**Self Advocacy Resource Unit (SARU) Submission**

**Department of Social Services**

**Review of the National Disability Advocacy Framework**

**July 2015**

**Introduction**

*“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 Report:** Fyffe, McCubbery, Frawley, Laurie & Bigby

The Self Advocacy Resource Unit (SARU) is pleased to have the opportunity to provide input into the review of the National Disability Advocacy Framework. The SARU feedback will specifically focus on the need to develop an independent, national self advocacy sector as a vital component within the framework.

**Please note:**Throughout this document the term self advocacy refers to group self advocacy and the term self advocates refers to self advocacy group members.

**Group Self Advocacy**

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

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.

Australia has a long history of self advocacy which was at its strongest in the 1980s. During this time there were groups in nearly every state and a national peak body, People First Australia.

**Self Advocacy Funding**

*“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 “N*othing 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.

**Self Advocacy Resource Unit (SARU)**

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) in 2007.

The SARU was established to resource and support self advocacy groups run by and for people with intellectual disabilities, acquired brain injury or people with high communication support needs including people who are deafblind.

The key deliverables of the SARU are to:

* Strengthen and build the capacity of existing self advocacy groups
* Support the establishment of new groups
* Promote Network Development
* Develop resources materials to support self advocacy
* Describe and improve advisor practice

The SARU model has proven highly successful in reinvigorating self advocacy across Victoria. The number of self advocacy groups has increased significantly and two state-wide networks have been established. With support from the SARU self advocacy groups have also established an NDIS Self Advocacy Working Group.

In 2012 an extensive evaluation of the SARU was undertaken which recognised the Resource Unit model was a highly efficient and effective means of supporting groups to develop and grow.

The evaluation also recognised the extent of the often unpaid work self advocacy groups undertake on a number of levels to empower people, change and strengthen the disability specific and mainstream service systems, undertake systemic advocacy and build more inclusive communities.

The SARU has enabled, and continues to support self advocacy groups, to be linked with local advocacy services, some of which provide limited support to the groups, e.g. meeting spaces.

**Group Self Advocacy and the NDAP**

Self advocacy groups undertake much of the work outlined in the definition of disability advocacy as follows:

Supporting people with disability:

* stand up for their rights and choices.
* take part in the community
* find training
* feel value and respected
* have their say

As with many disability advocacy organisations the work undertaken by self advocacy groups can be funded through multiple funding streams. Some of the work groups undertake could potentially be funded through the NDIS ILC.

However, self advocacy groups also undertake significant systemic advocacy which must be funded outside of the NDIS. In Victoria self advocacy groups work closely with disability advocacy organisations, disability specific and mainstream community organisations and the three tiers of government.

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 development and implementation
* Supporting people in group homes to have a voice and learn about self advocacy.
* Undertaking significant and important community development projects.

Consequently the NDAP must fund independent self advocacy groups and resource units throughout Australia.

**Response to Question 1**

The SARU ‘vision’ of advocacy within the current Framework is one which includes support and funding for a strong national independent self advocacy sector including:

1. Funding to ensure a core number of independent self advocacy groups in each state.
2. Adoption of the Victorian Self Advocacy Resource Unit model as a proven cost effective way of supporting the development of a strong self advocacy sector across Australia.

Therefore we consider the framework needs to feature group self advocacy.

**Response to Question 2**

The principles underpinning the framework are strong and reflect core human rights. The principles support the SARU vision of advocacy in the NDIS environment as needing to include group self advocacy and importantly, its resourcing.

If the NDAP is to operate and abide by these principles then it must include funding for group self advocacy. Self advocacy groups undertake considerable work which reflect the principles. The following provides some examples of this work.

* Promotes the interests and wellbeing of people with a disability.

Self advocacy groups by their very nature work towards promoting inclusive communities and awareness of disability issues.

Example:

* **Deafblind World** **-** **Deaf Blind Victorians**

*Deafblind World* is an initiative of Deaf Blind Victorians (DBV), a self advocacy group run by and for people who are deafblind. DBV is the only such group in Australia, they receive no ongoing funding.

Deafblind world is an immersive interactive workshop which enables participants to explore the experience of what it is like to be deafblind.

The workshops are aimed at businesses, local councils, government, services providers and the broader community.

* Disability advocacy seeks to influence positive systemic changes in legislation, policy and service practice and works towards promoting inclusive communities and awareness of disability issues.

Example:

* **It can Happen If . . . . . Creating Positive Change for Parents with Intellectual Disabilities -** **The Powerful Parent Self Advocacy Group**

The Powerful Parent Self Advocacy Group (PPSAG0 is a self advocacy group run by and for parents with an intellectual disability. The group was formed three years ago, the group has no funding.

A key issue for PPSAG is the high rate of removal of children from parents with an intellectual disability. PPSAG is also concerned about the limited access time many parents get with their children. PPSAG held a forum targeted at service providers and government funded agencies, PPSAG enlisted the support of the Healthy Start program and the Office for the Public Advocate (OPA). The forum was full to capacity and featured a range of speakers including group members, an academic, an MP, a high level bureaucrat and a representative from OPA.

The forum provided a platform for self advocates, sector workers, service providers and academics to come together to discuss the issues. It resulted in a range of positive outcomes including raising awareness, agencies exploring the idea of developing coalitions, the need for improved professional development opportunities around people with intellectual disabilities, including PPSAG resources in training packages and exploring potential changes of practice and attitude.

* Promotes leadership and capacity building of people with disabilities

Self advocacy group membership by its very nature promotes leadership and builds capacity. Self advocacy groups provide the opportunity for members to receive education and support from people who have shared experience. The ARC Self Advocacy Position Paper states the following in relation to self advocacy and capacity building for people with an intellectual disability:

*‘’Without these groups they did not have a way to learn about important self-advocacy skills or topics like:*

* *Their rights as citizens, such as the right to vote;*
* *Development of leadership and assertiveness skills;*
* *Confidence in their own abilities;*
* *Using their expertise as people living with disabilities;*
* *Development of public speaking skills and problem-solving techniques, and involvement in group decision-making;*
* *Involvement on boards and task forces and with policymakers at the local, state, and national level.*

*Without self-advocacy skills, people with….. 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](http://www.thearc.org/who-we-are/position-statements/rights/self-advocacy)

* Strengthens the capacity of people with disability to speak up for themselves by actively encouraging self advocacy.

Example:

* **Know Your Rights Self Advocacy Training - Reinforce**

Reinforce started in 1981 and is the longest running self advocacy group in Australia. The group is run by and for people with intellectual disabilities. It operates on a small amount of recurrent funding.

Reinforce was concerned many people with intellectual disabilities were unaware of their rights and lacked the confidence to speak up. In response to this Reinforce developed a peer-to-peer training package which provides information for people about self advocacy, decision making, their rights and legislation that protects their rights.

Reinforce has been running this training in partnership with the SARU for the past five years.

* Foster effective strategic alliances to develop capacity and respond to the needs of people with disability.

Throughout Victoria self advocacy groups work in partnership with multiple organisations including all tiers of government, disability specific and mainstream services, other advocacy organisations, and statutory bodies.

**Response to Question 3**

The outcomes listed are particularly relevant for the future of disability advocacy and reflect the outcomes that self advocacy groups are actively working towards, and in many cases achieving. In particular, the Victorian Self Advocacy Network recently developed an action plan which aims to achieve outcomes that match some of those listed. In particular:

* Economic participation and social inclusion.

The Inquiry into Social Inclusion and Victorians with Disability determined the Victorian Government needs to take a role in leading a social inclusion agenda. The report stated the

*“Victorian Government could provide critical leadership in the areas of strengthening the Building Inclusive Communities Program, self-advocacy programs and other community capacity building initiatives to ensure they align with the NDIS and effectively contribute to increased social inclusion.”*

In its submission to the Inquiry the Victorian Equal Opportunity and Human Rights Commission stated:

*‘’Social inclusion and consumer control by people with disability relies on active and engaged advocacy and self-advocacy bodies.*

* *People with disability enjoy choice, wellbeing and are supported to pursue their life goals.*
* *People with disability are able to make decisions that affect their lives.*
* *Involvement in all aspects of the development, delivery and evaluation of disability and broader government policies and programs.’’*

**Response to Question 4**

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

*‘’Self advocacy is therefore 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.’’*

While the Outputs in the Framework continue to be relevant additional outputs which recognise and reflect the importance of developing a strong self advocacy sector should be included. Self advocacy groups generate Outputs that reflect those in the Framework.

Some examples include:

* Undertaking research in group homes to ascertain issues faced by residents and the level of understanding they have in relation to their rights. As a result of this research the peer-to-peer My House, My Home My ‘Rights’ project was developed
* Working in partnership and communicating with all tiers of government, the advocacy sector, disability specific and mainstream services and the broader community.

**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 having 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, thus ensuring the vital systemic work undertaken by self advocacy groups continues, is acknowledged and enhanced.

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.’’*