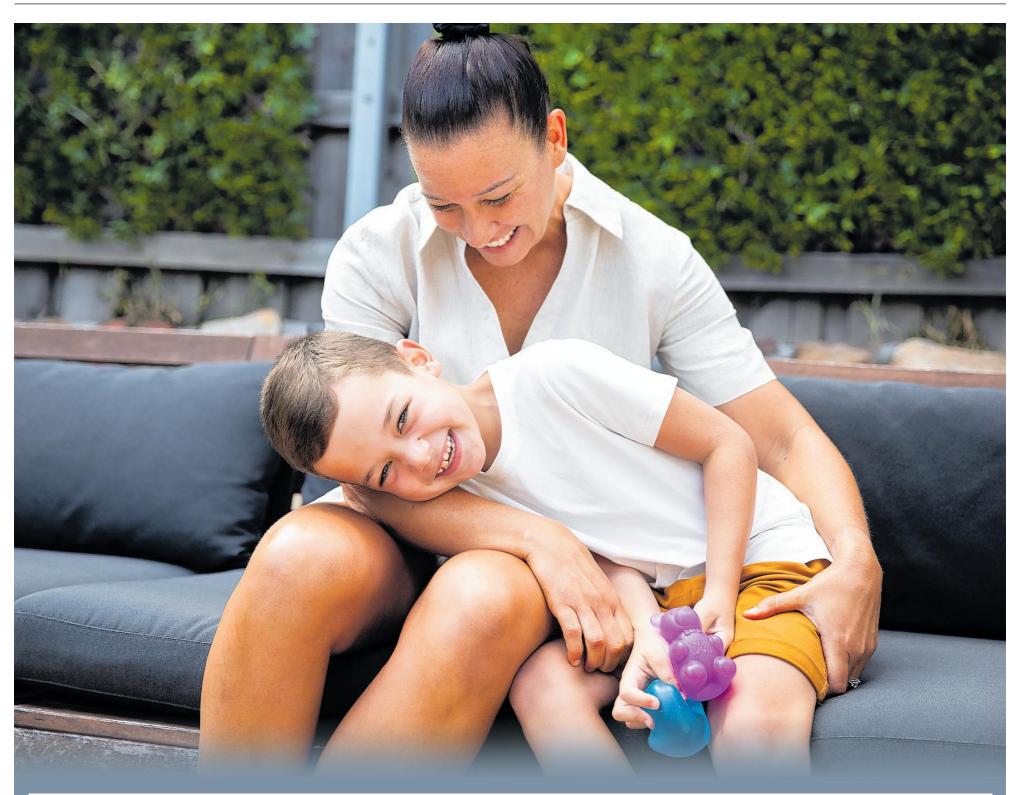
SUNDAY, APRIL 7, 2024 **NEWS 23**



HOPE FOR A BETTER FUTURE

Australia is looking at a landmark national approach to autism, which families and advocates say could create life changing - and life saving - benefits... if it is done right

RHIANNA MITCHELL AND ELEANOR CAMPBELL

ed Oakley can recite every Mickey Mouse episode from start to finish, loves swimming and waterslides and is the bravest, most joyous and resilient person his mum Leanne has ever known.

Mrs Oakley firmly believes the world would be a kinder and happier place if everyone had the chance to spend time in the orbit of people like Jed, 7, who is autistic.

Her "beautiful little boy", pictured above with his mum, was diagnosed with autism just before he turned two, about 12 months after Mrs Oakley first noticed that he was not playing or engaging with others, was uncomfortable in social settings and was not performing gestures like clapping or waving.

The diagnosis opened a door to an often overwhelming and challenging journey involving "amazing" therapists, a special school for students on

the autism spectrum, NDIS funding and a sports group for kids with disabilities. But it has also been rewarding, as Ms Oakley, her husband William and their

younger daughter Bonnie watched their son progress.

"He's now out and about, he is able to go to different places and see different people, the beach, the park, playgrounds... he is limited verbally and I didn't know if I would ever heard a word out of his mouth but he has

the ability to request in one word the things he wants and needs," she told the Sunday Times.

That progress has been made possible thanks to the couple's unwavering advocacy for their son, and the "endless support" of their extended family.

"They have been the people to get us through hard times and continue to support us every single minute of every day," she said.

This week, at the beginning of World Autism Month - a time for raising awareness and promoting acceptance and inclusion - the federal government unveiled a draft of its new national autism strategy as part of a bid to better support autistic Australians at every stage of their lives.

It's the first time Australia has looked at a national approach to autism, and disability advocates believe it could benefit millions – if it's done right.

The draft strategy, released by Social Services Minister Amanda Rishworth, left, on Tuesday, is the result of months of consultation with more than 2000 autistic people, families, carers and

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researchers. It follows South Australia, which released its own autism strategy in 2022 and appointed Emily Bourke to the role of assistant minister for autism, the first portfolio of its kind.

Unveiling the federal draft plan Ms Rishworth said a federal strategy would be a "whole-of-life plan for all autistic Australians".

She said it could pave the way for sweeping reforms across the nation's health, education, social services and employment sectors.

Key goals included boosting social and economic inclusion and strengthening supports and services, including for diagnosis.

Under the government's vision, autistic people in Australia would have the same access to support services and opportunities as other people in the community.

To do so would need changes to how autism is identified, including the development of standardised professional development and resource tools to support health practitioners when diagnosing the condition, the draft said.

Other kev measures include more public awareness campaigns about autistic Australians in the workplace and an overhaul of workplace recruitment processes.

It also calls for greater representation of autistic people in political leadership, media, and a greater seat at the table in policy decisions. Autism Awareness Australia (AAA) chief executive Nicole Rogerson said a national plan could be a

"once-in-a-generation" opportunity. "I think the fact that there is a strategy in and of itself is an important thing. We need all government departments to focus on tackling and solving key issues and it's only through a co-ordinated strategy that can happen," Ms Rogerson said.

"But in saying that there are there are certain issues with it. I's a very, very, long laundry list of things that we've known for a very long time were problematic – so it's short on answers and long on problems.

"My great fear is it's no one's coming to save us and this disability strategy does not make me feel confident in any way shape or form that they've got this."

Autism can be considered as a spectrum of neurodevelopmental conditions

It's diagnosed in people who show differences in social communication, repetitive behaviours, intense or focused interests and/or sensory differences.

More than 205,000 Australians have autism, according to the latest estimates from the Australian Bureau of Statistics, but the draft fact far higher.

Autism rates have risen significantly in Australia over the past few decades, largely due to increased awareness and shifts in diagnostic criteria that qualify more people for a diagnosis.

According to an ANU study published in November, Australia has some of the highest rates of autism prevalence in children in the world.

Ms Rogerson said improving educational outcomes and



support for autistic students was a key issue that needed to be tackled. She pointed to "diabolical" new

survey findings released this week by the AAA that found more than a third of Australian parents had their autistic child either discouraged or refused enrolment by schools

About 50 per cent of families reported experiencing this within Australia's public school system.

"When we look at the impact of that on a child's mental health, it's enormous. Not to mention the message it sends to the broader school community, which is, hey, we don't do different, we don't do hard, when in fact there are lots of different types of kids with learning difficulties at school," Ms Rogerson, pictured left, said.

"The problem in schools and not only just managing our kids, accepting our kids, the effect that then has on the community more broadly and those families and those kids' mental health, if we're not getting to that issue, then this has honestly been a waste of time."

Life expectancy rates of autistic people in Australia are 20 years less than the general population and they are nine times more likely to die by suicide, according to the federal health department

Autistic people are almost eight times more likely to be unemployed and they are at a higher risk of homelessness and violence

About 95 per cent of autistic Australians also have other disabilities or neurodivergent diagnoses.

Whitehouse, who leads the autism research at the Telethon Kids Institute, the national draft strategy falls short on a number of key issues that are facing autistic

people every day.

"I interact daily with kids and families who are struggling and very often in crisis. The majority of these issues are not currently taken account of within the draft strategy," he

said.

"The areas such as

I interact daily with kids and families who are struggling and very often in crisis

evidence-based practice, housing, justice and aged care, these are the things that are truly at crisis point and it would be wonderful for a strategy to incorporate these urgent and pressing issues."

According to a recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, people with disability have been "conspicuously absent" from national housing and homelessness policy plans. The findings of the report,

released in November, called for an urgent supply of accessible housing, more tenancy protections for people with a disability and better regulatory oversight of supported accommodation.

Professor Whitehouse said that while a lack of housing was primarily a state-based issue, the federal government had a major role to play to support the development of broader options and supply in that area. "The first thing families ask me

as a clinician and a researcher is what's going to happen to my child after I die? The current draft doesn't provide many answers or at least a path to help us support families through answering that question," he said. "It really needs to be matched to

meet the needs and it might be, for families and understanding how people get to choose where they stay and who they stay with, or it might be supported accommodation where a person is living by themselves or even within a family home."

Professor Whitehouse warned that Australia's prison system was ill-prepared to provide a safe environment for autistic people, and that would become an "urgent challenge" as more children and kids receive autism diagnoses. According to the government's

draft autism plan, Australia will commit to improving understanding of attitudes toward autistic people across all of society, including in criminal justice.

While there are no clear statistics as to how many autistic people are incarcerated in Australia, research shows that people with autism are overrepresented and at more serious risk of sexual and physical violence than the general prison population. "What we need to do is to think

about ways in which we can firstly keep autistic people safe, free of physical and sexual abuse, but then also how can we create diversionary programs when autistic people might be at risk of perpetrating themselves," Professor Whitehouse said.

"It's an urgent challenge that we need a strategy to address."

For Mrs Oakley, she hopes a national strategy would allow each person and family to be seen and treated as individuals.

"All children with autism are so different. I am so grateful for what the NDIS has done for us, without it we would be absolutely struggling, but in saying that, the process of receiving the support, I had to advocate for, and continue to advocate for every day. I never thought I would have to be so strong in my actions and thoughts as I have been," she said.

"My biggest wish is that there is some way of looking at individual

"Whether Jed will ever get to an independent life I highly doubt it, but we will do everything we can do for him to get there and we need the help and support."

She also hopes for more awareness and understanding around autism across the wider community

"Jed might not have the words to speak, but if you're lucky enough to spend time with him, and watch and listen in other ways, he has taught me more than anyone in my whole life," she said.

"The way he looks at the world, he's so happy, pure and innocent. I wish that every family had the chance to learn more about ASD."

MEET AUTISM AWARENESS AUSTRALIA'S AMBASSADORS







MIRJANA

'I'm an example of someone who has achieved a lot despite my diagnosis and I believe that everyone should be given a chance to reach their full potential. While most people with autism have another co-occurring condition as well, I think that our society needs to stop stereotyping ASD with just boys and dismissing the girls on the spectrum who show such obvious signs. Being overlooked makes it a lot harder for girls with ASD and I think we could even save more lives by diagnosing girls sooner. I feel like society still doesn't realise just how common #autism is in girls as well. Fun facts about Mirijana:

1. A few years ago I took off on my first solo trip and have released the book (My Balkan Heart on Amazon) to inspire more people on the spectrum to travel and live life to the fullest likewise

2. I have been on a few beautiful dates with Michael (the most popular one from the show Love on the Spectrum) and there could be a potential for more dates together in the future.

'Jed is beautiful, fun loving, and adventurous. He is brave, resilient and stronger than anyone I have ever known. I wish that every family had the chance to learn more about #ASD, as it would definitely make the world a happier and kinder place to live in.' (Jed's mum Leanne)

Some fun facts about Jed ...

1. Jed can recite every Mickey Mouse episode from start to finish, despite being very limited verbally.

2. Jed LOVES swimming, the beach and sliding down waterslides!

TOMMY

'I'm an Ambassador For Autism because so many of the influential, inspiring and supportive people in my life are #autistic. My life has been shaped by it and I'm forever grateful. That they are just as capable of love, friendship, wisdom and ability as anybody

Fun facts about Tommy ...

1. I'm obsessed with horror movies, the more ridiculous the better!

2. I also paint miniatures.

'I am an Ambassador For Autism because I live with Autism everyday. Autism is a lot like speaking another language - you just need to take the time to learn how I communicate.' Fun facts about Raffie ...

1. I love books and Roblox.

2. I'm an expert at Google Maps and can memorise directions to any location after just one visit.

HUGO

'I like being on autism websites and posters showing everyone how great I am and not to be afraid of me. There's nothing to be worried about if your kid has it [autism] or you have it. It's just apart of you and that's

Fun facts about Hugo ...

1. I like Minecraft, dinosaurs and animals. I can name thousands of dinosaurs and

2. When I grow up I want to be two things....a marine scientist and zookeeper.

From top: Mirjana, Jed, Tommy, Raffie and Hugo. Pictures: @autismawareaus