Chapter 80

The Adult Transition Challenge of Autistic Individuals and the Way Ahead:
A Sibling's Perspective

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ABSTRACT

Autism is a life-long neurodevelopmental condition characterized by difficulties in social communication, restricted and repetitive behaviors, and sensory processing issues. In India, there is a huge question mark regarding autistic individuals after they transition into adulthood, more specifically in housing and work options. In this chapter, beginning from the general considerations for upbringing of an autistic individual, attention is given to the need for future planning of autistic adults, more specifically in residential options. Some of the major residential centres are described followed by projections on establishing residential facilities. Following this, examples of life skills training, employment, and inclusion initiatives taking place in India are mentioned. Finally, research directions and other expectations aimed at increasing support for parents and siblings and also improving the lives of individuals on spectrum are discussed.

INTRODUCTION

Raising a child with autism is challenging and rewarding at the same time. Challenging because parents have to march on a long journey right from diagnosis stage to search an appropriate school to find occupational therapy centers and other services, all these alongside managing finances, their own health, personal lives, social circles and looking after their neuro-typical off springs too. Rewarding in the sense that they develop greater sense of empathy and have unique perspectives and experiences, appreciating the neuro-diversity of their autistic daughter/son. Acceptance and good communication among family

members play a crucial role in the overall development of the autistic individual. At the same time, awareness levels and acceptance in the community also have a great impact.

In general, there are 3 stages in an autistic individual's life and her/his family members and surrounding support structure: (1) the diagnosis and early intervention, (2) schooling: either regular school or special school and (3) transition to adulthood. In India, fortunately the services and know-how in the first two stages is increasing but there is an alarming need to find solutions regarding challenges encountered in stage (3). Even in the conditions when the parents and the entire family are diligently working towards individual's development, they become worried when their daughter/son reaches 18-22 years of age. This is due to the question of "What after us?". Also after a particular stage it becomes difficult for the parents to care because even their age is increasing leading to decreasing energy levels and rise in health issues. It is also a stressful condition for siblings as they not only have to look after their affected siblings but also their ageing parents while balancing their own career, ambitions and family goals. The need to find residential solutions for adults is highlighted book titled 'Autism and the Family in Urban India' by Vaidya (2016).

The challenges encountered in stage (3) are in the domain of work options, finding vocational education and regular education sources, residential arrangements, financial security, health screenings, provision of recreational activities and a good lifestyle, guardianship and other legal aspects. While pre-planning of these activities by parent's/family's end can be very difficult but it is much better than the sudden unplanned outcomes that may affect the autistic individuals negatively. The difficulties stem from the dearth of services and even more adversely by lack of information on these. Majorly parents get too consumed in taking care of their child that they fail to realize that this very child will grow into an adult and cluelessness about the future arises when the initial hints of their incapability to provide further care becomes evident. Another important but often neglected point to be noted is that: future planning should be a combined family activity. In cases when the autistic individual has sibling(s), even they should be actively involved in making decisions. In absence of siblings, parents must form a support structure consisting of their relatives or friends or professionals, well in advance so that there will be people to look after their daughter/son after them. Lindahl et al. (2019) noted that in some cases parents identified multiple people to take care, basically distributing the caregiving activities like residential arrangements, legal aspects, health screenings, likewise.

Another big factor is inclusion. Now inclusion first starts from respecting neuro-diversity, acknowledging the fact that autistic individuals' perception is different than ours (the neurotypicals). There may be intellectual disability, there may be sensory issues and there may be kaleidoscopic situations to deal with; but it is our inadequacy if we are not able to provide them platform, give them chances to grow and more urgently, understand them the way they are. One must not try to fit them into the neuro-typical box, rather their neurodiversity should be embraced. In India, situation and fate of 'autism' is unique-on one end there are people who still haven't heard about this term at all and on other end it has a huge population of autistic adults which require urgent attention.

Author's younger brother is a non-verbal severely Autistic individual who is 23 years old now. Since the subject matter described is experiential rather than from a well-defined generalized study, the points discussed in the chapter are thus a little biased towards non-verbal, severely autistic persons. The chapter is intended to provide an overview of the present scenario and future planning which may be helpful for parents/siblings and other care-givers working for the betterment of lives of the persons on spectrum.

Following are the objectives of the chapter:

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