Group Self Advocacy Partnership Project

Report & Model

February 2019

Diversity and Disability

BIM

POSITIVE POWERFUL PARENTS

SARU
We are stronger when we work together
Self Advocacy Resource Unit

Contents

Contents

"People with disability get to be consultants, but we don't usually get to be the drivers. In this project we are the drivers."

Partnerships Project Worker.

1.0 Summary

'Many people with cognitive disability and complex communication support needs are discriminated against, and are yet to be fully included in Australian society. Because of this self advocacy groups continue to work to create an equal society where all people are included and respected.

To successfully run projects in partnership with a range of organisations self advocacy groups need:

- More time. Time to apply, time to plan, time to build relationships, time to involve group members, time to learn, time to do the work, and time to devise next steps.

- Long term strategic investment in the groups and supporting structures.

- Inclusion in networks across sectors.

- Choice and control over the projects they work on and the people they work with.

- Opportunities to take risks and run projects on their own.

- Information and resources that support safe work practices.

- Organisations to be knowledgeable about the benefits of self advocacy, inclusive practice and including people with diverse lived experience.

- A staged approach to partnerships.

2.0 Background

As part of the transition to the NDIS the Self Advocacy Resource Unit (SARU) was funded by the Victorian DHHS to co-ordinate a Self Advocacy Partnership Project.

The goal of the project was to develop recommendations for self advocacy groups to work in partnership with other organisations.

2.1 About Self Advocacy Groups

Self advocacy groups are run by people with disability for people with disability. Self advocacy groups support people with cognitive disability and complex communication support needs to come together and develop their own agency and power.

Self advocacy groups also bring people together with shared purpose to work toward all people with disability having equal access, participation and influence in civic and community life.

2.2 About this project

Three diverse Victorian self advocacy groups were chosen to be part of this project: Brain Injury Matters (BIM), Positive Powerful Parents (PPP) and Diversity and Disability (DnD).

Each group had its own individual project that included working in partnership with a mainstream organisation.

Once a month the three groups came together as a working group to discuss their progress, learnings and challenges, and to share skills and ideas.

3.0 Overview of the Groups & Group Projects

3.1 Brain Injury Matters

Brain Injury Matters is Australia's leading self advocacy and community education group for people with acquired brain injury. Previously, BIM developed the "Hitchhiker's Guide to the Brain Maze" a resource kit for people with a newly diagnosed brain injury.

Building on the kit, BIM's project was to develop an online resource for people with a newly diagnosed brain injury.

BIM chose to build an app – ABI Wise. BIM collaborated with six ABI support groups and networks to create the app. BIM chose to partner with *Brain Injury Australia* and *Leadership Plus* to promote and launch the app.

3.2 Positive Powerful Parents

Positive Powerful Parents was founded to combat the alarming overrepresentation of families where parents have an intellectual disability within the child protection system.

PPP provides a safe and supportive environment for parents with intellectual disability to meet, share stories and common experiences, and works to create change and equality for parents.

PPP's project was to develop resources for child protection workers about the experiences of parents with intellectual disability, and raise community awareness around this issue.

PPP chose to partner with the *Parenting Research Centre* (PRC) to do this.

3.0 Overview of the Groups & Group Projects

3.3 Diversity and Disability

Diversity and Disability is a self advocacy program run as part of the *Migrant Resource Centre* North West (MRCNW) in St Albans. DnD works with all people with disability from non-English speaking backgrounds.

DnD's project was to develop a model to support the growth of self advocacy in CALD communities.

DnD chose to partner with the *Ethnic Community Council of Victoria* (EECV) and the *Ethnic Council of Shepparton and Districts* (ECSD) to create the model.

3.4 The Self Advocacy Resource Unit (SARU)

The SARU was established in 2008 to support and resource Victorian self advocacy groups for people with intellectual disability, people with acquired brain injury and people with complex communication support needs.

In 2014 SARU established the *Victorian Self Advocacy Network* (VSAN). VSAN works to connect Victorian self advocacy groups and facilitate forums and campaigns to raise the voices of people with disability.

3.0 Overview of the Groups & Group Projects

3.4 The Self Advocacy Resource Unit (SARU) *continued*

SARU also facilitates *Voice and the Table* (VATT). VATT provides training and resources to ensure that people from the above cohorts have the skills, support and confidence to sit on boards, committees and advisory groups within government, service providers, community and mainstream organisations at a local, state and national level.

VATT also provides inclusive practice training for government and community organisations.

SARU's role was to assist the groups to plan, develop and deliver the projects.

SARU provided human resource and financial management support, co-ordinated the groups to come together to share learnings, developed easy English planning and reporting templates, and provided supervision and intensive support as required.

4.0 Key Project Activities

4.1 Overall project activities

- Easy English planning and reporting templates developed, tested and used by groups; groups submitted their own project plans and reports to DHHS.

- Employed six people with a disability for the duration of the project.

- Self advocacy partnership resources developed for the Voices Together website.

4.2 BIM project activities

- Outreach and consultation with six metro and regional ABI peer support groups.

- BIM developed and launched the ABI Wise App. ABI Wise shares resources, supports, information and tips for people with a newly acquired brain injury.

- BIM has project based partnerships with Brain Injury Australia and Leadership Plus.

- The voices of 60 people with ABI have been captured in the app.

4.0 Key Project Activities

4.3 PPP project activities

- Outreach and consultation with four regional parent support groups.

- PPP are developing the Parent Voices resource kit.

- PPP delivered the Hand in Hand report into the lived experience of parents with intellectual disability.

- PPP joined the International Parenting Advocacy network.

- PPP created and launched the Positive Powerful Parents Advocacy CD.

- PPP has an ongoing partnership with the PRC.

4.4 DnD project activities

- A member of DnD sits on a regional CALD NDIS Advisory Group.

- DnD developed the Self Advocacy and Diversity Model (SAnD).

- DnD hosted two self advocacy feasts, one in Shepparton and one in Broadmeadows.

- DnD facilitated advocacy community consultation sessions.

- DnD has ongoing partnerships with the Ethnic Community Council of Victoria and the Ethnic Council of Shepparton and Districts.

5.0 Key Findings

5.1 Overall project findings

- With adequate investment, support and planning self advocacy groups can deliver projects that meet community needs and lead the way for the cultural change that the roll out of the NDIS promises.

- Secure, ongoing funding is essential for groups to rise to the challenge of delivering quality, innovative projects that are equal in the open marketplace.

- Traditionally self advocacy groups have been run and managed by volunteers. The shift to the NDIS has people with disability moving toward employment goals. Advocacy has the potential to be a sector that employs significant numbers of people with disability *(see key issues for further discussion).*

- Group self advocacy networks support peer learning and strengthen the self advocacy sector.

- Group self advocacy networks support attitudinal change within the disability community.

- Outreach and formalised networks support groups to be in touch with and knowledgeable about current issues relevant to people with disability across the population.

- To have strong partnerships groups need to be strong.

5.0 Key Findings

- Strong groups require:
  - Clear and easy to use governance processes
  - A space to work from
  - Training about group process, communications and leadership
  - Adequate support from experienced and skilled community development workers
  - Training about jobs and projects
  - Mentorship from skilled and experienced professional supporters

- Partnerships with advocacy groups supports mainstream organisations to ensure their practice, culture and infrastructure is accessible and inclusive. It also supports organisations to connect with hard to reach and marginalised people within the populations they service.

- Organisations who have not traditionally worked in the disability sector presented less barriers to partnership than disability service providers. Many disability service providers are not ready to work as equals with user led advocacy groups.

- Some mainstream organisations see working with user led advocacy groups as good for business and welcome the opportunity to learn from the groups.

- Working in partnership with aligned mainstream organisations presents a significant opportunity for advocacy groups to infiltrate mainstream practice, creating a new, inclusive standard across a range of sectors.

5.0 Key Findings

- Paternalistic attitudes toward the lived experience and wisdom of people with disability still exist within the health and service delivery systems. These attitudes serve to continue a top down "expert" led approach to working with people with disability, diminishing individuals' decision making capacity and skill development. User led projects clearly demonstrate the capacity of people with disability to not only make appropriate decisions regarding their own lives, but also influence and create change across society.

- Groups need more time to apply for funding and more time to run projects, this is an access requirement.

- Self advocacy groups need choice and control over the projects they run and the partnerships they form.

- A staged approach to partnering is recommended. Groups move from networks, to partnering to run single events and resources, then moving toward delivering projects in full partnership.

- When self advocacy groups run projects they have choice and control over the terms of engagement.

5.0 Key Findings

5.2 The power of *user led* projects

Through their partnership with the Parenting Research Centre PPP have made numerous connections with organisations across Australia.

A number of organisations who do not identify as user led have expressed interest in partnering with PPP.

During a conference call with potential partners PPP communicated that the language used in that call was not accessible.

PPP made it clear that future collaboration would only be possible if organisations made sure they used accessible language and accessible work practices.

PPP also encouraged the other organisations to include people with lived experience in their future planning.

In a scheduled follow up conference call two organisations have committed to including parents with intellectual disability, and all organisations have agreed to use accessible language.

User led projects support self advocacy groups to exercise significant power and control over project terms and practices.

5.0 Key Findings

5.3 PPP project findings

- There are numerous small parents' advocacy support groups in operation throughout Australia. Currently these groups work in isolation. Forming a parent advocacy network will support these groups to have greater representation at all levels of policy and decision making.

- Parents with intellectual disability whose children are in out of home care are fearful of speaking up and advocating for themselves because of the perceived risk to their children. People also report fearing that they could have reduced access to their children if they speak up.

- The grief and trauma experienced by parents when their children are removed is not recognised or supported by the removal system.

- Parents who have had their children removed cannot access parent skill building resources and training.

- Systemic discrimination against parents with disability is currently being reported by advocacy workers across all Australian state and territory child protection systems.

- In Victoria there is insufficient advocacy for parents with disability specific to child protection and child removal.

5.0 Key Findings

5.4 BIM project findings

- The capacity of self advocates and self advocacy groups can be underestimated. When groups are given the power to make their own decisions and adequate resourcing, groups can achieve project outcomes that are equal to mainstream organisations.

- Good group governance and communication is essential for groups to run successful projects.

- Many people with ABI report that they do not feel confident or do not have access to digital technology. Digital technologies are a tool that continue to be under-utilised by people with cognitive disabilities.

- Hospitals and health service providers tend to take a medical model approach to working with people with disability. The traditional doctor/patient relationship presents a barrier to self advocacy groups working as equals alongside health organisations.

- Previous traumatic experiences with medical services and professionals can act as a barrier to self advocacy groups engaging with health organisations.

5.0 Key Findings

5.5 DnD project findings

- People with disability from CALD communities are under-represented in terms of access to services, the NDIS and self advocacy. Changing this requires a new, culturally sensitive way of working with people with disability from CALD communities.

- The needs of people with disability who are newly arrived in Australia are different to people who are second generation migrants. These differences must be considered when planning and providing service and supports to people from CALD communities.

- There are some migrant communities in Australia that hold negative beliefs about disability. There is the potential that there are people with disability in those communities who are unknow outside of their family group. Reaching those people and their families will take a long term commitment involving multiple stakeholders at local, state and federal levels, working together with community.

'Equal access to educational opportunities is considered a fundamental right, according to the Australian constitution. However, it is clear that when it comes to delivery of such educational opportunities to disabled people, real educational opportunities are hard to come by.'

Shut out: *The experience of people with disabilities and their families in Australia*, 2009

5.0 Key Findings

5.6 Key Issues

5.6.1 Shift to Employment

- Traditionally self advocacy groups have been run and managed by volunteers. The shift to the NDIS has people with disability moving toward employment goals and project based paid employment. Advocacy has the potential to be a sector that employs significant numbers of people with disability. There has been long standing under investment in the education and training of people with disability, particularly intellectual and cognitive disabilities. This gap leaves people underprepared for the requirements of employment and project management. A long term national investment strategy in group advocacy has the potential to turn this around and create a sector that employs large numbers of people with disability.

- Many people with intellectual disability have not worked in open employment. Time and resources are needed to support people with disability through the employment process. This includes getting tax file numbers, superannuation accounts, police checks etc. Resourcing is also needed to support people to communicate income with Centrelink, ATO and Department of Housing. Workplace inductions and orientations are essential and need to be tailored so people with intellectual disability understand their rights and responsibilities.

- Easy English training is needed to support skills developed in the areas of teamwork, workplace communication, conflict resolution and OH&S issues.

5.0 Key Findings

5.6.2 Fears

- Some people with disability are fearful of partnerships due to past experiences of marginalisation, discrimination, trauma and abuse by practitioners, service providers and the system that delivers supports. Forming relationships through networks is a way to overcome fears and build trust between organisations before committing to working in partnership.

- Some community organisations are fearful of partnerships. A number of organisations clearly articulated that past experiences of other associations making promises that could not be delivered or sustained had left them reluctant to engage in short term projects.

- Traditionally, self advocacy groups have attracted little funding. Because of this groups do not feel confident asking for what they need and are fearful of having support withdrawn. Fear stifles creativity and innovation. A stable, ongoing core funding base will provide groups with the foundation they need to invest in long term community partnership projects.

5.0 Key Findings

5.6.3 Risk

- When people who have experienced abuse or the denial of their human rights speak out they can risk further consequence. Providing safe yet effective pathways for change is essential to ensuring people with disability can take up equal roles throughout the community.

   Anecdotal evidence suggests that this is especially true for parents with disability whose children are in out of home care, and for people with disability living in regional and rural areas.

5.6.4 Managing Risk

At the beginning of this project one of the self advocates identified that they were risking significant personal repercussions if their involvement in the project was made public. Because of the risks that person chose for their work on the project to be anonymous.

Taking appropriate action to ensure the projects do not harm a self advocates situation has been challenging.

Timelines and outcomes have been adjusted and re-adjusted to ensure that all group members feel comfortable and supported in their work. Guaranteeing confidentiality, privacy and de-identification has taken considerable time and resources.

5.0 Key Findings

Taking all concerns about risk and repercussions seriously has proven to be a gamer changer for some individuals.

After a year of working on this project the self advocate who had chosen to remain anonymous made independent contact the organisation they feared and shared their work.

When speaking about the catalyst for this change the self advocate said they are now ready to share their work, feel more confident to take action if there are any negative changes to their situation, and are beginning to develop trust in the people around them.

5.6.5 People with disability from CALD communities

- The challenges and barriers for people from migrant backgrounds advocating and having a presence in advocacy groups are different to the challenges other people in the community face. This is especially true for people who are newly arrived in Australia. Current research suggests that many people with disability who do not speak English are not accessing appropriate supports and services. A new approach specific to this cohort is needed to make a real difference in this space.

  *Anecdotal evidence suggests that this is also true for people with disability from Aboriginal and Torres Strait Islander backgrounds. A self advocacy strategy specific to these groups is essential to turning this around.

6.0 Partnerships Model

The group advocacy partnerships model recognises that strong partnerships grow from strong groups and inclusive networks. It also recognises that self advocacy groups have formed and continue to exist because of the discrimination faced by people with disability.

Because of the discrimination and abuse people with disability have encountered groups can be reluctant to partner and trust other organisations.

Groups cannot overcome these fears and hesitations on their own.

Cross sector engagement is needed with a strategy in place to ensure self advocacy groups and mainstream organisations have the skills, resources and the commitment necessary to work well together and create change.
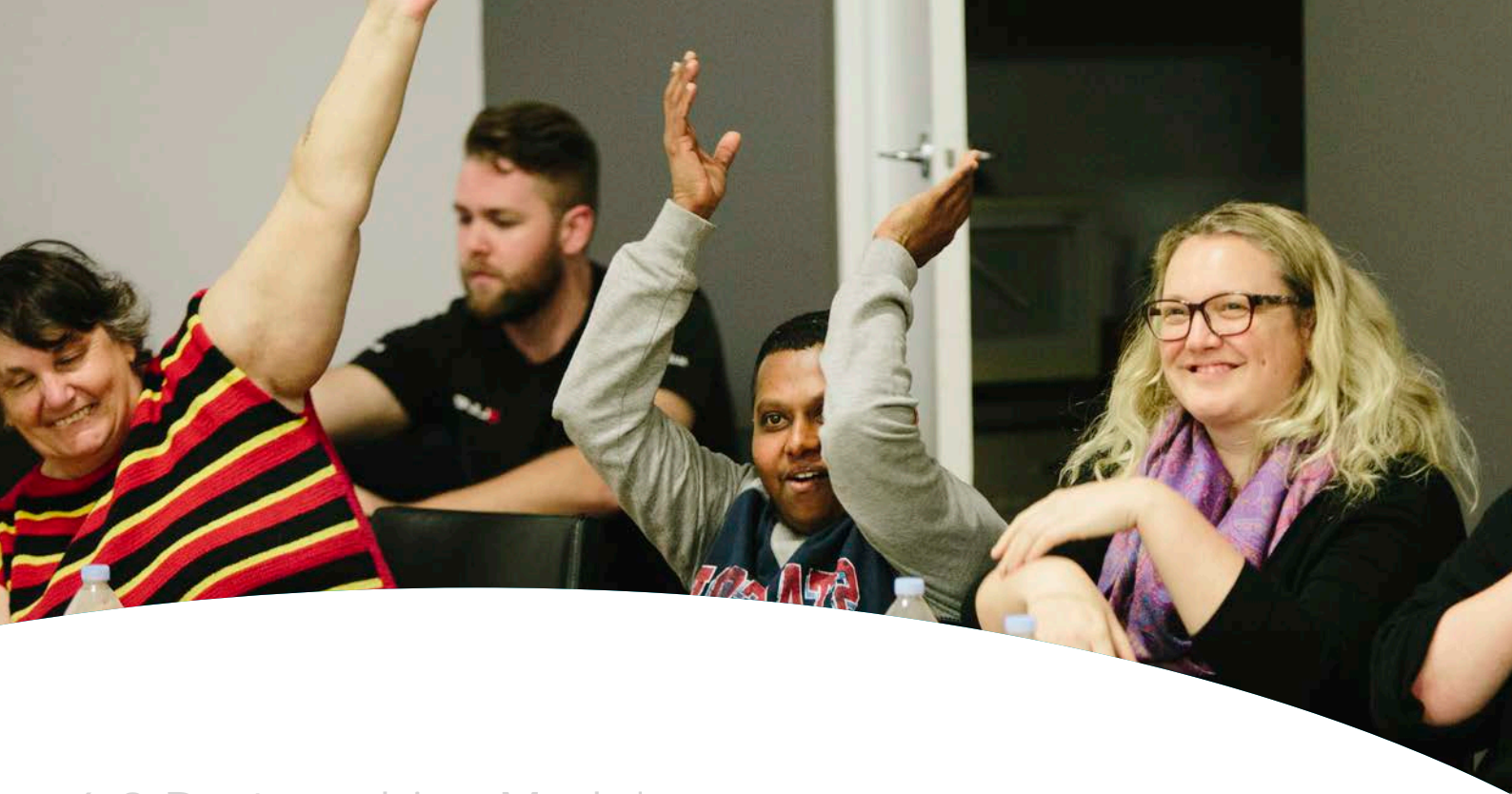
A staged approached to partnering is recommended.

Groups move from low risk relationships through networks, to working on single events and resources in partnerships allowing time for groups and organisations to learn from each other.

From this stable foundation bigger projects and partnerships can grow.
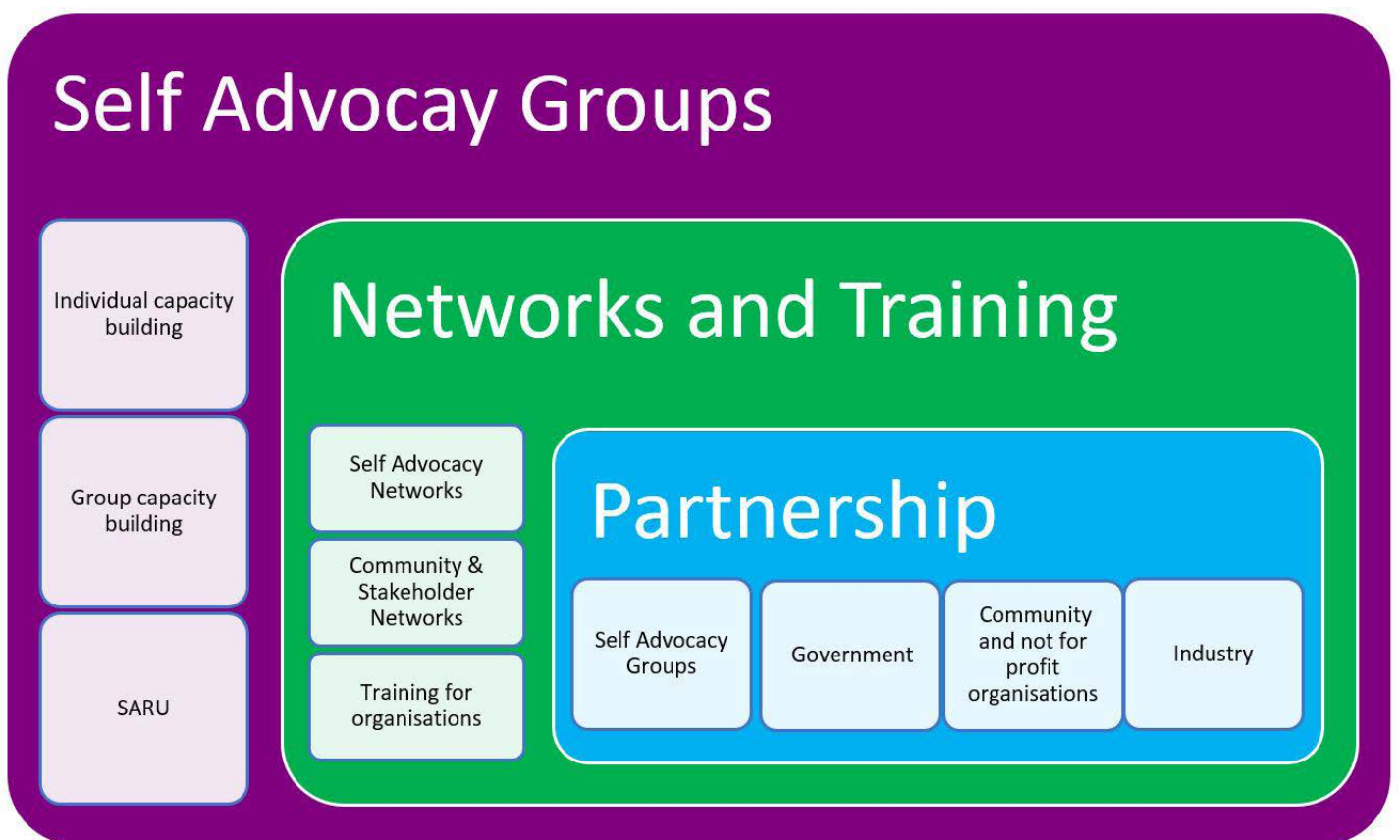
6.0 Partnerships Model

6.1 Self Advocacy Groups

In order to deliver projects groups need stability. Making sure groups have an accessible place to work from and are supported by skilled community development worker may seem obvious, but unfortunately groups do not always have access to these resources.

Ongoing investment in self advocacy will create the stable base that groups need to flourish and achieve goals.

Many people with cognitive disabilities and complex communication support needs have not had equal access to education, training and employment.

This lack of opportunity and investment in individuals can leave members of self advocacy groups without the skills they need to work as equals with people from other organisations. It can also leave groups without the skills needed to work as an effective team and without an understanding of workplace practices and expectations.

6.0 Partnerships Model

6.1.1 Individual Capacity Building

SARU facilitates the VATT training program. VATT builds the skills and capacity of people with intellectual disability, acquired brain injury and complex communication support needs to sit on boards and advisory committees, working to ensure that people's contributions are meaningful and relevant. The skills and confidence that VATT participants develop are relevant to the work that self advocacy groups undertake. Access to tailored and specific professional development programs such as VATT supports individuals to gain the skills, information and experience they need to work as equals with others who do not have cognitive disabilities or communication support needs.

6.1.2 Group Capacity Building

Before undertaking large projects groups need training and skill development in organisational processes and communication.

Group skills need to extend beyond good meeting practices to include managing workloads and work plans, co-ordinating tasks and potentially managing staff.

Volunteer and workplace orientations, appropriate professional development opportunities and accessible organisational governance training are all essential.

6.0 Partnerships Model

The work of self advocacy groups can be emotionally demanding, people often draw on their own lived experience of discrimination and abuse to bring attention to issues.

Trauma informed accessible support is essential to ensuring individuals have the resources they need to sustain the vital work they do.

Groups need access to the equivalent resources and processes that other organisations rely on and benefit from in order to work well.

Access to employee assist and counselling services from professionals that have expertise working with people with cognitive disabilities and communication support needs are necessary.

Groups also need to sustain themselves by attracting new members to avoid burn out and fatigue.

Outreach by groups within disability day, accommodation and peer support services is an effective tool for educating people with disability about self advocacy.

In this project each group utilised outreach to connect with more people with disability and broaden their support base.

Building outreach into projects promotes the long term sustainability of groups, supports connection with hard to reach individuals and educates disability service providers about self advocacy and the untapped abilities and potentials of many people with cognitive disabilities.

6.0 Partnerships Model

6.1.3 Developing, growing and sustaining a self advocacy workforce

This project has worked with people who have a lived experience of

- Traumatic brain injury
- Disability, child removal and associated family conflict
- Disability, migration and cultural diversity

One of the goals of each project was for members to use the wisdom of their lived experience to create resources that improve the lives of others with similar experiences, and inform the policies and practises of organisations working with these groups.

Drawing of traumatic personal experience to improve the lives of others is demanding work.

While the Australian mental health sector has significant research and resources to support peer workers, there is little to support peer workers and organisations in the disability sector.

Information and resources that support this emerging workforce are needed to ensure the safe professional growth and development of everyone working in this sector.

6.0 Partnerships Model

6.1.4 SARU

All groups commented that they could not run a project like this without the support of an organisation such as the SARU.

SARU provided ongoing supervision and intensive support to all project workers and volunteers.

SARU provides formal and informal support to self advocacy groups and their members.

With an open door policy SARU is a place any self advocate can come to seek advice about the work they are doing and the challenges they are facing.

SARU's support has extended from training, resource development, workplace orientations, meeting support and group conflict resolution processes all the way through to people accessing identification and managing Centrelink reporting requirements.

As previously discussed, many people with disability have not worked in open employment before, SARU has provided the intensive support that people have needed to work on the project.

> **"Being part of this working group has taught me how important easy English is for people with intellectual disability and that it can be good for everyone."**
>
> *Partnerships Working Group Member*

6.0 Partnerships Model

6.2 Networks and Training

6.2.1 Self Advocacy Networks

Throughout this project the three groups came together once a month to discuss their projects and learn from one another, this working group was supported by SARU.

The diversity within the three groups proved to be one of its strengths.

Learning about the challenges faced by people with disability in other cohorts strengthened each group's knowledge of the sector.

Very quickly the working group acknowledged the potential for the people in the group with intellectual disability to be marginalised in the meetings.

Each group member made a commitment to simplify their language and stop to explain any abstract or unfamiliar terms.

Respect between group members increased and equality within the working group was strengthened.

As the projects progressed each group had a keen interest in the successes and learnings of the others, common threads and challenges were identified and discussed between the groups.

Working to ensure equality in partnerships was an issue that was reflected on at each meeting.

Through discussions a checklist for identifying and sustaining equal partnerships was developed.

6.0 Partnerships Model

6.2.2 Victorian Self Advocacy Network

The *Victorian Self Advocacy Network* is facilitated by a partnership between self advocacy groups and the SARU.

VSAN brings Victorian self advocacy groups together to lobby for change. This network also provides an opportunity for new and emergent self advocacy groups to learn from established groups, and supports established groups to work together as a united sector.

The practice in partnership and working together that is fostered through self advocacy networks paves the way for groups to work in partnership with other organisations.

6.2.3 Community & Stakeholder Networks

Early in the project the groups identified that there was a preference for partnering with organisations that they had previously developed rapport with.

All groups identified negative experiences with organisations in the past as a barrier to partnering.

All three groups chose to work with at least one partner that they had already had a positive experience with.

6.0 Partnerships Model

Formalised community and stakeholder networks are a low risk opportunity for self advocacy groups to establish links and relationships with organisations.

Working in this way gives self advocacy groups the time they need to assess other organisations' values, attitudes and work practices without the pressure of running projects together.

Networks also support other organisations to learn the value of working with self advocacy groups, gain a greater understanding of accessible work practices and see firsthand the expertise that people with lived experience bring to the table.

Government has a role to play in encouraging and supporting formal stakeholder networks.

Many community and not for profit organisations working in this space access government funding.

Regularly bringing funded organisations together to discuss projects and challenges, and including self advocacy groups in these networks, gives all organisations a soft entry to working together.

6.0 Partnerships Model

6.2.4 Training for organisations

Voice at the Table works with organisations to build their capacity to be inclusive. VATT also supports organisations to provide meaningful opportunities for people with cognitive disabilities and complex communication support needs to advise and influence policies, programs; service planning, development, delivery and evaluation. VATT works to support organisations to make the attitudinal shift and upskilling needed to work well with people with diverse disabilities.

Currently VATT is a project of the SARU and is yet to attract ongoing funding. Having a training program such as VATT available to community and not for profit organisations would provide the crucial upskilling in inclusive practice that many mainstream organisations are missing.

> "*Voice at the Table* fills a much needed gap. It provides resources to people with disability so they can be actively involved on boards, advisory panels and organising committees. But perhaps more importantly, *Voice at the Table* also provides resources to boards, advisory panels and organising committees so they can become accessible to people with disabilities."
>
> *Dr. Piers Gooding, Postdoctoral Research Fellow, Melbourne Social Equity Institute, University of Melbourne.*

> **"It takes time to develop successful partnerships. Developing a trusting relationship where all partners feel that there is mutual benefit from the partnership is essential for success. This cannot be achieved in one or two meetings or where there has been a history of tension with another partner or organisation."**
>
> VCOSS Partnership Practice Guide

6.0 Partnerships Model

6.3 Partnership

All groups identified short timelines as a project constraint. All groups operate with a volunteer committee that meets once a month.

Developing successful partnerships and delivering projects in a 12 month period is unrealistic for self advocacy groups.

Often access needs mean that more time is needed to complete tasks and time pressures can lead to unnecessary stress. Also, many people with disability have associated health needs that need to be taken into account when planning.

The unexpected can (and did) happen.

One project worker was unavailable for 6 weeks because of a fall, another found that wheelchair breakdowns impacted their availability.

To run successful projects groups need flexible and extended timelines.

Through the project the groups identified that they can't be educating partnering organisations about self advocacy and the rights of people with disability and running projects together at the same time.

To partner successfully organisations need to have shared values, openness and a commitment to the equal rights of people with disability.

Training such as VATT has the potential to broaden partnering opportunities by educating more organisations about working well alongside people with disability.

6.0 Partnerships Model

One group chose to end a partnership partway through the project. They felt that the partnership was not accomplishing its goals and that mutual respect and equality was not being achieved.

The partnership ended amicably with the organisation happily agreeing to continue to offer some support to the project.

Another partnership was secured and the group expressed delight at the ease with which the new arrangement flowed.

Of note here is that the second partnership was with an organisation that the self advocacy group had previously worked with and had a good understanding of self advocacy, the first did not.

> **"I've learned that it is important that our group makes decisions together. If one person makes all of the decisions then the others feel left out and that is not self advocacy."**
>
> *Partnerships Project Working Group Member*

> **"When partners understand self advocacy we spend less time educating them and more time on the project and achieving the project goals".**
>
> *Partnerships Project Worker*

6.0 Partnerships Model

6.3.1 Choice and Control

In this project BIM chose to develop the ABI Wise App in collaboration with ABI support groups, but felt it was important that they retained creative control over all aspects of the App. BIM identified that their project would benefit from expertise in product endorsement, promotion and launch. BIM sought partners that could provide skills and networks in these areas, rather than partnering to create the App. Retaining control over all aspects of the App was important to the group. Producing ABI Wise without assistance from a non-disability led organisation has been a significant achievement for BIM, proving that self advocacy groups canachieve outcomes equal to mainstream organisations.

6.3.2 Self Advocacy Groups

This project has demonstrated the benefit of self advocacy groups working together. Peer knowledge and skill sharing strengthens the self advocacy sector and works to ensure that the diverse voices and lived experiences of people with disability are reinforced.

Through engagement across disability cohorts people with disability working in the self advocacy sector broaden their understanding of disability issues, making them experts in access and inclusion across cohorts.

There is a potency and power when user led groups work in partnership without mainstream organisations. When choice and control rests with the people with disability dignity of risk is encouraged and groups have the opportunity to expand skill sets and learnings.

6.0 Partnerships Model

6.3.3 Community and Not for Profit Organisations

The focus of this project was self advocacy groups forming partnerships with community organisations.

Each group devised project plans and identified what they wanted from a partner.

Groups spent time researching potential partners, looking to see if organisations' values, missions and goals were aligned with that of their group and self advocacy in general.

Groups had robust discussions about the pros and cons of potential partners.

Each group had a list of organisations that they would not work with due to previous negative and discriminatory experiences.

Groups approached potential partners to share information about the work they were doing and gauge organisations' level of interest and response.

Groups engaged with potential partners via email, telephone and face to face meetings.

Observations and thoughts were then taken back to the wider groups for feedback and decision making.

Through these interactions groups formed strong opinions about the organisations they thought were a good fit for the goals they wanted to achieve.

> "Through our partnership with DnD we now realise that the disability community is very isolated and in need of our support. We do not see a lot of clients with disability but we know they are there. This is why with DnD's help and skills we hope more public events will raise awareness. We need to change how people feel in the ethnic community about disability and help them involve their family members in self advocacy ."

Andrew Murley, Ethnic Council
of Shepparton and
Districts

6.0 Partnerships Model

Each group chose to take a low risk approach to partnering by asking organisations to work with them on specific aspects of their project. This approach gave groups the time they needed to assess the partnership and feel secure that the relationship was mutually beneficial.

A slow step by step method of partnering gives all organisations time to learn about working together, and gives groups time to establish good working methods.

The three groups have now established good working relationships with partnering organisations and are in positions to apply for funding together should they choose.

Self advocacy groups and mainstream organisations benefit from partnerships. Skill and resource sharing support the inclusion of people with disability across all sectors.

DnD partnered with the Ethnic Council of Shepparton to run a self advocacy feast, spreading the word about self advocacy in Shepparton.

DnD benefited from the extensive community connections and networks the Ethnic Council have and their local knowledge and expertise.

The Ethnic Council benefited through greater disability awareness by their staff and a greater understanding of the challenges faced by people with disability in their local community.

6.0 Partnerships Model

6.3.4 Government

The National Disability Strategy 2010-2020 identified *'involving people with disability in the development and implementation of government policies and programs, not just disability-specific policies and programs'* as one of six key actions for driving change and embedding the voice of people with disability in policy development.

This project has identified the support of a self advocacy group and network as pivotal to individuals feeling confident to speak up and know they are genuinely representing the needs and views of other people with disability.

When returning from meetings and consultations individuals rely on other group members to de-brief and gather the strength they need to continue to advocate at this level.

By engaging with and partnering with groups rather than individuals, government can lead the way in inclusive and safe practice; groups provide the ongoing support that individuals need for this sometimes emotionally challenging work.

The National Disability Strategy also recognises the unique needs of people with disability as does the NDIS.

Disability led groups and organisations also have individualised needs.

Funding and grants for groups and projects often come from government.

Current national and state funding applications, reporting, timelines and evaluation processes are slow to recognise the individual and unique needs of disability led groups.
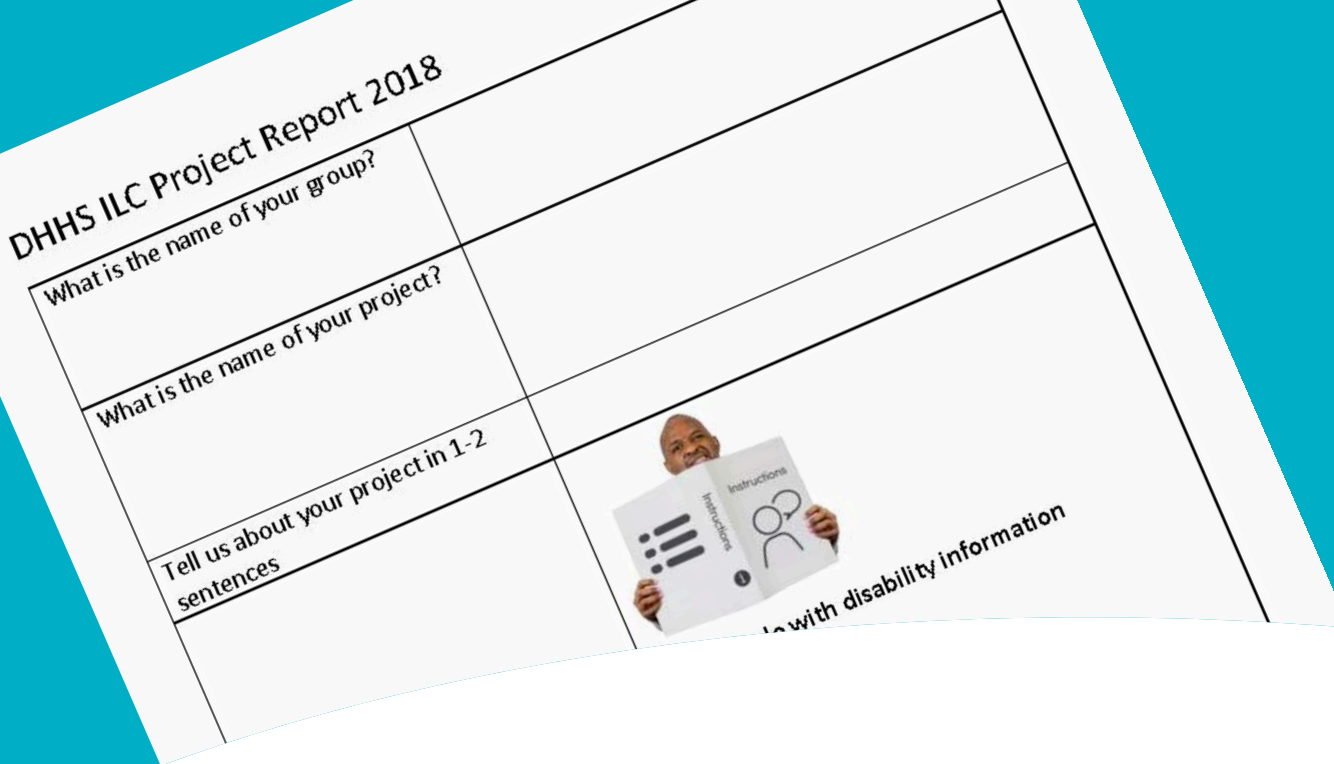
6.0 Partnerships Model

This is especially true for groups led by people with cognitive disabilities. Projects and funding agreements are an opportunity for groups and government to strengthen partnerships and work collaboratively to ensure that groups are meeting project outcomes, and governments are providing accessible, and inclusive application and reporting processes, and realistic timelines.

This project has trialled using Easy English project plans and report templates.

The templates were developed with the groups in consultation with DHHS. In the future groups hope to be able to use video as a means of communicating projects' applications and outcomes, thus removing the literacy barriers many people with cognitive disability face.

This project has identified that because people with cognitive disabilities often learn and work at a slower pace than people without cognitive disabilities timelines need to flexible.

If a project is genuinely going to be led and run by a group of people with cognitive disability then project timelines must be adjusted to reflect people's diverse learning and working styles.

Government also has a role to play supporting formalised community and stakeholder networks as previously discussed.

6.0 Partnerships Model

6.3.5 Industry

Currently people with cognitive disability and complex communication support needs work and consult with government, and in the not-for-profit and community sectors.

Full participation means moving beyond these sectors and also engaging as equals with industry and the for-profit sector.

Engagement with industry through a formal mentorship program would support the growth of organisational leadership in self advocacy groups.

Linking a mentorship program to training such as *Voice at the Table* would support disability awareness and inclusive practice in industry and offer considerable skill development opportunities for self advocates.

A well planned, resourced and executed strategy for developing self advocacy groups, organisations and networks today will move groups in the direction as equal players in a range of fields into the future.

> **"All Australians have a role to play in working together to achieve a society that enables people with disability to reach their full potential."**
>
> *National Disability Strategy 2010-2020*

Group Self Advocacy Partnership Project Report & Model

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Diversity and Disability

BIM

POSITIVE POWERFUL PARENTS

SARU — Self Advocacy Resource Unit

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