Carers Australia VIC

Carers Victoria submission

Consultation paper for state disability plan 2021-2024

May 2020

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

People receiving care could be a parent, child, partner, grandparent, other relative or friend. Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership-based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This response was prepared by Carers Victoria's Policy and Research Team and is informed by insights gained through the delivery of carer supports and services. Carers Victoria frequently receives feedback from individuals, carer support groups, staff, network partners and committees. The case studies and quotes used throughout use pseudonyms to ensure carers' confidentiality.

For information contact:
Scott Walker
Chief Executive Officer
Carers Victoria
Telephone: 03 9396 9500
Facsimile: 03 9396 9555
Email: scott.walker@carersvictoria.org.au
Website: www.carersvictoria.org.au

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Summary of recommendations

Carers Victoria recommends the State Disability Plan 2021- 2024:

1. Be complementary to the Victorian carer strategy 2018-22.
2. Describe disability as individually differentiated.
3. Include prescriptive frameworks for Government departments and local councils to facilitate meaningful consultation with carers with disabilities as a special needs group.
4. Detail how the Government intends to provide sufficient resources to Statutory bodies to undertake their duties as guardians and/or administrators in keeping with the Guardianship and Administration Act (2019).
    a. Outline how the Victorian Government intends to promote the new legislation to people with disability, families and carers.
5. Indicate how the Government intends to respond to the recommendations of all existing Royal Commissions and begin implementation of the recommendations to which it has already committed.
6. Outline a platform to celebrate people with disability, families and carers.
7. Outline expectations the NDIA:
    a. implement the decisions made at the Administrative Appeals Tribunal (AAT) to all affected participants.
    b. Establish protocols to ensure planning meetings genuinely support the aspirations of people with disability, their families and carers equally to pursue their goals of economic and social participation.
8. Outline the Government’s intentions to conduct a comprehensive audit of current services for people accessing disability, mental health and aged care services focusing on the perspectives of people with disability, their families and carers as well as advocates.
9. Advocate for better cooperation between the NDIA and government departments and agencies and less adversarial approaches at the AAT.
10. Outline the Government’s intentions to build community capacity and inclusivity in existing mainstream services using rigourous research and expert advice.
11. Identify minimum standards of accessibility and equity and ensures each locality within the State has sufficient resources for its population.

Introduction

Carers Victoria welcomes the opportunity to comment on the Consultation Paper for the State Disability Plan 2021-2024 (the Plan). We acknowledge the importance of the Plan as a crucial mechanism in addressing systemic disadvantage and discrimination experienced by people with disability, their families and carers in Victoria.

Carers Victoria appreciates the aspirational vision of an inclusive society with concrete outcomes for people with disability. However, without appropriate reference to and complementarity with the Victorian carer strategy 2018-2022, the Plan is likely to perpetuate the invisibility of families and carers whose unpaid work underpins disability, formal health, mental health and aged care services, as well as mainstream systems like education and housing.

Carers Victoria is concerned the Consultation Paper:

- Perpetuates an inaccurate division between people with disability and families and carers evident in earlier Plans. The Paper makes only superficial references to families and carers and does not refer to solutions which can recognise carers and address problems associated with unsupported care relationships
- Does not make reference to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, nor allude to the fact the Government is likely to provide evidence to the Commission as a funder and provider of historic and current services and how the Government is likely to receive the recommendations made within the timeframe of the next Plan, and
- Does not make reference to the Guardianship and Administration Act (2019) which situates Victoria as the first Australian jurisdiction to recognise supportive guardianship and administration orders. Without adequate reference to the legislation, the Plan will fail to harness this novel framework which can support better legal recognition of people with decision-making impairment and their natural supports.

This submission will selectively respond to questions posed in the Consultation Paper drawing on the expertise of families and carers amongst clients, our membership base and our staff.

Background: facts about carers in Victoria

Victoria’s carers are as diverse as the people they care for. They provide a range of emotional and practical support and provide this care anywhere from a couple of hours a day to around-the-clock assistance.

- 37 per cent report living with a disability themselves,
- Nearly 38 per cent of primary carers have a disability compared with 16 per cent of non-carers,
- Male primary carers are more likely to report living with a disability than female primary carers. However, similar proportions of male and female primary carers report having a profound or severe limitation,
- Median gross income is $455 per week – compared with 2018 minimum wage of $719.20 per week,
- 78 per cent live with the person receiving care,

- 41 per cent care for their partner; 29 per cent care for their child (including adult children); 21 per cent care for their parent; and 9 per cent care for another relative or friend,
- 27 per cent spend more than 40 hours per week caring for the person they share a care relationship with,
- 29 per cent felt it was their family responsibility to take on the caring role; and 9 per cent felt they had no other choice,
- 58 per cent had not received assistance from formal services in the last six months,
- 28 per cent didn't know the range of services available, and
- 34 per cent had not participated in any social or community activities without the person receiving care.

What is a 'care relationship'?

Care relationships between people providing care and people receiving care are multifaceted and dynamic. Carers work together with the person receiving care to support and ensure their wellbeing, navigate service systems, advocate for rights and inclusion and provide hands-on care. Unsupported and/or under-resourced, this often comes at significant personal and financial cost. Care responsibilities can commonly have an adverse effect on the emotional and physical wellbeing of carers who experience greater exhaustion, stress, anxiety depression, injury and physical ill health than those not in a caring role. This can impact on the capacity to sustain the caring role, function effectively in other areas of their life and reduce their quality of life and sense of wellbeing. Carers require support together with and independent of the person(s) for whom they care to reach their full potential.

The disability, mental health, aged care and carer support sectors have each been undergoing major reforms in recent years, with increasing nationalisation of previously State Government or jointly funded services. Carers Victoria wishes to reiterate that due to restrictive eligibility criteria, funding changes and teething problems associated with new systems, families and carers continue to experience significant gaps in both metropolitan centres and regional areas.

Carers Victoria has consistently advocated for increased recognition of carers in State Government disability policy, as people with needs in their own right and as an acknowledgement the needs of and outcomes for people with a disability are inextricably linked with people who are in care relationships with them.

The legislative basis for this is the Victorian Carers Recognition Act (2012) which is intended to support care relationships by:

- having each person in the care relationship and the care relationship itself respected and honoured.

- Considering the views of each person in the care relationship in the assessment, planning, delivery, management and review of services affecting each individual and the care relationship.

Further, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) affirms:

“Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities” (Preamble, Section x).

> *“We believe that for people with a disability to receive quality disability supports and to achieve positive life outcomes, the role of their natural supports such as families and carers need to be recognised and respected”*
>
> Laurie Harkin AM; Victorian Disability Services Commissioner 2007-2018

Victorian Carer Strategy

Carers Victoria’s primary recommendation is the Plan be complementary to the Victorian carer strategy 2018-22.[1] The Plan and future strategies should include commitments for respective enhancement and connection.

Recognising and supporting Victoria’s carers: Victorian carer strategy 2018-22 is the first Victorian whole-of-government strategy to support carers in their own right.

The strategy sets out a framework to better recognise and support carers and outlines ways carers, peak organisations, service providers and communities will work with the State Government to address five key priorities. These priorities are:

1. Carers have better health and wellbeing
2. Carers are supported in school, study and work environments
3. Carers can access support and services that meet their needs
4. Carers have less financial stress
5. Carers are recognised, acknowledged and respected.[2]

For the Consultation Paper to be complementary to the Victorian carer strategy 2018-22, reference to and integration with Priority 5 is essential.

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[1] https://www.carersvictoria.org.au/media/1091/dhhs-victorian-carer-strategy.pdf

[2] Carers Victoria, 2017. Developing a Victorian Carer Statement, pp. 46.

Priority Five: Carers are recognised, acknowledged and respected

What will be different:

Victorian Carers will be recognised, acknowledged and respected for the role they play,

'Hidden' carers will be encouraged to access support and services to meet their needs, and

Victorian carers will be listened to, respected and involved in decision making about services and programs for people they care for.

Carers Victoria is committed to working with the Office of Disability and other Victorian Government Departments to achieve the objectives of the Victorian carer strategy which will improve the lives of carers and the people for whom they care.

Topic 1: Improving how we describe disability and disability inclusion in the next plan

Questions

1. How should we set out a description of disability and a human rights approach in the next state disability plan?

2. Are there other statements you'd like the next plan to say about what disability is, what it means to you, and how Victoria needs to do its work to be more inclusive?

Carers Victoria recommends the Plan describes disability as individually differentiated to increase awareness that different disabilities manifest in very different ways and people with the same diagnosis or condition are impacted differently.

Additional descriptions of disability should:

- Emphasise disability intersects with other social markers such as age, gender and sexual identity, cultural background and locality, religion,
- Address practices which inadvertently reinforce ableist assumptions such as highlighting people with physical or sensory disabilities as the public voice of disability advocacy, or including people with mild intellectual disabilities who subsequently act as proxies for all people with intellectual disability, and
- Recognise the perspectives and experiences of people with severe and profound intellectual disabilities require specific support, usually informed by engagement with their natural supports.

Topic 2: Finding better ways to include people with disability in making the next plan

1. What are other groups that we need to reach out to?

Carers Victoria is disappointed the Consultation Paper does not identify carers with disabilities as a special needs group, despite the fact primary carers have a higher rate of disability,[3] long term health conditions and significantly worse mental health than the general population.[4]

Carers with disabilities often remain hidden as consumers either by the person(s) for whom they care, themselves or by service providers. This is likely to result in ineffective assessment and inadequate service delivery which is disadvantageous to them or the person(s) for whom they care.

Carers with disabilities themselves need disability, health and mental health services which understand and support their care relationships, so they are able to carry on their caring roles.

Carers Victoria recommends the next plan includes prescriptive frameworks for government departments and local councils to facilitate meaningful consultation with carers with disabilities as a special needs group and the organisations representing them when developing and reviewing their disability action plans and to report on the consultations.

2. What are some of the specific things we can do to engage effectively with particular groups?

Effective engagement with families and carers involves genuine recognition of their role and care relationships in a manner which is consistent with and complementary to the Carer Recognition Act (2012) and the Victorian carer strategy 2018-22.

Further, arrangements for face-to-face engagement with families and carers with and without disabilities should include options to share their perspective with the person(s) they care for and unaccompanied. This will enable families and carers to honestly relate their experiences of their care relationships and identify ways care relationships can be better supported by the community and services. To allow families and carers to independently attend face-to-face consultations, provisions for 'respite' or substitute care and transport should be included in early budgetary planning.

3. What are some of the things we can do to let people know that we have taken their advice seriously and have brought it into the development process?
4. What codesign approaches do you think would be good for the next state plan?
5. What examples have you come across of codesign working well in government policy development?

In 2017 Carers Victoria worked in partnership with the Victorian Government to consult with families and carers to inform the development of the Victorian Carer Strategy. Carers Victoria devised and undertook a multi-faceted community engagement strategy involving a carer

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[3] Australian Bureau of Statistics (2015), Survey of Disability, Ageing and Carers (SDAC), Australia

[4] Edwards, B., D.J. Higgins, M. Gray, N. Zmijewski and M. Kingston (2008) *The nature and impact of caring for family members with a disability in Australia,* (Research Report No. 16) Australian Institute of Family Studies, Melbourne.

survey, community forums with carers and services providers and special interest focus groups to address barriers some groups face in participating in consultations and engagement such as young carers, families and carers of people living with mental illness, people from culturally and linguistically diverse backgrounds, people who identify as Aboriginal and Torres Strait Islander or as lesbian, gay, bisexual, transgender, intersex or queer/questioning. This strategy engaged over 1100 carers who responded to the carer survey, 387 individuals and 85 peak bodies and service provider organisations who participated in community forums and special interest focus groups. Face to face consultations were conducted in a range of locations including many regional towns such as Mildura, Horsham, Bendigo, Sale, Wodonga and Geelong. Over 15 face-to-face consultations occurred in the Melbourne Metropolitan Region supported with feedback from carers themselves.

The responses of carers informed the development of the Victorian Carer Strategy 2018-22.

Topic 3: Strengthening the state disability plan outcomes framework

1. What do you think about a new outcome around people's intimate lives?

Carers Victoria supports the introduction of the new outcome around people’s intimate lives with the option of adding a new outcome area under Fairness and safety.

The full realisation of this goal will require the Government to reduce high rates of violence between residents in group homes by addressing the extent to which a lack of meaningful housing choices for people with disabilities contributes to behaviours of concern, including violence and sexual assault.

Carers Victoria also believes better outcomes for people’s intimate lives will be adequately developed, measured and evaluated with explicit reference to the Guardianship and Administration Act (2019). Indeed, the Plan is a timely opportunity for investment in a state-wide awareness campaign about the Act.

As the first jurisdiction in Australia to enact legislation to recognise supportive guardians and/or administrators, Victoria has an opportunity to breakdown existing barriers to legal recognition of people with disability, particularly those with cognitive disabilities. Families and carers often report to Carers Victoria the complications they encounter with health authorities and government agencies when the person for whom they care is expected to express their will and preferences and their natural supports are denied opportunities to support them to do so.

Carers Victoria recommends the Plan should detail how the Victorian Government intends to provide sufficient resources to Statutory bodies to undertake their duties as guardians and/or administrators in a manner which reflects the Represented Person’s will and preferences, rather than their best interests. These measures should include the State Trustees, the Office of the Public Advocate and the Victorian Civil and Administrative Tribunal.

The Plan should also outline how the Victorian Government will promote the new legislation to people with disability, families and carers for whom the new regulatory framework will facilitate improved legal recognition, particularly when liaising with government agencies, health authorities and service providers who make important decisions about individual’s lives.

The Consultation Paper makes no reference to the Royal Commission into Violence, Abuse, Neglect and Exploitation against people with disability (Cmlth), the Royal Commission into Aged Care Quality and Safety (Cmlth) and the Royal Commission into Victoria's Mental Health System.

The Consultation Paper is silent on the Government's potential evidence to the Disability Commission as a historic and current funder and provider of disability services including accommodation.

Notwithstanding delays attributed to the COVID-19 pandemic, all current Royal Commissions are expected to deliver their Final Reports within the timeframe of the next Plan.

Carers Victoria recommends the Plan indicates how the Government intends to respond to the recommendations of all three Royal Commissions and begin implementation of the recommendations to which it has already committed.

2. What do you think about a new outcome around recognition and pride?

Carers Victoria supports the strengthened outcome focus around recognition for people with disability.

The Victorian Disability Awards have historically focused on service providers which reinforces perspectives people with disability are invariably users of specialist disability services.

However, an Awards platform which predominantly recognises and celebrates the achievements of disability services is not the same as an Awards platform which recognises families and carers. The conflation of service providers and carers in the Consultation Paper suggests the two are interchangeable and substitutable. As stated earlier in this submission, the UNCRPD affirms families and carers as natural supports and allies for individuals; disability service providers augment the resources of families to keep care relationships sustainable.

By perpetuating divisions between people with disability, families and carers, the Consultation Paper reinforces narratives of disability which emphasise individuals as independent atoms at best or segregated service users at worst, rather than members of families like everyone else in the community.

A safer, more responsive and accountable disability provider landscape is only one aspect in the ecology of a more inclusive society.

Carers Victoria recommends the Plan outline a platform to celebrate people with disability, families and carers through a competitive process which recognises their achievements in categories such as advocacy, music, art and/or acting, business/employment, education, sport and community participation. Carers Victoria believes this supports recognition of the interconnectedness of ordinary life, as well as efforts to change communities at a local or global level which has always involved families.

Topic 4: Introducing overarching approaches to strengthen government commitments under the new plan

1. What do you think about including community attitudes and universal design as guiding approaches in the new plan?
2. Are there important things that Victoria needs to do through the next state disability plan that are not reflected under Community attitudes and Universal design? What are they?

3. What are other ways we can strengthen the design and accountability of commitments under the next state plan?

Carers Victoria believes the design and accountability of commitments under the next Plan will be strengthened by greater complementarity to the Victorian carer strategy 2018-22. As stated earlier in this submission, the Plan and future strategies should include commitments for respective enhancement and connection.

The Victorian carer strategy outlines a number of priorities for the Victorian Government to support families and carers and people with disability, particularly those who are NDIS participants such as:

- Continue to work with the NDIA for greater support for people with a disability, their families and carers.
- Work alongside the National Disability Insurance Agency for greater potential access to education and work environments for people with a disability, their families and carers.
- Support carers to better understand the role of the NDIS in improving wellbeing and economic participation for people with a disability and their carers.
- Increase carer understanding about what support people in care relationships can receive through the NDIS, including through the ILC part of the scheme

Moreover, there are other mechanisms the Victorian Government can utilise to strengthen the design and accountability of commitments under the next State Plan. These can include:

- Transferring the Office of Disability to the Department of Premier and Cabinet from Department of Health and Human Services. Being located in a more central department such as the DPC is likely to support the efficient coordination of actions under the Plan and associated reporting across the whole of government.
- Implementing transparent reporting including disaggregated data regarding service delivery
- Connecting the Outcomes Frameworks to Key Performance Indicators for Department Executives
- Appropriate planning, evaluation and review of services that include the experience of people with disabilities, their families and carers.

Topic 5: Strengthening the NDIS and mainstream interface

The introduction of the NDIS has not only disrupted disability service provision but entire ecologies of support and services for people with disability, families, carers and government departments. Persistent gaps include transport, health interfaces, thin markets in regional and rural areas and for people with complex needs and behaviours of concern. The Consultation Paper does not address the limitations of the NDIS for participants, families and carers, and ‘residual services’ for people who do not meet eligibility requirements for the NDIS. These topics are explored in detail below.

The Consultation Paper should also acknowledge the current Disability Plan did not adequately anticipate or address the poor implementation of the NDIS. While the Victorian Government delivered the Transition Support Program, the Victorian disability advocacy futures plan 2018-2020 and the intensive support team (IST), these resources have failed to stop too many individuals and families falling through the cracks.

Limitations of the NDIS for participants, families and carers

Only 10 per cent of Victorians with disability are eligible for NDIS funded support packages and its implementation has created many challenges for participants, families and carers. As previously stated in this submission, a safer, more responsive and accountable disability provider landscape is <u>only one aspect </u>in the ecology of a more inclusive society.

The poor implementation of the NDIS is commonly reported in mainstream media. Disability advocacy services have witnessed an increased demand on their services from NDIS participants, families and carers whose plans are inadequate.

Carers Victoria believes the Participant Service Guarantee, originally expected to commence on 1 July 2020 but is now deferred due to the COVID-19 pandemic, is a welcome framework which provides clear information about timelines to all those involved. However, it is unlikely the Guarantee will address some of the very complex problems participants, families and carers face.

For example, families and carers continue to report planners from the Agency and Local Area Coordinators are not sufficiently equipped with adequate skills and experience to make sound and fair judgements as to a person’s eligibility and support needs. Commonly, participants, families and carers report they have not been able to acquire and submit adequate documentation and ‘proof of disability’, due to a lack of awareness of what is required among health professionals and the costs associated with obtaining some evidence.

Other reports show costly assessments and subsequent recommendations from medical and allied health professionals have not been considered or included in the participant’s NDIS plan. Many reports indicate no feedback is provided as to why recommendations are not implemented.

Individual participants, families and carers make difficult decisions to pursue unfair and unreasonable decisions to the fullest extent possible at the Administrative Appeals Tribunal (AAT). However, the decisions made at the AAT are rarely implemented at a broader level despite the fact clarification regarding legislation and regulations is meant to do precisely this. The issue of transport – particularly the McGarrigle decision of 2017 – is illustrative of the NDIA’s refusal to implement AAT decisions in other participant’s plans. Carers Victoria believes it follows that the Victorian Government should advocate the NDIA implement the decisions made at the Administrative Appeals Tribunal to all affected participants.

Further limitations of NDIS implementation are the inadequate supports provided to people that will ultimately undermine the aspirations and outcomes of the State Disability Plans. This refers to a consistent lack of capacity building supports for participants over the age of 15, reflecting an absence of future-oriented planning sessions. According to the NDIA’s own data collection, such as the NDIS quarterly dashboards, capacity building supports sharply decline for participants aged over 15 with the bulk of funded supports focused on core supports despite the fact 85.7 per cent of participants aged between 15 and 24 years and 87.6 per cent of participants aged 25 years and older are categorised as having low to medium levels of function.

For the cohort of participants aged between 15 and 24 years, funds for capacity building supports are extremely low: daily activities 11.3 per cent; social and civic 1.7 per cent; relationships 2.4 per cent; choice control 1.0 per cent; health and wellbeing 0.2 per cent; home living 0.0 percent and lifelong learning 0.0 percent.

For the cohort of participants aged 25 years and over, funds for capacity building supports are as similarly low: daily activities 7.1 per cent; social and civic 1.2 per cent; relationships 0.8 per cent; choice control 0.8 per cent; health and wellbeing 0.2 per cent; home living 0.1 percent and lifelong learning 0.0 percent.[5]

The data reflect low expectations by the Agency and its partners. The effects of such plans are likely to leave many people vulnerable to missing out on building essential independent living skills so they can participate more fully in the community. The NDIA's published quarterly reports and 'dashboards' show this to be a consistent trend since rollout commenced in July 2016.

Carers Victoria recommends the Victorian Government to advocate planning meetings genuinely support the aspirations of people with disability, their families and carers equally to pursue their goals of economic and social participation.

'Residual services' for people who do not meet eligibility requirements for the NDIS

As stated earlier in this submission, the NDIS was intended to provide individual support packages to 10 per cent of Victorians with a disability. Carers Victoria is concerned the Victorian Government has not released a comprehensive Strategy or Plan to address the needs of the remaining 90 per cent of people with disability in Victoria who are ineligible for the NDIS because of the nature of their disability or because they do not meet residency or age requirements.

There is broad acceptance within the community that Local Area Coordinators (LACs) are not undertaking their community building and connection functions for all people with disability because there is too much pressure to develop participant plans.

An inability to access adequate services results in increased demand on families and carers who are required to provide additional care without support or assistance themselves.

Through the reach of its State-wide service delivery, Carers Victoria hears reports of the impact of the NDIS being felt beyond participants, families and carers and service providers. The NDIS now provides a new avenue of income for a wide range of professionals and workers and the price guide indicates the cost of doing business in an NDIS-world (for participants whose funds are managed by themselves/families, brokers or the Agency). In some cases, the cost of doing business is now being charged to non-NDIS participants who are unlikely to have financial resources to afford them. For instance, families and carers from

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[5] Victorian Public Dashboards 30 June 2019; https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2018-19

Mildura have reported the cost of local speech therapists has increased. Prior to the NDIS, the hourly cost was $90; now it is $160 per hour in line with the NDIS price guide.

Decisions made by individual speech therapists put further pressure on access to speech therapy because families cannot afford high out of pocket costs. The Victorian Government should provide more access to allied health services to ensure the adequate prevention, diagnosis and treatment of a wide range of conditions.

1. Where are the gaps between NDIS and mainstream services?

The gaps between NDIS and mainstream services such as transport, health, education and justice are too numerous to list here. These gaps are exacerbated for people living in regional and rural areas of the State and people with complex disabilities and behaviours of concern. People with disabilities, families and carers who identify as Aboriginal or Torres Strait Islander; as gay, lesbian, bisexual, transgender, are intersex or queer or people from culturally and linguistically diverse backgrounds are also likely to experience more barriers in accessing the NDIS and culturally appropriate access and treatment in mainstream services.

As the rollout has been scheduled to be finalised in December 2020, it is still difficult to fully determine if these problems can be attributed to the transition period or if they are inherent limitations of a regulated market in disability services and the legislative and regulatory framework in which the Scheme itself exists.

Carers Victoria recommends the Plan outlines the extent to which Government intends to conduct a comprehensive audit of current services for people accessing disability, mental health and aged care services focusing on the perspectives of people with disability, their families and carers as well as advocates. To investigate the interface between the NDIS and mainstream services across the State, federal agencies delivering health such as primary health networks (PHNs) and other experts in health, education, justice and transport should be consulted.

Further, Carers Victoria believes without improved ‘rules of engagement’ between the NDIA (at all levels) and State departments, many problems will continue and impact on the most vulnerable in the community. **At a high level, Carers Victoria recommends the Victorian Government advocate for better cooperation between the NDIA and government departments and agencies and less adversarial approaches at the AAT, as well as greater transparency and accountability to individual participants, families and carers.**

Carers Victoria also expects the Plan to outline the Government’s commitment to develop Key Performance Indicators which demonstrate how State Departments and agencies are working with the NDIA to resolve significant gaps in the NDIS/mainstream interface such as:

- Streamlined and coordinated care for people with a disability within the universal health system and specialist disability supports provided by the NDIS,
- Opportunities for some NDIS funded supports to be utilised if a participant is admitted to hospital to support the participant as well as families and carers, and
- Continued reliance on the multi-purpose taxi program by participants, despite increases in transport funding endorsed by the Council of Australian Governments (COAG) Disability Reform Council in October 2019[6] as well as restrictions on

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[6] https://www.dss.gov.au/sites/default/files/documents/10_2019/communique-drc-9-october_2019.pdf

participant's ability to use their core funds for transport purposes independently of their service provider(s).

2. How do we ensure mainstream services are inclusive of all people with disability?

Embedding inclusive practice in mainstream services is an ongoing process which requires expert advice, localised responses and sufficient resourcing.

Carers Victoria recommends the Plan outlines the extent to which the Government intends to build community capacity and inclusivity in existing mainstream services. Government Departments should commission research and expert advice about what inclusive services look like and how to measure them. It is important to involve people with disability, families and carers in developing the more subjective of these measures; however, the Government must commit to objective standards of access and equity that can be found anywhere in Victoria.

To this end, the Government should recognise competitive application processes do not always ensure mainstream services are inclusive of all people with disability. The Victorian Government's Children's Facilities Capital Program minor grants program is illustrative of the limitations of a competitive application process.

In 2018 this Program invited applications from individual kindergartens and/or childcare centres which offer integrated kindergarten programs to compete for financial assistance to upgrade their outdoor play areas to ensure children with disability are able to play alongside their peers.

The process involved kindergartens and childcare centres allocating resources such as time to work on applications, liaison with designers and landscapers, disability advocates and/or input from parents. Management would need to fund printing, photos and backfill.

While the intention of the program is positive and many individuals developed skills in tender writing, the implementation is problematic from an access and equity perspective. Competitive applications are likely to benefit already privileged individuals, families and geographic areas where extensive resources are used and maintain areas of concentrated privilege.

Evidently, those facilities which were unsuccessful for a grant remain inaccessible to children with disabilities and therefore limits their capacity to learn in a new environment and experience social interaction with their peers. Moreover, the flow-on effect to parents and families who cannot find accessible kindergartens for their children close to home is also significant. Some parents are likely to delay their return to work or can only work reduced hours to accommodate their child's early childhood education needs.

Therefore, Carers Victoria recommends the Government identifies minimum standards of accessibility and equity and ensures each locality within the State has sufficient resources for its population.

Topic 6: Strengthening disability inclusion under the Disability Act 2006

1. What are the most important things that a review of the Disability Act 2006 should consider? What are the biggest improvements we can make?

Carers Victoria is a member of the Disability Act Review Advisory Group and the organisation will refer its recommendations via this policy mechanism.

2. How should the Act ensure that Victoria can fulfil its role in promoting the inclusion, participation and rights of people with disability?
3. How does the Act need to change to reflect Victoria's role in delivering disability services after the implementation of the NDIS?
4. How should the Act reflect, protect or enhance human rights? What changes are needed to ensure the human rights of people with disability are protected in relation to compulsory treatment, the justice system and restrictive practices?
5. Are there any specific groups of people that it is important we speak with during the review? Are there particular issues that we need to talk to them about?