After eight years of struggling to communicate, a new device has helped to unlock Ace’s world

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Throughout Melbourne’s six COVID lockdowns, 10-year-old Ace Bartlett’s parents struggled with the challenge of explaining to their son why he couldn’t attend his regular swimming sessions.

Ace lives with a rare neuro-degenerative disorder called Aicardi-Goutières syndrome (AGS), which affects his brain, muscle control and movement.

He uses a wheelchair, needs care and assistance with every day activities, and is non-verbal. He doesn’t understand what COVID or lockdowns are all about.

But thanks to the NDIS, Ace’s parents didn’t have any trouble understanding just how much their son wished he was swimming again.

For years, Ace struggled to communicate his needs and wants to those around him.

That all changed when a communication device, funded through Ace’s NDIS plan, unlocked his world.

“The NDIS has given Ace a voice, and we’re so grateful for that,” said Ace’s Mum, Bianca Bartlett of Rowville.

“After 8 years, we finally had a little boy who had a voice, who was speaking, and it’s still almost hard to believe.

“He can put words into a message bar and make a sentence, and then speak the sentence, and he can clearly tell us what he wants. And that’s just amazing.”

Ace uses a finger to operate a Tobii Dynavx voice output device with a software program called Compass. It generates a child’s voice and is programmed for Ace’s unique needs.

A speech therapist, funded through the NDIS, has trained Ace to use his device.

“He tells us constantly he wants to go swimming,” Bianca said. “He’s always loved the water since he was very young, so it was hard during lockdowns, he missed it.”

For Ace, swimming is not only his favourite thing, it’s the activity that best keeps him strong, fit and active.

Ace has NDIS funding for a support worker who usually takes him swimming every week.

“When he first started, Ace couldn’t use both of his arms to swim, but he was so determined to do everything the other kids were doing,” said NDIS support worker, Kat Roberts.

“It’s through his determination and swimming that Ace has learned to find the pathways in both his arms.”

And thanks to an Australian company called Para Mobility, swimming continues to be accessible for Ace as he grows.

The company designs and makes the Pelican Pool & Spa Access Hoist, which gives Ace and others with disabilities safe access to public and home pools without manual lifting.

Ace uses a hoist at his local pool and also received NDIS funding for a hoist at home.

“When Ace was younger, I could carry him on my hip, but as he grew, I couldn’t do that, so we were having to lift him onto the concrete and lie him down and it’s just not dignified for him, and it's not safe for him and it's not safe for us,” Bianca said.

“Having the Pelican hoist means Ace can continue swimming, which is so important to keep him strong and healthy as he gets older.

“In the water, Ace is just like everybody else. He swims independently so he has this freedom and you can see the pure joy that gives him.”

Ace continued to receive other NDIS supports during lockdown, including his support worker Kat caring for him twice a week in her home.

“It was so important for Ace to have that,” Bianca said. “It helped with his mental health and his behaviour to be in a different environment. We wouldn’t have functioned without those two days.

“It also meant my husband and I could both continue working. I could keep supporting my family, which is so important for my own mental health too.

“The NDIS has been absolutely life-changing for us. It’s helping to keep us together as a family, it's helping Ace live his life to the absolute fullest and we're a happier, more cohesive family.”

Ace’s story showcases the impact we can all have when we see people for who they are and the things they can do.

To help celebrate the day you can download the IDPwD pack including a social media pack, poster, virtual meeting background and email signature block on the IDPwD page.

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