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"We will look after him for as long as possible. He is our son."

These words sum up Shiva and Charu Iyer's love for their children and their determination to keep 34-year-old son, Kaarthik, who has Down syndrome and schizophrenia, in their home under their care for as long as they are physically able to look after him.

Until Kaarthik was around 27-years-old, Shiva thought his son would eventually live a mostly independent life. He had even bought Kaarthik an apartment close to a train station so he could move out of home and make his own way to and from work.

"He was working full-time and was doing really well," Shiva said.

"We never had any thought of him having to be fully supported 24/7."

As he moved into his late 20s however, Kaarthik began to "lose himself".

"Something happened five or six years ago. We didn't know what was wrong and we spent two years with multiple specialists, psychologists, psychiatrists, neuro-psychiatrists, neurologists, pet scans and cat scans," Shiva said.

"The doctor eventually told us that his symptoms fit with schizophrenia. But it took a long time to get to that stage because no one knew what was happening for two years."

After 27 years of looking after their son on their own with no assistance, Shiva and Charu suddenly found themselves needing help.

"We thought he would be able to look after himself one day, but then this happened six years ago and now he cannot. Things change, and that's what life is. We can't do much about it. So now he will need the support more than what I thought," Shiva said.

Kaarthik now receives funding through the National Disability Insurance Agency for a support worker to help him with daily living, including showering, shaving, getting ready for work, and going to the gym. He also receives funding for occupational therapy, speech therapy, and home maintenance.

After several years out of the workforce following his schizophrenia diagnosis, Kaarthik is now back working. He also undertakes job training and literacy and numeracy training, fully supported by the NDIS.

Shiva said the NDIS support was helping him to prepare his son for the day when he would no longer be able to take care of him.

“I would like to look after my son as long as possible. I don’t want to put him in accommodation. But with the realisation that I won’t be there one day, the NDIS support is great.”

“Karthik lives with us and we will look after him for as long as we can, physically and mentally. But if I do not prepare for the eventual day when he has to be on his own, I would be remiss in doing my duty.”

Shiva said the NDIS had made a huge impact on their lives, and was especially important for people from other countries who may not have any family support.

“The NDIS has made so much difference compared to what we received prior. One year you could get something and the next year you could get nothing. It was so unpredictable, and so little.”

“It is definitely so much better to have that support, it really has made a lot of difference. This applies even more to people who migrate from one country to another country. Quite often the rest of the family is in the other country, so they don’t have the family support structure that would normally be available in their country with their own families.”

Shiva migrated to Australia from India 40 years ago, looking forward to the opportunities that could be provided by a country with “open spaces, nice weather and good people”.

Charu soon followed, and Kaarthik and his older sister Priya were both born in Sydney. Priya now lives in Texas with her husband and two small children, and visits her parents every year.

Shiva, now 71, studied law in India and completed post-graduate studies in Information Technology at the University of Technology Sydney. He worked as an information technology consultant in Australia, before retiring in 2001 to look after Kaarthik full-time.

Shiva said that his daughter Priya worried about her parents and their ability to look after Kaarthik as they got older.

“My daughter is so caring and she says to me ‘Dad you’re getting old, what is going to happen to Kaarthik, and if something happens to you I can’t just come over there because I have two little kids. Just move over to America and I’ll look after you’. She wants to support her brother and us,” Shiva said.

“But this country’s support structure is ‘plus one thousand’ so that is very important. There is so much support here medically and with the NDIS.”

“I said to her ‘it is alright for you to worry about us, but you’ve got to live your life with your kids and your family’. This is a great country here. We are looked after and we are okay’.”

Shiva and Charu have found some further support in an organisation they co-founded called Samarpan (meaning ‘dedication’ in Sanskrit), a network of Australian families of Indian and Asian descent who have children with disabilities.

“I’m probably the oldest member of the group, though I’d never tell them!” Shiva laughed.

Samarpan is currently working towards developing a culturally-appropriate accommodation model to meet the long-term care needs of their children.

“Everyone has the same issue at the end of the day: who is going to look after their kids when they can’t do it any longer,” Shiva said.

“We are actively looking at different options for future accommodation for our children.”

Shiva said that he had not always found the NDIS easy to deal with it, but that he expected any issues to be ironed out over coming years.

“The NDIS is a God-send but, as with any big change like this, I understand that you cannot expect it to work 100% for 100% of people. It’s new and it’s understandable that some people will feel left out, while others may get more than what they expect. Hopefully in a few years’ time it will settle down.”

"Looking toward the future, it is better than it would have been without the NDIS."

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