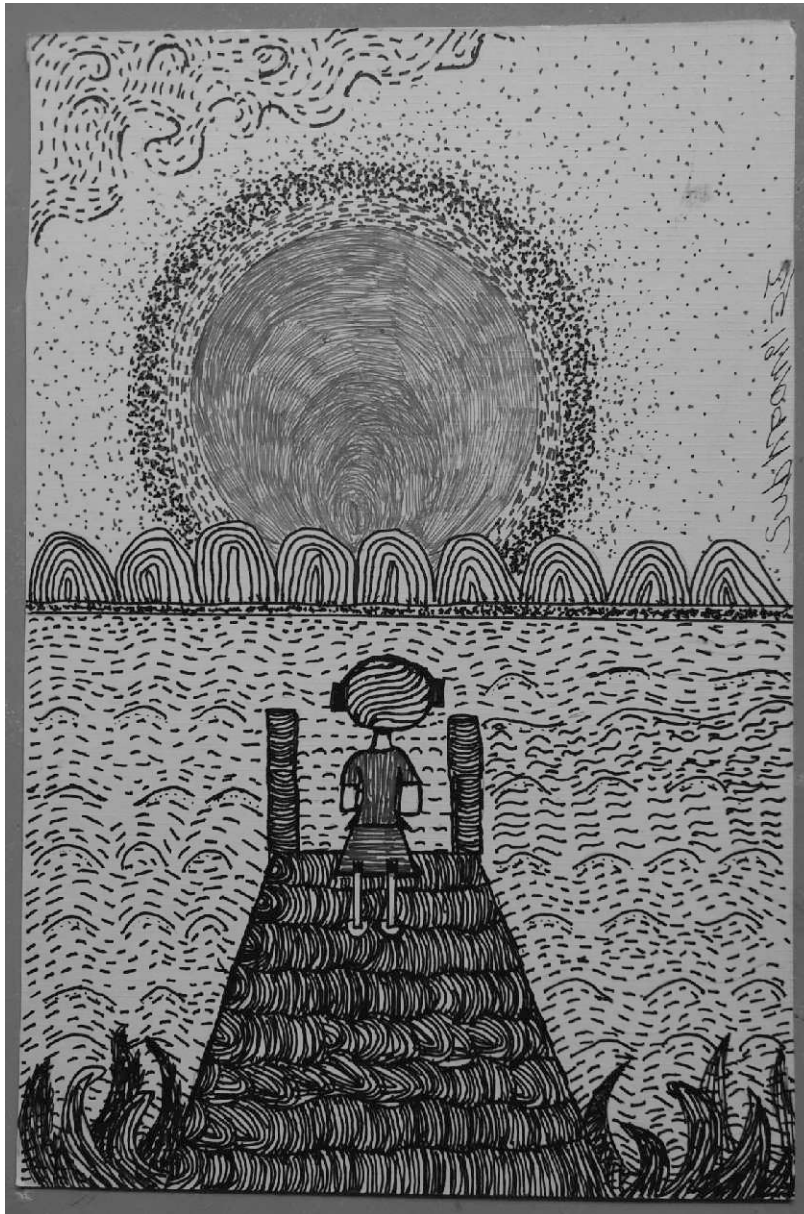
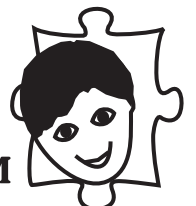


autism network

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ACTION FOR AUTISM



autism network

2023

VOLUME 20

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 Jetty by Subhranil Das

Subhranil Das is a young autistic artist from Santoshpur, West Bengal. He was home-schooled and couldn't hold a pencil till the age of 7 years. Today, he expresses his inner turmoil through art and feels that art is his alternate means of communication. His work was exhibited at India Habitat Centre, New Delhi, at a short-film festival with neurotypical adult artists, and telecast by NDTV, besides receiving wide coverage in the print and television media of West Bengal. His work was also exhibited in 2018 in two galleries in London by the Hoffman Foundation, UK.

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PAGE ONE

Two decades back it was hard for most parents to confront the reality of their autistic children growing up into, and living their lives out, as autistic adults. That is changing. Fast forward to the present, parents are keenly aware of their own mortality as their children age. The question ‘What after us?’ has become a buzzword; because not all neurodivergent adults will live their adult lives without requiring any form of support.

The surge in adult living options is an excellent development providing not only lifelong living options but also the possibility of short stays for neurodivergent adults who want a break from their families’ social forays.

This issue shares a few perspectives and experiences of the evolving assisted living scenario in India. This is very much a nascent field. The understanding of what constitutes a good life for autistic adults varies widely from organisation to organisation and individual to individual. Independence, safety, autonomy, respect, dignity and even abuse, are terms that appear relative with hugely divergent interpretations.

Perhaps in a later issue we can explore this further in the context of assisted living, as well as in general.

Happy reading.

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A Home of Their Own

Merry Barua

Introduction

It was in 1998 that somewhere outside Copenhagen I got the opportunity to visit a place where young men with autism lived semi-independently, in a nice airy one-storied home in a quiet neighbourhood outside of the city. The home, very Nordic with pale clean lines was home to 12 young men. I remember three or four of them sitting around their dining table on that late morning in what was a very home-like environment curious about this strange brown woman visiting them.

I had accepted by then that my autistic son may have difficulty in living on his own when I was no longer living, given how unstructured and chaotic things were back home. But I had little idea what that future might look like, especially with no extended family to fall back on, unreasonable though the latter expectation might be. This home outside Copenhagen was an eye-opener. The possibility of this kind of 'home' with no parents in sight was exciting to say the least. For the first time, I had a sense of what my son's future might look like if he needed significant support as an adult.

Following that visit, over the years I grabbed every opportunity to visit homes across the world. These were varied: A townhouse in the suburbs of London where five young men lived with minimal support from a visiting social worker, and going out to day jobs. A large 36-acre farm outside Dublin for individuals requiring a mixed range of support, working at things they enjoyed: pottery, tending animals, working in the fields. A home in Johannesburg for all genders where the women shared a bright large airy bedroom with colourful counterpanes. A house in Chicago, the kitchen neatly

ordered and labelled, where the residents went out to day jobs in sheltered workplaces. One in New Jersey that gave us ideas on how to plan common spaces. Each place I visited, in Germany, Australia and elsewhere, there was so much to learn.

When AFA considered setting up an assisted living, as we tackled the hurdles of resources and worked towards setting up a place, we took the opportunity of visiting already running residential places in India. We discovered 'homes' that have been running for decades. Many taught us what we don't want to do. As many showed us what we want to and can. A home for women in Hyderabad, several in and around Mumbai, in Una and for mixed genders in Dehra Dun.

When Action For Autism started Ananda Assisted Living, it was not just based on our learning through our own work at Action For Autism over the years; it also incorporated gleanings from all the homes we were fortunate to visit. Though we use the term 'assisted living', Ananda provides both assisted as well as independent living opportunities, though the former is predominant. It currently has one apartment that is home to 19 individuals – with and without disabilities. It's a home where residents have their bedrooms – a few shared but most single-occupancy based on choice, with a main living room and dining area, another two smaller spaces to retire to, and an open kitchen. Over our years of operation, we find this works well for us. There are of course things that we know would be good to change, and things that are just right for when we set up another apartment. We are currently raising funds and planning for the construction of the latter. In the following the writer will attempt to share

some thoughts and learnings from our experience of running an assisted living service that is established on several decades of interaction with and service provision for autistic people.

The Scene for Independent and Assisted Living

There is a significant population of the 13.5 million autistic citizens who need varying levels of support in their everyday lives. Our governments at the centre and in the states, run homes for orphaned and abandoned children, and adults with and without disabilities. While some are well run, most of them leave much to be desired and are not places where anyone would willingly want to have a loved family member reside. We are not a welfare state and hence marginalised and vulnerable people are often left to their own devices, and of their families, if the families have any devices to spare.

Neither do we have a system of professional social workers who are appointed by the state to visit homes for senior citizens, disabled people, homeless children and other marginalised and vulnerable populations as part of providing support or monitoring quality of services. In countries more developed than ours, social workers also visit their disabled citizens who sometimes continue to live in their own homes when family support ceases after the death of their parents. Every day there are parents ageing and dying. Siblings moving away.

In a culture where children largely continue to stay with their parents even after adulthood and parenthood, families in India find it hard to contemplate a separation from their adult wards with disabilities. Sometimes this is also due to the burden of societal censure: What a horrible family! Sending their disabled child away! Parents often don't consider having their children with disabilities move out to live elsewhere in their own 'home', till it is absolutely necessary, when age and illness make it impossible for them to provide the support their ward needs. Anyone running an assisted living

service knows that there are many more individuals seeking a home than there are homes available. It is in response to this demand that there has been a mushrooming of 'homes' for those neurodivergent adults who need assistance in their activities of daily living, that the family is no longer able to provide.

A Home of my Own

A home is a place of one's own. A place where one feels safe. A place where one feels one belongs. A place where one is happy to return to at night or when one seeks a haven to retire to. That is what an assisted living services aims to provide.

What are some of the things that would make a good home for neurodivergent adults? There is often the perception in our society that it is okay to provide less than average resources – learning materials, school buildings, accommodation etc to disabled people. Of course, much depends on financial muscle. It is not that homes (or other services) must be plush – though they can be if the money is there. Homes can be anything from basic to plush. But living arrangements for our disabled people must be the best that the finances of the organisation permit. Our people deserve to live in good homes just as much as they deserve to go to good schools. Any organisation that believes for instance, that they must provide the best accommodation for the parents, but sloppy ones for their residents is showing a lack of respect for their disabled population.

Financial Implications

Finance is undoubtedly a big challenge. Homes have to charge sufficiently to enable them to be sustainable, else they would collapse. There are the everyday expenses on food, health, hygiene, clothes, medical emergencies and long-time treatment, other personal necessities, upkeep and cleanliness, power, generator back up, internet, salaries to be paid, maintenance. Further, if one wants to provide a quality of life, that would mean that the residents don't spend their entire life confined to the insides of

their home. Regular outings to local markets and malls, catch a show sometimes, attend community events, at least a vacation each year: all these clock up additional expenses. The list grows through experience and practice. Addressing these expenses as well as staying sustainable ends up making it harsh for families with modest finances. There are some places which have a sliding scale in place, charging higher rates from those with means and subsidising those who don't. The variety of these arrangements make it possible for families of autistic people to choose a place they like and can afford.

Varied Models

The wide range of homes coming up is civil society's response to the dearth in services. There are communities that have been created where parents live in their own houses across the road or outside the gated premises of the disabled residents. In some, parents share common spaces with their wards and contribute to the running of the home. In others, they have no say in the day to day running of their wards' home. In these setups, parents have moved from their original homes with the intention of living close to their wards till the end of their lives.

Another form of home is one where wards move to their new homes sans family. There are a range of these as well. There are also homes with bedrooms, living areas and kitchen and are much like typical middle class homes in India. There are others that run as hostels and dormitories. While a privileged lens prompts some to dismiss the latter structure as not being a true 'home', they actually provide clean and affordable living spaces to many who may be of limited means. Besides, homes are 'made' by those who people those homes, and less by the physical structure and amenities. More on that later.

Resident Engagement

What is of greater import is the engagement of the residents in their home. Is it a place where they lead meaningful lives? Do they have opportunities to participate in the chores around the home, go out to

work in sheltered or open employment, enjoy recreational activities like the rest of us. Do they go out and engage with the community the home is located in? Are they a part of the community's social life? Do they go for walks, movies, shopping, eating out, annual vacations, and all the other activities that marks everyday lives. Do they go to visit their parents and other family members the way we do, and do their families too, get to visit them?

Philosophy

Assisted living spaces address the 'What after us?' parental query. They serve this focussed primary purpose – a place for adults to live when parental support is no longer there – even if the intent behind the start-ups may vary. Some are started by parents to provide a space that they believe will be 'safe' for their offspring. Some are started by organisations as one more service that they provide. Some are started as profit-making businesses. All of these intentions are equally valid. What matters is the philosophy and belief systems that the individuals/organisations bring to the place, as that is what determines the quality of life.

The philosophy that drives the founding parents or organisation influences the homes' activities. It informs the actions of the leadership, which in turn affects the actions of the support people. Does the leadership see the disabled residents as valued individuals or merely as helpless receivers? Does overprotectiveness countervail the desire to promote independence? Do they view them as people who continue to learn develop and grow like all of us? Or do they view them through the lens of incapacity despite coming from a place of love and affection? It is the foundational beliefs of the leadership that the support persons will imbibe and bring to their work.

The Service Providers

The home can be basic, the diet can be simple, there may not be enough resources for too many outings. But all of that matters less than does the quality of

the team directly supporting the individuals. They, finally, determine the quality of life of the residents. Do the support persons believe autistic lives matter - to use a cliché. Do they believe autistic people are as worthy as themselves. Or do they discuss them in a language that is unwittingly demeaning? Do they trust the ability of the disabled residents or do they see them as deficient people to be merely bathed, dressed and fed – however caringly? Do they try to understand how autistic brains work? Do they acknowledge that autistic people have a different way of experiencing the world? That they are not 'violent people' who automatically have 'challenging behaviours'. That behaviours are an indication that there is something we the support providers have to change, either in our communication, in the instructions we give, in our expectations and demands. Do they introspect that their interaction may have led to a behaviour?

A question often asked is, do care providers have to be educators? Well, if a special educator is interested in the work, then sure. In our experience, we have had people with a background in education, in psychology, graduates in non-related fields, high school pass and even school drop outs. What matters more than the qualification is the desire to be in this area of work; which quality, combined with in-depth training that is ongoing, can shape an interested person into a great care provider. Positive working conditions are of course essential. Pay, leave and living conditions are variables that each organisation addresses in their unique ways. But the most important is respect, dignity and trust. Treating our support persons with respect dignity and trust, as valued members of the team.

What is equally important is how the leadership views support persons. When the leadership team treats our disabled people's support providers as equals, the latter in turn treat our disabled residents as equally worthy. When they are respected by the leadership team, they learn to respect the people they

support. Their interactions with the people they support will reflect their interactions with the leadership team.

Conclusion

Finally, our neurodivergent people should not be made to move to their new homes through coercion. Sometimes families make the mistake of threatening to send their neurodivergent family member to live away from them. When life away from parents is painted in such a negative light, they cannot be expected to be happy with their new life. For a population for most of whom change and transition is difficult, this change is something that has to be planned, the individual prepared for in such a manner that they see the value in and want to make the move. No matter how much support an individual requires, how 'severe' we presume they are, they all benefit from a positive and supportive transition. More of that in a latter issue.

In coming times, homes for neurodivergent people will proliferate driven by a growing demand from aging family members. Just as autism is viewed as a spectrum, the lens through which families and service providers view autistic people, too, is a spectrum. Whatever that lens, most service providers agree there are certain fundamentals that has to underlie the service that is provided. For one, there has to be transparency. Making an effort to be open has to be at the core of the service. As a home, and not a penal setup, we have to be open to visits by family members, and vice versa. This is not a prison but a home.

And above all, we have to provide to our people a life that is full and meaningful.

Merry Barua is the Director of Action For Autism, National Centre for Autism.

A Home for My Brother

Geeti Das

Familial accounts of autism can be pretty problematic. There is a genre of writing about autism that is premised on the idea that the presence of an autistic person means suffering for family members, and that presents familial acceptance as the ultimate, hard won, inspirational goal. In these accounts autistic people tend to be spoken for or barely spoken about as people. In order to avoid that I'm trying to write this account in a way that presents some of the decisions and dynamics we navigated as a family, while protecting my brother's privacy, so I am not naming him here.

My brother has always lived at home. I think we thought of making his home in two main ways: creating a safe space, and optimising his environment. The first involved setting up routines, communicating about people coming and going, not inviting anyone with whom he wasn't comfortable or who might exclude him, and making sure that anyone who came into the house had some sense of what to expect and how to accommodate and welcome him being himself. My father had instituted a lot of stability through this. Whether it was friends or family or workers coming to repair and maintain things, almost everyone coming in got to know my brother, and they were asked to come back only if he was comfortable with them. This has sometimes meant deciding not to invite certain people against what social norms would have mandated. Not everyone will recognise that autistic people deserve some space in which they are not always being asked to bend to neurotypicality, or faulted for "failing" it. He needed a home that wouldn't send him the message that his ways of being are deficits.

The second approach - optimising his environment - goes beyond safe space though it includes it. For us, this focused a lot on lighting, colours, art, textures,

smells, and everyday objects. We all like to put a lot of thought and attention into these anyway, with two architects and designers in the family, so this has been consistently fun for us and a way in which we all show affection. One problem here was that my brother's own mobility to go out and choose his own stuff was always limited by the places he could go. Online shopping made things a little easier, once we could show him pictures of things he might like and see how he reacted. The rest has been trial and error. My brother's avenue for gifting us things has been through his drawings.

The harder part of optimising home was managing sound. It was one of the most important and always one of the most unsuccessful because sound could enter freely but our ability to manage it stopped at the gate. When we first moved to our family home in the 90s, we were surrounded by empty lots. In some ways it was ideal for us and for my brother, with lots of open space and views, a quiet street with almost no cars, and the freedom to go outside safely. By 2021, when he moved to Ananda, all this was long gone. The street was loud with cars and the sounds of drills and floor sanding machines as the house got dwarfed by OYO's and guesthouses. There was a gym across the street with a persistent thudding beat during workout hours and a temple nearby with a lot of infernal clanging. Random shouting increased. Even the cows seemed depressed.

We made the decision to move my brother to Ananda during the pandemic. I had left India after high school in 1999, and home was a place I visited. I moved back permanently a little before Covid. Around the start of the pandemic, I came home to live with my brother. As travel was restricted, for a few months it was just me and him and two other people who had been caregivers to him, one for a

very long time. Our father couldn't be with us, and even when travel restrictions eased a bit, the risks of travelling, especially for an older person, were high. We didn't want to risk exposure for my brother because that would mean his having to deal with hospitals. So we isolated ourselves at home for as long as possible.

One thing the pandemic gave me was time to live with my brother again for the first time since our childhood. But living, rather than visiting for summer holidays, and under pandemic conditions, meant that longstanding dynamics had to quickly and significantly change. My work schedule meant locking myself in my room to spend hours on zoom teaching while my brother dealt with my door being locked much longer than usual. It was different from our usual relationship, in which I would be gone for a long time but very present with him when at home. He never liked phone or video calls, but when that became his only conduit to his father, he started doing them, and expanding it to friends and relatives he could no longer meet. We learned to schedule this with more communication in advance so that he could anticipate them, and experimented with phone volume and distance.

We had known for a while that something would have to be done, but I think the pandemic brought home to us how limited and precarious our arrangements were. The first few months of lockdown were very comfortable auditorily. Outside had gone mercifully quiet, but also a little too quiet. My brother liked hanging around by the gate watching the activity in the street, and suddenly there was almost nothing to watch. Going to the park, which he did twice a day, was no longer an option. Nor was going to the local outdoor markets, especially the vegetable and fruit market where he routinely met people with whom he had developed some mutual friendliness and comfort. In the absence of all this, he changed his routines and circuits of movement, sometimes experimenting and communicating in new ways, sometimes much more quiet and still than usual.

Then construction permits were being issued even as everything else was at a standstill, and the sanding and drilling started again with nothing much else to muffle them. With movement so limited, sound pressed in. Things broke or stopped working and couldn't be easily fixed. We had depended on the labour and presence of people who were open to my brother, less judgmental and more curious, but they were themselves in highly precarious positions and some of them had to leave. Strangers came to fix things when anything could be fixed. I developed new scripts to explain and prepare them to come into the house, and my brother watched whenever anyone came, but at more of a distance than when he could observe things being done by people who would take the time to give him some explanation and a clear view.

Covid also brought home to us how my brother is the youngest and by far the healthiest of all of us, and how urgently we needed to think about a time when we're gone. I'm not sure exactly when we first heard about a spot opening up at Ananda, but it was in that context. AFA had known our family for a long time and worked with him when he was much younger, and we already trusted their approach.

We took our time turning over the idea, visiting Ananda with my brother, having conversations, starting the processes, and Ananda took their time with us, all of us assessing whether this would be a good fit and we could work well together. I had several indications that Ananda would be able to provide a lot that we couldn't. Ananda had quiet, lots of open space, and swings, all of which my brother loves, and a framework of autonomy that I think everyone deserves. They had structure and routine and fun, and I could see that being there would mean access to a social life for him in which he wasn't an outsider or the most noticeably different person.

My father and I decided we would treat it as another experiment and if we ever felt it wasn't right for him, we would stop the process and not make the

move, but that we needed to at least try. We had had so many failed experiments over the years, not with assisted living but with therapies and tools that had been recommended to us. I had learned to be wary. Some nonstarters were benign; a weighted blanket got nowhere even though my father and I both took turns getting under it and trying to demonstrate how nice it felt. Others not so much; there were many first meetings and no second ones with schools and therapists and doctors who leaned on coercion and on terms like "correct" and "appropriate" and "normal" and seemed to have almost no metrics by which to ask if an autistic person is comfortable or trusts the process and people, let alone likes whatever is being recommended.

We found none of that with Ananda. The functional assessment process was fairly emotional for us. My father and I would pat each other on the arm from time to time, or put an arm around each other, while we sat in front of my laptop talking and talking, trying to crystallise and verbalise all the things we knew about my brother intuitively, the things we did through habit and routine and observation and the ways we all fit together, trying to cover everything, worrying about what we might have forgotten. Aditi was patient with us as we sometimes went over the same ground again and maybe talked a little too long about how we managed toothpaste in the house. Her assessment returned things we sort of knew but hadn't put together, like the fact that he likes water. I remember an early conversation with Preeti from AFA in which she said something about how my brother had "a lot of sensory issues". It was such a difference from how even some of our close friends and family had seen my brother, framing his behaviour as problematic without seeing how he was always responding to something, or the reality and impact of the things to which he was responding.

As we started planning, we had to think about new routines, new objects in a new space. Unlike in the first year of the pandemic, this time it wasn't just a question of exigency. I duplicated some things that were familiar, like his toothbrush holder and soap

dish. But there were lots of new things, which meant more room to think about what he might like and to talk to him about how they would fit with his new space and routines and friends. I got him colourful plastic clothes hangers and he carried them all around the house. He squished up against me, shoulder to shoulder, watching me use an allen wrench to put together a utility cart in his favourite colour, fire engine red.

The move itself was hard and I don't want to write about it except to say that my brother gave me the image of it that has stayed with me, of watching him from the back as he turned and left me faster than I had expected and walked straight into his new home.

Ananda made it clear that there would be no daily updates after the first few days, and no surveillance cameras, all of which I found reassuring because it meant that they valued his privacy and autonomy. In the first couple of months there were a lot of surprises in the pictures and videos we get from Ananda in a WhatsApp group called '[My brother]'s Family Group'. Almost immediately, he seemed comfortable sitting together with people right next to him at a table, and an early picture shows him even voluntarily resting his arm on someone's shoulder. An environment normed on non-neurotypical people means people don't invade my brother's boundaries or try to get him to hug them, and he's now completely comfortable with people standing right behind him when that used to be a privilege extended only to his immediate family and household. He used to position himself in a group with multiple exits and a clear view of everything, and now he's comfortable being in the thick of things. We get pictures of him doing things we never, or rarely, managed to enable for him, like going on a trip to a hill station, staying in a hotel room, going on walks and treks, going to a restaurant, and dancing in a group. Other things he liked, like riding a scooter or a bike, are now more feasible on a regular basis and there is space for them. I get videos of him strumming a guitar, using a lawnmower on a stretch of grass cordoned off with rope, getting henna on his hand, eating all kinds of

white food. He's more confident being around loud sound and music, and orders me to sing on the phone for longer than before, and I think it's because he knows he has the freedom to step away or cover his ears whenever he wants. So even sound has become much more agentic.

I watch him trying all these things and realise a little more clearly how much my brother has had to adapt to a neurotypical dominated environment, how he was always adjusting his habits to accommodate the preferences of neurotypicals. Ananda are clear in their defence of the principle of differences, not deficits, and they use the language of family rather than infantilising or corporatised language to describe their relationship. It seems more like the language of intentional family, which I find more meaningful both personally and politically. In addition to what I think were our two major approaches at home, Ananda has others, like working with him on communicating, that had receded a bit with us. They have the will, knowledge, systems, and time to work with him to expand his repertoire of choices not just physically but by working on his ways of communicating and accessing them.

When I visit, we're not inviting each other to our rooms as we used to, and we spend more time in a car because now for the first time we can go together to a restaurant. Some of the older forms of play we had have been replaced by new ones most of which my brother has invented, and I follow his lead. In the last year or so I've found out that he does the best

video calls ever as he translates some of our physical dynamics into virtual ones. He has his own social life now, entirely independent of our relationships to others. We're not taking him along, but following along. I visit him but I almost never feel like I am interceding for him like before, like trying to stave off others' attempts at hugs, defending his routines, or asking people to talk softer, except once in a while when we go out together. There's a lot more room to play without needing to defend against an outside.

Despite the trust it took to do this in the first place, I think at first I was imagining this as a net loss because he would no longer have his home and family with him. I wondered how much he would want me in his life when he wasn't made as dependent, by an often hostile outside, on my mediation. It turned out I needn't have worried about how he feels about me. Something is lost, in that I am sometimes a little lost navigating a changing relationship. I don't always know how to go on, or how often to ask to talk to him rather than leave it up to him to call. I live far away, and sometimes feel that I am relying on the mediation of others to talk to him and plan visits. I miss him and rely more on his decisions. This is exactly the autonomy I have wanted for him.

Geeti Das is a political scientist and a faculty member at Krea University in Andhra Pradesh

Arunima

Aparna Das

Runi, (Arunima) was diagnosed with Autism in 1986, at a time when very little was known about the term. The family spent the next 20 years, learning by living it every day, and of course, extensive reading, attending courses and workshops on the subject. Life

continued otherwise too, and while there were some days when one felt that we were on track, there were many others that hit us out of the blue. But like everything else, one falls into a rhythm, and life goes on.

I completed my certification in Special Education, and dedicated myself to understanding Runi better, while making Special Ed my career too.

But there was a huge, unaddressed elephant in the room. We had found a rhythm of sorts, but what was going to happen "after us"? Maybe the elephant surfaced in conversations, but it was so frightening to think about that one tended to just push it back down and ignore it. Luckily though, the thought refused to be buried.

To cut a long story short, once the exploration began, it became clear that the options available to us as a family, especially Runi, were unthinkable. If we wanted to ensure that her life was in sync with how we had brought her up, the space needed to be created. And that is how, Project Arunima was born in April 2011.

Evolution and Change

The model has evolved significantly since its inception. This sort of facility was unprecedented, and we had to learn along the way. What helped immensely was that the team has always been driven by person centered planning, and so, the individuals using the services have always been our North Stars, pointing us in the direction that is best for them. The most important question that has always guided us is: "What would a typical 20/30/40 year old want from their home, their life?" This does not need to be a "hostel" or an "institutional model". Arunima is meant to be a collection of homes for adults who should be able to live with dignity, safety, and the maximum independence possible.

The most suitable model that emerged after a couple of years was that of "apartments" for small groups of three to four people, like a typical family would be.

A Glimpse into Home Life at Project Arunima

Cut to an apartment with 3 men aged between 28-35.

Young bachelors wake up in the morning. One makes milk for himself, while the other wants only chai, adrak waali. He will make it for himself and

his other friend, a fellow chai lover. The young man drinking milk reminds everyone to take their almonds too. The staff on duty (and this apartment needs only one) along with the young men will do some gupshup with chai and biscuits before everyone starts their yoga.

What is happening In another apartment where there are 4 women, with higher support needs? The two staff on duty may be talking to individual ladies about what they want to wear to work. Looking at two to three options. Helping them to choose.

In yet another apartment with four residents (and two staff) you may find two guys arguing about what tv channel to put on. Sigh! Like any other family.

Having this apartment system helps us to individualise what is done, rather than expecting one size to fit all. People thrive in this environment that is actually home away from home.

The Staff

The team at Project Arunima including the Executive Director, is made up of people who fit different roles:

The Residence Supervisor manages the overall running of the apartments, from the weekly menu and food, to the oversight of cleanliness, safety, as well as distribution of food and maintenance supplies.

Floor Supervisors ensure the overall smooth running of the apartments

The Program Coordinators manage the work in the different work places run by Project Arunima. An army of DSPs (Direct Support Professionals) work with the friends, and play an important role in the fulfillment of our vision: A life of dignity and maximum independence possible for each individual. Some DSPs work at both the residence and the workplace, while others work only at the residence. They play various roles in the lives of our

friends: that of a brother or sister at home, sometimes a parent, a mentor, a friend and at the workplace, a job supervisor too.

The Accounts, Purchase and Maintenance Departments, Vocational Head and Fundraiser are part of the admin team, while Janitorial Staff, Kitchen and Driving Staff form a strong support system.

Employment

Something that almost everyone who lives at Arunima looks forward to, is work. Work is at a couple of places in the community – some started by Arunima, and one, a corporate office at the other end of town.

The skilling center or "The Office" is a place that many of the friends go to. Work starts at 9:40 and goes till 1:30 pm. While we do not believe in one on one "therapy programs" for adults, our friends develop many different skills while they spend their time here.

Social Skills: Interactions with one another, with staff, visitors, shopkeepers and others when we go out, as well as social skills training sessions in groups, are a part of the routine at the skilling center.

Communication: Communication is an important aspect of life – perhaps the most important. A variety of experiences at work help hone communication abilities. Discussions about current events, emotions, family, festivals and health, to name a few, build expressive and receptive language skills.

Vocational Training: All adults want to work and earn money. Our vocational training program is designed for those who need to develop work habits that they may not have experienced or learnt earlier. A variety of activities, including retail work, computer related work, kitchen skills and handicrafts, form our vocational training program. There are skills beyond vocational training, and

these pertain to grooming, good manners, punctuality etc. These "job skills" are learnt as people get employed in our different work areas: Administration, The Tiffin Service and The Production Unit.

Functional Education: Education is life long, but there is a point when we must develop those skills that will come in handy through daily life. Building general knowledge, understanding calculations, reading recipes – these are some examples of the functional education program at Arunima.

The Tiffin Service was set up because we could see that a number of people were really enjoying work to do with food – preparation of raw ingredients, cooking, as well as serving. Today, the small business employs 8 individuals with disabilities, who are supported by three DSPs. Arukriti Tiffin Service churns out delicious and healthy meals, that are prepared and packed daily, and delivered around Dehradun.

Evenings and Weekends

Everyone returns to their apartments in the afternoons or later, by four. Evenings are a time for household chores and then an opportunity to do things that people enjoy. Some love to go for a walk. Others look forward to Zumba. Musically inclined individuals may participate in music lessons. Many people like to cook their evening meals in their apartments.

Saturdays are community exploration days – a movie at the mall, a trek in the foothills, a visit to a village, a picnic at a park. The Arunima gang is out and about, having fun, and in a most unobtrusive way, raising awareness and working towards inclusion too. The stares are fewer, and acceptance is on the rise.

Sundays are usually days for chilling at home. Walk in to find manicures, pedicures and facials in progress. Some people want to sleep in, while others will relax with music or tv. It is a lazy day in every sense. Lazy till the evening, that is, when

most people get together to enjoy dancing, singing, and a meal all together.

It sounds like a typical community, and in some sense, more active and energetic than your regular community. This kind of life is possible because at Arunima, we have purposely stayed away from crowding people into small spaces, a hostel, or institutional model. Experiencing the good things of life is of prime importance for physical and emotional wellbeing.

May we always keep our sights focused on our North Star – the friends at Arunima.

Aparna Das set up and headed the Learning Disabilities Program at the Woodstock School. She served as Head of the Special Needs Program till she left to establish ARUNIMA in 2011. Aparna's sister, Arunima, is on the Autism Spectrum, and the inspiration for the program.

Working Towards Independent Living

Neena Wagh

In the early years of parenting a child with special need one gets drowned in the immediate, what with looking for an inclusive school or running from one therapy centre to another, consulting a new specialist with kindled hope for getting "better results", while praying secretly for some miracle cure all this time!

Yes, we all have been there, however, in the past twenty years I have seen the focus shifting from the immediate to the long-term planning as well. Being a parent of one such individual myself, when my son who is also on the autism spectrum turned into a teen, I started looking around to find the answer to "what after us", which set me off to a long and arduous journey to find the satisfactory answer. In the beginning the situation looked very bleak to me as apart from the government funded charity-based institutions there wasn't much to talk about.

With that in mind I formed a community group on Facebook by the name of Forum for Assisted Living Solutions and started collating information related to assisted living in our country and started inviting fellow parents/professionals to report, share information and their experiences of such facilities.

Today there are around 70-80 such facilities listed on this forum, with more than 3000 stakeholders and the list is growing. There are many parents who are in the same boat worried about their child who would require lifelong assistance. While it's good to know about the growing number of options, I think there are many prerequisites which a parent should look into first.

Start early to prepare your child towards independence. Take something as basic as toilet training, eating without anyone's help, self-grooming or sleeping independently and various other activities of daily living. Every milestone achieved will boost the confidence in your child and reduce the dependency on the mother who ends up being the primary caregiver for her entire life. I understand that there are always delayed milestones in our children compared to the neurotypical ones, however if we as parents are persistent then our children can also catchup sooner or later.

Decision making should be encouraged as early to boost the self esteem in the child. It can be as simple as giving them the choice to select which clothes or shoes they would like to wear, what book

to read, which activity they would like to do and then build it towards critical thinking. Teaching them the consequences of good and bad behavior is very important as each meltdown cannot be result of Autism alone but a simple lack of behavior modification.

Peer Interaction is as important as activities of daily living or making choices as we are all social beings and want to interact with others. The more your child gets exposed to different environment and gets to interact with different sets of people without being overwhelmed by the constant parental supervision the more independent he/she will become to form and adjust in a peer group.

Now your child is ready to step away from your umbrella and can forge ahead towards independence. You may again start with baby steps, like leaving him at home, maybe with a caregiver other than the mother herself, or sending him to stay overnight to a relative or the NGO where he is going as that will mentally prepare him/her towards the adulthood.

Start looking for the best possible option for your child. Start thinking as to what kind of life and living standard do you perceive for your child as there are many kinds of models coming up in our country. There are several models where you will have the option to either send your child or you can live along with him/her. In the beginning you don't have to straightaway make long term commitment; you may opt for short term respite to begin with as that way you will get to experience the quality of the facilities and will be able to assess their deliverables more accurately.

Become part of parent communities so that you don't feel isolated plus you will learn a lot from your fellow parent's experiences. In case you feel strongly that you would like to start your own residential setup then also it is imperative as you will be able to find some parents who will share your vision for a desired model.

In case you feel that you do not want to send your child to any of such model and would like him or her to live with you for the rest of his/her life then please ensure that the child has a good circle of support comprising of fellow parents, few professional like therapists, doctors, peer group, lawyers, job consultants or guides because the fact of the matter is that whether our children are high functioning or at the lowest level of the ladder, they will require lifelong assistant to various degree. Like even if they are able to go to work, they may be vulnerable in terms of taking decisions related to financial matters or develop or sustain relationships on their own, hence they will require this entire battery of people.

Working and focusing in this particular area of assisted living I come across many cases almost on daily basis where either there is a severe gap in the child's capacity building or the over protecting parenting has resulted in absolute dependence on care-givers so when such a parent reaches out to an assisted living facility there is whole lot expectations from the service providers and they have to take up more than their fair share of the responsibilities.

In order to create a better echo system wherein our children thrive and build a meaningful life with respite and good support to the child's family and a secure future, it is very important that all of us take the onus and do our bit, for only then I see beautiful, happy and secure communities of special need people being nurtured across the country.

Neena Wagh is a parent, a poet, playwright and Hindi language translator. She is the Founder Trustee of ALAP; Assisted Living for Autistic Persons which provides residential facilities to autistic individuals. She is an autism advocate with over 20 years of experience in the sector.

The Making of the Community Living Association of Parents of Special Citizens (CLAPS) Community

Sanjay Rao Bantwal

The Seed

About six years ago the thought of a parent community came to the minds of the front runners at CLAPS. Several attempts were made in the past in Chennai and also in other places of the country and most of them failed at the initial stages and some of them after construction. There was no successful running community. One day Mr. Gurumurthi one of the front runners of the Claps community approached Mrs Vasudha Prakash of Vexcel Group of Institutions to come forward and help parents form a community amongst themselves.

An eager Vasudhaji called for a parent meeting and announced 'Why don't you parents start a community' and shared the benefits of a parent run community. In the audience were many parents with a burning desire to start a community. Some among them were Mr Elangovan, Mr Hariharan and Mr Sanjay Rao Bantwal.

The meeting concluded with parents deciding to start a WhatsApp group and many active members came forward to take it to the next step. Many closed-door meetings took place and steps forward were considered. Mr. Gurumurthy and Elango were the most active amongst the parents. They would initiate frequent discussions with Vasudhaji and request her to motivate parents in the institutions.

In order to have a trial run of a residential setup to understand the cost and challenges that may come up from such a setup, Vasudhaji suggested running a parent run group home and take care of the Special Adults within the city limits.

Though there were a few parents volunteering for this project, there was little real action due to the

hesitation and fear of the concept of leaving the children alone. Six months went by when one day the team decided to visit a Group Home in Hosur very close to Bangalore. Guru, Elango, Sanjay Rao and a couple of parents joined the trip. It was a well-constructed building but there were very few takers for the Group Home. In fact, when the team visited this place, the only Special Adult living there was the son of the founder of the institution. One more indication of the lack of acceptance of the concept of a group home based on the fear of leaving ones children with strangers'.

This fear and hesitation gave the insight into the fact that a group home is not what these parents around us were looking for, but a full-fledged living community where parents could stay along with their children, that will be the answer for the question in the minds of parents "what after us?".

Everybody's child is everyone else's child

This statement looks idealistic but was it realistic was the question in the minds of the Team front-ending the conversation. So, many trips were organised to holiday destinations such as Top slip, Kodaikanal, Kolli Hills and along with the recreation a study was conducted to know how parents treat other special children. The result was astonishing. Not only parents cared for other children they too felt comfortable with other parents.

That rang the bell for race towards community.

Face of Claps

Since there was a lot of work ahead of the Team and all this work needed a 'Face'. A 'Face' to face the government and compliances. For this the team met

more than 25 professionals from various institutions who could give guidance on this subject. It was finally decided after many hours of deliberation that a Society would be 'The Face' for the future of CLAPS and to undertake contracts with different vendors and contractors a Limited Liability Partnership company would be ideal. So, these identities were created and the ball started rolling.

Starting with a Give

The team decided to start by 'Giving' to the cause. There were a lot of resources that the team had to 'Give' – time, money and much more. The team unanimously agreed to give for the cause all that was needed without a penny in return. The institutions would be operating on Zero Profit.

Landing on the Land

After having wandered all around the length and breadth of the Chennai area and its suburbs it was a moment of cheer when the team identified 8 acres of land and owned by one individual. Quickly the team moved forward. However it took six months for the owner to get convinced and sell the property. The team pumped in the initial money and made a sale agreement with the owner, with the commitment to pay within 3 months.

The Early Birds

Surprisingly none of the members who were parents could take a decision to move forward. Hesitation filled their minds. With some prayer and will power the team moved ahead and made presentations in four institutions.

The new set of parents were highly excited about the concept and clarity in our minds and slowly membership started flowing in. The existing parent's hesitation also vanished and they joined the path by becoming a member.

The Boundaries

After having secured the trust of 30 families it was time to start planning for the infrastructure. The team decided to secure the property first and started constructing a boundary wall. The budget for

constructing a wall was childishly planned as 30 to 40 Lakhs. However, it was a shock to learn that it would cost 70 to 80 Lakhs, i.e. double the cost. The boundary ran to 0.75 kms and for the sake of stability a solid foundation was requested and there was no possibility of compromise.

The Construction Team

An Architect was already in place and he was someone who had the vibrations matching the purpose of the project. With his guidance a Construction Team was formed. The project team had a mix of parents and contractors. Every step was reviewed in weekly meetings.

Designing the Nest

Designing the family dwelling unit started with a villa concept however for the sake of more free space it was changed to an apartment model. How, the blocks would be formed were decided over many sittings. The final scheme was a four-block model with four apartments in every floor and ground plus 2 floors totalling 48 apartments.

Upon arriving at the number of dwellings the decision to restrict membership to 48 was also taken.

The Ship to Independence

CLAPS concept circles around the problem 'what after us' and hence it was very imperative to decide how we will take the Special Adults towards a solution. Making them independent becomes an important component.

For this a place was required away from the home and that too a 24 hour living experience for the special adults. Not only a living but a livelihood experience.

A Residential Living Unit was planned based on the above thought. How should the rooms be designed? Where should everything be placed?

Promoting Camaraderie

Planning separate rooms like a college hostel in a row looked very mundane and boring. Our special

ones should build camaraderie with their fellow ones. How to do it?

Forming clusters was a suggestion that was accepted by all. The clusters would not only build camaraderie but also ensure safety of the Special ones. So four Rooms were placed in a cluster that had one room in the center. Typically, like a four-bedroom apartment, the room in the center was for the caretaker. Independence for the special ones with individuality was ensured by providing personal space, personal wash rooms, personal balcony however, being in a cluster would ensure fellowship.

Becoming One Among Them

The Construction picked up momentum and reached a stage where the apartment needed to be allotted to individual members. The billion-dollar question was, which apartment goes to which member?

The team always wanted to have a mindset of giving and oneness with others. In spite of suggestions coming from well-wishing parents the team went for a 'lot' to pick the parent-to-apartment choice. Members were asked to submit a choice of 10 apartments in a chronological order of their personal choice. Once these were submitted all the members' names were put on a lot and a special adult was made to pick the lot. The name that came up was given the choice. Likewise, the rest followed one by one. The rest got their choice if it was free when their lot came up.

The Campaign

Once again, a campaign was launched to bring awareness about this project. Members of the team volunteered for online video interviews with parent groups and this brought in more parents as members.

The membership started growing.

Funds Flow in Synchrony

The team had in itself experts in various fields. Expertise in managing projects led to parent

members who helped manage funds, made a flow chart of the construction activity and managing the collection drive and so on. All this was happening in synchrony due to this expertise.

Help from Unexpected Quarters

It was time for taking approvals and the government machinery has a lot bottlenecks. Whatever expertise available within the group could not help in liaising with the Government. It was time to turn to help outside the group. This came in the form of another special parent who was in the IAS fraternity. Doors opened like never before and work happened at the speed of lighting and at no extra cost.

Migrating Forever for their Special Ones

Birds migrate by instinct and special parents do it impulsively for their special ones. Parents migrated from Delhi, Mumbai, Salem, Bangalore and Overseas searching for a safe nest for their special ones cutting across language and religious barriers.

Covid Times

The project came to a halt due to covid. Prices shot up and made times difficult. However, the parents took good care of the laborers by ensuring food supply and preventive medicine supply.

To keep the parents engaged many whatsapp groups were formed earlier and this came handy to keep all the wards engaged by conducting online yoga and dance sessions. Fancy dress competitions and foster parenting games were conducted to pass the covid waves without much psychological damage.

Time for Family Waves to Touch the Feet of CLAPS

Throwing the woes behind and not looking back on it made the parents move forward and speed up the construction. Volunteering for site visits increased and with the good work all the final work happened at a good pace. It was handover time and 21 August 2022 was the day for the community to start operating. A team of volunteers negotiated a cooking contractor and lined up the cooking team. Procurement of vegetables, grocery, utensils,

checking equipment all happened one after the other.

Some volunteers burned the midnight oil to get things going. Water and sewage treatment plants functioning, power availability, etc.

A wave of parents moved in and...

Building of Bricks Over, Now it is Building of People

Challenges of manpower, getting caregivers is a big challenge.

Salary package planned was like a joke. The expectation was double that of the offer. The team had to go ahead and accept reality.

Special Adults felt CLAPS was like a haven for them. Some called it a resort as they stepped in.

Many Special Adults who went out of Claps in private engagements expressed deep desire to return back.

Parent emotion was the most challenging to handle. Emotions spilled all over the community. Gradually as months passed by there was clarity in the minds of people.

Parents jointly celebrated festivals in oneness. Children enjoyed the oneness.

Claps – A Village Within the Village

Caring for one another is universal in claps. Parent doctors take care of the sick inside the campus. Emergencies are handled by the community in a spirit of togetherness.

An unwritten promise that is being written as a bylaw is the commitment by all the parents that no son or daughter who comes to CLAPS shall be asked to leave no matter the circumstances. A promise that gives every claps parent an unexplainable peace of mind with the essence of 'after us'.

A happy group of 28 special adults start their daily schedule with walking and have a beverage before doing some farming activity and followed by breakfast and taking bath in their residential units.

They then move into the vocational centre to start with prayer and work. Work involves mat making, jewellery making and many such activities. Post lunch they enjoy some music and start physical activities such as yoga, gym etc. In the evening skating, football, cricket, cycling etc. are enjoyed by the special ones.

The Team continues to believe that construction of the building is 50% and the remaining 50% is in the construction of the people. Construction of people is highly dependent on what brings them together.

What can bring people together

Just living together cannot....

Money cannot...

Even the need for a solution for 'what after us' cannot...

Only LOVE CAN. Realisation that when we are bound by love, anything can be achieved so why not an INFINITY COMMUNITY....

The CLAPS Team is on a mission to find ways and means to invoke love within each and every CLAPSIAN and when this happens....

One can call 'CLAPS PROJECT COMPLETED'.

Sanjay Rao Bantwal is a parent and a CLAPS family volunteer. He is a strong professional with total technology experience of 35 plus years. He is an experienced director with a demonstrated history of working in the Security Systems Industry.

असिस्टेड केंद्र के लिए तैयारी

प्रीति सिवाच

जब घर में एक बच्चे का जन्म होता है तो उस समय घर में एक अलग रौनक होती है। माता पिता ना जाने बच्चों के भविष्य के लिए तभी से कितनी योजनाएं बनाना शुरू कर देते हैं। बच्चा चाहे कितना भी बड़ा हो जाए पर माता-पिता उसको अपने दिल के पास ही रखना चाहते हैं, जब तक ना कोई उनकी अपनी मजबूरी या बच्चों के सुखद भविष्य की बात हो। ऐसा हर परिवार में देखा जाता है, चाहे वह बच्चा ऑटिस्टिक हो या नॉन ऑटिस्टिक।

लेकिन जब बच्चे के साथ ऑटिस्टिक शब्द जुड़ जाता है तो माता-पिता बच्चों के भविष्य की प्लानिंग में एक बात और सोचने लग जाते हैं कि मेरे बाद इसका क्या होगा? उसका कौन ख्याल रखेगा? क्या मेरा कोई रिश्तेदार इसको संभालेगा? क्या यह अपने भाई या बहन के साथ रह पाएगा? क्या इसकी शादी कर दें जिससे इसको कोई संभालने वाला मिल जाएगा? क्या करें और क्या ना करें? अत्यधिक सवाल आते रहते हैं। और यह चिंता और अधिक बढ़ जाती है जब बच्चा एक युवक अवस्था में पहुंचने लगता है। आज इस आर्टिकल के जरिए हम इसी बात पर चर्चा करेंगे कि अभिभावक के बाद बच्चे को रहने के लिए कैसे तैयार किया जाए। यह आर्टिकल कुछ अनुभवों के आधार पर लिखा है जो हमें ऑटिस्टिक एडल्ट्स और उनकी फैमिली के साथ काम करके प्राप्त हुए हैं।

अभिभावक इस बारे में जब भी कभी सोचते हैं तो बहुत से सवाल उनके मस्तिष्क में आते हैं। जो अपने बच्चों की सेफ्टी और अत्यंत लगाव के कारण दूर जाने के डर से आते हैं। निम्नलिखित कुछ सवाल है जो एक अभिभावक अपने से करते हैं और शायद बहुत कम लोगों को ऐसे अवसर मिलते हैं जहां वह किसी ऐसे के साथ साझा करें जो उसको निष्पक्ष होकर सुन सके और सही सलाह दे पाए।

1- सुरक्षा का विचार: सबसे पहला सवाल हमेशा एक अभिभावक के मन में रहता है कि क्या हमारे बच्चे को वह सुरक्षा मिलेगी जो हम दे रहे हैं? यह सवाल मन में आना स्वाभाविक है क्योंकि हमारे बच्चे बहुत *oyujscy* होते हैं। जो शायद समझ सब कुछ जाते हैं लेकिन उन भावनाओं को बोल कर नहीं परंतु अपने व्यवहार से ही बता पाए कि उनके साथ क्या चल रहा है। और ये बहुत कम लोगों को समझ आता है। तो इसके लिए शायद अभिभावक को बहुत पहले से ही खोज शुरू कर देनी चाहिए एक ऐसी जगह के लिए जो उसके लिए सुरक्षित हो। जहां बच्चे के साथ क्या चल रहा है उसकी जानकारी हो। इस आर्टिकल के अंत में इसका उल्लेख किया है कि सही जगह का चुनाव करते समय आप किन बातों का ध्यान रखेंगे।

2- हम जब तक है, तब तक क्यों कहीं भेजें?

यह सवाल और यह उलझन शायद अभिभावक को हमेशा रहेगी, चाहे बच्चों को उसकी सही जगह भी रहने को मिल जाए क्योंकि यह अभिभावक का प्यार कहिए। लेकिन सही बात तो यह है कि इस निर्णय के लिए अपने को दोषी न मानकर सही समय पर सही फैसला लेना चाहिए। अगर हम अपने बच्चों के बेहतर भविष्य की कल्पना करना चाहते हैं तो शायद तैयारी हमें हमारे सामने ही करनी चाहिए वह भी उस

समय जब माता-पिता में दौड़ भाग करने की शक्ति है। हमेशा यह सोचकर चलना चाहिए कि हमारे बाद ऐसी जगह रहे, जहां वह खुश रह सके। लेकिन वह खुशी भी बच्चे को जब ही मिलेगी अगर हम उसका एक अपना घर तैयार करके दे जहां उसकी जरूरत का पूरा ध्यान रखा जाता हो और उसकी एक इज्जत वाली जिंदगी हो। सोचिए एक माता-पिता के लिए कितनी संतोषजनक जिंदगी होगी, जब वह अपने बच्चे को अपने घर में सम्मान के साथ रहते हुए देखेंगे। अपने सामने अगर कोई बदलाव की जरूरत होगी तो वह आराम से कर सकेंगे। तो बच्चे के सुखद भविष्य के लिए आज ही से शुरूवात करना एक सही कदम होगा।

3- बहुत सारे पैसे जमा कर दे तो उसको किसी की क्या जरूरत है? कुछ अभिभावक की सोच होती है कि बहुत सा पैसा जमा कर देते हैं जिससे उसकी सभी जरूरतों को पूरा किया जा सकता है। ये तो सही है कि पैसों से बहुत सी जरूरत पूरी हो सकती है लेकिन सोचिए की क्या आपके बच्चे को पैसे से वो सभी भावनाओं को समझा पाएंगे? उनको एक नैतिक सहायता की भी जरूरत रहेगी। और एक वयस्क के लिए सिर्फ पैसा ही खुशी नहीं देती। सब व्यक्ति की खुशी की परिभाषा अलग होती है। जो उसको समझते हुए उसके साथ रहना चाहेंगे। पैसे हमारी कुछ ही जरूरत को पुरा करता है लेकिन भावना को अगर कोई नहीं समझने वाला ना हो तो क्या वो पैसा भी रखा रह जाता है। पैसे को अगर बच्चा संभाल नहीं सकता तो क्या गारंटी की जिसके साथ वो रहेगा वो उस पैसे का इस्तमाल सही रूप से बच्चे के लिए ही करेगा।

4- भाई-बहन या रिश्तेदार हमारे बच्चे का ख्याल रखने के लिए है तो क्यों उसको बाहर किसी और जगह पर छोड़ना चाहिए? अत्यधिक माता-पिता की सोच यह होती है कि उसका भाई या बहन तो है उसका ख्याल रखने के लिए और जहां भाई-बहन नहीं होते हैं वहां अपने किसी रिश्तेदार को वह अपने बच्चों का ख्याल या देखभाल रखने के लिए चुनते हैं। लेकिन जरा ध्यान से सोचिए कि जब बच्चे के भाई या बहन बड़ा हो रहा है तो उसकी अपनी भी कई जिम्मेदारियां होंगी, उसका भी अपना परिवार होगा और ऐसे में कोई भी यह गारंटी नहीं दे सकता कि जिनसे उनकी शादी होगी वह भी उसी तरह से उसके ऑटिस्टिक भाई-बहन को अपना लेंगे जैसे उसके अपने भाई या बहन ने अपनाया है। सबसे महत्वपूर्ण बात यह है कि क्या आप चाहेंगे कि आपका बच्चा किसी पर बोझ बने। ऐसा जरूरी भी नहीं कि सभी एक जैसे होते हैं पर किसी की कोई और मजबूरी भी तो हो सकती है। तो जो भी सोचे वह अपने दोनों बच्चों को एक ही तराजू में रखकर सोचे, किसी का पलड़ा इतना भारी न करें जिससे वह उसकी जिम्मेदारी को संभालने में सक्षम ना हो और दोनों भाई-बहन को उसका समान अधिकार मिले ना कि एक पर जिम्मेदारियों का बोझ डाल दें और दूसरे को उसकी अपनी सही पहचान ना मिल सके। रही रिश्तेदारी की बात तो वह भी ऊपर लिखे हुए बातों में ही कहीं ना कहीं आते हैं और अगर यह मान भी ले की हो सकता है, कोई भाई-बहन या रिश्तेदार बहुत मन से बच्चे को अपने पास रखना भी चाहता है, पर क्या आप इस बात से संतुष्ट रहेंगे?

5- क्या इसकी शादी कर दें?

यह सवाल अधिकतर उन अभिभावकों के मन में आता है जहां यह देखा है कि बच्चा अपना ख्याल थोड़ा बहुत तो रख ही पाता है और दिखता है कि उसमें इतना ऑटिज्म नहीं है, परंतु वे यह भूल जाते हैं कि उसे कहीं ना कहीं बहुत सी जगह पर सपोर्ट की जरूरत होती है। दूसरा यह सवाल कई बार फैमिली के मन में इसलिए भी आता है जिससे वह अपने बच्चों को संभालने के लिए किसी को ले आए या फिर उसके सेक्सुअल डिजायर्स पूरी करने की इच्छा से भी आता है। इस पर मैं बहुत कुछ टिप्पणी तो नहीं करना चाहूंगी परंतु यह जरूर है कि अगर कोई आपके बच्चे को इस तरह से अपना सके जैसा वह है और उसके डिफरेंस को भी समझ कर उसको अपनाना चाहे तो अवश्य आप इसको देख सकते हैं परंतु यह सुनिश्चित जरूर कर लें कि जो पार्टनर है वह हकीकत में मन से उसको अपनाना चाहता है, अगर ऐसा नहीं है तो यह कभी ना करें क्योंकि आखिर में परेशानी आपके अपने बच्चों को ही ज्यादा होने वाली है। तो जो भी करें बहुत सोच विचार कर और परख कर करें।

चाहे बच्चा किसी और जगह रहे या फिर अपने परिवार के किसी और सदस्य के साथ फिर भी हमें बच्चों को अभिभावक के बिना रहने के लिए तैयार करना आवश्यक है। जैसा कि हम सभी जानते हैं कि हम जिस तरह के रूटीनस अपने बच्चों को सिखाएंगे वह वैसे ही उसमें ढल जाते हैं और इसलिए यह जरूरी है कि इसको ध्यान में रखकर ही हमें अपने बच्चों की परवरिश करनी चाहिए।

तो चलिए अब इस पर चर्चा करते हैं कि हम कैसे अपने बच्चों को तैयार कर सकते हैं एक असिस्टेंट लिविंग के लिए जिसमें यह तैयारी हम अपनी परवरिश के जरिए ही कर सकते हैं इसके लिए कुछ अलग से करने की जरूरत नहीं होती।

निम्नलिखित कुछ सामान्य सी बातें हैं जो हम अपने बच्चों की दिनचर्या में ला सकते हैं। इन सब क्षमताओं को सिखाते समय हमें अपने बच्चों की जरूरत और उसकी समझदारी के हिसाब से कुछ और भी बदलाव लाने पड़ सकते हैं जो हमारा बच्चा हमें गाइड करता है।

1- संरचना के साथ एक दिनचर्या बनाना:

तैयारी का सही समय आज से ही है अर्थात् जैसे ही हमें यह समझ आए कि हमारे बच्चे को कभी तो हमारे बिना रहना होगा। इस समय से ही तैयारी करना जरूरी है। इसके लिए आप अपने वातावरण में कुछ ऐसे बदलाव लाए जो आपके बच्चे की जरूरतों को ध्यान में रख कर बनाया गया है। जितना जल्दी हो उतना ही अच्छा है, क्योंकि हमें बच्चों को ऐसे परवरिश देनी है कि वह इस तरह के वातावरण में खुश रह सके जो इनकी जरूरतों को समझकर बना है, तो यह जरूरी है कि बच्चों के सही रूटीनस बनाने के लिए हमें शुरू से ही ध्यान देना होगा। जैसे घर के छोटे छोटे काम बच्चे से करवाना, सामान जहा से उठाए वहीं पर वापिस रखवाना इत्यादि। और ये सिखाने के लिए आप कुछ विजुअल्स का उपयोग भी कर सकते हैं। जिससे बच्चे को सीखने में आसानी होगी और बिना किसी सहायता के वो काम करना सीख जाएगा। जो भी रूटीन आप दे उसको हमेशा एक ही तरह से और लगातार करवाए।

2- प्रमुख कौशल: इसमें निम्नलिखित कौशल आते हैं...

1- अपना काम स्वयं करना: इसमें अपना ख्याल रखने वाले सभी कौशल शामिल होते हैं जैसे खाना, नहाना, टॉयलेट जाना अपने कपड़ों का ध्यान रखना इत्यादि। यह

वह कौशल हैं जो एक व्यक्ति के लिए बहुत जरूरी है और आमतौर पर बहुत से माता-पिता इन सभी कौशल के ऊपर बहुत बाद में ध्यान देते हैं। जब बच्चा छोटा होता है, तो माता-पिता पहले उसके पढ़ाई-लिखाई और दूसरी फ्यूचर की चीजों के लिए ध्यान देते हैं, जिससे इस कौशल पर जितना ध्यान देना चाहिए वह कभी-कभी कम हो जाता है। जब बच्चा बड़ा हो जाता है तो वह बहुत से रूटीनस सीख लेता है, जिसको बदलना बहुत मुश्किल हो जाता है। जबकि यह आना बहुत जरूरी है। हमारे बच्चे को कोई भी अच्छे से रख सकता है अगर हम बच्चे को इन सब कौशलों में स्वयं पर निर्भर कर दें। हां कभी-कभी कुछ इंडिविजुअल को सेंसरी या मोटर क्षमताओं में मुश्किल आती है, जिसके लिए भी हम ऑक्यूपेशनल थैरेपिस्ट से बात करके उसके ऊपर काम कर सकते हैं। दूसरा हमें ऐसा वातावरण और दिनचर्या देनी चाहिए जो किसी भी जगह स्वीकार्य हो जैसे की टॉयलेट पोट में ही करना है जैसी आदतों को बढ़ावा देना।

2- लचीलापन और सामान्य करण: यह शब्द देखकर ही लगता है कि ऑटिस्टिक बच्चे और चेंजेस के साथ डील कैसे करे? यह सबसे महत्वपूर्ण कौशल है, जो आना चाहिए क्योंकि हमारे आसपास का वातावरण बहुत ही अनप्रीडिक्टेबल है और बार-बार बदलाव होते रहते हैं। यह भी हमें पता है कि हमारे जाने के बाद उसको ऐसा ही माहौल नहीं मिलेगा कुछ ना कुछ तो बदलाव अवश्य आते रहेंगे। तो शुरू से ही एक फिक्सेशन न रखकर कभी-कभी बदलाव को भी उसकी दिनचर्या में शामिल करें। समय पर थोड़े-थोड़े से बदलाव अपनी दिनचर्या में लाते रहे और यह बदलाव अगर आप लिखकर या फिर पिक्चर के द्वारा करेंगे तो अत्यधिक मददगार होते हैं। बच्चे को अच्छे से समझ भी आ जाते हैं, जिनसे उनको कोई घबराहट भी नहीं होती। वह सीख जाते हैं कि वातावरण में ऐसे बदलाव आने से हमारी दिनचर्या सुगम तरीके से चल सकती है। अपना वातावरण इस प्रकार से बनाएं कि जहां बच्चे को आने वाले समय के बारे में अच्छे से पता है कि अब क्या होने वाला है और क्यों होने वाला है? तो हमारे बच्चे सबसे ज्यादा फ्लैक्सिबल हो सकते हैं। शुरू से ही इस पर ध्यान देना चाहिए जब हम बात करते हैं सामान्यकरण की तो उससे तात्पर्य है कि जब बच्चे को कुछ भी सीखा रहे हैं उसको दूसरे व्यक्ति, जगह और वातावरण में भी साथ-साथ सिखाएं जैसे बच्चे को जब यह समझ आ जाए की टॉयलेट में टॉयलेट करना होता है और वह अपने घर के टॉयलेट को इस्तेमाल करने लगता है, साथ में यह भी सिखाना जरूरी है कि दूसरी जगह पर ऐसे टॉयलेट में जाकर कर सकते हैं। जिससे बच्चे को सिर्फ एक ही टॉयलेट की आदत ना हो। वह हर जगह और हर तरह के टॉयलेट को इस्तेमाल कर सके। हां कुछ बच्चों के लिए कुछ अलग से सपोर्ट चाहिए होते हैं तो उसके लिए ऐसे सपोर्ट ले, जिसको दूसरी जगह के टॉयलेट में कहीं भी आसानी से अपना सके। इस तरह से खाने में भी सभी प्रकार के खाने को जरूर शामिल करें। हां कुछ बच्चे सेंसरी कारण होने से सभी तरीके के खाने खाना पसंद नहीं करते हैं परंतु उसके लिए भी हम किसी अच्छे ऑक्यूपेशनल थैरेपिस्ट से सलाह ले सकते हैं, कि कैसे बच्चे के खान-पान में नए तरीके के खाने को हम शामिल कर सकते हैं।

3- बच्चों को अकेले रहना सिखाएं:

इसमें सबसे पहला कदम तो है कि बच्चों को अपने से अलग दूसरे कमरे में सोना सिखाएं। अधिकांश तौर पर देखा गया है कि भारतीय माता-पिता अपने बच्चों को अपने साथ सुलाना ज्यादा सुरक्षित समझते हैं परंतु ऐसा करके हम अपने बच्चों को अपने ऊपर ज्यादा निर्भर कर लेते हैं। और बच्चे इसको रूटीन में ले आते हैं जिससे

बच्चों को और अभिभावक दोनों को बाद में अलग सुलाने में बहुत परेशानी होती है। इसके लिए शायद माता-पिता को बहुत पहले से ही काम शुरू कर देना चाहिए। अधिकांश देखा गया है कि ऑटिस्टिक व्यक्ति की नींद थोड़ी कम होती है या डिस्टर्ब नींद होती है जिसके कारण माता-पिता उसको बिजी रखने के लिए या उसकी सुरक्षा के लिए उसके साथ ही रात को सोते हैं। लेकिन साथ सोए बिना भी हम बच्चे के रूटीन को ऐसे बना सकते हैं जिससे वह अकेले अपने अपने कमरे में सो सके। बच्चों को ऐसा रूटीन देना जरूरी है कि नींद आए या ना आए पर रात के समय उसे अपने बिस्तर पर ही रहना होता है। इसके लिए रात का एक फिक्स रूटीन बनाना जरूरी है जिससे बच्चों को उन क्रियाओं से यह पता चलना चाहिए कि अब मेरा इस रूम में रहने का समय है। चाहे जो भी हो बच्चे के साथ एक बार गुड नाइट बोलने के बाद रात में कोई एक्टिविटी ना करें। इसके लिए और बहुत से सुझाव हैं जो हमारे पहले के जनरल में बताए गए हैं जिनका पालन कर हम बच्चे को अलग कमरे में सोना सीखा सकते हैं। जब बच्चा अलग सोना सीख जाता है तो कोशिश करें कि आप अपने घर में किसी और रिश्तेदार को लेकर आए जिसके भरोसे आप अपने बच्चों को कुछ समय के लिए छोड़कर घर से बाहर जा सके। ऐसा करने से आपके बच्चे को यह समझ आएगा कि मैं किसी के भी साथ सुरक्षित रह सकता हूँ। ऐसे ही आप दूसरे के घर भी रुकने के लिए जाएं जिससे उसे यह समझ आए कि वह अपने रूटीन किसी के भी घर जाकर पूरा कर सकता है। इससे हम बच्चे को यह सीखा रहे हैं कि वह कहीं भी रहेगा, वहां उसका अपना रूटीन पूरा हो सकता है। जब बच्चा आपके साथ किसी और रिश्तेदार के घर रुक जाता है तो उसको कभी-कभी अकेले उसे रिश्तेदार के पास एक या दो घंटे के लिए छोड़ कर जाएं, अगर हमारे पास कोई रिश्तेदार या दोस्त नहीं है तो अपने आसपास ऐसा पेंट्रस सपोर्ट ग्रुप जरूर बनाएं जिसमें यह कौशल सीखने के लिए हम एक दूसरे के बच्चों की मदद कर सके। ऐसा सपोर्ट ग्रुप अभिभावक के लिए बहुत तरह से लाभदायक होता है।

4- आत्म वकालत: यह कौशल ऐसा है जो एक दिन में नहीं सिखाया जा सकता अगर आप भी देखेंगे तो यह शायद बहुत से लोगों के लिए मुश्किल होता है, किसी सही बात का चयन या अपने लिए आवाज उठाना। यह क्षमता या कौशल इसलिए भी जरूरी है क्योंकि अपने हिसाब से चयन की गई चीज हमें ज्यादा संतुष्टि देता है और इससे हमारे अंदर एक अलग विश्वास आता है। जो किसी को भी प्रोत्साहित करता है अपने लिए बोलने में। तो बच्चे को शुरुआत से ही कुछ चीजों में कंट्रोल दें और उन्हें अपने लिए सही चयन करना सिखाएं। साथ साथ उन्हें उनके डिफरेंसेस के बारे में बहुत ही सकारात्मक तरीके से बताते रहे। और उनकी छोटे छोटे अच्छे काम को हमेशा सकारात्मक तरह से एक्नोलेज करे। साथ में उनके स्ट्रेंथ और मुश्किलों को भी बताते रहे और ये जरूर बताएं कि इनके होने से वो क्या अच्छा कर सकते हैं और अपने चैलेंजिस के लिए क्या सपोर्ट अपना सकते हैं। हमेशा कोशिश करें उनके व्यवहार को उनके नजरिए से देखने की। इसके साथ बच्चे को अपने घर के छोटे छोटे काम में व्यस्त जरूर करें और बाद में उसको इस काम की जिम्मेदारी लेने के लिए उत्साहित जरूर करें। ऐसे करने से बच्चे को अपनी जिम्मेदारी का एहसास होगा। शुरुआत से ही बच्चों को उसकी पसंद और ना पसंद वाली चीजों में चयन करना सिखाएं और फिर दोनों पसंद वाली चीजों में सही चयन करना सिखाएं, इसी तरह से घर में भी अपने साधारण कार्यों के बीच भी इसी तरीके से चॉइस लेना या चयन करना सिखाते रहें, इनसे बच्चा यह भी सीख रहा है कि जीवन में उसका भी कोई कंट्रोल है और वह भी अपने लिए सही चयन कर सकता है। इस तरह से हम उसको तैयार कर

सकते हैं अपनी बात को दूसरो के सामने रखने के लिए और अपने लिए सही चयन करने में।

5- चाहते और जरूरतों की सही पहचान करना: अपनी चाहतों और जरूरतों में फर्क करना बहुत मुश्किल होता है। एक ऑटिस्टिक इंडिविजुअल के लिए शुरू से ही इसके बारे में बताते रहना चाहिए। यह बताना बहुत जरूरी है कि हम पहले अपनी जरूरत को पूरा करते हैं और फिर अपनी चाहतों को। लेकिन हमारे इंडिविजुअल को हम शायद उसकी चाहतों को ही पूरा करना सिखाते हैं इसलिए जरूरी है कि उनको अपनी इच्छाओं को पूरा करने से पहले यह जरूर बताएं कि उसकी जरूरत का सामान क्या है और वह कैसे आता है, ऐसी परिस्थितियां बनाएं जिसमें वह अपनी चाहतों को पाने के लिए कुछ समय इंतजार कर सके। उनके मांगते ही सामान दे देने से हम उसकी चाहत को और बढ़ावा दे देते हैं, तो यह जरूरी है कि जब भी बच्चा हमसे अपनी चाहत रखता है तो हम उसको बहुत अच्छे से विजुअल कैलेंडर दिखाकर बताएं कि उसे कितना समय इंतजार करना होगा, अपनी चाहत को पूरा करने के लिए। उसको पूरा करने के लिए कुछ पैसा बचाना भी जरूर सिखाएं। जो हम ले कर नहीं दे सकते हैं तो उसका वादा कभी न करे, उल्टा क्यों नहीं ले सकते उसको चित्र या चार्ट के जरिए जरूर समझाएं। यह सिर्फ बोलने से ही नहीं आएगा इसके लिए हमें बहुत सी चीजों को धीरे-धीरे सीखना होगा और यह विजुअल तरीके से बताया जाए तो बहुत अच्छे से समझ आता है। इसका इस्तेमाल हर जगह करना जरूरी है। इस तरह से आप बच्चे को यह सीखा रहे हैं कि हमें पहले अपनी जरूरत को पूरा करना चाहिए और अपनी चाहते हम बाद में भी पूरा कर सकते हैं। इसके साथ-साथ पैसों को सोच समझकर खर्च करना भी बच्चे को आता है और पैसों की सही वैल्यू समझ आती है। अगर उसको कोई चाहत वाली चीज नहीं मिलती तो वो उसके लिए आराम से इंतजार कर सकते हैं।

6- ऐसे सपोर्ट सिस्टम बनाएं जो कहीं भी अपनाए जा सके: बहुत से लोगों को यह पता है कि एक ऑटिस्टिक व्यक्ति का जीवन खुशनुमा बन सकता है अगर हम उनकी जरूरत को समझ कर उसके अनुसार वातावरण में बदलाव ला सके और सही तरह के सपोर्ट सिस्टम दे सके जिससे एक वातावरण को समझना और उसमें सही रूप से काम करने में आसानी हो। सपोर्ट सिस्टम से तात्पर्य है कि ऐसे सिस्टम जिसके साथ किसी भी काम को कम से कम या बिना किसी सहायता के व्यक्ति स्वयं पूरा कर सके। निम्नलिखित कुछ सिस्टम हैं जो मददगार हो सकते हैं:

- बातचीत करने के लिए एक सही सिस्टम (कम्युनिकेशन बुक, टैक्स्ट, मोबाइल एप्प इत्यादि)
- शेड्यूल/वर्क सिस्टम/शेड्यूल/वर्क सिस्टम
- कुछ ऐसी एडेप्टेशंस जो बच्चे की जरूरत के हिसाब से दी जाएं (अप्रोन का प्रयोग सफाई से खाने के लिए/ऊंची थाली का प्रयोग खाना अच्छे से चम्मच में लेने के लिए इत्यादि)
- अधिक विजुअल चित्रों का प्रयोग किसी भी भाषा को समझने के लिए जिसे देखते ही समझ आए बच्चों को क्या करना है और कैसे करना है

7- बच्चों को शुरू से यह बताते रहना की सबका अपना घर होता है और एक दिन आपको भी अपने घर रहना होगा। यह इतना आसान नहीं है बताना एक ऑटिस्टिक इंडिविजुअल को क्योंकि कुछ

बच्चों को अलग हो जाने से डर लगता है लेकिन ये उनके साथ ज्यादा होता है जो माता पिता स्वयं ऐसी सोच रखते हैं या बच्चे की जिंदगी से लोगों का जाना एक नकारात्मक तरीके से हुआ है, तो कोशिश करें कि उसको शुरू से यह दिखाते रहे कि बहुत से बच्चे अपने मम्मी पापा से दूर रहते हैं। एक अलग घर में क्योंकि उनको अपने लिए कुछ ना कुछ करना होता है। आप बच्चे के पसंदीदा अभिनेता, अभिनेत्री या आदर्श व्यक्ति के उदाहरण दे सकते हैं। जैसे आप अगर अपने माता-पिता से अलग रहते हैं तो यह बताएं कि देखो दादाजी और दादी एक हाउस में रहते हैं और मम्मी पापा एक अलग घर में रहते हैं और मम्मी पापा अपने घर में जब रहते हैं तो उनका अपना एक कमरा होता है और वो भी अपना काम स्वयं से कर पाते हैं। जब हम वयस्क हुए तो हम अलग अपने घर में रहने आ गए। इसी तरह से आपका भी एक घर होगा जो मम्मी पापा के घर से अलग होगा। आप कभी कभी हमसे मिलने हमारे घर आओगे और हम भी आपसे मिलने आपके घर आया करेंगे। इस बात को बहुत ही समझदारी और सहजता से बताने की जरूरत है और यह जरूर बताएं कि आप माता-पिता से अलग रहोगे। जहां आपका भी अपना कमरा होगा और वहां आपकी जरूरत का पूरा ध्यान रखा जाएगा। आप अपने तरीके से उस कमरे को सजा सकते हैं। आप अपने घर में भी ऐसे ही चयन कर सकते हैं इत्यादि इत्यादि। ऐसा करने से यह नहीं लगेगा कि आप उसको कहीं ऐसे ही छोड़ आने की बातें कर रहे हैं। जब आप अपने बच्चों की परवरिश इस तरह से करते समय यह ध्यान रखें कि आप एक समझदार व्यवस्क बनाने की कोशिश कर रहे हैं। ऑटिस्टिक व्यक्ति के साथ बहुत से एंजायटी या घबराहट के अलग इश्यूज हो सकते हैं तो आप अपने बच्चों को समझते हुए इस तरह से एक-एक पॉइंट को शामिल करें उसकी अपनी दिनचर्या में।

8- लोगों की मृत्यु के बारे में बताते रहना:

घर में या किसी जानकार के जाने के बाद सभी को दुख होता है पर हमें यह भी समझ आ जाता है कि जो चला गया वह नहीं आया और हम शायद उनकी यादों के साथ अच्छे से रह पाते हैं। अब यह कल्पना कीजिए कि आपको कोई बताए ही नहीं कि आपके किसी जानकार की मृत्यु हो गई है और आपको यह बोलते रहे कि वह अभी कहीं गए हैं, बाद में आ जाएंगे आप कितने दिन तक सन्न करेंगे। शायद ज्यादा दिन नहीं। अगर सच्चाई पता नहीं होगी तो आप बहुत बेचैनी भी महसूस करेंगे लेकिन सच्चाई पता होगी तो शुरू में दुखी होंगे बाद में समझ आ जाएगा कि वह अब कभी नहीं आया। हम इस बात को स्वीकार लेते हैं कि जिंदगी दी है तो एक दिन मृत्यु भी होगी। यह सब हमने भी ऐसे ही समझा है, तो यह मत सोचिए कि ऑटिस्टिक व्यक्ति इस बात को नहीं समझेगा, वह भी समझेगा अगर हम उनको भी इसका हिस्सा बनाएंगे। उनके लिए भी किसी की मृत्यु को स्वीकारना आसान हो जाएगा अगर हम उसे बहुत सहज और समझदारी के साथ बताएं तो। तो घर में चाहे किसी की भी मृत्यु हो उसके बारे में जरूर बात करें और यह भी बताएं कि किसी के जाने से हमारी दिनचर्या में ज्यादा बदलाव नहीं आता है। जब भी हमें उनकी याद आए तो हम उनकी खुशनुमा यादों को याद कर सकते हैं। इसको बहुत ही समान्य तरीके से बताएं जितना सहजता से हम इन बातों को बताएंगे उतना ही सहज एक ऑटिस्टिक व्यक्ति को भी लगेगा। यह बताना इसलिए जरूरी है, क्योंकि ऑटिस्टिक व्यक्ति की लाइफ से भी उसके माता-पिता या कोई और भी ऐसे ही जाएगा और उसके बिना भी बच्चे को रहना होगा तो यह तैयारी शुरू से ही दे तो ज्यादा अच्छा होता है और बच्चे को आखिरी समय में स्वीकार करने में मुश्किल कम होती है।

9- फाइनेंशियल सुरक्षा:

यह बिंदु शायद सबसे पहले आना चाहिए था पर इसके लिए माता-पिता कुछ ना कुछ पूरी जिंदगी करते रहते हैं या इसके बारे में सोचते जरूर हैं। एक ऑटिस्टिक व्यक्ति की थैरेपीज में और उसके मेडिकल ट्रीटमेंट में पहले से ही बहुत सा खर्चा हर महीने होता है तो यह बहुत जरूरी है कि उसके आने वाले भविष्य के लिए भी माता-पिता को और भी ज्यादा पैसा जमा करने की जरूरत होती है। और यह जरूरत और बढ़ जाती है अगर उसका कोई भाई या बहन हो। क्योंकि माता-पिता को दोनों के लिए करना होता है। अधिकतर यह देखा गया है कि जिस व्यक्ति के भाई या बहन होते हैं माता-पिता सारा पैसा उसके नाम कर देते हैं, इस सोच के साथ कि वह उसका खर्चा करेंगे पर यह बिल्कुल गलत है हमें दोनों को बराबर का हिस्सा करके देना चाहिए और अगर घर में भाई-बहन नहीं होता है तो हम शायद यह सोचते रहते हैं कि जब मेरा आखिरी समय आएगा मैं वसीयत बना दूंगा या बना दूंगी लेकिन यह भी गलत सोच है। क्योंकि किसी की जिंदगी का कोई भरोसा नहीं होता तो सही समय पर सही फैसला लेना जरूरी है। सही समय पर अपने बच्चों के लिए एक ट्रस्ट बनाएं और उसके सदस्यों का चुनाव बहुत सोच समझकर करें। ट्रस्ट बनाते समय वकील की सलाह अवश्य लें।

10- इन्हीं सबके साथ हमें बहुत से कागजी दस्तावेजों की भी जरूरत होती है और यह दस्तावेज शायद एक व्यवस्क की पहचान भी होती है तो यह जरूर बनवा कर अपने पास पहले से ही रखें:

- गार्जियन सर्टिफिकेट
- डिसेबिलिटी सर्टिफिकेट
- यू-डी-आई-डी- कार्ड
- आधार कार्ड
- वोटर कार्ड
- मेडिकल हेल्थ इश्योरेंस
- बैंक अकाउंट (ये ज्वाइंट अकाउंट हो सकता है)

उपरोक्त वर्णित सभी कौशल पर काम करने के साथ साथ एक सही असिस्टेंट लिविंग या अपने बच्चों के लिए घर ढूंढने की भी खोज जारी रखना आवाशक है। किसी भी एसिस्टेड लिविंग में डालने से पहले उसका सही चयन बहुत महत्वपूर्ण है। तो नीचे कुछ ऐसे बिंदु हैं जिन्हें हम ध्यान में रख सकते हैं चयन करते समय:

- जो एक ऑटिस्टिक व्यक्ति की जरूरत को समझता हो
- ऐसी जगह जहां सभी व्यक्तियों (ऑटिस्टिक और नॉन ऑटिस्टिक) को एक समान समझा जाए
- ऑटिस्टिक व्यक्ति के लिए प्रोडक्टिव लाइफ हो
- व्यक्ति को भी कुछ डिसेजन और चयन करने का अधिकार हो
- सफाई, सुरक्षा और सही मेडिकल फैसिलिटी प्राप्त हो
- एक घर के जैसा वातावरण हो जहां व्यक्ति की इच्छा, जरूरत और उसके पसंद को ध्यान में रखकर बनाया गया हो

तो चलिए और तैयार हो जाएं अपने बच्चों के सुंदर भविष्य की तरफ एक कदम उठाने के लिए----

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: Rs. 500 Professionals: Rs. 1000 Institutional: Rs. 3000

Online bank transfer may be made to:

Beneficiary: Action For Autism

Bank: Vijaya Bank, Defence Colony, New Delhi, India

SWIFT No: VIJBINBDDCD IFSC Code: VIJB0006005

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