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## **Parenting and Educating Children with Autism: Lived Experiences of Lusaka Parents - Zambia**

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### **Abstract**

This study sought to establish lived experiences and roles of Lusaka parents in the education of their children with autism. The study employed the qualitative paradigm and the research design used was Phenomenology. The objectives of this study were; to establish parents' lived experiences in the education of their children with autism, to establish teachers' views about parents' participation in the education of their children with autism and to find out parents' roles in the education of their children with autism. The sample for this study comprised of 20 participants, consisting of 10 parents of children with autism and 10 teachers. Parents were the main target sample while teachers complemented the sample as informers to enrich the data in this study. Purposive sampling procedure was used to select the participants. The study established different experiences of parents of children with autism. Parents suffered frustration, stigmatization, embarrassment and psychological stress in the upbringing of their children with autism. It was also revealed that with support from the community, experiences of parents in educating their children would be seen to be less stressful and encouraging. Further, the study reveals that some parents did not actively participate in the education of their children with autism, limiting their roles to helping in homework, taking their children to school and buying the children books. A few parents that were engaged in the education of their children gained confidence and satisfaction of their role.

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Based on the study findings it was recommended that, schools should link parents to support groups where they acquire knowledge and skills to manage unusual behaviors of their children with autism, community sensitization about the negative attitudes towards parents and children with autism needs to be carried out, thus emphasis on laws against stigmatization should be made clear to members of the community and that the Ministry of General Education in Zambia through schools with learners with autism should embark on sensitization of parents about the roles in the education of their children with autism.

**Keywords:** Autism; Parents; Learners; Children; Roles; Lived experiences.

## **1. Introduction**

Autism is a behavioral disorder affecting social functioning, interaction, communication and interests in activities but should not be confused with mental retardation or intellectual disability. [1, 2] explain autism as a severe impairment in social relatedness and language development and the presentation of unusual, repetitive and stereotypic patterns of behavior. The several behavioral dispositions of children with autism such as autistic loneliness, limited awareness, emotional remoteness, and failure to share in activities, pleasures, poor or no language expression, preoccupation to limited activities among others [2] tend to bother parents who are alien to the condition. But the role parents play in helping the child develop is questioned. The causes of autism are not clearly known [3] although it is strongly believed to be neurologically based [3]. Reference [3] explain that autism can pose difficulties for parenting because adolescents with autism portray unusual and inappropriate sexual behaviors, can easily break the law, and dispose moody behaviors and obsessive compulsive disorders. It has several comorbidities [2, 3], which result from the behaviors they portray. Autism, can also be found in children with other disabilities like visual impairments, hearing impairments and cerebral palsy. There is little research done in Zambia in the area of autism, hence the prevalence of learners with autism in Zambia is not yet known. There is no data from the Zambia Central Statistics Office (CSO) or the Ministry of General Education on learners with autism at all levels of the education system. Autism is instead embedded in the intellectual disabilities category when it is supposed to be considered as an independent category of special needs or disability like other well-known disabilities such as visual, hearing, intellectual and physical disabilities. The condition is not very well known in Zambia [4]. If students at University of Zambia could not be aware of Autism (79%) of the total respondents of 488, Reference [4] then the lack of knowledge and awareness about the condition could affect parents' knowledge of autism for those who have never been to school or have limited education. Reference [5] reported that most parents had no knowledge about Autism and lacked information on the nature of the disorder. With limited research on Autism in Zambia, this study sought to find out the experiences of Lusaka parents in educating their children with autism.

### **1.1. Statement of the problem**

While studies show positive results and achievement in children without disabilities whose parents participate in their education, Reference [6] found that parents of children with higher developmental risks reported less family involvement and poorer relationships with their child's teacher. Several factors can affect parental participation in the education of children. Reference [7] report that language can be a serious barrier in this

regard. For children with autism who have no verbal language, the impact can be devastating ranging from personal relations with the children to their participation in their education. Bonding, social, emotional, cognitive and linguistic development of children is dependent on communication with the children [8]. In Zambia, parental participation in the education of their children with autism and their personal experiences have not been explored, yet necessary support to parents as well as their children with autism is key to success in education and to reach their full potential. It is for this reason that this study was conducted, to establish the parents' roles and lived experiences of educating their children with autism.

### ***1.2. Objectives of the study***

This study was guided by the following objectives.

- To establish parents' lived experiences of educating their children with autism.
- To establish teachers' views about parents' participation in the education of their children with autism.
- To find out parents' roles in the education of their children with autism.

### ***1.3. Research Questions***

- What are parents' lived experiences of educating their children with autism?
- What were the views of teachers about parents' participation in the education of their children with autism?
- How do parents themselves perceive their roles in the education of their children with autism?

### ***1.4. Theoretical Framework***

This study sits in Urie Bronfenbrenner's 1979 Ecological Systems Theory. According to this theory, a child's optimal development should be supported at different levels, namely the Micro- system (Family level), Meso-system (Neighborhood level), Exo-system (Education-School level) and the Macro-system (policy level). In this paper, we will not dwell on the latest Chrono-system level. The support for the child with autism is necessarily and can be appreciated once positive attitudes and physiological needs are provided starting with the family going up and also once policies at Macro-system level positively impacts the lower level. In this study therefore, reflections should be made as we establish parents' experiences and ascertain levels at which the child with autism's development is likely to be affected.

## **2. Literature review**

### ***2.1. The concept of autism***

Autism is a behaviorally defined disorder which occurs within the first three years of life. Autism is a life-long, complex, and severe disorder. Autism is a diverse and complex developmental disorder which has been found throughout the world in all racial, ethnic and social groups. In South Africa, it is estimated that there are approximately 270 000 autistic/ aspergers children and adults - 1 out of every 158 births. It is more common in

boys than girls [2]. Autism Disorder was first identified by the American psychiatrist, Leo Kanner, in 1943 [9]. Learners with autism tend to be extremely unresponsive to others, show poor communication skills, have limited skill at imaginative play and often demonstrate self-stimulatory or self-injurious behaviors [9]. Learners with autism have many common characteristics. Language delay is one of the most significant and serious characteristics of students with autism. They also often experience abnormal responses to sensations, relate to people and objects in abnormal ways, and have disturbed social skills. The causes of this disorder are still unknown but researchers have made significant progress. Past theories of blaming the parents have been replaced by theories about differences in autistic persons neurological and brain systems. Educating students with autism presents a challenge to parents and teachers. Many effective technologies have been developed to ensure that these students can function adequately in society. Overcoming stimulus over selectivity and a lack of motivation are just as important as teaching these students' academic skills. Reference [10] conducted a study in Zambia on autism with a focus on effectiveness of picture exchange strategy on the communication skills development in autistic children. It was established that parents were going to be helped by the study as their children would be able to initiate communication through the use of picture exchange method, however, this study did not look at the role of parents in the education of their children with autism.

## ***2.2. Experiences of parenting children with autism***

Parents suffer stress in managing autistic child behaviour mostly because they lack knowledge of the condition. Parents understanding of the autistic condition of their children is influenced by factors such as social support, severity of autism symptoms, financial difficult and parents' perception and understanding of autism. Parents suffer stress when parenting their children with autism to some other extent because of anxiety and worries about their child's future [11]. Parents are always hopeful about their children's future even when the child has autism or any other disability and desire to have support to achieve such dreams. Parents go through different and difficult experiences to extents of needing professional support. In a study by [12], lack of communication and effective collaboration was noted as a problem experienced by numerous parents in educating their children with autism. Certainly, lack of communication can be a barrier to participation of parents in their children' development. Reference [7] note language as a barrier to educational achievement. It is worse with a communication barrier that involves autism because language is actually none existent. Because children with autism have been known to be aggressive and disrespectful, many who are not helped to attain acceptable social skills are suspended from school [12], an experience parents in this study by [12] said was a result of lack of skills by teachers to manage the behaviours of their children. When teachers themselves lack skills and knowledge about the condition, parents are likely to remain stressed up and stranded because they would have nowhere to consult on how to deal with certain strange behaviours. It is also important that parents are educated about the early signs of ASD so they can recognize these aspects as soon as possible if the signs appear in their child's behavior [13]. When parents are educated early enough, they accept the condition and work towards improving the quality of life for their children with autism [14]. From the study findings of [14], when parents with autistic children accept the illness of their children and obtain necessary information for quality child care, they will be able to organize their interests and life schedules as well as the interests and plans of their ill children and other family members

### **2.3. Roles of parents of children with autism**

Education begins at birth, right in the early days when the child begins to interact with his or her environment. In this regard the parents as well as the family as a whole, play the role of the direct leaders as well as supporters of the implementation of the education of their children. As this is one of the core factors of influence, it can be seen as the fundamental one which with no doubt has a greater influence on the overall development and creation of the human personality. The roles and functions of a family in child rearing cannot be overemphasized. The family has a duty to provide love and affection, the basic needs for livelihood and at times with sacrifice in providing such child care. There should always be a jovial environment for child play and interaction with peers. The contemporary concept over parental role and contribution in this regard, in a way rejects the so called single direction of influence of the parents over their children development, replacing it with an intense interaction of three factors such as; the child, the parent and the wider social environment. This interaction is constantly being seen as a mutual influence and process moving from the parent to the child and the other way around, which as such triggers a variety of factors which in one way or another may impact the children's development and education, in both, positive as well as negative sense. The parents take a crucial stand, when it comes to their children's development and education as a whole, as the parents themselves are the ones to take care on the overall children's physical and intellectual development, till the point they get independent and ready to face the challenges of the society they live in. When parents involve themselves in the education process of their children, usually the outcome can be qualified as a positive and encouraging one. In this regard, they are usually connected and act under their own parental attitudes, which are transmitted through their demonstration of mutual confidentiality regarding the children's capabilities and their overall learning capacity which leads them towards succeeding over the learning, education as a complex process. Therefore, parents should get involved in supporting their children in doing their homework, as in this way they offer their parental support as one of the key strategies leading towards a successful education of their children at school. Educational level of children in the family depends more on the level of the parent's education, so this factor strongly affects family relationships and the successful development of children. A study in South Africa by [15,16] perceived parental involvement in the education of their children with autism as instrumental to improving children's access, attendance and retention in school. It also has the potential to improve parents' sense of empowerment, and support the greater achievement of valued educational outcomes. Parental involvement may even compensate for the lack of meaningful learning in schools, especially when a conducive environment is created in the home for learning. Nevertheless, Reference [15,16] did examine the role of parents in the education of learners with Autism. The role of parental participation in the education and general development of their children with autism cannot be overemphasized. There are higher chances of children with autism learning new skills and correcting behaviors is highly dependent on how actively parents are involved in the educational program. Based on previous research, it was hypothesized that parents who have a positive attitude towards their child's education are able to positively influence their child's academic performance by two mechanisms: (a) by being engaged with the child to increase the child's self – perception of cognitive competence and (b) by being engaged with the teacher and school to promote a stronger and more positive student teacher relationship [16]. Research found evidence that higher parental participation in a child's education contributes to an increase in a child's perceived level of competence [18]. Parents have several roles

to play which include the implementation of interventions that aim at developing social skills in their children with autism and if they work closely with professionals and especially teachers, their children's development is likely to score positive achievements in attaining good social behaviours. A study by [19] showed parents' involvement at school influenced by the extent of school staff who encouraged, assisted and provided parents with opportunities for involvement. Thus, with parents' lack of understanding of their roles, they can be limited in their participation to providing food, books, and paying school fees. They should participate in behaviour rehabilitation intervention programmes designed for their children by specialists and teachers. They should participate in helping their children do their school work. But all this depends on the parents' skills to communicate with children with autism. It also depends on the attitudes of the parents towards the education of their children with autism. Studies by [6] found that parents of children with higher developmental risk reported less family involvement and poorer relationships with their child's teacher. Several factors can affect parental participation in the education of children. Differences between teachers and parents over the education of children with autism may emanate from attitudes of either the parents or the teachers. Such differences may further emanate from the frustrating behaviours of the children which teachers may blame on parents and it may also be as a result of parents not helping out in activities that teachers give the children to do at home. Reference [7] report that language can be a serious barrier in this regard. There are several factors that make it easier for parents to participate in the activities of their children with autism and these include financial resources, frequent communication with providers, support from family members and friends, and the initiative of staff to provide parents with information regarding interventions and resources [20]. However, improved communication about the children's needs between parents can help children with autism to benefit from school.

### **3. Methodology**

This study adopted the qualitative paradigm. The research design used was Phenomenology. The choice of the paradigm and design was influenced by the researchers' desire to understand, describe and report the experiences of parents in parenting children with autism. The study sample consisted of 20 participants; 10 parents of children with autism and 10 teachers. Parents were the main target sample while teachers complemented the sample as informers to enrich the data in this study. Thus, teachers were used as informants in the study, to report about the parents' roles in the education of the children with autism they taught. Purposive sampling procedure was used to select the participants. The researchers visited the schools and teachers helped using their records to connect the researchers to the parents who had children with autism in the schools. In-depth interview guide was used to collect qualitative data for the study. Participants were asked to describe their experiences and role in educating their children with autism. In the description of the experiences and roles, they were also asked about the challenges they faced.

The findings were analyzed according to themes. Similar themes were noted and interpreted. Codes were used to distinguish participants and their contributions. Thus, since there were two groups of participants, group A, participants were parents identified as A1-A10 male or female while participants from group B were teachers identified as B1-B10 male or female. All participants participated willingly with informed consent and their names and other identities have not been unveiled for ethical reasons.

#### 4. Findings

Findings of this study showed that parents suffered frustration, stigmatization and psychological stress in the upbringing of their children with autism.

##### 4.1. Experiences of upbringing a child with autism

Participant A8 F explained that like she had mentioned earlier, where sleeping was concerned, sometimes her son does not sleep early, to make matters worse he would be up too early and this would force her to be awake as she would not know what step he might take next. Her son is on and off the sick bed, psychologically she gets affected to an extent that one cannot understand, unless one is experiencing what she is going through, she further explained that people seem not to understand what they go through in living and bringing up a child with autism. In her statement she reported, *It has not been an easy experience as am expected to go for work in the morning and he also has to go to school. So we are all disturbed in the house with his sleeping patterns and to be honest it is frustrating. We survive by the grace of God, I can say* (A8 F 28/03/19). Another parent reported that raising a child with autism has been an awful experience, he said that his daughter has sleeping problems and this is disturbing, because he has to go to school in the morning and we also have other things to do, apart from sleeping problems his daughter also has eating problems, and this worries him a lot because sometimes she goes to school on an empty stomach. Participant A5 M further reported that, *sometimes she would totally refuses to eat anything as she leaves for school and it is so disturbing, what disturbs the most is when the food which was packed for her comes back the way it was packed, un tempered with. Even when we go to visit, it feels very bad when she refuses to eat in people's homes, not just any people, but relatives. It is embarrassing and frustrating, it appears as though we do not inculcate good manners in her* (A5 M 21/03/19) In the above findings parents get stressed up with the behavior of their children of not sleeping early. They constantly got worried because this affected their plans for taking their child to school the following day since they did not have enough sleep Parents also experience negative attitudes from the community. The following excerpts show what some of the parents felt having a child with autism was like to live within the community. In their experiences, some parents felt ashamed moving with their children in public. Two parents expressed some nature of shame as follows. *At the beginning of this year, we were in the city center with all our children, including Muma (not a real name) our autistic daughter. We decided to go and eat at one of the restaurants. Muma suddenly got up, (they move so fast that sometimes you cannot notice) and went to one of the tables and just grabbed somebody's drink. We were so ashamed. The people were offended such that they left the restaurant uttering bad words. I remember one lady saying, 'niofunta' meaning, she is 'mad.' It was so heart breaking. Anyway, we are used hearing such kind of words from people and it is not easy to explain her disability every time we go somewhere* (A6 F 25/03/19). Another parent reported *I remember one Sunday at Church, my son was running around and this group of women called me outside, they started lecturing me that my son was too big to be behaving like a two year old baby. One lady even said that, 'this is the end result of spoiling children, they become stupid.' I could not open my mouth as they were not giving me chance to explain, meanwhile they know my child and I had tried to explain on his condition sometime back. It was so bad, that I felt ashamed. I just involve God in everything that goes on with my child as I draw my strength from Him. It has been a hard battle to fight I can say, because when I go back to the community where we live, people call my*

son names, some even refer to him as that 'mad' boy. It is really heart breaking and very disappointing coming from a Christian community (A 10 F 30/03/19) The above excerpts demonstrates how difficult it is parenting a child with autism. Parents receive the largest share of blame and ridicule out of the behaviors their children exhibit in the community. However, some parents explained the positive contributions of the community in which they live with. A role played by the community in sensitization has helped some of the parents accept the condition of their children with autism. The following excerpt explains an experience of how some parents benefit from their communities:

*It would not have been easy had it not been the support from the community where I come from. The community where I live made it seem easier. I almost withdrew myself from the community where I lived, I stopped attending funerals, I stopped attending social gatherings and other activities which required community gatherings until my caring neighbors noticed. They started encouraging me and I also felt free to explain the condition of my child. In the community where I live, parents have taken it upon themselves to explain to their children and other children in the community the condition of my daughter and this has helped a lot in the way my daughter is treated by her peers and elderly people. I can say it is just by the grace of God. (A3 F 15/03/19)*

One parent reported receiving support from members of the family and the community where he and his family live. The school where his son attends lessons has also shown a lot of support. He further explained that even though the diagnosis for the son was done early, and that support is given by family members and the community what really hurts the most is what the child passes through. The parent had this to say; *The school as a community where my son attends lessons have shown without any reasonable doubt that indeed people are different in the way they perceive things. We have been receiving support emotionally. The teachers pay attention to my son's wellbeing and look forward to seeing him be independent one day just like we hope for as parents. They have encouraged me so much to continue taking him to school as there is change from the time he started attending lessons at the same school. We do thank God for what he is doing for us, as we believe it can only be God, the disability is not an easy one to deal with (A9 F 29/03/19)* However, it was revealed that with support from the community experiences of parents in educating their children would be seen to be less stressful and encouraging. From the three parents, it appears community support is crucial in helping parents adapt to having a child with autism. The experiences were shared by parent A3 F, parent A4 M and parent A9 F.

#### **4.2. Teachers' responses on roles played by parents in the education of their children with autism**

When teachers were asked about the roles of parents in the education of their children with autism, most teachers expressed worries at the negative attitudes of some parents towards the education of their children with autism.

Teacher 1-male said that, he had observed that children whose parents come from shanty compounds pay less attention to the education of their children, the belief is that the children are brought to school because maybe someone somewhere might have told them, the child can learn. However the conviction that the child can really learn and achieve something in future is not there on the part as parents. Mostly, when such parents are called for meetings or anything pertaining their child, they never showed up. For such parents as long as the child has attended class, all is well and it has been done. In other cases the child will miss school for days such that even after being called as parents they take things lightly, mostly will not come but you will just see the child in school after being absent with no explanation at all. (08/03/19) Another teacher reported that *It matters where the parents come from for*



*them to pay attention or play a role in the education of their children with autism. In this school we have a problem of parents coming from shanty compounds not playing their roles in the education of learners with autism. To them bringing their child to school is enough and you would be surprised that some parents even think that they are doing us teachers a favor by bringing their children to school. However, some parents, it has been observed that pay particular attention to their children and the roles they play are seen by us the staff in this school. When called upon to discuss the child's progress, they come. Because they are aware that their children require parents in taking care of their special needs. Parents have knowledge that sometimes, we teachers do not have. (Teacher 2 Male- 13/03/19).* Sharing a similar thought was another teacher who reported that residential areas were a factor when it comes to parents playing a role in the education of their children with autism in school. The teacher narrated that parents from shanty compounds were very difficult to work with concerning their children with autism. He explained that parents gave excuses from January to December just to avoid facing the teacher. In her report, the teacher stated that such parents usually sent their older children or other relatives to discuss the progress of their children on open days. This was construed as a negative attitude. One teacher reported that, *Some parents that we have in this school believe that teaching is the work of teachers, this leads to a good number of parents to not participate in educational activities of their children as they probably are not aware that their participation influences academic performance and how do we as teachers, help such parents. Some parents more especially father, sometimes say attending to a call from school is the mother's job. I don't know whether I should say they lack information or what (Teacher 4 Male- 15/03/19).* Another teacher reported that *I am quiet disappointed with the attitude that some parents put up when it comes to educating learners with autism. Some parents are not willing to actively play their role as parents in the education of their children, especially men. One day I was shocked when one male parent openly asked me that, 'are we not just wasting money on this child?'* Such negative attitude cannot build someone, no matter how you convince him, the mind is already set, even as such a parent continues to bring the child to school, he has no hope and bringing the child to school can be said to be just for formality's sake (Teacher 5 Female- 18/03/19). From the findings, parents did not play active roles participating in their children's education. However, when asked as to why that was the case, some teachers reported lack of information on the significance of parental participation in the education of their children with autism. They however highlighted that some parents participated and supported their children's education. One of the teachers narrates; *I can give you an example of parents to these children (pointing at some children), they are very committed towards the education of their children, and the role played by these parents in the school is that, these parents come to different school activities whenever called upon and they also take part in the activities. Committed parents in this school have even made a support group where they come to encourage each other and share their experiences, this also helps us as teachers to know how to handle these children and what to expect from the children. For the support group the parents meet two times in a month at this very school (B3 F 15/03/19).* When asked if parents really played a role or not in the education of their children with autism, teacher 6, Male reported that teachers easily see contributions made by certain parents from homework given to the learners. The parents sign on the given homework to show they helped the child with the homework, an observation that was described by the teacher as encouraging. One teacher explained that *In this school we have two types of parents, the only common thing they share is that they have children with autism, otherwise some parents have quite a lot of information on the disability and because of this they really pay attention to the education of their*

children such that their role in the education of their children is visibly noticed. Some parents make an effort of bringing their children to school and wait for them. (Because we keep these children in this our school for only two hours) and for some parent, the hours are manageable. Parents in this school attend workshops where some of them even facilitate certain topics for the workshop. These parents are those with a lot of information on the disability and they have shared that, having seen autistic children becoming successful in other countries, they believe it will be so with their children. This has motivated us as teachers in this school. However, like I have mentioned that we have two types of parents, some parents due to not having or having little information are just not interested in the wellbeing of their children where school is concerned (B7 F 27/03/19). Another teacher explained how parents participated in the school activities for their children. He stated that, We have some parents who are very committed to their children's education. Some of the roles that some of these parent play in this school are that they take part in the IEP team process, we have some very active parents who ensure they are involved with and they do take active roles as part of the IEP team, they take part in our school's extracurricular activities when they are requested to do so because they realized that children can also learn in such a way. The parents also play a role in core curricular activities by helping their children do their homework

(teacher

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Male-28/03/19)

From the above findings some parents do play a role in the education of their children, the kind of roles that parents play in the education of their children included, parents attending to different extra-curricular activities in the school, parents taking a lead in the IEP, bringing their children to school and waiting for them and helping their children with homework etc. Six teachers reported of parents not actively playing a role in the education of their children with autism, while four parents reported that some parents do play a role in the education of their children with autism.

#### **4.3. Parents' responses on the roles played in the education of their children**

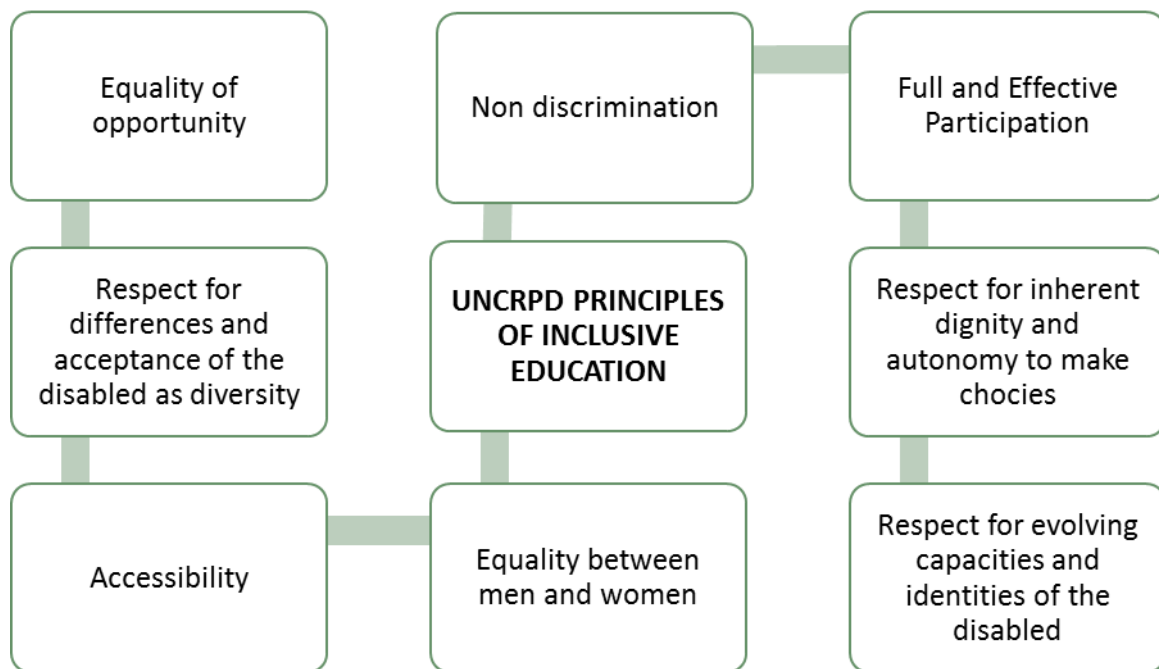
When parents were asked about what role they play as parents in the education of their children with autism, what commonly came out was that they played the roles of taking the children to school, helping them with homework and buying books. One parent described his role as follows; *I bring my child to school by myself to make sure he enters class and I wait for him until he knocks off, being a business lady I know I have to make my business run, but a few hours waiting for my son who needs special attention when at home, at school or anywhere will not make my business go down I believe. I help with his homework every time he is given at school. Besides I just have to wait for him at school as I noticed some negativity in some teachers, I fear for his wellbeing sometimes* (A9 F 29/03/19) Participant A6 F when asked what role she plays in the education of her daughter explained that, she is a team player in the Individualized Education Program (IEP) plan designed for her daughter. She further said that she follows what she is advised concerning her daughter as far as academic work is concerned, however, when she sees something wrong in any matter concerning her daughter's education she does not hesitate to speak out. Participant A6 F also reported that she works hand in hand with other parents and this had helped her get new ideas on how to manage the education of her daughter. The concept of the IEP was also mentioned by other participants as can be seen from the verbatim below *I am in contact with my child's school to make sure I do not miss out on any update about my child and I am part of the team that monitors his progress. In doing so I believe it is another way of monitoring his learning. I do not even mind how many times I go to report to the school when my son is not attending class. He is off and on sick bed most of the*

*times, nevertheless, this does not discourage me from taking him to school the times that he feels better. I always make sure that he is not overburdened with school work looking at his sickly condition. He is very bright but sickness disturbs him (A8 F 29/03/19). Another parent explains, I view myself as a member of the team that takes care of my child. I know what my child's strength is and what he needs. The role that I play in his education is that am involved in the evaluation and placement of my child and this has made me encourage other parents who are in the same situation as me to do the same. I am aware of each and every step taken before and after moving him to the next level. Even just paying school fees for my son is playing a role because if you look at it, if I don't pay school fees would my child be allowed in class forever and ever without I being summoned or would anyone not concerned or have any connection with him just wake up today and pay his school fees. The fact that I pay school fees is also a role that I play (A 10 F 30/03/19).* Generally, participants in the above verbatim have a positive attitude towards the education of their children with autism, hence the active roles they play in their education. Based on the above verbatim, some parents know for sure that the IEP is indeed a cornerstone for the education of their children. The parents expressed pleasure on how involved they are in the education of their children. Their role in the IEP helps them see clearly the progress of their children. The findings showed that the fact that some parents play certain roles in the education of their children they do understand that their contribution in whichever form towards the education of their children have an impact in the lives of their children. Intervention in the learning of children with autism by parents maximizes learning, improves the quality of family life and will help in enabling parents to sustain their efforts with their children over time. However, according to the reports given by some teachers there is need to sensitize some parents on the importance of playing a role in the education of their children if they are to see their children live independently as adults. In the findings, some teachers confirmed the roles played by some parents while some teachers reported to parents not playing any role whatsoever.

## **5. Discussion**

From the findings, it was established that children with autism have sleeping problems. Irregular sleeping and waking up patterns as a lived experience of parents created stress and anxiety in parents. The findings are in line with [21] who in their study on autism found that poor sleep quality of children with autism had strong impact on mothers and fathers as well as on the child with autism. Parents' and child's sleep quality has important between-person and within-person, day- to- day association. This behavior is particularly stressful on parents and are strong predictors of psychological well-being for both mother and fathers. Generally, poor sleep quality has been shown to contribute to the occurrence of stressors [22] what more on a child with a disability. With poor sleep quality affecting both children and parents of children with autism, emotional instability is likely to affect the way they live in a home and even at work. For instance, parents may go to work tired and fail to keep up to the demands of their jobs as a result, leading to job ineffectiveness and subsequently being laid off or fired. Personal relations with other people can be affected when one is always stressed up at home. Community negative attitudes as an experience of parents demonstrates some degree of ignorance of the disability by the general community. In the findings it was established that children with autism as well as their parents are stigmatized. These findings are in line with a study done by [23] who stated that, mostly parents of children with autism spectrum disorder experience stigmatization which is not easy to handle. Stigmatization affects parents and their children in that it makes their lives more challenging as they are compelled to withdraw. Because of

their children being different from others they are left out of activities and verbally bullied. The experience of stigma can extremely be damaging to the personal identity of an individual with autism. Stigmatization interlinks with a negative impact upon the parents' social life as they exclude themselves due to fear of embarrassment caused by their children or are excluded deliberately. Exclusion of oneself from the community as a result of stigmatization leads to child withdraw from play which eventually affects the child's social and intellectual development as a whole. Children develop optimally by engaging actively in the environment. As revealed in this study, the few communities with positive attitudes allow children's freedom and that of their parents to move and interact with other people in the community. The community is key in preparing the quality of life for learners with disabilities and their families [24]. Further, the revelation that stigmatization and discrimination of parents of children with autism and their children with the condition exists in the communities of Lusaka works against the scores Zambia has made towards domesticating the major pronouncements on the rights of persons with disabilities and generally on inclusion and inclusive education policies so far being implemented. For instance, on the 8 principles of inclusion as construed from article 3 of the United Nations Convention on the Rights of Persons with Disabilities UNCRPD [26; 27; 28], stigmatization and discrimination can affect access to not only school but generally access to many social amenities. Figure 1 below shows the 8 principles:



**Figure 1:** the 8 principles of the UNCRPD

Discrimination and stigmatization waters down the Zambia Persons with Disabilities Act of 2012 [29], which admonishes discrimination, and tagging it as illegal practice that can be attract a penalty before the courts of law. Negative attitudes and discrimination of persons with disabilities in itself works against respect for individual respect for human capacity and participation in society. People feel out of place because they are negatively treated with bad attitudes. Currently, the advocacy should be '*Leave no one behind*', thus, society should be devoid of negative stereotypes [30], in language use referring to persons with disabilities as was

discovered in this study through some verbatim referring a child with autism as 'mad'. The negative comments society makes on parents of children with autism creates negative self feeling on the parents and it has more devastating effects on their participation in their children's welfare. For instance, parents may feel a sense of inadequacy in skills of parenting yet it's the disability that creates the pressure on them. As such they may withdrew from interacting with the community and this failure has a negative impact on the children's general development [31]. Community negative attitudes abrogates most of the UNCRPD principles and works against the Sustainable Development Goal number 4 on Inclusion, equity and life long learning for all. Although this study was qualitative, making it difficult to absolutely conclude on how wide spread the negative attitudes were, the tips from it call for further studies of a quantitative nature to establish the gravity of the problem and to institute measures to overcome negative attitudes. There is a high possibility that such negative attitudes may be caused by lack of the community's understanding of the nature of the disability as was reported by [4;5]. Parental participation in the education of their children with autism is a predictor to academic achievement and personality development of their children with autism. Literature shows that children who witness the presence of their parents in school improve both in personal development and academically [25]. This is because they realize the importance of their parents' place on their education. In this study, the discovery that most parents did not take part in the education of their children with autism leaves teachers more stressed with work and also denies the children the opportunity to be encouraged to learn by their parents. The findings of this study are similar to that of [16] who stated that parental support of their children is insufficient and parents do not generally discuss or participate in their children's school work. If parents lacked information on the roles they are required to play, they need to be informed of their roles and the significance of their participation. Parents have a duty to help in homework to encourage their children to learn. They have a role to help their children with autism to improve in communication and attainment of social cues. This can be realized by their participation in the individualized education programs that the schools set for individual children. However, in this study, the revelation according to teachers that some parents of children with autism exhibited negative attitudes towards their own with autism's education needs further exploration because several factors such as poverty and low education backgrounds may be at play. One pointer to this is the revelation that parents from low economic suburbs in Lusaka were the ones that appeared to be disinterested in the education of their children with autism. It is not clear why parents generally did not participate in the education of their children with autism, although some literature says there are factors such as illiteracy. For instance, a study done by [32] reported that it is illiteracy that hinders them from carrying out this role.

## **6. Conclusion**

In conclusion, this study established different experiences of parents of children with autism. Generally, parents experienced stress and embarrassment resulting from difficulties managing unusual behaviors of their children with autism. Some unusual behaviors spurred negative attitudes towards parents. Further, the study revealed that some parents did not actively participate in the education of their children with autism, limiting their roles to helping in homework, taking their children to school and buying the children books. A few parents that were engaged in the education of their children gained confidence and satisfaction of their role. Parents from compounds considered to have low education levels were mostly considered as having negative attitudes towards participation in the education of their children with autism. Although teachers accused parents of

negative attitudes towards the education of their children with autism, future research must explore factors that inhibited parental participation in the education of their children with autism. We further conclude that discrimination and stigmatization can affect positive efforts to implement the UNCRPD principles on inclusion of persons with disabilities in education and society in general as illustrated in figure 2 below:



**Figure 2:** How discrimination and stigmatization can affect implementation of UNCRPD Principles

From figure 2, we realise that the need to find measures to address vices that fight against the attainment of inclusiveness become crucial if we are to attain the sustainable development goal number 4 on inclusion, equity and lifelong learning. While the *Zambian education policy 'Educating our Future'* 1996 and the *'Disability Act'* of 2012 promote equalisation of education opportunities to education and beyond, the ugly face of discrimination and stigmatization of persons with disabilities continues to frustrate such willful efforts aimed at ameliorating the lives of persons with disabilities. Above all, children with autism and their parents need support in order to fully participate in education and other developmental activities of their nation.

## 7. Recommendations

Effective education and management of behavior for children with autism requires active participation of parents. In light of the findings, the following recommendations were made;

- The Ministry of General Education in Zambia through schools with learners with autism should embark on sensitization of parents about the roles in the education of their children with autism.
- Community sensitization about the negative attitudes towards parents and children with autism needs to be carried out. Thus emphasis on laws against stigmatization should be made clear to members of the community.

- Parents need to be equipped with skills to manage unusual stressful behaviors in their children with autism.
- Schools should link parents to support groups where they acquire knowledge and skills to manage unusual behaviors of their children with autism.

### **8. Limitation of the study**

This study was limited by the design which was qualitative and therefore, the findings may apply to the parents studied in Lusaka alone. However, lessons can be learned by parents and stakeholders in similar situations. The voices of the children with autism would have added rigour to this study. Further, the limitation in communication that children with autism exhibit restricted the access to first hand data from the children about how their parents participate in their education. Further research should establish broader views and experiences of parents of children with autism and the factors that affect their participation in the education of their children with autism.

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### **References**

- [1]. C.R. Reynolds and E. Fletcher-Janzen. Handbook of Child Neuropsychology. USA: Springer. 2009.
- [2]. E.A. Zillmer, M.V. Spiers, and W.C. Culbertson. Principles of Neuropsychology. Canada: Thompson Wadsworth. 2008. pp 311.
- [3]. J. Chan, CPNP, and R. M. John. Sexuality and Sexual Health in Children and Adolescents with Autism. The Journal for Nurse Practitioners – JNP, Vol 8, 4, 306-315. April 2012.
- [4]. T. Chansa-Kabali, J. Nyoni and H. Mwanza. Awareness and Knowledge Associated with Autism Spectrum Disorders among University Students in Zambia. Journal of Autism and Developmental Disorders. Vol 49, (9) pp 3571–3581. September 2019.
- [5]. J. Nyoni and R. Serpell. The impact on parents of raising a young child with autism: A phenomenological study of parents in Lusaka, Zambia. International Journal of Disability, Community & Rehabilitation, Vol 11, (1). 2012, Available @ [http://www.ijdc.ca/Vol11\\_01/articles/nyoni.shtml](http://www.ijdc.ca/Vol11_01/articles/nyoni.shtml).
- [6]. S. A. Garbacz, L. L. McIntyre, and R. T. Santiago. Family Involvement and Parent-Teacher Relationships for Students with Autism Spectrum Disorders. Sch Psychol Q.; vol 31(4):478–490. doi: 10.1037/spq0000157, Dec 2016.
- [7]. E. Munsaka, and B. Kalinde. Laying the foundation for optimal outcomes in early childhood education, Lusaka: UNZA Press. 2017.
- [8]. D. Poepelmeyer and & L. Reichert, Pioneering Program Teaches Families Sign Language Through Tele-Intervention. ODYSSEY. 2015.

- [9]. J.P Comer and N.M. Haynes. (1992). Parent Involvement in the Schools: An ecological approach. *Education and Society*, 3: 271 – 277.
- [10]. M. Mbewe. Effectiveness on picture exchange strategy on the communication skills development in Autistic children. Lusaka: UNZA. 2016.
- [11]. K. Ilias, K. Cornish, A. S. Kummar, M. Sang-Ah Park and K. J. Golden<sup>1</sup>, Parenting Stress and Resilience in Parents of Children With Autism Spectrum Disorder (ASD) in Southeast Asia: A Systematic Review. *Frontiers in psychology*, vol 9: 280. 2018 Apr 9. doi: 10.3389/fpsyg.2018.00280.
- [12]. E. M. Starr and J. B. Foy. In *Parents' Voices: The Education of Children with Autism Spectrum Disorders*. *Journal of Remedial and Special Education*, vol 33(4) 207–216. 2012.
- [13]. A.M. DePape and S. Lindsay. Parents' experiences of raising a child with autism spectrum disorder: A Qualitative metasynthesis. *Qualitative Health Research*, Vol. 25(4) 569–583. 2015.
- [14]. F. Mohammadi<sup>1</sup>, M. Rakhshan, Z. Molazem, N. Zareh. Parental competence among parents with autistic children: A qualitative study. *Journal of nursing and midwifery studies*, vol 7 (4), 168-173. 2018.
- [15]. G.S. Lewis and S. Motala. Who controls Schools? Education Decentralization and the quest for equity: Democracy and Quality in Chisholm, L (ed.) *Changing class: Education and social change in post-apartheid South Africa*. Capetown: HSRC Press. 2004.
- [16]. B. Fleisch. *Primary education in crisis: Why South African School children under achieve in reading and mathematics*. Capetown: Juta. 2008.
- [17]. D. Anderson – Butcher. Transforming Schools into the 21<sup>st</sup> century community learning centers. *Children and School*, vol. 26 (4) pp, 248 – 250, 2004.
- [18]. A.R. Gonzalez – Dettass, P.P. Willems, and M.F. Holbein. Examining the relationship between parental involvement and student motivation. *Educational Psychology Review*. 17: 99 – 107. 2005.
- [19]. P. Benson, K. L. Karlof, G.N. Siperstein. Maternal involvement in the education of young children with autism spectrum disorders. *Journal of Autism*, <https://doi.org/10.1177/1362361307085269>.
- [20]. Moroz. Exploring the factors related to parent involvement in the interventions of their children with autism. Master of social work, University of California. Spring, 2015. Available @ [sophia.stkate.edu > cgi > viewcontent](http://sophia.stkate.edu/cgi/viewcontent).
- [21]. I. Mihaila and S.L. Hartley. *Parental sleep quality and Behavior problems of children with autism*. Madison: University of Wisconsin. 2002.
- [22]. L.D. Doane, and E.C. Thurston. Associations among sleep, daily experiences and loneliness in Adolescence: Evidence of moderating and bidirectional pathways. *Journal of Adolescence*, vol 37, pp 145-154. 2014.
- [23]. J.M. Cafiero. *Meaningful exchange for people with Autism: An Introduction to augmentative and communication*, Bethesda, MD: Woodbine house. 2005.
- [24]. J. Aceves. *Overview of Learning by Observation in children and adolescents*. Berlin: ZDF. Mainz. 2016.
- [25]. G. Horny. *Parental Involvement in Childhood Education, Building Effective school family partnership*. London: Springer. 2011.
- [26]. Leonard Cheshire. *The Disability Rights Advocacy and Campaign Project*. Leonard Cheshire. 2019.



- [27]. Leonard Cheshire. *Understanding Disability: A training manual for communities on the convention on the rights of Persons with Disabilities*. Leonard Cheshire. 2019.
- [28]. United Nations. *Convention on the Rights of Persons with Disabilities and Optional Protocol*. United Nations. n.d.
- [29]. Government of the Republic of Zambia. *The Persons with Disability Act 2012 No 6, of 2012 67. GRZ, 2012*.
- [30]. K.K. Muzata. *Terminological Abuse vs Inclusion: An analysis of selected Terms used to describe Persons with Disabilities in Luwala*. *Journal of Lexicography and Terminology*, vol 3 (1), 1\_32, 2019.
- [31]. K.K. Muzata. *Factors affecting parental participation in the education and general development of children with deafness: The case of Zambia*, a paper presented at the Disability rights in Africa Conference Regional Roundtable: Inclusive education in the African context and Salamanca 25+ Consultation. Theme: Conference theme: 'Are we learning together? Addressing barriers to inclusive education in the African region. Pretoria, South Africa, 6 – 7 November 2018.
- [32]. G. Crozier. (1999). *Parental Involvement: Who wants it?* London: University of Sunderland.