

## BRIEF REPORTS

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# Role of Caregivers of Children with Intellectual Disabilities and Support Systems Available to them in Ghana

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### ABSTRACT

**Purpose:** *This paper explores the role of parents, teachers and house mothers, and the support services available in promoting effective education for children with intellectual disabilities in Ghana.*

**Methods:** *Qualitative research approach and exploratory design were adopted. Simple random sampling technique was used to select parents, while purposive sampling technique was used to select the teachers and house mothers. Data was collected at interviews, using an interview guide and making audio recordings and notes. Data transcription from the notes was compared with the audio recordings to ensure consistency. The main themes that were developed and coded using data-led approach have been presented as the major findings.*

**Results:** *The study revealed that most parents refuse to visit their children with intellectual disability in school. They also shirk their responsibility in providing training materials. It was found that training programmes are not organised for house mothers, teachers and parents of pupils with intellectual disability. Also, no incentives are given to teachers and house mothers of these pupils.*

**Conclusion:** *The study provides insight into the specific roles of parents, teachers and house mothers, and the appropriate support services available for these caregivers. There is a need to highlight these issues for policy making.*

**Key words:** *House mothers, parents, teachers, intellectual disability, caregivers, support systems, Kumasi Metropolitan Area.*

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## INTRODUCTION

Persons with intellectual disabilities are usually characterised by sub-average intellectual functioning and simultaneous limitations which are observed in two or more adaptive skills: conceptual skills, social skills and practical skills (American Association on Intellectual and Developmental Disabilities - AAIDD, 2010). The presence of sub-average intellectual functioning, coupled with limitations in one or more of the above adaptive skills in persons with intellectual disability, signal the need for special caregiving to promote their well-being (Schalock et al, 2010). This highlights the fact that effective caregiving for pupils with intellectual disabilities has become an issue of major concern to disability experts. Le (2011) opined that quality caregiving that comes from the heart has the ability to promote the physical, emotional, mental, spiritual and social well-being of the care receiver. There are different kinds of caregivers with diverse responsibilities. Some caregivers render 24-hour care, others live with care receivers, some care from a distance, and this has led to diverse classification of caregivers (American Society of Clinical Oncology, 2015). The National Alliance for Caregiving (NAC, 2004) categorised caregivers as formal and informal (family) caregivers. Formal caregivers are trained individuals and professionals, including healthcare providers, who render care and are paid for their services (NAC, 2004).

In advanced countries such as the United States of America, United Kingdom, Canada, France, Germany, and others, individuals with disabilities are often cared for by professional caregivers, although relatives of persons with intellectual disabilities render diverse forms of assistance (NAC, 2004). Comparing the quality of care given to pupils with intellectual disability in developed countries with their counterparts in less-developed and developing countries in Africa, studies (Hobson et al, 2013) have indicated that the quality of care given by both relatives and professional caregivers is below standard. In Ghana, parents and house mothers play a significant role in the education of children and persons with intellectual disability (Ghana Education Service, 2005). When parents effectively perform their respective roles – providing required training materials on time, motivating their children and ensuring that their wards are well catered to by their teachers – there is a strong tendency for their children to involve themselves thoroughly in all training modules and quickly become partially independent. According to Desforges (2003), the degree of parents' involvement is determined by the social status of the family, educational level of parents, single parent status and, sometimes, their ethnicity. Teachers are another class of caregivers,

as affirmed by the State University of New York (2015). In general, teachers are expected to treat pupils with love and respect, motivate them to repeat right behaviour, and correct wrong actions. Those in the special education domain, in particular, serve as effective caregivers when they love and respect pupils, assist them to complete academic and vocational assignments, contribute towards the building of self-esteem by treating every student as having dignity or worth, and enable pupils to obtain first-hand appreciation of morality by treating them in a moral way (State University of New York, 2015).

According to the World Health Organisation (2012), the availability of appropriate support systems for caregivers enables them to perform their respective roles effectively, and vice versa. It therefore recommended that providing information, financial support, encouraging respite care and organising training programmes for caregivers would equip them to overcome challenges associated with caregiving.

### **Objective**

Parents, teachers and house mothers play different, overlapping roles in the lives of pupils with intellectual disability, depending on the environmental and social roles assigned to them. However, there exists limited data on the specific role of parents, teachers and house mothers of children with intellectual disability in Ghana. This could be attributed to the fact that there is little or no research on the subject. In view of this, the study sought to ascertain the specific roles played by parents, teachers and house mothers, as well as the available support systems within three selected special schools in the Ashanti Region of Ghana.

## **METHOD**

A qualitative and descriptive study was conducted to ascertain the specific roles of the caregivers and the support systems available to them.

### **Study Settings**

The research was conducted in three special schools in the Kumasi Metropolis - the Edwinase Rehabilitation Centre, Garden City Special School and Community Special Vocational School. These schools provide vocational training for children or individuals who fall within any of the levels or ranges of intellectual disabilities (mild, moderate, severe and profound levels). Specifically, the dominant groups

of intellectual disabilities that were identified in all the three settings were persons with Down syndrome, Autism Spectrum Disorder, Dyslexia, Fragile X syndrome and Attention Deficit Hyperactivity Disorder (ADHD). The schools are committed to providing training and education for children with intellectual disability to enable them acquire basic life, functional, gross motor and fine motor skills.

### **Population and Sample**

The study population comprised teachers and house mothers who had worked in the schools for a period of three years and more, as well as parents who had enrolled their children with intellectual disability in the three selected schools. The researchers were interested in teachers who had longer work experience in their respective fields. In all, there were 30 study participants: 12 teachers, 9 parents and 9 house mothers.

House mothers are women who work in the selected special schools as helpers, and assist the pupils with activities of daily living. Simple random and purposive sampling techniques were used to select the participants. Purposive sampling technique was used to select the teachers and house mothers who could provide relevant information about their roles and the support systems available to them. Simple random sampling technique was used to select the parents whose wards were enrolled in the selected schools. The researchers visited these schools during Parent-Teacher Association (PTA) meeting days to interview the parents. Each of the parents present was given a piece of paper on which to write their full names. These papers were folded and put in a bowl, shaken, and then one of the researchers randomly picked 9 names (3 parents from each school).

### **Data Collection and Instrument**

Face-to-face interviews with the three sets of participants - teachers, parents and house mothers - were conducted at the three study sites. Individuals present during a single interview included one researcher (interviewer), one participant and one research assistant (to take notes). An audio- recorder was also used during the discussions. Each interview lasted for approximately 40 minutes.

In-depth interviews were held, using an interview guide to collect data from participants. The interview guide was given to the Committee on Human Research, Publications and Ethics of the Kwame Nkrumah University of Science

and Technology for scrutiny, after which a pilot study was conducted in two special schools (New Horizon and Dzorwulu Special Schools) in Accra, Ghana, prior to the actual study. Interviews for the head teachers and teachers were conducted in English while Twi language was used to interview the house mothers and parents/guardians.

### **Data Analysis**

The audio-recordings in English were transcribed verbatim by the researchers, while the recordings in Twi Language were given to experts at the Department of Modern Languages, Kwame Nkrumah University of Science and Technology, to be converted to English transcripts. To ensure consistency, the researchers compared the transcribed data with the notes the research assistants took during the interviews at the study sites. All the transcripts were then coded by the 3 research assistants, under the supervision of the researchers. The researchers studied the coded data and identified the dominant themes, based on the research questions. They used both emerging and deductive approaches to compare their respective summaries, and then merged the major themes. Extra readers were invited to help resolve any differences between the researchers' summaries. Direct quotations of some of the responses were used to support the themes.

### **Ethical Considerations**

Ethical approval was 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. Participants were told that participation in the study was voluntary and they were free to withdraw from the study at any time. They were assured of confidentiality and anonymity, as no information was collected on possible identifiers such as names, telephone and house numbers. Readers can obtain the full data of this work from the Centre for Disability and Rehabilitation Studies under the Department of Community Health, School of Medical Sciences, Kwame Nkrumah University of Science and Technology.

## **RESULTS**

The findings revealed that majority of the participants were below the age of 50 years. In terms of education, it was found that most of them had obtained their first and second degrees (undergraduate and post graduate) (the teachers and

parents), while a few had studied up to middle school (the house mothers). More females took part in the study than males, partly because the house mothers were all females. Again, the results indicated that majority of the teachers and house mothers had worked in the selected schools for a period of 6 years and more.

**Table 1: Demographic Characteristics of the Respondents**

Variables	Frequency (N=30)	Percentage (%)
<b>Status of Caregivers</b>		
Teachers	12	10
House mothers	9	30
Parents	9	30
<b>Total</b>	<b>30</b>	<b>100</b>
<b>Gender</b>		
Males	9	30
Females	21	70
<b>Total</b>	<b>30</b>	<b>100</b>
<b>Age Group</b>		
30-39 years	11	37
40-49 years	10	33
50-59 years	9	30
<b>Total</b>	<b>30</b>	<b>100</b>
<b>Educational Status</b>		
Middle School Leavers	9	30
Senior High School	6	20
Tertiary	15	50
<b>Total</b>	<b>30</b>	<b>100</b>
<b>Work Experience (Teachers and House Mothers)</b>		
3-5 years	8	38
6 years and above	13	62
<b>Total</b>	<b>21</b>	<b>100</b>

Source: Field Data, 2016

## The Role of Parents as Caregivers

Parents perform several roles as primary caregivers of children with intellectual disability. These include taking care of physiological and emotional needs, visitation and communication, as well as provision of educational materials.

**Physiological and Emotional Needs** - Parents indicated that it was their duty to provide their wards with basic needs such as clothing and good food, and ensure that they received plenty of affection. The general perception was that their main role as caregivers was to provide whatever was required for the daily upkeep of their children. Some of the parents remarked:

*“..... As a parent, I believe I have to make sure that he does not lack clothing and provisions. I have to provide him with everything that he needs to make him feel happy such as ensuring constant supply of his basic needs”* (Parent, individual interview).

*“.....for me, I believe providing physical needs like finance, clothes and provisions, are the most important thing and not visiting”* (Parent, individual interview).

**Visitation and Communication** - Another major duty for parents was to visit their children regularly and maintain constant communication. In one selected special school, parents were expected to visit their wards at least three times during a term. In one of the other schools, visiting could be done every day. The parents visited their wards four to six times per term. The reason for the frequent visits, according to the parents, was to ensure continuous family-level interaction. One of the parents said:

*“..... I have to always pay a visit to the boy to ensure that he is fine...I believe visiting my ward enables me to know the needs and problems of my son...it also helps me to monitor the progress of my son”* (Parent, individual interview).

**Provision of Educational Material** - Another role played by parents was to provide educational material such as books, pens, cardboard, leather, wood, beads, school uniforms and other teaching and learning aids. They were of the view that it was their responsibility to provide training material to enhance effective teaching and learning for their children. A parent said:

*“...If we parents claim that we are responsible and do not want our children to become burdens on us, then aside providing for their feeding needs, toiletries, clothing and medical, we have to make sure that the materials that they need to learn their vocations are also provided on time”* (Parent, individual interview).



## The Role of House Mothers as Caregivers

House mothers perform several roles as primary caregivers, such as ensuring that pupils are in good health, assisting them to perform activities of daily living and monitoring them to ensure their safety.

**Health** - House mothers contribute to the health and well-being of the children by making sure that the pupils are well-fed, free from danger; and have enough sleep. The study revealed that house mothers had been trained to provide first-aid treatment and to detect symptoms of common ailments such as malaria for further treatment by health professionals in the hospital. One of the house mothers said:

*".....I perform the role similar to that of the biological parents of the pupils. My role includes making sure the pupils eat on time, have adequate sleep, and everything that ensure that the pupils have excellent well-being, apart from spiritual protection which is God's role" (Housemother, individual interview).*

**Supporting with Activities of Daily Living** - The findings revealed that the house mothers helped the pupils to put into practice the functional and daily living skills they had learnt in class. They guided the children to perform daily tasks such as cleaning teeth, washing clothes, bed laying, observing personal hygiene, toilet training, personal grooming, communication skills, and identification of items belonging to them such as their school uniforms. One of the house mothers asserted:

*"..... We guide them in the morning for them to take their baths, brush their teeth, dress up and prepare them for class" (Housemother, individual interview).*

Another house mother added:

*"....I always ensure that they wash their clothes and lay their beds themselves..... Those who find it difficult to do these activities are guided in order for them to learn it well" (Housemother, individual interview).*

**Monitoring to Ensure Safety** - It was revealed that most of the pupils had behaviour disorders which made them sometimes get into fights and throw objects like stones. All the house mothers were expected to be present wherever the pupils were, to ensure their safety at all times. One of the house mothers said:

*".....Some of the pupils are hyperactive and have behavioural disorders which make them behave strangely and aggressive. Sometimes you will hear them cry from afar*



*and I have to quickly rush there to make sure that they don't injure themselves... Else if the school authorities find out, I would be blamed" (Housemother, individual interview).*

### **The Role of Teachers as Caregivers**

The teachers mainly impart functional skills to the pupils and support them financially.

**Imparting Functional Skills** - Most of the teachers considered themselves as caregivers because they impart life skills, gross motor skills, fine motor skills and communication skills to the pupils, as well as activities of daily living skills by employing task analysis. A teacher remarked:

*".....I am a caregiver because a caregiver is anybody who is found in the peripheries of this institution. I teach daily living skills which is part of caregiving. I train the pupils so that they become functional and independent. Independent is not all about securing jobs but also one's ability to wash clothes, brush your teeth, self-care and being able to mix up with other, and I teach all these as a teacher" (Teacher, individual interview).*

*".....I am supposed to be in this class with an attendant who will see to it that pupils who defecate are cleaned, those who drool are cleaned up and provide other needed assistance when necessary. It is unfortunate that I don't have any attendant to support me. I clean them up when they defecate and drool, and this has been very challenging for me" (Teacher, individual interview).*

**Financial and Emotional Support** - Although it is the responsibility of parents to provide the financial and material requirements of their children, the study revealed that teachers sometimes supported some of the pupils whose parents failed to meet their needs. Contrary to the statements by the parents (that they provide for the financial needs of the children), some teachers mentioned that there were parents who paid little attention to their children. One of the teachers said:

*".....It is very pathetic that majority of the parents of these pupils seem not to care about what their wards learn here. This is because all that they know is to buy their provisions, clothes, toiletries and give their wards upkeep money without including training materials" (Teacher, individual interview).*

Another teacher added:

*“.....I see them as my children as well. So I support some of the pupils whose parents have abandoned their educational and training needs. Some of the things I support them to buy include leather, cardboards and sometimes cloth for their practical works. This is difficult though, but I manage”* (Teacher, individual interview).

Again, the teachers indicated that the pupils became very sad when they ‘miss’ their parents. This results in not participating in class, and they cry and break down emotionally. The teachers said that they provided emotional support to children in such situations through ‘pampering’ techniques. A teacher explained:

*“.....Sometimes, some of the pupils miss their parents to the extent that they fail to follow instructions. In that case, what I do is to call the pupil’s parents for him or her to interact with them. Also, I draw them close to me sometimes and I tell them sweet words with the assurance that their parents will visit them soon”* (Teacher, individual interview).

### **Available Support Services for the Caregivers**

Majority of the parents asserted that they did not receive support of any sort from school authorities, non-governmental organisations or the central government. They added that no workshops were organised for them. However, a few parents said that sometimes, during Parent-Teacher Association Meetings, they were taught how to care for their wards. A parent asserted that:

*“.....Honestly speaking, no periodic training programmes are organised for we the parents. ...Sometimes during PTA meetings, the teachers educate us on the need to have affection for our wards”* (Parent, individual interview).

The study revealed that no training programmes or workshops were organised for the house mothers, either by the Ghana Education Service or the school authorities. For instance, one of the house mothers reiterated:

*“....We don’t receive any kind of support from the school or the government. ... In terms of training programmes, no training programmes are organised for us at the moment. ... No additional money is received apart from our salaries, which is very small...It is the fulfilling nature of the work and the passion we have for the work that keep us going”* (House mother, individual interview).

Also, all the house mothers stressed that they need periodic training in order to be updated about modern trends in caregiving. They added that relying on their experience and observation alone was not the best way to render quality care to the pupils. A house mother said:

*"....We learn from experience. That is, we observe the child to know the child's behaviour in order to know how to cope and handle him or her and this is not good enough...we need advanced knowledge and skills to be able to cater for the pupils effectively" (House mother, individual interview).*

The study revealed that no periodic in-service workshops were organised for the teachers, apart from the knowledge and skills they acquired many years earlier during their school days. A teacher asserted:

*"..... Neither the school nor any other organisation organises in-service programmes for us. It might seem surprising to you that I have not participated in any training programme ever since I completed school. .. Sometimes I take the initiative to learn online to get acquainted with modern methods of teaching pupils with ID" (Teacher, individual interview).*

However, a few had attended training programmes with a view to enhancing their skills and knowledge on teaching and caring for pupils with intellectual disability. They funded the cost of attending these programmes themselves, without any support from either the central government or the school authorities. For instance, a teacher remarked:

*"...I fought to attend a training programme which was organised by some whites from the College of Education, Columbia University, and I was given skills in teaching them how to identify and sort their names, like names on shirts or dresses. I see training programmes to be very important but some are not organised for us" (Teacher, individual interview).*

## DISCUSSION

Parents spend most of their time attending to the daily and emotional needs of their wards because the children's adaptive functions like reasoning skills, interpersonal communication skills and personal care are affected as result of their condition. This is in line with the report by the American Psychiatric Association (2013) which stated that persons with disabilities have affected adaptive functioning in communication, social judgment, memory, personal

care, self-management, home care, learning, self-direction and difficulty in undertaking daily living activities. Therefore, parents have to constantly care for their wards to help promote holistic well-being.

It is a pity that some parents fail to visit their wards in the boarding house very often. These children, because of their impairment, need their parents to ensure that they receive quality care from both the school authorities and the house mothers. One reason for infrequent parental visits, especially to their wards with intellectual disability, is the perception that such children are unlikely to become successful academically, financially and economically. Another reason could be the parents' own low educational levels, which fosters their tendency to link disability with curse, disease and other religious beliefs. This is in line with the views of Desforges (2003) that parents who are hooked to traditional beliefs and have low educational backgrounds are likely to not get involved in the education of their wards with intellectual disability.

Regarding the role of house mothers, it is difficult to categorise them as either formal or informal caregivers because, according to the National Alliance for Caregiving (2004), formal caregivers are trained individuals and professionals, including healthcare providers, who render care and are paid for their services. The house mothers could be described as the 'second parents' of the pupils. Their role is to ensure that all pupils are healthy, that they are safe, and to provide assistance and train them to perform activities of daily living. Since most of the pupils have profound and multiple intellectual disabilities, they are unable to undertake basic activities such as cleaning, bathing, washing, communicating, personal hygiene and grooming, which makes the assistance of house mothers very important. Although most of the house mothers are not professionally trained, they have learnt through experience to promote quality care for the pupils and monitor them to stay safe. Unfortunately, with no formal training in caregiving and without fully understanding the condition and needs of the pupils, they would not be fully equipped to cope with the associated challenges, possibly leading to lapses in performance. On the part of teachers, it could be said that their responsibilities of imparting functional skills to the pupils, providing emotional support, assisting pupils with activities of daily living and providing financial support to the needy, are all geared toward making life comfortable for the pupils. For effective teaching and learning, teachers are supposed to add affection to the teaching and learning process. The finding that teachers provide emotional support corresponds with the assertion by the State University of

New York College (2015) that teachers are expected to treat pupils with love and respect, motivate them to repeat right behaviour, and correct wrong actions. Failure to add love and affection to the training process could make the pupils withdraw from class activities and throw tantrums.

Moreover, it is obvious that providing financial support is not the duty of teachers. However, because some of the parents fail or feel reluctant to fulfil their responsibilities, teachers are compelled to take this on themselves. In the process of imparting functional skills to the pupils, task analysis (breaking down activities into smaller portions for pupils to easily assimilate and accommodate what is taught) is adopted. This finding corresponds with Baine's (1991) suggestion that trainers should break every task that they want their wards to learn into small units.

### **Support Systems available for the Caregivers**

From the findings of the study, it can be surmised that support services such as training programmes are crucial when it comes to building parents', house mothers' and teachers' capacity to provide education for children with intellectual disabilities. This supports the claim by Ashwell and Ridley (2004) that information is important in caregiving because it helps to address some of the numerous challenges that all caregivers encounter. It is very unfortunate that in the special schools selected for the study no periodic training programmes are organised for the caregivers, especially for parents and house mothers. This may lead to caregivers not knowing their specific roles and how they can cope with the challenges associated with caregiving. This is the reason why WHO (2012) recommended that support services in the form of workshops should be organised for caregivers. Again, a resource centre can be designed for the caregivers, to enable them to obtain easy access to information about caring. As Carpinter and Irwin (2000) opined, there should be a known and approved database for caregivers where they can access information to build their capacity for effective caring.

The finding that the caregivers are not motivated in any way is very disturbing. Although they have passion for the work (intrinsic motivation), their commitment level could decrease as time goes on. The caregivers, especially house mothers and teachers, need extrinsic motivation like financial support to be able to wholeheartedly deliver quality care for a long period of time, as recommended by WHO (2012). The finding that the house mothers are the least paid in the

special education sector, with no extra duty allowance, points to the possibility of reduced interest in their work, which can further lead to shoddy care and a high turnover rate. When house mothers resign from their jobs frequently, the health and well-being of the pupils would be compromised, resulting in several health complications in the long term.

## CONCLUSION

The study revealed that the majority of parents know their responsibilities but are reluctant to put them into practice. Most of them do not see the need to frequently visit their wards after providing for their basic needs. The responsibilities of the house mothers include ensuring that all the pupils are healthy; ensuring the safety of the children; providing assistance; and training pupils to perform activities of daily living. However, it was discovered that most of the house mothers were not professionally trained. Teachers performed several roles which included imparting functional skills to the pupils; providing emotional support; assisting the pupils with activities of daily living; and occasionally providing financial support. Caregivers have no access to support systems such as training programmes, workshops, financial support and other relevant incentives.

### Limitations

The study focussed only on special schools for persons with intellectual disabilities in the Kumasi Metropolitan area, without including special schools in other regions of Ghana. Hence the findings may not be representative of the situation in the country and cannot be generalised.

### Recommendations

Based on the findings of the research, the following recommendations have been made.

- Authorities of special schools for pupils with intellectual disability should organise workshops or training programmes for house mothers and parents of pupils with intellectual disability. This would enable parents to understand and appreciate the condition of their wards, which would in the long run make them shoulder their responsibilities effectively.
- The Government of Ghana, through the Ministry of Education and the Ghana Education Service, should periodically organise training programmes for



teachers and house mothers of special schools for persons with intellectual disabilities in the country. This would help build the capacity of teachers and house mothers to adopt modern approaches to caregiving.

- Further studies should be conducted on the role of the Government of Ghana in promoting education for persons with intellectual disabilities.

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