

The Family and Disability in Ghana: Highlighting Gaps in Achieving Social Inclusion

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ABSTRACT

Purpose: *There are social and environmental barriers faced by persons with disabilities which have been reported in literature. In discussing these barriers, attention is yet to be given to the support from families to members with disabilities. This study aimed to examine family support and its impact on the lives of persons with disabilities in Ghana.*

Methods: *The study participants were 48 persons with disabilities - physical, hearing and visual disabilities - who were members of Disabled Peoples' Organisations. They were conveniently drawn from 4 districts in the Northern region of Ghana.*

Results: *The study found that the families of the participants did not give them adequate support to access services that would improve their lives. For instance, limited access to education resulted in inability of participants to secure jobs.*

Conclusion: *Without the primary support of the family, persons with disabilities might be unable to break down social barriers due to their inability to access education and other developmentally useful services. The implication of the study for policy-making has been discussed extensively.*

Key words: *Persons with disability, Ghana, family support, poverty, social support*

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INTRODUCTION

The starting point for the development of personality is the family, which performs instrumental service of raising children to become responsible adults (Meadan et al, 2010). The quality of support and upbringing that children acquire from the family, determines the quality of life they may live (Dixon et al, 2000). Consequently, children with disabilities also have the right to be treated with dignity and to be supported in accessing opportunities available in society to guarantee them better future. In fact, the Convention on the Rights of Persons with Disabilities (CRPD) mentions the need for states to make legislations that would guarantee persons with disabilities effective protection at the basic level - which is the family (United Nations, 2006). However, despite the existence of legislative and legal frameworks, persons with disabilities seem to encounter barriers in their efforts to participate in social and economic activities (Filmer, 2008; Palmer, 2011). It appears the family has reneged on its responsibility to support its members with disabilities to overcome barriers erected in societies.

In the Ghanaian context, blood relations define family systems which encompass both the nuclear family and extended family (Clark, 1999). Apparently, even after marriage, individuals have responsibilities and maintain healthy relations with members of the extended family. Individuals who identify themselves with these family systems owe allegiance to other relatives as they may be called upon to make contribution in times of challenges (Takyi & Gyimah, 2007; Amanor, 2010). Nevertheless, it appears that individuals with disabilities do not enjoy this mutual support due to negative cultural interpretations of disabilities (Agbenyega, 2003; Naami et al, 2012; Baffoe, 2013). There are stereotyped views about disabilities in Ghanaian societies, where individuals with impairments are seen as punishment from Gods. Consequently, most families are not interested in their development – resulting in their dependence on society (Avoke, 2002; Agbenyega, 2003; Baffoe, 2013; Badu, 2016; Gregorius, 2016). Accordingly, the absence of family support to persons with disabilities, in terms of developing their potential, denies them the opportunity to access productive activities that could improve their living conditions (Agbenyega, 2003; Filmer, 2008; Naami et al, 2012).

Specifically, when it comes to educating their members with disabilities, families see it as a waste of scarce financial resources (Kassah, 2008; Baffoe, 2013; Opoku et al, 2015). Without formal education, persons with disabilities may have limited or no skills to engage in productive economic activities. As a result, persons with disabilities may become idle and unable to survive on their own (Naami et al,

2012).. In Ghanaian culture, raising children is an investment and since persons with disabilities are unable to support others once they are adults, they are at times, pushed to devise their survival strategies (Agbenyega, 2003; Gregorius, 2016). One of the easily available opportunities for them is to engage in begging which is probably an activity that requires no skills or training (Kassah, 2008). Apparently, this is a total deviation from the family system of Ghana, where every member is expected to support one another to have a means of livelihood.

Despite unanimity in accepting CRPD, there seem to be challenges among countries in relation to enforcing the provisions spelt out in the document. In other low-income countries, cultural interpretation of disability results in discrimination and exclusion of persons with disabilities from societal activities (Opoku et al, 2016, 2017a, 2017b; Aldersey et al, 2017; Morrisson et al, 2017). Their right to participation is possibly curtailed and they are unable to engage in life-improving activities. Interestingly, in advanced societies, the situation seems not too different as families delegate their caregiving responsibility to carers or even keep their children with disabilities in respite homes (Nakade et al, 2017; Sauer & Lalvani, 2017; Tough et al, 2017). This contributes to poor social networks or weak bonds between the family and the child (Lim, 2017). This lead to situations where siblings are unable to support each other or grow up together and develop a strong relationship (Jacobs & MacMahon, 2017). Evidently, they may spend the rest of their lives in residential facilities or end up on the streets and homeless (Nishio et al, 2017). It comes as no surprise that persons with disabilities could grow up with low self-esteem, perceiving themselves as dependants on others in the society.

In achieving an inclusive society, the family is probably the anchor for its members with disabilities, and serves as intermediary between them and society. In this way the family could play a vital role in guaranteeing persons with disabilities reasonable participation in public services.

Traditionally, disability is viewed as a pathology, a defect, impairment or deformity residing in an individual which limits one's functional capabilities (Avoke, 2001). This medicalised view of disability regards the individual with impairment as a problem, and consequently the burden of disability is placed on the individual. However, the social model of disability, which is the framework of this study, discusses disability as a social, cultural, and political phenomenon rather than a personal tragedy (Oliver, 2013). This notion shifts the dialogue on disability from the medical perspective to a model which characterises disability as limitations

imposed on the individual by societal barriers (Hanisch, 2007; Goodley, 2011; Barnes, 2012). Subsequently, persons with disabilities are disadvantaged not only because of their impairments but as result of limitations imposed on them by social, cultural, economic and environmental barriers (Shakespeare, 2006; Oliver, 2013). In other words, society is responsible for the limitations persons with disabilities experience in accessing education, employment, information, housing, public transport, and leisure opportunities (Matthews, 2009; Oliver, 2013). Therefore, for the development of persons with disabilities, support from family is required to enable them to overcome the obstacles already erected in society.

In Ghana, just like any sub-Saharan African country, there is the absence of a robust social support system (World Health Organisation, 2011). This has been attributed to the lack of political commitment on the part of governments that are uninterested in advancing the lives of persons with disabilities (Badu, 2016). In the absence of a formal social system, the family probably bears the duty of navigating persons with disabilities past the pre-existing barriers in societies. Although caring for children with disabilities has been found to be a source of stress to families (Mulroy et al, 2008; Meadan et al, 2010; Latta et al, 2014; Badu, 2016), their continued support could have a lasting impact on their lives. The social model, unlike the medical model, focusses not on the functional limitations of the individual but looks broadly in the society for factors responsible for the exclusion of persons with disabilities (Shakespeare & Watson, 2001; Barnes, 2012). The responsibility of family towards the development of persons with disabilities includes (but is not limited to) supporting their education, financial assistance, emotional support, support during crisis, advocacy for their acceptance, and housing (Palmer, 2011; WHO, 2011). Arguably, the capacity of persons with disabilities to be productive is dependent on the extent of support and encouragement they get from home.

Therefore, this study aimed to document the perspectives of persons with disabilities on the impact of family support - or lack thereof - on their adult lives in Ghana. For the purpose of this study, disability is defined according to The Persons with Disability Act 715, as individuals with physical, sensory or visual impairment which is impacted by social or cultural barriers that affect their daily activities (Government of Ghana, 2006).

Objective

This study answered the following questions: a) what have been contributions and consequences of lack of family support in the development of persons with disabilities; and, b) what are the living conditions and survival strategies of persons with disabilities in Ghana? This study involved persons with disabilities who were members of Disabled Peoples' Organisations (DPOs). The DPOs constitute three main groups: Ghana Society of the Physically Disabled, Ghana National Association of the Deaf, and Ghana Blind Union, all of which are under the umbrella of the Ghana Federation of Disabled (GFD).

METHODS

Study Participants

Data was collected from participants between March and June 2016 in the Northern region of Ghana. Out of 20 districts, participants were conveniently recruited from 4 district capitals. They were all members of Disabled Peoples' Organisations (DPOs); therefore only persons with physical, visual and hearing disabilities (who had formed associations) participated in this study. In each district, the DPOs had meetings once a month, so arrangements were made for the interviews to be conducted at the time of their meetings.

All participants were interviewed using a structured interview guide which was developed from the literature (Fitzgerald, 2007; Filmer, 2008; Groce et al, 2011; Aldersey, 2012; Naami et al, 2012). The use of a semi-structured interview affords flexibility to both the interviewer and participant. The interviewer is able to ask questions which are not on the guide, and even probe for details, while the participants also have the flexibility to discuss more in detail without any restrictions (Baker et al, 2012). The face-to-face discussions were organised to gather first-hand information from the participants, during which, according to Denscombe (2003), the interviewer asks questions and records accounts of participants accurately. Most questions were open-ended which allowed the participants to discuss their views and experiences in detail. Data collected from 4 districts during 4 different meetings was deemed sufficient, and it was decided to stop at 48 participants once data saturation was attained. According to Fusch et al (2015), saturation refers to a point in data collection where no new information is evolving from the interviews.

Ethical Considerations

The researchers sought approval from Institute of Governance, Humanities and Social Sciences, Pan-African University, Cameroon before going to the field to collect the data. The study objectives were explained to all potential participants, and those who agreed to take part in the study gave their written informed consent. Participation was voluntary, and participants were free to withdraw at any point in time. They were assured that their identity would be kept anonymous throughout reporting of the study.

Data Collection Procedure

Prior to data collection, a letter was sent to the regional executive of Disabled Peoples' Organisations (DPOs) in the region. The first author was invited to attend their monthly meetings to conduct the interviews. Arrangements were made with all the district executives to give their members prior notice about the intended study. On the day of the meetings, members who agreed to participate in the study were asked to report early or to wait for a while after the meeting and be interviewed by the first author. The interviews were conducted in separate rooms at the meeting venues and participants responded to issues or questions raised during the interview process. Discussions were focussed on family support, consequences of lack of family support, and coping strategies. The interviews were recorded with permission from members after the objectives of the study were explained to them. Although the interview guide was in English, the participants were allowed to speak in Twi (a common language in Ghana) when they were unable to speak English. Each interview lasted between 30 minutes - 1 hour. Translation into English was done by the first author who is fluent in both English and Twi. For hearing impaired participants, the researchers hired a sign language interpreter to assist in communicating with them, and the interpretations were recorded on the audio-tape used during the interviews.

Data Analysis

A constructivist approach was followed, where reality was viewed from the perspectives of the participants. Based on this, audio transcripts were sent to some participants to review and confirm whether their views had been well represented. This, according to Creswell and Miller (2000), enhances the quality of data for reporting the findings of the study.

The researchers performed content analysis, following O'Leary's (2010) six steps in analysing qualitative data. The steps followed were: reading through data; organising and coding; searching for patterns and interconnections; mapping and building themes; building thematic data; and, drawing conclusions. To begin with, the first author and second author transcribed the audio-recorded interviews verbatim after listening to the audio recordings several times to ensure accuracy. In the process of reading through the transcripts, a list of concepts and meanings were generated and relationships were established among the concepts. The data was categorised based on the objectives of the study, and evolving quotes were grouped into categories to form themes and sub-themes. Identical quotes were pulled together to support the reporting of the study based on study objectives.

RESULTS

Demographic Characteristics

Table 1 summarises the demographic characteristics of the study participants. Eight of the participants were executives of DPOs and were also members of the fund management committee. On the types of disabilities, 22 (46%) participants had physical disabilities compared to 11 (23%) who had hearing disabilities. Regarding gender, there were 28 female participants and 20 males. Among them, 16 had no formal qualifications while 4 had tertiary qualifications. The average age of participants was 39 years; 17 were between 21 and 30 years while 3 were between 61 and 70 years. There were 22 who were single while 5 were widowed. In terms of employment, 18 were unemployed while 3 were teachers (see Table 1).

Table 1: Demographic Characteristics of Participants

Category	Frequency	Percentage (%)
Type of Disabilities		
Physical disability	22	46
Visual disability	15	31
Hearing disability	11	23
Sex		
Male	20	42
Female	28	58

Marital Status		
Single	22	46
Married	15	31
Divorced	5	10
Widowed	6	13
Education Status		
Primary	11	23
Secondary	7	15
Tertiary	4	8
Professional	10	21
None	16	33
Age of Participants		
21-30	17	35
31-40	13	27
41-50	7	15
51-60	8	17
61-70	3	6
Mean	39	
Occupation		
Farmers	8	17
Apprentices	12	25
Teachers	3	6
Students	7	15
None	18	37

Family Support

During discussions it emerged that most participants (33) lacked the support of their families. Families were reluctant to provide for the needs of persons with disabilities. Some participants (21) bemoaned rejection by their families, while others complained about the failure of their immediate family members to cater to their needs. Participants revealed that if parents were poor and unable to provide for the needs of their children, no other family member would come forward to assist the children with disabilities. As a result, participants were left to their fate and had to fend for themselves or struggle to make a living.

“It would be better for family members to help us but they will not help you. I know one disabled person whose mother is very rich, but she doesn’t help her. Moreover, she is begging now. I can’t compare my mother to anybody’s mum but my mother does not have money, but she considers my disability and helps me.” (Male with visual disability)

“Families are supposed to take good care of persons with disabilities and provide them with their needs, but they are not helping us. My uncle is a rich man who could help me, and I always go to him to collect money for food. However, I felt like I’m disturbing him, so I have stopped following him” (Female with physical disability).

“My brother has money. He could buy me the disabled motor for the disabled, but he will not do it. He wants me to beg him before he does it but I’m shy. I can’t tell him but I know he helps other people” (Male with physical disability).

Some participants also reported that the myth surrounding disability motivates families to hide their members with disabilities from public ridicule. Disability is seen as shameful and a taboo in some societies, so efforts are made by individuals to distance themselves from their members with disabilities (Avoke, 2001). One participant said that some of the family members always locked her up in the room whenever there was a function at home because they did not want people to see that they had a relative with disabilities. Another participant summed it up as follows:

“Persons with disabilities are poor mainly due to lack of support, especially from the family. Families keep children with disabilities at home because they don’t want them to go out for people to associate the family with the disabilities. In the end, they keep the children in the room denying them the opportunity to learn skilled training. When the persons grow up, they become useless as they lack the skills to do anything meaningful. That is why some are begging by the roadside” (Male with physical disability).

On the other hand, a few participants (7) mentioned that their families were willing to help them, but poverty was a barrier to giving assistance. According to them, their families’ income level prevented them from providing the necessary support. In addition, there were many siblings in the family, so the low-income levels meant that not much would be available to support all the children’s requirements.

“My father is only a farmer who is not having so much money to cater for all of us. I have eight other siblings, and everyone has to be given what he or she deserves. I don’t blame him much because I know the money was not there” (Male with visual disability 6).

“I thank my parents for their support, and I know that they would have done much if there was money. I am from a poor home, and I know how life was difficult for us when I was growing up. My parents would have done their best if they were having” (Female with hearing disability).

Family support is essential to enable persons with disabilities to achieve equal social participation.

Challenges Faced by Participants

Almost all the participants indicated that the absence of family support affected their chances of having access to some necessities of life. The role of the family in the development of individuals facilitates effective integration in society (Meadan et al, 2010). Therefore, the inability of the families to fulfil this responsibility meant that individuals were left to their fate. Although several challenges which resulted from lack of family support were mentioned, most participants pointed to poverty and education. For example, participants discussed that they were uneducated due to lack of support from their families. Although there is free education up to secondary school in the Northern region (to encourage participation in education), participants mentioned that there were other things needed for their learning to succeed. Some of these necessities included sandals, uniforms, stationery, and even money for food. The lack of family support in providing these basic school needs resulted in school dropouts, accounting for the high rate of illiteracy among participants. The following quotations summarise the experiences of two participants:

“Going to school is very expensive now so without parents who are rich, it will be difficult for anyone to attend. I remember, during my primary education, there wasn’t any money for feeding which made it hard for me to make any progress.” (Male with physical disability)

“I was always last in class because I did not even have exercise books. The teachers encouraged me to drop out and learn vocational skills because of the way I was struggling. Life is hard for ‘disables’ since our families are not prepared to spend much money on our education.” (Male with physical disability)

Participants also discussed that they were unable to get jobs because they had no support to access education. Responses indicated that education brightened the chances of securing jobs, and without any qualification their chances were very slim. A participant commented:

“It is hard for me to get the job because I do not have any qualification. That’s the system in this country. Life is difficult for ‘disables’ since we have no source of income to depend on. They tell us to learn skill training, but there is no money for us even to have necessary tools to start.” (Male with hearing disability)

Participants further reported that the lack of family support contributed to the high prevalence of poverty among persons with disabilities. Almost all participants (45) mentioned that persons with disabilities are poor mainly because they are idle and not engaged in any economic activity. With no qualification, they were unable to access jobs and consequently had no income to support their daily living.

“Hmmm! Life is not easy if you have a disability. Your family won’t help you and the government has nothing to give to you. They say there is poverty in the North, but our case is severe. Only God knows what we are going through to survive” (Male with visual disability).

Without family support, most persons with disabilities are dependent on the larger society for their daily bread.

Coping and Survival Strategies

Participants discussed their means of livelihood as well as how they were coping with regard to daily survival. The majority of participants (31) were unemployed due to their disabilities and were struggling to lead independent lives. The onset of disabilities in adulthood, in particular, had a major effect on their ability to work. Two of the participants shared their experiences:

“I have not been working ever since I had an accident. I was once a trader, but have lost all my capital and currently not working. The reason is that both my husband and my son died. Moreover, my son left me with one child. So I was using my capital to support myself, my mother and the child, and since the business was also not going well, I lost all my capital. As we are speaking now, my grandson has stopped schooling because I don’t have money to care for him.” (Female with physical disability)

“I was selling shea butter (local oil), but I quit this business when I became disabled. Currently, I am not working. I sometimes farm during the rainy season. I have children, but they care for themselves because there is no one to help them and I am also not working. Life is hard, but I always look to God.” (Male with physical disability)

Some participants (29) indicated that because of the extent of their poverty, many persons with disabilities had resorted to begging. Faced with inadequate support from their families, as well as limited jobs, they reported that they had to depend on the benevolence of others to survive on a daily basis. However, a few admitted that they were self-employed and made a living regardless of their disability. Some shared their experiences:

“I’m very happy to be working. I can work with any other person. It is my prayer that every disabled person learns some vocational training to generate his or her income. Because of how hard I have worked my employer now recruits other ‘disables’ that are without jobs. Now there are other ‘disables’ working with us. I always advise other ‘disables’ who are not working to come to us and learn the sowing.” (Male with hearing disability)

“I always plead to authority to help create opportunities for ‘disables’ begging on the streets. Even if they can’t take part in skilled training, they could be supported to do business. Everything starts small. I was selling bread on a small table in front of our house. That’s how they should begin, and it will surely grow with time. I was able to generate money from this small business I was doing to learn a vocation. I didn’t rely on people. It took determination to get to where I wanted to be. They told me am working that is why I’m saying that. However, they don’t know how I suffered to come by this job.” (female with physical disability)

Despite the challenges they faced in society, they had been able to learn either a vocation or trade to make a living and support themselves.

DISCUSSION

Over the years, persons with disabilities and social commentators have advocated for societal restructuring to enable equal participation of all persons in socioeconomic activities (Shakespeare, 2006; Hanisch, 2007). The argument has been that these adjustments could enhance the living standards of persons with disabilities who are usually without jobs. In achieving this goal, the family is expected to liaise between their members with disabilities and society as a

whole (Aldersey, 2012; Aldersey et al, 2017; Lim, 2017; Nishio et al, 2017; Sauer & Lalvani, 2017). This study aimed to examine the support given by families to enable the full inclusion of persons with disabilities. It was, however, found that persons with disabilities were unable to get the necessary support from their families, leading to negative consequences in fostering equal participation in society.

Exclusion, discrimination and marginalisation of persons with disabilities have become a topical issue in contemporary development discourse. Previously, unjustifiable restrictions in society were reported to be the major contributory factor which had led to high rate of poverty among persons with disabilities (Palmer, 2011; WHO, 2011; Naami et al, 2012). While persons with disabilities have been doing their best to fight for equality, it was expected that the family would supplement their efforts, by providing emotional and financial support. However, as found by this study, the family is yet to come to terms with the capabilities of persons with disabilities and continues to view them from the medical perspective, that is, as individuals with defects. Families seemed uninterested in the well-being of the study participants, which had put them at a disadvantage in the society. As a result, participants were usually left out of school because support to their other siblings may have been prioritised. Previously it has been argued that access to education is a significant step towards overcoming barriers faced by persons with disabilities (WHO, 2011). Persons with disabilities are consistently seen as liabilities, and this explains why families deny them the chance to have access to necessities of life such as education (Aldersey, 2012). The social order is usually against the education of persons with disabilities who are seen as individuals who need to be supported to live, rather than be empowered to be independent (Fitzgerald, 2007; Baffoe, 2013). According to WHO (2011), the inabilities of persons with disabilities to get support from families render them powerless to fight for their rights when violated. Therefore, it is not surprising that most of the participants in this study could not assert their rights and had become dependent on the benevolence of others for their daily bread.

Breaking social barriers depend largely on having economic freedom, and this can be safeguarded only when persons with disabilities participate in economic activities (Fitzgerald, 2007; Groce et al, 2011). The main way to empower persons with disabilities to take control of their lives is when they are supported to have access to education and become competitive in the job market (Groce et al, 2011; Opoku et al, 2017a). However, without any qualification, the ability of persons

with disabilities to secure gainful employment is minimal (Filmer, 2008; Naami et al, 2012). Given this situation, if they remain unemployed, participants of this study are unlikely to break the yoke of poverty as they would continue to depend on others in the society. Without any qualification, it might be hard for the study participants to market themselves or even compete with others in the society. Certainly, the unavailability of economic opportunities has contributed to the situation where persons with disabilities (as discussed by participants) are forced to beg for alms to survive. According to the laws of Ghana begging is illegal (Kassah, 2008), but participants indicated that they had no option other than engage in this illegal activity to make a living.

Persons with disabilities are aware of the fact that they have been maligned in society. Sometimes when the family lacks the financial resources to provide for all the family members, only the typically developing siblings are supported. Probably, the negative perception that persons with disabilities are unproductive informs the decision of the family to educate other siblings at the expense of children with disabilities (Naami et al, 2012; Gregorius, 2016; Opoku et al, 2015). Although some have managed to engage in income-generating activities, they fear that without deliberate state intervention, many of their peers might live in abject poverty and resort to unscrupulous means, such as begging, to survive. As expected, they have made a clarion call to the government to rescue them from their present predicaments.

CONCLUSION

The purpose of this qualitative study was to highlight the impact of family support on the lives of persons with disabilities in Ghana. The study findings have confirmed the rationale that the nature of family support predicts the quality of life of individuals in adulthood. From the social perspective of disability, there is admission of barriers being erected against persons with disabilities (Avoke, 2001, 2002; Groce et al, 2011). Without concerted effort, persons with disabilities may not achieve much in their lives. As expected, this study has demonstrated the dire consequences of lack of family support on the lives of persons with disabilities as they have to contend with poverty and low status in the society. There are deep-seated socio-cultural norms used to explain disability in societies (Agbeneyega, 2003; Green et al, 2005; Baffoe, 2013; Gregorius, 2016; Opoku et al, 2016). Consequently, persons with disabilities have been at the receiving end – caught in the yoke of poverty mainly because of limited access to education and

employment (Fitzgerald, 2007; Opoku et al, 2017a, 2017b). The call for inclusivity is to enable persons with disabilities to be regarded as equal members of society. Achieving inclusivity should start with appropriate support at the family level in order to make children grow and become responsible adults. Inadvertently, lack of family support may render persons with disabilities powerless to socialise in the larger society. Without the support of the family, persons with disability may be unable to acquire education and other useful services needed for their development.

Implications

The resilience of persons with disabilities is undeniable as they have been able to withstand difficulties. This reinforces the fact that disability is not inability and hence, it is high time the family takes the lead in assisting family members with disabilities to overcome barriers that are limiting their inclusion in society. Ultimately, the fight for inclusion should not be a political pronouncement, but the government must show commitment by institutionalising awareness campaigns, advocating for acceptance of persons with disabilities in the society. It calls for an affirmative policy where conscious efforts would be made to project the image of persons with disabilities. The family should be encouraged to give support to its members with disabilities so that they could be able to confront other barriers in the larger society. Therefore, in building a social support system that is aimed at alleviating poverty among persons with disabilities, it is appropriate for it to be woven around the family system.

Limitations

This study cannot be generalised because of the narrow scope within which participants were recruited. They were all members of DPOs and were drawn from only three disability groups. Their views may not be representative of all persons with disabilities in the Northern region of Ghana. Therefore, it is recommended that future studies investigate the consequences of family support on the lives of persons with disabilities who are not members of DPOs.

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