

# **Submission: Foundational Supports**



Peak body for independent disability advocacy in Victoria

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## A. Acknowledgement of Country

1. Disability Advocacy Victoria acknowledges the Wadawurrung, Wurundjeri and Boonwurrung speaking people of the Kulin Nation as the Traditional Owners of the grasslands, waterways and basalt plains known as Naarm. We pay our respects to Elders past, present and those that are yet to come. We acknowledge that this always was, and always will be Aboriginal Land.

## B. Disability Advocacy Victoria

2. Disability Advocacy Victoria is the peak body for independent disability advocacy agencies in Victoria.
3. Member agencies are funded from a variety of sources, both State and Federally, and through a range of government departments.
4. Our Guiding Principles and Values include leadership by people with disability and operating in accordance with the United Nations Convention on the Rights of Persons with Disability ("CRPD").
5. Members of Disability Advocacy Victoria, include disability led advocacy agencies, including members of Disabled People's Organisations Victoria.

## C. Introduction

6. Disability Advocacy Victoria welcomes the opportunity to comment on General Foundational Supports, acknowledging the government's intent is to design and deliver information, advice and referral services to improve access to and visibility of mainstream services and supports.
7. We note that disability advocacy, apart from self-advocacy, has been excluded from this swathe of reforms, citing that this will be addressed through the National Disability Advocacy Framework. Disability Advocacy Victoria believes it would be a missed opportunity not to consider Individual Advocacy and Systemic Advocacy alongside self-advocacy and would welcome National Cabinet investment in achieving nationally consistent access to all forms of disability advocacy services with improved coordination across levels of government.
8. While individual disability advocacy is unique and specialised, it cannot be separated from the provision of information, advice, referral and capacity building. We believe that people with disability should be able to access professional advocacy advice and support from trusted organisations, specific to their needs, that does not require them to engage with and access separate systems.
9. We would like to highlight the perilous state of National Disability Advocacy Program funding and Victorian Disability Advocacy Program funding for independent disability advocacy. The impact of this fiscal uncertainty on the sustainability of disability advocacy organisations can be seen in the overwhelming unmet client need with ever increasing waiting lists, the narrowing of different organisations' advocacy focus,

and the reduction of available funding for advocate positions. Hence, we would like to see further details about how disability advocacy would be sustainably funded, remaining independent and free of conflicts of interests clarified.

10. While we note that the government has committed to a strong focus on co-design with people with disability, Disability Advocacy Victoria believes the process of consultation with people with disabilities that government is required to undertake has not occurred in a manner consistent with the CRPD. For that reason, no final decision-making should occur in relation to foundational supports until the requirements of the CRPD have been satisfied.

## D. Background to Foundational Supports Consultation

11. The genesis of Foundational Supports emerged out of the NDIS Review which recommended a new ecosystem of supports (Recommendation 1) and improvements to mainstream services and supports for people with disability (Recommendation 2). The NDIS Review asserted that National Cabinet should jointly invest in achieving nationally consistent access to individual disability advocacy services, with improved coordination across levels of government.
12. In December 2023, the Commonwealth reached agreement with the states and territories to fund Foundational Supports in a 50-50 split. In January 2024, National Cabinet announced that \$11.6 million has been invested into a Foundational Supports Strategy.
13. The NDIS Review proposed that individual advocacy could be a foundational support, potentially shifting how individual advocacy is funded. In addition, the Federal Government's response to the Disability Royal Commission in July 2024 announced a new advocacy program, without detail about how funding would be distributed, how it would relate to the Foundational Supports Strategy, or which kinds of advocacy would be included.

## E. General Comments on Foundational Supports

Foundational Supports must rise above politics and make clear the parameters of this commitment.

14. There have been concerns that in the current political environment, noting the manner in which the narrative has been portrayed in the media, that the design, funding and implementation of both general and targeted foundational supports is vulnerable to political decision-making.
15. The current commitment from the commonwealth and state governments to fund foundational supports in a 50/50 split is welcomed, however we await further information on the parameters of this commitment, particularly around the funding

allocation for foundational support and eligibility to access targeted foundational supports.

Foundational Supports needs to build on existing and trusted relationships that people with disability have with their disability advocacy organisations - instead of building another system to navigate.

16. Independent disability advocacy organisations across the country have been funded by Commonwealth, state and territory governments for decades to provide disability advocacy services for people with disability - this cannot be separated from the role of providing information, advice and referral. This long history of partnership with people with disability has seen the development of a set of principles and practices designed to deliver information, advice and referral using a rights-based framework free of conflicts of interest. This approach has promoted and protected the interests of the person with a disability.
17. Over the decades, people with disability have developed a trust in independent disability advocacy organisations. Independent disability advocacy organisations have developed relationships as a result of providing information, advice and referral that values the person with disability, ensures the advocacy support is led by the person with disability, supports their decision making, and promotes and upholds their rights throughout the process.
18. We submit that separating individual advocacy from the provision of information and referral, as occurred when the NDIS was established, has not benefited the disability community. It has fractured supports, with no positive demonstrable outcomes. There is significant crossover between advocacy and provision of information and referral. Unless one is closely working with the disability community, referrals can be misplaced, information can be erroneous or irrelevant. Given the significant discrimination against people with disabilities, as canvassed widely by the recent Disability Royal Commission, the simple process of a referral may need advocacy to ensure success. People with disabilities themselves, and organisations that have a long history of working alongside them, are best placed to provide relevant, accurate information and referrals in a seamless way.
19. It is critical that when developing foundational supports, we do not unintentionally create another cumbersome and inaccessible system for people with disabilities to navigate. We need to design the scheme to be seamless, flexible and person-centred to ensure that people with disabilities have what they need, when they need it.
20. The benefits of having disability advocacy as a part of Foundational Supports are that state and federal government can utilise an existing funded program, leverage the expertise that already exists, and grow the capacity of an existing sector that is already a trusted independent source of support and knowledge for people with disability.

21. However, the disability advocacy sector is chronically underfunded and subject to short term funding contracts. This has resulted in a high level of workforce turnover due to job insecurity, and demand for services greatly exceeding supply, with most organisations reporting long waiting lists. Without adequate and urgent resourcing, this situation is predicted to worsen. It is estimated that the demand for advocacy services will grow at approximately 5 per cent per annum on average<sup>1</sup>. Due to short term, inadequate funding contracts, the disability advocacy sector is currently in survival mode across the country, with no ability to forward plan, or level up the impact of its work and innovate.
22. If individual advocacy was included as a Foundational Support, then it would be included under all supports funded by the 50:50 split with Commonwealth and state/territory governments as per the agreement brokered between all governments.
23. This may enable recognition of and clearer commitment to equally funded individual advocacy at both state/territory and Commonwealth levels. Improved coordination and clear accountability for coverage across different regions would ultimately contribute to more people with disability having access to individual advocacy when they need it.”<sup>2</sup>
24. We recommended that disability advocacy funding should be a funded Foundational Support in addition to the current investment of disability advocacy and allocated appropriate resources across the country to ensure that there is equal access to disability advocacy, wherever and whenever a person with disability needs it.

## The role of Independent Disability Advocacy

25. Disability advocacy is a vital source of intermediaries between people with disability and the disability support system and should be appropriately funded as a Foundational Support.
26. Disability advocacy has an important role in supporting people with disability to enact their human rights and access entitlements. Its role is to act in a person-centred way that responds to the needs of a person with disability at any one time. An individual may need information and support to develop their capacity to self-advocate, require a professional disability advocate to work alongside them to understand and navigate complex systems, or want assistance to activate a systemic advocacy campaign. Much of the time, a combination of approaches is utilised.
27. Advocacy approaches are interconnected and unable to be separated in order to achieve effective change. Our members consistently give examples of how this occurs. For example, when supporting a family to advocate for their child with disability to access their entitlements in the education system, the advocate will work

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<sup>1</sup> Increasing funding to meet demand for disability advocacy services, Taylor Fry and the Centre for International Economics (CIE) September 2023, <https://disability.royalcommission.gov.au/system/files/2023-09/Increased%20funding%20to%20meet%20demand%20for%20disability%20advocacy.pdf>

<sup>2</sup> Disability Advocacy Network Australia “Foundational Supports and Disability Advocacy” October 2024

with the family to educate them of those rights and entitlement, increase their capacity to self-advocate, support the family to navigate their specific circumstances and identify areas of systemic change which need sustained advocacy to achieve reform.

28. To do this work disability advocates are required to be skilled in areas such as:
- a. disability awareness and specialist knowledge in supporting people with different kinds of disabilities;
  - b. systems, laws, legal instruments and jurisdictions;
  - c. disability and mainstream oversight systems and complaint procedures;
  - d. negotiation, lobbying and campaigning strategies;
  - e. human rights and its place in advocacy.<sup>3</sup>
29. It is these skills and expertise that are critical to supporting people with disability to navigate their rights and entitlements in the complex system of disability supports, inclusive of mainstream support and access, NDIS and other targeted schemes, and what will become foundational supports.
30. The disability advocacy sector, with its unique skillset to navigate through these complexities is an untapped resource that needs to be utilised and boosted, rather than the creation of new and separate deliverers of service. It has been estimated that independent disability advocacy provides \$2.92 of cost savings for every \$1 spent in mainstream services systems through its work in assisting the system to become inclusive and accessible to people with disability<sup>4</sup>.
31. When designing Foundational Supports, it is important that the disability advocacy sector are strong partners in assisting with identifying the barriers that people with disability experience in their interactions with various systems, and to assist with innovative solutions on how to address these barriers, alongside people with disabilities. However, disability advocacy needs to be appropriately resourced to do this work.

The independence of disability advocates is critical when supporting people to navigate their rights and entitlements in market-based systems - this should be resourced and sustained.

32. Independent disability advocacy is critical to the success of not just the design of Foundational Supports, but also for the success of the disability support system as a whole. Disability advocacy is independent from all systems that a person with

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<sup>3</sup> What Disability Advocates Do, "what is disability advocacy", Disability Advocacy Resource Unit 2017, <https://daru.org.au/daru-publication/what-is-advocacy/what-disability-advocates-do/>

<sup>4</sup> Increasing funding to meet demand for disability advocacy services, Taylor Fry and the Centre for International Economics (CIE) September 2023, <https://disability.royalcommission.gov.au/system/files/2023-09/Increased%20funding%20to%20meet%20demand%20for%20disability%20advocacy.pdf>

disability interacts with, and this in itself makes disability advocacy services a Foundational Support.

33. The design of the NDIS has created conditions where a NDIS participant has become a customer, and the disability support system a commercial marketplace. When NDIS participants are working to access the support they need, many disability services are 'selling' their services to them, hence a greater need to safeguard the rights of people with disability in a marketplace. Mainstream service systems outside of the NDIS are required to be accessible and inclusive to people with disabilities, however, often do not have the skillset in their workforce or capacity within the systems to make this work seamlessly, or at all.
34. Disability advocates work across these sectors, alongside people with disability to educate, promote and assist with navigation of these rights and entitlements. Given that the disability advocacy sector is funded by the state and federal government, independently of the NDIS and mainstream service systems, they are a trusted source of support and information, referral and capacity building that people with disability lean into.
35. Disability Advocacy Victoria supports the notion that information, advice and referral should be more nationally consistent, better connected and coordinated, and more available to people with disability. This is already being done through face to face in-person solutions, online, digital and phone-based approaches that operate together as part of a continuum. Independent disability advocacy organisations have been using these methods to provide information, advice and referral for a significant period of time. Our experience in doing this, having earned the trust of people with disability, is what can make the rollout of Foundational Supports successful.

### For Foundational Supports to succeed and to tap into an experienced workforce ready to meet the need, we need to address Current Overwhelming Demand for Independent Disability Advocacy

36. The disability advocacy workforce is informally already delivering the information, referral and capacity building role that foundational supports seeks to address- however this is unfunded and stretched to breaking point due to lack of sustainable resources.
37. Sector surveys and research by DAV and DANA have demonstrated that independent disability advocacy is currently:
  - overwhelmed with demand
  - attempting to manage and respond to heavy demand alongside reductions in staff capacity due to loss of funding
  - having to respond to increasing complexity of work and support needs, which exacerbates the demand pressures
  - requiring people who seek assistance from independent advocacy services to wait up to 3 months to get assistance.



- minimising outreach and attempts to reach areas in the community of need due to lack of capacity.
38. While there is an already skilled workforce, there are many sectors and vulnerable groups of people with disability who are unaware of disability advocacy or how to access it, and there is little capacity to bring them in as clients on top of already burgeoning waitlists.
39. In policy making and reviews, including the Disability Royal Commission, there has been an excessively narrow focus on relatively easily measured demand (based on contacts and waitlists) rather than the much wider levels of community need that are more difficult to define, and are too easily rendered invisible.
40. We know that from the demographic measures of disability, there are large numbers of people with disability who need this support but cannot access it, leaving many people trapped in situations of risk and harm, isolated and without access to important supports. It also places those working in disability advocacy at risk from the intersection of excessive workloads and moral distress at not being able to respond to needs in the community.
41. It would be a missed opportunity for government not to tap into an existing, skilled workforce that stands ready to support in this reform, however it does need to be adequately resourced.

### Foundational Support needs to meet people with disability where they are - and not require them to fit into a predetermined “one size fits all” system.

42. The design and delivery of Foundational Supports also needs to be embedded in the social model of disability and be culturally safe for First Nations people with disability. In the design of foundational supports, we need to ensure we are not just considering people with disabilities that are already captured in the system - we need to be inclusive of and ensure that there are appropriate responses and approaches to, groups that are currently marginalised and under-served. Such groups include people with disability living in closed environments, CALD people with disability that are currently not receiving supports, First Nations people with disability in remote areas that are not able to access supports in the way that they are currently being offered, and people who have communication support needs.
43. It is also vital that foundational supports are not designed in a ‘one size fits all’ manner. Disability Advocacy Victoria highlights that there are a range of different groups of people with disability that would be disadvantaged by a move to digitalise information, advice and referral. People with disability who would be disadvantaged by a “single website, digital app, online chat and/or phone service that provides or links to quality information, tools or resources about disability, or childhood development, and links or refers you to local supports and services”, include:

- People with cognitive impairments who may have low literacy and numeracy skills
  - People with disability with low digital literacy skills
  - People with disability living in poverty
  - First Nations people with disability living on remote Indigenous communities with limited access to the internet
  - People with disability from culturally and linguistically diverse backgrounds
  - People with disability detained in closed environments
  - People with disability with limited communication skills
44. The Australian Digital Inclusion Index 2023 Report, “Measuring Australia’s Digital Divide” states “substantial numbers of Australians continue to experience affordability stress, meaning they would need to pay more than 5% of household income to maintain quality, reliable connectivity. These include people with disability (55.1%, down from 72.0%).<sup>5</sup>
45. To meet the needs of the intersectional, diverse cohort of people with disability across the country, Foundational Supports need to have a variety of mechanisms for engagement, including face to face, place based support to navigate local systems, phone services, online services and, most critically, effective, culturally safe outreach services. All services need to provide consistent, real-time information and navigation support through the system, and allow people to choose and move between different modalities.
46. A key strength of independent disability advocacy is the ability of advocates to support people with disability with what they need, and not to be limited in the scope of their activity, or by the time matters can take to resolve. The needs of people with disability are often multi-layered and can be very complex, involving multiple services systems and can challenge existing federal, state and territory legislation and policies. Creating artificial boundaries around information, advice and referral can dramatically compromise the effectiveness of advocacy support, particularly when it is working to address gaps between systems.

## Using the Convention on the Rights of Persons to Guide Consultation

47. The design and delivery of Foundational Supports is of the utmost importance for the disability community, and therefore the disability advocacy sector. Therefore, for Foundational Supports to succeed in the way that it is intended, there continues to be a need for a closer and more equitable working relationship on its design and implementation between the Department of Social Services, Disability Representative Organisations and Disabled Person’s Organisations. This is not a choice if Australia is to meet its international obligations in this regard.

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<sup>5</sup> Australia’s Digital Inclusion Index 2023, “Measuring Australia’s Digital Divide” 2023

48. As a signatory to the Optional Protocol, the Australian Government has many responsibilities to ensure compliance with the CRPD, including ensuring the participation of people with disabilities in decisions that affect them, as per General Comment 7, which elucidates the obligation of States parties to closely consult and actively involve persons with disabilities (Art. 4 (3)).
49. These obligations include, but are not limited to, the following:
- a. the active and informed participation of everyone in decisions that affect their lives and rights, particularly in public decision-making processes;
  - b. meaningful consultation with and involvement of persons with disabilities, through their representative organisations;
  - c. consultation beginning in the early stages of all decision-making processes;
  - d. ensuring that all people with disabilities, including those with psychosocial or intellectual disabilities, can effectively and fully participate without discrimination on an equal basis with others in measures directly and indirectly affecting them;
  - e. giving due consideration and priority to the opinions and views of organisations of people with disabilities, when addressing issues directly related to them;
  - f. ensuring that full and effective participation for people with disabilities is not a time-limited event, but a process;
  - g. providing reasonable and realistic timelines for consultation;
  - h. giving the views of people with disabilities due weight, ensuring any approach to consultation is not a mere formality, or tokenism;
  - i. ensuring that people with disability have access to all relevant information, including the provision of reasonable accommodations to ensure they have access to that information, including Braille, and augmentative and alternative communication as an example.
50. Disability Advocacy Victoria 's position is that, while there is a stated commitment to co-design with people with disability through this process, the consultation described above has not occurred.
51. While it may be said that the current three-month submission process provides opportunity for consultation, we understand that the process has not been informed by people with disabilities. The information required to be considered lacks sufficient clarity from our organisation's perspective, and therefore it is difficult to appreciate how that information is accessible to the full breadth of the disability community. Through the consultation papers, it could be inferred that government already has a preferred outcome, despite a nominal consultation process

### Using a disability-led process, rather than co-design.

52. Access to appropriate disability supports has a significant impact on an individual's health, well-being, future prosperity and the ability to have their human rights upheld. The Australian disability community must lead this process in partnership with Government, and their views must be given due weight.

53. We believe that it is vital that the work of designing and developing Foundational Supports is 'disability led'.
54. A disability led framework for designing and developing Foundational Support would mean people with disability are in leadership roles and drive better-informed lived-experience practice. A 'disability led' framework would see people with disability involved in formal and informal decision making.
55. The disability community is crying out for **disability led** services and **disability led** policy change. To emphasise, both the process of reform and the support made available must be led by disabled people. Whilst it is extremely well evidenced that people who have been historically disenfranchised need agency and control of the systems designed to support them, we are still fundamentally failing to deliver this.
56. Co design and consultation are touted as solutions to the helplessness and entrenched lack of agency felt by people with disability. But 'co-design' cannot be a tick box process, and consultation doesn't work if the government is inviting responses to a model that has already been evolved.
57. The disability community is witnessing increasingly complex presentations of disability, along with growing rates of chronic health and psychosocial disabilities. Incidents of stress related ill health multiply with every ill-informed bureaucratic announcement, and the more hopeless people feel the more help they need to survive. The social and economic cost is enormous.
58. It is very clear that Foundational Supports is yet another model that has been developed **for** disabled people, not **by** disabled people. Until we correct our approach and ensure that solutions are disability led, these efforts are destined to fall wide of the mark.

### A growing sense of confusion amongst the disability community

59. There is a growing sense of confusion amongst the disability community in relation to the purpose, design, and delivery of Foundational Supports. Of particular concern is the impact on people with disability. A number of factors are contributing to this confusion including:
- a. The short timeframe for the consultation.
  - b. The absence of a disability led framework: including mechanisms for people with disability to lead the conversations, and a lack of formal and informal mechanisms for participation and inclusion by people with disability in development and decision making.
  - c. Limited amount of detailed information about key aspects of the design and delivery of Foundational Supports including how Foundational Supports will be funded and implemented, and how (and why) mainstream service systems

are being raised as appropriate alternatives to provide information advice and referral to the disability community.

- d. The absence in consultation documentation of the role that independent disability advocacy organisations are already playing as trusted providers of information, advice and referral.
- e. The perilous financial situations for disability advocacy organisations.

60. A concept as significant as negotiating a new national program to design and deliver Foundational Supports for people with disability should have clearly visible disability led mechanisms of decision-making. As noted earlier, there is a clear absence of people with disability from disability representative organisations and disabled persons organisations and independent advocacy from the centre of the thinking, and planning of Foundational Supports. We feel this should have embedded and independent mechanisms that promote and support people with disabilities to lead the process. We are disappointed to see that the principle of 'Nothing About Us Without Us' appears to not have a meaningful role in the process of consultation and in the documentation that has been made available to the sector. This needs to be resolved in order for foundational supports to succeed in its vision.

## F. Conclusion

61. Disability Advocacy Victoria believes that for Foundational supports to succeed, Disability Representative Organisations and Disabled Peoples Organisations need to take a leadership role in the design and implementation of Foundational Supports to ensure a genuine disability-led process.

62. It would represent a significant missed opportunity not to harness an existing workforce that stands ready to support and deliver some components of Foundational Supports in the disability advocacy sector. However, this needs to be adequately and sustainably resourced.

63. This would also prevent introducing another siloed system into the lives of people with disability, when the vision we are collectively aiming for is a seamless system of supports for people with disability - whatever their circumstances may be.

64. Disability Advocacy Victoria welcomes further consultation on Foundational Supports - however ensuring that the process is disability-led and aligned with Australia's UNCRPD commitments is the key to a successful reform.

### **65. Quotes by DAV Members**

*"Deaf Victoria has been engaging with the Foundational Supports consultation process and has spent 5 hours reading, preparing and participating in consultations. All of which are unfunded, as we are not funded through the National Disability Advocacy Program. The level of expertise required in providing quality inputs to a large consultation process like the Foundational Supports needs to be recognised and resourced."*

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