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Cross sectional survey of access to social services by families of persons with intellectual disability (PIDs) in Imo State, Nigeria

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Abstract

This study was designed to ascertain the awareness, availability and utilization of social services by families of PID in Imo State, Nigeria. Survey was conducted with 1147 family members of PIDs aged 10 years and above (560 males and 587 females) sampled through snowballing, using semi-structured questionnaires from September to December, 2012. Six IDIs and Twenty-one FGD sessions with 160 study participants comprising adult male and female members of the communities were conducted. Results indicated that not all the families who were aware of the existence of social services utilized them. The distribution revealed that 8 (66.7%) of the 12 respondents who indicated awareness of the existence of social services utilized such services while 33.3% did not. The qualitative data attributed poor utilization to either ignorance of the existence of such facilities or distance and lack of financial resources to access them. Also ignorance on the usefulness of such facilities prevented families from utilizing available social facility. The study concluded that social services for PIDs in Imo State are grossly inadequate and inaccessible to families and recommended the need for social workers to be involved in policy development for effective planning of social services.

Keywords: Persons with intellectual disability, Social services, Imo State.

Introduction

Intellectual disability [ID] is a major social, educational and health problem worldwide. It is a lifelong condition and results in substantial limitation in many living activities, such as the affected individuals' ability for their personal care, express and receive language, learn, and live independent and economically self-sufficient lives (Solarsh & Hofman, 2006). Those with severe ID will need more intensive support and supervision their entire life and this constitutes major burden on care givers and families (Burns, 2011). Social services are therefore designed to help families cope with the challenges of having a PID in the family.

About 450 million people are afflicted with ID (World Health Organisation [WHO], 2003). For every four families, one has at least a member with a mental disorder. Despite this global public health importance of the burden of ID (Prince, et al, 2007), gaps are observed between the needs and availability of quality services in response to these needs (Faydi, et al, 2011). The Rights of Persons with Disabilities [CRPD] was adopted in the United Nations Convention on December 13, 2006. Nigeria as one of the parties to this convention ratified this convention on September 24, 2010 with commitment to its implementation (United States International Council on Disabilities, 2012). In January 23, 2019, President Muhammadu Buhari signed into law the Discrimination against Persons with Disabilities (Prohibition) Act of 2018. This act prohibits discriminations on the basis of disability and imposes fines and prison sentences to those who contravene it. It also stipulates access to social services especially right to an all-inclusive education and health care; equal treatment and participation of persons with disabilities [PWDs] across the nation as well as having disability friendly buildings.

The development of a variety of social services at the community level is a means towards equalization and participation of PWDs in the social life (Chiriacescu, 2006). However, section 10 of Nigerians with Disability Decree (1993) made provisions for supportive social services for PWDs. Specifically, it promised to develop programmes to assist the families of the disabled to adjust to disability. Despite this, social services for PIDs remain poor and inefficiently run (Kohn, Saxena, Levav, & Sareceno, 2004). According to International Federation of Social Workers (IFSW, 2012), PIDs [and their families] experience barriers in accessing health and social services. Though significant advances are recorded in general health promotion and prevention, management of ID is yet to experience any improvement. ID is still subjected to stigmatization and prejudice due to widespread ignorance (Saxena, Thornicroft, Knapp, & Whiteford, 2007). Worse still, an analysis of the WHO's Atlas on global resources for PIDs demonstrates a case of widespread, systematic and long term neglect of resources for intellectual health care in Low and Middle Income Countries [LMAICs], including Nigeria (WHO, 2007). The WHO Atlas also revealed that vital community based mental health care services exist only in half of LMAICs, while only 60% of countries globally have facilities to train primary health workers in mental healthcare.

Families remain the primary care providers for PID. The families, and to a lesser extent community, form the basis for mental health care in Nigeria (Alem, Jacobsson, & Hanlon, 2008). The implication of this is that often family care givers are stressed and sometimes lack knowledge on the best way to help the PID in the family acquire the necessary skill for independent living. There is therefore need for provision of support services for families with PID. Family support services are vital and require services from specially trained social workers (IFSW, 2012).

The culture bound theory of diseases (Erinosho, 2006) formed the theoretical basis of this study. It postulates that a person's perception of health is determined by socio-cultural factors which differ from one society to another. Socio-cultural factors to a large extent determine help seeking (knowledge, access, and utilization) of social services (Odinka, et al, 2015; Rumun, 2014; Jack-Ide & Uys, 2013). In Africa, illnesses and diseases are seen either as deriving from a curse, or that they are destined to afflict their victims by their personal chi (god) as a punishment of sorts (Chukwuezi & Chukwuezi, 2010). Amongst the Igbo of Imo State, who are deeply religious, the belief that the casual explanation of virtually everything situation and condition is spiritually related is quite strong in society. Socio-cultural beliefs and practices may influence health seeking by families and access to social services.

In Imo State, there are only three Non-Governmental Organizations [NGOs] that focus specifically on PIDs. However, the Federal Ministry of Social Development and Women Affairs lists only two rehabilitation Centers for PIDs in Imo Sate. These are Destitute Centre for the intellectually disabled persons, Umuneke, Ngor Okpala and Akpodim Rehabilitation Centre, Ezinihitte, Mbaise. Another center, The Don Guanella Centre for the mentally disabled, Nnebukwu, Oguta is owned by a private religious body. At the time of the study, none of these centers engage the services of trained social workers even though various Universities across the country offering social work programmes have produced a myriad of professional social workers.

Social work profession has a long history of work with vulnerable and marginalized persons. Some of the earliest settings of social work practice have been in homes for PIDs, mental health/psychiatric institutions (Bigby & Frawley, 2010). In recent years, the profession has begun to recognize disability not as a medical problem or pathology but as diversity (National Association of Social Workers [NASW], 2007). Beaulaurier and Taylor (2001) aver that social workers in their commitment to human rights, promote a holistic understanding of the PID to see his/her impairment only as an aspect of what makes the person who he/she is. Thus social workers advocate and help ensure that social services are not only available but accessible in an equitable and affordable manner. Through advocacy, they also ensure that such services are of good quality and that PIDs and their families receive them from service providers in an ethical manner (Njenga, 2009). Being a profession committed to social justice and equity, social workers through counselling guarantee clients' right to self-determination, person centered approach, confidentiality and non-discrimination attitude towards PIDS and their family members. Through counselling, they help family members understand the nature of the disability in order to be of assistance to the PID (Zastrow, 2000). Furthermore, social workers are engaged in counselling, empowerment, resource linkage/mobilization, social care, policy development, research and advocacy to aid provision access and utilization of social services (Australian Association of Social Workers [AASW], 2016; Okoye, 2013). The study therefore sought to find out from families of PIDs their experiences with accessibility and utilization of social services for PIDs in the communities in the LGAs studied with a view of providing adequate social work interventions.

Materials and methods

The cross sectional survey method employing quantitative and qualitative instruments of data collection was utilized for the study. The quantitative (survey) tool was used to elicit information from household members, who have a PID, based on interviewer-administered household survey instrument. Qualitative methods of In-depth Interviews [IDIs] and Focus Group Discussions [FGDs] were employed to collect data from key persons and family members to provide contextual data on access to social services by families of PIDs in the study communities. The study was located in Imo state, southeast, Nigeria which has three senatorial zones (Okigwe, Orlu, and Owerri) and twenty-seven local government areas [LGAs]. The choice of Imo state is derived from the fact that amongst the Igbos, some sociocultural beliefs and myths influence cultural practices and attitudes toward illnesses and may influence utilization of social services.

The 2006 estimated population of 3,927,563 for Imo state constituted the general study population (Federal Republic of Nigeria, 2009). The target population was persons aged 10 years and above and was estimated at 2,985,106 persons, constituting 76% of the former, and is made up of approximately 1,488,873 males and 1,496,233 females respectively (National Population Commission, 2006). This sub-population was chosen on grounds of sufficient intellectual maturity to understand the issues that were raised in the study and would have personal experience concerning PIDs that includes being in a household or knowing one that may include a PID. Another rationale was the knowledge of about 2.9 percent estimated prevalence of PID in a typical population size. Thus, the estimated population of PIDs in Imo state was calculated to be about 113,899.

A total of 1200 persons aged 10 years and above who have at least one PID in their household was statistically computed, using an ID prevalence of 2.9% in Africa (Christianson, et al, 2002) and confidence interval of 95% with an estimated 3.0% precision level in the three LGAs. Through simple random sampling [SRS] or balloting, Ihitte/Uboma LGA was drawn from the six LGAs in Okigwe Zone, Ahiazu Mbaise from the eleven LGAs in Owerri Zone, and Ideato North from the ten LGAs in Orlu Zone. Using the probability proportional to size [PPS] technique, the sample size was allocated among LGAs as follows: Ahiazu Mbaise, 459; Ideato North, 419; Ihitte/Uboma, 322. The sample was drawn equally from both sexes to ensure gender balance. The snowball sampling technique also known as “chain referencing sampling” or “respondent-driven sampling” was employed in the study, because this is a “hidden population” (Heckathorn, 1997). The first household was located with the help of the community or ward or religious leaders during key informant interviews. Subsequently, each case helped identify other cases and location of the households.

The study was conducted from September to December, 2012. The questionnaire was interviewer-administered. This was done by the researcher and six trained research assistants. Over one thousand (1147) questionnaires were duly filled in and returned for the analysis. 21 FGDs were conducted with groups of 6-8 persons made up of homogeneous groups of adult males and adult females separately. Participants for the FGDs were chosen based on consent of the participant and willingness to participate. These were conducted in locations, on days and at time that were convenient for the participants. 6 sets of IDI guides were employed in collecting information from the director of an institution for care of PIDs, heads of the three LGAs social welfare departments and two community leaders respectively.

The quantitative data was processed and analyzed with Statistical Package for the Social Sciences [SPSS] version 20.0. Descriptive Statistics like frequencies and percentages were employed to interpret the data. Data from the qualitative sources were entered in a word processor and saved as a Rich Text Format [RTF] file, which was formatted and coded using the ATLAS.ti programme. Phrases with contextual or special connotations were noted and pulled out as illustrative quotes to complement the quantitative data. The process of analysis of the qualitative data started by reviewing the interview and discussion experiences with the field assistants who facilitated and recorded interviews and discussions to obtain their views on the factors that inhibited or animated discussions. A more detailed analysis began with reading the transcript. During the first reading, notes were made of major concepts and the second reading utilized a system of open coding. A re-reading of the texts was done to discern patterns in the ordering and clustering of themes, which provided guide on the systematic development of codes to be used in Atlas.ti software. This process ensured inter-coder reliability and facilitated triangulation of data from discussions and interviews (Okeibunor, et. al, 2013). Analysis of the data placed emphasis on the interpretation, description and recording/writing of what is actually said. The transcripts were first done in the local language and translated into English.

Ethical considerations

This paper is based on a PhD Dissertation. Monitoring and evaluation of the ethical conduct of the research was undertaken by the Postgraduate Board of the Departments of Sociology/Anthropology and Social Work, University of Nigeria, Nsukka. The ethics review committee of the University of Nigeria, Nsukka approved the scientific and ethical designs of the study. Thus the principle of do-no-harm was adhered to in this study. Informed study approval was sought and received at the level of the State, Local Government, community and the household level while verbal informed consent was obtained from all individuals that were involved in the study. Verbal consent was used to reduce sensitivity of the respondents, most of whom were rural and suspicious of anything demanding their signature on paper. This was approved by the Postgraduate Board of the Departments of Sociology/Anthropology and Social Work, University of Nigeria.

Results

Table 1: *Distribution of respondents by access and utilization of social services in Imo State*

Availability/utilization of social services	**Frequency**	**Percentage (%)**
Social services	**N=1147**	**100.0**
Yes	12	1.0
No	785	68.4
Don’t Know	350	30.5
Support services received	**n=12**	**100.0**
Counseling	10	83.3
Help families form social networks	1	8.3
Others	1	8.3
Availability of agencies and facilities for PID	**N=1147**	**100.0**
Yes	12	1.0
No	785	68.4
Don’t Know	350	30.5
Whether PID was sent there (Utilization)	**n=12**	**100.0**
Yes	8	66.7
No	4	33.3
Knowledge of families that utilized social service	**n=12**	**100.0**
Yes	8	66.7
No	1	8.3
Don’t know	3	25.0

The results in Table 1 indicated that most of the respondents were not aware that such services existed, not to talk of using them. Responses from the table further indicated very poor awareness of the availability of social services within the study communities. Majority of the respondents (68.4%) indicated that there were no social services for PID and their families. The study also found that 30.5% of the respondents indicated lack of knowledge of such services while only a small proportion (1.0%) indicated awareness of existence of such services. Responses from the various FGD sessions conducted in the communities indicated non-availability and poor awareness of social work services as can be seen from the following quotes:

> *Persons with mental impairment do not benefit from any facility since there is none around us here.* **[Participant: FGD; Adult Female]**
> *The Social Welfare Department in the local government is not doing anything for such persons.* **[Participant: FGD; Adult Female]**
> *If the welfare exists we do not know. I have not observed any assistance from the social welfare department to such families.* **[Participant: FGD; Adult Male]**

Lack of facility for the care of PID in the state was further highlighted by the views of the Social Welfare Officer and the FGD participants. Some of the challenges, even where the people were aware of the facilities is the distance. Both the Social Welfare Officers and FGD participants lamented that distance the people have to cover to get to the facilities. Worse still, the facilities are non-residential, meaning that when they come they must return. See evidence in the quotes below:

> *Here in Imo State, we don't have special place for them or to keep them. We have emm one mentally this thing at Ngor Okpalla owned by state but the operation there is not okay.* **[Participant: IDI]**
>
> *None is close to this community. They don't come to this community but we have a lot of MI persons in the community. They should come and take these children, give them special education and vocational training.* **[Participant: FGD; Adult Female]**
>
> *In our local government area here, there has never been a time when the welfare department has come to the village to assist these people. It is our brothers who go overseas and bring visitors that help these people. The local government is not doing anything.* **[Participant: FGD; Adult Male]**
>
> *One of the reasons is the distance and they do not have residential facility. The distance from here to Mpam is about 3km. So if the government made a van available to be picking and dropping them daily, it'll help.* **[Participant: FGD; Adult Male]**

Table 1 further indicated that not all the families who were aware of the existence of social work services utilized them. The distribution revealed that (66.7%) of the respondents, which indicated awareness of the existence of such social services indicated that they have utilized such services while 33.3% did not send the PID to such facility. However, in terms of absolute figures, the number of families that made use of such facilities is small compared to the number of PIDs studied. Reasons for not making use of social work services as indicated by the respondents and the FGD participant includes: cost, distance and ignorance. The few institutions that are available are fee paying and largely unaffordable given the economic situation of the families. According to some of the participants:

> *One of my relatives who has a child with ID wanted to place him in an institution. I travelled all the way from Mbaise to Oguta with him. When we got there and spoke with the authorities, we couldn't afford to put him there because it was too expensive.* **[Participant: FGD; Adult Male]**
>
> *My nephew that has ID was sent to the institution at Enugu for care but he was withdrawn from the institution after primary education because of the cost of his secondary school training. To be honest, we want to train him but the money involved is a much* **[Participant: FGD; Adult Female]**

The issue of ignorance was presented by another participant who argued that institutions for PIDs are not helpful in improving the condition of PID. According to her:

> *The condition is worsened because the PID meets others with worse conditions and may start to imitate their behavior. I know of one that was sent there and the parents had to withdraw her because of this reason. In fact, the institutions do not provide any solution to the problem.* **[Participant: FGD; Adult Female]**

Discussion

Results from this study have revealed that care givers were family members with mothers and other female family members constituting the greatest proportion. It is a well-documented fact that family members are often the primary caregiver of PIDs in Africa and do not have access to professional services (McKenzie, McConkey & Adnams, 2013). The burden of mental disorder on family members is difficult to assess and quantify, and is consequently ignored. However, it does have a significant impact on the family's quality of life (WHO, 2003).

Literature shows that individuals with mental health problems needing care often do not seek services. Completion rate among those that receive care is often low (Corrigan, 2004). This present study therefore sought to ascertain among the respondents that indicated awareness of the availability of social work services, what proportion actually utilized such services. Social services for PIDs in Imo State as results revealed are grossly limited. Majority of the respondents as well as the participants in the various FGDs indicated very poor knowledge of availability and utilization of social work services. This is evidenced by the fact that only 1.0% of the respondents were aware of the existence of such services. According to Eleweke and Rodda (2002) only 2.0% of individuals with disabilities in developing countries receive any form of social service. Unlike in the western world, they have little or no access to social services.

Reasons for poor utilization of social services as the results indicated were distance, poor knowledge of their benefits and cost. Some families see placing their family member in an institution for the training of PIDs as having no value (African Policy Forum [ACPF], 2011). Facilities where they existed are very far from the communities and many families with PID lack the economic resources to access them as indicated by the qualitative data. Ignorance of the usefulness of institutional care of PID by family members is also an issue for non-utilization of services. As indicated by the qualitative data, some family members were of the view that the mental condition of their ID family member got worse in an institutional facility. There is therefore suspicion on their part with regards to the effectiveness of institutional care. Similar studies in Nigeria had indicated that families of persons with mental disorders have poor knowledge of social services and their benefits (Jack-Ide, Makoro, & Azibiri, 2013; Aniebu & Ekwueme, 2009).

Furthermore, the findings of this study hinged on its theoretical orientation. The culture bound theory of diseases (Erinosho, 2006) provides an explanation that because beliefs about the supernatural causes of ID are deeply entrenched in the society, the condition carries some shame and stigma. Such traditional beliefs, make family members of PIDs hide them because of shame and thus do not seek the use of social services. This has been corroborated by literature that understanding of ID in the

African perspective that is deep-rooted in superstition, stigma and fear impact negatively on access and utilization of social services by PIDs and family members (Mung'omba, 2008).

Conclusions

The key finding of this study is the need to help most PIDs lead fuller, happier lives through social services. Unfortunately, despite recent advances, most PIDs in Imo State, Nigeria do not receive the professional help they need. It is therefore recommended that improving access to social services should be a priority at community levels to reduce the gap and enable families with PIDs have physical access to social services. The distance from facilities for care can be improved upon through establishing day-care centers within the communities. Household rather than institutional care appears to suit the PID better. In this setting, trained social workers will aid family members through family counseling and assistance. Families could be encouraged with family counseling to provide emotional, practical guidance and support of the PID.

It is suggested that there is need for facilities. Institutional provisions should be put in place where family-based-care fails. There is a need for more community-based-care for PIDs by establishing day-care centers in the communities. Given the incessant funding deficit, larger institutions are increasingly becoming unpopular as they fail to engage high quality professionals required for quality care. Also there is need for more services for PIDs in the future. Both the public and private sectors should pull their wide range of skills and resources to better serve the PIDs.

The implication of findings for social work profession is that, social workers play an important role in policy development through advocacy and research. This will enable effective planning of social services for PIDs and families as well as help reduce the gap experienced in accessing social services by families of PIDs. Services for PIDs are often neglected in part due to dearth of advocacy by and for them (Njenga, 2009). It is without doubt that for services for PIDs to be effective and provided in an ethical manner, social workers must be involved. According to DuBois and Miley (2005), social workers' interventions are generally initiated to strengthen human functioning and to enhance the effectiveness of societal structures that provide resources and opportunities for clients. Effective social work practice with PWDs requires a re-focused conceptual framework that will support and promote client self-determination, empowerment. confidentiality, equity and social justice. Thus, active involvement of social workers in the development and provision of social services to PIDs and their families in Imo State is strongly recommended.

Finally, ignorance about availability of social services for PID and benefits of services by the population could be mitigated through public enlightenment and education. The ministry of information should liaise with social workers and embark on the dissemination of information to the populace on social services availability and benefits.

One limitation in the analysis and interpretation of this study however, had to do with the condition of mind of the informants. Some of them were often very sentimental and take every opportunity to lament their situation in the context of an abuse. This may have introduced some bias. For instance, questions relating to social services may have been interpreted by the informants relating to instances of abuse, given the preponderance of abuse among the victims. However, with the mixed method design adopted in this study it was possible to clear such possible bias and employ data that were collaborated from different sources. The results of the pretest also prepared the data collectors to guide against such bias. This was further strengthened by the other-administered approach used for data collection. Another limitation is the sensitivity of the subject. Families with PIDs suffer subtle stigmatization in the community and are easily suspicious of anyone coming to discuss the PIDs in their homes. The snowball sampling methods was very helpful. When they know that they were identified through someone that shares their concerns they relaxed and provided information for the study. We also failed in this study to give support to the PIDs and their families. This was due to our efforts at protecting the scientific validity of the data we collect. In the informed consent note, it was made clear that this is a PhD study and that the researcher is a student. No promises were made and the informants we happy to contribute to the study.

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