



Association for Children with a Disability

Support Educate Influence Achieve



Submission to the Victorian State Disability Plan 2017-2020

About the Association for Children with a Disability (ACD)

Established 35 years ago, ACD is a not-for-profit community based organisation representing children with a disability and their families living in Victoria.

ACD Statement of Purpose

- To empower families of children with a disability to be as self-sufficient as possible in advocating on behalf of their child and family.
- To promote and advance the rights of children with a disability and their families.
- To advocate on behalf of children with a disability and their families to ensure the best possible support and services are available.
- To work collaboratively with other organisations to improve the service system for children with a disability and their families.

Introduction

ACD is keen to work closely with government to ensure that the new State Disability Plan responds to the needs of children with a disability and their families and carers. This submission to the process of developing the State Disability Plan for 2017-2020 is informed by the thoughts and feedback from ACD members and supporters through a discussion forum and online survey, as well as the input of ACD parent support and community education staff who are regularly engaged with parents and families from across the State.

To undertake this submission, ACD engaged in the following preparatory activities:

- ACD held a discussion forum on the State Disability Plan, with members, supporters and staff attending and discussing their thoughts through a facilitated process on the discussion paper and plan.
- An online survey based on key issues and recommendations raised at the forum. We received a number of valuable responses from the wider members and parents of children with a disability. Their stories, concerns and expectations helped ACD identify the needs of children with a disability that should be addressed in the new plan with a whole of Government approach.

ACD found six areas that should be addressed in the State Disability Plan, along with recommendations for each area.

The areas are:

- Access to a quality education
- Post-school transition
- Changing social attitudes to people with a disability
- Access to advocacy and legal aid
- Access to information and support services in relation to the NDIS
- Implementing the plan, driving outcomes and the government's role

Access to a quality education

"I have two boys on the spectrum and education is our greatest concern. Teachers are not trained or given resources to create an appropriate setting for learning. Aides are so difficult to obtain funding for and I have been having to educate our school and teachers for 4 years now. My boys want to learn but instead are made to feel deviant and naughty, just because they cannot cope in the environment offered." ACD parent

"New teachers (and old) do not know how to cater for children with disabilities in the classroom."
ACD Parent.

A quality education for people with a disability is of upmost importance. People with a disability must have equal access to opportunities, and that means access to a quality education. A quality education is vital in facilitating the economic participation of people with a disability. Without a quality education, engaging in the workforce and developing career pathways is not possible. Furthermore, for people with a disability to be active citizens, that is, to be able to participate in the community as leaders, decision makers, spectators and volunteers, a quality education which equips them with leadership skills, confidence and life skills is needed.

50% of survey respondents agree that ensuring people with a disability have access to a quality education that responds to their needs and prepares them for participation in the workforce is the most important issue the State Disability Plan should address.

ACD has identified key issues that should be addressed in the State Disability Plan to ensure that people with a disability receive a quality education.

- ACD members and clients consistently report that schools and teachers are not equipped or trained adequately to effectively teach their children. 77% of survey respondents agree that in order to address the lack of knowledge of disability standards in school, a training program to ensure that teachers understand the needs of students with a disability is a top priority. This echoes the findings determined through the review of the Program for Students with Disabilities (PSD) where teacher training and skill development was a major focus of the review and the Government's response.

Recommendation: Ensure that teachers understand the needs of students with a disability by implementing a training program, in line with and supporting the complementary recommendations of the PSD review.

- 39% of survey respondents agree that ensuring people with disabilities are equipped with the life skills and supports to live as independently as possible is the most important issue the State Disability Plan should address. No child with a disability should be denied the opportunity to obtain the skills and knowledge necessary to live an independent life and exercise choice and control.

Recommendation: Ensure that life skills, with the intention of provided independence and control, are provided to young people with a disability, either through the provision of quality education or via other high quality supports.

- Career pathways should be addressed in secondary school, as they are for young people who do not have disabilities. 39% of survey respondents agreed that mentor programs for young people with a disability in which mentors model success and participation in career pathways for young people with a disability is a top priority. Mentoring programs such as that facilitated by the Inner Melbourne VET Cluster (IMVC) under the Broaden Your Horizons initiative are a good example of how this can be developed and what can be achieved.

Recommendation: Ensure that career and further study pathways for young people with people with a disability are addressed in secondary school through the implementation of new or further rollout of existing implementing a mentor program for young people with a disability in which success and participation in career and further education pathways are modelled.

Post-school transition

"It's difficult to get coordinated health care for a young adult, it was difficult to move away from a paediatrician when our daughter was almost 23 years of age. Hospitals don't prepare you for the move from paediatric to adult ward & doctors on adult wards don't have the understanding of disability that paediatric doctors have in dealing with our daughter with complex epilepsy & associated conditions." ACD parent

"I feel I need more information about support with living options, adult carers & respite" ACD parent

The post-school transition can be difficult for young people with a disability and their families. Finding further education and employment options is often challenging. In order for people with a disability to be able to participate in the workforce, post-school transition to further education or employment needs to be addressed. The transition to adult health and housing services is consistently mentioned as an issue for ACD families. With the NDIS rolling out in Victoria over the next few years, it is important that there is a continued focus on the accessibility and usability of mainstream services. Transitioning to adult services continues to be a sticking point.

51% of survey respondents agreed that finding and transitioning to adult support services was a key concern in terms of transition to adulthood, 48% agreed that finding appropriate employment was a key concern, and 31% agreed that transitioning from children's to adult hospital was a key concern.

ACD has identified key issues that should be addressed in the State Disability Plan to ensure that people with a disability transition out of school and into adulthood successfully.

- The post school transition involves moving from secondary school to further education, training or employment. For this to occur employment opportunities need to exist – and with a focus on employment opportunities outside of the traditional areas of employment. Targets such as public service quotas are a positive and necessary step forward (and which have not been progressing as adequately as necessary). Furthermore, greater emphasis should be placed on utilising these quotas as a stepping stone to build the skills, confidence and experience to enable people with disabilities to build a career through and/or beyond the public service.

Recommendation: There should be a focus on meaningful employment opportunities and career paths rather than employment in only closed environments or public sector employment opportunities. The state government can implement quotas that focus on meaningful employment in the public service and government contracted work. More inclusive employment opportunities such as job sharing could be considered.

- Housing for young people with a disability remains a core issue, and a major concern for parents of these children as they consider their futures. There are high numbers of people looking for suitable housing and the NDIS will further increase housing demand. Therefore, improving the accessibility of housing should be a priority.

Recommendation: The State Disability Plan could involve working to legislate accessible universal design of housing as a regulation instead of a voluntary measure.

- ACD has consistently found that transitioning from child to adult health services is stressful, problematic and difficult to navigate for young people and their families with a disability. Health services should be accessible and usable for all people, therefore this is an area that needs to be addressed.

Work has been undertaken previously within the RCH and guidelines have been developed which have assisted in transitioning, however it remains an area of key concern, and one of the three major priorities of the Paediatric Clinical Network forum, as well as being discussed across the primary health sector. Investment in developing and piloting more streamlined and supported transitions will achieve a reduction in family/carer stress, and improve health outcomes for the individual, with a flow on effect on whole-of-life outcomes—especially at such a formative life stage.

Recommendation: Address the transition from paediatric to adult care for people with a disability, including the expansion and further development of transition programs across the relevant hospitals for the period of the next plan.

Changing social attitudes to people with a disability

"I am very hurt as a few of my child's friends have been asked to stay away from my daughter (by their parents) as she is deemed "naughty". My daughter has become the target of bullying, which has never before happened to her. She is in grade 2. My concern is that parents need to be more educated (maybe from schools) to be able to help their children be more compassionate towards their peers who, like my daughter, struggles for acceptance. As she's getting older, it appears she is being segregated from her friends." – ACD parent

"We need to make higher expectations on people with a disability. There should be an expectation that ALL people should be able to participate in sport, cultural activities, leadership, and education." – ACD member

Negative attitudes, along with misconceptions and lack of awareness, present barriers to social inclusion for people with a disability including in education, employment, and community participation. Negative attitudes in the community lead to limited involvement in social activities, poor educational outcomes and disadvantaged economic participation. In education, negative attitudes are one of the difficulties faced by children and young people with a disability. Negative attitudes among both teachers and student peers (including their parents) are a barrier to inclusive education. It is well recognised that "the heaviest burdens of disability arise from personal interaction and not from disability itself".

20% of survey respondents' agree their greatest concern regarding their child with a disability is negative societal attitudes towards disability that result in exclusion. Over one quarter of respondents indicate that the State Disability Plan should address changing societal attitudes to disability and inclusion.

ACD has identified key issues that should be addressed in the State Disability Plan to change negative attitudes towards and misconceptions about people with a disability.

- Children and young people with a disability experience significant negative attitudes in various domains of their lives. There are lower expectations on their capacity to participate in sport, cultural activities, leadership and education, with comparing to their peers without a disability. ACD members have raised the issue that children with a disability benefit the most when all members of the community, including their family members, place a greater emphasis on their strengths and increase their expectations of what they are capable of, now and in the future.

Recommendation: Work from an expectation that all people should be able to participate in mainstream educational, sporting and cultural activities. The Victorian government should play a leading role in organising a disability awareness program for the public that focuses on recognising the abilities and understanding the lives of people with a disability.

- Negative attitudes held by school teachers, parents, and peers has created a less inclusive environment in which children and young people with a disability are more likely to become isolated and discriminated.

Recommendation: Place an increased focus on changing attitudes toward disability at school, and increasing the inclusion of children and young people with a disability in the education domain particularly.

Access to advocacy and legal aid

"Ongoing State-wide (Rural, Regional & Metro) Support and Advocacy to ALL Victorian Families & their person with a disability!" – ACD Parent of children with a disability

"I am concerned about ongoing human rights violations by government funded organizations towards people with a disability." – ACD Parent of children with a disability

Advocacy issues have been highly prioritized by ACD members. Children and young people with a disability and their parents and carers find it challenging to make complaints or deal with discrimination issues as a result of lacking knowledge, strategy and support. The current rollout of the NDIS throughout Victoria is already demonstrating the need for families and carers of people with a disability to be well supported, educated and resourced to achieve the best possible outcomes under the NDIS. Disability advocacy services in the Barwon launch (or transition) site have reported significant increases in demand, and ACD are seeing an increase in demand for individual support and group information sessions coming out of the North East region.

A third of survey respondents believe that the State Disability Plan should include the establishment or expansion of advocacy mentor programs for parents of young people with a disability to ensure empowerment of families of children with disabilities. 48% of respondents agree that the Victorian government should provide a robust legal and economic framework so that people with a disability can participate fully in community and economic life.

The Victorian Government can assist families of children with a disability to protect their rights and have a stronger voice, by continuing to invest further in independent disability advocacy – both through one-on-one advocacy support and through the provision of information and resources, peer support, and peer advocacy programs. Families with independent advocates, or with a strong capacity for self-advocacy, are achieving more successful outcomes than those who are unsupported. It is important to avoid compounding disadvantage, as those who have a reduced capacity to advocate for their child, are often the most vulnerable in our society and in the most need of support.

ACD has identified key improvements that should be achieved in the State Disability Plan to ensure that people with a disability and their families access to advocacy and legal aid.

- A majority of respondents believe that the new State Disability Plan should ensure parents and carers of people with a disability have the capacity and education to advocate for their child. In the new consumer driven market of the NDIS, it is vital that people with a disability and their families and carers are able to receive and fight for quality services.

Recommendation: The plan should introduce an advocacy mentorship or training program, so families of children with disability are able to advocate and manage in the NDIS environment.

Recommendation: Safeguard advocacy and legal aid services through a commitment to ongoing funding for the next 3 years to cover the period of the NDIS rollout, and a growth in funding of 20% for the next 3 years to enable advocacy organisations to address the short to medium term growth in demand for advocacy.

Access to information and support services in relation to the NDIS

"I would like a detailed guide of the NDIS sent to EVERYONE." – ACD parent

"ACD needs to continue to be available & represented for ALL families across Victoria & a similar advocacy agency for ALL adults with a disability & their caring families. ACD needs to be funded appropriately to support ALL Victorian families & their child with a disability to inform, empower skill-up & coach families through the NDIS changes!" – ACD parent

The State Disability Plan should provide information and support to help families make the most of the NDIS. Many members of ACD have raised concerns that the most vulnerable people may fall through the cracks due to difficulty in accessing the NDIS.

72% of survey respondents believe that the Victorian Government should provide services and support to bridge the gap between the NDIS and mainstream services

ACD has identified issues that should be addressed and improvements that can be achieved through the State Disability Plan to ensure that children and young people with a disability and their families and carers can better access to information and support services

- ACD members have reported their concerns in finding adequate information and support as the NDIS rolls out.

Recommendation: Provide continued government support to organisations who provide NDIS information, advocacy and support.

- There are concerns that gaps will increase in services, particularly in rural and regional areas, due to the market driven nature of the NDIS.

Recommendation: The State Disability Plan should include a commitment to and increased resourcing regarding the continuity of services in rural and regional areas once the NDIS is rolled out. Furthermore, the Strengthening Parent Support Program should be continued and be funded more intensively to assist rural/regional families to receive the information they need and build local support networks.

Recommendation: Encourage organisations to undertake an access audit to assess and address the barriers that exist with their services or programs and to make their services responsive to the needs of people with disability.

- Increasing amounts of information and support services are available online, but this is not accessible to all. Digital inclusion is of increasing importance in the emerging NDIS-era and building the necessary skills and infrastructure to ensure people with disabilities have choice and control in an increasingly digital marketplace.

Recommendation: Address digital inclusion to ensure that all people can access information and support through focused programs around skill development and infrastructure.

Implementing the plan, driving outcomes and the government's role

In creating, implementing and driving the outcomes of the State Disability Plan, ACD recommends the following:

- Clarify the government's roles and responsibilities in supporting people with a disability, as well as community and business sectors role.
- The plan should clearly articulate how it links with broader reforms and related strategies such as Mental Health, Family Violence, as well as its connection with the NDIS.
- The plan should take an intersectional approach to recognise different groups including women, family groups and CALD, as well as those who are most vulnerable.
- The diverse needs, abilities and experiences of people with a disability should be taken into account. There is no one statewide 'experience of disability'.
- Outline concrete actions in the 2016-19 plan that are detailed and include measurable performance measures and outcomes.
- Unlike the current State Disability Plan for 2013-2016, the next Plan need to include a full evaluation of its progress and outcomes. There need to be structures or mechanisms in place to evaluate and assess the plans progress yearly and upon its conclusion. This information should be made publicly available.

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