



## **NATIONAL DISABILITY STRATEGY**

### **STAGE 2 CONSULTATION**

**Submission from:**

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## Introduction

Scope (Aust) Ltd (“Scope”) is one of the largest not-for-profit organisations in Australia. Our origins stretch back to 1948, when a group of parents who wanted better lives and opportunities for their children with disability established the Spastic Children’s Society of Victoria. The values these families championed are demonstrable and enduring, ensuring our priority is always to ‘See the person’.

Scope’s mission is to enable each person we support to live as an empowered and equal citizen.

Scope supports more than 7,000 people with disability across metropolitan and regional Victoria with services including Supported Independent Living, therapy, individual support, communication access and supported decision making. Our individualised and customer-driven approach is closely aligned with the principles of the NDIS and the National Disability Strategy.

## Consultation process

This submission is being made on behalf of a group of 20 customers who are supported by Scope in Specialist Disability Accommodation or attend our day and lifestyle options services.

Scope has established Customer Reference Groups across the state, providing opportunities for customers to meet with their peers and discuss matters that are important to them, to build the capacity of customers to self-advocate and to create future leadership and governance pathways.

Members of these groups and other customers have been enthusiastic contributors to discussions about the development of the next National Disability Strategy. Owing to the COVID-19 pandemic, planned face-to-face Stage 2 consultations were cancelled, but people still wanted the opportunity to have their say, notably people who use Augmentative and Alternative (AAC) communication systems. Scope has facilitated seven online consultations for these customers to seek their ideas and opinions.

An estimated 1 in 500 people in Australia have severe communication disabilities (Perry, Reilly, Bloomberg and Johnson, 2002). The *Listening to Those Rarely Heard* research (Watson, 2011) developed an approach to supported decision making for people who do not communicate formally. It also aimed to develop robustly tested resources that could be used to facilitate best practice in supported decision making. We have drawn on this research in developing our consultation process, including tailoring online ‘Talking Mats’ for the purpose (see **Appendix One – Talking Mats**).

As highlighted by Beamer and Brookes (2001), when supporting people with disability “the starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions”.

## Outcome areas

### Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

The customers contributing to this consultation agree that the vision and outcome areas continue to describe the things that are most important to them in the context of the National Disability Strategy. They do not rate any of the outcome areas as more or less important than the others.

There is some hesitancy among a few customers about whether the next plan to implement the Strategy will make a real difference, given that in some areas there has been little progress. Having the opportunities for formal learning and environmental accessibility are two outcome areas that people are very concerned about. Opinions vary though, with most believing “there’s lots of improvements”, while still agreeing with the statement from one customer that “I think community has gotten better, but it needs to be more better [sic]”.

One person says that “things are worse than they were 10 years ago”.

Each of the customers consulted also personalised the impact that the Strategy may have on their lives and mentioned that “making sure there is enough support”, and the money to pay for those supports, are both critical.

## Guiding principles

### What do you think about the guiding principles proposed here? What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

As with the outcome areas, customers express solid support for the proposed guiding principles.

There is some scepticism about the effectiveness of codesign, with one respondent maintaining that “it’s hit and miss. People might be unaware of what to do or how to do it”. The overriding considerations are that codesign needs to be genuine and inclusive.

Nearly all customers are keen to address community attitudes, which they see as fundamental to tackling many of the barriers they encounter in their lives.

“Most people are unaware of us”.

“They think that we shouldn’t be in the community. They think we should be underground. I’ve had people say that to me”.

“Make us more visible”.

The primary goal, according to the customers we consulted, should be to turn each of the statements in the box on its head: To make people aware of people with disability; to ensure they are part of the community; and to increase their visibility.

One customer says barriers often stem from self-limiting behaviour, which is a reaction to community attitudes: "I have avoided doing some things in life because I expected discrimination".

Customers participating in the consultation are eager to share their experiences in domains related to the Outcome areas and Guiding principles to illustrate that attitudinal barriers are unfortunately intrinsic to their lives (see **Appendix Two – Customer Quotes**). They believe that addressing these barriers requires an approach that is both systemic and individualised.

## Strengthening accountability

### Role of government and non-government sector

"I think the government firstly needs to set some laws on accountability. Be able to enforce that things are done. It needs to flow through all levels of government".

While some customers are uncertain about the relationship between different levels of government and their various responsibilities, most are adamant that "people from government need to understand how we live". For the customers Scope supports, it will be essential to ensure the pathways for engagement are open and easily negotiated. This includes making provision for AAC users, who often feel left out.

One customer with complex communication suggests that government departments "should train up a few people" in how to engage with AAC users.

From a pragmatic standpoint, there is strong agreement with the following statement: "Every law that gets made – include people with disability in that law".

The people we consulted are less confident about the role of the non-government sector, excluding the disability support services that they use (Scope and others), which are more responsive to their individual needs. There is a widespread view that businesses, especially big and medium businesses, do not have the motivation to upgrade the customer experience for people with disability. Small and local businesses, such as cafés that people go to often are more accommodating, particularly around access issues.

When discussing non-government organisations adopting universal design principles most customers we consulted agree "they've got too much jargon and don't want to listen to people with disability. They'd rather wait for somebody to pick up the pieces". This is also considered to reveal a lack of curiosity about people with disability or any compulsion to learn more: "You don't know what you don't know".

For larger organisations, one tactic people think would be successful is to "have people with disability on boards of management", particularly if they earn money from people with disability.

## Reports

There is strong agreement from Scope customers that annual reports are the best way to provide updates on progress with implementation of the National Disability Strategy. The annual reports should come out at roughly the same time each year. It will be important to let people know that the reports have come out and where they will be able to find the them. There should also be thematic subsets of the report published separately that talk about things that are important to people with disability, such as “being included in the community”, “having a job”, “getting around” (transport) and “staying healthy”.

Customers we consulted think that all of the following elements should be included in the annual report:

- Stories from people with disability who are involved in delivering the Strategy
- Descriptions of what happens to demonstrate where there has been progress
- Pictures that tell stories about the Strategy and show how things change over time
- Details about who is accountable for the Strategy at all levels of government

Statistics and graphs are less important to the customers that we consulted.

All reports should be made available in accessible formats, including pictographs and Easy English, being mindful that abstract concepts are often difficult to convey. It would be preferable, for example, to tell a story with a video or accompanying pictures that illustrate ideas as well as translating documents into Easy English.

## Putting policy into action

The use of Targeted Action Plans is considered by the people we consulted to be helpful, including the use of both short and longer-term targets. Setting the actual targets to be measured, however, is somewhat contentious: “It’s all well and good to set targets but it depends what they are”.

Most customers agree with the following (or similar) remark: “Ask us. We know what we’re aiming for”.

There is some reluctance toward levying fines or penalties if targets are not met. Nevertheless, several customers advocate either subsidising organisations to enact disability positive policies or taking a punitive approach if they fail to do so: “It’s hard, but sometimes nothing gets done unless there’s an incentive or a punishment”.

Several customers remain unconvinced about the potential for targets to make any difference: “I think people don’t want to do anything if they have to pay money to make it happen”.

The customers we consulted are receptive to the idea of having a Disability Ombudsman in a monitoring role, “as long as they have somebody with a disability with them”. Several customers observe that if a Disability Ombudsman is appointed, it should be a person with lived experience of disability, and that they or some of their staff should be AAC users.

## Involving people with disability

There is an eagerness, among the people we consulted, to be involved in engagement activities that help shape future disability programs, policies and services; and if they are not selected to participate in these activities themselves, they want a broad range of people with disability to be engaged. The consensus view is that “if they talk to people with disability, they will know actually what people with disability want”.

Customers also want the opportunity to provide feedback as the Strategy progresses over the next 10 years: “We can make sure they’re on the right track”.

People in our consultation who use AAC, however, are concerned that they may be overlooked in formulating and implementing plans because of the additional time it takes to listen to what they have to say.

With respect to codesign, most people we consulted agree that “it’s helpful because it’s listening and doing all the things that’s going to get the best result”. Yet as referred to in the *Outcome areas* section above, there remains concern that organisations will pay “lip service” to the idea and not work in a committed way alongside people with disability.

Several people want education modules to be developed by people with disability to ensure that best practice in codesign is widespread: “Too many people are unaware of what we need to do to make life better”.

These proposals touch on the systemic approach to addressing the issues referred to in the *Guiding principles* section above. But the customers we consulted think an individualised approach, which they say is just as important, will be much more difficult to achieve with the power imbalances that continue to exist in society. Several people believe that they challenge overt discrimination from people in their daily lives, but also recognise that sometimes they don’t, and that discrimination can be hidden by the way the world is structured: “It’s not equal”.

## Closing remarks

Many of the people we spoke to say that during the COVID-19 pandemic they have engaged with a broader range of people than they would have otherwise through social networking and conference applications. They have also learnt to use online technologies that they did not know about before and will continue using into the future.

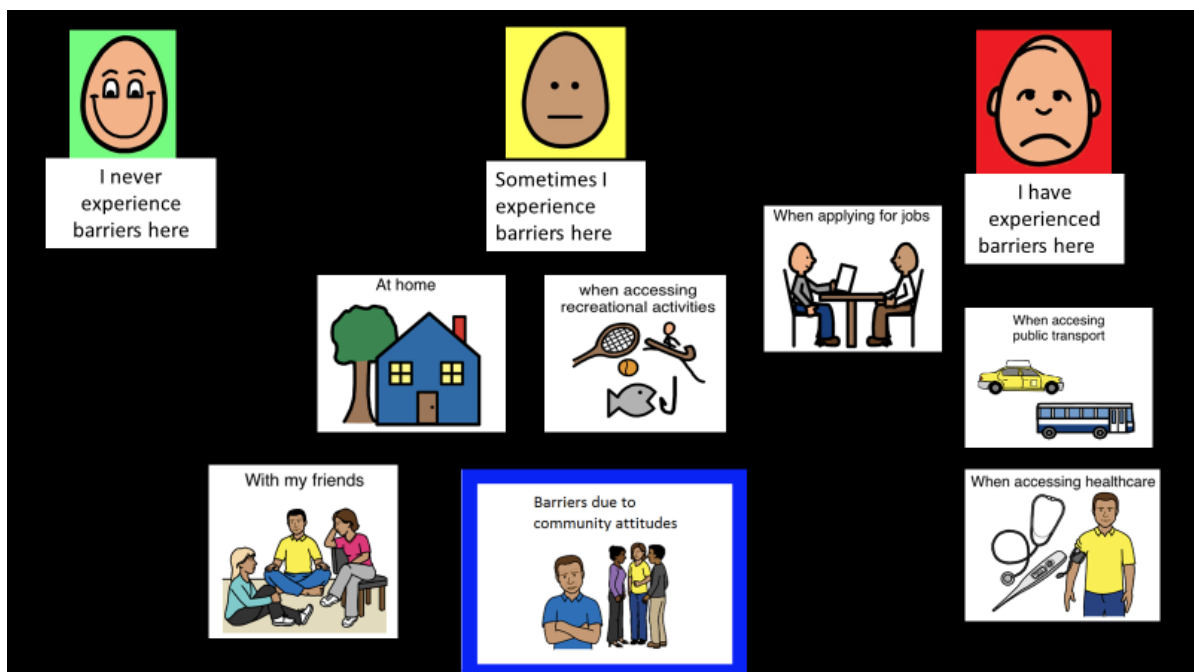
Several of the people involved in this consultation, including AAC users and people with intellectual disability, would be pleased to make themselves available for engagement related to developing policies and programs to implement the National Disability Strategy.

## Appendix One – Talking Mats

Talking Mats are suitable for people who understand photos, pictures or line drawings and allow people to express their opinions on certain topics. The person is provided a selection of ideas or emotions relevant to the topic. They then need to place the symbol somewhere along a continuum to reflect their feelings or experience of the topic i.e. don't like, so-so, like. This would usually be done in-person, with the symbols physically placed onto a mat.

Talking Mats have now been adapted for use online with people indicating their responses using their preferred communication style (e.g. choosing colours; eye gaze; yes/no). The responses also frequently lead to further and deeper conversations that may be conducted using sub mats.

Below is an example of a Talking Mat used throughout these consultations. The bottom tile outlined in blue is the topic for the discussion; and customers place the other tiles along the 'barriers' continuum to express their views.



## Appendix Two – Customer Quotes

Domain	Comments
Communication access	<p>"It's out there, but not enough".</p> <p>"People won't understand me [if I go out on my own]".</p> <p>"It's hard if they [people] can't understand you".</p> <p>"When you're verbal like me people do tend to listen more (if they want to)".</p> <p>"It's easier to ignore [us]".</p>
Education and employment	<p>"I want to do a course, but I have no idea where to start".</p> <p>"Let people make mistakes along the way. Everybody learns by making mistakes. You shouldn't feel bad about making mistakes".</p> <p>"I thought I would never get a job".</p> <p>"I feel like it's equal opportunity to have a job".</p> <p>"We all have capabilities in one way or another and it should be shown in the job that we do".</p>
Healthcare	<p>"The hospital wouldn't help me with my PEG because they said it was half-working".</p> <p>"They want to take over instead of listening to us".</p> <p>"Sometimes they make my appointment late and that makes me late for other things in my life".</p> <p>"People have to be trained about what to do in hospitals – and not relying all the time on the person with the person".</p>
Physical access	<p>"There should be ramps everywhere".</p> <p>"Once I get someone to assist, it's a piece of cake".</p> <p>"If I go out to lunch I have to sit outside because I know I can't get in. There should be space for wheelchairs in restaurants. On the footpath there's not enough room".</p> <p>"The city designs things for able-bodied people".</p> <p>"I've avoided going into some places because I was scared that I was going to knock things over because there wasn't enough room left".</p>
Public amenities	<p>"If they don't have an accessible bathroom then I'm stuffed".</p> <p>"I had to explain that you can't lift a person in a public toilet".</p> <p>"There's not much toilets when I go out".</p> <p>"If you can't go to the toilet on a plane you just have to go in your pad and hope it doesn't wet the seat".</p> <p>"I had to wait ten minutes to use the toilet because someone without a disability was in there".</p>