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In her work with the University of Melbourne's School of Population and Global Health, Professor Anne Kavanagh has long been committed to unravelling why society makes some people healthy and others sick. Studying this uncomfortable reality was one thing. Living it was another matter altogether.

Anne doesn't need to go searching for markers of a time she's glad to have left behind. The "Do not disturb" sign on her desk that's been half buried by more pressing paraphernalia. The variation that hangs from the handle inside her office door and reads "Resting". The giveaway - a mat wedged upright against the wall between cupboards and shelving.

"I used to sleep on it for one to two hours, just to get through the day," Anne says of returning to work after she was diagnosed with multiple sclerosis.

She'd been unwell for months - debilitating vertigo, vomiting, the strength draining from her seemingly by the day to the point that she needed a walker to stay mobile. The diagnosis brought some clarity, but no relief. "The other major symptom was extraordinary fatigue, I'd never experienced that before. I'd had a Caesarean section with our first child, I remember being tired then but it just didn't compare. I was absolutely exhausted - and even that's not the right word. All I could do was lie down."

It was 2011 and Anne was in her late 40s. With partner Evelyn she had two sons - Declan, then aged eight and with autism and an intellectual disability, and Alistair, who was in prep. She'd been with the university for seven years, a respected academic with a team of staff under her.

And suddenly she was disabled.

"It was frightening, particularly as I was the main money earner. It was scary. Sometimes you wondered whether it was too much, whether we would stay together as a family - not that we wanted to split up, but whether the family was going to be able to meet all that we needed."

Then there was the question of what it would mean to her career. "It was a big challenge to my identity," Anne says.

Yet she heard opportunity knocking. Her compass has always been driven by social justice, which shifted her career path from that of a doctor working in hospitals to an epidemiologist studying how factors like gender, race, geography, employment and socio-economic status affect our physical and mental wellbeing. Her changed circumstances prompted a narrowing of her research, into how much more dramatically society influences the health of people living with disability.

It wasn't lost on her how fortunate she was to have an established career, a permanent position, an office where she could lay down a mat, close the blinds and recharge. "They're all things that I reflect upon as enabling me to be in the workforce," Anne says. "I wonder if a new graduate coming into academia who had the same experience would have been able to get back into the workforce, whether people would have been accommodating around having a sleep in the middle of the day for instance.

"I could say, 'I can't do this or that', and people would say, 'Ok, what do you need to cut back on? What can we do to support you?'"

She recalls countless times as a doctor when people presented at emergency with complaints that were a simple joining of the dots to their circumstances of poverty, homelessness, unemployment and other societal problems. Addressing it became her passion, dovetailing with a desire to change community attitudes around people living with disability.

"We have some idea around racism, there's a lot of surveys looking at racism and racist attitudes, sexism too. But we don't really know that about disability. We have to know what we're actually dealing with - what are the misconceptions? What are the myths?" Media peddling a narrative of systematic roting of disability assistance infuriates her. "Underlying that is a kind of ableism."

After moving into disability research Anne identified people around Australia who were doing good things in the space, started collaborating with them, formulated a vision of something bigger and better. She was conscious that traditional funding organisations like the National Health and Medical Research Council (NH&MRC) had rarely funded disability research, and only ever on a small scale. She pressed on, leading a team that worked for months on an application for an NH&MRC Centre of Research Excellence in Disability and Health. Only four are funded in Australia each year, a success rate of just 12 per cent.

"To be honest I thought we had no hope, there was no way we'd be able to sell this to the NH&MRC, that the health of people with disabilities is something they should care about. Mostly public health has been about preventing disability, not about thinking of people with disabilities as having health in and of themselves."

Last September came news she regards as a career high - a green light for the Centre of Research Excellence, operating out of the Melbourne School of Population and Global Health. Where the NDIS is service-focused, the CRE (which will be officially launched in June) will zero in on traditional issues such as appropriate housing and employment. Anne has assembled a team with broad skillsets - health economics, expertise in built environments, etc - and targeted experts who will feel a sense of ownership and commit for the long haul.

"We made a strategic decision early on to bring in a mix of senior and mid-career people," Anne says, an approach that shifted from the norm of targeting only senior people, often in the

twilight of their careers, as investigators. “We wanted to recruit more academics into the field who would be there for the long term. I think that was a wise decision, I’d like to congratulate myself on that.”

She’s needed her sense of humour. Declan’s challenges changed her understanding of disability, from the initial difficulty in simply getting a diagnosis – a bedrock needed before even attempting to access resources. A parent’s intuitive concerns were ever-present. How well can we support him? How will the future be for him when we’re not around? What will his journey mean for my own health? How will others respond to him?

Reaching school age laid bare how much still needs to change, from a kindergarten that didn’t utilise funding to help Declan as it could have, to a school that prioritised bureaucracy over his simple need to at times be taken out of class to give his mind a break. A local school specific to supporting children with disability refused to take Declan because he was “too autistic”. When Anne requested a December meeting to protest, the school responded that a building program was underway and they couldn’t be seen until February. Now, he spends three hours a day riding a bus to and from an autism-specific school, an impost that’s not ideal for anyone.

The experience carried a formative upside. While wading through the maze, someone put it to Anne that she should join the school council. She figured she had little to offer in pure fundraising acumen, but saw openings in strategy, negotiation, policy and procedure that she could hopefully fill. “I don’t know how much difference I made, but it was really exciting. We saw big changes over time.

“The most important thing for me, it was an eye-opener to look at what was happening at a school level and with families within the school, and to understand and think carefully about curriculum, and assumptions that are made about kids with disabilities.”

The intersection of her home and work lives is a constant source of learning. The fear that naturally accompanied Declan’s diagnosis gave way to a loosening of the expectations we place on our children, a freeing experience she’s sure has benefitted second son Alistair too. “To have less of those expectations of what it means to be a good person, ‘normal’ in quotation marks, I like that. I like how Deccy does that all the time – he challenges that in me and everyone around the place.”

Through diligence of diet, exercise and relaxation, Anne’s own health is good. The new bike that sat idle for almost a year after her MS diagnosis now carries her the best part of 10 kilometres each way to and from work. She swims regularly too, but reminders that she has a chronic condition are frequent – not the can’t-get-out-of-bed fatigue of 2011, but still weakness in the legs, loss of balance and exhaustion. She monitors her health carefully in the face of an intense home life and a responsible job, pulls back when needed and works from home two days a week.

She smiles a lot, and is clearly energised by her job. The whiteboard in her office is alive with ideas that, through the agency of the Centre of Research Excellence and the passion of the staff she's assembling, will surely bring about change. "I love my staff," Anne says. "It's fantastic - to know you're contributing to developing a new workforce, the next generation, it's special."

On the whole Declan is doing well. Behavioural issues raise the bar on the challenges they face, but Anne is confident that with support he'll be able to stay home longer, develop more independent skills, and ultimately find a housing model suited to his needs. Employment, too. She can envisage a time when a fully implemented NDIS could be life-changing, but knows we're not there yet. "There's a long way to go in terms of having the funding for innovative developmental services for children like Declan who have 'challenging behaviours' associated with conditions like autism, and also having a significant intellectual disability. Under current funding models these services aren't viable."

Declan loves watching coffee being made, and making it himself. He's become a fixture at Preston Market, where café owners let him put cups and spoons on saucers and ferry coffee to customers. "They're just so supportive of him - if a customer gets upset they're like, 'Stuff them, we don't want them as a customer.' Just through those ordinary interactions, those people have come into his life."

When their son was younger, Anne Kavanagh remembers she and Evelyn getting scolded by parents at birthday parties when Declan would take food that was about to be thrown away, or had been left by another child. She found herself feeling anger towards them - or worse, chastising Declan. The experience was awful, and comes back to her when she ponders whether the world is becoming a better place for people with disability.

"Now I would heartily encourage any child to steal food off the birthday party table."

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