

Challenges that Parents of Children with Physical Disabilities Face in Providing Social Support to their Children in Inclusive Schools in Tanzania

ABSTRACT

It has been seen that although parental support is very important especially for the children with physical disability in inclusive education but children with disability could not get enough support from their parents. It is from this fact that the study explored the challenges that face parents in providing social support to their children with physical disabilities in inclusive education. The study was qualitative in nature, using a sample of four parents, four pupils and eight teachers who were selected purposively from two (2) districts of Katavi region. Data were collected through semi-structured interviews and were thematically analysed. Findings revealed that parents faced financial constraint in such a way that they could not afford the cost of buying mobility devices, medical services which were important for their children to adapt learning in inclusive education. It was found that pupils with physical disabilities could not use school latrines instead they spent a lot of time going back home for toilet services. This posed a challenge to the parents as it limits them from engaging in economic activities to raise their families' income. Moreover, pupils with physical disabilities were subjected to bullying and abuse since they could not defend themselves which adds more emotion burdens to the parents. Furthermore, the study findings revealed that family instabilities and separation was another challenge faced parents of the children with physical disabilities. Most of pupils who participated in this study were receiving social support from their mothers after their fathers run away left them with mothers who could not provide necessary support. The study concluded that, apart from great effort done by government and nongovernmental organization to create awareness to the community about children with disability, still large part of the children with physical disabilities face stigma, bullying, rejection with their biological fathers and unfriendly infrastructure especially latrines in inclusive schools. All these pose challenges to the parents in providing social support to their children with physical disability in inclusive education.

Keywords: inclusive education, challenges faced by parents, physical disabilities, social support

1. INTRODUCTION

Parental support is a very important factor for the academic success of children and even more important for the child disabilities. Kisanga (1) contends that apart from sending children to school, parents have a great role to play in the monitoring learning of their children and take necessary measures to make sure that their children achieved the best when they are sent to schools. Parental support is very important as it motivates and enhances academic achievement of respective children with disabilities (2). Children with physical disability (CPD) need more support to adapt school environment.

Physical disability is a physical condition resulting to inability to walk, point, or to make any purposeful movement which may interfere with daily performance (3). Mobility impairments can affect children in different ways like, someone may not

be able to move from one place to another, enter into a certain building or room, and perform a certain activity in such a way that they need supportive device. CPD, like other children with disabilities were discriminated in all aspect of social life including their right to education (4, 5). In different society these CPD disability were hidden as a result they missed their right to access education as other children (6, 5).

Nowadays, a big proportion of societies have started to recognise that children with disabilities are just like any other children and have the right to quality education so that they can make useful contribution not only to their own life but also to society and the nation at large. This has been enacted in different international and national policies, legislation, guidelines and conventions (7). Thus, the right to quality education to all children without discrimination was granted through inclusive education whereby children were educated in nearby schools (7). In the context of Tanzania, inclusive education is defined as an approach which transforms education system, including its structure, policies, practice and human resources to accommodate all learners in the mainstream regardless of their diversity needs without discrimination (8). Inclusive education involves adaptation and modification of curriculum contents, teaching and learning resources, teaching strategies and environment to ensure access to and participation in quality education for all learners regardless of their conditions without discrimination (7). Inclusive education is about how to develop regular school and classroom community that fit, Nurture, and support educational needs of every student, making the regular school a place where everyone belongs, accepted and is supported by his/her peers and other members of school community (9). In particular, the national policy of disability (2004) states that the government, in collaboration with stakeholders collectively will strive to provide a conducive environment for inclusive education which would accommodate the special needs of children with disabilities (7). Parents as among the key education stakeholder have responsibility to provide support to their children so that they can manage learning in inclusive education settings.

Inclusive education is more about equity than equality, that is children with disabilities need extra support so that they can cope and adapt learning in inclusive education. CPD require extra support with everyday tasks such as; getting out of bed, dressing, transportation to school, encouragement, advice and provision of assistive devices and equipment for better learning (10). Social support for the CPD and with intellectual disability is of important to enable them to succeed in inclusive education. Xu and Burlson (11), define social support as the assistance that people provide in order to help others to cope with life changes and situational demand. Xu and Burlson added that social support can be categorized into emotional support, network support, tangible support, and informational support. Emotional support refers to as offering of empathy, concern, affection, love, trust, acceptance, intimacy, encouragement, or caring. Tangible support refers to as provision of

financial assistance, material goods, or services. These forms direct ways on how people assist others. Informational support refers to the provision of advice, guidance, suggestions or useful information to someone.

Parents are expected to provide social support to their CPD in home and school context (12). However, different studies indicate that CPD are not receiving full support from their parents (2, 13, 14, 15). It was revealed that, other CPD failed to continue with studies because they do not have mobility device that could enable them to move around school environment (14).

While the issue of parent support to the CPD has been of increasing concern, only few studies have focused on challenges that parents of the CPD face in providing social support to their CPD in inclusive education. Thus, the current study intended to investigate the challenges parents of CPD face in providing social support to their children in inclusive education settings.

2. MATERIAL AND METHODS

The study employed a qualitative research approach. Gay and Airasian (16) argued that in order to achieve detailed understanding of a phenomenon a qualitative researcher must undertake an in-depth and in-context research that allows them the opportunity to uncover more subtle and less overt understandings. Qualitative researchers study things in terms of the meanings, attempting to make sense of or to interpret a phenomenon in terms of meaning people bring to them (17). Hence, the qualitative approach enabled the researcher to meet the parents in their real context (home place) that facilitated to capture rich, detailed and relevant information about the challenges parents of the CPD face in providing social support to their children in inclusive primary school contexts. The study was conducted in Katavi region. Katavi region was chosen due to the fact that it is a region with the lowest number of CPD enrolled in primary school in three consecutive years (18, 19, 20). This raised the interest to understand challenges parents face in supporting their CPD in inclusive education since they are the most important to initiate and support the education of their children. Sixteen participants from Mpanda Municipal Council and Nsimbo districts in Katavi Region were involved. This includes four pupils with physical disability. Four parents of children with physical disability, Eight teachers (four class teachers and four headteachers) of selected children. Face-to-face semi-structured interview elicited the challenges that parents face in providing social support to their CPD. The method provided the researcher with an opportunity to further ask unplanned questions that were triggered by the information provided by the interviewees to generate deeper understanding. The collected data were subjected into thematic analysis. Thus, triangulation across participants was used to build a coherent justification of the themes. Since the study involved minor (pupils with physical disability, who were under 18 years old), permission was sought from parents to allow their children to be interviewed. Names of participants were disguised and pseudonym names were used (S1, S2 ...

S4, were used to represent names of schools, P1, P2 ...P4 were used to represent names of parents, PP1, PP2 ... PP4 were used to represent names of pupils, R1, R2 ...R4 were used to represent names of head teachers while RR1, RR2 ... RR4 were used to represent names of teachers).

3. RESULTS AND DISCUSSION

Data were analysed in relation to the challenges parent of the CPD face in providing social support to their children in inclusive education.

3.1 Financial Problem

Financial problem referring here means inability of the parents with CPD to afford necessary basic needs. Analysis of data revealed that parents' financial hardship was one of the major challenges in providing social support especially tangible support to their CPD in inclusive schools. CPD in the present study they lived in poor families that could not provide them with any supportive mobility devices or special learning materials/device to enable them to cope with smooth learning in inclusive schools. The CPD claimed that they did not receive supportive mobility devices from their parents rather they received them from government and good Samaritans. Due to financial constraint, the CPD received less support from their parents. On the other hand, this may indicate that most of the parents of CPD had low income in-such a way that they could not afford the cost of buying mobility devices especially the expensive one, for example, wheel chair. This was confirmed by one parent who had this to say:

I could not afford the cost of buying wheelchair since it is so expensive. One wheelchair worth about TSh 250,000, how could I afford, I am not employed I am just depending on farming to sustain our daily bread.

I used to carry her on my back to and from the school until the headmaster provided her with this wheelchair
(P4, Female, single)

These statements implied that CPD were born from poor families. Most of the parents who participated in this study were depending on small scale farming and labourers in construction site. This may signify that, children who participated in this study were living in families with low income. Parents face financial constraint that they could not support their children in inclusive education. This implies that most of CPD lacked opportunity to participate in social activities including their right to quality education because of the poverty. As a result, it is likely that they will remain dependent for the whole of their life.

The study further revealed that some parents felt that this is tiresome work to carry the children to and from the school every day. Carrying the children to school every morning and pick them after school hours was a challenge as they have responsibility for other children in the family. In addition, as they get older, they become heavy to carry. Consequently, most

of the CPD were hidden and thus missed the opportunity to be enrolled in school to learn and acquire quality education like other children without disability. This was supported during interview as one teacher had this to say:

They usually get motives in the different meetings held at school where we always tell them about inclusive education and that they should not hide their children inside. So, after such an advice some decide to bring them to school. But sometimes those with physical disabilities their dropout rate is high because as they grow up it becomes difficult to be carried to and from the schools as they don't have (RR4, male, class teacher, S4).

This narration indicated that CPD were less likely to attend school or to graduate due to lack of supportive mobility devices. Thus, they are denied their right to equal access to education like other children without disabilities. This implies that those who failed to receive aids from government or good Samaritans may not attend schools. However, this should inform parents that apart from economic constraint they are facing, they have the role to provide their CPD with mobility devices so that they can adapt to the school environment. Lack of assistive mobility devices acted as a barrier for CPD to access services and participated in school activities.

In addition, the findings from this study revealed that CPD lived in poor families as compared to their counterpart due to the following reasons. First, children from poor family lacked proper information about health care and proper medical treatment that prevented or treated the impairment. Parents claimed their children's condition may have been improved if they could have proper information and were capable of attending medical services. This was narrated by one parent of CPD who said:

Because of our poverty we do not have enough information on how to raise these children with disabilities or about medical treatment. Someone told me if I could take him to CCBRT early his condition could improve but I did not have such information before. We are depending on you educated people to help us (P2, female, single).

Other parents claimed that when they received the information but they could not attend the medical consultations fully because of financial inability. This was reported by one parent who had this to say:

...I took her to CCBRT and they examined her. They found that the baby has a problem, the abdominal muscles are weak so he can't stand and the backbone seems to be slightly bent. So, they began to give her exercise for six days. However, depending on the distance, I have no money and I had left other children with no help, I had to return. Therefore, I could not keep up with the exercises. If I could continue with exercise, she could be better than now (P3, female, single).

These narrations suggested that the children's condition might have been improved if the parents could have proper information during the early stage of child development. Parents' financial inability limits the access to necessary medical services which may prevent or treat the child's disability. Another reason might be associated with the geographical location. It was found that the parents from urban area have at least some information about the medical assistance of their children as compared to the parents in the rural areas who had no or little such information. Most of rural areas were faced with shortage or lack of means to access that information. Even those who received information failed to complete the medical treatment due to distance and financial ability as those centres are situated in Dar es Salaam. Consequently, many CPD who live in poor family lacked access to appropriate medical services. This finding is contrary to the medical model of disability which assumes that, with medical treatment or intervention, the individual can be helped to overcome their limitation (21). Early identification followed by treatment has the potential of eliminating onset of disability and or reduce impact of disability in adult life.

Secondly, it was found that children with disabilities might increase the risk of family being poor due to the fact that family experienced higher expenditure of raising children with disability than raising children without disability. The presence of CPD put additional cost due to the medical facilities and additional of special equipment to cope with the environment. This was confirmed during interview by P2 who had this to say:

My brothers and I last year we struggled to sell charcoal, sold peanuts, till we managed to hire the expert who came here at home and straightened those legs. They were not like this. I used all the money but I am happy because I saw some improvement (P2, female, single).

These narrations implied that families spend little money they have for the children with disabilities than other developmental activities, which sometime make the family to remain in poverty. Raising children with disabilities is too expensive than raising a typical child due to expenses that may arise from medical equipment, medical care, care giving expenses, private education, learning equipment or specialized transportation (4, 22). For example, child with physical disability may require wheelchair, which is expensive as, compared to parents' financial ability. In the families of children with physical disability, financial was drain because of the necessary medical, social, and special educational services (13). This may contribute to the family of child with disability to become poorer than family of the children without disability.

Time Constrain

The findings revealed that, parents spend more time in taking care of their children since they cannot manage themselves. This reduces time of engage in productive work. Both parents of CPD reported to spend much time with their children, which

limit them to engage in economic and social activities. As a result, they could not provide supportive devices and learning materials to their CPD. The parents reported that they have to guide them in the morning preparation and sometimes to escort them to school. Parents of the CPD, most of them claimed to investing much time for their children to assist them doing different activities such as using toilet, taking bath, eating, and changing clothes. Most of the parents claimed that they could not engage in meaningful economic activities since they had to take care of their children. During interview, one parent had this to say:

The biggest challenge I face is to prepare my child in the morning. When you wake up it is the first one to put her on, dress her up and let her go with her sister. In previous years, I have to send him myself. Another challenge if she wants to go to the toilet you have to pick her up and take her back (P1, female, single).

This was also supported by one teacher who had this to say:

But the most challenge parent face is to bring their children and take them back to their home daily. This is the greatest punishment to them. The same parent needs to go and find something for the whole family at the same time to bring a student to school during morning and taking him/her back during afternoon (R2, male, S2).

This limits the parents to engage in economic activities and, as the result, they found themselves remain poor depending for the grants and aids to support their children's education in inclusive schools which is not a guarantee. Odongo (23) maintained that taking the CPD to school daily and pick them up at the end of the day is a tiresome job to the parents, as the result, some of these parents gave up and keep their children at home which denied their right to education.

School Infrastructure

Findings revealed that school infrastructure posed another challenge to the parents of CPD. It was reported that CPD were not able to use school latrine. As result, they were forced to go back home whenever the needs arise. Indeed, lack of appropriate infrastructure in schools added more burden to parents as they had to stay at home waiting to support their children when they went back home for toilet services. One parent explains how lack of appropriate latrines affected parents' daily schedule:

I can't go out because I have to wait for my daughter when she comes back from school. I cannot get away from my home because there is a time when they brought her back to urinate. I have to be here because she cannot use school toilets. I cannot go away. That is why I have shifted my jobs to be done here. I am tailoring here at home that is why even my customers are not many as compared to when I was at the market place or other business centres (P1, female, single).

This quote implies that school infrastructure was not conducive to accommodate all the pupils including those with disabilities in inclusive schools. CPD spent a lot of time going back home for toilet services. This suggests the following. First, participation of CPD in learning was destructed and their academic performance was likely to be low. Second, inaccessibility of school latrines caused not only challenge to CPD but also challenge to parents as it limits them from engaging in their daily activities which contributed to their income.

Despite of the implementation of inclusive education in our country for more than twenty years, infrastructure is still a challenge not only to CPD but also to parents. This is contrary to the aims of inclusive education as MoEST (7) stated that inclusive education always works to reduce educational barriers and exclusion to accommodate all students in successful learning. The findings were also against the social model of disability which insists that education institutions should remove unnecessary barriers which prevented people with disabilities to participate in all school activities (24). This implies in order to ensure equal access and participation in education; school environment should be made conducive to accommodate all learners without discrimination. Ishmael (25) pointed out that a school should make sure that one gained free movement within the school premises and classrooms. Interaction with the environment can take place not only in the least restrictive but also most facilitative. Children with disabilities needed support that give them freedom and independence to allow them to do things on their own because when they became adults, they will be less people around to assist them. The need to create conducive environment is imperative in order to prepare them to be less dependent on other people around them on everything they do (26). When CPD are provided with mobility devices in a less restrictive environment, they become more independent which, in turn, reduced the burden to the parents.

Family Disharmony

The findings revealed that most of the children who participated in this study were living with their mothers. It was found that birth of child with disability raises conflicts in the family, which mostly ended up with separation. In most of the time mothers were the ones who were left with the children. Unfortunately, they were unable to afford the cost of raising disabled children and other children. This was revealed by RR1 who said:

In this society, most of the times we receive complaints from mothers that they were being abandoned by their husbands simply because they had children with disabilities. Mothers were left alone with the children with disabilities without support from their fathers (RR1, academic, S1).

This was also supported by RR3 who said:

... I am saying it is the mother because most of the children with disability live with the mothers only. When you ask them about the fathers, they will tell you that when the fathers realized that the child was disabled, they abandon them. So, the mother remains with all the responsibilities of taking care of the child (RR3, female, S3).

The above quotes implied that the society is still holding negative attitude towards people with disabilities. Apart from all the efforts in creating awareness about negative impact of stigmatization of people with disabilities in our society, still some people hold that people with disabilities are helpless, hopeless and a curse in the family. Sometimes the disability was seen mother's mistake. With regard to this, fathers who held negative perceptions tend to abandon their families and left the entire responsibilities to their wives to take care of the family. Community members had misconceptions and supernatural beliefs on the children with disabilities (27). Thus, issues of stigma, ridicule and prejudicial were critical barriers toward acceptance and supporting the children with disabilities.

Under this circumstance, mothers faced financial difficulties to overwhelming role of taking care of the child with disability and other children. Studies from other country reported that mothers with children with disabilities were more likely to be divorced compare to mothers without children with disabilities (28, 13, 29, 30, 31, 21). Studies from developed countries indicated that the rate of divorce was high in families with children with disabilities than in other families while the findings of this study indicated that fathers left the responsibilities of raising children with disabilities and other children to mothers. The process of divorce involved legal agreement between the two parts regarding the right of the child from his father. However, when the father abandoned the family the support of the child is left to the mother. Mothers are always the one who struggled to ensure the survival of children with disabilities due to lack of support from their biological fathers. With this situation, CPD did not receive the support they needed to cope with learning in inclusive schools from their parents. Family separation led to financial constraint; single parents were not able to support their CPD with needed materials like mobility devices to enable them to cope with learning in inclusive education. This implies that most of children with physical disabilities missed their right to social participation like right to education or sometime were delayed to be registered until someone else volunteer to provide them with mobility device and other services since their parents did not provide them.

Inhuman Practice to the Children with Physical Disabilities

The findings revealed that parents of the CPD faced challenge on taking care of their children when they were at home or on the way to school or back home. The findings indicated that CPD were not safe since people tended to bully or abuse them when they were alone. This was also narrated by another parent who said:

I cannot leave my daughter alone even here at home. I am worried about rapists. Someone can do anything harmful to her. One day there was one child who forced her to drink urine about five years ago. He came from there he put urine in a bottle and forced her to drink it. Another day when she was coming back from school, they left her wheelchair and they threw her over there. It is a challenge even in school when she was standard one. They fed her with germs. Some people are not good to these children (P1, female, single).

The foregoing quote indicates that CPD were more likely to be victims of child abuse by other children without disabilities. This might be due to the reason that the CPD were the victims of abuse since the disabilities limit their ability to defend themselves. This suggests that these children were not adequately protected despite of great effort in creating awareness about the rights of children with disabilities. Children with disabilities were more likely to be sexual and physical abuse three times than the typically developed children (32). Similarly, Okeke and Mazibuko (33) reported that parents complained that their children were abused sexually and were stigmatized by other children of the same area. Our society is not considering these children as normal human beings that is why they tended to abuse them. Under this circumstance, parents needed to be close to their children at home or when on the way to or when at and from school. This added burden to their life. The parents used most of their time to take care of their children instead of engaging in productive work which may increase their income.

Negative Perception of their Capabilities

The findings revealed that parents of CPD were facing the challenge from within the society. Some people viewed child with disabilities as someone who is incapable of doing anything. It was revealed that other pupils without disabilities believed that CPD in the class could not perform better than them. When they found their performance is better than their performance, they started abusing them. This was demonstrated by one parent who had this to say:

It is a challenge even in school one pupil when they came home from school; he told her you are smarter than us. When they got near the bridge, he said today I am going to kill you! He released her wheelchair and wanted to throw her into the river. Fortunately, one man was ahead and saved her (P1, female, single).

Similar experience was reported by one pupil who said:

There is a tendency from other pupils to say abusive words without a reason that makes me to feel bad. When I performed well than them, they tell me Look at her that is why "it" cannot move. I feel so bad (PP2, female).

Similar challenge was voiced by P3 who said:

Another challenge is low expectation from parents of the children without disabilities who believed that their children can perform better than the children with disability. One day, one parent came here with the paper that the children they have done she asked her all the questions to confirm if it is true that she alone performed to that extent. She answered all the questions correctly. That parent felt shy and apologised. She said she could not believe that disabled children could lead the class (P3, female, single).

The analysis of above quote statements revealed that the pupils with disabilities in inclusive classes were seen as incapable regardless of the kind of disability. They were viewed as the one who could not perform well in their academic. Even parents of the children without disabilities viewed the CPD as incapable of everything. Thus, they could not perform as their children without disabilities. This view is contrary to the social model of disability which views disability as socially constructed and that inability in one aspect does not mean inability in everything. It focuses on the child's strengths and opportunity to achieve. The social model of disability assumed that person's impairment is not the cause of disability but rather disability is the result of the way society is organised which excluded people with impairment (34).

It was found that CPD had good academic performance that allowed them to continue with the next level of education. This is because most of physical disabilities do not interfere intellectual ability. Thus, they can learn in the same pace as other children without disabilities provided that the environmental barriers will be removed. However, the findings revealed that even those who struggled to graduate they find it difficult to secure employment. Lack of opportunities after graduation discouraged to those in school since they did not see the relevance or the importance of their education. Ideally, parents' expectation that education provide to their children is one way or another would change their life since they would be employed and earn some income to sustain their life. However, the situation is different now days as narrated by one parent who claims that:

His performance has started to decline since he saw his brother who is also disabled graduated from college and has not found a job for three years now. He is reluctant because from the beginning I was telling them that I will educate them as much as I can because later education will help them. Now when he saw his brother has finished schooling and he has not secured a job, he has lost all the hope. I am still having a hard time encouraging him to go to school. (P4, female, single).

This narration indicates that although there is a problem of employment for graduates, the problem is severe to those graduates with disabilities because of stigmatization of people with disabilities. There has been a wrong notion that people with disability they don't have prerequisite competencies and skills to do work. This is because they are treated as the group

of people who depended on their families and other organs for support throughout their life. This is contrary to the persons with disabilities Act, 2010 which states that every employer, public or private shall, where there is a vacant post fits for a person with disability and a person apply for the vacancy, give the employment to the person with disability who meets a minimum qualification for such employment. In addition, the ministry shall, in consultation with the ministry responsible for labour, make regulations requiring every employer with the work force of twenty and above to employ person with disabilities based on quota system and to ensure that three percent of it constitutes persons with disabilities (35). Although the country has adopted policies aiming at promoting the right of person with disabilities still social stigmatization of people with disabilities contribute to low employment rate to people with disabilities. This negative attitude towards people with disabilities makes many people with disabilities to live in poverty because they cannot access work due to their disabilities. Consequently, it affects the way parents provide social support to their children with since the education they are struggling for will have no impact in the future life of their children.

4. CONCLUSION

Basing on the findings of the study it was concluded that there were so many challenges, which parents of the CPD face in provision of social support to their children. Despite of the efforts made by the government and non-governmental organizations still same societies do not accept people with disabilities in various social activities. In most families, parents especially fathers are not ready to live with CPD. Most of the father run away from their family after birth of the CPD leaving all responsibility of taking care of the family on the hands of the mothers who sometimes could not afford the cost of taking care of the CPD and the family. likewise, negative perception on the capability of the CPD held by society in general, is another challenge not only to the children with physical disability but also to the parents as it affects them emotionally and psychologically in providing social support to their CPD in inclusive education. Furthermore, school infrastructure poses another challenge to the parents since other CPD could not use school latrine which require them to go back home whenever the need arise. This is challenge to the parents since they should stay at home to assist the child when they come back for toilet service

ABBREVIATIONS

CPD Children with Physical Disability

MoEST Ministry of Education Science and Technology

URT United Republic of Tanzania

Disclaimer (Artificial intelligence)

Option 1:

Author(s) hereby declare that NO generative AI technologies such as Large Language Models (ChatGPT, COPILOT, etc.) and text-to-image generators have been used during the writing or editing of this manuscript.

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Details of the AI usage are given below:

- 1.
- 2.
- 3.

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