

It's all about Matthew – using support to build a life

Wendy Farrelly

My son, Matthew, can choose who he wants to associate with and do so when it suits him. He is not grouped only with other people with disabilities and who don't share his interests or goals. This means he is not limited in those ways. Until recently, people with disability did not have this freedom.

The emergence of self managed funding has meant that Mathew can live a life that suits him – that enables him to do the things that will keep him healthy and expand his interests, his skills and his relationships.

Matthew fills his week with things that make sense for him. He doesn't have to 'fit in' with others.

He regularly goes to the gym, where he uses the treadmill and swims. He attends drumming lessons, he goes horse riding. He also does sit-ups, squats and other exercises. He goes shopping and enjoys interacting.

It is very important for Matthew that he keeps fit and that his day includes lots of activity as this means he remains well and healthy.

He goes to the same places at the same times to increase the chances that he will meet the same people – creating the opportunity to build meaningful relationships. At the gym and at other places that he frequents, people who work there now know him and interact with him even though he cannot speak. People ask how he is going. People look out for him. Matthew knows more people than I do. I am known as 'Matthew's mum'.

Matthew likes routine but at times it is good to do something different as no one always wants to do exactly the same things. Because Mathew's support is self managed, we can make changes to Mathew's week when we feel like it. We don't need to notify or get permission from other people.

Another benefit is that we can decide who provides the support. Finding the right people can be a challenge but allows a degree of control that is very important for Matthew's happiness and health.

We found people to provide support by starting with people we know and then by advertising. We have discovered that it is important to have more than one staff member to ensure ongoing support. If you are relying on one person and they leave or are sick, that is an issue.

Before hiring anyone, we talk about the talents they bring. We want people who are reliable, who are outgoing and who will help Matthew make connections. Matthew

cannot speak for himself so we also want people confident enough to speak up for Matthew if necessary.

We are also able to communicate with staff about our expectations and the reasons for them. We train his support workers how to work specifically with Matthew, since his needs are the priority and he has different needs to other people. The training is tailored for him.

Because people are being employed solely to support Matthew, we can ensure they are physically fit and that they don't smoke. It is important that Matthew not be made unnecessarily vulnerable by factors such as smoke.

It is also important for Matthew to use his walker and walk. With this support and with the assistance of his support worker he walks and does not have to rely on his wheel chair. It helps maintain his strength and flexibility. We are able to make sure that the people we hire to support Matthew are comfortable with this focus and understand it.

It is very important that anyone providing support has good rapport with Matthew. They need to connect with him.

In thinking about what Matthew's week will look like we are guided by his goals, his needs and what he enjoys.

He needs to be fit and he loves to swim so that is a great thing for him to do. It also provides him with the possibility of social interaction.

Like many of us, he doesn't necessarily love doing squats and stretches but it is important for him so he does.

Matthew cannot always communicate with words but I know what he is enjoying and what he isn't by the way he acts.

Matthew paints and does some amazing art work. He has a Facebook page, *Matthew Farrelly Artist* which displays many of his paintings. He has sold some and donated some too.

When we started thinking about how Matthew would spend his week, talking with the school and with others that know him was really helpful. They were able to provide input into what he liked and what he didn't like.

For instance, when he was at school he was taken 10 pin bowling on a regular basis. We found that he did not enjoy bowling and it is not necessary for his well being so, now, he doesn't do it.

It is important to keep track of what Matthew is doing and how he is spending his funding. We keep a diary that is filled in every day. It notes who he has met, where he has been, what he has done and what he has spent. We keep a copy of our vision for Matthew's future at the front of the diary to remind us of what it is all about.

We also have an ideas book. If people have an idea of something that could be a useful and interesting addition to Matthew's week they can write it in the book for consideration.

Like the rest of us, how Matthew spends his week will change as he changes.

Like the rest of us, some weeks are better than others.

Most importantly, self management allows Matthew's life to be all about Matthew.

For more information visit: <http://www.resourcingfamilies.org.au>

