



## Response to the National Disability Strategy Position Paper, July 2020

Please find below our response to the National Disability Strategy Position Paper produced in July 2020 by the Department of Social Services. This response is submitted in support of Australians living with all forms of Neurofibromatosis (NF). Our Support Services team regularly engage with community members who experience disability and functional impairment which has significant impacts on their daily lives.

NF is a group of three distinct genetic conditions - NF1, NF2 and Schwannomatosis. They are progressive neurological conditions, which cause mostly benign tumours to grow on nerves throughout the body. NF Type 1 is more common than cystic fibrosis, Huntington's Disease and Duchenne Muscular Dystrophy, but due to its variability and no single, clear disease pathway, awareness is low and subsequently receives very little recognition comparatively.

As the only national charity supporting more than 10,000 Australians impacted by these conditions, the Children's Tumour Foundation of Australia (CTF) exists to provide a pathway from fear to hope by investing in promising research, advocating for better resources and empowering individuals and their families with knowledge, connections and support needed at every stage of their journey.

Many tumours associated with NF while benign, can cause functional impairment leading to disability due to their size and function. NF is a life-long genetic condition with few treatment options and no cure. While surgery is often the only option available to people, it carries the increased risk of permanent disability and weighing up whether to intervene or not is difficult. For people with NF1 other complications such as cognitive impairment, scoliosis and other bone abnormalities can also cause disability.

The CTF believes that all people with NF deserve a voice, and that with one voice we can pull together the diverse experiences and impacts of these debilitating conditions so that those impacted are no longer left unheard.

Below are the detailed responses to the questions posed by the Position Paper.

### 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?***

Many people with NF fall through the cracks of the health, disability and education systems, due to .....Enabling people with disability to fulfil their potential as equal members of the community is in line with our goals and is a vision the community we support strives for whole-heartedly. We believe that continued investment of time and resources in pursuing this vision is appropriate into the next decade is critical

It is important that any new National Disability Strategy covers all areas of concern and value for people impacted by disability in Australia to reach their full potential in the community as set out in the vision for the Strategy.. The six outcome areas brought forward from the current



Strategy do appear to cover the comprehensive issues and aspects of life that need to be considered and the CTF believes it is wise to continue with these key areas into the new Strategy.

## **QUESTION 2**

***What do you think about the guiding principles proposed here?***

The guiding principles outlined in the Position Paper are all valuable additions to the Strategy. We believe that those pertaining to support and engagement are the most important of the five proposed.

In terms of addressing the barriers faced by priority populations, we believe that the parameters for this would need to be clearly detailed by the Strategy and this principle should be amended to ensure equitable access for all people with disability where possible.

## **QUESTION 3:**

***What is your view on the proposal for the new strategy to have a stronger emphasis on improving community attitudes across all outcome areas?***

Community attitudes are central to inclusivity in our society, and we therefore support the intended emphasis on this in all outcome areas for the new strategy.

We feel that the strategy should be developed in such a way as to ensure that all levels of government lead the way in facilitating and role-modelling the shifts necessary to successfully achieve this.

## **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?***

Role clarity is always important regardless of the context. Establishing clear guidelines and ensuring roles and responsibilities at every level of governments across each outcome area is crucial. It ensures services and systems are easily accessible and used appropriately and efficiently by consumers.

It will therefore also be important to set out how outcomes will be reported and where people with disability can access this information. It should be reported in an accessible format and available to whoever is interested.

To make it easier for people with disability to access, the accountability of government should include the commitment to working collaboratively to produce reports across the sectors. It seems logical then that the Department of Social Services should be responsible for collating and distributing reports as appropriate.

## **QUESTION 5**

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



*(Examples of the non-government sector include big, medium and small businesses, community organisations, employees of these businesses, private research, investment organisations and individuals.)*

Non-government organisations play a key role in the disability sector. These organisations providedirect assistance to people with disability, including those on the periphery, like CTF, and should be represented. They are responsible for leading the way in upholding and working towards change that takes the concepts, values and plans set out in the strategy into consideration.

Other organisations further removed from the direct provision of disability services should also be represented in the strategy and should be encouraged to strive to not just meet requirements set out by law, but to take the strategy to heart in all their business activities.

#### **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?*

Information should be made available at least annually to the public. A combination of forward-looking and reflective reporting should be considered.

Given government terms are short and the landscape around policymaking changes from time to time, a yearly policy plan outline does seem reasonable, as does a bi-annual review, so that the public can see what has been achieved.

We consider there is no reason that both suggestions put forward be taken on board to demonstrate government's accountability to the public.

#### **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)?*

Every strategy needs targeted objectives. Providing clear guidances in the strategy around targets and timeframes is sensible to aid in prioritising and moving projects forward. It ensures the reporting process is as easy as possible for already stretched services.

This concept will also give non-governmental organisations clear structure to work within to meet the desired outcomes and timeframes to meet the needs of people with disability; supporting them in way that non-governmental organisations may not be familiar with.

#### **QUESTION 8**

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



The engagement plan should put specific frameworks in place to ensure people with disability and their communities are heard. This might include the formation of advisory groups where one does not already exist. This structure provides opportunity for people with disability and their advocates, such as the CTF, to provide direct feedback and coordinate feedback on the strategy, and targeted action plans along the way.

This plan should be explicit in the requirements to ensure that there is equality of engagement around the country and between governments.

### **Concluding remarks**

Thank you for the opportunity to contribute through these consultations. The Children's Tumour Foundation of Australia looks forward to the new National Disability Strategy and would welcome the opportunity to contribute further to ensure the outcomes for our community members with Neurofibromatosis-related disability and to working with key areas of government and community to progress the strategy.

Yours sincerely,

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