

# EVENTS OF REALIZATION: A PARENTAL EXPERIENCES OF CHILDREN WITH AUTISM

**K. Sandeep**

Research Scholar, Department of Anthropology, University of Hyderabad, Telangana, India

Email – ksandiep@gmail.com

**Abstract:** *The 'realization' of the distinctive behavior of the child is an important stage in the whole caregiving trajectory of the families with children with autism. However, the experiences and perspectives on realization vary from family to family and from person to person. Therefore, the present article reveals the socio - cultural context of such different in parental perception and experiences. Thematic analysis of the data were collected through ethnographic fieldwork among families of a Northern district of Kerala state. 'Delivery complications', 'unusual incidents later the birth', 'delay in developmental milestones', 'strange behaviour' are the major realization events family members experience. Present article argues, the conceptualization of human conditions, such as autism, reaches its integrity when describing experiences of the companions by incorporating social and cultural contexts.*

**Key Words:** *autism, family, Kerala, qualitative research, realization.*

## 1. INTRODUCTION:

Autism is a neurological condition that is manifested through daily activities and the nature of communication. The term 'autism', biomedically defined as Autism Spectrum Disorder (ASD) and later known as Autism Spectrum Condition (ASC), was first used by psychiatrist Eugen Bleuler in the early 20th century to represent the people who were disconnected from social reality. Later, Leo Kanner, a child psychiatrist adopted the term in his article titled '*Autistic disturbances of affective contact*' in 1943. Kanner is the scholar who started to observe and define the condition and sought attention from the medical and academic community. Kanner described the children's condition as "pathognomonic fundamental disorder of the children's inability to relate themselves in an ordinary way to people and situations from the beginning of life" (Kanner, 1943: 242). In 1944, Hans Asperger, an Austrian pediatrician, also talked about human behavior similar to the observation of Kanner. He analyzed the behavior of a group of boys who were facing challenges in social interaction. Interestingly, Asperger called the children "little professors" because they show high performance in academics. After these observations by these medical professionals, much research has been done and is still going on in autism.

The most widely accepted definition for autism is given in the Diagnostic and Statistical Manual (DSM), it explains that the diagnostic criteria of autism as deficits in social, emotional reciprocity, deficits in non-verbal communicative behaviors, deficits in developing and maintaining relationships appropriate to developmental level (DSM- V, 2013). The growing number of diagnoses of autism around the world has led the researchers and the activists' interest to it.

'Autism' is an emerging study area of many disciplines such as anthropology, sociology, disability studies etc. Earlier times, the inquiry related to autism was confined to psychiatry and medicine, but now attempts are being made to explain the issue from a social scientific point of view. In addition to this, the academic community expanded the focus to explore the experiences from global North to global South countries (Grinker & Cho, 2013). It is at this point that India becomes an important site for autism research. It continues by revealing and analyzing the experiences of caregivers, family members, professionals (Vaidya, 2008, 2016; Sarrett, 2015; Daley et al., 2014; Daley, 2004). In the exploration and the conceptualization of autism, 'family' plays an important role. Because, in generally family serves as an important site for the birth and growth of children. Children grow up and learn to interact with the social world under the family comprised of single parent or the members with mother, father, sibling and grandparents. The family atmosphere becomes a witness to many eventful stages.

Mechanic & Volkart, (1961) unveils the perception, evaluation, and actions against the symptom experienced by a person through the concept of "illness behavior". Similar to this, Suchman (1965) suggests the encounter with medical care happens through several stages which deals with the "seeking, finding and carrying out of medical care" (p:114). 'Symptom recognition' is the primary stage in the process of medical care he put forward. In this stage, one can 'realize' that '*something is not right*' in the child at the physical or cognitive level. In the present study, 'realization' of a child's distinctive behavior by the parents of the children is an important stage in the journey of

'labelling' of the condition autism. It is the stage where parents begin to make frequent visit with the medical practitioners and think of alleviating the condition. Hence, the present paper explores the parental perspectives on various events which leads to the realization of the different behaviour of the child.

## 2. METHODOLOGY:

Primary data were collected through ethnographic fieldwork among the families of the children with autism in rural and semi-urban households in a Northern district of Kerala, South India. A total of thirty-six families residing in different parts of the district from middle and lower-income backgrounds were participated. The initial selection of families was done through the Autism Centre<sup>1</sup> and Special education institutions for the children with intellectual disabilities. After that, the participants were selected through purposive and snowball sampling. The interviews were conducted both at home and educational institutions. Mothers who are full-time caregivers gave the major amount of data for the present study. Participant and non-participant observation, semi-structured and informal interviews were used for the data collection. Prior to data collection, parents were communicated about the purpose of the study verbal consent was obtained.

## 3. BRIEF PROFILE OF THE PEOPLE:

Among the selected families 15 are extended in type and 21 are nuclear. In extended families, in some cases there are only father, mother, children and grandparents and in other cases only mother, child and grandmother. 23 families belong to Hindu religious backgrounds, 12 families are Muslims, and one family is Christian. In terms of family size, 12 families have one child, 13 families have two children, eight families have three children, two families have four children, and one family has five children. If the position of child in the birth order examined, 25 autistics are first born (in this, 11 are single children and one is pair of twins), five autistics are second- born, four are third- born, and two are fourth- born.

The age of the mothers ranged from 28 to 49. In the educational qualification, 15 mothers are completed the secondary school level education, 10 of them studied up to Higher Secondary and Pre Degree Course, eight studied up to Degree level and three up to Post Graduation level. Among the mothers, 32 of them are not doing any paid work. Among this, two mother were at paid job, but one took leave, and another one resigned for giving full-time care for the autistic. One mother is a special school helper where her autistic son is studying. Three mothers presently working as school teachers. Among the fathers, 11 are doing daily wage labour, nine are in the service sector, eight are working in Gulf countries, two are self-employed, two are unemployed, and one is a doctor.

The age range of the autistic persons in study is between six and half to 26. Among the 36 autistics, 10 of them are enrolled in regular schools but not attending regularly. They are taking therapies from the school-provided institutions. Three autistic people are attending regular school. Eight people are studying in BUDS<sup>2</sup>, and nine are in special schools. Three are in parent-owned schools for autism. Two are at home, and one has not attained the age to attend the school. Other than autistic features, all of them have co-morbid conditions biomedically known as Epilepsy and Attention Deficit and Hyperactivity Disorder (ADHD). Most of them do not have proper speech and verbal communication, and some of them have Echolalia and vague speech.

## 4. THE EVENTS OF REALIZATION:

There are four types of events in which parents reach a state of realization. In sequential order, 'delivery complications' is the first event, following 'unusual incidents later the birth', 'delay in developmental milestones', and 'strange behaviors and activities' of the child are the other events.

### *Delivery complications*

In some cases, the parents realize that the child have some issue immediately or nearly after the birth. They did not consider the complication related to delivery as the reason behind the child's present condition, but it was the starting event. The early suspicion of the child's 'normal' growth is possible only when the child's birth is considered as '*a complicated delivery*'. The parents widely used the phrases, '*the delivery was not normal*', '*there are complications during pregnancy period*', '*fluid dried*', '*early birth*', and '*low birth weight*' to express different types of delivery complications. Those who have had such experiences had to maintain constant contact with the hospital from the time

1 Autism Center is an institution that provides various training and therapies, specifically for children with autism. This is the only center in the study area that focus on autism. Admission is open to children between the ages of three and 15. It operates under under the auspices of the Block Resource Center, which works to ensure academic support for teachers and schools.

2 BUDS are the special institutions for the person with intelletually disabled. These operate under the supervision of the local self government. Although the institution is primarily aimed at educating those people over the age of eighteen, it accomodate the children of all ages.

of delivery and are frequently subjected to medical care. We can get the details of such incidents by looking at a few particular cases. In the case of Disha, a six and half year-old girl, the parents realized the child's differences shortly after the birth by noticing 'low growth rate', and the 'early birth' because of the seventh and half months of birth. She is a twin sister of a typical child. Most of the time, Disha interested in staying inside the home by hearing songs because she has difficulties walking. She showed discomfort when she was forced to come out of the room.

In some cases, the realization event happens a couple of days after the family leave the hospital with the newborn. For example, in the case of Unais, a 15-year-old autistic boy, the parents returned to the hospital after noticing that the child did not drink milk even seventh days after the birth. Because of this, the parents gave the 'Holy water'-prescribed by the religious specialists. Subsequently, the child's condition worsened, eyes went up, showed no response and the body color turned blue.

Similar to this, in the case of Amith a 14-year-old young boy, the parent notices the issue few hours after delivery. This even created a heated debate between the child's family members and hospital authorities. The child's delivery was 'normal', but he has not cried and fed milk the whole day. After the BCG - Bacille Calmette-Guerin, a vaccine for tuberculosis disease- was given, the child's body color became blue, and the limbs became rigid. This incident made the parents to shift the child to another hospital and be admitted there for two months.

The issues in the child's physical features at the time of delivery are also considered as an event of realization. In the case of Shahul, a 11-year-old male, the parents recognized that the child's head was not hard at the time of delivery, and the amniotic fluid was affluent. They reported the child's tongue was thick, and he always suffering with fever and mucous.

#### **Unusual incidents later the birth**

Some families experienced 'unusual' incidents that happened few months after the child birth. Parents are memorizing those incidents as an 'event' which was not 'something significant or particular' in those days. Now, parents consider such incidents as the beginning of the behavioral changes of the child. In the case of Safiya, an 11-year-old girl, the mother experienced an event when the child was sleeping in the cradle. The child suddenly raised her hands when she was sleeping. However, the mother does not realize it was anything serious. After reporting this incident to her mother, she realized it was an unusual situation. In the case of Farhan, a 13-year-old boy, the parents reported that the child fainted at the age of one and a half years. The mother also reported the 'less sleep' which was noticed in the early days. However, the mother did not see it as a problem because of the local narratives that, '*this time children are like this, they do not sleep*'. Unusual changes in the child's body feature makes the parents to suspect issues. In the case of Shahina, a nine-year-old girl, the mother noticed the unusual changes in the child's behavior at the age of two. The mother reported, the child always kept her eyes closed and noticed the reddish color and scars on the body, in addition fits come frequently.

#### **Delayed developmental milestones**

Observing and reporting developmental milestones such as rolling over, crawling, sitting, standing, walking, smiling, and speaking is common in children's families. If a person meets the family with a child, the conversation will progress by asking, "What is the child doing?" "Is the child turning?" "Speaking?". It is a tool to measure the regular physical and psychological development of a child. The expected milestones in a particular age are considered as the proper development with a healthy body and mind; otherwise, the growth becomes questionable. Deviance from the expected behavior and inability to achieve developments in a particular stage leads to the conclusion '*child has some problem*'. Therefore, usually, parents could alert to observe these developmental milestones. The delayed developmental milestones are one of the common realization events among the families of autistic persons. In the case of Adwath, a 10-year-old male, the mother, Suramya, reported that her son's activities were not similar to other children. He did not have strength in his neck and did not start rolling even after six months. In another case Meena, a seven-year-old girl, the parents noticed the delay in a developmental milestone at the age of two or three months; usually the 'normal' children started to initiate the physical activities. The parents also doubted her development because she was constantly shaking heads. In another case of Subhash, a 21-year-old male, parents reported that the child was not starting to look at a person's face which in usual cases children often do at two or three months. The parents recognized, he did not respond or smile when they showed something like a flower or anything to attract their attention. Moreover, he did not drink breast milk by sucking.

Lack, limited or reduction of speech is a popular measurement tool of developmental milestones. In many cases, even if the early developmental milestones were proper, the speech reduction was noticed over the years. In the case of Safiya, an 11 year- old girl, parents noticed that her speech was proper up to the age of three but then reduced. They believed that it will improve when they start to mingle with the children. Hoping this, they enrolled her in *Anganwadi*, an institution provide pre- school education. However, in *Anganwadi*, parents compared her activities with other children, and they felt that she has much delay in activities and also the child has no control over urinary bladder.

Her mother, Amira, expressed her worries, "*I do not know from where she left our hands*". Similar to this, in another case, Abhijith, a 14-year-old autistic boy, the mother Saira recognized the lag in the speech by comparing with other children. They notice the speech delay at the age of two and a half compared to other children of the same age. In activities also he was backward. The lack of perfection in toileting is also considered a delay in development.

### ***Strange behaviors and activities***

Realization through 'strange behavior' and 'odd activities' is another event among many families. It is challenging for the parents to recognize the symptoms when the children do not show any significant problem at an early age. If the child does not have any other developmental issues, the autistic behavior is usually recognized after two or three years. Usually, the realization and reporting of this behavioral aspects happens in the later stages of the child's development when compared to other symptoms recognition events. Parents considers a child as a 'normal child' before they realize the deviations. Most of the mothers shared, '*earlier, child was normal*', '*the child has spoken many words*', and '*activities were normal*'. when a child who showed normal behavior for a long duration starts to exhibit unusual behaviors the parents feel such changes as a high shock. One mother commented that a child before and after the realization of autistic behavior feels like two individuals. The professional consultation is also very tough, because in many a case the mothers take time to convince the child's strange behavior to remaining family members.

Temper tantrums is a common behavior usually parents recognize in a child. In the case of Anand, an eight-year-old boy, the parents consulted a doctor at the age of three years and four months because of tantrums. Along with such behaviour the child also showed disinterest in eating food and spent most of the time in front of the television. In another case Krishi, an 18 years old boy, it was his father Mohan who noticed the difference in the child's behavior at the age of one and half years because the child did not allow for cutting nails and hair. Mohan, a doctor by profession had a preconceived notion of autistic behaviour, and he doubted whether his son is autistic. Krishi showed interest only in red toy cars. Also, the boy never allowed his parent to feed him, rather he himself used to serve his food. The babbling stopped at the age of one and a half, and he pointed what he needed. He showed fear and then cried when hearing some songs. He used to run away when he hears the noise of the mixture grinder. In this particular case, the parents observed every minute details of the child's deviant behaviors when compared to other parents. The early realization of the strange behavior in this case when compared to other cases is because of the reason that here the parents had the knowledge on autism. Due to this the parents of Krishi were able to get the consultation of the experts without much confusions and delays.

In some other cases, parents recognize strange behavior by noticing the attachment and response shown by a child with some material objects and sounds. In the case of Naveen, a 12-year-old autistic boy, the parents realized the child's differences when the child used to smile while hearing the sounds of falling of coconut leaves, falling of glass plates, shaking hair. He was fond of iron objects, rods, and women's hair. The parents also noticed the child's a particular way of engagement with the toys. Instead of rolling the toy vehicles, he used to sit on it and tried to roll. He would not say hungry but he expressed it through cry. At that age, he did not recognize or name food items as 'normal' children do. He did not inform to go toilet, even he was three years old. The parents thought it was because the child is yet to attend school and learn 'normal' behaviors. Moreover, they believed that it was because no one was available at home to have conversation with the child, and he would be fine after being admitted to the school. Believing that, they admitted him to an Anganwadi. They sent him to the primary school for one year. In the classroom, he used to climb the windows, held iron bar, jumped, and did not give attention to the teacher. He never listened to anyone and but was living in a world of his own. When he was hungry, he came to the kitchen and ate food. The child used to say contradictory matters and sing songs all time. Similar to this, in the case of Akash, an eight-year-old boy, the parents noticed the child did not start to speak, even after two years of age. The parents sent him to Anganwadi at the age of three to encourage him to mingle with other children. In the pre-primary level he started to show strange behaviors such as dangerously jump from the top of the chair. Then they parents sent him to kindergarten. Even though he learned to write alphabets and few basic words, mother reported, he was failing to acquire any 'general knowledge'. Then, they sent him to a Government Pre-Primary school. However, there also he continued to behave very strangely. Therefore, the teachers started to complain about the difficulties in managing the child. According to the teachers, he behaved like a *little rowdy*, not sitting the class, walking restlessly and disturbing his fellow students. In another case, Darsh, a three-year-old autistic, the parents notice that the child often concentrates on certain things. Everything he does has some strangeness. If he plays, it has also in a special way. He was not interested in playing with toys. He is not interested in mingling with his peers. When the parents left him to play, he used to collect the leaves or stones in the premises and put them in a particular pattern. In contrast to the cases given above, in a case of Ashish, an eight-year-old boy, the strange behavior was recognized by a physician rather than the family members. The difference in behaviour was identified at the age of two when the parents consulted a doctor for the child's fever. The doctor noticed his activity, such as covering the ear and headbanging. The doctor's opinion prompted the parents to suspiciously assess certain behaviors that the child had before. His mother remembered that at the age of one and a half, he would get heavy temper tantrum. The descriptions of the experiences

above make it clear that, the 'realization' and the 'meanings' the parents give to it vary from person to person. At the same time there is another thing that needs to be explained that the distinctive experiences do not happen in a vacuum, but there are socio-cultural factors behind the distinctions in the people's perception (Fabrega, 1971; 1972).

## 5. THE CONTEXT OF REALIZATION:

The above descriptions make it clear that parents have different experiences and perspectives on realization events about their children's deviant behaviors. Their experiences range from difficulties during or after childbirth, to problems experienced during the child's developmental stages, to problems encountered during school periods. This diversity make it clear that labeling of autism is not something that is recorded only in the background of a particular event or behavior but parents go through a number of stages.

Although some families cite certain events as the beginning of their realization, their experiences do not end there. They also experience other realization events in the later stages of a child's development. It can be seen that some parents go into events that they consider to be the beginning, while other parents in some cases come in as the second or third event. Parents who suffer from 'delivery complications' may experience delay in developmental milestones, and behavioral problems in different ages of the child. By giving meaning to contexts and understanding their significance, parents often recall such experiences in a sequential way. When asked the question of when you realized the problems, parents easily get to that point. Moreover, parents speak not by isolating the events of realization, but by exposing the underlying factors involved in it.

The realization of a child's differences happen at different time, place, and by different actors. In most cases, the home serves as the primary space and family members as the primary actors. Among the family members, especially mothers and grandmothers, situate the primary actors in realization. In a social context where child care and rearing are primarily the responsibility of women, mothers and grandmothers spend more time with children and easily recognize the physical and mental development patterns of children. Parents never experience the mental states of the children go through. But through daily interactions with children and monitoring them, parents are able to adapt to their conditions. The experiences that parents describe in that way. Therefore, the parents simultaneously have the objective and subjective positions in perceiving child's differences.

But in some other cases where 'complicated delivery' has been reported, the hospital where the child was born acts as a primary space of realization. In such cases, doctors and nurses are criticized by the parents and their irresponsible attitude is considered to be the 'cause' of the child's present condition. In cases where 'delivery complications' and incidents have been reported, parents' emphasis is often on describing the incident. But in cases reported such as 'delay in developmental milestones' and 'strange behavior', the incidents are often measured and evaluated based on the child's age.

Some of the parents involved in this study have single child and some other have more than one child. Even if the parents have more than one child, there is only one child has this condition. The rest of them are 'typical' developing children. Therefore, for everyone, this condition of the child is the first experience. At the realization stage, parents do not determine what the name of this condition, as they have no previous experience with such conditions. The labeling of the condition can only happen after expert consultation. Eventhough they do not understand the names given to such conditions, but they do realize that *'there are some issues with the child'*. Labeling of the condition is no longer a matter at this stage. Beyond the question of whether or not such events presented by parents fall within the label of autism, parents recognize such events as a link of the present situation.

The knowledge prevailing with the 'normal development' related to a child's features play a crucial role in realization events (Daley, 2004). Both the 'local' and 'scientific' knowledge related to the 'normal' development of children plays an important role in this regard. There are many contexts in which local knowledge is often confirmed in conjunction with scientific knowledge. In this way, the knowledge is not working as a local or scientific duality, but it works together. There exists a prevailing belief that, after a 'normal delivery', the child should cry or drink breast milk by sucking and such behaviors are considered 'normal'. Things that happen in a different way are often considered 'abnormal' conditions. In most cases, recognizing significant delay in normal behavior happens by comparing the developments with other children the same age. The deviations from this are marked as the symptoms of 'some issues', in fact a case of 'autism'.

## 6. CONCLUSION:

This article seeks to unveil the events of realization that parents experience regarding the children distinctive behavior, leading to professional consultation. The data shows, parents go through a variety of experiences related to realization events. Beyond medical definitions, such experiences of parents include many social and cultural dimensions. Although parents often go through a variety of events, they present as the beginning of the journey the moments that have most disturbed them, shocked and shaken their consciousness. This makes clear that, parents classify their experiences not based on the medical definition of autism but on the direct difficulties they face in their daily lives. At

the same time, it can be seen that parents evaluate their children's differences from time to time by marking the context of their living environment. In this way, the paper argues, the conceptualization of human conditions, such as autism, reaches its integrity when describing experiences of the companions by incorporating social and cultural contexts.

#### REFERENCES:

1. Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous child*, 2(3), 217-250.
2. American Psychiatric Association (2013). Diagnostic and Statistical Manual of Mental Disorders Fifth Edition. Washington DC. American Psychiatric Association.
3. Grinker, R. R., & Cho, K. (2013). Border Children: Interpreting Autism Spectrum Disorder in South Korea. *Ethos*, 41(1), 46–74.
4. Vaidya, Shubhangi. (2008). A Sociological Study of Families of Autistic Children in Delhi [PhD Thesis]. Jawaharlal Nehru University.
5. Vaidya, Shubhangi. (2016). *Autism and the family in urban India: Looking back, looking forward*. Springer.
6. Sarrett, J. C. (2015). Custodial Homes, Therapeutic Homes, and Parental Acceptance: Parental Experiences of Autism in Kerala, India and Atlanta, GA USA. *Culture, Medicine, and Psychiatry*, 39(2), 254–276.
7. Daley, T. C., Weisner, T., & Singhal, N. (2014). Adults with autism in India: A mixed-method approach to make meaning of daily routines. *Social Science & Medicine*, 116, 142-149.
8. Daley, T. C. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science & Medicine*, 58(7), 1323–1335
9. Fabrega Jr, H. (1971). The study of medical problems in preliterate settings. *The Yale journal of biology and medicine*, 43(6), 385.
10. Fabrega Jr, H. (1972). The study of disease in relation to culture. *Behavioral Science*, 17(2), 183-203.
11. Mechanic, D., & Volkart, E. H. (1961). Stress, Illness Behavior, and the Sick Role. *American Sociological Review*, 26(1), 51–58.
12. Suchman, E. A. (1965). Stages of illness and medical care. *Journal of Health and Human Behavior*, 114–128.