Bagwere cultural interpretation of Physical-Disability Before and During Disability Inclusion

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This study investigates how the Bagwere people, an ethnic group in eastern Uganda, interpret physical disabilities in their culture, both before and after the introduction of disability inclusion policies and practices. The study uses a qualitative research method to collect data from 30 participants, half of whom have physical disabilities and half of whom do not. The article analyzes the data using thematic analysis and reveals that the Bagwere culture has negative attitudes and beliefs towards physical disabilities, which affect the social inclusion and well-being of persons with physical disabilities. The article also examines the impact of the legal framework and the historical context of disability inclusion in Uganda and globally on the Bagwere culture. The article concludes with some recommendations for improving the cultural and social inclusion of persons with physical disabilities in Uganda.


Keywords: persons with physical disabilities; inclusion; discrimination, Bagwere; culture;
penyandang disabilitas fisik; inklusi; diskriminasi; Bagware, budaya

Abstract

A. Introduction

The study investigated the Bagwere cultural interpretation of physical-disabilities before and during disability inclusion. Physical disability includes a broad range of impairments ranging from severe to mild. Physical disability sometimes affects all or some stages of engagement and functioning in the social and cultural environment (Duquette, 2015). This study defined Disability Inclusion as follows: People with physical disabilities feel comfortable and welcome, have equal opportunities, freedom and human rights, value their differences and facilitate their participation in all activities of society to the greatest extent desires and abilities (UNESCO, 2017).

The Legal Framework Pertaining to Inclusion or Non-Discrimination

Uganda has disability policies and laws pertaining to inclusion or non-discrimination that include the Uganda's Persons with Disabilities Act – UPwDA (2020). It has also subscribed to several international laws to several international instruments that require to uphold non-discrimination principles, such as UN Convention on the Rights of Persons with Disabilities - UNCRPD (2006); International Covenant on Economic, Social and Cultural Rights (2013):

Providing the right to adequate housing, food, education, health, culture, work and social security. (UNCRPD, 2006, p. 4).

Before and After the (1990’s) Disability Inclusion

Inclusion originated from the fact that people with disabilities faced discrimination that prevented them from participating in the cultural, political, social and economic life of society (UNESCO, 2017). Disability inclusion means that individuals with disabilities have the opportunity to participate in every aspect of life to the fullest extent possible (Emberson-Bain, 2021). Based on the social inclusion in disability studies, Rimmerman (2013) defines disability inclusion as follows:

Being accepted and recognized as an individual beyond the disability; ii) having personal relationships with family, friends and acquaintances; iii) being involved in recreation and social activities; iv) having appropriate living accommodation; v) having employment; and vi) having appropriate formal and informal support. (Rimmerman, 2013, p. 1).

While persons with physical disabilities in many parts of the world were historically supported through segregated solutions like special schools and residential institutions, in the 1970’s, Disability Peoples’ Organizations (DPO’s) around the globe began to change the situation using disability-rights approach (Rimmerman, 2013). The notion of Inclusion was proposed within the UN’s framework of “Education for All” (EFA) which was motivated by the 1990 Jomtien Declaration. Further,
the national, regional and international human rights instruments were set up to protect the rights and opportunities for persons with disabilities through UN’s 1993 ‘Standard Rules on the Equalization of Opportunities for Persons with Disabilities’. To advance the policy and practice of EFA and the ‘Equalization of Opportunities’ a framework, in 1994 UNESCO provided ‘The Salamanca Statement on Principles, Policy and Practice in Special Needs Education’.


Following the above, the study considered the period before the 1990’s to be ‘before disability inclusion’. This period ‘before disability inclusion’ viewed disability as an individual problem and object of pity (according to the Charity model) or problem requiring medical care according to the Medical model (Al Ju’beh, 2015). On the other hand, this study considered the period after the 1990’s to be ‘during disability inclusion’. This period ‘during disability inclusion’ was socially constructed (Social Model) and human rights driven according to the Human Rights Model (Woodburn, 2013). The Models strive to change unjust practices as well as systems and uses the UNCRPD (2006) as its major point of reference by appreciating people with disabilities as the ‘central actors’ in the decision making of their own lives based on their rights and citizenship. Many disability practices and policies are based on the social and human rights models Rohwerder (2015) to which this study is grounded (Rohwerder, 2015).

The Bagwere culture

Allison Julander writes that Webster (2014) defines culture as: “the beliefs, customs and arts of a society, group, place or time” (Julander, 2015). Culture involves sharing everyday life, experiences and similar ways of life leading to shared values, customs and language The Bagwere is a Bantu ethnic tribe in Uganda, believed to have migrated from Toro and Bunyoro after the collapse and disintegration of the Bachwezi dynasty upon the arrival of the Luo (Wachsmann, 1971). They traveled along Lake Kyoga, crossing River Mpologoma and settled in eastern Uganda. According to the population census, there were 621,150 Bagwere in 2014 occupying an area of 2,388.3 km in districts: Butebo, Kibuku, Pallisa and Budaka District (Uganda Bureau of Statistics, 2017). The Bagwere have over 80 clans that include the following:
Bagomolo, Balalaka, etc. The Bagwere are mainly cultivators and grow crops like millet, cassava, ground-nuts, sorghum, soya-beans and rice which also double as their cash crops and staple foods.

**Statement of the Problem**

The study on Bagwere cultural interpretation of physical disability before and during inclusion falls within the mandate of UPwDA (2020) and UNCRPD (2006) agitation for the rights of persons with disabilities. The rights of persons with disabilities are paramount and therefore, cultures or customs and practices must appreciate and respect them, UNCRPD (2006) thus:

> Take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities. (Article 4, General obligations). (UNCRPD, 2006).

This is emphasized by UPwDA (2020) prohibiting discrimination, inhuman and degrading treatment of persons with disabilities as follows:

> A person with a disability shall not be subjected to any form of torture or cruel or degrading treatment...harmful traditional or cultural practices; or forced sterilization...a person who subjects … commits an offense and is liable, on conviction, to a fine not exceeding twenty currency points or imprisonment not exceeding one year, or both. (Uganda Government Gazette, 2020, pp. 2–3).

Although the above legal system exists in Uganda, the European Parliament (2018) contends that there is inadequate information on cultural practices that hinder, stigmatize and deprive people with disabilities from enjoying their basic rights in Uganda (European Parliament, 2018). In an effort to bridge the gap of general absence of data and statistics on disability in Uganda, the study explored disability inclusion in one of Uganda’s cultures (Bagwere) because, although the available data on physical-disabilities among the Bagwere culture pays attention to activity limitations or impairment, it does not capture the evidence-base required for proper public policy which can enhance persons with physical disabilities’ well-being. It is against this background that the study investigated the interpretation of physical disabilities among Uganda's Bagwere culture before and during the concept of disability inclusion.
General Objective

The study investigated Bagwere cultural interpretation of physical disability before and during the concept of disability inclusion and recommended the removal of all barriers to improve the quality of life of persons with physical disabilities.

B. Materials and Methods

1. Research Locations

The study focused on two districts of Kibuku and Budaka districts. Kibuku district has two counties namely: Kabweri and Kibuku Counties. Budaka district also has two counties namely: Iki-Iki and Budaka counties. Out of the four districts (Pallisa, Butebo, Kibuku and Budaka) inhabited by the bagwere, data collection took place in two districts namely Kibuku and Budaka that had less tribal influence from neighboring non-Bagwere tribes like the Iteso who mainly inhabit districts of Pallisa and Butebo (Uganda Bureau of Statistics, 2017).

2. Participants

from Budaka district) were people with physical disabilities purposely selected. For purposes of gender balance, 5 male and 5 female participants with physical disabilities were selected from each district. Each district has 2 counties whereby all the 4 four counties were included in the study. Every participant was assigned an individual code for retaining anonymity whereby, the first letter within the code referred to the district either Kibuku (K) or Budaka (B), whereas the second letter and third letter correlated with the participant’s identification for example (KP.A up to KP.J for Kibuku district), while (BP.K up to BP.T for Budaka district) as indicated in the table below:
3. Methods

This qualitative research employed a non-probability sampling of homogenous purposive sampling technique in engaging participants so as to get in-depth and detailed data regarding the phenomenon that was being explored. The qualitative research was suitable for gathering the participants' behavior, perceptions and experiences (Tenny et al., 2023). The study was therefore, grounded in the views and experiences of People with Physical Disabilities by listening to their ideas and experiences as supported by disability research (Shakespeare, 2015).

The selection of 20 participants was based on the principle of saturation because many qualitative researchers conducting interview-based studies experience little new information generation after interviewing 20 participants (Roller & Lavrakas, 2015). Accordingly, the study was limited to 20 participants (persons with physical disabilities) from two districts of Kibuku (i.e., 10 participants) and Budaka district (i.e., 10 participants). A set of features shared by participants with physical disabilities included: inability to use arms, hands, fingers, or walk etc., and those people using assistive devices like: wheelchairs, crutches, walking sticks, prostheses, calipers, canes etc.
A semi-structured interview guide was used for data collection. The explorative interview study with Persons with Physical Disabilities in Kibuku and Budaka districts in Eastern Uganda was carried out between April 2021 and March 2022 by two investigators. The analysis of data was done using the qualitative data analysis that involved recorded interview transcripts being the basis for textual analysis. It involved Coding by grouping responses from participants into categories that combine similar ideas, concepts and themes. Some fundamental quotes were selected to back-up the findings.

The reliability of instruments was proved using preliminary results derived from the pilot study. The protection of the rights of persons with disabilities is a legal requirement and therefore was strictly observed. An equal number of male and female participants per district was considered. Fully informed consent and voluntary participation was sought. Participants were free to refuse to answer questions or withdraw from the study at any point without providing any reasons. The study followed the Presidential directive informed by the Ministry of Health in line with WHO (WHO, 2020) guidelines of Pre-screening, masking, use of PPE, hand-washing and social distancing.

4. Ethical Approvals and Consent to Participate

The study was reviewed for ethics and scientific merit and received approval by an accredited ethics committee in Uganda - Uganda Christian University (UCU) Research Ethics Committee (REC) [Protocol Reference number: UCUREC-2021-179]. Informed consent was obtained from the participants before conducting the interviews.

C. Results

1. Recognition as Individual Beyond the Disability

The study explored Bagwere cultural respect and advancement of freedom and fundamental human rights of persons with physical disabilities in light of inclusion, before and during its inception by assessing the following:

Misconception of causes of physical disability: Before the notion of disability inclusion, the Bagwere culture believed that physical disability was caused by witchcraft and spiritual anger and therefore had traditional shrines where PwPDs were ordained and sacrifices of sheep made to appease the disabling evil spirit known as Walugono thus:

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In the past, people said that my physical disability was a curse and caused by the evil spirit called Walugono….during harvesting season ceremony Kwakila, my parents used to take me to the shrine, drumming…..but nowadays, our neighbor who has two children with physical disabilities says that disability was caused by Satan so, always keeps praying to God. (BP. O).

Attitude, discrimination and stigmatization: The attitude of the Bagwere culture towards physical disability was negative because they used to isolate, confine and hide PwPDs in the backyard so they could not be seen by visitors as evidenced below:

My father had over 60 children. He refused me to play with peers and used to send me away whenever he got visitors. (KP. F).

The negative attitude led to PwPDs being labeled and stigmatized. Before inclusion, different nicknames were given to persons with physical disabilities both from family members and the community as indicated below:

When I got married, I was nicknamed all sorts of names like muleme (cripple); Makwetu (the crawler). (BP. O).

PwPDs and their families were ridiculed and stigmatized by the community thus:

People laugh at us, they laughed at my husband for marrying a woman with a disability (KP. D).

Even when moving, people look at you, disgrace you as a disabled. (KP. A).

However, the participants said that, there was some improvement in terms of changing negative attitude towards PwPDs due to community sensitization by Civil Society Organizations as supported below:

In the past, the community openly called me by nicknames but now they do it secretly (BP. O).

Parents, especially the father in the Bagwere culture, provided support in the form of raising dowry for their sons to marry. However, PwPDs were deprived as follows:

My father discriminated against me when he supported all my brothers by giving them cows and goats to pay dowry and nothing for me. (BP. P).
Participation: The study identified that before inclusion, due to isolation, PwPDs had no opportunity to participate in meetings, play and other activities because they were regarded as sick, weak, isolated and unable to perform any work thus:

It was difficult to do work or business because some able-bodied people never wanted to touch what you have touched for fear of getting disability. (KP. C).

During inclusion, the participants reported that they had not yet got government funds for development and for that reason, they were requesting assistance to boost their businesses. Some women with physical disabilities participated in politics and became councilors while others were able to do some small business whose income they used to support their families as below:

We now participate in politics to become councilors and can do business to get income. I bought a blanket for my husband and paid tuition for our children. (BP. M).

Unfortunately, PwPDs complained that able-bodied persons were always meddling in their social, economic and political affairs thus depriving them of some opportunities as indicated below:

Our voices need to be heard but we get interference from able-bodied persons especially during political campaigns so we end up with wrong leaders. (KP. A).

Able-bodied people deprive us from benefiting from our programs. (BP. R).

Physical abuse: Some participants revealed how they were often abused in the form of beating, starvation, tied by ropes and took several days without bathe or clothing, inadequate food or drink. This was exemplified as below:

When carrying water in clay-pots I used to fall and when the pot broke I was seriously beaten. (BP. N).

Another abuse was the cultural mutilation of dead bodies of PwPDs when they died as follows:

A person with physical disability was buried late in the evening at 7.00 PM, in a swampy water logged area, accompanied by a sheep sacrifice, secret mutilations done accompanied by traditional drumming. The body was wrapped in a bark-cloth and no coffin. I was shocked to learn how PwPDs were treated when they died! (KP. E).
However, during disability inclusion, when PwPDs die, their bodies are now respected, treated and buried in the same way like the able-bodied persons.

Government programs and officials: There was a general outcry from all the participants that, in addition to being excluded from most of the government programs, government’s support to PwPDs was too small as indicated below:

Although the government has come up with many programs, they forget us and mainly focus on able-bodied people. (BP. L).

Most of the participants lamented on how they had been mistreated by government officials whenever they visited the government offices. The participants suggested that PwPDs should be appointed in official positions because they understand the vulnerability of persons with disabilities as follows:

PwPDs need respect like other people……sometimes government officers including Community development officers (CDOs) at district and sub-county level mistreat us. I suggest that CDOs should be persons with disabilities. (BP. T).

2. Personal Relationship with Family and Community

Parental care: Parental attitude and affection varied from parent to parent but was mainly negative before inclusion. But due to some participation in political and economic activities during inclusion, some parental attitudes are becoming positive thus:

Now, I am a carpenter and my father now finds me useful. He apologized for having tortured me. (KP. F).

Succession and ownership to property: In the past before inclusion, in Bagwere culture it was not common for girls and PwPDs to inherit property like land as this was allocated to able-bodied sons only as follows:

All my siblings were given land by my father except me. (KP. H).

Relationship with family and community: The study revealed that in the past and currently during inclusion, PwPDs male and female faced challenges in getting intimate friends or lovers due to negative attitude and stigma attached to the disability, not forgetting their financial status.

For me, the community used to call me spirit Walugono Walukone. (BP. N).

Some community members hated me. (KP. A).
3. Equal Access to Basic Services of Education and Health Care

a. Education

Poverty: Before inclusion, all levels of education paid tuition and due to poverty many parents could not afford to pay for their children's education as indicated below:

I am poor and many other PwPDs are also poor like me and cannot afford to pay for their children's education. Government should help to sponsor our children in education and also provide financial support at household level. (KP. C).

However, during inclusion, the government introduced the Universal Primary Education (UPE) for free education but parents were required to provide uniform, lunch and scholastic materials.

Attitude and Discrimination: Before inclusion, the perception of teachers and students towards PwPDs was negative. During inclusion, the teachers, students and other members of the school community still exhibit negative attitude towards learners with physical disabilities as per the testimonies below:

Children were scared of me and used to run away from me for fear I might spell witchcraft on them (Empagama). (KP. G).

Children refused to sit with me in class, they nicknamed me Walugono meaning spirit. (KP. H).

When I was in school, I always received a lot of beatings from the teachers and schoolmates. (BP. M).

Before inclusion, parents did not take children with physical disabilities to school as reported thus:

All my siblings are educated and have employment. The parents never took me to school. (KP. C).

The study noted that during inclusion, where both parents had positive attitude towards their children with physical disabilities, they supported and motivated them to go to school thus:

Inaccessibility: Before inclusion, there were very few schools. Some children with physical disabilities could not move from their homes to the school because of the long distance as evidenced below:
I walk slowly because my legs are weak. I dropped out of school because of the long distance between the school and our home. (KP. I).

During inclusion, the long distance between home and school is no longer a big problem because many schools have been built that almost each village has a public or/and private schools. The problem might be lack of assistive devices to facilitate the mobility of PwPDs as expressed below:

I move by crawling. I did not have a wheelchair it was expensive so I did not go to school. (KP. J).

The study discovered that during inclusion, many children with physical disabilities are now going to school thus:

Now I can see PwPDs in school and they are bright (KP. E).

Somehow, the government has helped PwPDs to go to school instead of being kept behind the house. (BP. M).

However, the study also revealed that during inclusion, some children with physical disabilities were deprived of going to school as follows:

Although we are now empowered, many PwPD’s are not attending school. (KP. A).

b. Health care

Before inclusion, PwPDs had little access to health care services and very few parents among the Bagwere’s culture sought medical care or advice from Health professional because they believed that the causes of physical disabilities were curses or spirits so parents accused each other for the causes which often led to domestic violence and breaking-up of families:

My father always accused my mother of having contributed to my disability that her clan has disabling spirits. (KP. F).

Other causes of physical disabilities were believed to be accidents and lack of immunization against polio. During inclusion, most Bagwere now take their children to healthy centers for immunization against diseases like polio, measles, whooping cough, etc. Although PwPDs can now seek medical treatment from Health centers, they lamented how they suffer whenever they visit these Health centers due to negative attitude from the medical personnel and the inaccessibility to buildings, raised beds, narrow doors and costly medical charges. The participant said thus:
We face the problem of lining up for treatment in the hospital, by the time you reach the doctor, you are already exhausted. (KP. D).

D. Discussion

1. Recognition as Individual Beyond the Disability

The recognition of PwPDs as individuals beyond their disabilities was discussed in light of:

Misconception of causes of physical disability: The study revealed that before inclusion, the Bagwere culture believed that physical disability was caused by bad luck, witchcraft and curse (Aley et al., 2016). The Bagwere culture had misconceptions about physical disability and so despised, feared and linked PwPDs to evil spirits and thus, did not recognize them as individuals beyond their disabilities. The research agrees with Rohwerder’s (2020) study on culture, beliefs and disability in East Africa that misconceptions and harmful traditional beliefs affected the rights and roles of persons with disabilities (Rohwerder, 2020). The findings are also in-line with Luborsky (2014) revelation that, from a cultural perspective, one’s position as a full person is dehumanized and degraded upon the loss of independent motor control common among people with physical disabilities (Luborsky, 1994). The degradation of PwPDs dates as far back as the Middle-Ages in Europe where PwPDs were considered to be at the ‘Edges of society’ (Metzler, 2013). Accordingly, DSPD (2016) of the UN categorically condemns harmful beliefs concerning disability.

However, during inclusion, the Bagwere culture believed that it was Satan, old age, congenital defect, accidents, polio and other diseases that caused physical disabilities (Adesina et al., 2021). It was also during inclusion that disability was considered a human rights issue, UPwDA (2020) out-lawing discrimination and inequalities experienced by PwPDs for example; confinement, being considered not legally competent, being sterilized, European Parliament (2018) without consent (European Parliament, 2018; Uganda Government Gazette, 2020).

Attitude, Discrimination and Stigmatization: Before inclusion, the Bagwere’s negative attitude towards PwPDs involved depriving them of play and other basic human rights, isolation, confinement and hiding them in the backyard so they could not be seen by visitors thus, their basic rights were denied rendering them dependents (Ferguson, 2015). In addition, PwPDs were traumatized with all sorts of nick-names like Mukosefu (sickly/weak), muleme (cripple); Makwetu (crawler), Kateyamba (incapable) and laughed at men who married women with disabilities and vice-versa. The study therefore, agrees with Barnes (2017) on how ‘ableism’ reinforces stigma and prejudice towards PwPDs because it is directed towards their disability. The labeling of children with physical disabilities also carried the guilt and blame to
the parents’ shoulders causing a feeling of discrimination in the family, school and community generally. However, during inclusion, there was some little improvement in terms of positive attitude towards PwPDs due to community sensitization by Civil Society Organizations because in the past, the community openly called PwPDs using labels ‘nicknames’, but now they do it secretly.

Before inclusion, PwPDs among the Bagwere culture were denied inheritance and ownership of property (like land and cows) by family members. While it was common practice in the Bagwere culture for parents to support their sons to marry by raising dowry for them, this opportunity was denied to sons with physical disabilities. Whyte (2020) provides that, this exclusion which originates from family members extends to policy makers and implementers leading to destitution among PwPDs (Whyte, 2020). The denial of property inheritance to PwPDs among the Bagwere culture represents direct discrimination. These findings are in-line with Emberson-Bain (2021) who identified that intentional or purposeful discrimination amounts to direct discrimination although it appears to be non-discriminatory in some social norms (Emberson-Bain, 2021). Girls and women with physical disabilities were also discriminated against and double disadvantaged in-terms of being female and secondly for having physical disabilities which put them at higher risk of exploitation, maltreatment, neglect and abuse (Ministry of Gender, Labour and Social Development, 2016).

Participation: Before inclusion, PwPDs had no opportunity to participate in meetings, play and other activities because they were regarded as sick, weak, isolated and unable to perform any work. Yet, participation facilitates PwPDs to take part in all life aspects and to have an influence on how political, cultural, social and institutions are designed (Emberson-Bain, 2021). In addition, when PwPDs are not present in public discourse, the community does not gain from their ideas. As a matter of fact, their exclusion from involvement in politics indicates that all citizens’ interests are not fully represented by the government (UNICEF, 2021).

During inclusion, many PwPDs participated in politics and became councilors representing persons with disabilities while others participated in small businesses and were struggling with small incomes to support their families in terms of paying for tuition, house rent, medical, food/nutrition and other household items. The study agrees with Whyte (2020) that many Persons with disabilities in Uganda struggle to financially sustain themselves and their families on limited incomes (Whyte, 2020). Unfortunately, PwPDs also complained that able-bodied persons always interfered in their social, economic and political affairs thus depriving them of some opportunities.

Physical abuse of the living and the deceased: The study revealed that in the Bagwere culture, PwPDs were often abused in the form of beating, starvation, tied by ropes and took several days without bathe or clothing, got inadequate food or
This discovery agrees with previous studies by UNICEF (2021) that physical disabilities reduce the ability to escape or defend oneself physically from abuse (UNICEF, 2021). Ferguson (2015) contends that, due to PwPDs' dependency on other people for mobility or personal care, they are unwilling to report them in case they are abused (Ferguson, 2015). PwPDs are often victims of torture and violence that includes beatings, sexual harassment which sometimes results in their injuries, disease infections like HIV/AIDS or death (UNICEF, 2021). Among the Bagwere culture, the torture of PwPDs continues even when they are deceased by being buried on ant-hills in swampy water logged areas, the dead bodies wrapped in bark-cloth without coffin, accompanied by traditional drumming, chanting or spiritual incantation with sheep and chicken sacrifices by witchdoctors. These acts were quite traumatizing for PwPDs. However, during disability inclusion, when PwPDs die, their bodies are now respected, treated and buried in the same way like the able-bodied persons.

Access to Assistive Devices: Before inclusion, it was quite difficult and expensive to access assistive devices like crutches, calipers, wheelchairs and other orthopedic appliances (Whyte, 2020). Similarly, the study revealed that during inclusion, persons with disabilities were poor and could not afford to buy or maintain wheelchairs and other assistive devices (Whittaker & Wood, 2022). The study corresponds with WHO (2018) which provides that, out of 75 million people world-wide who require wheelchairs only 5% to 15% can get them (WHO, 2018).

Inclusion in government programs: There was a general outcry of extreme poverty, Mitra (2017) by all the participants in addition to being excluded from most of the government programs (Mitra, 2017). Government's support to PwPDs in the form of small grants was too small. The research therefore agrees with Pinilla-Roncancio (2015) studies that, the likelihood of more PwPDs living in poverty is often the result of neglect and ignorance which is reinforced by government as well as development programs and policies that are discriminatory without providing for the rights and inclusion of persons with disabilities socio-economically (Pinilla-Roncancio, 2015). Further, most of the participants lamented on how they had been mistreated by government officials whenever they visited the offices. The participants suggested that PwPDs should be appointed in official positions because they understand the vulnerability of persons with disabilities.

2. Inter-Personal Relationship with Family and Community

PwPDs inter-personal relationships was discussed in-light of the following:

Relationship with family and community: Very few participants acknowledged having been loved by both parents before inclusion. Parents hated their children with physical disabilities, labeled them, did not want to be accompanied when visiting, never took them to school and did not provide sufficient basic support and
necessities even when they became ill! Further, the community prevented their children from associating and playing with children with disabilities and the parents (of children with disabilities) struggled to isolate (Ipsen & Gimm, 2021) and over-protect them against being harmed or injured by the community. Parents accused each other for being the cause of their children’s physical disabilities causing family conflict and break-up. These research findings agree with DSPD (2016) that PwPDs suffer from lack of love and support from the community and parents due to the negative attitude which creates a state of denial, isolation and stigmatization or status lowering within the society. However, during inclusion when some parents were sensitized, they started taking their children with physical disabilities to school.

Succession and ownership to property: Before inclusion, in Bagwere culture, it was uncommon for girls and PwPDs to inherit property like land and cattle as this was allocated to able-bodied sons. PwPDs were also considered to be dependents and unable to manage property and therefore their shares had to be taken by their siblings. This was a denial of their rights to attaining and inheriting property (UPwDA, 2020).

Marriage and intimacy: Most of the participants narrated how hard it was to get lovers and testified having had challenges regarding sexual identity which is part of self-esteem and personality development. Metzler (2013) provides that in the past, especially during the Middle-Ages in Europe, the community believed that in addition to not being able to function physically in terms of mobility, PwPDs were perceived to be infertile (Metzler, 2013). However, the research findings in this study disagree with previous research because, considering the number of children and wives PwPDs had, proved that they were sexually active. One male participant even boasted of having 20 children from several women, while another woman with physical disability had produced nine children! Women with physical disabilities also reported that men did not want to marry them but just wanted to use them for sex in the darkness and shy away from them during daytime.

3. Equal Access to Basic Services of Education and Health Care

The study sought to evaluate Bagwere cultural provision of people with physical disabilities with equal access to basic services of education and health care as follows:

a. Education

Before inclusion, many parents in the Bagwere culture did not send their children to school due to shame, poverty and inability to understand the benefits of education (Inguanzoz, 2017). PwPDs testified having forced themselves to go to school by following their peers without their parent’s consent or support due to negative attitude and were forced to drop-out of school due to lack of tuition and other scholastic
materials, (Kuno et al., 2021). The study discovered that, due to negative attitudes, Kruse and Dedering (2018), children with physical disabilities often received brutal beatings from teachers even at the slightest mistake (Kruse & Dedering, 2018). In addition, they were bullied and called by nick-names by schoolmates. School children were scared and refused to sit on the same bench in class with children with physical disabilities for fear of being infected or bewitched (through Empagama). This study agrees with Banks and Polack (2014) that inclusive education affects the lives of PwPDs, but disagrees that inclusive education lessens the extent of exclusion for the individual specifically and community generally (Banks & Polack, 2014).

Before inclusion, there were very few schools. Some children with physical disabilities could not move from their homes to the school because of the long distance which forced them to drop out of school (Kuno et al., 2021). During inclusion, many children with physical disabilities are now going to school although assistive devices like wheelchairs are limited and very expensive to buy and maintain (Musenyente & Eron, 2017). The study agrees with Shang and Fisher (2020) about the inability of children with physical disabilities joining special or local schools due to lack of special care, assistive devices like a wheelchair and inaccessibility (Shang & Fisher, 2020).

b. Health Care

Before inclusion, PwPDs were not provided with sufficient medical care and necessities to the extent that when they became sick, they were treated by witch doctors using local herbs and sacrifices of sheep and chicken to appease the spirits. This period before inclusion was occupied by witch doctors, traditional healers and very few disability support services (Emong & Eron, 2016). The study agrees with European Parliament (2018) which revealed that in Uganda, impostors and witch doctors pretend to provide a cure for disability but in some cases physically injure PwPDs. During inclusion, many Bagwere now take their children to healthy centers for immunization against diseases like polio, measles, whooping cough, etc. However, while there were massive immunization campaign programs by the government, several participants reported that they got disability after injections when they suffered from measles and fever. During inclusion, some people among the Bagwere culture (especially old people) still believe that physical disabilities are caused by curse or evil spirits.

E. Conclusion

The study assessed the extent to which the Bagwere culture achieved disability inclusion before and during the 1990’s. Before inclusion, there was social construction or misconceptions on how physical disability was caused and lack of awareness and
understanding of disability. Generally, the superstitions that existed among the Bagwere culture regarding the causes of physical disability contributed to PwPDs being subjected to a variety of treatments which were harmful. Following the stigma linked to physical disability and coupled with poverty, PwPDs often became victims of human rights abuse and discrimination.

The stigmatization and social attitudes restricted PwPDs opportunities to fully participate in the economic, political and social life. The study therefore concluded that, prior to the 1990's i.e., before inclusion, PwPDs among the Bagwere culture were not recognized as individual beyond the disability but degraded as unable to make decisions, charitable giving objects who relied on assistance and therefore were socially oppressed and considered a minority group among the Bagwere culture. However, during inclusion, there has been some little improvement in terms of changing negative attitudes towards PwPDs due to Civil Society Organizations' community sensitization and awareness raising about disability rights and inclusion. During disability inclusion, although PwPDs actively participated in social, economic and political activities, they had very small incomes and received limited financial support from the government and so, were struggling to support their families in terms of paying for tuition, house rent, medical, food /nutrition and other household items. In a nutshell, the study finally concluded that, although the Bagwere culture in Uganda has undergone a lot of transition before and during inclusion (i.e. prior to 1990 and after), it has not yet achieved full disability inclusion. The study recommended that, PwPDs among the Bagwere culture urgently need more support (i.e., economically, socially and politically, removal of all barriers as well as raising public awareness on disability rights and attitude change) from all stakeholders and most especially the government to enable PwPDs improve their quality of life.

F. Declaration of Competing Interests

The authors declare that no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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H. References


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