National Disability Strategy Stage 2 Consultations

Down Syndrome Tribe Submission

As parents of children with a disability, the genetic condition Trisomy 21, we recognise that the new National Disability Strategy has the potential to significantly impact on the wellbeing and opportunities for our loved ones with a disability and families as a whole.

VISION

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

OUTCOMES

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

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?

Response:

As parents of children with Trisomy 21 we support this vision and these outcomes, with three exceptions being a) the lack of attention paid to secure, safe housing for people with disabilities, b) economic security should specifically include employment c) inclusive and accessible communities should specifically include education.

Housing
Government must commit to increasing the supply of affordable housing for people with disabilities and ensure housing is available in areas with good access to public transport to enable access to support services and employment.

Employment
Government must commit to improving access to open, meaningful employment for people with a disability, particularly people with an intellectual disability.

Education
Government must set a goal of ensuring a universally accessible and fully inclusive education system and move expeditiously and effectively towards that goal by adopting clear targets and timetables.

GUIDING PRINCIPLES

Involve and engage people with disabilities at every step of policy development, universal design that utilises assistive technology, engaging broader community in opportunities for disability inclusion, address barriers for priority populations, support carers and supporters.

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

Response:

We support these guiding principles, noting that there needs to be greater investment in support for carers, as this has been under-resourced and will lead to more wholistic improvements.

ADDRESSING COMMUNITY ATTITUDES

Changing community attitudes is a pre-requisite for overcoming the barriers to participation faced by people with disability in their daily lives. Barriers to employment are a key issue.

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?

Response:

We support a strong focus on addressing community attitudes.

We call for high quality multi-media campaigns that engage the Australian community with the humanity, humour, resilience and equal worth of people with disabilities and their loved ones. These multi-media campaigns should also call out discrimination and name the very real barriers that people with disabilities face in Australia today.

More inclusive education, workplaces and community life will lead to greater visibility for people with disabilities. The more personal experience the Australian community has with people with disabilities, the more attitudinal barriers will be challenged.

Prenatal screening

Government must ensure that families have the information they need to make informed decisions about prenatal screening for chromosomal conditions. It is unethical to have a screening program in place without access to good information and support.

Only 5 percent of women who receive a prenatal diagnosis of Trisomy 21 continue with the pregnancy. Some families who receive a diagnosis of Trisomy 21 have reported that doctors questioned their choice to continue their pregnancy, or have told them that their child would face a lifetime of suffering.

This provides context for the need to improve community attitudes to disability, including intellectual disability, both amongst health professionals and the broader community.

Government should partner with disability peak bodies to include improved training and education for doctors and midwives, improved access to post-screening counselling, and the development of a public awareness campaign to tackle negative community attitudes and stigma about chromosomal conditions and intellectual disability. Providing balanced information about chromosomal conditions should include opportunities to connect with families with a person with that disability.

ACCOUNTABILITY

The new strategy provides an opportunity to strengthen accountability at all levels of government and clarify the roles and responsibilities of various levels of government in disability policy and service delivery. It will also be important to outline the role of the non-government sector.

Strategies to enhance accountability and improve implementation:

- an outcomes framework with a comprehensive set of performance indicators to measure progress against the six existing outcomes
- a commitment to the collection of data and to public reporting of performance
- a commitment to undertake policy and program evaluations
- a strengthened approach to implementation.

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?

Response:

Legal Rights
Government should financially support independent legal services that advise and represent people with disabilities and their families in regards to mistreatment in the workplace, the education system, the NDIS, housing etc. It is often hard for people with disability and their families to ensure they obtain their rights in all aspects of life.

Employment

Federal and state governments need to take responsibility for ending segregated and unfair models of employment that affect most people with disability, including unfair remuneration and higher vulnerability to abuse in segregated workplaces. International examples demonstrate that it is possible to move away from segregated employment models and have good outcomes for people with intellectual disabilities, but this must be led by government and national strategy.

Government must commit to improving access to open employment for people with an intellectual disability. This includes addressing barriers, supporting specialised Disability

Employment Service (DES) providers, ensuring appropriate supports are provided under NDIS, and developing better support for transition from school to open employment.

Health

Government needs to invest and prioritise funding to address the poorer health outcomes for people with intellectual disability through an investment in primary care programs and university training. For example, medical doctors in both the public and private health

system require more in-depth training in developmental disabilities. There should also be incentives or accountability for doctors to regularly review patients with disabilities.

Education

Government must set a goal of ensuring a universally accessible and fully inclusive education system and move expeditiously and effectively towards that goal by adopting clear targets and timetables.

Inequity

Clearer responsibilities must also address who is responsible for addressing issues of inequity. There are clear examples of inequity within the NDIS, with children with similar conditions receiving widely disparate funding supports. The system currently relies on carers to have the resources and capacity to submit a review and challenge the funding allocation. This is compounding significant inequity, particularly for children in out of home care and CALD communities. Which level of government will take responsibility for this?

Migration

Government must remove the discrimination in the migration regulations based on whether a person has a disability.

Question 5: How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with a disability?

Response:

The Strategy should strongly promote mentoring for people with disabilities in the workplace, including people with intellectual disabilities. Policies that incentivise businesses to employ people with disabilities should be more actively tested and implemented. This may include government co-contributions towards the salaries of people with disabilities.

The Strategy should mandate the representation of people with disabilities on all boards and committees that address matters regarding disability, and strongly promote inclusion of people with disabilities on boards and committees more widely.

The Strategy should include a Government commitment to provide ongoing, recurrent funding for disability-specific peak bodies to ensure the important role they provide in advocacy and informing government is sustainable.

Private sector

The private sector has an important role to play in employing people with disabilities, recognising the skills and commitment each person brings to their role. Employment often can provide social participation, structure, a sense of purpose and other benefits, and the private sector should be incentivised to prioritise the employment of people with disabilities, including intellectual disabilities.

There are strong examples in Australia that demonstrate private sector success in improving gender diversity in leadership once targets were set and senior management were held accountable for achieving targets. What is measured gets done. Similar strategies can be employed in regards to significantly improved inclusion of people with disabilities in the private sector.

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?

Response

Public reports addressing performance addressing the guiding principles and reporting against key outcomes should be published bi-annually, if not annually. This should be delivered from the highest levels of federal and state government.

The report should be widely accessible, and publication announced in the mainstream media as well as to all peak bodies and associations engaged with disability.

This communication should be promoting disability inclusion as an essential aspect of Australian community life, and given high priority status. Given 4.4 million Australians are living with a disability, communication on disability inclusion should be given the level of investment given to communicating about the COVID 19 pandemic.

As parents of children with a disability, none of us had heard of the National Disability Strategy, nor had we heard about the consultations underway until an extension was announced. This indicates a serious communication gap in communication both with the broader community and also with disability organisations, associations and advocates.

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)?

Response:

There needs to be clear and measurable outcomes along with appropriate delegation of tasks with consequences for inaction.

There should to be opportunity for regular reassessment making way for adjustment to plans in response to regular evaluation, feedback or barriers identified.

Response:

Contact can be made by the government to all Australians, utilising SMS and public announcements as in the case of the COVID 19 pandemic, engaging the community in the disability inclusion strategy and seeking feedback. Particular feedback should be sought from people living with a disability and their carers.

Peak bodies and associations can be actively utilised to disseminate information and gather feedback. It shouldn't be up to people with disabilities, their carers, and the public to search a website for updates on the strategy. More active community engagement in this strategy will build a culture of awareness and change in the broader community.

The National Disability Strategy should adopt a "nothing for us, without us" principle – in that nothing is discussed, planned, decided or evaluated in regards to disability without people with disabilities and their families active participating.

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?

Response:

Contact can be made by the government to many Australians, utilising SMS and public announcements as in the case of the COVID 19 pandemic, engaging the community in the disability inclusion strategy and seeking feedback. Particular feedback should be sought from people living with a disability and their carers.

Peak bodies and associations can be actively utilised to disseminate information and gather feedback. It shouldn't be up to people with disabilities, their carers, and the public to search a website for updates on the strategy. More active community engagement in this strategy will build a culture of awareness and change in the broader community.

The National Disability Strategy should adopt a "nothing for us, without us" principle – in that nothing is discussed, planned, decided or evaluated in regards to disability without people with disabilities and their families active participating.

This submission was made on behalf of a group of parents who have a child with Trisomy 21 (Down Syndrome).

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