

family

A D V O C A C Y

**Submission on the New National Disability Strategy
Position Paper - Stage 2 Consultations
October 2020**

“The continuing inequality we face will not be rectified by ramps, lifts and accessible communications, or by the outlawing of discriminatory behaviour, welcome as these may be. The wellspring of our oppression comprises deeply held social attitudes that reflect generations of prejudice, fear and discrimination towards disabled people in education, work and social life. The main reasons are negative attitudes and stereotypes, which are based on untrue ideas that have been around for thousands of years, and which are amazingly persistent.”

Richard Rieser, disabled academic, advocate and educator

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Acknowledgement: Family Advocacy would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land

Summary of recommendations

Recommendation 1

That Australia adopt a Statutory Bill of Rights to ensure that ensures human rights are protected and strengthen the potency of the National Disability Strategy.

Recommendation 2

Amend the vision to include the terms “by participating”, “citizens” i.e.:

An inclusive Australian society that enables people with disability to fulfil their potential by participating both as citizens and members of the community”.

Recommendation 3

Continue with the six outcome areas provided a clear roadmap be created in alignment with the United Nations Convention on the Rights of Persons with Disability (CRPD).

Recommendation 4

That Australia adopt the Australian Coalition for Inclusive Education’s, “Driving change: A Roadmap for achieving inclusive education in Australia”.

Recommendation 5

That a national disability employment roadmap be created that incorporates the recommendations from the Willing to Work report and contains targeted general measures for increasing workforce participation, including addressing structural workplace barriers.

Recommendation 6

That a national plan be developed to promote independent living and address the many housing issues faced by people with disability.

Recommendation 7

The NDS and any associated policies, frameworks or documentation have an Easy Read version in accessible formats and multiple languages.

Recommendation 8

That Principle 1 in the position paper, **Involve and engage**: reflect the intentions of the CRPD for genuine and “deeper engagement” of people with disability.

Recommendation 9

That Principle 2 in the position paper be adjusted to read as follows:

Design universally:

Universal design extends to the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

It is expected that the principles of accessible design will be applied as a general rule when developing policies or programs in alignment with the National Disability Strategy.

Recommendation 10

That Principle 4 in the position paper **Address barriers faced by priority populations** include people with developmental disability.

Recommendation 11

That Principle 5 in the position paper be amended to:

Support carers, supporters and advocates: making specific reference to independent individual and systemic advocacy as essential services for people with disability.

Recommendation 12

That a Principle 6 be added to read as follows:

Rights and Inclusion:

Have the rights of people with a disability been considered in the policy and program? How have the principles of inclusion, a human rights-based approach, and the critical objective of ending segregation been considered in the development of this policy or program?

Recommendation 13

That a commitment be made at federal, state/territory and local levels of government towards funding projects and initiatives focused on promoting inclusion and improved community attitudes towards disability (including evaluation).

Recommendation 14

That greater accountability is required with the need for:

- a robust, independent and transparent complaints policy and procedures
- improved mechanisms that monitor compliance
- establish cross-agency collaboration within and between federal and state/territory government
- establish a central administering body to facilitate both the government and non-government sectors.

Recommendation 15

That the federal and state/territory governments commit to both annual and longitudinal reports across the life of the strategy and that such reports be tabled within parliament.

Recommendation 16

That the government conduct an audit of existing action plans which align with the key outcomes of the new strategy, looking within and beyond government departments.

Recommendation 17

That education, employment, housing, and accessible communication be key focus areas for reform in the new strategy.

Recommendation 18

That independent advocacy be adequately funded by state/territory and federal government as a way to achieve the Engagement Plan.

Recommendation 19

That the National Disability Strategy place an onus on governments to ensure people with disability are included and receive targeted support in COVID-19 recovery measures.

About Family Advocacy

Family Advocacy is a state and federally funded **disability advocacy organisation** that works across **New South Wales (NSW)**. It was founded by families 29 years ago **to advance and protect the rights and interests of people with developmental disability**¹ (hereinafter “disability”) so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians.

This includes being included in things such as education, employment, and community and the right to live safely and with dignity, free from violence, abuse, neglect or exploitation. We recognise that the advocacy

¹ Developmental disability is a disability that occurs in the developmental period of a person’s life (in the period from conception to adulthood) and includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability.

undertaken by a family can be one of the greatest safeguards and influence of inclusion and safeguard in their family member's lives.

Family Advocacy works across New South Wales (NSW) and supports families in their advocacy to represent people with disability from a wide range of socioeconomic backgrounds, First Nations people, and culturally and linguistically diverse people, from metropolitan, rural and remote areas. Some of the areas we provide advocacy support include education, employment, housing, guardianship and NDIS.

We provide support in the following ways:

- Statewide Advocacy advice and advocacy information to individuals;
- Advocacy development for family members of a person with disability - Advocacy is often undertaken by families and these efforts can be required over the lifetime of their family member; and
- Systemic Advocacy - informing government regarding legislation, policy, funding, monitoring, and practice in areas that impact on the needs of people with disability.

Our work includes specific funding and activities around the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereinafter, the Disability Royal Commission). As such, part of our policy and advocacy work involves being discerning and constantly questioning the quality and effectiveness of the disability sector.

One of our initiatives, Resourcing Inclusive Communities, is an initiative of Family Advocacy and works across NSW. We hold the philosophy that people with disability thrive in the heart of the community, sharing the same everyday experiences as their fellow Australians. We share our vision of social inclusion with the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD).

One of the eight guiding principles of the CRPD outlines that all people with disability have the right to experience full and effective participation and inclusion in society. Resourcing Inclusive Communities works with many allies in the community to support this vision. We provide information through our online platforms, through events such as webinars, workshops and conferences, we design tailored training, mentoring and supports for external services, develop extensive resources and have a 1800 number that provides support across NSW. We support positive change through working closely with people with disability, their family members, service providers, mainstream services, businesses and the broader community.

Introduction

Family Advocacy welcomes the opportunity to provide a submission to the Department of Social Services (DSS) in response to the “National Disability Strategy (NDS) Position Paper”.

The NDS was an important document as it was the first time in Australia’s history that all governments committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes.

We continue to believe the NDS is a key driver for inclusive policy and practice across all government levels and the implementation of principles espoused in United Nations’ *Convention on the Rights of Persons with Disabilities* (CRPD). As Australia has signed and ratified the CRPD, any strategy concerning people with disability must be based on its principles. Australia is a wealthy country with a high standard of living and consequently, should be held to the highest standards with regard to its CRPD obligations.

However, it would be a huge oversight for us not to mention a more powerful driver for inclusive policy would be for Australia to actually enact the laws required of signatory parties to UN Conventions. Unfortunately, Australia has failed to legislate to protect the rights of its citizens. As a result, even scrutiny and criticism from the United Nations does not ensure that the Australian government has to meet the responsibilities of the CRPD. Without a legal system that ensures human rights are protected, Australia has been able to contravene the CRPD without retribution. Commonwealth law overrides state/territory law, so state government can enact a charter of rights without needing to deliver on them. For this reason, **we strongly recommend Australia adopt a statutory Bill of Rights² to strengthen the potency of the National Disability Strategy.**

Putting the person with disability at the centre of the NDS is a critical component. Co-design and co-delivery of the new NDS must happen in partnership with representative organisations which are recognised under the CRPD in its implementation and monitoring.³ This will ensure that obligations under the National Disability Agreement are reflected in other Commonwealth-State and Territory Agreements to strengthen the visibility of a whole of government responsibility to people with disability.

We acknowledge the positive reforms that Australia has initiated since the commencement of the NDS, particularly the National Disability Insurance Scheme (NDIS) and the establishment of the Royal Commission into the violence, abuse, neglect and exploitation of people with disability.

² <https://www.humanrights.unsw.edu.au/news/five-reasons-why-australia-should-adopt-statutory-national-bill-rights>

³ Committee on the Rights of Persons With Disabilities, General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/C/GC/7).

However, the NDS had serious implementation issues and extensive work still needs to be done to create the structural and cultural shifts and understanding required within and between governments at all levels and society more broadly. Certainly, from the experiences we hear about, it appears to have had very little impact on the implementation of inclusive education, employment, health, independent housing options and community life. People with disability continue to be segregated in these areas of life which has an “othering” effect, living their lives parallel to the rest of society rather than being in and part of society.

And the NDIS with its group costing of Supported Independent Living continues to support the notion of congregation, whereby a person with disability is funded only half the amount required to be able to afford accommodation and as such are forced to find a place to live with another person with disability. In our opinion, this is just like institutionalisation just done on a smaller scale.

To have a chance at being effective at implementing authentic inclusionary practices across education, employment, health and housing over the next 10 years, the new NDS must expressly and coherently provide a roadmap, articulate key outcomes, and how they will be monitored, measured, reported and reviewed. Vital to the integrity of the NDS is a requirement that the DSS expressly acknowledge that segregation is not consistent with the CRPD and is a violation of the fundamental rights of people with a disability. The NDS roadmap must be bold and make transformational changes to transition away from segregation.

Our responses follow the specific questions which are in the discussion paper and are premised upon 29 years of experience working with families who have promoted and defended their family members’ interests and rights and particularly supported their family member to be authentically included. The areas of Education and Employment have always been an issue of particular importance to Family Advocacy. In Education for example we have worked with families and the NSW Department of Education and many other stakeholders with a view to enabling all students to be welcomed and educated in the regular class of their local neighbourhood school with the right support. Family Advocacy is a member of the Australian Coalition for Inclusive Education (ACIE). ACIE is a coalition of organisations that share a commitment to advancing Inclusive Education in Australia. For this reason, much of our discussion comes from this frame of reference. Any examples or comments shared by our family members have been purposefully deidentified.

Recommendation 1

That Australia adopt a Statutory Bill of Rights to ensure that ensures human rights are protected and strengthen the potency of the National Disability Strategy.

Vision and Outcome areas

Question 1: During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

Vision

The discussion has proposed the vision under the new Strategy as: *An inclusive Australian society that enables people with disability to fulfil their potential as equal members of the community.*

Recommendation 2

Family Advocacy suggest the following alteration:

An inclusive Australian society that enables people with disability to fulfil their potential by participating as equal citizens and members of the community.

Outcome Areas

The six outcome areas of the current Strategy which are proposed to remain the same are:

1. Economic security
2. Inclusive and accessible communities
3. Rights protection, justice and legislation
4. Personal and community support
5. Learning and skills
6. Health and wellbeing

Family Advocacy agrees the broad outcome areas are still the right ones. To change course midstream would capsize any momentum already achieved. **Words, however, will not be enough.** It is worth noting the dictionary defines the word “strategy” as a plan of action designed to achieve a long-term aim. **We are content for these outcome areas to remain the same so long as there is a clear roadmap in alignment with the CRPD to achieve the vision of the NDS.**

Inclusive Education

For example, under “**Learning and Skills**”, the DSS must acknowledge the current structure of the dual system

of education contravenes the CRPD, denying students with disability from accessing an inclusive education⁴, and **create a roadmap for achieving inclusive education** in Australia. The NDS needs to develop a national Action Plan for Inclusive Education that includes a legislative and policy framework that fully complies with Article 24 and CRPD General Comment 4.

The NDS has not achieved an inclusive education system across Australia. This is evidenced by our anecdotal evidence, our intelligence as a member of the Australian Coalition for Inclusive Education and several reports and inquiries at state and national levels. There is currently no actual plan for NSW Department of Education to implement Article 24 and CRPD General Comment 4, with the only approach being taken is to name these key documents as being considered. Words to actions are completely removed from this implementation process.

Education issues constitute over half of our enquiries from parents and based on what we hear, parents continue to struggle to have their children included on the same basis as their peers. All too often we hear about the barriers that prevent students with disability achieving equitable outcomes which include gatekeeping the enrolment, partial enrolments, low expectations, lack of inclusive curricula, lack of individual education plans, lack of ongoing reasonable adjustments leading to a rise in suspensions, lack of reasonable assessments, use of restrictive practices, and poor transitions. The success of inclusion is too often dependent on the skill and commitment of school leadership and personnel as there is a lack of systemic capacity to meet the educational and social needs of all students and this goes beyond a lack of funding.

It is very frustrating to see that in our recent submission on the 2020 Review of the *Disability Standards for Education 2005*, we made very similar recommendations for improvement to our 2015 and 2010 submissions. For case studies from parents, see **Appendix 1 - Case Studies from parents of students with disability** 1 - Gatekeeping, 2 – Partial enrolments, 3 - Low expectations 4 - Suspensions, and 5 – Restrictive Practices.

Our NSW experience is echoed by disability advocacy organisations across the country, with our experience as a founding member of the Australian Coalition of Inclusive Education (ACIE). The broad consensus is that the NDS has failed to achieve any actual outcomes, or even made substantial progress for people with disabilities.⁵ Disability based segregation in Australia and home-schooling have increased over the last decade.⁶

Segregation of students with disability has increased significantly over the past decade, with a shift towards students with disability attending special schools and away from attending mainstream schools. The number of

⁴ <https://www.family-advocacy.com/assets/Uploads/FA-Submissions/35ab551ed0/Family-Advocacy-submission-inclusive-education.pdf> and <https://www.family-advocacy.com/assets/Uploads/FA-Submissions/0c68d7ce4f/Royal-Commission-Submission-No.2.pdf>

⁵ Family Advocacy's enquiries relating to education have doubled over the last 5 years.

⁶ Australian Institute of Health and Welfare, *People with disability in Australia*, Report, 3 September 2019. <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/education-and-skills>
Disability based segregation in Australia and home-schooling have increased over the last decade.

students with disability attending a special school increased by 35% between 2003 and 2015. This increase is supported by a funding incentive, whereby a child with disability receives higher funding if they attend a special school rather than a mainstream school.⁷ The NDS needs to address the increasing rate of segregation of students with disability and redirect adequate resources to full inclusion into mainstream schools.

Several recent reports and inquiries have looked at the impact of the NDS, and show there is much room for improvement in the implementation of inclusive education.⁸ For example, the Productivity Commission highlighted inadequate monitoring and accountability and laid out a proposed model to improve the effectiveness of the NDS.⁹ The ACIE has already developed a 10 year plan and we strongly **recommend the adoption of, [Driving change: A Roadmap for achieving inclusive education in Australia](#)** to help realise equitable education outcomes for students with disability. The 10 year plan is underpinned by six pillars that are drawn from the evidence base and embed the rights of students as outlined in the CRPD.

Employment

Similarly, under “**Economic security**”, DSS must acknowledge the current structure of the dual system of segregated employment for people with disability through Australian Disability Enterprises (ADE’s) where they do not have meaningful employment or appropriate wages (with less than 1% having opportunities to move into mainstream employment). This area must also include a roadmap to transition out of segregated employment models over the next 10 years. It is imperative that any outcomes being measured must distinguish between different types of employment, looking at the percentage of people in real employment versus ADE’s. Australia continues to run the significant risk of being left behind the shift in this regard in other countries.

In terms of employment in the open market, Australia has a poor record. People with disability are nearly twice as likely to be unemployed as people without disability.¹⁰ Compared to OECD countries, Australia has one of the lowest employment participation rates for people with disability at 53.4 per cent compared with 84.1 per cent for people without disability. Of 15-64 year old’s, 37.9 per cent have their main source of personal income from a government pension or allowance.¹¹ Complaints about discrimination in employment make up a significant

⁷ Students with disability at a mainstream school attract a students with disability loading of 186 per cent of the base per student amount; those at a special school attract a students with disability loading of 223 per cent. See: Senate Standing Committees on Education and Employment (15 January 2016) [Chapter 5: How to better support students with disabilities in schools](#) in ['Access to real learning: the impact of policy, funding and culture on students with disability'](#).

⁸ Community Affairs Reference Committee, Australian Senate, *Delivery of Outcomes under the National Disability Strategy 2010-2020 to Build Inclusive and Accessible Communities* (Report, 2019); Laura Davy, Karen R. Fisher, Ayah Wehbe, Christiane Purcal, Sally Robinson, Rosemary Kayess and Danielle Santos, *Review of implementation of the National Disability Strategy 2010-2020: Final Report* (Social Policy Research Centre UNSW, Report August 2019) <<https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020>>.

⁹ Productivity Commission, *Review of the National Disability Agreement* (Study Report, 2019) <<https://www.pc.gov.au/inquiries/completed/disability-agreement/report>>.

¹⁰ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, Catalogue number 4430.0, 24 October 2019

¹¹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, Catalogue number 4430.0, 24 October 2019

proportion of all disability discrimination complaints made to Australian anti-discrimination agencies.¹²

The review of the National Employment Framework was narrowly reduced to only focus on the Disability Employment Services (DES) program and has failed to deliver the comprehensive reform required. *Disability Employment Services (DES)*¹³ continue to deliver poor employment outcomes for people with disability.¹⁴

The recommendations from the 2016 *Willing to Work* report have not been implemented.¹⁵ The Inquiry made recommendations with respect to Commonwealth laws and actions that could be taken to address employment discrimination. **We recommend a national disability employment strategy that incorporates the recommendations from the *Willing to Work* report and contains targeted general measures for increasing workforce participation, including addressing structural workplace barriers.**

The current employment pathways for students with disability at school and transition beyond school do not align with the objectives of the CRPD. The current situation with work experience and other programs deemed to be helpful in transition are not on offer for a lot of students with disability or the programs on offer are segregated and ineffectual. This is despite current policies that state otherwise. Students with disability, even when considered to be capable of work, are intentionally funnelled into Australian Disability Enterprises (ADEs) as part of a work experience placement. Our position is that there are clearly both moral and social impacts to this pathway for many people with disability and the status quo of this pathway needs to be challenged.

Some families report to us that their child has been requested to stay at home instead of participating in work placement like other students, with many families having to negotiate with the school around such arrangements.

There is generally a lack of supported and flexible work experience and this impacts their knowledge of career planning and employment prospects. For my son, I had to advocate rigorously to get the school to give permission for my child to have a flexible work experience as it was not practical for him to do it every day for 2 weeks. Instead, the school gave us permission to go once a week for 2 hours for a few months. As it was well thought through and the right supports were put in place; this has led to future employment for my son. He now runs his own business as a mail courier. At the same time, I received a letter from the NDIA assuming the only option for my son was for a Day program for work experience. If I did not have a clear vision for my son to have an inclusive life, and the support of Family Advocacy, his life would be on a very different path. I feel lucky to be educated and have English as my first language. What about those families that are not and do not know any better and do not have the support?

Carole

¹² Australian Human Rights Commission (2016) [Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability](#), AHRC, Sydney.

¹³ Australian Government, [Disability Employment Services](#). Department of Social Services.

¹⁴ Disabled People's Organisations Australia (DPOA) [Factsheet: Employment of Persons with Disability](#). DPOA, Sydney.

¹⁵ Department of Social Services (DSS) [National Disability Strategy, Second Implementation Plan: Driving Action 2015–2018](#).

The above example illustrates one of our parent's experience of advocating for a flexible arrangement for her son's school work experience.

To counteract these issues, Family Advocacy, through its initiative 'Resourcing Inclusive Communities', was recently successful in obtaining an Information Linkages and Capacity building (ILC) grant funded through the National Disability Insurance Scheme (NDIS) but now the DSS. This grant will go towards lifting expectations of families in relation to post school transitions whilst utilising normative school pathways to achieve real employment outcomes in the workforce.

Importantly, all students in all settings will be targeted in this project, as each young person has the ability to contribute to the Australian economy. We will also be working with families concerning the flexibility of arrangements, such as shorter work experience placement sessions over a longer term than the usual two-week time frame, that may be helpful for students with disability obtaining work experience. This is a three year grant and the intention is to target many families across NSW and different age groups in High School.

Delivering this grant will also equip Family Advocacy with more knowledge of the extent of the system barriers that are currently occurring within the NSW education system. We strongly recommend that the DSS assist by promoting this School to Work project and support the findings and recommendations upon completion. For this reason, we would welcome the opportunity to be part of the development of the employment framework.

Success in employment for people with disability is usually driven via families with a determined vision of meaningful employment. For example, we have heard about families taking unique approaches to supporting their family member with disability, using innovative and contemporary models of employment, such as customised employment, and microenterprises that support this cohort. Customised Employment is a process that matches a person with disability to the needs of an employer, creating a match in a customised job. It is based on identifying the strengths of a person with a disability through a process called 'Discovery'.¹⁶

A microenterprise is a very small business, owned and run by an individual. It's simple to start, and needs minimal capital. It can have a vital purpose in improving people's quality of life and sense of contribution to society. It can give a person a valued role in their local community providing a service or goods, and be based around the person's passions, interests and skills. It is highly individual – able to happen at whatever level best suits a person. Microenterprises create independence and empower people to make a contribution while using skills and talents.¹⁷

We also provide an example in the form of a film and recommend you watch [Josh's story](#) (6 minutes) which

¹⁶ June Alexander, 'Customised Employment', Presentation, Let's Get to Work Virtual Conference 2020, July 2020.

¹⁷ <http://microboard.org.au/>

illustrates that employment can be the norm following an inclusive education rather than a day program and/or sheltered workshop. Josh now runs his own mail delivery business and is a valued and respected member of his community.¹⁸

On the basis of the above, the NDS and its policies must employ measures to ensure that people with disability can access employment services that meet their individualised needs, and which are focused on long-term outcomes.

Of particular significance, is the strong nexus between segregated education settings and poor employment outcomes. A 2018 comprehensive review of research by the European Agency for Special Needs and Inclusive Education, concluded that attending a special school setting is correlated with poor academic and vocational qualifications, employment in sheltered workshops, financial dependence, fewer opportunities to live independently, and poor social networks after graduation.¹⁹ Therefore, our poor inclusive education record limits the possibilities for students with disability, threatens Australia's human capital development and undercuts their future economic development. If we are to achieve the aims of inclusion under the NDS, the national and state/territory governments must get serious about ensuring inclusive education becomes a reality in Australia.

Also, under outcome 2 “**Inclusive and accessible communities**”, we want to ensure emphasis is placed on ensuring **the NDS and any associated policies, frameworks or documentation have an Easy Read version in accessible formats and multiple languages.**

Housing

One concern is that housing should be more prominent rather than it being subsumed under outcomes 1 and 3.

There is no national framework for the closure of residential institutions in Australia. More than 5.2% of people with disability live in cared accommodation such as group homes,²⁰ with a further 2.8% living in supported accommodation facilities.²¹ This data is not disaggregated. People with disability in residential care die at least 25 years earlier than the general population.²²

Access to appropriate, available, accessible and affordable housing remains a major issue for people with disability, becoming more evident with the roll out of the NDIS. There are more than 200,000 people on waiting

¹⁸ Family Advocacy, *Josh's Story*, YouTube, 24 November 2019. <<https://www.youtube.com/watch?v=OTdRgyh1dV0>>

¹⁹ European Agency for Special Needs and Inclusive Education, *Evidence of the Link Between Inclusive Education and Social Inclusion: Literature Review*, 2018, p 14.

²⁰ Australian Institute of Health and Welfare 2017. [Australia's welfare 2017](#). Australia's welfare series no. 13. AUS 214. Canberra: AIHW. See also: Australian Government, [Australia's Combined Second and Third Periodic Report under the Convention on the Rights of Persons with Disabilities](#), 1 September 2018.

²¹ *ibid.*

²² NSW Ombudsman (2018) [Report of Reviewable Deaths in: 2014 and 2015, 2016 and 2017, Deaths of people with disability in residential care](#). NSW Ombudsman, Sydney.

lists for public and social housing across the country.²³

One model that supports the objectives of the CRPD and the NDS is the Independent Living Options model which is being offered under the NDIS, and we share the NDIS website:

“Where we live, who we live with and the supports to live the life we want are very important to everyone.

Individual Living Options (ILO) are focussed on working with the participant and their family to consider their needs and preferences, and design a flexible package of supports. Implementation often happens in stages and the package includes a primary support approach and supplementary supports. Once established the living arrangement is closely monitored and fine-tuned.

The following describe a variety of living arrangements under the ILO heading.

- Co-Residency – support resides full time or part time in the participant's home
- Host Arrangements – participant resides full time in the home of a non related host who provides support
- Living Alone – support is provided in the home of the participant in a variety of ways
- Living Together – participant lives with other people of their choice and receives support

Individual living options aims to be a viable alternative to a group home.

The NDIS encourage and support the introduction of ILO models in participant plans and is currently developing an ILO policy. Current ILO arrangements will be maintained in participant plans.”

We recommend that the **NDS develop a national plan** for the closure of residential institutional environments, and **develop genuine community based housing** and support options for people with disability; significantly increase the range, affordability and accessibility of public and social housing to ensure that people with disability can maximise their level of independence and freedom; and allow people with disability to control the resources they require to live with dignity in the community, ensuring that people with disability are able to choose where and with whom they live.

Recommendation 3

Continue with the six outcome areas provided a clear roadmap be created in alignment with the United Nations Convention on the Rights of Persons with Disability (CRPD).

²³ Australian Institute of Health and Welfare 2017. [Australia's welfare 2017](#). Australia's welfare series no. 13. AUS 214. Canberra: AIHW.

Recommendation 4

That Australia adopt the Australian Coalition for Inclusive Education's, "Driving change: A Roadmap for achieving inclusive education in Australia".

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That a national disability employment roadmap be created that incorporates the recommendations from the Willing to Work report and contains targeted general measures for increasing workforce participation, including addressing structural workplace barriers.

Recommendation 6

That a national plan be developed to promote independent living and address the many housing issues faced by people with disability.

Recommendation 7

The NDS and any associated policies, frameworks or documentation have an Easy Read version in accessible formats and multiple languages.

Guiding Principles

Question 2: What do you think about the guiding principles proposed here?

The discussion paper has proposed the following guiding principles for the new NDS:

- **Involve and engage:** has the policy process or program design engaged with and listened to people with disability at all stages of planning and implementation and provided accessible information and opportunities for feedback?
- **Design universally:** have the principles of universal design been applied where possible and has the project taken advantage of accessible and assistive technology where available?
- **Engage the broader community:** how has the broader community been informed of, involved in, and been made responsible for removing barriers and supporting the inclusion of people with disability?
- **Address barriers faced by priority populations:** how have the priority populations noted by the National Disability Strategy been identified and what action has been taken to specifically address the barriers they may experience?
- **Support carers and supporters:** how have the needs of the family, carers and circles of information and formal support for the person with disability been considered in the development of the policy or program?

These principles are generally sound and appropriate (with some alterations discussed below) for the new NDS. Family Advocacy suggests the addition of a 6th principle:

- **Rights and Inclusion:** Have the rights of people with a disability been considered in the policy and program? How have the principles of inclusion, a human rights-based approach, and the critical objective of ending segregation been considered in the development of this policy or program?

We also make the following suggestions in relation to the following guiding principles.

Involve and engage: The current wording in this section reflects a limited way to provide input. We are concerned that simply listening to the people with disability is a shallow way to engage them. And we have certainly experienced the situation where an agenda is predetermined by a government department and then information/input is sought and that is as far as it goes. In accordance with the CRPD, we advocate for a deeper engagement process where people with disability have shared responsibility, are active partners in making decisions and shaping policy/systems. We ask that this section be altered to reflect this deeper engagement with the intentions of the CRPD.

Design universally: As the term “universal design” was originally created in the context of buildings and homes, we would like universal design to be clearly defined as per the broader definition of the CRPD: .

*‘The design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed’.*²⁴

This has significance in the application of UDL in the education sphere to ensure schools learn about how UDL applies to the application of making reasonable adjustments in order that a student can access the curriculum. Therefore, it is imperative that UDL’s broader definition be included in this principle.

Address barriers faced by priority populations: It is essential that people with developmental disability are identified as a priority group within the NDS. To be clear, developmental disability is a disability that occurs in the developmental period of a person’s life (in the period from conception to adulthood) and includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability. People with developmental disability tend to experience greater discrimination, worse education and employment outcomes²⁵ and face difficulty gaining access to information and support. Often issues around developmental disability (often invisible) are neglected in the development of policy responses. Given that approximately 1 million Australians have a developmental disability, (750,000 Australians identify as

²⁴ United Nations, *United Nations Convention on the Rights of People with Disability*, op cit., p. 4.

²⁵ <https://data.ndis.gov.au/media/1562/download>

having an intellectual disability²⁶ and 205,000 identify with autism ²⁷, 34,000 with cerebral palsy²⁸), and they experience the worst outcomes, it is essential they are prioritised in the NDS.

Support carers and supporters to be altered to Support carers, supporters and advocates: It is important that the role of family, carers and supporters are recognised, we are cautious that the focus of the NDS should be on their needs. Rather, this general principle ought to embrace how the NDS can collaborate with family, carers and supporters to further the rights and interests of people with disability, how they can support their decision making and self-determination when considering the development of policy/systems. This principle must also include independent advocacy, which is discussed in detail under the heading “Independent advocacy”.

Recommendation 7

The NDS and any associated policies, frameworks or documentation have an Easy Read version in accessible formats and multiple languages.

Recommendation 8

That Principle 1 in the position paper, **Involve and engage:** reflect the intentions of the CRPD for genuine and “deeper engagement” of people with disability.

Recommendation 9

That Principle 2 in the position paper be adjusted to read as follows:

Design universally:

Universal design extends to the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

It is expected that the principles of accessible design will be applied as a general rule when developing policies or programs in alignment with the National Disability Strategy.

Recommendation 10

That Principle 4 in the position paper, **Address barriers faced by priority populations**, include people with developmental disability.

²⁶ <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4433.0.55.003main+features102012>

²⁷ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

²⁸ <https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebral-palsy/facts-about-cerebral-palsy/>

Recommendation 11

That Principle 5 in the position paper be amended to:

Support carers, supporters and advocates: making specific reference to independent individual and systemic advocacy as essential services for people with disability.

Recommendation 12

That a Principle 6 be added to read as follows:

Rights and Inclusion:

Have the rights of people with a disability been considered in the policy and program? How have the principles of inclusion, a human rights-based approach, and the critical objective of ending segregation been considered in the development of this policy or program?

Increased focus on community attitudes

Question 3: What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

Community misunderstanding, stigma, prejudice and discrimination impact significantly on people with disabilities. We agree with the proposal as it is vital that the new NDS has a stronger emphasis on improving community attitudes and this should extend to those working within government. First and foremost, attitudes need to be addressed within each government department at national/state/territory levels. Governments need to “look in” rather than “look out”. They need to be a role model and lead the way for community.

We recommend a commitment be made at national, state/territory and local levels for funding projects and initiatives focused on promoting inclusion and improved community attitudes towards disability, which also includes evaluation. Such an investment must be across the life of the NDS and needs to recognise this goal will require an ongoing and sustained effort.

Any attempt to address both government and community attitudes needs to intentionally address the inherent devaluation of this group and the unconscious bias that exists in both community members and our systems. Family Advocacy currently addresses this is both our systemic and capacity building work by utilizing the Social Role Valorisation theoretical and practical framework. This framework has proven essential in developing people's understanding of both the impact of current attitudes and how to redress this to achieve more inclusive

communities.

For an in-depth discussion on how to tackle the unconscious bias within community and improve community attitudes, Family Advocacy's [Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Submission No.3 - Rights and Attitudes Paper](#).

Culture change in education

Specifically in relation to education, the NDS must find ways to foster an inclusive culture to improve its effectiveness by promoting the *Disability Education Standards 2005*. Many of the parents we hear from would say the current culture is one that does not welcome all learners and/or celebrate diversity. More can and should be done to increase awareness of making reasonable adjustments and inclusion among both teachers and parents of students with and without disability. It is only through the broader cultural understanding and acceptance of the value of diversity to the whole of society that the Strategy will be able to be implemented in the way it was intended.

From a broad system perspective, we recommend a schoolwide approach to social, emotional and wellbeing school policies are required to influence school culture and climate. Culture is shaped by the schools' values and expectations whereas climate tends to be associated with teaching practices, attitudes to diversity and the relationships with stakeholders. Also, an Individual Education Plan for each student with disability will help direct this work across schools.

Family Advocacy has produced two videos about school inclusion and how reasonable adjustments were made: '[Jacob's Story](#)'²⁹ (18 minutes) and '[Al's Story](#)'³⁰ (15 minutes), which illustrate inclusion in a public high school and give positive views from different members of the school community, peers, and the school Principal and teachers.

The common theme to a positive inclusive experience has been the "**will**" of the school to give it a go (mindset of a welcoming culture), see inclusion as a journey (a process not a target), upgrading the "**skill**" of the teacher and the willingness to **collaborate** with the family (positive partnerships). We recommend these videos be watched by the relevant staff from the DSS working on the NDS and encourage the use of these videos more broadly to national and state/territory Departments of Education staff, the Ministers for Education and their staff.

Parents need to be handed information about the rights of a child with disability, the obligation of the school to provide a reasonable adjustment plus the student behaviour strategy in all enrolment kits, in our experience many parents are still not getting access to this information.

²⁹ Family Advocacy: *Inclusive High School Education - Jacob's Story* <https://www.youtube.com/watch?v=YuLu8Dmv7OQ>

³⁰ Family Advocacy: *Al's Story*, (Video, 23 October 2019), <<https://www.youtube.com/watch?v=Ikbsmv22wCg>>

Family Advocacy recommends the following to enhance the educational opportunities of students with disabilities and the inclusive culture of schools:

- that the Standards be enhanced to create greater awareness and recognition of the rights of students by developing pamphlets and other communication strategies for families of students with and without disability explaining the DDA and the benefits of an inclusive society and an inclusive education community
- that information about the Disability Standards be included in all enrolment kits across Australia, and on the enrolment pages of the DOE website
- that complaints mechanisms, including internal and external, be included in all enrolment kits across Australia
- that the Department of Education engage in a targeted advertising campaign to alert parents of children with disability to the fact that their child has a right to be included on the same basis as other children, including in the regular classroom
- that as well as mandatory training on the Standards to school staff, this training should also be made available to other people that enter the lives of a child with disability such as the General Practitioners, Paediatricians, allied health professionals, obstetrician, early childhood professionals, tertiary leaders, NDIS participants, other parents, and the broader community
- training resources should be updated to show positive stories of substantive inclusion through reasonable adjustments in regular classroom settings so education leaders and teachers can see the positive impact of an inclusive education
- additional case studies should indicate good practice of curricular and social participation for students with intellectual and sensory needs in general education environments
- building more awareness of the rights and benefits of an inclusive society including an inclusive school community
- implementing strategies to build inclusive school communities.

Each Department of Education needs an Inclusive Education Implementation Team to ensure that accessible summaries of rights, obligations and complaints processes are provided to **all** prospective students as part of enrolment processes in every education setting; published on every education institution's website; and is prominently displayed in education facilities. Another suggestion is that the Standards are emailed and/or sent in

hard copy to all participants in the NDIS for school aged children.

Recommendation 13

That a commitment be made at federal, state/territory and local levels of government towards funding projects and initiatives focused on promoting inclusion and improved community attitudes towards disability (including evaluation).

Strengthening Accountability

Question 4: How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

One of the impediments to implementing a NDS is the challenge posed by the silos within the 3 tiers of government. The NDS needs to be a transferable piece from National to State/Territory to local governments. There is a need for clearly defined roles and responsibilities for each government and other key stakeholders in the NDS to overcome the current confusion, and people falling through the cracks.

In the education sector, **greater accountability** is required with the need for a **robust, independent and transparent complaints policy and procedures**. Currently, the system investigates itself.

Yes, I complained and I was told I was ungrateful.

Parent

There is no independence to complaint systems. Parents of students with disability and students with disability are very vulnerable to the consequences of lodging complaints. Therefore they tolerate harassment and victimisation that many others would not. The system is geared to the education staffer being presumed in the right, especially as the process is initially undertaken by the school itself. It could be vastly improved by an independent complaints process.

Parent

A significant proportion of students and families continue to feel fortunate just to be enrolled in a school and thus are unlikely to complain for fear of retribution or placing their child at further disadvantage. Their confidence, for

example, to seek to enforce the school's responsibility to adjust the curriculum, ensure the teacher uses strategies likely to engage the student, provide accessible transport for a school excursion and ensure that the school camp is held in an accessible venue, is balanced against their fear that they will be labelled a "trouble maker" or that their child will be victimised by staff who feel forced to implement a strategy they disagree with, not see as necessary, or perceive as "too much work".

In cases where a parent does complain, a recent survey of our families revealed 70% of parents were not satisfied with the current complaints process (27% very dissatisfied and 43% dissatisfied), with only 17% stating they were satisfied. The current complaints mechanism lacks objectivity, accountability, transparency and timeliness. The experiences shared by families tell of a system that polices itself. The Principal backs the teacher, the regional office backs the Principal, and so it goes up the bureaucratic line within the Department. A big problem lies in the complaints process not being independent.

This lack of due process must be remedied. The NDS needs to:

- Ensure each Department of Education has clear policy with independent procedures and processes for responding to allegations of failure to make reasonable adjustments and to appeal suspensions/expulsions to set clear guidelines and expectations for the benefit of external complaints. It is very important to ensure the school community understands how to make complaints of this nature and how the complaints will be investigated. It is critical that families and others also have a chance to feed into this.
- Ensure accessible online content in plain English or Easy Read advice is provided to parents about the right to complain about the lack of reasonable adjustments and how the complaint will be investigated, as well as the right to appeal a suspension/expulsion (and this must be an external process).
- Ensure there is an independent complaints/review process for a school's refusal to make reasonable adjustments, forced partial enrolments, suspensions and expulsions.
- Acknowledge input from all stakeholders such as the Principal, teacher, school learning support officer (SLSO), allied health professional, parent, external expert with evidence-based practices as to what constitutes a reasonable adjustment.
- Create an independent evidence centre for learning (at State or Federal level) to guide schools/parents as to what constitutes a reasonable adjustment.
- Acknowledge that whilst guidance can come from evidence-based examples, students with disabilities are not a homogenous group and so to apply a "one size fits all" approach can be dangerous when it comes to reasonable adjustments. See the individual first not the diagnosis.
- Ensure no Principal investigates a complaint against themselves.
- Maintain the rights to due process.

- Have an independent appeals process for suspensions/expulsions.³¹

Additionally, while a complaints mechanism is usually the last resort for families, Family Advocacy suggest making further use of the role of the NSW Ombudsman or another type of independent body (that can be real-time responsive) to help track and provide a fuller picture of breaches of the Disability Standards of Education in relation to a lack of reasonable adjustments. This would provide a less formal option for family complaints than the Human Rights Commission. Most parents are currently unaware of the Ombudsman's role in addressing complaints regarding schools.

In this regard, Family Advocacy recommends:

- further use of the role of the NSW Ombudsman, the NSW Ageing and Disability Commissioner or another independent body to help track and provide a fuller picture of breaches of the Standards in NSW, and that the Ombudsman be resourced to do so
- that the Department's of Education in each state/territory improve mechanisms to monitor compliance and that the Australian Human Rights Commission (AHRC) be empowered to intervene in cases of breach.

Monitoring compliance

They are not taken seriously, schools are aware of their obligations but choose to break them by constant gatekeeping on enrolment and curriculum, and bully parents who hold them accountable to these standards. To me it is just paperwork with no power in it because the standards are being ignored and schools continue to diminish their responsibility to the student and not take the Standards as seriously as they should. Need greater compliance and enforcement.

Parent

In considering the possibilities of implementing the objectives of the CRPD, there is a self-fulfilling prophecy built into the current processes. One of the difficulties of the NDS is that there is no mechanism to monitor compliance. For example, the only way in which a student and their family can take action for a breach is to make a complaint under the Disability Discrimination Act to the AHRC. This is an emotionally and potentially financially costly exercise with very detrimental impacts on the student with disability and their family.

We need an independent assessment of the extent to which a school was not meeting their obligations towards taking steps to providing reasonable adjustments and eliminating discrimination. Another mechanism to strengthen the onus on schools to provide an education free from discrimination is to give the AHRC the

³¹ In Victoria, they now have an independent body for appeals of expulsions and the number of expulsions has dropped from 285 in 2018 to 185 in 2019. <https://www.theage.com.au/politics/victoria/school-expulsion-rates-plunge-after-students-gain-new-power-to-appeal-20200819-p55n8l.html>

authority to take action where there are breaches of Standards without a student or parent having to take the action or allow an organisation to take action on their behalf.

We need to create a more proactive model of compliance monitoring to allow for a more consistent implementation of the NDS. At the moment, resolution of formal complaints are confidential and this limits the systemic improvements that may occur with precedent setting and media exposure.

Family Advocacy therefore recommends:

- **improving mechanisms that monitor compliance**; enabling AHRC to intervene where there is a breach of the Standards
- greater accountability regarding the decision making of schools exercising unfettered discretion and a review of the current complaint mechanisms and practices which call into question issues of procedural fairness, take unreasonable lengths of time and often fail to resolve issues

Strengthen the protocols around collaboration

Collaboration requires a commitment and a planned approach by all parties working towards a common goal by sharing responsibility and expertise. For example, the successful inclusion of a student with disability, collaboration in schools takes many forms and involves multiple stakeholders working together to support the teacher such as the student, parent, teachers' aides and other professionals. For collaboration work to be effective, time and space need to be allocated for collaborators to develop a working relationship, establish roles, plan, implement, and reflect.

In this way, all governments need to collaborate internally and externally with their own departments, with other departments and between state and federal governments as well as local councils. The NDS should ensure commitment from all sectors to **establishing cross-agency collaboration** as a key approach incorporated in the document.

Question 5: How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability? (Examples of the non-government sector include big, medium and small businesses, community organisations, employees of these businesses, private research, investment organisations and individuals.)

It is clear that whilst government will always have a primary role in ensuring people with disability are included as citizens, inclusion at the community level as expressed in the CRPD is often dependent on the attitudes and values held across the private sector. We expect the new NDS place a greater emphasis on

the role of the non-government sector in facilitating inclusion for people with disabilities. In an ordinary day, it is very likely that a person with disability will engage with a range of public and private entities.

It is essential that support and information is provided to help the private sector to understand and fulfil their responsibilities. We suggest an independent administering body be funded to achieve the same. This body could also be a point of contact for feedback from people with disability as well as to assess and evaluate the NDS, provide education and training, information and advice.

Recommendation 14

That greater accountability is required with the need for:

- a robust, independent and transparent complaints policy and procedures
- improved mechanisms that monitor compliance
- establish cross-agency collaboration within and between federal and state/territory government
- establish a central administering body to facilitate both the government and non-government sectors.

Reporting

Question 6: What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

There needs to be an evidence-based measurement framework to track the success of the NDS.

Transparency and clear communication on the NDS's progress to the public is needed, at least yearly combined with longitudinal progress reports, and tabled in Parliament. As an advocacy organisation, we are required to report yearly with stringent rules and requirements to justify our funding and effectiveness. It should be no different for a government department. It is imperative that all governments and local councils take on a transparent, collaborative approach to the continued development of the NDS and its policies.

In all jurisdictions around the country, there has historically been a poor collection of disaggregated data regarding people with disability across all settings. In education, there is little known in mainstream/support units/segregated settings about enrolment rejections, educational attainment/completion, tertiary study, suspension/expulsion rates, employment upon leaving, and the use of restrictive practices for students with disabilities. In employment, little is known about the efficacy of day programs and Australian Disability Enterprises. Certainly, this applies to restrictive practices generally across all settings in each state/territory.

This needs to change and there is no excuse not to do so as the technology exists to support it. The purpose of this data will shine a light on differences both positive and negative to enable shared learnings of good practice

as well. It will also inform where there may be 'hot spots' or whether certain schools, employment providers or regions need more attention, training and support, and also whether any systemic changes need to occur. For transparency, all of this data should be publicly available and easy to access. Hence, data collection should be a priority for the NDS. Any data collected should be consistent across jurisdictions to enable comparison, which can be helpful in ensuring all jurisdictions are held accountable.

We note that a National Disability Data Set is in the process of being developed. Such a resource will without doubt have significant usefulness in terms of understanding the needs, service usage and service delivery for people with disability.

The NDIS reporting system, as provided under s.174 of the *National Disability Insurance Scheme Act 2013* (Cth) provides a good reporting framework template which we consider should be adopted in determining the success of the NDS. The NDIS reporting framework provides national, state and territory progress reports against key outcome areas as well as a breakdown of spending across each jurisdiction.

Additional aspects of the NDIS reporting scheme which would have benefit in the context of tracking the success of the NDS include:

- **Reporting on participant satisfaction** – a similar evaluation could be made in relation to the satisfaction of people with disability regarding progress across the NDS key outcome areas;
- **Assessment of participant outcomes** – this is vital to determine the actual effectiveness of strategies, and should therefore be part of the evaluation of any project or scheme under the NDS;
- **Longitudinal tracking** – the NDS is a 10-year scheme with broad application across the whole of society - it is important to track progress against the key outcomes over its life span to ensure that progress is being made across long term projects as well as tracking whether incremental progress is being met as part of these long term objectives;
- **Public transparency regarding funding streams and distribution of funding** given that the NDS is a national scheme, with shared responsibilities across federal, state and territory governments, it is important to ensure that there is equitable allocation of funding to ensure that jurisdictional inequities do not arise;
- **Reporting on the ongoing financial sustainability of the Scheme as a whole** - this should include reporting on any risks to ongoing financial sustainability and strategies to mitigate these risks.

Recommendation 15

That the federal and state/territory governments commit to both annual and longitudinal reports across the life of the strategy and that such reports be tabled within parliament.

Targeted Action Plans

Question 7: What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years)?

We support the idea of targeted actions with defined periods of time. It is necessary to have targeted actions to ensure forward progression and accountability for the implementation of the NDS. There is also a need for clear mechanisms for evaluating the impact of the NDS and an evaluation framework must be designed and implemented by people with lived experience, and their family representatives or advocacy organisations.

Given there are a large number of organisations and interests being represented, the challenge will be to determine who and what is prioritised within each outcome area. Obviously, we would strongly recommend that the people with disability from marginalised groups need to be prioritised as they are a more vulnerable cohort, such as people with developmental disability, ³²First Nations people, cultural and linguistically diverse backgrounds, rural and remote areas, and those that fall within multiple disadvantaged groups.

We would note that potential action plans already exist across several issues of importance for people with disability. For example, Australian Communications Consumer Action Network (ACCAN) has produced an Ideal Accessible Communications Roadmap as a national plan to meet Australia's international and domestic obligations to provide full and equal access to all communication technologies and services for people with disability. This roadmap was the product of consultation across 35 organisations (including Disabled Peoples Organisations, advocacy groups and disability service providers) and 9 individuals about accessible communications [1].³³

Therefore, we would recommend **that the government conduct an audit of existing action plans** which align with the key outcomes of the new strategy, looking within and beyond government departments. **Areas which we have identified requiring significant attention over the life of the new Strategy include education, employment and housing (as previously discussed) and accessible communication.**

Recommendation 16

That the government conduct an audit of existing action plans which align with the key outcomes of the new strategy, looking within and beyond government departments.

³² Accessible communication is vital to ensure that people with disability can fully participate in community life. Many people with physical disabilities still experience barriers in accessing information, both when engaging with government and in the broader community.

³³ For more information on the Accessible Communications Roadmap - <http://accan.org.au/Ideal%20Accessible%20Communications%20Roadmap.pdf>

Recommendation 17

That education, employment, housing, and accessible communication be key focus areas for reform in the new strategy.

Engagement Plan

Question 8: How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

The need for proper consultation and a steering committee

The NDS must proactively engage with people with disability, advocacy and community organisations as well as external experts with evidence based practices to ensure the lived experience of students with disability is heard, understood and the effective strategies applied. We do not feel our families have been consulted in a meaningful way other than feeding in their input/information/opinions. Having all stakeholders part of the design of the monitoring process is essential.

At present, we have not received a copy of any draft policies. And we are very concerned, moving forward, that there will not be adequate consultation of people with disabilities, their family members, advocacy organisations, and other relevant stakeholders.

The success or otherwise of this Strategy will depend on how it ends up being implemented 'on the ground'. We believe it critical that an ongoing steering committee be involved in the implementation and monitoring process to feed in with proper guidance and the lived experience sought from parents of students with disability, and Family Advocacy and other disability advocacy organisations. We are invested in getting this right and must all work together towards realising this.

Therefore, we recommend **independent advocacy must be adequately funded as this is a way that the proposed Engagement plan could be achieved.**

The ongoing need for a strong independent advocacy sector is undisputed. The most vulnerable in our society need to have someone in their corner to help navigate the many complex systems and services, give people with disability a voice to be heard when governments make decisions affecting them, and to help affect systems change. The NSW Ageing and Disability Commissioner recently stated, "The need for advocacy will continue to

be an important part of the lives of people with disability to ensure the continued promotion, protection and security of their rights, and enable their genuine participation in the community.”³⁴

Adequately funding the advocacy sector is a step in the right direction in contributing towards the proposal to address community attitudes.

Because the needs of individuals are complex, a suite of many different ‘forms’ of advocacy is required. No one kind of advocacy will provide ‘the answer’ nor will a ‘one-stop’ shop approach work towards reducing or removing the multitude of barriers experienced by people with disability. Therefore, it is important to differentiate between the different forms and functions or mechanisms of advocacy.

Forms of Advocacy:

- **Individual Advocacy** - of which there are subsets:
 - self advocacy: people with disability advocating for themselves
 - family advocacy: parents or relatives advocating on a person’s behalf with the support of advocacy advice, advocacy development strategies, information and referral
 - citizen advocacy: an ordinary citizen taking up the advocacy issue on behalf of a person with disability
 - paid, formal advocacy: advocacy conducted by paid advocates
- **Systemic Advocacy** - of which group or representative advocacy are subsets.
- **Legal Advocacy**

Each different form of advocacy uses different advocacy mechanisms or strategies:

Individual advocacy uses a combination of advocacy development (developing the person’s advocacy skills), provides advocacy related advice and information provision, so that the person is knowledgeable about the issue at hand and referral when necessary.

Advocacy undertaken by families is the most significant and plentiful form of advocacy that exists, as families are advocating with or on behalf of their family member, in some form or another, sometimes from birth to death. Children cannot advocate for themselves and nor can many people with cognitive impairment without support. The majority of people with disability in NSW that have their issues taken up are represented by a parent or family member.

³⁴ Dr Robert Fitzgerald, *Review into Disability Advocacy in NSW: A report by the NSW ageing and Disability Commissioner*, 19 December, 2019.

Family Advocacy strongly recommend paid advocacy be funded as well as the provision of increased funding in perpetuity for agencies committed to supporting unpaid, informal advocacy, for example, Citizen Advocacy and advocacy agencies that provide advocacy advice and development for families (such as Family Advocacy). We strongly recommend that it is necessary to increase and continue both forms of advocacy.

When formal advocacy that focuses on *doing for*, is only utilised it also creates an environment whereby the remedy and reliance are only on support to do for others, instead of providing support to equip others to do for themselves. Further to this and when considering families, it is almost guaranteed that issues requiring advocacy will continually emerge for their family members with disability. As families' competencies in advocating and understanding systems develop, we have noted a reduction in the contact with our organisation over time, hence minimising the reliance on formal advocacy supports. These same families may reconnect with our organisation when they come into contact with another system or barrier that they are unfamiliar with and the process starts again.

Family Advocacy has spent many years building the advocacy competencies of families and has many examples of how this advocacy leadership development has created safer and more optimum arrangements for many people with disability. This also extends to the impact that families have had in creating systems change across NSW and also across the country.

It has long been recognised within the advocacy arena that 'paid' advocacy has the potential to drive out unpaid or voluntary advocacy. This comes about for a number of reasons starting with the strongly held assumption within our culture that professional solutions are best. Instead of 'doing for', empowering people who are willing and well positioned tremendously bolsters the advocacy efforts and most importantly adds a vital layer of protection for people with disability.

The 'quick fix' mentality which is also rampant in our culture, can also mean that the easy, 'solvable' issues get attention by paid staff so that 'outcomes' can be produced whereas the more difficult, long-term issues that can have life-changing outcomes for a person, may be relegated to the 'too hard basket' and not be given the attention they rightly deserve.

Again, an advocacy sector that supports both formal and informal advocacy models is essential in ensuring that the vital layers of protection are in place across Australia and for the long term. Furthermore, with the likely pressures on Government over the next 10 years post-COVID-19, it makes sense to invest in supports that are likely to yield the greatest economic benefit in the long term to inclusion. That is, lower welfare and health costs to society and more economic and community participation due to stronger relationships between people with disability and their family members.

Systemic advocacy uses a combination of strategies such as: lobbying, campaigning, holding public meetings, responding to Inquiries, state and federal submissions, meeting with and writing to those in positions of power to

take up issues pertaining to law, policy and procedures, resource allocation and other decisions made by government and other agencies, attendance at roundtable discussions, reference groups, consultations and a wide variety of stakeholder meetings.

It is common for agencies carrying out systemic advocacy to be aware of emerging issues that have the potential to impact profoundly on people with disability in the future, and which people with disability themselves may not be aware of. One example of this was the extensive work undertaken by NSW advocacy organisations in relation to progressing the closure of large institutions in NSW. This issue was not necessarily identified through individual advocacy responses received across the state but was seen as a critical step that government needed to take from a social justice perspective and a human rights framework.

Australia, like many countries, often tends to think in isolation to what is occurring around the world and in many cases is behind many jurisdictions concerning the progression of the rights and living conditions of people with disability. It is the job of systemic advocacy organisations to keep track of this and to gather learnings from these countries concerning these progressions, make contacts with relevant agencies abroad and to then translate that to 'our environment' for possible development.

Systems advocacy should also operate as an "early warning system" so that actions are taken preventatively. This monitoring role requires an extensive network of contacts and information sources. Advocates focused on individual issues are unlikely to have the time, expertise or networks to facilitate this. Once a problem has arisen and is already impacting on people, it can be much harder to undo than if it had been prevented in the first place. Proactive systems advocacy is an essential element of any advocacy system; it must not be stymied by a narrow approach and should be guided through a human rights framework such as the CRPD.

Also having a 'systems view' to identify and attempt to alleviate the multitude of issues experienced by people with disability is key to the systemic work undertaken. It is not uncommon for many mainstream and service systems to have within them many points of tension that significantly impact on the rights and interests of persons with disability. It is a requirement of the systemic advocate therefore to pinpoint the 'most appropriate' point that will work towards alleviating the tensions more broadly, instead of attempting to address all the tensions that exist. As the latter approach would not lead to the necessary adjustments and most potent systems reform needed, this work can therefore occur over the longer term and in some case many years.

Confusion over responsibility between State and Federal Governments

The Productivity Commission's Report into the National Disability Agreement identifies confusion within Government at both State and Federal levels, as to whose responsibility it is to fund Advocacy. It states that

“The exact supports to be provided through the National Disability Advocacy Program, ILC grants and NDIS plans at full scheme are yet to be fully clarified or established.”³⁵

As a result, much of the current state/territory government funding of disability advocacy appears to be operating on a ‘wait and see’ basis.”³⁶ Clearly this is not good enough and furthermore, this notion of ‘wait and see’ relies heavily on the notion that these systems, when fully established, will resolve the inherent discrimination that occurs for this group of people.

Given that Australia is a signatory of the CRPD, people with disability in Australia and their own state/territories require a clearer, more consistent commitment to the ongoing provision of strong, vigorous, independent advocacy support now and in the long-term. This should always form a foundational component of the Australian and state/territory government’s commitment to people with disability.

The Advocacy sector aligns with the CRPD

Currently, there is no jurisdiction in Australia that aligns with the principles and objectives within the CRPD. Therefore, standards and directions that the advocacy efforts can take are subjective in relation to the individual organisations perception of what is needed. This is particularly prevalent in the systems advocacy work undertaken, therefore creating a missed opportunity for the continual progression of the rights and interests of people with disability.

The CRPD clearly outlines the obligations, and the directions required, to ensure that people with disability realise their rights and interests as full citizens. Aligning the advocacy efforts with the UNCRPD would enable a more consistent and potent approach across Australia and avoid misaligned work to be undertaken - which currently stagnates and at times pushes backwards - the realisation of full citizenship. By utilising the CRPD, it would also assist government in consistently working towards their obligations as a signatory to the Convention.

It is important to note that this NDS consultation is being conducted at a time when there is no guarantee of funding for NSW advocacy services post June 2021.

For an in-depth discussion on the important role of independent advocacy, see our [Submission to Ageing and Disability Commission NSW Disability Advocacy Review \(October 2019\)](#).

Recommendation 18

That independent advocacy be adequately funded by state/territory and federal government as a way to achieve the Engagement Plan.

³⁵ Although the Department of Social Services, through the Disability Reform Council’s Senior Officers Working Group, is currently reviewing advocacy projects, policies and priorities (Commonwealth of Australia 2018a, p. 11

³⁶ Productivity Commission Study Report, Review of the National Disability Agreement, January 2019, Box 3.12, pg 91

Other issues

Question 9: Is there anything else you would like to share about the ideas and proposals in this position paper?

Impacts of COVID-19

The COVID-19 pandemic has made very clear the lack of priority provided to people with disability, which was highlighted by other sectors being provided with resources and information before those with disability.³⁷

Whilst each person with disability had their own individual experience, and some benefited from remote learning but the effect of COVID-19 appeared to widen the gaps that already existed for people with disability.³⁸ We heard many stories from children with disabilities being left behind. See **Appendix 2 – COVID-19 school case studies from parents of children with disabilities**, which includes 10 short case studies to illustrate this.

Recommendation 19

That the National Disability Strategy place an onus on governments to ensure people with disability are included and receive targeted support in COVID-19 recovery measures.

Conclusion

We look forward to the development of robust new National Disability Strategy which reflects a commitment to empowering and including people with disability in all areas of life. We encourage the adoption of our recommendations and are happy to provide further information or clarification on any matters we have raised. We look forward to participating in the NDS processes and facilitate the involvement of people with developmental disability and their family advocates as the National Disability Strategy progresses.

³⁷ Dickinson H, Yates S. *More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic*. Melbourne: Report prepared for Children and Young People with Disability Australia 2020.

³⁸ Dickinson H, Yates S, Smith C, Bertuol M. *Not even remotely fair: Experiences of students with disability during COVID-19*. Report prepared for Children and Young People with Disability (June 2020)

Appendix 1 – Case studies from parents of students with disability

1. Gatekeeping

At a 2016 Family Advocacy event, we asked parents to list the explanations they had been given by Principals and other school staff as to why their child could not access the regular class or did not belong at the school.

Set out below are the answers we received:

<p><i>But this is what we have always done</i></p> <p><i>Teachers aren't therapists</i></p> <p><i>Special schools are best practice and this is reality</i></p> <p><i>We do reverse integration</i></p> <p><i>You have your head in the clouds</i></p> <p><i>You do realise your child has a disability</i></p> <p><i>Our school is heavily unionised</i></p> <p><u><i>When they grow out of disability they can come</i></u></p> <p><i>You haven't accepted your child's disability</i></p> <p><i>We already have a child with disability</i></p> <p><i>We have done all we can for your child</i></p> <p><i>We only take children with high functioning disability</i></p> <p><i>You don't always get what you want in life</i></p> <p><i>Your child is not disabled enough for individual funding</i></p> <p><i>There is such a big academic gap so it won't work</i></p> <p><i>They are not a good fit</i></p> <p><i>This will be too exhausting</i></p> <p><i>We don't have enough resources</i></p> <p><i>We don't know how to teach children in mainstream</i></p> <p><i>Our teachers aren't babysitters</i></p> <p><i>Our teachers aren't nurses</i></p> <p><i>We have no specific disability knowledge</i></p> <p><i>Your child is a risk to others</i></p> <p><i>In high school the gap gets wider</i></p> <p><i>Your child excludes himself/herself</i></p> <p><i>Not in our area</i></p>	<p><i>We are already dipping into the general budget</i></p> <p><i>Kids are cruel so they are better off somewhere else</i></p> <p><i>Their self-esteem will be affected</i></p> <p><i>We have no resources</i></p> <p><u><i>We don't have the skills</i></u></p> <p><i>We can't afford the modifications</i></p> <p><i>Your child won't get funding</i></p> <p><i>Our school is heritage listed so it's not a good idea</i></p> <p><i>When she is toilet trained</i></p> <p><u><i>My teachers don't have to teach your child</i></u></p> <p><i>You got lucky in primary school</i></p> <p><i>The gap gets wider so why put them through it?</i></p> <p><i>They will take teacher's attention away from the students</i></p> <p><i>Will you be paying for this?</i></p> <p><i>You don't realise how tired this will make the teachers</i></p> <p><i>We are not experts</i></p> <p><i>They won't identify with their peers</i></p> <p><u><i>You will get backlash from other parents</i></u></p> <p><i>We don't teach them</i></p> <p><i>He doesn't meet school requirements</i></p> <p><i>She can't come here because we can't lift her</i></p> <p><i>We can't solve all the world's problems</i></p> <p><i>Your child is not a good fit</i></p> <p><u><i>There are special places for your child</i></u></p> <p><i>You are ruining your child's future</i></p> <p><i>You are not doing the best for your child Your child doesn't belong with adolescents</i></p> <p><i>We will get a teacher's assistant to teach them</i></p> <p><i>There is best practise and there is reality</i></p> <p><i>It will be an unjustifiable hardship</i></p>
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In Term 1 of 2020, Family Advocacy asked on our Facebook page if families could share their gatekeeping experiences and the reasons given by the principal/school staff. The post reached an audience of 1,763 and we received the following comments. We suspect we would have received more responses but it was also at the same time the Covid-19 pandemic was heating up and we believe that many families were more focused on keeping their families safe. Regardless, it is our view that the comments received (as set out below) reveal gatekeeping is continuing for parents:

'Your son doesn't have the skills and behaviours required for Kindy'

'Your son will only get an hour a week support'

'After meeting your son, unfortunately we don't have any spots available'

'Your son is not achieving the goal of improving social skills in mainstream, so he should go to a support unit'

Melinda

We have experienced gatekeeping with both our children. Our son has a diagnosis of Sensory Processing Disorder and our daughter is dyslexic. We tried to enrol our son in a Catholic primary school. Our son has a diagnosis of Sensory Processing Disorder and we advised the school. When they met with us they told us that they would only accept our application if we agreed to enrol in their program for Autistic students (he is not Autistic and had been assessed by a Clinical psychologist). They suggested that we would need to seek a second diagnosis or not be accepted at all.

We were looking for a high school for our daughter with an assessment of dyslexia. We were told by one of our chosen high schools that "it isn't really the place for children with dyslexia as we can't offer any support or remediation".

Vicky

I have a 5yo son with ASD. He is a gifted child and during the meeting and cognitive assessment stage of enrolment for kindergarten last year, he scored higher than any student they had ever seen. He was polite and happy meeting everyone. I took this as a good sign. Two weeks later I was asked to come to see the principal where I was told that because of his diagnosis the school did not have the capacity to meet his needs, and they feel he wouldn't learn well so they "regretfully" cannot accept his enrolment. I was very nicely asked to look at finding a special needs or autism school for him instead. I did put him in an aspect school where he is doing amazingly, but the fact they ignored his amazing mind and wonderful personality because of his diagnosis clearly shows they were discriminating against him.

Kathleen

'What makes you think your daughter is suitable to come here? You know she would only get about two days' worth of support across the week.'

'There is an autistic boy here in kindergarten and his parents pay for his support so you could do that but he will probably go to a special school at the end of this year.'

'We would have to make a lot of changes. We can help you fill out the forms for schools with the expertise and she can get the support she needs there.'

'I would encourage you to think about a multi cat classroom because then you have the best of both worlds.'

Ashlee

In our experience working with families, significant compromises to their vision of inclusion occur as they start their educational journey. In an attempt to counteract this, Family Advocacy has been running, for many years,

state-wide advocacy information sessions and workshops for families specific to the rights, standards and policy consideration in relations to supporting their child to have an inclusive education. Many families are startled by the information they receive as it is often contrary as to what they have been informed by the school. It is essential at these events that families are upskilled in how to advocate effectively at the school level as unfortunately, this is seen as a necessity in interacting with schools.

The following stories, written by some of our families, show the importance of having a strong vision in order to survive the education system:

My child was rejected by 13 schools on the Central Coast. Due to no public schools accepting my child, I had to send him along to a special school 50 minutes' drive away, so four trips a day with his younger sibling. Not only was this travel wearing us down, this became a problem when his younger sibling had to start Kindergarten at our local school with the same start/finish times.

Aside from the fact that I was refused transport by the NSW government, I really wanted both my children to go to the same school together as I had learned that all the statistics show inclusive education is beneficial for kids with disability, and in fact, all students. I also wanted my children to be educated in the same school and with neighbourhood friends.

I found a school where the principal was prepared to enrol my child in the support unit with the idea to transition him to mainstream. I was contacted by a person from the Department of Education who told me the decision is not up to the principal and that we needed to undergo further IQ assessments, which we did and the results stating my child's disability was moderate/mild. The lady from the Department of Education met my son for a few minutes in the waiting room before the IQ test, called me later stating he was severe, needed a lot of support and is best suited to an IO (moderate intellectual disability) class or she can force a particular special school setting, which I won't name, to take him. I have since heard from schools "off the record" saying the suggested school has a reputation for moving kids with disability away from other schools all the time. She advised me that all places in mainstream classes were full and told me she had 30 years of experience with kids with a disability and he needed to be with his own kind.

After a lot of stress, advocacy and persistence, we finally have found a school that would accept both my kids and I have one drop off and pick up time. The school has been welcoming, accepting, made adjustments to the curriculum, included my child so he feels like one of the kids and is in the regular class and not a support unit. There is no change to my funding situation, just the attitude from the principal and teachers, whom I am so grateful for.

Gillian

My five-year-old was rejected by 12 schools, 7 [non-government] and 5 Public Schools. We applied north, south, east and west of where we lived. Eventually, we found a school willing to give our son a "fair go" but it meant we had to move away from our family base and our chosen parish. At the time of this search for a school that accepted my child he wasn't even in kindergarten. This was a rude awakening to our family that our much loved son would be rejected in this way.

The schools kept wanting to get him IQ tested. But we disagree with this completely because our son is a human being, he is not someone you apply a number to and stick him in a box, because you can't summarise a person based on a particular number. No number can measure that he is so caring, loves to learn, adores play, is a beautiful brother to his siblings. These tests medicalise people but he needs to be educated with his peers within his local school, where his siblings attend. In this way, it's the safest place for him. What he learns socially is just as important as academics.

James

For simplicity let's call him Bill, aged 10. Bill's other Grandmother has recently died and his Mother is sad. Bill is concerned about his mother so is not sleeping well. In class, he should be doing a spelling test assessment however he can't focus so the special needs assistant says, "Come on Bill, you can do better." Bill crumples up

the paper and storms out of the classroom. No one checks on Bill. So Bill leaves the school and walks 1.6 km home. A policeman sees him and returns him to the school. The school now somewhat on the back foot and retaliatory, sees Bill as a flight risk and he is now sent to a disciplinary unit in a neighbouring suburb for two weeks.

The class teacher delayed putting in the behavioural form and the term of exclusion went over two weeks by one day. Bill attended the unit for what he thought was 2 weeks with a particular end date but it ended up being a day longer due to the teacher's delay. He became very angry and distressed. He felt he had completed his punishment. The staff member at the unit who had been threatened by Bill but not harmed said to me, "This is the second time he has got angry with me if he does it again we will have to take further action." I never found out what the further action was. Are we going to throw him in gaol for running home to his Mum? I just wanted to wrap my arms around him and take this poor boy home.

In total he lost three weeks of schooling because the school refused to shut the gates during school hours (we got them closed after a letter to the local MP).

Bill is now 12 and going to High School for the first time. The Primary School psychologist deemed Bill to be a difficult child (which he is) and he should be in the Autism class in High School. The Psychologist did not like Bill nor does she like many of those she should be nurturing as she doesn't realise visitors to the school can hear her staffroom chatter, "That child will never be any good". So despite the ASPECT (Autism Spectrum Australia - an autism-specific service provider) report indicating that Bill was high functioning and quite intelligent she recommended him for a life skill Autism class.

Bill had several orientation days at the High School. He was happy to go with his Year 6 class and refused to attend any that introduced him to the Autism class. He wanted to be in the mainstream and was looking forward to it. Unfortunately, he was placed in the Autism class. He was and still is miserable, depressed and a flight risk. Instead of being able to behave and communicate his ability to be in the mainstream his anger consumes him and he runs away. When his father brought him back to the school the Head of the Special Needs said to a sobbing child, "Stop being a sook." She has surmised him to be a discipline problem and he needs, "To be brought into line."

Bring Your Own Device iPads that are a school requirement are denied to the Autism class because they, "like them too much." Which may be the case however if the mainstream are allowed these as an educational tool then we are denying them equality of access to technology and information.

Grandmother of Bill

2. Partial enrolment

Many families whose children with disability are partially enrolled in school have informed us that their child was experiencing full attendance at a preschool or previous school settings and is quite able to manage a full day without incident.

When my son moved from a special school to a mainstream school, he was put on a trial from 9am-3pm without a teacher's aide and all went well. Despite this, the school said he needed to be on a partial enrolment from 9-12.30pm for five weeks. We wanted to question the purpose of partial enrolment and why five weeks? There was no reason for this. But there is such a power imbalance between us as parents of a child with disability and the principal, we dared not ask. We were so happy our son was being given a chance.

In this time, our son absolutely loved being in a mainstream school in a regular class. His horizons expanded enormously. He quickly identified and wanted to participate in the debate team, a talent show, computers and netball. He was given a Teacher's Aide for 1 hour per day for Maths support as his avoidant behaviour can be

disruptive. There were no incidents over the five weeks. We expected full time attendance would follow. On the last day of the partial attendance plan, the school told us it would rezone the plan for another five weeks from 9am-2pm. They simply said we would like him for full attendance next year but we will see how we go. This cut off the last session of the day, which was netball or computers, the subjects he was really interested in. So it didn't make sense to us when the school told us the reason for not giving him the full time enrolment was because our son had told them he was not sure he wanted to be there the whole day. Again, as parents we do not feel we have the power to argue with the principal and have to accept what we are given. It was clear our son is happy to go to school, he has a sense of belonging. He specifically asked for the teacher aide to be out of the way in maths and he should sit with the boys. He has his eyes on the future, can't wait for school camp and has set a goal to

be the school library prefect. We can see how now he feels like a citizen, like he belongs, he is recognised. This did not happen when he was at the special school.

Meg

After 6 half hour trial sessions at a school we were told: "Your son is too high needs for our school (local primary school closest to my home), he needs a specialist school and 2:1".

Country area. No specialist school. My son has been in partial enrolment at the school he attends for two years now.

Ellen

We had a terrible experience with our son when we approached our local school.

We met with the school Counsellor and a learning support coordinator. I thought I was just meeting the latter, but the School Counsellor was there and drove the meeting. The first thing she did was ask for any reports. I provided a Disability Specialist Unit report stating Global Development Delay. She asked me about ten times if I was sure mainstream was the best option. I kept saying yes, we were. I asked how we could support his transition to school. She thought he would be better placed in a support unit. I said no. She said she could take me on a tour of one, so I could see how it would benefit my boy. I said no, we want him at our local school. Then she was telling me how there is a big school population and Jimmy would struggle. He would get knocked over. 'The walkway is like grand central station.' There were stairs. He would be pushed down and hurt. There were big distances between classrooms, and he would fall behind and fatigue. And academically he would fall behind, and lose his confidence, 'he would be a shell of the child he used to be' and by the time we realised he should be in a unit, it would be too late and there wouldn't be any places!!! She was horrific but we stood our ground.

We persevered. She hadn't met my son. I thought once she met him and saw him doing well in a mainstream preschool that she would back down. I thought she would realise my son was more than the DSU report! We arranged a time for the two to come to the preschool and watch Jimmy. They talked to the staff at the preschool. Staff later asked me if he would be better placed in a support unit. I was furious that the Counsellor had influenced his preschool teachers to do her bidding. Later she conceded that Jimmy could attend the school if we really wanted him to, but that he would need to start on a few hours a day, and that he would start a week or two later, after his class mates had settled in. It meant that he wouldn't be there for lunch or recess so he would miss opportunities to make friends. She couldn't tell me how long that would go on for...I argued that he had been doing full days at preschool and the reduced hours wouldn't be necessary. She wouldn't back down. It was partial enrolment or nothing. I know we could have sent him.

We knew they had to take him, even though they acted as if they needed to approve his attendance. But we weren't prepared to risk him attending somewhere that he was expected to fail, and that had such low expectations of him. We started at a different school but transferred to our local school in term 3 of kindergarten. It was a totally different experience as the gatekeeper had left, and the teacher we met with was very inclusive and supportive of our attendance. Jimmy is doing really well. I am angry that, because of the Counsellor, we didn't start at our local school to begin with. I can't believe the experience we had, to be honest. I understand the Counsellor was reprimanded for her actions. But I also know that she is at another school and my friend battled with her all of last year to keep her boy in mainstream and out of the support unit. People like this should be retired!

Jo

3. Low expectations

The following stories (written by families and provided to Family Advocacy) are just a few examples of what we consistently hear about low expectations of students with disabilities.

It became obvious my preschool child had a good day whilst he was in an inclusive learning space in a regular day-care (where he was treated like a child first before a label) but not in the Early Intervention Centre (EIC), which was therapy based. I wanted him to be in a regular class at his local school but was pressured by the school that he would be better off in the support unit.

In term 1 of Kindergarten in a support unit (SU), he received an award for being the most inclusive child in the school playground where all children, including from the mainstream, played together. In term 2, they decided to restrict all the SU kids to a sandpit with a locked pool fence euphemistically named "the sensory garden". This is a form of social and environmental restrictive practice. He could not read or write by the end of the year. He regressed socially and academically. He displayed similar behaviour to when he attended the EIC. His speech went backwards, he would only grunt like when he was 3 years old.

He refused to enter the classroom. He could not read or write.

During this period, I started to learn about my child's rights and the legal obligation of the school. I decided to move him to a regular class in a mainstream school. By the end of Year 2, he could read and write at peer level and when he is sick, his friends run up and tell him they missed him.

The difference? The attitude of the Principal and teacher treating him like one of the kids and providing support where needed. See him as a person first and label after that. Staff have a collaborative working relationship with me with the focus on what is best for the child.

Krystal

She can't start school, you need to go and write a letter to the education department". This was the [non-government] system, who also withdrew all hearing support teachers.... At the bottom of meeting agenda, alternative education options is always there. Definitely comments towards low expectations. 'You just need to get it into your head your child is going to struggle her whole schooling life'. That was from Itinerant AP hearing (Itinerant support teachers (hearing) are supposed to assist and support schools through the learning and support team). Well, statistically you know you can't ignore them. School kept insisting on IQ assessment for pure purpose to enrol elsewhere. After the test, they said "We were shocked her nonverbal IQ came back so high. She is intelligent.

Leilla

We were given no option but the support unit, and told he would have better support for his learning. Every day I picked him up he was sat in front of Wiggles videos.

Janice

I wanted mainstream but was forced into special school setting. How will his speech improve when he is in a class with children who don't speak?

Matilda

Originally, I selected a special school because I was told he would be given more attention and better learning (six children ratio to a teacher and a teacher's aide). At the end of the year, his books came home with pages of empty worksheets, Now he is in mainstream and having to play catch up but is making progress in literacy and numeracy.

Bronwyn

The way the NSW school curriculum is currently, means nothing to my daughter in Year 8, who has an intellectual disability. Sadly, too often she has very few goals expected for her at school other than for her to be compliant. This is problematic when I sense she is often inadequately supported or completely disengaged.

John

Regarding adjustments and supports - these are lacking at the best of times, so let alone now in the COVID-19 crisis. Some teachers are good but most have less capacity or regard for including my daughter. However, a positive thing that happened for us was a conversation with our school Deputy Principal when I was at my wits end about how to make the online work accessible and the pressure I was feeling with so much work that required better access. She told me that it was the teacher's responsibilities to make the adjustments. (I have always known this but it is not our lived reality). At least by her saying it I felt there was some validating leadership in the school who had the intention of supporting teachers and encouraging this expectation. Whether it will happen in a time where teachers are stretched to the limit and stressed by everything that is happening, is yet to be seen. After years of expecting and hoping for this, my daughter is in Year 10, I am losing hope.

Tina

4. Suspensions

The following are examples of what we hear from our people across NSW about suspension and exclusion of students with disability. The first two examples (Peter and John) have been written by Family Advocacy staff based on lengthy phone calls by those staff with parents. The third example is a written response shared by a parent with Family Advocacy (Leanne):

The school is framing my 6 year old child as violent! This is a problem. No child is born "violent" or wants to be in trouble. By using this phrase, there is a subtle criminalisation of a child's behaviour. His behaviour is partly due to his disability but really it is due to the system that does not support his disability. I am concerned if these suspensions continue, he will enter the school to prison pipeline. If the school keeps alienating him, he will end up in the justice system.

In an effort to get more funding, the school did a series of standardised tests on my child to get a diagnosis. The tests were done in an unwelcoming room with a stranger. After this, his behaviour was triggered and the school's response was heavy handed. He had 7 suspensions in 2 terms, ranging from 1 to 5 days. We were threatened with 20 day suspensions if we did not comply.

I was self-employed. I had to drop a project and clients and had to borrow money. It is impossible to work with all the school meetings and getting called in regularly to collect your child because there has been an incident. Before, my child was stigmatised as “trouble” and so there are no playdate invitations, so it’s isolating and we didn’t feel like we are part of the school community. Now, my child has positive days; he plays with other kids and we now interact with other families from the school. The attitude of the teacher had a huge impact on my child’s behaviour.

I would question what the antecedent to the behaviour. Often, I would not be told the whole story. It would become clear that my child’s needs were not being met, or it was from not understanding him as a person first, his developmental needs were not being recognised, and/or not enough care had been provided to him, being expected to do things he did not have the capacity to do. If the teacher had recognised my child’s behaviour was his way of telling her something, a form of communication, there may have been a different end result. No kid wants to be in trouble.

We found a very insightful psychologist who taught the teacher that time out for my child is unhelpful, suspension will embed the behaviour, and the child needs support not punishment. Using words like violence is stressful and unhelpful. For a child with severe ADHD and Autism, if they are feeling elevated, it is important to have a safe space to go to such as the library and a safe person to talk to, to build a strong relationship with an adult at the school.

To the school’s credit, they took the psychologist’s advice and after a long process of teacher/parent collaboration, my child is happy and calm, attending full time hours, maturing as he feels he is in a secure environment that is supporting him. The teacher has a personal passion for different learning styles, made incredible accommodations for our child such as wobble chairs, or making the alphabet out of 3D foam so my child could learn in a tactile way. My child is thriving. Behavioural issues were a daily occurrence. Now they are just every now and again.

John

H is 9, in Year 2 and he has had success in school. Why? Because he had an experienced teacher, a “straight” class – a class of his peers, a support worker who understood his support needs. He finished the year well and was proud at the final assembly to receive his certificate with his class mates. The next year H was suspended twice in his last two terms and pushed to be “unable to succeed at school” (I felt). Why? He was put in a 3 - 4 composite class with many kids with issues and strong personalities with a teacher who was in their second year out of university, with a young inexperienced support worker. In year 4, on his first day, my worst nightmare had come true after I received a phone call from the school principal that H had an outburst in the classroom which scared his teacher and classmates and the police were called. They restrained him with handcuffs. My 9-year-old boy.

Leanne

5. Restrictive Practices

Below are some examples of restrictive practices that have been written by Family Advocacy staff based on phone calls with parents:

Physical

My son came home from school very distressed. Once I finally managed to calm him down he told me he had been pinned to the ground in a prone position by multiple staff members at school. I was not informed that a

restrictive practice had taken place. He did not have a behaviour support plan in place at the school. This is not acceptable. He has been traumatised ever since.

My son came home upset after school one day and told me the learning support teacher dragged him by the leg whilst hiding under a table. The school did not report this incident to me. Apparently, he was wanted access to the computers and was not allowed to. Rather than give him some space and time to accept this, he was boxed into a corner by the teacher which felt threatening so he hid under a table. Again rather than keeping calm and giving space to allow for reasoning and self-regulation, the teacher chose an antagonising approach which only made things worse. My son was grabbed by the leg and dragged along the floor. My son is a teenager. He felt ashamed and still does when in this teacher's company.

Chemical

After an incident occurred where my son "lashed out", I was told my son could not come back to school unless he took medication to calm him down. What they failed to tell me, and I subsequently found out, was that he was surrounded by four boys and he was being bullied. If the school had addressed the bullying, the behaviour would have stopped. Instead, my son was in fear of his life and he retaliated to protect himself. When I picked him up, he was laying on the floor in the foetal position, clearly distressed and traumatised.

Mechanical Restraint

My son was not allowed to use his motorised wheelchair at recess in the name of "safety" and so the staff turned the power off to the chair and he was left without any way of moving.

Psycho-Social

In Kindergarten, he had the most amazing teacher that understood different learning styles, really got to know him and my son would run out of class with a smile on his face. The next term he got a new teacher who was the polar opposite, rule oriented without flexibility and with a punitive approach. One day, he would not come out of class and I found him under the table, screaming. The next morning he got himself ready early saying he wanted to go to the bin. Turns out, the teacher had chastised him for not sitting still for one hour, ripped his sticker book rewards chart and told him he would have no friends if he kept behaving that way. I say again, this is in Kindergarten.

Social

In Year 7, my son who is in a wheelchair was placed in the "out of bounds" area with two teacher's aids and no one else around. It was at the top of a hill. All the Year 7's played at the bottom of the hill. So isolating. This went on every recess and lunch for a whole term before I found out. There was no discussion or problem solving, nothing.

In Year 10, all the students were to attend a tax seminar but the room it was scheduled in was upstairs so he could not attend. This was his fourth year in the school and this basic consideration was overlooked.

Organisational

My child was specifically asked not to attend the swimming carnival, athletics carnival, excursions, incursions or school camp. No inclusion happening at all. I believe this was the school's way to get us to leave. Often, permission notes would 'accidentally' not come home.

Communication

My child was never given support by someone that can communicate Auslan sign language with her, the language she can understand and respond to. The teacher's aide knew key word signing she had learned at a special school, this is very different to Auslan and my child could not communicate in this language. It's like having a Spanish speaking teacher when you speak English. Also, my child had an FM system, which is a microphone that would need to be attached to the teacher's lapel and feed into her hearing aide. This was sometimes used and sometimes not. The teacher was supposed to take it off during classwork time when she was going around to individuals but it would often be left on. This was very distracting and meant my child found it hard to concentrate to do classwork.

Seclusion

Use of sole confinement and time out placing my son away from their peers and natural supports and safeguards.

My child was being placed in their wheelchair in the out of bounds area of the school clearly away from their friends. His friends told me this, the school did not even consider changing this, I think it suited them.

I dropped into school and saw my child facing a wall in a line with other students in wheelchairs. I decided right away that that was his last day in the school and we moved to the local regular class, much better.

Appendix 2 – COVID-19 school case studies from parents of children with disabilities

As you will see, there is a disconnect with what is being proposed by the Department and what is happening on the ground. Families are not feeling confident and are confused with the messaging as to whether or not it will be safe for their child, particularly if they are at high risk, to go back to school. It would be really helpful if the Minister could make an announcement directed at families of children with disability and Principals to provide clear guidance about safety, what measures are being put in place in relation to PPE for not just teachers, but teachers aids. Also, it will be important to come up with a strategy at a broader state and regional level of what to do with children who will remain at home and cannot come in to school. Families are asking “Can measures be put in place where online learning with support continues when school goes back face to face?”

Case study 1 – Lack of support

S currently has three kids - one in Year 6, one in Year 12 and M in Year 9. All are doing their school from home. M usually has SLSO support in the classroom.

"If NSW Ed is going to do a half-half job of closing schools then students who have significant support needs (e.g. full-time SLSO) should be allowed / encouraged to attend. Either that or their in-school funding should be used to pay support workers (or SLSO's) to come to their homes to continue their education."

Case study 2 – Poor communication

A student in Year 12 with Autism will not access the online learning or even register his attendance. He will not take any instructions from his mother. The school are threatening to mark him down as an unjustified absentee. His mother has received no support or contact from the school to solve this issue, despite numerous attempts to contact the school via phone and email. The student has a receptive language deficit and therefore, without an educator supporting him directly, mum will find it very hard to try and explain what processes he needs to follow in the work the school provides online. The subject of English is of great concern, as he failed to complete an assessment prior to the Easter break and an email was received from the head teacher of English stating that he will now receive a non attendance letter. Mum tried to both call and email the teacher for clarification and support, and received no answer.

Case study 3 – No reasonable adjustments

One parent reported that the Year 7 work is coming home or online without any adjustments. This parent is not working, comes from an English speaking background, is educated and tech savvy and knows how to make adjustments. She is having to make every adjustment and is feeling very stressed. She also has another child who is remote learning. We can only imagine the extra work and stress for parents who don't have these advantages, such as from CALD or lower socioeconomic backgrounds.

Case study 4 - Vital social connection not provided even though the capacity is there

One parent is very concerned. The last few weeks of Term 1, whilst remote schooling, there was no video contact with the teacher and the kids. L specifically requested if they could go on Google classroom to give her son some social connection plus learning. The school wrote an email saying the only connection they will have will be via email. L says this issue is due to the Principal's inflexibility.

She was initially sending A to school but no one was there except teachers. He was getting lonely plus he did not have his usual SLSO. All learning moved online with no supports whether at school or at home. The school suggested he take home work from the support unit. A refused.

At the moment, the entire onus is on the parents to teach him. They have made adjustments and connected the topic to practical things in the house, eg. recycling, they showed him the rainwater tanks, where the grey water goes. He was engaged in his learning but both parents work full time and this is not sustainable for a term. This should be the teachers' role.

Case study 5

Single mum of four children (some with Aboriginal backgrounds), all with additional needs at the same primary school. Lack of communication, coordination or direct support from the school. All children given different formats for learning, some video, some simply PDFs, which has made it extremely difficult for the mum. One morning a 50 page PDF was sent through to be worked on that morning for one child - in primary school. There was no time for the mum to read this so she could prepare and support her child whilst also supporting the other three children.

There needs to be better intelligence/information coming from the regional offices to have consistency. This mum should have been flagged as needing extra support. Even when things go back to normal, not all kids will be able to go back. This needs to be addressed.

Case study 6

"The number of Zoom meetings has been an issue for us too - really fatiguing and leading to extra homework. I've started giving feedback to ask which meetings are essential (still a work in progress)."

Case study 7

"There is a real 'dancing' going for parents with schools as they try to ask for extra accommodations yet keep positive relationship happening."

Parents should not be put into this position in the first place. The extra accommodations should have been thought through in advance or at least a conversation should have been instigated by the school not the onus being placed on the parent.

Case study 8

"What is a reasonable time expectation for a school to create a modified curriculum program for a child? My daughter has moved to a new mainstream school, (Year 2) and they have been great, have embraced my daughter and have supports in place, but no real clarity around expectations, or a directed and focused plan."

Clearly, a policy needs to be put in place to properly guide teachers on what to do in this situation.

Case study 9

A has language disorder and is currently not able to write. Teacher has requested he has to provide written work to indicate lesson outcomes. The teacher will not consider other ways to show learning outcomes. Mum has tried

to talk with the teacher and she is very pleasant but will not make these adjustments. Teacher is new this year and does not seem to be getting any better guidance from the school leadership.

Case study 10 – Low expectations

One child in Year 6 was given the reading at Year 1 level which is well below his reading ability.