

Hunter and Lucy get a Better Start

Think of a footy final crowd in Australia of about 80,000. That's the likely number of families in Australia carrying or affected by an intellectually disabling genetic condition, Fragile X Syndrome...and most people don't know anything about it.

Every week in Australia one child is born with Fragile X and 20 children are born who are carriers with the potential to pass to later generations.

Lucy and Hunter are two of those children who are fully affected. Their Mum, Candice, had heard about the Government's Better Start for Children with Disability (Better Start) program through the Fragile X Association of Australia.

Better Start provides eligible children with up to \$12,000 in funding for early intervention services like speech pathology, occupational therapy and psychology. Fragile X is one of the disabilities covered in the program and both Hunter and Lucy met the eligibility requirement and were both diagnosed before they were six years old.



Hunter was diagnosed with Fragile X at 2.5 years of age and started using Better Start funding immediately.

"We had been paying for Hunter's speech, occupational and physiotherapy privately prior to diagnosis and this was a huge demand on our family budget," Candice said.

"We have found an excellent speech therapist and Hunter has made such progress going from non-verbal to now having at least 15 words in his vocabulary. If it were not for the Better Start funding, I don't believe he would have improved as much."

Lucy is not as badly affected but has required assessments by therapists which her Better Start funding has covered.

"Lucy attends monthly speech therapy sessions and these are not only helping her but easing our minds that she is rapidly improving and 'catching up' to where she should be.

The intense therapy that my two Fragile X children have been able to access through the Better Start Initiative has been, I believe, soul saving - we would have had to sell our house or re-finance to be able to afford therapies they both require to reach their full potential. Occupational Therapy intervention helped us better understand their sensory processing differences and use strategies that helped them stay more calm and attentive. The OT showed us how to develop our child's play, learning and independence skills so that they could participate more at home and preschool". Candice said.



Early intervention services are gradually transitioning to the National Disability Insurance Scheme (NDIS). The NDIS is a new way for people to get disability support that takes an individualised and life-long approach. Most families receiving early intervention funding won't be affected by this change for some time.

For more information on Fragile X visit www.fragilex.org.au or call **1300 394 636**.

Find out more on the NDIS by visiting www.ndis.gov.au/people-disability or calling **1800 800 110**.

For more information on Better Start visit www.dss.gov.au/betterstart or call **1800 778 581**.

