RURAL & REMOTE AND THE NDIS

COVID – PERSONAL STORY

COVID CHANGING PRACTICES

RURAL AND REMOTE SERVICES

Hilary Johnson

IDA Editor

Welcome to the September edition of IDA Magazine

Our September edition continues the theme of rural and remote with an emphasis on a changing world of service provision. COVID-19 continues to challenge many Australians and New Zealanders with little research completed on the best and safest ways to move forward. The importance of having evidence on which to base practice is highlighted in the editorial of Research and Practice in Intellectual and Developmental Disabilities journal (https://www.tandfonline.com/doi/full/10.1080/23297018.2020.1765847). You might also like to read the guidance provided in the UK (https://doi.org/10.1111/jppi.12352).

Being isolated resonates with our theme of providing rural and remote services and Angela Dew and her team describe some of the challenges in planning for services delivered through the NDIS (Page 5). Sarah Flagstaff discusses the need for appropriately trained therapy assistants, not instead of health professionals but as an additional resource (Page 9). Stuart Wark and Laura Hogan provide a summary of the recent ASID webinar as ASID reaches out remotely to members (Page 11). The increased distance between the service provider and the end user has caused a huge up take in the use of platforms like Zoom in both our work and social life. Monica Wellington reports on the use of Zoom to bring people with intellectual disabilities together and minimise the digital divide (Page 13). Catherine Cataranich contributes a personal insight of being locked down in Victoria with a cry from the heart "there's a piece missing" (Page 16). There has been an expansion of COVID information in accessible formats with the latest planning tools from Queenslanders with Disability Network (Page 17). If you are out there wearing a mask and finding it hard to communicate take a leaf out of Key Word Sign's book and follow Libby Brownlie's advice to use your hands (Page 18).

Don't forget to keep up to date with the latest events and podcasts found on our website (Page 22). If you really want a challenge, go to our Quiz and do it with a colleague at the start of your next Zoom meeting - or if you're not locked down, face-to face over coffee! (Page 23).

We will be continuing the theme of providing remote supports in the December edition with an annual round up of ASID's training and new ideas. We welcome ideas, comments and suggestions. Please contact me.

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PRESIDENT'S REPORT

I would like to start my report with a special call out to the ASID community in Victoria, who are living through the worst outbreak of COVID-19 in Australasia to date. The heartbreaking death toll and continued life under level 3 or 4 restrictions for regional and metro residents retrospectively is simply horrible, our thoughts are with you all.

As I write this report, the news breaks on my phone about new community transmission cases in Sydney and Auckland. I am hopeful that we have learnt from previous mistakes and will manage to prevent another large-scale outbreak in either Australia or Aotearoa New Zealand.

Many within the ASID community have closely watched or contributed witness statements to the recent public hearings on the experiences of people with disability during the ongoing COVID-19 pandemic for the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation or People with Disability. Across the 4 days, witnesses spoke to the broad range of issues and challenges experienced by people with intellectual disability ranging from personal issues such as impact on mental health and the loss of in-person connection with family and friends through to systemic issues associated with staffing, adequate and accurate information and access to resources.

Access to information for people with intellectual disability has been an ongoing challenge across the pandemic. I am aware that many different groups across Australasia have been working on ways of addressing these gaps. In Aotearoa New Zealand, ASID Board Director and Director of the Donald Besley Institute, Dr Brigit Mirfin-Veitch contributed to the development of the clinical guidelines for responding to patients with an intellectual (learning) disability during COVID-19 in Aotearoa New Zealand. Last week, NSW Health in collaboration with NSW Council for Intellectual Disability published a new website for people with disability to access information about COVID-19. Although NSW centric, the site provides important preventative health information and a range of easy read resources.

Over the past few months, I've been proud of how the ASID community through our Divisions has come together to keep information flowing. In addition to our journals, IDA and podcasts, we now have a vibrant schedule of webinars on a range of topics. Thanks to Queensland, NSW, Victoria and Western Australia Divisions for your contributions to the webinar schedule to date. I'm also aware that the Aotearoa New Zealand committee are busy working on webinars to add to the calendar of events.

ASID continues to work through how continue to provide you with platforms to connect, share and learn. We are in the process of scoping a new website and developing an alternative model of annual conferences in response to COVID-19 restrictions. I look forward to sharing more about this with you soon.

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PLANNING FOR A BETTER LIFE IN REGIONAL, RURAL AND REMOTE AREAS UNDER THE NATIONAL DISABILITY INSURANCE SCHEME

ABSTRACT

Person-centred planning is a key NDIS process for identifying goals, supports and funding for people with disabilities. People in regional, rural and remote areas of Australia experience unique service access and service delivery challenges. An Australian Research Council funded project is investigating how planning is occurring for Aboriginal and non-Aboriginal people, including those with intellectual disability, in regional, rural and remote areas of Central Australia and Western NSW.

INTRODUCTION

Is person-centred planning with individualised funding different for people with disability who live in regional, rural and remote Australia compared to those in metropolitan areas? An Australian Research Council funded project involving researchers from The University of Sydney, the University of Canberra, Deakin University, and Centre for Remote Health, Flinders University in the Northern Territory, seeks to answer this question. In this article, we provide background as to why this research is needed and briefly outline what we plan to do.

PERSON-CENTRED PLANNING IN THE NATIONAL DISABILITY INSURANCE SCHEME

The Australian National Disability Insurance Scheme (NDIS) aims to provide people with disability with choice and control over the supports and services they need and want to live an inclusive life. Person-centred planning is a key process for NDIS participants to identify their aspirations and goals, the supports they need to achieve these, and determine the funding they will receive to engage services. Given the importance of planning, we asked ourselves how well the person-centred planning process was working for people living in regional, rural and remote geographic areas, including Aboriginal and Torres Strait Islander people, given additional factors previously identified for this group of Australians with disability. For the one third of NDIS participants who report having an intellectual disability there is evidence that some people lack previous experience of decision making and planning requiring additional time and the support of a highly skilled planner to engage fully in the planning process (Collings, Dew & Dowse, 2018). The need for additional planning support is likely to increase if the person with intellectual disability is living in a regional, rural or remote location.

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SUMMARY

- Person-centred planning is a key NDIS process for identifying goals, supports and funding;
- People in regional, rural and remote areas experience unique service access and delivery challenges;
- Some people with intellectual disability in regional, rural and remote areas lack previous experience of decision making and planning and need additional time and support from highly skilled planners to develop a good plan;
- Some Aboriginal and Torres Strait Islander people with intellectual disability from regional, rural and remote areas may experience lack of cultural understanding from service providers and policy makers;
- This research will examine how planning is occurring for these groups.

The focus of our research project is to understand planning for people with a diverse range of impairments, including those with intellectual disability, living in regional, rural and remote areas of Western New South Wales (NSW) and Central Australia. The NDIS Rural and Remote Strategy 2016-2019 (2016, p. 57) has a goal that "effective, appropriate supports [are] available wherever people live". According to the March 2020 NDIS quarterly report to the Council of Australian Governments (COAG), of the 364,879 current NDIS participants 1.5% (n=5551) live in, or close to, our project region of Central Australia, Barkley, and Western NSW. Data on Aboriginal and Torres Strait Islander participants by region is not publicly available, however the latest report to COAG indicated that this group represented 6.9% of all NSW NDIS participants and half of those in the Northern Territory (National Disability Insurance Agency, March 2020).

CHALLENGES OF SERVICE ACCESS AND DELIVERY IN REGIONAL, RURAL AND REMOTE AREAS

Undoubtedly, all people with disability living in regional, rural and remote Australia have the same rights to receive supports and services as their peers in metropolitan areas; however, previous research conducted by our team highlights service access and service delivery challenges in these geographic areas. Service access challenges include: lack of required services due to "thin markets" where gaps in the market mean people cannot access what they need; limited availability of technology especially internet; high economic and social costs due to the need to travel long distances to access existing services available in larger regional centres or cities; and/or intermittent access to fly-in/fly-out or drive-in/drive-out services resulting in a lack of continuity and follow-through which is particularly important for people with intellectual disability and Aboriginal and Torres Strait Islander people with disability.

People with intellectual disability from Aboriginal and Torres Strait Islander backgrounds, and particularly those from remote communities, experience significant additional barriers associated not only with geographic isolation, but also due to a lack of cultural understanding on the part of planners, service providers and policy makers. Our previous work in very remote communities in Central Australia highlighted the disconnect between the strong desire of Anangu from the NPY Lands to remain living on their Country and perceived pressure for them to relocate to regional centres to access services (Dew et al., 2019). These concerns were also highlighted by family members of children, many of whom had intellectual disability. Families reported feeling that relocation to larger regional centres was necessary to access appropriate education, medical support, and other services not available in their geographically isolated

local communities (Ryall et al., 2019). There is widespread acceptance that moving off Country to access services adversely impacts on the physical, cultural, and emotional health and wellbeing of Aboriginal and Torres Strait Islander people.

Likewise, service providers working in regional, rural and remote geographic areas, including those working with Aboriginal and Torres Strait Islander communities, report specific challenges in *delivering* support. These challenges may include: additional costs associated with transport and accommodation; potentially low client numbers at a given location (contributing to "thin markets"); difficulties organising appropriate staff supervision and support; and high levels of staff turnover. Additionally, at the policy level, the geographic challenges experienced by people with intellectual disability, family members and service providers are rarely acknowledged or planned for.

NDIS PLANNING PROCESS

Early Childhood Early Intervention (ECEI) Coordinators, who work with the families of children with developmental delay up to the age of six years, and Local Area Coordinators (LACs), who work with all other eligible age groups, are employed by non-government organisations to assist people to navigate the NDIS including through the planning process. The National Disability Insurance Agency (NDIA), which administers the NDIS, employs planners who record an individual's person-centred plan goals and make funding recommendations. Concerns have been expressed that some planners lack experience working with people with more complex needs including factors associated with rurality, intellectual disability, Aboriginal and Torres Strait Islander cultural considerations and complex communication needs. Following the NDIA plan approval, ECEIs and LACs work with the family/person to implement their goals within budget, drawing on available supports and services within their local community. As previously stated, this can be difficult to achieve in regional, rural and remote areas where required supports may be lacking. The planning process and workers' roles have changed a number of times since the rollout of the NDIS resulting in lack of clarity and confusion. Additionally, the March 2020 NDIS dashboard report for COAG highlights significant underutilisation of allocated NDIS funds for those living in regional, rural and remote locations compared to the NDIS benchmark. The Northern Territory data indicates only 37% utilisation of the plans for people living in very remote communities and 66% for those in remote communities. Similarly, in NSW 36% of the plans of people from very remote areas and 51% of the plans of those in remote communities were utilised. Overall, for the areas included in our project, only 65% of the funding allocated to plans in Western NSW have been utilised, 46% in Barkley and

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66% in Central Australia (National Disability Insurance Scheme, March 2020). This underutilisation suggests that the plans themselves may not be fit for purpose for people in regional, rural and remote areas.

PROJECT TO UNDERSTAND PLANNING IN REGIONAL, RURAL AND REMOTE AREAS

The authors, who are all members of the research team, have collaborated on a number of other research projects in regional, rural and remote areas of Australia including in very remote Aboriginal communities in Central Australia and Western NSW. In this project, the team is led by Aboriginal academic and lead author, Associate Professor John Gilroy, and includes non-Aboriginal academics (the other authors) who work in partnership with Aboriginal community-controlled organisations using decolonisation principles and culturally appropriate data collection methods (e.g., Yarn Ups).

We will speak with Aboriginal and non-Aboriginal people with disability and their families or guardians, ECEIs, LACs and NDIA Planners. Our aim is to find out, from these different perspectives, how planning is occurring in the two identified areas which encompass regional, rural and remote communities. We will identify the skills, expertise and attitudes of the ECEI, LAC, and NDIA Planner workforce to engage effectively with people with a disability, both Aboriginal and non-Aboriginal from central Australia and north west NSW. As indicated in the evidence described previously, a well-prepared and trained NDIS workforce is essential to ensure that participants in regional, rural and remote areas, both Aboriginal and non-Aboriginal people with disability, and those with intellectual disability, are supported to develop, implement and fully utilise NDIS plans that meet their unique and potentially complex needs. Data collection has been impacted by the COVID-19 pandemic and will commence once social distancing restrictions are lifted.

If you are interested in knowing more about or participating in the project, contact John Gilroy on john.gilroy@sydney.edu.au

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HOW CAN WE ENSURE THAT PEOPLE WITH INTELLECTUAL DISABILITY LIVING IN RURAL AREAS GET ACCESS TO GOOD THERAPEUTIC SUPPORT?

Sarah Wagstaff

Rural and remote areas of Australia experience significant shortages in the provision of disability services. Allied health professionals (AHPs) are hesitant to work in rural areas due to limited resources, lack of career development, difficulty accessing resources, and few networking opportunities (Dew et al., 2016). For people with disability, staff shortages lead to long travel times, long waiting times and limited access to treatment (Dew et al., 2012).

Approaches such as outreach, fly-in fly-out (FIFO) services and teletherapy avoid challenges associated with attracting and retaining staff by situating them in more populated areas and either travelling long distances to deliver face-to-face services or offering services through technology. An alternative model — the hub and spoke model — is typified by staff living in the communities they are servicing ('spokes'), while still supported in administration and professional development opportunities by a regional centre ('hub').

One way of employing a hub and spoke model is to employ Therapy Assistants in rural communities. Therapy Assistants do not need any formal qualifications, so can be sourced from local communities and trained to work under the delegation and supervision of AHPs. Therapy Assistants can carry out programs designed by AHPs but cannot conduct assessments or make clinical judgments and do not replace AHPs. Having locally based Therapy Assistants available in rural communities can complement the outreach, FIFO or teletherapy work of more distantly based AHPs.

Having access to Therapy Assistants residing in the same geographical area as clients can provide many benefits to people with intellectual disability. Therapy Assistants can work with clients in the settings needed to generalise skills. Therapy Assistants can also be trained to create easy-to-read resources to support their clients to understand new concepts. As they are less costly than AHPs, Therapy Assistants are a good option for teaching tasks that require regular practice.

SUMMARY
- There is a shortage of allied health professionals (AHPs) in rural areas
- Therapy Assistants can be used to conduct therapy programs designed by AHPs
- Therapy Assistants can provide skilled, regular, face-to-face support in rural areas. This has a lot of benefits for people with intellectual disability
- Service providers must ensure that Therapy Assistants are adequately trained and supervised
- The Centre for Disability Studies developed a competency framework to ensure their staff have the skills to work as Therapy Assistants

From 2018, the Centre for Disability Studies (CDS) has been delivering Therapy Assistant services to people with disability in rural NSW through a hub and spoke model called 'here 2 enable'. CDS currently has Therapy Assistants based in Bathurst, Cobar, Coonamble and Coonabarabran. This initiative was greatly inspired by the work of the University of Sydney's Wobbly Hub Rural Research Team and supported through funding from the NSW Government's Disability Sector Scale-Up Business Acceleration Grant Program.

here 2 enable team therapy assistants.

While CDS relied on grant funding to establish here 2 enable in 2018, hiring Therapy Assistants through a hub and spoke model has become a more viable option for service providers since the release of the NDIS's 2019-20 Support Catalogue. This release introduced the line item of 'Therapy Assistant- Level 2', who are "…able to work independently without direct supervision at all times" (p. 58, NDIS, 2019). Level 2 Therapy Assistants are now able to charge over 50% more than their Level 1 counterparts that require direct supervision.

One concern with the high rates that Therapy Assistants can now charge is that service providers may be tempted to employ staff under this job title without understanding the training and supervision required to ensure quality support is provided within the Therapy Assistant's scope of practice. While the Certificate IV in Allied Health Assistance provides staff with many skills relevant to the job, it is focused on the skills needed by allied health assistants working under direct supervision in health settings and does not adequately prepare staff for the requirements of working in the disability sector, particularly under remote supervision. CDS addressed this issue by developing a competency framework for Therapy Assistants. The framework is based on a literature review, sector consultation and guidelines released by Allied Health Professional Associations.

The employment of Therapy Assistants under remote supervision provides an exciting opportunity to offer people with intellectual disability living in rural areas the option of regular, face-to-face therapy sessions that would not otherwise be available. While choice (and control) are important facets of NDIS supports, the staff delivering this support must be adequately trained, supervised and always work within their scope of practice. As shown by CDS's experience, developing a competency framework is a good option for ensuring people with intellectual disability living in rural areas receive good support.

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ISSUES FOR PEOPLE WITH INTELLECTUAL DISABILITY IN RURAL AND REMOTE AUSTRALIA

Stuart Wark & Laura Hogan

Another 2020 webinar coordinated by ASID NSW/ACT occurred on the 15th July 2020 and looked at issues for people in rural and remote Australia. This webinar was presented by Laura Hogan from the Centre for Disability Studies an affiliate of Sydney University and Stuart Wark from the School of Rural Medicine at the University of New England in Armidale.

The purpose of this webinar was two-fold. Firstly, it started with Stuart providing an overview of some of the challenges and barriers for rural people with intellectual disability, based on existing research reported in academic mediums including the *Journal of Intellectual and Developmental Disability, Research and Practice in Intellectual and Developmental Disabilities,* and *Intellectual Disability Australasia*. The second and probably more important aspect of the webinar was Laura's illustration, through narratives from practitioners in regional and remote areas, how some of these barriers are being successfully overcome.

At the beginning, participants in the webinar were encouraged to actively consider the following three key questions throughout the discussion:

- To what extent are crucial service systems, such as general and specialist healthcare, readily available in rural areas?
- With fewer services to access in rural communities, will this limit a person's opportunity to exercise meaningful choice and control?
- How important will collaboration between individuals, their families and service provider as the emerging needs become apparent?

The general overview of the research concluded that access to both general and specialist health and community services is often very poor for rural residents when compared to metropolitan peers. Underpinning the problems is that, while the concept of choice is written into legislation, it is only when desired options are actually available, that being able to choose actually make a difference to individuals, their families and friends. The practical questions that arose from this were:

- How do we build the structures in rural areas to support people with intellectual disability more appropriately?
- How do we attract and retain high quality support staff with particular expertise?
- Who provides essential support options if government doesn't, and who should pay for them? For example, is it the responsibility of the individual to spend their limited NDIS package on training for staff?

Laura then provided some examples of proposed future directions for rural areas to address these concerns. These options were suggested in relation to the implementation of innovative care models, the reconceptualisation of funding packages (NDIS), and the development of specialist training and support models for families, disability sector workers and general healthcare staff. A practical example included proactively working with individuals, families, NDIS planners and Local Area Coordinators to align meeting dates. This facilitated services and clinicians to undertake joint visits and see multiple participants in remote communities, thus reducing costs of travel and providing safety. The new Intellectual Disability Health team model in western NSW was also discussed. This specialist resource, situated actually in the area it serves, allowed the collaborative building of capacity of services and families, and provided streamlined and integrated services for people with intellectual disability.

The webinar concluded with some general discussion around the issues and problems facing rural people, and it was agreed that collaboration between existing disability and health providers is going to be essential to facilitate meaningful choice and to supported individualized services whilst also overcoming the complicated issues of distance, lack of transportation, and loss of highly skilled staff.

If you haven't watched this webinar tune in on the ASID website https://www.asid.asn.au/publications/webinars.

SEXUAL LIVES & RESPECTFUL RELATIONSHIPS: WORKING VIRTUALLY

Monica Wellington

ABSTRACT

Whilst physically held apart by a global pandemic, the Sexual Lives & Respectful Relationships network (SL&RR) continued to seek connection and professional learning. Bringing innovation and creativity to the fore allowed the third annual SL&RR conference to forge ahead, virtually! We share our ideas for hosting your own successful virtual event.

SUMMARY

- Consider virtual events as a way of continuing your work during COVID-19 restrictions.
- Virtual events can help people come together without the challenges and added cost of travel.
- Training and support are important for access and confidence using technology.
- Plan and record key presentations in advance. This can be a good way to work with experts and presenters who live in different time zones.

PREPARING FOR OUR FIRST ONLINE CONFERENCE

Sexual Lives & Respectful Relationships (SL&RR) is a peer education network focussed on the relationship rights of people with intellectual disabilities, in the School of Health and Social Development at Deakin University. It is a peer led sexuality and relationships program run by people with intellectual disabilities and community professionals who are trained and supported by the SL&RR team at Deakin.

2020 was to mark the third consecutive national Sexual Lives & Respectful Relationships (SL&RR) conference, a place to gather and learn more about training others on sexuality rights. We held our first very successful conference at Deakin Downtown in Melbourne in 2018, followed by 2019, and we were keen to continue the exchange of ideas this year. However, the new decade has brought so many unimaginable challenges, including to the ways in which we could continue professional development.

Despite the global pandemic preventing us from meeting face-to face, the SL&RR network of Peer Educators and Program Partners continued to seek connection with the program and with each other. To foster inclusion and ensure that SL&RR would withstand the widespread effects of the COVID-19 pandemic, we chose to continue the annual SL&RR conference virtually.

We were unsure if an online conference might pose unexpected challenges for our core audience – people with intellectual disabilities who are often perceived to be on the margins of the digital divide. However we were surprised to realise that going online has possibly improved access for much of the network, which spans from Gippsland in Victoria to Sydney and the Blue Mountains in NSW. Importantly, the group the changed circumstances as an opportunity to connect with each other digitally and to support people to use technology to make and maintain relationships.

Thirty people attended the online conference, including14 people with intellectual disabilities, some using Zoom for the first time. Zoom worked really well, thanks to the behind-the-scenes work of SL&RR team member Monica Wellington who, with careful planning, supported attendees to plan their access to Zoom and to run through the processes, meaning that everyone felt confident using the technology on the day.

On the day of the conference, some attendees chose to log into the Zoom meeting up to 30 minutes before the start time. This meant they gained confidence and allowed the team enough time to trouble shoot any connection issues. Having two conference facilitators available during this log in time also meant that one person could welcome attendees and another could virtually assist people to connect.

THE SL&RR VIRTUAL CONFERENCE

The conference included a keynote address by Dr Claire Bates from the UK relationship rights movement, Supported Loving. Dr Bates prepared a pre-recorded presentation about her research and the work of Supporting Loving. A Question & Answer type discussion followed, proving to be just as effective on the virtual platform as it would have been in person. We were really motivated by Claire's work in supporting the sexuality and relationship rights of people with intellectual disabilities in the UK and the synergy with our own work in Australia.

We concluded the conference with the presentation of the Janice Slattery Award for an SL&RR Peer Educator or Program Partner who has made an outstanding contribution to their SL&RR site. With a record number of nominations this year and Janice Slattery herself in attendance to make the presentation, the award went to Rachael Walters from SL&RR in Gippsland. Rachael is a Peer Educator who has been involved in the Gippsland network since they commenced their work with SL&RR over 10 years ago.

Rachael's colleague Alisha said in her nomination:

"Rachael is a role model and an educator for people with and without disabilities. For meetings or program delivery, and whether the session be near or far, Rachael is always on time (or early), always prepared, always focused and committed to her work, and to contributing to a safer and more inclusive world for people with disability."

A deserving recipient – congratulations Rachael!

WHAT'S NEXT FOR SL&RR?

Technology is interwoven into our lives more than ever before. Since the event, members have expressed appreciation for their new found skills, including how important strong technology skills are for social connection and for success in their work places.

Although we are looking forward to seeing each other face to face again in the future, we have received many requests for more digital forums, where our network can connect with their peers, colleagues, domestic and international specialists, and the Deakin SL&RR research team from the comfort of their own homes.

In this network, people with disability hold the space regarding sexuality rights for their own lives. Like a lot of other advocacy movements in Australia, the current requirement for physical distancing has not halted our agenda or discontinued our social connections. With the end of this pandemic far beyond the horizon, we encourage you to consider connecting and working on virtual platforms as a productive and valid option.

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TIPS FOR VIRTUAL EVENTS FROM THE SL&RR TEAM

- Online events can support social connectedness, as do in-person events.
- Online events can improve access for people living regionally who find it challenging to travel to inner urban venues.
- Use PowerPoint slides and pre-recorded presentations. These can be a good way to connect with presenters who live in different time zones.
- Offer training and support in preparation for an event. This can help people feel confident with using technology and can help to build skills that are useful for other settings.
- Offer all communications in plain English to suit a range of audiences.
- Using zoom on a laptop can be the most convenient format, rather than an IPad or phone. A laptop can run on Wi-Fi (to save on phone data) and is a more hands-free approach.
- It's important to have the zoom phone number on standby for an optional backup connection.
- Offer the opportunity to connect to the meeting in advance. This can help people feel comfortable that they have enough time to troubleshoot any connection issues.
- It is a good idea to share passwords or remove passwords for easy access.
- Encourage people to mute their microphone during presentations to avoid background noise.
- Investing in support and training can help to build skills for future events of a similar kind.

THERE'S A PIECE MISSING: LIFE IN LOCKDOWN

I hear my sister, Catherine's voice, on the other end of the phone… "There's a piece missing". Catherine is referring to the 15th jigsaw puzzle she has done since March. Jigsaw puzzling is a new hobby she has taken up since lockdown. "I'm doing one with flowers".

The jigsaw piece is not the only element currently missing in Catherine's life. Catherine lives alone in Melbourne. "I wish someone could come and have a cup of coffee with me". Living in lockdown during a pandemic is difficult for anyone. However, when you live alone with an intellectual disability, reliant on family and services for support and social contact, it can be particularly challenging.

Jo Watson & Catherine Catarinch

"I can't go to the coffee club anymore, which makes me feel a bit down, but I have plenty of jigsaws to keep me going". Catherine does have some visitors during the week. "I am lucky because the lady who cleans for me comes, and we have a chat. My Occupational Therapist (OT) is coming too, but she said she might have to stop".

Catherine's OT has been working with her to develop her digital skills. "I want to learn Zoom so I can talk to people, but it is hard. I need more lessons". Developing these skills is important to Catherine. For many people with intellectual disability the digital divide is real. Although she sometimes expresses frustration about being excluded from the digital world, Catherine's digital skills are progressing. "I'm using Facebook more on my tablet. I share photos of my jigsaws". Catherine understands that her regular social interactions are severely curtailed at the moment, but is hoping she can learn how to use her computer to "catchup with people more often".

Catherine and I chat about the restrictions, and what they mean to her. "I saw a thing on the telly about COVID. It didn't make sense because there were all drawings. They should use photos of someone wearing a mask and washing hands. I think that would help people understand what they have to do". Catherine has worked with Scope Australia's Accessible Information service as a consumer tester for many years. Ensuring information is accessible to everyone is something that is very close to Catherine's heart. "When Dan [Andrews] talks to us, it's good he has a signer [Auslan interpreter] there. But what about Easy English".

Catherine feels that the restrictions aren't all negative. She is now "the jigsaw queen of the world" and is "learning new things on the computer". She says, "I'm lonely, but everyone is in the same boat".

Catherine, I am sure we will find that missing piece in the puzzle before we know it. Hang in there!

Jo Watson and Catherine Cataranich

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COVID-19 PLANNING RESOURCE FOR PEOPLE WITH DISABILITY TO MAKE A PLAN FOR THEIR OWN INDIVIDUAL NEEDS AND SITUATION DURING COVID-19

Internationally, it has been acknowledged that people with disability have been left behind in disaster preparedness and consequently, experience greater disadvantage and challenges. People with disability are disproportionately affected before, during, and after disaster triggered by natural hazard emergencies.[1]

It is broadly acknowledged that people with disability face additional risks, barriers and impacts in emergency planning and response. This relates not only to their health and disability needs, but is also impacted by individual and contextual factors such as age, gender, socio-economic status, family environment, where someone lives, whether they are Aboriginal or Torres Strait Islander and whether they are from culturally and linguistically diverse backgrounds.

The COVID-19 pandemic has shone a light on a broad range of service and system gaps that have existed for people with disability over many decades. COVID-19 has also driven a rapid and collaborative policy and system response to put in place a number of key policy, strategies and initiatives to ensure people with disability could continue to access essential day to day disability supports, food and nutrition, housing, health care and other essential services.

People with disability, including people with intellectual disability need access to information, tools and resources that are focused on individual disability functional-based supports. This ensures people with disability can have person-centred planning conversations to make a plan and communicate this with their support network before, during and after a disaster or emergency. This aligns and reinforces the capability approach and enables people with disability to be empowered.

This planning guide helps people with disability to get the facts about Coronavirus (COVID-19) and make a plan for how they will manage the impact of this situation. People with disability need a plan that is tailored to their unique support needs.

This planning guide was developed by researchers at The University of Sydney who lead research on disability inclusive disaster risk reduction. It was developed in partnership with the Queenslanders with Disability Network with funding from the Queensland Government Department of Communities, Disability Services and Seniors. We work in partnership with people with disability to make sure they are included in all decisions about emergency management and disaster risk. This resource was co-designed with people with disability and their representatives.

We collaborated with the Australian Government Department of Health to make this guide nationally relevant – so that all Australians with disability can make a COVID-19 plan that is tailored to their capabilities and support needs. The Australian Government Department of Health supported the translation of this planning guide into an Easy Read format.

These resources are available at https://qdn.org.au/home/covid-19/make-a-plan and https://collaborating4inclusion.org/covid-19-person-centred-emergency-preparedness.

For any questions, please contact Michelle Moss at mmoss@qdn.org.au.

Director Policy and Strategic Engagement
Queenslanders with Disability Network Ltd (QDN)

1. Stough, L., & Kelman, I. (2017). People with disabilities and disasters. In H. Rodriguez, J. Trainor, & W. Donner (Eds.), Handbook of Disaster Research 2nd ed., pp. 225-242. Cham, Switzerland: Springer. https://doi.org/10.1007/978-3-319-63254-4_12

MASKS, COMMUNICATION AND KEY WORD SIGN

In this time of a global pandemic, masks are increasingly becoming part of normal dress, especially for those of us in Stage 4 lockdown in Victoria. Some of us find that masks act as a barrier for successful communication - speech is a little muffled and facial expression and other such cues are largely invisible. Think about the experience of children and adults with an intellectual disability who have some trouble understanding what others say - it's even harder now when their communication partners are wearing masks. Key Word Sign (KWS) and the clear use of natural gesture are more important than ever. For a video about this, go to: https://www.facebook.com/KWSAustralia/posts/2712093349073214.

KWS is the use of manual sign and natural gestures to support the communication and language development of children and adults with communication difficulties. KWS is one of the most widely used strategies utilised by people of all ages who cannot communicate by speech alone. KWS uses manual signs from the local deaf sign language (Auslan in Australia), but unlike Auslan users, we use speech with sign, and the signing used is simplified.

Signing the word 'tunnel'.

Use of KWS and gesture can help people understand what is being said to them and can be a way of sending a message for someone whose speech is unclear or still developing. KWS has been used in Australia for over 30 years with people of all ages who have difficulties with spoken communication. The use of KWS can help promote communication, participation and inclusion for children in the early years. (Cologon & Mevawalla 2018). Many children who use KWS will go on to develop speech and gradually reduce their use of sign. Some people with more significant problems producing speech will continue to use KWS alongside aided forms of communication such as picture-based books or electronic communication devices. Some adults with intellectual disability rely on KWS as a primary means of communication. (Dark, Brownlie & Bloomberg, 2019). These people are heavily reliant on their communication partners' skills and knowledge and their ongoing use of KWS to support communication.

Communication is a shared responsibility and it's important that the communication partners of people who have problems with communication take responsibility for learning and supporting the communication techniques of the person with little or no speech. This is true for people using aided forms of communication as well as those who rely on KWS and gesture to understand what others are saying to them, and/or to get their message across. We know that the use of KWS can increase the ability of adults with communication difficulties to understand what is said to them and to express themselves (Rombouts, Maes, & Zink 2017).

"Sam*" is a good example of how important it is for communication partners to learn and to use KWS and gesture. Sam is a man who has never developed speech. He used to live in a house in a country area with several other men with ID. The staff who worked in that house were all familiar with KWS and used it consistently. Sam was able to understand what others were saying to him and could get his message across with an

Signing the phrase 'thank you'.

extensive use of sign and natural gesture. He also developed a range of "idiosyncratic signs", largely to refer to people. These were not conventional or easily recognisable signs, but Sam's family, friends and support staff all understood who the signs referred to.

Sam moved to a different house and was then living with and being supported by people who did not use KWS. No-one really saw the need to learn because Sam could communicate his basic needs with natural gesture or by going to the place or thing that he wanted. Sam's support staff felt that they "understood everything he wants". But Sam was used to having much broader communications with people - he liked to have a chat about what he had done that day, what he might be doing tomorrow and to joke about the people he knew. And no one knew enough sign to understand anything more than a simple request for something. Sam became increasingly unhappy and his behaviour became increasingly challenging.

Eventually Sam moved again, and this time his support staff and the people he lived with all learned KWS. They also documented his idiosyncratic signs, so that everyone knew what Sam was saying. Sam is now a happy and jovial man, with a number of friends and involved in a wide range of activities.

KWS workshops are available for these communication partners, whether they be family, friends or support staff. KWS workshops are delivered by accredited KWS Presenters. Currently there are about 150 accredited KWS Presenters across Australia. However, as with all services, access to this training and support is much more limited in rural and remote areas. One of the benefits of the recent pandemic is that we are all becoming more familiar and adept with a range of technological tools for staying connected and coming together to meet and to learn. With this, KWS Presenters are beginning to offer workshops online, extending the accessibility of training.

For more information on KWS and its use, go to: www.kwsa.com.au or follow us on Facebook: https://www.facebook.com/KWSAustralia.

not his real name

Elizabeth Brownlie

National Coordinator of Key Word Sign Australia

keywordsignaustralia@scopeaust.org.au

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Cologon, K., & Mevawalla, Z. (2018). Increasing inclusion in early childhood: Key word sign as a communication partner intervention. *International Journal of Inclusive Education*, 22(8), 902-920. https://doi.org/10.1080/13603116.2017.1412515

Dark, L., Brownlie, E. & Bloomberg, K. (2019). Selecting, developing and supporting key word sign vocabularies for children with developmental disabilities. In N. Grove and K. Launonen (Eds.), *Manual sign acquisition in children with developmental disability.* Nova Science Publishers Inc.

Rombouts, E., Maes, B., & Zink, I. (2017). Key word signing usage of adults with intellectual disabilities: Influence of communication partners' sign usage and responsivity. *American Journal of Speech-Language Pathology*, 26(3), 853-864. doi:10.1044/2017_AJSLP-16-0051

DIVISION REPORT

September 2020

Aotearoa NZ ASID Division Report

The past month has been a challenge for all New Zealanders with the country going into Level 3 lock down again in August in the Auckland region and Level 2 in the rest of the country. It is really pleasing to know that although life is more restricted there are a number of reports from members of the excellent support people with intellectual disabilities are continuing to receive despite the impact of the pandemic on everyone's lives. At our recent division meeting it was agreed that it would be desirable for ASID to facilitate some forums where some of these stories could be shared. The first of these will take place in the Auckland region once lock down has been lifted. The division is organizing a number of webinars to keep members interested and involved. Details of these webinars will be listed on the ASID website when they are finalised.

Members may be interested to read the sobering, recently released report by New Zealand Chief Ombudsman, Peter Boshier entitled *Off the Record: An investigation into the Ministry of Health's collection, use, and reporting of information about the deaths of people with intellectual disabilities*. The link to this report is https://www.ombudsman.parliament.nz/resources/off-the-record.

Our division extends our best wishes to our friends and colleagues in Australia and look forward to the time we can meet up in person again at ASID conferences.

Debbie Espiner

Chair, Aotearoa NZASID

NZchair@asid.asn.au

UPDATE ON PODCASTS

Welcome to new members of the fabulous podcast team with Gordon Duff from NSW; Giang Le from South Australia and Emily Churchill from Victoria https://www.asid.asn.au/publications/podcasts.

WHAT'S COMING NEXT IN THE ASID PODCAST SERIES?

The podcast team is currently working on the following offerings for the remainder of 2020:

The challenges of living in rural and remote areas.

We talk to researchers about their recent work on rural services the NDIS. We include the perspectives of NDIS Participants, their families and carers about the challenges to finding the right services and supports, and to their service provider about the practical difficulties, but also the innovation that is occurring during the pandemic.

Dedifferentiation.

Dedifferentiation means including people with intellectual disability in the broader group of people with disability rather than regarding them as a separate group for the purposes of policy, service provision and professional practices. ASID has released a position statement https://www.asid.asn.au/files/1479_dedifferentiation_position_statement.pdf on the advantages and disadvantages of dedifferentiation, based on a recent literature review published in Research and Practice in Intellectual Disabilities. We speak with prominent researchers about what dedifferentiation means in practice in the context of current reforms in Australia and internationally, and what this means for social inclusion and citizenship outcomes for people with intellectual disability.

Please tune in – so far we have had 2933 total listens!

LOOKING AHEAD TO 2021

Do you have ideas of suggestions for topics or research you would like to see covered by an ASID podcast? Do you have research you would like to share with the ASID community. Please contact the ASID podcast team through the email link below so that we can plan an engaging and impactful series for 2021.

■ communications@asid.asn.au

QUIZ *Answers on page 24*

1 **Recently, the Aotearoa New Zealand Minister for Disability Issues publicly released a cabinet paper titled, 'Framework to accelerate progress towards accessibility in Aotearoa New Zealand'.**

Who is the current Minister for Disability Issues?

A. Carmel Sepuloni

B. Chris Hipkins

C. Nanahia Mahuta

D. Dr Megan Woods

E. Poto Williams

F. Tracey Martin

2 **Which of Studio A's talented roster of artists had their work featured in *The National 2019: New Australian Art* at Carriageworks, Sydney last year?**

A. Emily Crockford

B. Katrina Brennan

C. Guy Fredericks

D. Thom Roberts

E. Mathew Calandra

3 **People with a disability and their families were recently surveyed about their experiences since COVID-19. As you can probably guess, the response was not positive.**

What is the title given to the survey report?

A. 'We've been forgotten'

B. 'Let down and locked out'

C. 'Left out and locked down'

4 **Actor Chadwick Boseman tragically died recently. One of his most well-known roles is as Black Panther in the Marvel Cinematic Universe. Which was the first film that Boseman appeared in as the Black Panther?**

A. Black Panther

B. Avengers: Age of Ultron

C. Avengers: Infinity War

D. Captain America: Civil War

5 **There are two species of native bat/pekapeka still alive in Aotearoa New Zealand. They are different by having either a long or short which part of the body?**

A. Ears

B. Nose

C. Tail

D. Teeth

E. Wing

QUIZ ANSWERS

Question 1:   **A. Carmel Sepuloni**

An Easy Read version of the paper is available at the People First NZ website: https://www.peoplefirst.org.nz/cabinet-paper-from-the-minister-for-disabilities.

Question 2:   **B. Thom Roberts**

The work is titled, 'Thom Roberts Counts Trains'.
All the other artists on this list have contributed to important large exhibitions recently and are highly recommended.

More information about Studio A's artists can be found at their website: www.studioa.org.au

Question 3:   **C. Left out and locked down**

'We've been forgotten' was one of the "overwhelming messages" that came out of the survey results.

More information about the survey is at the Every Australian Counts webpage: https://everyaustraliancounts.com.au/left-out-and-locked-down-the-experiences-of-people-with-disability-and-their-families-during-covid19.

Question 4:   **D. Captain America: Civil War**

Question 5:   **E. Tail**

There is the long-tailed bat and the short-tailed bat.

WHY JOIN ASID

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

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

FREE JOURNAL SUBSCRIPTIONS

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

DISCOUNTS TO ATTEND WORKSHOPS, CONFERENCES AND OTHER EVENTS

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

ASID MONTHLY E-NEWS

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

INTELLECTUAL DISABILITY AUSTRALIA MAGAZINE (IDA)

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

USE OF OUR LOGO

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

OPPORTUNITY TO MEET AND EXCHANGE IDEAS

Our membership will also provide you with eligibility to be a decision maker and participate within the organisation, membership of a division that meets on a regular basis to pursue issues of local, national or international relevance together with locally organised regional conferences, seminars, workshops and social gatherings.

It will also offer opportunities to meet and exchange ideas with people having similar interests in other parts of your region and the country.

BECOME INVOLVED IN THE GOVERNANCE OF ASID BY BEING A MEMBER OF THE BOARD, YOUR LOCAL DIVISION COMMITTEE OR ON A BOARD COMMITTEE

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

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

ASID COMMITTEES

COMMITTEE	CHAIR AND EMAIL	ROLE OF COMMITTEE
Finance	Allyson Thomson treasurer@asid.asn.au	• To review and monitor financial processes • To help the board generate more income • To help the board spend less money • To help the board decide how to invest our money
Publications	Angela Dew angela.dew@deakin.edu.au	• Develop and oversee policies and procedures related to ASID's peer-reviewed journals • Provide interface between the ASID and contracted publishers (Taylor and Francis) • Develop processes, for and oversee appointments of Editors and Editorial Board Chairs
Position Papers	To be appointed	• To establish and document definitions, processes and guidelines for the development and endorsement of position statements, for presentation to the Board for approval • Develop a strategy for the widest possible dissemination of position • The committee will formulate a timely response to any reactions to position statements
Communication	Hilary Johnson communications@asid.asn.au	• Produce and publish IDA 4 x per annum • To develop and distribute high quality, responsive, accessible communications with external stakeholders including members, consumers and stakeholders we wish to influence
Partnerships and Projects	Bernadette Curryer bcur3628@uni.sydney.edu.au	• To identify partnerships currently in place, at both a divisional and national level, sharing what is happening and strategies used across all divisions • To identify and link with potential partners, ensuring mutual benefit eg. shared memberships

WRITING AN ARTICLE FOR IDA

Articles are read by a range of people so please avoid the use of jargon and acronyms (always provide the name in full for the first time).

Use size 12 font. Don't worry about specific indenting or spacing as your article will be set up by the publisher. If you use references please use APA 6th style. An example of a journal article and book chapter are as follows:

> Johnson, H., Solarsh, B., Bloomberg, K., West, D. (2016). Supporting people with complex communication needs through community capacity building: the Communication Access Network. Tizard Learning Disability Review. 21, 130-139.

> Iacono, T., & Cologon, K. (2014). Inclusion of children through AAC supports In K. Cologon (Ed.), Inclusive education in the early years Melbourne: Oxford Press.

Write your article separate to your email. Include a title on your article, your name or a contact, work position and website (if appropriate), an email address and a clear head and shoulders photo.

For on theme articles of 1400-1900 words include an abstract of up to 65 words; References maximum of 100 words and a summary box 100 words – (dot points of key messages). For shorter articles omit the abstract but include a summary box.

We are also interested in book, film, theatre and art reviews, please keep these to 300 words but include a photo relating to the event.

Please see past issues of IDA on the ASID website for examples of different types of article accepted. Please contact the editor idaeditor@asid.asn.au with any questions.

Hilary Johnson

■ idaeditor@asid.asn.au

asid
research to practice

WHY ADVERTISE IN IDA?

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

ARTWORK SPECIFICATIONS

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

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

Please email secretariat@asid.asn.au for further information about rates, specifications and our advertising policy.