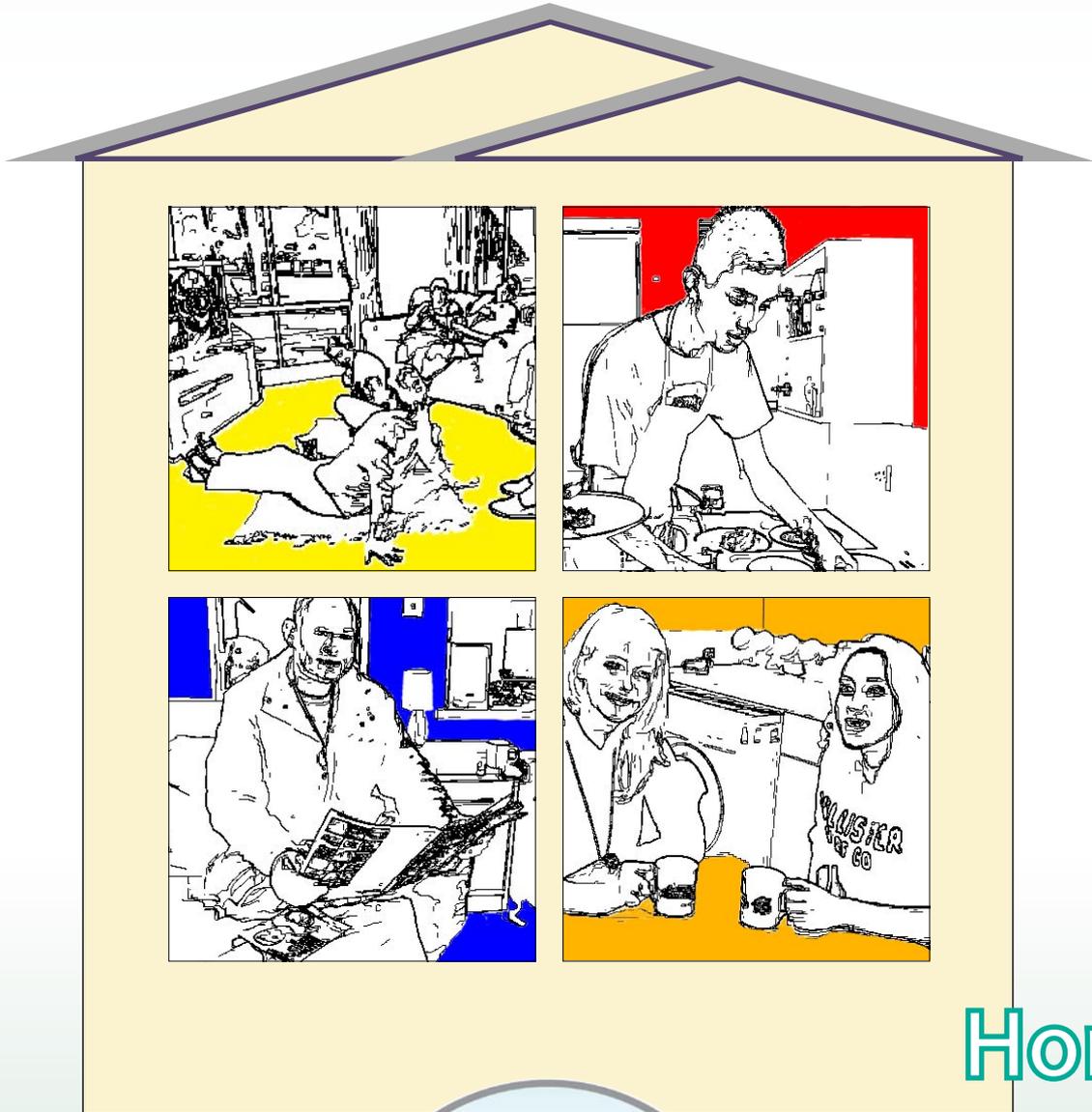
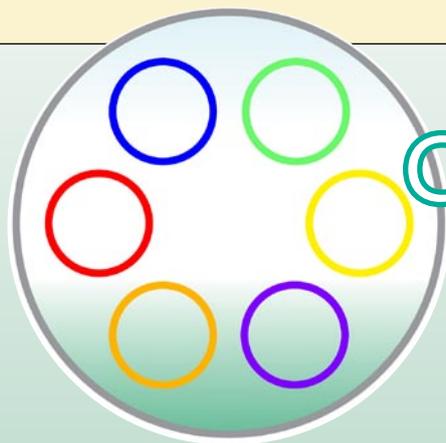




Intellectual Disability Australasia



Home and Community



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Editorial



As we move into cool mornings of autumn the seminars and workshops throughout the country heat up with discussions on ways forward.

This edition focuses on homes for people with an intellectual disability.

Professor Christine Bigby has been presenting booked out workshops in South Australia, Victoria and New South Wales. Accounts of these workshops highlight key issues to which service providers need to attend and the need to be continuously vigilant in services to order to provide a decent quality of life. In addition, we have a thought provoking article by Piers Gooding from The Conversation about the issues people with an intellectual disability face when attempting to find a home of their own. Cate MacMillan reminds us to think about the support neighbourhoods might provide and to think about what makes an ideal neighbourhood.

ASID hopes you will be registering to attend the ASID conference in Hobart to engage in further conversations on this subject. We have profiled three of the keynotes to provide you with some insights about their work and what to expect.

This IDA issue continues with its theme on education and intellectual disability with students' perspectives of a MOOC from NSW.

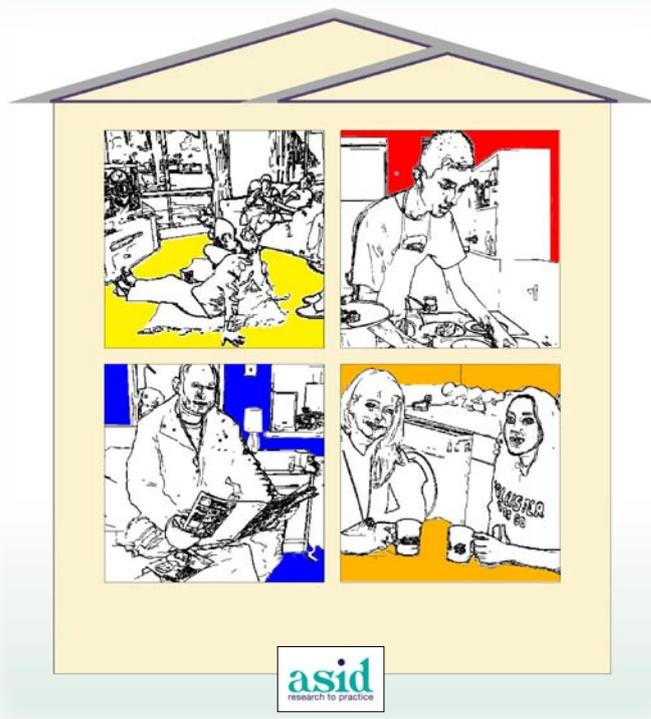
We have also started our first regular article on introducing you to our organisational members and the member is NADO. Member organisations are welcome to submit an article to IDA about their service written by, or in collaboration with, a person with an intellectual disability.

We are hoping to increase a multitude of ways you can connect with ASID's work through podcasts, facebook, website and enews.

Contributions to IDA are welcome as are questions and comments. Please contact me at idaeditor@asid.asn.au

Hilary Johnson

What makes a Good Group Home ?



Recently Professor Christine Bigby has presented seminars in South Australia, NSW and Victoria on what make a good group home.

We have four accounts of these seminars and the take home messages. For those of you who could not attend (all seminars were sold out) here is the link to one of the main JARID articles. This is an open access article so you should be able to click on the link and download the full article.

<http://onlinelibrary.wiley.com/doi/10.1111/jar.12291/full>

Below is the title and abstract of the article:

Improving Quality of Life Outcomes in Supported Accommodation for People with Intellectual Disability: What Makes a Difference?

Christine Bigby

Living with Disability Research Centre, La Trobe University, Bundoora, Vic., Australia; and

Julie Beadle-Brown

Tizard Centre, Kent University, Kent, UK

Background

The quality of life (QOL) of people with intellectual disability living in supported accommodation services is variable, influenced by many possible factors. Various frameworks have attempted to identify these factors without assigning value, direction of influence or relative impact on outcomes.

Methods

A realist review of the literature aimed to expose different propositions about variables influencing QOL outcomes and review the strength of supporting evidence for these, to identify their relative influence. Evidence was reviewed for and against each of five clusters.



Prof Christine Bigby

Results

Evidence was strongest for the presence of staff practices (use of Active Support), front-line management practice (use of practice leadership), culture (enabling and motivating), human resources policies and practice (that support front-line leaders and recruitment of staff with the right values), adequate resources, and small, dispersed and homelike settings.

Conclusions

The evidence informs policy and practice but in some clusters remains limited, warranting further research which measures outcomes on all QOL domains. ●

Is there such a thing as a Good Group Home?

The South Australian Experience

by **Denice Wharldall**

Executive Manager Client Services
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South Australia (SA) is an interesting landscape with the underfunding of many group homes. Sometimes funding only just covers basic rosters and in some situations not even the basic roster. For many service providers the introduction of the NDIS will see reasonable and fair funding for the first time in many years.

As someone who has been involved in managing group homes for most of the last 28 years I am aware of the complexity of group homes and often feel that most funders had no concept of the complexity. Coupled with this is the disrespect and devaluing of the Support Workers (who are often called carers) and who are sometimes frowned upon if they are not willing to do the extras such as use their car for transporting a client or put in extra hours to ensure the person they support has access to time away from the home.

I am aware, again like many of my colleagues, that Group Homes are a flawed model. Compatibility issues alone make the model flawed but at present, even under an NDIS, there are not financially sustainable models for individuals with complex needs who live with an intellectual disability.

There has been a movement within SA to introduce Active Support, however this had varying results. As a Service Provider I have looked for solutions to assist in ensuring we were operating Good Group Homes. These solutions usually involve ensuring Support Staff understand their role, have the right values and the training. Active Support appeared to be the solution and over the last 8 years I have worked to implement Active Support alongside many of my colleagues from various organisations.

So it was with great anticipation that we awaited Chris Bigby's workshop.

It was an enlightening experience for us to hear from Chris the integration of many research studies related to Group Homes. I had been following the studies, some of which have been going for over five years but the workshop gave a great opportunity to bring them all together, discuss them and be challenged.

I like many of my colleagues in SA are very thankful that someone has taken the bull by the horns and undertaken such comprehensive research on the least "sexy" area of disability research.

The take home messages for us were:

- It is complicated
- One thing alone will not work e.g. Active Support
- It takes a whole of organisational approach, for example HR practices are key
- There are now a range of Organisational Cultural factors that research tells us make a difference
- Your best performing group home can become the worst performing due to a single change such as a key Team Leader leaving
- Local leadership plays a key role in success
- The effort is constant and no one can afford to take their eye off the ball so to speak

It is great to be able to utilise the research in conversations with staff, funders and Boards of Management.

Thank you Professor Bigby for a great enlightening workshop. It is reassuring that we are not alone and our experiences are similar both within SA and Australia. ●

Is there such a thing as a Good Group Home?

Commentary by Coral Farr

ASID Vic committee member

on a presentation by Prof Chris Bigby

Friday 28th April 2017

Melbourne



It was with great interest that I attended this workshop as both a practitioner in the disability sector as well as having a family member living in shared supported accommodation. Recent media coverage (such as the Four Corners episode “Fighting the System” aired on the ABC on 27th March 2017) has revealed the negative consequences of abuse perpetrated on people with intellectual disabilities living in group homes. Professor Bigby’s research explored both the positive and negative factors that influence the quality of services delivered in the residential sector.

It was evident that Professor Bigby’s presentation attracted the attention of disability service organisations, carers and interest groups as the workshop was booked out. Attendees arrived from both interstate and rural areas.

Prior to the workshop, Chris sent an email with a dropbox containing workshop materials and class activities. This invaluable resource enabled participants to consider the different residential models and the quality of care outcomes for participants in these services.

Professor Bigby based her research on the Active Support model devised by Jim Mansell and Julie Beadle Brown (2012). Researchers observed and recorded the levels of engagement of participants in the activities of the house. These measurements were then applied to human rights standards as determinants of outcomes for people with intellectual disabilities.

Interestingly, Professor Bigby found that staffing levels did not influence the standard of care provided to group home participants. It was the culture of management and work practices of group homes that contributed to the quality of service provision. Professor Bigby asked participants to consider the mission statements of the organisations they work

for. How do these mission statements influence the policy and procedures, and implementation of work practices in the daily lives of people living in group homes?

Professor Bigby identified a number of key findings from her research which defined the differences between well run and poorly operated group homes.

1. Management is in touch with what happens at the level of direct service provision.
2. There is a culture of training, mentoring, monitoring and review applied at all levels of management and daily work practices in the group home. Regular opportunities provided for reflection on staff practice and participant outcomes during staff meetings and supervision sessions.
3. The quality of documentation did not necessarily indicate what happens in direct service delivery.
4. All stakeholders are on the same page and focused on achieving positive outcomes for the people they support.

Professor Bigby’s workshop was thought provoking with attendees contributing their experiences and perspectives on the issues raised.

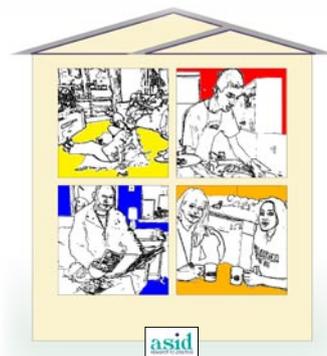
The results of Professor Bigby’s research serves as a timely reminder that it is possible to achieve quality of life outcomes for people residing in group homes through a positive and committed approach to daily routines and continual appraisal of outcomes. Having an open, transparent and inclusive approach can build confidence and capacity for providing quality services to the people who are directly impacted by it.

The Victorian branch of ASID is planning to produce a podcast interview with Professor Bigby on this workshop. Keep a lookout for the link on the ASID website. ●

Is there such a thing as a Good Group Home?

by **Laura Hogan**
laura.hogan@sydney.edu.au

NSW ASID Division workshop



On the 9th of June, Centre for Disability Studies (CDS) in partnership with ASID NSW/ACT Division hosted Prof Christine Bigby to present her workshop titled “Is there such a thing as a good group home”, at the University of Sydney.

As NSW progresses to full scheme implementation of the NDIS and with the recent successful tenders for the transfer of supported accommodation from government to non-government providers, the event was well received by the sector and was fully booked within 2 weeks of opening registrations.

The event was attended by 54 participants including: organisational managers, board members, team leaders, clinicians, project offices and direct support professionals. Participants represented 12 non-government organisations, 3 government agencies and a handful of independent providers.

The workshop pulled together an extensive quantity of research spanning numerous decades, allowing participants to reflect on positive and negative

perspectives both historical and with a view to the future. For more detail on the content presented and discussed in the workshop refer to the articles by Elizabeth Brownlie, Coral Farr from Victoria and Denice Wharldall from South Australia

Participants in Sydney discussed and debated the research presented in comparison to their own opinions and experience of: quality of life indicators, staffing ratios, practice leadership, group culture and models of practice including, active support.

At completion of the workshop feedback from participants was overwhelmingly positive regarding the timeliness of the workshop, the depth of material presented, the opportunity to network and workshop the concepts presented.

Centre for Disability Studies in partnership with ASID NSW, thank Prof Bigby for travelling to Sydney to present this informative and thought provoking workshop. We plan to keep the topic alive through a program of professional development and networking events over the next 12 months. ●

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Prof Bigby presenting to the group



Participants Bev Allen, Linda Ward, Bernadette Curryer & Bob Davidson



Prof Bigby with staff from Dept Family & Community Services (FACS) & Laura Hogan (ASID & CDS)



Participants

Is there such a thing as a Good Group Home?

by Elizabeth Brownlie

ebrownlie@scopeaust.org.au

*Report on workshop by Professor Chris Bigby
Friday 9 June 2017 at University of Sydney
Camperdown Campus*



This workshop about “what makes a good group home” provided both information and the opportunity for discussion about research that is helping to quantify what is involved in providing quality services for people with disabilities. Professor Bigby’s focus is on the quality of life outcomes for people in group homes, and how this correlates with the quality of the service provided, especially the level of engagement and use of active support principles. Much of this information is applicable and transferable to day services for people with intellectual disability. Workshop attendees were given access to useful resources including research articles, videos and online training packages.

There are approximately 17,000 people living in group homes, most of whom have an intellectual disability. The roll-out of the NDIS across Australia will put greater pressure on service providers to demonstrate that they are providing quality services.

Professor Bigby has found that two factors reliably predict quality of life outcomes for people in group homes: firstly, peoples’ levels of adaptive behaviour and secondly, staff practice. Even in relatively good group homes the rate of engagement is consistently lower for people with more severe disability – on average these people spend 63% of the time doing nothing, while people with less severe disability spend 32% of the time doing nothing. The picture is bleak for people with little or no speech – only 6% of those people had communication strategies/aids that appeared to be effective. Research indicates that even the relatively good group homes score poorly on interpersonal relationships and personal development.

We know that person-centred active support correlates with increases in people’s engagement and skill development, and results in more choice and control, and less challenging behaviours (Mansell & Beadle-Brown, 2012). These all lead to better outcomes across the quality of life domains. Professor

Bigby’s research suggests that it is quite difficult to establish and maintain consistent implementation of active support practices. She outlines five components that determine how well this happens, the two most important being staff and management practices, and a culture that is coherent, enabling, motivating and respectful. Consistent implementation of active support does not need to cost more, rather the available resources need to be used more efficiently.

“Culture” in services for people with intellectual disability is something that is often discussed but not always well understood. Professor Bigby’s research has broken “culture” into a range of elements that help to quantify whether the overarching values of an organization are being reflected in what actually happens. A PhD student is currently working on the “Development of Group Home Culture Scale”, which will measure the factors associated with better outcomes and provide a useful diagnostic tool and framework for facilitating positive changes. There are currently a number of “buzz-words” that are well-known and frequently used by managers and staff (eg. “active support”, “person-centred”, “community participation”, “choice and control”), but do staff really know what these things look like as concrete realities? For example, “community participation” is not just taking a group of people to a park or café, unless they are having real interactions with people in those situations. This is where front-line practice leadership is important. Regular one to one supervision, coaching and mentoring of staff, a strong focus in team meetings on increasing engagement and on furthering quality of life outcomes are all important in the explicit translation of organisational values into staff practice. These values also need to be reflected in broader organisational characteristics and processes. For example, staff and managers are often required to complete mandatory paperwork, which is not clearly tied to improving the engage-

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The forgotten 660,000 locked out of home ownership



By Piers Gooding

Postdoctoral Research Fellow,
Disability Research Initiative,
University of Melbourne



Imagine two people in their 30s, Lee and Sarah. Both want to acquire their first home. They've saved a deposit of A\$70,000 each and want to buy the same type of apartment in the same block.

Lee is able to buy off the plan with a mortgage and receive a First Home Owner Grant. Sarah is not.

What's the difference? Sarah could be any one of 660,000-plus Australians with an intellectual disability

Barriers at every turn

People with intellectual disability face so many barriers to finding a home of their own that it's hard to pick one. Rates of unemployment and underemployment are high. Only 23% are wage or salary earners and around one-third of these work for less than 15 hours per week. And pay rates, according to the Australian Human Rights Commission, are extraordinarily low. In other words, a mortgage is largely

off-limits. For most, family support then becomes a precondition for acquiring a home.

But, if family earnings have been negatively affected by their supporting responsibilities, financial assistance may not be possible. If funds are available, one option is to create a family trust. For Sarah, a family member could acquire the apartment and act as a guarantor on a mortgage. However, unlike Lee, Sarah couldn't get the first home owner and stamp duty concessions, which are not available under a family trust arrangement. On the other hand, she could get Commonwealth Rent Assistance as she would count as a renter not an owner.

Another option is for Sarah's family to set up a "special disability trust". This would enable her to have access to first home owner concessions, although that would require confirmation from the revenue office of the relevant state or territory. Even

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Good Group Home Workshop

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ment of clients. This means that staff often have reduced direct engagement time, and managers are tied to their desk rather than spending time with staff, coaching them to provide good support.

Work done by Professor Bigby and others in the field suggest that many elements of organisational structure and staff practice need to come together to create better outcomes for people with disabilities, and that good practice is quite a fragile thing and can fall apart quite quickly. We know that staff train-

ing in person-centred active support is important, but that training alone achieves very little change. Capacity building of such organisations and services is a long-term proposition. ●

Reference:

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers

The forgotten 660,000 Locked Out . . .

continued from page 9

then, opening a special disability trust is onerous. It requires specialist legal and accounting advice. Annual fees and reporting requirements would quickly outweigh any first home owner concessions. Further, the beneficiary can't pay rent to the trust, which would otherwise serve as a proxy for servicing a mortgage.

A third option is to help Sarah buy a home in her own name. However, many people with intellectual disability are unlikely to reach the threshold of mental competency required under current law. The person may then need to be placed under guardianship or trusteeship.

This raises a host of human rights concerns and has the potential to further disempower the person. First home owner concessions may be available to guardians on the person's behalf, depending on the state or territory. But, again, discovering this information tends to require specialised legal advice. Victoria has the unusual option of appointing "supportive attorneys". The supporter doesn't take over decision-making, but instead helps the person by gathering information. This can be a way to avoid removing legal capacity. Yet, it appears supportive attorneys cannot assist with the acquisition of property.

In short, all options come at a significant cost to the person or their family. The one measure that is possibly useful for Sarah – claiming rent assistance for a property owned by a family trust – appears to exist by accident rather than design. Unequal and a waste of taxpayer dollars.

The lack of support for acquiring a home drives people with intellectual disability into group homes, either state-run or for-profit. While these facilities may be acceptable for some, for many they perpetuate what Gerard Goggin and Christopher Newell describe as "social apartheid". They also make people vulnerable to abuse and marginalisation. Nowhere is this more evident than on the ABC's www.abc.net.au/4corners/stories/2017/03/27/4641276.htm Four Corners report.

Group homes are also expensive. In New South Wales, the average total cost to house a group-home resident, according to the Social Policy Research

Centre, (www.adhc.nsw.gov.au/_data/assets/file/0017/311246/Supported-Accommodation-Evaluation-Framework-Summary-Report.pdf) is \$137,000 per year. That is \$2,634 per week.

Ask most people with intellectual disability and their families to suggest better ways to spend \$137,000 per year, and I'm sure they'll have suggestions for wiser public spending.

Current mindsets are fixated on congregate-care models, such as group homes, as well as highly professionalised models that cost enormous amounts.

Social housing is another option, but Sarah would have to join the nearly 200,000 Australians on a waiting list. Even if she did manage to get a home this way, it is questionable whether being congregated with other disadvantaged groups will improve her chances of social inclusion.

No wonder people are www.humanrights.gov.au/twentystories/video-dees-place.html seeking alternatives Low-cost and no-cost solutions.

As a starting point, state and federal governments could easily provide clear information about the various options available to people with intellectual disabilities who wish to acquire a home. People shouldn't need law degrees to know their options.

Procedural equality could be improved by giving access to first home owner concessions to people with a disability who acquire a home through a family trust. For those needing funds for a mortgage, government-subsidised co-ownership schemes could be a great help.

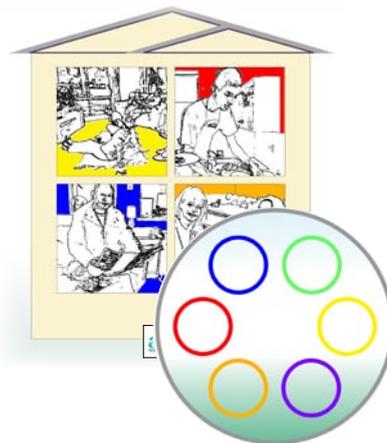
These solutions should not replace efforts to improve employment rates, access to mortgages and all the typical pathways to home ownership. To help open up these pathways, people with intellectual disability would need to be able to buy a home with support and safeguards.

Funds should be re-invested from congregate care to the ongoing costs of supporting people with an intellectual disability to live in their own home.

Housing policy has tended to overlook home ownership for people with intellectual disability, which suggests the soft bigotry of low

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It is the neighbourhood - not the house - that matters



Seeking independent living opportunities for adults with intellectual disability

By **Cate MacMillan**
& **Nicholas J Stevens**

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Our neighbourhoods need to be safe, accessible and inclusive places to live work and play. Everyone, especially the most vulnerable in our community, deserves the opportunity to live independently of the family home, if, and when they choose.

Upwards of 670,000 Australian live with an intellectual disability (ABS, 2016). Many of these are young adults seeking opportunities to live independently outside of the family home (Wiesel & Bigby, 2015).

They, like others their age, want to be able to choose where they live and with whom they live.

A young adult with Down syndrome or Autism may not necessarily require a purpose built house or apartment to live independently. Having attended mainstream education and now competing in the mainstream workforce, many 'may not identify particularly' *continued page 12*

The forgotten 660,000 Locked Out ...

continued from page 9

expectations is at play. Barriers to housing for people with intellectual disability don't seem to have been driven by malice. Instead, these barriers emerged from countless decisions not to afford them equal opportunities. Each barrier on its own seems unfortunate; together they appear tantamount to neglect and discrimination. ●

theconversation.com/profiles/piers-gooding-207492
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This article was originally published on theconversation.com The Conversation

Read theconversation.com/the-forgotten-660-000-locked-out-of-home-ownership-74926 original article



strongly as “a person with a disability”, but rather as a unique individual who merely happens to have a disability’ (Taleporos et al., 2013, p 15). With the appropriate support and funding they are able to live in a normal house, alone or sharing with others (Bigby, 2000).

So if the house or apartment is not an issue, can we expect adults with intellectual disability to live anywhere?

A research project on the Sunshine Coast in Queensland Australia is currently exploring why some neighbourhoods offer better independent living opportunities than other neighbourhoods. The aim is to determine the neighbourhood values and functions that are important to achieve independent living for adults with intellectual disability (adults). Data has been collected through interviews with young adults (18-40 years old), their families and subject matter experts in the disability, housing and built environment sectors.

We asked them about design features of ‘ideal’ neighbourhoods. This incorporated questions regarding the engineering and planning elements of the area. We asked participants to tell us about what, in a neighbourhood, makes them feel welcome and safe in a community.

In brief, the results indicate that what is needed to support an independent living opportunity, is a house in a street where neighbours are friendly and supportive, there is good reliable public transport and there is an identifiable inclusive community.

More specifically, the adults interviewed indicated that they want to be close to family and friends and live where they have a connection to place. For example, they want to reside in a neighbour-

hood that is familiar to them, so that they can feel safe. A place where they know the transport system and the work and educational opportunities available to them. They were more likely to have access to work and recreational opportunities in a community where they, and their families, are known. Inclusiveness and conviviality are also maximised for an adult where they feel welcome and can be involved in community life (Wiesel & Bigby, 2016).

So where are these streets?

The theoretical concept of the Just City (Fainstein, 2010), which has as its foundation the principals of democracy, equity and diversity, underpins our exploration of neighbourhoods and their design. The premise is that the inclusion of specific neighbourhood design elements in the delivery of new and refurbished neighbourhoods will help provide more independent living opportunities for adults. Neighbourhood design based on the concepts of democracy, equity and diversity form the foundation of Just City neighbourhoods (Fainstein, 2010). This theoretical concept is not new to Australian urban design research (Bostock & Gleeson, 2004; Gleeson, 2001; Steele et al., 2012).

However in recognising the complexity in determining the combination of components required to establish an ideal neighbourhood, new approaches have been used. A human factors and sociotechnical systems analysis (STS) was applied to the data gathered through a best practice literature review and the interviews. We consider the neighbourhood as a system of interrelated objects and functions. For example, we explored the roles that streets, pets, recreation, employment, education, transport, tolerance and diversity, have in the entire system we call a ‘neighbourhood’. In total more than 210 elements have been included in the system.

It is the neighbourhood

continued from page 12



In line with this human factors approach we consider:

- people as assets in the system
- technology as a tool to assist people
- promotion of quality of life
- respect for individual differences
- responsibility of all stakeholders.

What is needed to achieve ideal neighbourhoods?

Three high level functions were identified as crucial in the design of new or refurbished neighbourhoods. These are:

- The actual and perceived safety within the neighbourhood and, in particular, in the street;
- The ease of mobility to access services, recreation and employment opportunities, whether it be walking, cycling or public transport; and
- A sense of community that encourages local neighbourhood activity and participatory inclusion.

To achieve these functions diversity within the neighbourhood is understood to be critical. Neighbourhood design needs to encourage a diverse mix of residents. A mixed residential demographic is effective in minimising the vulnerability of adults to abuse, corruption and the exploitation to behave inappropriately or illegally (Robinson & Chenoweth, 2012). To create a diversity in the neighbourhood demography there needs to be a diversity in the types, scale and intensity of buildings, a variety of residential accommodation and tenure types and a mix of commercial operations.

Ideal neighbourhoods are 'near to things'. Adults want to be able to get to 'work', to see their friends and family and to be able to continue doing the things they do while living at home. The fear of

change - change of doctor, bus service, or sporting team - creates a barrier for many adults who want to experience independent living.

These young adults, having been encouraged to participate in mainstream life, have a need to be part of a community. Social, recreational and employment opportunities typically provide convivial engagement with in a neighbourhood (Wiesel & Bigby, 2016). It is acknowledged that community education to help residents understand the behaviours and needs of adults with disability goes a long way to promoting inclusion in neighbourhoods (Putnam, 1995). The harnessing of the social capital within a neighbourhood would surely contribute to the overall success of independent living for an adult.

Why are we not delivering these neighbourhoods?

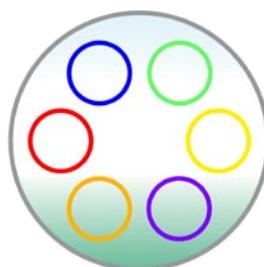
The answer to this question may lie in urban design and planning. In Australia the design and delivery of neighbourhoods is at the local government level in strategic planning. However, this strategic planning is reliant on State and Commonwealth government legislation and funding.

In systematically scrutinising legislation at all levels of government, it becomes apparent that a complex web of policies, guidelines and government departments exist, often in isolation, to influence urban design. The complexity for built environment sector of operating in this multifaceted and multilevel bureaucracy compounds the delivery of 'ideal' neighbourhoods.

How we propose to influence the delivery of ideal neighbourhoods.

Using the Rasmussen (1997) STS method, we have developed a neighbourhood design framework.

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Parents, disability and social housing and built environment delivery decision makers can use this tool to better assess neighbourhood design for safety, accessibility and inclusivity. This framework has been developed using the interview and literature review data. It has been workshopped with parents, urban designers and planners, social housing and policy sector experts and further refined before being applied by parents actively seeking independent living opportunities. A process of sample testing the framework on old, new and refurbished neighbourhoods on the Sunshine Coast is underway. As a final test the framework will be applied in a practical setting by urban designers and planners.

The aim is to ensure this framework is a practical tool for parents, the disability and social housing sectors and for the built environment design and delivery industry across the globe.

Neighbourhoods that are good for this group of people should inevitably be good for us all. ●

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Bio:

Cate MacMillan has several qualifications Dip Teach HPE & Geography (KGCAE), Grad Dip Teach Exceptional Children (USQ) & BBus Property Economics & Development (USC).

She is currently undertaking a PhD in Urban Planning by Research with the Centre for Human Factors and Sociotechnical Systems at USC. Cate's career as a secondary school teacher and principal in primary and secondary schools in Queensland, always had a focus on the inclusion and education of young adults with disabilities.

President's report

Dr Angus Buchanan



I am writing my Presidents report just having spent a week travelling and working in Vietnam. I was in Ho Chi Min City for a week of teaching to a group of therapy assistants from two rural provinces near the Cambodian border. The students took time to share the recent history of their provinces which includes significant trauma but also a strong sense of resilience and hope. Both areas are still impacted by the legacy Agent Orange and its associated causal impact on disability. During a workshop session we explored what are fundamental human rights. It was a great conversation and the group very quickly generated a long list of what they considered to be human rights. What was pleasing and not surprising is what these students identified as human rights were exactly the same that I would identify with. We then went further to explore if people with disabilities shared these same rights in their rural provinces. Not surprisingly and sadly they universally expressed that people with disabilities who they were aware of, did not experience basic human rights describing circumstances that we perhaps would find very unacceptable. It has however been great working with people who want to make a difference in what are very challenging and under resourced environments. On my recent visits to the two provinces I was confronted by the level of unmet need for people with disabilities for issues that we now hopefully assume no longer exists in Australia and New Zealand. I was incredibly impressed by the energy and focus of a group of people who on learning about new ways of thinking and action left the course with a belief they can start to make a real difference.

Experiencing countries like Vietnam is always a timely reminder of how far Australia and New Zealand have come developing contemporary responses for

people with intellectual disabilities. It is however, very easy and a risk after a visiting a location like rural Vietnam to view the current circumstances in Australia and New Zealand with a degree of complacency and satisfaction. However we still have far to go to ensure people with intellectual disabilities are having their citizenship and human rights met. As part of the training I spent a considerable time with the group exploring in detail the United Nations Convention for the Rights of People with Disabilities (CRPD). It was a good and timely reminder for me to revisit the Convention - what it says, means and the need to continue to strive to see its intent come to full life in Australia and New Zealand. I encourage you, if you have not read the convention recently, to take the time to explore its content, meaning and the enormity of its intention for people with intellectual disability. The reality is that the human rights I experience within my life are not necessarily the same for people with intellectual disabilities in Australia and New Zealand and it is essential we strive towards bringing this gap.

ASID's vision – to improve the quality of life of people with intellectual disability is very much about the ongoing improvement of the quality of life for people with intellectual disabilities and their families. This is embodied in our logo Research to Practice and seen in action through regional forums and events, the Australasian Conference, the publications and contributions to policy. ASID's strength is in the connection of its membership so please try to be part of the events that take place. I encourage you to think about attending the next ASID conference in Tasmania in November with the highly relevant theme of Pushing the Boundaries. It is an opportunity to see ASID in action – engage and network with research-

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**Back row: Samuel Arnold, Dee Siddhu (EO) Debbie Espinier Ben Crothers, Mark DiMarco, Angus Buchanan, Laura Hogan , Sharon Brandford
Mid row: Allyson Thomson, Bernadette Curryer, Adrian Higgins, Paul O’Dea, Darryleen Wiggins, Sue Salisbury Richard O’loughlin, Maurice O’Connor, Hilary Johnson**



Presidents Report

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ers, providers and practioners, families and people with disabilities. ASID conferences are unique events and participation is always well rewarded by the experiences.

The Board have recently held a two day face to face meeting in Melbourne. This was a highly productive meeting and signed off the Committee work plan priorities, formalised a new committee structure, allowed exploration of the role of the new Executive Officer and the Secretariat, and commenced the implementation of a new risk management plan. A recent decision was made to reduce the size of the Board, which currently has 21 Directors (3 from

each division) 14. Over the next election cycle each Division will now only have 2 Directors on the Board. This decision is consistent with modern governance trends and with the committee structure it is expected to streamline decision making processes. As I often comment all Board members give their time as volunteers and I thank each one of them for the contributions that they each make to the organisation. We are now fortunate to have Dee Siddhu, our Executive officer who will bring considerable operational capacity to the Board and ASID. As an ASID member you will start seeing evidence of this capacity in the near future. ●



Aotearoa NZ

by Fran Hartnett

The New Zealand Division met on May 15 via teleconference and all committee members were able to attend. Olive Webb updated members on progress on the upcoming Support Workers' Conference sponsored by ASID NZ which will be held in Christchurch on August 11 & 12, 2017. Olive reported that things were on track, publicity was being prepared and the planning committee was anticipating an attendance of around 100 participants. Olive also reminded committee members of the need to recruit new members to ASID and to follow-up with former members.

Planning for the Division's national conference which will be held in 2018 is underway and the Division is currently seeking competitive tenders from conference organisers to ensure our next conference will be as innovative and competitive as possible. Sharon Brandford and Jonathon Goodwin agreed to be Co- Convenors of this conference. A discussion paper on possible themes for the conference, prepared by Brigit Mirfin- Veitch was circulated for committee members' feedback. Members were keen to see that issues relating to the care and protection of children were included in the conference in light of a recent report by the Children's Commissioner which reported a number of failures within the New Zealand system.

Considerable focus during the teleconference was given to the preparation of the New Zealand Division's budget that will be presented in Melbourne in June 2017. The committee is grateful for the considerable work that Judy Garriock, Treasurer has done in preparing this. Judy also reported that the Division's financial status was healthy.

The N.Z ASID Division is actively promoting the Tasmanian conference and Adrian Higgins has obtained the logo to use for this. A number of our

members hope to join fellow ASID members at this conference in November and we wish the Tasmanian conference planning committee every success.

NSW & ACT

by Susan Collings

During our recent operational planning day the ASID NSW/ACT Division committee identified memberships as a focus for 2017. We are working together with other states to streamline the process for new members and come up with strategies to increase memberships. To achieve this second goal, we need to understand what motivates individuals and organisations to join ASID and their decisions around membership renewal. ASID NSW/ACT are conducting a survey of current and past members to gather feedback about what benefits individuals or organisations seek from ASID as well as barriers to membership renewal. The results will be used to better tailor our activities to the needs and preferences of our members.

With NDIS implementation, a number of new providers are entering the disability sector in NSW. This represents a timely opportunity to reach out to these new organisations that may not be aware of ASID. We will use the NDIS website provider list to email these individuals and organisations and share a link to the ASID website and secretariat contact details for further inquiries.

Based on the success of our Roadshow event last year on 'Ethical Issues in Ageing', ASID NSW / ACT is hosting an interactive webinar series to further this conversation. There will be 4 one-hour webinars in the series, the first is planned for 22nd June titled; 'Who Decides the When and How of Retirement for People with intellectual Disability?', led by Professor Roger Stancliffe, Professor of Intellectual Disability, University of Sydney. Following this, on the 20th July, Dr Angela

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Dew, Senior Research Fellow, UNSW Intellectual Disability Behaviour Support Program will lead a webinar focusing on ethical issues for families. The webinar costs are: \$5 for members and those with concessions, and \$20 for non-members. For more information or to register to attend the first webinar, head over to the ASID website events page: www.asid.asn.au/events

South Australia

See Group Housing article by Denice Wharldall on page 4

Queensland

no report

Victoria

See Group Housing article by Carol Farr on page 5

Western Australia

no report

Tasmania

by David Treanor

The ASID 2017 National Conference (<http://www.asid2017.com.au>) call for papers has now closed and we have an exciting and terrific range of presenters that will offer papers and workshops on pertinent issues to our professional practice.

The keynote speakers include Judy Huett, a self advocate, Associate Professor Leanne Dowse from University of New South Wales, Mr Rob Greig from the United Kingdom, Dr. Jenifer Clegg from the University of Nottingham and Adjunct Professor at La Trobe University in Melbourne, Professor



The Grand Chancellor Hotel, the Conference venue.

Monica Cuskelly, Associate Dean of Research at the University of Tasmania. For more information about the speakers see this edition and the next edition of IDA The conference is being held in Hobart from November 8 until 10, 2017 and I urge you to register at <http://www.asid2017.com.au> as soon as possible.

The Australasian Society for Intellectual Disability is an organization that champions research and evidence-based best practice in the field of intellectual disability. It is well respected amongst people with intellectual disabilities and their families, providers of services to people with intellectual disabilities and all levels of government departments concerned with people with disabilities.

The conference theme is Pushing The Boundaries. This theme reflects the critical challenges facing all communities in Australia and New Zealand who desire to realize the goals of the UN Convention on the Rights of Persons with Disabilities. In Australasia, it encompasses the issues arising from new approaches to service provision such as increased self-direction, choice and control.

The ASID board is committed to realizing the goals of the UN Convention on the Rights of Persons with Disabilities and we invite you to join us to explore how evidence based research is making a difference to people living with an intellectual disability. ●

conference keynote profile:

Monica Cuskelly

Associate Dean of Research
University of Tasmania



What led you to begin researching in this area?

My interest in intellectual disability began when I was asked by the Queensland Department of Education to be part of the team set up to establish several early intervention services for children not yet of school age, who might be at risk of failure in the regular system. The majority of children who attended these services had a developmental disability, many with intellectual disability. Parents, almost always mothers, were central to the ways in which many of these services operated and so this experience was also the originating source of my interest in families of children with intellectual disability. My life as a researcher did not begin until a number of years after this initial experience; however, when I did return to study I chose to focus my research on children with Down syndrome and their families.

By great good luck, my first academic job was at the Fred and Eleanor Schonell Special Education Research Centre at the University of Queensland. One of the projects being carried out at the Schonell Centre was a longitudinal study of the development of children with Down syndrome. This program began by recruiting families when their child with Down syndrome had just been born and these individuals, many of who remain in the study, will be 40 years old in 2018. I became a member of the team with carriage of this project and this has remained central to my research over the years.

Longitudinal work is slow to produce results but is crucial to understanding how development proceeds and what influences developmental change(s). Recent analyses of the data from the Down syn-

drome longitudinal study have revealed important aspects of cognitive and language development in those with Down syndrome. While cognition and language development have been central to the ongoing project, the focus has always adapted to reflect the current issues facing the participants. We are currently engaged in a new tranche of data collection which is collecting information about mental health along with cognitive and language performance.

My research has included other investigations related to functioning of individuals with Down syndrome separate from the longitudinal study, family functioning when there is a family member with intellectual disability, and, most recently, aspirations for the future held by individuals with intellectual disability and their families.

What have been your highs in doing research?

Relationships are at the core of successful longitudinal studies. While the originators of the Down syndrome longitudinal study cemented the relationships between the research team and the families who participated, I have benefitted from these initial bonds and have had the opportunity to also build important connections with a number of families.

Being a researcher is a role in which one is always learning and this is one of the aspects that I find most satisfying. In addition to the longitudinal research mentioned above I have conducted research on a number of topics that have been absorbing, including the impact of having a sibling with a disability on children, self-regulation and mastery motivation of children with Down syndrome, and parenting.

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How does your research change practice and what needs to change?

Some research, while contributing to knowledge, does not immediately translate into practice or policy, and much of my research is focussed on understanding the developmental trajectories of important aspects of functioning. Understanding development is useful in itself, as is building a solid understanding of behavioural phenotypes even though knowledge of these things does not lead directly to practice implications.

What does ASID need to do to facilitate the implementation of your findings?

The annual conference organised by ASID is a useful beginning to overcoming the gap between research and practice, as it is often attended by practitioners.

This may become less useful in the future unless the NDIA and service providers are able to agree on the importance of funding ongoing professional development for staff working in services for individuals with a disability. Another useful activity is the publication of the journal *Research and Practice in Intellectual and Developmental Disabilities (RAPIDD)*, a journal which has the specific intent of reporting research in a way that makes clear how findings might be translated into policy and practice.

Developing strong relationships with government and other organisations that provide information or take on advocacy roles should continue, with strong representation about the need for decisions to be made on the basis of evidence. This is a role that ASID should (and does) embrace. ●

The image shows a screenshot of the ASID Facebook page. At the top, there is a Facebook login bar with fields for 'Email or Phone' and 'Password', and a 'Log In' button. Below the login bar, there is a green banner with the text '6 GREAT REASONS TO JOIN ASID' and 'ASID is on Facebook.' A sign-up prompt says 'To connect with ASID, sign up for Facebook today.' with 'Sign Up' and 'Log In' buttons. The banner lists several reasons to join ASID:

- Strong and active local and national community
- Annual conferences featuring leading international speakers
- Regular journals, magazines and publications
- Networks for pursuing areas of special interest
- workshops & social gatherings
- conferences, seminars,

The ASID logo is visible in the bottom left corner of the banner, with the tagline 'research to practice' and 'ASID Non-Profit Organization'.

conference keynote profile:

Leanne Dowse

Associate Professor and
Chair in Intellectual Disability
and Behaviour Support at UNSW
l.dowse@unsw.edu.au



In July 1992, as a clinical speech pathologist in a metropolitan intellectual disability service in Australia, I attended a group home in response to a referral from the House Manager to see a young man I will call 'Jamie'. The staff were concerned that Jamie had problems comprehending spoken language and seemed unable to understand when they told him to make his bed. Jamie had just turned 19. He had recently moved to the group home from his family home, had just finished school and had no other day activities. The staff reported their problem as Jamie not seeming to understand instructions to do simple tasks, him being unwilling to help with the daily tasks of the house and becoming aggressive if forced to do anything. They reasoned this was because he did not understand them and their aim was to get him to comprehend what they wanted him to do. They understood it was my job as the speech pathologist to teach him to comprehend and follow their requests.

When I asked where I could find Jamie, the staff revealed the unsettling information that he in fact sat in his small darkened bedroom all day, lashing out at anyone who tried to approach him. Back in my office at the end of that day, I pondered Jamie's predicament and listed all the factors that had culminated in the emergence of the 'communication problem' I had been called in to fix. These included social exclusion and isolation, lack of appropriate support, living in an institutional regime (dressed up as a suburban house with a very high fence), being a teenager, having nothing to do and being harangued

by staff insisting that he make his bed and do the washing up. This was all in the context of a difficulty understanding others and communicating in ways that they could or were prepared to understand.

I knew there was little I could do to change almost all of these things. I could try to work directly with Jamie to help him more 'appropriately' express his feelings, I could try working with the staff to develop some empathy and insight in an effort to make them better communication partners and supporters of Jamie or I could refer him to another arm of the professional team who were tasked with delivering the fledging approaches now associated with positive behaviour support. I knew however that none of these actions could begin to penetrate the complex web of material, social, political and cultural relations in which Jamie's life was embedded and through which he was marginalised and oppressed.

The experience of that day brought into focus a range of unsettling realisations about the ideologies, values and practices which made up the system in which Jamie, the group home staff and I found ourselves. It raised for me the question of how this oppressive control and ordering of life for people with intellectual disability could be challenged. I realised that the frameworks and processes of which we were part buttressed a system of repressive social management and cultural othering of Jamie. As simple as it sounds I realised that day that I was part of a problem and that I needed instead to be part of a solution. That realisation culminated in my pursuit, in the intervening twenty-five years, of

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Leanne Dowse

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a career focused on knowledge production with and about people with intellectual disability.

In the mid 1990s I was fortunate to work with a group of scholars at UNSW pioneering the introduction of what is now known as disability studies in Australia. This new field of inquiry began with the foundational recognition of a 'social model' of disability which gave me a framework to understand the clash between the individualising and pathologising approaches to disability embedded in our systems of social care and in our culture up to the that time, and opened up my thinking to the ways these embedded social relations could be challenged. The beginnings of the social model emerged from the experiences of disabled people in UK and North America, predominantly men with physical disability, and my PhD work, completed in 2007, was an early attempt at exploration of the barriers for people with intellectual disability in having their voices represented in 'social model' debates and more broadly in social and cultural responses to disability. Working with self-advocates in the UK and in Australia on the research project for my PhD set me on the path of inclusive and collaborative research with people with intellectual disability, an approach which is now, I'm happy to observe, widely embedded in the field of intellectual disability studies.

My experiences in disability research over the past twenty-five years have been diverse and perhaps best described as a journey in 'inter-disciplinarity'. For those of us working in the area of intellectual disability there can be no doubt that the lived experience is so much less about IQ scores or diagnostic labels, than it is about the complex ways that the presence of impairment opens up the lives of people with intellectual disability to complex social disadvantage

associated with poor service responses, vulnerability, poverty, violence, incarceration and social isolation. My current work as Chair in Intellectual Disability at UNSW focuses on an intersectional analysis that re-conceptualises this group of highly marginalised people in our society and promotes knowledge, policies and practices across disability and beyond to mainstream service provision which recognises their right to appropriate and responsive support from our social care system. As Australia's National Disability Insurance Scheme hurtles toward its full roll out in 2019, I am increasingly concerned that issues for this group are becoming caught up in the machinations of interface principles and arguments focused on cost shifting and service responsibilities across and between sectors.

As researchers, supporters and allies to people with intellectual disability we have come a long way since my experiences in 1992. Many people with intellectual disability undoubtedly enjoy much better lives in 2017, but my concern remains that without concerted attention and action we run the risk of re-inscribing a framework that sees those most marginalised cycle between out-of-home care as children, to hospitals, nursing homes and prisons as adults. These responses are fundamentally at odds with a human rights approach, assuming as they do that people's lives and support needs map neatly on to the currently silo-based service system. ASID has a significant role to play in this new landscape, and I am encouraged that there is now commitment to the use of this influence nationally in supporting calls for attention to ensuring that people with intellectual disability and complex support needs are not again left behind in the new disability services future. ●

conference keynote profile:

Jennifer Clegg

Associate Professor,
University of Nottingham, UK
Adjunct Professor,
La Trobe University, Australia



What led you to start researching ID?

As an undergraduate I disliked behaviourism's neglect of emotions, but as a post-grad trainee clinical psychologist in the 1970s I found behaviourism was the only game in town. So I practiced behaviourally for 5 years in Scotland, Devon and Manchester, but became increasingly convinced that absent or unhelpful relationships are significant issues for people with ID. I then got a life-changing doctoral fellowship at the University of Nottingham that allowed me to research social relationships. It led to the position I held for the next 25 years, 50/50 in research and practice at the University of Nottingham. I won more research grants with sociologists than psychologists, many of which examined the transition from school. This moment is a pinch-point that reveals the way policies are and are not working. My return to clinical practice after the PhD was problematic: behavioural approaches not only lacked emotional sensitivity, for me they were also too individual and too powerful. I entered further training to qualify as a family therapist, which gave me rich new ways to understand and address the difficulties experienced by adults with ID, and by their parents, staff and carers. I worked alongside nurses and professionals in an assessment and treatment unit (ATU) for the very small number of acutely disturbed or distressed people who could not be supported in the community. As I came to appreciate the situation and skills of staff and families, they came to appreciate how research might enable them to better support the person with ID.

What's good about doing research?

A clinical psychologist once described his research as long, lonely, and pointless. He'd lost all interest in the topic by the time his paper came out. You do have to like your own company as you stare at blank screens, and cudgel your brain into seeing connections and expressing half-formed ideas in words. Yet there is always the hope of writing something that matters, and of provoking new ideas in others. In a small field like ID there won't be many compatible people working where you are. You have to discover what the poet e. e. cummings called 'delectable mountains' - people whose thinking is both close enough and different enough to make conversation fizz. My virtual network keeps me trying, failing, and trying again to connect research data, ideas, and practice. A career high was hosting a small international seminar, Counterpoint (reported in *Journal Intellectual Disability Research*, 2010, v54 Supplement 1). Researchers from Australia, England, Germany, Holland, Scotland, USA, & Wales presented papers that had been read beforehand so they could be fully discussed. Twenty of us took over a small country house hotel for three days, affordable because the owner waived her usual £8k fee and provided it at cost in order to support our work. In the group picture (next page) you may see two Australian Professors, Christine Bigby (front row, 3rd from left) and Brendan Gleeson (far right). That's me in the stripey dress.

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Jennifer Clegg

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Lively conversations with researchers in Amsterdam and Brussels and a growing relationship with La Trobe University and ASID continue to energise me in retirement.

Does it change practice?

Clinically-informed research has changed practice but there are barriers to implementation. Clinicians who meet representatives of about half of the population tend to forget they know little about the other half. Research can also be misused to constrain innovation. An example is the UK's current requirement that staff implement Positive Behavioural Support (PBS), which makes service inspectors blind to new forms of intervention even when services produce research that demonstrates positive effects. It is full steam ahead for PBS despite the government's own full research review (rather than its Bowdlerised summary) which characterises the evidence base for all interventions as weak or non-existent, and their recommendations as no more than advisory.

One of the founders of practice-based research in ID, the New Zealander Jack Tizard, wrote this. 'The major impact of most research ...[is] at a local level and on the 'climate of opinion'.... It is the experience, knowledge, and way of looking at problems which research workers have, which could be of most use to ... policy What research workers have to offer government may often be by calling them as experts or consultants rather than by asking departments to commission specific pieces of research and then

attempt to assimilate directly the results of a large number of disparate enquiries.... [Researchers] if they are any good, look at their problems in a wider perspective.'(1979). Research-active services are high quality not only because their critical examinations help practice to evolve, but also because openness to people and ideas protects vulnerable people in challenging settings.

What else can ASID do to implement research effectively?

ASID's conferences have always been innovative: I first attended in 2003. It is in a good position to get proponents of different positions and modes of existence to talk to each other, so that they can identify what works well for whom. Since the World Economic Forum recently identified increased polarisation within societies as one of 5 major threats, here are some topics I would encourage working groups to discuss.

1. How to design services that address the needs of healthy people with milder ID in non-stigmatising ways, and justify and plan services that can address the needs of people with chaotic lives, severe ID, or complex needs.
2. Identifying the minimum requirements for adults with ID to live a life of dignity.
3. How can the relationship between parents and service-providers become less adversarial, more collaborative?
4. Innovation in a policy context that seeks certainty. ●



Louisa Smith

In mid 2014 a team of disability studies scholars and educational developers at UNSW embarked on producing two Massive Open Online Courses (MOOCs) called *Disability and a Good Life: Thinking through disability* and *Disability and a Good Life: Working with disability*. Both courses have since run twice on the FutureLearn platform, reaching 17 000 learners from countries as diverse as Papua New Guinea, Botswana, Slovenia and Italy.

Both MOOCs offer a foundation to understanding disability in a contemporary context. As such, they are grounded in a social understanding of disability and a human rights based approach. The first MOOC, *Thinking Through Disability*, introduces how our ideas about disability can have a significant impact on how people with disabilities can live their lives. We unpack the difference between disability and impairment, what counts as disability and the diverse experiences of disability depending on age, socio-economic status, gender, race and sexuality. The second MOOC, *Working with Disability*, continues to question and challenge big ideas often used in relation to people with disabilities. These include human rights, access, contribution and activism and advocacy.

In developing the materials, we aimed to be inclusive. We employed an Advisory Group of people with disabilities and their allies to advise us from the outset of course development. Through consultation and collaboration with this group we developed a curriculum and resources that reflected their concerns and stories.

Disability and a Good Life MOOCs

Louisa Smith, PhD
Kelley Johnson, PhD
Leanne Dowse PhD

The core resources for the MOOC emerged from collaboration with people with disabilities. We employed Taste Creative, an inclusive production company, to work with us in producing fourteen short films about the lives of people with disabilities. We also made short films of interviews with disability activists, academics and advocates from around the world. These core resources enliven the theoretical materials and text that surrounds them, and enable different learners to access the materials in different ways.

This idea that courses need to accommodate different learners and different learning needs is central to the MOOCs. We adopted a Universal Design for Learning (UDL) framework to ensure that the resources were accessible to a diversity of learners. This means that not only are all resources available in different formats, but that all learners can choose how they engage with the learning.

While one of the participants in the Advisory Group identifies as having a cognitive disability, the MOOCs are not always accessible to people with cognitive disability without support. As educators we struggled with making this decision. While the basic levels of the material are often in plain English, the clearly labelled extension and expansion steps are not always cognitively accessible. There have been learners with cognitive disability who have done the courses with a support worker and this contribution has been valuable.

The majority of the MOOC learners do the MOOCs for personal or professional development. Many comment on how the MOOCs have guided them through a transformational process, where they come out the other end understanding themselves and society differently.

For further information please contact
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A student's reflection on completing the Good Life Working with Disability MOOC

Elicia Ford
**-National Disability
Coordination Officer
(NDCO)**

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With a busy schedule and an abundance of apparently amazing learning opportunities all vying for my attention and professional development dollar it can be really difficult deciding upon a course of action, and so more often than I'd like to admit the chosen course is inaction. I entertain the idea of expensive events and even consider postgraduate coursework, but the reality is I don't have the time or the budget.

As a professional, working strategically to improve access and participation for people with disability in the Australian context, I really do value the chance for continual learning to develop and deepen my understanding of disability. I am fortunate to get a great deal of exposure to informal learning opportunities through my work, so when I am looking for more formal learning, what I really want is credibility, currency, quality, cost effectiveness and flexibility. Online courses can but often don't meet my needs, and I have been known to pick them up and put them back down again when they fail to engage me as a learner. The Massive Open Online Course (MOOC) Disability and a Good Life: Working with Disability is entirely different, it met all my needs and so much more.

The 'Disability and a Good Life: Working with Disability' course is freely offered over six weeks by the University of NSW on the FutureLearn platform. It is interesting and engaging, offering Australian and global perspectives on disability which are grounded in social, political and legislative context, defined and interpreted for modern application and implementation. The course adheres to universal design principles, is well-paced and well organised

into a logical sequence which scaffolds and builds upon learning each week, and with educators and mentors available to provide support and guidance, and actively involved in discussions, ensures learners of all abilities globally can participate. The ability to interact and converse with such a diversity of learners enhances the learning experience, offers deeper understandings of how disability and associated issues of access, inclusion, support and care are culturally understood and constructed, and challenges the learner to critically reflect on their own knowledge and perspectives.

Professional and lived experience expertise are balanced and blended throughout the course, offering invaluable insights and ideas about the importance of decision-making and independence, contribution, and access. This in particular caused me to reflect upon what it is like for people with intellectual disability to move out of home, have relationships and get a job – all the 'usual' stuff associated with transition to adulthood. Capacity, choice and rights were thoroughly explored through themes such as sexuality, legal representation and living in one's own home, and excellent case studies challenged societal norms around what it means to contribute and highlighted many valuable non-economic means.

Throughout the course I felt like people with disability were sharing their stories and themselves with me, and with a good deal of common sense, generosity and passion have brought me along on an important journey of discovery about exactly how much I do not know. ●

student reflection on Disability and a Good Life: Thinking Through Disability and Disability and a Good Life: Working with Disability MOOC

by the University of New South Wales

Jacki Brown

jackijbrown@hotmail.com



Student reflection on Disability and a Good Life: Thinking Through Disability and Disability and a Good Life: Working with Disability by the University of New South Wales

I have undertaken the UNSW Disability and a Good Life MOOCs, once as a student and three times as a mentor for both the courses. I have disabilities, both cognitive and physical and have found the courses to incorporate universal design as much as possible throughout the content.

As a student I found the course to be engaging and thought-provoking. I particularly enjoyed listening to the video guest presenters in the course, all of whom had different kinds of impairments, talking about their lives and their reflections on the topics each week. The learner guide for the courses Mel, made reflections that really resonated with me, and from other student's comments, they also appreciated her honest and candid examples. Mel was able to make the content of the courses applicable to her own life and the lives of other people with disabilities she was friends with or had worked with. This gave the content that we were exploring a relevance to our own lives as people with disabilities but also for those undertaking the course who did not have disabilities a chance to reflect on what it could mean for people living those experiences.

The University of New South Wales has created content which is engaging, informative and accessible to a wide variety of students, some of whom have disabilities and others who may have English as a second language. They have been able to achieve

this by providing content in a variety of formats: MP3/audio, transcripts and videos meaning that the course content is accessible and able to be engaged with in a manner that works best for the individual student.

Disability rights is a big and complex topic, which for people who may not have engaged with it before, could feel intimidating, however, the course structure enables these important ideas to be broken down and unpacked for most students in a manner which has transformed thinking and perceptions. Unfortunately, due to the nature of this course dealing with complex, abstract ideas it may not be fully accessible to some people with intellectual disabilities.

The disability community is diverse, in terms of the types of impairments that we live with, our access requirements, and our level of engagement with the social model of disability and disability rights. These courses centre the voices of people with disabilities throughout, one of the guest presenters identified as having an intellectual disability, so together these presenters were able to highlight the different perspectives and experiences people with varying impairments have. This highlights the diversity of disability and also in doing so makes it accessible and engaging to people who may experience a variety of impairments similar to the presenters.

I discovered a course which models universal design and a commitment to challenging attitudes and promoting equality of people with disabilities. ●

Disability studies in **New Zealand**

AUT

NURS604 Health, Illness & Disability
– Currently offered (3rd Year undergraduate)

Lincoln University

None

Massey University

Health: 250.317 Disability in Society
– Currently offered Dr Mary Breheny.

Sociology: 176.317 Sociology of Disability
– Not currently offered

University of Otago

Education: EDUC105 Disability Studies:
An Introduction
– Currently offered Dr Gill Rutherford

Nursing: NURS433: Intellectual Disability – Theory
into Practice
– Not currently offered

University of Canterbury

Sport Coaching:
SPCO 308 Athletes with Disabilities
– Currently offered

University of Auckland

Faculty of Education And Social Work – Disability
Studies: DISABTY 111 Disability and Support
– Currently offered

Faculty of Education And Social Work – Disability
Studies: DISABTY 113G Making Disabilities: The
Construction of Ideas
– Currently offered

Faculty of Education And Social Work – Disability
Studies: DISABTY 200 Disability Frameworks
– Currently offered

Faculty of Education And Social Work – Disability
Studies: DISABTY 316 Supporting Active
Participation
– Currently offered

Victoria University of Wellington

Education: EDUC 342 Exceptional Learners: Special
Education
– Currently offered - Larah Van Der Meer

The University of Waitako

Disability and Inclusion Studies (offered through
the Faculty of Education)

NB: This is not an exhaustive list as it is limited by
the search for disability in the title. Other courses
will have a focus on disability, but will not have a
primary focus on disability. As you will see, these
papers, apart from the University of Otago nursing
paper are pan-disability. There is no overt focus
on intellectual disability in any other paper we can
identify.

PhD Supervision

PhD opportunities tend not to come directly from
these courses and are more likely to be topic / indi-
vidual driven. There are a number of people who
supervise intellectual disability related PhD's includ-
ing myself (Donald Beasley Institute / University of
Otago), Professor Leigh Hale (University of Otago),
Professor Kate Diesfeld (Auckland University of
Otago), Dr Jenny Conder (Donald Beasley Institute /
University of Otago) and Carol Hamilton (University
of Waikato) as the more known supervisors in this
area. I currently have 3 PhD students working on
intellectual disability related topics, and 2 students
with a focus on ASD.

Again, this is not an exhaustive list but highlights
some key people in the field.

introducing organisational members:

NADO

by Joshie Hwang

NADO is a community-based charity that supports people with disabilities, their families and carers in Western Sydney, including the Hawkesbury, Blue Mountains, Penrith suburbs and surrounding areas. NADO is an ASID member

I am Joshie Hwang and I have been thinking a lot about what story NADO wants to share with IDA audiences, and finally I have decided to share our independent living support stories. So I went to see our Accommodation Manager, Vanessa Vella, who looks after the entire process of independent living from end to end.

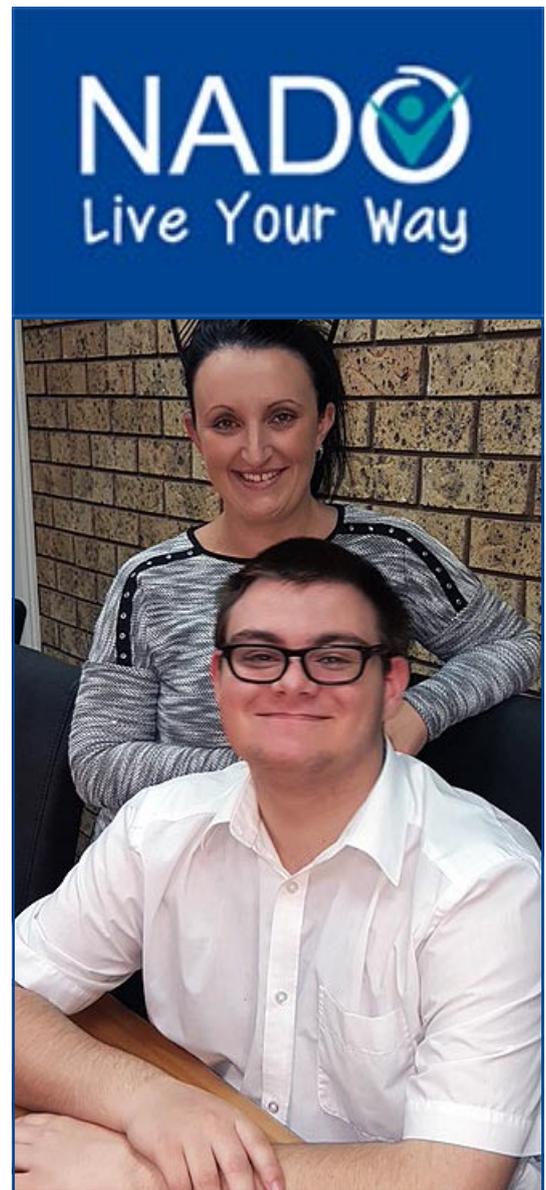
She manages the responsibilities of each team leader and helps them to manage their support workers to achieve participants' goals and lifestyle. One of the challenging parts of the job is rostering, ensuring staff for 24/7 care in accommodation where a support worker is needed to assist participants' daily lives such as cooking, cleaning, groceries, teaching them how to select healthy ingredients and how to cook, banking, paying bills, taking them to doctor appointments, etc.

Vanessa oversees 11 places of accommodation, including group homes, respite cottages and independent living support.

Vanessa said, "Everything that our participant needs for 24/7, we help them stand up on their own feet, we are behind the scenes making sure their plans are being followed and troubleshooting day to day problems, we are trying to do 'with' our participants, not 'for', so that they can learn and have confidence to Independently live their lives in their way".

She shared with me so many incredible stories, I struggled on whose stories to share and finally, I decided to share Michael, Graham and Bradley's stories, (with their permission), who are all working hard to be independent and achieve their dreams.

Michael has been temporarily residing in one of our respite cottages proudly shared his achievement of learning to cook so that he can be more independent. Important to him is building a better relationship



Vanessa Vella and Michael Kimble

with his mum. He found the transition of moving out of his house and moving into the cottage not too hard because he felt very well supported. He also made some friends as well. His next goal is to move into a shared home and get a job.

Graham recently came to NADO, but for the last eleven years no one noticed his interest in music, and he doesn't have the communication skills to communicate his opinions to others well so he was just sitting and listening to others. Vanessa and the other staff realised that he loves music and he wants to learn how to play the guitar, so she suggested joining a music class, and ever since, he is just so happy, he carries around his guitar everywhere. His tutor noticed his guitar was strung incorrectly and after adjustments, his love and ability to learn and play music has changed his life. Vanessa said, "When I can help our participants find their happiness that makes me so happy. That is *continued page 30*

Upcoming Events

<p>11 Aug 2017</p>	<p>ASID NZ 2017 Support Workers Talking: <i>What, Where and How?</i> Christchurch, New Zealand Contact: Olive Webb owebbnz@gmail.com https://www.asid.asn.au/events/78_asid_nz_2017_support_workers_talking</p>
<p>15 Aug 2017</p>	<p>ASID WA Divisional Conference 2017 <i>Looking to the Future</i> The Boulevard Centre, Floreat WA Contact: Allyson Thomson Allyson.Thomson@curtin.edu.au https://www.asid.asn.au/events/72_asid_wa_divisional_conference_2017</p>
<p>8 - 10 Nov 2017</p>	<p>Australasian Society for Intellectual Disability Annual Board Conference <i>Pushing The Boundaries</i> The Grand Chancellor Hotel, Hobart https://www.asid.asn.au/events/53_2017_asid_conference__pushing_the_boundaries</p>
<p>13 - 16 Nov 2017</p>	<p>2017 IASSIDD 4th Asia-Pacific Regional Congress <i>Inclusiveness and Sustainable Development</i> The Ambassador Hotel, Bangkok, Thailand https://www.iassidd.org/conference/index.php/2017APRC/2017APRC/schedConf/overview</p>

If you want to advertise in IDA's upcoming events section, please e-mail Hilary Johnson: idaeditor@asid.asn.au



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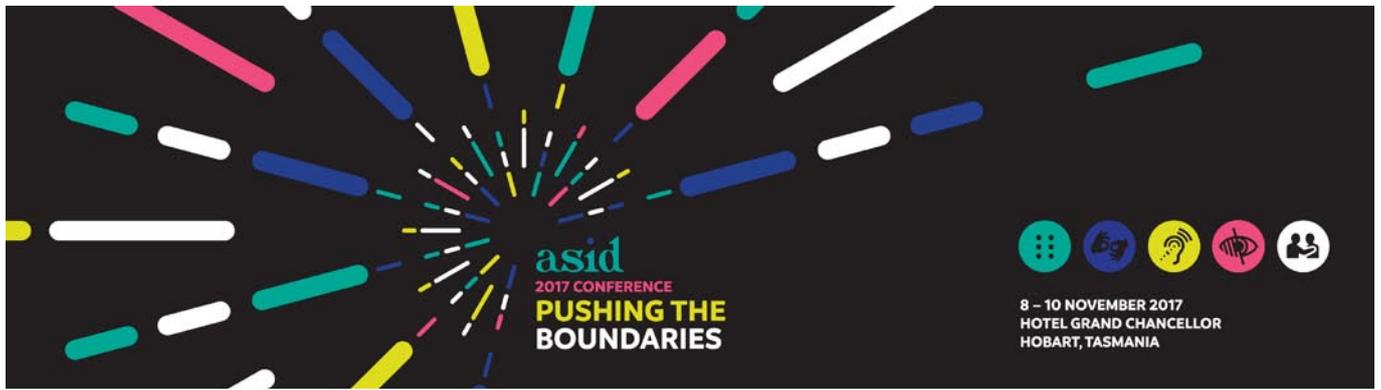
what we do in NADO, we care for each participant, to connect with them, to understand what can motivate them to try harder and achieve happiness along with independence”.

Bradley had been wanting to learn how to read for a very long time, and NADO support workers, Danielle, Janelle, Belinda and Karen have been helping him with how to read for at least an hour every day. Now he is able to read! It is not easy to for him, but with reading, he puts all of his effort into learning and now, with the help of our team he can finally read his favorite Marvel comic books and also he can text his family and friends. He has reached his goal and now, all he wants to do is read, reading aloud so that others can hear and enjoy with him.

At NADO, we don't just provide services to our participants, we want our participants to achieve their goals because that achievement empowers them to try their best to live their way.

Most of us take day to day tasks for granted, but they are not easy tasks for our participants. They overcome fear and difficulty every day to live their way, step by step, with support of their friends, family and NADO being their shadow to guide them to learn how to enjoy the freedom responsibly and with hope. They move forward every day, towards independent living.

For further information please contact Joshie Hwang, Marketing Director of NADO jhwang@nado.org.au



**Early bird registration closes 30 July ...
2017 Australasian Society for Intellectual Disability Conference
Hobart on 8 - 10 November 2017**

**Keynote
Speakers:**



Judy Huett



Jennifer Clegg



Monica Cuskelly



Leanne Dowse



Rob Greig

Further information available on the [ASID 2017 website](#)