

National Disability Strategy Position Paper July 2020 Submission

THE DEAR DYSLEXIC FOUNDATION

The Dear Dyslexic Foundation (DDF) is a dyslexic-led organisation. Our mission is to empower young people and adults with learning disabilities to reach their full potential. DDF gives young people and adults a platform to share their lived experience of dyslexia and other learning disabilities. Our service model is built on peer-led support principles, and we use storytelling to give dyslexic individuals, their parents, and carers a voice as a means of empowerment and self-advocacy. DDF operates under a social model of disability, whereby dyslexic individuals are properly supported by the community according to their individual needs.

We actively seek to address the many challenges that dyslexic individuals face, including barriers to diagnosis, lack of visibility, acceptance and inclusion in school and employment, and access to support services. Through a collective dyslexic voice, we produce regular podcasts, provide a 1800 peer-support helpline, and have a growing online community. The online community increases inclusivity, in respect of differing levels of confidence, preferences and safety whilst increasing capacity to access and learn from peers.

Dyslexia

Dyslexia affects one in ten Australians. It is a neurobiological-based specific learning disability that significantly impacts an individual's ability to learn how to decode and read words, with impairments in processing the phonological aspects of language (Lyon, Shaywitz, & Shaywitz, 2003). When reading, speed, fluency, comprehension and spelling are compromised (Berent, 2017; Nation, 2019). Secondary difficulties are less obvious to identify but will co-occur with dyslexia. These difficulties include working memory, motor skills, organisation skills, expressive language skills, mathematics and left and right confusion (Neil Alexander-Passe, 2018). Dyslexia is recognised as a disability under the Discrimination Act 1992. Under the Equality Act (2010) of which disability is one of the nine protected characteristics, dyslexia is recognised as a disability.

Dyslexia is a life-long disability, unaltered by the level of educational attainment or the quality of teaching (Lyon et al., 2003; Tanaka, 2011). Dyslexia, like other specific learning disabilities, is on a spectrum from mild to severe and is not related to one's intelligence (Aaron, Joshi, & Williams, 1999). In

National Disability Strategy Position Paper July 2020 Submission

addition, other specific learning difficulties can be comorbid, or co-existing, with such conditions as dyscalculia, (difficulties in maths), dyspraxia (developmental coordination disorder) or attention deficit hyperactivity disorder (ADHD); any one of which exacerbates the combined debilitating effects of dyslexia.

Over the past two decades there has been an increase in recognition of dyslexia within the education sector, including an awareness of the impacts this disability can have on learning and development outcomes of a child and young person. Yet the support is still inadequate and furthermore has not transpired for adults, particularly in the workplace, leaving many with this disability unrecognised, unsupported and unheard.

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?

Dyslexia affects all aspects of one's life and the six domains represent the key areas that a person with dyslexia may struggle in.

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

We would question how the guiding principles will provide a voice for underrepresented populations such as those with dyslexia who are not supported under the NDIS. With regards to engaging the broader community, we would see a need still for raising greater awareness about dyslexia. This should include more than education and other social institutions, but also within employment and professional environments.

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?

We believe improving community attitudes is critical for those with disabilities to feel accepted and valued as members of our society. Dyslexia is one of the most dominant disabilities within our society, yet there is a significant lack of awareness and understanding of the condition. This lack of awareness and understanding has led to institutionalised barriers and stigmatisation due to poor

National Disability Strategy Position Paper July 2020 Submission

attitudes towards people with dyslexia, prohibiting them from fully participating as equal members of the community. It also leads to discrimination through ignorance, and individuals living with the anxiety of their disability becoming known and in dread of possible negative consequences. We know that those with dyslexia face emotional challenges such as anxiety, low self-esteem, poor self-concept, lack of confidence, frustration and anger (Burden, 2008; Carroll & Iles, 2006; Madriaga, 2007; Wilson, Deri Armstrong, Furrie, & Walcot, 2009).

Dyslexia is highly represented among prison populations in many developed countries. Figures cited range from 14%-47% (Ankney, 2019; Samuelsson, Herkner, & Lundberg, 2003) and in young offender institutions as many as 50% (Kirk & Reid, 2001). Those with dyslexia face:

- Significant levels of depression and anxiety (Wilson et al., 2009).
- Self-harm tendencies- Males predominantly self-harm with alcohol, followed by food and then rarely with bodily. While females predominantly self-harm with food, then bodily harm and lastly alcohol (Neil. Alexander-Passe, 2015).
- 46% more likely to have attempted suicide, which is much greater than the average population (Fuller-Thomson, Carroll, & Yang, 2018).
- Research tells us that shame is one of the strongest feelings that those with dyslexia face (Bohdanowicz, 2015).

A key instrument of change could be institutional policy development, in respect of the Equality Act (2010) of which disability is one of the nine protected characteristics, and dyslexia being a disability. Policy should clearly state a duty to employers, managers and trainers, to make reasonable adjustments in the workplace for persons suffering with disability including dyslexia, and that support legislative demands of Australia's anti-discrimination law.

We know that community attitudes must change for those with dyslexia to feel more accepted and valued members of our community. It is imperative that the strategy looks at ways to improve the community's attitudes towards those with dyslexia and other learning disabilities so they too can live healthier, happier more connected lives within our community.

National Disability Strategy Position Paper July 2020 Submission

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?

Dyslexia is a lifelong disability; it doesn't go away once we leave school or transition into adulthood. If dyslexia is left unidentified and unassisted, it can cause social and emotional suffering and is associated with poorer life outcomes across the social determinants of health and wellbeing. This can result cumulatively in reduced education and employment opportunities, and a life trajectory that includes low economic status, poor health literacy, and, most distressingly, an over-representation in the justice system' (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004). In much the same way the Federal Government has, over the past 30 years, streamlined and brought the states into alignment on education standards, road safety and licensing, and elements of the criminal code. There is now a need, to lead the states and territories in ways that address the needs of people with dyslexia in education, and the workplace. Unfortunately, the highest need area is in the domain of criminal justice and corrections.

We know that many dyslexic people go undiagnosed and are therefore unsupported across their schooling, further education and workplace lives. Many Australians cannot afford the out of pocket expense of a dyslexia assessment which ranges from \$1500.00 - \$2500.00. This leaves many without either a diagnosis, or the support they need to participate, and contribute, fully within the community. As dyslexia is not covered under the NDIS nor under the Medicare there is:

- No clear description of the roles and responsibilities of government, including that of the NDIS, to support those with dyslexia.
- No reporting on outcomes committing to the collection of relevant data to enable effective monitoring and reporting.
- No approach to the evaluation of policies and programs that could support and improve the life outcomes for those with dyslexia.
- No clear roles and responsibilities of government to ensure those with dyslexia can access disability-specific and mainstream services.

National Disability Strategy Position Paper July 2020 Submission

Considering the high rates of dyslexia compared with other hidden disabilities such as Autism Spectrum Disorder this should be reviewed with a view to taking action. Data needs to be collected and surveillance measures implemented to truly determine the significant impact that dyslexia has on individuals. This should then be followed by suitable policies and programs to support dyslexic people.

Currently student data is being collected through National Consistent Collection of Data (NCCD) on dyslexia covering up to the age of 16. Beyond 16 there is no collection of data occurring across the NDIS, Centrelink, ABS and MBS. At a minimum for this cohort of people, the NCCD data on dyslexia should be accessed to guide policies and the national disability strategy.

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.)

The role of not-for-profit organisations in the education of business communities, schools, service providers and social institutions cannot be overstated in terms of the function that they serve in the community. Raising awareness, supplying information and direction to those who require help, in order to meet the needs is a duty of care towards those with a disability such as dyslexia.

If governments and service providers are to be held to account, through the 'new' strategy, those concerned will need to be well informed about specific disability needs. The knowledge, skills and lived experience can be usefully deployed to shape services and policy.

In order to participate and contribute fully as active citizens, those who live with dyslexia, and their families, need to be heard. Invariably they are a source of strong, well informed advocacy. They are the experts on the disability and all that it entails. Thus, they and are best placed to inform other groups such as employers, educators, and service providers, about what barriers to inclusion exist *disabling the individual with dyslexia*, physically, and attitudinally, in both society and the environment.

Those with dyslexia can make a significant contribution to our community. Through engagement as leaders within the broader community and organisations, they can make valuable and expert contributions to policy and become an instrument for positive change. The strengths of dyslexia are many, and specific skills make a valid contribution in the Sciences, Arts, Social Science, the environment

National Disability Strategy Position Paper July 2020 Submission

and conservation. Many dyslexics possess entrepreneurial skills and become successful in business, becoming employers themselves.

A shift on disability policy that this National Disability Strategy will hopefully bring-about must provide greater opportunities for the dyslexic individual to succeed, for the pathway to be cleared of barriers to success, and for those who employ, teach or provide for their needs, to be fully aware of the strengths but also the weaknesses that this disability impacts on the dyslexic person's life.

The Dear Dyslexic Foundation is a dyslexic led organisation with well represented board members and volunteers being dyslexic themselves. We provide a voice for young people and adults with dyslexia to share their lived experiences. Please see attached some of our case studies and link to our podcast series which provides a platform for those with dyslexia to share their lived experiences. The Foundation is well positioned to collaborate with government to increase the dyslexic voice to inform strategy and policy decision making. The Foundation has a closed Facebook group with 165 members and 3500 followers across our social media channels including Facebook, LinkedIn, Instagram and Twitter. We have an international podcast following with over 10000 downloads.

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?

Data on dyslexia and other learning disabilities should be recognised as a unique data point and as such be captured at a federal level through NDIS, Medicare, ABS, Centrelink, Corrections, and in Education through the Nationally Consistent Collection of Data (NCCD). This data should be made available to the public to help inform decision making processes by local and National governments, states and territories, and, to support Non-Government Organisations (NGO) working in this space, to provide evidence informed decisions that better support those with dyslexia. Without surveillance data those with dyslexia get left behind, become disenfranchised, feel alienated and unable to contribute fully to society.

National Disability Strategy Position Paper July 2020 Submission

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 Targeted Action Plans should include dyslexia and other learning disabilities and focus on making improvements in specific areas. Data should be reviewed every 12 months with a specific action plan set out by government every three years. This will ensure that those with dyslexia are appropriately catered for enabling them to reach their full potential.

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 include the dyslexic community including NGOs such as the Dear Dyslexic Foundation that work to support those with dyslexia from across Australia. We recognise the high proportion of dyslexic individuals living with psychosocial disabilities which are secondary to their 'invisible dyslexia' and create associated barriers to active citizenship. Dyslexic Individuals have expressed feelings of stigma, discrimination, alienation from peers and the need to disguise their challenges, using coping strategies to hide their authentic self, creating a second persona (Alexander-Passe, N, 2015). The dyslexic voice and the lived experience of individuals with this hidden disability is not being heard and it is imperative that they are consulted when delivering and monitoring the next strategy.

National Disability Strategy Position Paper July 2020 Submission

Appendix

Case studies:

Karen is a Dear Dyslexic Community Member, who shares her story of how Dear Dyslexic has supported her.

“I was working in the disability sector and also with children at a Rudolph Steiner School as the extra lesson practitioner and in private practice. I was enthusiastic that tired and stressed as you know we always have to work extra hard to compensate. I wanted to work with and connect to other people and bring awareness.

I was hoping to find other people to talk to about coping in the workplace with dyslexia. I was hoping to find people that are understood and could give advice. Because Dear Dyslexic was also aimed at adults it was fresh but I really liked that. I also liked that they had podcasts. It was good to be able to look at the website and listen as I was feeling a bit anxious to meet people straight away.

The podcasts because I could listen to the safety of my own home. At 56 years old there is years worth of experience in the workplace in relation to dyslexia and that can be overwhelming when you take the lid off. Even as an experienced counsellor there is nothing like hearing your own truth echoed acknowledged and validated. This had helped me make space for the needs of my nervous system even though I’ve made many improvements to my situation over the years. Not being understood or given an allowance or even not telling people because of judgment has been challenging.”

Shanan Dear Dyslexic Member. He owns his own business and has dyslexia. He recently returned to study to develop his skills. As part of that, he came across the Dear Dyslexic site and found the resources and community really useful.

“I was looking to connect with other dyslexics and find out about all the assistive technology that is help them throughout the years of their time at uni.

National Disability Strategy Position Paper July 2020 Submission

It's made by dyslexics for dyslexics. The online community is really engaging, and I've received a lot of excellent advice. All the resources on the website are fantastic, especially the section on strategies for students at TAFE and university. I'm extremely enjoying the podcast it's really interesting hearing about everyone's unique journey and the different ways they've overcome adversity and achieved success."

Dr Nola Firth leading dyslexia expert

'Dear Dyslexic' is unique. It is run by and for people who have dyslexia. Consequently, all web content is easily accessible by text to speech technology and the site features an extensive collection of podcasts that give voice to people from all walks of life who have dyslexia. Additionally, there is a strong focus on assisting adults, especially young adults, in dealing with the impact of having dyslexia - including in the workplace, where it is very often ignored here in Australia.'

Dear Dyslexic Podcast Series

The Dear Dyslexic Podcast Series is about sharing stories of the lived experiences of people who have dyslexia and other learning disabilities, as well as those who care for, live and or work with us.

Shae Wissell the creator of the Dear Dyslexic Podcast Series states "I wanted to use podcasts as the medium to share unique stories of everyday Australians who have dyslexia and other learning disabilities, to shine a light on the success and the challenges of life with dyslexia. Without the reading barrier, we can all listen and learn."

You can listen to a variety of guest speakers from authors, to actors, entrepreneurs and every day dyslexic people not just surviving but thriving.

Find out more: <https://www.deardyslexic.com/dear-dyslexic-podcast-series>

National Disability Strategy

Position Paper July 2020

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