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Submission to 2020 National Disability Strategy- Stage 2 Consultations

October 2020

About Down Syndrome Australia

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down Syndrome Australia is making this submission on behalf of its members. Down Syndrome Australia and its members work together to provide support for people with Down syndrome and to make Australian society inclusive for people with Down syndrome. We work in partnership to maximise the opportunities and support for people with Down syndrome and their families and support networks.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.[1]

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[1] Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from **https://www.downsyndrome.org.au/about-down-syndrome/statistics/**

Submission to 2020 National Disability Strategy-

Stage 2 Consultations

Down Syndrome Australia (DSA) welcomes the opportunity to provide a submission to the Department of Social Services (DSS) on the development of a new National Disability Strategy (NDS).

The NDS is a key mechanism for driving inclusive policy and programs across all levels of government and the implementation of Australia's commitments as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The new Strategy must be designed and delivered in partnership with people with disabilities and representative organisations which have recognised status under the CRPD in its implementation and monitoring.[2]. The strategy must articulate a clear roadmap for achieving a more inclusive society over the next 10 years across education, health, housing, justice, employment, and community life. The Strategy must also articulate key outcomes to be achieved and how these outcomes will be measured and reported.

It is essential that in the development of the Strategy, DSS recognises that segregation is not consistent with the UNCRPD and is a violation of the fundamental human rights of people with a disability. The NDS must include a focus on structural changes to disability policy to support a transition out of segregated settings including in employment, housing, and education.

Our responses relate to the specific questions which have been outlined in the discussion paper provided by the Department of Social Services.

Vision and outcome areas

The discussion paper has proposed the following Vision Statement for the new NDS: *An inclusive Australian society that enables people with disability to fulfil their potential as equal members of the community*.

DSA suggests a small change to this statement:

An inclusive Australian society that enables people with disability to participate as equal members of society.

It has been proposed that the outcome areas remain the same as the current NDS. These are as follows:

- Economic security
- Inclusive and accessible communities
- Rights protection, justice, and legislation
- Personal and community support

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[2] Committee on the Rights of Persons With Disabilities, General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/C/GC/7).

- Learning and skills
- Health and wellbeing

DSA agrees that these broad outcome areas provide an adequate framework for the development of the NDS. We suggest an addition of an outcome area focused on housing "Secure and appropriate place to live"

It is critical, however, that each of these policy areas covers the full breadth of the issues of importance to people with a disability and takes a rights-based approach with a focus on achieving inclusion. The current NDS provides "Areas for future action" but does not create a vision for what should be achieved over the ten-year period and how this will be measured.

Under each outcome area there should be a discussion of the current situation, and an overview of what we need to achieve in 10 years. This approach should include a consideration of where segregation is still normalised within Australian society (special schools, Australian Disability Enterprises etc) and a clear pathway of how we can move away from these models to full inclusion. The outcome areas should also link to recommendations made by the recent UN Report on Australia's performance under its obligation to the UNCRPD and should identify how these gaps will be addressed. This will provide the basis for Targeted Action Plans which can focus on how this vision can be achieved.

It is critical that the content of each outcome area is developed in consultation with people with disability and the disability sector. The current position paper focuses on the broad structure of the NDS and does not provide the detailed information required to enable our organisation to provide feedback on these issues. While the broad outcome areas provide an adequate framework, the detailed content of these areas require further work.

For example, within the policy area 'Learning and Skills' there should be an acknowledgement that we currently have a dual system of schooling where many children with disability do not have access to inclusive education.[3] As has been clearly outlined in a range of reports, inclusion within schools has decreased over the period of the last National Disability Strategy.[4] The Strategy has not been successful in achieving the vision of an inclusive Australian society. The NDS should include a goal of achieving full access to inclusive education within Australia over the 10 years and how this will be achieved and measured.

Similarly, within Economic security, employment of people with disability must focus on opportunities for meaningful employment with appropriate wages. This must include a roadmap for the transition out of segregated employment models.[5] The current NDS does not make any acknowledgement of the issue of segregated employment other than noting the work they have done to improve the viability and outcomes of the Australian Disability Enterprises (ADEs). Any outcomes measured within employment must include a distinction between different types of employment outcomes (% of people with a disability employed within mainstream employment vs ADE's).

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[3] https://www.downsyndrome.org.au/wp-content/uploads/2019/12/Position_Statement_Education_PDF.pdf
[4] https://www.aihw.gov.au/getmedia/34f09557-0acf-4adf-837d-eada7b74d466/Education-20905.pdf.aspx
[5] https://www.downsyndrome.org.au/wp-content/uploads/2019/12/position_statement_on_employment_PDF.pdf

Within the outcome area of personal and community support there needs to be consideration of how all people with disabilities, regardless of whether they have access to NDIS, get access to the support they need. As part of this it is important to consider issues around access to a skilled workforce who is renumerated and appropriately trained.

Guiding Principles

The discussion paper has proposed the following guiding principles for the new NDS:

- **Involve and engage:** has the policy process or program design engaged with and listened to people with disability at all stages of planning and implementation and provided accessible information and opportunities for feedback?
- **Design universally**: have the principles of universal design been applied where possible and has the project taken advantage of accessible and assistive technology where available?
- **Engage the broader community:** how has the broader community been informed of, involved in, and been made responsible for removing barriers and supporting the inclusion of people with disability?
- **Address barriers faced by priority populations**: how have the priority populations noted by the National Disability Strategy been identified and what action has been taken to specifically address the barriers they may experience?
- **Support carers and supporters**: how have the needs of the family, carers and circles of information and formal support for the person with disability been considered in the development of the policy or program?

These principles are generally sound and appropriate for the new NDS. DSA suggests the addition of a 6th principle:

- **Rights and Inclusion:** Have the rights of people with a disability been considered in the policy and program? How have principles of inclusion, a human rights-based approach, and the critical objective of ending segregation been considered in the development of this policy or program?

There needs to be further elaboration on "**involve and engage**". It is generally agreed that involvement can be conceptualized as a continuum ranging from no involvement to shared leadership, adapted from Arnstein's original concept of a ladder of participation.[6] At the continuum's lower end, people are involved through providing information, but they have limited input into the process. The provider, organization or system define their own agendas and then seek input. At the continuum's higher end, engagement is defined by shared responsibility, with people being active partners in making decisions and shaping policy or systems. The principle as it stands would support and promote a basic level of 'consultation/information' but would not necessarily lead to partnership or true co-design. For this reason, this principle should be changed to:

- **Involve and partner**: has the development of the policy or program adopted a disability inclusive approach including partnership with people with a disability at all stages of planning and

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[6] Arnstein, S. (1969) A Ladder of Community Participation. Journal of the American Institute of Planners, 35, 216-224.

implementation? Have the views of people with disability been incorporated into the design of the program? How have the relevant disabled persons organisations/disability representative organisations been engaged in the design of this program?"

Intellectual disability should be included as a priority population under guiding principle 4. People with intellectual disability have been shown to experience greater stigma and discrimination[7], worse education and employment outcomes[8] compared other people with a disability and face significant difficulties in accessing appropriate information[9] and support. For example:

- In a Victorian survey of community attitudes, 56% of people said they were likely or very likely to avoid a person with an intellectual disability (compared to 28.6% for people who use a wheelchair, or 29% for deaf people).
- Only 32% of adults with intellectual disability are participating in the labour force (compared to 53.4% of people with other disabilities, and 84% of people without disability.
- One in five Australians surveyed indicated they were uncomfortable with their children sharing a classroom with other children who have an intellectual disability.

Often issues around intellectual disability are neglected in the development of policy responses or program delivery. Given that 3% of the population (or approximately 750,000 Australians)[10] identify as having an intellectual disability and the worse outcomes experienced by them, it is essential that they are identified as a priority group within the NDS.

Increased Focus on Community Attitudes

As the discussion paper notes community attitudes are one of the barriers faced by people with disabilities in several different domains including health, education, employment, and community participation. Stigma about intellectual disabilities tends to be even greater than other types of disabilities. People with Down syndrome are often subject to harmful and inaccurate portrayals, resulting in some community members adopting negative attitudes towards them.[11,12]

A recent survey of community attitudes in Victoria highlights the exclusion and discrimination faced by people with intellectual disability.[13] It found that:

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[7] Victorian Government. Department of Health and Human Services. Survey of Community Attitudes Towards people with a disability.

[8] https://data.ndis.gov.au/media/1562/download

[9] Oldreive, W. and Waight, M. (2013), "Enabling access to information by people with learning disabilities", Tizard Learning Disability Review, Vol. 18 No. 1, pp. 5-15

[10] https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4433.0.55.003main+features102012

[11] Gilmore, L., Campbell, J, & Cuskelly, M. (2003). Developmental Expectations, Personality Stereotypes, and Attitudes Towards Inclusive Education: community and teacher views of Down syndrome. International Journal of Disability, Development and Education, 50(1), 65-76.

[12] Gilmore, L. (2006). Perceptions of Down Syndrome in the Australian Community. Journal of Developmental Disabilities, 12(1), 1-13

[13] Victorian Government. Department of Health and Human Services. Survey of Community Attitudes Towards people with a disability. **https://www.statedisabilityplan.vic.gov.au/application/files/5415/7526/0530/University_of_Melbourne_Community_Attitudes_Final_Report_19.06.19_-_PDF.PDF**

- 75% of respondents indicated that they were likely or very likely to 'pity' a person with intellectual disability
- 56% of respondents indicated that they were likely or very likely to avoid a person with an intellectual disability.
- One in five responded that children with disability should only be educated in special schools, and that employers should be allowed to refuse to hire people with disability.

Negative attitudes and a lack of awareness also extend in some cases to the health profession. A 2011 study conducted with 1,500 physicians found that nearly a quarter of physicians (24.3%) felt that including students with Down syndrome in classes with typically developing students is distracting. In addition, almost 10% of physicians indicated that they did not feel comfortable providing medical care to people with Down syndrome.

Given these findings, DSA welcomes a focus on community attitudes within the NDS. It is essential that in the implementation of the NDS, tailored approaches are taken to addressing community attitudes as often public awareness type campaigns might focus on physical disabilities but do little to address stigma associated with intellectual disabilities. It is essential that any strategy to tackle community attitudes recognises the diversity of disability types and the experiences of people with a disability.

The implementation of the NDS must take into account the multiple ways that changes in community attitudes can be achieved. One example is the interaction between negative community attitudes about intellectual disability and the practice of segregation of people with intellectual disabilities. Exposure to children with intellectual disabilities has been shown repeatedly to have a positive impact on awareness and attitudes about intellectual disability[14]. Not surprisingly, children who grow up without exposure to people with disability have less understanding about disabilities and are more likely to develop negative attitudes[15]. Segregation leads to lack of community awareness, due to a lack of exposure, and that stigma/misunderstanding leads to further segregation. Fostering inclusion and addressing systemic practices of segregation can contribute to breaking the cycle of stigma associated with disability.[16]

As outlined by the Social Policy Research Centre in 2011[17], there are several principles that need to be considered to successfully address attitudes about disabilities. These include:

- Adequately resourcing the approach
- Supporting people with disability (and disability representative organisations) in the development and implementation of any awareness initiatives

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[14] Cairns, Bernadette & McClatchey, Kirstie. (2013). Comparing children's attitudes towards disability. British Journal of Special Education. 40. 10.1111/1467-8578.12033.

[15] Thomas, R. and Rose, J. (2020), School inclusion and attitudes toward people with an intellectual disability. Journal of Policy and Practice in Intellectual Disabilities, 17: 116-122. doi:10.1111/jppi.12322

[16] Cologon, K (2013). Inclusion in education – Towards equality for students with disability. Retrieved from **https://www.pc.gov.au/inquiries/completed/childcare/submissions/post-draft/submission-counter/subdr903-childcare-appendix3.pdf**

[17] https://www.dss.gov.au/sites/default/files/documents/05_2012/39_community_attitudes_to_disability_accessible.pdf

- Addressing multiple levels of intervention
    - Personal- changing the attitude of individuals through information, education, training, positive portrayal and supported opportunities for contact
    - Organisational- focusing on changing attitudes within a particular sector (inclusion Ambassadors within a school, or disability action plans within a major company)
    - Structural- Changing policy/legislation to improve inclusion and promote positive attitudes (for example changing Disability Education Standards to promote inclusion within schools).
- Recognising the diversity of disability types and circumstances of people with disability
- Implementing the strategy over a prolonged period to reinforce positive attitudes and replace negative attitudes.

These principles should be included as part of the framework for the increased focus of community attitudes within the National Disability Strategy.

In particular, addressing attitudes to disability cannot be undertaken through a lens of "responsabilisation" where the issue is located with individuals and collectively, the community. In this regard, governments play a key role in demonstrating leadership and the prioritisation of the rights of people with disability though clear and robust legal and policy frameworks to protect those rights. Without governments demonstrating their strong commitment, individual or community-based initiatives to change attitudes are likely to have limited impact.

Strengthening Accountability

A key criticism of the current NDS has been a lack of accountability, accurate measurement of outcomes and clear reporting to the community.[18] DSA welcomes the focus in the position paper on strengthening accountability in the new NDS.

Roles and Responsibilities

One of the concerns raised about the implementation of the NDS has been there has been a lack of a consistent systemic approach. [19] There have been a range of positive local initiatives, but a lack of systemic implementation of the goals of the strategy. As identified by several reviews, a central agency (e.g. DSS) needs to take responsibility for coordination of the implementation of the strategy and be adequately resourced to drive this work. Initiatives which are funded through the Strategy need longer-term funding (at least 3-year agreements) provide the opportunity to implement sustainable systems and achieve change).[20]

The NDS must include a clear and concise overview about the roles and responsibilities of various levels of government in delivering on the Strategy, including the coordination function. The overview of roles and responsibilities should also include a consideration of the important role of Disabled Persons Organisations (DPOs) and Disability Representative Organisations (DROs) have in implementing the strategy. The

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[18] https://www.dss.gov.au/sites/default/files/documents/04_2019/review-implementation-national-disability-strategy-2010-2020-final-report.pdf
[19] Senate Community Affairs References Committee, 2017, 'Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities'
[20] Ibid.

approach outlined in the Position paper which suggests that the document should link to other documents which summarise the role of various Governments with regards to NDIS and mainstream services may lead to confusion and would not provide accessible information.

For the NDS to be successful it must be accompanied by appropriate levels of funding for the implementation of the Strategy. As outlined in the 2019 review of the NDS, this must include funding to support the coordination of the strategy, the participation of people with disabilities, implementation of structural systemic changes, funding to develop the evidence base and for data collection and evaluation.[21] The NDS should include transparent information about how the implementation of the Strategy will be funded including the role of ILC funding and other Federal funding.

Measuring Outcomes

The measurement of outcomes must be more nuanced than in the previous NDS and may require the collection of additional data. For example, in the 2016 report on the implementation of the NDS, the 'indicators of changing trends' for the learning and skills outcome area focused on Year 12 completion, and non-school qualifications[22]. There was some high-level discussion of feedback received from people with disability, but no clear data was provided. Key indicators were missing from the report, such as the proportion of students with a disability accessing inclusive education versus special schools. Much of the reporting against outcomes was listing of specific programs in local areas.

It is critical that a comprehensive outcomes framework is developed to measure progress against the NDS. For each outcome area there should be clearly identified and measurable goals. Each of these goals should be mapped to data that is currently available or gaps should be identified where further data collection is required for the purpose of monitoring the NDS.

It is essential that the views and experiences of people with disabilities are captured as part of measuring success against the outcomes of the strategy. Where possible this should be done in a consistent quantitative approach so that outcomes can be tracked over time. The measurement and analysis of outcomes of the NDS must be funded appropriate. In some cases, there will need to be specific data collected which is not part of other data collection processes.

Reporting

Public reporting on progress against the NDS is crucial for both transparency and accountability. It also provides an opportunity to refocus the implementation depending on how outcome measures are tracking against the targets. For these reasons annual reporting which includes measuring progress against each goal, reporting on structural or systemic changes, as well as an overview of outcomes from key policy and programs would be appropriate. The proposal in the Position Paper of a progress report every two years does not provide the level of transparency and accountability required by such an important Strategy (for comparison, the NDIS provides quarterly reports to COAG which are publicly available).

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[21] https://www.dss.gov.au/sites/default/files/documents/04_2019/review-implementation-national-disability-strategy-2010-2020-final-report.pdf

[22] https://www.dss.gov.au/sites/default/files/documents/01_2019/final-national-disability-strategy-2016-progress-report-pdf.pdf

The report should focus on high-level systemic changes that have real impacts on people with disabilities, rather than a listing of specific disability initiatives in each jurisdiction. This approach could include outcomes of an annual survey of people with disability which provides their views and experiences against each of the outcome indicators, as well as utilising the new National Disability Data Asset, the Nationally Consistent Collection of Data on School Students with Disability and data collected through the ABS surveys.

Targeted action plans

The proposed targeted action plans that focus on making improvements in specific areas within a defined period of time provide a way of focusing the efforts on delivering on a key aspect of the National Disability Strategy. It is essential that these action plans be co-designed with people with disability and that the priorities for the action plans are identified by the sector. The Targeted Action Plans could be one way of addressing systemic segregation with an initial focus on areas which have been highlighted by the UN report on Australia's compliance with its obligations under the CRPD.

The challenge is ensuring that the Action Plans do not take away the overall focus of delivering on the NDS. For example, if the Government decides to create a Targeted action plan on improving employment outcomes for people with a disability it should not necessarily be prioritised over other key areas of the Strategy such as inclusive education, or access to health care. One approach would be to create a targeted action plan for each outcome area.

Engagement Plan

The new Strategy should include an Engagement Plan which clearly articulates governments' commitment to ensure that people with a disability can be meaningfully involved and partner in shaping future disability policies, programs, and services. This Plan should specify how people with disability will be supported to be involved in all aspects of the implementation of the NDS. This must include additional consideration for how people with intellectual disability will be engaged and supported in their involvement. This Engagement Plan must include funding to support involvement and to reimburse individuals for their valuable time and expertise

The Engagement Plan should also identify how DRO's and DPO's can assist in facilitating this level of involvement and provide collective information about the views and experiences of their membership. It is essential the Engagement Plan does not focus on just involving a few individuals, but ensure that the Strategy, and future disability policies, programs and services are informed by the collective views, experiences and wisdom of people with disabilities.

Summary

The NDS is a key mechanism for driving inclusive policy and programs across all levels of government and the implementation of Australia's commitments as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The new Strategy must articulate a clear and achievable roadmap for achieving a more inclusive society over the next 10 years across education, health, justice, employment, and community life.

For the new NDS to be effective it must:

- Include a plan for ensuring meaningful engagement of people with disabilities in all aspects of the implementation, evaluation and reporting of the NDS
- Articulate a clear roadmap for achieving a more inclusive society including the phasing out of segregated settings for people with a disability
- Be appropriately resourced for the coordination and implementation of the strategy, outcome measurement and reporting, and support for the involvement of people with disability.
- Have clearly defined and measurable goals for each outcome area which can be reported against on an annual basis.
- Have clear and focused Targeted Action Plans which include structural changes to policy to achieve outcomes for people with disabilities.
- Clearly identify the roles of DPOs and DROs in supporting the implementation of the strategy and how they will be resourced to do so.
- Identify intellectual disability as a priority population under the guiding principles.
- Consider workforce implications of the Strategy.

It is also essential that DSS provides another opportunity for consultation on a fully developed draft of the National Disability Strategy to ensure that people with disability and relevant organisations have an opportunity to provide feedback on the detailed content of the NDS.