

## **Socio Cultural Perspectives on Parents with Autistic Child: A Case Study in Yangon**

Khin Muya Aung<sup>1</sup>

### **Abstract**

In recent years, there has been increasing awareness level on autism around the world, low and middle income countries including Myanmar. The aim of this paper is to highlight the perception of socio cultural conditions of parents who have been providing with their autistic child and to illustrate how autistic child is harmonious in their community. The study is descriptive study design. The study applied Qualitative research method and collected data by observation, key informant interview, individual-depth interview and available data from journal and newspapers. Parents support autistic children by helping and practicing them on their weaknesses so that they can live like other people in social community properly. Without neglecting those people with autism, they need to support them to survive independently and stand individually. The main perception of they being supported is to be able to stand along their lives with less dependence on others and to become valuable children.

**Keywords:** Autistic child, socio cultural conditions, descriptive study design, perceptions valuable child

### **Introduction**

Each society in the world is established by its culture. People never live in isolation. People usually live in organized groups, which we call societies. Culture in its broadest sense is socio-cultural behavior. It means the totality of man's learned accumulated experience which is socially transmitted through social learning. In fact, it includes all that is learned through social learning. The members in the society have different kinds of relationships and so long as relations differ, there arise different social activities. In a society, it is common that some members are not harmonious in their social structures of the society. When there is no harmony in the society, social problems bring about. Some men are disabled through different reasons. Some are innate, some out of sickness, accident. Concerning the disability, "Disability is focused on the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the individual. Disability has its genesis in a health condition that gives rise to impairments in body functions and structures, activity limitations, and participation restrictions within the context of personal and environmental factors" (Robert L. Schalock et.al, 2007). Similarly, the World Health Organization (WHO) defines disability as "Disabilities is an umbrella term, covering impairments activity limitation and participation restrictions" ([https:// www.disabledworld com](https://www.disabledworld.com)>d). There are two types of disabilities in the world; Physical disability and intellectual disability. A physical disability is a limitation on a person's physical functioning, mobility, dexterity or stamina. Other physical disabilities include impairments which limit other facets of daily living, such as respiratory disorder, blindness, epilepsy and sleep disorder ([https://en.m.wikipedia.org>wiki> physic...](https://en.m.wikipedia.org/wiki/physic...))11.11.19. Intellectual disability is a disability characterized by significant limitation in both intellectual functioning and in adaptive behavior which covers many everyday social and practical skills (Autism/ intellectual Disable and Health, Nov 25, 2015). Autism refers to a collection of neurological disorders affecting, communication, social, and behavioral development (Christopher E. Nealy, 2015). Autism is a kind of intellectual disability.

Social anthropologists study and analyse how men or groups treat each other including autism; they live through certain rules and regulations Thus, disability is a complex

---

<sup>1</sup> Daw, Lecturer, Department of Anthropology, Dagon University

phenomenon reflecting an interaction between features of a person's body and features of the society in which he or she lives. People with disabilities are often labelled "the other"; somehow separate from people who are not considered to have disabilities. Autism is a developmental disorder characterized by difficulties with social interaction. Since, the 1980s, the number of diagnosed causes of autism in the United States has increased dramatically (Savannah Montanez, 2016). Autism Spectrum Disorder is complex lifelong neuro developmental and behavioral disorders manifesting in infancy or early childhood. Although the causes of ASD are unknown evidence. ASD are characterized by impairments in social interaction and communication and by repetitive behavior (Mohammad Hussein Rahbar.2010). So, the number of who are recognized to be autism all over the world increase year after year and one family affects health, education, economy and social factors in a country. As the number of autism increase all over the world including Myanmar gravely affects not only the family but its nations. In my study area, there is no exact data yet for the rate of autism occurrence and the rate of autism is also increasing. The possibility of autism among boys is greater than that of girls. Autism depends on family and society's attitudes, beliefs, experiences, perceptions, supports for their survival. Autism is studied from different disciplines all over the world, especially psychology and medicine. Concerning the autism of intellectual disability, those persons such as parents who support them are studied.

The study area is the special school in Yangon where Myanmar Autism Association has been founded. The special school is defined as a school for training children with special needs. This association has been providing guidance mainly for the autistic issues in Myanmar. The special school in Yangon Region is selected as the study area to be able to collect the information and data related with autism for this academic work. Therefore, in this paper, how parents can be supportive and perceptions based on raising up their children with autism will be studied from socio-cultural perspective.

### **Method**

The research is descriptive study design. To collect data, qualitative research methods includes secondary source of information, library research, book, Journal, Observation, Participant observation, Key Informant Interview (KII) and Individual Depth Interview (IDI) were done. Key Informant Interview (KII) was done with authorized person of Myanmar autism association, the parents of autism child. There are 10 key informants. The parents of the people who have experiences of autism were selected for key informant interview. For individual depth interview, feelings of parents with regard to their children who are identified as autistic children, and difficulties that parents have been facing in their daily social environment.

### **Finding**

In Myanmar, understandings and perceptions on autism are various based on different societal groups in Myanmar. According to the different religious and cultural backgrounds of Myanmar people, there are various assumptions and treatments on autism. In my study area, Autism is a kind of intellectual disability. Before using the term 'autism,' there were various perceptions and beliefs about that term. Actually, autism means the situation of someone's lifelong living with deficiency in communication, thinking and creativity due to growing up with unbalanced capability or abnormality. Autism is not mental illness as well as it cannot be hereditary and communicable People, who have autism symptoms, have suffered from capability deficiencies for their whole lives due to the unnatural development processes of their brains and nerves. In reality, they are not sick. Normally, autism symptoms are defined as

an abnormality of intellectual development. In my study area, when a member is specified to be autism in a family, members face different kinds of stress and strain. Most of the citizens are Myanmar Buddhist. Parent's beliefs on disabilities are something wrong in their past lives which have resulted in their disability at the present lives. Moreover, people also think an autistic person is a reincarnation of a custodian spirit; as he or she was reincarnated from a treasure trove, they do not speak; it is an incurable malady as a result of past misdeeds. According to interview, in the educated community, they define autistic children as "children who need special care" or "children who are difficult for normal teaching".

Rather, the cause of autism is over development in some places of the brain or atypical brain development that makes problems that are inharmonious with other organs' development. Due to that abnormal process; they have to live with capability deficiency for their entire lives. Some significant deficiency symptoms in autism are social, communicative and repetitive behaviors. Deficiencies in each autistic individual are usually unique.

Concerning the social communication and interaction, it will reveal that being the disabled, sufficient trainings and supports are provided for them to obey rules and regulations, customs and ideals of the society in which they live so that they could live harmoniously and understandably. Without neglecting those people with autism, they need to support them to survive independently and stand individually. Although they are not the people who have intellectual inability, they feel awkward in their daily lifelong routines as they cannot properly do things like other people. Thus, they need support. Regarding the autistic people, there are various perceptions which create labels such as abnormality, intellectual inability, mental illness, half-wit, clot and nutcase. In fact, autism is not because of genes or the environment that they have grown up in. Lay people who are familiar with autism believe that it is a "brain abnormality". Most of the parents of autistic children from study area have said;

"the characteristics of autism are 'linguistic problems' and 'lack of social skills'".

Some parents mentioned their repeating behaviors or lack of cognition. Medically, it is noted as a problem of the brain and nerves (not a disease) which is significant in autistic people more than in normal people.

One of the fathers, 58 years' old who is authorized person from Myanmar autism association said that,

"experiments take about six months to identify "autism", because it cannot be comprehended by examination with X-ray or in a laboratory. The experts who can diagnose autism for the children with autistic symptoms is the child brain and nerves specialists or psychotherapists or doctors from children hospitals after completing the official examinations".

It can only be confirmed by examining with a child medical specialist, autism specialist, psychotherapist, occupational therapist, physiotherapist, or speech therapist. Diagnosing "autism" can only be specifically defined when a child is three years old, but possible autistic symptoms can be recognized before the three years of age if carefully watched. Beyond 2012, child brain and nerves specialists mostly identify the autism. In study area, there are various beliefs, assumptions and usages on 'autism' among societies and communities. Even though an expert defined as "autism," parents are still used to treating their children based on their ways of traditions and religions. Moreover, as they do not have awareness and knowledge of autism, its diagnosis process is delayed. Regarding the abnormal children, their parents still bear in mind based on diverse beliefs and inferences. If there are

some behavioral defeats in children, they still treat their children according to their different therapies based on beliefs, religions and traditions.

Starting from one or two years old, their abnormal behaviors start changing. Abnormal behaviors mean causing sleeplessness at night, no playing with others, decreasing voices in spite of making sound at first, avoiding eye contact and declining in happiness and social interaction. Decreasing voices mean although they spoke one or couple of words at first, later they do not speak. At the initial stage of autistic symptoms, the main problem is not sleeping regularly and sleeplessness. At the beginning, parents may not have consciousness or be negligent on those abnormal characteristics. Later, parents go to various hospitals or clinics to take treatment because their children's development process is slow and unusual. Being slow in development does not mean no eating and no physical development. It means delaying intellectual, behavioral, communicative development. When the age is one year, parents start consulting with doctors for their children as they do not grow up properly. Normally, child specialist doctors assume it as deafness. Whenever children, who probable the autistic children, are medical checked up, they are assumed as deficiency in the sense of hearing. However, when they are checked up for the sense of hearing, the answer is that it is not because of deficiency in the sense of hearing. Then, they check with nerve specialist doctors because the child specialist doctor refers to do it. Although children are being examined with such various ways, it is answered as the suspect of autism. Autism is definitely diagnosed only a child is three years old. When children are diagnosed as the Autism Spectrum Disorder (ASD), parents do not know and understand on what autism is as they are not knowledgeable. There are many criticisms from their environment on that situation. While the physicians said it is the autism disorder, parents also thought that autism disorder can be cured by taking medicines. They do not know that they have to face this situation for their whole life. They assumed that if there is a wound, there will be a medicine to cure it. Once they know it is autism, some parents suppose that their life is gone as they can do nothing on it.

Regarding the behaviors of autistic children, people from their social environment have various perspectives including strange attitude and blaming. Some people look down them by saying delinquents or half-wits. For the repeating behaviors of autistic children, people make an inference such as uncontrollable contraction of muscles or infantilism or being possessed by evil spirit. Parents of autistic individuals have also been criticized and blamed for their autistic children behaviors. If their son or daughter is diagnosed as an autistic child, parents have to support their child by facing and overcoming various stresses and depressions. In such case, the role of both of father and mother is essentially crucial. Although a father of autistic child does not give much time to take care of his child, he supports by trying to earn money for his family. When the mother feels very stressful, the father is used to taking care of his autistic child. Moreover, if autistic child is a boy, the father has to support by not only finance but also other activities that his mother is unable to help and train. Parents have to support autistic children so that they can stand in their daily lives and in social environment harmoniously. Parents support autistic children by helping and practicing them on their weaknesses so that they can live like other people in social community properly. The main perception why they are supporting is to be able to stand along their lives with less dependence on others and to be valuable children.

Parents have been supporting such autistic children as much as possible so that they can stand harmoniously in their social environment with the least assistances of others. In general, parents' supports to their sons and daughters are not a strange phenomenon, but nurturing of parents to their autistic children for better future is an essential thing. Parents are not cultivating their autistic children by expecting them to become a doctor or an engineer, or an outstanding expert. However, the main intention that they support their children from the

stages of baby to adult is to improve physically, mentally and socially. As autistic children are not like normal people, parents have to provide endless supports in every time and everywhere. Normally, a person grows up step by step on time. Differently, since the children have been identified as autistic individuals, parents have to support them from the daily routines to the death of themselves or autistic children.

Even though it is diagnosed as autism; there are still various beliefs and assumptions on it. They may suppose that the child is reincarnated from a treasure trove; or a deficient baby was born due to committing evil; or it is a result of past misdeeds. Some parents also believe that this is a consequence of Kama (fortune), and as the child committed a sinful action on someone in the past life, he or she has to compensate in this life. Some parent said that as this situation is given by the God, it is a must to accept. Regarding the autism, perceptions of parents of the autistic children are: it happens due to Kama (fortune) or a wish of the God. Then, he or she will be blessed by the God in other matters. Some parent thinks, it is a shameful situation in the social environment. They also believe that belonging a child, who has an autism symptoms and needs special care, is a fundamental cause to reach to a good haven. Some parents are pretty sick for belong such children who need special care. They have cried daily but become patient and tolerant on everything after facing many bad things. They also become understood the concept that they cannot make to happen whatever they want. They also feel happy whenever they see their children's progress, and such happiness cannot be exchanged with others. Parents mainly expressed their perspective with regard to their son who has a difficulty in learning education because of autism. Correspondingly, (38) years old, mother who is nurturing her seven years old autistic child expressed her opinion that;

“i do not hope my autistic child to be an educated person. As I know very well that he is unable to learn, I won't pressure on him. Now, he is attending at the special school. I just aim him to live properly in his daily life.”

Based on religious teachings and beliefs, parents are nurturing their children as much as possible by eliminating their mental stresses and worries and facing the realities. When interviewed to a mother, who is taking care of an autistic child with 12 years of age, she said;

“I just realized the autism when my son was five years old. Now he is 12 years old. As I am a Buddhist, I believe that this is a result of Kama (fortune). Since the situation is undeniable, I have to face it. Although I didn't do that, I accept it as a fortune. According to the view of religion, I believe that I and he did a sinful thing together in the past lives, and we have to compensate it in this current life. Thus, I have tried to remove my feelings and support him as much as possible so that he can stand along his life's path accordingly. I also ever think how can I support him with my best.”

Similarly, when an Islamist mother, who nurtures her nine years old autistic daughter, was interviewed, she explained;

“I was just aware of my daughter's abnormal behaviors when she was one-year-old. It was started through no eye contact and no play. Now, she is nine years old. According to my religion, I have to accept it as it was granted by Allah. Only can Allah do everything. I deserve with this situation because of my fortune. I believe that I will receive other good deeds by nurturing my daughter carefully. As I am one of the parents, whatever I do is mainly for

my child to be better life. With the expectation that my daughter to be recovered, if even did everything by avoiding the religious teaching.”

When interviewed to a Christen mother, who is cultivating an autistic child with the age of 12, she said;

“Autistic child is a strange person and a present of the God. The God will bless me more by valuing and supporting that present.”

With regard to being an autistic child, a Hinduism mother explored her experience;

“I can do nothing. This is a fortune that I cannot change it. As this is my child, I have to accept it whatever he is. May be, we did the bad things together in my past life. This might be the result of misdeeds. Thus, I’ve noted that we need to requite it together in this life.”

They also believe that belonging a child, who has an autism symptoms and needs special care, is a fundamental cause to reach to a good haven. Some parents are pretty sick for belong such children who need special care. They have cried daily but become patient and tolerant on everything after facing many bad things. They also become understood the concept that they cannot make to happen whatever they want. They also feel happy whenever they see their children’s progress, and such happiness cannot be exchanged with others. Correspondingly, 49 years old woman who is nurturing her seven years old autistic child expressed her opinion that;

“I do not hope my autistic child to be an educated person. As I know very well that he is unable to learn, I won’t pressure on him. Now, he is attending at the special school. I just aim him to live properly in his daily life.”

They mainly expressed their perceptions with regard to their son who has a difficulty in learning education because of autism. At first, parents had lots of hopes for their autistic children. They imagined that they will send their autistic children to the most reputable school and try their best. They also have to ever think what they should support for the future of their autistic children. However, in the reality, they have to ever think how they should support as much as possible so that their children can harmoniously stand in their lifelong. Parents are worried very much on how they should leave their autistic children when they passed away. They cannot be assured for their autistic children until their last minute. Being an autistic son or daughter, some parents had to resign from their work in order to nurture them, speak with them warmly, and support full time for their weaknesses. Even they are not able to attend schools, parents have hopes for them to be able to stand in their social environment harmoniously. Some parents just accept that being an autistic child is not as worse as a death. Some parents said they can a little bit console because when compared to the polio symptoms, autism can still be supported through systematic trainings. Moreover, parents have been supporting their autistic children with different ways, hopes and beliefs for their improvements by facing various criticisms. Based on religious teachings and beliefs, parents are nurturing their children as much as possible by eliminating their mental stresses and worries and facing the realities. Consoling with their religious teaching, they have decided to support the autistic children with their best so that they may be valuable people in the next world with their contributions and live conveniently like other people although they cannot contribute to the current world.

On the other hand, parents want their children to be treated as normal people by social environment although they are identified as autistic children. The parents want them to be alive as other normal people. They do not like if their autistic children are treated with strange manner or discrimination by other people. Although the children have autism symptoms, they

have feelings but they cannot express their feelings to other people know. Those children with autistic symptoms need special care and support for their whole lives. Parents have believed that their autistic children are the ones who can stand in the community as other people do. Moreover, being parents of autistic children is also regrettable because they cannot expect their children to become a doctor or engineer as parents of normal children do. They have just hoped them to be able to work in vocational occupations so that they do not need to rely on others to survive for their daily lives by standing themselves. In fact, autistic children are innocent and invaluable for their parents as they do not have any greed and wish to possess. Thus, parents believe that they are rewards bestowed by the God.

### Discussion and Conclusion

According to the study, it is observed that perception and knowledge of parents who nurture autistic children are crucial. When experts diagnosed their children as autistic children, normally parents think that it is like being dumb or deficiency of nerves while some parents believe that it can be cured by taking injections or tablets as they are not familiar with the term, “autism”. The main problem is hindrance to make necessary medical check-up due to rareness of experts and provide them with effective supports due to information and knowledge gap among parents. Moreover, it is learnt that the reason why experts for autism are rare is due to lack of training for caring and nurturing autistic children and enhancement for enough awareness.

Parents with an autistic child were followed different religions were observed in this study as their belief involved as a crucial role in the concept of nurturing an autistic child. With regard to belonging an autistic, Buddhist and Hindu parents believe that it is a compensation due to the past sins and misdeeds. This is a kind of compensation due to the consequence of *kama* that they might committed sins together in the past life. Moreover, Islamic parents said that they accept it because it is given by Allah. If they nurture them well, they will be praised by Allah with other alternative ways. Similarly, Christian parents also believe that it happens as the God wishes. They have to accept it as it is honored by the God. As such, it can be studied that concepts of nurturing are mainly based on each of their religions that they believe and value.

Moreover, it is noted that through the National Education Conference for Children with Intellectual Disabilities in Myanmar in October 2019, the Ministry of Education explained the plan for children with intellectual disabilities to be able to learn formal education without any discrimination (18 October 2019, Kyemon Daily Newspaper). To equally treat intellectual disabilities, including autistic children, broadcast media and print media have highlighted in stories and movies such as “Joe” film movie.

In summary, autistic children are being supported by parents, with the best ways. However, they still have a few difficulties to stand freely without having helps from others. Thus, this paper is presented from the perceptions of socio-culture that parents have been providing with best ways for autistic children so that they will be able to become valuable human beings and live in society and community equally and harmoniously.

### References

Christopher E. Nealy, Lindsey O’ Hare, Joelle D. Powers and Danielle C. Swick, (2015), the impact of autism on the family: A Qualitative study of mothers’ perspectives. *Journal of family: Social work*.2015; 15:187-201

- Mohammed Hossen Rabbar, Khalid Ibrahim, (2010), "Knowledge and attitude of general practitioners regarding, Journal of dev. disorder original paper
- Neeraja Ravind, (2012), Cultural influences on perceptions of health, illness and disability: A review and focus on autism. 21:311-319
- Robert L. Schalock et.al, (2007), The reaming of Mental Retardation: understanding the change to the term intellectual disability. Intellectual and Developmental Disabilities, Vol, 45, No.2: 116-124
- Savannah Montanez, (2016), An Anthropological perspective on the prevalence of autism: Sociology and Anthropology 4(5) 315- 319