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INDIVIDUAL SAFEGUARDING

MERISSA VAN DER LINDEN

PROMOTING PERSONAL SAFETY

SALLY ROBINSON

2018 KEYNOTE SPEAKERS

CHRIS HATTON &
DR BRIGID MIRFIN VEITCH

SAFEGUARDING



Hilary Johnson
IDA Editor

*Welcome
to the June
edition of IDA.*

The theme of safeguarding has brought several contributions from different perspectives. Safeguarding is particularly pertinent in Australia as the National Disability Insurance Agency launches the National Quality and Safeguarding framework. Merissa Van Der Linden ([p.5](#)) suggested five levels of informal and formal safeguards from personal empowerment to legal enforcement to provide a safe environment for people with an intellectual disability. Anthony Kolmus, ([p.8](#)) provides some case studies of the work of the office of the Victorian Disability Service Commissioner in investigating abuse and neglect highlighting the critical role played by staff. The office estimate that in the last year 22% of complaints about allegations of physical and sexual assault were made by support workers. The vulnerability of people with an intellectual disability can be exacerbated when people have difficulty communicating. A part solution may be to provide people with communication aids with appropriate vocabulary www.speakupandbesafe.com.au but staff training to use these aids is also necessary ([see p12](#)). One of the core tenets of providing a safe environment is ensuring people have a range of relationships. It is well established that people with intellectual disability, especially those in group homes have limited social networks often entirely composed of paid staff. The key role of trusted relationships is explored by Sally Robinson and her co researchers ([p.14](#)) who suggest that building a sense of security and safety in young people is essential. Patsy Frawley & Amie O'Shea echo similar themes and emphasise the need to provide an ecological model that targets the individual, the community and the surrounding system ([p22](#)).

Organisation for the ASID national conference is underway with 6 confirmed key note speakers and IDA features an extended introduction to two speakers Prof. Chris Hatton from the U.K. And Dr Brigid Mirfin-Veitch from New Zealand ([p.32](#)). For more local events check out the divisional reports and the events on the ASID website http://www.asid.asn.au/events/show_all_events. Don't forget to have some fun on the way and get along to a film or gig- and share your thoughts with us on twitter or Facebook. A recent evaluation of the National Disability Insurance Scheme indicated poorer outcomes for people with an intellectual disability ([see 39](#)). The theme for September edition of IDA is Individual planning – for, by or with people with an intellectual disability. Can you tell me what the process or outcome of planning has been for you? Please start writing and contact me at idaeditor@asid.asn.au!

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PRESIDENT'S REPORT

2018 is whizzing by, I can't believe we're already up to the June edition of IDA. As President of ASID I am often invited to attend events, make comment on or support positions related to intellectual disability. As with all voluntary posts, sometimes decisions have to be made about what we do and don't have capacity to participate in. To provide you with an update on some of the things we have participated in over the past few months:

In February I attended in the 'Right Here, Right Now' symposium on preventing abuse and promoting personal safety for young people with disability. This was an excellent opportunity to explore, discuss, debate and make collective action plans on new research by Sally Robinson, Anne Graham (SCU), Karen Fisher, Ariella Meltzer, Megan Blaxland, Kelley Johnson (UNSW). This research addresses a knowledge gap about personal safety and abuse prevention by exploring the perspectives of young people with disability, their supporters and families about feeling safe and developing strategies to stay safe. If you want to know more about this research you can access the full report, summary and plain English material [here](#).

During February ASID also became a signatory to an open letter prepared by Jim Simpson (NSW Council for Intellectual Disability) and Professor Julian Trollor (UNSW), to the NSW Health Minister. The letter focused on the physical and mental health inequities experienced by people with intellectual disability and was further to the ASID endorsement of the joint NSW Council for Intellectual Disability, Inclusion Australia and Australian Association of Developmental Disability Medicine Position Statement on the Health of People with Intellectual Disability which can be found [here](#).

At the end of March, I participated in the 2018 National Roundtable on the Mental Health of People with Intellectual Disability. Another very important day bringing together key experts from the health and disability sectors across Australia to address emerging and contentious issues, and lead national and state action on improving mental health of people with intellectual disability. The event was focused on the large translational research and capacity building partnership, the details are [here](#).

At each of these events, it was a pleasure to work alongside other ASID members and Board Directors. It's excellent to see that we have so many well regarded and sought after subject matter experts within our membership, many who take on leadership roles within our Divisions and our Board of Directors. If you're not currently a member I would strongly encourage you to join, not only do you get to be part of an extensive network across Australasian, there are a whole host of other benefits, all the information is on our [website](#).

Laura Hogan

2018 ASID President
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INDIVIDUAL SAFEGUARDING

Merissa Van Der Linden

Safeguarding individuals is fundamental to high-quality care and support, and all people, regardless of their disability, or capacity, should have their rights safeguarded¹. The principles of safeguarding are founded on the articles of the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD), and is enshrined in local and national legislation.

When people with disability are vulnerable or at risk of experiencing compromised rights, quality of life, or outcomes, safeguards can act as a response to minimise vulnerability and risk. Individual safeguards can be precautionary, preventative or reactionary; implemented to protect an individual from vulnerability and/or risk, harm, or reduce vulnerability and risk.

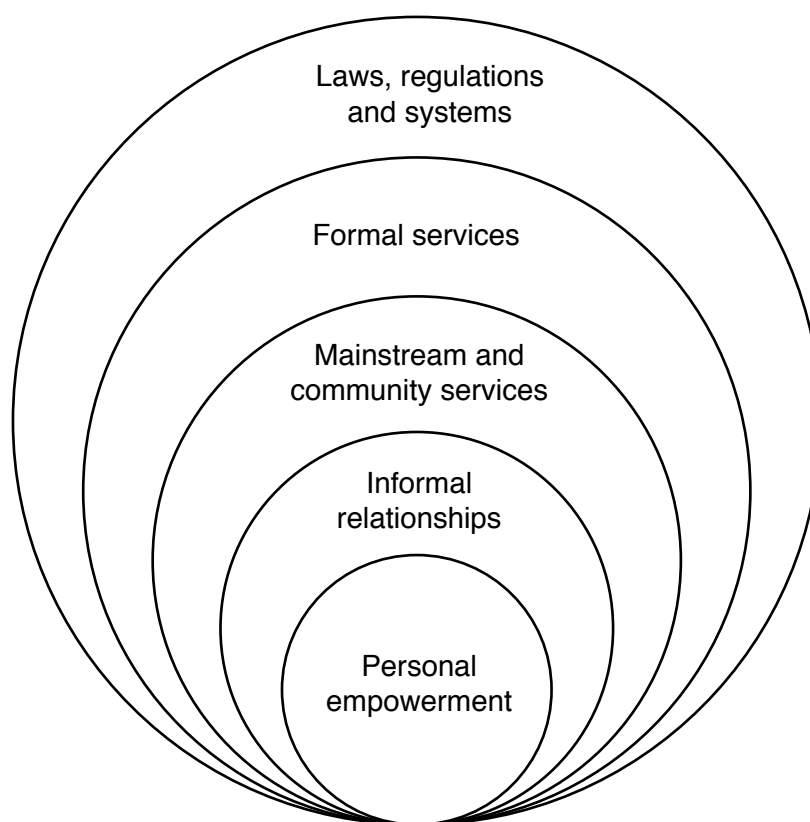
Understanding vulnerability

All people experience vulnerability and risks at points in their life. While it is not always in our control to prevent vulnerability and risks in our lives; we generally anticipate that we have the resources and capacity manage, or mitigate the vulnerability or risk we experience. The individuals we support within services may not always have the resources at their disposal.

While there are no pre-defined assessment tools, or checklists, that can reliably identify individual risk or vulnerabilities, social and other factors experienced by people with disability may reduce their ability to identify, manage and mitigate risks and vulnerabilities, and may exacerbate vulnerability. These factors can include personal characteristics, experiences, access to information, financial stability or instability, environmental factors and geographical location (where an individual lives), cultural identity, dependency on others for communication and basic needs, and health and wellbeing. While each of these factors can shape an individual's vulnerability, when multiple factors co-occur a person's vulnerability can be intensified². When an individual is highly dependent on others for their communication, or to have their basic needs met, their vulnerability and need for safeguarding can be significant.

Developing safeguards

There is standardised approach to developing and implementing individual safeguards³. For people with disability, safeguards can include a range of informal and formal supports and mechanisms operating at the level of the individual, the community, services sector and overarching government systems and legislation (see Figure 1). Safeguarding also encompasses effective responses to allegations of harm and abuse, responses that are in line with organisational policies and procedures, and contractual and legal requirements.

Figure 1. The range of safeguards⁴

Safeguards developed at all levels should balance individual dignity of risk with duty of care, and impose the least possible restrictions. Safeguards should be proportional, tailored to the individual, and include strategies to enhance the wellbeing and safety, while providing the individual with opportunities to make and assert choices in a 'safe to fail' and 'safe to learn' environment.

Figure 2. Safeguarding considerations.

Proportionality:	Safeguards are proportionate and responsive to the individual's level of vulnerability and the potential risks/hazards.
Personal Power:	Safeguards maximise an individual's opportunity to build capacity.
Prevention:	Safeguards prevent abuse, neglect and harm.
Capacity:	It is assumed the individual has the capacity to make decisions and exercise choice, regardless of their disability. Supports are provided to the individual to assist them in decision-making processes about safeguarding.
Minimal restriction:	Safeguards place the least possible restriction on the individual.
Accountability:	There is accountability and transparency in the delivering and monitoring safeguards.

All organisations that work alongside people with disability have a responsibility to do no harm and ensure the people they support are safe. To effectively safeguard individuals we are required to following some basic principles of 'good' support.

- Ensure there is deep understanding of needs, interests and preferences of individuals, and their supporters.
- Assume individuals have capacity to shape and guide their supports and services, and participate in decision-making processes.
- Assume all people have the right to live without fear, threat or violence, and can access support, advice or practical help (when required and relevant) about personal safety and risks.
- Implement all reasonable measures to ensure the risks of harm to individuals is minimised, without restricting the individual's rights.
- Ensure where there are concerns about the welfare of individuals that appropriate actions are taken to address and minimise or eliminate those concerns.
- Ensure all staff are aware of their safeguarding responsibilities and are able to recognise and respond to risks and vulnerabilities.
- Ensure safeguarding is considered at all stages of service design, provision and review.
- Work to agreed policies and procedures and demonstrate compliance with the relevant service standards and (changing) contractual and legislative requirements, and ensuring there are policies and procedures in place that demonstrate a commitment to safeguarding.

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¹National Disability Insurance Agency (NDIA), (2014, n.p.) website indicates that the term 'safeguards' refers "...to a range of supports and mechanisms that ensure safety and wellbeing while supporting a person to have a good quality life, to be an active and equal citizen, and to be able to reach their potential". <http://www.ndis.gov.au/participants/safeguards>

²Martin, A. (n.d). *The Social Determinants of Vulnerability Framework*.

³Even capacity assessments undertaken through Guardianship and Administration processes, by the Office of the Public Advocate and the State Administration Tribunal are not based on standardised tools or assessments. They are instead heavily dependent on the input and reports of people who know the person (the Proposed Represented Person) well.

⁴Disability Services Commission (DSC). (2014). Position Paper: Individual Safeguarding.

CHAMPIONING PEOPLE'S RIGHT TO LIVE FREE FROM ABUSE AND NEGLECT IN VICTORIAN DISABILITY SERVICES

Anthony Kolmus

As a community, there is much we can do to ensure that people with an intellectual disability lead meaningful lives as respected and contributing members of our community.

One way is by resolving complaints and promoting the right of people with a disability to be free from abuse. This is our role at the Victorian Disability Services Commissioner.

As the only office of our kind nationally, we give Victorians with a disability, their family, friends and support workers a dedicated mechanism for obtaining advice and assistance about resolving complaints about Victorian disability services.

Quick stats from 2016-17

1,213 Enquirers and complaints we handled

44% Family members who contacted us to make a complaint or enquiry

38% Complaints raised to us about services provided to people with an intellectual disability

25% In-scope complaints relating to allegations of physical and sexual abuse

16 Investigations finalised

Our work is vital in preventing and responding to abuse and neglect. The Victorian Inquiry into abuse in disability services found that abuse can take many forms and occur in a range of settings ([https://www.parliament.vic.gov.au/file_uploads/FCDC - Inquiry into abuse in disability services_HtW37zgf.pdf](https://www.parliament.vic.gov.au/file_uploads/FCDC_-_Inquiry_into_abuse_in_disability_services_HtW37zgf.pdf)). In addition to there being an increased risk of abuse for some cohorts, the Inquiry found links between neglect and unexplained deaths, and highlighted the normalisation of abuse in the sector.

Our own experience supports the Inquiry's findings. Last financial year 25 % of our 254 in-scope complaints related to allegations of physical and sexual abuse, an increase of 19 % since 2013-14. We also finalised 16 investigations relating to abuse and neglect, of which 13 were justified. We have investigated cases where families notice issues of concern such as signs of bruising or changes in behaviour in family members who have limited communication.

Our work also highlights the critical role that staff and support workers have in this space. Last year, 22 % of complaints about allegations of physical and sexual assault were made by support workers. Stemming from the Inquiry, amendments have been made to the Disability Act 2006 (the Act) to expand our powers. These changes aim to help us respond more effectively to abuse in the sector, and to improve the safety and wellbeing of Victorians with a disability.

How our powers have expanded to respond to abuse and neglect

Historically we might have conducted an investigation into a Victorian disability service provider if we directly received a complaint. Since August 2017, we can now also conduct investigations if:

- We receive concerning information about a Victorian disability service provider (even if a complaint hasn't been lodged directly with us).
- The Minister for Housing, Disability and Ageing (the Minister) has asked us to investigate a matter.

At the Minister's request we are now investigating deaths in disability services to better understand how the provision of Victorian disability services can be improved in the future. We can also investigate any incident reports relating to assault, injury or poor quality of care that we feel warrant additional investigation.

The Act's changes have also given us the power to inspect the premises of Victorian disability services without notifying the provider in advance. Our Authorised Officers have conducted three inspections to date.

Case study: How our Authorised Officers helped Robert

Robert contacted us to tell us that staff from his disability service regularly lock him in his bedroom during the afternoon and evenings. He also told us that he has to sleep on a mattress on the floor. Robert told us that he attends a day service full-time and has been living in his group home for a number of years.

Given the nature of the issues raised in Robert's complaint, which related to his personal safety and wellbeing, we referred the matter to investigation.

To ensure a timely response we sent two Authorised Officers to Robert's group home soon after we received his complaint. This was so that we could assess whether Robert was being properly supported.

Upon arrival at the group home, our Authorised Officers informed the disability service that they were there to conduct an unannounced site inspection. They also shared the reason for the visit.

Upon entering the home, our Authorised Officers gathered information and evidence, including taking photos of the locks on Robert's bedroom door and of his mattress – which was on the floor.

We met with the disability service to discuss the information and evidence we had gathered. We issued the service with a Notice to Take Action. This included requiring them to get Robert a proper bed and to take the lock off his door. We also required that the disability service provider report back to us on what they had done.

During our investigation we also referred the matter to the Senior Practitioner – Disability so that further work could be done to ensure that Robert was supported well.

At the end of our investigation, Robert told us that he felt more comfortable about living in his home.

In circumstances where we cannot respond to a matter ourselves, we still provide support to those who need it.

Case study: an example of how we help respond to abuse and neglect

Debra contacted us about Amy, a 19-year-old woman with an intellectual disability who lives at home with her family and no paid supports. Debra called us because she was worried that restrictive practices were being used to manage Amy's behaviours of concern, including Amy being held down and tied up.

Although Debra's complaint was out-of-scope as it was not about supports provided by a disability service provider, we gave her information on how she could proceed. With her consent, we also referred her concerns directly to the Department of Health and Human Services to ensure that reporting and follow-up actions were being undertaken. Debra later advised that as a result of our referral, Amy was being supported by an advocate, she had received a medical and funding review, and her application for shared supported accommodation was given priority status.

By speaking up and raising her concerns, Debra was able to start making changes in Amy's life that improved her safety and wellbeing.

What more can we do as a sector?

There is more we can do as a sector to reduce the risk of abuse or neglect in the disability services sector. This includes:

- More thorough assessment of risks faced by people with limited communication and intellectual disability.
- Listening to the person with a disability, and ensuring that a person's verbal and non-verbal communication is understood.
- Better collection of data and investment in prevention as well as response.
- Improved response from all services (e.g. health, disability, family violence and justice) in supporting victims of assault who have a disability.

Anyone who may have a concern or complaint about abuse and neglect in a Victorian disability service is encouraged to contact us on **1800 677 342** or visit www.odsc.vic.gov.au



Anthony Kolmus

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Looking to the future: NDIS Quality and Safeguards Commission

As the NDIS rolls out across Victoria, our work will transition to the newly established NDIS Quality and Safeguards Commission.

The NDIS Commissioner is expected to commence operations in each state and territory by July 2020.

SPEAK UP AND BE SAFE FROM ABUSE

Elizabeth Weston, Naomi Rezzani & Hilary Johnson

When it comes to reporting abuse and neglect, people with communication difficulties are “highly victimized because perpetrators believe they will not be able to successfully tell anyone about the crime” (Wilczynski & Connolly, 2014,p.10). The Speak Up and be Safe from Abuse project was developed in response to a recognition that people with little or no speech are at increased risk of physical, mental or sexual abuse as compared to others in the community due to barriers associated with their communication (Collier, McGhie-Richmond & Odette, 2006). The project involved training for frontline staff supporting adults with intellectual disability and the development of a communication toolkit.

Over the duration of the project, Scope’s Communication and Inclusion Resource Centre delivered training to 352 frontline disability staff across Victoria. The one-day workshop addressed the unique risk factors for those with communication support needs in relation to abuse and neglect, as well as a guide to the different kinds of communication support needed. A large component of the Speak Up and be Safe from Abuse training consisted of practical experience using communication tools and strategies. Those who attended the training were offered opportunities to practice using communication books and boards to assist a conversation. Practical activities also addressed how to use the tools in a way that enabled the person with communication support needs to lead the conversation, and how to facilitate a conversation without making judgements about what was being reported.

The toolkit has been created with the understanding that those with communication support needs require appropriate vocabulary to describe their thoughts and experiences relating to abuse and neglect. See www.speakupandbesafe.com.au for free downloads of communication aids. Much of the vocabulary in the communication resources are rarely seen in mainstream communication resources and relate specifically to abuse and neglect.

The Speak Up and be Safe from Abuse project included a research component to evaluate the outcomes of the training program. The study involved qualitative interviews with 16 frontline disability workers from across Victoria who had attended the training. Research participants were interviewed over the phone three months following their training. The results revealed that frontline workers recognised that the potential for the resources in the Speak Up and be Safe toolkit to be used, however the toolkit was not actually used in practice to identify abuse, even if abuse was suspected. This research identified that frontline disability staff required more support than a single day of training in order for them to feel confident enough to share what they had learnt during the training with their colleagues, and to use the resources with the people with communication support needs with whom they worked. Although the first iteration of the Speak Up and be Safe from Abuse training has been a promising start in terms of providing safeguarding resources, building expertise in staff in supporting people with limited communication skills requires a different approach.

In recent months Scope’s Communication and Inclusion Resource Centre has been offered an opportunity to trial the delivery of the Speak Up and be Safe training using a different model in Scope’s



Elizabeth Weston



Naomi Rezzani

accommodation services. This presents an exciting opportunity to address the gaps identified in the research. The updated delivery model involves on-site group home training for staff members followed by eight weeks of support for staff to practice the skills addressed in the training. In addition, strategies to individualise the ways the tools are used will address the unique communication support needs of each resident. It is hoped that this training model will not only allow frontline workers to gain confidence in using safeguarding strategies in a real world scenario, but also allow them to process how to adapt the skills and resources for the individuals with whom they work.

Most of the communication resources in the Speak Up and be Safe from Abuse toolkit are available for free download from the Speak Up and be Safe website, www.speakupandbesafe.com.au. Information about upcoming training dates can be accessed through this website, including dates for an upcoming Speak Up and be Safe national tour in partnership with AGOSCI.

The authors would like to thank the Department of Health and Human Services for providing funding for this project.

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References

- Collier, B., McGhie-Richmond, D. & Odette, F. (2006) Reducing the risk of sexual abuse for people who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 21, 62-75.
- Wilczynski, S. M., Connolly, S., Dubard, M., Henderson, A., & McIntosh, D. (2015). Assessment, prevention, and intervention for abuse among individuals with disabilities. *Psychology in the Schools*, 52, 9-21.

PROMOTING PERSONAL SAFETY AND PREVENTING ABUSE FOR YOUNG PEOPLE WITH DISABILITY:

NEW RESEARCH AND YOUNG PEOPLE'S ADVICE FOR IMPROVING SERVICES AND SYSTEMS

**Sally Robinson, Jaimsie Speeding, Jesse Brewer,
Tara Coughlin, Nimali Pathirana**

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Young people with disability are not well heard about safety.

Little attention is given to building a sense of personal safety and security in these young people's lives, even though they experience high rates of abuse and neglect (Jones et al., 2012). Policy in disability and youth areas also fails to address the safety and abuse prevention needs of young people with disability, attending mostly to the experience of harm already experienced (Llewellyn et al, 2016).

The recent Royal Commission into institutional Responses to Child Sexual Abuse puts great weight on the importance of addressing culture and practice (2017a), including in contexts specific to children and young people with disability (2017b). New research shows that young people's expertise and experience dovetails with this. We need ways to resolve harms, of course - but more than that, we need ways to build and promote a sense of security and safety in young people. This is not only important for a flourishing adulthood, but is an early form of abuse prevention. Just as importantly, it aligns with the experiences and expectations we have for the non-disabled peers of young people with disability.

Young people's views about safety

Our national study with young people with disability and their supporters about promoting safety and preventing abuse was released in 2018. You can read it in detail [here](#).

Young people with intellectual disability were involved in every stage of the research as participants, advisors and co-researchers. Click [here](#) to see a video of Community Researcher Jaimsie Speeding talking about how young people were involved in the project. In this article, Jaimsie and members of the CCYP Young People's Advisory Group who worked on the project have given some advice about how readers can put this research into practice to help young people with intellectual disability to be safer.

In our research we spoke with 68 young people with disability. Of the participants in the research, two-thirds were young people with intellectual or cognitive disability. Forty young people spoke with us either individually or in small groups. Sixteen people with high support needs were also included, using modified methods. A survey for young people was also conducted. All names in this article are pseudonyms.

What do young people say is necessary for personal safety?

As part of the research, we developed a model to explain the factors that young people identified as necessary for their personal safety. This reflects the priorities of young people in the research for promoting and sustaining their personal safety: being physically safe, being emotionally safe, having access needs met, and feeling capable.



Figure 1: Personal safety model

Young people's safety strategies

Young people shared many strategies with us for how they kept themselves safe, or regained a sense of safety if they were not safe. These are summarised in Figure 2, below. Their ideas for improving their safety cover a wide array of areas. They are impressively detailed, and range from tailoring individual relationships through to incorporating human rights principles. Underpinning these strategies is the basic need expressed by all young people participating in this research to be listened to, to be treated with dignity, and to have their concerns heard and responded to. For example, Elizabeth shared these concerns through her narrative:

Over four interviews, Elizabeth shared through sign, pictures and communication support how kids in school bullied her and poked her with sticks. She told the teachers, and they gave those kids time out, but it didn't stop them from hurting her next time. More recently at respite, she said she has been bullied by other people staying there. She told the manager, who told her to ignore them and do something else. This did not stop the bullies either.

Strategies that young people identified that they can do themselves to be safer included:	<ul style="list-style-type: none"> • Build stronger and deeper connections and relationships with people who can support them – for advice, guidance and support • Learn skills that will help them to be more resilient, emotionally strong, and able to support peers • Learn who to seek help from, when and how • Know how to act to be safe in common situations • Focus on wellbeing
Strategies that young people identified that other people can do that will help them to be safer included:	<ul style="list-style-type: none"> • Take action when something goes wrong (but not take over) • Have proactive strategies and measures to prevent harm in place • Lay strong foundations with high quality relationships – so young people feel comfortable, valued, respected • Understand and respond to the young person's specific context – what is safe for one person is not for another • When one part of a young person's support is lacking, build it somewhere else • Promote young people's capability – learn young people's safety strategies and help them use them & find new ones • Make the most of opportunities for learning – not just training • Change the environment so that young people feel welcome and included (and less personally responsible for keeping themselves safe)
Strategies for how services can improve safety included:	<ul style="list-style-type: none"> • Increasing the priority of responding to concerns about harm (e.g. bullying and violence in schools; abuse and violence in services) • Increasing meaningful choice and control in & over services • Addressing gaps in services that make people unsafe (e.g. lack of choice of same gender or culture provider; lack of services in regional & rural areas) • Education for staff and young people: how to recognise & respond to harm, about all kinds of relationships, & also for leadership development & peer support
Strategies for improving safety at a community level included:	<ul style="list-style-type: none"> • Building a sense of belonging, to help young people feel more welcome in their communities • Focusing on universal access measures • Connecting safety to a human rights agenda • Focusing on systems reform where young people's safety is at a turning point – legal, out of home care, housing, child protection, domestic and family violence, and school systems • Prioritising choice and control in disability policy reform

Figure 2: Young people's safety strategies

Young people also identified important gaps between what they were able to do, and where they needed help from other people, organisations and communities to be safe.

Problems in being physically safe were more likely to create a response from services and systems, because they activated policies or procedures in an easy-to-see way. However, young people described strategies that they used to keep themselves safe that sometimes came at a significant cost to their own wellbeing or personal growth. For example, some young people did not go out at night time or alone, or minimised their presence in the wider community. For example Mick, who has an intellectual disability and a vision impairment, said that after an abusive encounter in the street of his regional town,

... if there's anything coming towards me that worries me or frightens me... that's when I need to have two or more people with me.

While services and systems prioritised physical and sexual safety, young people's priorities were much more strongly around their emotional safety. They focused most consistently on relational and interpersonal safety issues in their lives, which were much more difficult to name, ongoing, and more complex to negotiate. Central concerns for almost all the young people were security and insecurity in relationships, navigating interactions and relationships with paid and unpaid supporters, and forming and maintaining peer relationships. For example, one young woman (who preferred to remain un-named) described the impact of abuse on the way that viewed the world in saying

The way I see it is that it's not your skin that gets damaged but your insides that do.

The ways that young people thought about access was much broader than services and systems had accounted for. They were sensitive to how barriers to access to the wider community made them feel – whether they felt unwelcome in spaces, like they did not belong, or that they were out-of-place. The ways that their access needs were met (or not) established or made fragile their sense of safety outside of known relationships and spaces, and made a difference to how confident they felt. Widening the lens of accessibility to think about the ways that both places and interactions can help (or constrain) young people with disability in feeling safe may be helpful in understanding how we can improve our communities on a range of levels.

It was important to young people that they were able to use their safety strategies and ideas as much as possible. It also mattered to them that when they needed help, it was provided in a way that complemented their effort, rather than took control away. Few young people in this research were focused on independence – rather, they were keen to maximise their own capability and capacity to learn. Supporters focused much more strongly on creating safe environments, minimising risk, building trusting relationships, and worried about the lack of safe opportunities that young people had for exploring boundaries. Jesse put it well in saying

The biggest issue for me comes when somebody acts before even considering whether you need their help, which comes from a complete misunderstanding of disability ... they either assume far too little, or far too much.

Finally, and very importantly for IDA readers, many young people with intellectual disability had greater difficulty in implementing safety strategies than some of their peers without disability or with sensory or physical disabilities. Their lives were framed through a lens of impairment, rather than youth. The lack of normative opportunities to develop relationships, reduce isolation and develop social capital affected their personal safety more than deficits in cognitive functioning or speech.

Implications of this knowledge

The four elements in the safety model underline the complex interplay between young people being protected by having their safety needs met and being active agents participating in determining what they want and need to feel and be safe.

Young people's experiences and views about safety intersect with important gaps in policy and practice frameworks in youth, disability and violence settings. Their priorities offer a new way of approaching longstanding problems in safety and harm.

This new knowledge reveals an emphasis on the importance that young people placed on relationships, particularly in having people who they trust as stable parts of personal networks. It also highlights tensions and constraints in the way that these relationships are known and expressed – such as the ways in which movement of key people in and out of young people's networks is often out of their control.

For too long, discussion about safety for young people with disability has focused rather too much on abuse, and rather too little on what it takes to be a safe and confident person in the world. Finding ways to make safety a part of conversations with young people, families, workers and managers is a priority. For this to happen in ways that are not restrictive of young people's rights to participation and inclusion, their priorities and preferences need to be promoted – notwithstanding the support that many people need from day to day. A natural jumping off point for considering personal safety are open dialogues which are part of the opening up of the world that happens (or should happen!) in young adulthood.

Taking Action

To read the Safety Project report in full, summary and plain English versions, follow this link: www.rcypd.edu.au/safety.

References

- Jones, L., Bellis, M., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T. & Officer, A. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, 380, 899-907.
- Llewellyn, G., Wayland, S. & Hindmarsh, G. (2016). *Disability and Child Sexual Abuse in Institutional Contexts*. Sydney, Australia: Royal Commission into Institutional Responses to Child Sexual Abuse.
- Royal Commission into Institutional Responses to Child Sexual Abuse. (2017a) Final Report: Preface and Executive Summary. Commonwealth of Australia.
- Royal Commission into Institutional Responses to Child Sexual Abuse. (2017b) A brief guide to the Final Report: Disability. Commonwealth

Taking action

Two things really stood out to the young people who are part of our research team about this project.

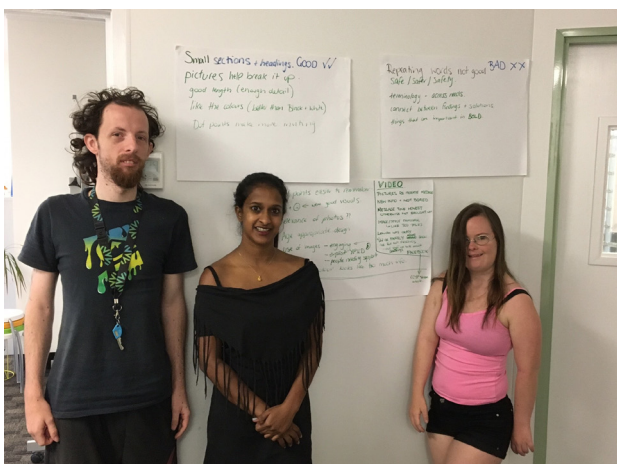
1. Promoting personal safety is about more than stopping things from being terrible – it's about making life good for young people so their adult lives can be great.
2. What really mattered to all of the young people in the research was to be listened to, to be treated with dignity, and to have their concerns heard and responded to.

Now you have read our article, here are some ideas from our team for what you can do to help young people to be safer:

- You can BE that person who can be trusted.
- Show faith in young people's ability to do things, even when they might doubt themselves.
- Find out more about safety and harm so you know how to respond when a young person asks for your help.
- Make time to sit together, talk, listen. Find a way to help the young person to have their say and make choices about their safety.
- Help the young people you support to plan a safe place to go if they don't feel safe.
- If you find good information about safety, share it! You never know who will be looking on public Facebook pages and Instagram.
- If you see something, say something. Don't stay silent about abuse.



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'LISTEN TO ME' – EXPLORING NEW WAYS OF SUPPORTING THE SAFETY OF PEOPLE WITH INTELLECTUAL DISABILITY

James Bannister

With the establishment of the first national Quality and Safeguards Commission for people with disability being supported by the National Disability Insurance Scheme (NDIS), the specific quality and safety requirements for workers and service providers are clearer than ever before. Having established the 'what', the question remains on the 'how' – specifically, how to bring about the cultural change required to ensure the safety of people with disability and how the voice of people with disability leads this change.

NDS has been exploring this issue through the *Zero Tolerance Initiative* since 2013. *Zero Tolerance* takes a human rights-based approach to build understanding of workers at all levels within disability service providers - from volunteers to board members – on their role in supporting cultures in which people with disability are safe and feel safe. Drawing on local and international research and cross-sector consultation, the [Zero Tolerance Framework](#) sets out a curriculum of practical actions for providers and disability support workers. Having articulated these actions, focus then switched to making them happen.

The first step was to partner with advocacy organisations to ask people with disability around Australia their views on safety. Participants across Australia (over a third of whom identified as having an intellectual disability) were asked about specific actions providers can do to make people feel safer. The resultant report [Speaking up about Safety](#) reveals a clear and consistent answer: 'listen to me' - listen to my experiences; respect my choices; include me in decisions about how and when I am supported, and who by.

'Listen to me' is a stark reminder of the uneven power dynamics common to all forms of abuse and violence. Such power imbalances are especially common for people with cognitive or intellectual disability who report incorrect assumptions of capacity and risk averse, paternalistic support. The vast majority of disability support workers are well-intentioned and want to do the right thing, but until the 'choice and control' mantra of the NDIS becomes reality, the power dynamic remains uneven.

Addressing this imbalance has been a key focus for Zero Tolerance. Drawing on *Speaking up about Safety* and Schalock's Quality of Life indicators, we developed the [Empowerment Circle](#). This self-reflection tool prompts workers to reflect on how to support people with disability empowered in all areas of their life and the impact of their own actions on the people they support.

The Empowerment Circle underpins [Understanding Abuse](#), a set of training resources which use filmed scenarios with actors with physical and intellectual disability portraying examples of uneven power dynamics, and how even well-intentioned actions can impact negatively on people with disability.

The scenarios for all Zero Tolerance resources are drawn from real life experiences. For all new projects we work with advocacy organisations and small groups of people with disability to explore aspects of support. Working closely with Inclusion Australia we have been able to ensure the experiences of people with intellectual disability have been reflected in all our films to date.

We seek to increase the involvement of people with disability with each new learning resource. For [Recognising Restrictive Practices](#) people with intellectual disability provided on-screen commentary on the scenarios alongside other experts. For [Responding to Abuse](#) this extended to people with intellectual disability being full and active members of the project working group with roles in scripting, performing and even aspects of filming. Actors were encouraged to workshop scripts and bring their own experiences and language to their performances to ensure the scripted scenarios feel and look true to life, resulting in our strongest films to date.

Reinforcing films and eLearning with other methods, NDS partnered with VALID to co-present a series of nationwide forums on abuse. Combining *Understanding Abuse* and VALID's *Staying Safe* resources (powerful yet accessible short films to empower people with disability to 'speak up, reach out and get help') we intentionally brought people with disability and frontline workers together in the same room to deliver the same message; that abuse and neglect are not okay.

This approach is informing work with the Victorian Government to deliver abuse training to group home staff. Face to face workshops are co-facilitated by presenters with disability, combining evidence-based practice and lived experience. Creating this equal platform for conversations about abuse, neglect and rights is a critical part of our ongoing work to create more balanced rights-based cultures.

Feedback has been highly positive. This reinforces that 'listen to me' is more than just a well-intentioned sentiment but represents the solution to the 'how'. After so many years of 'nothing about us without us' this will come as no surprise to people with disability. However, it feels that perhaps Australia is finally listening.



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■ www.nds.org.au/resources/zero-tolerance

SEXUAL LIVES & RESPECTFUL RELATIONSHIPS: A RIGHTS BASED APPROACH

A/Prof Patsie Frawley & Dr Amie O'Shea

Deakin University

The SL&RR model

Sexual Lives and Respectful Relationships (SL&RR) is a community based model of sexuality education, information and activity that brings people with an intellectual disability together with professionals from community organisations to focus on sexuality rights for people with an intellectual disability. There are four parts to the SL&RR model. 1. Peer to peer work on sexuality rights through the peer led sexuality and respectful relationships program; 2. Supporting change in support relationships through learning partnerships 3. Sector development through partnerships with community organisations involved in domestic/family/ sexual violence, women's and community health and disability advocacy; and 4. Systemic change through research and translation of outcomes.

(See figure 1 SL&RR Model, Frawley, 2011)

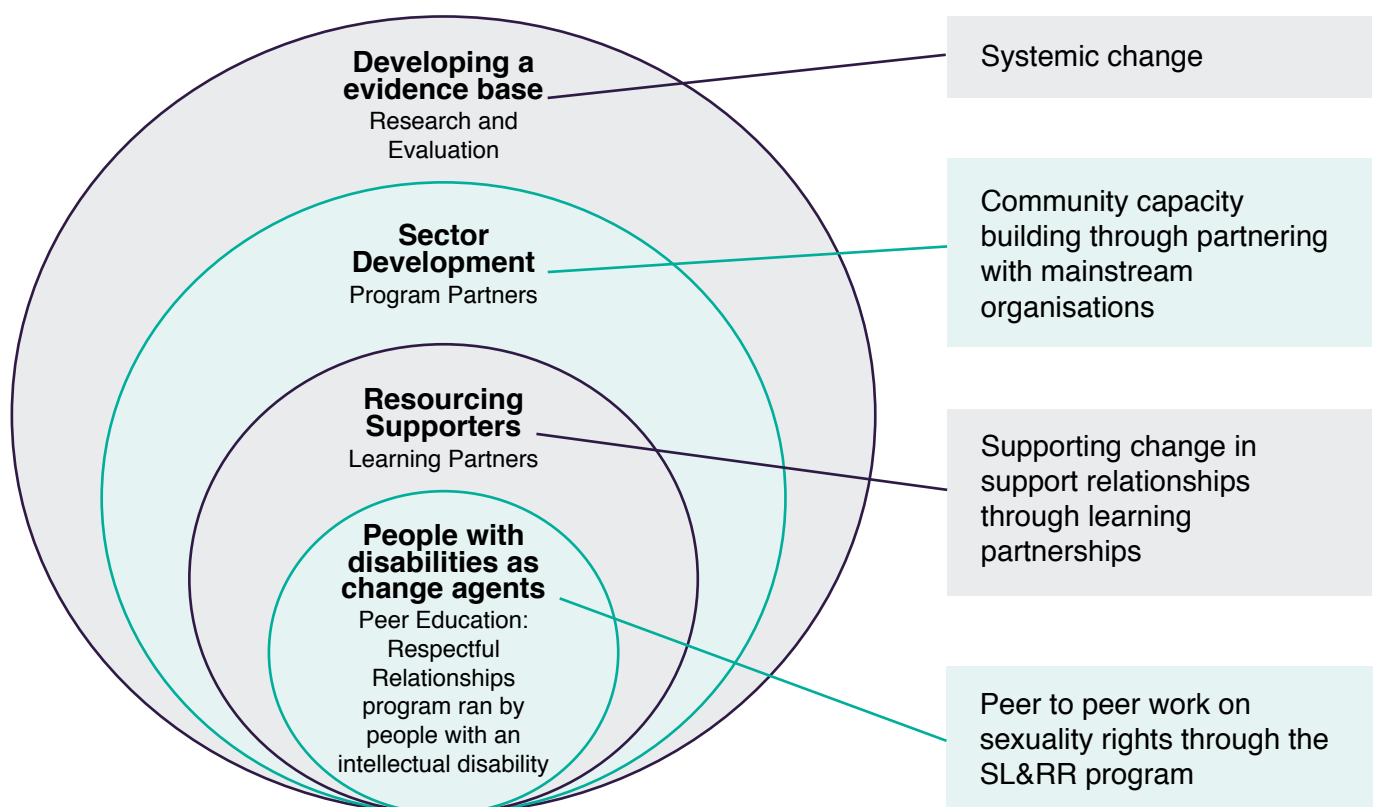


Figure 1: SL & RR Model

SL&RR is a social ecological model for challenging stereotypes, systems, beliefs and behaviours that underpin violence and abuse in relationships including those that are gendered and ableist. The SL&RR model is based on the work of the World Health Organisation which informs domestic policy in Australia including the National Plan to Reduce Violence against women and children (DSS, 2010¹) which SL&RR is also aligned with. It recognizes that work needs to be done at individual, community and system wide levels to prevent violence and abuse in relationships and has at its centre a focus on respectful relationships at all levels including personal and social relationships. Equality is a key principle that underpins these models and dismantling attitudinal, interpersonal and social barriers to equality a focus of the work informed by these approaches.

Research into the SL&RR program has examined how the model works to effectively connect participants with mainstream services and also build the capacity of these services to support people (cohealth, 2016; Frawley & Anderson, 2014; Frawley & O'Shea, 2012).

Peer to peer respectful relationships program

Sexual Lives & Respectful Relationships (SL&RR) is a peer education program for and by people with intellectual disability (Frawley et al., 2017). Based around the real life stories of people with an intellectual disability collected in research (Johnson, Hillier, Harrison, & Frawley, 2000), the program is delivered using adult learning principles (Merriam & Bierema, 2013). The program is co-facilitated by Peer Educators and Program Partners who have completed the train the trainer program delivered by Deakin University and who work together in local community-based sites. There are currently 7 SL&RR sites in operation, with 4 more in development in NSW, Victoria, Sweden and New Zealand. A version of the program is currently being adapted for use with people with acquired brain injury, in partnership with Synapse NSW. The sites, along with all SL&RR activities, follow the dictum of the self-advocacy movement “nothing about us without us”, claiming a rightful place for people with an intellectual disability as experts about their own experiences and as advocates about their sexuality rights.



Image 1 and 2: SL&RR rights cards © Deakin University

¹The peer led and community partnered SL&RR model was piloted from 2009 – 2011 with funding from the first National Plan to Reduce Violence against women and children. An evaluation of this pilot is reported in Frawley, Barret and Dyson (2011).

Importantly, the SL&RR program is strident in its assertion of the rights of people with intellectual disability – in this case focusing particularly on their right to relationships that are respectful. It also recognizes their right to be present in this space, and their expertise, gained through lived experience and a unique connection with program participants that is part of the program's success. Environments which foster such forms of inclusion and visible representation of people with disability have been shown to have positive outcomes (Frawley, Dyson, Robinson, & Dixon, 2015). Rights are a theme throughout the program, and the focus of the SL&RR Rights Cards, an activity using an easy English version of the rights first articulated by researcher Ann Craft (1983).

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References

- cohealth. (2016). *Living Safer Sexual Lives: Respectful Relationships Metropolitan West Evaluation*. Melbourne, Victoria: cohealth.
- Craft, A. (1983). Teaching programmes and training techniques. In M. Craft & A. Craft (Eds.), *Sex Education and Counselling for Mentally Handicapped People*. Tunbridge Wells: Costello.
- Frawley, P., & Anderson, S. (2014). Adopting mainstream approaches: Taking account of and including people with an intellectual disability in violence and abuse prevention. <https://www.vichealth.vic.gov.au/media-and-resources/publications/adopting-mainstream-approaches>: VicHealth Innovation Research Grant.
- Frawley, P., Dyson, S., Robinson, S., & Dixon, J. (2015). *What does it take? Developing informed and effective tertiary responses to violence and abuse of women and girls with disabilities in Australia: State of Knowledge report*. ANROWS. NSW. Retrieved from <http://www.anrows.org.au/publications/landscapes/what-does-it-take-developing-informed-and-effective-tertiary-responses>
- Frawley, P., & O'Shea, A. (2012). Relationship education by people with an intellectual disability: An Australian peer educator model. Conference presentation. 14th World Congress International Association for the Scientific Study of Intellectual disabilities, Halifax, Nova Scotia, Canada. *Journal of Intellectual Disability Research*, 56(7&8), 726. doi: 10.1111/j.1365-2788.2012.01583_7.x
- Frawley, P., O'Shea, A., Stokoe, L., Cini, V., Davie, R., & Wellington, M. (2017). *Sexual Lives and Respectful Relationships training manual*. Geelong: Deakin University.
- Johnson, K., Hillier, L., Harrison, L., & Frawley, P. (2000). *People with intellectual disabilities: Living Safer Sexual Lives*. Melbourne: Australian Research Centre in Sex, Health and Society.
- Merriam, S. B., & Bierema, L. L. (2013). *Adult learning: Linking theory and practice*: John Wiley & Sons.

DIVISION REPORT

June 2018

Aotearoa, New Zealand

On April 27 2018 our division met face to face in Wellington. Due to the wide geographical spread of members we usually meet via teleconference during the year. We are grateful to Inclusion NZ for hosting us. The main focus of this meeting was the programme for the upcoming conference to be held at the Rydges hotel in Wellington on July 2 & 3rd 2018. Sharon Brandford and Jonathon Goodwin as Co-convenors in partnership with Paardekoopers have done a great job organising the conference. Participants can be assured of a programme that will inform, challenge, provoke debate and stimulate positive action. The programme is now up on the ASID website and early bird registration closes May 25 2018. ASID NZ Committee members who attended the meeting are photographed below.



Standing left to right: Adrian Higgins, Deborah Espiner, Chairperson, Anne Mathieson, Claire Stewart, Jonathan Goodwin, 2018 Conference Co-convenor, Judy Garriock, Treasurer, Brigit Mirfin-Veitch
Seated left to right: Sharon Brandford, 2018 Conference Co-Convenor, Christine Wilson, Fran Hartnett, Secretary, John Grant

Olive Webb and Hamish Tavernor are also on the committee. Our committee hopes to see many of you at our July 2018 conference. You will not be disappointed.

Fran Hartnett

■ NZchair@asid.asn.au

New South Wales/Australian Capital Territory

On Tuesday 24th April, 23 people participated in a workshop on planning conducted by Dr Angela Dew and Ms Laura Hogan (pictured on the cover). The workshop was co-hosted by ASID NSW/ACT, the Intellectual Disability Behaviour Support Program (UNSW Sydney), the Intellectual Disability Rights Service, and the Centre for Disability Studies (The University of Sydney).

Workshop participants were introduced to the 'Living the life I want: A guide to help with planning' resource authored and published by the Intellectual Disability & Behaviour Support (IDBS) team. Based on empirical research and refined with people with intellectual disability, family members and support workers, the guide is designed for use by and with people with intellectual disability and uses Easy Read and pictorials along with an example of a person called Layla. A supporters' section in the back of the guide provides those helping a person with intellectual disability to plan with additional material to assist them through the process.

The workshop was very hands-on, with participants willing to put their bodies on the line in order to experience body mapping (pictured below) as a technique to support a person with intellectual disability to make a plan. Working in groups using case studies of people with intellectual disability, participants applied pre-planning and planning skills to map goals for the fictitious person. The maps were then shared with the full group. Participants reported it as a fun and worthwhile experience providing them with an alternative way to engage a person with intellectual disability in planning.

The 'Living the life I want: A guide to help with planning' can be downloaded for free from the IDBS website: arts.unsw.edu.au/idbs/support-planning



Another recent activity, as part of our Ethical Issues in Ageing series, was a very interesting webinar on End of Life presented by Dr Michele Wiese from Western Sydney University and Joan Ryan from Palliative Care NSW. They gave a clear message about the importance of discussing end of life issues with people with intellectual disability. A recording of this webinar will be available on the ASID website soon.

The next webinar in this series will be conducted by Dr Angela Dew on Thurs 28th June 2018, exploring the issues for families as people with intellectual disability age. Registrations for this event will be open on the ASID website soon.

Western Australia

This quarter ASID WA brought together a number of research academics to discuss the future of Intellectual Disability Research in Western Australia. This session arose from the findings of an earlier audit by members of ASID WA to identify both researchers in WA and the research being undertaken in the area of Intellectual Disability. The discussion, facilitated by Professor Angus Buchanan, centred around the impact of the current service environment on research, access to research grants, higher degree research, consumer-driven research and translation. This session generated a number of collaborative ideas to develop the research agenda and ASID will be hosting further networking opportunities for researchers into the future.

In the coming weeks, ASID WA will be holding their Sundowner featuring a panel discussion that will focus on “What is Evidence in the NDIA world? Innovation informing outcomes.” This panel discussion will aim to connect innovative practice and research with evidence to inform positive outcomes for people with disability. Panel questions will focus on what evidence is required by participants for the NDIA, and feedback on what participants have learnt about providing evidence. Please check ASID website for details <https://www.asid.asn.au/events>.

Christine Kuca-Thompson

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Queensland

The Qld division committee has been very busy assisting with the organisation of the upcoming national conference on 14-16th November 2018, being held on the Gold Coast, in particular consulting with local stakeholders and self-advocates across Queensland. We also have been organising an upcoming workshop, being presented by Professor Nick Lennox titled 'People with intellectual disability: How to promote good physical and mental health and healthcare' being held on the 4th of June in Brisbane. Anyone interested in Brisbane can go to the link http://www.asid.asn.au/events/117_professor_nick_lennox_workshop to register. The Qld division has also requested the ASID Association National board to write a letter to the Qld premier Honourable Annastacia Palaszczuk MP, to draw her attention the Human Rights Watch report “I needed help, instead I was punished: Abuse and Neglect of prisoners with Disabilities in Australia’ published on February 6th 2018, on the experiences of People with Intellectual and cognitive disabilities in prisons in Queensland.

Victoria Tucker

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BOARD MEMBER PROFILES

Meet Ruth Firstbrook

Ruth has worked in the intellectual disability services sector since 1970 in a career that has progressed from disability nursing to nurse education, staff training and management. The Ruth was involved with AGSOMD, a very early predecessor to ASID and has regularly attended conferences both nationally and IASSID internationally.

Ruth is now self-employed and provides training to support workers, developmental educators and organisations in best practice support for people with intellectual disability.

Ruth has a particular interest in supporting people with intellectual disability who demonstrate behaviours of concern. She commenced an organisation in the Riverland of South Australia in 1986. The expanded service continues today providing quality support to individuals in their rural region and Ruth remains on the Board.

Ruth has a specific interest in support services and staff training in rural regions and the development of best practice models that serve the individuals and their communities.

Like many people who live in rural areas, Ruth is a member of several community boards ranging from health to hospitality. Ruth is a passionate 'quizzer' and a regular at local quiz nights she enjoys cooking, reading, some gardening and is always interested in learning something new!



Meet Sharon Brandford

Kia ora tatou. I'm one of two NZ Directors on the ASID Board. My roots are in the far south of NZ (Invercargill), with its chill southerly winds, open spaces and warm hearts. I now live happily in Wellington with my partner Paul. We are often tramping. I like sharing my tramping pictures and stories!. I can be a rowdy person, so the silence of the mountains helps me get anchored again. Currently I volunteer some of my time to a group managing traplines to eradicate rodents that threaten our native birds.

Most of my work involves strengthening services for people with intellectual disability and families supported by non-government providers. I used to work as a clinical psychologist. Now I'm self-employed, I do project work with service providers needing a hand to



respond better to the needs of people.

I have a longstanding regard for elders with intellectual disability, especially those facing re-institutionalisation due to dementia and health concerns. I am interested in how we investigate the deaths of people with intellectual disability in NZ; I think this indicates how much we care about their lives.

With all the transformations of how we support people with learning disabilities and their families, its more important than ever that ASID promotes the value of good practice being informed by solid research and lived experiences.

Meet Paul O'Dea

Hi my name is Paul O'Dea. I have lived on my own for 21 years in a unit in Woolloowin. I have 3 younger brothers and my dad who lives in Brisbane. My mum lives permanently in Spain but comes over every couple of years to see us. I work 3 days a week at an ADE and have been doing that for 18 years. I do volunteer work at Community Living Association as treasurer and have been doing that for 21 years also, I am treasurer for Independent Youth Housing Group which is a not for profit company that is run and managed by people with a disability.

My role at Queenslanders with Disability Network is NDIS on the grid project and that is about talking to hard to reach people that might be eligible but don't know that they are and to give them information about the NDIS. That finishes at the end of June. I have been connected with QDN or a few years now. People can ring the NDIA to see if they are eligible or not.

People are supporting each other by getting the necessary documents together for example they may need a letter from their doctor to confirm what disability they have or they may need to go for a IQ test as well.

My proudest moment is coming 1st in my bowling league last year. My personal motto is say no to bullying as I have been bullied myself.

What motivates me is that I want to make sure people with disabilities are heard round the country

The government needs to listen to people with a disability more in relation to

- Housing
- How they want to live their own lives
- To help people with disability to be more socially active





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, 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.

Dr Kathy Ellem

Dr Kathy Ellem is a Senior Lecturer in the School of Nursing, Midwifery and Social Work at The University of Queensland, Australia. She has been an advocate, researcher, lecturer, and social worker in the disability field for over twenty years. Kathy is a parent of a young man with intellectual disability and it is from this experience that her interest and passion for improving the lives of people with intellectual disability began. Kathy's program of research centres on the lived experiences of people with cognitive disability, particularly those people with complex support needs and multiple disadvantage who have come into contact with the criminal justice system.



Dr. Ann Fudge Schormans

Dr. Ann Fudge Schormans is an Associate Professor in the School of Social Work at McMaster University (Ontario, Canada). She was a practicing social worker for many years, working with people with intellectual disabilities in the Community Living and Child Welfare sectors. This practice background, combined with ongoing activist work and her experiences parenting her daughters with intellectual disabilities influence her teaching and research. Much of her research has focused on issues that co-researchers with intellectual disabilities who have worked with her have identified as needing attention. For example, the parenting experiences and aspirations of people with intellectual disabilities, being homeless with an intellectual disability, inclusion in city life, friendships, and how people with intellectual disabilities are represented in cultural media. You can find out more about Ann's projects here: www.socialsciences.mcmaster.ca/people/schormans-ann-fudge



Monica Cuskelly

Professor Monica Cuskelly, Associate Dean of Research at the University of Tasmania. Monica works in the areas of intellectual and developmental disabilities, with a focus on self-regulation and mastery motivation. She is involved in a program of research in Down syndrome: longitudinal study of the cognitive development of individuals with Down syndrome now in its 35th year; longitudinal study of the development of self-determination in individuals with Down syndrome now in its 20th year; maternal influences on developmental outcomes of individuals with Down syndrome.



Andrew Jahoda

Andrew Jahoda is Professor of Learning Disabilities in the Institute of Health and Wellbeing at the University of Glasgow. He also has a clinical role as honorary Consultant Clinical Psychologist at NHS Greater Glasgow and Clyde. Andrew's research interests concern the mental health and wellbeing of people with learning disabilities, and the contribution made by a range of psychological and social factors, including stigma and social exclusion. He is also interested in adapting psychotherapeutic approaches in a manner that is sensitive to the lived experience of people with learning disabilities.



2018 Conference Speakers



Chris Hatton

Professor of Public Health and Disability
Co-Director, Public Health England Learning Disabilities Observatory
Regional Co-Director, NIHR Research Design Service North West

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When the Editor of IDA asked me to write a short biography/profile, she sent through four questions to get me started. These stopped me in my tracks a bit, so rather than do the usual biography I thought it might be more interesting to answer these questions instead.

What led you to work in this area?

In the late 1980s I was doing a psychology undergraduate degree in Manchester, England, and one of the final year options was called 'three devalued groups', taught by clinical psychologists working out of a shrinking (but not completely closed) Victorian institution on the northern outskirts of Manchester. The buildings are still there today, hemmed in by an urban motorway, a massive supermarket and TGI Fridays. Strongly influenced by Wolf Wolfensberger, they talked about the lives of people with dementia, people with psychosis and people with intellectual disabilities, how the institution they were working out of was a physical manifestation of society's devaluation, and how they were trying to find alternatives. I was furious and inspired in equal measure, and was lucky enough to have a world-class research centre working with people with intellectual disabilities on my doorstep, the Hester Adrian Research Centre. And although I am now a proud uncle of my niece who has a label of intellectual disabilities, that course was where it started – thank you Ian Fleming and Alan Tatham!

What have been your highlights?

I've found this a really hard question, so there are a few ways of (not) answering it. The first is that the kind of work I do is never done alone – it always involves colleagues and teams of people and is much the better for it, and any highlights of mine are because I've been lucky in my colleagues. The second is that it's for others rather than me to say what any highlights have been - our work needs to be judged on how it has been part of any positive changes in the lives of people with intellectual disabilities, and I'm not in the best position to make those calls. The closest to a real answer is that although a new database brings a glint to my eye, I'm always most energised by working with self-advocates, families, and other people who are doing good stuff – that gives me a real buzz.

How has your work changed practice and what needs to change?

Another difficult question. I've been working for over 25 years now, in times that felt hopeful in terms of progressing the rights of people with intellectual disabilities and in times like now where it feels that these rights, never completely realised, are being dismantled. So some research work, for example on small community-based supported housing, person-centred planning, personalisation and short breaks for families and children/young people with intellectual disabilities, has felt like we have provided some of the bricks for building progressive social change. In less hopeful times research work can feel like it has a more defensive function: putting rocks in the road to ameliorate unhelpful policies or practices, providing some supportive evidence for those articulating a progressive case, and laying some foundation stones to be built on in better times.

And although I'm a long way away from this in my work so far, the way that research itself is commissioned, conducted and used needs to change – starting with people with intellectual disabilities being in positions of decision-making authority about what gets researched, who does the research, what counts as evidence, and how research can be used to effect social change.

What will you be presenting at ASID and how might it help attendees' practice/thinking?

At ASID, I'll mainly be talking about the work I've been involved in for almost 10 years as part of a collective running a Public Health Observatory focusing on people with intellectual disabilities. We have been trying to document and understand the health inequalities experienced by people with learning disabilities, and help people use that evidence to tackle these health inequalities. At ASID I'll be discussing a question that has been on my mind for a long time – evidence is all very well, but what is really needed to eliminate the pervasive health inequalities people face? I'm hoping that together we can come up with a convincing answer.

2018 Conference Speakers



Brigit Mirfin-Veitch

Director, Donald Beasley Institute

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What led you to work in this area?

I completed my undergraduate degree in Sociology with a growing awareness that diversity can lead to disadvantage, and with a passion for qualitative research. My ambition at that early stage was to pursue a career in health research. After my requisite Kiwi overseas experience, I returned to New Zealand, moving from Christchurch to the even more southern city of Dunedin. After a series of “odd jobs” and volunteer work I applied for fixed-term, half-time position as a Research Assistant with the Donald Beasley Institute in 1994, which was an organisation I knew nothing about at the time. What initially attracted me to the job was the opportunity to finally get the chance to undertake real research, with real people, in the real world; an exciting proposition for a recent graduate who was starting to question whether a Sociology degree had any practical value outside of the University gates. Within several weeks of starting work at the Donald Beasley Institute, another grant came in and I was offered fulltime work. Twenty-four years later I am still with the DBI, albeit in a different role, and my drive to understand and challenge inequity and injustice continues to motivate me. My penchant for qualitative methodologies has also remained intact.

What have been your highlights?

It is the quiet and perhaps more hidden aspects of my work that have been my personal highlights over the past 24 years. In particular, people with learning (intellectual) disabilities trusting us enough to share the intimate details of their lives and experiences in the hope that this will lead to positive change for others has always been the most inspiring aspect of my work. I have also been extremely fortunate to work in disability research in an era where I have been able to observe, and to some extent be part of the slow progress from invisibility to (increased) visibility for people with learning disabilities within their local communities, and more broadly in society. I have also highly valued the many opportunities I have had to learn from many inspiring “trailblazers” who exemplify the meaning of the word perseverance.

How has your work changed practice and what needs to change?

An honest answer to this question is that my work has often but not always led to changes in policy and practice. In my experience, it is not often that a researcher can state, unequivocally, that their research has been translated to practice in all the ways it potentially could be. Even with the greatest will in the world, we are not always able to change the system despite having generated strong evidence to support change. That said, I think there is an increasing awareness and commitment to evidence-based policy and practice which makes it more difficult to ignore research findings that indicate that doing things differently would lead to improved outcomes for people with learning disabilities. In terms of what needs to change, I have observed over many years that people with learning disabilities continue to identify the same set of core issues when asked to talk about the parts of their lives that they find difficult or would like to change. This suggests that we have still not achieved the level of change that people with learning disabilities are looking for, or at least not for everyone.

What will you be presenting at ASID and how might it help attendees' practice / thinking?

I have been asked to talk about my research and education in New Zealand in relation to the legal system. Over the past 5 years I have been involved in several research and education projects and initiatives designed to contribute to the development of a more responsive legal system for people with learning disabilities and other individuals who may experience vulnerability when involved in legal proceedings. My presentation will focus on the notion of access to justice in a broad sense, describe what we have learned through our research, how we have tried to translate findings into policy and practice, and will give an honest assessment of what we have and have not been able to achieve. In particular, I will discuss the extent to which we have worked affirmatively or transformatively across this body of work, and share my views on which approach is more effective in "shaking things up."

OUTCOMES MEASUREMENT IN DISABILITY SERVICES

Dr Stella Koritsas and Dr Nick Hagiliassis



Dr Stella Koritsas

Manager, Strategic Research
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Outcomes refer to the impact or the effect that a service or support has on users (Miller, Cooper, Cook, & Petch, 2008). For individuals, having access to outcomes data can help them track changes and determine whether results have been achieved (Batty et al., 2012). For service providers, this data can provide information about whether a service is achieving its objectives and it can help identify areas for service development (Garralda, Yates, & Higginson, 2000). From a Government perspective, outcomes data can provide insight into the effectiveness of policy and investment value (Department of Health, 2014). Despite the obvious advantages of collecting outcomes data, it is not a particularly consistent or widespread practice in disability services. Since the introduction of the National Disability Insurance Scheme (NDIS), there has been increased interest in outcomes measurement, which has raised many questions for service providers, including what types of outcomes should be captured and practical ways to achieve this.



Dr Nick Hagiliassis

Senior Psychologist
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At Scope, our research into outcomes has spanned more than a decade. We have conceptualised outcomes from a 'whole of life, whole of person' lens in which the impact of services and supports can occur across a range of important areas of the person's life (e.g., wellbeing, social, economic) and adopted an approach that is sufficiently versatile to allow measurement across the range of services and supports a person might seek (e.g., therapy, supported accommodation, community inclusion). This includes an emphasis on self-report so that, as far as possible, a person's own perception of his or her life is captured and their agency is affirmed, inclusive of people with intellectual disability.

Although there are a number of outcome measurement tools in existence, their use is limited by the following issues:

- Very few focus specifically on the outcomes of service provision and so conclusions about services cannot be made;
- Few take a whole of life, whole of person approach, instead they focus on narrowly defined outcomes or are clinically oriented;
- Many have been designed to obtain information from proxies or, because of complexity, rule out use by people with disability,

particularly intellectual disability; and

- Validity and reliability have not been established and so measures cannot be used with confidence.
- Many involve complex or lengthy administrative procedures or require specialised training, which may not be feasible for many providers.

In order for disability service providers to use outcomes measures more consistently, these issues need to be addressed. Further, in order to build outcomes measurement into day-to-day practice, measures and processes need to have minimal impact on the provision of services, which means they must be practical, affordable, require minimal training, low effort and time for administration, analysis and interpretation scoring.

To this end, we have developed and validated two outcomes measures specifically for disability service providers: The Outcomes and Impact Scale – Revised (O&IS-R; Wilson, Hagiliassis, Koritsas, & Caldwell, 2014) and The Measuring Outcomes in Services and Supports Tool – Short Form (SF-MOSS; Hagiliassis, Nicola-Richmond, Wilson, & Mackay, 2014). The O&IS-R was developed to elicit information directly from a person with disability and measures the impact of a service across nine life domains identified from the literature and review of Government policy directives. It takes between 5-10 to complete, is available in both a standard and Easy English, and has been found to be reliable and valid (Koritsas, Hagiliassis, & Cuzzillo, 2017). The SF-MOSS is an instrument to set person-directed goals and evaluate the extent to which they are realised in the course of service delivery. It is administered as an interview to the person with disability by a staff member and measures the progress of a goal (performance and satisfaction) at pre and post-service points (and other time points if needed). The results of research have indicated good face, content, and concurrent validity (Hagiliassis, Koritsas, & Cuzzillo, 2017). Both surveys are now available for use online within an outcomes measurement app ([Outcomes Measurement Frameworks | Socialsuite](#)) which enables the collection, compilation and analyses of outcomes data in one single, easy-to-access location.

<https://www.scopeaust.org.au/>

Summary

- Outcomes data about services assist with service development, and planning and reporting back to funders about the impact of services.
- Processes and measures for measuring outcomes of disability services are limited, which makes routine collection of outcomes data difficult.
- Outcomes measures need to be inclusive of people with intellectual disability and include Easy English versions
- Online surveys that measure outcomes need to be valid, reliable, affordable, practical and quick to administer

References

- Batty, M. J., Moldavsky, M., Sarrami Foroushani, P., Pass, S., Marriott, M., Sayal, K., & Hollis, C. (2012). Implementing routine outcome measures in child and adolescent mental health services: from present to future practice. *Child and Adolescent Mental Health*, 18(2), 82-87.
- Department of Health. (2014). *The Adult Social Care Outcomes Framework 2015/2016*. United Kingdom: Department of Health.
- Garralda, M. E., Yates, P., & Higginson, I. (2000). Child and adolescent mental health service use: HoNOSCA as an outcome measure. *The British Journal of Psychiatry*, 177(1), 52-58.
- Hagiliassis, N., Koritsas, S., & Cuzzillo, C. (2017). *Measuring Goal Realisation associated with Disability Services and Supports: Initial Evidence for a new tool*. Paper presented at the 2017 IASSIDD 4th Asia-Pacific Regional Congress, Bangkok, Thailand.
- Hagiliassis, N., Nicola-Richmond, K., Wilson, E., & Mackay, A. (2014). *Measuring Outcomes in Services and Supports - Short Form (SF-MOSS)*. Melbourne: Scope.
- Koritsas, S., Hagiliassis, N., & Cuzzillo, C. (2017). The Outcomes and Impact Scale - Revised: The psychometric properties of a scale assessing the impact of service provision. *Journal of Intellectual Disability Research*, 61 (5), 450-460.
- Miller, E., Cooper, S.-A., Cook, A., & Petch, A. (2008). Outcomes important to people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 5(3), 150-158.
- Wilson, E., Hagiliassis, N., Koritsas, S., & Caldwell, M. (2014). *The Outcomes and Impact Scale - Revised*. Melbourne: Scope.

EVALUATION OF NATIONAL DISABILITY INSURANCE SCHEME

Relatively poorer outcomes for people with intellectual disability.



Susan Jackson

PhD. candidate, La Trobe
University

The Evaluation of the NDIS final report (Mavromaras et al., 2018) was released recently. It indicates that people with intellectual disability have relatively poorer outcomes from participation in NDIS than participants as a whole and are at greater risk of receiving inadequate levels of support. The evaluation found NDIS is in general leading to higher levels and quality of services and support, improved choice and control over supports, and increased participation and well-being for participants. However access, outcomes, and benefits were not equitably shared across all people with disability. The report states that:

The NDIS was identified to work best for participants and families who were able to strongly advocate for themselves. In contrast,

poorer outcomes were reported for NDIS participants with intellectual disability, psychosocial disability and complex needs or with older carers facing their own health issues. NDIS participants from CALD (Culturally And Linguistically Diverse) backgrounds and living outside urban areas were similarly considered to be disadvantaged under the NDIS.

While many NDIS participants experienced improved supports and outcomes, up to 20 per cent felt worse off than before and about one-third felt no better off. People with intellectual disability and those with mental/psychosocial disability were least satisfied that their NDIS supports were adequate. Those unable to understand NDIS processes or to effectively express their needs were considered to be at risk of receiving inadequate levels of support. Indeed the report goes so far as to say that, 'People with disability who are unable to advocate for themselves or who struggle to navigate NDIS processes are at risk of receiving lower levels of services than previously and many have.' (Executive summary p. xv)

People with intellectual disabilities fared less well than participants generally in relation to several further key outcome areas. They experienced poorer choice and control over their supports, less clear benefits in relation to social participation and reported poorer wellbeing than people with other types of disability.

The report highlights the unfavourable and inequitable impacts that can affect people who have difficulty accessing, understanding and navigating NDIS information and processes and who are less able to advocate for themselves. Whilst a need for better assistance with planning and advocacy emerged clearly through the evaluation research advocacy, as the report notes, is not funded under NDIS.

The evaluation draws on qualitative data from in-depth interviews as well as quantitative data from a large scale survey to assess the impacts of the three-year NDIS trial. It was undertaken between 2013 and 2017 by researchers from the National Institute of Labour Studies at Flinders University with funding from the Commonwealth Department of Social Services. The report can be accessed in several formats, including audio, at (<https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/national-disability-insurance-scheme/ndis-evaluation-consolidated-report>).

References

Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., Goode, A., Walton, H., . . . Flavel, J. (2018). *Evaluation of the NDIS. Final report*. Retrieved from <http://apo.org.au/system/files/143516/apo-nid143516-732911.pdf>

INCLUSIVE RESEARCHERS COLUMN

No Research About Us Without Us

Safeguarding our rights to a good life

Since the last time we wrote for IDA we have been busy as a group of inclusive researchers learning how to be Quality Checkers. We think that Quality Checking is a way to support people with intellectual disability to have better lives. We would like to share with you what is a Quality Checker; what we learned at the training and how we are going to practice Quality Checking with other people with intellectual disability that we have met through Achieve Australia. CDS and Achieve Australia are working together to pilot Quality Checking as a safeguard for people getting the lives that they say that they want to live.

A Quality Checker is a person who visits people with intellectual disability in their homes or at work or a place where people feel comfortable. The Quality Checker has a list of questions that they ask the person they are visiting about how satisfied they are with their living or work place. These questions are based upon the National Disability Standards of Australia and cover things like:

1. I choose who I live with
2. I choose where I live
3. I have my own home
4. I choose how I am supported
5. I choose who supports me
6. I get good support
7. I choose my friends and relationships
8. I choose how to be healthy and safe
9. I choose how I am part of the community
10. I have the same rights and responsibilities as other citizens
11. I get help to make changes in my life

As a Quality Checker we are matched with another person who can be a peer, a support staff member or a family member who we meet before we make the visit to work out our Quality Checker Plan. It is important for us to listen to the person and allow them to say a person's reply with another questions to find out more about what the person has said. These questions are called probes.

At the time of our writing this article we are only starting to make our first visits following two days of training with Dr. Thomas Doukas who is a researcher from Choice Support which is a big organisation for people with intellectual disability in London. Thomas is fun to be with and made us laugh a lot. At the beginning of each day he asked us all what we have seen on the way to the training. This helped us all to get to know one another better. At the training we learned alongside other people who want to be

Quality Checkers from Achieve Australia which is funding this pilot. CDS with Achieve Australia are also researching what happens in the pilot.

When we visit the person who would like to have a Quality Check about how satisfied they are with their life we always go in pairs. We soon will be going for another training day with Thomas Doukas on how to write up a report that will be discussed with the person having the Quality Check at a later date. These reports will support the person and Achieve Australia to check that people with intellectual disability are leading the lives they want to .

In the United Kingdom the government has funded Choice Support to set up a system of Quality Checkers where Quality Checker pairs visit people throughout the UK. Thomas told us that people with disability have said that they feel very comfortable talking with someone like us who has the lived experience of disability.

You will see some photos below of us mixing with one another at the training. We have been told that this IDA is about safeguarding and we think that Quality Checking is one way in which we can safeguard that people with intellectual disability can be heard. Sometimes checking is only done by people asking questions that are ticked like a survey. Checking without real listening is not safe. What we like about Quality Checking that we have learned is that people are visited where they live or work and talk about what they think is going well and what could be better.

We look forward to telling you more about our experience in the next IDA but if you would like to become a Quality Checker you can contact us.

From the CDS Quality Checkers: Susie, Bruce, Mark, Jack, Kelly, Michelle, Maaki, Megan, David, Tanya, Patricia.

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FILM REVIEW

The Grown-Ups

Directed and Written by Maite Alberdi

This is a Spanish film with English subtitles about a group of people with Down Syndrome. It showed at the 2018 film festival in Melbourne, Launceston and Canberra. Keep an eye out for it and read the IDFA Film Review by Guy lodge:

<http://variety.com/2016/film/reviews/the-grown-ups-review-1201924620/>

The film consists of a group of actors or people playing themselves who have been attending the same school/day service for over 20 years. At the day service they are taught about independence but payed a pittance for their work. At home, their family expectations have not changed since they were children. The actors dream of love, marriage and having a place of their own, their dreams shaped by what they see their family members doing. Community inclusion and equality are far from being realised.



REMEMBERING JOAN

Dr Justine Joan Sheppard died on 31st March 2018 after living with cancer.

Joan was an honorary Adjunct Associate Professor in the Communication and Communication Disorders program, Department of Biobehavioral Sciences at Teachers College, Columbia University, and has presented many training workshops in the USA, Canada, Australia, New Zealand, Singapore and Europe. Dr. Sheppard, working with her clinical and research colleagues, developed the Dysphagia Disorder Survey and associated tests and assessment tools specifically for children and adults with developmental disability. She conducted many training sessions in Australia and presented at ASID and IASSID conferences. She will be remembered by many colleagues for her insightful and meticulous work and her generous nature. She was a colleague, mentor and friend to many and will be sorely missed.



ONLINE RESOURCE

World-First Online Resource to Support People with Intellectual Disability Understand End-Of-Life

Talking End of Life...with people with intellectual disability (TEL) is a free online resource that shows you how to teach people with intellectual disability about end of life. It is designed for disability support professionals (DSPs) but is also helpful for families, health professionals, and educators. With assistance, people with intellectual disability might also find the TEL information helpful.

TEL comprises 12 modules, on topics like funeral wishes, what death is, and cultural beliefs. Each module includes activities, case studies, videos, resources and links to the research. TEL also offers a set of additional website resources and videos.

TEL reflects 10 years of Australian research on end of life and people with intellectual disability. The project leaders are Professors Roger Stancliffe and Josephine Clayton from The University of Sydney, Dr Michele Wiese from Western Sydney University, Ms Gail Jeltres from Unisson Disability and Professor Jennifer Tieman from Flinders University and CareSearch.

TEL is funded by the Australian Government Department of Health under the Public Health and Chronic Disease Grant Program.

You can find TEL at <https://www.caresearch.com.au/TEL/>

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THE ROCKHEADS



The Rockheads are a rock band based in the Barwon Region, Victoria and they are made up of young people with a disability who expressed an interest in music and how it could support them to be more involved in the community. They have been rehearsing and performing for three years. The members come from a number of councils and shires in the G21 region of South West Victoria – Geelong, Golden Plains and the Surf Coast. The concept for the group emerged from a research project into making community music accessible to young people living with disability.

The group was initially brought together by music therapist, Melissa Murphy, and Scope's Community Inclusion Officer, Emmanuel Pimentel. Melissa is an experienced music therapist with over 20 years of experience working in the disability sector with children and adults. She started the project as part of her PhD research into improving social connections for young people with a disability after they leave school and transition into adulthood. See <https://bit.ly/2Kf85MY>

The initial project that was the germination of The Rockheads was called Linking In and Grooving Out and it had the aim of bringing together a group of young people with a disability once a week for a jam session and other musical fun. A key part of the jam sessions and rehearsals was that they be held in a community setting to increase the opportunities for social connections. These sessions allow the members to express themselves creatively, improve their social connectedness, make decisions and to work collaboratively. As the research progressed, the band members expressed their interest in making The Rockheads a permanent fixture in their lives beyond the conclusion of the initial project.

Melissa (now Dr. Melissa!) worked with Emmanuel to set up the band as a sustainable ongoing group. An important part of the band's charter is that it is open to all local people with a disability, not just people supported by Scope. This helped to develop new contacts and community networks. The band also rehearses in community spaces such as The Fort Youth Drop In Centre and The Salvos site in Corio. The initial members made up an organising committee to decide on what type of music group they wanted to be, what type of music they would play, who could join up, and where they would rehearse. Most importantly, the group decided on the name "The Rockheads"!! The band has a core of 6 people with a disability and the stability of consistent supports who buy into the philosophy of the band and also includes Mel and Emmanuel. A feature of the band is the camaraderie and shared experience and no one band member is more important than another. The band play a variety of music including some original songs written by members of the band and cover songs based on member's preferences.

The Rockheads meet each week in Geelong and often invite community members to join in – it is not uncommon to have people from the community wander into the bandroom and start dancing or singing and making requests!

The band is always proactive in looking for sponsorships and grants and they wish to particularly thank the Rosaleen and Ron Raitman Family Grant and the Geelong Community Foundation. The Rockheads have performed numerous gigs including the Having a Say conference in Geelong in 2017 and 2018, the International Day of Disability Event for the Surf Coast Shire and Disability Pride at the Victorian College of the Arts. For more information see the blog at <https://www.scopeaust.org.au/rockheads-rock-costa-hall-geelong/> or contact Emmanuel Pimentel.



"I like music with my same support workers. They know my music. I like music because I play the bass."
Joel Green



"I like the band. The people are very nice. I like singing."
Tom Lock

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FACEMATCH

USING FACE-MATCHING TECHNOLOGY TO HELP FIND A DIAGNOSIS FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY

Dr Tracy Dudding-Byth

Despite the diagnostic power of advanced genomic sequencing, many individuals with moderate to severe intellectual disability (ID) are unable to be diagnosed due to the sheer number of genes with unknown function. With the vision of improving rate of diagnosis and health outcomes for this group of individuals, Dr Tracy Dudding-Byth and Professor Brian Lovell have recently launched the international FaceMatch Project, which uses computer face-matching technology to match the faces of children around the world with moderate to severe ID who remain undiagnosed following genetic testing.

Intellectual disability [ID] is one of the largest unmet challenges in health care. In developed countries, the most common cause of ID is genetic, and up to 50% of individuals with moderate to severe ID have associated craniofacial anomalies. Presently, only 30-40% of these children have a causative DNA variant in one of the known developmental disorder genes, and there are ~ 2000 ID genes still to be characterised. Furthermore, an estimated 70% of the genes in humans are of unknown function (Wright, Fitzpatrick & Firth, 2018). When DNA variants are detected in these genes, it is challenging to determine if they are normal variations or the cause of the ID. Comparing the DNA variants of two individuals with similar features can lead to novel ID gene discovery and diagnosis. When a diagnosis is not made by genetic testing, doctors manually presented facial images of their patients at medical conferences or record written information into databases hoping to locate another individual with similar features. To solve this clinical dilemma, FaceMatch has repurposed advanced face-recognition technology and developed a first of its kind innovative, international project to provide a means for effectively and efficiently comparing the facial images of the 70% of patients with ID who remain undiagnosed following genetic testing.

Computer face-matching technology

The technology within the FaceMatch Project was initially developed to match facial images of individuals for the primary purpose of recognizing blurry faces in CCTV for policing and counterterrorism. The software is being used to detect persons of interest in large crowd gatherings through various police and other security agencies. Since the software was developed for CCTV, high quality professional photographs are not required and even poor quality historical photographs can readily be used. This technology is unique as it uses low-resolution structural and frequency domain features rather than high resolution features. It is based on spatial textures and statistical models and is simultaneously insensitive to pose, illumination, expression, obscuration, blurring, decoding artefacts, and low-resolution images. Our health research FaceMatch team published an automated approach to matching the faces of non-identical individuals within the same syndrome subgroup within a database of 3,145 images and reported that, using two-dimensional photographs, the technology accurately matches the facial gestalt of unrelated individuals with the same syndrome form of intellectual disability ($p < 0.000001$). (Dudding-Byth et al., 2017). Utilising this technology, FaceMatch has forged a solution to locating undiagnosed patients around the world who have similar facial features.

The FaceMatch Platform

The unique dual parent/doctor participation model is future focused and recognises that parents are partners in health care. Every new image is matched against all images within the database generating a ranking list and matching score which is more efficient and accurate compared to the human eye. This state-of-the-art internationally accessible model can be initiated by the parent or the doctor. Parents are asked to nominate a doctor to allow the FaceMatch team to work together with the parent and their own doctor. Images, medical information, and genetic data are securely stored. Notification emails are generated and maintained within the secure FaceMatch system. Parents, doctors, and the research team each have an individual dashboard which summarises status and outcome.

Benefits of an early diagnosis

Patients and families often endure long and isolating journeys toward a diagnosis, and the benefits of an early diagnosis for ID are substantial. A diagnosis can inform the child's prognosis and management; reduce parental isolation; provide information about possible recurrence risk in a subsequent child; reduce the number of invasive investigations and triage eligibility for novel therapeutic trials. Although each of these conditions are individually rare, collectively they inform our knowledge of the complex biological pathways involved in normal cognition and provide the first steps towards targeted treatments for ID.

How to participate

Participation is open to parent or guardians of:

1. Children (or adults) with moderate to severe intellectual disability who remain undiagnosed following review by a clinical geneticist or,
2. Children (or adults) who have a known genetic cause for their intellectual disability.

More information about the project including privacy, confidentiality and security can be found at facematch.org.au

■ Dr Tracy Dudding-Byth is an Australian Clinical Geneticist within the New South Wales Genetics of Learning Disability service and an Early Career Researcher within The University of Newcastle GrowUpWell Priority Research Center. Professor Brian Lovell is the Professor of ITEE at the University of Queensland.

References

- Wright, CF., Fitzpatrick DR., & Firth, HV. (2018). Paediatric genomics: diagnosing rare diseases in children. *Nature Reviews Genetics*, 19(5), 53-268. doi: 10.1038/nrg.2017.116
- Dudding-Byth, T., Baxter, A., Holliday, E., Hackett, A., O'Donnell, S., White, SM., Attia, J., Brunner, H., de Vries, B., Koolen, D., Kleefstra, T., Ratwatte, S., Riveros, C., Brain, S., & Lovell BC. (2017). Computer face-matching technology using two-dimensional photographs accurately matches the facial gestalt of unrelated individuals with the same syndromic form of intellectual disability. *BMC Biotechnology*, 17(1):90. doi: 10.1186/s12896-017-0410-1.



UPCOMING EVENTS

www.asid.asn.au/events

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**19 June
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ASID Victoria - Workshop

Decision making support for people rarely heard.
Deakin Downtown

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ASID Webinar Series - New South Wales/Australian Capital Territory

Ethical Issues in Ageing Webinar: Family Dilemmas
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**2-3 July
2018**

ASID New Zealand 2018 Conference

"Responding to the call: Building partnerships that enrich lives"
Rydges Wellington, Wellington NZ

www.asid.asn.au/events/83_asid_nz_2018_conference

**21 -26 July
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International Society of Augmentative and Alternative Communication (ISAAC)

“AACcess All Areas”
Gold Coast Convention and Exhibition Centre

www.isaac-online.org/english/conference-2018/

**14-16 November
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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

ASID podcasts

Good news! ASID research to Practice Podcast is back for a second season with a new sound and style. This season we promise to live up to our name “Research to Practice” more than ever. You can still look forward to hearing about the latest research in the field. But we will also be hearing from more people living with intellectual disability including people with intellectual disability themselves, self-advocates, practitioners, policy makers, family and friends.

Episode one will feature Dr. Jo Watson from Deakin University to speak about her research into Supported Decision Making for people with severe and profound intellectual disability. Michael and Gloria will show us the lived experience of supported decision making in everyday life.

We are also looking forward to episode three which will give everyone a taste of the ASID 2018 “Let’s Shake it Up: Human Rights for Everyone” Conference in November. We will feature keynote speakers, delegates and conference committee members updating you on the conference highlights.

To get a taste of what’s in store, have a listen to our Season 2 Preview Episode at <https://player.whooshkaa.com/episode?id=197955> by subscribing on iTunes or wherever you get your podcasts by searching for ASID Research to Practice. Otherwise, you can find all the episodes on the podcast tab of our website asid.asn.au , you can keep an eye on ASID Twitter feed @asid_ltd or Facebook page @asid.asn.au . Let us know what you think!

Sophia Tipping

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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

Free online and print 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.



Intellectual Disability Australia Magazine (IDA)

Every 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.



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.



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.

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.

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of article length and format.

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by or with people with an intellectual
disability**

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