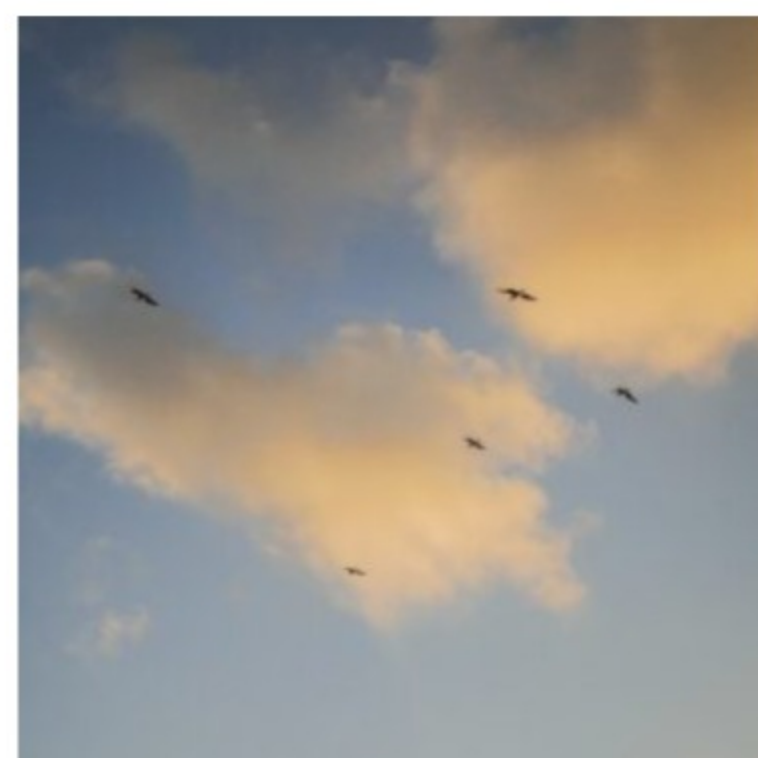


## One Parent's Experiences: A SAPNA Story

🕒 April 28, 2021 📁 Mental Health, Service in Action

April has been Autism Awareness Month. We began with a feature on one of our newer programs, South Asian Persons of Neurodiverse Abilities, or SAPNA. You can read that [here](#). To close Autism Awareness Month, we are sharing the story of one of SAPNA's members. These are Kalpana's experiences raising a son with autism.



Autism Awareness Month is important for sharing resources, facts, and support. In the South Asian community, it's even more important. Autism, which primarily affects social interactions, is still heavily stigmatized around the world. South Asia is no exception, and those stigmas often carry over into diaspora communities.

Parents can face shame from community members, who attach disabilities to the parents' karma or sins. Genuine diagnoses are explained away as bad parenting or the child's laziness. As a result, parents can feel pressure to hide their children with autism. They may feel pressure to try to change them. Blame themselves for what they may have done in the past. But our treatment of neurodiverse persons is the real sin.

We have a long way to go. We started SAPNA to, in part, break down the stigmas in our community. For people like Kalpana, SAPNA has been a supportive community. Kalpana counts herself blessed to have extended family who did not misunderstand her or her son. However, the unfortunate reality is that many of Kalpana's peers in our community are not so lucky.

### Kalpana's Experience With Autism

Kalpana is a parent of two. Their youngest son was diagnosed on the autism spectrum at age four, which is the average age of diagnosis in the US. Still, many children are not diagnosed until they are older, if they are diagnosed at all. Generally speaking, early diagnoses are best. Early diagnoses mean children can develop essential social skills more easily.

Kalpana and her spouse had their suspicions early. As a baby, their son didn't exhibit behaviors that would be considered "typical." For example, he stopped talking mere weeks after he began. They struggled through his toddler years, trying to understand him better. Kalpana says that they noticed he favored communication through gestures, so they tried sign language. It didn't help much; it mostly frustrated him and caused him to shut down. Kalpana felt that a different, more constructive approach was necessary.

When their son was two years old, they enrolled him in early childhood education. He improved quite a bit and moved past many of his previous hurdles. Nonetheless, it wasn't until they got a diagnosis two years later that things began to make sense.

### How Is Autism Diagnosed?

Though autism can be diagnosed as early as 18 months, diagnoses from age two and onward are considered more reliable. However, many children don't get a final diagnosis until much later. Some don't receive diagnoses until they are adolescents or adults and thereby miss some of the early help that is needed.

Autism diagnoses are not like most other medical diagnoses. There's no medical tests, like blood tests, that can give any answers. Doctors instead look at a child's developmental history and behaviors. Early signs of autism can be:

- Avoiding eye contact
- Having little interest in other children or caretakers
- Limited display of language (such as in the case of Kalpana's son)
- Getting upset at minor changes in routine

You can read the full CDC page on signs of autism [here](#).

### Stay in Touch

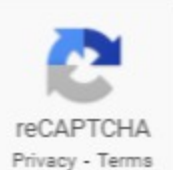
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### After Diagnosis

Right away, they began specialized therapies for their son, which helped. Like all parents of children with autism, they had many times of emotional growth and change. Kalpana counts herself blessed to have in-laws who did not share the stigmatizing attitudes that still pervade the South Asian community. Nonetheless, they were not safe from judgement.

"We had experiences when people from this community passed comments when we were handling the melt down with my son when he was young in public places," Kalpana recalled while sharing her experiences with SAPNA.

Despite being initially offended by the judgement passed against her family, Kalpana grew to look at it differently. "We felt those individuals are the ones who need intervention to make them feel they are matured adults."

Instead, they focused on learning as a family. Balancing attention between both children was an early challenge. As they came to understand the emotions they were feeling, Kalpana and her spouse realized that they needed to do more. Despite providing equal opportunities for both of their children, they knew there were still unanswered questions.

Soon, Kalpana found Fraser, a Minnesota nonprofit. One of Fraser's specialties is working with children with autism. The therapy sessions they began there proved to be instrumental in their son's development. It proved to be instrumental for Kalpana as well.

They used what they learned with Fraser to bridge the gap between their son's therapy and the resources he had at school. In filling those gaps, Kalpana brought some new ideas to school administrators. It wasn't long before those new ideas were implemented. Their son benefitted, as did all of his classmates with autism.

### What Therapies Are Common?

Therapies for autism are meant to reduce symptoms and ultimately improve functionality. It's important that children begin therapy as early as possible, as their brains are still in rapid-development mode. Most reliable research on therapies for autism is for young children. Research is still needed for therapy in adolescents or adults, but it is ongoing.

Methods of therapy for autism are varied and numerous. Therapies include applied behavior analysis, social skills training, occupational therapy, physical therapy, sensory integration therapy, and the use of assistive technology. Here are a few of the most-accepted options:

- Behavior and communication approaches (such as social skills training and speech therapy)
- Relationship-based approach, AKA "Floortime"
- Applied Behavioral Analysis, which is a measurable approach that encourages positive behaviors and discourages negative ones
- Occupational therapy, for teaching skills that allow one to live as independently as possible

There are also diet and alternative medicine-based approaches. Some parents report success, but there is little hard evidence to support them.

You can read the full CDC page about therapies [here](#).

### Proud Moments of the Present Day

Today, Kalpana's younger son is looking forward to graduating high school in June 2021 with a 3.75 GPA. He's been accepted to two colleges and plans to pursue a degree in accounting. Kalpana knows there are still challenges in her and her son's futures. She and her family are resolved to face those challenges with the same determination as ever.

"For majority of the world this might seem to be a normal process," Kalpana explained. "To me, it is a moment of my life which will remain proud forever in my heart and soul."

Kalpana hopes that all families facing similar situations can use all the resources available to them. There's a lot of awareness of the neurodiverse community. But that awareness is yet to fully reach our own. We hope that all in our community can find the strength to be like Kalpana and her family, offering not judgement, but support and love.

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[Click here to read about Fraser's autism programs.](#)

[Read an article written by a woman with autism on her experience growing up in the South Asian community.](#)

[Read an article by South Asian parents of a child with autism and their struggle to un-learn cultural stigmas.](#)

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