



National Disability Strategy Governance and Engagement Section
Department of Social Services
GPO Box 9820
Canberra, ACT 2601

By email: disabilityreform@dss.gov.au

18 December 2020

Re: National Disability Strategy and NDIS Outcomes Framework submission

ABOUT STAR

STAR Victoria Inc. (STAR) is a community organisation that advocates on a statewide basis for the rights of people with an intellectual disability and their families.

Inclusion, equitable treatment and access to justice underpin the advocacy work of STAR.

STAR was established in 1970 when parents of people with an intellectual disability recognised that, whilst trying to improve the circumstances for their own children, it was essential to change community attitudes to intellectual disability.

Then, as now, we are committed to equity and full community inclusion and participation for people with intellectual disability, from pre-school through to adult education and employment, recreation, and all aspects of ordinary life. We do this by supporting families and self-advocates with information and support.

STAR seeks to drive legislative change that places at the heart of Victoria's legal framework the rights of families and the human rights of people living with an intellectual disability without systemic, economic or structural restraint.

STAR is a member of Disability Advocacy Victoria, the peak body of independent disability advocacy organisations.

While all aspects of inclusion are fundamental to people living with intellectual disability enjoying full citizenship rights this submission will focus specifically on;

- the rights of parents with intellectual disability; and

- rights to inclusive education.

We welcome the opportunity to make a submission to the draft outcomes frameworks. In summary, we note that the purpose of the framework, to provide inclusive, consistent and accessible outcomes for people with disability, presents an opportunity to refine qualitative and quantitative data collection processes to achieve this aim.

We also note the focus on the six domains will assist in achieving the vision set out in the framework. In addition, greater investment via more targeted funding to service organisations will set the conditions to give life to the national disability strategy and the National Disability Insurance Scheme (NDIS). It is the experience of STAR that further cultural, policy and legislative change is

necessary to achieve systemic change for people with disability in our core advocacy areas: supporting parents with intellectual disability and inclusive education.

A properly funded NDIS and an overarching national disability strategy informed by the voices of people with disability can meet Australia's obligations to all our citizens, and our national and international obligations.

We make the following recommendations:

RECOMMENDATION ONE:

That the vision be amended to include the term 'citizen':

"An inclusive Australian society that enables people with disability to fulfill their potential as equal **citizens** and members of their communities."

RECOMMENDATION TWO

To drive cultural change, Government fund a national education and advertising program informing the community on the capacities and rights of people with disability to participate in all aspects of ordinary life, from birth to pre-school through to adult education and employment, recreation, intimate relationships, parenting and all community opportunities.

RECOMMENDATION THREE

That the inclusive and accessible domain specifically reference access to communication materials in formats that reach a broad range of people with differing language, comprehension and numeracy skills.

RECOMMENDATION FOUR

Parents with intellectual disability are presumed to be capable, with relevant and appropriate supports, of providing care to their children.

RECOMMENDATION FIVE

In order to meet Australia's objectives under the United Nations *Convention on the Rights of Persons with Disabilities* the objectives of all state and national legislation be amended to include a presumption of capacity for people with disability in all aspects of ordinary life.

RECOMMENDATION SIX

The education system include a foundation principle that all students have access to mainstream education, with reasonable adjustments and supports to enable inclusive education.

RECOMMENDATION SEVEN

The establishment of a central administrative function to oversee the data capturing, analysis, reporting and quality of services delivered to people with disability.

RECOMMENDATION EIGHT

Government to fund providers and advocacy services to address support gaps in service provision and as a mechanism to identify emerging and systemic issues arising for people with disability.

THE QUESTIONS:

Q.1 What do you think about the different elements in draft structure for the Outcomes Frameworks?

The Vision

The national disability strategy and the NDIS are crucial elements of a public policy approach that can affect real and sustainable change for people with disability.

In the advocacy work STAR undertakes we regularly encounter historical cultural barriers that limit the rights of people with intellectual disability to their rights to be parents or to participate in mainstream education. Segregation in schooling remains a common response to disability across the education sector.

Further, the nature of the child protection system creates conditions where an expectant mother with an intellectual disability is, in our experience, subject to having an 'unborn report' made prior to any substantive assessment undertaken of her capacity to, with appropriate supports, parent her child safely. It is our experience that mothers who are under a child protection order and are seeking reunification with their child experience considerable difficulty interacting with the child protection and justice systems. Our submission expands on these issues below.

To give life to the essence of Australia's commitment to the United Nations Convention on the Rights of Persons with Disabilities (CRPD)¹, the vision statement can be strengthened to publicly recognise the rights to full *citizenship* that all Australians are owed. In addition, an appropriately funded education and advertising campaign can be implemented across the community demonstrating the capacities, rights and contributions of people with disability.

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The Domains

The six domains reflect a broad alignment with Australia's international obligations under the United Nations Convention. At an overarching level the domains present a logical way to structure public

¹ United Nations Convention on the Rights of Persons with Disabilities. Accessed 16 December 2020.

<<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>>.

policy responses to the needs of people with disability. Of course, many people's needs will overlap and our comments are best captured in the specific domain areas outlined below.

Inclusive and accessible communities

In respect of inclusive and accessible communities we submit these can be enhanced by developing specific language that recognises the needs for accessible and inclusive communication material.

Genuine inclusion and access to services across every facet of life is dependent upon people with varying literacy and numeracy skills being able to understand how they can achieve full social and economic participation.

At STAR we often find that easy English material is not made available to people, and this limits people's capacities to assert their rights and be fully engaged in the community.

By discretely setting out these various features of inclusion and accessibility service delivery approaches are changed at a systemic level. This includes developing the skills of workforces and in turn, genuinely providing accessible services for people with disability.

RECOMMENDATION THREE

That the inclusive and accessible domain specifically reference access to communication materials in formats that reach a broad range of people with differing language, comprehension and numeracy skills.

Health and wellbeing

In one of our key advocacy areas, parents with intellectual disability, we have identified negatively-framed legacy cultural responses to the capacity of parents, mostly women, to parent well with appropriate supports.

STAR has advocated for parents who have had their children removed from them by the child protection system, where an intellectual disability is included in the parenting assessment. It is our experience that limited effort has been made to examine the capacities of parent/s prior to the state removing the child from the love and support of their parent/s.

The systemic disadvantage for parent/s is further entrenched in the child protection and court system. We have advocated for people who, having had their child removed, have then been forced to engage in a judicial system via child protection orders² that does not adequately accommodate the needs of parent/s as set out in the inclusive and accessible domain response above. Inclusion cannot be achieved while negative presumptions about the capacity of parents remain, further entrenched by the failure to provide critical procedural information in an accessible format.

STAR submits that the reference to 'maternal health and wellbeing' be enhanced by acknowledging and committing to the international rights of people with intellectual disability. Specifically, a presumption of capacity and access to supports is included in the national strategy and recognised in the NDIS.

RECOMMENDATION FOUR

Parents with intellectual disability are presumed to be capable, with relevant and appropriate supports, of providing care to their children.

² <https://services.dhhs.vic.gov.au/child-protection-orders>

Rights, protection, justice and legislation

STAR welcomes the attention to raising citizenship rights and equality as a focus area. As set out in our previous recommendations, the right for people with disability to access the full suite of citizenship liberties, from consensual intimate relationships to mainstream schooling and access to community is yet to be realised.

As has been highlighted in this submission it is the experience of STAR that parents with intellectual disability are often considered to be a risk to their children and are not provided with sufficient supports to assist them in their parenting role. This assumption must be reversed. The child protection and justice systems must be underpinned by a service provision perspective that ensures parents have access to the supports they need, with removal of a child a last resort.

RECOMMENDATION FIVE

In order to meet Australia's objectives under the United Nations *Convention on the Rights of Persons with Disabilities* the objectives of all state and national legislation be amended to include a presumption of capacity for people with disability in all aspects of ordinary life.

Learning and skills

People with intellectual disability share equal rights to lifelong learning opportunities. STAR has recently run a successful series of online workshops, the 'ABCs of inclusive education'³ for parents and educators, to improve knowledge of the rights and opportunities available within the mainstream education system.

Inclusive education as a best practice model achieves three main objectives. First, as argued by Jackson (2003), it is a moral question. Exclusion of any sort creates lifelong barriers to full participation and enjoyment of life. Second, inclusion is directly related to our values. When society includes everyone, positive cultural change, particularly in respect of acceptance, shifts for the better. Third, policy and curriculum development based on inclusion not only educates people with intellectual disability but contributes to breaking down barriers in other aspects of life. Jackson (2003) further argues that a review of the international literature on segregation and inclusion finds overwhelmingly support for inclusive education:

In a recent review of the literature that I did for an international conference on inclusion, I could **NOT FIND ONE** (author's emphasis) research article comparing inclusion with segregation that favoured segregation. Professors and Heads of Education at Australian Universities were written to stating that finding and asking if they knew of any contrary finding. No one came up with a contrary finding. The finding was not challenged by any of the international experts at the conference who indeed agreed with my finding. Similarly, Directors General of Education in all Australian States were asked for the research base on which they recommended segregated schooling. While many referred to government reports, they also could not provide empirical evidence in support of segregated schooling for children with an intellectual disability⁴.

³ <https://starvictoria.org.au/inclusiveeducationvictoria/>

⁴ Jackson, B, (2003). *Should schools include children with a disability*. Accessed 8 October 2020. < <https://www.family-advocacy.com/assets/Uploads/Downloadables/7bbb05fb26/11177.pdf>>

Jackson has much more to say on this matter, and STAR Victoria felt confident that, in Victoria at least, the evidence battle was won. We realise that there remains a view that children with intellectual disability require special treatment, and this can best be delivered in a purpose-built environment. However, this is clearly counter to the evidence, and takes much needed resources from mainstream schools who will have less capacity to provide the necessary supports for students with additional needs to be educated alongside their peers. Current debates continue to support inclusive education as the main priority in the delivery of education services⁵.

RECOMMENDATION SIX

The education system include a foundation principle that all students have access to mainstream education, with reasonable adjustments and supports to enable inclusive education.

Q.2 How we can best implement the Outcomes Frameworks to enable governments and stakeholders track the effectiveness of the Strategy and the NDIS?

Under Australia's federated system of government, local government, states, territories and federal government all hold responsibilities in the shared domain areas. In addition, the complexity of the NDIS system and differing approaches by all levels of government, non-government agencies, the business sector and the broader community requires an overarching data capturing, analysis and reporting administrative function.

In one sense this complicates the 'consistent' approach the federal government is seeking. On the other hand, setting out in the national strategy and outcomes framework a robust mechanism that recognises this overlap provides central oversight of all services provided to people with disability. In this regard STAR submits an independent administrative body be established that sets out the range of services provided by each tier of government, non-government agencies, the business sector and community sector.

RECOMMENDATION SEVEN

The establishment of a central administrative function to oversee the data capturing, analysis, reporting and quality of services delivered to people with disability.

Q.3 What else should be considered when we are monitoring and measuring the impact of activities on people with disability?

The most recent available data indicates there are about 4,400,000⁶ people with disability in Australia. The September 2020 NDIA quarterly report confirms there are just over 410,000 people accessing the NDIS⁷.

⁵ Cologan, K, (2019). *Towards inclusive education: A necessary process of transformation*. Accessed 16 December 2020. <<https://apo.org.au/node/36129>>

⁶ Australian Bureau of Statistics, (2019). *Disability, Ageing and Carers, Australia: Summary of Findings - 2018*. Accessed 16 December 2020. <<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings>>.

⁷ National Disability Insurance Scheme, (2020). *NDIS Quarterly Report to disability ministers, 30 September 2020*. Accessed 16 December 2020. <<https://www.ndis.gov.au/about-us/publications/quarterly-reports>>.

Research data has underscored the difficulties with accessing the NDIS⁸. The Disability Royal Commission is highlighting persistent and harmful gaps in services for people with disability. The changes to working practices imposed by COVID-19 provide further important insights into the complexity of delivering appropriate and quality services for people with disability⁹.

In our advocacy work we are aware of the gaps in service delivery for people with disability who often have complex and multiple needs. We have service providers contacting us seeking advocates for people whose circumstances require significant interaction with a range of service providers. These can include complicated familial relationships, behaviours of concern, medical needs, family violence, and stress and trauma responses to past or current sexual, physical and/or emotional abuse.

We also provide advocacy services for people who have either not been assessed as having an intellectual disability sufficient to access NDIS services or who have received services only after several application processes. We acknowledge the NDIS exists for the purpose of providing reasonable and necessary supports and is not a scheme which people are eligible for on the sole basis of a disability. Nevertheless, we find in our role that people who have difficulty articulating their needs are refused services by a system that struggles to match the reality of people's lives with a decision-making framework based on metrics.

The NDIS needs to be fit for purpose, and therefore be sufficiently funded and staffed to provide the suite of services necessary for people with complex life needs.

A larger skilled and knowledgeable workforce trained in the complexities of drawing together services for people living with disability is an important part of the success of the NDIS and the long-term disability strategy.

The capturing of meaningful data and multifactorial analysis of the data collected would ensure funding is applied where it is needed, when it is needed. This would reduce the incidence of people falling through the gaps and would likely be more cost effective than picking up the pieces of shattered lives.

In addition to more comprehensive and detailed qualitative and quantitative data capture and analysis on the lives of people with disability, the strategy can be enhanced by setting out how service providers are managing complex caseloads, how often they are seeking advocacy services and the types of issues that required providers to seek additional resources.

This data will assist governments in better determining the funding envelope to support the vision and human rights of people living with disability.

RECOMMENDATION EIGHT

Government to fund providers and advocacy services to address support gaps in service provision and as a mechanism to identify emerging and systemic issues arising for people with disability.

⁸ Warr, D, Dickinson, H, Olney, S, et. al. (2017) *Choice, Control and the NDIS*. Melbourne: University of Melbourne. Accessed 16 December 2020 < https://social-equity.unimelb.edu.au/data/assets/pdf_file/0008/2598497/Choice-Control-and-the-NDIS.pdf >.

⁹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020. *Statement of Concern - The response to the COVID-19 pandemic for people with disability*. Accessed 16 December 2020. <<https://disability.royalcommission.gov.au/publications/statement-concern-response-covid-19-pandemic-people-disability>>.

If you require more information or would like to discuss the matters raised in this submission, please do not hesitate to contact Karen Douglas on policy@starvictoria.org.au or 0419 412 401.

Yours Sincerely
STAR VICTORIA

A handwritten signature in black ink, appearing to be 'DB' or 'Denise Boyd', written in a cursive style.

Denise Boyd
Executive Officer

A handwritten signature in black ink, appearing to be 'K Douglas', written in a cursive style.

Karen Douglas
Policy Officer