



**The Victorian Self Advocacy Resource Unit (SARU) and
Self Advocacy Groups submission to the Draft National
Disability Advocacy Framework.**

Recognition of Self Advocacy Groups

'We recognise the members of Self Advocacy Groups who have worked tirelessly over the years for the right to live in the community and for equality and human rights for all'

The Self Advocacy Resource Unit (SARU) welcomes the opportunity to input into the review of the National Disability Advocacy Framework (the Framework). The SARU has recently consulted with Victorian Self Advocacy groups around the development of a framework for the Victorian Disability Advocacy Program. The groups consulted were a cross-section and included Self Advocacy groups representing regional, metropolitan, CALD, LGBTIQ+, ABI, Intellectual Disability and complex communication. Some of the information and insights collected from those consultations has been included in this submission.

1. Do you believe the new NDAF encompasses your vision of advocacy? If not, what changes are required?

- The current Draft National Disability Advocacy Framework, 2022-2025 defines Self Advocacy as 'undertaken by someone with disability who speaks up and represents themselves. Support and training for self advocacy is available through community-based groups'.
- This definition implies that Self Advocacy is purely individual and is taught by community groups, it fails to recognise an entire movement or sector – Self Advocacy groups, run by and for people with disabilities. Without such acknowledgement group Self Advocacy, and indeed individual Self Advocacy, become 'less important' than other forms of disability advocacy.
- The Framework, with its reductive description of Self Advocacy as purely individual, does little to encourage and support the group Self Advocacy sector.
- Whilst this is not the appropriate forum to raise the issue of funding for Self Advocacy groups, it is still a major barrier to a vibrant and important Self Advocacy sector, and there are comments about this throughout this submission.
- The NDAP, both in its Framework and a funding model that is equitable, needs to recognise and fund Self Advocacy groups across Australia.

History of Self Advocacy in Victoria

- Group self advocacy began in Sweden in the early 1970's and evolved to become a significant worldwide human rights movement for **people with Intellectual Disability**.
- Victoria, however, is unique in that there are also self advocacy groups run by and for people with an Acquired Brain Injury and people with **Complex Communication** support needs including people who are **deafblind** and people from **CALD** communities.
- Self Advocacy groups are run by people with disabilities who have joined together to have their voices heard and to support each other. Self Advocacy groups work together to make sure they have the same rights, choices, and opportunities as anyone else.
- In 2008 the Victorian Government funded the establishment of the Self Advocacy Resource Unit (SARU).
- The SARU resources and supports Victorian Self Advocacy groups run by and for people with an Intellectual Disability, Acquired Brain Injury and people with complex communication support requirements.
- In November 2015 the Australian Government Senate Community Affairs References Committee Inquiry into Violence, Abuse and Neglect Against People with Disability in Institutional and Residential Settings emphasised that all levels of government need to acknowledge the vital role that formal and informal advocacy, including **Self Advocacy**

groups, plays in addressing violence, abuse and neglect of people with disability.¹

- The **recommendations** included 'further consideration of the Victorian Self Advocacy Resource Unit, with a view to roll out across other states and territories.'
- In 2016, the Parliament of Victoria Family and Community Development Committee Inquiry into Abuse in Disability Services included the recommendation that 'The Victorian Government use its position on the Disability Reform Council to support the roll-out of a self-advocacy program nationally, based on the **Victorian Self Advocacy Resource Unit model**.'²
- Also in 2016, the SARU was funded through the NDIA to work with Self Advocacy groups across Australia to develop a sustainable National Model for Group Self Advocacy. Unfortunately, after comprehensive consultations the NDIA did not implement the report's recommendations.

Why Self Advocacy Groups Matter and why they need to be recognised in the Framework

- 'Group self advocacy is important for many people with a disability, most typically those with an acquired brain injury, intellectual disability or high communication support needs, whose voice is most at risk of not being heard. These groups

¹The Senate Community Affairs References Committee, Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability, Recommendation 15, (2015)

² PARLIAMENT OF VICTORIA Family and Community Development Committee Inquiry into abuse in disability services , Recommendation 6.1 (2106)

are often isolated within disability advocacy, within support services and within the community more generally.³

- 'Self Advocacy is about change. It is about changing lives, opening minds, and shifting attitudes. It is about giving people information, opportunity and support. It is about individuals and it is about society. It is about the changes we have made on so many levels. Change is what group self advocacy does. It changes individuals who become involved and it changes the hearts and minds of people who become aware and lets our country and our society know where change is needed.'⁴ People First Canada (n.d)
- The current disability system, that is the NDIS, has the individual as its main focus. Because of that, Self Advocacy groups form an even more important part of many people with disabilities' lives. In the right environment and with ongoing funding Self Advocacy groups could grow and provide a greater voice for people with disabilities across Australia.
- Victoria is the only state in Australia that has a Resource Unit (SARU) to support the development of, and resource, Self Advocacy in a systematic and coordinated way. In Victoria the approach to Self Advocacy is not necessarily about the notion of individuals taught to advocate more effectively on their own behalf; the approach is more about supporting and resourcing Self Advocacy Groups to position

³ Fyffe, McCubbery, Frawley, Laurie & Bigby (2005)

⁴ People First Canada (n.d)

people with disabilities as proponents of change in their communities.

- The SARU has performed a vital role in expanding the way group self advocacy works, encouraging groups to connect with their local communities and actively engage in community capacity building strategies. SARU has actively resourced Self Advocacy Groups to develop a much stronger awareness of all the tools of community development practice and to engage in local planning and partnerships, which help to change the way community organisations respond to people with disabilities.
- The work of the Self Advocacy group is often based on consensus, where decisions are reached on the different, but common personal experiences of group members, and through this a collective story or response is developed. Self Advocacy groups feel pride and power because they are representing something bigger than their individual selves, their individual struggles.
- On a more practical level, Self Advocacy also supports individuals and groups to develop skills and confidence to be able to take the lead on a range things. For example, in their groups; in discussions with government; on community boards and in community planning forums.
- Self Advocacy groups give their members the opportunity to talk about and deal with the exclusion, abuse and trauma they experience, to feel listened to and empowered. The

group enables people to find a place to deal with the politics of their exclusion.

- Self Advocacy groups provide strength to individuals because they know the group is there for them. These can be breakthrough moments where, for the first time, a sense of shared vulnerability is a source for creating community in people's lives.
- Self Advocacy groups give a voice to some of the most marginalised in our community, people with an Intellectual Disability, an Acquired Brain Injury or people with complex communication support requirements. Self Advocacy groups facilitate communication with community, government, service providers, other decision makers and individual members.
- Self Advocacy groups are also intersectional, groups like Rainbow Rights for people with an Intellectual Disability who identify as LGBTIQ+, Power in Culture and Ethnicity with its focus and membership around people from CALD backgrounds, Positive Powerful Parents, a Self Advocacy group run by and for parents with an Intellectual Disability.

'Through Rainbow Rights we show that we have sexual preferences and that I'm not just a person with a disability. We show that we have choices about who we want to love; where we want to love and this gives us confidence that we can change community. We can change the way community thinks who we are and what we want to do'.

(Member, Rainbow Rights)

'We tell our story and we share our stories at presentations and we have social meetings with new parents where we share our stories; we also let Child Protection know about our lived experience by doing projects. We reviewed Child Protection documents and made them into Easy English and by doing this we made them know what should have happened that didn't happen. At the meetings with Child Protection I told them my story and they still told me it didn't happen.'
(Member, Positive Powerful Parents)

- These ground-breaking groups give people who experience multiple layers of disadvantage and exclusion a powerful voice and the opportunity to make change, with mostly no funding.
- The majority of Victorian Self Advocacy groups have been, and are, doing a great deal of work with little or no funding; they are now beginning to speak up about the need for ongoing funding.
- Many Self Advocacy groups and their members are tired of working for nothing, noting their counterparts in the Disability Advocacy sector get funding and get paid for their work. Members feel this is yet another means of discrimination and exclusion of people with disabilities.

'Self Advocacy assists inclusion and would be great for government to fund Self Advocacy ongoing so we can run projects and prevent people from being isolated'. (Self Advocacy Group Member)

'I love being part of a Self Advocacy group. We've got a good group. We don't want to have to fight for funding every year'. (Self Advocacy Group Member)

2. Are the principles of the NDAF appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

- The Framework identifies a Person Centred Approach, 'Nothing About Us Without Us' as a key principle but only mentions that disability advocates should be 'educating individuals in self advocacy'. The focus, once again, is on disability advocates, doing for, and individual Self Advocacy; there is no consideration of Self Advocacy groups, run by and for people with disabilities (with adequate funding). Self Advocacy groups are the embodiment of a 'person-centred approach'.

3. Are the outcomes of the NDAF clear and achievable? Should different ones be included? If so, what should be included?

- There is again a focus on individual advocacy and deliver or 'doing for and receiving', for example...'The demographics of people with disability **receiving** individual advocacy reflects the diversity of the communities that the agencies are operating in'.....'accessing quality and independent advocacy support'. With adequate resourcing, people could access both quality and independent advocacy **and** Self Advocacy support. Disability advocacy should be better defined to include group Self Advocacy (again, with adequate resourcing).

*'Community development is an automatic go to. We do it because it gets the best outcome **for everyone**. If we don't use Self Advocacy*

as a process of community development, it's rubbish. Self Advocacy is not an add-on to community development, its essential'. (Self Advocate, Power Culture and Ethnicity)

4. Are the responsibilities, reform and policy directions of the NDAF relevant or should different ones be included?

- Here there is mention of 'including promoting linkages between individual and systemic advocacy'. Again, where is group Self Advocacy, given it does both individual advocacy through peer to peer support, and systemic advocacy through community awareness campaigns, training, lobbying and making change happen?

'In agreeing to this Framework, the Commonwealth, state and territory governments are committing to working together to achieve an effective network of disability advocacy across Australia. This includes supporting the capacity building of disability advocates and the development of nationally consistent guidelines and processes.'

- The latter part of this excerpt focusses on 'disability advocates', often people without disabilities and sometimes with, that are employed to advocate with or on behalf of. There needs to be a statement that supports the capacity building, including equitable funding of Self Advocacy groups.
- This could also include the funding of a national resource unit, and state and territory resource units to support the capacity building of Self Advocacy groups throughout Australia.
- A National model, co-designed by Self Advocates across Australia, has already been developed by the SARU.