Sexual Autonomy Matters

Marginalization of Central Experiences for Women with Intellectual and Developmental Disabilities in Tanzania

Bijal Lal

Supervised by: Dr. S.M. Rodriguez

GRÓ GEST, University of Iceland

May 2023

Acknowledgments

I extend my gratitude to the GEST program, its organizing team, and all the visiting professors who have contributed towards enriching my understanding in various ways.

Dr. SM Rodriguez – Thank you for your tremendous insights in crafting this essay and your encouragement during the various developments of writing this essay.

GRO GEST Fellows 2023 – Thank you for the challenges, the support, and the lasting memories.

My family – Thank you for your patience and understanding as I continue this journey of self-growth.

Finally, I would like to thank my students; this essay offers intimate glimpses of your journey and your impact on my being.

Abstract

Sexual autonomy, the agency to make an informed decision regarding one's sexual experiences, is a fundamental right for all individuals, yet Women with Intellectual and Developmental Disabilities (WwIDD) are often excluded from this experience. This essay examines what barriers exist and impact the sexual autonomy of WwIDD in Tanzania using a feminist reflexive and autoethnographic methodology. The historical accounts of the disability rights movements are introduced, and the current shifts within the Intellectual and Developmental Disabilities (IDD) category are highlighted. The essay discusses a global understanding of the sexual autonomy of WwIDD and presents the Tanzanian context, including its divergence in labeling the disability categories, the legislative gaps, and the impact of language. The theoretical frameworks used are intersectionality and the matrix of domination, the disability justice framework, and the Ubuntu philosophy. The barriers to sexual autonomy identified are cultural misconceptions, differential access to social rights, increased instances of violence & abuse, and the capacity of WwIDD to consent. Finally, recommendations on strengthening the self-advocacy movement, building cross-movement alliances, advocating for improved disability data, and government accountability are suggested.

Keywords: Intellectual and Developmental Disabilities, sexual autonomy, Tanzania, disability rights, women with disabilities

List of Acronyms

CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled People's Organization
IDD	Intellectual and Developmental Disabilities
MwIDD	Men with Intellectual and Developmental Disabilities
PwD	Persons with Disabilities
SHIVYAWATA	Shirikisho la Vyama Vya Watu Wenye Ulemavu Tanzania
WwIDD	Women with Intellectual and Developmental Disabilities

Table of Contents

Chapter 1 - Introduction

Within the heart of Dar-es-salaam[1] is a classroom filled with laughter, determination, self-advocacy, and never-ending curiosity. The class has been labeled as 'special' and I have been applauded for the 'noble' work I do in simply teaching the students. My students have various labels, some of which are medically oriented, and most of the others are painful. Many of the students are said to have 'invisible disabilities', yet it is not only their conditions that are 'invisible'; within many communities, it is their presence that has been made invisible.

Yet my students exist; they exist within locked homes, they exist within shaman prayer houses, and they exist within some public spaces (if lucky). I cannot shame my community for denying my students their presence and undermining their rights when I have a similar guilt to carry. Yet, guilt has not immobilized me, it has provoked me. More than self-growth, my students' tenacity has transformed 'inclusion' from being this buzzword to an explicit practice that we can deliberately cultivate.

I always imagined inclusion to be limited to spaces such as classrooms, playgrounds, restaurants, offices, and others. Of course, I continue to have a lot more to learn, and from Zaitun's[2] journey toward negotiating her sexual autonomy, this new chapter in my learning arose and the true basis of this inquiry. Here, I attempt to unpack the various questions that my students have raised, such as: Why is the right of choosing a partner and being in a consensual relationship never theirs? Why are their intimate conversations 'policed'? Why are their explorations of different sexual and romantic experiences equated to being easily manipulated? Why are their experiences of romantic relationships invalidated in the name of abuse? Equally, I write this essay as a response to policymakers, faith-based leaders, community gatekeepers, teachers, and parents who create systemic barriers for Women with Intellectual and Developmental Disabilities (WwIDD) from actualizing the human experience of exploring their sexuality.

---

[1] City in Tanzania

[2] Student name (alternate pseudo name used for confidentiality)

This essay specifically questions what barriers exist and impact the sexual autonomy of WwIDD in Tanzania and how the lack of access to sexual autonomy impacts WwIDD in Tanzania. WwIDD are prioritized in this essay due to their differential experiences in expressing and accessing their sexual autonomy. In relation to WwIDD in Tanzania experiencing their sexual autonomy, barriers being explored include entrenched cultural misconceptions and norms, differential access to social rights, increased vulnerabilities to abuse and violence, and stigma concerning the capacity to consent.

Methodology

Two methods were used to collect data. Firstly, the essay draws on feminist reflexive and autoethnographic accounts from my experiences as a special education needs (SEN) teacher in Tanzania for the past seven years. Accordingly, I reflect on anonymized conversations with students, which are anecdotally curated and integrated into different parts of this essay. Secondly, I analyze official, secondary data from legislative records and other governmental and non-governmental reporting agencies in Tanzania. I have prioritized an intersectional and social lens in the readings of secondary data. Furthermore, the readings are compiled alongside the literature review from various academic journals focusing on the triple nexus of disability, gender, and sexual autonomy.

Historical Context – Disability Rights Movement in Tanzania

The history of the disability rights movement illuminates how the past shapes and continues to interact with the current realities for disabled people. It maps out how disabled people have been perceived within regional discourses, specifically the roots of dehumanizing their presence. The disability rights movement has a long history in Tanzania. Flowing from the pre-independence era of the 1900s, where the influences of colonialism and religion shape the ideologies of disability, towards the 1960s post-independence movement of building vocational centers, special schools and assimilating disability rights to the legislation through quota systems (Kalugendo, 2021). Tanzania has ultimately curved towards the current movement of national-level umbrella organizations representing the collective voices of disabled people (Kalugendo, 2021).

The medical model of disability views disability as a biological health condition that needs to be "fixed" by medical professionals, thus, creating the entrenchment of viewing disabled people as flawed individuals who need to be 'rehabilitated' to fit within our societies. The medical model's deficit-based view is also reflected in the current language used to address disabled people. In Tanzania's national language, Kiswahili, the othering of these 'flaws' is seen in how disabled people are addressed using the '*ki*' prefix, for instance, *ki*pofu (blind person), *ki*lema (disabled person). However, the 'm' prefix is used when describing non-disabled people, for instance, *m*toto(child), *m*wanamke (woman; Waliaula, 2009). The use of language to create a false binary between disabled people and non-disabled people is one of the many manifestations of the rooted stigma towards disabled people.

The moral model of disability views disability as a mark of blame, shamefulness, or wrongdoing and attributes these characteristics to the disabled person and/or their family. The consequences of shaming families for having disabled children disproportionately fall on mother figures, such that it is believed that a woman's sins and wrongdoing largely contribute to the disability in their children (Kisanji, 1995). The consequences of "blaming" mothers are reflected in 2004 statistics, where single mothers raised 86% of disabled children in Bukoba district in Tanzania (Kalugendo, 2021). The moral model of disability can be explored in various ways, and the stigma and oppression inflicted on disabled people can stem from the ideologies of this perspective.

In Tanzania, there is a unique dilemma for individuals with hidden disabilities to identify themselves as disabled, considering the harsh and negative views held within our communities and the marginalization that stems from it. Focusing on my students' experiences toward inclusion in schools, Maiko[3] became my student when he was nine years old; he had moved through 6 schools in his short education span, and each school found a 'behavioral' challenge that was used as grounds for expulsion. Discrimination was never explicit; it was always masked with 'valid' school behavioral policies. His grandmother, exhausted with the situation, decided to knock on more school doors, but this time, she mentioned his diagnosis, hoping for more

---

[3] Student name (alternate pseudo name used for confidentiality)

understanding from the schools. Suddenly, the discrimination was blatant; no mainstream school wanted Maiko to 'spread' his disability, they worried parents would withdraw students from their school, and the only solution left was knocking on the doors of special schools. Parallel with Maiko's case, disclosing one's disability, considering the realities of the moral model, could mean immediate exclusion from various spaces. Global disability rights movements should acknowledge that local contexts and their spaces vary significantly regarding their acceptance of disability. This could have a myriad of implications in different spaces, such that the nuances of different spaces need to be accounted for while advocating for change and growth within the larger disability rights movement.

As we move through the different dominant models of disability, within Tanzania, especially at the level of legislation, we see a movement towards the social model of disability. The social model of disability understands disability as a social construct, and it is the social and structural barriers that limit the ability of a disabled person to exercise their rights in everyday life experiences. It differentiates disability from impairments which are the physiological, neurological, anatomical, or psychological abnormalities of bodily functions. The Persons with Disabilities Act (2010) in Tanzania defines disability by infusing the social, medical, and moral model; the law states that disability should be seen "in relation to an individual means loss or limitation of opportunity to take part in normal life of the community on an equal level with others due to physical, mental or social factors" (p.7). Similarly, the Tanzanian national umbrella Disabled People's Organization (DPO), Shirikisho la Vyama Vya Watu Wenye Ulemavu Tanzania (SHIVYAWATA), in their publications use language that promotes the social model of disability and is moving away from the medical and moral models.

The progress towards the social model of disability by the government and various Tanzanian DPOs is in line with Tanzania being a signatory of various key international human rights conventions such as the Convention on the Rights of Persons with Disabilities (CRPD), African Charter on Human and Peoples Rights (ACHPR) and the Convention on the Elimination of all Form of Discrimination against Women (CEDAW). Despite this solid legal framework supporting global trends on the rights of disabled people on paper, Tanzania has little evidence to demonstrate its implementation track. Tanzania has not been compliant in meeting the

reporting obligations of each treaty since 2007, 2008, and 2014, respectively (UNICEF, 2021). The challenge of translating policy into actual gains and rights for disabled persons is a known uphill battle such that, in the Tanzanian National Policy on Disability, the preface cautions, "The challenge before us is an open secret. To translate the optimism embodied in the policy into realism" (2004, p.6).

Current Shifts – Intellectual and Developmental Disabilities (IDD) in Tanzania

The challenge of actualizing the rights of disabled people in Tanzania has been a complex journey for Persons with Intellectual and Developmental Disabilities (PwIDD). Intellectual and Developmental Disabilities (IDD) is an umbrella category that refers to differences in functioning that are present at birth, and which affect an individual's development (U.S. Department of Health and Human Services, 2021). This essay focuses on IDD conditions affecting the nervous system, particularly Down syndrome, Cerebral Palsy, and Autism Spectrum Disorders (ASD). The experiences shared in this essay focus on students with these mentioned conditions.

Despite the existence of students with IDD in my classroom, the global categorization of IDD does not formerly exist in Tanzania. The formation of language around IDD is still developing in Tanzania, such that conditions such as Down Syndrome do not have an agreed upon Kiswahili term for it. The lack of language for different categories of disabilities and their implications is well documented in the experiences of Elly Kitaly, a mother of a child with Down Syndrome in Tanzania. She reflected how disheartening it is not to have appropriate terms that reflect her daughter's condition and how current terminology in Kiswahili associates her daughter with dwarfism, being a 'retard', or a zombie cursed by her ancestors (BBC News, 2019). It is not only Down Syndrome but conditions such as Cerebral Palsy (CP), Muscular Dystrophy, Specific Learning Disorders (SLD), and others within the IDD umbrella that rarely have agreed-upon diagnosis terms in Kiswahili. Also, other conditions, such as ASD, have agreed upon terms (Usonji) in Kiswahili, yet they are not part of commonly used terminology in Tanzania.

The absence of language to express IDD conditions within Tanzania creates a multitude of problems, including barriers to academic discourse in Kiswahili, lack of access to services and benefits, delay in diagnosis, and problematic beliefs such as IDD being 'western diseases' among

others. In addition to the absence of language for IDD in Kiswahili, language describing IDD conditions globally has also evolved in the past centuries and continues to develop. In the past, people with Intellectual Disabilities have been addressed using terms such as idiocy, feeble-minded, and mentally handicapped (Schalock et al., 2007). However, the field now has moved towards intellectual disabilities, and this growth in the preferred term demonstrates the importance of advocacy to reconstruct the narrative around stigmatized labels. While the absence of language creates clear challenges, it also provides an opportunity within the Tanzanian disability rights movement to prioritize a common understanding of disability categories, specifically creating spaces where PwIDD can be at the forefront of building their own narratives using their preferred terms and languages.

Similar to the gaps in language for IDD categories, Tanzania's data on disability statistics is also insufficient. The prevalence and incidence rates of IDD are not known within Tanzania, and there is inadequate monitoring of the effectiveness of disability-specific legislative policies on the lives of PwIDD. According to the Tanzania Disability Survey Report (2008), the prevalence of disability is estimated at 7%; however, there is no specific data on specific disability categories, especially within the IDD categories, and the report mainly focused on the levels of activity limitations. The 2022 Tanzania Population and Housing Census is the first time that data on some IDD-specific categories, such as ASD and Epilepsy, was collected. While the disability-specific census data is yet to be published, it is a positive move towards quantitatively documenting the presence of PwIDD in Tanzania (Rugeiyamu et al., 2022).

The presence of PwIDD in Tanzania is systematically being made invisible, from the lack of language to represent their collective presence to insufficient data to acknowledge their national existence. The invisibility journey of PwIDD starts from their first diagnosis and extends to systems of discrimination that are rooted in language, culture, and legislation; each of these systems moves beyond just negating their presence to actively oppressing their rights. I focus specifically on the right to experience sexual autonomy, which is complicated for many Tanzanian women and a forbidden taboo for WwIDD.

Chapter 2 – Theoretical Frameworks

In amalgamation with the autoethnographic method of inquiry, I apply three theoretical perspectives to unpack the questions raised by my students. These perspectives range from dominant feminist perspectives to current developing understandings of disability. I also draw upon pre-colonial African philosophies that provide a contextual lens to view disability.

Intersectionality & Matrix of Domination

Intersectionality refers to the multiple oppressions and privileges created as we simultaneously live through and experience our overlapping identities (Crenshaw, 1989). It moves forward from a single framework of understanding our experiences and encompasses how each of our individual identities can come together to form unique spaces of persecution or opportunities. The identities of disability and gender uniquely interact and are made distinctively vulnerable within institutionalized discriminatory systems. The intersecting identities of being a woman and being diagnosed with IDD will be the primary focus of this essay. Other intersecting identities, such as sexuality, age, and class, are not explicitly explored in this essay. However, these identities can also intersect differentially to affect one's experience of vulnerability or opportunity.

While the intersecting identities of gender and disability disproportionally experience multiple forms of oppression, it is the institutionalized systems that perpetrate these vulnerabilities and oppression. Hence, Collins (1990) concept of the matrix of domination is also used to understand the domains of power that shape oppression in Tanzania; in particular, the structural and hegemonic domains of power will be critically examined. The former is in terms of how systematically exclusionary the social institutions in Tanzania are towards WwIDD, specifically the differential access to social rights. The latter highlights how the culture and beliefs of non-disabled people have normalized and actively marginalized WwIDD from their right to sexual autonomy. Similarly, self-advocacy is explored as a recommendation for WwIDD to reclaim their power in self-defining their needs at an interpersonal, community, and institutional level.

Disability Justice Framework

The disability justice framework, the second wave of the global disability rights movement, is conceptualized by queer, multi-racial, disabled people. Each intersecting identity partly felt alienated within the larger disability rights movement due to its neglect of using an intersectional approach and its indifference to intellectual and psychosocial disabilities (Sins Invalid, 2017). The disability justice framework focuses on ten principles for their movement building, among which the principles of intersectionality, commitment to cross-movement solidarity, and recognizing wholeness will be spotlighted in exploring the barriers to sexual autonomy for Tanzanian WwIDD.

The principle of intersectionality, especially the intersecting identities of gender and disability, is primarily focused on, as described above. The principle of commitment to cross-movement solidarity involves an important recommendation for WwIDD to form alliances within the Tanzanian feminist movements and national DPOs, and gain momentum within Tanzania's current political climate of creating safe spaces for women within various social structures. The principle of recognizing wholeness acknowledges the inherent worth of disabled people and values their experiences without any qualifications. Similarly, this essay gleans from the voices of WwIDD as a source of knowledge to build the argument for their sexual autonomy, equally recognizing that one of the most significant barriers perpetrated by society is not recognizing the wholeness of disabled people, especially WwIDD.

Ubuntu – An Alternative African Perspective on Disability

The disability rights movement has largely been restricted to understandings from the geopolitical north, such as the impoverished medical view of considering disability as an illness to be 'cured'. However, within the African context, disability in the pre-colonial context was viewed quite differently, especially for nations that adopted the Ubuntu philosophy. Ubuntu is an African philosophy of viewing the world as interrelated, communal, and interdependent, such that the Ubuntu model of disability views disability as a natural part of human diversity (Berghs, 2017).

Shared humanity is core to the Ubuntu philosophy, and the disability justice framework strongly echoes the principles many African nations have always lived with. For instance,

Nzimakwe (2014) highlighted the key values of Ubuntu philosophy, which resonate so closely with the ten principles of the disability justice framework. Parallels are experienced in the key value of the 'solidarity spirit' in Ubuntu philosophy which encourages from a young age to collectively promote justice for all; this is similar to the cross-movement solidarity and collective liberation principles that advance joint liberation. Similarly, the value of dignity closely relates to the principle of recognizing wholeness; both elude towards the concept of inherent value that is not disqualified due to one's disability status.

Considering the entrenched cultural stigma towards disabled people, moving towards philosophies such as Ubuntu holds great value, especially within the African context, where specific disabilities are viewed only as 'western diseases'. Also, consciously crediting and aligning 'global' disability movements with pre-existing philosophies of living can further help unlearn the 'otherness' that is created for disabled people, especially within the post-colonialism capitalist era.

Each of these theoretical frameworks is the guiding principle in analyzing the barriers faced by WwIDD in experiencing their sexual autonomies. They help unpack not only my female students' experiences but also allow for incorporating their experiences and linking them to the global literature centering on sexual autonomy for WwIDD.

Chapter 3 – Barriers to Sexual Autonomy for Women with IDD (WwIDD) in Tanzania

Sexual Autonomy

Sexual autonomy is the agency to make an informed decision regarding one's sexuality, sexual experiences, and sexual choices (Valentiner, 2021). Sexual autonomy as a human right stems from the 1994 International Conference on Population and Development (ICPD); historically, it has been contentious for women to have this right legalized within the human rights framework, and it continues to be difficult under international law (Lai & Ralph, 1995).

International conventions such as the CRPD and CEDAW have space to unequivocally support the right to sexual autonomy, such that they currently euphemize this basic right as the capacity to make choices and the right to make choices. For instance, Article 12 of the CRPD highlights equal opportunities in 'all aspects of life' and equal legal capacity, and the guiding principles of CRPD emphasizes the freedom of choice for Persons with Disabilities (PwD), yet the rights towards sexual autonomy are not explicitly stated in either. Similarly, the rights toward sexual autonomy in decision-making and legal capacity are alluded to in the CEDAW Articles 12 and 15, yet the emphasis is on sexual and reproductive health. The CRPD and CEDAW implicitly recognize this inalienable right to sexual autonomy, yet there is a marked absence of this right being explicitly stated.

Green (2020) conceptualizes sexual autonomy as prima facie rights, such that they are self-evident, which aligns with the implicit assumptions stated in the CRPD and CEDAW and the disability rights framework, specifically the principle of recognizing the inherent wholeness of the human experience. Green (2020) argues that sexual autonomy is seen as the right to engage in sexual activity consensually, and its violation is experienced when someone has non-consensual sex or is prevented from consensual sex. Green's definition and explicit delineation of sexual autonomy is used in this essay.

WwIDD & Sexual Autonomy – Global Context

Mahari[4], a student who recently transitioned to the Senior Girls class, was unaware of how quickly life would change for her. During a tea break, a group of teachers came together to discuss Mahari and the attention she was getting from most of the boys at the school. Each teacher shared their action plan, including requesting her mother to buy a "loose" uniform, reducing her movement to the Senior Boys class, and volunteering to keep an extra lookout during her free time. Reflecting on those discussions, I realized that we teachers held two implicit assumptions: there was an increased risk of her being abused at school and an erroneous lack of trust in her abilities to navigate her sexual autonomy independently. Despite never discussing this with her, it was Mahari who approached me. She was curious why her duties to pass supplies to different classes had stopped, why she was now forced to spend her lunchtime in our class, why all her friends from the Senior Boys class had stopped talking to her, and lastly, why she felt "not so happy anymore" in our school. Mahari's identity as a woman and her identity as a PwIDD meant that she was exposed to the most extreme and explicit forms of control of her sexual autonomy. This included prohibiting her interactions, monitoring her movement, and controlling her activities—each oppression was justified by the invalid assumption of Mahari's lack of capacity to explore her sexual autonomy independently.

Mahari's experience does not stray far from the dominant global narrative on sexual autonomy for PwIDD. Kramers-Olen (2016) documented that across many countries, men with IDD (MwIDD) are often perceived as hypersexual beings with difficulties controlling their sexual impulses, and WwIDD are often infantilized or assumed asexual. These entrenched perspectives are also reflected in how classes in some special schools in Tanzania are divided, such that gender segregation in classrooms starts from the Junior level (age 11 onwards). While not explicitly stated, one of the main reasons for this segregation is to limit interactions of 'sexually hyperactive' male students with the 'vulnerable' female students. The social narrative of PwIDD experiencing their sexual autonomy is largely perceived within a deficit framework which has various implications.

---

[4] Student name (alternate pseudo name used for confidentiality)

Within this framework, WwIDD differentially experience the impacts of these misconceptions such that instances of sexual violence are significantly higher for WwIDD than nondisabled people and MwIDD (Barger et al., 2009). Moreover, Meer & Combrinck (2015) note that accurate data on instances of sexual violence for PwIDD is challenging due to barriers, such as underreporting, lack of access to appropriate healthcare facilities, and difficulties in data collection. They state that statistics vary greatly, and some statistics have suggested that the rates of Gender Based Violence (GBV) for MwIDD are at 25% and WwIDD at 61%. However, in many African countries, especially Tanzania, data collection barriers are further deepened due to the under-diagnosis of IDD, mistrust towards accounts shared by PwIDD, and increased acceptance of intimate partner violence.

The barriers that perpetrate these inequalities in Tanzania are explored using the questions raised by my students, as highlighted in the introduction section. While each question is unpacked using a specific barrier, these are not standalone barriers, and each can uniquely interact with others to create varied individualized experiences of oppression for WwIDD.

WwIDD & Sexual Autonomy – Barriers within the Tanzanian Context

Kramers-Olen (2016) points out that most scholarship on sexual autonomy focuses on the difficulties experienced by PwIDD, such as understanding 'acceptable' sexual behaviors, the lack of privacy in living situations within care and support networks, the lack of sexual independence due to increased monitoring of movement and the questions of diminished capacity to consent. Similarly, WwIDD in Tanzania are made vulnerable through systemic barriers that impede their right to sexual autonomy. Within the Tanzanian context, barriers such as cultural misconceptions, differential access to social rights, increased instances of violence and abuse, and concerns around the capacity to consent create a hostile and demeaning environment for WwIDD to access and experience sexual autonomy. These barriers will be analyzed in the following sections.

Cultural Misconceptions

Why are the sexual and romantic experiences of WwIDD equated with being easily manipulated?

Cultural norms are the shared expectations and beliefs of acceptable behavior within a community. Culture can negatively affect access to living a life with dignity when it perpetuates

misconceptions that create or exacerbate the marginalization of certain groups. Certain cultural practices differentially intersect with one's gender and disability status, such that these practices can adversely impede WwIDD from pursuing their right to sexual autonomy.

Harmful cultural misconceptions such as the virgin cure can disrupt WwIDDs right to explore their sexual autonomy safely. The virgin cure is a deeply entrenched myth where it is thought that women and girls with IDD can cure instances of HIV, such that having intercourse with a virgin with IDD will transfer the virus from the assaulting man to the assaulted virgin woman/girl (UNICEF, 2021). The implications of such dangerous myths have real consequences, such as a positive correlation between the increased number of HIV cases for Women with Disabilities (WwD) when compared to Men with Disabilities (MwD; UNICEF, 2021). Also, such misconceptions further create unsafe spaces for WwIDD to explore their sexual autonomy independently.

Similarly, deeply entrenched stigma within Tanzanian communities has contributed to WwIDD being treated as sub-humans, such that their rights can be infringed upon without real consequences. ADD International (2017) documented that in Tanzania, WwIDD are being locked up inside houses, beaten, and starved by relatives and guardians. Similar parallels can also be seen within living conditions, where misconceptions of IDD being an easily transmittable disease can lead to isolation, owing to the ungrounded fear of PwIDD 'infecting' others. In Mbwilo et al.'s (2010) study, some Tanzanian parents reflected on their experience of neighbors coercing them to relocate due to the 'fear' of the consequences of their daughter with IDD mingling with other children. The consequences of 'Othering' PwIDD creates spaces where PwIDD have no real opportunities to explore their sexual autonomy safely; the perceived sub-humanity creates power dynamics where PwIDD, especially WwIDD, may not be seen as equal partners within sexual relationships.

The gendered dimensions of cultural misconceptions create a dilemma where WwIDD are unsafe inside and outside their homes. The perceptions of the gullibility of WwIDD in their experiences of sexual autonomy stem from harmful cultural practices where WwIDD are perceived as naïve, as well as the dangerous beliefs that misconstrue WwIDDs' sexuality with a

form of treatment. The wholeness of WwIDD is denied within various cultural practices, and such beliefs create harmful and manipulative environments which prevent WwIDD from safely exploring sexual autonomy. Examining such cultural practices instead of stigmatizing WwIDD experiences as easily manipulatable is vital.

Differential Access to Social Rights

Why are WwIDDs intimate conversations 'policed'?

WwIDD often experience others policing their sexual autonomy. Zaitun's courage in speaking out and questioning her differential experiences in exploring her sexual autonomy highlights the exploration of this barrier. Zaitun has often been curious about different aspects of romantic relationships; however, she never shared her experiences but often asked very nuanced questions. During a lunch break, she excitedly shared her experience of being in touch with a man from a different city and how their conversations had transitioned to thinking about a future together. The joint response of teachers included furtively checking her messages with the man and informing her mother about her new interactions. Since then, there have been various random checks on her phone without her consent, and her conversations during different community gatherings almost always have someone else present to ensure 'safety' This has led to her challenging our responses and wondering why her social right to forming romantic relationships led to teachers and family resorting to strict policing.

One of the fears expressed by her family was Zaitun's 'new' desire to get married and have children. Zaitun had always shared her dream of being a mother, and she was 'allowed' to indulge in this 'fantasy'; however, with the knowledge of her having a new potential partner, there was an immediate panic to control her 'irrational' impulses. Zaitun's experiences are a microcosm of the oppressions WwIDDs face in Tanzania, where the society revokes many aspects of sexual autonomy and decision-making from WwIDD. The relationship between marriage and sexual autonomy is closely intertwined within the Tanzanian context, such that sexual encounters before marriage are not "officially acknowledged," and the right to marriage eludes WwIDD due to societal misconceptions (MacSwan, 2012). Aldersey (2012), during their research in Dar-es-salaam, highlighted the story of a WwIDD named Aziza, who voiced her

'enthusiastic' response to questions about marriage. However, this contradicted her family's response, who shared concerns about the increased likelihood of an abusive husband and Aziza's lack of ability to counter the 'assumed' abuse. Aziza's family also hoped that she could have children who could care for her in the future. Other parents raised similar concerns, suggesting demeaning notions of children as better caretakers than the WwIDD themselves. Furthermore, ADD International (2017) highlights that WwD in Tanzania are forced into marriages to primarily shift the 'burden' of care from the family to the husband. There was a marked difference for families with MwIDD, who voiced that the importance of marriage for MwIDD was linked to living a life of 'dignity and respect' (Aldersey, 2012). Marriages are a status symbol for MwIDD, whereas for WwIDD marriage incites worries of abuse, concerns over children as caretakers, and even functions as a transaction of responsibility. MwIDD have more autonomy than WwIDD, whose choices are secondary if at all allowed.

Many WwIDD face immense barriers to pursuing their right to motherhood. Zaitun was never explicitly denied her right to have children, but she was limited by those around her to indulge only in the 'fantasy of motherhood'. Scholarship has shown that WwIDD in many countries are denied the right to motherhood by institutions and caregivers through unconsented sterilization practices (Kramers-Olen, 2016). Björnsdóttir et al. (2017) explore how sterilization within institutions is usually limited to WwIDD and not all PwIDD. Sterilization becomes a systemic form of oppression, specifically affecting WwIDDs from making autonomous decisions about their sexual autonomy and reproductive rights. UNICEF (2021), in a situational analysis of PwD in Tanzania, alludes to concerns about forced sterilizations for WwIDD in Tanzania but calls for more data to substantiate the claim.

Zaitun's experience of her close family members and teachers turning into 'spies' mirrors closely the global experience of many WwIDD who report excessive policing of their movements guised as acts of security and protection. Mbwilo et al.'s (2010) study in Tanzania reflects that both MwIDD and WwIDD have increased surveillance of movement by their guardians. However, it was highlighted that MwIDD were surveilled for hyperactive behaviors, while WwIDD were surveilled for safety concerns against abuse. This differential control of movement has numerous implications. Kramers-Olen (2016) highlights that the increased surveillance of movement for

PwIDD results in decreased opportunities to explore their sexual autonomy, and the perceptions of caregivers and/or family dictate the sexual explorations and expressions of the sexual orientation of PwIDD.

As reflected in Zaitun's experience and Mbwilo et al.'s (2010) study, policing movement, conversations, and rights to sexual autonomy of WwIDD are often defended as appropriate and necessary due to the increased risk of abuse and violence. While violence and abuse are significant barriers to experiencing sexual autonomy, they should not be used as a justification to limit rights and control the movement of WwIDD.

Violence & Abuse

Why are the experiences of romantic relationships of WwIDD invalidated in the name of abuse?

35% of women globally have experienced some form of sexual violence (World Bank Group, 2019). 40-68% of WwD globally have experienced some form of sexual violence (Rajan, 2004). Within Tanzania, 90% of WwIDD have reported facing some form of sexual abuse (ADD International, 2017). As the identities of gender and disability status intersect, there is an extreme multiplication of experiences of sexual violence, creating systematic forms of marginalization for WwIDD from experiencing their sexual autonomy safely. Kramers-Olen (2016) postulates that the increased risk of abuse and violence on WwIDD can be attributed to the lack of accessible sexual education, controlled living environments such as institutions, communication barriers, and harmful cultural perceptions, among other reasons (Kramers-Olen, 2016).

ADD International (2017) reports that nine out of ten girls and women with IDD reported experiencing sexual abuse in Tanzania, yet WwIDD differently experience the right to report sexual abuse. Their report highlights three key barriers to reporting abuse in Tanzania (2017): Firstly, support and interventions are limited by the family and community, and if the perpetrators are their primary caregivers, the channels to report abuse narrows down further due to the unequal power dynamics driven by the society between a disabled person and their support network. Secondly, bribery and corruption are common in Tanzania, and undisputed acquittals can lead to more disastrous outcomes, such as revenge violence, which further increases the risk of violence for the victim. Lastly, there is in general a lack of accessible reporting

mechanisms for sexual violence cases; however, reporting mechanisms are even more inaccessible for WwIDD due to the authorities' perceived mistrust in WwIDDs ability to testify, making them less likely to register these cases. The report provides further evidence of the multiple layers of oppression perpetrated on WwIDD, where WwIDD are not only at higher risks of experiencing violence and abuse, but they also have no secure pathways to report these forms of abuse (2017).

Systematic barriers are further intensified within Tanzanian legislation, such that none of the current Tanzanian national policies are compliant with CEDAW, which specifically addresses the intersectionality of gender and disability (UNICEF, 2021). Without this intersectional lens, embedded cultural misconceptions disproportionality continues to expose WwIDD to abuse and violence. These misconceptions disguised as norms maintain and create the barriers that prevent WwIDD from experiencing sexual autonomy; additionally, the lack of legislation that acknowledges their intersecting identities and the oppressions unique to them restricts WwIDD from seeking legal support.

It is these bleak realities of experiencing multiplied forms of violence for WwIDD, lack of reporting mechanisms, and unsupportive legislative policies that are often used by the families and caregivers of WwIDD to justify and disguise their tendencies to excessive control movement. Also, the brutal realities of abuse for WwIDD create a mirage where all relationships, even consensual relationships, can be met with deep-seated fears held by families, thus invalidating all forms of relationships and masking them as abuse. The importance and implications of the violence perpetrated on WwIDD does not and should not undermine the right of WwIDD to experience their sexual autonomy. The legislation, cultural gatekeepers, communities, schools, support workers, and families make WwIDD one of the most vulnerable groups; hence points of intervention should involve these stakeholders to eliminate the barriers placed on WwIDD, as opposed to penalizing WwIDD by creating further barriers to safely explore their right to sexual autonomy.

Capacity to consent

Why do WwIDD lack the right to choose a partner and be in consensual relationships?

When most external guests visit classrooms of students with IDD, there are always questions and curiosity around how much the students 'truly' understand, glances at the whiteboard and the subtle 'oh, they can do XYZ also', such perceptions of low expectations and doubts about the capabilities of PwIDD have always been present within our society. Similarly, within our society and academia, there remains the contested question of whether WwIDD can consent to sexual experiences. The barriers discussed in this essay have primarily focused on external factors such as culture and legal and institutional frameworks; however, the responsibility for the capacity to consent lies within the PwIDD. Nevertheless, it is these misconceptions around the lack of abilities of PwIDD that externalizes and stigmatizes this internal decision-making.

Cognitive ableism is a form of bias based on one's cognitive abilities, and the question of one's capacity to consent stems from the prejudiced notions of cognitive ableism (Davy, 2015). Cognitive ableism contradicts the principle of wholeness, such that one needs to attain a certain level of cognitive ability to be considered an independent decision-maker. Cognitive ableism has contributed to marginalizing WwIDD, such that it assumes PwIDD are not self-determined individuals, hence they cannot independently experience sexual autonomy. Davy (2015) notes that cognitive ableism has been critiqued not only by disability rights groups but also by feminist groups. Feminists have critiqued cognitive ableism due to its heavy restriction on agency and denying of personhood, its neglect of social and relational aspects of life, and its mere focus on individualistic perspectives (Davy, 2015). This gap in understanding ableism and autonomy has contributed towards feminists conceptualizing relational autonomy.

Relational autonomy advocates for the social and relational aspects of autonomous decision-making, such that the environment can impair one's ability to make independent decisions (Björnsdóttir et al., 2017). For instance, an environment that is coercive, paternalistic, or discriminatory drastically limits one's ability to make informed choices. The relational autonomy perspective incorporates the interdependence principle of the disability justice framework and the role of interrelatedness within the Ubuntu philosophy; hence it is a valuable

framework for studying the sexual autonomy of WwIDD. Relational autonomy acknowledges that WwIDD can make decisions about themselves but may need accommodations such as supported decision-making frameworks to best meet their needs (Davy, 2015). The relational autonomy model can be used to counter society's perceived notions of WwIDD's inability to experience sexual autonomy, such that it realistically acknowledges and advocates for support if and when required, yet the final decision-making power is rightfully placed on WwIDD. The model's emphasis on collaboration and interdependency between different groups emphasizes the involvement of WwIDD and their support networks to jointly express their concerns on sexual autonomy while respecting that the individual will make the ultimate decision, not their support networks.

For relational autonomy to be an informed reality for WwIDD in experiencing their sexual autonomy, sexual health education must be provided in accessible formats, such as plain language (Kramers-Olen, 2016). Ito et al. (2022) note that sexual health education is not part of the Tanzanian national curriculum; moreover, discussing about sex within the society is considered taboo. However, within special schools in Tanzania, there is a lot of flexibility in curriculum implementation, especially within subjects such as life skills, where sexual health education can be incorporated. Considering the increased instances of sexual abuse perpetrated on WwIDD in Tanzania, the inclusion of sexual health education in curriculums should be advocated for at the earliest.

Chapter 4 – Recommendations & Conclusion

Recommendations

 Reflecting on the magnitude of the barriers and their differential and intersecting impact, some recommendations are provided to advance the right to sexual autonomy for WwIDD globally and more contextually in Tanzania.

Strengthening the self-advocacy movement

Self-advocacy is the action of communicating and asserting one's own needs or desires. The self-advocacy movement grew out of the frustrations experienced by PwIDD, who felt that they were not adequately represented within the first wave of the disability rights movement (Friedman et al., 2014). Self-advocacy involves PwIDD having meaningful roles within all decision-making hierarchies, both personal and public spaces. Friedman et al. (2014) explore sexual self-advocacy as the action of communicating one's own choices about sexual experiences, knowing the rights and responsibilities, and asserting these when desired. In Tanzania, there is no established self-advocacy group of PwIDD, within the larger disability-rights NGOs there is a lack of representation of PwIDD in decision-making positions, and there are no active DPOs run by PwIDD; each of these can be changed with explicit and intentional efforts. Self-advocacy can be taught at the school level, especially within special schools, this can be included with the use of comprehensive guides. NGOs can be more deliberate in ensuring that voices of PwIDD are represented within their work, especially making spaces within leadership positions to practice the "Nothing about us, without us" motto, instead of limiting participation to symbolic gestures and tokenism within their advocacy efforts. Within the self-advocacy movement, there will be many competing priorities, and this essay strongly advocates for including sexual autonomy. However, the priorities should be set and led by PwIDD such that allyship can play a supportive role in setting priorities.

Building cross-movement alliances

Reiterating the monumental undertaking of fighting for the rights of PwIDD, specifically the rights of WwIDD in experiencing their sexual autonomy, cannot be fought in isolation. Similarly, the principles of the disability justice framework prioritize cross-movement solidarity in changing the

embedded narratives of ableism through alliances with different social justice movements. In Tanzania, an alliance of WwIDD can be created with national organizations of WwD and with national feminist movements such as the Movement of Disabled Women in Tanzania and the Tanzania Gender Networking Program, respectively. These alliances can voice important aspects of the intersectionality of gender and disability. Also, they can provide mainstream platforms to self-advocates with IDD and amplify the voices of these intersecting identities.

There is no representation of PwIDD within Tanzania's umbrella organization, SHIVYAWATA, which has led to a lack of representation and an almost invisible presence of PwIDD within the national disability rights movement. Forging alliances with SHIVYAWATA will amplify the voices of PwIDD and strengthen their movement towards achieving their inalienable rights. The emphasis of cross-movement alliances will only be representative of the voices of PwIDD if these alliances are formed with PwIDD and not for PwIDD, such that the gains from the self-advocacy movements can be forged through national-level alliances and provide a platform for PwIDD to advocate for their priorities.

Improved collection of disability data

Disability data is a vital tool within the disability rights movement and its advocacy efforts; it is similarly crucial at a country level for policy planning, management, and service rendering. Within Tanzania, disability statistics are expanding to include the various disability conditions. However, the inclusion of different categories of disability is largely dependent on advocacy efforts, hence some categories of disability get prioritized, leading to an unequal representation of the disability statistics. Also, efforts need to be extended from predominately collecting data on the prevalence of disability types to meaningful data collection on the interactions of demographics such as sex, social economic status, and age. Furthermore, there is a need for accurate data on violence and abuse perpetrated on PwIDD, especially WwIDD, this marks a significant gap in research and can impact provisions of support mechanisms for these groups. Prioritizing disability data is critical for PwIDD and other hidden disabilities, as it can validate their presence, especially within communities where specific disability categories are only assumed to be a 'western problem'.

Government Accountability

To ascertain the rights to sexual autonomy for PwIDD, supportive legislation must not only be signed but also have to be implemented at all levels. As highlighted, Tanzania is a signatory of various international treaties, yet significant gaps exist in implementation, monitoring, and reporting to these treaties (UNICEF, 2021). The disability rights movements in Tanzania should advocate for the Tanzanian government to meet their obligatory duties of reporting to key human rights conventions such as CEDAW and UNCRPD and advocate for legislative changes that explicitly address the systemic oppressions perpetrated at the intersectionality of gender and disability. Beyond international treaties, various country-level commitments, such as the Tanzania National Policy on Disability (2004), lays strong grounds for protection, equality, and rehabilitation services for PwD. A systematic review is needed on the awareness of such policies by PwD, the status of its implementation, and the differential impacts of these policies over time.

Conclusion

Globally WwIDD have been made one of the most vulnerable groups due to the systemic oppressions, entrenched cultural stigma, perceptions of incapabilities, and targeted violence and abuse perpetrated on them to maintain their 'sub-human/other' status within our society. Sexual autonomy is a self-evident right, yet WwIDD are explicitly denied this fundamental right. Within Tanzania, barriers such as cultural misconceptions, differential access to social rights, increased instances of violence and abuse, and questions about the capacity of WwIDD to consent obscure the realities where WwIDD are actively denied their rights to experience sexual autonomy. The barriers highlight the difficult advocacy journey ahead for WwIDD towards accessing their rights, especially their right to sexual autonomy. Some recommendations highlighted include a call to differing stakeholders, specifically the education sector, national disability rights movements, government, and most importantly, WwIDD.

Within the heart of many educational institutes, homes, and centers continue to be the presence of a heterogeneous minority, students with IDD. Advocating for their presence and their rights has almost always started with a struggling or inspiring story, a palatable entry point for non-disabled people to empathize with. My experiences with Zaitun, Maiko, and Mahari's journey are curated to provoke and illuminate the invisible labor that they and many other PwIDD

have had to endure due to living in rigid systems that actively marginalize their access to fundamental rights. Their stories have highlighted their struggle - to negotiate their sexual autonomy, to educate 'well-meaning' allies, and lastly, to demand for their rights.

The impact of the barriers intensifies and multiplies for WwIDD, yet they continue to be resilient in their fight for their inalienable rights. Unpacking the questions raised by my former students highlights a trail of entrenched stigma held within individuals, societies, and legal systems. Dismantling these stigmatized perspectives and systems requires strong self-advocacy from PwIDD, which can be fostered at the school level, it requires positive role models who can support PwIDD during their advocacy journey, it requires non-disabled allies who make space and amplify the voices of PwIDD, and it requires societal commitments that can be cultivated within faith-based leaders and community gatekeepers. Each barrier discussed in the essay examines the various entry points for change that can be adopted by PwIDD, allies of the disability rights and feminist movements, the government, and other stakeholders. These barriers can only transform when inclusion is no longer a box to tick at schools, organizations, and government institutions but an active practice where we intentionally and deliberately question our interactions, spaces, and systems and actively create change in these spaces to embrace the varied human diversity.

References

ADD International. (2017). (rep.). *Disability and gender-based violence. Peer research in Kibaha and Mkurunga, Tanzania.* (pp. 1–12). ADD International, Tanzania.

Aldersey, H. M. (2012). Family perceptions of intellectual disability: Understanding and support in Dar es salaam. *African Journal of Disability*, *1*(1). https://doi.org/10.4102/ajod.v1i1.32

Barger, E., Wacker, J., Macy, R., & Parish, S. (2009). Sexual assault prevention for women with intellectual disabilities: A critical review of the evidence. *Intellectual and Developmental Disabilities*, *47*(4), 249–262. https://doi.org/10.1352/1934-9556-47.4.249

BBC News. (2019, June 4). *There is no word for Down's syndrome in my language*. BBC News Africa. Retrieved March 20, 2023, from https://www.bbc.com/news/world-africa-48252939

Berghs, M. (2017). Practices and discourses of ubuntu: Implications for an African model of disability? *African Journal of Disability*, *6*. https://doi.org/10.4102/ajod.v6i0.292

Björnsdóttir, K., Stefánsdóttir, Á., & Stefánsdóttir, G. V. (2017). People with intellectual disabilities negotiate autonomy, gender and sexuality. *Sexuality and Disability*, *35*(3), 295–311. https://doi.org/10.1007/s11195-017-9492-x

Collins, P. H. (1990). *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment*. Hyman.

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum*, 139–168.

Davy, L. (2015). Philosophical inclusive design: Intellectual disability and the limits of individual autonomy in moral and political theory. *Hypatia*, *30*(1), 132–148. https://doi.org/10.1111/hypa.12119

Friedman, C., Arnold, C. K., Owen, A. L., & Sandman, L. (2014). "Remember our voices are our tools:" sexual self-advocacy as defined by people with intellectual and developmental disabilities. *Sexuality and Disability*, *32*(4), 515–532. https://doi.org/10.1007/s11195-014-9377-1

Green, S. P. (2020). Autonomy and consent. *Criminalizing Sex*, 19–36. https://doi.org/10.1093/oso/9780197507483.003.0003

Ito, K., Madeni, F. E., & Shimpuku, Y. (2022). Secondary school students' and peer educators' perceptions of adolescent education in rural Tanzania: A qualitative study. *Reproductive Health*, *19*(1). https://doi.org/10.1186/s12978-022-01418-6

Kalugendo, P. (Ed.). (2021). *From stories to history: The trek of people with disabilities to actualise self advocacy in Tanzania*. Inclusive Development Promoters & Consultants (IDPC).

Ministry of Labor, Youth Development and Sports, National Policy on Disability (2004). Dodoma; United Republic of Tanzania.

Kisanji, J. (1995). Interface between culture and disability in the Tanzanian context: Part I. *International Journal of Disability, Development and Education*, *42*(2), 93–108. https://doi.org/10.1080/0156655950420202

Kramers-Olen, A. (2016). Sexuality, intellectual disability, and human rights legislation. *South African Journal of Psychology*, *46*(4), 504–516. https://doi.org/10.1177/0081246316678154

Lai, S. Y., & Ralph, R. E. (1995). Female Sexual Autonomy and Human Rights Recent Developments. *Harvard Human Rights Journal*, *8*.

MacSwan, A. (2012). Dangerous misconceptions. The Guardian. Retrieved April 2023, from https://www.theguardian.com/journalismcompetition/tanzania-sex-before-marriage.

Mbwilo, G. S. K., Smide, B., & Aarts, C. (2010). Family perceptions in caring for children and adolescents with mental disabilities: A qualitative study from Tanzania. *Tanzania Journal of Health Research*, *12*(2). https://doi.org/10.4314/thrb.v12i2.56400

Meer, T., & Combrinck, H. (2015). Invisible intersections: Understanding the complex stigmatisation of women with intellectual disabilities in their vulnerability to gender-based violence. *Agenda - Gender & Disability*, *29*(2), 14–23. https://doi.org/10.1080/10130950.2015.1039307

National Bureau of Statistics, Ministry of Finance and Economic Affairs, Disability Survey Report Tanzania 2008 (2008). Dar es Salaam.

Nzimakwe, T. I. (2014). Practising Ubuntu and leadership for good governance. *African Journal of Public Affairs*, *7*(4), 30–41.

Persons with Disabilities Act 2010, Article 9 (2010). http://parliament.go.tz/polis/uploads/bills/acts/1452071737-ActNo-9-2010.pdf

Rajan, D., Violence against women with disabilities1–9 (2004). Ottawa; National Clearinghouse on Family Violence.

Rugeiyamu, R., Ackim, J., & Shayo, A. (2022). The Tanzania Housing and Population Census 2022: A Panacea for Local Service Delivery and Development Drawbacks. *Local Administration Journal*, *15*(1).

Schalock, R. L., Luckasson, R. A., & Shogren, K. A. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, *45*(2), 116–124. https://doi.org/10.1352/1934-9556(2007)45[116:tromru]2.0.co;2

Sins Invalid. (2017). Skin, tooth, and bone – the basis of movement is our people: A disability
   justice primer. *Reproductive Health Matters*, *25*(50), 149–150.
   https://doi.org/10.1080/09688080.2017.1335999

U.S. Department of Health and Human Services. (2021). *About intellectual and developmental
   disabilities (IDDs)*. Eunice Kennedy Shriver National Institute of Child Health and Human
   Development. Retrieved April 16, 2023, from
   https://www.nichd.nih.gov/health/topics/idds/conditioninfo#:~:text=These%20condition
   s%20can%20also%20cause,problems%20with%20the%20nervous%20system.

UNICEF. (2021). (rep.). Situation Analysis of Children and Young People with Disabilities in
   Mainland Tanzania and Zanzibar (pp. 1–204). UNICEF.

Valentiner, D.-S. (2021). The human right to sexual autonomy. *German Law Journal*, *22*(5), 703–
   717. https://doi.org/10.1017/glj.2021.35

Waliaula, K. W. (2009). Negotiating local knowledge II: Kiswahili and attitudes toward disability.
   Disability Studies Quarterly, *29*(4). https://doi.org/10.18061/dsq.v29i4.1009

World Bank Group. (2019, September 25). *Gender-based violence (violence against women and
   girls)*. World Bank. Retrieved March 26, 2023, from
   https://www.worldbank.org/en/topic/socialsustainability/brief/violence-against-women-
   and-girls