

Reimagining the future of disability post the COVID-19 crisis

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COVID-19 has presented unprecedented challenges for people with disabilities across Australia, with spikes in anxiety, depression, neglect, domestic violence and even death. The majority of disability service providers have stripped community-based supports to “essential services”, with practically no alternatives offered for community participation, recreation, social or emotional support. People who have had choice and control over their lives have now had their liberties trampled on, with little attention paid to their social and emotional wellbeing. This paper utilises the social model of disability to explore the various responses to COVID-19 restrictions by disability service providers & workers in South Australia. One of the objectives of this paper is also to briefly present the historical context of disability care in South Australia with a view to link to the current COVID-19 conditions. Using an interpretivist view, this paper reflects on the situations where workers have found creative and innovative ways to bridge the gap in face to face service provision and the COVID-19 restrictions. This paper will also discuss situations where people were involuntarily left at home alone to manage without their usual wellbeing supports. This paper’s findings will have some direct and profound implications on service delivery options for people living in rural and remote areas of Australia who may have little or no access to quality disability services. An additional element in this paper is to reflect on qualitative data drawn from informal interviews with service providers, workers and people with disabilities, and those reflections are further supplemented by electronic, print and social media; providing a narrative of South Australian’s living with disabilities during COVID-19.

Key words: *Social model of disability, innovative care, COVID-19, rural and remote, South Australia, NDIS*



Introduction

People with disabilities are experiencing new and significant challenges to their service provision due to the COVID-19 pandemic. Across the globe, there has been increases in anxiety, depression, neglect, domestic violence and even death, including in South Australia. For many people with disabilities, the COVID-19 restrictions have created huge impacts on their quality of life, with many of their community-based supports removed with little to no alternatives offered. Following the Methodology section, an overview of South Australia history in relation to disability and the current context of COVID-19 and the disabling environment, which is likely to have long term consequences is presented. The recently introduced COVID-19 restrictions on movement and socialisation to minimise the spread of the disease has resulted in significant disabling factors for people. This paper will explore the challenges and triumphs within the disability sector in South Australia during this time of crisis, and identify the innovative ways in which people have minimised the impact of this new disability. The paper is an exploration of the responses by service providers and disability workers to support the increasingly complex social, emotional and community needs of people with disabilities, and aims to highlight the triumphs, innovations and creativity of workers and participants.

Methodology

This paper is based on qualitative data drawn from observations and informal conversations with people with disabilities and disability workers; and is supplemented by electronic, print and social media sources. Data sourced from media articles were determined to be relevant only if published during the COVID-19 epidemic, starting in December 2019 in Wuhan, China. This research is informed by the interpretivist view and positionality, acknowledging the author's own biases and preferences surrounding disability and disability service provision, which in turn influence the collection and interpretation of the data (Bourke, 2014; Pulla & Carter, 2018). The interpretivist view recognises that realities are socially constructed, so this paper does not simply focus on the evolution of disability service provision, but on the meaning and understanding given to that instance of service. It recognises the confronting Australian history whereby people with disabilities as wrongfully positioned as 'othered', different, to be unseen and without value; and seeks to challenge this (Carling-Jenkins, 2014).

The author uses a critical lens to understand the concept of disability that moves forward from the medical model and models of impairment, and into a critical social model of disability. Disability under this framework is then seen as lying not within an individual's deficits or limitations; but within the social and physical interactions within the world around them, and the systems that lie within (Bigby, Tilbury & Hughes, 2018; Hiranandan, 2005; Meekosha & Dowse, 2007).

Historical Context of Disability in South Australia - 1900-2020

Post-1900 in Australia, people with disabilities were denied full citizenship rights and were seen as having little to no value in society. This perspective was drawn from colonial Britain's understandings of disability that had strong links to criminality, rather than being drawn from the First Australian's understanding of disability (Carling-Jenkins, 2014; Velarde, 2018). These colonial views of wanting to protect the community from people with disabilities led to the institutionalisation of many people. Institutionalisation separated people from their rights as citizens, which at the time was supported through legislation (Carling-Jenkins, 2014).

Institutionalisation imposed a paternalistic model of care, where society is protected from people with disabilities, and people with disabilities are given a lifetime of protection from society (Carling-Jenkins, 2014). This allowed for people to be kept completely hidden from society in a heavily structured, prison-like setting with no social rights. No respect was given to people with disabilities, with many "raped, assaulted, verbally abused, locked up, chemically and mechanically restrained, sterilised, exposed to unsanitary conditions and deprived of human touch". Some were held in cages, with reports of the routine removal of teeth upon entering institutions to prevent biting. People were "denied their basic human rights of privacy, safety and dignity", respect or medical care; denied any opportunities to learn basic life skills, eliminating the possibility of future independence (Carling-Jenkins, 2014).

Upon the return of many service men and women from the Second World War in the 1940s, the view around acquired disabilities began to change and alternative options to institutionalisation were sought (Carling-Jenkins, 2014).

Deinstitutionalisation was the process that initiated the closure or downsizing of institutions that housed people with disabilities and provided people with supports to move into the community and participate in societal life (Wiesel & Bigby, 2015). This process began in the 1960s and resulted in significant life improvements for some, however relocating people who had experienced a lifetime of denied skill development into an overwhelmingly unequipped and under resourced community resulted in further segregation, discrimination, abuse and exploitation for many (Carling-Jenkins, 2014).

Following the International Year of Disabled People in 1981 (United Nations, n.d.), there was international pressure on Australia to improve social inclusion for people with disabilities. Deinstitutionalisation was already underway in most Australian states, however there were still many people living in institutions up until the late 1900s. Despite advancements for those living in the community including the Disability Support Pension introduced in 1991 and the Disability Discrimination Act in 1992 (Commonwealth of Australia, 2016; Commonwealth of Australia, 2018), the remaining institutions were "characterised by overcrowding, disease, neglect, a culture of resident abuse, regimentation of daily activity and restriction of individual

freedoms” (Wiesel & Bigby, 2015). Smaller group homes had been developed and run by non-government organisations or businesses at the closing of the larger institutions, however many of these were facilitated with the same regimented care model and without any focus on independent skill development or connection to community. Those deinstitutionalised without access to supportive family homes or small group homes had very limited options and often were found in hospitals, aged care homes or hostels unequipped to support them adequately (Carling-Jenkins, 2014).

In 2007, Australia signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, n.d.) and was one of the first countries to enshrine this into national legislation in July 2008. The Australian Government recognised that the disability sector needed a nation-wide overhaul, and consulted with community members to develop the most recent National Disability Strategy (NDS) 2010-2020 (Commonwealth of Australia, 2019; Department of Social Services, 2009). This independent process produced the Report ‘Shut Out: The Experience of People with Disabilities and their Families in Australia’ (Commonwealth of Australia, 2019) which helped inform the NDS from the perspective of people with disabilities. A second stage of consultations for the NDS was scheduled to be completed in 2020, but has been postponed due to COVID-19 (Department of Social Services, 2009).

In 2011, the Australian Government released the Disability Care and Support Report which determined that the current disability sector was “underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports” (Productivity Commission, 2011). The report also provided a range of recommendations for the future of disability care in Australia, including the recommending that the National Disability Insurance Scheme (NDIS) be developed. With large community support, the Australian Government committed to the development of the NDIS and began implementation in trial phases across Australia in 2013, beginning in South Australia for children under 14 (Carling-Jenkins, 2014; NDIS, 2019a).

By mid-2018, the NDIS was fully implemented across South Australia and has been said to be the “most significant social policy reform since Medicare” (Bigby, Tilbury & Hughes, 2018). It has resulted in a move away from the puzzle of block-funded services to using insurance principles to distribute individually allocated funding according to personalised, goal-oriented supports. This shift from welfare models of disability have sought to maximise independence, and social and economic participation (Roberts, Webber, Spreckley, Scheinberg, Forrester & William, 2017; Wiesel & Bigdy, 2015). As of April 2020, 33,383 South Australians have benefited from the scheme (NDIS, 2020). Almost 18,000 of these people are receiving support for the first time, highlighting clear improvements in service accessibility through the NDIS.



The Disabling Context of the COVID-19 Pandemic

The World Health Organization (WHO) was notified in December 2019 of the pneumonia outbreak with an unknown cause in the city of Wuhan, China (WHO, 2020b). The cause was identified as a new type of human coronavirus, which came to be known as COVID-19. The first confirmed case of COVID-19 in South Australia was at the end of January 2020; by the end of June there were 440 recorded cases with almost half a million deaths worldwide (“SA Health”, 2020, para. 1; WHO, 2020a). In Australia, COVID-19 poses the greatest risk to Aboriginal and Torres Strait Islander people (particularly those in rural and remote areas of Australia), older people, people living in aged care facilities, and people with underlying medical conditions (Department of Health, 2020a). Internationally, people with intellectual and learning disabilities have also been identified as high-risk groups due to higher incidences of comorbidities such as diabetes and cardiovascular disease (Turk, Landes, Formica & Goss, 2020; WHO, 2018).

In South Australia on the 22nd of March 2020, a Major Emergency was declared and as a result, the State Government gained powers to prohibit travel and gatherings of people, direct people to undergo medical testing and to impose quarantine or isolation periods (Justice Connect, 2020). All non-essential businesses and premises including religious institutions were ordered to close to the public, recreational spaces such as parks were blocked off, restrictions were placed on the number of people who could gather socially and there was a recommended 1.5 metre space between all individuals (Government of South Australia, 2020a; Government of South Australia, 2020b). Strict hygiene and distancing measures were put in place for people accessing health services, and disability service providers rapidly upskilled their support workers in infection control measures.

Within a few weeks of the declaration, approximately one million Australian’s became unemployed or had a significant portion of their regular income lost due to COVID-19 restrictions or related changes (Hayne, 2020). The Australian Government swiftly created new Centrelink payment types with streamlined processes, including the JobKeeper, and two supplementary payments – the fortnightly \$550 Coronavirus Supplement and the two-time \$750 Economic Support payments (Services Australia, 2020a). By mid-May, there were more than six million people on the JobKeeper payment alone (Hayne, 2020). People with disabilities who were working or job searching at the time of COVID-19 were often eligible for the new Centrelink payments; despairingly, those receiving the Disability Support Pension were excluded from receiving the fortnightly Coronavirus Supplement despite the increase in their living costs (Services Australia, 2020b). The costs of daily living have increased across the globe, with shortages and price hikes in fresh food, pantry items, hygiene products and medications (Hermant, 2020; Wright, 2020). People with disabilities have become particularly vulnerable due to these price increases and severe shortages in gloves, hand sanitiser and



facemasks – hygiene items that in many homes are necessary to protect both workers, people with disabilities and their family members.

There have been no tailored, accessible COVID-19 resources created for people with intellectual or developmental disabilities to inform people and their families about the restrictions and how best to protect themselves (Dickinson & Yates, 2020; Pheonix, 2020). Without the appropriate resources, people with disabilities, their families and workers have been placed at a higher risk of infection, transmission and death during the COVID-19 period. In May, the Australian Government opened the Disability Information Hotline, which has now been able to provide information and referrals for people with disabilities who require support because of COVID-19 (Department of Health, 2020b). There has been the creation of a series of YouTube videos in sign language explaining COVID-19, including updates and advice, however, the most viewed of these was the introductory video, which has only 241 views by the start of July (Department of Health, 2020c). Either this suggests that people who are deaf didn't know about this resource, or that this wasn't a large need due to many people being able to read the required information from other government sources.

Dissolving Services During the Pandemic

With the closure of non-essential services, many disability service providers shut their physical doors with very little contingencies in place. Agencies rushed to redesign services to be delivered remotely or in person - abiding by the new restrictions on gatherings and square metre footage per person. Whilst some services such as counselling for many would be accessible via teleconferencing services, many of the roles provided by disability support workers have required a greater level of innovation and creativity to continue to meet the physical, social, community and emotional needs of people with disabilities. We also need to recognise that the technology required for teleconferencing-type services are not accessible or appropriate for people with disabilities who have exceptional needs, or those who are unable to afford the required technologies.

During March 2020, approximately one third of surveyed NDIS participants reported that their disability support workers had cancelled – many of which was at very short notice (Dickinson & Yates, 2020). Support workers under the NDIS assist with a wide range of activities including personal care, social support, meal preparation, transport, assistance at the workplace or education, housework, and recreational and community access support (NDIS, 2019b). Whilst some of these services are seen to be essential, the majority are not, which has led to many people feeling locked out of a community that has previously been accessible. Face to face delivery of essential personal care activities, housework and the delivery of food packages only scrape the surfaces of meeting the often very complex physical, emotional and social needs of people with disabilities during COVID-19 isolation. The impact of being locked out of community for many people would detrimental. Those who had experienced

deinstitutionalisation who now felt locked within their own homes are likely to experience a re-traumatisation effect and unless significant supports are put into place then the wellbeing of this population is likely to deteriorate quickly.

Now predominantly stuck at home with decreased supports and oversight, people with disabilities are likely to experience significant social isolation, changes in routine and have the potential for serious and life changing skill regression (Dickinson & Yates, 2020; Pheonix, 2020). Practiced physical and social skills which may have taken years to develop are likely to decline without the opportunities to continue these skills. For example, a man has been having transport and gentle physical support three times a week to develop his gross motor skills through a gym workout at a local gym. Gyms and recreational parks have been closed off due to COVID-19 and a strict 1.5 metre physical distancing measure has been put in place for non-essential activities. This man is no longer able to maintain a meaningful gym routine at home and his strength, balance, muscle memory, elasticity and movements are likely to have regressed significantly in the 3 months of restrictions.

This isolation also heightens the risk of neglect, domestic violence and exploitation. People with disabilities are more likely to experience domestic violence and often face significant challenges in finding accessible domestic violence related supports; so the lack of worker sight within a home significantly increases this risk of violence (Commonwealth of Australia, 2009; Krnjacki, Emerson, Llewellyn & Kavanagh, 2016). There have been several horrendous accounts of neglect and avoidable deaths of people with disabilities during COVID-19 across Australia (Visontay, 2020; Henriques-Gomes, 2020), all of which with additional oversight would have been avoidable. COVID-19 has meant that many disability service providers or support workers are choosing to not support people face to face, resulting in many people having to rely on family or friends to provide personal care and support; and in cases where they cannot provide this, are forced to go without or have services much less frequently. There has been a reported increase in the use of online domestic violence tools during COVID-19 in New South Wales, a significant spike of domestic violence related injuries in Emergency Departments in Queensland and an overwhelming rise in South Australian migrant women seeking domestic violence related support (Bavas, 2020; Talwar, 2020). Victoria too has reported significant increases of domestic violence related reports in during lockdown, with many being first reporters (Mills, 2020). It is apparent that across Australia, people are more likely to experience domestic violence due to being isolated at home with the likelihood of one or more adults being unemployed in many households and home all hours of the day, with devastating outcomes for women, children and other vulnerable people.

Increased isolation and changes in routine has resulted in sharp decline of the mental health of people with disabilities and their families (Dickinson & Yates, 2020; Galea, Merchant & Lurie, 2020; Pheonix, 2020). Skill regression is also likely for emotional, psychological and social skills with limited options to practice these skills along with being locked out of community.



For example, for the last two years a child with significant social anxiety has been supported by a support worker to leave her home twice a week to combat deteriorating mental health and a social disconnectedness. With the current restrictions, she and her worker now feel limited to activities within the home – something she feels much more comfortable with, however means that the skills she has developed slowly over the past two years are no longer being used and will need to be progressively learnt again once restrictions lift. It is likely that the change in routine and lack of community connection will also create disruptions for the child's home life, self-esteem and general wellbeing. For others who enjoy socialising and leaving the house, this time isolated at home is likely to create increased anxiety and depression without the ability to take part in their regular activities. The new disability through COVID-19 is huge for people such as these and workers need to be creative in doing what they can to continue practicing these learnt skills.

COVID-19 has created significant disabilities for people in ways that could not have been predicted. It may take years to counteract the effects of this disability, and the unlikelihood of additional supports provided only heightens this disabling impact. People with disabilities should have the same life choices and rights as people without disabilities, and have just as much of a right to social, recreational and community access (Carnaby, Roberts, Lang & Nielsen, 2011). Whilst people may need guidance to understand and abide by the restrictions in place, self-determination within these restrictions must be respected and creative opportunities should be explored to continue activities that people enjoy, to have opportunities to practice their skills, to communicate their own knowledge to people about ways of working, and continue to live a meaningful life.

An Exploration of Responses

Thirteen of the largest disability agencies providing services in South Australia were researched online through their company website and social media presence, and informal conversations were had with support workers and participants. Majority of these agencies had very little online presence related to their response to COVID-19; much of the information explored was through informal conversation and a strong online presence from one agency. Responses by Australian disability service providers and support workers during the time of COVID-19 have been varied. Many have simply cancelled supports, whereas others have wanted to continue in the same manner without considering risks. Some group housing providers have been reported to be locking people in their rooms, or not letting them out of the house at all. People have been prevented from participating in their rehabilitation plans, and many have had all visitors and agency support workers refused entry from their building (Magarey, 2020). These reports are incredibly concerning and are likely to have left residents feeling scared, anxious and that they have no rights.



The majority of supports have been scaled back to include essential supports such as personal care, cleaning and food preparation. There are workers who are providing regular conversation through phone calls or applications such as Facetime, Zoom or Facebook Messenger, and for some, their support may have included ensuring that their participants have upgraded and knew how to use their technology so that they can independently receive these calls. Whilst valuable, these online conversations alone are unlikely to meet the increasing social and emotional needs of people, particularly those living alone. There have also been workers who directly translate their work in the community to now doing this in the home, attempting to recreate these experiences. For example, instead of providing transport to and from a participant's home and a coffee shop, having a latte and cake; to now having a coffee and chat in the participants home. There are still clear infection risks associated with this form of support, and there is the potential for both these options to appear as tokenistic forms of support; so further exploration of creative and innovative support options is necessary.

Creative and Innovative Support Work

The creative and innovative responses that have been identified have been divided into three categories: virtual worlds, home based support and safe community access.

Support workers and participants have been using video calling applications in more creative ways than simple conversation and check-ins. Some innovations in remote service delivery include the creation of virtual worlds and using this to conduct activities such as art classes, 'cook offs' together step by step, interactive exercise and movement classes, playing online games or connecting gaming systems, singing lessons, watching sporting games and playing instruments together; all the while communicating via video calls (Hireup, 2020; Hireup, ca. 2020; Life Without Barriers, ca. 2020). There are also virtual events run online with a focus on interests such as gaming or musical concerts that are being used for people to participate online with.

For those support workers who were committed to supporting people face to face, people have spoken through windows or back doors, or set up a backyard with a long table so people can sit at either end and communicate safely (Hireup, 2020). Others have been physically distanced in shared spaces and planned activities to complete once restrictions lift, for example, planning a new garden bed and working through the steps to achieve this. A very creative response discovered has been for a worker and participant to meet at a quiet local park and do yoga at a distance.

These creative and innovative responses in providing support to people have been interesting and meaningful, and seek to minimise their disabilities in such a disabling context. Such activities could reduce the risk of skill regression, depression, anxiety and boredom, along with meeting their social, community and emotional needs.



The virtual world model and the reimagining the future of disability support

The virtual world model of remote service delivery has the potential to meet a service gap in regional and remote areas of Australia, where people are often unable to find services or support workers that meet their needs, personality and interests. Under this framework, workers and participants connect online in a variety of creative ways that allow for participation in activities that work towards meeting identified goals, interests or purposes. There is always a connection in this virtual world – either by video or voice - and activities will be purposeful and meaningful, rather than just a ‘catch up’, surface level conversation. Skills can be developed, interests pursued and overall wellbeing maintained through the creative engagement of workers and participants alike.

This model would allow people to source high quality workers across Australia to provide services under the NDIS that are responsive, innovative and creative. Participants will no longer be confined to choosing from available workers in their area, or those workers who are willing to travel large distances. Unfortunately, this model of service delivery is unlikely to be accessible for people with exceptional disabilities unless expensive virtual reality (VR) options are utilised.

The virtual world model poses great potential for bridging the divide between face to face and remote service delivery for a diverse range of people in isolated areas of Australia. This new model may also be a viable choice for people in metropolitan areas seeking alternative forms of support.

Recommendations

1. Disability service providers should consider whether the virtual world model of remote service delivery is a relevant opportunity for their agency; training workers as appropriate and positioning themselves to be able to provide this service both in metropolitan, and regional and remote areas of Australia.
2. The NDIS should consider increasing funding packages for participants who have been disabled by COVID-19 and who have had noticeable skill regression; providing additional support to rebuild these skills and confidence.
3. Disability service providers should create policies and processes to plan for creative remote service provision, home based supports and safe community access in the likelihood of another pandemic which imposes restrictions around physical distancing and gathering.

Conclusion

The historical context of disability in South Australia presents a confronting history of institutionalisation, horrendous accounts of abuse and the denial of human rights. There have



been significant advancements in the disability sector over the past 60 years, including deinstitutionalisation, small group housing options, community-based supports, and the recent introduction of the NDIS. The COVID-19 pandemic has caused detrimental and disabling impacts for people with disabilities including ceasing community access, significant potential for skill regression, a decline in mental health and heightened risks of COVID-19 infection, neglect and violence.

It is recommended that the NDIS create processes to review the support plans of people significantly impacted by COVID-19 and provide additional funding to ensure that people can rebuild their regressed skills promptly. Disability service providers must put policies and processes in place to respond to and prepare for current and future pandemics that influence the way that services are delivered. These changes should be harnessed as an opportunity for positive development within the sector to provide improved outcomes for people with disabilities.

Remote service delivery options for people with disabilities should hold real value and meaning, and work to address unmet social, emotional, recreational and community needs. Service providers and support workers should look at innovative and creative ways to meet the evolving needs of individuals during this pandemic such as the virtual world model, and reimagine the future of disability support.

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