



asid

2017 CONFERENCE

PUSHING THE BOUNDARIES



8 – 10 NOVEMBER 2017
HOTEL GRAND CHANCELLOR
HOBART, TASMANIA

Special Olympics Australia strives to ensure that everyone living with an intellectual disability has the opportunity to participate in sport. Our dedicated network of volunteers create accessible sports training, coaching and competition opportunities that allow people with an intellectual disability to reach their personal best – in sport and in life.



**Special
Olympics**
Australia

The facts:

We're not the Paralympics which is mainly for athletes with a physical disability. Special Olympics is for athletes with an intellectual disability.

At Special Olympics everyone is welcome. The Paralympics is only for elite athletes.

We're not just a major sporting event. Special Olympics provides year-round sports training as well as regular competition.

We offer:

Sports training week-in, week-out in:

Alpine skiing	golf
aquatics	gymnastics
athletics	netball
basketball	sailing
bocce	snowboarding
cricket	softball
equestrian	tennis
figure skating	tenpin bowling
football (soccer)	



Competition opportunities:

World Summer and Winter Games
Asia Pacific Games
National Summer and Winter Games
State Games
Intra-club competitions



Lifestyle programs:

Healthy Athletes Program
Athlete Leadership Programs
Young Athletes program
Unified Sports



P: 1300 225 762

E: info@specialolympics.com.au

www.specialolympics.com.au





WELCOME FROM ASID PRESIDENT

I am delighted to welcome you to the 2017 ASID Board Conference in the lovely city of Hobart.

ASID conferences are a wonderful and unique experience, hearing presentations and the latest research, networking, and renewing and making new friendships. If you have previously participated in an ASID Conference you will understand what I mean. If this is your first time make the most of what it has to offer – you will not be disappointed.

The Conference theme is “Pushing the Boundaries”. It reflects the major challenges facing all communities who desire to realise 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. It is important because it makes us ask the questions – what needs to change?; what work still needs to be done?; and how do we ensure that what is happening in an authentic and truly reflects the voice of people with intellectual disability.

The conference program provides everyone attending with the opportunity to explore current research and practice with presentations from people with intellectual disability and their families, service providers and academics. I would like to welcome our international and Australasian keynote speakers. We are fortunate to have speakers who will challenge us with a diverse range of perspectives.

Over the next three days you will hear about current research and practice and discover ideas you can take away and implement in your own context. I also hope we all leave with many ideas about what we need to be doing, developing and researching to “push the boundaries.”

I would like to thank the Organising Committee for their commitment and hard work to bring you this Conference.

Enjoy the ASID Conference experience!

Professor Angus Buchanan
President
ASID

WELCOME FROM COMMITTEE

The Conference theme is “Pushing the Boundaries”

It reflects the major challenges facing all communities who desire to realise the goals of the UN Convention on the Rights of Persons with Disabilities.

We would like to acknowledge the Keynote speakers, Dr Jennifer Clegg, Professor Monica Cuskelly, Associate Professor Leanne Dowse, Rob Grieg and Judy Huett along with the many presenters over the 3 days, for their contribution to the Conference.

A special thank you to the sponsors for supporting the ASID 2017 Conference.

We hope that everyone attending the Conference has a great 3 days of learning, sharing and networking.

ASID 2017 Organising Committee

Angus Buchanan (Conference Chair)

Christine Bigby

Hilary Johnson

Allyson Thomson

David Treanor

Darryleen Wiggins



The Australasian Society for Intellectual Disability is a nearly 50 year old organisation 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.

ASID operates as a company (limited by Guarantee) and its local activity is managed across its seven Divisions—six in Australia (New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia) and one in New Zealand.

ASID's annual conference is the premier event led by the ASID Board. The Board has a longstanding tradition of rotating the conference's location around the divisional regions so that everyone gets the opportunity to take full advantage of new ideas, innovations and be challenged.

The conference showcases current research and practice across Australia and New Zealand. It typically attracts enthusiastic people from a wide range of backgrounds and organisations throughout Australasia and beyond. The conference enables those involved with intellectual disability to learn about each other's challenges, resources and achievements.

There are many benefits for members of ASID, including:

- Membership of a strong and active association comprising people working or studying in the area of intellectual disability, people with an intellectual disability and their families or carers.
- Membership of a regional association which meets on a regular basis to pursue issues of local, national or international relevance.
- Annual conferences hosted by each regional association featuring keynote addresses from leading international speakers.
- Locally organised regional conferences, seminars, workshops and social gatherings.
- Opportunities to hear touring international and national experts sponsored by the Society.
- Opportunities to meet and exchange ideas with people having similar interests in other parts of your region and the country.
- Opportunity, through a united society, to influence developments in the area of intellectual disability.
- Quarterly issues of the Journal of Intellectual and Developmental Disability which has an international readership and contributor ship.
- Quarterly issues of the society's magazine, Intellectual Disability Australasia, which includes articles of general interest and contributions from regional associations.
- Opportunity to join various networks within ASID which pursue areas of special interest.
- Access to a new journal, Research and Practice in Intellectual and Developmental Disabilities, which is issued twice per year.

Joining ASID or renewing your membership

If you would like to become a member visit the website at www.asid.asn.au, if you need to change your membership type, please contact the Secretariat on email secretariat@asid.asn.au or by calling 1800 644 741 (within Australia).

GENERAL INFORMATION



Accessibility

The Hotel Grand Chancellor is an accessible venue, please enquire at the registration desk about guidance on accessibility within the venue. The venue is wheelchair accessible with wheelchair access bathrooms on the function level. Volunteers will be available to assist you if required.

Accommodation

If you have any queries relating to your accommodation booking, first speak to the staff at your hotel, or alternatively, Leishman Associates' staff at the registration desk.

Your credit card details were supplied to the hotel you selected as security for your booking. If you have arrived 24 hours later than your indicated arrival day, you may find that you have been charged a fee. You will be responsible for all room and incidental charges upon check out, and may be asked for an impression of your credit card for security against these charges. This is standard policy in many hotels.

Additional Tickets: Conference Social Program

The Welcome Reception is included in the cost of a full conference registration. Additional tickets for the Welcome Reception can be purchased for \$100. Please check availability with staff at the registration desk if you would like to purchase a guest ticket.

ATM's

There is an ATM available in the lobby of the Hotel Grand Chancellor. Other ATM's can be found within an easy five minute walk from the Hotel Grand Chancellor in the Gasworks precinct.

Conference Name Badges

All delegates, speakers, sponsors and exhibitors will be provided with a name badge, which must be worn at all times within the conference venue, as it is required for access to all the conference sessions and the Welcome Reception.

Conference Dinners

Selection for the various conference dinner options were made available to choose during registration.

Please check with staff at the registration desk if places are still available.

Dress code

Dress throughout the day is smart casual or informal business

Emergency Medical Care

For any medical emergency please telephone 000. The staff at your hotel will have information if you require contact details for a doctor, dentist or other health professional.

Entry to Conference Sessions

It is suggested that delegates arrive at preferred sessions promptly to ensure participation in the session. If sessions become full then late delegates will not be allowed entry.

WiFi Access

Wireless internet will be available throughout the conference venue for the duration of the conference. To access wifi, please connect to the ASID2017 network and use the following password. If you have trouble connecting please see the staff at the registration desk.

USERNAME: ASID2017 (uppercase)

PASSWORD: asid2017 (lowercase)

Mobile Phones

As a courtesy to other delegates, please ensure that all mobile phones are turned off, or in a silent mode, during all sessions and social functions.

Parking

Car parking is available for hotel guests and is located under the hotel. An additional cost is payable if hotel guests wish to use the car park. Access to the car park is from the rear of the building on Macquarie Street. From the hotel's main entrance drive along Davey street (which is one way), turn right on Argyle Street, and immediately right again onto Macquarie Street.

Valet parking; \$18 per vehicle overnight
Undercover self-parking; \$9 per vehicle overnight (limited space)

GENERAL INFORMATION

Photographs, Videos, Recording of Sessions

Delegates are not permitted to use any type of camera or recording device at any of the sessions unless written permission has been obtained from the relevant speaker.

Registration Desk

The Registration Desk is located on the Mezzanine Level. Please direct any questions you may have regarding registration, accommodation, or social functions to Leishman Associates staff at this desk.

Registration Desk Opening Times

Wednesday 8 November	8.00 am – 5.30 pm
Thursday 9 November	8.00 am – 5.30 pm
Friday 10 November	8.00 am – 4.00 pm

Smoking

The Hotel Grand Chancellor, Hobart is a non-smoking venue. Guests can smoke outside in designated areas.

Social Media Networks

Facebook is a social utility that helps people connect and share with their friends, colleagues, family, association, brands and more.

Remain up-to-date on topics and posts from ASID
<https://www.facebook.com/asid.asn.au>

Twitter is a social networking service that allows you to answer the question “What are you doing?” by sending messages up to 140 characters in length to your friends or “followers”.

Start following ASID on twitter
https://twitter.com/ASID_Ltd / @ASID_Ltd

Speakers and Speakers’ Preparation Room

All speakers should present themselves to the Speakers’ Preparation Room, located on the Mezzanine Level at least 2 hours before their scheduled presentation time, to upload their presentation.

Speakers are requested to assemble in their session room 5 minutes before the commencement of their session, to meet with their session chair and to familiarise themselves with the room and the audio visual equipment. For information on the chairperson attending your session, please see the registration desk.

A technician will be present in the speaker’s preparation room during registration hours. There will be facility to test and modify your presentation as required.

Special Diets

All catering venues have been advised of any special diet preferences you have indicated on your registration form. A special table has been set aside for dietary requirements; please see the venue staff for more information.

Disclaimer

The ASID 2017 Conference reserves the right to amend or alter any advertised details relating to dates, program and speakers if necessary, without notice, as a result of circumstances beyond their control. All attempts have been made to keep any changes to an absolute minimum.

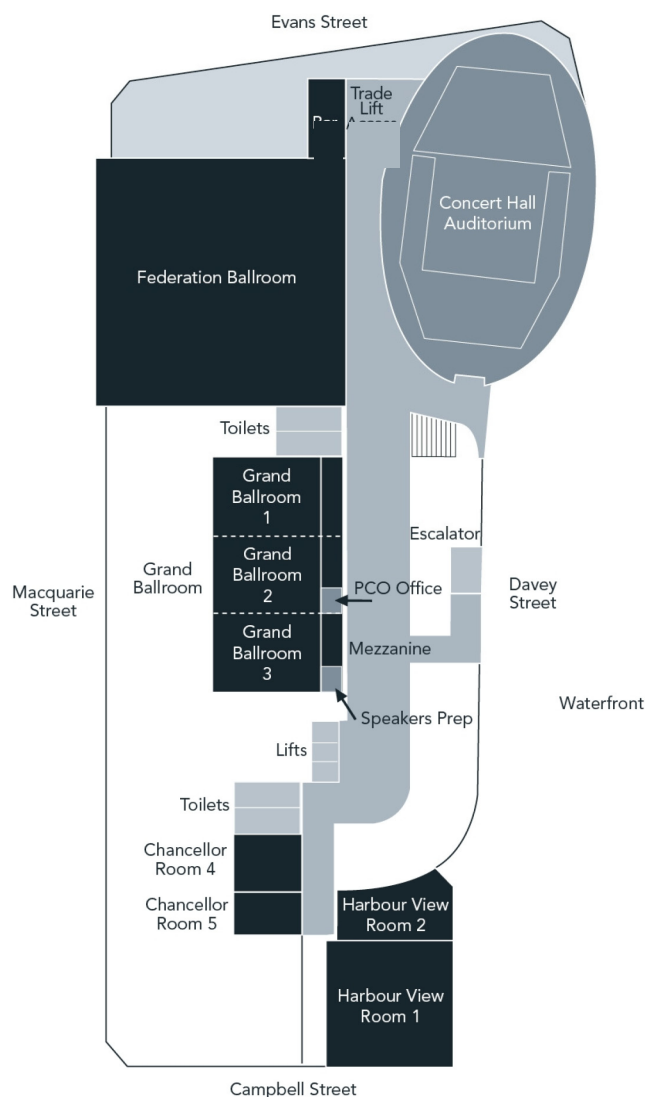
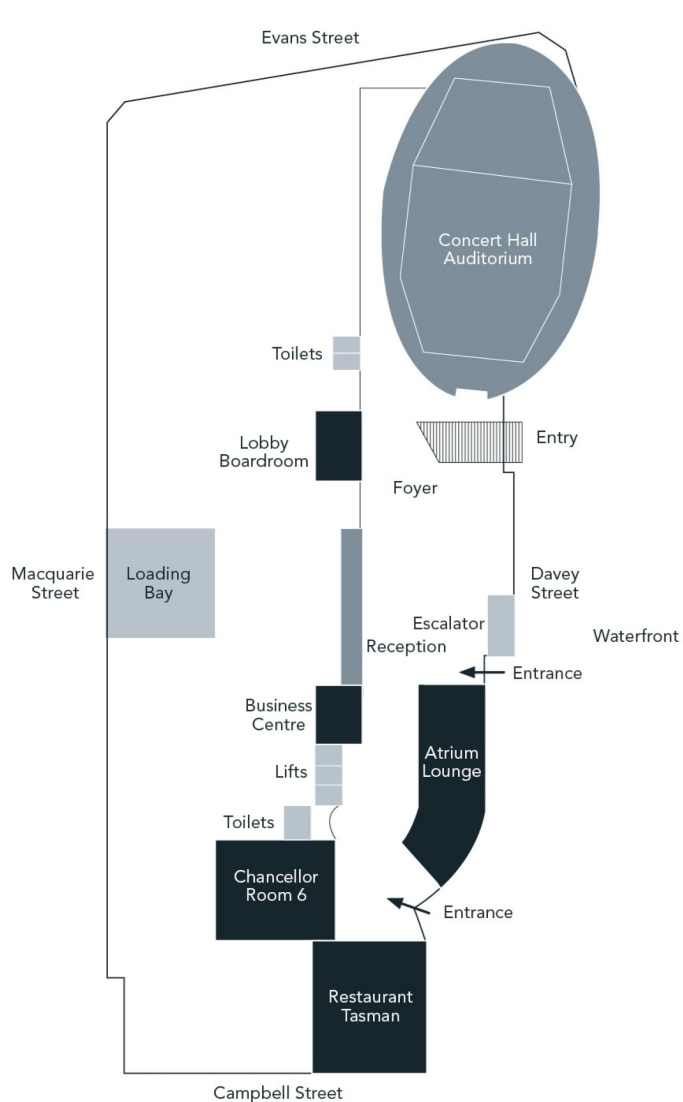
Conference Managers



227 Collins Street, Hobart, Tas 7000
170 Elgin Street, Carlton, Vic 3053
Phone 03 6234 7844

www.leishman-associates.com.au

VENUE MAP



pushing the boundaries

SOCIAL PROGRAM

Welcome Reception

The Welcome Reception is a great opportunity for all delegates to meet and greet, it's time to start networking.

This function is included with a Full Registration.

DATE: Wednesday 8 November 2017

TIME: 5.30–7.30 pm

VENUE: Hotel Grand Chancellor, Mezzanine Level

COST: Included in Full Registration. Guest tickets available – \$100.00

DRESS CODE: Smart casual

Conference Dinners

Various conference dinner restaurants. There are a number of delicious options to choose from. Experience some of Hobart's fine food and wine to suit your tastes.

Dinners are an additional cost, limited spaces available.

DATE: Thursday 9 November 2017

VENUE: Various dinner venue options

DRESS CODE: Smart casual

A keynote speaker will host one of the locations as per below.

Mures Upper Deck: Monica Cuskelly

Frank Restaurant: Jennifer Clegg

Astor Grill: Leanne Dowse

Drunken Admiral: Rob Greig

Awu Delicious Food Chinese Restaurant: Judy Huett



Living with Disability
RESEARCH CENTRE

RESEARCH BRIEF - 2017

OUR RESEARCH FOCUS

The LiDs Research Centre projects, publications and partnerships are conducted across three broad themes:

- Effectiveness of disability services;
- Building the evidence base for participation and inclusion; and
- Enabling mainstream services to be more inclusive.

Embedding Active Support and Practice Leadership in supported accommodation services

Quality of life for people with intellectual disabilities improves if staff consistently practice active support. Active support is hard to embed in services and LiDs research aims to find out what are the most important organisational factors to pay attention to. Interim findings to date in this major project are available:

www.bit.ly/CBigbyPapers

www.latrobe.edu.au/lids

Effective Decision Making support for people with Cognitive Disability

We are investigating the impact of decision making resources on the practices of decision making supporters and the person being supported. A randomised control trial (the most powerful type of research possible) is being conducted in three jurisdictions (NSW, QLD and VIC). Participants are being sought:

www.bit.ly/LiDsDecisionStudy

LiDs researchers and higher degree students at ASID 2017

- Professor Christine Bigby
- Dr Tal Araten-Bergman
- Dr Emma Bould
- Professor Jennifer Clegg
- Ms Lisa Hamilton
- Mr Lincoln Humphries
- Ms Gail Ritchie
- Ms Michelle Browning
- Professor Magnus Tideman
- Ms Sophia Tipping



Still from the video resource on supported decision making

LiDs online resources

"Every Moment Has Potential" is a free online learning resource that introduces support workers to the four essentials of Person Centred Active Support.

activesupportresource.net.au

'Supporting Inclusion' focuses on how active support can be used by support workers out in the community as well as in supported accommodation services.

supportinginclusion.weebly.com

Dr Jennifer Clegg

University of Nottingham, UK, & La Trobe University, Australia

Honorary Associate Professor at the University of Nottingham, Adjunct Professor at the La Trobe University, Australia. Jennifer's recent work has focused on transition from child to adult services, with particular attention to ideas that drive services and how people and systems co-operate in the delivery of services.



She is particularly interested in the influence of human interaction in the construction and delivery of services, and intellectual disability psychiatry.

WEDNESDAY 8 NOVEMBER 2017

PLENARY SESSION

1.30–2.20 PM

4.1 PLAIN ENGLISH KEYNOTE

11.45 AM–12.30 PM

Living with intellectual disability in the twenty-first century

Current international policy for people with intellectual disabilities originated 50 years ago. This shifted away from regarding cognitive impairments as the origin of difficulties and, instead, regarding such difficulties as socially produced and common to all people with disability. Like all policy revisions, it sought to correct the failings of its predecessor and brought many positive changes. Specialist settings and services have been closed, and people with intellectual disability are increasingly regarded as members of the broader collective 'people with a disability'. The paper draws on a research review with Christine Bigby that examined the intended and the unintended consequences of this policy of dedifferentiation. It makes the case for renewing policy in the light of research findings concerning its impact, and of recent changes in our understanding of intellectual disability, community, and social justice. It draws on Bauman, who criticised the deification of happiness as a life goal and consumer choice as the means to attain it, advocating instead a social justice approach that avoids interest groups being pitted against one another in a battle for diminishing resources. Creating a twenty-first century vision of intellectual disability requires different stakeholders to act together in ways that allow new alternatives to emerge.

KEYNOTE SPEAKERS

Professor Monica Cuskelly

University of Tasmania

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.



THURSDAY 9 NOVEMBER 2017

PLENARY SESSION

1.30–2.20 PM

FRIDAY 10 NOVEMBER 2017

8.1 PLAIN ENGLISH KEYNOTE

1.00–1.45 PM

Pathways to self-determination for individuals with intellectual disability

Self-determination is a key marker of adulthood. It can be considered to be a developmental construct as its beginnings are observable early in life but it generally does not reach its mature form until sometime in late adolescence/early adulthood. Self-determination is influenced by a number of factors including individual characteristics, aspects of family functioning, and interactions and opportunities at school and post-school. It is not, however, entirely an individual ability. It requires environments that are open to the expression and enactment of the individual's preferences and wishes. For many individuals with intellectual disability, the experiences necessary to support the development of the capacity to be self-determining are absent from their lives. Drawing on several streams of research across childhood, adolescence and adulthood, this presentation will discuss a number of contributors and barriers to the development and exercise of self-determination by those with intellectual disability.

Associate Professor Leanne Dowse

University of NSW

Leanne Dowse is Associate Professor and Chair in Intellectual Disability Behaviour Support at the University of New South Wales. She has been a scholar, practitioner, supporter and ally in the area of cognitive disability for over twenty-five years.



Leanne leads a program of research and teaching aimed at creating and exchanging knowledge to build capacity to support people with cognitive disability and complex support needs. Leanne's work utilises a multidisciplinary approach to investigate social justice issues for people with complex needs and their families and supporters, in particular at the intersections of cognitive disability with psychosocial disability, challenging behaviour, social isolation, early life disadvantage, substance misuse, violence and abuse and contact with the criminal justice system.

She is committed to ensuring that issues for people with cognitive disability and complex support needs remain at the forefront of consideration in reforming and transforming systems of social support.

FRIDAY 10 NOVEMBER 2017

PLENARY SESSION

9.05–9.55 AM

WEDNESDAY 8 NOVEMBER 2017

8.1 PLAIN ENGLISH KEYNOTE

1.45–2.30 PM

Out of the 'Too Hard Basket': Tackling the critical issues for people with cognitive disability who have complex support needs

As systems of social care the world over move toward individualisation and market-based provision, some changes long argued for by people with disability and their allies and supporters are being taken up in the principles of reforms such as Australia's National Disability Insurance Scheme. However, as researchers, practitioners and advocates with people with intellectual or cognitive disability, we know from experience, that equitable access to comprehensive and effective supports is far from a level playing field. This is particularly so for people with cognitive disability who have complex support needs, that is, those who experience interconnected disadvantage associated with some or all of multiple domains such as mental health, challenging behaviour, drug and alcohol, trauma, abuse and violence, inter-generational and circumstantial disadvantage, homelessness and incarceration. The complexity of support needs is primarily related to the lack of capacity or willingness of services and the systems underpinning them to accommodate and address these interconnected support needs. It is this group who arguably have the most to gain from a responsive and effective NDIS, but who at the same time are most at risk of being marginalised in the Scheme precisely because of their interconnected experiences of disability and significant contextual, social, and systemic disadvantage.

This presentation canvasses current knowledge about people with complex support needs in Australia. It will present the argument for understanding complex support needs as not simply additional needs, but rather as qualitatively different, requiring unique and specialist approaches to support, up-to-date estimate of prevalence in the Australian population, and analysis of current challenges in addressing the human rights of this group. With the NDIS hurtling toward full roll out, there are now urgent challenges in ensuring that the scheme's vision to 'maximise independence and social and economic participation' encompasses all people with disability. The paper concludes with suggestions for ways we can collectively work to ensure that tackling issues for people with cognitive disability and complex support needs are elevated from the 'too hard basket' to a central consideration in our shared endeavour for disability equality.

KEYNOTE SPEAKERS

Rob Greig

National Development Team for Inclusion

Rob has been Chief Executive of the NDTi since May 2008. Before that he spent six and a half years as the UK Government's National Director for Learning Disabilities, providing national leadership on the delivery of the cross-Government Valuing People Now policy.



He was the creator and original manager of the Valuing People Support Team and the prime author of Valuing People. Whilst working for Government, Rob was also involved in the work of the Office of Disability Issues, including as Vice-Chair of the Expert Panel that oversaw the development of the Independent Living Strategy. He also was a contributor to many other elements of health and social care policy – seeking to promote their relevance to people with disabilities and others who are marginalised in society.

Prior to this, Rob worked in a variety of roles, including managing and planning both mental health and learning disability services in both local government and the NHS and managing a voluntary sector development programme. In 1995 he established the Community Care Development Centre at King's College and prior to that worked as a consultant with various organisations – including the NDT in the early 1990's.

Rob's great concerns have always been in how to effect change in public services and society to benefit people and groups who are marginalised and excluded. This has resulted in a range of interests over his life and career, including action around employment, housing, racism and the health service.

He is a member of the Equality and Human Rights Commission Committee.

Rob was awarded a CBE in the 2010 New Year Honours List for his work described above.

WEDNESDAY 8 NOVEMBER 2017

PLENARY SESSION

9.25–10.15 AM

4.1 PLAIN ENGLISH KEYNOTE

11.00–11.45 AM

Individualised funding/personalisation in England: What worked, what didn't, and why

Individualised funding (under the overall heading of personalisation) has been at the core of policy for people with intellectual disabilities in England for over 10 years. There have been some notable successes for individuals, but the aspiration that this would change services and lives for all people has not been realised. Looking at the history of how policy was developed and implemented, and the evidence on progress (or lack of it), this presentation will seek to understand what can be learnt from this experience in England and thus translated into similar approaches in Australia.

In particular, the extent to which Government actions did or did not support changes to service culture and practice, the impact of 'austerity' and the extent to which service systems really bought into a shift in power to the person and their family, will be addressed.



Judy Huett

Speakout Advocacy

Judy Huett is a 44 year old woman with intellectual disability. She lives in Burnie, Tasmania with her husband Peter. Judy was born and raised in a small community on the West Coast of Tasmania where she attended primary and high school. Since then she has attained qualifications in Disability Support, Aged Care, Information Technology and Small Business Management; and completed leadership development training through Leaders for Tomorrow (2012) and Voice at the Table (2016).



Currently Judy works part-time with Speak Out Association of Tasmania in Self Advocacy Liaison and Support. This involves capacity building with her peers and the Speak Out Members' Executive. She is admired and respected by people from all walks of life.

An accomplished leader, Judy is best known for her extensive contributions via her voluntary work that includes travelling to Geneva, Switzerland in 2013 with the expert group to talk to and present to the United Nations Committee on the Rights of Persons with Disabilities (UN CRPD); the national Our Voice Committee (immediate past Chair) and their many projects around Zero Tolerance and employment, Board member of Inclusion Australia, two terms with the Tasmanian Premier's Disability Advisory Council (PDAC) and member since inception of the Intellectual Disability Reference Group (IDRG). The longevity of Judy's commitment to the NDIS is evidenced by her participation in the delegation of self advocates to Parliament House Canberra to lobby for the NDIS.

Her long-standing commitment to promoting the human rights of people with intellectual disability and her contribution at a local, national and international level to developing self-advocacy resulted in her being awarded the Tasmanian Disability Community Achievement Award in 2010, and the Individual Award for Human Rights in 2012.

Judy is a skilled speaker and has presented at many conferences over many years including Having a Say, NSWCID, Speak Out, DARU and NDS.

THURSDAY 9 NOVEMBER 2017

PLENARY SESSION

9.05–9.55 AM

The NDIS Independent Advisory Council and the IDRG

The NDIS Independent Advisory Council and the Intellectual Disability Reference Group are key sources of design information for the NDIS. Judy Huett, a woman living with intellectual disability from Burnie, Tasmania will talk about her representation on these bodies, her journey to national representation, and the importance of supporting the skill development of self-advocates.

PROGRAM

DAY ONE Wednesday 8 November 2017			
8.00 am	REGISTRATION		Mezzanine Level
9.00–10.30 am	SESSION 1 OPENING PLENARY Chair: Angus Buchanan		Grand Ballroom 2 & 3
9.00–9.05 am	Welcome to ASID 2017 <u>Angus Buchanan</u>		
9.05–9.15 am	Welcome to Country <u>Kartanya Maynard</u>		
9.15 - 9.25 am	ASID President's address <u>Angus Buchanan</u>		
9.25–10.15 am	Individualised funding/personalisation in England: What worked, what didn't, and why <u>Rob Greig</u>		
10.15–10.30 am	Special Olympics Australia <u>Corene Strauss, Chief Executive Officer</u>		
10.30–11.00 am	MORNING REFRESHMENTS  Taylor & Francis Taylor & Francis Group		Mezzanine Level
11.00 am–12.30 pm	CONCURRENT SESSION 1		
	GRAND BALLROOM 1	GRAND BALLROOM 2	HARBOUR VIEW ROOM 1
	1.1 Symposium: Participation – Community Exploring community participation programs	1.2 Symposium: Rights – Safety Freedom from exploitation, violence and abuse: improving policy and practice by using research to sharpen our focus	1.3 Symposium: Research – Inclusion Centre for Disability Studies Inclusive Research Network
11.00–11.30 am	Identifying conceptualisations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability. A scoping review <u>Christine Bigby</u> , Sian Anderson, Nadine Camerson	What is important to children and young people with intellectual disability about safety in institutional settings? <u>Sally Robinson</u>	Pushing the Boundaries of publication in inclusive research <u>Elizabeth Young, Mark Walters, Tanya Riches, Patricia O'Brien, Bruce O'Brien, Megan Noyeaux, Lesley Lewis, Marie Knox, Jack Kelly, Suzy Jessep, Robert Griffiths, Alex Butters, Sarah Butler, Susan Adrian</u>
11.30 am–12.00 pm	A case study of an Effective Community Participation program <u>Christine Bigby</u> , Sian Anderson, Nadine Camerson	Applying lived experience to service landscapes: how can we bring perspectives of people with intellectual disability into policy and practice? <u>James Bannister</u>	The two of us: An exploration of the relationships of people with Intellectual Disability in different social contexts <u>Jack Kelly, Emma Doukakis, Sarah Wagstaff</u>
12.00–12.30 pm	Dogs as catalysts for community participation of people with intellectual disability <u>Emma Bould</u> , Christine Bigby, Pauleen Bennett, Tiffani Howell	Applying lived experience to new contexts: informing responses for women with disabilities in domestic violence services <u>Patsie Frawley</u>	It was a very proud moment for me": The experiences of researchers with intellectual disability reporting their research findings to their support organisations <u>Suzy Jessep, Sarah Butler, Jack Kelly, Marie Knox</u>



11.00 am–12.30pm	HARBOUR VIEW ROOM 2		CHANCELLOR ROOM 6 Chair: Morrie O'Connor	
	1.4 Symposium: Education Knowing myself in the world through Moving and Sensing – new perspectives on the sensory motor experiences of autism		1.5 Services – Behaviour Support	
11.00–11.30 am	Clinical history and management of catatonia diagnosed in a 43-year-old female with autism Margaret Kyrkou, Jenny Curran, Nicole Kyrkou, Kerry Rye, Jane Nugent		Quality control for positive behaviour support in disability services Brent Hayward	
11.30 am–12.00 pm	An overview of motor dysregulation and autism and the implications for self-regulation Jenny Curran, Kerry Rye, Christel Burton, Margaret Kyrkou, Nicole Kyrkou, Jane Nugent		Improving behaviour support plan quality via targeted professional development Maria Vassos	
12.00–12.30 pm	Development of interception in children and young people with autism within an educational context Nicole Kyrkou, Emma Goodall, Jenny Curran, Margaret Kyrkou, Kerry Rye, Jane Nugent		Extraordinary (Positive Behaviour) Support in an Ordinary Way – Challenges in the NDIS Anna Posselt, Michelle Atkinson	
12.30–1.30 pm	LUNCH & POSTERS			Mezzanine Level
1.30–2.20pm	PLENARY Chair: Christine Bigby Living with intellectual disability in the twenty-first century Jennifer Clegg			Grand Ballroom 1 & 2
	 Living with Disability RESEARCH CENTRE			
2.30–3.30pm	CONCURRENT SESSION 2			
	GRAND BALLROOM 1 Chair: Hilary Johnson	GRAND BALLROOM 2 Chair: Richard O'Loughlin	HARBOUR VIEW ROOM 1 Chair: Paul O'Dea	
	2.1 Participation – Community	2.2 Rights – Safety	2.3 Research – Inclusion	
2.30–3.00 pm	Sydney user-led advisory team Carol Smail, Lachlan Billing, Stavros Nanos, Audrey O'Connor, Tony Giles, Matthew Collins	Young people with cognitive disabilities and the police: Service provider perspectives Kathy Ellem	Recruitment: It's challenging Angus Buchanan, Kimberlee White, Rebecca Waters	
3.00–3.30 pm	Trauma Informed Positive Behavior Support: Outcomes of a model for people with disability and a history of adversity Nicola Crates, Matthew Spicer	Disability support staff views on the use of mechanical restraint: A systematic review. Gemma Dodevska, Keith McVilly, Kathryn White	What makes for Inclusivity in Inclusive Research? Tanya Riches, Patricia O'Brien	

PROGRAM

2.30–3.30pm	HARBOUR VIEW ROOM 2 Chair: Deborah Espiner	CHANCELLOR ROOM 6 Chair: Morrie O'Connor
	2.4 Education	2.5 Services – Accommodation
2.30–3.00 pm	Teaching children with ASD: Investigating teachers' evidence-based strategy choices <u>Traci-Ann Garrad</u> , Christopher Rayner, Scott Pedersen	Nexus Independent Living Program (NILP) <u>Mark Jessop</u>
3.00–3.30 pm		Can motivational interviewing follow- up calls improve the implementation and retention of a specific communication support (Key Word Sign) by staff supporting people with an intellectual disability? A pilot project <u>Laura Le Van</u> , Rocco Crino, Sam Corneille
3.30–4.00 pm	AFTERNOON REFRESHMENTS	 Taylor & Francis Taylor & Francis Group
		Mezzanine Level
4.00–5.30pm	CONCURRENT SESSION 3	
	GRAND BALLROOM 1 Chair: Bernadette Curryer	GRAND BALLROOM 2 Chair: Ian Pearce
	3.1 Participation – Community	3.2 Rights – Safety
4.00–4.30 pm	From private to public: Community development practice and people with Intellectual Disabilities <u>Morrie O'Connor</u> , <u>Paul O'Dea</u>	Factors contributing to the sexual abuse of people with intellectual disability: A review of the literature. <u>Gail Ritchie</u> , Christine Bigby, Jacinta Douglas
4.30–5.00 pm	Community Living Association Trainers Project <u>Sarah MacDonald</u>	The Victorian Centres Against Sexual Assault: Responding to victim/survivors with intellectual disability or complex communication needs <u>Dagmar Jenkins</u> , David Rose, Louise Harms
5.00–5.30 pm	Easy English: Functional choices – Everyday words and sentences <u>Cathy Basterfield</u>	Speak Up and be safe from abuse <u>Hilary Johnson</u> , Naomi Rezzani, Denise West, Katie Lyon, Ruby Yee



4.00–5.30pm	HARBOUR VIEW ROOM 2 Chair: Deborah Espiner	CHANCELLOR ROOM 6 Chair: Adrian Higgins
	3.4 Workshop: Education	3.5 Services – Accommodation
4.00–4.30 pm	Interoception Workshop: An interactive experience for learning and teaching the eighth sensory system of interoception <u>Margaret Kyrkou, Jenny Curran, Kerry Rye, Nicole Kyrkou</u> , Emma Goodall	Quality and outcomes of individual supported living (ISL) arrangements for adults with intellectual disability <u>Errol Cocks</u> , Allyson Thomson, Stian Thoresen
4.30–5.00 pm		Dimensions of group home culture as predictors of quality of life outcomes <u>Lincoln Humphreys</u> , Christine Bigby, Teresa Iacono, Emma Bould
5.00–5.30 pm		Lessons from the past for the future – a young man’s journey from restriction to participation <u>Charley Hodgson</u>
5.30 pm	DAY ONE CLOSE	
5.30–7.30 pm	WELCOME RECEPTION	Mezzanine Level

PROGRAM

DAY TWO Thursday 9 November 2017			
8.00 am	REGISTRATION		Mezzanine Level
9.00–10.30 am	PLENARY Chair: Darryleen Wiggins		Grand Ballroom 2 & 3
9.00–9.05 am	Welcome <i>Darryleen Wiggins</i>		
9.05–9.55 am	The NDIS Independent Advisory Council and the IDRG <i>Judy Huett</i>		
9.55–10.30 am	ASID Awards		
10.30–11.00 am	MORNING REFRESHMENTS		Mezzanine Level
11.00 am –12.30 pm	CONCURRENT SESSION 4		
	GRAND BALLROOM 1 Chair: Allyson Thomson	GRAND BALLROOM 2 Chair: Ben Crothers	HARBOUR VIEW ROOM 1
	4.1 Plain English Keynotes	4.2 Rights – Supported Decision-Making	4.3 Workshop: Ethics – Ageing
11.00–11.30 am	11.00–11.45 am Individualised funding/ personalisation in England: What worked, what didn't, and why <i>Rob Greig</i>	Supporting self-determination of adults with intellectual disability – the family perspective <i>Bernadette Curryer</i> , Roger J Stancliffe, Angela Dew, Michele Wiese	Exploring ethical issues in Ageing: an Australasia perspective <i>Angela Dew, Laura Hogan, Sharon Brandford</i> , Bernadette Curryer, Emma Doukakis, Michele Wiese, Stuart Wark
11.30 am –12.00 pm	11.45 am–12.30 pm Living with intellectual disability in the twenty-first century <i>Jennifer Clegg</i>	The process of supported decision making: Learning from the experiences of people with intellectual disabilities and their supporters in Canada <i>Michelle Browning</i> , Christine Bigby, Jacinta Douglas	
12.00–12.30 pm		Lived experience of supported decision-making for socially isolated young people with cognitive disability- using existing research to inform a participatory study. <i>Danielle Notara</i>	
12.30–1.30 pm	LUNCH & POSTERS		Mezzanine Level
12.45–1.30 pm	ASID AGM		Disability, end of life and bereavement; national community of practice <i>Anna Holliday</i>



11.00 am–12.30 pm	HARBOUR VIEW ROOM 2 Chair: David Treanor		CHANCELLOR ROOM 6 Chair: Richard O'Loughlin
	4.4 Services and Policy		4.5 Employment
11.00–11.30 am	Risk-Need- (Un)responsivity: Addressing the changing needs of New Zealand Care Managers <u>Adrian Higgins</u>		Meaningful employment for adults with Intellectual Disability and High Support Needs through Small Business Enterprises (SBEs) <u>Errol Cocks</u> , Allyson Thomson, Stan Thoresen
11.30 am–12.00 pm	Working relationships between people with intellectual disability and support workers: What role does policy play? <u>Sally Robinson</u> , Karen Fisher, Anne Graham, Kelley Johnson, Ed Hall, Sandra Gendera, Kate Neale		Disability Employment – The Client Consultant Intersection. A systems analysis of the factors that lead to successful employment outcomes <u>Peter Smith</u>
12.00–12.30 pm	Tracing Policy Reform for Inclusive School Education of Students with Intellectual Disability – A Grey Literature Review <u>Teresa Iacono</u>		Social enterprise – innovative approaches to promoting the labour market participation of people with disability <u>Peter Smith</u> , Keith McVilly
12.30–1.30 pm	LUNCH & POSTERS		Mezzanine Level
12.45–1.30 pm	ASID AGM		Disability, end of life and bereavement; national community of practice <u>Anna Holliday</u>
1.30–2.20 pm	PLENARY Chair: Laura Hogan Pathways to self-determination for individuals with intellectual disability <u>Monica Cuskelly</u>		Grand Ballroom 2 & 3
2.30–3.30 pm	CONCURRENT SESSION 5		
	GRAND BALLROOM 1 Chair: Hilary Johnson	GRAND BALLROOM 2	HARBOUR VIEW ROOM 1 Chair: Sharon Brandford
	5.1 Rights – Safety	5.2 ASID Board	5.3 Ageing – Death & Dying
2.30–3.00 pm	Which trumps - the right to freedom or the right to well-being? The challenge of balancing support for people with intellectual disability, despite UNCPD <u>Fiona Redgrove</u>	The work of the ASID Board: have your say! <u>Deborah Espiner, Maurice O'Connor, Angus Buchanan, Ben Crothers, Sharon Brandford, Laura Hogan</u>	Death and disability - Lets have the conversation <u>Anna Holliday, Li-ve Tasmania together with Focus Group Participants</u>
3.00–3.30 pm	Supporting people with intellectual disability to report violence; building bridges across sectors <u>Ellen Fraser-Barbour</u>		Disability, death, end of life care and bereavement; perspectives, insights and experiences of Tasmanians <u>Anna Holliday</u>

PROGRAM

2.30–3.30pm	HARBOUR VIEW ROOM 2 Chair: Deborah Espiner		
	5.4 Round Table: Services		
2.30–3.30 pm	Maintaining Professionalism in the NDIS environment <u>David Treanor</u> , Keith McVilly		
3.30–4.00 pm	AFTERNOON REFRESHMENTS		Mezzanine Level
4.00–5.30pm	CONCURRENT SESSION 6		
	GRAND BALLROOM 1	GRAND BALLROOM 2 Chair: Ian Pearce	HARBOUR VIEW ROOM 1 Chair: Denise Whardall
	6.1 Workshop: End-of-life	6.2 Health	6.3 Health – Mental Health
4.00–4.30 pm	Supporting clients of disability services at end-of-life: A disability service model for implementation <u>Andrea Grindrod, Anna Holliday</u>	"Our agenda is not the same as the patient's": Emergency doctor and nurse accounts of treating people with cognitive disabilities <u>Christine Bigby</u> , Ruth Quibell, Jacinta Douglas, Teresa Iacono	Social worker's attributions towards individuals with dual diagnosis of intellectual disability and mental illness <u>Tal Araten- Bergman</u> , Shirli Werner
4.30–5.00 pm		What factors affect the perceived health of adults with intellectual disability? <u>Allyson Thomson</u> , Errol Cocks, Stian Thoresen	Mental health and school experiences of individuals with high functioning autism spectrum disorder: Preliminary findings <u>Nadia Ollington, Belinda Jarman</u> , Christopher Rayner, Kim Beswick
5.00–5.30 pm		Building capability in NSW Health Services for People with intellectual disability – The essentials <u>Tracey Szanto</u>	Knowing, being or doing? A comparative study on human service professionals' perceptions of quality in day-to-day encounters with clients and students with intellectual disabilities <u>Jens Ineland</u>
4.00–5.30pm	HARBOUR VIEW ROOM 2 Chair: Deborah Espiner		CHANCELLOR ROOM 6
	6.4 Round Table: Services – Behaviour Support	6.5 Workshop: Employment	
4.00–5.30 pm	Responding to behaviour support needs in a Disability Services Future <u>Leanne Dowse, Laura Hogan, Angela Dew</u> , Peter Conway, Shoshana Dreyfus		Building the business and economic case for supporting people into paid work <u>Rob Greig</u>
5.30 pm	DAY TWO CLOSE		
7.00 pm	CONFERENCE DINNERS		



DAY THREE Friday 10 November 2017		
8.00 am	REGISTRATION	Mezzanine Level
9.00–10.05 am	PLENARY Chair: Sharon Brandford	Grand Ballroom 2 & 3
9.00–9.05 am	Welcome <u>Sharon Brandford</u>	
9.05–9.55 am	Out of the 'Too Hard Basket': Tackling the critical issues for people with cognitive disability who have complex support needs <u>Leanne Dowse</u>	
9.55–10.05 am	ASID 2018 Queensland promotion	
10.05–10.30 am	MORNING REFRESHMENTS	Mezzanine Level
10.30 am–12.00 pm	CONCURRENT SESSION 7	
	GRAND BALLROOM 1 Chair: Allyson Thomson	GRAND BALLROOM 2 HARBOUR VIEW ROOM 1 Chair: Emma Bould
	7.1 Participation – Communication and Relationships	7.2 Symposium: Services – Complex Support Needs Exploring complex support needs for people with intellectual disability and their families across the life course
10.30–11.00 am	Communicating beyond the boundaries- A case study in Communication Potential <u>Amy Callaghan</u>	7.3 Health – Mental Health Barriers and enablers to Accessing Mental Health Services for People with an Intellectual Disability <u>Erin Whittle</u> , Karen Fisher, Simone Reppermund, Julian Trollor
11.00–11.30 am	Pushing boundaries through story telling <u>Deborah Espiner, Frances Hartnett</u>	10.30–10.50 am Young people with cognitive disability and complex support needs: Service provider views on supporting transitions <u>Louisa Smith</u> , Leanne Dowse, Kathy Ellem, Philip Mendes, Pam Snow, Susan Baidawi, Nirosha Boaden 10.50–11.10 am Adults with cognitive disability and complex support needs: Using body mapping to explore the planning experience <u>Isabella Dillon Savage</u> , Angela Dew, Susan Collings, Emma Gentle, Leanne Dowse 11.10–11.30 am Families with complex support needs: parents' actions in supporting their family member with challenging behaviour <u>Leanne Dowse</u> , Shoshana Dreyfus, Peter Conway, Laura Hogan



PROGRAM

11.30 am–12.00 pm	Do as I say (not as I do): The UNCPRD and dilemmas for those supporting people with intellectual disability to enjoy their sexuality <u>Judith Darragh, Fiona Redgrove</u>	11.30–11.50 am Parents with intellectual disability: addressing complex support needs in the child protection system <u>Angela Dew, Julia Wren</u> , Susan Collings, Margaret Spencer, Erin Cooney, Leanne Dowse	Do thoughts predict symptoms of anxiety and depression amongst adults with low ability? <u>Steve Edwards</u> , Henry J. Jackson
10.30 am–12.00 pm	HARBOUR VIEW ROOM 2 Chair: Ben Crothers		CHANCELLOR ROOM 6
	7.4 Families	7.5 Publishing Research	
10.30–11.00 am	Multidisciplinary pilot service for children with intellectual disabilities: Further evaluation survey of parents and carers <u>Denise Campbell</u> , Katrina Zaballa, Jacqueline Milne, Julie Johnson, Laurel Mimmo, Gail Tomsic, Natalie Ong, Natalie Silove	JIDD <u>Jennifer Clegg</u>	
11.00–11.30 am	Among the outliers: A socio-legal perspective on the transition to adulthood for people with disability <u>Michelle King</u>	RAPPID <u>Christine Bigby</u>	
11.30 am–12.00 pm	Innovation in Dual Disability Residential Services – increasing participant's choice and control over their community and home life <u>Leonie Davey, Davo Mann, Kelly McLachlan, Carolyn Connelly</u>	Taylor & Francis <u>Natalie Davall</u>	
12.00–1.00 pm	LUNCH & POSTERS	APS AGM	Mezzanine Level
1.00–2.30 pm	CONCURRENT SESSION 8		
	GRAND BALLROOM 1 Chair: Morrie O'Connor	GRAND BALLROOM 2 Chair: Darryleen Wiggins	HARBOUR VIEW ROOM 1
	8.1 Plain English Keynotes	8.2 Services – NDIS	8.3 Service – Behaviour Support and Education
1.00–1.30 pm	1.00–1.45 pm Pathways to self-determination for individuals with intellectual disability <u>Monica Cuskelly</u>	Outsider's perspective on NDIS—An observation from China <u>Jing Li</u> , Patricia O'Brian, Trevor Parmenter, Marie Knox	Preliminary findings of an investigation of policy for positive behaviour support <u>Brent Hayward</u>
1.30–2.00 pm	1.45–2.30 pm Out of the 'Too Hard Basket': Tackling the critical issues for people with cognitive disability who have complex support needs <u>Leanne Dowse</u>	Four years of NDIS: The experiences of two families <u>Nadia Ollington, Lisa Risby, Isabel Duharte, James Minchin</u>	Visual Cognitive Behavioural Intervention: An adaptation of Cognitive Behaviour Therapy for people with intellectual disability and mental health difficulties <u>Michelle Carney, Carol Le Lant</u>
2.00–2.30 pm			It's not all child's play – virtual reality as learning and training <u>Stewart Koplick, Chris Beaumont</u>



1.00–2.30 pm	HARBOUR VIEW ROOM 2 HARBOUR VIEW ROOM 2 Chair: Angus Buchanan	
	8.4 Workshop: Rights – Supported Decision- Making	8.5 Participation – Civic and Political
1.00–1.30 pm	Pushing the boundaries of supported decision making: An interactive session exploring dilemmas of practice <u>Michelle Browning</u>	Impact on identity and every-day life – people with intellectual disability and self-advocacy in Sweden <u>Magnus Tideman</u>
1.30–2.00 pm		Dear Community, are you ready? <u>Carolyn Stobbs</u>
2.00–2.30 pm		Strategies to support people with intellectual disability to participate in voting: Results of a survey <u>Sophia Tipping.</u> Christine Bigby, Emma Bould
2.30–3.00 pm	AFTERNOON REFRESHMENTS	Mezzanine Level
3.00–3.15 pm	CLOSING PLENARY	Grand Ballroom 2 & 3
	Performance by BrightStars	
	Acknowledgements	
	Performance by BrightStars	
3.15 pm	CONFERENCE CLOSE	



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Service providers can use our platform to promote their products and services. We help you identify and reach your target groups easily and quickly, saving you time and money.

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WEDNESDAY 8 NOVEMBER 2017 PLENARY SESSION

9.25–10.15 AM

Individualised funding/personalisation in England: What worked, what didn't, and why

Rob Greig¹

¹National Development Team for Inclusion

BIOGRAPHY

Rob has been Chief Executive of the NDTi since May 2008. Before that he spent six and a half years as the UK Government's National Director for Learning Disabilities, providing national leadership on the delivery of the cross-Government Valuing People Now policy.

He was the creator and original manager of the Valuing People Support Team and the prime author of Valuing People. Whilst working for Government, Rob was also involved in the work of the Office of Disability Issues, including as Vice-Chair of the Expert Panel that oversaw the development of the Independent Living Strategy. He also was a contributor to many other elements of health and social care policy – seeking to promote their relevance to people with disabilities and others who are marginalised in society.

Prior to this, Rob worked in a variety of roles, including managing and planning both mental health and learning disability services in both local government and the NHS and managing a voluntary sector development programme. In 1995 he established the Community Care Development Centre at King's College and prior to that worked as a consultant with various organisations – including the NDT in the early 1990's.

Rob's great concerns have always been in how to effect change in public services and society to benefit people and groups who are marginalised and excluded. This has resulted in a range of interests over his life and career, including action around employment, housing, racism and the health service.

He is a member of the Equality and Human Rights Commission Committee.

Rob was awarded a CBE in the 2010 New Year Honours List for his work described above.

ABSTRACT

Individualised funding (under the overall heading of personalisation) has been at the core of policy for people with intellectual disabilities in England for over 10 years. There have been some notable successes for individuals, but the aspiration that this would change services and lives for all people has not been realised.

Looking at the history of how policy was developed and implemented, and the evidence on progress (or lack of it), this presentation will seek to understand what can be learnt from this experience in England and thus translated into similar approaches in Australia.

In particular, the extent to which Government actions did or did not support changes to service culture and practice, the impact of 'austerity' and the extent to which service systems really bought into a shift in power to the person and their family, will be addressed.

CONCURRENT SESSION 1

11.00 AM–12.30 PM

SESSION 1.1 Symposium: Participation – Community

Exploring community participation programs

Introduction: This symposium brings together three papers from an ongoing program of research at La Trobe University about community participation for adults with intellectual disability. [three separate abstracts for papers to be included in this symposium have been uploaded as the instructions were far from clear] The papers are 1. Bigby et al., Identifying conceptualisations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability. A scoping review. 2. Anderson et al., A Case study of an Effective Community Participation Program, and 3. Bould et al., Dogs as catalysts for community participation of people with intellectual disability.

Contributions to the symposium: The first paper provides a conceptual overview of community participation and the different ways it is framed by programs designed to facilitate participation.

The second paper is a case study of Arts Access a program designed to support community participation as Belonging and Identify.

The third paper reports a pilot study of an innovative intervention using dog walking in a person's local area as a catalyst for supporting convivial encounters between people with intellectual disability and community members.



ABSTRACTS

Implications: This work adds to the body of knowledge about supporting community participation and can be used by disability support organisations to design individualised and/or group based programs to support community participation.

Identifying conceptualisations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability. A scoping review.

Professor Christine Bigby¹, Dr Sian Anderson¹,
Dr Nadine Camerson¹

¹Latrobe University, Living With Disability Research Centre

BIOGRAPHY

Professor Christine Bigby is the Director of the Living with Disability Research Centre at La Trobe University. She has a strong track record of competitive research grants and publications around issues of programs and practices that support the social inclusion and quality of life of adults with intellectual disability. She is the founding editor of Research and Practice in Intellectual and Developmental Disabilities (RAPIDD) and a Fellow of the International Association for the Scientific Study of Intellectual and Developmental Disabilities.

ABSTRACT

Background. Supporting community participation of people with intellectual disability has been a policy aim since the 1980s. This is a slippery ambiguous concept and the absence from empirical research of consistent conceptual frameworks combined with interchangeability of terms means there is often little clarity about intended purpose or outcomes of programs that aim to support community participation.

Method. We aimed to identify the features of programs designed to support community participation. A scoping review was conducted of peer reviewed literature, published between 2000-2015, about interventions to support community participation for adults with intellectual disability.

Results. The seventeen studies identified represented three different ways of conceptualising participation – as social relationships, as convivial encounters, or as belonging and identity based on shared talents or interests. No matter how conceptualised programs all included three core components, (place, social interactions and activities) but the nature and emphasis of these depended on the way participation was conceptualised. There is only a small body of evidence about program design and effectiveness and little very about costs.

Most evidence relates to programs to support various kinds of convivial encounter including use of active mentoring or active participation in community groups, and facilitative support worker micro skills and practices.

Implications. The literature shows the diverse and person centred nature of community participation, and demonstrates the need for larger scale studies of promising interventions that include details of costs, and outcomes to guide implementation of policies to support community participation.

A Case Study of an Effective Community Participation Program

Professor Christine Bigby¹, Dr Sian Anderson¹,
Dr Nadine Cameron¹

¹La Trobe University, Living With Disability Research Centre

BIOGRAPHY

Professor Christine Bigby is the Director of the Living with Disability Research Centre at La Trobe University. She has a strong track record of competitive research grants and publications around issues of programs and practices that support the social inclusion and quality of life of adults with intellectual disability. She is the founding editor of Research and Practice in Intellectual and Developmental Disabilities (RAPIDD) and a Fellow of the International Association for the Scientific Study of Intellectual and Developmental Disabilities.

ABSTRACT

Background. There is relatively little evidence about the design and effectiveness of programs to support community participation of adults with intellectual disability. A scoping review found programs conceptualised participation in one of three ways – as social relationships, as convivial encounters, or as belonging and identity. We report on a case study of the third type of program, Arts Access

Method. We interviewed 6 staff at various levels, 5 participants, and their family members about their program experiences, undertook participant observation and reviewed documents. Data were analysed to develop a program logic model, and identify outcomes.

Findings. The program has a clear theory of change, 'If we create a space in which individuals with intellectual disability are supported to produce art, then they will develop a sense of belonging to the arts community, and an identity as a working artist'. The day to day operations coherently reflected this, through for example, framing all participants as artists, employment practices that requiring fine arts qualifications, hand in glove support model, gallery visits, collaboration with external artists, exhibiting and selling art works.



Participants developed a sense of identity of belonging to an art community and had regular interactions with the staff and volunteers at Arts Project and external artists. They also had a sense of belonging to the local community where the program was situated.

Conclusions. Though the program could be characterised as segregated and centre based it's clear sense of purpose and careful design successfully created one type of community participation for its participants.

Dogs as catalysts for community participation of people with intellectual disability

Dr Emma Bould¹, Professor Christine Bigby¹, Associate Professor Pauleen Bennett², Dr Tiffani Howell²

¹La Trobe University, Living with Disability Research Centre, School of Allied Health, ²La Trobe University, School of Psychology and Public Health, Science, Health and Engineering

BIOGRAPHY

Emma has a diverse background of research experience which is underpinned by quantitative methodologies and analysis. Since August 2011 Emma has been working as a Research Fellow in the Living with Disability Research Centre at La Trobe University.

The focus of her work is on front line practice that supports quality of life outcomes and enables community participation for people with intellectual disability. Her current research projects are examining the effectiveness of supported accommodation services, and the nature and meaning of social inclusion for people with intellectual disability.

ABSTRACT

Background. This study pilots a program to provide individual support to adults with intellectual disability to regularly walk a dog in their local area in order to facilitate convivial encounters with other community members.

Method. Participants were allocated to one of two groups; Participants in Group 1 had 14 weekly outing with a handler and a dog, whilst Group 2 went out for 14 weeks with the handler alone, followed by 5 additional outings with the same handler and a dog. Validated measures were used to evaluate the impact of the program on their social connections, quality of life and emotional wellbeing.

Results. Dogs can be catalysts for fleeting convivial encounters with community members for individuals with intellectual disability. The impact of the program on participants' quality of life and emotional wellbeing are also discussed.

Implications: The program addresses the urgent need in Australia to trial person-centred approaches of supporting people with intellectual disabilities to be more socially included, and to develop and maintain social relationships.

SESSION 1.2 **Symposium:** **Rights – Safety**

Freedom from exploitation, violence and abuse: improving policy and practice by using research to sharpen our focus

Background: Freedom from exploitation, violence and abuse has been a goal of disability legislation and policy for over two decades. Yet the lived experience of people with intellectual disability is too often far from safe and free from harm. People with intellectual disability experience abuse and neglect at rates significantly higher than their peers.

As the National Disability Insurance Scheme rolls out, focus has turned to safeguarding and quality systems. However, attention solely to the NDIS may fail to fully consider the ways in which many people with intellectual disability live their lives, and leave the safety of the bulk of people with intellectual disability ill-considered.

Introduction: In this symposium, three papers will be offered by presenters working with people with intellectual disability on issues of exploitation, violence and abuse in three different contexts, demonstrating the diverse and multiple nature of harms and consequent responses needed in order to adequately address exploitation, violence and abuse across the diversity of people with intellectual disability. The symposium chair will provide a brief overarching introduction which sets the context.

Contributions to the symposium: Papers will highlight research focused on three discrete groups of people with intellectual disability (children and young people; people using disability support services; women experiencing domestic violence).

Implications: Following each paper, and at the conclusion of the presentations, interactive audience discussion will focus on the implications of the research with each group for better understanding safety and harm; improving prevention and response; and developing effective policy and practice in the light of current and future reforms.

ABSTRACTS

What is important to children and young people with intellectual disability about safety in institutional settings?

Dr Sally Robinson¹

¹*Centre For Children & Young People, Southern Cross University*

BIOGRAPHY

Sally Robinson researches with children, young people and adults with intellectual disability about safety and abuse prevention.

ABSTRACT

This study explored what helps children and young people with intellectual disability and higher support needs to feel and be safe in institutional settings. Twenty-two children and young people with intellectual disability contributed to a participatory study conducted for the Royal Commission into Institutional Responses to Child Sexual Abuse, alongside family members and service providers. This paper reports on methods and findings of priority to children and young people.

A number of key issues important to children and young people, policy and practice can be drawn from the study findings. These include identified need for: understanding of the impact of systemic limitations and failures, segregation, lack of choice and discrimination on children and young people's lives; work to assist children and young people and their supporters to recognise and assess the relative risk of harm; concerted monitoring of the nature and quality of support relationships; and support of active participation of children and young people with intellectual disability so they are better involved in decisions across in a number of domains, including their education, health and disability support services.

Applying lived experience to service landscapes: how can we bring perspectives of people with intellectual disability into policy and practice?

James Bannister¹

¹*National Disability Services*

BIOGRAPHY

James Bannister leads sector development in abuse prevention and supports training for workers and people with disability.

ABSTRACT

National Disability Services (NDS) is the Australian peak body for non-government disability service providers, with more than 1100 members nationwide. NDS is leading the Zero Tolerance initiative, to build the capacity of disability service providers to recognise, prevent and respond to abuse, neglect, violence and exploitation of people with disability. This paper discusses the process and outcomes of building consultation with people with intellectual and other disabilities into the early stages of this service development initiative.

In developing Zero Tolerance, NDS recognised that people with disability needed to have a central role in shaping the initiative. We partnered with disability advocacy groups and specialist organisations to run focus groups in all states and territories to explore the views of people with disability on personal safety. Additional groups were organised for women with disability, people with complex communication support needs and remote indigenous communities. In total 58 people shared their experiences of safety at home, in the community and when using disability services.

The resultant report, *Speaking up about Safety*, highlights actions for disability service providers to improve approaches to safety of the people they support. The report also repositions the national conversation about abuse, neglect and violence to include the broader denial of basic human rights which risk becoming normalised for people with disability.

Speaking up about Safety was a critical building block of the Zero Tolerance Framework. It also informed the Zero Tolerance Empowerment Circle model which underpins the training and education models now used to influence frontline practice.



Applying lived experience to new contexts: informing responses for women with disabilities in domestic violence services

Dr Patsie Frawley¹

¹*Deakin University*

BIOGRAPHY

Patsie Frawley researches with women with intellectual disability about violence and respectful relationships.

ABSTRACT

Women with disabilities experience all forms of violence and abuse at higher rates than non-disabled women, however their voices are rarely heard in research that informs practice. In this study of how domestic violence services responded to women with disabilities we sought insights from three cohorts of women with disabilities as part of a larger mixed methods study; 1. Women with disabilities who had used domestic violence services 2. Those who had used other support services 3. Women who represented 'harder to reach' women with disabilities. Their experiences and insights informed both the research approach and the research findings.

The first and second cohort were involved in focus groups and the third cohort formed a consultative research group that met throughout the life of the study informing research approaches, considering emerging data and guiding dissemination. All data was analysed thematically.

Domestic violence services use a 'whatever it takes' approach with women with disabilities. Engaging with women with disabilities as research participants, advisors and collaborative research partners enabled these services to have a more prolonged engagement with this 'harder to reach' and 'harder to respond to' group, gaining important insights that informed improved practice approaches.

Barriers to inclusion of women with disabilities in research about responses to violence and abuse were significant. This study indicates the importance of their insights to inform research approaches findings.

SESSION 1.3 Symposium: Research – Inclusion

Centre for Disability Studies Inclusive Research Network

BIOGRAPHY

The Centre for Disability Studies Inclusive Research Network began meeting monthly in 2010. It has conducted a wide range of research projects on topics including the National Disability Insurance Scheme, and the United Nations Convention on the Rights of Persons with Disabilities. We have presented our research findings at conferences in Australia and overseas. Within the Inclusive Research Network university scholars, support workers and people with intellectual disabilities work as co-researchers together. Thus, people with intellectual disabilities are able to contribute to the research, rather than have research done on them. Our motto is "Nothing about us without us."

Pushing the Boundaries of Publication in Inclusive Research

Elizabeth Young, Mark Walters, Tanya Riches, Patricia O'Brien, Bruce O'Brien, Megan Noyeaux, Lesley Lewis, Marie Knox, Jack Kelly, Suzy Jessep, Robert Griffiths, Alex Butters, Sarah Butler, Susan Adrian

Background and Aim: One of the greatest challenges for inclusive groups that encourage the voice, choice and control of people with intellectual disability is pushing the boundaries in the dissemination of research findings. In particular, there are various barriers for inclusive research groups seeking to publish of their findings in reputable peer-reviewed journals.

Introduction: After seven years working as researchers, the Centre for Disability Studies' Inclusive Research Network identified peer-reviewed scholarly publishing as its greatest challenge, and initiated a review of other inclusive research groups, interviewing key researchers involved in inclusive research in order to identify how university staff and co-researchers navigate the tensions involved in this process.

Contributions to the Symposium: This presentation draws upon the findings of the group in relation to the perceptions on the relationship between participation in the research, authorship and ownership of the research between university researchers and co-researchers with and without intellectual disability.

ABSTRACTS

Implications: The research found a wide range of approaches under the banner “inclusive research.” We will explore these in relation to the practices of the CDS Inclusive Research Network, and suggest wider implications for inclusive research.

The Two of Us: An Exploration of the Relationships of People with Intellectual Disability in Different Social Contexts

Jack Kelly, Emma Doukakis, Sarah Wagstaff

Background: There has been a significant body of research done on the subject of people with intellectual disability and social isolation, however people with intellectual disability have a range of different relationships that are important to them.

Introduction: This presentation focuses on a piece narrative research aimed at characterising relationships that are important to people with disability. Participants identified a person with whom they had a significant relationship, and invited this person to join them in sharing the story of their relationship.

Contributions to the Symposium: Themes explored included the formation of the relationship, its significance to each person, and factors that contributed to an ongoing and sustainable relationship. This research was conducted by a team including a member of the Inclusive Research Network as a paid research assistant. This is testimony to the role that inclusive research can play in career development for young researchers with disability.

Implications: This presentation will reflect upon the importance and diversity of relationships identified by people with intellectual disability, and the significance of relationships for their lives.

It Was A Very Proud Moment For Me: The experiences of researchers with intellectual disability reporting their research findings to their support organisations

Suzy Jessep, Sarah Butler, Jack Kelly, Marie Knox

Background: We are members of The Centre for Disability Studies Inclusive Research Network. We recently developed a set of person-centredness indicators based on research interviews with people with intellectual disability using 3 disability services. We used these indicators to check if they were consistent with the organisations’ person-centredness policies. We then formally presented our results to organisational senior personnel. This presentation explores our experiences of as network members with intellectual disability in undertaking this formal reporting process.

Introduction: A university co-researcher conducted 3 focus groups each with 3-5 network co-researchers with intellectual disability to explore our experiences in undertaking the formal organisational presentations. Issues explored included, experiences of making the presentation to the senior personnel, reporting on the positive and the negative findings, answering audience questions, what helped to make the presentation work, what were some of the difficulties experienced. We then analysed the data from the transcripts of the focus group proceedings to discover the important themes.

Contributions to the Symposium: The themes we identified included, amongst others, pride tinged with nervousness about presenting to the senior personnel, being listened to respectfully, the importance of good preparation and needing to think on your feet.

Implications: We clearly demonstrated the importance of valuing the knowledge and experiences of researchers with intellectual disability in inclusive research studies. In this presentation we will explore the implications for people with intellectual disability in reporting back to services who they rely on for support. We will also discuss the opportunity for voice in the service and the changing relationship between service user and provider promoted under the NIDS .

SESSION 1.4

Symposium: Education

Knowing myself in the world through Moving and Sensing – new perspectives on the sensory motor experiences of autism

Background: The role of the movement system and the eighth sensory system known as interoception are integral to our ability to self-regulate and maintain wellbeing.

Introduction: This session explores how these two systems can impact on the experiences of autism and highlights the important factors that can either facilitate or hinder positive wellbeing outcomes for people on the autism spectrum.

Contributions: This starts with a presentation of a detailed case study of a female with autism and intellectual disability who developed the often under-recognised movement disorder known as catatonia. A chronological presentation of clinical features in the context of progressive sensory motor difficulties, eventual diagnosis and ongoing management will be detailed.



The second presentation explores the current research on the many unusual movement behaviours known as motor dysregulation and their comorbidity in autism. This includes the clinical implications of several case studies for considering the context of 'behaviour' in autism and understanding when 'behaviour' is motor dysregulation and requires a medical approach.

The third and final presentation describes interoception and how the interoceptive system can be developed in children and young people with autism. Details of the interoception program will be explored and how it has been applied in a novel approach to help students utilise their interoceptive system to self-regulate in the classroom.

Implications: The movement system and interoception are both important aspects to be considered in working with people with autism who exhibit motor or behavioural difficulties.

Clinical history and management of catatonia diagnosed in a 43 year old female with autism

Dr Margaret Kyrkou¹, Dr Jenny Curran¹, Nicole Kyrkou², Kerry Rye¹, Dr Jane Nugent³

¹Centre for Disability Health (DCSI), ²Department for Education & Child Development, ³Healthy possibility Pty Ltd

BIOGRAPHY

Margaret is a medical practitioner, as well as the mother of an adult daughter with significant disability. She has been working in the disability field for over 30 years, relating to parents and staff of children and young people with disability in clinics and educational settings. She also works at My Therapy House, and is a lecturer in Disability Studies at Flinders University, South Australia. She has given numerous national & international presentations and lectures, trained carers in Australia and Malaysia, and has had journal articles published. She was recently awarded a PhD for her thesis on females with disability, and was recognised nationally with an Order of Australia Medal for services to children with disability. Background: Clinicians tend to relate catatonia to people with a major psychiatric disorder, they are not aware it can also occur in people with autism who do not have a major psychiatric condition and with a very different clinical presentation that is often considered as just behaviour.

ABSTRACT

Contribution: The case study will detail the clinical presentation with the timeline of features presented, as they unfolded in the consulting room. It will also follow progress post diagnosis with detail about treatment options and outcomes.

Implications: This presentation highlights to clinicians the impact of catatonia on people with autism and the importance of early diagnosis and management.

An overview of motor dysregulation and autism and the implications for self-regulation

Dr Jenny Curran¹, Kerry Rye¹, Dr Margaret Kyrkou¹, Nicole Kyrkou², Christel Burton³, Dr Jane Nugent⁴

¹Centre for Disability Health (DCSI), ²Department for Education & Child Development, ³Women's and Children's Health Network, ⁴Healthy possibility Pty Ltd

BIOGRAPHY

Dr Jenny Curran is a Senior Psychiatrist at the Centre for Disability Health in South Australia. She has extensive clinical experience working in developmental psychiatry working with both adults and children with intellectual disability and autism.

Kerry Rye is a Registered Nurse with a graduate diploma in mental health nursing; currently working for DCSI at the Centre for Disability Health in the role of a Nurse Consultant. The focus of her work is in the area of child and adolescent dual disability emotional and physical wellbeing and health.

She has been working as a nurse in the area of intellectual disability health since 2001 and is currently transitioning to multidisciplinary work with SA Health in promotion of emotional wellness for students in South Australian schools.

ABSTRACT

Background: A wide range of unusual motor (movement) behaviours have been noted in people on the autism spectrum, but the relevance to everyday parenting, school and service responses is extremely limited within current research.

Contribution: This presentation with case studies will enable the audience to become familiar with movement disorders including catatonia, and will also explore the possible ways such movement patterns can be confused with 'behaviours'. Alternative strategies for management will be discussed. These case studies highlight an alternate framework to consider 'behaviours' and the possibility of a differential diagnosis of motor dysregulation.

Implications: This has relevance for anyone relating to people with autism, as motor dysregulation has long term impact on quality of life when under-recognised and left untreated.

ABSTRACTS

Development of interoception in children and young people with autism within an educational context.

Background: The ability to self-regulate in the classroom and be a successful learner can seem like an impossibility for many students with autism. Underpinning these important abilities are the essential and often overlooked skills of interoception.

Contribution: A novel approach has been trialled in South Australia to support students to develop their interoception skills as a precursor to self-regulation and becoming successful learners at school. This approach utilises an interoception program that has been successfully used 1:1, in small group sessions, classrooms and as a whole school approach to improve student outcomes. Incidentally it has also proven successful in supporting other students struggling to stay regulated and on task in class.

Implications: This work will be of interest to anyone relating to people with autism and seeking new ways to understand and interpret behaviour. Interoception skills create a new lens with which to view the behavioural support needs of people with autism or others who struggle with self-regulation.

Development of interoception in children and young people with autism within an educational context

Dr Jenny Curran¹, Dr Margaret Kyrkou¹, Kerry Rye¹, Nicole Kyrkou², Emma Goodall³, Dr Jane Nugent⁴

¹Centre for Disability Health (DCSI), ²Department for Education & Child Development, ³Women's and Children's Health Network, ⁴Healthy possibility pty ltd

BIOGRAPHY

Nicole Kyrkou is a Developmental Educator, a multi-disciplinary disability specialist with an interest in the interface between disability, health and behaviour. Her current role in Department for Education and Child Development as the Program Manager Complex Needs and Mental Health has been focused on how we can better understand and respond to the complex and challenging needs of students with disability within education.

ABSTRACT

Background: The ability to self-regulate in the classroom and be a successful learner can seem like an impossibility for many students with autism. Underpinning these important abilities are the essential and often overlooked skills of interoception.

Contribution: A novel approach has been trialled in South Australia to support students to develop their interoception skills as a precursor to self-regulation and becoming successful learners at school. This approach utilises an interoception program that has been successfully used 1:1, in small group sessions, classrooms and as a whole school approach to improve student outcomes. Incidentally it has also proven successful in supporting other students struggling to stay regulated and on task in class.

Implications: This work will be of interest to anyone relating to people with autism and seeking new ways to understand and interpret behaviour. Interoception skills create a new lens with which to view the behavioural support needs of people with autism or others who struggle with self-regulation.

SESSION 1.5 Services – Behaviour Support

Quality control for positive behaviour support in disability services

Brent Hayward¹

¹Melbourne Graduate School Of Education, University Of Melbourne

BIOGRAPHY

Brent is a registered nurse and credentialed mental health nurse. He has wide experience in disability services in direct support, clinical services, policy and legislation. He is currently the coordinator for school-wide positive behaviour support in the Victorian Department of Education and Training. Brent is also completing his PhD in the Graduate School of Education at the University of Melbourne where he is investigating the necessary systems-level infrastructure for the implementation of PBS in Victorian disability services.

ABSTRACT

Background: Positive behaviour support (PBS) is now synonymous with the provision of contemporary disability services. Its application is supported by empirical research, an established values base, definition, and processes. While many disability services proclaim to be using PBS, closer examination reveals that they are not. Disability services, people with disabilities, and stakeholders may benefit from criteria which indicates the presence of PBS in practice.

Method: Through triangulating data sources (federal and state government policy, disability service provider policies, and published literature) a set of quality indicators for PBS in Australian disability services was devised.



Results: The indicators identify characteristics of policy, organisational systems, individual outcomes, and staff practices which are consistent with PBS in disability services.

Implications: The indicators establish a method of quality control for disability service providers who proclaim to be using PBS. The indicators are practical, and can be used by service providers themselves to improve policy and practice, as well as service users and their families to evaluate if PBS is evidenced in practice.

Improving behaviour support plan quality via targeted professional development

Dr Maria Vassos¹, Simon Wardale¹, Kate Burton¹, Chloe Lafon¹

¹*Endeavour Foundation*

BIOGRAPHY

Dr Maria Vassos has a professional doctorate in clinical psychology, specialising in the assessment and treatment of child behavioural problems, and adult depression, anxiety and adjustment disorders. She is also in the final stages of completing a PhD in psychology, focused on investigating the psychosocial factors related to why parents or carers seek out-of-home care for their family member with a disability.

For the last nine years, Dr Vassos has worked in various university and disability service sector positions related to disability research, undertaking projects related to evidence-based practice and clinical governance in the disability service sector, support staff well-being, and behaviour support plan development and implementation. She is currently the Senior Researcher at Endeavour Foundation in Queensland.

ABSTRACT

Background: Since 2015, the Specialist Behaviour Service within Endeavour Foundation has made a concerted effort to improve the quality of the behaviour support plans they prepare, e.g., undertaking targeted training and literature reviews to build clinician knowledge, and implementing a routine process of peer review. The aim of this study was to evaluate the quality of plans written by the Specialist Behaviour Service from May to December 2016, in relation to clinical integrity (compliance with positive behaviour support), and readability (use of plain language).

Method: Twenty seven plans were evaluated for readability using the Flesch-Kincaid Grade Level and Flesch Reading Ease scores available in Microsoft Word. Clinical integrity was evaluated using the Behaviour Intervention Plan Quality Evaluation (BPI-QEII), with the plans scored by an external consultant proficient in BPI-QEII scoring. Findings were compared to a previous evaluation conducted in 2013.

Results: Plan quality has considerably improved since the 2013 evaluation, with plans on average being rated as 'good' or 'superior' using the BPI-QEII scoring categorisation. Flesch-Kincaid and Reading Ease scores indicate variability across the four sections of the written plan, with the implementation section typically written in more complex language compared to the assessment and intervention sections.

Implications: These findings imply that behaviour support plan quality can be greatly enhanced with cost- and time-effective professional development within clinical teams implementing positive behaviour support. Authors need to be mindful of using plain language when drafting plans, as plans written in inaccessible language may not be implemented to their full extent.

Extraordinary (Positive Behaviour) Support in an Ordinary Way – Challenges in the NDIS

Anna Posselt¹, Michelle Atkinson¹

¹*My Place*

BIOGRAPHY

Anna Posselt is a Social Worker who has worked in numerous roles within the Disability Sector in WA over the past 23 years. This includes as a Support Worker, Social Worker, Local Area Coordinator, Snr Policy Officer and most recently as a Co-ordinator and Training and Development Officer with My Place.

Michelle Atkinson is a Social Trainer with more than 30 years' experience working with people with disability. For the past 13 years, Michelle has worked as a Co-ordinator and more recently as a Team Leader with My Place in the area of supporting individuals and families to be their own employers and self-direct their services.

My Place is a not for profit Disability Organisation that was developed 21 years ago. My Place works in partnership with people with disability and their allies to live in their own home and receive supports that meet their individual needs and preferences.

ABSTRACT

Background: In 2013, the Western Australian Disability Services Commission implemented the Positive Behaviour Framework across the Disability Sector. The underlying objective was to build and sustain a culture within all service provider organisations that promotes high quality services and minimises any opportunity for abuse, neglect or inappropriate practices. Provision of Positive Behaviour Support (PBS) now requires implementation by specialist providers under the NDIS.

ABSTRACTS

This paper aims to present the argument that PBS isn't "extraordinary" (i.e something to be adopted in the face of behaviours of concern) – rather it should be the foundation of any effective service design.

Method: Based on the experiences of My Place providing highly individualised, person centred support in non-segregated arrangements, the presenters will share several stories that support research literature that the introduction and implementation of PBS is not a matter of simply applying a set of techniques and/or passively accepting PBS as a theoretical framework. It requires a proactive culture of support and the ability to have a service built around an individual's unique needs and preferences. Central to this is recognising the natural authority of the individual with disability and their families.

Results: Individual outcomes for service users with an intellectual disability support the idea that when PBS is applied as a rule, rather than an exception, people's quality of life improves and behaviours of concern diminish significantly.

Implications: Integration of PBS becomes a fundamental part of service design rather than being viewed as a discrete specialist area of support subsequently creating a natural culture of positive support.

PLENARY SESSION

1.30–2.20 PM

Living with intellectual disability in the twenty-first century

Dr Jennifer Clegg¹

¹*University of Nottingham, UK, & La Trobe University, Australia*

BIOGRAPHY

Honorary Associate Professor at the University of Nottingham, Adjunct Professor at the La Trobe University, Australia. Jennifer's recent work has focused on transition from child to adult services, with particular attention to ideas that drive services and how people and systems co-operate in the delivery of services.

She is particularly interested in the influence of human interaction in the construction and delivery of services, and intellectual disability psychiatry.

ABSTRACT

Current international policy for people with intellectual disabilities originated 50 years ago. This shifted away from regarding cognitive impairments as the origin of difficulties and, instead, regarding such difficulties as socially produced and common to all people with disability. Like all policy revisions, it sought to correct the failings of its predecessor and brought many positive changes.

Specialist settings and services have been closed, and people with intellectual disability are increasingly regarded as members of the broader collective 'people with a disability'. The paper draws on a research review with Christine Bigby that examined the intended and the unintended consequences of this policy of dedifferentiation. It makes the case for renewing policy in the light of research findings concerning its impact, and of recent changes in our understanding of intellectual disability, community, and social justice. It draws on Bauman, who criticised the deification of happiness as a life goal and consumer choice as the means to attain it, advocating instead a social justice approach that avoids interest groups being pitted against one another in a battle for diminishing resources. Creating a twenty-first century vision of intellectual disability requires different stakeholders to act together in ways that allow new alternatives to emerge.

CONCURRENT SESSION 2

2.30–3.30 PM

SESSION 2.1

Participation – Community

Gig Buddies Sydney user-led advisory team

Carol Smail¹, Matthew Collins¹, Lachlan Billing², Stavros Nanos², Audrey O'Connor²

¹*ACL Disability Services*, ²*Gig Buddies Sydney*

BIOGRAPHY

Carol is the CEO of ACL Disability Services and Gig Buddies Sydney. Carol has worked in the disability sector for over 20 years and has a strong commitment to social change and individual empowerment. Carol's enthusiasm, dedication and belief in the Gig Buddies Sydney initiative has inspired a passion for the project that is shared among the wider Gig Buddies community.

Tony is funding and sponsorship coordinator for the Gig Buddies Sydney project and also provides participant support, assists with volunteer training and has contributed to the pairing of over 50 buddies since the project's inception in early 2015. As a regular live music gig attendee, Tony is passionate about tackling social isolation and providing opportunities for people with learning disability to experience live music first-hand.

Lachlan is a Gig Buddies Sydney participant with a passion for live music, musicals and comedy shows and has been paired with his volunteer Michelle for the past 18 months. Lachlan has been an active member of the user-led advisory team "Soul Fly Band" since its inception.



Stavros joined Gig Buddies Sydney as a participant in 2016 and is a founding member of the Soul Fly Band user-led advisory team. Stavros was paired with his volunteer Jess after realizing their mutual enthusiasm for heavy metal music while attending a Gig Buddies social event, and have been to many metal gigs together since.

Audrey is one of the first participants to sign up to Gig Buddies and has been paired with her buddy Marissa since late 2015. Audrey has a passion for acting and the theatre and sees the user-led advisory group, Soul Fly Band, as an important part of the Gig Buddies project and an effective way to advocate for people with learning disability in Sydney.

ABSTRACT

In 2016 Gig Buddies Sydney took steps towards becoming a user lead project in order to be informed by the community we work with, adults with learning disability & autism.

The Soul Fly Band, led by five active Gig Buddies with disability was formed and now meet monthly to assist in shaping policy and to provide strategic direction at a corporate governance as well as the operational level of our organisation.

The Soul Fly Band have to date overseen the Volunteer and Gig Buddy online application process, formalized marketing suggestions to promote the project to a wider audience as well as assisting with the recruitment of service users.

The Soul Fly Band have been instrumental in developing Gig Buddies code of conduct and have provided advice around fundraising initiatives.

By having a diverse representation of Gig Buddies in the Soul Fly Band, the group has played a key role in selecting venues for Gig Buddies socials, events that challenge preconceived attitudes towards the traditional disability function.

This has facilitated a level of inclusion in the mainstream social life of the community as well as supporting service users to explore their passion for music, sport or other cultural experiences.

In line with the mission statement of the Soul Fly Band 'We help people with disabilities get out more and do different things' the Soul Fly Band's input as a peer group adds social role valorization to all Gig Buddies Sydney participants.

Input from active service users enables Gig Buddies Sydney to inform the wider community, change perceptions and attitudes regarding disability as well as creating opportunity for people with disability to lead an inclusive life.

The soul Fly Band plays an integral role in ensuring Gig Buddies Sydney delivers on its mission statement: To promote social inclusion and enable people with disability to become actively involved with Sydney's live music and events scene

Trauma Informed Positive Behavior Support: Outcomes of a model for people with disability and a history of adversity

Nicola Crates¹, Matthew Spicer¹

¹ Oak Possability

BIOGRAPHY

Nicola qualified as a Speech Pathologist at Flinders University and has specialized for over 20 years in developing and delivering services for people with complex needs as a practitioner and senior clinical manager with extensive experience in both Government and Non-Government sectors. She currently works as Director of Service Management and Development for OAK Possability.

Her values of compassion, excellence and adventure are reflected in her long standing commitment to developing person centered services that meet the needs of individuals who are at risk of homelessness and exclusion due to presenting behaviours of concern. Utilising her knowledge and skills in positive behaviour support, staff development, leadership and service design she has developed and implemented effective service models for individuals living with behaviours of concern resulting from intellectual disability, autism and trauma. Her motivation comes from seeing the life changing results that can be achieved when staff, families, individuals and clinicians work collaboratively to design and implement individualized service approaches.

Her work on training staff in PBS, crisis management and the reduction of restrictive practices has been published in peer reviewed journals and been presented at conferences including IASSID Conference 2016 "Goals, Aspirations, Achievements" which explored Co-Design and Plan Implementation under the National Disability Insurance Scheme and the International IABA Conference 2017 "Multi Element Trauma Informed Support".

ABSTRACTS

ABSTRACT

Background: Prevalence rates for adverse and potentially traumatising events are more common than might be expected. The rates of exposure to such events is considerably higher for people with disability. Positive Behaviour Support (PBS) provides an inclusive framework for incorporating a range of evidence informed practices to assist people in improving their quality of life. The integration of trauma informed care (TIC) approaches with PBS is an emerging area of practice in support of people with behavior of concern and complex needs related to early experience of adversity.

Method: A multi-tiered, milieu based, out of home care residential service model based on PBS and TIC principles is used to support the recovery of young people with intellectual disability, a history of adversity and behaviour of concern. Universal, targeted and individualised strategies are described as an approach to implementing supports.

Results: Standard programme and individual progress monitoring data are presented. Outcomes are reported for individual behaviour tracking and broader outcomes from the Health of the Nation Outcome Scales - Child and Adolescent scale (HoNOSCA).

Implications: Outcome data suggests this as a promising approach to support practices when implemented systematically. Synergy between Positive Behaviour Support and Trauma Informed Approaches are highlighted with commentary on the opportunities for value adding. Identified challenges and strategies for managing service implementation are discussed.

SESSION 2.2 Rights – Safety

Young people with cognitive disabilities and the police: Service provider perspectives

Dr Kelly Richards¹, Dr Kathy Ellem¹

¹QUT

BIOGRAPHY

Kathy Ellem (BSW, PhD) is a lecturer at the School of Public Health and Social Work, QUT. Her research interests include the experiences of people with cognitive disabilities in the criminal justice system, disability advocacy and social work with families who have a member with a disability.

Kathy has practiced as a social worker in the disability field for many years and has been extensively involved in individual, citizen and systems advocacy. She currently sits on the Brisbane Regional Disability Advisory Council for the Queensland government.

ABSTRACT

Background: Young people with cognitive disabilities (YPWCD) (including young people with intellectual disability) are overrepresented as offenders in the criminal justice system. Most of the existing research in this area examines overrepresentation in courts and corrections rather than at the police gatekeeping stage of the criminal justice process.

Method: 21 service providers from legal services, disability support services and youth services in Queensland, Australia, were interviewed using qualitative semi-structured interviews. Participants were asked questions on how contact with police had occurred for the YPWCD to whom they provide services. Data were analysed thematically using the theoretical explanations for the overrepresentation of PWCD (the susceptibility, psychosocial disadvantage and differential treatment theses) as a framework.

Results: Participants typically accepted aspects of more than one of the theoretical explanations for the overrepresentation of YPWCD. They saw police as having a gatekeeping role, and believed YPWCD could be diverted at this stage of the criminal justice process. One identified point of entry into the criminal justice process was families calling on police to intervene with their children with CD. While service providers advocated that police processes accommodate CD in such a way that this group were not be disadvantaged, very little focus was on how the lived experience of youth contributes to over-representation.

Implications: Further academic and practical attention is needed on the perspectives of YPWCD and their families in regards to police contact. There is a need to equip police to work more effectively with YPWCD to ensure socially just outcomes.

Disability support staff views on the use of mechanical restraint: A systematic review.

Gemma Dodevska, Kathryn White, Professor Keith McVilly¹

¹University Of Melbourne

BIOGRAPHY

Gemma Dodevska is a research fellow for Disability & Social Inclusion, in the School of Social & Political Sciences at the University of Melbourne. Gemma has a particular interest in service evaluation and is currently working on projects related to volunteer supported services for persons with disability. Prior to her academic career, Gemma worked in a variety of roles with disability service providers in Melbourne including; volunteering, direct support, service coordination and management.



Therefore, Gemma is pleased to have the opportunity to share with you Katie Whites research related to the views of mechanical restraint from the perspective of service delivery staff."

ABSTRACT

BACKGROUND: A systematic review was undertaken to identify what is currently known about the views and perspectives of disability support staff concerning the use and impact of mechanical restraint in the support of adults with Intellectual Disability who exhibit challenging behaviours that might be of harm to themselves or others. An in-depth understanding of these issues could provide the basis for policy and practice interventions to decrease, or ideally eliminate, the misuse of mechanical restraint.

METHOD: Papers were identified through searching the following databases: PsycInfo, CINAHL Complete,

MEDLINE Complete, Academic Search Complete, Psychology and Behavioural Sciences Collection, Scopus and Web of Science.

RESULTS: There is a paucity of literature concerning staff perspectives on the use of mechanical restraint on people with intellectual disabilities. There were common themes amongst the four studies identified. Most predominantly that staff have strong negative feelings towards using mechanical restraint, and that multiple systemic barriers impede the reduction of its use.

IMPLICATIONS: By investigating staff beliefs, values and knowledge surrounding challenging behaviour which has potentially contributed to the use of mechanical restraint on the individual with an intellectual disability, we can start to hypothesise how the external, social and cultural environment might act to enable (promote) the use of such practices, or act as a barrier to restraint reduction in disability services. Such findings can in turn inform both policy developments and professional development / education.

SESSION 2.3 Research – Inclusion

Recruitment: It's Challenging

**Kimberlee White¹, Dr Angus Buchanan¹,
Rebecca Waters¹**

¹Curtin University

BIOGRAPHY

Dr Angus Buchanan (DBA, DSM, BApSc) is a registered Occupational Therapist working in the role of Associate Professor and Head of School in the School of Occupational Therapy and Social Work at Curtin University. For 16 years, prior to commencing at Curtin in 2008, Angus held senior management and leadership roles at the Disability Services Commission of Western Australia. Current research areas include social inclusion, occupational justice, innovative respite for older carers living in rural and remote areas and the measurement of function and occupations of adults living in accommodation services. Angus is the President of the Australasian Society of Intellectual Disability (ASID).

ABSTRACT

Background: Difficulties in recruiting people with intellectual disability to actively participate in research is a recurring topic of discussion that has been minimally investigated to date. Capturing this issue and its depth is essential to involving people with intellectual disability in research.

Method: Semi-structured interviews were utilised to obtain perspectives of recruitment from 12 academic researchers with substantial experience in the field. Data was analysed using Straussian grounded theory.

Results: The core category was 'Recruitment: It's challenging', informed by seven categories; differentiation of people with intellectual disability as a research population, lived experience of researchers, gatekeeping, ethical considerations, research design, collaboration, and rapport.

Conclusions: Researchers developed and employed strategies over time and experience in response to recruitment challenges. These strategies largely focused upon creating, strengthening and supporting a connection between themselves and people with intellectual disability. There is potential for future investigation and further development of strategies to improve recruitment.

What Makes for Inclusivity in Inclusive Research?

Dr Tanya Riches¹, Professor Patricia O'Brien¹

¹*The Centre For Disability Studies*

BIOGRAPHY

In 2009 Patricia returned to Australia from Trinity College Dublin to take up the position of Chair in Disability Studies and Director, Centre for Disability Studies, University of Sydney. She pioneered the CDS Inclusive Research Network with Dr Marie Knox.

Dr Riches is a Research, Training and Development officer at The Centre for Disability Studies. She currently co-ordinates the centre's inclusive research network. In her PhD Tanya coproduced research on religion and community development with urban Aboriginal and Torres Strait Islander peoples.

ABSTRACT

Background and Aims: While many scholars agree theoretically that people with disability should be involved in the research process, internationally there is a paucity of research publications that deliver this objective. The recent Audit of Australian Disability Research (Llewellyn, 2014) identified a lack of research that had been co-produced by people with disability. Additionally, The National Disability Service website states, "there is a limited body of research that enacts service user participation, particularly with respect to individuals with intellectual disability."

Method: The authors reviewed the available scholarly, peer-reviewed literature. They charted the development of this field through participatory, emancipatory and inclusive research paradigms. In addition, they sought to understand the types of inclusive research that had been published in the past ten years, their methods, and theoretical base. While similar fields provide hierarchical models to categorize participation accordingly (Freire 1968, Arnsetin 1969, Kumar 2002), Nind 2014's model advocates for a more flexible approach. The idea of a hierarchy of inclusivity has proved controversial.

Findings: The authors present the current state of the field, and the particular boundaries that shape the endeavours of university researchers who desire to embark on inclusive or co-produced research over the longer term. Some themes include the challenges of upskilling co-researchers, limited funding and pressures for university researchers to "publish or perish."

Conclusions: The authors suggest that inclusivity should be evaluated within the disability research, and in line with the varied aims of people with disability for effecting change in government, market and society. They present a model that reflects these varying objectives of inclusive research.

SESSION 2.4

Education

Teaching children with ASD: Investigating teachers' evidence-based strategy choices

**Traci-Ann Garrad¹, Dr Christopher Rayner²,
Dr Scott Pedersen¹**

¹*University Of Tasmania*, ²*University of Tasmania*

BIOGRAPHY

Currently in the final year of doctoral studies in Education at the University of Tasmania, Ms Garrad specialises in inclusive education practice specifically in relation to children with autism spectrum disorder (ASD). In addition to her research, Ms Garrad teaches in a range of units including Inclusive Practices in Education Settings, Adapted Physical Activity, Motor Development Across the Lifespan and Advanced Motor Learning. After completing honours research exploring the attitudes of Australian teachers towards the inclusion of students with ASD in regular education classrooms, Ms Garrad turned her attention to the exploration of supportive classroom practices. This resulted in the development of a survey instrument to investigate teachers' decision-making processes in adopting and utilising evidence-based practices in supporting children with ASD. As an active member of the Australian ASD community over the past decade, Ms Garrad has worked to support greater community awareness and understanding of ASD in general.

ABSTRACT

Background: The Australian Senate's Education and Employment References Committee reported that teachers of children with disabilities often employ intervention strategies that lack empirical evidence. Recently, two large-scale international literature reviews worked to determine the most effective evidence-based practices (EBP) when working with children with autism spectrum disorder (ASD). However, the use of these practices and associated predictor variables have not been measured within Australia. Due to the recentness of these reports, a lack of available measurement tools existed. This resulted in the researchers' developing an instrument to explore teachers' decision-making processes when adopting EBPs to support students with ASD.

Method: The purpose of this paper was to test the validity and reliability to the developed instrument. Decision-making theory and previous literature were used to create a series of questions that identified current usage, aspects that influenced initial adoption and factors that were likely to result in abandonment of the various practices. Content validity and inter-rater reliability analyses were undertaken.



Results: The instrument was found to have good content validity and to be reliable based on test-retest findings. The presentation will provide details of the literature reviews' recommended strategies and the potential facilitators and barriers to adoption as well as reasons for ceasing use.

Implications: Having an instrument that assists the identification of the facilitators and barriers to the adoption and continued use of strategies shown to be effective should provide a basis for policy development (around teacher support and education) in turn, improving the educational outcomes for children with ASD.

SESSION 2.5 Services – Accommodation

Nexus Independent Living Program – 12 months in, did it work?

Mark Jessop¹

¹*Nex-us Inc*

BIOGRAPHY

Nexus grew from the deinstitutionalisation of people from Willow Court in the 1980's. In 2013 when Mark became CEO it ran 9 "group homes". The NDIS offered opportunity for growth with the trial focused on younger people at that time. Seeing the opportunity to break the mould Mark worked with Housing Choices Australia to develop a program around 4 single units in an 80 unit complex - so was born the NILP program. Mark is a registered psychologist who has worked in open employment programs, managed youth justice and child protection services as well as disability and justice evaluation and policy. NILP was evaluated by Dr Chris Fyffe and her material is used in this paper.

ABSTRACT

Background: The NDIS provide the opportunity to look at programs – not beds and allowed Nexus to imagine a new way to support people to live in the community. Focused on people with a high level of function and challenges mainly from mild ID and Autism, NILP uses a training model to support people to develop the skills they need to move to a greater level of independence and lower overall cost to the NDIA. This evaluation looks at process and outcome issues – for the participant, service provider and accommodation manager.

Method: This study reviews 18 months of the program which was initially established as a pilot. The experience of nine participants, staff, family, funders and organizations are considered. The research followed a traditional evaluation model, looking at both process and outcomes. Some rudimentary economic modelling is considered.

Results: Most participants were able to quickly reach a level of competency on domestic and daily roles. Social and employment outcomes were harder and less influenced by the program. Transitioning from the program to living independently in the community was limited by available housing options.

Implications: While the basic training system is established and had strong outcomes, each participant responded to community living in different ways. Placements with a "crisis" element were more difficult and underlying mental health issues became influential. Using staff from residential service backgrounds presented training and cultural issues

Can Motivational Interviewing improve implementation and use of a communication support? A pilot project.

Laura Le Van¹, Associate Professor Rocco Crino², Sam Corneille³

¹*Royal Far West*, ²*Charles Sturt University*, ³*Indigo Psychology*

BIOGRAPHY

Laura Le Van is a Clinical Psychologist who has been working with people with intellectual / developmental disabilities and their families for more than 10 years. Laura has worked within both the government (Department of Family and Community Services – Ageing Disability and Homecare) and non-government (Disability Services Australia and Royal Far West) sector. One of her primary areas of interest involves collaborating with staff who support people with an intellectual disability to improve their implementation of strategies and therapeutic recommendations designed to increase engagement and improve quality of life.

ABSTRACT

Background This study examined whether Motivational Interviewing (MI) follow-up calls improved the extent to which a specific therapeutic technique (Key Word Sign) presented in training was retained and implemented by staff supporting people with an intellectual disability.

Method Thirty-eight residential support workers who attended Key Word Sign (KWS) training were divided into 3 groups. One group received post training MI follow-up calls, the second received non-MI "check-in control" (CIC) follow-up calls and the third received no follow-up calls.

ABSTRACTS

Results Both follow-up conditions outperformed the no follow-up condition on the knowledge retention measure (a quiz) and the use measure (a brief questionnaire). No significant differences were noted between the MI and CIC condition in this study.

Conclusion The results highlight the value of post-training follow-up in promoting knowledge retention and implementation of skills. Methodological challenges (including treatment fidelity issues across groups) prevented firm conclusions about the impact of MI from being drawn.

CONCURRENT SESSION 3

4.00–5.30 PM

SESSION 3.1

Participation – Community

From Private to Public: Community Development Practice and People with Intellectual Disabilities

Morrie O'Connor¹, Paul O'Dea¹

¹*Community Living Association*

BIOGRAPHY

Morrie O'Connor graduated with a Social Work degree from the University of Queensland in 1974 and Master of Social Welfare and Administration in 1980.

At the grassroot level, he has played a role in the formation of many people's organisations such as the Nundah Community Enterprises Co-op (NCEC), WWILD-SVP a sexual assault counselling and victim assist service, IYHG a housing company where all the Board Members are people with an intellectual disability, Community Centres, Housing Co-ops and Resident Action Groups.

He is currently the Chair – ASID QLD Division, Co-ordinator of Community Living Association, Adjunct Lecturer at the University of Queensland, Board Member of Foresters Community Finance.

In the past he has served in the Board of Management of a number of national, state and local organisations – ACOSS, QCOSS, Oxfam. Morrie has also served on a number of Government Advisory committees.

Paul O'Dea has been a strong voice in the community and in addressing issues that are affecting the lives of people with disability. His passions and interests have led him to get involved in a number of activities and be part of various groups and organizations, such as being a board member on the Community Living Association Inc. and Independent Youth Housing Group Limited for almost 20 years now, as well as the Talking about Bullying group and People of the Air radio group.

His voice in organizations is now on a national scale as he is a member of the National Committee for the Australasian Society for Intellectual Disability (ASID) QLD.

ABSTRACT

Background: Community Development practice involves supporting individuals who have common individual concerns to come together and act to achieve change.

Method: This presentation will summarise three case studies of community development practice with people with intellectual disability. Community Development practice prioritises capacity building and the three case studies will consider the capacity building approaches utilised. Each of the case studies has a different genesis and takes a different form. Case studies were developed by people with intellectual disabilities who were members of the Community Development process, and contain historical information and personal reflections of members. Two case studies were proudly developed by members as a record of their history with the support of an editor. The third case study was funded by the Brisbane City Council and compiled by an independent author.

Results: In each case study individuals who shared common concerns came together and developed a joint response to their issue of concern.

Implications: The potential for those who work with people with intellectual disabilities to facilitate the move from private concern to public issue is under-recognised.

Community Living Association Trainers Project

Sarah MacDonald¹

¹*Community Living Association, Inc.*

BIOGRAPHY

Sarah holds a Bachelor of Social Work (Hons I) and a Bachelor of Arts from the University of Queensland. She has worked alongside people with intellectual and learning disabilities in direct practice, research and governance roles for the past seventeen years. In 2011 she commenced doctoral research at the University of Queensland on the transition to adult life experiences of young people with intellectual disability exiting out-of-home care. Sarah is currently undertaking projects at Community Living Association in Nundah, Brisbane on mental health system access by people with intellectual disability and self-advocate led service provider training. Sarah is inspired by listening to the voices of people with an intellectual disability and learning from their personal stories and knowledge.



ABSTRACT

Background: People with intellectual disability are frequent service users, but seldom participate in training and workforce development of service providers intimately involved in their lives. By sharing their knowledge and experiences as service users, people with intellectual disability can influence the professional development of service providers and support workers; collectively improve the quality of services and supports provided to people with intellectual disability; develop new skills; and access new opportunities for employment and/or meaningful role.

Method: The CLA Trainers Project supports people with intellectual disability to directly influence workforce development and access paid employment opportunities as training consultants. Six adults with intellectual disability participated in five workshops facilitated by the CLA Training Project Worker to generate training content grounded in their lived experience and perspectives as people with intellectual disability and service users.

Results: Group members identified five core knowledge points and associated skills for “good workers” and shared personal vignettes to illustrate their lived experience as service users. Group members prepared and delivered training to service providers and support workers in Brisbane, Queensland.

Implications: The CLA Trainers Project provides an innovative model for collective influence and participation in NDIS workforce development by people with intellectual disability, and a paid employment opportunity for training consultants.

Easy English: Functional choices – Everyday words and sentences

Cathy Basterfield¹

¹*Access Easy English*

BIOGRAPHY

Cathy Basterfield is an experienced Speech Pathologist, with a background of 29 years working with people with Complex Communication Needs and Easy English.

Cathy was awarded a Victorian Government Ethel Temby scholarship for an investigative study into international trends and accreditation for Easy English writing and publications in 2011. Her most recent published article is Plain Language for Accessibility, Democracy and Citizenship, in The Clarity Journal, 2014 72(2).

Acknowledged by her peers as a highly skilled practitioner in the field of Easy English, Cathy was involved in the development of the first guidelines for writing Easy English in Australia in 2005, and its companion Images for Easy English. In 2014, the Victorian State Government commissioned her to develop Easy English How to comply with the Victorian Government Accessible Communication Guidelines, which is available on their Intranet. Cathy has a national and international reputation in the development of Easy English.

ABSTRACT

Background: For consumers with limited literacy skills to be full and effective participants in society, documents must be available for them in a way they can read, understand and use meaningfully.

To date there is no research that investigates specifically the language used in Easy English documents. A previous paper looked at vocabulary selection and any core words in Easy English documents. This paper will address the language used in Easy English documents.

Method: A retrospective meta-analysis of 5 Australian Easy English documents was completed.

The meta-analysis considered:

- Sentence Length;
- Morphological endings;
- Structure of sentences;
- Regular and irregular verbs and tenses.

Comparisons were made across documents to identify patterns of use that assist the development of quality Easy English documents.

Results: Building on the previous findings about vocabulary and core word use in these documents, the results of this analysis indicate:-

- range of sentence length is limited;
- morphological endings are rare;
- sentences are in active tense.

Implications: This data adds to the current knowledge about what makes Easy English documents. Further research needs to compare these same language elements in Easy Read and Information for All documents to see if the same elements make up all three types of document. This will begin to build the evidence base about the specific measurable elements that constitute a quality document for people with limited literacy.

SESSION 3.2

Rights – Safety

Factors contributing to the sexual abuse of people with intellectual disability: A review of the literature.

Gail Ritchie, Professor Christine Bigby¹, Professor Jacinta Douglas

¹*Latrobe University*

BIOGRAPHY

The author has a Master of Social Work and Graduate Diploma of Education. She has worked extensively in the public welfare field including child protection, youth justice and drug and alcohol abuse treatment. She has also worked extensively in the field of intellectual disability including case management and team leadership.

More recently the author has worked in the area of disability service quality. This includes staff training, developing and implementing service feedback systems including consumer surveys, conducting focus groups and reviews.

The author is currently completing a PhD at La Trobe University.

ABSTRACT

Background: The high rate of sexual abuse of people with intellectual disabilities by carers has been raised in a number of inquiries and investigations recently in Australia. The findings of these investigations draw on individual testimony and expert submissions

Method: This study reviewed the literature in regard to factors that contribute to sexual abuse of people with disabilities and the propositions inherent therein.

Results and Implications: There is only limited research on this topic in the field of intellectual disability and the evidence is not strong. However, the literature suggests the factors that contribute to the sexual abuse of people with an intellectual disability by carers are complex. This includes theories ranging from “bad apple” or individual to “bad barrel” or organisational factors.

It is argued that further research including an analysis of the large body of grey literature may provide valuable insight to this area.

The Victorian Centres Against Sexual Assault: Responding to victim/survivors with intellectual disability or complex communication needs

Dagmar Jenkins¹, Dr. David Rose¹, Professor Louise Harms¹

¹*The University Of Melbourne*

BIOGRAPHY

Dagmar Jenkins is a Master of Advanced Social Work (Research) candidate at The University of Melbourne. Ms. Jenkins has worked as a Counsellor/Advocate at the South Eastern Centre Against Sexual Assault since 2003. For the last six years Ms. Jenkins has been the project worker on “Making Rights Reality”, which has a focus on increasing access to counselling, the criminal justice system and the Victims of Crime Assistance Tribunal for people with disabilities who have experienced sexual assault.

ABSTRACT

Background: Accumulating evidence demonstrates high rates of sexual assault experienced by people with intellectual disabilities and/or complex communication needs. This group of victim/survivors is thought to be impacted in similar ways to the broader population, however there is little information available to counsellor/advocates (C/As) on which counselling and advocacy approaches are most helpful for this client group in their recovery after sexual assault.

In addition, there can be significant barriers for victim/survivors with disabilities in accessing services following an experience of sexual assault. In Victoria, the Centres Against Sexual Assault (CASAs) are funded by government to provide crisis support, counselling and advocacy to victim/survivors.

Method: Counsellor/Advocates from all Victorian CASAs were invited to participate in an online survey. A mixture of quantitative and qualitative data was collected. Areas explored included experience and training, confidence, interventions used, goals for counselling and advocacy, therapeutic approaches, awareness of resources and barriers to access.

Results: Themes emerging from the qualitative and demographic data will be presented. Barriers and facilitators of service provision highlighted by the research will be discussed. Findings indicate a desire amongst Victorian C/As for more training, and for an increase in referrals.

Implications: The data arising from the survey will be used to add to the knowledge base to assist C/As working with victim/survivors of sexual assault to provide a skilled and accessible service to people with disabilities.



Speak Up and be Safe from Abuse

Dr Hilary Johnson¹, Naomi Rezzani¹, Denise West¹, Katie Lyon¹, Ruby Yee²

¹Scope, ²University of Melbourne

BIOGRAPHY

Hilary Johnson is the strategic research projects advisor for Scope's Communication and Inclusion Resource Centre in Victoria. She has extensive experience in the disability sector. Over the years she worked as a speech pathologist, manager and researcher. Since 2002 she has worked at Scope providing management direction and developing a new state-wide model of professional leadership and capacity building. In 2012, she was awarded her PhD from La Trobe University for a study on developing positive relationships for adults with complex communication needs. Currently she involved in research concerning people who have communication disabilities. She has published three books, six book chapters and has 36 referred journal articles.

ABSTRACT

Background: People with cognitive disabilities have been marginalised by the community's negative attitudes and are overrepresented as victims of abuse. Scope's Communication and Inclusion Resource Centre (CIRC) has been working with Department of Health and Human Services to research and trial a range of supports to enable people with communication support needs and intellectual disability to talk about abuse and neglect. A project was set up to investigate to what extent the tools and resources and training developed by the CIRC have been helpful for staff and for adults who have reported abuse. This presentation will describe the aids developed and report on the experiences and views of staff who attended the training.

Method: Scope's Human Research and Ethics Committee approved the research. Training was delivered in 15 locations across Victoria to disability support workers and coordinators. 200 staff attended the training (webinar or face-to-face) and 20 staff consented to be interviewed. Semi-structured telephone interviews lasting between 15-30 minutes were conducted with these staff members 3 months after they had attended training. Data was analysed using a thematic approach.

Results: Initial results indicate an enthusiastic response to the usefulness of the training and aids. Most staff had not used aids to assist in communicating with people with intellectual disability before. They reported the picture boards were useful but rarely used for reporting abuse. Data collection will be completed in July.

Implications : Staff reported the face-to face communication aid training was more useful than the webinar training.

SESSION 3.3

Workshop: Research – Inclusion

How Inclusive is Inclusive Research?

Elizabeth Young¹, Mark Walters¹, Tanya Riches¹, Patricia O'Brien¹, Bruce O'Brien¹, Megan Noyeaux¹, Lesley Lewis¹, Marie Knox¹, Jack Kelly¹, Jessup Suzie¹, Robert Griffiths¹, Alex Butters¹, Sarah Butler¹, Susan Adrian¹

¹The Centre For Disability Studies

BIOGRAPHY

The Centre for Disability Studies Inclusive Research Network began meeting monthly in 2010. It has conducted a wide range of research projects on topics including the National Disability Insurance Scheme, and the United Nations Convention on the Rights of Persons with Disabilities. We have presented our research findings at conferences in Australia and overseas. Within the Inclusive Research Network university scholars, support workers and people with intellectual disabilities work as co-researchers together. Thus, people with intellectual disabilities are able to contribute to the research, rather than have research done on them. Our motto is "Nothing about us without us."

ABSTRACT

Background and Aims: Following on from their presentation on the ethics of publication in inclusive research, The Centre for Disability Studies' Inclusive Research Network invites you to an interactive workshop that explores the meaning of inclusive research for co-researchers, and continues the discussion regarding participation in, authorship and ownership of the research

Method: Members of the Inclusive Research Network will discuss the group's challenges in pushing the boundaries of inclusive research.

Findings: This workshop will explore our findings to questions such as:

- What does inclusive research mean to us?
- What is our process?
- What are the barriers we have identified to publication in reputable, peer-reviewed scientific journals?

Conclusions: The group will present these findings with those at the workshop in an interactive, fun environment, and answer questions on their research together.



SESSION 3.4

Workshop: Education

Interoception workshop: An interactive experience for learning and teaching the eighth sensory system of interoception

Dr Jenny Curran¹, Dr Margaret Kyrkou¹, Kerry Rye¹,
Dr Emma Goodall², Nicole Kyrkou²

¹Centre For Disability Health (DCSH), ²Department for Education and Child Development

BIOGRAPHY

Nicole Kyrkou is a Developmental Educator, a multi-disciplinary disability specialist with an interest in the interface between disability, health and behaviour. Her current role in Department for Education and Child Development as the Program Manager Complex Needs and Mental Health has been focused on how we can better understand and respond to the complex and challenging needs of students with disability within education.

Dr Jenny Curran is a Senior Psychiatrist at the Centre for Disability Health in South Australia. She has extensive clinical experience working in developmental psychiatry working with both adults and children with intellectual disability and autism.

Margaret is a medical practitioner, as well as the mother of an adult daughter with significant disability. She has been working in the disability field for over 30 years, relating to parents and staff of children and young people with disability in clinics and educational settings. She also works at My Therapy House, and is a lecturer in Disability Studies at Flinders University, South Australia. She has given numerous national & international presentations and lectures, trained carers in Australia and Malaysia, and has had journal articles published. She was recently awarded a PhD for her thesis on females with disability, and was recognised nationally with an Order of Australia Medal for services to children with disability.

Dr Emma Goodall is an author, researcher and the Senior Autism Adviser for the Department of Education and Child Development in South Australia. She is reviewing programs and developing and implementing research based policy and programs to enable students on the autism spectrum to flourish. Emma combines her professional and academic skills and knowledge with her lived experience of Aspergers to help people understand what it means to be on the autistic spectrum and how different life is for those on and not on the spectrum.

Emma is passionate about helping families and schools to facilitate success for children on the spectrum. She is also on the executive committees of the Australian Society for Autism Research and the Autistic Self Advocacy Network of Australia, New Zealand and Oceania.

ABSTRACT

Purpose: The role of the eighth sensory system known as interoception is integral to all of us in our ability to self-regulate and maintain wellbeing. It has even greater significance for people with autism and/or intellectual disability who are unable to develop these functional skills without explicit teaching and consequently struggle to self-regulate. This workshop will engage participants in interactive activities to learn and explicitly teach interoception skills.

Session format: This workshop will provide a quick overview of interoception and its theory. Through interactive activities participants will have the opportunity to explore their own interoception skills and consider the diversity of interoception experiences within the group.

As participants work through activities and case scenarios they will develop a deeper understanding of the impact of interoception skills and how these can be dysfunctional when under or over utilised by a person. Behaviour will be explored within the context of interoception and the assumptions that are often made when trying to understand and respond to behaviour.

This will be a unique opportunity for participants to explore interoception skills and develop the confidence to apply this knowledge in their own work or personal context.

SESSION 3.5

Services – Accommodation

Quality and outcomes of individual supported living (ISL) arrangements for adults with intellectual disability

Professor Errol Cocks¹, Dr Allyson Thomson¹, Dr Stan Thoresen¹

¹Curtin University

BIOGRAPHY

Adjunct Professor Errol Cocks has been involved in the area of intellectual disability since the 1970s. He has contributed for many years to the conceptualisation and realisation of normalisation and social role valorisation for people with disability. His most recent research has focussed on areas of health disparity for adults with intellectual disability, disability employment, and individual supported living for adults with intellectual disability.



Professor Cocks has recently retired from active research, but continues to mentor and support members of the research team at Curtin University.

ABSTRACT

Background: The Individual Supported Living (ISL) project examined adults with intellectual disability living in a home of their choice, with people they chose, and with the necessary supports to do so. In this project we identified four main types of living arrangement – living alone, with a host family, with a co-resident, and living with someone with whom the person had a relationship.

Method: Evaluations of living arrangements were conducted by three or four trained team members using the ISL Manual. Outcome measures of community involvement, level of support need, and quality of life were also completed. 130 reviews were conducted across Western Australia, New South Wales, Victoria, and the Australian Capital Territory.

Results: People had been living in their home for between one month and thirty years, and their support needs ranged from low to very high. More than half lived alone, with varying amounts of paid and unpaid supports. Overall, arrangements scored very highly on the 'My Home' and 'One Person at a Time' themes from the ISL Framework. Areas including long-term planning and social inclusion were identified as underdeveloped.

Implications: ISL arrangements can be sustained for long periods of time, however extra efforts can improve outcomes. The ISL Framework and Manual provided a useful tool to identify aspects of living arrangements that were working well, and others needing targeted development. As such, the instrument is a valuable tool for helping adults with intellectual disability, their families and supports to improve their living circumstances.

Dimensions of group home culture as predictors of quality of life outcomes

Lincoln Humphreys¹, Professor Christine Bigby¹, Professor Teresa Iacono², Dr Emma Bould¹

¹La Trobe University, ²La Trobe University

BIOGRAPHY

Lincoln Humphreys is a PhD student at La Trobe University.

ABSTRACT

Background: Research has shown that there is variability in quality of life (QoL) outcomes for people with intellectual disabilities who live in group homes. The aim was to examine the association between group home culture and QoL outcomes.

Method: The Group Home Culture Scale (GHCS) was used to measure staff culture in 23 group homes. Quality of life data were available from 98 people with intellectual disabilities who lived in the group homes. Multilevel modelling was used to examine the associations between the GHCS subscales and four QoL dependent variables.

Results: Of the GHCS subscales, Effective Team Leadership and Alignment of Staff with Organisational Values were significantly associated with engagement in activities. Supporting Well Being was significantly associated with community involvement. None of the GHCS subscales were significantly associated with domestic participation and choice making.

Implications: The findings suggest that strategies which improve the team leadership skills of house supervisors and the way staff teams provide support to people with intellectual disabilities may contribute to enhancing certain QoL outcomes.

Lessons from the past for the future – a young man's journey from restriction to participation

Charley Hodgson¹

¹ Disability & Community Services, Tasmanian Government DHHS

BIOGRAPHY

Charley has had many roles in his 22 year career within the disability sector which include support worker, case manager, policy officer and state manager of a disability support organisation. He has also had over 15 years' experience in working with organisations to deliver positive behaviour support to people with behaviours of concern which includes 4 years managing the Disability Assessment and Advisory Team based in Burnie.

Charley originally trained as a social worker and brings his passion for protecting the rights of vulnerable people to his current role as Acting Senior Practitioner – Disability and Community Services (Tasmania).

ABSTRACT

Background: It is rare for behaviour support practitioners to have the opportunity to trace the progress of the life of a person with behaviours of concern over a significant period of time once the referral they are working on has concluded. This paper describes a 10 year longitudinal single case study and discusses data that highlights the factors helping and hindering a young man's journey from a restrictive life to a life of community participation.

ABSTRACTS

Method: The author collected behavioural data (including frequency, severity and occurrence of restraint) and information from file reviews as part of his involvement with the Institute of Applied Behavioural Analysis longitudinal training program. 10 years later the author revisited the participant's situation by interviewing key support staff and analysing subsequent behavioural data and file notes.

Results: When the behavioural data were compared with events occurring in the life of the participant it became clear that factors such as a stable, skilled support team and team manager, and a behaviour support plan with strategies addressing the function of the behaviour all contributed to a reduction in the participant's behaviours of concern. Conversely, unstable support and lack of compatible accommodation options were factors identified as barriers to achieving the goals of the behaviour support plan.

Implications: These findings, although not surprising, have implications for the sector and the NDIS as transition to full scheme continues. Although workforce training is addressed in the NDIS Quality and Safeguarding Framework efforts to further professionalise the workforce need to occur to attract and retain quality staff. In order to truly achieve 'choice and control' people with disability also need to have better access to accommodation that better meets their needs.

THURSDAY 9 NOVEMBER 2017 PLENARY SESSION

9.05–9.55 AM

The NDIS Independent Advisory Council and the IDRG

Judy Huett¹

¹*Speakout Advocacy*

BIOGRAPHY

Judy Huett is a 44 year old woman with intellectual disability. She lives in Burnie, Tasmania with her husband Peter. Judy was born and raised in a small community on the West Coast of Tasmania where she attended primary and high school. Since then she has attained qualifications in Disability Support, Aged Care, Information Technology and Small Business Management; and completed leadership development training through Leaders for Tomorrow (2012) and Voice at the Table (2016).

Currently Judy works part-time with Speak Out Association of Tasmania in Self Advocacy Liaison and Support. This involves capacity building with her peers and the Speak Out Members' Executive. She is admired and respected by people from all walks of life.

An accomplished leader, Judy is best known for her extensive contributions via her voluntary work that includes travelling to Geneva, Switzerland in 2013 with the expert group to talk to and present to the United Nations Committee on the Rights of Persons with Disabilities (UN CRPD); the national Our Voice Committee (immediate past Chair) and their many projects around Zero Tolerance and employment, Board member of Inclusion Australia, two terms with the Tasmanian Premier's Disability Advisory Council (PDAC) and member since inception of the Intellectual Disability Reference Group (IDRG). The longevity of Judy's commitment to the NDIS is evidenced by her participation in the delegation of self advocates to Parliament House Canberra to lobby for the NDIS.

Her long-standing commitment to promoting the human rights of people with intellectual disability and her contribution at a local, national and international level to developing self-advocacy resulted in her being awarded the Tasmanian Disability Community Achievement Award in 2010, and the Individual Award for Human Rights in 2012.

Judy is a skilled speaker and has presented at many conferences over many years including Having a Say, NSWCID, Speak Out, DARU and NDS.



ABSTRACT

The NDIS Independent Advisory Council and the Intellectual Disability Reference Group are key sources of design information for the NDIS. Judy Huett, a woman living with intellectual disability from Burnie, Tasmania will talk about her representation on these bodies, her journey to national representation, and the importance of supporting the skill development of self-advocates.

CONCURRENT SESSION 4

11.00 AM–12.30 PM

SESSION 4.1

Plain English Keynotes

Individualised funding/personalisation in England: What worked, what didn't, and why

Rob Greig

National Development Team for Inclusion

Please refer to Keynote section for biography and abstract

Living with intellectual disability in the twenty-first century

Dr Jennifer Clegg

University of Nottingham, UK, & La Trobe University, Australia

Please refer to Keynote section for biography and abstract

SESSION 4.2

Rights – Supported Decision-Making

Supporting self-determination of adults with intellectual disability – the family perspective

Bernadette Curryer¹, Professor Roger J Stancliffe¹, Dr Angela Dew², Dr Michele Wiese³

¹Centre for Disability Research and Policy, University Of Sydney, ²University of New South Wales Australia, ³Western Sydney University

BIOGRAPHY

Bernadette brings a perspective to issues involving intellectual disability based on a wide range of lived experiences – personal, academic and professional. She has worked in the disability sector for over 14 years, primarily in the fields of self-advocacy and adult education.

She is currently undertaking a PhD at the University of Sydney, with a focus on self-determination of adults with intellectual disability within the context of family relationships. These professional experiences have occurred in conjunction with her experiences as a parent, assisting her adult daughter to negotiate the maze of disability support programs, including individualised funding and the NDIS.

ABSTRACT

Background: In line with the United Nations' Convention on the Rights of Persons with Disabilities (2006), Australia has incorporated self-determination principles into current disability policy. Through the receipt of individualised funding from the National Disability Insurance Scheme (NDIS), it is expected that individuals with intellectual disability, together with family, will experience increased choice and control. While the involvement of family is frequently referred to, there is limited research on this relationship, particularly in regards to the way families support self-determination or how decisions are negotiated when the preferences of the adult with intellectual disability differ from those of the family.

Method: Semi-structured interviews were conducted with family members who are actively involved with the choice and decision-making of an adult with a mild to moderate intellectual disability. An Interpretative Phenomenological approach to analysis was used to understand the meaning family members gave to their experiences.

Results: Emerging themes based on the lived experience of family members as they support choice and decision-making will be presented. The participants' perception of possible benefits of, and barriers to, self-determination of adults with intellectual disability will be examined. Practical examples will be provided of the way families negotiate the challenge of balancing the individual's right to choose with concerns about decision-making skills and understanding of consequences.

Implications: Exploration of the lived experience of family members will increase the understanding of the role and needs of the family in regards to the development and support of self-determination of adults with intellectual disability.



pushing the boundaries

ABSTRACTS

The Process of Supported Decision Making: Learning from the Experiences of People with Intellectual Disabilities and their Supporters in Canada

Michelle Browning¹, Professor Christine Bigby¹, Professor Jacinta Douglas¹

¹Living with Disability Research Centre, La Trobe University

BIOGRAPHY

Michelle Browning is nearing completion of her doctorate at La Trobe University which focused on developing an understanding of supported decision making in the birthplace of the concept, British Columbia, Canada. Michelle works with organisations and individuals wanting to improve their knowledge of and skills in supporting decision making. She is passionate about using research to better inform the important work of people facilitating decision making support. Michelle is based in Melbourne, Australia.

ABSTRACT

Background: Research was needed to understand the process of how people with intellectual disabilities are supported with decision making in the context of legal frameworks that recognise supported decision making such as representation agreements and microboards.

Method: This paper reports the findings of PhD research exploring the experiences of 7 people with intellectual disabilities and their support networks engaging in supported decision making in Canada. A grounded theory analysis, using 100 hours of observation and 34 in-depth interviews, led to the development of a model outlining the process of supported decision making.

Results : Supported decision making involved a dynamic interaction between the will and preferences of the person and the responses of their supporters. This interaction was shaped by the attributes and experiences the person and their supporters brought to the process, the quality of their support relationship, the nature and consequences of the proposed decision and the environment in which decision making occurred. How supporters responded was influenced by the intention behind their support. Supported decision making was characterised by support with the intentions of accepting and clarifying the person's will and preferences.

Implications: A greater understanding of the process of supported decision making will enable decision supporters to engage in more reflective practice and law makers to develop appropriate environmental support and safeguards.

Lived experience of supported decision-making for socially isolated young people with cognitive disability – using existing research to inform a participatory study.

Danielle Notara¹

¹The Centre For Children And Young People at Southern Cross University

BIOGRAPHY

Danielle holds a 3 year PhD Scholarship at the Centre for Children and Young People at Southern Cross University, where she has also been working as a Research Assistant. Commencing in February 2016 the PhD is embedded in the ARC Linkage project titled, 'Young people with cognitive disability: relationships and paid support'. It is exploring the role of supported decision making for socially isolated young people with cognitive disability.

Danielle's background is in the community sector spanning ten years in research and community development roles across a wide range of areas including disability, children and young people, information and communication technology, homelessness and domestic violence. With a strong commitment to social justice, her research interests are driven by finding innovative and effective ways to influence social policy.

ABSTRACT

Background: Supported decision-making is being trialled, evaluated and measured across Australia and internationally to improve the rights and wellbeing of people with disability. Research has occurred with organisations that deliver services, support workers and families of people with disability, yet less often with people with disability themselves. This scoping review of literature informs a PhD study investigating supported decision-making processes for socially isolated YPWCD.

Method: The aim of a scoping review is to "...map rapidly the key concepts and the main source and types of evidence available" (Arksey and O'Malley, 2005). This scoping review asked – What are the perspectives of socially isolated YPWCD on supported decision making and how is their lived experience reflected in research? A systematic search of five key databases, and a hand search of relevant journals and grey literature was undertaken. The combined results of over 400 articles were reduced through a process of inclusions and exclusions, to a final 16 articles for analysis.

Results: The results provide a snapshot of the small number of existing studies in the area of supported decision-making that draw directly on the lived experience of YPWCD who are socially isolated. The role of environments and relationships in facilitating supported decision-making was highlighted across the research, along with the challenges this presents for this already marginalised group.



Implications: Key to addressing the disadvantaged faced by socially isolated YPWCD, will be to ensure participation in research that informs future development of supported decision-making policy and practice.

SESSION 4.3

Workshop: Ethics – Ageing

Exploring Ethical Issues in Ageing: an Australasia perspective

Laura Hogan¹, Emma Doukakis¹, Dr Angela Dew², Bernadette Curryer³, Dr Michele Wiese⁴, Dr Stuart Wark⁵, Sharon Brandford⁶

¹Centre For Disability Studies, University of Sydney, ²School of Social Sciences, University of NSW, ³Faculty of Health Sciences, University of Sydney, ⁴School of Social Sciences and Psychology, Western Sydney University, ⁵School of Rural Medicine, University of New England, ⁶Consultant on Disability Support

BIOGRAPHY

Angela Dew is Senior Research Fellow and Research Lead with the Intellectual Disability Behaviour Support Program at UNSW. Angela is a sociologist with over 30 years working in the disability field in direct service, management, teaching and research roles. Angela's main research interests relate to the lived experiences of people with a disability and their family members.

Angela completed her PhD at The University of Sydney graduating in 2011. Angela's PhD thesis explored the later life relationships of adults with cerebral palsy and their non-disabled siblings as parents aged.

Angela has published widely on issues related to rural and remote service access and delivery. Angela is a member of the Aboriginal and Torres Strait Islander Disability Research Network, a NSW committee member for the Australasian Society for the Study of Intellectual Disability, and a member of the International Association for the Scientific Study of Intellectual and Developmental Disability.

Laura Hogan is an Occupational Therapist (Bachelor of Applied Science), she also holds a Masters of Health Science (Developmental Disability) and a Certificate IV in Training & Assessment. Laura has worked for many years with people with disability across the lifespan with a special interest in supporting adolescents and adults with complex support needs.

Laura is actively involved with a number of peak disability bodies including her role as the Vice President of the Australasian Society for Intellectual Disability (ASID) Board of Directors and a committee member of the NSW Division of ASID Ltd

Sharon is from Wellington New Zealand. She is currently self-employed as a consultant on disability supports. For several decades, she has held clinical leadership roles in non-government organisations across NZ, where her work has largely focussed on development of positive options for people with intellectual disability and their families. In recent years, this has seen her supporting elders with intellectual disability, and exploring what providers can do to enable them to have a good life, for all of their life.

ABSTRACT

Presenters: Dr Angela Dew, Ms Laura Hogan, Dr Michele Wiese, Dr Stuart Wark, Ms Sharon Brandford, Ms Bernadette Curryer

Background: The numbers of older people with intellectual disability are set to double between 2000 and 2030. Life expectancy for the majority of people with intellectual disability is now similar to the general population. In 2016, ASID NSW/ACT Division hosted a forum on "Ethical Issues in Ageing" during which four key themes: Family, Health, Retirement and End-of-Life, were presented and the ethical issues surrounding them debated.

Purpose: Findings from the NSW event will be briefly presented before delegates participate in a facilitated World Café style event during which the four topic areas will be discussed. A World Café is designed to encourage collaborative dialogue around questions on a specific topic. Summarised discussion group feedback will be visually graphed. The World Cafe format provides participants with an opportunity to contribute to an Australasian perspective on the issue to ensure future work has broader applicability.

Controversial perspectives: Taking an ethical approach to ageing, the event will highlight a number of opportunities, challenges and risks for people with intellectual disability, those who provide direct support, professionals and researchers.

Implications: As people with intellectual disability age, they may require higher levels of support from family and from mainstream services such as aged care, retirement groups, and palliative care. The person and their family may experience barriers in accessing mainstream services. Mainstream service providers may feel ill-equipped to support an older person with intellectual disability. These issues are especially relevant to the current trajectory of the NDIS in Australia.

SESSION 4.4

Services and Policy

Risk-Need-(Un)responsivity: Addressing the changing needs of New Zealand Care Managers.

Adrian Higgins

BIOGRAPHY

Adrian is approaching his fourth decade of working to support people with learning disabilities. Over the past 14 years he has worked extensively in community settings with people whose behaviours may at times present a risk to themselves or others. As a means of easing towards retirement he is undertaking a doctorate to investigate the rehabilitative outcomes for people with intellectual disability made subject to New Zealand's Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

ABSTRACT

Background: The Intellectual Disability (Compulsory Care & Rehabilitation) Act 2003 (IDCCRA) enables offenders who have an intellectual disability to be placed under compulsory care and rehabilitation orders. The New Zealand Ministry of Health administers the Act and funds hospital and community services to provide care and rehabilitation programmes. Rehabilitation is not defined within the act.

Rehabilitative approaches at the inception of the legislation drew primarily on applied behaviour analysis, viewing criminal offending as a class of challenging behaviour. Over the intervening 13 years alternative theoretical approaches have been proposed; the most recent combines risk management with rehabilitative and desistance theories. This paper examines these changes and considers workforce implications.

Method: Documents from 2003–2017 related to developing a national model of care for IDCCRA care recipients were reviewed.

Results: Considerable changes in theoretical orientation were apparent.

Implications: Care Managers have the responsibility for writing and implementing IDCCRA care and rehabilitation plans. At the inception of the IDCCRA they were required to complete a tertiary level Diploma in Care Management and Co-ordination (High and Complex Needs). This was discontinued in 2006. No comparable training to upskill Care Managers in current IDCCRA rehabilitative approaches has been made available.

Working relationships between people with intellectual disability and support workers: What role does policy play?

Dr Sally Robinson¹, Professor Karen Fisher², Professor Anne Graham¹, Professor Kelley Johnson², Dr Ed Hall³, Sandra Gendera², Dr Kate Neale¹

¹Centre For Children & Young People, Southern Cross University, ²Social Policy Research Centre, UNSW, ³University of Dundee

BIOGRAPHY

Sally Robinson is the Chief Investigator leading this ARC Linkage project. The research seeks to better understand relationships between young people with cognitive disability and their paid support workers. Sally has a long history of collaborative and participatory research with people with intellectual disability. Her work focuses particularly around abuse and safety; belonging and relationships; and quality in services.

ABSTRACT

Background: Very little is known about how relationships between people with intellectual disability and their support workers are positioned in policy. With the policy shift towards individualised approaches and self-directed funding, the nature of their relationship assumes a more prominent role in the quality of support practice.

Method: This paper reports on a policy review that applies Honneth's recognition theory to explore the role that paid relationships play in the ongoing identity formation of young people with intellectual disability. The policy review focuses on the extent to which current disability policy acknowledges, promotes or diminishes the role of relationships between people with intellectual disability and workers.

Results: The policy review applied a three-stage process: categorization of policies, textual analysis and content analysis. Four policy levels were involved – international, federal, state and local (the latter linked to two case study organizations).

Implications: The review reveals that while a rights framework is explicit in most policies, the emphasis on the conditions for recognition within a relationship between people with intellectual disability and workers is compromised in instructional policies that attempt to manage the tension between choice and risk.



Tracing Policy Reform for Inclusive School Education of Students with Intellectual Disability – A Grey Literature Review

Professor Teresa Iacono¹

¹*La Trobe University*

BIOGRAPHY

Teresa Iacono is Professor of Rural and Regional Allied Health in La Trobe Rural Health School and a member of the Living with Disability Research Centre where her work focuses on strengthening mainstream service systems for people with disability. Her research expertise is in complex communication needs, augmentative and alternative communication, and assessment and interventions for people with severe intellectual and developmental disabilities across the lifespan. Current research is addressing hospital experiences of people with cognitive disability and harnessing expertise to support inclusive school education of children with disability. Her publications include over 100 peer reviewed journal articles, 14 book chapters and one co-edited book.

ABSTRACT

Background: Despite government commitment to the rights of children with disability to inclusive education, in Australia, as elsewhere, those with intellectual and developmental disabilities continue to experience exclusion and unequal treatment within school education. The aim here was to review Australian and Victorian reforms addressing this problem in the context of inquiries and international literature.

Method: A review of the grey literature began with key word searches of Pandora, Google and A+ Education, then checking references of papers addressing inclusive education of students with disability, published in the public domain since 2010. Previous relevant legislative, policy and inquiry documents were also included and summarised.

Results: Seventy-nine papers were included, comprising legislation, government inquiries, submissions, and commissioned reports. A timeline was developed to map key events, culminating in the Victorian Review of Programs for Students with Disabilities (PSD, 2016) and the Government's response (2016). These documents demonstrate continued violations of human rights being played out in schools and continued failure to achieve inclusion and quality education for children with intellectual and developmental disabilities, despite legislation and policy initiatives. Some positive practices were evident (e.g., collaborations across Specialist and Mainstream Schools), but they appeared mostly to be short-lived. Also evident was a problematic nexus between the National Disability Insurance Scheme and the PSD, even though both focus on reasonable accommodations as a key inclusion strategy.

Implications: Recent reforms demonstrate the government's will to realise inclusive education for all children. Success will require practice strategies with incentives as well as repercussions for non-compliance.

SESSION 4.5

Employment

Meaningful Employment for Adults with Intellectual Disability and High Support Needs through Small Business Enterprises (SBEs)

Dr Allyson Thomson¹, Professor Errol Cocks¹, Dr Stian Thoresen¹

¹*Curtin University*

BIOGRAPHY

Adjunct Professor Errol Cocks has been involved in the area of intellectual disability since the 1970s. He has contributed for many years to the conceptualisation and realisation of normalisation and social role valorisation for people with disability. His most recent research has focussed on areas of health disparity for adults with intellectual disability, disability employment, and individual supported living for adults with intellectual disability.

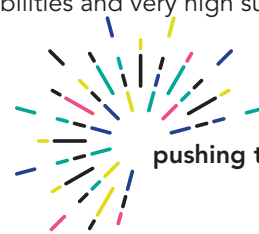
Professor Cocks has recently retired from active research, but continues to mentor and support members of the research team at Curtin University.

ABSTRACT

Background: Adults with disabilities are much less likely to have meaningful employment than adults without disabilities. Lack of employment contributes substantially to the high risk of poverty persons with disabilities face, as well as to poor social and economic outcomes more broadly.

Method: A range of people involved in four Small Business Enterprises (SBEs) were interviewed for these case studies. SBEs are: specifically designed around a person, in these cases with intellectual disability and high support needs; owned and controlled by the person with disability or those close to him or her; generate some income, and; foster the development of relationships with people in the community.

Results: This presentation briefly describes four case studies. Two SBEs were established over a decade ago and have become well-known examples of leading-edge approaches to providing meaningful vocations for adults with intellectual disabilities and very high support needs.



ABSTRACTS

The other two businesses were established within the past two years for three young adults with intellectual disabilities and high support needs. They highlight some of the challenges in establishing SBEs. All arrangements illustrated how parents developed tailored SBEs around their sons' interests, skills, and needs.

Implications: Employment can play a major role in promoting social and community inclusion, and these four case studies clearly illustrated this. The project highlights the importance of individualised approaches to support positive outcomes for persons with intellectual disability and high or very high support needs.

Disability Employment – The Client Consultant Intersection. A Systems Analysis of the Factors that Lead to Successful Employment Outcomes.

Peter Smith¹

¹Centre For Disability Employment Research & Practice
BIOGRAPHY

Mr Peter Smith (MHLthSc, BAppSocSc) is the Director of the Centre for Disability Employment Research and Practice, recently completing a PhD in the area of disability employment at the Sydney Medical School, University of Sydney. Peter has an extensive work background with people with disabilities and others with significant barriers to inclusion in society, having worked as a disability support worker, counsellor in Disability Employment Services and Job Services consultant.

In recent years he has worked with the disability peak bodies and community groups throughout Asia, Pacific and North American settings. He has contributed to a number of government inquiries into disability and employment. His primary interest is the practical application of evidence based practices to solve community and individual problems, with a focus on disability employment. His current work focuses on developing a dynamic model of practice for disability employment utilising the evidence based customised employment process.

ABSTRACT

BACKGROUND: Disability Employment Services (DES) is the primary vehicle in Australia charged with promoting and supporting successful open employment opportunities for people with intellectual and developmental disabilities. This research examined the client consultant dynamic to see what factors were at play in promoting successful employment.

METHOD: Research was undertaken using a Multiple Perspective Design that resides within the Interpretative Phenomenological Analysis methodology. Clients with a wide variety of ID/DD (n=30) and Employment Consultants (n=30) were interviewed using semi-structured interviews in small group settings.

The data was analysed using Interpretative Phenomenological Analysis (IPA) that allowed for themes to be developed.

RESULTS: The research themes provided a base to develop an understanding of some of the factors influencing employment outcomes amongst the client participant base and the disability employment consultants. This highlighted disparities in perceived abilities, attitudes and a lack of understanding between the system participants. The results also highlighted the influence of ecology on employment outcomes and a high level of disequilibrium within the employment system and environment.

IMPLICATIONS: The inability of the disability employment system to use evidence based processes that support clients with ID/DD and consultants has resulted in a system that lacks any real understanding of the client and consultant needs, placing primacy on compliance and system needs ahead of the stated purpose of the program which is to support people with a disability to gain and maintain meaningful employment consistent with their capacity and career aspirations.

Social Enterprise – innovative approaches to promoting the labour market participation of people with disability

Professor Keith McVilly¹, Peter Smith²

¹University Of Melbourne, ²Centre for Disability Employment Research & Practice

BIOGRAPHY

Mr Peter Smith (MHLthSc, BAppSocSc) is the Director of the Centre for Disability Employment Research and Practice, recently completing a PhD in the area of disability employment at the Sydney Medical School, University of Sydney. Peter has an extensive work background with people with disabilities and others with significant barriers to inclusion in society, having worked as a disability support worker, counsellor in Disability Employment Services and Job Services consultant.

In recent years he has worked with the disability peak bodies and community groups throughout Asia, Pacific and North American settings. He has contributed to a number of government inquiries into disability and employment. His primary interest is the practical application of evidence based practices to solve community and individual problems, with a focus on disability employment. His current work focuses on developing a dynamic model of practice for disability employment utilising the evidence based customised employment process.



ABSTRACT

BACKGROUND: Social Enterprise is a hybrid business model; integrating values traditionally associated with community services sector, and those of the commercial sector. Social Enterprises have both a strong sense of mission, and a commercially viable business model. We investigated a range of Social Enterprises across Australia, and investigated the opportunities to involve people with Intellectual Disabilities.

METHOD: Purposive sampling was employed; with organisations selected on the basis of their established reputation for operating an economically sustainable businesses and being inclusive of people with disability. Geographic diversity was also a consideration, considering socio-economic factors. Subsequently, CEOs and senior managers were interviewed, and the data subject to Interpretative Phenomenological Analysis (IPA).

RESULTS: The induced themes provide the basis for a successful Social Enterprise, which is inclusive of employees with Intellectual Disability. These themes included: having a clear understanding of what constitutes a Social Enterprise; having a focus on career development; a commitment to award wages; being innovative; and engaging leadership with both business expertise and a strong ethic.

IMPLICATIONS: Social Enterprise, if well implemented, can increase the economic participation of people with disability. However, Social Enterprise represents a radical departure from the operation of existing Australian Disability Enterprises (ADEs). Its implementation requires specialist knowledge and high level commitment from agencies if it is to be implemented authentically, and to realise its full potential as a third-wave, hybrid business model.

PLENARY SESSION

1.30–2.20 PM

Pathways to self-determination for individuals with intellectual disability

Professor Monica Cuskelly¹

¹University of Tasmania

BIOGRAPHY

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.

ABSTRACT

Self-determination is a key marker of adulthood. It can be considered to be a developmental construct as its beginnings are observable early in life but it generally does not reach its mature form until sometime in late adolescence/early adulthood. Self-determination is influenced by a number of factors including individual characteristics, aspects of family functioning, and interactions and opportunities at school and post-school. It is not, however, entirely an individual ability. It requires environments that are open to the expression and enactment of the individual's preferences and wishes. For many individuals with intellectual disability, the experiences necessary to support the development of the capacity to be self-determining are absent from their lives. Drawing on several streams of research across childhood, adolescence and adulthood, this presentation will discuss a number of contributors and barriers to the development and exercise of self-determination by those with intellectual disability.



CONCURRENT SESSION 5

2.30–3.30 PM

SESSION 5.1

Rights – Safety

Which trumps – the right to freedom or the right to well-being? The challenge of balancing support for people with intellectual disability, despite UNCPRD

Fiona Redgrove¹

¹*Flinders University*

BIOGRAPHY

Fiona Redgrove is a PhD candidate in the School of Health Sciences at Flinders University, researching the conceptualisation of adulthood as it applies to young people with intellectual disability in the years following secondary schooling and the subsequent transition from childhood. Fiona has over 30 years' experience in special education and community services for people with disability.

ABSTRACT

Background: The period of transition to adulthood for young people with intellectual disability has been well researched, yet remains a time of tension for parents of young people and those supporting them through this transition. Why this continues to offer challenges for stakeholders is unclear.

Method: Using focus groups and face-to-face interviews, this qualitative research and concept analysis explored the conceptualisations of adulthood by young people with intellectual disability, their parents and their support staff. These were mapped for compatibility and incompatibility to explore whether differences contributed to the tensions identified between stakeholders.

Results: Different criteria for offering adult status were used by each of three groups of interviewees. Beliefs about independence and autonomy as criteria varied amongst the young people, their parents and their supporting staff. As a result, questions of the applicability of the UNCPRD for those living with intellectual disability arose. Young people's right to "live in the community, with choices equal to others" (Article 19, UNCPRD) is not universally accepted.

Implications: The UNCPRD offers a statement of rights that fails to differentiate between those with intellectual disability and those with other types of disabilities. Its declaration of rights does little to resolve the conundrum for stakeholders in the lives of young people with intellectual disability between prioritising the right of people to make autonomous decisions or their need for protection from harm.

Supporting People with Intellectual Disability to report violence; building bridges across sectors

Ellen Fraser-Barbour

¹*Flinders University*

BIOGRAPHY

Ellen Fraser-Barbour, a PhD student at Flinders University, is passionate about research which genuinely honours the voices of people with disability and contributes to advocacy movements. Ellen's current focus is on researching violence against people with disability, extending on her recent honours thesis titled; 'Supporting People with Intellectual Disability to report sexual violence and link with violence response-services'. Ellen also has the privilege of working with families and allied health professionals under the NDIS model in a number of roles as a Developmental Educator (Disability specialist), therapy assistant, family support worker and support coordinator. Ellen is contracted by families to consult within the home, childcare or school environments. Ellen brings a human rights approach to her practice, with a particular focus on intentionally developing rich, safe playful environments where kids with disabilities have opportunities to develop positive behaviours, meaningful communication (AAC, PECs, Sign) and social and practical life skills.

ABSTRACT

Background: In recent years there have been a number of reports and inquiries evidencing an epidemic of violence against people with disability. There is further evidence suggesting that people with intellectual disability are excluded from accessing adequate support or justice. This paper investigates how people with intellectual disability can genuinely be listened to and supported throughout the process of reporting and engaging with violence-response services in the aftermath of violence.

Method: This paper stems from a small qualitative study carried out through interviews with seven South Australian service providers in the disability and mainstream violence-response sectors. The study aimed to identify barriers and facilitators to supporting people with intellectual disability in (a) reporting within service systems and (b) linking to violence response services beyond disability services.

Results: This study identified that people with intellectual disability are routinely excluded from decisions about what happens after abuse is identified, further adding to the trauma. The participants highlighted a range of people across both disability services, specialist services and within the justice system who are key facilitators with a key role to play in genuinely honouring the voice of people with intellectual disability. They also gave various examples of supporting people with intellectual disability throughout the process of reporting and engaging with violence-response services.



Implications: The findings indicate a need for greater investment in building bridges between disability services and broader community violence response sectors. A key to ensuring such bridges is the development of training across sectors with an agenda to improve a) awareness of supporting people with intellectual disability, and b) a trauma informed approach to supportive decision making. Both are key aspects in effective support and the true honouring of the voice of people with intellectual disability.

SESSION 5.2

ASID Board

The Work of the ASID Board: have your say!

Deborah Espiner, Maurice O'Connor, Associate Professor Angus Buchanan, Ben Crothers, Sharon Brandford, Laura Hogan

ABSTRACT

Background: The ASID Board of Directors has a number of committees. These committees focus on different areas of board business. One of these committees is the Inclusion Committee. The Inclusion Committee is working on accessibility and inclusion for the work of the Board and other areas of ASID business

Purpose: The Inclusion Committee and ASID President will run this workshop. We want to hear from people with a lived experience of intellectual disability, however everyone is welcome. Come along and hear about the work that the ASID board is doing now and what we are planning for the future. The work of the ASID Board is for the whole organisation across Australia and New Zealand. Participants will work together in small groups. Groups will discuss current and future plans for ASID, everyone will have their say.

Implications: All participants will have the opportunity to hear about what each group came up with. Ideas, suggestions and feedback will be shared with the whole ASID Board at the next Board of Directors Meeting.

SESSION 5.3

Ageing – Death & Dying

Death and disability – Let's have the conversation

Anna Holliday¹, People with disability Various¹

¹Li-ve Tasmania, ²University of Tasmania

BIOGRAPHY

Anna has a diverse and extensive background in the disability industry spanning over 20 years. Her roles have included service design and innovation, operational management and delivery of quality services in a range of settings and across government and non-government spheres.

Anna is passionate, energetic and highly committed to strengthening communities to be responsive to the needs and wishes of people with disability as they prepare for, and experience death and/or bereavement. Anna's focus on developing and nurturing partnerships and working collaboratively has seen instrumental enhancements within the Tasmania service system for people with disability, their families and those who support them.

ABSTRACT

Background: Death is a socially challenging topic within Australian culture. This is exacerbated for people with disability. In Tasmania, people with disability report feeling confused, uninformed, isolated, and excluded from treatment planning, conversations about their prognosis, and are not connected to Palliative Care services in a timely manner.

Carers report they commonly try to 'minimise' the effects of grief/loss for people with cognitive disability by presenting modified information. In reality, avoiding the topic significantly adds to people's confusion, isolation and fear.

It is imperative that our community listen to the wishes, needs and preferences of all people as they adjust to loss and/or approach end of life.

Method: Tasmanians with disability are working together to develop a campaign to enhance community awareness, willingness and confidence to engage with, and value the contributions of people with disability regarding death, dying and bereavement.

Results: People with disability will deliver this presentation as a mechanism to share their journey to greater social inclusion regarding the topic of their mortality, their experiences with death and bereavement with the ASID conference delegates.



ABSTRACTS

Implications: Tasmania service providers and community in general have indicated a strong interest in further understanding the experiences and perspectives of people with disability with life limiting illness and those who experience grief and loss. It is time for Tasmanians with disability to establish a clear voice and visibility within our community and be respected and valued for the contributions they offer to this complex and confronting topic.

Disability, death, end of life care and bereavement; perspectives, insights and experiences of Tasmanian's

Anna Holliday¹

¹*Li-ve Tasmania, ²Palliative Care Tasmania, ³Better Access to Palliative Care*

BIOGRAPHY

Anna has a diverse and extensive background in the disability industry spanning over 20 years. Her roles have included service design and innovation, operational management and delivery of quality services in a range of settings and across government and non-government spheres.

Anna is passionate, energetic and highly committed to strengthening communities to be responsive to the needs and wishes of people with disability as they prepare for, and experience death and/or bereavement. Anna's strong focus on developing and nurturing partnerships and working collaboratively has seen instrumental enhancements within the Tasmania service system for people with disability, their families and those who support them.

ABSTRACT

Background: In 2016, anecdotal evidence suggested Tasmanian disability services were not considering death or end of life care proactively for people they supported. As a result, people with disability were being transferred to unfamiliar environments (aged/acute care) at end of life when continuity, familiarity and security are so vital.

In response, Li-VeTasmania conducted inaugural research, asking Tasmanian's with disability and those who support them to share their insights, perspectives and experiences regarding death, dying, end of life care and bereavement.

Method: Invitations to participate in the consultation process for this project were distributed to a broad range of recipients across the Tasmanian community. Participants (N=110) were people with disability, their families/friends and service providers and contributed via individual interviews, small group discussion groups or larger community forums.

Results: Tasmanians with disability feel confused, uninformed, isolated, and excluded from treatment planning, conversations about their prognosis, and are not connected to Palliative Care services in a timely manner. Families and service providers clearly lack confidence and willingness to engage in the topic of death and dying.

Results clearly identified a significant need for the Tasmanian service system to consistently and capably respond to the needs, wishes and preferences of people with disability (and those who support them) as they prepare for their death.

Implications: Significant, sustainable, systemic changes are required to enhance the experiences for people with disability (and those who support them) as they prepare for, and experience death and bereavement. "Let's have the conversation".

SESSION 5.4

Round Table: Services

Maintaining Professionalism in the NDIS environment

Dr David Treanor¹, Professor Keith McVilly²

¹*University of Tasmania, ²University of Melbourne*

BIOGRAPHY

David Treanor received his Ph.D. from the University of Tasmania, Australia where he specialized in Disability, Ethics and Friendship. He became interested in friendship and ethics studies through his personal experiences with people with and intellectual disability and the philosophical and theological discourse of Jean Vanier. His research on friendship and ethics introduced him to the philosophy of personalism and John Macmurray's concept of persons in relation—human relationality (or personal friendships) constitutes the fulcrum or essence of human nature. Treanor's commitment to actualizing and live relationally with other people immersed in interdependent philia is congruent with his commitment to L'Arche. David is currently the National Leader of L'Arche Australia & New Zealand.

ABSTRACT

Background: The National Disability Insurance Scheme (NDIS) is a Copernican revolution for administering, funding and governance of the disability services sector in Australia. It is expected that when the scheme is fully rolled out, the sector will employ approximately 90 000 Full Time Equivalent (FTE) positions. This is good news for an Australian economy that has experienced a downturn in traditional industries such as mining and housing.



Presenters: Professor Keith McVilly (University of Melbourne) and Dr. David Treanor (L'Arche Australia).

Purpose: This roundtable will invite a range of personnel in the disability services sector to explore how s/he envisages the future of Direct Support Professionals (DSP's) in the NDIS environment. The panel will also invite DSP's to offer their perspective. The facilitators suggest that this significant increase in the number of DSP's will have substantial implications to the quality and safeguarding framework. Furthermore, some significant questions arise from an expanding service sector such as: (a) who, if anybody, ought to take responsibility for shaping the form the workforce might need to take; (b) what ethical practices will be expected from the workforce and (c) is the current provision of education and recognition of competence qualifications sufficient to meet the needs of the people? The roundtable style will be dialogical and anticipates that attendees will engage with panel members and share their views.

Controversial perspectives: The presenters suggest that little attention is being paid to the development of robust ethical practices in the current roll out of the NDIS.

Implications: DSP's may pay greater attention to the professional development needs.

CONCURRENT SESSION 6

4.00–5.30 PM

SESSION 6.1

Workshop: End-of-life

Supporting clients of disability services at end-of-life: A disability service model for implementation

Andrea Grindrod¹, Anna Holliday

¹La Trobe University Palliative Care Unit, ²Li-VE Tasmania

BIOGRAPHY

Andrea Grindrod is the Health Promotion Projects Manager at La Trobe University's Palliative Care Unit. Andrea has over 20 years' experience in public health project management, health promotion policy and practice, and extensive experience in the development of communities to address health and social issues. Andrea applies this expertise in the context of end-of-life by combining research, policy development, advocacy and community practice to produce sustainable changes in the field.

For the last four years, Andrea has been partnering with both welfare and local government to build end-of-life capacity in these sectors, and has developed in partnership with community the 'Healthy End of Life Program (HELP)'; offering, asking for and accepting help', to create collaborative community culture that attends to local end-of-life needs. Her work to improve end-of-life outcomes for people with intellectual disability has produced changes in policy and practice at national, state and organisational level.

Anna has a diverse and extensive background in the disability industry spanning over 20 years. Her roles have included service design and innovation, operational management and delivery of quality services in a range of settings and across government and non-government spheres.

Anna is passionate, energetic and highly committed to strengthening communities to be responsive to the needs and wishes of people with disability as they prepare for, and experience death and/or bereavement. Anna's strong focus on developing and nurturing partnerships and working collaboratively has seen instrumental enhancements within the Tasmania service system for people with disability, their families and those who support them.

ABSTRACT

Aim: There is broad consensus that the end-of-life care for people with disability should be the same as for other citizens. In practice however, additional barriers are encountered making it more difficult to achieve quality care.

A four year study conducted in partnership with the disability sector in Victoria resulted in an evidence-informed organisational model to assist disability services to provide end-of-life support for their clients. The model introduces the organisational, structural and cultural considerations required for systemic and sustainable change in end-of-life practice in disability services.

Purpose: A partnership between researchers at La Trobe University Palliative Care Unit and Li-VE Tasmania proposes to pilot the implementation of this model to develop an organisational kit with national application. The purpose of this workshop is to share evidence, engage and explore with participants the practical considerations of workforce and service requirements within the solution and asset-based organisational model developed through research.

ABSTRACTS

Description of Session Format: This workshop will take participants through a supported journey of exploration and active reflection of the provision of end of life and bereavement care in the disability sector. Varied and short expert presentations from both the palliative care and disability sectors will bring these disciplines together in an integrated and considered manner, guided by models known to improve end-of-life care outcomes for people with disability. Group activities and facilitated discussion will contribute to the development of practice resources in the model.

SESSION 6.2

Health

Our agenda is not the same as the patient's: Emergency doctor and nurse accounts of treating people with cognitive disabilities

Dr Ruth Quibell¹, Professor Christine Bigby¹, Professor Jacinta Douglas¹, Professor Teresa Iacono¹

¹*LiDS, La Trobe University*

BIOGRAPHY

Professor Christine Bigby is the Director of the Living with Disability Research Centre at La Trobe University. She has a strong track record of competitive research grants and publications around issues of programs and practices that support the social inclusion and quality of life of adults with intellectual disability. She is the founding editor of *Research and Practice in Intellectual and Developmental Disabilities* (RAPIDD) and a Fellow of the International Association for the Scientific Study of Intellectual and Developmental Disabilities.

ABSTRACT

Background: People with intellectual disabilities attend hospitals more often than the general population. Recent studies in the UK and Australia reveal that this group not only present with more complex health conditions, but also experience worse health outcomes, including higher mortality rates.

We explored the hospital encounters of participants with cognitive disabilities (intellectual disabilities or acquired brain injury), from admission to discharge. We sought the perspectives of all the people involved — people with cognitive disability, people who support them, hospital staff — through interviews, observations and document review in order to better understand the way clinical treatment and care is delivered in this complicated environment.

Method: We report the findings of a grounded theory analysis of a subset of the data: interviews with doctors and nurses who had cared for a participant with cognitive disability during the study period. Semi-structured interviews about 58 people with cognitive disabilities were conducted with 20 doctors and 42 nurses, drawn from three hospital networks (2 metropolitan, 1 rural).

Results: The analysis revealed: i) doctor and nurse awareness of burdens of the hospital environment for many patients with cognitive disabilities; ii) positive examples of discretionary and ad hoc accommodations; iii) difficulties in navigating their clinical requirements and aligning these with the treatment expectations and agendas of people with cognitive disabilities and/or the people who support them.

Implications: A better understanding of the circumscribed and choreographed nature of the hospital environment sheds light on why doctors and nurses act in the ways they do. The study provides insights into ways that quality of care might be improved by adjusting expectations and responses of both hospital staff and carers of people with cognitive disabilities, and negotiating their differences.

What factors affect the perceived health of adults with intellectual disability?

Dr Allyson Thomson¹, Professor Errol Cocks¹, Dr Stian Thoresen¹

¹*Curtin University*

BIOGRAPHY

Allyson has worked in the field of intellectual disability research for some years. Her main interests are individualised services and programmes, and health issues for people with intellectual disability.

Allyson works towards achieving an inclusive society for all people through a combination of research and practical volunteer work for Befriend, an inclusive social organisation in Perth.

ABSTRACT

Background: Adults with intellectual disability (ID) experience poorer overall health than the wider population. Identification of personal and demographic characteristics, aspects of support services, and lifestyle factors affecting health status will provide opportunities to improve health outcomes.

Methods: The study was a cross-sectional survey of adults with ID in Western Australia. Interviews were conducted between January and July 2013. Univariate and multivariate analyses were performed using self- or proxy-reported general health as the dependent variable and a range of personal, demographic, lifestyle and service system factors as independent variables.



Results: Fewer than one-quarter of informants (22%) described participant health as Fair, Bad or Very Bad. Poorer perceived health was independently associated with increasing age, undergoing financial hardship, smoking, and living in their own home rather than with family or in a congregate option. Physical exercise was a protective factor and was inversely associated with reported poorer health.

Implications: Subjective health may be improved by attention to the factors identified in this study. This could include closer monitoring of the health of people with ID as they age and if they live in a home of their own. Similarly, targeted programs promoting physical activity and smoking reduction could improve perceived general health for adults with ID. Sufficient financial resources for all people with ID would also support improved health outcomes.

Building Capability in NSW Health Services for People with Intellectual Disability – The Essentials

Tracey Szanto¹

¹*NSW Agency For Clinical Innovation*

BIOGRAPHY

Tracey Szanto is the Manager of the Intellectual Disability Health Network at the Agency of Clinical Innovation, a pillar of NSW Health. Her role includes working with clinicians, consumers and managers to design and promote better healthcare for people with intellectual disability.

ABSTRACT

Background: The NSW Agency for Clinical Innovation (ACI) Intellectual Disability Health Network after extensive consultation with consumers, carers and colleagues across the state, has developed 'Building capability in NSW Health services for people with intellectual disability: The Essentials' which guides and supports health services in the way they deliver quality health services for people with intellectual disability. Key findings from the Network's 2014 survey of NSW Local Health Districts found 42% of LHD Disability Action Plans did not include support for people with ID and 73% provided no staff training in ID awareness.

Method: Through surveys, interviews, a solution design workshop and forums the key drivers for change and a prioritised list of suggested actions were identified against which health services could assess themselves. With support from the resources developed by the Network and others, The Essentials assists health service to decide where to concentrate their efforts for service improvement.

Results: Through using the self – assessment toolkit as a guide, supported by tools and resources, local health services are improving their services and demonstrate alignment with current policy reform.

Implications: The consultation process, the self-assessment toolkit and the tools and resources to support change are changing the way we deliver health services for and with, people with ID in NSW. This change includes using co-design methodology and embedding consumer reported measures. More inclusive health services and better health outcomes are expected from actions across the identified domains of workforce, data, communication and systems.

SESSION 6.3

Health – Mental Health

Social workers' attributions toward individuals with dual diagnosis of intellectual disability and mental illness

Dr Tal Araten-bergman¹, Dr Shirli Werner

¹*La Trobe University*

BIOGRAPHY

Lecture in the Department of Social Work and Social Policy, School of Allied Health, La Trobe University.

Researcher in Living with disability Research center based in the School of Allied Health at La Trobe University.

ABSTRACT

Aim: The present study aimed to explore the applicability of the attribution model to social workers' stigma towards individuals with dual diagnosis of intellectual disability and mental illness. Specifically, the study examined the relations between social workers' attribution of responsibility, causality and dangerousness, emotional responses and behavioural reactions toward clients with dual diagnosis.

Method: 279 Social workers employed in community and health services were asked to report on their professional experience, contact and knowledge of dual diagnosis. In addition, the social workers were presented a vignette followed by a questionnaire measuring their attributions of responsibility, causation and dangerousness, and reported on emotional and behavioural reactions to potential clients diagnosed with dual diagnosis.

ABSTRACTS

Results: Most social workers reported high levels of helping behaviours. The strongest predictor of discriminatory behaviours was the stereotype of dangerousness. Social workers who reported feeling less anger and more pity toward clients with dual diagnosis, tended to report higher levels of helping behaviour. However, contrary to attribution theory, fear and anger did not predict discriminatory behaviours. Furthermore, no association was found between prior contact in professional setting, knowledge of dual diagnosis or specific training to the social workers' professional behaviour.

Conclusion: The results are discussed in relation to the core values of social work and to professional identity.

Mental health and school experiences of individuals with high functioning autism spectrum disorder: Preliminary findings

Belinda Jarman¹, Dr Nadia Ollington¹, Dr Christopher Rayner¹, Professor Kim Beswick¹

¹University Of Tasmania

BIOGRAPHY

Belinda Jarman is a PhD student at the University of Tasmania. Belinda's research aims to find out more about the experiences at school of females' with autism spectrum disorder in order to find new ways to improve those experiences, and to work towards improvements in mental health. Belinda has a close connection to her research as a female with high functioning autism spectrum disorder.

Nadia Ollington is an adjunct lecturer at the University of Tasmania. Nadia's current research focuses on school engagement, and includes work to enhance the inclusion of individuals with a disability. As the parent of a daughter with an intellectual disability, Nadia has a sincere empathy in her approach to teaching and research.

ABSTRACT

Background: School can often be a stressful and anxiety provoking environment for students with high functioning autism spectrum disorder (HFASD) (Humphrey & Lewis, 2008). There has been limited research carried out that focusses specifically on the experiences of females with HFASD at school, and how their experiences compare to their male counterparts. This research aimed to contribute to an understanding of situations at school that may impact the social and emotional wellbeing of females with HFASD.

Method: Parents of children with HFASD aged 7-14 years completed anonymous online surveys, consisting of demographic and open-ended questions. Surveys were analysed from parent responses of 29 females and 9 males.

Results: Six key areas were highlighted by participants. These were: emotional states (sadness, low mood, depression; anxiety, stress, worry; anger, frustration; irritability), Positive and negative situations at school, Positive and negative social relationships at school, loneliness and isolation, restrictive and repetitive patterns of behaviour, and support received in and outside of school. While all parents of children with HFASD identified anxiety, stress, and worry as a problem for their child, only females with HFASD were diagnosed with Generalised Anxiety Disorder (24%).

Implications: Greater support is needed for students with HFASD, particularly in relation to the social aspects of school, and managing hypersensitivity and anxiety. This might be achieved through education to help both teachers and peers to develop an understanding of ASD that leads to positive interactions and a community of support.

Knowing, being or doing? A comparative study on human service professionals' perceptions of quality in day-to-day encounters with clients and students with intellectual disabilities

Associate Professor Jens Ineland¹

¹Department of Education

BIOGRAPHY

Jens's research is about social and institutional conditions in school, social services and society for people with developmental disabilities. Among other things, he has studied how cultural and artistic activities within the welfare state organizations affect integration, identity and influence for people with developmental disabilities.

Together with Martin Molin at Högskola Väst, he has written the book "intellectual disabilities, Development Disorder, Society and Welfare" (Gleerups, 2013) that challenges the social environments in which professionals and people with disabilities meet, such as school, work and employment, living, leisure and health and family life issues.

ABSTRACT

Background. How professionals respond to needs and preferences among clients with intellectual disabilities is commonly viewed as an important aspect of quality in welfare services. But what does it mean to decide, act and behave in a professional manner towards people with intellectual disabilities? This presentation analyse views among professionals from three welfare organizations.

Method. The respondents of the study were 421 human service professionals working with people with intellectual disabilities in three different organisations: schools (n=168), social services (n= 152) and healthcare (n=101). The data is based on an open-ended question within a



larger digital questionnaire: “What characterises quality in professional encounters with people with intellectual disabilities?” Hence, written excerpts were the primary empirical data. In all, 872 excerpts were analysed: 368 from school, 294 from social services and 210 from healthcare. To analyse the data, a content analysis were applied.

Results. Findings revealed that quality in encounters with people with intellectual disabilities were associated with a) personal attributes, b) pertinent knowledge, c) professional actions and d) ideological awareness. Findings also show differences in responses, both quantitatively (frequency) and qualitatively (content), which seem to be associated with organization.

Implications. The results has ethical implications; clients may need to internalise an institutional rule and norm systems to pursue professional relations and activities without conflict. The results also has implication relates to inter-professional collaboration; i.e. abilities to bridge organisational cultures and resolve differences – e.g. norms, values and views on quality in daily work – to meet complex needs while at the same time maintain external legitimacy. The results indicate that organisational context needs to be considered to enhance knowledge on how different categories of professionals view quality and moral worth when working with people with intellectual disabilities.

SESSION 6.4

Round Table: Services – Behaviour Support

Responding to Behaviour Support Needs in a Disability Services Future.

Associate Professor Leanne Dowse¹, Laura Hogan¹, Dr Angela Dew¹, Peter Conway¹, Dr Shoshana Dreyfus¹

¹School of Social Sciences, Faculty of Arts and Social Sciences, UNSW

BIOGRAPHY

Please refer to Keynote section for Associate Professor Leanne Dowse biography

Laura Hogan is an Occupational Therapist (Bachelor of Applied Science), she also holds a Masters of Health Science (Developmental Disability) and a Certificate IV in Training & Assessment. Laura has worked for many years with people with disability across the lifespan with a special interest in supporting adolescents and adults with complex support needs.

Laura is actively involved with a number of peak disability bodies including her role as the Vice President of the Australasian Society for Intellectual Disability (ASID) Board of Directors and a committee member of the NSW Division of ASID Ltd

Dr Angela Dew is a sociologist with 35 years’ experience in the Australian disability sector as a direct service provider, manager and researcher. Angela is currently Senior Research Fellow at the Intellectual Disability Behaviour Support (IDBS) program at the University of New South Wales, Sydney where she is engaged in research related to people with cognitive disability and complex support needs. Informed by her practitioner background, Angela has developed a program of research based on understanding the specific issues faced by people with cognitive disability and a range of complexities including living in rural and remote locations and coming from an Aboriginal background.

ABSTRACT

Background: Up to 40% of people with intellectual disability may exhibit challenging behaviours at some point in their lives and 20% of the same population will have a psychiatric diagnosis. Lack of support for complex challenging behaviour can mean poor quality of life for people with disability, social isolation for families and criminalisation for some individuals. The Intellectual Disability Behaviour Support (IDBS) team at UNSW have conducted a project to identify the challenges to the availability and provision of high quality behaviour support in the disability services’ future in Australia.

Purpose: Findings from the project including practitioner and family experiences will be presented prior to a facilitated roundtable which will engage participants in discussion on the issues, challenges and future directions for behaviour support. Practitioners, researchers, family members, managers, and people with a lived experience are encouraged to participate.

Controversial perspectives: This roundtable seeks to explore key issues in the current context and from a spectrum of perspectives and to understand their implications for policy and practice.

Implications: There is no single profile or diagnosis of a person with intellectual disability and challenging behaviour. Service provision in this area is time consuming, costly and requires specialised skills and experience and the capacity to work in partnership with people and their families. The long term sustainability of high quality services is essential for people with disability and their families and for the broader community. Acknowledging the issues and exploring options is an important part of ensuring this sustainability.

ABSTRACTS

SESSION 6.5

Workshop: Employment

Building the business and economic case for supporting people into paid work

Rob Greig

National Development Team for Inclusion

BIOGRAPHY

Please refer to Keynote section for biography

ABSTRACT

People with intellectual disabilities want to work and yet, according to the latest statistics, the number of people with intellectual disabilities who are known to the health and social care system in England and in paid work is only 6%. Despite the evidence that a person being in work saves money for the taxpayer, public services are cutting employment support and the personalisation policy is having no impact on the numbers in work. Drawing on a major research study by NDTi, this session will look at the cost effectiveness and outcomes of different types of employment support, why public services do not seem to see paid work as a priority and what actions by local services have been shown to increase the numbers of people in paid work.

FRIDAY 10 NOVEMBER 2017

PLENARY SESSION

9.05–9.55 AM

Associate Professor Leanne Dowse¹

¹*University of NSW*

Out of the 'Too Hard Basket': Tackling the critical issues for people with cognitive disability who have complex support needs

BIOGRAPHY

Leanne Dowse is Associate Professor and Chair in Intellectual Disability Behaviour Support at the University of New South Wales. She has been a scholar, practitioner, supporter and ally in the area of cognitive disability for over twenty-five years.

Leanne leads a program of research and teaching aimed at creating and exchanging knowledge to build capacity to support people with cognitive disability and complex support needs. Leanne's work utilises a multidisciplinary approach to investigate social justice issues for people with complex needs and their families and supporters, in particular at the intersections of cognitive disability with psychosocial disability, challenging behaviour, social isolation, early life disadvantage, substance misuse, violence and abuse and contact with the criminal justice system.

She is committed to ensuring that issues for people with cognitive disability and complex support needs remain at the forefront of consideration in reforming and transforming systems of social support.

ABSTRACT

As systems of social care the world over move toward individualisation and market-based provision, some changes long argued for by people with disability and their allies and supporters are being taken up in the principles of reforms such as Australia's National Disability Insurance Scheme. However, as researchers, practitioners and advocates with people with intellectual or cognitive disability, we know from experience, that equitable access to comprehensive and effective supports is far from a level playing field. This is particularly so for people with cognitive disability who have complex support needs, that is, those who experience interconnected disadvantage associated with some or all of multiple domains such as mental health, challenging behaviour, drug and alcohol, trauma, abuse and violence, inter-generational and circumstantial disadvantage, homelessness and incarceration. The complexity of support needs is primarily related to the lack of capacity or willingness of services and the systems underpinning them to accommodate and address these interconnected support needs.



It is this group who arguably have the most to gain from a responsive and effective NDIS, but who at the same time are most at risk of being marginalised in the Scheme precisely because of their interconnected experiences of disability and significant contextual, social, and systemic disadvantage.

This presentation canvasses current knowledge about people with complex support needs in Australia. It will present the argument for understanding complex support needs as not simply additional needs, but rather as qualitatively different, requiring unique and specialist approaches to support, up-to-date estimate of prevalence in the Australian population, and analysis of current challenges in addressing the human rights of this group. With the NDIS hurtling toward full roll out, there are now urgent challenges in ensuring that the scheme's vision to 'maximise independence and social and economic participation' encompasses all people with disability. The paper concludes with suggestions for ways we can collectively work to ensure that tackling issues for people with cognitive disability and complex support needs are elevated from the 'too hard basket' to a central consideration in our shared endeavour for disability equality.

CONCURRENT SESSION 7

10.30 AM–12.00 PM

SESSION 7.1

Participation – Communication and Relationships

Communicating beyond the Boundaries – A case study in Communication Potential

Amy Callaghan¹

¹The Disability Trust

BIOGRAPHY

Amy completed a Bachelor of Applied Science (Speech Pathology) at The University of Sydney. Since graduating in 2011, she has worked in Private Practice, Public Health and NGO sectors with both the adult and paediatric population. She has also worked as a Speech and Language Therapist in England. She is currently working at The Disability Trust with Trusted Clinical Services in NSW. Amy is passionate about providing holistic Speech Pathology intervention and working as a team with the participant and their significant others to achieve meaningful outcomes.

ABSTRACT

Background: Communication and interaction is an area of high need for many individuals with ASD and Intellectual Disability.

Under the National Disability Insurance Scheme, participants have more choice and control around the supports they receive. This includes access to Speech Pathology services which may have otherwise been limited or previously not available at all.

This case study demonstrates the successful implementation of a SGD with a young man with ASD, based on the factors that influence successful implementation of Augmentative and Alternative Communication (AAC). These included organisational practices, support provided to key stakeholders and education provision around key stakeholder's attitudes and perceptions of AAC use in adults with ASD.

Method: A 24-year-old male, with ASD and ID, was trialled with an Accent 1000 SGD with Unity software. The implementation featured collaboration between the group home staff, day program staff and Speech Pathologist. The Goal Attainment Scale (GAS) was used to measure specific outcomes for communication.

Results: Outcome measures, across 6 GAS domains, demonstrated significant gains. The success was highlighted through the male's improved attention and reduced challenging behaviours while using the device.

The successful organisational practices, support provided to key stakeholders, and education around key stakeholder's attitudes and perceptions of AAC use in adults lead to a successful trial implementation of the high tech SGD.

Implications: Implementation strategies were crucial to the successful outcomes, and these factors will be presented to highlight the importance of collaboration between the Speech Pathologist and supporting staff.

Pushing boundaries through story telling

Deborah Espiner¹, Frances Hartnett²

¹University of Auckland, ²Imagine Better

BIOGRAPHY

Deborah Espiner is a Principal Lecturer at the School of Counselling, Human Services and Social Work, University of Auckland, New Zealand. She is Chair of ASID New Zealand Division, Citizen Advocacy Auckland and Circle of Courage Trust and on the Board of a mental health service provider.



pushing the boundaries

ABSTRACTS

Fran Hartnett is a Partners Adviser for Imagine Better. She is Chairperson of Arahura Trust, on the Committee of ASID NZ Division and on the Board of Citizen Advocacy Auckland.

ABSTRACT

Background: Increasingly people with learning disabilities are being encouraged to share their experiences through telling their personal stories. This presentation illustrates how one woman, whose voice had been ignored and unheard for many years, told her story through the making of a documentary illustrating her life.

Method: A phenomenological approach was used to capture and amplify the lived experience of the storyteller, supported by her advocate. Non-directive interviews, archive footage and photos were used to ensure control remained with the storyteller.

Results: The storyteller had a long awaited opportunity to tell her important story. This had been a personal aspiration for thirty years. The documentary was launched at a local theatre attended by over one hundred community members. The storyteller has since been a guest speaker at conferences and training events and has recently featured in local newspapers.

The storyteller has in her own words transformed from a person who was, "a victim of the system" to a woman who now sees herself as an "advocate and spokesperson on behalf of people with disabilities."

Implications: Listening to and acting upon the voice of disabled people will contribute to realising the goals of the United Nation Convention on the Rights of Persons with Disabilities. Listening to and acting upon the voice of disabled people will assist in the development of service provision and support that increases self-direction, choice and control.

Do as I say (not as I do): The UNCRPD and dilemmas for those supporting people with intellectual disability to enjoy their sexuality.

Judith Darragh¹, Fiona Redgrove¹

¹*Flinders University*

BIOGRAPHY

Both Judith and Fiona are PhD candidates with Flinders University researching in the area of intellectual disability. Their research overlaps in the area of rights of people with intellectual disability and the role of parents and disability workers in either upholding their clients' rights, or as gatekeepers who place restrictions and limitations on access to social media and internet sites. Both Judith and Fiona have a particular interest in relationships and sexuality for people with intellectual disability.

ABSTRACT

Aim: This paper will present challenges identified from two research projects focussed on the rights of people with intellectual disability under the United Nations Convention of the Rights of People with Disability and how these rights are supported (or not) in practice.

Method: Both authors' papers used qualitative research methodology which included focus groups and interviews with people with intellectual disability, their parents and their support staff. One paper researched how parents and carers viewed the rights of people with intellectual disability, the other research specifically targeted issues of clients' rights to information and full expression of sexuality.

Results: The UNCRPD upholds the rights of all people with disability to "live in the community, with choices equal to others" (Article 19). This right forms an ethical framework for training of disability support staff. However, the findings from the research into sexual rights for those living with intellectual disability identified significant gatekeeping practices by caregivers who oversaw their son/daughter's or clients' online and social media activities. The potential to deprive clients of their rights to relationships was a finding of concern.

Conclusion: There exists a quandary for carers in balancing support/duty of care while upholding the rights of clients in sexual matters. This research suggests carers are guided more by their sense of duty to protect their clients than to uphold the UNCRPD articles.



SESSION 7.2

Participation – Communication and Relationships

Young people with cognitive disability and complex support needs: Service provider views on supporting transitions

Louisa Smith¹, Associate Professor Leanne Dowse, Kathy Ellem, Philip Mendes, Pam Snow, Susan Baidawi, Nirosha Boaden

¹University of New South Wales, Sydney

BIOGRAPHY

Louisa's research interests centre on the relationship between experiences of disability and social policy and social change. Her research works across the disciplines of sociology, disability studies and policy studies. Louisa leads the education and training arm of this program, increasing understanding and awareness about intellectual disabilities and complex support needs both in the university and in the service sector. In Louisa's research and teaching she utilises arts-based methods, knowledge translation and universal design to make her work as accessible as possible.

ABSTRACT

Background: For young people (aged 16-25) with cognitive disability and complex support needs, transitioning between services and sectors can be a time of unmet need and service withdrawal.

Method: Focus groups and interviews were conducted with over 70 service providers and frontline workers in Qld, NSW and Vic, from multiple sectors supporting young people with complex support needs. Transcripts from all focus groups and interviews was analysed to identify key themes.

Results: Uncertainty around systemic transitions had a significant impact on the ways in which services and professionals were able to support the transitions of young people with complex support needs. Service providers identified uncertainty around how disability supports could be provided in different sectors (such as education and out of home care) as a key challenge with the roll out of the NDIS. Despite this national policy change around disability on a systemic level providers struggled to identify and articulate how 'disability informed' practice can be developed in mainstream services.

Implications: Overarching policy change and best practice approaches have significant impact on the way workers in the service sectors experience and approach their work with young people with complex support needs. With higher expectations on mainstream services to support people with cognitive disabilities as the NDIS is implemented, a clear understanding of how these supports will be funded and an acceptance of a disability informed approach will be vital

Adults with cognitive disability and complex support needs: Using body mapping to explore the planning experience

Isabella Dillon-Savage¹, Dr Angela Dew¹, Dr Susan Collings¹, Emma Gentle², Associate Professor Leanne Dowse¹

¹University of New South Wales, Sydney, ²The University of Sydney

BIOGRAPHY

Ms Isabella Dillon Savage is a Research Assistant at the Intellectual Disability Behaviour Support Program at UNSW, Sydney. Ms Dillon Savage has a Masters in Development Studies and is currently enrolled in a Masters of Public Health at UNSW. She has worked in the human rights field with both refugees and women experiencing violence.

Ms Emma Gentle is a PhD student at the Centre for Disability Studies, The University of Sydney. Ms Gentle is an arts therapist with a history of working with people with intellectual disability in Australia, the United Kingdom, and Mexico.

ABSTRACT

Background: Many adults with cognitive disability and complex support needs face barriers in planning for the future and are often excluded from research due to difficulties in expressing views. Research was undertaken to develop a resource to support these individuals with planning conversations.

Method: Arts-based research methods can assist people with complex communication needs to express their views and reflect on experiences. Body mapping is a method that involves creating a life-sized outline, populated with images to represent multiple aspects of an individual's experience. The researchers and an art therapist facilitated five body mapping workshops with 5-6 participants in each. Participants worked one-to-one with a researcher to create their body map. A written record of participants' planning experiences and an explanation of the body map images were created. These artefacts were analysed using thematic and visual analysis methods.

ABSTRACTS

Results: Body mapping was found to be a highly effective research method for engaging individuals with cognitive disability and complex support needs. Participants used symbols, colours, materials, words, and placement on the body map to represent various aspects of their planning experiences. The body map outline facilitated the expression of internal experiences (thoughts and feelings), and external influences (support people, resources, and processes).

Implications: Participants reported feeling empowered by creating their body map and displayed self-reflection and insight about the opportunities and barriers they faced in planning. Participants and support staff indicated an intention to incorporate body mapping in future planning activities, suggesting its utility as a research method and planning tool.

Families with complex support needs: parent's actions in supporting their family member with challenging behaviour.

Associate Professor Leanne Dowse¹, Dr Shoshana Dreyfus², Peter Conway¹, Laura Hogan¹

¹University of New South Wales, ²University of Wollongong

BIOGRAPHY

Please refer to Keynote section for Associate Professor Leanne Dowse biography

ABSTRACT

Background: Families who have a member with intellectual disability who has challenging behaviour typically experience great stress, social isolation, poorer health outcomes and higher instances of depression and other mental health issues.

Method: Interviews were conducted with 29 families across Australia to explore experiences of support for their family member and for their family as a whole in the context of managing and responding to their family member's challenging behaviour.

Results: Families identified overall incapacity in the system to provide responsive support for them and their family member. Families commonly reported experiencing personal violence, property damage and social isolation as a result of their family member's challenging behaviour. Families identified a range of skills, capacity and resilience they possess but many noted that in seeking support these are rarely recognised or supported. Instead they experience interventions by 'experts' which have limited capability to address the range of support needs they experience. Peer support models were noted by some families as the most responsive and effective form of support.

Implications: Better understanding the support needs of families who have a member with challenging behaviour has the potential to inform more responsive, cost effective and sustainable system enhancements and service models which include but move beyond specialist clinical intervention for challenging behaviour

Parents with intellectual disability: addressing complex support needs in the child protection system

Dr Angela Dew¹, Julia Wren², Dr Susan Collings¹, Dr Margaret Spencer³, Erin Cooney¹, Associate Professor Leanne Dowse¹

¹University of New South Wales Sydney, ²Intellectual Disability Rights Service, ³The University of Sydney

BIOGRAPHY

Dr Angela Dew is a sociologist with 35 years' experience in the disability sector as a direct service provider, manager and researcher. Angela is currently Senior Research Fellow at the Intellectual Disability Behaviour Support (IDBS) program at UNSW Australia where she is engaged in research related to people with cognitive disability and complex support needs.

Ms Julia Wren is employed by the Intellectual Disability Rights Service as a Case Manager and Advocate supporting parents with intellectual disability in the Parents Project.

ABSTRACT

Background: Parents with intellectual disability are over-represented in child protection matters and have an elevated risk of child removal. NSW is the only state with a specialist disability advocacy service offering free legal and non-legal support to parents with intellectual disability involved in the child protection system. A review of the parents' support model was conducted in 2016.

Method : As part of the review, qualitative methods were used to explore the views of parents and volunteers who support parents involved in child protection proceedings. Interviews with ten parents and focus groups with five volunteers were analysed to identify key themes.

Results : The main theme for both groups was powerlessness in the face of perceived systemic injustice by court and child protection systems that assumed parental incompetence due to intellectual disability. Parents described negative contact with child protection and courts including feeling undermined and confused. Parents did not regard the information they received as accessible and felt misled about the likely outcome. The advocacy and emotional support received from the specialist program helped them to negotiate these systems.



Volunteers viewed the program as critical to giving these parents a chance at achieving a just outcome; however, they were pessimistic about the prospects of parents being reunited with their children. Volunteers were at risk of burnout due to the emotional demands of the work.

Implications: Both groups identified the critical nature of the support provided by the project suggesting a need to enhance the service and replicate it in other jurisdictions.

SESSION 7.3

Health – Mental Health

Barriers and Enablers to Accessing Mental Health Services for People with an Intellectual Disability

Erin Whittle¹, Professor Karen Fisher², Dr Simone Reppermund¹, Professor Julian Trollor¹

¹*Department of Developmental Disability Neuropsychiatry, University of New South Wales,*
²*School of Psychiatry and Social Policy Research Centre, University of New South Wales*

BIOGRAPHY

Erin Whittle, BA (Hons) USyd, MPH UNSW is a research officer and PhD candidate at the Department of Developmental Disability Neuropsychiatry (3DN) within the School of Psychiatry and Social Policy Research Centre (SPRC) at UNSW. Her research interests are gender, disability, qualitative research methods, the social determinants of mental health and wellbeing and health inequities.

ABSTRACT

Background: People with intellectual disability experience poorer mental health outcomes compared to the wider population, and face barriers to accessing appropriate mental health care. The aim of the study was to examine the lived experience of accessing mental health care to identify key barriers and facilitators that impact mental health services access for people with intellectual disability.

Method: A qualitative study using an inclusive design of the lived experience of barriers and enablers to accessing mental health was undertaken. Data were collected from people with intellectual disability, carers and service providers. Consumer engagement and inclusion was a feature of the research process from inception to dissemination. This study formed one arm of a larger study, which represents multi-disciplinary collaboration with key health, disability, and consumer agencies and included analysis of large scale linked datasets and analysis of policy related to mental health service access for people with intellectual disability.

Results: Multiple barriers and enablers were identified at systemic and personal levels, including service availability, service quality, communication and collaboration, and advocacy.

Implications: Findings will provide the evidence base to develop improved access and quality of mental health services for people with intellectual disability. The project emphasises translational outcomes, and the intersection of the linked data and lived experience has a wide range of implications for service design and implementation, including recommendations for improving the capacity of mental health services to meet the needs of people with intellectual disability via collaborative working, relationship building and clinician education

Addressing Persistent Barriers to Mental Health System Support for People with Intellectual Disability: Recommendations of the Community Living Association Mental Health Advocacy Project

Sarah Macdonald¹, Morrie O'Connor¹

¹*Community Living Association, Inc.*

BIOGRAPHY

Sarah holds a Bachelor of Social Work (Hons I) and a Bachelor of Arts from the University of Queensland. She has worked alongside people with intellectual and learning disabilities in direct practice, research and governance roles for the past seventeen years. In 2011 she commenced doctoral research at the University of Queensland on the transition to adult life experiences of young people with intellectual disability exiting out-of-home care.

Sarah is currently undertaking projects at Community Living Association in Nundah, Brisbane on mental health system access by people with intellectual disability and self-advocate led service provider training. Sarah is inspired by hearing the voices of people with an intellectual disability and learning from their personal stories and knowledge.

ABSTRACT

Background: Substantial research demonstrates people with intellectual disability are at increased risk of mental health conditions, however, practice experience shows this population experience persistent barriers to mental health system services and support. Better understanding of the experiences of people with intellectual disability in the mental health system can inform strategies to address ongoing barriers.

ABSTRACTS

Method: The CLA Mental Health Advocacy Project Worker interviewed thirteen service providers, family members and self-advocates and gathered stories of the experiences of people with intellectual disability seeking mental health system services and support. Thematic analysis of case studies developed from interviews was conducted to identify key themes.

Results: Findings highlight persistent barriers to mental health system services and support for people with intellectual disability, including gaps in primary care providers attitudes, skills and knowledge for assessing and responding to mental health issues in people with intellectual disability; marginalisation of individuals, family members and key supporters from assessment and treatment processes; and a lack of responsiveness to intellectual disability in general practice, hospital and community mental health systems and processes.

Implications: Recommendations for improved mental health system responses to people with intellectual disability include, intellectual-disability informed mental health practice training to primary mental health care providers; specialist intellectual disability consultants in primary mental health systems; and mental health system knowledge development for service providers, family members and key supporters.

Do thoughts predict symptoms of anxiety and depression amongst adults with low ability?

Dr. Steve L. Edwards^{1,2}, Professor Henry J. Jackson²

¹Federation University, ²University of Melbourne

BIOGRAPHY

Dr. Steve Edwards is a Senior Lecturer in clinical psychology at Federation University. He has long standing interests in mental health amongst adults with intellectual disability as well as homeless men.

ABSTRACT

Background: The cognitive theories of anxiety and depression originating with Aaron Beck have considerable empirical support and underpin cognitive behavioural therapies (CBT) in the general population. Adults with low ability have typically been excluded from general population theoretical research based on assumptions about how ability effects their capacity to participate. Few studies have tested aspects of cognitive theories in samples with low ability and only one has tested Beck's key concept of cognitive content-specificity for anxiety and depression but ability was not measured or co-varied. Evidence that anxious and depressive thoughts predict symptoms of anxiety and depression would lend support for the use of CBT with this neglected group.

Method: Sixty-eight adults attending support services and unselected for mental health problems were interviewed using Beck's paradigm of the Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI-II) as well as cognitions checklist – depression (CCL-D) and cognitions checklist – anxiety (CCL-A). Receptive language was assessed on the PPVT-4 with standard scores ranging from 20-95 and a mean of 62.25.

Results: Hierarchical regression showed that depressive cognitions were the only predictor of depressive symptoms but ability predicted a greater proportion of anxiety symptoms than anxious cognitions did.

Implications: This is the first study to investigate cognitive content-specificity using Beck's assessment paradigm and to co-vary ability in as sample with ID. The substantial variance in symptoms predicted by depressive cognitions in an unselected sample of adults with low ability adds support for the use of CBT for depression amongst adults with ID

SESSION 7.4

Families

Multidisciplinary pilot service for children with intellectual disabilities: further evaluation survey of parents and carers

Dr Denise Campbell¹, Dr Katrina Zaballa¹, Dr Jacqueline Milne², Dr Julie Johnson³, Laurel Mimmo¹, Gail Tomsic¹, Dr Natalie Ong¹, Dr Natalie Silove¹

¹The Sydney Children's Hospital Network (Westmead), ²School of Public Health and Community Medicine (UNSW), ³Center for Healthcare Studies, Northwestern University

BIOGRAPHY

Denise Campbell is a senior project manager (part time) in the Centre for Kidney Research where she is responsible for supporting volunteer writers in the development, updating and completion of renal guidelines. Since November 2016, Denise has also been working as a project officer (part time) with the Specialist Disability Health Team (Fairfield) which is a pilot service affiliated with the Sydney Children's Hospital Network (Westmead). In this role, she is responsible for supporting the multidisciplinary team in the development of reports for the Ministry of Health (NSW) and conducting and writing up research about the unit's activities.

In 2006, Denise completed her Master of Public Health at the University of Sydney. In 2011, she commenced a PhD at the University of Sydney on the topic 'Preventing infection in incident peritoneal dialysis patients.' In February 2016, Denise submitted her PhD which was awarded in October 2016.



ABSTRACT

Background: To help meet an identified service gap, a pilot Paediatric Assessment Clinic commenced in 2012, funded by the New South Wales (Australia) state government. An evaluation of the service was conducted during 2012-2013. Responses were rated by parents on a 5-point Likert scale from 1 to 5. We have recently repeated the survey of parents/carers.

Method: The parent/carer completed the questionnaire with a researcher in person, following a clinic visit with their child. A printed questionnaire was given to them with a reply paid envelope. The researcher went through the questions with the parent/carer and interpreter, if present, and the completed questionnaire was placed in an envelope and then in a sealed box.

Results: Top concerns to interviewees were their child's physical health, their child's behaviour, and how their child communicates. Questions about communication with the clinical team show that scores of 4 or greater were achieved for 11 of 13 listed outcomes. Overall satisfaction with the clinic was high with a mean score of 4.25. Parents/carers were asked about the usefulness of the different team members and they identified the paediatrician, allied health staff and transition care coordinator as the most important.

Implications: The results identify the most important concerns that parents/carers have about their child and show that they feel they can communicate well with the team. Those using the service are happy with it and identified the team members whom they feel are most valuable. Comparisons with previous survey findings will be presented at the meeting.

Among the Outliers: A socio-legal perspective on the transition to adulthood for people with disability

Michelle King¹

¹*Queensland University of Technology*

BIOGRAPHY

Michelle is a socio-legal researcher with a focus on the operation of law in practice in the regulation of adulthood and disability. She is admitted as a solicitor in Queensland, and is currently working on her doctorate in law. Her research examines the social and legal constructions of the transition to adulthood of young people with severe cognitive impairment. Her step-daughter is now 18 and lives with profound disabilities.

ABSTRACT

Background: Shared societal understandings underlie our legal system, and how our laws and regulations shape what an adult is and what an adult can do. The transition to adulthood is a time where we gradually acquire legal and social rights, obligations and duties. As 'outliers' in our social and legal systems, people with cognitive impairments provide a lens through which to examine how we understand a person as a social and legal construct, and how we deal (or fail to deal) with challenges to that idea of legal 'personhood' raised by people with cognitive disabilities.

Method: This paper gives an overview of several key regulatory systems in Australia that impact the transition to adulthood for those with cognitive impairments. These core regulatory systems inform a discussion of the key markers of 'adulthood' and citizenship in Australia.

Results: The concept of outliers is used to explore how the law frames, reflects and shapes our shared understanding of adulthood, disability, and cognitive impairment. Mapping our core assumptions about adulthood in law provides an essential guide for disability advocacy and reform.

Implications: As we consider adulthood, disability, and the law, we must consider those whose impairments challenge our legal and regulatory systems at their core. This paper provides a preliminary map to inform further research, and suggests the concept of "outlier" as an essential tool in understanding our legal and social constructions.

Innovation in Dual Disability Residential Services – increasing participant's choice and control over their community and home life

Leonie Davey¹, Davo Mann, Kelly McLachlan, Carolyn Connelly

¹*Mind Australia*

BIOGRAPHY

Leonie Davey is the Dual Disability Practice Advisor at Mind Australia Limited (Mind). In addition to a degree in social work and eleven years' of training experience in both tertiary settings and workforce learning and development, Leonie has a graduate diploma in equal opportunity administration, a Vocational Education and Training diploma and has also undertaken extensive training in person centred approaches.

Leonie began working in the Mental Retardation Division of the Health Commission in 1984 during the course of the first closure of a large institution in Victoria. This was a time of great change – the introduction of normalisation and deinstitutionalisation.



Leonie has worked directly with people with a range of disabilities and their families/carers. Leonie's current role involves her providing clinical expertise to Mind's Dual Disability services, ensuring the support provided in these services continues to successfully combine a person centred approach and a recovery oriented framework.

ABSTRACT

Background: Mind has over 18 years experience in the delivery of specialist Dual Disability residential support services, the only service model funded by government of this type. To support the complex needs of individuals with an intellectual disability and mental ill health Mind has successfully combined a person centred approach and a recovery oriented framework.

With the introduction of the NDIS and the NDIA's estimate that nationally 20,000 individuals with DD will be entering the scheme, we have reviewed our model to ensure that participants exercise choice and control over their own lives in the community and in their shared group living environment.

Mind developed an inclusive evaluation approach with consumer participation at its core.

Method: Deakin University recommended an inclusive evaluation approach following a small trial of evaluation tools, giving its primary focus to self-report of residents.

Building on this, Mind developed its own method of evaluation data collection.

All 11 residents engaged in the Mind evaluation process in March 2017. The evaluation tool will be implemented again in 6 and 12 months' time.

Results: The results of the initial Deakin trial demonstrated rating scales were largely ineffective, effective support and questioning techniques were crucial, the use of graphical aids important, and close consideration given to 'who' conducted the interview.

These findings strongly influenced Mind's approach.

The presentation will explore the findings and learning's from these evaluations.

Implications: Community based mental health and disability support providers will benefit from learning about the service model, outcomes of this research and the methodology used.

SESSION 7.5

Publishing Research

JIDD

Dr Jennifer Clegg

University of Nottingham, UK, & La Trobe University, Australia

Please refer to Keynote section for biography

RAPPID

Professor Christine Bigby¹

¹Latrobe University, Living With Disability Research Centre

BIOGRAPHY

Professor Christine Bigby is the Director of the Living with Disability Research Centre at La Trobe University. She has a strong track record of competitive research grants and publications around issues of programs and practices that support the social inclusion and quality of life of adults with intellectual disability. She is the founding editor of Research and Practice in Intellectual and Developmental Disabilities (RAPIDD and a Fellow of the International Association for the Scientific Study of Intellectual and Developmental Disabilities.

Natalie has a First Class Bachelor of Science in Molecular Genetics from King's College, University of London. Natalie is the STM (Science, Technology and Medicine) Publisher at Taylor & Francis, based in the Melbourne office. Natalie oversees the publication of the Australasian STM journals, working closely with global teams, and with ANZ-based editors and societies, and also undertakes outreach and educational programs for Early Career Researchers. Previously, Natalie also worked as Editorial Manager at Oxford University Press in Melbourne, and Map of Medicine and F1000 Medicine in London.



Taylor & Francis

Natalie Davall¹

¹*Taylor & Francis*

BIOGRAPHY

Natalie has a First Class Bachelor of Science in Molecular Genetics from King's College, University of London. Natalie is the STM (Science, Technology and Medicine) Publisher at Taylor & Francis, based in the Melbourne office. Natalie oversees the publication of the Australasian STM journals, working closely with global teams, and with ANZ-based editors and societies, and also undertakes outreach and educational programs for Early Career Researchers. Previously, Natalie also worked as Editorial Manager at Oxford University Press in Melbourne, and Map of Medicine and F1000 Medicine in London.

CONCURRENT SESSION 8

1.00–2.30 PM

SESSION 8.1

Plain English Keynotes

Pathways to self-determination for individuals with intellectual disability

Professor Monica Cuskelly

University of Tasmania

Please refer to Keynote section for biography and abstract

Out Of The 'Too Hard Basket': Tackling the critical issues for people with cognitive disability who have complex support needs

Associate Professor Leanne Dowse

University of NSW

Please refer to Keynote section for biography and abstract

SESSION 8.2

Services – NDIS

Outsider's perspective on NDIS—An observation from China

Jing Li¹, Professor Patricia O'Brian¹, Emeritus Professor Trevor Parmenter¹, Dr. Marie Knox¹

¹*Centre For Disability Studies, The University Of Sydney*

BIOGRAPHY

Jing is a PhD student in the Centre for Disability Studies of the University of Sydney, her research topic is community living for the adults intellectual disabilities in Chinese context.

ABSTRACT

Background: Australia governments from the Federal and state levels have rolled out the National Disability Insurance Scheme (NDIS) from 2013 which has made a significant progress for the persons with intellectual disabilities. However, during the trials and implementation process, some challenges have emerged.

Method: This paper will review the key policy documents, existing literatures and academic discussions to provide some insights about the limitations of the NDIS as a national initiative, from an outsider's perspective.

Results: In particular barriers in the implementation approach in the State of New South Wales will be highlighted. The paper will argue that the NDIS "one fit for all" strategy as a "better" option for eligible disabled persons actually limits their choice finally. As more individual contractors or non-professional staffs work in this areas, the quality of services can become worse without adequate training, professional development and timely monitoring. As the NDIS does not cover the majority of the disabled population in the end this will bring about a bigger gap and inequality on welfare benefits and services among the disability community. The very individualized funding/budget approach will exacerbate the existing fragmented services which in turn will weaken both the disability collectivism and some integrated service/community-based services.

Implication: The paper will conclude with recommendations to remedy the shortcomings outlined based on Chinese philosophies and communitarianism dimensions from the western political sciences tradition, inclusion, meaning of community and belonging will be some key topics in the discussion.

Four years of NDIS: The experiences of two families

Dr Nadia Ollington¹, Lisa Risby², Isabel Duharte, James Minchin

¹University Of Tasmania, ²TasTAFE

BIOGRAPHY

Isabel Duharte and James Minchin are 23 year-olds with a zest for life. They have been participating in the NDIS since its rollout in 2013.

Nadia Ollington, Isabel's mother is a lecturer in education at the University of Tasmania, and Lisa Risby, James' mother is an English Language Support Teacher at TasTAFE.

Lisa is also the President of the Board of Management for the Association for Children with Disability Tasmania, and Nadia Ollington is a board member. Lisa also serves on the Carers Advisory Board and the Autism Advisory Panel.

ABSTRACT

Background: The NDIS was rolled out in July 2013 in Tasmania. Two of its first participants, Isabel and James (now 23) have been accessing services since that time. Isabel and James are both on the autism spectrum, and like many other individuals with intellectual disability, reflect the needs of a large proportion of NDIS participants (Dowse, Weise, Dew, Smith, Collings, & Didi, 2015). The intention of the NDIS was that there would be a significant level of choice for participants and their families in terms of service provision, and also in tailoring supports in relation to individual need, and goals for the future (Brien, 2016). Such choice, however, presents a challenge for young adults such as Isabel and James, who have complex support needs.

Method: This presentation is based on the lived experience of Isabel, James, and their mothers, and discusses the issue of choice for those with complex support needs.

Results: Four key areas for reform are suggested. These are: (a) accountability towards outcomes, (b) employment of skilled professionals in supporting roles (c) access to education, and (d) a stronger connection to individual need.

Implications: The presentation highlights important goals towards meaningful participation in the NDIS and beyond, for individuals with a disability and their carers.

SESSION 8.3

Service – Behaviour Support and Education

Preliminary findings of an investigation of policy for positive behaviour support

Brent Hayward¹

¹Melbourne Graduate School Of Education, University Of Melbourne

BIOGRAPHY

Brent is a registered nurse and credentialed mental health nurse. He has wide experience in disability services in direct support, clinical services, policy and legislation. He is currently the coordinator for school-wide positive behaviour support in the Victorian Department of Education and Training. Brent is also completing his PhD in the Graduate School of Education at the University of Melbourne where he is investigating the the necessary systems-level infrastructure for the implementation of PBS in Victorian disability services.

ABSTRACT

Background: Positive behaviour support (PBS) is widely acknowledged as an evidence-based framework for the provision of disability services, to reduce challenging behaviour and improve individual outcomes. Despite the international application of PBS, little guidance for policy development is available to support its implementation and sustainability. In an era of significant change in disability service provision, and public demands for improved support of people with disabilities, policymakers and researchers would benefit from suggestions to maximise policy and subsequent outcomes for people with disabilities.

Method: Two separate methodologies were adopted: (1) the literature was explored using a conceptual framework of innovation diffusion to understanding the existing nature and scope of PBS policy, and (2) a combined literary approach was used to scrutinise an existing Australian state PBS policy.

Results: Little research exists to guide the development or implementation of PBS policy. The example policy analysed revealed alternative meaning and rhetoric. Initial suggestions for improved policy are provided.

Implications: While PBS continues to exist as policy at all levels of the service system, its application is disadvantaged by poorly written documents and a failure to maximise practices which influence its adoption. Opportunities are highlighted to advance the use of PBS by disability services.



Visual Cognitive Behavioural Intervention: An adaptation of Cognitive Behaviour Therapy for people with intellectual disability and mental health difficulties

Michelle Carney¹, Dr Carol Le Lant¹, Dr Julie McMillan¹

¹Flinders University

BIOGRAPHY

Michelle Carney is a Doctor of Education by Research Student who has undertaken research alongside people with intellectual disability and mental health difficulties to develop and measure a visual Cognitive Behavioural intervention. Michelle has 20 years practice in the Disability Sector coordinating and delivering social inclusion programs and recreational opportunities to people with disability.

Carol is currently an Early Career Researcher and lecturer in special education at Flinders University in the Initial Teacher Education program. Her Doctoral research was in the area of student engagement, with a focus on working with students with intellectual disability requiring specific, explicit strategy teaching in an area of reading. Her research interests are in student engagement, inclusion, differentiating curriculum for students with diverse needs and single case study design.

Julie McMillan

ABSTRACT

Background: Evidence indicates that people with intellectual disability (ID) are at greater risk of developing mental illness (MI) than the general population. The impact of MI has significant costs for individuals, their families and the community. Currently, pharmacological treatment is the primary intervention used for adults with the dual disability (DD) of ID and MI. To date, there has been limited research on the use of Cognitive Behaviour Therapy (CBT) for people with DD. Researchers have suggested adapted versions of CBT combining visual material with cognitive behavioural treatment may be an appropriate approach (Taylor, Lindsay and Willner, 2008).

Method: This study utilised a multiple baseline, single-case experimental design to investigate whether five adults with ID could (a) increase their self-management to (b) decrease their mental health difficulties using a visual CBT system.

Results: Results demonstrated that visually adapted CBT can be effective for some people with DD. Randomisation tests indicated the overall result for participants was not statistically significant for reduction of mental health difficulty ($p=0.76$ providing a rank of 544 out of 720) or for self-management ($p=0.45$ providing a rank of 327 out of 720).

However, clinical significance of the overall intervention was determined by calculation of a large effect size of $d=0.72$ for reduction of mental health difficulty and an overall medium non-overlap of all pairs effect size of 0.34 for self-management.

Implications: Several factors were implicated in these findings and will be discussed in the presentation including: frequency of use, functional level of disability, capacity and readiness, and commitment to the intervention.

It's not all child's play – virtual reality as learning and training

Stewart Koplick¹, Chris Beaumont¹

¹Endeavour Foundation

BIOGRAPHY

Stewart currently works within the field of education and disability, managing the development and delivery of education programs for people with a disability and has recently been appointed as one of two Service Implementation Specialists at Endeavour Foundation.

Stewart has taught in public and private schools, worked in child protection and lectured at university in the field of education.

He has spoken at state, national and international conferences in areas relating to child protection, identity, masculinity, post secondary education and disability, and more recently the impact of technologies for people with disability attending post-secondary education.

Stewart's latest foray into the world of technology and education is in the research and development of Virtual Learning Environments. Working closely with colleagues and research institutes, Stewart is attempting to make real learning opportunities for people with a disability in the virtual space.

Stewart is also an Advance Queensland Community Digital Champion.

Chris fulfills the role of Service Design and Implementation Partner at Endeavour Foundation. With a focus on utilising technology to support people with a disability – in particular, virtual, augmented and mixed reality – Chris, together with people attending Endeavour services and external software developers, co-designs scenarios that support people to learn various life skills within safe and familiar environments.

ABSTRACTS

Having spent the last 20 years working in the disability sector, Chris applies human centred design principles to his work and enjoys tackling the big issues. He has a young family made up of boys and is inspired by what current and future technological trends and devices can bring to families and in particular young people.

ABSTRACT

Background: The internet, smart devices and computer games such as Second Life and Minecraft have long held the fascination of people, offering potentially unique learning and development opportunities. The next step, particularly in the gaming evolution is within the domain of virtual reality (VR), including augmented reality and mixed reality. Already used in the fields of mental health, rehabilitation and armed services, the possibilities of VR in supporting people with a disability through gamification in areas relating to public transport, life skills and employability skills is just starting to be explored. This paper presents research and prototypes developed in collaboration with Endeavour Foundation customers, staff and Queensland University of Technology, including accessing public transport and training of safe work practices within Australian Disability Enterprises.

Method: VR learning scenarios and prototypes have been co-designed with people with a disability utilising hardware such as Oculus Rift and Samsung Gear, complemented with curriculum development and upskilling of staff.

Results: Observations regarding engagement with these prototypes suggest emerging pedagogies relating to safe work practices; identification and awareness of public signs and symbols at public transport facilities; increased dialogue between user and facilitator and motivation to engage in the learning process.

Implications: The presentation will note the challenges of innovating in a space that traditionally views technology as back end systems used for reporting and data collection, and how being agile and responsive is critically important when developing new service delivery models.

SESSION 8.4

Workshop: Rights – Supported Decision-Making

Pushing the Boundaries of Supported Decision Making: An Interactive Session Exploring Dilemmas of Practice

Michelle Browning¹

¹*Michelle Browning Consulting*

BIOGRAPHY

Michelle Browning is nearing completion of her doctorate at La Trobe University which focused on developing an understanding of supported decision making in British Columbia, Canada. As a consultant Michelle works with organisations and individuals wanting to improve their knowledge of and skills in supported decision making. Michelle is based in Melbourne, Australia.

ABSTRACT

Aims: This workshop will bring together conference delegates who are involved in supported decision making both decision makers and supporters. The aim of the session is to explore some dilemmas delegates experience when they engage in supported decision making. It will use case studies to facilitate discussion on two dilemmas identified in current research: managing risks and balancing relational closeness and neutrality. The workshop will provide an opportunity for delegates to think about their practice in more detail and share helpful insights with each other.

Description of Session Format: The 90 minute session will commence with a video illustrating what supported decision making is in practice. Delegates will be asked to consider the problems and dilemmas they face when engaging in practice. These will be listed on a whiteboard and grouped according to similarities. Two dilemmas from the research will be presented to the group to explore in detail. Workshop delegates will be divided into smaller groups to focus on one dilemma. Groups will be asked to reflect on a series of scenarios related to the dilemma and discuss with each other how they might go about resolving the issues involved. Groups will be encouraged to 'push the boundaries of their responses' to align with the human rights principles at the heart of supported decision making practice.

The session will conclude with a summary of practical strategies that each group identifies to address both dilemmas.



SESSION 8.5

Participation – Civic and Political

Impact on identity and every-day life – People with intellectual disability and self-advocacy in Sweden

Professor Magnus Tideman¹

¹*La Trobe University, ²Halmstad University*

BIOGRAPHY

Professor of Social Work at La Trobe University, Australia and Professor of Disability studies at Halmstad University, Sweden

ABSTRACT

Background; Self-determination and the ability to express opinions and preferences are fundamental to all people. Some people with intellectual disability no longer accept a subordinated role as disabled and new self-advocacy groups have evolved. The aim of this study was to analyse the meaning and importance of engagement in a self-advocacy group for self-advocates daily life and identity.

Method: An interpretative abductive approach was used to analyse data from interviews with 26 self-advocates from six self-advocacy groups in Sweden in relation to the theoretical concepts; recognition, social capital, culture capital and self-determination.

Results: The key finding is that the vast majority of the participants experienced a changed self-perception, as more skilled, social and confident people, depending on group affiliation, their personal engagement and positions within the group.

Implications: The conclusion is that self-advocacy is important for daily life and identity of people with intellectual disability. The self-organized movements indicate an important change in society and the results are of importance not only for the target group but for shaping future support and treatment from society of people with intellectual disability.

Dear Community, are you ready?

Carolyn Stobbs¹

¹*IHC NZ Ltd*

BIOGRAPHY

Carolyn's background is in adult education and she enjoys creating a fun and interesting place to learn. She has developed and is leading a work programme which is working across different areas of community to support people to recognize and respond to the human rights of people with intellectual disability.

ABSTRACT

Background: The Community Advocacy Programme helps communities to better recognise and respond to the human rights of people with intellectual disability. We work to enable people to have a say in their lives, to be supported to be active and valued citizens in their community. Our work raises awareness of the UNCRPD and the importance of making rights real in everyday life. In this work, we hear about the significant barriers people experience in having their human rights recognized and responded to.

Method: Drawing on IHC's contributions to 2014 Inclusion International's Right to Decide Campaign we developed and delivered workshops and learning material focused on supported decision making. We continue to gather information from people to inform our work priorities to make human rights real in people's lives. Our work is evaluated by the people we work with and for.

Results: Formal evaluation and feedback helps us to develop our work. Feedback shows that the human rights approach which underpins our work has a positive impact on the way in which people are understood, valued and supported. We are implementing more detailed analysis and developing new methods to understand the impact of this work in people's lives in communities.

Implications: We will share the goals and outcomes developed to build knowledge and confidence. Our hope is that this approach will trigger and influence responses by other organisations to increase the recognition of and response to the human rights of people with intellectual disability.

ABSTRACTS

Strategies to Support People with Intellectual Disability to Participate in Voting: Results of a Survey

**Sophia Tipping¹, Professor Christine Bigby¹,
Dr Emma Bould¹**

**¹Living With Disability Research Centre, La Trobe
University**

BIOGRAPHY

Sophia Tipping is a Research Associate at the Living with Disability Research Centre with a background in social worker, advocacy and community development. Her research interests center on citizenship, democracy and people with intellectual disability in Australia. She is in the process of completing a PhD.

ABSTRACT

By Sophia Tipping, Christine Bigby & Emma Bould

Background: The right of people with intellectual disability to political participation through voting has been enshrined in the UNCRPD. However, there is scarce empirical research to guide practice to make this a reality, particularly in the Australian context. As part of a broader action research partnership with the Victorian Electoral Commission and Inclusion Melbourne, the aim of this study was to identify factors that hinder and enable voting by citizens with intellectual disability and determine strategies to increase voter participation for this group.

Method: A mixed-methods survey of family members and workers across various organisations was conducted. Quantitative data were collected on experience supporting people with intellectual disability to vote, attitudes to voting for people with intellectual disability and barriers and enabling factors. Open-ended responses were thematically analysed.

Results: Preliminary results indicate that few staff or organisations have supported people with intellectual disability to vote. Attitudes from some respondents are at odds with current human rights discourses. Access to, and support to understand, appropriate information related to various elements of the voting process and political issues was a key enabling factor.

Implications: Increased support from service providers and social networks are required to ensure meaningful voter participation for this group. Strategies to address this problem across the various sectors, including political players, service providers and advocacy organisations are discussed.

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EASY ENGLISH PROGRAM SPONSOR

Access Easy English

Access Easy English is available nationally to provide quality Easy English training, consultation and document development. Access Easy English will assist organisations to become more accessible and more inclusive by developing written information that better meets the needs of the 44% of the adult Australian population who do not have the literacy skills to manage a range of day to day reading tasks.

<http://accesseasyenglish.com.au/>





Able Australia

Able Australia is a leading not-for-profit organisation, supporting people living with multiple disabilities, including deaf, blindness and those in need of community support. From its humble beginnings in 1967, Able Australia has grown into a diverse and dynamic organisation and today supports more than 4000 people around the country.

www.ableaustralia.org.au



Centre for Disability Studies (CDS)

The Centre for Disability Studies (CDS) is a non-profit organisation, affiliated with the University of Sydney and has been in operation since 1997. Our vision is Building Capacity for Change.

The Centre for Disability Studies offers:

- Research, evaluation and consultancy
- A range of inclusive projects
- Professional development and training
- Clinical services

Our work is guided by the lived experience of people with disability, and we strive to meaningfully engage people with disability in the creation, development and execution of all our programs.

www.cds.org.au

CDS

Centre for

Disability

Studies

ClubMates Travel

ClubMates Travel are the Global leaders in Fully supported holidays and vacations for people with a disability. National or international, individual or group travel the experienced and knowledgeable people at ClubMates realise the importance of good quality care and support to allow our members a holiday of their dreams.

ClubMates Travel are the Global leaders in Fully supported holidays and vacations for people with a disabilities allowing our members a holiday of their dreams.

www.clubmatestravel.com



ClubMates
TRAVEL



EXHIBITORS

Flinders University

The mission of the Disability and Community Inclusion Unit at Flinders University is to educate human service professionals to facilitate, advocate and support the quality of life, community inclusion and self-determination of all people living with disabilities and their families.

Flinders University Disability programs include the Bachelor of Disability and Developmental Education, Honours program in Disability and Developmental Education, Graduate Certificate in Disability Studies, Master of Disability, Policy & Practice and PhD in Disability Studies. All programs are available internally and online.

www.flinders.edu.au



National Disability Services

The Centre for Applied Disability Research is an initiative of National Disability Services, the peak body for disability service providers in Australia. CADR seeks to improve the wellbeing of Australians with disability by gathering insights, building understanding and sharing knowledge.

Our applied research agenda is helping to build the evidence base and support stakeholders to better understand what works, for whom, under what circumstances and at what cost.

www.nds.org.au



NSW Council for Intellectual Disabilities

NSW CID is a change-movement driven by people with intellectual disability. Our vision is a community where all people are valued and heard.

We are experts in:

- Easy Read and accessible information translations
- Inclusive research
- Inclusion audits
- Inclusive service design

www.NSWcid.org.au



EXHIBITORS



ShowMe Images

ShowMe Images are a great resource for anyone who needs to communicate clearly with children. They are an especially useful tool for communicating more effectively with children who need visual supports, have special needs, have intellectual disability, are on the autism spectrum or speak English as an additional language.

Let us show you how easy ShowMe images are to use and how you can use ShowMe Images to create your own resources.

www.showmeimages.com



The Information Access Group

We make documents easy to read and websites easy to use. We work with government, community and disability organisations to help them communicate more effectively.

One of our specialities is Easy Read – a great tool for communicating with people with intellectual disability. When you use pictures to explain key concepts, the text is easier for people to understand. Come and find out about the work that we do and how your organisation can benefit.

www.informationaccessgroup.com



Independence Australia

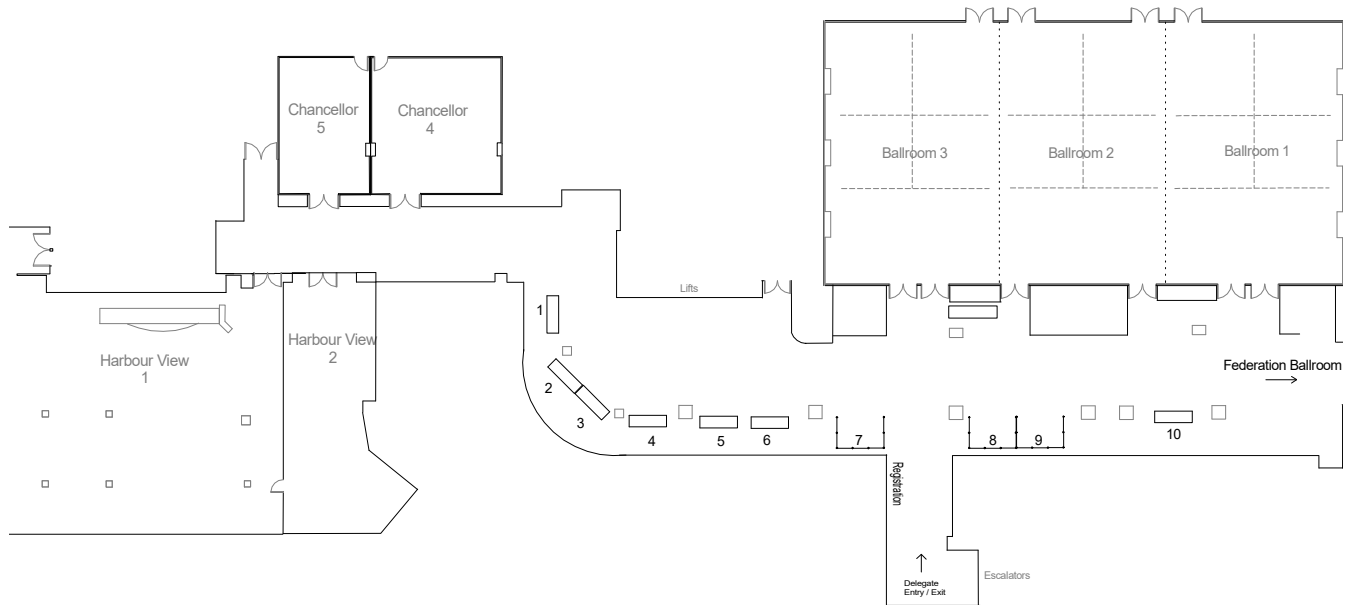
Independence Australia is a social enterprise that provides choices for people living with a disability or other personal need, supporting them to regain and retain their independence.

We stock over 12,000 products across all the major brands and offer expert advice to ensure you have the best products to meet your needs. Our extensive range includes: continence and urology, wound and skin care, nutrition, medical consumables, general supplies, and mobility aids.

www.independenceaustralia.com



EXHIBITOR FLOOR PLAN



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TOGETHER
WE CAN
ACHIEVE
YOUR GOALS

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