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Why the NDIS should matter to all **Toowoomba locals**

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Michelle Jensen with her son Hugh. Hugh is one of only 600 people in the world with a disorder that causes swallowing, hearing and development delays. Hugh and his family are on the National Disability Insurance Scheme. Nev Madsen



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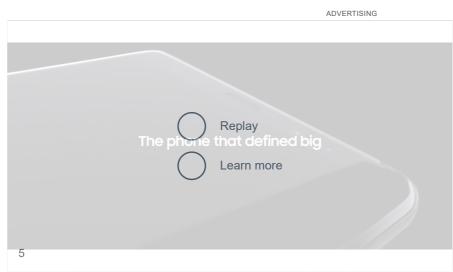
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THE future might look pretty grim for little Hugh Jensen if he did not have access to funding under the Manurase Disability Insurance Scheme.



One of about 9400 residents with disabilities, the two-year-old has an extremely rare chromosome disorder that makes his muscles floppy and tied his tongue.

The tied tongue meant he could not swallow, impacting his ability to thrive and develop.

Surgeons were able to fix his tongue and now Hugh undergoes a range of therapies to improve his speech and eating abilities.

"Hugh had no control over his tongue - it was stuck to the bottom of his mouth," his mother Michelle Jensen said.

"That's why he had a swallowing issue. He was trying to do his best but he was only getting enough food to make his organs function," Ms Jensen said.

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Hugh requires ongoing therapeutic and other supports and it's up to Ms Jensen to apply for the funding that pays for these needs.

That's where the NDIS comes in.

Toowoomba residents began signing up to the \$22 billion scheme in July last year and the rollout across our region is expected to finish this year.

When it is fully operational, the NDIS will provide funding packages for 460,000 Australians with impairments.

But experts fear thousands of rural and remote residents with disabilities will miss out on the NDIS.

There are concerns many people will not sign up because they do not consider themselves disabled, they have not heard of the NDIS or they do not know how to access the scheme.

The NDIS is available to any Australian under the age of 65 who has a physical, intellectual, psychiatric or other disability.

This includes people who become incapacitated through workplace accident, car crash or other means after the Australia-wide rollout ends in mid-2019.

Ms Jensen has worked her way through the complex application process to ensure the NDIS meets all of her little boy's needs.

The process requires each applicant to document every form of support they currently receive, the equipment they use and even the things family members do for the person with a disability.

"We are so blessed in this country that we have support for people with disabilities," Ms Jensen, a teacher, said.

"I was very well-equipped to complete the NDIS plan - I was able to define Hugh's needs up to the age of 21.

"I think people who don't have the same skill sets as myself, they will not always be able to clearly communicate the exact needs of their child to the NDIS and therefore they will not get all of the funding that is available."

CHOICES AND CHALLENGES

Choice, Passion, Life Disability Support Services provides a range of therapeutic and other support options for Hugh and other residents.

It is also a registered NDIS provider, supporting thousands of clients across regional Queensland and Northern NSW.

CPL chief executive officer Rhys Kennedy said: "One of the big changes is that for the first time ever, people with disabilities are being given the opportunity to choose where they'll get their services from.

"That means they can become more informed consumers and they can choose services that will help them achieve their goals," Mr Kennedy said.

While there are positives under the new system, the rollout is not without major hiccups.

"One of the biggest challenges is supporting people to navigate the system," Mr Kennedy said.



Disability advocates report some consumers are struggling to complete the NDIS application process while others have ended up with packages that provide less support than the old system.

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Disability advocates report some consumers are struggling to complete the application process while others have ended up with packages that provide less support than the old system.

Remote, indigenous and multicultural Australians are the main group of people who could miss out on the scheme's support, UNSW Social Policy Research Centre Professor Karen Fisher said.

"Research shows people from indigenous or other cultural and languagediverse backgrounds are less likely to use a disability label or use disability services," Prof Fisher said.

She said the NDIS's reliance on would-be clients being able to make indepth plans could backfire for people with complex needs.

"People who need support paid for by the NDIS, first need support to work out how to use and navigate the scheme," she said.

"People with multiple and complex support needs are an example of this exclusion.

"They may have a variety of needs from a life that could include mental illness, drug and alcohol use, poverty, poor education, criminal justice contact and cultural and language barriers.

"Or they may have particular circumstances, such as living in a remote community, that do not reconcile with the market-based structure of the NDIS."

There are also fears disability advocate numbers will be slashed as federal and state governments transition to the new funding model.

Queensland Advocacy Incorporated director Michelle O'Flynn said the flaws in the system could be overcome if the Federal Government slowed the rollout.

"There are massive issues and the NDIS lacks a concerted personalised approach," Ms O'Flynn said.

"People are being squashed through a scheme that is not ready to take them and we have got planners who are not necessarily understanding of people with more complex needs."

Ms O'Flynn said one of the main bugbears for many consumers was continually showing authorities they had a disability.

"They've done this over and over again and they don't feel that they should have to prove this for the rest of their life," she said.

"The point of the NDIS was to provide an individual approach but instead it has been homogenous and does not recognise each person's unique needs.

"People who are living in boarding houses and hostels, exiting prisons or indefinitely detained in forensic and mental health facilities have not even been considered to date except by advocates."

Despite the issues, official complaints about the scheme are low with just 429 people contacting the Commonwealth Ombudsman last financial year.

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When it is fully operational, the NDIS will provide funding packages for 460,000 Australians with intellectual, cognitive, neurological, sensory, physical and/or psychological impairments.

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However, this was a 700% increase from the 62 complaints lodged in 2015-16.

An NDIS spokesperson said: "The National Disability Insurance Agency will continue working with people with disability, their families and carers to resolve any issues during this unique period of transition and remains committed to getting the balance right between participant intake, plan quality and the sustainability of the scheme." - **NewsRegional**

DON'T MISS OUT

You may be eligible for the National Disability Insurance Scheme if:

You are under 65.

You are an Australia citizen, a permanent resident, or New Zealand citizen who is a Protected Special Category Visa holder.

You have a permanent or significant disability that requires help from others to do things or you need special equipment or assistive technology.

Your child is aged under 6 and has a developmental delay.

• You or your child have a disability that is likely to be permanent or early supports would reduce how much help you or your child need to do things in the future.

Source: Australian Government



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