

Development of Autism Support Groups in Sikh Community of Canada- Case Studies

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Abstract

Introduction- This paper is an attempt to understand the struggles and challenges of Sikh parents who migrated to Canada and are raising their autistic child. The researcher tried to understand and find how difficult it was for parents personally and socially. What kind of and how much help from the community support systems was available to such parents.

Methods- The researcher went through all the available online platforms where these parents have made their existence visible to the world, be it YouTube, Twitter, Facebook, Instagram handles and established autism support groups of Canada. Secondary research of Canadian medical websites and Canada National Public Health Services was also taken up.

Findings- It has been found that though the number of Sikh migrants in Canada is quite high and the community has a very powerful existence there, all this has not led to the development of strong community support systems to help autistic children or their parents. Infact, within the community, the disability is treated like a taboo which makes communication among the community members more difficult. The diagnosis, in fact, becomes a reason for shame and guilt for parents. However, some parents are not only raising their autistic children well but are also embarking on a journey to create a strong community support system, to help children with autism and their parents. They are not only creating awareness but an acceptance for autism.

Conclusion- Community Support Systems are a big help and they should be created by the community members. Disability should not be treated as a taboo. Community members have to come together to help each other. Community support systems are in fact a ready available source of help, security, health and mental peace.

Keywords- Autism, Parents, Community Support Groups, Sikhs, Canada

Abbreviations Used-

QoL - Quality of Life

ASD- Autism Spectrum Disorders

WHO- World Health Organisation

CTV- Canadian Television Network

ACT- Autism Community Training

1. Introduction

1.1 What is Autism?

Autism is a neurodevelopmental disorder. According to WHO:-

“Autism spectrum disorders (ASD) are a diverse group of conditions. They are characterised by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities and behaviours, such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensations.” [1]

Though there are some common global characteristics that may include anxiety, depression, sleep disorders, difficulty in communication and making eye contacts, self-injury but the levels of intellectual functioning differs widely among the autistic children. While some need little help or may live independently, others may require life- long care and support.

1.2 Struggle of Parents raising children with autism

It is not only the children with autism who need support but also their parents. WHO mentions, “The demands on families providing care and support can be significant. Societal attitudes and the level of support provided by local and national authorities are important factors determining the quality of life of people with autism.” [2]

The United States Library of Medicine mentions the challenges faced by parents raising autistic children. It states, “Parents of children with autism spectrum disorder (ASD) tend to experience greater psychological distress than parents of typically developing children or children with other disabilities.” [3]. It also emphasises on formulation and development of ASD specific- Quality of Life (QoL) measures to not only include all aspects of autism but also to understand autism from parents’ perspective and provide them with much needed support.

Many research studies done in India also bring the tough and difficult lives of parents raising autistic children on the surface. Patil(2012) concludes in her research work that parents raising children with autism go through more parenting stress and have poor psychological well-being.[4]

Not only mothers, it is tough for fathers as well. Vijaya(2018) researched that diagnosis of autism, had been a very low point for fathers also. The diagnosis as well as being regular with the treatment had been very stressful for fathers.[5]

It is not easy for parents to accept that their child is autistic. Also the kind of support that the child needs, be it physical or financial, might get too much for them. The parents are on their toes all the time.

Parents, while raising a child with autism and also fulfilling the daily responsibilities and their job requirements, do need support. Their physical, emotional and mental fatigues and strains are probably beyond explanation. Support from the community, society and the government at large- all are needed and are indispensable.

1.3 Sikh Community in Canada

According to the demographics data of Canada 2021, Sikhs constitute 1.4% of Canada’s population.[6] Interestingly, it is not the number but the power that the community yields together.

Sikhs are a very powerful community today in Canada. And this is much because of their community structure. The Sikhs have not shed their culture even after migrating to Canada. Punjabi is today the third most spoken language in Canada, after English and French.[7]

Sikhs have internal unity and can raise funds in no time with community support. Organisational skills, dedication towards ‘service’ (sewa), ‘Never Die’ attitude and culture of grass root politics- all these reasons are enough to make them influential.

“From the beginning, gurdwaras were the central community institutions of Canadian Sikhs. Through them, Sikhs provided extensive aid to community members in need.”[8]. Gurdwaras are the central institution of community support. There are many gurdwaras in Canada today. Sikhiwiki jots down the list of 84 gurdwaras in Canada.[9]

With the internet explosion, community support has moved one step up, from physical to digital. There are many websites maintained by Sikhs to provide community support to people and they also work to raise funds for the organisations, gurudwaras and people in need. Also, there are many websites to disseminate religious information to people to provide them spiritual guidance and help.[10]

1.4 ASD in Canada

Approximately 1 in 66 children and youth are diagnosed with ASD in Canada in 2015. This is as per National Autism Spectrum Disorder Surveillance System (NASS) 2018 Report, which is duly made in Canada and provides first reporting of the national data.[11] Not only this, 1-2% of the Canadian population are on the autism spectrum [12]. There are approximately 135, 000 people autistic people in Ontario.[13]

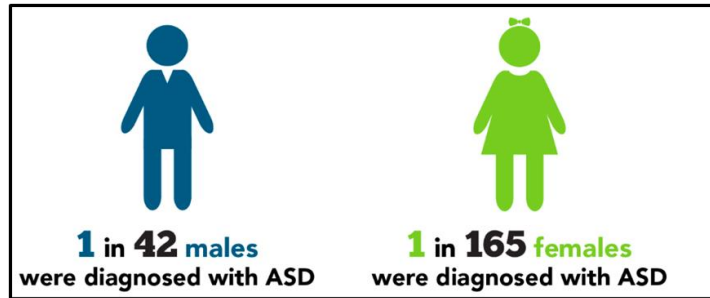


Fig 1:-ASD Prevalence by Sex, Canada, 2015
(Source- Canada Public Health Services [14])

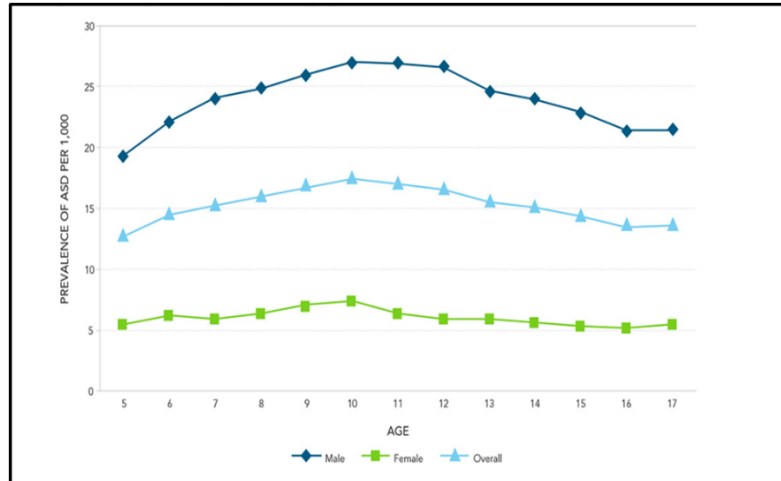


Fig 2:-ASD Prevalence per 1000, by age and sex, 2015
(Source- Canada Public Health Services [15])

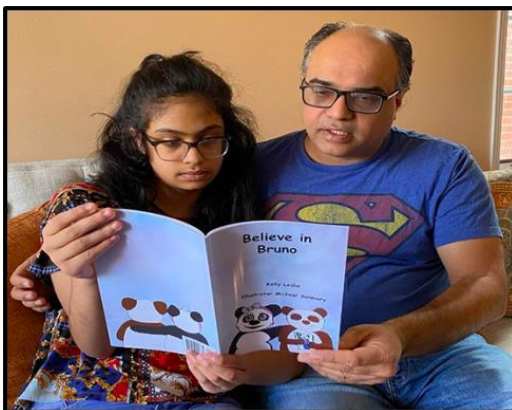
Figure 2 clearly shows that ASD prevalence is not decreasing with age. Rather, the majority of cases have been diagnosed in younger age groups. The reasons responsible for this trends could be “increased incidents or other factors.”[16]

There are many Sikh children who are suffering from Autism in Canada, however the number is not clear. But this does not mean that Sikh Parents are not affected or they do not need help. However, there is very little communication in the community regarding the same.

2. Case Studies of Sikh Parents in Canada for creating awareness and acceptance for their children

1) Baljeet Ghuman-

Baljeet Ghuman, a Sikh, based in Ontario, is trying to create a lot of awareness in the Sikh Community in Canada regarding Autism. Baljeet’s daughter was diagnosed with ASD at the age of 6 years.



2.1 Baljeet Ghuman with his daughter Sikhs for Autism

In an interview with CTV News [17], he openly surfaces his experiences with autism, which made him realise that there are not enough resources in the community where a person can look up to for help. Most importantly, there is not enough conversation in the community regarding ASD and other disabilities. The people in the community are also reluctant to find ways to diagnose an autistic child and to raise her. Disability is a taboo in the Sikh community.

This all makes the struggle of the parents all the more difficult and hard. The lack of support is a contradiction to Sikh faith. 'Sewa' or selfless service is an important pillar of Sikhism. Serving humanity has been considered the highest expression of love and compassion in Sikhs. Hence, he launched his social media platform- '*Sikhs For Autism*' in the month of April, which is a 'Sikh Heritage Month'.

His Social Media Platform- '*Sikhs For Autism*' emphasises on discussing disability openly and not treating it as a taboo. It is a time to break down barriers and talk about disability in the community and to create resources to help autistic children and their families. It is not a matter to be swallowed inside.

The online campaign got a huge response from the community. This showed that there were many Sikh families who were struggling at their end and wanted to talk, but what lacked was a simple initiative. Many educators and teachers also connected with the campaign.

Parents of autistic children are afraid of how their child will be taken care of, once they are gone. This is their greatest fear. Baljeet aims to create a support structure around autistic children of his community, so that this fear of the parents can be erased to its maximum.

Baljeet has been successfully writing articles on autism and creating a strong support system by opening new channels of communication. The followers of the campaign are comparatively quite less, with just a number of 370 but this is not stopping him. The online campaign marks its presence on Twitter and LinkedIn too. He keeps coming with a lot more social interactions, discussions and debates to create awareness. Not only this, he has been trying to take awareness regarding autism to a next political level. He posed a questionnaire to all the political parties as to their future policies for autistic children and their families. The answers were duly posted on the instagram account of '*Sikhs for Autism*'. Baljeet is trying not only to create awareness in the community but acceptance for autistic children.

2) Sunita Braich- Part of Autism Community Training



Sunita Braich is a special education teacher and a parent. Her daughter is autistic. She is a part of Autism Community Training (ACT) and is helping parents to deal with autism in a better way. She shares her own experiences with them. ACT is providing support to Sikh parents by providing them the resources in Punjabi language. In her videos, she shares the emotional struggle she has to go through when her daughter was diagnosed with autism.

She shares that mothers especially go through the feelings of guilt, shame and blame themselves when their children are diagnosed with autism. She mentions how our community and family blames women for autism, although it is not their fault.

Braich's videos especially talk about the mental state of mothers and the shock they go through when a child is diagnosed with autism. She is trying to help mothers and especially those families who are not able to speak or understand English properly. It gets all the more difficult for non-English speaking parents to take care of their autistic child, while trying their best to settle abroad. So, providing resources in Punjabi to such families and Punjabi resource persons, becomes a big help.

She does mention in her videos that it is pretty difficult in our society to share our problems with each other. Opening our hearts out to someone who understands her is very important for parents rearing children with autism but in our culture, where autism is a taboo and communicating about it is all the way difficult, the problem for the child and parents increase manifold.

Her videos further help parents by discussing the steps that should be taken by parents for better education and rearing of the autistic child, like choosing a good team of counsellors and consultants, and remaining in touch with teachers. Not only this, she encourages parents to take care of themselves- their body and their mind at all cost, during this process. Because if the parent is in a good state of health then only he/she can take better care of children.

She clearly mentions that the established community support groups can provide a lot of support and guidance to parents rearing children with autism. Coming together as a community to help, understand, communicate and share things with each other is a big support system in itself.

3. Analysis

On a close analysis of the case studies, we got to know that Sikh parents who are rearing their autistic children are in dire need of help. Disability is a taboo in Sikh Community. Parents of autistic children do not get a good support system from Sikh community in raising their children. There is very little awareness, few resources and few people to talk your heart out. Also as migrants, working hard day and night to settle themselves in another country (here, Canada), paying bills and then on top of it paying for counsellors, doctors to help the child out- this all comes at a good cost and is financially straining too. Moreover, many times, the English language becomes a barrier for Punjabi speaking families.

Family comes as a first and readily available support system but hearing the experiences of Sunita Baraich, it is quite shocking that sometimes parents do not wish to share the reality of autism with extended family, as this leads to a feeling of shame, guilt and mutual accusations among the family members.

Society is the next support system that Sikh parents look up to. Here too, the parents feel unlucky and lost. They have to tread on the path themselves. Few resources, little help and more communication gap, feeling of shame and guilt- all this makes the journey harder.

These challenges not only affect the parents financially, socially but emotionally. Their mental peace and state deteriorates. They suddenly find themselves in a dip dark pit with no idea as to where to go further.

Gurudwaras are the central institutions to provide support to the community. In such scenarios, help from Gurudwara can make the way easier but unfortunately no such provisions are there as of now.

As per Sikhism, the concept of health and happiness is personal but equally social. The concept of 'Sewa' makes sure that an individual is well-fed and taken care of by the society. Similarly, individuals must responsibly contribute physically or financially to ensure a happy and healthy society. Physical and emotional health can only be maintained if personal life, family life and social life of a person comes in better sync.

However, the efforts put in by parents, who have been affected by Autism, to not only support themselves but also to create awareness in the society to help others, are worth praising. Parents like Baljeet and Sunita are doing their best to create a support system within the community in the interest of children diagnosed with autism and for better health of their parents.

Also the increasing cases of autism, is clearly an indication that the lifestyle that an individual, family or a society follows must be deeply inter- linked with nature and cosmos at large. Natural and cosmic processes do influence our health. Similarly, our activities influence cosmos and nature. It is a two-way process. If we disturb and disrupt the natural and cosmic energies, we surely will see the effect in our lives. Hence, alignment of individual energies with the cosmos is indispensable. Human beings are a part of God's creation and cannot exist aloof and away from the cosmos.

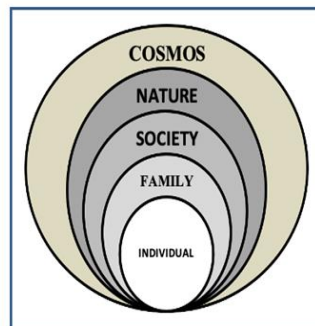


Figure 3: Representation of inter- connectivity of an individual's life with family, society, nature and cosmos at large

4. Conclusion

Sikhism already has a social model for the community to come together, work as a team, create huge heaps of resources. This makes the community not only independent and self-sufficient but also able to help others. The feeling of 'we have enough' is created. It is the manifestation of the thought that there is nothing running short in the kingdom of the Almighty.

On the other hand, it develops the qualities of brotherhood within the community, where there is no one top or down the ladder. Everybody is equal and is assigned a duty- to serve the Lord and His people.

But until this theory is worked upon in all big and small things that the community faces, individuals like Sunita and Baljeet have to struggle all alone. However, the case studies are also a ray of hope. Parents like Baljeet and Sunita are successfully creating a strong support system within the community to help others in all the ways possible. This all is happening slowly but surely.

It is important for the community members to come out of their cocoons and communicate freely, to be a support system for each other. We have to remember that outside our own country, we as diasporas, are each other's first support system. This makes everybody's life easier and manageable. Hence, community support systems should be intentionally created and should not be neglected. Their existence can be of great help to families, especially those who are rearing children with autism.

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