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Self Advocacy Resource Unit (SARU) Submission
Department of Social Services
Review of the National Disability Advocacy Program
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"Self advocacy is important for many people with a disability, most typically those with an acquired brain injury, intellectual disability or severe communication impairment, whose voice is most at risk of not being heard. These groups are often isolated within disability advocacy, within support services and within the community more generally. **Self advocacy Resource Unit Model Development: Fyffe, McCubbery, Frawley, Laurie and Bigby**

The Self Advocacy Resource Unit (SARU) is pleased to have the opportunity to respond to the review of the National Disability Advocacy Program Discussion Paper. The overriding focus of the SARU response will centred on the need to develop and fund an independent, national self advocacy sector as a vital component of the program.

Please note: Throughout this document the term self advocacy refers to group self advocacy and the term self advocate/s refers to self advocacy group members.

Over the past three years there has been an increased awareness of the importance of group self advocacy and the need for a strong self advocacy sector within the changing environment generated by the roll out of the NDIS, particularly in relation to the move from a state focussed system to that of a national system.

Increased recognition of the importance of self advocacy was reflected in the Australian government Senate Community Affairs References Committee Inquiry into Violence, Abuse and Neglect Against People with Disability in institutional and residential settings. Specifically, the report recommended '*an increase in funding for self advocacy programs.*'

The report also recommended that '*all levels of government acknowledge the vital role that formal and informal advocacy plays in addressing violence, abuse and neglect of people with disability, including the need for:*

- *Government service contracts to include provisions to enforce access to facilities for advocates, requirement for self-advocacy programs; and*

- *Further consideration of the Victorian Self Advocacy Resource Unit, with a view to roll out across other states and territories.'*

More recently the Victorian Parliamentary Report 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.'*

The NDIA has developed an awareness of the importance of a strong self advocacy sector and the need for a national focus. Proposed ILC funding priorities in the area of advocacy may focus on giving priority funding preference to user led groups including self advocacy groups.

Discussions with the NDAP have also indicated interest in giving consideration to ways of supporting self advocacy across Australia.

Self Advocacy Background and Overview

'*Without self-advocacy . . .people with intellectual disabilities have little impact on their own situations or on public policy that affects them.'*

The ARC: www.thearc.org/who-we-are/position-statements/rights/self-advocacy

Self advocacy groups are run by and for people with disabilities who have joined together to have their voices heard and to support each other. They work together to make sure they have the same rights, choices and opportunities as anyone else in the community. This definition aligns closely with the main aim of the NDAP, which is to '*ensure people with disability are provided access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation.'*

The concept of self advocacy groups evolved in Sweden in the early 1970s and the idea quickly spread around the world. Today many countries, including the United Kingdom, U.S.A., Canada, New Zealand, Japan and Malaysia have strong and active self

advocacy sectors that include both localised self advocacy groups and national self advocacy peak organisations.

Throughout the world self advocacy groups have worked on a national level to undertake systemic change. In the United States self advocacy groups are running an ongoing and sustained campaign to get rid of the "R" word in film and television. In Canada self advocates boarded a bus and undertook the "Freedom Tour" a successful grass roots campaign that led to the closure of all institutions in the state of Ontario. In New Zealand self advocates are actively involved in the development of that countries' UNCDRP Shadow report.

Australia also has a long and proud history of self advocacy which was at its strongest in the 1980s. During this time, there were self advocacy groups in nearly every state, a national peak body, People First Australia, and a national self advocacy resource unit. However, since 1992 self advocacy across Australia has declined due to a lack of funding for and resourcing of a sustainable self advocacy sector.

Self Advocacy and a National Focus

"The trouble remains that support and funding for self advocacy since its . . .beginnings in the late 1970s has at best been modest. Compared to other countries such as the UK and U.S. and New Zealand, funding and support has been minimal. Indeed, self advocacy survived significant de-funding in the early 1990s.

Against this background, the survival of a small rump of 'independent' self advocacy groups has therefore been a real challenge and has relied upon the leadership of committed self advocates who have given the best part of their lives to keeping the dream of self advocacy alive and to searching out funding opportunities in harsh times. It is to these people that independent self advocacy owes a debt."

SARU Evaluation Associate Professor Paul Ramcharan, Global Urban and Social Studies, RMIT

The National Disability Advocacy Program has a history of funding self advocacy; from 1986 to 1990 it funded the National Self Advocacy Kit Project, later known as the People First Resource Unit. The funding of this national resource unit led to the emergence of a strong and vibrant self advocacy sector within Australia. Self advocacy groups undertook significant systemic work including lobbying for the closure of institutions, lobbying for people with cognitive disabilities to have seat at the table and input into policy making, and developing and promoting the concept of "*Nothing about us without us*".

The loss of funding for the national resource unit precipitated a significant decline in the number of self advocacy groups around Australia.

In 2008 the Victorian government recognised the importance of self advocacy and responded to the decline in self advocacy groups by funding the establishment of the Self Advocacy Resource Unit (SARU). The success of the SARU model in reinvigorating self advocacy across Victoria demonstrates the value of resource units as the foundation for a strong self advocacy sector.

As the NDIA rolls out nationally there must be a joint commitment at all levels of government including the NDIA and the NDAP to work together to support the development of a strong and equitable national self advocacy sector, including a minimum number of funded independent self advocacy groups in each state and territory.

Self Advocacy Groups and Funding

'Self advocacy is . . . not just important but, rather, a vital and essential ingredient to the successful accomplishment of each and every progressive change taking place in service systems for people with disabilities in Victoria and further afield.'
SARU Evaluation Associate Professor Paul Ramcharan, Global Urban and Social Studies, RMIT

As with many disability advocacy organisations the work undertaken by self advocacy groups may be funded through multiple funding streams. Some of the work groups undertake could potentially be funded through the NDIS ILC, particularly in the areas of empowering individuals, improving services, community education and capacity building.

However, self advocacy groups also undertake significant systemic advocacy which must be funded outside of the NDIS and as such should be funded through the NDAP. Systemic advocacy work undertaken by groups has included:

- Campaigning for the closure of institutions.
- Running the "Plain English Less Jargon" campaign, calling for the adoption of accessible information formats including easy English and DVD formats for people who may have reading difficulties.
- Promotion of the concept "Nothing About Us Without Us" across government and service systems.
- Increasing the number of self advocates sitting on committees and advisory groups.

- Advising on, and informing policy & program development and implementation.
- Undertaking a "Best Practice in Group Homes" project.
- Working to address the high level of removal of children from parents with an intellectual disability.
- Undertaking significant and important community development projects.

Response to Questions

As stated previously this paper will focus on answering the questions from the perspective of group self advocacy and the potential role of the NDAP in supporting the development a viable self advocacy sector across Australia. As such all answers will be relevant to this perspective.

1. Models of Advocacy

Question: *How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?*

Answer: From the perspective of self advocacy groups in Victoria it is vital that the NDAP continue its funding to current advocacy services even though they may provide only one or two models of support because:

- Many self advocacy groups have developed close working relationships with existing advocacy services and have worked in partnership to undertake significant projects.
- Several self advocacy groups are dependent on the support of existing advocacy organisations for survival.
- It takes considerable work and time for self advocacy groups to develop trust and to feel comfortable to work in partnership with advocacy services; any change to this would have a significant impact on self advocacy.

Question: *How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?*

Answer: As previously stated the group self advocacy model is seriously under-represented throughout Australia. The self advocacy sector is underfunded and in many cases exists with no funding at all. However, evidence has shown that a strong and viable self advocacy sector plays an essential role within all models of advocacy.

In particular, self advocacy groups are best placed to undertake systemic advocacy either in their own right or in partnership with other organisations. The lived experience of self advocates ensures they have a clear insight into systems that impact directly on the

quality of their lives. Since the 1980's self advocacy groups have worked together to bring about significant systemic change that has impacted positively on the lives of people with disabilities.

The NDAP must give serious consideration to ensuring equitable access to self advocacy groups across Australia including regional and remote areas. SARU is proposing that the strategies for developing an effective model of self advocacy on a national basis should include a combined commitment and a will from all levels of government, including the NDAP and the NDIA. Methods for supporting an equitable self advocacy sector in Australia can be varied and innovative, including:

- Funding through the NDAP to establish of a minimum of three independent stand-alone self advocacy groups in each state and territory which would have a focus on systemic issues. Estimate cost $735,000 per annum based on $35,000 per group.

- NDAP working with the NDIA to develop a joint approach to supporting a national self advocacy sector including:

  - Identifying and supporting project funding opportunities that do not relate to systemic advocacy through the ILC.
  - Resourcing self advocacy on a national level based on the Victorian SARU model.

- Providing leadership and support for advocacy organisations throughout Australia to establish, host and work in partnership with self advocacy groups. The Victorian experience has demonstrated the value added two-way benefits of this approach. Potentially the NDAP could provide a funding pool to support this process.

2. Improving access to advocacy supports

Question: *How do we improve access for:*
- *people with disability from Aboriginal and Torres Strait Islander communities and their families?*
- *people with disability from culturally and linguistically diverse communities and their families?*
- *people with disability in rural, regional and remote locations?*
- *people who are very socially isolated including those with communication difficulties and those in institutional care?*

Answer: The Victorian experience has demonstrated that self advocacy groups can play an important role in supporting access to advocacy supports on a number of levels as follows:

- The establishment of self advocacy groups that represent specific communities including:

  - Eight groups run by and for people with disabilities living in rural, regional and remote locations. These groups have a specific focus on issues relating to living in rural locations including public transport, lack of housing options and employment. Through involvement in the group, they have had the opportunity to link with their local communities including local government, local advocacy services, Rural Access workers and high-level bureaucrats within state and federal government.

  - Deafblind Victorians is a self advocacy group run by and for people who are deafblind. The group has provided members with an increased awareness of and links to advocacy organisations and the supports they provide.

  - Diversity 'n Disability as self advocacy group run by and for people with disabilities from a CALD background. Involvement in this group has provided members with a broader awareness of disability advocacy organisations and the supports they provide.

- SARU operating as a portal for advocacy services to disseminate information to self advocacy groups.

- Regional and rural self advocacy groups working closely with and informing regional advocacy services.

- Word of mouth and information provision about different advocacy services between group members.

- High level of awareness within self advocacy groups of the existence of advocacy organisations with a specific focus, e.g. AMIDA an advocacy service specialising in accommodation and self advocacy.

- SARU supporting and resourcing self advocacy groups to develop partnerships and working relationships with local advocacy organisations.

- SARU working in partnership with DARU, ensuring self advocacy is an integral part of forums, conferences and discussion.

- Working with the First Peoples Disability Network and the Victorian Aboriginal Disability Network to develop relationships and partnerships with people with disabilities from Aboriginal and Torres Strait Islander communities and their families.

Question: *What are the strategies or models that have worked? What are the strategies that do not work?*

Answer: The Victorian experience has demonstrated that the existence of a strong self advocacy sector can result in increased awareness of and improved access to advocacy services. The Victorian model has resulted in a strong and vibrant self advocacy sector, providing people with disabilities with increased access to self advocacy groups. This self advocacy sector growth has been a direct result of the establishment and funding of the SARU and improved funding to several self advocacy groups.

3. Improving the advocacy evidence base and coordination on systemic issues

Question: *What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?*

Answer:

'Self Advocacy is vital to accomplishing the basis of future policy and practice both within government, disability services and more broadly in connection with all those community organisations which will make an equitable community life a possibility for people with disabilities.' **SARU Evaluation** Associate Professor Paul Ramcharan, Global Urban and Social Studies, RMIT

Self advocates and self advocacy groups are best placed to have an understanding of the systems that are failing to meet their needs as they have a lived experience of those failings. Self advocacy groups have a strong view and understanding about how systems need to change and improve, as these systems directly affect the quality of their lives. As outlined above self advocacy groups have also developed and undertaken projects and campaigns aimed directly at systemic change.

Self advocacy groups, with support from SARU, have actively worked to ensure information on systemic issues gets to relevant government areas, service providers and organisations. Examples of this includes establishing the Self Advocacy NDIS Working Group that meets with NDIA CEO David Bowen and other senior NDIA bureaucrats every

six months. For the past four years, self advocacy groups have also regularly met with high-level bureaucrats within DHHS Victoria.

Self advocacy groups have a history of working in partnership with advocacy services to capture and frame systemic issues that need addressing. The most recent example of this was a forum on the issues faced by parents with intellectual disability jointly run by the Powerful Parents Self Advocacy Group, the advocacy service STAR Victoria and the Office of the Public Advocate.

However, the core issue is not the getting of information to the right people and organisations but the advocacy work required for governments and organisations to act on the information.

The development and adoption of a consistent mechanism across government to hear and act on the issues that are raised is vital. Once again self advocacy groups are uniquely placed to be a part of this as governments and organisations are often more likely to respond to the combined voice of self advocacy groups, they recognise theirs is the voice of lived experience and they are the experts.

Without a clear and consistent mechanism to gather and act on systemic issues people with disabilities will continue to get more of the same; they will continue to suffer systemic and ongoing abuse, they will continue to be denied real choice and control.

Question: *How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:*
- *disabled people's organisations (DPOs)*
- *the Australian Human Rights Commission*
- *Ombudsman organisations*
- *aged care advocacy organisations*
- *state disability advocacy organisations*
- *peak bodies?*

Answer: In Victoria, self advocacy groups, with support from the SARU and in their own right, have actively worked with a significant number of organisations with similar aims. These include advocacy services, the Disability Services Commissioner, DPOs, Women with Disabilities Victoria, People with Disabilities Australia, First Peoples Disability Network, Disability Advisory Councils, health organisations, rural and metro access workers,

community art organisations and the Victorian Equal Opportunity commission, to name a few.

The methods for supporting and fostering these working relationships include:

- The creation of a register of self advocacy groups' areas of interest that are sent to organisations requesting work on projects or want to consult with self advocates and self advocacy groups.
- Resources units (SARU and DARU) disseminating regular updates and opportunities for collaboration.
- Hands on activities including forums, conferences and workshops that bring together diverse organisations.
- Self advocacy groups generating projects and working in collaboration with a cross-section of organisations to undertake the project. For example, the Powerful Parents Self Advocacy Group working in collaboration with the Office of the Public Advocate, the Sydney University, Women with Disabilities Victoria, and legal services on issues faced by parents with an intellectual disability.

A key to these successful collaborations and working relationships is the role of Resource Units. Both the SARU and the DARU play a key role in information dissemination, running forums and workshops and supporting advocacy and self advocacy services to link with other organisations and the broader community.

4. The interface with the NDIS and addressing conflict of interest
Question: *What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?*

Answer: It is envisaged there would be minimal conflict of interest in regards to self advocacy groups and the NDIS and NDAP. At this point in time self advocacy groups have strongly rejected any notion of registering as service providers within the NDIS. They believe to do so would change the essence and the grass roots nature of the self advocacy sector. Many also strongly believe truly independent advocacy services should not provide services under the NDIS.

However, in the future self advocacy groups seeking funding through the ILC to undertake a range of activities such as capacity building and information provision may be reluctant to undertake systemic advocacy for fear that to do so may affect their NDIA funding. As some self advocacy groups will also be looking for funding from the NDAP to

undertake systemic advocacy, consideration must be given to developing and distributing clear and accessible guidelines that will reassure groups that their funding will not be at risk if they undertake systemic advocacy.

Question: *How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?*

Answer: It is imperative that the NDIA and NDAP, in collaboration with self advocacy groups and the disability advocacy sector, develop a strong relationship and protocols between the two areas to ensure any gaps are minimised and ultimately addressed.

Question: *What policies and strategies do we need to protect the rights of people with disability?*

Answer: In its submission to the Senate Community Affairs References Committee inquiry into Violence, abuse and neglect against people with disability and the Inquiry into a NDIS Quality Safeguards Framework, Women with Disabilities Victoria noted that *'Australia's history of disability rights has shown funded advocacy, self advocacy and systemic advocacy supports to be an essential safeguard that build capacity amongst people with disabilities and service providers. Victoria's Self Advocacy Resource Unit (SARU) has demonstrated the power of supporting self- advocacy. SARU support a range of groups which are run by, for example, people with Acquired Brain Injury, people with intellectual disabilities, and people with intellectual disabilities who have lost their children through child protection. Members of these groups work together, setting goals, running forums, sharing information, meeting with government representatives, and making change.'*

Women with Disabilities Victoria recommended that *'government recognise and resource peer groups, independent advocacy, self advocacy and systemic advocacy supports as essential safeguards.'*

The recommendations of the Senate inquiry clearly stated that self advocacy groups and self advocacy resource units, in particular the Victorian model, are a key component in the development of strategies and policies to safeguard the rights of people with disabilities. Examples of work undertaken by groups and resource units include:

- Development and dissemination of accessible rights information and resources such as:

- Rights focused resources developed by the SARU include the PSSSTTT!!! Have You Heard about the Convention DVD and information kit, Get into the Act Book and DVD, Know Your Rights Training, etc.
- Resources developed by self advocacy groups. For example, the "My House, My Home My rights DVD developed by Reinforce, the STOP Bullying DVD developed by the New Horizons group.

- Shared knowledge and experience and peer-to-peer support between group members about rights, available supports and strategies.
- Targeted forums and events that focus on rights education and information.
- Supporting self advocates and self advocacy groups to link to and work with organisations that have a rights focus, such as advocacy services, DPO's, other self advocacy groups, the human rights commission, etc.
- Supporting new members to become empowered and self advocacy groups' work to empower individuals, improve services, to build an equitable, fair and inclusive society.
- Supporting and employing self advocates as peer educators and trainers.
- Developing the skills of self advocates to sit on boards and committees.
- Training and supporting service providers and community organisations to ensure their committee and other meetings are inclusive and that they encourage the participation of members of self advocacy groups and their members.

The support for and resourcing of self advocacy groups and resource units are a vital strategy to safeguard the rights and protection of people with disabilities.

However, whilst self advocacy and advocacy can play an important role protecting the rights of people with disabilities, it is important that funders of services are able to readily and swiftly penalise any breach of rights, and ensure those breaches are remedied immediately.

In Conclusion

Human rights principles form the basis of the NDAP Framework. SARU considers it imperative that the framework informs and underpins the way in which the NDAP is funded. SARU stresses the role of group self advocacy should be recognised within the framework.

Whilst individual self advocacy is an important element of empowering individuals, group self advocacy must be recognised and valued for the depth of work it undertakes; the

change it creates, the role it plays in empowering people, the way it builds people's skills and the expertise it provides to decision makers at all levels. Often individual self advocacy is given priority; however, without group self advocacy making positive systemic change that comes from a lived experience of disability becomes more difficult.

In this submission, SARU demonstrates the level of systemic and other work undertaken by self advocacy groups throughout Australia. It is imperative that, by adhering to the Framework, the NDAP give consideration to expanding funding to group self advocacy and its resourcing, thus ensuring the vital work undertaken by self advocacy groups continues, is acknowledged and enriched.

In the evaluation of the Self Advocacy Resource Unit, Associate Professor, Paul Ramcharan stated:

'The Shut Out report . . . pointed to a service system that was broken, fragmented and underfunded. By listening to people with disabilities and placing their experiences at the very forefront of guiding and advising policy the Shut Out report presented a 'snapshot' of people's experiences.

Self advocacy seeks to do the same but not just by providing a still picture of people's experiences but one which continually reflects their (changing) experiences, their views and their preferences.

Self advocacy is therefore vital to accomplishing the basis of future policy and practice both within disability services but more broadly in connection with all those community organisations which will make community life a possibility for people with disabilities.'