

Challenges in transitioning to adulthood for individuals with Autism Spectrum Disorder in India

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Abstract

An increasing number of individuals with ASD are entering adulthood in India. There is growing concern among parents of these individuals, about their employability, future living arrangement, financial independence and safety, particularly as the caregivers grow older. Majority of these individuals struggle with communication and social isolation, according to parent narratives. The participating adults continued to live with their families, having limited social interface and faced a lack of employment opportunities at the time of the study.

The study also indicates a need for shift in parental attitudes towards long term planning for the child early into the intervention years.

This descriptive study also points to the need for psychoeducation and focused intervention for better adult outcomes and the ongoing need for trained personnel who are specialized in working with adults, apart from residential options for all socio-economic sections of the affected population.

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Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that disrupts typical developmental milestones and affects social, communicative and behavioral aspects of the individual. ASD is defined by social and communicative difficulties and a tendency for routinized behaviors (APA 2013). Adults with ASD are known to struggle in aspects of adult functioning including employability, independent functioning and engagement. According to the Center for Disease Control (CDC), 1 in 59 children are diagnosed with Autism Spectrum Disorder in the U.S.

The current prevalence of ASD in India is only an extrapolation of the CDC figures, at an estimated 2 million children affected by this disorder, although Autism research in India is sparse (Kandasamy & Manohar, 2018). The number of adults on the spectrum remains an unknown figure. With an increase in the number of children identified with ASD in the 1990s (Newschaffer et al., 2005), there is now an increased momentum towards building resources for these individuals who are now adults on the spectrum. There is very little information on what happened to the adults born in India born before the 1990s. The influx of these adults with ASD into the community, in addition to the unique cultural and socio-economic conditions that prevail, results in a large gap between existing services, available resources, trained personnel and job opportunities for the affected individuals.

I. LITERATURE REVIEW

Early detection and intervention of Autism Spectrum Disorder has received interest around the globe as it results in favorable outcomes (French & Kennedy, 2018). Early intervention for special needs and children with Autism Spectrum Disorder is gaining momentum in India in the last decade. According to Volkmar et al. 2017, evidence based interventions and early detection results in a more effective and favorable outcome into adulthood.

Once these children turn 15 and above, there are not many services available to match their unique needs both educationally and vocationally, placing these individuals at high risk for increased behavioral and mental health difficulties (Shattuck et al, 2012; Taylor & Seltzer, 2010). This is in contrast to the West, where the state provides security and community based living and employment options, and a support system to reduce the parental stress of caring for the individual.

Employment and independent living are important factors for increasing the quality of life for individuals with intellectual disabilities (Nota, Ginevra, & Carrieri, 2010, Wehmeyer & Bolding, 2001). The

challenge for those on the spectrum on various accounts including social, communicative, conceptual and practical areas makes job opportunities scant. The transition into adulthood is trying both for the individual himself and the family involved, as clear expectations cannot be set. On the personal front, the transition into adulthood is met with increased risk for health problems both physical and mental. Psychiatric comorbidity is common, and the use of pharmacological therapies is not rare: there is an increased risk of anxiety (rate range: 22-84%) (Vasa & Mazurak, 2015) and depression (rate range: 10-70%) (Chandrasekhar & Sikich, 2015). Research indicates that the stress levels for mothers of these children is high as they transition into adulthood and begin to worry about the future (Lounds et.al, 2007). Mothers of children with ASD are known to experience caregiver's burnout, post-traumatic stress disorder and poor physical and mental health (Smith, Greenberg & Mailick, 2012). In this study, three major themes consisting of the quality of life for the individuals transitioning into adulthood, independent living skills and the parental attitudes towards the disorder itself are examined.

II. METHODOLOGY

3.1 Setting

The study was conducted in Chennai, in South India. The primary languages spoken here are Tamil and English. The study summarized the current outcomes of 9 individuals and living in the urban setting. While the study was conducted during the Covid-19 pandemic and imposed lockdowns, all questions were asked in context of pre-pandemic situations.

3.2 Participants

Child/Young Adult Participants: n=9. The age of the participating individuals ranged between 17 and 24. Of all the participants, 7 were male and 2 were female, with a mean age of 20. All individuals met the autism diagnostic criteria on the MCHAT and CARS, in addition to a clinical observation. All of the participating children/young adults had relatively low verbal abilities or were able to speak but majority of the speech consisted of echolalia or repetitive vocalizations with no intent to communicate.

Parent Participants: n=9. The parents were all mothers and their age ranged from 39 to 56 years with a majority of them holding a graduate degree. The primary languages spoken were English and Tamil. One parent did not complete the form, resulting in the number of final participants being 9. Participation in the study was voluntary and not compensated.

3.3 Data Collection: Survey Methodology and Data Analysis

The study combined questionnaires, interviews and follow up discussions to understand the adult outcomes and the factors driving parental attitudes towards their children and the challenges of transitioning into adulthood with a diagnosis of ASD. The questions were compiled in a written survey, and a half of the participants were sent a copy of the survey for completion while the other half received telephonic interviews and the questionnaire was filled based on their responses. In addition to this, further clarifications were obtained via telephone, based on the answers filled by the stakeholders of the participating individuals. The written survey consisted of 33 questions. The format of responses to questions included yes and no responses, multiple choices and open-ended responses. An excerpt of the survey is listed below:

1. What does you're young adult struggle with the most?
2. How would you describe your young adult's communication capabilities?
3. Does he have any extraordinary skills/is he particularly gifted in any field?
4. Did you think in the past, that he/she would catch up with his typically developing peers?
5. Describe a typical day in the life of your young adult
6. List all the interventions received from the time of diagnosis
7. Looking back, what could have been done differently?
8. Did you/do ever think your child would get married?
9. Have you thought about how he/she is going to fulfil his/her sexual needs?
10. Where do you see your child 10 years from now?

All survey results were coded and entered into an excel spreadsheet by the primary author, and reliability was checked by the second author. Interrater reliability of a 100% was achieved.

III. RESULTS AND DISCUSSION

The Emerging Adulthood Theory (Arnett, 2000) states that the transition period to adulthood is characterized by identity exploration and individualism. "Emerging adults" were more likely to be responsible for themselves, establish a personal value system and change the nature of their relationship with family members to that of adults (Arnett, 2001). This is a challenge often faced by young adults on the spectrum who

require extra assistance to obtain the required independence to be responsible for themselves, and change the way they relate to family members from elders to fellow adults.

Theme 1: Quality of life Outcome

Quality of life has been defined by the (World Health Organization, 1997) as:

... a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment. (p. 1).

For this segment of the ASD population, with little formal education and low levels of communicative abilities, establishing a personal value system, individualism and recognizing their own identities is a concept they continue to struggle with. This leaves the young adults in the same space that they were in as children and adolescents, adhering to the established routines and expectations, patterns of behavior that were set when they were much younger.

Social Engagement: 1 out of the 9 participants were reported to have friends while the others did not have any active friendships or peer relationships. 5 out of the 9 participants attended a vocational set up where they shared space with their peers but did not actively engage or initiate interactions with them. One family reported that their child had friends. All the participants were reported to go on outings with their families, meet cousins and extended families during the holidays and family occasions. None of them went out of the house by themselves, unless accompanied by a family member or a therapist. None of them could use public transport. All the participating parents indicated that their child went out for walks. 1 out of the 9 participants went on walks independently, within the gated community, while the others remained dependent on being accompanied either by a therapist or a family member. Two families reported that their young adults spent close to 6 hours a day using a phone or tablet for leisure.

Employment and Living: Studies have shown that many individuals with ASD do not have an employment in spite of having completed school or received other trainings (Roy & Dillo, 2018). 40% of the participating young adults were receiving training at a vocational center. 1 out of the 9 participants was preparing to write the National Institute of Open Schooling Exam (NIOS) to obtain his high school diploma. The participating parents indicated that their children would function optimally in a sheltered work environment. One parent indicated that the family was planning to start a business venture to involve their child. All the participants, at the time of the study were living with their families.

Mental Health and wellbeing: 3 out of 9 participating individuals had a history of seizure disorder and actively received medical intervention for the same. Anxiety disorders and borderline depression were reported by 3 families while 3 others reported the presence of obsessive compulsive behaviors. 8 out of 9 participating individuals received medication for a combination of the above-mentioned comorbidities.

Problem Behaviors: 8 out of the 9 participating families reported instances of problem behavior in their child that included hitting, biting self, pulling hair, pinching, and hoarding. The presence of these behaviors limited their social interactions and ability to live independently, and limits their access to naturally occurring reinforcement opportunities.

Theme 2: Independent living skills

The concept of independence was explored through the following sub-themes:

- Self-care and hygiene
- House hold chores
- Kitchen and cooking skills
- Voluntary assistance in assisting other family members

Of the 9 participants, a third were completely independent in self-help skills. Out of them, the mother of a 23-year-old remarked that though her son could complete the tasks independently, she was unsure of the quality of his practices in prompting her to assist him fully in bathing once a week. The other adults needed verbal prompts to complete self-care tasks. The mothers indicated that their child could complete the tasks but needed them to be present to prompt them to turn on or off the faucet, wipe themselves and wash their faces. One of them needed help with orienting clothes before putting them on, though he could dress himself independently otherwise. 4 of the individuals were tasked with completion of certain household chores every day and would self-initiate and complete them, the others needed reminders and supervision to initiate and complete the tasks. 2 of the parents indicated that their child would sometimes refuse to do the tasks assigned to them and aggress towards the family if they insisted on task initiation and completion. The tasks assigned to them consisted of putting away folded clothes into the appropriate places in the cupboard, filling water bottles as necessary, hanging washed clothes on the clothes line, watering potted plants or taking the garbage out to the main garbage container in the community. The emergence of patterns of problem behavior such as compulsive completion of tasks resulted in tasks being completed as a part of a compulsive process rather than an assigned

chore. When given the exact amount of money, one of the participants could walk down the road and retrieve ironed clothes from the shop. Another participant would spend his day with technology but would not charge the handheld device if it ran out of battery while he was using it, instead pick up another available device and continue to do what he was doing, while expecting an adult to charge the device. This resulted in prolonging his dependence on the adult for a task that was relevant for him.

Two of the mothers reported that their child was capable of assisting with changing pillow covers and bedsheets on request. 4 of the participating young adults were trained at an early age in the basic cooking skills of peeling, cutting and cleaning greens, in addition to being trained to fix themselves a simple snack or a beverage, cook rice and grill a sandwich. Only 2 of these trained adults were using the skills learnt to make tea or chop vegetables at home. 2 others would cut vegetables on request, but not the entire quantity required to cook a meal. 7 of the individuals would clean up their plate, glass or cutlery if any, after a meal and put them in the sink. Only 2 of them washed the utensils and transferred them to the drying rack. None of them volunteered to assist in any additional tasks in the house, though some of them would on request. All of the young adults in the study did not possess an entire set of skills for independent living. Adaptive behavior including daily living skills (DLS) such as handling finances, shopping, planning the day, cooking, navigating the physical environment, personal hygiene, being able to communicate with the larger community and adequate leisure and productive engagement are important to independent living and employment.

Despite research demonstrating that individuals with ASD performed better in DLS skills than in social and communicative adaptive skills (Bal et al. 2015), the current study found that none of the participants exhibited independent living skills, signifying DLS impairments. Higher level of DLS dependence is correlated with poorer quality of life and institutionalization (Mlinac & Feng, 2016). Close of 50% of the participants in the study needed prompts and reminders to complete the tasks assigned to them. According to research by Mlinac & Feng (2016) it is important to distinguish between an individual's ability to complete the task versus the individual's ability to recognize that the task needs to be accomplished without a prompt. One parent stated that she was pleased that her son had learnt to systematically take out the trash to community trash bin, it was only later that she realized that he was motivated to do the task since he liked to examine the contents of the community bin. Performing the task versus understanding the rationale behind it whilst completing it became the next barrier for the parent and the adult to cross.

Theme 3: Parental Attitude

Parental attitudes towards the disorder was analyzed and divided into the following subthemes:

- Presence of giftedness and savant like abilities
- Reflection on the intervention process
- Future living arrangements

One of the underlying beliefs of autism is that these individuals have a special talent that is often hidden or not recognized. In an earlier study, the authors found that parents of younger children with ASD that believed that their child had a hidden talent, which would place their child in a different league and took it upon themselves to discover that special talent (Srikanth & Narayan, 2020). In the current study, 7 parent participants stated that they believed their child had an extraordinary skill. One of the parents stated that their child was talented at music. When asked if they believed that the approach to intervention or education to their child could have been different in any way, two of the parents opined that there were not enough services available when their child was a toddler, and they stated that outcomes might have been different. One mother stated that she wished she had focused more on music, the child's area of interest over academics. Two mothers regretted not knowing enough about expressive communication when their children were young. When asked about living arrangements for their child after their lifetime, 8 out of the 9 participating parents reported that they had not thought about future living arrangements. A minority mentioned that they might explore community assisted living in the future. 2 of them mentioned that they would want their child to be in a familiar environment with a caretaker, however they had not devised specific plans towards this end. 2 of the participating parents mentioned that it would not be fair for them to expect the sibling to care for **their** child with autism. Transition to adulthood included the skill of being flexible to changes that naturally accompanied the process of growing up. Social competence and flexibility are important qualities for succeeding in private and professional life (Roy & Dillo, 2018). All participating parents agreed that their children struggled with social communication, interaction and repetitive behaviors. Fixations and rigidities exhibited by these individuals formed a significant portion of the challenges faced by them. Mothers insisted that their children were capable of performing certain tasks independently, despite which the mothers did not expect them to do so. It was noteworthy that the same mothers encouraged their children to learn certain skills at a younger age but did not encourage or set the expectation in adulthood. Parenting a young adult on the spectrum is distinctly different from their experience of parenting a young child with autism, mothers expressed a sense of fatigue accompanying a mode of resignation, prompting them to take on the responsibility for the daily functioning of their child.

Many times, it would seem that the parent's behavior is that of avoiding a possible conflict with the child resulting in "walking on egg-shell" behavior. This behavior is seen to be counterproductive to the stated goal of independent living, as it continues the dependence of the child on the parent. Mothers of adults with ASD are three times as likely to experience one stressful event on a given day, than a comparison group of typically developing offspring. The stressful events could consist of arguments, avoided arguments, stressors at home and in the social network. They also spent reportedly less time in leisure activities for themselves, while spending more time providing care and doing chores for their child with Autism (Smith et al., 2012)

IV. LIMITATIONS AND CONCLUSION

Similar to any other study, all results are interpreted understanding the inherent limitations. The limited sample size and the abilities of the group in the study cannot be generalized to the population affected by Autism Spectrum Disorder. This study investigated the outcomes and challenges faced during transition to adulthood for the specific population. The format of data collection relies on self-reporting and automatically is subject to inaccuracies. Further investigations into parental beliefs of giftedness in autism can be evaluated using the Wechsler tests to see if the individual meets criteria for one or more exceptional area of skill.

Research and access to therapeutic and educational services for the population affected by ASD has improved over the past 3 decades (Howlin et al. 2004; Wood and Gadow 2010), additionally studies depict that a small minority of these individuals who grow up to live independently and develop meaningful social relationships with others, while a majority of them continue to be dependent on others for their daily functioning.

Adult outcomes for this population affected by ASD continues to remain largely undocumented. The study highlights the importance of counselling and psychoeducation for families with younger children with autism. This will enable them to shift the focus of intervention towards the core deficits of autism, keeping in mind the long term goal of an independent and meaningful life. Increased focus on skills equipping them towards an independent living and appropriate supported living measures are the need of the hour and would ensure greater progress for these affected individuals and their families.

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