

ASID WEBINAR SCHEDULE

JUNE 2020 – FEBRUARY 2021

3 June, WA soundbite

Experiences and Perceptions of NDIS Planning

Prof Angus Buchanan - a.buchanan@curtin.edu.au

The National Disability Insurance Scheme (NDIS) is attempting to address long term inequalities experienced by people with disabilities. Through planning, the NDIS aims for people with disability to exercise choice and control over supports. People with intellectual disability will be the largest group of NDIS participants. It is important to understand how they experience and perceive NDIS planning.

10 June, WA soundbite

Improving mental health in Children with ID

Associate Prof Jenny Downs - Jenny Downs - Jenny.Downs@telethonkids.org.au

Background

Mental health is at the centre of your health. Symptomology is generally elevated in approximately 30-50% of children with disability. This presentation summarises the findings of three systematic reviews aimed to estimate the prevalence of psychiatric conditions and symptoms in children and adolescents with cerebral palsy, intellectual disability or those who have a genetically caused disorder associated with intellectual disability.

Method

MEDLINE and PsycINFO databases were searched systematically. Eight papers described prevalence in children cerebral palsy; 19 papers described prevalence papers in children with intellectual disability; and 40 studies were included in the final pool across 10 syndromes, including five that were predominant: Down syndrome, 22q11.2 deletion syndrome, Fragile X syndrome, Williams syndrome and Prader-Willi syndrome. The Strengths and Difficulties Questionnaire, the Child Behavior Checklist and the Developmental Behaviour Checklist were commonly used assessment tools for mental health symptoms. Meta-analysis was conducted to derive pooled prevalence of psychiatric diagnoses and mental health symptoms in each study.

Results

The prevalence of elevated mental health symptomology was approximately 28-35% in cerebral palsy in cerebral palsy and 38-49% in intellectual disability. Differential vulnerability for psychiatric disorders across genetically caused syndromes was observed. The pooled prevalence with total scores above the clinical threshold on the Child Behavior Checklist was lowest for Down syndrome (32% [95% CI, 19%-44%]) and highest for Prader-Willi syndrome (71%). There was a parallel trend for the social subscale scores, suggesting that creating socially supportive environments could improve mental health in children with neurogenetically caused intellectual disability.

Discussion

Better estimation of the prevalence and nature of psychiatric problems can inform anticipatory guidance and planning for the provision of appropriate resources and services. These high prevalence data suggest that multi-pronged efforts such as strengthening social and family supports, as well as non-specialist and specialised services would be important.

17 June, WA soundbite

Participation in a circus program for teenagers with ID

Nada Murphy - Nada.Murphy@telethonkids.org.au

Meaningful social and community participation includes having fun, experiencing success, belonging and learning. The “Experience Collider” program continued over 18 months and involved the combined efforts of Circus WA and DADAA Ltd, the peak body of arts for persons with disability in Western Australia. It supported teenagers with multiple support needs to participate in workshops developing to a final performance in a professional theatre space. This study evaluated the participation of the teenagers with multiple support needs within a quality of life framework.

24 June, WA soundbite

Ageing parent carers and future planning

Wendy Simpson - wendydean3@bigpond.com

Australian research has found that there is an increasing number of ageing parent carers continuing to provide care for their adult child with intellectual disability at home. Since the late 1980s, when institutions began closing, many families made the choice to provide care at home, which may become a concern when they age and ask the question “who will care when I am gone?” The purpose of this study was to explore the reasons behind the decision families made, what barriers they experienced, and what plans they had in place for future accommodation for their adult child with intellectual disability.

1 July, WA soundbite

Using Photovoice and Talking Mats to hear from people with intellectual disability

Dr Allyson Thomson - allythom2@gmail.com

Background

One aspect of community participation that is consistently difficult for people with intellectual disability is accessing community activities. People with intellectual disability may face different obstacles to participation than people with physical and sensory impairments. These may include slow processing and reaction time, difficulty understanding complex systems, and low literacy rates. The aim of this pilot study was to identify and explore, using a combination of two visual communication methods, issues related to accessibility of community activities.

Method

The study used two visual communication methods: Photovoice and Talking Mats.

Each volunteer carried out two photographic assignments: (1) to photograph community activities they like to do and (2) to photograph community activities they find hard to do. To explore the meanings represented within the photos, interviews were conducted using a combination of Photovoice and Talking Mats techniques to guide discussions about barriers and facilitators in each context.

Results

Two adults with ID were recruited to the study. Participants liked several activities in the community including shopping, work, cafes, and the cinema. One participant wanted to do photography, the other spoke of the various types of job she would like to do. Support from family, friends and staff helped them doing these activities, and lack of money and fear stopped them from doing new activities.

Problems encountered included slow recruitment, limited photographs taken during assignments, and insufficient information from interviews. Strategies to address these limitations will be considered before further research is done in this area.

Discussion

Adults with intellectual disability and limited paid or family supports may have trouble completing Photovoice assignments. For such people, allowing the use of their mobile phone for taking photos may be more acceptable.

Talking Mats may be more useful if the question format is co-produced with people with intellectual disability, thus reflecting the capacities and thoughts of the study population.

8 July, WA soundbite

The Quality of Life Inventory – Disability

Associate Prof Jenny Downs - Jenny.Downs@telethonkids.org.au

Background

Children with intellectual disability encounter daily pleasures and challenges beyond those captured in current quality of life measures. This study developed and pilot tested a new parent-report measure for children with intellectual disability, the Quality of Life Inventory–Disability (QI-Disability).

Method

We conducted 77 interviews parents of a 5-18-year-old child with intellectual disability (Down syndrome, Rett syndrome, cerebral palsy or autism spectrum disorder) and identified 50 questionnaire items from the data. These items were administered to 16 parents using cognitive interviewing (“think aloud”) and 41 items were retained for piloting with 253 primary caregivers. Exploratory and confirmatory factor analyses and additional validation studies were conducted. A larger dataset (n=435) was collected to evaluate the relationships between functioning, community participation and quality of life.

Results

Six factors were identified from 32 of the 41 items: physical health, positive emotions, negative emotions, social interaction, leisure and the outdoors, and independence. Compared to Rett syndrome, children with Down syndrome had higher leisure and the outdoors and independence scores, whereas children with autism spectrum disorder had lower social interaction scores. More frequent community participation

was independently associated with better quality of life, adjusting for the child's level of functioning in daily activities.

Discussion

Ongoing consumer feedback shaped the development of QI-Disability. Initial evaluation suggests that QI-Disability is a reliable and valid measure of quality of life across the spectrum of intellectual disability. Better quality of life can be partly explained by more frequent community participation. Ongoing use of QI-Disability for children with intellectual disability will allow clearer identification of support needs and measure responsiveness to interventions.

15 July, Webinar

Issues for people in rural and remote Australia

(see IDA v 42, issue 3 for further details)

Dr Stuart Wark - Laura Hogan - swark5@une.edu.au

It is already known that access to both general and specialist health and community services is often poor for rural residents. This webinar will consider examples of barriers and impediments to effective support options, and discuss what changes may facilitate improvements for individuals with intellectual disability. Examples of proposed future directions for rural areas include implementation of innovative care models, reconceptualization of funding packages (NDIS), and the development of specialist training and support models for families, disability sector workers and general healthcare staff.

15 July, WA soundbite

What does resilience look like for people with intellectual disability?

Dr Allyson Thomson - allythom2@gmail.com

Background

Resilience refers to the action of rebounding after adversity. Although there is little agreement on what elements protect against adversity and promote resilience, many of the factors identified in the literature share commonalities and link together into domains and dimensions. Resilience is a multi-dimensional and dynamic concept involving both personal and environmental factors, and the interactions between them.

Method

Informed by thematic analysis of literature from the last decade, a conceptual framework was constructed to connect in an hierarchical fashion the factors that contribute to resilience. Many elements were identified from a number of scales commonly used to measure resilience. Special attention was paid to papers describing resilience in people with intellectual disability.

Results

The framework identified two dimensions of resilience: psychological well-being or assets; and social and environmental support or resources. The assets were further divided into: ways of thinking; ways of acting; and ways of believing – all domains associated with the personal characteristics of the individual. Resources were: support from individuals and individual interactions; community support; and political support.

Discussion

Many of the factors identified in this framework are difficult for people with intellectual disability to attain or access. This framework can guide future investigations into ways to promote the psychological well-being of people with intellectual disability and to develop community supports. These factors will act to build the capacity for resilience and to better help people with intellectual disability deal with adverse events in their lives.

August

Employment Futures - A forum on employment and people with intellectual disabilities

Dr.Katherine Moore, Elly Desmarchelier/ Jenifur Charne & Craig McAllister - k3.moore@qut.edu.au

This forum was a blend of academic and practical experience. The practical aspect of the forum was provided through examples of how people with an intellectual disability have attempted to open up new employment opportunities for themselves.

The seminar commenced with Dr Katherine Moore – Lecturer, School of Management, QUT Business School speaking to her research article ‘Emerging Trends affecting the Future Employment Opportunities for People with Intellectual Disabilities’ The Case of a Large Retail Organisation.(Katherine received a research award from ASID for this article at ASID National Conference 2019). She presented a case study of a large employer with a history and a policy base of employing people with intellectual disability. She detailed how that policy had been eroded by centralised HR systems which reduced the opportunity for local level managers to determine the potential for person with intellectual disability to be included in workplace. She also identified the push for productivity as a barrier. Kathy identified the need for legal, structural requirements (welfare to work incentives), incentive, moral and value based decision in business (meeting social expectations of employment options for people with a disability) and HR systems (internally legitimised disability employment practices) as the three pillars that needed to be addressed in creating employment opportunities for people with intellectual disability.

Jenifur Charne and Elly Desmarchelier spoke next from a lived experience perspective employed as Queenslanders with Disability Network and QDeNgage consultants. The Network has created a consultancy arm which is providing employment to people with disability. Jenifur and Elly spoke of their consultancy work on the QLD Transport new ticketing machine and made arguments for the inclusion of people with intellectual and other disabilities in the consultation phase of any major project. Examples of this type of work are paramount in shaping the future of inclusive businesses and organisations.

Craig McAllister rounded off the seminar by sharing his employment story after ten years of knockbacks and rejection, He has participated in the creation and growth of Nundah Co-op, and developed his own business He became one of the founding members of NCEC, a workers co-op of people with intellectual disability. He showed a video that he had created as his first production in his new business. The video was a 4-minute pitch for the purpose of advancing a submission from the Co-op to the 2nd round of a funding proposal. They got to the second round and won the grant. Well done, Craig and best wishes in your future business.

11 August, Webinar

Service Provider perspectives on supporting people with intellectual and developmental disability from refugee backgrounds

Presented by Angela Dew, on behalf of the research team: Mariano Coello, Caroline Lenette, Louisa Smith, Ruth Wells, Julia Lappin, Katherine Boydell, Helen Bibby, Mitchell Smith, Shanti Raman, Katina Velkou, Karen Zwi, David Isaac - angela.dew@deakin.edu.au

Background

Over the past few years, 15 million Syrian and Iraqi people fled their homes because of war and human rights violations. In 2015, Australia committed to settle 12,000 of them as humanitarian entrants. Following Australia's 2008 ratification of the United Nations Convention on the Rights of Persons with Disabilities, in 2012 the Government streamlined the health waiver for all humanitarian visa applicants meaning that people with disability were more likely to get a visa. An estimated 1.4% of the 17,555 humanitarian visa recipients in 2015-16 received a health waiver. Despite the health waiver coming into effect in 2012 and anecdotal evidence of increased numbers of people with disability arriving as part of the refugee intake, little is known about the implications of this change for Australian service providers. In part, this is because information about the number and circumstances of refugees with a disability who have resettled here is limited. This webinar described one part of a larger study to explore the impact of resettlement in Australia for Iraqi and Syrian refugees with disability, their families and service providers.

Method

Seven practitioners employed in four South Western Sydney, NSW refugee and health support services were interviewed about their experiences of supporting people with disability from Iraqi and Syrian refugee backgrounds. The practitioners were employed as social workers, nurses, counsellors, early childhood workers, occupational therapists, and paediatricians. The interviews were analysed using thematic analysis and constant comparison.

Results

Analysis identified three themes: (1) Organisations' responses to disability; (2) Cultural understanding of disability; (3) Experiences of the National Disability Insurance Scheme (NDIS). Practitioners described how their refugee support organisations responded to refugees with disability, including intellectual and developmental disability, through a range of service enhancement strategies. These strategies included the establishment of teams of workers with disability expertise to work directly with this group and their family members to increase access and reduce waiting times for disability-specific supports, and hosting support groups for family members run by bi-cultural workers to enhance access to information in people's languages and reduce social isolation. The second theme, included recognition of the varied cultural understandings of intellectual and developmental disability and how this impacted on people's help-seeking behaviours and expectations. The fourth theme related to practitioners' experiences of assisting people to access the NDIS. In particular, issues around lack of access to NDIS information due to language barriers and the limited availability of culturally appropriate support to engage in the planning process and then to connect with services. Finally, practitioners recognised that people with disability from refugee backgrounds require intensive, long-term support which was not always available as part of their NDIS funding.

Implications

This study has important implications for understanding the ways in which organisations support the complex physical/mental health and social needs of people with intellectual and developmental disability from Iraqi and Syrian refugee backgrounds.

26 August, Webinar

Sexuality education and students with intellectual disability: Sexuality education in New South Wales high schools

Professor Iva Strnadová (UNSW Sydney) & Julie Loblinzk (Self Advocacy Sydney and UNSW Sydney) - i.strnadova@unsw.edu.au

Students with intellectual disability often do not receive holistic sexuality education, unlike students without a disability. According to the UN Convention on the Rights of Persons with Disabilities, people with a disability such as adolescent students with an intellectual disability have a right to quality education, with the information provided in an understandable and accessible way. This also applies to sexuality education.

This inclusive study, conducted by the team of academic researchers and a co-researcher with intellectual disability, explored sexuality and sexual identity education for students with intellectual disability in NSW high schools. The researchers spoke to students (n=11), teachers (n=10) and parents (n=9) about their experiences with and perceptions of sexuality education.

The interviews and focus groups were analysed using the inductive content analysis. Data analysis revealed some key issues that need further attention:

- Many teachers had experiences with their students with intellectual disability disclosing sexual abuse and domestic violence.
- Some parents and students highlighted that sexuality education does not always include other than heterosexual identities.
- Students suggested a variety of ways in which lessons can be made more accessible by their teachers (e.g., Easy English resources, use of videos and pictures to explain new concepts, checking for understanding).
- Teachers, parents and students reflected that students do not tend to be involved in developing their Individualised Education Plans.
- Sexuality education is not always incorporated in Individualised Education Plans.

Several recommendations are discussed. These include, for example:

- Incorporating sexuality education-related goals in an Individualised Education Plan (IEP);
- Focusing on students' self-determination, agency, and rights regarding sexuality education (including actively involving the students in developing their IEPs); and
- Providing schools with accessible resources to teach sexuality education.

8 September, Webinar

Enabling hospitals to be more responsive and inclusive to people with intellectual disabilities

Presented by Professor Christine Bigby, with acknowledgements of other members of the research team, Professor Teresa Iacono, Jacinta Douglas and Dr Jo Spong - C.Bigby@latrobe.edu.au

Background

The study concerns the interfaces across mainstream service systems, people with disabilities and their families, and disability service systems. The study aim was to provide evidence about the processes and practices that enable mainstream services such as hospitals to identify and respond to the particular needs of people with disabilities as a matter of course.

Method

The study used mixed methods and was conducted in Victoria across two metropolitan health networks and one rural health network. Sixty primary participants (50 with intellectual disabilities and 10 with traumatic brain injury) were recruited as they commenced a hospital encounter and each stage of their journey through the system was documented. Data about patient's experiences and those accompanying them (predominantly family members and disability support staff) were collected using unstructured non-participant observation (107) and semi structured interviews (93). Similar methods were used to collect data about the perspectives of hospital staff involved with primary participants during their encounter (137).

Results

We identified promising individual ad hoc and systematic processes and practices – Promising Practices – that helped to accommodate the needs of people with cognitive disabilities and facilitate their receipt of high-quality hospital care. These were conceptualised as four inter-related constructs: support, information, collaboration and knowledge that could be used to guide the development of hospital practices to improve the care experiences and health outcomes of people with cognitive disabilities.

This presentation explains each of these constructs and outlines the next translational part of this program of research.

13 October, Webinar

What do disability support organisations believe about Positive Behaviour Support?

Brent Hayward - hayward.brent@gmail.com

Background

Despite the increasing promotion of positive behaviour support (PBS) in intellectual disability services and the NDIS, few studies have considered PBS policy. This webinar described the examination of PBS policies from non-government organisations to uncover policy beliefs about PBS. Policy beliefs are important because policy reflects the beliefs of organisations, which then go on to influence staff behaviour.

Method

The study used a model for understanding policy development called the advocacy coalition framework (ACF). We obtained a variety of online policies from Australian disability service providers and used a method called discourse network analysis (DNA) which is a combination of content analysis and social network analysis. This method helps to code beliefs in written documents, in this case policies. We used a number of algorithms in speciality software to analyse the results.

Results

The results showed that only around half of the beliefs about PBS are shared by service providers. We went on to identify the thirteen dominant beliefs about PBS and created a diagrammatic representation of these. This showed that there is an inherent contradiction in the beliefs about PBS: that the rights and safety of people with disability is promoted, but policy allows, and in most circumstances directs staff how to use restrictive interventions. We believe that many Australian PBS policies have become documents of informal rules for restrictive interventions.

Implications

We have started to examine what may be influencing these beliefs and our preliminary results show that different Australian states and territories and exerting influence through networks of people. These persons are promoting specific interpretations about PBS, leading to variability in policy beliefs.

Thirty years ago, PBS ushered a new philosophy of supports for people with intellectual disability. The original values underpinning PBS have never changed. Robert Koegel said in 2018 that the procedures in PBS need to be positive and so do the outcomes. Our study of Australian PBS policies shows that the former is not represented in these policies. One cannot promote positive behaviour support on one hand and restrictive interventions on the other.

A first step forward is for disability service providers to separate PBS from restrictive interventions. The second step is for disability service providers to define PBS accurately and apply it in an informed way using the paper by Nick Gore and colleagues available here: <https://www.bild.org.uk/wp-content/uploads/2020/01/Definition-and-scope-for-positive-behavioural-support.pdf>. Nick was a keynote presenter at ASID's 2019 Annual Conference. Resources are available on the PBS Academy's website: <http://pbsacademy.org.uk/>

20 October, Webinar

Left out and locked down – the experience of people with disability and their families during COVID-19

Kirsten Deane, Campaign Director at *Every Australian Counts*

October, Webinar

What is fair and reasonable? Norms and strategies guiding the distribution of assets by testators who have an adult child with intellectual disability Legal context

Jill Wilson, Cheryl Tilse, Ben White Linda Rosenman

See Tilse, C., Wilson, J., White, B., Rosenman, L. & Feeney, R. (2015) Having the Last Word? Will making and contestation in Australia. The University of Queensland. <https://espace.library.uq.edu.au/view/UQ:354699>

29 October, Webinar

Mean As

Paul Milner, Senior Researcher, Donald Beasley Institute - brigit.mirfin-veitch@otago.ac.nz

Background

Despite sexuality being central to our humanness, people with a learning disability tell us that they do not have the same opportunities to have relationships or explore their sexuality. Sex and sexuality, they say, can be like the needle in the hay stack. People with a learning disability have also been at the margins of disability research, and as a consequence, have had little chance to speak back to the professional narratives that police their sexual (non)citizenship.

Method

In the Mean As! project, eight story tellers and four emerging researchers with a learning disability worked alongside artists, actors, sound engineers, community sexual health, violence prevention and disability support services as well as academic researchers to create an online library. Their hope was that the combined weight of their storytelling and reading might assist them to realise the right to live and love the same way as other New Zealanders.

In the project, the research team adopted an Individually Responsive Research method, obliging story gatherers to explore the creative possibilities of an “unfixed” method and storytellers the freedom to introduce the tools they felt they needed to tell the story they wanted. As a consequence the library has filled with a tapestry of wildly different and highly personal stories, including pūrākau, deconstructed poetry, a letter written to others who may have been sexually abused, and a couples story that takes the form of a political love song.

Results

Four emerging researchers with a learning disability listened to recorded versions of the stories to create a set of key messages that now sit alongside each of the stories. Those who read the library will be exposed to their ideas and theorising that is the equal of any in the libraries of the academy.

Implications

In the webinar, Paul and Brigit described the work of the storytellers and readers, introduced the Mean As! library and in the process made transparent how 12 New Zealanders with a learning disability answered the presumptions of incapacity that underwrite their exclusion from the interconnected strands of disability research and relational and sexual citizenship.

18 November, Webinar

We can achieve more when we work together as a team: talking about inclusive governance

Robert Strike , Justine O’Neill

CID board member Robert Strike AM and CEO Justine O’Neill explain how inclusion strengthens the vision, unity and focus of a board. We talk about how we make it work at CID and outline practical steps to inclusion.

CID is a disability rights organisation led by people with intellectual disability. For more than 60 years CID has worked in systemic advocacy and on projects with a vision of a community where all people with intellectual disability are valued. Over half of CID’s board are people with intellectual disability.

Robert Strike AM has been on the board of the Council for Intellectual Disability for more than 25 years and has a deep understanding of governance and how important it is to include people with intellectual disability on boards. Robert founded Self Advocacy Sydney, an organisation that offers both advocacy and advocacy training to organisations and individuals. In 2017 and 2018 Robert spoke at the United Nations in New York about how to include people with intellectual disability in events and organisations. Robert received an Order of Australia in 2017 for his services to the community in the area of disability advocacy.

Justine O’Neill is the CEO of Council for Intellectual Disability (CID). Justine is a social worker and has worked in service delivery, advocacy, policy development and management in health, ageing, justice and disability contexts.

10 November, Webinar

Oral health needs of people with intellectual disabilities

Dr. Jo Watson and Richard Zylan - joanne.watson@deakin.edu.au

This webinar is facilitated by members of the Oral Health and Disability Consortium, Nathan Despott, Kerrie Punshon and Jo Watson. The presenters highlight the rights of people with intellectual disability to receive support to achieve good oral health. It introduces and explores the resource, Your Dental Health guide, the result of a collaboration, driven by Inclusion Melbourne, between people with intellectual disability, dentists, doctors, allied health professionals, disability support workers and families. Your Dental Health guide details key components, protocols and recommendations for people with intellectual disability, health professionals and family members relating to oral health and intellectual disability.

8 December, Webinar

Social Skills Project for adults with intellectual disability

Emily Churchill - emily@egspeechpathology.com

Background

Social skills programs offer one way for people to improve their skills and independence over time. There is evidence to suggest that when delivered effectively they can assist people to increase community and workplace participation, enhance social relationships, and support positive mental health. There is a need for programs targeting people with intellectual disability and/or Autism to pursue their social goals and aspirations that can be delivered in the NDIS operating environment and for which there is evidence.

Method

Nine people with an intellectual disability participated in a 26-week pilot social skill program in which social skills (e.g., personal distance, listening positions, interrupting, asking questions, commenting) were taught explicitly. The program was delivered by a speech pathologist, in partnership with a day service, an objective being to upskill direct support staff to deliver the program in future. Families were supported to promote translation of skills to the person's natural environments. Outcomes were measured using surveys and a clinical tool.

Results

Surveys completed by families and staff indicate a positive impact of the pilot program in all areas surveyed, as well as positive change between pre- and post-administration of the Pragmatic Protocol. Practitioner reflections reveal enablers and barriers to the successful delivery of the pilot program.

Implications

The initial evidence highlights that the pilot program can assist people to develop skills for achieving social goals and aspirations. It provides insights into working alongside a person's formal and natural supports to build capacity, delivering group interventions under NDIS, and building simple but effective program evaluation into everyday practice.

Following the pilot, the program has continued and expanded to provide services to a larger cohort of adults for the duration of a year and with an expanded range of skills including tone of voice, voice volume, introductions and ending a conversation. The intake for the program initially doubled but was then reduced during COVID-19 due to a lack of access to technology for online sessions. The program was able to run for the duration of COVID-19 with weekly speech pathology telehealth sessions and remained sustainable working under NDIS.