Parents' Experiences in Provision of Social Support to Children with Intellectual Impairment in Tanzania Inclusive Primary Education Settings

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Abstract

The aim of this study was to explore experience of parents in provision of social support to their children with intellectual impairment in inclusive primary education settings. The study is qualitative in nature. It used a sample of sixteen participants from three primary schools in Katavi Region. Data were collected through semi-structured interviews and were thematically analysed. The finding revealed that parents' provision of all kinds of social support to their children with intellectual impairment is inadequate. Thus, it can be concluded that inadequate provision of social support by the parents to the children with intellectual impairment is a challenge to the children with intellectual impairment to cope with learning in inclusive education setting and hence to acquire quality education.

Keywords: *social support, intellectual impairment, inclusive education*

Introduction

Children with intellectual disabilities usually have sub-average functioning of adaptive behaviour (mobility, dressing, washing, housekeeping, toileting, preparing meals, managing money, medication, responsibility, self-esteem, follow rules, obey laws avoid victimization, using expressive language, reading and writing, and self-direction) and intellectual functioning (ability to understand, learn reason, judge and solve problem) (American Association on Intellectual and Developmental Disabilities [AAIDD, 2022];Tasse, Luckasson and Schalock, 2016). In this regard, support to children with intellectual impairment is imperative as it helps them to manage their education in inclusive education. Parents by virtue of their custodian role are key stakeholders in the education of their children with intellectual impairment. Parents have an important role to play in everyday school life of the children and have additional role for the children with intellectual impairment studying in the setting of inclusive education as well (Bagadood, 2022).

Parents as socialising and caregivers notice and influence many changes in their

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child's development (Mohsin, Khan, Doger & Awan, 2011). Arguably, unlike other parents, the parents of children with intellectual impairment bear additional roles in caring and socialising obligations. It is generally accepted that social support enables people with disability to participate in social activities including education as other members of the society. Parental support is a very important factor for the success of children with intellectual impairment in inclusive education.

Conceptualisation of Intellectual Impairment through the Lens of Social Model of Disability

AAIDD (2022) defines intellectual impairment as a significant limitation of both intellectual functioning and adaptive behaviour as expressed in conceptual, social and practical adaptive skills which originate before age 18. Children with intellectual impairment like other children with disabilities were seen as helpless, hopeless, and a curse in the society (Thwala, Ntinda & Hlanze, 2015). Under this perspective, they were discriminated in all social activities including education. The social model of disability views disability as a societal construct, rather than a medical impairment (Lang, 2007; Petasis, 2019). The social model conceptualizes disabilities as a collective issue caused by the physical environment, inappropriate or inaccessible services and attitudes, and lack of understanding (Oliver, 1983). Shakespeare (2010) contends that disability is something imposed on top of impairments, and that an individual with disability is unnecessarily isolated and excluded from full participation in the society. It attempts to switch the focus away from the functional limitations of individuals with impairment on the problems caused by disabling environments, barriers, and cultures (Oliver, 2004). The social model seeks to remove unnecessary barriers, which prevent participation of individuals with disabilities in society, accessing work and living independently (Lang, 2007). This places the moral responsibility on society to remove the burdens, which have been imposed, and enable those with disabilities to participate (Shakespeare, 2010).

The social model provides an understanding of the ways children with intellectual impairment can learn when the school and home environment meet the needs of every child with intellectual impairment. Similarly, emotional support and appropriate supportive devices enable the respective children to feel and realise that they are recognised and supported. The provision of appropriate teaching and learning strategies and resources enable the children with intellectual impairment to learn and benefit in inclusive education even if is not as the same pace as the children without impairment (Cornelius & Balakrishnan, 2012). In addition, positive attitude towards pupils with intellectual impairment will break the barriers to enable them to acquire quality education. Thus, children with intellectual impairment require

social support to enable them to manage their daily life including school life in inclusive education setting.

The concept of inclusive education for a learner with intellectual impairment in Tanzania

Inclusive education enables marginalized children including those with disabilities to access education in a nearby school. Inclusive education originated from the 1994 Salamanca statement which stated that schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic, or other conditions (UNESCO, 1994). It was conceptualized and maintained that all children have a fundamental right to education and must be given the opportunity to achieve and maintain an acceptable level of condition for learning in regular education system (UNESCO, 1994). In the context of Tanzania, inclusive education involves social disadvantaged children, learners from nomadic and seminomadic families, refugee learners, out of school children, working children, learners with chronic illness, orphaned children, learners with specific learning difficulties, gifted and talented learners, learners who live in extreme poverty, children who live far from school, learners with disabilities, boys and girls, and children in conflict with law (MoEST, 2022).

However, despite the observed enhancement of the right of education and increase in enrolment for the children with disabilities in Tanzania, several studies conducted in Tanzania, indicate that, children with intellectual impairment in inclusive primary education faced several challenges that impede the success of their education (Ngata, 2011; Sijaona, 2011). For example, Sijaona (2011) reported that, teacher to pupils' ratio is higher and it affects teachers' ability to manage the behavioural and academic problems of individual learners with intellectual impairment. In addition, teachers lacked training on how to teach pupils with intellectual disability that lead to their poor performance (Ngata, 2011)

On the other hand, children with intellectual disabilities experienced more emotional and behavioural disturbance as compared with their typically developed peers in that they needed social support for their mental health wellbeing (Campbell & Gilmore, 2014). All these posed different problems in the process of the child's learning and consequently hindered their academic achievements in inclusive education. Most of the pupils with intellectual disability require direct and intensive instruction in reading, writing or mathematics which is difficult to meet in general education classes (Gal, Schreur & Yeger, 2010). Inclusive education is more about equity than equality. Therefore, children with intellectual impairment need extra support so that they can cope and adapt learning in inclusive education (MoEST,

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2022). Mitchell (2015) contended that, children with disabilities need additional support and attention to enhance participation, and facilitate learning in educational activities, routines and play in inclusive education. Social support for the children with intellectual impairment is of great importance to enable them to succeed in inclusive education.

Social support for the children with intellectual impairment

Social support is defined as the assistance that people provide in order to help others to cope with life changes and situational demand (Xu & Burlson, 2001). Mattason and Hall (2011) described three types of social support as emotional support, informational support, and tangible support. According to them, emotional support is communication that meets an individual's emotional or affective needs. It includes caring, empathy, love and acceptance. Informational support is communication that provides useful information. Tangible support is any kind of physical assistance provided by others such as material, or actions to help them in challenging situations. The kind of problem one has determines the type of support that is provided. Since children with intellectual impairment faced stressful situations caused by both physical and social environment, the provision of social support is fundamental for enabling them to cope with learning in inclusive education.

Social support is based upon the premise that people must depend on one another to satisfy certain basic needs (Jang, 2012). Sultan, Malik and Atta (2016) argued that a human needs social support to not only improve their physiological condition but also assist an individual to improve his or her quality of life psychologically and socially so that he or she could spend a happier and satisfied life. Children with intellectual impairment are characterized with low intellectual functioning and adaptive behaviour which impede their capacity to learn and social life as other typical developing children (AAIDD, 2022). The studies have revealed that parents' support to children with intellectual impairment increases children learning competence, health social relations and fewer behavioural problems (Bagadood, 2022; Oranga, Obuba, Sore & Boinett, 2022).

Parental support to children with intellectual impairment in inclusive education

While the school is important for the academic achievement of the learner with intellectual impairment, parents are the most important people to the achievement of the children with intellectual impairment (Bagadood, 2022, Laing, 2016). It was argued that the role of parents of children with impairment do not end in taking the children to school but also to support their academic matters to compensate

what they missed in classroom since they cannot learn in the same pace as their peers without impairment (Cornelius & Balakrishnan, 2012; Kisanga, 2017). Bryan, Burstein and Bryan (2001) argued that pupils with intellectual impairment may have more difficulty understanding the requirements of the homework assignment, or may have reading and writing deficits that affect their ability to complete homework. Researches also have shown that high levels of parents' provision of social support to the children with disability in general in inclusive education correlate with improved more positive attitudes towards school, higher homework completion rates, fewer placements in special education of the children with disabilities, higher math and reading score (LaRocque, Kleiman, & Darking, 2011; Xu & Filler, 2008).

While the issue of parent support has been of increasing concern, only few studies have focused on the experience of parents of children with intellectual impairment in provision of social support. Thus, the current study intended to investigate the experience of parents of children with intellectual impairment in providing social support in inclusive education settings.

Methodology

The study employed a qualitative research approach. Gay and Airasian (2000) 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 (Cohen, Manion & Morison, 2011). Hence, the qualitative approach enabled the researcher to capture rich, detailed and relevant information about the perception of parents of the children with intellectual impairment 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 children with intellectual impairment enrolled in primary school in three consecutive years (Reginal Administration and Local Government [PORALG], 2016; 2017; 2018). This raised the interest to understand parents' experience in supporting their children with intellectual impairment in inclusive education since they are the most important to initiate the education of their children. Sixteen participants from Mpanda Municipal Council and Nsimbo districts in Katavi Region were involved. This includes five pupils with moderate intellectual impairment who were living with single parents who were the mothers; five parents of children with intellectual impairment and six

teachers (three head teachers and three class teachers) of the selected children.

Face-to-face semi-structured interview elicited the kind of social support parents provide to their children with intellectual impairment to manage learning in inclusive education. 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 intellectual impairment, who were under 18 years old), permission was sought from parents to allow their children to be interviewed.

Findings and Discussion

Data were analysed in relation to three kinds of social support which included tangible support (learning resources), emotional (acceptance and encouragement), and informational support (providing useful information, information on carrier choice), support on independent living skills and supervision of homework.

Tangible support to pupils with intellectual impairment

The findings from interviews with pupils with intellectual impairment revealed that they did not receive learning materials from their parents. One pupil said, "I do not have exercise books, pen or school bag" (Pupil 2, male, class II, school 1). These findings are supported by the teachers, who all stated that parents did not supply any educational materials for pupils with intellectual impairment.

One teacher had this to say:

> Parents are not helping them. When they bring them to school, they feel like they have finished everything and sometimes they see them as a burden at home. Pupils with intellectual disabilities need learning materials, for example, exercise books, reading and mathematics book so that they can learn at home since they are slow learners; they refuse and think it is wastage of money (teacher 1, female, class teacher, School 2).

In addition, one parent had this to say, "He does not have exercise books because he cannot write. I do not think he can learn anything. It is wastage of money to buy exercise books for someone who cannot even write (Parent 3, female, single)". This implies that parents considered their children with intellectual disability as the ones who could not learn anything. So, they did not see the need to provide them with even exercise books or pencils.

The findings revealed that pupils with intellectual impairment did not receive learning facilities from their parents even the basic ones like exercise books and pencils like other pupils without disabilities. These findings are contrary to the Tanzania education circular Number 3 of 2016 which states that parents have responsibilities to provide their children with school and sports uniforms, and all required learning materials including exercise books and pens/pencils regardless of their conditions (United Republic of Tanzania [URT] 2016). As the findings revealed, parents did not provide their children with those materials since they had low expectation of their academic performance. This implies that when parents found that the academic progress of their children with intellectual impairment was very low as compared to children without disability, they lost hope. They did not believe that their children could learn anything in school. Consequently, they became reluctant to provide them with learning materials. Based on the circular, children with disabilities have the right to receive learning materials from their parents the same as other children without disabilities including special learning materials so that they can cope with learning in inclusive education.

Furthermore, children with intellectual impairment need a lot of visual aids to enable them to learn basic concepts in inclusive education since they have limitations in learning abstract concepts (AAIDD, 2022). During interview, one teacher claimed that:

> These parents of pupils with intellectual impairment think that after sending their children to school, they have finished everything. Remember, these children are slow learners. They can learn but slowly and most of the time they can learn better by seeing. But when you tell their parents to collect some equipment that is available in their environment for their children, no one will bring anything (Teacher 2, Female, class teacher, School 3).

The narration suggests that negative perceptions held by parents of their children learning can affect the way they support them on learning or they may not have the very basic education which may help them to support their children to learn. Campbell and Gilmore (2014) reported that children with intellectual disabilities have prevalence rates of mental health problems which in combination with the problems in communication, attention, self-regulation and behaviour disorders adds to challenges already facing them. It is possible for the parents to identify the needs of the specific child and provide them with relevant learning materials available in their environment which will assist the child to learn basic skills. Lundgvist (2016) argued that the support provision to children with disabilities was crucial while lack of support may risk creating circumstances where children

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cannot participate and learn, and thereby not benefiting optimally from their education. This finding is contrary to the social model of disability which focuses on the removal of barriers and provision of appropriate services. The social model of disability stresses that problems faced by people with disabilities are the result of external factors and society failure to provide adequate and appropriate services (Petasis, 2019; Shakespeare, 2010).

Emotional support to children with intellectual impairment

Acceptance and love: Parents of children with intellectual impairment did believe that the disabilities of their children are God's wishes; so, they need to accept them as they are. This was narrated by one parent who said:

> I feel good because scriptures inform us to be thankful for everything. I had to receive her as she is because she is a human being. I could not throw her away. It is how God created her, nothing can be changed (Parent 1, female, single).

The foregoing statement indicates that parents believe that all human beings are created by God. Thus, they cannot challenge God's work. Instead, they need to accept them as they are. This can be attributed to the reason that parents of the children with intellectual impairment do not take the initiative to register the children in schools. It was revealed that some parents of children with intellectual impairment did not bother to register their children to school because they perceived them as being incapable of learning or coping with school environment. The findings revealed that children with intellectual impairment were registered to schools after teachers' and other people's efforts to trace them and advise their parents to register them to schools. This was confirmed by one parent who had this to say:

> They announced at the church that those with children with disability should send them to school, so I sent her to school. When I sent her, the headmaster said I will accept this child until the school for the disabled is complete, we will send her there (Parent 2, female, single)

Similar experience was also reported by another parent who said: ''I was not aware of her ability to go to school due to her condition, but some people came here and advised us to send her to school, and since then I took my daughter to school (Parent 5, female, single). This was also supported by teacher 4 who had this to say:

> Most parents register their children with intellectual disabilities due to external forces. When we do the census, we realize that there are children with disabilities above six years old who have not been registered in schools. We started advising them to register

their children as most of them used to hide them (Teacher 3, male, academic and sport and games teacher, School 3).

The quotes revealed that parents of the children with intellectual impairment accept their children because there is no way they can reject them. This made them believe that it is their responsibility to take care of their children and they should remain as they are for the rest of their life. Parents viewed their children with intellectual impairment as people who could not participate in any social activity like other children. Aydin and Yamac (2014) were of the opinion that the way parents accept their children with disabilities determines the positive acceptance of the children in the society. That means parents can make their children accepted or not accepted depending on how they perceive their own children's disabilities. Parental love and acceptance given to children with disabilities strengthen them and give them confidence which, in-turn, determine their success in school life and child development.

Encouragement: The findings revealed that no one is encouraging children with intellectual impairment about their academic progress. The parents of children with intellectual impairment just let them go to school. They did not have hope that their children could learn anything from school. As a result, they did not encourage their children in academic matters. This was demonstrated by parent 1 who said: "*I have nothing to advise about her academic progress. Her progress is not good. She doesn't know even how to read. She has to go to school but I have no hope that she can learn.*" (Parent 1, female, single).

The similar view was voiced by Pupil 2 who said, "*My parents and teachers say nothing about my academic progress. I have never received a gift for any of the school activities*" (Pupil 2, male, class II, school 1).

This implies that parents of children with intellectual impairment hold negative attitude towards their children's learning. Parents saw their children with intellectual impairment as the ones who could not learn anything thus; they tended to ignore their academic matters. This makes parents allow their children with intellectual impairment just to attend schools with no hope that they will learn anything. This might be associated with teaching style in inclusive education which does not recognize the diverse needs of learners. Children with intellectual impairment in inclusive schools learn the same content using the same teaching style and resources as typical developing children that make them lag behind, as they cannot learn in the same pace as their peers without disability, as a result, they are considered incapable. Children with mild and moderate intellectual impairment are educable and can learn basic skills which could allow them to become independent (Sahay, Prakash, Khaique & Kumar, 2013).

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Moreover, parental positive attitude, encouragement and support will give the children hope and confidence that can help them to grow stronger and more resilient. All the children need love, encouragement and support, and for children with intellectual impairment, positive reinforcement can help to ensure that they emerge with a strong sense of self-confidence and determination that will build the foundation for lifelong success. Children with intellectual impairment lack self-motivation and thus, they depend on external motivation rather than internal motivation because they always have fear to fail (Shree & Shukla, 2016).

Information Support

Provision of useful information: Teachers who participated in this study claimed that parents were not making follow ups of their children's progress at school. Teachers claimed that parents were not visiting the schools to seek information about their children learning or provide information to the teachers about their children's development that could help them to support their children in academic progress. This was claimed by teacher 3 who said that there was very low participation of parents since it was very rare to find parents with children with disabilities coming to school. He added that he had never met a parent who came to give advice about his/her child's ability (teacher 3, male, academic, sport and games School 3).

The foregoing views were supported by another teacher who had this to say:

> Their cooperation is very low because they believe that once they bring their children to school, they have finished their responsibilities. It was expected that they could keep regular communication with teachers because they are the ones who know everything about their children (teacher 4, female, head teacher, School 3)

The above narrations indicate that teachers were missing useful information from parents which could help teachers to assist the children in the school environment to learn better in inclusive education. Also, parents missed important information from teachers that could help them to support their children. Parents thought that their responsibilities to their children end when they send them to school. These findings are contrary to the Tanzania education circular for implementation of fee free education which states that role of parents is to make follow-up of their children academic progress and performance (URT, 2016). Kisanga (2017) found out that the children with disabilities reached higher education because their parents played a great role by monitoring their learning and ensuring that they teach them at home to compensate what they missed in the classroom. Thus, parental support is very important since parents know their children's needs better than others. Odongo (2018) reported that children with disabilities were taken to school and left in the

care of the teachers who were overwhelmed by a large number of children in classes that they could not pay much attention to individual children with disabilities.

Parents are the ones who know more about their children's peculiarities than anybody else. Thus, their information is valuable for the success of their children's education. Parents can provide information about developmental characteristics of their children which, in turn, could help the teachers to meet the needs of the children with intellectual impairment in classroom teaching and learning. Parents are the central and most important link in the care, education and supervision of persons with intellectual impairment (Kendel & Merrick, 2007).

***Information on career choice*:** The finding revealed that none of the parents had provided any guidance to his/her child with intellectual impairment information on career choice. All pupils with intellectual impairment who were interviewed claimed that they had never been advised about their future career by their parents. This was noted by Parent 3 who said: "*Haaahaaa! Now what shall I advise him. What will he be able to do? I don't really think if he can do anything. He cannot even work in my store, Haahaaa! He can't. He will be a homemaker*" (Parent 3, Female, single).

This statement indicates that parents of children with intellectual impairment had no hope that their children were capable of doing anything. They regarded their children as a burden of the family. It seems that parents failed to realize that learning difficulties did not mean being difficult in everything. Children with intellectual impairment are capable of performing different activities of which if guided it will help them to become independent adults. This was revealed in the narration by one teacher who had this to say:

> The boy you interviewed is 13 years old but he is not assigned any piece of work at home. Here at school, he can clean the classroom and wash clothes. I also send him to market and he buys everything and he brings them but if you explain it to his parent, it becomes very hard to believe. His mental disabilities will not hinder him from bringing out the best in him (teacher 5, male, head teacher, School 1).

The narrations indicated that parents lacked an understanding of the capabilities of their children with intellectual impairment. Most of the pupils with intellectual impairment could not proceed with academic path beyond primary level. Thus, parents have the role to find the alternative path that could enable the pupils to live an independent life in the future. Pupils with intellectual impairment may not succeed in academic path but they can succeed in vocational path. It is important

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to identify the potentials that children with intellectual disabilities have so that they can nurture and guide them in the right path. It is also important for parents to understand all educational options available for their children and be informed of the impact that their children's educational path and experiences may have on options and outcomes in future (Hirano & Rowe, 2016). It is only with the crucial information that parents could make informed decision on how best they can support their children to become independent adults. Moreover, Fabian and Pebdani (2013) contend that having disabilities expose individuals to unique experiences that may influence their career development. Hence, both teachers and parents need to understand these unique features of the children with intellectual impairment so that they can guide them to the right path.

Support on independent living skills: The findings revealed that other parents of children with intellectual impairment did not assign their children any piece of work to perform or teach them other life skills because they believe they have no capability to perform. During interview one parent had this to say:

> Aaaa! No, I am not assigning her anything to do. I have no hope that she will be able to support herself. Even if she gets good education I don't know if she will be able to support herself. What will this person be able to do (Parent 4, female, single).

This was also supported by another parent who said: "He is not doing anything at home, it's just playing. What kind of work can you assign him, he's just playing. As I told you, he's just playing; he returns home when he feels hungry" (Parent 3, female, single).

The above narrations imply that parents of children with intellectual impairment perceived their children as being incapable of performing daily activities as children without disabilities. As a result, they demanded less and offer fewer opportunities to participate in home activities. In this regard, children with intellectual impairment could not learn much which make them dependent throughout their life. Parents need to assign their children with intellectual impairment different activities so that they can observe the potentials of their children and guide them to develop living skills. By providing them with independent living skills, children with intellectual impairment can adapt learning in inclusive education. In addition, it would help them to get alone with others and adapt to various social conditions that would enable them to make healthier choice, resist negative pressures, and avoid risky behaviours.

Homework supervision: Parents who were interviewed explained that they did not help their children on academic matters because they could learn anything. For

them, they take them to school to reduce burdens at home and because they were forced to do so. During interview, one parent had this to say: "What can I teach him? He does not know how to write or read; he is not even assigned homework (Parent 5, female, single)". This situation implies that pupils with intellectual impairment did not get support in academic matters whether from school or at home. Children with intellectual impairment in inclusive schools are neglected in academic matters. Most teachers did not consider them in the process of teaching and learning. They perceived them as being unable to learn, and that they do not pay attention to whether they are learning or not. This was revealed by one parent who said, "He is not given homework. Neither does he sit for a test. He is in standard three now" (Parent 2, female, single). Teachers claimed that these children could not even write; Teachers' perception is contrary to Raty, Kontu and Pirttimaa (2016) who reported that students with intellectual impairment could learn different skills by using different strategies. They reported that students with intellectual impairment could learn different skills more effectively through the use of read by sight word or by phonics, decoding strategies, phonological decoding, combination of visual aids and discussion. This means that teachers should find an alternative way of accommodating these pupils in regular classes rather than neglecting them so that they can learn which, in turn, will motivate their parents to provide social support to their children with intellectual impairment. Previous studies reported that children with disability who managed to access higher education learning were those whose parents recognised that their role is not only to send their children to school but also support them at home, pay for extra classes and teach them at home to compensate for what they had missed in regular classes (Kisanga, 2017).

Conclusions

Children with intellectual impairment show limitations on intellectual functioning, adaptive behaviour and daily practical skills (AAIDD, 2022). Thus, they need not only tangible support but also emotional and informational support to manage their daily life. Children with intellectual impairment need close guidance to develop living skills that will help them to cope with learning in inclusive education and also to become independent adults in future. Likewise, parents have a crucial role to play in upbringing children with intellectual impairment. They have important information that could help teachers to assist their children at school since these children cannot learn in the same pace as their peers in inclusive education. Also, the way parents accept their children with intellectual impairment will determine how they will provide social support to them. That is, if parents accept their children with intellectual impairment positively, they will be in position to assist

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them in all aspects of their life including their education, thus it improves their learning. Thus, inadequate social support provided by parents to their children with intellectual impairment acts as a barrier to the children to cope with learning in inclusive education.

Recommendations

Based on the findings of this study, the following recommendations were made. First it is recommended that parents should provide learning materials to their children with intellectual impairment so that they can assist their learning in inclusive education. Second, parents should involve their children with intellectual impairment in household chores so that they can learn independent living skills and identify the potential they have. Third, it is also recommended that parents should make a close follow-up of their children's academic and social progress in inclusive schools.

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