

FIRST CONTACT

This child had extraordinary intellectual capacity – and no one knew. Now a life-changing program is giving hope to non-verbal children with autism ... and it could be a lifeline for the NDIS

BY SARAH HENDER



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ne Sunday two and a half years ago, Chris and Mel Mury were driving back home to the Hunter Valley with their three children after attending a family funeral in Canberra. Half-way through the trip their eldest son Charlie, who lives with severe autism and is non-verbal, started bashing his head against the car window, yelling and flailing his arms. Charlie's meltdowns were not unknown to the Mury family but none had lasted as long as this. By the time they reached home, with frequent stops along the way, everyone was exhausted. Even then, 17-year-old Charlie was still going. Finally, in desperation, his mum Mel sat down at the kitchen table with pencil and paper and asked him to help her help him. He took her hand holding the pencil and, guiding it, he

wrote his first words to her in 17 years: "Tomorrow is a happy day. Today is sad because a nanny died in Canberra."

Mel burst into tears.

She and Chris told Charlie how grateful they were that he'd shared that with them. It had been the children's grandmother's funeral. A very bad day had just turned into one of the best days of their lives.

That first "conversation" was just the tip of the iceberg. No one knows why the breakthrough happened exactly then, although they acknowledge that the day had been a particularly emotional one. From that moment on, Charlie was eager to communicate.

The next day, Mel and Chris, both architects, went to see the principal of Charlie's school,

Tracey Rapson at the Hunter River Community School (HRCS). They told her what had happened. Rapson suggested that Charlie be assessed by a psychologist. It was by no means the first assessment he'd ever had, but now that he could respond the outcome was very different. Until the breakthrough, the school and his family had assumed that Charlie was intellectually disabled. This testing revealed he had no intellectual disability and was academically capable. It was a shock to everyone.

As a baby, Charlie had met his physical milestones of crawling and walking but was still not speaking by two and a half years old. Concerned, Mel and Chris took him to a hearing specialist who, with an interdisciplinary therapy team, diagnosed Charlie with severe

autism at two years and 10 months. Despite many subsequent assessments over the years by medical professionals and school counsellors, there was nothing to indicate Charlie's intellectual capacity, which has recently been revealed as extraordinary. "Because he didn't have the tools to alert others, it was really hard to get an accurate assessment of his capacity," Rapson explains.

Until his breakthrough Charlie had never shown any interest in communicating, apart from indicating his basic needs with a gesture, a noise or occasionally using an augmented assistance device to make a simple request.

Mel had begun writing with Charlie during the Covid pandemic in 2020 and it had not gone well. Charlie had been sent home during

lockdown with cards showing dotted letters of the alphabet for him to trace over while using the hand-over-hand technique. It was the first time Mel had held a pen for Charlie, allowing him to guide her hand to trace the letters. She recalls he was completely unmotivated and she had to do all the work.

"I remember thinking, 'What a waste of my time!'" says Mel. And yet, these sessions turned out to be the building blocks that would help Charlie find the way to break through his internal world just over a year later.

And then there was so much to learn about Charlie. The family was eager to find out exactly how much was going on inside his brain. They were shocked to discover just how much. He could remember what he did for his first

birthday. He could remember other kids' birthday cakes that even their parents couldn't remember.

"We asked him things we had always wondered about him," says Mel. "For instance, why had he always stared at the leaves on trees? He was able to tell us that it made his brain calm."

Charlie had watched children's programs on his iPad in different languages for years, but the family had always assumed it was just white noise to him. Mel asked him if he knew any languages. Using the hand-on-hand writing technique, Charlie responded that he understood "Polish and Croatian". Using Google Translate, she asked in Polish how old he was. He wrote back in English: "17 years old."

Mel was feeling her way, opening up pieces of Charlie's world as she went. Engaging with her son was a joy. At the end of the conversation about language, just for fun, Mel used Google Translate again to type in Hebrew: "You're a goose." She wasn't really expecting anything back from Charlie but he grabbed her hand and wrote: "I'm not a duck". Charlie's untapped internal universe was enormous.

"We had always been under the impression that autism was all-pervasive, that it was in every part of that person," says Mel. "We've changed our minds. It's more like a wrapper which Charlie managed to break through."

It's clear that while he was communicating only his basic needs, Charlie had been absorbing complex information from a range of sources. As a young child, Mel would take him to the library where he made a beeline for the engineering section, focusing intently on books about train wheel gauges. Mel assumed that he just liked the pictures, but now it seems he was taking in a lot more than that, developing an advanced understanding of mathematics while at school receiving an education that was mostly kindergarten level, Year 2 at best.

"In my 15 years working as a psychologist I have not experienced anything quite like it," says his psychologist, Dan McAlpine of Oracle Psychology in Newcastle. "Charlie has a recall that is impressive. He recalls things from his distant memory and processes and calculates information to a degree that few people can."

Now that Charlie wanted to communicate, the Mury family needed the school to be on board with his chosen method as he had no interest in learning any other. Some therapists



Potential: Charlie Mury today, aged 19; opening pages, as a young boy

"It was so frustrating because everyone thought I was dumb and stupid"

have contested the benefits of the hand-over-hand method but it's one of a range of therapies used at Charlie's school which have shown to support severely autistic students.

His class teacher and the principal, Rapson, observed a couple of sessions with Charlie's mum and were satisfied that he was writing his own responses to their questions. His teacher then learnt how to work with Charlie as his scribe, finessing his style and control over time. He began with writing short stories. His teacher tried some simple maths with him. "Too easy," he wrote. When they tried something harder, it was still too easy. Before long he began working on past NAPLAN tests, achieving near-perfect scores. Charlie's knowledge was beyond anything he had been learning at school.

"I think what Charlie's case has demonstrated has really reinforced something I've talked to staff about for many years, and that is that we can't take the lack of feedback as an indication of what students are learning," Rapson says.

It wasn't long after his breakthrough that Charlie said he wanted to sit the HSC, because,

as he told his teachers, he was tired of being thought of as "dumb and stupid". No one really knew if he could manage it, especially with just a 14-month run-up. But with the help of his teachers and the local high school, Charlie successfully completed the HSC requirements, the first at his school to do so, although the exam itself proved impossible due to Charlie's high anxiety. Later that year, he received an award for student achievement from the NSW Minister for Education, another first for a student with complex autism.

Charlie had bigger plans yet. Now, he is in his first year of studying advanced maths at the University of Newcastle with the help of his disability support worker and a university-appointed scribe. He achieved a solid pass in his mid-semester exam. Another milestone.

The Mury family have had to completely shift their mindset about Charlie. They have no idea what life will look like for him but it's certainly not where it was. Mel is sure of one thing. "Our lives have improved for knowing him better," she says.

How could this have been missed by so many for so long – until Charlie was on the cusp of adulthood? And what therapies and communication could have been adopted for Charlie to help him have a very different life?

Of course, two decades ago, our understanding of autism was vastly different, with less focus on early indicators. Today's increased awareness means that any developmental concern is more likely to be noticed earlier, yet we are still hampered in our ability to improve the prognosis for children. First, a diagnosis of autism generally cannot be clinically made until at least the age of three, when it is more likely there will be a full range of symptoms. NDIS funding is often diagnosis-dependent, so even where parents notice something different about their child, help may not be available until later in their child's life – and by then the greatest chance to influence the course of their development might have passed.

Enter an international research team led by Professor Andrew Whitehouse, director of CliniKids at the Telethon Kids Institute. Whitehouse, working in conjunction with the Child and Adolescent Health Service in Western Australia and La Trobe University, led the landmark *Australian Infant Communication and Engagement Study* (AICES), a four-year randomised controlled trial that began in 2016. The results were published in the prestigious journal *JAMA Pediatrics* in 2021. The study found that a specific type of pre-emptive therapy which supports the social development of kids aged just 9-14 months and displaying very early signs of autism reduced the likelihood of an autism diagnosis for them by an incredible 66 per cent.

"It was one of those moments when you push your chair away from the computer and your jaw drops," Whitehouse says.

The therapy, formerly known as iBASIS-VIPP, was renamed "Inklings". In April last year Bill Shorten, Minister for the NDIS, pledged funding for a pilot of the Inklings program in Western Australia involving 700 families, "to examine more closely whether earlier intervention can lead to better outcomes for infants and families, including lower levels of support being needed as they grow and develop".

Inklings essentially involves parents working with clinicians to identify a child's unique differences and create the right environment to help them learn in a way that suits them best.



Breakthrough: Professor Andrew Whitehouse

This is different from many therapies for autism, which try to replace developmental differences with more "typical" behaviours. Inklings uses video feedback to help parents comprehend their baby's unusual or unique attributes and to use these as a foundation for development. The therapy had two major benefits: it supported parents to connect with their babies in ways that they may not have been able to do before – particularly as parents can become frustrated when their baby doesn't appear to behave "normally". Second, this type of interaction actually mitigated the developmental disability experienced by the child to such a degree that the child was less likely to meet the "deficit-focused" diagnostic criteria for autism.

While autism is caused by differences in genetics, Whitehouse stressed that "by changing the way we as parents try to connect with our babies, rather than changing the way they try to connect with us, we can make a major difference to their lives".

It has been understood in the medical world for more than 50 years that the first two years of life is when the human brain undergoes the

Early intervention: the bottom line

Researchers have predicted a likely \$3 return to Australia's National Disability Insurance Scheme (NDIS) for every dollar invested in the iBASIS-VIPP therapy (now the basis for Inklings) during infancy. The University of South Australia and Telethon Kids Institute, in partnership with the University of Manchester, La Trobe University, Griffith University and the University of Western Australia, modelled downstream costs to the NDIS to find that use of the therapy would return a net saving of \$10,695 per child by age 13.

most change and is likely to be the most responsive to therapy. Says Whitehouse: "This study is the first to show just how responsive children's development can be, and it provides a blueprint of how we can better support the next generation of kids and their families."

The federal government recently increased its funding to expand the Inklings pilot into other states, with the total amount of funding allocated in the last budget to be \$22.1 million over the next four years. "While the pilot will run for three years, the evaluation will run for four to fully assess its effectiveness, and inform a broader Australian rollout," Shorten says. "I think it is very exciting for future generations and for early intervention mainstream services outside the NDIS."

Shorten certainly would be excited. A program with the genuine potential to curtail the ballooning autism diagnoses crippling the NDIS without depriving those in need of critical services sounds like the kind of miracle governments dream of.

Those living with autism as their primary disability represent a third of the 610,000 people receiving support from the NDIS, at a total cost of \$35 billion and rising. For the NDIS to continue to be sustainable and effective, addressing ways to reduce that number has become a priority for the Federal Government. As Shorten said in his address to a national conference of the disability sector in 2022, "the NDIS can no longer be the only lifeboat in the ocean for people with disability to swim to".

Disability groups have expressed concern that if NDIS support is reduced for those with autism, it will leave families to seek assistance from hard-pressed state-funded services in child development.

Last December the NDIS review handed down its report recommending two key changes that will affect the way in which the NDIS operates. The first is that the assessment process should be less diagnosis-dependent, focusing instead on a person's level of function. Currently, a child showing developmental delay is unable to access any NDIS-funded support without an autism diagnosis – which means delay in getting help, and when it does become available the only pathway is clinical, which in some less serious cases may not be what's needed. The second is a recommendation that follows from the first. Where a child is assessed as having sufficient function to not

warrant NDIS support but may still need help for emerging developmental delay, the review acknowledges the current absence of such public services outside of the NDIS, recommending a joint investment of federal and state governments in early supports for those children. The government has responded with its recent announcement of a new \$10 billion scheme to do just that, this cost to be shared equally between the Federal Government and the states.

Professor Bruce Bonyhady, who headed up the NDIS review, said recently: "Those supports should be primarily delivered where children already are, in existing services such as maternal and child health, integrated child and family centres, early childhood education and schools."

Whitehouse believes this is where Inklings can help. It is a therapy that can easily translate from one that is parent-led to a broad range of professionals who work in early childhood settings. With such a large captive audience in early childhood education and care settings, he sees it as a great opportunity for this groundbreaking therapy to reach a wider population.

For all of the attention it is attracting, you might expect something more complex – but the beauty of Inklings is in its simplicity. The program consists of 10 sessions, each delivered fortnightly, within a six-month period. Each session focuses on different scenarios, such as eating, independent play and interactive play. For five to six minutes, the parent and the baby are recorded on video in these scenarios. The parent will then sit down with the practitioner supervising the session to watch the video and discuss the parent's thoughts on what had happened in the session. The parent then uses the skills they've learnt to engage and interact with their baby in a certain way at home. Since the clinical trials, the age parameters of the therapy have been broadened to allow for a greater age range of babies, from six months to 18 months.

Michelle, 40, a secondary school teacher, and her husband Jake, 32, the primary carer of their two-year-old twins, Frankie and Aubrey, are from Mullaloo in Perth. At a little over a year old, neither of their daughters were saying any words although Frankie was making noises. Michelle, who had an understanding of autistic behaviours and had experienced her own issues with auditory processing, was concerned about the girls' lack of speech. She heard about the Inklings program at the twins' daycare cen-



Progress: twins Aubrey and Frankie with their mum

"When she cried I had no idea what she wanted"

University researcher Patricia Macchiaverni (pictured below) found out that her daughter Lara had Down Syndrome *in utero*. At around six months old, Lara stopped engaging, smiling or making eye contact. Lara was already receiving physiotherapy and occupational therapy but up until six months she had been engaging with others. Patricia was told Lara's behaviour could indicate autism, but she would need to wait until she was five years old for a clear diagnosis. Patricia became increasingly worried about Lara and was also struggling to parent her effectively. "It was difficult to know if she was happy or not," she says. "When she cried I would have no idea why or what she wanted." Although her daughter was older than the target age, the team at Inklings advised Patricia that Lara might benefit. And she did. "It was game-changing for us," says Patricia. "It helped me discover that Lara was actually communicating with me much more than I realised."



tre. Jake was sceptical about how it would help but agreed to attend the sessions. The girls were 18 months old when they started.

"I came out of it probably with more of an appreciation than I ever thought I would have about acknowledging and recognising cues, whether they be verbal or physical, or just things that I didn't realise Frankie was doing when she was interacting with me," Jake says. "It makes you a better parent because you are aware of how to interact with them once you're aware of how they want to interact with you."

Michelle agrees. "It's about giving them the opportunities to communicate the way they want to," she says.

"There is just nothing like this out there that can show you how you interact with your children," adds Jake. "You wouldn't consider sitting down and filming yourself with your child."

Since starting the program, the twins are engaging more, and becoming increasingly vocal. Their progress will be reviewed by Inklings staff in another 12-18 months, by which time the most benefit is expected.

So, what about the brave, brilliant 17-year-old Charlie Mury? We can't travel back in time, but Whitehouse believes there's a fair chance that Charlie's world may have opened up to him much earlier with a program such as Inklings. "Charlie was almost certainly communicating very early on," he says. "All children communicate, we just need to give the tools to parents to recognise this. Those signs might not have been missed if Charlie had been given more opportunities to communicate as a baby in the way that Inklings promotes, in his own unique way, rather than in the way most children are typically expected to communicate."

It's clear that Charlie's inability to communicate in a typical way shaped the course of his early life. But the Murys don't think about the lost opportunities of the past, and neither does Charlie – they are just grateful for a future they thought he would never have.

In a written speech that Charlie presented to the 2022 NSW Regional Principals' Conference, he opened up about his former life, stating: "I was stuck inside my brain. This was so frustrating because everyone thought I was dumb and stupid. This is the way most people see people with autism."

Charlie leaves us in no doubt about how he feels now. "Communication has saved my life." ●

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