21 March 2018

Today, March 21, is World Down Syndrome Day, and there's an important message Shona Byrne (and her mum, Penny) want people to know – every person with Down syndrome has something to offer and given a chance they can make significant contributions to society.

As a call to action, and to show support for this significant day, Shona and Penny are encouraging people with Down syndrome to share their stories about what they bring to the community and their family.

"Today is a great day to better educate people about the meaningful contributions people with Down syndrome make, and to stamp out negative attitudes that prevent them from making meaningful contributions," Penny said.

And when it comes to meaningful contributions to the community, or to the world, Shona is no 'shrinking violet'.

She is a published author, proud of her poetry book, titled *The Beauty of Life*, and in 2012, the 36-year-old from Tweed Heads stood before thousands of people at the United Nations World Down Syndrome Convention to share her life story.

"It was a great experience," Shona said. "I talked about my life and how important it was to me to live independently; to have the same opportunities as everyone else and to be treated fairly and equally."

Shona has lived independently in the past and is keen to get back on track and go it alone again.

"Instead of Down syndrome, I want 'Less Parent syndrome'," she said with a laugh.

In her NDIS plan, Shona, who confidently self-manages with only a small amount of help from Penny, has been able to communicate all her needs to her local area coordinator; implement her plan and interview and employ her own support workers.

"I'm a good manager," she said. "I find self-managing is easy. I love computers and one of my support workers showed me how to do all the interviews."

Penny said Shona is enjoying having choice and control so much she no longer gets to join in when her daughter interviews potential support workers.

"She does it herself with one of her support workers," Penny said. "It's important I am fully independent and I'm working hard to reach my goals," Shona added.

As for their experience navigating the NDIS, both women say it has been really good.

"It's important to do your research first," Penny said. "The idea of the NDIS is scary for people because they have no idea about it; how it is going to work and what they have to do.

"Shona and I spoke to people involved with it, then we realised it wasn't going to be much different from the NSW system we were on, which certainly made it easier for us.

"There's also been some good information sessions around and some people who are fairly well trained in helping you to draw up your plan, which is important," Penny said.

"I had a good planner and I felt like I was listened to," Shona said. "I got lots of supports – help to get out into the community; to look after my health and wellbeing and to learn to cook.

"One day I hope to own my own restaurant and I'll invite mum and dad and cook for them," she said proudly.

As for self-managing your NDIS plan, both women say there's lots of advantages.

"When you go through a support agency, no matter how well they try to do things, you are still subject to staff who work for an agency, not staff who work directly for you," Penny said.

"I think it makes a big difference because when they work for you directly, you have one-on-one contact with them and they are aware of what the goals are and what they need to do. Whereas, if you go through an agency, you have to fit into the organisation's formulaic approach, so I think for as long as we can support Shona to self-manage, we will.

"The NDIS has been great for Shona, and also for me and our family. It's improved her self-confidence, although there's always been a lot there, but the self-worth and the happiness it has brought her is just priceless," Penny said.

Shona and Penny have produced this video telling her story - you can view it here (external - transcript and closed captions will be available at a later date).

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