THE WEEKEND AUSTRALIAN

A father's love and the battle to give Shane a fighting chance

Told his disabled son couldn't attend a school camp, David O'Reilly's response was indignant: 'We'll see about that.' What happened next is a story so extraordinary, it could change Australia's future.

By HELEN TRINCA

Jordan and Laura O'Reilly. Picture: Nick Cubbin

From **The Weekend Australian Magazine** September 25, 2021
13 MINUTE READ • 5

Dark, handsome, with a rugby player's strong body, David O'Reilly was charismatic and intense in his 20s. It was the 1970s, and the political journalist took no prisoners. He loved scoops, loved chasing leads. Journalism was the prize and he gave it everything.

O'Reilly had grown up hard in Sydney, with a single mother whose husband left when he was three and his younger brother Peter a few months old. "It was one of the reasons he did not want to get married for years," his wife Sue Corrigan says. "But when he did decide to commit, he decided he was going to be the best father ever – and he was."

They met in Canberra in 1975 when O'Reilly flew from Sydney to cover the Premiers' Conference and Corrigan, working in the press gallery, was given the job of collecting him from the airport. It would be 1984 before they married, having followed each other back and forth across the country and to London, chasing their careers – and each other. Two years later, their daughter Laura was born, followed in early 1988 by Jordan.

By then they were living on five acres at Murrumbateman, north of Canberra, in a house O'Reilly had built. He was delighted with his family and his job as national political correspondent for weekly magazine The Bulletin, working out of the press gallery. Then something happened that would change the O'Reilly family – all of them, parents and children – in the most profound way, taking them on a journey they could never have imagined. Or as Corrigan says: "The whole thing got turned on its head – the life plan."

David O'Reilly with Laura, Shane and Jordan, 1991. Picture: supplied

I knew David O'Reilly, but not well. He was The Australian's bureau chief in Perth in 1979 when I was appointed the junior but he left very soon afterwards. Later, in Sydney in the 1980s, he was a colleague. Then he was gone. It would be some years before I saw him again, on a pleasant Sunday in a town in West Sussex, England. It was 1995 and the family had not long arrived from Australia. It was good to see them, but also deeply shocking. Their rented house was sparsely furnished. They had scraped together everything to make the trip.

We went to the pub with the kids and talked as Laura and Jordan raced around. Their five-year-old brother Shane clung to his father throughout the afternoon. Shane had severe cerebral palsy and virtually no independent movement. He had been born at the old Canberra Hospital three months premature but was doing well enough in intensive care when, at 10 days old, he contracted a golden staph infection. Says Corrigan: “I was going home that day, it was the first time I was going to see Laura and Jordy since Shane had been born and I left with all these promises that they would get the antibiotics and get onto it. I got home and about an hour later, the hospital rang and said, ‘Come back immediately, he is dying’. I could never really get to the bottom of it but it was Sunday and I don’t think the antibiotics properly arrived, so it did massive damage and he was on life support. But he pulled through and was left with massive brain damage.”

In the house at Murrumbateman, baby Shane screamed in distress for the first 12 months of his life. Corrigan made the 40-minute trip to Canberra for his therapy sessions, often cradling him on her lap as she drove, in an effort to calm him. “He was like an iron bar, but you are so naive and everyone kept saying it was a result of being premature and it will sort itself out,” says Corrigan. “He was only eight months old when the pediatrician said it was brain damage and that he would probably never walk. And again the incredible naivety. I remember saying, ‘Might he need calipers?’ No idea really. It was blindingly obvious to everyone except us. But right from the beginning, David was just amazing. He was very determined, in a way a bit too determined.”

That afternoon in West Sussex in 1995, O’Reilly and Corrigan filled me in on what happened next, the story of their battles to get Shane into good treatment programs and a regular school, of their increasing dismay at the poor level of assistance available to people with disabilities in Australia, and of their hopes that now, in England, their little boy would have a brighter future.

O’Reilly had given up his job at The Bulletin to support him while Corrigan went back to work. “I had got very involved in researching effective therapies,” she recalls. “We found this school in England which had a system called conductive education and we decided to leave everything and get Shane into that school. Everyone thought that we were mad.”

Laura O’Reilly remembers those years in England as a challenge. “The period through my early and mid-teens were tough. We moved around a lot and changed schools several times, and it definitely wasn’t easy,” says the 35-year-old, who now has three young children. But even through the toughest periods there was a sense of drawing meaning from her relationship with her youngest sibling. “The tone was set by both my parents, but particularly my dad, that come what may we look after each other, we protect each other, we fight for each other,” she says.

Over the years she would learn the practical tasks of caring for her brother, sharing the load with her parents, feeding, bathing, toileting, sometimes sleeping in Shane’s room, so she could help him roll over several times a night. He was in a wheelchair from about five, but whenever his father could he would lift him up and help him move, holding him around the waist, separating his legs, determined to support the little boy to walk.

O’Reilly was working on a biography of former Australian Democrats leader Cheryl Kernot, which would be published in 1998, and freelancing. Corrigan took the train to London to work when she could, eventually getting a full-time job as a feature writer on the Mail on Sunday.

At age 12 Shane went to school as a weekly boarder, at home on weekends and school holidays. He still needed round-the-clock care, and had limited independent movement. But he was smart and funny. More than anything, he had always been included. “My father was absolutely dedicated to Shane,” Laura says. “He was determined to give Shane absolutely everything that he could. And that has really influenced Jordy and me now in the work that we do in the Australian disability sector. There’s a bit of relentlessness in us about making it happen, which we learnt from our parents.”

Corrigan says: “Laura and Jordy saw from the beginning the effort David was putting into Shane, including him in everything. He set him up so he could ride his bike with them, play with them.”

Sue and David with children Shane, Jordan and Laura in 1998. Picture: supplied

They had returned to Australia for a year when Shane was about nine and he attended the local primary school. “His class was going on a three-day bush camp and they said Shaney could not go. David’s attitude was, ‘We’ll see about that’. In the end, he went on the camp with Shane and all these nine-year olds, and just carried him around on his shoulders, running around in the bush and sitting around the campfires and sleeping in the tent with him. It was an extraordinary commitment and Jordy talked about it for years afterwards. David was just determined that Shane was not going to be excluded.”

With Shane in weekly boarding, O’Reilly embarked on a PhD in politics through Monash University, and with Corrigan working full-time and Laura and Jordan in local government high schools, life for the family became more stable. Then, another curve ball. O’Reilly had been a keen rugby player in his young days, and he looked after his health, but one day in July 2006 he collapsed in agony. He was diagnosed with bowel cancer that had spread to his liver, and died just three months later, aged 55. He’d just completed his PhD and was proofing the book it sparked, *The New Progressive Dilemma: Australia and Tony Blair’s Legacy*, which was published the next year.

(Many years later, Corrigan would receive $180,000 from Britain’s National Health Service after a judge found the NHS had breached its duty of care by failing to discover and treat O’Reilly’s tumour during medical consultations in 2003.)
Back home in Australia, friends and former colleagues were saddened. *The Australian* ran an obituary under the headline: “Dealt a difficult hand, but respected across the political divide”.

Early in 2008, Corrigan rang me. With David gone, life in the UK had proven too tough. She and Shane and Jordy were back in Australia while Laura stayed on to take up a coveted place at Cambridge. Shane was 17, desperate to finish school and go to work, but Corrigan was appalled at how poorly served the disability sector was compared with the opportunities in the UK.

She was exhausted but determined, and later that year this magazine published a feature by her proposing a radical insurance scheme for people with disabilities. A handful of people were lobbying the then Labor government for a system that would eventually become the National Disability Insurance Scheme (NDIS), putting funding choices into the hands of those with disabilities.

At 19, Jordan was the primary carer for Shane, who was enrolled in a local school. “Laura was on the right track academically. I wasn’t, and had fallen into the wrong crowd at school,” he says. “My father’s death was a real turning point. It was a huge moment in my life because my purpose all of a sudden became clear. I had to step up and be able to support my mum and brother. It was natural because I had been watching my dad do it.”

A conversation with a neighbour set him on a new path – an occupational therapy degree at Sydney University. Then, in 2010, Corrigan launched a not-for-profit in memory of her late husband. Called Fighting Chance, it raised money to fund therapy and equipment for people with disability. “The disability system in Australia was still so bad and there were desperate people everywhere without funding for even the basics,” she says. “So I was just raising money and handing it out to anyone I came across.”

After completing her Cambridge history degree with first-class honours, Laura came back to Australia and took over a reimagined Fighting Chance, while also enrolling in law at UNSW with plans to go to the Bar. “Coming home was hard,” Laura says. “I had imagined my life in London and it took me a long time to find my feet in Sydney. But after Shane died, I realised I had found my calling in Australia, in Fighting Chance and the work we were doing in the disability sector.”

Shane O'Reilly was 21 when he died in his sleep in July 2011. He'd spent his final years in a post-school day program. He was desperate to work but there were no real job opportunities for him. Says Corrigan: "Shane was really entrepreneurial. He set up a little business, called Shane the Computer Man, and put a sign on his bedroom door saying 'Open for Business'. Here was a young man, a school-leaver with ambitions but with little chance of realising them. It was heartbreaking."

"We realised the way things are now in the broader society, Shane is never going to get the opportunity to work, to move out of home, or make great, lifelong friendships," says Jordan. "So we hatched the plan to build Fighting Chance in order to create the employment, social and accommodation opportunities Shane and his peers needed. We opened our first little office basically to give Shane and his friends jobs. Shane picked out his desk.

"And then we woke up one morning and Shane was not with us anymore. It was a really dreadful moment."

A few weeks back, Jordan and Laura O'Reilly fronted the cameras as the venture capital arm of recruitment giant SEEK announced it was leading a $40 million capital raising for Hireup, an online platform the siblings launched six years ago. Its purpose is to connect people with disabilities and the support workers who help them with a range of activities from showering and dressing to taking them on a picnic, shopping or to the movies.

Until then, Hireup had attracted some $6 million in funding from impact investors including the Myer Foundation, the Liberman family's Jagen, Impact Generation Partners, the Scalzo family and the Salteri family's CAGES Foundation, as well as the William Buckland Foundation and the Melbourne Lord Mayor's Charitable Foundation.

SEEK's entry was a big moment for the co-founders, a recognition by mainstream funders that the company, triggered by the experiences of their brother, was making a real difference. "Shane left an indelible mark on our hearts and souls and it was a no-brainer that we would continue our work in his memory," says Jordan of the decision to continue building Fighting Chance after his death and to later set up Hireup. They decided to split their efforts, with Jordan stepping down from an operational role at Fighting Chance to work full-time on Hireup while Laura continued to run Fighting Chance.

“The NDIS was on the far horizon when we started,” says Jordan. “But it framed our thinking that maybe we could pioneer something really important for a post-NDIS disability sector using investment from people whose goal is social impact.”

Traditionally in Australia, state and federal governments block-funded agencies to provide support to people with disabilities. Says Laura: “In the old days the money would go to the agency and they would decide how much you would get and how. Shane and my mum would... be allocated a worker but there was no choice or control over who it was, and limited control over the hours of support.”

Later there were packages allowing a little more control, but in general provider agencies rather than the clients called the shots. “That was the experience we had with Shane in the last few years and it was what triggered Hireup,” says Laura. “We would open the door in the morning and find a new worker standing there... so we thought, let’s get the middle man, the agency out of the picture and let Mum and Shane build a relationship with a person they choose and let them be in control of the relationship.”

The NDIS, which began to be rolled out in 2016, increased the power of those with disabilities, with allocated individual funding to buy one-to-one support, therapy or equipment directly. Hireup’s online platform allows customers to search for support workers in their areas, check their interests and general profile and their hours of availability, then contact and engage their services directly. It employs thousands of casual support workers for more than 10,000 people and their families every year. The SEEK backing will allow it to scale up to a much greater level.

Says Laura: “All the things we do at both Fighting Chance and Hireup are innovative, but Hireup is a real game-changer. To people not in the sector, it is perhaps not very innovative to say that people can choose their own support workers, but to people who understand the way the disability sector has worked for decades and continues to work, it is a profound shift.

“Hireup is one of the very few organisations that is genuinely moving power into people’s hands, and the technology means it is something we can do at scale. It is saying, ‘This is what services can look like if we think a bit differently, and trust people with disability to make the best decisions for their own lives’. It is a real opportunity to genuinely effect transformational change in terms of where power sits and how support is delivered.”

Ten years ago, interest from mainstream investors would have seemed “unthinkable”, she says. “The disability sector was largely a not-for-profit, NGO space, where the government would write cheques in return for a fairly underwhelming approach to service delivery.”

Setting up Hireup as a for-profit, for-purpose company was intentional. “I don’t think that Shane, or anyone with disability, necessarily needs ‘charity’,” Laura says. “Shane needed high-quality, meaningful opportunities and services to help him live the life of his choosing. He was a consumer who deserved quality.”

HELEN TRINCA, THE DEAL EDITOR AND ASSOCIATE EDITOR
Helen Trinca is a highly experienced reporter, commentator and editor with a special interest in workplace and broad cultural issues. She has held senior positions at The Australian, including deputy editor, ma... Read more