

## **Challenges in the Care and Management of Developmental Disabilities in Ghana**



**CENTER FOR LEARNING AND CHILDHOOD DEVELOPMENT**

**ADVANCING RESEARCH, PROMOTING LEARNING AND SAVING LIVES**

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The Center for Learning and Childhood Development – Ghana (CLCD) is a research-based, non-profit organization that designs and implements solutions for children's survival and development.

We partner with organizations and institutions to pursue priority research, programmatic and policy needs in early childhood development.

The Center focuses on the urban poor and rural residents, the population with poorer early child development outcomes and where research indicates the greatest impact could be made.

Currently, its program areas are in maternal, neonatal and child health, developmental delays and disorders, early child education and basic education.

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# Challenges in the Care and Management of Developmental Disabilities in Ghana

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## Background/Significance:

Developing countries like Ghana bear a disproportionate burden of developmental delays and disabilities among children. Approximately 80% of those living with developmental disabilities and delays live in developing countries, and the number of children being diagnosed is rising. The ability of caregivers and health workers to provide consistent and adequate care to children living with developmental disabilities and delays (CLWDD) in Ghana is limited by a diverse array of challenges within and outside of the medical system. The goal of this study is to provide a comprehensive overview of these challenges, and to suggest evidence-based recommendations for enhancing the care management and survival of CLWDD.



## Specific Aims:

- Describe the lived experience of caregivers with CLWDD in the home, community, and hospital settings.
- Identify key knowledge gaps in diagnosis, treatment, and referral of CLWDD.
- Conduct in-depth assessment of knowledge gaps in care management for three common developmental disabilities: autism, ADHD, and cerebral palsy.

## Methods:

### *Setting & Participants:*

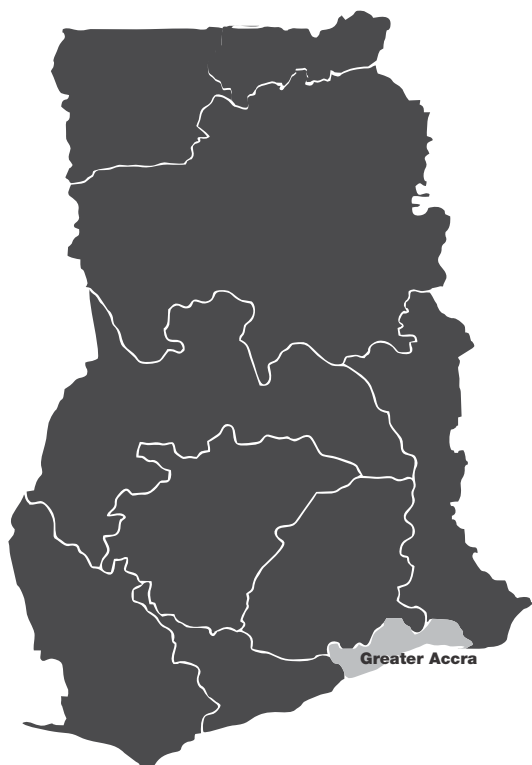
This study was conducted with the participation of caregivers of CLWDD and health workers across five government hospitals within the Greater Accra Region of Ghana.

## *Methods and Analysis*

Caregivers took part in focus group discussions whose general topics included: societal perceptions of developmental disability, the availability and accessibility of current support systems, and major challenges encountered by caregivers. Specialist and non-specialist health workers participated in a survey to assess their knowledge of developmental milestones and developmental disabilities as well as their experience with identifying, treating, and referring CLWDD. In addition, health workers were asked to participate in a free-listing activity where they recalled a list of developmental disabilities and delays, their causes, possible interventions, and referral options. Finally, a sample of health workers participated in an in-depth interview whose general topics included: common developmental disabilities seen in the hospital, societal perceptions of developmental disability, current supports and tools, and major challenges faced by health providers who care for CLWDD. Surveys and free-listing exercises were analyzed using descriptive statistics. Thematic analysis was applied to focus group discussions and in-depth interviews.



Method	n (Sample size)
Focus group discussions	4 groups
Survey	95
Free-listing	40
In-depth interviews	33



**Focus group participants**

- Caregivers with children with cerebral palsy
- Caregivers with children with down syndrome
- Caregivers with children with learning difficulties

**Survey and Free-listing participants**

- Nurses, Midwives, Medical officers, Physician Assistants, and Pediatricians

**In-depth interview participants**

- Child Health and Disability Specialists
- Nurses, Midwives, Medical officers, Physician Assistants

## Results

### Social Issues

#### Stigma

**Children with developmental disabilities are negatively associated with spiritual forces and mothers are pressured to kill their children.**

“ I had people saying it was a **spiritual matter** and so we took the baby there for prayers. Later, I was told I had to take the baby to the fetish priest and so we went there as well. People assumed it was a **river child** and so we should go and **dispose the baby**. I really went to places like the prayer camps, shrines and all that, it was later that I came to realize that all these were untrue.”

“ It becomes more difficult when the family is against your keeping of such baby. They tell you to go and damp [kill] the baby since it is a **river child** and might turn to snake to bite you one day....They would tell you **if you do not bid farewell to the child, one day your life will be miserable** since the child is a **river god** and can turn into something to be draining your money.”

“ I would want to say that even the people that we come across lead us to grieve more. Some of them might be friends, others too are not. They would look at you and say, **if it's true you worship God, would you go and have such a snake baby?** When you hear all these and do not stand firm or look up to God, you might go and damp your baby.”

“ It was not easy even with the way people will look at the child when they see the child. My mother told my husband that there was this pastor in our home town who said **we should bring the baby so he may wish the baby a farewell and damp the baby away.**”

#### Stigma leads to economic deprivation and social castigation

“ At times, **when you have such children and you sell food**, people do not buy. At first they patronize it when they have not seen the child but immediately they come across your child, they quit. I am talking from experience. I used to sell beans at 'Brong Ahafo' (a region of Ghana). They used to patronize the food but stopped patronizing when I came for my child from 'Accra' and took the child to with me to 'Brong Ahafo'. It was from the house that I lived that one member (tenants) went and broadcasted that it's my child who stirs the beans and since she drools, some have been pouring into the cooked beans. In fact for three days, **no one came to buy the food**. When it happens like that **it becomes pathetic and very sad as well as difficult to even take care of the child since there would not be money to do so**. Their medicine too is quite expensive and demands us to work before we can afford to purchase it.”

“There is this pastor that I visited around Kumasi. It has not even been two months since he said he is a pastor. We went and when we were leaving, **we had spent more than seven million Ghana cedis** meanwhile they are not able to bring the deliverance needed. Mostly it even worsens the situation when leaving.”

“I was tagged '**the witch**'. You see all kinds of things, [They say] 'maybe she has used her child for some ritual and a lot of things'. They will be nice to you when they see you but behind you...so for my home, nobody comes there; even when I'm there [or] I'm not there...Don't come, [I] don't need you in my home. **You come and see my child's face and say a lot**. Some just want to hold the child not because he/she has something to say but just to rub their hands around the child for the child to react just to know whether the child is human or something else.”

“...another mother was telling me that they made her – she went to one church to look for solution for her child and the pastor said she has sinned that's why she has the child and the pastor dragged her and her husband to the front of the church for them to apologize for something she didn't know.”

## Broken Relationships

**Mothers of children with cerebral palsy are abandoned by their spouses and left with the huge burden of caring for their children on their own.**

“We mostly have those men we give birth with to such children **running away and leaving us with the babies**. They mostly give the excuse that in their family, such ailment do not exist there and that it was our wombs that the children were born from. Since the children came from us, we may know the source of such children. This pushes us [to] send the child wherever we are going since **you would not get care takers when you leave them behind or when you leave them home**, you might come and meet something more painful. This demands us to always pay special attention to them and take them along wherever you are going. **This brings a lot of burden to us the mothers.**”

“...due to these children, there are broken marriages. **The man would tell you to send the child to wherever you got it from and this normally leads to the breaking of the marriages**. Also, when you have children like these, you can get someone who has not met your child before to marry you but the marriage normally breaks immediately when they find out what kind of children you have. So with this situation, if God is not strong on your side, you won't have anyone to marry.”

“It's very painful when you have four boys and your only girl child happens to be in this situation. Such children are lovely especially when they smile so it makes it difficult to throw them away. It becomes very difficult **when you do not get the support from your husband at that stage, you may want to poison yourself and die**. It is very difficult.”

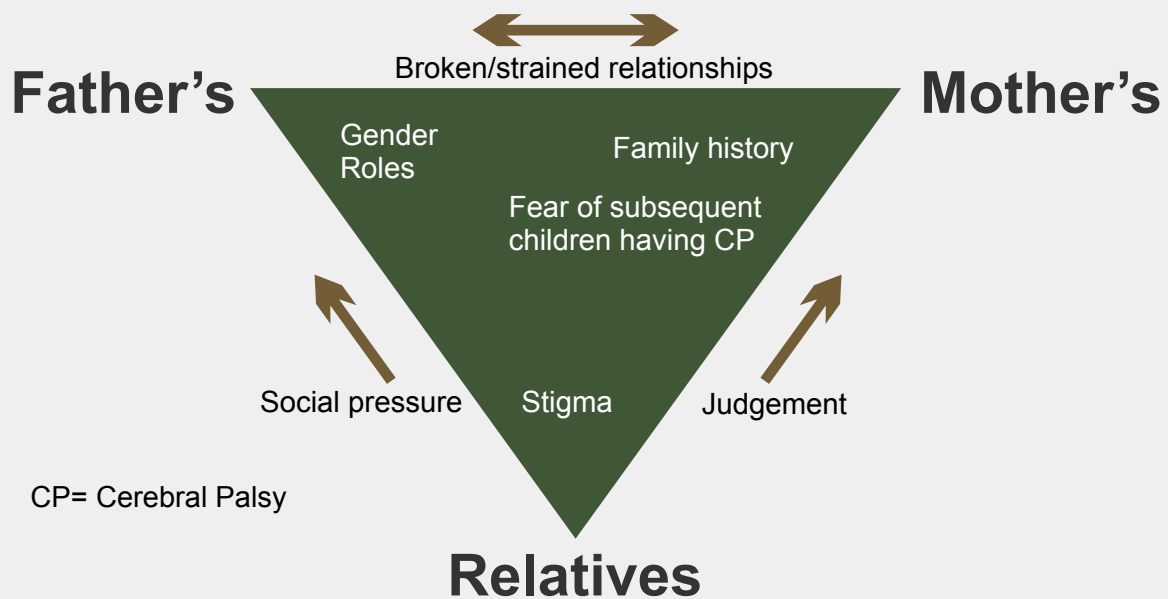


Fig 1. Conceptual framework of factors leading to strained relationships between couples after diagnosis of a child with developmental disability.

## Education

### Discrimination

#### **CLWDD are routinely denied admission to schools.**

“One of the schools I checked out told me **unless the child is able to talk and even say I want to go to toilet they can't be admitted.** But with me, the child makes signs when it's time to go to toilet. Mostly I allow the child to go to toilet in the 'pampers' since when the child sits on the chamber pot it would take forever for the child to be done. Please it's a problem since we have to wait until they talk before admissions to schools and this further delay their studies”

“**No school wants to accept our children.** Some of the children though they have walked, they drool and so when you take the children to the school they would be wondering what class will benefit such child. The headmaster will not accept the child. Those who are polite will tell you there is no admission but those who are not polite will tell you **there is no admission for such a child.** In fact it's not easy.”

“Most of them [CLWDD] like schools but cannot get admission to schools. When my child's mood swings, what she says is that she would like to go to school but **since there is no school for her, she is made to stay at home.**”

### Inconsistent schooling

#### **CLWDD who are admitted to schools are often withdrawn due to the inability/unwillingness of teachers and administrators to properly care for them**



“I took mine to a school and by God's grace mainstream school accepted her. I decided to check up on her every afternoon since she was the only cerebral palsy student. I discovered they normally carry the other children to join other classes leaving her alone in the class. That was what the teacher was doing. The head mistress did not even know but on my third visit to the school and seeing the same thing happening to my child, **I said no way and redrew my child from the school.** So now she is with me because when you take her to another school, no school accepts her since **the teacher would say they do not have time for only that one child** leaving the rest behind.”

“With my child, he got admission into where my other children were schooling and so I became a bit free. But due to financial constraint I had to change my children's school (the twins) and left the one with the issue at the old school but not knowing, **the headmistress had informed the teacher I should not bring the child to that school again** without informing me. In all, I decided not to question the headmistress though it worried me. **So now the child is with me at home.**”

## Health

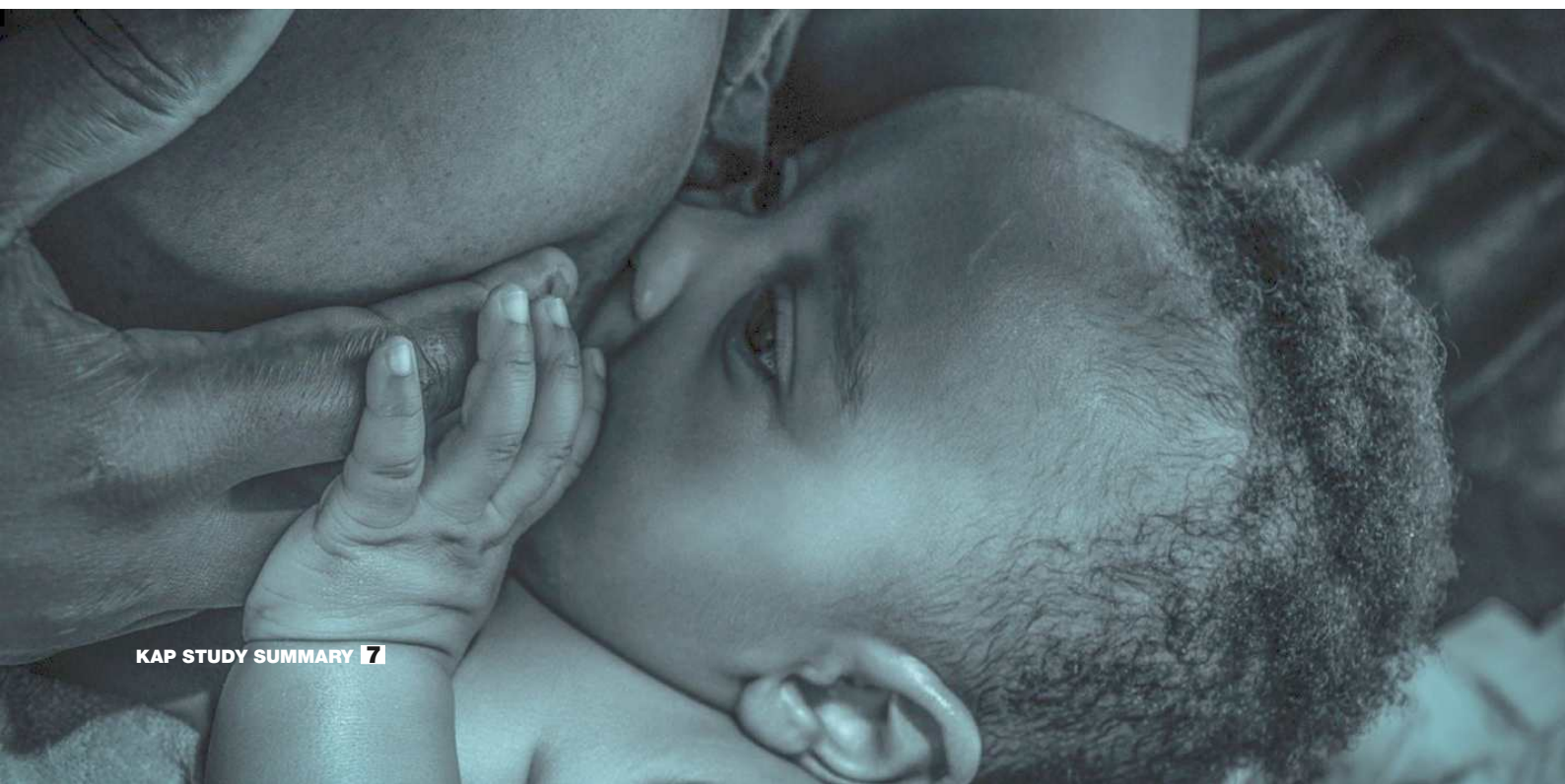
### Problems with diagnosis

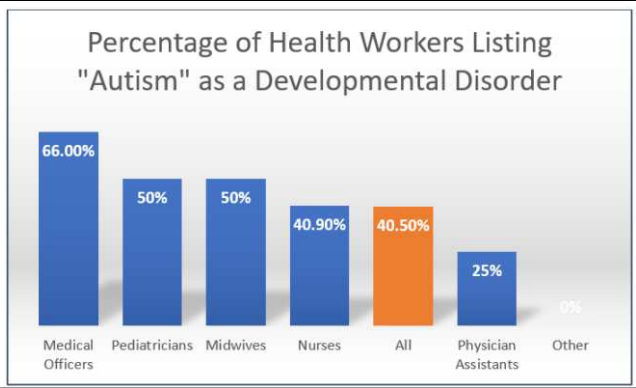
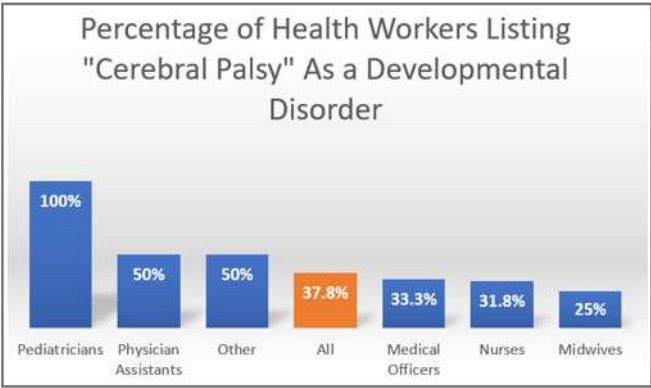
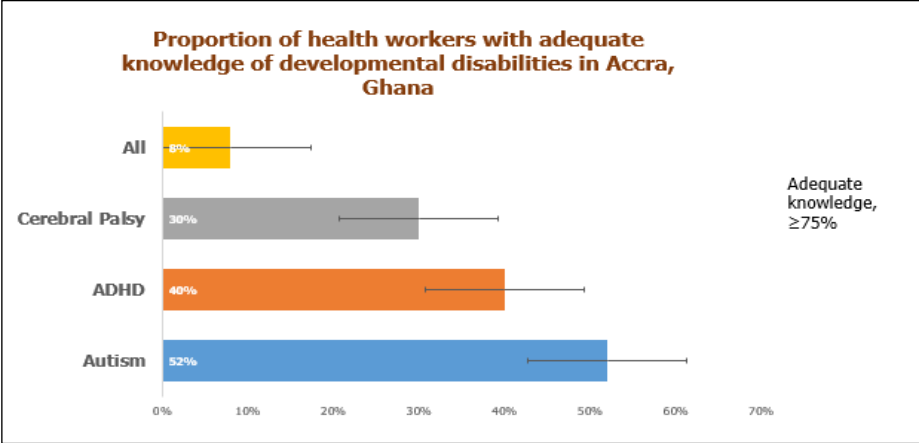
Health workers are inadequately trained to recognize symptoms of developmental disability

“...those nurses who have not seen the condition before will just give **the wrong injection** to your child all in the name of they seeing the child's case as an emergency - meanwhile it is not that.”

“So I remember one time, I was going for review and I told the doctors, that I realized my girl's neck is still falling back. I was getting worried because the breast milk wasn't coming and it was affecting my daughter's weight. The response I had was, **'madam go and give your child food and stop what you're telling us.'** So at that point, I also decided that we won't go to the clinic again. It was my husband's friend whom we met; she had also come for her review. When she saw my child, she said no your girl has CP. So the first time we heard CP was from a mother! Not a medical person ... a mother!”

“**I got to know that [my child] had cerebral palsy before my doctor even** ... because I kept asking my doctor but he refused, I don't know whether he thought that when he tells me I will feel devastated or something.”





**3%** of health workers listed **ADHD** as a developmental disorder.



## Knowledge of health workers on treatment and support services for cerebral palsy (CP) children



**15%** of health workers named a specific hospital or clinic that provides CP care



**0%** of health workers listed a school/care center for CP children or specific providers or NGOs that provide CP care



**54%** of health workers listed physiotherapy for treatment of CP



**85%** of health workers did not list speech therapy, support groups, vision or hearing assessments as part of needed care CP children

## Knowledge of health workers on treatment and support services for CLWDD:



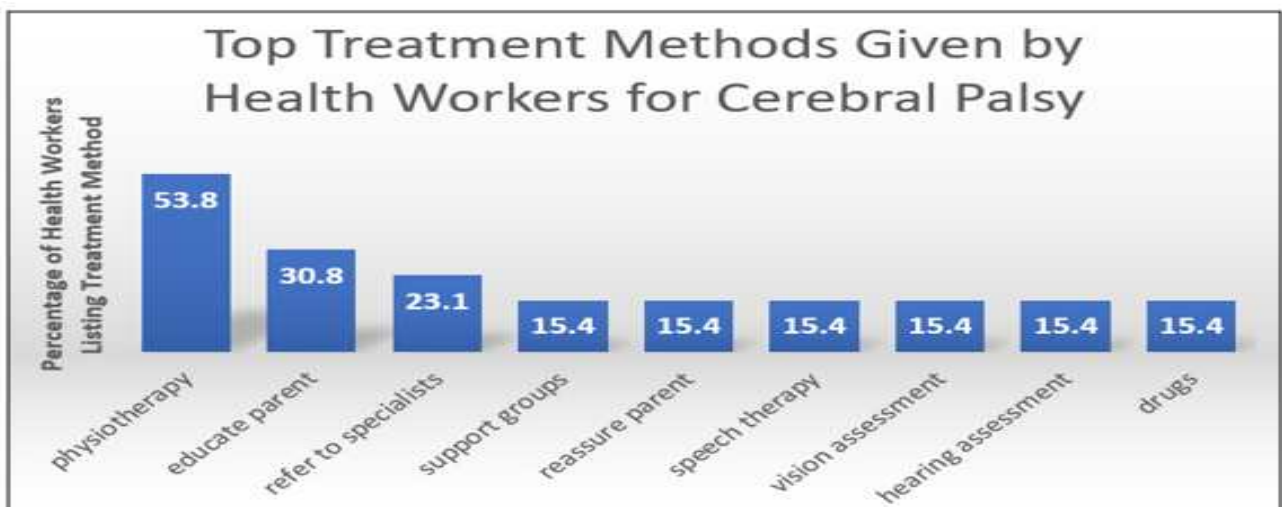
**22%** of health workers named a specific hospital or clinic that could provide care for children with developmental disabilities



**14%** of health workers named a specific school/care center that could care for children with developmental disabilities



**3%** of health workers named a specific NGO that could provide assistance for children with developmental disabilities





## Caregivers have challenges in identifying delays and disabilities early in Children when they are born

*“In Ghana, when they are born, they name them after the first week, **so they keep them tightly wrapped** until the naming day. The day they take off their clothes, they see that they are very yellow and that’s when they discover that **the child is very jaundiced**. Then, when they bring them here, it’s like **‘Oh my God! Why didn’t you do anything?’** They say **‘Oh we didn’t see, we didn’t know.’** Then the child gets damaged—the **jaundice level is too high for the brain**, and they end up in the neuro clinic with cerebral palsy.”*

*“I thought my child was normal. **People will say ‘ah your child’s neck is not stable,’ but I couldn’t connect it to anything.** Meanwhile, I was very punctual at the weighing clinic. Every month, I’ll go and weigh my child and ask questions, but nobody said anything till she was nine months old. I was going for her inoculation and I saw that another person’s nine months baby was there. Her baby could stand and mine couldn’t, so I felt that there was a problem. That was when I decided to go to the hospital to check.”*

*“Most of the time, **they come quite late, unfortunately.** When, maybe **the child has been in school for maybe four-five years and is not doing well**—sometimes later, much later. Then they send them to us. Mostly because the child is not doing well in school (that’s the most common complaint) or, the child is not talking, or the child has seizures. **So, that’s the way they come to us: self-referred.**”*

## Problems with treatment

### Caregivers face significant financial barriers when seeking care for their children; Ghana's National Health Insurance Scheme has limited capacity to cover the costs of caring for children living with developmental disabilities

*“As I said earlier, when I gave birth I was taking the child to 'Nsawam government hospital' and the doctor told me to have a transfer to Korle Bu. Before he told me to go to Korle Bu, he asked me if I was financially sound. If not I should wait and prepare financially before taking my child there. What does it mean? It means **if I don't have money my child cannot receive the appropriate care.** Truly when I came, it cost much to receive care from Korle Bu so **up to now, I have not been able to send the child to the hospital.**”*

*“Most of the health institutions have not got a special way of attending to people with Cerebral palsy. You join the normal queue meanwhile when we meet with government, they tell us if you have a cerebral palsy child, you do not need to join any queue since there are special package for you but it's the opposite when you visit the hospital. **The health insurance too does not cover up** and even if it does, you would have to join long before you can use it to receive care.”*

*“**It is few hospitals that accept health insurance for their treatment.** All the other ones need to be paid by you. Just imagine if you have five children ( yeah I have 5 children) and you have to be taking this child for physio three times a week. You have to get money for your in-and-out transportation, 7 Ghana Cedis or more to pay for the session and all these cannot or will be very difficult to adhere to if you do not have work to fetch you this money. Imagine your husband has also run away and left you behind with this baby, if you refuse to take the child for physiotherapy too, the child will have the bones stiffen and will not be able to walk or do anything again. **Physiotherapy is a big issue and few of the community can afford it.** Sometimes you will meet the children having stiffened bones and all that simply because the parents could not afford physio and also buy their medicine and food for their growth.”*

### Tension between caregivers and hospital staff drive CLWDD out of medical care

*“She [the doctor] just took my folder and asked me to go in for another head scan. She did not even ask how the baby was faring or anything. So I told the doctor I just went in for a scan, then she said: 'I know but you go for another one before coming to see me.' To do the scan cost so much so in fact at that time, **I knew she was my devil. She really got me angry and because of her, I did not even step foot there again.**”*

*“They yell at the mothers when you go there [the physiotherapy center]. And actually at Korle Bu, my child laid in an incubator and just for that mere fact, I didn't want to go there. **They mistreat mothers. I didn't want to take my child to nurses who do not have the heart for such children, I didn't want to go.**”*

### Lack of resources leads to improper treatment for CLWDD

*“Some [health workers] are professionals but they cannot do physiotherapy well because for instance, at Korle Bu and 37 the standing frame is the same. **One standing frame for every child** - the children are different, their heights are different, their weight is different so you cannot put my child on the same standing frame with GP's child; **they have to be unique or adjustable, but they use a paper type and it's the same.**”*

## **Dissatisfied with the medical system, caregivers disengage and seek alternative options**

*“...with my child, when the illness started we first went to 37 Military Hospital. From there **my mother's friend took us to see a fetish priest**. He also did all he could and even stopped my child from eating so many things but all these were to no avail. We were then taking to another place where we spent much money but to no avail. **There was no drug at the hospital** and so I went to places. I travelled all the way to 'Wenchi' because I was hurt when the child's dad left with the reason that there is no such ailment in his family. **I visited various shrines** at 'Tachiman' and they all took huge sum of money without solving the issue. There was this man too from 'Sisala' whom they claimed could help but that even worsened [the situation] such that my child started 'rotten' such that when he breathed on you could not stand it. It smelled like rotten fish.”*

*“But the medications, honestly, I have stopped because when I give the medicine to my child, I notice that it is affecting her in a negative way rather than making her improve. So me, I have stopped going to Korle Bu because **my child's condition is deteriorating**. I told them last year, I told them, I told the **physiotherapists that I won't come there again** because it's not one person who works on the child. Today, if this person does it, the next time, another person will do it. I don't know if they study the child's history before doing it. Anybody who comes holds the child's hand or somewhere and starts massaging. They use shea butter. I realized that when I stay at home and do it with my child, I see improvement. I can play with her and get enough time for her rather than go to the physiotherapist and pay money only for her to get worse.”*

*“I saw that they [the doctors] were rather destroying my child so I stayed home, stopped work, and decided that this time, **I will rather learn from the internet and then apply it**. So I started going to the internet...”*

*“**I went to those cherubim and seraphim churches**...when they are dancing and jumping, you would also have to be doing same and you will leave there same or with a worsened state. Sometimes, they give you soap to buy for not less than five hundred Ghana cedis. **I took those steps when medicines were delaying me.**”*

### *Problems with referral*

#### **Most cases are referred to Korle Bu hospital, where numerous mothers have negative experiences**

*“...We came to Nyaho (a local clinic). It was this local clinic that referred us to Korle Bu physiotherapy. I remember when we got there, an Indian lady was there. She asked if I delivered at Korle Bu, I said yes, I delivered at Korle bu. The unfortunate thing is that my folder got missing...before I could realize, when I wanted to pick the folder, **we couldn't trace the folder again.**”*

*“I was at Ghana Canada hospital (private hospital) from the very day that she was transferred to Korle Bu. My husband would come for breast milk and send to her. When he sends it, they don't give it to the child. I learned they put it on top of the incubator and ants would gather around it. What also happened was that they couldn't find a vein to give blood to the child so they passed it through her neck. So her neck lay in one position for close to two months. **They were not looking after her. They didn't care, nothing!**”*



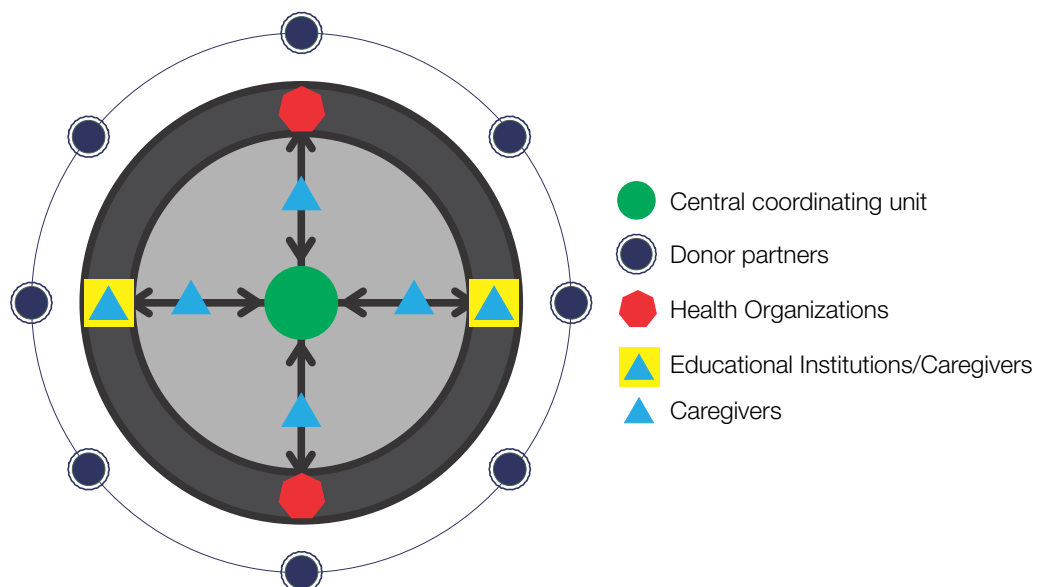
## Recommendations

- Create awareness about developmental disabilities and programs to reduce its associated stigma
- Remodel caregiver support groups to deliver paid and unpaid child care services, including teaching skills for school readiness, coping strategies, and best strategies to meet the children's developmental needs
- Provide counseling to affected couples to minimize rates of divorce and reduce caregiver burden among women.
- Develop a community-based or home-based physiotherapy program to increase access to care
- Improve capacity of educational institutions to properly care for CLWDD and include caregivers to provide support services to the children (e.g. feeding, toileting, exercise)
- Establish a referral/coordinating system for linking caregivers to existing services
- Create training materials and programs for health workers, teachers, and caregivers on developmental delays and disabilities
- Collect data on developmental disabilities in national, regional, and local child related surveys, including developing electronic data based systems at the health and educational levels

## Recommended Model of Care

### *Bicycle Model of Care Supporting Families with Children living with Developmental Disabilities*

The Bicycle Care Model is an integrated approach to improving care management for CLWDD in Ghana. Through a rigorously coordinated system of caregivers, health facilities, and educational institutions, the care model takes advantage existing support systems and services to promote care continuity and streamline care management in the home, hospital, and community settings. The Bicycle Care Model identifies essential stakeholders who are responsible for ensuring high-quality care management for CLWDD: health facilities, educational institutions, caregivers, and donor partners. A central coordinating unit provides foundational support for each of these stakeholders and ensures proper flow of information and resources between them. The items below are the responsibilities associated with each component stakeholder of the model:





### *Central Coordinating Unit:*

- Link caregivers and stakeholders to support systems and resources for CLWDD
- Produce and translate high-quality research, monitoring and evaluation data for advocacy, program development, and planning
- Produce regular reports on the quality of care provided in hospitals and schools for CLWDD
- Partner with existing government, non-government, and funding agencies (e.g..Ministry of Health, UNICEF, The World Bank to support comprehensive programs and policies aimed at improving care for CLWDD
- Create training/educational programs for caregivers, health workers, and educational institutions
- Promote effective evidence-based strategies for improving care management of CLWDD in home, hospital, and community

### *Caregiver Groups:*

- Participate in assisting CLWDD with activities of daily living (bathing, grooming, toileting, exercise, etc.) both in school and home settings
- Provide social support to caregivers with CLWDD and training on local strategies to improve the wellbeing of CLWDD
- Advocate on behalf of CLWDD
- Participate in training programs created by central coordinating unit
- Provide feedback to central coordinating unit about effectiveness of care provided in hospitals and school settings
- Refer and connect caregivers to health, educational, and support services

### *Health Facilities:*

- Deliver specialized care and facilitate primary care for CLWDD
- Integrate evidence-based recommendations into clinical practice
- Encourage training on developmental delays and disabilities as part of continuing education for health workers
- Disseminate educational services provided by central coordinating unit to other stakeholders
- Collect routine data on care of CLWDD

### *Educational Institutions:*

- Partner with caregivers to ensure appropriate care is provided for CLWDD in schools
- Encourage participation of teachers and administrations in training programs designed to improve care for CLWDD in school settings
- Disseminate educational services provided by central coordinating unit to other stakeholders
- Provide a nurturing, safe, and physically equipped environment to foster CLWDD's learning

### *Donors:*

- Partner with central coordinating unit and government agencies to enhance quality of care for CLWDD
- Hold central coordinating unit accountable for improved outcomes
- Use collective influence to advocate on behalf of CLWDD



### *Benefits of the Bicycle Care Model*

- Unify relevant stakeholders at all levels
- Provide opportunities for communication and feedback from stakeholders at all levels
- Provide economic opportunities for caregivers to work in schools
- Reduce caregiver burden by improving capacity of hospitals and schools to care for CLWDD



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