

39

3 September, 2018

# IDA

**asid**  
research to practice

**INTELLECTUAL DISABILITY AUSTRALASIA**

Magazine for the Australian Society for Intellectual Disability



**OUR FAMILY'S NDIS  
JOURNEY**  
JANE TRACY

**STRATEGIC PLANNING**  
ASID PRESIDENT'S REPORT

**PLANNING WITH  
PEOPLE WITH COMPLEX  
SUPPORT NEEDS**  
ANGELA DEW AND LEANNE  
DOWSE

# PLANNING



**Hilary Johnson**  
IDA Editor

*Welcome to  
the September  
edition of IDA  
Magazine*

Everyone seems to be talking about planning at the moment and the recent quarterly report from the NDIS (<https://ndis.gov.au/medias/documents/report-q4-y5-pdf/2018-Q4-June-COAG-report-Part-A-Accessible-PDF.pdf>) suggests plans have been received positively. However for people with complex support needs and those who cannot advocate for themselves it is a different story. In this issue Leanne Dowse and Angela Dew report on their research and discuss the interrelatedness of multiple domains that are essential to include when planning ([page 20](#)). Reading two parents' accounts of their struggle to get planning right for their sons, links back to the lack of resources available to planners – and unfortunately is also evident in service providers ([page 6](#) and [page 13](#)). A person with an intellectual disability talks about her struggle even though well supported by two of her sisters. Jaquie Mills reports on a successful project in WA that looked at preplanning with people with complex support needs who needed a voice. Their work reminds us that not all people have “plans” or “goals” in their lives and this can be a strange concept for some cultures. For people with complex support needs the very concept of planning may need to be taught before a “plan” can be developed.

ASID continues to be active within the divisions and reports indicate seminars on health ([page 26](#)), supported decision making, and group homes are well attended.

IDA likes to present a variety of information quarterly and Amie O'Shea reports on some early research among people with intellectual disability and their identification with the LGBTIQ community, we hope to hear more about this in the future.

In early July the New Zealand Division successfully held their two-day conference with an emphasis on mental health. You can access their key note presentations by on [page 28](#) (or by [clicking here](#)) November 16th will see the launch of ASID's annual conference on the Gold Coast, this edition of IDA has information on more of the key note speakers so keep tuned to ASID's websites for updates click here (<http://www.asid2018.com.au/>). Remember Let's shake it up – human rights for everyone!

Keep tuned for the next podcast on voting and the next edition of IDA with a focus on justice for people with an intellectual disability. I welcome comments and contributions.

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# PRESIDENT'S REPORT

The monumental overhaul of the disability sectors across Australia and New Zealand has provided a timely opportunity for ASID to consider our own position, strengths, values and beliefs, and ensure that we continue to make relevant and meaningful contributions to disability research and practice.

The ASID Board of Directors started 2018 with a strategic direction day, at the first face to face meeting of the year. The day was externally facilitated and provided a mechanism to reflect on our work to date, our strengths, challenges and, our place in an ever changing Australasian disability sector. The outcome of this work provided strategic direction that matches our mission, vision and organisation sustainability.

At the completion of the day in February 2018 we collectively agreed ASID's current strengths were:

- The provision of platforms for the dissemination of research with a primary focus on intellectual disability,
- The provision of platforms for the presentation of research informed practice and lived experience and,
- Holding a unique and important role in advocating for people with intellectual disability to receive high quality, evidence informed services.

Following on from this, our discussions and debates culminated into four (4) questions for the board to answer via work plans:

1. How do we most effectively become influencers and advocates for real change in society?
2. How do we create the networks and partnerships we need to help achieve our mission?
3. How do we engage people with intellectual disability as respected leaders in their own cause?
4. How do we develop a board that is inclusive, innovative and decisive to achieve our goals?

In June, when the Board of Directors reconvened, our goal was to answer these questions by means of an operational plan (who, will do what, how and by when), supplemented by a business plan (resourcing our operational plan via a combination of income generation and expenditure).

We put the wheels in motion for this by asking all Directors to answer two (2) questions:

1. What is the most significant thing that ASID currently does or has recently done?
2. If ASID was going to do one significant thing in the next 12 months, what would it be?

Whilst there was diversity in the answers regarding the most significant work of ASID, all answers could be grouped broadly into three (3) themes:

- ASID publications
- ASID conferences & events
- ASID's 7 Divisions (knowledge of and responsiveness to local need)

We're not quite ready to announce our new directions, so watch this space. However when asked to share one word that captured how each Director felt about our future direction, the picture on the front cover says it all.



**Laura Hogan**

2018 ASID President  
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# OUR FAMILY'S NDIS JOURNEY

Jane Tracy

## **Over the rainbow: a journey needing courage, thought, heart and perseverance.**

The National Disability Insurance Scheme (NDIS) promises great benefits for both individuals and our society. People with a disability, their loved ones, those who share their lives at home and at work, and all those who want an inclusive community enriched by the diversity within it, have much to gain through the implementation of this transformative social reform.

The NDIS is a visionary plan, built on a solid foundation of human rights and social justice. It acknowledges the benefits, both social and economic, of enabling the participation and contribution of all citizens. The Scheme is, however, still in the developmental stage and requires support and guidance from us all if it is to reach its potential and realise the promised outcomes. The enormity, complexity and challenges of the task of building this social reform, however robust the foundation, are evident in current discourse about the Scheme.

Our family advocated and fought for the NDIS and have defended it against its detractors. We have been involved in taskforces, working groups, workshops and seminars about the Scheme for many years. We were, therefore, in the privileged position of understanding the history, philosophy and intention of the Scheme better than most.

As the time approached to embark on our personal NDIS journey we were excited and optimistic. From a distance, the possibilities looked like glistening prizes at the end of a rainbow. The prizes were the new opportunities for our 33-year-old son, Nick, to build skills and independence, communication and friendship, and enjoy greater community participation. The path to those prizes, the rainbow, seemed enticingly real, close and affirming.

The reality of our journey has, however, been more difficult than we anticipated. It was challenging to get started; the route has been winding and at times unclear; and the prize has been elusive. For me, as for many others engaging with the Scheme for the first time, the experience has been enormously time consuming and emotionally exhausting, and, so far, the benefits have been modest. I have been fortunate to have, and relied heavily upon, the support of my family over this challenging time.

I involved Nick, as much as I could, in identifying, developing and articulating his goals, but the job of navigating his entry into the Scheme was mine. He has an intellectual disability and is not able to understand what the Scheme would or could mean for him, nor could he play an active role in the preparation required to enter the Scheme. I felt a tremendous weight of responsibility for getting it

“right” for him. If I “succeeded”, then his life experience and opportunities could be greatly improved and enriched, if I “failed” then he would miss out. I would have failed him.

In the year prior to rollout in our region, I sought information from the NDIS, service providers and other parents who had already commenced their NDIS journey. This was both helpful and confusing. The Scheme was, and still is, continuously changing and evolving, and different people in different regions at different times have widely different experiences. I understood that the Agency was learning from each new rollout, each new dilemma, each new situation encountered, but trying to stay up to date with the changes was a time consuming business.

When rollout in our area was imminent, I went to NDIS education sessions run by the NDIA, service providers and consultant groups. In each I learnt a little more, and in each I saw how much more there was to learn. I accompanied my son to several sessions, including one run by VALID, so he too had the opportunity to hear and see information about the Scheme presented in a variety of ways and from a range of perspectives.

I prepared Nick's pre-planning document for his planning meeting ... many, many times. I sought input, contribution and feedback from family and others who knew him well. I used different formats and templates; refining, re-prioritising and re-wording goals. In the end, his goals focused on increasing independence in communication, finding and building friendships, maintaining independent mobility, and exercising more choice and control in his life. I carefully considered and itemised the reasonable and necessary supports that would enable him to work, and make progress towards, those goals.

Formulating, developing, articulating and documenting those goals, in preparation for the planning interview, was both challenging and deeply rewarding. It enabled me to express on paper my vision for my son's future; to capture my knowledge of what is important TO him and FOR him; and to share that vision and knowledge in a way that would have lasting impact. As an older parent, I think about the time when I am no longer able to advocate for Nick. To be able to capture and share what I know, after spending much of the last 33 years together, was both a relief and, in a sense, liberating.

When the time came for the planning interview I was well prepared, but still felt anxious when considering the responsibility I had to present Nick's goals and support needs succinctly and effectively in order that he would receive the package of support he needed. I felt I had one chance to get it right, one 90-minute window of opportunity. If I blew it, Nick would miss out. The planner was knowledgeable, kind and listened well, but was under considerable time pressure. It was challenging to present the proposed plan, answer his questions, and complete the additional information required by the NDIS in the time available. By the end of the meeting, I felt we had been heard; the planner had met Nick, discussed his goals, and had the information he needed. Then we waited.

When the plan arrived, it reflected our planning conversation well and provided Nick with funds for the supports he would need to work towards his goals. I was tremendously relieved. There were some details I wanted to discuss and refine, and there were some relatively minor errors that needed correction. I was, however, unable to make contact with the planner to have these addressed and, after several attempts, I gave up and decided to work with what we had.

Then came the job of implementing Nick's plan. That has been much harder than I anticipated. Despite having Support Coordination and Plan Management, I have struggled to bring to life the vision I had for Nick's plan. We are now 6 months into the plan, and full implementation is still far from complete.

On the plus side, Nick now has a wonderful speech pathologist and physiotherapist who are sharing the responsibility with me for addressing his communication and mobility goals. He has a great relationship with them both and is making real progress. This is a tremendous relief for me, both in terms of the success of their work with him, and the sense of shared responsibility I now feel.

On the other hand, there are some important aspects of his plan I have not yet been successful in activating, despite having the funding to do so. This concerns me as it means we are likely to underspend for this year, and therefore it may be assumed by NDIS decision makers that Nick does not need the same level of funding in his next plan. This is not the case. The reason for unspent funds is the difficulty I have had in identifying and organising the people and services to do the work required. Half way through this first plan I am tired but know I need to step up the time and energy I invest to ensure the plan is realised and Nick can benefit from the opportunities the funding offers both this year and into the future.

In addition to the difficulties I have encountered in bringing Nick's plan to reality, there remain other areas of great concern that I share with many other families. Nick does not communicate through speech and, in the past, has expressed his distress, both physical and psychological, through changes in his behaviour. These have, at times, been labelled 'behaviours of concern' and we have needed the assistance of specialist behaviour support professionals to understand and resolve the issues for Nick, his family, and others who live and work with him. Behaviour support is not included in his current plan as it is not required, however if unanticipated events occur and Nick once again needs behaviour support, his plan will need to be reviewed and amended quickly. This is a concern as NDIS processes appear not well suited to the flexible and timely response required in urgent and crisis situations. Likewise, if Nick requires hospitalisation for any reason, he will need 1:1 support in hospital. Once again, if this were an unplanned and unanticipated event, it is unclear to me how support would be funded and arranged in a timely manner.

At present, our family feel very fortunate. Nick is happy and well. He lives with people whose company he enjoys and is supported by a staff group who know him and care for and about him. He enjoys the educational, recreational and social activities he does during the day, and the company of those with whom he shares them. He has a family who love and support him, and enjoy his company and contribution to family time and events.

Nick's NDIS journey is our family's journey too. So far, it has been more challenging than we anticipated; the route is still being mapped, the path still being graded, and destination still being built. We can, however, see the enormous potential in the many opportunities the NDIS offers Nick to build experience and skills, independence and autonomy, participation and friendship, connection and contribution. We are optimistic about the changes the NDIS can bring to Nick's life, our family and our community and look forward to contributing to the development of the Scheme so it can fulfil its promise for Nick, and all those who follow him. We are on this journey together.

## Summary

- The NDIS is a transformative social reform built on a solid foundation of human rights and social justice.
- It acknowledges the benefits, both social and economic, of enabling the participation and contribution of all citizens.
- There are concerns about aspects of the planning and implementation process with heavy reliance on people with disabilities and those who advocate for them to drive and enact the plan.
- There is a need to develop the Scheme's timely responsiveness when unanticipated needs arise or crises occur.
- The Scheme is still in the developmental stage and requires support and guidance from us all if it is to reach it's potential and realise the promised outcomes.



**Jane Tracy**

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## Want to read more from Jane Tracy?

Jane Tracy (2014) Building Partnerships between Service Providers and Families of People with Disabilities: One Family's Journey, *Research and Practice in Intellectual and Developmental Disabilities*, 1:2, 128-141, DOI: [10.1080/23297018.2014.961592](https://doi.org/10.1080/23297018.2014.961592)

# CATHERINE'S NDIS JOURNEY

On an icy August afternoon in Melbourne I sat down over a cuppa with my sister Catherine to discuss her experience of the NDIS. Catherine lives in the eastern suburbs of Melbourne. Until recently she lived with her son. Her son has moved out and Catherine now shares her home with her cat, Misty.

Catherine likes where she lives: "I like living here because it's nice and quiet. It's close to transport and doctors. My neighbours are nice and they help me if I ask them. Like the other day I asked a man from down the road to help me pull out some conifers".

Catherine works as an Easy English Consultant at Scope Australia and recently was awarded the Scope Quarterly 'Doing it right' Award for this work. She was also a member of the team who took out the prestigious Victorian Disability Excellence in employment outcome award for 2018.

When Catherine found out about the NDIS back in 2017 she was very excited. In November 2017, Catherine and her sister Sharon began investigating her eligibility for the scheme. Catherine and Sharon completed the paperwork together and Sharon sent it off to the NDIS in Canberra for consideration. Catherine described the process of ascertaining her eligibility for the NDIS. "Sharon helped me with all the paperwork. There were so many bits of paper and it took a long time to fill them all out. I had to give so much information and it was hard to work out what they wanted to know. Some of the questions were really hard to understand. If it wasn't for Sharon, I wouldn't have understood what the questions were. I wouldn't have had any hope. If people like me didn't have someone to help them, I reckon they would give up".

In January 2017, Catherine received notification that she was eligible for NDIS funding. This was great news for Catherine and our family. However we were in the dark as to how this new system of funded support was going to work. Collectively, our family has had decades of experience providing or receiving disability support services. Despite this familiarity with the system, we were anxious about what lay ahead. Catherine described how she felt once she received notification that she was eligible. "I was really relieved. I could do some things that I wanted to do. But I felt anxious, because it was all so unknown and new to everyone. I wanted things to change straight away".

In late January, Catherine had her first planning meeting with her Local Area Coordinator (LAC). Sharon and I went with her. Catherine's planner, gave us a lot of time and tried her best to answer our many questions. I thought she was very helpful. Catherine described how she found the meeting.

"I was a bit flustered. I didn't understand what was happening. She used such big words and it's really hard to understand. When people talk like that, I get flustered, I can't understand and then I just give up. Not everything was clear, so it helped to have Sharon and you [Jo] there".

During the planning meeting we discussed the pros and cons of self-management. Catherine decided that self-management wasn't for her.

Once Catherine's plan was approved it was time to put it in place. This was daunting for us all, especially Catherine. "I didn't know what I was supposed to do. Who to ring? How to get started?" Despite Catherine having opted out of self-management, there was no funding allocated in her plan for service coordination. This was problematic as Catherine needed support to make her plan a reality. We as a family soon became overwhelmed, finding that we didn't have the time and ability to take on the responsibility of coordinating Catherine's plan. Catherine felt like she had been given a gift but didn't know how to open it. "I felt like I just wanted to give it back".

Catherine and I applied for a review of her plan and as a consequence three months later her plan was amended to include funding allocation for service coordination to be provided by her service provider. Catherine's plan has been in place for approximately four months. She has begun working with her service provider to achieve her goals. These goals include improving her independence at home and in the community, improving her physical and mental health and furthering her education.

Catherine has joined a social group which she enjoys. Her needs have been assessed by an Occupational Therapist, and she now has some assistive technology to assist her in the kitchen. The travel allowance Catherine receives through the NDIS allows her to go out in the evening with family and friends, expanding her opportunities to socialise and strengthen her friendship circle.

One of Catherine's main goals is to develop her computer literacy skills. "Computers are the way of the world, and it is the way everything is going. Everyone is always doing things on them with their friends and family. I feel left out and left behind". Catherine has had a computer assessment through her package, however, is yet to have any lessons accessing the computer. "I really want to learn how to use the computer, and we made sure that was in my plan didn't we? But there's nothing happening. I'd really like to learn how to use the computer". Catherine has tried contacting her service coordinator to discuss this with him, however he is yet to return her call.



*Catherine (left) and her sisters, Sharon (middle) and Jo (right)*

Although Catherine's service provider has been allocated funding for service coordination she is yet to hear from her service coordinator. "I felt really happy that I was given a support coordinator, but I've heard nothing from him. So I don't know whether I'm Arthur or Martha. I want to give up again. What's the point of it all if I don't know what's going on? I feel like I had been swept under the carpet to work it all out by myself".

Catherine's NDIS journey has had its ups and downs. As our third cup of tea began to disappear from our cup, I asked Catherine what key message she would like to give the NDIA and her service provider. "I wish people would just communicate with me so I can understand what's going on". I share Catherine's frustrations. Although, I can see that the NDIS has provided Catherine with some wonderful new opportunities, without consistent and responsive service coordination, I can't see her goals being achieved.

**by Joanne Watson and her sister  
Catherine Catarinch**

### **OUR TIPS FOR THE NDIS AND THOSE PROVIDING SERVICES TO NDIS PARTICIPANTS**

- Keep working on making the NDIS system easy to understand. Catherine says: "It is very complicated at the moment. Sometimes I don't know if I am Arthur or Martha"
- Communicate to participants in a timely and responsive way. Catherine says: "Why does it always take so long for someone to get back to me?"
- Build the capacity of service coordinators. Catherine says: "I don't know what the service coordinators job is, I have never heard from them".

# PLANNING FOR PEOPLE WITH INTELLECTUAL DISABILITY

**Caroline Livanos**

## **Complex information**

I have recently emerged, covered in red tape, from a prolonged period of planning for my 16-year-old son who has low-functioning autism. Michael's NDIS plan meeting coincided with his disability support pension eligibility in November last year and both processes have left me feeling frazzled and frustrated! After years of fighting for funding packages for things like school holiday activities, respite and nappies, I was excited to see how the NDIS might help Michael learn new skills and enjoy new activities.

My goals for Michael's first year in the NDIS were to improve his independence, communication and social participation. My aim was to find therapists (speech, OT and physio) to meet Michael and write assessment reports. I planned to implement their recommendations, with the help of his support workers, and work towards achieving his goals.

But no amount of planning could help me get past the barriers I faced along the way.

## **A complicated NDIS planning process**

- Many important areas that were discussed in the planning meeting were not factored into Michael's plan. I was not able to view his plan before it was approved, so the only way I could address the errors was via a review. It's been six months since I submitted the review and I still haven't had a response. This means I have not been able to progress with some parts of his plan.
- Michael's plan did not have a holistic approach. For example, why include funding for support workers to achieve a goal of community access without funding travel? And why include funding for speech therapy without funding assistive technology?
- I have found there is no accountability for poor planning, poor communication, long delays for reviews and complex approval processes for things like therapy products or home modifications.

## **Difficulty finding quality services**

- Good services are hard to find, especially when demand is high. This relates to therapists, continence specialists, disability support workers, support coordinators and plan managers. The only way to find quality services is via a good support coordinator, friends in the same situation or a lucky Google search. Now the NDIS has an up-to-date service provider list, but it still takes a lot of time and luck to find services that meet your needs. I think we need an NDIS 'Urban Spoon' for the disability sector! How else can we find out about exciting new products and services?
- I was able to find some great therapists to write Michael's assessment reports but they became unavailable for different reasons. I can't seem to find energetic, inspirational therapists who can help Michael to reach his goals, so this part of his plan has come to a stand-still.



*Michael and Caroline Livanos*

- In this new climate, services have developed a business-first approach. Many of our meetings have focussed on budgets rather than Michael's needs, which is disheartening.
- I have found that many support workers lack the skills and experience to provide quality care in the home and community. Most are underpaid and many don't have appropriate qualifications. I feel lucky to simply find people who are reliable. It seems like a big leap to ask these support workers to implement therapy activities during their shifts.

### **Complex information**

- I found the information in Michael's plan to be complex, inconsistent and unreflective of everyday terms. For example, 'improved life choices' refers to 'plan management'; 'core supports' usually relates to support workers and the role of plan managers vs. support coordinators is confusing. Headings in Michael's printed plan didn't match the information in the NDIS portal. It took a lot of time to get my head around the language and rules about each section of the plan. I don't know how people with low English literacy manage – especially if they don't have support coordination in their plan.
- Paperwork is still the enemy of participants and their families. That includes the NDIS process, service agreements, therapy assessments and care plans. If only I could include all of Michael's information in one central portal with access provided to services as required.

As the first year of Michael's NDIS plan comes to end, I can say I'm grateful for the reliable respite and continence funding. But I am still a long way off helping Michael to achieve his goals of improved independence, communication and social participation. While I don't have the answers, it's clear to me that we can only achieve positive outcomes for people with intellectual disability and their families if we remove existing barriers to support and start thinking about the big picture.

## LET'S MAKE IT EASIER FOR FAMILIES AND CARERS TO PLAN FOR PEOPLE WITH INTELLECTUAL DISABILITY

### *Improve communications*

The NDIS and all service providers in the disability sector should provide information in plain language, Easy English and different languages as required. People should be able to understand important information and make informed choices.

### *Reduce paperwork where possible*

Families and carers are well and truly over it! We need one central, streamlined record-keeping system.

### *Make it easier to find disability products and services*

Can someone please create a user-friendly 'Urban Spoon' for the disability sector?

### *Let's get back to a person-centred approach*

Avoid focussing on budgets and pricing in therapy meetings.

### *Improve the NDIS planning process*

Understand the user experience and make (lots of) changes to improve the process.

## **Caroline Livanos**

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### **Post Script**

A while ago I was taking Michael for a walk when I was stopped by an older woman who smiled at Michael and told me she has an adult son living in supported accommodation. She said she was unhappy with the way he was treated and wanted him to have better care. She had heard of the NDIS but felt anxious about 'another government program for people with disability.' She spoke broken English, had no car or computer and limited ability to use her phone. She felt hopeless and upset that she could not help her son.

In contrast, this year I met a woman who was visiting from Sweden. She said she had an adult son who had been diagnosed with autism when he was around six years old. As soon as he received the diagnosis, she was inundated with support, financial and otherwise, from the government. This support was not only clearly explained, it was easy to access and use. As a result, years later, her son is living semi-independently and is meaningfully employed. Thanks to this support, she and her husband were also able to work and live a balanced life.

# INCREASING AAC-CESS TO INFORMATION, CHOICE AND CONTROL FOR NDIS PLANNING: A PROJECT IN CO-DESIGN

Jaquie Mills and Laura Jones

## *Abstract*

This paper shares strategies for including adults with complex communication needs (CCN) who have not had access to robust augmentative or alternative communication tools (AAC) until adulthood in NDIS planning. We found that a lack of resources and strategies for this group means they are often excluded from planning processes and that supporters may need to explicitly model and scaffold planning and planning vocabulary for it to be understood. The emotional needs of AAC users in building trust that planning is meaningful and that their plans will be heard and enacted was also found to be critical for engagement.

## *Context*

Inclusion in planning for the National Disability Insurance Scheme (NDIS), or indeed any planning, for adults with complex communication needs (CCN) who have not had access to robust augmentative or alternative communication tools (AAC) until adulthood can be complex. Merger of Minds is a group of adults with CCN lead by ISAAC award winner Eli Dickenson who meet weekly to explore AAC, literacy and the supports needed to engage in adult life. They were the co-design group for Developmental Disability WA's ILC grant project exploring how to include adults with CCN in their NDIS planning process. This group of men have a label of profound intellectual disability and all require 24/7 support. They all have AAC systems but are in the early stages of use and continue to need support to learn increasingly effective and efficient ways to communicate using their AAC systems.

## *Process*

The group met weekly over 3 months to find out which planning concepts, vocabulary and experiences were needed for them to understand NDIS planning. They engaged in the design of a planning process and resources to support this process by trying things out and giving us feedback, engaging in shared reading and writing, and making and following through plans and reflecting on them.

## *Challenges*

Where adults have not had access to robust AAC they generally also have gaps in their education, and most of the men had limited experience of academic education, with one not having been allowed to attend school until age 12. Consequently there was uncertainty about their understanding of concepts and language related to planning. None of the men are living with their parents and for two of the men high staff turnover is a challenge which impacts the quality of their communication support. However, as a peer group of AAC learners they have been meeting for between 3 and 5 years and have a shared

understanding of their innate capacity as a communicators and growing sense of their rights to self-determination. Four of the men involved have microboards, a formalised network of unpaid supporters committed to supporting their self-determination throughout their lives.

## 10 Things About Planning

Ten themes emerged about how we approach planning with this group of people. Overall, it was clear that it is important to emphasise with families and services that planning for a person's life should not be lead by NDIS review dates.

### 1. Don't plan for the NDIS - plan for the person

Genuine person-centred planning means that planning as a concept and practice is part of the AAC learner's regular supports, and that pathways to lay the foundation for, enact and review plans are embedded in daily and weekly support practices. If planning, enacting and reviewing is embedded in this way, when the NDIS review comes around, the role of supporters is to translate the individual's existing, self-determined plans into NDIS goals.

### 2. Model planning

AAC learners need to see others model how they plan and to model using the language of planning that exists in the AAC learner's AAC system. This needs to reflect the natural ways we plan. NDIS planning is necessary, but not what people typically do and our aim is to create natural rather than bureaucratic planning processes in a person's life. We need to mitigate the risk that planning becomes yet another thing we impose upon AAC learners. We asked supporters to explicitly model the natural and random ways they make plans in their own lives so AAC learners could witness and process what planning is.

### 3. Don't plan unless there is capacity to follow through

It was found that many plans are made with AAC learners where they have been asked what they like and want in the past but without following through in ways that showed them a relationship between expressing a desire for something and that thing actually happening. For AAC learners exploring what



*Eli Dickenson - Host of Merger of Minds*

planning is, it was important that there was a timely follow through to make the connection between making a 'plan' and an action happening. Long-term planning was felt to be relatively meaningless at this stage as the time between the plan being made and something happening was too long. When engaging in early planning with this group, plans were made together and on an individual basis which could be followed through, for example a plan to do an activity together, to buy something, or to go somewhere. Where plans are expressed and follow through is not possible, something tangible needs to happen in response, for example putting a photo or drawing on the planning wall for later reference, or deciding a smaller step towards that plan. For planning to work for the AAC learner, trust needs to be built in the process. We are very vulnerable when expressing the desires for ourselves in our own lives, and people need to know and feel they are safe to be able to make and express their plans.

#### **4. Strategies to get a wide range of options on the menu**

This group of AAC learners have significant limitations in the options available for them and are dependent on their communication partners to find ways to expand the range of choices. A range of visual supports were used to do this. For example, planning for a holiday, tourism brochures were used and AAC learners browsed through photos of many different places to visit, places to stay and activities to do. Their supporters cut out any photos they expressed an interest in and made a collage which became the foundation for further planning conversations.

#### **5. Support for decision-making**

Once AAC learners had identified a number of things they had interest in, a modified talking-mat approach was used to help them identify the things they liked, didn't like or wanted more information about. For planning a holiday we made card sets with the ideas the whole group had come up with to expand the options further. Any interest in activities were followed through right away if possible - for example one AAC learner said he'd like to make damper on a holiday, but when asked if he'd like to try it that week he said yes, and he came back to group the following week to show everyone photos of him making damper at home as a result of the plan made in Merger.

#### **6. Support to understand concepts**

There are many visual resources available that explain the NDIS, however resources explaining foundational concepts and language were not found. This group of AAC learners needed support to understand that the NDIS is a funding program, but they didn't necessarily understand what money was, and two of the men had never handled money or handed money over to purchase something. Working with the AAC learners we identified the concepts of money, what the NDIS does, what I can do with the money the NDIS gives me (in practical terms), goals, plans, choices and control all needed explicit opportunities to be learned, understood and used. Consequently the early process included planning to buy things with money and then doing that during the week.

#### **7. Scaffolding planning in AAC systems**

All of the AAC learners use PODD books, and one man has PODD for Compass on his iPad. Using Predictable Chart Writing (PCW) turned out to be a valuable way to start planning conversations. A new pragmatic branch was created for planning and different areas of life in which plans could be made were scaffolded using Categories. Communication partners scanned the different categories asking if there was an area in which the AAC learner would like to make a plan, and then having a conversation about that Category with the person. PCW used 'My plan is about (Category). I want to ... We discovered that the AAC learners had unexpressed plans which would never have been revealed without an explicit

opportunity to talk about planning. For example, one man, Dan, said he had a plan about Transport. He wanted to go for a drive with Joe. Joe is the friend and housemate of another AAC learner who comes to the group, and had not previously hung out with Dan. As a result of doing the PCW, Joe made a time to go for a drive with Dan, and now this is a regular occurrence and a friendship has resulted.

## 8. Adding planning vocabulary to the AAC system

Most of the AAC learners did not have words like 'plan', 'choice' or 'goal' in their AAC systems. In addition to adding this vocabulary we created a specific planning pathway under Activities in PODD which scaffolds planning as something you choose to 'do', 'get' or a place you want to 'go'. Developmentally we feel this is the next step to the Categories based scaffolding mentioned previously. Additionally links to 'with' (person) and 'when' are included. Planning so often focusses on the activities, and not on people and relationships, however who we do an activity with can be more important than the activity itself. Excluding planning for relationships from planning generally contributes to the isolation of AAC learners.

## 9. Embedding planning in weekly schedules

Our conclusion is that unless planning is part of a person's weekly schedule, then it is easily overlooked. It is very difficult for AAC learners, even when supported by committed communication partners, to express plans. Our AAC learners had many plans they wanted to make which their supporters were unaware of prior to this project. The concept of 'planning' as an activity needs to be explicit so AAC learners can let their supporters know they want to make a plan. However this is not enough and we feel that planning should be an innate part of the weekly schedule for AAC learners and properly scaffolded and supported. Follow through on plans made needs to be reviewed and systems need to be in place to honour the plans of AAC learners so they maintain trust in the process of planning and so they can achieve greater self-determination in their lives.

Ideally understanding and practice of planning will happen at school and students who use AAC will be included in their own IEP goal setting process and other curriculum planning using these kinds of strategies. We need to be asking AAC learners if they want to make plans to go somewhere, do something or see somebody regularly.

## 10. Visual resources for understanding planning

We made a number of readers to understand planning and NDIS planning as part of this project. They were helpful for the AAC learners to process planning vocabulary, concepts and processes. They will be available on the Developmental Disability WA website ([ddwa.org.au](http://ddwa.org.au)) from the end of September.



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# THE RELATIONAL NATURE OF PLANNING WITH PEOPLE WITH INTELLECTUAL DISABILITY AND COMPLEX SUPPORT NEEDS

Angela Dew and Leanne Dowse

## Person-centred planning

While it is true that we all make plans, few of us create a formal document to do so, beyond perhaps our last will and testament. In contrast, people with intellectual disability have had their lives and activities documented in written plans for the last 30-40 years since individual service, education and health plans were introduced. Since the 1970s, the term 'person-centred planning' has been widely used in this context based on the work of John and Connie O'Brien in the USA (O'Brien & O'Brien, 2002). The intention of person-centred planning is to create a positive life plan by building on the individual's valued relationships, aspirations and capabilities (Mansell & Beadle-Brown, 2004; O'Brien & O'Brien, 2002). The development of person-centred planning was in reaction to the previous deficit-based focus of traditional planning processes about, rather than with, an individual with intellectual disability (O'Brien & O'Brien, 2002). At its core, person-centred planning is an approach to support the person to explore their goals and make decisions about the services that can help to achieve them (Mansell & Beadle-Brown, 2004).

For people with intellectual disability eligible for the Australian National Disability Insurance Scheme (NDIS), a plan is the basis on which funding is allocated and hence a vital mechanism to ensure people's choice of, and control over, the 'reasonable and necessary' supports and services they require (Walsh & Johnson, 2013). Research we have undertaken at the Intellectual Disability Behaviour Support Program at UNSW, Sydney has highlighted the challenges people with intellectual disability and complex support needs may encounter when engaging in NDIS and other social care planning (Collings, Dew & Dowse, 2018; 2017; 2016; Dowse & Dew, 2016). Conducted over the past three and a half years, our research was undertaken in partnership with people with intellectual disability and complex support needs, family members, practitioners including planners, and inclusive of those from Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander backgrounds.

## Complex support needs

The term 'complex support needs' encompasses the interplay of intellectual, psychosocial, and/or physical health conditions in conjunction with adverse environmental factors, such as, behavioural risks, substance misuse, criminal justice contact, insecure housing, cultural or intergenerational disadvantage, or a history of violence, trauma and abuse (Dowse, Cumming, Strnadová, Lee & Trofimovs, 2014). Typically, complex support needs have both breadth and depth as they may span multiple domains and/or involve high levels of need in one or more areas (Rankin & Regan, 2004). Given the inherent complexity of effectively engaging with people with intellectual disability and complex support needs, our work and that of others has identified the need for more frequent and intense contact between the person and their planner. Also important is the role of those within an individual's informal network

– family and friends - who may help them to identify and articulate the goals they wish to include in their plan. However, the very nature of the complexity inherent in their lives means that not all people with complex support needs have informal network members to assist them in this way. Nonetheless, individuals with complex support needs typically require assistance with the planning process to occur over a longer period of time than may be required by others with less complex support needs (Collings, Dew & Dowse, 2018; O'Connor, 2014; Soldatic, van Toorn, Dowse, & Muir, 2014; Rosengard et al., 2007). These aspects have proven to be challenges for planning in the NDIS in that people with intellectual disability and complex support needs may be further disadvantaged by engaging in a time-constrained and/or impersonal planning process.

## **Relational nature of planning**

A key component of our work is a focus on the relational nature of planning from the perspectives of people with intellectual disability and complex support needs, their family members and the practitioners who work with them (Collings, Dew & Dowse, 2018; 2017; 2016). As highlighted in our work, these relational aspects are the crux of effectively planning with this group: having a consistent, trusted, skilled, knowledgeable, and helpful person to guide and support the person with intellectual disability and complex support needs through planning. In Figure 1 we have illustrated the relational domains of planning identified across the IDBS work in New South Wales with people with disability, family members, practitioners and planners. Nine relational planning domains are identified grouped under three headings: 1. Building rapport involving taking time, listening and being respectful; 2. Connecting at a personal level involving developing trust, showing understanding and being culturally aware; and 3. Having skills involving imparting knowledge, providing choice, and being consistent. As represented by the matrix lines in Figure 1 we see each of these domains as interdependent rather than discrete.

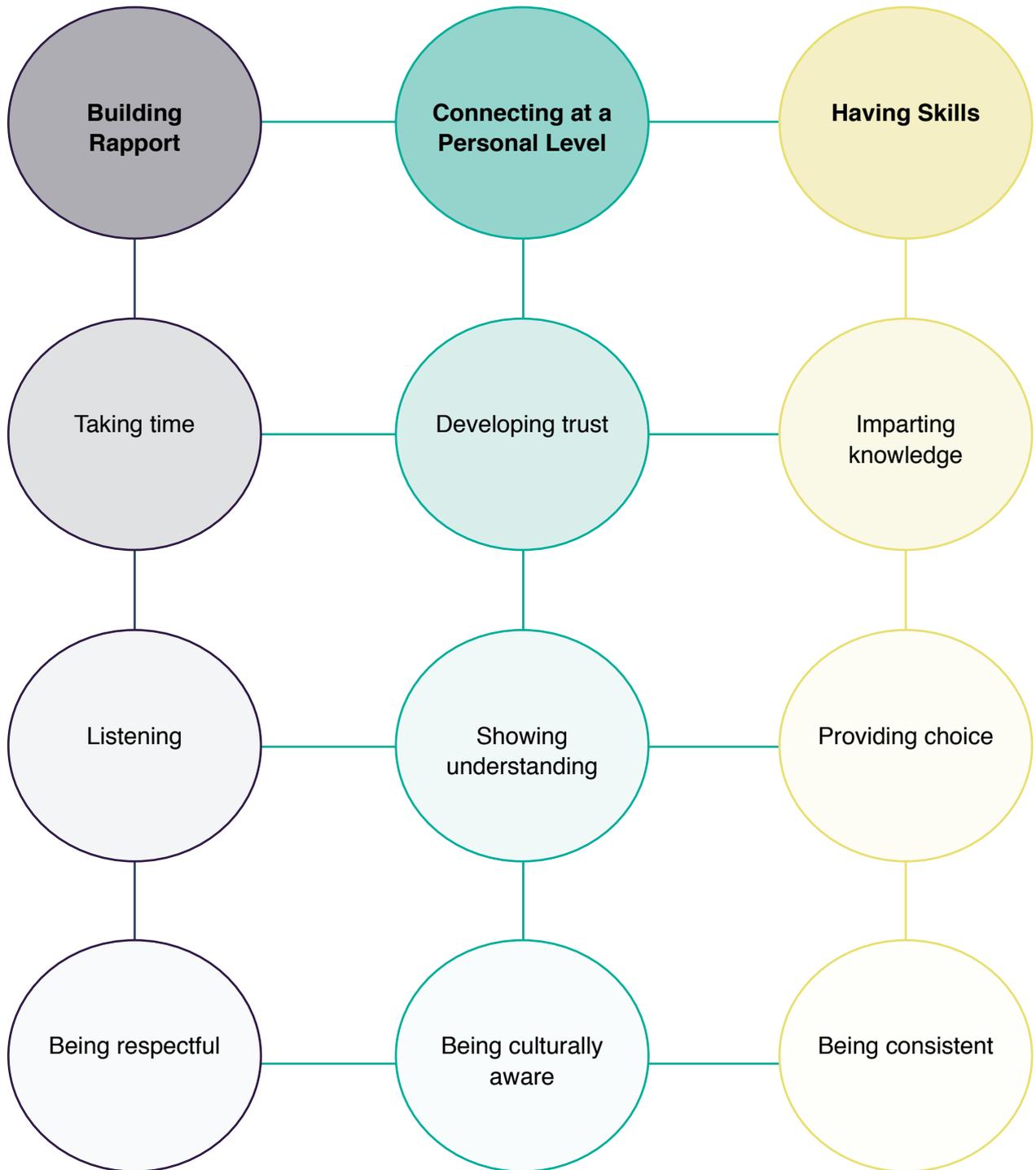
### *Building rapport*

Building rapport between the person with intellectual disability and complex support needs and the planner is an essential relational planning component mentioned by all participants in our work. Building rapport does not happen in one meeting but rather develops over time through multiple interactions during which the planner earns credibility and the pair establishes a working relationship. For people with complex support needs related to disadvantage, discrimination, and marginalisation, building rapport may be inhibited due to past negative experiences with governments, professionals and service providers. Listening is also important and participants with intellectual disability were highly attuned to identifying planners who really listen as opposed to those who come into the meeting with preconceived notions of what the plan would contain. A planner's ability to build rapport and really listen are indications of the level of respect shown by the planner towards the person. Feeling respected was particularly highlighted by Aboriginal and Torres Strait Islander community members with disability and their carers and is linked to planner's understanding the impact of colonisation and displaying a non-judgemental attitude about people's lives and life choices.

### *Connecting at a personal level*

Connecting at a personal level may seem obvious; however, participants told us that this is often overlooked within a planning context where the focus is on identifying and recording the person with disability's needs. Connecting at a personal level includes the development of trust between the person and planner so that the person feels comfortable discussing with the planner private and perhaps intimate aspects of their lives around which they wish to make plans. Sharing a lived experience of disability either personally or by having a family member with disability was identified by people with disability as aiding this personal connection. A participant described this as "they need to be able to have

Figure 1 Relational Domains of Planning



walked in our shoes” (Collings, Dew & Dowse, 2017, p. 8). Rapport and trust are closely aligned with the planner’s understanding of the person and his/her goals. For participants from CALD and Aboriginal and Torres Strait Islander backgrounds, planner’s cultural awareness is a fundamental aspect of demonstrating connection as imposing dominant cultural values and expectations on people from CALD or Indigenous backgrounds was viewed as both insensitive and perpetuating a dominant culture paradigm.

### *Having skills*

Having skills to work effectively with people with disability was also identified by all participants and reflected a sense of frustration on the part of some that not all planners had knowledge about disability and about relevant, available supports and services. Skilled service providers, many of whom worked with individuals over a long period of time, reported being excluded from the planning process. While some understood this was an attempt to focus planning on the person and remove perceived coercion for the person to continue using their service, they also felt their exclusion, particularly for some people with complex support needs, meant the person was unsupported in planning meetings without family, or service provider involvement. Planner knowledge is also linked to the ability to present and discuss choices with people with disability. A lack of knowledge on the part of planners was perceived as limiting choice for the person as discussions may only occur around known supports and services without consideration of other, less well known, options. Being consistent relates to people’s preference for engaging with the same planner over time so that subsequent planning encounters build upon, rather than have to initiate, the relationship between person and planner.

### **Summary**

Our body of work around planning with people with intellectual disability and complex support needs reinforces the importance of the relational nature of planning as fundamental to ensuring good outcomes for this group who are often excluded or exclude themselves from supports and services due to past poor experiences. Taking the time and having the skills necessary to build rapport and connect personally has been identified as essential to maximising the planning process so that the outcome is a positive life plan that encapsulates the person’s goals and aspirations. Practitioner, person with disability and Aboriginal and Torres Strait Islander specific planning resources developed by the IDBS team can be downloaded for free from: <https://www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/resources/>



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# BOARD MEMBER PROFILES

## Meet Morrie O'Connor

Morrie O'Connor born in Republic of Ireland, came to Australia when two. Lived most of his life in Queensland both North and South. Became involved in anti-freeway protest at University and when graduated involved in a range of local resident and tenant action groups. Later involved in developing a range of community organisations, community centres, housing and worker co-operatives. Began working for an intellectual disability organisation in 1990. Have used my learnings from my earlier work to support people with an intellectual disability form their own People's Organisations to address issues such as housing, employment, bullying and exploitation.

Married with four children. Enjoy the water and remote places.

## Meet Deborah Espiner

Deborah Espiner is a long standing member of ASID and is currently the Chair of the Aotearoa New Zealand Division. She is a Senior Lecturer in the School of Counselling, Human Services and Social Work, Faculty of Education, University of Auckland in papers that have a focus on disability studies, community inclusion and community leadership. Debbie has worked as a teacher, as an Adviser to the Education Board and has been involved in many Ministry of Education contracts that have focused on developing a more inclusive education system within New Zealand. The disability sector in New Zealand, like many other countries, is undergoing rapid change and evolving as choice and control is increasingly moving to people with the lived experience and their families. Debbie's research and interests lie in developing individualised and facilitated approaches that capture the 'voice' of the young person or adult in ways that are engaging, accessible and supportive of personal aspirations. She is Chair of two community organisations, that recognise the generosity that exists within society and the importance of relationship building between community members.





# DIVISION REPORT

SEPTEMBER 2018

## **New South Wales/Australian Capital Territory**

**Professor Tom Shakespeare**, of the University of East Anglia (UK) was in Sydney recently as part of his work with the Centre of Research Excellence in Disability and Health, UNSW and the University of Sydney. NSW/ACT Division Committee member, Bernadette Curryer attended two of his talks and the following is a brief outline.

11th July, University of Sydney:

### **What does it take to achieve choice & control for people with disabilities?**

(Available as a podcast: [www.credh.org.au](http://www.credh.org.au), co-presenter Sue Salthouse)

Tom started his presentation with a brief outline of the history of denial of choice and social participation for people with disability, based on what can be viewed as paternalistic control by families, services and institutions. He recognised the achievements of the disability movement as it pushed to have the voices of people with disability heard, to have increased participation, choice and control based on human rights. He noted that attaining choice and control requires respect for the dignity of people with disability and transference of power to that individual. However, he also recognised that support to make choices may be required, including for some an interpretation of their will and preference. Therefore safe guarding to prevent abuse, neglect and exploitation remains important.

Tom also identified barriers to choice and control. One of the main ones being excess bureaucracy, when what is required is a system with a light touch which provides parameters but not control. Other barriers noted included rationing of funding, limited options and difficulty recruiting suitable staff. People in rural areas were particularly likely to experience such barriers.

He then questioned where the collective voice of people with disability has gone? Proposing that with the introduction of individualized funding, there is a danger that the collective voice will disappear.

13th July, presentation to the University of Sydney's Disability Research Student Group (DRSG):

### **Does the social model of disability theory fail us?**

Tom spoke of the multifactorial aspect of disability, using the analogy 'one aquarium, many windows'. He noted that impairment occurs on a continuum and this needs to be acknowledged. While there is a social impact of impairment that results in disability, the difference in mind and/or body also needs to be recognised, together with other factors such as gender, race and socio-economic status.

Tom then challenged people to go beyond identity politics, encouraging the 'equality of the individual', believing that people need to be recognized as equal yet different. He does not believe impairment

should define a person, and warns that if one's identity is closely linked to a disability, then this can result in that person not being viewed as an individual.

The above report is Bernadette's perception of Tom's message, and she recognizes that other people may have taken different meanings from his words. Although his presentations were not specifically about intellectual disability, many of his messages are very pertinent to this group. In particular his reference to the support for choice needing to be in response to the will and preference of the person with disability is particularly important for people with intellectual disability who may find it difficult to express their views. (This issue is discussed at length in the recent ASID Victoria podcast with Dr Jo Watson <http://www.asid.asn.au/publications/podcasts>. Issues with individualized funding, including excess bureaucracy and lack of options, is of interest to all people with disability. However, this is particularly so for people with intellectual disability and complex needs who are possibly at most danger of not being able to navigate the system. How to maintain the collective voice of people with intellectual disability, seen in organisations such as Self Advocacy Sydney and NSW CID, within a system that is primarily focused on the needs and goals of the individual also requires consideration.

Although not everyone may fully agree with Tom's views, it cannot be denied that he is an extremely interesting and engaging speaker who constantly challenges views regarding disability.

### **Bernadette Curryer**

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## **Queensland**

*'People with intellectual disability: How to promote good physical and mental health and healthcare' presented by Professor Nick Lennox.*



*Nick Lennox*

There was a large attendance at this workshop held on 4th June 2018 in Brisbane. Professor Nick Lennox is the former Director of QCIDD and has 25 years' experience offering health care to adults with intellectual disability, their families and supporters.

Professor Nicholas Lennox was the Foundation Director and now honorary Professor at the Queensland Centre for Intellectual & Developmental Disability (QCIDD). During his 20 years as Director, he has taken the centre from a small unit to a thriving and productive centre which has led the world in innovation in the health care of adults with intellectual disability.

Originally trained as a general practitioner with time in post graduate psychiatric training, he has twenty five years' experience providing healthcare to, and education about adults with intellectual disability and autism. He has also lead world first innovations in education and applied research, which has changed healthcare delivery across the globe. These innovations include: the development of the Comprehensive Health Assessment Program (CHAP) and very successful UQx, Able X web accessible education series of MOOCs

on health and intellectual disability (with over 14,000 enrolments globally - See <https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x-1>) His contribution was recognised by his peers in 2016 when he was made a Fellow and awarded the 2016 Distinguished Research Award of IASSID. He feels passionately about improving the health and health care of people with intellectual disability especially when this is driven by empowering adults with a disability, their families and supporters, and healthcare providers.

He has been part of developing many innovations to improve and assist advocacy to improve the physical and mental health, and healthcare of adults with intellectual disability. During the workshop he discussed strategies which make real difference on-the-ground, drawing on his understanding and experience of providing support adults with intellectual disability, their families and supporters, and their health care providers.

The evidence indicates that people with intellectual disabilities have lower life expectancy and greater frequency of unmet health needs than the general population. Nick highlighted the challenges for people with intellectual disabilities to recognise, and explain their physical health issues to others and the importance of carers/support workers or GPs being alert to some of those issues. For instance people with challenging behaviour are likely to have physiological causes such as dental, musculoskeletal and gut related issues. Other health areas discussed included that approx. 50% of people with intellectual disabilities have hearing or visual impairments; and about 16-40% of people with intellectual disability have a mental health diagnosis, half of which generally go unrecognised. He told several stories about particular experiences of patients which helped to put some of the workshop material into context for the attendees.

Nick discussed the issue of people needing medication and the issue of side effects. Also some strategies/resources support workers can use to record health information about clients, and also about how to present them to the GP; and questions carers/support workers can ask GPs as well. Nick discussed some of the work QCIDD has done around resourcing carers/support workers around accessing the health system, such as developing the Comprehensive Health Assessment Program (CHAP) tool, which can be accessed at <https://qcidd.centre.uq.edu.au/resources/chap>; and also the Able X series where they have developed online courses available for support workers to improve their knowledge around physical and mental health for people with intellectual disability. See <https://www.edx.org/xseries/intellectual-disability-healthcare#courses>.

Thank you to Nick for his contribution to ASID Qld's efforts to improve knowledge and practice around supporting people with intellectual disability to access health care systems in Australia; and also assisting this fundraising and lead-up event for the ASID National Conference Gold Coast, being held on the 14th – 16th November 2018. All profits will go towards assisting self-advocates to attend the National Conference. See the link to find out more - [www.asid.asn.au/conferences/asid-2018-conference-lets-shake-it-up-human-rights-for-everyone](http://www.asid.asn.au/conferences/asid-2018-conference-lets-shake-it-up-human-rights-for-everyone).

## **Aotearoa, New Zealand**

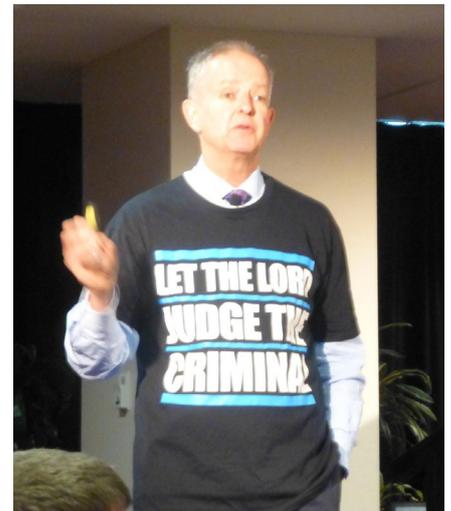
The highlight of 2018 has no doubt been the very successful “Responding to the call: Building partnerships that enrich lives” conference held at Rydges Hotel in Wellington from July 1-3 2018. Co-convenors Sharon Brandford and Jonathan Goodwin in partnership with conference organiser,

Paardekoopers did a wonderful job in planning and organising the conference. Interest in the conference was so great that registrations had to close at 160 participants. The conference attracted presenters and participants from New Zealand and Australia and participants were rewarded with an experience that challenged, affirmed and pointed to new directions for those interested in learning from quality research in the field of intellectual disability. The atmosphere was friendly and inclusive and a team of volunteers from People First did an excellent job in directing people to venues, acting as timekeepers and in some instances as chair people. Delegates were thrilled to listen to an inspiring version of Alleluia sung by South Wellington Intermediate school's kapa haka group as part of the Mihi. Debbie Espiner, Aotearoa NZ ASID Chairperson welcomed delegates and reminded them of the importance of being responsive and developing partnerships in a time of change and uncertainty. The four keynote speakers challenged and inspired the delegates with both the quality of the content and the delivery of their keynote addresses. The programme included three workshops and 38 presentations on a wide range of conference themes.

Dr Sarah Leitch from BILD in the United Kingdom (UK) gave the opening keynote and provided an overview of Positive Behaviour Support (PBS). Sarah presented UK data on the challenges of implementing PBS and described strategies for ensuring quality delivery and sustainability of PBS through applying practice leadership using coaching. Sarah also provided information on BILD's partnership with Explore in New Zealand. She described an evaluation model that measures the effectiveness of PBS programmes for both individuals and organisations. A number of papers during the conference further elaborated on how PBS has been implemented in New Zealand in partnership with BILD.

On the Monday afternoon, Dr Sheridan Forster from Australia gave a powerful presentation on the work that she is doing to build partnerships when interacting with people with profound intellectual and multiple disabilities. Dr Forster was able to draw on research, clinical practice and her own experience of sitting down with the person and thinking "how do I need to be in order to be with you?". She was able to illustrate her presentation with videos that provided important clues as to how to work with people with profound and multiple disabilities in a way that builds respectful and enriching partnerships.

Judge Andrew Becroft opened Day Two of the conference with a powerful call to New Zealanders to do something different to address the high rates of criminalising and imprisonment that occurs for young people with neurodevelopmental disorders. Justice Becroft presented sobering statistics showing the much higher prevalence rates of these disorders among young people within the New Zealand prison system compared to the general population. He



*Judge Andrew Becroft*



*Martyn Mathews*



*Sheridan Forster*

argued that society needs to respond differently as what is currently happening is not working. Justice Becroft suggested the current approach is very ineffective as young people with neurodevelopmental disorders do not understand the consequences of their actions and end up being further damaged in the criminal justice system with its focus on punishment and containment. He pointed out that young Maori are represented disproportionately within the prison system and in the poverty statistics. Judge Becroft advocated possible solutions including the need for more comprehensive research, improved diagnosis, more prevalence studies, better pathways and support and an urgent need to listen to the voice of young people. He concluded with the challenge to all of us “ If I cannot do great things, I can do small things in a great way” (Rev. Dr Martin Luther King).

Dr Martyn Mathews’s presentation concluded the conference with a thought- provoking examination of the clash between science and values which recent research into autism has precipitated. In order to explore this clash Mathew contrasted New Zealand research findings on mental health and people with autism and neurological research with the strong values and human rights principles on which Disability support services in New Zealand are based. Mathew raised important questions relating to community inclusion, the use of positive behaviour support for mental health problems and the reliance on psychotropic medications. Mathew presented a model of support for people with autism and severe intellectual disabilities which “ put it all together” and incorporated strategies from neuroscience, positive behaviour support, positive psychology and psychiatry. These strategies included reactive strategies that shift cognitive focus and reduce fear, skill development of activities to increase communication, having fun, activities aimed to help people flourish and active medication reduction.

The keynote presentations from the conference are available on the ASID website.

<https://www.asid.asn.au/conferences/asid-nz-2018-conference>

### Frances Hartnett

Secretary Aotearoa, New Zealand Division

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### Victoria

ASID Victoria in partnership with Deakin University presented a successful workshop on “Decision making Support for People rarely heard” on Tuesday 19th June 2018. The event attracted a good cross section of participants in the disability sector of students, parents and practitioners. The workshop aimed to bring research to practice with Jo Watson demonstrating how to facilitate effective communication and understanding of the preferences and choices of people who live with a severe intellectual disability. Assisting Jo at this workshop was Gloria Jelleff who is the carer of Michael who has an intellectual disability and limited verbal communication. They contributed their lived experiences of supporting Michael to express his choices and helping other people to understand him.

See [page 44](#) for a full report of the workshop



*Jo & Jane - On Richards Side*

ASID Victoria is very excited to announce the launch of Season 2 of



*On Richards Side*



*Leith Condon - On Richards Side*

the ASID podcast series. With the support of the national ASID board, we have upgraded the production quality of the ASID podcasts and placed them on a web platform enabling them to be accessed by a wider audience. The first episode for Season Two was a podcast presentation of Jo's workshop on Decision making support. The attendees at the workshop were sent the link for this podcast. The podcast link is <http://www.asid.asn.au/publications/podcasts>

We would encourage those who listen to the podcast to provide us with feedback about the podcasts. Production is currently underway for the second episode which is a presentation of "Promoting political participation for people living with an intellectual disability". Thank you to ASID Vic committee members, Sophia Tipping, Hilary Johnson and Jo Watson for producing these podcasts.

ASID Victoria in association with Deakin University presented the screening of "On Richard's Side" followed by discussion with the film's director, Leith Condon. The event was held on Thursday 9th August on the lovely Mornington Peninsula. This event focused on the lived experience of being a parent and carer of a young adult living with a severe intellectual disability.

The ASID Victoria committee would like to acknowledge the outstanding contribution of committee member Jo Watson for putting these workshops together.

Our next focus is on the ASID Victoria AGM in October where we hope to have speakers talking about their research projects on client outcomes. Look forward to seeing you there.

### **Coral Farr**

■ [VICchair@asid.asn.au](mailto:VICchair@asid.asn.au)

## South Australia

On the 11th April over 20 people participated in a dinner and local event:

### ***The term Intellectual Disability does it help or hinder those who live with intellectual disability?***

In the lead up to the event ASID SA met with the Self Advocacy Group, Our Voice SA, to ascertain their thoughts on the term Intellectual Disability. Although we expected the Our Voice members to not like the term intellectual disability we were shocked by the intensity of their feelings. There is no doubt that they had each experienced discrimination and bullying as a result of the label of intellectual disability. The Our Voice members wanted very much to be part of a whole disability group and the intensity of their feelings was confronting.

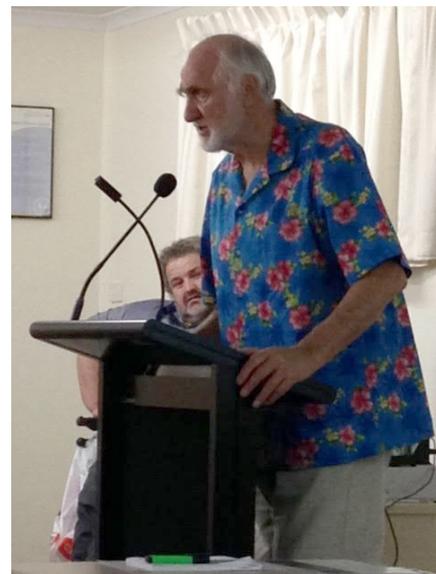
The event included an introduction to the topic of **Addressing the Shortcomings of Dedifferentiation** with Professor Christine Bigby kindly providing us with a video clip of a short discussion on the topic. This assisted in stimulating debate and discussion.

Professor Richard Bruggemann is a member of the NDIS Intellectual Disability Reference Group and he provided us with an update from the group and the work they are undertaking. Richard felt strongly that the NDIS is listening to the reference group. This discussion fitted very well with the topic as it highlighted how dedifferentiation had worked against those living with an intellectual disability.

ASID SA would like to congratulate Our Voice SA who were successful in securing an ILC grant for a two-year project focusing on Information and linkages for South Australians living with intellectual disability. Funding will be directed towards employing a project officer, developing co-designed information resources and distributing information via Our Voice meetings, community venues, and service providers. ASID SA have been approached to be part of the reference group for the project.

### **Denice Wharldall**

 [dwharldall@homeplace.com.au](mailto:dwharldall@homeplace.com.au)



*Professor Richard Bruggemann,  
Senior Practitioner*



## Tasmania

ASID Tasmania hosted Professor Christine Bigby on Monday 30th April in Hobart to present her workshop entitled “Is there such a thing as a good group home”?

Professor Christine Bigby from La Trobe University, Living with Disability Research Centre focussed on presenting the latest research related to group homes, the impact of the culture in group homes and the role of local leadership, taking off rose coloured glasses and the alternatives to group homes. It was also a great opportunity for attendees to network with peers.

The workshop was attended by 25 people across several non-government organisations and some staff from the government sector also attended.

It was a very informative and thought provoking workshop that had many attendees questioning current practices and keen to discuss ways in which the information presented could be implemented in their own organisations.





# ASID 2018 QUEENSLAND

## Let's shake it up: Human Rights for everyone

We invite everyone to attend the 2018 National Australasian Society for Intellectual Disability Conference to be held at the Gold Coast Convention Centre, 14 – 16 November 2018. The title of the conference is **'Let's Shake It Up: Human Rights for Everyone'**. The title has been chosen by a group of self-advocates who came together for the purpose of talking about the key issues that affect their lives. These issues include bullying and abuse, dual disability, NDIS, and employment. The conference looks to attract a diverse range of people including self-advocates, families, academics, service providers, policy makers. ASID welcomes and encourages this diversity.

Currently the QLD Division is supporting a group of local self-advocates to plan on the involvement of self-advocates in the conference. The Conference will also welcome a range of international speakers (see below) who have expertise across a wide range of issues impacting on people with an intellectual disability.

When thinking about the theme of the conference the self-advocate group identified that in Australasia people with an intellectual disability are still pushed around and this has to end.

### Paul O'Dea

Paul O'Dea has been leading change and self-advocating since the mid 1990's with a keen interest in helping others with intellectual disability around important issues like housing, bullying, roles in the governance of organisations and more recently the NDIS. Paul has been part of Community Living Association for twenty years and been involved in various allied groups including Independent Youth Housing Group, shaking things up to ensure the rights of people with disability. He is now Treasurer of both CLA and IYHG, and is also the first person with intellectual disability on the National Board of Australasian Society for Intellectual Disability (ASID). Paul has worked with HELP enterprises for the last 16 years.



# 2018 Conference Speakers



## Ann Fudge Schormans

Associate Professor in the School of Social Work at McMaster University (Ontario, Canada)

■ fschorm@mcmaster.ca

I am not sure I know what led to my involvement with people with intellectual disabilities. I have been the parent of two (wonderful) daughters with intellectual disabilities, and while this has led some to think becoming a parent was the impetus, I met my daughters (both adopted) through my work. Although there was no single moment or event, after obtaining an undergraduate degree, I began looking for work in this area. This was in the mid 1980's and, in Canada, de-institutionalization had taken hold. I accepted a job with an agency that was moving people from large-scale institutions into smaller community-based group homes – exciting but also difficult work as we learned what being institutionalized included. After several years of working in the community living sector, I moved into child welfare/protection, working with children and youth with intellectual disabilities. It was eye-opening (to say the least) to learn that, despite de-institutionalization, so many children and youth with disabilities were growing up in other forms of institutionalized 'care'. Both of these experiences spurred my involvement in emerging (self)advocacy efforts. After completing my Ph.D. and starting work at McMaster University, I became more involved in participatory and collaborative research with people with intellectual disabilities.

Each step has brought its own challenges and highlights, meeting my daughters being the most significant. A recent highlight has been the opportunity to work with a group of adults with intellectual disabilities (members of a research project on living in the city with a disability) to make a documentary. With assistance from an artist facilitator, film director and crew, they determined the important messages they felt non-disabled others should now about what it means to live in the city with a disability, the challenges they face, how they make a life for themselves, and what they believe needs to change. This was a collaboration – everyone involved brought their own skills and knowledge to the making of the film, however, the adults with disabilities were very much in charge and had full editorial control over the final documentary. For similar reasons, working with different groups of self-advocates in two other projects (one on re-imagining parenting possibilities, the second on experiences of homelessness) to create forum theatre scenes that we then show to numerous academic, professional, and community-based audiences has been a highlight. Seeing the multiple ways that audiences are impacted by both the work and their conversations with the self-advocates, has been particularly powerful. It can be challenging to know how one's work is taken up by others, and how it may affect how people live, work, and engage with people with disabilities. I do know that my work is used in post-secondary

programs, to prepare social workers and others who will be working with people with disabilities in different capacities. I (along with others) have been quite active at the university where I work to bring greater attention to disability, access, and rights for disabled students and, while there is still much work to do, change is happening. Students consistently report that the disability course I teach disrupts what they thought they knew about 'disability'. The documentary has been screened at international film festivals and academic conferences; been part of a curated exhibit on accessible cities; adopted as a curriculum material for secondary students in a large Canadian city; and is being used in a number of post-secondary courses. It is also starting to be used in service organizations, to make staff aware of the importance of attending to engagement in one's community as part of person-centred planning.

In my keynote presentation, I will be sharing my thoughts, experiences and learning about the use of the arts when engaging with people with intellectual disabilities in collaborative research. While it has much to offer, one must tread carefully as well. I hope that by pointing to the benefits and tensions of such, as well as thinking through audience responses, we can consider too the implications and questions that get raised for inclusion and collaboration more broadly. I will also be conducting a workshop, with the assistance of people with intellectual disabilities and others who support them. While this workshop will address similar questions and concerns, the interactive nature of forum theatre affords attendees a different way to experience and thus consider the use of the arts in collaborative work with people with intellectual disabilities.



## Angela Dew

Senior Research Fellow  
Intellectual Disability Behaviour Support Program  
UNSW, Sydney

<https://www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/>

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Next year I'll have been working in the Australian disability sector for 38 years. I arrived from New Zealand in 1980 with an undergraduate degree in Sociology and my father's words ringing in my ears: "What job are you going to get with that?" My first 'proper' job in Australia was as a Field Officer with the Royal Blind Society in Sydney. The grounding I received there has underpinned my subsequent work. By way of induction, I spent two weeks wearing a blindfold while engaging in high risk activities such as navigating the escalators at Burwood shopping centre, chopping up fruit and vegetables, and operating a talking book machine (the latest technology in those days!) A naïve 20 something, I took these experiences with me as I visited people in their homes to give them advice and equipment to help them adjust to life with restricted vision. Subsequent jobs brought me into the intellectual disability field at a time of enormous change with deinstitutionalisation and normalisation revolutionising the disability landscape. It was an incredibly exciting time to be working in the sector. After two decades as a practitioner and service manager, I returned to study completing a Masters in 2005 and a PhD in 2011.

The highlights of my career have undoubtedly been the people I have worked with – people with disability, family members and colleagues. One highlight was helping arrange the wedding of a couple who moved out of Marsden Rehabilitation Centre into a group home in the late 1980s. Their wedding was a joyous occasion, but it also challenged the thinking of many who questioned their right to 'tie the knot'. Another highlight was completing my PhD aged in my early 50s. My PhD identified the importance of reciprocity in adult sibling relationships where one sibling had cerebral palsy and I met the most amazing brothers and sisters. Given that most of the sibling literature was focussed on the burden of having a sibling with disability, I was proud to contribute the viewpoint of participants with and without cerebral palsy who spoke about their shared, life-long relationship as providing each of them with strengths, values and skills beyond those typically identified. Further highlights were the experiences I had conducting research in rural and remote areas of NSW and Central Australia including with Aboriginal communities. Throughout the four years I was project manager for the intriguingly named 'Wobbly Hub and Double Spokes' project at the Faculty of Health Sciences, University of Sydney, I went to places I'd never visited before and met the most inspiring people who demonstrated the celebrated Australian bush resilience and humour despite significant challenges accessing services those in the city take for granted. More recently, I have expanded my research repertoire by introducing arts-based methods which enable the participation of people for whom traditional research approaches may be difficult. Along the way, I have been very fortunate to work with, and be mentored by, some of Australia's top disability academics and, in turn, I have mentored colleagues and supervised excellent students.

My early career as a practitioner - and inheriting my practical father's genes - means my research is focussed on changing practice. The Wobbly Hub work resulted in a model of rural and remote therapy service delivery adopted by the then Western NSW Department of Family and Community Services to fund a range of projects within NGOs to increase access to therapy for children with disability 0-8 years in rural and remote locations. This project highlighted the benefits of funders 'thinking outside the box' to address geographic challenges. In my current position at the Intellectual Disability Behaviour Support (IDBS) Program at UNSW, Sydney, I instigated an action research approach that involved people with disability, family members and service providers in the development of a range of practice guides spanning planning, behaviour support, case reviews and use of psychotropic medications. A number of these guides are being used in training the disability workforce in Australia and other parts of the world.

A specific focus of the IDBS program is people with disability and complex support needs particularly those who engage with multiple service sectors such as child protection, criminal justice, and drug and alcohol. This is one area where change is needed to ensure that people are not further marginalised through exclusion from the National Disability Insurance Scheme.

In 2014, I completed a Knowledge Translation (KT) Professional Certificate at the University of Toronto, Canada. This course, and an ongoing collaboration with Professor Katherine Boydell a Canadian leader in the KT field, provided me with skills to ensure that translation of research into practice underpins my research approach. Identification of and engagement with key stakeholders throughout the research process is essential to ensuring outcomes are useful to, and used by, practitioners. Distilling research outcomes to focus on main messages and presenting them in accessible formats is also key to ensuring uptake. Finally, research should be disseminated through a variety of platforms and modalities to reach the broadest audiences. Oh, another great strategy is to come up with an intriguing and catchy research title!

# ASID EVENTS COMMITTEE

ASID Board recognises the importance of events. This reflects our commitment to forge interaction between intellectual disability research, policy and practice.

Our Events Committee meets every month by teleconference. On behalf of the Board, we

- Develop guides and branding and oversee the implementation of procedures
- Help set Board agenda for event themes and facilitate the agenda of events
- Develop and oversee appointment of ASID Event Management
- Ensure ASID events promote and demonstrate inclusion of persons with lived experience of intellectual disability
- Develop a policy and template for Divisional event budgets.

As you can see, our role is not to run events for ASID, but to build a stronger infrastructure so that quality events can occur across our Divisions and Australasian.

## Who are we?

**Sharon Brandford**, NZ Director (Chair Events Committee)

**Christine Bigby**, Victoria Director

**Angus Buchanan**, West Australia Director

**Ruth Firstbrook**, South Australia Director

**Darryleen Wiggins**, Tasmania member (seconded)

**Morrie O'Connor**, Queensland Director and 2018 Conference Convenor

Convenors 2019 Conference (Denyse Wharldell and Ian Pearce, South Australia)

### 1. *The future of Conferences*

We recognise events are important to us all for different reasons. This year the Board has reviewed what it seeks from Conferences and divisional events. We welcome ideas and contributions from across divisions. Tell us what works best for you as our sectors undergo significant changes.

### 2. *Long term Conference organiser*

We are very pleased this year to have secured a long term Conference organising company to provide continuity over three years, as the conference location moves around the regions of Australia and NZ. We have had great support for the past couple of years from Leishman Associates. In Adelaide 2019, you will get to meet our new partners in conference organisation, Conference Design. Planning for 2019 conference in Adelaide is already underway. We always welcome enthusiastic members with skills to assist planning the event.



# THE ASID JOURNALS

## Professor Angus Buchanan

Chair of the ASID Journals committee and Head of School  
School of Occupational Therapy, Social Work and Speech Pathology  
Faculty of Health Sciences, Curtin University, WA

■ [vicepresident@asid.asn.au](mailto:vicepresident@asid.asn.au)

ASID members can very proud of the organisations long history of publishing quality research. One of the objectives of ASID is to forge interaction between intellectual disability research, policy and practice. One of the ways that ASID achieves this aim is through the publication of research. ASID owns and in partnership with Taylor and Francis publishes two scholarly peer reviewed journals.

**The Journal of Intellectual and Developmental Disability** has been published since 1970 with a number of title changes over its history - Australia and New Zealand Journal of Developmental Disabilities (1982 - 1995), Australian Journal of Developmental Disabilities (1980 - 1981) and Australian Journal of Mental Retardation (1970 - 1979). The Journal is published 4 times a year and each member received a hard copy and can access content electronically via the ASID Website membership portal. The purpose of the journal “is to publish substantive original research from both established and newer academic disciplines (such as sociology and geography) that address the situation and concerns of people with intellectual disabilities, and their families and staff. It accepts research into commonly associated developmental and neurodevelopmental disabilities only when these are in conjunction with intellectual disability. JIDD welcomes qualitative, quantitative and mixed method research; formal literature reviews; well-structured case studies, and theoretically-informed commentaries. It also reviews highly specialist books that are unlikely to be reviewed in other ID journals.” (Taylor and Francis, 2018)

**Research and Practice in Intellectual and Developmental Disabilities** was launched in 2014 and is published twice per year. Members also receive a hard copy of RAPIDD and have access to the content of the journal electronically via the ASID Web Site membership portal. The “primary aim of RAPIDD is to draw out the implications of research for practice and policy, the journal also aims to generate informed debate on contemporary issues that matter to the lives of people with intellectual disabilities and their families.” (Bigby, 2014. P1).

Each Journal has an honorary editor and editorial board. Professor Jennifer Clegg is the editor for JIDD and Professor Chris Bigby for RAPIDD. Chris and Jennifer are very happy to speak with prospective authors.

Each year the Publisher provides the ASID Board with a comprehensive report describing the performance of each Journal. It is pleasing to see that the Journals are both continuing to show signs of growth and success. In 2017 there were 56,990 article down loads for JIDD, a 21% increase on 2016. Sixty five percent of the downloads are from international sources and the Journal is being accessed by 21,000 library's. JIDD, being an established journal has an impact factor which is a measure of citations coming from the Journal. The journal impact factor has slightly increased to 1.176 which is respectable for this subject matter. RAPIDD will most likely achieve an impact factor in 2018. For such a new journal and only two publications/year the downs loads are very positive 8,450 for 2017, a slight increase

on 2016. Given the context of the Journal it is not surprising that 63% of the downloads come from Australasia.

One of the newer measures being reported by the Publishers is Altmetrics. An Altmetric score is a high-level measure of the quality and quantity of online attention that an individual article has received. The score is based on relevant mentions from social media sites, newspapers, policy documents, blogs, Wikipedia, and many other sources.

Interested in publishing in the ASID Journals? Have a look at the respective websites for each journal that provide author instructions. Also if you are going to the Conference on the Gold Coast take the opportunity to participate in the Journal Workshop and speak to the publishers.

The following are the top down loaded articles in 2017 for each Journal. You can access these via the ASID Website if you are a member.

<b>Journal of Intellectual and Development Disability</b>	<i>No. of downloads</i>
K Ilias, JHJ Liaw, K Cornish, M Sang-Ah Park, KJ Golden. (2017) Wellbeing of mothers of children with “A-U-T-I-S-M” in Malaysia: An interpretative phenomenological analysis study. 42(1)	1595
S Collings, A Dew, L Dowse. (2017). Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. 41(3)	936
C Bigby, E Bould, J Beadle-Brown. (2017). Conundrums of supported living: The experiences of people with intellectual disability. 42(4)	890
<b>Research and Practice in Intellectual and Developmental Disabilities</b>	
MH Mehling, MJ Tassé, R Root. (2017) Shakespeare and autism: an exploratory evaluation of the Hunter Heartbeat Method. 4(2).	730
K Soldatic, G van Toorn, L Dowse, K Muir. (2017). Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme. 1(1).	610
J Clegg, C Bigby. (2017). Debates about dedifferentiation: twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group 12. 4(1).	483

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Christine Bigby (2014) Editorial, Research and Practice in Intellectual and Developmental Disabilities, 1:1, 1-5, DOI: 10.1080/23297018.2014.924613

Taylor and Francis (2018). Journal of Intellectual and Developmental Disability <https://www.tandfonline.com/loi/cjid20>

# INCLUSIVE RESEARCHERS COLUMN

## No Research About Us Without Us

Suzie Jessup & The Inclusive Research Network

In one of our last articles we promised to share our thoughts about our code of research practice that we use as a standard to make sure that the voice of people with intellectual disability is heard.

### The history of our code of practice:

In 2012 the Centre for Disability Studies held an inclusive research conference in the Sydney University Law School with Disability Rights Activist Susan Salthouse as a special guest speaker along with Sally French, also an activist and social model theorist from the United Kingdom.

Suzie Jessup is one of the founding members of the Inclusive Research Network. She has been involved in inclusive research since 2010. She remembers many international and interstate guests who came to the conference.

During this conference, the convening group wrote a code of practice about making research inclusive as a guide for the presenters. The CDS Inclusive Research Network has now worked on this code putting it into Easy English. You might want to think about whether your organization would like to adopt a code of practice for research like this too!

### THE CDS CODE OF PRACTICE (Easy English Version)

- No research about us without us!
- The people with disability own the research
- We do research that matters to us
- We present together
- We are inclusive
- We try to use and produce accessible research materials
- We try to research in an accessible way
- We are ethical in our research
- We want to change the research agenda.

A code of practice doesn't always mean that you are perfect in these areas. It's a set of standards that you can measure against.

Suzie notes some of the big challenges faced by the CDS Inclusive Research Network. For example, different people have different support needs. So she noted that things aren't always immediately accessible but the group tries to think ahead and make written materials accessible, such as the use of large print for people with vision impairment. It is part of the CDS Code of Research Practice that members are there to support one another to understand what they would like to research and how.

It's also hard for research findings to always transfer to real life. Susie says that the research she is involved in is slowly but surely meeting this goal.

Susie commented, that "Each time we do a research project and report on our findings, we are making research more available to everyone."

She explained that being an inclusive researcher is about teaching other researchers with a long research history that people with disabilities have voices. But also here are some other things the group thought too.

### **Researching is about:**

- Putting ourselves in someone else's situation to imagine what would it be like - how would this person feel?
- Another way of putting yourself in the person's shoes
- Drawing upon your own and other people's lived experience
- Co-researching, which means we need to support one another
- Sharing different experiences and skills, different ideas.

### **The rights of an inclusive researcher:**

Suzie thought it was important that we also think about the rights of the researcher with disability.

Using a list created together with the CDS Inclusive Research Network, she thought this was a good way to say it.

### **As a researcher we:**

- Have a voice
- Are listened to
- Feel part of the group
- Respect confidentiality
- Our research is about something important to us
- Have flexibility
- Have choice and control
- Everyone brings something to the table
- Need mutual respect
- Can bring passion and joy
- Can have fun!

If you would like to join the Inclusive Research Network, please contact the co-ordinator Dr Tanya Riches:

■ [tanya.riches@sydney.edu.au](mailto:tanya.riches@sydney.edu.au)



Suzie says

*"Our group meets once a month on a Thursday afternoon at the Centre for Disability Studies.*

*Would you like to come and join us?"*

# DECISION-MAKING SUPPORT FOR PEOPLE RARELY HEARD

A workshop by Jo Watson and Gloria Jellif

The right to exercise choice and control in one's life is a central principle for NDIS participants. This can be empowering and enabling for people who can speak for themselves, explain to others what is important to them and what their hopes and dreams are.

However, a relatively invisible group are those people with severe and profound intellectual disability, people who do not have a formal means of communication. How can their voices be heard? How can we support them to have true "choice and control"? This workshop explored those questions and offered some strategies.

Often decisions are made for people who do not have or have not been given a means of communication. These decisions are perceived to be in that person's interests, but are still made without that person's participation. This is termed "substituted decision-making". Article 12 of the UN Convention of the Rights of Persons with Disabilities (UNCRDP) says that substituted decision-making is not sufficient. We continue to violate that right for a large number of people in Australia.

In this workshop Jo and Gloria told us stories and outlined some strategies that can be used to support more inclusive decision-making for people who do not have a formal means of communication.

Supporting true decision-making, choice and control takes time and requires discussions between people who know that person well. Creating a "Circle of Support" - a group of people who support someone to build and act on their decisions, is a key strategy. The Circle of Support works together to determine the person's likes and dislikes, brainstorms a range of possible activities the person may like, videos the person during these activities, and discusses the person's responses to form an opinion of their preferences. Preferences can be developed into expressions of choice, and choices then become decisions about the activities that person wants in their life. This can be a time consuming process, and lack of funding for this is one of the biggest barriers to it becoming a more common practice.

Sensory preferences can also be the building blocks of decisions. We all respond to what we experience and a Sensory Profile can provide valuable information about a person's preferences and dislikes. Telling stories is how we share our lives and let others know about who we are. People without a formal means of communication can be supported to do this through multi-media profiles or Personal History books.

Another barrier is that for many people with severe levels of disability, most if not all the people in their life are paid staff. However we know that the more close and caring relationships a person has, the better their preferences are observed and known. Developing strong and caring social networks for

these people is a vital element in supporting them to make and express their decisions.

This work reminds us that all people, regardless of their level of disability, can and do attempt to communicate. Whether or not they actually succeed at communication depends entirely on the people they are attempting to communicate with. A person's level of capacity is not as important as the support they have.

This work challenges us to follow the lead of the UNCRPD - rather than the various forms of making decisions for people based on their perceived best interests, let's devote more resources to supporting people to make decisions based on their will and preferences.

### **Libby Brownlie**

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**Want to know more – listen to the podcast**

<http://www.asid.asn.au/publications/podcasts>



# LGBTIQ PEOPLE WITH INTELLECTUAL DISABILITY

**Amie O'Shea and Nathan Despott**

Sexual Lives & Respectful Relationships (SL&RR) is a rights based peer education program for people with intellectual disability about their rights in sexuality and relationships. The SL&RR model contains four key components; peer education by people with an intellectual disability delivering a respectful relationships program; supporting change in support relationships through learning partnerships; sector development through partnerships with community health, sexuality and violence and abuse support and disability services and systemic change through research and translation of outcomes (Frawley et al., 2017). SL&RR is part of a research program at Deakin University led by a team of researchers and project workers including people with an intellectual disability. The respectful relationships program is run by people with an intellectual disability trained as peer educators and professionals who work in the partner services who are trained as program partners. In May 2018 SL&RR partnered with Inclusion Melbourne through a grant from the Gay and Lesbian Foundation of Australia to pilot a version of the SL&RR program featuring and targeted to LGBTIQ (lesbian, gay, bisexual, trans\*, intersex, queer) people with intellectual disability. The program was delivered by a SL&RR Peer Educator with Ginger Ekselman from SECASA (South Eastern Centre Against Sexual Assault) and Amie O'Shea (Deakin University) and has been independently evaluated by a research team at the University of Melbourne. SL&RR uses the real life stories of people with intellectual disability as the core learning resource.

These stories are gathered with people with an intellectual disability who are interested in sharing their experiences about sexuality and relationships. There is a core set of stories that were collected through research (Johnson, Hillier, Harrison, & Frawley, 2000). Following evaluation of the program these stories were augmented by a research project in which new stories were gathered from LGBTIQ people with intellectual disability. In this article we will introduce some of the key themes to emerge from that research, and reflect on the processes of organizing and facilitating this program and what this can mean for LGBTIQ inclusion in other intellectual disability spaces.

Developing new stories – LGBTIQ people with intellectual disability

With human research ethics approval from Deakin University, researcher Amie O'Shea worked with participants to gather their stories. This involved meeting together several times to talk about the person's life and what they wanted to share about their experiences and sexuality. Such accounts are scarce in the current academic literature, particularly from women and non binary people with intellectual disability. Early themes to come from the new stories collected showed some areas of similarity with existing SL&RR stories. Themes are worked into key messages about sexuality and relationships which are discussed with program participants. Common themes included the desire for a relationship, experiences of violence or abuse, and the importance of others in people achieving their desired outcome. In addition there was a strong message that people managed their identities in complex ways: Carol , talked about

not telling people at her Church about her sexuality, for example. Another storyteller Johnno said most of the staff in his residential home were OK with him being gay, but that “you don’t talk about being gay in front of Leigh”, referring to a particular staff member he described as homophobic. Both Carol and Johnno talked about how they navigated public spaces with an eye to being safe from verbal or physical homophobic abuse: making decisions about if and when to hold another person’s hand, for example.

Another key theme from the stories was the poor experiences with sex education to date, including at school. Storytellers felt excluded from sex education which assumed they were heterosexual – something which is also reported in a review of sex education programs for people with intellectual disability (Gill, 2015). The pilot program delivery trialled a ‘blank spot’ of unallocated time on the third day where participants could decide in advance what they would like to discuss. Reflecting on their poor experiences of sex education, the group sought information of safer sex resources and so the Victorian AIDS council were invited to present to the group on this topic.

### **Piloting the new stories in SL&RR**

We learned a number of things while working together on this project. Across the research recruitment and pilot program delivery we saw an over representation of men with intellectual disability. This is in line with international reports on the same phenomenon, leading to an ‘almost total invisibility’ of women with intellectual disability, and an entire absence of non binary people with intellectual disability, in the literature (Abbott, 2015). We will continue to focus on this area to ensure that everyone’s voices can be heard.

Organizing the SL&RR program meant that we spoke to potential participants beforehand. This was for several reasons: to confirm people identified themselves with the target group of LGBTIQ people with intellectual disability, to discuss the program content, and to work out the logistics for individuals to attend. This meant that people who attended the program already had support for their LGBTIQ status at home (with their families or in residential services). We had to consider what it would mean for people to attend a program which might inadvertently out them, talking through questions of who would know where they were going, how that might be received, and who could be a support person if they wanted to talk about any issues raised in the program or through their attendance. While this process meant that pilot program attendees were adequately supported at home and at the program, we know that this is not the case for all people with intellectual disability, and we see the need for support providers and advocacy organisations to encourage acceptance and visibility by including all sexualities and genders when working with people with intellectual disability,

### **SUMMARY**

- Researchers worked with LGBTIQ people with intellectual disability to gather their stories for use in the SL&RR program
- The stories formed part of an SL&RR program for LGBTIQ people with intellectual disability run by Deakin University and SECASA with Inclusion Melbourne
- There were additional considerations when running the LGBTIQ SL&RR program to ensure it was accessible and comfortable for everyone
- LGBTIQ people with intellectual disability who participated in the SL&RR program agreed with the key messages to emerge from the stories, which we will continue to work with to inform an understanding of their needs and experiences

and being proactive by engaging with staff to reflect this approach. This is an area we hope to elaborate on in a future publication.

Moving forward, the SL&RR team will continue to work with the new stories to articulate their key messages for use in the SL&RR program, using the same approach followed for the existing SL&RR stories. A group of LGBTIQ SL&RR Peer Educators and Program Partners will be working with the SL&RR research team to incorporate the stories and other things we learned from the pilot and its evaluation into the overall SL&RR program. This research will continue to inform the way we consider sexuality and relationships rights for LGBTIQ people, and inform our advocacy and responses to policy and practice and approaches to sexuality rights for LGBTIQ people with an intellectual disability.



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# UPCOMING EVENTS

[www.asid.asn.au/events](http://www.asid.asn.au/events)

For further information about Events visit [www.asid.asn.au/events](http://www.asid.asn.au/events) or email [secretariat@asid.asn.au](mailto:secretariat@asid.asn.au)

## 14-16 November 2018 **ASID 2018 Conference**

*"Let's Shake It Up: Human Rights for Everyone"*  
Gold Coast Convention Centre

[www.asid.asn.au/events/97\\_asid\\_2018\\_conference](http://www.asid.asn.au/events/97_asid_2018_conference)



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## Podcasts

## **ASID Podcast Season 2**

Episode 2 in the studio

<https://www.asid.asn.au/publications/podcasts>

Our supported decision making podcast has been very successful. Our next podcast focuses on updating listeners on the Voting for people with Intellectual Disabilities project that we heard about in the first season. Ahead of the Victorian State Election in November, a very generous group of self-advocacy groups and politicians sent in voice memos responding to questions about voting for the next episode of the ASID podcast. As well as a very thorough chat with the Victorian Electoral Commission and a bonus episode conversation with Inclusion Melbourne this episode is shaping up to be a very interesting and timely discussion of the issue of political citizenship for people with intellectual disabilities.

Listen in...

# WHY JOIN ASID

ASID was established over 50 years ago and is still committed to the ideals that led to its creation to improve the quality of life for people with an intellectual disability. It is a strong and vibrant association comprising people working or studying in the area of intellectual disability, organisations providing services to those with intellectual disabilities and people with an intellectual disability and their families or carers.

Membership of ASID provides you with access to invaluable information, resources and the opportunity to develop contacts to better inform and equip your organisation to provide the best quality service to those with intellectual disabilities. We believe that this work has never been more important than it is today and ASID membership provides the opportunity, through a united society, to influence developments in the area of intellectual disability.



## Free Journal Subscriptions

Individual members receive online and print access and organisational members receive online access to the leading journals in intellectual disability: Research & Practice in Intellectual and Developmental Disabilities (RAPIDD) and the Journal of Intellectual & Developmental Disabilities (JIDD). Organisational members have discounted access to 6 other journals and individual members have online access to two other journals. Individual Members have free online access to two other leading journals.



## Discounts to attend workshops, conferences and other events

ASID members enjoy significant discounts on the ASID Annual Conference, divisional events and workshops delegate fees. Organisational members are entitled to discounts for several staff to attend according to their level of membership.



## ASID Fortnightly E News.

Don't have time to keep up with the intellectual disability news and social media world each day? Don't worry, this fortnightly service will arrive in your inbox and tell you what you have missed.



## Intellectual Disability Australia Magazine (IDA)

Each quarter you will be emailed a copy of IDA that includes articles of general interest, stories from the intellectual disability community, forthcoming workshops and events.



## Use of our Logo

Organisations are entitled to use the ASID logo on their organisation websites and promotional material (Subject to conditions).



## Opportunity to meet and exchange ideas

our membership will also provide you with eligibility to be a decision maker and participate within the organisation, membership of a division that meets on a regular basis to pursue issues of local, national or international relevance together with locally organised regional conferences, seminars, workshops and social gatherings. It will also offer opportunities to meet and exchange ideas with people having similar interests in other parts of your region and the country.



## Become involved in the governance of ASID by being a member of the board, your local division committee or on a board committee

Membership of ASID entitles you to join your local division committee and give you the opportunity to contribute and influence the development of ASID. As a divisional committee member you may stand for election to be a member of the board of ASID Ltd. You can also join one of the board committees.

For information on how to join, membership types and rates <https://www.asid.asn.au/members>

# ASID COMMITTEES

Committee	Chair and Email	Role of Committee
Membership	Allyson Thomson registrar@asid.asn.au	<ul style="list-style-type: none"> <li>To review and monitor ASID Ltd membership</li> <li>To recommend membership fee rates to the Board</li> <li>To attract and retain members as a part of the company's income generation strategy</li> </ul>
Finance	Ben Crothers treasurer@asid.asn.au	<ul style="list-style-type: none"> <li>To review and monitor financial processes</li> <li>To help the board generate more income</li> <li>To help the board spend less money</li> <li>To help the board decide how to invest our money</li> </ul>
Events	Sharon Brandford events@asid.asn.au	<ul style="list-style-type: none"> <li>Develop and oversee guides and procedures</li> <li>Oversee appointment of Event Management</li> <li>Ensure ASID events promote and demonstrate inclusion of persons with lived experience of intellectual disability</li> </ul>
Publications	Angus Buchanan vicepresident@asid.asn.au	<ul style="list-style-type: none"> <li>Develop and oversee policies and procedures related to ASID's peer-reviewed journals</li> <li>Provide interface between the ASID and contracted publishers (Taylor and Francis)</li> <li>Develop processes, for and oversee appointments of Editors and Editorial Board Chairs</li> </ul>
Position Papers	To be appointed	<ul style="list-style-type: none"> <li>To establish and document definitions, processes and guidelines for the development and endorsement of position statements, for presentation to the Board for approval</li> <li>Develop a strategy for the widest possible dissemination of position</li> <li>The committee will formulate a timely response to any reactions to position statements</li> </ul>
Communication	Hilary Johnson communications@asid.asn.au	<ul style="list-style-type: none"> <li>Produce and publish IDA 4 x per annum</li> <li>To develop and distribute high quality, responsive, accessible communications with external stakeholders including members, consumers and stakeholders we wish to influence</li> </ul>
Partnerships and Projects	Bernadette Curryer boardsecretary@asid.asn.au	<ul style="list-style-type: none"> <li>To identify partnerships currently in place, at both a divisional and national level, sharing what is happening and strategies used across all divisions</li> <li>To identify and link with potential partners, ensuring mutual benefit eg. shared memberships</li> </ul>



*Intellectual Disability Australasia (IDA)*  
*is produced and distributed by the*  
*Australasian Society for Intellectual*  
*Disability.*

ISSN: 2206-4311

The views expressed in this newsletter are not necessarily those of the Australasian Society for Intellectual Disability.

The magazine is produced four times a year, March, June, September and December. The editor welcomes contributions, please contact for details of article length and format.

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The theme for the June 2018 edition is The justice system – access issues for people with an intellectual disability.

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## WHY ADVERTISE IN IDA?

Intellectual Disability Australia (IDA) is ASID's full-colour, electronic downloadable magazine. Published quarterly, it is distributed to ASID's members and subscribers and made available free to all readers of the Association website.

### Artwork Specifications

All artwork must be supplied as high-resolution (min 300 dpi) electronic files: jpeg, TIF, PDF or eps, with all fonts embedded. A4 portrait PDF would be easiest for us. If you have pre-made ads, we can just place these in without too much time. If you require artwork to be created for you, please contact us to confirm the cost and the time allocation.

A broad range of advertising options are available in IDA to suit your specific needs.

Please email [secretariat@asid.asn.au](mailto:secretariat@asid.asn.au) for further information about rates, specifications and our advertising policy.

