders and traditional healers for explanations, solutions and advice. The instinct to determine the cause and to "fix" the "problem" of a child's autism is consistent across classes and cultures, but the default means by which to do so are unique. In a culture or amongst a socio-economic cohort that values biomedicine, answers will come from professionals who address issues of the mind and body within a medical paradigm, while those from less biomedically inclined environments and backgrounds will justifiably consult a different form of "expert."

No Cultural Narrative of Autistic Value

A cultural narrative that speaks to the success, achievement, or even basic intelligence of autistic people does not exist in Tanzania. There is no pervasive discourse or pop culture icon such as Dustin Hoffman's autistic character, Raymond Babbitt, in the film *Rain Man*, possessing the power to impact societal attitudes about intellectual differences on a major scale. No culturally resonant stories of autistic success, or accounts of endearing autistic quirks. Stigma and abuse of people considered to have an intellectual disability in Moshi is normalized. To consider an autistic person as anything other than crazy is exceptional. As such, the probability of locals celebrating

cognitive differences and championing the attitudes outlined in the neurodiversity movement is limited. In the absence of these narratives, one's assessment of an autistic child's potential is based solely upon the skills and abilities they possess as youngsters, operating in conditions that do not support their success. We believe what we see, and we question what we don't. I asked a government education officer if she thought an autistic child could grow up to have a job. She humoured me, "I am not sure, having a job?" then pointed to a colleague, "Have you seen one?" They both laughed.

Autism and intelligence were generally referred to as mutually exclusive. When I shared an anecdote about one of my former students, teachers were not convinced, "He is very clever. He cannot have autism." Another asked for clarification, "Autistic kids can do things like kids who are normal?" While visiting an immaculate and expansive school for the disabled, Mama G asked the director why we hadn't seen any students with intellectual disabilities, to which he replied, quite simply, "because those kids can't learn." In the car afterward, Mama G seethed, "My son is very smart, the smartest of all my children. You tell him to do something, and he has already done it!" When I recounted stories of autistic writers, inventors, or professors, I was faced with reluctant disciples. One of the heads of the special needs teacher's college all but threw her hands up in disbelief, "How is it possible for an autistic person to be a lecturer? How!" Mr. K jumped in to explain her incredulity, "Madame is surprised, she doesn't think there can be a professor with autism. It is different in our country. They are surprised. They cannot believe you what you are saying. They think, 'This woman, she is cheating us.'"

Mr. K suggested I provide some evidence: "It is better to prove the issues you say. When you come back in your motherland you can send us short notes via email about

how Canada people treat autism, send materials." He encouraged his colleagues to query outsiders, "We teachers, we need to ask: How are these people treated in your country?" Another teacher expressed the need "to develop teachers to have more knowledge about intellectual impairment and autism because they do confuse them sometimes." She proposed: "More seminars and more training, even trips to other countries to better serve these children. We have little knowledge. We need more. In your country autistic people can do many things. We need that knowledge, to widen our knowledge. Autism is confusing, not very simple to just stand and say 'autism is this and this and this.'" I wondered if it would help to see pictures or watch videos of successful autistic people. His answer was affirmative: "We don't know the destiny of these children. We don't know, at the end, what happens. That is the problem in our country."

Chapter 7: Discussion: What Does it Mean to be Autistic in Tanzania?

Disassembling the Myth of the Hidden Disabled

I began my research hopeful that I could help to dispel the widely held misconception that children with disabilities are systematically mistreated in “Other” cultures, a pervasive discourse that circulates in the Global North and which Ingstad (1995) has termed “the myth of the hidden disabled” (p.139). I intended to shed light on the reality of individual lived experiences that get whitewashed by this recently created “north-south myth” that stereotypes the behaviour of cultural others by suggesting that all people from non-western, supposedly “under-developed” nations, hide disabled people away out of shame, ignorance or heartlessness, effectively undermining the various efforts that these people make to support disabled individuals, despite significant obstacles, while also ignoring the complexity of cross-cultural experiences of disability. I was critical of NGOs, including the one with which I was to be working, that employed this “sensationalist” myth as a “ploy” to attract funding and attention to their cause, however worthy. To support my argument, I drew upon the work of Kisanji (1995), eager to incorporate the voice of a native Tanzanian scholar speaking out on behalf of his country.

In order to understand historical and contemporary attitudes toward disability in Tanzania, Kisanji (1995) analysed a number of Tanzanian proverbs, striving to counter dominant discourses that use the myth of the hidden disabled to paint a negative picture of traditional African cultures (p.6). In oral cultures such as those in Tanzania, proverbs encompass cultural values instructing personal conduct and are used to teach younger

generations, and remind the older ones, of what it means to be a “good” citizen. In his analysis, Kisanji (1995) found that many proverbs spoke to issues concerning disability, and very few of them expressed negative or rejective attitudes. The proverbs encouraged fairness and equal opportunities for all, including the disabled, while urging everyone to contribute to community welfare to the best of their ability. Some proverbs illustrated a fear of disabilities in the form of metaphors reminding community members to behave in socially accepted ways (Kisanji, 1995, p.15).

Kisanji (1995) provides the following examples to represent specific themes including: Disability as a social leveler; Human rights; Parental responsibility in bringing up a disabled child; and Training for survival and independence.

1) *Kabla hujafa usikashifu kilema* – Before you come to your deathbed, do not laugh at someone’s deformity or disability.

2) *Usimdharau kilema hata kama si ndugu yako* – Do not look down upon a disabled person even if s/he is not your relative.

3) *Ni bora uwe nacho cha thamani ndogo kuliko kukosa kabisa* – It is better to have something of less value than nothing, i.e., a disabled child is better than no child at all.

4) *Hata kama ni jinga litengzee upinde* – Even if stupid, give him a bow and a quiver of arrows.

While some disabled people in Tanzania and other African countries have indeed suffered mistreatment, both historically and presently, Kisanji (1995) notes that this mirrors global experience. In all cultures, reactions to disability can be seen to form a continuum. Therefore, specific negative instances should not be taken to represent the

non-western status quo. Despite this continuum, O'Toole (1988, as cited in Kisanji, 1995) explains that writing on non-western cultures is rife with descriptions of negative attitudes: "In the West the disabled have been stereotyped as being dependent, isolated, depressed and emotionally unstable...Such negative feelings are amplified in LDCs [Least Developed Countries] where the overwhelming impression, from published literature, is of attitudes towards the disabled which are very negative" (p.3). While, Ingstad (1990) cautions readers not to take the accounts of charitable organizations engaged in disability work in LDCs at face value, claiming that "In order to raise money and create awareness... a picture of the situation for disabled people has often been painted as negatively as possible, emphasising shame, hiding, killing, etc" (p.188).

Armed with this information, I intended to tackle the myth head on. I turned a critical eye to the website of ACT. This webpage, which has since been changed to reflect a more culturally sensitive message, is intended to educate its visitors about the dire situation of children and adults with autism in Tanzania. Prior to its revision, at the time of my research, it provided a perfect example of the myth in action, claiming that:

In third world countries children with disabilities such as autism are often forgotten. They are hidden away in their homes and denied access to school due to the lack of education about the causes of their disabilities, knowledge on how to best help them, and the myths that exist due to the disabilities these students face.

Putting aside the fact that my anthropological sensibilities were offended by the typecasting of "third world countries" in this generalized statement, I also assumed that it

was overly dramatic, hyperbolized for emotional impact, and exemplified a worst-case scenario that was perhaps based in truth, but certainly could not be the norm. I had Kisanji's (1995) proverbs on my side, and I was trained to approach the precepts of international development with caution, assuming guilt of cultural bias until proven otherwise.

However, after spending time in the field, my perception of ACT's statement, and of the "myth of the hidden disabled" in general, altered significantly. While I still hold that the above quote is poorly expressed and is an example of the sort of blanket statements that perpetuate harmful stereotypes about developing nations and their supposedly "backward" or "ignorant" cultural practices, I now believe that when applied to Tanzania specifically, at least in the Kilimanjaro region, the underlying concept which it seeks to express: that children with disabilities are kept at home, often mistreated, generally denied basic human rights, and fundamentally under-valued, is in fact the *norm*, and that deviations from this script are unusual cases; I'd even venture to call them exceptional.

Time and again, my informants provided examples of people with disabilities being treated abhorrently: young girls raped (some informants cited a common belief that perpetrators expect this act to bring them good luck); children locked up by their families for hours on end, some even bound by chains; sons and daughters destined to roam the streets as "crazy people," disowned by their families. I do not doubt that the stories are true. I witnessed a young boy, likely autistic, trapped in the cement framework of a never-to-be-built room, exit blockaded by a fiercely prickled branch. His parents were off getting drunk, according to the neighbours, despite repeated promises to bring their son to

the local special education unit. Others are outcast, left to wander the streets, unaware and ill-equipped, their erratic behaviour buttressing local perceptions that the terms “disabled” and “crazy” can be used interchangeably.

This left me in an interesting position. I had set out to dispel a myth, to highlight local tolerance, and to temper sensationalist claims of mass misconduct, yet what I found did not support my objective. On the one hand, I recognized that “international acts of ‘child saving’ have been criticized as creating “another arena for the transfer of Western social values, technologies, and professional forces” (Scheper Hughes & Sargent, 1998, p.8) and that such human rights rhetoric, Lock (1997) argues, is constructed by the governments of wealthy countries, exported by their activists and social scientists, and “designed to discipline politically or ‘ethically’ backward countries” (p.507). However, I was observing what I perceived to be a violation of basic rights – to education, to non-discrimination, to equal representation – and I wanted to champion them. My skepticism as to the ethical soundness of ACT quickly turned to admiration for their cause and a desire to provide assistance. Suddenly, my strict adherence to cultural relativism felt like enforced indifference, a baseless unwillingness to help. I kept searching for ways to justify my initial criticisms, but all I could see was mass injustice and an organization working to eliminate it. Was my academic integrity in opposition to my personal morality?

Scheper-Hughes & Sargent (1998) capture my predicament in their description of the dilemma faced by all anthropologists today: “Our disciplinary training obligates us to see the good, the right, and the just in local cultures that do not participate in Western values. Modern anthropology was designed to liberate taken-for-granted “truths” from

their unexamined Eurocentric presuppositions” yet when we attempt to examine instances of child neglect or sexual exploitation from a traditionally cultural relativist stance, we need to question whether we are “suspending the ethical” and in doing so, unwittingly participating in the harming of these vulnerable populations (p.9). In this vein, Scheper-Hughes (1995) has suggested that traditional notions of cultural and moral relativism may be ill-suited to our increasingly globalized world. She calls for a new ethics in anthropology, while acknowledging the quandary created in trying to identify an ethical standard, without excluding vastly different cultural beliefs, practices and traditions. She reflects on her research in Brazilian shanty-towns in which some mothers seem to have “suspended the ethical” by depriving their weak and sickly children of empathy and care, doing nothing to prevent their untimely deaths. Although the survival instinct that informs this neglect can be understood and rationalized, in Scheper-Hughes’ (1995) opinion, anthropologists should not shy away from questioning the moral and political issues generated by these acts. This careful attention to the specificities of the “local” context is problematized by the fact that in countries across the globe, constitutions and bills of rights are being altered and invoked to reflect a “growing world-wide consensus (at least among the elite and often Western-trained public intellectuals) concerning the individual human rights of women, children, sexual minorities, the sick, and the unjustly accused” (Scheper Hughes & Sargent, p.10). As I witnessed in Tanzania, ‘rights talk’ is increasingly seen as politically correct and used by educated, middle class citizens as a way to participate in a global conversation, to voice their concerns, and perhaps less productively, to juxtapose themselves against the supposedly ignorant, uneducated, and abusive “villagers”. Language, particularly that which is standardized and privileged as a

recognized discourse, is a critical instrument in the process of “othering,” both within and between cultures.

So what is the best course of action for an anthropologist when addressing issues of human ethics? Scheper-Hughes and Sargent (1998) suggest that we attempt to “straddle the middle ground” by acknowledging the risks associated with “rights talk,” such as the tendency to ignore the influence of cultural context on the construction of categories such as child or mother, essentializing these roles and flattening their differences, while “on the other hand, anthropologists need to accept that most local societies and cultures are at least as much influenced today by what goes on outside their borders as within them” (p.10). As people in seemingly remote and disparate locales all begin to take up the language of rights, anthropology can play an important role in witnessing this translation process, documenting how these discourses are taken up, re-interpreted and mobilized in a variety of different social, cultural and historical contexts (Scheper-Hughes & Sargent, 1998, p.10). This process allows for a more nuanced understanding of what rights discourses really *mean* to the people who employ them and how they can be adapted to more accurately address the needs of diverse populations. It is with this in mind that I have endeavoured to stand in this liminal space, observing and commenting on the complex after-effects of cultural collision, and archiving the unique renditions of discourses that emerge from such an impact.

That being said, the myth of the hidden disabled does not entirely escape my critical gaze. I take issue with the rationale it offers as to why people with disabilities are victimized. Yes, the conditions are terrible and the situations dire, in this way the “myth” is based in truth, but ignorance is too easy an explanation. It fails to capture the manifold

forms of intersectionality (Crenshaw, 1989) that when combined, produce such dismal circumstances. Crenshaw (1989) coined the term intersectionality to describe the “multidimensionality of marginalized subjects’ lived experiences” (Nash, 2008). In Naomi Klein’s oft-cited criticism of early human rights activism, she argues that this type of advocacy often “detaches violations of human rights from the political, economic and social contexts which make them possible and even rational” (as cited in Marks, 2011, p.59). Her critique has initiated a newfound attentiveness on the part of activists to the underlying causes at the root of human rights abuses, but the “myth of the hidden disabled,” with its simplistic attribution of a widespread and undifferentiated “ignorance” to people in developing nations, suggests the continued relevancy of Klein’s critique. Some activism, including that of ACT, is guilty of under-complicating their issues of interest, at least in the way they present and describe their mission in the media or otherwise, to garner public support.

My pre-fieldwork deconstruction of the myth in my research proposal is another example of this over-simplification. While I was highly attuned to root causes, I made assumptions about the nature of the behaviours they produced. I argued that in conditions of poverty, parents make the difficult, but necessary *choice* to keep their child with disabilities home, perhaps locking them up to keep them safe while they go to work, or to protect them from malevolent community members. In retrospect, this view is irreconcilably ethnocentric and highly speculative. It implies that parents engage in a conscious deliberation process whereby they weigh the pros and cons of sending their child to school, asking for support, or seeking medical attention. In most cases, I do not believe this is so. In reality, parents hide their children, because to do differently would

be an act of radical deviance from the norm. There is rampant and *normalized* abuse of people with disabilities in Moshi. Most parents are unaware that an alternative exists. As choice is a privilege attached to wealth and education. Those parents that possess this privilege are conscious of their children's potential success in a way that the economically disadvantaged are not. Citizens are conditioned to react to people with disabilities in a negative way, due to a complex medley of social and economic influences. As Marks (2011) points out, "...civil and political rights affect and are affected by economic, social and cultural rights. Attention is called to the links between violence, on the one hand, and poverty, discrimination, marginalisation, and social exclusion on the other" (p.61). In the recommendation section of this thesis, I suggest a few targeted ways in which we can emphasize certain cultural strengths that I identified in Moshi to create a new social norm for the treatment of the disabled.

Competing Explanations: Biomedical vs. Sociocultural

Based on Stone-Macdonald's (2014) finding that Tanzanians predominately reference biomedical discourses to explain disabilities and very infrequently mention curses, claiming that beliefs in witchcraft are outdated and no longer relevant, while also recognizing the role of religious forces such as God's will, I expected my research to warrant similar results. Indeed, my results were similar, but I would like to highlight some critical differences. While the majority of my informants provided various biomedical influences as potential causes of disabilities, almost ALL of them mentioned witchcraft and curses. However, there is a caveat: They NEVER attributed those beliefs

to themselves. Superstitions and beliefs in curses were always associated with an “other” (Johnson et al., 2004).

According to Johnson et al. (2004), “Othering is a process that identifies those that are thought to be different from oneself or the mainstream, and it can reinforce and reproduce positions of domination and subordination” (p.253). In this case, I detected a strong sense of knowing what the *right, expected, or progressive* answer was when it came to rationalizing the manifestation of disability. Given that biomedical discourses of disability are widely circulated amongst educated Tanzanians, they are aware that the “true” cause must be rooted in biology. Those who had attended ACT seminars made an exception in the case of autism, being that there is no agreed upon cause, even in medical circles. However, even these educated individuals pointedly acknowledged the prevalence of socio-cultural beliefs in the supernatural, mitigating the potential to be perceived as ignorant by firmly locating the adherents of these beliefs in a separate social cohort. It was during these conversations that a clear binary emerged, a systematic case of othering: “They” – the uneducated – feel this way, but “We” – the enlightened- know better. For instance, when I inquired as to how the community in general perceived of its disabled members, I often encountered a binary response: Those who are educated treat them well, those without education do not. This dialectically charged answer was usually directly linked to a rural/urban divide, which is also intrinsically tied to ideas about tradition and modernity, religion, and tribal differences.

As Sheila, a minister in training, and a member of a local charitable organization serving the disability community, summarized:

Those who do not believe in God say that they (parents of disabled children) are not blessed. That's why they have come to have such daughter or children like that one, but those who have education, they know that it is biological. Those who have been educated, they have got another vision, but those who have not got an education believe that that is a mistake. So they care for them, they don't isolate them, but those who are not educated, they isolate them, abuse them, and find that they are useless in the families. They can't do anything, they can't take anything, they can't care for themselves.

In Sheila's biased opinion as a church representative, formal religion, either Christianity or Islam, was correlated with education, and progressive, empathetic treatment of the disabled:

A lot of the families, especially the ones who do not believe in God, they believe that disabled children are a punishment from God. Maybe their mother is a wizard, or what not, or they haven't been blessed from their parents. That's why they have disabled children... for those who believe in God, especially the bible, they know that disabled children, they are children like other children and God can create somebody as he wants. Or it was a mistake, a misfortunate when he/she was born, maybe the mother didn't get better services for the delivery, or she was delayed to get services, and that's why the children have been injured.

As Veronica, a neighbor of mine who offered friendly assistance to children with disabilities in her community, explained:

The Chagga people since Nyerere, they were educated, they built many waves of communication... those who were educated earlier, they have been well educated because if I went to school, I would fight to enable my children to go to school, but if I didn't go to school, I cannot see the importance of sending my daughter to school. If they didn't go to school...they can't realize the importance of even loving God, even to look for religion, or to know God's principles. Let us come to our point on disabilities... because those people are not educated, they are not given religions, whether Muslim, whether Christian, it is difficult to assist them, to allow any type of assistance to reach them, because they haven't been educated. They are unaware."

Like Sheila, Veronica cited a direct correlation between education and religion and compassion and acceptance of those living with disabilities. She highlighted the resistance and mistrust felt by those without education toward those attempting to introduce ideas of acceptance. Her explanations were highly situated: rural villages are sites of sciolism, stagnancy, tradition and godlessness, while more progressive, charitable attitudes can be found in urban areas. Just as the myth of the hidden disabled creates an inter-cultural juxtaposition between the "advanced" and the "ignorant," the adoption of discourses exported from the Global North and consumed by a highly specific local demographic reproduces this duality inter-culturally. Not wanting to be the ignorant party, guilty of such transgressions as hiding and abusing disabled children, wealthy and educated Tanzanians foist this image upon the poor, the uneducated and the traditional.

However, even amongst those who shunned supernatural explanations and said all the “right” things, I noticed hesitation and sensed some uncertainty. It was if there was some unspoken caveat at the end of every sentence. Yes, we accept the official discourse that carries the sway of high power knowledge producers, *but* at our core, we have difficulty truly internalizing this message. Very few people seemed to believe that those with impairments possessed the capacity to be productive community members, even with the proper training and support. In fact, this view was expressed almost exclusively among special education teachers who had learned about this potential in college, but who still referred to it rather abstractly, not having witnessed such a thing firsthand. When I asked Ms. Okafar, an experienced special education teacher, what causes autism, she answered, “I don't know, something wrong in the brain,” and explained that some informants mask their true beliefs: “Other people may say the same sentence as me, but they don't believe it, they say that in front of people, but when they are alone, they say it is a supernatural power”

Countless times, I recorded positive views about the abilities and potentials of children with disabilities by those in the special education field, yet they always seemed to be lacking in conviction. These answers felt rehearsed. The equivalent of an eager student supplying the teacher with an answer they know to be correct - one that will please her and elicit praise - but an answer to which the student attaches no emotional meaning beyond the rote memorization of a taught concept, random and foreign information internalized as fact. I would not characterize the general sentiment toward disability expressed in my interviews and conversations with informants as positive or optimistic. Those who did show compassion and support constantly drew attention to the

exceptional nature of their approach, juxtaposing themselves against society, or “Tanzanians” writ large, to emphasize the exceptionality of their opinion.

The teachers at Amani helped me to compile a list of the supposed causes of autism which included: alcohol consumption after conception; working too much, smoking or doing drugs while pregnant; prolonged labour; doctor improperly using a vacuum device to deliver the baby; careless nurse during delivery; an accident; or “local beliefs.” One of the most pervasive “local beliefs” about the cause of intellectual disabilities involved witchcraft and was brought to my attention by several informants. In this origin story, parents who “want to make a lot of money” attempt to make a deal with a witch doctor, exchanging their child’s intelligence for cash. Mama G concurred, explaining that her husband’s financial success was often considered by their peers to be linked to his son’s disability, as opposed to his business acumen. If a family remains poor, it is considered to be the result of failed bargaining.

In a meeting with the two heads of the special education teacher’s college, Mr. Bura and Mrs. Degera, an interesting dynamic emerged. The two had very different perspectives. Mr. Bura seemed to want to portray an exaggeratedly progressive image at the expense of recognizing continued stigma, superstition and abuse, while Mrs. Degera emphasized the need for continued education due to the enduring and habitual ill-treatment of people with disabilities. He tells me that when they first began teaching about autism, the community was not aware: “They think they have something else from normal human beings, bad spirits... This is African culture. And that they cannot live in a normal community. Historically, people like this were killed in the forest, but now with the development of technology and science, they have changed their mindsets to

positive.” Yet, Mrs. Degera was more restrained, noting that some have changed their minds, but certainly not all, calling attention to common sociocultural narratives of autism: “Some community members think someone in the family has done bad to destroy that child, the mother or father or any relative, or society surrounding. Sometimes parent clash because they both think it’s from the other’s clan. It’s a tug of war. Sometimes divorce, or the father quits the family thinking the mother caused it. In most cases, the mother takes the trouble.” Mr. Bura interjected, claiming that this was the case from colonial times to the 60s and 70s, but Mrs. Degera held firm, “This is now.” Finally he acceded, “Now we’ve changed, not completely, people are changing bit by bit. Villages and rural areas are still in trouble.”

This anecdote is meant to elucidate the desire among educated Tanzanians to appear modern and advanced by shunning sociocultural beliefs in favour of foreign, biomedical discourses, as well as the impulse to foist those beliefs onto supposedly nescient populations, the easy targets being villagers. I witnessed enough single mothers and grandmothers raising autistic children after being abandoned by their husbands or sons to know that this is not just a problem of the past, nor is it a phenomenon relegated only to rural locales. While sociocultural discourses that involve supernatural influences run contrary to ideas of modernity and progression and are therefore denounced by the elite, they are still widely circulated. I am not convinced of their declining potency. As Mr. K confided in me, people will tell you the correct reasons for the cause of autism, they will tell you that autistic people can be smart and productive, but it is not what they truly believe. Ms. Okafor concurred, speaking about parental detachment: “They don’t

support them in word or physically, which means they believe it's a punishment from God, even though they don't say so."

Sociocultural beliefs are powerful. They are deeply entrenched, bonding people together and characterizing their worldviews. Kisanji (1998) understood this. In a later publication, he expands his analysis of proverbs to include multiple forms of metaphorical communication including stories, poems, folksongs, and riddles, examining "the manner in which language was used metaphorically in African folklore in relation to people with impairments" (p.4), aiming to tease out underlying perceptions and attitudes about these community members. He references Lakoff and Johnson (1980) who argue "that a community's system of concepts is metaphoric and, therefore, people's language and behavior is organized metaphorically," and that metaphors are "one of our most important tools for trying to comprehend partially what cannot be comprehended totally: our feelings, aesthetic experiences, moral practices and spiritual awareness" (Kisanji, 1998, p.4). Folklore provides a useful framework for understanding interactions amongst community members, or between one subset of a community and another (Kisanji, 1998, p.5). As it is metaphoric and embedded within daily life, "Folklore can also be considered to provide the community's account for its actions in a way that is intelligible and justifiable to its members." Bearing this in mind, Kisanji (1998) collected sayings, riddles, folksongs, poems, proverbs and folktales through documentation and interviews from Tanzania, Liberia, Zaire and Zambia containing notions of impairments and/or people with impairments for content analysis. While I did not conduct a similarly systematic analysis of folklore, I did encounter a great deal of metaphorical language and folk stories when interviewing my informants, and I believe these forms of

communication and cultural knowledge sharing are an invaluable source of information pertaining to dominant ideas about disabilities of all kinds.

However, the results of Kisanji's (1998) study which attempts to explain community attitudes toward disabilities (a fundamentally Western term, local languages were not found to express a similarly general and inclusive category of *disability*, but rather referenced the following impairments specifically and separately: blindness or partial-blindness, deafness, physical impairments, intellectual impairments, behavioural difficulties and mental illness) do not align with my findings on the subject. First, his folklore analysis revealed a common belief that impairments are an unavoidable part of human nature that can befall anyone at anytime regardless of socio-economic standing, and that despite their limitations, those impaired were positively contributing members of their communities, or possessed the ability to be so, given the right teaching and support (Kisanji, 1998, p.6). Second, the evidence gathered from thematic analysis pointed towards a primarily positive attitude regarding disabilities, with only three proverbs extolling a negative view, and all stories pointing toward a positive perspective.

Conversely, my interviewees referenced popular myths and stories that espoused much less encouraging views. There was no clear consensus that disabilities are what one might refer to as a "great equalizer," affecting all citizens impartially and without cause. Instead, I was often supplied with many probable causes for a child's disability including, but not limited to; a mother's negligent behavior during pregnancy – drugs, malnutrition, improper care; hereditary causes – resulting in parental conflict over whose family is to blame; and supernatural causes – parents trading their child's intelligence for money, or being punished for their sins by giving birth to an impaired baby. Others referenced a

common belief that having sex with a disabled woman would bring a man good fortune, explaining the prevalence of rape and unwanted pregnancy among young women with disabilities. Nobody mentioned proverbs, and none of the myths advocated humane treatment.

I do not dispute the accuracy of Kisanji's (1995) findings, however, I now believe them to be based on an assumption of cultural boundedness, representing an attempt to quantify the behavior of a static, homogenous, and unchanging "traditional" culture which does not, and cannot, exist. What Kisanji (1995) makes clear is that at some point, when proverbs were still widely employed as a method of social and cultural transmission of values and behavioural guidelines, there was a belief and an expectation that those without disabilities should treat the disabled with kindness, making a concerted effort to include them in community affairs. Yet, not a single one of my informants mentioned these proverbs, or any proverbs for that matter. The only references that touched on similar sentiments came directly from organized religions, either Christian or Muslim, and were based on more general religious instructions to treat others with kindness and to extend a helping hand toward the less fortunate. This raises the question: How relevant are proverbs in modern Tanzania? What caused the shift away from this mode of cultural sharing and the positive messages about disabilities it espoused?

Taking Kisanji's (1995) analysis as accurate and reliable, it follows that something(s) caused a major shift in attitudes and actions toward people with disabilities. What are those things? I wish to suggest that the strong presence of colonial forces in Moshi precipitated the birth of a globalized region, in which capitalist and individualist attitudes prevail and less thought is given to flourishing collectively, as families peg their

hopes on the individual within their clan with the greatest potential to “make it” in a dog-eat-dog world. In this environment, resources being scarce and competition proving fierce, it is not in a family’s best interest to devote precious little funds to furthering the education and championing the well being of a child with a disability.

The current state of disability in Moshi is inextricably linked to its poverty and its political economy. Far from a secluded cultural enclave, functioning on the basis of mutual cooperation, modern Moshi is a bustling international hub with a competitive tourism market. Every second man I met, it seemed, owned a safari company, and those who did not were mountain guides or porters, aspiring to one day work their way up from the bottom, while dreaming of a future in which they could assume a powerful and lucrative leadership role. Naturally, this fosters a spirit of individualism, which runs counter to the traditional notions of mutuality, reciprocity and collaboration that Kisanji’s (1993) proverbs suggest, and the inclusive, accepting and positive approach toward the disabled that he uncovered in his 1998 analysis of folklore.

Ironically, if we take Kisanji’s proverbial examples to be accurate, a more “traditional,” rural village life may have, and still may, in actuality provided a more nurturing, supportive environment in which community members with disabilities would have more potential to flourish. The overarching presumption by both educated, urban-dwelling Tanzanians and Western aid providers when it comes to discussions of disability, is that people in villages do terrible, ignorant things. However, given the current state of disability awareness in Moshi, and the dearth of unfulfilled potential amongst children with disabilities attending special education units in the region, one might argue that, at least in theory, villages are better conditioned spaces for inclusion.

My experience in a small town, Madena, a few hours from Moshi supported this theory. Here, the sociocultural discourses had a positive spin. “They are treated well in the surrounding community,” a teacher assured me, “There are a few cases where they are treated badly, but most are treated well according to the belief that you’ll get a good future.” Subsequently, incidences of mistreatment were rare and inclusion was easier to facilitate. Another teacher added, “They are treated well in our school community because we have tried our level best to communicate and make aware...so they are treated well, but not 100 percent. People think that when they help people with disabilities they get a good future. They get blessings.” When I asked if this was a religious belief, they nodded yes: “Christian and Muslim. All religions.”

There was only one school, with a detached special education unit. The teachers were not familiar with the official medical discourse regarding the cause of autism, one ventured a guess: “Maybe it is according to the disarrangement when the woman get pregnant. The disarrangement of the information of the child from the beginning of the pregnancy to the extreme end.” They hadn’t attended seminars, nor received additional autism education. Yet, their religious and cultural beliefs promoted the same outcome: acceptance and inclusion. Their inability to recite facts did not impact their capacity to practice empathy.

The unit’s four teachers had the same ideals as others I had interviewed, but unlike the others, their message seemed to stick. The compactness of their community and accessibility to their audience made all the difference. The entire community belongs to one tribe. Of course, some parents are resistant, “We are doing the work of educating them (parents) that by the ability of God, they (disabled kids) can be nearly normal or

normal. Some agree with us. Some believe it is a punishment of God and cannot be changed.” But because the community is so close knit, it is easier to change their minds. All 4 teachers exuded Mr. K levels of dedication, “When we decided to go get knowledge of teaching disabled students, we were told by our college teachers to be ready to fight with other teachers. They will not agree with you. You have to communicate with parents to get pupils. All pupils here have parents with good communication with us. You have to be passionate because it is a tough job.” The secret to their success, they say, is “Cooperation. Between the community, the government, the parents and the teachers. To work together.” This communal, collaborative framework has had a tremendous impact, proving that the designation of discourses, whether sociocultural or biomedical, is hardly important. What really matters is an inclusive, empathetic and supportive approach to caring for disabled community members, regardless of its discursive rationale.

Neurodiversity as Possibility

Neurodiversity advocates treat autism as an identity, consider themselves a part of an autistic community, and fear that traditional autism awareness groups and campaigns pose a threat to the continued existence of their people. Going into the field, I was intrigued by this concept: Was it unique to the Global North? Could it exist in Tanzania? Would I uncover the notion of neurodiversity under a different name? I was hopeful that I would discover a synonymous concept that might facilitate some sort of global linkage. However, I soon feared that was a wildly optimistic, and somewhat naïve, aspiration, given the shortage of resources and the stagnation of knowledge mobilization. My first instinct, reluctantly, was to posit that Tanzania’s lack of established services for autistic

individuals cannot support the development of so-called “high-functioning” autism, which in turn serves to prohibit the development of a distinctive autistic culture and community like that of ASAN. Yet, I struggled with this decidedly pessimistic hypothesis. I detected hints of attitudes that could support the idea of neurodiversity, and I sensed great potential. I was wracked by a host of new questions, amidst which, one stood out as most pertinent: Is medicalization a necessary stepping stone on the road to acceptance? Do we have to start with a bio-medical approach to generate sufficient awareness to begin constructing a more identity-based, socio-cultural understanding of autism’s unique gifts? I suspected this to be true, although it disappointed me to stray so far from the ideas of the neurodiversity movement.

Such a facile conclusion did not sit well with me. A year after returning from the field, I was still at a loss as to what meaningful message I could articulate from my data. I knew I wanted to engage with the concept of neurodiversity, but I wasn’t sure it was applicable in a Tanzanian context. Could autism possibly be recognized as a “unique way of being” in a context where it is barely acknowledged as a legitimate term, and where the notion that an intellectually impaired person can be bright is generally deemed laughable, given that intelligence and disability are perceived to be antithetical? What is the best step to take when faced with a blank slate? The infancy of autism awareness in Tanzania at first seemed an insurmountable obstacle, but a revolutionary 2015 publication by celebrated science writer, Steve Silberman, transformed my perspective of this unfamiliarity, turning what I thought was an obstruction into a unique advantage.

Silberman’s (2015) game-changing book, “Neurotribes: The Legacy of Autism and the Future of Neurodiversity” was brought to my attention by a posting on ASAN’s

facebook feed, having been excitedly endorsed by autistic readers as the first in-depth exploration of autism history and an excellent resource for bringing the neurodiversity movement's message to the masses. Indeed, it is both, and so much more. Silberman (2015) chronicles the complex and fascinating development of autism, from its initial recognition, to its recent proliferation, illuminating the precise confluence of social forces that led to the sudden barrage of diagnoses in the 1990s, while highlighting the unique contributions that autistic intelligence can, and has, continuously offered to the world. In an unprecedented fashion, Silberman (2015) explains how competing medical agendas shaped the discourse of autism, influencing how it was viewed, discussed and treated for decades, and examining how the hegemonic perspective that autism is a childhood affliction causing profound and devastating impairments has persisted, creating harmful stereotypes which critically impact the ability for autistic people to flourish in modern social landscapes.

At the core of Silberman's (2015) argument, is the belief that pathologizing autism is a mistake that has cost us dearly, and that ignoring the potential of people on the spectrum effectively muzzles some of the most potentially prodigious thinkers, creators and inventors in the world. He offers ample evidence to support this thesis, using the core narrative of the clashing opinions of autism's simultaneous, yet discrete, discoverers, Leo Kanner and Hans Asperger, to carry his argument throughout the book. In 1938, Asperger facilitated the first public discussion of autism, presenting a radically divergent position on cognitive disabilities by declaring that "not everything that steps out of line, and is thus 'abnormal,' must necessarily be 'inferior,'" telling health professionals: "Your therapeutic goal must be to teach the person how to bear their difficulties. Not to

eliminate them for him, but to train the person to cope with special challenges with special strategies; to make the person aware not that they are ill, but that they are responsible for their lives” (Silberman, 2015, p.128). He empathized with his patients, calling them his “little professors,” and urged his colleagues not to give up on these children whose gifts and abilities might not be immediately apparent, advising his fellow doctors that helping autistic children fulfill their potential, would surely benefit society as a whole (Silberman, 2015, p.129; Wing, 1998).

This perspective is echoed by Ne’eman and the disability rights community, reemerging some 60 odd years later, yet in the gap between, competing medical perspectives would intervene, keeping this celebratory frame of reference blocked from public conversation. In 1944, while Asperger was in Croatia, his clinic at the University of Vienna was bombed, and “his concept of autism as a broad and inclusive spectrum...that was ‘not at all rare’ was buried with it,” (Silberman, 2015, p.140) creating the perfect conditions for the rise of a very different conceptual model.

In what is still considered to be one of the great coincidences of twentieth-century medicine, across the Atlantic, another clinician by the name of Leo Kanner, discovered autism nearly simultaneously, albeit framed in a very different fashion (Feinstein, 2010; Silberman, 2015, p.140). Following a prestigious fellowship at Johns Hopkins University, Kanner was asked to set up a new child-behaviour clinic as a way to merge the fields of pediatrics and psychiatry, motivated by the recognition that would surely accompany the establishment of a new field of psychiatric expertise. Instead of viewing autism as a continuum that lasted into adulthood, he portrayed it as a disease that occurred only in children, introducing the idea of “toxic parenting,” which posited that

overprotective “refrigerator mothers,” inadvertently caused their children’s autism, making “his syndrome a source of shame and stigma for families worldwide while sending autism research off in the wrong direction for decades” (Silberman, 2015, p.188). Rather than championing what Asperger referred to as “the social value of this personality type” and a “specialized form of intelligence,” (Silberman, 2015, p.188) not at all uncommon, Kanner demonized autism as a rare, debilitating disorder (Wolff, 2004). An assertion which Silberman (2015) argues was influenced by the fact that only the most affluent, well-connected families could afford to be passed through “the rounds of pediatricians, psychologists and neurologists until they were referred to a specialist like Kanner,” (p.193) and that his referral system was imbalanced in such a way as to only attract the most blatantly disabling forms of autism; Those whom were less obviously affected, or who belonged to minority communities flew under his radar. Kanner worked hard to establish himself as the sole expert on a condition that he characterized as extraordinary and monolithic and which he attributed to flawed parenting practices (Feinstein, 2010).

However, a rebellion against this interpretation was brewing, spearheaded by passionate parents who were tired of being type-casted and scapegoated. In 1965, a gathering of 35 such parents, bonding over discussions of how best to demand access to education and services for their children, served as a catalyst for the formation of a new organization with this objective at its heart: the National Society for Autistic Children (NSAC) (Silberman, 2015, p.296). Fueled by a deep discontentment with the treatment and portrayal of their children, NSAC took off, establishing several chapters across the United States (Feinstein, 2010). As such, Kanner started to lose his grip on the autism

narrative, eventually issuing a public absolution of parental responsibility for autism at an NSAC congress in 1970, although, out of the lime light, he maintained his original pejorative position, evidenced by his reference to autism as “childhood psychosis” caused by parents who were “cold, humourless, perfectionists lacking genuine warmth” in a collection of essays published in 1973 (Silberman, 2015, p.302).

Yet, all was not copacetic within NSAC either. While all parents aimed to help autistic children achieve social acceptability, a rift emerged when determining the means by which to reach this target. Two distinct paths materialized: change *society* to make it a more accepting and accommodating place, or change *the child* to make them more worthy of societal acceptance (Grinker, 2007; Silberman, 2015, p.304). It is here that the aforementioned competing discourses, socio-cultural and bio-medical, come into play. Silberman (2015) outlines the emergence of several different voices speaking to both sides of this split, from autistic individuals like Temple Grandin providing a narrative of their own experiences, to Dr. O. Ivar Lovaas, the psychologist responsible for creating ABA therapy, which, in its earliest form, prescribed the use of harsh punishments, called “aversives,” to “extinguish autistic behaviours” (p.306). Since then, autism has become highly visible, entering the cultural lexicon as a “buzz word” mired in a spiral of speculation and heated debate over the potential influence of vaccines, genetics, diet and the like, most clearly captured in the stand-off between Autism Speaks and ASAN. Silberman (2015) proposes that these theories and the expensive alternative and experimental therapies that accompany them, have negatively impacted the autism community, distracting attention from the immediate needs of autistic individuals, particularly adults, as a result of its preoccupation with immediate childhood

intervention. He concludes his book with a compelling argument for neurodiveristy, explaining how the term was coined by sociologist Judy Singer following the mass increase of autism awareness and connection afforded by the internet in the 1990s. In online communities, people with autism began to bond over their shared experiences, finding empowerment and pride in emphasizing their deviance from mainstream culture, and not attempting to pass as “normal” (p.453). Singer envisioned neurodiversity as disability rights’ answer to the powerful activism of similarly marginalized groups including feminists and gay rights activists (Jaarsma & Welin, 2012; Silberman, 2015; Solomon, 2008). Quietly, via the world wide web – the perfect haven for those uncomfortable with traditional social interaction –alternative communities have sprung up, creating what Silberman (2015) refers to as “autistic spaces” (p.454). The existence of Ne’eman’s network and his appointment to the U.S government in 2010, are the direct result of this connection, of society “becoming more autistic” as technological understanding and accessibility have flourished (Jaarsma & Welin, 2012).

Silberman (2015) argues that rather than ascribe diagnostic labels to particular forms of intellectual difference, we should instead attempt to understand neurodiversity in terms of “human operating systems,” a decidedly less complicated and more organic form of comprehension, which focuses on creating a world that offers “a variety of sensory friendly environments,” (p.471) developed in autistic spaces and catering to those whose neurology leads them to experience typical environments as eminently uncomfortable. In this world, autism is not a glitch to be corrected, but a gift to be celebrated, one “which society should regard as a valuable part of humanity’s genetic legacy, while ameliorating the aspects of autism that can be profoundly disabling without

adequate forms of support” (Silberman, 2015, p.470). From this perspective, harkening back to Asperger’s original “continuum” conception, autism can be destigmatized and depathologized with relative ease, as we focus on creating spaces that are accommodating to individuals wherever they fall on the spectrum, rather than wasting energy trying to “fix” their alleged shortcomings.

As I immersed myself in this riveting tome of autism knowledge, gaining a new understanding of the condition’s trajectory and becoming privy to its sordid history, I began to see Tanzania’s autism illiteracy as hugely advantageous. Being that its history is largely unwritten, we are presented with the unique opportunity to avoid a number of missteps and mistakes that have impeded the process of embracing neurodiversity in the Global North, fracturing the autistic community, and causing harm to autistic individuals. The struggles that Silberman (2015) so poignantly narrates in “Neurotribes” can be avoided in Tanzania, simply because it does not possess the medical infrastructure necessary to support the overwhelming medicalization of behavioural differences which has characterized autism awareness in more economically-stable countries. While I was initially deflated by the apparent inadequacy of autism recognition and understanding in Tanzania, believing that widespread poverty effectively diminished the potential for “high-functioning autism,” and that as such, medical intervention was a necessary evil on the path toward creating the conditions in which self-advocates can be borne. However, when re-framed in the light of Silberman’s (2015) saga, and within the perspective of autism put forth by ASAN - they express offense at the concept of “high functioning” autism being that it suggests that all behaviours can be standardized into categories of greater or lesser functionality based on their proximal resemblance to the behaviours of

what they refer to as “neurotypicals” – Tanzania becomes a fertile ground for progressive understandings of disability rights to be planted.

If disability rights activists were to launch a campaign in Tanzania, they would have significantly fewer obstacles to overcome, able to focus the bulk of their energy on eliminating stigma and increasing visibility, without having to become mired in the biomedical maelstrom of competing causation theories and alternative therapies. In this sense, being a few steps behind is propitious in that it allows for progression with the benefit of hindsight. There is no industry of alternative therapies, pharmaceutical prescriptions, and other interventions aimed at eliminating autistic tendencies to distract from the message of acceptance, thus ACT’s mission to educate parents and destigmatize intellectual disabilities in communities can be more easily accomplished. As I spent time “on the ground” with ACT, my negative preconceptions of cultural imperialism melted away, and a deep respect for their mission and their struggles blossomed. With Mama G at the helm, ACT is shaped by an implicit knowledge of Tanzanian parenting practices, widely held beliefs about health and disability, and the best way to address target audiences. Because there is no biomedical framework to rely on, their focus on raising awareness, increasing acceptance, creating support networks, and accessing resources that will help people with autism to communicate and fulfill their potential is extremely progressive and aligned with the work of autistic self-advocacy organizations. While this non-medical approach may not be fully intentional, its an adaptive strategy that may actually prove superior to operating within a strictly biomedical paradigm.

Seeing Potential: Meeting Mooty

Arguably, it is easier to take a socio-cultural approach to autism advocacy and awareness in less economically privileged countries, because it requires fewer resources and can achieve success simply by creating new narratives and introducing alternative stories. I visited one center where a new understanding of autism had begun to take hold, not because of traditional health promotion or awareness initiatives, nor through formal disability rights campaigns, but simply by virtue of exposure and inclusion.

During my time in Moshi, I rented a room in a house in a semi-affluent suburb. My neighbor directly to the right was a boarding school for boys. An imposing building, its façade mostly obscured by an 8 foot fence, which housed a motley crew of youngsters rescued from a life on the streets. From my side of the fence, I would catch glimpses of an impressively manicured lawn. I could hear the boys outside, blasting music and dancing rambunctiously. Yet, when the merry-making was at its most subdued, I heard a distinctly different sound: a loud, low, moaning which often escalated to a bark, somewhat eerie and difficult to identify. I was soon informed of its origin: Mooty, the school's only autistic student. Of course, I wanted to meet him, and a few enquiries later, I had an appointment to interview Mooty's principle caregiver, Adam.

Adam turned out to be a convivial young fellow with above-average English conversational skills. He met me in the foyer and led me to the lunchroom where, amidst a sea of raucous boys, I was introduced to Mooty. Displaying stereotypical autistic characteristics, Mooty avoided eye contact, made uncoordinated, jerky movements and did not speak, instead making the same loud noises that had precipitated our meeting. The other boys tended to give him his space, which made sense, after Adam explained,

“Mooty remembers. You get Mooty, he will remember. Maybe not right away, but he will get you back.” However, he is not feared or shunned, and is treated with respect as an established member of the school community. Students and teachers have a sense of his personality, understand his quirks, and adjust their behaviour accordingly.

Adam and Mooty have been working together for the past three years. Before that Adam worked as a “normal teacher,” and Mooty was paired with an American assistant whom Adam said, “did a really, really good job with him and taught him many things like going to the bathroom and bathing.” In the intermediary period between the two, Mooty was partnered with another Tanzanian who eventually quit, admitting, “He could not handle Mooty.” Of all the special education teachers I observed, Adam’s approach most closely resembled that of Western professionals. Adam explained that special education is not prioritized in Tanzania, that “normal education” is considered more valuable, and that many teachers with special education certificates end up working office jobs: “In my class maybe I am the only one working specifically with these children and the rest go to normal classes...the government decides where you go and because schools have a shortage of teachers, they find it is more important to put me in a normal class because I can teach English.” Adam claims that the special education certificate program itself is “like an introductory course,” only skimming the surface of what needs to be learned. He supplied an anecdote to support this assertion:

They don’t know a lot. For instance, one Mama who taught at a unit in Moshi asked me for help getting a child to take a bath. The child lives with her mother and her sisters, so I suggested they try turning it into a game, with splashing and playing and it worked. She was fine after that. So you see, they do not know.

This story is also illustrative of the general lack of creativity in Tanzanian education, a legacy left behind by the nation's former colonizers. Teachers generally rely on a system of rote memorization in preparation for standardized testing; thinking outside of the box is not encouraged (see Vavrus, 2009; Hardman et al. 2011). As Semali (1999) surmises, "The system is still beset by undue reliance on facts, rote memorization and regurgitation" (p.311). This standard hinders progress in special education, as it is theoretically founded in a commitment to learning and practicing a new, innovative instructional methodology. Conversely, Adam breaks the mould, experimenting with different approaches and exposing Mooty to a variety of situations.

Like a behavioural therapist, Adam works closely with Mooty to improve important life skills. Every Friday, Adam brings Mooty to his home to hang out and cook. He takes Mooty to the market, gives him a few Tanzanian shillings, and teaches him how to purchase food. On these outings, Adam observes the reactions of his community members: "People are afraid of Mooty. They think he is crazy. But they also feel pity for him. People on the dala dala pass him money." When Adam first started bringing Mooty home, "the neighbours were like 'Huh?' but now they are okay. Even some of my friends, they like him." The pair also travel to a vocational school, so Mooty can learn some basic carpentry skills. "He can sand and cut," Adam tells me, "but he doesn't know when to stop, he will just keep sanding and sanding." Such diligence could easily be translated into an occupational niche, but could Mooty get hired? "Maybe if the school employs him," Adam says, "but in our country, nobody else will." Obviously, there is much progress to be made, but within the realms where Mooty's presence has lost its

novelty and peculiarity – his school and Adam’s neighbourhood – people, are willing to engage him, to adjust their perceptions, and to afford him a higher degree of personhood.

These examples hint at the potential for acceptance, suggesting that acceptance can be achieved through exposure, not necessarily preceded by a formal “awareness” in the sense of medical definitions, labels, and symptoms, but that by increasing the participation of autistic people in communities - making them more visible - we could achieve normalization, initiating a unique rendition of traditional “awareness.”

Traditionally, “awareness” denotes an ability to supply definitions and recite facts, to be conventionally educated about an issue. Most public health awareness campaigns encourage citizens to take certain actions, seeking assistance from specific professionals and their efficacy is measured according to the number of respondents (Giordan, 2000). In Tanzania, this model is irrelevant, as there are few established professionals and avenues for assistance are exclusive. Conversely, the type of awareness that stems from experiential learning and sociality does not necessarily require that one be able to supply official definitions or explanations, as long as they are willing to acknowledge the value and humanity of people whose behaviour or appearance deviate from the norm. This is neurodiversity by a different name.

I discussed neurodiversity with Adam. Although unfamiliar with the term explicitly, once explained, he recognized the idea from books he had read. I queried further, did he think those ideas could be brought to Tanzania? “Yes, but it will take time, because where you are from, it is people with high functioning autism speaking for themselves, right?” Adam asked, “But I have never seen a Tanzanian with high functioning autism. I have seen them only in movies.” It is important to note that Adam is

the only one of my informants who had ever seen a film featuring characters with disabilities. Intrigued, I pressed on. Did he think it would be helpful to show people these films? “Yes, but it is difficult, because I only became interested in these movies after my degree, and other people will not be interested. I even tried to show my colleagues and they were not interested, so it is very hard.” Obviously, there is much progress to be made, and hurdles to be overcome, but the potential is infinite and opportunities abound.

Chapter 8: Recommendations: Targeted Solutions for Positive Change

Creating A Relatable Character: Tanzania Needs a Rain Man

There are strategies to be introduced at a governmental, organizational, community and individual level to help develop and foster acceptance of autism and other disabilities in Tanzania. As I discussed in the themes section, there is no codified cultural narrative of autism in Tanzania. In the Global North, most people learn more about autism from popular culture than they do from spending time with autistic people. The roles we see autistic characters playing in movies, on television, or in stories, shape our perceptions of their abilities, their potential, and ultimately, their worth. While this mode of cultural transmission certainly has problematic elements - it risks homogenization and reification of autistic individuals based on a few stereotypical traits – it is also one of the singularly most influential, and authoritative means of raising consciousness across diverse populations. Silberman (2015) acknowledges the tremendous impact that *Rain Man* had in raising public consciousness of autism, unifying the public around a single, positive image of the autistic savant. Suddenly, mothers with autistic children began to be approached by strangers who had seen the movie, strangers who were newly curious and unusually compassionate. Silberman (2015) supplies the anecdote of a mother who received a withering look from another woman in the grocery store while shopping with her autistic son, shortly after the film debuted. She asked: “Did you see *Rain Man*?”

“Oh yes,” the woman replied, “I loved that movie.”

“Well, my son Johnnie is like Raymond Babitt,” the mother said.

Suddenly much softer, the woman adjusted her gaze. “Oh Johnnie,” she said, “Do you have autism? I understand.”

People wrote to Hoffman, sharing their stories. A grandmother who had refused to acknowledge the existence of her grandson to her friends until she saw the film, and an autistic child who rarely spoke, yet declared proudly, “I’m autistic,” on the way home from the theatre (Silberman, 2015). Silberman (2015) calls it the *Rain Man* Effect: “By putting one autistic person on the screen, the filmmakers had made innumerable others visible – to their loved ones, to their neighbours, to their teachers and doctors, and to themselves” (p.378). Viewers now had a real life example, a popular figure with a name and a personality, to attach to the term ‘autism.’ Tanzanians have no such reference. They are expected to take us on our word, and if my suspicions are correct, most acceptance stems more from politeness, than it does from conviction. A popular media representation could change this.

Ms. Okafor suggested that non-print media sources would provide a more effective platform for autism education in a Tanzanian context:

Tanzanian people don't like to read, they like to watch and listen. Our leaders watch and listen. So we need to go on radio and television with this information. They are not interested in reading because they learned to listen and watch. In school, for lack of books, the teaching was more 'preaching' and this is how they like to receive information. I try to inform the NGO person to go on TV to inform the people, educate them, to maybe get one step ahead of autism. To mention real examples of people in the street who have this problem, I know so many.

Both the history of autism consciousness in the Global North, and Tanzania's preferred means of learning and entertainment, suggest that creating novel narratives of autism through television and radio stories could be more powerful tools for reframing the conversation around intellectual disabilities than printed documents and seminars which impact only a select audience. If North America's experience is any indication, a Tanzanian Rain Man could create unprecedented recognition of the term and the people it describes.

Considering The Power of Religion

Religion is a unifying force in Tanzania. Christians and Muslims each make up 30% to 40% of the population, while the remainder ascribe to African spiritual traditions (Zou et al., 2009; Heilman & Kaiser, 2002). Religious activities, communities and beliefs inform the daily behaviours and attitudes of citizens (Zou et al., 2009). While Christians and Muslims experience friction in many countries, Tanzania's history of harmonious co-existence between the two communities is exceptional (Rasmussen, 1993). Religion is understood as a given. New friends often questioned me about my religious background. When I tried to explain my agnosticism, I was met with confusion: "You're a Pagan?"

The prevalence and popularity of religion, whatever the denomination, provides an omnipotent forum for introducing new ideas and changing established narratives. As Ms. Okafor surmised, Tanzanians are big fans of preaching. They tend to accept information supplied by authoritative orators, chiefly those of a religious persuasion. A study by Zou et al. (2009) assessed the influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes in Tanzania, finding that religious beliefs strongly

influence shame-related HIV stigma, and that shame was significantly more prevalent amongst people who view HIV as a punishment from God. As such, “religious organizations are influential social networks that have the power to support or stigmatize...to mitigate or exacerbate shame” (Zou et al., 2009, p8). The study suggests that “religious leaders may have the power to address shame related HIV stigma in their congregation, thereby enhancing the faith community’s potential to facilitate emotional healing and support,” recognizing that “religion mediates HIV-related shame in several ways... and that the shame-dimension of stigma may be reduced by appropriate interventions in religious communities” (Zou et al., 2009, p.8). The same could be true for autism and disability related stigma and shame. Religious organizations are powerful sites of knowledge production in Tanzanian culture. If religious and spiritual leaders systematically lectured on the importance of acceptance, encouraged followers to support and nurture people with disabilities, and disseminated important information about specific disabilities and resources, it could precipitate a major cultural attitude shift, creating the conditions for improved quality of life and increased participation in society by those who have been heretofore ignored.

Consulting the Real “Experts”

Additionally, I urge future researchers to treat autistic people as experts on their own experience. This includes those people in the research population – by allowing them to narrate their own experience and privileging their perspectives – as well as within the larger public sphere – by seeking out the work of autistic academics, consulting and incorporating the opinions of autistic self-advocates, and reviewing literature that

expresses non-hegemonic perspectives of autism. ASAN has a comprehensive website replete with resources including a formal guide to Community Based Participatory Research (CBPR or PAR) methodologies: “An approach that brings together professionals and community members to serve as equal partners throughout the research process, focusing on research that is relevant to the community” (Retrieved from: <http://autisticadvocacy.org/home/about-asan/operational-policy-on-research-inquiries/>).

Chapter 9: Conclusion

Like most African countries, Tanzania has very few resources and services devoted to supporting individuals with autism and other cognitive disabilities. There is much confusion and mythology surrounding causation theories (not unlike that which characterizes public conversations of autism in the Global North) ranging from the socio-cultural belief that disabilities are the result of curses or punishments from God, to biomedical explanations that include drug use during pregnancy, or mistakes made by medical professionals during delivery. Autism is still an obscure term, recognized only by those with direct involvement in the medical or education sectors, if at all, and used as a synonym for crazy (kichaa) or abnormal. In an increasingly globalized and modernized society, people with autism are seen as a burden and a source of shame. Parents are reluctant to invest in their schooling and it is not uncommon for children and adults with disabilities to be hidden in their homes. Some attend special education units, but lack of training and resources ensure that they make little progress beyond basic social interactions. Once they age out of the system, these people have little chance of successful integration and meaningful participation in communities.

While this dearth of information, normalized discrimination, and lack of formal services and medical infrastructure, is at first discouraging, I suggest that it may actually be advantageous. The history of autism in the Global North is rife with tragic medical and psychological misinterpretations that initiated grotesque “treatments,” subjecting autistic people to decades of unnecessary interventions, and causing families to suffer from immeasurable pain, shame, and guilt. With the emergence and the rising popularity of the neurodiversity movement, heralded by autistic individuals and communities fighting for

the recognition and valuation of cognitive differences, experts are beginning to transition away from a purely biomedical approach to the treatment and understanding of autism. Organizations like the Autistic Self-Advocacy Network (ASAN) are expressing a powerful desire for funds to be diverted away from biomedical causes and cures, to be put toward social services, tools and resources that will improve quality of life for autistic people, allowing them to engage more fully in public life. In Tanzania, we are afforded the unique opportunity to benefit from hindsight. The absence of an established systemic medical approach to autism makes it possible to bypass the harmful aspects of a medicalization phase, skipping right to an approach that aligns with the views expressed by autistic self-advocates.

Autism Connects Tanzania (ACT) is a community based organization (CBO) working to decrease the stigma and shame attached to autism in the Kilimanjaro region. They have made an impressive impact on the level of autism literacy among special education teachers and government officials, as well as parents, by hosting seminars and workshops that explain autism and offering suggestions of methodologies, strategies and activities that will benefit autistic people. Their forced reliance on a socio-cultural approach – due to the inability to refer people to medical interventions, which either don't exist, or are inaccessible – unintentionally aligns with the neurodiversity perspective. With a local mother and respected community member at its helm, their organization's mission to address and to alter negative attitudes, to eliminate harm, and to improve autistic quality of life, is culturally salient and exhibits a high degree of potential impact. Based on my research, I have made some suggestions to harness that potential, including the use of media sources such as television and radio to disseminate

information and create new narratives of autism, as well as educating and involving local religious leaders about autism, who can then encourage inclusion and acceptance amongst their congregations. Furthermore, I suggest that future autism researchers consult with members of the neurodiversity community, formulating and conducting studies that respect their unique expertise as self-advocates. In combination, these approaches and strategies can help to address autism in countries outside the Global North in a culturally relevant and resonant manner, increasing the visibility of autistic people, reducing stigma, and honouring the simple, unifying fact that across the globe, the slogan holds true, autistic people are “different, not less.”

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Appendix A - Participant Observation Guide:

The following questions are examples of the types of inquiries I made while volunteering and visiting various schools and rehabilitation centres. In practice, the wording varied, as these exchanges were informal and conversational. Questions also varied depending on the person's status within the center as staff, volunteer, parent or visitor. The purpose of these questions was to understand the ins and outs of a typical day at the centre, as well as to get a sense of how staff and attendees felt about their various roles.

- How long have you worked here/ been coming here? How often do you visit?
- How long does it take to get here? How do you get here?
- Do you enjoy your time here? What is your favourite part of the day?
- Has your life changed since you started coming here?
- Do your friends and family members know about the Gabriella Center and/or autism?
- Do you think most people know what autism is?
- How long do you think your child will continue to attend the center?
- How long does a child typically attend the center?
- What have you learned here? What does your child learn here?
- Are there other places like the Gabriella Center in Tanzania?

The following is a list of things I may have recorded during or after participant observation. This data was gathered mainly through observation, rather than conversation.

- Structure of the day
- Types of activities performed and types of materials used
- Number of visitors
- Typical tasks for staff
- Interaction amongst children, between children and staff/volunteers, and amongst staff/volunteers/visitors
- Rules and regulations
- How children/staff/volunteers spend their free time
- Which activities children seem to like/dislike
- Conflicts
- Topics of conversation among staff/children, common concerns

Appendix B - Interview Guide

Questions for Parents: (in plain English for ease of translation)

Experience Raising a Child with Autism:

- Tell me about your experience having a child with autism.
- How did you hear about this center/school? What made you decide to attend?
- Can you describe your autistic child to me, what is he/she like?
- How old were they when they were diagnosed? Who diagnosed them? When did you first notice these characteristics?
- How is your child treated by other people in the community?
- What is your biggest parenting challenge?
- Do people treat you differently because you have an autistic child?
- What sort of future do you envision for your child? Where will they live? What will they do?

Ideas About Autism and Neurodiversity

- When did you first hear the word autism?
- What is autism?
- What causes autism? Do you think autism can be cured? Is it a disease?
- Have your ideas about autism changed since attending this school/center?
- How is autism talked about in your community?
- Is autism a disability?
- Have you heard of disability rights? What do you think about them?

Basics:

- Age of parent and child(ren)
- Place of Birth
- Current Place of Residence
- Language
- Education
- Number of People in the Household
- Livelihood —> What is a typical day like for you?

Appendix C - Interview Guide

Questions for School/Center Staff: (in plain English as interviewees have various levels of English language comprehension)

Job:

- What lead you to work at the center/school?
- What is your role at the center/school?
- Do you have special training, if so, where?
- How has the center changed since partnering with EdPowerment?
- What is the center doing to help? Is it working? What are its future goals?

Ideas About Autism, Neurodiversity and the Myth of the Hidden Disabled

- When did you first become aware of autism?
- How do you define autism? Is it a disease? Can it be cured? What causes it?
- Where do you get your information about autism?
- How do you think autistic people are treated outside of the center?
- Are autistic people often mistreated in your community? Explain.
- Have you heard of the term neurodiversity?
- What do you know about disability rights?

Basics:

- Age
- Place of Birth
- Language
- Current Place of Residence
- Education
- Livelihood —> What does a typical day look like for you?
- Number of people in household

Appendix D - Interview Guide

Questions for Personnel and Volunteers associated with EdPowerment (most likely native English speakers)

Job Details:

- How long have you worked for EdPowerment?
- How many times have you been to Tanzania?
- How does EdPowerment support the Gabriella Center? What is the nature of that relationship?
- What is the goal of Autism Connects Tanzania?
- How can that goal be achieved? What progress has been made? What still needs to be addressed?
- What is your role in the Autism Connects Tanzania project?

Ideas about Autism, Neurodiversity and the Myth of the Hidden Disabled:

- What is your experience with autism in Tanzania?
- How do you think autism is viewed in Tanzania?
- Do you think autism is an illness? Are you hopeful for a cure?
- Have you heard of neurodiversity? If so, what do you know about it?
- Have you noticed a similar way of viewing autism as an identity in Tanzania?
- Do you think autism is experienced in the same way across cultures? explain
- In your opinion, what is the biggest issue faced by autistic children and their families in Tanzania? What is the best way to combat this challenge?

Background Information:

- Age
- Place of birth
- Current place of residence
- Language
- Education
- Occupation