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Western Sydney's Lisa Loader tears up when she talks about the opportunities the National Disability Insurance Scheme (NDIS) has given her son, Austin, his siblings and her.

The single mum of three said her 14-year-old, her eldest, was the 26th baby born in the world with a rare chromosomal disorder called Q10 26.3 translocation to 8P, which left him with Duane syndrome – a congenital eye disorder where the optic nerve on the outside of his eyes never developed, leaving him with a turn and blurry vision.

Lisa said it also left Austin with two forms of epilepsy; kidney problems, which will eventually lead to dialysis; a heart murmur and Perthes disease, which affects his hip and impacts his mobility.

"Austin's condition makes it hard for him to function but since he's been part of the NDIS, he's really improved," she said. "Now he gets regular therapies, which previously I could never afford.

"Austin's physio has been brilliant. He actually picked up Perthes disease in Austin's hip. If it had of gone unnoticed there would have been a high chance he would need a hip reconstruction. Hopefully through physio we can try to avoid that."

"Regular therapies are something I always wanted for Austin, for years and years, but being a single parent and going to Uni, to try and better myself to support my kids, I just couldn't afford it, so when it was granted as reasonable and necessary we were just so happy."

Lisa said since Austin has been seeing his OT, his writing has started to progress too. "I have just noticed so much improvement," she said.

"I also get one-on-one in-home support for Austin, a few hours a week, which means now I can get to Uni and work on time.

"I engaged local support provider, Sunshine, because I wanted to choose a qualified female support worker – someone he would love and relate to. We hit the jackpot with Emma. She's a perfect fit – he just loves her and she loves him."

Lisa said Emma picks Austin up from school on Monday's and she comes to their home every Wednesday, at 7am, to help Austin build his life skills.

"Emma supports him to get dressed, brush his hair, his teeth, and make his breakfast and then she takes him to school.

"It works well because Emma can stop and take her time with him in the morning, where I can't, and he's not having me do everything for him, it's giving him more independence."

"The NDIS has really worked for us," Lisa said. "It's been amazing. It was difficult and hard for me to set up because I was at Uni full-time, down at Strathfield, the kids were doing Jujutsu, and I had constant other children's appointments but everyone fitted me in. If they couldn't get me, they would email or call," she said.

"I know setting up to be part of the NDIS is a long hard road but when you get there, it's easier and it's so good – it's just so worth it! I get a bit teary, it means so much.

"The NDIS is giving people with disability so many more opportunities. I think if you're a parent, a grandparent or a carer of a special needs child, it's just amazing to have that extra help so you can actually do things for them where you couldn't before.

"I don't have 50 hours in a day, and I didn't have much but now we have the NDIS to help us and it's just wonderful!" Lisa said.

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