"We are Seen but not Recognized"; Disability Stigma and Disabled People's Exclusion from Community Activities: The Case of Disabled People in a Traditional Community in Ghana

Acheampong Enoch[1]   Kofi Akohene Mensah[2]   Rose Odotei Adjei[2]   Anthony Kwaku Edusei[2]
Paul Okyere[2]   Emmanuel Appiah-Brempong[2]
1.Centre for Disability and Rehabilitation Studies (CEDRES)
Department of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi-Ghana
2.School of Public Health, Kwame Nkrumah University of Science and Technology, Kumasi-Ghana

Abstract

Society has a way of categorising and assigning expectations to its members. There are also rules regarding the norms and processes of dealing with problems of daily life. If a rule is broken during interactions between individuals in society resulting in abnormal situation, it can be labelled as stigma. When people perceive individuals as possessing socially unacceptable attributes, they assign negative qualities to the person and results in devaluation of the individual. Data was collected from disabled people and their leaders in the Kumasi Metro who were registered with the Department of Social Welfare. A qualitative study was conducted in which Interview and Focus Group Discussions were employed to collect data from respondents. Purposive sampling technique was adopted to select 35 respondents for the study. After each data collection activity the recorded audio tapes and field notes taken during the interview were translated into English and later word processed. Data editing and categorisation was done manually based on the research objective.

The study found that disability is stigmatised as a result of the reaction of society towards individuals who have impairments, disabled people have been given names based on their disability, disabled people have also lost the opportunity to inherit family wealth and to be installed as chiefs, and are unable to represent their communities and families at social functions. It is recommended that there should be effective public education on disability and the scientific causes of the condition.

Keywords: Stigma, Community-exclusion, Ghana, Disability, Society, Culture and Labeling

1.0 Background of the study

Stigmatisation is considered to be a set of social processes with the key step being the recognition of something different in the person (Smith, 2002). Society has a way of categorising and assigning expectations to its members (Goffman, 1963). There are also rules regarding the norms and processes of dealing with problems of daily life. If a rule is broken during interactions between individuals in society resulting in abnormal situation, it can be labelled as stigma (Bennstam et al., 2004). When people perceive individuals as possessing socially unacceptable attributes, they assign negative qualities to the person and results in intense devaluation of the individual. The term stigma connotes a moral judgment of an individual and often results in complete devaluation of the person. The basis of the devaluation is the observation that the person possesses certain devalued social attributes, such as, membership of a devalued racial group or unacceptable sexual preference (Dodor, 2009).

Every society has a way of establishing means of categorising persons and the characteristics felt to be common and accepted for members to possess. The attributes society expects the person to possess is the 'virtual social identity'. As we interact with the person, the attributes we discover that the person possesses is the 'actual social identity'. When any member of society is seen to possess attributes (actual social identity) that make him different from societal expectations, usually a less desirable one (virtual social identity), the person is "thus reduced in our minds from a whole and usual person to something tainted and discounted". The individual's social identity is spoiled and he or she is assumed to be incapable of fulfilling the role requirement of social interactions. Thus, the discrepancy between the characteristics and attributes that we expect ordinary members of society to have and what they actually possess is stigma (Goffman, 1963: Dodor, 2009).

Historically, some illnesses and conditions have been used from time to time to mark people out as set apart from normal people. The characteristics seen as stigmatising vary from one culture to another, and depend on what is defined as normal at a particular time in history (Davey and Seale, 2002).

Disability is a condition that has historically been stigmatised and the individuals who have the conditions are always subjected to devaluation of their persona. The history of the portrayal of disabled people is the history of oppressive and negative representation. Disabled people over the years have been presented as

socially flawed able bodied people, not as disabled people with their own identities (Barnes, 1992). Disabled people are often perceived as 'objects of pity', incapable of doing things for themselves, sick, and needing 'help'. From childhood, most of them grow to be disempowered adults, denied the power and authority to make and to take decisions, solve problems or take the initiative (Avoke, 2002).

The attitudes of society toward disability are the major barriers to disabled peoples' full participation. From pity, awkwardness and fear, to low expectations about what disabled people can contribute. Stereotypes and negative attitudes hold people back. Disabled people regularly identify societal attitudes as the most potent and negative stressor in their lives. As long as negative attitudes persist, the full rightful acceptance of disabled people is unlikely (Massie, 2006).

In both low-income and middle-income countries in Africa, it is estimated that between 76 percent and 99 percent of people with serious mental disorders do not have access to the treatment they need for their mental health problems. Political apathy combined with widespread stigma, hinders the progress disabled people in most developing countries. People who have or are perceived to have disability may find it difficult to access services due to stigma and discrimination and these reactions obstruct participation (WHO, 2011).

Article 8 of the United Nations Convention on the Rights of Persons with Disability enjoins member states to:undertake to adopt immediate, effective and appropriate measures: To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities; To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life; To promote awareness of the capabilities and contributions of persons with disabilities.

The Disability Act of Ghana in Section 4 also states that; a person shall not discriminate against, exploit or subject a person with disability to abusive or degrading treatment. Ghana is a signatory to the United Nation's Convention on the Rights of Persons with Disability and even eight years after the passage of the Persons with Disability Act by the Parliament of Ghana in 2006, stigmatisation of disability continues to exist in the country. The political and social incorrectness of language used by individuals, groups, government and non- government organisations not only constructs disability, but also enhances the cultural stereotype and their stigmatisation.

In Ghana, stigmatization of disability starts at birth. Pregnancy and birth is highly regarded as a blessing and is characterized with high expectations. There is no reason a family can give to explain why a child is born with a disability except that the anger of the gods has been visited on them. As a result, disabled people tend to be ostracized and excluded from mainstream society and community life, including social gatherings (Avoke, 2001).

In one of the regions (Brong Ahafo), pregnant women are barred from eating fish caught from a river called 'Nsuakoraa'. The people in this area believe that the river is a god and the fish are its children, and eating fish from this river will result in miscarriages and 'retarded' children. People born with disabilities receive labels with various dehumanizing names and their parents become victims of isolation and mockery. With the above notion of cultural ideology, persons with Down's syndrome in Ghana are believed to be children given by the river gods, and hence they call them 'Nsuoba', meaning water children (Avoke, 1997).

Persons with 'mental retardation', as it is still called among Ghanaians, are the hardest hit victims of labeling. Two tribal groups, the Ewes and the Gas, refer to them as 'Asotowo', and 'Buluus' meaning idiots or fools, and reduced intellectual abilities respectively. The most dominant tribe in Ghana, the Akans label persons with intellectual disabilities as 'Nea wanyin agya n'adweneho' which means 'feeble minded'. In the tradition of the tribe, these are very offensive and dehumanizing labels, which are equated with insults (Avoke, 1997).

In typical traditional communities, crocodiles, and snakes are considered to have some special powers and any cruelty against them can lead to the individual giving birth to a disabled child. Riches in some traditional societies in Ghana are viewed with mixed feelings. Many people believe that parents can exchange any part of the child's body spiritually, with money such that the part so exchanged will become defective. Consequently, a rich family with a disabled person is labeled "sikaduro" (juju money

Since stigma is often rooted in social attitudes, disabled people in Ghana are often disliked, rejected, shunned and could experience sanctions, harassment, and even violence. This study was therefore conducted to explore the role of disability stigma in disabled people's exclusion in community activities.

2.0 Methods

The purpose of the study was to explore the role of disability stigma in disabled people's exclusion in community activities. The researcher conducted a qualitative study and this was considered appropriate because qualitative study permitted the researcher to carry out the study in natural real life setting. Qualitative research seeks to understand issues from the perspective of the society, organisation or setting and resists the tendency to impose meanings on issues. It examines and explains the culture and behaviour of humans and their groups from the view point of those being studied. It also helps to clarify the values, languages, and meanings attributed to the various roles played by people in a society (Bryman, 2004).

The study could not cover all the disabled people who live within the Metro under consideration. The researcher therefore used non-probability sampling technique in selecting the respondents. The sampling technique used in selecting the respondents was purposive sampling which focused on individuals, groups and settings that could provide relevant information on the topic. This strategy allowed decisions about the sampling to be reviewed during the research process and to stop recruiting more participants when data saturation was reached (Darlington and Scott, 2002; Dodor, 2009).

The study population was disabled people and leaders of Disabled Peoples Organization (DPOs) who have been registered with the Department of Social Welfare in the Kumasi Metro as well as opinion leaders in Asokwa Sub-Metro which happened to have more disabled people registered. Estimated number of disabled people registered by the department as of the time of data gathering was 295 out of which 176 being males and 119 being females, with 235 being those with difficulty in moving and 35 and 25 being difficulty in seeing and others respectively (Department of Social Welfare, 2014).

The sampling units for this study was all registered disabled people who were 18 years and above, leaders of DPOs who are registered with the department of social welfare,

The Register of the disabled people at the Department of Social Welfare was used as the frame from which the respondents were drawn. Considering the total population and the type of study being conducted a sample size of 35 disabled people were selected. The sample size was arrived at based on the principle of the 'point of saturation'. Interview and focus group discussion were used as methods of collecting data from the study participants. Focus group discussions were conducted for the disabled people and their leaders in addition to the interview. Five separate discussions were held on three different days with each discussion comprising 10 disabled people. Three of these discussions had mixed groups in terms of sex, while the other two comprised males only group discussion as well as females only group discussion.

Since the study was qualitative, words rather than figures were used to explain the data. This means that the data was analyzed and presented through inferences that were made out of the responses. Part or some of the responses have been paraphrased and presented in the findings. After each data collection activity the recorded audio tapes and field notes taken during the interview were translated into English and later word processed. Data editing and categorization was done manually based on the research objectives.

Ethical approval was sought and obtained from the Committee on Human Research, Publications and Ethics, Kwame Nkrumah University of Science and Technology, School of Medical Sciences and Komfo Anokye Teaching Hospital and also the consent of the respondents was sought and they were assured of anonymity by removing all identifiers from the research instrument. The principle of voluntarism was followed where respondents were asked to participate in the study freely from their own will and anyone who did not want to participate was free to refuse.

The complete data of this work can be obtained from the department of Community Health, School of Medical Sciences, Kwame Nkrumah University of Science and Technology.

2.1 Limitation of the study
The major limitation of the study was the inability of the researchers to include persons with difficulty in hearing and speech impairment in the study due to communication barrier as there was no sign language interpreter to facilitate the discussion.

3.0 Findings and discussions
The study aimed at exploring stigmatization of disability and disabled people's exclusion from community activities. The findings revealed that in their daily lives, disabled people experienced stigma and discrimination from various groups of people. The themes generated from the data were; stigma and shame, name calling, selection of disabled people to represent the community, denial of opportunities.

3.1 Demographic characteristics of respondents
The sex and age of people have a greater influence on their thinking pattern and also individuals are affected differently by a social issue based on their sex and age. The researcher collected data from respondents who were found in both sexes (male and female). The number of male respondents was relatively more than females based on the sex distribution of the disabled people's register at the Department of Social Welfare which was used to select the disabled people. In terms of age, the respondents for the study were mostly youthful with the highest number of respondents falling within twenty to thirty nine (20-39) age group with relatively few respondents being exactly forty (40) years or more.

The findings revealed that the disability of the respondents were found in two main categories (difficulty in moving and difficulty in seeing) with majority of them falling within the difficulty in moving category.

3.2 Stigma and shame

The study has found that stigma attached to disability has resulted in various stigmatising behaviours from members of the society making the condition shameful. Though most disabled people try to endure the shame they face as a result of their condition, certain stigmatising behaviours and practices of the larger society make their shame unbearable. Certain practices within the community and family levels were mentioned frequently by the participants as making suffering from disability shameful. It was revealed that in most households disabled people are not allowed to dine with the rest of the family members, their cups and plates are separated from those used by the rest of the household.

> *…Akane tete no se nifrani be wua na mpaninfuo no mpene mma wondedano. Na ode mmofra woyare nso hye edan mu senea ebeye na obiara nnhu no"(Which means in the past, when disabled die, they were normally not allowed to be laid in state and disabled children were also hidden from the larger society* (Male respondent, individual interview).
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> *.....Me kae se na mesua no, na menua nom ne mabusuafuo fre me 'bayifo' (Meaning; My siblings and other family members use to call me witch because they thought I was responsible for any misfortune that happened to our family and found it difficult to associate myself with other people* (female respondent, focus group*).

The core feature of stigma is the possession of attribute(s) that convey a devalued social identity, which is widely shared and well known among members of the culture, and becomes a basis for excluding or avoiding such person(s) (Goffman, 1963). As Ervin Goffman argues, "when an individual who might have been received easily in ordinary social intercourse possesses a trait that can draw the attention of others and turn those he meets away from him such an individual possesses stigma, an undesired differentness from what we had anticipated" (Goffman, 1963). To members of this community, disabled people were seen to possess attribute(s) that make them different from other members of the larger society.

The views expressed by the respondents with regard to how other members of the society perceive their condition was similar to what other scholars have shared on stigma. For example Bennstam et al (2004) contended that when people perceive individuals as possessing socially unacceptable attributes, they assign negative qualities to the people which results in intense devaluation of the individual. Thus the term stigma connotes a moral judgement of an individual and often results in complete devaluation of the person. It was not different from the findings of Dodor (2009) when she studied Tuberculosis stigma in Ghana. She found that members of the stigmatized group were discriminated against by the larger society based on the misconceptions and multiple interpretation of the cause of their disease.

3.3 Name calling

It was found that in this Ghanaian community, disability is shameful due to the names given to the conditions by members of society. People do not call disabled people by their real names but use their impairments to call them. There were others who also said that they have been subjected to derogatory name callings which are very shameful in the local languages. Names such as 'bafan' (meaning cripple), 'bayifuo'(witch), 'bosom ba' (child of god), 'nifrani' (blind person) are usually used to call disabled people without calling them by their real names.

> *......My real name is not known by most of the people especially the young ones.......people call me 'Kwadwo bafan'* (meaning Kwadwo cripple) *and I feel ashamed about it but do not know how to confront them so I reluctantly respond when they call me* (male respondent, focus group discussion).
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> *.....It is not easy to be a disabled person because the shame is too much....... I am always referred to as 'Onifrani'* (meaning blind person) *without thinking about the effect this is having on me as a person....There is no regard or respect for you if you have an impairment in my area* (female respondent, focus group discussion).

These descriptions according to the participants brought some amount of pain and shame to them. Thus inherent in the language used to label and inscribe, and to construct the disabled in Ghana is premised on the dominant cultural ideology that marginalizes, silences and constructs subjectivities through the society. With language we often exaggerate the nature of people who differ from us. This position has been expressed by several writers that disabled people receive labels with various dehumanizing names and their parents become victims of isolation and mockery. For instance, Avoke, (1997) and Agbenyega (2002) both indicated that persons with Down's syndrome in Ghana are believed to be children given by the river gods, and hence they call them 'Nsuoba', meaning water children.

3.4 Selection of disabled person to represent the community

Community leaders would not agree to the selection of a disabled person to represent the community in any official capacity if they were available or any 'non-disabled person was available. They were of the view that selecting disabled person meant that there was no qualified 'able person' and this may result in ridicules from

members of other communities at the function. Disabled people (DPO leaders) also indicated that they will not agree to represent their communities in any social gathering. They anticipated cold reception and disgrace from the other members of the community and to prevent this from happening they said they would not be ready to accept such a duty.

Selection of disabled people to represent the community is very unlikely in the study area because community leaders indicated that they would not agree to that even if they were not present. Disabled people themselves are not willing to accept the offer of representing their communities in social gatherings and functions.

> ....*Do not even ask because my answer is a big no, there is no way as a leader I will allow someone to represent my community when I am around and even if I am not around, I will find someone suitable to replace me and that person will certainly not be a disabled person* (community leader, individual interview).
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> ......*My people will not be happy with me if such a thing happens in this community during a social function or any gathering.... they can be present to witness the occasion but not to be the main speaker or the representative of the community* (community leader, individual interview).
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> ....*I do not think I will go or accept such an offer because people at the function will definitely not accept me and are likely to make fun of me. I will respect myself by not attempting to go or accept such an invitation* (DPO leader, individual interview)
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> …*if the person has good knowledge of the work he/she is supposed to do, I don't have any problem with that. We could choose an 'able-body' person to represent us and the person might not work* (Social welfare officer, individual interview).

The position of the community leaders in relation to disabled people supports what Crandall (2000) observed that those who stigmatise others are conscious of what they are doing and usually base their actions on certain moral, ethical, legal and social beliefs which enable them to continue to stigmatise with a clear conscience. Crocker and colleagues also pointed out that stigmatisation may enable individuals to believe that they are better than those they stigmatise, and this may enhance their self-esteem (Crocker et al., 1998).

3.5 Denial of opportunities

As a result of the stigma and the misconceptions associated with disability coupled with the negative attitude of people towards disability, disabled people are denied a lot of benefits and privileges as members of the larger society. The study found that disabled people have lost the opportunity of inheriting family or parents' wealth. Others also indicated that they have lost the opportunity to become chiefs and queen mothers of their land as a result of their conditions as disabled people. Most traditions and cultures prevent disabled people from becoming chiefs and queen mothers so when the opportunity came for them to be installed the whole community and the king makers objected:

> ....*I was the first son of my father, but when my father died, my uncles and other relatives especially my younger siblings did not allow me to take my position as the first child of the family. My junior brother inherited my father's estate and he has neglected me due to my condition as a disabled* (male respondent, focus group).
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> .....*'Menua' (meaning my brother) my family even settled on the one to inherit my mother without my knowledge because they thought there is no point in telling me even though I knew I was the right person to take over from her* (female respondent, focus group).
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> ....*As a royal I could not become a chief because my people would not allow me and when I insisted, they asked me if I have ever seen a chief or king who is a disabled and that they will not install me to incur the wrath of the gods and the ancestors. I was eventually ignored and another member of the family who was far younger installed* (male respondent, focus group)

This information somehow supported the views of Ocloo et al (2002) that disability often carries a stigma that many people don't want to be associated with. Disabled people whether from birth or acquired later in life through injury or illness, are often marked as being weak, fragile and unable to do even the simplest things for themselves. The society sees disabled people as objects of pity or people to be looked down upon. Ocloo et al (2002) again noted that majority of Ghanaians, through belief systems, labelled disabled people as social misfits, social outcasts and in most cases treat them like animals.

When any member of society is seen to possess attributes (actual social identity) that make him different from societal expectations, usually a less desirable one (virtual social identity), the person is "thus reduced in our minds from a whole and usual person to something tainted and discounted". The individual's social identity is spoiled and he or she is assumed to be incapable of fulfilling the role requirement of social interactions. Thus, the discrepancy between the characteristics and attributes that we expect ordinary members of

society to have and what they actually possess is stigma (Goffman, 1963: Dodor, 2009).

4.0 Conclusion

The findings have shown that disability stigma is created by members of the society through their reactions toward those who have disability. The stigma attached to disability has resulted in various stigmatising behaviours from members of the society making the condition shameful. Name calling has become integral part of disabled people's life.

Again, it has been found that as a result of disability stigma, disabled people have lost opportunities to inherit family wealth and to be installed as chiefs, and inability to represent their communities and families at social functions.

It has also been found that community leaders would not agree to the selection of a disabled person to represent the community in any official capacity if they were available or any 'non-disabled person was available. They were of the view that selecting disabled person meant that there was no qualified 'able person' and this may result in ridicules from members of other communities at the function

5.0 Recommendations

It is recommended that stakeholders should intensify public education on disability. The focus should be on the capabilities of disabled people in order to disabuse the minds of people from stigmatising disability. The education should also include disabled people themselves because if they are well informed about their condition, they are able to have the confidence needed to stand-up to stigmatising behaviours from other members and reduce self-stigmatisation.

It is also important to target community leaders during the public education exercises. This is because such individuals have much power within the community setting and their attitudes and behaviours towards disabled people may affect the experience of stigma among the general population.

It is also recommended that there should be enactment and enforcement of laws that protect the right of disable people. Such laws should aim at preventing and punishing individuals who subject disabled people to dehumanizing practices.

There should be political will on the part of central government to enforce Persons With Disability Act which will go a long way to improve the conditions of disabled people in Ghana.

Again, it is recommended that the government should put into effect the dictates of the United Nations Convention on the Right of Persons With Disability especially article 8 of the convention which aims to combat stereotypes and discrimination.

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Table 1: Demographic characteristics of participants

Variables	Frequency N=35	Percentage %=100
Age group		
Below 20 years	5	14
20-29 years	12	34
30-39 years	13	38
40 years and above	5	14
Sex of respondents		
Male	19	54
Female	16	46
Disability type		
Difficulty in Moving	22	63
Difficulty in seeing	13	37

Source; authors' field work (2015)