



Voluntary Sector Initiative: Journey of Akshadhaa, a Voluntary Sector Organization Providing Support for People with Neuro-Developmental Disability in Bangalore, India

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Introduction

Autism was recognized as a disability by the Indian legislation through the “Rights for Persons with Disabilities Act” (Math et al., 2019). The prevalence of the diagnosis of Autism Spectrum Disorder (ASD) has increased globally but recognition and support for people with autism remain patchy at its best. Identification of ASD is still a problem in India (Joon et al., 2021) which can be affected by a range of factors including awareness, access to healthcare, stigma, and social attitudes. Challenges related to the urban – rural distribution of expertise and resources is an important factor as well (Chakrabarti, 2023). Overall, there is a shortage of good epidemiological studies which are necessary to understand the true nature of the problem (Patra & Kar, 2021).

Parents who play a major part in supporting people with ASD in low- and middle-income countries such as India face several adversities such as problems in

their marital relationship leading to divorce, poor personal functioning, unemployment, poor mental health, and poor quality of life (Shorey et al., 2020; Smith et al., 2014). India has made some significant improvements in the support of people with autism through innovative approaches (Lord, 2020). Focus on family-based interventions and working with parents of people with ASD are key elements of this. Although there are some government initiatives in India that provide residential services, education, and vocational training to individuals with autism, a significant proportion of support for people with ASD in low- and middle-income countries like India comes from voluntary sector provision (Barua et al., 2017). We are providing here the journey of a voluntary sector organization initiated by the parents of an autistic individual.

Story of Akshadhaa

The initiation of the Akshadhaa Foundation took place in a context where we as the parents of a child with autism, two of the authors faced numerous challenges and had to navigate a complex system to support their child. Moving from pillar to post, we encountered various barriers in accessing our child’s necessary services and therapies. Frustrated by the fragmented nature of the support available, we recognized the need for a comprehensive approach that would address our personal experience and a desire to

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make a difference, we founded this organisation. The aim was to create a community where families could access a wide range of therapies and support services under one roof. Akshadhaa team strives to ensure that every individual the team works with becomes the better version of themselves, leading a fulfilled life for them and their families. The foundation sought to bridge the gaps in the existing system, providing a one-stop solution for families seeking comprehensive care for their children with autism.

Akshadhaa Foundation has made significant progress in its mission to address the needs of individuals with autism. Starting initially as a classroom for a small group of children with autism, the organisation has now grown to support children and adults. Current support includes.

1. **Education, skills training, and parents' support.** Akshadhaa continues to run educational and skills development sessions for children with autism and additional support for their parents with parental training and emotional support. We provide several therapeutic interventions along with education which include cognitive behavioral interventions, communication support and physiotherapy tailored to the needs of each child.
 2. **Vocational training:** Akshadhaa has developed a thriving vocational training unit as their original cohort of children have now grown up into their adulthood. The organisation provides a range of skills development opportunities and supports young adults with autism in obtaining meaningful employment where possible. Akshadhaa has developed relationship with prospective employers in and around Bengaluru including the multinational companies. We work with these companies to identify suitable employment opportunities for people with autism and provide the right occupational and social skills development support for the individuals to function in these roles.
 3. **Supporting local communities to improve inclusive practices:** Akshadhaa works with corporate and community organisations to improve their inclusive practices for neurodiversity of their employees and the wider community. Through curated programs like 'inclusive carnivals' Akshadhaa aims to improve the understanding of our community about value of inclusion of neurodiverse individuals and how they could be better supported and integrated into our community.
- The Inclusive carnival is organized in partnership with large corporate employers as a fun activity to make employers and their employees sensitive to the needs of neurodiverse individuals. Over the years, the Inclusive Carnival has been well-received at corporate companies, educational institutions, and community centers.
- The Inclusive Carnival involves a unique set of activities which can lead the individual to understand Autism in an experiential manner. The program creates an opportunity to experience sensory challenges by peeping into the world of people with neurodiversity. This will be done using activities like inclusive quizzes (inquisitive), live performances by neurodiverse individuals and exhibitions. There will be a display of solutions showing how neurodiverse individuals can be supported better in their workplace. Most sessions will be led by people with neuro-developmental disabilities demonstrating the ability of special needs individuals to bring enthusiasm and discipline to a workplace situation.
- The participants also undertake activities (small projects like making gift items) along with neurodiverse individuals providing them with hands on experience of working with neurodiverse population. There are display of relevant literature coupled with practical demonstrations which makes this program unparalleled in terms of the potential to make society more inclusive.
4. **Sensitizing the future generations on neurodiversity:** Akshadhaa various universities in placing their students in Akshadhaa as part of their training to gain useful experience of volunteering and working with neurodiverse individuals. The Akshadhaa team provide support and mentoring for the students to make use of this placement as part of their education.
 5. **Equip the Special Million (ETSM):** Partnering with other Non-Government Organisations (NGOs), Akshadhaa has now developed an outreach to remote rural areas, where we help identify and assess children with autism as well as provide training for the staff and parents to support them well. We train other NGOs on early

intervention strategies for empowering parents and teachers to support children who have developmental challenges. Through our ‘Train the Trainers program’, we have trained many teachers, parents and community health workers which undoubtedly will create a ripple effect of direct and indirect benefits.

6. **Supported living for autistic people:** The next stage of Akshadhaa’s development is “supported living”. Akshadhaa Foundation envisions a community where individuals with autism are engaged in activities that bring them joy, fulfillment, and a sense of purpose. This includes designing programs and environments that cater to their specific needs and interests, providing opportunities for skill development, socialization, meaningful employment, and community participation. The plan is to create a community with four distinct areas / functions:
1. Education and engagement center.
 2. Living areas for the people with autism with the right support and assistive technology. The use of assistive technology would enable individuals to live as independently as possible.
 3. Living areas for families and visitors. While supporting individuals with autism to be as independent as they can for a life after they don’t have the support of their parents, we would keep families close to the person with autism. We also aim to accommodate healthcare and other professionals as visitors to support our residents in a proactive manner.
 4. A network of outreach centers or inclusive workspaces, which will include spaces for neurodiverse corporate employees as well as retail links with restaurants and bakeries.

Challenges

To achieve this vision, Akshadhaa Foundation, as a small charity initiated by parents, faced, and continues to face various challenges. Ensuring funding to initiate and maintain the programs is a challenge which includes the requirement of capital and revenue funding as well as securing suitable spaces for the work. Securing these resources to run these programs has been a mammoth task with very little support from the public sector. We also had various

challenges from the local community which seem to originate from the stigma of having an organisation for disabled children in their neighborhood. Various corporate organisations have been helpful through their social responsibility programs, and we are ever indebted to the parents of the children we support for trusting us, working with us, and doing whatever they can to sustain us. Support from government agencies, policymakers, and other organizations is essential to address these challenges and ensure the successful implementation of these initiatives.

In establishing a supported living placement, a significant challenge is the lack of support for parents of people with autism to think about the future and plan. Although there is an increasing recognition of the need to prepare parents, there is much to be achieved in this area. Parents face lots of dilemmas balancing the need to promote autonomy and independence with their concern about the safety and security of their children when they can’t look after them. With very little preparation to think and plan, they often find themselves unable to make any decisions until too late.

Discussion and the Way Forward

The prevalence of autism has been increasing. Considering the size and diversity of India’s population, governmental support alone will not meet their needs. Many small charities like the Akshadhaa foundation are playing a crucial part in supporting people with autism and their families in India. To become more proactive in supporting Akshadhaa Foundation and similar organizations, governments and policymakers need to make it easy for organisations like this to access specific funds or grants. Providing dedicated funding streams for autism-related programs can ensure the sustainability and growth of such organisations.

There is a need to look at policies related to inclusive education, vocational training, supportive living, and healthcare services to make these fit for purpose and effective in supporting people with autism. This should include streamlining licensing procedures and more robust measures to ensure compliance with quality standards. By involving relevant stakeholders like parents and organisations like Akshadhaa in policy discussions, policymakers can ensure that the

voices and perspectives of those directly involved in supporting individuals with autism are heard and considered. Clear and supportive regulations can create a favorable environment for organizations like Akshadhaa Foundation to deliver their services effectively.

There is much that can be done to improve awareness of autism. Government and society's efforts are needed to steer awareness campaigns, educational programs, and community initiatives that aim to reduce stigma, increase understanding, and foster a more inclusive environment for individuals with autism.

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Declarations

Conflict of interest First author is the trustee of the charity, Akshadhaa foundation. Second author is the founding director of the charity, Akshadhaa foundation. Akshadhaa foundation is in receipt of donations from various companies for activities supported by the foundation.

Ethical Approval This is a description of the service that Authors have developed. No need for ethical approval.

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