

NEWSLETTER

www.valid.org.au

December 2017



The Bollard Project was an idea that came from the Belonging in Geelong Peer Action Group. Group members wanted to promote inclusion and to raise awareness of people living with various disabilities in the local community and to make sure they are visible and represented.

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The Committee and Staff of VALID wish our members and readers a happy and safe Christmas and New Year



VALID Men with Mo's Men are facing a health crisis that isn't being talked about. They are dying too young, before their time. Jon, Anthony, Dom & Rick (not pictured) signed up again to Movember to help raise awareness of men's



health.

Ripple effect from VALID work....

Jon, Luke and Jade were invited to present disability awareness to some Interior Design students at Swinburne college earlier this year. The focus was on how to design homes and rooms for people with disability in mind. This was the first time a disability awareness presentation by people with disability had occurred in this certificate.



The facilitator and students of the course were incredibly impressed by the presentation they received, that they have decided after many conversations to find an accommodation service provider to partner with. This partnership would offer the Interior Design students the opportunity to work with the residents of the service to co-design and re-model their bedrooms.



Swinburne partnered with Scope in Box Hill, 5 residents of the home worked with the students over a period of months to create a bedroom for each based on what was important to them. The students fund raised, obtained donations from suppliers and labour from tradesmen to ensure that the residents got everything they wanted in their rooms, right down to the electric drawn window coverings.

This demonstrates the successful outcomes from a presentation to students who have nothing to do with disability, by a VALID team which included people with a disability. The project was so successful for Swinburne and the residents, that it is going to be included as a permanent part of the curriculum and the next intake of students will finish the house at Scope.

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Senate Hearing Submission 19th September 2017

Joint Standing Committee on the National Disability Insurance Scheme

Inquiry into and report on the transitional arrangements for the NDIS.

Introduction

VALID has been an active supporter of many people with disability and their families during the NDIS Trial Phase and now during the full transition to the NDIS. VALID was an early and unwavering supporter of the campaign for the introduction of the NDIS and remains convinced it is the best model able to deliver outcomes for people with disability in a sustainable manner. The comments and suggestions made in this submission are intended as constructive feedback offered in the spirit of co-design aimed at helping the scheme achieve its full potential. They should not be misinterpreted as any weakening of our support for the scheme.

There is no question that the NDIS has brought huge improvements to the lives of many people with disabilities, especially people who have never received support and people who are able to navigate the new system well. There is a danger, in the context of current problems, of overlooking these very significant improvements.

VALID was one of the first and main advocacy organisations to identify and campaign on the issue of Unmet Needs. From the late '80's and throughout the '90's, we worked continuously to have governments confront the issues of duplication and overlap, and to address the cruel waiting lists for services. To see those waiting lists now being eliminated, and to see people now accessing the services they need, is something that must not be forgotten or taken lightly.

However, whilst it might be true that the NDIS has been delivered largely 'on time and on budget', there is no escaping that fact that the transition has been beset by a large array of problems and obstacles. We therefore welcome this opportunity to discuss these issues, in the interests of ensuring the NDIS remains capable of living up to the hopes that we, and all Australians, have placed in it.

Kevin Stone, VALID CEO: said 'We've been a strong supporter and remain a strong supporter of the NDIS. We provide individual advocacy support to people across the state and systemic advocacy representation. We also provide a wide range of information and capacity-building activities and programs, selfadvocacy training and support, familyadvocacy training and support and information around the NDIS in particular. We've delivered programs to around 3½ thousand people over the last 18 months. We're heavily engaged out there in making the NDIS understandable to people to the extent that we can and also in systemically trying to make sure the NDIS is responding and getting it right for the people that we represent....

Given the scale, size and complexity of the reform, it's not surprising to us that there are problems and issues that have arisen during transition. What has been surprising and disappointing, however, is the lack of effective collaboration and communication between jurisdictions - Commonwealth and state - to address the problems and issues. I think that that's partly explained by the fact that there's been such pressure placed upon everybody. What's even more surprising and disappointing is the lack of effective collaboration and communication with people with a disability and their families to actually work together to find solutions.

If this were a relay race, we might describe it as a baton being passed from one runner to the next, with neither party managing to get a firm grasp to match the other's pace or to carefully transfer those who might otherwise be dropped and left behind. For many people with disability who are able to run their own race or who have families who are able to support them in their journey, the transfer has been relatively smooth. For those who need more intensive preparation and more specialised support, however, the experience has been more like a gruelling marathon. We provide a range of case studies in here, drawn from our advocacy case load...

Over the past 18 months VALID has supported many people who have been let down or failed by NDIS planning processes...

Our strong experience is that the quality of life for a person with intellectual disability is often dependent on the quality of the planning and vision that goes into it. We therefore very much endorse the recommendations of the Department of the Premier and Cabinet, the DPC - and I note that the DPC made its submission earlier - against the practice of doing plans over the phone. That's been a nightmare for many people. It's just not an effective approach, as DPC says, for participants, particularly those who have cognitive, psychosocial and other mental health disabilities, as well as participants who are less able to advocate for themselves.

VALID has welcomed the agency's and DHHS's recent acknowledgement of these planning problems. I think there's been a lot of discussion about it, and we were really pleased to see the CEO's letter of apology, coming out and conceding. We also very much welcome their commitment to develop a new participant pathway, and we welcome their commitment to actually co-design that pathway. These are good things. They're overdue...

NDIA's submission made some commitments that we absolutely endorse - and we'll hold them to it. I just want to state the importance of some of the commitments they've made. Their submission states:

In terms of current practices to deliver high quality plans, the NDIA has established a National Technical Advisory Team, with a primary focus on:

- Driving consistency in the application of the NDIA's "reasonable and necessary" decision-making framework, tools and operational guidelines,

And here's our emphasis - within the context of the NDIS Outcomes approach;

The nuance there is that we've seen those delegates making decisions based purely on the letter of 'reasonable and necessary' without an understanding of what it takes to actually deliver outcomes to people, but sometimes the rules don't get you there; it's the understanding and the experience that get you there.

So, we need delegates who have strong experience... and sometimes you actually need to be flexible; you can't be governed by the rules. It's imperative that delegates have that understanding.

The next point that they make about the team's focus is:

Providing technical advice and support to NDIA staff and partners in relation to unusual or rare disability-related needs, or complex service delivery matters; ...

We say, 'Absolutely.' This is critical. But to provide technical advice and support they need to have that expertise in the first place. And they haven't had the capacity to recruit and really build up their own expertise around these issues upon which they are passing judgement - so, often finding people in there who just don't know what they're talking about. So we say, yes, if they want to play that role, then give them the capacity to recruit for excellence.

The next point is:

Contributing to tactical research that informs best-practice service delivery; ...
We say, 'Absolutely.' We've been crying out for a proactive approach to research and development. It's not as if the NDIS has created all these problems for us. These problems have been around forever. They are inheriting what has been a mess. What needs to be happening is a real investment in best practice, funding services for outcomes, working with them and actually developing best practice models, tactical research. It is absolutely critical.

And their final point is:

Supporting the application of insurance principles within the disability sector. Again, we say, 'Hear, hear!' Insurance principles mean that you will invest in people with disability, you will invest in the services and you will look for outcomes. The more you invest in people, the greater dividends you'll redeem.

So, we say yes to all of that. But what we doubt is that they've actually got the expertise and the capacity to deliver on these promises.

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New Self Advocacy Working Group

VALID has started a new Self Advocacy Working Group, which met for the first time on the 31st October.

The role of the Self Advocacy Working Group is to support members to speak up about their rights, develop and use their self advocacy skills and learn new things. The group will represent the issues of people with a disability and raise ideas on how to improve services and supports for people with a disability.

The first meeting went well, and included a consultation with Sophia and Will from the Latrobe University Research department about the experiences people with a disability have with voting, so they can try to make it better and easier.

Something that was talked about was how many people with a disability have found voting hard, because they are not allowed to have a support person with them to help them.

One person talked about using a postal vote, which can be done at home. By doing this her Mum can read out the persons name and what they say they will do, and she then writes a number next to each persons name (1 being her favourite) and then her Mum helps her write the numbers next to the names on the ballot paper (voting sheet).

We also talked about how important voting is, although it can be a bit scary because it's a big decision to make. After the consultation some people who have not voted before, or who have stopped voting, said they would think about voting in the future.

We are really excited about the new working group, and look forward to the next meeting, where the group will decide on a name.

Anti Bullying Morning Tea

The Bellarine Peer Action Group hosted an Anti Bullying morning tea in October.

The event attracted over twenty people and it was great to welcome four students and the principal from Point Lonsdale Primary school.

Guest speakers were Pippa Swanwick a passionate anti bullying campaigner and Peer Action Group member and Katie from Bully Zero Australia Foundation.

The group will be hosting another event on 16th March 2018 which is the National Day against Bullying and Violence.

For more information about the 2018 event contact Kylie Fisher. kylie@valid.org.au





My Journey So Far......

Since 2015 I had been telling my coordinators and other appropriate people involved with improving my life that I need a new electric wheelchair as although it was 3 years old I was constantly having breakdowns that were happening more frequently than 6 months. This made it especially difficult as I am an extremely busy lady that travels to and from Melbourne sometimes 3 times a week. It was getting to the point where I would get into my wheelchair and wonder if it was going to be safe.

On September 15th, 2016, my trust in my wheelchair came to an end. It was a wet afternoon, my wheelchair slid across the footpath causing me to slam into a bollard; at the time I thought I was extremely lucky.

An hour and a half later I went to go to the toilet but as I was trying to get up out of my wheelchair I was in the most horrid pain I have EVER experienced. With my act when I returned to VALID it was late after a lot of November mid December I was so finally got the happy to return.

From September all the way through to February I was constantly trying to contact the NDIS. Thankfully, my coordinator was also stating my case that I need a new wheelchair. We were told the same answer, "You already have a four year old wheelchair, you don't need one and aren't eligible for another one for another one until 2019 / 2020.

My occupational therapist and my GP wrote great arguments to why I needed this new wheelchair and reminded them that it falls under reasonable and necessary which are two of the rules requirements.

I was extremely lucky to test drive a wheelchair for a week to see how I think it handled under different circumstances and if it could handle the business of Melbourne as well as Geelong.

From February to mid May it was not unusual for me to call the mechanic every week until finally the wheelchair was declared unsafe and unroadworthy.

During this time I was worried about where the funding was going to come from. Eventually funding came through for a hire wheelchair, but the cost and length of time was uncertain which caused me huge amount of anxiety and at times caused my emotions to flare and ignite, a side I don't like to show.

I had a review my OT, GP and coordinator in July who wrote letters of support for my case of having a new wheelchair, which were later denied stating it was not reasonable or necessary.

With my accident slowly healing and after a lot of fighting a year went by, I finally got the news I had been waiting for... I was getting a new wheelchair!

Although I am delighted, I am also annoyed at the whole situation as it was totally an unnecessary stress to place on anyone. My hope is that the NDIS consider what participants need and not necessarily concentrate on the financial side as it was supposed to be person centered which makes me more determined to share my story so others can be inspired to speak up about things that aren't right in their lives.

Simone Stevens



Bollard Project Geelong

In honour of International Day of People with Disability, the Belonging in Geelong Peer Action Group (BIGPAG) wanted to promote inclusion and raise awareness of people living with various disabilities in their local community.

An iconic feature in the City of Geelong are the bollards or statues which are carved from large poles and placed around the Geelong foreshore area. Each bollard depicts people who have made a contribution to the city over time. Members of the Peer Action Group noticed that the bollards in Geelong, whilst inclusive of gender and race, didn't include people with a disability. Members wanted to make sure people with disability were included and thought this was a great way to become visible in the Geelong Community.

With the support of VALID Community Development Worker, Kylie Fisher, the BIGPAG approached ArtGusto, an already established artistic space for people with disability. ArtGusto was happy to get involved and had fantastic connections with the Geelong Baptist College, whose year nine students were also happy to take part.

The three groups worked together, creating bollards with varying abilities, some visible and others not so visible. Fast friendships were formed throughout the months spent building the bollards and the groups plan on working together again in the near future. Students involved in the project also learned firsthand about the diverse nature of lived experience of disability and about International Day of People with a Disability.

The bollards were unveiled at an event for International Day of People with a Disability. People from the Geelong community attended the event and were impressed with the final products. The bollards are transferable, ensuring that the BIGPAG will be raising disability awareness in other communities and bookings inviting them for events are rolling in.

The project was funded by VALID through an NDIA Disability Support Organisation Grant.

List of artists involved in the project:

Year 9 Students from Geelong Baptist College supported by David were Matilda, Zoe, Coby, Colby, Marcus, Noah, Casey, Aylah, Brendan, Tynan and Sebastian

VALID's Belonging in Geelong Peer Action Group Members: Jenny, Elica, Eliza, Meredith and Kylie

ArtGusto Artists supported by Sharon Christian were Meg, Caroline and Sari – Deakin Uni Intern

Other friends: Neville – Geelong Baptist College Maintenance Man Extraordinaire Georgie, Bryan, Stevie, Sue and Mele





The proposed Victorian Registration & Accreditation scheme

The Victorian Government has committed to establishing an' independent, legislated registration and accreditation scheme for Victoria's disability workforce'. The scheme is intended to complement the work of the new National Insurance Scheme Quality and Safeguards Commission that will begin work in July 2018. The NDIS QSC will have the power to register and de-register service provider organisations but will not require the registration of individual disability workers.

The Victorian Government plans to bring in a Registration & Accreditation Scheme as an extra level of quality and safeguarding for Victorians with disability. The Victorian scheme will cover more than just NDIS participants, although the scope is yet to be finally determined.

How a Registration & Accreditation scheme might work

The focus of a registration and accreditation scheme is to set and maintain minimum standards for entry to, and practice in, a profession or occupation. A registration and accreditation scheme would also deal with breaches of these minimum standards. If a scheme is set up then a regulator will be established.

Typical functions of the regulator include:

- Setting enforceable qualifications for entry to practise as a disability worker (noting that VALID has advocated for registration to include a level that does not require minimum qualifications)
- Pre-registration screening of workers
- Accrediting education and training programs
- Maintaining a public register of qualified workers
- Providing practice guidance: the regulator issues standards, codes and guidelines
- Monitoring ongoing fitness to practise

 Managing complaints and discipline: the regulator receives and investigates complaints about poor or unethical conduct. Where a registrant presents a



Catherine McAlpine

risk to the public due to poor performance or misconduct, the regulator takes the necessary action to protect the public.

- Managing prosecutions
- Reporting and linking data

VALID supports a Registration & Accreditation scheme

VALID supports an *independent*, *legislated* registration and accreditation scheme for Victoria's disability workforce. People with an intellectual disability need the support of workers who have the appropriate values, qualities, knowledge and skills to help them reach their goals. Skilled support workers are needed to enable people with an intellectual disability to achieve their potential for independence; unskilled workers without the appropriate values and qualities can sometimes create further dependency, or 'learned helplessness'.

All support workers should have:

- Values that are consistent with human rights principles
- Personal qualities that enable them to provide person-centred and empowering support
- Training to ensure they have specific knowledge and understanding of the diversity of disability support needs

All workers involved in supporting people with higher needs, particularly either medical or behavioural needs, require *skills* training and higher level qualifications.

VALID has expressed concerns about a Registration & Accreditation scheme

VALID believes there are certain current realities that need to be addressed in the development of the proposed registration and accreditation scheme:

- Family members are often 'forced' to self-manage their adult child's funding because service providers do not provide staff with the appropriate values, qualities, knowledge and skills to work reliably with people with high medical and/or behavioural support needs.
- Many people with intellectual disabilities do not have the support or involvement of family members or informal networks and are more likely to experience abuse or neglect.
- Service providers often fail to adequately screen prospective workers
- Current training courses often fail to equip support workers with the range of knowledge and skills required to meet the diverse needs of people with a disability
- Current training courses fail to draw upon the experiences and learnings of people with disabilities and their families, both in their design and delivery.

Having the appropriate values and qualities, whilst critically important, does not necessarily enable support workers to meet the diversity of disability support needs, nor equip them with the tools to build the capabilities of people with an intellectual disability; workers with the appropriate values, qualities, knowledge and skills can often be the difference between a wasted life and a life worth living.

People who self manage must be able to opt out

People with a disability and families who choose to self-manage their NDIS funding and to employ and train their own support workers must be allowed to employ unregistered workers, should they choose to.

For many people with a disability and family members, there is no higher expression of the right to control and choice than the power to self manage and self employ. For those who choose this path, and have the capacity to meet the necessary requirements, this right must be guaranteed.

Having a Say Art Competition



The Art Competition is open to all people with disability who attend the Having a Say conference.

The four top entries will receive a cash prize of up to \$600

The art competition is sponsored by the Office of Professional Practice.

Entries close 12th January, 2018

Entry forms are available from the VALID website: www.valid.org.au or email: brenda@valid.org.au

Dulcie Stone Writers Award

The Dulcie Stone Writers
Competition is open
to people with
intellectual
disability. It is
designed to
showcase the voices of people
with intellectual disability and
recognises the lifetime contribution
of Dulcie Stone to services for
people with intellectual disability
and writing.

The theme for the 2018 writers award is

Community - Here I Come!

Competition entry forms are now available on the VALID website or email brenda@valid.org.au

There will be a book launch at the Having a Say conference showcasing all the entries received for the 2017 competition.

Cathy
Townsend, a
member of the
VALID Self
Advocacy
Eastern
Network, was
one of the



winners in 2017. Cathy will be reading her story as part of the Writer's Award presentation at the Having a Say conference on the Wednesday morning.

Participant Pathway workshop

In August the National Disability Insurance Agency (NDIA) asked members of VALID's Self Advocacy Forum, Networks and Peer Action Groups if they could attend a consultation (feedback) session in Canberra. The NDIA wanted to talk to people with disabilities on how to make the NDIS better.

Luke, Paul, Mark from VALID and a group of self advocates from Geelong went to the NDIA Canberra office to give their feedback on how the NDIS can do things better and make it more accessible for current and future participants.

The self advocates gave their feedback on:

- The pathway to NDIS
- · How to make an NDIS plan
- How to make the NDIS website easier for people with disabilities to use
- How to let people know how to join the NDIS
- The role of the Local Area Coordinator
- How to use the NDIS Website
- NDIS frequently asked question fact sheet



"It was a good experience and it was good to expand the knowledge and to give feedback to shaping the future of NDIS." *Luke Nelson*

Rights in Specialist Disability Accommodation Consultations

VALID was engaged by the Department of Health and Human Services to conduct consultation sessions with people with disabilities living in shared support accommodation. These consultation sessions were to gather advice and opinions on resident rights, and also to look at legislation that may need to change, under the NDIS model for supported accommodation.

Under the NDIS, supported accommodation will be separated into two different parts:

- Support services (Staff support), known as Supported Independent Living (SIL); and
- Specialised housing (the house itself including repairs and maintenance).
 Shared supported accommodation or community residential units, will be known as Specialist Disability Accommodation (SDA).

Under the NDIS, SIL providers will be different from SDA providers. This separation may improve choice and control for residents by allowing for a change of one support or accommodation provider without necessarily changing the other.

VALID developed a slide show presentation which was used during each consultation to assist the facilitator to explain the different topics to the participants. People that were part of the consultation were then asked for feedback regarding these topics and their rights under the Disability Act.

The topics included:

- Agreements e.g. Residential Statements
- Choosing housemates
- Accessing the house and Resident rooms
- Paying Rent and Money Management
- · Modifying the House
- Repairing Damages
- Notice to Vacate and Relocation
- House Management
- Legislation

Overall the consultations were well received and valuable feedback from residents was recorded.

Below are examples of the side show used with some feedback from participants.

Housemates and the NDIS

People don't get much choice about who they live with now.

With the NDIS people may be able to choose their "housemates" – who they live with.





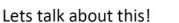
VALID

"Living with one person for me would be a great choice to have and I hope the NDIS would permit this to happen and at least give me the choice to. It should be OUR choice not the carers' or providers' choice".

Group Homes and the NDIS

People will have:

- One service that looks after the house (SDA)
- One service that looks after the staff (SIL)





VALID

"The idea seems good. I would like to see it first because it is hard to predict or imagine what it will look like or how it will happen and what will happen."

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VALiD's Ballarat Peer Action Group welcomes increased accessibility in the region

Ashleigh McMillan



Access-minded: Shane Everard's brother Jim Everard, Showbiz Group director Chris Jones and Matt Mattson's daughter Lorraine O'Toole.

Picture: Jeremy Bannister

The local VALiD Peer Action Group have named Showbiz Cinemas as Ballarat's most accessible venue.

The Everard and Mattson Memorial Award was presented yesterday by Buninyong MP Geoff Howard as an acknowledgement of the cinema's effort to make their venue wholly accessible for those with disabilities.

The award was part of celebrations for International Day of People with a Disability, which is held annually on December 3.

It was named in memory of local disability advocates Shane Everard and Matt Mattson.

The Victorian Advocacy League for Individuals with Disability (VALiD) provide a range of advocacy and information strategies for people with disabilities.

Ballarat VALiD Peer Action Group leader Mark Thompson said Showbiz Cinema received the award for ample parking, seating and closed and open captions on films for people with disabilities.

"It's not just about a disabled chair, they have captioning and new autism-friendly screenings, they've done a whole heap of stuff," he said.

"What they intend to do in the future is fantastic too."

"Shane Everard and Matt Mattson worked tirelessly to make our community more aware and inclusive of other people with disabilities.

"We rung up the Men's Shed through the week and asked if they'd mind coming to cook the barbecue, and it wasn't a problem, because there's now no stigma attached.

"It's important, and if locals don't make their businesses more accessible, we won't shop there and we don't spend our dollars there, we'll go somewhere else."

Showbiz Group director Chris Jones said the cinemas were committed to increasing the ease of access and enjoyment for those with disabilities.

"Because it was a new build, we were presented with the opportunity to ensure that we made it as accessible as possible to all communities and all people," he said.

"Our philosophy is that we want as many people to come to our cinemas as possible, and to achieve that, we need to be accessible."

VALiD was created in 1989, and has a current focus of assisting people to access the National Disability Access Scheme.

Ballarat's Peer Action Group is planning a twilight screening of Defiant Lives, chronicling the disability rights movement in

Australia, Britain and the United States.

Recognition: Ballarat's VALiD Peer Action Group leader Mark Thompson at the event marking International Day of People with a Disability.

Picture: Jeremy Bannister



Taking Control of My Life

Karen Hiam is a member of the Clayton Peer Action Group which was established in 2015. This was one of the first groups set up through the DSO Project funding.

Michelle Wilcox is the facilitator of the group and used her contacts at a service provider to recruit members for the group.

Michelle has many years of experience in public speaking and facilitating groups. Michelle also has personal experience of self managing her ISP and was eager to share this knowledge and experience with people who know little about self management let alone the National Disability Insurance Scheme (NDIS).

Until recently Karen received support through her local council and the HACC program. Karen had spent eight years on the DHHS waiting list to receive an ISP package and was close to breaking point.

The NDIS rolls out in the Southern region in 2019 and Michelle knew it was important for people with disabilities to be prepared for the transition.

Before joining the Peer Action Group, Karen knew very little about the insurance scheme. "I knew that it was national and that it was insurance but I didn't know how it would benefit me." Michelle talked about the NDIS and the importance of setting goals before meeting with the NDIS planner. Even though the NDIS was still two years away, with the help of Michelle and the group,



Karen decided to put together her list of goals.

"I knew that I wanted a better life and so I thought big when I put together my goals." Karen knew she needed more access to the community and to work on her fitness.

Together with the planner, Karen was able organise support to go to the gym and local swimming pool. "I was even able to arrange one hour a week for support with looking after my assistant dog, Sandy."

"If I hadn't had the support of the Peer Action Group and Michelle I wouldn't be living this life. I have more control of my life. I am now able to look after my beloved dog and take care of my fitness."

Get NDIS Savvy!

VALID has developed a series of videos to help you better understand the National Disability Insurance Scheme (NDIS)

The videos are presented by Christine Scott from VALID who delivers this information in plain English. As a mum of an NDIS participant, and as an advocate, Christine communicates in language that everyone can understand.

The videos can be viewed on the VALID website: www.valid.org.au/video-presentations

NDIS Update

Every day VALID advocates work hard to understand the NDIS, and every day there is more to learn. Over the past 12 months, VALID has directly supported more than 100 people with individual advocacy as they become NDIS participants for the first time. We have seen some great outcomes for people, and we work with others who are really struggling to have their basic needs met.

Some of our observations over the past year include:

- The NDIS both commissions and then rejects allied health assessments. The NDIS does not expressly inform therapists about the information they need to include in their reports to meet NDIS standards of evidence. Participants play an expensive guessing game as more and more reports are commissioned with vital support needs debated for months.
- Some service providers, in response to funding uncertainty, are retreating into group-only service provision and increasing the time clients are spending in centrebased activities not related to the individual's NDIS plan goals.
- Refusal of the NDIS to lead the work on developing new, innovative services for people with severe intellectual disabilities and behaviours of concern who are rejected by other providers.
- Lack of a consistent approach by the NDIS about who can speak for an NDIS participant. Some NDIS participants have no representation in their planning meeting beyond paid staff despite having no formal

- system for communication. We met a self-advocate who carefully prepared for their NDIS planning meeting only to be completely by passed by the NDIS who completed the planning session over the phone with their mother who lives interstate.
- The NDIS unreasonably defers responsibility for challenging structural inequity in other systems. This can mean taking on a hospital to change their policy of restraining patients with autism, challenging the Medicare system's rules against paying for home visits even though there is no other option to have medical treatment, or lobbying to have local government install more street lights because the NDIS won't fund lights for your wheelchair.

On a positive note, we are also noticing that NDIS planners are learning fast and are spending more time with participants with complex needs in planning meetings. We are seeing some enthusiasm by the NDIS to support young people with disabilities to move into their own home. And we are seeing some service providers responding to the NDIS by developing and sharing new ideas as participants are finally feeling confident to ask, 'What can you do for me?'

There are many challenges still ahead, but we are certainly making progress.

Let's keep going! To full roll out and beyond!

Sarah Forbes Advocate



Keys to Success Program and Staying Safe

Murray Human Services contacted VALID to run the Keys to Success training and Staying Safe sessions in Echuca and Swan Hill.

Echuca ran a 'Staying Safe' session on the 24th October and one in Swan Hill on 22nd November. There was a fantastic turn out of participants, staff and residents, of Department of Health and Human Services - Disability Accommodation Services.



The Keys to Success Program training for participants of Murray Human Services were held during October and November. The training was held on one full day a week over 4 weeks. Pictured below are the participants with their certificates.

VALID staff were impressed with how the participants engaged in the conversations and really embraced the contents, relating it to their personal situations.

The Keys to Success team have also been delivering the training in Gippsland visiting services in Sale and Bairnsdale.





Fantastic Flicks

The VALID Banyule Peer Action Group presented Fantastic Flicks, a screening of films made by people with disabilities about people with disabilities, at the Watsonia Library on Tuesday the 28th of November.

The films captured the lived

experience of disability across a range of contexts and explored themes of love, relationships, politics and activism, work,



everyday fears and hopes and a range of other issues associated with membership and participation in community. We showed sixteen films in total as part of the program.

The screening was made possible through the generous support of our partner film making and producer organisations - City of Port Phillip, Arts



Access Victoria, the Self Advocacy Resource Unit (SARU) and stART Community Art – who helped us source our films. The films included local productions and 2 international films from Great Britain and the United States, provided by Arts Access Victoria from the **Other Film Festival** archive.

Another feature of the screening was the moving tribute by Colin Hiscoe from Reinforce, who reminisced about the campaign to close Caloola Institution in the context of the films Witness and Windy Day made by Michael Buckley in collaboration with Colin and John Harrowell. We appreciated Colin's harrowing account of life in one of the large institutions in Victoria, which was made even sadder for Colin, given that many people, his friends, who stood alongside him in the campaign are no longer with us.

A big thank you to Barbara Armstrong, and her team at Watsonia Library, who support the Banyule PAG by giving us access to a meeting room each month, as well as providing us with the space to screen Fantastic Flicks.

This was the Peer Action Groups first go at Fantastic Flicks and we are now planning to offer screenings in local communities where our PAGs are based. Our next Fantastic Flicks screening will be in Moe hosted by the Moe PAG at the Moe Library on Friday 2nd March.

More information about the Moe screening will be available soon. In the meantime, if you would like to find out about Fantastic Flicks, or hold a local screening in your community, please contact Heather Forsyth heather@valid.org.au or Paul Dunn at VALID paul@valid.org.au

Paul Dunn Community Development Officer



Choice Mentor Launch at Box Hill Town Hall



The official launch of the Choice Mentor Program was held at the Box Hill Town Hall in November. Annette Axen, coordinator of the Choice Mentor Program, chaired the morning session and Tess McCarthy from the Office of the Public Advocate (OPA) spoke about their partnership with VALID in developing this project.

The introduction of the National Disability Insurance Scheme (NDIS) brought with it many positive changes but also some possible challenges. One challenge that OPA identified was that a number of people with cognitive impairments joining the scheme would likely have difficulty participating in the planning and reviewing process.

It was anticipated these people would be unable to participate as fully as possible in the life of the community, and exercise choice and control over their supports, because they did not have access to much-needed support with their decision making.

OPA joined with VALID to develop a program aimed to address this problem by matching volunteers trained in the practice of supported decision making, with NDIS participants who wanted and needed this type of support. VALID is now funded to extend the program to a

select number of participants in the Eastern and Northern Metro roll out area.

After months of planning, recruiting and training, we were thrilled to launch the program to members of the community, new participants and volunteers, the newly elected Mayor of the City of Manningham, Councillor Andrew Conlon and staff from OPA and VALID. David Craig, Manager of the VALID Community Development team launched the program, expressing the importance of community engagement within the disability sector, providing more choice and control in their daily lives.

The event concluded with a delightful morning tea and a chance for the new volunteers to meet with the new participants.





Heather Speaks Up

Articles on self advocacy by Heather Forsyth, a highly experienced self advocate, who has overcome many challenges in her life to become a leader and support worker for other people with a disability.



Mainstream and Me Project

A new team of Community Workers have started working at VALID for the roll-out of its latest community based project, Mainstream and Me. The Mainstream and Me project aims to empower people and make the broader community more inclusive for people with a disability.

We plan on working with people from local businesses, community organisations and local councils.

The team will be working with VALID Peer Action Groups throughout Victoria to develop projects that are linked to individual goals of group members, such as employment independence and education. Each of us will either be running an event or working with local radio and television.



Speak Out Tasmania Conference

One of the highlights in 2017 for me was attending the Speak Out Tasmania conference with Zoe and Lisa from VALID. The theme of the conference was "Out of the Shadows - Into a Life!", I was involved in the Our Voice presentation "Self Advocacy Around Australia" with other Our Voice members.

The Our Voice members talked to other self advocates at the Having a Say conference in February. We asked them what self advocacy meant to them.

Some of the comments we received were:

- We don't get listened to
- We don't get a choice about where we live

I also talked about my life and the journey so far, about how I was abused as a child. This was well received and started a conversation with people sharing their stories about abuse and neglect. Later that afternoon, Zoe from VALID did a presentation about Abuse and Neglect and how it's NOT okay.

Network News

It's been an exciting few months for guest speakers at the VALID Self Advocacy Network Meetings.

In July we had Legal Aid, who with the help of some self advocates, did a role play about what to do if you are interviewed by the police.



In August Kelly from Metro Trains talked about being safe of the trains and Authorised Officers, finishing with a fun "Family Feud" game.



In September Consumer Affairs talked about your rights when you go shopping, and how important it is to keep your receipt. They also talked about online scams, and that you should never give your private information (like bank account numbers) to people you don't know.

In October the Disability Services Commissioner (DSC) attended the Western and Southern Network Meetings. The DSC takes complaints about disability services in Victoria. They talked about how speaking up can make things better for you and for others too.

Rick from VALID was the guest speaker at the Eastern Network Meeting in October, talking about getting ready for the National Disability Insurance Scheme (NDIS). The NDIS is a new way to help people. People with disability are equal and have the same rights as everyone else in their community.

People have the right to:

- Be supported to reach their goals
- Choose their support
- Learn, grow and have a good life

The NDIS will help you to build skills to use mainstream services like Medicare, public housing, transport and education. Rick also told people to talk to people in their lives about their goals so they can put it in your plan.

There will be Local Area Coordinators (LAC) and support coordinators to help you find services that are in their plan. You need to write down your goals so you don't forget them.

We are looking forward to the Self Advocacy Network Christmas Break Ups in December, and some new guest speakers next year.

Simone Stevens Reporting





Future Metro Trains Update

From the beginning of the year I have had the great honour in participating in designing Melbourne's new Metro trains which will have not just a new look but will be fully accessible for everyone, from people with physical disabilities, vision impairment to people who are deaf and of course people who have intellectual disabilities.

The consulting process in September was different from previous meetings on the design, as each person could go to Hallam and physically see the progress and make suggestions to what would make accessibility better for people who have different disabilities. As I was representing VALID I personally wanted to ensure every aspect was looked at thoroughly. The lines that the trains will be running on will be Cranbourne and Pakenham which will be starting mid 2019.



There is still work to be done before 2019 which I look forward to share and update you on this very exciting project. The trains will also benefit the general public too with prams as well as the elderly. My personal experience came from two angles.

Some of the issues that the group have looked at include:

- 1. The ability to have input and physically walk through the mock up train to make suggestions like button heights and what colour they should be which should be bright and easy to press for people who have trouble pressing buttons.
- 2. Visibility for anyone who has trouble with low vision or reading maps on the train as well as the height of the map for better accessibility.
- 3. A clear intercom system, clear video camera systems where the passengers can talk to the driver if there is a problem for example: The train has broken down in a tunnel, with the new train I suggested to have a separate RED button to press to alert the driver.
- 4. The signage to be changed from white background to black background with white writing in large front as well as clear announcements though in more time so people with disabilities can have more time to prepare to exit the train more safely.
- 5. Accessibly seating to be different colours and roomer for extra comfort for each individual in a wheelchair or with some other equipment that needs some space
- 6.Ramps: there will be two portable ramps that the driver slides out than pulls down for wheelchair users than up and in for easy storage was another thought I had to save drivers back in the very back or front (depending on which way the train direction is) there will be a low floor which will meet the platform like tram stops to make it even easier for the driver as well as maximising the wheelchair / person with a mobility equipment independence.

I am excited to head to Hallam again in the near future to see the final result before the roll out of the trains in 2019.

Self Advocacy Forum Report

Elections

The VALID Self Advocacy Forum Committee recently held an election to vote on which two members will replace Lisa McLeish and Luke Nelson to represent them on VALID's Committee of Management (COM).

Six Forum members put their hand up to be nominated for the COM but only two could be voted in.



The two successful candidates were Paul Campbell and Samson Hauli. Congratulations Paul and Samson. We are all sure that you will do a wonderful job.



Also a big thank you to Lisa McLeish and Luke Nelson who have represented the Forum on the committee for the past couple of years they have both been valued advocates and their skill, knowledge and dedication is highly recognised by all.

Forum News

The Forum members have been in demand and extremely busy the past couple of meetings. At the July meeting Rebekah, Ross, Nick, and Marie from DHHS asked the Forum for their opinions on the design of a new awareness campaign on pain and the use of pain medication. The team from DHHS showed the Forum members three posters targeted at people with disabilities and support

staff on how to recognise pain and the dangers of the over use of pain medication.

Forum members where asked what the best ways are for people to speak up when they feel sick, pain, itchy, uncomfortable or fuzzy. Also how support staff can identify some of the signs of pain when working with people who may not be able to speak up when in pain. They also talked about letting people know that it is important to have the least amount of medication to keep you well.

At July's meeting Rhiannon from Stabilise wanted the Forum's expertise and feedback on their new relationship program. Rhiannon's relationship program looks at what relationships are and the different types of relationships. Rhiannon ran a series of role plays and scenarios and asked the members of the Forum if the role plays would help people to learn the way to talk and touch people in different ways depending on the relationship.

At September's meeting the guest speaker was Tess Karambelas who is a University student on placement with Melbourne City Mission. Tess is doing a project for MCM about shared supported accommodation and wanted the Forum's feedback on how people who live in group homes can have a say and make decisions. Tess also wanted to know what makes a good group home and what other ways people may want to live, for example do they want to live independently or with a friend.

... Continued from page 4

They're great promises, but we question whether the agency has sufficient policymaking freedom and budget capacity to truly deliver on these promises. We therefore strongly endorse the Productivity Commission's recommendation that the Australian government 'should reconsider the staffing cap on the National Disability Insurance Agency'.

We say lift that cap and give them the freedom to actually recruit and get the job done. ...

The reason we've got the NDIS from my perspective, going back 35 years, we were one of the first organisations to lobby on the issue of unmet needs. We were sick and tired of the Commonwealth and state passing the buck between them about responsibility for people with disability. We had the Commonwealth State Territory Disability Agreement, which was constantly doing that. We welcome the NDIS as the seamless universal approach to doing it. What we've seen up until recently is just a continuation of that same buckpassing mindset between jurisdictions, without regard to the people who fall between the cracks.

The positive news is it's starting to heal. We've made a series of recommendations here about what needs to continue and what needs to be done. The most critical of all of those issues or recommendations, from our perspective, is to engage with people with disability and families and find solutions. The most powerful way to drive this system is through co-design, co-production, having people with disability at the table, and solving these problems together.

TAC introduces a new way to report suspected abuse or neglect

The Transport Accident Commission (TAC) now has a dedicated phone number and web page to assist people to report abuse, neglect or quality of care issues of people with a disability.

The specialist report line, email address and web page have been launched to encourage any person to report suspected instances where a TAC client may be being subjected to abuse or neglect or poor quality of care by a TAC funded service provider.

The specialists who answer calls on this line understand disability and are sensitive to the needs of people with disability. The purpose of the line is to provide advice and referral options, and in some instances, direct follow up.

Phone: 1800 931 233

Email: reportabuse@tac.vic.gov.au/reportabuse

The report line is open 9am to 5pm Monday to Friday. The TAC encourages clients, family, carers and service providers to call or visit our website if they have concerns for any TAC client.

To find out more information visit tac.vic.gov.au/reportabuse.

Having a Say Conference 2018



Monday 5th, Tuesday 6th & Wednesday 7th February

Deakin University, Waterfront Campus, Geelong



Australia's largest conference for people with disability

The Having a Say conference is a place where people can speak up and have their voice heard, be respected and empowered and it's a lot of fun!

Red Faces Talent Show Auditions, entries forms are now available (note the competition is limited to 20 acts, so get in early)

Competition entry forms are available from the VALID website: www.valid.org.au or by emailing: havingasay@valid.org.au



National Open Employment Forum 2018

Discover how the NDIS & Disability Employment Services can increase open employment opportunities and deliver positive outcomes for people with intellectual disability.

Be a part of the discussion! Tickets on sale now at Eventbrite (see link below) \$99(+booking fee) includes morning/afternoon tea and lunch.

 $\underline{https://www.eventbrite.com.au/e/national-open-employment-forum-2018-tickets-39857607176}$



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