

RACP Submission to the new National Disability Strategy Position Paper Stage 2 Consultation

October 2020

#### About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 18,000 physicians and 8,500 trainee physicians, across Australia and New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

#### **Executive Summary**

The RACP welcomes the opportunity to provide feedback on the key features being proposed in the <u>National</u> <u>Disability Strategy position paper</u> to be included in the new National Disability Strategy (the new Strategy).

We would welcome the opportunity to engage with the Department of Social Services and other stakeholders on the development of the new Strategy and believe that this type of expert engagement would be of significant benefit. This submission provides comment on the proposals for the new Strategy as outlined in the position paper, based on the RACP positions on the National Disability Insurance Scheme (NDIS) and disability, and has been developed in consultation with medical specialists from the RACP, including paediatricians, public health physicians and occupational and environmental physicians.

The RACP acknowledges the <u>First Peoples Disability Network</u> (FPDN) as the peak national organisation of and for Aboriginal and Torres Strait Islander people with disability, their families and communities. We encourage appropriate consultation and engagement with the FPDN to ensure Aboriginal and Torres Strait Islander perspectives and input is adequately included in the new Strategy.

# 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?

The RACP supports the proposal that the six outcome areas in the current Strategy are still the right outcome areas to focus on in the new Strategy, listed below.

- 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

The RACP believes it is essential that health remains a key outcome area of the new Strategy. The submissions and testimonies provided to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the Review of implementation of the National Disability Strategy 2010-2020<sup>1</sup> show that the health of people with disability has remained a serious area of concern in Australia. The RACP would like to emphasise the relevance of health in all the outcome areas, e.g. promotion of human rights, and the resulting necessity for collaboration across the outcome areas.

### Question 2: What do you think about the guiding principles proposed in the position paper?

The current principle *Address barriers faced by priority populations* in the existing strategy should include a commitment to eliminating inequities faced by different groups including children, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people, women, LGBTIQ+ people and people living in regional and remote communities.

The RACP suggests that four new guiding principles are included in the new Strategy: *Embracing Diversity, Ongoing Collaboration, Public Accountability* and *Proportionate Universalism.* 

Adding a guiding principle of *Embracing Diversity* is important to help ensure legislation, policies, procedures or processes support positive community engagement with children, adolescents and adults with disability and their families. As well as acknowledging the diversity of the population of people with disability, the new Strategy should acknowledge and recognise that some forms of disability are more readily understood by the public and people without disability than others.

<sup>&</sup>lt;sup>1</sup> Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2018) Review of implementation of the National Disability Strategy 2010- 2020. Social Policy Research Centre

A key concern identified by RACP Fellows and others in the disability sector is a frequent absence of *Ongoing Collaboration between professionals.* The addition of this as a new guiding principle would support and encourage agencies already endeavouring to ensure participants do not fall through the gaps. Improving coordination and sharing of expert knowledge at all levels will promote efficiency, minimise duplication and enhance the experience and outcomes for scheme participants.

The RACP supports a principle committing to *public accountability*. As highlighted in the position paper, public reporting is fundamental to government transparency and accountability, and the current Strategy has not been effective in ensuring action or accountability.

RACP Fellows also suggested that a principle on *proportionate universality* should be considered for the new Strategy. Taking a proportionate universality approach within the new Strategy would ensure when developing policy and design of programs that greater resources are provided to those with the greatest need. This has the potential to address key social determinants of health and reduce inequities often faced by people with a disability.

### 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?

The RACP strongly supports a greater focus on community attitudes in the new National Disability Strategy. There is a strong link between community attitudes about disability and the extent to which people with disability are included in society.<sup>2</sup> The RACP notes improvements in attitudes and awareness of some types disability has seen positive progress in the past 10 years through improved visibility of people with disability in mainstream media and the introduction of the NDIS.<sup>3</sup> Positive community attitudes can be shaped by normalising and embracing difference in this way. For example, strategies to access after school care and ensure teachers can adapt school curriculums to their students' needs are equally important for children who have a disability to those who do not have a disability.

However, negative attitudes remain embedded in all levels of communities, from personal interactions to formal policy and law across multiple levels of diversity.<sup>4</sup> We would encourage the new Strategy to drive initiatives for improving community attitudes which are tailored to the needs of specific populations such as remote/regional families, children in care and protection services, Aboriginal and Torres Strait Islander families, culturally and linguistically diverse populations, as well as young parents.

While education and awareness campaigns are important, the government must also commit to funding and delivering dedicated programs to improve community attitudes and establish measurable goals, setting concrete targets for improvement and reporting against them. This must include actions to promote the long-term inclusion of people with disability in society, including:

- Improving access to health care and disability services;
- Creating liveable, accessible communities;
- Supporting access to meaningful employment which is appropriate and adequately supported;
- Improving accessibility of information; and
- Inclusive education policies.

Governments have a range of policy tools available to support delivery of these actions, including for example, regulations, incentive programs, government-funded programs, partnerships with other organisations, and community awareness and education campaigns. Governments need to take concerted action to drive inclusion of people with disabilities, in addition to building community acceptance. This should be reflected in

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<sup>&</sup>lt;sup>2</sup> SHUT OUT: The Experience of People with Disabilities and their Families in Australia. National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council [Internet]. 2016 [cited 20 October 2020];. Available from: https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-peoplewith-disabilities-and-their-families-in-australia

<sup>&</sup>lt;sup>3</sup> Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2018) Review of implementation of the National Disability Strategy 2010- 2020. Social Policy Research Centre.

<sup>&</sup>lt;sup>4</sup> SHUT OUT: The Experience of People with Disabilities and their Families in Australia. National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council [Internet]. 2016 [cited 20 October 2020];. Available from: https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-peoplewith-disabilities-and-their-families-in-australia

the new Strategy, which should detail the actions that Governments at all levels will take to increase inclusion of people with disabilities.

The RACP acknowledges that attitudes towards people with disabilities often result in barriers to accessing quality health care due to limited knowledge and understanding of disability and its impacts. The new Strategy should emphasise the importance of improving attitudes within the health sector, and that addressing this issue must be incorporated into professional standards and training.

## 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?

We strongly urge a planned and purposeful cross-sector collaboration across health, disability and education sectors as the current siloed approach is leading to adverse outcomes, particularly for children. This collaboration requires active direction and action at the national policy level. Health, disability and education departments could actively pool their expertise and coordinate their supports, enhancing the power of the sector to offer children the best chance of optimising their developmental opportunities. The Commonwealth Government should maintain a mechanism for coordination of policy initiatives across Government such as a high-level multi-agency steering group, supported by an advisory body or network to engage constructively with service providers and other stakeholders. Key portfolios which should be involved on a regular basis include: Health, Education, the National Disability Insurance Agency (NDIA), Social Services, Disability, Housing and Veterans' Affairs portfolios. Other agencies could be called in on specific matters.

The RACP questions whether the need in this area is to clarify the role of governments as much as different organisations and government services work together to provide services. We agree that a lack of clarity has a negative impact, as outlined below, however we advise caution in simply thinking this can be solved by providing information about government roles and responsibilities.

The lack of clarity at the interface of the NDIS and mainstream service systems, particularly the health system and the lack of clear explanation of funding responsibility between the NDIS and state and territory services, is leading to people missing out on, or experiencing delayed access to, some services. This is particularly important in the provision of health care for people with disabilities where there is joint involvement of Commonwealth and state governments in service delivery. The role of the new strategy in informing state initiatives should also be made clear.

Actively seeking to engage priority families (e.g. young parents, parents with mental health issues) should be a key approach, with early intervention before age four, as often children are not identified as needing help until they begin kindergarten. Children with developmental needs and disability are more likely to have other health issues such as epilepsy or attention deficit hyperactivity disorder (ADHD) so it is important to also address any potential discrepancy in access to specialist services, in particular in regional and rural areas.

Clearly defined roles and responsibilities are fundamental for achieving accountability and for ensuring that adequate supports are available for all people with disability and their carers. The new Strategy must clearly outline the roles and responsibilities of all levels of Government in disability-specific and mainstream services and commit to providing this information in a range of accessible formats. This should also include clear descriptions of early intervention pathways available to children and families. The new Strategy should actively engage and encourage all agencies to seek collaboration and coordination of services when this in the best in the interests of participants.

However, people with disabilities want and deserve a better experience of disability services. Articulating roles and responsibilities is a fundamental part of this, but the RACP's view is that it should go further. People with disabilities should be able to access a seamless and integrated portal for government services, that provides clear visibility of the services available in the person's geographic area. This should be agnostic to whether the service is provided by the Commonwealth or State/Territory Government and be broader than the NDIS to ensure that a broad range of services are included.

This should also be accompanied by work to streamline and clarify the function of each of the roles of levels of government and services, to ensure clarity within government departments of their own responsibilities.

#### Question 5: How do you think the Strategy should represent the role that the nongovernment sector plays in improving outcomes for people with disability?

The RACP acknowledges the critical importance of collaboration across government, industry and community to strengthen the disability sector and strongly urges that this be emphasised in the new Strategy. The RACP would like to see the new Strategy include actions for mainstream businesses, community groups and other non-government organisations to support the full participation and engagement of people with disabilities in the community.

The RACP recognises our own role in improving outcomes for people with disability, as a medical college which trains, educates and advocates on behalf of over 18,000 physicians and 8,500 trainee physicians in a broad range of medical specialties across Australia and New Zealand. Within the health care sector, non-government organisations (NGOs) also play an essential role in the provision of services and the new Strategy should emphasise the importance of building intersectoral collaboration across these NGOs.

It may be helpful for community understanding and attitudes to include examples of effective collaboration enhancing outcomes for children and families participating in disability services in the new Strategy. Examples might include delivery of therapeutic supports, respite care and the use of non-government services to support access to mainstream care. For example, a long-term therapeutic relationship with an experienced psychologist throughout a child's development can significantly improve acquisition of social and academic skills where their disability gives rise to significant anxiety.

The RACP supports the ideas mentioned in the position paper that the new strategy should introduce an outcomes framework as a mechanism to hold governments and service providers to account for the outcomes being achieved by programs and services they are delivering to people with disability. Without good baseline data, it is difficult to measure the success of programs and services, to be able to track, assess and modify. Mechanisms should be introduced to monitor the consistency, utilisation, quality, and outcomes of services with routinely collected data. This should take a value based care approach to ensure not only just effectiveness and efficiency of services are recorded and assessed but outcomes that matter to consumers, the consumers experience of the care and the providers experience of delivering the care are included.

### 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?

The RACP supports public annual reporting methods which measure progress towards the outcomes of the new Strategy. Measures which the RACP supports include:

- Outcomes and measurements related to access and equity for Aboriginal and Torres Strait Islander people and children living with disability. Aboriginal and Torres Strait Islander people should be involved in determining measures that are meaningful to them.
- Health disparities, including mortality, and access to health services, access to health prevention, e.g. cancer screening.
- Reporting on education and employment participation, through measures meaningful to people not the economy.
- The number of young people living in aged care accommodation due to lack of supported alternatives for care and overall the appropriateness of accommodation for each person.
- The number of homes being built to meet accessibility standards.

## 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)?

The RACP supports an action-oriented approach to implementation and the proposal of Targeted Action Plans within the new strategy to allow a more intensive focus on achieving specific deliverables to drive real change within shorter timeframes. Targeted Action Plans should be targeted to different disabilities and their needs to ensure no group is left behind.

To ensure the implementation of Targeted Actions Plans, the new Strategy must have a clear governance structure, leadership and coordination to raise the strategy's profile across government departments. The RACP is concerned that no single government agency or body had responsibility for coordinating the implementation of the current Strategy at either Commonwealth or State/Territory levels, which negatively affected implementation progress and momentum. The establishment of a multi-agency steering group as described earlier in this document would assist in addressing this issue.

## 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 RACP supports the proposed new engagement plan to ensure the new Strategy is informed by people with disability, their families and carers. The RACP would like to see the Engagement Plan:

- Build ongoing relationships with key individuals and peak organisations which are developed and maintained.
- Commit to including people with disability in leadership and decision-making roles.
- Ensure timeframes for consultations and delivery are realistic to allow stakeholders enough time to provide a considered response.
- Encourage a diverse range of views, experiences and perspectives from across the population spectrum.
- Use a variety of formats for engagement of people with disability.

### Question 9: Is there anything else you would like to share about the ideas and proposals in the position paper?

The new National Disability Strategy presents an important opportunity to engage health and disability experts in demonstrating the benefits from fostering coordination and collaboration across health and disability agencies. There is a great deal to be learned for health and disability agencies from the implementation of the NDIS so far, and improvements to the NDIS are key to achieving the goals of the new Strategy. RACP Fellows suggested the following issues with the NDIS should be considered in the new Strategy:

- It is often assumed that the NDIS can assist all people with disability. There is no market in many areas, particularly in rural and remote parts of Australia and the new Strategy must address this.
- There are challenges in the integration of the NDIS with services for children and the elderly. Because of the focus on disability rather than the person, separate systems attempt to provide services for people at different times of their lives which can create further disability for those at age thresholds.
- The Strategy should stress the importance of a focus on functional, needs-based eligibility for NDIS rather than diagnosis. Functional needs-based supports are particularly important as children transition out of Early Childhood Early Intervention (ECEI) and any focus on requiring a formal developmental diagnosis for the purpose of maintaining NDIS eligibility is likely to promote negative outcomes.

RACP Fellows also suggested the below areas to be considered to ensure new Strategy addresses the needs of people with disability living in Australia:

- The new strategy should support people with disabilities to engage in productive and meaningful work as a priority. This would have multiple social and economic benefits, not only for the individuals but for society as a whole. The RACP would like to highlight the principles of the Consensus Statement on <u>Health Benefits of Good Work</u><sup>5</sup>, developed by the Australasian Faculty of Occupational and Environmental Medicine (AFOEM). Ensuring that people with disabilities are engaged in good work requires not only a comprehensive assessment of the person focusing on their abilities (as opposed to their disabilities) and the job demands to ensure that these are congruent.
- The special needs of children, including those with psychosocial disability are very different to those of adults and this would appropriately be specifically mentioned in the new Strategy and reflected in all policy and support programs. Support and treatment during developmental years can make a significant difference to transition to adulthood, helping children reach their potential and significantly reducing costs in the medium to long term.

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<sup>&</sup>lt;sup>5</sup> The Australasian Faculty of Occupational and Environmental Medicine (AFOEM). Consensus Statement on the Health Benefits of Good Work [Internet]. 2017. Available from: https://www.racp.edu.au/docs/default-source/advocacy-library/afoem-realising-the-health-benefits-of-work-consensus-statement.pdf?sfvrsn=baab321a\_14

• The new Strategy needs to outline a new governance model for disability services. Disability is a complex policy area where funding and services are delivered by multiple levels of Government as well as the private and community sectors. There remains a risk that people with disabilities will continue to suffer because of a lack of coordination.