

Parents of quadriplegic man say NDIS delay extended hospital stay by six months at '\$1,500 per day'

ABC Tropical North By Sophie Meixner and Tara Cassidy

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The parents of a quadriplegic man say they were left "distraught", "broken", and "completely traumatised" by the process of obtaining funding through the NDIS, which they say unnecessarily extended their son's stay in hospital by at least six months.

Ethan Hassett sustained a burst fracture C4/5 spinal injury in a quad bike accident in December 2016 at the age of 17 and was left a quadriplegic.

The injury, sustained outside Mackay, required emergency transfer to Brisbane, where Ethan stayed for 17 months in hospital and six months in an accessible transition house before moving back to Mackay almost two years later.

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PHOTO: Before his accident, Ethan loved riding dirt bikes, walking his dogs on the beach, and going fishing. (Supplied: Hassett family)

His doctors advised there was no medical reason for Ethan to stay in hospital longer than seven months, but delays with obtaining NDIS funding meant there was nowhere else for Ethan to live.

A spokesperson from the Princess Alexandra Hospital said, while each patient in the spinal injuries unit received individualised care, bed costs to the taxpayer were "commonly at or upwards of \$1,500 per day".

Ethan's parents Sharon and John said NDIS staff made them feel "like [they] were wanting everything for nothing" and nobody from the funding scheme ever met Ethan in person.

"After we learnt Ethan was a quadriplegic, that was difficult, but nothing prepared us for the next two years, and what the NDIS were going to throw at us," Ms Hassett said.

Homeless in a hospital bed

The family said they were told by builders and occupational therapists that the best option would be to build Ethan an

accessible granny flat attached to the family home in Mackay.

Based on the recommendations, the family lodged their application for complex home modifications through the NDIS in August 2017.

"We had a small room out the back where our oldest children always went, and Ethan was moving out there at Christmas before the accident, so we suggested [a granny flat] would probably be best once we realised how much equipment and care he would need," Ms Hassett said.

Despite three occupational therapists determining the minimum size of the room, in November 2017 the NDIS rejected the application, deeming the dimensions were "in excess of the participant's disability-related need" and instead approved a much smaller space.



PHOTO: Ethan Hassett with dad John and mum Sharon in his newly built granny flat in Mackay. (ABC Tropical North: Sophie Meixner)

\$1,500 taxpayer dollars per day

Ms Hassett said the room dimensions stipulated by the NDIS would have affected Ethan's quality of life.

"If we went ahead, Ethan would be living in what he refers to as a 'dog box'," she said.

"There was no room for storage of his clothes or equipment, there was no room for a television ... he couldn't have a companion bed.

"We just didn't feel that he should go backwards, just because he had an injury."

Ms Hassett said, to make matters worse, nobody from the NDIS ever met with Ethan in person, and he remained in a hospital bed for a further six months while the dispute continued.

"They didn't even come and visit him, not once," she said.

"To this day they have never seen Ethan — they only know from a bit of paper what Ethan has wrong with him."



PHOTO: The granny flat includes a ceiling-mounted bed hoist as well as space for Ethan's wheelchairs and equipment. (ABC Tropical North: Sophie Meixner)

'Zapped the happiness out of him'

The Hassetts said the drawn-out process with the NDIS was "horrible for all of us".

"We never anticipated the process would go on for just under two years. By that stage, we were just completely traumatised," Ms Hassett said.

"I was crying in a park asking for help, for someone to get him out ... but they just didn't seem to care.

"We all know what it's like to live in hospital for a week, you can't imagine becoming a quadriplegic and then having to live there for 17 months, which is what Ethan did at 17 years of age.

"He had his 18th birthday there, two Christmases, it's just crazy."

According to Ms Hassett, Ethan became a "shell" of himself, losing his lust for life, and lost all sense of hope.

"It just took too long. [The process] just zapped all the happiness out of him," she said.

"We should have been focusing on Ethan and integrating him back into society, not having him stuck homeless in a hospital bed and fighting over what they think is necessary."



PHOTO: Sharon and John Hassett had to both find full-time jobs in Brisbane so they could be with Ethan. (ABC Tropical North: Sophie Meixner)

Separate funding approved in two weeks

The family appealed against the NDIS decision in the Administrative Appeals Tribunal but before the case was finalised, one of Ethan's doctors suggested applying for funding under another scheme — the National Injury Insurance Scheme Queensland (NIISQ).

The granny flat funding was approved by the NIISQ in less than two weeks.

"Under the NIISQ, Ethan has a caseworker, he's met with her, she knows Ethan, she knows his needs," Ms Hassett said.

"She even comes up with things ahead of what we even know because, as parents we are still learning, we don't know about spinal cord injuries, we were still trying to learn about that as well as navigate the NDIS, but it all became about the NDIS and not about Ethan's injury."



PHOTO: Since his injury Ethan Hassett has started breeding snakes, which he says improves his finger dexterity. (ABC Tropical North: Sophie Meixner)

Finally back home

Ethan's granny flat was eventually completed in November 2018 and Ethan moved home to Mackay after 23 months in Brisbane.

"It was like a big breath of fresh air, I still remember when they got off the plane at the airport I just started crying to myself," Mr Hassett said.

"It was just so good to have the family back together again after such a long drawn out ordeal."

A spokesperson for the NDIA, the agency that administers NDIS funds, said the "NDIA regrets any distress the planning process caused the Hassett family" and had allocated about \$150,000 to fund assistive technology and home modifications, including ramp and bathroom modifications.

"The NDIA funds standard home modifications, which are reasonable and necessary, are value for money, likely to be beneficial for the participant, and allow them to effectively access a room or area," the spokesperson said.

"The NDIA does not employ tradespeople and will generally not fund home modifications which are above-standard, or capital building additions, for example, the addition or extension of rooms."



PHOTO: Ethan Hassett's modified bathroom at his Mackay home. (ABC Tropical North: Sophie Meixner)

Delays in hospital discharge

A Queensland audit office report on the NDIS for 2017–18 outlined 13 case studies of patients in three public hospitals who experienced delays in hospital discharge.

"The total cost of the additional days for the 13 case studies ... was \$3.7 million," the report stated.

"If they had been in the community or their own homes, supported by an NDIS package, the cost to the state would have been \$65 per day or \$145,000 in total.

"In addition, delays in discharge create hospital blockages and delays for other patients who could have used the beds."

In a statement, the NDIA said there were many contributing factors associated with the hospital discharge delays "experienced prior to the introduction of the NDIS, particularly where accessible housing is required".

'Same old, same old'

Director of Queensland Advocacy Incorporated Michelle O'Flynn said there were "systemic" issues with the NDIS in Queensland and around Australia, and Ethan's experience was not isolated.

"We've had a system that wasn't terrific in the first place and we've replaced it with a system that is probably fraught with more problems and more bureaucracy than before," she said.

"We were promised a system that was going to work and redress a broken state system and instead we have something that for quite a lot of people is still broken and not working for them."

According to Ms O'Flynn, the current system focused on deficits and "on what patients can't do, rather than what a person could do with the right support and services".

"The NDIS was supposed to move us away from a welfare system to a rights-based approach for people with a disability, to elevate their status as full citizens in this country," she said.

"Instead we have another mechanism that is proving more and more to be the same old, same old."

"People feel like their lives are being devalued and people with complex support needs are being disallowed from what they need to have under the system."

In a statement, the NDIA said it "never intended to replace other mainstream government services" and "delivering ground-breaking reform of this size and scale ... will inevitably involve challenges."

But it said it "ultimately is a significantly better way of providing support for Australians with a disability, their families and carers".



PHOTO: After 23 months in Brisbane, Ethan is happy to be home with his siblings, friends, and parents in Mackay. (ABC Tropical North: Sophie Meixner)

'It should be shut down'

Ethan Hassett said the experience left him with no faith in the NDIS.

"I think they should be shut down," he said.

"I haven't heard anything good, they need to restart the whole scheme and make a new one, get all new different workers.

"I only think they can fix it by shutting it down.

"NDIS doesn't work at all."

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