act Autism Community Training

ACT's Autism Manual for B.C.

Living and Working with Children and Adults with ASD

Chapter 13:
GUIDE TO WORKING WITH SOUTH ASIAN FAMILIES AFFECTED BY AUTISM

Contributed by Preetinder Narang, M.Ed., BCBA

Chapter Contents

The "Introduction to ACT's Autism Manual for B.C." provides valuable context to this chapter. See www.actcommunity.ca/autism-manual for many chapters relevant to special needs in B.C., including:

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AUTISM SPEAKS CANADA
It's time to listen.
Il faut écouter.

This guide would not have been possible without the support of ACT's South Asian Autism Project Committee (ASAAP). Formed in 2013, ASAAP began by targeting the needs of the Punjabi-speaking South Asian community in the South Fraser region of Metro Vancouver. ASAAP's primary goal is to raise awareness of the need for early diagnosis and treatment of autism within the South Asian community.

For more information about the work of ASAAP, its membership, and for links to all the resources for the South Asian Community, see www.actcommunity.ca/information/act-in-punjabi/.

13 GUIDE TO WORKING WITH SOUTH ASIAN FAMILIES AFFECTED BY AUTISM

Contributed by Preetinder Narang, M.Ed., BCBA

ACT – Autism Community Training has the responsibility of providing information and support to families affected by autism across British Columbia. We are very conscious of the profound needs of the many families with children with autism who are marginalized by virtue of speaking English as a second language and by being recent immigrants or refugees. These are families who are working very hard to establish themselves and often have little engagement with mainstream culture. They are challenged with the complex process of setting up an in-home autism intervention program — a significant obstacle even for families who are well-educated, fluent in English, and financially established.

Most families struggle with the challenge of discovering that their child has a profound social and communication disability, but it is particularly difficult when you are unable to easily communicate in English and haven't benefited from the autism awareness campaigns that have helped educate many Canadians about the potential of individuals with autism to flourish. In Canada there has been a profound shift in attitudes over the last decade about the potential of individuals with disabilities of all kinds, in particular children affected by

For the sake of brevity, and to avoid initials, this guide will use autism instead of the term Autism Spectrum Disorder.

autism, in large part due to the efforts of families who have founded autism societies and organizations like Autism Speaks Canada. However, most of this activism and awareness has been done in English and is not widely available in the non-English-speaking media — although this is changing, thanks to the efforts of many young community professionals like those who have founded ACT's South Asian Autism Project (ASAAP).

ACT believes that ensuring new Canadians have access to information that addresses their need to understand autism is essential if we are to address the needs of their children. In addition, families require access to intervention programs for their children that are sensitive to their needs from professionals who understand their unique perspective.

Across Canada, there is a shortage of behavior support programs that take into account the cultural and linguistic needs of families raising children with autism. This is especially significant in B.C. where the funding model places responsibility on the family to actively manage their child's home-based early intervention program, leaving non-English speaking families at a distinct disadvantage when organizing services for their children.

In this guide, Preetinder Narang uses her own experience to explore the challenges faced by professionals in working with culturally and linguistically diverse families. Although Ms. Narang is focusing on the Punjabi-speaking South Asian community in Metro Vancouver from the perspective of a behavior consultant, there will be parallels with many other cultural or linguistic communities, and her advice is relevant to professionals other than behavior consultants working with families in their homes.

In examining cultural beliefs and their impact on service delivery, Ms. Narang explains the benefits of employing a culturally informed, family-centered approach guided by the "Cultural Assessment Tool." The research support for the use of this tool is reviewed and a case study to illustrate its potential for application with a South Asian family is included.

It is ACT's hope that this Guide will create opportunities for families and service providers from a variety of disciplines to meaningfully discuss the role of cultural variables in developing effective interventions for children with autism and how professionals can support families to understand autism and the needs of their children.

REFLECTIONS: DEVELOPING EFFECTIVE RELATIONSHIPS WITH SOUTH ASIAN FAMILIES

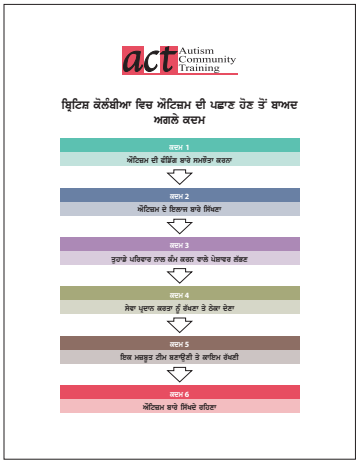
Like many behavior analysts, I started in the field as a home-based behavior interventionist for children with Autism Spectrum Disorder (ASD). One of the first families I worked with was a Punjabi-speaking South Asian family with twin 4-year-old girls with autism. The family held traditional Punjabi values and lived in a joint household that included the paternal grandparents, an unmarried uncle, the parents and an older brother. Life in the household was chaotic at times as there were two early intervention teams, each with 4-5 therapists, simultaneously providing between 25 and 30 hours of 1:1 ABA (Applied Behavior Analysis) therapy per week.

Applied Behavior Analysis, or ABA, is a treatment approach to autism which focuses on increasing behaviors of social significance such as academics, communication, adaptive functioning, and social/play skills. It is based on the theory that a behavior can be increased or decreased based on the consequence it receives.

During the daytime both parents worked outside of the home, which meant that the twins' grandparents were their primary caregivers and were responsible for supervising the home therapy teams.

Over time I began to notice how different the twins' behaviors were outside of the therapy room. Our therapy sessions were well-planned and highly structured, enabling our team to work on a number of social, communication, and behavioral goals with great success. However, between sessions and under the supervision of their grandparents and uncle, I observed the following:

- Problem behaviors were being reinforced, such as escape and attention-motivated crying, hitting, and throwing of toys.
- Skill acquisition goals were not being reinforced, such as the failed communicative attempts made using Picture Communication Symbols.
- Numerous opportunities for learning were missed throughout the day: during meal times, TV time, free play, and the wait time in between therapy sessions.



ACT's Next Steps Guide in Punjabi helps families in setting up an intervention program for their child. See www.actcommunity.ca/resource/2702.

I began to wonder, why aren't the extended family members invited to our team meetings? Surely there must be a way to include them! Yes, the grandparents knew very little English and communicated primarily in Punjabi, but did this mean they couldn't learn and implement the same strategies we were using? In fact, couldn't we have our intervention materials in Punjabi so that the grandparents could participate? As primary caregivers, wouldn't it make sense to incorporate the uncle and grandparents in all aspects of the ABA program?

These questions stayed with me long after I had left the family. I was genuinely puzzled: I knew something was missing, but, being relatively inexperienced, I didn't feel it was my place to comment on how services were being pro-

vided. Reflecting on this experience now, I think that we as in-home service providers often prioritize the direct teaching of skills in structured settings and overlook the importance of building systems of support so that learning continues beyond the therapy room. As professionals, it is our responsibility to ensure parents and care providers are central — not peripheral — to their child's intervention.

Cultural Beliefs About What Causes Disability

1 in 5 Canadians identified themselves as a member of a visible minority, with South Asians constituting the largest visible minority group and accounting for 25% of the total visible minority population.[1]

The quality of life of a child with a disability is greatly shaped by the degree to which their needs and potential are understood by their immediate and extended family. Family members' beliefs regarding the cause and treatment of disability affect their ability to promote their child's health and development. Specifically, cultural factors influence the resources families expend, the social opportunities they provide, and the short- and long-term expectations of achievement they have for their child.

Perceptions and attitudes towards the cause and nature of disability, in general, and autism, in particular, differ across cultures and are changing rapidly across the world. Traditionally, some cultural groups view disability positively, such as the Navajo tribe where a child with a disability is seen as having "a sixth sense or a unique gift to offer."[2]

In many traditional societies, however, it is far more common to perceive disability as a negative. In Puerto Rican culture, for example, a child with a disability may be considered a punishment for the sins of the mother; blame, in this case, is directed solely towards the child's mother.[3]

In South Asian traditional culture, there are pervasive negative cultural beliefs about disability that can affect how autism intervention is perceived by families. The mother is frequently blamed for producing a child who is deemed defective.[4] Another common belief is that disability is a tragedy or punishment for misdeeds in a past life, also known as "karma." According to this cosmic principle, parents of a child with a disability must use this life to learn "lessons" in the hope that their next life will be better.[5]

A problematic attitude is that a child with a disability cannot learn, as disability is equated with inability. This causes some South Asian families to focus on their own adjustment and personal sacrifice rather than intervention for their child.[6]

Cultural Stigma and Treatment of Autism

Many South Asian families are actively engaged in their child's treatment program, but even these families may be concerned about being stigmatized by the wider South Asian community, as misconceptions about all types of disability, including autism, are common and still serve as a barrier to accessing treatment.

As South Asian mothers are often blamed for producing a child with autism, families may strive to conceal the diagnosis from extended family, friends, and the community.[7] Some South Asian families may not seek treatment for a girl, as the stigma would adversely affect her chances of finding a desirable marriage partner in the future;[8] in addition, shame and fear are experienced for the marital prospects of siblings.[9]

The Relationship Between Parent and Professional

For those families that pursue treatment for their child's disability, cultural factors also affect the perception of the relationship between parent and professional. Many cultures believe that a professional "expert" holds greater authority than parents and close family members.[10] As a result, some families may adopt an "uninformed and in need of help" attitude and not strive to understand the benefits of creating the collaborative partnership that many professionals desire.[11]

In situations where the autism professional is not committed to empowering the family to understand autism and their role in their child's treatment, the family may not understand their right to advocate for being included in a meaningful way in developing the program.

Indeed, it may be a mistake for service providers to assume that the collaborative approach, conceived and advanced in Western societies, can easily generalize to children with disabilities living in communities without effort on their part to explain the importance of collaboration to the family.[13]

Treatment goals that professionals develop with families are shaped by the cultural context in which they are created. In Western culture, a high importance is placed on individual achievement and accomplishment, whereas most traditional societies, including South Asian cultures, prioritize the success of the group over the individual.[14] These families may wish to address goals that will enhance family and community well-being, rather than individual skills and independent functioning. The potential for conflict exists as mainstream services for autism often emphasize self-reliance and self-help skills.[15] However, being aware of these cultural differences can make it easier for the professional to help mentor the family with respect and sensitivity.

COMMON MISCONCEPTIONS OF SYMPTOMS OF AUTISM IN SOUTH ASIAN CULTURE[12]

- A 3-year old girl who does not socialize with same age peers is considered a "**mature child**"
- A mother is not concerned that her 4-year-old son is not speaking, as "**Indian boys talk later**"
- A child who is quiet, keeps to themselves and does not cause trouble is perceived as a "**good child**"

In South Asian cultures it is frequently thought that professionals are superior due to the specialized knowledge they possess; essentially, South Asians trust that "doctor knows best."[16] South Asian parents may not expect to play a role in their child's intervention program and may also disapprove of or be confused by a service provider's attempt to collaborate.

Treatment outcomes depend, in large part, on the quality of communication between parent and professional. In the absence of a strong partnership, plans of intervention may be implemented inconsistently, or not at all, and a lack of involvement could unknowingly facilitate the continuation of ineffective services.

IMPLICATIONS FOR SERVICE DELIVERY

Culture has a profound effect on the interactions between families and service providers. If the role of culture is unacknowledged or ignored, the resulting lack of cultural understanding can make collaboration and service delivery challenging. For professionals to do their best with the children they work with, they must learn how to best engage with each family. Without developing trust and rapport with the family, the professional will face difficulties in:

- Identifying problem behavior.
- Identifying the contexts they occur in.
- Delivering appropriate, effective intervention.[17]

Given these obstacles, what can service providers do to ensure they are being effective when working with families who may not understand autism or the important role of families in optimizing autism treatment? One way is to develop what is referred to as cross-cultural competence, which is defined as a "set of congruent behaviors, attitudes, and policies that come together and enable a system, agency, or professional to work effectively in a cross-cultural situation."[18]

The development of cross-cultural competence with families has been associated with three essential elements:

- An awareness of one's own culture and heritage.
- Knowledge specific to the target family's culture.
- The ability to apply cultural knowledge and develop skills necessary to work with the family.[19]

While there is agreement amongst educators and mental health professionals that the development of cross-cultural competence is critical to establishing culturally appropriate services, there is no single technique to developing this ability that has been universally accepted.[20] Fortunately, scientific research conducted in the discipline of positive behavior support provides us with a promising path forward towards developing culturally responsive services for children with ASD and related disorders.

Culturally Responsive Positive Behavior Support

Over the past 25 years, positive behavior support (PBS) has emerged as a collaborative, assessment-based approach to developing effective interventions for individuals with challenging behaviors. Guided by the principles of ABA and Person-Centered Planning, practitioners of PBS strive to help parents and other family members make meaningful improvements in their child's problem behavior and enhance the quality of life of the family unit. A family-centered PBS approach emphasizes the development of collaborative partnerships with family members and key stakeholders that are respectful, trusting, and reciprocal in nature.[21]

Most family-centered PBS studies have been conducted with mainstream, English-speaking participants living in North America, and little research has been conducted with culturally and linguistically diverse families.[22] The growing diversity of Canada's population creates a need for PBS services that are culturally and contextually appropriate.

In response to this need, researchers at the University of British Columbia (UBC) have conducted research on the development of culturally responsive PBS plans. They have used an excellent tool, "Questions to Guide Culturally Responsive Practices"[23] which guides the practitioner through the planning and family assessment stage of program development. It also includes a section on self-evaluation. (See Appendix B for a complete list of questions.)

After studying the tool, the UBC research team concluded that there is tremendous value in its use for:

- Building an understanding of the family's culture.
- Providing guidance for the development of cultural competence.
- Promoting cultural self-reflection and thoughtful analysis.

What are the implications of using the cultural assessment tool for practice and service delivery? The following case study will demonstrate the tool's value and use in effective service delivery.

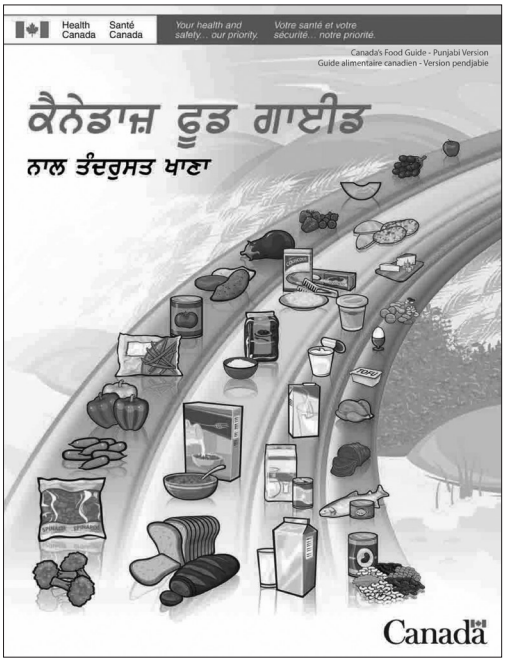
CASE STUDY: JEEVAN

After five years of working as a behavioral interventionist, while I studied psychology and behavior analysis, I became a behavior consultant for children with autism and developmental disabilities. One of the first families I worked with was a South Asian Punjabi-speaking family living in the South Fraser region of B.C. They had a nine-year-old son, whom I will call Jeevan, who was diagnosed with autism and ADHD.

I first met Jeevan in his family home during my initial visit and intake interview. As is traditional, Jeevan lived in a multigenerational household comprised of his father, mother, younger sister, infant brother, and paternal grandparents. His father was a full-time truck driver and his mother worked part-time in a beauty salon. Jeevan's grandparents lived in the basement of the two-storey home and provided childcare for their grandchildren during the day. The results of the intake interview with Jeevan's mother indicated the main concerns to be Jeevan's weight, which was 115 pounds, and the food-seeking aggression that occurred in the kitchen.

I asked Jeevan's mother to begin taking baseline data on the quantity and type of food Jeevan was consuming per day. It was summer and Jeevan was home every day, so I was confident that the food intake data would be accurate and informative. My clinical director suggested I consult the Canada Food Guide to create developmentally appropriate goals for Jeevan.

According to the Canada Food Guide, the recommended number of food servings per day were as follows: 6 servings of fruits/vegetables, 6 servings of grain products, 3-4 servings of milk and alternatives, and 1-2 servings of meat and meat alternatives.



After two weeks of collecting information on Jeevan's eating habits, it was revealed that Jeevan was consuming 3-4 times the recommended number of grain servings per day, not meeting the recommended number of fruit/vegetable servings per day, and was over-consuming high-calorie, high-sugar items like Coke and ice cream.

Jeevan's mother and I designed a food plan in which Jeevan's food intake was reduced by 2-3 rotis (Indian bread) per day, which equates to 3-5 less servings of grain. This was achieved by stuffing the rotis with spinach; not only did Jeevan eat fewer rotis per day, the daily spinach intake constituted a three-serving increase in fruits and vegetables. In addition, Jeevan's mother substituted watered-down Diet Coke for Coke, and the behavior support plan ensured that food was out of Jeevan's reach so he no longer had free access.

After ensuring that the plan would be implemented faithfully, I returned to the home a month later, expecting to see a decrease in Jeevan's weight.

To my surprise, Jeevan had not lost any weight despite the dietary changes and behavioral supports in place. Not only had he gained four pounds, there was no sustained reduction in food-related aggression. Upon further discussion with Jeevan's mother, I soon realized my error: I had not included Jeevan's grandparents in the intervention planning process.

Grandparents, regardless of culture, are a well-recognized potential source of support for all families who have a child with autism.[24] South Asian grandparents are no exception: they hold a highly respected position in the family unit and play a critical role in the upbringing of their grandchildren.[25] South Asian grandparents, grandmothers in particular, are often the primary caregivers for their grandchildren during the daytime as their adult children often work outside the home full-time.[26]

In Jeevan's case, his Dadi-Ma (grandmother) was the main cook in the joint home and did not view overeating as a primary concern; in fact, she believed that her grandson had a "healthy appetite" and was "still growing."

The concept of "autism" had not been explained to Jeevan's grandparents and neither had the program to monitor his food intake. Culturally, the grandparents found it very difficult to deny a hungry child food, so when Jeevan was unsuccessful upstairs, he went downstairs to eat Dadi-Ma's food; of course, this meant that what Jeevan ate in Dadi-Ma's kitchen was undocumented.

APPLICATION OF THE CULTURAL ASSESSMENT TOOL

Following the discovery of Jeevan's additional food source, I wondered what I could do differently to support Jeevan and his family. A more effective treatment plan could be created if I used the cultural assessment tool in a framework of Positive Behavior Support prior to implementing the intervention, as follows (see Appendix B for the complete list of assessment questions):[27]

Planning Phase

1. How do I learn about the family's interaction and communication style?

In order to learn about the family's routines and communication style, I could have asked to meet at a time when both parents and grandparents were available, not only Jeevan's mother. This might have meant a late evening or weekend appointment, at a time convenient for the family.

2. How do I ensure that the meaning of words I use are translated accurately from English into the family's language?

Although Jeevan's mother was fairly comfortable in English, I should have systematically checked on her understanding of the service model I was proposing, the paperwork she was signing, and the role she would be expected to play in a behavior change program. If a significant language barrier existed,

I could have enlisted the help of a translator, if available, or sought assistance from English-speaking relatives in the extended family.

3. How will I discuss differences with families when their practices conflict with program or mainstream values?

Jeevan's grandmother did not believe that overeating was a problem, representing a conflict with mainstream Canadian values. Had this difference been identified during the planning phase, I could have prepared for a thoughtful conversation with the family, the grandmother in particular, around healthy eating and the dangers of childhood obesity for long-term health.

Family Assessment Phase

1. Who are members of the family, including the extended family?

A culturally sensitive approach would focus on understanding the role all family members play in the care of the child. In Jeevan's case, this conversation would have revealed the pivotal role played by his grandparents and subsequently informed the allocation of time given to family training, implementation support, and follow-up.

2. What is considered respectful and disrespectful in the family?

In some Asian and South Asian cultures, not accepting tea or snacks is considered disrespectful when visiting someone's home, whereas inquiring about the health and well-being of loved ones prior to discussing the business at hand (i.e., engaging in small talk) is considered polite. As there were occasions when I politely declined tea and did not engage in small talk, I would change my behavior in order to demonstrate my respect for the family.

3. Who makes decisions in the family?

In Jeevan's home, the grandparents were revered elders who the adult children deferred to on important matters. If I had known to ask who makes decisions in the family, I could have made a conscious effort to involve Jeevan's grandparents in the development of a treatment plan.

4. To whom does the family turn for support, assistance, and information?

In some cultures, the judgments of family members and friends can be more trusted and valued over those made by community professionals like behavior consultants. Had I asked to whom the family turns to for support, assistance, and information, I would have learned much sooner about the key role of extended family members.

5. What are the family's values and customs?

Close family ties that endure across the life-span are a traditional South Asian value. By neglecting to examine the family's values and customs, I missed learning about how important it was that Jeevan's parents live in a multi-generational household.

6. What are the family's child-rearing practices, forms of discipline, and expectations of children?

A discussion with the family regarding their child-rearing practices, forms of discipline, and expectations of children would have revealed how much time Jeevan spent in his grandparents' care. This discussion would also have identified the grandmother's values and expectations around food and eating, specifically that Jeevan was a "healthy boy" and "still growing."

7. What are the family's concerns and priorities related to their child with a disability?

While weight was an immediate concern for Jeevan's mother and for me, I did not discuss the family's collective concerns and priorities as a unit. A more inclusive conversation could have allowed me to explore the grandmother's reluctance to deny Jeevan food and reassure her that she was not neglecting Jeevan by doing so.

8. What community resources can I use to better serve this family?

Community resources that I might have accessed to support this family are parent support groups, agencies that provide settlement services for new or recent immigrants, and the family's social worker. ACT – Autism Community Training has many useful resources for families — see Appendix A of this Guide for details.

9. What is the most efficient way for the family to collect data (e.g., writing, videotaping, audiotaping)?

Data for the food reduction program was collected via a written log, which was efficient for Jeevan's mother to use as she could read and write in English. Unfortunately, Jeevan's grandmother could only read and write in Punjabi, so data collection for food eaten in grandmother's kitchen was missing. Creating and providing a Punjabi data sheet for Jeevan's grandmother was an important step I would not know to take without first considering the cultural context.

Self-Evaluation

1. What information do I need to help this family?

To work effectively with Jeevan's family, knowledge of South Asian culture and family structure was essential. As a South Asian person with conversational Punjabi language skills, I initially did not feel I needed to familiarize myself with South Asian culture to be successful. This approach, however, was ill-advised and I now feel I could have benefitted from a review of South Asian beliefs and practices.

2. Have I clarified what the family expects of me and other services providers?

The treatment of autism through home-based behavioral intervention is a western phenomenon that has no parallel in South Asian culture. Given this reality, I could have focused more on understanding what the family expected of me as a service provider in their home.

3. Have I discussed the roles and responsibilities of family members and service providers in a process of PBS?

While I did discuss the roles and responsibilities expected of all parties in a process of behavior change, I do not believe I was using a PBS approach. A PBS approach would have called for a meeting of the whole team, including those from within the extended family, during the assessment phase. Most importantly, a plan would not have been finalized without consensus.

4. Have I provided information on the family's legal rights regarding their child's educational program?

This question is not applicable to the work I did with this family, as this references US legal requirements. In B.C., I could have provided the family information from ACT's Autism Information Database (AID) on IEPs in Punjabi: www.actcommunity.ca/resource/2405. In addition, there is an online video on IEPs, see Appendix A for details.

5. Are there any concerns about my interaction with the family that need to be discussed or clarified?

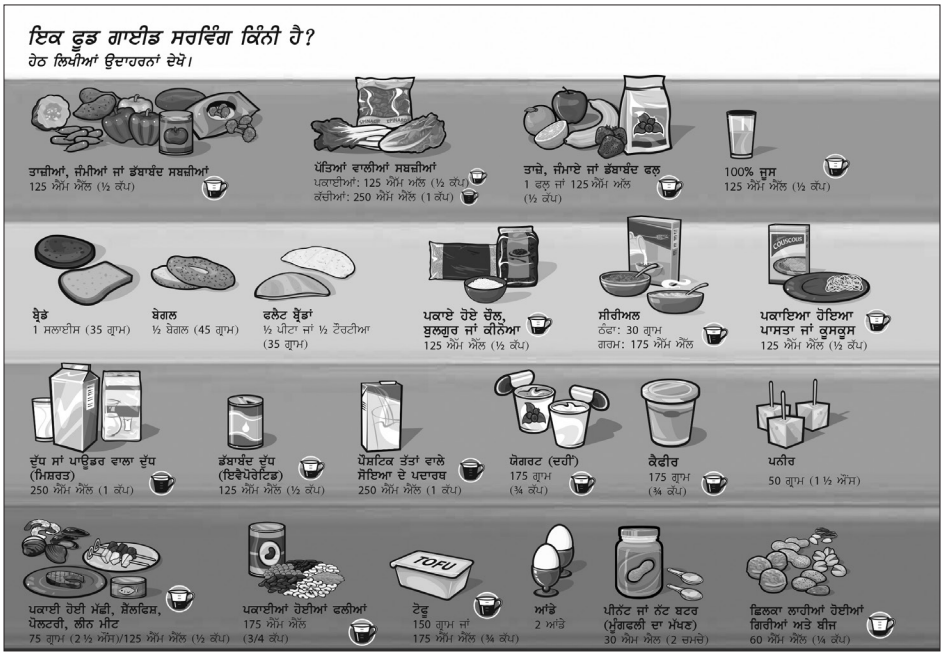
Even though Jeevan's mother did not express any concerns about my interaction with the family, in South Asian culture there is a reluctance to question those perceived to have expert knowledge, power or authority. In retrospect, I could have made a deliberate effort to emphasize the equal nature of our partnership and created an environment in which Jeevan's family was comfortable expressing any and all concerns.

Correcting Course

Once I had realized my mistake in excluding Jeevan's grandparents from the behavior intervention process, I organized a meeting at a time when all four family members were free to attend. I began the meeting with an apology, taking full responsibility for the ineffective treatment plan and specifically expressed my regrets to Jeevan's grandmother. I switched between English and Punjabi, which ensured that all parties understood the meaning of my words and also allowed the family to feel comfortable speaking in their primary language. (For professionals who do not have knowledge of the primary language of the family, finding an interpreter is an important step.)

In my discussions with the family, I proposed that we start again from the beginning, using a person-centered planning approach. We identified the family's hopes and dreams for Jeevan, his strengths and areas of need, and collaboratively designed a road map to support him in achieving his future goals. Through this process I achieved common ground with Jeevan's grandmother; we both wanted Jeevan to be happy and healthy, and for mealtimes to no longer be a source of tension and stress.

Once we had reached this agreement, I produced a Punjabi version of the Canada Food Guide, which I had found online, and a data collection sheet that I had translated into Punjabi.



ਨਾਮ: ਹਰਵੀਰ ਗਿਲ ਮਿਤੀ: ਅਗਸਤ 16, 2007

ਸੁਝਾਅ: ਖਾਣੇ ਦਾ ਸੁਝਾਅ

ਸ਼ਮਾ	ਖਾਣਾ ਖਾਇਆ	ਤਰਲ ਪਦਾਰਥ	ਖਾਣੇ ਦਾ ਤੇਲ	ਹਿਸਾਬ ਰੱਖਣ ਵਾਲਾ
8:30	ਸਿਰੀਅਲ 2% ਦੁੱਧ ਨਾਲ		1 ਕੌਲੀ	ਮਾਤਾ
10:30	ਸ਼ੇਬ		1	ਮਾਤਾ
12:30	ਰੋਟੀ		2	ਮਾਤਾ
1:00	ਸਾਗ ਪਨੀਰ		½ ਕੱਪ	ਮਾਤਾ
4:00		ਦੁੱਧ	1 ਗਿਲਾਸ	ਮਾਤਾ
8:00	ਪੀਜਾ		1 ਟੁੱਕੜਾ	ਪਿਤਾ
9:00		ਸੰਗਤਰੇ ਦਾ ਰਸ	2 ਗਿਲਾਸ	ਪਿਤਾ

Using these tools, I modeled for Jeevan's grandparents how data was to be taken, role-played how to implement the behavior reduction strategies, and offered to be available to coach the family members, in person, the following day. Over the next nine months, Jeevan lost a total of 22 pounds and reduced the number of aggressive incidents from 40 per week to less than three per week!

Lessons Learned

My experience with Jeevan and his family taught me three powerful lessons:

1. The development of cross-cultural competence requires time, patience, and hard work, and the results are well worth the effort.
2. Cross-cultural competence is not "optional." Professionals have both an ethical and moral obligation to meet the cultural and linguistic needs of the families we serve.
3. Being part of the same culture as the family, in this case the South Asian culture, did not guarantee a culturally sensitive service.

Six Keys to Success

During the year that I worked with Jeevan's family, I also developed the following six strategies or "keys to success" in supporting the family. These strategies can be applied to work with all South Asian families who are relatively recent immigrants or who are living with their extended families.

1. Respect the Home Language

By speaking in Punjabi, I made Jeevan's family more comfortable with both myself as a professional and the process of behavioral change I was hoping to achieve. By respecting the language, I respected the family.

2. Do not be the Expert, be the Family Friend

Recognizing the South Asian belief that experts have power and authority, I tried to interact as more of a "family friend" than "expert," which made it easier for the family to share personal details of their daily life with me.

3. Always say "Yes" to Tea!

South Asian families take pride in caring for visitors by providing refreshments such as tea and light snacks. I always accepted the food or drink that was offered, even if I wasn't hungry, as not doing so would be considered rude and disrespectful.

4. Use Culturally Appropriate Examples

To describe the behavioral intervention, I refrained from using examples that reflected dominant Canadian culture. Instead, I created culturally relevant scenarios that the family could identify with, such as going to the temple, attending a wedding, eating Indian food, or watching Bollywood movies.

5. Share Similar Experiences

Disclosing a few details of my private life (within ethical parameters) made the family more comfortable and willing to trust me. This trust allowed us to discuss sensitive topics the family would much rather have avoided.

6. Recognize the Head of the Household

The true decision-maker in the home was the knowledgeable elder, Jeevan's grandmother. I ensured that I spent time with Grandma during each visit to the home, asked Grandma's opinion in all important decisions related to the behavioral plan, and conveyed respect by addressing her as "Auntie."

CONCLUSION

This Guide has aimed to bring to light the complexity of working with diverse families of children with autism. The specific concerns of families of South Asian heritage have been highlighted, and Jeevan's case study illustrates the real-world potential of the Cultural Assessment Tool. It is my strong belief that the establishment of respectful and reciprocal relationships via culturally responsive practices will increase the probability that behavioral interventions are experienced as effective, acceptable and sustainable over time by South Asian families in British Columbia.

Reflecting on my experience with Jeevan and his family, the lessons I learned from working with them still inform the work I do with culturally diverse families to this day. The experience helped me appreciate that autism is a disability that affects individuals from all socioeconomic, religious, linguistic, and ethnic backgrounds, so it is important for service providers to understand how different cultures and societies view disability and its causes.

In order to promote best outcomes for children with ASD, professionals must recognize the developmental features of the disability, which are common to all, and the cultural perceptions that are characteristic of families and societies around the world. When both types of knowledge are utilized within a framework of positive behavior support, home-based service providers are offering families a collaborative, evidence-based approach to the treatment of autism.

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23. For more information regarding studies of the Cultural Assessment Tool, please see the following resources:
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    - Schroeder, C. (2012). *Culturally responsive, family-centered positive behaviour support with a Taiwanese family of a child with autism in two home settings* (Unpublished master's thesis). University of British Columbia, Vancouver, Canada.
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APPENDIX A: ACT RESOURCES IN PUNJABI

With the assistance of the members of ACT's South Asian Autism Project (ASAAP), and our sponsors, ACT has been able to both create and identify valuable resources for the Punjabi-speaking community in British Columbia:

- The Next Steps Following an Autism Diagnosis in B.C. Guide is a Punjabi-language translation of the key information families require to understand how to set up a treatment program for their child, including how to hire a service provider. Laid out in six clear steps, it provides families with reliable, evidence-based information on autism. This is also available in Chinese and Korean.
- Autism Videos @ ACT is a free online video service that hosts two videos in Punjabi: An Introduction to Individualized Education Plans (IEP's) in Punjabi and One Parent's Journey.
- The Autism Information Database (AID) contains over 2,000 resources selected by ACT staff. Search by keyword "Punjabi" to find autism-related information resources in Punjabi. There are also resources in other South Asian languages. Do you have resources to suggest? We welcome your suggestions; send them to info@actcommunity.ca.
- The Registry of Autism Service Providers (RASP) is a listing of professionals qualified to work with children under the age of six using autism funding. You can search the RASP listing to see which professionals provide service in Punjabi; there are 38 languages included in the RASP search tool.
- ASAAP's Monthly Parent Support Group – call the ACT office for more information about the next meeting.

APPENDIX B: CULTURAL ASSESSMENT TOOL QUESTIONS[28]

Planning Phase

1. How do I learn about the family's interaction and communication style?
2. How do I ensure that the meaning of words I use are translated accurately from English into the family's language?
3. How will I discuss differences with families when their practices conflict with program or mainstream values?

Family Assessment Phase

1. Who are members of the family, including the extended family?
2. What is considered respectful and disrespectful in the family?
3. Who makes decisions in the family?
4. To whom does the family turn for support, assistance, and information?
5. What are the family's values and customs?
6. What are the family's child-rearing practices, forms of discipline, and expectations of children?
7. What are the family's concerns and priorities related to their child with a disability?
8. What community resources can I use to better serve this family?
9. What is the most efficient way for the family to collect data (e.g., writing, videotaping, audiotaping)?

Self-Evaluation

1. What information do I need to help this family?
2. Have I clarified what the family expects of me and other services providers?
3. Have I discussed the roles and responsibilities of family members and service providers in a process of PBS?
4. Have I provided information on the family's legal rights regarding their child's educational program ?
5. Are there any concerns about my interaction with the family that need to be discussed or clarified?