"autism network"

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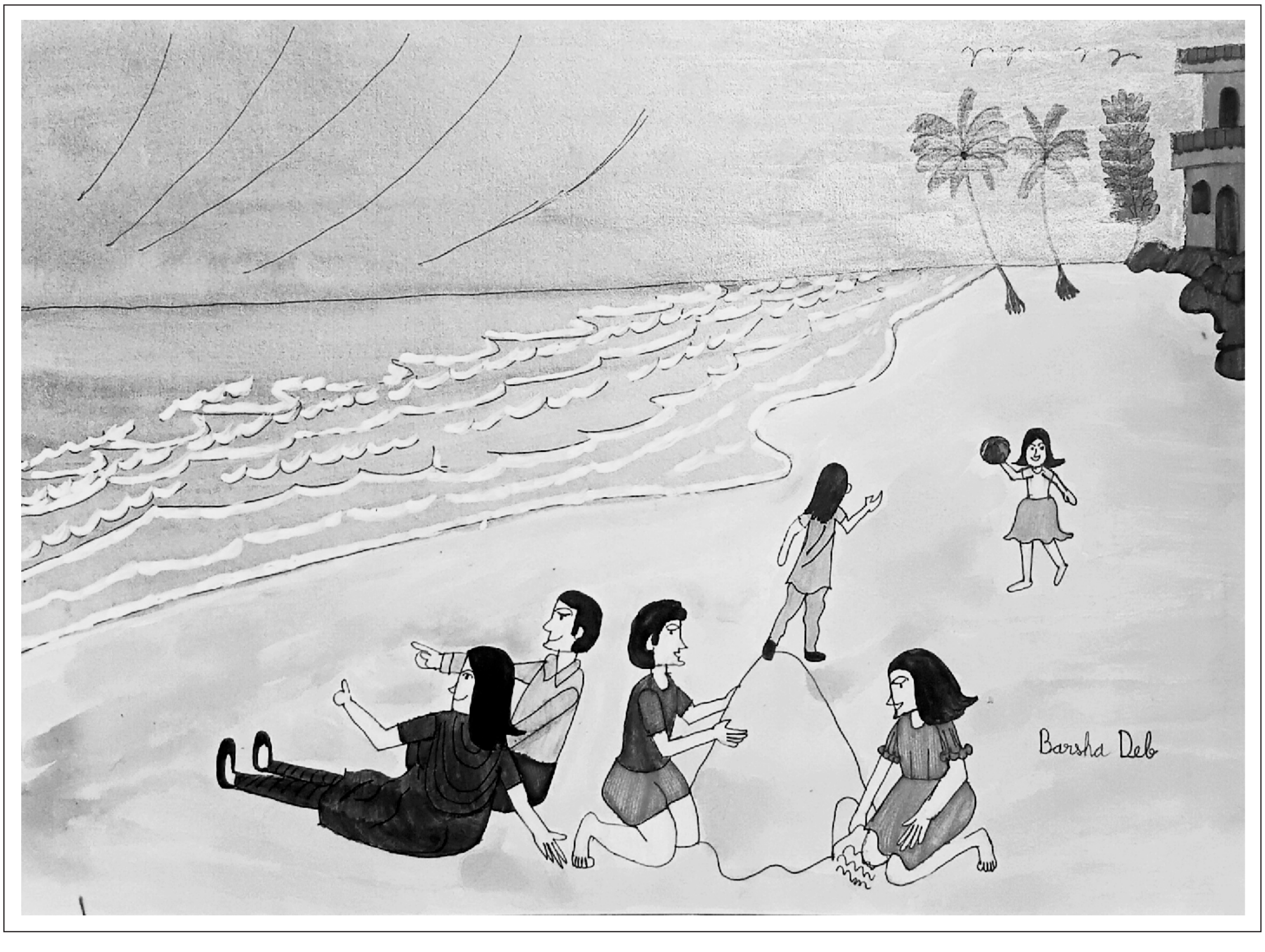

ACTION FOR AUTISM

autism network

2024 VOLUME 23

Action For Autism is a registered, non-profit, national parent organization. Autism Network is published by Action For Autism to provide information on education, therapy, care and to provide interaction for families and professionals across the country.

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In referring to a child with autism, Autism Network often uses 'he', 'him' and 'his', not as a prejudice against the girl child with autism but for reasons of simplicity and because the vast majority of children with autism are male. However, many articles also use 'she', 'her' and 'hers'.

Cover Illustration 'At the Beach' by Barsha Deb

Barsha Deb is an autistic artist from Kolkata who uses her creativity and discipline to champion inclusive art. She founded a creative enterprise that empowers neurodivergent individuals through artistic expression and meaningful work.

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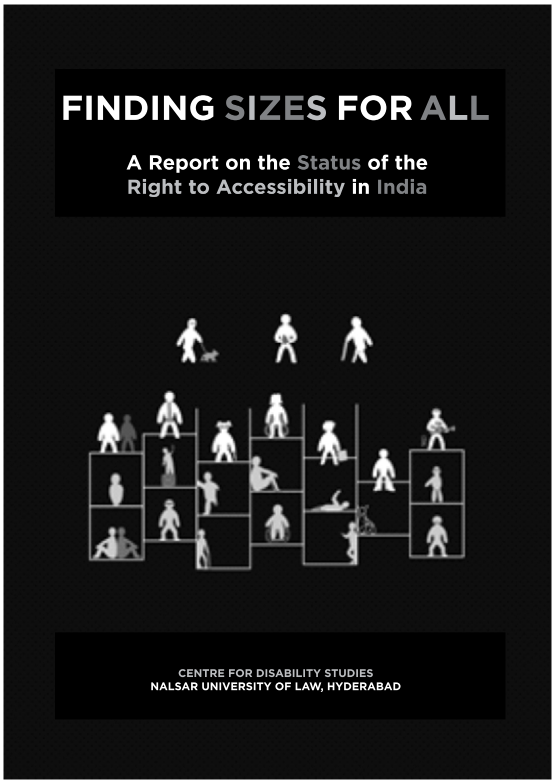
CONTENTS

PAGE ONE

On 8th November 2024 the Supreme Court of India delivered a landmark judgment that set new benchmarks for accessibility. The judgement had its genesis in a PIL filed by Rajive Raturi in 2005, seeking accessibility for persons with visual impairment and other disabilities to roads, public spaces and infrastructure. In December 2017 the Supreme Court had directed states and union territories to ensure that the accessibility standards in the Rights of Persons with Disabilities Act (RPDA) were implemented in public infrastructure.



FINDING SIZES FOR ALL

A Report on the Status of the Right to Accessibility in India

CENTRE FOR DISABILITY STUDIES
NALSAR UNIVERSITY OF LAW, HYDERABAD

However, nothing came of the Supreme Court's directive. In the light of the lack of compliance and inaction from governments, the Supreme Court tasked the Centre for Disability Studies at NALSAR University of Law (CDS-NALSAR) under the dynamic leadership of Professor Amita Dhanda to prepare a comprehensive report on the measures required to make public spaces fully accessible.

Typically and quite frustratingly, accessibility has always been seen as a requirement confined to those with physical disabilities – those with mobility conditions or with visual and hearing impairment. The Harmonising Guidelines of 2021 brought about a shift, not only acknowledging the need of accessibility for all disabilities including developmental disabilities and autism, it went further and included seniors, children, pregnant women, those with temporary disability, etc. However even while acknowledging the diversity of accessibility needs, the guidelines were limited in laying down requirements of communities beyond physical disabilities.

In order to ensure the report truly reflected stakeholder needs, the CDS-NALSAR team invited inputs from persons with disabilities, disabled peoples' organistions and civil society organisatons (including Action For Autism) from all across the country. Individuals with disabilities listed in the RPDA as well as those not yet finding a place and including non-speaking and speaking individuals with autism, all shared their experiences of exclusion and requirements of accessibility.

The report, aptly titled 'Finding Sizes for All' reflecting its participatory nature, also drew attention to Rule15(1) of the RPD Act which had made accessibility guidelines recommendatory rather than mandatory. The Supreme Court ruled that this went against the very intent of the RPD Act.

The report led to the ground breaking Supreme Court judgement of November 2024 that has held the right to accessibility as integral to right to life, dignity and freedom of movement, and takes a pragmatic two-pronged approach: the need to retrofit already existing spaces, infrastructure, etc to make them accessible; and ensuring that future initiatives are accessible from the outset.

This is a truly celebratory event for the disability community.

Let us hope that its implementation does not stumble on the hurdles of stigma and negative perceptions of the implementers, who are as much a part of the community as disabled people themselves.

Autism in Community, Beyond Pathology

Lessons from History, Anthropology, and Self Advocacy

Paras Arora

“Neurotypical Syndrome…[is]…a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity.”

(Bagatell 2010: 40)

While conducting fieldwork with an autistic adults' support group in the US, Nancy Bagatell, an occupational therapist and anthropologist, found out that she was neurotypical. Or as per this sarcastic take on the DSM's framing of autism that she found online, Bagatell realized that she had or was a person with the made-up "Neurotypical Syndrome". With this subtle change in language, neurotypicality becomes almost like an appendage that could perhaps be removed over time with the right therapeutic interventions. I am not just opening this essay with a clinical description of the Neurotypical Syndrome instead of the Autism Spectrum Disorder because I wish to transcend a "common DSM impulse" (Yergeau 2018: 20) that pathologically contains "autism's multivalent, aesthetic, and identitarian dimensions" (Fein 2020: 19). But I am also inaugurating this essay with this scene to shore up the clerical, confounding, and concerning classifications that autistic and neurodivergent individuals are discursively subjected to. Yet, the DSM's criteria for autism, which frames it as a disorder with persistent deficits in social interaction, communication, and behaviors, is only one source and rendition of the pathos that the autistic community is supposed to contend with. Surveying the blending of clinical and popular cultural understandings of autism's putative pathology, Anne McGuire observes:

> “(A)utism…[is framed as]…a *pathology of the mind and body*; a grueling cost; a life draining *epidemic*; a dangerous *threat*; a biological *problem* necessitating a biomedical *solution*; an illness needing to be *stopped, cured, fixed, eliminated.* Autism is some *'thing'*….not *'someone'* —some 'thing',…*we (collectively) do not want to have around.*” (2016: 19-20; emphasis added)

In this essay, I survey how historical, ethnographic, and self-authored accounts of autism from the last two decades challenge this wide-ranging culture of framing autism as necessarily pathological.

Historical Accounts: *Uncovering Epistemic & Affective Contexts*

“So powerful are some stories even that they are widely understood *to not be stories at all*……[just like] an etiological *origin story* of autism as *a biological condition* remains a taken-for-granted *(natural or unstoried)* fact.”

(McGuire 2016: 14; emphasis added)

Autism's varied histories are often recounted in popular culture as discoveries by "single pioneers" with very little attention paid to "the socio-historical context that made their discoveries thinkable" (Fein 2020: 13). By paying close attention to these forgotten socio-historical contexts, historians of science and disability studies scholars foreground how autism's multiple histories gesture at certain patterns about science and scientific research. These patterns concern the epistemic (McGuire 2016) and affective (Silverman 2012) investments that informed scientific experts' normative assumptions as they assigned certain ways of being into the realm of pathology. That is, the normative ends towards which the scientific gaze was destined made autism appear as primarily a *disorder* that necessitated a solution to restore it to order.

To clarify, historical accounts of autism do not deny the material existence of autistic and neurodivergent experiences in the present (or past). Rather, they reveal the historical sieves through which these experiences have constantly been (and continue to be) put under the threat of classificatory and curative violence. Therefore, the certainty with which twentieth and twenty-first century science came to delimit autism, as "symptoms", then "disturbances", then "psychopathology", then caused by "lack of maternal warmth", then "developmental spectrum disorders", and so on, is historically contingent.

Written in essay to several cases of parents murdering their autistic children in Canada in the late 2000s, Anne McGuire's 'War on Autism' (2016) provides a disability-studies perspective on the underlying normative violence of autism advocacy. As McGuire expertly traces how parent-driven autism advocacy comes to locate itself "against an undesirable biological condition" (2016: 11) in the Western world, she simultaneously follows the epistemic commitments that made scientific experts look at autism the way they did. For instance, while autism was initially defined as a kind of thinking that anyone (especially, schizophrenics) could slip into by Eugene Bleuler in 1919, autism was redefined (or discovered) as an innate disorder that required classification and surveillance under the child psychiatrist's gaze closer to the Second World War in the 1940s. Following other historians of autism, McGuire insists on locating Leo Kanner and Hans Asperger's foundational work in discovering autism within the wider epistemic context of racial eugenics, whereby, ensuring the "fitness, health, or hygiene of the individual" (2016: 33) was tantamount to ensuring state power. The child psychiatrist's will to knowledge was structured, then, through a widespread desire for "a scientifically perfectible human race" to which autistic children were framed as clear obstructions (McGuire 2016: 36).

Even when autistic children were themselves not marked as sites of pathology, the relations that surrounded them bore that brunt. For instance, turning her attention to the role of affect in molding scientific research, Chloe Silverman (2012) focuses on the history of autism vis-à-vis the contentious role of the parents. She unearths the "ambivalent and sometimes tragic qualities" (2012: 62) of theories and treatments that emerged in the wake of psychoanalysis' claims to cure autism through love in postwar America. In the 1960s, without even any formal training in psychology, Bruno Bettelheim was able to garner widespread public support through "a series of salvation stories" (2012: 67) for his theory that autism was caused primarily due to the lack of maternal love. Silverman locates Bettelheim's shaky but widespread expertise in a wider context of Freud's discovery by the Americans, whereby, the so-called "normals" were increasingly turning to the therapist's couch.

The affective investment of scientific expertise in privileging a certain kind of (interpretative) love not only stigmatized mothers and familial relations, but it informed the future of autism treatments and advocacy. Not only does Bettelheim's image of the autistic child as emptied of love and developmentally regressed continue to inform contemporary representations of autism as a disorder that holds the "real" child captive and behind (McGuire 2016). But parent-led advocacy that took shape in the immediate aftermath of Bettelheim pushed for a greater emphasis on locating pathology back within the autistic child (Silverman 2012).

The revelation of these historical contingencies indeed highlights the vested interests and affects that allowed for autism to become discoverable and sustainable as a pathology. But simultaneously, these revelations open up the ground for future possibilities to redefine autism as something more than a pathology (for instance, as neurological diversity). Interestingly, these contemporary re-definitions do not wholesale reject biomedical language, but they refashion some cognitive traits over others to sustain a stable sense of self (Fein 2020). Before I turn to such re-definitions in the last section, I shall first turn to how anthropologists have traced autistic presence in and through varying kinds of communities and socialities.

Anthropological Accounts: *Autistic Community & Sociality*

> "When certain *ways of being* are considered *outside of sociality*, they are more likely to be considered outside of the *protection, care,* and *respect* afforded to human life."
>
> (Fein 2020: 15; emphasis added)

Responding to the clinical framings of autistic children and individuals as interactively, communicatively, and behaviorally disordered, ethnographers have produced a rich set of cultural portraits that render autistic lives as embedded in and constitutive of vibrant socialities and communities.

Richard Roy Grinker's *'Unstrange Minds: Remapping the Worlds of Autism'* (2007) is one of the most widely read ethnographic texts on autism around the world. Taking the reader on a literal journey across multiple historical epochs and countries alongside his autistic daughter, Isabel, Grinker argued against an epidemical understanding of autism at a time when it was still being publicly imagined as only a threat to children. However, it is his ethnographic accounts of autism parenting and advocacy from other countries, like India, South Korea, and South Africa, that most vividly widen given understandings about the lack of social relations that autism exists in.

For instance, Grinker discovered an unprecedented degree of sociality between autistic children and their mothers in India when compared to several other cultures. Holding the "Hindu child-rearing practices" (2007:118) responsible, which privilege an eternal and embodied bond between a mother and her child, Grinker documents how the Indian mothers he worked with enjoyed an intensely reciprocal emotional bond with their autistic children. These children, however, often refused to engage with their extended or joint family. Even though the child's estrangement from wider family and kin caused rifts, many mothers built upon their culturally privileged relationship to their autistic children as the basis for autism advocacy and cultural reimagination. Autism, therefore, isn't destined to be a disorder of social disengagement across relations and cultures.

Anthropologists have indeed prioritized parents of autistic children as prime ethnographic subjects to trace how biomedical knowledge comes to be reclaimed, reproduced, or refused by families of autistic children. But since the 2010s, ethnographic attention is being increasingly paid to at least high-functioning and verbally articulate autistic individuals to elicit their own understandings of identity, subjectivity, and community (Fein 2020). This small but certainly growing field of ethnographic inquiry provides a rich portrait of how autistic individuals build communities of support for and with each other often against the paternalistic presence of medical experts, educators, and parents.

In *'From Cure to Community: Transforming Notions of Autism'* (2010), Nancy Bagatell offers one of the first ethnographic accounts of a small but very active autistic adults' support group from the US. Even though one might assume that "people with autism….lack the skills essential for the establishment and maintenance of a community" (Bagatell 2010: 34), Bagatell's interlocutors proved such pathological assumptions to be wrong by co-creating an accommodative environment. From imbibing the discourse of tolerance for different neurological makeups, to meaningfully engaging in self-stimulatory motions often in a synchronized fashion, members of the support group sustained the community around a commitment to not erasing shared and even disparate cognitive characteristics.

Bagatell paints a picture of the support group as a "figured world" (2010: 38), whereby, autistic members actively engaged in routine occupations, discourse creation, and artifacts production that reproduced the group. Bagatell was often surprised not only by the ingenious sociability of her interlocutors, but the neurotypicality of her own conceptions of sociality. For instance, it was only gradually that Bagatell realized that one didn't have to engage in face-to-face dialogue or small talk to socialize. Instead, she ended up spending time with her interlocutors either silently or solving confusing riddles or surfing the internet. Participating in autistic sociality, therefore, made Bagatell question her unchecked predispositions to socializing through certain modalities over others, which were socially dominant but not naturally normal.

Some anthropologists have even employed the tools of linguistic anthropology to devise an understanding of how through the fulfillment of some situational conditions, an autistic sociality may emerge as a "systematically observable and widespread phenomenon in everyday life" (Ochs & Solomon 2010: 69). Elinor Ochs and Olga Solomon conducted a decade-long linguistic ethnography of how autistic children on varying ends of the spectrum interacted with their social environments at home, school, and other community settings in the US. Ochs and Solomon successfully showcase that a belief in the communicative incapacities of autistic children is contingent upon severely rigid and narrow modes of understanding what constitutes "good" communication and sociality. Some of these narrow modes include face-to-face interaction, unmediated subjective topics, long conversational sequences, primacy of speech, heightened affect, etcetera. Ochs and Solomon argue that when certain situational conditions reverse these rigid expectations, then, there is a high likelihood for "social coordination" (2010:71) to emerge between autistic children and their interlocutors.

Thus, autistic sociality is not always the opposite of neurotypical sociality. Rather, Ochs and Solomon insist that the possibilities for communication across the spectral divide may emerge out of "the gray areas of sociality shared by those diagnosed with autism and neurologically unaffected persons" (Ochs & Solomon 2010: 70). One among several such gray areas of possible sociality could emerge through multimodal affordances. For instance, while describing how one of their non-verbal autistic interlocutors showed great willingness to communicate through nonverbal means (that is, by pointing at a sign board), Ochs and Solomon note:

> "…pointing is *not only a developmental precursor* to speech but also *an opportune semiotic alternative* for enhancing severely affected autistic children's *potential for human sociality.*"
>
> (2010: 84; emphasis added)

As some of the only ethnographic researchers who have focused on autistic individuals with high support needs, Ochs and Solomon demonstrate not only the alternative possibilities offered by multimodal communication. But they also initiate a crucial conversation about the transformative role that certain object affordances may play in extending the subjective experience of autistic individuals to the world.

Ethnographic accounts of autism, then, successfully challenge assumptions about the fundamental anti-sociality of autistic individuals. And in true anthropological fashion, they critically turn the ethnographic gaze back upon the unchecked neurotypical expectations for absolute commensurability while communicating and socializing.

Yet, not all ethnographers are neurotypical. One of the most recent ethnographic pieces related to autism is authored by an autistic ethnographer herself.

Cinzia Greco's *'Divergent Ethnography: Conducting Fieldwork as an Autistic Anthropologist'* (2022) is an auto-ethnographic reflection on her fieldwork experience as an autistic migrant woman across three European countries. According to Greco, being autistic meant that she was an ethnographer among neurotypical people long before she actually became an anthropologist. She had been unknowingly using research methods to break down social facts that didn't seem obvious to her. The idiom of doing ethnography among strangers, therefore, gives Greco (and other autistic writers) the vocabulary to describe what it is like to socialize in neurotypical settings.

Interestingly, once Greco actually began her ethnographic research outside her home country and mother tongue, she found comfort in having the freedom to ask questions and take notes during social interactions. But doing ethnography also made her vulnerable to unanticipated sensory stimuli.

Therefore, autistic self-reflexive accounts of ethnography, or what Greco calls "divergent ethnography" (2022: nd), offer an exciting opportunity to contemplate how ethnography can be made inclusive for not only autistic interlocutors but also for autistic researchers. Moreover, divergent ethnography also constitutes a fascinating method to explore what autistic sociality and community may look like across cultural and linguistic differences. In the following section, I turn to the richness of self-authored accounts by autistic academics that Greco's work contributes to and builds upon.

Self-Authored Accounts: *Re-Storying Autism as Neurological Queerness*

As much a disability and neurological difference, autism is also a "constellation of stories" (Yergeau 2018: 20). Routinely, these stories are authored by and for those who are themselves not autistic. Even when authored by those who care for their autistic loved ones, these stories may represent autistic people as antisocial, passive, uncommunicative, and even destructive. How do these stories displace certain forms of being human outside the realms of what is considered imaginable and livable? And, most importantly, how do autistic people themselves inherit, relate to, and re-narrate these stories?

Beginning with one such charged story about their childhood obsession with their excrement, Remi Yergeau's *'Authoring Autism: On Rhetoric and Neurological Queerness'* (2018) is an evocative and timely response to these questions. According to Yergeau, an autistic activist and rhetorician, autistic people are "storied into autism" through a repertoire of narratives (both clinical and familial) that constantly elide autism into "that which contrasts" (2018: 2). Autism is, thus, made to contrast with everything that may be associated with humanity itself—language, empathy, sociality, etcetera. For instance, Yergeau turns to their own mother's dramatic narrations of Yergeau's infantile obsession with their poop. Yergeau recounts how effortlessly these narrations would slip into a series of opinions about other behavioral mishaps that, according to Yergeau's mother, caused them to have a lonely childhood. Other parents of autistic children too articulate such "pathos-driven genres" (2018: 3), whereby, the presumably horrified audience is expected to identify and empathize only with the parent who had to selflessly clean the whole house that was smeared with their autistic child's shit. Further, these narratives seamlessly turn into conversations about the neuropathological symptoms that this obsession with shit truly represents.

But for Yergeau, "these narratives are shittier that the shit that they claim to represent" (2018: 3). Refusing to create clear demarcations between such familial and clinical modes of storying autism, Yergeau builds an argument around how rhetorical framings of autism are used to deny autistic people a *right to be rhetorical* and, therefore, right to be human. Yergeau's contention is not that autistic people cannot legibly speak back against these pathological stories. Rather, Yergeau argues that when autistic people do produce counter-narratives about themselves (and some of their special interests in shit, for instance), they are denied the same right to be rhetorical or convincing by non-autistic people.

That is, in some cases, autistic advocates are considered "too articulate" to be autistic in the first place. In other cases, non-autistic audiences blame an autistic person's autism to be doing the talking because no typical human being could possibly defend playing pleasurably with their own excrement. Therefore, Yergeau posits that autism is produced as a rhetorical condition through stories that render autistic people as "rhetorically residual subjects" (2018: 32). Here, rhetoric has a capacious meaning. To be rhetorical, one is expected to possess intention, free will, sociality, audience awareness, among other qualities. But since autistic people are rhetorically framed as incapable (or residual) on all these fronts by non-autistic people, autistic advocacy and authorship is rendered either unreliable or impossible. Autistic people's testimonies (about why they like playing with shit, for instance) are, therefore, read as either too sophisticated (not autistic enough) or too pathological (too autistic and, thus, in need of curing).

One among several of Yergeau's political and intellectual commitments, then, is to reframe or re-story autism as a neurological form of queerness that challenges normative modes of thinking, communicating, behaving, and socializing. One of Yergeau's collaborators in developing and pushing for this framework is a queer and autistic psychologist, Nick Walker.

In her widely circulated and celebrated book, *'Neuroqueer Heresies'* (2021), Nick Walker provides a lucid introduction to what she calls "the neurodiversity paradigm", which further paves the way for "neuroqueer" (2021: 6) to become an increasingly claimed identity within and even beyond the autistic self-advocacy community. According to Walker, the neurodiversity paradigm emerges directly through the digitally mediated sociality amongst autistic individuals, and the paradigm has three fundamental principles. First, diversity among minds is natural, healthy, and valuable to humanity. Second, just like there is no "normal" ethnicity, gender, or culture, there can be no normal or right style of the human mind. Third, dynamics of inequality, oppression, privilege, and power between different neurocognitive groups is a result of social organization and construction. Therefore, it is not just natural for people with a specific cognitive style to be (dis)advantaged across all social milieus.

Under this perspective, then, autism is a "neurodivergence", one minority community of neurodiversity, which intrinsically orients an autistic individual's "psyche, personality, and fundamental way of relating to the world" (Walker 2021: 24). Therefore, attempts to remove or diminish autism, as per Walker, are attempts at removing autistic people, who are an essential and valuable part of humanity.

Walker is careful to point out that the anxiety that autistic people might experience in certain social contexts is not a symptom innate to autism itself. Rather, it is a symptom of the "traumatic oppression" (Walker 2021: 56), ranging from subtle rejections to outward hostilities from others, that autistic children are subjected to since a young age. Thus, Walker argues in favor of autistic individuals' decision to rely on psychotherapies that may lower their anxiety response to traumatizing social encounters.

Even though Walker relies on biomedical language and research to define autism, she profusely refuses to pathologize autistic modes of thinking, behaving, communicating, and socializing. Instead, she repeatedly compares diversity in neurocognitive styles to diversity in sexuality and gender expression. These diversities cannot and shouldn't be eradicated. This further informs her, and Yergeau's, framing of "neuroqueer" (Walker 2021: 111) as an identity which is now being increasingly claimed by autistic and neurodivergent individuals.

While historians of autism have explored the epistemic and affective conditions that made autism's first scientific appearances contingent and incomplete, ethnographers have revealed the rich potentialities of autistic socialities and communities. In this process, anthropologists have come to question their own presuppositions about what constitutes seemingly natural socialization and communication.

Finally, self-authored accounts have variously critiqued how autistic voices are themselves rendered residual to discourses around autism. In doing so, these accounts have not located pathos as singularly stemming from biomedicine or scientific expertise alone. Families and popular culture are by no means less complicit as per these accounts. Therefore, in this essay, I have focused on how recent historical, ethnographic, and self-authored accounts of autism reframe it as not "something" but "someone" existing in excess of pathology and entangled within varied communities.

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Re-envisioning Supported Living for Autistic Individuals with High Support Needs

(Just a mother and her son sharing their thoughts)

Chitra Paul and Tarun Paul Mathew

As a caregiver to a young adult who identifies as a non-speaking autistic, I am often asked to share my thoughts on the kind of residential setting I would choose for my son. I am a strong believer of the tenet 'Nothing for Us, Without Us,' one that I strive to follow in all domains of my life. Hence, I decided to co-author this article with my son so that both of us could share our thoughts on the topic of our choices in residential settings for him. The reason I decided on this was because the person with the lived experience should have the first and last point. In my role as an ally, the primary focus is to amplify the voices of people like my son. This is just our personal thoughts on the said topic.

Vision of a Home

As a caregiver, I do have a certain envisioning of what I would love for my son to live a life of quality, experiencing the good things of life. But let me stop there and try to go back in time to when I was growing up, or for that matter, when any of us were growing up – we each had our visions for what we wanted in life, right? Some of us fought hard to follow the path we wanted to, some got away with a little bargaining with our parents or family, following some dreams while shedding some away forever or putting aside some for a later date, perhaps? And yes, some of us perhaps got minimal to no opportunities to follow our visions for our lives.

Every one of us has enjoyed some phases in life and not liked some. But I am sure all of us would agree that across all the groups of people I described above, the common thread one would notice would be a sense of fulfilment every time the person got to choose, got to make decisions on matters related to their lives, no matter what the result. Right?

The reason I am talking about this is to highlight how important a role autonomy and choice play in every single person's life in ensuring that the person gets to live a life of quality. Coming back to people like my son and others like him, those with disabilities, autistic individuals, people with intellectual disabilities, if we take a moment and ask ourselves the question – how much autonomy do they have over their own lives? It is then that we realise how connected autonomy and the quality of life that a person experiences are.

Hence, though I may envision everything under the sun for my son, I would like to focus on what he envisions for his life. My envisioning can then either become a part of his envisioning, or it could be left behind when I align my thinking with how best to support him to live his life. I know my inputs will come in so that his vision can become a reality, and to help balance his dreams with reality, all with the intent to support him. In other words, a re-envisioning of life ahead for him as he sees it.

It's his life. Going by this line of thought, my son and I had a brief conversation about his vision for a home in times beyond the lifetime of us, his parents. Sharing some snippets from our conversation so that you can get an insight into what he envisions for his life. The effort here is to amplify voices like his so that more people working in this space seek to listen to their voices and their choices.

Me: Do you understand what living options mean?
Tarun: Yes
Me: Could you tell me a little about your present living arrangement?
Tarun: Yes, I live in Kochi in a flat with my parents.
Me: Are you happy with your present living arrangement?
Tarun: Yes
Me: You are going to be 20 years old soon. Other young people your age often want to move out and live on their own, either in a hostel, as a paying guest, or in a home of their own. Would you want to move out of your parents' home and live on your own?
Tarun: Yes
Me: Would you want to do it now?
Tarun: No
Me: Why?
Tarun: I like living with parents.
Me: At some later point in life, you would like to move out, is it?
Tarun: Yes
Me: But, right now, you are happy staying with your parents, is that it?
Tarun: Yes
Me: Have you ever felt that because you stay with your parents, you are not able to do things that you would like to do?
Tarun: Have opportunity to initiate action if I really want to do different things, only need to talk to my parents.
Me: So glad to hear that you have confidence in us. So, at a later point, you would look to move out into your place, is it?
Tarun: Yes
Me: How would you like that place to be?
Tarun: I enjoy most at home being with my good family. So, I would like to be in a single home only.
Me: What do you mean by single home?
Tarun: You do stay only in a home with people you love and who care greatly for you.
Me: Now, who would these people you love and who care for you include?
Tarun: Your family and friends.
Me: Would you need someone to help you with your day-to-day life?
Tarun: Yes
Me: So, would you look for this help from family or friends, or rather prefer a paid person to support you?
Tarun: No may mostly need paid person
Me: I am going to ask you something. There are living spaces specially being developed for people like you with disabilities, specifically autism. These places are called residential setups where many such individuals stay together, often away from their own families and in small places, sometimes even villages. Would you want to stay in such a place?
Tarun: No
Me: Could you explain the reasons why you don't want to stay in such a place?
Tarun: Not bringing me happiness because have to not live my life the way I think is best for me and how I want to live life. My happiness only revolves around my family and having people who care for me and who I care for around me. Like, not made to do things I have no interest in.
Me: What are the things you feel are best for you?
Tarun: Possibly having opportunity to learn new things, get knowledge. Protect my present lifestyle. Live with people only known to me.
Me: How do you want to live life?
Tarun: Look to live like everyone around, little work, little play, above all, enjoy every moment.
Me: Suppose you need to stay in an assisted living setup; how would you want that place to be like?
Tarun: Kind of like my home. Have only feeling of freedom to do the things I would like to do, but also get the feeling of responsibility because it is my home. Have the freedom to do the work I want to do, follow the routine I want to follow,

dress according to my wishes, enjoy food I like, find enjoyable opportunities my way.

This conversation shows the clarity he has on what he envisions for himself. As a parent and, yes, as a mother, I do fear for his safety, that he doesn't get further rejected or isn't hurt emotionally by those he interacts with. However, at the same time, I do realise that the reality is that I am only a mere human being. I do not control his destiny nor mine. I can only help him take risks while I am around, so that he learns to cope, develops strategies to survive, and develops resilience. I can try to create the relationships of support around him, of people who care for him and who he cares for, as he says. As he states clearly, he wants to be in the driver's seat of his life journey, and in every aspect of this journey, too. As a mother, it is only right that I respect his decision.

The beginning, then, should be from what the individual wants for their life and then working to see how best it can be achieved. My son knows he will need support and that family alone may not be able to meet it, but for what and how, are his decisions to make. That, then, is what I, as a mother, need to respect. I need to remember that he is not an extension of me or his dad, but an individual in his own right. So insightful.

Having said that, if I think deeply about what my role as a parent and as a mother could be in this. Well, we all know there are a lot of things lacking in the space of assisted living for neurodivergent individuals. To begin with, there are no guidelines or regulations set in place. It then becomes imperative to develop standards and frameworks that guide practice. As an ally again, here I would insist that people with lived experience be included in framing these.

Another point to be cautious of when setting these frameworks and standards is not becoming overly bound by them, such that the human element is overlooked. The people being served need to be always at the centre of every decision made, not our sense of fear or safety. Decisions should not be made based on our understanding of what is best for them.

I leave you with the line shared by my son about wanting to live in a place that feels like home, with people who care for him and whom he cares for; to live a meaningful life, with some work, some play, and enjoying every moment to the fullest.

So, Let Us…….
~ Let us then begin to re-envision an assisted living setting as a 'HOME', keeping the individual and their choices at the centre of the exercise.
~ Let us re-envision it as a 'HOME' instead of just a living space!
~ Let us re-envision it as a 'HOME' where one lives with close and dear people instead of with strangers!
~ Let us re-envision it as a 'HOME' where one dreams and configures how to make them a reality instead of merely passing through life!
~ Let us re-envision it as a 'HOME' where real and thriving human beings, just like each one of us live, instead of as inmates in an institution!
~ Let us re-envision a true 'HOME' instead of a make-believe one for autistic individuals – one that they envision for themselves!

***Chitra Paul** is an inclusion advocate, parent, and Program Specialist at Keystone Institute India. She co-founded Allinclusive Foundation and works to amplify non-speaking autistic voices.*

***Tarun Paul Mathew** is a 20-year-old non-speaking autistic advocate from Kochi who types to communicate. He is a nature-loving poet, math enthusiast, and youth fellow with Rising Flame.*

The Puzzle of School Frustrations

Prakriti Ghosh

School is supposed to be the halcyon days of one's life. Those are the days when you make friends, your teachers run after you and your work is fun. But is this always true for autistic individuals? From my experience, I would say we have our own set of challenges to contend with, of which there are many. It would be my pleasure to tell you what they are. So here they are.

Sensory issues
My inability to sit in a noisy classroom has not changed since the second grade. Even today, being in the classroom raises my cortisol, making me wish I could just get out of there, thanks to 59 other kids talking loudly enough to make me feel that I just can't take their screaming anymore.

If this happens in substitution periods, I usually ask the teacher permission to visit the library. Fortunately, this request is granted.

Other behaviors caused due to sensory issues are:

- Moving hands: For me, this takes the form of tracing cursive letters in the air. This serves as a form of visual stimulation and also satisfies my fixation with certain words (e.g. soothing)

  Other reasons for the same behavior could include tactile stimulation (pressure induced by rocking hands results in increased body awareness) or visual stimulation (rocking hands in front of a tubelight results in certain patterns). Alternatively, this could be used to serve as a distraction from other sensory input.

- Jumping: This takes place more often at home than in public places. I usually do this when listening to electronic music or thinking about some imaginary cartoon. Often, I end up visualizing a certain movement, which triggers this action.

Social expectations
Difficulty with reading and understanding neurotypical social cues is characteristic of autistics. But then social expectations keep changing as per age, culture and several other factors. And there are more exceptions to them than rules.

For example: If children are taught 'Honesty is the best policy', then adolescents and adults have to learn that there are situations in which lying is a necessary life skill, not a sin.

Social environment in school


Me when talking about my classmates...

Fig 1

The following are some of the challenges I have faced during that period.

- Difficulty making friends inside the class: School tends to create a cut-throat environment, and Fig 2 illustrates students' concerns.

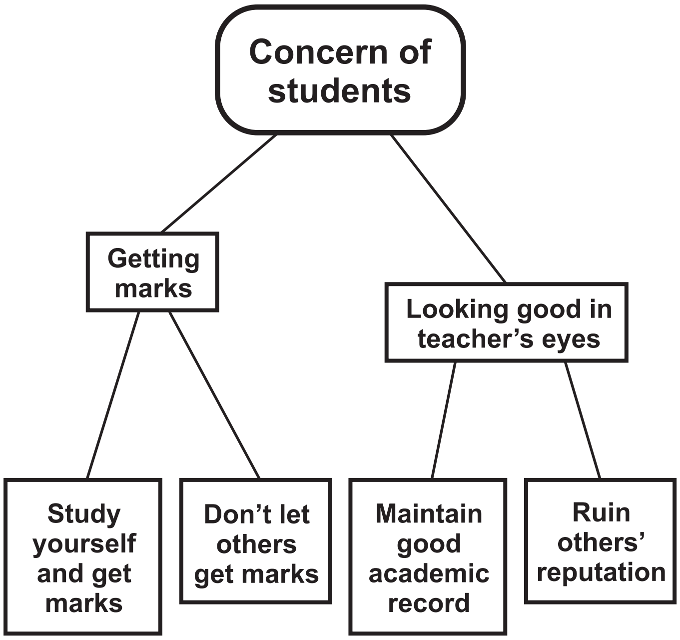


Fig. 2

Unfortunately, some will opt for ruining others' reputations and not letting others get marks. School, especially in the senior years, creates an environment where classmates perceive each other as threats.

This is why some of the students in the Science and Humanities are my good friends. This is also the reason I do not feel satisfied with my relationships with my Commerce peers (don't know whether to trust).

- <u>Interactions:</u> I am not a fan of discussing topics like nonsensical Instagram posts, rumours about other schoolmates (especially those concerning boy-girl pairs), and film stars. Career talk, day-to-day issues and special interests appeal more to me.

  Which gives others the impression that I'm a serious, studious and no-nonsense student. I suppose it's okay for the Science students and all teachers, but in Commerce, anyone like that would probably be a misfit amongst the students as was my experience.

Managing academic and extracurricular activities

I am in my last year of school and have the following areas to worry about:

- <u>Entrance exams:</u> I take coaching for design entrance exams, which means on weekends, I have to travel 1 hour, sit for 3-6 hours (except for breaks) and another 1 hour is used up in going back home.

- <u>Board exams</u>: A one of a kind Indian festival, whose preparation includes collecting and attempting earlier question papers, undergoing academic-related stress, attending tuitions and pre-exam discussions. Preparations begin in April and end before the next February.

- <u>Extracurricular activities</u>: You also have to mention these in your portfolio (for colleges and job applications.) People will tell you how competitive today's job market is. After discourses like these, I wonder: “Am I good enough?”

  Considering that autistics have executive difficulty, managing all three tasks is certainly not a cup of tea.

Bullying

Explicit
Can be determined immediately
Can be labelled as "bullying" at once
Example: physical abuse, teasing, name-calling

Implicit
Cannot be determined immediately
Need time to realize that this is "bullying”
Example: gossip, rumors

Fig. 3. Types of bullying

Bullying is something that many individuals, be they neurotypical or neurodiverse, face. What the autistic has to learn is:

- Identify bullying
- What to do
- How not to land in trouble

Bullying need not be the explicit kind (Fig 3). Some examples of implicit bullying are:

- <u>"Let's You and Him/Her Fight":</u>

  Here's an example: A 'friend' and classmate of mine, Sania (name changed), told me. "You know, when some of our classmates laugh at you, I wish I could slap their faces."

  Sania expected this: since I am short-tempered and have behavioral issues, I will go and fight with those classmates. As expected, I will land into trouble. If I tell the teacher, "They laugh at me, Sania said so." chances are she will deny the whole thing.

  So I just cut off contact with her.

- <u>Insincerely praising something the autistic has/does:</u> An example could be telling Sally, an uncoordinated child "Why don't you show us how to swim?" and then laughing at Sally as she thrashes about in the water. (adapted from Roger Meyer's chapter in *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum, edited by Stephen Shore*)

- <u>Rumours and fake friendship:</u> The bully acts friendly towards the victim, taking what seems to be a genuine interest and concern in them. When the victim tells the bully a secret, it gets spread around wherever possible, leading to teasing.

Emotional regulation

As I mentioned before, I am short-tempered and have behavioral issues. Often, I land into unwanted situations like pushing somebody, throwing books at someone, yelling at the teacher, emotional 'lows' etc.

Most of the reasons for this are:

- Premenstrual syndrome (mood swings taking place before periods).
- Frustration (may be due to threat culture of the classroom, anxiety about certain events).
- Sensory overstimulation
- Overthinking: I have difficulty figuring out social situations and often don't know whether to rely upon intuition. My detailed mind looks at the minutiae of each situation and then determines the solution.

Disclosure & Advocacy

Here are some reasons why autistics may need a mention their diagnosis (by a parent, or self-disclosed, if that verbal)

- Need for extra support (as in case of sensory issues)
- Explaining cause of certain behaviors (stimming, for example)

However, this decision is not risk-free. My greatest fear, on reaching the 11th standard, was my classmates finding out that I am autistic. To me, this event was associated with the preceding two years of bullying and being taken advantage of.

Another risk is the teacher's attitude towards the mention of your diagnosis. While this may sometimes be very helpful, it can also be extremely unhelpful, and everything in between.

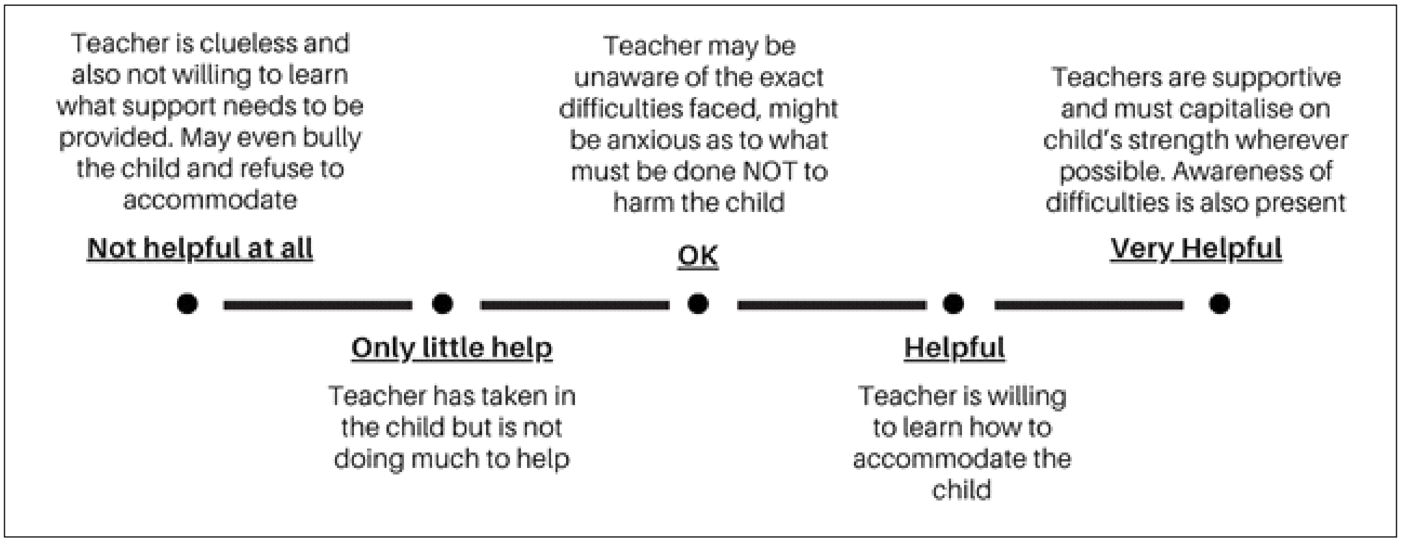


Fig 4. Scale for "How helpful was telling the teacher about your condition?"

Also some well-meaning teachers, unaware of possible fallout of disclosure and hence the importance of respecting students' experiences, may end up disclosing diagnosis to the class with the intention of helping the class should learn from the autistic person's struggles and achievements. This often ends up with the damaging results.

So while school has been good in terms of academic pursuits, negotiating the everyday neurotypical social world has been wrought with challenges. One can only hope that students being older and developing greater maturity, things will get better in college.

__Prakriti Ghosh__ is a student of economics at the Shri Ram College of Commerce, University of Delhi. She also takes a keen interest in art and design, and a relentless advocate for persons with ASD.

Communication: Beyond Words

Shweta Pathania

It was early morning of August 14, 2010, that Aadi came into our lives. My first memories of Aadi are of a baby, coming into the world, wailing and shrieking, as if grossly upset with everyone around for having been rudely brought into this world at such an early hour.

After being fed, as the little babe settled in my arms, I was amazed at how perfect little humans can be. Nothing till date compares to the pride we (my husband and I) felt holding our precious little baby Aadi for the first time. In that moment we had no idea, how this little, almost perfect, tiny person, would change our lives forever to come.

I am Shweta Pathania, mother of a 14-year-old, Aadi Kumar and my aim of writing this article is to share how AACs (Alternative and Augmentative Communication), and in our instance PECS (Picture Exchange Communication System) and AVAZ app have changed our lives for the better. But before going onto our Communication Journey, I am allowing myself the laxity of delving into some of our past experiences.

As Aadi started growing into a toddler, we started noticing his lack of eye-contact, minimal interest in seeking our company, delayed development of speech and so forth. By the time Aadi was 2.3 years old, we had a diagnosis of Autism in hand. Our road ahead was set.

Our lives started revolving around hospitals and therapy centers. Every waking hour was soon meticulously time-tabled into – Speech Sessions, Occupational Therapy Sessions, Special Education Sessions, Sports Classes, Music Classes and so on. Luckily, we were introduced to PECS (Picture Exchange Communication System) pretty early on in our life, courtesy Parent Child Training Program at Action for Autism. By the time Aadi turned four he already had a repertoire of forty picture-words on his PECS (Picture Exchange Communication System) folder. He could join words to make small three letter sentences. With PECS alongside a visual schedule at home, Aadi was a fairly happy child.

At four years of age, we admitted Aadi to his first school. At school they did not use any modes of Alternative and Augmentative Communication for their children's communication. Instead, they vehemently advocated that only rigorous speech sessions focused on verbal communication and no other means of expressive communication, would somehow kickstart speech. A faint glimmer of hope for the elusive vocal expressive communication as well as the belief that the school knows best, kept us from putting our foot down and insisting that Aadi be provided with his PECS folder at school.

As Aadi grew, so did his challenging behaviors – crying, self-hitting, self-biting, sometimes hitting others. Every time, we did an in-depth behavior analysis, the conclusion used to be the same. The cause: a lack of adequate communication skills. Meanwhile, with almost eight hours of school, plus additional therapies spread through the day, Aadi's PECS learning graph remained stuck at the level he had reached before turning four. Soon, every teacher, every therapist that he worked with, would say, “Pata nahi kyon ro raha hai” (We don't know why he is crying), “Do minute pehle to theek tha” (He was okay, just two minutes back). We changed schools, therapy centers, even decided to change cities.

Now looking back in time, it is difficult to find the tipping point, where we decided to turn things around. Perhaps it was the time when Aadi was refused further continuance at a small school, quoting his challenging behaviors beyond classroom management. Slowly we again started working on our Picture Exchange Communication System. Words in form of pictures – nouns, actions (verbs) were added. Every communication was encouraged. Small little baby steps and slowly we started noticing a difference. On the advice of one of the speech therapists that Aadi used to go to, we introduced Aadi to a free mobile communication app, Jabtalk. This app had a lot of flexibility in terms of adding pictures to the vocabulary and soon Aadi started using it extensively.

In 2020, Covid came, schools, therapy centers, my own work, everything was shut down. This downtime was almost God-sent for us. In April 2020, after consultation with another speech and language therapist, we introduced Aadi to AVAZ App for picture communication. I had no formal training in the AVAZ App, but Aadi took to it like a fish to water, possibly because of his training in PECS and familiarity with Jabtalk app. Initially on AVAZ, I taught Aadi to find pictures/ icons of things that he likes – edibles, toys, places. Soon I taught him to join picture-words to form sentences. Over the next few months, Aadi started exploring the app on his own. He himself picked up labelling of actions being done, things in front of him. His communication repertoire skyrocketed.

Before putting down my pen, just sharing a few takeaways from our turbulent communication journey for other fellow parents sailing in the same boat;

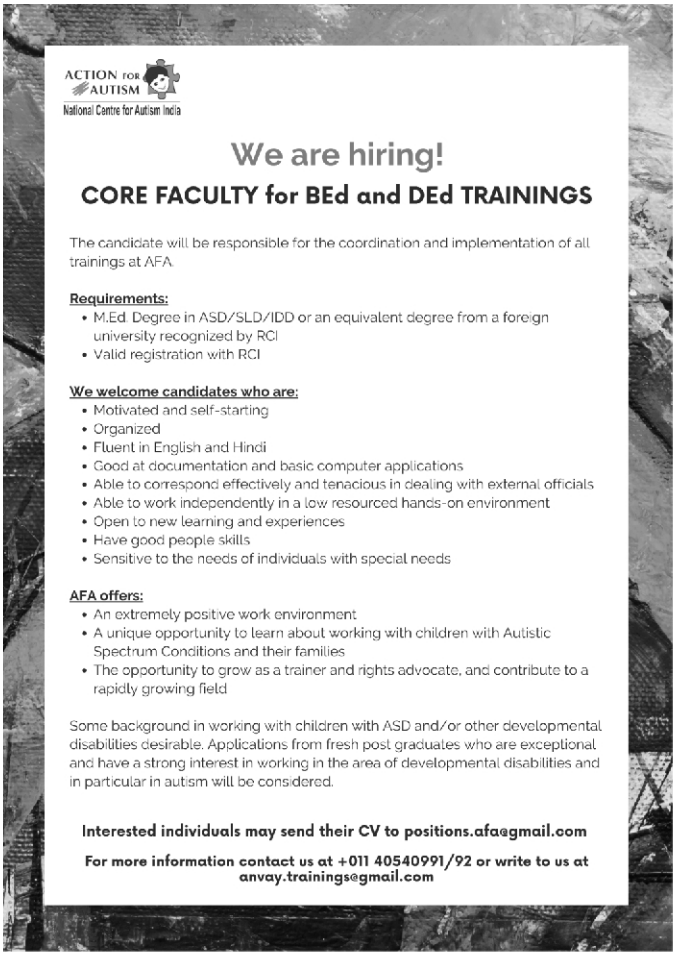
a. Build a Solid Foundation: Teach Picture exchange before teaching Apps. Begin teaching using PECS (picture exchange communication system) or other similar forms of communication. The whole concept of picture exchange revolves around understanding that no communication is complete until it is conveyed to a communicative partner. As a result, our children using PECS or other similar systems, inherently learn the importance of communicating to another person rather than keeping their words to themselves. In my years of working with other children, I have many a time come across fairly vocal children who keep repeating their needs / demands in their own closed space without realizing the need to communicate their needs / demands to another person / adult. I therefore firmly believe that the training in PECS or other similar communication systems is extremely helpful for when the child moves to more high-tech forms of communication using Apps.

b. Stick to basics: Always keep the PECS / communication folder handy. Even after your child becomes proficient in using any communication App, do keep his PECS folder handy. This takeaway comes from a 5-day trip we took to Andamans in December 2019, when Aadi was using Jabtalk extensively. Somehow during our Adaman trip, the App crashed. Luckily tucked away in Aadi's bag-pack was his PECS folder. As a result, we as a family had one of our best vacations ever. Since then, we have made it a habit to keep Aadis PECS folder handy. It's been almost 5 years since Aadi is using AVAZ app and even today tuckered away in a dusty old drawer in his cupboard, the communication book still lies, waiting for any day that Aadi might need it.

c. A complete language: Another thing that we have learnt on this journey with Aadi is that using pictures to communicate is a complete language in itself. And if one person speaks a particular language, a richer conversation ensues if the other person uses the same language as well. As a result, now, oftentimes we use the same App to communicate with Aadi that Aadi uses with us.

It's been almost five years and we know we still have miles to go on our communication journey. But now I can say with certainty that my calm and happy boy is back.

***Shweta Pathania**, B.Ed (LD), D.Ed (ASD), BA LLB, is a Special Educator at Samarth Autism Center, Mohali. She is also the mother of 15-year-old Aadi Kumar who is autistic.*



पैसे का प्रबंधन

प्रशस्ति श्रीवास्तव

पैसे के प्रबंधन का जीवन में महत्व

हर व्यक्ति को यह समझना ज़रूरी होता है कि पैसा सीमित होता है और उसकी ज़िम्मेदारी से योजना बनाकर उपयोग करना चाहिए। मनी मैनेजमेंट हमें यह निर्णय लेने में मदद करता है कि किस चीज़ पर पैसा खर्च करना है और किस पर नहीं। यह तय करने में कि हमारी ज़रूरतें क्या हैं और इच्छाएं क्या हैं, मनी मैनेजमेंट एक मार्गदर्शक की तरह काम करता है। उदाहरण के लिए, खाना, दवाई और किराया ज़रूरतें हैं, जबकि महंगे कपड़े या हर हफ्ते बाहर खाना खाने की इच्छा हो सकती है।

मनी मैनेजमेंट: आत्मनिर्भरता और रोजगार की दिशा में एक सशक्त कदम

मनी मैनेजमेंट केवल पैसे की गिनती या खर्च की योजना बनाने तक सीमित नहीं है, बल्कि यह एक महत्वपूर्ण सॉफ्ट स्किल है जो हर व्यक्ति को आत्मनिर्भर और ज़िम्मेदार बनाता है। यह स्किल हमें सिखाती है कि हम अपनी ज़रूरतों और इच्छाओं में संतुलन कैसे बनाएं, पैसे को कब और कहां खर्च करें, और भविष्य के लिए बचत कैसे करें। यह कौशल जीवन के हर क्षेत्र में काम आता है—चाहे वह घर चलाना हो, किसी कार्यक्रम की योजना बनानी हो या फिर नौकरी से मिलने वाली आय का सही इस्तेमाल करना हो। ऑटिस्टिक वयस्कों के लिए, यह स्किल और भी जरूरी हो जाती है क्योंकि वे कई बार तत्काल इच्छा के प्रभाव में आकर खर्च करते हैं, बिना यह समझे कि यह खर्च वास्तव में जरूरी था या नहीं। ऐसे में मनी मैनेजमेंट उन्हें निर्णय लेने की शक्ति देता है और उनकी समझदारी को मजबूत करता है।

ऑटिस्टिक वयस्कों के लिए यह स्किल क्यों ज़रूरी है?

अक्सर देखा गया है कि ऑटिस्टिक व्यक्ति अपने निर्णयों में स्पष्टता की बजाय भावनाओं या आदतों से प्रभावित होते हैं। वे अपने पसंदीदा शौक, ऑनलाइन ऐप्स, खाना, या ब्रांडेड वस्तुओं पर पैसे खर्च करने को अधिक प्राथमिकता देते हैं, बजाय इस पर विचार किए कि किसी ज़रूरत को पहले पूरा किया जाना चाहिए। उदाहरण के लिए, ₹500 मिलने पर वे तुरंत गेम टॉप-अप करवा सकते हैं, जबकि घर के लिए जरूरी वस्तु या यात्रा का खर्च ज़्यादा ज़रूरी हो सकता है। इसीलिए, उनके लिए यह समझना ज़रूरी है कि पैसा एक सीमित संसाधन है, जिसे सोच-समझकर इस्तेमाल करना चाहिए। उन्हें यह भी सिखाना ज़रूरी है कि पैसा कैसे कमाया जाता है, मेहनत की क्या अहमियत होती है, और खर्च करते समय क्या-क्या सोचना चाहिए। जब वे इस प्रक्रिया को समझते हैं, तो वे अधिक जिम्मेदारी से फैसले लेने लगते हैं और धीरे-धीरे आत्मनिर्भर बनते हैं।

इस स्किल का उपयोग स्वतंत्र जीवन जीने में कैसे होता है

जब कोई व्यक्ति पैसे को समझने लगता है, तो वह छोटे-छोटे निर्णय लेने में सक्षम होता है—जैसे कि दिन का खाना कहाँ से लेना है, किराए का भुगतान कब करना है, या महीने के अंत तक कैसे पैसे बचाकर चलना है। एक ऑटिस्टिक वयस्क जब अपने खर्चों की योजना बनाता है, ज़रूरतों और इच्छाओं को पहचानता है, और हर बार के खर्च का हिसाब रखता है, तो वह केवल पैसे ही नहीं, अपने समय, ऊर्जा और प्राथमिकताओं को भी प्रबंधित करना सीखता है। यह उसे स्वतंत्र रूप से जीवन जीने की ओर आगे बढ़ाता है। उदाहरण के लिए, यदि किसी को ₹1000 महीने के पॉकेट मनी के रूप में दिए जाते हैं, तो यह समझना कि उसमें से कितने पैसे किराया, खाना, ट्रैवल और बचत में लगने हैं—ये सब आत्मनिर्भरता के प्रतीक हैं। मनी मैनेजमेंट सीखने के बाद व्यक्ति खुद से शॉपिंग कर सकता है, ऑनलाइन और ऑफलाइन खर्चों की तुलना कर सकता है, और फिजूलखर्ची से बच सकता है।

रोज़गार और नौकरी में मनी मैनेजमेंट की भूमिका

रोज़गार की दुनिया में मनी मैनेजमेंट एक ज़रूरी स्किल है। जब कोई व्यक्ति नौकरी करता है और उसे हर महीने सैलरी मिलती है, तो उससे

जुड़े फैसले उसे रोज़ लेने होते हैं। जैसे कि सैलरी मिलते ही सारा पैसा खर्च न कर देना, समय पर बिलों का भुगतान करना, यात्रा खर्च संभालना, और बचत करना—ये सभी एक कार्यरत व्यक्ति से अपेक्षित होते हैं। ऑटिस्टिक वयस्कों के लिए यह और भी जरूरी है क्योंकि यदि वे यह स्किल नहीं सीखते, तो कमाई के बावजूद वे दूसरों पर आर्थिक रूप से निर्भर रह सकते हैं। उदाहरण के लिए, एक ऑफिस में कार्यरत व्यक्ति को अपने लंच का खर्च, यात्रा का टिकट, कभी-कभी उपहार, और आकस्मिक खर्चों की योजना बनानी होती है। अगर वह जानता है कि हर महीने कैसे बजट बनाना है, कहां से MRP देखनी है, कितना पैसा देना है और कितना वापस मिलेगा—तो वह न केवल आत्मनिर्भर होता है बल्कि दूसरों से सहायता लेने की आवश्यकता भी कम हो जाती है।

मनी मैनेजमेंट सिखाने के व्यावहारिक तरीके

मनी मैनेजमेंट कोई केवल गणितीय कौशल नहीं है, बल्कि यह एक जीवन कौशल है जो निर्णय लेने, योजना बनाने और आत्मनिर्भर बनने की प्रक्रिया से जुड़ा होता है। ऑटिस्टिक वयस्कों के लिए यह कौशल सिखाना तभी प्रभावी होता है जब हम इसे व्यवहारिक, दृश्य और दोहराव आधारित तरीकों से सिखाएं। हम शुरुआत में नकली नोटों और सिक्कों का उपयोग करके 'दुकान' का रोल-प्ले कर सकते हैं, जिसमें वयस्क ग्राहक और दुकानदार दोनों की भूमिका निभाएंगे। इस अभ्यास से वे पैसे का आदान-प्रदान, गिनती, और वित्तीय लेन-देन की वास्तविक समझ को बेहतर तरीके से सीख सकते हैं।

1(A) मनी मैनेजमेंट स्किल का व्यवहार बचपन से ही विकसित होने लगता है। जब बच्चा दुकान पर जाता है और सामान के बदले अनुमानित पैसों का लेन-देन करता है, तो यह प्रक्रिया उसके भीतर मनी मैनेजमेंट की प्रारंभिक समझ को विकसित करती है। बच्चे सीमित पैसों में आवश्यक वस्तु को चुनना और खरीदने की योजना बनाना सीखते हैं। यह आदान-प्रदान की प्रक्रिया बच्चों को यह सिखाने में सहायक होती है कि बार-बार उपयोग में आने वाली वस्तुओं की कीमत और उनके महत्व को वे समझ सकें और मनी की पहचान विकसित कर सकें।

1(B) निम्नलिखित कुछ तरीकों से मनी मैनेजमेंट सिखाया जा सकता है और हम बचपन से ही इसे सिखाना शुरू कर सकते हैं

- **ज़रूरत और इच्छा में अंतर समझाना**

ऑटिस्टिक वयस्क कई बार खर्च करते समय तुरंत मिलने वाली खुशी पर ध्यान देते हैं, जिससे ज़रूरत की चीज़ें पीछे रह जाती हैं। इसलिए सबसे पहले उन्हें यह सिखाना ज़रूरी है कि ज़रूरतें (जैसे—भोजन, दवाइयां, यात्रा) हमारे जीवन के लिए आवश्यक होती हैं, जबकि इच्छाएं (जैसे—मिठाई, नई घड़ी, सजावट की चीज़ें) हमारी खुशी के लिए होती हैं। इस बात को समझाने के लिए हम तस्वीरों या वस्तुओं की मदद से छँटाई का खेल कर सकते हैं, जिसमें उन्हें चीजों को "ज़रूरत" और "इच्छा" के डिब्बे में डालना हो।सॉर्टिंग के बाद हम अलग-अलग तरह की वर्कशीट्स का संदर्भ ले सकते हैं, जिनमें ज़रूरत की चीज़ों को गोला लगाना और अनेक क्रियाएँ बच्चों की रुचि के अनुसार कर सकते हैं।

ज़रूरत और इच्छा में चयन करने की क्षमता, पैसे को सुचारु रूप से ख़र्च करने की क्षमता को विकसित कर सकती है।, अगर किसी को ₹100 मिले हैं और वह ₹60 का चिप्स और ₹40 की दवाई ले सकता है, तो यह समझाना ज़रूरी है कि दवाई लेना ज़रूरी है और चिप्स बाद में भी खाया जा सकता है। यह प्राथमिकता देने की सोच विकसित करता है, जो जीवन के हर क्षेत्र में काम आती है—चाहे वह खर्च करना हो, समय देना हो या काम चुनना हो।

- **नोट और सिक्कों की पहचान और जोड़-घटाव करना**

पैसे की समझ और उपयोग की शुरुआत बचपन से ही होनी चाहिए, जब बच्चे पहली बार मुद्रा के रूप में नोटों और सिक्कों को पहचानना सीखते हैं। यह केवल एक शैक्षिक गतिविधि नहीं, बल्कि आत्मनिर्भरता की दिशा में पहला कदम है। बच्चों को यह सिखाना ज़रूरी है कि ₹10 का सिक्का और ₹10 का नोट मूल्य में समान होते हैं, भले ही उनका आकार या रूप अलग हो। इसी तरह, किसी तय राशि को अलग-अलग नोटों और सिक्कों से कैसे चुकाया जा सकता है—जैसे ₹75 के लिए ₹50 + ₹20 + ₹5 देना या ₹100 देकर ₹25 वापस लेना—यह समझ विकसित करना भी ज़रूरी है। इस कौशल को मज़ेदार और व्यावहारिक तरीके से सिखाने के लिए 'दुकान वाला खेल', रोल-प्ले गतिविधियाँ या जोड़-घटाव की गेम्स का सहारा लिया जा सकता है। आज के डिजिटल युग में कई ऐप्स और कैलकुलेटर-आधारित टूल्स उपलब्ध हैं जो गणना को सरल बनाते हैं और बच्चों में

आत्मविश्वास बढ़ाते हैं। इस प्रकार का अभ्यास न केवल वित्तीय गणनाओं में सहायक होता है, बल्कि वास्तविक जीवन में स्वतंत्र रूप से खरीदारी करने, पैसे संभालने और धोखाधड़ी से बचने जैसी क्षमताओं को भी विकसित करता है। पैसे की सही समझ एक व्यक्ति को समाज में आत्मनिर्भर और सक्रिय भागीदार बनाती है।

- **एमआरपी पढ़ना, बिल समझना और सही पैसे देना**

जब कोई व्यक्ति खरीदारी करता है, तो उसे यह जानना ज़रूरी होता है कि चीज़ की सही कीमत क्या है और बिल कितना आया। MRP यानी अधिकतम खुदरा मूल्य पढ़ना और तुलना करना एक वित्तीय निर्णय है। हम उन्हें यह सिखा सकते हैं कि किसी उत्पाद पर लिखा MRP देखना ज़रूरी है ताकि कोई उन्हें गलत कीमत न बतादे।

उन्हें यह भी सिखाएं कि यदि कोई वस्तु ₹135 की है, और उनके पास ₹200 हैं, तो वे ₹200 दें और ₹65 वापस लें। यह तब और मजबूत होता है जब हम उन्हें बिल की रसीद पढ़ना, कुल राशि देखना और उसमें से कितना दिया और कितना वापस मिलना चाहिए—यह निकालने का अभ्यास कराएं। यह उन्हें धोखाधड़ी से भी बचाता है।

- **पॉकेट मनी और वेतन की समझ विकसित करना**

ऑटिस्टिक वयस्कों को जब पॉकेट मनी दी जाती है, तो यह केवल एक आर्थिक लेन-देन नहीं होता, बल्कि आत्म-निर्भरता, ज़िम्मेदारी और योजना बनाने की क्षमता विकसित करने का एक महत्वपूर्ण अवसर होता है। इस प्रक्रिया में यह सिखाना ज़रूरी है कि पॉकेट मनी सीमित होती है और इसे सोच-समझकर प्राथमिक ज़रूरतों के हिसाब से खर्च करना चाहिए। हम उन्हें यह भी समझा सकते हैं कि वेतन या आय मेहनत और काम के बदले में मिलता है, और इसका उपयोग पहले ज़रूरी चीजों—जैसे भोजन, परिवहन या व्यक्तिगत ज़रूरतों—के लिए किया जाना चाहिए। जब पॉकेट मनी दी जाती है, तो यह ज़रूरी है कि खर्च पर नियंत्रण व्यक्ति का खुद का हो—वह यह तय करे कि कहाँ, कितना और कब खर्च करना है। इस तरह की नियमित अभ्यास से वे न केवल आर्थिक रूप से आत्मनिर्भर बनते हैं, बल्कि निर्णय लेने और सीमित संसाधनों के भीतर संतुलन बनाना भी सीखते हैं। इसके लिए हम एक साप्ताहिक बजट चार्ट या खर्च योजना सूची बनाकर उन्हें योजना बनाने, खर्च का रिकॉर्ड रखने और आवश्यकता के अनुसार प्राथमिकता तय करने की प्रैक्टिस दे सकते हैं जैसे:

- **बजट बनाना और उसका अभ्यास**

बजट बनाना, यानि पैसे की योजना बनाना, उन्हें यह सोचने की क्षमता देता है कि उनके पास कितना पैसा है और उसे कैसे खर्च और बचाया जाए। शुरुआत में हम दैनिक बजट बनवाएं, जैसे कि आज उन्हें ₹100 मिले हैं, और उन्हें तय करना है कि ₹20 नाश्ते पर, ₹10 यात्रा पर और ₹20 बचत करें। धीरे-धीरे यह अभ्यास साप्ताहिक और फिर मासिक स्तर पर किया जा सकता है।

उन्हें रंगीन चार्ट, पिक्चर कैलेंडर और सरल टेबल की मदद से बजट सिखाया जा सकता है। हम यह भी सिखा सकते हैं कि "अगर इस महीने मेरे पास ₹2000 हैं, तो ₹1000 ज़रूरतों के लिए, ₹500 इच्छाओं के लिए और ₹500 बचत के लिए रखूं।" यह स्पष्ट सोच उन्हें वास्तविक जीवन में बड़ी ज़िम्मेदारियाँ लेने के लिए तैयार करती है।

- **बचत की आदत और इसका महत्व**

बचत करने का मतलब केवल पैसा जमा करना नहीं है, बल्कि यह आत्म-सुरक्षा, भविष्य की योजना और स्वतंत्रता का संकेत है। उन्हें सिखाना ज़रूरी है कि बचत से वे अपनी इच्छाएं बाद में पूरी कर सकते हैं और किसी संकट की स्थिति में आत्मनिर्भर रह सकते हैं। हर दिन उन्हें एक पॉकेट मनी ट्रैकर दिया जा सकता है, जिसमें वे लिखें कि आज उन्हें कितना पैसा मिला, कहाँ खर्च किया और कितना बचा। इससे उन्हें अपनी दिनचर्या में पैसे का हिसाब रखना आता है। सप्ताह के अंत में जब वे अपना सेविंग बॉक्स खोलकर यह देखते हैं कि कितना पैसा बचा—तो यह उन्हें संतुष्टि और जिम्मेदारी की भावना देता है। साथ ही, वे डिजिटल दुनिया का हिस्सा बनें, इसके लिए धीरे-धीरे UPI, ATM कार्ड, और ऑनलाइन शॉपिंग की समझ भी देना जरूरी है।

हम उनके लिए सेविंग जार या पिगी बैंक रख सकते हैं जिसमें वे हर सप्ताह कुछ पैसा डालें। फिर महीने के अंत में उसे खोलकर देखें कि कितनी रकम जमा हुई। उन्हें यह दिखाएं कि ₹20 प्रति सप्ताह बचाने पर महीने में ₹80 और साल में ₹960 हो सकते हैं—जो कि एक अच्छा हेडफोन या नए कपड़ों के लिए काफी है।

हम रीयल लाइफ उदाहरण जैसे "मोबाइल खराब हो जाए तो सेविंग काम आती है" भी दे सकते हैं। यह उन्हें दीर्घकालिक सोच की ओर बढ़ाता है।

मनी मैनेजमेंट केवल पैसे का हिसाब-किताब नहीं है, यह एक जीवन कौशल है जो किसी भी व्यक्ति को आत्मनिर्भर और ज़िम्मेदार बनाता है। ऑटिस्टिक वयस्क जब धीरे-धीरे यह सीखते हैं कि पैसा कैसे कमाया जाता है, खर्च और बचत कैसे होती है, तो वे अपनी रोजमर्रा की ज़िंदगी और कामकाजी दुनिया—दोनों में अधिक सक्षम हो जाते हैं। यह कौशल उन्हें न केवल आर्थिक स्वतंत्रता देता है, बल्कि उनके आत्मविश्वास और निर्णय लेने की क्षमता को भी मज़बूत करता है।

रोज़मर्रा के खर्च से लेकर ऑफिस की सैलरी तक, बजट बनाना, ज़रूरतों को पहचानना, धोखाधड़ी से बचना और भविष्य के लिए योजना बनाना—ये सभी जीवन के ऐसे क्षेत्र हैं जहाँ मनी मैनेजमेंट उन्हें एक सुरक्षित और सम्मानजनक जीवन की दिशा में ले जाता है।

प्रशस्ति श्रीवास्तव एक जॉब कोच हैं जो एक्शन फॉर ऑटिज़्म, नई दिल्ली में काम करती हैं। वे ऑटिज़्म स्पेक्ट्रम पर मौजूद युवाओं और वयस्कों को रोज़गार की तैयारी, कार्यस्थल पर सफलता, और व्यक्तिगत विकास के लिए मार्गदर्शन और सहयोग प्रदान करती हैं।

AFA MEMBERSHIP FORM

Action For Autism(AFA) is a parent organization that strives to create an environment where individuals with autism and their families can live as fully participating members of the community.

To support AFA to further its mission, please complete the form below and return to: Action For Autism, The National Centre for Autism, Sector 7 & 8, Jasola Vihar, New Delhi - 110025.

Please complete in BLOCK letters and mail to Action For Autism

Name ______________________________

Address ______________________________

____

City ______________ State ______________

Country ______________ Pin/Zip ______________

Phone ______________ Email ______________

I am a: *(Check all that apply)*

☐ Mother ☐ Father ☐ Other (please specify) ______________

☐ Professional: Name of Organisation ______________

For Parent of a person with autism ONLY:

Child's Name ______________________________

Gender: ☐ Female ☐ Male Date of Birth ______________
dd mm yr

Diagnosis ______________________________

Diagnosis received from ______________________________

I wish to become a member of AFA. Enclosed is a contribution *(Check as applicable)*

Via: ☐ Cash ☐ Online ☐ Demand Draft
(in favour of Action for Autism, payable at New Delhi)

Online Transaction/Draft No ______________ Dated ______________

Drawn on ______________________________

Amount in Words ______________________________

Annual Membership Charges:
Parent: INR 1000 (USD 43) Professionals: INR 2000 (USD 55)
Institutional: INR 5000 (USD 100)

Bank Details:
Domestic Transactions
Beneficiary Name: Action For Autism
Account No: 76620100007129
Bank of Baroda, Defence Colony, New Delhi 110048, India
IFSC No: BARB0VJDEFE (5th digit is Zero)
Overseas Transactions
Beneficiary Name: Action For Autism
Account No: 40029268651
State Bank of India, 11 Sansad Marg, New Delhi 110001, India
SWIFT: SBININBB104

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