



## ‘Nothing about us, without us’: Voices of leaders of disabled people’s organisation in management of disability fund



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### ABSTRACT

In 2005, the Ghanaian government established cash grants for persons with disabilities (PWDs). However, PWDs are still living under deplorable conditions, which have raised questions about the involvement of fellow PWDs in the disbursement of cash grants. Using a human rights-based approach, nine participants with disabilities (hearing, visual and physical) who were leaders of the Disabled People’s Organisation in four districts were interviewed to explore their perspectives, which was thematically analysed. The results showed that leaders were not consulted or involved in the allocation of grants to PWDs. This paper discusses the need for bureaucrats to respect and involve PWDs in matters concerning their livelihoods.

### 1. Introduction

The body of literature has reported on widespread poverty among persons with disabilities (PWDs) in many parts of the world (Lindsay, 2011; Mitra, Posarac, & Vick, 2013; Yeo & Moore, 2003). In developing countries, the causal link between disability and poverty has been blamed on systematic social and environmental barriers, which restrict the participation of PWDs (Mitra et al., 2013). These barriers include inaccessible and non-inclusive schools, leading to less or no educational attainment, non-employment, limited social contacts, a lack of information concerning job opportunities, discrimination, inaccessible transportation, lower earnings, increased expenditures related to disability, and a lack of disability benefit programmes (Lindsay, 2011; Yeo & Moore, 2003). The disproportionately high representation of PWDs among the poorest of the poor has triggered the enactment of international conventions, such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which entreats states to eradicate attitudinal and environmental barriers that hinder PWDs’ full, effective and equal participation in society (United Nations, 2006). This convention has influenced the development of legislation in many countries to promote the well-being and rights of PWDs.

This paper is situated in the human right-based approach to disability, which is underpinned by the principles of the social model of disability (Degener, 2016). In studying the development and welfare of PWDs, the human right-based approach has been proposed as a useful lens to

understand the living conditions of PWDs (Katsui & Kumpuvuori, 2008; Katsui, 2008; Liyanage, 2017). Poverty and denial of basic services to minority groups are deemed as a right violation (Liyanage, 2017). Disability has become a human right issue because of the global poverty, rejection and unfriendly living conditions of PWDs (Lindsay, 2011; Mitra et al., 2013). Indeed, international law and donor communities advocate meaningful living conditions for all persons (Liyanage, 2017; WHO, 2011). In disability studies, the situation of PWDs is assessed from the efforts made by the government to ensure that their needs and welfare are considered in national planning and development. This probably justifies the use of a human-rights lens to study the leadership and management of cash grants for PWDs in Ghana.

Within the human-rights based discourse, disability is viewed as the loss or limitation of opportunities to take part in social activities on an equal basis with others due to physical and social barriers (Degener, 2016). It considers persons with impairment as being disabled due to a given social, economic, political and environmental barriers (Groce, Kett, Lang, & Trani, 2011). Under the human-rights based approach, two main areas have been identified as useful to advance the lives of PWDs: mainstreaming and empowerment. First, in terms of mainstreaming, states operate within an international, legal framework in which they are expected to create a conducive environment for the participation of all persons in national development. Besides political and civil rights, PWDs are entitled to social, economic and educational rights within society. States are expected to mainstream the needs of PWDs in all spheres of

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lives. This would enable them to enjoy their fundamental rights and be able to participate in societies. For instance, the institution of social grants to PWDs has been argued as a fundamental human right in efforts to create equitable access to life-improving activities in society (Aguilar, 2017; Devereux & White, 2010; Schneider, Waliuya, Musanje and Swartz, 2011). In order to uphold the rights to PWDs, the government of Ghana has instituted cash grants to ensure that they access the fund to better their livelihoods.

The second component of the human rights-based approach is empowerment. There is a discussion regarding the need for PWDs to be allowed to make decisions concerning their lives (Liyanage, 2017). This is against the backdrop of consistent rejection, dependence, and denial of the rights of PWDs in societies (Devereux & White, 2010; Groce et al., 2011). These injustices make PWDs powerless, and their rights continually violated in societies. In order to bridge the gap between PWDs and non-disabled in society, respect should be given to PWDs as bearers who can make decisions on matters concerning their livelihoods (Katsui & Kumpuvuori, 2008; Liyanage, 2017). In studying the role of the disability organisation's leadership in the disbursement of case grants in Ghana, it is of equal, if not greater, importance to focus on the central role played by PWDs.

In Ghana, previous studies have mainly studied attitudes towards persons with disability, poverty, parenting children with disability and limited access to social services to PWDs. In order to expand, it has been reported that cultural interpretation of disability compounds the vulnerability of PWDs (Anthony, 2011; Naami, 2014, 2015). Culturally, people in most communities believe that disability is caused by anger or curses from gods or deities due to a family member's past sins. Some also attribute the causes of disabilities to evil or magical powers, sorcery, or witchcraft (Avoke, 2002; Naami, 2014; Naami, Hayashi, & Liese, 2012). Consequently, most families do not invest in the education of their members with disabilities or support them to acquire basic services in societies. They are trapped in a vicious circle of poverty with little or no encouragement to participate in productive activities (Naami et al., 2012; Opoku, Nyamfi et al., 2017). This reduces them to dependants, as they feed on other people's benevolence on a daily basis. Due to their dependence on society, they are usually disrespected and not invited to partake in family decisions (Kiani, 2009; Opoku, Huyser, Mensah, & Amponteng, 2015; Yeo & Moore, 2003). They are not consulted on matters concerning their lives (Kiani, 2009; Kleintjes, Lund, & Swartz, 2013; Lord, Stein, & Fiala-Butora, 2014; Opoku et al., 2015), not considered in national political activities (Munsaka & Charnley, 2013; Opoku, Mprah, & Saka, 2016; Sackey, 2014; Virendrakumar, Jolley, Badu, & Schmidt, 2018), and excluded from international development policy, practice and research (Yeo & Moore, 2003). This apparently underscores the need to ascertain the extent of their involvement in the management of social programmes developed to alleviate poverty among them and enhance their participation in economic activities.

Due to the poor living conditions of PWDs, in 2006, the Ghanaian government enacted Disability Act 715 to fully recognise PWDs as rights-holders who require better living conditions (Republic of Ghana, 2006; Reynolds, 2010). This development was preceded by a declaration by the Ghanaian government to allocate 5% of Metropolitan, Municipal and District Assemblies' (MMDAs') revenue to PWDs (Sackey, 2009). As a nation, Ghana practices a decentralised political system of governance, where political power is delegated from the central government to 230 political, administrative units across the country. Each MMDA is headed by a chief executive, who is appointed by the government to oversee the day-to-day administration. Annually, the central government allocates the ceded revenue in four tranches to the MMDAs to support infrastructural developments. Three per cent of each disbursement has been reserved for PWDs (Sackey, 2009). All PWDs in the area are eligible to apply, provided they can establish how they intend to use the fund. Although it is a one-off payment, beneficiaries are eligible to apply for more funds once they are able to show proof of proper utilisation of the initial allocation. In each MMDA, there is a five-member Disability

(Common) Fund management committee, made up of one executive of the DPOs, a district social welfare director, and other members appointed by the MMDAs (Sackey, 2009). However, the perspectives of the PWDs' representatives on the management and disbursement of funds to their members are not fully understood.

### 1.1. Disability rights-movement

Historically, policymakers were designing programmes for and on behalf of PWDs (Priestley, Waddington, & Bessozi, 2010). This approach was critiqued by the disabled population, who advanced strong arguments for their inclusion and participation in matters concerning their well-being. With the benefit of education, PWDs became aware of their rights and insisted on their recognition, equal rights, citizenship and independence (Jayassoria and Ooi, 1994). With inspiration from civil rights protests by women and black activists, PWDs in the USA and Britain began to fight for equal rights and recognition as equal members of society. Particularly, after the Second World War, veterans who were confined to wheelchairs joined the disability social movements to fight for equality in societies. In Britain, the first action of the disability movement was to stage a violent demonstration against inaccessible transportation (Oliver & Barnes, 2010). This led to the famous slogan 'nothing about us, without us'. Subsequently, several governments and international bodies have recognised the need to consult PWDs and support them to overcome the barriers erected against them in societies. With their exclusion from formal structures in societies, PWDs were convinced that they must come together and advocate for themselves (Jayasooria & Ooi, 1994). This culminated in the global springing up of DPOs to struggle for the participation of PWDs in policymaking and development frameworks (Shakespeare, 1993).

Ghana was not left out of the global wave of self-advocacy by PWDs. After years of systematic exclusion and discrimination against PWDs in Ghana (Ganle, 2016; Kassah, Kassah, & Agbota, 2012; Kuyini, Alhassan, & Mahama, 2011), they realised the need for them to come together and fight for equal rights and participation in all spheres of society. This led to the formation of the Ghana Federation of Disability Organisations (GFD) in 1987, which is an umbrella organisation including the Ghana Blind Union (GBU), the Ghana National Association of the Deaf (GNAD), and the Ghana Society for the Physically Disabled (GSPD; Sackey, 2009). The GFD has offices in all regions and districts and collaborates with affiliate organisations on projects and socialisation among members (Sackey, 2009). Its main aim is to promote the rights of PWDs and lobby for the interest of PWDs (Sackey, 2009). Agitations from the GFD and its affiliates led to the allocation of a 3% share of district assembly common funds to PWDs, enactment of the Disability Act in 2016 and ratification of UNCRPD in 2012. In every district, the DPOs have representatives involved in the management of the Disability Fund, and we intend to examine their involvement in the disbursement of the funds to beneficiaries.

### 1.2. Accessibility of cash grants to persons with disabilities

A decade after the Disability Fund's creation, few studies have been conducted on its impact on the lives of PWDs in Ghana. Exceptions are studies by Edusei et al. (2017) and Opoku, Nketsia, Agyei-Okyere, and Mprah (2018), who found that the fund has had little impact on the lives of PWDs. In other African countries, many studies have documented the experiences of PWDs in terms of cash grants. Particularly, it has been reported consistently that PWDs face barriers in accessing cash grants (Banks et al., 2017; Gooding & Marriot, 2009; Mitra, 2005; Schneider, Waliuya, Munsanje, & Swartz, 2011). For instance, a review by Banks et al. (2017) found that PWDs are usually unable to invest funds received through social programmes in long-term economic activities. The funds are insufficient, which forces beneficiaries to use them to cover consumables rather than investing in productive ventures (Katsui & Kumpuvuori, 2008). Consequently, they become dependent on the state

throughout their lives since they are not given enough funds to have sustainable livelihoods (Aguilar, 2017; Katsui & Kumpuvuori, 2008). Devereux and White (2010) explained that many countries rely on external donors to finance social programmes and thus, obtain little to sustain these programmes. Designing a social programme to have an impact on the lives of PWDs, therefore, requires proper planning and structures to achieve its intended goal.

One major barrier to the accessibility of cash grants by PWDs is the existence of weak structures and a lack of legal frameworks in the management of disability grants (Shumba & Moodley I, 2018). Although disability grants are intended to improve the lives of PWDs, the beneficiaries are usually not involved in its management which results in improper utilisation of funds (Aguilar, 2017). In many developing countries, governments do not have data on PWDs, which makes it difficult for them to be aware of their needs (Sepulveda Carmona, 2017). This leads to poor targeting of beneficiaries, as many people are unable to access cash grants. There is the possibility of the funds not reaching the intended targets because representatives of PWDs are not consulted in such discussions (Schneider et al., 2011). Moreover, without data, the government tends to administer grants through bureaucratic structures, and it has emerged that programme staff are sometimes unaware of PWDs' living conditions and needs (Bernabe-Ortiz et al., 2016; Gooding & Marriot, 2009; Sepulveda Carmona, 2017). This contributes to their inability to provide accessible information and maintain effective means of communication with members (Mittra, 2005). There are also instances of corruption and embezzlement of funds by programme staff and thus, tend to deny beneficiaries access to the funds (Gibelman & Gelman, 2004; Heltberg, 2007). Due to weak institutional frameworks, the government tends to politicise cash programmes as they give to individuals who are aligned with the ruling elites only (Cecchini & Madariaga, 2011; Hickey, 2008; Katsui & Kumpuvuori, 2008). It is apparent that social programmes could make a substantial impact in the lives of beneficiaries with disabilities once there are stakeholder engagements, including leaders of DPOs, on the best ways to manage the disbursement processes.

Although previous studies have explored the barriers faced by PWDs in their effort to access cash grants (Aguilar, 2017; Banks et al., 2017; Gooding & Marriot, 2009; Katsui & Kumpuvuori, 2008; Opoku et al., 2018), little is known about their involvement in decision-making and disbursement of cash grants designed to alleviate poverty. This study intends to fill this scholarly gap and document the DPO leaders' perspectives on the management and disbursement of the Disability Fund. In Ghana, PWDs leaders are supposed to be involved in the management and disbursement of the Disability Fund. The present study focused on these representatives to ascertain their experiences and participation in decision-making concerning the disbursement of fund to members.

## 2. Methods

### 2.1. Study participants

This study forms part of a larger study that assessed poverty and access to social support for PWDs in Ghana (Gyamfi et al., 2017; Opoku, Swabey, Pullen, & Dowden, 2019). A qualitative approach was used to assess DPO leaders' involvement in the management and disbursement of the Disability Fund in four districts in the Northern region. After nine interviews, we realised that no new themes were emerging; thus, recruitment was ceased (Fusch & Ness, 2015). In the districts, the members of DPOs have monthly meetings to discuss pertinent issues about their welfare. The data were collected from leaders during one of such meetings.

Table 1 presents a summary of the demographic characteristics of the study participants. In all, nine participants took part in this study; four were present members of the fund management committee, while five had served on the past committee. Three focus group discussions made up of seven members, as well as two face-to-face interviews, were conducted. In district one, focus group discussions were organised with two

**Table 1**  
Demographic characteristics of participants.

Category (N = 9)	Frequency	Percentage (%)
<b>Interview format</b>		
Focus group discussion	7	78
Interview participants	2	22
<b>Type of Disabilities</b>		
Physically disability	4	45
Visually impaired	2	22
Hearing disability	3	33
<b>Gender</b>		
Male	7	78
Female	2	22
<b>Marital Status</b>		
Single	2	22
Married	6	67
Divorced	1	11
<b>Education Status</b>		
Primary	1	11
Secondary	3	33
Tertiary	5	57
<b>Age of participants</b>		
21–30	2	22
31–40	5	57
41–50	1	11
51–60	1	11
Mean	37 years	
<b>Occupation</b>		
Teachers	3	33
Civil servants	4	45
Self-employed	2	22

executives of the GSPD; in district two, one executive from the GSPD and two executives from the GBU engaged in a focus group discussion; in district three, one interview was conducted with GBU executive; in district four, one focus group discussion, made up of two participants from the GNAD and a one-on-one interview, was conducted (Table 2). Four participants were living with physical disabilities; seven were males; six were married; five had tertiary qualifications; five were 31–40 years old; four participants were civil servants. The mean age of the participants was 37 years.

### 2.2. Instrument for data collection

Due to insufficient research in the area, a qualitative design was deemed appropriate for this study. In view of this, the data were collected using a structured interview guide which was developed from the literature (Aguilar, 2017; Devereux & White, 2010; Hickey, 2008) and the theoretical lens (Katsui & Kumpuvuori, 2008; Liyanage, 2017). The issues discussed relate to the role of leaders in the management of the Disability Fund (mainstreaming), their involvement in cash distribution, and the impact of the grant on the lives of PWDs (empowerment) (Appendix A).

### 2.3. Data collection procedure

The researchers sought approval from the institutional review board

**Table 2**  
Disaggregation of data.

Participants	District	Codes	Format
Participant 1	District 1	Physical disabilities Present 1	Focus group
Participant 2	District 1	Physical disability Former 2	Focus group
Participant 3	District 2	Physical disability Former 3	Focus group
Participant 4	District 2	Visual disability Former 1	Focus group
Participant 5	District 2	Visual disability Present 2	Focus group
Participant 6	District 3	Physical disability Former 4	Interview
Participant 7	District 4	Hearing disability Present 1	Focus group
Participant 8	District 4	Hearing disability Former 2	Focus group
Participant 9	District 4	Hearing disability Former 3	Interview

at the Institute of Governance, Humanities and Social Sciences, Pan African University, Cameroon. Afterwards, a formal letter was sent to the regional executives of the umbrella body of all DPOs in Ghana, i.e. the GFD. The GFD gave the research team a letter to be sent to leaders of the affiliate organisations in the districts selected for this study. The district executives agreed to participate in the study, and they informed the researchers to collect data during their meetings. The members of the DPOs lived in several communities; thus, the monthly meetings were deemed an appropriate time to collect data. Prior arrangements were made with the leaders to inform their members about this study. After recruiting some members to partake in the study's first stage, the executives who were members of the Disability Fund management committee were also engaged. Some agreed to take part after their meetings, while arrangements were made with others to collect data at their convenience. In three districts, the executives agreed to participate in focus group discussions; other district executives opted for one-on-one discussions.

The data collection occurred between November 2015 and June 2016 (an 8-month period). The interviews lasted between 30 min and 4 h. On the day of the meetings, the study was introduced to prospective participants, sharing its purpose and significance to the participants. Participants who wished to take part in this study responded by a show of hands and had to sign (or place their thumb print on) an informed consent form before being interviewed. Participation was voluntary as there was not any reward given to the participants. They were assured that neither their identity nor location would be used to report the data. Therefore, during the interviews, participants were given a code (Table 2). The data were collected by the first author and a trained research assistant who is a native speaker of the local language (Dagbani) and proficient in Ghanaian sign language in order to communicate with deaf participants.

#### 2.4. Data analysis

In analysing the data, the researcher performed a thematic framework analysis. The steps were as follows: reading the interview transcripts, coding, identifying patterns and linkages between data, mapping and thematising, and writing the results (Lacey & Luff, 2001; O'Leary, 2013). The trained research assistant transcribed each interview, which was then forwarded to some of the participants to confirm whether their views have been captured appropriately. This is to ensure that the data are a true and valid reflection of participants' views (Creswell & Miller, 2000; Lacey & Luff, 2001). Six participants provided feedback confirming that we accurately captured their statements. The first author rang the other three participants and discussed key highlights in the transcribed data to be used in reporting this study.

All the authors read the interviews to be familiar with the content before coding. After reading, the authors agreed on *a priori* themes, which guided the data analysis (See Appendix B). The initial coding was performed by the first author. We then gave the transcribed data to an academic with experience in qualitative research to code. The first author had a meeting with the academic to discuss the coding, and disagreements were resolved through discussions. The first author then proceeded to complete the coding and assign categories to similar ideas and inscriptions. The categories were then grouped into themes. The first author wrote the first draft, which was shared with all other authors whose feedback of the results were incorporated into the final draft.

### 3. Results

This study was conducted from the perspectives of the human rights-based approach to explore the extent of involvement of representatives of DPOs in management and disbursement of cash grants to PWDs. Although participants discussed membership of the fund management committee, participants reported not taking part in decision-making on grant disbursements. They also reported that funds were channelled into projects without their consent; what is more, they were denied access to

vital information. The results are presented under the following themes: non-involvement in the disbursement, channelling fund into other projects, lack of information and concealment and impact of the fund (Appendix B).

#### 3.1. Non-involvement in the disbursement

Participants were asked about their involvement in the disbursement of grants to beneficiaries. Almost all participants said that they only receive applications from members and forward them to the social welfare officer for consideration. One leader of persons with visual disabilities said as part of the process, those who need money have to be members of DPOs then the leaders would follow up on their request for funding' (Physical disability former 4). Another participant added that 'some of our members live in villages, so the only thing we do is to receive their application and send it to the social welfare office' (Physical disability Former 3). However, when it comes to the disbursement of funds, almost all of them said they were not called to be part of the decision-making.

Aaaah ... for me they only call me to come and collect money to give to some of our members. I don't know how they decided on beneficiaries. They select just a few people while many of our members don't get anything (Visual disability Present 2).

It is a pity how they treat the leaders. They [others members of the fund management committee] don't call us for meeting, and we are powerless, so we can't force them in our meetings. I wish they could come down to our meetings to know how disables are suffering (Hearing disability Former 2).

They don't know anything about us, and when we tell them our people want to do business, they tell us it's not possible. The people who are disbursing the money don't believe in our abilities. I always ask them what they expect us to do with the little money given to us (Visual Disability Present 2).

Some participants stated that they have tried to engage authorities concerning the need for their involvement in the disbursement process, but it has yet to be taken into consideration.

The money they give to our members is not enough. I have personally told the social welfare officer to call me anytime they are disbursing the money, but he doesn't. It's wrong for them to share money to disables while their leaders are not part of such meeting (Hearing disability Present 1).

People want to do business, but they don't give them the required amount. They think disables are hungry so let's give them something small to keep quiet. They don't understand our needs, so they do what they like. I have sent petition to the district chief executive to tell them to involve us in disbursement of funds, but no action has been taken (Visual disability Present 2).

#### 3.2. Channelling fund into other projects

Some participants discussed that the assemblies have been channeling their share of the Disability Fund into projects without their knowledge. Although they acknowledged the relevance of such projects, they insisted that they should have been informed since they were leaders of PWDs in the area. Besides, they serve as a conduit through which PWDs can have access to the fund; thus, it was necessary for them to be informed about such initiatives. Some participants commented as follows;

Last year, the social welfare director called me to a handing over ceremony. They told me they have use our share of Disability Fund to buy white canes and glasses for our members, so they called me to be

present at the ceremony. I left the meeting since I can't be part of such arrangement. It's good to buy those things, but they should inform us before buying them (Visual disability Former 1).

It's recently I got to know that they have bought goats to some of our members to rear. Some of our members were not happy to have been left out. I explained to them in our last meeting that we, the executives, have no idea about that project (Hearing disability Present 1).

They use the fund to start projects and expect the association [DPOs] to own it when they have already begun. If they consult us, we would make contributions and tell them where such projects should be cited and who should be involved. Such projects fail because they think they know better than us (Physical disability Former 2).

It also emerged that sometimes, the MMDAs channelled PWDs' share of the Disability Fund into developmental projects. Participants commented that sometimes they would be told the MMDAs has run out of money; thus, nothing is left for PWDs. Some also said that they were told the assemblies had so much debt that all governmentally released monies had to be used to settle these debts.

The assemblies [MMDAs] have not been given the money to us because they prioritise other things ahead of our legal share ... They give excuses that they have used the money to pay contractors building schools, so there is nothing left for disables (Physical disability Former 3).

The DCE called us to a meeting and told us that they have used monies released by the government to pay debts. He told us to wait until next year before any of our members could benefit from the fund. That's the painful truth about how we are struggling to access money we are legally entitled to (Physical disabilities Present 1).

### 3.3. Lack of information and concealment

Participants were asked about their knowledge of the total amount released by the government, out of which the 5% PWDs' share was calculated. Almost all participants stated that they were never told and were completely unaware of the total amount released by the government to the MMDAs. In fact, many participants commented that they do not even know when the Disability Fund is released to the assemblies.

If you ask me, I will say that I don't know anything about how much is released to the assembly and when the money comes. The only time I will be called to the assembly is to go and collect money for some members. They [MMDAs] only say that the government has not released Disability Fund, but the assembly is giving us something small to share. Does that make sense? But we have no choice (Physical disabilities Present 1).

One surprising thing is that no one will tell you the amount released by the government and how the 3% share is calculated. I think they are hiding something from us, that's why they don't want us to know. We have told them several times to give us the figures so that we would know the amount involved, but they continue to hide it from us (Physical disability Former 3).

... Who will give you that information? They won't tell you, and we have tried to have access to that information without success. When you ask the finance officer, he will tell you DCE told him not to tell us (Hearing disability Present 1).

Some participants said that they know the law and how much is supposed to get to them, but people in authority have made it difficult to obtain access to such information. The assemblies have made it sound as if they are beggars coming for alms.

They don't respect disables in this country that is the reason why they are denying us our right. It is legal for us to be given the fund, but when you go to them, they would tell you they are favouring us. Are we not Ghanaians? Can't they respect us for once? (Physical disability Former 4)

I get annoyed anytime I go to the assembly to enquire about the fund. They treat us like beggars meanwhile, it is a legal requirement that disables are given the money. Why? Last week, I went to the office to ask if our money has come, and the DCE told me there is no money for us this year. I challenged him that the law makes it mandatory for him to release the money, but he told me that he has decided not to give us anything until next year (Physical disabilities Present 1).

### 3.4. Impact of the fund

Participants discussed the Disability Fund's impact on the lives of PWDs. Almost all participants said that the fund has had little impact on their members because they were unable to invest in income generation activities. Many also said that they were not involved in the disbursement and that decision-makers are unaware of their needs. Some said that if they were involved in such processes, they would advise those who are eligible to access the fund and useful ventures to invest the fund.

They have no idea of what they are doing. They don't know us and our needs, but they sit in their office and decide amount to give to each person. They should call us to the meeting to decide who should be given the money (Visual disability Present 2).

This fund is supposed to help everybody, but the local assemblies have failed us. They won't tell us anything, and we only hear that they have shared the money without proper interviewing. They don't ask them what they are going to use the money for or guide them to invest. All they know is come and take the money and give to them [beneficiaries] (Hearing disability Former 2).

Almost all participants commented that the money given to beneficiaries is too little to be invested in economic activities. Moreover, they stated that those who received funds were given far too little to be able to conduct any business activities. Most added that those who received money spent it on food and other consumables, as they would not be able to invest the money. Some participants commented as follows:

I will say that the money they give to disables is an insult. It can't be use for anything, so those who get the money use it to buy food and pay debts. Many disables want to work, but I don't think the money they share would get us anywhere (Hearing disability Former 2).

They think they know better than us! They call five to ten people and give them GH¢ 500 [US\$ 120] for a whole year or even two years. What is that for? What do they expect them to use that money for? People take the money and use it to buy food, and in few weeks, they are back to square one (Visual disability Present 2).

This money can't be use for any business. Look, there is a boy who want to go to teacher training college, but they gave him GH¢ 300 [US\$ 75] last year, which couldn't even pay his school fees. How do they expect him to feed, buy books and other basic needs? He has drop-out of school and now at home (Physical disabilities Present 1).

The truth is that the money is not enough for us to start business. I call it 'chop money' rather than something to invest. It is not enough, but they think they are doing us favour, so we have to take it like that. They should know that we are not beggars, so they have to respect us and give us something appreciable (Visual disability Present 2).

Most participants cried over the irregularity of funds. They said that the disbursement of funds was infrequent and would be insufficient to adequately alleviate poverty among PWDs if they were not made

regularly available. One participant said that they keep writing letters to ask for information, but no one has responded to them (Physical disabilities Present 1). Another participant also said that 'We are tired of waiting for the money. Everyday people call to ask if they money has come' (Visual disability Present 2).

The fund is not regular. The whole of this year nothing has been given to any of our members. People are hungry, but there is nothing available for them to start a business. We are not happy to see disables begging on the streets, but I think it's not their fault. If you tell them to stop begging, who will feed them? The government should think about how to make this money regular (Physical disability Former 4).

People have been waiting for the fund for long. We are supposed to be given something every three months, but that's not the reality on the ground. We have been waiting since last year .... They always tell to be patient, but nothing has been happening (Visual disability Present 2).

Some participants also commented that the distribution of the fund has been politicised and, as such, only members who were affiliated to the (current) government's political party received their funds. Some participants commented as follows:

Look, they see me as member of the opposition party, so they don't want to me to get close to them. They give the money to those who they know are in the same political party. All the time, the same group of people are given the fund, while the majority suffer. Is that how to help the disables? (Physical disability Former 3).

Everything has been politicised in this country. The money is for us [disables] the poor, but the condition is that you have to get a party card before you are given. Poverty affects everyone, and it's better for us to put politics aside and alleviate poverty among disables in this country. (Physical disabilities Present 1).

#### 4. Discussion

Despite the existence of DPOs in Ghana and their mainstreaming through their representation on the Disability Fund management committee, participants claimed they were not consulted in disbursements of funds to beneficiaries. One of the core arguments advanced by proponents of the human rights-based approach to issues of disabilities is granting PWDs or their representatives the opportunity to take part in the decision-making process on matters concerning their well-being (Priestley et al., 2010). The formation of DPOs was based on the premise that PWDs would be able to steer their own affairs and, particularly, be involved in decision-making (Jayasooria & Ooi, 1994). The only role they play is receiving funding applications from their members and forwarding them to the Disability Fund management committee for consideration. They do not take part in the deliberation on how much should go to the beneficiaries. This finding is consistent with studies from different contexts that reported that PWDs or representatives do not take part in management and disbursement of cash grants and decision-making about issues concerning their lives (Aguilar, 2017; Kiani, 2009; Kleintjes et al., 2013; Virendrakumar et al., 2018). Yeo and Moore (2003) argued that this exclusion reflects and reinforces the wider social, economic and political exclusion of disabled people within the household, community and state that result in the disproportionately high representation of PWDs among the poorest of the poor. The non-participation means that the fund may not be properly distributed to deserving applicants. This could have ramification on effort towards using the Disability Fund as a tool to alleviate poverty as the funding may not be used for its intended purpose.

The right to take part in decision-making coincided with the recognition of PWDs as individuals who are capable of identifying their interests and work (Degener, 2016; Katsui & Kumpuvuori, 2008).

However, a novel finding this study adds to the literature is the participants' claim that the fund management committee members invest funds in projects without informing them and their members. Participants stated that they were informed only after decisions had been made to procure the assistive devices. They were then called to attend handing-over ceremonies or distribute items to the members. This is a clear departure from the principles of self-determination as other members of the fund's management committee still operate from the medical view of disability. They seem to perceive themselves as 'experts' who are in a better position to determine the needs of PWDs. Consequently, they make decisions on their behalf and without their knowledge. These bureaucratic attitudes are an affront to the move towards recognising PWDs as rights-holders capable of determining their needs. This most likely underscores the need for training bureaucrats to understand that PWDs are rights-holders who can make decisions about their livelihoods.

As rights-holders, society ought to recognise and respect the needs of PWDs (United Nations, 2006). Accordingly, PWDs should have their needs provided and be given an opportunity to explore different possibilities in society. However, this study found that the funds intended for PWDs were sometimes diverted into other developmental projects. This finding partly corroborates with studies by Bernabe-Ortiz et al. (2016), Gooding and Marriot (2009) and Jayasooria and Ooi (1994), who found that bureaucrats entrusted to administer disability grants lacked knowledge and capacity to administer the grant. This finding suggests that PWDs, who are known to be poor (Naami et al., 2012; Naami, 2014, 2015; Opoku, J-F, Swabey, Pullen & Dowden, 2019) and have pressing needs, would not be given what is due them. It is possible that the administrators do not understand the needs of PWDs, thus deemed it appropriate to channel their share of the Disability Fund into other projects. Some participants confirmed that the fund managers do not respect them and channelled their share of national cake into projects they considered irrelevant. Participants said that PWDs were denied their legal share of national resources; however, they seem helpless to fight for their members. This apparently connotes and deepens the vulnerability of PWDs as they suffer rights violations in the face of legal frameworks.

Access to information would mean that PWDs would be able to assert their rights and fight for what is due to them (Oliver & Barnes, 2010; Shakespeare, 1993). In this study, it was reported that participants were denied access to information by bureaucrats managing the grants. For instance, they were not provided information about the amount of money released by the government to the assemblies or how much had been allocated to PWDs. This finding is consistent with studies by Mitra (2005), who reported that the concealment of grant information from PWDs affects their ability to access the funds. Bureaucrats may want to hide information and channel funds to other projects or embezzle funds intended for PWDs. In all fairness, there should be transparency between bureaucrats and DPOs, allowing them to know how much has been released by the central government and the amount that would be given to PWDs.

Poverty among PWDs has been deemed a violation of fundamental rights (WHO, 2011). However, participants claimed that the fund had had little impact on PWDs due to administrative and managerial challenges. For example, participants claimed that they were not involved in disbursements of cash grants and to them, they thought the administrators were not doing a good job by sidelining them. More so, the insufficiency, irregular disbursement, and politicisation of funds were reasons given by participants for the reduced impact of funds on beneficiaries. This finding corroborates the findings of Banks et al. (2017), Devereux and White (2010), Gooding and Marriot (2009), Hickey (2008), Helberg (2007), Katsui and Kumpuvuori (2008), and Selpulveda Carmona (2017), who reported barriers such as improper administration, limited funds, and the inability of funds to reach intended targets, have emerged as barriers to the administration of disability grants. The high prevalence of poverty among PWDs have been argued as grounds for the institutionalisation of cash grants to enable them to participate in productive ventures (Aguilar, 2017; Cecchini & Madariaga, 2011; Hickey, 2008).

The inability of the funding to improve or alleviate poverty means that Ghana may need to rethink the institutionalisation of the Disability Fund for PWDs. Notably, there needs to be urgent engagement in the success and failure of funding to maximise the utilisation of funds for PWDs.

**5. Study limitations**

The study has limitations, and, as such, the results should be interpreted with caution. First, the study relied on only DPO leaders' voices without including non-disabled members on the fund management committee. Future studies should include perspectives of non-disabled members who are members of the fund management committee. Also, the study was limited to only four districts out of 20 districts in Ghana's northern region. It is recommended that future studies employ a quantitative method involving a large number of participants to get a holistic picture of DPE involvement in the administration and disbursement of the Disability Fund. Despite these limitations, this study has substantially contributed to the literature by adding the voices of DPO leaders regarding their involvement in the disbursement and management of cash grants to PWDs.

**6. Conclusion**

Persons with disabilities are rights-holders and, as such, should be involved in matters concerning their livelihood (Jayasooria & Ooi, 1994; Oliver & Barnes, 2010). Like any other fund, the Disability Fund intends to alleviate poverty; hence, a conscious effort should be made to engage DPOs in areas requiring investment as well as the needs of their members. This study explored the perspective of DPO leaders regarding their involvement in decision-making about the disbursement of the Disability (Common) Fund in Ghana. We found that both present and past DPO members were not involved in decision-making regarding the disbursement of cash grants to PWDs. According to participants, bureaucrats involved in decision-making do not make decisions in the interest of PWDs who are the beneficiaries. This has partly contributed to the inability of funds to reach intended beneficiaries or has negatively impacted PWDs. This study has seemingly given credence to

policymakers' need to involve PWDs in matters concerning their lives. Although the idea of having cash grants to alleviate poverty among PWDs is a laudable initiative, it may not achieve the intended goal of alleviating poverty if steps are not taking to solicit PWDs' views on national issues affecting their welfare.

This study has both short- and long-term implications for policy-making on cash grants to PWDs in Ghana and similar contexts. In the short term, bureaucrats should respect PWDs as rights-holders who are capable of making informed choices. Therefore, they should desist from making decisions on behalf of PWDs whose voices regarding their welfare and well-being are important. In the long term, the government could consider making a conscious effort to obtain data on all PWDs to directly transfer their disability funds to them without going through other political structures. Furthermore, the government should consult DPO's regarding the selection of non-disabled members on the Disability Fund management committee. This will enable the screening and appointing of persons with the right attitudes and knowledge concerning the needs of PWDs.

**Credit author statement**

MPO and WN were involved in the design and implementation of the study, field work, data management, analysis, interpretation of the data, and writing of the manuscript. MPO performed data analysis with the guide from WN. MPO and WN provided significant input to the manuscript, revised it critically for important intellectual content, and gave their final approval for the version to be published. All authors have read and approved of the final manuscript.

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**Declaration of competing interest**

The authors declare no conflict of interest.

**Appendix A**

Interview Guide Scheduled for Study Participants.

1. Could you please tell me a brief background about yourself?
2. What is (was) your role as a leader of DPO?
3. How do you see the living conditions of persons with disabilities in Ghana?
4. How has the leadership of DPO contributed towards reducing poverty among persons with disabilities in Ghana?
5. Let us talk about the Disability Fund. How involved are leaders of DPOs in the management of fund?
6. Please how is(was) your relationship with other non-disabled members on the fund management committee?
7. Please tell me how the cash are disbursed to the beneficiaries.
8. Please do you participate in decision-making on disbursement of cash grant to beneficiaries?
9. In your opinion, do you think the disability has helped to alleviate poverty among persons with disabilities in Ghana?
10. Please can you share our views on some of the barriers towards the management and disbursement of the disability fund?

**Appendix B**

Summary of the thematic analysis.

Themes	Sub-themes	Codes
Non-involvement in the disbursement	Application for the fund Requirement to access the fund Sideline of DPO leaders	Receive application for disables, member of DPO, not invite us to meetings, involve us minimally, little engagement on funding

(continued on next column)

(continued)

Themes	Sub-themes	Codes
Channelling fund into other projects	Non-engagement in purchases Use of fund for non-disabled projects	Transparency in use of the funding, buying assistive devices, Useful but they don't involve us, diversion of funds, not use for intended purpose, weak to ensure accountability
Lack of information and concealment	Release of fund from government Release of disability fund Lack of disclosure	No information on funding to MMDAs, no knowledge of release of disability fund, unwilling to share the amount, no one willing to disclose, unaware of amount for the fund
Impact of the fund	Little impact Insufficient fund Irregular patterns in release of fund Politicisation of the funds	Beneficial, not enough for poverty alleviation, only short term, too little, not enough for investment, for consumables, no timetable for release, long wait for funding, difficult to know when to expect, political interference, victimization

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