

AUGUST 2021 EDITION

STAR VICTORIA



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Census figures indicate in Australia, almost one in five people, that is around 4.3 million, have a disability. Over 700,000 Australians live with an intellectual disability.

Within research and advocacy groups in Victoria there is a growing concern for parents who have an intellectual disability and their interaction with Child Protection Services. Parents are often considered unable to parent before any assessment or training is carried out. The situation is so bad that current practices have been referred to as creating 'a new stolen generation.'

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In 2015, Victoria's Public Advocate, Colleen Pearce, called for reform to the State's child protection system for parents with disabilities. Ms Pearce was speaking at the launch of a major research report calling for system change to ensure the human rights of both parents with disabilities and their children to live in loving biological families.

"The state's child protection system is removing children from parents with disabilities, especially cognitive disabilities or mental illnesses, at a much higher rate than parents without disabilities, as disability is assumed to be a risk to children," Ms Pearce said.

"It is as if a box has been ticked on a form and so the parent comes under intense negative scrutiny, rather than receiving the support and encouragement they may need to successfully parent their children,"

"There is no credible evidence to support this assumption".

Ms Pearce said that she did not support any child being exposed to neglect or abuse, whether their parents had disabilities or not, but that it was a case of justice for parents with disabilities to have the support of 'the village' and the rights of children to live in loving, biological families, where possible.

Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities. Article 23, paragraph 4 says:

'Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures that such separation is necessary for the best interests of the child. In no case shall a child be separated from a parent on the basis of a disability of either the child or one or both of the parents.'

On 25 September 2019, the United Nations released its Report Card to Australia on its performance in its obligations under the Convention. Point 43 notes that:

"The Committee is concerned about:

(a) Parents with disabilities having their child more likely removed, often on the basis of disability and by the lack of support in their exercise of parental responsibilities for their children;"

STAR shares this concern. In our advocacy work, we are seeing parents with intellectual disability having their children removed, often with little or no warning. While there are often other concerns, the very fact that intellectual disability is used as a reason to remove a child because authorities think that the child is at risk is contrary to Victoria and Australia's legislation and international obligations.



DO YOU KNOW HOW TO PARENT?

There is an assumption that parents with intellectual disability are unable to parent safely, often before any assessment has been carried out or training provided. Parenting capacity assessments underpinned by the medical model of disability, claim that people with an intellectual disability cannot be taught or retain information. This is untrue, yet the weight of an expert opinion from a practitioner with this outdated view of people with intellectual disability can convince the Family Court that the child cannot be returned to its parent and needs a long-term care arrangement in place.

We know that people learn in different ways. A parenting course with lots of reading material offered to a person who has literacy difficulties may not be practical. Some people benefit from an individualised style of learning in preparing for the birth of a child, and may need regular support in facing the challenges of caring for a new baby, for example through an NDIS package or changes to an existing plan.

It would be reasonable to expect that parents are counselled and their skills and capacities genuinely assessed pre-birth to ensure all the necessary supports are in place to enable them to parent successfully. Unfortunately, it is all too common that the first indication of involvement by Child Protection is arrival of officers at the hospital who may then take the child into protective custody on the spot.

SEPARATION ANXIETY

Taking a child away from the birth parents and putting them into care triggers a series of events which can permanently separate the parent and child. Child Protection cases are tackled in a setting associated with neglect and abuse, yet there may have been no neglect or abuse by the parent with an intellectual disability.

The parent is forced into an adversarial process through the Family Court, which is primarily concerned with assessment of risk to the child, not the capacity of the parent. Court hearings are routinely delayed and deferred, often for many months, during which a child and parent remain separated. The longer this goes on, the chances are the separation becomes permanent as the Court may decide that it is in the interests of the child to stay with the carers because returning to the parents would be too traumatic.

One parent that STAR has supported has been waiting over a year for the court to make a ruling and has faced many court deferments of her case, due to reports from experts being delayed. At no stage has she been given court information in an accessible format or been told why her baby was removed while she was in the hospital. She has contact with her child only a few times a week. No training, support or help is extended to her through the court. She is expected to turn up when the court decides and cannot speak in the court to show her competency or her pain.

Victoria can do better than this. We need a state-wide program, based on successful domestic and overseas models, to support parents in individually identified areas of need to provide positive parenting practices and thus decrease the risk of unintended neglect or harm to the child. The implementation of the NDIS means this help can be personalised.

STAR is working with parents, advocacy groups and researchers to expose this problem and ensure the rights of parents with intellectual disability, and their children, are upheld and protected. We welcome the interest and engagement with the Department of Families, Fairness and Housing which is actively exploring this problem with us and our partners.

Partner Profile



Positive Powerful Parents

Positive Powerful Parents (PPP) is a self advocacy group run by and for parents with intellectual disability.

The group was formed when a parent discovered she was not the only parent with intellectual disability to be involved with the child protection system.

Most of the parents who are members of PPP do not have custody of their children.

PPP is also a group that try to get better outcomes for parents with intellectual disability that become involved in the child protection system.

PPP hope that one day every parent with intellectual disability get the parenting support they need in a way that suits them so they get the best chance of keeping their children at home with them.

PPP believe that every parent has their own unique way of parenting and the voice of parents with an intellectual disability needs to be heard and listened to.

PPP wants child protection services to see the ABILITY and not the disability.

Positive Powerful Parents have two Facebook pages. The page with the red logo is for anyone to join, and the page with the purple logo is for parents with disability only. That's because parents need to feel free to discuss issues and share information with each other.

All PPP's event information is shared through social media as well as email.

Positive Powerful Parents also have online catch ups with parents and hold Face To Face Friday Friendships for parents in Melbourne and Morwell.

The website www.positivepowerfulparents.com.au is a great place to go for information, contact PPP if you have questions, get on the mailing list and introduce us to parents you know.

PPP always welcomes new parent members.



Scan Me

Use the camera app on your phone to find the Positive Powerful Parents home page!

'When they first took my son away I asked what is wrong with my parenting. After 3 meetings of asking they finally said it was my intellectual disability. Well, it would have been good to know that earlier so I could work with my support person to know how to address that – get the right support to learn what I needed to know.'



COMMITTEE MEMBER PROFILE - JAMES HENRY



'Being a parent is a challenging thing, anyway, and I felt like I needed some advice and support', states James, one of the members of the STAR Committee. 'Someone gave me a little A4 folded up brochure for STAR, and I thought – I want to know everything. I didn't know much about the system, or anyone who could help, but I wanted to know everything'.

James became a member of STAR because of his son, Kingsley. Kingsley was born with autism and an intellectual disability, and James has been advocating for him his whole life. First, at Kingsley's specialist school, then at his secondary school, and now at TAFE. 'Now my son's 19, and a lot of things are different. But still, there's a lot of challenges with advocacy with him, and working with other services. But knowing other parents, other families, has been really good, and knowing more about how the system works.'

'You can never stop learning – if you're interested. There's always more.'

James is also passionate about the rights of AAC users (Augmentative and Alternate Communication), and hopes to one day see a support group for AAC users in Australia. 'I found a group in the UK, set up by a couple of parents and a speechie (speech pathologist), and they did weekend activities, camps, and had a lot of professional supports, and you would see a room of people and there were 10 or 15 communication aide users using high tech devices and some really good experienced role models and mentors'.

While James might still be learning, he's also a member of STAR's committee. The Committee meets once a month to discuss current issues that are facing people with intellectual disabilities, 'I would like to give something back a bit, because I've learnt quite a lot, just through my own journey with Kingsley, and also through STAR'.

Raising Children.net is an Australian Government initiative that provides free information and videos to parents. Information is divided by age group, with extra information on autism and disability. Each section contains information on health, feeding and development of your child.

Raising Children also provides 'parenting in pictures'- key information written in an easy to understand way with pictures.



Dietary guidelines in pictures: children 4-8 years

What do children 4-8 years need to eat each day? Our illustrated dietary guidelines make it easy to serve up the right amount from the five food groups.



Healthy lunch box ideas for children: in pictures

Need some healthy lunch box ideas for children? Go for 'rainbow food': different coloured foods from each of the five healthy food groups, plus tap water.



Child-friendly fruit and vegetables: in pictures

How can you get kids to eat fruit and vegetables? Try our Mr Veggie Face pizza or rainbow plate to make fruit and vegies fun for your child. Get more ideas.

CHANGES TO THE NDIS

In August 2020, the NDIA announced that participants would have independent assessments to determine their level of funding. This was to replace the current system, which involves a review of documentation collected from a participant's healthcare providers, such as psychologists, therapists, and primary care professionals.



This was a concern to many participants, as the assessments were to be a three-hour interview conducted by a health professional who did not know the participant. Though the NDIA stated that this wasn't intended to cut participant's funding, many felt concerned that their needs would no longer be met.

Though the NDIA had already conducted one trial of the independent assessments between 2018 and 2019, they listened to the community's concerns, and paused the roll out of these assessments. They then consulted with participants through the 'you said, we heard' report, and extended the second trial of the independent assessments.

The report found that many participants did not understand the changes, and that the NDIS had not explained them in a clear way. It also found that while participants saw the potential for improved, cost-effective access to health professionals in some regions, participants were anxious about the skills of independent assessors. Though the NDIS would provide training, participants were concerned about the assessor's ability to understand and advise on their needs in under four hours. Most people strongly preferred their treating health professional to complete their assessments.

Meanwhile, the second trial found that assessors struggled to conduct the interviews and input information at the same time, that meetings were too long and participants were unable to concentrate for the duration, and that technology issues interfered with interviews conducted remotely. There were mixed feelings about the results of the assessments – while some participants were happy with their report, some felt it didn't focus enough on their needs and life goals, were too general, and were hard to understand.

The results of the consultation and second trial were reviewed by NDIA and its Independent Advisory Council, and on the 12th of July 2021, the Minister for the NDIS, the Hon Linda Reynolds CSC, announced they would not be going ahead with independent assessments. This means that the current application and review process will remain unchanged.

The next focus for the NDIA is to address the alleged fraudulent and dishonest practices of some NDIS providers.



TIMELINE OF NDIS CHANGES

2018 to 2019 the NDIS runs trials of independent assessments.

Independent assessments are intended to replace the current application process.

They will be done by an assessor who does not know the participant

August 2020 The NDIS announces that all NDIS participants will complete independent assessments.

November 2020 The NDIS listens to participant feedback, and pauses the rollout to do more consulting.

Participants are given time to share concerns, and the NDIS continues more trials of independent assessments.

February 2021 The NDIS and its Independent Advisory Council review the findings and talk to state bodies.

July 2021 The NDIS announces that it will not proceed with independent assessments.

OUTCOME: NO CHANGES WILL BE MADE TO THE NDIS APPLICATION OR REVIEW PROCESS.



You can read more about the NDIS changes...

At planpartners.... <https://planpartners.com.au/knowledge/articles/independent-assessments-ndis>

Or on the NDIA website... <https://www.ndis.gov.au/about-us/history-ndis/independent-assessments-proposal>

Scan me with the camera app on your phone!



Plan partners



NDIA Website

WHAT STAR MEMBERSHIP MEANS TO ME: JAMES HENRY

'It's good to know you're not alone when you're struggling. I think that's an important thing – a lot of people are struggling, and it's hard when you feel like you're alone and you don't understand the system. So, I've always appreciated STAR. People like Denise, Cynthia, Esther, Karen... working so hard, trying to make things better, trying to help families and trying to change the system. Gotta admire that.'

Although James and his son have never needed to use STAR's individual advocacy support, he is aware of the importance of having a community and source of knowledge he can fall back on. STAR was one of the key organisations that provided James with information and knowledge on how to best support his son who lives with intellectual disability. This enabled James to become better informed about his son's right to an inclusive education, identify barriers to genuine inclusion, and gave him the confidence and determination to seek out the supports his son would need.

'Even when you're struggling with your own stuff, you don't always reach out very well... I know when I'm stressed and trying to make things better for my child, I get more isolated. I don't reach out and connect with others.'

'It's hard, and it's a team effort. STAR can help people with information that helps them in their lives. Some people who join do come out of the advocacy, or maybe they join and need advocacy later.'

James thinks there's a need for organisations like STAR to support people like him and his family.

No matter where you are on your journey, or your background and experience with disability, you're helping STAR just by joining. 'Diversity makes things better and stronger, we can't always have the same view, and it is good when we don't.'

James has certainly appreciated the view of others – both other parents of children with intellectual disabilities, as well as adults with intellectual disability, 'Diversity of views, diversity of experience are both important'.

STAR IS CURRENTLY OPEN FOR MEMBERSHIP APPLICATIONS. IF YOU WOULD LIKE TO BECOME A MEMBER, PLEASE CONTACT US ON [INFO@STARVICTORIA.ORG.AU](mailto:info@starvictoria.org.au) FOR INFORMATION ON HOW TO APPLY.

THIS IS ALSO A REMINDER FOR CURRENT STAR MEMBERS WHO HAVE NOT YET RENEWED THEIR SUBSCRIPTION TO DO SO AS SOON AS POSSIBLE, AND BEFORE THE 2021 AGM MEETING ON 24TH NOVEMBER. ANY QUESTIONS OR HELP WITH YOUR RENEWAL PLEASE CONTACT THE OFFICE ON 03 9650 2730 OR EMAIL US [INFO@STARVICTORIA.ORG.AU](mailto:info@starvictoria.org.au)

CONTACT US

We all need to look after ourselves and each other, so Ross House and the STAR office is closed and our staff and volunteers are working from home.

We are still working our usual hours, 9:30 am to 4:00 pm Tuesdays, Wednesdays and Thursdays and you can call us or email us if you need help or advice.



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STAR acknowledges the Traditional Custodians of the land on which we operate, the Wurundjeri people of the Eastern Kulin Nations, and pays its respects to elders past, present and emerging.

